

**From Transfer to Transformation:  
Rethinking the Relationship between Research  
and Policy**

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September 2003

A thesis submitted for the degree of Doctor of Philosophy  
from The Australian National University



Except where indicated otherwise, this thesis is the original work of

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## Acknowledgments

To my supervisors, Bev Sibthorpe, Stephen Duckett and Gwen Gray, thank you for your keen interest and insightful direction. I especially want to thank Bev for eight years of unstinting support and for many enjoyable supervisory sessions. She kept me in touch with the human and humorous side of research and policy. Thanks also to the staff and students at the National Centre for Epidemiology and Population Health for providing a stimulating and supportive environment in which to study.

I would like to thank the public health researchers, policy makers and two former Commonwealth Health Ministers who agreed to be interviewed for this study. They were generous with their time and open in sharing their story.

Thank you to my colleagues in the Australian Government Department of Health and Ageing for helping me to study part-time. The Department provided me with a Development Award that enabled me to spend 15 months studying nearly full-time. I would like to thank Marion Dunlop in particular for her support in applying for that Award and for reading this whole thesis and offering sound advice, as usual.

Thank you to my friends—Claire Parkhill for her expert advice on editing and formatting and for being so generous with her time and talents, Frances Byers for reading wobbly drafts and keeping me honest, and Andrew Webster for long walks and Big Ideas.

Thank you to my father for nurturing practical skills and a tradesman's pride in a job well done. I wish he were here to see this. Thanks to my mother for many things intellectual and spiritual but particularly the sheer tenacity to see a thing through.

This thesis is dedicated to my wife Beth without whom it would not have been possible or worth doing, and to our three children, Dorothy, Judith and Alison—you light up my life in a way that a mere thesis never could.



## Abstract

The most common and enduring explanation for the way research is used (or abused or not used) in policy is the ‘two communities’ theory. According to this theory, the problematic relationship between research and policy is caused by the different ‘cultures’ inhabited by policy makers and researchers. The most common and enduring types of strategies that are put forward to increase research use in policy involve bridging or linking these ‘two communities’. This study challenges this way of thinking about the relationship between research and policy. Four case studies of national public health policy in Australia—breast cancer screening, prostate cancer screening, needle and syringe programs in the community, and needle and syringe programs in prisons—are used to present the context, events, processes, research, and actors involved in policy making. Three theories are deployed to explore the relationship between research and policy in each of the cases individually and across the cases as a whole. These theories bring different determinants and dynamics of the relationship to light and each is at least partially successful in increasing our understanding of the relationship between research and policy. The Advocacy Coalition Framework (ACF) understands the relationship in terms of a power struggle between competing coalitions that use research as a political resource in the policy process. The Policy Making Organisation Framework (PMOF) understands the relationship in terms of institutional and political factors that determine the way data is selected or rejected from the policy process. The Governmentality Framework (GF) understands the relationship in terms of the Foucauldian construct of power/knowledge that is created through discourse, ‘regimes of truth’ and ‘regimes of practices’ found in public health policy and research. This study has found that in three of the four case studies, public health policy was strongly influenced by research, the exception being NSP in prisons. In all cases, however, it is not possible to construct a robust and coherent account of the policy process or the policy outcome without considering the multifaceted role of research. When these theories are explored at a more fundamental level they support the argument that when research influences policy it is transformed into knowledge-for-policy by being invested with meaning and power. This process of transformation occurs through social and political action that mobilises ideal structures (such as harm minimisation and the World Health Organisation’s principles for evaluating screening programs) and material

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structures (such as medical journals and government advisory bodies) to resolve meta-policy problems (such as how to define complex public health problems in a way that makes them amenable to empirical research and practical action). This study provides good evidence that the notion of ‘research transfer’ between ‘two communities’ is a flawed way of understanding the research–policy relationship. Rethinking the relationship between research and policy involves building an enhanced theoretical repertoire for understanding this complex social interaction. This step is essential to the success of future efforts to make public health policy that is effective, just and emancipatory. This study makes a contribution to this task.



## Preface

Policy making is a value-laden activity regardless of the intellectual rigour with which it is pursued. Research on policy making is no different and the reader is entitled to know about the values I bring to this study.

This thesis grew out of my experience as a Commonwealth public servant involved in policies and projects such as the National HIV/AIDS Strategy, BreastScreen Australia, the Australian Childhood Immunisation Register, the National Drug Strategy, the Public Health Education and Research Program, national public health information infrastructure development, and various public health research projects such as the Longitudinal Study on Women's Health and an analysis of 'returns on investment' in public health. In my attempts to make evaluation, research and information a more influential part of the policy process, I began to read literature on research utilisation. I found that the parts of this literature that took the sociology of knowledge and theories of public policy making seriously were very interesting and I wanted to explore their application in Australia further. However, I also found that most of the literature on how to link research and policy in practice were not informed by this literature. Rather, they were based on the relatively simple idea that the use of research in policy was determined by the interpersonal dynamics of researchers and policy makers and that measures to enable research use in policy should aim to overcome the cultural differences between these 'two communities'. My practical experience told me otherwise. The rise of the idea of 'evidence-based policy' also intrigued me. There was a part of me it appealed to, but there was a larger part of me that wanted to problematise it. This research project is the result of these two strands of interest. In Chapters 1 and 3 I note the ways that my interests and experience informed the design and conduct of this study.

In relation to the role of public health as 'the organised response by society to protect and promote health, and to prevent illness, injury and disability' (Commonwealth of Australia and State and Territory Governments of Australia 1997), I consider myself something less than a true believer. While I have often been an advocate within the Department for greater engagement with and expenditure on public health by the Commonwealth, I have nevertheless tried to maintain a critical perspective. This

ambivalence is reflected by the inclusion of the Foucauldian framework of ‘governmentality’ as one of the three theories considered in this study.

I believe that public health policy should aim to be effective, just and emancipatory. ‘Effective’ in the sense that it results in a healthier population and does not cause harm. ‘Just’ in the sense that it strives to achieve the best health possible for the whole population and especially the sickest (who, more often than not, are the poorest). ‘Emancipatory’ in the sense that the process of developing and delivering public health policy should aim to increase the control that people can attain over their lives and their environment.

I realise that these goals may sometimes conflict and that the process of policy making requires more than a statement of values and objectives. The best word I have found to describe what I believe is the essence of good policy making is Aristotle’s ‘phronesis’ or ‘practical judgement’ (Klein 2000: 65). This concept appeals to me because it captures the requirement that policy is based on sound understanding of the way things are and the way we want them to be. As Flyvbjerg has argued, ‘*Phronesis*... is that activity by which instrumental rationality is balanced by value-rationality...’ (Flyvbjerg 2001: 4). Critiquing the exercise of phronesis in any particular situation is dependent on the further exercise of the same ability. It is what Vickers describes as an ‘ultimate category’ (Vickers 1965: 13).

I think that the exercise of phronesis is promoted and protected by the institutions and processes that underpin democracy generally. In specifying these, I am also specifying what I believe are the appropriate processes for giving research its due weight in policy making. I think that public health policy making processes should include a continuous, explicit, rigorous and accountable engagement with research. The goal is not research use for its own sake but the best use of the best available research in the service of practical judgement. What constitutes ‘best use’ and ‘best available research’ is unavoidably contestable. There are qualifications to these general principles that are related to the costs involved in terms of time, money, and the possible risks associated with acting too soon or acting too late. While I have sympathy for Gaughwin’s argument for ‘minimum standards of deliberation’ in making public health policy (Gaughwin 1998), I do not think they could ever be agreed or implemented across Australia’s nine jurisdictions and across all areas of health policy.

I began this study with a general sympathy for the aspiration that research use in policy should be increased. I now think that the goal of increased research use for its own sake makes little sense. I also began this study thinking that one of my goals was to help ‘improve’ the relationship between research and public health policy. I have gradually abandoned this idea too. I think it is impossible to specify what the relationship between research and policy should be like. The idea that policy should mirror the findings of the best available research or be more ‘research-informed’ adds nothing to a more general specification of good policy making as set out above. It also suggests that it is possible to bypass the inevitable contests over how research should be interpreted. I find myself agreeing with Janet Weiss, one of a group of social scientists in the United States in the 1970s who studied the use of social science in public policy, when she wrote:

The study of social science and public policy has recently grown out of its adolescent preoccupation with the struggle of Good (use of social science) and Evil (no use of social science). In the venture toward maturity, we have grown increasingly ‘agnostic’ about the ultimate value of using social science, and in so doing have dramatically improved our understanding of the links between social science and policy making. (Weiss 1979: 437)

Improved policies... are unlikely to be found in mere increased incidence of use. First, more is not the moral equivalent of better. Second and more important, strengthening the knowledge base of policy making is an important but insufficient condition for improving policy. (Weiss 1979: 457)

I am unsure if my own agnosticism was something that I came to gradually over the course of this study or if it has been latent in my approach all along.

Lastly, there is the matter of whether I think policy making should be more rational. When the goal of rationality in policy making is put forward it is often characterised as the adversary of a too-great influence of values and politics in policy making. I believe that policy making can never proceed independent of questions of values or the contest of politics. In Chapters 2 and 9 I discuss this relationship and argue that the question of the role of values in policy making is of critical importance to the study of research use in policy.



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## Abbreviations

ACF	Advocacy Coalition Framework
ACS	Australian Cancer Society
AHMC	Australian Health Ministers' Council
AHMAC	Australian Health Ministers' Advisory Committee
AHTAC	Australian Health Technology Advisory Committee
AIH	Australian Institute of Health (now AIHW)
AIHW	Australian Institute of Health and Welfare
ANAIDUS	Australian National AIDS and Injecting Drug Use Study
ANCA	Australian National Council on AIDS
ANCAHRD	Australian National Council on AIDS, HIV and Related Diseases
BBV	Blood Borne Virus
BCS	Breast Cancer Screening
CARG	Commonwealth AIDS Research Grants
CRC	Colorectal Cancer
DAC	Dominant Advocacy Coalition
EBHP	Evidence-based Health Policy
EBM	Evidence-based Medicine
GF	Governmentality Framework
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
MJA	Medical Journal of Australia
NAIPIC	National AIDS in Prisons Information Clearing House
NCCI	National Cancer Control Initiative
NH&MRC	National Health and Medical Research Foundation
NSP	Needle and Syringe Programs
PCS	Prostate Cancer Screening
POL	Policy Oriented Learning (part of the ACF)
PMO	Policy Making Organisation
PMOF	Policy Making Organisation Framework
RCT	Randomised Controlled Trial
WHO	World Health Organisation

# 1. Introduction

## 1.1. Research objective and questions

This thesis addresses the question ‘how might we best understand the relationship between research and public health policy?’. The aim is to contribute to the field of research that studies the use of research in policy. By ‘understand’ I mean theoretically coherent and empirically grounded ways of appreciating the research–policy relationship. Unlike much of the writing and research in this field, this research project is agnostic on the normative questions of whether research is used as much as it could be, or used in the way that it should be. Like Weiss, I consider agnosticism on these questions an aid to better understanding of the relationship between research and policy (Weiss 1979: 437). While Hanney and others might be correct in their assessment that ‘...it is widely agreed that health policies do not reflect research evidence to the extent that in theory they could’ (Hanney, Gonzalez-Block et al. 2003: 2), I distance myself from the assumption that it is possible for any individual or organisation to establish themselves as the final arbiter of what constitutes the correct use of research in public health policy.

The theory of the relationship between research and policy is underdeveloped, a point which Landry has also made (Landry, Amara et al. 2001: 397). While a plethora of ‘models’ of research use have been developed (some are discussed in Chapter 2), there have been relatively few attempts to link the wide range of factors influencing research use in policy into a coherent relationship. I am not proposing that there should be a single general theory to explain all aspects of research use in policy, rather, I am proposing that the field could benefit from increasing its theoretical repertoire and from discussing what the requirements of an adequate theoretical approach might be.

The general lack of attention to theory has meant that one particular theory of the relationship between research and policy, known as the ‘two communities’ theory, has enjoyed remarkable longevity. This theory (sometimes referred to as a hypothesis or metaphor (Dunn 1980)) was first developed in the 1970s when the study of research use in policy was in its infancy. At this time, there were various theories proposed to explain the non-use of research in policy (Caplan, Morrison et al. 1975: x-xi) but the



‘two communities’ theory is the one that has endured. The theory is an adaptation of the argument advanced by C.P. Snow in Britain in 1956 that ‘the intellectual life of the whole of western society is increasingly split between two polar groups...the literary intellectuals... and scientists’ (Snow 1963: 11-12). Snow’s argument was transposed into a theory on the dysfunctional relationship between social science research and policy as follows:

...social scientists and policy makers live and operate in separate worlds with different and often conflicting values, different rewards systems, and different languages. The social scientist is concerned with ‘pure’ science and esoteric issues. By contrast, government policy makers are action oriented, practical persons concerned with obvious and immediate issues. It is argued that the gap between the knowledge producer and the policy maker needs to be bridged through personal relationships involving trust, confidence, and empathy. (Caplan, Morrison et al. 1975: x-xi)

While there are continuing explicit references to the ‘two communities’ theory in current writing and analysis (Innvaer, Vist et al. 2002: 242; Lavis, Ross et al. 2002: 145; Hanney, Gonzalez-Block et al. 2003: 14), just as important is the continuing emphasis on articulating the differences between researchers and policy makers as a way of explaining perceived problems in research use. For example, Lomas writes:

...researchers and decision-makers seem to proceed largely independently. Each have their own (often misplaced) ideas about the other’s environment. Opportunities for ongoing exchange and communication are few. Because most of the study has emanated from researchers, their activity has focused more on understanding the assembly and dissemination than on the uptake and use of research evidence. Because most of the determinations are made by decision-makers, their focus is on the applicability, usefulness and context dependency of researcher findings. It is like two people trying to assembly a jigsaw puzzle, each with half the pieces... but each working in a separate room. (Lomas 1997: i)

The effect of the ‘two communities’ theory is to continually focus attention on the interactions between researchers and policy makers rather than on the determinants of those interactions. The study of research use in policy has often been a ‘prisoner of the proximate’, an expression used by Anthony McMichael to describe the concentration of modern epidemiology on individual risk factors to the neglect of the determinants of the health of populations (McMichael 1998). The parallel with the study of research use in

policy is a strong tendency to study individual decision maker's perceptions of their use of research (Innvaer, Vist et al. 2002) as if the way research is used in policy is a simple aggregation of their individual skills, choices and perceptions. The current crop of strategies to increase the use of research in policy, referred to as 'research transfer' and 'linkage and exchange' or 'collaboration' (Lomas 2000; Matthews, Jenkin et al. 2001), owe their design to the 'two communities' diagnosis of the perceived problem. The close connection between these 'solutions' and the 'two communities' diagnosis is shown by the way that the current strategies seem to have advanced very little since they were first articulated alongside the theory in the 1970s (Caplan, Morrison et al. 1975: 50-52; Caplan 1979: 468).

I began this research project because I was dissatisfied with the insights that the research utilisation literature provided to my own work as a public health bureaucrat. I felt that there was no shortage of contact with researchers or with research and that, while there are systematic differences between researchers and policy makers in their worldviews, skill sets and professional values, these did not seem important to the way research is used in policy. From my day to day work in public health, it was clear that some researchers had excellent access to the bureaucracy and some did not. It was also clear that some research was treated with great respect in policy arguments and some was disregarded. None of this seemed to be simply a function of the ability of researchers and policy makers to communicate across what is often described as 'the gap' between researchers and policy makers (Caplan 1979: 460). The quality of the research played a part but not consistently. The political preferences of the government mattered but seldom overwhelmed or excluded all other considerations. To get to the bottom of this, I wanted to pursue ways of understanding the research-policy nexus that did justice to factors such as the role of interest groups, the constitutional realities of making policy in federation, the beliefs, values and assumptions of policy actors, and the subtle but pervasive influences of public discourse. All of these seemed to have some impact on the way research appeared in policy debates, was filtered, shaped, or rejected.

To make this research task manageable, I have broken my general research question into two clusters of more specific questions. First, what role does research play in the policy process? Does research influence policy? If so, in what ways does this occur? How does it occur? To what extent does it occur? Second, what happens when research and policy

are at odds? Why does policy sometimes change in response to discrepant research, and sometimes not? I also needed to target my theoretical efforts. Through the process described in Chapter 2, I arrived at and developed three ‘focal theories’:<sup>1</sup>

- the Advocacy Coalition Framework (ACF) of Sabatier and Jenkins (Sabatier 1993);
- the Policy-making Organisation Framework (PMOF) developed from the work of David Dery (Dery 1990) and elaborated with insights from the public policy literature on the role of institutions;
- the Governmentality Framework based on the work of Michel Foucault (Foucault 1991a) and several of his interpreters, particularly Mitchell Dean (Dean 1999), and Rose and Miller (Rose and Miller 1992).

My specific research question in relation to these theories has been ‘what contribution do these theories make to our understanding of the research–policy relationship?’. Further, I have asked ‘what do the results of this analysis mean for our understanding of the relationship between research and public health policy in Australia?’.<sup>2</sup> To assist in answering this question I have used a framework developed by Rudra Sil for considering both the adequacy of social theory and the opportunities for theoretical eclecticism (Sil 2000).

Public health policy is a broad and complex field. To make these research questions tractable, I have had to develop a methodologically sound way of scoping and focusing data collection and analysis. I did this by adopting a case study design and selecting four case studies of ‘national public health policy’—Breast Cancer Screening (BCS), Prostate Cancer Screening (PCS), Needle and Syringe Programs in the community (NSP-Community), and Needle and Syringe Programs in prisons (NSP-Prisons). The definition and scope of national public health policy are discussed below and Chapter 3 presents a detailed discussion of the case study design and case study selection.

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<sup>1</sup> By ‘focal’ theories I mean theories that are the focus of empirical analysis in this thesis. Chapter 2 gives a rationale for their selection based on their explicit acknowledgment of research within the process of policy development.

<sup>2</sup> The three research questions are brought together in the Chapter 1 appendices.

## 1.2. The research–policy problematic

The problem of how we understand the relationship between research and policy is important for four reasons. First, the relationship has long been described as problematic. Second, there are attempts within Australia, in other countries and internationally to try to ‘improve’ research use in health policy. Third, the idea of Evidence-Based Health Policy (EBHP) is attracting increasing attention and is premised, in part, on the assumption that research use is not all that it could be or should be. Fourth, research use in policy is now being proposed as a measure of the value of research and a yardstick for evaluating the return on investment in research. Each of these aspects of the research–policy problematic will be discussed as a way of locating this research in a wider context and to introduce some of the major themes that will recur during the thesis.

It seems that the most vigorous exponents of the art of problematising the research–policy relationship are researchers who argue the relationship is like ‘the sound of one hand clapping’ (Lomas 1997) or ‘a dialogue of the deaf’ (Last 1999). There are many anecdotes to support this rhetoric. Lomas tells the story of how it took the British merchant navy 263 years to introduce citrus juice to prevent scurvy among sailors following the demonstration of its effectiveness in 1601 (Lomas 1997: i). A more recent example is the continuing 40 year struggle to introduce anti-tobacco policies following research showing the damaging effects of smoking on human health (Chapman and Leeder 1991; Fritschler and Hoefler 1996). Policy responses to the growing body of research showing that socio-economic inequalities generate a corresponding gradient in morbidity and mortality seem to follow a tortuous route (Whitehead 1998). McMichael has recently argued that the science showing the deleterious effects of global warming has so far been unable to generate sufficient political will in the United States for that country to support the Kyoto Protocol (McMichael 2001).

While it is relatively easy to develop lists of research that has had a tardy or interrupted passage to policy influence, it is much harder to understand why this has occurred. The facile response is to lay blame, either implicitly or explicitly, on the intelligence or principles of policy makers. How else could a policy maker not ‘know’ that citrus prevents scurvy given its clear demonstration in a scientific experiment and then not give it to sailors? Of course, each of the examples above expands the scope of the policy required to respond to the problem identified by the research. Citrus juice is something

that can be delivered locally while the Kyoto Protocol is a policy of staggering complexity. As the scope of policy decisions broadens, so too does the range of parties with vested interests, the research that is germane to the policy, and the room for debate about how to interpret the research and what its policy implications are. It is also worth remembering that it is not just policy makers who have difficulty changing their minds in response to new data or ideas that contradict cherished beliefs and challenge professional or political interests. The history of science is replete with examples of distinguished scientists demonstrating this human foible (Kuhn 1962: 59). In the rush to find fault or ‘fix’ the perceived problem of lack of research use, it is possible that some more fundamental factors are overlooked. For example, in Mauldon’s analysis of the tardy response to the research showing citrus prevents scurvy, she argues that the problem for James Lind, the experimenter, was that he did not believe his own results. ‘To begin with there existed no belief system which could account for the apparent effect of fresh fruit on scurvy...’ and so for others at the time, his findings were ‘effectively irrational’ (Mauldon 2000: 41,42).

In light of the above, perhaps the most productive kind of relationship between research and policy would be one that is characterised by perpetual tension. From the policy side, it seems highly impractical and unwise that policy makers should change policy every time a new piece of research appears. From the research side, the evangelical zeal driving some public health researchers means that they see it as their duty to assail the powerful with their research and demand government action and accountability on matters relating to the health of the public.

This tension between deliberation and advocacy is important for considering the theories used to understand the relationship between research and policy. The research utilisation literature, particularly the ‘two communities’ theory, has difficulty accounting for the role of researchers as advocates. As noted in the quote from Caplan above, researchers are cast in a role where they are in search of the ‘pure’ and the esoteric and are disinterested in politics. These assumptions simply do not hold in the field of public health. Advocacy is part of the credo for many public health researchers. This is shown by the continuing references in public health discourse to the heroic narrative of John Snow’s removal of the Broad Street pump handle in mid-19<sup>th</sup> century London to prevent the spread of cholera. In this narrative, the researcher identifies a cause of ill health and takes direct action to protect the health of the population by

changing the physical environment despite the fierce opposition from vested interests. Samet argues that the Broad Street pump example is the quintessential example of epidemiology influencing policy (Samet 2000). Alex Wodak invokes this narrative to support the actions of public health activists around the world who broke the law in order to introduce Needle and Syringe Programs and protect injecting drug users from HIV and other bloodborne viruses (Wodak 1997). Breslow's reflections on the public health struggle against tobacco in the United States led him to conclude 'Boldness in advocating preventive measures based on strong epidemiological evidence' is the most important thing to learn (Breslow 1996: 375).

The tradition and ethic of public health advocacy resonates strongly with the Enlightenment ideal that science can and should contribute to a better world. Tesh (Tesh 1988: 167) analysed the hidden politics of disease prevention policy and argued that:

...science is both a collection of ideological beliefs and an agency for liberation. As an agency for liberation it substitutes democracy for political and religious authority. Demanding evidence for statements of fact and providing criteria to test the evidence, it gives us a way to distinguish between what is true and what powerful people might wish to convince us is true.

Donald, like Tesh, invokes the Enlightenment ideal when she argues that Evidence-based Medicine (EBM) has been a liberating force in the UK health system, reducing the negative effects of 'uninformed authority' just as '...scientific rationalism was eagerly promoted by people longing to be free of the blind authority of the Church' (Donald 2001). The views of Donovan, Tesh, Wodak, Samet and others point to a tradition of idealism and activism that leads public health researchers to problematise the research-policy relationship. This is not a recent phenomenon. Writing in 1961, Rosen reviewed the public health struggles over a period of 100 years in the United States and concluded:

If the history of public health teaches us anything, it is this. Just as the pioneers of public health used facts, figures, ideas and social action to improve the health of the community, we too, if we wish to be true to their spirit, cannot remain content with good intentions but must endeavour to put into practice the knowledge that is ours. Where we do not have it, we must try to obtain it. For we have a professional and moral responsibility to work for a social and cultural environment in which human beings can live a healthier and happier life (Rosen 1961: 1017).

Thus, the quest to get policy to respond to research is not new and researchers have often seen it as their moral duty and their historically ordained role to harangue reluctant governments into action. Seen in this light, the roles played by public health researchers in the case studies that follow will come as no surprise. The capacity of the ‘two communities’ theory to cope with this feisty view of the role of the researcher is limited.

This is not to say that there is consensus among public health researchers on the matter of advocacy. There are some public health researchers who eschew policy activism and think that they should stick to science (Samet 2000). In the case of Needle and Syringe Programs for example, Moss regrets the implications for the perceived independence of epidemiology occasioned by epidemiologists engaging in ‘moral crusades’ (Moss 2000a). Des Jarlais disagrees with him, arguing that when lives are at stake, research and advocacy are inseparable (Des Jarlais 2000). Those coming from the perspective of the critical social sciences, particularly feminist researchers, are willing to join epidemiologists in advocacy on behalf of disempowered groups (Lawless, Kippax et al. 1996; Waterston 1997).

It should also be mentioned that there are other perspectives that question the Enlightenment view of science and its historic mission. This critical view of public health will be elaborated in the discussion of the Governmentality Framework in Chapter 2.

The concept of Evidence-based Health Policy (EBHP) has highlighted a conceptual and normative problem for the study of research use in policy, which is the difficulty in specifying the goal of research utilisation. In 1980, Dunn asked the question ‘Knowledge utilisation for what?’ and challenged the implicit assumption that knowledge utilisation automatically results in effective problem-solving (Dunn 1980: 532). Lavis and others also note that research use per se does not result in well-informed policy (Lavis, Ross et al. 2002: 140).

The concept of EBHP provides something of an answer to the question of the purpose of research use in policy, but not a complete one. In an article titled ‘Evidence-based policymaking: Research must inform health policy as well as medical care’, Ham and others argued that health service ‘reforms’ should go through a period of pilot testing before being introduced. They also argued that there should be an independent institute for health policy analysis with an independent source of funding to ensure that

unpalatable research results were not buried. The institute would act as a ‘bridge’ between research and policy. They also proposed that new policies should be ‘...accompanied by a statement of the evidence that was consulted in their preparation’. This might not stop ‘oddball’ policy completely, but ‘...it would at least give politicians pause for thought’ (Ham, Hunter et al. 1995). Seen in abstract terms, Ham and others were proposing five principles for making evidence-base policy: a commitment to evaluation research and the pursuit of policy that is effective and efficient; an independent policy research infrastructure; increased accountability of policy makers; more structured engagement between research processes and policy processes; and, an explicit and transparent engagement by policy makers with research.

There are two points to make in regard to Ham and others’ prescription. First, they argue for separate roles for research and policy, imply that there will be strong tensions between those roles, take a pejorative view of policy vis-à-vis research, but still argue for co-operation across ‘bridges’. This might be thought of as the ‘conflict’ version of the ‘two communities’ theory, one that Caplan refers to in his original outline in 1975 (Caplan, Morrison et al. 1975: xi). In my reading of the literature, this version of the ‘two communities’ theory is much less in evidence than the version that focuses on differences in culture, expectations and language that can be overcome with better communication and opportunities for collaboration, linkage and exchange. This issue will be taken up towards the end of the thesis in further discussion of the ‘two communities’ theory. The second point to note here is that discussions of EBHP should be thought of as discussions about how policy should be made. That is, they are attempts to propose a policy on policy making or, as I argue in Chapter 9, they are attempts to make ‘meta-policy’. In Chapters 9 and 10 I take this discussion further and specify the challenges associated with making meta-policy in public health. Further, I argue that the field of research on research use in policy requires a thorough discussion on this matter if it is to progress beyond the normative and theoretical hurdle that is presented by the question ‘research use for what?’.

There is one further matter that makes this research project timely and relevant and that is the politics and policy making around health research funding. In 1998, the Commonwealth Government commissioned the Health and Medical Research Strategic Review which, among other things, recommended increased resources for ‘priority driven research’, ‘strategic research’, and ‘health services research’ (Health and Medical



Research Strategic Review 1998). The National Health and Medical Research Council has recently been considering how it should fund such research and make sure it makes an impact on policy. Jonathon Lomas was invited to present to them on this matter recently (Lomas 2003). Landry has also noted the increasing need for research to demonstrate its value for money by showing impact on policy (Landry, Amara et al. 2001) and the same matter is now on the agenda of the World Health Organisation (Hanney, Gonzalez-Block et al. 2003: 2). The question of whether research should be evaluated in terms of its impact on policy is an important one that is dependent, at least in part, on how we understand the relationship between research and policy. This matter is considered in Chapter 10 in the light of the findings of this research.

### **1.3. Scope and definitions**

#### **1.3.1. *'Public health' and 'national public health policy'***

Researching the role of research in health policy faces many methodological problems, not least of which is how to construct a typology and sampling frame of health policies (Lavis, Ross et al. 2002: 126-32). This problem was resolved by choosing to focus on a particular area of Australian health policy that can be described as 'national public health policy'. 'Public health' is taken to mean 'the organised response by society to protect and promote health, and to prevent illness, injury and disability' (Commonwealth of Australia and State and Territory Governments of Australia 1997). Thus, it is primarily concerned with those aspects of health policy variously described as health protection, health promotion and disease prevention. This study does not attempt to deal with health policy relating to primary health care, acute care or aged care though it is often difficult to draw strict boundaries between these and public health as defined above (Starfield 1996). I also recognise that 'public health' is not a static concept. It would be possible to do another thesis on the role of research on changing conceptualisations of public health. This would cover, for example, the impact of bacteriology on the 'new public health' of personal hygiene in the early 20<sup>th</sup> century, and the impact of epidemiology and health promotion on the 'new public health' of lifestyle modification of the late 20<sup>th</sup> century (Nutbeam 1986; Fee 1991; Holman 1992).

There is no single, integrated government document that carries the title 'Australia's national public health policy'. Rather, over a period of decades, the Commonwealth and

the States and Territories have agreed to policies and programs that are accorded the status of ‘national policy’ or ‘national strategy’ or something similar. These vary in their scope and focus and in the resources devoted to them. The main reason for this evolutionary approach is that under the Australian Constitution, responsibility for public health as defined above rests with State and Territory Governments. The only exception to this is human quarantine which the Commonwealth is responsible for. Ever since a national program of grants to the States to combat tuberculosis and venereal disease began in 1915 (Rydon and Mackay 1989: 206), the Commonwealth Government has been involved in an increasing number of public health matters. Using section 96 of the Constitution it has provided Specific Purpose Payments to State and Territory Governments for an increasing number of programs (Rydon 1989: 23). These institutional factors receive some attention but not as much as they could in a study with a different focus. It would be possible, for example, to conduct research on the role of research in what Lavis and others would call the overall ‘trajectory’ (Lavis, Ross et al. 2002: 132) of the public health effort in Australia, but that would be a much larger study than that which is pursued here.

The primary way chosen to represent and discuss ‘national public health policy’ is in terms of policies that the Commonwealth and State and Territory Governments have deemed to be such. The list of these policies has varied over time. The list I used for selecting case studies in 1999 came from a document endorsed by the National Public Health Partnership, the most senior committee of Commonwealth and State and Territory Government officials that deals wholly with public health policy (National Public Health Partnership 1999). It is a subcommittee of the Australian Health Ministers’ Advisory Committee. The list of policies and the sampling strategy are set out in Chapter 3.

### **1.3.2. ‘Research’**

What do I mean by ‘research’? The Organisation for Economic Cooperation and Development definition is:

creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of man [sic], culture and society. (OECD 1994)  
(Short 1997: 66)

I think this is a useful starting point. The focus of this study is public health research, by which I mean research that seeks to increase the stock of knowledge about the health of human beings, or measures to improve the health of human beings. Also relevant to the study is research that could be used to make informed judgements about how government might best act to improve the health of the population. One further qualification is important—the focus is on research that is published in some form or another. When the word ‘research’ is used, it is in this sense of citable, population-health-relevant research. Lavis and others use the concept of ‘citable research’ in their study of research use in Canadian health policy (Lavis, Ross et al. 2002: 134).

I have chosen to exclude public opinion polling because the primary purpose of that research does not seem to be about health per se. It is relevant to the research–policy nexus, not because it fits the definition of research but because it is another input to policy-making processes.

I do not use the word ‘evidence’ interchangeably with ‘research’, though many writers such as Elliott and Popay (Elliott and Popay 2000) and Black (Black 2001) do. This appears to be a confusion brought about by the EBM movement where ‘evidence’ sometimes appears to denote a status given to published research after it has been evaluated and synthesised in a systematic review, but not always. The process of selecting research and constructing a new entity called ‘evidence’ seems to have the intent of investing research with additional status in the policy process. This process is part of what will be studied in this thesis and the distinction between ‘research’ and ‘evidence’ will be maintained throughout.

### **1.3.3. ‘Policy’**

Definitions of ‘policy’ are something that even the largest public policy textbooks avoid (Wildavsky 1979: 2; Parsons 1995: 1-16). However, a brief discussion of definitional issues will highlight a critical issue for this study.

Considine says a ‘standard definition’ of policy is ‘...an action which employs governmental authority to commit resources in support of a preferred value’ (Considine 1994: 3). Palmer and Short’s definition of health policy is consistent with this but less specific about what kind of ‘action’ has to take place before it can be called ‘policy’. They say that health policy is “...courses of action that affect that set of institutions,

organisations, services, and funding arrangements that together is called the health care system” (Palmer and Short 1994: 23)’ (Short 1997: 66).

These definitions do not include policy discourse or policy argument within the ambit of policy. A post-modernist perspective argues that the language, rhetoric and metaphor used in policy are critical to understanding its power and authority (Majone 1989; Fischer and Forester 1993; Rein and Schon 1993; Danziger 1995; Legge 1996). As will become clear in the case studies, unless we include language and argument within our conceptualisation of policy there is a chance that a primary point of articulation between research and policy will be missed (Weiss 1991). For example, the language of problem definition and agenda setting are well recognised as key aspects of the policy process (Dery 1984; Miller 1999; Parsons 1995: 87-92). Failure to capture these within the definition of ‘policy’ would mean that the basic task of epidemiology in identifying the size, causes and characteristics of a disease outbreak or some threat to the health of the population is lost from view.

The above definitions also do not include the possibility that government *inaction* may be as much a deliberate policy as government *action* (Heidenheimer, Hecllo et al. 1990: 5). Two of the case studies explore the role of research in the decisions not to introduce Needle and Syringe Programs in Australian prisons or Prostate Cancer Screening and, therefore, inaction is included within the definition of ‘policy’ used here.

#### **1.4. Thesis overview**

The next chapter reviews the literature on the relationship between research and policy. It identifies the problems with that literature in terms of the lack of an adequate theory of the research–policy relationship. The three focal theories are then introduced. It is argued that they each show promise in overcoming the problems in the current literature. Chapter 2 also introduces Sil’s framework for theoretical eclecticism (Sil 2000) that will be used to compare and evaluate the three focal theories and enable the development of criteria for an adequate theory of the research–policy relationship. Chapter 3 outlines the research methods including the rationale for case study selection and analysis.

Chapters 4 to 7 present the four policy case studies—Breast Cancer Screening (BCS), Prostate Cancer Screening (PCS), Needle and Syringe Programs (NSP-Community) in

the community, and Needle and Syringe Programs in prisons (NSP-Prisons) respectively. These chapters are presented in two halves. The first half presents an account of the policy process, the political context, key events and the actions of policy actors. The second half analyses this data using the three focal theories to identify particular patterns and causal relationships between various events and factors in the research–policy nexus. There is a ‘Key Events Table’ for each case study in the Appendix. These present the chronology of the policy process. There are also tables of Australian research, who it was done by, the affiliations of the researchers, and their position with regard to the policy issue at hand. At the conclusion of each of the case study chapters is an evaluation of the three theoretical frameworks and a discussion on the more general theoretical issues raised by the focal theories. This is guided by Sil’s framework. The concluding section of each case study gradually builds a theoretical argument that is brought together in Chapters 8 and 9.

In the first part of Chapter 8 I conduct a cross-case analysis. The study design of three focal theories and four case studies creates many possible combinations and permutations for cross-case analyses. I have chosen to focus on the contribution of each of the focal theories to our understanding of the research–policy nexus. In the second part of Chapter 8, I continue the process of general theorisation, building on the discussions at the end of each of the case study chapters.

In Chapter 9 I discuss the quest for EBHP, drawing on the findings and ideas from the previous chapters. I argue that discussion of the concept of EBHP is still in its formative stages and that some fundamental conceptual work is required before this discussion can proceed. The particular issue addressed at the beginning of Chapter 9 is that there is no consensus on a definition of EBHP and the quest for EBHP has not yet been adequately specified. I argue that this quest is an attempt to make meta-policy, or policy on policy-making. When this is recognised, a number of meta-policy-making challenges emerge. The second part of that chapter discusses the application of the new knowledge developed from the case studies to the resolution of these challenges in the everyday world of policy making.

In Chapter 10 I revisit the ‘two communities’ theory and highlight the way it is still being used as the default explanation for the dynamics of the research–policy nexus in the most recent literature on research use in policy. I then identify ten assumptions that underpin the ‘two communities’ theory and strategies such as ‘research transfer’ and

argue that the data from this study suggests they should be abandoned. I conclude the thesis by arguing that the way forward in the study of research use in policy requires the development of new metaphors, a wider theoretical repertoire, more sophisticated methodologies, and attention to the task of making meta-policy. I identify the contribution made by this thesis to each of these and discuss the limitations of this study.

## **2. Models and Theories of the Relationship Between Research and Policy<sup>3</sup>**

### **2.1. Introduction**

The purpose of this chapter is to review the literature that describes or theorises the relationship between research and policy, argue the need for a richer theoretical repertoire to understand this relationship, and propose three theories that show promise in doing this. The research utilisation literature is divided into those approaches that focus on describing the research–policy relationship through descriptive models and those that attempt to explain the relationship through theory. The limitations of current approaches are identified as: the tendency to focus on the individual decision maker separate from their social or organisational context; the tendency to adopt relatively simplistic models of policy making; the perception of research as apolitical; the neglect of power and values; and a lack of reflexivity in failing to see the quest for research utilisation as a political act. Landry has argued that ‘...the field of knowledge utilisation is still in its infancy regarding the development of a general theoretical framework that explains the conditions under which research is utilised’ (Landry, Amara et al. 2001: 397). I agree with this point but add that the field is not so much devoid of any theory, rather, it is overly reliant on the ‘two communities’ theory. To redress this, I discuss some general theoretical orientations to the research–policy nexus and then introduce the three focal theories used in this study. The basis for their selection is the promise they offer in overcoming the problems identified above. Lastly, the framework for theoretical eclecticism proposed by Rudra Sil is introduced and its role in evaluating the focal theories and identifying a general theoretical form is discussed.

### **2.2. Theory and the study of research use in policy**

Attempts to understand the relationship between research and policy can be divided into two strands. The major one of these has concerned itself with developing descriptive

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<sup>3</sup> A version of this chapter has recently been published as Gibson, B. (2003). 'Beyond "Two Communities"'. Evidence-based Health Policy: Problems and Possibilities. V. Lin and B. Gibson.

models of how research is used in policy. The minor one has attempted to explain research use in terms of a theory that posits causal relationships between the variables and factors in the research–policy nexus. While the descriptive models have become very sophisticated (the latest one put forward by Hanney and others being a case in point (Hanney, Gonzalez-Block et al. 2003: 9-11)) they share a fundamental weakness which is an inability to identify the role of power in the selection of values that guide research use in policy making. The relatively small amount of theoretical work has been done to explain how, where and why research influences policy (or is used or not used in policy), is underdeveloped, dependent on the ‘two communities’ theory, and poorly articulated with the plethora of descriptive models on offer.

Innvaer and others make the same distinction I have made here but do not identify the differences between these approaches in the same way (Innvaer, Vist et al. 2002: 242).

### **2.2.1. Models of research use in policy**

The study of research use in policy has produced a large number of models of the research–policy nexus (Beyer and Trice 1982; Weiss 1986; Bryant 1995; Short 1997; Oh 1998; Landry, Amara et al. 2001; Hanney, Gonzalez-Block et al. 2003). This work began in the field of social science research utilisation in the 1970s and grew out of the ‘disenchantment’ of social scientists with the use of their work in policy (Weiss 1986: 40). Not surprisingly, for some of the model builders the act of describing how research is used has been closely related to prescribing how research should be used (Bryant 1995; Elliott, Harries et al. 1996; Short 1997; Lomas 2000).

In the following analysis of various models of research use in policy, I will explore two separate themes. One is the way that some versions of these models attempt to come to grips with the notion of research *transformation* which will be discussed later in the chapter. Related to this is the way that all of the models deal with two fundamental dimensions of research use in policy, one that deals with the *form* of research use and the other that deals with the *manner* of research use. I argue that the second of these dimensions is poorly handled in all of the models developed so far.



Weiss's typology of the seven uses of social science research in policy (Weiss 1986) is a point of reference for many subsequent attempts to understand the research–policy nexus (Innes 1990: 12; Hanney, Gonzalez-Block et al. 2003). Weiss's models are set out along with some comments from me pertinent to the discussion that follows.

- *The knowledge-driven model*: this is a linear model where knowledge and information from basic research leads to applied research which leads to developmental research and application. Weiss identifies the pathway from biochemical research to the contraceptive pill as an example (Weiss 1986: 31–2). The assumption is that the mere existence of the knowledge will create an impetus to its application in technology. Weiss is arguing that in this model the role of overt political value choices is either absent or implicit.
- *The problem-solving model*: This is where policy makers search for research to solve a problem. The pathway in this case goes from the definition of a problem, to identification of missing knowledge, to acquisition of research (either ready made or commissioned), to interpretation of research for the decision context, to policy choice. Weiss argues that this model is also linear and only applicable around 'low-level, narrow gauge decisions' (Weiss 1986: 34). I think that this model is not so much a different form of use but a different process by which research is produced.
- *The interactive model*: This is where policy problems give rise to untidy processes involving networks of consultation and communication between decision makers and stakeholders, including researchers. The most likely scenario is that for any policy problem there is unlikely to be any directly applicable research, and what is available is not convergent. Weiss also described this as the interaction of Ideology, Interests, and Information or I-I-I model. (Bryant 1995). I think that the critical element of this particular model is the high degree to which researchers and other stakeholders are involved in the process of producing and interpreting research.
- *The political model*: This is where research is used as a political resource to support positions that are politically derived by various interests. I think that this model can be distinguished from the previous one by the way that researchers and other stakeholders are excluded from the process of research

selection and interpretation and that the values that drive research selection are imposed for political reasons.

- *The tactical model*: This is where political actors use research to manipulate policy processes—the act of commissioning or conducting research might be a tactic to delay decision making or garner support from various interests. Other tactical uses of research might be to align particular policy positions with prestigious researchers or institutions so as to gain support. Beyer and Trice described the ‘symbolic’ use of research to denote what Weiss separates out as the ‘political’ and ‘tactical’ models. (Beyer and Trice 1982).
- *The enlightenment model*: This is where research influences policy by framing the way that problems are thought about through theories and concepts that enter into everyday discourse and thinking of policy makers. Weiss cautions, however, that research might lead to as much ‘endarkment’ as ‘enlightenment’. I think that when Weiss talks about ‘endarkment’ she is identifying an overtly political form of what is sometimes referred to as the ‘conceptual’ uses of research.
- *The intellectual enterprise model*: This is where research is not an independent variable acting on policy but a dependent variable alongside policy with both interacting with currents of thought and other factors in the wider society. According to Weiss’s description here, I do not think this is actually a form of research use in policy so much as a wider effect of research that may then lead back into policy via one of the other forms of research use.

Other model builders have taken Weiss’s seven models and suggested their own variations. Bryant makes an important addition that has influenced the health research transfer literature (Bryant 1995). He presents four models, three of which are drawn largely from Weiss: social engineering, interactive, and enlightenment. The fourth, the ‘dialogical model’, is based on the British sociologist Anthony Giddens’ understanding of the relationship between sociology and the wider society. In this model, sociology and society interact and change each other in the process. This is referred to as the ‘double-hermeneutic’ where the social world reflexively appropriates knowledge about itself and changes as a result.

Elliott and Popay (Elliott and Popay 2000) have tested the ‘dialogical model’ in research on decision making at the local level of the British National Health Service. They compared it with Weiss’s ‘problem solving’, and ‘interaction’ models in seven case studies of specific research projects. They found only limited explanatory power for the problem solving model because it failed to account for the fact that it is the process of problem definition that is often intractable and contentious (Elliott and Popay 2000: 462). The interactive model had more empirical support because it reflected researchers’ experience of having to jockey for positions of influence in the policy process. The dialogical model reflected the way that some researchers and policy makers attempted to work with each other but did not seem to capture all of what was occurring in the research–policy nexus. Elliott and Popay make an unacknowledged shift between their exploration of the dialogical model as an explanatory framework and their adoption of the notion of ‘dialogue’ between researchers and policy makers as a normative model that they believe should take place. Hence their conclusion is that ‘The study highlights the role for sustained dialogue between researchers and the users of research in improving the utilisation of research-based evidence in the policy process’ (Elliott and Popay 2000: 461). They reach this conclusion despite their analysis of the data that seems to point to the interactive model being the best explanation for what actually took place in the case studies. They also seem to misunderstand the dialogical model as they slip into talking about dialogue between researchers and policy makers and hence default to a simple communication model. A more thorough appreciation of Giddens’s concept of dialogical processes needs to include the possibility that there is some kind of transformation taking place when groups work together to create new knowledge and act on it.

Short has explored research utilisation models in the Australian context (Short 1997). Drawing on Weiss, Short explicated four research utilisation models. Her ‘engineering model’ is roughly equivalent to Weiss’s ‘knowledge-driven’ model. She adopts the ‘enlightenment’ model, as per Weiss’s framework, and locates it in the sociology of Durkheim. Short adds a ‘materialist model’ which combines Weiss’s ‘political’ and ‘tactical’ models but overlays them with the idea that policy making and idea generation are a function of the interests of the ruling class working in a capitalist society. Short develops a new model, the ‘Elective Affinities’ model which she locates within the larger sociological tradition of Max Weber. She uses it to denote the interaction between ideas and interests as in Weber’s understanding of the interplay between the religious

ideas of Calvinism and the economic interests of the entrepreneurial classes in the development of capitalism.<sup>4</sup> This model has some of the elements of Weiss's 'interactive' and 'intellectual enterprise' models.

Short explores the value of these four models in explaining the role of research in Federal Government funding for the Consumer Research Development Funding Program and the Community Organisations Support Program in the late 1980s. In a very truncated analysis of the value of the models she concludes that the engineering and materialist models provide little by way of insight. She argues that the elective affinities model provides the best explanation of the role of research as the particular pieces of research involved had been commissioned by the Health Ministers of the time in order to build support for programs that they wanted to fund. Short concludes that '...the elective affinity model suggests that research is more likely to affect policy development when it reinforces the values and goals of policy makers, and when the outputs of the research process are compatible with policy makers' perceptions of the pragmatic realities of the policy-making process' (Short 1997: 79). This finding echoes Fox's conclusions on health research use in US health policy (Fox 1990). It is also supported by Aldrich's case study of the development of the Chlamydia Control Campaign in NSW between 1989 and 1991 where a small amount of research of dubious quality had a significant impact on policy once it was framed in a way that supported the prevailing constellation of interests and ideologies (Aldrich 1995).

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<sup>4</sup> Short's use of the term does not do justice to Weber's concept. The term 'elective affinity' refers to a chemical reaction where two elements in stable coexistence are thrown into a wild reaction by the introduction of a third. Goethe used the term as a metaphor in a novel with the title *Elective Affinities* to describe the changes wrought to a marriage by the arrival of a third house-guest Goethe, J. W. v. (1963). *Elective Affinities*. Chicago, Henry Regnery Company. Weber borrowed the term from Goethe as an analogy for the interaction of ideas and interests in the interaction between Protestantism and Capitalism. The essence is not just that Protestantism provided the capitalist personality with a commitment to hard work and success and frugality. This is just the first stage of the reaction. The result is just as important—the growth of wealth led to a change in the Protestantism and to a particular kind of Capitalism. Weber argues that asceticism created a world order which now binds and determines the lives of all individuals born into it. The 'cloak' of material possessions which the saint should be able to throw off anytime has become an 'iron cage'. Further, the capitalism that asceticism created no longer requires that asceticism. '...the pursuit of wealth, stripped of its religious and ethical meaning, tends to become associated with purely mundane passions, which often actually give it the character of sport' Weber, M. (1930). *The Protestant Ethic and the Spirit of Capitalism*. London, George Allen & Unwin Ltd.. Thus the term is meant to identify the way ideas and interests choose each other but are both changed irrevocably.

Short's study is valuable because of its methodological contribution. Its problems lie in the way that the 'elective affinities' model is insufficiently differentiated from Weiss's 'interactive' model to warrant the new term, and in the way the analysis of the value of the different models is so truncated that the conclusions seem less than robust. She, like Elliott and Popay, slips between explanatory and normative use of models—at one point she identifies the elective affinities model as preferable because it 'supports a more democratic research process' (Short 1997: 71). Short also seems to not use the 'elective affinities' concept in its full sense of mutual attraction leading to interaction and the transformation of all parties involved.

Two key points emerge from this brief review of research utilisation models. The first is the way that each of the groups of models include some recognition of what might be called 'transformative' social processes in the use of research. That is, that through the processes of interaction between policy makers, researchers and others, change can occur in the way that people think and in the way that research is perceived. This notion is present in terms like 'enlightenment', 'dialogical', and 'elective affinities'. This will be discussed further below.

The second key point is that all of the models are dealing in different ways with the *form* of research use and the *manner* of research use. The form of research use is seen to vary between the 'instrumental' use and 'conceptual' use. Most model builders identify particular types of research that tend to get used in more or less conceptual or instrumental ways. For example, the results of trials of the cost-effectiveness of a new pharmaceutical to control blood pressure will be used in an instrumental manner. The decisions it is likely to inform are described by Weiss as 'narrow gauge'. This kind of research is unlikely to change the way policy makers think about blood pressure or ways of evaluating pharmaceuticals. On the other hand and hypothetically speaking, a study showing that government funding mechanisms were systematically biased towards funding pharmaceuticals rather than more cost-effective forms of preventive interventions would challenge policy making processes themselves and its use is likely to be more conceptual, indirect and long term. The *form* dimension is further specified in the table below and tends to be well captured in all of the groups of models.

The second fundamental dimension concerns the *manner* in which research is selected and appraised for policy. This can vary between democratic, transparent and cooperative processes on the one hand and coercive, secretive and authoritarian

processes on the other. What is at stake in this dimension is the way that power is used to determine what values will guide the selection of research to inform or support policy. This dimension is not well handled and causes most confusion and problems for the research use model builders.

The commonly made three-way distinction in forms of research use between ‘instrumental’, ‘conceptual’ and ‘selective’ (Innvaer, Vist et al. 2002: 242) makes the error of confusing these two dimensions. I believe that the ‘selective’ use of research can apply equally well to either the instrumental or conceptual forms of research use but is commonly differentiated because of the need to capture occasions where the imposition of political values in the process of research use is particularly coercive.

The reason why the democratic–coercive dimension causes confusion in model building is that there is a general reluctance in the research utilisation literature to accept that values guide all research use. Thus, it is only when the value-base of research selection is imposed politically that there is seen to be a need to separate it out from what are viewed as value neutral kinds of processes.<sup>5</sup>

The two dimensions of research (form of use and manner of use) are set out in tables 2.1 and 2.2.

**TABLE 2:1 THE FORM OF RESEARCH USE CONTINUUM: FROM INSTRUMENTAL TO CONCEPTUAL**

<b>Instrumental</b>	<b>Conceptual</b>
Research outputs are relatively simple involving specific answers to specific questions—Yes/no, How much? How many? Where? How?	Research outputs are complex, equivocal, unresolved by single studies, multidisciplinary
Use of research is instrumental—the direct application of specific research findings to specific policy problems	Use of research is conceptual—the indirect consideration of research along with other sources of information
More likely to occur with quantitative research especially in the physical or biological sciences	More likely to occur with qualitative research especially in the social sciences

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<sup>5</sup> On this basis, I would argue that Hanney and others recent development of eight new models of research use is flawed. They begin by making the common distinction between instrumental and conceptual uses (which they render as ‘conceptual modelling’ and ‘data-based policy’) and this provides the first dimension of their models. However, the second dimension, begins by distinguishing between ‘technical’ and ‘political’ choices of data. I would argue that there is no such thing as a purely ‘technical’ use of data and when this appears to be the case it is because the values questions have become invisible because they were resolved in establishing the policy frame that guides data selection. The other types of research use that they identify are elaborations of the different ways in which power and values choices affect the way policy actors use research in different settings. While these distinctions are insightful and useful, I believe the process of research use model building has reached the point of diminishing marginal returns.

<b>Instrumental</b>	<b>Conceptual</b>
Application moves relatively quickly to capitalise on latest knowledge	Application moves slowly via changes to conceptual models.
Often related to the way things are done—doing things right. Can challenge instrumental decision making in procedures and practices	Often relates to the way things are thought about—doing the right things. Can challenge beliefs and values
Application driven by technology and economic considerations.	Application mediated by social processes.
The research–policy nexus is situated in a relatively closed system with few other variables intervening	The research–policy nexus is situated in an open system with many other interacting variables
Research moves in a linear fashion to development and implementation	Research and policy processes interact in an iterative fashion

**TABLE 2:2 THE *MANNER* OF RESEARCH USE CONTINUUM: FROM DEMOCRATIC TO COERCIVE (OR POWER AND VALUES CONTINUUM)**

<b>Democratic</b>	<b>Coercive</b>
Researchers and decision makers collaborate in the conduct and interpretation of research	Decision makers pursue their own interests in ignorance or defiance of research
Researchers and other stakeholders included in decision making processes	Decision making processes closed and secretive
Strengths and weaknesses of research evaluated and communicated	Research used selectively to suit political purposes
Researchers and decision makers are equal partners and joint problem solvers	Researchers are subordinates who contribute when asked
Values of open, critical inquiry predominate	Attainment and maintenance of power is the dominant value
Purpose of research is to redress problems of human health and welfare	Purpose of research is to solve political problems

There is a connection between the emerging notion of ‘transformation’ in the use of research in policy and the latent concern with the democratic to coercive (power and values) continuum in the manner of research use in policy. Later in this thesis I will argue that when research influences policy, it does so by becoming invested with meaning and power through social processes of ‘transformation’. I will argue that, regardless of how democratic or coercive the *manner* in which research is used, the intended effect is always the same, that is to give some research the status and authority required to support government policy. Understanding the relationship between research and policy means understanding the critical role of power and values in research use in policy. An adequate theory of the relationship between research and policy has to come to grips with this dimension of research use. The next section discusses how well the ‘two communities’ theory and the notion of ‘research transfer’ does this.

### **2.2.2. The ‘two communities’ theory and ‘research transfer’**

Explicit attempts to build theory to explain research use in policy have generally taken second place to the conceptual and descriptive approaches set out above. While the model builders have identified a large number of factors at work in the research–policy

nexus, there have been relatively few attempts to specify how these relate to one another in the form of an explanatory framework or theory.<sup>6</sup> A consequence of this is that it does not seem to matter how elaborate the descriptive models become, the ‘two communities’ theory and its derivatives remain the most common mode of explanation for research use in policy. In this section I will demonstrate the resilience of the ‘two communities’ theory and its legacy in terms of strategies that focus on ‘research transfer’.

In Caplan’s empirical research on the ‘two communities’ theory, he compared it with two other theories of research use, the Knowledge-Specific theory and the Policy Maker-Constraint theory. Using multivariate analysis of attitudinal data from 204 upper level US government executives he found that ‘...the items representing the Two Communities position accounted for the largest proportion of explained variance between users and nonusers’ (Caplan 1979: 461). Based on this, he argued that particular attention should therefore be given to theories that ‘...stress the lack of interaction between social scientists and policy makers as a major reason for nonuse’ (Caplan 1979: 461). However, he was cautious about taking this finding and translating it into strategies that simply tried to create alliances between researchers and policy makers arguing that ‘...achieving effective interaction of this sort necessarily involved value and ideological dimensions as well as technical ones’ (Caplan 1979: 461). He also argued that there could never be a ‘single system’ for linking policy makers and researchers.

Caplan’s key finding about the importance of social interaction to explaining use and non-use stands out as the single most consistently reported finding from research utilisation studies. What is just as striking, however, is that the *theoretical interpretation* of this finding is almost always made with reference to the ‘two communities’ theory. Innvaer and others report on a systematic review of studies of policy maker’s use of

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<sup>6</sup> The distinction made here between descriptive models and theoretical models or frameworks is based on the extent to which the models attempt to provide explanations of what causes what in the research-policy nexus. Most of the models following on from Weiss’s, including Hanney and others (2003), are generally limited to describing variations in the type of research use, though some writers have tried to explore their explanatory power and/or ascribe a normative value Short, S. (1997). *Elective Affinities: Research and Health Policy Development. Health Policy in Australia*. H. Gardner. Melbourne, Oxford University Press: 65-82. . Some of these might be thought of as ‘ideal-type’ models, others are ‘normative type’ models Parsons, W. (1995). *Public Policy: An Introduction of the Theory and Practice of Policy Analysis*. Aldershot, Edward Elgar.



research. They say ‘The results of this review support the “two communities thesis”, since the most commonly identified facilitator of the use of evidence was personal contact between researchers and decision-makers’ (Innvaer, Vist et al. 2002: 242). While they also discuss the finding in relation to ‘use of research’ concepts, and later say that the extent of empirical support provided to the ‘two communities’ theory is limited (Innvaer, Vist et al. 2002: 243), it is clear that the ‘two communities’ remains the dominant point of reference for interpretation and explanation.

In a similar vein, Lavis and others report ‘Our exploratory study suggests that interaction between these “two communities” does influence the use of research by policy makers...’ (Lavis, Ross et al. 2002: 145). The implication of this for attempts to improve research use flow directly from this. They write ‘The interaction between researchers and policymakers and the existence of accountable “receptor” function in government (Lomas 1997) appear to be the conditions most favouring the use of health services research specifically and information more generally in the policymaking process’ (Lavis, Ross et al. 2002: 146). As in the Innvaer review article, the ‘two communities’ theory acts as the default theoretical interpretation and gives rise to specific measures to create ‘bridges’ across the ‘gap’.

The basic principles of the ‘two communities’ theory are sometimes expressed in more general terms. For example, Landry and others argue that there are four groups of ‘explanatory variables’ in the research utilisation literature. These focus on technological, economic, institutional or social interaction variables (Landry, Amara et al. 2001: 399). They argue that:

The social model integrates the explanatory factors of the prior models in a general model by using the following explanatory factors of research utilisation: types of research outputs, organisation interests of users, adaptations of the products disseminated, dissemination efforts, and institutional and social linkage mechanisms (Landry, Amara et al. 2001: 400).

However, while these factors are included in the model, the basic theoretical premise of the ‘two communities’ theory remains, that is, ‘...that the more sustained and intense the interaction between researchers and users, the more likely it is that there will be utilisation’ (Landry, Amara et al. 2001: 400).

The link between this premise and the development of strategies to increase research use is shown in Hanney and others recent extensive review of the research utilisation literature for the World Health Organisation, Hanney and others write:

Increasing attention is focussing on the concept of interfaces between researchers and the users of research. This incorporates the idea that there are likely to be different values and interests between the *two communities*, with their different time-frames, and that research is less likely to be utilised in a significant way unless networks and mechanisms are established at the interfaces... The 'permeability of the interfaces' becomes important given the potential problems in the transmission of views and findings between researchers and policy makers. (Hanney, Gonzalez-Block et al. 2003: 14) (emphasis added)

The 'two communities' way of thinking leads directly to the specification of what they call the 'interfaces and receptor model' (Hanney, Gonzalez-Block et al. 2003: 18-19). To be fair, Hanney and others make a number of references to the broader factors at work in the policy environment. For example, they write: 'Epistemological, social and institutional issues are all relevant to the role of the research receptor'<sup>7</sup> (Hanney, Gonzalez-Block et al. 2003: 16). However, these ideas are relegated to the role of providing interesting background and are not developed within the model presented.

A particularly influential researcher in the field of health research utilisation is Jonathon Lomas. He holds the position of Director of the Canadian Health Service Research Foundation, an organisation charged with the task of enabling evidence-based decision making in the health sector in Canada (Canadian Health Services Research Foundation 2000) and has influenced work on this topic in Australia (Lomas 1997) (Matthews, Jenkin et al. 2001) and the United Kingdom (Black 2001). Most recently, the Health Services Research Working Group of the National Health and Medical Research Council invited him to write a paper for them on this topic (Lomas 2003). He makes considerable use of the social science research utilisation literature in his writing on health research transfer (Lomas 1990; Lomas 1997; Lomas 2000; Lomas 2000; Lomas 2003).

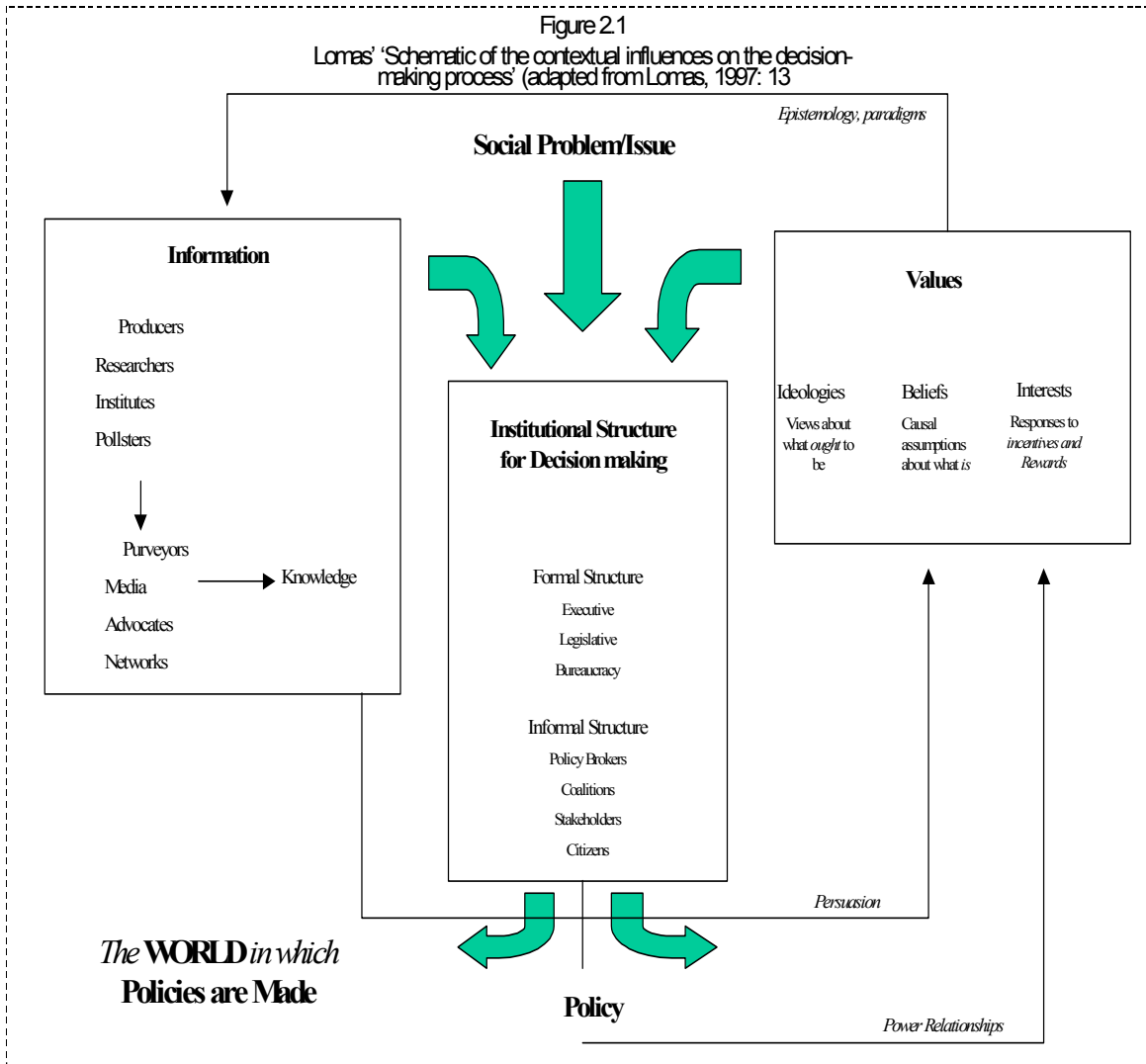
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<sup>7</sup> The 'research receptor' is a policy maker given this title by Hanney and others to denote their responsibility for being the point of receipt of research by government.

The ‘two communities’ theory plays a particularly important role in forming Lomas’s analysis of the research–policy problematic and in proposing solutions. His views on the differences between researchers and policy makers were quoted at length in Chapter 1 and came from his report *Beyond the Sound of One Hand Clapping* (Lomas 1997). This report is part analysis and part prescription for fixing the problem of lack of research transfer. He identifies the major problems as, firstly, the way researchers and policy makers view each other and work independently of each other (Lomas 1997: 2-5), and secondly, the failure to appreciate the differences in information needs between clinical decision makers, administrators and ‘legislative decision-makers’ (Lomas 1997: 5-9). His prescription for fixing these problems is to improve the relevance of research through new kinds of research funding and commissioning processes (Lomas 1997: 24-28); develop new kinds of workers, especially ‘research-brokers’ to communicate across the cultural divide between research and policy (Lomas 1997: 28-30); and, create new organisational models that would enable linkage and collaboration between researchers and decision makers of various kinds (Lomas 1997: 18-23).

The influence of the ‘two communities’ theory in this is shown by the way that he identifies the fundamental problem as the ‘miscommunication’ between a ‘research community’ and a ‘decision-maker community’ who have inaccurate and simplistic appreciations of each others’ worlds and therefore end up in cycles of mistrust and further miscommunication (Lomas 1997: 2-3, 30-31). Lomas’s solutions emerge directly from this conceptualisation—the recommended changes to the organisational structures of bureaucracy and the academy appear like pontoons reaching out from adjacent islands while the ‘research–policy brokers’ travel the diminishing spaces in between with special powers of translation and interpretation.

None of Lomas’s solutions deal with the institutional or sociological factors raised in his own ‘framework for understanding the context of decision-making’ which appears in the same publication and is reproduced in Figure 2.1 below. This has three interrelated domains: institutional structures for decision making including the formal structures of the executive, legislature and bureaucracy, and the informal structure of stakeholders and coalition; the values, beliefs, interests and ideologies that mediate the selection and interpretation of research; and the information production process including the interaction between research and the media (Lomas 1997: 13-15). The



variables set out in this framework show an appreciation of the work of Sabatier and Jenkins on advocacy coalitions (discussed below) as well as institutional processes that are developed in the Policy Making Organisation Framework (also discussed below).

How can we make sense of the gap between the sophistication of the conceptual frameworks developed by Lomas and by Hanney and others and the relative simplicity of the proposed solutions—the solutions seem to leave out of consideration many of the important variables in the research–policy nexus. Part of this relates to what is tractable to practical action by individuals and groups who want to achieve increased use of their particular pieces of research. In this sense, they are in the same boat as policy makers who are confronted with long-term structural problems but must find some way of acting in the present to at least partially achieve their goals. However, I think there is another reason for this inevitable retreat to proximate variables and it is about the faulty

assumptions that underpin much of the research utilisation literature and come through particularly in the writing on the ‘two communities’ theory. These assumptions are spelt out in full in Chapter 10 where the findings of this thesis are summarised in the form of a critique. At this point, the most striking is the influence of methodological individualism in the research utilisation literature.

Methodological individualism is shown by the concentration on the individual policy-maker as the unit of analysis for studying research use. From Caplan’s study of senior federal decision makers in the United States in the early 1970s (Caplan, Morrison et al. 1975), to Weiss and others’ 1980 study of how particular decision makers evaluate individual pieces of research (Weiss and Bucuvalas 1980), to Oh’s study of how decision makers use information to construct problem definition (Oh 1998), to the recent systematic review of health policy-maker’s perceptions of their use of ‘evidence’ (Innvaer, Vist et al. 2002), research use in policy is researched primarily as an individual phenomenon. The implicit assumption in this is that policy making is an aggregation of individual decisions. A primary theoretical challenge for the study of research use in policy is to move beyond methodological individualism and generate theory that gives sufficient weight to group, organisational, and societal factors.

### **2.3. General Theoretical Orientation**

The three focal theories set out below sit within larger theoretical orientations; their selection and development owes something to my appreciation of their broader intellectual roots. The work of David Dery builds on the work of Majone (Dery 1990: 28) who set me on the path to thinking about the idea of ‘transformation’ rather than ‘transfer’ in the research–policy relationship. Majone used the idea of transformation to denote the difference between ‘data’ and ‘information’ on the one hand, and ‘evidence’ on the other (Majone 1989: 48). Majone’s main interest was to try to understand the role of policy analysis and its relationship to policy. His ideas include the concept of policy communities of experts working to sustain core policy ideas (akin to advocacy coalitions in policy subsystems that are central to the Advocacy Coalition Framework set out below). He also introduced me to the idea that the relationship between policy and evaluation research is analogous to the relationship between scientific theories (or research programs) and the available data. He argues ‘A policy, like a theory, is a cluster of conclusions in search of a premise: not the least important task of analysis is

discovering the premises that make a set of conclusions internally consistent, and convincing to the widest possible audience' (Majone 1980). David Dery drew on this idea (Dery 1990: 28-9) and it has influenced the development of the Policy Making Organisation Framework. Majone is also part of a stream of post-modernist policy analysis often referred to as the 'argumentative turn' (Fischer and Forester 1993; Rein and Schon 1993; Danziger 1995; Legge 1996) that has informed my thinking that research use in policy argument is a social and political process involving investment with meaning and power.

Another stream of intellectual activity that overlaps with post-modernist policy analysis is the sociology of scientific knowledge. While the Foucauldian perspective, which is developed at length below, has informed some of this work in recent times, it has a much longer and different pedigree in the sociology of knowledge (Law 1986; White 1998), and in history and philosophy of science. In this latter field, the work of Kuhn (Kuhn 1962) and philosophers such as Imre Lakatos have had a particular influence on Dery (Dery 1990), Majone (Majone 1980), and on the evolution of the Advocacy Coalition Framework (Munro 1993). Kuhn in particular is recognised as providing the cornerstone of the sociology of scientific knowledge (Barnes 1990: 64-5). Across all this literature are two dominant themes that permeate this thesis. The first is a rejection of rationalist conceptions of scientific knowledge and hence a rejection of the idea that policy making can or should somehow follow rationalist models in its use of research. The second is a problematisation of the power relations involved in the production and use of knowledge. While this is implicit in some of the more sophisticated work on research utilisation such as that of Weiss (Weiss 1986) and Lomas (Lomas 1990), all too often it seems to disappear from view. As Albaek argues, there seems to be a reluctance to own the issues of power and acknowledge the dangers of elitist and technocratic models of policy making implicit in the quest for research utilisation (Albaek 1995).

The idea, developed more fully towards the end of the thesis, that research can become invested with meaning and power through social and political processes owes something to Innes' case studies of social indicators (Innes 1990). Like Innes, I found an implicit assumption in much of the research utilisation literature that use of research should follow '...an oversimplified and somewhat mechanistic conception of science'. In this view, when policy maker's '...actions do not appear to be influenced by the

evidence—as is often the case in practice—this view would attribute to the policy makers laziness, duplicity, or undue responsiveness to pressures of special interests’ (Innes 1990: 3). From her research, Innes argues that indicators become influential when they take on ‘socially shared meanings’ (Innes 1990: 4). This leads her to adopt a ‘model of the linkages between knowledge and policy that ... is grounded in an interpretive or phenomenological view of knowledge, rather than in the positivist perspective. It is more contextual, more evolutionary, and more complex than the scientific model’ (Innes 1990: 3). Interestingly, Dunn made an early attempt to operationalise the two communities model in a way that saw its primary value in its implicit assumption that ‘...knowledge production, transfer, and use are subjectively mediated social processes...’ (Dunn 1980: 516) but this line of thought seems to have disappeared from the knowledge utilisation literature.

In a similar vein, the idea that knowledge might best be seen as an ongoing social project in which research can play a critical role has been informed in general terms by Callon’s ‘sociology of translation’ (Callon 1986). Through a case study of the role of research and researchers in attempts to solve the problem of overfishing of sea scallops in St Brieuc Bay in France, Callon develops his theory of translation. While the scientists pursued their scientific interests they also negotiated their way into decision making about farming practices and policy on fishery management. Callon’s theory of ‘translation’ argues that scientists gained power in a series of stages which begins with having their definition of the problem become the accepted definition and culminates in the researchers being the ones who can speak for all stakeholders. Callon argues that ‘Closure occurs when the spokesmen are deemed to be beyond question’ (Callon 1986: 220). Callon’s work pointed me towards looking for ways of understanding how the social action of researchers and their intellectual products had particular effects on the ideas and the social organisation of the policy process.

Out of these broad inputs from public policy, the sociology of knowledge, and the sociology of scientific knowledge, I chose to develop and use three ‘focal theories’ to explore the research–policy nexus. The rationale for selection was that each of them posited a significant role for research but did so within a relatively coherent view of policy-making as a whole, a methodological principle articulated by Dunn (Dunn 1980: 516). Their views of the research–policy nexus are different from each other but are somewhat complementary in that the ACF focuses on coalitions of interest groups

formed around common interests and values, the PMOF focuses on government institutions, and the GF brings a more societal perspective.

## **2.4. The Advocacy Coalition Framework (ACF)**

The Advocacy Coalition Framework (ACF) is the work of Paul Sabatier and Hank Jenkins-Smith (Sabatier 1988; Jenkins-Smith and Sabatier 1993; Sabatier 1993; Sabatier and Jenkins-Smith 1993). It constructs the research–policy problematic in terms of the interaction between groups of actors referred to as ‘advocacy coalitions’ that seek to control policy subsystems.

Policy subsystem and interest group network theory have been an important part of Australian health policy analysis (Duckett 1984; Sax 1984; Gardner 1989; Lin and Duckett 1997). British policy studies have preferred the concept of ‘policy communities’ to policy subsystems (Jordan 1983; Peterson 1993; Duke 2000) and this approach has also been applied to Australian health policy analysis (Edwards 1997; Fitzgerald and Sowards 2003).

The ACF is a particular approach to policy subsystems that belongs within the American pluralist tradition of political science that analyses political life in terms of ‘...interactions of more or less organised interest groups, on the assumption “that people participate in those areas they care about the most” (Polsby, 1959: 235). The interests at stake in political life are therefore the ones that people organise around and campaign for’ (Hindess 1986: 115). Some Australian political scientists have cautioned against the adoption of simplistic pluralist models in the Australian context (Parkin 1980; Gardner 1989).

From the Advocacy Coalition Framework perspective, advocacy coalitions use research and analytical debate to influence policy. Advocacy coalitions’ motivation for engaging in research is to build support for their arguments while undermining their opponents’ arguments as they compete for power and control of the policy subsystem. They engage in debate around research findings when they see that the advantages of doing so outweigh the disadvantages. Their approach to research is framed by their beliefs about the important variables and causal relationships pertinent to the policy problem. Underpinning the whole policy subsystem dynamic is the distribution of power within



the policy subsystem and the subsystem's vulnerability to forces in the wider policy environment.

According to the ACF, research can lead to policy change as a result of 'policy oriented learning' which, Sabatier says '...refers to relatively enduring alterations of thought or behavioural intentions which result from experience and which are concerned with the attainment (or revision) of policy objectives' (Sabatier 1988: 133). 'Experience' can include research on the performance of a policy or on the fundamental assumptions about the nature or causes of the policy problem. Sabatier argues that policy-oriented learning comes about as '...an ongoing process of search and adaptation motivated by the desire to realise core policy beliefs' (ibid: 151).

The concept of 'policy subsystems' is central to the ACF. These are made up of:

...actors from a variety of public and private organisations who are actively concerned with a policy problem or issue...' including '...actors at various levels of government active in policy formulation and implementation as well as journalists, researchers and policy analysts who play important roles in the generation, dissemination, and evaluation of policy ideas. (Sabatier 1993: 17)

Sabatier argues that the actors in sub-systems combine into advocacy coalitions on the basis of shared belief systems i.e. a set of basic values, causal assumptions, and problem perceptions. These advocacy coalitions show a 'non-trivial' degree of coordinated activity over time (Sabatier 1988: 139). The dominant advocacy coalition (DAC) in any policy sub-system is the one whose belief system dominates the policy theory.

The structure of beliefs systems is also central to the ACF. Sabatier argues that belief systems are made up of three layers:

...a deep core of fundamental normative and ontological axioms that define a person's underlying personal philosophy, a near (policy) core of basic strategies and policy positions for achieving deep core beliefs in the policy area or subsystem in question, and a set of secondary aspects comprising a multitude of instrumental decisions and information searches necessary to implement the policy core in the specific policy area. (Sabatier and Jenkins-Smith 1993: 30)

These are arranged in terms of decreasing resistance to change from the deep core to the instrumental.

According to the ACF, the kinds of research and analysis that advocacy coalitions undertake are quite specific and relate to their own beliefs and values and those of their opponents. They will conduct or gather research with three goals in mind: improving their understanding of the state of variables defined by their belief system, or by competing advocacy coalitions, as important; refining their understanding of logical or causal relations important to their belief system; and, identifying and responding to challenges to their own belief system (Jenkins-Smith and Sabatier 1993: 42-3).

Research and its use in policy making is first and foremost a function of its ability to be used as a political resource. The ACF argues, however, that research can act somewhat independently in the policy process and prompt change to beliefs and to policy. This happens because advocacy coalitions can not afford to be too far out of step with credible research if it makes them liable to attack from opponents. Hence, research can lead to policy change despite, as well as because of, the political objectives of policy actors. The same driving force is in play—competition between advocacy coalitions—as they strive to realise their core beliefs and values. The ACF describes this change as ‘policy oriented learning’ (POL) and might be thought of as an unintended consequence of the main dynamic of advocacy coalition competition in the policy environment. POL is defined as ‘...relatively enduring alterations of thought or behavioural intentions that result from experience and which are concerned with the attainment or revision of the precepts of the belief system of individuals or of collectivities (such as advocacy coalitions)’ (Jenkins-Smith and Sabatier 1993: 42).

The ACF argues that POL is constrained by several factors. The first is the level and type of conflict between advocacy coalitions. The ACF hypothesises<sup>8</sup> that:

Policy-oriented learning across belief systems is most likely when there is an intermediate level of informed conflict between the two. In such a situation, it is likely that: 1) each coalition has the technical resources to engage in such a debate; and 2) the conflict be between secondary aspects of one belief system and core elements of the other or, alternatively, between important secondary aspects of the two belief systems’ (Jenkins-Smith and Sabatier 1993: 50).

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<sup>8</sup> Sabatier originally proposed the ACF with nine hypotheses on policy. Following empirical testing, Sabatier and Jenkins-Smith now propose twelve hypotheses including revisions to the original nine. All twelve are relevant to the case study analyses and can be found in the appendices for Chapter 2. At this point, only those relating to policy oriented learning are discussed.

The second constraining factor on policy-oriented learning is the analytical tractability of the policy issue and whether there is a shared, quantitative definition of the problem and indicators of performance. The ACF hypothesises that:

Problems for which accepted quantitative data and theory exist are more conducive to policy-oriented learning than those in which data and theory are generally qualitative, quite subjective, or altogether lacking. (Jenkins-Smith and Sabatier 1993: 52)

Problems involving natural systems are more conducive to policy-oriented learning than those involving purely social or political systems because in the former many of the critical variables are *not* themselves active strategists and controlled experimentation is more feasible. (Jenkins-Smith and Sabatier 1993: 52)

The third constraining factor on policy-oriented learning is the process and context of engagement between advocacy coalitions. The ACF hypothesises that:

Policy-oriented learning across belief systems is most likely when there exists a forum that is 1) prestigious enough to force professionals from different coalitions to participate; and 2) dominated by professional norms. (Jenkins-Smith and Sabatier 1993: 54)

The hypotheses and dynamics of the ACF are based on pluralist assumptions about the way policy making works. An important threshold condition for POL, which is omitted from the ACF hypotheses, is that there is ‘dispersed power’ in the political system. When power is dispersed, actors ‘... can seldom develop a majority position through the raw exercise of power. Instead they must seek to *convince* other actors of the soundness of their position...’ (Jenkins-Smith and Sabatier 1993: 45) (emphasis in original). It follows that POL will be limited to the extent that power in the policy subsystem is centralised.

The ACF allows an analysis of the research–policy nexus that hypothesises about who will do research, why it will be done, the kinds of questions it will focus on, how it will be used, and the conditions under which it is likely to lead to policy change. It has significant advantages over the ‘two communities’ construction of the research–policy nexus in that: it conceptualises policy making at a level above that of the individual decision maker; it conceptualises research as a political act that is part of the policy process, not separate to it; it theorises power as an explicit determinant of the research–

policy interaction; and it is able to specify the conditions under which interventions designed to improve research uptake ('linkage' and 'networking') might or might not work. Chapter 3 sets out the way the ACF will be used to analyse the case studies and how it will be evaluated.

## **2.5. The Policy Making Organisation Framework (PMOF)**

I developed this framework for understanding the research–policy nexus on the basis of the work of David Dery (Dery 1984; Dery 1990). Dery's fundamental insight in *Data and Policy Change* (Dery 1990) is that the selection and use of research in policy is an organisational rather than an individual phenomenon. While he does not neglect the important role of interest groups in the policy process, his primary focus is on the role of the state which he discusses in terms of 'the policy making organisation'. This has salience in the Australian context given the importance for health policy that many analysts have ascribed to the Australia's Federal system and the way responsibilities for health policy have evolved within the constraints of the Australian Constitution (Sax 1984; Gardner 1989; Gray 1991).

Dery problematises the research–policy nexus in terms of 'organisational epistemology' which is an organisation's rules of inquiry, observation and inference. An organisation's epistemology is like a lens that filters research into and out of contention on the basis of whether or not it fits with predetermined criteria of relevance (Dery 1990: 31). Dery's focus on the organisation rather than the individual is a major break from most research utilisation literature that, while it acknowledges the role of structural factors, continually defaults to the role of individual policy makers.

The primary metaphor for Dery's theory is that the policy making organisation is like a organism submerged in a data swamp (Dery 1990: 12). It is completely enveloped by information that is trying to push its way in. While the PMO needs some of this information to carry out its mandated functions, it must be selective. It is impossible to perform as if the assumptions and theories underpinning current policy were correct while simultaneously holding those same assumptions and theories open to serious question. Deciding what information is potentially relevant is relatively easy. The hard bit is deciding when to pay attention to information that is hostile to current policy settings. If it ignores this information completely then it is courting eventual disaster. If it accepts every piece of hostile data as true, then it will be paralysed into inaction.

Dery's hypothesis is that if an organisation is unequivocally responsible for the consequences of policy error, and if an audience with the ability to hold the organisation to account can independently observe the error, and if the standards for success or failure are clearly defined, then the organisation is vulnerable to the consequences of its errors. It will then have an incentive to avoid error and to pursue research that might inform it of the success or otherwise of its policies. On the other hand, 'When organisations are immune, not from the possibility of error but from its consequences, they are and remain self-perpetuating belief systems' (Dery 1990: 47).

### **2.5.1. Indicators of PMO research responsiveness**

I have used Dery's work to identify five indicators of the openness of a Policy Making Organisation's (PMO's) epistemology. These might be thought of as indicators of research responsiveness:

*PMO responsibility*—the extent to which the PMO is unequivocally responsible for the policy problem, either in terms of legislative requirements or precedent established by prior action. Perceptions of PMO responsibility are affected by whether or not they are shared with other jurisdictions or with individuals and 'the community'.

*PMO capacity*—the extent to which the PMO has the capacity and the power to effect change in the problem. This will be influenced by the availability of affordable, effective and acceptable interventions. It will also be influenced by whether or not action on one front has to be traded off for action on another front. For example, PMO capacity to introduce anti-tobacco advertising might be reduced by its capacity to forgo tax receipts from the sale of tobacco products.

*PMO performance*—the extent to which it is possible to measure the PMO's performance in relation to the policy problem. To the extent that there is an agreed definition of the problem, its underlying causal relationships, agreed indicators and standards to measure performance, and data available to measure performance, then PMO responsiveness will be increased.

*Theatre of justification*—the extent to which performance information and other data relevant to the problem are available for public scrutiny and debate. PMO responsiveness to research will increase to the extent that there is an accessible and open forum for questioning that information, for calling the PMO to account, and for having

alternative views heard. Dery refers to this as the ‘social context of justification’ (Dery 1990: 46) where participants engage in a contest to arm and disarm ‘facts’.

*Vulnerability to the consequences of error*—the extent to which there is a cost (political or economic) for policy failure. Research responsiveness will increase as these costs increase.

Each of these indicators points to an environment where the policy making organisation is likely to be more, rather than less, research-responsive.

Three ‘ideal type’ scenarios might be envisaged. The first is where each of these indicators is scored a ‘high’ (that is, there is a single level of government that is unequivocally accountable for a public health problem, it has the capacity to respond, and so on). In this situation, the PMOF predicts that there will be a high degree of research responsiveness and research could be expected to play a significant role in the policy process. Vaccine preventable disease comes close to qualifying for this type of public health problem with the only proviso being the sometimes low level of salience to the general public of outbreaks of diseases such as measles and therefore the low level of ‘vulnerability to the consequences of error’ for those responsible. The fact that outbreaks can be blamed on irresponsible parents also reduces the extent to which government might be held unequivocally responsible.

The second ideal type scenario is where each of these indicators rates at the ‘low’ end. In such cases there are fundamental tussles over what the problem is, what causes it, whether or not government is responsible, what be could done about it and so on. The current state of public health policy debate on health inequalities fits this scenario quite well.

The third ideal type scenario is where there are mixed ratings across the indicators. Illicit drugs fits this scenario well. There is a tussle over the definition of the problem as to whether it is a law enforcement problem or a public health problem, difficulties determining cause and effect in both the problem and the available interventions, difficulties determining the extent of PMO responsibility and capacity, and so on. But unlike health inequalities where government responsibility is somewhat vague, there is a clear expectation in Australia that the State and Federal governments will do something about illicit drugs and take responsibility for trying to reduce supply and demand.

### **2.5.2. Indicators of PMO bias in data selection**

However, just being responsive to research does not capture the way in which research is likely to be appraised and the strength with which a policy making organisation is likely to resist change or embrace change. Dery proposes the following paradoxical hypotheses:

**Hypothesis I:** Politicians or administrators reject data that do not coincide with behaviour they are unwilling to change.

**Hypothesis II:** Politicians or administrators change behaviour that does not coincide with data they are unwilling to reject. (Dery 1990: ix)

This paradox suggests a two dimensional model where the pressure for accepting hostile data (a function of the PMO's research responsiveness) is pitted against the pressure for rejecting that hostile data. This pressure to reject hostile data comes from the bias of the PMO based on numerous factors.

One way of analysing the tendency or pressure to bias is by exploring the different kinds of risks and opportunities that are faced by the PMO. These might usefully be divided into those that face the political arm of the PMO and those that face the bureaucratic arm of the PMO. This allows for the possibility that the bureaucracy and ministers might have conflicting interests and agenda.

The following risks and opportunities are proposed for the model.

*Electoral risks and opportunities*—winning or losing votes, seats, or opinion poll ratings. This indicator is primarily concerned with inter-party power plays. The relevance and reception of particular problems to the media is a key determinant of the importance of this indicator.

*Tactical risks and opportunities*—opportunities or risks vis-à-vis power or status within the cabinet, government, party, or with important stakeholders; realising personal goals and ambitions; gaining advantage over rivals in government; distracting attention from other issues. This indicator is primarily concerned with intra-party power struggles.

*Economic/financial risks and opportunities*—opportunities or risks in relation to costs to government; impact on budget strategies; and impacts on broader fiscal policy.

*Contextual risks and opportunities*—risks and opportunities that arise from the concurrence of other problems in the policy environment that might interact with the policy issue at hand.

*Ideological risks and opportunities*—opportunities to realise goals that are personally or socially important for ideological reasons.

Taken together, these five indicators of risk and opportunity provide a barometer of the likely preferences of the PMO in terms of policy initiation, change or the status quo. The indicators have a degree of interaction—for example, failure to keep expenditure under control can be damaging for a health minister in the parliament, the electorate and the party room.

In terms of the bureaucratic arm of the PMO, the following additional factors might be considered in relation to each of the indicators of risk and opportunity.

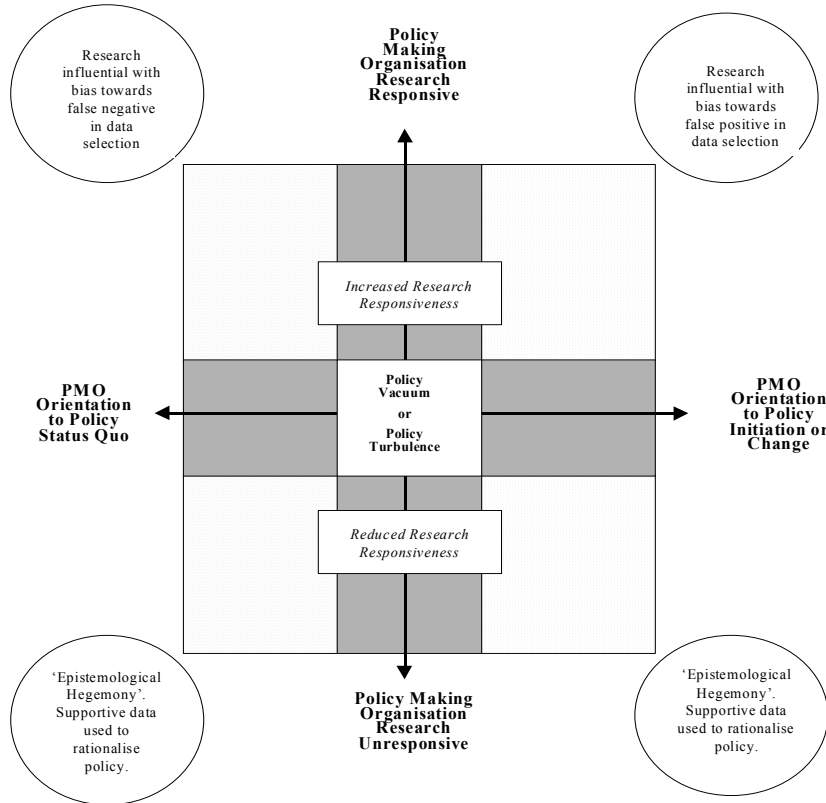
*Economic or financial risks and opportunities*—potential impacts on the program budgets; impact on related program budgets; impact on whole portfolio budget; impact on department's budget strategy; impact on financial relationship with States and Territories.

*Tactical risks and opportunities*—shifts in the balance of power in intergovernmental relations or relations with the medical profession; increasing power or status or degree of control of the department; increasing standing with minister and government.

*Contextual risks and opportunities*—the 'garbage can' (Cohen, March et al. 1972) of other issues that are related only because of the proximity in time and some other factor e.g. opportunities to reallocate work across organisational units, departmental restructuring, resolving internal problems such as conflict between divisions and senior staff, changing relations with external stakeholders, being caught up in some other conflict or issue with the finance departments or the ministerial offices and so on.



**Figure 2.2**  
**Research responsiveness and the policy orientation of policy making organisations**



Again, three ideal type scenarios can be envisaged. In the first, a particular policy option appears to be a winner on all fronts—it wins votes, saves money, enhances the status of the minister, accords with ideological preferences, and helps resolve pressure on other policy fronts. In the second, a policy problem presents no opportunities and a nest of political risks—failure to manage the problem will lose votes, reduce status in the government, lose money, affront ideological values, and create negative flow-on effects on other policy fronts. The third scenario is where the policy problem involves a mixture of risks and opportunities.

The two dimensions of the PMOF—research responsiveness and the bias towards policy change or the status quo—enable the construction of a conceptual model of the research–policy nexus. The model is represented in Figure 2.2 above.

The PMOF problematisation of the research–policy nexus is that there is a tension between research responsiveness and the political risks and opportunities presented by the policy problem. This tension will be resolved in different ways depending on the nature of the policy problem and contingent factors in the wider policy making environment.

Dery argues that there is a dynamic at work around the acceptance or rejection of data by policy making organisations which involves ‘minting’ or amplifying data that is advantageous and muting data that is not. Like the development of paper currency, the social dynamic is one of trust based on the authority and standing of those who will accept the currency as legal tender. Policy actors observe closely the way others accept or reject research and hope to avoid being caught promoting arguments on the basis of data that others will reject. Thus, to call something ‘knowledge’ is not something that inheres in data itself but is an expression of consent to take a statement as knowledge. Dery acknowledges the influence of Richard Rorty when he says ‘We understand knowledge... when we understand the social justification of belief’ (Dery 1990: 46). The variables identified in the model above attempt to capture the main influences on the social justification of belief for policy makers.

The operationalisation of this framework is set out in Chapter 3.

## **2.6. The Governmentality Framework**

This section develops a ‘Governmentality Framework’ based on the work of Michel Foucault, an influential 20<sup>th</sup> Century French intellectual and philosopher. Foucault’s concept of ‘governmentality’ offers an entirely different problematisation of the research–policy nexus to either of the preceding frameworks. Governmentality has become a key concept in the sociology of public health knowledge, a perspective largely ignored in the literature on research utilisation and health research transfer. This is not surprising—the sociology of scientific knowledge is want to challenge the very basis for separating out science from politics as if they are distinct things. In his review of Roy MacLeod’s *Public Science and Public Policy in Victorian England*, White argues that the construction of science as a neutral sphere of truth is a highly political act. He says:

It was precisely by embodying political disinterestedness that science would prove most valuable to modern statecraft. Its non-partisanship would play a crucial role in

making the evidence for highly negotiable programmes and projects seem neutral, and the ensuing policies in the general interest. (White 1998: 302)

The sociology of knowledge perspective, therefore, sees the processes by which the research–policy nexus is problematised as part of the analysis of that nexus.

A good metaphor for the governmentality framework is that of a collective psychic web<sup>9</sup> where the human subject struggles in and co-creates a web of knowledge/power. It is a dark image of human reality in the sense that humans can never free themselves from socially created webs of knowledge/power, they can only struggle to realise their freedom within the webs of governmentality that make up their world at any particular point in time. Research is part of the web of knowledge/power. Discrepant research is part of a new web or different web spun through different discourses and practices and regimes and may enable subjects to resist dominant discourses.

For Foucault, the practice of public health involves the exercise of power and is inextricably linked with the production of knowledge about the health of the public. Gordon argues that from a Foucauldian perspective ‘...what is most interesting about links between power and knowledge is not the detection of false or spurious knowledge at work in human affairs but, rather, the roles of knowledges that are valued and effective because of their instrumental efficacy’ (Gordon 1994: xviii).

### **2.6.1. Governmentality**

Foucault’s concept of governmentality was not static—it evolved over time and its various formulations have led to a large and diverse secondary literature that has no agreed paradigm of definitions and methods (Dean 1999: 4). This makes the adoption of governmentality as a framework for analysis hazardous and difficult. It is hazardous because there are many grounds on which critics could argue that the analysis presented here does not represent a true or adequate use of the concept as Foucault meant it. It is difficult because it requires the selective appropriation of particular parts of a diverse and unwieldy literature that seem relevant and useful to this research project. The

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<sup>9</sup> I am borrowing Gareth Morgan’s metaphor of the ‘psychic prison’ Morgan, G. (1986). *Images of Organisation*. Beverly Hills, Sage Publications, though my application of it is based on Foucault’s concept of governmentality while his is based on Plato’s allegory of the cave. What they have in

success of this framework should be judged on the same terms as the other frameworks, that is, their usefulness in producing robust and meaningful answers to the research questions, rather than in terms of some measure of their faithfulness to Foucault's original intentions and methods (as these have insufficient coherence to enable such evaluation).

### **2.6.2. Definitions of governmentality**

Dean argues that Foucault developed two broad meanings of the term 'governmentality'. The first was a general meaning that relates to the 'mentality' of government, and the second was a specific application to the modern form of liberal government that developed in Western Europe from the end of the 16<sup>th</sup> century. These are discussed in turn.

Dean explains that in its first and general meaning '...governmentality...deals with how we think about governing, with the different mentalities of government'. 'Thinking' in this definition is a collective activity, '...it is a matter...of the bodies of knowledge, belief and opinion in which we are immersed' (Dean 1999: 16). This understanding of governmentality resonates with that proposed by another Foucault interpreter, Colin Gordon, who says that governmentality is '...a way or system of thinking about the nature of the practice of government (who can govern; what governing is; what or who is governed), capable of making some form of that activity thinkable and practicable both to its practitioners and to those upon whom it is practiced' (Gordon 1991: 3).

The 'second' meaning of governmentality in Foucault's work, according to Dean, is the rise in Western Europe of a form of government concerned with the economic prosperity of the nation state and the health of the population—a government of 'each and all' (Dean 1999: 19). This meaning of governmentality has given rise to a large secondary literature that seeks to understand the way power and authority operate in liberal and neo-liberal forms of government. (Rose and Miller 1992; Burchell 1993; Osborne 1997; Ballard 1998). Of particular relevance is the concept of 'governing at a distance' which is discussed further below.

There is, however, a third meaning of governmentality not referred to by Dean. For several other writers (Burchell 1993; Turner 1997; Tyler 1997), the key to understanding Foucault's concept of governmentality is to see it as the 'point of contact' between the government of populations and the government of the self, between 'disciplinary power' and 'biopower'.

I will use 'governmentality' to refer to 'mentalities of government' where 'government' has the Foucauldian meaning of the 'conduct of conduct', which includes any attempt to shape the conduct of the self or others. This definition dissolves the usual distinction between the state and civil society, and between the exercise of authority at a corporate and at an individual level. 'Neo-liberalism' will be used to refer to the form of governmentality that emphasises the strategies of 'governing at a distance'. The idea of governmentality as a 'point of contact' will be taken up below.

For the purposes of this study, public health policy will be understood using three Foucauldian concepts: technologies of self; technologies of population; and the technology of governing at a distance. It will be argued that national public health policy becomes possible with the coalescence of these three elements. Public health research will be explored using another three Foucauldian concepts: discourse; 'regimes of truth', and 'regimes of practices'. Before explaining these further, two other overarching Foucauldian concepts need some elucidation: the concept of power/knowledge and the Foucauldian concept of power.

Foucault's understanding of the relationship between knowledge and power is an important part of his work and has been summarised as follows:

Power, according to Foucault, cannot be conceived as separate from the operation of knowledge. They imply one another: there is no power relation without the correlative constitution of a field of knowledge; and similarly there is no knowledge that does not presuppose and constitute at the same time power relations. The exercise of power is perpetually creating knowledge and conversely knowledge constantly induces effects of power. (Hillyard and Watson 1996: 326-7)

In relation to power, Foucault studied what he saw as new forms of power that arose in Western Europe from the 16<sup>th</sup> century (Foucault 1980b; Foucault 1991a). He was critical of political analysis that fails to '... cut off the head of the king ...' (Foucault 1976: 89) by continuing to conceive of power as something that emanates from

centralised sovereignty and has the primary function of negating the power of others. He wrote:

What makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms of knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression. (Foucault 1980b: 119)

With these concepts of power/knowledge in mind I can now formulate a framework for governmentality analysis of the research–policy nexus.

### **2.6.3. Regimes of truth**

For Foucault, 'truth' is the status accorded to the knowledge produced by the dominant scientific discourse. Foucault argues that what is important is '...in seeing historically how effects of truth are produced within discourses which in themselves are neither true nor false' (Foucault 1980b: 118). He proposes a constructionist view of 'truth' whereby society has a regime that produces and sanctions some statements as true and some as false (Foucault 1980b: 131). He specifies the 'regime of truth' in the following proposition:

'Truth' is to be understood as a system of ordered procedures for the production, regulation, distribution, circulation and operation of statements. 'Truth' is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extend it. A 'regime' of truth. (Foucault 1980b: 133)

The 'regime of truth' includes the infrastructure of knowledge production such as research methodologies, technologies, and procedures for investigation. These are closely linked with the exercise of power (Foucault 1980c: 102).

### **2.6.4. Regimes of practices**

Dean's primary focus of attention is on Foucault's idea of 'regimes of practices' which is inclusive of the idea of 'technologies of government' and envisages a complete

entanglement of such practices with the production of knowledge. In Dean's view, regimes of practices are

... more or less organised ways, at any given time and place, we think about, reform and practice such things as caring, administering counselling, curing, punishing, educating and so on (Foucault, 1991b). Regimes of practices are institutional practices, if the latter term means the routinized and ritualized way we do these things in certain places and at certain times. These regimes also include moreover, the different ways in which these institutional practices can be thought, made into objects of knowledge, and made subject to problematizations. (Dean 1999: 21).

Dean argues that there are four dimensions to regimes of practices, first proposed by Deleuze (1991, cited in Dean 1999: 30), that provide something of a framework for their analysis. These dimensions are: the 'visibility' created by the regimes; the techniques and instruments used to constitute authority and establish rule; the forms of knowledge (thought, calculation, rationality) that support and seek to change the regime of practice; and the forms of subjectivity created by the regime in terms of the forms of person, self and identity that are presupposed by the regime and the sorts of transformations these regimes seek.

Foucault's concept of 'practices' had many negative connotations. Habermas says, 'Foucault builds into the concept of "practice" the moment of coercive, asymmetric influence over the freedom of movement of other participants in interaction' (Habermas 1994: 51). However, Foucault also described in his later work the critical interplay between the exercise of freedom and the exercise of power. He argued that there is a 'permanent provocation' between the two, a 'mutual incitement and struggle', not a face to face confrontation that paralyses (Foucault 1994: 342).

### **2.6.5. Discourse**

According to Cheek, discourse "...is a system of statements which cohere around common meanings and values... [that] are a product of powers and practices, rather than an individual's sets of ideas" (Hollway, 1983, P.131)' (Cheek, Shoebridge et al. 1996: 174). Discourse is also a route to power and a means of exercising power. Cheek says that 'Claims to knowledge and authority by proponents of certain discourses are thus in effect claims to power' (Cheek, Shoebridge et al. 1996: 174). Therefore the

study of discourse is a primary means of studying the relationship between knowledge and power.

The discourses that are of particular interest here are those that establish the reasons for national public health policies. Rose and Miller (Rose and Miller 1992) refer to these discourses as ‘political rationalities’ which have several forms. The *moral* form of the discourse is the way it expresses the fitting power and duty of authority and the distribution of tasks between authorities (political, spiritual, military, pedagogic, familial). Political rationalities also have an *epistemological* character in the way they define the objects to be governed (eg which part of the population) and locate them within the wider population with rights and responsibilities. Political rationalities also have an *idiomatic* content in the way they render reality thinkable and make it amenable to political deliberation. Taken together, these forms of discourse problematise that which requires government and justifies and makes thinkable particular forms of government (Rose and Miller 1992: 179).

### **2.6.6. Technologies of self**

Technologies of self are the means of exercising ‘disciplinary power’ (Foucault 1980c), power that is exercised by and through individuals in relation to themselves and others. It flows through the extremities of social relations rather than out from the centre. Foucault wrote:

... in thinking of the mechanisms of power, I am thinking rather of its capillary form of existence, the point where power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives. The eighteenth century invented, so to speak, a synaptic regime of power, a regime of its exercise *within* the social body, rather than *from above* it. (Foucault 1980e: 39)

Public health programs exercise this kind of power when they set out to shape the behaviour and life experiences of individuals and the population as a whole. This connection between disciplinary power and public health was analysed by Foucault (Foucault 1980d) and has been the subject of considerable attention since (Lupton 1995; Petersen 1997; Turner 1997).



### 2.6.7. *Technologies of population*

Technologies of population are exercised through ‘biopower’, or power related to the body of the population. ‘Biopower’ is concerned with the government of population. Foucault defined biopower and its relationship to disciplinary power by arguing that they formed two poles linked together by a cluster of interrelations.

One of these poles—the first to be formed, it seems—centred on the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines: an anatomo-politics of the human body*. The second, formed somewhat later, focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary. Their supervision was effected through an entire series of interventions and *regulatory controls: a biopolitics of the population*. The disciplines of the body and the regulations of the population constituted the two poles around which the organisation of power over life was deployed. (Foucault 1976: 139) (emphasis in original).

Foucault’s evidence for this argument is the emergence since the 16<sup>th</sup> century in Europe of the disciplines of the workhouse, the prison, the school, the factory as well as the practice of observing birth rates, longevity, migration, public health, and housing. Foucault argues ‘...there was an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of population, marking the beginning of an era of “biopower”’ (ibid: 140). He argues that it was biopower that ‘... brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life’ (ibid: 143).

When he refers to interventions designed to regulate the population and its physical environment to achieve the objective of health, Foucault has public health interventions clearly in mind. In his lecture on the politics of health in the 18<sup>th</sup> century he describes the rise of ‘The imperative of health: at once the duty of each and the objective of all’ (Foucault 1980d: 170).

### **2.6.8. 'Governing at a distance'**

Rose and Miller argue that political power today

...is not so much a matter of imposing constraints upon citizens as of 'making up' citizens capable of bearing a kind of regulated freedom. Personal autonomy is not the antithesis of political power, but a key term in its exercise, the more so because most individuals are not merely the subjects of power but play a part in its operation. (Rose and Miller 1992: 174)

Rose and Miller argue that the main task for liberal political discourse is to enable 'government at a distance' by promoting the maximal functioning of 'civil society', a domain which is seen to be outside politics but which must be managed '...without destroying its existence and autonomy' (Rose and Miller 1992: 180). Rose and Miller propose that 'This is made possible through the activities and calculations of a proliferation of independent agents including philanthropists, doctors, hygienists, managers, planners, parents and social workers' (Rose and Miller 1992: 180). Public health researchers, practitioners and policy makers would all fit comfortably within the class of 'agents' referred to here.

### **2.6.9. A governmentality hypothesis**

The governmentality perspective argues that research must be conceptualised as knowledge/power. Its production and attempts to have research influence policy tie it to societal regimes of truth that produce statements that are accepted as true. Foucault argues that public health research and its techniques of calculation in relation to the health and management of the population have been integral to the course of governmentality since the mid 18<sup>th</sup> century.

While this argument is of historical interest, it does little to penetrate the dynamics of the research–policy nexus in public health at it occurs today. One way to gain greater traction on the research questions for this study is to identify several propositions that seem to be implicit in the governmentality perspective and then to explore these through the case studies.

The concept of governmentality connects disciplinary power and biopower in a way that enables the regulation of the health of the population by and through the self-disciplines of individuals. Technologies of population and technologies of self combine to produce

the effect of governing, but ‘at a distance’. A first proposition then is that national public health policies will be a mixture of, or point of contact between, technologies of population and technologies of self. Further to this, in order for policies to be successful within liberal forms of government, they must be composed in such a way that the requirements for ‘government at a distance’ are fulfilled: they should facilitate the process of individuals estimating risks and making choices and thereby making themselves up in a ‘regulated kind of freedom’; and they should enable the mobilisation of a diverse range of forces associated with ‘civil society’ which might be agents of governmentality but will not be seen to be the agents of ‘the government’ as it is normally conceived.

A corollary of this argument is the proposition that **the formation of national public health policy becomes possible and more likely to the extent that technologies of self can cohere with technologies of population within the conditions of ‘governing at a distance’**. This might be thought of as an hypothesis that sets out the conditions of possibility for the formation of national public health policy from the perspective of governmentality. But how does research figure in this governmentality hypothesis?

Research might be thought of as an integral part of three interrelated elements of ‘regimes of truth’, ‘regimes of practices’, and ‘discourse’. These provide three nodes of analysis for exploring the role of research in relation to the three key elements of national public health policy: ‘technologies of self’, ‘technologies of population’, and ‘governing at a distance’. Chapter 3 sets out the way this approach has been operationalised for the case studies.

## **2.7. Theory evaluation and theoretical eclecticism**

Given my research objective and questions, my major theoretical task is to find and make use of the best that the focal theories have to offer in terms of understanding the research–policy nexus. This might be divided into two parts. The first is to evaluate how well the theories work in themselves and in relation to each other. The second is to find a way to bring their respective contributions together to support a more robust theoretical appreciation of the relationship between research and policy.

Theory evaluation is a daunting task as it opens up a whole vista of questions about the philosophy of science. Parsons argues that the way we evaluate theory is partly

dependent on what we want to use it for. Is the purpose explanatory or exploratory? Is it to construct an ideal-type model? Or is it to prescribe the way the world should be? (Parsons 1995: 57-64). In these first two chapters I have raised issues about the adequacy of the explanation of the research–policy nexus found in the research utilisation literature. Answering my second question will require investigating how well the three focal theories account for the case study data. Explanatory adequacy is, therefore, an important criterion for theory evaluation in this thesis.

Parsons' review of theory evaluation identifies three criteria that form an evaluation framework. The first is how well a theory holds together and makes sense in itself—its coherence. The second is about how well it explains the available data—its congruence, parsimony and comprehensiveness. The third is the contribution it makes to our current knowledge and our ability to change the world for the better—its theoretical and practical importance and usefulness (Parsons 1995: 65 - 67).

A criterion that Parsons does not take into account that I think is important for this research project is what Bohman refers to as knowledgeable and reflective social actors and the problem of theoretical indeterminacy. He says:

...social actors are not simply the passive bearers of social forces or judgemental dopes within a cultural order. Equipped with capacities for knowledge and reflection, agents may alter their circumstances and conditions of life... If agents become aware of and change the conditions under which they act, no factor or set of factors can fully or determinately explain a social event or action. By becoming aware of social influences on them, agents may undermine their causal efficacy. Causal explanations in the social sciences, then, cannot be expressed in terms of universal, and hence determinate, laws... Thus, the protean character of reflective, social agency evades all attempts to discover some determinate theoretical use of all such explanatory terms in the social sciences. (Bohman 1991: 13)

While explanatory adequacy is central to Bohman's theory evaluation framework, he also requires that social theory take account of the agency of social actors and the indeterminacy that this creates. This might be brought into the evaluation framework set out above in terms of one of Bohman's central requirements for social theory—that it make sense of the relationship between the micro and the macro level of explanation. By his account, individual action can never be fully accounted for by macro social forces, and macro social events can never be fully accounted for by the proximate

actions of individuals (Bohman 1991: 146). This problem may also be thought of as the agency–structure relationship in social science theory and it is a feature of the struggle for theoretical synthesis.

Presentation and evaluation of the three focal theories provides us with some new knowledge of the relationship between research and policy but the contribution would be enhanced if we could find ways in which the theories complement each other and contribute to a more robust understanding. This requires a larger theoretical framework and a language that can incorporate the concepts of each of the focal theories without destroying their integrity. Sil framework provides a way of approaching this task to the limited extent possible within the scope of this thesis (Sil 2000).

Sil argues that the fundamental tensions and arguments in social theory can be captured in a two-way juxtaposition of ‘materialist’ approaches with ‘ideal’ on one axis and ‘agency’ and ‘structure’ on the other axis. The agency–structure distinction relates to the relative significance given to individual agents and their choices vis-à-vis the structures that they find themselves in—their socially defined roles and positions and identities. The material–ideal distinction relates to the relative significance given to material factors such as wealth, resources, rules and social networks vis-à-vis the ideal features of norms, beliefs, symbols, and cognitive schema (Sil 2000: 354). These can be shown in the following figure.

**TABLE 2:3 THE INTERSECTION OF AGENCY–STRUCTURE AND MATERIAL–IDEAL ASPECTS OF SOCIAL LIFE (SIL 2000: 360)**

	Material	Ideal
Structure	I	II
Agency	III	IV

In these four cells Sil orders the major approaches as follows: Structuralist approaches in Box I (eg most Marxist theory and historical institutionalism); Culturalist approaches in Box II; Rational choice theorists relate to Box III; Ethnomethodological and psychological approaches are in Box IV. Sil argues that most sophisticated theories work hard to make up for weaknesses inherent in their primary orientation but in the final analysis will assert the primacy of either agency or structure on the one hand, and the primacy of material or ideal factors on the other.

Sil argues that the possibilities for eclecticism are related to the preparedness to become ‘epistemologically agnostic’, to let go of a primary theoretical orientation on the

agency–structure, material–ideal divide and look for dialectical and reflexive relationships between them. He argues that Giddens’s notion of ‘structuration’ and Bourdieu’s concept of ‘habitus’ share this characteristic and provide the basis of theoretical eclecticism (Sil 2000: 376-9).

I propose to use this framework in several ways. At one level it enables a meaningful approach for comparing and contrasting the focal theories. In Chapter 8 I analyse the focal theories in terms of the way they deal with ideal and material structures and their interaction with agency. At another level the framework provides the tools for answering question 3—the implications of the case studies for the theory of the relationship between research and policy.

The concept of ‘structure’ is ubiquitous to social science but poorly defined. For the purposes of this thesis, Sewell’s definition will be used. Social structures will be thought of as

...sets of mutually sustaining schemas and resources that empower and constrain social action and that tend to be reproduced by that said action. But their reproduction is never automatic. Structures are at risk, at least to some extent, in all of the social encounters they shape—because structures are multiple and intersecting, because schemas are transposable, and because resources are polysemic and accumulate unpredictably. (Sewell 1992: 19)

## **2.8. Summary**

In this chapter I have argued that most current proposals to improve the relationship between research and policy are too reliant on what is known as the ‘two communities’ theory of the research–policy problem. The result is that solutions continue to focus on tools and mechanisms to achieve research ‘transfer’ and fail to come to grips with the social and political processes involved in making policy. The search for the next generation of measures to improve the research–policy relationship might be informed by exploring different ways of seeing the problem.

The three focal theories provide different constructions of the research–policy nexus. The worth and potential of these theories will be evaluated using a framework that looks at their coherence, comprehensiveness, and parsimony. Their contribution to a more

general theorisation of the research–policy relationship will be explored using Sil’s framework for theoretical eclecticism.

Lest there be any confusion, the point of this chapter is not to argue that communication is irrelevant to the research–policy relationship. Nor is it to argue that better communication between researchers and policy makers is unnecessary or undesirable. Nor am I suggesting that there are no important differences between the organisational and cultural environments within which researchers and policy makers work. Rather, the point is that the ‘two communities’ theory might not capture the most important determinants of the relationship between research and policy.

## **3. Study Design and Method**

### **3.1. Introduction**

The objectives and questions for this research project were set out in Chapter 1 and the theoretical background to this study was established in Chapter 2. In this chapter I describe the research design that links the data collection strategy with the research questions and the methods used to collect and analyse the study data. Unfortunately, there is a lack of agreement on what constitutes good qualitative research (Yin 1994), on whether or not the case study method is a subset of the qualitative approach or vice versa (Guba and Lincoln 1989), and whether or not the principles underlying the criteria used to judge the rigour of quantitative research are meaningful or appropriate for an assessment of the quality of qualitative research (Miles and Huberman 1994; Daly 1996). In the appendix for this chapter I review a range of strategies common to several epistemological positions and discuss how they were used in this study. Ethical issues are discussed in the same appendix. This chapter concludes by outlining the non-sequential and iterative way in which the design of this study grew.

### **3.2. Rationale for using a case study design**

I adopted a case study design. Yin argues that this design has advantages over other research designs in the following circumstances: when ‘how’ or ‘why’ questions are being asked about contemporary events over which the investigator has little or no control; when the phenomenon is being studied in its ‘real-life’ context; and when the boundaries between the phenomenon and its context are not clearly evident (Yin 1994: 9-13). For these reasons, the case study method is widely used in the field of public policy analysis (Vickers 1965; Allison 1971; Parsons 1995; Flyvbjerg 2001). Case studies are also commonly used in studies of research utilisation (Hanney, Gonzalez-Block et al. 2003: 11). The cases may be particular pieces of research, whole research programs, or particular cases of policy development.

A single case study design would suffice if it were possible to test an existing theory through a critical, unique or extreme case of national public health policy (Yin 1994:



38-41). As no such theory exists, and as national public health policies are diverse (see below), a multiple case design is required to support broader generalisations.

Yin argues that multiple case studies should be viewed in terms of ‘replication’ rather than ‘sampling’ with each individual case study being analogous to an experiment where previous theory is confirmed or challenged (Yin 1994: 45-6). Miles and Huberman support the idea that case selection can be ‘theory-driven’ (Miles and Huberman 1994: 27) but are less concerned with the conceptual distinction between selection for the purpose of ‘sampling’ from a population, and selection for the purpose of ‘replication’ vis-à-vis theory. The case study selection rationale set out below uses both a sampling and a replication rationale for a four-case design.

Miles and Huberman argue that theory development and empirical observation should proceed in an iterative fashion in case study design. They identify a range of views among qualitative researchers over the extent to which theory should lead or follow in this process. They contrast ‘tight’ and ‘loose’ approaches—‘tight’ approaches emphasise theory and hypothesis development prior to data collection while ‘loose’ approaches work in the reverse order (Miles and Huberman 1994: 16-17).

I have taken a relatively ‘tight’ approach because my prior studies in public policy and my experience as a Commonwealth public servant working on public health policy made it difficult to enter the field with a conceptual tabula rasa. This approach is supported by methodological considerations. Yin argues that prior specification of theory and hypotheses is a strategy for enhancing case study rigour (Yin 1994: 28). Parsons argues that ‘facts’ and ‘observation’ are theory dependent. They do not exist outside a prior framework of theory or expectation, even where this is unspecified or belongs to ‘common sense’ (Parsons 1995: 48-9). Different theoretical frameworks will bring different ‘facts’ to light and invest them with different meaning and significance. An exemplar of public policy case study research is Graham Allison’s analysis of the Cuban missile crisis. In this he writes ‘Conceptual models not only fix the mesh of the nets that the analyst drags through the material in order to explain a particular action: they also direct him to cast his nets in select ponds, at certain depths, in order to catch the fish he is after’ (Allison 1971: 4).

### 3.3. Data collection and analysis

Strauss (Strauss 1987) describes the process of qualitative research as a continual movement between three interrelated phases: data collection, coding and memoing. Miles and Huberman advocate a similar approach where data collection iterates with data reduction, data display, and conclusion drawing and verification (Miles and Huberman 1994: 10-12). In this research project I have continually moved from the questions, to data collection, presentation, interpretation and theorisation, back to data collection and question refinement. The last section of this chapter describes this iterative process in more detail.

I used two basic types of data for this study: documents of various sorts and in-depth interviews. Hanney and others note that these are the two sorts of data used most frequently in studies of research utilisation (Hanney, Gonzalez-Block et al. 2003: 12).

Each case study commenced with document collection and analysis. The documents were of the following types: Government or departmental publications found in the library of the Commonwealth Department of Health and Ageing, on Departmental files and book shelves or in the National Library of Australia; reports of committees, especially National Health and Medical Research Council (NH&MRC) committees and committees of inquiry and 'expert' working groups, and Commonwealth-State officials committees; proceedings of conferences or fora on the problem or issue or on the policy itself; targeted searches of national daily newspapers around times of policy announcements, debates or events; and targeted searches of parliamentary papers e.g. Parliamentary Committee Hansards. I also searched electronic data bases such as Medline, the Australian Public Affairs Information Service (APAIS), and Sociofile. More detailed information on documentary search strategies are provided in the Notes on Method sections of the appendices. The Alcohol and Other Drugs Council of Australia (ADCA) library (funded by the Commonwealth through the National Drugs Strategy) was an important source of documentary material for the two NSP case studies.

One simple strategy for exploring the research-policy nexus was to follow up references made in policy documents to published research or reports of inquiries. These references led to other papers or points of view that were in dispute with each other or with policy. I could then follow up these discordant studies and gain an understanding

of what the official policy documents had selected from the available research and how discordant data or points of view had been treated.

The documentary record enabled the creation of a chronological table of key events for each of the case studies. These included research ‘events’ such as the commencement or publication of particular studies, policy events such as the establishment of committees of inquiry, or other events in the social or political context that were referred to because they had some kind of bearing on the way policy developed.

The documentary record also enabled the creation of a list of key informants for interviews. It became clear very quickly who the most prominent researchers or dissidents in a particular field of research were because it was their research that was referenced most often and/or the Medline and other database searches showed them to be the most widely published researchers on a particular topic. Key actors from government and non-government organisations also became clear because of their multiple memberships of various committees that were charged with reviewing research and/or formulating policy. The limitation of this approach is that some policy actors may have withdrawn or been deliberately kept out of committees so their activities go on without obvious recognition by formal policy documents. The searches of the medical literature, newspapers and the web provided some check on this (vocal and strong opponents of government policy use these vehicles to make their voice heard) but there is the possibility that some critics were not identified.

The primary selection criterion for interviewees was participation in policy debates or policy processes either through membership of government departments, membership of committees appointed to advise on policy, or through the overt attempts they made to influence policy by expressing opinions in the media (major daily newspapers or the *Medical Journal of Australia*). Of those who fell into this group, selection was aimed at having a mix of informants from Commonwealth and State government departments, researchers, people appointed to government advisory or policy making committees for their expertise in the policy issue, and those who expressed views that dissented from current policy. I also approached each of the Commonwealth Health Ministers who had served during the period covered by the case studies (Neal Blewett, Brian Howe, Graham Richardson, Carmen Lawrence, and Michael Wooldridge). Neal Blewett and Carmen Lawrence were interviewed and the others did not respond to my request. As there were few consumer representatives involved in these committees, I only

interviewed one person who worked on a national committee in that capacity. This means that the views of consumers and what might be called a consumers eye view of the research–policy nexus has not been explored in this research. A breakdown of the number of people approached for interview, the number completed, and the ‘type’ of key informant is provided for each case study in the relevant appendix.

The number of interviews was guided mostly by the principle of redundancy—the point where it became clear that each new interview was adding very little by way of new information on the policy process and the policy–research nexus.

I recorded the breast cancer case study interviews by hand and taped the interviews for the other case studies except in one case where a respondent declined to have the interview taped. I changed the recording strategy in order to reduce the burden on me during the interviews and to capture a more complete record of the interview. Regardless of the transcription method, informants were sent transcripts of the interview and invited to make corrections or additions. For the sake of convenience and efficiency, most interviews were conducted by telephone. Several Canberra-based respondents were interviewed face-to-face. In one case, a respondent had a strong preference for a face-to-face interview, which necessitated travel outside Canberra.

The interviews followed a semi-structured format and interviewees were provided with a list of questions beforehand. Key informants were asked about their role in policy or research related to the case study, their views on how and why policy took the shape it did, and their views on the role of research in the policy process. The questions and the interview process were designed to elicit information relevant to the focal theories. For example, with respect to the Advocacy Coalition Framework, respondents were asked about their views on policy advocates and policy critics and on the beliefs and values that informed their respective position. With respect to the Policy Making Organisation Framework, respondents were asked about their perceptions of the risks and opportunities that confront the politicians and the bureaucracy. Respondents were asked about their views on the role and influence of research and why some kinds seemed to have particular potency in the policy environment, a question of relevance to all three focal theories including the Governmentality Framework. The interview questions for each case study are in the appendices.

I used two related strategies to analyse the transcripts of interview. The first strategy was to triangulate the interview data with the documentary data on key events, individuals, organisations and contextual material about the research and policy environment. The second strategy was to analyse each interview in terms of each of the focal theories using ‘templates’ that identify the data, hypotheses and propositions that are central to those theories. These templates are briefly reviewed below and are reproduced in full in appendices for Chapter 3. Once each interview had been analysed separately, the data were looked at collectively and ‘cross-sectionally’ by posing the question: what do the data mean for the Advocacy Coalition Framework? The Policy Making Organisation Framework? The Governmentality Framework?

### **3.4. Case Study Selection**

Sampling within qualitative research aims to select those cases that will contribute most to theory building or to testing propositions or hypotheses. The aim is to support theoretical or analytic generalisation rather than statistical generalisation (Strauss 1987; Miles and Huberman 1994; Yin 1994; Mays and Pope 1996; Flyvbjerg 2001). With this overall goal in mind, the case study selection strategy was guided by the goal of building maximum internal and external validity.

A case study selection strategy that goes some way towards establishing internal validity is one where there are at least two like cases but a different policy outcome. This is expressed as a ‘positive case’, where a public health policy has been developed and implemented, and a ‘negative case’ where a similar public health intervention or problem failed to generate the development of national public health policy. Comparison between the cases enables assessment of the relative importance of the various factors influencing policy and increases the chance that the critical factors involved in producing the different policy results will come to light. The power of this strategy is increased if the cases are as similar as possible except for the policy outcome—the decision to introduce or not introduce policy.

On its own, however, this strategy would reduce external validity because of the diversity of public health interventions and problems. External validity is increased if there are two or more cases that represent quite different public health policies but have similar outcomes. This suggests a ‘2 x 2’ design involving four cases—two pairs of case studies drawn from quite diverse areas of public health which contain within them one

‘positive’ case and one ‘negative’ case—offers at least some internal and external validity. Its design enables several cross-case analyses and comparisons with the wider field of public health policy. The internal validity of conclusions about any particular case is strengthened by comparison with its pair. The validity of generalisations to national public health policy as a whole is strengthened by comparison of the non-alike pairs. This is described by Flyvbjerg as a ‘maximum variation’ sampling strategy which increases relevance across a wide range of circumstances and outcomes (Flyvbjerg 2001: 79).

The starting sampling frame is the set of national public health policies and strategies recognised by the National Public Health Partnership, a committee of senior Commonwealth and State/ Territory public health officials. This is set out in table 3.1.

**TABLE 3:1 NATIONAL PUBLIC HEALTH POLICIES**

<b>Established Strategies</b>	<b>New and Emerging Strategies/Strategies Under Development</b>
Alternative Birthing Services Program	A National Environmental Health Strategy for Australia
BreastScreen	Active Australia: A National Participation Framework
Female Genital Mutilation Program	Food and Nutrition Policy
National Aboriginal Health Strategy	Maternal and Child Health Strategy Plan
National Cancer Control Initiative	National Alcohol Strategic Plan
National Cervical Screening Program	National Asthma Strategy
National Communicable Diseases Surveillance Strategy	National Injury Prevention Strategy
National Drug Strategy	National Strategy for an Ageing Australia
National Health Plan for Young Australians	National Tobacco Strategy
National Hepatitis C Strategy	
National HIV/AIDS Strategy	
National Immunisation Strategy	
National Indigenous Australian’s Sexual Health Strategy	
National Mental Health Policy	
National Women’s Health Policy/ National Women’s Health Program	
National Youth Suicide Prevention Strategy	

Source: (National Public Health Partnership 1999)

Before considering case study selection guided by internal and external validity, a threshold issue for selection of the primary cases (those where policy has been developed and implemented) is empirical tractability. The length of time the policy has been in place and the ready availability of policy documents and key informants enhance this.

An important consideration for me as a researcher and as a Commonwealth public servant was whether or not I should research policies that were under active

development or going through some kind of change. I deliberately chose to focus on cases where there had been a long period of relative stability and where the major policy decisions were taken prior to the change of Federal Government in 1996. This enabled me to look closely at the political issues involved without raising concerns from my Department or key informants that my research process would interact with current policy development processes. The most important down side of this decision is that policy development processes prior to 1996 may be different to those post 1996. Following the case studies as closely as possible up to 2000 has offset this. This creates the added advantage of being able to take into consideration the influence on policy of the change in Federal Government in 1996. The fact that policies under consideration have remained relatively stable despite changes in the composition of the Federal Government is a finding that can be used to explore the study questions and the theoretical frameworks. A second down side is that events are sometimes over 15 years in the past and key informants were less confident of their recollections than they might otherwise be. The up side is that key informants could reflect on their role and the process as a whole with some sense of distance and detachment.

The impact of this choice on the sampling frame is to remove those policies listed in the 'emerging' category. From the 'established' list it also removes: the National Cancer Control Initiative; the National Immunisation Strategy (though this was established under the previous government it has been and remains a major focus of policy attention by the current government); the National Indigenous Australian's Sexual Health Strategy; and the National Youth Suicide Prevention Strategy.

As noted above, selecting case studies from different categories or types of public health action enhances external validity. There are various ways of categorising public health. One kind of typology relates public health action to major disease types: communicable disease, non-communicable disease, and injury. Injury is excluded because it is an 'emerging' strategy. The communicable–non-communicable disease divide has a prima facie policy importance because of the time frame within which problems appear and the speed with which governments are required to act (quickly versus slowly). On this basis, one pair of case studies was chosen from the communicable diseases field and one from the non-communicable diseases field.

The established non-communicable disease strategies that remain under consideration are the breast and cervical cancer screening strategies, Alternative Birthing, FGM, the

Aboriginal Health Strategy, the National Drug Strategy, the National Women's Health Policy, and the National Mental Health Policy. FGM can also be excluded on the basis that it is a comparatively small program in terms of resources devoted to it, the policy attention given to it and the size of the health burden associated with—external validity would not be greatly enhanced by selecting it as a case study. It would also be difficult to find a like-pair case study.

Of the remainder, the strategies that have devoted a sizeable proportion of their resources to public health as defined in Chapter 1 are the cancer screening strategies, and the National Drug Strategy. The others (Alternative Birthing, the Aboriginal Health Strategy, the National Women's Health Policy and the National Mental Health Policy) have had their major focus on the acute and/or primary care sectors with disease prevention, health promotion and disease protection as relatively small components.

Within the field of communicable diseases, the strategies that remain for consideration are the National HIV/AIDS Strategy and the National Communicable Diseases Surveillance Strategy. The latter can be excluded because it is a strategy for collecting data rather than doing public health (an important part of the research–policy nexus in its own right, however).

This process of exclusion leaves the breast and cervical cancer screening strategies, the National Drug Strategy and the National HIV/AIDS Strategy as the policies that are most analytically tractable and most focussed on public health, though this a matter of degree rather than categorical difference as the primary and acute care elements of these strategies are also significant.

Another public health typology that relates to external validity is concerned with the type or modality of public health intervention. Holman (Holman 1992) provides a five fold classification for public health interventions set out in the following table.

**TABLE 3:2 A TYPOLOGY OF PUBLIC HEALTH INTERVENTIONS BY STAGE OF HISTORICAL DEVELOPMENT OF PUBLIC HEALTH PRACTICE—DERIVED FROM HOLMAN (HOLMAN 1992)**

<b>Strategic Approaches to Health Advancement in Human Populations</b>	<b>Modes of Intervention or Practice</b>	<b>Examples</b>
Health Protection	Enforced Regulation of human behaviour. Enforced standards of hygiene, safety etc Regulation of human activity and environment	Quality and safety of water, air, food. Transport regulations - seat belts, speed Advertising regulation - no tobacco



Strategic Approaches to Health Advancement in Human Populations	Modes of Intervention or Practice	Examples
Preventive Medicine	Primary prevention – prevent onset of illness Secondary – stall progress of disease Tertiary – minimise complications of illness	Immunisation  Screening – breast etc Management of diabetes
Health Education	Facilitate voluntary adaptations of behaviour conducive to health Social marketing Active participation of learner	Commercial marketing to reduce smoking School health education Within client-provider relationships
Healthy Public Policy	Creation of social, economic and physical environment conducive to healthy choices Intersectoral action – in both public and private institutions and in non health portfolios System level action	Healthy Cities Pricing policies on food, alcohol, tobacco Disabled access Advocacy on poverty, unemployment
Community Empowerment	Build capacity of communities and individuals to respond to and resolve their problems Community development Participation Advocacy Change to society power structures	Temperance Movement Women's movement Social action campaigns

Generalisation to public health policy as a whole will be enhanced if the case studies encompass as many of these interventions as possible. From those policies that are left for consideration, cancer screening falls largely within the ‘preventive medicine’ modality, while the National HIV/AIDS Strategy and the National Drug Strategy are ‘multi-modal’ and include interventions from across the spectrum. On this basis, one pair of case studies should come from cancer screening thus representing a non-communicable disease and preventive medicine approach to public health. The other pair should come from the National HIV/AIDS Strategy and the National Drug Strategy and attempt to capture a multi-modal, communicable disease public health policy.

In choosing between a case study on breast or cervical cancer screening I decided to focus on breast cancer screening because I had been working on an evaluation framework for the program in 1999 and already had some understanding of the policy and of the most relevant policy documents and research. It was, therefore, a pragmatic decision based on my own ability to quickly capture the required data. For a ‘negative’ case study pair there were initially two options available, prostate cancer screening and colorectal cancer screening. As the latter became the subject of renewed policy interest in 1999 and has now been introduced in a pilot phase, it was excluded from consideration.

The breadth of the drugs and HIV/AIDS strategies posed the problem of their tractability within the resources available. To select from within them, however, created the possibility of losing their ‘multi-modal’ characteristic. One intervention stood out for its multi-modal characteristics and for its importance as a communicable disease control measure with central relevance to illicit drugs policy—needle and syringe exchange (NSP). It is funded from the National HIV/AIDS Strategy but is recognised as an exemplar of the harm minimisation philosophy said to underpin the National Drugs Strategy. Its implementation entails intersectoral action with law enforcement agencies and legislative change in relation to the distribution of injecting equipment.

The task of selecting a ‘negative’ case for NSP became clear after an initial appraisal of the literature on NSP. This showed that no jurisdiction in Australia had introduced NSP within its prison system even though there was a prima facie valid public health argument for introducing NSP in prisons. NSP in the community and NSP in prisons became a case study pair that promised some opportunities for building internal and external validity.

The four case studies might be set out as follows.

**TABLE 3:3 CASE STUDIES IN RELATION TO IMPLEMENTATION STATUS AND CASE STUDY CHARACTERISTICS**

		Policy Case Studies	
		Yes	No
<b>Case Study Characteristics</b>	<b>Disease Type:</b> Non Communicable Diseases. <b>Intervention Type:</b> Preventive Medicine	Mammography Screening	Prostate Cancer Screening
	<b>Disease Type:</b> Communicable Diseases and Drug-Caused Harm <b>Intervention Types:</b> Health Protection, Health Education and Healthy Public Policy	NSP in the community	NSP in prisons

### 3.5. Case study analysis

Using the theoretical frameworks set out in Chapter 2, I developed three templates that specified and organised the data collection and analysis process for the case studies. These templates are set out in full in appendices for Chapter 3. This section provides a brief overview of their structure and content. Each template sets out a series of steps.

### **3.5.1. ACF case study analysis template**

Step one aims at identifying whether or not the notion of a policy subsystem with competing advocacy coalitions makes any sense within the particular policy area. Individuals and groups involved in the policy process are identified and questions about their shared beliefs and actions are explored. The second step focussed on analysing the origins, purposes and uses of research within the policy process. It involves identifying what research was done, who did it and paid for it and how it fitted with the ACF's predictions for the behaviour of advocacy coalitions with regard to research. In particular it focuses on how research related to the strategy of improving understanding of goals and other variables important to the Dominant Advocacy Coalition's belief system (eg monitoring critical variables); refining understanding of the logical and causal relationships underpinning the Dominant Advocacy Coalition's beliefs; and identifying and responding to challenges to the Dominant Advocacy Coalition's belief systems.

The template then focuses inquiry on evidence for the phenomenon of 'policy oriented learning' and the conditions under which it may or may not have occurred. Issues of conflict between coalitions, the analytical tractability of the policy issue, the availability of 'professional' fora for debate, and the distribution of power within the policy subsystem were all explored. The final step is to review the findings from the analysis and discuss the limitations of the ACF analysis in relation to the study questions. This involves checking rival hypotheses and identifying data that the ACF does not take adequate account of.

### **3.5.2. PMO case study analysis template**

The first step of this analysis is to assess the degree of 'research responsiveness' of the policy making organisation. Each of the indicators set out in Chapter 2 is explored in turn: PMO responsibility; PMO capacity; PMO performance; the 'theatre of justification'; and vulnerability to the consequences of error. A summary table gives an overall qualitative grading of the extent of research responsiveness.

The second step analyses the orientation of the political arm and the bureaucratic arm of the PMO towards policy initiation or change, or towards the policy status quo. Each of

the indicators identified in Chapter 2 is discussed and an overall assessment of the political and bureaucratic risks and opportunities are arrived at.

With this basic information in place, an assessment is made of the relationship between research and policy in terms of the PMOF model. Will the policy making organisation be relatively more or less research responsive? Will it be more or less inclined to policy initiation/change or the status quo? Or will it be ambivalent? These expectations are then compared with the case study data to identify how well the framework accounts for the observed outcomes. Lastly, the findings of the PMOF analysis are discussed and limitations canvassed.

### **3.5.3. Governmentality case study analysis template**

This template involves systematically working through an analysis of discourses, regimes of practices, and power/knowledge as it relates to regimes of truth. Technologies of self, technologies of population, and ‘governing at a distance’ are discussed within consideration of the governmentality hypothesis.

The large scope, complexity, and epistemological vagaries of Foucault’s work make a mechanical approach to a governmentality analysis difficult. Despite this, an attempt was made to work systematically through each of the nodes of analysis and relate them to the other nodes. As with each of the other frameworks, the case study analyses conclude with an appraisal of the findings and the strengths and weaknesses of the governmentality framework.

## **3.6. Case study presentation**

As noted above, my approach puts an emphasis on theory and I take the view that ‘facts’ are theory dependent. This creates a challenge for case study presentation. If I adhered strictly to this point of view it would mean presenting each case study in three different ways, leading to twelve separate case study stories with a great deal of repetition. As a compromise I have chosen to present the case study data as completely and coherently as possible first and then to do theoretical analysis that does not, by and large, introduce much by way of new data or repetition. The overviews are not independent of theory but rather are made up of data that are salient to at least one of the focal theories. The overviews are made up of several general categories of things: policy

events, processes, policy actors, the policy context, policy content, and the relevant research. These are similar to those reported to have been used in other case studies of research use in policy (Hanney, Gonzalez-Block et al. 2003: 11).

### **3.7. Researcher affects**

I have taken the view from the very beginning that this study required a level of scepticism about the value of the public health interventions that form the basis of the case studies. I've attempted to look at the policy and at the research by switching 'hats'. I've asked myself how I might perceive policy arguments if I were an advocate of this policy, and how I might perceive them if I were a critic. But despite this, I do have some relevant views on the cases.

I am sceptical of the benefits of cancer screening in general and very conscious of the harms it may cause. I remain perplexed as to the ethical conundrum that it presents—screening can bring benefits and harms but these are experienced by different groups of people. How can harming one group of people be justified by the benefit it does to another group? The concept of net benefit to the population is part of the justification and the individual trade-off between relatively insignificant harms versus significant possible benefits clearly satisfies a lot of women—as long as they are given accurate information and a chance to consider it thoroughly. My scepticism with regard to screening has been confirmed by my reading on prostate cancer for the same reasons.

On NSP I find myself a reluctant supporter. I was directly involved in the evaluation of the National HIV/AIDS Strategy in 1995 and played a role in facilitating the completion of the cost-effectiveness analysis of NSP by Hurley and others (Hurley and Butler 1996; Hurley, Jolley et al. 1996; Hurley, Jolley et al. 1997). I saw that the study was potentially very valuable, particularly if it demonstrated cost-effectiveness for a politically vulnerable program. So I have been a direct participant in the process of funding and using research as a policy resource. I am no stranger to the strategies I describe in the case studies. The reluctance in my support comes from my personal aversion to injecting drug use and my concern that, at a personal and societal level, it occasions more harm than good. The chance that NSP might contribute to a climate of acceptance of IDU is an ongoing fear for me. On the question of NSP in prison, I find myself a supporter of more research. I found myself getting angry during the case study at the control which prison authorities wield over prisoners and the services they

receive. I am not unsympathetic to the job that prison officers have to do. In my view, the lack of accountability of correctional authorities and our society's apparent thirst for mass imprisonment as a solution to complex social problems are an indictment on our society.

Making these orientations clear does not mean that they are tucked safely away and will no longer affect the research outcomes. I have tried to be aware of how they might influence the way I do the research and tried to provide a mental check on that myself. It is up to the reader to form a judgement on how successful I have been.

Lastly, the researcher effects on the key informant interviews need to be considered. There are two possible effects worth noting. The first is that I made clear to the informants the topic of my research and sent them the questions ahead of time. It is possible that those involved, many of whom played a direct role in the policy development process, wanted to give me a view of the role of research that I wanted to hear. To guard against this I tried hard not to convey an impression that I expected research to be significant or not. I placed the specific question on the role of research at the very end and went through a number of questions about the policy 'story' before getting to it. The semi-structured nature of the interviews allowed me to encourage the informants to recreate the policy story in their own terms and to structure the story according to their own experience. Most interviews went for longer than 45 minutes, some for over 90 minutes. I am reasonably confident that during this time the interviewees became very engaged with their own view of the policy process and any desire they might have had to give me a particular view of research in the policy process that they thought I wanted to hear was minimised. Even if there was a social desirability bias at work, I do not know whether it would have led to key informants over or under-emphasising the role of research. Some could have thought that I wanted to hear that research had been important and influential, some may have thought the opposite. Thus, I do not think this bias would have worked in a systematic way.

The second researcher effect in relation to key informants could have come from their perception of me in my role as an employee of the Commonwealth Department of Health and Ageing. I had had at least some contact with many of the key informants prior to the interviews through my work on public health. In several cases I could have been viewed as someone who might be in a position of influence over decisions that might affect them at some stage in the future. While I cannot discount the possibility

that this perception existed, I am uncertain what particular bias it might have introduced into the way informants answered the questions or whether it would have worked systematically. At this point I note it and leave the reader to consider its implications.

### **3.8. How the research was done**

It is often acknowledged that the logical and sequential form in which research is reported bears little relation to the way the research was done. This project is no exception. The elaborate design of three ‘focal theories’ and a global synthesising theory exploring four case studies arranged in a 2 X 2 design evolved over the course of the study. Miles and Huberman support this iterative approach for qualitative research and argue that it moves between four interrelated components: data collection, data reduction, data display, and conclusion drawing/verifying (Miles and Huberman 1994: 12). My experience supports this, however, in a multi-case study and multi-theory design I would add a fifth component, that of theory and method revision and elaboration.

I began my research with the general area of the relationship between research and policy in mind. I commenced by reading broadly on the history of public health and the theoretical literature on research utilisation and public policy. I developed a single, general theoretical framework and completed the first case study on Breast Cancer Screening. While I had always intended to do more than one case study, the idea of doing four cases came some way into the second case study (NSP in the community). At this point I became concerned that having two case studies of policies on interventions that had been implemented (ie ‘positive cases’) may bias the findings of the study towards a positive view on the impact of research. I decided to do two further case studies of policies where a public health intervention had been rejected (ie ‘negative cases’).

It was also during the second case study that I developed concerns about my single all-encompassing theoretical framework. This framework attempted a synthesis of the work of Dery, Sabatier and Lomas among others and was somewhat useful in analysing the first case study. However, I began to find that it contained serious tensions because of the continuing commitment to the ‘two communities’ theory among Lomas and other research utilisation theorists. I thought that there may be more value in comparing and contrasting the Advocacy Coalition Framework approach with the institution-focussed

approach of David Dery. At about the same time, I also decided that I needed to do something about the unease I felt in not using the ‘governmentality’ perspective simply because it seemed so empirically intractable. The work of Foucault in general and the notion of governmentality in particular has been becoming increasingly prominent over the last two decades in the sociology of knowledge and its relationship to government (Gordon 1991) and public health (Lupton 1995). The decision to include the governmentality perspective had implications for the way that I handled all three theories. Because the ACF was already well developed into an empirically evaluable form before I began this thesis, I decided that the work of Dery and Foucault needed to be rendered into similar forms. As I acknowledge at various points, there may be a number of post modernists who reject the very basis of this step as far as Foucault’s work is concerned. However, I think the findings of this research project indicate the benefits of this approach and justify the risk taken.

Lastly on the theory front, I added the use of Sil’s framework for theoretical eclecticism after exploring various approaches to theory evaluation such as those suggested by Parsons (Parsons 1995: 66-7) and Bohman (Bohman 1991). This literature steered me away from simply trying to decide which of the theories was better than the rest and towards the view that the different theories may have different strengths and weaknesses but they may all add something in terms of our understanding of complex social phenomena. Thus, the design, method, theory, data collection, data reduction, and data display have been continuously interacting components of this study since its inception. Presentation in a logical and sequential form is not intended to hide this process.



## **4. Breast Cancer Screening**

### **4.1. BCS policy, research and the research–policy nexus**

This is a case study of the research–policy nexus in breast cancer screening (BCS) policy<sup>10</sup> in Australia. The first section presents the main events and processes in BCS policy development, research relating to BCS in Australia, and the nexus between the two. The later sections analyse this data using the theoretical frameworks from Chapter 2. The events and processes are not presented in chronological order. I begin with what might be seen as the high point in public visibility of policy making on BCS, then move out to explore the context of policy making, the actors involved, the process and the content of policy and research. A chronology of events is set out can be found in the appendices for Chapter 4.

#### **4.1.1. *BCS as a political opportunity***

On 3 March 1990, during a Federal Election Campaign, the then Prime Minister Bob Hawke announced that, if the Labor Party were re-elected, it would introduce a ‘national program for the early detection of breast cancer’ (Wright 1990). Three days later the then Leader of the Opposition, Mr Andrew Peacock, issued a Liberal Party Policy Statement saying ‘We will increase the number of screening units so that more women will have easier access to effective screening at a cost of \$10m in the first year’ (Peacock 1990). The Labor Party was re-elected and the national program commenced in 1991. It was renamed BreastScreen Australia in 1995 and continues under this name today.

The Labor and Liberal election promises in 1990 were attempts to attract the votes of women. This is evident from the way their announcements were packaged with other items targeted at the ‘women’s vote’. Key informants were almost unanimous in their view that politicians at Federal and State level saw mammography screening as politically popular. For several years up to and following these promises,

mammography screening attracted a high level of media attention that reported both its benefits and problems (Short 1992; Lupton 1994).

The announcement by Hawke pre-empted the release of the *Future Directions*<sup>11</sup> report, which recommended the introduction of a mammography screening program, in June 1990. There is evidence, however, that the findings of the report were known to the government and the opposition at the time of the election campaign. Williams reports that Michael Fett was called to the Health Minister's Office during the election campaign to give advice on the progress of the evaluation of the pilot screening programs (Williams 1991). Dr John Donovan, a member of the AHMAC Steering Committee responsible for *Future Directions* said that he was contacted by both major parties during the campaign for advice on BCS.

#### **4.1.2. The prima facie significance of research**

Many of the key informants for this case study were closely involved in BCS policy and felt that the research-policy nexus was exceptionally close. They said things like:

Mammography screening was the quintessential example of evidence-based policy making.

(Mammography screening was)...one of the few examples of where research and policy have worked together in Australia.

Research was the crystal around which everything else grew...at least that is what I'd like to think.

Research provided the impetus for and the foundation of the program.

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<sup>10</sup> This is sometimes referred to as 'mammography screening'. The more general term is used here because other forms of screening, such as Breast Self Examination (BSE) or Clinical Breast Examination (CBE), were taken into consideration in the policy process.

<sup>11</sup> *Future Directions* refers to the report by the Australian Health Ministers' Advisory Council (AHMAC) Breast Cancer Screening Evaluation Steering Committee titled *Breast Cancer Screening in Australia: Future Directions*. AHMAC Breast Cancer Screening Evaluation Steering Committee (1990). *Breast Cancer Screening In Australia: Future Directions. Prevention Program Evaluation Series No. 1*. Canberra, AGPS. Canberra. It was written by the Committee's Secretariat, the Australian Institute of Health's Screening Evaluation Coordination Unit headed by Dr Michael Fett.

Most key informants said international research on mammography screening, particularly the published results of the randomised controlled trials, were very influential in the development of the national policy. Health economics was also referred to as being particularly influential, as was research showing the advantages of breast cancer surgery being done by breast surgery specialists.

Some key informants thought that an overly optimistic interpretation had been made of the research available at the time of the election announcements and that politics was driving the policy agenda, not research.

One key informant said that program advocates and researchers convinced politicians of the electoral appeal of the program to get them to commit to the program. They warned politicians of the loss of electoral support that would follow a failure to commit.

Key informants thought that research influenced policy in concert with other forces. It was a common factor that encouraged radiologists to screen, women to seek screening, epidemiologists to promote screening, cancer councils to lobby for screening, and State Governments to assess screening. Each of these actions reinforced the others.

While the studies showing mammography screening in a favourable light were promoted, the results of the Canadian National Breast Screening Study were not. This study, published in 1992, found marginal additional benefit for mammography over clinical breast examination for women over 50, and no benefit for women 40-49 (Miller, Baines et al. 1992; Miller, Baines et al. 1992). When prompted, most respondents recalled the publication of the study but said, quite unprompted, that they recalled the study being ‘dismissed’. One respondent said, ‘Everyone was happy to find the faults of the study.’

### **4.1.3. Structural foundations**

A review of the historical literature on screening reveals four larger factors that are not specific to breast cancer screening but seem to have had some influence.

The first is the application of screening to the increasing problem of chronic disease in developed countries after the Second World War. Screening had previously been applied to ‘stamp out the human reservoir’ of communicable diseases (Wilson and Junger 1968: 15). The application of screening to chronic disease was an innovation

that, Fee argues, was driven by public health agencies' need to re-invent their reason for existence in face of the decline in communicable diseases (Fee 1991: 13). Morrison attributes the growth in chronic disease screening to the development of the Papanicolaou smear test (Morrison 1985: 4). In 1951 the United States Commission on Chronic Illness (CCI) defined screening as “the presumptive identification of unrecognised disease or defect by the application of tests, examinations or other procedures which can be applied rapidly” (quoted in Wilson and Junger 1968:11). By 1957, the CCI had ‘accepted the value of multiple screenings as “contributing to good medical practice” and identified breast cancer as one among many possible diseases that might be screened for’ (Wilson and Junger 1968: 18).

The second structural factor underpinning the development of BCS was the development of X-ray technology. In 1948, proposals emerged to extend the existing mass X-ray screening programs for tuberculosis to lung cancer (Collins and Barry 1996: 1977). While X-ray technology had been used to diagnose breast cancer as early as 1913, the application to screening became apparent in the US in 1960 (Wright 1990).

The third structural feature driving chronic disease screening was its symbiosis with the interests of the medical profession. This created tension within public health agencies (Fee 1991: 9-10). Clinicians could see a burgeoning practice built on the search for ‘the iceberg’ of occult disease using epidemiology as the tool for identifying diseases that might be screened for (Last 1963).

Lastly, there was the transition in epidemiology itself. This shift in the pattern of disease burden from communicable diseases to chronic diseases was accompanied by a transition in epidemiology as it developed new approaches to measure and describe and attribute causation in chronic disease and evaluate interventions. The Health Insurance Plan study of mammography screening (see 4.1.5 below) is recognised as ‘...the predominant stimulus to the development of epidemiologic methods...’ in the evaluation of early diagnosis and treatment (Morrison 1985: 14).

#### **4.1.4. Snails v's evangelists and the rise of meta-policy**

Mammography screening began in Australia in 1971 as part of ‘multiphasic screening’ offered at Medichcek in 1971 (Croll, MacMillan et al. 1977). However, by this time enthusiasm for screening was being reassessed by researchers (Wilson and Junger 1968:

18; Fowler and Austoker 1991: 1583). Sackett and Holland described the conflict between screening enthusiasts (usually clinicians) and epidemiologists as a conflict between ‘snails’ and ‘evangelists’ (Sackett and Holland 1975). Wilson and Junger’s *Principles and Practice of Screening for Disease* (Wilson and Junger 1968) was a response to this conflict. Their principles have become a policy to guide screening policy—a meta-policy. They were used in the Australian evaluation of mammography (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 15).

Key informants identified Lazlo Tabar, a Swedish radiologist, as the most prominent ‘evangelist’ in Australia. He was the lead investigator on the ‘Two Counties’ screening trial and promoted screening in Australia (Tabar and Dean 1991b). He persuaded local experts (Mitchell 1987; Wright 1988), assisted screening services (Baker, McCaffrey et al. 1988), and published in the MJA (Tabar and Dean 1991a; Tabar and Dean 1991b). He is accused of mounting an international campaign to undermine the credibility of the Canadian National Breast Screening Study (Batt 1994: 44).

Key informants said local radiologists were also important. They played a key role in the development of a pro-screening position in the NH&MRC (see below). Joan Croll, one of the directors of the Medichack facility was among the earliest advocates of mammography screening in Australia (Croll, MacMillan et al. 1977; Croll 1978; Croll 1987). She was concerned, however, that the economic motives of private sector radiologists would lead to an increase in screening without proper training (Croll 1987).

Several key informants identified surgeons such as John Forbes as important proponents of mammography. Forbes was a surgeon from the Hunter Valley in NSW who used the media to promote screening. Surgeons vigorously opposed the public sector approach to mammography screening in the 1994 Senate Inquiry arguing that there should be a Medicare rebate for screening and that funding was being wasted in creating ‘another bureaucracy’ (Barraclough 1994: 1289-1305).

Among the ‘snails’ might be counted Heather Mitchell who, in 1987, argued against mammography screening (Mitchell 1987). Swan reported that she and Jane Hall were critical of the haste to introduce mammography screening (Swan 1990). In 1990, Hall and others argued that a national program should not be introduced until cost-effectiveness studies were completed on the pilot projects (Gerard, Salkeld et al. 1990). In 1992 she reported the cost-utility as \$16 000 per quality adjusted life year saved, an

increase from \$7 000 when quality of life is not considered, and argued that it could not be supported in the absence of calculations of alternative courses of action (Hall, Gerard et al. 1992). At interview, Hall argued that she was not opposed to screening per se but to the overly positive appraisals of the evidence. On the other hand, however, a number of epidemiologists (who Sackett and Holland say are usually associated with the ‘snails’) were identified by key informants as the most influential individuals involved in establishing screening trials in Australia in the 1980s—Bruce Armstrong, Michael Fett, Ian Ring, and David Roder belong to this group.

#### 4.1.5. *The HIP study—impact and aftermath*

The National Cancer Institute initiated the Health Insurance Plan (HIP) study of New York in 1963 in response to the publication of data showing X-rays could detect breast cancer (Shapiro, Strax et al. 1971; Wright 1990; Kaufert 1996: 170). The study is credited with providing ‘...the impetus behind the international developments in breast cancer screening’ (J Mark Elwood Foreword to (Adams 1991).

The first results appeared in 1971 (Shapiro, Strax et al. 1971) and were positively received in Australia (Editorial 1971). In the US, the results led to the Breast Cancer Detection Demonstration Project that screened 280,000 women between 1973 and 1981 (Kaufert 1996: 170). The fact that both the US President and Vice-President’s wives had breast cancer facilitated this (Skrabanek 1985). In 1976, however, Bailar (Bailar 1976) claimed that HIP could have caused as many deaths from radiation as it saved. The furore led to an inquiry that found unsafe X-ray equipment and unnecessary surgery which led to changes to machinery and guidelines (Batt 1994). These events were reported locally (Hanson 1977).

A further seven randomised controlled trials of mammography screening have been reported (Glasziou, Woodward et al. 1995).

TABLE 4:1 MAMMOGRAPHY SCREENING RANDOMISED CONTROLLED TRIALS

Study	Year Started	Age at Entry	Method	Interval (Months)	Deaths/No. Invited	Deaths/No. Control
HIP United States	1963	40-49	1. CBE + M 2. Control	12	39/14,839	48/14,849
Malmö Sweden	1976	45-49	1. M 2. Control	18-24	8/3,658	16/3,769
Two County Sweden	1977	40-49	1. M 2. Control	24	50/19,844	37/15,604

Study	Year Started	Age at Entry	Method	Interval (Months)	Deaths/No. Invited	Deaths/No. Control
Edinburgh UK	1979	45-49	1. CBE + M 2. Control	12, 24*	13/5,913	15/5,810
Canadian	1980	40-49	1. CBE + M 2. CBE entry	12	38/25,214	28/25,216
Stockholm Sweden	1981	40-49	1. M 2. Control	28	20/14,375	12/7,103
Gothenberg Sweden	1982	40-59	1. M 2. Control	18	6/7,050	10/7,050

#Adapted from (Glasziou, Woodward et al. 1995: 3). \*Respective interval for CBE and mammography. CBE = Clinical Breast Examination; M = Mammography

There have been many systematic reviews of these trials (Forrest 1986; Eddy and McGivney 1988; Eddy 1989; Adams 1991; Glasziou, Woodward et al. 1995; Kerlikowske, Grady et al. 1995; Glasziou and Irwig 1997; Breast Cancer Screening Advisory Group 1998; Josefson 2002). The latest found mammography ineffective (Gotzsche and Olsen 2000a). The Cochrane Breast Cancer Group disowned this review but Gotzsche and Olsen subsequently published an approved review (Olsen and Gotzsche 2002) with an extended version in the *Lancet* which said that women in the screened arms had received more aggressive treatment (Olsen and Gotzsche 2001). Horton opined ‘...even in the best organisation raw evidence alone is sometimes insufficient to influence opinion’ (Horton 2001).

#### **4.1.6. Pilot studies—a mechanism for technology diffusion**

The results of the HIP study gave rise to pilot projects in the United Kingdom in 1975 (George, Gleave et al. 1976) and Australia a decade later. The first Australian pilot project began at the Royal Women’s Hospital in Brisbane in 1986 (Baker, McCaffrey et al. 1988). Pilot projects were recommended for New Zealand in 1988 (Adams 1991) and commenced in 1991 (Elwood 1998). The same pattern also occurred in other countries (Shapiro, Coleman et al. 1998).

In the mid- to late 1980s, ten pilot projects were established across five States in Australia. There were three projects in NSW (one run by Dr Joan Croll and one by Dr John Forbes, both identified as champions of mammography by key informants), two in Victoria (one run by Dr Ian Russell who was also on the AHMAC Breast Cancer Screening Evaluation Steering Committee), three in Queensland (one run by Dr Cherrell Hirst and one by Dr Christine Baker—both identified by key informants as influential people in the development of mammography), two in Western Australia, and two in

South Australia (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990). Some commentators felt that the pilot project created an unstoppable momentum. Swan reported that ‘Professor Langlands believes it is impossible to stop the drive towards national screening but that we could well find ourselves disillusioned’ (Swan 1990). Langlands was already on record in an article in the MJA in 1987 where he attempted to dampen the expectations of what a national program was likely to deliver in terms of mortality reductions (Langlands 1987).

One key informant was quite clear that the purpose of the AHMAC evaluation of the pilot studies was to create a bridgehead for the introduction of BCS, not a potential barrier to its introduction. The task of the evaluation was to work out *how* to do mammography screening in Australia, not assess *whether* it should be introduced.

It appears that the Commonwealth government was having difficulty in arguing that screening services should not be made more widely available until the evaluation was completed. Swan reported that in late 1989, the Prime Minister announced that the Commonwealth would spend \$400,000 to buy mobile mammography machines for women in rural areas (Swan 1990).

#### **4.1.7. NH&MRC—a hostage to evangelists?**

Between 1977 and 1989 the NH&MRC made five statements on mammography screening. The first two said there was insufficient evidence to support it. The second two were supportive but suggested different screening strategies. The last urged caution in the adoption of BCS before the trial and evaluation process had been completed.

**TABLE 4:2 NH&MRC STATEMENTS ON MAMMOGRAPHY SCREENING**

Date	Session	Position on BCS with mammography
Apr 1977	83	Insufficient evidence to support screening mammography.
Jun 1978	85	Insufficient evidence to support screening mammography.
Oct 1979	88	Benefits of annual screening with physical examination and mammography exceed the risks in women over 50. ‘Sample surveys’ required.
Jun 1984	97	Breast Health and Mammography. All women should be taught BSE, expect regular clinical examination by their doctor, have baseline mammograms at age 40 and 3-5 yearly mammograms thereafter or more frequently if they have risk factors.
Jun 1989	107	Introduction of Screening Mammography in Australia. Expressed concern at pressure to introduce screening mammography. Recommends careful evaluation of pilot projects.

The change in the position of the NH&MRC was accompanied by a change in the committee providing the advice (see committee membership in the table on NH&MRC deliberations in the appendices for Chapter 3). The first two statements were made on



the recommendations of the Epidemiology Services Standing Committee (NH&MRC 1977a). This position was criticised by Croll (Croll, MacMillan et al. 1977; Croll 1978). She argued that Medichcek Service had addressed the issue of radiation dose and the Clinical Oncology Society of Australia was addressing the matter more broadly (Croll 1978).

In June 1979 the NH&MRC issued the report *Mammography - Use or Abuse* prepared by the Medicine Advisory Committee comprised largely of the Royal Australian College of Radiologists and the Royal Australian College of Surgeons (NH&MRC 1979a; NH&MRC 1979b). The pro-screening position was justified by ‘technical advances in mammography’.

Over the next three years the NH&MRC made fruitless attempts to develop mammography screening pilots in Australia. It decided that ‘sample surveys’ of screening were required before developing a national program (NH&MRC 1979b). It put aside \$20 000 to pay for these and over the next fifteen months it consulted Dr Bruce Armstrong at its Special Epidemiology Unit in WA, each State Anti-Cancer Council, and each State Government. This process came to nothing and in June 1983 it set up a new working party in response to a report by Dr Kynaston of the Royal Australasian College of Radiologists (NH&MRC 1983a). Kynaston chaired the Working Party that produced the 1984 *Statement on Breast Health and Mammography*. It included representatives from the Royal Australian College of Surgeons, the NSW Cancer Council, and Dr Joan Croll (NH&MRC 1983a).

In 1989 the NH&MRC issued *The Introduction of Screening Mammography in Australia* (NH&MRC 1989). Ironically, this expressed concern over the mounting pressure for the introduction of mammography screening.

No key informant said the NH&MRC had any influence on BCS policy in Australia. This perception is supported by the lack of a single reference in *Future Directions* to the NH&MRC.

#### **4.1.8. Cancer societies—snails, brokers and advocates**

The earliest published research was funded by the Anti-Cancer Council of Victoria (McKeown and Thomas 1966). It were consulted by the NH&MRC on the development of ‘population surveys’ in the early 1980s and involved in its 1984 Working Party

(NH&MRC 1984a). In 1986 the ACS formalised its support for BCS and Tony McMichael and Bruce Armstrong communicated its views in the MJA (McMichael and Armstrong 1988). McMichael would later chair the AHMAC BCSESC and Armstrong played a key role in Western Australia.

The views of the ACS led to discussions between the Cancer Foundation of WA and the Minister for Health in that State, and subsequently to a Ministerial Working Party chaired by Bruce Armstrong (Working Party on Screening Mammography 1987:6). Armstrong was appointed because of his role as Director of the NH&MRC's Research Unit in Epidemiology and Preventive Medicine in WA. The committee included the Australian Medical Association, and the professional bodies for surgeons, radiologists and pathologists. Considering the cross-committee memberships of various individuals highlights the brokerage role of the ACS. For example, Furnival was the ACS representative on the National Advisory Committee for the program. He was also represented the Royal Australasian College of Surgeons (Senate Standing Committee on Community Affairs 1994: 1306-1350) and was a member of the National Breast Study Committee of the ACS in 1988 (Furnival and Porter 1988).

Bob Hawke's election announcement made special mention of the role of State and Territory anti-cancer councils (Wright 1990). The Commonwealth funded them to produce education materials for general practitioners (Department of Human Services and Health 1994: 15).

Most key informants identified the Australian Cancer Society and its State and Territory counterparts as being particularly influential. Some said it brought intellectual integrity to arguments about screening. Others said it was a vehicle used by individuals and State cancer councils to progress their interests. The NSW and Victorian cancer councils helped establish pilot programs in those States and built non-partisan political support for screening. Several key informants said cancer councils worked successfully to build support with influential women across the political spectrum. Informants noted the important role played by Nigel Gray and the Victorian Anti-Cancer Council in developing screening in Victoria and influencing other jurisdictions via the Australian Cancer Council. In 1987, Gray said how he thought screening policy in Australia should develop in the ACS's journal, *Cancer Forum* (Gray 1987). The close fit with what actually took place suggests that he was either remarkably influential or remarkably prescient.

The cancer societies appear to have been able to combine the caution of ‘snails’ with professional and political brokerage, and advocacy.

#### **4.1.9. State governments—leaders or followers?**

The first mammography screening program in Australia began in Queensland at the Royal Women’s Hospital in Brisbane in 1986. Dr Ian Ring recounted at interview how it grew out of the work of Cancer Epidemiology and Prevention Program in Queensland Health which was designed to take information from cancer registries and advise where and how government might intervene. He said that mammography screening was the obvious first intervention that should be put in place because of the strength of the evidence from the HIP study and the Swedish studies. The political popularity of the program made it easier to implement though there was vigorous debate at the local level about the program.

As noted above, the Victorian Anti-Cancer Council was particularly influential in having a pilot project established in that State and encouraging a single, integrated service for the whole State. In NSW, the Women’s Health Policy Review of 1985 identified BCS as a high priority. The NSW Cancer Council sent a copy of the *Forrest Report* to the government and asked for a pilot screening project. The women’s health program budget and infrastructure were critical to the pilot projects.

In July 1977, the Western Australia Ministerial Working Party recommended pilot projects using the 2x2x2 design—two views of the breast, read by two radiologists, every two years—with an age range of 40-64 years. (Working Party on Screening Mammography 1987).

In November 1997, the South Australian Ministerial Task Force on Breast Cancer in Women and Gynaecological Cancer held its first meeting. Like the WA committee, the SA committee included medical specialists and cancer council representatives. It also recommended pilots based on the 2x2x2 design but with an age range of 50-64. Women 40-49 could attend if they self-referred (Ministerial Task Force on Breast Cancer in Women and Gynaecological Cancer 1988).

While there are some similarities in the approaches of the various States to BCS, they each followed their own path to mammography screening at roughly the same time and drawing on the same pool of international data. Key informants recalled active

networking between the States on matters of common cause. One key informant said that State action was motivated by a need to get the de-facto screening occurring under the Medicare Benefits Schedule under control because it was putting pressure on State and Territory resources. This key informant said that the States were ‘desperate’ to get the Commonwealth involved because they saw women’s increasing demand for mammography screening and an increasing rate of de-facto screening ‘coming at them like a freight train’.

#### **4.1.10. AHMAC-AIH evaluation—the political dimension**

In November 1987, an AHMAC sub-committee that included Bruce Armstrong and Michael Fett recommended a national evaluation of the pilot projects as a joint Commonwealth–State initiative. The Commonwealth Government made \$3.6m available to support the process (Senate Standing Committee on Community Affairs 1994: 4). The committee membership and position on BCS is set out in the following table.

**TABLE 4:3 AHMAC BREAST CANCER SCREENING EVALUATION STEERING COMMITTEE MEMBERSHIP AFFILIATIONS**

<b>Committee Member</b>	<b>Related work or affiliation</b>
Professor Tony McMichael (Chair)	Reported on the Australian Cancer Society’s position in support of BCS (McMichael and Armstrong 1988). Argued for ‘haste not speed’ in 1989 (Short 1992).
Dr Susan Britton (SA Health Commission)	Member of the SA Ministerial Working Party that recommended pilot projects.
Ms Kay Collett ( Radiographer)	
Ms Carla Cranny (NSW Health Dept)	Involved in establishing screening pilot projects in NSW.
Dr John Donovan (AIH)	Epidemiologist – wrote the MJA editorial in 1971 welcoming the HIP study (Editorial 1971)
Ms Jane Hall (Health Economist)	Critical of pace of implementation and overly optimistic interpretation of trial data (Swan 1990)
Professor William Hare (Radiologist)	Member of original NH&MRC committee that recommended against BCS in 1977 (NH&MRC 1977a)
Mr Roy Harvey (AIH)	
Dr Paul McCann (Royal Hobart Hospital)	
Dr Ian Ring (Qld Health)	Involved in establishing pilot project at Royal Women’s Hospital in Brisbane
Dr Cathy Mead (Commonwealth Dept of Community Services and Health)	
Mr Ian Russell (Surgeon)	Chair of National Breast Study Committee of the ACS. Advocated research on BCS through pilot projects in Australia (Russell 1987).
Dr Peter Wilson (Radiologist)	
Professor Martin Tattersall (Department of Cancer Medicine, University of Sydney)	Supported the establishment of screening projects (Tattersall 1987).
Dr Michael Fett (Secretary/Convenor AIH)	

Health Ministers endorsed *Future Directions* in June 1990 (Senate Standing Committee on Community Affairs 1994: 4-5)<sup>12</sup> and it has been referenced as the national policy statement for some time since (Glasziou, Woodward et al. 1995: 8; Australian Institute of Health and Welfare 1998). Key informants referred to it as the ‘basis’, ‘blueprint’, or ‘foundation’ for the program. Several saw its primary purpose as skill and constituency building. One described it as a ‘beach head’ for the program. Another said that it showed that ‘a de-facto policy decision had already been made’. One said no government could withdraw screening once the pilots were established.

Key informants also thought that the structure—a highly skilled Unit at the Australian Institute of Health working to an AHMAC subcommittee—boosted the impact of its work. One said, ‘Evidence based policy requires bipartisan support and Commonwealth-State support—fragmented support leads to a political environment’. Another commented that the structure was ideal because the researchers were part of a process that had political and bureaucratic commitment.

#### **4.1.11. AHMAC-AIH evaluation—the research dimension**

The Screening Evaluation Coordination Unit (SECU) at the Australian Institute of Health brought together medical doctors, epidemiologists, health economists and statisticians (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 107). Epidemiological and economic studies figure highly in the references of *Future Directions*—of 67 references, 23 are to publications arising from trials including four published randomised controlled trials. A further 15 are to economic studies.

There are 12 Australian references but only four are specific to the question of BCS in Australia and just one could have created concern about the screening decision. This study found wide variation in treatment of cancers at the same clinical stage (Hill, Giles et al. 1990: 69). However, *Future Directions* only referred to this study to identify possible cost blow-outs associated with treatment, not to question the adequacy of treatment standards per se (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 35). This is despite the National Women’s Health Policy emphasising

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<sup>12</sup> It is worth noting here that the Senate Committee report says that Commonwealth government commitment to the program came after the AHMAC/BCSESC Report whereas the report was not

the need for access to adequate treatment services as a prerequisite of screening in 1989 (Short 1995: 75).

The research done for *Future Directions* is probably the largest single breast cancer screening research project in Australia to date. It included a meta-analysis of trial data; a cost-effectiveness analysis (published separately with significant revisions several years later (Carter, Glasziou et al. 1993)); and, an analysis of data from the 10 pilot projects.

*Future Directions* gives no voice to the critics of mammography screening. The views of Skrabanek are not mentioned (Skrabanek 1985; Skrabanek 1985; Skrabanek 1988). Nor is the poignant letter by Maureen Roberts, a leader in the breast cancer screening trials in the United Kingdom who died from breast cancer. Her letter, published posthumously, urged a ‘rethink’ because of the results from the trials in the United Kingdom and Sweden (the Malmo trial). She claimed the decision to introduce screening was premature and politically motivated in an election year (Roberts 1989).

*Future Directions* noted that the Malmo and UK trial results ‘have been interpreted by some commentators as casting doubt on the effectiveness of mammography’ (p 19). But it says that the studies had had only had a relatively short period of follow up. The SECU conducted its own meta-analysis using a method developed by Paul Glasziou, David Roder and Adrian Esterman (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 109). It concluded that the results from the RCTs showed a 30 to 35 per cent reduction in breast cancer mortality from screening (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 18-21).

#### **4.1.12. Commonwealth engagement with BCS—base motives?**

Commonwealth action on BCS prior to 1990 was a reaction to the problem of de-facto screening. *Future Directions* presents data showing the rapid increase in screening under Medicare from 1985 to 1989 and says this was a key Commonwealth problem that needed to be fixed. Key informants from within and outside the Commonwealth Government repeatedly emphasised the centrality of financial motives to the Commonwealth’s actions. One key informant said, ‘the bottom line for the Department was to stop Medicare being used for mammography screening’. The Commonwealth’s

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presented to AHMAC until June 1990, three months after the Labor Party announced its election

growing use of Special Purpose Payments to the States and Territories (Rydon and Mackay 1989) provided an alternative financing mechanism enabling the Commonwealth to cap expenditure on mammography rather than have it continue in the uncapped Medicare program.

Once the Program was announced and implementation began, there is little evidence of direct political involvement in decision making. One key informant said she had been to many national events over a period of five years—launches, conferences, meetings—and never once saw a Health Minister or an elected politician.

The implementation of the Program stuck reasonably closely to the recommendations of the *Future Directions* report. There is evidence of a number of very deliberate uses of research to inform BCS policy. In particular, the question of the effectiveness of screening women in the 40-49 year age groups has been approached through systematic reviews of the research literature (Glasziou, Woodward et al. 1995). Some key informants saw the original decision to allow this group access to the program as politically motivated. Others saw it as pragmatism given the uncertainty of the research and the demand from women in this age group. Some key informants saw ‘political correctness’ type politics in the way access was emphasised across rural and ethnic and racial lines. The two Senate inquiries in 1994 and 1995 into treatment and early detection showed that the public-private sector conflicts around the program were live political issues. However, they resulted in the public sector nature of the program being consolidated.

#### **4.1.13. Women’s health**

The women’s health movement and second wave feminism more generally led to the establishment of the National Policy on Women’s Health in 1989 and a Commonwealth-State cost-shared program of women’s health services (Gray 1998).

The NWHP created an affinity between politicians who could support BCS as a way of showing their credentials on women’s health (Short 1995: 75), and advocates of mammography screening could use the NWHP to sell BCS to politicians. The NWHP also created the administrative capacity to put the program in place. The establishment

of women's health units within government meant there were skilful, motivated administrators, some of whom had control over funds for women's health programs, who could make the necessary administrative wheels turn on BCS. Key informants identified women's health advocates as critical to the development of BCS. These included Anne Kern, Deputy Secretary in the Commonwealth Department, Wendy Silva in Western Australia, Margaret Connelly in Neil Blewett's Office, Onella Stagoll in Brian Howe's office, Elaine Henry and Jeanette McDonald with the NSW Cancer Council, and Carla Cranny in NSW Health.

Williams (Williams 1991) has argued that it was 'networks of influence' among 'femocrats' that made mammography screening possible in the ACT. The plausibility of femocrats playing a key role in mammography screening is supported by Gray's analysis of the introduction of the national women's health program which she attributes in part to the role of femocrats in State, Territory and Commonwealth bureaucracies (Gray 1998: 111-112)

There are marked contradictions and ironies in the boon to mammography from the NWHP. The women's health movement sought to supplant the medical view of health with a social view. Willis says '...the notion of a technological response to women's health such as mammography confronts ideas and values about women's health service generally' (Willis 1999: 51). Because mammography was seen to belong to the medical view (Short 1995), there was a level of active opposition from the movement, including among some women who ended up being involved in the program. Their view was that if this was going to happen, then they wanted to make sure it worked for women. Several key informants said the Roberts letter in the British Medical Journal (referred to above) was faxed around to the women who were opposed to screening and was referred to, along with the views of the screening critic, Skrabanek.

Ward argues that the methods of obtaining informed consent do not conform to the principles of the women's health movement (Ward 1999). Lupton questions whether mammography meets the interests of women or of others (Lupton 1992).

There were some marked differences of views among key respondents over whether the rise in de-facto screening demonstrated women's agency (they were 'voting with their feet') or women's lack of control over their health care (doctors were directing women to screening). Several respondents saw mammography screening as a way for the Labor



Government to do 'safe' women's health that would appeal to the middle-aged and the middle class rather than the politically more difficult areas such as domestic violence and women's refuges.

#### **4.1.14. Continuity and controversy**

The design of BCS still largely reflects the recommendations of *Future Directions*. While the way the Commonwealth provides funding to the States has changed, and program administration has evolved, changes have been incremental rather than radical. The multi-stakeholder advisory committee structure has continued.

There are a number of matters that had the potential to bring about change but did not.

The debate over the public sector model for the program was scrutinised in the Senate Standing Committee on Community Affairs Inquiry into Breast Cancer Screening and Treatment (Senate Standing Committee on Community Affairs 1994). The Royal Australian College of Surgeons argued that there should be a Medicare rebate for screening to improve access (Hansard of 4 February 1994: 1289 -1305). The Australian Association of Surgeons argued that biopsies should not be carried out under the auspices of the program (Hansard, 4 February 1994: 1351-1379; Senate Standing Committee on Community Affairs 1994: Chapter 5). Several key informants said the debate over public versus private died out after this inquiry.

The Canadian National Breast Screening Study could have caused a rethink but did not. It found no mortality benefits for women in the 40-49 age group, and no additional benefit from mammography over clinical breast examination in the 50-69 year age group (Miller, Baines et al. 1992; Miller, Baines et al. 1992; Miller 1993). These results caused a major furore in the United States (Kaufert 1996) (Wells 1998) but not here.

Key informants reported that 40-49 year screening has been debated in Australia but not to the same extent as in the United States. There have been several systematic reviews on the topic in the 1990s (NH&MRC 1992; Glasziou, Woodward et al. 1995; Ward 1999). Glasziou and Irwig argued that because of the uncertainty, there should be greater engagement with women to determine the appropriateness of screening in this group (Glasziou and Irwig 1997).

The apparent lack of mortality benefits from mammography in Sweden (Mayor 1999) led to the Nordic Cochrane Centre meta-analysis referred to above. The controversy has been largely played out in medical journals. It attracted some mainstream media attention in Australia which led Professor Mark Elwood from the National Cancer Control Initiative to reject the study findings and urge doctors to continue to encourage women to have mammograms (Carter 2000). Elwood is a long time supporter of mammography screening (See his forward to Adams, 1991). A leader of evidence-based medicine in the United Kingdom, Professor J Muir Gray, described the study as ‘half baked’ (David Wainwright, personal communication).

#### **4.1.15. Australian Research**

Medline was used to search for Australian research on the topic of breast cancer screening using the key terms ‘mammography screening’, ‘breast cancer screening’, and ‘BreastScreen’. Opinion pieces arguing for particular views but not presenting any original data were excluded from the analysis. A review by Cockburn and White on behavioural aspects of screening mammography commissioned by the Commonwealth Department of Health was also used (Cockburn and White 1994). It is likely that there is some Australian research done on aspects of breast cancer diagnosis and treatment of relevance to screening is not captured here. The results are presented in Table A:6 Australian Research on BCS in the appendices for this Chapter.

Forty-nine separate studies were identified. Most of the research has been published since the inception of the program in 1991. Thirty-six of the publications are clearly supportive of mammography screening and were done with the purpose of informing its design. There were only eight that indicated a lack of support or ambivalence for the program. One was a 1960s study of mammography. Five are sociological analyses of the development of the program and its implications for women. Two are economic analyses urging caution and expressing ambivalence about the cost-effectiveness of the program.

There are a total of 85 separate authors. Sixty-five appear once, 13 twice, and 10 appear three or more times. The most prolific authors are J. Cockburn (15), L. Irwig (8), D. Hill (7). Each of these published with the other two, individually or as a group.

The focus of the research is heavily weighted towards practical aspects of mammography screening program management, particularly the issue of recruitment methods (12 separate studies). Women's knowledge, attitudes and behaviours in relation to screening, and their experience of screening is another major focus (9 studies). Three of the early publications deal with the performance of the pilot projects. Three deal with the cost-effectiveness of the program. Two studies deal with the quality of educational material available to women. Four of the later studies deal with program outcomes: a study of trends in breast cancer mortality; a study of interval cancer rates; a study of de-facto screening under the Medicare program before and after the introduction of the screening program; and an economic analysis of the cost-effectiveness of the program. Two of the studies questioned the value of screening women in the 40-49 year age group—the study of interval cancers (Kavanagh, Mitchell et al. 1999), and the meta-analysis of screening in the 40-49 year age group (Glasziou, Woodward et al. 1995).

Reports containing program statistics such as rates of participation, cancer detection, program sensitivity, and breast cancer incidence and mortality are becoming more frequent (Commonwealth Department of Health and Family Services 1996; Australian Institute of Health and Welfare 1998; Australian Institute of Health and Welfare 2000).

## **4.2. An advocacy coalition framework analysis**

The ACF analyses the research–policy nexus by charting the formation of a policy subsystem made up of advocacy coalitions and identifying how they use research as a resource to try to control policy.

### **4.2.1. *The BCS policy subsystem and advocacy coalitions***

The major policy actors in the BCS sub-system appear over the course of three decades. From an ACF point of view, the belief that public health has a mission to control chronic disease in the population and the belief in screening as a primary public health tool comprise the core beliefs which enabled the development of BCS. Given that State and Territory governments have primary responsibility under the constitution for public health in Australia, it is they who are the primary custodians of the public health paradigm in Australia. But they are not alone in this or even at the forefront of developments in this paradigm. Public health advocates in academia and in non-government organisations like cancer councils are part of the tradition. However, it is

not surprising that the States led, at the behest of these other groups, and the Commonwealth followed.

The first study of mammography in Australia in the 1960s identifies an important axis in what would become the Dominant Advocacy Coalition. That study was funded by the Anti-Cancer Council of Victoria and conducted by radiologist researchers. In the 1980s, the State cancer societies played a unique role in bringing various policy actors together at both the state and national levels. They created networks that encompassed clinical and epidemiological perspectives, they reviewed research and made authoritative statements, they advocated to State governments and persuaded them to take action, and their members are ubiquitous to government advisory committees.

The Commonwealth Government did not become a significant participant in the Dominant Advocacy Coalition until after the Program was announced and responsibility for it shifted to the Health Advancement Division. The development of the National Advisory Committee that included all key stakeholders represented a crystallisation of the Dominant Advocacy Coalition. It included dissenting but pragmatic feminist voices such as those of Jane Hall (Swan 1990) and Leonie Short (Short 1992).

While there has always been opposition to mammography screening, this has taken diverse forms without much to unite it. The feminist critique found in the writings of Lupton (Lupton 1992), Short (Short 1992) and Willis (Willis 1999) sometimes overlaps with a pragmatic approach to making sure mammography works well for women, and is sometimes rejected by feminists who support mammography. Former Health Minister Carmen Lawrence thought there was nothing inconsistent between support for mammography and feminism. The key role played by women's health units in establishing screening pilots suggests that this view of the synergy between women's health and mammography was the dominant one. This does not preclude a continuing feminist critique of the program for its departures from the principles of the women's health movement (Ward 1999).

Though there was opposition from epidemiological experts such as Mitchell (Mitchell 1987) and many words of caution from senior figures in the cancer field (Langlands 1987), this was not opposition to screening per se but to the timing and form that the program would take and unrealistic expectations about its likely benefits. There was also concern about the over-zealous and financially motivated advocacy from

radiologists. The opposition to BCS from radiologists and surgeons expressed to the 1994 Senate inquiry was not about screening per se either, but about the public nature of the program. There was some level of opposition or ambivalence to BCS within each of the major groups that supported BCS but this opposition was fragmented.

The Dominant Advocacy Coalition in BCS is made up those who wish to promote a population health approach to chronic disease control and who have a strong commitment to evidence-based policy within the framework of the WHO screening principles (public health experts and the cancer societies), combined with a number of professional groups whose interests were well served by such a policy (radiologists and surgeons), as well as support from ‘femocrats’ and women’s health units within government. The Commonwealth’s interests in containing Medicare expenditure by having a capped public program coincided with the influence of the public health experts and the women’s health units to ensure the program adopted a primarily public sector rather than private sector model.

#### **4.2.2. Beliefs and values of the BCS advocacy coalitions**

There appear to be two prominent beliefs and values at the core of the cancer council movement—one is the commitment to action on all cancers and on all aspects of cancer from prevention to palliation, the other is the commitment to principles of scientific methods. Thus they encompass ‘snails’, ‘evangelists’, and ‘honest brokers’ within an advocacy role promoting policy action on cancer.

The WHO screening principles gave the ‘snails’ and ‘honest brokers’ an advantage in the policy process and placed a premium on the use of the research. The principles are underpinned by utilitarianism (benefits must outweigh harms) which bypasses the potentially anti-screening value position of the Hippocratic oath—first, do no harm. Utilitarianism says ‘do no net harm’. The principles include consideration of opportunity cost and are therefore readily acceptable to Governments and others who pay for medical care. The principles potentially offer a tool for controlling the introduction of new screening technology as we will see in the next case study.

The tensions within the women’s health movement over mammography were partly about values and partly about tactics in the struggle. The value dimension concerned the way that mammography supported the ‘medical model’—it focuses on a body part, uses

high technology, and is professionally controlled. Against this is the reality that breast cancer is a major cause of death and suffering for women and BCS offers a service designed specially for women. On the tactical side, mammography supporters saw it as an opportunity to capture resources and make practical gains for women. Opponents viewed it as a sell out to middle class and politically safe feminism. The same resources could have gone to more radical programs such as sexual assault services and refuges.

The values and beliefs at the core of BCS policy are diverse enough to enable subscription from a wide range of groups—a focus on a major cancer affecting many women, prevention (albeit secondary), evidence, quality control and standards, practical action. Radiologists, surgeons and GPs could support it but some voiced strong opposition to the public sector model chosen.

#### **4.2.3. Research and struggle over BCS**

The ACF conceptualises the role of research in policy as part of power struggles to control the policy subsystem and policy outcomes.

If we look at the work of the NH&MRC we see the close interplay between research and organisational politics. From 1976 to 1978 the NH&MRC disapproved of screening because the benefits did not outweigh risks. They were strongly influenced by Bailar's critique of the HIP study in the United States (Christie 1977). The NH&MRC's position was formed by the Epidemiology Services Standing Committee. In 1979 the Medicine Advisory Committee took control of the issue. It had advice from Bruce Armstrong at the NH&MRC's Epidemiology Unit that the absence of proof of benefit only applied to women under 50. Armstrong had a 'watching brief' on mammography. The MAC instigated a new Working Party (NH&MRC 1979a) and in October that year the NH&MRC formally changed its position.

Once it decided that mammography screening was effective, the NH&MRC attempted to sponsor its own research ('population surveys') but without success. By August 1982 some new articles in the *Lancet* occasioned another review. In June 1983 the NH&MRC received a report from Bruce Kynaston, a radiologist, and established a new Working Party with Kynaston as chair. It produced the 1984 statement supporting mammography screening for women over 40 years.

The ACF hypothesis that major change in policy is occasioned by changes in the structure of the Dominant Advocacy Coalition is supported by this narrative. While it is difficult to say which came first, the new research or the new committee, there is apparent symbiosis between the two.

The role of research as a key resource for the cancer councils in promoting screening is clear. It is central to their advocacy in Western Australia with Bruce Armstrong again instrumental. He and Nigel Gray at the Anti-Cancer Council of Victoria were in close contact (Armstrong interview). And the NSW Cancer Council used the UK's review of research (the *Forrest Report*) as the basis for a request that the NSW government establish screening pilot projects. Independent of these developments was the work of Ian Ring's epidemiology unit in Queensland using research to justify the first program in Australia. There is evidence to show that there were networks forming between State Governments, cancer councils and researchers (Roder, Bonett et al. 1985).

Since the introduction of the national program, the majority of the research has been funded and supported by the Dominant Advocacy Coalition, particularly the State-based anti-cancer councils. It has been designed to deal with indicators or problems that were critical to the beliefs and values of the DAC—the views of women, methods of recruitment, participation rates and the like. The small amount of dissenting research is closely aligned with the beliefs and values of the dissenting groups—feminist sociology and health economists. There is also a small amount of epidemiological research on mortality rates and interval cancer rates that could be called 'interrogatory' because it opens up the possibility that it will challenge the success of the program. This work conforms closely with the continuing commitment of researchers within the Dominant Advocacy Coalition to scientific method.

#### **4.2.4. Research and power in the BCS subsystem**

ACF theory is that policy stability is a function of stability of power relations within the policy subsystem. If the same Dominant Advocacy Coalition keeps control, then policy stability will follow. This analysis fits with the observed continuity of policy-making structures and policy. From the time of the Ministerial advisory committees in the mid-1980s to the present National Advisory Committee the key players have been cancer councils, medical specialists and, to some extent, general practitioners, academic experts, and State and Territory and Commonwealth officials.

The publication of discrepant research (eg Canadian trial, Nordic Cochrane Centre review) presented a potentially significant challenge to BCS policy. The ACF explanation for the lack of impact of this discrepant research is that the findings did nothing to create or empower an alternative advocacy coalition. Because the various opponents (some feminists, some cautious epidemiologists and health economics, and some anti-public sector surgeons) had little in common there was no basis for unified action. As well, the discrepant research could all be accommodated within the beliefs and values of the major power holders. As noted above, the findings of the Canadian study were particularly negative for screening women under 50 but there was already a question mark over that in Australia. The subsequent meta-analysis confirmed a position of continuing policy ambivalence (Glasziou, Woodward et al. 1995). The findings from the Nordic Cochrane Centre review by Gotzsche and Olsen (Gotsche and Olsen 2000a) have seemingly had no impact either because there are experts in senior positions in the policy subsystem who discount the meta-analysis. Alan Roger, who is chair of BreastScreen Victoria and on the Cochrane Breast Cancer Editorial Group, says that the trial data is now somewhat out of date and screening can be supported by other data (Roger 2002).

#### **4.2.5. *The ACF and the research–policy nexus***

BCS represents a particularly interesting test of the ACF because some of the key players in the Dominant Advocacy Coalition have a belief in research and in evidence-based approaches to policy as part of their core beliefs and values. For the epidemiologists and cancer council advocates, this belief appears more important than a commitment to mammography per se. There are policy actors motivated by the same beliefs who disagree with and criticise the position on mammography—epidemiologists like Heather Mitchell, the health economist Jane Hall, and the health services researcher Jeannette Ward. But these researchers lack a power base to promote the discrepant research and challenge the Dominant Advocacy Coalition.

The important role of research in this case study is highlighted by the plausible proposition that mammography screening could come to a halt if there was new research that caused the current mammography supporters in the ranks of senior epidemiologists and public health experts to change their views. There would still be a major problem for the Commonwealth because of the possibility that any retreat from



an organised public program would simply lead to an explosion in the rate of de-facto screening under Medicare. But even with this, the emergence of discrepant research could challenge the current alliance between public health experts and researchers and the Commonwealth Government. The question is: what would it take for those researchers and public health experts to change their minds? The recent Cochrane Review has led to further dispute among experts rather than a change in expert opinion as a whole.

### **4.3. PMOF analysis**

A PMOF analysis of the research–policy nexus focuses on the policy making organisation’s data selection behaviour as it constructs evidence in the interaction between its research responsiveness and the bias introduced by its policy preferences.

#### **4.3.1. The policy orientation of the PMO**

The documentary and interview data suggest the following in relation to each of the five indicators of policy risks and opportunities.

##### ***Electoral risks and opportunities***

The announcement by Bob Hawke of the Labor Party’s commitment to the introduction of mammography screening was an attempt to win women’s votes in the March 1990 election. This opportunity arose from the politicisation of the ‘women’s vote’ in the 1980s and the creation of the National Women’s Health Policy in 1989 (Gray 1998). The platform for an election initiative like mammography screening could not have been better. Bob Hawke’s announcement was as part of a package of measures targeting women. *The Canberra Times* headline read ‘PM Tells of Extra \$70m for Women’. Nearly all of the money (\$64m) was for mammography but the pitch was to women voters. The announcement two days later by the Liberal Party was an attempt to neutralise any political advantage to Labor. It is clear that despite the controversies over mammography in the media in the lead-up to the election (Lupton 1992), at that point in time the politicians saw political advantage in being aligned with a pro-screening position and a political risk in being opposed. This point is supported by Carmen Lawrence’s recollection that the main pressure from the opposition on BCS when she was Health Minister was to implement the program more quickly. The fact that the

policy has survived a change in government at the national level and many changes of government at the State level indicates that the electoral politics of mammography remains largely unchanged.

### ***Tactical risks and opportunities***

There is no data to suggest that intra-party or intra-government power struggles influenced the policy orientation of the PMO.

### ***Economic/financial risks and opportunities***

There is good evidence that Commonwealth decision making on mammography was influenced by a desire to reduce pressure on Medicare spending by creating a capped public sector program for mammography. Some key informants argued that this was a major factor and *Future Directions* said the steep rise in de-facto screening was a significant policy problem for the Commonwealth. What is hard to assess is the relative importance of this influence on the Commonwealth. Neal Blewett's perception was that it was there in general terms but it was not decisive. His perception was that it was more important to introduce mammography to demonstrate Labor's bona fides in relation to women's health generally than to save Commonwealth dollars. Financial pressure from de-facto screening explains State and Territory reactions to pilot projects. They told the NH&MRC that they could not afford 'population surveys' in 1980 when the NH&MRC first approached them but it seems they were quite enthusiastic in support of pilot projects in the mid-1980s when de-facto screening was increasing and affecting their hospital services.

### ***Contextual risks and opportunities***

The major contextual factor influencing Commonwealth action was the interaction with women's health policy, which, as suggested above, reinforced a positive bias to mammography.

### ***Ideological risks and opportunities***

The chance to introduce a public screening program as opposed to a private screening program would have been seen as a positive aspect of BCS to the Commonwealth Labor Government.

### ***The policy orientation of the bureaucracy***

It seems that there were many positive sides to the introduction of mammography for Commonwealth and State-level bureaucracy. At the Commonwealth level, after some jostling between Divisions, the program gave an opportunity for a large expansion in the role of the Health Advancement Division in a major policy initiative. At the State level, the chance for women's health units and epidemiology units to secure a major policy and program initiative also had its advantages.

**TABLE 4:4 SUMMARY OF PMO POLICY ORIENTATION ON BCS**

<b>Dimensions of Risk and Opportunity</b>	<b>Political Arm of PMO</b>	<b>Bureaucratic Arm of PMO</b>
Electoral	Strongly oriented to support of BCS from the mid- to late 1980s	Opportunities to reduce pressure on diagnostic spending under the MBS and expand health advancement, women's health and public health epidemiology.
Tactical	N/A	
Economic and Financial	Financial benefits to the Commonwealth in introducing BCS	
Contextual	In support of BCS	
Ideological	In support of a public program of BCS	
Summary	Strongly oriented towards BCS adoption	

### ***4.3.2. The research orientation of the PMO***

The interview and documentary data suggest that the PMO was inclined towards being more rather than less responsive to research.

### ***PMO responsibility for breast cancer and BCS***

The Commonwealth was undertaking a gradual shift towards taking responsibility for chronic disease prevention and control in the 1980s. This is signalled by the creation of the Health Advancement Division, engagement with the WHO Health for All agenda, and engagement with the Australian Cancer Society on cancer priorities (Chapman 1988). It seems, however, that the Commonwealth's general concern with chronic disease or cancer was less significant than its responsibility for the MBS—the latter was mentioned in *Future Directions* and by key informants, the former was not.

De-facto screening also created the problem of quality control for the Commonwealth. In 1987, Nigel Gray, the then Director of the Anti-Cancer Council of Victoria argued that screening can produce benefits or harms and that 'Brownie points and votes can be won or lost very readily on an issue such as this' (Gray 1987: 2). The Commonwealth

was going to have to take some responsibility for the outcomes of de-facto screening even if it was occurring without its consent.

### ***PMO capacity in relation to the policy problem***

The pilot projects demonstrated that screening could be carried out in Australia. *Future Directions* put the capacity issue beyond doubt by designing a screening program which, it argued, was feasible, cost-effective and appropriate to the needs of Australian women. The choice was one of allowing a de-facto program to continue at a cost of \$17,748 per life year saved or introducing an organised program that would cost \$10,671 per life year saved with only a 30 per cent increase in total costs (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 30). It would be difficult to argue incapacity on the basis of this analysis.

### ***The measurability of PMO performance***

PMO performance in relation to the level of de-facto screening was highly measurable. Breast cancer incidence and mortality rates are also highly measurable as is the stage of development of the cancer when detected. Once the pilot programs began, access to mammography was also highly measurable, especially the lack of access in rural areas (Short 1992).

What is still difficult to measure is the impact of screening on breast cancer mortality rates (Roger 2002). But if everyone believes that mammography works then surrogate measures do the job just as well in terms of increasing PMO accountability and research responsiveness.

### ***The transparency of PMO performance and the 'theatre of justification'***

One of the roles played by the Cancer Councils is that of 'theatre of justification'. This is clearly demonstrated by the warning given in the quote by Nigel Gray on 'Brownie points'. The various cancer societies are among the few organisations with enough expertise to award such points. One of the benchmarks available for those in the theatre of justification was the commitment of other countries to screening. While the US enthusiasm for screening could be discounted by reference to general American

enthusiasm for the latest technology, the British decision to introduce screening could not.

### ***PMO vulnerability to the consequences of its errors***

The PMO was quite vulnerable to the perceived error of not introducing a mammography screening program. Conversely, the PMO is apparently quite invulnerable to a Type 1 error (ie falsely accepting the hypothesis that mammography works). With the first kind of error, vulnerability arises because failure is immediate and readily apparent. Unfortunately, the second kind of error is much harder to spot because it will take decades to become apparent and may be explained away. In these circumstances, there is a strong incentive to err on the side of a Type 1 rather than Type 2 error (ie falsely rejecting the hypothesis that mammography works).

### ***The research responsiveness of the PMO***

Table 4.5 summarises the research responsiveness on BCS.

**TABLE 4:5 SUMMARY OF PMO RESEARCH RESPONSIVENESS ON PCS**

<b>Indicator</b>	<b>Rating</b>
PMO responsibility	Moderately High
PMO capacity	Moderately High
PMO performance	Moderately High
Theatre of justification	High
PMO vulnerability to error	High
Summary	High

### ***4.3.3. The PMOF view of the research–policy nexus***

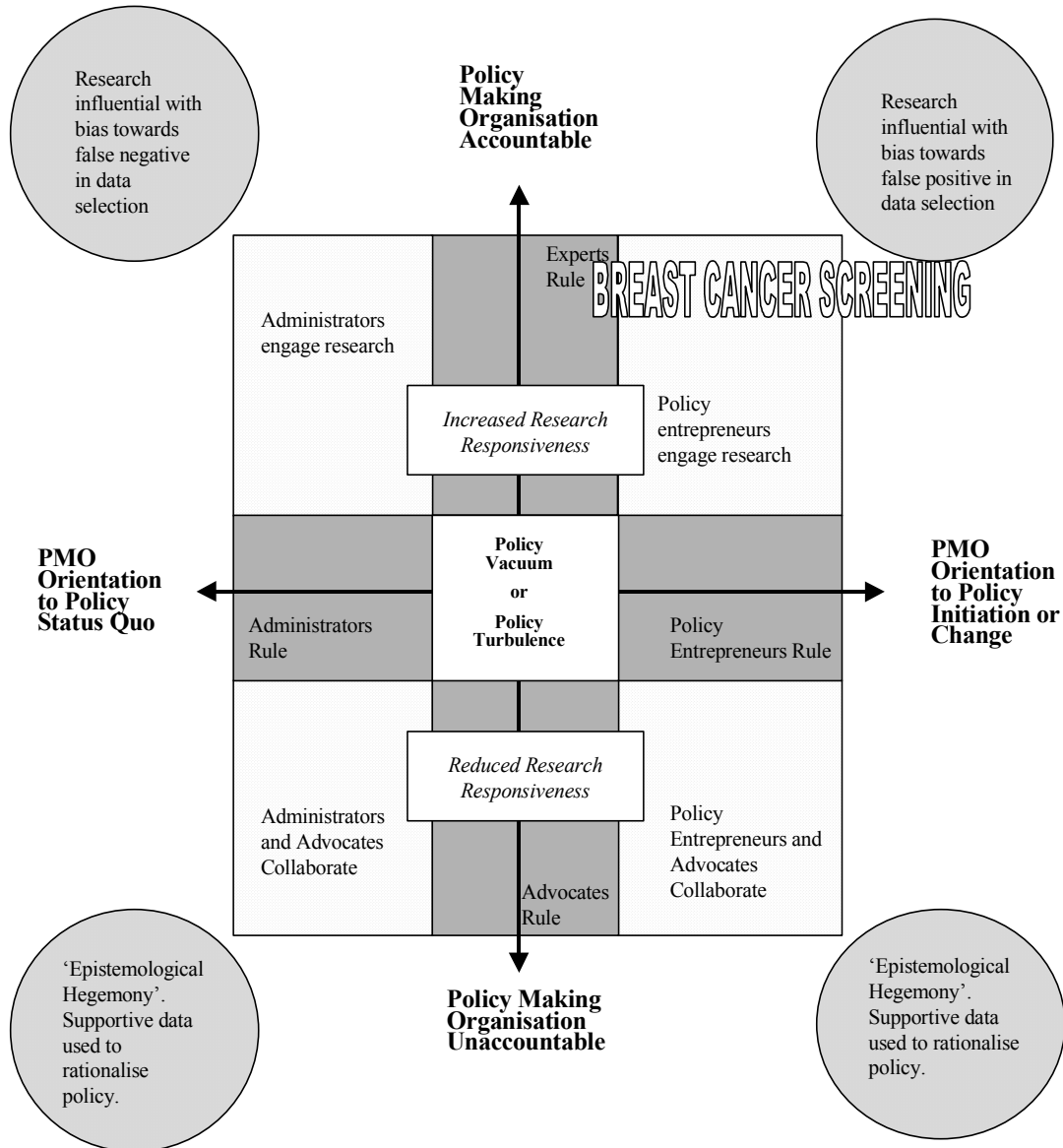
Figure 4.1 below locates the issue of breast cancer screening policy at a point which is both highly responsive to research and strongly biased towards falsely accepting the research that says mammography is effective.

The PMOF argues that the immutability of policy is in tension with the irrefutability of data. At this stage in the mammography screening debate, policy seems immutable regardless of the fact that the data on which Australia based its programs is now seriously challenged.

The PMOF allows us to chart the rise in the immutability of mammography screening. For many key informants it was at the point of the introduction of the pilot projects.

Once State governments had committed themselves to pilots, the level of evidence required to go into reverse would have been extra ordinary in part because of the legal consequences of having submitted large numbers of women to danger. The idea of

**Figure 4.1**  
**Location of Breast Cancer Screening in the PMOF Model**



pilots as a 'beachhead' and as 'just a slow way to start a program' as stated by two key informants resonates with this assessment.

From the Commonwealth point of view, the failure to act on de-facto screening was tantamount to accepting the inevitability of a screening program. Having allowed it to develop a head of steam among radiologists, general practitioners and women, the line of least resistance was in the direction of an organised national program. The task of clamping down on screening while the NH&MRC's 1984 advice that all women should have a 'baseline mammogram' at age 40 and thence every three to five years (National Health and Medical Research Council 1985) would have been difficult.

The immutability of Commonwealth support for mammography screening increased again in 1989 when the National Women's Health Policy said it hoped that screening would be available to all women as soon as good data on how to do it was available (Short 1995: 75). When the Commonwealth provided funding to the States and Territories for mobile screening services in late 1989 (Swan 1990) it seems that any chance of a Type 2 error from the national evaluation was almost zero. The election commitments in 1990 made it zero.

This has continued to the present day. The recent reappraisal of all the randomised control trial data by Gotzsche and Olsen has led to no formal and open reassessment of mammography screening in Australia. The Commonwealth's Chief Medical Officer participated in an expert panel convened by the WHO's International Agency for Research on Cancer (IARC) in March 2002 to reject the review findings (Commonwealth Department of Health and Ageing 2002: 27). In Australia, the National Cancer Control Initiative rejected the review as well. There is no evidence of the National Advisory Committee engaging in a reassessment or inviting anyone else to do a reassessment. A recent commentary on the issue from Alan Roger, Chair of BreastScreen Victoria and a member of the Cochrane Breast Cancer Editorial Group, says that the data on the size and staging of cancers identified through screening indicate that women with screen-detected cancer are likely to have a better prognosis and survival. He concludes saying 'Women should be made aware of these facts, along with any doubts raised by reviewers of somewhat out-of-date trials' (Roger 2002). Thus program advocates are now rejecting the very kind of data that was regarded as irrefutable at the time that BCS was established because the policy has now become

immutable. The bias towards avoidance of a Type 1 error on mammography based BCS is well and truly entrenched.

#### **4.4. Governmentality analysis**

As noted in Chapter 2, the application of the governmentality framework entails a number of conceptual shifts. The first is to a societal level of analysis rather than that of interests groups (the ACF approach) or institutions (the PMOF approach). The second is to reframe questions about the research–policy nexus. Research is related back to ‘regimes of truth’ or systems that operate so as to produce statements that are promoted and accepted as ‘the truth’. Policy is a performative discourse made up of ‘rationalities’ of government action that create the objects that need to be governed and the reasons why. Government is the conduct of conduct, and is found wherever power is used to create the fields of possibility within which people live and think and act. Finally, the nexus between research and policy is best understood as a space occupied by what Foucault called power/knowledge. The metaphor suggested in Chapter 2 is that power/knowledge is a collective psychic web continually produced through regimes of knowledge, practices and discourses. Public health policy is that particular web connecting technologies of self with technologies of population and governing at a distance.

##### **4.4.1. BCS policy discourse**

One of the striking things about BCS policy discourse is the powerful role played by the ‘meta-policy’ of the principles and practices of screening. This is one of the most successful and dominant discourses on screening policy as demonstrated by the central role it plays in framing the rest of the policy discussion in the *Future Directions* report. It is the policy template that is simply accepted as given.

The Governmentality Framework suggests that the screening principles are successful because they provide a coherent political rationality that combines moral, epistemological and idiomatic aspects.

Its moral characteristics are found in the way it sets out the circumstances under which the state has the power and a duty to intervene in the lives of healthy individuals. According to these principles, the state may test individuals for occult disease in



situations where the problem is significant for the population as a whole, where the test meets certain performance requirements, where treatment meets performance requirements, and so on. Further, the discourse locates the right to exercise authority through screening in the hands of public health agencies.

The epistemological character of this policy discourse is found in the way it determines which parts of the population might be ‘governed’ through screening (eg target groups identified on the basis of disease prevalence and natural history). The idiomatic character of this discourse is found in the way that it makes occult disease amenable to the process of government. The screening principles set out the rules to guide the government of occult disease.

#### **4.4.2. BCS and ‘regimes of practices’**

Breast Cancer Screening is a regime of practice in the sense that it organises many different practices (recruitment, counselling, testing, screen reading, biopsy taking, histopathology, radiation oncology, chemotherapy to name but some) into a coherent whole known as the ‘screening pathway’. What marks this out as a ‘regime’ is the way that each of the parts are the subject of knowledge and can be problematised separately, and in relation to each other, and as a whole. Screening organises these separate practices into a whole that is greater than the sum of its parts.

One of the things that separates those who wanted to accelerate the move to screening and those who were cautious was that the cautious ones were concerned that the additional rigour required to make the pathway effective would be difficult to achieve and the result would be harm to women. In this way, those who are seen to be critical of screening are not critical of screening per se but of the capacity of health systems to deliver screening to the required level. No one was critical of the process of problematising breast cancer through screening.

The RCTs and the pilot projects seem to play a critical role in the development of the screening regime. The pilot project regimes had to displace the regime of practice associated with de-facto screening. The regime of truth around the RCT was critical to this. The pilot projects had to justify their existence in terms of a discourse about the need for screening programs to be properly designed and tightly controlled in order to ensure that benefit outweighed harm. The RCT regime of truth established a uniform

way of thinking about the screening through benchmarked indicators of quality. These were concerned with: participation rates, cancer detection rates, rates of detection of cancers of different types and sizes, biopsy rates, positive to negative biopsy rates, the rate of different types of breast surgery in relation to different stages of breast cancer, and so on. There was never any suggestion that local pilot projects could invent their own indicators of success. The regime of practices has a globalised dimension closely linked with a globalised knowledge-base (Shapiro, Coleman et al. 1998).

#### **4.4.3. BCS and power/knowledge**

A Governmentality Framework analysis of Australian research emphasises its dependence of the international regime of truth built around the primacy of the RCT. Australian research has confined itself to contextual and operational matters that enable the local application of the universal design features worked out through RCTs and pilot projects on other continents, and the universal screening principles set out in the WHO meta-policy.

The Governmentality perspective highlights the continuities between the work of the NH&MRC and what came later. The work of the NHMRC was a precursor and foundation builder. It was the first point of entry and amplification of the international research. It proposed local pilot projects and commenced discussions with the cancer societies. It was the bridgehead for the new knowledge about screening in Australia.

The controversies of the last decade over the findings of the Canadian National Breast Screening Study and the Nordic Cochrane Centre review are continuous with the same process. The highest authority in the dispute is given to the regime of truth based on RCT methodology and its embellishment through the method of systematic review as promoted by the Cochrane Collaboration. While there is a dispute over the findings and proper interpretation of the RCTs, there is no dispute that the scientific method, properly followed, delivers the truth. The sequelae to the dispute over the findings of the Canadian study are particularly instructive in this light. Claims were made that the process of randomisation in the study had been ‘subverted’. This led to the appointment of independent investigators who engaged a specialist in fraud detection to examine the documentary records from the trial sites. The review found that ‘...even if there had been acts of subversion, they could only have been few in number and, given that there was only 1 death from breast cancer in the group reviewed, the alterations could have

had only a trivial effect on the study findings as reported in 1992' (Bailar and MacMahon 1997: 193). The language here is particularly interesting. Use of the word 'subversion' is normally reserved for attacks on legitimate authorities. Its use to describe possible failures to implement correct study procedures tells us that the writers saw something profound and fundamental at stake. Despite the findings of the review and subsequent hopes that the study would be rehabilitated (Bryant 1997) it appears that the damage was already done as the study had long been discounted.

#### **4.4.4. BCS and the governmentality hypothesis**

The location of breast cancer screening within a wider agenda of chronic disease screening and management makes it an extension of the historical role of public health begun in the 18<sup>th</sup> century. The 'health transition' is a rhetorical device to aid the development of a new stage of growth in public health's quest to realise 'the imperative of health: at once the duty of each and the objective of all' (Foucault 1980d: 170). These developments have manifested themselves across the developed world in the second half of the 20<sup>th</sup> century. Australian policy is a local manifestation of a global phenomenon.

At the individual level, Robertson's study of the phenomenology of risk of breast cancer makes a direct link between the promotion of mammography screening and breast self examination and the embodiment of risk—women come to see their breasts as flawed body parts, like a 'time bomb' or an 'Achilles' heel' (Robertson 2001: 297). Women's response to the perception of being at risk is to constantly monitor their bodies and their lifestyles—they 'swallow the panopticon' of surveillance (Robertson 2001: 303). Women can choose not to be screened, but emphasis on choice is part of constructing the citizen as an 'entrepreneurial self' (Rose 1990 in (Robertson 2001: 300). The critique of screening programs for not empowering women sufficiently to make choices reinforces women as self-governing citizens (Slaytor and Ward 1998; Ward 1999; Ward and Slaytor 1999). This is particularly encouraged for women aged 40-49 where the RCTs have yet to deliver unassailable truth (Glasziou and Irwig 1997) and they have been researched to find out what they want (Cockburn, Pit et al. 1999).

Some forms of political analysis would see the role played by cancer societies as state power coopting non-government organisations to help the state achieve its goals. A governmentality analysis turns this on its head. The cancer societies have been steadily

at work for nearly a century coopting the state to increase the government of cancer. They have promoted research to understand its many forms, understand its causes, natural history and distribution in the population, develop methods of prevention, treatment, and palliation, and educate the public about it. Central to this task has been the development of cancer registries in each State and Territory. These are controlled by the cancer societies for the purposes of their research. It is the cancer societies that have been gradually coopting the state to assist them in governing cancer ‘at a distance’.

#### **4.4.5. Governmentality and the research–policy nexus**

Foucault created the neologism of governmentality to describe the form of government that arose in Europe from the 16<sup>th</sup> century onwards (Foucault 1991a). It describes the new arts of government developed in response to the new problems of governing populations. The governmentality frameworks locates the roots of BCS in the process of problematising the changing age and disease profile of populations in developed countries in the mid-20<sup>th</sup> century. Epidemiology and the practice of public health were critical to that problematisation.

The power of public health research and public health practice lie in the way they have made the diseases of ageing into the objects of government. The concept of the ‘epidemiological transition’, created by epidemiology, also creates the platform for a transition in public health governmentality. The need to respond to chronic disease and the idea of using screening as a chronic disease control method came *before* mammography screening began. Thus it was a particular mentality of government, derived from epidemiology and the mission of public health, that came first.

The next phase in this governmentality was development of the WHO screening principles in 1968 (Wilson and Junger 1968) and the discourse within clinical practice about ‘snails’ and ‘evangelists’ (Sackett and Holland 1975). These are further developments in the political rationality of screening. The HIP study became an exemplar for the development of screening and in so doing created a nexus of knowledge/power that continues in screening policy discourse. The pilot projects continue this nexus—the sine qua non of pilot projects is the simultaneous trialling of practice and the surveillance of that practice through research.

The global dissemination of mammography screening requires an explanation that moves beyond local actors and institutions. The Governmentality Framework provides one such explanation (others could derive from a Marxist or diffusion of innovation perspective (Kimberly and Pouvoirville 1993)). The governmentality approach draws connections between neo-liberal forms of government and the interconnected web of the regime of truth based on experimental methods, the regime of practice that addresses both populations and individuals, and the political rationality found in screening discourse. The case study material shows a lively interaction between discourses about feminism, the women's health movement and mammography screening. The governmentality perspective would perhaps see the women's health movement and the mammography screening movement as alternative modes of problematising women's health that are sometimes in competition but ultimately synergistic in increasing the level of government of women's health. A major impact of feminism on BCS appears to have been to shape the moral form of the program's discourse whereby women are encouraged to be active participants in the creation of their subjectivity through screening.

#### **4.5. Theoretical considerations**

The point of this exercise is to generate greater insight into the research–policy nexus than that afforded by the ‘two communities’ approach, and to use whatever theoretical tools are available to inform practical action to build better public health policy. The first of these tasks is well accomplished. Whether it is the dynamics of advocacy coalitions working across the government–non-government divide, or organisational epistemology governing data selection behaviour, or the role of discourses in constructing the objects and reasons of government, each of the theoretical frameworks adds depth to our understanding of the research–policy nexus. Before proceeding to the higher order theoretical task, I will briefly appraise how successful each of the theories is in terms of providing a coherent, congruent, parsimonious and comprehensive account of the case study data.

##### **4.5.1. Theory evaluation**

Of the three frameworks the ACF seems to offer the most parsimonious account. When research is seen as a political resource for use by advocacy coalitions it opens up a

fruitful line of investigation that links changes in policy development processes with changes in the interpretation of research and changes in policy. It is particularly parsimonious because of the multiple roles that advocacy coalition values and beliefs play. These simultaneously work as the basis for advocacy coalition formation, the basis of the assumptions that form the policy core, the seeds from which questions for research and analysis grow, and provide the primary point of attack on competing coalitions. However, the emphasis on values and beliefs leaves the role of material interests somewhat out of the picture. For example, it is clear from the case study material that radiologists were central to driving the rise in de-facto screening by purchasing large numbers of machines at a critical period in the 1980s. While they appear as part of the advocacy coalition, their material interests are muted by the emphasis on beliefs and values. The factors that are down-played or overlooked in the ACF account are: macro-sociological influences working globally; the agency of women in seeking out screening; the role of the media in promoting the rise of consciousness about breast cancer and screening; and the role of the institutional capacity and interests of the State and Territory governments in supporting pilot projects.

Some of these same problems are apparent in the PMOF, particularly the inability to deal adequately with the role of international factors in promoting diffusion and uptake of mammography. The strength of the PMOF is in identifying the institutional factors that gave rise to the need for and the capacity to respond to the mammography screening issue. For example, the role of women's health units as points of receptivity for research on screening and bureaucratic capacity to respond to demands for screening are well highlighted. So too is the way that the PMOF locates a kind of grappling-hook effect of existing government responsibilities—because the Commonwealth funded Medicare then de-facto screening was a problem it needed to address. The focus of the PMOF on organisational epistemology, while parsimonious, fails to take account of the origins of research and casts the PMO in a largely defensive role vis-à-vis research. Research is just one more kind of data to be sifted and sorted and excluded if threatening. As with the ACF, the agency of women in seeking screening is absent.

The GF is conceptually wasteful. It has many big concepts and analytical tools but their interrelationships are poorly defined. Even more so than in the other frameworks, the agency of social actors is virtually absent. They appear largely as 'judgemental dopes'

that cannot avoid bearing the burden of neo-liberal governmentality. The strength of the GF is in locating the global trends towards mammography screening and in public health more generally in a larger social process. It makes powerful connections between the international regimes of truth and regimes of practices that characterise the global nature of medical research and medical practice to some extent. It also casts a cold and critical light back onto the practices of public health. It invites critical reflection on the contestable processes of research interpretation that are often presented as the ‘truth’—the AHMAC-AIH evaluation process being the best example and the recent Nordic Cochrane Centre evaluation showing just how negotiable such ‘truths’ can be.

None of the theories brings the interests and resources and influences of medical technology industries into the analysis. Clearly, companies that make radiology equipment and screen film as well as other diagnostic and treatment technologies have an interest in seeing mammographic screening spread round the globe. While their direct influence is difficult to detect in the Australian case study, Kaufert argues that it was clearly at work in the United States. She reports television advertisements by General Electric (makers of radiological equipment) and Dupont (makers of screen film) promoting mammography screening to young women (Kaufert 1996: 174)

#### **4.5.2. Theory development**

As discussed in Chapter 2, the task set out by research questions 3 and 4 requires a higher order organising framework that will allow us to capture points of synergy between the three focal theories. Sil’s ‘foundations of eclecticism’ provides such a framework (Sil 2000).

#### **Material structures**

For the purposes of this study, the key question is what were the material structures of significance in the research–policy nexus that were highlighted by one or more of the focal theories? Another way of putting this is to ask what material structures enabled the mobilisation of research as a resource to influence policy?

The most obvious is the AHMAC-AIH screening evaluation process made up of a committee appointed by AHMAC and a group of experts at the Australian Institute of Health to conduct research and evaluation. Related to this were the ten pilot sites around Australia each employing research expertise alongside radiological, clinical and

administrative expertise and providing data for the national evaluation. In continuity with this structure was the AHMAC sub-committee that preceded it and recommended that the evaluation be set up and which included some of the same people and organisations. The National Advisory Committee structure that followed also reflected some continuity though its role in bringing research to the task of policy making was not so central as it was for the AHMAC-AIH committee.

Other structures that explicitly brought research into the policy process were the expert committees of the cancer societies, the Ministerially appointed committees in the several States that established them, and the State and Territory government public health units and women's health units. Preceding them all was the NH&MRC that went through three distinct phases of explicitly reviewing research to determine the current state of 'knowledge' on the topic.

These structures might be called 'deliberative structures' because of the way their reason for being is to find and exhaust the value of research for government action on particular policy questions.

There are other material structures that clearly influence the production and use of research that could not be called 'deliberative' in the above sense. The most obvious in this case study are those of private medicine and the medical technology industry. These were central in mobilising the earliest mammography research and, as in the case of radiologists in the Medicine Advisory Committee of the NH&MRC, actually using governmental structures to form policy statements based on particular interpretations of research.

### ***Ideal structures***

The key question here is what were the ideal structures (ie collective mental schema, systems of beliefs or values, or shared meanings) that mobilised research in some way in relation to policy?

The central one appears to be the WHO screening principles in the sense that it was these principles that provided the organising framework for analysing and presenting data on mammography screening. Each of the principles creates one or more questions that needs to be answered empirically. While they do not say how the answers should be evaluated (ie they do not say what a good enough test is, or how cost-effective screening



should be before it is acceptable in relation to competing priorities in the health system) they create a demand for research and ensure policy arguments make reference to research. These principles also incorporate implicit value statements that guide decision making. Of critical importance is the implicit acceptance of the principle that causing harm to some people is acceptable so long as the screening program as a whole brings about net benefit for the population.

Two other ideal structures of less formal recognition or specification also seem important in mobilising research. One is the belief underpinning the expanding role of public health in relation to chronic disease and cancer and the role of epidemiology in informing that. The other is the growing promotion of the role of scientific evaluation of medical interventions that would come to fruition in the 1990s in the Evidence-Based Medicine movement.

### ***Commonalities between the theories***

What I am concerned with here is the process by which the ideal and material structures identified above constrain and enable social action in the research–policy nexus and are changed as a result (Sewell 1992: 16-21).

A common point of significance for all theories is the AHMAC-AIH national evaluation process that produced the *Future Directions* report. Each of the theoretical frameworks recognises this as a point where a material structure (government empowered committee) and an ideal structure (the WHO screening evaluation principles) enable and constrain the agency of a range of social actors as well as empower research in relation to policy.

The ACF approach constructs this in terms of the formation of a policy subsystem focussed on breast cancer screening, dominated by an advocacy coalition made up of representatives from government departments with responsibility for public health and women's health, clinical specialists, epidemiologists and public health experts, and with strong connections to non-government organisations. The WHO screening evaluation principles are conceptualised as a part of the core values and beliefs of this Dominant Advocacy Coalition and therefore are accepted and promoted as the proper basis of decision making. Agency and 'structuration' is understood in terms of the way this DAC worked strategically through whatever material structures were available to realise

their goals, thus the AHMAC-AIH structure was just the largest and most significant structure which key players used to realise their agenda. They also worked through State Government processes, the NH&MRC, the State and Territory and national cancer societies, and the women's health networks.

From the PMOF perspective, the AHMAC-AIH structure reflects the extent of the policy making organisation's research responsiveness. By putting this committee and evaluation process in place, the PMO is accepting responsibility for breast cancer, accepting the possibility that it may have the capacity to respond to breast cancer, and creating a 'theatre of justification' that can observe its successes or failures. In doing this, the PMO is overcoming its hostility to possible policy change by suspending the assumption that it already knows everything it needs to know (according to Dery, this is fundamental to closing off new information (Dery 1984: 37)). The screening evaluation principles are significant in the PMOF because they are the basis for data selection behaviour—they become the organisational epistemology, the basis for determining what data is relevant. Agency and 'structuration' are conceptualised in the PMOF in terms of the biases created in the data selection process towards the preference for a Type 1 error (the preference for mistakenly accepting the hypothesis that mammography screening works). This bias is created through, for example, pressures on the PMO to find a solution to exponential increases in de-facto screening.

The GF conceptualises the AHMAC-AIH process as the primary local realisation of a 'regime of truth'. Through all the trappings of scientific methods—systematic literature reviews, pilot projects, national data collections, an oversighting committee chaired by a senior public health scientist—the process is designed to manufacture statements that will be recognised as the 'truth'. The WHO screening principles provide a discourse that creates breast cancer as a legitimate object of government, gives authority to public health experts to determine the worth of screening, and makes the surveillance and intervention in the lives of healthy women seem not only sensible but imperative for their health and the health of the population. Agency and 'structuration' are understood in terms of the exercise of power by public health and clinical experts working within their particular 'regimes of truth' to establish 'governing at a distance' in relation to breast cancer.

## 4.6. Final comments

The development of breast cancer screening in Australia provides a case study rich in events and processes that show intricate interactions between research and policy. While some public health advocates, including most of those interviewed for this case study, view BreastScreen Australia as a good example of evidence-based policy, others argue this is not the case. Regardless of where one stands on BCS policy, what is unarguable is that the process of breast cancer screening policy development has involved a long-term, multifaceted, and decisive engagement with research. The three focal theories provide new and interesting insights as to why this engagement has taken place and why the observed outcomes have occurred. The question of whether these insights are able to be generalised to other settings will be taken up in Chapter 8 where the commonalities in findings across the case studies will be discussed. Sil's macro-theoretical framework has helped locate the more fundamental dynamics that may be at work in the research-policy nexus. Of particular interest is the interplay between material and ideal structures and the way they both enable and constrain the agency of policy actors. These ideas will be explored further in the 'theory development' sections at the end of each of the case study chapters.

## **5. Prostate Cancer Screening**

### **5.1. PCS policy, research and the research–policy nexus**

This is a case study of the research–policy nexus in prostate cancer screening (PCS) policy in Australia. The first section presents the main events and processes in PCS policy development and research in Australia. A chronology of events is set out in the appendices for Chapter 5.

#### **5.1.1. Policy on PCS**

When the Prostate Specific Antigen (PSA) was first listed on the Medicare Benefits Schedule (MBS) in 1989, it was for use in the treatment of symptomatic individuals, not for population screening. From the early 1990s, there was a rapid rise in the rate of testing and in prostate cancer leading to debate about the extent to whether it can be, and was already being used as a screening test (Kaye 1995; Hirst, Ward et al. 1996). In 1994, the Commonwealth Government explicitly rejected prostate cancer screening using the PSA test in the *Better Health Outcomes For Australians* report (Commonwealth Department of Human Services and Health 1994). However, testing and prostate cancer incidence continued to increase. In 1995, the NH&MRC's Australian Health Technology Advisory Committee was asked to provide advice on PCS. On 13 August 1996, the Federal Minister for Health, Dr Michael Wooldridge, endorsed the report of AHTAC, *Prostate cancer screening*, which recommended against PCS (Australian Health Technology Advisory Committee 1996). This rejection of PCS in 1996 was a confirmation of existing policy. The policy has since been re-affirmed by the Commonwealth's Medical Services Advisory Committee (MSAC) in 2001 but with a concession that effectively allows annual screening.

#### **5.1.2. The emergence of the PCS policy problem**

The PSA was first approved for disease monitoring by the US FDA in 1986 and immediately created controversy (Chase 2000).

In 1991, Catalona, a urologist, published a study claiming PSA screening could increase cancer detection by 20 per cent over other screening methods (Catalona, Smith et al.

1991). He advocated in the *Wall Street Journal* that men over 50 should be screened. The views of the US National Cancer Institute were reported to be cautious (Winslow 1991). In 1993, Schroder reported that most US urologists were screening their patients and that pressure for screening was growing around the world with the support of American Urological Association and the American Cancer Society. (Schroder 1993). Taylor reported a tenfold increase in the number of PSA tests and a threefold increase in prostatectomies in Canada between 1990 and 1993, a result of aggressive promotion of the PSA test in the US by PSA test manufacturers (Taylor 1994b).

Critics of PCS often argue that the commercial interests of test manufacturers and urologists have driven the spread of screening. These include the National Cancer Institute of Canada (Taylor 1994b), Dr David Wasson in his address at the First National Men's Health Conference in 1995 (Wasson 1995), and Dr Jeannette Ward (Ward, Hughes et al. 1997). Catalona's early study was partly financed by Hybritech Inc, the company that makes the blood test (Winslow 1991). Most key informants pointed to the potential conflict of interest for urologists who promote screening.

PSA testing in Australia increased rapidly from 1989<sup>13</sup> and most rapidly between 1992 and 1994 (Smith and Armstrong 1998). In 1994, Parkes and Killer reported that veterans were being screened (Parkes and Killer 1994). By 1995 one in five Australia men over 50 were being screened annually (Ward, Hughes et al. 1997; Smith and Armstrong 1998).

In 1993, the President of the Urological Society of Australasia, J Stuart Taylor, said screening was being discussed in the profession and the press because prostate cancer had become the most common cancer affecting men in New South Wales. But, he said, prostate cancer treatment was a matter of controversy. His association's view was:

Serum prostate specific antigen assay should not be done as a screening test on all men over the age of 50, nor should all men with an elevated prostate specific antigen level be routinely referred for transrectal ultrasound with needle biopsy.  
(Taylor 1993)

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<sup>13</sup> Between 1989 and 1993 the PSA test was listed with 12 other biochemical tests so its use in that period can only be estimated. Since 1993 it has been included along with the prostatic acid phosphatase (PAP) test and most testing under this item is attributed to the PSA rather than the PAP test.

This position raised medico-legal issues for doctors (Gerber 1994; Sladden, Dickinson et al. 1994) which remain an important factor in GP PSA test ordering (Girgis, Ward et al. 1999).

Loh and others argued that a ‘prostatic imperative’ had developed which led to an increase in case ascertainment from de facto screening and the possibility of over-treatment of prostate cancer (Loh, O'Brien et al. 1994).

Some urologists, most notably Professor Keith Kaye, were active promoters of PSA screening. Many key informants referred to Professor Kaye as a key figure in debates over PCS policy in Australia. He was the head of the Urological Research Centre of Western Australia, which was set up by urologists and the Australian Kidney Foundation in 1993. Kaye held the first Chair of Urological Surgery in Australasia through the University of Western Australia (Urological Research Centre 2000). The Centre promoted screening through its annual Prostate Awareness Week (PAW) when men were offered free PSA testing. Kaye advocated PCS in the MJA one month before the commencement of AHTAC’s deliberations (Kaye 1995).

The increase in prostate cancer incidence became apparent through routine work on cancer rates by epidemiologists in government and cancer societies (Taylor 1993). McCredie argued that the best explanation for the increase was the increase in PSA testing, not an increase in the rate of disease (McCredie 1995).

Early and consistent opposition to PCS came from the Australian Cancer Society (ACS) (now The Cancer Council Australia or TCCS). In 1995, two months before the AHTAC process began, the ACS rejected screening on the grounds that it lacked randomised controlled trial evidence of effectiveness (Rogers 1995). The ACS position on PCS put it at odds with the American Cancer Society. Under its new guise as The Cancer Council Australia (TCCA), the ACS has continued its opposition to PCS arguing it should be discouraged until evidence of benefit warrants a national program (The Cancer Council Australia 2001: 87).

### **5.1.3. First response to the PCS problem**

The first explicit national policy position on PCS was made in 1994 in the *Better Health Outcomes for Australians* report (Commonwealth Department of Human Services and Health 1994). It recommended against screening because there were ‘...no results from

randomised controlled trials that screening for prostate cancer reduces mortality'. It argued that 'Strategies should be developed to ensure that such a policy is effective in preventing unnecessary screening of men for prostate cancer' (ibid: 165). It recommended training for GPs in how to explain the risks and benefits of screening to men and said there was a need to educate the media so they do not increase demands for PCS (ibid). It also noted that the Australian Cancer Society was currently constructing a policy on PCS, and that the NH&MRC was reviewing the evidence.

#### **5.1.4. AHTAC process, findings and recommendations**

There is no evidence that the recommendations of *Better Health Outcomes for Australians* were implemented. In June 1995, the NH&MRC tasked AHTAC with reviewing the evidence on PCS because of concern about rising incidence of prostate cancer, differing views in the medical profession on PCS and calls for the introduction of PCS from groups in the community (Australian Health Technology Advisory Committee 1996: xi). AHTAC formed a seven-person working party comprising two urologists, a general practitioner, a health economist, an AHMAC representative, a consumer representative who was also a sociologist, and an expert in biomedical engineering.

The AHTAC found that the increased incidence of prostate cancer was the result of increased testing and that de facto screening was occurring (Australian Health Technology Advisory Committee 1996: xii). It evaluated PCS against the WHO screening criteria and recommended against the screening of asymptomatic men (Australian Health Technology Advisory Committee 1996: 79). However, it did not discount that PCS may one day be found to be effective and recommended that the position on screening be regularly reviewed (Australian Health Technology Advisory Committee 1996: xvii).

The core of the AHTAC deliberative process was a review of the available research by Dr David Weller from Flinders University and the newly established Australian Cochrane Centre (Australian Health Technology Advisory Committee 1996: 2). In the Foreword to the report the Health Minister, Michael Wooldridge, stressed that it was based on 'the strength of the evidence' (Australian Health Technology Advisory Committee 1996: iii).

The AHTAC recommendations are nevertheless surprisingly accommodating of continued de facto screening. It recommended an extension of the indications for PSA testing to include monitoring treatment of benign prostatic hyperplasia. It also recommended that men being offered, or requesting, the PSA test be fully informed of its limitations and the possible further diagnostic and treatment choices they might be faced with (Australian Health Technology Advisory Committee 1996: xvii). In justifying this position, AHTAC said that the choice of whether or not to be screened is ‘...not a choice that society can make on behalf of all men and ultimately the choice of whether or not to have a screening test rests with each individual’ (Australian Health Technology Advisory Committee 1996: 80). It made extensive recommendations on an education program targeting patients, doctors and the community at large on the risks and benefits of testing for prostate cancer.

Given that no man would be forced to participate in a national screening program, and that such a program would need to communicate all the risks and benefits of participation to consumers, the ethical argument about leaving the decision about testing in the hands of individuals is redundant and makes for an ambiguous message about screening.

#### **5.1.5. AHTAC aftermath—policy ‘paralysis’ and ‘confusion’**

Taken together, the AHTAC position on PCS was quite soft, unlike the active anti-screening position of the *Better Health Outcomes* report. AHTAC did not recommend any policy action to reduce de facto screening and the Commonwealth did not take any. This is despite the continued rise in the number of PSA tests being ordered each year (Pathology Services Table Committee 2000). AHTAC’s position could easily have been interpreted as one of ‘not yet’ given its recommendation on the need to keep the matter under review and its view that men should not be denied access to the test.

AHTAC’s recommendations on education and information had the effect of reframing the policy goal towards achieving informed consent for testing of asymptomatic men. The report implies that AHTAC believed that by promoting informed consent it could dampen the level of demand for the test and achieve a reduction in de facto screening in a relatively painless way (Australian Health Technology Advisory Committee 1996: 72).



When asked for this study how they would describe policy on PCS, some key informants described it as ‘policy paralysis’, or ‘confusion’.

### **5.1.6. An uneasy truce in policy debate**

There is agreement among protagonists that a final decision on PCS cannot be made until current trials are completed. There is also agreement that policy should focus on education for men and doctors. The Cancer Council Australia (TCCA) policy says that education ‘should neither encourage nor discourage screening but provide accurate and unbiased information’ (The Cancer Council Australia 2001: 88). The Cancer Strategies Group of the National Health Priorities Action Council (the descendant of the committee that produced *Better Health Outcomes for Australians*) argues that promoting informed choice by men should be a priority (Cancer Strategies Group 2001: vii).

Opponents and supporters of screening have both continued to call for action on AHTAC’s recommendations (Ward 1998a; Gardner 2001b). Pinnock and Marshall report that men see the lack of information as a cynical act of government (Pinnock and Marshall 1997). There has been some action on education for GPs in 2001 in the form of a trial of ‘academic detailing’ (Wooldridge 2001).

However, the protagonists see different purposes for education programs—those opposed to screening see education as a means of reducing screening while those who take a positive view of screening see education as a necessary accompaniment to informed choice.

The respective protagonists also have very different views of the data that have been emerging since AHTAC. While Labrie and colleagues reported a study of 46,000 men in Quebec, which they claim produced a 2/3 mortality reduction in the screened population, critics argued the response rate to screening invitations was too low to draw conclusions (Pollack 1998). A study in the State of Tyrol in Austria found mortality declines after men there were offered screening (Bartsch, Horninger et al. 2001). But in an accompanying editorial in *Urology*, Carter argued that the real cause was new methods of prostatectomy introduced in the early 1980s. He still concluded, however, ‘I believe - as do most urologists - that PSA testing saves lives’ (Carter 2001). Mortality rates have also declined in the US but some argue that the decline has been too soon to

be the result of PSA testing (Tarone, Chu et al. 2000). Some Australian experts say the data are consistent with the hypothesis that early detection and treatment is beneficial (Frydenberg, Duchesne et al. 1998) but Burton argued at interview that declines are also being observed in the UK where there has been very little screening.

### **5.1.7. Men's health, gender politics and PCS**

Key informants said the issue of 'men's health' has influenced the PCS policy process. This is apparent in the way that some tried to use it as a platform to argue for resources for prostate cancer comparable with breast cancer (Frydenberg 1995). AHTAC said this link was fuelling community demand for PCS (Australian Health Technology Advisory Committee 1996: xii). However, others saw the PCS controversy as a way to get men's involvement in a broad men's health movement (Fletcher 1994).

The Melbourne *Age* pitted the pro-screening views of the Apex Club against the anti-screening views of the Victorian Anti-Cancer Council in the lead-up to the First National Men's Health Conference (Dow 1995b). However, the then Health Minister Carmen Lawrence wanted to break any political synergy between the issues (Dow 1995b) and wanted to focus on the underlying attitudes and beliefs about 'masculinity' (Lawrence 1995). This strategy was apparent in the Commonwealth's choice of Professor John Wasson as one of the keynote speakers. His negative views on PCS were known (Wasson, Cushman et al. 1993; Wasson 1995) and his speech warned of the financial interests of those promoting screening (Talbot 1995).

While advocates of PCS still use gender equity as an argument for greater attention to prostate cancer, the men's health agenda seemed to evaporate with the change of government in 1996. The Second National Men's Health Conference in 1997 was not organised by the Commonwealth Department of Health and the new Liberal health minister Wooldridge did not participate. The conference continued an emphasis on a broad view of men's health (Binns 1997) and tried to convince the Commonwealth to re-establish a men's health policy process (Huggins 1997a; Huggins 1997b).

### **5.1.8. Consumer group mobilisation**

Several key informants noted the rise in the PSA testing increased the number of men who knew they had prostate cancer and led to the rise of the prostate cancer consumer

movement. The story of the development of the Prostate Cancer Foundation of Australia (PCFA) bears this out (Prostate Cancer Foundation of Australia 2002). The PCFA provides research grants for epidemiology, biology or treatment of prostate cancer.

The first national conference of Australian and New Zealand prostate cancer support groups was held in 2001 and featured a debate on PCS between two urologists, Phillip Stricker and Geoffrey Hirst, with Stricker presenting the pro-screening case and Hirst the negative. The report of the final workshop criticised the ‘widely publicised’ views of Hirst and Burton saying they ignore the number of men who die of the disease and the anger of those ‘...diagnosed with incurable prostate cancer, which might have been avoided by a timely PSA test’ (Gardner 2001b). The conference also strongly supported public education and rejected government pressure on GPs in the form of ‘Academic Detailing’.

The Lions Club has supported the prostate cancer consumer movement by sponsoring the Lions Australian Prostate Cancer Web Site (Gardner 2001b) that reports the work of the Australian Prostate Cancer Collaboration (APCC). The APCC has brought together the consumer movement, urologists, and the cancer councils under the one umbrella and is acknowledged by The Cancer Council Australia (TCCA) as the lead organisation in the development of prostate cancer policy in Australia (The Cancer Council Australia 2001: 88).

#### ***5.1.9. International parallels in PCS***

At about the same time AHTAC and the Australian Government ruled out screening, so too did the National Health Committee of New Zealand (NewzIndex 1996) and the UK National Health Service (Fletcher 1997). The United States is atypical with 18 State legislatures mandating screening test coverage in health insurance (Rathore, McCreevey et al. 2000). Rathore and others argue that gender-equity arguments were a major contributing factor to this outcome in the United States and local press coverage supports this (Gormley 2000). These arguments seem to have been less influential here and in New Zealand (New Zealand Press Association 2001).

The high rate of de facto screening is also evident in other countries. Peters (Peters, Jovell et al. 2001) reports a survey of 16 countries which found that no country supported screening but it is widely, if non-uniformly, practised.

Just as urologists are in the vanguard of those supporting screening in Australia (Kaye 1995; Stricker and Eisinger 1997), so they are in the United States, Ireland (O'Connor 1998), and New Zealand (New Zealand Press Association 2001).

### **5.1.10. Research and the AHTAC report**

The AHTAC report argues that the dilemma over prostate cancer derives partly from a lack of knowledge (Australian Health Technology Advisory Committee 1996: xx). McNeil and O'Brien say it is a controversy arising from lack of evidence of value rather than evidence of no value (McNeil and O'Brien 1999).

AHTAC used the WHO principles for assessing screening programs to assess PCS<sup>14</sup> and found support only for the criterion that the disease should be an important public health problem. AHTAC systematically appraised research on the epidemiology of prostate cancer, the performance of the PSA test, and the treatment of localised prostate cancer. It identified the lack of RCTs that compare aggressive treatment with watchful waiting and the lack of large population-based trials of PSA screening as major gaps (Australian Health Technology Advisory Committee 1996: xv).

Australian research figures little in the report. There are 16 Australian references out of 187. Five of these are publications on guidelines, one is to the *Better Health Outcomes for Australians* report and one is the Urological Society of Australasia's statement (Taylor 1993). Five are general publications on cancer in Australia. This leaves four specifically on the question of PCS in Australia: The Australian Cancer Society review of PCS; an analysis of prostate cancer incidence and mortality in South Australia (McCaul, Luke et al. 1995); McCredie's analysis of whether the increase in cancer incidence is real or an artefact of increased testing (McCredie 1995); and Parkes and Killer's analysis of Department of Veteran's Affairs administrative data to determine the rate of de facto PCS already occurring (Parkes and Killer 1994). The role of the Australian research, therefore, was limited to providing contextual information that made the debate about PCS relevant to Australia. No Australian research was used to argue the substantive questions related to screening.

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<sup>14</sup> See Appendix to Chapter 5.

### **5.1.11. Australian research relating to PCS**

Table A10 in the appendices for this chapter presents Australian research conducted on matters relating to PCS. Of the 15 studies identified, 8 were either clearly opposed to PCS or took the view that the current level or manner of de facto screening is problematic. Some do not give a view on PCS but suggest current approaches to men's urological and sexual health problems are inadequate. There are no articles saying the current level of de facto screening is good or unproblematic.

A common theme of the post-AHTAC research is the dynamics and quality of PSA test ordering by general practitioners. Ten of the studies looked at men's reasons for seeking tests, GP's reasons for offering tests, or both. Related to this are studies of the extent of de facto screening with eight articles identifying the proportion of men tested and four studying the role of the GP in test ordering.

Three studies were primarily concerned with the question of the rising incidence of prostate cancer and how it relates to PSA testing and/or to the rate of prostate cancer mortality.

Six of the studies had support from State cancer councils. Researchers associated with the Collaborative Centre for Prostate Health figured in three of the published articles. The NSW Health Department figures strongly through the work of the Central Sydney Areas Health Services Needs Assessment and Health Outcomes Unit. Several researchers are associated with more than one piece of research: Jeanette Ward, Carol Pinnock, David Weller, Villis Marshall, and Dallas English.

Four of the studies (Smith and Armstrong 1998; Threlfall, English et al. 1998; Pinnock, Weller et al. 1998b; Ward, Gupta et al. 1998b) were published in the same issue of the MJA in July 1998. They were accompanied by an editorial by McCredie and Cox (McCredie and Cox 1998) and all except Threlfall et al contained recommendations to policy makers. Smith and Armstrong wrote that the level of de facto testing was 'quite remarkable' given that PCS has never been recommended and said 'These findings have important implications for public health policy and for patient and practitioner education aimed at reducing prostate cancer screening' (Smith and Armstrong 1998).

In a reference to the then recently released NH&MRC guidelines on LUTS (Lower Urinary Tract Symptoms), Pinnock, Weller and Marshall say:

Current guidelines focus on when not to use the PSA test, but not when it is appropriate. There is no framework for doctors and patients which includes all the important elements of decision-making in this area, including evidence, patient preference and medicolegal issues. (Pinnock, Weller et al. 1998b)

Ward and others argue the need for strategies to reduce ‘unvalidated screening’ such as the performance-based contracts used in their local Area Health Services (Ward, Gupta et al. 1998b). But, they argue, these strategies need to involve consumers because doing so reduces the demand for screening. In the accompanying editorial, McCredie and Cox argue that men should be given the opportunity to make an informed choice before being tested because of the potentially harmful cascade of events that might follow, but this is not happening at present (McCredie and Cox 1998).

This idea was strongly promoted by Pinnock and Marshall in their paper at the Second National Men’s Health Conference when they bemoaned the lack of work on health promotion for men following the AHTAC report (Pinnock and Marshall 1997). Pinnock and others found in their qualitative study of urological health among older men that the lack of information ‘...was sometimes attributed to broader political issues such as gender politics or the government’s desire to cut back on health budgets at the expense of men’ (Pinnock, Wakefield et al. 1998a: 24).

The documentary evidence shows that there were attempts to mount a study of the effectiveness of PSA testing by Dallas English with support from the WA Cancer Foundation and involving Professor Keith Kaye (Bower 1998). The plan was to use existing data from the Busselton cohort study in Western Australia but it did not come to fruition for methodological reasons (Slevin interview). The Urological Research Centre also lists one of its projects as a ‘National population based case-control study into Prostate Cancer Screening’ (Urological Research Centre 2000). There is no evidence that this study had gone ahead.

### **5.1.12. *Snails, evangelists and meta-policy revisited***

There is a pattern in the PCS policy debate identified by Sackett and Holland as ‘snails’ versus ‘evangelists’ (Sackett and Holland 1975). Collins has analysed the conflict in terms of the uncertainties around PCS in these terms (Collins and Barry 1996) as did Geoffrey Hirst at interview. The ‘evangelists’ emphasise the similarities with breast cancer and take a positive view of the available research on early diagnosis and

aggressive early treatment (Frydenberg 1995; Kaye 1995; Stricker and Eisinger 1997; Frydenberg 1998). The ‘snails’ identify differences in the natural history of breast cancer, the treatments available, and the screening test performance (Hirst, Ward et al. 1996; Jones 2001).

At interview, most key informants described the PCS conflict in a way consistent with the ‘snails’ versus ‘evangelists’ schema. Slevin reports that the advocacy of Professor Keith Kaye and the Urological Research Centre increased de facto screening rates in Western Australia and led to joint action by the Western Australian Cancer Foundation and the State Government to educate general practitioners and discourage PCS (Slevin, Donnelly et al. 1999).

The WHO screening evaluation principles were used by AHTAC (Australian Health Technology Advisory Committee 1996) and other countries (Donovan, Frankel et al. 2001) as the basis for decision making.

### **5.1.13. *Continuity and change in policy machinery***

The policy making machinery on PCS has been in a state of flux over the entire period under investigation. Appeals to ‘evidence’ to justify policy positions, however, have been a common element in justifying policy positions.

The 1994 policy statement was the product of an AHMAC process and staked its claim on appeals to the lack of evidence of effectiveness for PCS (Commonwealth Department of Human Services and Health 1994: 165).

The AHTAC was a subcommittee of the NH&MRC, the premier medical scientific research and advisory body in Australia that included some representatives of AHMAC. As a hybrid of NH&MRC and AHMAC, AHTAC appears to have been an attempt by policy makers to fix the problem noted in the BCS case study where the NH&MRC appeared to be largely irrelevant to the deliberative process on BCS from the mid-1980s.

But AHTAC did not survive even a decade. The latest policy statements on PCS have taken two forms. One has been the Medical Services Advisory Committee (MSAC) consideration of the matter which led to a rewording of the Medicare Benefits Schedule. It included an update of the review of the scientific literature done for AHTAC. MSAC

is responsible to the Commonwealth Health Minister and its focus is the Commonwealth's funding of medical procedures and technologies through the Medicare Benefits Schedule.

The other recommendation has come from the National Health Priorities Action Committee's (NHPAC's) Cancer Strategies Group. It found that one of the most cost-effective interventions for cancer control in Australia at present was 'Promoting informed choice by men about prostate-specific antigen (PSA) testing and the early detection of prostate cancer through education for general practitioners and the community' (Cancer Strategies Group 2001: 35). The NHPAC is a subcommittee of AHMAC and a direct descendant of the policy machinery that produced the 1994 statement.

A closer look at the Cancer Strategies Group shows it is part of a network of organisational alignments and interconnections. For example, the Cancer Strategies Groups says that the work on PCS '...might be done by the National Cancer Control Initiative and the Australian Cancer Network in close association with the Australian Prostate Cancer Collaboration' (Cancer Strategies Group 2001: 37). The close alignment of their recommendations with the views of those of the Australian Prostate Cancer Collaboration stated by Pinnock et al in 1998 (Pinnock, Weller et al. 1998b) suggest that policy influences are highly networked. The NCCI, the ACN and the APCC are all linked with The Cancer Council Australia (formerly the Australian Cancer Society) by cross membership and by organisational affiliations (Coates 1998). They are also linked with government through project specific as well as infrastructure funding. The National Cancer Control Initiative is funded by the Commonwealth Government through The Cancer Council Australia and is located with The Cancer Council Victoria. The Australian Cancer Network is the organisation used by TCCA to link organisations with an interest in cancer in Australia into a single entity.

These organisations have links back to the institutional base for the Australian research related to PCS. The State and Territory cancer organisations and the Australian Prostate Cancer Collaboration have both a policy role and a research role. Only one key research group, the Central Sydney Area Health Service, is not directly linked with these organisations and has no obvious national policy role. There is no evidence that the professionals and PSA test manufacturers who promote the benefits of PCS play a role in PCS policy making.



## **5.2. ACF analysis**

An ACF analysis of the research–policy nexus on PCS begins by identifying the protagonists in policy debates, locating them within advocacy coalitions in the policy sub-system, and exploring the role of research in power struggles.

### **5.2.1. Advocacy coalitions in the PCS policy subsystem**

The first supporters of PCS were urologists and they used research to argue the case for screening (Catalona, Smith et al. 1991). The Urological Association of Australasia initially rejected screening but their website supports screening in all but name and juxtaposes its views with those of the Commonwealth Department of Health (Urological Society of Australasia 1999).

In 1994 the first formal government opposition to PCS appeared in the *Better Health Outcomes for Australians* report that was produced with the involvement of the Commonwealth, State and Territory Governments, the Cancer Councils and the NH&MRC. In March 1995, the Australian Cancer Society rejected PCS (Rogers 1995). Jeannette Ward authored that statement. Two months later, Professor Keith Kaye wrote an editorial for the MJA arguing for PCS (Kaye 1995). A rejoinder came from Geoffrey Hirst (a urologist), Jeannette Ward and Christopher Del Mar (Hirst, Ward et al. 1996).

Attack and counter attack continued with the publication of the AHTAC report. Kaye said ‘...hundreds of men will die if they take Government advice not to be tested...’ (Tan-Van Baren and Bower 1996). He argued that research showed improvements in treatment success rates.

In 1997, Ward and Hirst published data on the high rate of men being screened juxtaposed with men’s low level of knowledge of the risks involved (Ward, Hughes et al. 1997). In response, Phillip Stricker and David Eisinger defended men’s choice to be screened and argued that GPs are motivated by their patients’ needs, not the recommendations of public health professional bodies (Stricker and Eisinger 1997).

Hirst decided to work through the NH&MRC to develop clinical guidelines on the treatment of LUTS because of the way it triggers PSA testing. Ward was part of the committee and in 2000 they wrote:

Because of the somewhat entrenched positions about PSA testing by various groups, the working party correctly anticipated this might be a controversial recommendation, but we did not anticipate the longevity of the controversy. As recently as September 1999, the working party was polled about proposed changes to its recommendation as a result of ongoing ‘significant concerns’ conveyed to the NHMRC. However, the evidence for an association between LUTS and early prostate cancer remains dubious. (Hirst and Ward 2000)

Men’s groups seemed divided in the lead-up to the First National Men’s Health Conference. Dow reported that ‘...the evolving men's health movement is bitterly split over how to protect men from the cancer that is the unofficial symbol of their cause’ (Dow 1995b). However, the outcomes of the two conferences made no mention of PCS suggesting that those who prevailed in this movement saw no advantage in promoting PCS.

As indicated by the outcome of the first conference of prostate cancer support groups, urologists and consumers have worked together to attack the anti-PCS position, Geoffrey Hirst, Robert Burton, the Commonwealth Government, and the cancer councils (Gardner 2001b).

### **5.2.2. Beliefs and values of the PCS advocacy coalitions**

The following table compares the beliefs and values of these advocacy coalitions in PCS.

**TABLE 5:1 BELIEFS AND VALUES OF PRO- AND ANTI-PCS ADVOCACY COALITIONS**

<b>Topic</b>	<b>Pro PCS Beliefs and Values</b>	<b>Anti PCS Beliefs and Values</b>
Interpretation of current research on PCS	Current research increasingly supports the hypothesis that PCS is effective. Many men will miss out on its benefits while we wait for the RCTs to be completed.	There are sound alternative explanations for the findings of current research other than that PCS is effective. Many men are being harmed at cost to the health system while we wait for the RCTs to finish.
The primary consideration	The health system should do what it can for men with prostate cancer—waiting till men become symptomatic is less than the best.	First do no harm. Increased testing may benefit some but only at the cost of exposing many more to potential harm at considerable cost.
The purpose of ‘informed consent’	To ensure that men are empowered to make their own decision about the risks and benefits of screening.	To ensure that men are not unwittingly lulled into a cascade of potentially harmful medical interventions for little benefit.
The reason for high levels of de facto screening	Men are worried about their health and doctors order tests in the interests of their patients’ wellbeing.	Doctors test unnecessarily because they do not understand the evidence, are overly optimistic about treatment, because of their pecuniary interests, or for medico-legal reasons.
Views on AHTAC	Made the right call at the time but is now outdated—much has changed since then.	Made the right call at the time and is still relevant—little has changed since then.

Topic	Pro PCS Beliefs and Values	Anti PCS Beliefs and Values
The reason why the Commonwealth is opposed to PCS	The Commonwealth places costs above the health of men because they can.	The evidence does not support PCS. The Commonwealth's lack of action on de facto screening is because it is afraid of the political backlash from medical specialists and consumer groups.

### 5.2.3. Research and the struggle over PCS

There would have been little doubt in the minds of those establishing the AHTAC process about what its likely outcome would be. Before it began there had been the anti-PCS statements, presented as evidence-based, in the *Better Health Outcomes for Australians* report (Commonwealth Department of Human Services and Health 1994), the Royal Australian College of General Practitioners guidelines of 1994 (Ward, Young et al. 1998c), the recommendations of the 1994 Canadian Taskforce on Periodic Health Examinations (Woolf and Rothemich 1999), and the position of the Australian Cancer Society in March 1995 (Ward, Hughes et al. 1997).

In this light, AHTAC represented the largest piece of artillery available to government to win the battle over PCS.

What of the research that has occurred since the AHTAC report? The ACF notes that the research supports the position of the dominant advocacy coalition. It does precisely what the ACF predicts that research by an advocacy coalition should do. It 'problematizes the variables of interest' to the dominant advocacy coalition: it identifies high levels of de facto screening and it documents the inappropriate ways in which this is occurring. The research is often accompanied by recommendations that push the views of the dominant advocacy coalition. While these vary from hard-line anti-screening views through to 'informed consent' approaches, they all derive from the core principle that the current approach to de facto screening is problematic. On the other hand there is no research supporting the view that PCS is an effective intervention or recommending an increase in de facto screening.

### 5.2.4. Research and power in the PCS subsystem

The ACF argues that a threshold condition that influences the role of research is the distribution of power in the policy subsystem. Given that research appears to have been prominent in PCS policy, the ACF would predict that power is evenly distributed in the subsystem. Is this hypothesis supported?

Power in the PCS policy subsystem is reasonably evenly distributed but only because it comes in two different forms. The power over the wording of the MBS and over the decision to establish a national screening program is centralised in the hands of Health Ministers and the State and Commonwealth bureaucracies. However, the power to control what clinicians actually do is in the hands of clinicians and is supported by the constitutional provision that they are to be free from ‘civil conscription’.

Into this power struggle between the Commonwealth and clinicians comes policy brokers whose claim to credibility rests on their dispassionate approach to research-based policy—the NH&MRC, public health researchers and the cancer councils. Because AHTAC was a subcommittee of the NH&MRC, its core beliefs and values revolved around making recommendations on the basis of the available research. This means that research has to be seen to be central to the process. The timing of the AHTAC process meant that it could use the new Cochrane Collaboration, established by the NH&MRC in 1994, whose reason for being is ‘...the preparation and maintenance of systematic reviews...’ (Australasian Cochrane Centre 2002). Like the NH&MRC itself, the Cochrane Collaboration would be conceptualised as a ‘policy broker’ and ‘independent expert’ in the policy subsystem rather than a partisan participant in any advocacy coalition as such.

For the non-government players in this coalition, particularly the cancer councils, commitment to research-based policy is also part of their core values and beliefs. Research is one of the major resources they have available to influence the policy process. Their advocacy of research-based approaches enables them to play the role of the honest broker in the policy subsystem and provides government with a foil to the demands of the medical specialists. Without the cancer councils and the NH&MRC, Government appeals to research could be portrayed as mere rationalisations of politically or financially determined policy.

### **5.2.5. *The ACF and the research–policy nexus***

The ACF account of the research–policy nexus in relation to PCS is that the PCS policy subsystem is dominated by a coalition of government agencies, the NH&MRC, non-government cancer councils and public health researchers. However, because the Commonwealth lost control over the practice of PSA testing to clinicians, the pro-PCS advocacy coalition, consisting of urologists, prostate cancer support groups and some

men's advocacy groups, has the power to maintain the availability of the PSA test. The relatively wide distribution of power in the policy subsystem means that appeals to research and technical analysis can play a significant role in policy. This is further enhanced by the way that PCS is tractable to quantitative research, and by the central importance given to research-based public health policy by the key policy brokers found in the NH&MRC and the cancer organisations. The persuasive power of research is the principal tool available to the dominant advocacy coalition. Because of this, members of the dominant advocacy coalition have used research to prevent the introduction of PCS in Australia and to try to exert downward pressure on the level of de facto screening. Thus, the strong role played by research in relation to PCS is a function of the PCS policy subsystem, the distribution of power within it, and the central importance of the ethic of evidence-based policy to a number of influential policy actors in the dominant advocacy coalition.

### **5.3. PMOF analysis**

The central dynamic of the PMOF analysis of the research-policy nexus is the interaction between the research orientation and the policy orientation of the policy making organisation.

#### **5.3.1. *The policy orientation of the PMO***

##### ***Electoral risks and opportunities***

Politicians faced mixed signals from the electorate. Men were divided on the matter. Pinnock, who has researched men's views on sexual and reproductive health, said at interview that she thought that PCS would be electorally popular. Former Health Minister Carmen Lawrence reported in her interview that that there was pressure on backbenchers to introduce PCS. Despite this, partisan politics did not affect the debate in Australia.

Willis has argued that even though men are divided by class and ethnic division, they could be united around concern for their prostates (Willis 1997: 607). This has not been borne out despite higher socio-economic status men being more likely to have a PSA test (Threlfall, English et al. 1998).

***Tactical risks and opportunities***

There were no data from either the documentary record or the interviews to inform an assessment of tactical risks and opportunities affecting PCS policy making.

***Economic/financial risks and opportunities***

Economic and financial issues also gave mixed signals. AHTAC reported the current cost of testing was about \$9m per annum but noted a study by Wasson showing every \$US48 PSA test would result in a total of \$US294 health system costs. AHTAC said a screening program would increase radical prostatectomies tenfold in Australia and side effects such as impotence and incontinence would also generate costs (Australian Health Technology Advisory Committee 1996: 70). But AHTAC made no estimate of the costs of continued of de facto screening—tacit acceptance of de facto screening may be the most expensive option available.

***Contextual risks and opportunities***

The issue of controlling de facto PCS relates to the more general issue of control of clinician behaviour. The Commonwealth's tardy response to changing the wording of the schedule and to educating clinicians through 'academic detailing' suggests that it had little capacity or desire to change clinician behaviour.

***Ideological risks and opportunities***

There is no evidence to suggest that politicians or other key actors in the PMO perceived PCS as a vehicle to pursue ideological goals. If anything, PCS was a distraction to Carmen Lawrence's ideological interest in a more holistic view of men's health (Lawrence 1995).

***The policy orientation of the bureaucracy***

The Commonwealth bureaucracy appears not to have had strong preferences. Interviewees who were part of the AHTAC review process said that there was no pressure from the Department to adopt a particular policy position. Several pieces of data suggest that there was opposition to PCS from within State Governments. Studies by epidemiology units in South Australia (McCaul, Luke et al. 1995) and Western Australia (Threlfall, English et al. 1998) show that prostate cancer was under close

surveillance. Slevin reported at interview that joint action was taken by the WA Cancer Council and the WA Health Department to educate GPs and men about the lack of benefit of PSA testing. If anything, the bureaucratic orientation was non-committal to negatively disposed to PCS.

**TABLE 5:2 SUMMARY OF PMO POLICY ORIENTATION ON PCS**

<b>Dimensions of Risk and Opportunity</b>	<b>Political Arm of PMO</b>	<b>Bureaucratic Arm of PMO</b>
Electoral	Mixed signals from electorate.	
Tactical	Nil observed	
Economic and Financial	Organised PCS would be costly. However, de facto PCS also likely to be costly but not obviously so and costs would fall on States, some of whom were actively trying to stop it	
Contextual	Difficulty in controlling clinician behaviour generally made controlling de facto PCS problematic.	Promotion of technology assessment through AHTAC important to PMO
Ideological	Profile of PCS made it more difficult for Lawrence to sell holistic view of men's health.	Nil
Summary	Policy orientation to PCS not strongly inclined towards a false positive or false negative on PCS, but at the Commonwealth level the position that entailed fewest risks was probably continued tacit acceptance of de facto screening.	

### **5.3.2. The research orientation of the PMO**

#### ***PMO responsibility for prostate cancer and PCS***

Though the Commonwealth and State and Territory Governments carry a general responsibility for protecting and improving the health of the population, they have no specific obligation to reduce the morbidity and mortality associated with prostate cancer. It is clear, however, that breast cancer screening and cervical cancer screening created a precedent and a benchmark for government responsibility on cancer screening. This connection is used time and time again by advocates of PCS to gain leverage on government decision making (Gardner 2001a). Opponents of PCS continually point to the differences between mammography screening and PCS in order to break this expectation (Jones 2001).

The growth in de facto screening and the debate over PCS in Australia and overseas meant that the Commonwealth had an obligation to clarify the purpose of PSA testing. The perception of responsibility was increased by Carmen Lawrence's attempt to develop a men's health policy as PCS advocates argued that this was the test of taking men's health seriously. On release of the AHTAC report, the NSW, Victorian and

Western Australia health authorities were reported to ‘...acknowledge the importance of prostate cancer as a health problem but do not support screening programs.’

### ***PMO capacity in relation to the policy problem***

Commonwealth and State Governments had the capacity to implement a national prostate screening program if they were determined to do so, as evidenced by the Breast Cancer Screening program.

### ***The measurability of PMO performance***

The performance of the PMO in relation to prostate cancer mortality is measurable in the longer term, but not within the timeframe of one or two electoral cycles. At the time of the AHTAC report, it is unlikely that PMO data selection behaviour would have been influenced by a fear that data on prostate cancer mortality would show its current policy settings were wrong. The presence of confounding factors will always make direct attribution difficult. The AHTAC report rebutted the argument that PCS incidence was increasing and accepted the view that the increase in measured incidence was as a result of increased medical surveillance (Australian Health Technology Advisory Committee 1996: 15). The AHTAC report had the symbolic value of showing that government was taking action in relation to its responsibilities.

### ***The transparency of PMO performance and the ‘theatre of justification’***

The transparency of PMO performance in relation to cancer control policy is relatively high due to the fact that the collection and reporting of cancer incidence and mortality data is through registries that are independent of government. The registries are also controlled by the same organisations that analyse the data, and report and comment on it, suggesting that there is a well-primed theatre of justification in place on cancer policy matters.

### ***PMO vulnerability to the consequences of its errors***

The Commonwealth has positioned itself between support for and rejection of screening so that it will be able to move towards or away from screening and claim that, in either case, previous policy was consistent with this step. Pre-emptive introduction of



screening could have had high political costs if it had led to negative side effects. Two interviewees told me of two different instances of GPs who had had major complications resulting from infections following biopsies undertaken on the basis of positive PSA tests. In both cases the biopsies produced a negative result but their side effect was life threatening.

### ***The research responsiveness of the PMO***

On most indicators of research responsiveness the PMO could be expected to be more rather than less responsive to research.

**TABLE 5:3 SUMMARY OF PMO RESEARCH RESPONSIVENESS ON PCS**

<b>Indicator</b>	<b>Rating</b>
PMO responsibility	High
PMO capacity	High
PMO performance	Moderate
Theatre of justification	High
PMO vulnerability to error	Moderate
Summary	Moderately High

### ***5.3.3. The PMOF view of the research–policy nexus***

Figure 5.2 below represents the location of the PCS issue between the interaction of policy pressures and research responsiveness. It captures both a degree of research responsiveness that leads to ambiguous policy because of the unresolved status of the research on PCS, and the ambivalent policy orientation of the PMO that finds allowing continued de facto screening as the point of least political risk.

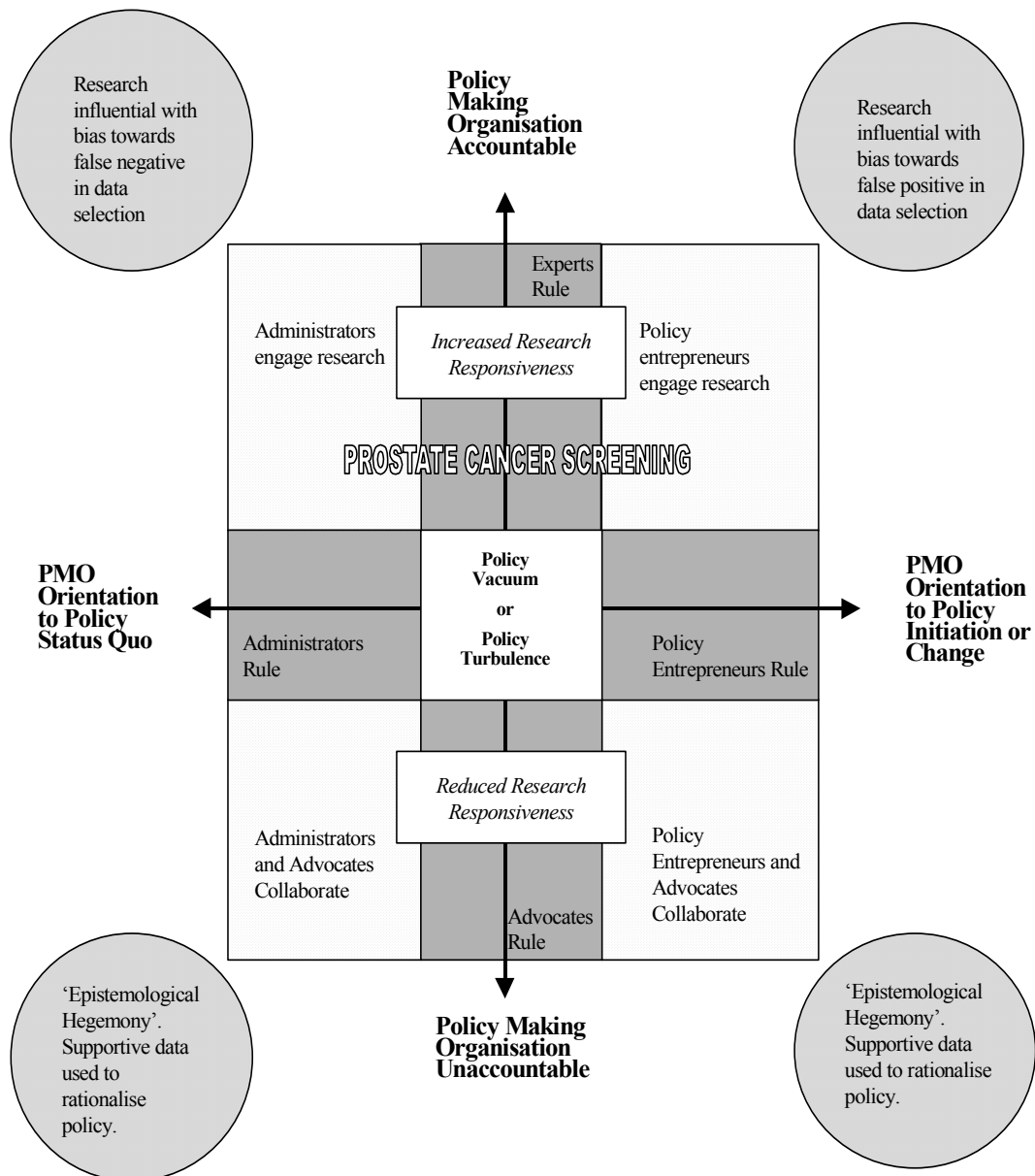
The moderately high degree of research responsiveness is supported by the extensive effort put into research-based policy processes like AHTAC and MSAC. The high degree of stability in policy on PCS mirrors the fact that the scientific jury on PCS is still out, pending the completion of the randomised controlled trials. The fact that there is no dissent among policy actors that the RCTs should be seen as the best guide to future policy adds to the face validity of the measure of research responsiveness.

The interaction between research responsiveness and political preferences is illustrated by reflecting on the circumstances in which the AHTAC process was initiated and what would have been known of its likely outcomes. It is possible that the Labor government would have been quite tempted to introduce PCS in response to demands from some men’s organisations and pressure on backbenchers. However, even before AHTAC

began its work, those in the PMO knew that most public health bodies around the world had already rejected PCS and that the definitive research projects were only just under way. They also knew of the possible harmful side effects of PCS as these had been rehearsed in the Australian medical literature. In this climate, how does a policy-making organisation defend itself from popular demands? One strategy is to ask the NH&MRC to review the scientific research and advise government, thus ‘minting’ (as David Dery would call it) the available negative or equivocal data on PCS so as to give credence to the government position.

**Figure 5.1**

**Location of Prostate Cancer Screening in the PMOF Model**



## **5.4. Governmentality analysis**

As discussed in Chapters 2 and 3, the central dynamic in the research–policy nexus from a governmentality perspective is the formation and operation of a collective psychic web of power/knowledge through regimes of knowledge, regimes of practices and discourses. Public health policy is that particular power/knowledge web connecting technologies of self with technologies of population and governing at a distance.

### **5.4.1. PCS policy discourse**

As with the BCS case study, the WHO principles for screening play a critical role in establishing the political rationality of screening. The moral form of the policy discourse is found in its identification of the proper power and duty of authority. The screening principles provide this. They are invoked in the AHTAC report without any justification or elaboration (Australian Health Technology Advisory Committee 1996: xiii).

While AHTAC could use the principles to recommend against population screening, it argued that it could not make decisions for individual men whose personal calculations of risks and benefits took precedence over government or expert committees (Australian Health Technology Advisory Committee 1996: 80).

As with BCS, the prior and largely implicit acceptance of the value positions that underpin the screening principles led to a set of empirical questions about test performance and the outcomes of treatment and enabled direct engagement with research.

The epistemological aspects of this application of the screening principles is found in the problematisation of prostate cancer as a thing requiring government. Various kinds of research from the biomedical to the epidemiological facilitate this process. At the same time, the behaviour of men who worry about their lower urinary tract symptoms and the behaviour of doctors in ordering tests is swept up in the problematisation process.

Curiously, the idiomatic part of PCS policy discourse is its ubiquitous references to mammography screening and the implication that to the extent that prostate cancer is like breast cancer then, it will require government in the template provided by BCS.

Research is made relevant in this process because it can be used to chart the differences and similarities (Collins and Barry 1996; Jones 2001).

#### **5.4.2. PCS and 'regimes of practices'**

As discussed in Chapter 2, Foucault's concept of practices is built on the interaction between the exercise of power and the will to freedom. The PCS case study shows this occurring between clinicians and their patients, and between governments and clinicians.

The PCS policy issue was created by the practice of de facto screening by GPs and urologists. The PSA test locked into a pre-existing practice template comprising: a standard set of assumptions about cancer (early detection is better); a standard response to patient troubles (ordering a diagnostic test); an accepted regime for governing health (state sanctioned and funded experts practising esoteric knowledge on the bodies of men). The international scope of the de facto PCS points to an international regime of practice.

Over and above the practice of medicine is the practice of managing the practice of medicine. 'Evidence-based medicine', using the techniques of systematic appraisal of research, is a new phase in this practice. It problematises medical practice by creating norms based on research.

In both these levels of analysis we can see that new kinds of technologies (PSA testing and evidence-appraisal techniques respectively) are entwined with new kinds of practices (de facto screening and evaluation of health practices respectively) which generate new kinds of problems (increases in prostate cancer incidence and an increase in the inappropriate use of diagnostic testing technology) that are bound up with particular types of knowledge (knowledge about the relationship between cancer and changes in blood chemistry, and methodologies for evaluating screening technologies respectively).

Both these regimes persist despite strong evidence of their ineffectiveness: de facto screening is of unknown effectiveness, and the evaluation of the effectiveness of screening technologies is ineffective in preventing the practice of de facto screening. This suggests that the practices are driven by factors other than the pursuit of the goals they espouse.

### **5.4.3. PCS and power/knowledge**

There is not a shadow of a doubt expressed anywhere in policy documents or in the discussions in the medical literature that the randomised trials of PCS in Europe and the US will generate the answers to questions about the efficacy of PCS that can be applied in Australia. This affirms the face validity of Foucault's notion that there exists a 'regime of truth' with strong links to the exercise of power and vice versa. The regime's authority is based on rigorous application of scientific method and PCS has to pass through a kind of 'obligatory passage point' (Callon 1986) of the randomised controlled trial before being permitted in Australia.

Running counter to this 'regime' is the practice of de facto screening. The key to understanding this alternative knowledge/power structure is found in the clash between the practice-based knowledge of clinicians and the centralised knowledge of bureaucrats and academics. Interviewees consistently pointed to this clash and explained it in terms of the respective focus of the two groups (clinicians focus on individuals while public health experts focus on the population).

The governmentality framework would argue that the discourse on 'snails' and 'evangelists' reconciles and rationalises these competing expert discourses, both of which owe strong allegiances to the authority of medical science. The difference between them is found in the different imperatives that the experts face and the justifiable use of knowledge in different ways. A view consistently put by those who are pro-PCS is that they care very much about proper scientific evaluation of screening tests, but they choose not to wait until the data from the trials is in because it will just confirm what they already know.

### **5.4.4. PCS and the governmentality hypothesis**

The governmentality hypothesis faces a challenge in relation to PCS because the status of PCS policy is ambiguous. While policy is formally opposed to PCS, in practice, de facto screening can and does take place under the MBS. Policy discourse espouses the contradictory position that PCS is unproven and therefore should not take place but asymptomatic men have the right to PSA testing so long as they are properly informed.

It is perhaps more useful to look at the governmentality that has developed in response to the problem of governing screening modalities like PCS. As noted above, the WHO

screening principles helped answer the second order policy question—how should we decide whether to introduce a screening program? But this is just the beginning. The United States National Institutes of Health said:

Frequently, the medical and lay community has assumed that earlier diagnosis of cancer of any type automatically confers benefit and that any diagnostic test that can identify early stages of disease must therefore be useful for screening. However, there is an emerging science of screening which affords a more rigorous approach to public health recommendations in the application of new technologies to screening and early detection. A number of public health groups and agencies are using an evidence-based approach in making recommendations. (Kramer, Gohagan et al. 1994)

The words ‘an emerging science of screening’, point to a new field of expert knowledge that generates a new power grid of power/knowledge. Interrelated with international screening evaluation networks are health technology assessment networks which have developed their own journal and institutionalised screening evaluation in some countries (Gray 2001). This can be further seen in the global research networks developed around PCS. Miller reports on the cooperation between various research teams on the development of Quality Adjusted Life-Year (QALY) measurement instruments (Miller, Madalinska et al. 2001).

When it comes to PCS and the technology of self there is an interesting continuity hidden within the conflict between the holistic view of the men’s health agenda and the promoters of PCS. All actors are engaged in increasing the extent to which men’s health is the subject of government. The holistic view is a not so much the antithesis of the ‘body part’ approach of the pro-screener as its complement.

#### **5.4.5. Governmentality and the research–policy nexus**

The arrival of PSA testing and other potential screening tools pushed the governmentality already developed for mammography screening through a new phase of problematisations. It yielded the new science of screening technology evaluation, based on the WHO screening principles, but extended through the practice of Evidence-Based Medicine. As with the WHO principles, this new science created a demand for new research and new kinds of research evaluation using the techniques promoted

through the Cochrane Collaboration. The AHTAC process was an early application of this approach in Australia.

As with BCS, the story of PCS needs to be seen in an international context. The research–policy nexus has a number of global characteristics: the technology and its producers, the research, the practice of de facto screening, the power of urologists, the status of the RCT as the creator of ‘truth’, and the willingness of the population to participate in screening for occult disease.

Also like the BCS case study, the governmentality view points to the complementarity between the holistic and the disease-treatment discourses in the task of problematising men’s health and making it the subject of government. The research on PCS and on other aspects of men’s health is central to this process of problematisation.

If we take the policy discourse on PCS as a whole there is a certainty that emerges regardless of the position adopted for or against PCS. That certainty is that at some stage during the 1990s prostate cancer went from a relatively hidden aspect of the bodies and lives of men to become part of the centre stage of problems requiring the full attention of government. As expected by the general thesis on governmentality, prostate cancer was just one more aspect of human health brought into the field of government by the gaze of medical practice, medical technology and research. If the need for government of prostate cancer is the first truth of policy discourse on PCS, the second is that RCTs should be the arbiter of the form that government should take.

## **5.5. Theoretical considerations**

### **5.5.1. Theory evaluation**

The ACF analysis works reasonably well as a coherent and parsimonious account but there are some difficulties. Coherence is reduced because the boundaries of the PCS policy subsystem are not obvious in relation to other possible constructions of the policy subsystem such as the ‘cancer policy subsystem’ or the ‘Medicare policy subsystem’. The ACF can adjust for this by arguing that the decision not to introduce PCS prevented the further evolution of a more clearly defined subsystem. What exist instead are latent advocacy coalitions that work together whenever the issue comes up for consideration such as when the results of the RCTs appear in the next few years. However, the

problem of subsystem boundaries is also evident when we consider the impact of the beliefs and values of evidence-based medicine. These seem to be particularly important in mobilising the resources of the NH&MRC and its Cochrane Collaboration and in bringing together support from the cancer societies and the relevant professional associations in Australia. These beliefs and values are not specific to PCS issues and point to more fundamental structures at work in the policy process.

The PMOF view captures well the ambiguous state of policy as a reflection of the ambiguous state of research on PCS and the ambiguous politics of PCS. Its account of the dynamics of data selection is parsimonious and focussed on a number of quite well specified factors. The problems with the PMOF are to do with its scope. It does not provide any explanation as to why research is undertaken by any of the policy actors. It constructs the policy making organisation as a passive and reactive entity that is in the business of selecting data rather than creating it.

The Governmentality Framework is again the least satisfactory of the frameworks because of the vague nature of the key concept and their interrelationships. While it highlights some of the most interesting developments in policy (e.g. the increasing sophistication of attempts to govern medical technology on an international scale through health technology assessment processes (Banta and Oortwiin 2001; Gray 2001)), the theoretical cost is a sense of incoherence in relation to the more mundane aspects of policy. For example, both the PMOF and the ACF are able to account for the skirmishes between the Commonwealth and clinicians over the use of the PSA test. The GF analysis of this aspect of policy making and its relationship to research could take any number of directions. The GF counter to this is that Foucault never tried to create a coherent theory of social action and that the objective of governmentality analysis is to chart the way that policy makers and clinicians both attempt to mobilise power/knowledge. Thus governmentality analysis is about unmasking the tactics of power holders rather than attempting to explain or predict the outcomes. However, Bohman would argue that the value of critique is related to the quality of explanation, not separate from it (Bohman 1991: 186-231), a view with which I have sympathy.



### **5.5.2. Theory development**

#### ***Agency–structure in the research–policy nexus***

With the third research question in mind and the objective of theory development, this section looks at one particular aspect of the research–policy nexus that is of some importance to all theories but for different reasons.

‘The medical literature’ is a relatively vague but pervasive concept in the case study material. What follows is an attempt to look at the role of ‘the medical literature’ as a structure with both material and ideal elements capable of strategic mobilisation by various social actors.

The *Medical Journal of Australia* has given considerable attention to the issue of PCS over the years and has been used by the various protagonists in the debate. Taylor used it to communicate the views of the Urological Association of Australasia (Taylor 1993) which was greeted with further analysis and comment from legal, epidemiological and clinical perspectives as outlined in the case study material. Kaye and Ward and Hirst respectively used the journal to fire arguments for and against PCS (Kaye 1995; Hirst, Ward et al. 1996). The debate here and overseas was cited by AHTAC as an indicator of the need to assess the research literature and make policy recommendations.

But the *MJA* is not just a passive purveyor of a debate occurring within the medical profession. In 1998 it printed seven articles on PCS which included policy-related opinion as well as reports of original research (Frydenberg 1998; Heathcote, Mactaggart et al. 1998; McCredie and Cox 1998; Smith and Armstrong 1998; Threlfall, English et al. 1998; Pinnock, Weller et al. 1998b; Ward, Gupta et al. 1998b). At one level, this might be thought of as common sense. The editors decide to run them as a group because each article creates greater salience for the others and the reader is able to get an update on the matter in one issue of the journal. However, if one considers what else was published in the *MJA* on 6 July 1998, the influence of the journal on the research–policy nexus becomes more important.

Also published on 6 July 1998 was an article on an AHTAC report on colorectal cancer screening that appeared soon after the one on PCS (Collett and Olynyk 1998). This article said the Commonwealth should get on with the job of solving the problems that lie in the way of implementing CRC screening in Australia. It said:

The way forward is clear. Research groups in Victoria, New South Wales, South Australia and Western Australia have proven expertise in the field of CRC screening. There should be a coordinated effort by these research groups and other groups throughout Australia to address issues and provide answers to the questions raised in the AHTAC report. (Collett and Olynyk 1998)

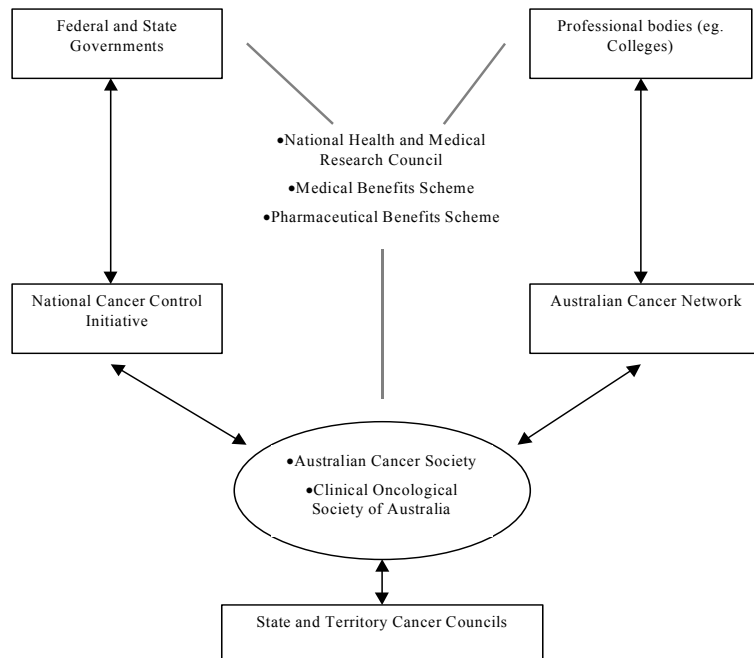
Taken together with the PCS-related articles and the opinion pieces on what the government should do all starts to add up to an attempt by the *MJA* to promote itself as a vehicle for substantive policy debate in public health in Australia. But the *MJA* did not stop there. As well as the PCS and CRC screening articles, it published an Editorial by Alan Coates as the Chief Executive Officer, Australian Cancer Society. The article included a figure that is reproduced below as figure 5.2.

The boxes on the left of the diagram are government agencies (the NCCI being a quasi-non-government organisation funded by the Commonwealth but run by the ACS). The boxes on the right are looser affiliations of non-government organisations. At the bottom are the ACS and the State/Territory cancer societies and the Clinical Oncology society linking the government and the non-government. In the centre are the instruments of government-funded research and health service financing. Coates' editorial argues for an integrated research→policy development→action cycle that also integrates non-government cancer organisations with government agencies into a 'partnership'. Coates says:

Research is a crucial requirement for improved cancer control. The Australian Cancer Society is collaborating with the National Health and Medical Research Council on strategic directions in cancer research funding, and is developing joint proposals to streamline and improve the peer review of cancer research funding by State cancer councils and other cancer-related funding bodies. A constructive partnership between all stakeholders will maximise the effectiveness of efforts to reduce the impact of cancer on all Australians. (Coates 1998)

This could be just wishful thinking on the part of Coates and the ACS if it were not for the close affinity between the ACS position on PCS and BCS and government policy. It would also be of less significance if it was not for the case, as noted in the case study materials, of the strong involvement of these networks of ACS affiliated or managed organisations in the work of the National Health Priorities Action Council Cancer Strategies Working Group. It would be less convincing if it were not to some extent a

**Figure 5.2**  
**Relationships between the Australian Cancer Society and related bodies (from Coates 1998)**



realisation of Chapman's vision from a decade earlier (Chapman 1988) where he proposed a national cancer control policy making process and infrastructure with the ACS as '...the "honest broker" of intersectoral interests in cancer control...' (p 72).

The purpose of this analysis is not to argue that there is anything wrong or suspect about the role of the Cancer Council Australia. Nor is it to argue that it is the only or even the most important driver of policy on PCS or BCS in Australia. Rather, it is to lay the ground-work for further consideration of various structural phenomena at work in the research-policy nexus. It appears from exploration of this one issue of the *MJA* that there is more going on than a simple reporting of research on PCS or a simple giving voice to medical views on policy.

The *MJA* might be thought of as a ‘structure of deliberation’—a resource which enables agency on the part of particular individuals and organisations so that they can publish research and promote views. It might be compared and contrasted with AHTAC as another structure of deliberation. AHTAC was formally constituted by government to impartially deliberate on the best interpretation of all research and give advice. A common characteristic of both these structures of deliberation is that they gave power to particular voices and, in particular, attempted to empower the voice of scientific expertise. They also controlled that power by working within particular rules (stated and unstated) for allowing those voices to be heard.

With regard to the *MJA*, rules of scientific quality and peer review underpin publication policy while a less obvious set of rules govern who can make statements like the one Coates made and what they can say. The AHTAC process was more explicitly rule-bound in that it was constituted to review research and offer advice. But it was a structure open to influence by individuals and organisations who could shape how those terms of reference were interpreted and applied. The use of the Cochrane Collaboration to review research and the use of the WHO screening principles to evaluate PCS were unstated in the terms of reference but central to the outcome.

In light of the above, the answer to the first research question might be to say that an adequate understanding of the research—policy nexus is one that takes account of the interaction between the agency of individuals and groups and the structures of deliberation, formal and informal, that empower and constrain them.

### ***The focal theories and the agency–structure relationship***

In ACF terms, ‘the medical literature’ is a significant material and ideal structure because it is one of the most readily mobilised resources for advocacy coalitions. This point is brought home by the way that some advocacy coalitions produce their own journals to publish research and discuss and debate matters of interest—the Cancer Council Australia’s journal *Cancer Forum* is an example. There was an issue of *Cancer Forum* devoted to prostate cancer in 1995 which included the policy position of the then Cancer Council of Australia on PCS. There is a further significance for the ACF in that the journal provides what might be thought of as a ‘professional forum’ for debate between competing advocacy coalitions. In ACF theory, the likelihood of ‘policy oriented learning’ across advocacy coalitions is increased with the availability of such

fora along with the political necessity to participate in debate to win policy arguments. The ACF provides a coherent understanding of how ‘the medical literature’ works as both an ideal and material structure that enables and constrains the agency of advocacy coalitions. The more that ‘experts’ like Kaye and Ward and Hirst and Stricker and Frydenberg and Coates use the *MJA* as a vehicle for voicing their views and publishing their research, the more being published in the *MJA* comes to take on a certain status. Thus the influence of journals like the *MJA* is fostered by all advocacy coalitions because this influence becomes a resource in policy debates. This interaction accounts very nicely for the mutually reinforcing but constraining influence of agency and structure.

With regard to the PMOF, ‘the medical literature’ plays a key role in the degree of research responsiveness of the PMO. This is because of the role it can play in the ‘social context of justification’ which was Dery’s way of describing the way that decision makers select and reject data with one eye on who they will have to satisfy as to the correctness of their choice (Dery 1990: 15-18). If decision makers know that research or opinion challenging their decisions will appear in prestigious medical journals and are likely to be taken seriously by an empowered stakeholder group then they know they will have to use political resources to respond to criticism. Related to this is the way policy actors attempt to ‘mint’ data which is supportive of their preferences and ‘mute’ data that is hostile (Dery 1990: 111-2). Medical journals provide a primary site for both minting supportive data and ‘barring’ hostile data. The whole edifice of trustworthiness in science is built on the concept of peer reviewed publications. Journal prestige is closely linked to the rigour of this ‘social context of justification’, and the more prestigious the journal the more researchers try to get their research published in it and the more notice is given to its publications. Thus the PMOF also provides a coherent account as to why the structure of ‘the medical literature’ both enables and constrains the agency of policy actors.

The Governmentality Framework constructs ‘the medical literature’ as integral to the ‘regime of truth’ and a primary site for experts to use in constructing policy discourse. Foucault would note that there are multiple levels of discourse at work here. At the surface level is the subject matter of particular research articles about PCS. At deeper levels is the discourse around medical journals as a source of authenticated knowledge. The more prestigious the journal, the greater the ‘truth’ value of the data presented and

the greater the coalescence of power/knowledge. For researchers, being published in prestigious journals is the route to a successful career and increases the researcher's ability to exert influence in the creation of knowledge/power in particular fields. If governmentality is unthinkable without the explosion of the human sciences, then the explosion of the human sciences is inconceivable without the structure of 'the medical literature'.

## 5.6. Final comments

PCS provides another case study where engagement between research and policy is multifaceted and critical to understanding the dynamics of policy and policy outcomes. Of particular interest in this case study is the way that the *prima facie* reason for selecting the case of PCS (ie a public health intervention which the Commonwealth decided not to introduce) is challenged by the ambiguities in policy and practice. While some public health experts would claim that PCS policy is a triumph of evidence over politics, the fact that there is extensive practice of *de facto* PCS now effectively sanctioned by the wording of the MBS makes it difficult to classify policy with any precision. It could be argued that PCS has a degree of convenient ambiguity—government does not support PCS but it can take place legally and with financial support.

Interestingly, each of the theoretical frameworks have no real difficulty accommodating policy artifice as either unresolved conflict between competing advocacy coalitions with quite different power bases (the ACF view), or the expected outcome of the interaction between research ambiguity and political uncertainty (the PMOF view), or as a temporary pause in one particular form of public health governmentality.

'The medical literature' emerged as a structure with both ideal and material elements that is capable of mobilisation by the agency of policy actors. Each of the theoretical frameworks provides a different but reasonably coherent account of 'structuration' as it occurs in this context. This makes it worth considering further in a theory of the research–policy nexus.

## 6. Needle and Syringe Program Policy

### 6.1. NSP policy, research and the research–policy nexus

This is a case study of the research–policy nexus in Needle and Syringe Program policy in Australia.<sup>15</sup> This first section presents the main events and features of NSP policy development and research in Australia, and the connections between the two. A chronology of events is set out in the appendices for this chapter.

#### 6.1.1. *From illegal practice to public policy*

On the afternoon of 12 November 1986, Alex Wodak, Kate Dolan and several other workers at the St Vincent’s Hospital Drug and Alcohol Service in Darlinghurst, Sydney, bought as many clean needles and syringes as they could with the cash they had on them. They put up a sign outside their workplace offering to exchange used needles for clean ones. They wanted injecting drug users in the local area to protect themselves from the spread of HIV by only using sterile injecting equipment. That afternoon no one came, but the following day the doorbell started ringing and the first Needle and Syringe Program (NSP) in Australia was in operation. Even though Wodak and Dolan were breaking the law, the police did not try to stop them. Nor did the hospital administration (Wodak and Dolan interviews).

This informal service soon became a ‘pilot project’ and other pilot projects were set up in other States and Territories (Schwartzkoff 1989; Paine and Lewis 1988; Dudman 1989). Diffusion across all mainland Australian States and Territories occurred between June 1987 (Western Australia, first) and January 1989 (South Australia, last). By the

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<sup>15</sup> NSP involves the provision of clean needles, syringes and other injecting paraphernalia such as swabs, vials of sterile water and ‘sharps bins’. These are distributed through a variety of outlets ranging from stand-alone facilities to hospital emergency departments to private pharmacies selling subsidised ‘fit packs’. NSPs may provide services such as education, information on safe sex, condoms, referral to drug treatment, medical, legal or social services. After hours, needles may be purchased from vending machines in some localities and there are ‘AIDS Buses’ that move around urban areas at night. Outreach services can take the form of ‘Foot Patrols’ involving workers with backpacks visiting injecting ‘hot spots’ in inner city areas Dolan, K., L. Topp, et al. (2000). NSP Needle and Syringe Programs: A Review of the Evidence. Sydney, Australian National Council on AIDS, hepatitis C and Related Diseases.

time the national HIV/AIDS policy Green Paper (*AIDS: A Time to Care, a Time to Act*), which recommended adoption of NSP, was tabled in Australian Parliaments in November 1988, NSP was already in place in most jurisdictions. Tasmania did not introduce a formal program until July 1993 (Byers 1995), though it is reported that NSPs were allowed to operate with tacit approval for several years before the legislation was passed (Wodak 1995a: 49).

By 2000, there were over 3,000 NSP outlets in Australia distributing approximately 20 million needles to between 100,000 and 175,000 injecting drug users at a cost of over \$13 million in Commonwealth and State/Territory Government funds (Lowe and Cotton 1999; Dolan, Topp et al. 2000). The institutional success of NSP has been matched by the continuing realisation of its public health goal—a continuing low rate of HIV among IDUs in Australia of less than 2 per cent (National Centre in HIV Epidemiology and Clinical Research 2001).

While the major pattern is one of policy continuity and expansion, incremental changes in policy and practice have occurred. For example, the word ‘exchange’ has been dropped reflecting a change in emphasis to appropriate disposal rather than exchange per se. The words ‘drug abuser’ and ‘drug addict’ have been replaced by the less moralistic term ‘injecting drug user’. And there have been constant shifts in the type of ‘paraphernalia’ distributed in response to cost pressures, problems with the unintended use of needles to inject methadone or steroids, and the higher infectivity of HCV compared with HIV.

### **6.1.2. The political context of NSP initiation in Sydney**

Three days after Wodak and Dolan began the first NSP in Australia, *The Sydney Morning Herald* published a letter by Wodak, Dr Gold and Dr Cooper. It was given ‘lead letter’ status with a headline saying ‘Wanted urgently: the Dutch AIDS Plan’. The authors argued that Australia needed to adopt NSP as the Dutch had done already. Gold was Director of the Albion Street Centre, and Cooper the Director of the NHMRC Special Unit in AIDS Epidemiology and Clinical Research at the University of New South Wales. The letter said that the Federal Health Minister Blewett was already an advocate of NSP (Wodak, Gold et al. 1986). Blewett’s position was supported by Senator Don Grimes in a statement in the Senate on 17 November 1986 in which he



argued that NSP was defensible and necessary given the threat of an HIV epidemic among Injecting Drug Users (IDUs) and its dire consequences (Grimes 1986).

Preceding Wodak and Dolan's actions, the National AIDS Task Force (NATF) supported NSP in principle in 1985 (I have only one secondary source on this). Chris Puplick (a key informant, former Liberal Party Senator, and Chair of the Australian National Council on HIV/AIDS and Related Diseases) reported at interview that the HIV/AIDS Parliamentary Liaison Group of the Commonwealth Parliament had also favourably discussed the possibility of NSP in 1985. And just two weeks before the St Vincent's NSP began, the Second National Conference on AIDS in Sydney supported a recommendation that Australian governments implement NSP as part of a package of HIV/AIDS prevention measures (Grimes 1986).

Wodak reports that soon after he had commenced the NSP, he phoned the chair of the National AIDS Task Force, Professor David Penington, to make sure Penington was supportive. And he was. Penington wrote an Editorial for the *Medical Journal of Australia* in early 1987 supporting NSP (Penington 1987). Wodak also called the Chair of the National Advisory committee on AIDS (NACAIDS), Ita Buttrose, who issued a press release titled 'Sterile Needles and Syringes a Must if Australia to Escape AIDS Epidemic'. (Dudman 1989: 2). An Editorial in Sydney's *The Sun-Herald* on 16 November 1986 urging the adoption of NSP said it was time government stopped 'pussyfooting' around on AIDS. 'If the NSW Government is worried about damaging electoral sensibilities... it is dodging responsibility to the people it was elected to represent' (Editorial 1986).

Wodak also recalled in his interview how the NSW Health Department had discussed the illegal NSP with him soon after it started. One official asked disapprovingly if he knew he was breaking the law, but another senior official told him that he would be 'looked after'. By April 1987, the Australian Health Ministers' Conference and the Ministerial Council on Drug Strategy (with health and law enforcement ministers from all jurisdictions) were advocating increased availability of clean needles, including via NSPs (Dudman 1989). However, the ongoing ambivalence of State governments is illustrated by the way the NSW government introduced further NSP pilot projects in 1987 but also changed the *Drug Misuse and Trafficking Act* making it an offence to possess injecting equipment (Editorial 1987).

### **6.1.3. Commonwealth engagement on HIV/AIDS**

The Commonwealth first became directly involved in HIV/AIDS policy through its responsibilities for the funding and viability of Australia's blood supply.<sup>16</sup> It shared responsibility with the States and Territories for funding the Blood Transfusion Services (BTS) run by the Red Cross, and it funded the Commonwealth Serum Laboratories as a statutory body. It also had responsibility for the quality control of the services of these agencies through the Commonwealth's Therapeutic Goods Administration.

When AIDS first appeared the NH&MRC set up a working party in June 1983, with David Penington as its Chair. Ballard and Altman argue that Neal Blewett, the Commonwealth Health Minister, was initially reluctant to get involved (Ballard 1989: 356; Altman 1992). However, in November 1984, two weeks before a Federal election, three babies died of AIDS after receiving contaminated blood from a homosexual donor in Queensland. The next day Neal Blewett announced a program of urgent initiatives, including funds for test kits (Ballard 1997: 5). He called an emergency meeting of health ministers at which Penington's NH&MRC working party became a subcommittee of the Australian Health Ministers' Advisory Council. Blewett also established the National Advisory Committee on AIDS (NACAIDS) with Ita Buttrose as chair.

It was the Commonwealth's direct responsibilities for blood policy that forced its earliest engagement with HIV/AIDS, and it was the proximity of the infection of the Queensland babies to an election that determined the size and urgency of that response. Ballard argues that the State and Territory health ministers were delighted to leave the problem to Blewett because they saw AIDS as 'political poison' (Ballard 1989: 358).

Neal Blewett is reported to have said 'What's good for votes is bad for public health' (Altman 1992: 57). There were early attempts at the Federal level to capture those votes. Ian Sinclair, the leader of the National Party in the 1984 Federal election campaign, is reported to have declared at the opening of the campaign "If it wasn't for the promotion of homosexuality as a norm by Labor, I am quite confident that the deaths of

these three poor babies would not have occurred” (*The Australian* 17 November 1984)’ (Ballard 1989: 358). However, the political volatility of HIV/AIDS policy led to an early agreement for a bipartisan approach when Bob Hawke, the then Prime Minister, and Andrew Peacock, the Opposition Leader agreed to ‘keep politics out of the AIDS problem’ (Grant 1986).

#### **6.1.4. The importance of the population threat**

All key informants said that one of the major factors driving the development and implementation of NSP was the size and immediacy of the threat posed by HIV/AIDS.

The possibility that the AIDS virus could spread via injecting drug use emerged soon after the beginning of the AIDS epidemic in the early 1980s (Wormser, Krupp et al. 1983). Between 1984 and 1986 a stream of reports appeared in the most prestigious international medical journals confirming the link and documenting rapid epidemics among IDU populations in Europe, Britain, and the United States (Landesman, Ginzburg et al. 1985) (Hardy, Allen et al. 1985) (Robertson, Bucknall et al. 1986). In Australia, Penington found two HIV positive cases in a survey of 100 IDUs in drug treatment in 1985 (Paine, Tonuma et al. 1985). Paine reported high levels of needle sharing behaviour in a similar population (Paine, Tonuma et al. 1985). In 1986, Blacker reported the spread of HIV from an IDU to his needle sharing and heterosexual sexual partners (Blacker, Tindall et al. 1986).

The argument that NSP protects the whole population is ubiquitous in HIV/AIDS policy documents. The 1988 Policy Discussion Paper, *AIDS: A Time to Care, A Time to Act*, argued ‘New infections among needle sharing drug users, both men and women, may increase rapidly, and infected drug users could pass on the infection to their sexual partners and perinatally to their children’ (Commonwealth Department of Community Services and Health 1988: 49). It referred to the experience of several cities in Europe and the United States to demonstrate that such rapid and large epidemics were possible (Commonwealth Department of Community Services and Health 1988: 132). A dramatic form of this argument appeared in *The Report of the Working Panel on*

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<sup>16</sup> This analysis of the Commonwealth responsibilities for blood is derived from Ballard Ballard, J. A. (1999). HIV-Contaminated Blood and Australian Policy: The Limits of Success. Blood Feuds: AIDS,

*Intravenous Drug Use and HIV/AIDS* (Working Panel on Intravenous Drug Use and HIV/AIDS 1989: 1). It also appears in each of the four national HIV/AIDS strategies (Commonwealth Department of Community Services and Health 1989: 16-17; Commonwealth Department of Health Housing Local Government and Community Services 1993: 21; Commonwealth Department of Health and Family Services 1996: 43; Commonwealth Department of Health and Aged Care 2000: 17). Most recently, the Australian National Council on AIDS, Hepatitis C and Related Diseases review of NSP said:

Needle and syringe programs protect the community from infections such as HIV and hepatitis C. In Australia, Needle and Syringe Programs have prevented thousands of cases of infections among people who inject drugs and, in turn, have protected the rest of the community. (Dillon and Dolan 2000: 4)

There is empirical evidence for the connection between this argument and public support for NSP. Lenton and Phillips showed that survey respondents become more supportive of NSP and harm reduction through appeals to self interest (self and family) (Lenton and Phillips 1997).

The communication of threat was important for galvanising action across government agencies and for getting street level support from police and health workers. Vumbaca recalled at interview how in his role as the NSP program manager in NSW in the late 1980s he went to regional health and police authorities in NSW to advise them on the establishment of programs in their area. He said the information that was most persuasive were the slides comparing rates of HIV among IDU in Edinburgh where NSP was not introduced and needle supply was restricted, and Glasgow, where needle distribution and harm minimisation approaches were followed.

#### **6.1.5. 'Wars', 'plagues' and the media**

The media embellished and sensationalised the threat posed by HIV/AIDS. On the two consecutive Sundays in late 1986 *The Sun-Herald* newspaper ran feature articles headed 'AIDS: National Plague' (Walker 1986), and 'AIDS: The world at war' (Palfreyman 1986). They put the number of people with HIV in 1986 at between 40,000 and

100,000<sup>17</sup> (Walker 1986). It was a time in which extreme solutions could be contemplated.

In her essay *AIDS and its metaphors*, Susan Sontag (Sontag 1988) argues that the use of the war metaphor is a rationale for the total mobilisation of society. ‘In all-out war, expenditure is all-out, imprudent—war being defined as an emergency in which no sacrifice is excessive’ (Sontag 1988: 11). References to ‘weapons’, ‘fighting’ and ‘combat’ in relation to HIV/AIDS abound in policy documents (Commonwealth Department of Health and Aged Care 2000: iv).

‘War’ is also heavily used in illicit drugs policy discourse, particularly in the United States with its ‘war on drugs’. The problem for NSP is that harm minimisation is seen to be ‘soft on drugs’. Public health officials in the United States have attempted to salvage the war discourse by simultaneously employing it in support of both drugs policy and HIV prevention policy. The US Secretary for Health and Human Services, Donna Shalala, is quoted as saying:

‘...this nation is fighting two deadly epidemics—AIDS and drug abuse. They are robbing us of far too many of our citizens and weakening our future. A meticulous scientific review has now proven that needle exchange programs can reduce the transmission of HIV and save lives without losing ground in the battle against illegal drugs. It offers communities that decide to pursue needle exchange programs yet another weapon in their fight against AIDS.’ In (Dolan, Topp et al. 2000: 22).

This quote is found in the Australian National Council on AIDS, Hepatitis and Related Diseases’ (ANCAHRD) review of the evidence on NSP suggesting that appropriating war metaphors is still important in Australia (Dolan, Topp et al. 2000: 22).

### **6.1.6. The role of IDU in Needle and Syringe Programs**

The idea of distributing clean needles to prevent blood borne virus transmission came from injecting drug users themselves in Amsterdam in 1983 (Coutinho 1995). Drug and

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<sup>17</sup> The current estimate of the total number of HIV infections that have ever occurred in Australia at 18,147 National Centre in HIV Epidemiology and Clinical Research (2001). [HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2001](#). Sydney, National Centre in HIV Epidemiology and Clinical Research University of NSW.

alcohol workers supported the idea (Buning, Coutinho et al. 1986). In 1984 in Bremen, Germany an IDU self-help group commenced needle distribution to prevent HIV/AIDS (Stover). Similarly, the first distribution of clean needles in Canada is reported to have been in Montreal in 1988 by an HIV positive former IDU known as ‘Windy Earthworm’ (Hankins 1998).

In Australia, two key informants said that IDUs commenced informal NSPs in their respective States with the tacit support of the local AIDS Council and government public health officials.

Wodak reported that IDUs were involved in a collective of IDU, drug and alcohol workers, and researchers in Darlinghurst to develop responses to HIV/AIDS. This collective later became the New South Wales Users AIDS Association or NUAA. Organisations representing IDU have been funded in all States and Territories at various times with the objective of providing peer education and support to injecting drug users.

#### **6.1.7. Bureaucratic activism**

A number of interviewees provided data to support the view that an important factor in NSP development and dissemination was the action of a relatively small group of highly motivated and networked public health officials. Wodak recalled at interview how he worked closely with an informal network of NSP program implementers who were committed to getting the program off the ground in the other States and Territories. Wallace also said that State Government officials were supportive of NSP and of the IDU users group. Another key informant who worked in a State health department said the small group responsible for implementing NSP were close knit and strongly committed to getting the program up and running. They worked closely with the Health Minister and gave him the information he wanted to hear about the threats posed by HIV and the necessity for NSP. The informant said they always used the direst estimates of the potential epidemic and trimmed down estimate of the cost of NSP so it would be a small target at budget time. As long as the Minister had this information, he was happy to let them get on with their work.

The extent of support from the public health bureaucracy is underscored by reports of the preparedness of the health and police bureaucracies to turn a blind eye to NSPs that were operating illegally in several States and Territories, including the ACT, NSW and

Tasmania, before the requisite legislation was in place. The fact that most legal barriers to NSP appear to have been overcome relatively quickly also shows strong bureaucratic support. Attention to the legal barriers to HIV prevention continued through the work of the Intergovernmental Committee on AIDS Legal Working Party (Legal Working Party of the Intergovernmental Committee on AIDS 1992). However, later reports and evaluations note that many of its recommendations were not implemented due to a lack of political will (Australian National Council on AIDS and Related Diseases (ANCARD) 1999: 78)

The Victorian and NSW Health Departments were involved in research relating to NSP. The Victorian health department produced: the first published survey of needle sharing among IDU in Australia which sounded a warning about the likelihood of an HIV epidemic among IDU given the high rates of needle sharing (Paine, Tonuma et al. 1985); a follow up study also showing high rates of needle sharing and concluding with a recommendation for increasing clean needle availability (Edgoose and Baillie 1987); a study of pharmacist's preparedness to assist with needle distribution and education efforts (Mullins 1990); and an action research project aimed at building local community support for NSP (Robinson 1994). The NSW Health Department produced: an evaluation of the pilot NSP projects (Schwartzkoff 1989), a study of community attitudes to NSP (Schwartzkoff, Spooner et al. 1990), and a qualitative study of 'functional' injecting drug users (Sharp, Davis et al. 1991).

When asked why NSP had been adopted so quickly in Australia and expanded ever since, two key informants argued that it was 'faceless bureaucrats' working on public health in State and Territory governments that drove the agenda.

#### **6.1.8. NSP, harm minimisation, drugs policy and methadone**

State Premiers and the Prime Minister agreed to make harm minimisation the central plank of the National Campaign Against Drug Abuse (NCADA) at a Special Premiers' Conference in April 1985. Various advocates have argued that this prior acceptance of harm minimisation enabled the adoption of NSP in Australia (Working Panel on Intravenous Drug Use and HIV/AIDS 1989: 1; Wodak 1990: 135; Single and Rohl 1997: 43). The same argument has been made about the adoption of NSP in Amsterdam in 1984 (Buning, Coutinho et al. 1986; Buning 1991).

References to harm minimisation are ubiquitous in National HIV/AIDS Strategies, the various National Drugs Strategies, and their respective evaluations. For example, the *Fourth Strategy* says ‘Where behaviour is identified as harmful, harm-minimisation interventions have been used in an attempt to reduce the health consequences—such as disease transmission and the resultant personal and social impacts—associated with that behaviour’ (Commonwealth Department of Health and Aged Care 2000: 9). Key informants reported that particular efforts were needed in recent years to attain an alignment between harm minimisation discourse in the National HIV/AIDS policy documents and the National Drug Strategy Documents.

Harm minimisation provides a common philosophical base for a range of interventions, particularly explicit sex education and methadone maintenance. Methadone treatment expanded in parallel to the diffusion of NSP. It commenced in Australia in 1969 and by the early 1980s there were approximately 3,000 clients nationwide (Methadone Working Party 1993: 3). It was endorsed as a treatment for heroin dependence and the prevention of HIV/AIDS among IDUs in the National Campaign Against Drug Abuse in August 1985 (ibid: 4). Methadone treatment increased exponentially from 5,000 clients in 1987 to 18,000 clients in 1995 (Australian Bureau of Criminal Intelligence 1996: 64), and 24,700 clients in 1998 (Lowe and Cotton 1999: 118).

Under the banner of harm minimisation, NSP has always been presented in national HIV/AIDS policy documents as one among an integrated package of interventions for injecting drug users. In the *First Strategy* these were very concrete measures: programs to encourage cleaning injecting equipment with bleach where sterile equipment is not available; improving access to general health services; and drug substitution programs (methadone) (Commonwealth Department of Community Services and Health 1989: 43). The *Second Strategy* added ‘...community-based education programs aimed at establishing peer norms and peer group support for sustained behaviour change’ (Commonwealth Department of Health, Housing, Local Government and Community Services 1993: 21). Later HIV/AIDS strategies continued the trend towards more sophisticated descriptions of NSP within a health promotion framework (Commonwealth Department of Health and Aged Care 2000: 17-19).

In the wake of the discovery of HIV transmission occurring among NSP attenders in North America, policy documents now argue ‘...that although Needle and Syringe Programs are crucial, they are only one component of a comprehensive blood borne



viral infection prevention program which should include counselling, support, education and drug treatment such as methadone maintenance programs' (Dolan, Topp et al. 2000: 19).

### **6.1.9. *Attacking NSP***

Key informants identified widespread and continuous opposition to NSP but thought that it was not centrally organised and coordinated. They identified periodic 'Not In My Back Yard' ('NIMBY') opposition coming from local residents, businesses, and local government politicians who are concerned with the siting of particular facilities. Wood has documented this kind of opposition and the constant threat perceived by NSP workers (Wood 1997). Several key informants reported that some NSP outlets have been forced to close down because of local level opposition. An important part of the perceived political risk of supporting NSP is the perception of being seen to be providing tacit support to illegal drug use.

Key informants also identified local media stories of needle stick injuries and improperly discarded equipment as a primary source of threat to NSP. From the late 1980s onwards, the policy response to this problem has often involved attempts to promote the development of retractable needles to prevent needle-stick injuries.

Key informants said that there were a small number of 'bastard politicians' who oppose NSP at the local level because they perceive political opportunities in 'junkie bashing'. Hando and others argue that bipartisan support for NSP appears to be dwindling (Hando, Hall et al. 1999: 52). Politicians generally want to distance themselves from NSP. Burrows reports how two New South Wales Health Ministers, one Liberal and one Labor, '...advised NSEP workers and the State's drug user group (NUAA) that they were not prepared to publicly support NSEP programs when articles were published in local suburban newspapers attacking the scheme' (Burrows 1998: 1116).

Several respondents identified organised opposition from diabetic groups aggrieved by the unfairness of their having to pay for needles. Others identified opposition from conservative political and/or religious groups opposed to harm minimisation approaches generally.

Dr Lucy Sullivan exemplifies the latter kind of opposition. Between 1992 and 2000 she published articles in health and medical journals (Sullivan 1994b; Sullivan 2000) as

well as letters to the editor of newspapers (Sullivan 1992b), and many articles in *News Weekly* (Sullivan 1993; Sullivan 1995; Sullivan 1999c; Sullivan 1999d). She identified herself as a psychologist, epidemiologist and a board member of 'Drugwatch Australia'. Her critique of NSP is that there is no evidence that it has made any difference to HIV transmission among IDUs. She is also a very strong critic of harm minimisation and argues that AIDS was a '...godsend for the harm minimisation strategy of regulated flouting of the law in the name of public health...' because it enabled the introduction of NSP (Sullivan 1999d: 8). Sullivan links NSP and harm minimisation with a covert attempt to introduce drug law reform.

The identification of hepatitis C (HCV) in 1989 and the subsequent documentation of a large and continuing HCV epidemic among IDU led to claims that NSP had failed (Sullivan 1999a; Sullivan 1999c). But these were not accepted and increased policy attention to HCV led to increased policy commitment to NSP (Lowe and Cotton 1999).

The decision by the Prime Minister to prevent a trial of heroin prescription in the ACT increased policy debate on illicit drugs and the philosophy of harm minimisation. While NSP was frequently criticised in the media and became the subject of close attention within government, the net effect on NSP was positive. The Council of Australian Governments (COAG) agreed to a 'Tough on Drugs' policy which included an additional \$130 million over four years to enhance the range of services, especially education, provided through NSP.

#### **6.1.10. Defending NSP**

Advocates of NSP have attempted to provide resources to politicians and community organisations to assist them in answering the criticisms about NSP. The Australian Federation of AIDS Organisations produced an NSP Lobby Kit in 1998 because of concerns that it was losing support politically (McLean and Moore 1998). The central element of this kit was a summary of the available Australian and international research on NSP, copies of some of the journal articles quoted, and a list of key references.

During 1999 the NSW Government initiated a 'Drug Summit' which came to be billed as 'harm minimisation versus zero tolerance' (Wodak and Baume 1999). A group called 'Communities for Constructive Drug Action' made up of the Royal Australasian College of Physician, the AIDS Council of NSW, the NSW Users and AIDS

Association, the Hepatitis C Council of NSW, the St Vincent's Hospital Alcohol and Drugs Service, and eight other groups put together a 'briefing paper' that provided statistics on drug use and research on the effectiveness of NSP in preventing Blood-borne Virus (BBV) transmission. It was published on the AIDS Council of New South Wales website and referenced studies such as that by Hurley and others on the cost-effectiveness of NSP (Communities for Constructive Drug Action 1999). Wodak and Baume said that the Drug Summit showed that a new form of advocacy had arisen involving the gay community working with injecting drug user groups to support NSP and other harm minimisation initiatives (Wodak and Baume 1999).

In the same vein, but in a much more sophisticated form, ANCAHRD produced *Needle and Syringe Programs: A Review of the Evidence* (Dolan, Topp et al. 2000). The Review systematically addressed the main points of attack on NSP that politicians experienced in their electorates (Dolan, Topp et al. 2000). It was accompanied by a media management kit to help those confronted with angry residents, local councils or questioning media to put the case for NSP—*Needle and Syringe Programs: Your Questions Answered* (Dillon and Dolan 2000).

All key informants identified research as an important part of the defence of NSP as exemplified by the ANCAHRD publications. ANCAHRD has also used its monitoring reports to prod State and Territory Governments to provide stouter defence of NSP (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: vii-viii).

### **6.1.11. International developments**

The chronology of events (10.6.2) shows that at the same time Australia was introducing NSP, the Netherlands, Sweden, Germany, the United Kingdom, Canada and the United States were also taking the same or similar steps and going through similar debates. In parallel with this was the development of international networks of researchers and drug and alcohol workers committed to the philosophy of harm reduction or harm minimisation. International conferences on harm reduction commenced in 1990 in Liverpool (Crofts and Deany 1999), the same place where *The Mersey Drug Journal*, later to become *The International Journal of Drug Policy*, began. It is a key vehicle for international research done within the paradigm of harm reduction principles. There is also an International Network of Cities on Drug Policy promoting an end to prohibition and drug law reform (Wodak 1994).

**6.1.12. Australian NSP research**

In the appendices for this chapter, Table A13 presents Australian NSP research which shows a plethora of studies in the late 1980s documenting HIV risk behaviours and HIV prevalence among IDUs. The first major national study, the Australian National AIDS and Injecting Drug Use Study (ANAIIDUS) began reporting in 1990. By 1992, a review of research on HIV/AIDS and IDU argued for a new generation of research more concerned with causal relationships and intervention research and less focussed on risk factor monitoring (Loxley, Ovenden et al. 1992). By the mid-1990s, research on the effectiveness of NSP appeared in the international literature (Des Jarlais, Hagan et al. 1995) and in Australia (Feachem 1995). Opposition to NSP in the United States led to five meta-analyses, including one by the Surgeon General. They all supported the public health benefit of NSP (Dolan, Topp et al. 2000). However, several studies showing HIV epidemics or higher rates of HIV among IDU attending NSP led to a new round of vigorous debate in the United States (Moss 2000).

NSP related research in Australia was largely funded through the Commonwealth AIDS Research Grants Program (CARG), and the National Drug Strategy. A handful of researchers (Alex Wodak, Kate Dolan, Nick Crofts, Wendy Loxley, Margaret MacDonald, John Kaldor) figure prominently in this research, as do Commonwealth funded institutions: the National Centre in HIV Epidemiology and Clinical Research; the National Drug and Alcohol Research Centre.

A national system for monitoring HIV, and other blood borne viruses among IDUs was organised in the mid-1990s (MacDonald, Wodak et al. 1997). It has consistently shown that HIV prevalence among IDU continues at less than 2 per cent, except for men who inject drugs and are also homosexually active (National Centre in HIV Epidemiology and Clinical Research 2001).

Of the 46 Australian studies published in journals or available from retrievable sources (see Table A13), 25 were quite explicit in their support of NSP and recommended its continuation, expansion, or refinement in some way. Of those that did not give explicit support, most were tacitly supportive in the sense that they stated support for harm minimisation approaches generally. Others, such as the surveillance reports of HIV and HCV prevalence among NSP attenders, might be assumed to be highly supportive given

that the research is done in partnership with the Collaboration of Australian Needle and Syringe Exchange Programs.

A major focus of the largest national studies—ANAIIDUS, ASHIDU, and NSP monitoring surveys—is monitoring HIV and HCV prevalence, needle sharing and other risk behaviours.

By way of comparison, NSP research in the United States has studied program effectiveness in far more depth than Australian public health research. US research has also studied the possible negative side effects of NSP. There has also been considerably more dissent and debate on NSP among US public health researchers than among Australian researchers (for the latest round of debate, see a colloquium of six papers in the *American Journal of Public Health* 90(9), 2000).

## **6.2. ACF analysis**

### **6.2.1. Advocacy coalitions in the NSP policy subsystem**

The NSP policy subsystem, to the extent that it can be separated from the wider HIV/AIDS and illicit drugs policy subsystems, seems to have been initiated by drug and alcohol workers who were also public health researchers. They took action with the tacit support of the main advisory bodies to the Commonwealth, State and Territory Governments on HIV, the Federal Health Minister, the wider HIV/AIDS policy subsystem, as represented by the attendees at the Second National HIV/AIDS Conference in early November 1986, and parts of the government departments responsible for HIV policy and programs. Two key informants commented on the importance of ‘faceless bureaucrats’ in State and Territory health departments who ran ahead with the implementation of NSP before formal approval processes had been completed but with the tacit support of their superiors. The rapidity of the diffusion of NSP across most jurisdictions suggests that there was a latent NSP advocacy coalition among many influential people working on HIV/AIDS policy.

The ACF argues that policy stability results from stability in the composition of the dominant advocacy coalition over time. This hypothesis is supported by the continuity in the structure, role and composition of the Australian National Council on HIV/AIDS, Hepatitis C, and Related Diseases (ANCAHRD) and its predecessors. The forerunner of

ANCAHRD was the Australian National Council on AIDS (ANCA). Set up in 1988, it created a single body with broad representational, advisory, and policy responsibilities and included bureaucrats, ex-politicians from both sides of politics, community sector organisations, researchers, and the medical profession. This committee structure reflected the composition of what has become known as the HIV/AIDS ‘partnership’. The formation and work of this partnership continues to be hailed as a major contributor to Australia’s successful response to HIV/AIDS (Commonwealth Department of Health and Aged Care 2000: iii).

There are no identifiable advocacy coalitions working in opposition to NSP in Australia. The case study data show a wide range of types of opposition from local residents and politicians concerned with public amenity through to opponents of harm minimisation such as Lucy Sullivan. The concern over needle disposal has been serious enough to bring action on retractable needles. However, this opposition has not formed into a coordinated advocacy coalition.

### **6.2.2. Beliefs and values of the NSP advocacy coalitions**

The ACF argues that the defining features of a dominant advocacy coalition will be that they share core values and beliefs and that the policy will reflect these values and beliefs. At interview, all key informants said that advocates of NSP were unified either by the values encapsulated by harm minimisation, or by the belief that NSP was effective in preventing an HIV epidemic among IDU in Australia, or both. These beliefs are found in all the major national HIV/AIDS policy documents.

On the belief that NSP could prevent an HIV epidemic, this was present in the earliest published defences of NSP where data from other cities around the world was used to show what could happen if Australia did not introduce NSP (Paine, Tonuma et al. 1985; Blacker, Tindall et al. 1986; Wodak, Dolan et al. 1987). This argument has been used consistently in every national HIV/AIDS Strategy document right up to the current one (Commonwealth Department of Community Services and Health 1989: 17; Commonwealth Department of Health, Housing, Local Government and Community Services 1993: 21; Commonwealth Department of Health and Family Services 1996: 43; Commonwealth Department of Health and Aged Care 2000: 17).

The case study material also showed that adherence to the principles of harm minimisation pervades HIV/AIDS policy documents and is the basis for an international harm reduction movement in the field of drugs policy and treatment.

### **6.2.3. Research and struggle over NSP**

Central to ACF theory is the view that research will be carried out and used by advocacy coalitions to win policy battles. It argues that research sponsored by the dominant advocacy coalition will be supportive of NSP and focussed on three things: first, improving understanding of variables important to its belief system (eg monitoring critical variables); second, refining understanding of the logical and causal relationships underpinning the dominant advocacy coalition's beliefs; and third, identifying and responding to challenges to the dominant advocacy coalition's belief systems.

There is good evidence to show that the research facilitated through the dominant advocacy coalition is supportive of NSP. The research relating to NSP has largely been funded from the National AIDS Program (the Commonwealth's budget allocation for the National HIV/AIDS Strategies) in the form of the Commonwealth AIDS Research Grants, and from the National Drug Strategy which has funded several drug research centres, especially the National Drug and Alcohol Research Centre at the University of NSW.

ANAIIDUS and ASHIDU were funded from both the HIV/AIDS and drugs programs and focused on monitoring variables of central importance to the beliefs and values of the dominant advocacy coalition.

Contrary to the ACF prediction that NSP research will focus on logical and causal relationships that underpin coalition beliefs, there has been little research using experimental or quasi-experimental designs to test the effectiveness of NSP within Australia. Several factors explain this. The fact that such studies were being undertaken in the US could be seen to make local research redundant. There would have been logistic and ethical difficulties in conducting such research in Australia given the strongly held view that it worked. And the continuing low rates of HIV among IDUs combined with international studies supported from Australia (Hurley, Jolley et al. 1997) added to the redundancy argument.

With regard to research on perceived threats to advocacy coalition beliefs and values, there have been Australian studies of community attitudes to NSP and harm minimisation. These appear to have been designed to assure NSP advocates that the concerns come from a minority and that the majority of the public support the interventions (Schwartzkoff, Spooner et al. 1990). There has been a study of an intervention designed to change community views on these matters (Lenton and Phillips 1997), and action research to develop local commitment to NSP while increasing safe needle disposal (Robinson 1994).

Given the community anxieties created by inappropriate disposal it seems surprising from an ACF perspective that there has not been more research on this topic especially as retractable needle technology was listed as a research priority in the first strategy. If the ANCAHRD Review of NSP is a guide, the main defence of the dominant advocacy coalition has been to argue that the number of needles inappropriately discarded is small and the risk of infection from them even smaller (Dolan, Topp et al. 2000: 17). In ACF terms, the ANCAHRD approach has been to use research to undermine perceptions of the size and importance of the problem of needle stick injury.

With regard to the criticisms of harm minimisation, the ANCAHRD review used North American research to dismiss fears that it leads to increasing drug use and crime and put the counter view that NSP works as a gateway to drug treatment (Dolan, Topp et al. 2000: 15-16).

#### ***6.2.4. Research and power in the NSP subsystem***

Given that ACF argues that a threshold condition for the use of research by dominant advocacy coalitions is that power is disbursed through the policy subsystem, and given the lack of opposition to NSP that was organised into an alternative advocacy coalition, how does the ACF account for the existence of any Australian research at all?

Those individuals and groups opposed to NSP do not form a united group and do not come from within the health, HIV/AIDS, or NSP policy subsystem. They have relatively little access to research resources, hence there is no research that explicitly challenges NSP in Australia. But these groups have relatively good access to political resources that can be used to threaten the dominant advocacy coalition. They use points of pressure outside the policy subsystem to make their concerns known: their Federal or



State members of Parliament, their local government, talkback radio and letters to the editor. Thus, the dominant advocacy coalition might be relatively secure in its control of the NSP policy subsystem but much less secure in terms of its ability to control interference from powerful actors outside the policy subsystem. The dominant advocacy coalition is vulnerable to perturbations coming from the wider policy environment and research is a resource it can use to try to protect itself.

Another major reason for the importance of research to the dominant advocacy coalition is that some of its members are researchers who hold a personal and professional interest in conducting research, regardless of the presence of any ‘threat’ from outside. Their core values relate to the prevention of blood borne virus transmission within a harm minimisation approach—research on NSP is a means to these ends.

#### **6.2.5. *The ACF and the research–policy nexus***

The ACF approach of identifying a dominant advocacy coalition within a policy subsystem conducting and using research to progress its core beliefs and values is a reasonable account of the NSP research–policy nexus. Over 15 years of policy stability has been accompanied by stability in the power structures of the policy subsystem. The Commonwealth AIDS Program and the National Drug Strategy have funded a number of significant research projects relevant to NSP. The multifaceted threats to NSP come from outside the NSP policy subsystem and outside the health sector. They lead to a perception that the opponents of NSP could mobilise political resources against NSP and therefore generate attention by the dominant advocacy coalition to research to defend NSP. The ANCAHRD publication is a clear example of the dominant advocacy coalition using research to defend the central tenets of NSP from a wide variety of threats that show themselves in many fronts. Key informants universally described the importance of research to NSP policy in terms of its value in rebutting argument against NSP and garnering political support. The type of research conducted conforms reasonably closely with ACF expectations of the way advocacy coalitions focus their research effort.

### **6.3. PMOF analysis**

The PMOF approach understands patterns in the research–policy nexus in terms of an interaction between the policy preferences of the policy making organisation and its degree of research responsiveness.

#### **6.3.1. The policy orientation of the PMO**

##### ***Electoral risks and opportunities***

There is considerable evidence that NSP is something of a pariah for politicians and no evidence that any politician used his or her support for NSP in an attempt to win votes. Neal Blewett’s support for NSP in August 1986 was carefully expressed as an option he would support if he was advised it was in the best interests of public health (Wodak interview). When required to take responsibility for NSP politicians adopt a statesman-position about reluctant acceptance of the need for NSP as the lesser evil when compared with the possibility of further HIV transmission.

Several key informants said that State and Commonwealth health ministers of various political persuasions had, at times, been strongly supportive of NSP in international fora and in parliament when legislative change was required. In this context, key informants said that research from overseas showing the large and rapid epidemics that have occurred in the absence of NSP was critical data for them to use. This data appears to be irrefutable and has continued to buttress arguments for NSP which politicians consider anything but an immutable policy option.

The PMOF suggests that the basis for bipartisanship on this and other aspects of HIV/AIDS policy is that it affords neither of the major political parties opportunities for political gain by being seen to be different. At the same time, bipartisanship is a way of neutralising potential political risks—if all parties agree then the political cost of being wrong is neutralised.

##### ***Tactical risks and opportunities***

Added to the lack of electoral appeal, there is no evidence of NSP providing politicians with political capital within their party rooms or Cabinet. Key informants noted the lack of political clout of injecting drug users so they were unlikely to be able to provide

politicians with any political ballast on other issues. Conversely, a health minister who failed to contain HIV and keep problems with injecting drug use out of the political spotlight would not be popular with his or her colleagues.

### ***Economic/financial risks and opportunities***

The practice of counting the cost of HIV/AIDS in economic and health financing terms started early (Landesman, Ginzburg et al. 1985; Penington 1987; Whyte, Evans et al. 1987). In the 1990s, first the NH&MRC and then the Commonwealth Department of Health funded Hurley and others to do a cost-effectiveness study of NSP (Hurley and Butler 1996). This has recently been updated and a further study of the economics of HIV prevention measures, including NSP, has also been carried out (Applied Economics 2003). Hurley's study was central to the evaluation of the *Second Strategy*. These data are used by the ANCAHRD (Dolan, Topp et al. 2000) and the Australian Federation of AIDS Organisations (McLean and Moore 1998) in their advocacy of NSP.

Together these data suggest that the PMO would have had a financial incentive to invest in prevention and that as data on the cost-effectiveness of NSP became available this incentive would have increased its bias towards accepting the proposition that NSP worked.

### ***Contextual risks and opportunities***

In terms of contextual factors supporting NSP policy initiation, several key informants noted that, at the time of NSP commencement, the fear and uncertainty around HIV/AIDS was extremely high and there was an expectation that exceptional measures were needed. *The Sun-Herald* Editorial from November 1986 supports this perception (Editorial 1986). The famous Grim Reaper television advertisement was shown in April 1987 increasing the level of fear and exceptionalism attached to HIV/AIDS. The introduction of NSP gave politicians something they could do in practical terms in response to this level of anxiety. The synergy between NSP and the harm minimisation approaches being adopted in sex education on HIV, as well as methadone and other illicit drug programs, made NSP seem less radical or extreme than it might otherwise have been and thus reduced the political risks associated with it.

### ***Ideological risks and opportunities***

Harm minimisation represents a socially progressive perspective on illicit drug use. Combined with approaches to policy making that are inclusive of affected communities it makes for an attractive ideological package for social liberals on both sides of politics. At interview, Blewett said that the success of NSP was based on the presence of these social liberals in key positions who could bring others with them. This is supported by the agreement between the Prime Minister, Bob Hawke, and the Opposition Leader, Andrew Peacock, to keep politics out of the response to HIV/AIDS which was supported on the Opposition side by key social liberals within the Liberal Party such as Chris Puplick and Peter Baume (Baume 1998).

### ***The policy orientation of the bureaucracy***

By adopting the position of being willing to act on the advice of public health experts, Neal Blewett was in effect empowering public health experts. NSP afforded State and Territory public health officials a practical and relatively inexpensive intervention that could be rolled out quite rapidly with minimal infrastructure in terms of facilities and skilled staff. It dovetailed with an already approved philosophy, harm minimisation, and was supported by a sound policy rationale in terms of communicable disease prevention. The Commonwealth had money to spend on HIV/AIDS and the State and Territory public health officials could use the Commonwealth requirement for matched funding to extract money from their own treasuries. The Commonwealth health department was going through a time of expansion on the back of the introduction of its Health Advancement Division to respond to the WHO's Health For All Strategy. This created a willingness and capacity to respond to HIV though Ballard argues that the States and territories and other policy actors made sure that the Commonwealth did not get control at the expense of NACAIDS and the National AIDS Task Force.

**TABLE 6:1 SUMMARY OF PMO ORIENTATION TOWARDS NSP**

<b>Dimensions of Risk and Opportunity</b>	<b>Political Arm of PMO</b>	<b>Bureaucratic Arm of PMO</b>
Electoral	Political risks associated with strong overt support of NSP (eg implication of being soft on drugs) countered by the political risk of failing to prevent HIV transmission among IDUs, their sexual partners and children.	NA

Dimensions of Risk and Opportunity	Political Arm of PMO	Bureaucratic Arm of PMO
Tactical power relations	High risks for Health Ministers in failure to prevent HIV but nil opportunities in supporting NSP and problems with pressure from disgruntled backbenchers hassled over poor needle disposal.	Commonwealth opportunities in expansion in public health role. State health opportunities in gaining ascendancy of harm minimisation over law enforcement objectives. New HIV/AIDS bureaucratic machinery opportunity to be at cutting edge of public health in Australia and the world.
Economic and Financial	High costs associated with failure to prevent HIV. NSP represents a relatively cheap and cost-effective prevention measure.	Commonwealth opportunities to increase public health budget and influence with State governments. Commonwealth and States both at risk of increased budgetary pressure on acute sector if HIV increases
Contextual	The fear and urgency around HIV/AIDS created an environment disposed to extreme policy options. Synergies between NSP and other harm minimisation interventions eg methadone.	Parallel increase in Methadone programs provide synergy with NSP in expansion of harm minimisation paradigm.
Ideological	Blewett opportunity to realise preference for consensual, inclusive models of policy development. Opportunities for Blewett and others to pursue social liberal public health policies such as harm minimisation.	Opportunities for public health advocates of health promotion and community empowerment in new bureaucratic machinery resulting from HIV/AIDS.
Summary	Net effect: inclined towards low key, low visibility support for NSP.	Net effect: Support for NSP

### 6.3.2. *The research orientation of the PMO*

#### *PMO responsibility for HIV among IDU*

State and Territory Government responsibilities for HIV/AIDS were unavoidable and represented a major challenge for public health organisational capacity. While it was clear early on that most of those affected were homosexually active men, the fear that continued well into the 1990s was that a ‘second epidemic’ would occur among IDUs and their sexual partners—the national strategy documents make this clear. This meant that prevention among IDUs occupied a central place in HIV/AIDS policy.

#### *PMO capacity in relation to the policy problem*

Wodak reports that the National AIDS Task Force gave in-principle support for NSP in 1985 (Wodak 1990: 134). As a subcommittee of AHMAC, the National AIDS Task Force was an extra constitutional mechanism without any jurisdiction. The recommendation still needed to be given effect by individual State and Territory Governments. The Commonwealth and State and Territory Governments made harm

minimisation the key principle of the new National Campaign Against Drug Abuse (NCADA) in 1985 (Wodak 1990: 135). This created an enabling environment for NSP but did not give any legal or financial backing for NSP. Both these policy changes increased the capacity of State and Territory Governments to introduce NSP, but it was still only a possibility. The action taken by Wodak and Dolan in 1986 demonstrated that the initial set up costs of NSP were quite modest even if whole population coverage would require an extensive organisational capacity.

### ***The measurability of PMO performance***

The measurability of government performance in relation to HIV prevention was very high. Though there was an evolving definition of AIDS, the number of people dying from AIDS were being counted closely by medical professionals and doctors under the close scrutiny of the AIDS Councils. It was the subject of close international attention. The World Health Organisation Collaborating Centre on AIDS was producing regular reports on the progress of the epidemic across the world from at least as early as 1984 (Blacker, Tindall et al. 1986), and there was pressure on countries to put adequate surveillance measures in place. As the plethora of early research on IDUs and HIV shows, any outbreak among IDUs would have become readily apparent.

### ***The transparency of PMO performance and the 'theatre of justification'***

HIV/AIDS policy has been a very lively 'theatre of justification' since its earliest days. The combination of intense mainstream media interest, the scrutiny by gay community based organisations and media, and the early rivalry between the National AIDS Task Force (NATF) and the National Advisory Committee on AIDS (NACAIDS) increased the level of scrutiny of government policy and made for a turbulent policy environment.

### ***PMO vulnerability to the consequences of its error***

Three factors made government inaction on HIV among IDUs difficult to sustain. Governments would inevitably pick up large health care bills associated with an HIV epidemic. An epidemic among IDUs would have flow-on effects to the children and sexual partners of IDU. And regardless of how socially marginalised IDUs and homosexuals were or still are, there would be only a small proportion of the population who would see HIV as a just punishment for the crime of drug injecting. No Australian

government would be politically invulnerable to demonstrated failure to prevent an HIV epidemic among IDUs.

### ***The research responsiveness of the PMO***

The Commonwealth, State and Territory Governments were all confronted with a policy problem for which they had a relatively high degree of accountability. While legal obstacles meant that the onus on government to implement NSP was not clear cut, failure to act was likely to be clearly evident, closely watched and could have had major implications for both political and bureaucratic careers. The following table summarises the position on the indicators of research-responsive.

**TABLE 6:2 PMO RESEARCH RESPONSIVENESS ON HIV AMONG IDU**

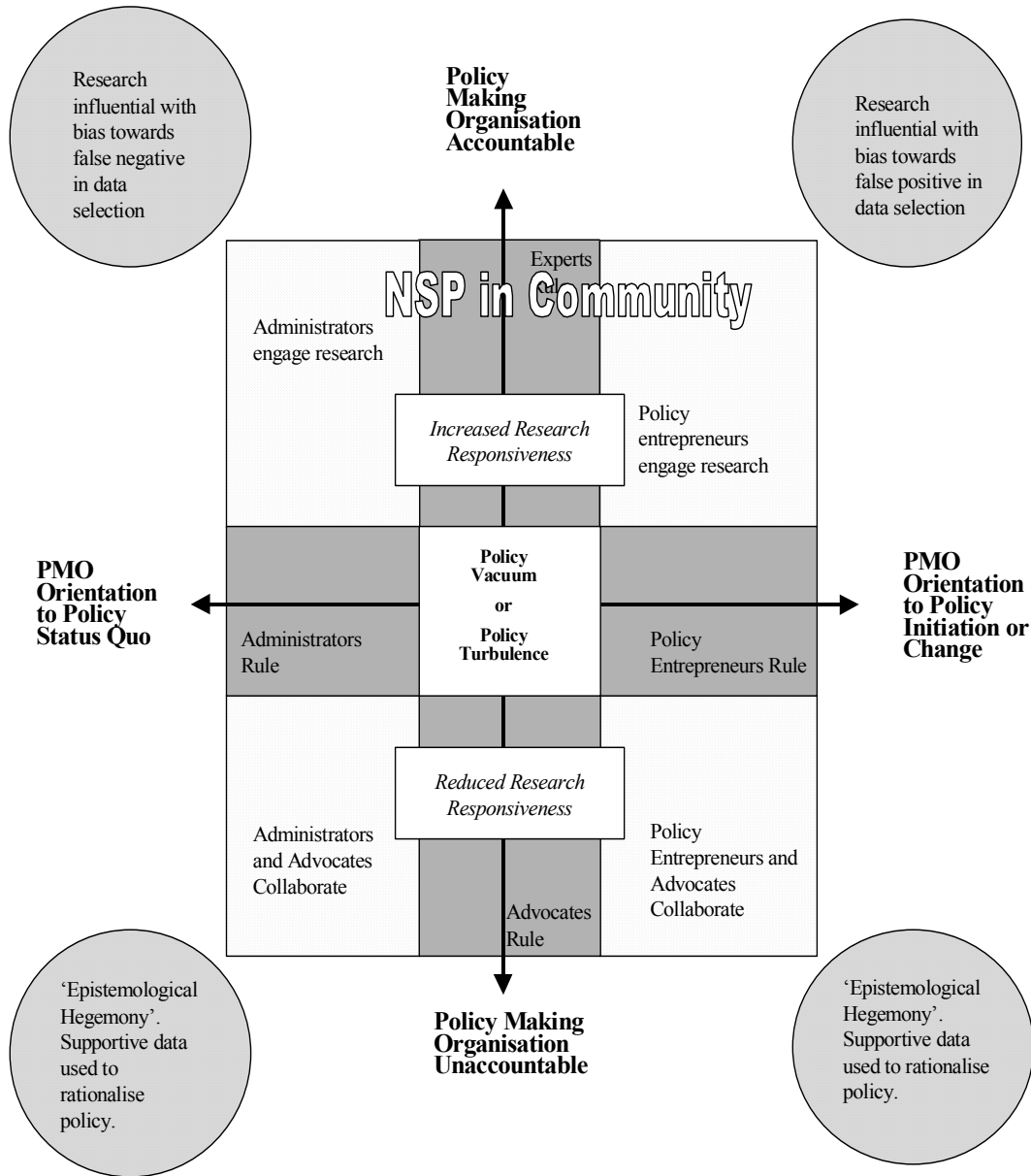
<b>Indicator</b>	<b>Rating</b>
PMO responsibility	High
PMO capacity	Moderate
PMO performance	High
Theatre of justification	High
PMO vulnerability to error	High

### ***6.3.3. The PMOF and the research–policy nexus***

From the PMOF point of view, the dynamic of the research–policy nexus is built around the relative immutability of policy and irrefutability of data. Figure 6.1 below locates NSP in relation to these factors. The combination of a political aversion to NSP with a high degree of political vulnerability if an uncontrolled epidemic of HIV occurred among IDU meant that a space was cleared for policy activism by the public health bureaucracies for whom NSP represented something of an opportunity. The PMO was therefore geared towards a ‘false positive’ which worked to produce a generous or positive appraisal of data on the effectiveness of NSP—that is, it was prepared to take the risk that it was false in its belief that NSP would be effective.

The same set of factors meant that research on HIV among IDUs was a critical component of policy making. Research provided the arguments that NSP supporters inside and outside the bureaucracy could use to sell NSP and to inform program design. The raft of research since then, largely funded by the Commonwealth, has performed the functions of maintaining the policy argument while monitoring NSP effectiveness. Research was integral to making the policy making organisation accountable. Systems of surveillance record cases of HIV and AIDS by mode of transmission in all States and

**Figure 6.1**  
**Location of NSP in the Community in the PMOF Model**





Territories and enable comparison between jurisdictions as well as progress over time. They also enable international comparisons so that Australia's efforts can be benchmarked against countries like the United Kingdom, Canada, and the United States. Costs, human and financial, are regularly calculated. As the apparent success of NSP in Australia compared with some other countries becomes more obvious, the irrefutability of the research on NSP increases.

In this light, the possibility raised by Canadian and US research that NSP might be ineffective cannot be countenanced by the PMO. The ANCAHRD report on the effectiveness of NSP is as good an example of 'monster barring' (ie dismissing the possibility that this data is correct and/or relevant to the Australian context) as any that can be found (Dolan, Topp et al. 2000).

#### **6.4. Governmentality analysis**

The metaphor suggested in Chapter 2 is that power/knowledge is a collective psychic web continually produced through regimes of knowledge, practices and discourses. Public health policy is that particular web connecting technologies of self with technologies of population and governing at a distance.

To understand NSP from a governmentality perspective one must begin by identifying that which is being brought into the sphere of government. Three things emerge: the disease (HIV/AIDS), the practice of injecting drugs that can lead to its transmission, and the person who injects drugs. A governmentality analysis, by definition, seeks to chart the development of the forms of thought that underpin NSP. A governmentality analysis of the research-policy nexus seeks to establish the particular role of research in that process. The major finding from this analysis is that NSP is part of a larger process of governing injecting drug users. Harm minimisation is the predominant policy discourse. NSP is one practice among many.

##### **6.4.1. NSP policy discourse**

If we look at the epistemological character of the policy discourse on NSP we find that it constructs the person who injects drugs in a particular way. O'Malley (O'Malley 2001) argues that drugs policy discourse has changed since the adoption of harm minimisation in the mid-1980s. The 'drug addict', 'drug abuser' and 'junkie' have given

way to the ‘injecting drug user’, an individual who makes choices about the risks associated with taking drugs which can be calibrated on a scale from more or less harmful rather than legal or illegal. The goal of abstinence has taken second place to the goal of promoting the exercise of responsible decision making.

Research has played a critical role in this evolution of the language away from moralistic categories and towards a construction of the drug user that dovetails with the requirements of NSP (ie NSP requires drug users to take responsibility for managing their exposure to risk). Some examples of this research are: the construction of the ‘functional IDU’ as a ‘worker’ and ‘parent’ and therefore not consistent with white male ‘junkie’ stereotypes (Sharp, Davis et al. 1991); the variations in patterns of HIV and risk behaviour across cities, gender, and age (Loxley, Carruthers et al. 1995); the relationship between injecting drug use and sexual behaviour among those in treatment (Darke, Hall et al. 1990); the elaboration of the needs of female IDUs as distinct from male IDUs (Dance 1994); the elaboration of the social settings and groups within which people inject drugs—the ‘tribes’ of ‘bikers’, ‘ravers’, ‘surfies’, ‘westies’ (MSJ Keys Young 1991); the processes of ‘initiation’ into drug use including the life circumstances surrounding first use and how it relates to other matters such as problems at home or school attendance (Crofts, Louie et al. 1995); the needs of gay injecting drug users (Wallace 1991).

The moral form of the policy discourse on NSP comes in the shape of harm minimisation. The case study material noted harm minimisation came out of the field of drug and alcohol treatment and predates NSP. It has occupied centre ground in justifying NSP for over 17 years. Its moral basis is utilitarianism—total harm in the population is minimised by providing the means for safe injecting. It is right and proper for government to make clean injecting equipment available and it is the responsibility of IDUs to use a clean fit for every hit and to dispose of used needles safely. The morality and criminality of injecting illegal substances is secondary to the primary goal of protecting the individual and the population from harm. The Intergovernmental Committee on AIDS Legal Working Party reported on *Legal Issues Relating to AIDS and Intravenous Drug Users* proposed legal reform to support measures such as NSP arguing for the primacy of public health objectives over law enforcement objectives (Schwartzkoff and Watchirs 1991: 4, 71).

Another part of the moral form of the NSP policy discourse relates to its economic efficiency. Such appeals have been included in national policy documents since the *Feachem Report* first published research on the cost-effectiveness of NSP (Commonwealth Department of Health and Family Services 1996: 43). These appeals appear in many publications advocating for NSP (Wodak 1997; McLean and Moore 1998; Dillon and Dolan 2000; Dolan, Topp et al. 2000).

The idiomatic form of the policy discourse on NSP is perhaps its most powerful and relates to the threat to the whole population arising from transmission of HIV among IDUs. As noted in the case study material, this is a constant element in all policy documents from *Green Paper* in 1988 through to the ANCAHRD defence of NSP in 2000. It was widely sensationalised in the media and through the government sponsored media campaigns such as the Grim Reaper. Epidemiology played a critical role in shaping this consciousness with concepts like the ‘susceptible population’ and identifying the spread of the disease in populations overseas. The media are willing and able co-authors of this discourse, using vivid stories of how individuals became infected with headlines such as ‘How AIDS threatens all of us’ (Stuttaford 1986).

The complement to the population threat discourse is the use of war metaphors to describe the kind of mobilisation required to combat the disease threat. This enables the prescription of individual protective behaviours as well as population-wide measures to make needles available.

#### **6.4.2. NSP and regimes of practices**

NSP is a remarkable technology of government and may be the quintessential form of ‘governing at a distance’. Rather than being a threat to the state, the direct action of drug and alcohol workers to establish NSP in extra-legal circumstances effectively extended the reach of government into a sphere that might otherwise have been viewed as out of bounds. Over time, the services became formalised and legal but the practice of injecting remains illegal and the government service is provided to citizens who use the service as part of a criminal activity. The further evolution in governing at a distance came with the process of providing funds to support and facilitate the work of IDU organisations who work at the unruly frontier of this new form of government.

Ballard has analysed Australia’s HIV/AIDS policy from the point of view of ‘governing at a distance’ and found it a compelling argument (Ballard 1998). He notes particularly

the way that government supported the action of community based organisations thereby enabling those organisations to make themselves up in a kind of regulated freedom, managing their own education and behaviour change campaigns. The health promotion and community education discourses and practices of the late 1970s and 1980s provided a mentality within which ‘governing at a distance’ could work (Ballard 1998: 9).

While the support of IDU organisations came later than the support for gay organisations, the same logic of community mobilisation and peer education was at work. It would be difficult to argue, however, that IDU organisations enjoyed anywhere near the acceptability or success of the AIDS Councils, probably because of the added difficulty for governments to be seen to formally support organisations that have law breaking as their reason for being. Their level of economic and political resources is also very different. Several key informants noted tension in the way funding was organised for IDU groups. But they certainly did receive support in most States and Territories and played an integral role in NSPs and in peer education and advocacy (Australian IV League 1992; Gore 1994; Byers 1995; Dodding No date).

#### **6.4.3. NSP and power/knowledge**

There are several mutually reinforcing processes at work around NSP and its networks of power and knowledge. The regime of truth associated with NSP has been built on the surveillance of HIV among IDUs. This took the form of the early national surveys, ANAIDUS and ASHIDU, and is now carried out through the regular national survey of NSP attenders (National Centre in HIV Epidemiology and Clinical Research 2001). The practice of NSP enables the creation of knowledge about HIV and IDUs that gives power a certain degree of power/knowledge to this way of governing HIV among IDUs. Any alternative approach to governing this problem would need to create a new or different form of knowledge/power. Sullivan attempted to challenge the basis of NSP by arguing that it did not prevent the spread of HCV and may have actually caused it, but Crofts and Kaldor were able to counter this with detailed calculations of the transmissibility of both diseases (Crofts, Aitken et al. 1999a).

The researchers who support NSP in Australia and elsewhere have attempted to increase the power of their particular ‘regime of truth’ by developing an international network of harm reduction and an associated international journal. There are parallels here with the

processes noted in relation to cancer screening and technology assessment where, for example, the collaboration on Prostate Cancer Screening research is occurring across Europe and North America (de Koning, Auvinen et al. 2002).

#### **6.4.4. NSP and the governmentality hypothesis**

NSP provides an excellent example of governmentality hypothesis in that it links together all the elements required for national public health policy in a clear and unambiguous fashion. NSP is a ‘technology of self’ in that it requires IDUs to take responsibility for managing the risks to their health. It is a ‘technology of population’ in that it aims to protect the health of the whole population and is effective to the extent that it reaches all those who inject drugs. And it fits the requirements for ‘governing at a distance’ given the role played by non-government organisations and given the special requirements to relax law enforcement processes in the vicinity of NSPs.

#### **6.4.5. Governmentality and the NSP research–policy nexus**

It is apparent from the policy development process that the early research on HIV among IDU, particularly that showing major epidemics in cities overseas, had a major impact on policy. Key informants attested to the way it motivated them and to the way it galvanised support from many others. The policy documents make this threat central to the rationale for NSP. When NSP is threatened in some way, research is the front line of defence—the ANCAHRD review of the research on NSP can be interpreted as a very deliberate attempt to construct a ‘regime of truth’ through its appeal to international science and agencies such as the US Surgeon General. This carefully constructed regime of truth meets resistance at many points but its power comes from the coherent connection it establishes between NSP as a technology of self, NSP as a technology of population, and NSP as a form of governing at a distance. It demonstrates the incursion of a neo-liberal governmentality into aspects of social life previously deemed ungovernable—the injecting practices of IDU.

The Governmentality Framework view focuses less on the specifics of the research than on how research became invested with power and how particular regimes of truth about HIV, IDU and NSP have been created and sustained. The predominant pattern of research relating to these topics is conducted by a relatively small group of experts working through a relatively small number of research institutions which, by and large,

have been funded from public health research sources in the Commonwealth and, to a lesser extent, the State Governments. The growth in this assembly commenced with a claim to knowledge about HIV transmission and an accompanying claim to power, the specific practice and technology of NSP, and the discourse of harm minimisation. The pattern of research, NSP practice and NSP policy since then has been one of continued symbiosis which has so far weathered the occasional resurgence of alternative constructions of IDU and attempts to make the morality and criminality of drug use more important than its public health aspects.

## **6.5. Theoretical considerations**

### **6.5.1. Theory evaluation**

Some of the weaknesses of the focal theories identified in the previous case studies are also evident here. For the ACF, there are difficulties identifying the boundaries of an NSP policy subsystem distinct from an HIV/AIDS or HCV policy subsystem or an illicit drugs policy subsystem. The issues and research and policy actors involved in NSP straddle these policy areas and NSP might be seen as a subset of both of them. Despite this, the concept of policy subsystem does not lose its worth as an analytic tool. A related problem is that the ACF concept of ‘advocacy coalition’ suggests tighter organisation and coordination of research in support of NSP than is apparent. For example, there have been several reviews of research relevant to NSP decrying its disorganisation and lack of funding (Loxley, Ovenden et al. 1992; Crofts, Webb-Pullman et al. 1996). Of course, these criticisms might be seen as attempts to generate greater coordination and cohesion between members of a loosely knit coalition. Or they might indicate that the coalition would be more organised if it had the time and resources to do so. Another problem for the ACF is that the agency of IDUs and the influence of international factors are not well accounted for.

The PMOF explanation lacks the ability to readily account for the impact of the ‘street level’ bureaucrats who responded to the available research and took action while their seniors provided tacit support. This raises the very important consideration that policy making organisations are not monolithic or homogenous entities and may, at times, show a high degree of fragmentation, disorganisation and internal conflict. The PMOF needs to recognise that bureaucratic organisations are resources that can be mobilised in

various ways by those that work in them. In keeping with this is the idea that organisational epistemology needs to be seen as something that, at various times, might be a mobile and dynamic thing capable of diverse renderings by different actors within the bureaucracy.

While the Governmentality Framework can more easily account for the international networks of researchers and the dispersal of harm minimisation discourse across international boundaries, there is a particular problem for the GF in explaining the failure of the United States to adopt NSP and in explaining the continuing opposition to it in Australia. The GF has the problem of suggesting that particular governmentalities have a sense of inevitability because they are in the service of some kind of inexorable force often called ‘neo-liberalism’ or ‘advanced liberalism’ and that the human sciences are the handmaidens of this governmentality. This means that when there are interruptions to the advance of neo-liberal governmentality, ad hoc theoretical defences need to be mounted to take account of these so long as they end up supporting the proposition of inevitability. Once again, this charge can be defended by pointing to the fact that Foucault was not in the business of building an integrated social theory but rather sought to unmask the agenda of power that he saw at work behind the facade of neutrality of the human sciences. The objective of the governmentality critique is served if power/knowledge is named in all its various forms even if it does not account adequately for the data that contradicts its premises.

### ***6.5.2. Theory development***

In the conclusions to the previous case studies I have used Sil’s broad theoretical concepts to create possible avenues for theory development on the research–policy nexus. There are some interesting continuities with the earlier case studies that enable further progress on this front.

#### ***Ideal structures and harm minimisation***

There is a strong sense in which harm minimisation is an ideal structure rather like the WHO screening evaluation principles. Like the screening principles, harm minimisation is based on a utilitarian philosophy that aims to achieve net benefit for the population while accepting the possibility that some harm may result from its application. As with the screening principles, harm minimisation fosters the development of a research

program focussed on the questions that flow from its application in various contexts—what are the harms and benefits that flow from this or that intervention? How can the intervention be modified to maximise the benefits and reduce the harms? We saw in relation to the screening principles that these underpinned an international network of researchers and agencies and governmental technologies for evaluating screening technologies. Harm minimisation has generated a similar network of researchers (Crofts and Deany 1999).

As with the screening principles, harm minimisation is capable of flexible application in different contexts for different purposes. As the case study material demonstrates, harm minimisation was first developed in the context of drugs policy generally in 1985 and then applied in the context of HIV/AIDS prevention. It could be applied to NSP as well as to explicit safe sex education programs for homosexually active men. The case study material also showed that harm minimisation could be mobilised by a variety of actors for a variety of purposes. For example, in their evaluation of the National Drug Strategy, the two evaluators, Eric Single and Tim Rohl, wrote a chapter on ‘The conceptual basis of the National Drug Strategy’. This was an attempt to make sense of the shifting meanings of harm minimisation and to reinvigorate and reinstate it at the centre of policy. Single and Rohl wrote:

Harm minimisation should be viewed as the middle ground where persons with widely differing views on drug policy can agree with one another regarding practical, immediate ways to reduce drug-related harm. Harm minimisation should foster meaningful alliances and support for as wide a variety of potentially effective interventions as possible from all who share the goal of reducing drug-related harm, even though they may disagree about major policy approaches to the prevention of use *per se*. (Single and Rohl 1997: 49)

In Advocacy Coalition Framework terms, Single and Rohl are describing the function of core beliefs and values in uniting diverse advocacy coalitions within a policy subsystem.

The other focal theories also identified harm minimisation as a central feature of the policy process and the research–policy nexus. From the PMOF perspective, harm minimisation is central to organisational epistemology. It frames the policy problem of HIV/AIDS among IDUs in a way that makes data about that problem relevant. In particular, it makes it possible to consider the value of an illegal intervention that would



have previously been outside the bounds of consideration. From the Governmentality Framework perspective, harm minimisation is the discourse of governmentality that makes the government of injecting drug use 'thinkable'. Of particular importance for the research-policy nexus, it enables the tools of the public health sciences to be mobilised in respect of a hitherto unresearched population and unresearched behaviour.

From this analysis we can see how harm minimisation has some very similar characteristics to the WHO screening principles as an ideal structure in the research-policy nexus. Both enable research to be mobilised in relation to policy problems. Both are generalisable from one policy issue to another and can be recreated and shaped to fit new problems and new contexts. This characteristic also means that they enable agency by policy actors who can use them to exert influence on the policy process by pushing their application to new problems and interventions. In Chapter 9, I extend this discussion of these two ideal structures to identify how they help resolve several key public health policy making challenges.

### ***Material structures and agency in NSP policy***

But where are the material structures that complement the ideal structure of harm minimisation? From the NSP case study material, these seem to have grown in tandem with the application of harm minimisation itself. The National Drug Strategy structures and the National HIV/AIDS Strategy structures appear to be the vehicles that both gave birth to and were carried along by the successful mobilisation of policy resources under the banner of harm minimisation. Harm minimisation was accepted in 1985 by a Special Premier's Conference as the basis of the National Campaign Against Drug Abuse (Single and Rohl 1997: 43) (which later became the National Drug Strategy) and could inform both prevention and treatment services. The case study material showed how it was adopted very early in HIV/AIDS policy documents and remained a central rationale for policy. Its centrality is underpinned by ANCAHRD's statement that continuing efforts to shore up support for it in the face of criticism and wavering commitment from State and Territory Government is a major challenge of current policy (Commonwealth Department of Health and Aged Care 2000: 18).

At a level of grass-roots action on NSP, Alex Wodak and Kate Dolan could use the status of St Vincent's as a non-government hospital (and therefore not under the direct control of the NSW Government) to deliver clean needles to IDUs even though it was

then against the law. While this example of local action was powerful in its own right, its wider effects required the existence of larger material structures in the form of the public health bureaucracy, the national advisory committees, the particular ‘agency’ of politicians like Neal Blewett and Don Grimes, and the resource of harm minimisation as an enabling ideal structure. Within the context of this agency–structure dynamic, the small amount of research on HIV epidemics among IDUs in other countries was mobilised to great effect.

Each of the focal theories attempts to capture this dynamic in different ways. For the ACF it is advocacy coalitions mobilising research that supports its central beliefs and values as it takes control of the policy subsystem. For the PMOF it is the construction of evidence in the tension between the mutability of policy and the irrefutability of data. For the GF, it is the creation of knowledge/power through the interaction of the discourse of harm minimisation, the regime of truth from public health research, and the emergent practice of governing injecting drug use. Each of the focal theories construct the dynamic in different ways and is more or less successful in creating a coherent account of it.

## **6.6. Final comments**

At this point in the thesis there are some emerging patterns of theoretical and practical importance. Each of the case studies shows that research and policy are anything but ‘strangers in the night’. Research has been part of the processes of agenda setting, program design and policy defence but, at the same time, it has always been the subject of contest and dispute. Each of the focal theories constructs the dynamics of the research–policy nexus in different ways but each of them has some way of taking account of the presence of ideal structures, material structures, and the agency of policy actors. From the point of view of building theoretical synthesis it is perhaps more important to focus on their commonalities rather than their differences. These ideas will be developed further in Chapters 8 and 9.

## 7. NSP in Prisons

### 7.1. NSP in prison, research and the research–policy nexus

This is a case study of the research–policy nexus in relation to NSP in correctional facilities. As with the previous case studies, it begins by setting out the events, features and patterns of the policy-making process, research, and the relationship between them. A chronology of events for this case study is set out in Table A16 in the appendices for this chapter.

#### 7.1.1. Tentative and equivocal policy

Since 1996, the National HIV/AIDS Strategies have stated that prisoners should ‘...have similar access to education and prevention initiatives as the rest of the community’ (Commonwealth Department of Health and Family Services 1996). This is known as the ‘principle of equivalence’ and is the foundation of the WHO guidelines on the prevention and management of HIV in prison (Bollini, Laporte et al. 2002). While not saying there should be NSP in Australian prisons, the policy rationale is there if any jurisdiction wanted to implement NSP. None has.

The following table sets out various statements relating to NSP in prisons made in the context of national HIV/AIDS policy in Australia.

TABLE 7:1 POLICY STATEMENTS ON NSP IN PRISONS

Date	Policy-related statements	Policy Position on NSP in Prisons
1986	NACAIDS Prison Subcommittee Minimising the Spread of HIV in the Australian Prison System. (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 42)	Position on NSP not known. Advocated free availability of condoms, voluntary testing and segregation of prisoners with HIV or AIDS.
1988	AIDS: A time to care, a time to act. (Commonwealth Department of Community Services and Health 1988: 141)	NSP recommended as ‘one option’. Expansion of methadone also recommended.
1989	Report of the Working Panel on Intravenous Drug Use and HIV/AIDS (Working Panel on Intravenous Drug Use and HIV/AIDS 1989)	NSP recommended ‘...via some mechanism acceptable to prisoners and corrective service officers...’ Also recommended less custodial sentences for drug offences.
1989	National HIV/AIDS Strategy (Commonwealth Department of Community Services and Health 1989)	NSP not mentioned. Access to condoms, sterilising agents, and methadone treatment recommended prevention measures.

Date	Policy-related statements	Policy Position on NSP in Prisons
1992	Report of the Evaluation of the National HIV/AIDS Strategy. (National Evaluation Steering Committee 1992)	NSP not mentioned. States and Territories criticised for lack of progress in making condoms, sterilising agents and methadone available.
1993	National HIV/AIDS Strategy 1993-4 to 1995-96. (Commonwealth Department of Health Housing Local Government and Community Services 1993)	Continuation of previous policy implied—no specific reference to HIV prevention measures in prisons—prisoners noted as a priority group for education and prevention.
1995	Federal Health Minister, Dr Carmen Lawrence, statement in television current affairs interview.	NSP recommended.
1995	Evaluation of the National HIV/AIDS Strategy 1993-4 to 1995-6 (Feachem 1995)	NSP recommended
1996	National HIV/AIDS Strategy 1996-7 to 1998-99 (Commonwealth Department of Health and Family Services 1996)	NSP in prison not mentioned. 'Principle of equivalence' stated: 'Residents of correctional and other residential institutions should have similar access to education and prevention initiatives as the rest of the community.'
1998	Protecting Our Investment (Australian National Council on AIDS and Related Diseases (ANCARD) 1998)	NSP 'warrants further consideration'.
2000	National HIV/AIDS Strategy 1999-2000 to 2003-4 (Commonwealth Department of Health and Aged Care 2000)	NSP in prison not mentioned. Principle of equivalence re-stated.

None of the National HIV/AIDS Strategies explicitly support NSP in prisons. These documents require State and Territory Government and Commonwealth Cabinet endorsement. The documents that do support NSP in prisons did not have to go through this approval process. Public health advocates, including the Chair of the Australian National Council of AIDS, Hepatitis C and Related Diseases (ANCAHRD), have argued that NSP should be provided in prisons, or at least trialled and evaluated (Harding 1987; Wodak, Shaw et al. 1991; Crofts 1997; Puplick 1998; Levy 1999). This has occurred successfully in Switzerland since 1994 and NSP is now being trialled in a number of other European countries (Nelles, Fuhrer et al. 1998)(Levy interview).

### ***7.1.2. The threat of the prison as 'HIV incubator'***

Early advocacy for NSP in prisons was based on the threat that prisons might be an 'incubator' for an HIV epidemic among IDU. This view was supported by the same research and the same epidemiological argument that supported NSP in the community. All the factors were present, only in greater measure. A high proportion of the prison population have a history of drug injecting; prisoners report drug injecting and needle sharing; needle supply is restricted so a large number of prisoners potentially use the same needle; and in male prisons there is the added risk of unprotected sex to fuel the epidemic.

Internationally, public health advocates urged action. T. W. Harding advocated NSP in prisons in *The Lancet* in 1987 (Harding 1987). At the same time, the World Health Organisation Special Program on AIDS convened a consultation on the control of AIDS in prisons with delegates from 26 countries including Justice Michael Kirby from Australia. It supported the principle of equivalence and suggested ‘further study’ on the provision of NSP in lower-security correctional facilities (Harding 1987: 1263-4).

Matt Gaughwin and Bob Douglas, two Australian epidemiologists, were well aware of the HIV/AIDS threat and the incubator hypothesis and set about assessing the prevalence of HIV risk factors in prison and estimating the risk of an HIV epidemic. Their 1989 publication contained a dire warning (Douglas, Gaughwin et al. 1989). Douglas reported at interview that it was his research on this topic that led him, as Director of the National Centre in Epidemiology and Population Health, to approach the Australian Institute of Criminology to co-convene the HIV/AIDS and Prisons conference in 1990.

### **7.1.3. The 1990 HIV/AIDS and prisons conference**

The research presented at the conference by Douglas, Gaughwin, Dolan and Wodak showed that drug injecting takes place in prison and argued that this was likely to happen regardless of attempts to stamp it out (Dolan 1991; Douglas 1991: 25; Gaughwin, Douglas et al. 1991; Wodak, Shaw et al. 1991). Wodak argued that attempts to prevent injecting would increase the risk associated with each episode of injecting (Wodak, Shaw et al. 1991).

Of the 27 speakers at the conference, the conference papers show that eight supported NSP in prison (usually by arguing for a pilot study). Four of these were public health researchers (Douglas, Gaughwin, Dolan and Wodak). None was from a correctional authority. Details of the speakers and their position on NSP are set out in Table A18 in the appendices for this chapter.

The conference communique said ‘...consideration should be given to a careful, time-limited evaluation of a pilot strict needle exchange program...’. This was faxed to every State and Territory politician in Australia and all relevant Federal Ministers (Douglas 1991: 24).

Correctional authorities at the conference were either guarded or hostile. Kerr questioned the motives of those who wanted to use HIV to influence prison health policy and said that academics and outsiders are ignorant of the real problems in prisons. He criticised the idea of NSP in prison as ‘unrealistic’ on the grounds of morality and safety. He said ‘... it is important to remember... that prison officers, prison management and prisoners will not be impressed by policies that emanate from public fear, if such policies are at the expense of their own legitimate interests’ (Kerr 1991: 118).

#### **7.1.4. The stabbing of Geoff Pearce**

The conference occurred soon after Geoff Pearce, a NSW prison officer, had been stabbed with a blood filled syringe by an inmate with AIDS. Every key informant said the Pearce case has influenced policy on NSP in prisons ever since because the public health argument had to contend with the prison officers’ argument that syringes in prison can become weapons. Pearce died of AIDS in 1997.

#### **7.1.5. NSP, prisoner advocates and political realities**

Key informants identified prisoners as a marginalised group in Australian society. The hardship they endure in prison, including exposure to disease risks, seems of little concern to the majority of citizens (Schurr 1991: 183). This is not unique to Australia (Bollini, Laporte et al. 2002).

All key informants were of the view that correctional ministers and governments want to be seen to be ‘tough’ on crime. Conversely, they want to avoid being seen to be making life too easy for prisoners. State and Territory election campaigns have for some time been characterised by ‘law and order auctions’ (Saunders 2001).

The stabbing of Geoff Pearce gave the then Minister for Corrective Services, Michael Yabsley, the opportunity to realise his ambition “...to be remembered as someone who has put the value back in punishment” (*The Independent Monthly*, October 1990)’ in (Egger and Heilpern 1991: 79). He ordered that all prisoners be stripped of their personal belongings in order to make it easier to detect every needle (Yabsley 1991). There are no political rewards for implementing NSP anywhere, let alone in prison. The

only politician who has supported NSP in prison on the public record is Carmen Lawrence in 1995 when she was Federal Health Minister (Selvanera 1996).

There is relatively little non-government advocacy for the rights of prisoners and their health. The notable exception is the Criminal Justice Coalition comprised of the Aboriginal Deaths in Custody Watch Committee, the NSW Council for Civil Liberties, CRC Justice Support (the acronym CRC is not explained in the documentation), the Prisoners Action Group, the Redfern Legal Centre, Justice Action, the Penal Reform Council, and Academics for Justice. This group has variously concerned itself with monitoring the treatment of prisoners in gaols in NSW, support services for prisoners and their families, and advocacy of prisoners' rights (Criminal Justice Coalition of NSW Australia 1998). Justice Action's website contains an article titled 'The case for needle and syringe exchange in prison' (Selvanera 1996). It identifies the groups who have come out in support of NSP in prisons as: the IGCA Legal Working Party, the WHO, the former Commonwealth Minister for Health, Carmen Lawrence, and the former President of the AMA, Brendan Nelson. Bollini and others note that the issue of HIV/AIDS has been a unique influence for reform of prison health services internationally, largely due to the interest of organisations external to the prison system (Bollini, Laporte et al. 2002).

Key informants felt that correctional authorities, government and the media generally disregarded the groups involved in the Criminal Justice Coalition. They have even come under surveillance by the Bureau of Criminal Intelligence because of the fear that they were a threat to prison security and officer safety (Wright 1998).

Dolan, Wodak and Penny wrote 'Inmates have few allies and only a small minority of public health advocates are willing to act on their behalf' (Dolan, Wodak et al. 1995: 826). In the same article they express powerlessness at being able to create change in the face of prison authorities that appear to be 'semi-autonomous'.

### **7.1.6. The correctional policy context**

#### ***Trends in prison ideology***

Prisons are said to have four basic functions: incapacitation, deterrence, retribution, and reformation (Editorial 1985; Puplick 1998: 208). It is commonly noted that the first three have a synergy and have been in ascendancy in the western world for several

decades in what is called ‘the justice model’ (Editorial 1985). NSP aims to keep prisoners healthy, and is therefore inimical to the retributive function of prisons. NSP implies that prisoners will be able to take drugs in prison and therefore undermines its deterrent value. While NSP may fit with a ‘reform’ view if this is conceptualised in terms of harm minimisation, there is no evidence that the goal of reform is a priority vis-à-vis the other prison functions, or that a harm minimisation view holds sway in drug treatment programs. The ‘justice model’ of prison ideology fits well with the ‘tough on crime’ wave.

### ***HIV/AIDS and ‘prison reform’***

HIV/AIDS emerged at a turbulent time in prison policy. A ‘prison reform’ agenda arose from various sources such as the Nagel Royal Commission into prisons in NSW in the 1970s. It found widespread corruption, abuse and maladministration in that State’s prison system and highlighted problems with prison health services (Levy interview). There were criticisms about a lack of transparency in prison administration and the inhumane treatment of prisoners (Vinson 1986). The Inquiry into Aboriginal Deaths in Custody in the 1990s kept this level of defensiveness high.

Concern over HIV/AIDS in prison systems emerged soon after the discovery of AIDS (Wormser, Krupp et al. 1983). In its *Report on HIV/AIDS in Prisons*, the WHO Global Program on AIDS argued that the response to HIV/AIDS in prisons should work on ‘humiliating and dehumanising conditions’, a lack of basic human rights, and overcrowding (World Health Organisation Global Program on AIDS and Crime Prevention and Criminal Justice Branch United Nations Office in Vienna 1990).

Disturbances in Australian gaols over HIV positive prisoners began in South Australia in 1985 (Behrens-Peters 1991: 200). The issues raised by HIV/AIDS included the question of compulsory testing for HIV and segregation of prisoners with HIV/AIDS, infection control procedures, education and training for inmates and staff, and privacy and confidentiality (Bloor 1991; Harmsworth 1991; Yabsley 1991). In all of these matters, the rights and interests of prisoners were often seen to be in opposition to those of prison officers and the good order of the gaols (Norberry, Gaughwin et al. 1991).



### ***Drugs in prisons***

From a public health perspective drug use is a health issue. In prison, drugs are linked with corruption, violence, stand-over tactics, intoxication, overdose, suicide, theft and drug trafficking (Aristidou 1996). Drug use was a major issue for all Australian jurisdictions and New Zealand in the 1990s as indicated by three national conferences involving all States and Territories and New Zealand in 1996, 1998, and 1999 (Ellem 1996; Ellem 1998). Queensland, South Australia and New Zealand had inquiries on the matter (Coyle 1998; Robinson 1998; White 1998).

Blood Borne Virus (BBV) transmission was not discussed at the first conference in 1996 that focussed exclusively on the development of a 'national strategy' on surveillance and security to eliminate drug use from prisons. The second conference in 1998 dealt with the 'corrections–health interface'. In his introduction to the conference proceedings, Ken Olsen from Queensland Corrective Services, described the interface as 'contentious' and 'polarised' (Olsen 1998). The conference resolved to try to improve the links with health authorities. A report of the third conference was not published but it did involve a discussion of NSP in prisons. Several key informants attended the discussion and described it as 'terrible', 'awful', and 'a step backwards'. There is evidence that prison authorities and prison unions saw NSP as a hindrance rather than help in resolving the problems they saw as priority (White 1998).

### ***Contested responsibilities for prisoners***

The question of the legal responsibility of governments for transmission of BBVs through drug injecting in prison is untested by the courts (Puplick, Egger, Anonymous and Vumbaca interviews). Correctional authorities have responsibilities set out under legislation and regulation to provide health services to prisoners and to exercise a duty of care in relation to prison staff and inmates (Godwin 1991; Harmsworth 1991). The critical question is how to interpret the meaning of '...reasonable medical care and treatment necessary for the preservation of health' (Harmsworth 1991: 127). All key informants felt that the most likely route to implementation of NSP would come from a successful court challenge by a prisoner infected while in gaol (Dolan, Wodak et al. 1995: 831). NSP was first introduced in a prison in 1994 as an act of 'medical disobedience' by a doctor working in a prison in the Swiss Canton of Solothurn (Nelles and Harding 1995) and soon after through a pilot project in a women's prison in the

Canton of Bern (Nelles, Fuhrer et al. 1998). Public health advocates have long criticised the way correctional authorities have exercised their responsibilities (Godwin 1991: 172; Egger and Heilpern 1991: 79; Crofts 1997; Levy 1999). At the 1990 HIV/AIDS and Prisons conference, Michael Kirby (Australia's representative on the WHO Global AIDS Commission) said 'Unless governments, and prison administrators can absolutely guarantee a totally drug-free environment, it is their plain duty to face up to the risks of the spread of HIV infection by the use of unsterile injecting equipment in prisons' (Kirby 1991: 18).

### **7.1.7. NSP—a health sector agenda**

Attempts to generate policy debate and research on NSP in prisons have come almost entirely from the health sector. In 1989 the Commonwealth Department of Community Services and Health commissioned Sandra Egger and Hans Heilpern to produce the report *AIDS in Australian Prisons—Issues and Policy Options* (Egger and Heilpern 1991; Fortuin 1992). This was followed in 1990 with funding for the National AIDS in Prisons Information Clearing House (NAIPIC) which attempted to bring a national effort to information, coordination and training with respect to HIV/AIDS in prisons (Fortuin 1991). The 1990 conference on HIV/AIDS and Prisons was convened by the National Centre for Epidemiology and Population Health and the Australian Institute of Criminology (Norberry, Gaughwin et al. 1991; Douglas interview). At the instigation of Michael Levy, the Public Health Association of Australia held a conference in 1999 on the issue of prison health (Public Health Association of Australia 1999).

When correctional authorities describe processes that have led to change in policy they emphasise that it occurs on their terms and involves negotiation with three groups—correctional administrators, prison officer unions, and prison medical services. People with expertise in HIV/AIDS, communicable diseases and education are coopted as required (Bloor 1991: 134; Kerr 1991: 117; HIV and Health Promotion Unit 1996: 147).

While Commonwealth Department of Health money was welcome in the early stages of HIV/AIDS in Australia, policy interference was not. Stephen Kerr (Manager, Corrections Health Service, Health Department, Victoria; Kerr 1992) said that the States do not give any credence to federal views on prisons because it is a State matter and the Commonwealth has no experience. More recently, the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) has been working with the

network of corrections health authorities on matters relating to BBV transmission and the establishment of national standards (Levy, Burton, Puplick interviews). Public health advocates lament the fact that the Commonwealth government is largely irrelevant to State and Territory correctional policy (Dwyer 1991; Public Health Association of Australia 1999; Dolan 2001). The ability of the Commonwealth to influence correctional policy is impeded by the lack of national corrections policy infrastructure with which to engage.

In 1992, Kerr argued that small jurisdictions do not accept the views of the large eastern States or the views of the commentators whose primary point of reference is those States. He said that prison systems are relatively small, fiercely independent, not given to research and development and education. ‘With these factors in mind, we can now understand why the policies that are suggested by academic and international bodies are not always achievable or indeed desirable in the Australian context’ (Kerr 1992: 49).

### **7.1.8. Patterns in the conflict between health and corrections**

#### ***Lines of accountability and authority***

The WHO *Report on HIV/AIDS in Prison* argued strongly that prison medical services should be given autonomy from their correctional masters in order to adequately serve their patients needs (World Health Organisation Global Program on AIDS and Crime Prevention and Criminal Justice Branch United Nations Office in Vienna 1990). New South Wales is the only jurisdiction that does this in Australia and this was introduced in 1994 (Levy and Egger interviews). This power struggle remains current (Harding 1997; Levy 1999). Polarisation of health and correctional world-views has reached extremes in relation to BBV transmission in prison. In 1997, Crofts described the prison health policy in relation to hepatitis C as a ‘cruel and unusual punishment’ and accused prison authorities and governments of not discharging their responsibilities for prisoner health (Crofts 1997). Two years later, Levy repeated Crofts’ criticism and argued that the prison policy of ‘zero tolerance’ is harmful to the health of inmates and staff (Levy 1999).

### ***The struggle to know what is going on in prisons***

In 1990, Egger and Heilpern criticised the approach to HIV testing in Australian prisons saying ‘The information available from the prison systems is inadequate to monitor the HIV epidemic in Australia’ (Egger and Heilpern 1991: 66). Several key informants said that, either by accident of design, correctional HIV testing policies were so designed to ensure that instances of transmission occurring in prison could not be identified.

The national monitoring system for HIV infection among prison entrants was agreed by all jurisdictions in 1991 and is coordinated by the National Centre in HIV Epidemiology and Clinical Research (McDonald, Ryan et al. 1999). The purpose of this system is not to measure BBV transmission occurring in prison but to measure prevalence of HIV among the population entering prison. A report from this system for the period 1991 to 1997 found that while HIV antibody testing was ‘high’ at 72 per cent, prevalence was low at 0.2 per cent (McDonald, Ryan et al. 1999).

In her reports of HIV transmission occurring in prison, Dolan notes how difficult it is to detect such cases due to rapid turnover in the prison population (Dolan, Hall et al. 1994b). She argues that the proposition that HIV transmission occurs less frequently in prison than in the community is less likely to be true than the proposition that it is just more difficult to confirm that the transmission took place in prison (Dolan and Wodak 1999a).

Others have noted the lack of standards and measurement tools to monitor correctional health policies generally (Lowe and Cotton 1999: 12) (Levy 1999). Kerr said that prison systems ‘...are hesitant about surveys of injecting drug usage and homosexuality as they fear adverse public reaction’ (Kerr 1992: 50). Against this general trend, Dolan and others twice measured access to bleach in NSW prisons and showed improvements over time (Dolan, Hall et al. 1994c: 3) (Dolan, Shearer et al. 1996a: 3).

### ***Discourse: harm minimisation versus security***

Another dimension of the struggle between health and correctional authorities is the struggle over language. NSP advocates have attempted to make harm minimisation discourse the dominant discourse. The *Fourth Strategy* says that in relation to people in custodial settings the first challenge is to ‘implement appropriate harm-minimisation

programs in custodial settings' (Commonwealth Department of Health and Aged Care 2000: 18, 19).

Correctional authorities are very aware of competing discourses and what is at stake in accepting harm minimisation language. At the 1996 *Drugs in Prisons* Conference representatives of each jurisdiction presented a paper on their jurisdiction's policy on drugs in prisons. Speaking from a Victorian perspective, Roach and Alberti said:

The Federal Government embraced the concept of harm minimisation in the 1980's. Fully endorsed, this approach embraces the reality that substance use will always be part of our community... In practical terms, a harm minimisation strategy encompasses such activities as needle exchange which are quite challenging for a prison environment. Issues of security, prison culture and personal values are significant obstacles to the full implementation of harm minimisation. Progressive programs have the task of addressing this clash of paradigms in order to develop and implement strategies which are truly in keeping with best practice. (Roach and Alberti 1996: 47-8)

The New Zealand representative wrote 'Harm minimisation... is a controversial area with much debate about the application of needle exchange and methadone programs to prisons...' (Asher 1996: 106). In acknowledging the tension between security objectives and 'liberal inmate management programs which are conducive to offender rehabilitation', the NSW representative says that 'In reaching an acceptable balance between these two aspects, it must be carefully identified which predominates in the public interest' (Kelly 1996: 51).

The delegates from South Australia said that harm minimisation was accepted as policy in that State and noted no conflict with security objectives (Leggat and White 1996: 75). As a key informant, White said that tension did exist in the practical application of harm minimisation and that correctional officers and administrators would often acknowledge that while harm minimisation was the official policy, they did not necessarily agree with it. In her paper at the 1998 *Drugs in Prisons* conference, White describes the process of attempting to introduce organisational change to prison drug policy using harm minimisation as the conceptual tool for structuring thought (White 1998).

When reporting on the adoption of NSP in a Swiss prison, Nelles pointed to the 'victory' in terms of competing discourses: '...Swiss authorities have shown their

colleagues elsewhere that it is possible to advocate public health measures in an environment where the language of discipline, security, and punishment predominate' (Nelles and Harding 1995).

***Discourse: 'incubators' versus 'security packages'***

The 'incubator' was the central metaphor used in the 1980s public health discourse on the need for HIV prevention in prisons. But as with the language of harm minimisation, correctional discourse challenged it on many levels. 'Incubator' emphasises connection with the outside world, the lack of control of prisoner drug taking, and makes public health research on epidemic dynamics relevant. Correctional discourse emphasises the closed and sealed nature of the prison system, the control and modification of prisoner behaviour and renders public health research on risk factor prevalence irrelevant. The Director of Prison Services in Victoria said detection and deterrence were just two of the 'weapons' from the substance abuse 'armoury' used to prevent 'breaching the security packages' of prisons (Delphine 1996).

Michael Kirby said that many people might not care if prisoners became infected but said that 'By protecting them we protect society' (Kirby 1991: 19). Douglas said that 'what goes on in the prisons could materially influence the course of the epidemic outside prison' (Douglas 1991: 24). The argument also appeared in the conference communique and elsewhere (Dwyer 1991; Egger and Heilpern 1991). It is now being used to promote change to prison policy on HIV to combat the newly emerging epidemics in Eastern Europe (Bollini, Laporte et al. 2002).

Michael Yabsley, the NSW Minister for Corrections, said that prisons were not an 'incubator' but a 'funnel' that brings together high-risk offenders. Harmsworth said that in 1985 prisons were dubbed as the incubators of HIV in society but by 1990 and 17,000 prisoners later, only 59 HIV positive prisoners had entered the Victorian prison system. 'Not exactly the deluge predicted in 1985 when prisons were seen as the "hot beds" for AIDS in society' (Harmsworth 1991: 130).

***Discourses: care versus punishment***

A third point of struggle between health and corrections discourse relates to '...the delicate balance between care and punishment' (Bollini, Laporte et al. 2002: 88). The principle of equivalence promotes care and erodes the differences between inside and

outside prison, and between prisoner and non-prisoner. In his address to the 1990 *AIDS in Prisons* Conference, Michael Kirby said that the infection of a prisoner with HIV/AIDS because that person lacked access to self protection was 'just as unpalatable' as the infection of a prison officer (Kirby 1991: 19). Speaking just two months after the stabbing of Geoff Pearce, this statement is an even more radical affront than it otherwise would be to correctional discourse because it says that prison officers are no different to prisoners, not even when it comes to the State's duty to provide care and protection.

### **7.1.9. Avenues to change in correctional policy**

If it were the case that correctional policy is immune to all change, then there would be nothing in particular about NSP to explain. But there are examples of change in correctional policy and practice that highlight particular mechanisms and approaches.

Vicki White, a consultant to South Australian Corrective Services from the Drug and Alcohol Services Council, has described her work on the development and implementation of an alcohol and other drugs strategy in that jurisdiction. This entailed keeping NSP off the agenda to avoid industrial opposition (White 1998: 75). This has enabled the gradual implementation of a methadone program in that jurisdiction.

Gino Vumbaca reported on processes of negotiation and change in relation to bleach and condoms provision in the NSW system. While condoms had originally been bracketed with NSP as a measure that prison officers opposed with equal vigour, over time the opposition to condoms weakened. When a court case on video rentals defined prisoners cells as 'private' spaces for the purposes of watching videos, it was more difficult for the Government to argue these were 'public' places with respect to sexual activity. In the end, prison officer representatives found it difficult to argue that condoms posed a real threat to prison officer safety and the path was cleared for a pilot project and implementation (Vumbaca interview). Clunies-Ross reports on processes of discussion and negotiation that occurred within the Communicable Diseases Committee of the Corrections Health Board in Victoria that led to the introduction of bleach in that jurisdiction (Clunies-Ross 1991: 277).

In contrast to these examples was an attempt by the National Drug and Alcohol Research Centre (NDARC) to conduct a feasibility study on NSP in prisons. This originated from outside and senior corrections administrators and prison officers

‘declined’ to participate in the focus groups and would only discuss the matter in a meeting of union delegates. The result was that they ‘...were unanimously opposed to prison syringe exchange, arguing that it would seriously threaten their safety’ (Dolan, Rutter et al. 1996b).

#### **7.1.10. Partial realisation of the principle of equivalence**

HIV and BBV prevention measures other than NSP that are available in the community have been partially and unevenly implemented in prisons. General education and training for staff and inmates was implemented by all correctional services in the 1980s. The *First Strategy* gave unqualified support to access to condoms, sterilising agents, and methadone maintenance treatment in prisons. Sterilising agents for cleaning needles became available in all jurisdictions in the early 1990s. While methadone has been available in NSW prisons since 1986, its implementation in other jurisdictions is limited to South Australia and small programs in Victoria and Queensland. Condoms have gradually become available in NSW since the mid-1990s, but in no other jurisdiction.

#### **7.1.11. Research and NSP**

If we turn to the pattern of research related to NSP in prisons we find that basic epidemiological research was the basis for the early fears that prisons might be incubators for HIV/AIDS (Wormser, Krupp et al. 1983; Harding 1987). Australian research, however, appears to have been slow to start and consists of a relatively small number of studies. These are set out in Table A17 in the appendices for this chapter. The research focuses on determining the nature and extent of risk factors, prevalence, and instances of BBV transmission in prison. Some research has evaluated the availability of bleach as a preventive measure and there is more research in train on the effectiveness of methadone as a BBV prevention measure (Dolan interview).

There is almost unanimous advocacy for NSP in prison among the researchers who have published in the field of BBV transmission in prisons. Of the 19 studies identified, the published reports of nine of these give explicit support for the provision of NSP in prison, usually expressed in terms of a recommendation for a closely controlled pilot study. The other 10 studies state no position on the question of NSP, but eight of these are by authors who elsewhere express explicit support for it. There is a small handful of researchers who are heavily represented among the authors of these studies. Some of



these researchers—Alex Wodak, Kate Dolan, Nick Crofts, Wayne Hall—were also prominent in the research on blood borne virus transmission among injecting drug users in the community.

When researchers have documented cases of HIV and HCV transmission in prison they have recommended that NSP be trialled in Australian prisons (Dolan, Hall et al. 1994b; Haber, Parsons et al. 1999; Dolan and Wodak 1999a; Post, Dolan et al. 2001). When research on trial NSP in European prisons appeared, Australian NSP advocates used this to advocate for similar research in Australia (Dolan, Rutter et al. 1996b). These recommendations tend to draw criticisms from prison authorities (Liew 1994; Eyland 1996).

## **7.2. ACF analysis**

### ***7.2.1. Advocacy coalitions in the NSP in prisons policy subsystem***

An Advocacy Coalition Framework explanation for the observed pattern in policy begins with the proposition that the dominant advocacy coalition on HIV/AIDS policy is unable to have its core values and beliefs adopted in correctional policy. It can articulate a national policy position supporting NSP in prison but it does not control correctional policy or practice. An ACF explanation suggests that there is a dominant advocacy coalition in the correctional policy subsystem that controls prison policy and is independent of the HIV/AIDS policy subsystem. These two policy subsystems have a shared interest in the HIV risk behaviour in prisons but different values and beliefs relating to the definition of that problem and possible solutions. The ambiguous position on NSP found in the national HIV/AIDS policy documents reflects a stalemate in an unresolved conflict between the dominant advocacy coalitions in the two policy subsystems.

The most concrete illustration of the existence of two discrete policy subsystems is that there is no cross membership between their respective national committee structures—the Australian National Council on AIDS, Hepatitis C and Related Diseases and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases, and the intergovernmental committee of corrective services administrators. More specifically, the national policy statements set out in section 7.1.1 were produced by the HIV/AIDS dominant advocacy coalition, not by correction authorities. The principle of equivalence

is retained because of its central importance to the core values and beliefs of the HIV/AIDS dominant advocacy coalition, which see the promotion of human rights as integral to HIV/AIDS policy. The lack of a specific requirement for NSP is because the HIV/AIDS dominant advocacy coalition does not have the political resources to direct policy in the corrections policy subsystem.

### ***7.2.2. Beliefs and values of the NSP in prisons advocacy coalitions***

Their beliefs and values illustrate the differences between the respective dominant advocacy coalitions. These are presented in Tables A19 and A20 in the appendices for this chapter. NSP advocates argue that prisoners have the same right to health and safety in gaol as prison officers (Kirby 1991), that prisoners are incarcerated as punishment, not for punishment (Puplick 1998), and that the promotion of human rights is integral to the goals of public health (Moodie, Timberlake et al. 1996). It is these beliefs that underpin the principle of equivalence. For correctional authorities, the safety of prison officers and staff comes first (Rutter, Dolan et al. 1995), and the practical management of gaols requires restrictions on the possessions and facilities available to prisoners (Kerr 1991; Yabsley 1991)

A second area where beliefs are markedly divergent is in relation to harm minimisation. While this might be described as the primary orientation of public health practitioners in relation to drug use, correctional administrations see security and the elimination of drug taking as higher order objectives. Attempts to incorporate harm minimisation into correctional practice face continual barriers (Hunter 1998; White 1998; White interview).

### ***7.2.3. Research and struggle over NSP in prison***

An ACF explanation for the pattern of NSP in prisons research is that the researchers who study matters relating to NSP in prison are part of the HIV/AIDS dominant advocacy coalition and not part of the corrections dominant advocacy coalition. A closer inspection of the form of the research should show that it follows a pattern designed to demonstrate the failure and culpability of correctional authorities and hence assist the cause of the HIV/AIDS advocacy coalition. As noted above, this is precisely the form and content of the research. The early work on risk factors had the effect of supporting the incubator argument and the later work documenting transmission had the

effect of highlighting the failure of correctional authorities. The 1990 HIV/AIDS and Prisons Conference was an attempt to create an environment in which public health research would have maximum impact on the prisons policy subsystem. The outcome suggests it succeeded at the level of shifting the views of the beliefs that attended but failed to achieve systemic change. The lack of national prisons policy infrastructure meant that there was no body with responsibility to take this forward.

#### ***7.2.4. Research and power in the NSP in prisons policy subsystem***

An ACF explanation for the way that virtually all the published NSP-related research comes from the HIV/AIDS dominant advocacy coalition and there is none from the corrections dominant advocacy coalition is that the latter is not required by other actors in its subsystem to engage in health related research or analytical debate in order to support its position.

For this to occur power must be highly centralised in the prison policy subsystem and its dominant advocacy coalition must be able to refuse calls for pilot studies with impunity. Those who conduct research on NSP related matters must be largely insignificant in the corrections subsystem. The testimony of key informants strongly supports this analysis. They said that due to the marginal status of prisoners in society, the political advantage in being tough on crime, and the lack of powerful prisoner advocates to call prison authorities to account, those authorities are largely immune to criticism from those who want to promote prisoner health needs.

#### ***7.2.5. The ACF and the research–policy nexus in NSP in prisons***

If the dominant advocacy coalition in the prison subsystem can act with impunity, how does the ACF account for the slow, if uneven, change in correctional policy on HIV/AIDS prevention in prisons? Is there any hope that research will have an impact on correctional policy?

The ACF argues that policy change occurs as dominant advocacy coalitions (DAC) adjust the strategies they use to realise their core beliefs and values. Change may reflect changes in the broader environment or ‘policy oriented learning’. The critical aspect of the change process is that DACs will adjust secondary or peripheral aspects of policy where necessary but not their core beliefs and values.

This explanation is a reasonable reflection of the way the correctional subsystem DAC has responded to the threats of HIV/AIDS. They quickly accommodated and implemented change in the form of education programs for staff and prisoners as these represented no threat to their core beliefs and values. The use of peer education techniques for both staff and prisoners fitted well with prison culture that emphasises hierarchy based on experience and respect within the ranks of prison officers and prisoners alike. Policy change was achieved by correctional authorities coopting outside expertise and negotiating change within the modus operandi of the prison environment. Thus change was accomplished without exposing the DAC to criticism or vulnerability. The introduction of bleach could be rationalised as a measure to improve hygiene generally, not an admission to the reality of drug injecting. Condoms became possible within correctional facilities in NSW because of changes to the law, not through any surrendering of core values and beliefs to the HIV/AIDS dominant advocacy coalition.

The NDARC attempt to undertake a feasibility study violated the rules for policy change. In ACF terms, it was an attempt to achieve ‘learning’ across advocacy coalitions. But the method used was highly likely to fail. The process was established by a rival advocacy coalition, external to the prison system, and it challenged one of the core beliefs of the dominant advocacy coalition—the primacy of prison officer safety over prisoner health objectives.

The partial success of harm minimisation approaches in South Australia is perhaps a product of the growing dependence of prison authorities on drug treatment expertise as a result of the increasing prevalence of drug users in prison. Duke has studied this phenomenon in the UK and found that drug treatment agencies also become dependent on prison authority contracts so a network of interdependent relationships develops (Duke 2000: 404). In ACF terms this signals a shift in the composition of the dominant advocacy coalition and opens the way for changes to the core beliefs and values and more significant long-term change to policy. This may occur in response to research but only to the extent that the dominant advocacy coalition is able to control the research process. The other route to change in ACF terms is a ‘major perturbation’ to the wider political environment that leads to change in the corrections dominant advocacy coalition. Given that the major inquiries of the 1970s, 1980s and 1990s failed to produce this effect it is difficult to see any change at any point in the future.

### **7.3. PMOF analysis**

The construct called the ‘policy making organisation’ as set out in Chapter 2 attempts to capture the institutions of the state directly involved in the deliberation, production and implementation of policy. The topic of NSP in prisons raises the possibility of competing responsibilities and political agenda, as well as cooperation and synergy between health and correctional authorities.

#### ***7.3.1. The policy orientation of the PMO***

##### ***Electoral risks and opportunities***

The case study material noted the low social status of prisoners and the electoral appeal of being ‘tough’ on crime. This translates into a minimalist approach to prisoner health and wellbeing that satisfies duty or care requirements but nothing else. Instigating NSP in prisons could carry the electoral risk of being seen to encourage drug use in prisons.

##### ***Tactical risks and opportunities***

Several key informants said that the correctional portfolio is at the bottom of the ministerial pecking order in State and Territory Governments. It is either a punishment post or proving ground—the end or start of political careers. The opportunities for political advancement come from risk management strategies with a bias towards conservatism. There are no political incentives for the Commonwealth to pursue greater involvement in correctional policy. There are no incentives for State correctional ministers to be the first jurisdiction to provide NSP in prison.

##### ***Economic/financial risks and opportunities***

There are financial incentives for the State and Territory Governments and the Commonwealth to avoid epidemics of BBVs occurring within prisons. However, it seems that the financial risks are borne by health portfolios, not correctional portfolios. On the other hand, were NSP to be implemented, the resources might have to come from constrained and contested budget allocations. There appears to be no financial risk for correctional authorities in not implementing NSP, and an opportunity cost in providing NSP.

### ***Contextual risks and opportunities***

The major contextual risk for politicians in relation to prisons is the management of the prison system as a whole. Prison authorities see drug injecting as a security and criminal matter primarily not a health issue. To the extent that NSP might compromise the management of these matters its relative priority will be low.

### ***Ideological risks and opportunities***

While prison reform ideologies may have had some appeal for some politicians in the 1970s when the worst horrors of the prison system were exposed, these seem to have gone from the political landscape some time ago.

### ***The policy orientation of the bureaucratic arm of the PMO***

Whatever dimension of prison administration one explores—relations with unions, the objectives of safety and security, drug treatment and rehabilitation—there seem to be few benefits for correctional administrators from implementing NSP.

Even if politicians and senior administrators thought that NSP was the right thing to do for prisoner health and welfare, they may consider the costs too high. As one key informant put it, if it comes down to deciding which risk to take—the risk of not implementing NSP and having BBV transmission go unchecked, or the risk of implementing NSP and facing major industrial action—Ministers and bureaucrats are much more likely to take the first risk. The risk calculation goes like this: there is no evidence that an epidemic will occur in the absence of NSP; there is no evidence that NSP would prevent an epidemic; HCV is so prevalent, it wouldn't have much impact anyway; HIV is so rare that NSP is unnecessary; if NSP did prevent an epidemic, you would not know about it; NSP draws attention to the possibility of BBV transmission and creates an expectation that it is a correctional responsibility; and, NSP would almost certainly guarantee industrial action. The threat of industrial action is not idle—the introduction of condoms into NSW prisons provoked threats of major industrial action (Lagan 1995).

If there had been a time when this risk calculus looked different to Ministers and senior administrators, it probably would have been when the uncertainties about the HIV/AIDS threat were at their peak, probably in the mid- to late 1980s. The fact that the dire

predictions about prisons as incubators did not eventuate has probably had the effect of confirming a conservative approach from correctional policy makers.

The table below summarises policy orientation of correctional ministers and authorities across the five indicators.

**TABLE 7:2 SUMMARY OF PMO ORIENTATION TOWARDS NSP IN PRISONS**

<b>Dimensions of Risk and Opportunity</b>	<b>Political Orientation</b>	<b>Bureaucratic Orientation</b>
Electoral	Many electoral factors against NSP in prison, none in favour of it. But Health authorities still committed to NSP in the community.	NA
Tactical battles	Nil increases in political power to be derived from NSP in prison.	Prison officers reject NSP and have determining role. NSP proponents are outside 'academics'
Economic and Financial	Costs of BBV transmission carried by health portfolio.	
Contextual	Primacy of 'zero tolerance' for illicit drugs over drug harm prevention in prison. Some acceptance of harm minimisation in the community.	
Ideological	Deterrence and retribution in ascendancy over reform in correctional policy generally. Health objectives carried by health portfolio.	Introduction of NSP would presume primacy of health objectives over security objectives and therefore rejected by corrections but supported by health.

### **7.3.2. The research responsiveness of the PMO**

#### ***PMO responsibility***

While prison health authorities have a responsibility for treating prisoners with BBV in prison, there has been no legal test case to establish the extent of their responsibility for preventing transmission within prisons.

#### ***PMO capacity in relation to the policy problem***

Correctional authorities could argue that they have limited capacity to provide NSP. While an increasing amount of research from overseas is demonstrating the feasibility of NSP (Nelles, Fuhrer et al. 1998), practical problems remain. NSP would still need to be justified against competing priorities such as smoking prevention. A number of key informants noted that one barrier to NSP is the generally limited capacity to expand health services. Several key informants were of the view that opposition from prison officers would prevent the implementation of NSP even if government adopted it as policy. While correctional health services could assist with the implementation of NSP,

key informants felt that it would be very difficult to have it work in the absence of prison officer support.

### ***Measurability of PMO performance***

The absence of action by correctional authorities on measuring BBV transmission is countered by the role of some prison health services and public health researchers outside prison. It is possible that a major epidemic of HIV or HCV occurring within prison would come to the knowledge of prison health authorities. The extent to which such information would become available to the general public is unclear. And despite the difficulties endured by researchers, they have now documented and published cases of HIV and HCV transmission occurring in prison.

### ***Transparency of PMO performance and the ‘theatre of justification’***

Attention to the success or failure of governments in controlling the spread of BBVs within their prisons appears to be limited to a small number of people who are actively involved in trying to document such cases. Other correctional system failures—escapes, deaths of Aborigines in custody, drug overdose deaths—appear to attract some public attention (Ellis 1998: 81). Once again, correctional health authorities, health departments and outside researchers are the only ones likely to be keeping an eye on BBV transmission within prison. Australia is not unique in this regard. In their discussion of the lessons to be drawn from the Swiss experience of trials of NSP in prison, Nelles and Harding argue that ‘...clear guidelines from international organisations carry little weight in the context of the security dominated world of penal systems’ (Nelles and Harding 1995).

### ***PMO vulnerability to the consequences of its error***

Documentation of cases of HIV and HCV transmission in prisons do not appear to have had any adverse consequences for correctional institutions.

### ***PMO research responsiveness***

The table below summarises the indicators of research responsiveness in the policy making organisation. Fragmentation across the corrections–health divide is noted. Each of the indicators points towards a low level of research responsiveness.



TABLE 7:3 RESEARCH RESPONSIVENESS OF THE PMO FOR BBV TRANSMISSION WITHIN PRISONS

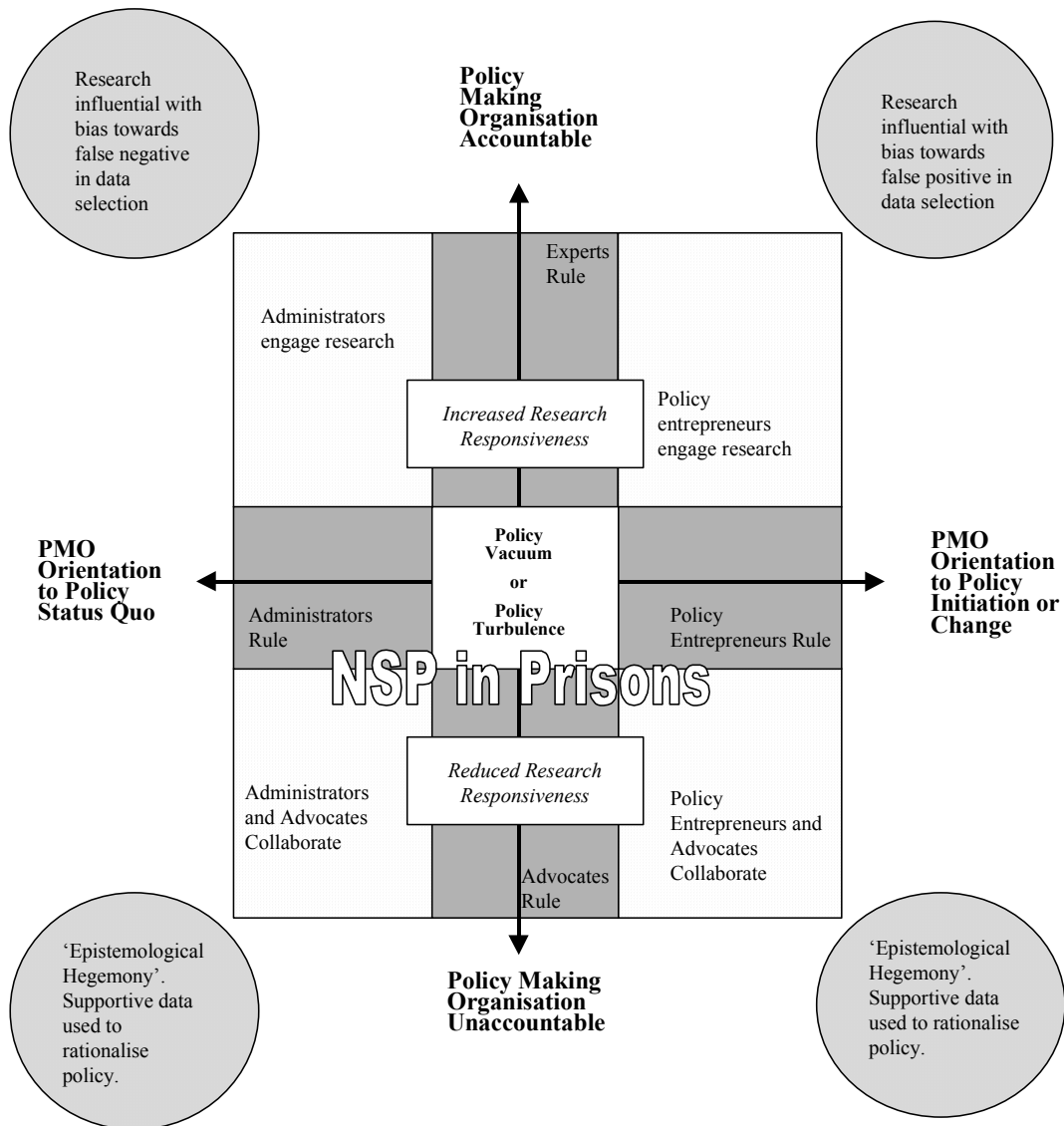
Indicator	Factors	Rating
Responsibility	Legal interpretation of duty of care untested. Prison health service mandate for BBV prevention poorly mandated.	Low
Capacity	Limited by the primacy of OH&S considerations for prison officers and the potential trade-offs with other prison health services.	Low
Measurability of Performance	Limited and kept limited by corrections. Countered by some data collection by health authorities.	Low
Openness of Theatre of Justification	Limited by lack of formal accountability structures and lack of public demand	Low
Vulnerability to Error	Could be high but only in extreme and improbable circumstances.	Low
Research responsiveness		Low

### 7.3.3. *The PMOF and the research—policy nexus*

The PMOF locates policy ambiguity and equivocation at the centre of the figure in Chapter 2 marked ‘policy vacuum or policy turbulence’. The current status of NSP in prison has elements of both ‘vacuum’ and ‘turbulence’. The fact that NSP is not implemented in any jurisdiction means there is a ‘practice vacuum’. The fact that policy is ambiguous at the national level and in tension with a lack of action at the jurisdictional level demonstrates ‘policy turbulence’. Figure 7.1 below indicates this position in relation to the PMOF model. In a situation of policy turbulence, the PMOF would expect that the policy making organisation is somewhat but not entirely immune to research. If it were entirely immune to research, it could impose an ‘epistemological hegemony’ (in David Dery’s words), and define reality in a way that is unassailable by other policy actors. Turbulence would disappear because there would be no data or argument to support questions about the policy choice preferred by the PMO.

The view of correctional organisations from this case study is that they come very close to achieving epistemological hegemony. Working against this epistemological hegemony are the health authorities but their power is limited. Correctional authorities can almost, but not completely, define the reality of the prison. Health authorities and health researchers can name alternative realities—that drug use and risky sexual practices continue despite correctional policy. But this countervailing force has not been strong and is not accompanied by a strong policy preference from health authorities with regard to implementation of NSP in prisons.

**Figure 7.1**  
**Location of NSP in Prisons in the PMOF Model**



## 7.4. Governmentality analysis

The prison occupies a central place in Foucault's work and gave rise to one of his most famous contentions that 'We live in a society where panopticism reigns' (Foucault 1994: 58). The Panopticon was a model prison designed by Bentham where an observer could view all prisoners continuously from a darkened central tower that prevented prisoners from knowing if, and by whom, they were being observed. Foucault's view was that through the instruments of modern governmentality, particularly the human sciences, the human subject has internalised the Panopticon and become imprisoned by societal norms. Gordon says that it does not matter who occupies the supervisory space for it to have the effect of power. 'One of the messages of Foucault's book (*Discipline and Punish*) is, therefore, that the apparent neutrality and political invisibility of techniques of power is what makes them so dangerous' (Gordon 1994: xv). The idea of panopticism is used regularly in post-modernist critiques of public health (Lupton 1995: 6; Cheek, Shoebridge et al. 1996: 177-183) and was noted in the BCS case study in relation to the way mammography screening and other public health interventions have created self-surveillance (Robertson 2001).

When it comes to a case study on the governmentality of BBV in prisons, the Foucauldian critique is folded back on itself. How should we make sense of the conflict between the virtual Panopticon of public health and the actual Panopticon of the modern prison with its surveillance cameras and urinalysis regimes?

### 7.4.1. *Policy discourse on NSP in prisons*

The case study data noted conflict between health policy discourse and corrections policy discourse in relation to NSP. Health policy discourse is built on harm minimisation philosophy, emphasises the rights of prisoners to the means to protect themselves from disease transmission, and sees the prison as potential 'incubator' of disease. This was juxtaposed to a correctional discourse that emphasises security, punishment, and social control (Nelles, Fuhrer et al. 1998). The quotes from the health and corrections sources show participants are aware of the competition between the discourses and their implications for correctional practice.

The conflict shows that fundamental questions about the governmentality of BBV in prison are unresolved. Contest about proper power and duty of authority, about the proper subject of government—the criminality of injecting or the harm to health that might result from it—and about the rights and status of prisoners continues.

#### **7.4.2. Regimes of practices and NSP in prisons**

Prison drug strategies as outlined at the various *Drugs in Prisons* conferences show increasingly detailed regimes for detecting, deterring and punishing drug use (Delphine 1996). The use of urinalysis, classification schemes for inmates based on their drug use histories, and the regulation of family visits based on these are integral to drug management strategies (Roach and Alberti 1996; Coyle 1998).

The introduction of NSP could challenge these evolving practices. Drug use is a form of resistance to prison as it allows prisoners to escape psychologically. When prison officers crack down on drug taking they are reinforcing their power over prisoners. Zero tolerance empowers prison officers to monitor prisoners' actions, inspect their bodies and their excretions, their belongings, and punish them for misdemeanours. NSP challenges the status quo by implicitly accepting that the prison authorities cannot win.

The practices of deterrence and detection shape the subjectivity of the prison officer as law enforcer. A number of commentators have noted the contradiction introduced in the prison officers' role when she or he is required to be both law enforcer and treatment provider (Frommel 1997; Hunter 1998: 111). Prisons have difficulty managing the dual roles of punishment and care (Bollini, Laporte et al. 2002).

#### **7.4.3. Power/knowledge and NSP in prisons**

Corrections systems have a 'regime of truth' based on criminal intelligence systems and drug use monitoring systems. These help maintain the mentality of security and coercion. Over and against this regime, public health research has continually brought the continuation of drug use and BBV transmission in prison to the fore. Using Foucault's language, public health research has 'disinterred' the 'subjugated knowledge' of prisoner's drug use and sexual behaviour in prison, combined it with the 'erudite' knowledge of the public health expert, and manufactured its truth value through medical scientific discourse (Douglas, Gaughwin et al. 1989; Gaughwin 1992;

Dolan, Hall et al. 1994b; Haber, Parsons et al. 1999; Dolan and Wodak 1999a). In so doing, it is establishing a new ‘regime of truth’ to inform a new regime of practices based on harm minimisation.

Public health research potentially renders visible that which is invisible to prison surveillance—the transmission of disease<sup>18</sup> and the poor health of the prison population. Prison surveillance of behaviour is designed to capture illegal behaviour and make the population visible as a criminal population. The logic of both regimes of truth is that they have a symbiotic relationship with particular types of the ‘conduct of conduct’. One shows the population to be sick, more vulnerable and in need of care. The other generates the need for more surveillance and punishment. Knowledge production through ‘regimes of truth’ is inextricably linked with the exercise of power through ‘regimes of practices’.

Both regimes of truth seek to establish the need for their continued expansion. Aristidou reports that the first *Drugs in Prisons* conference ‘...concluded that there was a definite need for a central repository to store statistics and intelligence data to establish national trends relating to criminal activity in relation to substance use within correctional facilities’ (Aristidou 1996: 6). On the public health research side, articles on BBV transmission within prisons call for more research to further establish the extent and nature of the problem and provide information to target interventions and evaluate their effectiveness (Haber, Parsons et al. 1999) (Gaughwin 1992: 102) (Dolan 2000).

#### **7.4.4. NSP in prisons and the governmentality hypothesis**

From a governmentality perspective, the state of policy ambiguity and equivocation on NSP in prison is a situation in which the conditions for the formation of national public

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<sup>18</sup> Data collection on the HIV status of prisoners was a major site of debate and contest among prison health authorities, correctional authorities, public health advocates and AIDS activists in the 1980s. The key issues involved were whether or not testing should be mandatory or voluntary, the privacy and confidentiality of test results, and related issues of segregation versus integration of HIV positive prisoners and access to adequate treatment services. A separate case study would be required to understand the points of continuity and discontinuity between the correctional and public health positions on this issue.

health policy, as set out in the ‘governmentality hypothesis’,<sup>19</sup> are in a state of continuing flux. A central issue is that of ‘governing at a distance’. Some prisons have created practices that accord with this notion to some extent.

Ballard has described HIV peer education as a form of ‘governing at a distance’ (Ballard 1998). Peer education was quickly adopted by all jurisdictions for both prisoners and prison officers (Chappell and Norberry 1992: 19). The provision of bleach also enables prisoners to calibrate their own degree of risk. Hamilton reported on the establishment of ‘K’ Division in Pentridge in the late 1980s to deal with HIV positive prisoners. It aimed ‘... to manage prisoners in such a way that they are encouraged to determine their own future and directions...’ (Hamilton 1991: 159). Community based corrections provides another kind of liberal space where the philosophy is that ‘...offenders must accept responsibility for their own behaviour, including protecting themselves from infection...’ (Clunies-Ross 1991: 275). In a similar vein, juvenile corrections demonstrate greater attention to liberal values, even down to acknowledging the ‘new public health’ and the Ottawa Charter (Ward and Jones 1991: 260).

Public health advocates in the form of prison medical staff have, in several other countries, shown the ability to ‘act a distance’ and have introduced NSP illegally but with eventual acceptance. The public health discourse of ‘Kalk’s refusal’<sup>20</sup> enables medical ethics to be invoked to override the directives of the state (Editorial 1991).

Another avenue for the possible introduction of NSP that sits comfortably with ‘governing at a distance’ is via a court determination. In the governmentality framework, courts are viewed as part of the plethora of agents in civil society that exercise the functions of government without being part of the formal institutions of government.

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<sup>19</sup> The governmentality hypothesis is that the formation of national public health policy becomes possible and more likely to the extent that technologies of self can cohere with technologies of population within the conditions of ‘governing at a distance’. See Chapter 2.

<sup>20</sup> Kalk and his colleagues in a Johannesburg hospital refused to allow political detainees who had been on hunger strike to return to prison after they had recovered from the effects of fasting on the grounds that ‘indefinite remand in custody without trial is torture’. The editorial says this raises difficult questions for prison medical staff when it comes to whether they should allow the incarceration of the mentally ill when they know it is damaging to their health. It is also used as a spring board for suggesting that prison medical authorities should be challenging prison authorities.

Debate over NSP perhaps represents a struggle over the limits of ‘governing at a distance’ within the prison system.

#### ***7.4.5. Governmentality and the research–policy nexus on NSP in prisons***

The unresolved status of NSP in prison represents a continuing power struggle over the ‘conduct of conduct’ of incarcerated IDUs. This power struggle can be observed in the clash between the discourses of public health and prison authorities and in the attempts by these authorities to build and privilege their respective Panopticons.

The GF focus on the research–policy nexus as power/knowledge highlights the power struggle over systems for creating knowledge about prisoners and the implicit construction of prisoners that these contain. Correctional systems define the injecting drug user in prison as a criminal and are closely linked with practices of surveillance and control. Public health knowledge seeks to redefine the prisoner as an at-risk individual whose ability for self-management can be realised through education and opportunities to exercise choice within a framework of harm minimisation. Public health research, practice and discourse might be thought of, ironically, as the vanguard of attempts to shift prisons from a model of power based on coercive, externally imposed ‘sovereign’ power, to internally based ‘disciplinary’ power. The Panopticon is attempting to return to prison and replace its crude ancestor.

### **7.5. Theoretical considerations**

#### ***7.5.1. Theory evaluation***

As with previous case studies, a limitation of the ACF is the specification of advocacy coalitions and the policy subsystem. While there are a number of public health researchers and prisoner health advocates who are supportive of NSP in prisons, they may not constitute a ‘coalition’ except in the very loosest sense. The Criminal Justice Coalition attempted to identify its fellow travellers in support of NSP. The National Drug and Alcohol Research Centre could also be said to have engaged in coalition building through its work on the NSP feasibility study. But do these groups belong to an NSP advocacy coalition? An HIV/AIDS coalition? An IDU coalition? A prison reform coalition? A harm reduction movement coalition? Or is this more a case of a latent

alliance of individuals and groups that have interests in all these things who occasionally make supportive statements with regard to NSP in prisons?

By emphasising coalition commitment to core values and beliefs, the ACF underestimates the possibility that coalition members have many beliefs and values that might come into conflict and lead to unpredictable outcomes. For example, in 1991 Gaughwin and Douglas published research in *AIDS* reporting that the rate of HIV transmission in prison was probably quite low due to the infrequency of injecting (Gaughwin, Douglas et al. 1991). The paper's appearance prompted an Editorial in *AIDS* saying that '...the prevalence of infection in these facilities is still lower than many of us expected' (Brewer 1991: 897). From an ACF perspective, this publication is not in keeping with the strategic use of research by advocacy coalition members as it undermines part of the case for the introduction of NSP in prison. For public health researchers, a strong belief in the scientific method may bring them into conflict with their commitment to NSP in prison if the former produces research that undermines the need for the latter.

The major problem with the PMOF in this analysis is the fragmentation of the policy making organisation at several levels. There is the division between the corrections portfolio and the health portfolio and then there are the divisions and tensions between the prison medical services and the rest of prison administration. The analysis could only really work to the extent it does by designating the prison administration as the PMO and seeing health authorities as in some sense external or secondary to the primary PMO. This seems a reasonable accommodation but it means that PMOF needs to move towards a more specific rendering of the fundamental concept of the policy making organisation. The key to this might be to explicitly define the policy making organisation in terms of both an organisational structure and an organisational epistemology.

The Governmentality Framework in this and the other case studies is weakened by its difficulty in explaining the complexity of the interaction between the discourse of security and the discourse of harm minimisation. The GF tends to create a simple dualism while there is evidence of many shades and complexities in their realisation. For example, the views expressed by White at the *Drugs in Prisons* Conferences and at interview show a less easily bifurcated picture even though the patterns of conflict and resistance are still in evidence (Leggat and White 1996; White 1998).



### **7.5.2. Theory development**

The case study material shows that current policy on NSP in prisons is ambiguous and unresolved—public health policy makers would like to see greater attention to blood borne virus prevention including the possibility of NSP while corrections policy makers have so far been unpersuaded by the arguments in support of the need for, or effectiveness and feasibility of, NSP in prison.

Each of the focal theories makes sense of this struggle by bringing together a combination of material, ideal and ‘structuration’ factors in the research–policy nexus. For the ACF, the material structures are the formal and informal social networks that are the context for struggle between advocacy coalitions in the policy subsystem. Its primary finding is that the NSP in prisons issue is one that straddles two subsystems and the advocacy coalition that has control of the material structures of the prison systems is the one whose views will prevail. The PMOF perspective highlights the way the organisational structures of the prison system mean that it is not responsible or accountable for blood borne virus transmission in prison. The GF highlights material structures through the coercive security practices of the prison system and sees these in a struggle with the self-protective practices of public health.

When it comes to ideal structures, the ACF constructs these in terms of the beliefs and values of the competing advocacy coalitions. Harm minimisation is at the core of the beliefs of the dominant HIV/AIDS policy advocacy coalition while security and punishment are at the core of the dominant prisons policy advocacy coalition. There might be common ground if a philosophy of rehabilitation came to dominate prisons policy but this is unlikely in the absence of wider social and political change in relation to the politics of crime and punishment. The PMOF identifies the ideal structure in terms of the organisational epistemology of the prisons system. This is steadfastly resistant to accepting data on BBV transmission within the prison system because the act of knowing might create a perception of responsibility. Health authorities continually challenge this attempt to know nothing. The Governmentality Framework identifies the conflicting ideal structures in terms of the conflict between the discourses of harm minimisation and security. These discourses attempt to construct the IDU in prison in fundamentally different ways and they each give rise to different kinds of knowledge about the prison population.

Underpinning each of the focal theories' explanations of why NSP has not been introduced in prisons in Australia is the idea of conflict and fragmentation across the material and ideal structures of policy making. Unlike NSP in the community where the ideal structure of harm minimisation and the material policy making structures held some synergy and could be mobilised by policy actors to support the introduction of NSP, the lack of synergy across material and ideal structures in the case of NSP in prisons means that policy actors have had no structures to enable agency. The 1990 conference was an attempt by public health actors to create the material and ideal structures necessary for agency. It brought together health bureaucrats and prisons bureaucrats into a conference and produced a communique. It tried to create a common ideational world out of the available research and the philosophy of harm minimisation. It was partly successful in creating a communique supporting HIV prevention measures in prisons. But in the absence of enduring structures of an organisational or philosophical kind to take the communique beyond a 'modus vivendi', there was no basis for action in the future.

## **7.6. Final comments**

In terms of the research–policy nexus, this theoretical development might be expressed in terms of a set of conditions that create and form the relationship between research and policy. For research to have an impact on policy there needs to be a complementary set of material and ideal structures available which, between them, are capable of being mobilised by policy actors to bring research to bear on policy. This idea will be pursued further in the next chapter and its practical implications explored in Chapter 9.

## **8. Transforming Theory**

### **8.1. Introduction**

In the first half of this chapter I discuss the findings from the case studies and assess the performance of the three focal theories in providing a coherent, cogent and parsimonious account of the case studies. In the second half of the chapter I advance an argument about the general form of theory on the relationship between research and policy. This brings together the discussions about material structures, ideal structures and agency that have been developing in the conclusions to the case studies. I also discuss the notion of ‘research transformation’ and why it offers a better understanding of research use in policy than the notion of ‘research transfer’. Lastly, I discuss the relationship between the focal theories and Sil’s framework for theoretical eclecticism and their contribution to the theoretical repertoire for understanding the relationship between research and policy.

### **8.2. Findings**

In very broad terms, the case study data supports the argument that research has had considerable influence on policy in all the case studies except NSP in prisons where its influence has been minimal. In the case of BCS and NSP in the community, research was critical to the process of shaping the policy problem, establishing the rationale for the intervention and defending the policy when it came under attack. The form and timing of the attacks were also influenced by research. With PCS, research was critical to shaping the policy problem and the lack of research on effectiveness was important in shaping the policy outcome.

By using the word ‘critical’ in these claims, I mean that research appears to play such a central role in the policy process that it is difficult to conceive of the policy process existing or taking the shape it did in the absence of at least some of the research. In the case of NSP in prisons, research was influential in establishing a debate and generating sufficient interest to get a significant number of senior policy actors to participate in one national conference on HIV/AIDS in prisons. Advocates of NSP in prison would probably argue that research has had little influence since then. However, the

incremental adoption of blood borne virus prevention mechanisms in some prison systems suggests that research has not been entirely without influence.

None of these claims means that research had an influence on policy that was intended or approved of by the researchers who produced it. Nor does it mean that research was the only or prime cause of policy or the actions of policy actors. The claims should not be interpreted to mean that the role of research in these policy processes is uncontested or that the policies in question are deserving of the epithet ‘evidence-based’. As will be discussed below, the dynamic of the research–policy nexus is what is at issue here. As we have seen throughout the case studies, this dynamic may be rendered in different ways by different theoretical perspectives.

The first two research questions are concerned with how and why research has influenced the policy process and whether there is empirical support for the focal theories. The following three sections work through each of the focal theories and identify their contribution to our understanding of the research–policy nexus based on the case studies.

### **8.2.1. ACF**

The ACF presents a complex argument on the role of research. In my view, the ACF presents the most cogent, coherent and parsimonious account of the research–policy nexus of all the theories. This is not surprising in that it has been in development through a considerable research program for nearly two decades. By comparison, the other two frameworks in the form they appear here are unique to this thesis.

From the ACF analyses, power needs to be dispersed across the policy subsystem before research will have an influence on policy. Where the dominant advocacy coalition is challenged it can rely on political resources to fashion policy in a way that suits its beliefs and values, regardless of what the research or researchers might say. But when power is dispersed, persuasion through research becomes more important.

In the case of NSP in prisons, the prison authorities and the prison officer unions represent the dominant advocacy coalition and seem to be able to determine the practices of imprisonment and punishment with little or no outside scrutiny or interference. There is an alternative advocacy coalition that espouses prisoner health rights but it is small and relatively powerless.

In the case of BCS and PCS, power is much more dispersed between government, clinicians, non-government organisations, researchers, cancer experts and consumer groups (recognising that some policy actors can wear more than one of these labels). This is not to say that the power these groups have comes in the same form or that it is dispersed equally. The point is that in relation to screening programs, effective government action requires cooperation and support from each of the other groups. Persuasive argument that makes a decent fist of the available research is important for cooperation. The case study material showed that the alliance between the cancer councils, cancer experts and government on the methodology for evaluating screening programs (the WHO screening principles) was particularly important. Thus, the dispersal of power among policy actors, plus the core value commitment to the use of research to make policy among some of those policy actors, were the key factors in ensuring highly visible, research-referenced decision making processes.

In the case of NSP in the community, while there is no identifiable alternative advocacy coalition within the policy subsystem, there are many critics of harm minimisation in the media. There is also widespread local opposition to NSP that feeds its way into the policy process via backbenchers to Ministers. Thus the dominant advocacy coalition relies on research as one of its main political resources for defending NSP.

After the distribution of power has been taken into account, the ACF argues that there are a number of other factors at work in the research–policy nexus. There is the contention that advocacy coalitions will use research to defend their core beliefs and attack those of their opponents. This is well supported in the case studies. The difference between the screening case studies and the NSP case studies is that the former largely involves debate between health experts while the latter involves a wider group of actors. The protagonists in the screening debates had several ‘professional fora’ (expert advisory committee, the medical scientific literature) in which to present their arguments. In the case of NSP in prisons, there is no shared professional forum for debate between advocacy coalitions and thus it is missing an important vehicle for enabling ‘policy oriented learning’.

In relation to the question of discrepant research and its ability to lead to policy change, the ACF argues that fundamental policy change requires change in the ruling dominant advocacy coalition and will only come about through some major disturbance outside the subsystem, not from discrepant research alone. The case study data supports this

view (see below). In all cases this data was unable to lead to fundamental policy change. Secondary aspects of policy may change as the dominant advocacy coalition responds to pressures within the subsystem—research that challenges policy settings is capable of generating this pressure by giving credence to the arguments of policy critics.

Each of the case studies showed a high degree of continuity in policy over a period of a decade or more accompanied by continuity in the composition and power of the dominant advocacy coalition. In the case of BCS and NSP in the community, there are clear cases of the dominant advocacy coalition taking discrepant research very seriously and responding with authoritative statements ‘barring’ that research. For example, the World Health Organisation produced a statement on the effectiveness of mammography in response to the meta-analysis of the Nordic Cochrane Collaboration (Anonymous 2002), and the Australian National Council of HIV/AIDS and Related Diseases responded to the twin threats of the HCV epidemic and Canadian research questioning NSP with its own systematic literature review (Dolan, Topp et al. 2000). On the other hand and, as the ACF would predict, there has been no equivalent response from prison authorities to research on BBV transmission in prison or to research showing NSP has been effectively trialed in other countries.

Taken as a whole, the ACF provides a robust and coherent account of the research–policy nexus in these case studies. Its limitations, as noted in previous chapters, relate to the difficulty in specifying subsystems and advocacy coalitions and in accounting for the international factors in public health policy development.

An important contribution of the ACF is to redraw the line of resistance to new data to that proposed in the ‘two communities’ theory. In that theory, the line of resistance is between researchers who are outside the policy process and policy makers who are inside. The concept of ‘advocacy coalition’ creates the possibility that sometimes researchers and policy makers will be on the same ‘side’ in a policy conflict and that they, along with other policy actors from industry or NGOs, will have a common bond based on some commonly held beliefs and values. Researchers can be among the most important members of a Dominant Advocacy Coalition. The line of resistance to accepting new data may therefore be quite different to one between a ‘research community’ and a ‘policy community’, and the form of resistance may be quite different to that of different ‘cultures’ or ‘languages’. For the ACF, the form of resistance and the avenue to change come from the beliefs and values of the advocacy

coalitions. The ACF does not preclude the possibility that the advocacy coalitions may be made up of policy makers on one side and researchers on the other. This is theoretically possible as the form of advocacy coalitions is not prescribed by the framework but none of the case studies showed this kind of advocacy coalition. While it is tempting to see the NSP in prisons case study in this light, the critical role played by the prison officer's union make a simple 'two communities' explanation unsatisfactory.

As mentioned in Chapter 2, the ACF approach is just one of a family of public policy theories that deal with 'policy networks' or 'policy communities' and is particularly indebted to the pluralist tradition in American political science. Other approaches based on policy networks or policy communities could also prove beneficial. For example, Duke (Duke 2000) studied prison drugs policy in the United Kingdom over the 1980s and 1990s using a policy networks perspective. This theory is more flexible than the ACF as it is premised on greater mobility in the formation of alliances around particular issues. As the policy agenda evolves, new problems emerge and old problems are reframed within the new ones. Using this approach, Duke identified shifting agendas and changing policy networks over two decades, as drug use in prison came to prominence and policy actors wrestled with the contradictions between 'punishment' and 'treatment'. The ACF is, therefore, one of a family of theoretical perspectives that could add to the theoretical repertoire available to the study of research use in policy.

In summary, the ACF makes a valuable contribution to understanding the research-policy nexus. It overcomes some of the limitations of the 'two communities' theory by politicising the production and use of research and identifying researchers as policy actors whose power varies depending on their alignment with advocacy coalitions and the power of those coalitions. The central dynamic of the research-policy nexus is identified as a power struggle to realise beliefs and values and it is within this struggle that research is taken up and used in policy arguments. The term 'research transfer' does not capture this dynamic as well as the term 'research transformation' as the latter has the connotation of research taking on additional social significance when mobilised to support policy argument.

### **8.2.2. PMOF**

In the PMOF, the extent of the influence of research on policy is dependent on the policy making organisation's degree of research responsiveness. This argument is

reasonably well supported by the major findings from the case studies. The only case where the PMO's research responsiveness was low was in the case of NSP in prisons and, to the extent there was any responsiveness at all, it was largely due to the presence of prison health authorities.

The indicators of research responsiveness seem to be particularly useful because they combine social factors (the presence of a 'theatre of justification') with institutional factors (the responsibility of the PMO) and factors that relate to the policy problem itself (its measurability). These indicators help to distinguish different levels of research responsiveness across the case studies. If we look at the NSP case studies, while BBV transmission in the general population is measurable and of concern to the public, its occurrence within prisons is not systematically measurable and appears to be of little concern to the general population. In the screening case studies, there seems to be little difference between the 'theatre of justification' for the two cancers, or in the degree of government responsibility for the policy problem, or in the extent to which government performance for the policy problem is measurable. This suggests that the policy making organisation should exhibit a similarly high degree of research responsiveness for both breast cancer and prostate cancer. The case study data supports this view.

The PMOF argues that research responsiveness will be in dynamic interaction with the policy preferences of both the political and bureaucratic arm of the policy making organisation. In the analysis of the BCS data, the PMOF argued that there has been a happy synergy between selected research showing the effectiveness of mammography, and the perceived political popularity of mammography screening. The result was bipartisanship. This synergy led to supportive data being amplified and hostile data being muted—a result of research responsiveness with a bias towards the risk of falsely accepting the hypothesis that mammography screening works.

The outcome on PCS was less happy for the politicians. The extent of research responsiveness meant that they could not avoid the issue but the research did not support the introduction of a screening program. The ensuing conflict between the government, public health experts, clinicians and consumers has simmered for a long time. In this case, the lack of a definitive research-based answer to the question of the effectiveness of PCS resonates with ongoing policy ambiguity.



In the NSP case studies, the unpopularity of NSP has led to what might be called defensive bipartisanship—agreement between the major parties to support NSP out of fear that the political consequences of uncontrolled HIV epidemic would be more difficult to handle than the problems associated with giving grudging support to NSP. With NSP in prisons, the political aversion to NSP and to prisoner's rights, combined with the relative certainty of prison officer objection to NSP and relative uncertainty about BBV transmission, has meant there is no political impetus to introduce NSP.

When research and policy are at odds, the PMOF argues that there will be a tension between the irrefutability of data and the immutability of policy. This is the basis of the two dimensional model presented in the case studies. In each of the case studies, we saw that there were data hostile to current policy but in each case the PMO could find ways to reject it. In the cases of BCS and NSP in prisons, there have been several instances of research challenging current policy settings but this has not led to policy change. Given the sheer size (in terms of the proportion of the population directly affected) and organisational momentum behind mammography screening as well as its apparent public support, it is difficult to imagine any research finding that would be sufficiently definitive and negative to cause a change in direction. With NSP in prisons, the data showing that BBV transmissions occur in prisons has so far been dismissed as insufficient grounds for introducing NSP.

As discussed in Chapter 2, the Policy Making Organisation Framework is something I created for this study based on the ideas of David Dery and complemented by my own thoughts on how the two arms of his fundamental conflict (irrefutable data versus immutable policy) might be operationalised. Out of this I created two axes, one which attempted to capture the factors that make data irrefutable (the research responsiveness axis) and one that attempted to capture the factors that make policy immutable (the policy preference of the PMO).

Unlike most of the approaches to research utilisation, the PMOF shifts the focus of attention away from the level of the individual decision maker to that of the organisation and makes data selection behaviour a function of organisational epistemology. Like the 'two communities' theory, the PMOF draws the line of resistance to hostile or new data at the boundary of the policy making organisation. But unlike the 'two communities' theory, it locates the drivers of data selection in the dynamic interaction between the structure of the organisation, the characteristics of the policy problem, and the political

risks and opportunities created by these. An important part of the PMOF is the idea that organisations are constantly in the business of selecting data and that policy preferences might be thought of in terms of risking-taking preferences—is the PMO more inclined to accept the possibility of a type I error or a type II error?<sup>21</sup>

Another contribution of the PMOF is that it identifies institutional factors that can affect research responsiveness. As noted in Chapter 1, the Commonwealth Government has no constitutional or legislative mandate for policy in the areas of public health. Each of the case studies has, therefore, shown a different route by which the Commonwealth became engaged in public health policy. But there is a pattern to this engagement—Commonwealth involvement has been an artefact of its other responsibilities. Commonwealth engagement on breast cancer screening might be seen as an artefact of its Medicare program and the system of rebating tests ordered by practitioners whose behaviour the Commonwealth finds it difficult to constrain or direct. The policy position on PCS has similar characteristics. Commonwealth involvement in HIV/AIDS policy was, in the first instance, the outcome of Commonwealth responsibilities for the blood supply. Without this, the Commonwealth may have been even more reluctant to enter the field of national policy on HIV/AIDS.

Seen in this light, the Commonwealth's Medicare and other responsibilities have had a grappling hook effect—policies and programs create a potential point of purchase for new issues and problems. Majone attributes to Wildavsky the idea that '...all that has happened within a policy space determines most of what will happen in that space. Increasingly, policy becomes its own cause' (Majone 1989: 159). Medicare reimbursement for diagnostic tests was the grappling hook in the screening case studies. In HIV/AIDS it was the blood supply responsibilities. Because of the grappling hook effect, research does not need to have a direct route to the inner circles of Commonwealth policy making for it to have an effect on national public health policy.

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<sup>21</sup> Dery writes that in the process of accepting or rejecting data in relation to an hypothesis such as mammography screening reduces breast cancer mortality by 30 per cent or NSP prevents the spread of HIV, policy making organisations are faced with a tradeoff between the probability of accepting a false hypothesis (Type I error), and the probability of rejecting a true hypothesis (Type II error) (Dery 1990: 53-56, 64). I have argued that in these two cases, due to the alignment of political risks and opportunities, the PMO was more prepared to run the risk that it was accepting these hypotheses even though they could be wrong than run the risk of rejecting these hypotheses even though they could turn out to be right. By contrast, the PMO is currently prepared to run the risk of rejecting the hypothesis

In mammography screening and NSP, research unleashed actions by others that had flow on effects in the health system that eventually dragged the Commonwealth into the policy arena. It is a moot point whether the Commonwealth would have responded in these matters to political pressure only in the absence of its other responsibilities and interests.

In summary, the PMOF makes a valuable contribution to our understanding of the research–policy nexus by identifying a set of institutional, social and political factors that work to ‘transform’ (or ‘mint’ in David Dery’s terms) research from its status as mere data into valuable currency in policy debates. Of particular value is the role of ‘organisational epistemology’ in this process. This idea transfers the notion of the theory-dependence of ‘facts’ from the world of scientific methodology to the world of policy making and argues that ‘facts’ do not speak for themselves but require the prior acceptance of a framework of beliefs and assumptions to make them relevant. In this light, policies have some of the characteristics of scientific theory, a point noted by other commentators as well (Majone 1980). This insight prompts the reformulation of the research–policy nexus away from the notion that research can be ‘transferred’ or ‘utilised’ in policy. It propels us towards a sociological perspective that argues for the primacy of larger policy frameworks and institutions.

### **8.2.3. Governmentality Framework**

The Governmentality Framework understands the relationship between research and policy in terms of the idea of power/knowledge, which is produced through the combined effects of discourse, practices, and regimes of truth. In answer to the question ‘does research influence policy’, the GF sets up a series of connections between research and policy discourse, research and those public health practices that are the subject of policy, and research and regimes of truth.

The application of the Governmentality Framework involves transposing the case study material into these arcane Foucauldian concepts and narratives. While all theorisation involves the imposition of theoretical constructs on mundane observations, the distance

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that NSP in prison is effective in preventing BBV transmission even though that hypothesis may be correct.

travelled and the effort involved seems greater with the GF than with the other frameworks. The question is whether it is worth the effort.

There are some observations afforded by the GF that seem particularly acute and justify the effort to some extent.

The GF highlights the way that the practice of public health, including its practices of research and surveillance, are intimately linked with constructing that which is to be governed—research makes policy thinkable and the behaviour of people governable. This observation is important in the NSP in prisons case study where the public health governmentality comes into conflict with the security governmentality. The power and importance of public health research in shaping the prison population as a disempowered and sick population comes into conflict with the ‘regime of truth’ constructed through prison surveillance. There is a power struggle at work in the research–policy nexus and one way of understanding it is to see it as a power/knowledge struggle. The competing discourses about prisoners and the connection between those discourses and different forms of knowledge are brought into view by the GF.

Another GF insight is the inexorability of the advance of public health governmentality—‘The imperative of health: at once the duty of each and the objective of all’ (Foucault 1980d). While the ACF and the PMOF are better at accounting for the local and proximate interaction between policy actors and policy structures and processes, the Governmentality Framework looks at something working over the longer term and at a deeper level in ‘the conduct of conduct’. The GF would argue that, in the long run, the BCS and PCS will be seen along with cervical cancer screening as the pioneers of the new frontier of public health governmentality where our DNA, our organs and our behaviour are subject to the gaze of public health. Public health authorities might evaluate and reject some forms of screening such as PCS and use scientific methods to do so but the long-term trajectory towards a more thoroughly screened population seems clear. There is a powerful message here, one that questions the notion that more public health is necessarily better public health. Thus the GF provides a way of seeing and naming a form of government that will increasingly affect the lives of each of us.

A related insight from the GF is the subtle ability of public health to reach the arm of government into socially, politically and legally ‘marginal’ populations and practices. This is demonstrated through the NSP case study where research is an integral part of constructing the behaviour and the population that needs to be governed. The value of the GF seems to be that it enables us to see and question processes that might otherwise be taken for granted and escape critical attention.

Lastly, a unique contribution of the Governmentality Framework is to identify the global dimension to public health governmentality. The constructs used by the other frameworks (eg policy subsystems and policy making organisations) are tied to a specific locality. The regimes of truth and regimes of practices and discourses that the GF identifies are not specific to Australia. For example, the ‘regime of truth’ associated with the medical and scientific journals attains additional power to promulgate ‘the truth’ because of its global recognition. Thus the global patterns in the research–policy nexus that consist of a global pool of research and patterns in the spread of public health technologies across countries are more visible through the GF than in the other frameworks.

The major problem with the Governmentality Framework is the obverse of its strength—the richness, complexity and lack of specificity in its concepts mean that any event or process can be turned into something of theoretical significance. And if everything is theoretically significant then perhaps nothing is. While the application of the GF can reveal surprising turns and twists there is a sense in which it is untameable, a hit and miss affair that could proceed endlessly with no coherence and no resolution. It also shares the problem of macro-functionalist frameworks that any event or process that contradicts the expectations of the theory can be explained through some new feedback loop in a homeostatic system (Bohman 1991: 156).

It may be that the deficiencies in governmentality noted in this thesis are related to my failure to grasp what Foucault meant by it. This is a possibility I acknowledged at the outset. However, it is worth noting that Foucault’s work on governmentality has been criticised for its lack of consistency. Fox argues that Foucault went from a relatively deterministic view in his earlier writing to a view that emphasised the autonomy of the individual in later writing (Fox 1997: 43). He says:

In summary, the shifts of emphasis in Foucault's ontology undermine most aspects of his earlier position concerning discourse and its relation to the non-discursive. This non-discursive 'residue' enables resistance to power/knowledge, no doubt providing a resource to the reflexive self as it is inscribed by discourse, while such subjects contribute to the generation of discourse through their texts. From what might be seen as an over-emphasis on determinism, we now find an over-emphasis on agency. Perhaps, as Rorty suggests, this was Foucault's dilemma, consequent on his twin aspirations—both to be a moral citizen concerned with power by taking on its own vocabulary of essentialised subjects (Rorty 1992: 330-1). While his earlier work met the latter objective at the expense of the former, the re-introduction of a self privileges the former but makes his previous ontology untenable. (Fox 1997: 44)

In constructing the GF I was aware of this criticism but chose to try to create a coherence through my formulation of the 'governmentality hypothesis' that linked the determinism of 'technologies of population' with the agency implicit in 'technologies of self'. I used the concept of 'governing at a distance' to capture a way of governing that Ballard had identified as an important part of Australia's HIV/AIDS policy (Ballard 1998). I am well aware that this is a unique formulation and make no claim as to whether it is more or less faithful to Foucault than other renderings of the concept. As mentioned several times already, Foucault did not create an integrated social theory and it may be that some Foucauldian scholars would see the approach taken as a fundamental misunderstanding of the nature of Foucault's thought. I chose to take this risk for two reasons. First because Foucault places public health at the centre of his theorising about the development of the modern form of governmentality, and second, because he locates the human sciences at the centre of public health practice and the modern form of governmentality generally. It seemed just a short step from Foucault's concept of knowledge/power to the central concern of this thesis—the nexus between research and policy. Of the three frameworks, this one is most critical of the idea of 'research transfer' and problematises the entire project of 'evidence-based policy'. The GF identifies transformation as a constant feature of all discourse that puts truth claims into circulation.

On balance, I think that the GF provides a sufficiently coherent and cogent account of the case study data, and provides a sufficiently different account from either of the other focal theories to warrant a place in the broad theoretical repertoire used in the study of

research use in policy. While it is anything but parsimonious, this line of theorising is in its relatively early stages of development and may become increasingly important as further empirical study is carried out and as the globalisation of public health policy increases.

### 8.3. Towards a general theoretical form

The third research question asks what the results of the case studies mean for theory of the relationship between research and policy in public health. In this section I use Sil's framework to discuss the concept of a general form for theory on the relationship between research and policy.

#### 8.3.1. BCS and a general theoretical form

In the BCS case study, I explored the applicability of the concept of material and ideal structures and asked how these were rendered in each of the focal theories. From this, I identified the WHO screening principles as an important 'ideal structure' and the AHMAC-AIH evaluation process as an important 'material structure'. I then identified the ways in which the focal theories analysed these structures and the agency of policy actors in relation to them. The following table presents the outcomes of this analysis.

**TABLE 8:1 MATERIAL AND IDEAL STRUCTURES AND AGENCY AND STRUCTURATION IN THE THREE FOCAL THEORIES**

Theory element	ACF	PMOF	GF
The key material structure—the AHMAC-AIH National Evaluation	Structure established by the dominant advocacy coalition	A body established by the PMO to select data for policy	The regime of truth
The key ideal structure—the WHO Screening principles	An expression of part of the core beliefs and values of the dominant advocacy coalition	The organisational epistemology that guides data selection.	The policy discourse that constructs the political rationality of screening.
Agency and 'structuration'—the process by which policy actors are enabled and constrained by the structures.	The dominant advocacy coalition creates or mobilises these structures to achieve its desired policy outcomes.	Policy actors influence these structures so they have a bias towards a type 1 error which reflects political preferences.	Public health and clinical experts use these structures to increase and extend the practice of screening.

#### 8.3.2. PCS and a general theoretical form

In the PCS case study I extended this analysis by looking for other examples of how the research-policy nexus might be thought of in terms of a combination of material and ideal structures that enable and constrain agency but are also recreated and mobilised by

that agency (which is the nub of Giddens concept of ‘structuration’). In the PCS case study, I looked at medical and scientific journals as an important material structure for each of the focal theories, and the notion of ‘peer reviewed, rigorous scientific publication’ as an important ideal structure for each of the focal theories. Both of these are primary sites for agency by health policy actors who wish to mobilise research to influence policy. Each of the focal theories has a different way of theorising the role and dynamics of these structures as set out in table 8.2 below.

**TABLE 8:2 THEORISATION OF MATERIAL AND IDEAL STRUCTURES AND AGENCY AND STRUCTURATION ACROSS THE THREE FOCAL THEORIES**

Examples of structures and structuration	ACF	PMOF	GF
Material structure—medical and scientific journals	An avenue through which advocacy coalitions can present data, argue their case and counter the views of opponents. Their prestige and importance is promoted by coalitions that want to promote ‘professional fora’ as a means of challenging other coalitions	Potentially, a central part of ‘the social context of justification’. Data on the performance of the PMO can be published and made available for criticism by policy actors.	A primary regime of truth for the human sciences. Along with the academy, the primary structure for generating statements of ‘truth’.
Ideal structure—the concept of the rigorous, peer reviewed scientific journal article	This notion appears as a core value for some public health advocacy coalitions. It has taken on additional importance with the tools of systematic reviews promoted through the Cochrane Collaboration and the Evidence-Based Medicine movement more generally.	The primary structure for ‘minting’ research. As the prestige of the journal increases so does the research published in it take on a more irrefutable status. If research challenging policy is published in the New England Journal of Medicine then watch for policy change or a major exercise in ‘monster barring’.	The discourse that supports the regime of truth. The discourse has been extended through the Evidence-Based Medicine movement. It is closely linked with the concept of hierarchy of evidence which the GF would argue is a thin veil for a claim to a hierarchy of truth. Claims to the purest form of knowledge through the RCT are also claims to the purest form of truth and are also claims that this knowledge should be given more power than any other kind of knowledge in the policy process.
Agency and ‘structuration’—the process by which these structures are mobilised and recreated through social action	Advocacy coalitions that need research as a political resource promote the importance of medical and scientific journals by conducting debates through them and promoting their credibility as a ‘professional forum’.	Policy actors can use journals to call the PMO to account for policy failures or to goad the PMO into action. The PMO can also use the journals for the purposes of ‘monster barring’, that is, rejecting hostile data.	Experts mobilise the regime of truth to further their knowledge/power.



### ***8.3.3. 'Ideal structures', harm minimisation and the WHO screening principles***

In the NSP case study, I drew attention to the role of harm minimisation as an ideal structure that has many characteristics in common with the WHO screening principles. Like the screening principles, harm minimisation can provide the basis for an extensive program of research in the sense that it frames a set of problems that can potentially be resolved through empirical research. Also, like the screening principles, the impact of harm minimisation was amplified through its application in formal policy making structures such as those responsible for the National Drug Strategy and the National HIV/AIDS Strategy. There were also strong parallels between the BCS case study and the NSP case study in the way that the focal theories constructed these material and ideal structures and described the agency of policy actors in relation to them.

The NSP in prisons case study ended with the observation that for research to have an impact on policy there needs to be complementary material and ideal structures available that can be mobilised by policy actors to bring research to bear on policy. The failure of research to have an impact on the question of NSP in prisons might be understood in these terms. That is, there is a lack of complementary material and ideal structures that enable agency by policy actors interested in mobilising research to promote the health of prisoners. The prevailing structures disempower NSP advocates.

### ***8.3.4. Reflections on a general theoretical form***

The foregoing points to the possibility of a more abstract theoretical form based on the material/ideal structure–agency framework. This enables some of the common points of emphasis across each of the focal theories to come into view and suggests the form of an adequate theory of the relationship between research and policy. While the focal theories may have different ways of identifying and analysing the importance of some key feature of the research–policy nexus, the fact that each of them does so adds weight to the argument that it should be taken seriously and explored further. There are quite a number of aspects of the research–policy nexus that could be brought to light through this method. Those referred to so far, like expert committees and the medical and scientific journals, represent a beginning but do not exhaust the possibilities.

In the next chapter, I take the concept of the ‘ideal structures’ of harm minimisation and the WHO screening principles a step further and ask how they might inform our understanding of the quest for evidence-based policy. In the remainder of this chapter, I will take up the challenge of reframing the research-policy nexus using some common threads in focal theories and Sil’s framework.

#### **8.4. Investing research with meaning and power**

In each of the case studies, there were instances where research was influential in forming and supporting policy arguments, and instances where research of seemingly similar type and status was ignored or actively rejected. For example, in the BCS case study I showed how the HIP Study enjoys an enduring value in policy narratives on the ‘evidence base’ mammography screening policy. The BreastScreen Australia Achievement Report of 2000 says ‘Since the early 1960s, a series of major randomised controlled trials have been conducted to investigate methods for the early detection of breast cancer. Substantial reductions in mortality from breast cancer were observed in women offered mammography screening in these trials’ (Australian Institute of Health and Welfare 2000: 1). There was only one RCT of mammography in the early 1960s and it was the HIP study which, as we have seen, was the subject of controversy in the 1970s over radiation exposure and the limited additional value of mammography over clinical breast examination (Bailar 1976). Despite this, it is woven into a narrative about its contribution to the science underpinning mammography screening. In contrast, the Canadian National Breast Screening Study, which failed to find the expected benefits and which the Nordic Cochrane Centre Review found of better quality than the HIP Study, was dismissed at the time its results were published and has been the subject of controversy ever since. As one key informant said ‘Everyone was happy to find fault with the study’.

What is it that is going on here that is relevant to the way we understand the nexus between research and policy? An initial point is that concepts of ‘research transfer’ or ‘research utilisation’ or ‘research uptake’ are not much help in capturing the active process of arming and disarming research. What seems to have happened with the case of the HIP study is that it has become invested with a certain status, a particular meaning and power in policy discourse, that continues despite the controversies surrounding it. David Dery describes this process as analogous to the ‘minting’ of paper

money into valuable currency. He argues that research is like paper money when it becomes invested with value on the basis of a shared expectation that others will treat it as valuable (Dery 1990: 111-113). When research is taken up and used in policy arguments it goes through a transformation that involves it being invested with meaning and power that it would not have as mere data. The Foucauldian view of this transformation is captured in the idea of knowledge/power where statements that claim to assert the truth are also claims to power. When they are accepted as true, they secure the authority of the truth holder to act as if they were true. In the ACF view, research is invested with meaning and power through its interaction with the values and beliefs of policy actors. Research that supports assumptions about causal relationships that are at the core of the policy actor's beliefs about a policy issue has a status of greater significance than just being a convenient justification for stubbornly held beliefs. In the ACF view, policy actors are not 'judgemental dopes' but knowledgeable, reflective social actors who are actively engaged in learning about the policy issue in which they are involved. In accepting research as true, the research takes on a social significance in relation to those beliefs because to surrender the research would challenge those beliefs.

The common thread across each of the focal theories is that when policy actors engage with research they are engaged in a process of transformation, they are 'minting' research which is important to their arguments, investing it with power, and testing its meaning in relation to their beliefs and values. There is a reciprocal relationship at work in this transformation. As research becomes invested with power and meaning in relation to policy, so policy can become welded to research. Every time policy discourse claims, for example, that the research supporting mammography screening is unimpeachable, it makes policy dependent on the ability to sustain that claim.

This argument can be supported by looking at what happens when the process of 'minting' goes into reverse, when research that was once regarded as unimpeachable becomes a liability. The current controversy over mammography screening occasioned by the Nordic Cochrane Centre Review gives an example. In Roger's discussion of Nordic Review, he undermines its potential status as evidence for policy in two ways. First, he argues that the trials included in the review are somewhat out of date because the technology and treatment they used are different to those used now. Second, he argues that given the impossibility of doing new screening trials based on current technology, judgements about effectiveness should be made on the basis of process

measures of quality and performance in the screening pathway (Roger 2002). What we can see here is a careful distancing of the policy rationale away from what was once its evidentiary core towards a new kind of argument based on new data. The randomised controlled trials of screening are being drained of the truth value with which they have been invested for a decade or more.

### **8.5. From ‘transfer’ to ‘transformation’**

As noted in Chapter 2, there are a number of writers who have attempted to understand the relationship between research and policy (or knowledge and policy, or social indicators and policy, or policy analysis and policy) and who have found that the intellectual product in question is ‘transformed’ in the process of being used. Rationalist conceptions of policy tend to render this as a process of distortion wherein ‘facts’ are put to the service of political interests. The sociology of knowledge perspective, on the other hand, argues that that the process of transformation is part and parcel of use. To wish that research should not be ‘distorted’ by use in policy is to condemn it to irrelevance.<sup>22</sup>

The central idea I am proposing is that ‘research transfer’ needs to be replaced with recognition that at the heart of the nexus between research and policy is a contested and political process that ‘transforms’ research into evidence and arguments. This notion has a broad history. The germ of the specific idea of transformation comes from Giandomenico Majone’s definition of ‘evidence’:

Evidence... is not the same as *data* or *information*. It is, rather, information selected from the available stock and introduced at a specific point in an argument ‘to persuade the mind that a given factual proposition is true or false’ (Encyclopaedia Britannica 1974). (Majone 1989: 48)

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<sup>22</sup> Working out when ‘use’ becomes ‘abuse’ is a difficult issue. Weiss has argued that when research appears it policy, it often does so in the form of ‘ideas’ or ‘arguments’. In both cases the trappings of research reports, such as qualifications about the limits of the study design, are lost. However, she contends, this does not necessarily compromise the research or the researcher. It has the benefit of getting the implications of research for policy clarified and it makes the value-base of the research open to scrutiny Weiss, C. H. (1991). Policy research: data, ideas, or arguments? Social Sciences and Modern States: National Experiences and Theoretical Crossroads. P. Wagner, C. H. Weiss, B. Wittrock and H. Wollmann. Cambridge, Cambridge University Press: 307-332.

This means that research only ever has the potentiality of evidence for policy. Before that potential can be realised, it must go through the process of being taken up and used in policy argument, ‘minted’, invested with power, and infused with the beliefs and values of policy actors. The reframing of the research–policy nexus I propose takes the following form:

$$\text{evidence} = \text{research} \times \text{meaning} \times \text{power}$$

When research influences policy it takes the form of evidence in policy argument and, in so doing, is transformed by being invested with new or additional meaning and power through social and political processes. Taking this a step further, I propose that when research has a particularly powerful influence on policy it has the effect of creating a binding rationale for policy.

By ‘binding’, I mean the effect of creating a rationale for policy such that, if the research were found to be wrong, there would be a serious problem in sustaining the policy. Policy makers would have to either find new data to support the policy argument or find some form of retreat from the connection between that research and policy. By saying that some research provides a ‘binding rationale’ for some policies, I am not arguing that research is the major or only cause of these policies—the case studies show that policy causation is far too complex to be attributed to one factor alone. What I am arguing is that when policy argument becomes fused with a set of claims derived from research, then a challenge to that research is a challenge to policy.

In the NSP in the community case study, this binding rationale come from the argument that, in the absence of NSP, there could be a devastating epidemic of HIV (and now BBVs) among injecting drug users, their sexual partners, and the wider population. As shown in the case study, the research to support this argument started out as a handful of studies in Australia and overseas. The body of research supporting the argument has grown, as have the systematic reviews of that research. It was also clear in the case study that this argument was not used just once at the point of policy initiation but has been used ever since.

With the NSP in prisons case study, we saw that a fundamental issue at the 1990 conference was whether prisons could be the incubators of an HIV epidemic. Advocates of NSP in prison presented data showing risk behaviour was prevalent and tied this with epidemiological theory to try to create a ‘binding rationale’ for trials of NSP in prison.

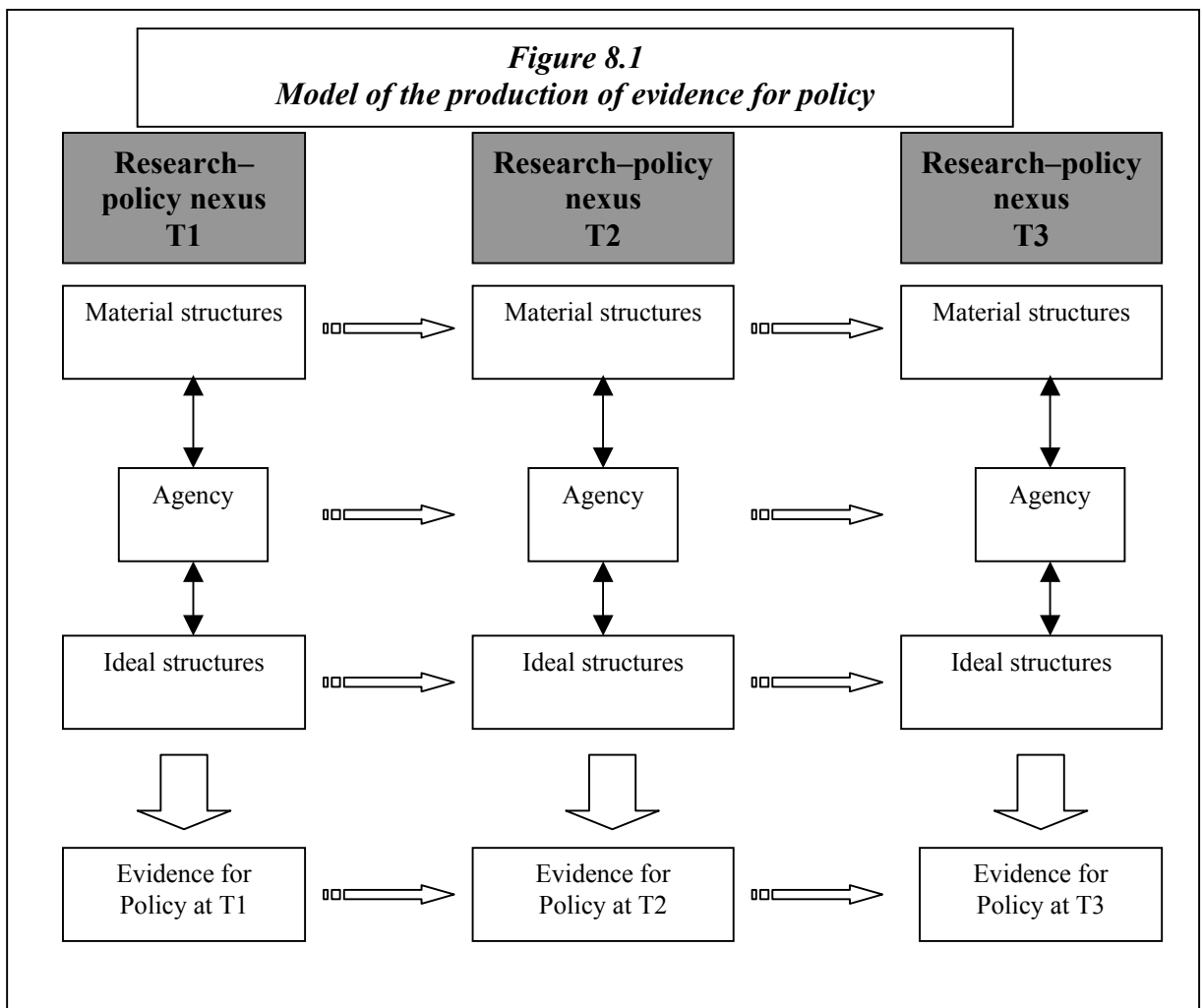
The anti-NSP protagonists such as the NSW Corrections Minister Yabsley and the Victorian Director General of Corrections, Peter Harmsworth, rejected the argument. They undermined its power by refusing to allow injecting drug use in prison to be reframed into public health discourse as ‘risk behaviour’ requiring harm minimisation. They continued with the correctional construction of injecting drug use as a criminal activity and a threat to security and orderly prison management. Even when research from Kate Dolan and Alex Wodak demonstrated transmission occurring, it failed to garner the necessary investment of meaning and power to overcome alternative constructions of the issue (Dolan and Wodak 1999a).

The process of transformation in the screening case studies show a similar pattern of tightly formulated and oft repeated arguments. In BCS, it is the argument that mammography screening saves lives. This claim, and its origin in research, was placed right at the centre of the policy rationale when Bob Hawke made the policy commitment in the lead-up to the 1990 election. He said ‘...studies indicated that a high-quality breast cancer detection and treatment program could save 370 lives a year’ (Wright 1990). As the case study showed, this claim was based on several randomised controlled trials in other countries, 10 pilot projects in Australia, and a meta-analysis of all the available data. While the case study data also showed that this electoral announcement was rank political opportunism, the influence of research through a variety of channels is also indisputable. But just as important is the sense in which the claim that mammography saves lives has taken on the status of a binding rationale for policy. Just as the claim that NSP prevents an HIV epidemic is repeated over and over, so too is the claim that mammography saves lives. The vigour of the refutations of the research that casts doubt on the effectiveness of mammography shows the flip side of the power and meaning invested in the research that shows mammography screening is effective.

In the case of PCS, I argued in the case study that the outcome of the AHTAC review of PCS was a foregone conclusion. The experts involved knew full well that there were no completed randomised controlled trials of screening because several other bodies had already trawled the same literature. The AHTAC process, set up under the auspices of the NH&MRC and AHMAC and using the resources of the newly established Cochrane Collaboration, was designed to invest the argument that there was no data to support PCS with maximum meaning and power.

## 8.6. The focal theories and a general theoretical form

A general theoretical form can be schematically illustrated with reference to Figure 8.1 below. The basic understanding of the research–policy relationship proposed is that for any particular policy issue there will be a unique configuration of policy actors, material structures and ideal structures that potentially create opportunities for research to be transformed into evidence or robbed of its relevance and validity. There is no single point of entry of research into the policy process and nor is there any single method by which research is mobilised to support particular policy arguments. Thus, structures and agency interact to create and constrain the possibilities for the transformation of research into evidence for policy.



This general theoretical form is limited because it does not propose any particular dynamic process of causation in the research–policy nexus. The form assists us in what might be called ‘theoretical triangulation’ whereby factors or events that are seen to be important across several case studies for each of the focal theories can be identified and given a significance that might otherwise have been lost. This ‘theoretical triangulation’

has been used to highlight the significance of the ‘ideal structures’ of harm minimisation and the WHO screening principles which otherwise might have gone unnoticed had the process of theorisation been left at the level of the focal theories. However, without the focal theories the particular role ‘harm minimisation’ is much more difficult to specify in a coherent way. Thus the focal theories remain the most accessible and tangible accounts of the research–policy relationship while the general theoretical form enables cross-case and cross-theory analysis such as that presented in the next chapter. Table 8.3 below sets out the way that each of the focal theories gives shape and meaning to the elements of the general theoretical form.

**TABLE 8:3 CONCEPTUALISATIONS OF THE GENERAL THEORETICAL FORM BY EACH OF THE FOCAL THEORIES**

<b>Dimension</b>	<b>ACF</b>	<b>PMOF</b>	<b>GF</b>
Agency	Beliefs and values motivate individual action. Individuals evaluate data through the lens of their beliefs and values. They may change their views but it is unlikely they will do this independent of changes in the beliefs of their advocacy coalition. Some individuals may play the role of policy brokers independent of advocacy coalitions.	The ‘policy orientation’ dimension of the PMOF conceptualises policy actors motivated by a desire to realise opportunities and reduce risks.	The ‘subject’ is made up in a struggle to realise freedom from various forms of domination. Researchers and policy actors are made up by the discourses and practices they create and perform.
Structure	Material and ideal structures are a site for competition between various advocacy coalitions. Formal, government appointed structures like AHTAC will reflect the distribution of power among advocacy coalitions.	The ‘research responsiveness’ dimension captures the material and ideal structures that variously constrain and enable the action of policy actors. Those structures within control of government are shaped by this interaction. The concept of ‘theatre of justification’ recognises that not all structures are controlled by government.	Structures are manifestations of the interaction between regimes of practices, regimes of truth, and policy discourse.
Structuration	Advocacy coalitions attempt to create, gain access to, or control structures and in so doing determine which beliefs and values will be most important in the conduct and use of research in policy.	Organisational epistemology will be a product of the interaction between the policy preferences of policy actors and the factors affecting research–responsiveness. Policy actors will attempt to influence those constraints to either increase or reduce research responsiveness.	Policy actors mobilise structures to produce knowledge/power and contest other forms of knowledge/power that contend with their own version.

## 8.7. Conclusion

In this chapter I have argued that the case study data support the conclusion that research does influence policy and that this happens through a variety of routes and



mechanisms as proposed by the three focal theories. The use and influence of research is selective, contested and political and it relates to the availability of structures (both material and ideal) that differentially empower policy actors who attempt to mobilise research as a political resource. When research is transformed into evidence for policy it is invested with power and meaning such that it creates a binding rationale for policy arguments.

The major shift in understanding proposed from this research is to view the entry of research into policy making as a process of transformation, not transfer. Transformation is a contested and political process that cannot be understood separately from different forms of power at work in the policy environment. Regardless of whether one conceptualises power in a pluralist, institutional or Foucauldian framework, the point is that it is central to all of them and should be made central to any theory of the research–policy relationship.

Both research and policy are multidimensional, contested and constantly evolving. They can both be thought of as the products of a system or as processes. Understanding how they relate to one another is a challenge for any theory. In this chapter I have argued that the minimum requirement for theory on this relationship is that it take account of material structures, ideal structures, and the way these constrain and differentially empower social actors. This might be recognised as a specification for social theory generally. An important contribution of this thesis is, however, to show that this specification has proven valuable in identifying particular components and interactions in the research–policy nexus that might otherwise have escaped attention. The next chapter takes the findings with regard to ideal structures and applies them to an analysis of the notion of Evidence-based Health Policy.

## 9. Reframing Evidence-based Health Policy<sup>23</sup>

### 9.1. Introduction

In this chapter I consider the implications of the understanding of the relationship between research and policy developed in the previous chapters for the idea of Evidence-based Health Policy (EBHP). The chapter is an attempt to answer more fully the third research question: what do the results of this analysis mean for our understanding of the relationship between research and public health policy in Australia? The need to address this is raised by the problem at the heart of the quest to increase or improve the use of research in policy—‘research use for what?’. In Chapter 1, I stated that this question presents a normative and theoretical hurdle for the field of study concerned with research use in policy. If the answer to the question is ‘so as to make Evidence-based Health Policy’, then the focus of attention shifts but new questions emerge. What is Evidence-based Health Policy? Can it ever be achieved and, if so, how do we know when we’ve made it?

One way of answering this question is by establishing an authority that claims to be the arbiter of what ‘correct’ policy should be (or ‘correct use of research in policy’ should be) on any particular health matter and then making comparisons between this standard and current policy. This approach is suggested by Hanney and others in their proposed method for assessing research use in policy (Hanney, Gonzalez-Block et al. 2003: 21). For reasons set out below, I think this approach is fundamentally flawed.

The approach developed here has been influenced by the philosophy of social science set out by James Bohman (Bohman 1991) as well as the post modernist policy thinking acknowledged in Chapter 2. Bohman’s particular contribution is to argue that ‘post empiricist science’ does not need to abandon criteria for quality and validity but to recognise knowledge as an ongoing social product for which we can find exemplars in the practice of science. From Bohman, I have taken a basic methodological principle

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<sup>23</sup> A version of this chapter has recently been published as ‘Framing and Taming “Wicked” Problems’ Gibson, B. (2003). Framing and Taming 'Wicked Problems'. Evidence-based Health Policy: Problems and Possibilities. B. Gibson and V. Lin. Melbourne, Oxford University Press: 298-310.

that a strategy for moving through problems that derive from irresolvable questions of values is look to how the problems have been handled in an exemplary (if not perfect) way in practice. There are two case studies in this thesis where public health research has, to some extent, had a direct impact on policy such that current policy owes its continuation to some extent to the acceptance of arguments based on public health research (this is the concept of ‘binding rationale’ developed in the last Chapter). This is clearly a guarded claim and stops short of saying that these policies—breast cancer screening and NSP in the community—are ‘evidence-based policies’. The main reason why I stop short is that there is no accepted formulation of what evidence-based policy is and views are so divergent that it is difficult to see one emerging in the near future (Lin and Gibson 2003). The discussion that follows is an attempt to reframe EBHP and suggest that by looking at practical examples of policy making we might understand what is involved in attempting to shape the way policy is made.

## **9.2. Evidence-based Health Policy and Meta-policy**

Unfortunately, prescriptions on EBPH making are often made without the recognition that they are themselves attempts at a particular form of policy making. They are an attempt to change the rules of policy making so that ‘evidence’ is privileged over other considerations in the policy process, particularly political considerations. Discussion about the problems and possibilities of EBPH is a ‘meta-policy’ activity. It belongs to the class of ‘meta-activity’ that has been described as follows:

Any serious human activity begets ‘meta-activity’, individual brooding or talk among a group. This is as true about hunting or gambling or house-building as it is about politics; and such talk always ‘feedbacks’ in some sense into the original activity itself. (W.J.M. Mackenzie, cited in Gregor, 1971:1 cited in Parsons (Parsons 1995: 1)

In arguing that policy should be evidence-based, proponents of EBPH are doing more than just ‘brooding’. They are arguing that there should be a policy on policy-making that specifies and guards the role of research. They are arguing, in effect, that there should be an explicit meta-policy to govern policy making. For example, in their prescription for EBHP discussed in Chapter 1, Chris Ham and others argued for a policy process that is committed to evaluation research and fosters independent policy research infrastructure. They say that there should be accountable and rigorous engagement with

research by policy makers (Ham, Hunter et al. 1995). Klein, a long-time health policy analyst in the United Kingdom, has poured cold water on attempts to prescribe meta-policy. He argues that policy is too complex to make simplistic assumptions about how research will inform its different components. He says, for example, that the role and capacity of research is very different across different policy tasks such as measuring the dimensions of a health problem, establishing its causes, and putting forward policy responses (Klein 2000).

This British debate has had an Australian echo. Gaughwin has argued for an approach to public health policy making based on ‘minimum standards of deliberation’ (Gaughwin 1998). He says that the central problem is ‘How to achieve health and wellbeing for all, justly and fairly, when there are reasonable disagreements about ends and means’. The standards could look to ways of having meaningful community involvement through citizens’ juries or panels and create structures in which policy arguments have to be justified ‘in the presence of the public’.<sup>24</sup> The question is whether such standards could ever be agreed and implemented. Swerissen’s reply to Gaughwin is that ‘minimum standards of deliberation’ will never eventuate and are unnecessary. He argues that the combination of parliamentary mechanisms and the media ensure that policy arguments are interrogated. ‘Policy progresses only by the testing of good ideas in the furnace of political debate’ (Swerissen 1998). Gaughwin’s proposal did not argue against the value of the ‘furnace of political debate’, but raised questions about who should be allowed to participate in debate and how the debate might be structured to ensure the best use of the best available research.

None of the debate so far has made much progress in finding a way of discussing and analysing meta-policy questions and problems. The approach taken by Ham and others, and Gaughwin is to promote particular ways of making policy that tend to resolve to two issues—how to make processes more democratic and how to make them more rigorous. As the rejoinders from Klein and Swerissen show, however, these are just as contestable as any other aspect of policy. A strategy for moving beyond this impasse is to consider how policy is made in the real world. The way ahead might involve looking

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<sup>24</sup> There is a resonance between Gaughwin’s ideas and some of the indicators of research responsiveness in the PMOF.

at breast cancer screening and NSP in the community as workable but imperfect policy-making accomplishments.

Before taking that on, however, I think we need to be explicit about the task of meta-policy making. In the next three sections I set out what I consider to be the three main conceptual challenges in meta-policy making: resolving questions about what criteria and processes to use to define problems, set priorities and make decisions; how to constructively and explicitly integrate values with empirical analysis; and how to ‘tame’ uncertainty and complexity that arise from the indeterminacy of health. After that I propose a way of using the knowledge from the BCS and NSP in the community case studies to see how these challenges were met in a workable if imperfect way.

### **9.3. Meta-policy and levels of abstraction**

People commonly make the distinction between different levels of policy making in health systems and distinguish between ‘practice policies’, ‘service policies’, and ‘governance policies’ (Black 2001). A less common distinction which complements this is the notion of ‘levels of abstraction’ (Alford and Friedland 1985: 21). At any given level of analysis (practice, service or governance), more and more complex or abstract questions might be asked. While I do not use the ‘levels of abstraction’ concept in the same way as Alford and Friedland, the essential point is that each level of abstraction represents a qualitatively different set of problems to other levels. It sometimes occurs that ‘levels of analysis’ and ‘levels of abstraction’ are conflated so that it is assumed that ‘governance’ policy making is assumed to have involved the most abstract form of policy making. It is worth distinguishing between these different kinds of levels to recognise that meta-policy questions can occur at all levels of analysis.

Three levels of abstraction can be identified in health policy making based on the kinds of question each of them asks:

- First order policy making—should we implement program x to fix problem y?
- Second order policy making—how should we decide whether to implement program x to fix problem y?
- Third order policy making—how should we decide whether problem y has priority over problem z, or if they should they be seen as a subset of a larger problem and approached quite differently?

One could keep posing higher order and more philosophical questions. However, three levels are sufficient to capture the essence of the meta-policy problem of how to make policy on policy making. Meta-policy discussion is primarily concerned with the second and third levels of abstraction. Discussion of the idea of EBHP needs to be viewed in relation to these questions.

While the first, second and third-order policy questions are conceptually distinct, I am not suggesting that in the real world of policy making they are answered in a discrete or logical fashion. One definition of a policy crisis is when policy makers have to ‘build the bicycle while riding it’, that is, concurrently formulate the problem, work out the process to make policy, and take action to fix it. It is quite possible that the availability of an affordable and feasible intervention will lead to its adoption without systematic or explicit consideration of the higher order policy questions. NSP in the community had this characteristic.

A major meta-policy challenge derives from the dynamic relationship between these different levels of policy making. The Pharmaceutical Benefits Scheme (PBS) is a good example. This PBS has established a robust and accountable second-order policy making approach based on cost-effectiveness analysis. New pharmaceuticals must be subject to rigorous empirical evaluation against a number of explicit criteria that incorporate safety, cost and benefit. The problem is that the Scheme has only modest influence over first-order decision making by clinicians. They may prescribe a cost-effective medicine in an inappropriate way and so cause harm to the individual at cost to the public purse. The Scheme also does not control which drugs will come before it for consideration—the third-order part of the process. The pharmaceutical companies decide which diseases and health problems they will focus their Research and Development on and their choices are commercially driven.

The task of making meta-policy must grapple with different kinds of reasoning, politics and research that are potentially relevant to these different levels of abstraction. This would seem entirely overwhelming if it were not for the fact that these questions are resolved on a daily basis in the real world of policy making. The question of whether or not they are being resolved satisfactorily is always open to contest but the fact that they have been resolved to a sufficient extent to enable practical action is beyond doubt.

## 9.4. Meta-policy, values and research

A second challenge of meta-policy is to resolve apparent tensions between empirical research and values in policy making. There is a strong tendency to see the inclusion of values in decision making as separate from and incompatible with the rational use of research. Values and research are often portrayed as being locked in a zero-sum game where the more that values drive policy making, the less the role that research can play. For example, Black says of ‘governance policies’ in the health system, ‘Clearly, research has only a limited role because governance policies are driven by ideology, value judgments, financial stringency, economic theory, political expediency, and intellectual fashion’ (Black 2001). Palmer says in relation to private health insurance policy in Australia that ‘...considerations of ideology, values and electoral appeal intrude heavily, making it inevitable that the role played by evidence has been very limited to date’ (Palmer 2000). As discussed in Chapter 2, the descriptive models of research use in policy deal inadequately with the way that values affect research use because they only identify the role of values when these are imposed through a coercive process. I argued that they are present in all processes where research was being appraised and used, even if the process of selection was open, transparent and democratic.

The dichotomy between the use of values in policy making and the rational use of research in policy making is, I believe, false and dangerous. It relates to a more fundamental debate about whether it is possible to distinguish between facts and values and whether it is possible to do value-free science. There is extensive literature and debate on this topic that will not be reviewed here in any detail. My position rests firmly on a the post-positivist view of science (Fischer 1995; Bohman 1991: 11). I take the view that facts and values are different and yet interdependent components of policy making just as they are different and yet interdependent components of science. This interdependence will be demonstrated in relation to the role of the WHO screening principles and harm minimisation. The policy studies literature is replete with attempts to recognise and capture this interdependence. For example, Vickers, writing well before the advent of post-positivist social science, described ‘value’ judgements and ‘reality’ judgements as interrelated parts of the conceptual ‘screen’ through which humans view the world. They are the ‘weft and warp’ of our system for appreciating the world (Vickers 1965: 41-42, 70).

The origin of the deep suspicion of values in policy making appears to come from a tendency to conflate the different levels of abstraction in policy making, and to confuse questions of what is rational with questions of what is reasonable. As can be seen from the BCS case study, the first order decision making carried out by the AHMAC-AIH national evaluation can seem as if it is a value-free evaluation of research in relation to policy options. But the BCS case study showed that it was not like this at all. In order for first order policy making to occur (that is, answer the question as to whether or not to introduce mammography screening), the second order question (how should we decide whether or not to introduce mammography screening) had to be answered. As was shown in the case study, this question was answered by the application of the WHO screening principles and these are infused with the ethical principle of utilitarianism.

While the relationship between reason and rationality is the subject of extensive philosophical investigation (Habermas 1984), Rawls' distinction between them might be usefully employed as a way of conceptualising the constructive and necessary role of values in policy making<sup>25</sup> (Rawls 1993). For Rawls, rationality relates to the capacity to know goals and interests, give them priority and to work out how to achieve them (Rawls 1993: 50). Being reasonable is about being prepared to propose and abide by 'fair terms of cooperation', given that others are prepared to do so (Rawls 1993: 49). The reasonable and the rational are different but complementary concepts and one cannot be reduced to the other. It is quite possible (and perhaps all too common) for powerful actors in health policy to act unreasonably in the pursuit of their own rationally chosen goals. However, perhaps a more common problem for health policy making is that reasonable people can agree to 'fair terms of cooperation' and can act quite rationally but still end up in major disputes. Rawls argues that this arises from the 'burdens of judgement' associated with being reasonable. These include the problem that research is often conflicting and complex and hard to evaluate. While it might be possible to agree on the criteria to evaluate research, it is still possible to disagree on the relative weight of the criteria. There may be different kinds of good things that have to be traded off against each other; the trade-off between personal autonomy and protection of the health of the community is a common one in public health. The fundamental burden is that complex problems will often have no clear answer and reasonable people will disagree.



Given that second and third-order policy problems are only resolvable by reference to values, it follows that resolution of meta-policy on these problems will always be contested, even when those involved want to act rationally and reasonably. Those who would want to promote EBHP must be prepared to enter debates about meta-policy without the expectation that the a higher court of scientific method will relieve the burdens of judgement. A major challenge of making meta-policy is to find a way of approaching it reasonably, and of integrating questions of values with questions of empirical research as separate-but-inseparable parts of policy making, not mutually exclusive foes. As with the first meta-policy challenge, the way to approach this challenge is to understand how it has been met in the actual practice of policy making.

### **9.5. Meta-policy, complexity and uncertainty**

It might be observed that the burden of judgement increases as problem complexity and uncertainty increases. This introduces the third challenge of meta-policy making. To understand how to resolve this challenge, we need to give some shape to complexity and uncertainty.

Rittel and Weber distinguished between ‘tame’ and ‘wicked’ problems (Rittel and Webber 1973). ‘Wicked’ does not mean morally reprehensible but something like ‘tricky’ or ‘intractable’. ‘Tame’ problems have boundaries within closed systems and are capable of being resolved given sufficient resources. ‘Wicked’ problems, on the other hand, do not have boundaries and can always be expressed in terms of some larger or related problem. They are not capable of final resolution—work on wicked problems stops when time, money or will to continue run out. Solutions to a wicked problem are not true or false but good or bad according to the values and interests of those making judgments (Rittel and Webber 1973: 161-166). Rittel and Weber argue that poverty is a classic wicked problem because it can be formulated in so many different ways. Each formulation of the problem suggests particular solutions that feed back into the need for more information about that way of defining and solving the problem. ‘The formulation of a wicked problem *is* the problem’ (Rittel and Webber 1973: 161).

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<sup>25</sup> I am indebted to Matt Gaughwin for bringing Rawls work and this reference to my attention.

‘Health’ is a wicked problem in that it is not definable in any absolute form. Every step government takes towards improving health is matched by the thing itself slipping over the horizon (Osborne 1997). Because everything in the world, ‘from the planetary to the molecular’ (Eckersley, Dixon et al. 2001: xv), can be implicated in the pathway to disease and because everything can be connected in larger and larger causal models, health policy has no boundaries. This is sometimes referred to as the ‘indeterminacy’ of problem definition in health (Miller 1999). Health policy only gets shape and scope as third and second order policy making questions are resolved.

The indeterminacy of health generates uncertainty. Friend and Hickling provide a useful approach to identifying uncertainty in a decision making context. They argue that all uncertainties in decision making can be grouped into three classes on the basis of the actions that decision makers take to try to resolve them (Friend and Hickling 1987: 11). There is uncertainty about values and objectives. Value uncertainty is apparent when decision-makers search for guidance from higher authorities or other policy actors on aims or priorities. The second is uncertainty about the environment. This is in evidence when policy makers instigate data collection, research and analysis in the quest for more information about a problem. The third type of uncertainty is about related decisions. This is about the relationship of one problem with other problems and is apparent when decision makers try to coordinate the resolution of one problem with the resolution of another, more fundamental or related problem. Uncertainty can only be reduced at a cost in terms of delay in settling urgent matters or it may be in terms of money, skills, or other scarce resources (Friend and Hickling 1987: 13).

Because health is an inherently ‘wicked’ problem, the process of health policy making continuously confronts each of these types of uncertainty. More important still is the realisation that any resolution to a meta-policy problem is only provisional, a *modus vivendi* awaiting a new round of contest and disagreement that may lead to a new provisional agreement. Because of the indeterminacy at the heart of health meta-policy questions, the health policy-making system has an unquenchable thirst for more information, more research, more coordination, and is forever engaging in contest over values and objectives.

But as with the other meta-policy challenges, it is clear from the day-to-day practice of policy making that the challenges of complexity and uncertainty are resolvable to some

extent. The rest of the chapter will discuss the ways in which the findings from this thesis might be used to inform this understanding.

Before doing that, however, I propose one last theoretical transposition to aid with the clarity of language. The focus of attention in the following discussion is on the WHO screening principles and harm minimisation. These were identified as important ‘ideal structures’ in policy making in BCS and NSP respectively. The question is, what type of ideal structures are they? There is such a wide range of things that could potentially be put under the heading of ideal structures that some finer grained category is warranted. A term that seems to work is that of ‘policy frames’ as proposed by Rein and Schon (Rein and Schon 1993). By ‘frames’, they mean the conceptual and perceptual lens through which policy participants view the world. They say that stubborn policy controversies arise when policy participants have different ‘frames’ through which facts, values, theories, and interests are integrated (Rein and Schon 1993: 145). Participants with different frames cannot even agree on the nature of their disagreements. In the discussion that follows, I will be referring to ‘policy frames’ in this sense and identifying the WHO screening principles and harm minimisation as examples of these frames.

## **9.6. BCS and the challenges of meta-policy**

In the 1980s in Australia, mammography screening represented a ‘first order’ policy problem for policy makers. Should Australia introduce a national program of mammography screening for breast cancer? As far as policy making processes go, the process to decide this question was, to some extent, transparent if only after the event. The Screening Evaluation Unit at the then Australian Institute of Health was given the task of evaluating the available research and making recommendations under the guidance of an Australian Health Minister’s Advisory Council committee chaired by Professor Tony McMichael. *Future Directions* lays out the data, analyses and assumptions that guided their recommendations (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990). There were many that disagreed with the interpretations of the available research, the recommendations of the report, and the pace of implementation (Swan 1990). There are some who still do (Willis 1999). However, there is no doubt about the basis of the AHMAC recommendations, the place

that research played in forming those recommendations, and the places where there was insufficient research to support or reject screening (eg for women aged 40 to 49).

What enabled this relatively transparent and explicit process of engagement with research to proceed was the resolution of the second-order policy question: ‘How should we decide whether or not to introduce mammography screening?’. The answer was to adopt the WHO screening evaluation principles first developed in 1968 by Wilson and Junger (Wilson and Junger 1968). These principles were also adopted in relation to prostate cancer screening policy making several years later. The continuing application of the screening principles is a remarkable achievement in health policy terms as there are very few health policies that could claim the longevity of these principles. They are just as well accepted in public health textbooks (Kerr 1998) as they are in the policy context.

What is it about the screening principles that enable them to ‘work’? The answer, I believe, is that they are an ‘ideal structure’ that helps to resolve meta-policy challenges. They combine empirical criteria with value criteria. The criteria generate questions about the ‘importance of the disease problem’ and the ‘acceptability of the screening test to the population’ that can be measured through empirical research, such as burden of disease and pilot surveys respectively. Just as importantly for this discussion, they do not determine what should count as sufficiently ‘important’ or sufficiently ‘acceptable’. These are matters of judgement. Thus, the screening principles provide a ‘policy frame’ (Rein and Schon 1993) that makes values explicit and creates a demand for research to support arguments about how judgement should be exercised in relation to the policy issue.

The screening principles do not directly resolve the other meta-policy challenges associated with mammography screening. With regard to the third order question of how to decide whether or not to do something about breast cancer, this was not so much resolved by Australian policy makers but hijacked by what Batt has described as the mammography ‘juggernaut’ (Batt 1994: 31). The rise of the juggernaut was well set out in the case study along with the structural foundations that produced it. One could ask what the point is of having a ‘policy frame’ that demands and structures the use of research in policy making if there is no ability to control the policy making agenda. The policy frame of the screening principles are, therefore, not a complete answer but they are of benefit. The PCS case study showed that they could be used to partially stop the

progress of the PSA testing juggernaut. They will be sorely tested when the PCS screening trials finally report their results. It is important also to restate the point made earlier that the different kinds of meta-policy challenges interact. Having a way to make second order decisions can help resolve third order decisions simply because they create a policy environment that is more manageable.

The meta-policy problems of indeterminacy and uncertainty were also not resolved by an explicit policy process in Australia. What the case study made clear was that the environment in which mammography developed was one deliberately promoted by public health agencies in the United States at the end of the Second World War in response to the increasing burden of chronic disease. Screening provided a way of making this large and difficult problem tractable within the historical context of the central role of the medical profession and expectations of being able to find a technological fix. As this example shows, current patterns of service delivery and financing have a major impact on how problems are defined and shaped. The screening 'paradigm' is now well entrenched as a dominant health system response to chronic disease. The screening principles probably reinforce this paradigm for several reasons. One is that they make policy making tractable. A second is that they provide a structure that is easily mobilised by powerful policy actors. As Sewell notes, 'Structures...empower agents differentially, which also implies that they embody the desires, intentions and knowledge of agents differentially as well. Structures, and the human agencies they endow, are laden with differences in power' (Sewell 1992: 21).

### **9.7. NSP and the challenges of meta-policy**

Somewhat like BCS, the mid-1980s presented a first order policy problem in relation to NSP in Australia. In 1985, the first case of HIV in an injecting drug user was detected (Blacker, Tindall et al. 1986). Other studies showed a high prevalence of needle-sharing among injecting drug users (Paine, Tonuma et al. 1985). Research from overseas showed that large HIV epidemics among IDUs were possible (Hardy, Allen et al. 1985). The question was, should NSP be introduced to prevent the spread of HIV among injecting drug users.

How were the meta-policy problems resolved in the example of NSP such that it has been able to endure through changes of government and continually expand since 1986?

What ideal structure provides the answer to the second order policy question ‘How should we decide whether to introduce NSP to prevent HIV transmission?’ The NSP case study argued that harm minimisation was the central and critical ideal structure in policy on NSP. The question is, ‘how did harm minimisation work to meet the challenges of meta-policy in relation to NSP?’.

In relation to the challenge of integrating value questions with empirical questions, harm minimisation works in a similar fashion to the WHO screening principles. The value-base of harm minimisation links the ethical consideration of expanding the autonomy of the drug user with the utilitarian principle of aiming to achieve net benefit for the individual and the community while recognising that some harm may come as a by-product of the interventions. The link between values and empirical research under harm minimisation is seen in the way the term is operationalised for the purposes of evaluating specific interventions. It generates a series of empirical questions: what harms are involved in this behaviour? What harms are reduced by this intervention? What harms might be created by this intervention? What is the net benefit measured in terms of potential infections averted compared with potential harms to health? The link between harm minimisation as a basis for policy action and harm minimisation as a basis for empirical research is further demonstrated by the extent to which the concept has provided a paradigm within which researchers can collaborate internationally (Crofts and Deany 1999) and engage with policy makers (Moodie, Timberlake et al. 1996).

In relation to the second order policy question of how to decide whether or not to introduce NSP, harm minimisation provides a less specific decision making framework than the WHO screening principles but the way it works in practice is very similar. The key concept is the notion of net harm (or net benefit) resulting from the intervention. By removing the issue of legality from the calculation of benefit, NSP can compete effectively with interventions that emphasise the achievement of law enforcement objectives over health objectives. Unlike the WHO screening principles, there was a formal process for adopting harm minimisation as a philosophical basis of Australian drugs policy. This occurred in 1985 at the Special Premiers Conference that set up the National Campaign Against Drug Abuse (Wodak 1990; Single and Rohl 1997) and has been continually reinforced in HIV/AIDS policy documents ever since (Commonwealth Department of Health and Aged Care 2000: 9).

Harm minimisation is particularly important in reducing complexity and uncertainty and making problems tractable to intervention. The panic induced by the HIV/AIDS issue in the early and mid-1980s was discussed in the NSP case study material. In the face of the potentially overwhelming range of issues generated by HIV/AIDS, harm minimisation provided a way to restrict and focus policy attention to the question of how to manage and minimise harm. As an ideal structure, it can be mobilised and transposed into policy contexts as diverse as law enforcement, education, and health care service delivery.

In terms of resolving meta-policy challenges, harm minimisation scopes the problem of HIV among injecting drug users and contains the three areas of uncertainty. In relation to values, it establishes the primacy of enabling individuals to self-care and reduce harm while they continue to inject drugs (at least in its original ‘narrow meaning’ (Single and Rohl 1997: 44). It delimits the range of issues that need to be dealt with in order for NSP to become operational—coordination between law enforcement, public health workers and drug user groups become central. And it focuses the empirical questions requiring research and data collection—the rates and distribution of high-risk behaviour and HIV and other blood borne viruses being central.

As the case study of NSP in prisons clearly shows, the simple availability of harm minimisation as an ideal structure does not guarantee anything in relation to specific interventions or policy outcomes. While HIV/AIDS policy actors have continually tried to mobilise harm minimisation as a resource to influence prisons policy, their inability to get a purchase on the material structures of prison policy and administration has meant that harm minimisation has only made minor break-ins. The struggle noted in the case study over the language of drugs policy in prisons highlights the importance of ideal structures in policy making and their symbiosis with the material structures of policy making. Policy actors who wish to mobilise harm minimisation as an ideal structure in support of an intervention like NSP will be unable to bring pressure to bear on policy unless they can also mobilise some material structures related to the policy process.

## **9.8. Policy frames and research use in policy**

The extent that research can be brought to bear powerfully on policy making is dependent on the availability of policy frames that create a demand for research and

enable the integration of values and data in policy making. These ideal structures need to have a symbiotic relationship with material structures through which policy making can occur. Their enactment is dependent on the availability of policy actors with the skills and motivation to mobilise and recreate these structures to achieve particular policy outcomes.

Whether or not the presence of these conditions will lead to successful policy making (in the sense that practical, workable policy is implemented) is dependent on the resolution of the three meta-policy challenges identified above.

To the extent that mammography screening and NSP are practical health policy accomplishments (even if continually contested), they offer some insights into the ways that meta-policy challenges are resolvable in the real world. What becomes apparent is that the three different challenges comprise a Gordian knot. Policy frames, like harm minimisation and the WHO screening principles, seem to be critical to the task of cutting that knot by helping to resolve those challenges simultaneously.

The values basis of the policy frames are explicit to the extent that they define what should count as benefit and harm in relation to the problems they deal with, and they provide a way of evaluating and making judgements about those. They define their respective 'problem space' in a way that makes them amenable to practical action. While any significant health problem like breast cancer and HIV transmission can be linked with larger problems (eg the causes of cancer, the determinants of risk behaviour), the respective policy frames successfully bracket these larger problems and stop them overwhelming first and second order problem solving. The policy frames influence research gathering in much the same way as a research program or paradigm (in the Kuhnian sense) in that they generate problems and questions that demand empirical research.

Drawing on the examples of harm minimisation and the screening principles, it is possible to make some generalisations about the role of policy frames and their limits in meeting the challenges of meta-policy. These relatively successful (workable and enduring) policy frames resolve meta-policy issues in a context specific way. The screening principles relate to screening. Harm minimisation relates to illegal and/or potentially harmful behaviour. While they have features in common, they are



operationalised on specific, empirically investigable problems that are entirely different from one another.

The policy frames have strong international and local dimensions that reinforce each other. Both harm minimisation (or harm reduction) and the principles of screening programs were developed and applied outside Australia before being applied here. They are not owned by any one sector—they might just as readily be adopted by government as by researchers and by non-government organisations as the proper basis for policy making. Indeed, both these policy frames had their origins outside government and were adopted by government as a way to deal with pressing policy problems of the third order (eg what to do about runaway de facto screening for breast cancer, what to do about HIV transmission among injecting drug users). Their transportation around the globe is as much a product of networks between academics and non-government organisations as it is of government agencies.

The policy frames strike a balance in the scope of the problems they deal with. They are broad enough to deal with current and emerging policy issues in relation to cancer screening, on the one hand, and blood-borne virus transmission on the other, but focussed enough to enable action to take place on specific problems in the present.

The policy frames integrate ethical considerations within their core principles. Issues of beneficence and non-maleficence are central to question of balancing potential harms from screening and needle distribution with their potential benefits. The centrality of these considerations is apparent from the way that it is precisely these issues that are the focus of debate about the programs. The principle of autonomy is central to both the policy frames and is also the subject of fierce debate. In the mammography field, critics argue that the program does not do enough to encourage informed decision making by women (Ward 1999). With NSP, critics argue that harm minimisation creates an illusion of choice for drug users that leads people who are vulnerable to take it up only to find that their choices are reduced through addiction, not expanded (Sullivan 1999b).

These ideal structures, while relatively successful, bring no guarantees and have their limits. In respect of harm minimisation, its meaning and application are hotly contested (Miller 2001) and it is open to colonisation from those who would seek to use its rhetorical power while emptying it of its original value-base (Single and Rohl 1997). It can also be rejected, as in the rejection of the prescription heroin trial by the

Commonwealth Government, even though such a trial would be completely in keeping with harm minimisation (Wodak 1998). With respect to the screening principles, the recent systematic review of eight randomised controlled trials of mammography (Gotzsche and Olsen 2000a) has underlined the extent to which the edifice of screening evaluation and the tools of Evidence-based Medicine do not circumvent the ‘burdens of judgement’.

## 9.9. Conclusion

In Chapter 1 I noted the way that the rise of discussion about EBHP made the question of how we understand the relationship between research and policy more relevant. However, it is not entirely clear how the quest for increased research use in policy and the quest for EBHP are related. There are enough statements that link them together to suggest that those who propose one have sympathy for the other but those statements carry uncertainties as well. For example, Hanney and others write ‘The existence of relevant research, though necessary, is not sufficient. Evidence-based policy is difficult to achieve and it is widely agreed that health policies do not reflect research evidence to the extent that in theory they could’ (Hanney, Gonzalez-Block et al. 2003: 2). In this chapter, I have argued that the quest for research use in policy and for EBHP are discussions about meta-policy or policy on policy making. When viewed in this way, discussion can move on from debates about how policy ‘should’ be made and how research ‘should’ be used to discussion about the particular challenges that face meta-policy relating to health. Unless particular attention is given to recognising and addressing the challenges of meta-policy then discussion of how to make policy ‘more evidence-based’ or ‘use more research’ are unlikely to move beyond an exchange of platitudinous pleasantries.

I have also shown how the enhanced theoretical repertoire developed in the preceding chapters can be used to further understanding of the relationship between research and policy. By using the strategy of studying how policy making works in practice to resolve meta-policy challenges, the role of ideal structures (policy frames) can be seen more clearly. In particular, the way these structures shape the research–policy nexus should lead to further consideration of the role of policy frames in the relationship between research and policy.



## **10. Conclusion**

### **10.1. Introduction**

In Chapter 1, I argued that the nexus between research and public health policy has been seen as problematic for several decades. From the earliest research on the use of research in policy in the 1970s (Caplan, Morrison et al. 1975) through to the latest review of this research (Hanney, Gonzalez-Block et al. 2003), the ‘two communities’ theory continues as the dominant diagnosis for perceived failures in research use. The commonly prescribed cures for this complaint flow directly from this theory and take the form of the ideas of ‘linkage and exchange’ and ‘research transfer’ using ‘receptor units’ and ‘research brokers’. I have argued that we need to rethink the relationship between research and policy and about what happens when research is used in policy. The concept of ‘research transfer’ should be replaced by the concept of ‘research transformation’ to capture the social processes involved in selecting and making sense of data, and using it to build and defend policy arguments. This conclusion is based on the analysis of four case studies and three theoretical frameworks for understanding the research–policy nexus. How robust are these conclusions? The next section discusses the limitations of the study and the problems of generalising beyond these particular cases. I conclude the thesis by discussing the main contributions of this research to our understanding of the relationship between research and policy. In section 10.3, I highlight the findings from this thesis that challenge nine enduring assumptions which underpin the ‘two communities’ theory. I then discuss the contribution made by this study to the way forward in this field of inquiry.

### **10.2. Study generalisability and limitations**

Once criticism could be that the multiple case study design was undermined because the two ‘negative’ cases turned out to be not so negative after all. I did not realise at the time of case study selection the ambiguous state of policy on PCS and NSP in prisons. I had thought that there had been a decision not to introduce PCS and I was unaware of the continuing high level of de facto screening and the changes to the Medicare Benefits Schedule that effectively allow de facto screening to occur legally. I had also thought that there was no policy support for NSP in prisons. I was unaware of the ambiguity

created by the ‘principle of equivalence’ or of the shift in emphasis over time from an argument based on the incubator hypothesis to an argument based on this principle. However, the design did not lose its power because of this, rather it gained the added element of needing to consider the relationship between research and policy which is ambiguous and unresolved. It created an extra challenge for the three focal theories to come to grips with. Had all the case studies been resolved to the extent of NSP–community and BCS (acknowledging of course that policy is never resolved for all time) there would have been less variation in the type of policy outcome needing explanation.

Generalisability is limited in several ways. The first is that the case studies have not considered resource allocation and implementation to a great extent. One could look at many dimensions of policy on resource allocation, for example, between national public health policies and programs, or between public health and other parts of the health system such as primary care and acute care system. This is one of the most important and vexed of policy issues and has received much attention in the field of health economics (Segal and Chen 2000).

A second limit to generalisability arises from the types of interventions involved in the case study. While they came from very different areas of public health, both NSP and the screening modalities are readily definable interventions with specific application based on medical technology and targeted at specific populations. There is a question about whether research and policy making with respect to interventions of this sort is different to that pertaining to ‘social technologies’ such as peer education for safe injecting, or broad scale interventions such anti-smoking television advertisements or point of sale legislation for under-age alcohol consumption. Even more remote is the category of what health promotion theory calls ‘healthy public policy’ such as income support, education and occupational health and safety legislation (WHO 1986).

A criticism of this study could be that I have not distinguished between the ‘instrumental’, ‘conceptual’, and ‘symbolic’ use of research as others have (Lavis, Ross et al. 2002; Hanney, Gonzalez-Block et al. 2003). This was because these distinctions were not important to any of the focal theories, and because of concerns about the adequacy of these distinctions discussed in Chapter 2. It is possible that had I deliberately looked for these types of research use, particularly instrumental rather than

conceptual or symbolic use, examples of the routine ‘transfer’ of research to policy making might have been apparent.

It could be argued that I have made something of a straw man of the ‘two communities’ theory and the notion of ‘research transfer’. This criticism is valid to the extent that many of those who use these ideas also refer to the broader public policy literature (Hanney, Gonzalez-Block et al. 2003). However, my criticism is that even in the most sophisticated models (such as that of Lomas presented in Chapter 2), as soon as discussion moves from description to explanation of the research–policy relationship the basic assumptions of the ‘two communities’ theory come to the fore.

It could also be argued that I have over-emphasised the connection between the ‘two communities’ theory and ‘research transfer’ type solutions. While I concede that there is no necessary connection between them, they do fit each other quite neatly at a conceptual level and they appear to have a mutually reinforcing effect as fellow travellers in the literature.

Lastly, I could have explored other possible theoretical approaches. These were acknowledged in Chapter 2 and include political economy (used by Kaufert to analyse the spread of mammography screening (Kaufert 1996: 174)), micro economics (Bardach 1984; Landry, Amara et al. 2001), diffusion of innovation theories (Kimberly and Pournourville 1993: 12), and theories from the sociology of scientific knowledge (Callon 1986). I have tried to counter this limitation to some extent by developing the idea of a ‘general theoretical form’ that might be used to compare and contrast other theoretical approaches.

On the whole, I think these limitations may moderate the strength of the findings and arguments presented but do not negate them.

### **10.3. Assumptions from the ‘two communities’ theory challenged by this research**

#### **10.3.1. *Research can give clear messages to policy***

The implicit assumption in much of the writing on research transfer is that if only research could make it across the ‘gap’ between the ‘two communities’ and into the policy process then it would speak for itself.

From the case studies in this thesis, nothing could be further from the reality. Even in policies based on rigorous systematic reviews of the available research (mammography screening and NSP-community being two examples), there are substantial and sometimes bitter debates occurring in learned journals about the best interpretation of that research. It seems that policy problems are often complex and multi-faceted, and that the relevant research is unlikely to answer all policy questions in an unequivocal manner. In the case studies, there were often gaps in the research and disagreements among researchers. The focal theories were used to explore how policy was made despite the uncertainty in the research and its policy implications.

### **10.3.2. Cultural differences explain the failure to use research**

None of the case studies provides support for the view that differences between policy makers and researchers were the most important drivers of the relationship between research and policy. The ACF formulation of advocacy coalitions divided by beliefs and values and whose success depends on their relative power within the policy subsystem provides a more robust approach to understanding group differences that impact on the research–policy nexus. This is theoretically superior to the ‘two communities’ theory because it allows for the possibility that in some instances researchers and policy makers may belong to opposing advocacy coalitions but the theory does not assume that this will always be the case.

The case of NSP in prisons demonstrates the inadequacy of the ‘two communities’ theory. Public health researchers were advocating trials of NSP in prisons and prison authorities were resisting. While this could be constructed as an example of what the ‘two communities’ theory predicts, the case study data showed that there were a number of other groups supportive of NSP trials and harm minimisation in prison including some key government advisory bodies and a Commonwealth Health Minister. The gradual implementation of harm minimisation measures and the continuing tensions around implementation of the ‘principle of equivalence’ are not well explained by the ‘two communities’ theory. This is because it is not grounded in a larger theory of policy making that can capture intra-governmental and inter-governmental tensions or alliances with external groups.

### **10.3.3.      *Research can be ‘transferred’ into policy***

A corollary of the uncritical acceptance of the value of the ‘two communities’ theory is the adoption of the idea of ‘interfaces’ between these communities and the notion that research can or should be ‘transferred’ across the interface. For example, Hanney and others devote a section of their review to ‘The interfaces between the health research system and policy-makers: transfer of research to policy-makers’ (Hanney, Gonzalez-Block et al. 2003: 15).

The mammography screening case study is an excellent example of the inadequacy of these concepts. Beginning with the several committees established by the NH&MRC in the 1970s and early 1980s, through the State-level ministerial advisory committees in South Australia and Western Australia, through to the AHMAC Breast Cancer Screening Evaluation Steering Committee, the research on mammography screening went through repeated processes of assessment and appraisal for the purposes of making policy recommendations. The case study showed how each of these processes involved an evolving group of stakeholders who produced particular interpretations of the research and actively promoted some research while refuting other research. Some very reputable researchers expressed negative views on mammography screening while other reputable researchers put forward strong views in support of mammography screening. The outcome is not explained by looking only at what research made it onto the table and what research did not. The problem is how to understand the processes of contest, interpretation and judgement that flow from the research. While the concept of ‘transfer’ continues to hold centre stage, the most important parts of the policy making drama are hidden from view.

### **10.3.4.      *Governments should be automatically interested in research***

The ‘two communities’ theory, and the research utilisation literature more generally carry the implicit assumption that governments have a duty to be interested in research and that any departure from this is problematic.

The findings from this thesis suggest that this assumption should be abandoned and that the starting point for understanding the position of research vis-à-vis government should be based on a well-developed theory of public policy. Research may, from time to time,



be of direct and immediate interest to government but not always. The three focal theories offer some insights into when and why governments will demand research or take an interest in it. The PMOF related this to institutional variables such as constitutional responsibility, the degree of accountability of the PMO for policy failure, and the relationship of the research to risks and opportunities of a political and bureaucratic nature. The ACF related government interest in research to whether or not it could be used to advance the cause of the Dominant Advocacy Coalition or rebut the arguments of rival advocacy coalitions. The GF related government interest in research to the way it relates to particular governmentalities and discourses. Each of these theories makes a strong case for the argument that no amount of research dissemination will generate government interest in research just because it is there. Arguments about whether or not governments 'should' be interested in any particular piece of research are inextricably linked with values and beliefs about the role of government and need to be recognised as such.

### **10.3.5. *Selective use of research in policy making is problematic***

Most of the literature on 'research transfer' assumes that the selective use of research by policy makers is problematic. For example, in a study of ways to increase research use in policy, Innvaer and others write: 'Two-way personal communication, the most common suggestion, may improve the appropriate use of research evidence, but it might also promote selective (inappropriate) use of research evidence' (Innvaer, Vist et al. 2002: 239).

As noted above, the available research rarely speaks for itself and the case studies clearly showed that the interpretation of the available research is always contestable. This means that policy making is unavoidably selective in the use and interpretation of the available research otherwise the policy process would be paralysed every time discrepant research appeared. When studies of research transfer begin with an assumption that selectivity is inappropriate then one of the most important issues in research use, that is, the process of selecting between competing interpretations of the available research, is lost from view.

### **10.3.6.        *Researchers and research are apolitical and disinterested***

The ‘two communities’ theory depoliticises the role of researchers, and the politics of research transfer receives little attention. Weiss and Albaek have discussed the issues raised by researchers taking on advocacy roles (Weiss 1991: 318; Albaek 1995) and Knott and Wildavsky have noted that advocacy for policy change can sometimes travel ‘under the guise of spreading knowledge...’ (Knott and Wildavsky 1980: 540).

Each of the case studies showed that some researchers were deliberately political in their actions and were sometimes very effective in achieving their political goals. While some researchers who were interviewed expressed reluctance about their advocacy roles, others saw political action as their responsibility. The ‘two communities’ theory is unable to capture this aspect of research because it puts political action, by definition, in the culture of the policy maker while the researcher pursues ‘pure’ and ‘esoteric’ matters. Each of the focal theories provides a coherent view of researchers as political actors.

### **10.3.7.        *Knowledge is something created and possessed by individuals outside a social context***

The ‘two communities’ theory and the research transfer literature are characterised by a focus on how individual decision makers think and relate to researchers. The irony of this is that the ‘two communities’ theory attempts to explain research non-use in terms of cultural difference. This individualism is illustrated in some of the earliest research on research use. When Caplan interpreted the results of a survey of research use among 204 senior policy makers in the United States in the mid-1970s, he described the ‘inquiry’ process they go through in making decisions of national significance. Without any explanation as to why individual rather than organisational or institutional variables might be more significant, Caplan concludes that ‘...the inquiry process involved in conceptual utilisation depends upon the properties of the *individual* rather than upon those of the bureaucracy’ (Caplan 1979: 465) (emphasis in original). The continuation of this individualism is illustrated by Hanney and others statement that ‘...it is our contention that many factors need to be brought together if assessment of research impact on policy-making is to contribute to an understanding of the issues and an

enhancement of utilisation. *The prime focus should be on the policy-maker*' (Hanney, Gonzalez-Block et al. 2003: 3) (emphasis added).

Policy-making is collective process, from this there is no escape. As a collective action, explanations of its patterns, including patterns in the way research is used, require a social dimension. This is particularly true when policy trajectories can be traced over a decade or more and there have been changes in Health Minister and in the people filling key positions in government and other organisations. Each of the case studies showed long-term policy trajectories (even when that trajectory was one of continuing policy ambiguity as in PCS and NSP-prisons), and the analysis made a strong case that the influence of individual actors cannot be understood independent of the structures that enable and constrain individual action.

### **10.3.8. Use of research by policy makers is a measure of the value of research**

Implicit in most writing on research transfer is the assumption that use of research by policy makers is a measure of the value of the research. For example, Hanney and others say: 'There is an onus on the Health Research System to ensure it identifies and publicises those characteristics of research that are likely to increase its appeal to policy-makers' (Hanney, Gonzalez-Block et al. 2003: 17). They also have a subsection in their review on 'research that policy-makers will be more likely to use'.

There seems to be no prima facie reason why having policy makers use research findings is a better indicator of quality in research than having policy makers actively try to disarm the research. The case study on NSP in prisons suggests that some very good public health research on blood borne viruses in prisons has been a consistent source of aggravation for prison authorities who seem to want to avoid responsibility for the issues raised by that research. As Bardach has argued, '...many policymakers should be expected to learn about the results of policy research in a strictly defensive context. But this does not necessarily make the research less valuable' (Bardach 1984: 141). Perhaps an alternative measure of the value of research could be in terms of the policy-changing potential of the research, that is, the extent to which the research results could potentially challenge current policy settings.

### **10.3.9. *'Research', 'evidence' and 'knowledge' are all the same thing***

These words have been used interchangeably by almost all writers on research utilisation since the field developed in the 1970s and the same is true of much of the writing on EBHP. Hanney and others sometimes talk about 'evidence-based policy' and at other times talk about policy being 'research-informed' but the differences are never discussed. They sometimes conflate 'research utilisation' and 'knowledge utilisation' and 'research impact'. (Hanney, Gonzalez-Block et al. 2003:, 3-5). Innvaer and others also talk about 'evidence', 'research evidence', and 'research' as if they were the same thing (Innvaer, Vist et al. 2002). There have been various attempts to try to tighten language use. For example, Knott and Wildavsky distinguished between 'data', 'information' and 'knowledge' (Knott and Wildavsky 1980: 547-8). Bardach presented a model for thinking about '...how the results of policy-relevant research, which we may think of as "knowledge" and the derivatives of "knowledge" like "policy arguments", are disseminated' (Bardach 1984: 125). Lavis and others present a disciplined approach to definitions of research and research use in their study (Lavis, Ross et al. 2002).

From this research project, it seems that it is well worth considering a more careful nomenclature. The case studies showed how important policy making processes are in taking the available research and constructing policy-relevant knowledge and evidence for policy arguments. When 'research' is equated with 'knowledge' and 'evidence', the social and political processes at work in valorising some research as 'the current state of knowledge' or 'the evidence' is lost from view.

## **10.4. The way forward**

On the basis of the findings of this research project, the 'two communities' theory and the idea of 'research transfer' between those communities provides an inadequate understanding of the research-policy nexus in public health policy in Australia. The existence of cultural differences between researchers and policy makers is not in question, just the importance of these differences in explaining the relationship between research and policy. Attempts to improve communication may reduce the sense of alienation between researchers and policy makers but the 'two communities' theory

does not provide any insight into the determinants of where, how and why such processes might come into existence and what their impact on policy might be.

Relinquishing the ‘two communities’ theory is an important step in improving our understanding of the research–policy nexus. Another step involves developments in four interrelated areas set out below. This thesis has made a contribution to each of these.

#### **10.4.1.      *Develop new metaphors***

This thesis is titled ‘from transfer to transformation’ to promote a new metaphor of what happens when research influences or informs policy. The notion of transformation is meant to provoke questions about how and why some research is invested with a particular status (ie transformed) in policy arguments and other research is not. It signals the social, political and institutional processes involved in data selection and knowledge construction.

The process of generating new language and new metaphors can help generate new understandings of the research–policy nexus. Metaphor and analogy have long been recognised for their contribution to the ‘invention’ involved in science. By proposing new metaphors and analogies it is possible to generate completely new ways of understanding complex matters (Leatherdale 1974: Chapter 1).

I do not claim that the term ‘transformation’ is original or that it is the best way of capturing the change process. Other researchers have used other language. For example, Sabatier’s concept of ‘policy oriented learning’ introduces the concept of change that accompanies the acquisition of new knowledge by policy actors. In Chapter 2, I referred to Giddens’s concept of the ‘dialogical’ relationship between knowledge production and change in the behaviour and relationships of the people involved in producing the knowledge. I also referred to Weber’s concept of ‘elective affinities’, first used by Short in the context of research use in policy (Short 1997), which is an analogy derived from chemistry to describe the change that occurs to both the knowledge and the knower when new ideas are adopted. Foucault’s concept of ‘power/knowledge’ brings power into the change process. David Dery used the idea of ‘minting’ research into policy ‘currency’ to capture the investment of power and meaning in research when it is used in policy.

The concept of ‘transformation’ as I use it contains some of each of the notions of ‘policy oriented learning’, ‘dialogical’ processes, ‘elective affinities’, ‘power/knowledge’, and the ‘minting’ of ‘currency’. Unless we are able to talk about the transforming role that research can play in policy arguments, as well as recognise the way that research is transformed when it becomes integral to policy arguments, we will miss the most essential characteristics of the relationship between research and policy.

#### **10.4.2. Develop a richer theoretical repertoire**

The need for a richer theoretical repertoire for understanding the research–policy nexus has been recognised for some time (Dunn 1980; Landry, Amara et al. 2001: 397). Hanney and others make a strong argument for the value of ‘conceptual frameworks’ for understanding research use in policy (Hanney, Gonzalez-Block et al. 2003: 12) and they make particular reference to Landry’s study of the seven steps on the ladder of research use (Landry, Amara et al. 2001).<sup>26</sup>

This thesis has made a number of contributions to the enrichment of the theoretical repertoire. The PMOF is, I believe, the first attempt to take David Dery’s work and turn it into an empirically evaluable tool for understanding the research–policy nexus. The benefit of this framework is that it brings institutional variables into consideration. The development of the Governmentality Framework is also, I believe, the first attempt to take ‘governmentality’ and turn it into an empirically evaluable tool. The advantages of this framework are its critical perspective on research use and its focus on discourse, the practices of public health, and regimes of truth as these might be found in public health. While this attempt might be considered marginally successful, it has provided sufficient new insight to be worth its keep within the theoretical repertoire. The application of the Advocacy Coalition Framework to public health policy in Australia also represents new ground for both the theory and the study of the research–policy nexus in Australia.

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<sup>26</sup> Landry’s study of the seven ‘steps’ in the ladder of research use actually looks at the extent to which social science researchers (not research) have progressed up the seven steps. This is an interesting adaptation of Knott and Wildavsky’s original conceptualisation of seven ‘standards’ of research utilisation which were not presented as stages from the least effective the most effective but as different was of conceptualising the end-point of utilisation Knott, J. and A. Wildavsky (1980). "If Dissemination Is the Solution, What is the Problem?" *Knowledge: Creation, Diffusion, Utilization* 1(4): 537-578.

The application of Sil's framework for theoretical eclecticism is another contribution. It helped isolate particular material and ideal structures and the opportunities they create for the agency of policy actors. The framework helps to specify the components of adequate theory of the research-policy nexus and enables specification of the notion of transformation at a general theoretical level. None of these theorists are referenced in Hanney and others review (Hanney, Gonzalez-Block et al. 2003).

#### **10.4.3.        *Develop a better understanding of meta policy***

When the issue of research utilisation was enjoying its first intense period of investigation over 20 years ago, Dunn asked: 'Knowledge utilisation for what?'. The question arose because he had found that research use does not automatically result in effective problem-solving (Dunn 1980: 532). Similarly, Knott and Wildavsky asked 'If dissemination is the solution, what is the problem?' (Knott and Wildavsky 1980). More recently, Lavis and others conducted eight case studies of health policy in Canada and wrote:

We were struck by our finding that for two cases in which research appears not to have been used, we considered the policymaking process particularly well informed. In both cases, structured processes gave play to a variety of research, other types of information, and values. Even more surprising to us, one of the cases in which research was used appeared to us to be one of the least informed policies. (Lavis, Ross et al. 2002: 140)

They comment that it seemed that the attempt to '...use as much research as possible for one policy issue... actually hindered a broader assessment of an equally important policy issue...' (Lavis, Ross et al. 2002: 140). They go on to argue the need for future efforts to establish the goals of making better use of research in policy and the possibility of focussing on '...the degree to which policy was *informed*...' (Lavis, Ross et al. 2002: 140) (emphasis in original).

The problem of identifying the goal of increased research use in policy and the relation of this to the notion of evidence-based policy is critical for progress in the study of research use. In Chapter 9, I argued that these issues are actually about meta-policy, not research use per se. Research use in policy and evidence-based policy are 'wicked problems' where the task of defining the problem is integral to the problem.

The contribution of Chapter 9 to this discussion is that it shifts the focus of attention away from research use per se to the way policy is made. This led to a specification of the challenges facing public health policy making and, in particular, to the relationship between concerns about technical rationality and the role of values in the policy process. I think a contribution of Chapter 9 is to identify the common misunderstanding that values and research are locked in a zero-sum game and to reframe them as complementary parts of policy making. This discussion relates back to the lack of adequate treatment of power and values in descriptive models of research use in policy set out in Chapter 2. The further contribution of Chapter 9 is that it makes a link back to the issue of research use in policy by identifying those features of policy frames that generate a demand for empirical research. Thus, policy frames are integral to both policy making, meta-policy making, and the development of policy-relevant research agendas much in the way that Kuhn saw scientific paradigms shaping the practice of ‘normal science’ (Kuhn 1962: 23-34).

#### **10.4.4.        *Develop more sophisticated methodology***

This study is unique because it uses four cases in a 2 x 2 configuration (two positive and two negative; two each on screening and NSP interventions), and compares three theoretical frameworks across the cases. While the case study method is relatively common (Hanney, Gonzalez-Block et al. 2003: 11-14), and there are a number of studies that use multiple cases (Lavis, Ross et al. 2002), there are few that compare two or more theories to two or more cases (Short 1997; Elliott and Popay 2000).

Much of the research utilisation literature belongs within the tradition of policy analysis that attempts to build knowledge *for* policy, that is, knowledge for practical application to the perceived problem of lack of research use. This study is distinguished by focusing on the task of building knowledge *of* the policy process (Hogwood and Gunn 1984: 29). This has enabled the study to be agnostic on the question of whether or not research should be used more in policy (Weiss 1979: 437). As such, it sits within the critical tradition of writing on this subject (Albaek 1995; Lupton 1995: 1; Nutley and Webb 2000). It is the only empirical study done within this tradition that I know of.

The study of research use in policy might be progressed by increased dialogue between the critical and applied streams of research, along with clarification of the values underpinning the research methods, and the application of innovative research designs. I



have argued that current strategies to increase research use in policy are closely tied to the ‘two communities’ theory. Considering the practical implications that flow from the alternative theories proposed here may help develop more effective strategies.

### **10.5. A final word**

Attempts to increase research use in health policy and to promote Evidence-based Health Policy are complementary endeavours pursued with varying degrees of enthusiasm and for different reasons by researchers, policy makers and other policy actors across the world. How, when, and why research is used in policy or influences policy are important questions and deserve to be approached with intellectual rigour and the best research tools available. Current understandings of the research–policy relationship show the enduring legacy of the ‘two communities’ theory and need to be rethought.

This study has found that when research influences policy it is transformed into evidence that binds policy arguments and commits governments to action by becoming invested with meaning and power. This process occurs through the action of policy actors in and outside government who mobilise ideal and material structures to resolve meta-policy problems. This finding might be contrasted with the prevailing mental model of the research–policy nexus known as the ‘two communities’ theory that was borne out of the frustration felt by social scientists over their inability to influence policy over a quarter of a century ago. Like other studies before it, this study has found that there is more going on in the research–policy nexus than that mental model suggests (Hanney, Gonzalez-Block et al. 2003: 2). However, rethinking the relationship between research and policy requires the application of theoretical tools and research designs that can identify patterns in the social, political, institutional and ideational factors influencing policy. Along with Lavis and others, I think our ability to understand the relationship between research and policy is a matter of how we understand what it is we are looking for, where we choose to look, and what tools we bring to the inquiry (Lavis, Ross et al. 2002).

This thesis has found discernible patterns in the research–policy nexus that come to light and are explained more or less successfully by three quite different theories. These are not the only theories available and may not provide the best ways of understanding

this rich and complex social world. But they do, in my view, represent a significant advance on the theoretical tools that are currently predominant. I hope this work will promote further debate and research on the important question of the relationship between research and policy in public health in Australia and in policy making generally.

# Appendixes

## Appendix to Chapter 1

### *Research Questions*

#### **Question 1**

How might we best understand the relationship between research and public health policy in Australia?

- What role does research play in the policy process? Does research influence policy? If so, in what ways does this occur? How does it occur? To what extent does it occur?
- What happens when research and policy are at odds? Why does policy sometimes change in response to discrepant research, and sometimes not?

#### **Question 2**

What contribution if any do the three selected focal<sup>27</sup> theories make to a better understanding of the research–policy relationship?

- The Advocacy Coalition Framework (ACF) of Sabatier and Jenkins (Sabatier 1993).
- The Policy Making Organisation Framework (PMOF) developed from the work of David Dery (Dery 1990) and elaborated with insights from the public policy literature on the role of institutions.
- The Governmentality Framework based on the work of Michel Foucault (Foucault 1991a) and several of his interpreters, particularly Mitchell Dean (Dean 1999), and Rose and Miller (Rose and Miller 1992).

#### **Question 3**

What do the results of this analysis mean for our understanding of the relationship between research and public health policy in Australia?

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<sup>27</sup> By ‘focal’ theories I mean theories that are the focus of empirical analysis in this thesis. Chapter 2 gives a rationale for their selection based on their explicit attempt to theorise the role of research or data or technical analysis within the process of policy development.

## Appendix to Chapter 2

### ***Advocacy Coalition Framework Hypotheses***

*'Hypothesis 1:* On major controversies within a policy sub-system when core beliefs are in dispute, the line-up of allies and opponents tends to be rather stable over periods of a decade or so' (Sabatier 1993: 27).

*'Hypothesis 2:* Actors within an advocacy coalition will show substantial consensus on issues pertaining to the policy core, although less so on secondary aspects' (Sabatier 1993: 32).

*'Hypothesis 3:* An actor (or coalition) will give up secondary aspects of a belief system before acknowledging weaknesses in the policy core' (Sabatier 1993: 33).

*'Hypothesis 4 (Revised):* The core (basis attributes) of a governmental program in a specific jurisdiction will not be significantly revised as long as the sub-system advocacy coalition which instituted the program remains in power within that jurisdiction—except where the change is imposed by a hierarchically superior jurisdiction' (Sabatier and Jenkins-Smith 1993: 217).

*'Hypothesis 5 (Revised):* Changing the policy core attributes of a government action program requires both (1) significant perturbations external to the sub-system (eg changes in socio-economic conditions, system-wide governing coalitions, or policy outputs from other sub-systems) and (2) skillful exploitation of those opportunities by the (previously) minority coalition within the subsystem' (Sabatier and Jenkins-Smith 1993: 222).

*'Hypothesis 6:* Policy-oriented learning across belief systems is most likely when there is an intermediate level of informed conflict between the two. In such a situation, it is likely that: 1) each coalition has the technical resources to engage in such a debate; and 2) the conflict be between secondary aspects of one belief system and core elements of the other or, alternatively, between important secondary aspects of the two belief systems' (Jenkins-Smith and Sabatier 1993: 50).

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*Hypothesis 7:* Problems for which accepted quantitative data and theory exist are conducive to policy-oriented learning than those in which data and theory are generally qualitative, quite subjective, or altogether lacking' (Jenkins-Smith and Sabatier 1993: 52).

*Hypothesis 8:* Problems involving natural systems are more conducive to policy-oriented learning than those involving purely social or political systems because in the former many of the critical variables are *not* themselves active strategists and controlled experimentation is more feasible' (Jenkins-Smith and Sabatier 1993: 52).

*Hypothesis 9:* Policy-oriented learning across belief systems is most likely when there exists a forum that is 1) prestigious enough to force professionals from different coalitions to participate; and 2) dominated by professional norms' (Jenkins-Smith and Sabatier 1993: 54).

*Hypothesis 11:* Within a coalition, administrative agencies will usually advocate more centrist positions than their interest group allies' (Sabatier and Jenkins-Smith 1993: 213).

*Hypothesis 12:* Even when the accumulation of technical information does not change the views of the opposing coalition, it can have important impacts on policy—at least in the short term—by altering the views of policy brokers or other important government officials' (Sabatier and Jenkins-Smith 1993: 219).

## Appendixes to Chapter 3

### 1. *Rigour in case study research*

While quantitative methods have well developed rules and conventions for establishing the validity of findings, qualitative methods do not (Cook and Campbell 1979; Mays and Pope 1996). The objective of this section is to outline the strategies used to build rigour in this study. These strategies were identified by reviewing four texts that made explicit recommendations on how to improve the rigour of qualitative and/or case study research. Patton (Patton 1990) and Miles & Huberman (Miles and Huberman 1994) label their methods ‘qualitative’, while Guba & Lincoln (Guba and Lincoln 1989) describe their method as ‘naturalistic’, and Yin (Yin 1994) claims a special status for the case study method. Seven strategies were supported by at least three of the four texts. Table A1 below presents in summary form the respective authors views on attaining rigour in qualitative research.

This attempt to construct a common framework for judging the rigour of qualitative research involves using the authors’ concepts outside their epistemological belief system. I think it is justified on the grounds that there are demonstrable similarities between the techniques used by the authors to build and demonstrate rigour. These can be assessed in their own right and, while the authors themselves might differ on the philosophical status of the result (eg ‘an approximation of the real world’ versus ‘one individually meaningful construction of experience’), they would still agree that the tools results in improved research quality.

Another challenge in constructing this common framework is that the authors use different conceptual hierarchies. For example, Patton argues that the credibility of the researcher is a criterion for establishing the credibility of the research project. He does not explain this and it could be argued that this quality is in the eye of the beholder rather than in the research method. Also, Miles does not create an overarching set of criteria but rather sets out 12 tactics for testing or confirming findings. Regardless of the conceptual arrangement provided by the authors, it is the tools and strategies themselves that are important. The seven tools or strategies are:

1. **Coherent data collection and analysis strategies.** For Patton this is about ensuring that within each of the data collection processes (interviews, participant observation, documentary analysis) particular procedures are followed which will improve the quality of the data. All the other texts present different approaches but agree on the fundamental principle. This strategy has been followed in the case studies through the development of three ‘templates’ to guide data collection and analysis.
2. **Auditability of the research process.** For each of these authors, this comes from providing sufficient detail to enable the reader to have a clear understanding of where the information came from, how it was manipulated, condensed and reproduced in a new form. There should be no magical box requiring a leap of faith by the reader.
3. **Use of triangulation.** All authors except Guba and Lincoln argue that triangulation is a key tool for the researcher. This strategy has been followed by triangulating within the different types of documentary data and by cross-checking between documentary and interview data.
4. **Negative case analysis.** This is agreed to by all authors as a basic tool whereby the researcher protects his/her integrity. They argue that no hypothesis or construction will account for all the facts or all experience and that open acknowledgment of where the loose ends are and what is left unexplained is clear a demonstration that the researcher is not prepared to give the findings greater weight than is due. This strategy is used within the individual case studies by exploring what is left unexplained by each of the theoretical frameworks. It is used as well by comparing the ‘positive’ and ‘negative’ case studies to check the strength of conclusions or identify qualifications or conditions that need to be placed on conclusions.
5. **Researcher affects acknowledgment and management.** All authors agree that the researcher can potentially affect what is found in the research process. This is both in terms of the researcher changing the environment simply by being there and asking questions and perhaps threatening people by wearing the label ‘researcher’. It is also possible that the researcher will be ‘captured’ by certain interests in the research setting. It is acknowledged by all except Guba & Lincoln that the researchers own perceptions and biases will influence how and what they see and report and find. Guba & Lincoln argue that the true constructivist process properly implemented

should eliminate researcher effects. I find this argument unconvincing. A statement on possible researcher effects appears below.

6. **Informant feedback.** While the four authors present this strategy in different lights, they all agree that a basic strategy is to go back to those who provided the information to seek their views on how the researcher has represented the matter under research. I have chosen not to do this, partly because of time constraints, and also because I did not feel confident that the key informants have sufficient level of interest in the analysis. The exception to this was that three of the key informants for the NSP case studies (Wodak, Dolan and Vumbaca) approached me some time after their interviews with the idea of publishing a history of NSP in Australia. I provided a copy of the draft chapter of NSP in the community to them and they provided comments on it.
7. **Testing of rival hypotheses.** Use of this strategy is central to the design adopted in this study. By using three different focal theories, I have set up a way of systematically generating alternative hypotheses. Three of the four authors list this as one of the most significant strategies for building rigour. It is inclusive of the tools of explanation building, ruling out of spurious relationships, establishing causal chains of evidence, and replication of findings by testing the rival hypotheses for their implications against other data. Its aim is to identify and ‘extinguish’ alternative rival hypotheses. The fundamental advantage which randomisation bestows on experimental and quasi-experimental designs comes from their being able to extinguish rival hypotheses without these being identified. While Guba & Lincoln do not refer to this strategy because of its epistemological home in ‘realism’, their method uses the same idea when they challenge groups of stakeholders to constantly increase the sophistication of their constructions by confronting the constructions of other stakeholders or by confronting new information. The constructions of the different stakeholders could be reframed as rival hypotheses that are then pitted against each other in debate and negotiation. From this point of view, all four authors could be said to build the rigour of their research process on this fundamental tool.

The table below presents these seven strategies for building rigour by author. It is noteworthy that Guba and Lincoln are the authors whose views are out of step most often. The underlying reason for this is their radical ‘naturalist’ epistemology and their



unyielding rejection of positivist epistemology (or at least their version of a straw man epistemology they label ‘positivism’).

**TABLE A1: ATTRIBUTES OF RIGOROUS QUALITATIVE RESEARCH METHOD BY SELECTED AUTHORS**

Qualitative Research Method Attribute	Author			
	Patton	Miles and Huberman	Guba and Lincoln	Yin
1. Coherent data collection and analysis.	√	√	√	√
2. Auditability of process	√	√	√	√
3. Triangulation	√	√	X	√
4. Negative case analysis	√	√	√	√
5. Management of researcher effects	√	√	X	√
6. Informant Feedback	√	√	√	√
7. Testing of rival hypotheses	√	√	X	√

## 2. *ACF case study analysis template*

### ***Step 1—Identify the subsystem actors, their beliefs, the coalitions between them, and the Dominant Advocacy Coalition***

- Identify the beginning of the policy, where the idea started, the proximate actors and their apparent motivations.
- Identify policy subsystem actors who support the policy. Is there any evidence they share a belief system (a set of basic values, causal assumptions, and problem perceptions)? Do they exhibit ‘a non-trivial degree of coordinated activity over time? Are there any ‘latent actors’—those who can be quickly mobilised and become involved to support or broker policy agreements?
- Identify actors opposed (including the active adversaries, and the aggrieved, as well as those who might potentially fall into these categories) and their beliefs and coordinated activities.
- Do ‘coalitions’ of actors exist? How do their beliefs and values compare—their basic values or normative beliefs (deep core beliefs—fundamental beliefs and ontological axioms); near (policy) core beliefs (basic propositions and policy positions for realising beliefs); secondary aspects of beliefs (instrumental decisions and pieces of

information that go to make up detail of policy); beliefs about the status of critical variables; and beliefs about causal relationships?

- Check for support of ACF Hypothesis 1: On major controversies within a policy subsystem (ie when core beliefs are in dispute), the line-up of allies and opponents will tend to be rather stable over periods of a decade or so.
- Check support for ACF Hypothesis 2 and 3: Actors within an advocacy coalition will show substantial consensus on issues pertaining to the policy core, although less so on secondary aspects. Hypothesis 3: An actor (or coalition) will give up secondary aspects of his (its) belief system before acknowledging weaknesses in the policy core; Does it look like these are shared?
- Note the role and actions of brokers – those interested in reasonable solutions. Advocates and brokers may be on a continuum. Note possible role for officials and politicians here.
- Identify change and continuity in policy over time.
- Identify the external factors in the subsystem and identify:
  - the stable factors: attributes of the problem (common pool versus excludability); constitutional; cultural values and social structure; relative power of interest groups, and
  - the dynamic factors: changes in socioeconomic circumstances; complexion of government; impacts from other subsystems.
- Check ACF Hypothesis 4: the core (basic attributes) of a governmental program are unlikely to be significantly revised as long as the subsystem advocacy coalition which instituted the program remains in power' and
- Check ACF Hypothesis 5: The core (basic attributes) of a governmental action program are unlikely to be changed in the absence of significant perturbations external to the subsystem, i.e. changes in socio-economic conditions, system-wide governing coalitions, or policy outputs from other subsystems'

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**Step 2—Analyse the origins, purposes and uses of research**

- What research was done on NSP and related areas? Who paid for it? Who did it? Who owned it?
- To what extent did the research focus on the following: improving understanding of goals and other variables important to the Dominant Advocacy Coalition's belief system (eg monitoring critical variables); refining understanding of the logical and causal relationships underpinning the Dominant Advocacy Coalition's beliefs; identifying and responding to challenges to the Dominant Advocacy Coalition's belief systems?
- To what extent does research conform to a process of search and adaptation motivated by the desire of the Dominant Advocacy Coalition to realise core policy beliefs?
- To what extent does NSP research take the form of: a response to threats to the core values of the Dominant Advocacy Coalition or to perceived opportunities to realise core values; an attempt to alert the Dominant Advocacy Coalition to the extent to which a given situation affects their interests and values.
- To what extent does the use of research by the Dominant Advocacy Coalition follow a pattern of advocacy for and justification and elaboration of the Dominant Advocacy Coalition's policy position.
- To what extent has the Dominant Advocacy Coalition attempted to use research to engage in analytical debate to substantiate its policy positions? To what extent might this strategy be seen as a surrogate or compensation for a lack of raw political power?
- Did the policy adversaries and the aggrieved challenge: the seriousness of the problem? the causal theory? the efficacy of the solution? Or did they try to mobilise support based on the costs incurred to them and others? What response did this bring from the instigating group? To what extent did the available research support or hinder their case?
- Is there any evidence of non-dominant advocacy coalitions documenting gaps in the performance of programs and trying to improve understanding of the causes for such gaps. Did the Dominant Advocacy Coalition attempt to provide evidence that these gaps do not exist?

**Step 3—Identify and analyse instances of ‘policy oriented learning’**

- Is there any evidence of Policy Oriented Learning ‘...relatively enduring alterations of thought or behavioural intentions which result from experience and which are concerned with the attainment or revision of the precepts of one’s belief system’. These might take the form of: 1. Improved understanding of the state of variables defined by the belief system as important or by competing belief systems as important; 2. Refinements to understanding of logical or causal relations internal to belief system. May be forced by experience and opponents. 3. Identifying and responding to challenges to one’s belief system. Can these be related back to ‘...an ongoing process of search and adaptation motivated by the desire to realise core policy beliefs’. What role did research play in this? What was the process through which this came about? Need to be sensitive to the possibility of change among some individuals that does not diffuse across all members of coalitions.
- What was the extent of Policy Oriented Learning and what were the processes that lead to it?
- Conflict—What was the level of conflict between the Dominant Advocacy Coalition and the other groups? Was it concerned with fundamental beliefs and values? Or was it more to do with minor or secondary issues? Did conflict lead to change in the beliefs and attitudes or behaviour of the adversaries or the aggrieved? (Hypothesis 6)
- Tractability—Are there accepted analytical tools and methods for evaluating data and validity claims? Is there agreement on how the problem should be measured? Is there agreement on the goal with which to compare options? Do the causal relationships span across policy areas? Are there conflicting policy objectives? (Hypotheses 7 and 8)
- Fora—Did fora for analytical debate exist? Did they engage people from across the subsystem including the adversaries and the aggrieved? How open or closed were they? Were they prestigious? Were they governed by professional norms? Did these lead to change in beliefs of various coalitions? (Hypothesis 9).
- Related to fora for debate are other strategies for managing stakeholders. Is there any evidence of the advocacy coalition working ‘...to keep potential losers from appealing to outsiders for assistance’? Note efforts made ‘...to provide inclusive negotiated compromises within the parameters of the program core.’

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**Step 4—Discuss the findings and limitations of the ACF analysis in relation to the study questions**

- What understanding of the relationship between research and policy in public health emerges from this analysis? Did research influence policy? If so, how, and to what extent and through what mechanisms? What happened when research and policy were at odds?
- To what extent does the ACF provide an adequate account for observations on the relationship between research and policy in public health in this case study?

**3. PMO case study analysis template**

**Step 1—Analyse the accountability of the policy making organisation**

- PMO responsibility: To what extent is the PMO responsible for the problem? What form does this responsibility take—is it mandated by law, is it established by precedent, or is it discretionary? Does responsibility cut across jurisdictions and/or portfolios?
- PMO capacity: Has the PMO the capacity and the power to effect change in the problem? Is there an affordable, effective and acceptable intervention available? To what extent does reality depart from this ideal?
- PMO performance: It is possible to measure the PMO's performance in relation to the problem? Is there an agreed definition of the problem? Is there an agreed understanding of the cause-effect relationships involved? Are there agreed indicators and standards to measure performance?
- Theatre of justification: Is information pertinent to the problem and the performance of the PMO available for public scrutiny and debate? Is there an accessible and open forum for interrogating that information, for calling the PMO to account, and for having alternative views heard?
- Vulnerability to the consequences of error: Is the cost (political or economic) of failure sufficient to motivate behaviour change? Does anyone care if the PMO gets it wrong?

- Conclusion: Does the level of accountability of the PMO incline it towards ‘increased research impact’ or ‘reduced research impact’?

***Step 2—Analyse the orientation of the political arm and the bureaucratic arm of the PMO towards policy initiation or change, or towards the policy status quo***

- Political risks and opportunities: To what extent does policy initiation or policy change present risks or opportunities for the Minister, his/her government, his/her political party when compared with the status quo?
  - ❑ electoral risks and opportunities (winning or losing votes, seats, or opinion poll ratings);
  - ❑ power risks and opportunities (increasing power or status within the Cabinet, government, party, or with important stakeholders; realising personal goals and ambitions; gaining advantage over rivals in government, opposition; distracting attention from other issues);
  - ❑ economic/financial risks and opportunities (costs to government; impact on budget strategies; impact on broader fiscal policy);
  - ❑ contextual risks and opportunities (the ‘garbage can’ of other issues that are related only because of the proximity in time and some other factor);
- Conclusion: Was the political arm of the PMO inclined towards the status quo or policy change/initiation? Were there clear political preferences emerging from the political arm of the PMO?
- Bureaucratic risks and opportunities: To what extent does policy initiation or policy change present risks or opportunities for the department compared with the status quo?
  - ❑ economic or financial risks and opportunities (impact on the program budget; impact on related program budgets; impact on whole portfolio budget; impact on Department’s budget strategy; impact on financial relationship with States and Territories);
  - ❑ power risks and opportunities (shift the balance of power in intergovernmental relations or relations with the medical profession; increasing power or status or

degree of control of the Department; increasing standing with Minister and government);

- contextual risks and opportunities (the ‘garbage can’ of other issues that are related only because of the proximity in time and some other factor e.g. opportunities to reallocate work across organisational units, restructuring Department, resolving internal problems such as conflict between divisions and senior staff, changing relations with external stakeholders, being caught up in some other conflict or issue with Finance or the Prime Minister’s Office etc);
- Conclusion: Was the bureaucratic arm of the PMO inclined towards the status quo or policy change/initiation?
- The PMO’s overall policy orientation: What was the combined effect of the bureaucratic and political calculus of risks and opportunities represented by an orientation to the status quo compared with policy change or initiation? Was there a clear preference or were there competing risks and opportunities?

***Step 3—Analysis of the accountability and policy orientation of the PMO and the expected relationship between research and policy in terms of the PMOF model***

- Given the PMO’s level of accountability and the PMO’s policy orientation, which of the five possible modes of research–policy relationship is most likely to be evident during policy initiation? During policy consolidation?
- Key observations:
- Paradigm formation: What are the paradigmatic causal assumptions and beliefs that underpin the policy? What did these come from? How much do they owe to research or to politics or to an interaction between the two?
- Research responsiveness: To what extent was research instrumental in the initiation and framing of the policy?
- To what extent did research precede and shape the way the policy problem was defined and constructed?
- To what extent was some data treated as irrefutable and a point of departure for all points of view in the policy debate?

- To what extent did the policy process take on board a previously existing problem definition or response design with its roots in public health research?
- To what extent did research cause and shape critical policy debates and influence their outcomes?
- Policy imperatives: To what extent were policy positions on the problem definition and response design determined politically and developed independent of and/or prior to public health research?
- Was research used as a tool for *post hoc* rationalisation? Was it used selectively and without reference to expertise independent of the political process?
- Is there evidence of politically supportive data being selectively chosen and ‘minted’ while ‘hostile data’ was devalued, ignored or disregarded?
- Treatment of hostile data: How was critical research dealt with in the policy process? Through ‘monster barring’—outright rejection of the counter example; ‘exception barring’ - the counter example remains an explicit exception to the original conjecture; ‘monster adjusting’ - reinterpretation of the counter-example so that it falls within the scope of the original conjecture; or, the ‘methods of proofs and refutation’ whereby ‘the original conjecture is modified in a way that increases its content’? Or did policy change in response to hostile research? Is there any evidence of a bias in data selection behaviour towards false positives or false negatives. Are there any examples of irrefutable hostile data confronting immutable policy? What was the outcome?
- Conclusion—research responsiveness or post hoc rationalisation? Is it possible to characterise the relationship between research and policy as ‘responsive’ or as ‘post-hoc rationalisation’.
- Is there any evidence for the hypothesis that as the PMO becomes more accountable (as defined in terms of responsibilities, capacities, the theatre of justification, the measurability of its performance and the cost of failure) it also becomes more responsive to research?
- Is there any evidence to support the hypothesis that as the policy orientation of the PMO becomes stronger and more undivided and unambiguous there is increased bias in data selection processes?



- Is there any evidence of the PMO attempting to undermine or reduce its level of accountability in relation to the policy problem (eg preventing the collection of data, hiding data, reinterpreting responsibilities—buck passing, claiming incapacity, stacking committees, stopping evaluation, redefining the problem) in order to avoid the implications of irrefutable or strong research?
- Is there any evidence of research leading to policy change? Does the PMOF framework provide a robust explanation of this event or not?

#### ***Step 4—Discussion***

The PMOF and the study questions:

- What understanding of the relationship between research and policy in public health emerges from this analysis?
- Did research influence policy? If so, how, and to what extent and through what mechanisms?
- What happened when research and policy were at odds?
- To what extent does the PMOF provide an adequate account for observations on the relationship between research and policy in public health in this case study?
- Are there any particular problems with the framework?
- Are there limitations in the study design which may lead to these conclusions being qualified or moderated?

#### ***4. Governmentality case study analysis template***

This template focuses on three ways of looking at national public health policy that are derived from Foucault’s notion of governmentality: the policy discourse; the ‘regime of practice’; and power/knowledge. While they are separated out here as particular nodes of analysis, this is purely for the purposes of exploration and analysis. There is no suggestion that they are three separate, reified things. Rather, they are inter-related and embedded within the taken-for-granted processes of governmentality. While they largely focus, respectively, on the relevant policy statements, the intervention/s, and the research relevant to the case study, this is also only for the purpose of making the

analysis tractable and its presentation coherent. It is taken as given that public health discourse is more than official policy statements and may be characterised by multiple competing discourses at any one time, that the ‘regimes of practices’ is more than the technology of the intervention, and that knowledge/power is about more than formal scientific research.

### ***Step 1—Analyse the dominant policy discourses***

The method of analysis outlined here draws largely on Rose and Miller’s (Rose and Miller 1992) understanding of political rationality as a form of discourse that supports governmentality and the neo-liberal form of government they describe as ‘governing at a distance’.

Identify the most important policy documents and the literature that forms the primary points of reference for justifying, elaborating, explaining, and supporting particular policy arguments. Identify the place of research reports within these.

- Identify the *moral* form of the discourse in terms of its expressions of: the fitting power and duty of authority; the proper distribution of tasks between authorities (political, spiritual, military, pedagogic, familial); the ideals and principles to which government should be directed eg equality, mutual responsibility, economic efficiency, good health etc. Identify the role and contribution of research to this discourse.
- Identify the *epistemological* character of the discourse by looking at how it: defines and identifies the objects to be governed (eg which part of the population); gives an account of the persons over whom government is to be exercised, that is, how it sees them as members of a population to be managed or as legal subjects with rights. Identify the role of research in this discourse.
- Identify the idiomatic content of the discourse by looking at its language and the intellectual machinery for rendering reality thinkable and making it amenable to political deliberation. Identify the process of problematisation within the discourse and the way that aspects of the self and the population were translated into problems requiring government (the conduct of conduct) and making particular forms of government thinkable. Identify where and how this particular form of government

became self-evident and taken for granted. Identify the role of research within this discourse.

- Analyse the policy discourse in relation to the governmentality hypothesis.

***Step 2—Analyse the public health intervention as a ‘regime of practice’***

The method of analysis outlined here draws largely on Dean’s development of Foucault’s notion of ‘regimes of practices’ (Dean 1999).

- Discuss the extent to which the public health policy and intervention/s might be described as a ‘regime of practice’, ie an organised way of thinking about, practising and reforming some aspect of promoting and protecting the health of the population in certain places and times. Identify the practices can be thought and made into objects of knowledge and the subject of problematisations (Dean 1999: 21).
- Identify how the regime of practice came into being, how it is maintained, how it changes, and ‘...how it gives rise to and is dependent on particular forms of knowledge and how, as a consequence of this, it becomes the target of various programmes of reform and change’ (Dean 1999: 21). Identify the role of research in forming the particular regime of practice.
- Identify the ‘programmes’ or the forms of thought that seek to transform the practices through the process of ‘problematisation’ whereby aspects of the ‘conduct of conduct’ are called into question. Identify the role of research in the process of transformation and problematisation.
- Identify the ‘...the forms of visibility necessary to the operation of particular regimes’. What is the field of visibility that characterises the regime? What kind of light does it use to illuminate and define certain objects and with what shadows and darkness does it obscure and hide others? (Dean 1999: 30). What is the role played by research in public health policy in rendering particular diseases or problems visible in particular ways to support public health policy.
- ‘...[B]y what means, mechanisms, procedures, instruments, tactics, techniques, technologies and vocabularies is authority constituted and rule accomplished?’ (Dean 1999: 31). What is the role of research in relation to the technical aspects of the particular regime of practice that is part of the public health policy?

- ‘...[W]hat forms of thought, knowledge, expertise, strategies, means of calculation, or rationality are employed in practices of governing? How does thought seek to transform these practices? How do these practices of governing give rise to specific forms of truth? How does thought seek to render particular issues, domains and problems governable? (Dean 1999: 31). What is the role of research ‘*episteme*’ of government?’
- ‘...[W]hat forms of person, self and identity are presupposed by different practices of government and what sorts of transformations do these practices seek? What statuses, capacities, attributes and orientations are assumed of those who exercise authority (from politicians and bureaucrats to professionals and therapists) and those who are to be governed (workers, consumers, pupils and social welfare recipients)? What duties and rights do they have? How are these capacities and attributes to be fostered? How are these duties enforced and rights ensured? How are certain aspects of conduct problematised? How are they then to be reformed? How are certain individuals and populations made to identify with certain groups, to become virtuous and active citizens, and so on?’ (Dean 1999: 32). What is the role of research in shaping subjectivities within particular regimes of practice?’
- Analyse the regime of practice in relation to the governmentality hypothesis.

### **Step 3—Analyse power/knowledge**

- Identify the particular research that rendered the population and the individual governable through this form of public health policy. The research that problematised the health of the population, established the parameters of the problem, established the norm against which deviations could be seen as problems, calculated and inscribed the population with the necessity for government, tamed some aspect of the body of the population such that it became governable.
- Identify the infrastructure of research that evolved in terms of ‘...the production of effective instruments for the formation and accumulation of knowledge—methods of observation, techniques of registration, procedures for investigation and research, apparatuses of control’ (Foucault 1980c). Identify if these conform to the thesis that ‘... power, when it is exercised through subtle mechanisms, cannot but evolve, organise and put into circulation a knowledge, or rather apparatuses of knowledge...’ (Foucault 1980c).

- Identify the pathways and connections between research, knowledge, discourses of truth, and the exercise of power (biopower and disciplinary power). Identify if these conform to the proposition that ‘Power never ceases its interrogation, its inquisition, its registration of truth: it institutionalises, professionalises and rewards its pursuit’ (Foucault 1980c).
- Is there evidence to support Foucault’s contention that “‘Truth” is to be understood as a system of ordered procedures for the production, regulation, distribution, circulation and operation of statements. “Truth” is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extend it. A “regime” of truth’ (Foucault 1980b).
- Identify the claims to knowledge and authority found in the discourses and relate these to claims to power in the policy arena. (Cheek, Shoebridge et al. 1996: 174)
- Analyse the system of power/knowledge in this particular area of public health policy in relation to the governmentality hypothesis.

***Step 4—Analyse research in relation to the governmentality hypothesis.***

- Identify the technology of self in the national public health policy.
- Identify the technology of population found in the national public health policy.
- Identify if and how the discourses, regimes of practices and power/knowledge bring these into contact and make them continuous within a unified system of power. Identify the role of research in this.
- Identify if and how the discourses, regimes of practices and power/knowledge develop and contribute to the art of governing at a distance. Identify the role of research in this.
- Analyse the extent to which the particular case study supports the ‘conditions of possibility hypothesis’ and the place of research within it.

## **5. Ethical Issues**

The study was given approval by the Departmental Ethics Committee of the Commonwealth Department of Health and Aged Care on 2 June 1999. It was also given

approval by the Human Research Ethics Committee of the Australian National University on 9 October 2001—this occurred late because I was not aware that the ANU required its own ethics committee to approve the project. It gave approval after adjustments were made to the interviewees consent form to restate that participation was voluntary and to give the contact details of the Australian National University's Human Research Ethics Committee.

One ethical issue was the potential for role conflicts between my status as an employee of the Commonwealth Department of Health and Aged Care which brings with it a responsibility to act according to the principles and requirements of the position I hold, particularly to abide by the Code of Conduct for Australian Public Service Employees. This Code restricts the information that can be disclosed about the business of government and potentially limited my work as a researcher and also constrained those public servants that I wanted to interview as key informants. This problem was surmounted by seeking and attaining permission from the then Secretary of the Department of Health and Aged Care, Mr Andrew Podger, to conduct the research and interview current and former APS Employees.

## Appendixes to Chapter 4

### 1. *Notes on method*

Data collection began with the *Future Directions* (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990) report. This identified other policy documents, research that was central to the policy arguments advanced in that report, and membership of the AHMAC Breast Cancer Screening Evaluation Steering Committee. Of critical importance to this study was a chance conversation with Dr John Deeble at the National Centre for Epidemiology and Population Health who told me that he had worked on an NH&MRC Working Party in the mid-1970s that had looked at the question of mammography screening and recommended against it. Given that *Future Directions* makes absolutely no mention of the NH&MRC ever having considered the matter, this set me on the path for an extensive investigation of NH&MRC deliberations on the matter and raised intriguing questions about the many iterations on BCS that occurred in Australia from 1976 onwards. The Medline database proved to be the most useful source of information for this case study and was used several times over the course of this study to identify the latest literature on breast cancer screening. Search strategies included key words such as ‘breast cancer’, ‘screening’, and ‘mammography’. Other databases such as PUBMED, OVID and the Australian Public Affairs Information Service (APAIS) and Sociofile were also used.

Interviewees were identified through the *Future Directions* report and through published research and media reports of policy discussion. Priority was given to those who had been most prominent in the policy documents and in the published research and in the commentary and opinion pieces on the published research. A deliberate attempt was made to talk to people who had expressed opposing views.

### 2. *BCS interviews*

TABLE A2: BREAST CANCER SCREENING CASE STUDY INTERVIEWS

Name	Description*
Anonymous	Researcher
Anonymous	Commonwealth Government Official
Armstrong, Prof Bruce†	Professor
Blewett, Dr Neal**	Commonwealth Minister for Health 1983-90

Name	Description*
Cranny, Ms Carla	NSW Women's Health Advisory 1985-1988, Responsible for implementation of the NSW Breast Screening Program, and NSW member of AHMAC Mammographic subcommittee that recommended range and scope of national program.
Dean, Dr Margaret	Senior Medical Adviser, Public Health. Chair, National Advisory Committee
Donovan, Dr John	Formerly of the Australian Institute of Health and Welfare (Author of the 1971 Editorial in the MJA on the outcome of the Health Insurance Plan of New York Study (Editorial 1971).)
Dorsch, Dr Margaret	Director, South Australian Breast X-Ray Service. Director, Breast Cancer Screening Section.
Fett, Dr Michael††	Head, AIH Screening Evaluation Coordination Unit. Secretary and Convenor of AHMAC Breast Cancer Screening Evaluation Steering Committee
Hall, Dr Janet†	Director, Centre for Health Economics Research and Evaluation
Lawrence, Dr Carmen**	Former Federal Minister for Health.
Mead, Dr Cathy	Executive Officer, National Public Health Partnership
Mitchell, Dr Heather†	Medical Director, Victorian Cervical Cytology Registry
Muller, Jennifer	Manager, Women's Cancer Screening Services, Queensland Health.
Parker, Frances	Director 1991-95 National Program for the Early Detection of Breast Cancer
Ring, Dr Ian	Queensland Health Department
Short, Leonie†	Representative of Consumers' Health Forum on the national Advisory Committee for the Early Detection of Breast Cancer. 2000 Senior Lecturer in Public Health at QUT. 2001 Federal Member for Ryan.
Wilson, Dr Peter	Nominee of the Royal Australian and New Zealand College of Radiologists

\*'Description' refers to the self-description of the interviewee at time of interview or on his or her interview consent form. Interviewees were given the option of remaining 'anonymous'. Many people have held more than one role in relation to the development of Breast Cancer Screening Policy and several have moved from being a researcher to a government official and back again.

\*\*The two former Commonwealth Health Ministers were interviewed in relation to the case studies that were relevant to their term as Minister—Blewett was asked about Mammography and both NSP cases; Lawrence about all four case studies.

† Indicates the person has published on the topic of mammography screening – see the list of references.

†† Dr Fett indicated at interview that he was the primary author of the *Future Directions* report (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990).

**TABLE A3: BCS INTERVIEWEES - NUMBER APPROACHED FOR INTERVIEW BY STATUS OF INTERVIEW**

Response	Number	Notes
Unavailable	-	
Declined	-	
No response	4	Three former Federal Health Ministers (Howe, Richardson and Wooldridge) and one former representative of the Royal Australian College of Surgeons
Completed	18	
Total	22	

### 3. *BCS interview questions*

What's your view on how and why the National Program for the Early Detection of Breast Cancer (now BreastScreen Australia) came into being in Australia? What shaped the design and implementation of that policy? What role did you play in the process?



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Who were the most influential individuals and organisations involved in the process?  
What role did they play?

What do you think were the major driving forces leading to the establishment of the Program?

What forces were working to stop or slow down the establishment of the program?  
Were there any threats to the program?

What in your view and recollection were the most critical debates in the decision to establish the program and in the design and implementation of the program?

What roles did you see the Commonwealth Department of Health play in the policy development and implementation process? What pressures do you perceive the Department was under with regard to the issue of breast cancer and mammography?

What role did Health Ministers play? (NB – Ministers were asked a different set of questions) What role did other elected politicians play?

What role did party politics play in the process?

What role and influence did research have on the policy process? What indicators of influence can you identify? What structures and processes were important in shaping the role and influence of research?

Are there any lessons that we can learn from the experience of the development of breast cancer screening policy about how to make the research – policy relationship work better?

#### **4. Interview questions for former Commonwealth Health Ministers**

Two former Commonwealth Health Ministers were interviewed on all the case studies in which they had some involvement. The interview questions for each of them are set out below.

***Dr Neal Blewett interview questions***

Neal, one of the case studies I'm looking at is the development of Needle and Syringe Programs for the prevention of HIV among injecting drug users. Obviously, NSP is one of the many things that was done in Australia as part of the response to HIV/AIDS and you are often given much credit for your leadership in developing Australia's policy on AIDS. I was wondering if you could comment on a couple of things—

Denis Altman has described AIDS as 'the most political of diseases'—from your experience, would you agree?

- In what sense political? Ballard has argued that in the early 1980s, all health ministers saw AIDS as political poison—would you agree?

What is your perception of how bipartisan Australia's HIV/AIDS policy was?

- A cynical view would be that it was a bipartisanship based on fear and lack of political opportunities for either side to exploit—is there anything in that?
- Was the Parliamentary Liaison Group important in supporting bipartisanship?
- In one of your articles you argue that politicians have to work hard to depoliticise AIDS and resist political point scoring—is that what bipartisanship means?

John Ballard has argued that the issue that brought the Commonwealth into direct involvement with HIV/AIDS was its responsibilities in the area of blood—would you agree?

- Would it have become involved anyway?

From the research I've done, I understand that the first NSP was started informally and probably illegally at the time out of St Vincent's hospital's drug and alcohol unit by Alex Wodak and Kate Dolan and others—that's what they've told me—in November 1986. But at the time there was a lot of discussion around the idea and latent support from people like Pennington and Buttrose and yourself. Is that the way you saw it?

- At the time there was plenty of international research showing that HIV had spread rapidly through IDU groups in some cities in Edinburgh and Italy and the US, and

there was some local research to show all the risk factors were present in Australia. But there was no research showing NSP was effective.

- Did you have to work hard to sell NSP in particular?

How important for getting NSP established was the prior acceptance of the principle of harm minimisation in the context of illicit drug policy?

How important was the general sense of fear of AIDS in allowing a degree of policy risk taking?

- Did you ever try to keep the sense of crisis and urgency alive in order to get controversial policies in place and secure resources for HIV/AIDS?

You were a strong supporter of investment in research as an integral part of the response to HIV/AIDS—what was your thinking on that?

Neal, NSP has never been implemented in Australian prisons. It is only just now being introduced in several European countries. What is your understanding of why no State or Territory introduced NSP in prisons?

- Was it something you tried to introduce?

I'd like to talk now about mammography screening.

Mammography is very different to NSP from a research point of view because by the time it came onto the policy agenda in Australia there had been several major studies overseas showing its effectiveness. But many people have put it to me that the only real reason the Commonwealth engaged with mammography screening was not the research but the pressure that de facto screening was putting on Medicare expenditures—is this a fair assessment do you think?

- What is your perception of how this issue came on the political agenda?

Do you recall any of the events around the announcement by Bob Hawke in the March 1990 election campaign that, if re-elected, Labor would introduce a national mammography screening program?

How important was the National Policy on Women's Health in providing a platform for mammography screening?

***Dr Carmen Lawrence interview questions***

Dr Lawrence, I'd like to start with Prostate Cancer Screening. This issue began to emerge in the early 1990s. I realise that it was some time ago but do you have any specific recollections about how it came to your attention as a policy issue when you were Health Minister?

- Some men's groups argued that men should have access to PCS for gender equity reasons given women have access to mammography. Did that argument hold any weight for you?
- You were interested in men's health and started policy work on a men's health policy—what was your thinking on that? Was it informed by data on men's health status? Did you see a political opportunity in promoting men's health?
- Were you ever tempted to introduce PCS because it could be seen as a practical demonstration of government commitment to men's health in the same way that mammography was seen as a practical commitment to women's health?
- Were you lobbied at all on this matter either by men's groups or medical specialists?
- The NHMRC set up an inquiry into PCS in June 1995 through one of its committees—AHTAC—do you recall being involved in that process at all?
- Was the cost of screening or the financial impact of prostate cancer an issue for you?
- The rate of de facto screening under Medicare was quite high—did you ever contemplate or did the Department suggest taking active steps to limit access to the test through Medicare?
- The Australian Cancer Society was strongly of the view that there should not be a program of PCS and that steps should be taken to reduce the rate of de facto screening—were you aware of their views on this?
- AHTAC reported in 1996 and recommended against a screening program because there was no evidence that it would be safe and effective? And that is still the position today. I haven't seen anything to suggest that any of the political parties take a different view of this—do you think there is bipartisanship on this?

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- Do you think of this policy have a strong evidence base?

Can we talk about mammography screening now?

- During your time as Minister do you remember this program being contentious in any way? Do you think there is strong bipartisan support for it?
- Did you think of it as having a strong evidence base?
- There has been a long-standing feminist critique of mammography screening saying that it has enjoyed undue priority compared with other concerns or that it isn't seen as proper women's health because of its medical focus on a specific body part. Were you aware of this kind of critique? Did you give it much attention?
- Under the banner of the Cochrane Collaboration a recent systematic review of the 7 randomised controlled trials argues that there is no evidence of either a survival benefit or a mortality benefit from screening. A main reason for this is that they excluded the data from the trials that showed greatest benefit because of methodological problems with those studies. A huge debate has erupted in the medical literature over this and the major expert opinion still seems to support mammography screening. I was wondering how a Health Minister makes sense of this situation? How do you decide which experts to trust?
- A hypothetical... If you were Health Minister at the moment and this issue arose again, how would you deal with it?
- On both mammography screening and PCS, the government policy up to and after 1996 has aligned pretty closely with the views of the Australian Cancer Society. Were you aware of its views during your time as Minister? How would you describe its role in cancer policy issues?

I'd like to talk about needle and syringe programs now. These were implemented before you became health minister as part of the whole HIV/AIDS strategy.

- Do you remember any particular issues you had to deal with on NSP as the Minister? Did it register much on your list of things to keep an eye on?
- Did you see it as having a strong evidence base?
- Did you sense strong bipartisan support for this program? What about now?

- How important was it for you as a Minister to have the framework of harm minimisation to draw on as a way of analysing and making decisions on this issue?
- You are the only Health Minister, Commonwealth or State, on record supporting the idea of introducing NSP in prisons—What was your reason for supporting NSP in prison?
- Why do you think no State or Territory has implemented NSP in prisons?
- People who are critical of Australia’s HIV/AIDS policy often claim that it is because of the power of the AIDS lobby or the gay lobby; those who support it see the involvement of the affected communities in policy making as simple good sense and good policy making in an inclusive democracy.

Lastly, I’d like to ask you to reflect a bit on how you view the notion of Evidence-based Health Policy.

- Are there any areas of health policy which seem to fly in the face of evidence?
- Were there any areas of health policy when you were Minister that you thought there was a direct conflict between what was politically palatable and what the evidence suggested policy should be?
- How important is the lack of evidence of the effectiveness of health policy?
- Are there any feasible strategies that you think could increase the impact of evidence on policy?

## 5. *Chronology of breast cancer screening events*

**TABLE A4: CHRONOLOGY OF BREAST CANCER SCREENING KEY EVENT**

<b>Year</b>	<b>Events</b>
1943	United States: Papanicolaou and Traut publish Diagnosis of Uterine Cancer by the Vaginal Smear (Morrison 1985).
1951	United States: The United States Commission on Chronic Illness (CCI) Conference on Preventive Aspects of Chronic Disease, held in 1951, defines screening (Wilson and Junger 1968).
1955	Australia: Cancer Conference held in Canberra to consider establishing ‘some permanent form of national organisation’ to progress cancer activities in Australia (Australian Cancer Society 1962).
1957	United States: The United States Commission on Chronic Illness (CCI) ‘accepted the value of multiple screenings for chronic diseases as ‘good medical practice’ (Wilson and Junger 1968).
1960	United States: The American Public Health Association strongly endorsed multiple screening in Chronic Disease and Rehabilitation: a Program Guide for State and Local Health Agencies (Wilson and Junger 1968). United States: Egan publishes ‘astonishing mammograms’ showing carcinoma (Wright 1990).

Year	Events
1961	<p>United States: Paper published (Gershon-Cohen et al 1961) show that mammography had the ability to detect nonpalpable carcinomas (Shapiro, Strax et al. 1971: 1777).</p> <p>United States: The Chronic Diseases Division of the US Public Health Service provided State services with project grants for setting up demonstration screening programs (not specifically breast cancer screening). (Wilson and Junger 1968)</p> <p>United States: The National Cancer Institute provides funds for the Health Insurance Plan (HIP) study of New York.</p> <p>Australia: Inaugural meeting of the Australian Cancer Society in Canberra in October (Australian Cancer Society 1962: 3)</p>
1962	<p>United States: Egan shows that mammographic findings could distinguish malignant neoplasia from benign conditions (Morrison 1985: 74)</p>
1963	<p>United States: Health Insurance Plan (HIP) Study of New York commences (Shapiro, Strax et al. 1971: 1777).</p>
1966	<p>Australia: First report of observational study of use of mammography to detect breast cancer. Funded by the Anti-Cancer Council of Victoria. (McKeown and Thomas 1966)</p>
1968	<p>World Health Organisation: Wilson and Junger publish 'Principles and Practice of Screening for Disease'. First articulation of rules of evidence to apply in evaluation and implementation of screening programs.</p>
1971	<p>United States: Shapiro et al publish first results of HIP study. Described as favourable but inconclusive (Kaufert 1996).</p> <p>Australia: Prime Minister opens 'Medicheck' facility Sydney screening well people for occult disease. Includes mammographic screening for breast cancer.</p> <p>Australia: MJA editorial welcomes HIP study results and urges preparation of facilities to cope with the likely broad demand for periodic breast examinations.</p>
1973	<p>United States: One the basis of early results of HIP, US National Cancer Institute funds the American Cancer Society to an amount of \$45m to mount the Breast Cancer Detection Demonstration Project (BCDDP). (Batt 1994).</p>
1975	<p>United Kingdom: Pilot mammography screening projects established on the basis of HIP results (Edinburgh Breast-Screening Clinic 1978).</p>
1976	<p>Sweden: Two Counties or WE randomised controlled trial commenced. Commissioned by the National Board of Health and Welfare – inspired by HIP (Batt 1994). A 32% reduction in breast cancer mortality reported 8 years later. Between 1976 and 1982, randomised trials commence in Stockholm and Malmo.</p> <p>United States: Bailer (Bailer 1976) publishes critique of HIP study saying: evidence of benefits of mammography alone is weak; the radiation hazards from mammography may have caused between 8 and 32 cancers, or close to the number of cancers discovered by mammography; and lack of exploration of radiation effects are inexplicable.</p> <p>United States: Critique by Bailer (Bailer 1976) leads to official inquiry and some Breast Cancer Detection Demonstration Program equipment was found to be unsafe. (Batt 1994)</p>
1977	<p>Australia: Croll et al report results of first mammographic screening service in Australia. (Croll, MacMillan et al. 1977)</p> <p>Australia: NH&amp;MRC says research evidence does not support mammography screening with or without clinical examination (NH&amp;MRC 1977a).</p>
1978	<p>Australia: NH&amp;MRC confirms earlier position on mammography screening (NH&amp;MRC 1978)</p> <p>United States: 'Lo Dose' film/screen combinations developed enabling safer mammograms (Wright 1990)</p>
1979	<p>Australia: NH&amp;MRC changes position on mammography screening and now says benefits of mammography screening with clinical examination for women over 50 outweigh risks. (NH&amp;MRC 1979b)</p>
1980	<p>United States: The National Cancer Institute jury issues guidelines recommending against screening the 40-49 group.</p>
1982	<p>United States: HIP publishes results showing decline in mortality in the study group .</p>
1983	<p>United States: The American Cancer Society starts media campaigns promoting regular mammograms as the primary weapon in the fight against breast cancer. (Batt 1994; Kaufert 1996).</p>
1984	<p>Australia: The National Health and Medical Research Council issues Statement on Breast Health and Mammography recommending annual mammography for women with risk factors and 3-5 yearly screening for all other women commencing at age 40.</p>
1984	<p>Netherlands: Case control studies published showing reductions in breast cancer mortality through mammography screening (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 19)</p>

Year	Events
1985	<p>Sweden: Two Counties trial results published showing mammography to be effective (Tabar et al 1985). Organised national screening program commences. (Shapiro, Coleman et al. 1998: 739)</p> <p>United Kingdom: Government establishes Working Group under Sir Patrick Forrest to consider the question of mammography screening (Forrest 1990: xxiii)</p> <p>Australia: Mammographic screening program introduced in Queensland at Royal Women's Hospital (Baker, McCaffrey et al. 1988).</p>
1986	<p>The Netherlands: Over diagnosis excluded as an explanation of findings in Nijmegen study (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990)</p> <p>Italy: Case control study showing mortality benefit from mammography screening published (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990: 19)</p>
1987	<p>United Kingdom: Secretary of State for Health announces a national breast cancer screening service based on mammography following recommendations of the Forrest Report. (Forrest 1990: xxiii)</p> <p>Australia: AHMAC subcommittee on breast and cervical cancer screening recommends establishment of an evaluation of mammographic screening as a joint initiative of the Commonwealth and the States.</p> <p>Australia – Western Australia: Working Party for Screening Mammography recommends the establishment of a pilot program to demonstrate the feasibility of mammography screening (Working Party on Screening Mammography 1987).</p>
1988	<p>Australia – South Australia: Ministerial Task Force on Breast Cancer in Women and Cynaecological Cancer recommends establishment of a pilot program for mammography screening.</p> <p>Australia: AHMAC establishes the Breast Cancer Screening Evaluation Steering Committee, chaired by Prof. A.J. McMichael, to oversee and direct the National Evaluation of Breast Cancer Screening Pilot Projects and to advise AHMAC on breast cancer screening programmes. Aim is to determine if it is possible to replicate the results of overseas screening mammography trials in the Australian environment in a manner acceptable to women (Batt 1994).</p> <p>Australia: Australian Cancer Society National Breast Cancer Study Committee and the Royal Australasian College of Radiologists make recommendations on the development of breast screening services (Adams 1991).</p> <p>Canada: Organised national screening program commences. (Shapiro, Coleman et al. 1998: 739)</p> <p>Iceland: Organised national screening program commences. (Shapiro, Coleman et al. 1998: 739)</p> <p>Netherlands: Organised national screening program commences. (Shapiro, Coleman et al. 1998: 739)</p> <p>New Zealand: Skegg Report published in NZ recommending establishment of pilot projects and delay to introduction of routine screening mammography (Adams 1991).</p> <p>Sweden: RCT in the city of Malmo reports a non significant reduction in mortality (Andersson 1988). Brings on 'vigorous debate' in Sweden (AHMAC 1990, p. 21)</p> <p>United Kingdom: Trial of Early Detection of Breast Cancer Group casts possible doubts on the effectiveness of screening by producing a non-significant reduction in mortality. Organised national screening program commences. (Shapiro, Coleman et al. 1998: 739)</p> <p>United States: National Cancer Institute changes guidelines to recommend screening for women under 50 years. Breast Cancer Detection Demonstration Project results published (Morrison et al 1988).</p>
1989	<p>United States: The US National Cancer Institute joined by ten other US medical groups in August 1989 urging women 40 years and older to seek regular screening mammograms and clinical breast exams (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990).</p> <p>Europe: In August 1989, a symposium of the Nordic Cancer Union concluded 'screening for breast cancer by mammography alone or mammography plus physical examination can reduce mortality from the disease'. These actions reflected an international consensus that the balance of evidence still indicated that mammography screening can reduce breast cancer mortality' (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990).</p> <p>Finland: Organised national screening program commences. (Shapiro, Coleman et al. 1998: 739)</p>
1990	<p>Australia: (March) During election campaign, Prime Minister R.J. Hawke commits his government to the establishment of a national program of free mammography for women over 40 years of age. (Batt 1994) (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990). Three days later, the leader of the Opposition commits a new Coalition Government to increased screening units.</p> <p>Australia: (May) AHMAC Breast Cancer Screening Evaluation Steering Committee makes its report recommending mammographic screening be available for all women over 40 and be targeted at women 50-69</p> <p>United States: Medicare provides for biennial screening for women over 65 years of age.</p>



Year	Events
1991	<p>Canada: Canadian National Breast Screening Study (CNBSS) principals, Miller and Baines, speak at Medical conference in London saying that the 40-49 screening group had a significantly higher mortality rate than controls. Story was run in the London Sunday times. Samuel Epstein publishes an article in the Los Angeles Times referring to data from the still unpublished study and raising doubts. The NCI and the American College of Radiology '...responded with press releases defending mammography in women under fifty and attacking Epstein for citing the deaths of women in the CNBSS before its results were in print. The following June, the Journal of the National Cancer Institute printed an article quoting radiologists in both Canada and the US, all of whom criticised the CNBSS' (Batt 1994).</p> <p>New Zealand: NZ Health Department publishes Options for Mammography screening in New Zealand: A Review of Recent Literature. (Adams 1991) Recommends continuation of Skegg Report recommendations ie introduction and evaluation of pilot projects.</p>
1992	<p>Canada: Canadian National Breast Screening Study (CNBSS) publishes results showing slight (non significant) increase in mortality in the screening group in the 40-49 year age group compared with the control group; and that the additional mortality benefits of mammographic screening over clinical examination alone for women over 50 are slight.</p> <p>Canada: Following results of CNBSS study, Basinski (Basinski 1992) says that the study showed that the benefits of early diagnosis are not evident. 'The initial results of the NBSS remind us that it is most prudent to temper optimism with caution. Rigorous testing often leads to sobering results, in this and other arenas.'</p> <p>Australia: NH&amp;MRC issues Mammography Screening for Women under 50 years of Age saying there is insufficient evidence to conclude that screening in this age group will reduce deaths from breast cancer. (Batt 1994) (NH&amp;MRC 1992)</p>
1993	<p>Australia: Paper 'Cost-effectiveness of mammographic screening in Australia' (Carter, Glasziou et al. 1993). Differs from AHMAC Report (AHMAC Breast Cancer Screening Evaluation Steering Committee 1990) estimate of cost effectiveness by factor of almost 2 (\$11,000 versus \$20,300 PLYS)</p> <p>Unites States: January 1993 American Cancer Society reviews the Canadian NBSS results and determines to continue to recommend screening for the 40-49 year age group (Kaufert 1996). In February 1993, National Cancer Institute holds workshop to discuss CNBSS study results. Screening advocates such as Shapiro and Kopans argue that Canadian study radiology was cause of problem. Others argue Canadian study was like real world conditions and therefore had greater external validity. NCI fails to develop guidelines until October when it notes absence of data on benefits to women 40-49 and that women be given the evidence and allowed to decide (Batt 1994).</p>
1994	<p>Australia: Inaugural National Breast Cancer Day to promote national awareness of breast cancer (Batt 1994).</p> <p>Australia: First national breast cancer consensus conference to develop a consensus statement on the optimum management of women with newly diagnosed breast cancer and a national approach to breast cancer control. Sponsored by the Clinical Oncology Society of Australia, the Australia-New Zealand Breast Cancer Trials Group, the Medical Oncology Group of Australia and the Breast Section, Royal Australian College of Surgeons. Opened by Mrs Anita Keating (wife of the Prime Minister), later to become Patron of Australia's Breast Cancer Day and the Kathleen Cunningham Foundation. (Batt 1994)</p> <p>Australia: The Senate Standing Committee on Community Affairs releases its report Breast Cancer Screening and Treatment in Australia (Senate Standing Committee on Community Affairs 1994) recommends continuation of current policy targeting 50-69 but allowing 40-49 year old women to attend.</p> <p>Australia: Report of the evaluation of the first phase of the National Program for the Early Detection of Breast Cancer says that program implementation is proceeding well.</p>
1995	<p>Australia: Meta-analysis of screening trials argues there is little or no benefit for women 40-49 (Glasziou, Woodward et al. 1995). NH&amp;MRC issues Guidelines on the Treatment of Early Breast Cancer. (Batt 1994). Commonwealth provides funds to establish the Kathleen Cunningham Foundation to improve outcomes for women through research (Batt 1994). NH&amp;MRC provides funds to the NSW Cancer Council to establish the National Breast Cancer Centre. (Batt 1994)</p>
1997	<p>Canada: Bailar and MacMahon (Bailar and MacMahon 1997) report on investigation into 'subversion of randomisation in Canadian NBSS and conclude that acts of 'subversion' could only have had a trivial impact on the outcomes of the Canadian NBSS as published in 1992.</p> <p>United States: National Cancer Institute changes policy to support mammographic screening for women aged 40-49 (Shapiro, Coleman et al. 1998) but only after vociferous and politically charged 'brawl' (Taubes 1997; Wells 1998).</p>
1998	<p>Australia: Australian Institute of Health and Welfare publishing screening data for 24 months 1996-97 showing screening participation rates of 52.2%.</p>

Year	Events
2000	International: Gotzsche and Olsen publish meta-analysis arguing mammography not effective (Gotsche and Olsen 2000a)
2001	International: 'Unapproved' Nordic Cochrane Centre Review published (Olsen and Gotzsche 2001)
2002	International: 'Approved' Nordic Cochrane Centre review published (Olsen and Gotzsche 2002). International: WHO's International Agency for Research on Cancer (IARC) convenes meeting of 24 experts from 11 countries and dismisses Nordic Cochrane Centre Review of mammography screening (Anonymous 2002).

## 6. NH&MRC Deliberations on Breast Cancer Screening 1976 to 1992

TABLE A5: NH&MRC DELIBERATIONS ON BREAST CANCER SCREENING 1976 TO 1992

NH&MRC Deliberations on Breast Cancer Screening		
Date (NH&MRC Session Number)	Committee	Outcomes
Oct 1976 (NH&MRC 1977a)	Working party of Epidemiology Services Standing Committee of NH&MRC. Members: Prof RRH Lovell (Chair), Dr David Christie, Dr J Deeble, Dr T Durbridge, Mr WB Fleming, Dr N Gray, Prof WSC Hare, Dr S Sax. (Terms of Reference below)	The minutes of the parent committee (the Epidemiology Services Standing Committee) on 2 November 1976, say that the working group was established by the Chairman of the Council prior to its inaugural meeting. This indicates that the question was being dealt with as a matter of urgency. The Minutes of the Working Party state that an a priori case can be made for early pre-symptomatic diagnosis by screening, on the assumption that there is a pre-metastatic stage when complete cure is possible. Argued that 'a radiologist directed mammographic examination of the breast' is the most accurate single method of detecting breast cancer. But as a routine screening tool it is 'considerably less effective and should be used in conjunction with history and clinical examination'. Reports that instruction on self-examination is a major part of the programs being conducted in 27 centres in the USA under the auspices of the American Cancer Society. Australian Anti-Cancer Councils 'are particularly active in this field'. On Risks it says that exposure to radiation is a known cancer risk but quantification is difficult and modern doses in mammography are far below those reported in the studies of Japanese women exposed to the atomic bomb. (Contd below)
Oct 1976 (NH&MRC 1977a) (Continued)	Terms of Reference: Advise the ESSC on: the present state of knowledge of screening for breast cancer; current activity in screening for breast cancer in Australia; Aspects of screening for breast cancer that need to be studied, studies that it might be feasible to undertake in Australia, their design and costs likely to be incurred.	On the HIP study it says that 'in the short term, the gain from mammography outweighed any risk.' But it says that data are insufficient to evaluate long term risks. The committee also noted the variability in results reported by various centres in response rates and in the ratio of benign to malignant biopsy ratio. They also note that it is difficult to accurately estimate costs. Recommendations: that women be encouraged in breast self-examination and education to expect such examinations as part of ordinary medical practice; 'a general recommendation for mass mammography in symptomless women cannot be made now. It would be imprudent to recommend it until it has been shown that benefit clearly outweighs any long term risk. Policy on this should be kept under review, especially in the light of developments that are occurring with low radiation dose techniques. Also reported that screening activity in Australia at that point appears to be quite limited. Note: references a BMJ editorial of 1976 which also discussed mammography.

<b>NH&amp;MRC Deliberations on Breast Cancer Screening</b>		
<b>Date (NH&amp;MRC Session Number)</b>	<b>Committee</b>	<b>Outcomes</b>
Nov 1976 (NH&MRC 1977a)	NH&MRC Epidemiology Services Standing Committee. Members: Prof RRH Lovell, Dr JW Donovan, Dr AI Adams, Prof MG McCall, Dr S Sax, Dr BHS Dixon	Accepted the Working Party's recommendations almost completely. Asked the committee to keep the matter under review and report again in 12 months time. The Secretariat to the committee was asked to collect information on current breast cancer screening activity in Australia outside the Medicare and the Shepherd Foundation. Also asked the committee to liaise closely with the UK departments of Health and Social Security and the Medical Research Council Working Parties of the United Kingdom, 'appropriate bodies' in the United States so that information might be shared and studies not duplicated.  The committee also asked that Council make the recommendations known via publication in the MJA and that 'State anti-cancer councils and health education organisations should be informed of the operation recommendations and be asked to promote their aims through education of the public and of doctors.'
April 1977 (NH&MRC 1977a)	National Health and Medical Research Council	Council accepts ESSC recommendations and rejects mammographic screening given 'present evidence'. Says the recommendations should be published in the medical press and anti-cancer councils and health education organisations should be invited to promote the aims of its statement.
June 1978 (85) (NH&MRC 1978)	National Health and Medical Research Council	Council reiterates its position from its 83 <sup>rd</sup> Session
May 1979 (NH&MRC 1979a)	Medicine Advisory Committee	Minutes report that the Council's position endorsed at its 85 <sup>th</sup> Session '...had aroused a good deal of interest and there were calls for the NH&MRC position on mammography to be reviewed.' Members looked at background papers as well as a report from Dr Bruce Armstrong '...who had been asked by Council to keep this rapidly changing area under review.' The minutes say that in essence the statement of lack of proof of evidence of benefit of mammography only applied for women under the age of 50 years. The MAC decided to set up a Working Party to review the evidence and revise the NH&MRC's position.
June 1979 (87) (NH&MRC 1979a)	National Health and Medical Research Council	Council notes that its statement on Screening for Breast Cancer 'had aroused much interest.' (Note: this may well be referring to Croll's MJA article which criticises the NH&MRC recommendation (Croll 1978)). Notes that the Medicine Advisory Committee had examined background papers indicating technical advances in mammography. Decides to establish a Working Party on Mammography to 'examine the present position with regard to breast screening and mammography. It should revise the previous statement given 'new knowledge'. Membership: RACR, RACS, Uni of Melbourne, Commonwealth Dept Health (convenor). (Note: this is a different parent committee, the MAC as opposed to the PHAC, setting up a different working party.)
August 1979 (NH&MRC 1979b)	Medicine Advisory Committee Working Party on Mammography	Considers Report 'Mammography – Use or Abuse' and recommends a change in the NH&MRC's position to one which supports the view that annual screening with mammography and physical examination is effective.
Sept 1979 (NH&MRC 1979b)	Medicine Advisory Committee	MAC accepts the report of the Working Party and forwards recommendations to NH&MRC

NH&MRC Deliberations on Breast Cancer Screening		
Date (NH&MRC Session Number)	Committee	Outcomes
Oct 1979 (88) (NH&MRC 1979b)	National Health and Medical Research Council	Council considers the MAC Working Party report and modifies views of June 78. Council notes 'that present evidence suggests that benefits of annual screening with physical examination and mammography exceed the risks in women over 50.' To be kept under review. Discussion paper Mammography - Use or Abuse commended for circulation. Council notes that its advice comes from one controlled trial only and results are not necessarily transferable. Advocates controlled introduction through 'samples' of the general population. Says that before advocating the development of a national program, the results of such sample surveys would need to be considered.
Oct 1980 (90) (NH&MRC 1980b)	National Health and Medical Research Council	Council recalls agreement of 88th Session re desirability of 'sample surveys' to 'evaluate screening for breast cancer before a nationally based breast screening program could be advocated.' Council agrees that it is 'important nationally' to commence action in 1981. Sets aside \$20,000 from MREF for initial survey of screening for breast cancer. Medicine Advisory Committee and Medical Research Advisory Committee to seek applications and select candidates.
June 1981 (91) (NH&MRC 1981a)	National Health and Medical Research Council	MAC reports on the appointment of a committee established to select a candidate to run the proposed 'sample surveys'.
Sept 1981 (92) (NH&MRC 1981b)	National Health and Medical Research Council	MAC reports receiving four applications for the conduct of the surveys, none of which met the selection criteria, and the decision to seek advice from Dr Bruce Armstrong from the NH&MRC's Epidemiology Unit in WA on the procedure to undertake the survey.
June 1982 (93) (NH&MRC 1982a)	National Health and Medical Research Council	MAC reports that Dr Armstrong had advised that an appropriate research group should be contracted to develop the 'Eddy' model in Australia and apply it to the problem of breast cancer. This could be used to assess the value of undertaking more detailed and expensive survey. MAC also reported that it decided to contact each of the various State Anti-Cancer Councils to determine what breast screening programs were currently being undertaken in Australia and to consider these replies along with Dr Armstrong's advice at its next meeting.
August 1982 (94) (NH&MRC 1982b)	National Health and Medical Research Council	MAC reports that 'Advice was given that enquiries to determine the feasibility of carrying out breast screening programs in Australia had revealed that mass screening could not be undertaken by State Health and Territory authorities. It was understood that questions of cost and administration were obstacles to such a course at the present time.' The MAC also noted that Dr RG Edwards had forwarded recent articles from the Lancet (not cited in the Minutes) and determined that it should consider them at its next meeting with a view to amending Council's previous statements.
June 1983 (95) (NH&MRC 1983a)	National Health and Medical Research Council	MAC reports that it considered a report from Dr B Kynaston (Director of the Queensland Radium Institute and a MAC member nominated by the Royal Australian College of Radiologists) on Screening for Breast Cancer and decided to set up a Working Party on screening for breast cancer to update the Council's statement on this topic made at its 85 <sup>th</sup> Session in 1978. (Note: this statement had already been superseded by its 1979 statement!). The Working Party would be Chaired by Kynaston and include Joan Croll as a member.

NH&MRC Deliberations on Breast Cancer Screening		
Date (NH&MRC Session Number)	Committee	Outcomes
20 May 83 & 8 July 83 (NH&MRC 1983b)	Medical Advisory Committee (MAC) Working Party on Screening Mammography. Membership: Dr B Kynaston (Chair), Dr NC Davis, Dr J Barrand, Dr J Croll, Prof C Hudson, Prof SR Leeder, Dr D Stanbury. ToR: To review the evidence concerning the screening of well women as a means of earlier detection of breast cancer, for the purpose of updating the Council's policy on this subject. In doing so the Working Party should address the following issues: The age for consideration of screening; the role of BSE, mammography and physical examination, alone or in combination; the role of other screening techniques; screening of the whole population as defined, or population cohorts where particular types of screening are recommended.	On the question of age for screening the committee decided that: cancer incidence in the 40-49 year age group is significant; screening is probably effective and at a level comparable to that for 50 year olds; previously consideration was given to the radiation risk to the individual from repeated mammography. With the reduction in breast dose if modern, dedicated equipment is used, an additional ten annual examinations from age 40-49 would probably not add significantly to the risk, while contributing a potential benefit; benefit when defined as reduced mortality is unproven in the 40-49 age groups, through the number of potentially curable cancers in appreciable. On Breast Self Examination (BSE)—its sensitivity and specificity are not known and it has not been shown to reduce mortality. BSE to be encouraged under certain circumstances: in close association with a primary care practitioner willing and capable of managing the patient with any breast abnormality. Committee made a distinction between case finding and screening. The former is 'the detection of disease in someone presenting to the health care system, but without symptoms of that condition (in contrast to diagnosis where symptoms are of the disease process).' The latter is 'the examination of a well population outside the health care system.' Noting that no national screening program exists anywhere, the Committee recommends a case finding approach which is essentially opportunistic screening ie examination of non-symptomatic women who have presented to the health care system, presumably for some other reason.
Sept 1983 (NH&MRC 1983b)	Medicine Advisory Committee	Receives the report of the Working Party on Mammography and decides to seek comment from the Public Health Advisory Committee. Kynaston and Davis (nominee of the Royal Australian College of Surgeons) undertake to prepare a statement on Breast Health and Mammography for Council.
June 1984 (97) (NH&MRC 1984a)	National Health and Medical Research Council	Council receives the Report of the Working Party on Screening of Breast Cancer and recommends it be made available to members of the medical profession and others interested in the issue of breast cancer. Council issued statement Breast Health and Mammography. It recommends all women be taught BSE, regular clinical examination by their doctor, baseline mammograms for all women at age 40, 3-5 yearly mammograms for all women, more frequent mammograms for some women. This approach is defined by the Council as a 'case finding' approach in the Minutes of the Council meeting but these words are not used in the Statement itself. Council also recommends that the Report of the Working Party on Screening for Breast Cancer be made widely available as a resource.

Note: the last meeting of the Medicine Advisory Committee was on 12-13 September 1984. Breast Cancer Screening was not considered at that meeting. The MAC was replaced by the Health Care Committee. Neither the HAC nor the Public Health Committee considered the issue of breast cancer screening between the 98<sup>th</sup> Session of the NH&MRC in 1984 to the 106<sup>th</sup> Session in 1988.

NH&MRC Deliberations on Breast Cancer Screening		
Date (NH&MRC Session Number)	Committee	Outcomes
June 1989 (107) (NH&MRC 1989)	National Health and Medical Research Council	Health Care Committee report says that it discussed the 'current pressure within the community for expanding the availability of mammography screening in Australia.' Council issued a statement saying 'Council was concerned at the recent pressure to accelerate the introduction of screening mammography prior to careful assessment of the optimum design options for a national program for Australia. Council therefore endorsed the current strategy of careful evaluation of pilot projects and stage introduction of mammography screening in an integrated program of breast health that ensured reliable, high-quality services acceptable to Australian women. Council agreed that its statement on Breast Health and Mammography adopted at its 97 <sup>th</sup> Session should be rescinded. Council endorsed the Statement Introduction of Screening Mammography in Australia. This statement notes a lack of consistency in the trial data on mammography screening but that where benefit is found it is for women over the age of 50 years. It notes that issues requiring attention are: recruitment strategies; follow-up of screen detected abnormalities; frequency of screening; benefits for those outside the 50-69 age group; quality control; workforce issues; treatment services; needs of disadvantaged groups. Council endorsed the current strategy of careful evaluation of pilot programs and staged introduction of an integrated program of breast health which ensures high quality and acceptability to Australian women. The rescission of the Breast Health and Mammography statement was made on the recommendation of the Women's Health Committee as noted in the HCC's Minutes.
June 1991 (111) (NH&MRC 1991)	National Health and Medical Research Council	Council was advised of the commencement of the national program for the early detection of breast cancer in October 1990. The report of the Health Care Committee notes that that Statement The Introduction of screening mammography in Australia adopted at the 107 <sup>th</sup> session should be revised given 'recent development in mammographic screening policy'. Makes changes to paragraphs relating to 'dose conditions to be met for the probably benefit of mammography.
Nov 1992 (114) (NH&MRC 1992)	National Health and Medical Research Council	Council endorses the report Mammography screening for women under 50 years of age. Notes that this issue was referred to the Health Care Committee by the Victorian Anti-Cancer Council. Notes that there is a lack of evidence of effectiveness of screening for women under 50 years of age. Notes the information leaflet prepared by the Working Party on Age Issues in Mammography Screening informing women of the lack of evidence of benefit from screening for women in this group.

## 7. Australian research on BCS

TABLE A6: AUSTRALIAN RESEARCH RELATING TO BREAST CANCER SCREENING.

Researchers	Reference and sponsor	Findings	Position on BCS with mammography
McKeown, M. Thomas, D.P.	(McKeown and Thomas 1966) Anti-Cancer Council Victoria	Study of 200 women concludes 'attempting to discover unsuspected neoplasms by routine mammography is of no practical value.'	Not supportive

<b>Researchers</b>	<b>Reference and sponsor</b>	<b>Findings</b>	<b>Position on BCS with mammography</b>
Roder, David Bonett, Anton Esterman, Adrian	(Roder, Bonett et al. 1985)	Study of outcomes of BSE promotion in south Australia finds that during the period after the campaign, more cancers were detected at an earlier stage in their development than in previous years.	Supportive
Hill, David White, Victoria Jolley, Damien Mapperson, Kathleen	(Hill, White et al. 1988) Anti-Cancer Council Victoria	Meta-analysis of 12 studies of BSE finds that there is 'good evidence of the benefit of encouraging women to preactise self-examination of the breasts regularly.'	Not mentioned
Cockburn, J Irwig, L Turnbull, D Simpson, J Mock, P Tattersall, M *	(Cockburn, Irwig et al. 1989)	Study of 200 GPs finds intention to recommend screening relates to knowledge, perception of importance of clinical examination and mammography, and attitude.	Supportive
Cockburn, J DeLuise T, Hill, D *	(Cockburn, DeLuise T et al. 1990)	Study of 135 women receiving GP recommendation to attend screening shows those older more likely to comply	Supportive
Gerard, Karen Salkeld, Glenn Hall, Jane	(Gerard, Salkeld et al. 1990)	Economic analysis of the Central Sydney Areas Health Service Pilot finds that the cost of finding an impalpable cancer to be \$18,700	Cautions against a national program until pilots demonstrate their cost-effectiveness.
Irwig, L Turnbull, D McMurchie, M *	(Irwig, Turnbull et al. 1990)	Reports effectiveness of various GP invitation strategies to mammography attendance.	Supportive
Webb, Gloria Jurisich, Rosemary Sanson-Fisher, Rob	(Webb, Jurisich et al. 1990) NSW Cancer Council	Study of consistency in State cancer organisation advice on skin, breast, colo-rectal and cervical cancer finds marked differences. All states support breast self examination.	Still to be determined*
Cockburn, J Murphy, B Schofield, P	(Cockburn, Murphy et al. 1991)	Cross-sectional survey of 668 women living near screening service on knowledge, attitudes to mammography and intention to attend screening	Supportive

<b>Researchers</b>	<b>Reference and sponsor</b>	<b>Findings</b>	<b>Position on BCS with mammography</b>
Dorsch, M Cheok, F Ingham, H *	(Dorsch, Cheok et al. 1991)	Study of GP letter in prompting screening attendance finds 69% of those receiving letter attended	Supportive
Hill, D White, V Borland, R. Cockburn J	1991	Study of Cancer-related beliefs and behaviours in Australia	Supportive
Irwig, L Cockburn, J Turnbull, D *	(Irwig, Cockburn et al. 1991)	Reports a cross-sectional telephone survey of women's knowledge and attitudes to breast cancer and screening.	Supportive
Rickard, M T Lee, W J W Read A J Scott D D Stephen J Grace	(Rickard, Lee et al. 1991)	Report of the Central Sydney Area Health Service pilot project performance concluding that results compare well with those of European screening studies.	Supportive
Sharan, A *	(Sharan 1991)	Cross sectional survey of 50 Arabic, Greek, Italian and Vietnamese women reports over 100% difference in knowledge of mammograms between ethnic groups.	Supportive
Turnbull, D Irwig, L Adelson, P *	(Turnbull, Irwig et al. 1991)	Study of 243 women receiving letter from screening program director finds this as successful as letter from GP.	Supportive
Williams, P	(Williams 1991)	Unpublished Masters of Sociology thesis argues that networks of influence among 'femocrats' is the best explanation for the establishment of the ACT screening program.	Not supportive
Adelson, P Irwig, L Turnbull, D *	(Adelson, Irwig et al. 1992)	Describes socio demographics of women attending screening – 48% of target group screened with younger more likely to attend.	Supportive
Clover, K *	(Clover 1992)	Unpublished PhD thesis on the implementation and efficiency of various recruitment strategies for mammography screening.	Supportive
Clover, K Redman, S Forbes, J Sanson-Fisher, R Dickinson, J *	(Clover, Redman et al. 1992)	Study of two GP strategies to increase screening attendance finds inclusion of education component increases attendance over simple recommendation.	Supportive



<b>Researchers</b>	<b>Reference and sponsor</b>	<b>Findings</b>	<b>Position on BCS with mammography</b>
Cockburn, J Cawson, J Hill, D DeLuise, T *	(Cockburn, Cawson et al. 1992)	Cross sectional survey of 96 women attending screening clinic finds 10% experience severe discomfort or worse	Supportive
Cockburn, J Hill, D DeLuise, T *	(Cockburn, Hill et al. 1992)	Cross-sectional survey of 138 rural women on knowledge, mammogram history, and intention to screen.	Supportive
Essendon Breast X-ray Program Collaborative Group	(Essendon Breast X-ray Program Collaborative Group 1992)	Reports results from 2 years operation of the Essendon pilot project showing 41% of the eligible population screened and a positive predictive value of 9.4% for an abnormal mammogram.	Supportive  Says the Program achieved good standards in detection, clinical assessment and treatment.
Hurley, S Jolley, D Livingston, P Reading, D Cockburn, J Flint-Richter, D *	(Hurley, Jolley et al. 1992)	Randomised trial of recruitment strategies finds personal recruitment more cost-effective than newspaper.	Supportive
Lupton, D	(Lupton 1992)	Sociological analysis of mammography screening program argues that it is not in women's interests and has been introduced without their involvement	Not supportive
Roberts, C Turnbull, D Irwig, L *	(Roberts, Turnbull et al. 1992)	Cross-sectional survey of over 200 GPs finds 86% recommend screening and identifies written material as most useful format for information.	Supportive
Short, L	(Short 1992)	Sociological analysis of the development of mammography screening from a feminist perspective argues that screening is unjustified and inappropriate for women.	Not supportive
Turnbull, D Adelson, P Irwig, L *	(Turnbull, Adelson et al. 1992)	Reports changes in knowledge before, during and after a promotional campaign for mammography screening in Drummoyne, Sydney	Supportive
Turnbull, D Irwig, L *	(Turnbull and Irwig 1992)	Study of letter box drop invitation finds that 500 leaflets needed for one attendance and only 8% attend after receiving invitation from friend.	Supportive

Researchers	Reference and sponsor	Findings	Position on BCS with mammography
Carter, Rob Glasziou, Paul van Oortmarssen, Gerrit de Koning, Harry Stevenson, Chris Salkeld, Glenn Boer, Rob	(Carter, Glasziou et al. 1993) Australian Institute of Health and Welfare	Modelling study of the cost-effectiveness of screening finds it is \$20 300 /LYS compared with the Future Directions \$11 000 due to more conservative mortality benefit estimates for 40-49 yr group	Supportive  Screening for >50 is cost effective. Screening for 40-49 should continue until better data is available.
Cockburn, J Hill, D DeLuise, T Flint-Richter, D *	(Cockburn, Hill et al. 1993)	Cross sectional surveys of 481 women attending screening finds high levels of satisfaction and association with length of waiting time.	Supportive
Henry, L *	(Henry 1993)	Descriptive article of strategies used to encourage screening in rural areas based on the PRECEDE model	Supportive
Hurley, S Cockburn, J Livingston, P Reading, D *	(Hurley, Cockburn et al. 1993)	Reports the number of complaints resulting from letter and telephone approaches to women re screening as <1%	Supportive
Bennett, IC Robert, DA Osborne, JM Baker, CA *	(Bennett, Robert et al. 1994)	Cross-sectional survey of 1000 women attending screening finds <2% find it 'very uncomfortable' or 'intolerable'	Supportive.
Cockburn, J Staples, M Hurley, S DeLuise, T	(Cockburn, Staples et al. 1994)	Cohort study of psychological effects of being recalled for further tests shows dysfunction still elevated one week after 'all clear' notice	Supportive
Cockburn, J White, V	(Cockburn and White 1994)	Literature review and summary of behavioural aspects of mammography including the characteristics of non-attenders, rate of screening and methods of recruitment.	Supportive
Hurley, S Huggins, R Jolley, D Reading, D *	(Hurley, Huggins et al. 1994)	An RCT of 2266 women shows letters with appointment times lead to greater attendance than those without.	Supportive
Lupton, D	(Lupton 1994)	Discourse analysis of breast cancer in 900 articles between 1987 and 1990 concludes that it reinforces the technological imperative and medical dominance.	Not supportive

Researchers	Reference and sponsor	Findings	Position on BCS with mammography
Schofield, P Cockburn, J Hill, DJ Reading, D *	(Schofield, Cockburn et al. 1994)	Longitudinal prospective study of 618 women reports predictors of attendance before and after receiving letters of invitation.	Supportive
Glasziou, Paul Woodward, Alistair Mahon, Catherine	(Glasziou, Woodward et al. 1995) Commissioned by the National Program for the Early Detection of Breast Cancer	Meta-analysis of research on screening 40-49 yrs finds no clear evidence of benefit.	Urges caution in recommending screening for 40-49s. Recommends consultation with women
Barratt , Alexandra L. Cockburn, Jill Redman, Sally Paul, Christine Perkins, Janice	(Barratt, Cockburn et al. 1997) NH&MRC National Breast Cancer Centre (NBCC) 1996 National Breast Health Survey	Telephone survey of 3014 to establish baseline data on women's knowledge of and participation in screening finds understanding high	Supportive
MT Rickard RJ Taylor MA Fazli El Hassan	(Rickard, Taylor et al. 1998)	Data linkage study of interval cancers Concludes that screening quality is acceptable and 'should result in a significant mortality reduction in the screened population'	Supportive
Slaytor, Emma K Ward, Jeanette E	(Slaytor and Ward 1998) The Sydney Breast Cancer Foundation	Review of information being given to women through 58 pamphlets from around Australia. Finds that women are not being given all the relevant data to make informed decisions about participation in screening.	Sceptical  Urges presentation of all the facts, not just those statistics that increase perceived risk.
Smith, Catherine L Kricker, Anne Armstrong, Bruce K	(Smith, Kricker et al. 1998) NH&MRC National Breast Cancer Centre	Study of trends in breasts cancer mortality from 1921 to 1994 finds 'Recent falls in mortality could be expected to continue as more women participate in the mammographic screening program.'	Supportive
Cockburn, Jill Pit, Sabrina Redman, Sally	(Cockburn, Pit et al. 1999) Uni of Newcastle Hunter Centre for Health Advancement National Breast Cancer Centre.	2 stage telephone survey of 200 women on perceptions of screening 40-49 age group shows 62% support screening even after presentation of information on 'downsides'	Supportive of >50  Supports information campaign on risks and benefits for women 40-49. Community views should be explored in situations of ambiguous evidence.

<b>Researchers</b>	<b>Reference and sponsor</b>	<b>Findings</b>	<b>Position on BCS with mammography</b>
Forrest, A Patrick M Anderson, Elaine DC	(Forrest and Anderson 1999) Professor James Garden and Hunter Research Fund.	Compares the Australian and UK screening programs and questions the large variation between states in the experience of radiologists, protocols for assessment of screen-detected lesions and the tardiness of national evaluation.	Supportive  Critical of the quality of Australia's program
AM Kavanagh H Mitchell H Farrugia	(Kavanagh, Mitchell et al. 1999) (Abstract)	Study of interval cancers using linkage of cancer registry with BreastScreen Victoria data finds program sensitivity increases with age but low for 40-49 year age group	Unstated  Questions benefit of screening in 40-49 year age group given high proportion of interval cancers.
Kricker, A Clements, M	(Kricker 1999) National Breast Cancer Centre	Studies rates of procedures related to breast disease and finds that the rate of bi-lateral mammograms reimbursed through Medicare fell sharply after the introduction of BreastScreen in 1991 and was still declining in 1996	Supportive
Willis, K	(Willis 1999)	Sociological analysis mammography screening finds effective screening promotion strategies undermine feminist principles by not empowering women to make an informed choice by presenting all relevant data.	Not supportive

\*This position is curious as it is presented as the Australian Cancer Society position as found in a 1985 publication on cancer-related health check-ups for doctors, not the 1986 position as communicated by McMichael and Armstrong (McMichael and Armstrong 1988)

## Appendixes to Chapter 5

### 1. Notes on Method

The AHTAC Report (Australian Health Technology Advisory Committee 1996) was the first point of reference for documentary sources on PCS. The Medline database was a critical source of information on research on PCS. Other databases such as OVID, Sociofile, APAIS, PUBMED, and Web of Science were also used. For this case study, the Dow Interactive database was available at the Australian National University library and this was searched using the terms ‘prostate’ and ‘cancer’ and ‘screening’ to find articles published in newspapers covered by that database. This captured articles in *The Sydney Morning Herald*, *The Age*, *The West Australian*, as well as articles in United States newspapers (eg *The Wall Street Journal*) and Great Britain.

Key informants were identified through the AHTAC report and through published research and media reports of policy discussion. Priority was given to those who had participated in the preparation of the AHTAC report and to leading individuals from organisations that have played a direct role in prostate cancer screening policy discussions: The Cancer Council Australia; the Australian Prostate Cancer Collaboration; the National Cancer Control Initiative; and the Prostate Cancer Foundation of Australia; the Collaborative Centre for Prostate Health; and the Urological Research Centre. The websites for these organisations were sources of information on their policies and their organisational affiliations.

### 2. PCS Interviews

TABLE A7: PROSTATE CANCER SCREENING CASE STUDY INTERVIEWS

Name	Description
Burton, Professor Robert†	Director, The Cancer Council Victoria
Gardner, Mr Max†	Chair, Support and Advocacy Committee, Prostate Cancer Foundation of Australia
Hirst, Dr Geoffrey†	Urologist
Lawrence, Dr Carmen, MP.	Former Federal Minister for Health
Marshall, Prof Villas	Urologist, Clinical Director, Specialty Services, Royal Adelaide Hospital.
Pinnock, Dr Carole†	Principal Research Scientist, Repatriation General Hospital, Daw Park. Chair, Australian Prostate Cancer Collaboration Education Committee.
Primrose, Dr John	Senior Medical Advisory, Health Care Access and Financing Division, Department of Health and Ageing
Slevin, Mr Terry†	Cancer Foundation, WA
Willis, Prof Evan†	Sociologist, La Trobe University

† Indicates the person has published on the topic of prostate cancer screening – see the list of references.

**TABLE A8: PCS INTERVIEWS - NUMBER APPROACHED FOR INTERVIEW BY STATUS OF INTERVIEW .**

Response	Number	Notes
Unavailable	1	A researcher and AHTAC committee member initially agreed by then withdrew due to ill health
Declined	1	A clinician who is a public advocate of PCS was contacted but declined to be interviewed
No response*	2	Former Federal Health Ministers Wooldridge and Richardson (issue not on policy agenda while Brian Howe was Minister)
Completed	9	
Total Number Approached	13	

\*I attempted to contact Professor Keith Kaye, a prominent figure in the case study, at the Urological Research Centre at the University of Western Australia but was advised he had returned to the United States in 1999 and the URC had no current contact details.

### 3. *PCS Interview Questions*

Firstly, I'd like to know about you. What roles have you played in debates on Prostate Cancer Screening or in research relating to Prostate Cancer Screening, or in policy development or program implementation?

Secondly, why do you think that a national Prostate Cancer Screening Program was not introduced in Australia? What do you think were the most influential factors?

Are the factors that shaped the AHTAC report different from those in the post-AHTAC report environment? Invite comparisons and contrasts with colorectal cancer screening and the lack of a national program despite AHTAC recommendations in 1997.

How would you describe the current policy situation of PCS – is it really a ‘no screening’ policy?

Who have been the most influential individuals and organisations working on Prostate Cancer Screening policy over the last 10 years?

Do you think those who argue in favour of Prostate Cancer Screening share common beliefs, values and interests? If so, what do you think these are?

Do you think those who argue against Prostate Cancer Screening share common beliefs, values and interests? If so, what do you think these are?

How important have gender issues been in prostate cancer policy, especially the idea that men should have PCS because women have BCS?

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Are there groups or individuals who are not really for or against PCS that have been influential?

What role have international factors had on policy development in Australia?

Thirdly, what is your perception of the role that Health Ministers played in Prostate Cancer Screening policy? What issues and factors do you think were influencing their decisions?

What is your perception of the role that Health Departments played in Prostate Cancer Screening policy? What issues and factors do you think were influencing their decisions?

What roles did the State and Territory Health Departments play in regard to Prostate Cancer Screening?

Fourthly, I'd like to know your sense of the role that research has played in the policy process. Has there been any Australian research that is particularly important in shaping the debate? Specific studies? Or programs of research? What were the most critical debates and the most critical times in the debates around Prostate Cancer Screening?

How were these debates conducted? Have these led to any change in policy? Do you think these debates led to any change of views among supporters? detractors? Bystanders? Was there any research that made you personally change your mind?

What influence do you think research has had on Prostate Cancer Screening policy?

How would you characterise the relationship between research and policy in this particular policy area? Would you say this is typical or atypical of the research-policy relationship in public health in general?

Finally, is there anything else you would like to say? Perhaps there was something that you thought would come out but you haven't had a chance to say it yet.

Is there anyone you could think of that would take a very different view of Prostate Cancer Screening that you could suggest I talk to?

#### 4. *Chronology of events in prostate cancer screening*

**TABLE A9: CHRONOLOGY OF KEY EVENT IN PROSTATE CANCER SCREENING**

Year	Event
1978	Germany—Population screening for prostate cancer made policy (Schroder 1993)
1983	Urology—New approach to prostatectomy with lower morbidity and higher physician and patient acceptance first described (Carter 2001)
1986	United States—PSA testing approved to monitor disease progression (Chase 2000; Tarone, Chu et al. 2000)
1987	Promotion of ultrasound as a screening tool for prostate cancer sparks conflict between urologists and radiologists (Levin 1987)
1988	
1989	August—PSA testing first listed on the Medicare Benefits Schedule in Australia (Smith and Armstrong 1998).
1990	USA—First published study of PSA screening compared with DRE and ultrasonography in the Journal of Urology (Australian Health Technology Advisory Committee 1996: 37).
1991	April 25—Catalona et al report on PSA testing in the New England Journal of Medicine and advocate its use as a screening tool (Winslow 1991).
1992	Belgium—Recruitment commences in the European Randomized Screening for Prostate Cancer Trial (de Koning, Auvinen et al. 2002). United States—Georgia mandates private health insurers cover prostate cancer screening, the first US State to do so (Rathore, McCreevey et al. 2000)
1993	Tyrol, Austria—program of free mass PSA screening introduced (Chase 2000). Western Australia—rapid increase in PSA testing and prostate cancer incidence. Annual Prostate Awareness Week commences in October (Threlfall, English et al. 1998). October—Executive of the Urological Society of Australasia says that until studies show morbidity and mortality benefits arising from screening programs, they should not be introduced (Taylor 1993). November—PSA testing separated out from 20 other biochemical tests on the Medicare Benefits Schedule (Smith and Armstrong 1998) United States—November: enrolment commences for the National Cancer Institute randomised controlled trial of PCS using PSA and DRE (Gohagan, Prorok et al. 1994). Canada—British Columbia Office of Health Technology Assessment issues report on PSA testing (Willis 1997).
1994	Australia—the Better Health Outcomes for Australians report says ‘In the absence of evidence of positive benefit, no screening for prostate cancer should be recommended’ (Commonwealth Department of Human Services and Health 1994: 165). Australia—Royal Australian College of General Practitioners preventive activities guidelines recommend against PCS (Ward, Young et al. 1998c). September—Largest mass screening ever takes place in the USA where men are encouraged to take PSA test for prostate cancer (Friend 1994). Canada—Canadian Taskforce on the Periodic Health Examination recommends against prostate cancer screening (Woolf and Rothemich 1999: 216). United States—Food and Drug Administration approves PSA test as a screening tool (Willis 1997: 605) United States—National Cancer Institute commences the Prostate, Lung, Colo-rectal, and Ovarian (PLCO) study involving 140,000 subjects. (Chase 2000) United States—American Cancer Society recommends annual DRE and PSA from age 50 (note change in 1998) (Rathore, McCreevey et al. 2000).
1995	March—Australian Cancer Society issues ‘Guidelines for Health Professionals’ recommending against screening (Ward, Hughes et al. 1997) May—South Australian research published showing increased cancer incidence related to increased testing and questioning its benefits (McCaul, Luke et al. 1995). June—AHTAC commences review of prostate cancer screening (Australian Health Technology Advisory Committee 1996: 1) August—First ‘National Men’s Health Summit’ in Melbourne to develop a men’s health policy. Sponsored by the Federal Government (check this) (Dow 1995a) Australia—rate of PSA testing peaks at 27 per cent for men aged over 50 years and 33 per cent for men aged 60-69 for the two years 1995-96 (Smith and Armstrong 1998). August—NSW Health Cancer Expert Working Group recommends health services actively discouragae



Year	Event
	<p>prostate cancer screening (Ward, Hughes et al. 1997).            United States—Congressional Office of Technology Assessment and the US Preventive Services Taskforce recommend against prostate cancer screening (Woolf and Rothemich 1999: 217).            Australian Prostate Study commences (Frydenberg 1995) with the Anti-Cancer Council of Victoria, NSW Cancer Council and the University of Western Australia Dept of Public Health.            Australia—Prostate Cancer Research Foundation set up by Roger Climpson and the Rotary Club of Lane Cove to raise funds for research (Prostate Cancer Foundation of Australia 2002).</p>
1996	<p>August 12—AHTAC report recommending no screening released and widely reported in Australian media (Skehan 1996; Young 1996). Only the WA report notes dissent from the AHTAC report (Tan-Van Baren and Bower 1996).            August 13—New Zealand’s National Health Committee also recommends against screening (NewzIndex 1996).            August 27—Urological Society of Australasia issues press release (Ward, Hughes et al. 1997)            Sweden—Swedish Council on Technology Assessment in Health Care recommends against prostate cancer screening (Woolf and Rothemich 1999: 216)</p>
1997	<p>Britain—February – National Health Service rejects prostate cancer screening on the recommendation of the NHS Centre for Reviews and Dissemination report (Fletcher 1997).            September—First use of brachytherapy to treat prostate cancer in Australia (Anonymous 1997)            United States—Congress approves Medicare funds for prostate cancer screening from 2000 (M2 Presswire 1998; Woolf and Rothemich 1999: 208).            Australia—Second National Men’s Health Conference, Freemantle, WA (Binns 1997).</p>
1998	<p>January—WA Cancer Foundation announces prostate cancer screening study (Bower 1998).            July—MJA publishes four articles on prostate cancer, PSA testing and screening along with an editorial taking a negative view of screening and current PSA testing practices (McCredie and Cox 1998).            Australia—Australian Prostate Cancer Collaboration established by clinicians and researchers to promote collaborative research on prostate cancer (Australian Prostate Cancer Collaboration 2001).            United States—American Cancer Society changes screening recommendation to one where screening is ‘offered’ along with information of benefits and risks (Rathore, McCreevey et al. 2000)            United States—American College of Preventive Medicine recommends against population screening (Ferrini and Woolf 1998)</p>
1999	<p>United States—Oklahoma State passes legislation requiring health insurance funds to cover the cost of prostate cancer screening for all men over 50 years and those men over 40 with risk factors (Associated Press Newswires 1999).            United States—New York State Governor signs a bill requiring health insurance funds to cover prostate cancer screening (Gormley 2000).            Australia—Medical Services Advisory Committee updates the AHTAC report (Pathology Services Table Committee 2000)            Australia—National Cancer Control Initiative establishes Working Party ‘to promote evidence-based use of PSA testing’ (Pathology Services Table Committee 2000)            Australia—the Prostate Cancer Research Foundation affiliates with the Cancer Society of Australia and then merges with the Australian Prostate Cancer Foundation to form the Prostate Cancer Foundation of Australia (Prostate Cancer Foundation of Australia 2002).</p>
2000	<p>Australia—The Pathology Services Table Committee finds a high rate of screening using PSA test and seeks consultation on the wording of the Medicare Benefits Schedule ‘to ensure appropriate and quality use of the test’ (Pathology Services Table Committee 2000).</p>
2001	<p>Australia—The Cancer Council Australia (formerly the Australian Cancer Society) issues The National Cancer Prevention Policy recommending against population-based screening for prostate cancer ‘at present’. (2001).            Austria—Results from the ‘natural experiment’ of providing free PSA testing and prostate treatment in the state of Tyrol show a decline in prostate mortality greater than that in the rest of Austria (Bartsch, Horninger et al. 2001).            29 June—First National Conference of Prostate Cancer Support Groups (Gardner 2001b).</p>

## 5. Australian research relating to PCS

The following table identifies published Australian research that has attempted to make a direct impact on policy related to PCS, including research cited in the AHTAC report.

**TABLE A10: PROSTATE CANCER RESEARCH PURPOSIVELY AND/OR DIRECTLY RELEVANT TO PCS IN CHRONOLOGICAL ORDER**

Researchers	Reference and sponsor	Findings	Position on prostate cancer screening
Parkes, Andrew J Killer, Graeme T	(Parkes and Killer 1994)	12% of Veterans have a PSA test annually but only 2% of those tested have a follow up. Suggests PCS already occurring.	Neutral
McCaul, Kieran A Luke, Colin G Roder, David M	(McCaul, Luke et al. 1995) South Australian Health Commission. Epidemiology Branch, Public and Environmental Health Service.	Finds that the relative risk of diagnosed prostate cancer was 1.36 in 1990-92, and 2.26 in 1993 compared with 1977-1989. Concludes that this is due mostly to increased disclosure of latent cases.	Opposed to screening 'Until there is experimental evidence of health benefits from screening and related investigations for prostate cancer in asymptomatic men, it will be difficult to reconcile benefits with costs' (p 520).
McCredie, M	(McCredie 1995). NSW Cancer Council. This article in one among several in an issue of Cancer Forum devoted to prostate cancer.	'On balance there is no sound evidence for a true increase in mortality.'	Neutral Refers reader to other articles in the issue of Cancer Forum that deal with that matter.
Sladden, Michael Dickinson, J	1995 (ref in Ward)(Ward, Young et al. 1998c)	Survey of 83 Tasmanian GPs finds 33% thinks they should screen for prostate cancer	
Gupta, L Ward, J Haywood, R	1995 (ref in (Ward, Young et al. 1998c)	Survey of 286 GPs in NSW finds 39% think G'Lines for PCS would be 'extremely' or 'very' useful.	
Australian Cancer Society		Systematic review of research on PCS	Opposed to screening
Cohen, Phillip	Victorian Anti-Cancer Council research project reported in (McCoy 1997)	Survey of 500 men 49-71 finds 55% have had a PSA test, 60% of these at the suggestion of the GP.	Not stated in report. VACC opposed to PCS (Gardner 2001b)
Ward, Jeannette E Hughes, Anne-Maree Hirst, Geoffrey H L Winchester, Lorraine	(Ward, Hughes et al. 1997) Authors from Central Sydney Area Health Service except Hirst, urologist from Taylor Medical Centre, Brisbane. Men's Health Study funded by the Commonwealth Dept Health and done by NHMRC Working Party.	Study of 340 men aged 40 to 80 in Sydney finds 22% of those over 50 had a PSA test in the previous 12 months and many men had an inflated perception of the risk of getting and dying of prostate cancer.	Opposed to screening Calls for a systematic public health initiative to discourage prostate cancer screening.

Researchers	Reference and sponsor	Findings	Position on prostate cancer screening
Threlfall, Tim. English, Dallas Rouse, Ian	(Threlfall, English et al. 1998) Health Dept of WA Dept of Public Health, Uni of WA.	Increases and decreases in prostate cancer incidence between 1992 and 1996 are the result of changes in the rate of PSA testing, not 'intrinsic' changes in incidence.	Not stated
Smith, David P Armstrong, Bruce K	(Smith and Armstrong 1998) NSW Cancer Council	Prostate cancer screening peaked at around 33% for men 60-69 over the two years 1995-96 despite contrary advice.	Opposed to screening. Recommends practitioner and consumer education to reduce screening.
Pinnock, Carole B Weller, David P Marshall, Willis R	(Pinnock, Weller et al. 1998b) Repatriation General Hospital, Anti-Cancer Foundation of Aust., Flinders Uni, under The Collaborative Centre for Prostate Health.	20% of a sample of 695 men over 40 reported PSA testing in the previous 12 months. The GP initiated 41% and visiting the doctor for urinary symptoms was an independent predictor of testing. 45 per cent had 'inadequate knowledge' of next step.	Not stated Concern at the rate of PSA testing for men with and without LUTS suggests opposition to screening. This is supported by complementary article by Weller (Weller, Pinnock et al. 1998).
Weller, David Pinnock, Carole Silagy, Chris Hiller, Janet E. Marshall, Willis R.	(Weller, Pinnock et al. 1998) Flinders Uni for Weller, Silagy and Marshall. Pinnock from Rep General Hospital. Hiller from Uni of Adelaide.	Another take on the Pinnock et al study. Belief in vulnerability to prostate cancer a strong predictor for PSA testing.	Opposed to screening Recommends need to promote adherence to NHMRC Guidelines on treatment for LUTS as a way of avoiding the negatives of screening.
Pinnock, C Wakefield, M Marshall, V O'Brien, B	(Pinnock, Wakefield et al. 1998a) Repatriation General Hospital South Aust., SA Health Commission, Flinders Medical Centre, Aust Nursing services.	Qualitative study of 137 men in 19 focus groups on urological health using health beliefs model. Perceived severity, susceptibility, and benefits high but perceived barriers present. Men may not seek screening even if a test becomes available.	Neutral on screening Argues that education messages should not send more confusing messages to men as these reinforce negative health behaviours.
Ward, Jeanette Young, Jane Sladden, Michael	(Ward, Young et al. 1998c) NSW Health Dept – Central Sydney Area Health Service Needs Assessment and Health Outcomes Unit. General Practice Evaluation Program Seeding Grant.	Find 43% of 1271 GPs think PSA testing effective screening test, 68% think it effective with DRE. 8% knew guidelines did not recommend screening. Half could not recall RACGP or ACS publications. 63%, 57% and 46% recommend DRE, PSA or both in health check up.	Opposed to screening Concludes 'Findings from this first national study behave proactive and highly targeted dissemination in general practice of the AHTAC policy.'

Researchers	Reference and sponsor	Findings	Position on prostate cancer screening
Ward, Jeannette Gupta, Leena Taylor, Nicholas J	(Ward, Gupta et al. 1998b) NSW Health Dept – Central Sydney Area Health Service Needs Assessment and Health Outcomes Unit.	Finds 57% of 118 PSA tests ordered by GPs were screening tests as defined by the NHMRC guidelines on management of LUTS.	Opposed to screening
Ward, Jeannette E Girgis, Seham	(Ward and Girgis 1998d) NSW Health Dept – Central Sydney Area Health Service Needs Assessment and Health Outcomes Unit.	Survey of 32 'key influentials' views on what men need to know to make an 'informed decision' about PCS. Support for info on risk, evidence for screening, test accuracy, investigation and treatment.	Opposed to screening Recommends similar study of men's groups to compare their view of information required.
Slevin, TJ Donnelly N Clarkson JP English DR Ward JE	(Slevin, Donnelly et al. 1999). Western Australian Cancer Foundation	56% of asymptomatic men in a sample of 400 had had a PSA test. GP did not discuss the pros and cons with 38%	Opposed to screening Men are being tested for prostate cancer with minimal pre-test counselling or written information.'
Girgis, Seham Ward, Jeanette E Thomson, Colin JH	(Girgis, Ward et al. 1999) NSW Health Department – Central Sydney Area Health Service Needs Assessment and Health Outcomes Unit	Found that 90% of 219 GPs in NSW would screen an asymptomatic patient and that 61% perceived medico-legal risk if they didn't. Perception of risk reduced to 46% after being made aware of guidelines.	Opposed to screening 'Inadequate efforts to disseminate evidence- based guidelines to Australian GPs compound this misguided clinical practice.'
Weller, D May, F Rowett, D Quin, L	Referenced in (Cancer Strategies Group 2001) Funding source unknown	Study of academic detailing to GPs re PSA testing shows it is feasible and acceptable (Cancer Strategies Group 2001)	Unknown
Steginga SK	(Steginga, Occhipinti et al. 2001) Queensland Cancer Council	Mailed survey of 1461 men with 46% response rate they found that the presence of urological symptoms acted as a risk cue for men to prostate cancer.	Opposed to screening 'This information should be used 'in the design of interventions to alter prostate cancer screening behaviour...'

## 6. WHO principles for a screening program

World Health Organisation principles for assessment of the effectiveness of a screening program:

- the condition should be an important health problem;

- there should be a recognisable latent or early symptomatic state;
- the natural history of the condition, including development from latent to declared disease, should be adequately understood;
- there should be an accepted treatment for patients with recognised disease;
- there should be a suitable test or examination;
- the test should be acceptable to the population;
- there should be an agreed policy on whom to treat as patients;
- facilities for diagnosis and treatment should be available;
- the cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole; and
- case-finding should be a continuing process and not a 'once and for all' project. (Australian Health Technology Advisory Committee 1996: xiii).

## Appendixes to Chapter 6

### 1. *Notes on method*

The first documents used in this study were the national HIV/AIDS policy documents that form a lineage in policy discourse since 1988 when the policy ‘green paper’ *AIDS: A Time to Care, a Time to Act* was tabled in the Commonwealth and all State Parliaments (Commonwealth Department of Community Services and Health 1988). It was followed by the first National HIV/AIDS Strategy in 1989, and subsequent strategies in 1993, 1996, and 2000 (Commonwealth Department of Community Services and Health 1989; Commonwealth Department of Health, Housing, Local Government and Community Services 1993; Commonwealth Department of Health and Family Services 1996; Commonwealth Department of Health and Aged Care 2000).

Interspersed with the national strategies are documents that review, evaluate and make recommendations on policy refinements. The first of these was the *Report of the Working Panel on Intravenous Drug Use and HIV/AIDS* (Working Panel on Intravenous Drug Use and HIV/AIDS 1989). The Working Panel was charged with consulting on those aspects of the *AIDS: A Time to Care, a Time to Act* relating to IDU and providing advice to the government on the drafting of the first strategy. The other review documents were the *Report of the Evaluation of the National HIV/AIDS Strategy* (National Evaluation Steering Committee 1992), *Valuing the Past...Investing in the Future: Evaluation of the National HIV/AIDS Strategy 1993-94 to 1995-96* (Feachem 1995), *Protecting our Investment* (Australian National Council on AIDS and Related Diseases (ANCARD) 1998), and *Proving Partnership: Review of the Third National HIV/AIDS Strategy*. Each of these documents includes specific endorsement of NSP as one of a range of strategies to prevent HIV among IDUs within a harm minimisation philosophy.

Research on NSP was identified from references in the above documents as well as by searching Medline, Sociofile and APAIS for references to injecting drug use and HIV/AIDS or hepatitis C or blood borne viruses. Searches were also made for studies about Needle and Syringe Programs and variations on this eg NSP, NSPs, NSEP, NSEPs, and Syringe Exchange. Newspaper articles were found by searching National

Library of Australia holdings of *The Sydney Morning Herald* for reporting on key events such as the Second National AIDS Conference in November 1986. The Alcohol and Other Drugs Council of Australia (ADCA) library was an invaluable source of documentary material including newspaper articles, government reports and research reports.

Key informants were identified through the policy documents and the published research. Researchers who had published a lot of material on the topic of NSP were identified. Those given priority were those who had published a number of articles on the subject of NSP or injecting drug use and HIV or HCV prevention; those who were responsible for research projects that were funded by government with the express aim of informing policy relating to NSP, injecting drug use, HIV or HCV; and those who were advocates or opponents of NSP, harm minimisation or related policy issues. I selected Government officials and non-government organisation representatives on the basis of their role in policy committees as outside ‘experts’.

## 2. NSP interviews

Because of the overlap in the subject matter for the NSP–community and NSP–prisons case studies, the interviews were conducted in a block and reported here together.

TABLE A11: NSP–COMMUNITY AND NSP–PRISONS CASE STUDY INTERVIEWS

Name ††	Description*	Case Study**
Anonymous	State Government Official	Community
Burton, Ms Donna	Formerly of Population Health Division, Department of Health and Aged Care	Community
Byers, Ms Frances	Assistant Director, Population Health Division, Commonwealth Department of Health and Aged Care	Community
Dolan, Dr Kate †	Senior Lecturer, National Drug and Alcohol Research Centre, University of New South Wales.	Both
Douglas, Emeritus Professor Bob †	Visiting Fellow, National Centre for Epidemiology and Population Health	Prisons
Eggar, Dr Sandra †	Associate Professor, Law School, University of New South Wales	Prisons
Gaughwin, Dr Matt †		Prisons
Lehmann, Mr Paul	Director, HIV/AIDS Section, Population Health Division, Department of Health and Aged Care.	Community
Levy, Dr Michael †	Director, Population Health, Corrections Health Service, NSW.	Prisons
Murphy, Mr Eamonn	Former Director, HIV/AIDS and HepC Section, Commonwealth Department of Health and Aged Care	Community
Puplick, Mr Chris †	Chair, Australian National Council on AIDS Hepatitis C and Related Diseases (ANCAHRD)	Both
Van Groningen, Prof John	Criminal Justice Consultant, Criminal Justice Research Group, Justice and Youth Studies, RMIT University, Bundoora Campus	Prisons
Vumbaca, Mr Gino	Executive Officer, Australian National Council on Drugs	Both

<b>Name ††</b>	<b>Description*</b>	<b>Case Study**</b>
Wallace, Mr Jack	Executive Officer, Australian Hepatitis Council.	Community
White, Vicki †	Consultant, Alcohol and Other Drugs Resource Service, Dept for Correctional Services, South Australia	Prisons
Wodak, Dr Alex †	Director, Alcohol and Drug Service, St. Vincent’s Hospital, Sydney.	Both

\*‘Description’ refers to the self-description of the interviewee at time of interview or on their interview consent form. Interviewees were given the option of remaining ‘anonymous’.

\*\* The number of completed interviews on NSP–Community only was 6; the number of completed interviews on NSP–Prisons only = 6; the number of completed interviews with respect to both case studies was 4.

† Indicates the person has published on the topic of NSP – see the list of references.

†† One of the ‘anonymous’ interviewees has published on the topic of NSP

**TABLE A12: NSP–COMMUNITY AND NSP–PRISONS INTERVIEWS : NUMBER APPROACHED BY STATUS OF INTERVIEW .**

<b>Response</b>	<b>Number</b>	<b>Notes</b>
Unavailable	3	1 researcher in favour of NSP, 1 opposed to NSP, and 1 NGO advocate of NSP all expressed willingness to be interviewed but a time could not be arranged.
Declined	2	1 corrections policy researcher accepted and then declined, 1 senior corrections official in Victoria declined and terminated the telephone conversation by hanging up
Non response	5	3 former Federal Ministers for Health (Howe, Richardson and Wooldridge), 1 former federal politician and 1 published criminologist did not respond.
Completed	16	
Total Number Approached	26	

### **3. NSP interview questions**

These questions were used for both NSP–Community and NSP–Prisons case studies with adjustments made depending on the background of the person.

Firstly, I’d like to know about you. What roles have you played in debates on NSP or in research relating to NSP, or in policy development or program implementation? Have you played any role in relation to the issue of NSP in prisons?

Secondly, I’d like to hear your views on the political dynamics of NSP policy making. In relation to NSP in the community, who have been the most influential individuals and organisations involved in supporting NSP? Was there any difference in views between NACAIDS and the NATF? What influence have international developments had on the Australian program? Opposition in the United States? International networks of researchers? Role of the WHO? Role of the International Narcotics Control Board?



Do you think NSP supporters share common beliefs, values and interests? If so, what do you think they are? Harm minimisation? Health promotion – Ottawa Charter? Similarities and tensions between government versus non-government? Commonwealth and States? AFAO and AIVL? AIVL vs NUAA and VIVAIDS? Researchers vs everyone else? Who have been the most influential individuals and organisations working to stop NSP or slow it down? Do you think NSP detractors think they share common beliefs, values and interests? If so, what do you think these are? Is this picture of NSP supporters and detractors and their beliefs and values different when it comes to NSP in prisons?

Thirdly, I'd like to hear your views on the role of policy makers and their organisations in NSP, particularly in terms of the pressures, risks and opportunities they have faced.

With regard to NSP in the community, what role did Health Ministers play with regard to NSP? What pressures risks and opportunities do you think they have faced? What about their Cabinet? What about other elected politicians play? What role did parliamentary processes play? What role has party politics played in regard to NSP? What roles did the Commonwealth Department of Health played in regard to NSP? What pressures, risks and opportunities do you think the Department has faced? What roles did the State and Territory Health Departments play in regard to NSP? What pressures, risks and opportunities do you think they have faced? Is this picture of pressures, risks and opportunities facing policy makers different when it comes to NSP in prisons?

Fourthly, I'd like to know your sense of the role that research has played in the policy process. What in your view have been the most critical debates around NSP? How were these debates conducted? Have these led to any change in policy? Do you think these debates led to any change of views among supporters? detractors? bystanders?

Was there any research that made you personally change your mind? What influence do you think research has had on NSP policy? How would you characterise the relationship between research and policy in this particular policy area? Would you say this is typical or atypical of the research-policy relationship in public health in general? Do you think the influence of research has been different with regard to the question of NSP in prisons?

Finally, could you sum up your views on how and why NSP came about in Australia and has continued to this day and the role of research in this. Are there any factors or issues that you think are important that haven't come out in this discussion?

Is there anyone you could think of that would take a very different view of NSP that you could suggest I talk to?

#### 4. *Chronology of events in NSP policy and research*

**TABLE A13: CHRONOLOGY OF EVENTS IN NSP POLICY AND RESEARCH**

Year	Event
1960s	Norway: Needles and syringes made available to drug injectors in an attempt to curb the spread of Hepatitis B (Moore 1995: 6)
1983	<p>Australia: March—First reported case of AIDS in Australia (Altman 1992: 56)</p> <p>United States: March—Report of 7 cases of AIDS among male, IDU heterosexual prisoners in New York between Sept 1981 and June 1982 (Wormser, Krupp et al. 1983).</p> <p>Australia: Sydney—AIDS Action Committee forms, the first community based AIDS organisation in Australia (Edwards 1997: 44).</p> <p>Australia: NH&amp;MRC establishes Working Party on AIDS with Professor David Pennington as Chair (Ballard 1989)</p> <p>Netherlands: Amsterdam—First Needle and Syringe Exchange initiated by the Junky Union (a drug users organisation) to prevent spread of HBV. Health authorities join forces with the Junky Union in small experiment. Expanded in 1985 in response to HIV. (Coutinho 1995)</p>
1984	<p>Australia: July—First case of AIDS from blood transfusion in Australia (Altman 1992).</p> <p>Australia: August—Australian AIDS Action Committee (forerunner of the Australian Federation of AIDS Organisations—AFAO) formed at the 9<sup>th</sup> National Conference of Lesbians and Homosexual Men. Meets with Neal Blewett (Edwards 1997: 44)</p> <p>Australia: November—Four babies die in Queensland from HIV infected blood donated by homosexually active man. (Edwards 1997: 44)</p> <p>National AIDS Task Force replaces NH&amp;MRC Working Party and now reports to Australian Health Services Council (forerunner of the AHMAC) (Ballard 1989). The Task Force was disbanded in 1987 and replaced by ANCA in 1988. (National Evaluation Steering Committee 1992)</p> <p>Australia: Neal Blewett, Federal Health Minister establishes his own National Advisory Committee on AIDS (NACAIDS) to advise on educational, legal, and social issues. Ita Buttrose as Chair and with 'community representatives' (Altman 1992) Replaced by ANCA in 1988. (National Evaluation Steering Committee 1992)</p> <p>Australia: Commonwealth establishes the NH&amp;MRC Special Unit in AIDS Epidemiology and Clinical Research at the University of NSW. Becomes the National Centre in HIV Epidemiology and Clinical Research in 1990 (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 34)</p> <p>Australia: Australia's Response to AIDS published</p> <p>Germany: Bremen—self-help group commences needle distribution to prevent AIDS (Stover)</p>
1985	<p>Australia: January—Minister for Health, Dr Neal Blewett, visits the USA and Europe to view the AIDS epidemic (Dudman 1989).</p> <p>United States: January—JAMA reports AIDS incidence of 323 per 100,000 among male IDUs in New Jersey for the year June 1983 to May 1984(Hardy, Allen et al. 1985).</p> <p>Australia: National AIDS Task Force advocates increasing the availability of sterile needles and syringes to reduce the spread of HIV (Wodak 1990: 134)</p> <p>Sydney: Early—AIDS Drugs Information Collective (ADIC), a group of past and present IDUs and health professionals established and attempts to get government funding.</p> <p>United States: February—The New England Journal of Medicine reports HIV prevalence up to 87% among IDU attending drug treatment agencies in New York (Landesman, Ginzburg et al. 1985).</p> <p>Australia: April—Special Premiers' Conference establishes the National Campaign Against Drug Abuse (NCADA) based on principle of 'harm minimisation' (Working Panel on Intravenous Drug Use and HIV/AIDS 1989)</p> <p>Australia: May—Australia becomes the first country to introduce screening of blood donations for HIV</p>

Year	Event
	<p>(Altman 1992: 57)</p> <p>Australia: May—Australian Health Ministers endorse a National Health Strategy for AIDS Control which stressed education and social and medical research (Ballard 1989)</p> <p>USA: August—Commissioner of New York City Health Department proposed NSP to Mayor (Dudman 1989).</p> <p>International: High rates of HIV reported among IVD users in Italy and Austria in <i>The Lancet</i> (Dudman 1989)</p> <p>Australia: Australian Federation of AIDS Organisations (AFAO) established, with Commonwealth Government funds, to represent some HIV-related community based organisations. (Commonwealth Department of Community Services and Health 1989: 6)</p> <p>Australia: Commonwealth funding to State and Territories for AIDS prevention and blood testing commences (Ballard 1989).</p> <p>Victoria: December—Health Dept Victoria survey reports 91% of IDUs from two drug rehab units in Melbourne sharing needles. (Paine, Tonuma et al. 1985).</p>
1986	<p>ACT: February—ACT Health Authority asks pharmacists to make needles and syringes available for sale to whomever wants them. (Dudman 1989)</p> <p>United Kingdom: February—<i>BMJ</i> reports HIV prevalence of between 50 and 85% among 164 IDU patients of a single general practice in Edinburgh following a rapid epidemic in late 1983 (Robertson, Bucknall et al. 1986).</p> <p>Australia: April—first case of AIDS in Australia where IDU is the sole risk factor (Blacker, Tindall et al. 1986)</p> <p>Australia: April &amp; May—National Drug and Alcohol Research Centre (NDARC) established in Sydney, National Centre for Research into the Prevention of Drug Abuse established in Perth with funding from the National Campaign Against Drug Abuse. (Source: Departmental file).</p> <p>Australia: Commonwealth Government establishes NH&amp;MRC Special Unit in AIDS Epidemiology and Clinical Research as a national centre for research. Renamed National centre in HIV Epidemiology and Clinical Research in 1990. (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 34)</p> <p>The Netherlands: June—<i>The Lancet</i> reports NSP in operation in Amsterdam by drug and alcohol services using harm minimisation philosophy and low rates of HIV among IDUs (Buning, Coutinho et al. 1986).</p> <p>NSW: September—police enquiry into extraordinary sales of syringes through pet shops in Sydney's western suburbs (Anonymous 1986)</p> <p>NSW: November 1-2—Second National AIDS Conference, Sydney, strongly supports distribution of clean needles (Grimes 1986).</p> <p>NSW: 12 November—Alex Wodak and Kate Dolan commence first NSP in Australia from the Drug and Alcohol Service at St Vincent's Hospital, Darlinghurst (Wodak and Dolan interviews). Research shows increasing HIV prevalence among IVD users (Anonymous 1987; Dolan, Topp et al. 2000: 8, 16)</p> <p>Australia: November—Chair of NACAIDS, Ita Buttrose, issues press release 'Sterile Needles and Syringes a Must if Australia to Escape AIDS Epidemic'. (Dunn and Clark 1986; Dudman 1989: 2).</p> <p>NACAIDS establishes IVDU Working Party as do several State health departments (Wodak 1990: 134)</p> <p>Federal Health Minister announces funding for pharmacy-based needle distribution (Grimes 1986)</p> <p>Pennington resigns from NACAIDS over dispute on advice to Aborigines on traditional practices and the influence of gay organisations (Anonymous 1986).</p> <p>World Health Organisation announced establishment of the Global Program on AIDS (Altman 1986).</p> <p>Sweden: November—NSP commences in Lund (Christensson and Ljungberg 1991).</p> <p>NSW: December—NSW Health Department and Pharmacy Guild of Australia introduce the Pharmacy Distribution Scheme to sell needles along with HIV information through pharmacies. (Schwartzkoff 1989: iii). The Federal Government pays for the syringes (Thomas 1986).</p> <p>International: WHO sponsored Consultation on AIDS among Drug Abusers concludes that giving clean needles is one strategy to reduce transmission of HIV. (Stimson, Donoghoe et al. 1990: 223)</p> <p>Australia: National Campaign Against Drug Abuse (NCADA) commences with the aim of harm reduction. \$100m made available over three years to expand drug treatment.</p> <p>ACT: December—Drug Referral and Information Centre and AIDS Action Council apply to NACAIDS for federal funding for pilot NSP (Dudman 1989: 2)</p> <p>Sweden: Syringe exchange program commences in Lund (Des Jarlais, Hagan et al. 1995).</p> <p>New Zealand: AIDS Advisory Committee endorses development of NSP and related education schemes (Lungley and Baker 1990).</p> <p>United Kingdom: Epidemic of HIV among IDUs in Edinburgh reported in the <i>British Medical Journal</i> (Loxley, Ovenden et al. 1992: 3)</p> <p>United Kingdom: Syringe exchanges commence operation. (Stimson, Donoghoe et al. 1990: 227)</p>

Year	Event
1987	<p>Australia: Ministerial Council on Drug Strategy supports 'increased availability of needles and syringes' (Dudman 1989: 2)</p> <p>Australia: Commonwealth AIDS Research Grant Scheme (CARG) established to provide designated funding for AIDS research. National Centres in Virology, Epidemiology and Clinical, and Behavioural research established. (Altman 1992: 63)</p> <p>Australia: April—Grim Reaper advertising campaign launched and runs for two weeks (Altman 1992: 57)</p> <p>Australia: April—Australian Health Ministers' Conference recommends increasing access to needles and syringes for IDUs including via NSP (Dudman 1989: 2, 9)</p> <p>Australia: June—the Intergovernmental Committee on AIDS (IGCA) established to enable liaison and coordination across States, Territories and the Commonwealth. (Schwartzkoff and Watchirs 1991: 4)</p> <p>Australia: National AIDS Task Force warns State and Territory Health Authorities of the need for urgent expansion of NSP in light of overseas epidemics (National Evaluation Steering Committee 1992).</p> <p>West Australia: July—NSP commences (Loxley 2000).</p> <p>NSW: NSP becomes government policy in NSW (Dolan, Topp et al. 2000: 8)</p> <p>Victoria: March—Health Dept Victoria study reports 14 cases of HIV among IDUs and 96% of IDUs in treatment sharing needles in the last 5 years. (Edgoose and Baillie 1987)</p> <p>ACT: July—NSP pilot commences in the ACT (Dudman 1989).</p> <p>NSW: September—Wodak et al report presence of HIV antibodies among needles returned to the pilot NSP in inner Sydney (Wodak, Dolan et al. 1987).</p> <p>Victoria: November—Four pilot centres approved to issue needles and syringes to IVD users (Paine and Lewis 1988).</p> <p>Australia: Campaign to 'Never Ever Share Needles' launched by Hazel Hawke, wife of the Prime Minister (Des Jarlais, Hagan et al. 1995: 1228).</p> <p>Scotland: Syringe exchange and sales begins in Glasgow. (Des Jarlais, Hagan et al. 1995)</p> <p>Canada: Bleach distribution commences in Toronto. Syringe exchange follows in 1989 (Des Jarlais, Hagan et al. 1995)</p> <p>Germany: Bremen—Needle and Syringe vending machines first installed (Stover).</p> <p>Australia: Researchers from NHMRC Special Unit in AIDS Epidemiology and Clinical Research report the average hospital cost per AIDS case to be over \$22,000 with a projected cost of AIDS treatment of over \$58m by 1991 (Whyte, Evans et al. 1987)</p> <p>United Kingdom: Government sponsored experiment involving 15 agencies across England and Scotland commences (Stimson, Donoghoe et al. 1990: 226)</p> <p>Australia: National Advisory Committee on AIDS (NACAIDS) commissions second IDU Working Group to, inter alia, promote NSP (Wodak and Penny 1988).</p>
1988	<p>NSW: January—NSP commences in NSW after earlier pilot projects (Byers 1995)</p> <p>NT: February—NSP commences in the Northern Territory (Byers 1995)</p> <p>United States: Syringe exchange program commenced in Tacoma, Washington. (Des Jarlais, Hagan et al. 1995)</p> <p>United States: Congressional ban on use of Federal funds to operate NSPs. (Dolan, Topp et al. 2000: 13) and a ban on grantees of the National Institute of Drug Abuse conducting research on NSP (Moss 2000).</p> <p>Australia: National Advisory Committee on AIDS (NACAIDS) IDU Working Group holds national workshop including IDUs, researchers and health officials and recommends expansion of NSP network (Wodak and Penny 1988).</p> <p>Australia: March—The Australian National Council on AIDS (ANCA) established by the Federal government replacing National AIDS Taskforce and the National Advisory Committee on AIDS (NACAIDS). (Commonwealth Department of Community Services and Health 1989: 8)</p> <p>Australia: AIDS Council of New South Wales forms Injecting Drug Use Working Group (Wallace 1991)</p> <p>New Zealand: May—NSP commences in New Zealand (Lungley and Baker 1990).</p> <p>Queensland: June—NSP commences in Queensland (Byers 1995)</p> <p>Australia: November-December—Tabling in the Federal Parliament and the State Parliaments of the policy discussion paper 'AIDS: A Time to Care, A Time to Act—Towards a Strategy for Australians'</p> <p>United States: November—Pilot NSP started in New York City by Health Department (Anonymous 1989).</p> <p>Canada: Montreal—Windy Earthworm, a young HIV positive former IDU commences sterile needle distribution from his backpack on the street. (Hankins 1998).</p>
1989	<p>South Australia: January—NSP commences in South Australia (Byers 1995)</p> <p>Australia: 31 August—First National HIV/AIDS Strategy tabled in Federal Parliament.</p> <p>Australia: National organisations representing injecting drug users, sex workers and people living with HIV join AFAO (National Evaluation Steering Committee 1992: 20)</p> <p>Australia: Comprehensive national HIV surveillance system established.</p>

Year	Event
	NSW: New South Wales Users and AIDS Association established (Groenhout, MacDonald et al. 1992) United States: New York City—Clandestine NSPs established by AIDS activists, IDUs and public health workers in Manhattan (Henman, Paone et al. 1998). Canada: Vancouver—First official NSP begins (Hankins 1998).
1990	Australia: February—Intergovernmental Committee on AIDS (IGCA) establishes Legal Working Party to identify legislative changes required to support HIV prevention. Australia: September—Sydney prison warder becomes HIV positive after being stabbed by a prisoner with an infected needle. (Altman 1992: 61) Tasmania: Tasmanian Users Community AIDS Advocacy (TUCCA) established (Groenhout, MacDonald et al. 1992) Australia: National Centre in HIV Social Research established, initially with branches at the University of Queensland, University of NSW and Macquarie University. (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 55)
1991	Australia: NSP now established in all States and Territories in Australia (except Tasmania) (Byers 1995)
1992	Australia: All available historical HIV surveillance data provided to National Centre for HIV Epidemiology and Clinical Research. Tasmania: Illegal NSP begins operation with tacit police support (Lucas and Easthope 1996). International: Coutinho and others publish study of NSP in Amsterdam showing ‘...no evidence that obtaining new needles or syringes via the exchange program was protective...’ against HIV (Coutinho 2000).
1993	Australia: National HIV/AIDS Strategy 1993-94 to 1995-96 commences. Continued support for NSP (Commonwealth Department of Health Housing Local Government and Community Services 1993). Australia: Commonwealth AIDS Research Grants (CARG) transferred from AIDS Branch to the National Health and Medical Research Council (NH&MRC) Australia: July—National Centre in HIV Social Research holds first HIV/AIDS and Society Conference in Sydney. They become an annual event aimed at promoting social research dissemination and use (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 76) Tasmania: July—Tasmania establishes NSP, the last Australian state or territory to do so
1994	Australia: April—Australian Health Ministers Advisory Council (AHMAC) requests the NHMRC set up Hepatitis C Taskforce (NH&MRC/AHMAC Task Force on Hepatitis C 1994: 3)
1995	United States: US Health and Human Services Secretary announces continuation of Federal ban on funding for NSP due to unpublished data showing NSPs are ineffective in preventing HIV transmission (Bluthenthal 1998: 1148) Feachem Report finds that NSEP... Australian Study of HIV and Injecting Drug Use (ASHIDU) finds continued low rates of HIV among IDUs but over 50 per cent prevalence of HCV (Loxley, Carruthers et al. 1995)
1996	Australia: March—International Conference on Drug Related Harm leads to establishment of the Asian Harm Reduction Network (Crofts and Deany 1999). Australia: December—Partnerships in Practice: National HIV/AIDS Strategy 1996-97 to 1998-99 commences. Continued support for NSPs as high priority. (Commonwealth Department of Health and Family Services 1996)
1997	International study finds NSP effective and cost-effective in control of HIV (Hurley, Jolley et al. 1997)
1998	Australia: Australian Federation of AIDS Organisation issues NSP Lobby Kit to affiliates to help counter attacks on NSPs. (McLean and Moore 1998) HCV Report
1999	Australia: April—Council of Australian Governments (COAG) approve \$221m package of measures on illicit drugs including funds to extend availability of NSPs. (Dillon and Dolan 2000: 1)
2000	Australia: National HIV/AIDS Strategy 1999-2000 to 2003-2004: Changes and Challenges commences. Supports continuation of NSPs as high priority. (Commonwealth Department of Health and Aged Care 2000) Australia: May—Australian National Council on AIDS, Hepatitis C and Related Diseases issues NSP Needle and Syringe Programs: A review of the Evidence and NSP Needle and Syringe Programs: Your questions answered in response to ‘much public debate’ about Needle and Syringe Programs. Australia: June—National Hepatitis C Strategy launched. (Burton interview).

## 5. Research related to NSP in the community

TABLE A14: AUSTRALIAN RESEARCH RELATING TO NSP IN THE COMMUNITY

Author/s	Citation/ Research Funder or Sponsoring Organisation	Findings	Position on NSP
S Paine M Tonuma B Monheit	(Paine, Tonuma et al. 1985) Health Dept Victoria.	Of 200 drug rehab clients surveyed, 96% reported injecting and 91% reported sharing needles.	Not stated Highlights the most common reported reason for sharing as the lack of access to clean equipment.
P Blacker B Tindall A Wodak D Cooper	(Blacker, Tindall et al. 1986) St Vincent's Hospital, Sydney	A survey of 200 IDUs found one HIV positive heterosexual male. Contact tracing of his sexual and needles sharing contacts found a further 4 HIV positive cases out of 6 contacts.	Not stated. Concludes that HIV has entered Australia's IDU population and recommends urgent action.
L Edgoose J Baille	(Edgoose and Baillie 1987). Health Dept Victoria	Of 136 drug rehab clients in Melbourne, 96% report needle sharing in the last 5 years, 71% doing so more than weekly. Also reports sexual risk factors.	Tacit support for NSP. Supports 'greater availability of needles and syringes to drug abusers' along with education.
A Wodak K Dolan A Imrie, J Gold, J Wolk, B Whyte, D Cooper.	(Wodak, Dolan et al. 1987) St Vincent's, Albion St Centre, NHMRC Special HIV/AIDS Unit	Reports that 1% (3) of the needles returned to the 'pilot' NSP in Darlinghurst were HIV positive.	Supports NSP. 'The rapid implementation of sterile needle-and-syringe exchange programs is imperative to stem the spread of HIV infection.'
P Burrows A Bingham N Bohm S Benzeville, H Goodwin, J Hillman, P Roth, B Murphy	(Burrows, Bingham et al. 1988) Medical students project. University of Newcastle	Reports on a study of 100 Methadone clinic attenders in Newcastle in terms of needle sharing a sexual risk behaviour and finds high rates of both.	Qualified support for NSP. Argues that increasing needle availability will be inadequate without education to persuade against needle sharing – a 'cultural' problem.
M McLaws J McGirr W Croker, D Cooper	(McLaws, McGirr et al. 1988) CARG	Reports 12% of 85 IDUs attending St Vincent's Hospital emergency department over 27 days in 1987 as HIV positive.	Supports NSP.
C Reilly P Homel	(Reilly and Homel 1988) NSW Health Dept	Reports 1071 drug users knowledge and attitudes regarding HIV/AIDS especially needle sharing	Not stated.
M Ross	(Reilly and Homel 1988) CARG	Survey of HIV risk factors among 2,601 randomly selected adults finds IDU prevalence highest among males under 24 at 1.6%.	Not stated. General conclusion is that HIV risk groups are smaller than previous estimates.
D Dwyer, J Bell R Batey, F Sanders T Patterson, R Howard, J Downie, Dpackham A Cunningham	(Dwyer, Bell et al. 1989) Westmead Hospital	Reports low prevalence of HIV in methadone program attenders and pregnant IDUs in the western Sydney, except of homosexual male IDU.	Not stated. Urges HIV surveillance to monitor the effectiveness of NSP and other programs.

Author/s	Citation/ Research Funder or Sponsoring Organisation	Findings	Position on NSP
F Dudman	(Dudman 1989) Drug Referral and Information Centre	The Report of the Evaluation of the ACT Pilot Needle Exchange Program: 1988. Reports service delivery data including rate of needle return.	Supports NSP.
J Schwartzkoff	(Schwartzkoff 1989) NSW Health Department	Evaluation of the Pilot NSW Needle and Syringe Program	Supports NSP
A Morlet, S Darke, J Guinan, Jwolk J Gold	(Morlet, Darke et al. 1990) Albion St AIDS Centre	1222 IDUs presenting to the Centre for HIV testing between 1985 and 1989 show 14.5% sero positive. Of these 43% homosexual and 5% heterosexual and no annual rate of increase.	Not stated. Warns of continuing risk of wider epidemic. Says there is no clear relationship between needle availability and sharing.
J Wolk A Wodak A Morlet J Guinan, J Gold	(Wolk, Wodak et al. 1990) Albion St AIDS Centre	Study of 181 IDUs from drug treatment services. 9% HIV positive and 80% shared needles due to inconvenience of access.	Supports NSP. Recommends giving drug dealers clean equipment to distribute and drug law reform in the interests of public health.
S Darke W Hall J Carless	(Darke, Hall et al. 1990) National Drug and Alcohol Research Centre	Survey of drug users attending opiate treatment programs shows enrolment associated with lower levels of risky injecting practice.	Not stated. Recommends that NSPs provide more information to IDUs on safe sex practices.
M Gaughwin R Ryan H Treffke, M Lee R Ali	(Gaughwin, Ryan et al. 1990) Uni of Adelaide. Drug and Alcohol Service Council.	Reports that two thirds of a sample of Adelaide pharmacies sell syringes.	Not stated. Concludes needle availability is 'adequate' in Adelaide.
B Matthews K Richardson J Price, G Williams	(Matthews, Richardson et al. 1990)	Study of risk behaviour and knowledge of HIV among 40 homeless youth showing higher levels of risk including needle sharing than controls.	Not stated.
R Mullins	(Mullins 1990) Health Dept Victoria	Of 560 pharmacies that responded to a survey, 325 were prepared to sell or provide needles and info.	Supports NSP. Recommends further distribution via pharmacies.
J Schwartzoff S Spooner B Flaherty, J Braw, A Grimsley, K Scanlon, K Stewart	(Schwartzkoff, Spooner et al. 1990) NSW Health Department	Focus Groups plus random telephone survey of 300 people on attitudes to harm reduction programs. Finds 90% support NSP and 89% support methadone programs	Supports NSP
G Swensen A Quigley S Lenton	(Swensen, Quigley et al. 1990) WA Drug and Alcohol Authority	Presents data from a study of HBV prevalence among 244 methadone clinic attenders in 1987-89 showing a significant decline from 51% to 33% following NSP intro.	Supports NSP. Concludes that results are suggestive of success of prevention measures like NSP

Author/s	Citation/ Research Funder or Sponsoring Organisation	Findings	Position on NSP
N Crofts M Hay	(Crofts and Hay 1991) Macfarlane Burnet Centre	A case-control study finds homosexual men with a history of IDU are at higher risk that heterosexual IDU and that HIV could spread to heterosexual IDU.	Not stated. Recommends further prevention of gays who inject drugs.
J Wallace	(Wallace 1991) Commonwealth AIDS Program through AFAO and ACON	Needs assessment of gay injecting drug users	Supports NSP. Recommends strategies to improve access and use of NSP by gay men.
M Gaughwin E Gowans R Ali, C Burrell	(Gaughwin, Gowans et al. 1991) National Centre for Epidemiology and Pop Health	Seven to 10 times more blood was transferred via 2 ml needles compared to 1ml syringes.	Not stated. Support of harm minimisation principles—recommends encouraging IDUs to use 1ml syringes rather than 2ml.
R Sharp M Davis G Dowsett S Kippax, S Hewitt S Morgan, W Robertson	(Sharp, Davis et al. 1991) NSW Department of Health	28 injecting drug users were interviewed in a qualitative study of 'functional' IDU. Drug use is a structured and patterned activity associated with norms and rituals.	Supports NSP. Recommends increased access to NSP as well as different approaches to education, drug law reform, and an end to 'junkie' stereotypes
National Evaluation Steering Committee	(National Evaluation Steering Committee 1992) Commonwealth AIDS Program.	Reports on the evaluation of the first National HIV/AIDS Strategy. Finds the number of needles distributed increasing but needle sharing persists, particularly in the context of intoxication	Supports NSP. Recommends further refinement to meet the needs of IDU
J. M. Kaldor J Elford A. Wodak J. N. Crofts S. Kidd	(Kaldor, Elford et al. 1993)	Review suggests education and prevention programs for HIV among IDU have been successful.	Not stated. Recommends improved methodologies so that the reasons for success might be better determined.
P Dance	(Dance 1994)	A study of 139 illicit drug users in Canberra finds critical gender differences in the reasons and risks associated with drug use between men and women.	Not stated. Support for harm minimisation.
Margaret Robinson	(Robinson 1994) Department of Health and Community Services, Victoria	This action research project put in place strategies to promote safe syringe disposal in St Kilda, Melbourne and build local support for NSP.	Supports NSP
R Feachem	(Feachem 1995) Commonwealth AIDS Program	Reports on the evaluation of the second National/HIV AIDS Strategy. Reports that NSP is cost saving.	Supports NSP. Recommends further expansion.
N Crofts R Louie D Rosenthal	(Crofts, Louie et al. 1995) Not stated, possibly NHMRC and CARG.	Reports on a study of 300 young injecting drug users 'initiation' into injecting. Finds no support for the stereotype of initiates being dragged into injecting by dealers.	Supports NSP. Recommends development of better education programs and non-blaming approaches to young IDUs.



Author/s	Citation/ Research Funder or Sponsoring Organisation	Findings	Position on NSP
W. Loxley S. Carruthers N. Crofts, K Dolan M. Gaughwin J. Kaldor	(Loxley, Carruthers et al. 1995) ASHIDU–CARG & National Drug Strategy.	Reports that HIV risk behaviour had declined among IDU between the ANAIDUS study in '89/90 and this study.	Supports NSP.
P Lucas G Easthope	(Lucas and Easthope 1996)	Reports reduction in needle sharing as a result of the introduction of NSP in Tasmania.	Supports NSP.
N Crofts J Webb-Pullman K Dolan	(Crofts, Webb-Pullman et al. 1996)	An analysis of trends over time in social and behavioural factors related to the transmission of HIV among injecting drug users and prison inmates	Supports NSP. Recommends further research on many aspects of IDU, HIV and interventions to reduce BBV transmission.
M MacDonald, A Wodak, R Ali, N Crofts, P Cunningham, K Dolan, M Kelaher, W Loxley, I van Beek, J Kaldor, Collaboration of Needle Exchanges.	(MacDonald, Wodak et al. 1997) CARG	Reports HIV prevalence of 2.1% among 1005 IDUs attending 21 NSPs across Australia in 1995.	Not stated. Strong support for NSP can be assumed given the study was done with the Collaboration of Needle Exchanges.
National Centre in HIV Epidemiology and Clinical Research	(National Centre in HIV Epidemiology and Clinical Research 1997) CARG	Annual Surveillance Report shows HIV and HCV prevalence and reported needle sharing among attendees at a sample of NSPs across Australia.	Not stated.
N Crofts D Jolley, J Kaldor, I Van Beek A Wodak	(Crofts, Jolley et al. 1997). Macfarlane Burnet Centre, VicHealth, Terumo Australia (Inc)	Prevalence of HCV among IDUs has been of the order of 60 - 70% since 1971. Duration of injecting and drug of choice are the main predictors.	Supports NSP. Recommends enhancement to prevention programs. Reduction of drug injecting should be the main long term policy goal.
S Hurley D Jolley J Kaldor	(Hurley, Jolley et al. 1997) CARG and Commonwealth AIDS Program	International study finding differences in HIV incidence between those cities with NSP and those without which is plausibly explained by the existence of the NSPs.	Supports NSP.
N Crofts C Aitkin	(Crofts and Aitken 1997)	Reports reductions in needle sharing over time among a longitudinal cohort of IDUs plus low rate of HIV transmission. High rate of HCV transmission which declined but not significantly. Reports HCV transmission among IDU who report no needles sharing.	Not stated. Recommends further research.
S Lenton M Phillips	(Lenton and Phillips 1997)	Reports success of an intervention designed to increase community support for NSP.	Supports NSP

Author/s	Citation/ Research Funder or Sponsoring Organisation	Findings	Position on NSP
National Centre in HIV Epidemiology and Clinical Research	(National Centre in HIV Epidemiology and Clinical Research (Editor) 1998) CARG	Annual HIV Surveillance report shows HIV and HCV prevalence and reported needle sharing among attendees at a sample of NSPs across Australia.	Not stated.
W Loxley J Bevan S Carruthers	(Loxley, Bevan et al. 1998) ASHIDU–CARG and National Drug Strategy	Presents data on the independent risk factors for Very Risky Sexual Behaviour among men and women.	Not stated. Supports harm reduction and modification of HIV education strategies for IDU.
D Burrows	(Burrows 1998) Aust Federation of AIDS Organisations – Commonwealth AIDS Program	Reviews access to clean injecting equipment in Australia and finds that some marginalised populations are underserved.	Supports NSP.
N Crofts C Aitken J Kaldor	(Crofts, Aitken et al. 1999a) Macfarlane Burnett. CARG	Presents data on risks related to needle sharing for different BBVs and concludes that HCV epidemic not prevented by NSP because it had started before NSP was introduced and because it has higher infectivity.	Supports NSP. Recommends expansion of NSP and increased points of sale for clean equipment.
National Centre in HIV Epidemiology and Clinical Research	(National Centre in HIV Epidemiology and Clinical Research 2000) CARG	Reports HIV and HCV prevalence and reported needle sharing among attendees at a sample of NSPs across Australia.	Not stated. NSP survey done in conjunction with the Collaboration of Australian Needles and Syringe Programs
K Dolan L Topp M MacDonald	(Dolan, Topp et al. 2000) ANCAHRD	Review of research finds NSP effective in reducing the spread of BBVs with few significant negative side effects.	Supports NSP
M MacDonald A Wodak K Dolan I van Beek P Cunningham J Kaldor	(MacDonald, Wodak et al. 2000) CARG	Reports changes in risk behaviours and in HCV prevalence among the IDUs at needle exchanges between 1995, 96 and 97.	Supports NSP. Recommends increased NSP.
National Centre in HIV Epidemiology and Clinical Research	(National Centre in HIV Epidemiology and Clinical Research 2001) CARG	Annual HIV Surveillance Report shows trends in HIV and HCV prevalence and reported needle sharing among attendees at a sample of NSPs across Australia.	Not stated. NSP survey done in conjunction with the Collaboration of Australian Needles and Syringe Programs

### ***Characteristics of NSP related research***

Most of the research found relating to NSP has not been focussed on NSP per se but on aspects of injecting drug use and blood borne virus transmission. The early ad hoc studies on HIV and needle sharing prevalence have been replaced by an annual national survey on blood borne viruses and risk factors among NSP attendees coordinated

through the National Centre in HIV Epidemiology and Clinical Research. The Collaboration of Australian Needle and Syringe Exchanges includes IDU advocacy groups (the Australian IV League), research centres, and organisations providing NSP.

The Commonwealth AIDS Research Grants Program has been the major source of funding. It funds the National Centre in HIV Epidemiology and Clinical Research and, in conjunction with the National Drug Strategy, has funded other specific projects such as the two large national cross-sectional surveys, ANAIDUS and ASHIDU.

Most research articles made explicit statements of support in favour of NSP. Many made no specific statements either for or against any aspect of NSP, however, some of these articles were co-authored by researchers who are strong advocates of NSP in other articles. No research article questioned the effectiveness of NSP or made any critical comments about its possible negative side effects. Where criticisms were made, they were aimed at improving the distribution and responsiveness of the program to the needs of particular groups of IDU.

## 6. *Beliefs and values underpinning NSP*

TABLE A15: BELIEFS AND VALUES RELATING TO NSP IN THE COMMUNITY

Deep (Normative) Core. Fundamental normative and ontological axioms	Near (Policy) Core Fundamental policy positions concerning the basic strategies for achieving normative axioms of deep core	Secondary Aspects Instrumental decisions and information searches necessary to implement policy core
<p>Health promotion beliefs*</p> <ol style="list-style-type: none"> <li>1. Advocate for political, social, economic, cultural, environmental, and behaviour conditions favourable to health.</li> <li>2. Enable people to realise their health potential by taking control of those things which determine their health.</li> <li>3. Mediate between differing interests in society for the pursuit of health.</li> <li>4. Build healthy public policy including legislation</li> <li>5. Create supportive environments.</li> <li>6. Strengthen community action through empowerment.</li> <li>7. Develop personal skills health</li> <li>8. Reorient health services to health promotion.</li> </ol>	<p>Causal Beliefs</p> <ol style="list-style-type: none"> <li>1. HIV transmission can be prevented by the use of clean injecting equipment and an epidemic of HIV among IDUs can be prevented by organised NSP.</li> <li>2. Prevention of an epidemic among injecting drug users will prevent further transmission to 'the general population'.</li> </ol> <p>Harm minimisation beliefs</p> <ol style="list-style-type: none"> <li>1. Prevention of the spread of HIV and drug related harm is of prior importance to prevention of drug use per se.</li> <li>2. It is not drug use per se that is problematic but the harm that is caused by some ways of using drugs.</li> <li>3. Injecting drug users are willing and able to make decisions that protect their own health and the</li> </ol>	<ol style="list-style-type: none"> <li>1. NSP should be provided through a variety of outlets: pharmacies, stand-alone services,</li> <li>2. Paraphernalia should be available at low cost or no cost.</li> <li>3. NSP should be linked with other types of services for drug users eg methadone maintenance.</li> </ol>

<b>Deep (Normative) Core.</b> Fundamental normative and ontological axioms	<b>Near (Policy) Core</b> Fundamental policy positions concerning the basic strategies for achieving normative axioms of deep core	<b>Secondary Aspects</b> Instrumental decisions and information searches necessary to implement policy core
	health of others if given the opportunity.	

\* Source *Ottawa Charter (WHO 1986)*

## Appendixes to Chapter 7

### 1. *Notes on method*

Documentary data collection began with the sections of the National HIV/AIDS policy documents dealing with prisons. However, the primary source documents for identifying the most important policy actors and central points of debate were the report on the National Conference HIV/AIDS and Prisons (Norberry, Gaughwin et al. 1991), and the two Drugs in Prisons conferences (Ellem 1996; Ellem 1998). The former was particularly important for identifying the research that was central to policy arguments and the researchers involved. I also conducted a search of electronic databases for publications on prisons (corrections) and HIV/AIDS, hepatitis C, blood borne viruses, injecting drug use, and needle and syringe exchange. These included Medline, and a number of on-line databases such as the Australian Public Affairs Information Service (APAIS), CINCH (criminology), Media\_Scan, AMI (Australian Medical Index), AFPD (policing), AGIS (policing), OVID. This identified 18 original research articles or reports. The search also found reference to the conference proceedings referred to above. The Alcohol and Other Drugs Council of Australia (ADCA) library was an invaluable source of documentary material including the Drugs in Prisons conference proceedings.

The interviews for this case study were conducted at the same time as those for the NSP–Community case study as some of the interviewees were common to both studies. There details as well as the questions asked are set out in the Appendix to Chapter 6.

The continuing sensitivity of the issue of NSP in corrections was apparent in the interview process. One senior corrections official in Victoria firmly closed off a telephone request for interview and directed all correspondence on the matter to Commissioner of Corrections. An academic working in police and corrections management training was reluctant to be interviewed. This kind of reaction did not occur for any other case study.

## 2. NSP in prisons chronology of events

TABLE A16: CHRONOLOGY OF KEY EVENTS ON NSP IN PRISONS

Year	Event
1983	USA: First cases of AIDS among IDU prisoners reported (Wormser, Krupp et al. 1983).
1985	International: Awareness of AIDS cases in prisons leads to serious disruptions in prisons in Belgium, France and Germany (Harding 1987). South Australia: Prison rioting and corrective services staff strikes in response to realisation of HIV positive prisoners in the prison system (Bloor 1991).
1986	Australia: The Prisons Committee of the National Advisory Committee on AIDS (NACAIDS) (Chaired by Professor John Dwyer) issues the first comprehensive policy paper dealing with HIV/AIDS in prisons. Advocates condoms, voluntary testing and segregation (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 42) NSW: April—Prison Methadone Program introduced (HIV and Health Promotion Unit 1996: 51). Queensland: May—HIV testing on prison entry made compulsory (McDonald, Ryan et al. 1999) Switzerland: Condoms first made available in some Swiss prisons (Nelles 1997). NSW: November 1-2—Second National AIDS Conference, Sydney, hears warning of the threat of AIDS transmission in prisons (Thomas 1986a).
1987	International: November—WHO Consultation on Prevention and Control of AIDS in Prisons recommends ‘...the practicality of making sterile needles available is worthy of further study’ and the provision of condoms (World Health Organisation Global Program on AIDS and Crime Prevention and Criminal Justice Branch United Nations Office in Vienna 1990). International: November—Harding publishes report on prison AIDS policies in 17 countries in the Lancet warning of dire consequences of failure to take science and ethics seriously. (Harding 1987). Tasmania: HIV testing on prison entry made compulsory (McDonald, Ryan et al. 1999). South Australia: HIV testing on prison entry made compulsory for prisoners staying longer than seven days (McDonald, Ryan et al. 1999).
1988	Europe: June—Council of Europe invites member states ‘...to allow, in the last resort, clean, one-way syringes and clean needles being made available to intravenous drug abusers in prison.’ Also recommends condoms be made available to prisoners (World Health Organisation Global Program on AIDS and Crime Prevention and Criminal Justice Branch United Nations Office in Vienna 1990).
1989	Australia: March—Commonwealth Department of Community Services and Health commissions AIDS in Australian Prisons—Issues and Policy Options (Fortuin 1992). Australia: Joint meeting of Police and Health Ministers rule out NSP in prisons (Gaughwin, Douglas et al. 1990).
1990	NSW: January—Disinfectants (Milton Tablets™) first distributed in NSW Prisons (Dolan 1994a). Australia: Commonwealth funds the National AIDS in Prisons Information Clearing House (NAIPIC) to create channels of communication and prepare background papers on AIDS and prisons (Fortuin 1992). NSW: July—Prison Officer Geoff Pearce stabbed by prisoner with HIV infected syringe. Dies of AIDS in 1997 (Australian National Council on AIDS and Related Diseases (ANCARD) 1998: 53) NSW: November—HIV testing on prison entry made compulsory. (Yabsley 1991: 121). Becomes voluntary in 1994. Australia: November—National Conference HIV/AIDS and Prisons (Norberry, Gaughwin et al. 1991). NSW: September—All prison officer required to wear an ‘AIDS Pouch’ (HIV and Health Promotion Unit 1996: 73) Australia: HCV test becomes available and Australian blood supply secured against this disease.
1991	NSW: Prisons (Syringe Prohibition) Amendment Act passed providing for increased penalties for the introduction or supply of syringes in prisons—two years imprisonment with the onus on the defendant to prove the supply was lawful (Chappell and Norberry 1992: 23) Australia: All states and territories agree to national monitoring system for HIV among prison entrants (McDonald, Ryan et al. 1999: 18)
1992	NSW: October—Liquid bleach introduced into NSW prisons to replace Milton Tablets™ due to the problem of prisoners using the tablets to render urine drug tests ineffective (HIV and Health Promotion Unit 1996: 53, 69) Australia: Second National Corrections Health Conference, Sydney (White 1998) Switzerland: Dr Franz Probst introduces syringe distribution within the medical service of Oberschongrun prison (Nelles 1997)

Year	Event
1993	Europe: October—Council of Europe recommends 'equivalence' in HIV prevention measures available to prisons and non-prisoners, and access to the means to adhere to 'rules of hygiene'. Specifically recommends condoms and bleach but not NSP. (Council of Europe Committee of Ministers 1995)
1994	Switzerland: Automatic needle and syringe distribution commences in Hindlebank women's prison (Nelles 1997) NSW: May—'Exit Kits' containing one condom and lubricant made available to prisoners on leaving prison (HIV and Health Promotion Unit 1996: 116) Australia: 6 June—Report of first documented transmission of HIV in prison appears in Medical Journal of Australia (Dolan, Hall et al. 1994b). Australia: NH&MRC Report on Hepatitis C recommends 'extension and amplification' of NSP in recognition of 'extreme prevalence and incidence of HCV' among IDUs. But no mention of prisons (NH&MRC/AHMAC Task Force on Hepatitis C 1994: 33). NSW: December—Voluntary HIV testing replaces compulsory HIV testing of prison entrants (HIV and Health Promotion Unit 1996: 74)
1995	Australia: February 6— Federal Health Minister, Carmen Lawrence, and President of the Australian Medical Association, Brendan Nelson, argue that NSP should be provided in prisons. (Dolan, Wodak et al. 1995) NSW: Labour Party makes pre-election commitment to trial of condoms in prisons (HIV and Health Promotion Unit 1996: 147) NSW: July—Minister for Corrective Services announces commencement of negotiations with unions and Corrections Health Service on condoms in prisons trial (HIV and Health Promotion Unit 1996: 147) Australia: November—Evaluation of Second Strategy, the Feachem Report, recommends extending NSP to prisons. New Zealand: Initiation of New Zealand Drugs in Prison Strategy (Coyle 1998). United Kingdom: Publication of first conclusive study showing significant HIV transmission in a Scottish prison (Dolan 1997: 8) Switzerland: Trial of prescription heroin commences in Oberschongrun prison (Nelles, Bernasconi et al. 1997).
1996	NSW: March—Department of Corrective Services commences 6 month condom availability trial in three prisons with 'little support' from custodial and nursing unions (HIV and Health Promotion Unit 1996: 50, 133). Australia: August—First Drugs in Prisons: Towards a National Strategy Conference organised by Victoria Police and Corrections involving all jurisdictions and New Zealand but without consideration of health issues. (Ellem 1998) NSW: November—Supreme Court of NSW takes bedside evidence from Richard Lynott, a prisoner dying of AIDS in Sacred Heart Hospice, in a case against the NSW Government for failing to provide clean needles and condoms in NSW jails. (Selvanera 1996). Queensland: December 1996 Report of the Commission of Inquiry into Drugs in Queensland Custodial Correctional Centres. (Robinson 1998) Switzerland: February—Results of trial Hindelbank prison NSP presented to international harm reduction conference (Nelles, Fuhrer et al. 1998).
1997	South Australia: April—Parliament of SA Social Development Committee recommends the introduction of condoms, bleach, and methadone but rejects NSP in prisons. (Parliament of South Australia Social Development Committee 1997) Switzerland: NSP commences in Realta prison for men (Nelles 1997)
1998	Australia: April—Second Drugs in Prisons: National Strategy Review & Corrections–Health Interface Conference. Police and Corrections officials meet and consider the health 'interface' issues on drugs in prisons. (Ellem 1998) Switzerland: British Medical Journal reports results of trial Hindelbank prison NSP (Nelles, Fuhrer et al. 1998). Australia: British Medical Journal reports much higher incidence of HCV among IDUs with history of imprisonment compared to those without (van Beek, Dwyer et al. 1998).
1999	Australia: July—Medical Journal of Australia reports a study demonstrating 4 cases of HIV transmission in the prison system of one state (Dolan and Wodak 1999a)
2000	Australia: The Fourth Strategy argues for equal access to prevention initiative as are available to those in the wider population. (Commonwealth Department of Health and Aged Care 2000: 19)

### 3. Research relating to NSP in prisons

TABLE A17: RESEARCH RELATING TO NSP IN PRISONS

Authors	Citation	Findings	Position on NSP in Prisons
R Douglas, M Gaughwin, R Ali, L Davies, A Mylvaganam, C Liew*	(Douglas, Gaughwin et al. 1989). Risk of transmission of the HIV in the prison setting	Rates of IDU, needle sharing, history of IDU, and homosexual activity demonstrate '... that the potential for rapid spread of HIV exists'	No stated position on NSP. Argues for 'action' while the window of opportunity exists.
M Gaughwin, R Douglas, L Davies, A Mylvaganam, C Liew*, R Ali	(Gaughwin, Douglas et al. 1990). Preventing HIV infection among prisoners: prisoners' and prison officers' knowledge of HIV and their attitudes to options for prevention	Reports 79% of prisoners and 99% of prison officers said info about AIDS had not changed injecting behaviour but 93 and 78% thought the availability of clean needles would.	Recommends bleach, condoms, methadone and testing. Does not recommend NSP because joint meeting of Police and Health Ministers had ruled it out in 1989.
M Gaughwin, R Douglas, C Liew*, L Davies, A Mylvaganam, H Treffke, J Edwards, R Ali	(Gaughwin, Douglas et al. 1991). HIV prevalence and risk behaviours for its transmission in South Australian prisons. Funded by CARG, SA DASC, and the Uni of Adelaide	42% of prisoners in 1989 engaged in risk behaviours while in prison. 60% of ex-prisoners injected once a month or less frequently. Transmission is not likely to be frequent.	No stated position on NSP. Recommends prisoners be given the means to inject safely
K Dolan	(Dolan 1991). HIV in British Prisons: Problems, Risk Behaviours and Prevention	Many drug injectors spend time in prison, and inject when in prison. Between 23 and 30 per cent injected when last in prison. Between 61 per cent to 75 per cent shared needles.	No stated position on NSP. Recommends trial availability of bleach and then of condoms.
Alex Wodak J M Shaw M D Gaughwin M Ross M Miller J Gold	(Wodak, Shaw et al. 1991). Behind Bars: HIV Risk-Taking Behaviour of Sydney Male Drug Injectors While in Prison. ANAIDUS study.	Reports a 'disturbingly high' level of HIV risk behaviours while among 209 IDUs who had been in prison (out of a survey of over 900 IDUs)	Recommends trial of NSP among other interventions.
Kate Dolan Wayne Hall Alex Wodak	(Dolan, Hall et al. 1994c). Bleach Availability and Risk Behaviours in Prison in NSW	Despite a policy of bleach availability in NSW prisons only 30 per cent of prisoners report access as 'easy'.	No stated position on NSP. Recommends more research on the effectiveness of syringe decontamination methods.
Kate Dolan Wayne Hall Alex Wodak Matt Gaughwin	(Dolan, Hall et al. 1994b). Evidence of HIV transmission in an Australian prison	Reports first documented case of HIV transmitted in prison despite difficulties in documentation.	Recommends trial NSP among other prevention efforts.
Richard Seamark Matt Gaughwin	(Seamark and Gaughwin 1994) Jabs in the dark: injecting equipment found in prisons, and the risks of viral transmission	Reports on the state of 58 syringes found in SA prisons in one year: 58% used repeatedly; 24% showing traces of blood.	Recommends NSP



Authors	Citation	Findings	Position on NSP in Prisons
N Crofts T Stewart P Hearn*	(Crofts, Stewart et al. 1995). Spread of blood borne viruses among prison entrants	39% prison entrants HCV positive, 33% HBV positive, and 64% of those with history of IDU HCV positive.	No stated position on NSP.  Recommends sentencing reform, preventive measures
Kate Dolan Scott Rutter Alexander Wodak Wayne Hall Lisa Maher David Dixon	(Dolan, Rutter et al. 1996b). Is a syringe exchange feasible in a prison setting	Reports on focus group discussions among stakeholders on NSP—prison officers refuse to participate.	Recommends further discussion of NSP in prison and pilot studies under the auspices of a NSW Parliamentary working group
Kate Dolan James Shearer Wayne Hall Alex Wodak	(Dolan, Shearer et al. 1996a). Bleach is easier to obtain but inmates are still at risk of infection in New South Wales Prisons.	Reports that bleach is easier to obtain, that there are growing numbers of reports of HIV transmission in corrections, and IDU is the source of greatest risk.	Recommends trial of NSP within prisons.
N Crofts W Thompson E Wale F Hernberger	(Crofts, Thompson et al. 1996). Risk behaviours for blood-borne viruses in a Victorian prison	Study of 51 prisoners shows half injected in prison at 5.5 times per month. 90% HCV positive, most shared unclean equipment	Recommends NSP and enhanced methadone and provision of sterile tattooing equipment.
Tony G Butler Kate A Dolan Mark J Ferson* Linda M McGuinness Phillip R Brown Peter W Robertson	(Butler, Dolan et al. 1997). Hepatitis B and C in New South Wales prisons: prevalence and risk factors	About one third of prison entrants are HBV positive, one third HCV positive and one third positive to both. For those with a history of IDU, over 60 per cent are HCV positive.	Recommends NSP and other prevention and education measures.
Kate Dolan Alex Wodak Wayne Hall	(Dolan, Wodak et al. 1998). A bleach program for inmates in NSW: an HIV prevention strategy.	102 out of 226 prisoners approached prior to release participated in a survey. 58% reported ever injecting, 48% reported sharing in prison and %46% reported syringe cleaning in prison.	No stated position on NSP  Recommends that other prevention strategies should be tried because of prisoners difficulties getting bleach and because of its possible ineffectiveness re HCV & HBV.
Kate Dolan Alex Wodak Wayne Hall Edward Kaplan	(Dolan, Wodak et al. 1998). A mathematical model of HIV transmission in NSW prisons.	Found upper and lower estimates of increases in HIV prevalence among NSW prison inmates of 0.8 and 6.7% over a 180 week period.	Recommends NSP among other prevention measures.
PS Haber SJ Parsons* SE Harper*	(Haber, Parsons et al. 1999). Transmission of hepatitis C within Australian prisons	Reports 4 cases of prison acquired HCV. Identifies routes of transmission as sharing IDU equipment, fights, and barbers shears.	No stated position on NSP.  Lack of NSP in prison noted. Recommends further research followed by control measures.
Kate Dolan Alex Wodak	(Dolan and Wodak 1999a). HIV transmission in a prison system in an Australian state	Reports 4 confirmed cases of HIV transmission in prison and 7 that may have occurred in prison	Recommends that NSP be considered for prisoners along with methadone maintenance treatment

Authors	Citation	Findings	Position on NSP in Prisons
Ann McDonald J Ryan*, P Brown, C Manners*, A Falconer*, R Kinnear*, W Harvey*, P Hearne*, M Banaszczyk*, J Kaldor	(McDonald, Ryan et al. 1999). HIV prevalence at reception into Australian prisons, 1991-1997	Reports 72% of prison entrants tested for HIV between 1991-7. HIV prevalence was 0.2%. 64% of these had been diagnosed on previous entry	No stated position on NSP  Part of suite of articles in MJA. Levy does editorial and advocates NSP
Jeffrey Post Kate Dolan L Ross Whybin Ian Carter Paul Haber Andrew Lloyd	(Post, Dolan et al. 2001). Acute hepatitis C virus infection in an Australian prison inmate: tattooing as a possible transmission route	As per title of paper but with the qualification that IDU cannot be ruled out as a source of transmission	No position on NSP stated  Recommends large prospective trial using controls to establish link between tattooing and HCV.

\* Denotes Correctional Health Services employee.

The research has been funded from health sources: the Commonwealth AIDS Research Grants (CARG), State Health Departments, the National Health and Medical Research Council, and the National Drug Strategy. Correctional authorities are sometimes acknowledged for their cooperation with the research. There is little or no published research by correctional authorities. A number of informants argued that the primary reason why corrections administrations do not conduct research on communicable disease transmission is that they would find out information that they did not want to know. It was argued by some that the shift from mandatory to voluntary testing in several jurisdictions was motivated by the desire of correctional authorities to reduce the possibility that prisoners could take legal action against the Crown. Some argued that while this cynical motive may not have been the driving force, the effect could not be denied.

### **1990 HIV/AIDS and Prisons Conference presenters**

Analysis of participants and speakers at the 1990 HIV/AIDS and Prisons Conference and their stand on NSP in prisons.

**TABLE A18: HIV/AIDS IN PRISONS CONFERENCE, 1990, SPEAKERS, ROLES AND POSITION ON HIV PREVENTION MEASURES**

Speaker	Role	Bleach	NSP ☀	Condoms
Michael Kirby	WHO Global AIDS Commission	Yes	Yes	Yes
Robert Douglas	Director National Centre for Epidemiology and Population Health (NCEPH)	Yes	Yes	Yes
Kate Dolan	Research Fellow Centre for Research on Drugs and Health Behaviour London	Yes	Yes	Yes

Speaker	Role	Bleach	NSP ☀	Condoms
Sandra Egger David Heilpern	Senior Lecturer, NSW Uni Law School Chairman, Commercial Tribunal of NSW	Neutral ‡	Neutral	Neutral
Judi Fortuin	Liaison Officer, National AIDS in Prisons Clearing House.	Neutral	Neutral	Neutral
Matt Gaughwin	Visiting Fellow NCEPH	Yes	Yes	Yes
John Dwyer	Director, Prince Henry Hospital Research and Treatment Centre for AIDS	Yes	No	Yes
Stephen Kerr	Manager, Corrections Health Service, Health Department, Victoria.	Yes	No	- ♣
Michael Yabsley*	Minister for Corrective Services, NSW	-	No	No
Peter Harmsworth	Director-General, Office of Corrections, Victoria	Yes	-	No
Ann Bloor	Coordinator, Health and Welfare Services, SA Dept of Correctional Services.	-	-	-
Christopher Liew	Director, Prison medical Service, South Australia	-	-	-
Paul Hamilton	Program Coordinator 'K' Division, Pentridge Prison	-	-	-
John Doyle	Prison Officers Union representative. Prison AIDS Project, Dept Corrective Services	-	-	-
John Godwin	Solicitor, AIDS Council of NSW Legal Working Group	Yes	Yes	Yes
Beverley Schurr	Solicitor, Secretary, Australian Council for Civil Liberties	-	-	-
Kim Mannion†	AIDS Coordinator, Department of Corrective Services, NSW	Yes	-	-
Ollie Behrens-Peters	Prison Health Project Officer, Dept Correctional Services, South Australia	-	-	-
Eileen Adamson	Senior Lecturer, AIDS Training, Corrective Services Academy	-	-	-
Helen Close	Principle, Helen Close Research, WA	-	-	-
Clive Begg	Executive Director, The Prisoner & Family Support Association, Queensland	Yes	-	Yes
Alex Wodak	Director, Alcohol and Drug Service, St Vincent's Hospital, Darlinghurst, NSW.	Yes	Yes	Yes
Frank McLeod	Director, NSW Prison Medical Service	Yes	-	Yes
Lisa Ward Gerard Jones	Manager HIV/AIDS and HBV Unit Special program Advisor CSV Victoria	Yes Δ	Yes Δ	Yes Δ
Tracie Walsh	AIDS Education Officer, Sydney West AIDS Education Unit, NSW	-	-	Yes ζ
§ Tony Clunies-Ross	Regional Manager, Office of Corrections (Community Based) Victoria	-	-	-
Stanley Nangala	Chairperson, Communicable Diseases Advisory Committee, ATSIC.	Yes	Yes	Yes

☀ 'NSP' refers to any form of needle exchange. Some writers offer support for 'strict' one-for-one exchange. Others argue for a well-controlled 'pilot' research project of strict one-for-one exchange.

‡ 'Neutral' means that the writer canvassed the issues for and against these interventions but did not indicate a preferred position.

♣ A dash '-' indicates the writer neither canvassed the issue nor offered a position.

\*While Yabsley did not comment on the bleach issue, the NSW Government policy at the time was not to make bleach available. It was, however, under pressure to do so. For example, Michael Kirby said in his opening address to the conference that it should be available and referred to a *Sydney Morning Herald* Editorial which supported that view on the basis of public statements made by Alex Wodak (Kirby 1991: 19).

† Mannion said her views were her own and not those of the Department.

Δ Ward and Jones are writing with respect to juvenile corrections in Victoria. While none of these interventions are provided within the facilities, condoms were at the time provided in advance of weekend releases and information about NSPs in the community was also provided. The authors make strong statements in support of self-directed harm reduction.

ς Walsh works in women’s prisons and reports that dental dams are available to women as a protection against HIV.

§ Clunies-Ross said that bleach was available in Community Based Corrections and information on safe sex provided.

#### 4. **Beliefs and values in the policy subsystem**

The following tables characterise and juxtapose the beliefs and values of those who are advocates of NSP in prisons and those opposed to NSP in prisons. These are derived from statements made in the papers of the conferences referred to above, from literature published in medical journals and from interviews with key informants.

**TABLE A19: BELIEFS AND VALUES OF NSP IN PRISONS ADVOCATES**

<b>Deep (Normative) Core.</b> <b>Fundamental normative and ontological axioms</b>	<b>Near (Policy) Core</b> <b>Fundamental policy positions concerning the basic strategies for achieving normative axioms of deep core.</b>	<b>Secondary Aspects</b> <b>Instrumental decisions necessary to implement policy core.</b>
<p>Public Health Beliefs                      1. Pro-NSP in prison advocates from the health sector share the Health Promotion* Beliefs as set out in the NSP Case Study including: their belief in their duty to: advocate for social, political and environmental conditions conducive to health; enabling people to realise their health potential by taking control of those things which determine their health; building healthy public policy including legislation; empowerment; and developing personal skills.</p> <p><b>Human Rights Beliefs</b>                      1. The rights of prisoners to health and safety in gaol are no less important than those of prison officers. (Kirby 1991)                      2. Prisoners are incarcerated as punishment, not for punishment (Kirby 1991; Puplick 1998).                      3. Promotion of human rights is integral to the achievement of public health goals (Moodie, Timberlake et al. 1996: 31).</p>	<p>Causal Beliefs                      1. HIV transmission can be prevented by the use of clean injecting equipment and an epidemic of HIV among IDUs can be prevented by organised NSP.                      2. Prevention of HIV transmission in prison will prevent further HIV transmission to those outside prison.</p> <p><b>Harm minimisation beliefs</b>                      1. Prevention of the spread of HIV and drug related harm is of prior importance to prevention of drug use per se.                      2. It is not drug use per se that is problematic but the harm that is caused by some ways of using drugs.                      3. Injecting drug users are willing and able to make decisions that protect their own health and the health of others if given the opportunity.</p> <p>Principle of equivalence                      1. Prisoners should have access to the same services at the same standard as those outside prison. (Crofts 1997) (Moodie, Timberlake</p>	<p>1. NSP should be provided as part of a package of harm minimisation and drug treatment services in prisons.                      2. Evidence from pilot projects in European countries show that NSPs can be run in prisons without adverse consequences for the safety of officers or other prisoners.</p>

<b>Deep (Normative) Core.</b> <b>Fundamental normative and ontological axioms</b>	<b>Near (Policy) Core</b> <b>Fundamental policy positions concerning the basic strategies for achieving normative axioms of deep core.</b>	<b>Secondary Aspects</b> <b>Instrumental decisions necessary to implement policy core.</b>
	et al. 1996: 26).	

\* Source *Ottawa Charter (WHO 1986)*

**TABLE A20: BELIEFS AND VALUES OF THE DOMINANT ADVOCACY COALITION IN PRISONS**

<b>Deep (Normative) Core.</b> <b>Fundamental normative and ontological axioms</b>	<b>Near (Policy) Core</b> <b>Fundamental policy positions concerning the basic strategies for achieving normative axioms of deep core.</b>	<b>Secondary Aspects</b> <b>Instrumental decisions and information searches necessary to implement policy core.</b>
<p>Public Health Beliefs                      1. Public health goals are secondary to prison goals of security and maintenance of law and order.</p> <p>Human Rights Beliefs                      1. Prisoners are dangerous and cannot be trusted.                      2. Any rights that prisoners might possess are secondary to the rights of prison officers.                      3. Prisoners needs are secondary to those of prison officers and the efficient running of the institution in terms of ensuring security.</p>	<p>Causal Beliefs                      1. HIV transmission can be prevented by preventing drug use within prisons.                      2. NSP in prisons will endanger the lives and wellbeing of prison officers, staff and other prisoners.                      3. NSP in prisons will encourage drug use within prisons and foster the behaviours and addictions that lead to incarceration in the first place thereby increasing rather than solving the problem                      'Harm minimisation' beliefs                      1. Harm minimisation is best achieved by enforcing a 'no drugs' policy first. To accept that drug taking takes place undermines officer commitment to policing drugs and sends the wrong messages to prisoners.                      Principle of equivalence                      1. Can only apply in a small number of specific situations. Each service needs to be evaluated in terms of other matters affecting prison operations such as cost and security.</p>	<p>1. Drug treatment such as methadone is a sign of weakness.                      2. Corrections models from Europe are completely irrelevant to the Australia situation where prison culture and prisoners are different.</p>

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