7 Challenges for national health information

The large amount of material presented in preceding chapters describes the current state of health in Australia at the end of the twentieth century. Australia has a well-developed statistical system, and is well served by institutions with a major commitment to national health information. Among these, the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) play leading roles in the collection, coordination and reporting of information on health and wellbeing. These two agencies, together with the Commonwealth, State and Territory health departments and the Health Insurance Commission, are responsible for implementing the National Health Information Agreement (NHIA). The bulk of the information presented in this report is sourced from one or more of the NHIA members.

The National Health Information Management Group (NHIMG), which oversees the NHIA on behalf of the Australian Health Ministers' Advisory Council (AHMAC), advises on health information priorities. Its National Health Information Development Plan (AIHW & AHMAC 1995) identified priority directions for a projected 10-year period. Since the release of the plan, progress has been achieved in each of its highest priority areas. However, new information demands have emerged, and NHIMG currently has the plan under review.

This chapter presents an overview of progress with the National Health Information Development Plan and outlines the emerging information requirements of new national health strategies. Information gaps that constrain reporting in the earlier chapters of *Australia's Health 2000* are also identified.

7.1 The National Health Information Development Plan

The objectives of the Plan are to 'promote the development of high priority health information and to increase the cost-effectiveness of Australian national health information'. Highest priority development directions of the Plan are:

- work with Aboriginal and Torres Strait Islander peoples to develop a plan to improve all aspects of information about their health and health services;
- develop a national health and welfare information model;
- in consultation with health service consumers and providers, undertake a comprehensive examination of the feasibility and usefulness of potential approaches to developing and enhancing the ability to link health records, and identify the linkages that will result in the greatest community benefit;

- develop a plan to improve health outcomes information by developing clinically specific measures of health outcomes for major health problems and enhancing the usefulness of clinical information systems for measuring the effectiveness and outcomes of interventions;
- develop and collect standardised information on the incidence, prevalence, consequences and outcomes of care of severe mental illness;
- develop and collect standardised information on primary and other non-institutional healthcare encounter data;
- undertake a systematic review of current major health data collections and make recommendations regarding rationalisation and improvements in the cost-effectiveness of collections; and
- develop ongoing surveillance of potentially modifiable, major disease risk factors, including biological measurements where necessary, ensuring adequate coverage of small, priority populations.

Achievements since 1995

Progress has been made in each of the priority directions.

Aboriginal and Torres Strait Islander health

In 1998, AHMAC endorsed *The Aboriginal and Torres Strait Islander Health Information Plan…This Time Let's Make it Happen* (ATSIHWIU 1997) and established a process for its implementation, to be managed by NHIMG. The ABS accepted responsibility for improving the quality of Indigenous identification in vital statistics collections. Good progress has been made in Queensland, which was the last State to commence Indigenous identification in birth and death records. Nevertheless, the quality of identification in the other eastern States has not improved sufficiently to permit publication of data on deaths.

The joint ABS/AIHW Aboriginal and Torres Strait Islander Health and Welfare Information Unit has taken the lead role in improving hospital morbidity data for the Indigenous populations. A pilot study has provided indicative results on the extent of coverage of Indigenous patients in hospitals (which ranged from 55% to 100%) and a methodology for testing coverage in other hospitals. AIHW has accepted the lead role in relation to cancer registries (where it is working with the Australasian Association of Cancer Registries) and in perinatal statistics (where it is working through its National Perinatal Statistics Unit to standardise and improve coverage in perinatal data collections).

National health and welfare information model

The National Health Information Model, version 1 (AIHW 1995), has been further developed and replaced by a draft version 2. Version 2 has been constructed as a high-level, conceptual model, quite different from version 1 which was constructed as an entity-relationship model. Unlike version 1, version 2 does not attempt to describe relationships between the entities in the model, as it is considered that these are more appropriately described at enterprise or operational levels of information modelling.

Version 2 provides an organising structure for the *National Health Data Dictionary*, which is now structured to present data elements in accordance with their relationship to Model entities (NHDC 1998).

Record linkage

The AIHW has built considerable record linkage experience using its National Death Index and the National Cancer Statistics Clearing House. The AIHW's Health Ethics Committee approved 41 projects involving linkage using these databases during 1998–99, a number that has increased markedly over 5 years. Studies have contributed to knowledge about health patterns in occupational cohorts (e.g. Radium Hill workers), specific population groups (e.g. older women, Vietnam veterans), selected communities (Western Sydney Area Health Service) and for specific diseases (e.g. hepatitis C, cardiovascular surgery outcomes). Other linkage projects have been undertaken to examine the potential for creating person-based records from hospital separations to examine the patterns of re-admission for cardio-revascularisation procedures.

Several States have established linked data sets with matched records from local hospital morbidity, mortality and other health records. Western Australia, in particular, has used health record linkage extensively in health studies, including prostate cancer survival analysis (Holman et al. 1999), an examination of hospitalisation of the elderly during the last year of life (Brameld et al. 1998), and estimation of the incidence of aortic aneurysm (Semmens et al. 1998). A study into the linking of data from the Western Australian linked data set with national data sets (e.g. Medicare data, data from the Pharmaceutical Benefits Scheme and the National Death Index) for people with diabetes is in the planning stages. Protocols for such studies are complicated by the need to meet privacy protection requirements under various administrative and legislative regimes. Identifying and resolving such issues is one of the objectives of the study.

Following a review of its household survey program, the ABS has announced that it will pursue the linking of survey data to administrative records with consent. The linkage would be done within the ABS under the protection of the secrecy provisions of the *Census and Statistics Act 1905*.

Health outcomes

The NHIMG, in response to a specific request from AHMAC, has developed a health outcomes indicator framework. The framework encompasses outcome and other indicators spanning prevention, management and maintenance services. It has been adopted for reporting under the National Health Priority Areas (NHPA) program. NHPA reports on injury and diabetes and a forthcoming report on asthma have applied the framework. The framework also provides a planning basis for data development for future NHPA reporting.

A register to monitor new cases and prevalence of acute rheumatic fever and rheumatic heart disease among the Indigenous populations has been established in the Top End of the Northern Territory. Data in the register permits monitoring of rates of compliance with treatment and provides data on the outcome of intervention. For cardiovascular disease in general, the AIHW has reported on medical care of cardiovascular disease and, in collaboration with the National Heart Foundation of Australia, on the use of cardiac surgery and coronary angioplasty procedures. The feasibility of establishing a

national cardiovascular procedures register is being investigated. This would provide reliable, longitudinal, risk-adjusted data for monitoring national indicators of quality and outcomes for cardiac procedures and cardiology interventions.

One of the indicator sets developed under the health outcomes indicator framework is that for monitoring the performance of the BreastScreen Australia program. These indicators seek to highlight progress towards the program objectives relating to participation, cancer detection, program sensitivity, cancer incidence and mortality. The mortality indicator is the ultimate test of the program's effectiveness, and between 1994 and 1998 there has been evidence of a reduction in mortality rates due to breast cancer of 2.5% per annum (AIHW & AACR 1999).

Severe mental illness

An ABS Survey of Mental Health and Wellbeing, conducted in 1995, reported on the prevalence of mental illness among adults in the community (ABS 1998). A complementary multijurisdiction study of people living with psychotic illness has provided information on people attending mental health services for treatment of psychotic disorders, including schizophrenia (Jablensky et al. 1999). New administrative data in mental health services have become available through implementation of a new National Minimum Data Set for Institutional Mental Health Services from 1997–98 (AIHW 2000). Progressive implementation of a National Minimum Data Set for Community Mental Health Services is proceeding, following its adoption by NHIMG.

Non-institutional healthcare data

Progress in this area has included the establishment in 1998 of a Survey of General Practice Activity (BEACH—Bettering the Evaluation And Care of Health—see chapter 5). The survey commenced in April 1998 with funding from a consortium of private pharmaceutical companies and several government agencies. A report on the first year of the survey was published in 1999.

A National Community Based Health Services Codeset, prepared by a consortium of Commonwealth and State health agencies, has provided the basis for implementing data collections that will fill a large gap in national health services information.

Improving cost-effectiveness of collections

The ABS has conducted a wide-ranging review of its household survey system, including the National Health Survey, and plans to introduce a new 3-yearly cycle of health surveys. Sample supplementation for the Aboriginal and Torres Strait Islander populations will be introduced over the first two surveys in the new program (2001 and 2004) and continue at 6-year intervals thereafter. Also included in the program is a 3-yearly General Social Survey that will permit analysis of the social determinants of the health of the population. An Indigenous General Social Survey will be conducted in conjunction with every second General Social Survey from 2002.

Some rationalisation has occurred in national hospital statistics, with a withdrawal by the Department of Heath and Aged Care from publication of its hospital casemix series. Re-establishment of the AIHW's Australian Hospital Statistics series on a regular and timely basis has permitted this rationalisation of publication activities.

Potentially modifiable disease risk factors

ABS National Health Surveys have provided information on disease risk factors, including smoking, alcohol consumption, exercise and unhealthy weight, based on self-report methods. National Drug Household Surveys, conducted by the Department of Health and Aged Care and its predecessors, provide information about use of and attitudes towards tobacco, alcohol and illicit drugs. Biomedical risk factor information, of the kind collected by the National Heart Foundation in three surveys during the 1980s, has not been collected during the past decade. A one-off survey of diabetes prevalence is being undertaken during 1999 and 2000 by the International Diabetes Institute, Melbourne, but plans for ongoing national monitoring of biomedical risk factors are still at the development stage. Options include a survey in conjunction with the ABS's National Health Survey in 2004 or a stand-alone survey.

7.2 Newly emerging information challenges

Since the release of the National Health Information Development Plan, new issues have raised unanticipated challenges for national health information. Major emerging themes are:

- plans to incorporate new communications technology into health care;
- increased focus on the health of rural and remote populations;
- increased focus on factors affecting the health and wellbeing of children; and
- coordinated attention to public health, brought by the National Public Health Partnership.

Plans 'to provide a basis for a national strategic approach to using information in the health system' have been released in a report by the National Health Information Management Advisory Council entitled *Health Online* (NHIMAC 1999). The Plan's scope includes information collection, privacy and confidentiality, and access, but also information transfer in interactive services and situations. Under the plan's information objectives, two strands of information development have been identified. One is concerned with development and adoption of information technology standards, for which much of the work occurs under the auspices of Standards Australia, its committee processes and international connections. The other strand is concerned with data standards, for which the NHIMG's management of the *National Health Data Dictionary* (NHDD) provides a well-established basis for future development.

Electronic health records offer an opportunity for expanded availability of statistical data, including linked data sets. The challenge for national health information will arise from the strict business requirements for an electronic health record that is transferable across healthcare settings. This will require standard definitions for data elements that are included in an electronic health record. The NHIMG's processes are well placed to handle this expanded requirement. As well, classification and coding schemes are required that are flexible enough to support the expected interchange of information across settings while continuing to meet the different business requirements for specific care settings. The World Health Organization's development of a Family of International Health Classifications is pertinent. The AIHW is a WHO Collaborating

Centre on health classifications (including the International Classification of Diseases and the International Classification of Impairments, Disabilities and Handicaps) and is actively participating in this work.

Increased attention to rural and remote health and health services presents challenges to improve the flexibility of geographic coding in major health data sets. Fixed regional boundaries, whether administrative (such as postcodes or local government areas) or statistical (such as statistical local area or statistical division), currently coded in most data sets, limit the capacity to support the area-specific analysis that is increasingly required to meet rural and remote health and environmental health management needs. Remote health issues are confounded by the poorer health of Aboriginal and Torres Strait Islander people who constitute a significant proportion of the population in remote areas (see chapter 4).

Demands for information about child and youth health and wellbeing are increasingly concerned with the influence of early social development as a determinant. Existing information systems are extensive, but are cross-sectional, not longitudinal. Opportunities exist through linkage of data sets to create longitudinal views at low cost.

Public health information has a higher profile since the establishment in 1996 of the National Public Health Partnership. Through its National Public Health Information Working Group, the Partnership has developed a National Public Health Information Development Plan (AIHW 1999). The challenges contained in this plan include establishment of an infrastructure for monitoring health determinants, health and causes of ill health of Aboriginal and Torres Strait Islander populations, socioeconomic disadvantage and health, intersectoral information on the physical environment and financial information on public health programs.

Across a number of health fields there is increasing demand for analytical work for the specification and production of broad health indicators and of performance indicators, either within specific program areas or more generally focused on the health system as a whole. General health indicator requirements cover fields such as burden of disease and health inequalities. Performance indicators include efficiency and effectiveness of services, including quality and outcomes.

The 1998 Australian Health Care Agreements include requirements for development of performance indicators across the health sector. This work is being led by the National Health Performance Committee.

7.3 Major gaps in this report

The requirement to report on Australia's health itself raises awareness of the gaps that are unable to be filled. This section provides an alternative view, from a reporting perspective, of the development required to augment information presented in the preceding chapters of this report.

The health of Australians (chapter 2)

As reported in chapter 2, mental health is the third most important contributor to the burden of disease. Although information available on mental health services continues to improve (chapter 5), there is no provision in the work programs of relevant agencies

for any ongoing data collection on population mental health. Information from the ABS 1997 Survey of Mental Health and Wellbeing was reported in *Australia's Health 1998* and some further information from that survey has been included in chapter 2. However, ongoing coverage of population mental health is not included in a comprehensive manner in the new ABS population survey program.

Chapter 2 is able to report in only a limited way on the oral health of Australians, particularly of adults. As reported in *Australia's Health 1998*, fluoridation of water supplies has reduced the prevalence of dental decay in cohorts that have lived all or most of their lives with such protection. Some information on decayed, missing or filled teeth (DMFT status) is available from self-report through telephone surveys conducted by the AIHW Dental Statistics Research Unit. However, periodic surveys including an oral examination are needed to verify reports on DMFT status and to measure other aspects of oral health.

Determinants of health (chapter 3)

Chapter 3 is devoted to the environmental and individual factors that determine health. This reflects the increasing attention being given to managing determinants through public health practice, evident at the national level in the establishment in 1996 of the National Public Health Partnership. However, only limited information could be presented in many areas of chapter 3. In particular, biomedical risk factor information is needed to monitor levels of modifiable risks to health from major disease categories, especially cardiovascular disease, diabetes and some cancers. Better information is also needed on environmental health risks, and on attitudinal and lifestyle factors, an area where the National Public Health Partnership has begun efforts to coordinate existing information activities.

Health and determinants in population groups (chapter 4)

The inability to report comprehensively on the health of Aboriginal and Torres Strait Islander people has already been discussed, as has the lack of longitudinal data to monitor child and youth health. Health of people with disabilities is another area where data is almost non-existent (see *Australia's Welfare 1999*). A particularly difficult group to monitor is homeless people.

Health resources and use of services (chapter 5)

Chapter 5 presents only limited information about health services other than those provided to admitted patients in hospitals and consultations with general practitioners. Ambulatory services provided within hospitals (accident and emergency units and hospital-based clinics) and in the community are important in their own right and as contributors to integrated care regimes that are emerging. A Community Based Health Services Codeset, developed by a consortium of jurisdictions, provides a basis for development of community services information, but will require a major coordinated effort to implement.

Health service strategies, performance and monitoring (chapter 6)

A number of frameworks for health system performance monitoring are receiving attention from national bodies such as the National Health Performance Committee. Information systems are being developed to support these frameworks, but some

components require prior work to develop concepts and specifications for indicators. For instance, in line with many countries, Australia has not developed valid and reliable indicators of the quality of health care.

Data systems for monitoring the performance of services and activities aimed at the health of Aboriginal and Torres Strait Islander peoples are a priority, as are performance information systems related to community-based health care.

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