

CHAPTER 8

ADEQUACY OF DATA COLLECTION AND ANALYSIS

Introduction

8.1 Term of reference (h) of this inquiry requires the Committee to assess:

the adequacy of current procedures for the collection and analysis of data relating to public hospital services, including allied health services, standards of care, waiting times for elective surgery, quality of care and health outcomes.

8.2 About 40 per cent of submissions commented on this term of reference and of these, the vast majority believed that current procedures for the collection and analysis of data relating to public hospital services are generally inadequate. The most commonly identified deficiency was gaps in the types of data collected. These gaps included data on health outcomes, effectiveness and cost-effectiveness of services, quality and adverse events, allied health and community care. The views of participants support the comment made by the Committee in its [First Report](#), that ‘one of the central difficulties for this inquiry has been the lack of available data upon which to base decisions’.¹

8.3 A view was expressed in many submissions that data collection to date has tended to focus on costs and payment systems at the expense of other areas. Other problems raised in submissions highlighted deficiencies in the data which is currently collected. These included a lack of standardised methodology across various jurisdictions and, related to this, an inability to link data sets. It is possible to argue that two key reasons underlying the inadequacies of data collection on particular aspects of public hospital services are the fragmented nature of Australia’s health system and a wide-spread under-investment in appropriate information systems in public hospitals.

8.4 Notwithstanding the shortcomings identified in evidence, the Committee also received other evidence indicating that improvements were either underway or planned in several areas of data collection and analysis. The Commonwealth Department of Health and Aged Care’s (DHAC) submission² included a useful overview of data collections, as well as current and future initiatives in this area and pointed also to aspects of data collection where shortcomings are evident.

1 Senate Community Affairs References Committee, *First Report: public hospital funding and options for reform*, July 2000, p.65.

2 Submission No.38, pp.40-45 (Department of Health and Aged Care).

National structural aspects of health data collection

8.5 In 1993, the National Health Information Agreement was signed between the Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. The agreement, which took effect from 1 July 1993, established 'cooperative processes and structures to facilitate and coordinate activities to improve, maintain and share national health information'.³ The agreement was renewed in 1998 for a further 5 years.

8.6 The National Health Information Management Group (NHIMG) was established to oversee the implementation of the agreement. The NHIMG comprises senior representatives of the signatories to the agreement. The National Health Data Committee is a standing committee of the NHIMG and is responsible for the assessment of data definitions proposed for inclusion in the *National Health Data Dictionary*. The *National Health Data Dictionary* is designed to make health data collections more efficient and to improve the comparability of data across the health sector. The Dictionary (now in its 8th revision) 'is the authoritative source of health data definitions used in Australia where national consistency is required'.⁴

8.7 Data on health services, including public hospitals, is collected by the Commonwealth 'for the purposes of policy analysis and development'.⁵ DHAC advised that the content and refinement of these data collections, which are often derived from State health services, are agreed between the Commonwealth and the States/Territories. The associated technical and definitional work is undertaken by reference to the NHIMG. The three main data collections are the [Hospital Morbidity \(Casemix\) Database](#)⁶; hospital and other performance measures collected under the [Australian Health Care Agreements](#) (AHCAs); and the National Health Performance Committee⁷ (NHPC) process, which was endorsed by Health Ministers in April 1999.⁸

3 Australian Institute of Health and Welfare and Australian Health Ministers' Advisory Council, *National Health Information Development Plan*, Canberra, AGPS, 1995, p.11.

4 National Health Data Committee, *National Health Data Dictionary*, version 8, Canberra, Australian Institute of Health and Welfare, 1999, p.xvii.

5 Submission No.38, p.40 (DHAC).

6 The National Hospital Morbidity (Casemix) Database contains about 33 million de-identified records, each of which consists of a mix of demographic items (such as age and sex), administrative items (such as insurance status) and clinical items (such as diagnoses and procedures). The database contains data on public and private hospital activity since 1991-92. The database and annual reports on hospital morbidity can be found at this web address: <http://www.health.gov.au/casemix/nhmdb1.htm>

7 The National Health Performance Committee has replaced the former National Health Ministers Benchmarking Working Group, which produced three reports on benchmarking and performance measurement in the health sector. These reports are available at this web address: <http://www.health.gov.au/hsdd/nhpq/pubs/pquality.htm> The National Health Performance Committee will have a broad focus across the whole health sector, including community health, general practice and public health (Submission No.38, p.44, DHAC).

8 Submission No.38, p.40 (DHAC).

8.8 DHAC's submission noted that hospital and other health performance measures data are collected under the provisions of Schedule C of the AHCAs, which commits the Commonwealth and the States and Territories to work together to develop and refine performance indicators in the following areas:

- public hospital activity levels and costs;
- waiting times for access to public hospital services;
- indicators of Aboriginal and Torres Strait Islander health;
- indicators of integration of care processes;
- indicators of access to primary care;
- measures of quality of care, including patient satisfaction;
- indicators of effort in medical and nurse training, and medical and health research;
- mental health reform indicators; and
- indicators of access to and quality of palliative care services.

The Australian Health Ministers Advisory Council (AHMAC) has agreed to the development of an annual report which should enable a comparison of the States and Territories against a range of acute sector performance indicators. In agreeing to the production of these annual reports, AHMAC noted that release will be subject to Ministerial approval. The first annual report, covering the first year of the AHCAs (1998-99) is expected to be published in December 2000.⁹

Recommendation 38: The Committee notes the range of developmental work which is proceeding in the area of performance indicators and RECOMMENDS that Health Ministers release the first annual report on hospital and other health performance measures under Schedule C of the AHCAs. It is possible that some of the gaps in data collection that have been identified by participants in the inquiry may be filled by these annual reports under the AHCAs.

Key data collections and reports

8.9 A wide range of data on public hospital services are currently collected, analysed and reported upon. Links are provided below to reports available online, as appropriate.¹⁰

9 Submission No.38, p.42 (DHAC).

10 A comprehensive listing of websites and online reports relevant to public and private hospitals is available from this Parliamentary Library Electronic Brief: <http://www.aph.gov.au/library/intguide/SP/hospitals.htm>

Australian Institute of Health and Welfare

8.10 The key agency which collects, collates, analyses and reports on hospital-related data is the [Australian Institute of Health and Welfare](#) (AIHW). Examples of relevant AIHW reports include:

- a comprehensive collection of data on public and private hospitals in Australia, including the number of hospitals and available beds, staffing, workload, costings and patient profiles, together with trends over the last six years can be found in the annual [Australian Hospital Statistics](#);
- expenditure on public and private hospitals by the Commonwealth and each State and Territory government as well as the non-government sector is reported in the [Health Expenditure Bulletin](#);
- comparisons of hospital-related data (public and private) between metropolitan and rural and remote areas can be found in [Health in Rural and Remote Australia](#);
- international comparisons are included in the report [International Health: how Australia compares](#);
- a comprehensive overview of public and private hospital-related data together with commentary and analysis can be found in the biennial [Australia's Health](#);
- the latest available national data on [waiting times for elective surgery](#) in public hospitals is reported periodically by the AIHW; and
- detailed workforce data for both public and private hospitals is available in the annual reports on the [medical labour force](#) and the [nursing labour force](#).

Australian Medical Workforce Advisory Committee

8.11 The AIHW also works with the [Australian Medical Workforce Advisory Committee](#) (AMWAC) which has produced a range of reports, including benchmarks for the Australian medical workforce and Australia's current and future requirements in individual medical specialities. AMWAC was established in the mid-1990s by the Australian Health Ministers' Advisory Council to advise on national medical workforce matters.

Australian Bureau of Statistics

8.12 The [Australian Bureau of Statistics](#) produces several collections of data which are relevant to the hospital sector. These include regular surveys such as [Private Hospitals Australia](#) (full text not available online) and occasional papers, including [Hospital Statistics, Aboriginal and Torres Strait Islander Australians](#).

Productivity Commission

8.13 The Productivity Commission, in its role as the Secretariat for the [Steering Committee for the Review of Commonwealth/State Service Provision](#), issues an

[annual report which compares](#) the performance of governments across several important areas of responsibility, including public hospitals. The Productivity Commission also issued a [research paper on private hospitals in Australia](#) in December 1999. This paper provides a detailed profile of the private hospital industry, an analysis of the sector's financial performance, explains the regulatory and legislative framework within which the industry operates and assesses the degree of competition in the private hospital market and the drivers of demand for private hospital services. This report is discussed in more detail in chapter 6.

Shortcomings in data collection and analysis

8.14 While these and other collections of data are valuable and useful, they are limited by a lack of focus on the outcomes of the services provided. Thus, while data exists on the costs and occasions of services, little is known about the outcomes, value or usefulness of the services. For example, in his submission, Professor Hindle stated that 'we currently know a little about costs and virtually nothing about value'.¹¹ In addition, the South Australian Government identified the need to collect and analyse data beyond the acute sector, stating that 'there is an overemphasis on hospital based services and insufficient attention to community and public health'.¹²

8.15 DHAC's submission also outlined several limitations of current data collection and analysis:

different parts of the hospital systems collect a great range of data, for example, data relating to organisational and clinical performance and services delivered to consumers. However, the data is often haphazardly collected and there is little analysis of anything but information relating directly to financial requirements.¹³

8.16 This view was supported by the Consumers' Health Forum (CHF) which provided a consumer perspective on the adequacy of data collection and analysis. Commenting on data collection in general, the CHF stated that the overall view of consumers was that 'inadequate data is available for them to really ascertain good information on many of the key issues of concern to consumers'.¹⁴ The Queensland Government commented that accessing data was often the biggest challenge, arguing that 'there is so much data around the place that it is hard to work out what you need, what you do not, where you keep it and how you access it'.¹⁵

8.17 The danger of collecting data for its own sake was raised by several participants in the inquiry. For example, the Northern Territory Shadow Minister for

11 Submission No.22, p.5 (Professor Don Hindle).

12 Submission No.60, p.28 (South Australian Government).

13 Submission No.38, p.45 (DHAC).

14 Submission No.72, p.29 (Consumers' Health Forum).

15 *Committee Hansard*, 22.3.00, p.479 (Queensland Government).

Health argued that data collection can be an imposition in small jurisdictions such as the Northern Territory and that there should be ‘an emphasis on data collection and analysis that provides appropriate and useful information to improve health comes, rather than data for data’s sake’.¹⁶ In a similar vein, the South Australian Government argued that data collection should not be a ‘significant burden on hospitals’ and that increased data collection would need to ‘consider the benefits as well as the costs of collection’.¹⁷

8.18 A link between the level of resources available to public hospitals and their capacity to collect data was raised by some participants. For example, in their joint submission, the Royal Australasian College of Physicians (RACP), the Health Issues Centre and the Australian Consumers’ Association (ACA) linked the issue of public hospital staff being required to increase activity without a commensurate increase in resources, with limits on the time available for clinicians to collect data.¹⁸ Similarly, the Australian College of Health Service Executives (ACHSE) argued that:

the tension between initiatives to drive down administrative costs and creating funding initiatives to improve data/information management of clinical processes is ongoing.¹⁹

8.19 A different perspective was offered by the National Rural Health Alliance (NRHA) which was concerned that the collection and availability of data on rural health and well-being required a more consistent and streamlined approach than currently is the case and argued that Australia does not make full use of the data which is collected at present. The NRHA commented that:

it is not so much a need for new data collections or series as the need to use existing series better, in particular by cross-matching existing data and freeing up information from some collections. Among other things this would help planning for health and well-being across all levels of government and at regional levels.²⁰

8.20 The view that Australia is not making full use of the available data was advanced also by the Centre for Health Program Evaluation (CHPE). CHPE’s Professor Richardson argued that:

we do in Australia have an extraordinarily good database by world standards, but we do not use it. Through the linkage of records we could

16 Submission No.78, p.4 (Northern Territory Shadow Minister for Health).

17 Submission No.60, p.27 (South Australian Government).

18 Submission No.45, p.30 (Royal Australasian College of Physicians, Health Issues Centre and Australian Consumers’, Association).

19 Submission No.62, p.4 (Australian College of Health Service Executives).

20 Submission No.66, p.28 (National Rural Health Alliance).

make an enormous impact onto this pool of ignorance about the effectiveness of different services.²¹

Data on allied health services

8.21 Allied health services encompass a wide range of services, such as pharmacy and physiotherapy, that usually are not part of an acute episode but which are, however, essential elements in a patient's treatment and rehabilitation. Evidence was received that identified shortcomings in data collection and analysis in the broad area of allied health services as being due principally to a focus on the acute episode at the expense of the continuum of services provided to patients.

8.22 Hence, evidence to the inquiry indicated a lack of systematic reporting of public hospital allied health services. The Society of Hospital Pharmacists of Australia (SHPA) noted in its submission that 'the standardisation of data collection in relation to hospital pharmacy services and utilisation of pharmaceuticals is a major issue'.²² A key reason for this lack of standardisation was identified by the SHPA who told the Committee that 'the IT infrastructure is not consistently in place across the country'.²³ In a similar vein, the National Allied Health Casemix Committee (NAHCC) gave evidence that system-wide, there is 'a large deficit in IT hardware infrastructure systems', with many allied health staff not having access to personal computers.²⁴

8.23 The Australian Physiotherapy Association (APA) argued that the lack of standardisation in data collection inhibited benchmarking in a number of areas 'except within States using the same system, which is a major problem for physiotherapy and other allied health professions'.²⁵ The APA pointed also to shortcomings in data collection affecting allied health services in rural and remote areas of Australia:

data collected is, by definition, data necessarily relating to services currently provided. In rural and remote areas where there are often physiotherapy and allied health position vacancies, the dearth of data means that the needs of communities may be overlooked in the planning of services. This can have an impact on the implementation of programs designed and funded to address particular health issues.²⁶

8.24 The Queensland Government noted in its submission that data collection and analysis of allied health services had been targeted for improvement. It commented that only data on occasions of service were currently collected in this area and made

21 *Committee Hansard*, 23.3.00, p.588 (Centre for Health Program Evaluation).

22 Submission No.52, p.7 (Society of Hospital Pharmacists of Australia).

23 *Committee Hansard*, 21.3.00, p.309 (Society of Hospital Pharmacists of Australia).

24 *Committee Hansard*, 23.3.00, p.573 (National Allied Health Casemix Committee).

25 Submission No.61, p.19 (Australian Physiotherapy Association).

26 Submission No.61, p.19 (Australian Physiotherapy Association).

the important point that ‘this permits limited analysis of services, and thus limits the ability to generate service improvements’.²⁷

8.25 In its submission, DHAC advised that refinements were underway in four areas that ‘may improve the collection of data on the provision of allied health services in public hospitals’.²⁸ The Commonwealth and the States and Territories have agreed to work proceeding on refinements to several indicators:

- agreement has been reached between the parties to expand the admitted patient morbidity data set in order to improve knowledge on the various components of services provided to an admitted patient, including those ancillary to treatment. This may include allied health services, pathology and diagnostic imaging;
- agreement has been reached also to develop a non-admitted patient morbidity data set by 30 June 2003;
- summary data is currently collected by the States and Territories on allied health services provided to non-admitted patients in outpatient clinics. The National Health Data Committee is currently working on a national clinic-based classification for outpatient services to ensure greater national consistency in collecting and reporting data on non-admitted patients; and
- agreement has been reached between the parties to develop measures for waiting times for outpatient services. The development of these measures will proceed following the finalisation of the outpatient classification system.²⁹

8.26 DHAC advised also that allied health professional codes have been incorporated into the procedure classification of the *International Classification of Diseases and Related Health Problems Tenth Revision–Australian Modification* (ICD-10-AM). This means that it is possible to search the data ‘using these codes to obtain information on allied health professional procedures on admitted patients’. However, while these codes are used for analysis at the local level they are not used at the national level.³⁰

8.27 Funding was provided by the Commonwealth Government during 1998-99 for a project that aimed to ‘develop a set of allied health indicators that will be a starting point for measuring the outcomes of allied health activities’.³¹ The project was undertaken by the National Allied Health Casemix Committee (NAHCC), which

27 Submission No.41, p.34 (Queensland Government).

28 Submission No.38, p.42 (DHAC).

29 Submission No.38, pp.42-3 (DHAC).

30 Submission No.38, p.43 (DHAC).

31 Submission No.38, p.43 (DHAC).

reported in January 2000. The NAHCC also provided evidence to the Committee at which a copy of the report³² was tabled. The NAHCC advised that:

we have developed a national activity hierarchy that standardises the way that allied health professionals describe their inputs to the health care system. We have also developed a minimum data set that describes characteristics of the clients and patients that are treated and we are in the process of developing patient focused performance measures or outcome measures for those clients where allied health have a large part to play in their outcomes.³³

8.28 The NAHCC explained to the Committee how its developmental work in this area would fit with the use of Diagnosis Related Groups (DRGs) which form the basis of casemix-based funding. While a DRG defines an acute episode it is not readily adaptable to include allied health treatments which may be unrelated to the original condition. For example, following acute medical treatment, a patient who has suffered a stroke may require assistance in learning to speak, which would be provided by an allied health practitioner. In this example, the acute episode would be defined by a DRG, while the allied health intervention would be described by a performance indicator developed by the NAHCC. The NAHCC advised that their indicators for allied health would intermesh with the DRGs by describing the allied health intervention, providing a performance measure and measuring the outcome of the intervention.³⁴

8.29 The Committee notes the work to date aimed at improving the identification, reporting and measuring of the allied health components of health interventions, and it is aware that work in this area is ongoing, particularly with regard to the development of performance indicators.

Data on waiting times for elective surgery

8.30 Waiting times for elective surgery are used in preference to waiting lists because they are regarded as a 'better indicator of hospital performance than numbers on waiting lists'.³⁵ Patients waiting for elective surgery are grouped into the following three categories depending on the severity of their condition and the corresponding necessity for treatment:

- category 1 is the most urgent and contains patients whose admission is considered desirable within 30 days;

32 Details of the report are as follows: National Allied Health Casemix Committee, *Report on the Development of Allied Health Indicators for Intervention (IFI) and Performance Indicators (PI) and Revisions of Allied Health-sensitive ICD-10-AM codes for inclusion in ICD-10-AM, Edition two*, January 2000.

33 *Committee Hansard*, 23.3.00, p.572 (National Allied Health Casemix Committee).

34 *Committee Hansard*, 23.3.00, p.579 (National Allied Health Casemix Committee).

35 Australian Institute of Health and Welfare, 'Elective surgery waiting times presented in new report', *Media Release*, 16 June 2000.

- category 2 includes patients whose admission is considered desirable within 90 days; and
- category 3 includes patients whose admission at ‘some time in the future’ is regarded as acceptable, although patients waiting more than 12 months are regarded as having an ‘extended wait’.³⁶

8.31 The AIHW has published three reports to date that present data on waiting times for elective surgery, the latest of which includes data for [1997-98](#) (released in June 2000). Although improvements are evident in each successive report, their usefulness is limited by a continued lack of standardisation in the way data is collected at the State and Territory level. This lack of standardisation limits any comparison of different jurisdictions and inhibits any knowledge of whether particular jurisdictions have improved their performance over time.

8.32 DHAC’s submission indicated that the States and Territories have agreed to provide data in line with the Waiting Times minimum data set. The annual reports under Schedule C of the AHCAs, discussed earlier, are expected to include data on the total number of admissions for elective surgery and the percentage of elective surgery patients admitted within the clinically appropriate time (ie category 1 within 30 days, category 2 within 90 days and category 3 within 12 months).³⁷ Some States and Territories are now releasing data in relation to waiting times for elective surgery, with some also posting issues of their elective surgery bulletin on departmental websites. An example is the [elective surgery bulletin](#) from the South Australian Department of Human Services.

8.33 The CHF provided a slightly different perspective on waiting list/waiting times data. It expressed the view that consumers are wary of data on waiting lists which they regard as being open to manipulation.³⁸ Commenting further, the CHF argued that ‘there is considerable debate about what waiting lists actually show, as studies have illustrated’.³⁹ CHF also raised the need for data on waiting lists for community care as a means of working towards a more integrated health care system.⁴⁰

8.34 The Committee has been concerned about the generally poor quality of data on waiting times for elective surgery. Some jurisdictions appear to be more advanced than others in making available information on waiting times to their communities, however the Committee is encouraged to learn that all States and Territories have agreed to provide consistent data in this area.

36 Submission No.38, p.43 (DHAC).

37 Submission No.38, p.43 (DHAC).

38 Submission No.72, p.29 (Consumers’ Health Forum).

39 Submission No.72, p.29 (Consumers’ Health Forum).

40 Submission No.72, p.31 (Consumers’ Health Forum).

Recommendation 39: That as a matter of urgency data on waiting times for elective surgery be standardised so that meaningful comparisons between States can be made.

Data on health outcomes

8.35 This section provides a synthesis and analysis of the evidence received that dealt with data on health outcomes. There is some degree of overlap between measurement and reporting of data on health outcomes and data collection on adverse events and initiatives to improve quality. Issues around adverse events, quality initiatives, benchmarking and performance indicators have been discussed in some depth in Chapter 7 which dealt with the inquiry's term of reference (i) on the effectiveness of quality improvement programs.

8.36 A number of submissions were critical of the lack of data collection and analysis in the area of health outcomes. By and large, submissions were less forthcoming on how health outcomes could be measured. Once appropriate systems are in place, it should be relatively straightforward to collect and analyse data on the inputs, processes and outputs of hospital services because all are tangible, measurable units. However, as was indicated by the earlier discussion in relation to data on allied health services, Australia is still some way from adequately collecting and analysing data on the complete episode of care. It is much harder to define and measure health outcomes. Adequate data collection in this area is obstructed by the difficulty of measuring accurately the outcomes of a great many health interventions.

8.37 Dr O'Connor from the School of Health Services Management at the University of New South Wales outlined for the Committee how health outcomes could be measured:

...health outcomes measurement means asking the patient. It is not asking the patient, 'Are you satisfied with health services?'; it is asking the patient, 'How do you feel? Can you walk, can you wash the dishes, can you do the shopping?' – all those sorts of very functional things associated with just living life normally.⁴¹

Dr O'Connor cautioned, however, that while patients can provide an assessment of how they feel and what they can do, 'they cannot tell you why they are not better'.⁴²

8.38 The joint submission from the Australian Healthcare Association, Women's Hospitals Australia and the Australian Association of Paediatric Teaching Centres⁴³ (AHA, WHA and AAPTC) argued that the focus of data collection on standards of

41 *Committee Hansard*, 21.3.00, p.328 (Dr O'Connor).

42 *Committee Hansard*, 21.3.00, p.328 (Dr O'Connor).

43 The Australian Association of Paediatric Teaching Centres is now known as Children's Hospitals and Paediatric Units Australasia, or Children's Hospitals Australasia for short (*Committee Hansard*, 18.8.00, p.703).

care and quality ‘remain substantially focussed on processes and inputs rather than outcomes of care’.⁴⁴ The South Australian Salaried Medical Officers Association (SASMOA) made the important point that outcome measures need to be relevant and useful. The Association argued that once relevant and useful measures of health outcomes were in place ‘you would then change practice’ and ‘we would be in a position to work out what models we should be practising in health care’.⁴⁵

8.39 Several participants pointed to the lack of systematic collection of data on clinical processes. For example, the submission from DHAC encapsulated succinctly the limitations of data collection in this area:

the use of data to improve performance in the clinical area is at a very low level while data for system-wide analysis is unreliable and poorly articulated and collected.⁴⁶

8.40 The Australian Healthcare Association (AHA) told the Committee that more information was required on the performance of the various players such as governments, hospitals and health authorities: ‘the notion of a national report card on health, on hospitals, on insurance funds, on practitioners, I believe is something we need to get far more aggressive about’.⁴⁷ The Committee believes that this is a strong argument for the role of an authority for overseeing quality programs in creating a more transparent system and holding all the players accountable for their performance.

8.41 Under-investment in appropriate information technology in public hospitals was raised by the NAHCC as an issue in relation to data on health outcomes. It commented that there is a ‘lack of available information technology infrastructure to collect and analyse activity that relates to patient outcome information’. This in turn limits the capacity of allied health professionals ‘to operate within a paradigm of evidence-based practice which we all strive to do’.⁴⁸

8.42 The Queensland Government, however, argued in its submission that some progress was being made in the collection, reporting and analysis of data on health outcomes. For example, it is spending \$1.6 million over four years to implement a program called *Health Outcomes Measurement and Feedback Processes for National Health Priority Areas*, drawing on funding available under the National Health Development Fund⁴⁹ of the Australian Health Care Agreements (AHCAs). The

44 Submission No.63, p.38 (AHA, WHA, AAPTIC).

45 *Committee Hansard*, 23.2.00, p.195 (South Australian Salaried Medical Officers Association).

46 Submission No. 38, p.45 (DHAC).

47 *Committee Hansard*, 11.11.99, p.108 (Australian Healthcare Association).

48 *Committee Hansard*, 23.3.00, p.573 (National Allied Health Casemix Committee).

49 The National Health Development Fund has been established under the AHCAs to fund ‘projects that improve: patient outcomes; efficiency and effectiveness, or reduce the demand for public hospital services; and integration of care between public hospital services and broader health and community care services’. Approximately \$253 million is available through the fund over the five years of the AHCAs (Submission No.38, p.7, DHAC).

Queensland Government anticipates that this program will ‘increase the cost effectiveness of health service delivery’. The objective of the program is to develop processes that will:

provide information on quality-of-care to clinicians and policy-makers and enable measurement of health outcomes across the continuum of care including primary prevention, treatment, secondary prevention and rehabilitation.⁵⁰

Patient satisfaction

8.43 Allied to this area of health outcomes is data on patient satisfaction. Many public hospitals make an effort to gain feedback from patients on their hospital stay, however sometimes the forms/surveys are not designed in such a way as to ensure that genuine, detailed feedback is obtained. For example, patient satisfaction surveys that require only a Yes/No answer may not always permit the patient to reveal the full details of the hospital experience. The CHF commented that although some consumers valued hospital patient satisfaction surveys, ‘the information most of them currently provide on the experiences of patients is extremely limited’.⁵¹

8.44 The CHF argued that for hospitals to gain meaningful feedback, consumers should be involved in the design of survey forms and could also assist in developing ways of administering the surveys. To illustrate the importance of community consultation in this area, the CHF provided an example of a large scale ‘Healthy Communities Survey’ of 25 000 people in Tasmania, the usefulness of which was limited by its design. The CHF commented that:

the survey required respondents to be able to write and answer complex questions. This automatically excluded those with low literacy or no English, vision impairment or other disability such that they could not complete a form. Data collection techniques must be inclusive or it will not adequately represent the population being surveyed.⁵²

8.45 A ‘real world’ example of a survey of patient feedback can be found in the 1997-98 annual report of the Western Australian Metropolitan Health Service Board. The Board surveyed 2565 patients in 1998, achieving a 48 per cent response rate. The survey found that the most important issue for patients was ‘care, respect and treatment as a person’, followed by ‘availability of staff’. Also important to patients was ‘continuity before, during and after care’.⁵³

50 Submission No.41, p.34 (Queensland Government).

51 Submission No.72, p.31 (CHF).

52 Submission No.72, pp.30-31 (CHF).

53 Metropolitan Health Service Board, *Annual Report 1997-98*, Perth, 1998, pp.106-109.

8.46 Surveys of patient satisfaction face a challenge in providing useful data on health outcomes. Dr O'Connor told the Committee that the role played by the medical practitioner in deciding the extent to which a patient receives services meant that:

the consumer does not know whether health services are adequate or not. If you ask people whether they are satisfied with health services, it is usually 70 out of 100—70 per cent are satisfied. That is a figure which you have found for years and years.⁵⁴

Data on quality of care and standards of care

8.47 Issues around data on quality of care was discussed in Chapter 7 which dealt with the inquiry's term of reference (i) on the effectiveness of quality improvement programs. DHAC advised in its submission that the following priority areas are under consideration for development and reporting of national quality of care indicators:

- patient satisfaction;
- patient complaints;
- services accreditation; and
- patient safety.

Any performance information that is developed in this area is expected to be reported in the annual reports under Schedule C of the Australian Health Care Agreements, which was discussed earlier.⁵⁵

8.48 The Australian College of Midwives Inc—Victorian Branch (ACMV) was concerned that current collections of data in relation to maternity services tend to focus on throughput rather than quality of care issues. In particular, elements that the ACMV regards as essential aspects of midwifery care such as telephone counselling, developmental work and education 'are not considered key indicators for measuring service provision' in regard to outpatient maternity services.⁵⁶

8.49 Data on standards of care appears to be sparse. For example, in its submission, DHAC stated that 'there is little information at a national level that relates to standards of care'.⁵⁷ DHAC offered the following definition of standard of care:

the level of conduct used to assess healthcare, particularly medical practitioners conduct for the purposes of determining its adequacy or especially, liability in negligence law or malpractice suits.⁵⁸

54 *Committee Hansard*, 21.3.00, p.327 (Dr O'Connor).

55 Submission No.38, p.44 (DHAC).

56 Submission No.75, p.10 (Australian College of Midwives Inc—Victorian Branch).

57 Submission No.38, p.44 (DHAC).

8.50 DHAC advised that the only general measure of standards of care that is currently reported is adherence to accreditation standards (issues around accreditation have been discussed in Chapter 7 on the effectiveness of quality improvement programs).

Information technology, quality of care and data collection

8.51 Discussion earlier in this chapter indicated that the use of IT systems in public hospitals had been driven largely by financial and cost data considerations. This section examines information technology in greater detail and discusses, in particular, individual patient identifiers and electronic health records. Evidence was received during the inquiry that indicated there was potential to increase quality of care by, for example, reducing the incidence of adverse events, through the introduction of unique patient identifiers and electronic health records. It is anticipated that data collection and analysis will be enhanced also through these developments.

8.52 Evidence to the Committee indicated that there needs to be greater priority given to the development of information technology (IT) in the health care system. DHAC confirmed that at present IT is being developed throughout the health system in an uncoordinated way and that without action these independent investments will be largely wasted.⁵⁹

8.53 AHA, WHA & AAPTIC commented on the lack of investment in information technology:

Healthcare...has focussed its investment more on the progressive application and transfer of new diagnostic and treatment methodologies than it has on the management of information necessary to assess its performance, understand its client base and improve its clinical management.⁶⁰

8.54 Barwon Health also noted that ‘the shortfall is not so much capturing of the data, but the development of integrated management systems with software development focusing on supporting management decision making’.⁶¹

8.55 Submissions also argued that there needed to be greater financial resources devoted to IT in the public hospital sector. For example, the Committee of Presidents of Medical Colleges (CPMC) stated that:

the level of information technology hardware and software in Australian hospitals is approximately equivalent to where Australian banks were 20

58 Boyce, *et al*, *Quality and Outcome Indicators for Acute Healthcare Services*, 1997, quoted in Submission No.38, p.44 (DHAC).

59 Submission No.38, p.54 (DHAC).

60 Submission No.63, p.37 (AHA, WHA, AAPTIC).

61 Submission No.37, p.5 (Barwon Health). See also Submission No.45, p.31 (RACP, HIC, ACA).

years ago. Without major investment, Australian hospitals will not have the information systems to reduce the incidence of adverse events and enhance quality, to produce reliable information on the full range of hospital activities and to allow proper management of waiting lists.⁶²

8.56 CPMC stated that in Victoria alone an investment of at least \$100 million is required to purchase reasonably satisfactory systems. Across Australia, the figure is likely to be in excess of \$500 million.⁶³

8.57 The National Expert Advisory Group on Safety and Quality in Australian Health Care (the Expert Group) stated that the development of IT for health, and in particular data communication, represents ‘a tremendous opportunity to break down some of the barriers between health services both within and across jurisdictions. The opportunity exists to ensure that full information about a patient is available within the Australian health care system wherever it is appropriate and needed’.⁶⁴

8.58 The adoption of IT advances by the Australian health care system has been fragmented and slow.⁶⁵ Currently there is no single record that contains a person’s health history. There is no computerised network to link GPs, hospitals and other health care providers, and consumers have little or no access to their medical records.⁶⁶

8.59 The National Health Information Management Advisory Council (NHIMAC) was established in 1999 to provide a nationally coordinated approach to improving health information management through the greater uptake of online technologies and to achieve national coordination among the Commonwealth and the States to reduce unnecessary duplication in the area of information technology. The Council will advise Health Ministers on options to promote a nationally uniform approach to information management within the health sector.

8.60 Two specific areas where improving IT to support service delivery as well as data collection and analysis were highlighted in the development of a unique patient identifier and electronic health records for patients. These are discussed below.

Unique patient identifier

8.61 Evidence to the Committee indicated that there would be advantages if there was a unique patient identifier that could be used across the various elements of the health care system.⁶⁷ At present individual health consumers are identified by name,

62 Submission No.40, p.1 (CPMC).

63 Submission No.40, p.1 (CPMC).

64 Expert Group report, p.16.

65 *Committee Hansard*, 23.3.00, p.544 (ACHSE); *Committee Hansard*, 23.3.00, p.499 (Professor Phelan).

66 NSW Health Council, *A Better Health System for NSW*, March 2000 (Chairman: Mr John Menadue), p.23.

67 *Committee Hansard*, 23.3.00, p.499 (Professor Phelan).

address and date of birth when their health records are forwarded to another health provider. This system is not always reliable and there is the potential for adverse patient outcomes if transfer of clinical information such as prescription data or medical history is not accompanied by a foolproof system of patient identification.⁶⁸ The advantages of a unique patient identifier are that:

- it would improve the safety and quality of health care of the individual patient. It would allow access, with patient permission, to information held by hospitals, the Health Insurance Commission on services provided by private medical practitioners, drugs prescribed under the PBS, and potentially, information held by other health care providers. It would ensure that an attending doctor could have access to information on what drugs had been previously prescribed and identify previous medical interventions;
- it would help prevent the repeat performance of various tests that were previously undertaken by another medical practitioner;
- it would allow patients to be tracked, in a de-identified way, across the health care system and also allow data to be linked with other administrative data sets. In this way information on longer-term outcomes of medical interventions could be obtained which is important in determining their effectiveness; and
- the availability of a unique patient identifier would encourage the development of an electronic medical record containing crucial medical information about a patient that could be made available to a health care provider whose access was authorised by the patient.⁶⁹

8.62 A number of factors inhibiting the development of a unique patient identifier and its use were also identified in evidence. These included:

- the lack of agreement between the Commonwealth, States, private health insurers, private providers of health care services and consumers on the desirability of having a unique patient identifier;
- the form a unique patient identifier would take – the Medicare number could be adapted as the unique identifier as the Health Insurance Commission holds a unique Personal Identification Number for each individual enrolled in the Medicare system;
- a ruling by the Privacy Commissioner prohibiting the linkage of Medicare and the PBS data. The Privacy Commissioner's determination was that there must be no linkage of data sets held by different government agencies;
- while public hospitals in some States record a patient's Medicare number at the time of attendance to determine his or her eligibility for free care under

68 NHIMAC report, p.27.

69 Submission No.40, Additional Information, 24.3.00 (CPMC).

Medicare, this is mainly for inpatient care and is not universal, particularly for attendances at outpatients and accident and emergency departments even in those States who record the Medicare number; and

- the only private health care services reported to the Health Insurance Commission are those that attract a Medicare Benefit – effectively those provided by a medical practitioner or an optometrist. Admission to a private hospital is identified only through information provided on a Medicare claim for a rebate for billed medical services.⁷⁰

8.63 Community concerns about privacy issues are often cited in relation to the introduction of a unique patient identifier. The NHIMAC stated that the use of a personal health identifier is a sensitive issue that has been addressed by the Privacy Commissioner in the *National Principles for the Fair Handling of Personal Information*. The Council noted that within this framework, strict guidelines would need to be legislated before a patient identification system could be implemented – ‘the extent to which health consumers will agree to the use of a health identifier, will depend critically upon their understanding of, and trust in, its use’.⁷¹ The Council stated that further work on the use of a personal health identifier should be guided by the following:

- a health identifier should be created primarily for patient safety and quality reasons, allowing certainty of identification and transfer of information with patient consent; and
- a health identifier should be fully transparent and remain in the hands of the health consumer.⁷²

8.64 CPMC also noted that the community could be better assured that access to information would be in their control by the use of available technology such as a combination of a pin number and a card similar to a credit card. Patients could also indicate different levels of access according to the needs of providers – thus providing for restricted access to certain sensitive information. CPMC stated that the privacy issues around a unique patient identifier have been discussed with the Privacy Commissioner and he was ‘very receptive’ to the arguments put by the College.⁷³

8.65 At the national level, the NHIMAC referred the issue of patient identification as part of a wider reference on the development of electronic health records and a health information network to the National Electronic Health Records Taskforce, a subcommittee of the Council. The Taskforce reported recently to Health Ministers at their 31 July 2000 meeting. Health Ministers welcomed the recommendations of the report and agreed to pursue the development of HealthConnect, a national health

70 Submission No.40, Additional Information, 24.3.00 (CPMC).

71 NHIMAC report, p.28.

72 NHIMAC report, p.28.

73 Submission No.40, Additional Information, 24.3.00 (CPMC).

information network.⁷⁴ This is discussed below, in the section dealing with electronic health records.

8.66 With regard to patient identifiers, the Taskforce recommended the:

establishment of a national health identifier to be used only in the health sector under strict privacy protocols and which is implemented concurrently with HINA. Similarly, providers and facilities/locations need to be reliably identified to eliminate any uncertainty about who was involved in an episode of care and where that care was provided.⁷⁵

8.67 Legislation introduced into Parliament on 6 September 2000 by the Minister for Health and Aged Care, Dr Wooldridge, proposes to use the Medicare Card number as a means of establishing the eligibility of patients for pharmaceuticals dispensed under the Pharmaceutical Benefits Scheme (PBS). The National Health Amendment (Improved Monitoring of Entitlements to Pharmaceutical Benefits) Bill 2000 proposes a three stage implementation, the final stage of which provides that there will be no payment by the Commonwealth to a pharmacist for a prescription without a Medicare number.⁷⁶

8.68 Privacy issues associated with the use of a personal health identifier are discussed below, in the section dealing with the broader issue of privacy and electronic health records.

8.69 At the State level, in NSW the report of the NSW Health Council (Menadue report) recommended that a unique patient identifier be developed and that it be trialed in at least two Area Health Services in that State. The report argued that it should be developed in consultation with the consumer organisations and clinicians. The report also argued that the Commonwealth Government and the Health Insurance Commission must be closely involved 'as there is little point in a Unique Patient Identifier being confined to State-administered services unless the number can be used when accessing GP services'.⁷⁷ Some jurisdictions have already adopted their own unique identifiers – for example, the ACT and the Northern Territory.

8.70 The Committee supports the development of a unique patient identifier and believes that its introduction needs to be accompanied by strong privacy safeguards. The Committee notes the recommendation of the National Electronic Health Records

74 Minister for Health and Aged Care, 'Health Ministers give green light to national health information network', *Media Release*, 31 July 2000.

75 National Electronic Health Records Taskforce, *A Health Information Network for Australia: report to Health Ministers*, Canberra, Commonwealth Department of Health and Aged Care, 2000. HINA means Health Information Network Australia, the Taskforce's working title for a national health information network. The announcement by Health Ministers giving their support to the development of such a network noted that the network is to be called HealthConnect.

76 House of representatives, *Debates*, 6 September 2000, p.18223.

77 NSW Health Council report, p.25.

Taskforce and the statement by Health Ministers welcoming the Taskforce's recommendations for the creation of a national electronic health network, including the establishment of a unique patient identifier.

Electronic health records

8.71 Currently the majority of health care records exist as discrete paper-based records held in a variety of different locations, resulting in a fragmented picture of an individual's health history. They cross traditional and non-traditional health care sectors, and health and related community support services. The information contained within them varies and problems often arise about the quality and appropriateness of the content of the current records.⁷⁸

8.72 There is increasing recognition across the health sector of the potential benefits of electronic health records in improving efficiency, safety and quality of care over paper-based systems. An electronic health record is a single, complete patient record of all health care information which relates to an individual. It records all information about treatments that an individual has received – including hospital admissions – and diagnostic information such as test results.

8.73 NHIMAC stated that:

Access to the appropriate information at the time of care delivery is central to good clinical decision-making – practitioners and consumers need the right information at the right time. The greater focus of health care policy on providing a “seamless delivery of care”, particularly for the frail aged, the chronically ill and those with complex care needs has highlighted the need to improve information exchange between different types of services and providers.⁷⁹

8.74 A number of advantages to both patients and health care providers have been identified with electronic health records:

- clinicians will have all the relevant information before them to diagnose a patient and provide treatment or organise a referral to another clinician;
- where patients are referred to another clinician relevant information can be transferred electronically if the patient consents;
- the onus will no longer be on the patient to retain and recall vital and often complex diagnostic information and advice; and

78 NHIMAC report, p.52.

79 NHIMAC report, p.52.

- when a patient's doctor arranges tests, the results can be transferred electronically to other relevant providers, thus avoiding the inconvenience and cost of having tests repeated.⁸⁰

8.75 The use of an electronic health record is widely regarded as a high priority in health care reforms in the United Kingdom, Canada, the USA and the Scandinavian countries.⁸¹ The National Health Service in the UK has now commenced developing a national system of lifetime electronic health records.⁸²

8.76 NHIMAC established a sub-committee, the National Electronic Health Records Taskforce, in November 1999 to develop a framework for electronic health records in Australia. The Taskforce comprised representatives of DHAC, the Health Insurance Commission, the States and Territories and clinicians. The Taskforce consulted widely with stakeholders to identify the form and key components of an electronic health records system for Australia; and other matters that need to be considered to enable electronic health records to operate, such as issues concerning record linkage, security and coding.⁸³

8.77 The Taskforce submitted its report on the development of an electronic health records system for Australia to Health Ministers in July 2000. Rather than the creation of a single electronic health record system, the Taskforce recommended the development of a national information network that 'can evolve from work already being undertaken by the many stakeholders in the health sector'.⁸⁴ [Health Ministers welcomed](#) the recommendations of the Taskforce and gave their approval for the development of HealthConnect, a national health information network. HealthConnect will provide for the creation and storage of electronic health records together with other health information.⁸⁵ However, as this proposal is unfunded the Committee recommends that the Commonwealth and the States commit the necessary resources to implement the changes (see recommendation at the end of the chapter). Privacy issues around electronic health records are discussed in a later section of this chapter.

8.78 At their July 2000 meeting, Health Ministers also supported, in principle, a proposal to develop a system of electronic medication records, to be called the Better Medication Management System (BMMS). [Announcing the support](#) of Health Ministers for the proposal, the Commonwealth Minister for Health and Aged Care, Dr Wooldridge, said that:

80 NSW Health Council report, p.24.

81 NSW Health Council report, pp.23-24, 27.

82 NHIMAC report, p.53.

83 NHIMAC report, pp.56-57.

84 National Electronic Health Records Taskforce report, p.vi.

85 Minister for Health and Aged Care, 'Health Ministers give green light to national health information network', *Media Release*, 31 July 2000.

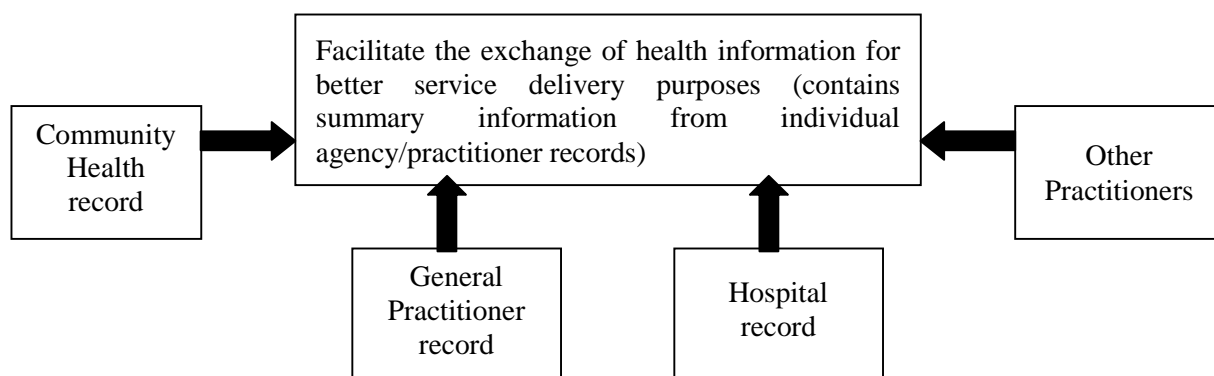
the Better Medication Management System (BMMS) is a way to bring together currently fragmented medication record systems by using information technology to link patients, doctors, pharmacists and hospitals.⁸⁶

The Minister's statement also noted that participation in the proposed BMMS will be voluntary for all parties and will offer consumers access for the first time to their own medication record. It is understood that the Medicare Card number will be used as the unique patient identifier for the BMMS.

8.79 This unique patient identifier is being developed without clear rules for collecting data on Medicare numbers or how they will be matched against other health insurance data. The Federal Government is creating one unique patient identifier to check a patient's eligibility for the PBS and plans to create another identifier to allow doctors, pharmacists and patients to access medication records as part of the BMMS. Australians are going to have multiple unique patient identifier numbers without first establishing a national health privacy regime. The uncertainty about multiple unique patient identifiers and their operation should not continue, as it could seriously harm public confidence in the Health Insurance Commission's data management system and set back the adoption of electronic records in the health sector.

8.80 The proposed framework of electronic health records is illustrated in the diagram below.

Figure 8.1: Proposed framework of electronic health records



Source: NHIMAC, *Health Online: A Health Information Action Plan for Australia*, November 1999 p.57.

8.81 NHIMAC stated that there will not be one record system but multiple record systems. This is because the information needs, and therefore the level and type of detail required for service delivery, vary across health care settings and among health care providers. It is envisaged that the health records system will contain several discrete components – perhaps a standard health record that could be used by GPs,

86 Minister for Health and Aged Care, 'Electronic medication records a boon for consumer safety—Health Ministers', *Media Release*, 31 July 2000.

one for hospitals etc. The Council noted that where there are multiple record systems, it is 'essential' for common elements to be agreed in order to achieve a high level of compatibility. The interchange of information between electronic record systems is expected to take place in a distributed data network. Data would reside essentially where it is collected, rather than a single, centralised repository of health records. Subsets of these records would be brought together for purposes of exchanging relevant clinical information.⁸⁷

8.82 NHIMAC emphasised that it was imperative in the area of data linking that there be consistency of approach across Commonwealth, State and Territory jurisdictions and in different forms of care – in the public and private sectors, and in the acute and community care settings.⁸⁸

8.83 At the State level there have also been moves advocating the introduction of electronic health records. The Menadue report into the NSW health services recommended that within two years NSW should be in a position to introduce electronic health records. The report argued that the introduction of electronic health records would dramatically improve the quality of care within the hospital system and reduce the number of medical errors.⁸⁹

8.84 The Menadue report noted that the electronic health record will have the following features:

- it will be accessible to the individual consumer and their providers, regardless of the location and with the appropriate attention to privacy and security safeguards;
- the individual will need to give consent about the type of information made available, and the transfer of information between providers;
- the record will contain clinical records, advice, specialist referrals, pharmacy details, diagnostic tests and results;
- the record will be able to provide GPs, specialists, public and private hospitals, community health centres, and other health providers with access to relevant information about the individual's medical history with the patient's consent;
- it will be linked to clinical protocols and clinical pathways and assist the health care provider in clinical decision making; and
- an information system based on the electronic health record will allow the collection of data that can be used to measure the quality and performance of

87 NHIMAC report, pp.53, 56.

88 NHIMAC report, p.53.

89 NSW Health Council report, p.23.

health care provision, and to assist the consumer in making informed health choices.⁹⁰

8.85 The report argued that there should be a staged approach to the development of an electronic health record allowing for the involvement of consumers, clinicians and relevant privacy bodies. The strategy should identify the types of information to be recorded, and specify privacy and confidentiality standards and should establish a timetable for a number of steps which are essential to introduce an electronic health record. These include the development of a unique patient identifier, improved links between patient management systems and improving clinical care systems. The report noted that the introduction of an electronic health record should commence with, and be evaluated through, a number of demonstration projects.⁹¹

Privacy and security considerations

8.86 The Committee acknowledges that a system of electronic health records, as with the introduction of a unique patient identifier, cannot be introduced until satisfactory arrangements are in place to ensure privacy and security considerations are protected. The Committee believes that a strong privacy regime is an essential precondition to ensure public acceptance of electronic health records.

8.87 NHIMAC also stated that it was important to ensure that health consumers are confident that the privacy of their personal records is protected. The Council noted that this is particularly an issue in the health sector 'where people are often at their most vulnerable and powerless, where information is often particularly sensitive and personal, and where inappropriate disclosure and use of personal information can have a devastating effect on people's lives and circumstances'.⁹²

8.88 One commentator noted that while electronic health records are increasingly seen as a way to achieve quality and continuity in treatment:

such systems run the risk of foundering in the wake of community concerns...Successful implementation of proposals for electronic record systems must learn from such experiences and demonstrate keen attention to delivering information useful to both citizens and clinicians, while ensuring privacy protection and promoting public accountability for secondary use of personal information.⁹³

90 NSW Health Council report, p.24.

91 NSW Health Council report, p.25.

92 NHIMAC report, p.20.

93 Carter M, 'Integrated electronic health records and patient privacy: possible benefits but real dangers', *Medical Journal of Australia*, Vol. 172, 2000, p.28. See also Mount C *et al.*, 'An integrated electronic health record and information system for Australia?', *Medical Journal of Australia*, Vol.172, 2000, pp.25-27.

8.89 NHIMAC stated that governments, industry and many health service providers are increasingly interested to see national arrangements established to provide a nationally consistent approach across jurisdictions in relation to privacy issues.⁹⁴ In this regard, the [Privacy Amendment \(Private Sector\) Bill 2000](#) was introduced into the House of Representatives on 12 April 2000. The Bill proposes to amend the [Privacy Act 1988](#) to establish a national scheme, through codes of practice adopted by private sector organisations and the National Privacy principles, for the appropriate collection, holding, use, disclosure and transfer of personal information, including health information, by private sector organisations. The proposed legislation will extend the national privacy regime to cover the private sector.

8.90 A [House of Representatives report](#) on the Bill noted, however, that a considerable number of submissions from consumer groups argued that health information should be removed from the Bill. Submissions representing this view argued that the Bill does not provide appropriate rights to privacy in respect of health information and access to health records. The main reasons for arguing this were that the regime established by the Bill will led to the creation of inconsistent standards governing privacy rights in the public and private sectors; that access rights contained in the Bill enabling individuals to access their own health information are inadequate; and that the health sector is so different from other sectors that any attempt to incorporate it within the general framework of the Bill is misguided.⁹⁵

8.91 In relation to security considerations, NHIMAC stated that moving to an electronic environment for these communications demands a high degree of confidence that the information will be transferred securely and that the identity of the parties is not in dispute.⁹⁶ As noted previously, the exchange of information across the health sector generally involves the transfer of highly personal and sensitive information.

8.92 The Health Insurance Commission is currently working on a project to develop methods to ensure that the transfer of health information will be secure. It is envisaged that for security purposes, health professionals will need to be issued with digital certificates – a form of smart card – as part of the provider registration process. Under the project, the Commission is working with security specialists to investigate the use of this technology to authenticate the identity of the sender of electronic documents and to ensure the integrity of transmitted information.⁹⁷

8.93 The Health Insurance Commission is also looking into the feasibility of operating a registration authority that would provide a security vetting function and issue digital certificates. This it is argued will provide for privacy and security

94 NHIMAC report, p.21.

95 See House of Representatives Standing Committee on Legal and Constitutional Affairs, *Advisory Report on the Privacy Amendment (Private Sector) Bill 2000*, June 2000, pp.65-66.

96 NHIMAC report, p.22.

97 NHIMAC report, pp.22-23.

safeguards to be built into the online services to ensure that only authorised people will have access to electronic health information and information.⁹⁸

8.94 Announcing their support for the development of HealthConnect, a national health information network, Health Ministers stated at their July 2000 meeting that they had agreed to protect people's privacy through the following provisions:

- individuals must freely agree to participate in the network in the first place and on an ongoing basis;
- an individual's information must only be used in a health care context;
- people must have access to their own information and must be able to control who can see their information;
- a stringent security framework must be in place wherever health information is collected, stored or exchanged, including audit trails and review mechanisms built into the network to track who has accessed information; and
- provisions must be in place to ensure, among other things, penalties for people who misuse the information.⁹⁹

8.95 As discussed earlier, the Minister for Health and Aged Care has introduced the National Health Amendment (Improved Monitoring of Entitlements to Pharmaceutical Benefits) Bill 2000 into Parliament. The AMA has expressed its concern about the Bill's proposal to use the Medicare Card number as a means of establishing patient eligibility for pharmaceutical benefits. The AMA is particularly concerned that an appropriate privacy regime will not be in place prior to the introduction of this new scheme and that the Medicare Card number is proposed also to be used as a patient identifier for the BMMS:

we have serious concerns about this proposal and we are calling for urgent, overarching health privacy legislation to prevent any transfer of Medicare numbers onto other databases, including the government's BMMS.¹⁰⁰

8.96 However, in his Second Reading speech on the Bill, Dr Wooldridge argued that:

implementation of the proposed arrangements will be founded on the well-established privacy principles under the *National Health Act 1953*. The national health amendment bill not only maintains current levels of privacy. It extends protections under the National Health Act to cover all aspects of

98 NHIMAC report, pp.22-25.

99 Minister for Health and Aged Care, 'Health Ministers give green light to national health information network', *Media Release*, 31 July 2000.

100 Australian Medical Association, 'AMA warns: Medicare numbers the new "Australia Card"', *Media Release*, 13 September 2000.

the use of the Medicare number, and other identifying data, for the purposes of pharmaceutical benefits entitlement monitoring.¹⁰¹

Conclusion

8.97 The Committee believes that the development and implementation of nationally consistent electronic health records can improve the safety and quality of health services. The Committee notes the decision of Health Ministers to support the development of HealthConnect, a national health information network, which will provide for the creation and storage of electronic health records. It notes also the measures to protect privacy which have been agreed by Health Ministers. The Committee supports these developments and, in the light of evidence presented to the inquiry, anticipates that benefits will flow from the early implementation, with appropriate safeguards, of HealthConnect.

8.98 Evidence discussed in this chapter has painted a mixed picture of Australia's current position in relation to data collection and management. In some areas, notably financial and cost data as well as data on patients treated in hospitals, systems are well advanced and data is now being collected and reported in a relatively timely manner. On the other hand, national data on such areas as waiting times for elective surgery and health outcomes is patchy and in some cases underdeveloped. However, there are signs that frameworks are being established which should lead to greater consistency in data collection in the different jurisdictions.

8.99 Adequate resourcing of public hospitals is clearly important here. Evidence received indicated that, at times, some public hospital staff feel that there is tension between their time available for patient care and the time required for data collection. Evidence to this inquiry indicates that Australia knows little about the effectiveness of its spending on public hospitals. Greater transparency of funding by each jurisdiction together with the development of meaningful indicators of performance and outcomes should enable increased knowledge in this area over time.

Recommendation 40: That funding for patient care and funding for data collection and performance measurement should be separately and transparently identified and acquitted. Sufficient staff should be employed in public hospitals to ensure that both functions are undertaken effectively.

Recommendation 41: That the urgent development of adequate IT systems in the health sector be undertaken, especially in relation to integrated management systems within hospitals and integrated patient records.

101 House of Representatives, *Debates*, 6.9.00, p.18223.

Recommendation 42: That the Commonwealth and the States commit the necessary resources to implement the HealthConnect proposal.

Senator the Hon Rosemary Crowley
Chair