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The Australian National University**

INTEGRATED HEALTH RECORDS

Christopher Mount, Ross Bailie

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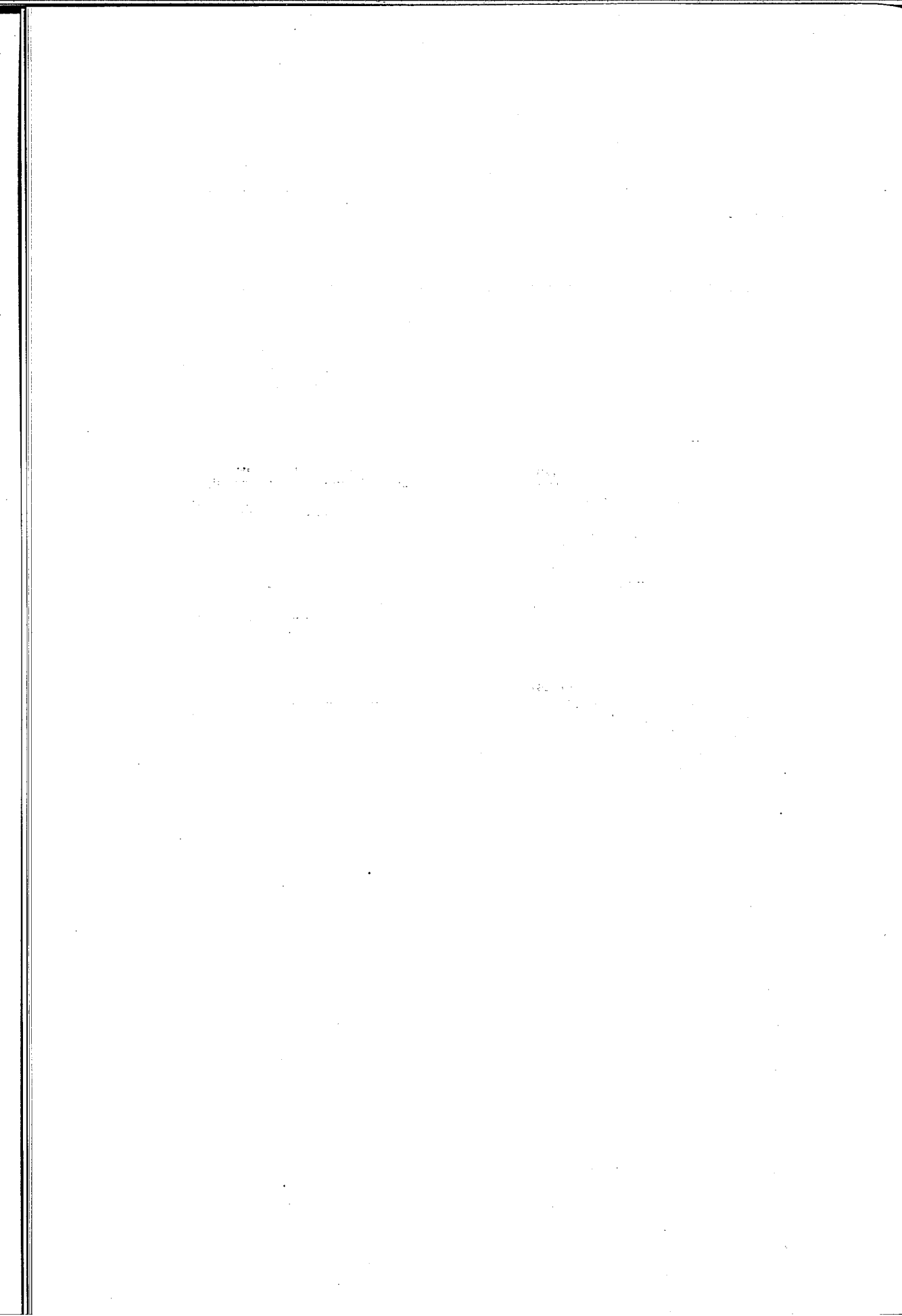
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Executive Summary

In October 1997 The House of Representatives Standing Committee on Family and Community Affairs recommended the design and deployment of a national health information system based on integrated health records. The implementation of such a large-scale proposal requires an understanding of the complex political, economic, legal, technical, logistical and cultural issues that would affect the form of such an endeavour.

This report describes an investigation which attempted to gather an understanding of these issues. The investigation is a preliminary stage of a project aimed at developing a system model for the national health information system recommended by the House of Representatives Committee.

Seventeen key informants were interviewed by the chief investigator. The informants were drawn from a wide spectrum of the health industry and included representatives of all major groups in health, namely: consumers, providers, administrators, policy makers, and researchers. Using qualitative analytical techniques within an information systems development framework the interviews were analysed and findings extracted.

Drawing on the findings from the interviews and knowledge derived from a detailed review of the literature the authors made conclusions which, it is hoped, will provide guidance to policy makers and system developers in any work undertaken on the design and deployment of a national health information system based on integrated health records. Given the qualitative nature of the investigation these conclusions must be treated as untested hypotheses.

The major conclusions of the investigation are divided into two groups. The two groups were; conclusions relating to the 'essence' of the system and conclusions relating to the 'implementation' of the system. These are summarised below:

Essential matters:

1. There is room for improvement in the use of personal health information.
2. Health records need to be centred on the individual.
3. Consumers should have some measure of control over their own record. Such control should include access for themselves and control in some form over access by others including disclosure to third parties.
4. New 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 health care system.
6. The benefits of a national system are likely to outweigh the costs but may not be the most effective use of health funds. Detailed analysis will be required.

Implementation matters:

7. Sufficient benefits must accrue to the suppliers of the information to the system to ensure the quality of the information and the success of the implementation process.
8. The costs and the benefits of any national health record system must be equitably shared between the relevant parties.

-
9. Consumer access to their records will strengthen the consumer-provider relationship but will require provider support to be successful.
 10. Six groups will have a role to play in the creation of a national health information system. These are: Consumer representatives, Provider representatives, Government, Academia, the Health industry and the IT industry. Key among these will be the Federal Government.
 11. The system will 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.
 12. The development and enforcement of agreed national standards will be required.
 13. Lessons must be learnt from other industries and other countries.
 14. Working within the principles of the Privacy Act detailed agreement needs to be reached on what constitutes the ethical use of health information, what conditions should apply to those uses and how such uses are to be supervised.
 15. Development and implementation of a national system would take between three and twenty years.

Acknowledgments

We wish to express our gratitude to the interviewees who gave their time freely and willingly. This report is built from their knowledge but the findings and conclusions are those of the investigators. No particular finding should be ascribed to any individual.

1. Background and Rationale

Currently most peoples' health records are scattered amongst the filing cabinets of the health care providers they have consulted. The information is usually stored in paper based systems with limited accessibility. The records are generally written notes plus pathology test results, diagnostic images, referral letters and discharge summaries¹.

Poor communication between providers and particularly between different sectors of the health industry is seen to be the cause of a significant proportion of adverse health events², p195 and is the primary reason for duplication, and consequent waste of health resources³. Some of these communication problems arise from the paper-based record systems utilised by many health care providers.

The practice of allocating resources on the basis of health outcomes is becoming more widespread. Successful implementation of this method requires sophisticated information systems², p196. Such systems do not currently exist in Australia. Furthermore, the difficulty of aggregating health information across populations adversely affects research and consequently future health care. This was recognised in the National Health Information Development Plan when making 'record linkage' one of the highest priority development directions⁴.

Three of the forces driving change in the management of personal health information are: changes in societal behaviour and expectations, changes in the delivery of health services and technological developments¹, p25 2, p195.

Increased mobility of both consumers and providers means that continuity of care being delivered through one provider is no longer possible for the majority of people. Consumer expectations of their role in the health encounter have changed significantly. The paternalistic approach to health care led to the record being treated as the personal preserve of the provider and its content, structure and medium reflect this view. A partnership approach requires greater sharing of information, provision of informed consent and agreement on proposed interventions - which in turn require changes to the management of personal health information.

Health service delivery is rapidly moving towards a multi-provider and multi-disciplinary approach and is moving away from acute hospital care towards a community-based care. These changes require improved communications and the provision of personal information at many more locations. Planners and administrators require better information to effectively allocate their ever-scarcer resources. Mooted changes in funding methods such as coordinated care would further increase the number of people interested in personal health information.

Substantial changes in the ability of computers to process and store information and for communication networks to transmit that information means that solutions now exist for the effective management of personal health information that were inconceivable only a few years ago.

In October 1997 the House of Representatives Committee on Family and Community Affairs completed a detailed investigation into the issues of information management in health. The committee made substantial recommendations in the areas of Health Information Management and Telemedicine in their report "*Health on Line*"⁵. One of the major recommendations was for a national health information system built from the creation of an integrated health record for all Australians utilising electronic health cards to access a network of distributed data warehouses.⁵, para 4.27 (See Appendix for the full text of the recommendation).

The implementation of such a large-scale proposal requires careful consideration of political, economic, legal, technical, logistical and cultural issues. An initial understanding of these complex issues can be usefully obtained from an appreciation of the views of key informants, that is people who have gained knowledge from regular involvement in such matters.

In February 1997 the authors submitted an application for a seeding grant to the General Practice Evaluation Programme to investigate, via key informant interviews, attitudes of the main stakeholders to client held health records. A second component of the project was to examine "state of the art" portable electronic data storage devices. (A copy of the original project synopsis and objectives is included in Table 1.) The grant was approved in December 1997. Work on the project commenced in March 1998.

Table 1 Project Synopsis and Objectives as proposed in the grant submission

Synopsis

Attitudes regarding client held health records of the main stakeholders in the health industry and consumer groups will be obtained through key informant interviews. A second component of the project will examine "state of the art" portable electronic data storage devices.

Objectives

This project is to be carried out in two stages. The objectives of the first stage are:

- 1.1 To explore the issues raised by the concept of a client held health record including:
 - a. health and productivity benefits
 - b. security of the information
 - c. authorisation of access
 - d. privacy concerns
 - e. replacement of lost data
 - f. correction of data
 - g. selection of data to be stored
 - h. ownership of the data
 - i. data linkage and aggregation of data
 - j. use of data for research and education purposes
 - k. other issues that arise during the course of the investigation
- 1.2 To outline the necessary and desirable features of a client held health record and establish a set of criteria against which available technology can be assessed.

The second stage of the project has the following objective.

- 2.1 To assess "state of the art" portable electronic data storage devices in order to ascertain their suitability for use as a client held health record

Upon commencing the project it was seen that there was a need to take into account the House of Representatives Committee proposal. Consequently the emphasis of the study was widened to consider health records generally, not just client-held health records, and to consider the issues of interest previously identified within the context of the proposed national health information system.

The chief investigator conducted a series of interviews with key informants from the health area. These interviews were unstructured and wide-ranging. During the course of preparing for the interviews and following an initial analysis it became apparent that the changed focus of the project was going to prevent the successful completion of objective 1.2. The utility of objective 2.1 was consequently seen to be significantly reduced. In addition the Department of Health and Family Services and the Health Insurance Commission had recently completed a major report on smart cards. Further efforts were therefore focussed on the primary objective as this was seen to offer the most substantial contribution to the debate on this issue at this time.

This report provides an overview of the literature pertinent to integrated health records and reports the analysis of the interviews. Some suggestions for policy makers and system developers are provided to conclude the report.

2. Literature Review

This review of the literature explores the history and purpose of health records, the history and effect of 'personal health records', the development of 'computerised health records', integrated health records and explores important information rights issues.

This structure is intended to enable the reader to appreciate the place of integrated health records within the broader area of health records, to gain an understanding of the technical developments that are occurring which are influencing the development of integrated health records and to understand how the important information rights issues of privacy and ownership and their subsidiary rights influence health records.

2.1 Terminology

During the following discussion a number terms of the form 'xxxx health records' are used. The relationship between these terms is shown diagrammatically in figure 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 differentiate the types of health records.

Personal Health Records: Health records over which the consumer has a measure of control. (Areas B, C, E & F in Figure 1)

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

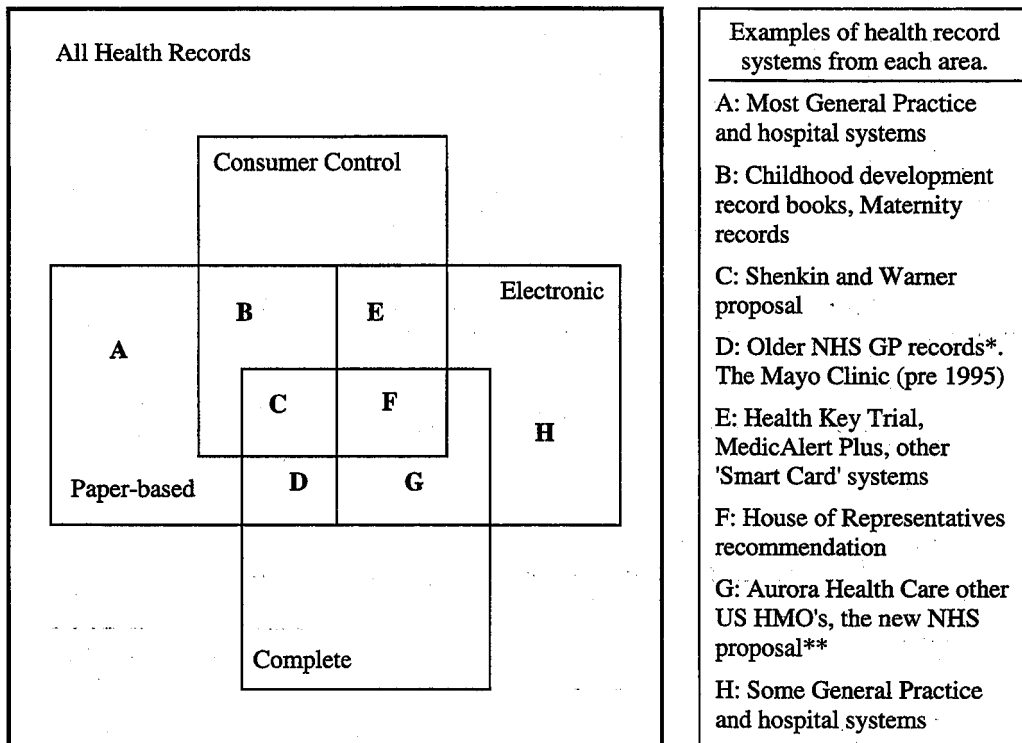
Electronic Health Records: Computerised health records which contain complete health information about an individual. (Areas F & G)

Integrated Health Records: Health records which 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 can be accessed readily if desired and appropriate.

The following notes are offered to clarify the proposed classification schema

1. Paper-based and electronic 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 summaries⁶. While electronic systems can and most likely will have paper outputs they were still 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 by the investigators was whether the consumer had 'some measure' of control over their record or not; primarily over access by others but sometimes also use, disclosure and content.
3. 'Complete' is a relative term; it would be impossible to collect all health information about an individual. The criteria used was an assessment of whether the record was reasonably complete and covered information from most of an individual's life.

Figure 1: Classification schema for Health Records



* 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.

2.2 The History and Purpose of Health Records

In the first part of Reiser's chronology of the health record he identifies six important evolutionary developments in the use of clinical notes up to the early years of the 20th century⁷. 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 18th century Morgagni was the first to compare evidence of disease derived from clinical records with the findings upon autopsy. During the 19th 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. The second major change in the 19th 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 1712⁸.

During the 20th century four major changes have occurred or are occurring. These are the concept and 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 first introduced in 1907⁹. The aim was to create a single record for an individual within any particular healthcare institution. Prior to this development clinical records were usually recorded serially as patients were seen and often kept in a bound book. The need for change arose from the 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 throughout health.

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's proposal for a paper-based approach would have resulted in a complete record but their proposal was never implemented¹⁰. In its initial conception the childhood personal health record was an attempt to create such a record up to age 18¹¹. The highest level of computerised health record, 'the electronic health record'¹², 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 recently to create a 'cradle-to-grave' health record for every Briton by 2005¹³. 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 reports on a meeting held in 1959 at the Rockefeller Institute of scientists and physicians which concluded that computers could and should be used in health record keeping, mass screening, description of the natural history of disease and national databanks¹⁴. 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 away¹⁵.

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 Record¹⁶, pg. 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 solution to the perceived problems was the "Problem-Oriented Medical Record". The major change in his proposal was the 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 20th 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*"^{Donabedian 1989 cited in 9.}

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 care quality assurance. They saw the feedback was at three levels, the clinician, the healthcare facility administrator and the 'societal resource allocator', which could be reasonably translated as government policy maker¹⁷.

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 records¹.

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 enquiry¹⁸. 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 lead to concerns over rights of access, use and control which are discussed later¹⁹⁻²¹.

In conclusion, the health record has undergone many evolutionary changes over the last three hundred years and is still changing. The two most important current changes are the move towards creating a single record for every individual containing all their health information, not just medical information, and the increase in the range of both the users and the uses of the information the records contain. These changes are being realised through the technical development of the computerised health record. An important feature of electronic systems is that they break the link between data 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.

2.3 Personal Health Records

2.3.1 Introduction

Personal health records are one approach to creating a single health record for an individual covering all 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 or alternatively by use of an electronic key that controls access to the record which is stored on a computer. The former often have the word 'held' in their name and are generally paper-based. The approach recommended in the "*Health on Line*" report is an example of the latter⁵.

Many names are used in the literature to describe concepts similar to 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 record, generally paper-based and held by the child's parents. The term 'personal health record' will be used in this report to encompass all types of record where a measure of control resides with that individual. Whilst this choice could lead to some confusion with the baby books, which shall be called 'childhood personal health records' hence forth, it is considered to be the most appropriate name.

2.3.2 History

Discussion in the literature on personal health records started with the publication in 1973 of a proposal by Shenkin and Warner to give people a copy of their medical record¹⁰. They saw that considerable benefits would accrue to the health care system and that the barriers they identified could be dismissed or resolved. An extensive literature developed looking at the potential benefits and barriers identified by Shenkin and Warner and later contributors. It is not possible to report the entire discussion; however, there have been a number of reviews pertinent to the issue.

Gilhooly and McGhee found that there were no substantial practical drawbacks and considerable ethical benefits to be derived from giving patients custody of their medical records²². 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 GPs; savings in clerical costs and the ability of individuals to correct inaccuracies in their record. Their analysis of the ethical concerns found that personal health records improve communication and increase trust. They dismissed concerns over confidentiality raised by some providers arguing that the duty of confidentiality does not preclude patient access and that confidentiality should not be confused with secrecy.

Cornwall's review of the literature on consumer access to health records, 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 concludes that legislative reform is required²³. The evidence she refers 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^{24, 25} and in maternity care^{26, 27}. Interestingly these are both situations where the normally healthy interact with the health care system. Other situations reported include patients discharged from a psychiatric hospital²⁸, homeless mentally ill²⁹, hospital outpatients^{30, 31}, ambulatory chronically ill older patients³², general practice clients^{33, 34} and rehabilitation patients³⁵. Of the uses identified the experience of childhood personal health records is most effectively documented and is discussed here in some length.

2.3.3 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 health 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, often plastic and kept by the parent of the child concerned^{11, 24, 36}.

They have been in use in many countries including Canada, the United States of America, France, Britain, New Zealand, some African nations as well as Australia.

McFarlane puts the position that the medical records of a child are primarily to aid the exchange of information between professionals. He asserts that the parents of a child are the professionals who carry out most of the health and illness care of an individual child²⁴. 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 places³⁷. These arguments are readily extended to the health maintenance and 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 RACGP developed a prototype childhood personal health record. This was trialed for 12 months in Modbury SA. 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 providers¹¹.

Following the trial the prototype was developed further and introduced across South Australia in 1981. NSW and the ACT introduced a similar system in 1988. Queensland was the last Australian State to introduce a childhood personal health record^{Unpublished report 1994 cited in 38}.

A number of trials have demonstrated high retention rates and high public acceptance of the records^{25, 39, 40}. 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 and community based nurses^{11, 36, 40, 41}.

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 conclusion childhood personal health records are widely utilised 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

2.3.4 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. 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 notes²⁷. Draper et al found similar results although they did report that a quarter of the women found them difficult to read or worrying²⁶.

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 the views of the health providers⁴². Reuler and Balazs issued a portable record to homeless chronically mentally ill people. They reported improved communication between health providers and the people involved found pleasure in reading their medical records²⁹.

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 idea³³. 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 health providers³⁴.

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

2.3.5 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 health care system, namely childhood development and maternity records.

The evaluations of the effect of personal health records have so far been limited, 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 health care providers. Importantly, improved communications have been reported between different providers and between providers and consumers.

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

2.4 Computerised Health Records

2.4.1 History

The attempt to computerise the medical record was underway as early as 1958¹⁴. As mentioned previously the widespread implementation of computerised health records is still thought to be five years away¹⁵.

Stead provides a good report of the first twenty-five years of computerised health records¹⁴. His major observation was that system development was too 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', for as Kahn puts it "*Today's 'state-of-the-art' technology is tomorrow's legacy system*"⁴³. Hopeful lessons can be learnt from the work reported by Nordyke and Kulilowski of a thyroid clinic, which has had a computer-based record system for 35 years. They have successfully managed the transition from punched cards, through an online mainframe system to a PC-based system and have longitudinal records for some of their 15,000 clients dating back to 1960⁴⁴. Similarly lessons can be learned from the Regenstrief Record Management System which has been in use and continual development for 25 years⁴⁵.

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*"¹. This report encapsulated most of the work that had occurred in the thirty years previous and outlined a plan for the wide spread adoption of computerised health records over the following ten years. The 1997 update to this report considers that the vision outlined in the first report "remains remarkably on target"¹⁵.

2.4.2 Current Status

Van Bommel et al reported recently that computer-based information systems are now abundant in a large percentage of European hospitals as well as primary care settings. However, this optimistic view

is conditioned by their observation that most hospital systems are administration focussed and seldom contain patient record data. None of those systems that do contain patient data fully replace paper-based patient records. They also see that privacy, standards for record architecture and data interchange and user identification are the major barriers that need to be addressed⁴⁶.

Tang and Hammond take a different perspective when reporting on the status of computerised health records in the United States of America. They found that no comprehensive review of the industry exists and would be soon out of date if it did. However, they see that promising signs exist 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 include the lack of a common data model and data elements, effective human-computer interfaces, standards, privacy, thorough cost/benefit analysis and leadership⁴⁷.

Hannan paints a less hopeful picture in Australia. There are no fully developed computerised health record systems and no specific projects directed to this end. There are 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. This institute would need to coordinate activities on five fronts: standards for coding and communication of patient data; standards for protection of patient confidentiality; increase knowledge of the state of the art; promote the use of communication networks, and evaluation of the effectiveness of information systems⁴⁸.

The three views reported above agree on the barriers that need to be addressed before widespread use of computerised health records is achieved. One issue on which there are notable differences is of some importance to Australia. The Americans note the lack of a conceptual model free of technological constraints; the Europeans report the emerging focus on conceptual models while Australia has one in the National Health Information Model⁴⁹.

There have been a number of important developments in Australia since Hannan's editorial was published. The House of Representative's Committee report "*Health on Line*" made substantial proposals on most of the important issues identified by Hannan. The Australian Health Ministers Council have established a National Health Information Management Advisory Committee⁵⁰. The Department of Health and Aged Care has commenced major projects on standards and the coding of health information. The Privacy Commissioner is undertaking a wide ranging consultation aimed at developing agreed principles for the fair handling of personal health information. There are also important initiatives underway in general practice computing and acute care.

2.4.3 Evaluating their impact

The primary benefit of a computerised health record is the use of health information that, 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*"⁵¹. The adjunct of this availability is the perceived need to link the health record information to knowledge bases, clinical decision support systems and statistical software packages¹.

Evaluation of the effect of computerised health record systems has largely focussed on the effect of decision support systems and other applications which use the information contained in computerised health records. It is not possible or even useful to provide a complete report of every study looking at

information interventions utilising a computerised health record, however, a quick overview will provide an important perspective on the lessons learnt.

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 planning⁵².

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 the inclusion criteria. The analysis showed an increase in consultation time of between 48 and 54 seconds, immunisation rates improved by 8-18%, an improvement in other preventive tasks by up to 50% and a 13-30% reduction in prescribing costs. Whilst one study 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 outcomes⁵³.

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 increased compared to the control group response of 29% ($p < 0.0001$)⁵⁴.

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 ($p < 0.0001$)⁵⁵.

Garrett et al reported that the use of computerised health records in a hospital setting resulted in significant reductions in the time required to obtain information from the record and in entering data into it. Significant reductions in medication errors were also noted⁵⁶.

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 cohort, a relative risk of 3.8 (calculated from figures contained in the report)⁵⁷.

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 report⁵⁸.

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 measured⁵⁹.

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 care⁶⁰.

From this brief overview it can be seen that the impact of computerised health records can be substantial. A detailed review of their effect needs to be tailored to the particular situation under consideration.

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 which utilised the card as a repository of clinical information in the management of people with diabetes⁶¹; the Exeter Care Card Trial which included 13,000 participants and the card held administrative, clinical, emergency and prescription data which was made available to two general medical practices, eight community pharmacists, a dentist, a community hospital and a general hospital⁶²; and the Delft Project which involved 250 people, three GP's and a pharmacy⁶³. France has adopted the wide use of smart cards that are primarily for health insurance purposes but also include a measure of personal health information^{Described in 64}. Canada had a trial in Rimouski near Quebec City, which included 7250 people and 300 health professionals⁶⁵. Quebec province is planning to issue seven million smart cards containing administrative information initially, clinical information is to be added later^{Described in 64}.

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 hospital⁶⁶. This trial did not proceed. A more elaborate version is being undertaken in Victoria currently involving 600 participants, 15 general practitioners, 12 pharmacists, several specialists and the Dandenong Hospital⁶⁷.

The recommended proposal in the "*Health on Line*" report is for a system that uses the electronic storage card as a key to a larger repository accessed using network communications technology^{5, para 4.27}.

2.4.5 Conclusion

Computerised health records are an emerging technology that has great potential to improve the delivery of healthcare services. Computerised health record development in Australia is slow but several important initiatives are underway which will result in major changes in the next two years.

The literature on the impact of computerised health records is growing and indicates important improvements in health care service delivery and health outcomes can be realised from successful implementations.

Attempts have been made to create personal health records based on computerised health record technology using electronic storage cards. These 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 facilities offer an alternative method of achieving an electronic personal health record.

2.5 Integrated Health Records

As mentioned previously the move to institution-based unit records commenced in 1907. Unit records are now utilised in most healthcare institutions. Moves toward a complete unit record for an individual encompassing information from all healthcare institutions from which they have received services have been very slow.

Personal health records and the highest level of computerised health record, the 'Electronic Health Records'¹², 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.

A number of authors have proposed expressions 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 record^{68/ p36}, Personal Life Health Plan⁶⁹, lifelong electronic health records¹³ and cradle-to-grave electronic health record⁷⁰. 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. We have used the term 'integrated health records' 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 existing health records, which are fragmented and scattered. It must be noted that the different components of the record need not reside in the same place, however, they must be readily accessible when desirable and appropriate.

Shenkin and Warner's proposal that people should be given a copy of all health records would have been a paper-based integrated record¹⁰. Their idea was never implemented outside of individual institutions^{33, 35, 71}.

Perhaps the closest realisation to an integrated record in any widely implemented system is the British NHS General Practice records. In Britain individuals are registered with one GP and when they move their records, which are owned by the Secretary of Health, are sent on to their new GP. 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 - Personal Communications)

The Mayo Clinic in Rochester has maintained a comprehensive record that includes essentially all the information on residents in Rochester since the early 1900's. They led the development of unit records, which were implemented in St Marys' Hospital Rochester in 1907⁷².

Recent developments in this area include the British National Health Service's proposal to create a form of integrated health record for all Britons by 2005⁷³. A number of Health Maintenance Organisations in the United States are also in the process of implementing major information systems that will include the complete health information for their members^{74, 75}.

2.6 Information Rights

The issue of information rights is 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 of that information.

It is a subject that induces much debate and considerable confusion partly due to differences in definitions and word usage. It is also a subject 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.

2.6.1 Ownership

The historical view of information rights is tied to the idea of ownership. The owner of information was seen to hold a right of absolute control of that information. The entity that collected the

information, traditionally an individual doctor although increasingly a health service provider organisation, was seen to be the owner. This position is still largely reflected in the legal status of health information.

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 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 whose information is involved. An important feature of confidentiality is that it is a provider-controlled mechanism which attempts to respect both the privacy needs of the individual and their desire for optimal care.

The control of the use and the disclosure of information by professionals 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 has seen 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. In order to understand this important change it is useful to explore the idea of privacy more fully.

2.6.2 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 20th century." Marc Rotenberg in 76

This bold prediction 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.

2.6.2.1 Definition

The Oxford Concise dictionary offers the following definition of privacy "*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."⁷⁷ 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 arises commonly 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^{Cited in 78}. 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 is considered to be an important breakthrough in the area of privacy and is regularly cited by later authors. Westin sees 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.*"⁷⁹ This definition is

commonly referred to when discussing this issue^{80, 81}. 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 one hand and their desire to be a part of society on the other. It also highlights the contextual and cultural nature of privacy.

This tension is also echoed in society's need to respect an individual's privacy with its need for information to enable the effective planning and management of an increasingly complex world. Westin sees the greatest threat to civilised social life as being a situation where each individual was utterly candid in their communication with others^{79, p37}. He also points out the fundamental belief in democratic societies in the uniqueness of the individual, thus allowing personal autonomy is an essential element of a democratic society^{79, p33}.

This definition, with its emphasis on the control of communication by the particular entity 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 at the same time or even the same person at a different time.

2.6.2.2 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 1981⁸². The Australian Privacy Act 1988, which is based largely on the OECD Guidelines, outlines eleven Information Privacy Principles (IPP's) (See Appendix 9.5)⁸³. 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 issues⁸⁴. Specifically in health, Australian Standard AS 4400-1995, which deals with personal privacy protection in any health care information systems, proposed the adoption of the IPP's by any organisation holding personal health information⁸⁵, the NSW Department of Health issued privacy guidelines in 1996 (Revised December 1998) which contain principles similar to the federal Privacy Act, in the Australian Capital Territory legislation has been passed giving effect to twelve principles similar to those in the federal Privacy Act⁸⁶ and Victoria is intending to do likewise in the near future. The Privacy Commissioner is proposing to consult with the aim of developing some national principles for the fair handling of personal information specifically focussed on health, by the middle of 1999.

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.

2.6.2.3 Derived Rights and Responsibilities

Another interpretation of the Information Privacy Principles is that they establish a series of rights and responsibilities which 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 the 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 in delivering information to a third party. Access involves the 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. These operational differences lie in the

Issues such as how legitimacy of use is agreed and who is to have access to the information require detailed consideration. There are a number of processes that exist which 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 some areas of use 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 sector⁸⁷ the recently proposed federal legislation will fill this gap⁸⁸.

2.6.2.4 Jurisdictional coverage of the Information Privacy Principles in Australia

The issue of jurisdictional applicability of the Information Privacy Principles 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 High Court decision in the case of *Breen and Williams (1996)* found "...that in the absence of a statutory conferral on an individual of a right of access to personal records about that individual, Australian law does not recognise such a right."⁸⁹ This case involved an individual requesting a copy of her health record.

Following this decision an attempt was made to extend the Information Privacy Principles to the private sector by the Attorney-General's Department⁸⁷. However, this work was halted following Prime Ministerial intervention. Subsequently the ACT Legislature passed its "*Health Records (Privacy and Access) Bill 1997*"⁸⁶ and the federal Privacy Commissioner engaged in a consultative process which resulted in the "*National Principles for the Fair Handling of Personal Information*"⁹⁰.

The Senate Community Affairs References Committee also undertook an investigation of access to medical records that recommended the implementation of "...comprehensive national legislation enshrining the rights of access to medical and other health records in the public and private sectors."⁹¹ 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. This group is still deliberating and not expected to finalise its work until late 1999.

The federal government recently announced a "light touch legislative regime" to support privacy principles in the private sector⁸⁸. 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 will ensure that all health care services have 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 a basket of information rights. The cultural transition will take longer.

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' government 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.

2.6.3 Consumer access to health records

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^{32, 71, 92, 93}, record quality^{33, 35, 40} and consumer/provider relations^{27, 30, 94}. Shenkin and Warner postulated other benefits but they have not been evaluated. These are expected to arise when consumers hold a copy of their record and include improved continuity of information, improvements in quality through peer review, provider education, the faster spread of new ideas and more efficient resource allocation¹⁰.

Difficulties that have been identified have been dismissed by later reports or can be controlled. These difficulties (with relevant discussion cited) include the risk of increased litigation^{O'Gara, cited in 23, 95}; censoring of the record^{30, 35}; lost control over the timing of disclosing information⁹⁶; a lengthening of consultations^{31, 97, 98}; loss of the ability to record speculative thoughts and third party information^{33, 99}, and concern over potential harm from an individual accessing their record^{Bouchard cited in 30, 100-102}.

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 detrimental effect of consumers accessing their records. Providers will 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 records¹⁰²⁻¹⁰⁵. Legislated rights of access do not lead to an increase in access^{106, 107} as the attitudes of providers^{96, 108} significantly affect the likelihood of consumers seeking access^{31, 109, 110}. 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^{35, 111}.

Where consumers are granted a right of access to their health records it would be necessary for the content and structure of the records to change in order to enable effective access to be achieved. Computerised health records avoid the legendary 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 further clarify and explain the information is an important feature of successful consumer access^{30, 102}.

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

2.6.4 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 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 societies views on privacy have opened up the idea of ownership of information and has created new rights of access, collection, disclosure, amendment which are no longer in the control of the owner.

The major challenge in satisfying privacy needs is the contextual, social and cultural nature of its construction making it 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 societies 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.

2.7 Overall Summary

The preceding literature review provides a background understanding of integrated health records and the issues pertinent to them.

The health record has undergone evolutionary changes over the last three hundred years and continues to do so. The important change is the move towards creating a single record for every individual containing all their health information. There are also changes in the range of users of the record of which the consumer is but one.

Personal health records have only been used to cover a limited range of information from small portions of an individual's complete healthcare history. However, they could be expanded to cover an individuals entire life. They have been well accepted by the general public but less so by health care providers.

Computerised health records are an emerging technology that has great potential to improve the delivery of healthcare services. Computerised health record development in Australia is slow but several important initiatives are underway which should result in major changes in the next two years.

Electronic information systems have broken the link between data capture and its 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 such as clinicians and consumers.

Attempts have been made to create personal health records based on electronic health record technology using electronic storage cards. These have been restricted in function and coverage to date primarily due to a lack of storage capacity. The use of networked communications technology is providing an alternative approach.

While proposals for 'integrated health records' have been made no significant progress has been achieved on creating a 'complete' health record for an individual. The recent NHS proposal would see

the creation of such a record for all Britons by 2007. This would be just two years shy of being one hundred years since the introduction of the institution-based unit record.

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 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 has created new rights of access, collection, disclosure, amendment which are no longer in the control of the owner.

The major challenge in satisfying privacy needs is the contextual, social and cultural nature of its construction making it highly dynamic and variable in nature. Tensions exist within each individual in their need to be both private and social and similarly within society between the need for information and the need to respect the privacy of the individual.

In conclusion the changing nature of the health record and of consumer expectations, in conjunction with available technology now make it possible for a health record which spans the entire life of an individual. Understanding of the issues involved in such a significant change in health service delivery is necessary to ensure that change such as that proposed by the House of Representatives committee is implemented in the most effective and efficient manner. The study reported in the following pages is an attempt to obtain such an understanding.

3. Aims and Objectives

3.1 Aim

The aim of this investigation was to identify and describe the important issues involved in the design and implementation of a national system of Integrated Health Records.

3.2 Objectives

The objectives of the investigation were to provide information to inform decision making by policy makers and to inform the development of a model of an Integrated Health Record and Information System.

3.3 Questions for Investigation

In order to achieve the stated aims and objectives the following questions were identified from the literature and by applying Structured Analysis design methodology to the project^{1,2}.

1. What are the shortcomings in the existing systems that a national system of Integrated Health Records would be intended to overcome?
2. Who are the potential users of a national information system?
3. What are the potential uses of a national information system?
4. What benefits would accrue from those uses?
5. What form might a national system take?
6. What are the constraints that would affect the form of the system? Eg Legal, Social, Economic, Logistic, Technical, Operational and Political
7. How would the information rights issues of ownership and privacy affect the implementation of such a system?
8. How could a national system be implemented?
9. What are the barriers that will need to be overcome or avoided in order to successfully implement a national system?
10. What are the costs and risks associated with such a venture
11. How long would it take to develop and implement?

4. Methodology

Interviews were conducted with key informants. A list of approximately 70 potential interviewees was created which included interviewees suggested by the members of the chief investigators supervisory panel. Thirteen of the potential interviewees were selected to be interviewed in 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) record of academic work in the area. The selection involved balancing the perspectives provided and people with a number of different perspectives were preferred.

Those selected included representatives of all major groups in health namely consumers, providers, government administrators and policy makers, and researchers. A number of health informaticians were included to provide perspectives on the technical issues. Three of the six health informaticians were also practicing health service providers, while a fourth had completed medical training and all were chosen for the multiple perspectives they could provide. The first group of thirteen included four people from the National Centre for Epidemiology and Population Health, whose interviews were used to trial the interview methodology as well as contributing to the data gathered.

The people selected were telephoned by the chief investigator 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 was approached and agreed to be interviewed. A fourteenth interview was conducted with a medically trained doctor of health informatics recently returned from the United States whilst the chief investigator was in Adelaide conducting other interviews.

A letter explaining the project was sent to the participants prior to the interview. The chief investigator conducted the interviews and an audio tape recording was made with the agreement of the interviewees on the condition that all findings would be reported on a de-identified basis. The interviews were unstructured using a theme list with prompts to ensure sufficient coverage of the issues of interest. A theme list was developed from the questions identified for investigation reported in section 3. The theme list was reviewed by the chief investigator's 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 chief investigator 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. Consequently only a few additional interviews were undertaken. These were seen to improve the balance of the group of interviewees.

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. A fourth interview with a General Practitioner with involvement in the software industry was planned but didn't occur due to scheduling difficulties.

The final list of those interviewed is included in the appendix. The following table indicates the mix of the interviewees in terms of their primary work roles.

Interviewees Primary Roles	
Health Informaticians	6
Consumer Representatives	3
GP Representatives	2
Government	3
Health Researchers	3
Other Roles of Interest	
Health Service Providers (past and present)	9 (5 GP's, 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 participants 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 this final report.

5. Analysis

5.1 Analytical Framework

The investigation's objective was to explore issues related to the design and deployment of a national health information system based on integrated health records. Such an exploration is the first stage of information system design. Consequently it was considered that Structured Analysis would provide a suitable framework within which to analyse the interviews¹¹². Structured Analysis is an established method of analysis utilised primarily by systems analysts in the development of information system models.

Working within the Structured Analysis framework the investigation was divided into two parts. The first considered matters relating to the 'essence' of the proposed system and the second considered questions of 'implementation'.

5.2 Preliminary Analysis

The transcripts were coded using NUD*IST software¹¹³. NUD*IST is a qualitative analytical tool which grouped together transcribed text from different interviews which related to a common theme. The text was grouped into a series of nodes that were then related in a branching form to create the index tree. Each theme identified was assigned a node and placed in the index tree. The index tree is included in the appendix.

The index tree was divided into two major parts: Essential issues and Implementation issues. The two parts were further divided into major themes and some of the themes were subdivided for ease of analysis. The branching structure is shown below.

Essential Issues

- Uses
- Users
- Benefits
- Existing Shortcomings
- Future Directions
- Health Reform

Implementation Issues

- Pathways
 - Drivers
 - Parties and Roles
 - Approaches
- Barriers
- Information Rights
 - Privacy
 - Access
 - Control
 - Ownership
 - Disclosure
 - Amendment
- Data Capture
- Standards
- Unique Identifiers
- Time Frame

Reports from each of the nodes of the index tree were made and the chief investigator considered the information contained in the nodes and extracted findings, which were then reviewed by the investigators.

5.3 Final Analysis

The general process was similar to the preliminary analysis. The three 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 chief investigator considered the information contained in the nodes and 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 aimed to avoid the association of any contribution to a particular participant.

6. Results

The results are reported in two parts, Essential Issues and Implementation Issues, both of which are further subdivided into a number of sections. They represent a distillation of the views of the interviewees as presented to the chief investigator and filtered through the analytical perspective of the investigators.

6.1 Essential Issues

The first three subjects reported are matters that relate to the environment within which a national health information system would be operating. They are an examination of the existing shortcomings, an exploration of future directions and the nature of the health care system and likely changes that such an information system would need to accommodate, support or even create.

The fourth subject reported deals with matters relating to how the system would interact with its 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.

6.1.1 Existing Shortcomings

There was a broad consensus that less than optimal use was made of personal health information. The cause of this was seen to lie partly in the nature of the existing information systems. The findings have been grouped into two subjects: The lack of an individual focus and record quality.

6.1.1.1 The lack of an individual focus

The lack of an individual focus to existing health information 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 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 the 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 important information can be obtained by the clinician by listening to how the consumer describes their condition. The fragmentation is utilised by consumers to control who has access to different parts of their health information. An example given being the person who goes to one doctor for most health matters but another one for sexual health matters. This type of control is likely to be desired by some consumers in any new system.

The institutional or provider focus arose from 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. Consequently *"...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."*

Lack of an individual focus was thought to leave the person disconnected from their information and in some sense from their care. *"From the patients point of view the disconnection of their information from themselves is probably at the core of a lot of problems that occur in health care."* The lack of an individual focus also prevents analysis based on an integrated individual record. This adversely affects researchers, administrators and policy makers. Furthermore, it makes it difficult to locate consumers in situations where it is necessary such as the treatment induced Cruetzfeld-Jakob Disease outbreak.

6.1.1.2 Record Quality

The content of existing health records was a major concern. A large proportion of health records are disorganised collections of written notes, letters, test results and other pieces of paper held in folders and filed away in filing cabinets. The nature of these records leads to problems of accessibility, comprehension, completeness and accuracy.

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

Once located 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 doctors letter or previous patient notes which were in the hospital so that they 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 perceived need for a coordinated approach to their use in the minds of the collectors. The lack of such a coordinated approach suffers 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.

6.1.2 Future Directions

Some pointers as to how health information might develop in the future were offered. The major observation was that there was a belief that health records would be electronic in some form. There was also an expectation that improvements in health would be achieved through better organised records both directly to the individual during clinical encounters and indirectly through analysis.

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 you could send out a questionnaire to providers. With the providers approval the software would scour her 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. Administrators 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 which would allow them to act with the knowledge of a specialist.

6.1.3 Changes in the Health Care System

A number of changes to the health care 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 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 importance 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 health care 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 by the population.

New jobs and changes in the role of 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 system and workflow changes. System and workflow change is extremely challenging performing it on a national scale would require skillful management and considerable effort. It is likely that the health care system will undergo information system induced change regardless of whether a national system is implemented. Consequently 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 the administrators and providers.

6.1.4 Users, Uses and Benefits

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 health care 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 health care 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. Policy makers, planners, financiers, 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 performing more accurate modeling of policy options based on evidence derived from the system and also to 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 for 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 records.

Automatic 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 allow for improved post-marketing surveillance. This would allow improvements in the detection of adverse outcomes and to 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 health practitioners 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 service 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 and that the most useful suggestion was to work with what you have available and which delivers sufficient benefits to justify the costs. There was a clear message that starting with a limited range of provider and increasing over time would be a sensible approach.

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 health care system along with fear of government surveillance and potential loss of privacy. It was recognised that financiers are reluctant to consider these sorts of 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.

6.2 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 particularly personal and sensitive nature of the information and also the range of information that is considered relevant to 'health' (see 6.1.1).

This investigation avoided exploration of technological issues. It was considered that this task could be left until later. To the extent that technology was discussed it was thought that the 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.

6.2.1 Pathways

Three features of the way from where we are to wards implementing a national health record system were identified from the interviewees contributions. These were: the parties needed to be involved and the roles to be performed, the driving forces which would determine the progress made and an outline of an approach that could be taken.

6.2.1.1 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 IT 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 from both the medical and allied professions. Government included both Federal and 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. IT industry was undifferentiated but considered essential.

The Federal government was selected 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 sometimes needs assistance from others playing to reach what for them may not be an easy vision.

One particular role 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 recently formed National Health Information Advisory Council may provide that focus.

6.2.1.2 Drivers

The clearest message 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 healthcare outcomes. The belief was widely held that a major barrier to improving information systems is the perception that benefits of a national health information system largely accrue to downstream users such as administrators, governments 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 the great majority of pathologists are computerised. It was suggested that general practitioners haven't turned to computerised systems due to the nature of the funding process, which favours rapid turnover and provides no incentives for installing information infrastructure.

Some suggested that a market approach to establishing the price of 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 becomes commercially important it gets 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 participants that this would be an unnecessarily narrow measure of the value of a national information system. 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 participants. Two examples were given. The first example related to the move to outcomes based funding for divisions of general practice and potentially to other sectors in health. Such a change requires considerable information in order to determine the outcomes achieved. The nature of the measurement will require the availability of more comprehensive individually 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, can 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 and would be beneficial.

6.2.1.3 Approaches

The strongest message from the interviews was that a national health information system would need to be developed incrementally. The types of incrementation were varied suggesting several axes of incrementation. The types included 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"*, e) focus on particular groups within the population e.g. chronic care and f) more general statements such as *"start with something manageable"*, *"build a system that could be added onto easily"* and *"work with the opportunities"*. It was seen that the process of incremental development would need to be bedded into a national framework, i.e. that the process would need *"to be 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 such an information system would both require and enable changes in the way health 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 individual and the community at large.

6.2.2 Barriers

A variety of potential barriers were identified including 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. That is, one that was often presented as a problem but was considered solvable and was 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. A complete version of an individual's integrated record would be difficult to use effectively 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 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 is that it maybe impossible to simultaneously involve everybody and to make significant progress.

The difficulties of organisational and workflow change arising from the implementation and use of information systems are well recognised. In a project of this scale these difficulties are a challenge that will be 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.

6.2.3 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.

6.2.3.1 Information Privacy

The most difficult question when discussing privacy was getting people to focus on the essence of the issue and not the means of achieving it. A number of participants 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 implying that there is no absolute definition of privacy. Perhaps the conclusion to draw is that just as talking about ownership creates blockages, talking of privacy does the same. It may be more helpful to talk about the means to achieving privacy such as fair information handling principles.

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 and that 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. The Privacy Commissioner is intending to consult about the development a set of "fair handling principles for personal health information".

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 through the use of

the word balance or whether there was an optimisation process involved. That is, could you satisfy personal privacy needs whilst maximising the public benefit.

An interesting observation was that the concept of "trust" arose quite often when discussing issues surrounding privacy. This point could be usefully explored further as it may reveal something of the essence of privacy.

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.

6.2.3.2 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 as it created blockages in that ownership is 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 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 which enabled effective adaptation to future technological and social change.

The Privacy Act 1988 has broken open the idea of ownership granting total control. The proposed privacy legislation will see all health care services covered by some form of privacy principles. However, concern was expressed that during a transition to the new order based on a basket of rights that private commercial interests could lock large amounts of information away. Furthermore it was suggested that ownership becomes very difficult 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 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 participants. 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 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 'identified' information.

It was argued that control through ownership was one mechanism for promoting privacy, however, it was not seen as being the only way of ensuring privacy.

6.2.3.3 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 to arise from this changed acceptance of responsibility.

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 as a 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 shouldn't have access. It was suggested that the response to this concern would involve providing people with sufficient information about why someone should 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 but from a consumer perspective was essentially the same.

6.2.3.4 Disclosure

This topic was not discussed by many of the participants. 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.

Consumers need to be able to determine who has access and under what conditions. 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 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, sometimes implied consent would be sufficient. Consent obtained in situations where refusal was for all practical purposes impossible was not seen to be acceptable. 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.

6.2.3.5 Control

There was a broad consensus that in an integrated information system consumers will have to have some measure of control. However, what that control would be exerted over and how complete the control would be were 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 currently the provider or their employer organisation controls it. It is reasonable to believe that in any future system individuals will want to maintain at least the same level of control. 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 should have some control on 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 should have some measure of control over the content of the information. Such control should include the right to amend or perhaps only to request an amendment to the record.

6.2.4 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.

6.2.4.1 Data Capture

There was a clear message that it was only 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 clinician. 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 clinicians would be reluctant to collect information other than that which they required for their own purposes, both 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 clinician. It was thought that the provision of feedback to clinicians on performance relative to their peers would be an acceptable extension of the range of activities for which clinicians might collect and supply data. Giving clinicians direct feedback through decision support software was another method 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 (something that has been continuously 'around the corner' for the last 25 years) would provide a further gain in efficiency. Clinicians 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 clinicians as they climbed the learning curve.

There was considerable variation on the issue of what would be useful to capture. An important guiding principle being to only collect what will be, or is likely to be used and not to collect information simply because it is possible.

6.2.4.2 Time Frame

A few of the participants 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 their estimated time frame.

6.2.4.3 Standards

The issue of technical standards was raised by some of the participants. 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 an important player in the development and implementation of standards. This 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.

7. Conclusions

These conclusions are intended to assist policy makers and system developers in any work undertaken on the design and deployment of a national health information system based on integrated health records. The following conclusions are a distillation of the findings reported above, interpreted in the light of the existing literature.

Given the qualitative nature of the investigation these conclusions should be treated with some caution. They represent the distilled opinion of the interviewees as filtered through the analytical perspective of the investigators and should be treated as untested hypotheses. Any weight that can be attached to the findings lies in the knowledge of the interviewees derived from their experience gained from working in the field and the contributions provided by the literature.

7.1 What type of Health Record is indicated by the findings?

It was accepted that there was considerable room for improvement in the use of personal health information in Australia. Reasons for this were thought to lie in the nature and content of the information systems currently in use.

Existing information systems are generally administratively focused and/or institutionally/provider-based. Information collection is not centred on the individual. The lack of continuity of information is a cause of unnecessary duplication of effort and adverse outcomes. Furthermore, records are poorly organised, inaccurate, incomplete, fragmented and sometimes lost, the information contained is not readily accessible and is sometimes incomprehensible.

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 on the effective utilisation of personal health information. Clearly the first of these implications is an argument for 'integrated health records'. An integrated health record is by nature patient centred, the only linking feature between the different parts of the record is the person to whom they relate. An integrated health record is also the only type of record which can, by definition, make available all the relevant information about a person wherever and whenever they need it.

There was also a broad consensus among the participants that the introduction of fair information handling principles to the health sector would result in consumers having some measure of control over their records. That is, there was an expectation that future records would also be a form of 'personal health record'. There was also a broad expectation that future health records would be electronically based. These three attributes together suggest that a future system of health records should be a type F system (Refer section 2.1).

This conclusion could be viewed with suspicion given the only example of a type F record system identified in this report is that recommended by the House of Representatives committee. A recommendation that was based on a submission to which the authors contributed. However, it is considered that whatever the flaws in the investigation the three attributes identified as desirable are very defensible. It is necessary to emphasise that the House of Representatives recommendation is only one way of achieving a type F health record.

There are currently two methods of implementing an integrated health record using electronic means in which consumers have a measure of control, that is a type F health record. Both methods could be implemented in a variety of ways.

The first method is to issue people with an electronic card that contains all their information that they can make available whenever they see a healthcare provider. It is important to note that such a system

may only provide a consumer control by means of withholding the card, as some variations of this model do not provide for consumer access to the information contained on the card.

The second method is to store a person's information in a networked data repository and issue them with a key that allows them to control the information contained. The key difference between these two approaches is the ability to support the needs of users other than clinicians and consumers. A need which has been clearly established in the literature.

A card-based storage system does not allow for any aggregated analysis or other forms of linkage and would require alternative mechanisms to support such uses. A networked database solution can support use by administrators, researchers and policy makers; however, the challenge is to ensure that the desired level of consumer control is achieved given the greater accessibility. A choice between these two approaches would need to be determined by detailed analysis of the benefits and costs, financial and otherwise.

7.2 The working environment

Looking at the environment in which a future national information system would operate the participants indicated several changes in the health care system that would need to be accommodated. These included changes in funding structures, changes in the accepted definition of what constitutes a health service, new jobs and changes in the roles of existing jobs, the continuing transition from tertiary to primary care and the move towards patient-centred health services. Each of the changes identified are substantial issues in themselves.

The increasing familiarity of the public with information technology and the availability of information on the internet is shifting the information power base and consumer expectations of their providers. These changes will have considerable effect on the use of information systems by health care providers.

An important possible development was that the responsibility for care could move down the training scale through the use of decision support tools and the accessibility of expert knowledge. Such a change would require careful management.

It is reasonable to expect that there will be changes in the way healthcare is delivered and managed so any information system that intends to support healthcare delivery would need to be adaptable and be able to evolve over time. Consequently the requirements of the system users and consumers need to be accorded a high status and continually monitored to enable changes to be made in a timely fashion. It is also reasonable to believe that the information system itself will promote changes in the way healthcare services are delivered. Organisational and workflow change is extremely challenging. Given the complexity and time scale of any implementation program such change will be a major ongoing element of the system.

7.2.1 Users, Uses and Benefits

A wide range of potential users and uses were identified, these were expected to give rise to considerable benefits. Improved decision making by providers and consumers would accrue from the availability of more a more complete collection of the relevant information wherever and whenever an individual encountered the healthcare system. Improvements in the ability to measure outcomes were seen to be beneficial to policy design, implementation and evaluation and also to an increased ability to monitor the performance of the system as a whole. Improvements in the conduct of research were anticipated. Public health professionals would benefit from improved monitoring of communicable disease and the ability to evaluate public health interventions. The ability to conduct post-marketing

surveillance of devices, drugs and treatments would provide opportunities to better evaluate their effectiveness and consequently improve the quality of health services delivered. All of these are potential benefits, realising them would require considerable effort, careful consideration and ongoing evaluation.

There was also a range of uses that were considered inappropriate. The use of the information by governments for control of health practitioners and of service use by consumers, by financiers to determine borrowing's and by employers and insurance companies to determine employment and insurance status were highlighted as being unacceptable uses. These limitations on use are part of the larger issue of the ethical use of health information, which will be discussed in more detail later.

It was broadly accepted that the benefits of such a system would outweigh the costs. There was an argument that the assessment of benefits and costs should make allowance for a number of intangible benefits including national pride, leading world practice and confidence in the national health care system as well as intangible costs such as fear of government surveillance. However, it was believed that the system would satisfy a hard nosed cost-benefit analysis. Clearly detailed analyses would be required to test this belief. If found to be true it would then be necessary to determine if it was the most effective use of health expenditure.

7.3 The implementation challenge

Having considered the environment within which the information system would operate and considered the range of potential users, uses and benefits it is necessary to determine how such a system could be implemented.

The interviewees were able to offer some suggestions for the parties who ought to be involved and some of the roles that need to be performed, forces which could drive or effect the change, and also identified some of the features required to maximise the chance of success. Some of the important barriers that would need to be overcome or circumvented were also identified

7.3.1 Parties and Roles

Many parties were identified as having a role to play in the creation of a national information system. These could be divided into six groups: Consumer representatives, Provider representatives, Government, Academia, Health industry and the IT industry. Key among these was that of the Federal government due to their dominance of the funding of the healthcare 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.

Given the large number of parties with an interest in any national health information system providing leadership and guidance will not be a simple task. The existing National Health Information Management Group was not seen to provide that role. Nor does a single agency or division of the federal department of health hold overall responsibility for national health information. The recently created National Health Information Advisory Council may be the vehicle to deliver such leadership.

7.3.2 Drivers

The main drivers identified were the delivery of benefits to the suppliers of the information, finance, the need for new information and the importance of the provider consumer relationship.

The first of these is crucial. If insufficient benefits accrue to the suppliers of the information the quality and completeness of the records would suffer. The benefits could be in the form of reduced time, cost, tedium or litigation, or in increased satisfaction, or healthcare outcomes. Indeed as

clinicians were expected to be the major suppliers it was thought that these types of benefits would be more persuasive than payment for information supplied.

The financial driver equates to ensuring that the costs and benefits are equitably shared. There was seen to be a belief amongst clinicians that most benefits accrue to downstream users such as government agencies and academics while most of the cost falls upon the collector. If financial equity is not achieved the chances of success would be significantly reduced.

The importance of the consumer-provider relationship could work either for or against the introduction of a national system. If the process of data collection and record use interferes with the relationship there will be resistance to change. However, it was believed that the technology is currently sophisticated enough to meet the needs of the system and the user. One of the expected elements of any system based on integrated health records is that consumers will have access to their records. Access by consumers to their records is a significant change to the status quo and could have an impact on the consumer-provider relationship. However, one of the strongest messages from the literature on consumer access to health records is that it strengthens the relationship between consumer and provider. This effect could work in favour of the system after it is introduced. However, failure to provide for consumer access at the very least will lead to resistance to the implementation of such a system.

The other important message from the literature is that systems that provide consumer access to their own records require the support and commitment of the providers involved. Getting provider commitment will be the necessary component of a program to effectively utilise the strength of the consumer-provider relationship to drive a change to a system of integrated health records.

7.3.3 Approaches

Having found the parties able to undertake the necessary roles and able to make best use of the drivers available, determining how the system would be built is the next step.

There was little doubt given the size and complexity of the task that implementing the system incrementally would be necessary. Five axes of incrementation were identified namely: system functionality, the range of provider types involved, the proportion of each type of provider, geographical coverage and the proportion of population covered. Such incremental development would need to occur within an agreed national framework in order to maintain a suitable level of coherence. In addition working with those most directly affected would be an important element of any approach taken to implementing a national information system. There was also a clear message of the need to build from where we are and not try to impose a new system upon the existing, a case of 'evolution not revolution'.

Given the current preference for market led solutions, the likely result of an incremental development strategy is that many elements would be developed at any one time by many different organisations, some in competition. The clear message was the need to ensure that the necessary standards are developed and enforced to ensure that the diversity of products are able to interact effectively. Here the current initiative on standards by the Department of Health and Aged Care and the future role of the National Health Information Advisory Council will be important

Few of the interviewees had any perception of the time involved in the creation of such a system. The most common time frame suggested was ten years although three years and twenty years were also put forward. Clearly the planning and implementation of such a system will take considerable time and policy makers would need to be cognizant of this in their planning.

It was also seen that lessons must be learnt from other countries and industries and to realise that such an information system would involve changes in how health services were delivered.

7.3.4 Barriers

A variety of potential 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. Taking account of these barriers and either eliminating or avoiding them or else ameliorating their impact will be necessary.

7.3.5 Information Rights

One of the greatest challenges to such a system will be in reaching acceptable solutions to information rights issues. There are a number of issues discussed which were brought together under the heading of information rights. They included the subjects of privacy, ownership, access, amendment, disclosure, and control.

The most important message was that talking about ownership of information contained in a record was unhelpful as it created blockages. The suggestion was made and broadly accepted that it is more helpful to talk about a basket of rights. Such rights would include: rights to collect, use, disclose, access and amend and to control these processes. Consumers, provider policy makers, administrators and researchers would have differing rights from each other and there would be different rights to identified unit records, de-identified unit records and aggregated information.

It was widely thought that individuals should have access to their record. Legislated access will become a reality with the passing of the proposed privacy legislation. The literature indicates that consumers do not take advantage of legislated access rights. The active involvement and support of health care providers is necessary before consumers regularly access their records.

There was a broad consensus that consumers should have some measure of control over the information contained in their record. There was uncertainty about the nature and extent of that control. Such issues would need to be resolved prior to implementation and early enough to allow incorporation of the control mechanisms into the design of an information system. One form of control that consumers currently have is to limit what they disclose to any particular provider through the use of multiple providers. It is reasonable to believe that in any future system individuals will want to maintain at least the same level of control.

The Privacy Act has broken open the idea of ownership granting total control, however, during the transition to a new order based on a basket of rights large amounts of information could be tied up by private commercial interests to the detriment of individuals and other users of health information. An important and currently missing element appears to be a detailed agreement within the framework established by the Privacy Act of what constitutes ethical use of personal health information, what conditions should apply to those uses and how such uses are to be supervised. Achieving agreement on such a sensitive subject given the existence of groups with significant vested interests and the politically sensitive nature of the debate will be very difficult. However, resolution of the question of who can use personal health information subject to the appropriate controls will allow the development of systems that satisfy these constraints and deliver the benefits believed to be achievable. The recently introduced legislative framework for privacy in the private sector represents an opportunity for the health sector to reach agreement on these issues.

7.3.6 Summary

The preceding conclusions have been summarised into the following points.

Essential matters:

1. There is room for improvement in the use of personal health information.
2. Health records need to be centred on the individual.
3. Consumers should have some measure of control over their own record. Such control should include access for themselves and control in some form over access by others including disclosure to third parties.
4. New 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 health care system.
6. The benefits of a national system are likely to outweigh the costs but may not be the most effective use of health funds. Detailed analysis will be required.

Implementation matters:

7. Sufficient benefits must accrue to the suppliers of the information to the system to ensure the quality of the information and the success of the implementation process.
8. The costs and the benefits of any national health record system must be equitably shared between the relevant parties.
9. Consumer access to their records will strengthen the consumer-provider relationship but will require provider support to be successful.
10. Six groups will have a role to play in the creation of a national health information system. These are: Consumer representatives, Provider representatives, Government, Academia, the Health industry and the IT industry. Key among these will be the Federal Government.
11. The system will 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.
12. The development and enforcement of agreed national standards will be required.
13. Lessons must be learnt from other industries and other countries.
14. Working within the principles of the Privacy Act detailed agreement needs to be reached on what constitutes the ethical use of health information, what conditions should apply to those uses and how such uses are to be supervised.
15. Development and implementation of a national system would take between five and twenty years.

This study started life intending to investigate the issues involved in people carrying around a copy of their general practice records. In the ensuing two years it has developed into an examination of the issues involved in creating a national health information system based on integrated health records. The ideas of the interviewees have been brought together by the investigators in a fashion that will hopefully shed light on this complex matter and assist in the further considerations of such a possibility.

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9. Appendices

9.1 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 NHMG 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.

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- 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, Information Management and Clinical Systems, NSW Health. Chair of Standards Australia's Health Informatics Committee, IT/14. NSW Representative on National Health Information Management Group. Convenor of ISO TC215 Working Group 1 - Health Records and Information Modelling.

9.2 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?

9.3 Index Tree

Q.S.R. NUD.IST Power version, revision 4.0.

PROJECT: GPEP interview; User: Chris Mount; 12:44 pm, Jan 27, 1999.

- (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

9.4 Full text of the House of Representatives Standing Committee's recommendation for a national data management system (para. 4.27 page 68)

In Chapter 4 of the "Health on Line" report which dealt with Health Informatics the committee made the following recommendation.

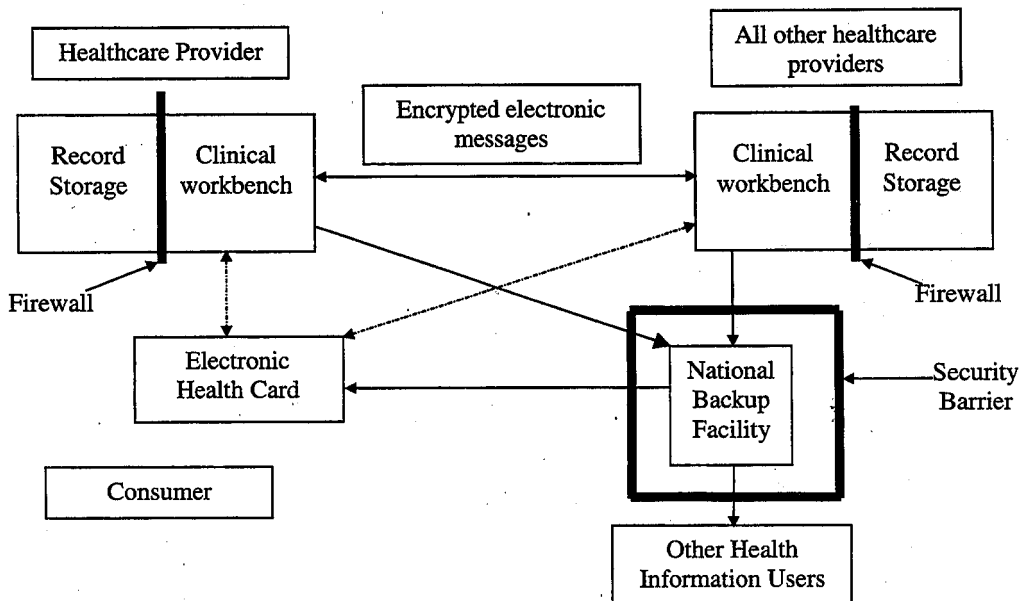
"The deployment of Health Informatics within the Australian health system, supported by a patient-held health electronic card, will provide a more effective means of information exchange. It will also address unreliability and fragmentation of health information and data management.

To this end the Committee recommends that the National Office for the Information Economy in consultation with the Department of Health and Family Services, the Australian Medical Association, The National Centre for Epidemiology and Population Health and the Health Insurance Commission develop and deploy within the Australian health system:

- (a) *patient-held health electronic cards supported by the Consumer Storage System with National Backup Facility developed by the National Centre for Epidemiology and Population Health; and*
- (b) *that the National Backup Facility be managed and controlled by the Health Insurance Commission, thereby ensuring the provisions of the Privacy Act 1988 apply."*

The following drawing relates to the recommendation above.

Option 3 Consumer Storage System with Backup



9.5 The Information Privacy Principles contained in Section 14 of the 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

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- (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

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- (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;

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- (b) the record-keeper believes on reasonable grounds that use of the information for that other purpose is necessary to prevent or lessen a serious and imminent threat to the life or health of the individual concerned or another person;
 - (c) use of the information for that other purpose is required or authorised by or under law;
 - (d) use of the information for that other purpose is reasonably necessary for enforcement of the criminal law or of a law imposing a pecuniary penalty, or for the protection of the public revenue; or
 - (e) the purpose for which the information is used is directly related to the purpose for which the information was obtained.
2. Where personal information is used for enforcement of the criminal law or of a law imposing a pecuniary penalty, or for the protection of the public revenue, the record-keeper shall include in the record containing that information a note of that use.

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 the disclosure.
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.

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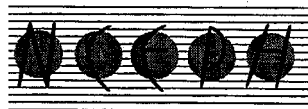
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