An Australian
Integrated Health Record
and
Information System
(IHRIS)

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February 2000

A thesis submitted for the degree of Doctor of Philosophy of
The Australian National University
This thesis is original work. Unless otherwise stated the research is my own.

Christopher Mount
I dedicate this thesis to my wife Kirsty. Without her love and support I would have neither undertaken this adventure nor managed to reach the end. I look forward with anticipation to our further adventures.

It is also dedicated to my children James, Marni, Rebecca and Alison. Without their help it might have been finished earlier but I would not have had as much fun along the way.

"Science is built up with facts as a house with stones. But a collection of facts is no more science than a heap of stones a house."

Jules Henri Poincare 1908

I hope the reader finds in this work something more than a heap of stones.
Acknowledgments

There are many people to whom I would like to offer my thanks and acknowledge their contributions towards the completion of this thesis.

Professor Bob Douglas encouraged me to begin this work and provided continual support throughout the project. Dr Ross Bailie was my first supervisor and saw the project through to completion even after moving to Darwin. Dr Len Smith provided endless ideas and time to talk through countless problems. Professor Tony Adams stepped into the role of chair after Dr Bailie’s departure and provided the necessary management of the supervisory process. Nigel Mercer offered excellent advice at many times throughout the project and constantly challenged my ideas. All of them provided prompt, thoughtful and detailed comment on my written work, a gift of immeasurable value.

The people I interviewed and the participants of the “Health on Line” discussion forums willingly gave their time and expertise, without them there would have been no project. Virginia Riddle successfully transcribed the recordings of the interviewees and forums even though the sound quality was at times appalling. The members of the UPI electronic discussion list provided important information that I would not have been able to get elsewhere.

The NCEPH student’s writing group gave excellent critical comment on many elements of this thesis and it was a delightful forum for learning many important skills.

I cannot fail to express my joy at having shared my workplace with the other members of Club Jelly. The support and encouragement they gave me was essential. The fun and games made my life as a student a great pleasure and far outweighed any concerns over time lost to more scholarly pursuits.

I would like to thank my father, Tony Mount, for his tireless interest and copy editing.

The interviews were funded from a seeding grant (GPEP 560) provided through the General Practice Evaluation Program.

There are many other people who have provided advice and information during my study. I thank them all.
Abstract

Health records have evolved to serve the needs of individual clinicians. As a consequence an individual’s clinical data is fragmented. In 1907 the institution-based unit record was first introduced and is now found in most healthcare institutions. The natural extension of the institution-based unit record is an Integrated Health Record (IHR) which could make available the data captured by all the institutions from which an individual received care.

The quality assurance movement in health has lead to an awareness by policy-makers, planners, researchers and others of the value of the data currently held by clinicians. Existing fragmentation and inaccessibility of these data prevent their effective use.

While an individual’s Integrated Health Record could support personal and clinical decision-making for that person, an Integrated Health Record and Information System (IHRIS) built from a collection of IHR’s could support decision-making by policy-makers, planners and managers as well as researchers.

Canada, England and New Zealand are all developing national health information systems based on some form of integrated record. Whether Australia should build a national IHRIS is not a simple question to answer. However, it is possible to examine whether a national IHRIS is a realistic alternative to the present arrangements. This study sought to demonstrate that a national IHRIS is a feasible alternative to present health records and associated information systems by answering the questions “Could an Australian IHRIS satisfy significantly more of the information needs of the Australian healthcare system than present health records and associated information systems?” and “Could Australia build a national IHRIS?”

In order to answer these questions data were gathered through two discussion forums and a series of key informant interviews and the published literature. A model and implementation strategy for an Australian IHRIS was developed using the Structured Analysis method. This model was used to test whether a national IHRIS could satisfy many of the unmet needs of the Australian healthcare system.

The investigation demonstrated conclusively that a national IHRIS would be a significant improvement on present arrangements. The arguments presented and the models developed will assist debate of an issue of national importance.
Glossary of common terms, acronyms and key documents

**Australian Health Ministers Council** This council includes the eight state and territory health ministers and the federal minister’s for health and aged care. It meets biannually.

**AIHW** Australian Institute of Health and Welfare. This federal government agency is responsible for producing national statistics on health and welfare. They also provide the secretariat for the NHIMG.

"**Computer-based Patient Records: an essential technology for healthcare**" This report was released in July 1991 by the US Institute of Medicine’s Committee on Improving the Patient Record. The committee started work in September 1989. Over 200 people contributed to the findings of the committee. A second edition of the report was released in 1997.

**CPRI** Computer-based Patient Records Institute. This organisation, formed as a result of the 1991 Institute of Medicine report, is a non-profit membership organisation committed to advancing improvements in health care quality, cost, and access through routine use of information technology.

**Divisions of General Practice** These are voluntary associations of general practitioners in approximately 120 geographical regions which together cover the whole country. Nearly all are funded by grants from the Federal government. They represent GP’s in the organisation of health care services within the region.

**GPCG** The General Practice Computer Group was established by the Australian Medical Association, the RACGP and the Federal Department of Health to oversee the systematic introduction of information technology in the General Practice community.

**HIC** Health Insurance Commission. This federal government agency is responsible for administering the national medical insurance scheme and pharmaceutical benefits scheme.

"**Health Online: an action plan for health information management in Australia**" This document was released in 1999. It outlined a vision for Australian health information management for the subsequent five to ten years. This
document was developed by NHIMAC and approved for public release by the Australian Health Ministers Council.

"Health on Line" This 1997 document reported the findings of the House of Representatives Standing Committee on Family and Community Affairs’ inquiry into health information management and telemedicine. The inquiry took 17 months and received 130 submissions and included 11 public hearings. The key recommendation of the committee was for a national data management system.

**NHDC** The National Health Data Committee reports to the NHIMG and is responsible for the development of national health data definitions.

**NHDD** The National Health Data Dictionary contains all national health data definitions developed through the National Health Data Committee. It has been updated annually since 1991.

**NDSS** The National Diabetes Supply Scheme subsidises the supply of ancillary equipment such as syringes and blood testing products to people with insulin treated Diabetes Mellitus.

**NHIA** National Health Information Agreement. This agreement, signed by the eight states and territories, the federal government, the AIHW and the Australian Bureau of Statistics came into effect in 1993.

**NHIM** The National Health Information Model is a high-level framework for information management and development developed by the AIHW. The first version was released in 1995

**NHIMG** National Health Information Management Group. This group manages the National Health Information Agreement. This group has responsibility for the management of the National Health Information Work Plan.

**NHIMAC** National Health Information Management Advisory Committee. The Australian Health Ministers formed this committee in 1998. Its role is as an expert body advising ministers on the most effective and efficient use of information technologies.

**NCEPH** National Centre for Epidemiology and Population Health

**RACGP** The Royal Australian College of General Practitioners
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Chapter 1 Introduction

This thesis seeks to establish that a national integrated health record and information system, or IHRIS, is a feasible alternative to existing health records and associated information systems. To achieve that the study has answered two questions. First "Could an Australian IHRIS satisfy significantly more of the information needs of the Australian healthcare system than present health records and associated information systems?" and second "Could Australia build a national IHRIS?"

The term ‘integrated health record’ is used in this text to describe any record that is a reasonably complete history of an individual’s health. The word ‘integrated’ was chosen to differentiate such records from present health records, which are generally fragmented and scattered.

This chapter explores the quality of care provided by the Australian healthcare system, looks at the history and theory of the quality assurance movement in health and then indicates where this thesis seeks to contribute new knowledge towards the task of improving the quality of care. Chapters two and three look at health records in general and then their state in Australia in particular. Chapters four and five report the investigations undertaken, while chapters six and seven cover the modeling and analysis undertaken based on the investigations and review of the literature. Chapter eight draws the work together and provides some recommendations for future work.

1.1. The Quality of Australian Healthcare

An Australian girl born in 1996 had a life expectancy of 81.1 years, while her male counterpart could expect to live to 75.4 years. This places Australian’s near the top of international comparisons of longevity\textsuperscript{31}. Australia has a burden of disease lower than most countries in the world\textsuperscript{151,166}. Australians spent 8.5% of their gross domestic product on healthcare services and products in 1996/97\textsuperscript{31,p164}. This puts Australia in the middle of similarly developed nations\textsuperscript{32,p126}. With long life expectancy, low morbidity and moderate expenditure Australia appears to be performing well. however, there are a number of signs that the Australian healthcare system is not delivering the quality of care that could be achieved.

An important recent study was the Quality in Australian Health Care Study (QAHCS)\textsuperscript{232}. Wilson and his colleagues reviewed 14,179 medical records considered
representative of Australian hospital care. Their primary findings were that 16.6% of admissions were associated with an adverse event, that is an injury caused by healthcare. Importantly 51% of the adverse events were considered to be ‘highly preventable’. Wilson et al estimated that 18,000 people died as a result of their healthcare in Australia in 1992. Nearly 70% of these deaths were considered to be ‘highly preventable’.

Outside the hospital sector the signs are less definite but still indicative. A study of medication management among Australia’s military veteran community by Parkes and Coper found that 7.8% were prescribed potentially harmful combinations of drugs, 50.6% were prescribed drugs relatively contraindicated in the elderly and 20% were prescribed 10 or more drugs with potential risks from polypharmacy\textsuperscript{182}. An investigation of incidents of potential or actual harm in general practice received reports of 805 incidents from 324 GP’s over a 21 month period. Seventy six percent of these were considered preventable\textsuperscript{42}. The cost of injuries caused by surgical and medical misadventure and adverse reactions to therapeutic drugs in Australia was estimated to be A$401m in 1993/4\textsuperscript{29}. This was the second highest cost of injury behind accidental falls at A$806m and was ahead of road accidents at A$370m.

These observations focus on the contribution of errors and less than optimum practice to the quality of care. Perhaps more important for the future quality of care is the ability to support continual improvement through measurement and feedback.

In 1998 the National Expert Advisory Group on Safety and Quality in Australian Health Care which arose in response to the findings of the QAHCS study considered that:

“... there remain opportunities for continuous quality enhancement and there are some areas of the health system that require improvement.”\textsuperscript{167}

This conclusion serves as a useful starting point for this thesis. However, before continuing it is necessary to discuss the origins and theory of the quality movement in healthcare, in order to locate the findings of this investigation in the broader context. A model is proposed which brings together the different areas of work discussed.

1.2. The Quality Assurance Movement - History and Theory

The quality assurance movement grew from work in manufacturing industries on quality control. The earliest documented work was centred in the Bell Telephone Company in
the 1880’s and early 1900’s\textsuperscript{22, p4}. Quality control emphasis’s the inspection and testing of completed products. In contrast to quality control, quality assurance focuses on the processes leading to the production of goods rather than waiting to inspect the final product. By 1922 the idea of quality assurance had extended to design, manufacture and installation and “Do it right first time” was established as the ‘motto’ for the movement.

The next phase of development in quality assurance occurred in Japan following World War Two. A number of engineers, who had worked in the US before and during the war, took the idea of quality assurance to Japan where they trained both managers and engineers. The success of Japanese manufacturing during the 1960’s and 70’s saw the ideas of quality assurance being exported back to the US, then across the world, beyond the field of manufacturing and into healthcare.

The key feature of quality assurance is the measurement of processes and outcomes. The purpose is to provide the data to improve the systems that produce the manufactured goods or services. This process where lessons learned from current practice are used to improve future practice generates continuous quality improvement.

Concerns over improvement in the quality of care are not new. Florence Nightingale observed in 1863\textsuperscript{173, p176}:

“In attempting to arrive at the truth, I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purposes of comparison. If they could be obtained, they would enable us to decide many other questions ... and, if wisely used, these improved statistics would tell us more of the relative value of particular operations and modes of treatment than we have any means of ascertaining at present. .... and the truth thus ascertained would enable us to save life and suffering”

Her objective was clearly congruent with the ideas of quality assurance and her choice of hospital records as the source of the information she sought is instructive.

While Codman’s work in the early 1900’s on ‘End Results’\textsuperscript{91} is closely aligned with current quality assurance theory, the systematic evaluation of the quality of healthcare did not start until the 1950’s\textsuperscript{89}. It took a major step forward in 1966 when Avedis Donabedian brought together much of the work that had been reported previously and set the shape of quality evaluation that operates today\textsuperscript{89}. He divided the evaluation task into the assessment of structure, process and outcome. He continued to develop and
refine this idea for more than 25 years. He defined structure as the physical and organisational properties of the settings in which care was provided, process as being what is done for the patient and outcome as what was accomplished for the patient. Donabedian considered that outcomes were the "ultimate validation of the effectiveness and quality of medical care". However, in recognising some of the difficulties in measuring outcomes he argued that measures of structure and process were also relevant to evaluating the quality of care. He considered it reasonable to focus on measurements of process in some situations and structure in others, and sometimes it would be necessary to observe all three to examine the interrelationships so that effective action could be taken.

The idea of quality at different levels of aggregation of both consumers and providers was an important extension to his earlier scheme. His 1966 paper concentrated on the direct consumer-provider interaction. His 1974 work considered aggregation of individuals at the family, provider ‘clientele’, ‘target’ population, community and society levels, and provider aggregation at institution, program and system levels. An important result of this extension was the acknowledgment that high quality healthcare at one level could result in less than optimal care at another. So for example successfully implementing an expensive intervention for one person may represent high quality care for that individual but may result in a lower quality of care at the community level if those resources could have been used to support a cheap and wide-reaching intervention with greater overall effect.

The late 1960’s and the 1970’s saw a considerable amount of work on the measurement of outcomes. This development culminated in a three year program based at the Rand Corporation and University of California, funded by the National Centre for Health Services Research of the US Government’s Health Resources Administration. The work of Brook et al sought to develop a framework for the development of outcome measures.

Taking a closely related approach, Archie Cochrane tackled the issue of the efficiency, effectiveness and equity of medical processes. His major aim was to ensure that the limited resources available should be used to provide what had been shown in properly designed evaluations to be effective healthcare. His method was the rigorous application of randomised controlled trials to determine the most effective intervention.
Cochrane's work has been significantly advanced by the Cochrane Collaboration which prepares, maintains and disseminates systematic, up-to-date reviews of all relevant randomised controlled trials of healthcare. These reviews are made available to decision-makers at all levels of healthcare systems.

Goonan and Jordan took Juran's theory incorporating quality improvement, quality planning and quality control and applied it to healthcare. It is noticeable that they adopted the language of manufacturing in describing healthcare as a process which transforms inputs into outputs. These three components, process, inputs and outputs, bear close resemblance to Donabedian's triad of process, structure and outcome respectively. The notable exception being Goonan and Jordan's idea of 'inputs' which focused on consumers with their conditions and distinguishing characteristics whereas Donabedian's idea of 'structure' focused on supplies provided by the health system such as clinician skills and knowledge, staff organisation, equipment and other supplies.

Elson et al also took a manufacturing perspective on healthcare. They treated clinical decision-making as the main production process. The process had 'inputs' in the form of patients, 'supplies' in the form of knowledge and patient data and 'outputs' in the form of decisions. They developed their model based on the 1972 work of Newell and Simon who had proposed a model of how the human mind solved problems. They assumed the mind worked largely like a computer. Given the complexity of the operation of the human mind as revealed more recently by Dennett, Calvin and Damasio this assumption is not realistic. However, Elson et al sidestepped this problem by treating the process of decision-making as a black box, and concentrated on the task of providing the necessary supplies in order to support that process.

There were two types of information supplies that Elson et al considered essential, both subdivided into two forms. The first type was patient data and the second was health knowledge. Both could be available either in the mind of the decision-maker, ie internal, or through external sources such as textbooks and health records. The conclusion to be drawn from the model of Elson et al is that it is the fusion of knowledge with patient data within the mind of the clinician that results in clinical decisions.

A similar view was put forward by Shortliffe when describing the core issues in the field of medical informatics. He identified the need for separate supplies of
biomedical knowledge and biomedical data in inferencing and retrieval systems for use by clinicians. This picture is entirely congruent with that of Elson et al but he introduces the idea of the computer as a possible point of fusion.

Clinical decision-making and its sequela and the task of health system management may be seen as examples of complex systems seeking to achieve ‘goals’. Cybernetics theory, as propounded by Weiner, proposed ‘feedback’ as the means by which systems were able to adjust their actions in seeking to achieve their ‘goals’226. The process of measurement for improvement that is central to quality assurance is a cybernetic mechanism.

Vickers ‘appreciative systems theory’220 saw the cybernetic approach as appropriate in situations where the system was clearly defined and highly structured, or ‘hard’, and had simple ‘goals’. However, cybernetics was too simplistic when dealing with complex ‘soft’ systems with a myriad of sometimes competing ‘goals’ such as a national health system. Vickers proposed a more complex means by which a system adjusted its behaviour in seeking to ‘maintain relationships’, a richer concept than the idea of ‘goal-seeking’. An important difference is that cybernetic ‘goals’ are defined from outside the system whereas the ‘relationships’ to be maintained are determined by the previous history of the system itself. Vickers theory encompasses the simpler cybernetic theory, which is a special case of the more complex theory.

Wirtschafter and Mesel applied cybernetic theory to develop a strategy for redesigning the medical record so that it provided the feedback necessary to achieve explicit healthcare goals233. Wirtschafter and Mesel’s proposed use of health records can be seen as an important example of the process of behavioural adjustment as proposed by Vickers.

The model of quality assurance described in figure 1.1 brings the preceding discussion together into a single picture. It starts with consumers as suggested by Goonan and Jordan116. The other two major inputs to the process are Donabedian’s structural components89 and Elson et al’s information supplies98. Decision-making and implementation is the central process in the model. From this process arise outcomes. Measurement of these outcomes provides the information necessary to achieve future improvements in the quality of care through behavioural adjustment.
The model identifies seven significant components involved in determining the quality of healthcare as well as the consumers themselves. These are consumer data, health knowledge, resources, decision-making, decision implementation, outcomes analysis
and behavioural adjustment. The key inference of this model is that improvement in any of these seven components or interactions between them would be expected to result in better quality healthcare.

Healthcare involves more than clinical decisions; it includes the activities of planners, researchers and policy-makers. The work of Goonan and Jordan, Elson et al, and Shortliffe focussed on clinical decision-making. It is necessary to ask whether health records can assist the work of those parties working at the system level. Wirtschafter and Mesel, saw feedback using health records operating at three levels: the provider, administrator and ‘societal resource allocator’. Similarly the 1991 Institute of Medicine report saw the role of the health record extending from the bedside to the formulation of national healthcare policy. In addition the Australian quality taskforce considered that a patient-centered computerised clinical information system could help managers, and clinicians, avoid preventable injury, disability and death.

It would seem that health records have a role in improving aspects of the healthcare system that impact on the quality of care as well as individual clinical care.

The study described here concentrates on the organisation and utility of consumer data, primarily in the form of health records and associated information systems, both in their direct role in optimising health-related decision-making and in supporting the process of behavioural adjustment necessary to improve clinical practice and system management.

Nightingale, Donabedian, Wirtschafter and Mesel, the Institute of Medicine and the taskforce on quality in Australian healthcare all saw the health record as an important source of information to measure and improve the quality of care. All of them lamented the state of the health records in their respective health systems. Several of them proposed ways of improving the health record to achieve those ends.

The modern health record was born in 1907 when St Mary’s Hospital, in Rochester USA, introduced the institution-based ‘unit record’. St Mary’s hospital realised the benefit of keeping each individual’s information in a single folder following an explosion in the quantity of data produced on each patient, primarily investigation results. This was a revolutionary improvement on the previous practice of recording data on all patents serially in a single bound volume. Unit records are now found in institutions throughout the healthcare system.
The natural extension of the institution-based ‘unit record’ idea is a ‘unit record’ that contained information from all health related events regardless of the institution in which they occurred. Such an integrated health record would greatly assist clinical decision-making. An information system built from integrated health records should be able to support the needs of the many other users of the data they hold.

There are programs of work currently underway by national governments in the United Kingdom, New Zealand, Canada and some large health institutions in the United States of America to establish comprehensive national, or multi institutional, health record systems.

This study looks at whether a national IHRIS would be a more effective way to organise health records than the present arrangements. From the quality assurance theory outlined in this chapter it has been inferred that improving the utility of health records would result in improvements in the quality of care. These gains would arise from better decision-making and improved practice and management through behavioural adjustment.
Chapter 2 Health Records

This chapter explores the history of health records and reviews recent developments. This exploration continues with an examination of the history and effect of ‘personal health records’, the development of ‘computerised health records’ and the concept of ‘integrated health records’. Following this is a description of some activities around the world that will shape future health records and associated information systems. Some of the requirements that future health record systems will need to satisfy are identified. It then turns to consider some important issues on information rights. The chapter concludes with the two questions that the thesis will answer.

2.1. Terminology

Health informatics is a relatively new field with a diverse set of participants. One of the consequences of this is that words are often defined and used differently by different people.

Healthcare involves four major stakeholder roles consumers, providers, managers and researchers. It is necessary to note that at times these individuals form groups, for example families, care teams, healthcare provider organisations and bureaucracies.

Consumers: This role consists of those people who use health services. Professional organisations, voluntary self-help groups and individual carers, friends, family or the individual themselves may provide these services. Others variously name people performing this role as patients, clients, customers, users and people. The first assumes that the people referred to are sick. The next two arise from a service provider centric view. The last two are potentially confusing as they are also used in a number of other contexts. The word ‘consumers’ is used here as the peak representative Australian group, the Consumers’ Health Forum has chosen it.

Providers: This role consists of those people directly involved in the provision of healthcare services. This role includes doctors, nurses, allied health professionals, self-help group members, carers and the individual when looking after themselves. Others, to describe healthcare organisations such as hospitals sometimes use the word ‘provider’. This text maintains a clear distinction between the two entities and describes the latter as ‘provider organisations’. The word ‘clinician’ was considered for this role but it has a strong association with professional healthcare services and can be seen to
exclude voluntary healthcare providers. Where this distinction is relevant the word ‘clinician’ is used.

Managers: This role consists of those people who organise the provision of healthcare services. This group includes institutional administrators, planners, policy-makers, bureaucrats, funders and politicians.

Researchers: This role includes all people who seek to generate new knowledge. This word is sometimes used to describe the more limited set of institution-based academic researchers. All forms of research including; clinical, healthcare service, commercial, administrative and personal are included under this role.

During the discussion on health records in this chapter a number of terms of the form ‘xxxx health records’ are used. The relationship between these terms is shown diagrammatically in figure 2.1 below. The examples given are offered as a guide, citations for each are provided in the text. The following definitions have been used to distinguish these different types of health records.

Paper-based Health Records: Health records that are captured, stored and distributed primarily using paper means. (Areas A, B, C & D)

Computerised Health Records: Health records that are captured, stored and distributed primarily using electronic means. (Areas E, F, G & H)

Personal Health Records: Health records over which the consumer has a measure of control. (Areas B, C, E & F in Figure 2.1)

Integrated Health Records: Health records that contain the complete health information about an individual. (Areas C, D, F & G) The complete nature of such a record does not mean that all of the information is always present but that it can be accessed readily if desired and appropriate.

Electronic Health Records: Computerised health records that contain complete health information about an individual. (Areas F & G)
Figure 2.1. Classification schema for Health Records

All Health Records

Consumer Control

Electronic

Paper-based

Complete

A: Most General Practice and hospital systems
B: Childhood development record\textsuperscript{47} books, Maternity records\textsuperscript{96}
C: Shenkin and Warner proposal\textsuperscript{200}
D: Older NHS GP records\textsuperscript{*}. The Mayo Clinic (pre 1995) \textsuperscript{141}
E: Health Key Trial\textsuperscript{155}, other ‘Smart Card’ systems
F: House of Representatives recommendation\textsuperscript{127}, para 4.27
G: Kaiser Permanente\textsuperscript{45} and other US HMO’s, the new British NHS proposal\textsuperscript{171}, **
H: Some General Practice and hospital systems

* British General Practitioners are becoming increasingly computerised

** It is not yet clear what level of control consumers will have in the proposed NHS system. The initial information indicates that they will have access but there is no suggestions that they will control use, disclosure or access by others.

Notes:

1. Paper-based and computerised systems are shown as mutually exclusive. It could be argued that there is some overlap, an example here would be Teng Liaw’s work on computer generated, printed patient summaries\textsuperscript{143}. While electronic systems can and most likely will have paper outputs they should still be classified as electronic systems.

2. Consumer control is not an either/or attribute as suggested by the schema. Consumer control has many dimensions; however, these were not usefully modelled in this schema. The criteria used was whether the consumer had ‘some measure’ of control over their record or not; primarily over access by others but also over use, disclosure and content.

3. ‘Complete’ is a relative term; it would be impossible to collect all health information about an individual. The criterion used was an assessment of whether the record was reasonably complete and covered information from most of an individual’s life.
2.2. The History and Purpose of Health Records

In the first part of Reiser’s chronology of the health record he identified six important evolutionary developments in the use of clinical notes up to the early years of the 20th century\textsuperscript{188}. Hippocrates and his disciples used the case record to demonstrate the natural causes of illness and to portray the clinical course of illness. In the 17th century Thomas Sydenham used the clinical records of individual patients to create disease histories in an attempt to create a classification for diseases. This process of classification is the essence of diagnosis in modern medicine.

In the 18\textsuperscript{th} century Morgagni was the first to compare evidence of disease derived from clinical records with the findings upon autopsy. During the 19\textsuperscript{th} century the focus moved from capturing causes and experiences reported by patients to a detailed description of the doctor’s search for indicators of anatomical changes. Another major development in the 19\textsuperscript{th} century was the use of records to evaluate therapy.

The sixth change chronicled by Reiser was the use of health records for medical education. Case-based teaching was introduced at Harvard in 1900. This was seen as being an important change from the lecture and bedside based training methods then prevalent. It is pertinent to note, however, that examples of the use of case notes for educating apprentice doctors have been documented from as early as 1712\textsuperscript{158}.

During the 20\textsuperscript{th} century four major changes have occurred or are still happening. These are the development of institution-based unit records, computerisation of health records, the introduction of the problem-oriented record and the increase in the number of parties using the health record.

The concept of the unit record was introduced in 1907\textsuperscript{141,189}. The aim was to create a single record for an individual within any particular healthcare institution. Prior to this development clinical events were usually recorded serially as patients were seen and often kept in a bound book, with the data on a single patient being interspersed with those of other patients. The need for change arose from a dramatic increase in numerical information stored in the record in the form of laboratory results, blood pressure readings and temperature charts. The concept of the unit record is now well established in most healthcare organisations.

The natural extension of the institution-based unit record, namely a single record for an individual containing information from every institution from which they have received
a healthcare service has not yet been realised. Shenkin and Warner proposed a paper-based approach that would have resulted in a complete record but it was never implemented\textsuperscript{200}. In its initial conception the Australian childhood personal health record was an attempt to create such a record up to age 18\textsuperscript{221}. The highest level of computerised health record, ‘the electronic health record’\textsuperscript{17}, is also an attempt to create a complete record, however, there are no working examples of these in the world as yet. The British Government made a pledge in 1998 to create a ‘cradle-to-grave’ health record for every Briton by 2005\textsuperscript{235}. This would be only two years shy of one hundred years from the introduction of institution-based unit records.

Attempts to computerise the health record started as early as 1958. Continual promise and continuing development have marked the following forty years. Stead reported on a meeting of scientists and physicians held in 1959 at the Rockefeller Institute which concluded that computers could and should be used in health record keeping, mass screening, description of the natural history of disease and national databanks\textsuperscript{204}. For all the early enthusiasm it is interesting to note that the recently revised edition of the Institute of Medicine report into Computer-Based Patient Records still sees the widespread adoption of computerised health records as being five years away\textsuperscript{87}.

An important development that was influenced by the early work on computerisation of the health record was that of Lawrence Weed’s Problem Oriented Medical Record\textsuperscript{225}. p\textsuperscript{595}. Weed considered the medical record (a subclass of health record) central to the system of communication upon which patient care, clinical investigation and medical education depend. However, he also saw it as an instrument full of serious faults. His “Problem-Oriented Medical Record” was a move away from a simple chronological listing of information about an individual to a structure organised around separate problems. Weed’s approach to medical records was revolutionary. His most important message was the idea of organising the information contained in the record to suit the needs of the user. His solution focussed on the needs of the clinician; other approaches may be necessary to meet the needs of other users.

The last major change in the 20\textsuperscript{th} century has been the expansion of the parties with an interest in using the health record. Early this century Codman proposed that “The patient, the student, the profession, the chief of service, the trustee, the community and world-wide medical science-each are part owners of ‘the case’. We must all be working
to learn from, to study, to organize, to aid, to be trusted by, to contribute to, to record and to analyze each ‘case’ and all cases” (cited in 189).

Wirtschafter and Mesel looked at the health record from a cybernetics perspective. They saw the possibility of the health record acting as a feedback mechanism supporting quality assurance. The feedback could occur at three levels, the clinician, the healthcare facility administrator and the ‘societal resource allocator’, which could be reasonably translated as government policy-maker.

The 1991 Institute of Medicine report on computer-based patient records listed 33 representative individual users of health records. This sample was categorised into five groups namely providers, consumers, managers, funders and ‘others’. ‘Others’ included government policy-makers, researchers and lawyers. They had a second list with 34 representative institutional users of health records.

There is no doubt that health records are being asked to perform tasks for many groups to whom they have not previously been available. This raises concerns over their ability to satisfy the sometimes competing needs of those users. For instance information that is recorded for funding purposes may be optimised to maximise funding and not be reliable for scientific enquiry. The need to satisfy the needs of multiple users will require a restructuring of the record similar to that proposed by Weed aimed at satisfying the needs of clinicians.

In paper-based systems the manner of presentation of the information is determined by the data capture process. Electronic systems have broken the link between capture and presentation. The consequence of this is that the information can be presented in a variety of ways and can be adapted to different categories of user and even personal preferences.

The increase in the number of potential users of the health record has also led to concerns over rights of access, use and control. These issues are discussed further in the section on information rights.

In conclusion, health records have undergone many evolutionary changes over the last three hundred years and are still changing. The two most important current changes are the move towards creating a single record for every individual containing all their health information and the increase in the range of both the users of and the uses for the data held in health records. These changes are being realised through the technical
development of the computerised health record. An important feature of computerised systems is that they break the link between data capture and presentation.

The next step is to look closely at the move to creating a complete health history of an individual. This is followed by a look at the enabling technology of computerised health records.

2.3. Personal Health Records

Personal health records are one approach to creating a single health record for an individual covering all of their health information. The distinguishing feature of a personal health record is that a measure of control resides with that individual. Control can be achieved through the person having physical possession of the record, which can be paper-based or held on an electronic storage device. Alternatively control can be achieved by the use of an electronic key that controls access to the record which is stored on a computer. The former often has the word ‘held’ in their name. The approach recommended in the “Health on Line” report\textsuperscript{127} is an example of the latter (see 2.6.2).

Many names are used in the literature to describe personal health records. These include patient-held records, patient-held health records, patient-carried health records, personal medical record card, parent-held child health records, personal child health records, portable medical record and client-held health record. The term ‘personal health record’ is sometimes used to describe the Australian childhood development record books. These are a particular variety of personal health records, held by the child’s parents. These are here called ‘childhood personal health records’ to distinguish them from the broader classification. In this text the term ‘personal health record’ will be used to encompass all types of record where a measure of control resides with that individual.

2.3.1. History

Discussion of personal health records in the literature began with the publication in 1973 of a proposal by Shenkin and Warner\textsuperscript{200} to give people a copy of their medical record. They saw that considerable benefits would accrue to the healthcare system and that the barriers they identified could be dismissed or resolved.

Gilhooly and McGhee’s\textsuperscript{113} review found that there were no genuine drawbacks and considerable ethical benefits to be derived from giving patients custody of their medical
records. From the practical viewpoint they were able to refute concerns over the loss of records, the need for providers to explain the contents and concerns over the cost. Furthermore they identified four practical advantages; namely: availability of information to locums and deputies during house calls; avoidance of delay in the transfer of records when people change GP’s; savings in clerical costs and the ability of individuals to correct inaccuracies in their record. From their analysis of the ethical concerns they found that personal health records improve communication and increase trust. They dismissed concerns over the duty of confidentiality raised by some clinicians, arguing that it does not preclude patient access and should not be confused with secrecy.

Cornwall’s review of the literature on consumer access to health records\textsuperscript{74}, a necessary aspect of any personal health record system, was that there was evidence supporting the benefits of consumer access and no evidence to substantiate arguments against. She concluded that legislative reform was required. The evidence she referred to is discussed further in the later section on consumer access to health records.

Personal health records have been used in a number of situations most commonly for childhood development records\textsuperscript{131, 148} and in maternity care\textsuperscript{94, 96, 213}. These are both situations where the normally healthy interact with the healthcare system. Other situations reported include patients discharged from a psychiatric hospital\textsuperscript{100}, homeless mentally ill\textsuperscript{191}, hospital outpatients\textsuperscript{53, 112}, ambulatory chronically ill older patients\textsuperscript{51}, general practice clients\textsuperscript{93, 199} and rehabilitation patients\textsuperscript{115}. Of the uses here identified the history of childhood personal health records is most effectively documented and is discussed here in some length.

2.3.2. Childhood Personal Health Records

Child health and development is one area of the health sector where it is usual for records to be kept by members of the public. They contain a variety of information commonly including identification, contact numbers, usual carers, immunisation records, growth charts, a health problem summary sheet, screening records and advice on first aid, accident prevention and other preventive health advice. They are usually paper based using loose leafed pages, either A5 or A6 size, bound in a cover, and kept by the parent of the child concerned\textsuperscript{148, 180, 221}. They have been in use in many countries
including the United States of America, France, Britain, New Zealand, some African nations\textsuperscript{147} as well as Australia\textsuperscript{221}.

McFarlane argues that the medical records of a child are primarily to aid the exchange of information between professionals. He asserted that the parents of a child are the 'professionals' who provide most of the health and illness care of an individual child\textsuperscript{148}. He also observed that the care of children is handled by a large number of people in a variety of locations. A record that travels with the child enables access to necessary information in all these places\textsuperscript{147}. These arguments are readily extended to health maintenance and the care of all people regardless of age.

In Australia, childhood personal health records have been in development for over 20 years. Following a conference in Canberra in 1974 the Royal Australian College of General Practitioners developed a prototype childhood personal health record. This was trialed for 12 months in Modbury, South Australia. The original purpose of the childhood personal health record was to provide an ongoing record of each child’s health from birth to 18 years. Evaluation of the trial showed good acceptance by parents but poor understanding of its use as a family record or the usefulness of presenting it to all health providers\textsuperscript{221}.

Following the trial the prototype was developed further and introduced across South Australia in 1981. New South Wales (NSW) and the Australian Capital territory (ACT) introduced a similar system in 1988. Queensland was the last Australian State to introduce a childhood personal health record\textsuperscript{47}.

A number of trials have demonstrated high retention rates and high public acceptance of the records\textsuperscript{102, 131, 149}. The rate of use of the records by doctors generally was found to be low and use by general practitioners was lower than that of health visitors (in the UK) and of community based nurses\textsuperscript{134, 149, 180, 221}.

There do not appear to be any evaluations of the effect of childhood health records on health outcomes in the literature. The investigations reported focus on consumer and provider perceptions, retention and use rates and completeness of recordings.

In summary childhood personal health records are commonly used around the world and are well accepted by the community if not particularly well utilised by the medical
profession. They perform a useful role in the communication of information between providers, a task that is readily extendable to the concept of a ‘whole-of-life’ record.

2.3.3. Personal Health Records in Other Settings

The literature on personal health records contains examples of their use in many different areas of health. Elbourne et al assessed a policy of women holding their obstetric records in West Berkshire, England. Women who held their records were significantly more likely to feel in control of their antenatal care and found it easier to talk to doctors and midwives. There were savings in clerical time and no evidence of an increase in the rate of lost notes\(^9\). Draper et al found similar results although they did report that a quarter of the women found them difficult to read or worrying\(^9\). The practice of women carrying their antenatal records has recently been introduced in South Australia\(^2\).

Essex et al piloted the use of shared care records for people with mental illnesses. The people involved found the records very acceptable and were enthusiastic about their use. However, while reporting improved communication among health staff, the patient’s enthusiasm far outweighed that of the providers\(^9\). Reuler and Balazs issued a portable record to homeless chronically mentally ill people. They reported improved communication between providers and that the people involved found pleasure in reading their medical records\(^1\). Sheldon sent his general practice clients a copy of their record summary. Ninety one percent indicated that they found the summary useful compared to one percent who definitely didn’t like the idea\(^1\). Dowell reported that for the most part his general practice clients seemed happy to have a written summary to read and to take to other providers\(^3\).

These examples of personal health records demonstrate the wide applicability and acceptability of personal health records. However, there needs to be further work to demonstrate clinical effectiveness and to examine the cost effectiveness of such systems.

2.3.4. Conclusion

To date personal health records have only included a limited range of information from small portions of an individual’s health history. However, they could be expanded to
cover the health aspects of an individual’s entire life. Importantly they have only been widely implemented in areas where the normally healthy interact with the healthcare system, namely childhood development and maternity care.

Evaluations of the effects of personal health records have so far been limited and most assessments having focussed on user perceptions, retention and rate of use by the various parties. They have been well accepted by the general public, less so by healthcare providers. Importantly, improved communications have been reported between different providers and between providers and consumers.

Most personal health records have been paper-based. Developments in information and communications technology and the computerised health record in particular may provide a means of extending the coverage and capacity of personal health records.

2.4. Computerised Health Records

Computerised health records have broken the link between data capture and presentation. The ability to break the record up into its components and present the data differently depending on the user, means that the health record could become more capable of serving the needs of many users. In theory, electronic communications and storage could usefully link all the fragments of an individual’s health record to create an integrated health record.

2.4.1. History

The attempt to computerise the medical record began as early as 1958 but the widespread implementation of computerised health records is still thought to be five years away.

Stead provides a detailed report of the first twenty-five years of computerised health records. His major observation was that system development was too focussed on the short term, involved a large amount of re-invention and constantly suffered from capacity shortcomings. His solution was that attention must be paid to the staying power of systems. That is they must be designed to be capable of evolution in order to prevent loss of data and avoid considerable development ‘downtime’. As Kahn puts it “Today’s ‘state-of-the-art’ technology is tomorrow’s legacy system”. Hopeful lessons can be learned from the report by Nordyke and Kulilowski of a thyroid clinic, which has had a computer-based record system for 35 years. This clinic has
successfully managed the transition from punched cards, through an online mainframe system to a PC-based system and has longitudinal records for some of their 15,000 clients dating back to 1960. Similarly lessons can be learned from the Regenstrief Record Management System which has been in use and continual development for 25 years.

The pivotal publication in the field of computerised health records is the 1991 US Institute of Medicine report “The Computer-Based Patient Record: An Essential Technology for Health Care”. This report encapsulated most of the work of the previous thirty years and outlined a plan for the widespread adoption of computerised health records over the following ten years, i.e. 2001. The 1997 update to this report considers that the vision outlined in the first report “remains remarkably on target.”

2.4.2. Current Status

Van Bemmel et al reported in 1997 that computer-based information systems were found in a large percentage of European hospitals as well as primary care settings. However, this optimistic assessment was conditioned by their observation that most hospital systems are administration focussed and seldom contain patient record data. None of those systems that did contain patient data fully replaced paper-based patient records. They saw privacy, standards for record architecture and data interchange and user identification as the major barriers that need to be addressed.

Tang and Hammond took a different perspective when reporting on the status of computerised health records in the United States of America in 1997. They found that no comprehensive review of the industry existed and would be soon out of date if it did. However, they saw that promising signs existed in the market in the increasing availability of systems that meet user requirements and in the increasing preparedness of users to actually buy systems. Remaining barriers to the wide adoption of computerised health records in the United States of America included the lack of a common data model and data elements, effective human-computer interfaces, standards, privacy, thorough cost/benefit analysis and leadership.

Hannan painted a less hopeful picture in Australia in 1997. There were no fully developed computerised health record systems and no specific projects directed to that end. There were multiple poorly coordinated departmental systems essentially supporting administrative functions. Hannan saw the need for a federal body with the
primary aim of establishing a national health information infrastructure based on computerised health records. That body would need to coordinate activities on five fronts: standards for coding and communication of patient data; standards for protection of patient confidentiality; increased knowledge of the state of the art internationally; promotion of the use of communication networks, and evaluation of the effectiveness of information systems\textsuperscript{120}.

The three reviews reported above agreed broadly on the barriers that needed to be addressed before widespread use of computerised health records could be achieved. One issue on which there were notable differences is of some cheer to Australia. The Americans noted the lack of a conceptual model free of technological constraints; the Europeans reported the emerging focus on conceptual models while Australia already had one in the National Health Information Model\textsuperscript{19}.

There have been a number of important developments in Australia in the two years since Hannan’s editorial was published. The House of Representatives’ Committee report “Health on Line” made substantial recommendations on most of the important issues identified by Hannan\textsuperscript{127}. The Australian Health Ministers Council established the National Health Information Management Advisory Committee\textsuperscript{174} and released “Health Online: A Health Information Action Plan for Australia” in November 1999. This document lists the many activities currently underway.

2.4.3. Evaluating their impact

The primary benefit of computerised health records is that health data, once captured, is readily available wherever necessary. The Computer-based Patient Record Institute sees them as supporting “continuity of care and serve as a resource for management of the health care system and in extension of knowledge”\textsuperscript{1}. Dick and Steen see that, along with ready availability, there is a need to link the health record to knowledge bases, clinical decision support systems and statistical software packages\textsuperscript{88}.

Evaluation of computerised health record systems has largely focussed on the effect of decision support systems and other applications that use the information contained in computerised health records.

Balas et al located 98 articles reporting 100 randomised-controlled trials of clinical information systems. They reported trials in outpatient primary care, outpatient
specialist care and inpatient care most of which (76%) evaluated the process of care. Eighty-five percent of trials reported positive outcomes. Their analysis found that four types of information intervention were successful: provider and patient prompt/reminders, patient education and treatment planning235.

Sullivan and Mitchell conducted a systematic review of published reports on the influence of computers on primary care consultations. A total of 30 papers satisfied their inclusion criteria. The analysis showed that consultation times increased between 48 and 54 seconds, immunisation rates improved by 8-18%, other preventive tasks improved by up to 50% and prescribing costs were reduced by 13-30%. The only study that looked at consumer outcome reported a reduction in diastolic blood pressure in mildly hypertensive patients, Sullivan and Mitchell considered that more work was needed to assess the effects on patient outcomes207.

McDonald et al sent reminders to physicians derived from information held in an electronic medical record informing them that indications for action existed. The response rate to the indications in the intervention group was 49% which was significantly more than the 29% response of the control group where no reminders were provided153.

Safran et al generated alerts based on information in the computerised health records of people with HIV infection. Alerts were sent electronically to physicians and nurse practitioners in the intervention group. The median response time to the clinical conditions which generated alerts were 11 days for the intervention group and 52 days for the control group for whom no alerts were generated196.

Garrett et al conducted a randomised control trial of the introduction of computerised health records in a hospital setting. They reported that the computerised health records resulted in significant reductions in the time required to obtain information from the record and in entering data into it compared to the existing paper-based records. Significant reductions in medication errors were also noted108.

Tierney et al used routine data from a computerised health record system to create a model for mortality prediction among patients with reactive airways disease. The intention was to use the model to target preventive health activities. Their model identified 24% of their test cohort as being high risk. The high-risk group contained more than half of the deaths in the cohort211.
Raschke et al implemented an adverse drug event alert system in a 650 bed hospital. The system was based on routinely collected information in the hospital electronic record system, but excluded drug allergies and drug-drug interactions as they were already dealt with by the existing system. Their system detected 596 true positive alerts in six months. In 44% of cases the attending physician was unaware of the clinical conditions which generated the report. McCartney et al provided feedback to general practitioners on their rate of prophylactic aspirin prescribing for patients with ischaemic heart disease. Drawing on information contained in practice computers the feedback was provided at a practice meeting with suitable educational input. A significant increase in the prescribing rate of 9% was measured over the control group where no feedback was provided.

A meta analysis conducted by Shea et al found 16 randomised-controlled trials of computer-based preventive care reminder systems in ambulatory settings. Their analysis showed that computer reminders improved preventive practices for vaccinations, breast cancer screening, colorectal cancer screening, and cardiovascular risk reduction but not cervical screening or other preventive care.

From this brief overview it can be seen that the impact of computerised health records can be substantial particularly when combined with decision support software.

### 2.4.4. Computerised Health Records and Personal Health Records

There are a number of examples where a personal health record has been implemented using an electronic medium. Most of these systems make use of an electronic storage card commonly known as a ‘Smart Card’. In Europe there are and have been a number of trials including the DIABCARD project that utilised the card as a repository for clinical information in the management of people with diabetes. The Exeter Care Card Trial included 13,000 participants and the card held administrative, clinical, emergency and prescription data that was made available to two general medical practices, eight community pharmacists, a dentist, a community hospital and a general hospital. The Delft Project involved 250 people, three GP’s and a pharmacy. France has adopted the wide use of smart cards, primarily for health insurance purposes but also include a measure of personal health information. Canada held a trial of smart cards in Rimouski near Quebec City, which included 7250 people and 300 health professionals. Quebec province is planning to issue seven million smart cards.
containing administrative information initially, while clinical information is to be added later\(^{169}\).

In Australia an attempt was made to trial an electronic storage card system at seven sites in the Yorke and Eyre Peninsulas of South Australia. This was to contain information derived from two surgeries, two accident and emergency services, two clinics and one hospital\(^{208}\). This trial did not proceed. A more elaborate version is being undertaken in Victoria involving 600 participants, 15 general practitioners, 12 pharmacists, several specialists and one hospital\(^{155}\).

The major difficulty with using electronic cards is that their storage capacity is limited. The \textit{"Health on Line"} report recommended an alternative system that used the electronic storage card to act as a key to a larger repository accessed using network communications technology\(^ {121}, \text{para 4.27.} \)

2.4.5. Health record quality

An important reason offered by proponents for a move to computerised health records is concern over the poor quality of existing records. There has been considerable debate in the literature on this matter. It seems that not only are there considerable problems with the current, mostly paper-based, records, there are also some quality concerns with computerised records.

\textit{Paper-based records}

The 1991 Institute of Medicine (IoM) report reviewed the strengths and weaknesses of existing health record systems\(^ {88}\). They found that paper-based record systems were the most common type of system. They identified five strengths of paper records, namely: familiarity, portability, flexibility in data recording, a lack of ‘downtime’ as compared to computer records (once obtained that is) and the ability to browse and organise the data to suit the user. Bolton has argued recently in Australia that there will always be a place for paper elements in health record systems and communications\(^ {43}\).

The IoM committee also found a large literature on the weaknesses of paper-based records\(^ {88}\). They reported significant problems in several areas; namely: content, format, accessibility, availability and retrieval, linkage and integration. There have been a number of subsequent reports that have supported the earlier findings of the Institute of Medicine.
Lyons et al successfully demonstrated that doctors' handwriting is significantly worse than that of other professionals\textsuperscript{146}. Steven et al found that 4\% of general practitioners records were illegible or extremely difficult to decipher\textsuperscript{205}.

Geiger et al found high levels of duplication of data when reviewing paper-based charting. In the particular health centre they reviewed they found 349 different forms in use. All forms had a ‘Patient Demographic’ field as would be expected, 110 forms had a ‘Working Diagnosis’ field, 32 forms recorded ‘Current Medications’ and 29 forms had ‘Allergy’ fields. Looking at sample patient records they found that the average record was 130 pages long, ‘Initial Diagnosis’ appeared on 20 pages, ‘History of Present Illness’ on 12 pages and ‘Allergies’ on 9 pages. Their conclusion was that multiple duplication of data compromised the integrity of that data\textsuperscript{109}. Problems arise when the same data is recorded many times as the likelihood of initial entry error is high and the difficulty of updating the record in all places a field is recorded is similarly high. The other problem to note is the sheer size of the records. Finding the necessary information within an average record of 130 pages would not be simple.

There has been considerable work on the accuracy and completeness of health records. The following sections look at three areas of the literature: work on medication records, studies of immunisation records and lessons learned from trials of consumer access to records.

\textit{Medication records}

Accurate records of medications being used are important in avoiding adverse drug-drug interactions. Atkin et al showed that elderly patients were taking a median of two medications of which their general practitioners were unaware\textsuperscript{25}. This finding supports the earlier findings of Price et al\textsuperscript{185} and Claoue and Elkington\textsuperscript{66} on general practice records and Feely et al\textsuperscript{101} with hospital records.

\textit{Immunisation records}

Studies have been made of the accuracy of immunisation records. Ferson showed that documentation in hospital records of immunisations for young children was correct in only 76\% of cases\textsuperscript{102}. Saffin and MacFarlane reported higher accuracy in clinic records (93\%) and parent held records (96\%)\textsuperscript{195}. Incidentally Saffin and Macfarlane found that
5% of clinic records were unavailable for inspection at the time of audit. This problem of availability is one of the problem areas identified in the Institute of Medicine report.

**Consumer access to health records**

The literature on consumer access to health records also provides some information on accuracy and completeness. Sheldon reported that 28 of 161 clients (18%) who were issued a copy of their medical summary requested additions, deletions or corrections to their medical summary. Additions included 4 cases of missing pregnancies, 2 of sensitivities and 5 of previous operations. Bronson et al asked 3,400 people who were sent a copy of their health record to read them and return an audit form. Six hundred and sixty five returned the form of which 272 requested corrections. This was 41% of respondents and 8% of all participants. MacFarlane and Saffin reported that 39% of general practitioners who had had experience of parent held child health records felt that the quality of record keeping had improved. Eight percent thought it had got worse. Tomson found that 33 of 100 problem summaries required amendment. Baldry et al reported that 12% of consumers found inaccuracies in their record. Interestingly only one third of them told the staff. Golodetz et al reported that 50% of their patients made amendments to the record.

**Computerised records**

Errors in accuracy are not necessarily caused by the technology. While existing health records are demonstrably lacking in accuracy and completeness this is not a necessary because they are paper-based.

Hogan and Wagner’s 1997 review on the accuracy and completeness of data in computerised health record systems found that there was little literature and it was highly variable in accuracy, design and the data studied. The computerised health record systems were highly variable in themselves. These differences made comparisons difficult. The reviewers concluded that knowledge of data accuracy in computerised health record systems was not commensurate with its importance and that further studies were required.

Jick et al compared computer-recorded diagnoses in British general practice records with diagnoses recorded in consultant letters. They found that the computer records accurately reported 87% of the diagnoses. Pringle et al also looked at the accuracy of
British general practice records. They were looking at four practices identified as high users of computerised systems. Recording of diabetes mellitus and glaucoma were 97% and 92% accurate. However, only 82% of diagnoses overall were recorded. The practices had both paper and computerised components to their record systems and this may have affected the accuracy of information within particular components. Barrie and Marsh found that overall completeness of data notified to the orthopaedic database in a Manchester hospital was 62% and the accuracy was 96% compared to the paper records. Whitelaw et al compared morbidity data recorded in a computer package used by most (78%) Scottish general practices, with information held in the practices’ clinical records which were invariably paper-based. They found that completeness of morbidity recording was 75% over all conditions examined and that accuracy was 100%.

The papers reported above are from a sample of the 20 articles reviewed by Hogan and Warner and highlight their concerns. Many studies reported either accuracy or completeness of the data but not both. Many compared computerised records with paper records, which are known to be error prone and consequently not a true ‘gold standard’. Several studies were conducted in situations where the record systems had a combination of paper and electronic components. The quality of data in computerised health records is often poor and that computerisation will not automatically solve the problems identified in paper-based records.

2.4.6. Summary

Computerised health records are a maturing technology that has great potential to improve the delivery of healthcare services. Development in Australia is slow but several important initiatives are underway which will result in major changes in the next few years.

The literature on the impact of computerised health records is growing and indicates possible improvements in healthcare service delivery and health outcomes could result from successful implementations.

Recent attempts have been made to create personal health records based on computerised health record technology using electronic storage cards have been restricted in function and coverage to date primarily due to a lack of storage capacity. A
combination of a card system and networked storage offer an alternative method of achieving an electronic personal health record.

While there are considerable arguments for using computerised health records in preference to paper-based health records, it is emphasised that many of the shortcomings identified in existing systems do not arise simply from the technology. Less than optimal data quality is a problem with many causes, and computerised health records will not address them all. The combinations of computerised health records and modern communications technology do offer the potential to create a complete or integrated record of an individual's health.

2.5. Integrated Health Records

A number of terms have been used to describe records containing information from multiple institutions and representing a reasonably complete picture of an individual's health. These have included: life long health record223, p36, Personal Life Health Plan111, lifelong electronic health records235 and cradle-to-grave electronic health record59.

Many authors and commentators use the phrase 'Electronic Health Record' to describe the larger idea but as previously argued this confuses the theoretical concept with a possible implementation technology. The term 'integrated health records' has been used here to describe any record that makes available health related information about an individual from multiple institutions and other sources. The word 'integrated' has been chosen to differentiate the concept from present health records, which are fragmented and scattered.

Unit records are utilised in most healthcare institutions, but moves towards integrated health records with information from more than one healthcare institutions have been very slow. Personal health records and the highest level of computerised health record, the 'Electronic Health Record'7, are both examples of records which contain information from multiple institutions. They respectively assume a measure of individual control and implementation using electronic means. These assumptions are likely but not necessary components of such a record. Shenkin and Warner's proposal that people should be given a copy of all health records would have been a paper-based integrated health record200. Their idea was never implemented beyond a few institutions52, 115, 199.
Perhaps the closest to an integrated health record in any widely implemented system is British NHS General Practice records. In Britain, individuals are registered with a single general practitioner (GP) and their records, which are owned by the Secretary of Health, are sent on to their new GP whenever they move. The records contain hospital discharge summaries and specialist letters as well as current and previous GP’s records. In practice the information that is transferred is less than complete particularly for information prior to 1980. (Dr Jennifer Douglas and Dr David Buckley, British GP’s - personal communications)

The Mayo Clinic in Rochester has maintained a comprehensive record that is said to include essentially all the information on residents in Rochester since the early 1900’s. The Mayo Clinic led the development of unit records, which were implemented in St Marys’ Hospital Rochester in 1907\(^{141}\).

Recent developments in the area of integrated records include the British National Health Service’s proposal to create a form of integrated health record for all Britons by 2005\(^{171}\). This proposal will be discussed in more detail shortly. A number of Health Maintenance Organisations in the United States are also in the process of implementing major information systems that will include complete health information for their members\(^{63, 165}\).

### 2.6. Integrated Health Record and Information System (IHRIS)

An Integrated Health Record of an individual would be able to serve all the clinical needs of that person. An information system that contained the Integrated Health Records of an entire population would be able to serve the needs of other users of data in health records through support for population level analysis. The term Integrated Health Record and Information System (IHRIS) is used here to describe such a system. An IHRIS would satisfy the two requirements for future health record systems identified earlier in this chapter, ie provide a single health record for every individual containing all their health information and support the needs of a wide range of users of the data contained in the health record.

There are no complete IHRIS projects that have been implemented on a wide scale. The current NHS general practice records contain reasonably integrated health records but are unable to support population level analysis. Consequently they are seen to be a system of Integrated Health Records but not an Integrated Health Record AND
Information System. This distinction is deliberately highlighted, as there are a number of ways of creating Integrated Health Records that would not constitute an IHRIS.

It would also be possible to create an information system containing reasonably complete information on all individuals in a population but not make use of that information for clinical purposes. Such system would not be an IHRIS, as it would fail to serve the needs of consumers and clinicians. Examples include the Danish civil registration system\textsuperscript{78} and the Australian government department of Veterans Affairs Health Care Information Repository project\textsuperscript{181} (see 3.1.2).

2.6.1. National IHRIS type projects

While there are currently no national IHRIS’s there are a number of activities underway around the world that will lead to recognisable national IHRIS’s. There have also been a number of activities undertaken in Australia, which are relevant to the creation of an Australian IHRIS.

\textit{Britain}

In September 1998 the British Secretary for Health announced that the National Health Service would implement an information strategy that would see a full ‘Electronic Health Record’ for all Britons available at the primary care level by 2005\textsuperscript{59}. The strategy builds on the fact that each Briton is registered with an individual general practitioner and the very high levels of computerisation in general practice. All hospitals would have Electronic Patient (i.e. institutional) Records and would contribute summary information to the records held in general practice.

The ‘Electronic Health Record’ is intended to support 24-hour emergency care as well as routine care. The record will be accessible to the consumer. Aggregated subsets of the record will be available for clinical governance, epidemiological research and the development of health improvement programs. The strategy has been costed at £1 billion over the seven years of the project\textsuperscript{171}.

\textit{New Zealand}

New Zealand has been building a national health information system since 1990, when they started development of their first national health information strategy\textsuperscript{133}. The infrastructure has been built around an on-line national health index (NHI) which provides a unique identifier for every healthcare user. The NHI has been gradually
expanded over the years, it covered 84% of the population in 1995\textsuperscript{133} and by late 1998 it covered 93%\textsuperscript{161}. This has been achieved with people being recruited either at birth or whenever they first encounter the healthcare system. It will be interesting to see if the NHI overshoots the 100% coverage mark; this will depend on how unique the NHI has been kept. By comparison the Australian Medicare PIN covers 102% of the population\textsuperscript{122}. This overshoot arises partly through people who are enrolled but are not Australian Citizens\textsuperscript{122}, it is reported that the slow removal of the dead also helps to keep this figure above the 100% mark. (John Deeble, NCEPH – personal communication).

The New Zealand system is intended to support patient care, the allocation of resources and the development and evaluation of policy. The total cost of the program is unknown as their second national Health Information Strategy only provides seed funding, in total NZ$3.75m, with the majority of the money coming from elsewhere\textsuperscript{176}. Their third 5-year national health information strategy is currently being prepared.

\textit{Canada}

In early 1999 a consortium including Health Canada, the Canadian Institute for Health Information and Statistics Canada published a Health Information Roadmap\textsuperscript{58}. The program of work proposed in conjunction with the work of the Advisory Council on Health Infostructure and some other Health Canada initiatives will provide Canada with a national health information system that will supply ‘person-oriented information’ for clinical care and aggregated analysis.

The approach taken in Canada is to work with an array of regional and provincial systems that serve local needs but operate within an agreed national framework and standards. This cooperation will allow aggregated analysis across the nation as well as supporting clinical care where people move or receive services in different regions.

The program is expected to cost C$90 million over the first three years and C$50 million every year thereafter. In addition to this cost the roadmap identifies C$100 million to be spent in the first three years on related initiatives along with C$2 billion being spent by provincial governments on physical infrastructure components for health information systems.
United States of America

There are no national IHRIS type projects currently underway in the United States of America due to the fragmented healthcare system in which the federal government plays a small role. An attempt was made in 1996 to standardise collection of detailed clinical information with every electronic claims made to Medicare and Medicaid as part of the Health Insurance Portability and Accountability Act\(^\text{121}\). This failed in the Congress, apparently due to privacy fears.

However, a number of private healthcare organisations are developing information systems to serve the needs of multiple users. One of the most substantial projects currently underway is Kaiser-Permanente’s National Clinical Information System (NCIS)\(^\text{45}\). Kaiser-Permanente has 8.6 million members, which is the equivalent of the population of a small country. They provide virtually all health services for those members. The NCIS will be focussed on supporting clinical care, but will also support research and administration. The project is expected to cost US$1 billion over 5 years. Other US healthcare organisations are undertaking similar work\(^\text{60, 154, 165}\).

Iceland

The Icelandic parliament passed legislation in December 1998, which provided for the creation of a national database containing the health records of all Icelanders. This database will contain medical records on every Icelander, which have been meticulously kept since World War One, tissue samples taken from a large proportion of the population and stored since World War Two and genealogical information on most of the population. This data base is to be used for genetic research purposes and Hoffman La Roche have paid the licensee, deCODE Genetics US$200 million to discover the genetic origins of 12 diseases\(^\text{41}\).

The creation of this database has been controversial, giving rise to debate in the British Medical Journal and on national radio in Australia\(^\text{15}\). Whilst this database will contain comprehensive records for virtually all Icelanders it is not intended to be used for clinical purposes.

2.6.2. IHRIS-related projects in Australia

There have been a number of projects in Australia, which have either attempted to implement an integrated health record of some sort, or proposed such action.
**The Australia Card**

In 1986 the federal government introduced the Australia Card bill into parliament. The Australia Card was to have been a national identity card. The purpose of the card was to assist in the management of various government programs such as taxation, health services and social security. The legislation required that the card be presented for a wide range of financial and government service transactions.

The Health Insurance Commission developed the project for the government. As part of the project the Health Insurance Commission was to receive administrative information on all Medicare-related services and hospitalisations. No clinical information was to be provided.

Public fears over the potential use of the card led to a campaign of resistance. The bill was twice rejected by the Senate and never became law. Subsequently the Tax File Number was modified and this enabled many of the administrative benefits in the areas of tax and social security to be realised.

The Australia Card project would have provided the important identification component of a national health information system. The information collected would not have been able to support clinical decision-making or clinical research, however it would have been useful for service planning and policy-making.

The lasting impact of the Australia Card was to create suspicion in the minds of the public over government programs involving collection of personal data and it has left bureaucrats and politicians wary of anything that looks or sounds like an Australia Card.

**Coordinated Care trials**

In April 1995 the Council of Australian Governments endorsed a reform agenda for the Australian healthcare system which included three streams of care; a general care stream, an acute care stream and a co-ordinated care stream. The coordinated care stream was intended to meet the needs of people who required a mix of services over an extended period of time who would benefit from having a dedicated care manager. As a consequence a series of coordinated care trials were established to develop and test different service delivery and funding arrangements.

One of the key features of all the trials was their management of data for trial management and evaluation purposes, and also for clinical care and care coordination.
purposes. Coordinating care for a person who uses multiple services over an extended period of time involves the collection and utilisation of a large amount of data from a variety of sources. Lessons learned from these trials will be important in the development of any national health information system.

One of the more interesting methods adopted was that chosen by the Illawarra coordinated care trial. They created an intranet-based electronic health record that linked general practitioners, care coordinators, the Illawarra area health service, the participants and the project management team.

*John Patterson’s Last Picture Show*

John Patterson was a senior bureaucrat in the Victorian department of Health and Community Services. Following a reorganisation of the bureaucracy in April 1996, he moved to a new department. As a parting gesture, with the agreement of the Premier, he left a set of slides outlining his proposal for national healthcare reform.

His proposal included the creation of an information infrastructure of patient-based records built progressively starting with the Medical Benefits Scheme data managed by the Health Insurance Commission. Over four years he proposed an incremental expansion by adding in further data derived from various health providers:

- Pharmaceutical Benefits Scheme, Veterans Affairs and Nursing Homes in year two,
- Hospital inpatient data in year three, and
- Hospital outpatients, mental health, Allied and Community Health and Health and Community Care programs in year four.

This would have resulted in information being gathered from services accounting for 93% of expenditure on healthcare.

His model was based on the idea of placing control at the output end of the production chain. This entailed giving considerable power to the consumer. He saw health records as a key element of the process. Importantly he saw the record as being important for both clinical care and for the creation of knowledge through analysis.

*The Taskforce on quality in Australian health care*

The Taskforce on quality in Australian health care was established in June 1995 in response to the preliminary findings of the Quality in Australian Health Care Study.
This study reported that a significant number of people suffered unintended injuries or complications as a result of their healthcare whilst being treated in hospitals.

The ‘vision’ proposed by the taskforce in their final report included the view that:

“A patient-centred computerised clinical information system which links health care providers is the only practical way to ensure all relevant information is always available.”

They made some detailed recommendations in the area of information issues. These included:

- A study of the information technology needed to improve patient-based links between healthcare providers,
- A demonstration project, at one or more hospitals, of a fully integrated and interactive computerised hospital information system and
- Feasibility testing and pilot studies of voluntary consumer-held ‘smart cards’ for health records.

Subsequently some effort has been made to implement these recommendations. The New Children’s Hospital in Sydney was built with a highly computerised clinical information system that is not yet completely integrated. The ‘Health Key’ trial in Melbourne has experimented with the use of consumer-held smart cards to carry summary health information155. Some efforts have been made to improve communications between hospitals and general practitioner’s primarily by Divisions of General Practice working with the regional health authority. In addition the Department of Health and Aged Care (then Health and Family Services) began a three-year initiative aimed at facilitating the shift to increased inter-operability of information systems in the Australian health sector23.

The House of Representatives “Health on Line” report

The House of Representatives Standing Committee on Family and Community Affairs undertook an Inquiry into the issues of Health Information Management and Telemedicine. The report of this committee127 was released in October 1997.

The committee’s key recommendation in the area of Health Informatics was for the development and deployment of a national information management system based on a proposal submitted by the National Centre for Epidemiology and Population Health127.
The proposed system was an early version of the IHRIS presented in this text. The system involved the use of consumer held smart cards as the carrier of that person’s health history and the provision of a national back-up facility which could replace information on lost and damaged cards and also support population-level analysis for policy-making, planning and research.

The federal government’s response to the report, released nine months later in July 1998, focussed entirely on the use of the smart card for clinical care. The response made no comment on the concept of a national health data repository for purposes other than clinical care.

"Health Online: A health information action plan for Australia"

In November 1999 a document entitled “Health Online: A health information action plan for Australia” was released for public discussion. This document was prepared by the Federal department of Health and endorsed by the National Health Information Management Advisory Council and the Australian Health Ministers. The plan proposed a major program of work to improve the organisation and utility of health information in Australia including the development of a two-tiered national health information system. The first tier would facilitate the exchange of health information for better service delivery. This tier would contain summarised information from individual agency/practitioner records. The second tier would inform policy, planning and research to improve quality of care and health. This tier would contain summarised information derived from individual records held in the first tier. This approach is closely related to the system recommended by the House of Representatives committee discussed previously and to the IHRIS outlined in this thesis.

The Health Online action plan is a serious policy commitment by the Australian Health Ministers and will have a major impact on the management of health information in Australia. The document reports on many of the activities currently underway that will contribute to a national health information system. The plan implies that completing the tasks outlined will result in the national system sketched out. But the detail of the proposed system is insufficient to determine whether this is true or not, and no cost estimates or budget allocations are included.
2.7. Health Information models

An important activity relevant to the development of health record systems that has been underway for some years has been the creation of conceptual models of health information. These conceptual models are free of technological constraints and provide an important tool for the development of information systems.

2.7.1. The Australian National Health Information Model

The first version of the Australian National Health Information Model (NHIM) was created in 1995. The work on the model was undertaken by a group of organisations including the Australian Institute of Health and Welfare, Commonwealth Department of Human Services and Health, the NSW Health Department and Health and Community Services Victoria. The model was endorsed by the National Health Information Management Group and included in the National Health Information Work Program. The model was an entity-relationship diagram of health information. It was intended to provide a framework for the management of health information. Some attempt was made to enable the model to represent welfare and community services information as well as health information.

The key features of the model are:

- A person-centred focus, including persons as individuals, and as members of families, groups and communities,
- the idea of people and groups acting in a variety of roles,
- the idea of a person’s or group’s state of wellbeing existing independently of the health and welfare system,
- the idea of external events influencing a persons state of wellbeing, and
- a temporal component which allows for the representation of events occurring over time.

The model has been further developed since 1995 and has now been incorporated into the national Health Information Knowledgebase (NHIK). The NHIM has been used in the development of the National Institution-Based Ambulatory Care Model (NIBAM), the Primary and Community Health Services National Information Model (PACHSNIM) and influenced work at the Department of Veterans Affairs.
Recently the NHIM has received international recognition and was adopted by the US Health Care Financing Agency for their new Enterprise Information Architecture. Furthermore, the board of the HL7 consortium identified the NHIM as the preferred logical framework for further development. The NHIM will be used to undertake a mapping and gap analysis of the HL7 version 3 Reference Information Model. (See also 2.7.3)

2.7.2. The Good Electronic Health Record Architecture (GEHR)

The Good Electronic Health Record Architecture dates back to work undertaken in the mid 1980's in Belgium and London. The word 'Electronic' has been substituted recently for the word 'European' to acknowledge the internationalisation of the earlier work. The GEHR Project (1991-1995) was funded by the Advanced Informatics in Medicine Program of the European Union. It produced a large quantity of documentation including a formal object model. This work is available on the World Wide Web at www.chime.ucl.uk.

The key element of the GEHR Architecture is the idea of a 'transaction'. A transaction is defined as being "an interaction between a Health Care Provider and the record, to be indelibly preserved once committed; and as such identified (at least) by the date/time stamp of its addition and the identity of the authorising clinician." A collection of transactions builds together to form part or all of an individual's health record.

The GEHR Architecture has received a high level of support in Australia, primarily in general practice. A Federal government funded consultancy into general practice computing recommended the adoption of the GEHR Architecture. The General Practice Computing Group is undertaking an implementation trial of GEHR architecture-based applications.

The GEHR architecture has also been adopted by the 'Littlefish' project. The aim of the 'Littlefish' project, which originated in Australia, was to apply the Open Source Software development methodology to the production of a health record application for use in developing countries and remote areas such as outback Australia.

2.7.3. Health Level 7 - Reference Information Model

Health Level 7 (HL7) is a standard for the definition of message sent between computer systems. Having standardised message codes allows different computer applications to...
communicate successfully. The message codes tell the applications what type of information is contained within the message. This allows the applications to successfully interpret the information.13

HL7 is a leading contender for the international standard for the communication of clinical health information. Development of version 3 of HL7 is currently underway. As part of that development a Reference Information Model (RIM) is being developed. It appears that the RIM has been reverse engineered from existing messages and there is a need to establish more robust design principles. This may explain the decision to use the NHIM to undertake the mapping and gaps analysis mentioned earlier (See 2.7.1).

2.8. Information Rights

Information rights are important in all information systems. In health this importance is heightened by the sensitive nature of the information and the potential harm caused from inappropriate disclosure or use.

This subject induces much debate and considerable confusion. It is also close to the hearts of many parties. This is particularly true in health where the information is of such a personal and sensitive nature and practices are based on traditions that date back hundreds and even thousands of years.

Information Rights involve considerations of ownership and privacy. There are also subsidiary rights of access, collection, amendment, disclosure, use and control.

2.8.1. Ownership

The historical view of information rights is tied to the idea of ownership. The owner of the record was seen to hold a right of absolute control over the information it contained. The entity that collected the information, traditionally an individual doctor although increasingly a provider organisation, was seen to be the owner. This position is still largely reflected in the legal status of health information, as found by the Australian High Court in the case of 'Breen and Williams'11 where it was established that, in the absence of legislated rights, the consumer had no right of access to a providers records.

Ownership endowed the owner with the right to control the use of, and access to the information and also the right to sell the information in the form of reports derived from health records and also the right to sell the records themselves. The right to control use and access were strongly modified by the ethical practice of confidentiality.
Confidentiality is an important element of the Hippocratic school of medicine\textsuperscript{48} and is designed to ensure that personal health information is only disclosed to people who would reasonably be expected to assist in the care of the individual concerned. An important feature of confidentiality in medical practice is that it is a provider-controlled mechanism that attempts to respect both the privacy needs of the individual and their desire for optimal care.

Control of the use and the disclosure of information by providers through confidentiality was seen as acceptable and appropriate by society for many centuries. Changes in societal ideas of privacy and consumer rights over the last thirty years have been accompanied by a change in the acceptability of purely professional control of information.

The new views of privacy have opened out the concept of ownership of information. In areas where there is legislation giving effect to privacy principles, the owner of information no longer has complete control over that information. To understand this important change it is useful to explore the idea of privacy more fully.

2.8.2. Information Privacy

"Privacy will be to the information economy of the next century what consumer protection and environmental concerns have been for the industrial society of the 20\textsuperscript{th} century." \textsuperscript{61}

This bold prediction of Rotenberg's suggests some measure of the potential importance of privacy in relation to the use of information. It is possibly more so in respect of health information due to its particularly sensitive and personal nature. To understand this issue it is pertinent to examine its meaning.

\textit{Definition}

The Oxford Concise dictionary offers the following definition of privacy "\textit{n. 1 a the state of being private and undisturbed. b a person's right to this. 2 freedom from intrusion or public attention. 3 avoidance of publicity.}"\textsuperscript{5}. This apparently straightforward definition is, however, somewhat circular but more importantly 'the state of being private and undisturbed' is relative, context specific and determined by personal, social and cultural factors. The challenge of interpreting the meaning and application of definitions of privacy is due to its contextual and social construction.
Privacy is sometimes defined by exclusion, i.e. identifying when it has been breached. Storey identified the following areas as constituting invasion of privacy: intrusions on home life; surveillance devices and collection of information; unwanted publicity, appropriation of name without consent; misuse of personal information and disclosure of personal information\textsuperscript{Cited in 177}. The categories suggested include intrusions upon a person’s personal information as well as physical intrusions. Health services often result in physical intrusions, however, such concerns fall outside the area of health records, and consequently the following discussion will focus on information privacy.

The work of Westin on information privacy in the 1960’s was an important breakthrough in the area of privacy and is regularly cited by later authors. Westin saw information privacy as “...the claim of individuals, groups or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.” \textsuperscript{228} This definition is commonly referred to when discussing this issue\textsuperscript{10, 215}. Interestingly the remainder of the definition is rarely quoted. It continues “Viewed in terms of the relation of the individual to social participation, privacy is the voluntary and temporary withdrawal of a person from the general society through physical or psychological means, either in a state of solitude or small-group intimacy or, when among larger group, in a condition of anonymity or reserve. The individual’s desire for privacy is never absolute, since participation in society is an equally powerful desire. Thus each individual is continually engaged in a personal adjustment process in which he balances the desire for privacy with the desire for communication of himself to others, in light of the environmental conditions and social norms set by the society in which he lives.” This continuation of Westin’s definition highlights the tension that exists between an individual’s desire for privacy on the one hand and their desire to be a part of society on the other. It also highlights the contextual and cultural nature of privacy.

The tension that exists in the individual is also echoed in the tension between society’s need to respect an individual’s privacy, and its need for information to enable the effective planning and management of an increasingly complex world. Westin saw the greatest threat to civilised social life as being a situation where each individual was utterly candid in their communication with others\textsuperscript{228, p37}. He also pointed out the
fundamental belief in democratic societies in the uniqueness of the individual requires that personal autonomy be an essential element of a democratic society.\(^2\) This definition, with its emphasis on the control of communication by the particular person or group concerned, demonstrates the dynamic and highly variable nature of privacy. An approach that satisfies the privacy needs of one person at one time may not be satisfactory for others in a similar situation or even the same person at a different time.

**Privacy Principles**

It is common to see information privacy described in terms of privacy principles. Privacy principles first appeared in substantive form with the release of the OECD’s *Guidelines on the protection of privacy and trans-border flows of personal data* which were issued in 1981\(^3\). The Australian Federal Privacy Act 1988\(^4\), which is based largely on the OECD Guidelines, outlines eleven Information Privacy Principles (IPP’s)\(^4\). These cover the collection, storage and security, individual access and correction, use and disclosure of personal information. The Australian Privacy Charter Council has proposed eighteen principles; these cover physical intrusions and surveillance as well as information privacy issues\(^3\). In health, Australian Standard AS 4400-1995, which deals with personal privacy protection in any healthcare information systems, proposed the adoption of the IPP’s by any organisation holding personal health information\(^6\). The New South Wales Department of Health issued privacy guidelines in 1996 (Revised December 1998) which contain principles similar to the Australian Federal Privacy Act\(^4\). In the Australian Capital Territory legislation\(^17\) has been passed giving effect to twelve principles similar to those in the Federal Privacy Act and Victoria is intending to do likewise in the near future. The Australian Privacy Commissioner was requested by the federal Attorney-General to undertake a public consultation with the aim of amending the existing national principles for the fair handling of personal information to account for health issues. The Federal government’s proposed privacy legislation\(^2\) covering the private sector will incorporate the revised document.

In engineering terms the Information Privacy Principles can be seen as a performance standard. They do not provide a prescription for how privacy is to be achieved. This task is too context specific to be dealt with in a prescriptive fashion. The relevant parties have to determine the means by which they will deliver the desired level of
performance. The principles provide a framework for negotiation and are a benchmark against which performance can be assessed.

Derived Rights and Responsibilities

Another interpretation of the Information Privacy Principles is that they establish a series of rights and responsibilities that together are deemed to satisfy privacy needs. Rights and responsibilities are distributed between the users of the information and the individual concerned.

The principles imply that there exist rights for the user to collect, store, use and disclose personal information. These rights are limited by obligations including the need to collect information for legitimate reasons and in a lawful and appropriate manner, to store it securely, to ensure its accuracy, to only use the information for lawful purposes and to disclose the information to others only under limited conditions.

The individual concerned is explicitly granted the right to know what their information is to be used for and by whom, to be able to discover what information is held about them, to access the record and to request amendment to the record.

One point that can cause confusion is the distinction between ‘access’ and ‘disclosure’. It lies in the recognition of the active party in the process. Disclosure of information involves the current holder delivering information to a third party. Access involves a third party coming and getting the information from the current holder. Clearly they are closely related activities and making the distinction is not always necessary but there are some operational differences that do need to be recognised.

Issues such as how legitimacy of use is established and who is to have access to the information require detailed consideration. There are a number of processes that create a legitimate right of use. History has given legitimacy to many uses particularly by clinicians. Legislation has led administrators and governments to have a legitimate use for some information. Researchers undertake ethics approval processes prior to collection and use of information. The privacy principles establish a further mechanism where the collector seeks consent from each individual. This mix of mechanisms leave open the question of whether there are some areas of use which are not subject to appropriate controls either legal or social. A key gap here is seen to be the absence of a
legislative framework covering the private sector. The proposed Federal legislation will fill this gap.

**Jurisdictional coverage of the Information Privacy Principles in Australia**

The issue of jurisdictional applicability of the Information Privacy Principles (IPP’s) has been vigorously debated in recent times. The Privacy Act 1988 only applies to Commonwealth and ACT government agencies and some financial activities in the private sector. The Australian High Court decision in the case of *Breen and Williams* (1996) found “...that in the absence of a statutory conferment on an individual of a right of access to personal records about that individual, Australian law does not recognise such a right.”. This case involved an individual requesting a copy of her health record.

Following this decision an attempt was made to extend the IPP’s to the private sector by the Attorney-General’s Department. However, this work was halted following Prime Ministerial intervention. Subsequently the ACT Legislature passed its “*Health Records (Privacy and Access) Bill 1997*” and the federal Privacy Commissioner engaged in a consultative process which resulted in the “*National Principles for the Fair Handling of Personal Information*”.

The Senate Community Affairs References Committee also undertook an investigation of access to medical records and recommended the implementation of “…comprehensive national legislation enshrining the rights of access to medical and other health records in the public and private sectors.”. The Federal Government rejected the committee’s recommendation and instituted a working party consisting of representatives of the Consumers’ Health Forum and the Australian Medical Association to develop a voluntary code of practice.

In late 1998 the federal government announced a “light touch legislative regime” to support privacy principles in the private sector. This legislation should see codes of practice broadly in agreement with the Privacy Act implemented across the entire private sector including private health practitioners. This was intended to ensure that all healthcare services had some form of privacy controls in place. Once complete this process will be the end of the legal transition from a paradigm based on ‘ownership’ to one based on information rights. The cultural transition will take longer.
2.8.3. Consumer access to health records

The debate over privacy has often focussed on the issue of individuals accessing their own records. This is an interesting phenomenon given public concerns about the possibility of access to their information by others, particularly 'Big Brother' but also employers and insurance companies. It is also significant given that individual access to records is a small, but important, component of the full privacy principles. However, it is useful to look closely at this issue given the emphasis that it is given in the public debate.

The issue of consumer access to health records has been discussed in the medical literature for over twenty-five years. This discussion has often been incorporated into the debate on consumers holding a copy of their records. These two ideas are related, but distinct concepts that are sometimes confused.

There are demonstrable benefits to consumers and providers derived from consumers accessing their health records. These benefits are in consumer knowledge, education and behaviour\textsuperscript{51, 52, 97, 118}, record quality\textsuperscript{115, 149, 199} and consumer/provider relations\textsuperscript{53, 96, 206}. Shenkin and Warner postulated other benefits but they have never been evaluated. These benefits were expected to arise when consumers kept a copy of their record and included improved continuity of information, improvements in quality through peer review, provider education, the faster spread of new ideas and more efficient resource allocation\textsuperscript{200}.

Difficulties that were identified by Shenkin and Warner and other commentators have been dismissed by later reports. These difficulties include the risk of increased litigation\textsuperscript{40, 74}; censoring of the record\textsuperscript{53, 115}; lost control over the timing of disclosing information\textsuperscript{103}; a lengthening of consultations\textsuperscript{112, 117, 124}; loss of the ability to record speculative thoughts and third party information\textsuperscript{199, 229}, and concern over potential harm from an individual accessing their record\textsuperscript{36, 53, 202, 205}.

The use of a dual record system, the provision of provider explanation and ensuring that the records can be kept private from other members of the household would minimise any detrimental effect of consumers accessing their records. Providers would need to develop new skills in communication and in dealing with situations that arise through early release of information.
Consumers are keen to have access to their records\textsuperscript{114, 156, 157, 202}. Legislated rights of access do not necessarily lead to an increase in access\textsuperscript{22, 24} as the attitudes of providers\textsuperscript{103, 227} significantly affect the likelihood of consumers seeking access\textsuperscript{50, 112, 130}. Both consumers and providers would need to be involved and supportive of any process allowing access by individuals to their record for it to be effective. Evidence of benefits to consumers would need to be widely demonstrated and accepted by providers before moves to greater consumer access to records will be successful\textsuperscript{115, 145}.

Where consumers are granted a right of access to their health records it is necessary for the content and structure of the records to change so that the data can be understood. Computerised health records avoid the legendary, and now proven\textsuperscript{146}, problem of the illegibility of doctor’s handwriting. They can also solve the problem of abbreviations by inserting the full text with little extra effort from the provider. The availability of providers to clarify and explain the information is an important feature of successful consumer access programs\textsuperscript{53, 202}.

In summary the published evidence indicates that consumers accessing their records as part of the normal care-giving process is likely to be beneficial to consumers and providers alike. Allowing access as part of the care giving process would require changes in attitude and in practice by providers and consumers.

2.8.4. Conclusion

The issue of information rights is important due to the sensitive and personal nature of the information involved and the force of centuries-old practices. Ownership of information, which largely resides currently in the hands of the collecting entity, has historically given rights of sale, use and disclosure. The exercise of these rights was strongly modified by the principle of confidentiality. Changes in society’s views on privacy have opened up the idea of ownership of information and legislation has created rights of access, collection, disclosure, amendment which are no longer in the exclusive control of the ‘owner’.

The major challenge in satisfying privacy needs is the contextual, social and cultural nature of their construction making them highly dynamic and variable in nature. There is a continuing tension within all individuals between their need for privacy and their desire to be social. Similarly there is a tension in society’s need to respect the privacy
of individuals and the desire for ever more information to assist in the effective management of an increasingly complex world.

2.9. **What are the questions of interest that arise from this review?**

Before outlining the questions to be answered in this thesis, it is worthwhile drawing out the key points from the preceding exploration of the literature on health records.

1. The health record has undergone many evolutionary changes and continues to do so. Two important changes currently underway are the move towards creating a single record for every individual containing all their health information, and the increased range of users and uses of the health record.

2. Computerisation allows data to be presented in ways that are independent of the method of capture. The consequence of this is that the information can be presented in a variety of forms and can be adapted to the needs of different users.

3. The computerised health record is a maturing technology that has great potential to improve the delivery of healthcare services. Development in Australia has been slow but several important initiatives are underway which should result in major changes in the next few years.

4. The ever-increasing capacity of communications systems to link health record systems will make integrated health records possible.

5. A number of countries around the world are moving towards national IHRIS type systems.

In summary, developments in communication systems and the computerised health record will make possible the changes underway in the health record. The approach taken by a number of other countries is to build a national IHRIS. Current activities in Australia mean that work on a national system of integrated health records could start in the near future.

Whether Australia should build a national IHRIS based on computerised health records and electronic communications, just as other countries are doing is not a simple question to answer. It is possible to demonstrate that a national IHRIS is a realistic alternative to the present arrangements.
The task taken up in this thesis was to answer the question “Could an Australian IHRIS satisfy significantly more of the information needs of the Australian healthcare system than present health records and associated information systems?”

Given that providers would continue to capture the data they currently use it is reasonable to assume that a national IHRIS would at least meet the information needs currently satisfied. The approach taken in answering this question was to start by establishing those needs that were not currently being satisfied. Quality assurance theory was used to identify some of the deficiencies in the current arrangements.

A system model for a national IHRIS was then developed. The system model was used to assess whether a national IHRIS could satisfy many of the unmet information needs identified previously.

However, simply demonstrating that a national IHRIS could satisfy more information needs than the existing arrangements would not be enough to classify a national IHRIS as a feasible alternative to the current situation. Unless a national IHRIS could be developed within the existing environment and within reasonable economic constraints there would be no point in undertaking further analysis. An important subsidiary question then is “Could Australia build a national IHRIS?”

In order to answer this question it is sufficient to demonstrate that there is a feasible implementation strategy for the proposed IHRIS given the existing situation and staying within existing resources and other constraints. This approach does not attempt to identify the very best model or implementation strategy, simply to demonstrate that there is at least one feasible solution.

A three-phase project was undertaken. The first phase consisted of two data collection exercises. These are reported in chapters four and five. The second phase involved the preparation of a system model for an Australian IHRIS, which is reported in chapter six. The third phase was to devise an implementation strategy for the proposed system, which is reported in chapter seven.

Before proceeding further it is necessary to explore the existing organisation of health records in Australia. This exploration provides the foundation for the implementation strategy developed in chapter seven; it also provides background for the discussion in chapter six. It is also an opportunity to identify some of the deficiencies in the present arrangements.
Chapter 3 The present state of health records in Australia

Chapter one established the role of health records in improving the quality of healthcare. Chapter two examined health records generally and outlined the research questions that this study will answer. This chapter examines the present state of health records and related information systems in Australia and identifies some of the deficiencies in the present arrangements.

3.1. Australian health information systems and current developments

The following section briefly describes the existing state of health records and related information systems in Australia. This task is not as simple as it may seem, just as individual's health data is currently fragmented, knowledge about health record and related information systems are also fragmented. Furthermore the knowledge that does exist is poorly documented.

The review starts by considering the major healthcare provider types and the major health system managers.

3.1.1. Healthcare provider organisations and types

The major provider organisations and types reported here include hospitals, specialist medical practitioners, general medical practitioners, pharmacists, community care providers and nurses.

There are some general comments to make before examining each group in detail. Firstly there is a transition underway from paper-based to electronic information systems. Each group is at a different stage of that transition, as are individual units within each group. Secondly while many different organisations may capture data about an individual, that data is rarely available outside that organisation.

Hospitals

There were 704 public acute, 323 private acute and 140 freestanding day hospitals in Australia in 1995/96. Public hospitals are managed by state and territory governments while private hospitals are operated by for profit and not-for-profit organisations.
There is no comprehensive review of public hospital clinical record systems readily available. However, some indications can be gleaned from a variety of sources.

Stage 1 of the 1996 Victorian government’s Information, Information Technology and Telecommunications (I2T2) strategy reviewed the information environment in Victorian public hospitals. The review found that the information systems provided "sub-optimal support for many hospital activities" and that they were not "oriented to achieving current and future business and clinical objectives". The review reported that extensive data existed but was not readily available for decision-making or comparable for analysis. These failings contributed to poorer patient outcomes as measured by length of stay.

In November 1995 the Queensland health department identified a need for A$373m in expenditure over seven years on operational and clinical systems for both hospital and community services. Funding of A$60m over three years was provided starting in the 1996/97 financial year.

There are a few flagship hospitals that have made a concerted effort to utilise computerised information systems for clinical purposes. The leading example is the New Children’s Hospital in Sydney which commenced a development program in 1994 that saw it with a paperless Intensive Care Unit, filmless radiology and extensive telehealth facilities by 1997 with more work planned. There is currently a project underway in cooperation with the Health Insurance Commission exploring electronic pathology ordering. Others of note include The Canberra Hospital in the ACT which recently completed the installation of an optical retrieval system for its medical records. This system creates a digital image of all the paper records. These images are then available to clinicians wherever they need them.

The picture in private hospitals is no clearer. As with public hospitals there are some flagships such as Brisbane’s Wesley Private Hospital that intends having electronic patient records available by December 2000. The Warrigal private hospital in Victoria has installed a wireless communication system that allows clinical and administrative staff to access and enter patient information, pathology results, pharmaceutical information and organisation data. However, no available review takes a comprehensive look at the state of health record systems in private hospitals.
Specialists

There were 15,318 medical specialists and 4,468 specialists in training in Australia in 199531. p186. The Australian Medical Workforce Advisory Committee identified 47 types of specialist in their 1998 report.

Specialist’s clinical records are generally paper-based with all the inherent shortcomings of that medium. Very little is known about the rate at which specialists are computerising their clinical records. In 1997 Walker made some ‘guesstimates’ on the use of computers in healthcare. Included in his list was a guesstimate that pathology laboratories were 99% computerised224.

The Australian and New Zealand College of Obstetricians and Gynaecologists carried out one of the few surveys of any specialty in August 199879. All members of the College were sent a survey about their use of information technology. Only 289, approximately 26%, returned completed questionnaires. This low response rate means no meaningful generalisations can be made from the results. Findings of note were that 55 respondents used computers for medical record purposes while 221 used them for report and letter writing purposes.

General Practitioners

There were 19,666 medical practitioners, plus 1,371 trainees working in primary care in Australia in 199531. p186. These doctors worked in approximately 5,500 practices139. p112. In general, clinical records are made by individual GP’s but usually shared within a practice.

The traditional record is a series of five inch by eight-inch cards annotated in pen and stuck together with tape to form a chronological history. The Royal Australian College of General Practitioners supply an A4 sized folder system with a summary sheet at the front and space for letters and laboratory results in a pouch at the back2.

Seven percent of GP’s kept computerised clinical records according to a survey conducted in 1998172. A significantly larger number had computers in their practice, primarily for administrative and financial purposes.

In the 1998 budget the federal government allocated A$15m to the development of information management infrastructure in general practice and A$64m in payments to general practices for computerisation as part of the Practice Incentives Program71. This
incentive is expected to increase markedly the number of GP’s who have a computer and a modem and use some clinical software. Initial indications suggest that the rate of computerised script writing had increased to 50% of GP’s by December 1999 (Frank Quinlan, GPCG - personal communication).

**Community Care**

A discussion paper prepared for the Council of Australian Governments (COAG) in January 1995 reported that data on community-based healthcare services was minimal. This compared unfavourably to the comprehensive data available on some other health services such as public hospitals.

As an example of the state of existing community health information systems the ACT government reported in 1997 that their systems were deficient in a number of areas, including:

1. No central client identifier
2. Inability to use Wide Area Networking
3. Inability to consolidate data
4. Limited reporting capabilities
5. Obsolete user interfaces
6. Inappropriate and non-standard coding systems
7. Lack of support
8. Inability to cope with a mobile workforce

As a consequence of these identified shortcomings the ACT government decided to join the Community Health Information Management Enterprise (CHIME). CHIME’s objective was to commission a Community Health Information System (CHIS) based on a model developed by NSW Health. The CHIS has a budget of A$4.65m and currently involves four states and territories, NSW, Queensland, South Australia and the ACT. There is some possibility that Tasmania will join the consortium in the future.

The first substantial components of the CHIS were expected to come online in late 2000. In association with this development the states involved considerably upgraded...
their hardware in order to support the new system. (Ian Mackenzie, ACT Community Care - personal communication)

Victoria, Western Australia and the Northern Territory are all developing their own systems. However, there has been an agreement to develop a common national codeset covering community services\textsuperscript{104}. This should allow for a useful level of compatibility between the different systems.

*Pharmacists*

There were 12,310 pharmacists in Australia in 1996\textsuperscript{31}. Many pharmacists work in hospitals others work for pharmaceutical companies. The former group have been reported by implication in the section on hospitals, the latter group are not relevant to this review. The other major group of pharmacists is those working in retail outlets also known as community pharmacies.

There were 4,942 community pharmacies in Australia in June 1999\textsuperscript{184}. Community pharmacies dispense prescription and over-the-counter medications. They are highly computerised according to Walker\textsuperscript{224}. This high rate of computerisation stemmed from the clerical task of claiming payment from the Pharmaceutical Benefits Scheme and was assisted by the payment of a small fee (2.5 cents) for all electronic claims submitted to the Health Insurance Commission during the late 1980's and early 1990's. (Michael Tatchell, Pharmacy Guild of Australia - personal communication). Pharmacy records contain data on medications dispensed including both PBS subsidised and non-subsidised scripts. Some pharmacies also capture information on over-the-counter medications and allergies.

*Nurses*

There are 180,000 registered nurses in Australia. The majority of those still practicing in their profession work in the hospital system, for medical practitioners or in the community health sector. They collect a lot of data pertinent to their clinical work. Few work outside of the health organisations already discussed.
3.1.2. Health System Managers

Health system managers provide the resources for healthcare providers to deliver healthcare services. They do not keep health records as such, however, they do have information systems that contain health data derived from health records.

*Federal government*

The Federal government department of Health and Aged Care itself holds few major data sets that contain consumer data. The primary one is the Casemix data set. The portfolio agencies the Health Insurance Commission and the Australian Institute of Health and Welfare (AIHW) have several major data sets, which will be described shortly.

The Casemix data set is similar in content to the National Hospital Morbidity Data Set maintained by the AIHW. Indeed the data is collected at the same time, with the AIHW and DHAC taking it in turns to approach the states. The key feature of this data set is that it contains data on all separations from publicly funded hospitals and the data is de-identified.

*Health Insurance Commission*

The Health Insurance Commission administers Medicare, the national public health insurance scheme, the Pharmaceutical Benefits Scheme (PBS) and maintains the Australian Childhood Immunisation Register (ACIR). The Medicare and PBS data sets contain a considerable volume of administrative data. They are well suited to the administrative task they are required to perform. However, they are deficient as sources of data for clinical and research purposes.

The Medicare dataset contains information on visits to providers registered with the Medical Benefits Scheme (MBS) for services covered by the MBS. This includes the majority of visits to doctors outside of hospitals and includes some services provided by some other provider types. The data captured includes identification of the consumer and provider involved, the date and time the service was provided, the fee charged and the type of service provided. No diagnostic information is recorded and many services are described only by their duration. As a consequence the MBS data set contains little clinical information.
The PBS dataset contains information supplied by pharmacists claiming payment for medications provided to eligible consumers. Currently the PBS pays for prescribed medications costing more than A$20.60 or more than A$3.30 for health card holders. The data captured with each claim includes the identification of the consumer, the pharmacist and the prescriber and details of the medication dispensed.

The major gap in the PBS data is medications costing less than the threshold figures. The BEACH survey recently reported that less than 45% of prescriptions issued by GP’s were recorded on the PBS. This includes both scripts that were never used and scripts that were below the subsidy thresholds. The other notable gaps are over-the-counter medications and medications requiring a prescription but not approved for subsidy under the PBS.

The shortcomings of these two major datasets are further compounded by the existence of legislative barriers preventing linkage of data from the MBS and PBS except in special circumstances.

The ACIR dataset includes information on immunisations of children under seven reported to the register. The doctors or community nurses who give the immunisations provide these reports. This register has been in operation since January 1996. This register is used to provide reminders to parents if their child doesn’t have an immunisation in accordance with the approved regime. It is also used to provide data on population immunisation rates.

_Australian Institute of Health and Welfare (AIHW)_

The AIHW was created in 1987 and it has the task of compiling and maintaining a number of major national data sets. These include the National Death Index (NDI) and the National Hospital Morbidity Data Set (NHMDS). It is also the manager of a number of disease registers including the recently commissioned Diabetes register.

The AIHW also provides the secretariat for the National Health Information Management Group. This group has the task of administering the National Health Information Agreement. The NHIA is an agreement between the Federal government, the State and Territory governments, the Australian Bureau of Statistics and the AIHW. The aim of the agreement is to support the creation of national health statistics.
The National Health Information Knowledgebase (NHIK)\textsuperscript{30} was developed and is maintained by the AIHW. The NHIK is an integrated repository of health information meta-data, namely:

- the National Health Information Agreement (NHIA) and NHIA process
- the National Health Information Model
- the National Health Data Dictionary
- data agreements, including national minimum data sets
- data collections (950 in total), including the National Directory of Data Collections in Health, Welfare and Housing
- information work programs, including the National Health Information Work Program

The National Death Index contains identified data on every death in Australia. The NHMDS includes data on every hospital ‘separation’ event. In approximate terms a report is issued every time an Australian is discharged from hospital. The difference between a ‘discharge’ and a ‘separation’ is discussed shortly. The data reported contains no identifying information on the person involved in the event. The data is provided to the AIHW by state and territory health departments.

The AIHW produces a biennial report entitled “Australia’s Health” which reports on statistics derived from these data sets.

\textit{Department of Veterans Affairs}

The Department of Veterans Affairs (DVA) pays for some of the health services used by Australia’s war veterans. In 1996 the DVA initiated the Health Care Information Repository project (now called the Departmental Management Information System project)\textsuperscript{181}. This project, when complete, will bring together information for all health services paid for by the DVA. The information will be stored in a data warehouse and be presented through a number of data marts. The first major outputs from the system are expected in December 1999 (Steve Neilsen, DVA - personal communication).

The primary purpose of the system is to support management decision-making. There will be an amount of clinical information contained in the system including pharmaceutical’s, nursing and hospital diagnostic data. Although initially lacking
clinical data from general practitioners, it would represent as complete a health record as found anywhere in Australia.

State and Territory governments

State and Territory governments are responsible for the provision of hospital and community care services. Their health agencies hold considerable quantities of clinical data. As outlined previously in the sections on hospitals and community care there are deficiencies in the systems used to capture and store that data.

Private Health Insurers

Private health insurance companies are another group that holds extensive health records. They store all claims relevant data for their members. While the data held includes some diagnostic as well as costing information, it is not used for clinical purposes.

Private health insurance covers hospital-incurred expenses and some other ancillary services. Consequently the data does not contain any information on general practice or community care services.

3.2. Developmental Activities

There are a number of activities underway that are aimed at improving the organisation and utilisation of health records. Some of these were discussed in chapter two. The activities of the National Health Information Management Advisory Council, Standards Australia and the National Health information Management Group are worth highlighting.

National Health Information Management Advisory Council

The Australian Health Ministers formed the National Health Information Management Advisory Council (NHIMAC) in early 1999. They developed a document entitled "Health Online: A Health Information Management Plan for Australia". This was released for public discussion in November 1999. The document outlines a vision for health information management in Australia. It also reports on many of the activities currently underway in the field. The document received the endorsement of the Australian Health Ministers and is a major policy commitment in the area. (see 2.6.2)
Standards Australia

The IT/14 Subcommittee of Standards Australia is developing a number of technical standards that will facilitate the development of electronic health records and the communication of health data. Their work includes co-operation with the International Standards Organisation Technical Committee TC 215 - Health Informatics. Standards released include:

- AS 4400 1995 Personal privacy protection in healthcare information systems,
- AS 4700.1 1998 Implementation of Health Level Seven (HL7) Version 2.3 Patient Administration,
- AS 4700.2-1998 Implementation of Health Level Seven (HL7) Version 2.3 Pathology orders and results,
- AS/NZS 4700.3:1999 Implementation of Health Level Seven (HL7) Version 2.3 Electronic messages for exchange of information on drug prescription
- AS 4390 1996 Records Management

National Health Information Management Group

The National Health Information Management Group was formed to support the national statistics gathering activities auspiced under the National Health Information Agreement31. The NHIMG has developed the National Health Information Model and National Health Data Dictionary and a number of data standards including a series of minimum data sets covering different areas of health services.

3.2.1. Summary

There are considerable quantities of data held in the health record systems of Australian healthcare organisations and administrative agencies. However, this data is fragmented. There is a clear division between clinical and administrative data. Clinical data is generally held by small to medium organisations. There is limited communication between these organisations and an individual’s record usually exists as fragments held in different organisations. Resource/costing data is generally held by large organisations such as federal government agencies and state and territory governments.

Another notable feature of Australian health record systems is that the technology used to store clinical data is in a transition from paper to electronic form. The different
provider types and organisations are at different stages of the transition to electronic storage. Administrative data sets are generally electronic.

The final observation is that knowledge of the health record systems in use in Australia is deficient. Studies of the types of systems used and data captured by the many members of the different provider groups do not exist, are not readily available or are not comparable across regions. The area of least knowledge is specialist computing.

The Council of Australian Governments’ Taskforce on Health and Community Services concluded in 1995 that the “data collection on the delivery of health and community services is patchy and most of what is available is focused on inputs to services rather than outputs and outcomes for individuals.” The review reported above, conducted four years later, sees little improvement in that situation although there are a number of activities aimed at improving the situation.

3.3. Some problems with existing systems

The preceding section described the current state of health record information systems in Australia. The following section outlines some of the deficiencies that arise as a result of the current arrangements.

The Australian healthcare system performs reasonably effectively given the information resources that are currently available. This section aims to describe some of the deficiencies in the present organisation and utilisation of health data.

The discussion starts with a brief look at problems in individual care and then has a more extensive look at problems that arise in policy-making, planning and research activities.

3.3.1. Individual Care

The most notable feature of the health record of Australians is that they are fragmented. Parts of the record reside in the record systems of all the provider organisations with which the individual has had dealings. As people move between different providers only some of their data travels with them through their own recollections and through referral letters and other provider communications. This fragmentation results in errors, inefficiencies and less than optimal decision-making.
Examples of these failings include people being given a medication that they have a previously known allergy to. It can also result in people taking a combination of drugs, prescribed by different doctors that interact causing adverse effects.

Another commonly described, if poorly documented, problem is the repetition of tests where the results of the previous tests were unavailable, generally because they were held in another institution. This problem is believed to occur quite commonly where people are referred to hospital by a general practitioner and where it is simpler and quicker for hospital staff to repeat tests than to locate the GP and get the previous results.

The Quality of Care in Australian Hospitals Study was the most significant study of adverse events in Australia. They examined hospital records of a representative sample of individuals admitted to selected hospitals. The principle findings of the study were that 16.6% of all hospital admissions were associated with an adverse event and that 51% of these were preventable. Whilst not explicitly listed information system failures were implicated in many of the preventable problems identified. These failures included knowledge-based errors, inadequate reporting, and failure to check or follow protocols, while communications and record keeping were two areas where efforts could be usefully directed to reduce recurrence.

Bhasale et al examined adverse events in general practice. While this was not based on a representative sample of general practice encounters important lessons can be taken from its findings. The authors identified a number of sources of preventable errors including poor communications between healthcare providers due to inadequate records and communication systems and unclear or uninformative records. Communication problems included poorly written prescriptions resulting in the use of incorrect medications or wrong dosage, and referral and discharge reports which were non-existent or arrived too late to be of use.

Aside from the two studies reported above there is little literature on the problems encountered in the care of individuals. There are examinations of such process measures as time to send discharge letters, but little on consequences of late or non-existent letters in terms of patient outcomes.
3.3.2. Policy making, Planning and Research

There are a number of information deficiencies at higher levels of the healthcare system. These deficiencies detrimentally affect policymaking, planning and research.

Post-marketing evaluation and adverse event detection

In manufacturing, once a product has been developed and released for sale an essential component of quality assurance involves monitoring its performance in practice. The equivalent activities in health involve post-marketing evaluation and adverse event detection. The two activities are complementary. Post-marketing evaluation aims to determine if the product or service performs its intended task effectively, while adverse event detection aims to determine if the service or product has unexpected detrimental effects.

Selected, high-risk therapeutic products in Australia are required to undergo clinical trials to demonstrate their effectiveness and safety before being commercially released. Medications must also pass an economic analysis before the government will subsidise their use. However, after being released there is no routine assessment conducted on their performance in the form of post-marketing evaluation. Services, as opposed to products, do not require formal approval before being utilised.

Kelman’s examination of implantable devices is an illuminating example of the failure of existing information systems to support post-marketing evaluation137.

Australia spends over A$500 million a year on implantable devices. Such devices include heart valves, hip joints, intra-ocular lenses, vascular grafts and pacemakers. No routine surveillance of these products is presently conducted. Kelman started work on this project in late 1996. He attempted to make use of national administrative data sets including the Medicare Benefits Scheme, Pharmaceutical Benefits Scheme, National Hospital Morbidity Data Set, the National Death Index plus information held by a major private insurance company, Medibank Private. His method was to conduct a six-year historical cohort study using linked information from existing data sets.

Over five thousand people were selected for inclusion in the cohort. It took 18 months to obtain ethics approval from the different agencies and individual consent from the participants. It took 6 months to extract the data from the different agencies. Ultimately partial data on only 35% of the cohort (1883 of 5316) was successfully linked and
analysed. In total the project took 3 years and the low participation rate and the incomplete nature of the data collected significantly compromised its findings.

For comparison Kelman undertook the same investigation in Manitoba province in Canada. The same work took 6 weeks, not three years. Kelman was able to successfully perform this investigation as Manitoba had an established system of linked data sets based on a unique identifier. The data collected was more extensive. The analysis included 100% of the selected sample due to the streamlined ethical approval requirements which did not require individual consent.

Another important activity in monitoring the performance of products and services is the detection of unexpected adverse events arising from the use of products, procedures and services.

In Australia there is an official agency, the Adverse Drug Reactions Advisory Committee (ADRAC), which seeks to identify adverse events arising from the use of medications. However, there is no formal reporting system for adverse events arising from other products and services.

The work of ADRAC relies on voluntary notifications of suspected adverse reactions. Healthcare providers generally provide these but consumers also submit notifications. This works well in situations where reactions are unusual or rare events that occur closely in time to the administration of the medications. However, as pointed out by Colditz and Brewer, adverse events that occur a long time after administration or are an increase in prevalence of a common affliction are rarely detected by case reporting systems.

A recent example of an adverse reaction where the current approach did not work was the detection of an increased rate of gastrointestinal bleeding arising from the use of selective serotonin reuptake inhibitors (SSRI's) particularly in conjunction with non-steroidal anti-inflammatory drugs (NSAIDS). A retrospective case-control study was conducted using an existing dataset of general practice records in England. The major findings were that people using SSRI's were three times more likely to suffer from gastrointestinal bleeding. This risk climbed to 15.6 times if they were also using NSAIDS. There had been only 2 reports of GI bleeding suspected of being caused by the use of SSRI's in Australia in the last 3 years (From data supplied by Ian Boyd.
ADRAC). Clearly the reporting process in place in Australia was unable to detect the adverse reaction.

Rectifying problems

Once a product or service is discovered to adversely affect the health of the recipients it is necessary to undertake remedial action. The manufacturing equivalent is a product recall. In the case of medications and other products this is possible for unused stocks. In the case of services already performed or products already used the appropriate response requires the provision of counseling or other remedial activities aimed at minimising the detrimental effect of the product or service. Such activity necessarily involves contacting the affected people. This process is sometimes called a ‘lookback’.

In recent times ‘lookbacks’ have been undertaken including the tracing of women at risk of HIV and Hepatitis B infection after contact with an infected health worker in the ACT\(^{18}\), the Bjork-Shiley heart valve\(^{56}\) and the Accufix atrial J pacemaker\(^{107}\). Some of these ‘look-backs’ relied on public calls for recipients to come forward, others were able to seek the individuals through existing records.

One notable ‘look-back’ of recent times followed the discovery of an association between the use of human-sourced hormones, hPG and hGH, for fertility treatment and during the period 1964 - 1985 and Creutzfeldt-Jakob Disease or CJD. The story of this ‘lookback’ has been thoroughly described by in the official Inquiry conducted by Allars\(^{20}\) and also by Cooke\(^{73}\).

In some respects this look-back was one of the most challenging ever likely to be encountered. The adverse outcome was rare, occurred many years after the treatment was performed and there was no accepted biologically plausible explanation. The association was consequently controversial. This problem was compounded by the fact that the disease could not be diagnosed until after death and there was no cure available. Furthermore, the treatment had been provided by a large number of practitioners in many different institutions. Recipients’ records were kept by those institutions.

The CJD lookback took nearly ten years with several false starts. The available data sources were inadequate to the task. The records were inaccurate, incomplete and sometimes unusable when they were available. Consequently extensive efforts were required to successfully identify and locate the recipients. These efforts were
undertaken many years after the treatment had been performed. The cost of the process is unknown (Tony Adams, NCEPH - Personal Communication).

**National statistics generation**

The Australian Institute of Health and Welfare has the task of compiling a number of major national data sets as described previously. Looking at just one of these, the National Hospital Morbidity Data Set, a number of problems are discernible. If we were to ask the question ‘How many Australians spent time in hospital in the last 12 months?’ it is not possible to get an accurate answer. The best answer available is that “There were 291 separations per 1000 population in Australia in 1997/98”\(^{12}\). There is no data on the average number of ‘separations’ per person who spent time in hospital in that year. Consequently this only tells us that somewhere in the range of 0.1% to 29.1% of Australians spent time in hospital in 1997/98. Resource management decisions would vary considerably depending on the answer.

The first problem with the NHMDS is that the data reported to the AIHW has no identifying information. This prevents analysis on how many individuals ‘separated’ from a hospital in Australia in a given period. Analysis at a state or regional level could provide an estimate of the average number of ‘separations’ per person who spent time in a hospital in a particular year as they have identifying information. This calculation would be an underestimate, as it would not include any ‘separations’ that occurred in other states or regions.

Getting a grasp on how many people visit a hospital during any one year requires the use of another data source, in this case the National Health Survey. So even though the answer exists within the source data for the NHMDS it is necessary to use a population and time-based sample relying on individual recall to get a reasonable estimate.

The second problem arises from the time it takes to generate the statistics. The states and territories take some time before sending data to the AIHW. One published report indicates that in Western Australia it takes up to 12 weeks for 90% of discharges to be entered in the state’s Hospital Morbidity Data Set\(^{216}\). Furthermore, each state and territory provides slightly different data fields and use different definitions for some of the data reported. These differences make comparisons and aggregation of the data challenging and time consuming. Consequently it takes up to 18 months before national figures are released by the AIHW.
The third problem is that a separation is not the same as a discharge. Separations include transfers from one hospital to another and also include situations where a person may stay in the same hospital bed but due to a change in status from acute to rehabilitation care a statistical separation is reported. The problems that this can cause are discussed further shortly.

The NHMDS is an important and useful data set. However, there are some opportunities for improvement, particularly in the timeliness of the statistics but also in the appropriate use of identified information. Another example of the difficulties of using this data set for policy purposes is described below.

*Policy decision-making based on the NHMDS.*

Injury prevention and control is one of the six Australian national health priority areas\(^5\). One of the major causes of hospitalisation among the elderly are fall injuries. The Australian Institute of Health and Welfare reported in 1997 on the rate of such falls. Their analysis of data in the National Hospital Morbidity Data Set indicated that the rate of hospital separations due to falls among people aged 65 and over had increased substantially in the four years from 1991/92 to 1995/96. For example in men aged 65-74 the increase was 33%. This increase represented a major policy challenge to the government, as their stated goal was to reduce hospitalisations due to falls by 20% by the year 2000.

However, the number of new injury cases resulting in hospital admission may be smaller than the number of separations. This is because one new injury might result in more than one separation. Harrison has examined the data and concluded that there might well have been less change, if any, in the incidence of falls requiring hospital admission. Separations due to falls had increased in this period but so had the proportion of separations that ended with transfer to another hospital, or a 'statistical type change'. He concluded that a trend towards an increasing mean number of separation events per incident case probably accounts for much of the increase in rates of separations. (A/Prof James Harrison, Flinders University - personal communication)

The method used by Harrison to allow for incident cases resulting in more than one separation depends on some assumptions that cannot be tested completely with available separation data. He argued that estimation of the incidence of falls (and other injuries) resulting in admission to hospital could be improved by including in the separations
Maintaining registers of people with particular diseases is a significant information activity. The effort involved in creating such a register is substantial. As an example the recent experience in creating a national diabetes register is instructive.

People with diabetes have regular contact with many parts of the healthcare system. However, there is no comprehensive prevalence or incidence data currently available. To rectify this problem a national diabetes register was proposed in 1996. Work on implementation began in 1998.

As it was deemed unacceptable to use data held by healthcare providers it was decided to utilise data from the National Diabetes Supply Scheme with some supplementary data from the Australasian Paediatric Endocrine Group. As a consequence the register collects data on people with insulin treated diabetes mellitus. This group includes nearly, but not quite, all people with type 1 diabetes and also some people with type 2 diabetes. It was decided to only enrol people registering with the NDSS for the first time after the 1st of January 1999. This allowed individual consent to be obtained. It does, however, mean that while incidence could be calculated no estimate of prevalence could be obtained from the register.

After 12 months of data collection the recruitment rate was approximately 60% of new registrants. Substantial work on the quality of the data is required before the first release of public data, which is not expected before the end of 2000, nearly three years from the start of work. No information on the cost of the establishment and operation of the register was made available.

The result of the considerable work committed to the diabetes register is a seriously deficient replication of data that already exists in clinical records but is unavailable for use for planning and research purposes. The register is unable to provide an answer to the very basic question “How many Australians have diabetes?”

Communicable disease surveillance

The surveillance of communicable diseases is the last example of deficiencies in existing information systems to be discussed. Communicable disease reporting relies on
reports sent to state government public health units by a variety of healthcare providers including general practitioners and pathologists. A major concern with such systems is the level of under-reporting. This is intrinsically difficult to establish. However, in a study of infectious intestinal disease in England it was discovered that for every case reported to the national surveillance agency 23 had presented to general practice and there had been 136 cases in the community. It is reasonable to think the level of under-reporting is similar in Australia.

3.4. Conclusion

These stories share a common theme. They are all examples of information system inadequacies where data that already existed was not accessible at the place and the time required. There are two major consequences of such information system inadequacies. The first is less than optimum decision-making, at both the clinical and system levels, and consequently poorer health outcomes and less than optimum use of health resources. The second is the construction of special purpose information systems that attempt to replicate data already captured in clinical records but unavailable for other uses.

The assumed consequence of these information system inadequacies is that the health status of individuals, and the nation as a whole, is lower than could be achieved with existing resources. The existence of these inadequacies does not mean that a comprehensive, national health record system such as those being developed in Britain, Canada and New Zealand would necessarily be the best solution. It may be that a continual refinement of existing systems, particularly through improvements in provider-to-provider communications and in the reports sent by providers to other agencies, would be a more effective approach. These failings do, however, indicate that there is room for improvement and that alternative approaches should be explored.
Chapter 4 The “Health on Line” Discussion Forums.

Data gathering for the project started with two discussion forums. These were convened following the release of the House of Representatives report “Health on Line” in October 1997\textsuperscript{127}. This report recommended the development and deployment of a nation data management system\textsuperscript{127}, para 4.27 based on a submission by staff at NCEPH\textsuperscript{163}. The model proposed in the NCEPH submission was an early form of the Integrated Health Record and Information System outlined in this thesis.

4.1. The First “Health on Line” Discussion Forum

On December 18 1997 NCEPH held a seminar to foster discussion of the issues associated with developing and deploying such a system. The seminar consisted of a brief presentation of the NCEPH model and three hours of open discussion.

4.1.1. Methodology

Participants were invited to attend as interested and knowledgeable individuals. They were drawn from many of the important stakeholder organisations and were intended to be representative of that group but were not representatives in a formal sense. The participant list outlines their work roles and experience in health and health informatics (see Appendix A). There was an element of convenience in the process of inviting the participants. This can be seen in the large proportion of the participants who were based in Canberra at the time. This was partly a reflection of the selection process but also of the large number of major stakeholders who had offices in the ACT.

The discussion was recorded on audiotape and transcribed. The participants were advised that the transcript would be unattributed. This was considered appropriate, as they were not acting as representatives of their affiliated organisations and it was also intended to encourage open and frank contributions.

Editing was carried out to render the spoken word more readable but maintain the speakers intended meaning. A thematic analysis was performed on the edited transcript. This was done using Microsoft Word by placing a numbered code at the start of each paragraph in accordance with a coding structure created by the author. The coding structure (see Appendix B) was developed from a careful reading of the transcript by the author. Where a paragraph was relevant to more than one theme additional copies of the
paragraph were made, and each copy given a different code. The related paragraphs were then grouped together using the ‘sort’ function.

From the sorted transcript, findings on the themes were extracted and compiled into a report of the meeting. This report was circulated to the participants who were requested to provide comments and identify any errors. The final version of the report was published in a bound volume\textsuperscript{160} which was distributed to relevant stakeholders and also published on the NCEPH Health Informatics web site \textsuperscript{164}.

### 4.1.2. Findings

The meeting was unstructured and many subjects were discussed. The participants spoke freely and contributed willingly to the discussion. Since the meeting was established as an exploratory forum for interested, knowledgeable people, no attempt was made to reach conclusions on matters raised.

This overview has been divided into five major sections covering: the opportunity that exists, the need for a shared vision, the benefits, the development task and other issues relevant to the idea of an Australian IHRIS.

*The Opportunity*

The most notable observation to arise from the meeting was the sense of the opportunity that existed. There was a clear belief that Australia was ready for a national approach to health information management. There was also a perception that not only was there an opportunity but there was a need to do something about the use of information in the field of health.

The optimism expressed was tempered by an awareness of the size of the task, the many hurdles to be cleared, the need to ensure that all interested parties were involved and the need to get it right. However, whilst everyone recognised the difficulties, there was a clear sense of a need to press on and work through the challenges.

*The need for a shared vision*

Many of the participants articulated the need for an agreed national vision in order to successfully implement a national data management system of the kind endorsed by the House of Representatives committee. Some participant’s felt that the vision already existed but that difficulties were being experienced in the implementation of that vision.
One of the major reasons identified for developing a shared vision was the large number of groups at work in the many different sectors of the health industry. Much work was being carried out at the grassroots level in different organisations, in both the public and private sectors. This work was needs driven and generally did not take account of issues of compatibility and interoperability beyond the institution or area for which it is being developed. Eventually those systems would grow and expand to the point where they would interact with other systems. The effort involved in making the systems work together at that time would be significant. Australia could create for itself a new "railgauge" problem just as it entered the new millennium.

To avoid recreating the problems of the past a national vision was considered necessary. From the vision a strategic framework could be established within which systems could be developed so that when they started to interact, the task of making them compatible was minimised.

Benefits

There was a broad consensus that there were considerable benefits to be realised from an Australian IHRIS. Those benefits would accrue to all parties involved in the health field, i.e. consumers, providers, managers, researchers and private enterprise.

There was a view expressed by some participants that the benefits would arise primarily to consumers and managers, not providers. However, others considered that, once providers were computerised, there would be benefits for them in the areas of efficiency, quality and satisfaction.

Overwhelmingly the participants considered that the likely benefits would outweigh the costs.

However, while everyone thought that significant benefits could be realised they saw a need to establish exactly what the benefits were, quantify them in some way and determine who would receive those benefits. This was considered necessary in order to ensure the benefits actually did outweigh the costs, to ensure a fair distribution of those costs and to inform the public debate. Furthermore, it was considered that the benefits to the economy as a whole would need to be included in the evaluation, not just those accruing to the healthcare system.
The benefits identified during the meeting could be broadly divided into two groups; those accruing to the individual, both consumer and provider, and those accruing to the community at large. Benefits to the individual were seen to arise from continuity of information and consumer access to their information. Benefits to the community were seen to arise from population level analysis.

**Continuity of information**

It is rare for an individual to deal with only one provider for all their health needs. In the absence of such continuity of care, continuity of information was considered essential to optimise healthcare. The benefits expected to arise from such continuity could include:

- improved clinical decision-making,
- reduced duplication of diagnostic testing and history taking,
- better medication management and
- increased adoption of screening programs and preventive health measures.

These changes were expected to lead to improvements in the health of the individual and also to more effective utilisation of healthcare resources.

**Consumer access to their information**

Engagement of individuals in their own health was seen to be a likely outcome of giving them access to their health information. It was considered that privacy and legal requirements would see individuals having some measure of control and access to their integrated record. One participant pointed out that giving consumers control of their information through an electronic key would not empower them to any significant degree if they could not read that information themselves.

**Population level analysis**

The ability to carry out population level analysis would deliver a number of benefits to the nation as a whole. The benefits expected to arise included:

- better informed policy development,
- improved resource allocation,
- collection of evidence upon which to base medical practice,
monitoring of disease outbreaks and adverse reactions and
post-marketing evaluation of drugs, devices, procedures and other treatments.

The development task

Many of the features of the development task were identified during the discussion. These included striking the right balance between the top down and bottom up approaches, the scale of the project, the need to identify what tasks would need to be carried out and by whom, standards development, and preparing the climate for change.

Striking the balance between a top down and a bottom up approach

In order to implement a national IHRIS, the correct balance between a top down and a bottom up approach would need to be struck. Some support was offered for the top down approach. There were concerns expressed, however, that the top down approach does not always deliver the expected results. There was recognition of the work being carried out currently at the grassroots level, but there was concern that as these projects grew they would eventually need to interact and without some guidance they would be incompatible.

It was thought that there needed to be a process established which translated the vision into action, could provide guidance to the work at the grassroots and had the commitment of all the players. A nationally agreed strategic framework which nurtured and provided guidance to the grassroots would combine the strengths of the top down approach with the activity that is already occurring from the bottom up.

Scale of the project

One of the identified features of the development task was the sheer scale of the project. The volume of information involved would be extraordinarily large. In addition there would be a large number of groups likely to be involved in the development and use of such a system.

The size of the task would require the development to be carried out incrementally. There were four possible axes of development identified during the forum: geographical area, proportion of the population covered, range of service providers included and functions supported by the system. As an example the system could be initially deployed in an area such as the ACT or Tasmania, cover only a small portion of the
community such as people with complex health needs, include only public hospitals, general practitioners and pharmacists and support limited functions such as demographic data, immunisation records and medication management. The system could then be expanded along any of these axes in appropriate stages until it delivered maximum benefits to the community as a whole.

**Tasks**

The tasks involved in the development of an Australian IHRIS were not fully identified. It was also uncertain who would carry out those tasks once identified. The interested parties identified were many and include consumers, providers, provider institutions, health insurance companies, professional associations, software, hardware and content suppliers, academics, state and federal legislators, health departments and ministers, the National Office for the Information Economy, the Australian Health Minister’s Advisory Council, the National Health Information Management Group, the National Health and Medical Research Council, Standards Australia, the National Forum of Directors of Government Health IT, the Health Insurance Commission, the Australian Institute of Health and Welfare and the National Centre for Classification in Health.

Determining how each of these groups would be involved in the development process would be very important. An inclusive process would be required to ensure the contribution and concerns of all parties were incorporated into the work. Such an approach would make the development task more complex but would increase the likelihood of ultimate success.

**Standards development**

The lack of standards was highlighted as an important shortcoming in health informatics in Australia. Ensuring compatibility requires the development and implementation of agreed national standards. A number of relevant standards were mentioned during the discussion. These included the National Health Information Model, the National Health Data Dictionary, the Australian adaptation of the HL7 messaging standard, the Good Electronic Health Record and AS4400 which deals with personal privacy in healthcare information systems. It was argued that further support of the standards development process was essential.
One particular area of concern was the need to establish an agreed health classification system. There were a number of different systems being used and developed in Australia. The lack of a national standard was thought to be slowing development of software applications and could lead to major incompatibility problems. It is worth noting that since the forum the Federal department of Health has held a workshop on the creation of a national approach to coding and classification. The results of this workshop have not yet been publicly released (John Payne, DHAC - personal communication).

An underlying concern was that the development of standards was currently an ad hoc process. The only available forum within Australia for determining the requirement for health informatics standards appeared to be Standards Australia’s IT/14 committee. However, this determination occurs in a strategic vacuum in the absence of a national vision. Furthermore Standards Australia has limited funds to initiate new projects and none to see that they are implemented. Again since the forum the Federal department of health has undertaken consultations aimed at establishing priorities for the establishment of standards in health informatics23.

Preparation the climate for change

It was suggested that part of the development process would be to ensure that the country was ready for its adoption. This preparation would include ensuring that the public and national decision-makers were aware of the benefits of the system, allaying fears and preparing users for its implementation. Change management processes are well established at the level of a single organisation. Applying this knowledge on a system-wide basis will be a challenging but essential component of the development task.

Issues

A number of more general issues were raised that were considered important in relation to an Australian IHRIS. These included privacy, ownership of the information, international experiences, Federal/State cooperation, provider computerisation and electronic healthcare cards.
Privacy

Without doubt one of the most important issues identified was personal information privacy. Many of the participants highlighted this area as a significant challenge and one that was essential to get right.

There was a definite sense that privacy concerns could be adequately addressed with the right framework and the right technology. Views were expressed that there was support and understanding in the community for the benefits of appropriate use of personal information for research purposes. The key was seen to be actively informing the public of what was being undertaken and why it was beneficial.

Ownership

Ownership of information is a complex issue. Under common law in Australia, ownership of the physical record resides with the person or institution that created the record. Some legislated entitlements to access and amendment exist, primarily in the public sector. The point was made that creating an integrated health record would require resolution of the ownership issue.

The issue of ownership of information was considered when creating the model presented to the meeting. It was assumed that providers would retain a copy of their own work for their own purposes. This was thought to be necessary to satisfy medico-legal requirements and also to provide stability to the system. There was some support for this position at the meeting.

One means of resolving the issue of ownership might involve a report detailing the health event being prepared by the provider, which was then supplied to the national system including a license providing the necessary information rights.

International experience

Several participants suggested learning from the experience of other countries would be a useful component of the development process. Countries including England, Denmark, Mexico, Germany, Hong Kong, Singapore and New Zealand were recommended for investigation. It was subsequently suggested that Canada and the USA also offered useful learning experiences.
Federal/State cooperation

One participant suggested that the division of responsibilities between federal and state governments in the health sector should be one of the baseline assumptions of the model. Others highlighted the non-unitary nature of our health system. This division of responsibilities meant that the cooperation of both levels of government would be necessary for the successful development and implementation of an Australian IHRIS.

Provider Computerisation

The need for providers to use electronic clinical record systems was one of the baseline assumptions of the model presented to the meeting. The low level of use of computers in general practice was discussed at length. The level of computerisation of clinical record keeping in general practice was unknown at that time, but the indications were that it is somewhere between 1% and 10%. (The later AC Neilsen survey found that the use of computers for clinical records in general practice was 7%.)172 There was wider use of computers for scriptwriting and extensive use was made at the front desk in managing accounts and bookings. Aside from pathologists and diagnostic imaging specialists, who are highly computerised, it was believed that the problem extended to private specialists.

The primary factors identified during the discussion that were holding back the adoption of computers by general practitioners were the business model and the need for training and ongoing support.

The Medicare schedule was pinpointed as the primary determinant of the business model for general practitioners. Hope was expressed that the Relative Values Study would change the existing structure, which encouraged short consultations. It was suggested that computer-assisted decision support did not fit into six-minute consultations. An alternative means of providing a business incentive to providers to computerise was suggested which involved the national system purchasing event records.

Training and support were identified as an important component of any program aimed at computerising general practice. Providers’ fear of looking foolish was exacerbated by the fact that some consumers were bringing information on their problems that they
extracted from the Internet to the consultation and asking their doctor to explain the content.

**Smart Cards**

There was considerable discussion of Smart Cards and their potential role in an Australian IHRIS. It was pointed out that the current capacity of such cards at eight kilobytes was too small to carry an individual’s entire health record. A portable data storage device with 128 kilobytes capacity was demonstrated and the possibility of a one-megabyte card was mentioned. However it was suggested that our ability to generate information will increase at least as rapidly as the capacity of storage devices and consequently it was considered that at best the card would contain an abstract of the complete record. One participant suggested that the abstract could meet 90-95% of the immediate information needs in a general practice consultation thus reducing the need to call information in from the larger system.

The suggestion that the card could act as a key to the system and/or provide pointers to where the information is stored was supported by a number of the participants.

One participant informed the meeting of some work on smart cards their organisation had performed. The key finding was that the costs of a smart card system would outweigh the benefits if it only supported administrative functions. The analysis performed, however, did not include the use of the card for health record purposes and had not taken into account the possible benefits to the community expected to arise from such use. It was suggested that the card might need to provide other services to be cost effective but that this raised concerns over its credibility in the market place.

Concerns were raised that the smart card was endorsed by the House of Representatives committee as being a necessary component of a national data management system when it was only one particular solution to the issue of access control.

**Subsequent discussion and comment**

Following the meeting a number of participants were involved in further discussions that were relevant to the forum. These highlighted a number of issues not considered during the discussion. Participants also contributed some additional comments when reviewing the first draft of the report.
Time Scale

The question of the time scale for development of the system was not raised during the discussion. Subsequently a number of participants pondered this question and considered that a ten year time frame would be the right order of magnitude.

One participant went further and suggested that the primary opportunity to implement such a system was as part of Medicare Agreement negotiations. These 5 yearly negotiations involve the federal, state and territory governments and establish the level of health funding. Given that the next agreement was due in 2003 they saw that there was approximately three years in which to agree a model leaving two years to convince Federal and State governments of the system's merits. During the marketing process there would be time for further development leading to initial implementation subsequent to the 2003 agreement and allow 5 years to scale the project up to its optimum size.

Cost

There was very little discussion of cost. The only allusions were when it was pointed out that a 20-cent payment for a report from each health related encounter covered by Medicare would cost A$20 million per year and that healthcare services cost over A$40 billion pa. Given the very preliminary nature of the discussions this lack of discussion was understandable. However, it was a question that would need to be considered in the near future. Perhaps the need would be to establish the real world limits. One participant pointed out after the meeting that if the system delivered an identifiable 1% efficiency saving this would represent A$400 million pa.

4.1.3. Comments

The first discussion forum reported above shaped a lot of the subsequent investigations and system modeling work. The influences of the findings can be seen in the theme list developed for the interviews described in the next chapter. Many of the features adopted in the final model and implementation strategy proposed in chapters five and six can be found in the preceding pages.

One of the noticeable features of the discussion was the dominance of implementation issues such as the development process, technology, the use of smart cards, privacy and general practice computerisation. The need for a vision was highlighted, but there was
little attempt to articulate that vision. Further development of the essential idea of the system was necessary prior to detailed consideration of the method of implementation. The second discussion forum reported below attempted to explore this element in more detail in seeking to find out the needs of the primary users of the system.

4.2. The Second "Health on Line" Discussion Forum

The second forum was held on May 19th 1998. It was more structured than the first. There was a brief presentation of the findings of the first meeting followed by 3 hours of discussion which followed an agenda agreed to by the participants (see Appendix C). As with the first discussion forum, participants were invited to attend as interested and knowledgeable individuals. They were drawn from many of the important stakeholder organisations but were not formally representing them. The participant list indicates their work roles and experience in health and health informatics (see Appendix D).

4.2.1. Methodology

An audio recording was made and transcribed. Unfortunately some of the discussion was lost due to equipment failure. Where possible participants notes and recollections were used to fill in the gaps. As the meeting followed the agreed agenda reasonably closely there was no need to code and organise the transcript.

From the transcript a report of the meeting was prepared by the author and circulated to the participants for comment. The final version of the report was published in a bound volume. This was distributed to relevant stakeholders and also published on the NCEPH Health Informatics web site.

4.2.2. Findings

The findings are divided into four sections: desired outcomes for different stakeholders, the factors that will encourage acceptance or opposition to the vision, other matters discussed and conclusions.

Desired outcomes for the different stakeholders

The clearest message arising from the meeting was the need to clearly specify the desired outcomes for all users of a health information system before discussions of how the system should work. Five groups of users were included in the proposed agenda, namely consumers, providers, researchers, managers and politicians. The question was
asked during the discussion why industry was not included in the agenda. The chairman advised that it had been felt that the immediate task was to define the needs of the users and that the role of industry was to satisfy these needs. It was emphasised that the needs of industry were important and would be considered further down the track.

The following section lists the desired outcomes identified during the discussion with a brief explanation where necessary. They have been arranged under the group expected to benefit.

**Consumers**

Access to the record was seen as the foremost need of consumers. The ability of consumers to check the information contained in their record was a prerequisite for any move to a comprehensive information system. A greater sharing of information and involvement in the decision-making process would be of significant benefit.

There was a strong belief that consumers were inadequately involved in the research process. Several improvements were suggested: these included the creation of a register of research activity, a strengthened consumer involvement in planning research directions and a stronger consumer focus to any process established to approve research where individual consent was not feasible.

Two other important requirements of any information system identified were the need to ensure that the intended outcomes were clearly articulated and that any system was easy to use. Those groups who currently under-utilise health services for cultural and capacity reasons could be further disadvantaged by an information system. The example given was of indigenes who do not carry their national insurance card as often as other Australians presently. It would be expected that they would be similarly disinclined to carry a card that enabled access to their health records.

**Providers**

The primary outcome desired by providers was the ability to access information that would enable provision of better quality service. This information fell into three categories, namely: clinical information, relevant explanatory information for the consumer and information that would enable the provider to evaluate the service they were providing.
Researchers

The most important outcome from a national health record system for researchers was access to a national health data set containing de-identified, but linkable integrated records. The key to carrying out retrospective case note reviews was seen to be assurance that the integrated records were complete histories of unique individuals.

Access to a national health data set would enable post-marketing evaluation of drugs, procedures and devices. This would allow 'real world' evaluation particularly where ethical approval for clinical trials was problematic such as young children and pregnant women.

Another desirable outcome from a national approach to health information would be the facilitation of data collection for prospective studies.

Managers

The foremost need for managers was the provision of information to provide assurance that they were getting value for the money spent on services provided. Other desirable outcomes for managers included:

➤ access to reliable, timely information that enabled them to make decisions on resource allocation,

➤ optimising the efficiency and reliability of processes and mechanisms for the collection of data,

➤ facilitating the compilation of national statistics and disease registers and

➤ a data set to help evaluate policy options.

Politicians

The needs of politicians were explored separately from other managers. The needs of politicians were focussed on the establishment of any proposed system. These included:

➤ A vision to take to the electorate.

➤ An easily articulated benefit for undertaking the work.

➤ Determination of how much it would cost and who would pay.

➤ Assurance that government was not interfering where the market was better placed to act.
What are the factors that would encourage acceptance of or opposition to the vision?

Having clarified the primary needs of the major users time was spent exploring the factors that would affect the relevant parties’ view towards the vision of a national IHRIS.

Providers

Several performance factors were raised as being important considerations for providers. These were that providers would need to see patient benefits in terms of clinical outcomes and that there were no detrimental impacts on provider/consumer interaction. Job satisfaction and process improvement were also cited as important considerations for providers.

A couple of financial factors were identified that would be a significant restraint on providers computerising and also becoming involved in a national system. Without a sound financial reason providers will not computerise their practice. There was also a concern among providers that many of the benefits arising from computerisation accrued to other parties. Consequently they would need to see that costs were apportioned in line with the expected benefit.

Other factors included:

➢ Peer acceptance. If providers see their colleagues adopting electronic methods successfully they will also adopt such methods.

➢ Training and support; particularly in the start-up phase when there would be increased workload and the provider would be least familiar with the system.

Consumers

Satisfying the privacy needs of consumers was seen as an essential component of any national system. This would include overt consent processes for the storage and disclosure of any information. It was suggested that a strengthening of the culture of privacy as well as technological and legislative protection’s would be important.

An important performance factor for consumers was ongoing demonstration that the information gathered was being used to improve policy and practice.
Practical factors included easy operation of the system particularly for groups who don’t make effective use of existing services, and the desire to avoid having to remember yet another PIN number.

**Government**

Two factors were identified that were seen to be important to government. The first was to undertake those tasks that are needed for the system to function; tasks that the market saw as being required, but which only government could carry out. Examples of such tasks being the OGIT Gatekeeper project, which is building national communication security infrastructure or the implementation of a universal identifier. It was also thought that government had a need to ensure that all key parties were involved in the process.

**Other matters discussed**

**The need for a champion**

It was suggested that there was a need for a powerful champion willing to stand up and declare that within a certain timeframe, say 5 years, Australia would have a comprehensive health record and information system. The demonstration of political commitment to such a project would focus the efforts of all the players and lead to considerable progress. Without such a champion the idea would not prosper.

**The ACT as a test bed**

There was general acceptance that the ACT could be a useful place to trial an IHRIS but that other places were also suitable and that any decision was likely to be politically determined.

**Making maximum use of existing systems and structures**

It was proposed that the development of any comprehensive system should make maximum use of existing systems and other development work, to avoid duplication of effort. It was also suggested that the system would need to be developed within a strategic vision, which would enable the identification of the gaps.

The work of the National Health Information Management Group (NHIMG) on data standardisation and minimum data sets carried out under the auspices of the National Health Information Agreement was identified as an important support to any integrated
information system. Establishing links to the NHIMG and its work programme would be a useful element in any development programme.

*Reservations*

It was pointed out that it is not always necessary to look for grand solutions. There may be simpler ways of addressing many of the needs and that a locally based approach rather than a national collection may be more realistic.

### 4.3. Summary

The two discussion forums provided a rich source of information for the development of the model of an IHRIS. The wide range of viewpoints represented enabled the identification and exploration of the relevant issues. Interaction between the various stakeholders focused attention on the important issues. The variety and depth of experience of the participants provide a measure of confidence in the findings. This confidence was reinforced by the iterative approach taken in preparing the final reports.

The nature of the discussion forums prevented the examination of issues in depth. Furthermore, participants could only contribute a little of their knowledge due to time constraints. In order to provide an alternative source of information that avoided these shortcomings, a series of interviews were conducted by the author with individual key informants. These are reported in the following chapter.
Chapter 5 Key Informant Interviews

The second source of new data used for this project was a series of key informant interviews. These interviews provided deeper understanding of the many issues touched on in the discussion forums through a more focussed discussion. They allowed the informants to explain their views and ideas more fully.

The interviews were funded by a seeding grant from the General Practice Evaluation Program (GPEP grant 560). The author was the chief investigator and Dr Ross Bailie was co-investigator. Dr Bailie's role was to provide supervisory support and quality control.

5.1. Methodology

A list of approximately 70 potential interviewees was created. This list included suggestions from the author and his supervisory panel. Thirteen of the potential interviewees were selected for the initial phase. The selection criteria included: 1) involvement in work related to information management in health, 2) experience with information technology applied to health or 3) a record of academic work in the area. The selection involved balancing the different perspectives. People with a number of different perspectives were preferred. There was an element of convenience in the list of interviewees chosen. This can be seen in the number of people who were based in Canberra and is also reflected in the number of health informaticians and academics chosen for interview. However, having indicated this potential weakness in the methodology an inspection of the list of interviewees will reveal a respectable array of experience and knowledge that was broadly representative of the study area.

Those selected included representatives of all major health groups namely consumers, providers, managers, and researchers. Six health informaticians were included to provide perspectives on the technical issues. Three of these were also practicing providers, while a fourth had completed medical training. The first group of thirteen included four people from the National Centre for Epidemiology and Population Health, these interviews were used to trial the interview method as well as contributing to the data gathered.

The people selected were telephoned by the author and asked if they would agree to be interviewed as knowledgeable, interested individuals, not as representatives of their
organisation. All except one of those approached agreed to be involved. The other person had left the country for a new job; his replacement agreed to be interviewed. A fourteenth interview was conducted with a medical doctor with a PhD in health informatics recently returned from the United States while the author was in Adelaide conducting other interviews.

A letter explaining the project was sent to the interviewees prior to the interview. The author conducted the interviews and an audio tape recording was made with the agreement of the interviewees, with the understanding that all findings would be reported on a de-identified basis. The interviews were unstructured but made use of a theme list with prompts to ensure sufficient coverage of the issues of interest.

The theme list was developed from the literature and from the findings of the discussion forums reported previously (see Appendix E). The theme list was critically reviewed by the author’s PhD supervisory panel and also by the members of NCEPH’s post-graduate students writing group. A verbatim transcript was created from the recording by a skilled transcriber. The author reviewed the transcript while listening to the original recording and made corrections as necessary.

A preliminary analysis was conducted on the first fourteen interviews. The details of the analysis are described later. The preliminary analysis showed signs of saturation in that little new information was being uncovered.

Three further interviews were conducted one with an officer of the Privacy Commission, a General Practice representative and an officer from a state health department. These three were seen to strengthen the mixture of the participant group.

The list of those interviewed is included in the appendix (Appendix F). There were six health informaticians, three consumer representatives, two provider representatives, three government and three health researchers. A notable feature of the mix was that over half of the people were or had been health service providers (5 General Practitioners, 2 Physicians and 2 Nurses).

The additional interviews were coded and analysis performed on all seventeen interviews. The findings were compiled into a draft report that was circulated to the interviewees for comment. Twelve of the interviewees provided a response to the draft
report. These responses were taken into account when revising the draft version in preparing the final report. The final report was published in a bound volume.162

5.2. Analysis

5.2.1. Analytical Framework

The thematic analysis of the interviews was performed using Structured Analysis236 which had been selected for the overall system model design. The principles of Structured Analysis are described in detail in the next chapter.

5.2.2. Preliminary Analysis

The transcripts were coded using NUD*IST software. NUD*IST is a qualitative analytical tool which was used to group together transcribed text from different interviews which related to a common theme. The text was grouped into a series of nodes that were related in a branching form to create the index tree. Each theme identified was assigned a node and placed in the index tree (see Appendix G). Reports from each of the nodes of the index tree were made and the author extracted findings from the information contained in the nodes.

5.2.3. Final Analysis

The general process was similar to the preliminary analysis. The additional interviews were coded using the same index tree as was used in the preliminary analysis. Reports from each of the nodes of the index tree were made. The findings of the preliminary analysis were revised to include the contributions of the last three interviewees. The findings were written in a manner that avoided the association of any contribution with a particular interviewee.

5.3. Results of the analysis

The results are reported in two parts, Essential Issues and Implementation Issues, both of which are further subdivided into a number of sections. This division is part of the structured analysis method.

5.3.1. Essential Issues

The first three subjects reported relate to the environment within which a national health information system would be operating. They are an examination of the existing
The fourth subject deals with how the system would interact with the environment. It is an examination of the potential users of the information system, the uses to which the system might be put and the identification of the benefits expected to arise from such uses.

**Existing Shortcomings**

There was a broad consensus that less than optimal use was currently made of personal health information. The cause of this was seen to lie in the nature of the existing information systems. The major shortcomings were the lack of an individual focus and record quality.

**The lack of an individual focus**

The lack of an individual focus to present health information systems was identified as an important failing. Some interviewees spoke of the administrative focus of many information systems. An administrative focus sees information gathered which relates to service provision and cost and contains little clinical information. An administrative focus leads to a paucity of information relating to the health status and health determinants of an individual other than their service usage.

Others talked about an institutional or provider focus where the information gathered reflects the needs of the institution. An institutional focus leads to the creation of islands of information. These islands rarely communicate effectively with each other and "the client disappears in and out of those (systems) in ways that are mysterious...". An institutional focus contributes to a lack of continuity of information. Lack of continuity has several consequences including unnecessary duplication of history taking, tests and adverse events arising from incomplete information.

It should be noted that some thought that repetition of history taking had some benefits, primarily the development of rapport, and that important information can be obtained by the clinician by listening to how the consumer describes their condition. However, these benefits need not be lost should a more integrated health record become available.
The existing fragmentation of health records is used by consumers to control who has access to different parts of their health information. An example given by one of the interviewees was of the person who goes to one doctor for most health matters but another one for sexual health matters. This type of control is always likely to be desired by some consumers.

The institutional or provider focus was developed at a time when people received care from one provider. It was pointed out that today we have a highly mobile population of both consumers and providers and commonly deal with multiple providers. As one interviewee put it “...the current situation is that we are working with a system that is grossly antiquated. It was designed essentially for personal carers of individual problems and isn’t integrated in any sense...”. Consequently they saw that “...the current situation is utterly unsatisfactory both from the point of view of the clinical management of the individual and the empowerment of the individual.”

There was also seen to be a lack of compatibility with information systems relevant to the broader concept of health but based in other sectors. These included Education, Justice, Social Security, Welfare, Housing and Aged Care. That is, the fragmentation that is found within the health sector is also found between health and other sectors of society.

Making records accessible to the consumer was seen as being likely to encourage a transfer of responsibility for an individual’s care from the provider to the individual. “We’re in the magic bullet situation at the moment where consumers tend to believe that it’s up to the provider to fix them.” This point is supported by published reports on trials where patients are given access to their health records44, 52, 53, 118, 212.

Lack of an individual focus was thought to leave the person disconnected from their information and in some sense from their care. “From the patient’s point of view the disconnection of their information from themselves is probably at the core of a lot of problems that occur in healthcare.” The lack of an individual focus also prevents analysis based on a complete (integrated) record of an individual’s health. This adversely affects researchers and managers. Furthermore, it makes it difficult to locate consumers in situations such as the outbreak of treatment induced Creutzfeld-Jakob Disease.
The content of present health records was a major concern. Interviewees reported that a large proportion of health records were disorganised collections of written notes, letters, test results and other pieces of paper held in folders and filed away in filing cabinets. The poor quality of health records has led to problems of accessibility, comprehension, completeness and accuracy. This view is supported by the published literature. The interviewees identified a number of problems that arise due to the poor quality of health records.

Practitioners, and locums in particular, are often unable to access relevant information when desired due to the disorganised state of the collection of paper. Even in well-organised notes data can be lost through sheer volume. Significant proportions of record folders are not available at the time required.

Written notes may be incomprehensible due to illegibility or the use of terse, cryptic writing styles suitable for the author but for no one else. “I had a case where a patient was admitted to hospital and I couldn’t read a single word of the doctor’s letter or previous patient notes which were in the hospital so that I had to ring him up and ask him. That’s a typical example.”

For a reader who has located the relevant notes and made sense of the information contained therein the next problem is that the notes may be inaccurate or incomplete. Institutional records are rarely complete due partly to shortfalls in communication between institutions. Records may also be incomplete due to a lack of a perceived need for a coordinated approach to their use, in the minds of the collectors. The lack of such a coordinated approach results partly from the absence of incentives for data collectors to gather information for other than their immediate needs and partly due to a lack of awareness of the needs of others.

Incomplete records also arise from poor record-keeping practices. The following is an illustrative example:

“I heard about somebody the other day who had been going to her GP over five years for a chronic set of complaints which were being labeled as psychosomatic and eventually the complaint went to the Health Complaints Commission. The GP record showed four encounters whereas the woman reported them to be weekly or monthly and
there were two referrals to specialists which they could prove weren't recorded in the local record."

One other concern about the record quality was the existence of unnecessary judgmental information about individuals.

The implications of these findings are that information systems need to become centred on the individual, efforts are required to improve the quality of data captured and more work is necessary to improve the effective utilisation of personal health information.

**Future Directions**

Some pointers as to how health information might develop in the future were offered. A consistent observation was that future health records would be electronic in some form. There was also an expectation that improvements in health would be achieved through better organised records. These benefits would accrue directly to the individual during clinical encounters through improved clinical decision-making and indirectly through analysis and subsequent improvements to health service systems and knowledge.

The integration of information systems that were previously incompatible would become possible. The possibility of integrating information systems was also an encouragement to those who thought that we need to collect more information than that which we can count and code. This includes information on perceptions, feelings and satisfaction. A need was identified for information on economic status, housing, transport, employment, poverty and social supports in order to assist with a more holistic approach to the care of individuals and the community. It was pointed out that such a holistic record would be extremely sensitive information.

The capacity of communication technology would allow for new ways of conducting research. One of the scenarios presented was that through the use of intelligent software a questionnaire could be sent to providers. With the provider's approval the software would scour their records and the answer would be returned to the researcher to be aggregated with other results. Alternatively questionnaires could be triggered upon the entry of a certain disease or treatment classification code and the provider could administer them immediately. The communications would also be two-way. Managers could send new findings, alerts and other advice to providers. Information about the provider's practice compared to similar providers could be supplied for self-assessment
and review purposes. Such mechanisms would need to take account of consumer views on control over such uses.

There were several suggestions made reflecting the possibility of moving responsibility for care down the training scale. Consumers could take more responsibility for their care through access to more useful records and advice. Nurses and medical receptionists could collect data on signs and symptoms for review by the doctor or allow them to diagnose common problems with the assistance of decision support tools. Similarly the ability to augment GP’s expertise through the use of decision support tools would allow them to act with the knowledge of a specialist to some extent.

*Changes in the Healthcare System*

A number of changes to the healthcare system that were currently underway or seen as being possible in the near future were identified.

The change to a more patient-centred health service is already happening. Consumers are becoming more knowledgeable and prepared to question providers. The idea that the consumer could share in the creation of the record was seen to be beneficial and could strengthen the consumer-provider partnership. Information systems such as the Internet are already shifting the information power bases enabling consumers to join the partnership on a more equal footing. Use of the word partnership was common and strong emphasis was placed on the consumer-provider relationship.

A shift from the use of tertiary care services to primary care services is already occurring and expected to continue. It was suggested that community services currently outside the ambit of the healthcare system may be the greatest consumer of health dollars next century. This would arise from the increased needs of those requiring complex care for chronic conditions. An example given was the use of home maintenance, home help and meals on wheels to reduce the rate of institutionalisation. A similar issue was identified in the increased use of complementary medicines and alternative therapies.

New jobs and changes in existing jobs were seen to be an ongoing area of change. The examples given were the jobs of care coordinators and nurse practitioners and the changing role of pharmacists.

The common effect of introducing an information system is to either require, or lead to, extremely challenging system and workflow changes. Undertaking it on a national scale
would require skillful management and considerable effort. It is likely that the healthcare system will undergo changes induced by changed information systems regardless of whether a national system is implemented or not. Such change will be an ongoing feature of the healthcare system.

Many of these changes would reflect changes in funding approaches. Alteration in the mix of public and private funding or a change from fee-for-service payments to either a capitation based payments or outcomes-based payments, would change the information needs of managers and providers.

_Users, Uses and Benefits of a better information system_

Improved decision-making by providers and consumers would accrue from the availability of more complete information wherever and whenever an individual encountered the healthcare system. Improvements in decision-making were expected to lead to improved health status and greater satisfaction with the healthcare experience as well as improved resource utilisation.

For consumers the ability to evaluate their health status and treatment options, and compare them to the rest of the community, was expected to lead to increased involvement in decisions regarding their care. In turn this would lead to an increased acceptance of responsibility and changes in behaviour likely to lead to improved health status. People would be able to make their records available when traveling for work or recreation, indeed wherever and whenever they encounter the healthcare system. Those suffering from multiple and/or chronic conditions were seen as being significant beneficiaries of such a system due to improvements in the continuity of their information.

For providers the information supplied would enable more effective use of decision-support tools generating alerts, reminders and advice. The use of these tools was expected to lead to reductions in iatrogenic disease, increase the uptake of preventive health and screening measures and to improve treatment selection and medication management. The decision-support tools would contain embedded expert knowledge that could be updated easily. These improvements in decision-making would improve provider satisfaction with their work and decrease their fear of litigation. The possibility of giving feedback to providers on their practice characteristics, along with
comparative information on similar practitioners, was seen as an important quality improvement mechanism.

Self-reporting of health status and regular measurements such as blood pressure, peak flows and blood sugar levels and signs and symptoms would provide for opportunities for improved monitoring of chronic conditions by consumers and providers.

Improvements in the ability to measure outcomes were expected to be beneficial to policy design, implementation and evaluation as well as for planning purposes. This would lead to a more efficient and accountable system. Having managers, providers, consumers and researchers all working from a common dataset would assist in achieving coherence in decision-making.

For policy-makers there was the possibility of more accurate modeling of policy options based on evidence derived from the system and also an increased ability to monitor the performance of the system as a whole.

Regional health administrators would be able to use more pertinent population information when making resource allocation decisions.

The availability of a complete dataset on the Australian population could allow epidemiologists to obtain almost instant evidence on the effect of an intervention, measure incidence and prevalence and gain greater understanding of the determinants of health. A system of integrated records would allow new ways of maintaining contact with prospective cohorts, including automated requests for additional information from the provider and/or consumer at the time of encounter. It would enable population-based cross sectional studies, historical cohort studies and case-control studies based on more complete health data.

Automated notification of infectious diseases would enable public health professionals to manage outbreaks more effectively. They would also benefit from improved knowledge of the relationship between disease and health determinants in the design of public health interventions. Further benefits would arise from improved selection of the appropriate intervention for the population group under consideration and in evaluating the effect of the intervention.

Tracking of devices and the management of disease and treatment registers would permit improved post-marketing evaluation. This would allow improvements in the
detection of adverse outcomes and would enable contact to be made with consumers in the event of a device recall or the need to intervene to ameliorate the effect of an earlier treatment.

There were some users and uses identified which were not considered to be beneficial. The use of the information by governments for ‘oppressive’ control of providers and service use by consumers, by financiers to determine borrowings and by employers and insurance companies to determine employment and insurance status were highlighted as being unacceptable.

The range of providers who could be part of a system of integrated records both as a user and a supplier of information was vast. They included general practitioners, specialists, pharmacists, hospitals (public and private), ambulances, allied health professionals, dentists, optometrists, physiotherapists, podiatrists, chiropractors, community care providers, blood banks, dietitians, fitness advisors, spiritual advisors, counselors and alternative therapists.

The discussion as to where the boundary of health lay was deemed to be endless by a number of people. The most useful approach was to work with what you have available and which delivers sufficient benefits to justify the costs. There was a clear message that it would be sensible to start with a limited range of providers and increase over time.

There was a broad measure of acceptance that a national information system would produce sufficient benefits to justify the costs incurred. Concern was expressed by some that such a system may not represent the most effective expenditure of health dollars. It was argued that when assessing the balance of costs and benefits there were a number of significant intangible items that ought to be included. These included national pride and togetherness, being at the leading edge of world best practice, innovation and confidence in the national healthcare system on one side with fear of government surveillance and potential loss of privacy on the other. It was recognised that financiers are reluctant to consider such intangible costs and benefits but it was considered that such a system would pass a hard-nosed cost-benefit analysis as well. No figures were offered to support this belief.
5.3.2. Implementation Issues

Implementation issues are those matters that restrict the range of possible solutions that satisfy the essential needs of the information system. Foremost among these is the question of how to move from where we are to where we decide we would like to be. This task can be divided into the parties involved and the roles to be performed by those parties, an understanding of the forces that would drive or affect the change and the different approaches that could be taken. An awareness of the potential barriers is important in plotting the path of implementation.

Another issue that is central to all information systems is the establishment of agreed information rights such as privacy, use, access and disclosure. This issue is particularly important in the field of health due to the personal and sensitive nature of the information and also the range of information that is considered relevant to ‘health’.

This investigation avoided exploration of technological issues. To the extent that technology was discussed it was thought that available products would be able to deliver the required performance once the applications and systems were developed, the physical infrastructure had been installed and organisational changes made.

Pathways
Three features of the way towards implementing a national health record system were identified from the interviewee’s contributions. These were:

a) the parties needed to be involved and the roles to be performed,

b) the driving forces which would determine the progress made and

c) an outline of an approach that could be taken.

Parties and Roles

Many parties were seen to have a role in the implementation of a national health information system. These could be divided into six groups: consumer representatives, provider representatives, government, academia, health industry and the information technology industry. Consumer representatives included privacy advocates and special interest groups such as mental health and HIV/AIDS interest groups as well as the peak representative bodies such as the Consumers’ Health Forum, ACOSS and the Australian Consumers Association. Provider representatives included professional colleges and associations from both the medical and allied professions. Government included
federal, state and territory governments including the executives and administrative sections as well as other relevant agencies such as the Australian Institute of Health and Welfare, Privacy Commissioner's Office and the Health Insurance Commission. No particular representative focus was identified for academia but the NH&MRC was mentioned as possibly performing that role. The health industry groups included administrators, funders and product suppliers. The information technology industry was undifferentiated but considered essential.

The federal government was identified, by most of the interviewees, as having a pivotal role in the creation of a national health information system, the key factor being their dominance of the financial aspect of the health system. There was a clear view, however, that the government was best suited to creating the environment through providing leadership, and guidance and not to actually carry out much of the work. There was also concern that the federal government would need assistance from others players to reach what for them may not be an easy vision.

A role that was identified as being essential and requiring considerable skill was that of achieving a guided consensus between the many groups, some of them in competition. There was uncertainty as to whether that expertise currently existed in any individual organisation.

A national health information advisory council was suggested by a number of people. It was proposed that the council would provide a single focus for facilitating and implementing agreement on issues related to national health informatics, a focus that was seen to be lacking. The existing National Health Information Management Group was not seen to provide that role. Nor was a single agency or division of the federal department of health seen to hold overall responsibility for national health information. The National Health Information Management Advisory Council, which met for the first time in April 1999, could provide that focus.

Drivers

The clearest message emerging from these interviews was that for change to occur there had to be benefits to the people feeding information into the system. These benefits could be in reduced time, cost, tedium or litigation or in increased satisfaction, or better health outcomes. The belief was widely held that a major barrier to improving information systems was the belief of many clinicians that the benefits of a national
health information system would largely accrue to downstream users such as managers and researchers. The suggestion was made by a number of people that providing feedback both instantly in the form of decision support and later in the form of comparative performance review, was an important mechanism for delivering benefits to data collectors.

There was considerable attention given to the value of information. Financial incentives were identified as being important. The example was given of pathologists who had discovered that there was a business advantage to managing their data using computerised information systems, as a consequence of which the great majority of pathologists were computerised. It was suggested that general practitioners have not turned to computerised systems due to the nature of the funding process, which favoured rapid turnover and provided no incentives for installing information infrastructure. Since the interviews the Federal department of health has supported the computerisation of general practice through the Practice Incentives Program. Some suggested that a market approach to establishing a price for information would promote the efficient distribution of information through the healthcare system. It was observed that most of the funding structures in health are ‘vertical into government’. There is no mechanism to track the intersectoral or horizontal movements and consequently no funding mechanism to support that effort. Others raised the concern that where information became commercially important it got locked away preventing its use outside the relevant organisation.

Finally it was observed that hard-nosed economic costing is very persuasive to government decision-makers. Concern was raised by a number of interviewees that this would be an unnecessarily narrow measure of the value of a national information system. As mentioned previously, there were seen to be a number of important intangible and difficult to quantify benefits and also costs that should not be ignored.

The need for new types of information was highlighted by a number of interviewees. Two examples were given. The first example related to the move to outcome-based funding for divisions of general practice and potentially to other sectors in health. Such a change would require considerable information in order to determine the outcomes achieved. The nature of the measurement would require the availability of more comprehensive individual-based information. Secondly epidemiology can currently
only explain a small proportion of existing disease. The example given was that all measurable risk factors only account for 30% of coronary artery disease. The concern was expressed that data from clinical encounters, which is driven by clinical needs, may omit information such as social context. The ability to base analysis on information drawn from a wider range of sources was seen to be important for uncovering new knowledge about the determinants of health. Such linkages would require careful consideration of the privacy issues.

The relationship between consumers and providers was seen to be extremely important by many parties. "The recording of information is a necessary evil but it’s not the objective...it’s that relationship between the practitioner and the patient". Any interference to that interaction caused by the needs of an information system would be a concern. This concern was not universal, some anecdotal evidence suggested that effective utilisation of the computer can contribute beneficially to the interaction. It was also suggested that a strengthening of the partnership was possible.

Approaches

The strongest message from the interviews, as from the discussion forums, was that a national health information system would need to be developed incrementally. The types of incremental development were varied suggesting several possible axes.

a) system functionality e.g. start with communications and then move to structured records, or set up registers of diseases and devices and expand their coverage,

b) the type of providers involved e.g. general practitioners, pharmacists, pathologists and allied health,

c) the proportion of each type of provider involved e.g. work with small groups and expand through peer pressure/training,

d) geographical coverage e.g. "you might look at establishing the system in the ACT", and

e) focus on particular groups within the population e.g. chronic care.

These five axes include the four axes identified in the discussion forums plus another that progressively built up the proportion of each provider type.
There was also a group of general statements including “start with something manageable”, “build a system that could be added onto easily” and “work with the opportunities”. The emphasis was one of evolution rather than revolution. It was seen that the process of incremental development would need to be embedded in a national framework, i.e. that the process would need “to be both top down and bottom up”.

The other common theme expressed was that the early and strong involvement of those who have to use the system was important. This would mean getting users involved early in the design. Providing training in the use of the system and raising awareness of the system were important to the success of such a project.

Several other comments were made which related to the approach that might be taken. Firstly the need to learn from others, both other countries and other industries. Secondly to realise that simply digitising the existing system would not work. The implementation of a national information system would both require, and enable, changes in the way healthcare services were delivered. Thirdly the need to keep in mind that change would be ongoing and mechanisms to allow for that change would be necessary. Finally there would be the need to create community awareness of the desirability of such a system and confidence in its operation in both individuals and the community at large.

Barriers
A variety of potential barriers were identified. These included complexity issues, stakeholder attitudes and suspicions, fiscal imbalance, and the lack of an agreed framework. Problems with data collection were seen to be a false barrier, often presented as a problem but in fact solvable and really an expression of a reluctance to change.

There were several aspects to concerns about complexity. The first was that health information was seen to be more complex than information used in other sectors such as banking and travel. Its sheer volume further compounds the complexity of the information. Using a complete version of an individual’s integrated record would be difficult within the constraints of a typical encounter, while managing and utilising a dataset of the entire nation would be an even bigger problem. Furthermore, rendering the information available for useful analysis was a complex challenge in itself. A
further complexity identified was the degree of workflow and organisational change that would need to occur during and after implementation of a national information system.

Another concern over complexity was the range and number of parties likely to be involved in the design and development of a national information system. The problem would be the difficulty of simultaneously involving everybody and making significant progress.

The difficulties of organisational and workflow changes arising from the implementation and use of information systems were well recognised. In a project of this scale these difficulties are a challenge that would need to be met and overcome. Failure to do so would be fatal.

Stakeholder attitudes to the project and suspicions of each other were seen to be a concern. Providers were seen to have concerns over loss of ownership and control. Governments were seen as lacking commitment to the broad idea, likely to focus on achieving a payback for investment and consequently looking for quick fixes and quick returns. Consumers were likely to have concerns about "lurking nasties" such as the use of the information for surveillance purposes by government. Suspicion of the intentions of other stakeholders by all parties would be an impediment that could prevent cooperation. Resolving stakeholder suspicions will require the establishment of a level of trust between the many players.

Concerns by practitioners, particularly GP's, that there was no business case for them to computerise were similar to concerns of government over achieving a payback for any investment. These concerns are suggestive of a fiscal imbalance existing between those who might fund such a system and those who receive the benefits.

The absence of an agreed framework for the ethical use of the health information of individuals and of populations was raised. The absence of such a framework would prevent any meaningful progress towards a national system as the many parties would either move in different directions or hesitate to start for fear of public reaction.

Information Rights

A number of subjects were discussed by the interviewees which have been brought together in this section on information rights. The subjects included information
privacy, ownership of information, access to and disclosure of information and control of these processes.

Information Privacy

The most difficult challenge when discussing privacy was getting people to focus on the heart of the issue and not the means of achieving it. A number of interviewees when asked about privacy talked about the technical aspects of keeping information secure such as encryption and PIN numbers. Others talked about access, disclosure and confidentiality. Few of the interviewees were able to talk about the essence of the idea. The only observation of substance was that privacy was a social construct and that there was no absolute definition of privacy.

The major observation was that the Information Privacy Principles contained in the Privacy Act 1988, while not perfect, reflected the best effort of society to define the acceptable rules of behaviour with respect to the use of personal information. There were differing opinions as to whether there should be an attempt to rework them or not. On one side was the argument that they needed to take account of changes in technology and society in the last ten years and the particularly sensitive nature of health information. A set of principles with a specific health focus would be beneficial. The other view was that they had served the nation well over the last ten years and that reopening the debate could be detrimental even given their imperfections.

There was seen to be a balance to be achieved between personal privacy and public benefit. What was not made clear was whether there was a direct trade off between the two as implied by the use of the word balance or whether there was an optimisation process involved.

Another point raised was that privacy is as much a concern for providers as it is for consumers and that this was not always appreciated. This concern was located in provider mistrust of governments who were seen as wanting to control them through the use of information. Others thought that providers used fears about privacy as a means to maintain ownership of the information.

The information rights issues discussed later in this section all have an impact on personal privacy. Whether privacy is an overarching concept and they are all
contributing elements or they are an interwoven web of issues that interact in ways that have an impact on privacy is unclear.

Ownership

One of the early interviewees reported that a lawyer, representing the Privacy Commission at the AIHW privacy review, suggested that talking of ownership of information was not helpful. It created blockages in that ownership was viewed as an all or nothing state, and that the idea of discussing a basket of rights was more productive. The basket of rights would include such things as rights of collection, access, amendment, disclosure, and use. Different parties would have different rights depending on their legitimate needs and the rights would differ for identified, de-identified and aggregated information. Most of the remaining interviewees agreed with this idea. One pointed out that associated with all rights must be the necessary controls and safeguards to ensure the rights are achieved and respected.

One person saw that the idea of a basket of rights as a useful step forward in their desired evolution from a situation where total control resides with the provider and none with the consumer to a situation where consumers have total control and providers are their servants. Few others saw the situation changing quite so dramatically. A couple of interviewees raised the concern that talking of rights can create an adversarial framework. They considered that the idea of establishing fair information management benchmarks was preferable. These benchmarks would involve agreement on the legitimate interests of the various parties through an ongoing process that enabled effective adaptation to future technological and social change.

The monopoly over control of information that ownership previously bestowed was broken by the federal Privacy Act of 1988, within those jurisdictions in which it applied, by granting various rights to the individuals concerned. The private sector privacy legislation, proposed by the federal government in December 1998, would see all healthcare services covered by similar privacy principles. Concern was expressed that during a transition to the new order based on a basket of rights, private commercial interests could lock large amounts of information away.

It was indicated that ownership becomes very difficult to determine in situations of shared care and would become more so as records became more complete and contained information from many providers. One problem arising from private ownership of large
collections of health information was the risk of hindering communication and restricting the use of the information for integrated care delivery and for research purposes. There was also concern over the prospect of privatised research based on private collections leading to the hoarding of knowledge for commercial interest reasons when it could deliver benefits elsewhere.

The idea of "nationalising" health information was proposed by a number of interviewees. The idea being that personal health information was a public good and that government management of personal health information on behalf of "the people" would enable the legitimate rights of all interested parties to be realised. Others saw this idea as being rather naive and simplistic and that it could result in people having less control over their health information than other personal information.

There were discussions about the boundaries of ownership. One suggestion was that providers only own their personal observations and that all results, investigations, diagnoses and treatments should be the property of the consumer. Another pointed out that existing systems prevent such a dissection of the information from occurring due to their paper-based nature. A distinction was also suggested between identified and de-identified information, where the first should belong to the individual and the latter to the country. A further distinction was made between 'fully de-identified' information where the record was stripped of any information from which an individual could be identified and 'simply de-identified' information where the record was complete but it was not immediately obvious who the record referred to. The former was seen to be rather valueless given the amount of information that would need to be stripped out to prevent identification. The latter was seen to be of important value to researchers but was in effect still 'identifiable' information.

Access

Access was discussed extensively. There were two major features identified. Firstly there was general agreement that the individual should have access to their record. Consumer access to the record was considered to be empowering as it allowed opportunity for reflection, inquiry and checking. This empowerment was expected to lead to consumers taking an increased responsibility for giving information and for their own care. Changes in behaviour were expected by the interviewees to arise from this
changed acceptance of responsibility. This view is supported by evidence in the literature\textsuperscript{44, 52, 118}.

The suggestion was made that a simple but powerful move towards consumers having greater access to their records would be to involve them more closely in the process of creating them. Concerns were raised that health records were complex constructs containing a large measure of specialist information and that they had the potential to confuse as much as to enlighten. The current process of provider control was seen by some to be an effective means of delivering the information to the consumer in meaningful packages.

Having in place accepted principles of consumer access with appropriate controls and a transparent process would avoid the adversarial nature of current requests for access, which are often viewed with suspicion.

The second and more complex issue was the process of determining who was entitled to have access to a record. It was suggested that the consumer should be the arbiter of who should have access. However, the concern was raised that they may not be well qualified to determine who should or should not have access. The dangers here were seen to be twofold. A consumer may release information to parties who may then use it or sell it without that person's knowledge and the person may suffer adversely from the misuse of that information. Secondly a consumer may withhold information which could be helpful in the provision of clinical care and consequently suffer adversely from actions being taken without full knowledge. It was suggested that the response to these concerns lay in providing people with sufficient information about why someone should or should not be allowed access.

An alternative suggestion was for a transparent process which included audit trails so that individuals could find out retrospectively who had accessed their record and would also have a reasonable idea prospectively over who may access the record. Such a process would allow consumers to control access to their information but only by withholding it completely. A particular concern was raised over whether non-health related third parties such as; the tax office, insurance companies and employers might have access to the information.

Suggestions were made about how access controls could be achieved. These included the idea of segmented access with different levels of access permitted to different parties.
with default settings and the ability for consumers or others to override in controlled circumstances. Concerns were raised that the use of information for administrative research lacked the ethical controls that exist for academic research even though from a consumer perspective the issues was essentially the same.

Disclosure

This topic was not discussed by many of the interviewees. However, some points of interest were raised.

People with conditions likely to lead to stigmatisation or devaluing such as RSI, chronic fatigue syndrome, mental conditions, STD’s and HIV/AIDS can feel that information can be and is misused to make judgments about them. As the anxiety increases about information being misused the more people want to have control over that information and determine where it goes.

It was suggested that consumers want, and possibly need, to be able to determine who has access and under what conditions. This would allow them to satisfy their need to control disclosure of information about themselves that Westin proposes lies at the heart of personal privacy. Consumers sometimes find out that their information is being used for purposes of which they were unaware. One interviewee referred to a submission by a public sector agency to a government inquiry in which the view was put that it would bias a lot of research if people realised that they were being researched. The submission expressed the view that people might alter what they say or selectively opt out if they were given the choice. The solution offered to this concern was the close involvement of consumer representatives when determining whether exemptions to the privacy principles were warranted in the public interest.

Appropriate consent processes prior to disclosure occurring was seen to be essential. Sometimes it would need to be opt-in, sometimes opt-out and in some cases consent might be able to be assumed or implied where the use of a service by the consumer was freely chosen. Consent obtained in situations where refusal was for all practical purposes impossible was seen by some interviewees as unacceptable. It was pointed out that Privacy Principle number 11 allows for disclosure in certain circumstances including where:
“the individual concerned is reasonably likely to have been aware, or made aware under Principle 2, that information of that kind is usually passed to that person, body or agency.”

Concern was raised that one of the greatest risks to the inappropriate use of information was the legitimate release of information to third parties that didn’t have the same appreciation of the need for privacy and later passed it on to others. Concern was also expressed that abuse of personal information by the initial party trusted with the information can render control through limiting disclosure ineffective.

**Control**

There was a broad consensus that in an integrated information system consumers would have to have some measure of control. However, what that control would be exerted over and how complete the control would be was unclear. There was a recognition that people currently control their information to some degree by limiting what they disclose to a provider and also through the use of multiple providers. However, once information has been disclosed the provider, or their employer organisation, controls it. It was thought reasonable to believe that in any future system individuals would want to maintain at least the same level of control as they currently have. If the system fails to provide such facility they will achieve it by adopting protective behaviours which may entail avoiding care or misleading carers by providing incomplete or false information.

In the context of an integrated system it was seen that the individual would have some control over who was granted a right of access to the information and to whom the information was disclosed. Potentially this control might be total. It was also seen that the consumer would have some measure of control over the content of the information. This control would include the right to amend or at least to request an amendment to the record.

**Miscellaneous**

There were a number of other issues that were commented on by a number of interviewees that were clearly implementation issues but didn’t fit in with any of the previous categories. These were data capture, time frame and standards.
Data Capture

There was a clear message that it would only be possible to collect and use a small portion of the total information that arises from health related encounters. There was an acceptance that data would need to be gathered at the point of encounter by the provider. The other notable observation was that the data collected would need to be determined by the requirements of the system users and not collected simply because it was possible.

It was seen that providers would be reluctant to collect information other than that which they required for their own purposes, either for the care of the individual involved and for practice management and professional review. Consequently downstream users of the data would need to extract the data required to satisfy their needs from the data collected by the provider. It was thought that the provision of feedback to providers on performance relative to their peers would be an acceptable extension of the range of activities for which providers might collect and supply data. This process is similar to an existing Health Insurance Commission program, however, it would be able to draw on more complete and pertinent information. Helping providers improve decisions through the use of decision support software was thought to be another approach that might increase the amount of data collected.

The mechanisms for data capture would need to be smart and efficient in order to cause least disruption to the encounter. It was thought that the technology was up to the task currently and that the eventual introduction of effective voice recognition products would provide a further gain in efficiency. However, as one interviewee indicated voice recognition software has been “just around the corner for the last 25 years”. Providers would also need to become familiar and comfortable with the various input tools. There was seen to be a need for training and support of providers as they climbed the learning curve.

Time Frame

A few of the interviewees put a possible time frame on the implementation of a national health information system. The estimates ranged from three years (“it’s on the edge, it just needs a push”) to twenty years (“If everything was optimised”). Three indicated
that ten years was achievable. The usual caveat was that work had to start today to meet the estimated time frame.

Standards

The issue of technical standards was raised by some of the interviewees. The standards mentioned covered: record architecture, minimum data sets, classification of terminology, communication, security and privacy.

It was considered that the existing processes of development and implementation of standards had been thorough but slow. The lack of agreed standards was seen to create a risk for providers when deciding which products to purchase. There was support for the idea of choosing a standard and making it work rather than trying to find the perfect standard or waiting for a decision to be made internationally. The adjunct of this view was that there would need to be allowance for future changes as no standard was, or ever could be, permanent.

Governments, both state and federal, were seen to be important players in the development and implementation of standards. Their role would be a leadership position but require consultation with the sector and use of its purchasing power to push the enforcement of the agreed standards.

5.4. Summary

The preceding findings are summarised into the following points.

Essential matters:

1. There was room for improvement in the use of personal health information.
2. Health records need to be centred on the individual consumer.
3. Consumers should have some measure of control over their own record. This control would include access for themselves and control in some form over access by others including disclosure to third parties.
4. Future health record systems are likely to be electronic in nature.
5. A national health information system would need to be able to adapt to, and enable changes, in the healthcare system.
6. A wide range of potential users and uses were identified.
7. The benefits of a national system would be likely to outweigh the costs but might not be the most effective use of health funds. Detailed analysis would be required.

**Implementation matters:**

8. Six groups would have a role to play in the creation of a national health information system, namely: consumer representatives, provider representatives, government, academia, the health industry and the IT industry. Key among these will be the federal government.

9. Sufficient benefits would need to accrue to the suppliers of the information to the system to ensure the quality of the information and the success of the implementation process.

10. The costs and the benefits must be equitably shared.

11. Consumer access to their records would strengthen the consumer-provider relationship but would require provider support to be successful.

12. Strengthening the consumer-provider relationship would be an important driver for change.

13. The system would need to be implemented incrementally due to its size and complexity. Five axes of incrementation were identified: system functionality, the range of provider types involved, the proportion of each type of provider, geographical coverage and the proportion of population covered.

14. The system would need to build from existing infrastructure and not try to impose a new system.

15. Agreement would need to be reached on what constitutes the ethical use of health information, what conditions will apply to those uses and how such uses would be supervised.

16. A number of barriers were identified including the complexity of such an undertaking, managing the organisational and workflow changes required by, and arising from, the new information system, stakeholder attitudes and suspicions, fiscal imbalance, and the lack of an agreed framework.

17. The development and enforcement of agreed national standards would be required.

18. Lessons must be learnt from other industries and other countries.

19. It might take ten years and work would need to start now.
Chapter 6 A System Model for an Australian IHRIS

This chapter describes a system model for an Australian Integrated Health Record and Information System (IHRIS). The chapter takes the findings of the initial investigations to develop the 'essence' of the system and then considers the technological constraints that would determine the form in which the system could be realised. The chapter concludes with an assessment of the ability of the proposed system to satisfy the unmet information needs of the Australian healthcare system identified earlier.

6.1. Structured Analysis

Structured analysis is a method of information system development that has been in use for 20 years. The elements of the structured analysis system model are derived from Yourdon's 1989 text\textsuperscript{236}. A system model built using the structured analysis method is made up of several components. These components are shown diagrammatically in Figure 6.1.

Figure 6.1. Components of a Structured Analysis System Model

6.1.1. The Essential Model

The Essential Model attempts to capture the essence of the system. That is, it describes what the system must do in order to satisfy the requirements of the users. Ideally it assumes nothing about how the system will be implemented and that perfect technology is available at zero cost. Yourdon argues that the speed of technological development and the time frame for systems development mean that the second assumption is functionally true.

The first task in developing the Essential Model is to identify the potential users and determine the uses to which they would put the system. From this information the Environmental Model and Behavioural Model components are created.
The Environmental Model

The Environmental Model describes how the system interacts with its environment. It consists of three components; a statement of purpose, the context diagram and an event list. The statement of purpose is the equivalent of a mission statement for the system. The context diagram is a simple data flow diagram, which outlines the users of the system and the data flows that cross the system boundary. The event list is a list of the 'stimuli' that occur in the outside world to which the system must respond. These 'stimuli' may be the supply of data or requests for data.

The Behavioural Model

The Behavioural Model represents the internal workings of the system, i.e. how the system delivers the desired outcomes in response to the stimuli received from its environment. It consists of a series of data flow models of progressively finer granularity until the processes described are primitive processes i.e. are unable to be further broken down, a process specification written for each of those primitive processes and a data dictionary that defines all the data elements.

6.1.2. The User Implementation Model

The User Implementation Model is the second major component of the System Model. Where the Essential Model assumed perfect technology the User Implementation Model takes into account constraints that limit the range of solutions that satisfy the essential needs of the system to those that could be implemented.

In the traditional systems analysis project this task involves detailed consideration of issues such as the

- Automation boundary i.e. where automatic and manual operations meet,
- Human-computer interface and
- Operational constraints such as: data volume, response time, politics, environment, reliability and security.

6.1.3. Modification of the Structured Analysis method

Structured analysis is an approach that works best in organisations with clearly defined boundaries and a formal command and control process. Consequently it has been used extensively in business systems development. The Australian healthcare system does
not conform to either of these two criteria. However, structural analysis does provide a useful means of analysing a complex situation such as information management in health, but it requires some adaptation.

The purpose of this project was to develop a broad-brush model that was sufficiently described so as to allow for a reasoned assessment of its utility and feasibility. As a consequence no process specifications or data definitions were prepared nor was the Behavioural Model downward levelled to the point of describing primitive processes.

As a further consequence of the decision to stop at a high level of abstraction the User Implementation Model was not able to consider the finer technical detail such as the human-computer interface or prescribe response times and the like. A liberal definition of what constituted operational constraints allowed for the incorporation of legal and cultural issues such as ownership and privacy.

The overall division of the analytical task into the ‘essence’ of the system and the ‘implementation’ of the system was adopted in the analysis of the interviews and also influenced the design of the second discussion forum.

6.2. What was learnt from the initial investigations?

The published literature, discussion forums and interviews together, provided the data with which to develop the model of a system which satisfied the needs and concerns of the users and other stakeholders. The major findings from these sources that shaped the system developed are summarised below.

6.2.1. Basic principles

The key message taken from the review of the literature in Chapter 2 is that future health records would contain data from multiple institutions and they would need to satisfy the needs of many users in addition to those of providers. The proposed IHRIS seeks to make available, where appropriate, information from virtually all health related events and be capable of meeting the needs of all identified users of personal health information.

The National Health Information Model\textsuperscript{19} and the Good European Health Record\textsuperscript{19} construct the health history of an individual from a series of events or ‘transactions’. Reports and summaries that provide the information required by any user can be
generated from reports of these events. The IHRIS system model has been constructed on the same basic principle.

6.2.2. Users and Uses

Potential users identified during the investigation included:

- Consumers
- Providers
- Public Health Professionals
- Researchers
- Policy Makers
- Health service planners and administrators
- Other Government Agencies
- Insurance Companies
- Medical Supplies Companies

Most of these groups could be further elaborated. For instance there were eighteen types of providers suggested during the investigation. Some of those types were, themselves, broad categories such as ‘specialists’.

Uses identified included:

- clinical decision-making,
- medication management,
- support for screening and preventive health measures,
- policy development,
- resource allocation,
- collection of evidence upon which to base medical practice,
- monitoring of disease outbreaks and adverse events, and
- post-marketing evaluation of drugs, devices and procedures.

Most of the users and uses were identified in the findings of the 1991 Institute of Medicine report. Notable additions were public health professionals and the monitoring of communicable disease outbreaks.
For simplicity all the users of the IHRIS have been grouped into four categories based on the role performed at the time of use. These roles are Consumer, Provider, Manager and Researcher. This matter was discussed in detail in Chapter 2. Two points to remember are that individuals may perform different roles at different times and that individuals may form groups such as families, clinical teams and healthcare organisations.

The uses of primary importance to the major stakeholders were identified through the second discussion forum. This was undertaken to maximise the likelihood of satisfying the major stakeholders.

Consumers indicated that their primary requirement was having access to their record. This assertion has been treated with some caution. Debate over access to records prompted by the ACT legislation was underway at the time of the second discussion forum. The proposed federal privacy legislation will grant consumers access to their health records. As a consequence, their expectations of the level of control they are able to exercise are likely to become higher. Allowing consumers the ability to make available all or part of their personal health information held in the IHRIS, wherever and whenever they wish, would be the toughest test that the IHRIS could have to satisfy. This requirement was assumed in the absence of better information. This issue would need to be clarified in any subsequent development program.

The primary outcome desired by providers was the ability to access information that would enable provision of better quality service. This information fell into three categories, namely: clinical data, relevant explanatory information for the consumer and data that would enable the provider to evaluate the service that they were providing. Of these three categories IHRIS would need to support the first and third. The provision of explanatory information to consumers would be best supported by other applications made available to providers. There would be some prospect of tailoring such advice based on data recorded in the IHRIS.

Providers indicated that the primary report that they required, to assist them in clinical decision-making, was a health summary. They rarely needed access to the complete record. This preference is reflected in the Royal Australian College of General Practitioner’s record system, which places a one-page health summary at the front of the folder. This was also suggested in the Institute of Medicine report88.
Researchers identified access to complete records of a number of people that could be linked to other data sets and used for analysis as their primary requirement. They indicated that the names of the people were not necessary for the analysis, simply the knowledge that the records were otherwise complete. However, the ability to link these records to other data sets could require or be considerably assisted by having the names. This requirement may conflict with consumer’s wish for privacy and for control over disclosure. A solution to this potential conflict is proposed later.

The foremost need for managers was the provision of information to provide assurance that they were getting value for the money spent on services provided. Other desirable outcomes for managers included:

- Access to reliable, timely information that assisted decisions on resource allocation.
- Optimising the efficiency and reliability of processes and mechanisms for the collection of data.
- Facilitating the compilation of national statistics and disease registers.
- A data set to help evaluate policy options.

**6.2.3. Other Essential Elements**

There are other important elements of the system that will shape how it performs. Primary among these is the need to satisfy the privacy needs of the people. The privacy needs of Australians have been codified into a set of principles in the Federal Privacy Act of 1988 (see Appendix H). These principles include the ability to inspect their own information and to seek amendment if it is believed to be incorrect, to be informed of the uses to which the information will be put and to be confident that the information is held securely.

One form of control over personal health information that consumers currently enjoy is the ability to disclose different information to different providers. This ability will need to be provided by the IHRIS. That is, the record will need to be able to be partitioned by the consumer for use in interactions with providers.

A number of uses were indicated as being unacceptable. These included: use of the information by governments for ‘oppressive’ control of health practitioners and service use by consumers, by financiers to determine borrowings and by employers and insurance companies to determine employment and insurance status. Clearly these are
only examples and each reflects the viewpoint of only some of the stakeholders. Government may want to undertake analysis for reasonable planning purposes which providers and consumers may see as being, or leading to, 'oppressive control'.

Agreement will be required on which general categories of use are acceptable or not and how to treat individual requests in the uncertain areas. It will be necessary to ensure that people are comfortable with the uses that will be made of their information and with the processes associated with determining and monitoring those uses. In the absence of such an acceptance, the system may be politically unacceptable, or many people may adopt disclosure strategies that are detrimental to the quality of data collected and possibly to the detriment of their own health.

6.3. The Essential Model

Working with the conclusions summarised above the first task was to build the Essential Model. This contains two major elements, the Environmental Model and the Behavioural Model. The key feature of the Essential Model is that it is a logical model. Ideally it assumes perfect technology and ignores constraints placed on the system by technology. In practice it was developed in parallel with the User Implementation Model which takes into account technological issues.

6.3.1. The Environmental Model

The Environmental Model contains three key elements: the Statement of Purpose, the Context Diagram and the Event List\textsuperscript{236}. Together these describe the environment within which the system operates and the stimuli it receives from that environment to which it must respond appropriately.

Statement of Purpose

The statement of purpose can be thought of as a mission statement for the system. It is intended to be a concise description of the system for use in describing it to high-level decision-makers. The Statement of Purpose was not investigated during the preliminary investigations. Should a development project be undertaken, reaching agreement between the many stakeholders on a Statement of Purpose would be one of the many details that would need to be finalised.
The following statement was developed by the author to assist in the development process.

"To improve the health of Australians, both individually and at a population level, through the provision of valid, relevant, timely and clearly presented data, derived from reports of health events, to authorised users, for authorised uses."

Contained in this statement is the dual aim of improving health directly through clinical care and indirectly through analysis and feedback by managers, researchers and professionals' representative and educational organisations.

In using 'reports from health events' the statement is tying the system strongly to principles of both the National Health Information Model and the GEHR Architecture. There is no direct reference to the event reports being from multiple institutions; this is taken to be implicit in the statement.

The use of the adjectives 'valid, relevant, timely and clearly presented' to modify 'data' could be seen as unnecessary as this is the ambition of all information systems. They have been included for emphasis. The challenges involved in meeting these criteria are significant and must not be forgotten.

Using the adjective 'authorised' to modify both 'users' and 'uses' is intended to suggest the overall security and privacy features of the system.

**Context Diagram**

The context diagram is a diagrammatic representation of how the system interacts with its environment. Three context diagrams have been provided, the first two describing the Users and the Uses of the system, while the third shows the grouped inputs and outputs of the system. Attempting to contain all this information in one diagram made them too complex and confusing.

In Figure 6.2, the Users diagram, the large circle in the centre of the diagram represents the IHRIS. The potential users are shown as boxes surrounding the system. These have been divided into the four roles: Consumers, Providers, Managers and Researchers.

The data flows between the users and the system are shown as named arrows. The names indicate the type of data and the arrowhead gives the direction of flow.
This diagram makes two important simplifications. Each exchange of information will involve a series of communications for quality control, validation, security and authorisation purposes. However, these have been omitted for clarity. The second simplification is in the naming of the data flows to the Managers and Researchers. There will be a wide variety of reports provided to these users but again clarity was chosen over comprehensiveness at this point. This issue is described in more detail in the next diagram.

**Figure 6.2. Environmental Model - Context Diagram 1 - Users**

The box entitled Consumers refers to people in the role of consumers of healthcare services. It is important to note however, that these are necessarily limited to those consumers registered with the IHRIS. This would not include all healthcare service consumers, as the system would not necessarily be compulsory.
Similarly the box entitled Providers refers to all health service providers registered with the system. As with consumers not all providers would be included. This arises because the system would not necessarily be compulsory but is also because of the difficulty in defining where the boundary of health services lies.

The remaining two boxes, Managers and Researchers, contain all other users of the system. The diagram includes a list of the major members of these two groups.

The box entitled Managers incorporates all the people and organisations that would use the IHRIS to organise and administer all or part of the healthcare system. This covers both government and private organisations.

The box entitled Researchers includes all the people who would use the IHRIS to generate new knowledge through analysis. Much of this information would be fed back to providers, consumers and managers to assist them in their decision-making. Some of the data will be used to inform commercial decisions and activities such as community risk assessment for insurance companies and also for market research for commercial enterprises. The issue of establishing the boundaries for the acceptable use of the IHRIS for commercial and other uses is discussed in more detail later.

The simplicity of the fundamental operation of the system is easily seen. Event reports from healthcare providers and consumers are supplied to the system and reports based on the information contained in the event reports are issued to users. This diagram does not outline the controls on access to, and use of, the information. That task is discussed at length later.

The Uses diagram, Figure 6.3, introduces some of the complexity hidden in the previous diagram due to the grouping of the users. The first point to note is that all data flows are outwards. The data flows stop at the initial terminator, which is shown as a box. The second point to note is that as far as the IHRIS is concerned subsequent use of the data supplied is of no relevance to the initial system design. This would be of importance, however, in an evaluation of the benefit of the system and in ensuring satisfaction of privacy requirements.

The Clinical Decision-Making and Personal Decision-Making Uses (Figure 6.3) relate closely to the Providers and Consumers respectively in Figure 6.2. The associated data flows involve the supply of data taken from the event reports of a single individual.
This may take the form of a health summary or a more complete report covering a wider range, or more focussed selection of data.

Figure 6.3. Environmental Model - Context Diagram 2 - Uses

The remaining four boxes are Uses which support the needs of Managers and Researchers. The major differences lie in the nature of the data supplied by the IHRIS. For the Maintenance of Registers for health purposes the data would be in an identified or at least identifiable form. For Record Linkage for Research the data would consist of all or parts of unit records with identifiable information, possibly including name. For Analysis the data would be aggregated, while for Payment Authorisation/Auditing the data would again be identified reports.
The purpose of the grouped flows diagram, Figure 6.4, is to assist in understanding how the system operates internally. Organising the inflows and outflows into different types of dataflow, as viewed by the IHRIS, makes it easier to plan the internal operations of the system. This diagram again emphasises the fundamental simplicity of the system. The complexity arises in the realisation of that system and will be discussed later in this chapter and also in the next chapter.

At the top of the grouped flows diagram are the parties involved in supplying information to the IHRIS. There are only two: Providers and Consumers. These suppliers provide reports of health-related events to the IHRIS. On the bottom of the diagram are the users of the IHRIS, that is those who seek information from the IHRIS.
**Event List**

The last element of the environmental model is the event list. This lists the stimuli or events that the IHRIS must respond to. There are in essence only two:

1. Supplier supplies an event report
2. User submits a request for a report

There are, however, many variations of both these events that will need to be taken into account in the operation of the system. Omitted from this list are the system’s administrative events such as registration of new consumers, providers and other users. These events would need to be included in any implemented version.

**6.3.2. The Behavioural Model**

The Behavioural Model consists of two major elements: the Data Flow Diagram and the Entity Relationship Diagram. Together these describe how the system operates internally in order to produce the desired responses to the stimuli received from the surrounding environment.

**Data Flow Diagram**

The grouped flows diagram (Figure 6.4) provides a useful lead into the behavioural model. The top-level dataflow diagram (Figure 6.5), shown below contains only two external entities: Suppliers and Users. These represent respectively the parties shown at the top and at the bottom of the grouped flows diagram (Figure 6.4).

There are five processes (shown as ellipses) and five data stores (shown as two parallel, horizontal lines) in the Data Flow Diagram. The processes shown in this diagram are briefly described below. The process starts with the supply of event reports to the IHRIS and follows through to the reports supplied by the IHRIS.

The first process is Input Control; this involves an exchange of messages between the IHRIS and the supplier. This exchange will initially establish the identity of the supplier, confirm they are authorised to supply information to the IHRIS and activate necessary security elements. The next step would be to establish that the event report being supplied satisfied the necessary content and quality standards and was clean of viruses and other extraneous material. It is worth noting that the event report itself would be a summary version of the data captured by the provider during the event.
Thirdly the event report would be given a unique identifier. Finally the event report would be passed to the Received Event Report data store to await further processing.

Figure 6.5. Behavioural model – Data Flow Diagram

The next stage is Rule-based Processing. This process is intended to occur very shortly after the event report was received. The Received Event Reports are inspected to elicit information necessary to perform several tasks. These tasks include passing on data required to update the person’s Health Summary and the generation of any automatic reports. It is necessary to point out that the method of establishing and maintaining the processing rules is not shown. This would be an important administrative task in managing the system.
The next process is Updating the Health Summary. This would occur rapidly to ensure that consumers, who move quickly from one provider to another, e.g. from a general practitioner to a pharmacist, would have their information available. The process Update Health Summary would take the data received from the Rule-based processing. This may be the full content of the event report. A copy of the existing Health Summary would be extracted from the Health Summary data store. A determination of what, if any, changes were needed would be made and performed. The new Health Summary would be sent to the Health Summary data store where it would supersede the previous version.

Automatic reports would be triggered in a process similar to Hripsac et al’s clinical events monitor\textsuperscript{128}. For instance, if the event report included the code for a notifiable disease a report would be generated which would be sent to the appropriate agency. Similarly if the person to whom the event report relates was registered with a research trial a report would be prepared and sent to the trial register. Other automatic reports could include a report to service funders that a particular service had been provided and reports to update other registers such as births and deaths, disease, device and treatments, and any others authorised to receive reports. All reports once created would be sent to the Report data store where they would be held until sent to the designated User.

After the Rule-based Processing is complete the event report would be sent to the Event Report data store. This would be the major repository in the system. Once stored the Event Report would remain there until archived.

The other end of the system starts with the process Output Control. This would be the second point at which the system interacts with its environment. This process would involve significant dataflows into and out of the system.

Looking at the inflows first. The first step would be for a User to submit a Report Request. These could take a number of forms including a Health Summary Request, an Automatic Report Request, a Routine Report Request and an Ad-hoc Report Request. Health Summary and Automatic Report types have been discussed previously. A Routine Report would be a report prepared and issued at nominated times. It could be, for example, a report on hospital separations prepared and issued monthly. A Routine Report Request would contain information regarding the timing and content of the
desired report. An Ad-hoc Report would be one-off report. For example, a researcher might request information on the incidence of a particular disease amongst a particular population.

The process of submitting a request would be similar to the process of submitting an Event Report described earlier. The identity of the User would be established, their authority to submit the particular request type would be confirmed and appropriate access rights and controls confirmed. The process by which the User’s authority to request certain information is established is not included in the diagram. This issue is discussed in detail later.

The next step would be to establish that the Report Request being submitted satisfied the necessary content and quality standards and was clean of viruses and other extraneous material. Thirdly the Report Request would be given a unique identifier. At this point different things would occur depending on the request type.

In response to a Health Summary Request the appropriate Health Summary would be extracted and sent to the User, this would occur very quickly. In response to an Automatic Report Request the appropriate rule would be registered and stored so that a report would be prepared if the appropriate data trigger was identified during Rule-based Processing of a subsequently received Event Report. In response to a Routine Report Request the necessary triggers would be set so that the required report was prepared at the appropriate time. The Routine Response Request would then be sent to the Report Request data store. In response to an Ad-hoc Report Request the request would sent to the Report Request data store pending generation of the desired report.

The next process described is Report Generation. A report would be generated in response to a Report Request. The process of Report Generation would involve examining the content of the request extracting copies of the necessary Event Reports from the Event Reports store and performing the calculations required to produce the desired information presenting it in the preferred form.

Once generated the report would be sent to the Report data store and held until issued to the User who requested it. This would involve appropriate security processes to ensure the report was issued to the appropriate User, that it maintained its integrity during delivery and was not observed by any other party.
The Entity-Relationship (E-R) diagram, Figure 6.6, describes the relationship between the data in the system. The E-R diagram can be divided into three groups: People, Events and IHRIS Reports.

The entities Person and Party in a Role describe the data relevant to the people who interact with the IHRIS and the roles they are performing when they interact with the IHRIS. Two points need to be made, firstly people may be performing two or more roles at the same time eg when an individual supplies an event report about themselves. Secondly some people will be acting on behalf of an organisation at the time they
interact with the IHRIS. This second point is covered in the National Health Information Model (NHIM). However, as far as the IHRIS is concerned the fact a person was working for an organisation would be relevant but of secondary importance.

The Event entity is the same as the Event entity in the NHIM. It involves one or more Consumers and one or more Providers, and occurs at a particular time and date in a particular location and setting. Each Event is classified as an Event Type either Health Service Event or Other Event. Each Health Service Event is classified as Health Service Event Type.

An important observation is that an Event may consist of an individual measuring their blood sugar level. In this situation the person would be both a Consumer and a Provider and, if they advise the IHRIS of this event, they could also be a Supplier.

Health Service Event Types would include, for example, a general practice consultation, the dispensing of a medication by a pharmacist, a hospital separation and a home visit by a community care worker. Each of the Health Service Event Types would have different data capture requirements defined in accordance with agreed profession requirements and established standards.

From a proportion of Events an Event Report would be prepared and supplied to the IHRIS by a Supplier. Each Event Report would refer to an individual Event and to an individual Consumer involved in that Event.

The consequence of potentially having more than one Consumer and more than one Provider involved in an Event is that there may be more than one Event Report supplied to the IHRIS that relates to the same Event. In the majority of Events this situation would not arise. However, rules for handling conflict between the reports would be essential. Requiring each Event Report to refer to only one Consumer would make access control simpler. The issue of how a Consumer could access Event Reports referring to other Consumers at the same Event would need to be resolved.

The previous group of entities referred to the input of data to the IHRIS. The last group of entities refer to the output from the IHRIS. A User creates an IHRIS Report Request. The request leads to the creation of an IHRIS Report, which is then issued to the User. The IHRIS Reports are created from information contained in the Event Reports.
6.4. The User Implementation Model

The User Implementation Model takes into account the technological constraints that determine the form of the system adopted. This model describes how the essential features of the system could be realised.

To understand how the national system could work it is helpful to start by locking at a regional IHRIS. The rationale behind the existence of regional IHRIS systems is explained in the next chapter. Figure 6.7 shows the general arrangement. Event reports are supplied by a Provider or a Consumer in accordance with the necessary security and quality controls as discussed previously. The Consumer’s Health Summary is updated immediately and the Event Report is then stored in the regional data warehouse.

Figure 6.7. User Implementation Model - A regional IHRIS

It is important to note that the relevant health summary may be stored in any of the regional data marts. Storing the Event Report would involve some processing of the data contained so that subsequent request for information could be responded to efficiently.
Requests for health summaries would be supplied directly from the regional data marts while other report requests would be satisfied from data stored in the data warehouses.

The national IHRIS is likely to be a distributed data warehouse. Figure 6.8 depicts the components of the national IHRIS. A secure communications network ensuring that the system acted as a seamless entity distributing information wherever necessary would link the regional IHRIS systems.

Figure 6.8. User Implementation Model - The national IHRIS

To support the national IHRIS there will be a number of national components. These would consist of administration and technical services. The former ensures the efficient and effective management of the organisation and the latter the operation of the system. Determining where ultimate responsibility for the management of the system would lie is an important political question that would need to be resolved during development.
Possibilities include the federal minister for health, the Australian Health Ministers Council and a national stakeholder partnership organisation.

Overseeing the operation of the IHRIS would be the necessary regulatory bodies and most importantly an ethical supervisory body. The ethical supervision of the IHRIS would most likely be an institutional ethics committee. This committee would need to be independent and have sufficient resources to ensure the required standards are maintained. The role of the institutional ethics committee is discussed further shortly.

The third diagram, Figure 6.9, depicts the data flows between the various physical components of the system. This is presented to highlight the nature of the interaction between the consumer and the provider.

**Figure 6.9. User Implementation Model - The physical diagram**

An illustrative example of how the system might operate in practice is presented in text box 6.1 to help the reader understand the physical processes described diagrammatically.
above. It is important to note that in any actual implementation the details would be different.

Text Box 6.1 An illustrative example of a health event interaction with the IHRIS

The stereotypical event that IHRIS would be involved in would be one Provider and one Consumer in one location at a defined period in time, for example, a general practice consultation. Following the preliminary introductions and initial explanations the Provider may ask permission to obtain a copy of the Consumer’s current health summary. The Provider would at some point, prior to the consultation, have turned their computer on and logged on using their provider card. They may have already entered some information into their clinical notes about this particular consultation. In order to grant access to their Health Summary the Consumer would insert their card into a reader. The first step would be a verification process, using a PIN or fingerprint; this would assure the system that the card refers to that particular Consumer. A further instruction to the system would provide the authority for the Provider to call up a copy of the Consumer’s Health Summary.

At the end of the consultation the Provider’s clinical notes system would automatically generate an Event Report by populating a report form with data captured by the provider in accordance with the national standards. The Provider and the Consumer might agree that the report was an accurate reflection of the encounter by clicking an OK button on the screen or on the card reader. The Event Report would then be supplied to the IHRIS as described previously.

An example event report would contain data identifying the provider, consumer and the location, the date and time, and data describing the encounter including items such as coded data on the reason for encounter, reported symptoms, diagnoses or proposed treatments.
6.5. Further clarification of the model

The following section aims to clarify several issues that are not made apparent in the system model outlined previously. These issues include privacy, ownership and Unique Personal Identifiers.

6.5.1. Privacy issues

There is a potential conflict between the desire of researchers to have a complete record for analytical purposes and that of consumers to be able to control disclosure and use of their information. A solution to this problem is crucial in that it would open the way to maximising the public benefit arising from the system while achieving the desired level of personal privacy.

In order to solve this problem it is necessary to look at the proposed uses of the data contained in the system and demonstrate how they can be achieved while satisfying individual privacy needs. The criteria taken for satisfying individual privacy needs are the Information Privacy Principles (IPP’s) contained in the January 1999 version of the “National principles for the fair handling of personal information”\(^{179}\). The potential impact of the changes to the national principles proposed by the Privacy Commissioner in December 1999 is discussed later.

The following groups of uses have been chosen for analysis. This selection is representative of the uses identified previously. The use of data by the individual concerned has been omitted as it necessarily satisfies the privacy needs of that person.

- Immediate clinical care
- Later clinical care
- Funding by government and other agencies
- Notifications a) of notifiable diseases, and b) to other legally required registers (Births, Deaths etc)
- Notifications to voluntary registers
- Creation of aggregated reports
- Linkage of individual records to other data sets for research.

The following analysis assumes that the majority of data held in the IHRIS would be collected by providers for immediate clinical purposes and subsequently reported to the
IHRIS for other uses. Many of the event records supplied by providers would be supplied with the concurrent consent of the individual concerned, for example a general practice consultation. There would be some event records that are generated in the absence of the individual, for example pathology results that would require consent to have been agreed previously or a mechanism for subsequent inspection and consent. Some of the event reports contained in the IHRIS may be supplied directly by the individual and would be assumed to have consent.

Having established a system whereby the supply of all event records to the IHRIS has the consent of the individual concerned, it could be argued that consent has been given for the subsequent use of the information. While such a view may be arguable, however, it is reasonable to apply a more stringent test on the assumption that any such consent is not fully informed. This lack would arise due to the nature of the collection process. Whilst the individual would be aware that information had been disclosed to the IHRIS it is not reasonable to assume they would be aware of all of the purposes to which it would be put.

Each of the uses will be explored in turn and the various elements of the solution proposed will be drawn together into a unified arrangement.

*Immediate clinical care*

Where a provider collects data for the immediate clinical care of that person the privacy principles are readily satisfied. This is no different to what happens today. The information has been collected for a lawful purpose directly related to the function of the collector (IPP 1.1). Indeed this stage of the process really falls outside of the domain of IHRIS. It could be argued that it is only when an event report is sent to the IHRIS that the system needs to consider how privacy concerns shape its subsequent operation. However, this distinction may not be recognised by the general public hence demonstrating that privacy requirements are satisfied for this use is appropriate.

*Later clinical care*

Where information disclosed to the system by a provider is used for later clinical care the first requirement is to ensure that the person has consented to that disclosure (IPP 2.1b). This is readily achieved, as the individual has to provide their authorisation at the time of the subsequent disclosure.
The second requirement is to allow people the ability to control the disclosure of their information to subsequent providers to the degree that they currently enjoy. This requires that consumers have the ability to partition their record. Partitioning the record could be achieved by allowing the person to set an access status to each event report. These access settings could be as simple or as complex as required. For example they could set it so that only Dr. Jones could access the event report or even that any provider other than Dr. Jones could access the event report. General default settings could be established which an individual could override if they desired.

Providers would argue that allowing such a partitioning of the record represents a risk to the health of their patients. This is probably true. However, it is necessary to recognise that people who choose to partition their record are entitled to do so. Controlling disclosure of information is the heart of the accepted idea of privacy. Managers of the system could argue that costs incurred by the system in the event that relevant information was not made available to the provider, would be to the detriment of other users and ought not to be allowed. While this is a fair argument, the current situation is that people already control what information is made available to the provider and will expect to do the same in the future. Furthermore, missing data due to inadequate communications is probably a greater problem than that of people choosing not to disclose certain data. That is a problem that the IHRIS would remedy.

*Purposes authorised under the law*

Use of the information for purposes required or specifically authorised under the law, such as funding by government and other agencies, notification of notifiable diseases and registration of events such as births and deaths, would be permitted under IPP 2.1f. This principle permits the use of personal information for purposes other than that for which it was collected where it is required or authorised under the law. The examples given are all ones that are unlikely to cause concern in the community. It would not be possible, and probably not publicly acceptable, to enact legislation to authorise all uses of the information.

*Notification to optional registers*

Notifications sent to registers such as disease, device and research registers, that is registers to which reporting is not legally required, would require the explicit consent of the individual (IPP 2.1b). The operational need would be to allow for an enduring
consent, which could be revoked and perhaps time-limited, to allow for these notifications to occur automatically and not require consent each time.

*Creation of aggregated reports*

The creation of aggregated reports for disclosure to others is likely to be one of the major public benefits of the system. It also represents the first major challenge in this discussion of privacy requirements. The challenge does not lie in the disclosure of the aggregated information, as this is no longer personal information. The issue is to ensure that the process of creating the reports satisfies the privacy needs of the community as a whole and of the vast majority of individuals.

This activity would be very similar to the work of the Australian Bureau of Statistics (ABS) on the national census. The ABS works with unit records for all Australian households and publishes aggregated data analyses for use by anyone. They perform analyses for individual parties on a commercial basis. They allow academics from authorised universities access to ‘Confidentialised Unit Record Files (CURFs)’ to undertake analysis for research purposes. The key difference between the proposed IHRIS and the work of the ABS is that the census data collection is required by law and is collected directly by the ABS. This allows the ABS to assert that the person who gave the information was aware of the purposes to which it would be put (IPP 1.3c) and it can therefore be used for that work. The IHRIS expects to work from information that was collected for immediate clinical care. However, an argument could be constructed that the information would be used for a purpose directly related to the purpose for which it was obtained (IPP 2.1a). This argument is probably not sustainable. Consequently a mechanism must be designed which enables the generation of aggregated reports to support the analytical activities that would assist managers and researchers while satisfying privacy requirements.

Potential solutions provided by the Information Privacy Principles are: advising people at the time the information is collected of all the uses to which it will be put (IPP 1.3c) and obtaining individual consent for each use (IPP 2.1b). It would be impossible for individuals to be informed by providers at the time information is collected of all the possible uses to which the information might be put, there are too many. It would also be functionally impossible in many cases to seek individual consent, particularly in the case of analyses involving thousands of records. The concern for researchers is that
analysis performed on less than the full set of records is potentially subject to selection bias. Finding a practical solution to this problem would be crucial to the utility of the IHRIS.

Research and partitioned records

Having argued that people are entitled to partition their record for clinical purposes it could be argued that consistency would require that such partitioning be allowed for research purposes. The validity of an analysis could be detrimentally affected by the completeness of each record. A distinction that can be made is between situations where the individual is either directly involved or could be directly affected by the use of the information and situations in which the individual is not involved and would not be directly affected by the proposed use. The acceptance of this distinction could enable the satisfaction of personal privacy while enabling the maximisation of the public good. Ensuring the distinction is maintained would be an enduring task.

Small cell inference

One concern over the free availability of aggregated data is the possibility of some information about an individual being discovered through small cell inference. If there is only one person in an area of a certain age and sex who happened to have gall stones, a report which sought the incidence of gall stones broken down by age, sex and area could allow someone to discover that someone they know has gall stones. The risk of this occurring is mathematically real but realistically improbable. The ABS circumvents this small risk by ensuring that the smallest number in any cell of the report is greater than five. They also require users of the data to sign binding agreements that they will not attempt to identify an individual. These agreements include strong penalties up to imprisonment in the event of an abuse of the data.

Record Linkage

An important method of investigation for medical research involves the linkage of health related information to non-health related data such as socio-economic status, occupation or environmental exposure. This requires a matching process to occur between the two sets of data to ensure that individual’s data is correct, prior to performing the aggregated analysis. Matching is achieved through a probabilistic
process which takes data fields such as age, sex, place of residence and where possible name. Where there is a unique identifier common to both sets this task is simplified.

The use of names is a sensitive issue to the general public. The response of the researcher is that the use of names is to maximise the matching prior to analysis and not to identify the person. Consequently the use of names would be expected to improve markedly the quality of the analysis and strengthen the value of the findings.

The ability to link health information to other information is a potential risk to individual autonomy. As such any process which enables linkage will require strong ethical supervisory mechanisms.

*The proposed solution*

Several features of the solution to the problem of satisfying privacy concerns while realising the maximum public benefit have been identified. These include:

- Allowing people to partition access to their record for clinical purposes
- Requiring consent from the individual to use previously collected information for clinical purposes
- Allowing for an enduring consent, which could be revoked and perhaps time-limited, for notifications to voluntary registers
- Accepting a distinction between situations where the individual is either directly involved or can be directly affected by the use of the information and situations in which the individual is not involved and cannot be directly affected by the proposed use
- Controlling for the risk of small cell inference in aggregated data tables
- Providing strong ethical supervisory mechanisms for record linkage projects.

The proposed solution is shown diagrammatically in figure 6.10. It assumes that the operation of the IHRIS would involve the establishment of an autonomous agency, similar to the ABS, which here shall be called the Australian Health Record Agency (AHRA). AHRA could equally be a unit of an existing agency such as the Health Insurance Commission or the Australian Institute of Health and Welfare.

AHRA would oversee the system, initially ensuring that the event reports are supplied with the necessary consent. AHRA would also ensure that requests for information for
use in clinical care had the necessary consent and that the provider was only supplied with the information allowed as determined by the access settings established by the individual. AHRA would be able to generate aggregated data tables from event records held in the IHRIS. AHRA could then issue the resulting tables to the requesting agency subject to controlling for the risk of small cell inference. AHRA would be able to link individual records to external data sets and then conduct the desired analysis before issuing the aggregated data or, where appropriate, issue de-identified linked records. They could also allow such linkage to be performed by other agencies if they had equivalent security and privacy arrangements.

The key requirement for the effective operation of the IHRIS, other than for clinical care, would be the establishment of a process whereby individual consent for every use of an event report was not a necessary requirement. This is an exemption that cannot be lightly granted. A process that had the support and approval of society would be required. The process proposed involves a competent, well-resourced ethics committee or data protection committee approving and supervising the use of the data contained in the IHRIS. The committee would need to be seen to act in the interests of the community and consequently would need to have strong consumer representation along with representation from other major stakeholders such as providers, government and researchers as well as professional members such as ethicists and lawyers.

One of the important tests that the committee would need to apply to any request for use of the IHRIS would be that individual informed consent was not realistic and that the individuals concerned would not be directly involved or directly affected by the analysis performed.

As outlined previously a political decision would need to be made as to where the ultimate responsibility for control of AHRA lay. It could be with the federal minister for health or with the Australian Health Ministers Council or perhaps a partnership of stakeholders. AHRA would need to be a national body but it would need to operate at the regional level to support the alternative solutions created but ensure that they are able to co-operate with others.
Figure 6.10. Proposed method for controlling access to data in the IHRIS

A mechanism does exist within the Federal Privacy Act that could be used to implement such an approach. Section 95 allows the National Health and Medical Research Council to issue guidelines for medical research, which permits research that may not otherwise comply with the Information Privacy Principles. (It is worth observing that this provision recognises that the public’s valuation of medical research can outweigh personal privacy concerns) The Privacy Commissioner will only approve the issue of such guidelines if they are satisfied that the public interest in promoting such research outweighs to a substantial degree the public interest in adhering to the IPP’s. The task would require the adoption of a broad definition of what constitutes Health and Medical
Research in order to allow for the administrative research that would support planning and policy-making and other such research.

*Potential effect of the proposed changes to the national principles for the fair handling of personal information*

In December 1999 the Privacy Commissioner released the report of his consultation on the revision of the national principles for the fair handling of personal information to account for health information. This consultation was conducted in order to advise the federal Attorney General who was preparing privacy legislation for the private sector.

The key change proposed that would affect the operation of the IHRIS is the addition of clauses 2.1d and 10.3. These two clauses have granted exemptions to the collection of personal health information for "research or the compilation of statistics, relevant to community welfare...". Such collection will be subject to a number of restrictions:

(a) The collection is necessary for research, or the compilation or analysis of statistics, relevant to community welfare; and

(b) there is no reasonably practicable alternative to collecting the information for that purpose; and,

(c) It is impracticable for the organisation to seek individual consent to the collection; and

(d) The information collected is:

   (i) as required or authorised by or under law (other than this Act); or

   (ii) in accordance with rules established by competent health or medical bodies that deal with obligations of professional confidentiality which bind the organisation; or

   (iii) in accordance with guidelines approved by the Privacy Commissioner under section 95A (Privacy Act 1988)

These proposed changes would make the task of undertaking research using the data held by the IHRIS simpler as they provide a number of alternative processes which would satisfy privacy requirements. However, it is not possible to assume the use of these new clauses as yet. Firstly the legislation has not yet been enacted and there may be some amendments made during the parliamentary process. Secondly the legislation
only relates to personal information in the private sector. It is not certain that the Federal Privacy Act will be amended to take account of the Privacy Commissioner’s recommendations.

Public support

Public support for any solution would rely on the creation of trust in the IHRIS by the community as a whole as well as the majority of its individual members. It will place a duty of care upon all researchers to respect the trust that they have been given to them by the community in allowing them to use individual’s information. There will need to be severe enforceable penalties in the event of an abuse of that trust. The establishment of trust would take time and would require continual reinforcement.

The views of the member organisations of the Consumer’s Health Forum (CHF) are enlightening on this issue. As part of an investigation of the use of consumer health information for research purposes the CHF surveyed its member organisations. Eighty percent of respondents were prepared in principle to allow researchers to have access to their records as long as they themselves had access and the right to amend their records first72. Appendix 5. The final report of this investigation pointed out that the debate over personal rights of privacy and public benefit has been falsely polarised as an either/or conflict. They preferred “...to emphasise the existence of parallel objectives and fruitful co-operation between consumers and bodies that seek to make use of consumers’ personal health information.” In addition the third of the basic findings of the report was that “Many consumers recognise that appropriate clinical, research and administrative uses of data that can bring significant benefits, both to individuals and the broader community”

The proposed IHRIS provides, as a matter of principle, access by consumers to their record. The test that the CHF report puts that the IHRIS must meet is that “...whenever the argument that individual consent is unachievable is used, any barriers that prevent the principle of informed consent from operating must be examined critically.” This would require demonstration of the benefit the system could deliver and that the methods of control ensure that people’s information is treated with the respect and care expected. In addition it would be necessary to demonstrate that it was not possible within the resources available to achieve the same results through other means. This
test would need to be applied when establishing the IHRIS and also when reviewing applications for individual queries.

Undoubtedly gaining and maintaining the support of the Australian public will be a major task. Without it the project is unlikely to succeed. The IHRIS must achieve equivalent status to that enjoyed by the Australian Bureau of Statistics with regard to its management and use of the national census records.

6.5.2. Ownership

The question "Who owns the data?" is one heard frequently in discussions on the use of health data from many parties. It is not a simple question to answer. The High Court in the 1996 case of "Breen and Williams" decided that no common law right of access existed for records held in the private sector. The case established that the property rights in the physical record resided with the provider or their employing organisation. The ACT Health Records: Privacy and Access legislation applied the Information Privacy Principles to all health records in the ACT including the private sector. This entitled an individual to obtain a copy of their record for a 'reasonable' cost.

Focussing on ownership only produces blockages and establishing a basket of rights to the use of the information is a more productive line of activity. It can also be argued that privacy had largely done away with issues of ownership. This may not be true.

The proposed IHRIS assumes in the first instance that providers will maintain their own records for their own purposes. The event reports supplied to the IHRIS would only be abstracts of the provider’s complete record. They would contain, in broad terms, matters of fact that may be relevant to future clinical care such as test results, diagnoses and treatments.

Providers claim that they have intellectual property rights in the diagnoses. This may be true. It is noted at this point that intellectual property rights can be purchased or licensed. Providers are also wary of giving away their information due to fear that their clients would subsequently use other providers. This last concern is unlikely to be acceptable to other stakeholders as a reason for not implementing the system. Market ideology requires that barriers to consumer choice be eliminated where possible. Government policy is driven by market ideology and consumer interests lie in enabling consumer choice.
Consumers may argue that as they commissioned the provider to use their skills in caring for them and consequently they have property rights in the information collected and created during the process. Such a claim would include the copyright in the information or else a licence to use the information for their own purposes later. The "Breen and Williams" case demonstrated that the consumer had no property rights in the physical record. In truth the question would require the determination of legal experts. It was assumed here in the absence of such advice that the provider's claim was valid as this represented the most difficult test to be satisfied.

Governments as the major funder of health services may claim that they have a right to sufficient information from the provider to provide assurance that they are getting value for the money spent on services provided. The sort of information that governments require may not include all the information preferably contained in an event report. Consequently they would not be able to justify asking for the full report. This would compromise the usefulness of the system.

One solution to this issue is to include as part of the contract for provider services, the purchase of an event report sent to the IHRIS, including all necessary licenses to use the information for subsequent purposes.

This answer may be acceptable to providers in that they would earn money from supplying the event reports. Unfortunately the IHRIS is unlikely to be able to pay more than a few cents for each report. However, this would be likely to cover the marginal cost of providing the report given that it would be an automated process drawing from what the providers had collected for their own use. However, it would not recompense providers for potential lost income from preparation of legal and insurance reports. When the proposed national legislation is introduced people would be able to obtain copies of their records anyway. This suggests that by the time the IHRIS was implemented this would no longer be an issue.

Consumers might see this answer as too favourable to the provider's feeling that it is their information anyway but they are possibly in a weak position to argue for a stronger position.

This answer would perhaps be acceptable to government, as they would have the information they need to be assured they are getting value for money spent. It would
also provide an important tool for improving quality. However, government may be reluctant to fund the purchase of the event reports supplied by providers.

The preceding three paragraphs are largely speculative and the issue raised and solution proposed would need to be examined further.

One problem with the positions outlined above and the solution proposed is that it assumes that information is an indivisible piece of property. Information is a peculiar resource, in that it is infinitely replicable and it is not consumed when used. The recent history of health records emphasises the increasing range of people who have legitimate interests in information contained in health records.

Providers are in a position of some power due to the historical developments. However, the recent change in the capacity of information systems to replicate, communicate and process information, along with changes in the delivery of healthcare services, requires new ways of thinking and an acknowledgment of the public benefit that can be derived from information captured in health records. This would entail providers relinquishing their grip on the information captured in the record and the acceptance by other users of that information that it is of value and took time and expense to collect.

An equitable sharing of these costs in line with benefits derived would potentially provide a more positive and enduring solution to the issue than trying to construct a legalistic solution based on power. Such an approach is probably idealistic; however, the nature of the IHRIS is one of trust and openness and sharing. Perhaps some means can be found over time to reach such an equitable solution. Realistically the pragmatic solution proposed above might be more achievable and if negotiated with goodwill could satisfy the major stakeholders.

6.5.3. Unique Personal Identifiers

The operation of this system will require the use of a Unique Personal Identifier (UPI). The use of a UPI is required to ensure that information supplied, particularly for clinical purposes, refers to the person concerned. Relying on data such as name, sex and date of birth leads to errors when linking any two records as mentioned earlier. Such errors would render the system ineffective and potentially dangerous.

The history of UPI's in Australia is dominated by the Australia Card proposal of 1987. This card was to have been an identification tool to control access to government
services. Currently every Australian State and Territory has some form of UPI in operation\textsuperscript{161}. These are sometimes termed Patient Master Indexes. They are often limited to use in public hospitals or only for administrative purposes.

The Health Insurance Commission has a Personal Identification Number (PIN) for every Australian registered for Medicare Services. As all Australian citizens are eligible for Medicare services this is an existing number which uniquely identifies all Australians. It must be noted that the Medicare PIN is different to the Medicare card number. Australians can have several Medicare card numbers during their life; however, these are all mapped to the single PIN.

Use of the Medicare PIN number as a UPI would require some legislative change and also some technical development. (Michael Parsons, General Manager Health Insurance Commission - personal communication) However, neither of these activities is viewed as being difficult. The primary issue would be to establish the uses to which the PIN would be put prior to seeking legislative change.

An alternative mechanism for introducing a UPI would be to build up from small areas to larger areas. To explain an example may help. The NSW Department of Health recently proposed the introduction of a statewide Patient Master Index. They were planning to create a PMI in each health region and then build a statewide index on top of the regional indices. This process could be further extended to a national approach by building a national index from state and territory based PMI's\textsuperscript{161}.

Getting the Australian public to accept the use of a unique identifier for health services would be a challenge. This issue is taken up further in the next chapter. Success will depend on the establishment of community support for the system. Seeking to implement a unique identifier without establishing the purposes for which it would be used and the means of controlling those uses would lead to almost certain failure.

One word of caution: the use of the word 'unique' is probably optimistic. People may be issued with more than one number through error or fraud. A single number may be issued to, or used by, more than one person. This will require robust validity checking and error rectification processes.
6.6. Discussion

Having proposed a system model for a national IHRIS the next step is to examine whether the system could satisfy any of the unmet information needs of the Australian healthcare system. The following section assesses the ability of the proposed IHRIS to meet those needs identified in earlier chapters. This assessment assumes that the system is fully operational. The challenges of making the proposed IHRIS fully functional are discussed in the following chapter.

There have been a number of needs identified in this thesis. Starting with chapter one it was proposed that the system should assist in the improvement of the quality of care provided. Can the proposed system provide that assistance? The system delivers more complete and better-organised ‘consumer data’ to assist decision-making by clinicians and policy-makers than the current arrangements. Furthermore the system can also provide important data to improve health knowledge through research and for the organisation and supply of resources through feedback to planners. These latter two are important means of achieving desirable adjustment in the behaviour of the healthcare system.

In chapter three a series of deficiencies were identified in existing health records and associated information systems. These included:

*Individual care*

- Administration of drugs to which the consumer was previously known to be allergic
- Drug interactions arising from drugs prescribed by different providers.
- Unnecessary repetition of tests due to non-availability of previous results.

*Policy-making, planning and research*

- Post-marketing evaluation
- Adverse event detection
- Tracing recipients of a defective service or product
- National statistics generation
- Creating and maintaining disease registers
- Communicable disease surveillance.
The proposed system would not be a miracle cure, for instance it will not detect all adverse events or prevent all medication mistakes, however, it would be able to improve significantly on the current situation in all these areas.

In chapter four a list of the primary desired outcomes of the major users were identified. Consumers wanted access to their record. However, for reasons discussed earlier in this chapter it was assumed that the ability to make available all or part of a consumer's personal health information wherever and whenever they wish would be a more suitable challenge. The IHRIS would be readily able to meet this need.

Providers wanted the ability to access information that would enable provision of better quality service. This information fell into three categories, namely: clinical information, relevant explanatory information for the consumer and information that would enable the provider to evaluate the service they were providing. The IHRIS would be able to support the first and last of these needs. It could also assist in the provision of explanatory information if used in conjunction with a smart knowledgebase that tailored the information supplied according to information in the integrated record.

Researchers wanted access to a national health data set containing de-identified but linkable integrated records. The key to carrying out retrospective case note reviews was seen to be assurance that the integrated records were complete histories of unique individuals. The IHRIS would meet the need for integrated records that were complete histories of unique individuals.

Managers wanted information that provided assurance that they were getting value for the money spent on services supplied. The ability to better target interventions and to undertake outcomes analysis would help assure managers that they were paying for effective services.

In chapter five the interviewees identified the two key problems with existing health records and associated information systems as the lack of an individual focus and record quality. The proposed IHRIS is intrinsically individually focussed. Record quality will be an enduring challenge. It is likely that automation will improve some data quality problems but not all of them. It must be emphasised that the preceding assessments have all assumed that the IHRIS was fully functional this would include the requirement that data of the appropriate quality was being supplied.
6.7. Summary

This chapter outlined a system model for an Australian Integrated Health Record and Information System. It was shown that the model proposed could satisfy many of the unmet information needs of all major stakeholders while meeting the privacy needs of the Australian people.

Therefore an Australian IHRIS could satisfy significantly more of the information needs of the Australian healthcare system than present health records and associated information systems.
In addition to the interviewees discussing the two key problems, one concerning health record and associated information sharing on the lack of an individual focus and record quality, the proposed DSS, health management indeed is fully functional. First of all, the DSS will be an excellent guide for handling health record and associated information sharing on the lack of an individual focus and record quality. The proposed DSS, health management indeed is fully functional. Second, overall, the DSS will be an excellent guide for handling health record and associated information sharing on the lack of an individual focus and record quality. The proposed DSS, health management indeed is fully functional.
Chapter 7 An Implementation Strategy

This chapter proposes an implementation strategy for an Australian IHRIS. The purpose of this work is to answer the second thesis question “Could Australia build a national IHRIS?” The simplistic answer would be that with enough money and time it would be possible to do anything. The answer becomes much less certain if constraints on money and time are applied; in that situation other limitations become more important.

The approach adopted in answering the question was to develop a feasible implementation strategy, thereby demonstrating that there is at least one pathway to an Australian IHRIS. No attempt has been made to identify the best strategy. The proposed strategy is compared with the approaches taken internationally.

7.1. Developing an implementation strategy

Many elements of the implementation task were identified during the discussion forums and interviews. These have been grouped into three categories:

**Overall strategy**

- The need for a shared vision and an agreed national framework for implementation
- Ensure necessary standards are developed and enforced
- Strike a balance between a top down and bottom up approach
- The process should be evolutionary not revolutionary
- Be aware that the process will take many years

**Tactical issues**

- Work closely with those most directly affected
- Involve a wide range of interest groups in the process
- Stakeholder suspicions will need to be accounted for
- Learn from other countries and industries

**Change management issues**

- Realise that the introduction of the system will lead to changes in the way healthcare services are delivered
Management of organisational and workflow changes will be complex and challenging

Preparing the country for the change will be necessary

These overarching principles have been incorporated into the strategy. However, the primary message from the discussion forums, and the interviews, was that development of an IHRIS would need to be incremental. Five possible axes of incrementation were identified, these were:

1. geographical area
2. the proportion of the population covered within each area
3. the range of provider types involved
4. the proportion of each type of provider type involved and
5. system functionality or record content

Developing an incremental process that expands along these five axes in a meaningful fashion was taken as the main task in creating the implementation strategy. Before outlining the strategy, each of the axes is discussed in more detail.

7.1.1. Geographic area

Incremental development by geographic area can follow three paths. It would be possible to start in one area and gradually expand the boundary until it encompasses the entire country. Alternatively it would be possible to develop the system in a number of contiguous areas and then link them up. A hybrid option would also be available where development occurred in a number of separated areas that then grew and also became linked.

Given that the IHRIS would not be implemented in a greenfield environment it would be necessary to work within existing health service structures. Using State and Territory boundaries as the demarcation of regions would be possible, however, such a division would be too cumbersome particularly in the larger states. Divisions of General Practice would be another candidate for defining region boundaries. However, these divisions are voluntary associations of GP's in a designated area and are not currently involved in the provision of many health services. Consequently they are not suitable candidates. Divisions of General Practice may become more involved in the provision
of healthcare services through extension of the coordinated care trials and should that happen a reappraisal would be warranted.

State and Territory health services, primarily public hospitals and community care services, generally operate within regions. These Area Health Services are essentially contiguous and cover the country. There is a level of complexity in the health services provided within an Area Health Service that would suit the implementation of the IHRIS. Generally within each area there are state and territory government funded hospital and community care services in addition to services provided by doctors, pharmacists and non-government allied health professionals.

Table 7.1. Number of Health Regions by State and Territory

<table>
<thead>
<tr>
<th>State or territory</th>
<th>No. of Health regions</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Queensland</td>
<td>13</td>
<td>38 Districts plus the Mater hospitals</td>
</tr>
<tr>
<td>New South Wales</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Northern Territory</td>
<td>1</td>
<td>Divided into 2 operational areas.</td>
</tr>
<tr>
<td>South Australia</td>
<td>8</td>
<td>7 Rural and Adelaide</td>
</tr>
<tr>
<td>Tasmania</td>
<td>1</td>
<td>Previously 3 but increasingly managed as a single unit</td>
</tr>
<tr>
<td>Victoria</td>
<td>9</td>
<td>4 Urban, 5 Rural</td>
</tr>
<tr>
<td>Western Australia</td>
<td>7</td>
<td>6 Rural and Perth (32 Districts)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>57</td>
<td></td>
</tr>
</tbody>
</table>

This table was compiled in June 1999 from contributions to the NCEPH National Health Informatics electronic discussion list and some follow up telephone calls with State health departments.

It is important to acknowledge that Area Health Services have permeable boundaries in that consumers move freely between them and some health services cross the area boundaries. There are approximately 57 Area Health Services in Australia with an average population of 320,000 people. It is noticeable that there is an inverse relationship between the total population and the size of an area health service. The larger areas such as the Northern Territory and rural South and Western Australia have smaller numbers of people, while urban area health services tend to have larger
populations and smaller areas. Table 7.1 sets out the breakdown of area health services by State and Territory.

The implementation strategy proposed is to work within the boundaries of the established area health services, build capacity within each region and then links them together. This model could be varied perhaps within state boundaries. Given the heterogeneity of health service administration between states this may be necessary.

South Australia is one example where a statewide implementation may be appropriate. The rural areas are all small (average population ~60,000) and they rely on the major metropolitan hospitals for many tertiary services. Assuming some amalgamation of area health services with small populations there could be about 50 regional IHRIS’s.

Working within boundaries defined by government services may favour hospital and community services in the development of the regional IHRIS. However, private specialist, general practice and pharmacy services functionally align themselves to the government health structures due to their smaller organisational unit size. Consequently using government service boundaries represents the path of least change. The necessary adjunct is to emphasise that the complete community of health services within regions would need to be involved in the creation of the regional IHRIS, not just government services. This approach was used in the United Kingdom when instituting the internal market reforms of the 1980’s (Dr Roopa Mehta, AT Kearney – personal communication).

7.1.2. Proportion of the population covered

The ideal system for researchers and planners would have the IHRIS cover 100% of the population. This might prove to be the desired endpoint but such an assumption should not be made at the beginning. Reaching 100% coverage would require a gradual process. There are significant elements of society that are suspicious of large information systems particularly where government is involved. In the case of the Australia Card, which was a compulsory national system, these elements were able to arouse sufficient political support to see the project abandoned. While a single transition point may have some appeal from an efficiency point of view the risk of the whole project being abandoned would be significant. A gradual process would allow for the development of security and privacy mechanisms, the assessment of the benefits
and the costs and most importantly allow trust in the system to be established in the community.

The IHRIS is inherently more likely to assist in the care of people who use more than one health service provider and those who use health services frequently. It has been estimated that 10% of the population consume 50% of health services. Starting with these people would offer important benefits to the individuals and that part of the system that could benefit most substantially.

An 'opt-in' process would necessarily enroll only those people who viewed the system favourably enough to make the effort to join. Should the IHRIS prove beneficial and should the system become acceptable to the community moving to an ‘opt-out’ participation method would result in all those who were indifferent to the system being enrolled. This could be achieved gradually by enrolling children at birth to support childhood development monitoring programs. Enrolling people whenever they next used a health service in the region would be a faster process. This latter method emulates the approach taken by New Zealand in implementing its National Health Index and also by Western Australia in implementing a unique patient identifier.

Achieving 100% coverage would require compulsory participation. A move to compulsory participation would require very careful consideration of the benefits and costs involved. The IHRIS would have to demonstrate that it could maintain security, respect privacy, establish a high level of trust in the community and also deliver significant benefits.

7.1.3. Range of provider types involved

The interviewees identified a long list of people and organisations who could be viewed as providing healthcare services. Included in this list were: general practitioners, specialists, pharmacists, hospitals (public and private), ambulances, allied health professionals, dentists, optometrists, physiotherapists, podiatrists, chiropractors, community care providers, blood banks, dietitians, fitness advisors, spiritual advisors, counselors and alternative therapists.

The discussion on where the boundary of health lay was deemed to be endless by a number of the interviewees. The most useful suggestion was to work with those who were available and who delivered sufficient benefits to justify the costs. The
interviewees emphasised that starting with a limited range of providers and increasing over time would be a sensible approach.

Increasing the range of provider types would require assessment of the net benefit of expanding the system to include a new type of provider. Each additional provider type would need to demonstrate that they had established the necessary physical and informatic infrastructure. They would also need to justify their inclusion on health and economic grounds.

7.1.4. Proportion of each provider type involved

Increasing the proportion of each provider type involved will occur gradually as physical infrastructure is installed and each provider decided that the benefits of joining were sufficient to justify the cost. Providing incentives for joining to targeted groups of providers could be beneficial to the operation of the system. These incentives could be in cash but could be in time, satisfaction or efficiency. Market forces could be sufficient to convince providers to join. Should the IHRIS prove to significantly improve health outcomes, duty of care considerations may cause the use of the system to be seen as necessary.

The proposed strategy assumes an ‘opt-in’ process for providers. Having all providers of certain types participating would provide some administrative efficiencies and health benefits. The task here would be to ensure that appropriate incentives are provided to justly compensate for any costs incurred.

7.1.5. System functionality or record content

The IHRIS will need to offer support for sufficient functions to make it valuable to users. The range of functions that it could support will be largely a question of the amount of data captured in each event report and the variety of event types captured. The latter being largely determined by the range of providers involved. Realising the benefits will require the development of decision support tools that can utilise the data that the IHRIS will supply.

The first group of users who will need to be supported would be providers. This follows from their role as the major data collector. In order to realise the expected benefits in consumer care the work of the provider is crucial. If providers do not find the system useful they won’t use it and the quality of data that is captured will deteriorate.
Providing support for clinical decision-making will develop progressively. Support for medication management would be an appropriate starting point. Subsequent stages could include information to support preventive health measures such as immunisations and screening tests, recent pathology and diagnostic image results, and tracking of risk factors such as smoking, weight and lipid levels. A parallel development path will be to automate structured communications such as notifications for communicable diseases and immunisations and the triggering of reminders and recalls to consumers.

The second group who will need support are the managers who administer the healthcare system. Enabling them to utilise resources more efficiently will provide the economic grounds to maintain the IHRIS. Their expressed desire is for information to provide assurance that they are getting value for the money spent on services provided. The IHRIS in its initial stages will not provide the comprehensive information on service consumption. Funding agencies will gather that information through their funding mechanisms. Early versions of the IHRIS could support the managers’ interests by providing information about the effectiveness of treatments through research on small groups, by supporting quality improvement processes such as professional review and by the avoidance of adverse events through the supply of more complete and accurate personal health data.

The last group to need support is the researchers. The major benefits to be derived from the system from knowledge creation lie in the future. These benefits are expected to be substantial. However, in the initial stages of the system the other users mentioned will have logical precedence. The necessary challenge is to ensure that early developments do not preclude later work intended to support the work of researchers.

7.2. Proposed staging to implement a national IHRIS

The following section proposes a staged implementation strategy developed from the preceding considerations. The pathway starts with intra-regional development and is followed by linking of the regions. The national infrastructure necessary for these staged developments to occur is discussed. Finally issues of project management, time and cost are covered to complete the section.
7.2.1. Regional development

The following section gives a brief outline of the three major stages proposed for intra-regional development. Details of each stage are provided subsequently.

Different regions could adopt different approaches in the initial stages. Some regions could start with a population afflicted by a particular disease such as diabetes, other regions could extend developments arising from a co-ordinated care trial and others could focus on pathology reporting. The task at hand is to demonstrate that there is at least one feasible strategy, medication management has been chosen a reasonable candidate for reasons outlined shortly.

The process starts with a very simple exercise in automation. This stage is intended to be simple in concept to increase the chance of success with the hope of breeding future success. Electronic transmission of prescriptions has been chosen for a number of reasons. It requires communication between two types of health provider. It fits well with the pharmacy intranet project which is building communications between pharmacists and other elements of the healthcare system. It also fits with the incentives currently provided under the Federal government’s Practice Incentives Program (PIP). The PIP pays approximately A$10,000 to full time GP’s who join the scheme, use medication management software and have an e-mail address.

The first stage introduces three major elements of the later stages; namely: a storage point in the system, the processing of information while being stored and the use of a card by consumers to control access to their information. Increasing provider skills and experience would be an additional benefit. The introduction of electronic scripts may also improve the business case for general practitioners to computerise.

Building on the success of the first stage, the second stage will introduce direct feedback, the use of a smart card for consumer control and the idea of a summary built from event reports. Specialists and hospital providers are added to the range of providers and there is an increase in the proportion of existing providers. The primary healthcare objective of stage 2 is to improve medication management decision-making, directly through provision of a medication summary and indirectly by professional feedback based on analysis of individual prescribing patterns.

Medication management has been chosen as the focus for stage two as it has been shown that considerable health and efficiency benefits can be derived.
Software development is very advanced in this area ensuring that effective products would be available. It builds naturally from the electronic script focus of stage one and the data required for a useful medication management summary is a large proportion of a full health summary.

Stage three will introduce the full health summary, the data warehouse and off-line analysis. Community care services are added, there is a further increase in the proportion of existing providers and also an increase in the proportion of the population covered.

Stage four and later stages see increases in providers, the proportions of each provider type, the proportion of the population covered and in system functionality.

Information storage within a region could be organised by provider type, with separate storage points for each of general practice, hospital, pharmacy and community care storage etc. These separate storage points could be linked to create a regional IHRIS. This might suit some areas; however, it has not been adopted in the following strategy where a single storage point in every region has been used. The only objection to such an approach is philosophical not technical. The IHRIS is intended to support integration of the care services and adopting a provider-based organising principle may perpetuate some of the divisions that currently exist.

*Regional development stage one: A simple beginning – Electronic Scripts*

In this stage the emphasis is on improving communications and introducing some of the fundamental elements of the IHRIS. The general practitioner sends an electronic script addressed to the consumer or rather to their Medicare card, to the storage point. The consumer gets a printed script that provides them with relevant information and can also act as a standalone script when necessary. The consumer goes to any participating pharmacy and calls up their script by swiping their Medicare card through a magnetic strip card reader. The printed script is signed upon receipt of the medication to satisfy legislative requirements. The pharmacist would send a message to the storage point to advise when a script had been completely or partially filled. Figure 7.1 provides a simple picture of the data flows.

Addressing the script to the Medicare card allows any family member or an appointed agent (someone given the card) to collect the medication from any pharmacy. This flexibility reflects current arrangements. Eventually the paper script would be
eliminated but this would require some legislative changes and possibly the introduction of a digital signature process that could involve smart cards.

Payment eligibility checking by the Health Insurance Commission would be performed while the script was held in the storage point. This would provide the pharmacists with some timesaving while dispensing. This saving would be in addition to the time saved in entering written scripts to their systems. Electronic transfer would also be expected to reduce transcription errors.

Figure 7.1. Regional Development Stage 1

Consumers would be recruited on an opt-in basis, focussing on multiple medication users. This group of people can benefit most from timesaving in collecting scripts and also in the reduction of errors. Enrolment would allow for education of consumers of the purpose of the system and the purposes for which it will be put. This would enable the provision of informed consent. There will also be a need to check that Medicare card details are correct.

As the Medicare card is used by all members of a family it will be necessary to obtain consent from all family members who are enrolled in the system to allow access to their medication data by the other family members. This need arises even if the 'sub-numerate' is used to differentiate each member of the family due to the small risk of accidental or deliberate typing mistakes. It is perhaps pertinent to note that should a family member wish to keep particular medications secret from family members they
could ask for a traditional paper script. As an alternative, family members could be issued with individual cards.

**Table 7.2. Regional IHRIS - Stage 1 Objectives and Size**

<table>
<thead>
<tr>
<th>Healthcare Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve medication dispensing efficiency and accuracy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>System Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduce a storage point in the system</td>
</tr>
<tr>
<td>Introduce processing of the information</td>
</tr>
<tr>
<td>Introduce consumer control through use of a card</td>
</tr>
<tr>
<td>Build provider communication capacity and experience</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>~5,000 participants</td>
</tr>
<tr>
<td>100 Providers (GP’s and Pharmacists)</td>
</tr>
</tbody>
</table>

Comparing the PBS data set with the record of scripts filled using the electronic system would show how many traditional scripts that enrolled consumers used and how many scripts were filled at non-participating pharmacies. One side benefit of this system is that information on the number of scripts written but never filled will be available for analysis. Potentially providers could be advised of this in certain cases. This would require detailed consideration of personal autonomy issues.

Specialist medical practitioners could be included on an individual basis if they have the appropriate facilities.

**Regional development stage two: Introducing feedback – A Medication Summary**

In this stage the emphasis is on providing support for clinical decision-making. It builds upon the developments in stage one, introduces some further elements of the system and increases the range and number of providers along with the number of participating consumers.
In stage two all prescribers would be able to call up a medication summary for use in medication management decisions, subject to consumer authorisation. This authorisation process would utilise a smart card. After every medication event an information enriched 'script' would be sent to the data repository and the existing summary updated. The enriched script will contain any new information relevant to medication management, eg medications, conditions, allergies and weight etc. The consumer can then have any scripts sent to them at a participating pharmacy through the use of the smart card. The pharmacist issues a summary update recording the dispensing event. Figure 7.2 shows a simplified version of the major data flows.

**Figure 7.2. Regional Development Stage 2**

Consumer control would be achieved through the use of a smart card and personal identification number. Control would be limited to authorising access to the medication summary. One possible option that could be explored would be the use of fingerprints to verify the match between the card and the person rather than a PIN. This could be achieved easily using a smart card and would only require the fingerprint to be stored on the card and no where else. None-the-less sensitivity to the use of fingerprints would cause this option to be only offered on an 'opt-in' basis with the right to 'opt-out'. The
primary advantages of using fingerprints would be to avoid the need to remember a PIN that was only occasionally used and to reduce harm arising from card theft and misuse.

Participants would be recruited on an opt-in basis, focusing on multiple medication users. Enrollment processes would require the creation of an initial medication summary. This could be built from PBS data and checked by the enrolling provider. As in stage one the enrolment process will allow for consumer education, the provision of informed consent and the checking of administrative details.

The existing electronic script mechanism would be offered to those people who wish to use them but are not recruited for the second stage. This would see a larger section of the community being introduced to some of the important concepts introduced in stage one.

**Table 7.3. Regional IHRIS - Stage 2 Objectives and Size**

<table>
<thead>
<tr>
<th>Healthcare objectives</th>
<th>Improve medication management decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>System Objectives</strong></td>
<td></td>
</tr>
<tr>
<td>Introduce feedback to providers – direct and indirect</td>
<td></td>
</tr>
<tr>
<td>Introduce a smart card for consumer control</td>
<td></td>
</tr>
<tr>
<td>Introduce the idea of a summary built from event reports</td>
<td></td>
</tr>
<tr>
<td><strong>Size</strong></td>
<td></td>
</tr>
<tr>
<td>5,000-10,000 Participants (Stage 2 functionality)</td>
<td></td>
</tr>
<tr>
<td>10,000-20,000 Participants (Stage 1 functionality)</td>
<td></td>
</tr>
<tr>
<td>200 Providers (GP’s, Pharmacists, Specialists and Major Hospitals)</td>
<td></td>
</tr>
</tbody>
</table>

Professional groups could provide feedback to individual providers based on a review of information in the summary repository. This would provide an important quality improvement mechanism.
Consumers could access their own medication summary through providers and appropriate government agencies. It would be possible to explore the issues involved in consumers accessing their information from home.

Hospitals would be able to call up medication summaries and would provide a summary update upon discharge. It is not likely that hospitals would be in a position to provide a report after every medication event while a person was in hospital. It is also reasonable to believe that such frequency of reporting would not be necessary.

*Regional development stage three: Increasing functionality – A full Health Summary*

In this stage the major development is in expansion of the analytical capability of the system, through the introduction of a data warehouse. There is increased support for clinical decision-making through the provision of a full health summary. System maturity and legislative developments should remove the need for a continuous paper trail. Consumers would still be provided with an information sheet containing relevant information that could act as prescription if necessary.

*Figure 7.3. Regional Development Stage 3*
In stage three providers would be able to call up a health summary from the data mart immediately, once consumer authorisation had been given. Further information could be obtained from the data warehouse but delivery times would be slower. After all health events a report is sent to the data warehouse and the health summary is immediately updated. The event reports would be processed in accordance with established rules and stored for use in analysis by researchers, administrators and other users. The processing would enable automatic notification of communicable disease, updating of disease, device and treatment registers and other activities. Figure 7.3 shows a simplified version of the major data flows.

Participants would be recruited on an ‘opt-in’ basis with the ability to ‘opt-out’ at any time. The selection criteria would focus on those consumers with complex care needs. Consumer control and access provisions would remain the same as in stage two.

**Table 7.4. Regional IHRIS - Stage 3 Objectives and Size**

<table>
<thead>
<tr>
<th>Health Objectives</th>
<th>System Objectives</th>
<th>Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve clinical decision-making</td>
<td>Introduce full event reports</td>
<td>10,000-20,000 Participants (Stage 3 functionalty)</td>
</tr>
<tr>
<td>Improve health system management</td>
<td>Introduce data warehousing</td>
<td>20,000-40,000 Participants (Stage 1 functionality)</td>
</tr>
<tr>
<td>Improve research</td>
<td>Introduce off-line analysis</td>
<td>300 Providers (GP’s, Community Care, Pharmacists, Specialists and Hospitals)</td>
</tr>
</tbody>
</table>

Stage one functionality could be supported during stage three. However, there would be no benefit in maintaining support for stage two functionality. An increase in the number
of people making use of electronic prescribing to around 10% of the population is proposed. System maturity at this time may allow for that function to be offered to the entire population.

Controls on the use of the stored information for analytical purposes would need to be established to satisfy the requirements of the participants. Given the 'opt-in' nature of the system at this stage a number of privacy concerns can be resolved with suitable education and consent processes. However, the opportunity should be taken to establish processes that can be sustained into the future when participation could become compulsory.

Stage four and beyond

Further development stages would retain the information system structure described in stage three. The major development would be in the proportion of the population covered, the range and proportion of providers involved and in improving the functionality of the system.

Increasing the proportion of the population covered would involve initially widening the selection criteria. At a later stage would be the possibility of moving to an 'opt-out' recruitment process. At this stage the ability of consumers to partition their record would need to be introduced. This ability would be necessary to respect consumer autonomy where they have not made the deliberate decision to participate. However, it would increase both the proportion of people positively interested in participating and those indifferent to the system. These effects would increase the total number of people who would be enrolled through an 'opt-out' process.

Increasing the range of provider types would involve assessment of the net benefit of expanding the system to include new groups of providers. There was a long list of providers identified by the interviewees who included a very wide range of providers including fitness advisers, spiritual advisers and alternative therapists. Each group would need to demonstrate that they have the physical and informatic infrastructure established. They would also need to justify their inclusion. Early candidates for the next stages would include providers such as dentists, physiotherapists and podiatrists.
Increasing the proportion of each provider type involved would occur gradually as physical infrastructure is installed and each provider decides that the benefits of joining are sufficient to justify the cost.

Increasing the system functionality would need to occur on an as needs basis where a business case can be made for introducing support for new functions or to increase the range of data captured.

7.2.2. Linking the Regions

Once a region has reached the third stage of development it would be able to usefully link its storage to other regions. In the first instance it would be most useful to establish links between areas with a high ‘trade’ in health services. There are two situations where ‘trade’ in health services exists: from rural areas to metropolitan hospitals and across state borders in highly populated areas. Examples of the latter would be the ACT and southern NSW, Albury-Wodonga and Tweed Heads-Coolangatta.

While each individual region would contain a single repository, linking two or more regions together would require distributed systems technology. Learning lessons from the linkage of just two regions would enable the development of the necessary systems to allow for the linkage of 50 or so regions. The aim is to have the systems act as a seamless whole.

There may be some political and administrative advantages in linking all regions within a state (Note the Australian Capital and Northern Territories along with Tasmania have only one region). The states and territories could then link together to form the national IHRIS.

7.2.3. National system elements

There will be some components of the IHRIS that will be national in nature. These would include administrative structures and operational support services.

Linking of information from separate regions would require national support services. A simple example would be a need to index all event reports. This central index would ensure that when a person has event reports stored in several different regions they could be located with ease rather than conducting an exhaustive search of the system.
This indexing facility could also maintain indexes based on provider, disease, device and treatment. Indeed the event reports could be indexed by any defined data element. Such organisation of the information would support the generation of reports from the IHRIS.

The indexing process could be extended to create registers containing some basic information, which would facilitate the generation of routine reports. For example these enhanced indexes could provide regular reports on incidence and prevalence of disease by age sex and region. Another use of the enhanced indexes would be providing data on hospital separation data reported by region or state on a monthly basis with the ability to identify the number of return visits regardless of location.

7.2.4. National Infrastructure Development

There are a number of national infrastructure development activities that will need to be undertaken to support the staged implementation outlined above. These can be divided into three categories: installation of physical infrastructure, development of informatics infrastructure and creation of the necessary legal infrastructure. Most of these activities will be ongoing. Some consideration of what order some of the activities may need to be undertaken will be necessary.

Installation of physical infrastructure

Physical infrastructure covers all the equipment required to support the IHRIS.

- Computers for all providers at their work places
- Connection tools linking providers to communication networks
- Communications capacity linking all providers and other relevant parties
- Distributed data storage capacity
- Security devices and machines (smart cards and readers)

Associated with the physical installations will be the necessary training of users to make effective use of the equipment and provision of ongoing support to keep them operating.

Each of the activities is substantial. Most of the work is expected to occur regardless of any attempt to implement an IHRIS. As a consequence most of the physical infrastructure expense incurred by the IHRIS will be in the distributed data storage capacity and in the security devices.
Development of informatics infrastructure

Informatics infrastructure covers a range of activities that are necessary for the effective operation of information systems generally in health. The major items that are pertinent to an IHRIS are:

- Standards development, implementation and enforcement; including
  - Communications
  - Record architecture
  - Minimum data sets
  - Data dictionaries
  - Data models
  - Classification systems
  - Security
- Human-computer interface
- Software development
- Software accreditation mechanisms
- Health IT industry development
- Security systems
- Unique Personal Identifier

A considerable proportion of this work will be needed simply to ensure that providers can communicate effectively and support their clinical decision-making. Consequently the costs of such work may be not be borne by the IHRIS. The major element of these costs to be incurred by the IHRIS will be the data warehouse operating software and the development of analytical tools that can work with the data stored in the warehouses.

Legal Infrastructure

The key legal infrastructure element is national legislation on privacy of personal health information. The proposed federal ‘light touch’ privacy legislation will be part of the appropriate legislative mechanism. However, the health sector will need to develop an agreed code of practice with enforceable controls. Furthermore, a uniform approach in the federal, state and private sectors will be required. Additional legislation may be
required to cover activities such as record linkage and the use of a unique personal identifier\textsuperscript{75}.

There will also be the need for legislation covering the creation, operation and regulation of the proposed Australian Health Record Agency (AHRA).

A legally sound resolution of ownership and intellectual property rights will be required. The establishment of privacy legislation and utilisation of the tradeable nature of intellectual property rights may form the basis of a solution.

7.2.5. Project Management

A clear message from the discussion forums and the interviews is that the development process will need to be a combination of a 'top down' and a 'bottom up' approach. Such an approach would need to maximise the contribution from those who are directly affected while ensuring developments occurred within a coherent framework.

The National Health Information Management Advisory Council (NHIMAC) would appear to be the obvious candidate to oversee the project. The membership of the council includes a wide representation of the relevant stakeholders, with the notable exception of researchers. It has a well-balanced mix of stakeholders in that no single group can dominate the decision-making. In addition it reports to the Australian Health Ministers Council which includes both federal and state and territory ministers.

The challenge for NHIMAC would be to provide sufficient structure so that work being undertaken by many different groups would still be compatible with each other, but to also allow sufficient freedom to allow useful diversity in products and methods and to allow the energy and enthusiasm of the grassroots activists to be effectively utilised.

Given that NHIMAC is expected to meet infrequently it is likely that there would be a need for a project team to monitor activities that NHIMAC commissions and to review overall progress. Whether this work was undertaken by the NHIMAC secretariat or a dedicated project team would be a detail to be resolved later. The details of the project management would be determined in some measure by the funding mechanisms used to support the development of the system.

A firm view that emerged from the interviews and discussion forums was that an inclusive consultation process would be necessary. This process would need to:

- Work closely with those most directly affected,

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atical activities of interest include the work in Britain, Canada and New Zealand on national health information systems and also the work of some health organisations in the United States of America such as Kaiser Permanente. Industries from which lessons in the integrated use of information could be learnt would include airlines, finance and tourist agencies. Lessons could also be learnt from the strategies used in the introduction of national activities such as the introduction of Medibank, Medicare, Casemix funding, the National Health Data Dictionary, the Medclaims payment system and the Australia Card.

7.2.6. **Time frame**

An important constraint imposed at the start of this chapter was to limit the time required to implement the system to within reasonable bounds. The interviewees were of the opinion that it would take up to ten years. Is ten years a ‘reasonable’ timeframe? This is largely a political question. Given the multitude of short electoral cycles in Australia ten years is probably too long. A five-year horizon might be more reasonable. Accepting the ten-year timeframe requires breaking the project into two sections with highly marketable end points.

Taking the stages outlined previously a simple timeframe, such as that in table 7.5, could lead to a system that was recognisably a national IHRIS within five years. A further five years could see a fully functional IHRIS.

Several unknowns are hidden within this simple timeframe that would significantly affect the time taken. These unknowns are the levels of resources available, the level of political commitment to the process and the time it would take to establish the required national infrastructure.

7.2.7. **Cost, funding and economic evaluation**

It is impossible at this stage to estimate the cost of implementing a national IHRIS. However, there are some international figures that can offer a guide. These need to be treated with caution as every case is different and it is not always clear what elements of the development and infrastructure work are being included in the project costs and
which are assumed to be provided through other mechanisms. These have been summarised in table 7.6.

Table 7.5. Implementation Timeframe

<table>
<thead>
<tr>
<th>Year</th>
<th>Activity</th>
</tr>
</thead>
</table>
| 1    | A small group of lead regions commence implementation of stage 1  
      | National infrastructure development continues |
| 2    | Lead regions implement stage 2  
      | Majority of regions implement stage 1  
      | National infrastructure development continues |
| 3    | Lead regions implement stage 3  
      | Majority of regions implement stage 2  
      | Remaining regions implement stage 1  
      | National system elements design  
      | National infrastructure development continues |
| 4    | Lead regions link  
      | Majority of regions implement stage 3  
      | Remaining regions implement stage 2  
      | National system elements established  
      | National infrastructure development continues |
| 5    | Last regions implement stage 3  
      | All regions link  
      | National system components fully operational  
      | National infrastructure development continues |
| 6-10 | Continued incremental development along the four remaining axes:  
      | Population coverage  
      | Provider types  
      | Provider coverage  
      | Record Content  
      | National infrastructure development continues |

It is necessary to make further adjustments aside from the elements of population and currency. The obvious element is expenditure on physical infrastructure. The proposed IHRIS implementation assumes that large proportions of the physical infrastructure, ie
computers and communications, are installed under other programs. The British project is able to rely on a considerable proportion of existing infrastructure. The Canadian initiative mentions expenditure of C$2 billion by Federal and Provincial governments on health IT infrastructure but doesn’t describe this work in any detail. Kaiser-Permanente’s project includes the provision of all physical infrastructure and consequently the project cost is considerably higher.

**Table 7.6. International projects – Funding and size**

<table>
<thead>
<tr>
<th>Country</th>
<th>System Cost</th>
<th>Population (Million) Mid 1997</th>
<th>In A$ adjusted for population</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom</td>
<td>£1 billion over 7 years</td>
<td>57.6</td>
<td>A$800 million</td>
<td>Considerable physical infrastructure already exist</td>
</tr>
<tr>
<td>Canada</td>
<td>C$190 million for the first 3 years</td>
<td>30.3</td>
<td>A$120 million</td>
<td>Excludes physical infrastructure. Provincial governments alone are spending C$2 billion on Health IT. (~$A1.2 billion pro rata)</td>
</tr>
<tr>
<td>New Zealand</td>
<td>NZ$3.75 million over 5 years (Seeding funds)</td>
<td>3.6</td>
<td>Not applicable</td>
<td>The NZHIS were unable to provide an overall cost of their strategy.</td>
</tr>
<tr>
<td>Kaiser Permanente</td>
<td>US$1 billion over five years (membership 1999)</td>
<td>8.6</td>
<td>A$3.3 billion</td>
<td>A complete clinical system including all physical infrastructure</td>
</tr>
</tbody>
</table>


Taking the issue of physical infrastructure into account the figure for the British program seems to be the one most applicable to an Australian IHRIS. Allowing for some differences in the level of integration between the British and Australian health
systems an estimate of A$1,000 million dollars seems reasonable. This number is also
suitably round emphasising its ballpark nature.

Assuming this money was expended over 5 years this would be A$200m pa or
approximately 0.5% of the total money spent on health\textsuperscript{31}. This is not a significant
proportion of total expenditure, however, it is necessary to ask where that money would
come from? Setting aside the question of the physical infrastructure, which is assumed
to be supplied by others, there are a number of possible answers. The simple answer is;
from Australian citizens in the form of taxes, fees, insurance premiums and direct
charges. The idealistic answer is; from all beneficiaries in proportion to the benefits
they gain from the system. The realistic answer is likely to be largely from the
commonwealth government health budget with some contributions from state and
territory governments during the development phase. If the commonwealth contributed
the entire amount this would be a little more than 1% of their budget.

The need then would be to justify a redirection of health funding from service provision
to service support services. The interviewees felt that a national health information
system could satisfy a hard-nosed economic evaluation. Undertaking such an evaluation
would be an important element of any development proposal. A favourable economic
evaluation would imply that the return on investment would be able to replace the
money spent and was the best way to spend limited health funds.

Given the staged nature of the proposed development, and the five to ten year duration,
it would be necessary for each stage to be economically justified. This is a harder test as
many of the indirect benefits in planning and research arise late in the process. This
suggests that benefits to providers and consumers would need to provide most of the
support for the initial business case.

The primary justification for the system would be in improvement in the efficiency and
effectiveness of the system. This ought to represent a significant saving in cost or gains
in health outcomes. Improved health outcomes would be expected to benefit the nation
but not necessarily the operating budget of healthcare funders. Measuring the benefits
and sharing the costs among the relevant parties would require detailed health economic
research and political commitment.

There would be some potential for revenue raising, once the IHRIS was operational,
through payments from commercial research organisations, such as pharmaceutical,
other medical and insurance companies. Post-marketing evaluation of treatment products could be funded by a requirement for the company supplying the product to fund independent research on the effectiveness and safety of their products. This requirement would supplement the requirement for clinical testing prior to registration, and it could also supplement the economic evaluation required prior to a product being approved for funding by the Pharmaceutical Benefits Scheme.

One of the major concerns of providers is that much of the burden of data collection would fall on them while a considerable proportion of the benefit would accrue to other users. Resolution of this concern over equitable distribution of costs and benefits would be necessary. The economic evaluation task described previously would inform this resolution. The answer may involve a transfer of benefits, primarily money, from other users to providers. This would constitute a considerable element of the cost of the system as far as government health budgets were concerned. It could, however, provide an opportunity to resolve ownership and intellectual property rights issues as well as the enforcement of quality and content standards. The automated nature of the event report generation and distribution would make the marginal unit cost quite small. However, even a twenty-cent payment for each event covered by the MBS would represent a cost of A$20 million.

Convincing providers to supply all the desired event reports to the system may be a challenge. Providers, or their employers, may decide that health events that are not funded by government, for instance, need not be reported to the IHRIS. The solution may be to pay the providers sufficiently so that the supply of event reports becomes a good business decision. Alternatively it would be possible to require that any provider registered to use the IHRIS would have to agree to supply all reports on all events. Consumer expectations, the needs of private funders and professional standards may provide sufficient force. It may require a mixture of all of these methods to capture the desired proportion of event reports.

7.3. Discussion

The implementation strategy proposed in this chapter is only one possible approach. There are a number of other strategies, possibly many, that could be considered including:

- A ‘big bang’ approach
Forced implementation by funders utilising economic and legislative power

Communications first, storage later

However, the purpose of the strategy outlined is simply to demonstrate that there is at least one feasible means of implementing the national IHRIS proposed, not to identify the best. While there is no objective means of proving the strategy is viable until attempted a comparison with the approaches adopted overseas is helpful (See 7.3.1).

During any actual implementation there would necessarily be adjustments to the strategy adopted, to account for changes in the political situation, technology and needs of the stakeholders. The strategy must be able to evolve as the environment changes.

The strategy is not perfect, it cannot be. The test of the implementation strategy is whether the flaws it contains could be overcome or would prove to be fatal. Risk of failure arising from the operation of the system, such as security breaches, poor data quality and useability failings, were considered in the previous chapter. Assuming that the necessary technology would be available, as the interviewees thought likely, there are three major risks that would confront the process of implementation, namely:

1. Providing sufficient benefits to all parties at each stage may prove impossible, or economically unacceptable.
2. Dealing with stakeholder suspicions may be impossible.
3. Continual change, as required by multiple staging, could induce resistance fatigue.

Delivering benefits to all stakeholders at each stage may be too hard a requirement. It may be necessary to get some stakeholders to defer reception of benefits until later stages. This would require agreement to proceed with those later stages of development before assessing the system’s effectiveness and deciding whether to proceed with those later stages.

Dealing with stakeholder suspicions would be a major challenge. Given that some stakeholders are necessarily in conflict, over some issues at some times, finding agreement could ultimately prove impossible. The equitable sharing of benefits and costs would be a central component of any solution. The use of open consultative methods of development aimed at developing greater understanding of the needs of other stakeholders would help develop a higher level of trust. The key step would be establishing a method of recognising the legitimate needs of other stakeholders.
Agreement of the legitimate needs of other stakeholders would feed into the establishment and supervision of the mechanism that controlled the use of the data held in the IHRIS.

Continual incremental steps carry a risk of change fatigue and resistance to further change. There is no simple answer to that problem. Change management has become a recognised business skill. The work of Lorenzi et al has illuminated the challenges in implementing information systems in health organisations. Adapting this knowledge to the unstructured organisation that is the Australian healthcare system would be an enduring challenge.

All three of the risks identified are unable to be totally eliminated nor accurately quantified. However, there exist strategies for minimising these risks, consequently it is considered they can be deemed to be non-fatal.

7.3.1. Comparison with other national strategies

One means of assessing the proposed strategy is to compare it to those adopted in Canada, the United Kingdom and New Zealand.

Canada

In 1999 a National Health Information Roadmap was developed through a national consultation process. This plan outlined the vision for a Canadian health information system. Five major areas of work were identified: person-oriented information, new data sets, common data standards, necessary ‘infostructure’ and analytical capacity. The Canadian concept of ‘Person-oriented information’ is equivalent to the concept of an ‘Integrated Health Record’. The new data sets are intended to support outcomes analysis for management of the healthcare system. The new data sets proposed will be based on ongoing surveys of a proportion of the population. The data provided would be linked to person-oriented information through the use of a national identifier. The remaining three areas of work are equivalent to the national infrastructure components identified by the author.

The implementation strategy outlined in the Roadmap is focussed on national strategies. There is little detail on the development steps to be taken. It is clear that the national system will be based on regional systems. A variety of regional initiatives developing within a national framework would allow patients to "move seamlessly between..."
hospitals, long-term care, home care and other settings depending on their needs”. It is also a requirement that the “systems in different regions must be able to communicate with each other not only when people receive treatment in another region but also provide the statistical foundation for population-level analysis.” These performance criteria and the approach taken are entirely congruent with the system and strategy outlined in this thesis.

Considerable effort is directed towards the development of national infrastructure components including standards, unique identification, data models and dictionaries, public key infrastructure, privacy and data protection. These activities are very similar to those listed in the implementation strategy above.

The Canadian approach is different in a number of places. It assumes that all consumers would be participants in the new system. Similarly it is assumes that 100%, of each type of provider included, would participate. This contrasts with the incremental approach taken in the strategy proposed in this thesis.

**Britain**

In 1998 the executive of the National Health Service (NHS) in Britain published “Information for Health”. This document outlined a seven-year implementation program for the information strategy for the NHS outlined in chapter 2.

There are a number of immediate similarities between the British approach and the strategy outlined in this thesis. Implementation will be undertaken at the regional level in accordance with a national framework. There will be incremental development in the data collected. There is suggestion of incremental involvement of different types of provider. These elements match three of the five axes of incremental development identified previously. There is also a range of national infrastructure development activities that will support the regional systems.

There are some differences. As with Canada, it has been assumed that all providers and consumers will participate in the system. In the case of the providers this assumption reflects the balance of power between the government and the providers. In the case of consumers it possibly reflects a higher level of acceptance of government involvement in health and in managing society generally.
Another important difference is the focus on the primary care record. This is a case of the United Kingdom working from its strengths. General Practice computerisation is very high and consumers are registered with an individual GP. This means that it is much simpler to start with the record held by the GP and then add components from other providers as they are proposing to do. The proposed IHRIS, on the other hand, focuses on the individual consumer. The resulting difference is that in the UK the GP will have considerable control over the disclosure of the information whereas the proposed system places that control with the consumer.

Overall it is fair to say that there are considerable similarities between the strategy adopted in the United Kingdom and this thesis. There are also some notable differences, many of which can be explained by differences in culture and existing structures.

New Zealand

New Zealand started development of a national health information strategy in 1990. They have focussed on building up their national infrastructure. The first major activity was the introduction of the National Health Index (NHI). This functions as a unique identifier. People have been enrolled progressively, 1995 the NHI covered 84% of the population, by early 1999 this had increased to 93%. They have also developed and implemented standards for technology, data, quality and privacy. They have established a national health intranet which went ‘live’ in December 1999. This communication service connects up those hospitals, GP’s and pharmacists who have established the appropriate infrastructure and seek to connect.

The New Zealand strategy is building incrementally along all five of the axes identified previously:

1. It is building geographically with those Independent Provider Associations (Loosely equivalent to the Australian Division of General Practice) who wish to participate.

2. It is enrolling consumers gradually over time.

3. It is working with a limited number of provider types.

4. It is involving only those providers who wish to participate.

5. It is capturing very little data for the integrated record, initially only medical warnings such as allergies.
The lead agency, the New Zealand Health Information Service (NZHIS), has adopted a business case driven strategy. They spend small amounts of money developing services which provide good benefits to the users and then allow the users to fund the implementation and operation of those services on a wider scale (Paul Cohen, NZHIS - personal communication).

The New Zealand approach has many similarities to the strategy proposed in this chapter. A major difference is the amount of data captured in the integrated record. Currently New Zealand captures very little and is not planning to capture more.

The proposed implementation strategy for an Australian IHRIS has many similarities to those used in the three other countries discussed. It is also clear that cultural and political differences make it impossible to simply import a method used elsewhere.

7.4. Summary

The proposed strategy could realise a national IHRIS within a reasonable timeframe and within reasonable expenditure limits. The proposed strategy is comparable with the strategies adopted by other countries. The conclusion drawn is that Australia could build a national IHRIS.
Chapter 8 Discussion and Conclusions

The health record is a continually evolving tool designed to assist in the delivery of healthcare services. It has evolved over hundreds of years to serve the needs of healthcare providers. Typically the record is maintained within a single institution or organisation and, for the vast majority of its existence, it has been a paper-based product wholly controlled by clinicians. This paradigm is currently being challenged by the unintended effects of past changes in the health record, changes in the needs of the healthcare system and changes in technology.

The ‘unit record’ was introduced in 1907. This was a revolution in the management of clinical data brought on by the dramatic increase in investigation results. Placing all data about an individual in the same folder made it simpler for clinicians to find the required data and provide better care for that person. It is a simple conceptual extension to go from the idea of an organisation-based ‘unit record’ to an ‘integrated health record’ that contains all of an individual’s health data regardless of the institution in which it was captured. This concept directly challenges the existing paradigm.

The quality assurance movement has had major impacts on many aspects of modern life including manufacturing and government. Healthcare systems have been subjected to the influence of the quality assurance paradigm since the 1960’s. The measurement of health outcomes and the application of evidence-based decision-making have become central to the development of funding and planning policies. Prior to this the information needs of planners and policy-makers focussed on the inputs to the system. As a consequence the data held in the clinical record were of little interest. At the same time researchers were ill served in their attempts to glean new knowledge due to the fragmented nature of clinical data. Finally the consumer of healthcare services often faced poorly co-ordinated efforts to manage their health as their health data was scattered between numerous provider organisations.

The realisation that clinical records contained considerable data of interest to policymakers, planners, researchers and consumers has become progressively clearer. Codman was perhaps the first to point out the many parties who had a legitimate involvement in the creation and use of the health record\textsuperscript{91}. Consumers are successfully gaining rights of access to health information through the legislation of privacy.
principles first proposed by the OECD in 1981. In practice few consumers make use of legislated rights of access unless their clinicians actively support the process.

Attempts to re-engineer the health record so that it could serve the needs of other users have been defeated by the paper-based nature of existing records. For example, Shenkin and Warner proposed a system of paper-based personal health records in 1973. This approach was never implemented.

Forty years ago saw the first work on the use of computers in medicine. Work on the computerisation of health records has continued to the present day. Promises of a full electronic health record have been made from the very beginning. Recent progress in communications and computer processing mean that technological barriers are no longer a limiting factor.

The consequences of these challenges to the existing paradigm can be seen in events unfolding nationally in the United Kingdom, Canada and New Zealand and in some American healthcare organisations where work on the implementation of some form of integrated health record is currently underway.

The effects of these forces have been felt in Australia. In October 1997 a House of Representatives Committee Inquiry into Health Information Management and Telemedicine recommended the development and deployment of a national data management system that would “serve the health needs of both the individual and the nation.” This proposal was ignored by the government in its response to the committee’s report. However, in August 1999 Australian health ministers endorsed “Health Online: a health information management action plan for Australia” which is “primarily about how the collection and transfer of, and access to, health information can improve the health of all Australians and further the objectives of the health system as a whole.” This document is an important starting point. It provides the outline of a strategic framework of the sort deemed necessary by the participants in the first discussion forum. It also represents a significant policy commitment from the federal, state and territory governments.

The document provides an excellent report on the activities currently underway toward establishing the national infrastructure required. However, the model outlined for the national health information system is lacking any substantial detail. It is possible
to ascertain that the basic principles of the model and the IHRIS model proposed in this thesis are thoroughly congruent.

Unfortunately the plan lacks an implementation strategy. It is clear that simply completing the activities underway would not result in the framework outlined. The lack of detail prevents any analysis of costs and benefits or any demonstration of whether there is any realistic chance of successful implementation. This thesis provides the framework necessary to answer these questions and has looked closely at the latter.

Strengths and weaknesses of the investigations

Before examining the contribution of this thesis it is necessary to examine the strengths and weaknesses of the study methodology. The data gathering involved the use of qualitative research techniques. The methods applied were reasonably simple; no complex analysis was undertaken. The participants reviewed the analysis of both the discussion forums and the interviews. This review considerably strengthened the conclusions drawn by the author.

There was an element of opportunism in the participants chosen. This was reflected in the number of people based in Canberra. However, efforts were made to ensure that the major stakeholder groups were well represented. Given the number of key stakeholder organisations based in Canberra the selection effect is not considered significant. A number of people were involved in both the discussion forums and the interviews. This would tend to result in their views having a stronger impact.

Another weakness of the study was that the modeling method used is best suited for more structured situations. Structured Analysis works well in the development of systems in organisations with clear boundaries and clear command structures. The Australian healthcare system lacks both of these requirements. The use of a liberal definition of what constituted ‘essential’ and ‘implementation’ issues allowed for useful exploration of the data. Choosing to develop only the higher level parts of the system model avoided the risk of producing a model with meaningless and unnecessary detail.

The main strength of the thesis is the synthesis of the disparate data that informed the system modeling. The data was derived from the knowledge and extensive practical experience both of healthcare and information technology, of the people who participated in the discussion forums and interviews. The contributors were representative of the broad range of the stakeholders in the Australian healthcare system.
They also had extensive experience in health information and the development and implementation of information systems in the healthcare environment.

What is the contribution of this study

This study aimed first to answer the question “Could an Australian IHRIS satisfy significantly more of the information needs of the Australian healthcare system than present health records and associated information systems?” A clear argument has been made that the answer is yes.

This argument was built from an examination of the information needs of the healthcare system based on the theoretical framework developed to explain the role of health information in assuring the quality of care delivered by the system. Further work, in particular an economic assessment of alternative approaches, would be required before it was possible to decide if a national IHRIS was the preferred solution.

The second question posed was “Could Australia implement a national IHRIS?” The implementation strategy that was developed demonstrated that there is at least one pathway for Australia to implement a national IHRIS.

By answering these two questions this study has established that a national IHRIS is a feasible alternative to present health records and associated information systems.

The other major contribution of this study lies in the development work on the model and implementation strategy. The detail of the IHRIS model provides a framework for undertaking further analyses of the technical, economic and political feasibility of such a venture. The simplicity of the core operation of the system and the power of its reporting ability make it highly adaptable and widely useful.

The five axes of incremental development identified and used in preparing the implementation strategy offer a means of breaking the project into achievable stages. They also provide a useful tool for analysing proposed strategies.

Further work

The work presented in this thesis is only a beginning. There are a number of directions in which the IHRIS project should develop. There is clearly a need to undertake an economic analysis of alternative solutions. The model proposed provides the framework for such an analysis.
There is enormous scope for the further development and refinement of the model and implementation strategy proposed. Investigation of alternative models and the development of multiple implementation strategies would usefully inform the economic analysis and also the work being undertaken by NHIMAC on the Health Online Action Plan.

Finally the implementation of a stage one regional system i.e. enabling the electronic transfer of scripts needs to be attempted. This would provide useful real world knowledge of the practicalities and difficulties of implementing the IHRIS. Given the utility of electronic script transfers such work would not be wasted even if nothing else followed.

8.1. Recommendations

There are a number of activities that would facilitate the development of an information system that could significantly improve the quality of care delivered. These activities would be beneficial regardless of the form that such an information system took.

- Develop an agreed strategic framework. The Health Online Action Plan has provided the starting point for this work.
- Develop and implement the necessary data, communications, coding, security and other technical standards
- Introduce a national unique personal identifier
- Continue installation of communication infrastructure
- Promote the use of computers by healthcare providers, particularly for communications and health record purposes
- Establish the necessary legislative, operational structures and security systems necessary to satisfy the privacy needs of the system users.
- Promote greater understanding among stakeholders of the legitimate information needs of other stakeholders

8.2. Conclusions

This study has established that a national IHRIS is a feasible alternative to present health records and associated information systems.

The arguments presented and the models developed help to provide the basis for national debate of an issue of national importance.


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Appendices

Appendix A. First Discussion Forum Participants

**Tony Adams**  Professor of Public Health NCEPH. Formerly Commonwealth Chief Medical Officer (1988-1997) and Chief Health Officer NSW (1983-1988)

**John Ainge**  Managing Director, MIMS Data Systems. RACGP National Informatics Committee, RACOG Informatics Committee; member General Practice Computing Group; Professional Liaison Officer, Medical Software Industry Association; member ACT Division of General Practice IT committee; member Standards Australia IT/14 Committee

**Brooke Alexander**  Policy Officer, Consumers’ Health Forum.

**Simon Bryant**  National Office for the Information Economy. Previously monitored telehealth developments within the online policy branch of the Commonwealth Department of Communications and the Arts. Departmental representative on a number of telehealth related committees and groups.

**John Deeble**  Visiting Fellow NCEPH. Board member Health Insurance Commission. Co-creator of Medibank and Medicare.

**Bob Douglas**  Director NCEPH. Epidemiologist and former General Practitioner. Longstanding interest in the application of computers to improved clinical and population health.

**Tony Firth**  Director client systems, MIMS Data Systems. Involved in the development and delivery of software to the medical profession since 1989.

**Ben Harris**  Advisor to the Minister for Health and Family Services.

**Simon Hawkins**  Senior Project Manager, Health Insurance Commission. Former Head of Research Analysis, Professional Review Division. Former Clinical Head and Program Manager, Neurology department Royal Canberra Hospital. Harkness Fellowship (1995-96) in Health Informatics. Special interest in computerised health information and decision support systems.

**Chris Kelman**  Ph.D. student at NCEPH investigating the use of record-linkage on Australian health databases for health-outcomes research, specifically the evaluation of implantable medical devices. Background in clinical medicine, engineering and health informatics, previously employed as chief medical advisor in the Therapeutic Devices Branch of the Commonwealth Department of Health.

**John Landale**  Acting Manager of the Electronic Commerce Branch, Health Insurance Commission. This branch is responsible for the strategic planning and promotion of the HIC’s electronic commerce and health information management.
Greg Lee Manager, Information Management Unit, ACT Department of Health and Community Care. 18 years experience delivering information technology and information management projects. Extensive experience in the public sector at senior levels for the Commonwealth, Western Australian and ACT Governments.

Tamir Maltz Special Projects Adviser to the Minister for the Arts, Communications and the Information Economy

Nigel Mercer Head of Data Management Unit, Australian Institute of Health and Welfare. Principal architect of the National Health Information Knowledgebase (www.aihw.gov.au). Member of the National Forum of Directors of Government Health IT. Previously project manager for the National Health Information Model project, and member of the Standards Australia AS4400 committee.

Michael Moore Member of the ACT Legislative Assembly. Special interest in health issues and in information Technology. Awarded a Masters Degree in Population Health in 1997.

Chris Mount Ph.D. student at NCEPH. Researching the concept of integrated health records and developing a model for an Integrated Health Record and Information System using structured analysis.

Prue Power Director of General Practice, Australian Medical Association; Adviser, Commonwealth Minister for Health and Family Services; and Secretary, Australian Nursing Federation ACT Branch. Current Board positions Director, ACT Health and Community Care Service; Chair, Community Services and Health National Industry Training Company; and Director, Musica Viva Australia.

Bev Sibthorpe Fellow at NCEPH. Anthropologist and epidemiologist whose primary interest is in the area of primary health care research and evaluation. Major current projects are in general practice and an Aboriginal community controlled health service.

Len Smith Consultant Epidemiologist and Visiting Fellow at NCEPH, former director of the Australian Institute of Health and Welfare, board member of the Health Informatics Society of Australia. Special interest: Health Information Systems

Michael Tatchell Director of Health Economics, National headquarters of the Pharmacy Guild of Australia. Closely involved in the Guild/government Pharmacy Intranet project, which will provide electronic links between pharmacies, the Health Insurance Commission and in due course medical practitioners.

Russell Trigg Director, Corporate Applications, Business Systems Branch, Information Technology Group, Commonwealth Department of Health and Family Services. Departmental Representative on Standards Australia IT/14 Health Informatics Committee, member of the Government Health IT Managers Forum. Has worked in the Information Management/Information Technology areas of the Commonwealth Department of Health for twenty-five years.
Appendix B. Coding framework for the first “Health on Line” Discussion forum

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Appendix C. Agenda for Second “Health on Line” Discussion Forum

"Health on Line" Discussion Forum

TUESDAY, 19 MAY 1998

AGENDA

1. Introduction of participants, with brief statements on their aspirations for the forum and a report of relevant current activities
2. Endorsement and/or modification of Agenda.
3. Review of consensus reached at Forum 1 – Chris Mount.
4. What are the outcomes being sought from a national health information system?
   a) for consumers of health services
   b) for providers of health services
   c) for administrators of health services
   d) for researchers into health services
   e) for politicians who must take responsibility for managing health systems
5. What are the factors that will encourage providers to embrace this system?
6. What are the factors that will encourage consumers to embrace and/or oppose this vision?
7. What are the needs of government in this area and how could an ongoing forum of this or any other kind be helpful?
8. Is there a test bed possibility in the ACT?
9. What work could NCEPH and other participants in the forum now carry out which would be helpful to those with carriage of policy development?
9. Should the forum meet again? If so, what form should it take, when should it meet, and what inputs should it have?
Appendix D. Second Discussion Forum Participants

John Ainge  Managing Director, MIMS Data Systems. RACGP National Informatics Committee, RACOG Informatics Committee; member General Practice Computing Group; President, Medical Software Industry Association; member ACT Division of General Practice IT committee; member Standards Australia IT/14 Committee

Mark Allenby  Acting Assistant Secretary, Strategic Development Branch, Portfolio Strategies Group, Commonwealth Department of Health and Family Services. Currently Director of Information Development Section responsible for cross portfolio information management and policy. Involved in the information/data management areas of both HFS and AS for the past 9 years.

Bob Douglas  Director NCEPH. Epidemiologist and former General Practitioner. Longstanding interest in the application of computers to improved clinical and population health.

Tony Firth  Director client systems, MIMS Data Systems. Involved in the development and delivery of software to the medical profession since 1989.

Janne Graham  Consumer; member of Consumers’ Health Forum and ACT Health Care Consumers’ Assoc.; member of Standards Australia electronic messaging working party. Special interest in consumer access to and use of health information.

Ben Harris  Advisor to the Minister for Health and Family Services.

Simon Hawkins  Senior Project Manager, Health Insurance Commission. Former Head of Research Analysis, Professional Review Division. Former Clinical Head and Program Manager, Neurology Department Royal Canberra Hospital. Harkness Fellowship (1995-96) in Health Informatics. Special interest in computerised health information and decision support systems.

Chris Kelman  Ph.D. student at NCEPH investigating the use of record-linkage on Australian health databases for health-outcomes research. Background in clinical medicine, engineering and health informatics, previously employed as chief medical adviser in the Therapeutic Devices Branch of the Commonwealth Department of Health.


Chris Mount  Ph.D. student at NCEPH. Researching the concept of integrated health records and developing a model for an Integrated Health Record and Information System using structured analysis.

John Nearhos  Health information management consultant. Medical Director. Health Communication Network. Short term consultant to the World Health Organisation. He is currently focussed on the Internet to develop information management and secure communication solutions for health care and to help GP’s cope with their changing environment.

Michael Parsons  General Manager, Consultancy Division, Health Insurance Commission. He has responsibility for directing major international consultancies in areas of health financing programs and for the
Commission’s electronic commerce and information management strategy. He is currently a Board Member of the Government Public Key Authority (GPKA) as a Commonwealth Government representative.

John Peoples
Assistant Director, Development, Acute Health, Department of Human Services. Responsible for I2T2 $100m project for Victorian Public Hospitals, and information development covering Transformation 21, Year 2000 and other major initiatives.

Prue Power
Director of General Practice, Australian Medical Association; Formerly Deputy Director, Australian Healthcare Association; Advisor, Commonwealth Minister for Health and Family Services; Secretary, Australian Nursing Federation ACT Branch. Current Board positions; Director, ACT Health and Community Care Service; Director, Musica Viva Australia.

Brian Richards
General Practitioner. Executive Director, ACT Division of General Practice. Member of the ACT Government’s Information Technology Reference Group and the steering committee for the ACT Health Communications Trial. He has been involved in the development of the AMA/RACGP IM/IT strategic plan for general practice and has overseen a number of divisional projects promoting the use of information technology in general practice.

Len Smith
Consultant Epidemiologist and Visiting Fellow at NCEPH, former director of the Australian Institute of Health and Welfare, board member of the Health Informatics Society of Australia. Special interest: Health Information Systems

Michael Tatchell
Director of Health Economics, National headquarters of the Pharmacy Guild of Australia. Closely involved in the Guild/government Pharmacy Intranet project, which will provide electronic links between pharmacies, the Health Insurance Commission and in due course medical practitioners.

Morris Trevethan
Senior Pharmaceutical Adviser, Health Insurance Commission. Member of the Management Committee and of the Technical Reference Committee to the Pharmacy Intranet Demonstration Project and member of the Drug Utilisation Subcommittee of the PBAC. Graduate in computing studies.

Russell Trigg
Director, Corporate Applications, Business Systems Branch, Information Technology Group, Commonwealth Department of Health and Family Services. Departmental Representative on Standards Australia IT/14 Health Informatics Committee, member of the Government Health IT Managers Forum. Has worked in the Information Management/Information Technology areas of the Commonwealth Department of Health for twenty-five years.

Apologies
Michael Moore (ACT Minister of Health)
Greg Lee (ACT Department of Health and Community Services)
Chris Brook (Victorian Department of Human Services)
Nigel Mercer (SMS Consultancy)
Simon Bryant (National Office for the Information Economy)
John Deeble (NCEPH)
Appendix E. Interview theme list

Interview Structure - Questions and theme list

Preamble

I am investigating the idea of an information system that could be deployed nationally based on integrated health records. I want to explore with you today the utilisation of personal health information in Australia, how we could improve the existing situation and the factors that would affect the form and implementation of a national information system.

Q0.1 Before I start the questions would you tell me about your interests in health and health informatics?

Part 1 Potential uses, users and benefits (10-15 Minutes)

Q1.1 Thinking about the possible use of personal information what are you currently unable to do that would be beneficial to the health of Australians?

Q1.2 How would you overcome these shortcomings?

Q1.3 What information would you like to be able to extract from a national information system enabling access to integrated health records for most Australians?

Further Probing

What use would you make of such information? What benefits would arise? What questions would you like to ask?

Who else do you think would be interested in using such a system? Why?

Part 2 Constraints and Pathways (10-15 minutes)

First Question - Constraints

Q2.1 What do you think a national health information system should look like?

Q2.2 What constraints will affect the nature of such a system?

Unacceptable uses

Are any of the uses mentioned previously likely to be unacceptable? Why?

Ownership, control, access, privacy and security

Who should own the information stored in an integrated record? Who should own the physical record?

How should the system meet the privacy needs of Australians?

Who should be allowed access to the information contained in the record? Who should authorise access? How?

Data collection requirements and constraints

How should information be collected? What quality requirements should be met during data collection?
Operation, management and financing

What performance measures would the system need to meet? Who should manage the system?

How could the system be financed?

Other legal, political, cultural and economic issues

What other legal, political, cultural or economic issues need to be considered?

Second Question - Pathways

Q2.2 How could a national health information system be implemented?

Pathways

Should development be incremental? If yes, what manner of incrementation would be appropriate? Who are the relevant groups? What roles should these groups play in developing and deploying a system?

How would you prepare the users of such a system for the changes involved?

Barriers

What is missing today that would prevent the implementation of an integrated health record information system?

What barriers exist that would prevent the implementation of an integrated health record information system?

Costs and Risks

What costs and risks do you see would arise from a national health information system? Do they outweigh the benefits?

Time Frame

How long do you think it would take to develop and implement such a system?

Final Questions

Q2.3 Is there any other matter you wish to raise at this time?

Q2.4 Who else do you think I should talk to?
Appendix F. Interviewee Profiles

Peter Broadhead
Assistant Secretary, Financing and Analysis Branch, Health Services Division, Department of Health and Family Services. Responsibilities included the departments access and use of Medicare data and the coordinated care trials. Former member of the NHIMG and Standards Australia IT/14 Committee. Previously Director, Information Management, Tasmanian Department of Community and Health Services. Has been involved in advising State and Federal governments on information technology and information management policy issues for ten years.

Branko Cesnik
Founding Director, Monash Centre for Medical Informatics. Associate dean of IT in the faculty of medicine at Monash University. Has worked in Medical Informatics for fourteen years. Currently President of the Asia Pacific Association for Medical Informatics. Member of the Board of the Health Informatics Society of Australia and editor of the proceedings of Medinfo ‘98.

Meredith Carter
Executive Director, Health Issues Centre. Has been involved in investigating and representing consumer views on privacy issues relating to their personal health information for many years. Has served on a number of Victorian Government committees looking at privacy issues including the Health Key Trial and the Victorian Hospitals Patient Register. Has recently completed a Masters of Law on the effect of IT on privacy in health.

Bob Douglas
Director NCEPH. Epidemiologist and former General Practitioner. Longstanding interest in the application of computers to improved clinical and population health.

Janne Graham
Consumer; member of Consumers’ Health Forum and ACT Health Care Consumers’ Assoc.; member of Standards Australia electronic messaging working party. Former member of the AIHW ethics committee. Former member of the NH&MRC. Special interest in consumer access to and use of health information.

Chris Kelman
Ph.D. student at NCEPH investigating the use of record-linkage on Australian health databases for health-outcomes research, specifically the evaluation of implantable medical devices. Background in clinical medicine, engineering and health informatics, previously employed as chief medical advisor in the Therapeutic Devices Branch of the Commonwealth Department of Health.

Nigel Mercer:
SMS Consulting. Previously Head of Data Management, AIHW. Principle architect of the National Health Information Knowledgebase and project manager for the National Health Information Model project. Previous member of the Australian and New Zealand Government Chief Information Officers Forum. and member of the drafting committee for Standards Australia AS4400.

Rhonda Nelson
Policy Officer, Privacy Commissioner’s Office. Has a long-standing interest in health privacy issues.
Debra O’Connor: Lecturer in public health and health promotion at La Trobe University Melbourne. A consumer representative on several national committees dealing with personal information management and information technology policy including SA IT/14, GP Computing Group, Health Insurance Commission Standards Implementation and evaluation working party. She has given a number of conference presentations presenting consumer perspective’s on the development of information technology and the uses of personal health information.

Mahomed Patel: Fellow NCEPH. Epidemiologist and Public Health Specialist. Formerly Director of Disease Control in the Northern Territory.

Prue Power: Director of General Practice, Australian Medical Association; Formerly Deputy Director, Australian Healthcare Association; Advisor, Commonwealth Minister for Health and Family Services; Secretary, Australian Nursing Federation ACT Branch. Current Board positions; Director, ACT Health and Community Care Service; Director, Musica Viva Australia.

Malcolm Pradhan: Director of Health Informatics and Associate Dean for IT at the Faculty of Health Sciences, The University of Adelaide. His major interests are the application of statistical decision theory in health care, clinical information systems, and decision support systems. Current projects include infectious disease monitoring, the development of adaptive therapeutic guidelines, and the evaluation of coordinated care trials.

Brian Richards: General Practitioner. Executive Director, ACT Division of General Practice. Member of the ACT Government’s Information Technology Reference Group and the steering committee for the ACT Health Communications Trial. He has been involved in the development of the AMA/RACGP IM/IT strategic plan for general practice and has overseen a number of divisional projects promoting the use of information technology in general practice.

Bev Sibthorpe: Fellow at NCEPH. Anthropologist and epidemiologist whose primary interest is in the area of primary health care research and evaluation. Major current projects are in general practice and an Aboriginal community controlled health service.

Don Walker: Retired country General Practitioner. Research fellow of the University of Adelaide. Honorary Director of information management, and consultant system designer and programmer to the Data Processing Unit, at the Department of General Practice, University of Adelaide. Chair Standards Australia sub-committee IT/14/2. Active in the foundation of Australian health-care informatics.

Jim Warren: Senior Lecturer, School of Computer and Information Science University of South Australia

Peter Williams: Director, Health Informatics, New South Wales Department of Health. Chair of Standards Australia Committee IT/14.
Appendix G. Index Tree for Interviews

Q.S.R. NUD.IST Power version, revision 4.0.


(1) Essential issues
(1 1) Essential issues/Uses
(1 2) Essential issues/Health Reform
(1 3) Essential issues/Users
(1 4) Essential issues/Benefits
(1 9) Essential issues/Existing Shortcomings
(1 10) Essential issues/Future directions

(2) Implementation Issues
(2 1) Implementation Issues/Information Rights
(2 1 1) Implementation Issues/Information Rights/Privacy
(2 1 2) Implementation Issues/Information Rights/Control
(2 1 3) Implementation Issues/Information Rights/Amendment
(2 1 4) Implementation Issues/Information Rights/Disclosure
(2 1 5) Implementation Issues/Information Rights/Ownership
(2 1 6) Implementation Issues/Information Rights/Access
(2 2) Implementation Issues/Pathways
(2 2 1) Implementation Issues/Pathways/Parties and Roles
(2 2 2) Implementation Issues/Pathways/Drivers
(2 2 3) Implementation Issues/Pathways/Approaches
(2 3) Implementation Issues/Barriers
(2 4) Implementation Issues/Data Capture
(2 5) Implementation Issues/Unique Identification
(2 7) Implementation Issues/Standards
(2 8) /Implementation Issues/Time frame

(3) Other Contacts
Appendix H. The Information Privacy Principles in the Federal Privacy Act 1988

Principle 1

Manner and purpose of collection of personal information

1. Personal information shall not be collected by a collector for inclusion in a record or in a generally available publication unless:
   (a) the information is collected for a purpose that is a lawful purpose directly related to a function or activity of the collector; and
   (b) the collection of the information is necessary for or directly related to that purpose.

2. Personal information shall not be collected by a collector by unlawful or unfair means.

Principle 2

Solicitation of personal information from individual concerned

Where:
   (a) a collector collects personal information for inclusion in a record or in a generally available publication; and
   (b) the information is solicited by the collector from the individual concerned;

the collector shall take such steps (if any) as are, in the circumstances, reasonable to ensure that, before the information is collected or, if that is not practicable, as soon as practicable after the information is collected, the individual concerned is generally aware of:

   (c) the purpose for which the information is being collected;
   (d) if the collection of the information is authorised or required by or under law—the fact that the collection of the information is so authorised or required; and
   (e) any person to whom, or any body or agency to which, it is the collector's usual practice to disclose personal information of the kind so collected, and (if known by the collector) any person to whom, or any body or agency to which, it is the usual practice of that first-mentioned person, body or agency to pass on that information.

Principle 3

Solicitation of personal information generally

Where:
(a) a collector collects personal information for inclusion in a record or in a generally available publication; and
(b) the information is solicited by the collector;
the collector shall take such steps (if any) as are, in the circumstances, reasonable to ensure that, having regard to the purpose for which the information is collected:
(c) the information collected is relevant to that purpose and is up to date and complete; and
(d) the collection of the information does not intrude to an unreasonable extent upon the personal affairs of the individual concerned.

Principle 4

Storage and security of personal information

A record-keeper who has possession or control of a record that contains personal information shall ensure:
(a) that the record is protected, by such security safeguards as it is reasonable in the circumstances to take, against loss, against unauthorised access, use, modification or disclosure, and against other misuse; and
(b) that if it is necessary for the record to be given to a person in connection with the provision of a service to the record-keeper, everything reasonably within the power of the record-keeper is done to prevent unauthorised use or disclosure of information contained in the record.

Principle 5

Information relating to records kept by record-keeper

1. A record-keeper who has possession or control of records that contain personal information shall, subject to clause 2 of this Principle, take such steps as are, in the circumstances, reasonable to enable any person to ascertain:
(a) whether the record-keeper has possession or control of any records that contain personal information; and
(b) if the record-keeper has possession or control of a record that contains such information:
   (i) the nature of that information;
   (ii) the main purposes for which that information is used; and
   (iii) the steps that the person should take if the person wishes to obtain access to the record.

2. A record-keeper is not required under clause 1 of this Principle to give a person information if the record-keeper is required or authorised to
refuse to give that information to the person under the applicable provisions of any law of the Commonwealth that provides for access by persons to documents.

3. A record-keeper shall maintain a record setting out:
   (a) the nature of the records of personal information kept by or on behalf of the record-keeper;
   (b) the purpose for which each type of record is kept;
   (c) the classes of individuals about whom records are kept;
   (d) the period for which each type of record is kept;
   (e) the persons who are entitled to have access to personal information contained in the records and the conditions under which they are entitled to have that access; and
   (f) the steps that should be taken by persons wishing to obtain access to that information.

4. A record-keeper shall:
   (a) make the record maintained under clause 3 of this Principle available for inspection by members of the public; and
   (b) give the Commissioner, in the month of June in each year, a copy of the record so maintained.

Principle 6

Access to records containing personal information

Where a record-keeper has possession or control of a record that contains personal information, the individual concerned shall be entitled to have access to that record, except to the extent that the record-keeper is required or authorised to refuse to provide the individual with access to that record under the applicable provisions of any law of the Commonwealth that provides for access by persons to documents.

Principle 7

Alteration of records containing personal information

1. A record-keeper who has possession or control of a record that contains personal information shall take such steps (if any), by way of making appropriate corrections, deletions and additions as are, in the circumstances, reasonable to ensure that the record:
   (a) is accurate; and
   (b) is, having regard to the purpose for which the information was collected or is to be used and to any purpose that is directly related to that purpose, relevant, up to date, complete and not misleading.
2. The obligation imposed on a record-keeper by clause 1 is subject to any applicable limitation in a law of the Commonwealth that provides a right to require the correction or amendment of documents.

3. Where:
   (a) the record-keeper of a record containing personal information is not willing to amend that record, by making a correction, deletion or addition, in accordance with a request by the individual concerned; and
   (b) no decision or recommendation to the effect that the record should be amended wholly or partly in accordance with that request has been made under the applicable provisions of a law of the Commonwealth;

the record-keeper shall, if so requested by the individual concerned, take such steps (if any) as are reasonable in the circumstances to attach to the record any statement provided by that individual of the correction, deletion or addition sought.

Principle 8

Record-keeper to check accuracy etc. of personal information before use

A record-keeper who has possession or control of a record that contains personal information shall not use that information without taking such steps (if any) as are, in the circumstances, reasonable to ensure that, having regard to the purpose for which the information is proposed to be used, the information is accurate, up to date and complete.

Principle 9

Personal information to be used only for relevant purposes

A record-keeper who has possession or control of a record that contains personal information shall not use the information except for a purpose to which the information is relevant.

Principle 10

Limits on use of personal information

1. A record-keeper who has possession or control of a record that contains personal information that was obtained for a particular purpose shall not use the information for any other purpose unless:
   (a) the individual concerned has consented to use of the information for that other purpose;
   (b) the record-keeper believes on reasonable grounds that use of the information for that other purpose is necessary to prevent or
Principle 11

Limits on disclosure of personal information

1. A record-keeper who has possession or control of a record that contains personal information shall not disclose the information to a person, body or agency (other than the individual concerned) unless:
   (a) the individual concerned is reasonably likely to have been aware, or made aware under Principle 2, that information of that kind is usually passed to that person, body or agency;
   (b) the individual concerned has consented to the disclosure;
   (c) the record-keeper believes on reasonable grounds that the disclosure is necessary to prevent or lessen a serious and imminent threat to the life or health of the individual concerned or of another person;
   (d) the disclosure is required or authorised by or under law; or
   (e) the disclosure is reasonably necessary for the enforcement of the criminal law or of a law imposing a pecuniary penalty, or for the protection of the public revenue.

2. Where personal information is disclosed for the purposes of enforcement of the criminal law or of a law imposing a pecuniary penalty, or for the purpose of the protection of the public revenue, the record-keeper shall include in the record containing that information a note of that use.

4. A person, body or agency to whom personal information is disclosed under clause 1 of this Principle shall not use or disclose the information for a purpose other than the purpose for which the information was given to the person, body or agency.
Appendix I. Publication resulting from this study

FOR DEBATE

An integrated electronic health record and information system for Australia?

Christopher D Mount, Christopher W Kelman, Leonard R Smith and Robert M Douglas

An integrated health record and information system, although costly and difficult to implement, would provide benefits for clinicians and patients through better clinical care, and for the healthcare system through better data for policy development and resource allocation.

IT IS ALMOST 100 YEARS since the introduction of the “unit record” at St Mary’s Hospital in 1907 marked the beginning of the modern medical record. The centenary would be an appropriate target date for the full implementation in Australia of a national Integrated Health Record and Information System (IHRIS) which goes beyond existing institution-based, sector-based or system-based records to cover all contacts with the healthcare system. In 1997, the House of Representatives report Health on Line recommended the development and deployment of such a system.1,2 The idea of an integrated national approach has been endorsed by the UK National Health Service information policy. It includes plans to create a lifelong electronic health record by 2005.4 The New Zealand Health Department is well advanced in the implementation of an integrated health record system,5 and a number of healthcare funding bodies in the United States have introduced comprehensive electronic health records and information systems.6-8

Here, we present the case for a national system, as recommended by the House of Representatives report. Our views have been strongly influenced by a series of multidisciplinary forums which we convened to explore the proposal.9-12

Health records

The health record has undergone many changes and is still evolving.10,11 The more significant current developments are the linking of all of each person’s health information to create a single integrated health record, and the increase in the range of both the users and the uses of personal health information. These changes are being realised through the development of the computerised health record.13,14

Traditionally, health records have focused on the needs of clinicians. Other users (such as planners, administrators, researchers and policymakers) have had to develop alternative systems to meet their needs, even though much of the information they require resides in the clinical record.

The Integrated Health Record and Information System

Central to the system recommended by the House of Representatives Committee is the integrated health record (IHR): a compilation of an individual’s health information, which is currently scattered throughout the healthcare system. This does not mean gathering the information together at one location; rather, it means a virtual integrated record based on the use of pointers to the location of the individual components, which are brought together as necessary.

The IHRIS would contain summary reports from every health-related event. The event report would be stored locally and indexed centrally. Linking all or some of an individual’s event reports would allow the creation of a completely or partially integrated health record.

It might be possible to satisfy clinical needs by creating an IHR for all individuals which could be stored on a portable storage device or even kept as a secure Web page, especially if supported by comprehensive provider communications. The Health Key Trial in Melbourne, by the Southern Health Care Network, is an example of such an approach.15 However, this approach would still require separate systems to meet the needs of other users.

The key feature of the IHRIS is that it is intended to satisfy the needs of clinicians and those of other users. The Figure shows the activities that would be supported by the IHRIS, while Box 1 outlines the principles and assumptions that underlie the model.

Benefits

We believe that the benefits of an Australian IHRIS would justify the costs and difficulties in developing it.

Benefits for clinicians and citizens

Few patients today deal with only one healthcare provider. This is particularly true for those who have complex health problems, for those who move frequently for work purposes, and for travellers generally. In the absence of continuity of care, continuity of information is essential to optimise healthcare. The benefits expected for individuals include:

For a national approach to be effective there will need to be a shared vision to enable the development of a national strategic framework.
The ability to perform epidemiological and other medical and health services research based on national data would deliver a number of benefits. These include:

- better-informed policy development;
- improved resource allocation and management;
- outcomes and cost–benefit analysis of interventions;
- identification of causes and risk factors of disease;
- more efficient collection of demographic data for management and epidemiological purposes;
- monitoring of disease outbreaks and adverse reactions;
- establishment of registers for diseases, devices and treatments; and
- postmarketing surveillance of drugs, devices and procedures.

Implementation

Introducing a national IHRIS will not be simple and will take time. The following are some of the factors that would be critical to the success of such an undertaking.

A shared vision, strategic framework and standards

For a national approach to be effective there will need to be a shared vision to enable the development of a national strategic framework. Ensuring compatibility requires the development and implementation of agreed national standards for the capture, classification, storage, communication and security of information.

The scale of the project

The size of a national health information system is likely to exceed that of any existing information system in the country. In addition, a large number of groups will be involved. It will be important to learn from the experiences of other industries and other countries.

The size of the task suggests that development should be carried out incrementally. There are at least five axes of development possible:

- geographical area (eg, start in one region or State and expand over time);
- proportion of the population covered (eg, involve specific groups and adopt an opt-in approach);
- variety of health providers supplying and using information (eg, include specific classes of providers initially);
- the proportion of each type of health provider involved (eg, adopt an opt-in approach); and
- record content (eg, start with a problem list, add in medication data etc.).

Any staged implementation strategy must be achievable and must provide sufficient benefits at each stage to justify continuation.

Privacy and security

There are significant privacy and security requirements which need to be satisfied. The needs of both consumers and providers must be addressed. This is essential, challenging, and achievable. Information privacy in health involves opti-
2: General practice

While away on work, Mr X, a truck driver, sees a GP. He complains of severe headaches and requests strong pain relief. He presents to the doctor as an unkempt man from out of town requesting a drug of addiction. After obtaining Mr X's approval to access his records, the GP calls up a medication report detailing all medications currently prescribed and dispensed to Mr X. The report shows no S8 drugs being dispensed.

A prompt pops up on the screen to advise the GP that the national adverse events register has recently detected an interaction between two of the drugs Mr X has been prescribed. The report advises that the drug combination was rare, but postmarketing surveillance based on the national iHiRIS had found a high incidence of hypertension and severe headaches. The GP discusses the issue with Mr X and prescribes an alternative medication.

mising individual rights and public good. We agree with the Consumer Health Forum view that this should not be seen as an "either/or" conflict, rather that these are "parallel objectives", and that cooperation between consumers and organisations wanting to use people's personal health information would be productive.19 Realising these objectives will require debate, policy development, and the use of appropriate security methods and technology.20

Provider computerisation

A threshold requirement of the system is the adoption of computer-based clinical records, especially in general practice. Currently, only 7% of general practitioners have electronic clinical record systems.21 The Practice Incentives Program22 is improving this situation.

Conclusion

The opportunity now exists to adopt a comprehensive approach to our health information management needs. It will require the involvement and commitment of all the relevant stakeholder groups in health, and will be a lengthy and challenging task. It is a task to which we believe our governments should now make a firm policy commitment.

3: Hospital

A person who had been found unconscious lying in the gutter and smelling of alcohol is brought in to the emergency department. A provisional diagnosis of ethanol intoxication is discarded when the doctor uses a contingency access protocol to view the patient's health records. The records show that the patient has a history of depressive illness.

The patient's medication report shows that a prescription for a tricyclic antidepressant was filled that afternoon. Upon seeing the information, the doctor promptly admits the patient to the intensive care unit, with a referral for psychiatric consultation the next morning.

Postscript

On 4 November 1999, the National Health Information Management Advisory Council released Health online: a health information action plan for Australia <www.health.gov.au/au/healthonline>. The framework outlined in Health online and the iHiRIS model presented here are based on entirely congruent principles.

Acknowledgements

We are indebted to the participants in the Health on Line Discussion Forums, who have contributed significantly to our views.

References