



# 7 National health information and its development

Australia has a relatively comprehensive health statistics system. This is demonstrated by the vast amount of health statistics used in the previous chapters.

Since its inception in 1993, the National Health Information Agreement has provided the framework for cooperation between government agencies that has supported this statistical system. Under the Agreement, principles and mechanisms for endorsing national minimum data sets and statistical standards have been established. The Agreement was extended to May 2004 and is being reviewed. A set of national health information development priorities was developed by the National Health Information Management Group and was endorsed by the Australian Health Ministers' Advisory Council (AHMAC) in 2003.

In the most general terms, health information is important for the understanding of the health status of the population, the extent and nature of various health problems and their determinants and causes, the services and interventions to reduce these problems and their health outcomes. Health information and statistics are fundamental to developing effective health policies and programs, to coordinating treatments and care, and to empowering consumers. There is increased use of statistical indicators to monitor levels and changes in health status and the performance of the health programs and systems. This has resulted in a better understanding of the quality of current data and the need for improvements to them to support the indicators. Indicator sets are developed or being developed for the system as a whole (for example for the national health performance report) and for a variety of health areas or sectors, for example each of the National Health Priority Areas, environmental health, hospitals and public health.

The sources of health statistics include administrative data systems such as those for hospitals, disease registers and surveys such as the various forms of household surveys and telephone surveys. A number of national minimum data sets that support performance indicators have been specified and developed, and administrative systems are being designed and organised so that they can generate agreed national minimum data sets. There have also been major improvements in health survey programs conducted by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), health departments and others. While there are still significant gaps and some inconsistencies, these surveys are providing relatively comprehensive data on the health conditions and behavioural health risk factors of Australians. Major health surveys are conducted at regular intervals and these are providing time series data.

Significant work has been done to develop a national network of electronic health records for use by health providers and consumers. The *HealthConnect* project, initiated by the Australian, state and territory governments in 2001, has completed its first phases of work, assessing user requirements and specifying preliminary system designs. Several trials are being conducted. Electronic health record systems have the potential to improve the provision of health statistics as well as clinical management if the systems incorporate statistical requirements as an integral part.

To improve the management of information technology and statistical issues in health information, a new national governance structure was developed and put in place in 2003. Two new high-level bodies were established under AHMAC. These two bodies will have responsibility for advising on and managing all aspects of health information management and associated information and communications technology activities.

This chapter discusses these aspects of the national statistical system.

## 7.1 New governance for national health information

In 2002, the Australian Health Care Agreements were reviewed, and new agreements were signed in 2003. As part of the review, a report by the Review's Reference Group of Information Technology, E-health and Research proposed that changes in governance arrangements were needed to increase the effectiveness of the investment in information management and technology. The report recognised the importance of information as an enabler for improvements in health service delivery. A new governance arrangement was proposed for consideration by AHMAC and the Australian Health Ministers' Conference (AHMC).

On 31 July 2003, AHMC endorsed the creation of two new bodies—the Australian Health Information Council (AHIC) and the National Health Information Group (NHIG)—to provide leadership on information management and technology, and to coordinate advice to AHMAC and AHMC.

The key role of AHIC is to provide independent advice to AHMC, through AHMAC, on long-term directions and national strategic reform issues, including views from consumer, clinical and private stakeholders and experts.

The NHIG has been established to advise AHMAC on planning and management requirements, and to manage and allocate resources to national health information projects and working groups. Membership of the NHIG is jurisdictional, with relevant agencies (including AIHW) having observer status.

The new arrangements have been designed to enable more-coordinated, coherent governance of national data collection, data standards and related information communications technology. The aim is that statistical aspects of information management and technical aspects of information management and their related standards work be brought together in a more integrated way.

To support the work program of the NHIG a number of standing committees have been established. The Statistical Information Management Committee (SIMC) replaces the

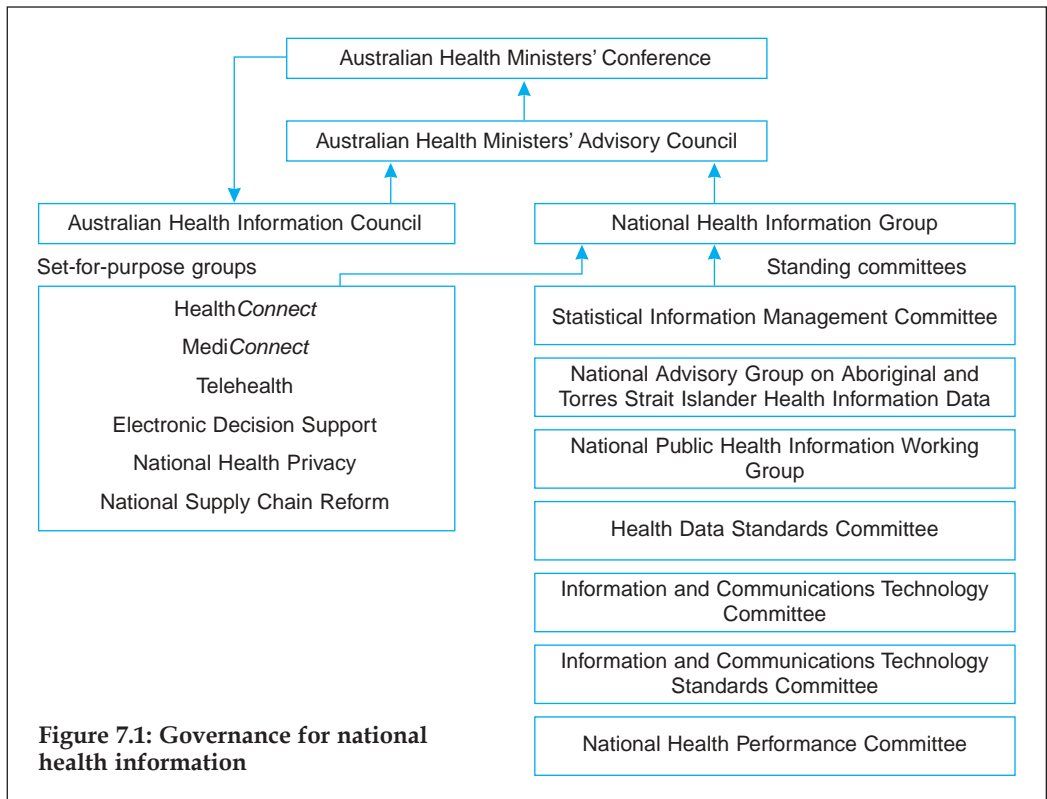
National Health Information Management Group and has responsibility for statistical matters. The Health Data Standards Committee (HDSC) replaces the National Health Data Committee and assumes responsibility and custodianship of the *National Health Data Dictionary*, along with responsibility for health terminology and classification.

Classifications and terminologies need to meet both statistical and clinical requirements. Recognising the importance and the size of the field of health terminology and its relationship with classification, a Classification and Terminology Working Group was established under the HDSC to advise on Australian adoption of standard classifications and terminologies and to link Australian work in this area with international efforts.

Two information technology committees have been created under the NHIG—the Information and Communications Technology Standards Committee that deals with communication and messaging standards, and the Information and Communications Technology Committee that deals with software and hardware matters.

The new governance arrangements also include time-limited working groups that are established for specific purposes. Related committees and working groups work closely through joint membership and through business rules.

The National Health Information Agreement that was signed in 1993 and propelled the considerable development of national health statistics is now being re-drawn to reflect the new arrangements.



## 7.2 National health information development priorities

While Australia's health statistics system is well established, there remain a number of areas where improvements are needed. There are also new and emerging issues that require attention. In 2001-02, the National Health Information Management Group developed 10 priorities for health information development and these were endorsed by AHMAC (NHIMG 2003). They are described below.

### Indigenous health

Improvements are being made to the quality and quantity of statistics on Indigenous health. An Indigenous supplement to the ABS National Health Survey in 2001 collected data on the health status of Indigenous persons in remote and non-remote areas of Australia. In 2004, the ABS will be collecting this information through the Indigenous Health Survey, which will be run in conjunction with the National Health Survey using a much larger sample. This survey will provide national and state/territory estimates of indicators of health status such as self-reported disease patterns and risk factor behaviours. In 2002, the ABS conducted its first six-yearly Indigenous Social Survey that collected health data along with other information on the various dimensions of economic, social and cultural circumstances.

Efforts are also being made to improve Indigenous identification in data collections on the use of health services. Identification is self-reported. National standards for Indigenous identification in hospitals have been adopted. However, the extent of this identification varies considerably between states and territories as well as across collections.

Estimates of basic Indigenous health status measures, such as birth and death rates, infant mortality rates and life expectancy, are affected by the quality of population and birth and death registration data that varies between states and territories. The ABS publishes experimental estimates of Indigenous death rates and life expectancy based on models (ABS 1998), but the reliability of these estimates is difficult to establish. Better quality data and better use of existing data (such as data linkage between vital and census records) are needed to verify and improve the assumptions underlying these models. Similarly, data on Indigenous health service use are not of consistent quality across the states and territories.

To further improve Indigenous statistics, AHMAC has established a National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data. Its role is to implement the National Indigenous Health Information Plan, in particular to improve the quality of Aboriginal and Torres Strait Islander population estimates and vital statistics (AHMAC 1997). At the present state of development, the state of Indigenous health is well described for some parts of Australia, but national trends are not reliably discernible. Care is needed to avoid false conclusions.

### Integration of services

To support the integration of health and related services, all data from the relevant sectors need to complement each other and be comparable. For example, to develop an integrated system of aged care, comparable data are required to help understand the complex flow of consumers of health care between hospitals, residential aged care and the community.

Much of Australia's current health statistics, however, are sector-specific, reflecting the timing of their development and the sectors' special data requirements. These separate data collections need to be harmonised and new data collections need to include comparability as one of their objectives.

Data of considerable detail have been available for some time from health institutions, for example on admitted patients in hospitals and residents in residential aged care. These are now being supplemented by the development of comparable data on services provided in other settings; for example, patients in hospital emergency departments, community-based mental health, palliative care, and alcohol and other drug treatment services. A regular AIHW survey of general practitioners, the BEACH program, provides data on the health conditions of their patients and the services they provide in response.

Despite recent efforts, there is still a great demand for further work to harmonise existing data collections and to develop data from other sectors such as rehabilitation and many allied health services. The development of comparable data is assisted by the existence of the *National Health Data Dictionary*, which provides standards in definitions, classifications and collection methods. In addition, the use of more than one data set together to support integrated health services also requires the capability and ethically agreed protocols to link data sets, including protocols for the construction and use of unique patient identifiers.

## Safety and quality in health care

The National Health Information Management Group's publication on health information development priorities noted that reliable national information on the safety of health services was not readily available (NHIMG 2003:18). For example, there are no accurate statistics on the number of preventable adverse events in Australian hospitals. Hospital data do include information on diagnosis and external causes of injuries and poisoning that provide some indication that an adverse event might have occurred. However, the data are incomplete as some adverse events can be coded to categories that may not indicate such an event, for example accidental poisoning (AIHW 2002:294). Data on maternal mortality and morbidity are not regularly reported and are inadequately analysed, although there are recent efforts to make improvements in this area of work.

The lack of data on safety in health care is more severe in other sectors such as aged care and community-based health care, including general practice. In 2000, AHMC established the Australian Council for Safety and Quality in Health Care to lead national efforts to improve the safety and quality of health care provision in Australia. The Council releases a regular national publication on patient safety (ACSQHC 2003). While efforts are focused on what providers and consumers should do to improve clinical safety, one of the Council's objectives is to promote high-quality information collection and analysis to understand the nature and level of adverse events to inform clinical safety. This includes supporting all jurisdictions to report on a common set of sentinel events, making better use of hospital data to measure adverse events and supporting the development of electronic health information to provide support for clinical decisions and better communication between clinicians.

## Information technology and health

Rapid advances in information and communications technology are changing the way health services are provided. These advances can significantly improve the collection, transmission and retrieval of clinical and demographic information to enable a more seamless continuity of care for better health outcomes.

A research program is being undertaken by the HealthConnect Program Office, an initiative of AHMC, to study the feasibility of establishing a network of national electronic health records that makes use of advanced technology. Although the primary objectives are for clinical use, such a network has the potential to provide statistics for research and policy use. Some of the statistical issues in the use of information from electronic health record systems are discussed later in this chapter.

## Population health and equity and access

Recognising that good health is not equally shared in the population, monitoring the health status of and access to health services by different population groups is a focus of all Australian jurisdictions. The National Public Health Partnership has established a working group, the National Public Health Information Working Group, to develop and promote the collection and analysis of routine health monitoring data that are nationally comparable and that can be used to monitor population health across the country. To this end, the National Public Health Information Working Group released a second National Public Health Information Plan. The priorities of the plan include the development of surveillance and monitoring strategies for communicable diseases and their risk factors, as well as developing environmental indicators (NPHIWG 2004).

The National Health Priorities Action Council (NHPAC) also promotes the use of indicators to monitor the progress of government-initiated strategies in the priority areas. These strategies all include, as a key aim, the reduction of inequality in health status and access to services.

Large-scale national surveys, such as those conducted by the ABS and AIHW, state surveys using computer-assisted telephone interview (CATI) techniques as well as disease registers maintained by the AIHW, all provide data that can be used to analyse health inequalities. These collections provide data on health behaviours such as alcohol consumption and smoking as well as self-reported and measured weight and height. Routine health administrative data, such as hospital data, provide information on the differences in service use by population groups.

Work is needed to harmonise data from ABS surveys and state-based CATI health surveys and to agree on a set of national indicators of health risk factors. The particular areas of concern are measures of physical activity and inactivity, the inclusion of teenagers aged 14 to 17 years of age in measures of tobacco smoking and alcohol consumption, and the use of 'measured' data for height and weight in addition to self-reported data (AIHW 2003c).

However, there has not been an official national survey of sufficient size that collects biomedical samples to give reliable and accurate measurements of blood glucose, cholesterol levels and other key biomedical markers. Thus, in terms of the progressive stepwise approach to surveillance of non-communicable diseases proposed by the World

Health Organization (WHO) (Bonita et al. 2001), Australia has collected data on the first two steps, self-reported health behaviour and self-reported height and weight, but has not progressed to the third and final step of collecting national biomedical measurements.

Recognising that the lack of data on biomedical measurements is an information gap, the Australian Government Department of Health and Ageing, the AIHW and the ABS conducted a pilot study of such a survey in 2003 (Box 7.1). The pilot study was based on a proposed linking of the measurement survey to the ABS National Health Survey and involved the taking of blood samples in pathology laboratories. The pilot study achieved an unacceptably low response rate (proportion of people agreeing to take part), and revisions to the protocols and re-testing will be necessary to ensure a successful survey of this type.

### **Box 7.1: Pilot study of an Australian Health Measurement Survey (AHMS)**

#### **Background**

*In 2002, AHMAC endorsed a pilot study of a survey to collect information on physical and biomedical measures of health status and risk factors with a view to conducting the survey in conjunction with the 2004–05 ABS National Health Survey, subject to adequate response rates and availability of funding.*

*This pilot study involving about 970 adults and children (aged 2–74 years) was conducted in Adelaide and Victoria in early 2003. The study's main aims were to test operational aspects and response rates, including the effect on response rates of the requirement to fast for a blood test.*

#### **The pilot study**

*There were three main stages in the pilot:*

- a standard National Health Survey interview in the home*
- a second home visit to take physical measurements and collect other data*
- a visit to a pathology collection centre for the collection of blood and urine samples.*

#### **Outcome**

*Operationally, the survey protocol worked well although response rates were not high. Around 64% of eligible people signed a consent form to participate in the AHMS. Just under 60% of those invited to attend a pathology collection centre did so, and the response rate was higher (although the difference was not statistically significant) among those asked to fast (62%) than those not asked to fast (54%).*

*Taking into account the households that did not respond to the National Health Survey component and those individuals who declined to be contacted about participating in the health measurement component gives a 'bottom-line' response rate of 23% for the blood sampling.*

*Because the response rate was relatively low and there was a lack of identified funding for further development for the main survey, it was decided not to proceed with the proposal to link a health measurement survey to the 2004–05 ABS National Health Survey. The case for a health measurement survey is still strong, however, and opportunities are being sought for linking it with current government priorities.*

## Health labour force

Data on registrable medical and allied health professionals are produced by AIHW to meet requirements for health labour force planning. Labour force planning is coordinated by the Australian Health Workforce Officials' Committee. Important structural changes are occurring to the health labour force, and there are significant and long-standing labour shortages in many health professions. These add to the requirements for more detailed and more up-to-date labour force data.

In recent years, as policy interest in this area has increased, all jurisdictions are working to improve the timeliness and quality of data. The nursing labour force collection has been redeveloped and national processing put in place. Similar work in other labour force collections is planned.

## Performance of the health system

The National Health Performance Committee (NHPC) has finalised the 2003 report on Australia's health sector performance (NHPC 2004). This is the second report based on the National Health Performance Framework adopted in 2001. The framework consists of three tiers: health status and outcomes, determinants of health and health system performance (NHPC 2001). Indicator sets were selected to measure aspects of each of the three tiers and in 2003 the set was revised and expanded.

While the NHPC framework and the indicator set have been developed for the NHPC national report, their potential is being promoted for use by states and territories and by other bodies. The NHPC intends to publish its national reports every two years and, in between, to use the framework to report on special interest areas. The NHPC also intends to extend its work into benchmarking best practices in acute care and primary health care.

Activities of the NHPC help to identify data gaps and comparability problems, and have an effect on future data development plans.

## Standards and classification

Under the National Health Information Agreement, considerable improvements have been made in developing and using common definitions and classifications of data items. This improvement has been particularly significant in supporting the establishment and use of national minimum data sets such as the Hospital Admitted Patient Care and Community Mental Health data sets. New minimum data sets are introduced as required and have expanded the *National Health Data Dictionary*.

To help develop an electronic health record network for clinical care purposes, the *National Health Data Dictionary* and its repository, the AIHW Knowledgebase, were reviewed and expanded. As part of this expansion, the HDSC (previously the National Health Data Committee) worked with Standards Australia and accepted for inclusion in the *National Health Data Dictionary* a specification of data elements that can help to identify health clients. Standards Australia is similarly developing specifications for identifying health service providers.

The expansion of the *National Health Data Dictionary* has also included disease-specific standard data set specifications for use by clinicians. Two such data set specifications were accepted as standards and were published in Version 12 of the *National Health Data Dictionary* in 2003—the National Cardiovascular Disease (Clinical) and the Diabetes (Clinical) data set specifications.

The OECD continues to refine its international System of Health Accounts. This system is designed to provide a standard conceptual basis for reporting expenditure on health care by functions of care, providers of health care and sources of funding (OECD 2000). An OECD publication presenting results of national accounts that employ the standard is expected to be released in 2004, and will provide guidance for further improvements in data quality.

Work on standard health classifications has also progressed. Australia is committed to using international standards where they are sufficient to Australia's needs. The International Classification of Diseases (ICD) and the International Classification of Functioning, Disability and Health (ICF) are the two reference classifications in the WHO Family of International Classifications (WHO-FIC), and they are also included in the Australian Family of Health Classifications. Australia has adopted the latest version of the ICD for the compilation of mortality and morbidity statistics, with an Australian modification of the ICD-10—the ICD-10-AM—being used for Australian hospital statistics. Following World Health Assembly endorsement of the ICF, AIHW has developed an Australian user guide to promote the use of the ICF in Australia (AIHW 2003a). Australia is an active participant in the WHO Collaborating Network on the Family of Health Classifications. Australian work in classifications, through the Classification and Terminology Working Group, is expected to contribute to the WHO Collaborating Network program. In October 2003, the International Classification of External Causes of Injury, the Anatomical Therapeutic Chemicals Classification and the ISO 9999 Technical Aids for Persons with Disabilities were included in the WHO-FIC. It is expected that these will also be included in the Australian Family of Health Classifications.

## Management of health information

The 2002 Health Information Development Priorities (NHIMG 2003) noted that the basic elements of a good-quality statistical system include best practice guidelines, protocols and standards for data development, collection, compilation, analysis and dissemination. It also noted that there are significant community and professional concerns to ensure any use of electronic records and data linkage safeguards privacy and meets appropriate ethical guidelines.

The SIMC has begun a series of audits of the quality of national data collections against users' requirements and agreed data standards. An audit of the hospital Admitted Patient Care National Minimum Data Set was conducted in 2002–03 as the first of such audits. A planned revision of this national minimum data set will be informed by results of this audit as well as new requirements arising from the signing of the new 2003–2008 Australian Health Care Agreements. The National Perinatal Statistics National Minimum Data Set is being audited and the next to be audited will be the hospital Admitted Patient Mental Health Care National Minimum Data Set.

The National Health Information Agreement aims to reduce duplication in data collection and to ensure data collections complement each other. The complementarity among data collections is demonstrated in the consistent use of data definitions and classifications in many related data collections. One example is the ABS Survey of Disability, Ageing and Carers and the AIHW collection of service usage data provided under the Commonwealth/State Disability Agreement. Another is the AIHW National Drug Strategy Household Survey and the routine state and territory data collection on the use of alcohol and drug treatment services. In both examples, administrative data on service use can be analysed in the context of need that is indicated in the related surveys.

However, there is still some duplication in data collection. For example, states and territories provide essentially the same data on hospital admitted patient care to the Australian Department of Health and Ageing under the Australian Health Care Agreements and to the AIHW under the National Health Information Agreement. There is a duplication of effort and a likelihood of inconsistencies arising from differences in the data provided and data processing details, although both collections follow the specifications of the *National Health Data Dictionary*.

Managing data linkage is also a function of the National Health Information Agreement. Linking data from more than one source is becoming increasingly important as an analytical tool. At the AIHW, cancer incidence data are linked to death data to calculate cancer survival rates. In 2002–03 a project was conducted on the flow of people from hospitals to residential aged care services and vice versa using linked data (AIHW 2003d). A more detailed study of the movement of long-stay hospital patients is being undertaken jointly by the Australian Government Department of Health and Ageing and the Western Australian Department of Health. This work provides de-identified linked health data to Australian institutions for approved research projects. Ethics committee approval is required for each project.

The five-yearly National Census of Population and Housing is a very rich source of data that could be linked to other data to yield very important longitudinal epidemiological information. For example, linking census data to mortality data for the Indigenous population could yield a much better estimate of Indigenous mortality than relying on imperfect Indigenous data from death registration and population estimates. Also, linking Indigenous census records between two censuses could throw much light on the dynamics of Indigenous identification at censuses. Submissions have been made by various organisations to the ABS to retain census records for these and other epidemiological purposes.

The potential of using linked data for statistical and policy research is immense and the National Health Information Management Group (now SIMC) has developed guidelines for data linkage and for the use of linked data.

## 7.3 Health indicators

The availability of the considerable amount of quality health statistics in Australia has allowed the construction of many sets of health indicators to meet various requirements. In many cases, the need for indicators has driven the development and collection of data; in many others, indicators were developed using existing data. As

indicated above, the NHPC has selected a range of indicators to measure the performance of the whole health system. In addition to the NHPC indicators, various agencies and committees have selected indicators to measure the progress of their particular aspects of the health system.

Indicators on hospital performance are published by the AIHW in its annual *Australian Hospital Statistics* (AIHW 2004) and by the Steering Committee for the Review of Commonwealth/State Service Provision in its *Report on Government Services* (SCRCSSP 2004). The Australian Health Care Agreements 2003–08 also provide for the publication of indicators of hospital performance by the Australian Government Department of Health and Ageing.

Another important use of health indicators is the assessment of the expenditure on and burden of diseases. In 1994–95 the AIHW published the first Australian study of the direct expenditure on diseases. In 1995–96 the first study on burden of disease, containing estimates of years of life lost and non-fatal consequences of disease, was also published by the AIHW (AIHW: Mathers et al. 1999). The disease expenditure work has been updated by the AIHW and is reported in this publication. The burden of disease work is being updated jointly by the AIHW and the University of Queensland.

Indicators are also developed and used in many specific health sectors. In 2002, the National Public Health Partnership undertook a project to develop public health indicators for the regular health performance report by the NHPC. Further work is also being undertaken to refine and expand on this preliminary set of public health indicators (NPHP 2002).

The health conditions of the population and services provided in the National Health Priority Areas are also monitored routinely through the use of indicator sets that are developed and endorsed by the respective expert advisory groups of these priority areas. In the cancer priority area, indicators are developed for general monitoring and also for monitoring specific cancer screening programs. Indicators for each of the priority areas are reported in this publication and are summarised in the Appendix. Indicators for arthritis and musculoskeletal conditions, a new priority area identified in 2003 by AHMC, are also being developed. The National Health Priority Areas expert advisory groups are also developing indicators that track the progress of the strategies adopted. These indicators, called strategic tracking indicators, provide information on the development, implementation and outcomes of a strategy or program.

Indicators were also developed, and are used, for monitoring child and youth health. In 2002 AIHW published a comprehensive report on the health and wellbeing of Australia's children based on a framework of indicators endorsed by AHMAC. Similarly, in 2003, the AIHW published a corresponding report on Australia's youth. Both the indicator sets for children and youth were based on the National Health Performance Framework.

A discussion paper containing examples of environmental health indicators was issued by enHealth Council in 2002 (enHealth Council 2002).

These uses of statistical health indicators illustrate the importance being placed on objectively measuring progress. The need for indicators is a driving force for the development of health data sets and statistical infrastructure in Australia.

## 7.4 Information development in several areas

The past two years have seen considerable effort in the development of new data sets or the revision of existing data sets to provide quality data for administering health programs and services. Three national minimum data sets were developed or revised, and were endorsed by the National Health Information Management Group under AHMAC. And, for the first time, two clinical data set specifications for use by clinicians—diabetes and cardiovascular diseases—and a data set specification of data items to be used for client identification have also been developed and endorsed for inclusion in the *National Health Data Dictionary* (NHDC 2003b). Incorporating clinical data standards into the *National Health Data Dictionary* will help the standardisation of terms used in clinical settings and should help improve the delivery of patient care and the production of management information and national statistics, thus supporting the electronic health record agenda.

These developments are described below.

### Hospital emergency department

While comprehensive national data on hospital care provided to admitted patients are available and being improved, only very limited data are available nationally on care provided to non-admitted patients. The lack of comprehensive non-admitted care data has been a barrier to understanding the complex interface between admitted hospital care, emergency hospital care, and community general medical practice. In 2001–02 the Commonwealth Department of Health and Ageing, in conjunction with the states and territories, initiated a project to develop a standard set of data elements on hospital emergency care. Important data elements include the triage category of the patient, waiting time to service delivery, duration of emergency care episode, and information about arrival mode and separation destination. An important data element not yet included in the data set is the nature of the health problems that caused the hospital emergency visit. This data element is being developed for inclusion in 2004–05.

This data set has been implemented from July 2003 in principal referral hospitals, specialist women's hospitals and children's hospitals, and large hospitals in major cities and regional and remote areas.

### Community mental health

Since 1993, under the National Mental Health Strategy, Australia has undertaken a national approach to mental health reform. A major area of reform has been the reduction and closure of institutions and their replacement by residential and non-residential care in the community. During this time, there has been substantial development of mental health information covering community-based care. Data on community mental health establishments became available in 1998–99 and data on their patients were collected for the first time in 2000–01. The National Minimum Data Set for Residential Mental Health Care was developed in 2002 and 2003 to collect information on staffed community-based residential services. This data collection is scheduled to start in July 2004.

During the development process, relevant data definitions contained in the hospital-based Admitted Patient Care National Minimum Data Set were reviewed and related

data items harmonised with those in the residential mental health care data collection. Data definitions and collection methods were designed to take into account the special nature of residential mental health care, for example extended stays.

## Medical indemnity

Medical indemnity for health professionals has become a prominent policy issue over recent years. However, despite the high level of policy and public interest in medical indemnity, there is relatively little information available about the number, nature and size of medical indemnity claims in Australia.

At the Medical Indemnity Forum in April 2002, AHMC agreed that urgent work was needed on a range of medical indemnity issues, including the establishment of a 'national database for medical negligence claims', to help determine future medical indemnity strategies. The Medical Indemnity Data Working Group was convened under the auspices of AHMAC and was commissioned to develop a national medical indemnity collection for the public sector.

The primary purposes of the collection are to:

- obtain ongoing information on medical indemnity claims and their outcomes;
- provide national data to identify trends in the nature, incidence and cost of medical indemnity claims; and
- provide data to assist the development of measures to minimise the incidence of medical indemnity claims and the associated costs.

In late 2003, the health authorities in all states and territories started sending data to AIHW for national collation and reporting. It is intended that, in future, the scope of the collection may be broadened to include private sector indemnity claims handled by medical defence organisations.

## Alcohol and drugs treatment

The Alcohol and Other Drug Treatment Services National Minimum Data Set covers community-based and non-admitted hospital-based alcohol and drug services in all states and territories. The data set was developed in 1998–99 after reviewing existing data collection practices and procedures. In December 1999, the National Health Information Management Group endorsed the Alcohol and Other Drug Treatment Services National Minimum Data Set and data collection began on 1 July 2000. Data elements of the data set include characteristics of the clients, including type of drugs used, type of treatments provided, duration of treatment and information about the agency that provided the service. Data from this collection can be analysed together with data from the National Drug Strategy Household Survey to shed some light on the extent that treatment services meet the potential demand.

In 2002–03, a review of the data elements was undertaken based on the experience in the collection of the data and changes in requirements. Changes were made to the categories of principal drugs of concern, descriptions of treatment types and reasons for cessation of treatment. These changes were endorsed and the new version of this data set was included in the *National Health Data Dictionary*.

## Health care client identification

The ability to uniquely identify individuals is critical to the provision of care. Accurate client (and provider) identification is crucial to any promotion of an e-health environment.

Australia does not have a population register and a unique personal identification system. A number of identification systems exist in different sectors (for example the tax file number system for taxation purposes and the Medicare number system for Australian Government reimbursement of medical and pharmaceutical fees). The Health Care Client Identification Data Set Specification is a standard set of data elements that would assist positive client identification in view of the lack of a unique personal identification system.

Standards Australia has published a standard called Health Care Client Identification in 2002 (SA 2002). In conjunction with the HDSC, this standard was updated and revised by Standards Australia in 2002–03 and was incorporated into Version 12 of the *National Health Data Dictionary*. The standard consists of a set of data elements including names, addresses, date of birth and other personal characteristics of patients. The data set does not include biometric elements.

A related data set specification on health service provider identification is being developed by Standards Australia International in cooperation with the HDSC.

## Diabetes clinical data

There has always been recognition that disease-related epidemiological data, in particular outcomes data, can help to inform clinical management. In 1993, a set of data elements was agreed at a New South Wales Diabetes Outcomes Workshop to form the initial diabetes clinical data set. This was later modified to be consistent with the 1996 New South Wales Diabetes Clinical Management Guidelines. Based on the specifications of this data set, collections were undertaken between 1998 and 2002 for both clinical, audit and benchmarking purposes. Further modifications were made to the specification and the resultant data set specification was endorsed in 2003 for incorporation in the *National Health Data Dictionary*.

The Diabetes (Clinical) Data Set Specification contains more than 40 clinical data elements. Many of these elements are diabetes-specific and some are general and also relevant to other diseases, for example risk factors such as excessive weight, raised blood glucose and high cholesterol levels (NHDC 2003a). These general clinical data elements are in addition to the usual demographic and service administration-related data elements. The National Diabetes Data Working Group, which developed the data set, is promoting its use among clinicians.

## Cardiovascular diseases clinical data

The Cardiovascular Disease (Clinical) Data Set Specification was developed by a working group called the CV-Data Working Group, initiated by the National Heart Foundation of Australia and the Centre for General Practice Integration Studies at the University of New South Wales. The development is supported by a range of cardiac and related clinical groups such as kidney and diabetes specialties as well as general practice.

The goal was to develop a nationally recognised clinical minimum cardiovascular data set that would support quality cardiovascular care. The data set comprises evidence-related data elements relevant to the prevention and outcomes of vascular health. These include definitions of patients' demographics, cardiovascular disease risk factors (behavioural, biomedical, social), clinical history and management characteristics. The data set also includes definitions relating to diabetes and renal impairment, in recognition of the strong relationships between these conditions and cardiovascular diseases.

Certain general clinical data elements exist in both the diabetes and the cardiovascular disease data set specifications. These have been made consistent between the two. After considerable consultation among cardiovascular clinicians, the Cardiovascular Diseases (Clinical) Data Set Specification was finalised and incorporated into the *National Health Data Dictionary* in 2003. Further data development work is being undertaken in this field, and a clinical data set specification is being developed for acute coronary syndrome (heart attacks and unstable angina) treated in hospitals.

## 7.5 Major national survey initiatives

### ABS surveys

The ABS has a comprehensive household survey program on health status and health service use. Following a review of its household survey program, the ABS has introduced an expanded program of surveys that collect health data. All health-related surveys collect information on individual demography and geography.

The 2001 National Health Survey collected information about the health of the population including long-term medical conditions and recent injuries, the use of health services, health-related aspects of lifestyles, and demographic and socioeconomic characteristics. The survey covered both urban and rural areas in all states and territories but sparsely settled areas were excluded. The next survey is scheduled for 2004–05.

The ABS has previously collected health information on the Indigenous population in 2001 as a supplement to the National Health Survey. A larger sample is planned for 2004–05 with the commencement of a six-yearly Indigenous Health Survey to coincide with every second National Health Survey. A disability module was included in the Indigenous General Social Survey conducted in 2002.

The Survey of Disability, Ageing and Carers (six-yearly) covers activity limitations and participation restrictions resulting from health conditions as well as information on the use of formal and informal care. This survey gives estimates of the prevalence of disability. The most recent survey was conducted in 2003 (the fifth in the series) with results expected in 2004. Because of the limitations of the size of the sample and the relatively low prevalence levels of disability, the survey does not generate accurate estimates of disability at small area levels, including smaller states and the two territories. The ABS is investigating ways to collect some disability information from the next Census of Population and Housing in 2006 to assist planning of disability services at local levels.

Along with other social data, the four-yearly General Social Survey also includes questions on self-assessed health status and the six-yearly Indigenous Social Survey, first conducted in 2002, contains questions on smoking, alcohol consumption, substance use and disability.

## AIHW and other national surveys

In addition to ABS surveys, the AIHW, on behalf of the Australian Government Department of Health and Ageing, conducts a regular (two- to three-yearly) household survey on tobacco, alcohol and drug use. This survey collects detailed data on the patterns of smoking, alcohol and illicit drug use in Australia, providing basic time series information to help monitor government policies and programs on drugs. It also contains questions on community awareness of drugs, and views on government drug and alcohol policies. The next survey is scheduled for 2004.

Most state and territory governments conduct health surveys using CATI to collect timely data on risk factors, disease patterns and use of health services. The National CATI Health Survey Technical Reference Group has been established under the National Public Health Partnership to encourage harmonisation of survey questions and methods for topics such as behavioural risk factors and chronic diseases. The Reference Group has published background papers on the development of survey questions relating to alcohol consumption, asthma, cardiovascular diseases, diabetes, food behaviour, physical activities and tobacco consumption as well as selected demographic characteristics (CATI TRG 2003a). National data will become available when all CATI surveys use a standard set of questions and Tasmania and the two territories are able to conduct these surveys themselves or commission other states to do the collection on their behalf.

A national survey of general practice activities has been conducted since 1998 by the AIHW's General Practice Statistics and Classification Unit at the University of Sydney. Called BEACH—Bettering the Evaluation and Care of Health—it is a continuous survey of about 1,000 general practitioners (GPs) each year. It is supported by funds from the Australian Government Department of Health and Ageing and from a number of pharmaceutical companies.

The GPs are recruited on a 'rolling' basis, each participant providing details about 100 consecutive GP-patient encounters. This produces an annual database pertaining to about 100,000 encounters, and in total the database now includes about 600,000 records.

Data collected in the survey include patient characteristics, patient reasons for encounter, problems managed and treatments including details of prescriptions. In sub-samples of encounters other topics are investigated, including patient risk factors such as body mass index, smoking behaviour and alcohol intake, and special interest topics.

A national physical activity survey was conducted in 1997, 1999 and 2000 with the support of the Australian Government Department of Health and Ageing and the Australian Sports Commission. The survey is a telephone interview survey that collects detailed data on physical activities for the week before the interview. These include walking for recreation, exercise or work, gardening, and all types of physical exercise (AIHW 2003c). The activity questions used in this survey are being used in several state telephone interview surveys.

Oral health surveys are conducted regularly by the AIHW's Dental Statistics and Research Unit at the University of Adelaide.

The Child Dental Health Survey has been conducted annually since 1977 on the state of oral health among Australia's school-aged children who receive care at state/territory school dental services. Information collected includes experience of dental decay (decayed, missing and filled teeth), provision of preventive fissure sealants, frequency of dental examinations in school dental services and demographic characteristics.

The Adult Dental Programs Survey, conducted in 1995–96 and 2000–01, collects information on the state of oral health of Australia's adults who are eligible for public-funded dental care provided through state and territory public emergency and general dental services. Information collected includes experience of dental decay (decayed, missing and filled teeth) and periodontal (gum) disease. A proposal is being made for an update of this survey in 2005–06.

The National Dental Telephone Interview Survey monitors changes in basic features of oral health, dental care and access to dental services in the Australian population. This survey has been conducted in 1994, 1995, 1996, 1999 and 2002. The next survey will begin in July 2004. Information collected includes self-reported oral health status, edentulism, self-reported number of remaining teeth, oral self-care, fluoride exposures, availability and use of dental services, dental insurance and eligibility for public-funded dental care.

The National Survey of Adult Oral Health collects information on the experience of dental decay (decayed, missing and filled tooth surfaces), periodontal (gum) destruction (periodontal recession and pocket depth), dental plaque and oral mucosal lesions. This survey includes dental examination by oral clinicians and telephone interviews that ask sampled adults about their preventive dental practices, access to dental care and socio-demographic background. Patterns in population oral health are analysed, including regional and socioeconomic differences and caries experience in adults with varying exposure to water fluoridation. The survey also examines the association of cardiovascular disease with periodontal disease. The first survey of this type was conducted in 1987–88 and the next is scheduled for 2004–05. Data from the 2004–05 survey will allow changes since 1987–88 to be evaluated.

## Gaps in surveys

Despite these efforts in survey development, there are three notable gaps in health survey information in Australia.

One is the lack of up-to-date information on diet and nutrition. The ABS and the then Commonwealth Department of Health and Family Services conducted the last survey of diet and nutrition in 1995, and there is no current plan to conduct another one. Given the clear link between nutrition and a range of diseases and the current policy imperatives in promoting healthy weight and to reduce the level of obesity in the population, this deficiency in food and nutrition intake data is a serious gap in the health statistics system in Australia. Indirect estimates using agricultural production data are affected by the quality of the basic data and the assumptions made for the estimation (AIHW: Field et al. 2003). These indirect estimates are only substitutes for survey data of actual eating habits and food intake. The ABS has indicated that it does not intend to continue its food consumption report based on production statistics.

The second serious gap is the lack of national information on biomedical health risk factors. Biomedical measures of population health include blood sugar and cholesterol levels and these have been included by the WHO in step 3 of a 3-STEP risk factor surveillance system that would provide important core indicators of the population health of a country (Bonita et al. 2001). There has not been an official Australian national survey that includes biomedical measurements, although a one-off survey was conducted by the International Diabetes Institute in 2000 (Dunstan et al. 2002) which provided base line data on the prevalence of diabetes, obesity and other cardiovascular disease behavioural and biomedical risk factors. In an effort to develop an ongoing monitoring system, a pilot study for a national biomedical risk factor survey was conducted in 2003 (see Box 7.1). Other comparable countries (United States of America, England and New Zealand) have well-established programs and a large survey is being implemented in Canada.

The third gap is the lack of an up-to-date survey on mental health status. The last ABS mental health survey was conducted in 1997, and there is no plan to conduct another one, although the three-yearly National Health Survey contains some information on mental health status and wellbeing.

## 7.6 A network of electronic health information

In 2001, Australian, state and territory governments commenced a two-year research and development project, known as *HealthConnect*, to assess the feasibility of a national electronic health record network. The concept of a national health information network was proposed by the National Electronic Health Record Taskforce in its 2000 report to AHMC. The project is undertaken by the *HealthConnect* Program Office, located in the Australian Government Department of Health and Ageing.

Under this concept, summary health-related information about an individual would be collected in a standardised electronic form at the point of care. With the consumer's consent, this summary information can then be accessed by authorised health service providers when and where it is needed for clinical care.

By combining disparate sources of health information into a comprehensive health record, both providers and consumers will have more rapid access to personal health information needed for clinical decision making. Efficiency gains are anticipated both through reductions in the time currently spent in gathering information held in other organisations across the health sector, as well as a reduction in pathology and diagnostic tests repeated unnecessarily in the absence of ready access to previous results.

Another potential benefit is the possibility of producing timely and quality statistical information. However, this would depend on the purpose of the statistical data generated from such a network. Data for program or service monitoring and health surveillance need to be representative, at any geographic level or for any particular population grouping. The proposed 'opt-in' basis of the information network could limit its statistical potential unless a very high participation rate can be achieved. Another potentially limiting factor could arise from the range of information included in the summary electronic record: the range of information required for statistical applications may be different from that included in the clinical summary record. In

addition, for the data contained in the summary record to be useful statistically, they need to be collected according to national standards and of sufficient detail for standard health classification.

In the past two years, *HealthConnect* work has progressed. In 2000–01, a business architecture document was developed for wide consultation, and Version 1.0 of this architecture was released in 2002. Based on business requirements contained in this document, a systems architecture was drafted and issued in 2003 for consultation. Proof-of-concept trials were fast-tracked in Tasmania and the Northern Territory, with longer-term trials in several sites in New South Wales and Queensland to test various aspects of the network.

The *HealthConnect* Program Office has released an Interim Research Report covering its findings from the first phase of the project (*HealthConnect* Program Office 2003). Health Ministers agreed in November 2002 to fund a further two years of research and development work including further trials, examination of cost issues and finalisation of the *HealthConnect* design. More recently, as part of its Medicare-Plus Package, the Australian Government committed funds for *HealthConnect* for the next three years, commencing with state-wide rollouts of the *HealthConnect* integrated medical records system in Tasmania and South Australia.

## 7.7 Future directions

The new health information governance arrangements have important implications for the future development of health information and statistics. By bringing together statistical and information technology aspects of information, the new governance arrangements will enable a more integrated approach to information development and management. The relationships between clinical information required by health providers, health information required by patients and statistical information required by policy developers and program managers will be better understood and managed. Efficiency will be gained if data collected at the clinical level can be used many times by clinicians, clients and government agencies for their different purposes. Work is required to document clearly information requirements and to ensure data standards are endorsed and applied consistently in different settings to enable data comparability and consistency. The ability of information systems developed for clinical purposes, such as those under *HealthConnect*, to provide higher level statistics will be critical in achieving any efficiency gain.

Considerable work is being done on improving the quality of data on Indigenous health. Progress, however, has been slow. Until good-quality Indigenous administrative data are available for a period of time, there will be difficulties in monitoring the health status of the Indigenous population and in drawing conclusions on whether Indigenous health is improving. Because a substantial proportion of the rural and remote population is Indigenous, improvements in Indigenous health data will also enable a better understanding of the health status of the non-Indigenous population in these areas.

Efforts to harmonise state and territory health CATI surveys can be expected to result in usable and up-to-date national health surveillance data, including broad measures of health status and behavioural risk factors. The National Public Health Information Working Group can play an important role in accelerating this development.

With the development of national minimum data sets in the various health sectors, there are opportunities to undertake more detailed analyses on issues that cut across different health sectors. For example, new national data from hospital emergency departments can be used jointly with data from the AIHW general practice survey and hospital inpatient data to understand the relationship between and the level of use of each of the three services. Similarly, AIHW general practice survey data can supplement Health Insurance Commission data on medical services and prescriptions and provide estimates of the health problems treated and funded by the Medicare and Pharmaceutical Benefit Schemes.

The lack of up-to-date information on food intake, nutrition and biomedical measurements is a serious gap. Measures of the levels, patterns and trends in a range of disease risk factors are therefore not available to help develop and monitor government and non-government initiatives to promote healthy behaviour.

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