



8 Developments in health information

8.1 What is national health information and why is it needed?

National health information is information that either is national in coverage or has national relevance and relates to:

- the health of the population;
- the determinants of the population's health, including external factors (physical/biological environment, social, cultural and economic) and those internal to individuals (e.g. psychological or physiological risk factors, attitudes and behaviour);
- health programs or health services, including those provided directly to individuals and those provided to communities, covering information on the nature of the services provided and their management, resourcing, accessibility, use and effectiveness; and
- the relationships among these elements.

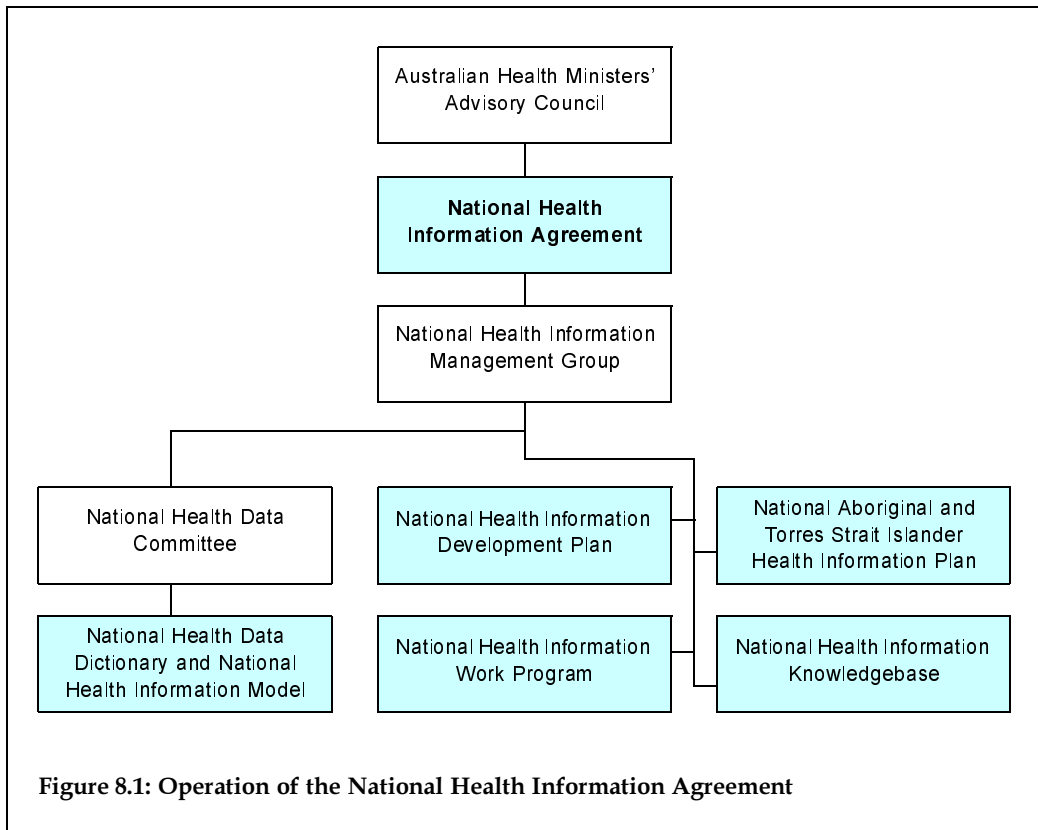
Health information is needed by consumers and providers of health services, the health industry, governments and the community to enable informed decision making. Consumers need information to guide their decisions to seek care, modify their behaviour, choose between different treatment options and understand the care they are receiving. Providers of health services need information about the needs of the populations they serve, the effectiveness of their interventions and for whom they are effective, and the acceptability of these interventions to the community. Providers also require nationally consistent information to be able to compare the effectiveness and efficiency of their operations with those of their peers. The health industry and governments need information to make decisions about how to provide services equitably, efficiently and effectively, and to monitor health service financing, performance and health outcomes.

8.2 Structures and data development processes for national health information

Australia has a well-established infrastructure to develop and provide national health information (Figure 8.1, page 230).

National Health Information Agreement

The foundation of the framework is the National Health Information Agreement. The Agreement, signed by the Commonwealth and State and Territory health authorities, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare,



came into effect in 1993, and has recently been extended to 2003. One of its objectives is to provide cooperative national structures and mechanisms to improve the collection, quality and dissemination of national health information. The Agreement is managed by the National Health Information Management Group.

The Agreement provides the basis for a national infrastructure, from which a number of important products have been developed. These include the National Health Information Work Program, the National Health Information Development Plan, the National Health Information Knowledgebase, the National Health Information Model, the National Health Data Dictionary and the National Aboriginal and Torres Strait Islander Health Information Plan.

National Health Information Work Program

The National Health Information Work Program is the rolling triennial program of priority health information development projects. Activities range from development work on standard definitions for community and primary health care, development of a national minimum data set for alcohol and other drug treatment services, to improved definitions and timeliness of existing collections such as hospital separations data.

National Health Information Development Plan

The National Health Information Development Plan (AIHW & AHMAC 1995) provides information planners, collectors and users with a list of priorities for national health information. Its purpose is to promote the development of high-priority health information and to increase the cost-effectiveness of Australia's health information systems. Progress on each of the highest priority development directions identified in the Plan is reported in Section 8.3.

National Health Data Dictionary

The National Health Data Dictionary (NHDD) has been produced each year since 1991. Originally it covered only the national minimum data set for institutional health care. However, since the implementation of the National Health Information Agreement in 1993, it has become the vehicle for all national data definitions developed through the National Health Data Committee. Coverage has extended beyond institutional health care, drawing on data development projects in the National Health Information Work Program. Consequently, Version 7, published in mid-1998, includes several new data elements for population health and non-institutional health care (NHDC 1998). Given the continuing policy interests in non-institutional health care, including continuity of care issues, further expansion of NHDD's coverage over the next few years is anticipated.

Commencing with the sixth edition of the NHDD issued in 1997 (NHDC 1997), a revised format for data definitions was incorporated based primarily on the international standard ISO/IEC 11179 *Specification and Standardization of Data Elements* (ISO & IEC 1997). The adaptation of this standard to health information is a progressive step in the management of metadata (the term used to describe data about health data).

National Health Information Knowledgebase

A significant advance in health information design in Australia was achieved in July 1997 with the launch by the Federal Health Minister, Dr Michael Wooldridge, of the National Health Information Knowledgebase (NHIK).

The Knowledgebase is an Internet-based electronic storage site and query tool for Australian national health metadata (AIHW 1997). Using international standards, it incorporates all of the national information development products and provides logical links between them. It offers free and coordinated electronic access to the full range of Australia's national health information development products. The NHIK was developed by AIHW under the auspices of the National Health Information Agreement (NHIA) and integrates:

- the National Health Information Model, a high-level framework for information management and development;
- the National Health Data Dictionary, reformatted in accordance with a metadata format based on the international standard ISO/IEC 11179 (*Specification and Standardization of Data Elements*);
- the *National Directory of Data Collections in Health, Welfare and Housing 1996*;
- the National Health Information Work Program;

- agreements to collect data, including National Minimum Data Sets; and
- the National Health Information Agreement itself, which provides the infrastructure for health information development in Australia.

The Knowledgebase provides a process for systematic development and registration of metadata and a repository (or *registry*) for metadata products. It helps users of shared data to develop a common understanding of the meaning, representation and identification of any unit of data and so facilitates data sharing across system and organisational boundaries. These latter features are of particular importance to organisations involved in electronic data interchange.

The Knowledgebase has the potential to become a comprehensive repository and data query facility that extends beyond the NHDD to incorporate metadata held at State/Territory, regional or local level, or by organisations in a particular field of specialisation.

The National Aboriginal and Torres Strait Islander Health Information Plan

The need to improve the quality of Indigenous health information was identified as the top national health information priority in the National Health Information Development Plan (AIHW & AHMAC 1995). The Aboriginal and Torres Strait Islander Health and Welfare Information Unit (a joint program of ABS and AIHW) was funded by the Australian Health Ministers' Advisory Council (AHMAC) to develop a National Indigenous Health Information Plan to remedy the data deficiencies. The Plan was presented to the October 1997 AHMAC meeting under a report entitled *The Aboriginal and Torres Strait Islander Health Information Plan...This Time, Let's Make it Happen* (AIHW & AHMAC 1998). AHMAC accepted the report, which has now been published. The Plan's major recommendations include:

- development, with the active involvement of communities, of specific protocols for the sensitive handling of data concerning Indigenous peoples;
- establishment of permanent and long-term positions for Indigenous personnel, to facilitate substantial improvements in the quality of information;
- ensuring all major health and related collections in all jurisdictions, including vital statistics, hospital separations, perinatal data and cancer registrations, have the capability to differentiate between Indigenous and other Australians;
- use of common identification classifications and collection protocols in all major collections;
- initiating processes to facilitate and oversee implementation of the Plan's recommendations in a cohesive, coordinated and cooperative manner; and
- encouraging the development of effective national leadership to facilitate and support jurisdictional initiatives, benchmarking, coordination and review.

To be fully effective, a commitment to sustained action is required. The National Health Information Management Group (NHIMG) has responsibility for overseeing the implementation of the Plan. A Working Group of representatives from NHIMG and relevant Indigenous health organisations has been created to facilitate this process. The ABS and

AIHW have accepted lead roles in working with organisations to implement Indigenous identification in priority information systems. ABS has this role for vital statistics (births and deaths) and AIHW for hospital separations, perinatal data and cancer registrations.

8.3 Progress and challenges in national health information

Progress in the National Health Information Development Plan priority areas

The National Health Information Development Plan identifies eight directions as the highest priority health information issues requiring national action:

- 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, examine the feasibility and usefulness of 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 health care 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.

Significant progress has been made in most of these priority directions.

Aboriginal and Torres Strait Islander health

As reported in Section 8.2, Health Ministers have endorsed a national plan to improve the quality of Indigenous health information. The challenge now is to implement the plan's recommendations in a cohesive, coordinated and cooperative manner.

National health and welfare information models

The National Health Information Model (NHIM) has been developed and is now used extensively as a framework for other developments in health information. The National

Health Data Dictionary (NHDD) will, in future, be presented according to the NHIM, starting with version 7.0. The National Community Services Information Model has also been developed, as the structural basis for the National Community Services Data Dictionary (NCSDD). The NCSDD is an important complement to the NHDD, and these developments will eventually lead to the integration of information models and data standards across both health and welfare.

Record linkage

Creating or using the capacity to link records in different health information collections can greatly increase the usefulness and, therefore, cost-effectiveness of information that is already collected. In particular, it can provide information on health service outcomes which is difficult to obtain in any other way.

The Australian Health Ministers' Advisory Council has given the AIHW the lead role to investigate possible approaches to developing and enhancing the ability to link health records for statistical and research purposes. The work will be undertaken in collaboration with the Department of Health and Family Services, the Health Insurance Commission, State and Territory health authorities and the WA Record Linkage project. The objectives of the project are to develop the means for accessing a range of health databases, to establish the technical feasibility for record linkage between these and AIHW databases, to define and implement demonstration linkage projects to investigate the value of this work, and to present the results of the project to the community.

The project entails gaining access to identifiable data held by the Health Insurance Commission, specifically data from the Medicare and Pharmaceutical Benefits Scheme databases. There are legislative constraints that limit access to these data in a format that enables record linkage. AIHW will seek to refine the data linkage process to enable access to records in ways that are consistent with privacy and ethical requirements.

AIHW and others proposed to the House of Representatives Standing Committee on Legal and Constitutional Affairs Inquiry into the Treatment of Census Forms in 1997 that the retention of census records by ABS should be investigated to permit linkage of census data across censuses and with other health data sets. Such arrangements are common in other countries, notably the United Kingdom. The Standing Committee had yet to report at the time of writing.

Health outcomes

In 1993, the Australian Health Ministers' Advisory Council adopted the following definition of a health outcome:

A change in the health of an individual, a group of people or population, which is attributable to an intervention or series of interventions. (AHMAC 1993)

This definition is equally applicable to clinical care and population health, and provides a common framework for the focus on outcomes in public health programs, health services delivery and the practice of clinical medicine.

The health outcomes focus provides the basis for the development of national health strategies and programs for some years, and the current national health priorities (see Section 4.1, page 75) had their origins in the setting of health goals and targets, initially released in 1988 through the *Health for All Australians* report. In 1996, the National

Health Information Management Group developed a classification of health outcome indicators, which recognised the complex process required to achieve health outcomes and identified the range of interventions (prevention, treatment, support and after care) involved. This classification has been used to develop indicators for the National Health Priority Areas initiative, which are used by the AIHW for monitoring health outcomes and reporting progress at the population level for the five priority areas.

Commonwealth Government and State and Territory Governments are jointly undertaking a series of coordinated care trials to determine the extent to which coordination of health services contributes to improved patient outcomes. The aim is to improve the matching of services to client needs, reducing the impact of access or other factors. A number of the trials target Aboriginal and Torres Strait Islander communities. To ensure nationally consistent evaluation of health and wellbeing outcomes, the SF-36 instrument has been adopted as the standard measure of health status for adults and the Child Health Questionnaire for children involved in the trials. The trials will conclude in December 1999.

Severe mental illness

Several initiatives are in progress under the National Mental Health Strategy to improve data standards for the collection of information on patients and care provided in institutions and in the community for severe mental illness.

A study of low-prevalence, severe mental illness was conducted in August 1997 in Melbourne, Brisbane, Perth and Canberra. This study, when completed, will complement the results of the National Survey of Mental Health and Wellbeing (ABS 1998a). A separate study was needed as severe illnesses such as bipolar disorder, schizophrenia and other psychoses have a prevalence of only about 1% and cannot be identified through random sampling in the general population. Estimates will be produced of the 1-month and 1-year prevalence of severe mental illness in the community and the extent to which services are being used currently, or have been used in the past (including government-funded specialised psychiatric services, non-government organisations, and services in the private sector such as general practice). The study will also make an assessment of the personal and social circumstances of people who have a low-prevalence severe mental illness.

A national minimum data set for mental health care has been developed for collecting information on a continuous basis on people who receive health care services for any mental disorder in both hospital and community settings. This will enable data to be collected on the demographic characteristics of patients, clinical diagnoses and how treatment is managed. Data on patients admitted to specialised psychiatric services in hospital will become available at the end of 1998, and data on service delivery (cost, size and volume of services) will become available in 1999. Data on patients receiving care from community mental health services will not be available until 2000.

Non-institutional health care data

General practitioners play an important role in the provision of primary health care services and in providing access for their patients to pharmaceuticals, specialists, hospitals and other health care services. Public expenditure on the services they provide

is uncapped and forms a substantial and increasing proportion of total government expenditure on health.

Despite this, few data have been collected on the activities of general practitioners, with the limited Medicare data being the only source of national, routinely collected information. No national data have been available on the 'casemix' of general practitioners, that is, on the characteristics of their patients, the problems or diagnoses managed, and the nature of the management.

In response to this need for primary health care data, AIHW and the University of Sydney are collaborating on a national, continuous survey of general practitioner activity, entitled 'Bettering the Evaluation And Care of Health' (BEACH).

This survey, for which data collection began in April 1998, builds on the experience of the 1990-91 Australian Morbidity and Treatment Survey (Bridges-Webb et al. 1992). Each year, it will sample about 1,000 general practitioners nationally on a rolling basis. The general practitioners will be asked to supply some information on themselves and on 100 consecutive patient encounters, including home visits and consultations in nursing homes and hospitals.

Data collected for each encounter will include demographic characteristics of the patient, payment type, the patient's reasons for encounter, up to four diagnoses or problems and, for samples of patients, information on the patient's smoking and alcohol consumption, general health and other characteristics. For each problem or diagnosis, information will be collected on medications prescribed or advised; procedures, treatments and counselling provided by the general practitioner; and referrals, admissions, pathology tests and diagnostic imaging ordered. First reports from BEACH are expected to be published during 1999.

BEACH's financing is innovative, with funders including government agencies and pharmaceutical companies. Although data will be released publicly at the aggregate level as for any AIHW activity, funders will receive sets of detailed reports and unit record data, as well as being able to add their own questions to the survey each year. Since public funds for health information are limited, the success of the public-private model for the BEACH survey will be closely monitored.

In addition to the developments in general practice described above, national minimum data sets are being developed in the areas of alcohol and other drug treatment services, mental health services and palliative care that include outpatient and community care within their scope.

Potentially modifiable major disease risk factors

A National Centre for Monitoring Cardiovascular Disease was established within AIHW in January 1996. Its role is to establish and maintain a national monitoring system for cardiovascular disease, its risk factors and management. A major project currently being undertaken is to standardise risk factor definitions and measurement for use in data collections including population surveys. National consensus has been reached on data standards for overweight/obesity and related measures. Work is continuing on developing national data standards for physical activity, smoking, high blood pressure and high blood cholesterol. Nationally agreed data definitions will be published in the National Health Data Dictionary.

AIHW has been selected to develop and maintain a National Insulin-Treated Diabetes Mellitus Register. The Register will provide a sampling frame for research, to monitor and report on insulin-treated diabetes mellitus (ITDM) incidence, to assess the feasibility and cost of estimating complete ITDM prevalence, to provide information to health service providers and planners at Commonwealth, State and local levels, and to assist in monitoring national diabetes indicators.

The planned start date for the Register is 1 September 1998. The main sources of data for the Register will be the National Diabetic Services Scheme (administered by Diabetes Australia) and the State-based databases maintained by the Australian Paediatric Endocrine Group. AIHW will undertake extensive quality assurance of these data, including confirmation of an insulin-dependent diabetes mellitus diagnosis. Major outputs from the Register will be in the form of incidence and prevalence reports. First reports are expected to be available 6–12 months after the start date.

Other achievements and developments in health information

Introduction of ICD-10 and ICD-10-AM

ICD-10 is the International Classification of Diseases and Related Health Problems—Tenth Revision, produced by the World Health Organization (WHO) as the most recent in its series of ICD classifications. It was adopted by the World Health Assembly in 1990.

ICD-10 is a comprehensive statistical classification, much improved over ICD-9 and more accurately reflecting current understanding of clinical conditions. The classification uses an alphanumeric coding scheme, comprising one alphabetical character generally followed by two, three or four numerals. This arrangement has more than doubled the size of the coding frame in comparison with the numerical format of ICD-9. The subject matter of each chapter of ICD-10 is generally the same as in ICD-9, although there has been some relocation of diseases and conditions to improve consistency between the classification and current medical knowledge.

The Australian Bureau of Statistics plans to implement ICD-10 from 1 January 1999 for coding causes of death. This is consistent with international moves to update to the new classification for mortality coding.

In Australia, for morbidity coding, the National Centre for Classification in Health (NCCH) has produced the International Classification of Diseases and Related Health Problems—Tenth Revision—Australian Modification (ICD-10-AM). NCCH has undertaken this work with the input of Australian clinicians and coding specialists, and in close collaboration with the WHO to ensure that international comparability is maintained (NCCH 1997).

ICD-10-AM consists of:

- a disease classification based on the WHO version of ICD-10 with modifications to ensure a current and appropriate classification for Australian clinical practice;
- a new Australian procedure classification based on the Medicare Benefits Schedule (referred to as MBS—Extended, or MBS-E); and
- Australian Coding Standards for selection of disease and procedure codes.

Hospitals in some States and Territories will begin using ICD-10-AM in July 1998, with the others to follow in July 1999.

Burden of disease, injury and risk factors

There is increasing international interest in summary measures of population health that combine the impact of mortality and morbidity in a single indicator. One such indicator is the health-adjusted life expectancy, which estimates a population's average expectation of years of equivalent good health (Wolfson 1996). A related measure, the disability-adjusted life year (DALY) allows the loss of health associated with specific diseases, injury and risk factors to be quantified.

Disease-specific measures of population health such as the DALY in principle allow measurement of the potential for population health gain (outcomes) in relation to a particular health problem, and monitoring of the actual health gain at population level for the health problem. The size of health problems is also an important input (together with information on the cost-effectiveness of potential programs) to help set priorities for health service programs, public health programs and for research and development. The results of cost-effectiveness studies can be expressed in dollars per DALY gained, allowing economic data on the cost per unit of health gain to be used in conjunction with population data on the potential for health gain.

The DALY was developed for the 1993 World Development Report (World Bank 1993) in order to carry out a complete assessment of the global burden of disease by region for 1990. It extends the concept of potential years of life lost due to premature death (PYLL) to include equivalent years of 'healthy' life lost by virtue of being in states of ill-health. The DALY has been used to provide a comprehensive assessment of the global burden of disease, injury and selected risk factors (Murray & Lopez 1996a, b), an analysis of the potential for cost-effective public health interventions at the global level (World Bank 1993; Bobadilla et al. 1994), and as the basis for an evidence-based approach to the identification of global priorities for health research and development (Ad Hoc Committee on Health Research Relating to Future Intervention Options 1996).

The DALY involves explicit underlying assumptions (particularly in relation to weights for health states). This explicitness exposes social choices and values that are often left implicit in the prioritising of health problems. AIHW will be undertaking a review of the DALY methodology during 1998-99, which will examine these issues, and plans to develop national estimates of disease burden.

Health satellite accounts

The UN *System of National Accounts 1993* (Inter-Secretariat Working Group 1993) introduced the concept of satellite accounts as a way of going beyond the rigidity of the national accounts structure to provide a focus on data which is of particular relevance to specific policy areas.

Satellite accounts enable the use of complementary or alternative concepts to those contained in the conceptual framework of national accounts. For example, the disease costing work of AIHW has used basic health expenditure data and subdivided it by disease, to give an alternative perspective on the data.

Satellite accounts enable the linkage of non-monetary data sources and analysis to the monetary accounting system. Monetary expenditure in health by itself tells us little about what is happening in the health system. But if these expenditures can be linked to output and outcome measures such as number of hospital separations and changes in

health status, then the expenditure information becomes more meaningful. Linking together expenditure and workforce data to calculate cost per full-time equivalent staff person is another example of the usefulness of linking.

In order to link expenditure, workforce, disease and other data in a useful way, the definitions used in each of these areas need to be clear. Thus a large part of the satellite accounts project being undertaken by AIHW involves documenting and refining the definitions and methodologies used in the health and welfare services expenditure area.

This information will be brought together in a publication *Health and Welfare Satellite Accounts: Concepts, Sources and Methods*, which will complement the ABS publications *Australian National Accounts: Concepts, Sources and Methods* (ABS 1990) and *Government Finance Statistics Australia: Concepts, Sources and Methods 1994* (ABS 1994).

This publication not only will provide an integrating framework for AIHW health and welfare services expenditure collections, but also will be a useful framework for all AIHW collections. It will spell out the exact relationship between the satellite accounts the AIHW produces and the ABS Australian National Accounts.

It will discuss issues such as:

- the definitions of 'health' and 'welfare services';
- the relationship between the Government Purpose Classification and the Australian and New Zealand Standard Industrial Classification in health and welfare services;
- the relationship between the household sector and the government and non-government sectors, particularly the not-for-profit sector;
- disease costing and appropriate and inappropriate ways of measuring disease costs;
- distributional aspects of health and welfare services expenditure, i.e. who uses and who funds the services; and
- international comparisons of health and welfare services expenditures.

AIHW has released satellite account discussion papers on:

- a conceptual framework for health and welfare services satellite accounts;
- estimating expenditure on welfare services by non-government organisations; and
- disease costing.

A discussion paper on capital expenditure, capital stock and the consumption of fixed capital in the health and community services sector will also be released in 1998.

International comparison of health expenditure statistics

Comparing health expenditure statistics internationally is difficult, as the scope of health services varies and different countries use different definitions and methodologies. For example, there are significant differences between countries as to what proportion of aged care expenditure is allocated to health and what proportion to welfare services.

Two international projects are under way to improve comparisons. First, the Organisation for Economic Co-operation and Development (OECD) has produced a comprehensive System of Health Accounts (OECD 1997), which provides a systematic conceptual framework for collecting health expenditure data. Second, Statistics Nether-

lands has been making detailed bilateral comparisons of health expenditure in the Netherlands with Belgium, Denmark, France, Germany and Switzerland. Comparisons have been made for 1992–93 and for 1994–95. Australia is now participating in this project.

Australian Longitudinal Study on Women's Health

In June 1995, a multidisciplinary team of researchers from the University of Newcastle (in partnership with the University of Queensland) was commissioned to carry out the first Australian Longitudinal Study on Women's Health (Brown et al. 1996). The study is funded by the Commonwealth Department of Health and Family Services, initially for 3 years, but the design provides for it to be continued for 20–30 years. The longitudinal research design will help clarify important cause–effect relationships, within a social model of health which incorporates input from a variety of academic disciplines.

The project involves three large age cohorts of women: 'young' women aged 18 to 23 years (14,762 at the time of baseline data collection in 1996), 'mid-age' women aged 45 to 50 years (14,072) and 'older' women aged 70 to 75 years (13,023); two smaller cohorts of women from the Philippines and the former Yugoslav republics (300 in each cohort); and three small cohorts of women from urban and rural Indigenous communities (Brown et al. 1998). Baseline data collection for the three main age cohorts and the Filipina and Yugoslav cohorts is completed, and data from the Indigenous cohorts will be available in 1998.

It is proposed to survey each of the cohorts at 3-yearly intervals, on a 'rolling' basis, beginning with the mid-age and Filipina cohorts in 1998, followed by the older and Yugoslav cohorts in 1999 and the young and Indigenous cohorts in 2000. Three-yearly surveys are necessary to ensure accurate documentation of major life events such as birth of first child (young), menopause (middle), and events such as widowhood and the onset of age-related health problems (e.g. dementia, Alzheimer's disease) in the older cohort. In the years between the 3-yearly follow-up surveys for each of the main cohorts, nested substudies are proposed, using qualitative as well as quantitative methodologies, to allow more in-depth investigation of issues arising from the main study.

8.4 Gaps and deficiencies in health statistics

The quality of Indigenous health statistics

Indigenous identification

ABS has developed a standard procedure for identifying Aboriginal and Torres Strait Islander peoples, based on self-reported Indigenous origin (see Box 8.1). The standard is contained in the National Health Data Dictionary (NHDC 1997) and is supported by Australia's Registrars of Births, Deaths and Marriages. It is used in most survey data collections and, as collection forms are revised, is gradually being adopted in administrative collections. However, at present there is considerable variation in the way Indigenous status is collected and recorded in administrative data collections, which reduces the value of the data for analysis.

Box 8.1: Indigenous status

The standard for identifying Indigenous people is based on the Commonwealth working definition of an Aboriginal or Torres Strait Islander. This is:

'...a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives'.

There are three components to this definition: descent or origin, self-identification and community acceptance. The standard question for identifying Indigenous people uses the first component:

Are you of Aboriginal or Torres Strait Islander origin?

For persons of both Aboriginal and Torres Strait Islander origin, mark both boxes.

No

Yes, Aboriginal

Yes, Torres Strait Islander

Although the question uses only the origin component of the definition, some people responding to this question may, however, interpret the concept more broadly than this.

Source: NHDC 1997.

Changes in Indigenous population counts and estimates

Recent changes in the estimated size of the Indigenous population present users of Indigenous health statistics with considerable difficulties in analysing changes over time.

Based on Census results, the final estimated Indigenous population of Australia at 30 June 1996 was 386,049 (ABS 1998b). This is a substantial increase over the 319,200 estimated population in 1991. The increase was mainly in the urban areas, and is much larger than could be expected due to natural increase. More information is needed about the propensity to identify as of Aboriginal or Torres Strait Islander origin to permit accurate interpretation of basic population and health statistics.

National surveys

The 1995 National Health Survey included a supplementary sample of households designed to increase the survey's Indigenous sample. The Australian Bureau of Statistics is analysing the results of the survey to assess the extent to which the enhanced sample is representative of the population. This will assist in developing strategies for collecting information on the health of Indigenous peoples in future surveys.

Whether a second National Aboriginal and Torres Strait Islander Survey will be conducted in the year 2000 remains the subject of discussion between the Australian Bureau of Statistics and stakeholders. An adequate evaluation of data quality achieved in both urban and rural/remote communities is an important input to this consideration. The Aboriginal and Torres Strait Islander Commission's plan to conduct a second Housing and Community Infrastructure Needs Survey in 1998 (or 1999) may permit collection of some information on health services infrastructure (and related issues) available to remote and rural Indigenous communities.

For evaluation and further planning of programs to improve the health of Australian Indigenous peoples, a comprehensive solution to the problem of obtaining reliable health outcomes data relevant to programs at national and regional levels needs to be found.

Quality of Indigenous birth and death registrations

The completeness of Indigenous birth and death registrations can be assessed by comparing the number of recorded births or deaths with the number expected, based on demographic characteristics of the population. However, because of the largely unexplained increase in the estimated size of the Indigenous population between 1991 and 1996, estimates of the completeness of Indigenous birth and death notifications for some States and Territories differ depending on whether they are based on the 1991 or 1996 Census year. Overall, only the Northern Territory, Western Australia, South Australia and the Australian Capital Territory are estimated to have reasonably complete coverage for the past few years. Other States, with the exception of Queensland which is estimated to be close to complete coverage for births and deaths in late 1996, have shown little improvement in their coverage since the early 1990s.

The Australian Bureau of Statistics has committed substantial resources and effort in each jurisdiction to overcome these long-standing deficiencies.

Other health data collections

Most other health data collections either do not have an Indigenous identifier or their completeness is unknown. In a recent study of the expenditure on Aboriginal and Torres Strait Islander health conducted by AIHW and the National Centre for Epidemiology and Population Health at the Australian National University, estimates of the number of interactions by Indigenous people with services and/or expenditure on Indigenous services were derived. Table 8.1 indicates those collections that were able to provide some information about the level of health service use by and expenditure for Indigenous people. It is clear that the majority of collections in most States are still not able to provide any reliable Indigenous statistics. Clearly, much still needs to be done to standardise and improve procedures for identifying Indigenous people in administrative collections.

Table 8.1: Indigenous expenditure information available from State and Territory collections

Services	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Hospitals—admitted patients	yes	yes	yes	yes	yes	no	yes	yes
Hospitals—non-admitted patients	yes	no	yes	yes	no	no	yes	yes
Mental institutions	yes	no	no	yes	no	no	n.a.	n.a.
Nursing homes	yes	no	no	yes	no	no	n.a.	yes
Community health	yes	yes	no	yes	no	no	yes	yes
Transport	yes	no	no	yes	no	no	no	yes
Public health	yes	no	no	yes	no	no	no	yes
Administration/research	no	no	no	no	yes	no	no	no

Note: 'yes' indicates some useful information can be obtained. However, this could well involve an uncertain level of underidentification of Indigenous peoples.

Source: DHFS 1998.

Data requirements for national health priority areas

The *First Report on National Health Priority Areas 1996* (AIHW & DHFS 1997) was unable to report progress against several of the NHPA indicators because of gaps and deficiencies in the data. Little information is available on the health of Indigenous peoples and efforts are under way in all priority areas to overcome this major deficiency in national data collections. There are no time series available for some indicators because of the infrequency of data collection, and data standards are either lacking or not consistently applied across all States and Territories.

- In the area of cardiovascular health, data were not available for reporting on more than half of the priority indicators. To overcome this, data development work on cardiovascular indicators is currently under way. Also, the indicator set is being revised to include indicators for stroke, in addition to those for coronary heart disease. National data standards and definitions have been developed for measuring the prevalence of overweight or obese people, and are being developed for smoking prevalence, physical inactivity, total cholesterol and blood pressure.
- Mortality data are extensively used for the cancer control indicators. There are some problems related to the use of mortality data, as not all conditions listed on death certificates have been coded in the past. The introduction of automated cause-of-death coding is expected to overcome this difficulty. Data on cancer incidence are currently available to 1994 for all States and Territories, except Queensland, for which data are available to 1990. There is very little data available on survival rates and patient satisfaction with cancer treatment services.
- Mortality data and hospital separations data are the major data sources for the injury prevention and control indicators. At present, information is not available on some of the factors relating to fatal injury, such as type of injury and place of injury. The introduction of ICD-10 coding will reduce this problem if relevant components are applied. Limited information is available about the large proportion of injury cases that do not result in death or admission to hospital. Also, little information is available on factors that increase susceptibility to injury, such as consumption of alcohol (except in the case of traffic accidents) and osteoporosis in fall-related injuries.
- Limited information is available for reporting on mental health. Problems with case identification and standardisation of psychiatric diagnoses contribute to the lack of reliable statistics. Some information on the prevalence of selected mental disorders is now available from the 1997 National Survey of Mental Health and Wellbeing (ABS 1998a). At present, no data are available about the consumers of mental health services in community settings. Depression has been identified as a specific condition for which indicators need to be developed.
- There is currently no reliable estimate of the prevalence of diabetes mellitus in Australia, and no national information on its incidence. The National Diabetes Register, currently being established by the AIHW, will provide some information for monitoring insulin-treated diabetes.

Health surveys

There is a need for ongoing surveillance of risk factors, by population surveys and other means, if preventive activities are to be appropriately targeted and adequately evaluated. This is especially true for biological risk factors, such as blood cholesterol levels. A workshop at AIHW in 1997 endorsed the need for a National Biomedical Risk Factor Survey that includes a blood sample, to meet the need for information in the areas of cardiovascular disease, diabetes, nutrition and communicable diseases. A steering group will further develop the survey and investigate options for funding.

The Australian Bureau of Statistics decision in early 1998 to review its health survey strategy provides an opportunity for a more comprehensive set of health surveys in Australia, combining the resources and requirements of all stakeholders. As well as risk factors, regular data on topics such as mental health, dental health and nutrition are needed.

Public health information

Public health is characterised by a focus on interventions at the population level and, hence, relies to an even greater extent than do clinical services on population-based health information for planning, priority setting, monitoring and evaluation. The areas best covered by current national data collections relate to disease, injury and aspects of biological and behavioural risk factors. Much less data are available for other determinants of health or for factors that enable or promote health.

Many existing health data collections could be more effectively used for developing quasi-national monitoring and surveillance indicators relevant to public health activities, if there were nationally agreed classifications and standards for survey instruments, methods and indicators. Current development of a National Public Health Information Development Plan by the National Public Health Partnership will consider these needs and provide a strategy for meeting them. AIHW has begun development of data items and definitions under the National Health Information Agreement for some determinants of health.

Socioeconomic disadvantage and related sociodemographic factors are now recognised as important determinants of health in addition to the better-studied individual biological and lifestyle risk factors. Cross-sectional population health studies have shown an association between aspects of socioeconomic disadvantage and worse health. However, such studies are unable to determine whether socioeconomic disadvantage causes worse health or whether health problems result in socioeconomic disadvantage. Australian longitudinal studies are required to clarify this aspect of causality. However, such studies are extremely expensive to mount as one-off research studies. Record linkage offers the potential for longitudinal studies to be conducted for considerably lower costs.

National information on health promotion and public health programs, their nature, the need for them, and their distribution, target populations and cost is minimal in comparison with information on treatment services. National data on public health expenditure is not currently available, although AIHW is undertaking work to rectify this.

Health service outcomes and quality of health care

There is little information about the health outcomes that result from the \$43 billion spent on health services in Australia. However, increasingly the data are available to partially understand the relationship between health services and change in health status.

With the advent of performance indicators in the health sector, there is increasing demand for consistent and timely data on the performance of health service providers including hospitals. The quality of care provided is regarded as an important indicator of performance, but, as noted by the Steering Committee for the Review of Commonwealth/State Service Provision, information is limited (SCRCSSP 1998).

At present the only indicator of quality of care for which there is data, is the number of beds in hospitals that have been accredited by the Australian Council on Healthcare Standards (NHMBWG 1996; see also ACHS 1996). Recommendations for improvements in the structure and direction of the quality of acute hospital care and health outcomes have been developed under the National Hospital Outcomes Program (DHFS 1997).

In the case of adverse outcomes, some potential hospital-level indicators of quality of care (unplanned readmission to hospital, unexpected return to operating theatre, and hospital-acquired infections) have recently been tested for validity and reliability and for the ease of collection of the data required for their measurement. However, a valid relationship between quality of care and the indicators tested could not be demonstrated and the data to measure these outcomes could not be extracted from the available administrative databases. The Quality in Australian Health Care Study (Wilson et al. 1995) also documented adverse events in health care, and similarly commented that useable information could not be extracted from data routinely collected on patients in hospital.

References

- Ad Hoc Committee on Health Research Relating to Future Intervention Options 1996. Investing in health research and development. Document TDR/Gen/96.1. Geneva: World Health Organization.
- Australian Bureau of Statistics (ABS) 1990. Australian national accounts: concepts, sources and methods. Cat. No. 5216.0. Canberra: ABS.
- Australian Bureau of Statistics (ABS) 1994. Government finance statistics Australia: concepts, sources and methods 1994. Cat. No. 5514.0. Canberra: ABS.
- Australian Bureau of Statistics (ABS) 1998a. Mental health and wellbeing, profile of adults, Australia, 1997. Cat. No. 4326.0. Canberra: ABS.
- Australian Bureau of Statistics (ABS) 1998b. Experimental estimates of the Aboriginal and Torres Strait Islander population. Cat. No. 3230.0. Canberra: ABS.
- Australian Council on Healthcare Standards (ACHS) 1996. Annual report 1995–96. Sydney: ACHS.

- Australian Health Ministers' Advisory Council (AHMAC) 1993. AHMAC Health Outcomes Seminar: outline of proceedings (including the AHMAC sunshine statement). Canberra: AHMAC.
- Australian Institute of Health and Welfare (AIHW) 1997. National health information knowledgebase. <http://www.aihw.gov.au>.
- Australian Institute of Health and Welfare (AIHW) & Australian Health Ministers' Advisory Council (AHMAC) 1995. National health information development plan. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) & Australian Health Ministers' Advisory Council (AHMAC) 1998. The Aboriginal and Torres Strait Islander health information plan...this time let's make it happen. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) & (Commonwealth) Department of Health and Family Services (DHFS) 1997. First report on national health priority areas 1996. AIHW Cat. No. PHE 1. Canberra: AIHW & DHFS.
- Bobadilla J-L, Cowley O, Musgrove P & Saxenian H 1994. Design, content and financing of an essential national package of health services. *Bulletin of the World Health Organization* 72(4):653-62.
- Bridges-Webb C, Britt H, Miles DA, Neary S, Charles J & Traynor V 1992. Morbidity and treatment in general practice in Australia 1990-1991. *Med J Aust* 157 Suppl: S1-S57.
- Brown W, Byles J, Bryson L, Dobson A, Manderson L, Schofield M & Williams G 1996. Establishment of the Australian longitudinal study of women's health. *J Womens Health* 5:467-72.
- Brown W, Bryson L, Byles J, Dobson A, Lee C, Mishra M & Schofield M 1998. Women's health Australia: recruitment for a national longitudinal cohort study. *Women Health* 28(2) (in press).
- Department of Environment, Sports and Territories 1996. State of the environment Australia 1996. Melbourne: CSIRO Publishing.
- (Commonwealth) Department of Health and Family Services (DHFS) 1997. Quality outcome indicators for acute healthcare services. Canberra: DHFS.
- (Commonwealth) Department of Health and Family Services (DHFS) 1998. Expenditures on health services for Aboriginal and Torres Strait Islander people. Canberra: AGPS.
- International Organization for Standardization (ISO) & International Electrotechnical Commission (IEC) 1997. ISO/IEC 11179 Specification and standardization of data elements. Geneva: ISO & IEC.
- Inter-Secretariat Working Group 1993. System of national accounts 1993. Brussels/Luxembourg, New York, Paris, Washington DC: Commission of the European Communities, International Monetary Fund, Organisation for Economic Co-operation and Development, United Nations, World Bank.

- Murray CJL & Lopez AD, eds 1996a. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Harvard: Harvard School of Public Health.
- Murray CJL & Lopez AD 1996b. Global health statistics: a compendium of incidence, prevalence and mortality estimates for over 200 conditions. Harvard: Harvard School of Public Health.
- National Centre for Classification in Health (NCCH) 1997. ICD-10-AM implementation kit. Sydney: NCCH.
- National Health Data Committee (NHDC) 1997. National health data dictionary, version 6.0. Canberra: AIHW.
- National Health Data Committee (NHDC) 1998. National health data dictionary, version 7.0. Canberra: AIHW (in press).
- National Health Ministers' Benchmarking Working Group (NHMBWG) 1996. First national report on health sector performance indicators: public hospitals – the state of play. Canberra: AIHW.
- Organisation for Economic Co-operation and Development (OECD) 1997. Principles of health accounting for international data collections (DEELSA/ELSA/HP(97)3). Paris: OECD.
- Steering Committee for the Review of Commonwealth/State Service Provision (SCRCSSP) 1998. Report on government services, vol. 1: education, health, justice emergency management. Melbourne: SCRCSSP.
- Wilson R McL, Runciman WB, Gibberd RW, Harrison BT, Newby L & Hamilton JD 1995. The Quality in Australian Health Care Study. *Med J Aust* 163:458–71.
- Wolfson MC 1996. Health-adjusted life expectancy. *Health Rep* 8(1):41–45.
- World Bank 1993. World development report 1993: investing in health. New York: Oxford University Press.