Public Health Information Development Unit

Final Report

Audit of Australian Chronic Disease and Associated Risk Factor Data Collections

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2010

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Summary

This Audit was undertaken in 2008 in order to update the previous Audit of Australian Chronic Disease and Associated Risk Factor Data Collections, and was funded by the Population Health Division of the Australian Government Department of Health and Ageing (DoHA). The first Audit was undertaken during 2001 and 2002 as one part of a four-part feasibility study to investigate the development of a nation-wide behavioural risk factor surveillance system for the then Commonwealth Department of Health and Aged Care. Any such system was envisaged as encompassing data collection, analysis, and reporting, on chronic diseases and associated risk factors, as a basis for policy and intervention developments. All jurisdictions participated in this update (see *Acknowledgements*) and the two-part table prepared as *Appendix D* reflects their contributions and underpins the information presented in Chapter Three.

The current policy situation is discussed in Chapter Two (see also *Appendix A*), and the 2006 *Blueprint for nation-wide surveillance of chronic diseases and associated determinants*, prepared by the National Public Health Information Working Group, is used to detail the essential elements of a national monitoring system. The *Blueprint* cites a continuing need to develop a sustainable system to coordinate the management of data, harmonise data collection components, and provide the capacity and resources for the system to operate. Four actions are identified as necessary:

1. the establishment of a Chronic Disease Surveillance Network to develop and support the collection, analysis and dissemination of nation-wide monitoring data for chronic diseases and associated determinants;
2. reporting that combines existing data on chronic diseases and associated determinants from state and territory population health surveys, national health surveys and other sources;
3. the development of an agreed prioritised set of national policy relevant indicators for chronic disease and associated determinants; and
4. capacity building – developing national standards and an adequate and sustainable workforce for health monitoring, including sharing infrastructure, skills and knowledge.

Chapter Three outlines the existing chronic disease and associated risk factor time series collections in Australia. The first section, *Australian time series data collections* details the major collections, compares the national health surveys with the state population health surveys using computer assisted telephone interviewing (CATI) (*Appendix B* provides more information), relates the advantages and disadvantages of each, and discusses some issues arising:

- the rising participant burden of household surveys;
- increasing need for small area data;
- increasing demand for timely, more rapidly released data;
- extensions to the use of existing data collection vehicles;
- the potential effect of learned social responses on survey responses; and
- the need for standardised reporting of response to enable easier comparison (*Appendix C* provides a worked example of different calculations).

The last section, *Linked data sets*, describes recent developments at the national and state levels and uses information on the WA Data Linkage System to examine advantages and disadvantages of data linkage, and the possibility of an additional direction for the future of chronic disease and associated risk factor data collections. Lastly, *Appendix D* provides detailed information on relevant data collections that includes details of population coverage; time series and frequency; number in, and method and mode of, collection; and ability to disaggregate by age, sex, Indigenous status, ethnicity, socioeconomic status and geographical area of residence.

Positive findings since the first Audit include:

- the ABS National Health Survey is now conducted on a triennial basis, with a dedicated Indigenous health survey, the National Aboriginal and Torres Strait Islander Health Survey, conducted on a six-yearly basis, and access to data has been enhanced;
- the state-wide population health surveys using CATI are well established and the various activities carried out in support of nation-wide harmonisation and data pooling have consolidated their potential; and
- data linkage systems and capabilities have been substantially developed, both nationally and in all states and territories, with more to come.

Major gaps, deficiencies and concerns include:

- the continuing lack of a dedicated national monitoring system on chronic disease and associated risk factors and determinants;
- data gaps in integrated nutrition, physical activity, and physical and biomedical measurements remain despite some recent improvements; and
- continuing concern over the adequate coverage of the population for state CATI health surveys due to changes in telecommunications and the now five-year absence of an electronic white pages (used both for direct sampling and for list-assisted random digit dialling).

1 Introduction

Background to the Audit

The first Audit, the Audit of Australian Chronic Disease and Associated Risk Factor Data Collections, was undertaken during 2001 and 2002 as one part of a four-part feasibility study to investigate the development of a nation-wide behavioural risk factor surveillance system for the then Commonwealth Department of Health and Aged Care (for the full reports of the feasibility study, see Chronic Disease and Behavioural Risk Factor Surveillance System 2003). It was envisaged that such a system would encompass data collection, analysis, and reporting, on chronic diseases and associated risk factors, as a basis for policy and intervention developments.[1]

At the time of the feasibility study, the then National Public Health Partnership (NPHP) had only just endorsed the development of an integrated chronic disease and behavioural risk factor monitoring and surveillance system, as part of its broader strategy for the "development of a framework and national work program for the systematic collection, aggregation and use of public health information at the national level".[2:vi] There were then no integrated, nation-wide data collections in Australia that had the capacity for monitoring chronic diseases and associated risk factors; existing national health information systems focused mainly on episodes of acute disease, communicable disease or other specific disease events; the National Health Survey was conducted only once in every six years; population health surveys in most states were in their infancy; and our knowledge of basic population health chronic disease issues such as the epidemiology of established or emerging associated risk factors was meagre. Although there were many information resources that could potentially contribute to any chronic disease information and monitoring system, they were widely scattered and information was not consolidated and readily available.

The first Audit was completed with the extensive participation and assistance of officers in all the Australian, state and territory governments, the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, and a number of non-government agencies, research institutions and universities around Australia. It was published in 2003 and was, at the time that this Audit commenced, still being used by staff in a number of agencies as a resource describing the scope of, and identifying gaps in, Australian data collections on chronic disease and associated risk factors and determinants.

This Audit was undertaken in 2008 in order to update the 2001-2002 Audit, again with the assistance of officers in all Australian, state and territory governments, the Australian Institute of Health and Welfare, and the Australian Bureau of Statistics (see *Acknowledgements*).

Methodology of the Audit

The Population Health Division of the Australian Government Department of Health and Ageing provided funding to update and extend the 2001-2002 Audit of Australian data collections of relevance to chronic disease and associated risk factor information and monitoring in 2008. The purpose was to provide information to support the further development of a national monitoring system for chronic diseases and associated risk factors.

All jurisdictions were advised of the Audit update and asked to nominate a contact officer. Nominated contact officers were briefed on the Audit update and asked to prepare a return with selected details on all data collections in their jurisdictions that were identified as in-scope. A two-part table has been prepared on the basis of these returns and additional information sought where necessary (*Appendix D*), and forms the starting point for the information presented in Chapter Three.

In addition to collection-based information provided by contact officers, a range of material has been reviewed, including documentation from the National CATI health survey technical reference group (CATI TRG), and associated projects of the Australian Bureau of Statistics (ABS). A desk review was also undertaken on policies of relevance to chronic disease and associated risk factors and determinants, and additional information sought on related developments and activities. The perceptions of a small number of personnel with lengthy and/or continuing involvement in the field were also sought to provide more in-depth information on the current situation and near future directions.

It is anticipated that this Audit would be extended to include question-level data that would be published in a database, with the potential to be linked to the AIHW online metadata registry METeOR and the AIHW chronic disease indicator database. Consultations with the ABS ensured that the overlap with the *Harmonised chronic disease and risk factor statistics - state of readiness for a national approach* project was productive and that ongoing developments were incorporated into the Audit. A protocol for the periodic revision or updating of relevant data in this Audit was also envisaged.

This report presents the results of the Audit. Chapter Two begins with a review of the current policy situation in relation to chronic disease and associated risk factors and determinants, nationally and in the states and territories. Chapter Three examines the existing time series data collections nationally and among the states and territories, with a special focus on data linkage and recent developments. A number of appendices supply additional details in support of the text, with *Appendix D* presenting detailed descriptions on the data collections in the Audit.

Terminology

In this report the words 'information and monitoring' are used in preference to 'surveillance'. Surveillance is the "systematic collection, analysis and interpretation of outcome-specific data essential to the planning, implementation, and evaluation of public health programs".[3] Although surveillance has positive active connotations for some public health practitioners it also has negative connotations to lay people and can imply unwanted government scrutiny into personal aspects of life. Indigenous organisations in particular have raised concerns about the use of the word surveillance in relation to disease monitoring systems.[4] The use of terms that do not have negative connotations is increasingly important as the most vital aspect of data collections and information systems that incorporate personal information is trust that they will be used appropriately.

The words 'risk factors and determinants' are used in this report in recognition of the growing international literature showing the importance of including socioeconomic determinants (such as income) alongside traditional risk factors (such as smoking) in any discussion of chronic disease.[5-7] These broader determinants affect health through a number of pathways including: material wellbeing (access to food, shelter, clothing, heating, etc.), healthy environments (access to recreational facilities, exposure to dust in remote areas), access to services (health, transport, education) and psychosocial wellbeing (work control, social support, general levels of stress). These broader determinants are recognised as providing the backdrop for many behaviours, and many behavioural risk factors, such as smoking, are subsequently socially patterned by socioeconomic status. These determinants are therefore important when considering strategies for developing information on chronic disease. The need for inclusion of a broader range of health determinants is recognised in Australia's national and state chronic disease strategies and in international work in the area; and is reflected in the World Health Organization's establishment of the Commission on Social Determinants of Health in 2005 to address social factors - including unemployment, unsafe workplaces, urban slums, globalisation and lack of access to health systems – that lead to ill health and health inequities.[8]

2 The current policy situation

2.1 National policies

At the time of the first Audit there was no overarching national chronic disease prevention and health promotion policy that could provide a guide for action in Australia, although the need for more co-ordination in the area had been recognised in the National Public Health Partnership's Australian Health Ministers' Advisory Council (AHMAC) endorsed *Guidelines for improving national public health strategies development and coordination*.[9,10] These guidelines called for the development of a framework for a more coherent approach to chronic disease prevention. The background paper *Preventing chronic disease: a strategic framework* was subsequently developed.[10] It outlined the key dimensions for a framework and action plan for chronic disease prevention in Australia that included:

- 'clustering' of risk and protective factors, biological risk factors (or markers) and preventable conditions (Figure 1);
- systematic building of the evidence base and information systems to provide the basis for action;
- a 'whole-of-life' approach to prevention and health promotion;
- a 'whole-of-system' approach to prevention and management of conditions across the continuum of care;
- an explicit focus on addressing and reducing health inequalities; and,
- a strategic management architecture to guide action and improve coordination.10: 3-7

The background paper outlined criteria for defining priority chronic disease topics in Australia, including:

- the diseases and conditions included contribute to a significant proportion of the burden of disease, overall and/or for particular population groups;
- they can be prevented, or controlled on the basis of current knowledge;
- they share common modifiable risk factors and underlying determinants which are amenable to prevention;
- there is a strong evidence base for the inclusion of each condition, risk or protective factor, including preventive measures;
- the conditions share elements in their pathogenesis and hence are frequently present as co-morbidities in the same individual, and in population groups with similar exposures;
- the interrelationships between psychosocial factors, mental and physical health are recognised;
- there is a logical relationship between the various components;
- the areas included are compatible with other credible policy frameworks (e.g., WHO);
- there is agreement and support for what is included among key stakeholders; and,
- improvements in coordination, collaboration and integration across the nominated areas are expected to deliver benefits which outweigh the costs of doing so.[10: 29-32]

A set of priority chronic conditions defined by the criteria were reported in the strategic framework (Figure 1) and used as the basis for the conceptual framework for the Audit. The background paper was endorsed by AHMAC in 2001 as the basis for further national collaborative action.[10]

Figure 1: Preventable chronic diseases, risk factors and determinants

Risk and Protective Factors	Biological Risk Factors/Markers	Preventable Chronic Diseases and Conditions
Behavioural Factors	▪ Obesity ▪ Hypertension ▪ Dyslipidemia (disordered lipids, including elevated cholesterol) ▪ Impaired Glucose Tolerance ▪ Proteinuria	▪ Ischaemic Heart Disease ▪ Stroke ▪ Type 2 Diabetes ▪ Renal Disease ▪ Chronic Lung Disease (COPD & Asthma) ▪ Certain Cancers (e.g., colorectal, lung) ▪ Mental Health Problems/ Depression* *Possible inclusion*: ▪ Oral Health* ▪ Musculoskeletal conditions#
▪ Diet ▪ Physical activity ▪ Smoking ▪ Alcohol misuse		
Psychosocial Factors		
▪ 'Sense of control' ▪ Social support/social exclusion ▪ Resilience and emotional well-being		
Early life factors		
▪ Maternal health ▪ Low birthweight ▪ Childhood infections ▪ Abuse and neglect		
Non modifiable factors: Age, sex, ethnicity, genetic make-up, family history **Socio-environmental determinants** (may or may not be modifiable): Socio-economic status, community characteristics (e.g., presence/absence of social capital), working conditions, environmental health etc.		

* can also be defined as risk/protective factors

Musculoskeletal disorders such as osteoarthritis are not preventable on the basis of current knowledge, although some conditions are related to obesity (eg osteoarthritis of the knee); and osteoporosis is related to diet and physical activity. The major reason for inclusion is that musculoskeletal disorders affect more than a quarter of the population; and frequently present as a comorbidity with depression, and with vascular conditions in older people. There are many opportunities to improve self-management and improve quality of life for people with these conditions in conjunction with health promotion programs targeting other health problems faced by older people.

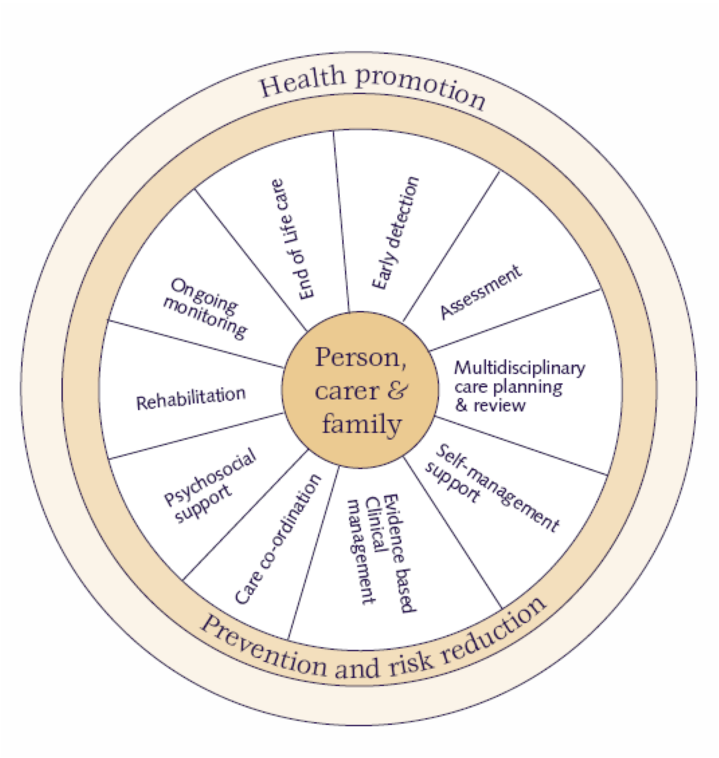
Source: NPHP. Preventing chronic disease: A strategic framework. Melbourne: NPHP, 2001, p. 31.

In 2002-03, AHMAC agreed to the development of a national strategic policy approach to chronic disease prevention and care, and the National Health Priority Action Council (NHPAC) managed the development process. Australian Health Ministers endorsed the *National chronic disease strategy* and the related supporting *National service improvement frameworks* for the national health priority areas of: asthma; cancer; diabetes; heart, stroke and vascular disease; and osteoarthritis, rheumatoid arthritis and osteoporosis; in 2005, as a national approach to chronic disease prevention and management in Australia.[11]

The primary objectives of the strategy were to:

- prevent and/or delay the onset of chronic disease for individuals and population groups;
- reduce the progression and complications of chronic disease;
- maximise the wellbeing and quality of life of individuals living with chronic disease and their families and carers;
- reduce avoidable hospital admissions and health care procedures;
- implement best practice in the prevention, detection and management of chronic disease; and
- enhance the capacity of the health workforce to meet population demand for chronic disease prevention and care into the future.11

Figure 2: Core elements of the continuum of chronic disease prevention and care



Source: NHPAC. National chronic disease strategy. Canberra: DoHA, 2006, p. 8 (adapted from NSW Department of Health. NSW Chronic Care Program Phase Three: 2006–2009, NSW Chronic Disease Strategy. Sydney: NSW Department of Health, 2006, p. 13).

The theme of strengthening activity across the continuum of chronic disease prevention and care is fundamental to these strategic objectives, together with the need for culturally safe and appropriate care (Figure 2). The strategy mandates a focus for improved outcomes across the entire continuum through committed action in all sectors and settings impacting on chronic disease prevention and care, both within and beyond the health system.[11:8] The strategy is currently being revised by the Primary Care Division in the Department of Health and Ageing (DoHA).

The *Blueprint for nation-wide surveillance of chronic diseases and associated determinants* (2006) was prepared by the National Public Health Information Working Group on behalf of the NPHP and the National Health Information Group, and has been endorsed by the Australian Health Ministers' Conference.[12]

The *Blueprint* details the essential elements of a national monitoring system, provides an *Australian priority setting tool* for agreeing information priorities (Figure 3), and identifies actions required to establish the system. It documented the positives and negatives of the situation at the time in relation to chronic disease and associated determinants. The positives included that:

- there was a wealth of existing data available (e.g., population health surveys, disease registers, administrative data collections and data from research studies);
- most states and territories had established monitoring systems that were 'to a large extent' harmonised – or had some content consistency - both with each other and with the National Health Survey and/or other national collections.[12:6]

The negatives identified were the lack of:

- a data collection dedicated to national monitoring of chronic disease and associated determinants;
- a 'system' to draw together the range of relevant data collections (that could provide information to such a monitoring system); and
- the fundamental system infrastructure (such as governance, policy context and priority-setting mechanisms, analysis and reporting frameworks) required to support such a system.[12:9]

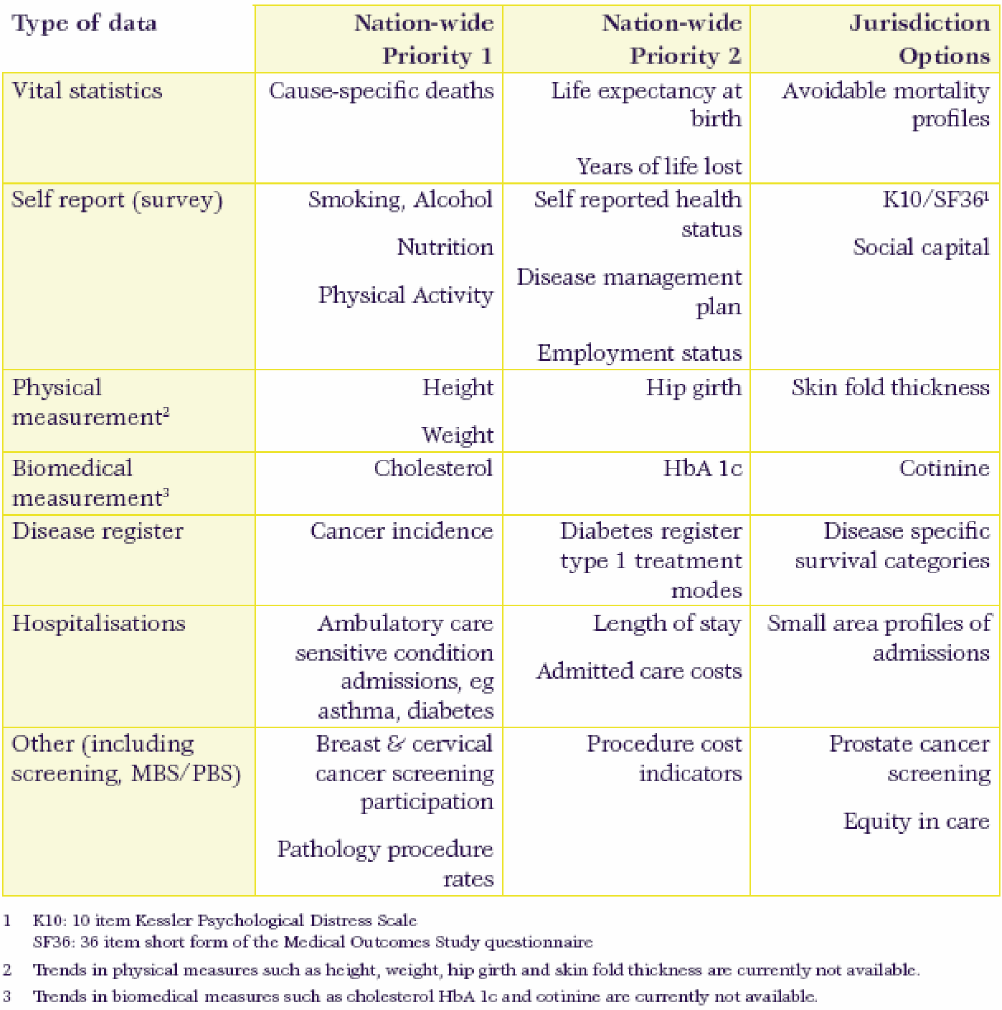
There was, therefore, a continuing need to develop a sustainable system to coordinate the management of data, harmonise data collection components, and provide the capacity and resources for the system to operate.

Ongoing issues were identified as the need for:

- consistency in content among data collections relevant to chronic disease, risk factors and determinants;
- content stability in data collections over time;
- the identification of gaps in existing information;
- timely reporting of data collected;
- availability of information on priority populations (including children, young people, older people, Aboriginal and Torres Strait Islander peoples, people from non-English speaking backgrounds, and regional population groups); and
- adequate capacity for integrated national – or nation-wide – reporting.[12:7]

Generally, and in relation to the hypothetical example developed in the *Blueprint* (Figure 3), it was noted that data gaps remained, and the necessity 'as a high priority to develop integrated data on nutrition, physical activity, and physical and biomedical measurements' as these were the 'most significantly deficient' in terms of the availability and quality of national data.[12:11,19]

Figure 3: An Australian priority setting tool: a hypothetical example



Type of data	Nation-wide Priority 1	Nation-wide Priority 2	Jurisdiction Options
Vital statistics	Cause-specific deaths	Life expectancy at birth Years of life lost	Avoidable mortality profiles
Self report (survey)	Smoking, Alcohol Nutrition Physical Activity	Self reported health status Disease management plan Employment status	K10/SF36[1] Social capital
Physical measurement[2]	Height Weight	Hip girth	Skin fold thickness
Biomedical measurement[3]	Cholesterol	HbA 1c	Cotinine
Disease register	Cancer incidence	Diabetes register type 1 treatment modes	Disease specific survival categories
Hospitalisations	Ambulatory care sensitive condition admissions, eg asthma, diabetes	Length of stay Admitted care costs	Small area profiles of admissions
Other (including screening, MBS/PBS)	Breast & cervical cancer screening participation Pathology procedure rates	Procedure cost indicators	Prostate cancer screening Equity in care

1 K10: 10 item Kessler Psychological Distress Scale
SF36: 36 item short form of the Medical Outcomes Study questionnaire

2 Trends in physical measures such as height, weight, hip girth and skin fold thickness are currently not available.

3 Trends in biomedical measures such as cholesterol HbA 1c and cotinine are currently not available.

Source: NPHP. Blueprint for nation-wide surveillance of chronic diseases and associated determinants. Melbourne: NPHP, 2006, p, 19.

Four actions were identified as necessary to implement the *Blueprint*:

1. the establishment of a Chronic Disease Surveillance Network to develop and support the collection, analysis and dissemination of nation-wide monitoring data for chronic diseases and associated determinants;
2. reporting that combines existing data on chronic diseases and associated determinants from state and territory population health surveys, national health surveys and other sources;
3. the development of an agreed prioritised set of national policy relevant indicators for chronic disease and associated determinants; and
4. capacity building: developing national standards and an adequate and sustainable workforce for health monitoring, including sharing infrastructure, skills and knowledge.[12:16-18]

Internet sites

The *National Chronic Disease Strategy* and the *National Service Improvement Frameworks:*
www.health.gov.au/internet/main/publishing.nsf/Content/pq-ncds

The *Blueprint for nation-wide surveillance of chronic diseases and associated determinants*:
www.health.gov.au/internet/main/publishing.nsf/Content/pq-ncds-bluepr

The background paper *Preventing chronic disease: a strategic framework:*
www.dhs.vic.gov.au/nphp/publications/strategies/chrondis-bgpaper.pdf

2.2 State policies

In the *NSW Chronic Disease Prevention Strategy 2003-2007*, NSW was to design, test, develop and evaluate a state-based pilot evaluation of an overarching 'integration' strategy to draw together existing programs and activities within state-wide portfolios dealing with tobacco, nutrition, alcohol, physical activity and mental health promotion, with a view to progressing state-wide implementation if evaluation results at pilot stage are favourable.[13] The *NSW Chronic Disease Strategy, Phase Three 2006–2009* is now in operation.[14]

The *Queensland Strategy for Chronic Disease 2005-2015* program evaluation recommended population tracking for outcomes and action research for process evaluation.[15] The evaluation framework comprises six key components:

- implementation process;
- health system responsiveness and supportive environments for healthy behaviour;
- intermediate-term impact;
- longer-term outcome;
- place-based initiatives; and
- economic evaluation.[15]

The evaluation planned to track changes across time in key outcome areas to allow comparison within the state between place-based initiative communities and other communities (at different stages of implementation). There would also be scope to compare data from communities outside Qld and to undertake whole-of-state comparisons. Evaluated changes would be mapped to data on changes in services and clinical practice through measures of change in individuals' behaviour, care received, and perceptions of quality and responsiveness of care.

Implementation of the strategy was perceived as a dynamic process that would occur in different ways across Qld over time. It was noted that the strategy was both complex in scope, and was not occurring in isolation from other changes in the health and social welfare system. Attribution of specific changes in outcome measures would therefore require a detailed understanding of what changed, how it changed and how it affected the prevention and management of chronic disease in Qld.

The strategy evaluation planned to use existing data sources where possible; however, in addition, seven new surveys/ studies/ interview processes were identified as needed:

1. an annual survey of key stakeholders (representative of key partners);
2. interviews with key Aboriginal and Torres Strait Islander informants (every three years);
3. a computer-assisted telephone interview (CATI) survey of people with an in-scope chronic disease (every two years);
4. a CATI survey of the general population (every two years);
5. key informant interviews with clinicians (every two years);
6. a random survey of service providers (every two years); and
7. a cohort study of people with chronic disease (annual data collection).[15]

System assessment tools such as the ABCD SAT adapted by Menzies School of Health Research for use in Australian populations were also considered useful.[16]

The *Northern Queensland Indigenous Chronic Disease Strategy* and the *Northern Territory Preventable Chronic Disease Strategy* are other well thought out strategies that contribute to the current policy environment.[17,18] *Appendix A* provides an extended list of policies of relevance to chronic disease and associated risk factors across Australia.

3 Existing time series data collections

This section outlines the existing chronic disease and associated risk factor time series collections in Australia. It is divided into four sections. The first section, Australian time series data collections, provides an overview of the major time series data collections in Australia nationally and in the states and territories. It is drawn from an Audit undertaken in cooperation with governmental health departments, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. *Appendix D*, Table 5 and Table 6 provide additional information on the collections described in this section:

- the National Health Survey, and the National Aboriginal and Torres Strait Islander Health Survey;
- state-wide population health surveys using CATI;
- the General Social Survey, and the National Aboriginal and Torres Strait Islander Social Survey;
- the Survey of Disability, Ageing and Carers;
- the Survey of Mental Health and Wellbeing;
- the Community Housing Infrastructure Needs Survey;
- the Australian Secondary Schools Alcohol and Drug Survey (ASSAD);
- health provider collections;
- vital statistics and demography collections.
- other time series collections; and
- longitudinal data collections.

This section also includes discussion on some additional issues arising:

- the rising participant burden of household surveys;
- increasing need for small area data;
- increasing demand for timely, more rapidly released data;
- extensions to the use of existing data collection vehicles;
- the potential effect of learned social responses on survey responses; and
- the need for standardised reporting of response to enable easier comparison.

The second section, *Linked data sets*, describes recent national and state developments in relation to data linkage across individual data collections and at the level of individuals. The data collections detailed (on which additional information can be found in *Appendix D*) are:

- the Western Australian Data Linkage System; and
- the Centre for Health Record Linkage (NSW).

3.1 Australian time series data collections

Australia has a number of data collections available on various aspects of chronic diseases and associated risk factor/ determinant topics. This section outlines the major time series collections in this area:

- the National Health Survey (NHS) and the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS);
- the various state-wide population health surveys using Computer Assisted Telephone Interviewing (CATI);
- the General Social Survey (GSS) and the National Aboriginal and Torres Strait Islander Social Survey (NATSISS);
- the Survey of Disability, Ageing and Carers (SDAC);
- the Survey of Mental Health and Wellbeing (SMHWB);
- the Community Housing Infrastructure Needs Survey (CHINS);
- the Australian Secondary Schools Alcohol and Drug Survey (ASSAD);
- the health provider collections (hospital morbidity, Medicare Australia, disease registers, BEACH); and
- the vital statistics and demography collections.

3.1.1 National health surveys

The National Health Survey (NHS) and the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) collect a range of health-related information on a triennial (NHS since 2001) and six yearly basis (NATSIHS since 2004-05) in face-to-face household surveys of the Australian population.

The objectives of the NHS are to:

- obtain national benchmark information on a range of health issues;
- enable trends in health to be monitored over time; and
- supply information on health indicators for national health priority areas (asthma; cancer; heart and circulatory conditions; diabetes; injuries; mental wellbeing; and musculoskeletal conditions, especially arthritis and osteoporosis) and for important population subgroups.

Surveys have a core component, repeated in all surveys to provide time series data, and a non-core component which may be varied from survey to survey. The NHS covers various topics including health status, long-term conditions, general health/ wellbeing, health-related actions, health risk factors and population characteristics.

An Indigenous supplement was included in the 2001 NHS, and in 1995 the National Nutrition Survey (NNS), which included the collection of objective measurements of blood pressure, height and weight, as well as dietary information and food habits, was linked with it. The 2007-08 NHS collected objective measurements of height, weight, and hip and waist circumferences.

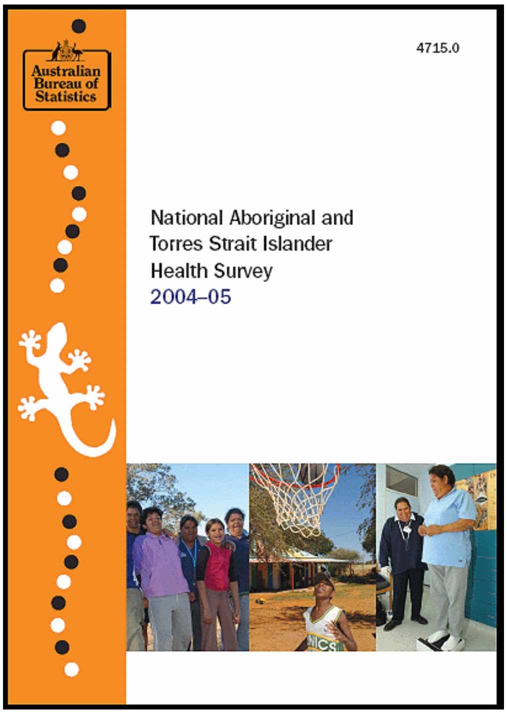
The NHS achieves the highest response rate (around 90%) of any ABS survey, proof of the interest in the topic of health among those surveyed.[19] High response rates and even higher agreement to being called back at the end of the survey demonstrate the level of trust achieved by the ABS (around 96% of respondents agree to being called back at the end of the survey for quality control and other administrative purposes).[19]

The National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) was first conducted in 2004-05 in all areas of Australia (both remote and non-remote areas). The sample size was the largest of any health survey of Indigenous Australians by the ABS (10,439 persons, or approximately one in 45 of the total Indigenous population) and included over-sampling of Torres Strait Islander peoples in certain areas.[20] Prior to the NATSIHS in 2004-05, health surveys in Indigenous Australian populations were collected in small supplementary samples associated with the NHS in 1995 and 2001.[1]

The objectives of the NATSIHS are to:

- provide broad information on the health of Aboriginal and Torres Strait Islander peoples by remoteness and at national and state/ territory levels;
- allow exploration of the relationships between the health status, health risk factors and health-related actions of Indigenous Australians;
- enable trends in the health of Indigenous Australians to be monitored over time; and
- allow comparison with results for the non-Indigenous population from the NHS (2001 and 2004-05).

Figure 4: Cover of the National Aboriginal and Torres Strait Islander Health Survey, 2004-05



Australian Bureau of Statistics

4715.0

National Aboriginal and
Torres Strait Islander
Health Survey
2004–05

Source: ABS. National Aboriginal and Torres Strait Islander Health Survey, 2004-05. ABS cat. no. 4715.0. Canberra: ABS, 2006.

Although they are separate surveys, the NATSIHS and NHS share a core data set that enables comparison of health information in the Indigenous and non-Indigenous populations. NATSIHS topics include health status indicators (including long term conditions), health risk factors and health-related actions, as well as demographic and socio-economic circumstances.

The NATSIHS survey instruments were modified for remote communities to take account of language and cultural issues, and community-level information on access to medical services and community health issues was also collected from agencies. Supplementary questionnaires – in non-remote areas only – collected information on substance use and additional women's health topics. Improvements in data collection practices have enhanced the enumeration of some important long term conditions (e.g., renal disease).[22:160]

The NATSIHS will be conducted every six years with the next survey due in 2010-11.

Advantages and limitations of the national health surveys as population monitoring tools

The key features of the NHS and the NATSIHS are described in Table 1 and an overview of chronic disease and associated risk factor topics covered in the surveys can be seen in Table 2 (with more

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[1] The ABS National Aboriginal and Torres Strait Islander Survey in 1994 provided information on 15,726 Indigenous people of all ages, including a sample of prisoners, but was not a dedicated health survey, although it did collect some health-related information. The survey provided the first broad, contemporary picture of Aboriginal and Torres Strait Islander peoples and was conducted in response to the finding of the Royal Commission into Aboriginal Deaths in Custody that there was little comparable data about Indigenous people available across Australia.[21:6]

details available in *Appendix B: Topics covered by national health surveys and state-wide population health (CATI) surveys*).

The advantages of these health surveys are that they:

- are national;
- cover people of all ages; non-Indigenous as well as Aboriginal and Torres Strait Islander Australians – and include Aboriginal and Torres Strait Islander Australians living in both remote and non-remote areas;
- use rigorous data collection procedures and have very good response rates;
- can provide time series data: the NHS has been collected over a substantial period of time (since 1989-90 for risk factor information, with limited comparability since 1977-78 for other topics such as long term illness conditions[23:66]; and possibly with the Supplementary Surveys in May 1968 and May 1974 on Chronic Illnesses, Injuries, and Impairments); the NATSIHS over less time (since 1994 and 1995) with more limitations reducing the comparisons possible;
- have, in recent years, substantially improved data availability and currency enabling more powerful analyses to be produced on more current data – the NHS through improved timeliness since 2001 when triennial surveys began, and the NATSIHS through increased sample size and coverage since 2004-05 when it commenced;
- are capable of extension – the NHS will incorporate some objectively measured individual characteristics in 2007-08 in addition to comparable self-assessed measures; and,
- in addition to general information dissemination from the surveys, data is available to sophisticated users at around the same time through Confidentialised Unit Record Files (CURFs) on CD-ROM, via the ABS Remote Access Data Laboratory (Internet access) or the ABS Data Laboratory (on-site access). Basic CURFs are provided to state health departments for free, as well as to universities which belong to Universities Australia (previously the Australian Vice-Chancellors' Committee).

The limitations of these surveys are that:

- the information is self-report (with the exception of some items in the NHS 2007-08 as noted above);
- they cannot generally provide small area data below capital city/ rest of state (although jurisdictions may purchase additional sample in areas), and the NHS sample does not support separate estimates for the NT[2] (the NATSIHS 2004-05 supports estimates for five remoteness areas nationally, and for all states and territories including the NT);
- there is a time lag between the end of data collection and the output of results. This time lag is, however, on a par with the current reporting lags of most state population health (CATI) surveys;
- unit record files cannot be released unless confidentialised (losing geographic detail); and,
- the cost of buying data can be expensive (although CURF prices have dropped to around $1,320 from over $8,000 previously).

The greater frequency of the NHS – triennial since 2001 (although at the expense of some sample size) has much improved data currency, with data from at least three surveys now deliverable in any one decade to policy-makers and program-managers. Final content is prioritised in discussions with the Health Statistics Advisory Group. The lack of an annual survey, however, intensifies competition for

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[2] "At the request of relevant health authorities the sample in the Northern Territory (NT) was reduced to a level such that NT records contribute appropriately to national estimates but are insufficient to support reliable estimates for the NT. This was requested to enable a larger NT sample to be used in the General Social Survey conducted periodically by the ABS."[24:70]

topic space, and may inhibit the inclusion of less apparent high-priority topics in a manner timely enough to reflect societal changes. Emphasis on the preservation of the time series and the constraints of survey size, respondent burden, and mode (commitment largely to a sole mode versus greater use of mixed modes, such as self-administered supplementary questionnaires) may also hold back some of the changes necessary to modernise and/or calibrate survey instruments.

Internet sites

For information on the National Health Survey and the National Aboriginal and Torres Strait Islander Health Survey and publications see the Australian Bureau of Statistics (ABS) website: www.abs.gov.au and navigate through *Statistics*, *Catalogue number* and *Health* to the listing of health-related publications.

The ABS Remote Access Data Laboratory (RADL) is a secure on-line data query service that clients can access via the ABS web site. It provides access to more detailed CURF data than that available on CD-ROM. Authorised users submit queries in statistical languages (SAS, Stata or SPSS) against CURFs (held within the ABS environment) using the RADL web interface. Query results are checked for confidentiality before being made available to users via their desktops. As the CURFs are kept within the ABS environment, the ABS can release more detailed CURF data via the RADL than can be made available on CD-ROM. For more information see the ABS RADL website: www.abs.gov.au/websitedbs/d3310114.nsf/home/CURF:+Remote+Access+Data+Laboratory+(RADL)

The ABS Site Data Laboratory (ABSDL) provides an interactive environment for the analysis of Basic, Expanded or Specialist (customised) CURFs on-site in all ABS offices. For sophisticated data users, the ABSDL provides a more responsive environment in which to analyse CURFs than that offered by the RADL. It is interactive, with no automated protections of data within the ABSDL. All outputs, however, are vetted by ABS staff before release to clients to ensure that the confidentiality of respondents is protected. It is fully cost recovered. For more information see the ABSDL website: http://www.abs.gov.au/websitedbs/d3310114.nsf/4a256353001af3ed4b2562bb00121564/55c077b4d87d2fbdca2572090006fbcf!OpenDocument

3.1.2 State-wide population health surveys using CATI

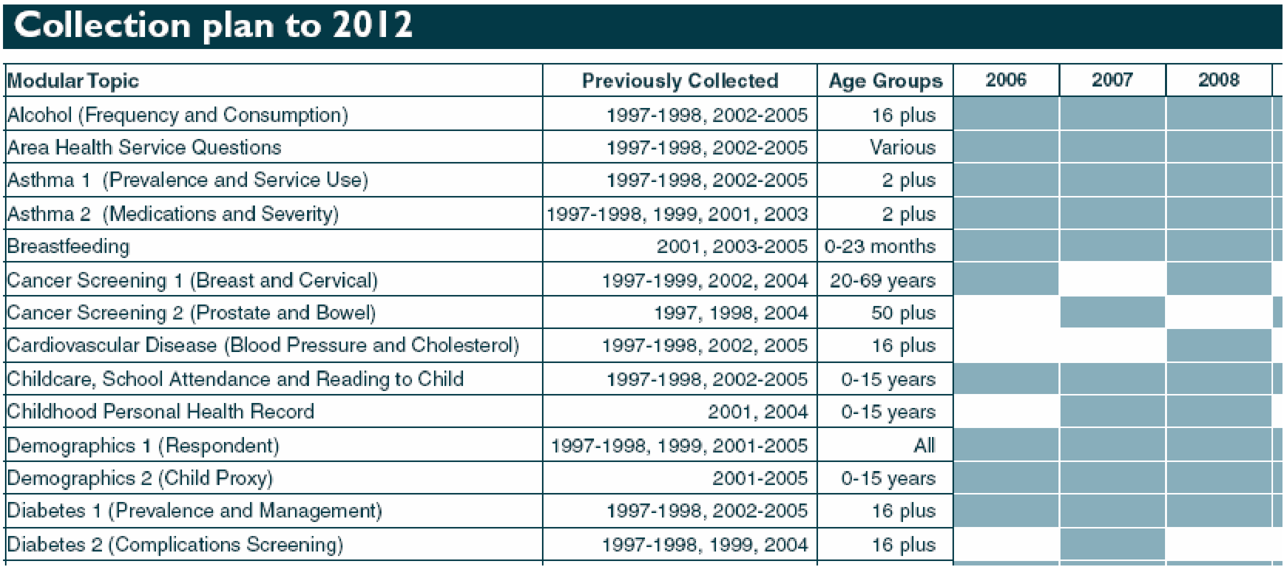
The majority of the state and territory governments have developed and routinely conduct state-wide population health surveys using computer assisted telephone interviewing (CATI) to collect self-reported information in adults, and in children to a lesser degree (NSW including ACT, Qld, WA, SA, and more recently Vic) (see Table 1). In 2001-02 when this Audit was first conducted, many of what have now become routine collections were just commencing.

Since the time of the first Audit, the states and territories have formed distinct groups in relation to their level of development and the paths chosen. Along the way there have been changes in sample strategy, sample size, routine reporting, and state governments' commitment to regular monitoring of population health. Table 1 summarises the key current features of the regular state population health (CATI) surveys at this time. Some of the changes and different strategies are described below.

The majority of the states (NSW, Vic, WA and SA) have well developed, funded, continuous or annual, health population surveys using CATI, although only NSW maintains an in-house CATI facility. Most have adopted the approach of core topic modules that may be added to as required, including at the request of sub-state regional facilities (e.g., the regional Area Health Services in NSW).

A major difference between states is in the degree of repetition between regular surveys. NSW maintains a programmed multi-year collection plan, showing the regularity of inclusion of different topics (Figure 5). Victoria has largely repeated the same or very similar set of topics each year, building up a time series in these, with a special focus on equity issues across and within the state. WA and SA survey core topics that may be added to as required. Queensland remains the mainland state with a seemingly irregular approach to population health surveying using CATI, however there have been a number of different surveys conducted between 2000 and 2007 (Table 5 and Table 6 in *Appendix D*).

Figure 5: NSW Population Health Survey collection plan to 2012: extract only



Collection plan to 2012

Modular Topic	Previously Collected	Age Groups	2006	2007	2008
Alcohol (Frequency and Consumption)	1997-1998, 2002-2005	16 plus	▨	▨	▨
Area Health Service Questions	1997-1998, 2002-2005	Various	▨	▨	▨
Asthma 1 (Prevalence and Service Use)	1997-1998, 2002-2005	2 plus	▨	▨	▨
Asthma 2 (Medications and Severity)	1997-1998, 1999, 2001, 2003	2 plus	▨	▨	▨
Breastfeeding	2001, 2003-2005	0-23 months	▨	▨	▨
Cancer Screening 1 (Breast and Cervical)	1997-1999, 2002, 2004	20-69 years	▨		▨
Cancer Screening 2 (Prostate and Bowel)	1997, 1998, 2004	50 plus		▨	
Cardiovascular Disease (Blood Pressure and Cholesterol)	1997-1998, 2002, 2005	16 plus			▨
Childcare, School Attendance and Reading to Child	1997-1998, 2002-2005	0-15 years	▨	▨	▨
Childhood Personal Health Record	2001, 2004	0-15 years		▨	▨
Demographics 1 (Respondent)	1997-1998, 1999, 2001-2005	All	▨	▨	▨
Demographics 2 (Child Proxy)	2001-2005	0-15 years	▨	▨	▨
Diabetes 1 (Prevalence and Management)	1997-1998, 2002-2005	16 plus	▨	▨	▨
Diabetes 2 (Complications Screening)	1997-1998, 1999, 2004	16 plus		▨	

Source: NSW Health. New South Wales Population Health Survey: Collection plan to 2012. Sydney: NSW Department of Health, 2007 [extract only].

The NSW Population Health Survey Program publishes a five year forward collection plan detailing topic modules, the years in which they are to be collected (and when they were last collected), and respondent age groups.[25] The plan makes it easy to see the frequency of data collection and the currency of available data that can support reporting, planning and evaluation of services and programs. For instance, a topic module on chronic health conditions was planned to be asked of all adult respondents (ages 16+ years) in 2007 and again in 2010. Questions on asthma prevalence and service use had been asked in relation to respondents aged two years and over in 1997, 1998, 2002 to 2005 and were to be asked again in each year from 2006 to 2012. Questions on diabetes prevalence and management were asked of adult respondents in 1997, 1998, 2002 to 2005 and planned for each year from 2006 to 2012; while questions on screening for diabetes complications were asked of adult respondents in 1997, 1998, 1999 and 2004 and planned for the years 2007 and 2010.

In relation to sample size and sampling strategy, Victoria now plans to sample at the much smaller local government area (LGA) level every third year (with sampling at state level in the remaining two years). The larger planned surveys have tended to reduce sample size (e.g., NSW – in line with a reduction in the number of Area Health Services), however, in reporting, more use is being made of collated annual samples (boosting effective sample size) and rolling averages (improving the accuracy of estimates) (NSW, Vic, WA, SA). In addition, NSW collates annual samples (for analyses of smaller numbers) and employs Holt's exponential smoothing model to estimate future prevalence (taking into account increasing/ decreasing trends in prevalence estimates over time).[26] In Victoria there has been a significant extension to the surveyed population with the addition of a time series survey in children from 2006.

Tasmania, the ACT and the NT have benefited from two 'buddy' surveys (conducted in 2000-01 and 2004 with the assistance of DoHA), however, only the ACT has so far cemented a buddy relationship (with NSW) for regular routine population monitoring. Although Tasmania purchased an over-sample in the 2004-05 NHS (with a responding sample of 1,949 - somewhat larger than the 1,215 Tasmanian adults surveyed in the 2004 'Filling the Gaps' CATI buddy survey), the Tasmanian Director of Public Health recently reported that:

> *Without the fundamental public health tool of a robust ongoing health risk factor monitoring and surveillance system for Tasmania (which stands virtually alone amongst the jurisdictions in this regard) my ability... to monitor and report on the causes of health trends is seriously compromised. state government investment in an ongoing health monitoring and surveillance system for Tasmania to assess trends in risk factors, health service utilisation and performance, and health outcomes should be a top priority in responding to the emerging burden of chronic disease and the need for service integration.*[27:34]

The Northern Territory meanwhile, has pursued a completely different development path, based around its unique features: small population, few large population centres, a correspondingly smaller number of health services, and a more integrated health system than other jurisdictions; and significant difficulties associated with its few population centres, many remote communities comprised of small, scattered, mobile populations, together with problems in attracting and retaining health professionals in smaller communities and centres. It has concentrated on improving the quality of its routine basic health data collections and collection processes (e.g., getting infrastructure in place and implementing robust distributed systems) and on improving general population health information, using data from some health services (e.g., hospitals) to cross-check and strengthen other data (e.g., disease registers). For example, it is developing primary health care electronic record systems which by June 2008 were to cover 60% of remote NT government health services, with the aim of achieving 100% state-wide coverage of all residents using government health services (by June 2009), together with data linkage across providers. The NT's approach is based, to a large extent, on individuals being uniquely identifiable throughout its health system – unlike almost all other jurisdictions.

In WA, the state with the longest history of data linkage, however, there have been some developments in the linking of population health survey respondents over time and across data sets. The WA Health and Wellbeing Surveillance System (HWSS) reports that over 90% of respondents agreed to being contacted again on health issues (in 2005). The main uses of this 'recontact' database are for: (1) case control studies in emergencies, (e.g., a food poisoning outbreak); (2) research on surveillance issues (e.g., validity & reliability, extra questions on specific areas); and (3) research projects. Respondents are also asked whether or not their survey information may be linked with other health data held by the Department of Health, WA. Around 80% consistently agree and provide their full name and date of birth for linking purposes.[28]

Internet sites

NSW: New South Wales Health Survey Program (NSW Health)
www.health.nsw.gov.au/publichealth/surveys/index.asp

Vic: Victorian Population Health Survey (Victorian Department of Human Services)
www.health.vic.gov.au/healthstatus/vphs.htm

WA: Western Australian Health and Wellbeing Surveillance System (WA Department of Health)
www.health.wa.gov.au/publications/pop_surveys.cfm

SA: Population Research and Outcome Studies (PROS) Unit (SA Department of Health)
www.health.sa.gov.au/PROS/Default.aspx?tabid=45

National CATI (Computer Assisted Telephone Interviewing) Health Survey Technical Reference Group (CATI TRG):
www.nphp.gov.au/catitrg/ (Page last updated: 13 December, 2004)

Table 1: A comparison of the key current features of the regular national health surveys and state population health (CATI) surveys

Survey	Frequency	Sample size & design	Area unit/ target populations	Collection details	Reports and data release	Other information
National heath surveys						
National Health Survey (NHS)	Triennial from 2001. Previously conducted 1989-90, 1995. Prior surveys 1977-78 & 1983 may be comparable, likewise Supplementary Surveys May 1968 & May 1974 on Chronic Illnesses, Injuries, and Impairments. The NATSIHS (see below) is to be run with every 2nd NHS from 2004-05.	~23,000 households; one adult and one child in each selected household. 25,916 persons in 2004-05 (19,501 adults and 6,415 children). 2001 NHS(I) ~3,700 Indigenous persons in a supplementary sample.	Australia Individual states & territories (except NT; excluding Indigenous population). Australia by ASGC Remoteness: Major cities, Inner regional, Outer regional (incl. Remote & Very remote); Capital cities/ Balance of state; & Section of state: Major urban, Other urban, Bounded locality, Rural. Data may be available at SD level.	CAPI since 2004-05; PAPI from 1989-90 to 2001.	Data dissemination strategy. Reports at end of survey (summary report within eight months), supplementary tables available online, & access to metadata online via ABS website. CURF available at cost.	Survey design: content of individual surveys differs somewhat around a common core data set that is maintained through the series. Survey design and comparison are complex; for more information see documentation and/or consult ABS.
National Aboriginal & Torres Strait Islander Health Survey (NATSIHS)	Every six years from 2004-05. Timed to coincide with every second NHS. Additional small samples from the 1995 & 2001 NHS(I) are available for time series analyses.	~11,000 persons with over-sampling of the Torres Strait Islander population. 10,439 persons in 2004-05 (5,757 adults and 4,682 children). 2001 NHS(I) included a supplementary sample of ~3,700 persons.	Australia Individual states & territories. Australia by ASGC Remoteness: non remote (Major cities, Inner regional & Outer regional) / remote (Remote & Very remote).	(1) CAPI in non-remote areas; with self-enumeration of 2 questionnaires (substance use, women's health); (2) PAPI in remote areas; community-level information also collected	Data dissemination strategy. Reports at end of survey (summary report within nine months), parallel S/T tables available online, & online access to metadata via ABS website. CURF available at cost.	Survey design: some differences in data and collection methods between remote communities and other geographical areas. Limited time series comparison is possible with the 1995 and 2001 NHS(I) supplementary Indigenous samples. See documentation/ consult ABS.
State population health (CATI) surveys						
NSW Population Health Survey Program - includes **ACT** from 2007.	Continuous from 2002, conducted Feb to Dec each year. Prior surveys 1997, 1998 adults 1999 older people, & 2001 children are available for trend analysis.	~12,000 persons of all ages each year in NSW; ~1,500 in each Area Health Service (AHS). 16,162 in total in 2007. Sampling by list-assisted RDD. ~1,300 persons in ACT in 2007.	NSW state-wide. NSW by area health regions (eight regions from 2005; 17 previously). NSW by urban/ rural (based on area health services so designated). NSW by urban/ rural LGAs. NSW Divisions of General Practice regions.	CATI & inhouse. PAL sent to households for which an address can be sourced.	Data dissemination strategy. Reporting annually on adult health for NSW & each region; monthly on adult health for NSW; biennially on child health for NSW; triennially on adult health for Divisions of General Practice; occasionally on health of specific sub-populations (e.g., Aboriginal adults & adults by COB). CURF available to AHS via HOIST (internet), other users by request.	Survey design: programmed topic collection with different topic modules scheduled for collection either continuously, biennially, triennially, or on a one-off basis. Capacity to add topic modules throughout the year. Survey available in five community languages: Arabic, Chinese, Greek, Italian and Vietnamese. Average length of interview ~25 minutes (2006).

Survey	Frequency	Sample size & design	Area unit/ target populations	Collection details	Reports and data release	Other information
Vic Victorian Population Health Survey	Annual from 2001, conducted Aug to Nov each year.	~7,500 adults each year with over-sampling in rural regions (2001-2007). Sampling by RDD. From 2008 plan to sample at LGA level (~35,000-40,000) every third year, returning to a state region-level sample in the intervening years.	Victoria state-wide Victoria by Department of Human Services (DHS) regions: five rural and three metropolitan (from 2004); five rural and four metropolitan (2001-2003). Victoria by LGAs (for LGA-level survey in 2008).	CATI & outsourced. PAL sent to households for which an address can be sourced.	Data dissemination strategy. Reporting annually for Victoria (usually by the following June). Regional fact sheets – in topic based sets – published for each DHS region (in 2008 on 2006 data; in 2004 on 2003 data). Future reporting anticipated at LGA level every three years.	Survey design: based on a core set of question modules and has included a set of questions on social capital and social networks since 2001. Survey available in six community languages: Mandarin, Cantonese, Vietnamese, Italian, Greek and Macedonian. Average length of interview between 20 to 21 minutes.
Qld Queensland Omnibus Survey program	Annual from 2000.	~1,200 to 2,500 persons (ages vary according to survey focus) per survey from 2003 to 2007. Sampling by extended EWP.	Queensland state-wide Qld by Urban/ Rural & remote (RaRA classification) Qld by ARIA classification	CATI & inhouse.	Internal reports at survey end Some survey data published in general &/or thematic reports (e.g., Health of Queenslanders, Infant and child nutrition). Will assess CURF/ data file availability on request.	Survey disposed as general population &/or targeted sub-population surveys each year. Annual general population surveys from 2004 to 2007. Targeted surveys in 2003 (3 surveys), 2005 (3) & 2006 (2).
WA Health & Wellbeing Surveillance System (HWSS)	Continuous from 2002, conducted Jan to Dec each year.	~6,600 persons of all ages each year (550 per month) planned from 2008, with over-sampling in rural and remote areas. Sampling by EWP. Various areas & age groups previously over-sampled; annual sample size from ~7,000-7,500.	WA state-wide WA by health regions. WA by Metro/ Rural/ Remote. Smaller geographic areas available with ethics approval. Additional aim is to build up a database allowing micro-level data analysis: total of >46,000 interviews conducted 2002-2008.	CATI & outsourced. PAL sent to households for which an address can be sourced.	Annual reports since 2007 by question, sex & age, for adults & children. Other survey results reported regularly in bulletins & special reports available on internet (e.g., Health of older people 2002-2004, adults 2006; Eating, exercise and body size; Heart disease; Type 2 diabetes). CURF available to regions.	Survey design: questions targeted to four major age ranges & tailored to the life course; some in common, others unique to target ages. Average interview length 22 mins. Approx. 90% of respondents agree to re-contact on health issues, ~80% agree to data linkage with other health data.
SA 1. South Australian Monitoring and Surveillance System (SAMSS) 2. Health Monitor Survey (HMS) 3. Social, Environmental and Risk Context Information System (SERCIS)	1. Monthly since July 2002. 2. Three times a year regularly since 1999 and additional ad hoc surveys may be conducted. 3. Varies, since 1995.	1. ~600 interviews conducted per month, all ages. 2. 2,000 households per quarter, adults (18+ years) or by design. 3. ~ 3,000 households, or more depending on need, adults (18+ years). 1, 2 & 3: Sampling by EWP.	1. SA state-wide and by Metropolitan/ Rest of state 2. SA state-wide and by up to seven regions depending on design & user requirements. 3. SA state-wide and by Metropolitan/ Rest of state.	CATI & outsourced. PAL sent to households for which an address can be sourced.	Survey results variously reported in thematic publications and/or research reports.	1. Core questions asked each month; additional questions in alternate months. Average interview length 16.4 mins. 2. Regular user pays service with organisations purchasing questions. Interviewing available in Italian, Greek Vietnamese, Other. Interview time up to 15 mins. 3. Irregular issue-specific user pays service.

CATI = Computer Assisted Telephone Interviewing, COB = Country of birth, CURF = Confidentialised Unit Record File, PAL = Primary Approach Letter, S/T = states & Territories, SD = Statistical Division

As is discussed below, (and illustrated in Table 2) the ABS work on data pooling and the harmonisation of state-wide population health surveys using CATI has shown, for the most part, minor differences between the state and territory collections and the NHS, making the production of national estimates from pooled jurisdictional data no longer out of the question. At a national level, however, smaller jurisdictions with markedly different population characteristics (such as the NT with its large Indigenous population, and the ACT with its generally more educated, higher income population) would not be accurately described; and even in the NHS, these jurisdictions will require different treatment.

Variations that remain between jurisdictional population health surveying using CATI relate mostly to minor differences in questionnaire wording and sequences, different choices of topics included and the regularity with which data on specific topics is sought (see *Appendix B* for more information). There may also be variations in the reporting of information, such as different categories combined in different ways that may make the compilation of nation-wide data more difficult.

The overall advantages and limitations of the state population health (CATI) surveys as monitoring tools are examined in more detail in a section following the overview of CATI standardisation activities. Table 2 on page 20 compares selected topics from the national health surveys and the state-wide population health (CATI) surveys circa 2004. It is based on the work of the ABS in preparing question comparison material for their Harmonisation Project in 2007, and the *Data reference package* for the 2004-05 National Health and National Aboriginal and Torres Strait Islander Health Surveys.[29] It shows the value of the Commonwealth funded capacity building and 'buddy survey' extensions to jurisdictions that lacked their own chronic disease and associated risk factor monitoring systems. In 2004 jurisdictions could provide data on the topics of self-reported:

- alcohol consumption;
- dietary behaviours;
- exercise/ physical activity;
- height, weight and body mass index (BMI);
- smoking;
- psychological distress;
- general health status;
- asthma;
- high blood pressure;
- high cholesterol; and
- diabetes.

The topic comparison also highlights some differences between national and state (CATI) health surveys. The topic of cancer shows these most clearly. It has been argued that (self-reported) cancer incidence (i.e. cases) is not an appropriate topic for population health surveys because more reliable (clinically verified) data are available from state cancer registries (and the National Cancer Statistics Clearing House). More appropriately asked in these surveys are questions on whether people have undertaken screening for specific cancers (e.g., breast, bowel) and prevention activities (e.g., in relation to skin cancer). Table 2 shows that cancer screening and prevention topics were more common than cancer incidence topics in state population health surveys.

Table 2: Comparison of topics: NHS & NATSIHS & state-wide population health (CATI) surveys circa 2004

Topic Area and topics	NHS 2004-05	NATSIHS 2004-05	NSW 2004	VIC 2004	QLD 2004	SA 2004	WA 2004	ACT, 2005	ACT, NT, Qld Tas 2004#
Health risk factors									
Adult immunisation	X	X	X	-	2003	-	X	-	-
Alcohol consumption - frequency & no. of drinks	X	X	X	X	2006	X	X	X	X
Breastfeeding	X	X	X	-	2003	X	X	X	-
Child immunisation	X	X	X[3]	-	-	X	-	X	-
Cultural Identification – Family removal, Stressors	-	X	-	-	-	-	-	-	-
Dietary behaviours – daily vegetable & fruit consumption & type of milk consumed	X	X	X	X	2005	X	X	X	X
Exercise	X	X	X	X	X	X	X	X	X
Height, weight, body mass	X	X	X	X	X	X	X	X	X
Smoking – prevalence & in the home	X	X	X	X	X	X	X	X	X
Substance use	-	X	-	-	-	-	X[4]	-	-
Psychological distress (Kessler 10/ Kessler 5**)	X	X (K5)	X	X	*	X	X	X	X
Health status indicators									
General health status (self-assessed)	X	X	X	X	X	X	X	X	X
Arthritis – ever told	X	X	-	X	-	X	X	X	-
Asthma – ever told	X	X	X	X	X	X	X	X	-
Cancer incidence – ever told[5]	X[5]	X[5]	-	X	-	-	X	-	-
Cancer screening – actions taken[5]	X	X	X	-	2003,2005	X	X	X	-
Heart and circulatory conditions[6] – ever told	X	X	-	X	-	X	X	X	-
Heart and circulatory conditions – used meds	X	X	-	-	-	-	-	-	-
High blood pressure – ever told	X	X	2005	X	2006	X	X	X	-
High blood pressure – last measured &/or actions to manage	-	-	2005	X	2006	X	X	X	-
High cholesterol – ever told	X	X	2005	-	2006	X	X	X	-
High cholesterol – last measured &/or medication to manage	-	-	2005	X	2006	X	X	X	-
Diabetes/ high sugar levels – ever told	X	X	X	X	X	X	X	X	-
Diabetes – diagnosed during pregnancy	X	-	X	X	X	X	X	X	-
Diabetes – type	X	-	X	X	X	X	X	X	-
Diabetes – age at diagnosis	X	X	X	X	-	-	-	-	-
Diabetes – actions to manage	X	X	X	X	-	-	-	-	-
Kidney disease and dialysis **	-	X	-	-	-	-	-	-	-
Osteoporosis – ever told	X	X	-	X	-	X	X	X	-
Long-term conditions (other): – depression/ anxiety – ever told/ diagnosed	X	-	-	X	-	X	X	X	-

Notes: * = see last column: risk factors only ACT, NT, Qld, Tas; ** = NATSIHS only; # = DoHA-funded SNAPS risk factor survey "Filling the gaps" conducted in Qld, ACT, NT, & Tas in 2004. **Data sources**: ABS. NHS and NATSIHS 2004/5: Data reference package, 2004-05 (cat. no. 4363.0.55.002). Canberra: ABS, 2006; ABS Question comparison material re Harmonisation Project, 2007 [unpublished data] – drawn from NSW, Vic, Qld, SA and WA population health (CATI) surveys in 2004; (plus NSW in 2005; Qld Surveys: Omnibus: Infant Nutrition in 2003, Older Persons in 2003, Fruit & Vegetable Consumption in 2005, and Omnibus in 2006; ACT population health survey 2005 [carried out by SA]); and the DoHA-funded 'Filling the Gaps' SNAPS (Smoking, Nutrition, Alcohol, Physical Activity and Stress) risk factor survey conducted in ACT, NT, Qld & Tasmania in 2004. **See *Appendix B*** for a fuller version of this table & important explanatory material and clarifications.

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[3] NSW Population Health Survey 2004: parental beliefs & attitudes & whether child vaccinated against meningococcal C disease.

[4] WA Heath & Wellbeing Surveillance System (HWSS) – current use of drugs & unsafe needle practices.

[5] NHS and NATSIHS 2004-05: specific for types of cancer, e.g., skin, breast, prostate, lung, etc. Note that for states more reliable information on cancer incidence was available from State Cancer Registries; questions on specific cancer screening/ prevention activities were more likely to be asked in state population health surveys than incidence. NATSIHS 2004-05: Women's health: mammograms (breast cancer screening), pap smear test (cervical cancer screening); NSW Population Health Survey 2004: Cancer screening – breast, cervical, prostate, bowel, Summer sun protection; Qld Older Persons Survey 2003: breast cancer screening; Qld 2005 Omnibus Survey 2005: colo-rectal cancer; Qld Omnibus Survey: Sunsafe 2005: sun protection practices; SAMSS 2004: sun protection; WA HWSS: sun protection.

[6] Heart and circulatory or cardiovascular disease conditions - primarily heart disease &/or stroke.

Comino and colleagues (2006) suggest that population health surveys should be extended to provide information on access to and use of primary health care (PHC) (information that is not currently captured elsewhere) to complement other community-based data collections and assist in the development of PHC policy.[30] They observe that PHC is under-represented in health statistics due to the lack of a comprehensive PHC data collection in Australia; and record linkage – while worthwhile in providing more comprehensive information – will not systematically capture the full range of services that comprise PHC (i.e. including both public and privately funded services) nor will it capture information on those people who need – but do not use – such services.[30]

Cross-sectional population health surveys have not been used much in health service research as they are 'considered the least reliable study design' - because they:

- rely on individual recall of information and events;
- cannot address issues of causality;
- are limited to individuals' propensity or inclination to report (i.e. bias).[30:486]

They can, however, be used to address access to and use of quality PHC - using a broad definition of 'access' that includes both 'availability' (potential access) and use of service (realised access). An examination of three surveys, however, found that limited information was sought on access to and use of PHC, and that the focus of survey questions was on individual care rather than use of services (NSW Population Health Survey 2002-03, ABS NHS 2001, and AusDiab 2000).[30] The National CATI health survey technical reference group (CATI TRG)'s work on formulating and promulgating standard question modules was praised, and the resulting standardisation found in the three surveys showed that it was possible to 'develop a consensus among stakeholders about both topics and questions', suggesting that further development in related areas could be effective.[30:492]

Accepting the limitations of using population health surveys for health services research, there are various ways in which their usefulness could be augmented, including:

- survey programs structured around the use of core questions (annual or included on a fixed term schedule) and supplementary questions (included at differing intervals) - a strategy adopted by the NSW Population Health Survey;
- re-approaching specific sub-groups identified through the main survey to undertake a supplementary survey (use of the population health surveys as a screener);
- using specialist surveys to collect enhanced information on topics and to identify question subsets that would be of use in (or could be developed for use in) more generalist population health surveys.

Finally, triangulation of population health surveys with other data sources could functionally add to their ability to explore information on the management of specific health conditions (e.g., diabetes) – to provide evidence on the impact of population health interventions in a time of rapid health systems change (e.g., introduction of various Medicare items such as chronic disease management; inclusion of allied health services in Medicare schedules).

CATI standardisation activities and progress

The National CATI TRG was established in 1999 (with funding from the Australian Government) as an advisory subcommittee of the National Public Health Information Working Group. The aim of the CATI TRG was to share the development of CATI population health surveys and develop best practice methods. This particularly included the development and testing of standardised and nationally consistent data tools for state population health surveys using CATI to collect self-reported health-related information in their populations.

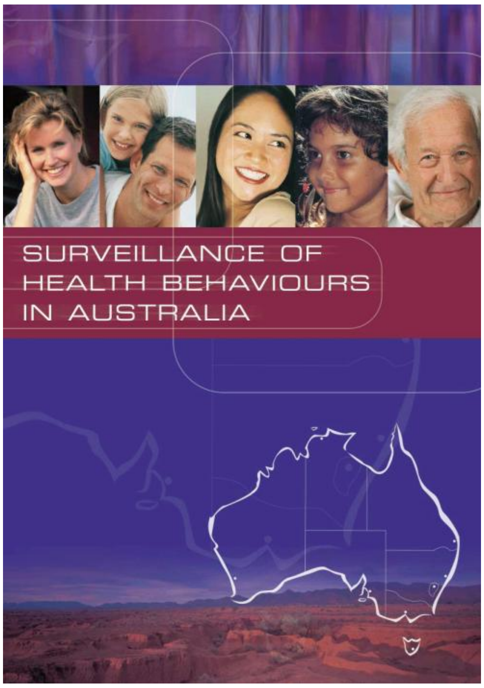
The CATI TRG provided a focus for the development and promotion of national standards, valid methods and capacity for CATI surveys to improve health surveillance and health outcomes. In 2006, when the national health advisory committee structure was reformed, the CATI TRG ceased its role.

The CATI TRG was composed of representatives of all state and territory health departments, DoHA, the ABS, the AIHW, PHIDU, and the New Zealand health department as an observer. It thus performed a valuable role in pulling together the major regular population health data collectors and data custodians in Australia across all jurisdictions.

During the period of its existence, the CATI TRG successfully carried out three main activities:

1. organising annual forums that brought together a wider group of people involved in CATI health surveying and frequently included international experts who provided a broader perspective in addressing topics of the moment;
2. the use of the existing CATI infrastructure to build capacity in jurisdictions with less CATI experience, through the conduct of 'buddy surveys' for states and territories that did not then have the capacity (NT with WA and SA in 2000; Tasmania with Victoria in 2001), and producing comparable point-in-time data on all populations in Australia in 2004 with the data catch-up 'Filling the gaps' Survey of SNAPS (Smoking, Nutrition, Alcohol Physical Activity and Stress) risk factors (Qld, Tas, NT and ACT; conducted by WA and SA jointly, funded by DoHA; with some results reported in *Australia's health 2006*[31:164, 172, 185]; and
3. conducted an extensive program of work to standardise question formats and data collection methodologies, to harmonise data reporting and to produce manuals that could guide the development and extension of population surveying into new areas of health interest in the future. Modules for the standardisation of CATI health survey questions on demographic characteristics and on self- reported chronic diseases (asthma, cancer, cardiovascular disease, diabetes, musculoskeletal conditions) and injury; and on associated risk factors (tobacco consumption, nutrition and food behaviours, alcohol consumption, physical activity, and health-related psychosocial factors) have been prepared and will be available from the PHIDU website.[32]

Figure 6: One of many CATI TRG publications



Major reasons for investing in the development of a health surveillance system across Australia were to ensure that it had the ability to make a difference by being part of an evidence-based approach, demonstrating links to interventions, and supporting epidemiological studies based on surveillance.[33]

During its life, the CATI TRG provided a valuable opportunity for representatives of all jurisdictions working in health surveying to meet together, gaining information and understanding on problems that were better addressed in common. Through its developmental work it advanced the causes of the standardisation of data, data collection tools and methodologies.[30:492] Members were able to accelerate their own development and advance that of jurisdictions that were less progressed, through sharing capacity and ability. Question development was enhanced by focus group and cognitive testing (provided by the ABS laboratories) and review work by CATI TRG members to recommend the best formats and appropriate data categories for standard questions to be incorporated into jurisdictional population health surveys.

The activities of the CATI TRG laid the groundwork and built the necessary predecessor relationships for later initiatives in the harmonisation and pooling of data across Australia. At a workshop hosted by the ABS in September 2007, the issue of the potential harmonisation of data from jurisdictional population health CATI surveys was explored through data pooling work by the ABS to establish the degree of commonality in collection methodologies (e.g., use of primary approach letters to promote participation) and survey timing, scope and coverage, sample design, handling of item non-response, weighting of data, and other related issues. Comparison of questions on chronic disease and associated risk factors revealed far more similarities than differences, a product of the previous work of the CATI TRG and all parties involved. Comparison of reported data between CATI population health surveys, and between these and the ABS National Health Survey (NHS) revealed where substantial differences still remained, and the reasons for these were expected to be further explored prior to the publication of the findings. An examination of the impact of missing states on national estimates showed that, with the exception of jurisdictions with small – but markedly different – populations (e.g., the NT), the impact on national estimates reporting of selected risk factors (e.g., smoking, fruit, vegetable and milk consumption) was marginal or non-existent. The jurisdictional data collections have thus come a long way from the earlier days that were reported in the first Audit when the differences between collections and their results were far more striking than the similarities.

Internet sites

National CATI (Computer Assisted Telephone Interviewing) Health Survey Technical Reference Group (CATI TRG):
www.nphp.gov.au/catitrg/ (Page last updated: 13 December, 2004)

Public Health Information Development Unit, The University of Adelaide
http://www.publichealth.gov.au/

Advantages and limitations of the state population health (CATI) surveys as monitoring tools

All survey modes have their associated pros and cons.[34] The previous Audit reported **six main advantages** in using CATI health surveys for population health monitoring:

- they are usually more frequent than large national household interview based surveys such as the triennial NHS and can therefore report more current data, more often;
- they have more timely reporting (i.e. the period between the end of data collection and the production of reports is shorter). The time delay for the NHS reports will be a minimum of eight months while CATI surveys can report more promptly;
- samples are less clustered and have the capacity to produce more reliable output for small geographic areas (such as health regions) and population groups (e.g., children and young people, older people, or people of Non-English Speaking Background [NESB])[35-37];
- they have the ability to reach some population groups more readily than other collection methodologies. This applies especially to populations living in remote and/or sparsely settled areas, and NESB populations through the ability to conduct multi-lingual interviews;
- they can be quickly adapted to collect information on emerging health policy and planning needs; and
- the unit cost of each CATI survey is generally lower than that of a face-to-face interview (partly because interviews are shorter and there are no travel expenses), which means that more interviews can be performed for the same expenditure. Both the NSW and SA systems have demonstrated that telephone interviews are more cost effective than face-to-face interviews for obtaining information especially on people in rural and remote areas.[38]

To this list of **advantages** can be added:

- the ability to maintain quality control over the entire data collection process, including questionnaire construction and survey administration.[39-41] Well-developed CATI systems enable more cost effective survey administration than face-to-face personal interviews – although the advent of computer assisted personal interviewing (CAPI) may negate some of this advantage;
- the ability to more closely and better supervise interviewers, resulting in less measurement bias in CATI compared to face-to-face surveys[42];
- telephone interviews can be less intrusive, and feel safer to potential respondents than inviting an interviewer into their home, for example, CATI surveys on sensitive topics such as sexual health and relationships have been found to be more acceptable to respondents than face-to-face interviews[43,44];
- telephone interviews can also be safer for interviewers;
- there is less item non-response with CATI (similar to CAPI) as respondents are better sequenced through questionnaires when compared to self-administered (mail) surveys – although developments in email and web-based surveys may diminish this advantage over time[34,45]; and
- telephone follow-up can be an effective (alternative or additional) method to contact non-respondents to mail and other survey modes; and, in continuing (longitudinal or panel) surveys, to maintain contact with respondents who have moved out of a survey's geographic area. [39,46]

The **limitations** of CATI surveys are that:

- the information is self-report - for instance, self-reported height cannot be verified by measurement; home hazards cannot be confirmed by observation[47-50];
- some questions or topics, for instance those that require the use of cue cards and/or visual aids, are better suited to personal interviews (e.g., questions on nutrition and medications; or those asked of Indigenous Australians and others for whom English is not their first language);
- some topics are better suited to the greater privacy of self-complete modes (e.g., collect or mailback) including topics such as illicit drug use, domestic violence and sexual abuse, that respondents may not feel comfortable with, or be able to answer honestly or safely, in a personal interview;
- telephone surveys have been found to have more socially desirable responses, more acquiescence, more evasiveness, more extremism, higher positive responses to the positive end of response scales, and greater recency effects when compared with other modes, especially self-administered surveys[45,51-53];
- households without telephones are not covered by CATI surveys and in some areas of Australia these include substantial components of the Indigenous population, who also suffer the worst health (e.g., in the NT and in WA)[28];
- the population coverage of CATI surveys is decreasing along with declines in fixed telephone lines and growth in mobile phones and mobile-phone-only households, and use of 'screening technologies' (e.g., answering machines, caller identification) which make it easier not to respond to the telephone.[54]

Previously reported **limitations** of CATI surveys that no longer apply to the same extent as they did at the time of the first Audit, were that:

- different states and territories were at different levels of development (in terms of funding, infrastructure and capacity); and
- aspects of the state and territory systems were not standardised and could therefore not be used to describe a nation-wide picture.

A more recent general limitation that affects both CATI and other survey modes and is common to Australia and other developed countries, is increasing refusal rates and declining response or participation rates, making it more challenging (and costlier) to achieve representative population samples.[55-57]

The analysis shows clearly that fixed-line home phone ownership is not evenly distributed in the community, is in relatively rapid decline, and that its continued use as the sampling frame for CATI population health surveys has the potential to introduce major biases to the monitoring of important health behaviours. Weighting telephone survey results by age and sex will not 'correct' the data for these potential (inherent) biases, and the results reported above suggest the need for extra caution when interpreting telephone-based survey results.[58]

Declining response rates – applies to all modes including CATI and CAPI on page 29 discusses this phenomenon.

Limitations of using the telephone as the only entry point to households

A much more important limitation lies in the lack of inclusion of certain types of people who are known to be under-represented in CATI surveys. Telephone surveys under-represent people without telephones, who are more likely to be never married, poorer, unemployed, younger, in single adult households, Indigenous, and living in remote areas[59-62], homeless or institutionalised (in prison, hospital, nursing home etc.).[63-65]

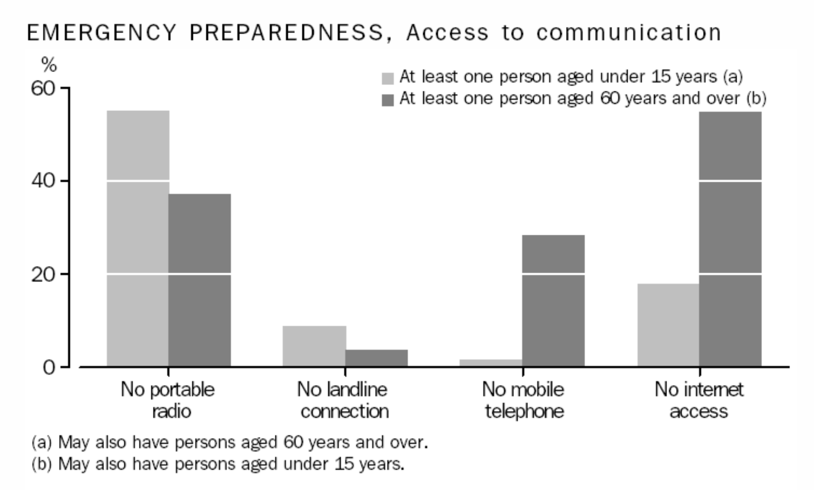
> "Steel and Boal concluded that surveys in which people with low income, young people, or people in rented accommodation are important, should not be made by telephone. However, in many surveys under-representation of these groups may not be a problem."
>
> —Steel D, Vella J, Harrington P. Quality issues in telephone surveys. Australian Journal of Statistics 1996; 38(1):15-34, p. 17.

Telephone coverage has been shown previously to vary according to household attributes, being lower for households of young, unmarried or low income people, and for those living in rented accommodation.[64,66] Households with these characteristics were more likely to be under-represented in telephone surveys. In Australia, because of the high telephone coverage in the 1990s, differences between those with and without telephones were unlikely to affect population prevalence estimates of health and health behaviours for most population groups.[36,67,68] At a time when telephone coverage was improving in Australia and in other countries, some concerns were voiced, as it appeared likely that as country-wide telephone non-coverage rates declined, those left without telephones were increasingly distinctive; i.e. the differences in characteristics of those covered and those not covered were larger in high telephone coverage countries than in low coverage countries.[69:24] With current changes in technology, this situation needs to be monitored (e.g., the same distinctions are likely to apply to households with and without Internet access).

Telephone surveys using the Electronic White Pages (EWP) for sampling (e.g., SA), were likely to under-represent those with unlisted (including silent) numbers (an estimated 15% Australia-wide in 2000, 20.2% in SA in 2002, and 12.5% in major SA country towns in 1998).[60,70,71] Households with unlisted numbers were more likely to contain people who were younger, in single adult households; separated, divorced or never married; and unemployed; and to be located in metropolitan areas.[36,59,60] Use of EWP rather than random digit dialling (RDD) sampling in telephone surveying had the potential for bias, with under-estimation of 'mover', single parent family, and unrelated persons households[70:269]; people of NESB, singles generally (widowed, separated, divorced and never married), and the least socioeconomically advantaged respondents, with a quantifiable effect on various health indicators and lower sample efficiency.[38] Although these differences were not large, they should be considered in line with the purpose of the survey. An additional complication for CATI surveys that have relied on the EWP for sampling is that the last EWP was generated in July 2004.

In Australia in 2000, 97.8% of households had a fixed line household telephone. In 2003, 72% of all households and 86% of households with a child under 15 years of age, had at least one mobile telephone.[72,73] Telephone coverage however, was not uniform. Although national data was lacking, recent state-wide estimates of households without a fixed telephone connection were 3.2% of households in SA in 2002; 4.7% in Qld in 2003; and 10.7% in WA in 2007 (Figure 7).[60,74,75]

Figure 7: Access to different forms of communication in relation to emergency preparedness, WA, October 2007



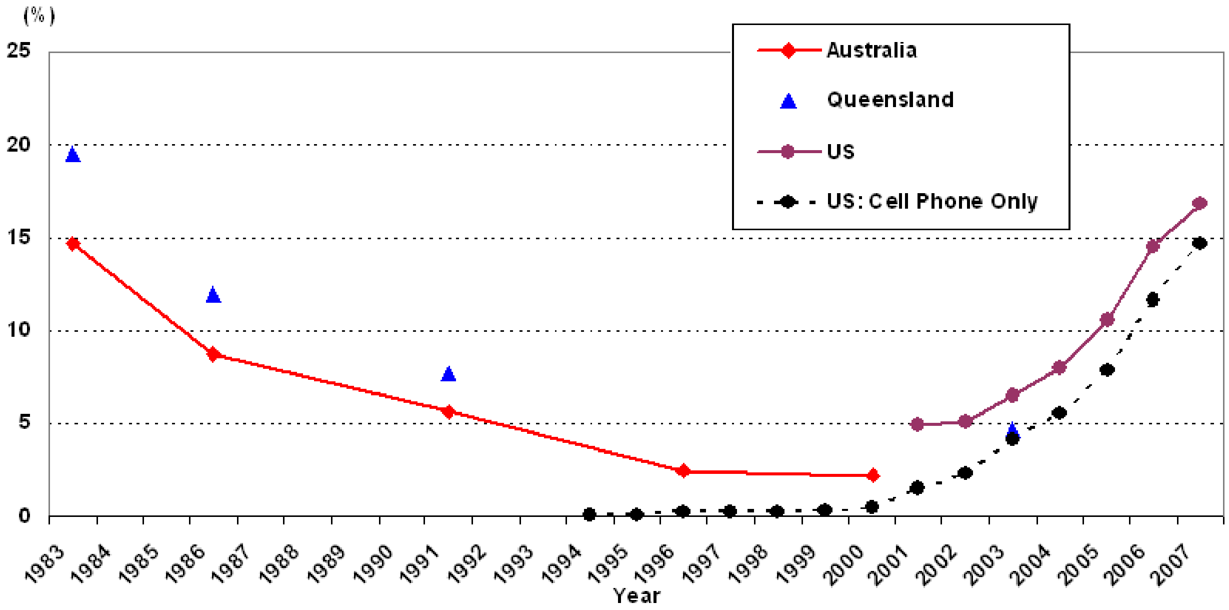
Source: ABS. Community preparedness for emergencies, Western Australia, October 2007. Canberra: ABS, 2008, p. 9.

The latest information from WA in 2007 shows a marked difference in the proportions of households without a fixed telephone connection according to their age and other characteristics. For example, 16.2% of 'young adult' households (with no household members under 15 years or over 60 years of age) had no fixed telephone connection. On the other hand, for households that included both those age groups, the proportion without a fixed telephone was too small to be reliably reported).[75:8]

How many of these same households – or their individual members – had only mobile rather than fixed telephones was unknown. For instance, 6% of people of ages 18-29 years in Qld in 2003 had a mobile phone only (no landline telephone) and more recent SA data suggest a slow rise in mobile-phone-only households.[19,74] A large rapid change is anticipated as has been the case in Europe, and to a lesser extent, the US in recent years. Figure 8 charts changes in the proportion of households with no fixed telephone connection, both in Australia and the US. The 2007 figures show that while 16.85% of US households had no fixed telephone connection, this represented 14.7% of households which had at least one cell (mobile) phone and the remaining 2.15% which had neither a fixed nor a cell phone.[63]

Latest estimates from the US National Health Interview Survey, which collects health-related information and data on telephone coverage, showed that in the second half of 2007, 15.8% of US households were mobile-phone-only households, with the highest proportion composed of unrelated adults (56.9%).[63] Those in rental accommodation had much higher mobile-phone-only rates than home-owners (30.9% versus 7.3%), as did younger households (e.g., 34.5% of people 25-29 years of age, 15.5% of 30-44 year olds, but only 2.2% of people aged 65 years and more). In the US, some marked differences had emerged in the characteristics of adults in mobile-phone-only households: the prevalence of binge drinking was twice as high (37.3%) as that in adults living in households with fixed telephones (17.7%), and they were more likely to be current smokers. Blumberg and Luke concluded that the potential for bias arising from population under-coverage was a present and growing threat for US surveys conducted only on fixed telephones.[63]

Figure 8: No telephone connection in household, Australia and US



Data sources: ABS Supplementary Survey (MPS) 1983, 1986, 1991; ABS Population Survey Monitor 1996, 2000; ABS Supplementary Survey (MPS) – Queensland 2003; US Mediamark Research 2001-2003; US Consumer Expenditure Survey: Cell Phone only 1994-2003; US National Health Interview Survey 2004-2007.

In Australia, the take-up of fixed telephone connections has declined in recent years, with the decline most marked in 18-24 year olds, who tend to be early adopters of new technologies such as mobile phones, Internet and VoIP[7].76:45, citing Roy Morgan Single Source, July 2004-March 2007, 14+ years old, sample=64,479 At the same time, use of mobile phones has increased. Although mobile phone ownership was highest in 18-34 year olds (well over 80%) and lowest in those over 65 years, the largest increase between 2005-06 and 2006-07 was in the latter, with around 50% owning a mobile phone in 2006-07. Around 20% of mobile phone owners surveyed said they would replace their fixed home phone with mobile phone services. 76:10, citing Roy Morgan Single Source, July 2005-March 2007, 14+ years old, sample=35,997

A recent analysis by PHIDU for the Population Health Information Development Group (PHIDG) examining data from Roy Morgan household surveys conducted over two periods (August 2001 to July 2003, and January 2006 to December 2007) found that:

- the number of responding **households with no fixed-line phone** had almost doubled (from between 4.0%-4.2% in the 2001-03 period to between 7.9%-8.2% in the 2006-07 period);
- **young males** (ages 18-24 years) had over twice the proportion (2.4 times, 18.9%) without a fixed-line phone when compared with the total population (18 years and over) while for **young females** the differential was almost as great (2.2 times, 17.6% without a fixed-line phone);
- **smokers aged 18-24 years** were more likely to be without a fixed-line phone (43% more males and 73% more females aged 18-24 years did not have a fixed-line phone when compared with all males/ females at these ages);
- **smokers at all ages** (18+ years) were almost twice as likely to be without a fixed-line phone (15.1% compared with 7.9%); and conversely, non-smokers at all ages were less likely to be without a fixed-line phone (5.8% compared with 7.9%);

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[7] VoIP is an acronym for Voice over Internet Protocol, also called IP (Internet Protocol) telephony, Internet or broadband telephony, or digital phone, describing voice conversations routed over the Internet or other IP-based networks.

- people of **acceptable weight** were 22% less likely than all respondents (18+ years) to have a fixed-line phone; while
- people who reported their height and weight at levels that are categorised either as **overweight or obese** were 15% more likely to have a fixed-line phone.[58]

The implications of these results for the use of telephone survey data are that these surveys are likely to under-estimate the number and characteristics of smokers and of people of acceptable weight; and to over-estimate the number and characteristics of non-smokers and people categorised as overweight or obese.

The analysis shows clearly that fixed-line home phone ownership is not evenly distributed in the community, is in relatively rapid decline, and that its continued use as the sampling frame for CATI population health surveys has the potential to introduce major biases to the monitoring of important health behaviours. Weighting telephone survey results by age and sex will not 'correct' the data for these potential (inherent) biases, and the results reported above suggest the need for extra caution when interpreting telephone-based survey results.[58]

Declining response rates – applies to all modes including CATI and CAPI

It has been observed, both in Australia and in other comparable countries (e.g., the US, Denmark) that both increasing refusal rates and declining response and/or participation rates are making it more difficult – and therefore more expensive – to achieve representative population samples generally, including for cross-sectional, case-control and cohort studies.[55-57,77] The reasons behind these continuing increases in refusals/ declines in participation include:

- the proliferation of surveys in recent times – including telemarketing surveys and political polls resulting in more requests to participate per person, and creating an 'over-surveyed' society[56,57];
- survey participation has become more dependent on the relevance of a given survey to the lives of those surveyed: an example is the high response rate (84.1%) to the initial NSW Child Health Survey in 2001 – much higher than the 70.8% response to the corresponding adult health survey in 1997 and the 67.6% response to the general population survey in 2002 , with respondents frequently remarking that they had never been surveyed about this topic before[77,78];
- the general decrease in volunteering and social participation in developed societies[56];
- community disillusionment with science, diminished belief in the validity of research claims and health-related messages, distrust of the medical professions, and fear of being exploited (or experimented on), all potentially hinder participation, particularly among minority groups (e.g., Indigenous Australians have long rejected their tokenistic 'participation' in scientific research)[56,79]; and
- dwindling availability of potential respondents as people have become harder to contact due to: changes in telephone technology and use (e.g., growth in unlisted telephone numbers and mobile telephones, increased use of telephone screening), and fewer people at home during the day – with an increased proportion of people working long and/or non-standard hours, more women in the labour force, and consequent reductions in free time, especially in urban areas.[56,80,81]

Suggestions that have been made to increase declining response, many of which are already employed by Australian state-wide CATI population health surveys, include:

- increasing the use of advance or primary approach letters/ postcards; and increasing the number of callbacks, the spread of times at which they are made, and the availability of 'appointments' at times suitable to respondents[57,82-84];[8]
- emphasizing the "uniqueness and importance" of the survey early in the interview introduction to motivate participants and reduce refusals[57:120];
- improving interviewer training and supervision and increasing the use of experienced interviewers[42,57];
- increasing the use of 'respondent-friendly' self-administered surveys using new delivery modes such as email and Internet, either as part of mixed mode surveys or in a stand-alone mode[34:15];
- shortening the length of interviews to increase response, maintain respondent motivation and improve data quality[57];
- reducing respondent burden by the use of mixed modes, and separating the sampling frame from the method of collection (previously part of the same process); for instance, recruiting using a 'lean survey' that collects information on key issues only by telephone, and collecting the rest of the survey data using different modes (e.g., self-administration of mail or internet questionnaires) asking questions that do not have mode effects[19,85];
- changing sampling practices to recruit once (i.e. to a panel) and interview periodically (e.g., every three months) during the term of the respondent's panel membership (e.g., a year). An example of a current panel survey is the ABS monthly Labour Force Survey. Panel surveys also need to be adequately resourced to provide incentives to retain panel members; and
- embracing the Do Not Call Register which was considered likely to improve response for health surveys; however, Link and colleagues found that the US register had had no significant impact (neither positive nor negative) on state-level response rates to the Behavioral Risk Factor Surveillance System.[19,86]

> "Rotating panel designs are often used when the main objectives are cross-sectional estimates and short-term estimates of net and gross change. Labour force surveys have a rotating panel design in many countries."
>
> — Lynn P. Longitudinal surveys methodology. Vitoria-Gasteiz: EUSTAT, 2005, p. 17.

Looking ahead

The trend towards mobile-phone-only households may require a move from household-based to person-based sampling, if Australia follows the US trend. US researchers have shown that there are relatively few mobile-phone-only households whose members share the same mobile phone as is common for landline connections. In the California Health Interview Cell Phone Pilot Study, Brick, Edwards and Lee found only 11% of mobile-phone-only households with adult members sharing a mobile phone; and Link and colleagues in a three state study as part of the Behavioral Risk Factor Surveillance System found similar proportions of mobile-phone-sharing among household members (11% to 15% with the differences not statistically significant).[84,87]

Mobile telephone advantages include the ability to retain respondents in longitudinal surveys when they move; while disadvantages include the less defined sample and the difficulty of combining mobile phone with fixed line surveys.[19] In the US, surveys sampling mobile phone

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[8] Brick and colleagues noted that in 2005 the California Health Interview Survey had a minimum of 23 callbacks.[84:803]

numbers have been shown to be feasible but costlier, and with lower participation rates, than their comparable 'traditional' (i.e. fixed telephone) CATI surveys.[84,87]

A final issue is whether existing face-to-face surveys can be used to generate information on the level of fixed line usage – and whether it is declining. In particular, current data are needed on the percentage of the population with mobile telephones, and on the characteristics of mobile-phone-only households, to delineate any significant differences from households with fixed lines (as found in the US, and in the analysis of Roy Morgan Australian household survey data reported above). It has been suggested that the role of ABS should include the collection of information on telephone coverage and the characteristics of telephone owners to provide an assessment of this trend.[19]

3.1.3 General social surveys

The General Social Survey (GSS) was first conducted in from March to July 2002 and collected a range of information, including self-reported health and disability status, from face-to-face household surveys for the adult (ages 18 years and over) Australian population (excluding those in remote areas, approximately 2% of the population). The GSS was conducted again from March to July 2006, and is scheduled to be repeated every four years.

The objectives of the GSS are to:

- obtain data on a range of social dimensions from the same individuals at a single point in time;
- enable analysis of the inter-relationships between social circumstances and outcomes, including exploration of multiple advantage and disadvantage; and
- provide a baseline for the comparison of social circumstances and outcomes over time and across population groups.[88]

The GSS was designed as a core set of topics, with the inclusion of a flexible component on contemporary and emerging issues in each survey cycle. Core information includes details of health and disability (self-reported health status, disability status; disability type; education and employment restrictions), housing, education, labour force, transport, crime, and indicators of family and community involvement; economic items (income and selected assets, liabilities and financial stress indicators); and demographic details. The 2002 GSS flexible component included topics on the extent of computer and internet access, attendance at cultural and sporting events, and participation in sport or other physical activity. In 2006 the GSS flexible component included topics on social capital, voluntary work and the category of visa held by Australian immigrants.[89]

The National Aboriginal and Torres Strait Islander Social Survey (NATSISS) was first conducted from August 2002 to April 2003 (commencing in the same year as the GSS), and will be repeated every six years. Coverage in the NATSISS is of Aboriginal and Torres Strait Islander residents (ages 15 years and over) in private dwellings across all states and territories, including people living in remote areas. Health topics included: self-reported health status, disability status, smoker status, alcohol risk levels, and substance use. Topics on social dimensions included: culture and language; presence and type of stressors; networks; removal from natural family; education; employment characteristics including barriers, use of support services and CDEP participation; income and financial stress; housing characteristics; crime and justice; transport; and information technology (computer and internet use).[90]

The 2008 NATSISS has an increased sample size from the previous survey, with enumeration of the national sample scheduled for completion in December 2008. The survey includes information on most of the dimensions from the 2002 NATSISS as well as some new items. Key new content includes an expanded number of items for children less than 15 years of age and maternal health information. Information from the 2008 NATSISS is expected to be released in late 2009.

Internet sites

For information on the General Social Survey and the National Aboriginal and Torres Strait Islander Social Survey and publications see the Australian Bureau of Statistics (ABS) website: www.abs.gov.au and navigate through *Statistics*, *Catalogue number* and *Social statistics - general* to the listings under catalogue number 4159.0.

3.1.4 Survey of Disability, Ageing and Carers

The ABS Survey of Disability, Ageing and Carers (SDAC) collects information on people with disabilities, older persons, people who provided care for older people and people with disabilities, and controls (for comparison of demographic and socioeconomic situations).[91] Commonwealth and state government departments (such as DoHA and FaHCSIA) use the information on the size and distribution of particular groups eligible for assistance as the basis for allocating and distributing program funds to state governments.[92]

In 2003, household interviews were again conducted using computer assisted personal interviewing (CAPI) to collect, store, manipulate and transmit data (CAPI was first used in the 1998 survey). In 2003 a total of 36,241 persons in households and 5,145 persons in cared accommodation were enumerated, with response rates of 89% of households 92% of cared-accommodation establishments.

Five national surveys have been run (1981, 1988, 1993, 1998 and 2003) and some information in each changes over time after consultations with users to ensure disability and caring issues are adequately covered. For instance, the scope of the survey was expanded from 1988, to collect information about informal carers of people with a disability and the 1993, 1998 and 2003 surveys collected information about people living in cared-accommodation, such as nursing homes, as well as those in households.[93: 3-4] In 2003, the number of questions on computer access and use was increased and the SDAC collected information regarding access to and use of the Internet at home and elsewhere for the first time.[93:2] Changes in the terminology used have improved the conceptual and definitional alignment with the International Classification of Functioning, Disability and Health. Comparison between surveys is complex.

Internet sites

For information on the Survey of Disability, Ageing and Carers and publications see the Australian Bureau of Statistics (ABS) website: www.abs.gov.au and navigate through *Statistics*, *Catalogue number* and *Welfare and social services* to the listings under catalogue number 4430.0.

3.1.5 Survey of Mental Health and Wellbeing

The ABS Survey of Mental Health and Wellbeing (SMHWB) was commissioned by the Australian Government as part of the National Mental Health Strategy, in response to a scarcity of information on mental health morbidity, disability and service use in the general population.[94,95] The first information collected comprised three components: a general population survey of over 10,600 adults, a survey of 4,500 children and adolescents, and a study of low prevalence (psychotic) disorders, such as schizophrenia. The adult population survey, conducted by the ABS in 1997, is described below.

The SMHWB objectives were to provide information on:

- the prevalence of selected major mental disorders (including anxiety, affective, and substance use disorders);
- the level of disability associated with these disorders; and
- the health services used and help needed as a consequence of mental health problems for Australians aged 18 years and over.[94:2]

Assessment of mental health in the general population using household surveys is complex as mental disorder is normally clinically diagnosed by health professionals in a healthcare setting. The major mental disorders selected for inclusion in the survey were those considered to have sufficiently high population prevalence rates and that were identifiable in an interviewer-based household survey.[94] The diagnostic component of the interview was administered through a modified version of the Composite International Diagnostic Interview and various other scales were also applied including the Kessler Psychological Distress Scale–10 (the K10[9]). Surveyed topics included: chronic physical conditions and disability, health service use as a consequence of a mental health problem and respondents' perceived need for health services, respondents' general health and wellbeing, and their demographic characteristics.

A second adult SMHWB was conducted by the ABS in 2007, and planned to achieve approximately 11,000 participants of ages 16 to 85 years (a slightly different age range to the first SMHWB which was restricted to ages 18 years and over). It collected information on: personal functioning; chronic conditions; specific mental health issues including dementia, depression, mania, panic disorder, social phobia, substance use, suicidality and others; as well as data on medications; social networks; caregiving; and demographic characteristics. Information from the survey was expected to be released in October 2008.

Internet sites

For information on the Survey of Mental Health and Wellbeing and publications see the Australian Bureau of Statistics (ABS) website: www.abs.gov.au and navigate through *Statistics*, *Catalogue number* and *Social statistics* and *Health* to the listings under catalogue numbers 4326.0 and 4327.0.

3.1.6 Community Housing Infrastructure Needs Survey

The Community Housing Infrastructure Needs Survey (CHINS) is a census of all discrete (separate and distinct) Aboriginal and Torres Strait Islander (ATSI) communities and Indigenous Housing Organisations (IHOs) in urban, rural and remote areas in all states and territories. The first CHINS was enumerated from August to October 1999 by the ABS on behalf of the (then) Aboriginal and Torres Strait Islander Commission (ATSIC).[97]

CHINS collects nation-wide details on Indigenous housing conditions (current housing stock, dwelling management practices, selected income and expenditure arrangements of IHOs providing housing to ATSI people); and details of housing and related infrastructure (e.g., water, electricity, sewerage, drainage, rubbish collection and disposal), as well as other facilities such as transport, communication, education, sport and health services, available in distinct ATSI communities.[98] In addition to environmental health topics (e.g., water, sewerage) health-related topics include the type of health facilities in the community and/or the distance to the nearest

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[9] This was the first collection of national information on psychological distress in the general population in Australia.[96] The K10 has since been included in both the NHS in 2001 and 2004-05 as it was found to be a better predictor of depression and anxiety disorders than the other short, general measures that had also been used in the 1997 SMHWB.[89]

health facilities outside the community (e.g., hospital, first aid clinic, chemist/dispensary); and health promotion programs conducted in the community.

The survey aims to provide information that can be used to:

- evaluate policies and programs designed to improve housing and infrastructure services for Aboriginal and Torres Strait Islander peoples living in both discrete communities and in other housing managed by Indigenous organisations.
- provide a basis for the design of future policies and to target programs to areas of identified need.[98:iv]

For example, CHINS data has been used to support the Aboriginal Rental Housing Program, the Community Housing and Infrastructure Program (CHIP), the National Aboriginal Health Strategy, and the Fixing Houses for Better Health program.[99]

CHINS was developed after an investigation by the ABS in 1999 found a lack of national Indigenous information. The ABS was commissioned and funded by ATSIC to conduct the survey under the *Aboriginal and Torres Strait Islander Commission Act 1989* to address this information scarcity.[97:iv] CHINS was conducted again in 2001 for ATSIC.[100] After a review of the 2001 CHINS in 2004 by the Aboriginal and Torres Strait Islander Services and key stakeholders, which assessed the overall value and benefit and future directions, a number of changes were made. The third CHINS, conducted in 2006 for the (then) Department of Families, Community Services and Indigenous Affairs, updated the information collected previously in 2001 and 1999. New items were added and some previously collected items removed, with the overall changes affecting an estimated ten per cent of topics.[98:96-100] In 2001 and 2006, CHINS data were collected in conjunction with the ABS' field preparations for the Census of Population and Housing.[98:96]

The survey is conducted through personal interviews with key members of IHOs and communities, including community council chairpersons, council clerks, administrators, housing officers, water and essential service officers and health clinic administrators. CHINS was the ABS's first survey undertaken in this manner and extensive testing and validation have confirmed the suitability of the methodology for this survey.[97: 61-62] The first CHINS in 1999 enumerated a total of 707 IHOs (20,424 dwellings) and 1,291 distinct Indigenous communities (15,603 dwellings, 109,994 persons).[97] In the latest 2006 CHINS a total of 496 IHOs (21,854 dwellings) and 1,187 distinct Indigenous communities (17,177 dwellings, 92,960 persons) were enumerated.[98]

CHINS is reported through publications and additional detailed tables available from the ABS. Access to unit records only for relevant agencies (no public availability) is through the Department of Families, Housing, Community Services and Indigenous Affairs, who will also consider cases for special data services.

Internet sites

For information on the Community Housing Infrastructure Needs Survey and publications see the Australian Bureau of Statistics (ABS) website: www.abs.gov.au and navigate through *Statistics*, *Catalogue number* and *Social statistics* and *Indigenous statistics* to the listings under catalogue number 4710.0.

To apply for special data services access to CHINS see the Department of Families, Housing, Community Services and Indigenous Affairs website: www.facsia.gov.au/internet/facsinternet.nsf/4b93590049083177ca256fa3001481ae/4ed4c9f8be4e02aeca2574a500146985?OpenDocument

3.1.7 Australian Secondary Schools Alcohol and Drug Survey

The Australian Secondary Schools Alcohol and Drug Survey (ASSAD) is a nation-wide collection on children and young people, notable for both the length of its time series and for being conducted in the schools setting. ASSAD is a survey of secondary school students (aged 12 to 17 years) that is coordinated nationally by the Cancer Council Australia (through state cancer councils) and carried out by individual states and territories; except in NSW where the NSW School Students Health Behaviours (SSHB) Survey (the NSW component of the Australian Secondary Schools Alcohol and Drug Survey) is coordinated by the Department of Health.

ASSAD has been run triennially since it commenced in 1984. The core survey material covers demographic characteristics, smoking, and alcohol; licit and illicit drug use (from 1996); and increasingly, health-related behaviours (e.g., sun protection from 1999). Individual states and territories may include supplementary surveys with the core survey. For example, in 2002 and again in 2005, the NSW SSHB Survey included two supplementary questionnaires with questions on attitudes to smoking, access to cigarettes, access to alcohol, and violent behaviour, in the first; and questions on eating behaviours, physical activity, injury and mental health, in the second.[101,102]

The objectives of ASSAD are to:

- provide baseline data on drug use and exposure, knowledge and attitudes;
- monitor and evaluate National Drug Strategy issues;
- detail trends in the prevalence of adolescent drug use and other health-related behaviours; and
- identify needs and strategies to address drug-related problems.[103:59]

Junior and senior schools identified through a random sample (of schools in the three main education sectors: government, Catholic and independent) are approached to participate in the survey, and if they agree, a random sample of approximately 80 students from mixed years is drawn from school rolls (20 students each from junior school years 7 to 10; 40 students each from senior school years 11 and 12). In 2005, a total of 599 secondary schools and 111 feeder primary schools (Year 7 students in WA, SA, Qld and NT) were approached, with 376 secondary schools participating, giving a response rate for secondary schools of 63% (similar to 2002) and 62 primary schools allowed Year 7 students to participate resulting in a 55% response rate for feeder schools.[104:7] In 1996, however, the overall school response rate was 77% (434 schools), and response rates – like those in other surveys – are declining as demands on staff and students (particularly year 12 students) increase, and as more surveys make approaches to schools. Chronic truants and early school leavers have previously been identified as likely to be under-represented in the survey.

Although coordinated nationally, each state/ territory runs its own survey and manages its own supplementary data, while the Centre for Behavioural Research in Cancer reports on the survey nationally. The Commonwealth has access through the provision of national 'uninterpreted' unit record data, which is used for broad level monitoring and evaluation of the National Drug Strategy and to inform policy interventions at both state and national levels. [101,102:59-60]

3.1.8 Healthcare provider collections

- The National Hospital Morbidity Database
- Medicare Australia data
- Disease Registries: Cancer including Mesothelioma, Diabetes, End stage renal failure, Organ donation
- Bettering the Evaluation and Care of Health (BEACH)

Australia's main health provider based information collections include hospital, Medicare, cancer and diabetes databases and registers. The BEACH program (Bettering the Evaluation and Care of Health), an ongoing national study of general practice activity that collects information about general practitioner (GP)-patient encounters also gives health provider information. Three additional registers provide information on joint replacements and organ donors. See *Appendix D* for more information on the majority of these collections.

The National Hospital Morbidity Database

The Hospital Morbidity Database is compiled by AIHW from electronic summary records collected in admitted patient morbidity data collection systems in Australian hospitals. The collection is essentially a census of (non-identifiable) summary information about patients who have been separated (i.e. discharged) from (almost all) public and private hospitals in Australia. Information include demographic, administrative and length of stay data, and data on the diagnoses of the patient, the procedures they underwent in hospital and external causes of injury and poisoning, information on the quality of the diagnosis, procedure and external cause data.[105] The database is based on hospital episodes and not individual patients, so those who separate more than once have more than one record.[106] Financial year data is updated every 12 months (currently held for 1993-94 to 2005-06) and reported annually in *Australian hospital statistics* and in *Australia's health*.[107-109] In financial year 2006-07 there were 7,602,917 hospital separations recorded from 1,301 hospitals.

Medicare

Medicare Australia (previously the Health Insurance Commission [HIC]) administers Australia's universal health insurance scheme, Medicare, and collects billing information on visits and procedures performed in public hospitals and by medical practitioners including GPs, specialists, participating optometrists and dentists (specified services only). On 30 June 2007, there were 21.1 million people registered.[110] Medicare Australia reports annually, provides interactive reporting through its website and can provide de-identified information for health researchers.

Medicare Australia operates a number of registers, including the National Bowel Cancer Screening Register, The Australian Organ Donor Register – these are described in more detail below – and the Australian Childhood Immunisation Register (ACIR). It has been suggested that ACIR should be expanded into a whole-of-life immunisation register as the number of vaccines increases, and some vaccines are of most relevance to adults (e.g., human papillomavirus vaccine for young adults, influenza vaccines for older adults). Newer vaccines in development are likely to be used to prevent chronic conditions (e.g., cervical and skin cancers), and the absence of such a register means that researchers and vaccine evaluators must rely on self-report which is known to be problematic.[111] The feasibility of expanding the ACIR into a whole-of-life immunisation register was being considered by the Australian Government.

Disease Registries

There are currently five major national population based disease registries in Australia and they collect information about cancer (including mesothelioma, and bowel cancer screening), diabetes, and end stage renal failure.

Cancer

All new cancer diagnoses (excepting non-melanoma skin cancer[10]) are required to be registered by state and territory law and the state cancer registries collate demographic, diagnosis and treatment information about people with newly diagnosed cancer from hospitals, haematologists, pathologists, radiation oncologists, cancer treatment centres and other sources. Information about cancer deaths is also collected from the state and territory Registrars of Births, Deaths and Marriages. The *National Cancer Statistics Clearing House* (NCSCH), maintained at AIHW, uses data collated from registries to monitor cancer incidence, mortality and emerging trends since 1982.[112,113] In 2004, the NCSCH held information on 98,336 cancer cases, and 38,489 cancer-related deaths.

Mesothelioma

The *Australian Mesothelioma Register* commenced in 1980 (as the *Australian Mesothelioma Surveillance Program*) to receive and collate voluntarily notified cases of mesothelioma (a rare cancer that develops decades after exposure to asbestos) from a network of medical specialists, pathologists, state and territory departments of occupational health, cancer registries, compensation authorities and other sources including the *WA Mesothelioma Register* and the *NSW Dust Diseases Board*. The register monitors asbestos exposure, publishes annual incidence reports, and has established occupational and industrial links and calculated lifetime risks for a range of occupations.[114] In 2007, the Australian Safety and Compensation Council (ASCC) agreed to improve the collection and dissemination of information on mesothelioma as notified new cases had become significantly less than those mandatorily notified to state cancer registries.[115] Information on the number of new cases of, and deaths from, mesothelioma, are now collected by the AIHW NCSCH (via state cancer registries), and in the *National Mortality Database*, respectively.[116]

Bowel cancer screening

The National Bowel Cancer Screening Register commenced in 2006 and is operated by Medicare Australia, working in partnership with DoHA to implement the National Bowel Cancer Screening Program. Medicate Australia sends invitations to, and follows up, eligible people (drawn from Medicare and Department of Veterans' Affairs records) to participate in the Screening Program, and the Screening Register records information including age, sex, results of screening tests, nominated doctor, and the results of any further tests undertaken (e.g., colonoscopy or biopsy).[117] The AIHW holds the *National Bowel Cancer Screening Program dataset* (received every six months from Medicare Australia) for the purpose of matching to cancer registry data for evaluation purposes, however, for researchers, the most detailed information is held in the Medicare Screening Register.[118] The 2006-07 Screening Program participation for those who were eligible (aged 55 or 65 years and sent invitations to participate between 7 August 2006 and 31 July 2007) was estimated at 41.0%.[118:5-8]

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[10] Estimates of non-melanoma skin cancer cases are provided intermittently on the basis of information collected by the National Non-melanoma Skin Cancer Survey – see *Appendix D*.

Diabetes

The *National Diabetes Register* was established in 1999 to collect information about Australians who had insulin-dependent diabetes and has since been expanded to collect information on individuals using insulin to treat all types of diabetes. It is operated by the AIHW using data from the National Diabetes Services Scheme and the Australasian Paediatric Endocrine Group.[113] The publication of the *National Diabetes Register statistical profile 2000*, the first statistical report of the National Diabetes Register, marked the availability of the register for research purposes.[119] In the period from 1999 to 2005 there were 76,124 people registered on the *National Diabetes Register.*, as reported in the latest *statistical profile 1999-2005*.[120]

End stage renal failure

The *Australia and New Zealand Dialysis and Transplant Registry* (ANZDATA) was established in 1977 (amalgamating the previously separate registries for dialysis and transplants), and is coordinated by the Queen Elizabeth Hospital, Adelaide. ANZDATA collects a wide range of statistics which relate to the outcomes of treatment of those with end stage renal failure.[121]

Bettering the Evaluation and Care of Health (BEACH)

The BEACH program (Bettering the Evaluation and Care of Health), is a continuous national study of general practice activity that has collected information about general practitioner (GP)-patient encounters since 1998. The survey is run by the AIHW and the Australian General Practice Statistics and Classification Centre (AGPSCC) at the University of Sydney with a sample drawn by the Primary Care Division of the DoHA every three months.[122] A random sample of approximately 1,000 general practitioners per year is selected from all recognised GPs who claimed a minimum of 375 general practice Medicare items in the most recently available three-month Medicare Australia data period (to ensure inclusion of the majority of part-time GPs).[122]

Each GP records details from 100 consecutive doctor-patient encounters on structured paper encounter forms that examine patients' health status, risk factors and existing morbidity as well as characteristics of the health care delivery (use and effectiveness of medication and treatment, use of other health services). GPs also provide information that describes themselves and their major practice. A supplementary component within BEACH, the SAND program (Supplementary Analysis of Nominated Data), collects additional information about the patient, from the patient. SAND collects core information on height, weight, patient-assessed well-being, alcohol use and smoking status with every survey. It also contains a section that varies to address different issues related to patient/health care delivery in general practice.[123]

The BEACH program has three primary aims:

- to provide a reliable and valid data-collection process for general practice that is responsive to the ever-changing needs of information users;
- to establish an ongoing database of GP-patient encounter information; and
- to assess patient risk factors and health states and the relationship these factors have with health service activity.[122:2]

GPs receive an analysis of their results compared with nine other unidentified practitioners, the national average and with targets relating to the National Health Priority Areas. Each participating GP earns 25 audit points from the Royal Australian College of General Practitioners towards their quality assurance requirements.

The AGPSCC publishes, through the AIHW, the annual results of each previous BEACH data year, providing an overview of general practice activity on a national basis.[122] Additional reporting on selected topics and specific research questions have included a comparative study of general practice activity in the states and territories[124]; a comparative study of general practice activity in rural and metropolitan areas[125]; and a report on more than 100 BEACH sub-studies.[106]

Internet sites

The National Hospital Morbidity Database website (AIHW):
http://www.aihw.gov.au/hospitals/nhm_database.cfm

Medicare Australia (previously the Health Insurance Commission [HIC]) website:
http://www.medicareaustralia.gov.au/about/index.jsp/

National Cancer Statistics Clearing House website (AIHW):
http://www.aihw.gov.au/cancer/ncsch/

National Diabetes Register website (AIHW):
http://www.aihw.gov.au/diabetes/ndr.cfm

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) website:
http://www.anzdata.org.au/v1/index.html

Australian Mesothelioma Register website:
http://www.ascc.gov.au/ascc/AboutUs/Publications/StatReports/Mesothelioma/AustralianMesotheliomaRegister.htm

Bettering the Evaluation And Care of Health (BEACH), general practice activity in Australia (AGPSCC) website: http://www.fmrc.org.au/beach.htm

Additional registers

Three additional registers provide information on joint replacements and organ donors.

Joint replacements

The Australian Orthopaedic Association (AOA) *National Joint Replacement Registry* (NJRR) was established in 1999 to collect information to assess the outcomes of patients receiving hip and knee replacements. It links individual patients, their diagnoses, the operative joint (including side) and the specific prostheses used.[126:10] The success or otherwise of a procedure can be determined by linking data to subsequent procedures for that individual. The national registry enables faulty prostheses to be identified and acted on. In 2007 the NJRR's role was expanded to include records on surgery for ankles, shoulders, wrists and spinal disc replacements and their effectiveness.[127] This information will help surgeons make better clinical choices about the most appropriate joint replacements for their patients. Up to 70,000 people were expected to have joint replacement surgery in 2007-2008.

Organ donation

Australia has two registries that relate to organ donation. The *Australian Organ Donor Register* – operated by Medicare Australia – is Australia's national organ and tissue donor register.[128] The register allows individuals to record their legal decision to consent or object to becoming an organ or tissue donor after death. The information recorded on the register can be verified at all times by authorised medical personnel, anywhere in Australia.

By contrast, the *Australia and New Zealand Organ Donation Registry* (ANZOD) – operated by the ANZDATA Registry at the Queen Elizabeth Hospital, Adelaide – collects and records data on all organ donors after death.[121] It also collects and makes available, the number of patients awaiting organ transplants in Australia and New Zealand, and various statistics including a summary of organ donations.

Internet sites

Australian Orthopaedic Association (AOA) National Joint Replacement Registry website:
http://www.dmac.adelaide.edu.au/aoanjrr/index.jsp

The Australian Organ Donor Register
http://www.medicareaustralia.gov.au/public/services/aodr/index.jsp

The Australia and New Zealand Organ Donor Registry (ANZOD) website:
http://www.anzdata.org.au/anzod/anzodwelcome.htm

3.1.9 Vital statistics and demographic information

Australia's detailed vital statistics collections based on births and deaths registrations are briefly described below. The major demographic collection is the five yearly *Census of Population and Housing* conducted by the ABS (most recently in 2006), and various collections producing population estimates (by age, sex, country of birth, Indigenous status, registered marital status, geographical distribution) as well as estimates of families and households.[129] Population projections are published regularly by the ABS, as well as statistics on births, deaths, marriages, divorces, overseas arrivals and departures, and internal migration.

Census of Population and Housing

There have been three major changes to the *Census* since this Audit first reported.

1. The first was the move to include a web-based option to the collection mode of the Census in 2006, with more than 720,000 households across Australia (including Australian bases in Antarctica) submitting their Census forms using the web-based eCensus program (with take-up ranging from an estimated 14.8% of households in the ACT to 5.9% in the NT, and a national average of 8.4%).[130]

2. The Census Data Enhancement Project aims primarily to enhance the value of the Census by combining it with future censuses and other datasets held by the ABS. A secondary aim is to support decision making by increasing the amount of relevant information on Australian society. The Census Data Enhancement Project has three main features:

- the Statistical Longitudinal Census Dataset (SLCD);
- use of the SLCD with specified non-ABS datasets (e.g., disease registers); and
- quality studies.[131]

The Project had been considered by the ABS for several years, and preliminary work included a public consultation process, focus groups, a discussion paper released in April 2005, public submissions, a privacy impact assessment, and a statement of intention released in August 2005.[132,133] The SLCD is based on a five per cent sample of the population from the 2006 and subsequent censuses, brought together with specified non-ABS data sets; followed by ABS data quality studies. The longitudinal data set was created using statistical techniques (i.e. using variables other than name and address to bring the data sets together). The five per cent sample will be augmented from the 2011 Census by choosing additional births and migrants since the previous census. It is anticipated that the quality studies will allow the ABS to make improvements to current collections (e.g., expected outcomes of the Indigenous mortality quality study include: better understanding of differences in Indigenous status recording between death registration and census data; identifying factors that contribute to under-coverage of Indigenous deaths).

Names and addresses are destroyed at the end of census processing, as usual, and no identifiable data will leave the ABS. All data released will be in non-identifiable tailored data sets appropriate to research projects which must have statistical purpose. Data laboratory access will be via the RADL (Internet access) or ABS Data Laboratory (on-site access) and outputs will be audited. There remain significant technical challenges in the de-individualised linking using probabilistic techniques as well as difficulties relating to the varying quality of data from different sources.[134]

3. In 2001, the *Census Information Legislation Amendment Act 2000* had enabled respondents to decide to have their imaged census forms retained by the National Archives of Australia for 99 years and to then be released for research purposes.[135:20] The Census Time Capsule Project led to the inclusion of a question in the 2001 Census on whether people wanted their census data to be retained for a data time capsule (the usual case for census data is that it is destroyed after processing). After a good response to the retention of data for a time capsule question in the 2001 Census, it was repeated in the 2006 Census and received an increased uptake. The retained personal information became part of the Census Time Capsule Project; around half of the 2001 records were retained.[135:20]

The National Mortality Database and National Death Index

State and territory Registrars of Births, Deaths and Marriages collect primary information relating to deaths through the legally required death certification process. Main and associated causes of death as recorded by Registrars, are coded for statistical purposes by the ABS, and made available to the AIHW *National Mortality Database* (NMD). The NMD holds all registered deaths in Australia since 1964, with information on the disease or condition leading directly to death and other contributing diseases or conditions, as well as demographic, occupation and administrative information. The data contained are reported in various AIHW publications, notably the *Australia's health* series, which presents information on the levels and trends in deaths overall and from various causes in Australia.[113,136]

State and territory Registrars also provide index level information on the fact of death (all deaths from 1980 on), directly to the AIHW *National Death Index* (NDI) on a continuous monthly basis. Each year when the ABS mortality data becomes available to the AIHW, the NDI is updated with cause of death from the NMD. The NDI is primarily used for the purpose of linking records across databases (e.g., state cancer registries) and the data are often combined with that from the NMD to provide a standardised underlying cause of death.[137]

Enumeration of deaths in Australia is considered to be near comprehensive; however, some demographic characteristics of the deceased may be more accurately reported in some states and territories than in others and data quality varies across, and over time within, states and territories.[138] Indigenous identification in death registrations, in particular, is of varying incompleteness across jurisdictions, with only data from Qld, WA, SA and NT considered to be of an adequate quality to report Indigenous deaths.[139] The AIHW is currently developing a separate Enhanced National Mortality Database (ENMD) to improve the reliability of estimates of Indigenous life expectancy.[139,140] The ENMD will contain data originally sourced from the NMD, with an enhanced Indigenous identifier derived from linking with various other health data collections to facilitate more accurate estimates of Indigenous life expectancy.[140]

The National Perinatal Data Collection

The Perinatal Database contains national data on all births and perinatal deaths in Australia, based on notifications from state and territory perinatal data collections, in which midwives and other staff, using information from mothers as well as from hospital and other records, complete notification forms for all births of 20 weeks or more gestation, or a birthweight of 400 g or more. The data is provided annually to the AIHW National Perinatal Statistics Unit (NPSU) based on a national perinatal minimum data set. The information collected includes the characteristics of the mother; previous pregnancies; the current pregnancy; labour, delivery and the puerperium; and the baby's birth status (live birth or stillbirth), sex, birthweight, Apgar scores and outcome.[141:1]

The NPSU publishes the annual *Australia's mothers and babies* report as well as other reports which draw on the perinatal data.[142]

Internet sites

Information and publications on Australia's major demographic collections, including the *Census of Population and Housing*, and vital statistics (births, deaths, marriages, etc.) can be found at the Australian Bureau of Statistics (ABS) website: www.abs.gov.au/

Information and publications on Australia's detailed vital statistics collections can be found at the Australian Institute of Health and Welfare (AIHW) website: www.aihw.gov.au/

AIHW National Death Index website: www.aihw.gov.au/cancer/ndi/index.cfm

AIHW National Mortality Database website: www.aihw.gov.au/mortality/mortality_database.cfm

AIHW National Perinatal Statistics Unit (NPSU) website: www.aihw.gov.au/npsu/index.html

Perinatal Data Collections website: http://www.npsu.unsw.edu.au/NPSUweb.nsf/page/NPDC

3.1.10 Other time series collections

National Drug Strategy Household Survey

The National Drug Strategy Household Survey (NDSHS) focuses on risk factors including tobacco and alcohol as well as illicit drug use, and has been collected approximately triennially since 1984. The AIHW has undertaken the last four surveys at the request of DoHA, and they have been conducted under the AIHW legislation, providing a high level of protection to respondents in respect of their personal information that includes information on illicit drug use and related behaviours that are, by definition, illegal acts.[143]

The latest NDSHS collected information from residents in private households across Australia of ages 12 years and over on their knowledge of and attitudes towards drugs, their drug consumption histories, and related behaviours. Drugs of interest included tobacco, alcohol, and illicit drug use of marijuana/ cannabis, ecstasy, pain killers/ analgesics used for non-medical purposes, and meth/ amphetamine (ice) among others. Conducted in 2007, the NDSHS surveyed 23,365 participants and achieved an overall response rate of 49.3%. The survey design has varied over time, with two modes (drop and collect, and CATI) employed in 2007 and 2004, while three were used in 2001 (drop and collect, face-to-face personal interviewing, and CATI) and the age range also varied, being from 14 years and over. The NDSHS results are reported by AIHW.[143]

Internet sites

Reports from the National Drug Strategy Household Survey can be found in the Publications section of the Australian Institute of Health and Welfare (AIHW) website: www.aihw.gov.au/publications/index.cfm

Dental health collections

The national time series dental health collections include the National Dental Telephone Interview Survey that has been conducted irregularly since 1994, with the latest in 2004-2006 forming part of the National Survey of Adult Oral Health, and the Child Dental Health Survey that (together with its predecessors) has monitored the dental health of children enrolled in state and territory operated school dental services since 1977.[144]

The National Survey of Adult Oral Health in 2004-2006 examined levels of oral disease, perceptions of oral health and patterns of dental care within a representative cross-section of adults across Australia, with selected survey participants subsequently invited to a standardised dental examination. Oral history interviews were also used to collect information on qualitative experiences of oral health and dental care from a small number of survey participants from each 'dental generation' (defined as the four generations born during two-decade intervals through the twentieth century).[145]

Internet sites

Information on the dental data collections can be found at the Dental Statistics and Research Unit (DSRU) website: www.arcpoh.adelaide.edu.au/research/dsru/

3.1.11 Issues arising

Issues arising since the time of the first Audit that are discussed in this section include:

- the rising participant burden of household surveys;
- increasing need for small area data;
- increasing demand for timely, more rapidly released data;
- extensions to the use of existing data collection vehicles;
- the potential effect of learned social responses on survey responses;
- the need for standardised reporting of response; and
- the changing nature of telecommunications and its impact on CATI surveys.

Participant burden

The number and scope of routinely conducted health-related surveys has expanded considerably since this Audit was first carried out in 2001. For example, the NHS has increased its frequency and is now conducted every three years as opposed to every six years; among the states, those that were previously without regular health surveys have introduced them (e.g., Victoria, annually; WA continuously), and those that did have them have increased their collection activity (e.g., SA now has three regular collection vehicles; NSW has introduced continuous collection and now covers the ACT). New data collections have sprung up, such as the Participation in Exercise, Recreation and Sport Survey (ERASS, since 2001, see *Appendix D*) and the GSS (since 2002). State-level collections have expanded into additional areas and populations (e.g., the Victorian Child Health and Wellbeing Survey, planned as a triennial survey with the first in 2006; the Queensland Infant Nutrition and Child Health Omnibus Surveys, planned as five yearly with the first in 2003).

A recent Victorian review revealed that a total of 220 surveys were anticipated to be in the field during 2008 and 2009 in that state alone. They included surveys commissioned by five state government departments, 73 local councils and three non-government organisations (NGOs), but did not include those surveys routinely conducted by the ABS, the Commonwealth government, universities, or commercial organisations; nor any of the program-based and one-off state government surveys (these not-included surveys were thought to exceed the 220 in number).[146] The majority of the state government surveys were to be conducted by telephone (10 of 14 surveys), with at least three in the field in any given quarter. Among Local Councils, 38 of 73 had a total of 206 surveys planned, and of those, 172 had a collection mode determined, with the majority to be administered by mail (91 surveys, 53%), and telephone (23, 13%).[146] The review concluded that over 200,000 Victorians (out of approximately two million households with fixed line telephones) could potentially be contacted by telephone to participate in the 220 surveys and noted the following issues related to data collection:

- that although data collections within individual state departments were coordinated, there was little coordination *across* the totality of state government collections;
- there was similarly little coordination across local government;
- the respondent burden for Victorians appeared to be considerable; and
- the level of telephone surveying was unlikely to be sustainable with response rates decreasing, and mobile-telephone-only households increasing (over 8% in the 18-26 year age group).[146] (See *Limitations of using the telephone as the only entry point to households*, on page 25 where this phenomenon is further discussed).

In consultations related to this Audit it was suggested that other ways of generating relevant indicators needed to be explored, to reduce the dependence on information sought from – and the respondent burden imposed on – the general population by population surveys. Examples drawn from the area of physical activity include using indicators of environment and community amenity that can be generated from council information, area maps, and other non-survey means, such as: access to pavements, walking tracks and parks in the local area; ratio of footpaths/ bicycle paths to roads; distance/ travel time from nearest beach or swimming pool; existence of healthy public policies for local areas. A review by Baker and colleagues included examples of environmental and policy indicators for physical activity such as 'Highway funds for non-vehicle transport' (under Policy and regulation) and 'Miles of walking trails and bike lanes per capita' (under Environmental change).[147]

Surveillance systems that tracked changes in health policies at national, state and local levels were also proposed; examples of physical activity policies and measurement indicators included 'Requiring residential developments to include sidewalks, bikeways and recreational facilities' (policy goal) and 'Percentage of counties/cities with ordinances requiring sidewalks, bikeways and recreation facilities' (sample indicator).[147] Other health-related indicators of this type include: availability of local chronic disease self-management opportunities; and: proximity to health care (the ABS Community Housing and Infrastructure Needs Survey includes various examples[100]).

> "[A]dvances in Canada are increasing the efficiency, capacity and utility of surveillance as a core public health function to inform policies on chronic disease, risk factors and their determinants. However, surveillance data are only one element in the package of evidence to influence healthy public policies. This should be viewed as an opportunity, in that the more diverse the data in the package, the more ownership there is of the arguments being made and the possible impact on public policy making. Partnerships between data collectors and users of the data may be an opportunity to improve the planning and evaluation of chronic disease prevention efforts. Finally, the full power of information technology is increasingly available to collect, analyse, interpret and communicate data in a timely fashion to a number of different audiences."
>
> — Stachenko S. Challenges and opportunities for surveillance data to inform public health policy on chronic non-communicable diseases: Canadian perspectives. Public Health 2008, 122(10):1038-1041, pp. 1040-1041.

There is a need to at least consider whether and what information can be obtained from other sources in order to limit the respondent burden in the population (see Stachenko 2008; and the 2005 Canadian Report of the Advisory Committee on Population Health and Health Security Surveillance Systems for Chronic Disease Risk Factors Task Group[148,149]).

Small area data

At the time of the first Audit a key deficiency in the then current situation with regard to chronic disease and associated risk factor information in Australia was the lack of small area data. Since then, the need for small area information – that is, information at local government area (LGA), community, and neighbourhood levels – has increased, with more chronic disease and risk factor prevention programs and planning occurring at local levels, in line with the public health principles set out in the *Ottawa Charter for Health Promotion*.[150]

In Victoria, for instance, more and more information, and reporting, is required at small area levels:

- to support the 31 Primary Care Partnerships (PCPs) funded by the Victorian government as part of the *Primary Care Partnership Strategy* (2000).[11] PCPs have been increasingly used as the vehicles to implement a range of commonwealth and state programs;
- to prepare and review: three yearly Community Health Plans required for PCPs[12]; three yearly Municipal Public Health Plans (MPHPs) required under the Victorian *Health Act 1958*[13]; and Municipal Early Years Plans, Neighbourhood Renewal Strategies, and other small area planning and reporting instruments; and
- to implement the range of initiatives that provide community-based early intervention services for people with chronic diseases, (e.g., Integrated Chronic Disease Management (ICDM) programs, and Early Intervention in Chronic Disease initiatives) delivered through community health services.[14]

Figure 9 shows the inter-relationship between Municipal Public Health Plans and Community Health Plans in Victoria, and illustrates the dependence on local-level information.

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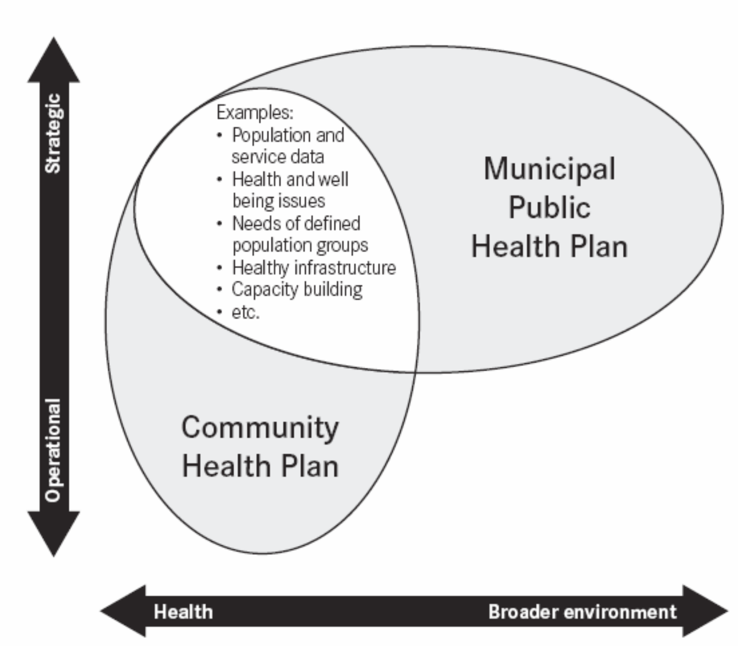
[11] Each PCP represents a region within Victoria (usually two to three LGAs) and has formed voluntary alliances with a range of service providers.[151] PCP members include Divisions of General Practice, hospitals, health services, community health centres, universities, schools, sporting clubs, churches, charities, other government organisations and NGOs.

[12] Each of the 31 PCPs were required to produce a Community Health Plan (CHP) for 2006-2009 (with annual updates), with a focus on the priorities of partnership development, integrated health promotion, service coordination, and integrated chronic disease management.[151] The PCP CHPs include planning and reporting mechanisms for each priority and were expected to be tailored to issues relevant to their geographic (catchment) locations.

[13] MPHPs prepared at three year intervals (with annual reviews) have been a requirement of the local government strategic planning process as specified in the Victorian *Health Act 1958* (since the 1988 amendments). MPHPs must, among other requirements, "enable people living in the municipal district to achieve maximum well-being"; and "provide for periodic evaluation of programs and strategies".[152:Version No. 102, s.29B:30]

[14] Early Intervention in Chronic Disease initiatives should, when selecting chronic diseases to focus on, "take into consideration *local* population health, burden of disease and other relevant data", according to the evaluation framework.[153:11, my italics]

Figure 9: Schematic of the relationship between Municipal Public Health Plans and Community Health Plans



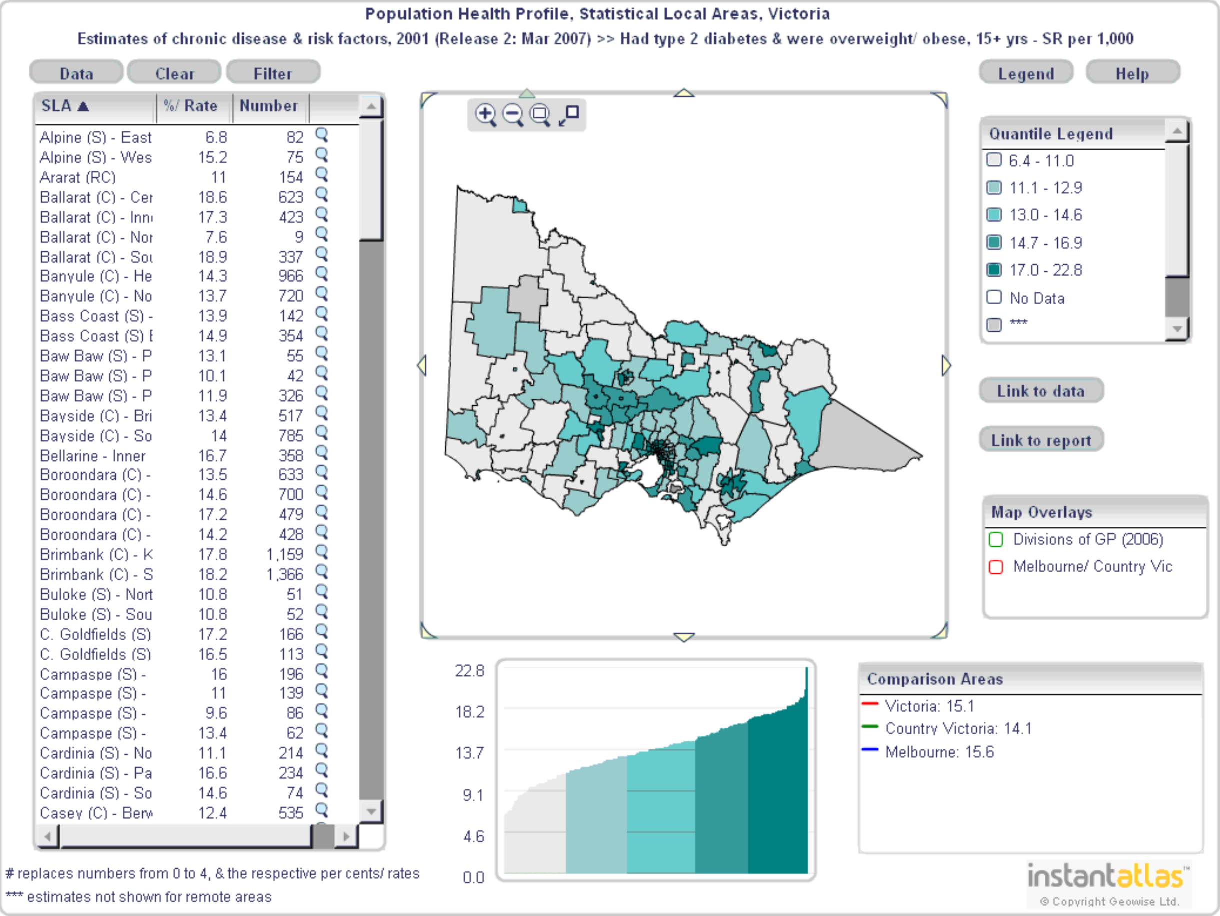
Source: DHS Victoria. Planning together: Community Health Plans and Municipal Public Health Plans. Melbourne: DHS, [2001], p. 2.

The annual Victorian Population Health Survey (VPHS) sample is based on the rural and metropolitan regions of the Department of Human Services and includes over-sampling in rural regions that enables production of regional fact sheets. Most of the other state-wide CATI population health surveys have similar region-based structures or capacity and report at sub-state as well as state-wide levels – see Table 1. NSW also produces triennial reports on adult health for each Division of General Practice in the state, using three years of data (e.g., 2005-2007) for analysis; and is a business partner in an Australian Research Council linkage grant on new methods for small group analysis from sample surveys (together with the ABS, the NZ Ministry of Health, the University of Wollongong and the Australian Bureau of Agriculture and Resource Economics).[154] In Victoria, funding has recently been announced to extend the VPHS to LGA-level sampling, in order to provide data for even smaller areas.

During consultations for this Audit on the desirable qualities of a chronic disease and associated risk factor monitoring system, it was suggested that data need not necessarily be *collected* at small area levels, but that it does need to be *reported* at these levels. Alternative methods include the production of synthetic estimates for smaller areas that are based on the data collected on larger areas. A fact sheet prepared for PCPs to assist them in planning ICDM initiatives provides information on those population health data sources that are available at LGA and PCP catchment level, including those based on synthetic estimates.[155]

PHIDU prepares interactive maps of population health profiles for both Statistical Local Areas (SLAs) (mostly equivalent to LGAs) and Divisions of General Practice across Australia. These profiles include estimates prepared by the ABS that synthetically predict the prevalence of selected chronic diseases and risk factors based on the known characteristics of areas and data collected in the NHS.[156,157] An example is shown at Figure 10.

Figure 10: Population Health Profile, SLAs, Victoria: Estimates of chronic disease and risk factors, 2001: Had type 2 diabetes and were overweight/ obese, 15+ years, indirectly age-standardised ratio per 1,000 population.



Population Health Profile, Statistical Local Areas, Victoria

Estimates of chronic disease & risk factors, 2001 (Release 2: Mar 2007) >> Had type 2 diabetes & were overweight/ obese, 15+ yrs - SR per 1,000

SLA ▲	%/ Rate	Number
Alpine (S) - East	6.8	82
Alpine (S) - Wes	15.2	75
Ararat (RC)	11	154
Ballarat (C) - Cer	18.6	623
Ballarat (C) - Inn	17.3	423
Ballarat (C) - Nor	7.6	9
Ballarat (C) - Sou	18.9	337
Banyule (C) - He	14.3	966
Banyule (C) - No	13.7	720
Bass Coast (S) -	13.9	142
Bass Coast (S)	14.9	354
Baw Baw (S) - P	13.1	55
Baw Baw (S) - P	10.1	42
Baw Baw (S) - P	11.9	326
Bayside (C) - Bri	13.4	517
Bayside (C) - So	14	785
Bellarine - Inner	16.7	358
Boroondara (C) -	13.5	633
Boroondara (C) -	14.6	700
Boroondara (C) -	17.2	479
Boroondara (C) -	14.2	428
Brimbank (C) - K	17.8	1,159
Brimbank (C) - S	18.2	1,366
Buloke (S) - Nort	10.8	51
Buloke (S) - Sou	10.8	52
C. Goldfields (S)	17.2	166
C. Goldfields (S)	16.5	113
Campaspe (S) -	16	196
Campaspe (S) -	11	139
Campaspe (S) -	9.6	86
Campaspe (S) -	13.4	62
Cardinia (S) - No	11.1	214
Cardinia (S) - Pa	16.6	234
Cardinia (S) - So	14.6	74
Casey (C) - Berw	12.4	535

Quantile Legend

☐ 6.4 - 11.0
▨ 11.1 - 12.9
▨ 13.0 - 14.6
▨ 14.7 - 16.9
■ 17.0 - 22.8
☐ No Data
☐ ***

Map Overlays

☐ Divisions of GP (2006)
☐ Melbourne/ Country Vic

Comparison Areas

— Victoria: 15.1
— Country Victoria: 14.1
— Melbourne: 15.6

replaces numbers from 0 to 4, & the respective per cents/ rates

*** estimates not shown for remote areas

Source: PHIDU. *Population Health Profiles, Statistical Local Areas, Australia* [Interactive mapping]. Adelaide: PHIDU, 2007. Data source: Chronic disease estimates and risk factor prevalence compiled by PHIDU using data estimated from the 2001 National Health Survey (NHS), ABS (unpublished). NHS respondents were asked whether they had been told by a doctor or nurse that they had type 2 diabetes, and were overweight or obese, based on self-reported height and weight; BMI calculated and grouped into categories (to allow reporting against both WHO and NHMRC guidelines) - overweight: 25.0 to less than 30.0, obese: 30.0 and greater. For a full description, refer to ABS (2002) National Health Survey (cat. no. 4364.0); and ABS (2003) Health Risk Factors (cat. no. 4812.0).[158,159]

Updated population health profiles for SLAs and Divisions of General Practice, based on data from the 2006 *Census of Population and Housing* including synthetic predictions on the prevalence of selected chronic diseases and risk factors in these smaller areas are currently being prepared and will be freely available from the PHIDU website.[32]

Internet sites

Victorian government Health Information: Primary Care Partnerships:
http://www.health.vic.gov.au/pcps/index.htm

Community Health Plans:
http://www.health.vic.gov.au/pcps/community/index.htm

Municipal Public Health Plans:
http://www.health.vic.gov.au/localgov/mphp/index.htm

Integrated Chronic Disease Management:
http://www.health.vic.gov.au/communityhealth/cdm/icdm.htm

Department of Human Services (DHS) Victoria 2008. Population health data sources for ICDM planning: Fact sheet for Primary Care Partnerships. Melbourne: DHS.
http://www.health.vic.gov.au/communityhealth/downloads/fact_sheet3.pdf

Ruth D, Sulaiman N & Harris C 2001. Primary Care Partnerships: Selecting and accessing population data – an information resource. Melbourne: Victorian government Department of Human Services.
http://www.health.vic.gov.au/pcps/downloads/publications/population_data_info_resource.pdf

For interactive maps of population health profiles for Statistical Local Areas and/or Divisions of General Practice across Australia, access the PHIDU *Interactive mapping* website and search for 'Division profiles' using the All words option:
http://www.publichealth.gov.au/interactive-mapping/

More timely and more rapidly released data

As with the need for small area data, another key deficiency reported in the then situation with regard to chronic disease and associated risk factor information was the lack of timeliness of available data. There is an increasing demand for timely and more rapidly released data, and this demand has risen to incorporate not only 'very recent' or 'current' data, but also data that is 'real time' (i.e. data that is captured, and made available as it is happening).

To some extent these calls for greater timeliness of data may reflect unrealistic expectations of frequent monitoring. They may also reflect the frustration of program and policy makers who are required to make decisions in data vacuums (such as the lack of small area data).

While the AIHW's *Australia's health* reports biennially, the NHS, from which much of the data for the health-related indicators is drawn, is collected triennially, with a time lag between the end of data collection and first reporting of just over half a year. Although there is concentrated interest on the health of Aboriginal and Torres Strait Islander peoples, the NATSIHS – the most comprehensive data collection to inform these issues – collects data on a six yearly basis. No matter how frequently data are reported, there is a lengthy time lag between programs that address chronic disease and associated risk factors, and the results of those programs. For instance, public health experts do not expect to see noticeable changes in the health of Aboriginal and Torres Strait Islander peoples for at least ten years. Rapid availability of collected data is frequently of more importance to policy makers than absolute accuracy and completeness, although there are suggestions that policy makers would sacrifice timeliness for accurate small area data.[160,161:746]

A number of state-level reports have been published recently which show 'flat trend line' graphs for certain chronic disease indicators over time (e.g., four to five years). The prevalence of asthma, as with many other chronic conditions, does not change significantly from year to year, and yet this is how it has been reported.[15] The optimal frequency of reported information has received little attention generally (see, however optimal intervals described in: Thacker & Stroup; Jorm & Puech; Ministry of Health NZ [3:390,162:5,163:14]).[16] While some indicators are best suited to ongoing or close time series surveying, others are needed far less frequently to detect meaningful changes. For example, detection of HIV requires close time series or continuous monitoring while cholesterol levels appear to have changed little in over 20 years and frequent monitoring is therefore unnecessary.[165]

More attention could be paid to determining and disseminating the optimal time intervals for usefully reporting various chronic diseases and associated risk factors. This may also include the need to better manage expectations of how (un)rapidly change in chronic diseases and associated risk factors can be expected (no matter how frequently they are monitored).

> "Usually a multi-pronged approach to prevention is required, and often the full benefit of these organised efforts towards public health takes many years to manifest in the form of improved population health outcomes data.
>
> "Similarly the data sources about chronic disease health outcomes... are by their nature retrospective, and reflect the aggregate influence of years of population health determinants."
>
> —Department of Health and Human Services, Tasmania. State of public health report 2008. Hobart: DHHS, 2008, pp. 3-4.

Extending the use of existing data collection vehicles

Given the expense and effort involved in establishing new data collections (and the lack of a dedicated chronic disease and associated risk factor collection in Australia), there were suggestions that more use should be made of existing data collection vehicles. For example, methods to extend the usefulness of existing data collections include:

- value-adding to existing ABS vehicles – examples include Tasmania and various other states increasing their NHS sample, Victoria piggybacking additional instruments onto the General Social Survey, and the use of Labour Force supplementaries such as the supplementary that determined the number of Queensland households with no fixed-line telephone.[74]
- making greater use of mixed modes, for example modes additional to CAPI in the NHS, such as extending the use of supplementary surveys that can be self-completed for more sensitive topics;
- restructuring the NHS sample so that there is an increase in the number of separate estimates can be provided for the ACT, Tasmania and the NT;
- developing a formal ABS program to incorporate into the NHS any remaining international standard instruments that are relevant and appropriate to enable comparison with comparable countries and that have not so far been incorporated, as has been the internationally used Kessler 10 Psychological Distress Scale. The Global Physical Activity Questionnaire is an example of an international standard instrument that has not been incorporated into the NHS;
- extending the collection of information on the use of primary care services, including unmet need, access, availability, affordability and discrimination (some of the reasons for

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[15] Any significant year on year changes are more likely to be artefactual – that is, related to changes in the survey process.

[16] This is true even in relation to infectious diseases where timeliness is often critical for outbreak response, see Jajosky & Groseclose (2004), who report their finding from a literature search (1970-2003) that few studies published measures of reporting timeliness, and those that did so did not evaluate timeliness in a standard manner.[164]

unmet need) in current collection vehicles [30], while acknowledging that a good start has been made, especially in the NATSIHS.

Ways of extending the usefulness of existing data collections in reporting include:

- further exploring the ability to produce and report national estimates from the pooling of state CATI population health survey data, especially in the in-between years of the triennial NHS and for continued comparison with the NHS (see *CATI standardisation activities and progress* on page 22); and
- more triangulation of population health survey data with other data sources, especially in relation to providing evidence more rapidly on the impact of population health interventions (see *Participant burden* on page 43).[30,149]

Effect of learned social responses on survey responses

Other issues include the influence of perceived, and trained socially-desirable responses – resulting from sustained community exposure to a focus on 'lifestyle' issues (such as smoking, alcohol consumption, physical activity, overweight and obesity) reported on in the media and socially desirable behaviours urged in social marketing campaigns – and the actual answers given by respondents to health surveys. Dillman and others have reported 'elevated social desirability scores' from telephone surveys when compared to surveys using other modes.[45,51,52] ABS note, for example, that while emphasis on the health and lifestyle issues of obesity and exercise was likely to influence actual levels of activity in the population, it might also have influenced the way respondents reported their behaviours, and that this possibility should be considered when interpreting apparent changes in NHS results over time.[166:86]

Need for standardised reporting of response

One final issue is the differing calculations of what is generally known as 'response rate' across different surveys, making it difficult to compare like with like, without delving into the methodology. It has been suggested that response calculations should be reported in a standard manner (including the reporting of disposition categories, e.g., original sample, sample loss, eligible, not contacted after all attempts, contacted but not available, completed) in order to improve the ability to compare survey methods with each other.[19] *Appendix C* shows different 'standard' ways of calculating response rates, and the difference that these calculation methods make to the proportion arrived at.

Changing nature of telecommunications and its impact on CATI surveys

As outlined earlier, in recent years there have been substantial changes in telecommunications with the increase in the proportion of households without a fixed-line telephone with a range of consequences for surveys using CATI (See *Limitations of using the telephone as the only entry point to households*, on page 25 where the impacts are discussed).

3.1.12 Longitudinal data collections

Since the Audit first reported, there have been a number of developments and an increase in the number of Australian longitudinal data collections that include some information in relation to chronic disease and associated risk factors.

Definitions: Longitudinal data collections

Longitudinal data collections include:

> *longitudinal study – a study over time of a variable or group of subjects;*
>
> *longitudinal panel – a longitudinal study of the same group of subjects (sometimes described as 'a true longitudinal study');*
>
> *cohort study - samples from the same group at different times (longitudinal approximation);*
>
> *cohort – a group having a particular characteristic, e.g., born in 1985.*

Collections of relevance include the following national longitudinal data collections:

- the Women's Longitudinal Health Survey, baseline 1996, 20 year follow up;
- the Household, Income and Labour Dynamics in Australia (HILDA) Survey - household panel survey, from 2001, funding guaranteed for 12 waves;
- Growing Up in Australia - the Longitudinal Study of Australian Children (LSAC), from 2003-04 onwards;
- Footprints in Time, the Longitudinal Study of Indigenous Children (LSIC) – proposed to concentrate on babies (0-12 months) and 4-5 year olds, pilot testing in 2007;
- Childhood Determinants of Adult Health (CDAH) Study (Menzies research grant 2001) - follow-up of around 8,500 people from around Australia who participated in the Australian Schools Health & Fitness Survey (ASHFS) as children in 1985;
- Australian Longitudinal Study of Ageing, cohort of adults aged 70 years and over, from 1992; and
- the following sub-national collections: NSW - The 45 and Up Study (Sax Institute, general population cohort study); Victorian Cohort Study (National heart Foundation, 20,000 subjects aged 55-64 years at baseline, 20 year follow-up, pilot); the Queensland Chronic Disease Strategy Evaluation Cohort (2,000 every two years of the ten year strategy); SA – the North West Adelaide Health Study (NWAHS), biomedical cohort study, from 2000; WA – the Busselton Health Studies (census of one town, longitudinal, cross sectional).

Additional information on some of these collections can be found in *Appendix D*.

3.2 Linked data sets

Data linkage systems extend vital statistics by linking them with morbidity, population health care service use and other related data systems, including in some cases, previously collected research data. Typically, the records in these data sets are linked for research purposes, and the linkage mechanisms are separated from the actual information that is held in the data sets that are linked. In the previous Audit, the only data linkage system in Australia was the WA Data Linkage System (WADLS), which was briefly reported with more information on the Diabetes Linkage Project which was to link ten years of primary care, hospital and death data.[1:146, 204]

The first data linkage conference in Australia in 1999 was followed by the first national *Symposium on health data linkage* in 2002, with several since then, and the *Second national symposium on data linkage and research* taking place most recently in 2008.[167-169]

3.2.1 National developments

Recent national developments in data linkage have included:

- The ABS is creating a Statistical Longitudinal Census Dataset (SLCD) starting from the 2006 census using a 5% sample of census records. The *Census data enhancement - Statement of intention* indicates that the use of the 5% SLCD with specified non-ABS datasets will proceed for particular datasets, only with the agreement of the custodians of the non-ABS datasets and for statistical purposes.[170] This will provide information on patterns in experiences over time and potential insight into the effectiveness of policy or the need for new policy interventions. See section *3.1.9 Vital statistics and demographic information.*
- A Statistical Information Management Committee project documenting the state of readiness of jurisdictions to create linkages between health data sets for research purposes, and current work on a framework for linkages at the national level.
- The National Collaborative Research Infrastructure Strategy (NCRIS) allocation (2006) to support 'Population Health and Clinical Data Linkage' and NCRIS Committee authorised facilitation of an Investment Plan for the Population Health and Clinical Data Linkage capability.[171]
- Bio21:MMIM (Molecular Medicine Informatics Model), moving from pilot towards a federated 'Australian Cancer Grid', a data grid to link clinical and genetic/ genomic data for research and other purposes with an emphasis on treatment for: oncology, neuroscience, diabetes, respiratory; and images.

The development of an Australia-wide data linkage capability through the National Collaborative Research Infrastructure Strategy (NCRIS) is underway. In 2004, the Australian Government announced the NCRIS as a strategic approach to investment in research infrastructure to meet the long-term needs of researchers.[171] Funding was allocated in 2006 to 12 NCRIS identified priority areas in which Australia should strive to develop research capability. The area of population health and clinical data linkage was one of these areas as potential was perceived in new technologies integrating and linking data sets to resource the monitoring of population health and health service effectiveness, as well as additional research.

The NCRIS Population health and clinical data linkage capability aims to:

- enhance the linkage and integration of health-related data collected in Australia;
- provide improved accessibility to these data for the research sector; and
- support the development of improved data collection systems.

An investment plan for the capability was approved by NCRIS in March 2008, and a funding agreement (funding from NCRIS with co-contributions from the states and territories) is being negotiated with the University of Western Australia as the lead agency for the national Population Health Research Network (PHRN) to develop capacity in all states and territories and nationally. The PHRN will build on existing capabilities in WA and NSW, and support the development of data linkage in SA/ NT, Vic, Qld and Tas.[172]

3.2.2 State developments

When the Audit first reported, the WA Data Linkage System was the only entry in this category, and it remains the most mature data linkage system in Australia. Since then, however, the NSW Centre for Health Record Linkage (CHeReL) has been established (in 2006) to create and maintain a record linkage system for health and human services in NSW and the ACT. The 45 and Up Study (which commenced in NSW in 2006) plans to employ data linkage (for consenting participants) with routinely collected health administrative data as an intrinsic part of the study design.[173] Other population health surveys and research studies have begun to integrate data linkage as a component of their data collection activities (i.e. in addition to questionnaire-based data collection). Other data collections were likely to introduce the option of linking to additional health data sets to their collection strategies (current examples include Women's Health Australia and the WA HWSS). More information on these collections can be found in *Appendix D*.

3.2.2.1 The Western Australian Data Linkage System

The Western Australian Data Linkage System (WADLS) was established in 1995. By May 2008 it contained 3.8 million linked chains of records drawn from six population based data sources spanning 39 years.[174]

In addition to the regular surveillance questionnaire, respondents to the WA population health survey (the HWSS) are asked whether their survey information can be linked with other health data held by the Department of Health; around 80% consistently agree to this request and provide their full name and date of birth for this purpose.[28:15]

Advantages and disadvantages of data linkage

Advantages of data linkage include:

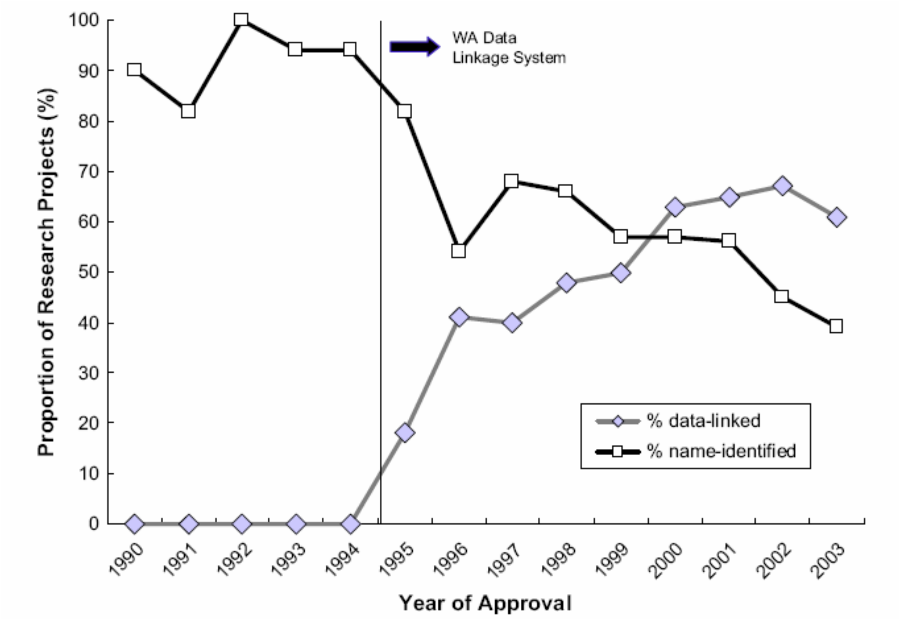
- ability to undertake ongoing linkage, including for study participants otherwise lost to follow-up[175];
- removes reporting bias (e.g., women reporting induced abortions) [176];
- can be used to study topics that are otherwise difficult to study using conventional methods, such as the ability to map/ study very infrequent events and/or low incidence diseases or conditions including those which occur together[177];
- the ability to improve the accuracy of Indigenous and non-Indigenous disease notification rates[178]; and to
- compensate for the lack of longitudinal data linking health-related behaviours to outcomes in Indigenous Australians.[179]

Disadvantages of data linkage include:

- limitations on what can be studied that are related to the limitations of the original data: record linkage will not systematically capture the full range of public and privately funded services that comprise primary health care, nor information on people who need – but do not use – these services[30];
- in some cases, lengthy approval processes (e.g., the requirement to gain approval from each and every data custodian) can hinder rapid access and timely studies.

The use of linked data to answer research questions had overtaken that of studies using identifiable data on individuals (named data) by 2000 (Figure 11).[180] This finding emphasises the growing importance of data linkage as a tool in population health and health service use assessment, and suggests a possible additional direction for the future of chronic disease and associated risk factor data collections.

Figure 11: Proportions of ethics-approved research projects (n=408) using name-identified and data-linked administrative health information in WA 1990-2003



Source: Trutwein B, Holman CDJ, Rosman DL. Data linkage conserves privacy in a research-rich environment. Annals of Epidemiology 2006; 16(4):280.

Internet sites

National Collaborative Research Infrastructure Strategy (NCRIS)
http://ncris.innovation.gov.au/

Western Australian Data Linkage System (WADLS) information:
www.datalinkage-wa.org.au/

WA Department of Health, Data Linkage Unit:
www.health.wa.gov.au/ICAM/data/index.cfm

Centre for Health Record Linkage (CHeReL) in NSW:
www.cherel.org.au

Please note

The Audit is an ongoing document. Please contact PHIDU to advice factual changes and/or amendments such as major changes in collections or to nominate additional collections of interest that could be incorporated in future versions.

The first Audit is available at: www.publichealth.gov.au/publications/chronic-disease-and-associated-risk-factors-information-monitoring-system%3a-the-results-of-an-audit-of-australian-data-collections-and-policies-and-a-review-of-the-international-experience.html

This Audit and other PHIDU publications and interactive mapping can be accessed at: www.publichealth.gov.au

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Glossary

Age-standardisation

Age-standardisation is a technique used to minimise the effects of differences in the age composition of populations, and in this case allows us to compare one population over a number of years.

Chronic

Persistent and long-lasting.

Data linkage

Data linkage is the activity of finding connections between different pieces of information that are thought to belong to the same person, or between events that occurred at the same place or happened at or about the same time.[181]

Geocoding

Geocoding is the process of assigning geographic co-ordinates to a street address. Geographic coordinates may be, for example, latitude and longitude coordinates, or geographic codes that associate an address to census geography units such as a collection district or mesh block.

Harmonisation

The word harmonisation is used to describe the adoption of consistent standards, question equivalence, and common or similar collection methodologies (e.g., use of primary approach letters to promote participation), survey timing, scope and coverage, sample design, handling of item non-response, weighting of data, and other related issues, in order to improve the usability of data pooled or combined from different sources (such as state and territory CATI population health surveys) to establish nation-wide trends.

Indigenous status

A measure of whether a person identifies as being of Aboriginal or Torres Strait Islander origin. This is in accord with the first two of three components of the Commonwealth definition: an Aboriginal or Torres Strait Islander 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. [108:363-371]

National health data dictionary (NHDD)

A publication that contains a core set of uniform definitions relating to the full range of health services and a range of population parameters.

Nation-wide

Nation-wide describes activities (e.g., surveys) at the state/territory and national levels, rather than at the level of a region or community.

Rural and Remote Area (RaRA) classification

The Rural and Remote Area (RaRA) classification scheme, is a scheme that distinguishes between seven areas ranging from ‘capital city’ to ‘other remote area’.

Remoteness Areas

A six category classification of the remoteness of locations using the Australian Standard Geographical Classification Remoteness Structure, based on the Accessibility/ Remoteness Index of Australia (ARIA) which measures the remoteness of a point based on the physical road distance to the nearest urban centre. The six categories are: Major cities, Inner regional, Outer regional, Remote, Very remote, and Migratory.[182]

Rural and Remote Area classification

The Rural and Remote Area (RaRA) classification[183], divides Australia's population into seven groups: Capital city, Other major urban, Rural major, Rural other, Remote major, Remote other, and Other offshore areas. The classification uses Statistical Local Areas (SLAs) as the base unit for designating populations into these seven categories. SLAs are defined as rural or remote by factors that include population size and density, distance from a major urban centre, and the presence of geographical barriers (e.g., mountains, oceans) that prevent easy access to large urban centres.[184: 14-15] By contrast, the ASGC Remoteness Structure[185] is a six category classification which structures the population, on the basis of Collection Districts (CDs) that share common characteristics of remoteness, into broad geographical regions called Remoteness Areas (which see).

Separation

An episode of care for an admitted patient, which can be a total hospital stay (from admission to discharge, transfer or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation). Separation also means the process by which an admitted patient completes an episode of care either by being discharged, dying, transferring to another hospital or changing type of care.[108:363-371]

Social capital

The ABS has adopted the Organisation for Economic Co-operation and Development (OECD) definition of social capital: "networks, together with shared norms, values and understandings which facilitate cooperation within or among groups". This definition is emerging as a common basis for international comparability.[89:7]

Shortened forms

AAPOR	American Association for Public Opinion Research
ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAP MDS	Aged Care Assessment Program Minimum Data Set
ACAT	Aged Care Assessment Team
ACCV	Anti-Cancer Council of Victoria
ACIR	Australian Childhood Immunisation Registrar
ACTPANS	Physical Activity & Nutrition Survey, ACT
AGPSCC	Australian General Practice Statistics and Classification Centre
AHMAC	Australian Health Ministers' Advisory Council
AHS	Australian Housing Survey [ABS]
AHS	Area Health Service [NSW]
AIHW	Australian Institute of Health and Welfare
ALLS	2006 Adult Literacy and Life Skills Survey [ABS]
ALSWH	Australian Longitudinal Study on Women's Health
ANZSIC	Australian and New Zealand Standard Industrial Classification [ABS]
ANZOD	Australia and New Zealand Organ Donor Registry
AOA	Australian Orthopaedic Association
AODTS-NMDS	Alcohol and Other Drug Treatment Services National Minimum Data Set [AIHW]
APEG	Australasian Paediatric Endocrine Group
ARCPOH	Australian Research Centre for Population Oral Health
ARIA	Accessibility/ Remoteness Index of Australia classification
ASCC	Australian Safety and Compensation Council
ASCO	Australian Standard Classification of Occupations [ABS]
ASGC	Australian Standard Geographical Classification [ABS]
ASSAD	Australian Secondary Schools Alcohol and Drug Survey
ATSI	Aboriginal and Torres Strait Islanders
BEACH	Bettering the Evaluation and Care of Health
CAI	Computer Assisted Interviewing
CAPI	Computer Assisted Personal Interviewing
CASI	Computer Assisted Self-Interviewing
CASRO	Council of American Survey Research Organizations
CATI	Computer Assisted Telephone Interviewing
CD	Collection district
CDMP	Chronic Disease Management Programs
CHeReL	Centre for Health Record Linkage, NSW
CHINS	Community Housing and Infrastructure Needs Survey [ABS]
COB	Country of birth
COO	Centre for Overweight and Obesity, NSW
CPSE	Centre for Population Studies in Epidemiology [NSW]
CSIRO	Commonwealth Scientific and Industrial Research Organisation
CSTDA	Commonwealth State/ Territory Disability Agreement
CURF	Confidentialised Unit Record File
DADHC	NSW Department of Ageing, Disability and Home Care
DEECD	Department of Education & Early Childhood Development [Victoria]
DHCS	Department of Health and Community Services [NT]
DHHS	Department of Health and Human Services [Tasmania]
DHS	Department of Human Services [Victorian]
DoHA	Department of Health and Ageing, Australian Government
DOHWA	Department of Health WA
DSRU	Dental Statistics and Research Unit [AIHW]
DVC	Department for Victorian Communities
ENMD	Enhanced National Mortality Database [AIHW]
ERASS	Participation in Exercise, Recreation and Sport Survey
ERP	Estimated resident population
EWP	Electronic White Pages
FaCSIA	Department of Families, Community Services and Indigenous Affairs, Australian Government
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs, Australian Government
FOBT	Faecal occult blood test
GP	General Practitioner

GSS	General Social Survey [ABS]
HILDA	Household, Income and Labour Dynamics in Australia (HILDA) Survey
HMDS	Hospital Morbidity Data Collection [WA]
HMS	Health Monitor Survey [SA]
HOIST	Health Outcomes Information Statistical Toolkit [NSW]
HOS	Health Omnibus Survey [SA]
HWSS	Health & Wellbeing Surveillance System [WA]
IHOs	Indigenous Housing Organisations
IRSD	Index of Relative Socioeconomic Disadvantage [ABS]
ISAAC	Integrated SA Activity Collection
IVR	Interactive voice response
LGA	Local government area
MBS	Medical Benefits Schedule
MDS	Minimum Data Set
MHIS	Mental Health Information System [WA]
MPS	Monthly Population Survey [ABS]
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey [ABS]
NATSIS	National Aboriginal and Torres Strait Islander Survey [ABS]
NATSISS	National Aboriginal and Torres Strait Islander Social Survey [ABS]
NBCSP	National Bowel Cancer Screening Program
NCSCH	National Cancer Statistics Clearing House [AIHW]
NDI	National Death Index
NDR	National Diabetes Register
NDSS	National Diabetes Services Scheme
NDTIS	National Dental Telephone Interview Survey
NESB	Non-English Speaking Background
NHS	National Health Survey [ABS]
NJRR	National Joint Replacement Registry
NMD	National Mortality Database [AIHW]
NOHSA	National Oral Health Survey of Australia
NOHSC	National Occupational Health and Safety Commission
NPDC	National Perinatal Data Collection
NSAOH	National Survey of Adult Oral Health
NZ	New Zealand
PA	Physical activity
PAL	Primary approach letters
PAPI	Paper and Pencil Personal Interviews
PBS	Pharmaceutical Benefits Schedule
PCPs	Primary Care Partnerships [Vic]
PE	Physical education
PHC	Primary Health Care
PHIAC	Private Health Insurance Administration Council
PROS	Population Research and Outcome Studies Unit [SA]
RADL	Remote Access Data Laboratory [ABS]
RaRA	Rural and Remote Areas classification
RDD	Random Digit Dialling
RRMA	Rural, Remote and Metropolitan Areas classification
RSE	Relative standard error
SACR	South Australian Cancer Registry
SAMSS	South Australian Monitoring and Surveillance System
SAND	Supplementary Analysis of Nominated Data [BEACH]
SCORS	Standing Committee on Recreation and Sport
SERCIS	Social, Environmental and Risk Context Information System [SA]
S/T	States and territories
SAL	Survey of Aspects of Literacy
SD	Statistical Division [ABS]
SDAC	Survey of Ageing, Disability and Carers [ABS]
SEIFA	Socio-Economic Indexes for Areas [ABS]
SERCIS	Social, Environmental and Risk Context Information System [SA]
SLA	Statistical Local Area
SLCD	Statistical Longitudinal Census Dataset [ABS]
SMHWB	Survey of Mental Health and Wellbeing [ABS]
SNAPS	Smoking, Nutrition, Alcohol, Physical Activity and Stress
SPANS	Schools Physical Activity and Nutrition Survey [NSW]
SSHB Survey	School Students Health Behaviours Survey [NSW]
TBA	to be advised
US	United States
VCHWS	Victorian Child Health and Wellbeing Survey
VoIP	Voice over Internet Protocol [Internet telephony]
VPHS	Victorian Population Health Survey
WACR	Western Australian Cancer Registry
WADLS	Western Australia Data Linkage System

Appendices

Appendix A: Policies and strategies related to chronic disease and associated risk factors

Existing strategies and policies that relate to chronic disease and associated risk factors and their monitoring in Australia are set out below. This list is not exhaustive and remains in process.

Source	Chronic disease and associated risk factor policies (extended list)
National	Be Active Australia: A Framework for Health Sector Action for Physical Activity 2005-2010 A National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis, and the Better Arthritis and Osteoporosis Care initiative (2006-07 to 2009-10) Blueprint for nation-wide surveillance of chronic diseases and associated determinants Council of Australian Governments (COAG) Human Capital Agenda COAG National Action Plan on Mental Health 2006-2011 Eat well Australia: an agenda for action for public health nutrition 2000–2010 Healthy mouths healthy lives: Australia’s National Oral Health Plan 2004-2013 Healthy Weight 2008: The National Action Agenda for Children and their Families (2003) Healthy Weight for Adults and Older Australians: A national action agenda to address overweight and obesity in adults and older Australians 2006–2010 Living Is For Everyone (LIFE): a framework for prevention of suicide and self-harm in Australia National Aboriginal and Torres Strait Islander nutrition strategy and action plan 2000–2010 National Aboriginal and Torres Strait Islander Sexual Health and Bloodborne Virus Strategy National Agenda for Early Childhood National Alcohol Strategy 2006-2009 National Binge Drinking Strategy (2008) National Cancer Prevention Policy (2007-2009) - published by The Cancer Council Australia National Cancer Screening Programs: Bowel Cancer, Breast Screening, Cervical Screening National Chronic Disease Strategy and Implementation Frameworks National Drug Strategy: Australia’s Integrated Framework 2004-2009 National Health Performance Framework National Health Priority Areas initiative National Hepatitis C Strategy 2005-2008 National HIV/AIDS Strategy: revitalising Australia's response 2005-2008 National Medicines Policy National Mental Health Strategy, National Mental Health Policy (1992), and National Mental Health Plan 2003-2008 National Occupational Health and Safety Strategy 2002-2112 National Strategy for Quality Use of Medicines, The National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003–2013 National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Well Being 2004 – 2009 National Strategy for Heart, Stroke and Vascular Health in Australia National Stronger Families and Communities Strategy (2004-2009) National Suicide Prevention Strategy National SunSmart Schools program National Tobacco Strategy 2004-2009 Preventing Chronic Disease: A Strategic Framework (2001) Towards Better Mental Health for the Veteran Community

Source	Chronic disease and associated risk factor policies (extended list)
NSW	NSW Government's State Plan: A New Direction for NSW (2006) State Health Plan - A new direction for NSW: towards 2010 (2007) [consultation paper: Future Directions for Health in NSW – Towards 2025] *'Live Life Well'* – common theme & call-to-action drawing together health & wellbeing initiatives Aboriginal Chronic Conditions Area Health Service Standards (2005) Aboriginal Mental Health and Well Being Policy 2006-2010 Alcohol Disease Prevention Plan Breastfeeding in NSW: Promotion, Protection and Support (2006) Carers Action Plan 2007-2012 Child and Adolescent Mental Health Policy (2005) Chronic Care Program, NSW Chronic Disease Strategy (Phase Three: 2006-2009) Clinical Service Framework for Optimising Cancer Care in NSW, A (2003) Dementia Action Plan 2007-2009 Fresh Tastes@School Health at Home program NSW Healthy School Canteen Strategy Implementing Rehabilitation for Chronic Disease (2006) Integrated Primary & Community Health Policy Implementation Plan 2007-2012 NSW Aboriginal Health Partnership Agreement and 'Two Ways Together': the NSW Aboriginal Affairs Plan 2003-2012 NSW Aboriginal Health Strategic Plan (1999) NSW Cancer Plan 2007-2010 NSW Chronic Disease Prevention Strategy 2003–2007 NSW Hepatitis C Strategy 2007-2009 NSW HIV/AIDS, STI & Hepatitis C Strategies: Implementation Plan for Aboriginal People 2006-2009 NSW HIV/AIDS Strategy 2006-2009: Overview and Action Plan NSW Interagency Action Plan for Better Mental Health NSW Sexually Transmissible Infection Strategy 2006-2009 NSW Tobacco Action Plan 2005 - 2009 Prevention of Obesity in Children and Young People: NSW Government Action Plan 2003-2007 Stronger Together: A New Direction for Disabilities Services in NSW 2006-2016 Youth Alcohol Action Plan
Vic	Growing Victoria Together: A vision for Victoria to 2010 and beyond (2005), and A Fairer Victoria: strong people, strong communities (2008) *Go for your life!* - the government's overarching healthy and active living campaign Rural and Regional Health and Aged Care Services (RRHACS) Division Policy and Funding Plan 2006-07 to 2008-09 Aboriginal Health Promotion and Chronic Care Partnerships Cancer Services Framework for Victoria (2003), and Victoria's four year Cancer Plan Care in your community framework (2006) Community Health Services - creating a healthier Victoria (2004) Early Intervention in Chronic Disease Program Environments for Health Municipal Public Health Planning Framework (2001-) Families where a parent has a mental illness Strategy Health and Aged Care Information Management Strategy Multiple and Complex Needs (MACN) Initiative Municipal Public Health Planning Framework - Environments for Health Primary Care Partnership Strategy, and Primary Care Partnerships strategic directions 2004-2006: Better health – stronger communities Restoring the balance – Victoria's Alcohol Action Plan 2008–2013 Sexually Transmissible Infections Strategy 2006-2009 State Disability Plan 2002-2012 Victorian Tobacco Control Strategy 2008-2013

Source	Chronic disease and associated risk factor policies (extended list)
Qld	Queensland Statewide Health Services Plan 2007-2012 Eat Well Queensland 2002-2012: Smart Eating for a Healthier State Northern Queensland Indigenous Chronic Disease Strategy Queensland Cancer Control Strategic Directions 2005-2010 Queensland Health Population Health Plan 2007-2012 Queensland Plan for Mental Health 2007-2017 Queensland Strategy for Chronic Disease 2005-2015
WA	WA Aboriginal Sexual Health Strategy 2005-2008 WA Health Cancer Services Framework (2005) WA Health Promotion Strategic Framework 2007-2011 WA Mental Health Promotion, Illness Prevention and Early Intervention Strategic Framework 2007-2009 WA Mental Health Strategy 2004-2007
SA	South Australia's Strategic Plan [Target T2.6 for chronic diseases aims to increase by five percentage points the proportion of people living with a chronic disease whose self-assessed health status is good or better]. South Australia's Health Care Plan 2007-2016 Chronic Disease Management Plan [released 2008] Eat Well South Australia: Public Health Nutrition Action Plan 2005-2008 Eat Well Be Active Healthy Weight Strategy for South Australia 2006-2010 Physical Activity Strategy for South Australia 2004-2008 South Australian Tobacco Control Strategy 2005-2010 Statewide Cancer Control Plan 2006-2009
Tas	Tasmania *Together* - goals and benchmarks guided by strategic directions Tasmanian Health Plan - guide investment in health services for the next 10 to 15 years, changing the focus of our health care system to prevent illness, as well as to treat it. Clinical Services Plan Community Nursing Strategic Plan Comorbidity Integrated Services Project - people with alcohol, drug and/or mental health comorbidities Oral Health Action Plan Primary Health and Community Care Policy Framework Primary Health Services Plan Strategic Framework for the Prevention and Management of Chronic Conditions (2005) Tasmanian Aboriginal Health and Well Being Strategic Framework Tasmanian Cancer Strategy Strategic Plan Tasmanian Food and Nutrition Policy Tasmanian Physical Activity Plan Agency Collaboration Strategy - better management of clients with complex, exceptional needs
ACT	ACT Mental Health Strategy and Action Plan 2003-2008 Aboriginal and Torres Strait Islander Health & Family Wellbeing Plan 2006-2011 Alcohol, Tobacco & other Drugs Strategy 2004-2008 Cancer Services Plan 2008-2010 Caring for carers policy Chronic Disease Strategy 2008-2011 Diabetes Services Plan 2007-2010 Eat Well ACT - A Public Health Nutrition Plan 2004-2010 HIV AIDS, Hepatitis C, Sexually Transmissible Infections Strategic Framework for the ACT 2007-2012 Mental Health Promotion, Prevention and Early Intervention 2006-2008 Action Plan Mental Health Strategy & Action Plan 2003-2008 Palliative Care Strategy 2007-2011 Primary Health Care Strategy 2006-2009 Smoke-free workplace policy
NT	Building Healthier Communities: A framework for health and community services, 2004 2009 – framework for better health and wellbeing for all Territorians (2004) Northern Territory Preventable Chronic Disease Strategy (1999) Northern Territory Food and Nutrition Policy and Action Plan, 2001-2006

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Appendix B: Topics covered by national health surveys and state-wide population health (CATI) surveys

The following table provides a fuller version of the earlier Table 2 comparison of chronic disease and associated risk factor topics in the National Health Survey (NHS) 2004-05, the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) 2004 05, and the state-wide population health (CATI) surveys circa 2004 with some additions. The material has been based on the spread sheet of data output items in the data reference package prepared by the ABS to assist users of the NHS and NATSIHS 2004-05[29], and on unpublished material prepared by the ABS on a question comparison related to the ABS Harmonisation Project, 2007. See the *Data sources* and *Explanatory notes and clarifications* following the table for additional details.

Table 3: Comparison of topics: NHS & NATSIHS & state-wide population health (CATI) surveys circa 2004

Topic Area and topics	**NHS 2004-05**	**NATSIHS 2004-05**	**NSW 2004**	**VIC 2004**	**QLD 2004**	**SA 2004**	**WA 2004**	**ACT, 2005**	**ACT, NT, Qld Tas 2004#**
Health risk factors									
1. Adult immunisation	X	X	X	-	2003	-	X	-	-
2.1 Alcohol consumption - frequency	X	X	X	X	2006	X	X	X	X
2.2 Alcohol consumption – number of alcoholic drinks	X	X	X	X	2006	X	X	X	X
3. Breastfeeding	X	X	X	-	2003	X	X	X	
4. Child immunisation	X	X	X[17]	-	-	X	-	X	
5. Cultural Identification – incl. Family removal/s, Stressors	-	X	-	-	-	-	-	-	-
6.1 Dietary behaviours – daily vegetable consumption	X	X	X	X	2005	X	X	X	X
6.2 Dietary behaviours – daily fruit consumption	X	X	X	X	2005	X	X	X	X
6.3 Dietary behaviours – milk consumption (type)	X	X	X	X	2005	X	X	X	X
7.1 Exercise - walking	X	X	X	X	X	X	X	X	X
7.2 Exercise – moderate exercise	X	X	X	-	X	X	X	X	X
7.3 Exercise – vigorous exercise	X	X	X	X	X	X	X	X	X
8. Height, weight, body mass	X	X	X	X	X	X	X	X	X
9.1 Smoking – prevalence	X	X	X	X	X	X	X	X	X
9.2 Smoking – in the home	X	X	X	X	*	X	X	X	X
10. Substance use	-	X	-	-	-	-	X[18]	-	-
11. Psychological distress (Kessler 10/ Kessler 5**)	X	X (K5)	X	X	*	X	X	X	X
Health status indicators									
1. General health status (self-assessed)	X	X	X	X	X	X	X	X	X
2. Arthritis – ever told	X	X	-	X	-	X	X	X	-
3.1 Asthma – ever told	X	X	X	X	X	X	X	X	-
3.2 Asthma – symptoms and/or treatment/ medication	X	X	X	X	X	X	-	X	-
3.3 Asthma – actions to manage	X	X	X	X	-	?	-	?	-

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[17] NSW Population Health Survey 2004: parental beliefs & attitudes to child immunisation & whether child vaccinated against meningococcal C disease.

[18] WA Heath & Wellbeing Surveillance System (HWSS) – current use of drugs & unsafe needle practices.

Topic Area and topics	NHS 2004-05	NATSIHS 2004-05	NSW 2004	VIC 2004	QLD 2004	SA 2004	WA 2004	ACT, 2005	ACT, NT, Qld Tas 2004#
4.1 Cancer incidence – ever told [Note (3)]	X[19]	X	-	X	-	-	X	-	-
4.2 Cancer screening – actions taken [Note (3)]	X[20]	X[20]	X[20]	-	2003,2005[20]	X[20]	X[20]	X[20]	-
5.1 Heart and circulatory conditions[21] – ever told	X	X	-	X	-	X	X	X	-
5.2 Heart and circulatory conditions – used medication	X	X	-	-	-	-	-	-	-
5.3 High blood pressure – ever told	X	X	2005	X	2006	X	X	X	-
5.4 High blood pressure – last measured	-	-	2005		2006	X	X	X	-
5.5 High blood pressure – actions to manage	-	-	2005	X	2006	X	X	X	-
5.6 High cholesterol – ever told	X	X	2005	-	2006	X	X	X	-
5.7 High cholesterol – last measured	-	-	2005	X	2006	X	X	X	-
5.8 High cholesterol – medication to manage	-	-	2005[22]	-	2006	X	X	X	-
6.1 Diabetes/ high sugar levels – ever told	X	X	X	X	X	X	X	X	-
6.2 Diabetes – diagnosed during pregnancy	X	-	X	X	X	X	X	X	-
6.3 Diabetes – type	X	-	X	X	X	X	X	X	-
6.4 Diabetes – age at diagnosis	X	X	X	X	-	-	-	-	-
6.5 Diabetes – actions to manage	X	X	X	X	-	-	-	-	-
6.6 Diabetes – last tested	-	-	-	X	-	-	-	-	-
7. Kidney disease and dialysis **	-	X	-	-	-	-	-	-	-
8. Osteoporosis – ever told	X	X	-	X	-	X	X	X	-
9. Long-term conditions (other): – depression/ anxiety – ever told/ diagnosed	X	-	-	X	-	X	X	X	-
10. Cause of long-term conditions	X	X	-	-	-	-	-	-	-

* = see last column: RF only ACT, NT, Qld, Tas; ** = NATSIHS only; # = DoHA-funded SNAPS risk factor survey “Filling the gaps” conducted in Qld, ACT, NT, & Tasmania in 2004.

Data sources: ABS. National Health Survey and National Aboriginal and Torres Strait Islander Health Survey 2004/5: Data reference package, 2004-05. ABS cat. no. 4363.0.55.002. Canberra: ABS, 2006; ABS Question comparison material related to Harmonisation Project, 2007 [unpublished data] – drawn from NSW, Vic, Qld, SA and WA population health (CATI) surveys in 2004; (plus NSW in 2005; Qld Surveys: Omnibus: Infant Nutrition in 2003, Older Persons in 2003, Fruit & Vegetable Consumption in 2005, and Omnibus in 2006; ACT population health survey 2005 [carried out by SA]); and the DoHA-funded ‘Filling the Gaps’ SNAPS (Smoking, Nutrition, Alcohol, Physical Activity and Stress) risk factor survey conducted in ACT, NT, Qld & Tas in 2004.

Explanatory notes and clarifications:

(1) The purpose, intentions, designs and uses of these surveys differ markedly and this rough topic comparison is not meant to imply that any are better or worse than any others. Also note that some state surveys – even though conducted annually - are programmatic in their design and

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[19] NHS and NATSIHS 2004-05: specific for types of cancer, e.g., skin, breast, prostate, lung, etc.

[20] NATSIHS 2004-05: Women’s health: mammograms (breast cancer screening), pap smear test (cervical cancer screening); NSW Population Health Survey 2004: Cancer screening – breast, cervical, prostate, bowel, Summer sun protection; Qld Older Persons Survey 2003: breast cancer screening; Qld 2005 Omnibus Survey 2005: colo-rectal cancer; Qld Omnibus Survey: Sunsafe 2005: sun protection practices; SA Monitoring and Surveillance System (SAMSS) 2004: sun protection; WA HWSS: sun protection.

[21] Heart and circulatory or cardiovascular disease conditions - primarily heart disease &/or stroke.

[22] NSW Population Health Survey includes other actions to manage high cholesterol in addition to medication.

will, over a period (e.g., three to five years) achieve similar topic coverage to, for example, the NHS (e.g., the NSW Population Health Survey is a case in point, with its published multi-year collection plan [NSW Health 2007]). The prevalence of many conditions (e.g., high blood pressure) does not change markedly from year to year, and the optimal frequency of collection on many topics may be three to five yearly or even longer (Ministry of Health, New Zealand 2001:14).

(2) There were variations – ranging from slight to substantial – between questionnaire instruments and variation in the ways that responses were elicited in the data collections reported above. These included differences in:

(a) the positioning of topic modules within questionnaires;

(b) the introduction or lead in to the topic/ question/s (e.g., in relation to asthma, the question may be preceded by a description of the symptoms of asthma);

(c) the number of questions asked on the topic;

(d) the question format – whether it was stand alone, asked with prompt cards (the NHS and NATSIHS), or asked with a response list to select from (e.g., as in the Victorian question "Have you ever been told by a doctor that you have any of the following conditions? Heart disease, Stroke, Cancer, Osteoporosis [not osteoarthritis], Depression or anxiety, Arthritis");

(e) the time period covered by or asked about in the question, and whether a time period was included (e.g., in relation to General health status, the NSW question was "Overall, how would you rate your health during the past 4 weeks?" while most other data collections asked a non-time period specific question of the format "In general [,] would you say [that] your health is?");and

(f) the actual question asked (e.g., in relation to Asthma, the NSW question was "Have you ever been told by a doctor or at a hospital that you have asthma?", the Vic, SA and ACT question was "Have you ever been told by a doctor that you have asthma?", the WA question was "Has a doctor of nurse ever told you that you have asthma?", the Qld question was "Have you ever been told by a doctor, nurse or at a hospital that you have asthma?", and the NHS and NATSIHS question was "Have you ever been told by a doctor or nurse that you have asthma?").

(3) Some topics were considered to be more or less appropriate for the state population health (CATI) surveys than for the NHS, for example, in relation to cancer, more reliable data on cancer incidence (cases) was available from other sources such as state cancer registries, and questions on specific cancer screening (e.g., breast, bowel) and prevention activities (e.g., in relation to skin cancer) were more likely to be asked in these surveys.

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Appendix C: An illustration of different calculations of response

The following table develops an example of the calculation of different types of response rates (the participation rate, the response rate, and the CASRO [Council of American Survey Research Organizations] response rate) using data from two years of an example survey.

Table 4 Example calculations of different response rates

Example Survey	Year 1	Year 2	
Original sample	83,678	116,101	
Sample loss	15,254	27,358	includes: non operating number, fax/modem, duplicate number, out of survey scope
Eligible sample	68,424	88,743	
Eligible not contacted after all attempts	21,003	24,215	includes: answering machine, engaged, no answer
Eligible sample contacted	47,421	64,528	
Contacted but not available	24,065	35,083	includes: refused, incapacitated, unavailable
Completed	23,356	29,445	
Participation rate	***49.3%***	***45.6%***	
Response rate	***34.1%***	***33.2%***	
CASRO Response rate	***36.9%***	***36.1%***	

Eligible sample contacted = original sample less (sample loss plus eligible sample not contactable)
(Year 1: 83,678 – (15,254 + 21,003) = 47,421)
(Year 2: 116,101 – (27,358 + 24,215) = 64,528)

Overall participation rate = number respondents completing survey divided by no. eligible sample contacted
(Year 1: 23,356 / 47,421 = 49.3%)
(Year 2: 29,445 / 64,528 = 45.6%)

Overall response rate = number respondents completing survey divided by no. eligible sample
(Year 1: 23,356 / 68,424 = 34.1%)
(Year 2: 29,445 / 88,743 = 33.2%)

CASRO response rate = number respondents completing survey divided by (no. eligible sample contacted plus proportion of non contacts)
e is the estimated proportion of cases of unknown eligibility that are eligible
(Year 1: 23,356 / [47,421 + *e* x 21,003] = 36.9% where estimated *e* = 47,421 / [83,678 - 21,003])
(Year 2: 29,445 / [64,528 + *e* x 24,215] = 36.1% where estimated *e* = 64,528 / [116,101 - 24,215])

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Appendix D: The audit of current Australian data collections

Australian chronic disease and associated risk factor data collections that have been identified by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), the Australian Government Department of Health and Ageing (DoHA), and by state and territory government health departments are described in two parts in Table 5 and Table 6 following.

Basic information on the collections is provided that may include (where relevant):

- **data collection title** (and custodian if not obvious from title), and details on:
    - population **coverage** (including the level at which data was collected, e.g., Australia, NSW state-wide);
    - details of **time series** (i.e. there is a commitment to ongoing funding of regular surveys) e.g., inception year;
    - **frequency** including year/s and/or *planned date (in italics)*;
    - **collection method** (e.g., census/ sample, including sample type);
    - **number in collection** (e.g., year and sample take – either for all collections undertaken since the last Audit in 2001-02, or for the most recent);
    - **mode** of collection (e.g., CATI, PAPI – see Notes after the tables);
    - **enumeration** (for a census) **/ response rate & calculation method** (for a sample); and
- the ability (yes/no/ details) to **disaggregate** collected data by:
    - **age**, **sex**, **Indigenous status**, **ethnicity**, socioeconomic status (**SES**), and
    - geographic area of residence (**geog area**) – include details (e.g., postcode, SLA, metro/ non-metro); and
- any **additional information**.

As space is at a premium, an asterisk (*) anywhere in the table entries indicates that additional information is provided in the last column of Table 6. Symbols used are listed below and acronyms and other short forms are listed from page 71.

Notes to symbols used in Tables

*	Additional information provided in last column of Table 6.
**	Ethnicity mostly derived from country of birth – sometimes language spoken at home and/or proficiency in English.
‡	Although the data for some topics or questions are potentially available from a survey, they may not be reliable or valid. For example, a survey that collects Indigenous status or ethnicity may not have a sufficient sample to produce estimates for these population groups. Surveys of the Indigenous population face the additional problems encountered in collecting data in remote areas, where it is estimated that around 20% of Australia's Indigenous population lives. Specific strategies to address this issue include over-sampling to increase the sample take for specific population groups, or for the remote areas. Estimates for small areas from available survey data can be addressed by the production of synthetic estimates, or amalgamation of data from subsequent surveys.
~	Approximately.
a	States, ACT & Australia (NT sample size does not support separate estimates); the first three ASGC Remoteness classes: Major cities, Inner regional, Outer regional/ remote/ very remote; Capital cities/ Balance of state and Section of state: Major urban, Other urban, bounded locality, Rural. Data may be available at the Statistical Division level.[186:153-154]
i	Identification of Indigenous people not accurately recorded in all states and territories; only data recorded in SA, WA and NT reliably identify Indigenous status on death certificates. From 1999 all jurisdictions except Tasmania are of 'acceptable' coverage.
n/a	Not applicable.
p	Sample too small for analysis.
q	Metro/ total state/ non metro.
s	Some jurisdictions only.
S/T	States and territories

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Table 5: Details of data collections in the Audit of Chronic Disease and Associated Risk Factor Data Collections – part 1 of 2 parts

	Details on:						
Data collection title	**coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
ABS 1. National Health Survey (NHS)*	Australia (excluding very remote areas) private households all ages	yes since 1989-90. (prior surveys 1977-78 & 1983 may be comparable*; as may earlier Supplementary Surveys on Chronic Illnesses, Injuries, and Impairments in May 1968 & May 1974.)	varies, 1989-90, 1995, 2001, 2004-05, 2007-08, *2010-11,* (triennial from 2001)	sample stratified multistage area sample (enhanced).*	2007-08: 20,788 persons 2004-05: 6,415 children & 19,501 adults. 2001: 4,467 children 0-6 yrs, 4,478 children 7-17 yrs & 17,918 adults; NHS(I) included a supplementary sample of ~3,700 Indigenous persons.	CAPI since 2004-05; 2007-08 includes measured: height, weight, hip & waist circumference (ages 5+ years). PAPI from 1989-90 to 2001. (PAPI also for 1977-78 & 1983.)	response rate 2007-08: 90.6% fully/ adequately responding households. 2004-05: 89.4% fully or adequately responding households. 2001: 92% fully responding households See calculation method below.*
ABS 2. National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)	Australia Indigenous Australians in private dwellings all ages	yes since 2001 (some time series data are available from 1995 & 2001 when there were additional small samples of Indigenous people [NHS(I)] to the NHS)	every 6 years 2004-05, *2010-11,* (1995 & 2001 NATSIHS data - additional small samples [NHS(I)] to the 1995 and 2001 NHS - are available for time series analyses.)	sample stratified multistage area sample	2004-05: 10,439 Indigenous Australians; 5,757 adults and 4,682 children. (Total sample composed of 10,044 respondents to NATSIHS plus 395 respondents to the 2004-05 NHS.)	two modes: (1) CAPI in non-remote areas; with self-enumeration of two additional paper questionnaires (on substance use and women's health); (2) PAPI in remote areas; with a limited amount of community-level information also collected from the local Community Council and Health Clinic.	response rate 2004-05: ~85% of in-scope households for the remote community area component; ~83% of in-scope households for the non-remote areas; 85% for the women's health questionnaire [non-remote areas only]; 78% for the substance use questionnaire [non-remote areas only].*
ABS 3. Survey of Disability, Ageing and Carers (SDAC)*	Australia (excluding NT remote areas) private and non-private dwellings all ages	yes since 1981* (1981 relatable to later surveys; 1993 onwards comparable on 1988 survey reduced back)	every 5-6 years 1981, 1988, 1993, 1998, 2003, *2009,*	two samples: (1) stratified multi-stage area sample of private dwellings; & (2) sample from list of non-private dwellings with separate component for cared accommodation	2003: 36,241 persons in households; 5,145 persons in cared-accommodation. 1998: 37,580 persons in households; 5,716 persons in cared-	two components: (1) household component - CAPI from 1998, & PAPI before 1998; (2) cared-accommodation component - mail out to establishments 1993, 1998, 2003, & PAPI in	response rate 2003: 89% fully responding in household component; 92% in cared-accommodation component.* 1998: 93%, with 84% fully responding. See calculation method

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
				establishments	accommodation.	1981 & 1988.	below.*
ABS 4. Survey of Mental Health and Wellbeing (SMHWB)	Australia (excluding very remote areas) usual residents (including Australian military personnel) living in private dwellings 1997: ages 18 years & over; 2007: ages 16-85 years	limited	1997, 2007.	sample stratified multistage area sample	2007: 8,841 participants (ages 16-85). 1997: 13,624 households; 10,641 fully responding participants.	CAPI	response rate 2007: 59.7% fully responding participants.. 1997: 78% fully responding participants.
ABS 5. General Social Survey (GSS)	Australia (excluding very remote areas) usual residents living in private dwellings ages 18 years & over	yes since 2002 (some information may have previously been collected in a range of more specific ABS surveys*)	every 4 years 2002, 2006, *2010,*	sample random multi-stage area sample	2006: 13,375 fully or adequately responding households 2002: ~15,500 fully or adequately responding households/ persons (18+ years)	CAPI	response rate 2006: 86.5% fully or adequately responding households. 2002: 91% fully or adequately responding households. See calculation method below.*
ABS 6. National Aboriginal and Torres Strait Islander Social Survey (NATSISS)	Australia Aboriginal & Torres Strait Islander usual residents in selected private dwellings in urban, rural & remote areas ages 15 years & over	yes since 2002 (Complements the 1994 NATSIS; some information collected in the NATSISS has also been collected in a range of other ABS surveys.*)	every six years 2002, *2008,*	sample two separately designed multistage area samples: (1) for community areas; (2) for non-community areas.*	2002: 9,400 ATSI people of ages 15+ years	two modes: (1) CAPI in non-remote areas; (2) PAPI in remote areas	response rate ~80% of pre-screened households in non-community areas that were identified as having an Indigenous usual resident aged 15+ years responded to the survey; and 78% of in-scope households in communities, fully responded, with a further 16% of households yielding some information.*

Data collection title	Details on: coverage	time series	frequency *italics = planned*	collection method	number in collection	mode	enumeration/ response rate & calculation method
ABS 7. 2006 Adult Literacy and Life Skills Survey (ALLS), and Survey of Aspects of Literacy (SAL), 1996	Australia (excluding very remote areas) private dwellings ages 15-74 years	yes limited comparability: a number of prose & document literacy tasks administered in the 1996 SAL were retained in the 2006 ALLS to enable comparison of levels of literacy over time.	1996, 2006,	sample multistage area sample	2006: 8,988 persons/ households 1996: 9,302 persons/ households	2006: CAPI & set of tasks providing an objective assessment of English literacy & numeracy skills in 5 domains: prose literacy, document literacy, numeracy, problem solving & health literacy. 1996: PAPI; & set of tasks in 3 domains: prose literacy, document literacy & quantitative literacy.	response rate 2006: 80.7% fully or adequately responding households; 1996: 87% fully or adequately responding households. See calculation method below.*
ABS 8. Community Housing and Infrastructure Needs Survey (CHINS)* – conducted by ABS for the Dept. of Families, Community Services & Indigenous Affairs	Australia all distinct (discrete) Indigenous communities and Indigenous housing organisations (IHOs) that provide housing to Aboriginal and Torres Strait Islander peoples	yes since 1999	1999, then five yearly with the Census: 2001, 2006,	census of all IHOs and distinct Indigenous communities 2001 & 2006: carried out in conjunction with ABS field preparations for the Census of Population and Housing.	2006: a total of 496 IHOs (21,854 dwellings) and 1,187 distinct Indigenous communities (17,177 dwellings, 92,960 persons) were surveyed. 2001: a total of 616 IHOs (21,287 dwellings) and 1,216 distinct Indigenous communities (21,290 dwellings, 108,085 persons) were surveyed. 1999: a total of 707 IHOs (20,424 dwellings) and 1,291 distinct Indigenous communities (15,603 dwellings, 109,994 persons) were surveyed.	2006: CAPI (personal interviews and telephone follow-up) using two questionnaires: (1) Housing questionnaire and (2) Community questionnaire.* 2001: PAPI using three questionnaires: (1) Housing form, (2) Community form & (3) Short community form. 1999: PAPI (Housing organisation items and Community items).	enumeration complete enumeration of all IHOs and distinct Indigenous communities, including organisations and communities located in urban and sparsely settled areas in all states and territories.

Data collection title	Details on:						
	coverage	time series	frequency *italics = planned*	collection method	number in collection	mode	enumeration/ response rate & calculation method
AIHW 1. National Hospital Morbidity Database*	Australia hospital separations public and private hospitals*	yes since 1993-94	continuous	collation of patient care records from hospital data supplied by state & territory health authorities	2006-07: 1,301 hospitals, 7,602,917 hospital separations. 2005-06: 1,291 hospitals, 7,311,983 hospital separations	state & territory health authorities provide data annually by the end of the calendar year	enumeration 2006-07: all private day hospitals & one small public hospital in the ACT, one private day hospital in the NT and one very small private hospital in Vic not counted. 2005-06: six small public hospitals in NSW & ACT, all private day hospitals in ACT, one private day hospital in the NT and one very small private hospital in Vic not counted.
AIHW 2. National Cancer Statistics Clearing House (NCSCH)	Australia all residents diagnosed with cancer or whose death was determined to be caused by cancer	yes since 1982	continuous	collation of cancer registry data from states and territories	2004: 98,336 cancer cases, 38,489 deaths	state and territory cancer registries provide data annually	enumeration/ ascertainment unknown but likely to be high as cancer diagnoses are required by law to be notified in all S/T
AIHW 3. National Diabetes Register (NDR)*	Australia individuals using insulin to treat diabetes (all types) all ages	yes since 1999	continuous	collation of National Diabetes Services Scheme (NDSS) and Australasian Paediatric Endocrine Group (APEG) data*	1999-2005: 76,124 registrants (7,550 deceased)	data from NDSS and APEG are provided quarterly, NDR updated annually	enumeration 55% NDSS registrants registered on NDR*

	Details on:						
Data collection title	**coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
AIHW 4. Bettering the Evaluation and Care of Health (BEACH) – AIHW & Australian General Practice Statistics and Classification Centre (AGPSCC)	Australia encounters between GPs and patients active recognised GPs (GPs with a minimum of 375 A1 Medicare items in a recent 3 month period)	yes since 1998	continuous	sample cluster sample of patients (100 consecutive patients of the sampled GPs) from random sample of GPs from DoHA sample frame of Medicare records of active recognised GPs (GPs with a minimum of 375 A1 Medicare items in a recent 3 month period).	2006-07: 930 GPs, 91,805 weighted GP-patient encounters. 2005-06:1,017 GPs, 101,993 encounters. 2004-05: 953 GPs, 94,386 encounters. 2003-04: 1,000 GPs, 98,877 encounters. 2002-03: 1,008 GPs, 100,987 encounters. 2001-02: 983 GPs, 96,973 encounters. 2000-01: 999 GPs, 99,307 encounters. 1998-99: 984 GPs, 96,901 weighted GP-patient encounters.	GP completion of structured paper forms capturing details of GP-patient encounters.	response rate 2006-07: 22.9% of GPs contacted & available. 2005-06: 31.1% of GPs. 2004-05: 28.1% of GPs. 2003-04: 23.7% of GPs. 2002-03: 28.9% of GPs. 2001-02: 32.3% of GPs. 2000-01: 29.8% of GPs. 1998-99: 38.4% of GPs. See calculation method below.*
AIHW 5. National Mortality Database (NMD)	Australia all registered deaths	yes since 1964	continuous	all registered deaths reported by state and territory Registrars of Births, Deaths and Marriages	2005: 130,714 deaths	information is provided by state and territory Registrars of Births, Deaths and Marriages and ABS cause of death coded data updated annually	enumeration near comprehensive; some demographic characteristics of deceased (e.g., Indigenous status) may be inaccurate in some S/T.
AIHW 6. National Death Index (NDI)	Australia all registered deaths	yes since 1980	continuous	all registered deaths reported by state and territory Registrars of Births, Deaths and Marriages	2006: ~140,000 records*, 2005: ~130,700, 1980: 108,695.	index updated monthly from S/T Registrars; cause of death (coded by ABS) updated annually	enumeration near comprehensive; some demographic characteristics of deceased (e.g., Indigenous status) may be inaccurate in some S/T.

	Details on:						
Data collection title	**coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
AIHW 7. National Perinatal Data Collection (NPDC) – AIHW National Perinatal Statistics Unit	Australia all live births and stillbirths of at least 400g or 20 weeks gestation	yes since 1991; core data elements standardised since 1997	continuous provision of information to S/T health authorities; annual provision by S/T perinatal databases to NPDC	all notified births reported to the perinatal data collection in each state and territory in Australia (mandatory collection)*	2005: 272,419 babies born to 267,793 mothers. 2004: 257,205 babies, 252,871 mothers. 2003: 256,925 babies, 252,584 mothers. 2002: 255,095 babies, 250,758 mothers. 2001: 254,326 babies, 250,071 mothers. 1991: 256,634 babies, 253,141 mothers.	births are reported to S/T health authorities & perinatal databases by midwives/ birth attendants who complete notification forms based on information from mothers, hospitals & other records. Selected details from these notifications are provided to the national database, updated annually.*	enumeration near comprehensive; the quality and completion of mother's Indigenous status may vary between jurisdictions and over time.
AIHW 8. National Drug Strategy Household Survey	Australia residents in private households ages 12 years & over or 14 years & over (2001: 14 years & over only)	yes since 1985	triennial from 2001 1985, 1988, 1991, 1993, 1995, 1998, 2001, 2004, 2007, *2010*	sample multi-stage stratified area random sample of households*	2007: 23,365 persons 12+ years. 2004: 29,445 persons 12+ years. 2001: 26,744 persons 14+ years.	varies 2007 & 2004: two modes: (1) drop and collect & (2) CATI. 2001: three modes: (1) drop & collect; (2) face-to-face; & (3) CATI. 1998: combination of PAPI & collect/ mailback.	response rate 2007: 49.3% (51.6% for the drop & collect mode & 39.3% for the CATI mode) 2004: 45.6% (47.8% for drop & collect & 37.8% for CATI). 2001: 50%.(39% for face-to-face, 49% for CATI & 51% for drop & collect). See calculation method below.*

	Details on:						
Data collection title	**coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
AIHW 9. BreastScreen Australia dataset*	Australia female Australian citizens and permanent residents of ages 40 years & over who have had a mammogram with BreastScreen Australia	yes since 1996-1997	continuous*	collation of BreastScreen Australia Program screening activity and outcome data from state and territory BreastScreen Australia units	2004-2005: total of 1,614,871 women (40+ years) screened, with 1,188,720 (74%) in the target age group (50-69 years). 2003-2004: 1,627,115 screened, 1,144,483 (70.3%) in target group. 2002-2003: 1,618,306 screened, 1,118,429 (69%) in target group. 2001-2002: 1,611,262 screened, 1,102,227 (68%) in target group. 2000-2001: 1,567,544 screened, 1,063,479 (68%) in target group.	national data updated annually from state and territory BreastScreen Australia units	program participation rate 2004-2005: 56.2% of women in the target age group of 50-69 years (range from 41.5% in the NT to 61.9% in SA). 2003-04: 55.7% (43.1% in the NT to 63.1% in SA). 2002-2003: 56.2% (44.5% in the NT to 63.6% in SA). 2001-2002: 57.1% (44.7% in the NT to 64.9% in SA). 2000-2001: 56.9% (46.3% in the NT to 64.3% in SA). See calculation method below.*
AIHW 10. National Cervical Screening Program dataset*	Australia all women* participating in the National Cervical Screening Program	yes since 1996-97	continuous*	collation of data from state and territory cervical cytology registries	2005-2006: total of 3,505,978 women screened, with 98.5% in the target group (20-69 years). 2004-05: 3,462,907 women screened, 98.4% in target group. 2003-2004: 3,412,852 women screened, 98.3% in target group. 2002-03: 3,318,354 women screened, 98% in target group. 2001-2002: 3,331,013 women screened (excluding NT women - data unavailable), 98% in target group. 2000-2001: 3,314,787 women screened, 98% in target group. *	aggregated data provided from states and territories on Excel files (no database)*	program participation rate 2005-2006: 60.6% of women in the target age group of 20-69 years. 2004-2005: 61.0%. 2003-2004: 60.7%. 2002-2003: 60.7%. 2001-2002: 61.0%. 2000-2001: 61.0% *

Data collection title	**Details on:** **coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
AIHW 11. National Bowel Cancer Screening Program dataset*	Australia Australians turning 55 or 65 years of age between 1 May 2006 and 30 June 2008, and those who were involved in the Pilot Program*	yes since 2006	continuous	collation of state and territory data (details of people eligible for the Program are drawn from Medicare and Department of Veterans' Affairs records and invitations to participate mailed out by states).*	31 July 2007: 149,262 people had agreed to participate (68,395 males; 80,867 females).	data from the National Bowel Cancer Screening Register maintained by Medicare Australia are received every six months	program participation rate 2006-2007: program participation for those aged 55 or 65 years who were sent invitations to participate between 7 August 2006 and 31 July 2007 was estimated at 41.0%.*
AIHW 12. Commonwealth State/ Territory Disability Agreement (CSTDA) National Minimum Data Set – AIHW	Australia CSTDA-funded services and persons with a disability accessing these services	yes since 1995*	continuous since 2002; annual 'snapshot' from 1995-2002.	collation of service provider data	2005-2006: 217,143 service users; 9,093 service type outlets	combination of paper forms and electronic data sent to S/T authority; data file then sent to AIHW for national collation	response rate 2005-2006: service type outlet response rate 94% (service users response rate unavailable)
AIHW 13. Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS)*	Australia all publicly funded agencies providing alcohol and/or drug treatment services, and all clients who completed treatment episode/s at in-scope services during the reporting period	yes since 2000-2001*	continuous	collation of service provider data on closed treatment episodes	2005-2006: 151,362 closed treatment episodes; 664 agencies.	S/T authorities provide data to AIHW annually	response rate 2005-2006: 97% of in-scope agencies covered.*
AIHW 14. Child Dental Health Survey – AIHW Dental Statistics & Research Unit (DSRU)	Australia (except NSW in 2002, 2001) children of ages 4-15 years enrolled in school dental services in public and private schools	yes since 1989	annual	sample stratified random sample of children from S/T school dental services (e.g., by selection from those born on specific days of the month). Sampled proportions vary within and across S/T and over time.*	2002: 136,505 children 4-15 years examined by school dental services (excluding NSW);* 2001: 110,834 (excluding NSW); 2000: 311,346 1999: 371,871.	data collected from routine dental examinations by dentist/ dental therapist in school dental services (includes demographic information and dental health status)	response rate 2002: unknown. The national sample does not contain representative percentages of children from each S/T; hence age-standardised data are used to compile representative data for comparison.

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
AIHW 15. National Survey of Adult Oral Health (NSAOH) – AIHW DSRU	Australia people of ages 15-97 years	no (a similar survey was undertaken in 1987-1988, the National Oral Health Survey of Australia [NOHSA]*)	2004-2006 (1987-1988: NOHSA)	sample three-staged, stratified clustered sampling design	2004-06: 14,123 persons (15-97 years) interviewed, 5,505 dentally examined. (1987-1988: NOHSA: 16,897 people aged 5 years or more selected from the 6 states & the ACT were interviewed & 14,430 of these (85.4%) had an oral examination.)	two modes: (1) CATI and (2) dental examination.* (1987-1988: NOHSA: Interview and oral examination)	response rate 2004-06: (1) 49.0% of those asked to participate in an interview (14,123 / 28,812 in-scope telephone numbers); and (2) 44% of interviewed people who were invited to the dental examination.
AIHW 16. National Dental Telephone Interview Survey (NDTIS) – AIHW DSRU	Australia Australian residents ages 5 years & over in private dwellings with telephones	yes since 1994	irregular 1994, 1995, 1996, 1999, 2002, (2004-2006: formed part of the National Survey of Adult Oral Health, which see)	sample stratified area random sample	(2004-2006: see NSAOH) 2002: 7,312 participants; 1999: 7,829 participants (6,589 18+ yrs), 1994, 1995 & 1996 combined: 17,691 participants	CATI (EWP variant)	response rate 2002: 64.8%; 1999: 56.6% (participants 18+ yrs); 1994, 1995 & 1996 combined: 71.5%. See calculation method below.*
DoHA 1. Aged Care Assessment Program Minimum Data Set (ACAP MDS)	Australia all individuals seeking government funded aged care services predominantly of ages 60 years and more	yes since 2003	continuous	census of completed ACAP assessments proportional (only completed assessments)	2006-07: 188,976 completed assessments, 2005-06: 179,354, 2004-05: 176,877, 2003-04: 176,555	administrative records provided by state and territory Evaluation Units which receive data from regional Aged Care Assessment Teams, derived from face-to-face assessments of individuals seeking government funded aged care services	enumeration 100% of completed ACAP assessments

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
DoHA 2. Private Health Insurance Administration Council (PHIAC) A Report: Chronic Disease Management Programs (CDMP)	Australia members of private health insurers (hospital treatment) including those receiving Chronic Disease Management Programs (CDMPs) all ages	yes members receiving CDMPs have been reported since June 2007	quarterly	census of private health insurers, membership, population coverage, types of benefits received and paid; including CDMPs, types of CDMP services and programs*	2008 March: ~9.477 million people (44.6% of the Australian population) covered by private health insurance: 2,442 people receiving CDMPs (1,100 males, 1,342 females). 2007 December: ~9.391 million people (44.4%) covered by private health insurance: 2,214 people receiving CDMPs (1,352 males, 862 females). 2007 September: ~9.292 million people (44.0%) covered by private health insurance; 1,242 people receiving CDMPs (691 males, 551 females).	administrative data submitted to PHIAC by private health insurers	enumeration private health insurers: 2007 June: 38 registered private health insurers.

Data collection title	**Details on:** coverage	time series	frequency *italics = planned*	collection method	number in collection	mode	enumeration/ response rate & calculation method
DoHA 3. National Children's Nutrition and Physical Activity Survey *Kids Eat, Kids Play* – CSIRO and the University of South Australia	Australian metropolitan and regional areas (230 towns and cities) in all states and territories residents of private dwellings with fixed line telephones children of ages 2-16 years	no	one off 2007 only	sample random sample using random digit dialling (RDD) to recruit participants in a total of 230 metropolitan and regional towns across all states and territories. Sample aimed to achieve ~4,400 children of ages 2-16 years (one child in each participant family household) (~4,000 nationally plus an additional 400 in SA)	2007: 4,695 participant children aged 2-16 years completed both initial and follow-up interviews.	CATI (RDD) recruitment to survey; two survey interviews: (1) CAPI initial interview and measures (see below), and (2)CATI follow-up interview (nutrition and time-use surveys recorded on audiotape). Objective measures: (1) number of steps taken) over a seven-day period counted by pedometer/ accelerometer (ages 5-16 only) (mail back); (2) measured weight, height and waist circumference (ages 2-16).	response rate 2007: 40%. Response rate calculated as 4,695 participants who completed both initial and follow-up interviews divided by 11,721 sampled eligible households.
DoHA 4. National Infant Feeding Survey – planned	*Australia – all states and territories* *mothers of infants of ages 0-4 years*	*planned:* *from 2008* *(Initial survey planned for 2008; second survey proposed for 2010-11)*	*planned for:* *2008,* *2010-11,* *additional surveys may occur to monitor changes.*	*sample* *planned random selection of parents of young children by method TBA.*	*2008 planned: expected to be at least 4,000*	*planned:* *mail-out questionnaire*	*n/a*
DoHA 5. National Nutrition and Physical Activity Survey Program – planned	*Australia* *all ages*	*yes* *may include longitudinal sample recruitment.*	*expected to be conducted every 3-5 years on different sub-populations, depending on survey complexity and size of sample required; initial survey planned for 2009-2010*	*sample* *expected to be random or cluster sampling*	*will vary with the size of the sub-population/s to be surveyed; expected to be at least 12,000 persons for each survey.*	*recruitment and interviews are expected to be conducted face-to-face; individual surveys may include a telephone, postal or internet-based follow up.*	*n/a*

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DoHA 6. The consequences of osteoarthritis and osteoporosis In Australia: Work productivity loss and health service utilisation – AFV Centre for Rheumatic Diseases, University of Melbourne (Australian Research Council Linkage Project grant), in partnership with DoHA and AIHW.	*Australia* *private households* *persons of ages 39 years & over*	*no*	*one off survey due to commence in 2008*	*random sample of sex and age groups, regions, and SES status*	*25,000 anticipated with 300 validated for each condition*	*several modes likely: (1) questionnaire assessment, (2) clinical assessment, and (3) in depth interview*	*n/a*
DoHA 7. Australian Childhood Immunisation Register (ACIR) – Medicare Australia	Australia all resident children under the age of 7 years enrolled with Medicare Australia	yes since 1996	continuous	register of children under 7 years, their immunisation status, and immunisation providers supplying valid vaccination information to Medicare Australia	31 Mar 2008: 1,944,924 children <7 years registered with ACIR; 31 Dec 07: 1,932,567. 30 June 2003: 1,844,679.	administrative data collated by Medicare Australia	coverage rate 31 Dec 2007: 91.3% children fully immunised at 12 months; .92.8% at 24 months; 88.2% at 60 months.*
DoHA 8. SNAPS (Smoking, Nutrition, Alcohol, Physical Activity and Stress) risk factor survey 'Filling the Gaps' – funded by DoHA, carried out in ACT, NT, Qld & Tas	state-wide in 4 S/T: Qld, Tas, ACT & NT residents of private households with a telephone ages 18 years & over	no	2004 only	sample	see separate entries: Qld 5., Tas 2., ACT 3., and NT 2.	CATI	see separate entries: Qld 5., Tas 2., ACT 3., and NT 2.
Other 1. Australian Mesothelioma Register – Australian Safety and Compensation Council (ASCC)	Australia all notified cases of mesothelioma	yes since 1982 for new cases; since 1997 for fatal cases (deaths)	continuous	register of all new cases of mesothelioma notified to state cancer registries, collated by the AIHW National Cancer Statistics Clearing House	1982-2004: total of 8,422 notifications of mesothelioma.	case data supplied to the National Cancer Statistics Clearing House (AIHW), by state cancer registries; data on fatal cases are collected in the National Mortality Database (AIHW)	enumeration/ ascertainment unknown, however the previously known rate of under-reporting is likely to have reduced (a reconciliation of case data from 1986-2000 showed the Register had 3.4% fewer notifications of new cases than the AIHW NCSCH).*

	Details on:						
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Other 2. Australian Secondary Schools Alcohol and Drug Survey (ASSAD) – Cancer Council Australia & state & territory governments *	Australia secondary schools & students 12-17 years attending.	yes since 1984	triennial 1984, 1987, 1990, 1993, 1996, 1999, 2002, 2005, *2008*,	sample random sample of junior & senior schools, & of students drawn from participating school rolls.	2005: 376 schools, 21,805 students.	PAPI in schools	response rate 2005: 63% schools (participating/ invited), students unknown.
Other 3. Women's Health Australia, the Australian Longitudinal Study on Women's Health (ALSWH) – University of Newcastle*	Australia adult females registered with Medicare, in 3 age cohorts in 1996: Younger 18-23 yrs, Mid-age 45-50 & Older 70-75.*	yes in the same subjects since 1996	longitudinal 20 year follow up from Survey 1 (S1) in 1996; age cohorts sequentially surveyed on a rolling 3-year basis: 1998-2000 (S2), 2002-03 (S3), 2004-06 (S4), 2007-*09* (S5), *2010-12 (S6),* *2013-15 (S7).*	sample random selection from Medicare database.	2004-06 (S4): 27,208 female adults in 3 age cohorts: 9,145 Younger (28-33 yrs), 10,905 Mid-age (53-58) & 7,158 Older (79-84). 1996 (S1): >40,000 fully responding: 14,247 Younger, 13,716 Mid-age & 12,432 Older.	mailback questionnaire; sub-studies can employ telephone interviewing.	retention rate 2004-06 (S4): 77.6% overall; Younger 67.5%; Mid-age 84.0% & Older 83.9%. 1996 (S1): initial response estimated at >40% overall; Younger 41-42%, Mid-age 53-56% & Older 27-40%. See calculation method below.*

	Details on:						
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Other 4. HILDA – Household, Income and Labour Dynamics in Australia (HILDA) Survey – Melbourne Institute (funded by FaCSIA)	Australia (488 CDs)	yes in the same subjects since 2001	longitudinal 12 Waves guaranteed 2001: Wave 1 (W1), 2002: Wave 2’ 2003: Wave 3, 2004: Wave 4’ 2005: Wave 5, 2006: Wave 6’ 2007: Wave 7, *2008: Wave 8,* *2008: Wave 8,* *2009: Wave 9,* *2010: Wave 10,* *2011: Wave 11,* *2012: Wave 12.*	sample random multi-stage sample (CDs, dwellings, households).	Sampling unit is the household. 2006: Wave 6 (W6) panel consisted of 7,139 households (12,905 responding individuals). A total of 8,864 persons had been continuously engaged in the survey and interviewed in all six waves. 2001: Wave 1 (W1) panel consisted of 7,682 responding households (13,969 responding out of 19,914 enumerated individuals).	face-to-face interview (with some use of CATI to reach panel respondents who have moved out of area)	response and attrition rates 2006 (W6): 76.3% households (94.8% of W5 respondents, 8.4% of W5 non-respondents, 75.4% of previous wave child [age 15 on 30 June previous] & 81.1% of new entrants to participating households; attrition rate of 5.6%) 2005 (W5): 78% households (94.4% of W4 respondents, 14.7% of W4 non-respondents, 74.6% of previous wave child & 81.7% of new entrants; attrition rate of 5.6%). 2004 (W4): 78.6% households. 2003 (W3): 81.8% households. 2002 (W2): 87.0% households. 2001 (W1): 66% households (92.3% eligible adults ages 15+ years).
Other 5. Participation in Exercise, Recreation and Sport Survey (ERASS) – Australian Sports Commission & state & territory departments responsible for sport and recreation.	Australia residents of private households with a listed telephone ages 15 years & over	yes since 2001	quarterly 2001-2007	sample random sample stratified by state and territory, selected from the EWP*	2006: 13,710 persons (15+ years) 2005: 13,726 2004: 13,662 2003: 13,644 2002: 13,632 2001: 13,640 (3,410 per quarter)	CATI	response rate 2006: 42% 2005: ~34% 2004:~41% 2003:~45% 2002: not given 2001: not given See calculation method below.*

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
Other 6. National Sun Protection Survey – funded by The Cancer Council Australia and the Australian Government and managed by Cancer Australia	Australia residents of private households with a telephone adults & adolescents, ages 12-69 years	yes	summer 2003-04, summer 2006-07, *summer 2008-09*	sample	2006-07: 5,085 adults (18-69 years) and 652 adolescents (12-17 years) 2003-04: 5,073 adults (18-69 years) and 699 adolescents (11-17 years.	CATI	response rate:
Other 7. National Non-melanoma Skin Cancer Survey*	Australia residents of private households ages 13 years & over	yes	approx. every five years 1985, 1990, 1995, 2002,	sample stratified sample of households	2002: 57,215 people interviewed, 4,098 reported being treated for skin cancer in the 12 months previous, and 3,198 gave permission for diagnoses to be confirmed with the treating doctor.	face-to-face survey between 1 January and 31 December 2002 to identify people who had been treated for skin cancer, self-reported diagnoses of skin cancer were confirmed with treatment providers.	response rate: 2002: responses from treating doctors were received for 2,502 people (80% of requests), giving a response rate of 61% for access to confirmation of diagnosis for those reporting treatment within the previous 12 months.
NSW 1. NSW Population Health Survey *	NSW state-wide residents of private households with a telephone all ages	yes since 2002 Previous surveys for trend analysis include 1997-1998 (adults), 1999 (older people), and 2001 (children).	continuous since 2002 Feb to Dec each year	sample stratified by health areas; list-assisted RDD.*	2007: 16,162 total; 2006: 10,345 total (7,962 adults 16+ yrs & 2,383 children); 2005: 13,701 total; 2004: 11,830 total; 2003: 15,837 total; 2002: 15,442 total; 2001: 9,425 children 0-12 years; 1999: 9,418 adults 65+ years; 1998: 17,494 adults 16+ years; 1997: 17,531 adults 16+ years.	CATI	response rate 2007: not yet available 2006: 59.3%. 2005: 57.7% 2004: 61.2% 2003: 67.9% 2002: 67.6% 2001: 84.1% 1999: 70.7% 1998: 65.0% 1997: 70.8% See calculation method below.*

	Details on:						
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NSW 2. NSW School Students Health Behaviours (SSHB) Survey – NSW component of the Australian Secondary Schools Alcohol and Drug Survey (ASSAD)	NSW state-wide secondary schools (government, Catholic & independent) & students 12-17 years attending.	yes since 1984 (previous NSW SSHB Survey conducted 2002)	triennial 1984, 1987, 1990, 1993, 1996, 1999, 2002, 2005, *2008,*	sample stratified two stage probability sample: (1) schools (junior & senior schools), & (2) students drawn from participating school rolls.	2005: 120 schools, 5,591 students (5,522 aged 12-17 years); 2002: 99 schools, 6,441 students returned questionnaires (6,180 usable records from students aged 12-17 years in the final sample).	PAPI in schools	response rate 2005: 62.3% schools (participating / invited); 2002: 23% schools.*
NSW 3. The 45 and Up Study – auspiced by the Sax Institute in collaboration with The Cancer Council NSW, Heart Foundation, NSW Health, beyondblue, & the NSW Dept. of Ageing, Disability and Home Care (DADHC)	NSW state-wide NSW residents ages 45 years & over at recruitment	yes in the same subjects since 2006	longitudinal cohort study with baseline questionnaire completed between 2006 and 2009. *5 yearly follow-up surveys planned.*	sample random selection from Medicare Australia's enrolment database	Feb 2008: 60,000 with plans to accrue an additional 17,000 participants per month during 2008. Full cohort of 250,000 to be recruited by December 2008.	self-completed mailed questionnaire Options for sub-studies amongst targeted populations and data linkage with routinely collected health administrative data.	response rate response rate to baseline questionnaire: 17.9%; plus individuals who volunteer to participate. See calculation method below.*

Data collection title	Details on:						
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NSW 4. NSW Centre for Health Record Linkage (CHeReL) – hosted at Cancer Institute NSW, supported by The Sax Institute, NSW Health, ACT Health, NSW Clinical Excellence Commission, and the Universities of Newcastle, NSW & Sydney	NSW & ACT state-wide including ACT linkages between administrative population health & other data held on NSW residents (including some cross-jurisdictional data)	yes in the same subjects, since, & for varying years. Databases currently approved to have records in the Master Linkage Key are: NSW Admitted Patient Data Collection, NSW Emergency Department Data Collection, NSW Midwives Data Collection, NSW Perinatal Death Review Database, NSW Central Cancer Registry, NSW Pap Test Register, NSW Registry of Births, Deaths and Marriages birth registration & death registration data, ABS Mortality Data, ABS Perinatal Mortality Data, & The 45 and Up Study.	longitudinal linked records	data linkage of administrative, registry and other records	July 2008: ~17.7 million records.	regular continuous linkage of administrative records using computerised probabilistic matching in a dynamic multi-set linkage system	enumeration/ quality of links unknown

	Details on:						
Data collection title	**coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
NSW 5. Schools Physical Activity and Nutrition Survey (SPANS)* – NSW Health with NSW Centre for Overweight and Obesity (COO)	NSW state-wide primary & secondary schools (excluding special schools, schools with enrolments of <180 students & schools in NSW remote regions) & students in schools ages 5-16 years (in school years K (Kindergarten), 2, 4, 6, 8 & 10)	*?planned* (some comparability with the 1985 Australian Health and Fitness Survey & the 1997 NSW Schools Physical Activity and Fitness Survey*)	2004, *[confirm whether another planned for 2011]*	proportional stratified (by education sector: government, Catholic & Independent) random sampling of NSW primary & secondary schools, and cluster sampling of students. An estimated 96% of the secondary school population and 82% of the primary school population were included in the sampling frame.	2004: ~5,500 children aged 5-16 years from 45 primary & 45 secondary schools.	six components: (1) main student survey, (2) bio-marker sub-study (year 10 students in Sydney metro schools only), (3) physical activity sub-study (years 8 & 10 only), (4) school environment survey, (5) school canteen questionnaire, & (6) response bias study. (1) study field staff guided questionnaire self-completion by students in years 4,6,8 & 10 under exam conditions (demographics extracted from school registers for years K & 2); weight, height & waist measured in all students; assessment of fundamental movement skills in years 2, 4, 6, 8 & 10; cardiorespiratory endurance in years 4, 6, 8 & 10 students.*	response rate 2004: many student response rates were well below 80%. To test whether there was a systematic response bias with regard to overweight and obesity (overweight students were less likely to participate in the study), study investigators devised a method to characterise the response bias and adjust estimates of the prevalence of overweight and obesity for the whole sample.*
Vic 1. Victorian Population Health Survey* – Victorian Department of Human Services	Victoria state-wide residents in private households with a telephone ages 18 years & over	yes since 2001	annual	sample stratified random sample using random digit dialling	2001-2007: ~7,500 adults (18+ years) each year	CATI	response rate 2007: 67% 2006: 62% 2005: 69% 2004: 61% 2003: 64% 2002: 65% 2001: 69% See calculation method below.*

Data collection title	**Details on:** **coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
Vic 2. 2006 Victorian Child Health and Wellbeing Survey (VCHWS) - Department of Human Services	Victoria state-wide residents in private households with a telephone principal caregivers of children aged under 13 years	planned from 2006	triennial 2006, *2009*	sample random sample stratified by metro/ non-metro & region, selected using random digit dialling	2006: 5,000 interviews with parents/ carers of children under 13 years of age; majority were female (84%); almost all were the survey child's biological parent (97.2%).	CATI	response rate 2006: 86.6% Response rate calculated as the no. of households where an interview was completed divided by the no. of in-scope households.
Vic 3. Indicators of Community Strength Survey – Department for Victorian Communities (DVC)	Victoria statewide residents in private households with a listed telephone ages 18 years & over	no	2004, 2006	sample random sample of 300 individuals (18+ years) in each of the 79 state LGAs; with additional sample in 35 neighbourhoods	2006: 23,700 adults (18+ years)	CATI	response rate 2006: quota sampling
Qld 1. 2003 Omnibus Survey: Infant Nutrition*	Qld state-wide residents in private households with a telephone biological mothers (ages 18 years & over) of at least one child aged less than 5 years*	yes in future	five yearly 2003, *2008,*	sample random sample selected via extended EWP*	2003: 1,201 mothers of children (18+ years) of children <5 years [Note that 2008 survey will sample biological mothers of children ages less than 13 months]	CATI	response rate 2003: 92% of contacted in-scope people See calculation method below.*
Qld 2. 2003 Omnibus Survey: Child Health*	Qld state-wide residents in private households with a telephone principal caregivers (ages 18 years & over) of at least one child aged under 13 years	yes in future	five yearly 2003, *2008,*	sample random sample selected via extended EWP*	2003: 1,596 principal caregivers (18+ years)	CATI	response rate 2003: 86% of contacted in-scope people See calculation method below.*

Data collection title	**Details on:**						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
Qld 3. 2003 Older Persons Survey	Qld state-wide residents in private households with a telephone ages 50 years & over	some prior surveys may be comparable (eg 1997 Women's Cancer Screening Survey)	2003	sample random sample selected via extended EWP*	2003: 2,200 older persons (50+ years) including 908 females aged 50-74 years.*	CATI	response rate 2003: 86.8% of contacted in-scope people See calculation method below.*
Qld 4. 2004 Omnibus Survey: Risk Factors	Qld state-wide residents in private households with a telephone ages 18 years & over	some prior surveys may be comparable	2004	sample random sample selected via extended EWP*	2004: 2,231 adults (18+ years)	CATI	response rate 2004: 71.3% of contacted in-scope people See calculation method below.*
Qld 5. 2004 SNAPS Data Collection (Filling the Gaps) – funded by DoHA	Qld state-wide residents in private households with a telephone ages 18 years & over	some prior surveys may be comparable	2004	sample random sample selected via EWP	2004: 1,210 adults (18+ years)	CATI	response rate 2004: 58.3% See calculation method below.*
Qld 6. 2005 Omnibus Survey: General Population	Qld state-wide residents in private households with a telephone persons ages 18 years & over	some prior surveys may be comparable	2005	sample random sample selected via extended EWP*	2005: 1,846 adults (18+ years)	CATI	response rate 2005: 70.1% of contacted in-scope people See calculation method below.*
Qld 7. 2005 Omnibus Survey: Sunsafe	Qld state-wide residents in private households with a telephone ages 18-64 years (adult survey) & 18-24 years (youth survey)	some prior surveys may be comparable	2005	sample random samples of adults of ages: (1) 18-64 years (adult survey), and (2) 18-24 years (youth survey), selected via EWP	2005: 1,586 adults (18-64 years) (adult survey), & 288 younger adults (18-24 years) (youth survey)	CATI	response rate 2005: 78.0% of contacted in-scope people (adult survey), & 75.3% of contacted in-scope people (youth survey). See calculation method below.*

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Qld 8. 2005 & 2006 Fruit & Vegetable Consumption (Go for 2&5) Surveys	Qld state-wide residents in private households with a telephone ages 18-54 years	some prior surveys may be comparable with some modules	2005, 2006.	sample random sample selected via extended EWP*	2006: 2,481 adults (18-54 years). 2005: 1,941 adults (18-54 years).	CATI	response rate 2006: 73.5% of contacted in-scope people. 2005: 72.7% of contacted in-scope people. See calculation method below.*
Qld 9. 2005 & 2006 Physical Activity (10,000 Steps) Surveys	Qld state-wide residents in private households with a telephone ages 45-75 years	some prior surveys may be comparable with some modules	2005, 2006.	sample random sample selected via extended EWP*	2006: 1,716 adults (45-75 years) 2005: 1,725 adults (45-75 years).	CATI	response rate 2006: 78.3% of contacted in-scope people. 2005: 72.9% of contacted in-scope people. See calculation method below.*
Qld 10. 2006 Omnibus Survey: General Population	Qld state-wide residents in private households with a telephone ages 18 years & over	some prior surveys may be comparable	2006	sample random sample selected via extended EWP*	2006: 1,521 adults (18+ years)	CATI	response rate 2006: 66.3% of contacted in-scope people See calculation method below.*
Qld 11. 2007 Omnibus Survey: General Population	Qld state-wide residents in private households with a telephone ages 18 years & over	some prior surveys may be comparable	2007	sample random sample ample selected via EWP, supplemented with RDD.	2007: 2,004 adults (18+ years)	CATI	response rate 2007: 68.5% of contacted in-scope people See calculation method below.*
Qld 12. 2006 National Oral Health Survey: Queensland Component	Qld state-wide residents in private households with a telephone ages 15 years & over		2006	sample three-stage stratified clustered sampling design (postcode, household, person >15yrs).	2006: 824 persons (781 after excluding subjects <18 years & those with missing or unreasonable anthropometric data).	CATI and anthropometric measures	response rate 2006: 49% for interview component & 44% for examination component of national survey (no data for Qld only).

Data collection title	**Details on:**						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
WA 1. WA Data Linkage System (WADLS) – Department of Health WA in collaboration with the University of WA School of Population Health, Telethon Institute for Child Health Research, & Curtin University	WA state-wide linkages between administrative population health & other data held on Western Australians (including some cross-jurisdictional data held on Western Australians) all ages	yes in the same subjects since, & for, varying years. Core WA data sets: Birth registrations from 1974, Death registrations from 1969, Hospital separations from 1970, Cancer notifications from 1981, Mental health clients from 1966, Midwives notifications from 1980, & Electoral roll from 1988. Commonwealth data system records - originating in WA - for: Aged care 1990-2003, MBS 1984-2004, PBS 1990-2004. Other WA data systems: Road injury 1987-2004, Silver Chain 1993-2001, Emergency dept. 2000-2003, Ambulance 1990-2005, Next Step (drug & alcohol services) 1974-2000. Research databases include the Busselton Surveys 1966-1987 & others.*	longitudinal linked records	data linkage of administrative, registry and other records including cross jurisdictional records. The system links core WA population health datasets with clinical and health service data sets. Over six million records (electoral, midwives, hospital & death records) in over one million individuals have also been geocoded.	Mar 2008: total of 19,974,736 records, 3,799,703 chains (maximum number of links in a chain 3,100, average chain length 5.26 links); including: 16,447,746 morbidity records, 228,356 cancer registrations, 365,923 mental health clients, 374,372 death records, 1,856,757 electoral records, >809,903 birth registrations, and 701,582 midwives records.	regular continuous linkage of administrative records using computerised probabilistic matching in a dynamic multi-set linkage system Data collections routinely linked by Data Linkage WA are: midwives notifications, cancer registrations, mental health clients, hospital admissions and emergency presentations. Electoral, birth and death records are linked routinely under a special arrangement with the WA Electoral Commission and the Registry of Births, Deaths and Marriages. Residential aged care records and Medicare enrolments are also linked under a separate Memorandum of Understanding with the Australian Government Department of Health and Ageing.	enumeration/ quality of links 2002: estimated linkage error rate of 0.3% (~3 chains in 1,000).*

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
WA 2. Hospital Morbidity Data Collection (HMDS) – Department of Health WA	WA state-wide all in-patients discharged from public and private hospitals	yes since July 1969	continuous	census of hospital admissions	2008: total of ~20,000,000 in-patient discharge records dating from July 1969 onwards; >800,000 in-patient episodes per year	administrative records provided by hospitals collated in database	enumeration unknown
WA 3. Western Australian Cancer Registry (WACR)* – Department of Health WA	WA state-wide cancer diagnoses and deaths due to cancer all people resident in WA at the time of diagnosis or death*	yes since 1982	continuous	mandatory notification by pathologists, haematologists and radiation oncologists, together with scans of death notifications	~250,000 persons currently registered. 2006: 9,692 new cases of cancer: 5,457 (56%) in males & 4,235 in females; 3,570 deaths due to cancer: 2,047 in males & 1,523 in females. 2005: 9,151 new diagnoses of cancer: 5,163 in males (56%) & 3,988 (44%) in females; 3,432 deaths due to cancer: 2,004 males & 1,428 females.	register copies of pathology reports are abstracted into a case-based database	enumeration/ ascertainment completeness estimated as varying between 94-99% in any reporting year; overall completeness improves as the period after the reporting timeframe lengthens (and late-received data is reconciled), as well as after data audits (e.g., of hospital-data-only cancer records).*
WA 4. Western Australian Health & Wellbeing Surveillance System (HWSS) – Department of Health WA	WA state-wide residents of private dwellings with a telephone all ages	yes since 2002	continuous - based on annual sample from 2002 to end 2004; - based on monthly sample from Jan 2005-	sample stratified random sample, selected from latest version of EWP up to 2004, & stratified by (1) Area Health Services from 2002-2006; & by (2) metropolitan, rural & remote areas since 2007. Rural & remote areas are over-sampled. Various areas & age groups have been over-sampled in the past.*	2007: 7,601 respondents completed interviews. 2006: 7,127 respondents (5,327 16+ years). Oct 2008: a total of >45,000 interviews had been conducted since 2002. 2008: planned sample of at least 6,600 persons each year (550 per month).	CATI	response rate 2007: 73.7% raw response rate (completed/eligible), 81.6% eligible response rate (completed/eligible contacts) and 89.4% participation rate (completed/[completed + refused]).

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
WA 5. Mental Health Information System (MHIS) – Department of Health WA	WA state-wide	yes	continuous	administrative records	approximately 41,000 people contact MH services each year (~26,000 hospital inpatient admissions, 480,000 public occasions of service in a non-admitted setting, & 25% are first time patients)	administrative records	enumeration complete
SA 1. South Australian Cancer Registry* – SA Dept of Health	SA state-wide residents who have been diagnosed with cancer all ages	yes since 1977	continuous	census of cancer notifications	~8,000 new cases per year plus information received on new developments relating to known cases	register cases of cancer are notified by parties nominated in legislation, including pathology laboratories, hospitals, radiotherapy depts, the Registrar of BDM and other sources.	enumeration/ ascertainment incidence and mortality, including active monitoring until case death from cancer or another cause. Ascertainment is near 100%.
SA 2. Integrated SA Activity Collection (ISAAC)* – SA Dept of Health	SA state-wide patients separated from public and private hospitals (including day-only facilities)	yes since 1995	continuous	census of patient separations from public and private hospitals	approximately 450,000 new cases [separations] a year	hospitals capture data on each patient separation and submit details to the SA Department of Health electronically or on paper forms	enumeration complete
SA 3. South Australian Monitoring and Surveillance System (SAMSS)* – SA Dept of Health	SA state-wide residents in private households with telephones all ages, including infants and children	yes since July 2002	monthly	sample random selection of all households listed in the EWP	2007: >40,000 interviews conducted to date, with ~600 interviews conducted per month. 2003-04: 6,738 persons; 2002-03: 6,145 persons.	CATI	response rate 2007: 69.4% 2003-04: 68.4% 2002-03: 69.3%. See calculation method below.*

Data collection title	Details on:						
	coverage	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
SA 4. Health Omnibus Survey (HOS)* – SA Dept of Health	SA Adelaide metropolitan area (77% of sample) & country towns of >1,000 population (rest of sample) residents in private households ages 15 years & over	yes since 1990	annual	sample clustered, multi-stage, systematic, self-weighting area sample	sample of 4,400 households; minimum of 3,000 persons per survey* 2004: 4,573	PAPI	response rate 2004: 65.9% 1991-2000: ~70%* Calculation method not available
SA 5. Health Monitor Survey (HMS)* – SA Dept of Health	SA state-wide residents in private households with telephones ages 18 years & over coverage may vary in additional ad hoc surveys*	yes since 1999	three times a year regularly additional ad hoc surveys may be conducted*	sample random selection of all households listed in the EWP	sample of ~3,400 households, ~2,000 persons (majority of surveys) sample size may vary according to survey needs*	CATI	response rate ~65%-70% recent actual response rate & calculation method not available.
SA 6. Social, Environmental and Risk Context Information System (SERCIS)* – SA Dept of Health	SA coverage & survey area tailored to customer needs residents in private households with telephones ages 18 years & over	yes since 1995	varies	sample random selection of all households listed in the EWP for specified geographical areas	surveys usually have a sample size of 3,000 households but may be higher depending on need	CATI	response rate usually between 70% and 80% recent actual response rate & calculation method not available.
Tas 1. Healthy Communities Survey	Tasmania state-wide residents in private households ages 18 years & over	no	1998	sample stratified random sample of households drawn from the electoral roll	1998: 18,680 adults (18+ years)	mailed questionnaire	response rate 1998: 75%

Data collection title	**Details on:** **coverage**	**time series**	**frequency** *italics = planned*	**collection method**	**number in collection**	**mode**	**enumeration/ response rate & calculation method**
Tas 2. 'Filling the Gaps' CATI survey – funded by DoHA	Tasmania state-wide residents in private households with a telephone ages 18 years & over	no	2004	sample random sample of households	2004: 1,215 adults (18+ years)	CATI	response rate 2004: 73.7%
ACT 1. ASSAD	ACT all secondary schools students ages 12-17 years	yes	triennial	sample random sample of junior & senior schools, & of students drawn from participating school rolls.	2005: 21 schools, 1,152 students.	PAPI in schools	response rate 2005: schools (participating/ invited) 60%, students unknown.
ACT 2. Child Health Survey – NSW Health	ACT residents in private households with a telephone ages 0-12 years	no	2001	sample (ACT sample)	2001: 516 children	CATI	response rate refer NSW Health
ACT 3. Smoking, Nutrition, Alcohol & Physical activity Survey (SNAPS) ('Filling the Gaps') – funded by DoHA	ACT residents of private households with a telephone ages 18 years & over	some potential with other surveys	2004	sample (ACT sample)	2004: 1,215 adults (18+ years)	CATI	response rate
ACT 4. Older Persons Survey – NSW Health (NSW)	ACT residents of private households with a telephone ages 65-97 years	no	1999	sample (ACT sample)	1999: 537 older persons (ages 5-97 years)	CATI	response rate refer NSW Health.
ACT 5. Physical Activity & Nutrition Survey (ACTPANS) – ACT Health	ACT primary schools year 6 students	some potential with other surveys	2006	sample stratified (by school type) random sampling	2006: 1,200 year 6 students	measurements by Community Nurses & paper questionnaire completed during classes	response rate 35 of original 37 schools agreed (95%), two replacements invited & agreed to participate. 83%

Data collection title	Details on: coverage	time series	frequency *italics = planned*	collection method	number in collection	mode	enumeration/ response rate & calculation method
							of children completed both components, 95% one component.
ACT 6. General Health – ACT Health commissioned, carried out by SA Dept of Health	ACT statewide residents of private households with telephones all ages	some potential with other surveys	2005	sample random sample based on RDD	2005: 1,238 persons	CATI	response rate April 2005: 80% Sept 2005: 78%.
ACT 7. General Health (NSW)	ACT statewide residents of private households with telephones all ages	yes	continuous from 2007	sample	2007: 1,300 persons	CATI	response rate refer NSW 1 above.
NT 1. Health and Wellbeing Survey (adult) 2000 – funded by DoHA	NT as part of tristate survey (WA, SA & NT) statewide residents in private households with telephones ages 18 years & over	no	one off 2000	sample random telephone sample	2000: 2,500 adults (18+ years)	CATI	response rate 2001: 80% response, weighted for non-Indigenous population (low coverage of Indigenous residents as many lack telephones)*
NT 2. Risk factor survey, 2004 (Filling the Gaps) – funded by DoHA	NT statewide residents in private households with telephones ages 18 years & over	no	one off 2004	sample random telephone sample	2004: 1,192 adults (18+ years)	CATI	response rate 2004: 66%, weighted for non-Indigenous population (low coverage of Indigenous residents as many lack telephones)*

Data collection title	Details on:						
	coverage	time series	frequency *italics = planned*	collection method	number in collection	mode	enumeration/ response rate & calculation method
NT 3. National Aboriginal and Torres Strait Islander Survey (NATSIHS) 2004-05 – ABS See ABS 2. for additional details on the NATSIHS as a whole.	NT statewide Aboriginal population (as part of national survey) all ages	some data since 2001 (additional small samples to the 1995 and 2001 NHS may be available for time series analyses)	every 6 years 2004-05, *2010-11,*	sample cluster sampling by household	2004-05: ~1,400 including children	two modes: (1) CAPI in non-remote areas; (2) PAPI in remote areas; & community-level information collected from local Community Council and Health Clinic.	response rate in NT not known – refer to ABS
NT 4. Chronic disease register – NT Dept. of Health and Community Services (DHCS)	NT 50% of remote Aboriginal communities all ages	dates of events are recorded	continuous clinical data system	register clinical assessment	2007: 20,000 persons	key summary of interview and examination stored as an electronic database	enumeration direct population record based on aggregated patient record. High coverage for Aboriginal population
NT 5. Central NT heath and community services data warehouse – NT DHCS	NT statewide, complete for Aboriginal population & for non-Aboriginal service population all ages	with linkage can provide historical record of significant health events	episodic	continuous service event recording	2007: 250,000 episodes of health care	clinical assessment	enumeration/ quality of links comprehensive record of NT Aboriginal population and of non-Aboriginal service population
NT 6. Primary health care electronic record systems – NT DHCS	NT aiming for state-wide coverage of all residents using NT Govt. health services (by June 2009) all ages	linkage with data systems allows longitudinal analysis of sentinel events and outcomes	episodic, but for remote communities 85% of population seen each year	summary of clinical events	2007: 50,000 primary health care records, with linkage across providers	developing data system, with linkages across providers	enumeration/ quality of links by June 2008: will cover 60% of remote NT Govt. health services by June 2009: 100% coverage planned.

Table 6: Additional details of data collections in the Audit of Chronic Disease and Associated Risk Factor Data Collections – part 2 of 2 parts

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
ABS 1. National Health Survey (NHS)	yes	yes	yes	yes COB & year arrived, language/s mainly spoken at home, proficiency in English	yes income, education level, occupation, labour force status	States & ACT only (not NT) a	The first survey in the NHS series was conducted in 1989-90 (number in collection = 54,241 persons); prior national health and related surveys collected some similar information and may be comparable for lengthier time series[23:66], as may the much earlier Supplementary Surveys on Chronic Illnesses, Injuries, and Impairments conducted in May 1968 & May 1974. Generally, the NHS collects basic demographic data about usual residents of households (including sex, age, date of birth, country of birth, Indigenous status, marital status) and details of the relationship between individuals in each household; information from adults on their demographic and socio-economic characteristics (including education, language, labour force, housing and income) and health characteristics (including self-assessed health status, long-term illness conditions experienced, mental wellbeing, injuries), selected lifestyle behaviours/health risk factors (including alcohol consumption; smoking; exercise; height, weight and body mass; dietary habits; adult immunisation; supplementary women's health topics), and health-related actions taken (including use of medication, visits to hospital, consultations with doctors and other health professionals); and information on children including their demographic and (for older children) socio-economic characteristics and various health characteristics (including breastfeeding; childhood immunisation; dietary habits). The content of individual surveys differs somewhat around a common core data set that is maintained through the series. Survey design and comparison are complex; for more information see documentation and/or consult ABS.[29,187] Sampling strategy - 2004-05: collected data on one child 0-17 years, & one adult 18+ per selected household; additional sample in SA, Tas and ACT[29]; 2001: all children under 7 years, one child 7 to 17 & one adult 18+ per selected dwelling, additional sample in ACT.[188] Tasmania over-sampled in 2004-05 with a responding sample of 1,949 [giving a total NHS sample in Tasmania of 2,873[189]]. 2004-05 response rate calculated as: number of fully or adequately responding households divided by number of sampled households (19,501 / 21,808 = 89.4%). Sampled households = selected households less total sample loss (25,234 - 3,426 = 21,808 in 2004-05).

	Disaggregations						**Additional information:**
Data collection title	**age**	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
ABS 2. National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)	yes.	yes	Indigenous only, non-Indigenous available through NHS	Indigenous only, non-Indigenous available through NHS	yes income, education level, occupation, labour force status	State/territory remote/non-remote	The 2004-05 NATSIHS was the largest health survey of Indigenous Australians conducted by the ABS. The sample size was 10,439 persons (~1 in 45 of the total Indigenous population), much larger than the 1995 and 2001 NHS(I) supplementary Indigenous samples. NATSIHS was conducted in remote and non-remote areas throughout Australia, and was designed to collect a range of information from Indigenous Australians about health related issues, including health status, risk factors & actions, and socioeconomic circumstances.[20] The NATSIHS collected data for all persons, however, age restrictions apply to specific items [eg. information on social and emotional wellbeing was collected only from Indigenous adults (ages 18+ years) using selected questions from the SF-36 and the Kessler Psychological Distress Scale]. There were a number of differences between the data collection methods used in remote communities and those used in other geographical areas. For instance, in remote communities, the standard household survey approaches were modified to take account of language and cultural issues; information on substance use was not collected; only a subset of the supplementary women's health topics was collected, through personal interview with adult female respondents; and a Community Information Form (CIF) was used to collect, from the Community Council and Health Clinic, a limited amount of community level information about CDEP, access to medical services and community health issues. In the non-remote communities, in addition to the main survey, there were two small paper questionnaires on (1) substance use (ages 15+ years) and (2) specific supplementary women's health topics (women of ages 18+ years), which were voluntary and self-enumerated. See the *User's Guide*[22] or consult ABS for additional information on collection methods. The NATSIHS was designed to produce reliable estimates at the national level and for each state and territory; and the Torres Strait Islander population was over-sampled to produce data for the Torres Strait Area and the remainder of Qld. The 1995 and 2001 NATSIHS data were additional small samples to the 1995 and 2001 NHS [NHS(I)] – rather than surveys in their own right - and are available for time series data, as is the National Aboriginal and Torres Strait Islander Survey 1994, which included some health-related data items. The response rate for the substance use questionnaire was 78% (non-remote areas only; substance use data was not collected in remote areas) with a substantial component of non-response appearing to reflect collection error where the substance use questionnaire may not have been offered to potential respondents.[20]

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
ABS 3. Survey of Disability, Ageing and Carers (SDAC)	yes	yes	no	yes COB	yes income, education level, occupat-ion, labour force status	States & ACT only (not NT) a	SDAC 2003 collected detailed information on people with disabilities, older people, people providing care for older people and people with disabilities, and comparative information on people who were not in these populations. Information was collected from people in both households and cared-accommodation (e.g., nursing homes) using different survey components and methods: (1) the household component and (2) the cared-accommodation component. In addition to household and demographic information, topics collected from older people, people with a disability, and people with long-term health conditions, included: impairments, long-term health conditions and cause of main disabling condition; difficulties experienced by people with a disability, and help required in the activities of self-care, mobility, communication, cognition or emotion, and health care; difficulties experienced and help required for people aged 60 years or more and people with disabilities in the further activities of paperwork, transport, housework, property maintenance, meal preparation; the type of assistance received for each of these activities other than cognition or emotion, the providers of assistance, the extent to which need was met, and reasons for unmet need; use of aids and equipment; and access to and use of computers and the Internet. Information was collected from people identified as primary carers of people with a disability on: the type of care provided; the availability or use of support; and the effect of the caring role on their daily life. Access to computers and Internet at home was collected for the first time. Primary carers also completed a self-enumeration form during the interview on their attitudes to and experience of their caring role. A subset of the household component data was obtained on people in cared accommodation using a mail-back form completed by an administrative staff member of the establishment.[91,93] Disability information was first collected - in a Monthly Population Survey (MPS) supplementary survey - in 1967, and twice more as an MPS supplementary in the 1970s; it was then collected in a series of Special Supplementary Surveys: 1981 (the Survey of Handicapped Persons), 1988 (the Survey of Disabled and Aged Persons - expanding the populations of interest to include older people and principal carers), and then as the Survey of Disability, Ageing and Carers in 1993, 1998 and 2003.[190] 2003 response rate calculated as: number of fully or adequately responding households divided by the sum of the fully or adequately responding households and part & non-responding households. Household component: 14,322/ (14,322+1,717) = 89.3%; cared-accommodation component: 542/ (542+50) = 91.6%.
ABS 4. Survey of Mental Health and Wellbeing (SMHWB)	yes	yes	no	yes COB	yes income source, education level, occupat-ion, labour force status	national, remote-ness,‡ state‡*	The 1997 SMHWB was designed to provide information on the prevalence of selected major mental disorders, the level of disability associated with these disorders, and health services used, and help needed, as a consequence of a mental health problem for Australians aged 18 years and over.[94:4] The 2007 survey collected information about personal functioning, chronic conditions, specific mental health issues including dementia, depression, mania, panic disorder, social phobia, substance use, suicidality and others, as well as data on medications, social networks, caregiving and a range of demographics. Data from the survey was released from October 2008.[191] In the 2007 survey 16-24 year olds, 65-74 and 75-85 year olds were over-sampled in order to obtain RSEs of 25% or better when analysed by sex. The survey was not designed for analysis below national level. Response rate calculated as: number of fully or adequately responding households divided by number of sampled households (10,641 / 13,624 = 78.1% in 1997). Sampled households = selected households less total sample loss (15,531 - 1907 = 13,624 in 1997).

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
ABS 5. General Social Survey (GSS)	yes	yes	no see NATSISS	yes COB & proficiency in spoken English	yes income, assets & liabilities, education levels, & labour force status	State/ territory part of state metropolitan, part of state extra-metropolitan, some ARIA categories *	The GSS is intended to include both core dimensions and a flexible component on contemporary and emerging issues in each survey cycle. Core information collected includes: details of health and disability, housing, education, labour force, transport, crime, and indicators of family and community involvement; economic items (income and selected assets, liabilities and financial stress indicators); and demographic details. The 2002 GSS: included three supplementary topics: the extent of computer and internet access, attendance at cultural and sporting events, and participation in sport or other physical activity. The 2006 GSS flexible component included topics relating to social capital, voluntary work and category of visa held by Australian immigrants. Some of the information now collected in the GSS was previously included in a range of more specific ABS surveys including the: Household Expenditure Survey; Survey of Income and Housing Costs; Australian Housing Survey; Survey of Disability Ageing and Carers; Survey of Education, Training and Information Technology; National Health Survey; Voluntary Work Survey; Crime and Safety Survey; Survey of Employment Arrangements and Superannuation; Labour Force Survey; Survey of Attendance at Selected Culture/Leisure Venues; and the Survey of Sports Attendance. The GSS is conducted in urban and rural areas and does not include people living in remote and sparsely settled areas (~2%); however, this has a minor impact on aggregate national and state level estimates (except for the NT). The 2006 GSS was benchmarked to the estimated resident population aged 18+ years (ERP) living in private dwellings in each state and territory (based on results from the 2001 Census of Population and Housing), excluding the ERP living in very remote areas of Australia, at 30 June 2006. The GSS estimates do not (and are not intended to) match estimates for the total Australian resident population (which include persons and households in non-private dwellings and very remote parts of Australia) obtained from other sources. Subject to data quality considerations, data may be made available for some categories of the Accessibility and Remoteness Index for Australia (ARIA). Sample sizes differed between the 2006 and 2002 GSS. In 2006, the number of fully or adequately responding households achieved in the survey was 13,375 compared to approximately 15,500 for the 2002 cycle. The 2006 cycle had a smaller initial sample size (17,700 possible dwellings) compared to the 2002 initial sample size (19,500 possible dwellings). There was a reduction in achieved proportions of the initial sample sizes due to higher sample loss in the 2006 cycle (more households with no residents in scope and/or dwellings that were vacant, under construction or derelict), and a higher rate of survey non-response from eligible households. These differences should be considered when comparing results.[89:83] Response rate calculated as: number of fully or adequately responding households divided by number of sampled households (13,375 / ~15,500 = 86.5% in 2006; ~15,500 / ~17,000 = 91% in 2002). Sampled households = selected households less total sample loss (17,700 - ~2,200 = ~15,500 in 2006; ~19,500 – ~2,500 = ~17,000 in 2002). [Note that in 2006 approximately 2,100 respondents (16%) did not provide one or more required answers but were deemed to have responded adequately; in 2002 the corresponding number and proportion were approximately 1,200 respondents (8%).]

Data collection title	Disaggregations						Additional information:
	age	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
ABS 6. National Aboriginal and Torres Strait Islander Social Survey (NATSISS)	yes	yes	Indigenous only, non-Indigenous available through GSS	Indigenous only, non-Indigenous data available through GSS. Main language spoken at home, whether speaks an Indigenous language, Whether identifies with clan, tribal or language group,	yes income, assets & liabilities, education levels, & labour force status	national remote & non-remote areas, State/ territory, national-level data for ARIA categories & data for some ATSIC regions*	Provides information about the Aboriginal and Torres Strait Islander (ATSI) populations of Australia for a wide range of areas of social concern including health, education, culture and labour force participation. Health data items included: self-assessed health status, disability status, smoker status, alcohol risk levels, and, substance use. The NATSISS was first conducted in 2002, however, some of the information was previously collected in a range of other ABS surveys including the: National Aboriginal and Torres Strait Islander Survey (NATSIS) 1994 (a landmark survey that provided the first broad and contemporary social picture of ATSI peoples); Australian Housing Survey (AHS) 1999; Community Housing and Infrastructure Needs Survey (CHINS) 1999 & 2001; National Health Survey (Indigenous) 2001; Population Census; Labour Force Survey; General Social Survey; and the Survey of Disability, Ageing and Carers. The samples for community areas and non-community areas were designed separately with each involving a multistage sampling process. The community sample was obtained from a random selection of distinct Indigenous communities and out-stations using a specially developed Indigenous Community Frame (ICF). Dwellings in non-community areas were selected using a stratified multistage area sample. The Torres Strait Islander population was over-sampled to produce data for the Torres Strait Area and the remainder of Qld. After screening about 233,000 households in non-community areas, approximately 2.5% were identified as having an Indigenous usual resident aged 15 years or over, and around 80% of these households then responded to the survey. This response rate does not take into account the 12% of households that were unable to be contacted to establish the Indigenous status of the occupants. In communities, 78% of in-scope households were fully responding, with a further 16% of households yielding some information.[90] There were a number of differences between the data collection methods used in communities in remote areas in WA, SA, Qld and the NT, and those used in other geographic areas. In the former, the standard household survey approaches were modified (as a result of pre-testing), to take account of language and cultural issues, although most underlying concepts remained the same across all areas. In distinct communities, and more generally in remote areas, interviews were conducted using a paper questionnaire. In communities, interviewers were accompanied, wherever possible, by local Indigenous facilitators, who assisted in the conduct and completion of the interviews. In addition, Community Information Forms (CIFs) were used to collect limited community level information from the Council Office, such as availability of services and facilities within the community. Interviews conducted in non-community, non-remote areas predominantly used CAPI.[90] Subject to data quality considerations, national-level data may be made available for each of the five Accessibility and Remoteness Index for Australia (ARIA) categories. Data for 8 of the 36 ATSIC regions and synthetic estimates for other ATSIC regions may be available, subject to data quality considerations.[192]

	Disaggregations						Additional information:
Data collection title	**age**	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
ABS 7. 2006 Adult Literacy and Life Skills Survey (ALLS)	yes	yes	yes	yes	yes	state/ territory [SAL was capital city/ rest of S/T]	The ALLS was the second survey of its type to be conducted, with its predecessor, the International Adult Literacy Survey (IALS), conducted in Australia in 1996 as the SAL. IALS was the world's first internationally comparative survey of adult skills. The ALLS was also an international survey completed by participating countries in successive waves & Australia was among the second wave of countries (with NZ, the Netherlands, Hungary & South Korea; those in the first wave were: Bermuda, Canada, Italy, Mexico, Norway, Switzerland & the US).[193] Two of the five literacy domains available from the 2006 ALLS (prose and document literacy) are directly comparable to those from the 1996 SAL. Due to major conceptual changes, time series analyses of the numeracy domain are not possible. The problem solving and health literacy domains were new in the 2006 ALLS and no time series information is available on these domains. 2006 ALLS initial sample consisted of 14,311 private dwellings, which reduced to 11,139 dwellings due to loss of households with no residents in scope, and dwellings that were vacant, under construction or derelict. Of the eligible dwellings, 80.7% responded fully or adequately, yielding a total sample of 8,988 persons. Response rate calculated as: number of fully or adequately responding households divided by number of sampled households (8,988 / 11,139 = 80.7% in 2006; 9,302 / 10,709 = 86.9% in 1996) Sampled households = selected households less total sample loss (14,311 – 3,172 = 11,139 in 2006; 13,008 – 2,299 = 10,709 in 1996).
ABS 8. Community Housing and Infrastructure Needs Survey (CHINS) – conducted by ABS for the Dept. of Families, Community Services & Indigenous Affairs	n/a	n/a	n/a	n/a	n/a	state/ territory, ATSIC regions, broad ARIA-based regions	Topics covered by the 2006 CHINS include: details of the current housing stock, dwelling management and selected income & expenditure arrangements of Indigenous organisations that provide housing to Aboriginal and Torres Strait Islander (ATSI) peoples; and in distinct Indigenous communities: details of housing and related infrastructure (e.g., water quality & supply, electricity supply, sewerage systems, drainage, rubbish collection & disposal); and details of facilities available (e.g., transport, communication, education, sport & health services). 2001 and 2006 CHINS data were collected in conjunction with field preparations for the Census of Population and Housing. In 2006, data collection was undertaken by ABS Census Field Officers during public relations visits to Indigenous communities and Indigenous Housing Organisations (IHOs) over the period March to June 2006 and through telephone follow-up from July to November 2006. Data were collected at the discrete Indigenous community and IHO level. Personal interviews were conducted with key community and IHO representatives knowledgeable about housing and infrastructure issues (including community council chairpersons; council clerks; housing officers; water & essential service officers; & health clinic administrators). For the 2006 CHINS, two electronic questionnaires were used to collect the data: (1) the Housing questionnaire collected information about Indigenous organisations managing housing provided to ATSI peoples in distinct Indigenous communities, towns & other localities. Data were collected on a range of topics (e.g., housing income & expenditure, type & condition of housing stock, dwelling acquisitions & disposals). (2) the Community questionnaire collected detailed infrastructure information from all distinct Indigenous communities with a reported usual population of 50 persons or more, and communities that reported usual population of less than 50 persons but were not administered by a larger Indigenous community or Resource Agency. Data were collected on infrastructure (e.g., details of water supply & quality, electricity & gas supply, sewerage systems, drainage & rubbish collection & disposal), transport & telecommunications, and access to education, health, sport & other community facilities. To reduce respondent reporting load, all other communities of less than 50 persons were asked a subset of questions (as in 2001); and information was collected from the larger administering community or Resource Agency responsible for the provision and maintenance of their services.[98] Disaggregations: n/a as the data are at the community and IHO level and no person-level data were collected.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
AIHW 1. National Hospital Morbidity Database	yes	yes	yes	yes	proxy measures only	state/ territory remoteness* SLA, postcode, statistical division	The National Hospital Morbidity Database is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals. Coverage: public sector hospitals not included are those not within the jurisdiction of a S/T health authority (eg, hospitals operated by the Department of Defence, correctional authorities, and those located in offshore territories). Enumeration: the database contains data relating to admitted patients in almost all hospitals, including public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free-standing day hospital facilities. All public hospitals were included for 2006-07, with minor exceptions; and the majority of private hospitals were also included - the few not included were mainly free-standing day hospital facilities. Counts of private hospital separations are therefore likely to be under-estimates of the actual counts: in 2005-06, the database reported 78,894 (2.8%) fewer separations than the ABS Private Health Establishments Collection, which may have wider coverage.[108:4] Hospital separations record hospital patient discharges, transfers, deaths and changes in care type, and a record is included in the database for each separation (rather than for each patient), therefore patients who separated more than once in the period will have more than one record in the database.[108:5] Geographic area includes Rural, Remote and Metropolitan Areas (RRMA), Australian Standard Geographical Classification (ASGC) and Accessibility/Remoteness Indicator for Australia (ARIA) for both hospitals and usual residence of admitted (although classifications are not available for some years).
AIHW 2. National Cancer Statistics Clearing House (NCSCH)	yes	yes	yes	yes	no	state/ territory, SLA, postcode	The NCSCH receives data from individual state and territory cancer registries on cancer diagnosed in residents of Australia. This commenced with cases first diagnosed in 1982. The data items provided to the NCSCH by the state and territory cancer registries enable record linkage to be performed and the analysis of cancer by site and behaviour.
AIHW 3. National Diabetes Register (NDR)	yes	yes	yes	yes	no	state/ territory postcode	The National Diabetes Services Scheme is the primary data source for the Register. The Australasian Paediatric Endocrine Group provides supplementary data for those aged 0-14 with insulin treated Type 1 diabetes mellitus. The NDR only includes people with insulin treated diabetes. Under-enumerated in the NDR includes those from NT and SA and those with Type 2 diabetes mellitus. Younger people are more likely to be registered than older people.

	Disaggregations						**Additional information:**
Data collection title	**age**	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
AIHW 4. Bettering the Evaluation and Care of Health (BEACH) – AIHW & Australian General Practice Statistics and Classification Centre (AGPSCC)	yes	yes	yes	yes NESB status	no	postcode	The BEACH© program continuously collects information about the clinical activities in general practice in Australia. Each participating GP completes details on 100 consecutive patient encounters using structured paper encounter forms. They also provide information that describes themselves and their practices. The information collected includes: characteristics of the GPs; patients seen; reasons people seek medical care; problems managed; and for each problem managed: medications prescribed, advised, provided, clinical treatments and procedures provided; referrals to specialists and allied health services; test orders including pathology and imaging.[194] Patient characteristics include: age; sex; NESB status; Aboriginality and Torres Strait Islander status; Health Care Card and Veterans' Affairs status; status to the practice (new/ seen before). SAND (Supplementary Analysis of Nominated Data) includes additional patient data (sub samples of encounters) including: population risk factors investigated (e.g., smoking status, alcohol consumption, body mass index) and may also investigate specific interests of BEACH stakeholders.[194] GPs must have a minimum of 375 A1 Medicare items in the most recently available 3-month Medicare data period. Department of Health and Ageing (DoHA) use Medicare records to construct the sample frame. Response rate calculated as: 2006-2007: 4,057 GPs were contacted, 2,810 declined to participate. Of the 1,247 who agreed, 317 withdrew and the final participating sample was 930 GPs, representing 22.9% of those who were contacted and available (930 / 4,057 = 22.9%).[122:24] 2005-2006: 3,266 GPs were contacted, 1,988 declined to participate. Of the 1,278 who agreed, 261 withdrew and the final participating sample was 1,017 GPs, representing 31.1% of those who were contacted and available (1,017 / 3,266 = 31.1%).[195:13] 2004-2005: 3,395 GPs were contacted, 2,148 declined to participate. Of the 1,246 who agreed, 293 withdrew and the final participating sample was 953 GPs, representing 28.1% of those who were contacted and available (953 / 3,395 = 28.1%).[196:49] 2003-2004: 4,224 GPs were contacted, 2,910 declined to participate. Of the 1,314 who agreed, 314 withdrew and the final participating sample was 1,000 GPs, representing 23.7% of those who were contacted and available (1,000 / 4,224 = 23.7%).[197:11] 2002-2003: 3,487 GPs were contacted, 2,239 declined to participate. Of the 1,248 who agreed, 240 withdrew and the final participating sample was 1,008 GPs, representing 28.9% of those who were contacted and available (1,008 / 3,487 = 28.9%).[198:9] 2001-2002: 3,044 GPs were contacted, 1,176 declined to participate. Of the xx who agreed, 285 withdrew and the final participating sample was 983 GPs, representing 32.3% of those who were contacted and available (983 / 3,044 = 32.3%).[199:9] 2000-01: 3,350 GPs were contacted, 2,126 declined to participate. Of the 1,224 who agreed, 225 withdrew, and the final participating sample was 999 GPs, representing 29.8% of those who were contacted and available (999 / 3,350 = 29.8%).[105:8] 1998-1999: 2,562 GPs were contacted, 1,394 declined to participate. Of the 1,168 who agreed, 184 withdrew, and the final participating sample was 984 GPs, representing 38.4% of those contacted and available (984 / 2,562 = 38.4%).[200:12]

Data collection title	**Disaggregations**						**Additional information:**
	age	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
AIHW 5. National Mortality Database	yes	yes	yes	yes	yes*	see note*	Information for the Database is provided to the AIHW by the state and territory Registrars of Births, Deaths and Marriages and coded nationally by the ABS. The database holds all registered deaths in Australia since 1964, and information held includes the disease or condition leading directly to death and other contributing diseases or conditions, as well as demographic, occupation and administrative information. Geographical areas include: state/ territory of death, registration district, state/ statistical division/ SLA of usual residence, RRMA and ASGC of usual residence.
AIHW 6. National Death Index (NDI)	yes	yes	yes	no	no	state/ territory	The NDI is used for data linkage purposes (not statistical analysis), therefore some deaths are duplicated if record information is different. The number of records will thus be higher than the number of deaths for any one year.
AIHW 7. National Perinatal Data Collection	yes	yes	yes mother only	yes mothers' COB*	SEIFA used as proxy*	state/ territory SLA, postcode *	Data on births are based on notifications to the perinatal data collections in each state and territory. Midwives and other staff, using information obtained from mothers and from hospital or other records, complete notification forms for each birth in each jurisdiction. This includes a uniform, core set of data elements known as the Perinatal National Minimum Data Set. Mother's date of birth, Indigenous status (data quality and complete may vary between jurisdictions), country of birth and area of usual residence are provided. [SEIFA (a summary measure of the SES of areas that can be used as a proxy for the SES status of persons living within them) has been derived from mother's postcode of usual residence using the IRSD.[142:63]]
AIHW 8. National Drug Strategy Household Survey (AIHW)	yes	yes	yes	yes	yes	postcode	Coverage - sample excludes: non-private dwellings (e.g., hotels, motels, boarding houses); institutional settings (hospitals, nursing homes, other clinical settings such as drug and alcohol rehabilitation centres, prisons, military establishments and university halls of residence); homeless people; and the territories of Jervis Bay, Christmas Island and Cocos Island. 'Illicit drug users', by definition, have committed illegal acts, and can be marginalised and difficult to reach; reported illicit drug use and related behaviours are therefore likely to be under-estimated. Sample variation: over-sampling in order to return reliable estimates for the lesser populated states and territories (S/T) produces a sample unproportional to the S/T distribution of the Australian population of the relevant ages (e.g., 14+ or 12+ years). 2001: Additional sample was funded by WA (targeting ages 14-34 years in metropolitan Perth, and using the drop & collect mode).[201] 2004: Additional sample funded by Qld (targeting ages 12-29-years, using the drop and collect mode).[202] Survey variation: 2004 & 2007: Not all respondents were asked all questions; a separate, shorter questionnaire was administered to 12-13-year-olds in order to minimise respondent burden. Persons of ages 12-15 years complete the survey with the consent of a parent or guardian. Response rate (total) calculated as: number of respondents completing the survey divided by number of eligible sample contacted (2007: 23,356 / 47,421 = 49.3%; 2004: 29,445 / 64,528 = 45.6%; 2001: 26,744 / 53,945 = 49.6%). Eligible sample contacted = original sample less (sample loss plus eligible sample not contactable) [2007: 83,678 – (15,254 + 21,003) = 47,421; 2004: 116,101 – (27,358 + 24,215) = 64,528; 2001: not reported].

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
AIHW 9. BreastScreen Australia dataset*	yes	women only	yes	yes	yes	state/territory ASGC	Coverage: BreastScreen Australia services are available for women in all S/T (except for some remote areas of the NT). Mammography for screening and diagnosis (i.e. investigating breast cancer symptoms) is also conducted outside the program (e.g., by private radiologists), and the reported results of the BreastScreen Australia Program therefore under-estimate the national screening total.[203:1] The program participation rate is a population-based indicator that measures the proportion of the eligible population attending the screening program within the recommended screening interval (every two years for asymptomatic women). All women who are Australian citizens and those with permanent residency status are eligible for breast screening. A high proportion of attendance for screening by women in the target age group (50-69 years) is needed to maximise reductions in mortality from breast cancer. [203:1] The program participation rate is the percentage of women in the population screened through the BreastScreen Australia Program in a 24-month period by five-year age groups for women aged 40 years and over and for the target age group 50–69 years. Program participation rates are calculated as: the number of women screened (in a 24-month period) as a percentage of the eligible female population calculated as the average of the ABS estimated resident population and age-standardised to the Australian population at 30 June 2001. [203:1-2] Unit records may not be available and there may be restrictions or limitations governing the availability or use of other data in this collection.
AIHW 10. National Cervical Screening Program dataset	yes	women only	yes*	no	no [socioeconomic status of area of residence used as proxy]	state/territory, postcode, address	Not all women in the population will require screening e.g., those who have had a hysterectomy; those who have never been sexually active etc. Program participation rate: the percentage of women screened in a 2-year period for women aged 20 years and over and for the target age group 20–69 years. Rates are calculated as the number of women screened as a percentage of the eligible female population calculated as the average of the ABS estimated resident population and age-standardised to the Australian population at 30 June 2001. Data are analysed in 2-year groups as this is the recommended screening interval for women in this age group who have been sexually active at any stage in their lives. Program participation indicators have recently been extended to include program participation data for 3- and 5-year intervals to allow international comparisons of cervical screening performance.[204:1] Indigenous status: identification of Aboriginal and Torres Strait Islander peoples in cancer registry records of new cases is incomplete as Indigenous status is not yet included in pathology forms, and reporting is primarily sourced from hospital records. Data not available for unit records – some data may therefore not be available for disaggregation.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
AIHW 11. National Bowel Cancer Screening Program dataset*	yes	yes	yes	yes	proxy: SES of area of residence	state/ territory, postcode	The program commenced in August 2006 and was to be phased in over a number of years to ensure that related health services (e.g., colonoscopy and treatment services), can meet any increased demand. People eligible to participate receive an invitation pack in the mail that includes: an invitation letter, information booklet, Participant Details Form, and Faecal Occult Blood Test (FOBT) kit. The test is completed in the privacy of the participant's home and mailed in the envelope provided, with the Participant Details form, to a laboratory for analysis. There is no cost involved to the participant for completing the FOBT. Results are sent to the participant, their doctor (if nominated) and to the National Bowel Cancer Screening Program Register by the pathology laboratory. Coverage: Australians only; temporary visa and temporary residents are excluded. Participants in the Pilot program (conducted between November 2002 and June 2004) are included. Program participation rate: There were a total of 475,198 invitations sent between 7 August 2006 and 31 July 2007. Of these invitations, 447,114 were to people aged 55 or 65 years and 28,084 to people involved in the Pilot study. Of the 447,114 invited to participate in screening, 10,780 people (2.4%) opted off or suspended participation in the national program for various reasons including having been previously diagnosed with bowel cancer, resulting in 436,153 eligible invitations. As at 31 July 2007, 149,262 people (34.2% of those eligible, but an under-estimate of the true screening participation rate because of the lag in response time) had agreed to participate in the program. After adjustment for the lag between invitation and response using the Kaplan-Meier method, estimated participation at 16 weeks (the longest period for which all states and territories had contributed data) was 41.0% nationally, ranging from a high of 46.6% in Tasmania to a low of 33.0% in the NT.[118:5-8] SES: A participant's socioeconomic status is classified using the participant's residential postcode according to the ABS Index of Relative Socioeconomic Disadvantage (IRSD). Much of the information for the program (e.g., name, date of birth, and postcode of eligible participants) is obtained from Medicare Australia's National Bowel Cancer Screening Program Register of eligible people and is provided to the AIHW for the purpose of matching to cancer registry data for evaluation purposes. The AIHW dataset is very new, and certain information is not available at present. More detailed information may possibly be accessed through the Register.
AIHW 12. Commonwealth State/Territory Disability Agreement (CSTDA) National Minimum Data Set (AIHW)	yes	yes	yes	yes	yes	state/ territory postcode	From 1995-2002, data was collected once each year as a 'snapshot' (on a single day). From 2002, annual data has been collected through the whole 12-month period.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
AIHW 13. Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS)*	yes	yes	yes*	yes	no	of establishment only: state/ territory, region identifier	The AODTS-NMDS is a nationally agreed set of data items collected by all in-scope alcohol and drug treatment service providers, collated by relevant health authorities and compiled into a national data set by the AIHW. The collection provides information on the demographics of clients who use these services, the drugs of concern nominated by clients, the treatment they receive, and administrative information about the agencies that provide alcohol and other drug treatment.[205] Coverage: Exclusions include halfway houses, sobering-up shelters and correctional institutions; as well as agencies whose sole purpose is to prescribe and/or dose for methadone or other opioid pharmacotherapies (the collection therefore excludes many clients receiving treatment for heroin). The calculation excludes Qld agencies as the number of missing non-government agencies has not been recorded (Qld supplied data from Qld Govt AODTS agencies and police diversion processes but not from other non-government-funded agencies). The 2005-06 AODTS-NMDS collection data count is based on 'closed treatment episodes' which refer to a period of contact, with defined dates of commencement and cessation, between a client and a treatment agency. Indigenous status: The number of Aboriginal and Torres Strait Islander clients may be under-counted as the majority of Australian Government-funded Indigenous substance use services and Aboriginal primary health care services that provide treatment for alcohol and other drug problems do not report as part of the AODTS-NMDS collection. Data for 2000-01 (the base year) is not fully standardised across all jurisdictions.
AIHW 14. Child Dental Health Survey – AIHW Dental Statistics & Research Unit (DSRU)	yes	yes	yes*	yes*	yes using the SEIFA Index to assign values to resident-ial post-codes see AIHW 10. & 11.	state/ territory, postcode	The dental health of children enrolled in S/T school dental services has been monitored since 1977. From 1977 until 1988 monitoring was managed centrally by the Commonwealth Department of Health as an evaluation of the Australian School Dental Scheme. In 1989, responsibility for collecting national data was transferred to the AIHW DSRU at The University of Adelaide, where it is conducted through the Child Dental Health Survey.[144:1] The annual Child Dental Health Survey monitors the dental health of children enrolled in school dental services operated by state and territory health authorities. Coverage: children not enrolled in school dental services are not included in the survey. 2002 reporting excluded results from NSW due to a lack of representativeness of the NSW sample. Collection method: Tasmania and Victoria use a different random sampling method. Different sampling ratios are used across the S/T and there is considerable variation both between S/T and over time.[144:1-2,206:1-2] Indigenous status and country of birth data for school dental services is not comprehensive. These items are omitted from reporting.
AIHW 15. National Survey of Adult Oral Health – AIHW DSRU	yes	yes	yes	yes	yes	state/ territory, capital city/ other places	The survey examined levels of oral disease, perceptions of oral health and patterns of dental care within a representative cross-section of adults in all states and territories of Australia. Survey participants who reported having some or all of their own natural teeth were subsequently invited to a standardised dental examination. In addition, people's qualitative experiences of oral health and dental care were recorded during more detailed 'oral history' interviews that were collected from a small number of survey participants from each 'dental generation' (defined and classified as the four generations born during two-decade intervals through the twentieth century).[145:1] The first national oral examination survey of Australians was the 1987-88 National Oral Health Survey of Australia (NOHSA). The NDTIS 2004-2006 formed part of the National Survey of Adult Oral Health.

Data collection title	Disaggregations age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	Additional information:
AIHW 16. National Dental Telephone Interview Survey (NDTIS) – AIHW DSRU	yes	yes	yes	yes	yes	postcode	Periodic telephone interview surveys of a general population sample to obtain data on range of items relating to dental health. The NDTIS 2004-06 formed part of the National Survey of Adult Oral Health (which see).[145] NDTIS 1994-96 & 1999 were reported in combined form.[144] Response rate calculated as: number of survey participants divided by the sum of the numbers of participants and refusals [2002: 7,312 / (7,312 + 3,966)]. Eligible sample equals total sample less (the sum of numbers out of service plus out of scope plus non-contact) [2002: 24,938 - (6,596 + 3,923 + 3,141)].
DoHA 1. Aged Care Assessment Program Minimum Data Set (ACAP MDS)	yes	yes	yes	yes	proxy, postcode	postcode	The Commonwealth Guidelines for the Aged Care Assessment Program (ACAP) provide a national framework for the operation of Aged Care Assessment Teams (ACATs) which assess the needs of frail older people and facilitate access to care services appropriate to their needs. Assessment by an ACAT is mandatory for admission to residential care or residential respite, and to receive various kinds of 'packaged care'; ACATs also refer people to community services and rehabilitation services. Individuals who seek approval as a care recipient to access government funded aged care services have their data collected by the Commonwealth. Health conditions of all assessed clients are collected, many of which can be classified as 'chronic'. Health condition codes are in accordance with codes used by the ABS. In 2005-2006, the ACAP MDS was expanded to include several new codes and data items, including reporting care coordination activity for the first time.
DoHA 2. Private Health Insurance Administration Council (PHIAC) A Report	yes	yes	no	no	no	state/ territory	Private health insurers are required by law to provide information to PHIAC concerning the use and cost of chronic disease management programs used by their members. PHIAC A Report is a quarterly publication detailing by state, the membership and benefits paid by health benefits funds for the period.[207:35] Part 5 shows: by sex and five-year age group, the number of insured persons, Chronic Disease Management Programs, and the dollar value of eligible benefits, ineligible benefits, total benefits, and fees excluding Medicare benefit paid.[208] Part 8 shows (1) the benefits paid and fees charged for Chronic Disease Management Programs by service type (planning, coordination, allied health services, other and total services); and (2) the number of programs, benefits paid and fees charged for Chronic Disease Management Programs by program type: risk factors for chronic disease, cardiovascular, diabetes, mental health, other and program type total.
DoHA 3. National Children's Nutrition and Physical Activity Survey *Kids Eat, Kids Play* – CSIRO and the University of South Australia	yes* 2-16 years only	yes*	yes*	yes*	yes*	state/ territory	First study combining nutrition and physical activity. First nutrition survey since the 1995 National Nutrition Survey (ABS).Data collected during two interviews: (1) a face-to-face home visit (CAPI) and (2) a telephone interview two weeks later (CATI). Food, beverage and dietary supplement intake information collected using standardised 24-hour recall methodology. Nutrient intakes will be calculated from these data. Information about children's activity patterns collected in children of ages 9-16 years and recorded using Multimedia Recall for Children and Adolescents (MARCA), a validated computerised instrument. Pedometers/ accelerometers used to collect data over a seven-day period on the number of steps taken (children of ages 5-16 years) and will provide an estimate of overall activity levels. Physical measurements (weight, height and waist circumference) taken during the face to face home visit. Interviews scheduled to capture daily and seasonal variations.[209] Disaggregations: while data were collected for each of the variables, not all data may be available on the Unit Record File.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
DoHA 4. National Infant Feeding Survey	** mothers of infants 0-4 years*	** sex of infant*	** unlikely due to expected low representation*	** unlikely*	** expected*	** national only*	*As the survey is still in the planning phase, this information is hypothetical. Initial survey planned for 2008. Second survey proposed for 2010-2011. Further surveys may occur after this date to monitor changes.*
DoHA 5. National Nutrition and Physical Activity Survey Program	** all ages, as each sub-population is surveyed*	*yes*	** yes – a survey targeted to the Indigenous population may also be undertaken*	** expected*	** expected*	** expected*	*As the survey is still in the planning phase, this information is hypothetical. However, it is expected that the survey program will eventually include targeted population surveys of all populations of interest to nutrition and physical activity policies and programs, and over time, surveys under the program are expected to cover the entire Australian population*
DoHA 6. The consequences of osteoarthritis and osteoporosis In Australia: Work productivity loss and health service utilisation – AFV Centre for Rheumatic Diseases, University of Melbourne (Australian Research Council Linkage Project grant), in partnership with DoHA and AIHW.	*n/a*	*n/a*	*n/a*	*n/a*	*n/a*	*n/a*	*A key activity of the Better Arthritis and Osteoporosis Care initiative is a survey of the consequences of osteoarthritis in Australia, including loss of work productivity and health service utilisation and arthritis and musculoskeletal data development and analysis.* *This will be a new data collection, contract yet to be finalised and signed. Work program and specific disaggregations yet to be agreed on.*

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
DoHA 7. Australian Childhood Immunisation Register (ACIR) – Medicare Australia	yes	yes	yes*	no	no	state/ territory, postcode, LGA	The ACIR is a national online database containing information on the immunisation status of all children living in Australia who are under the age of seven years. Children enrolled with Medicare are automatically included on the register. The major functions of the ACIR are to provide (1) an accurate measure of the immunisation coverage of children in Australia under 7 years of age, and (2) an effective management tool for monitoring immunisation coverage and service delivery. Data are recorded from birth up to 7 years. Reporting of indigenous status had been substantially improved by 2005.[210] The specifications for program reports (including content, frequency of provision and recipients of reports) are subject to ongoing development and review by DoHA and Medicare Australia. Coverage rate calculated as: number of children vaccinated divided by number of children in register x 100 equals percentage fully Immunised for age. Generally, coverage fluctuates at around 90-92% for 12 month old children. Reasons for the coverage rate not reaching 100% include: late reporting of vaccines (~1%); late administration of vaccines (~1-3%); and conscientious objectors (~1-3%).
Other 1. Australian Mesothelioma Register – Australian Safety and Compensation Council (ASCC)	yes	yes	yes (from state cancer registries)	yes (from state cancer registries)	proxy*	state/ territory, postcode	The *Australian Mesothelioma Register* commenced in 1980 (as the *Australian Mesothelioma Surveillance Program*) to receive and collate voluntarily notified cases of mesothelioma from a network of medical specialists, pathologists, S/T departments of occupational health, cancer registries, compensation authorities and other sources. By 2007, voluntarily notified new cases had become significantly less than those mandatorily notified to state cancer registries. Information on the number of new cases of, and deaths from, mesothelioma, are now collected by the AIHW National Cancer Statistics Clearing House (via state cancer registries), and in the National Mortality Database, respectively.[116] Under-enumeration in the Register is likely, based on an assessment of mesothelioma cases recorded from 1999 to 2001, long-term data from the Register, and comparison data from the AIHW National Cancer Statistics Clearing House. From 1986-2000, the Register had 3.4% fewer notifications of new cases of mesothelioma than did the AIHW National Cancer Statistics Clearing House.[114:1] SES: industry and occupation have been coded (using ANZSIC and ASCO) from details of past employment history available for ~600 cases notified to the Register 1999-2001 and have been used to study occupational exposure to asbestos.[114:1-2]
Other 2. Australian Secondary Schools Alcohol and Drug Survey (ASSAD) – Cancer Council Australia & state & territory governments *	yes	yes	yes p	yes	no	q	Monitors trends in the prevalence of adolescent drug use & other health-related behaviours. Nationally coordinated, may include state-wide supplementary surveys. Core survey every 3 years, illicit drug use included from 1996. 2005: aimed to survey students from 404 schools; to achieve this sample size, 599 secondary schools & 111 feeder primary schools (to survey Year 7 students in WA, SA, Qld & NT) were approached; 376 secondary schools participated, giving a response rate for secondary schools of 63% (similar to 2002) & 62 primary schools allowed Year 7 students to participate resulting in a 55% response rate for feeder schools.[104] 1996: number in collection = 31,529 students in 434 schools; response rate: students 91%; schools 77%.[211]

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
Other 3. Women’s Health Australia, the Australian Longitudinal Study on Women's Health (ALSWH) – University of Newcastle *	yes	women only	yes	yes	yes	urban/ rural/ remote*	The ALSWH aims to achieve a comprehensive view of all aspects of health throughout women’s lifespan. Information is collected on topics that include: physical and emotional health (e.g., well-being, major diagnoses, symptoms); use of health services (e.g., GPs, specialists and other visits, access, satisfaction); health behaviours and risk factors (e.g., diet, exercise, smoking, alcohol, other drugs); - time use (including paid and unpaid work, family roles and leisure); socio-demographic factors (e.g., residential location, education level, employment status, family composition); and information on life stages and key events (e.g., childbirth, divorce, widowhood). The project links social, environmental and personal factors in women's lives with health service use, by record linkage with administrative datasets. The ALSWH is a national research resource that provides an evidence base on women’s health issues to DoHA for the development and evaluation of service delivery policy and practice in areas that affect women.[212] Women in rural & remote areas over-sampled to ensure adequate numbers for statistical analysis. Additional age cohort response rates: 68.6% of Younger women (the most mobile age group) responded to Survey 2 (S2) in 2000 & 65.4% to S3 in 2003; 90.7% of Mid-age women responded to S2 in 1998 & 84.3% to S3 in 2001; 90.5% of Older women responded to S2 in 1999 & 84.9% to S3 in 2002. Some participants have agreed to data linkage with Medicare & other relevant data collections.[213] Retention rate calculated as: number of completed surveys divided by number of eligible respondents (e.g., 9,145 of 13,556 eligible younger women completing S4 in 2006 = 67.5%). Eligible respondents are those eligible to participate at the previous survey less those who became ineligible (due to decease, frailty [e.g., intellectual disability], withdrawal from study) before the next scheduled survey commenced (eligible Younger women in Survey 4 in 2006 were 13,886 – 330 [15 + 4 + 311] = 13,556).
Other 4. HILDA – Household, Income and Labour Dynamics in Australia (HILDA) Survey – Melbourne Institute (FaCSIA)	yes	yes	yes		yes education level, occupat-ion, income, assets	CDs (488), geocoded household addresses	Information on economic and subjective well-being, labour market dynamics and family dynamics. Wave 1 panel consisted of 7,682 households and 19,914 individuals (2001), funding has been guaranteed for 12 waves. Special questionnaire modules are included in each wave. Health variables: SF-36 (9 items), SF-6D health state (1 item). History variables: health: including: Chronic or recurring pain, Long term condition, Other long term condition (eg arthritis, asthma, heart disease, Alzheimers disease, dementia etc.). Questions on diet, numeracy/ literacy, diet & smoking history have been added to the interviewer person questionnaires, & there are new questions on alcohol consumption, diet & weight, food consumption, & the Kessler 10 measure of psychological distress in the self-complete questionnaire (Wave 7 in 2007). Response & attrition rate calculations are very complex, especially for later Waves; see the HILDA User Manual section Data Collection - Response Rates.[214]

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
Other 5. Participation in Exercise, Recreation and Sport Survey (ERASS) – Australian Sports Commission & state & territory departments responsible for sport and recreation.	yes	yes	varies* Indigenous status only from 2005-	varies* languages spoken at home only from 2005-	proxy education level, postcode	S/T, postcode	ERASS collects quarterly information on collects on participation in physical activity for exercise, recreation and sport by Australians of ages 15 years and over during the 12 months prior to interview. The data collected includes the frequency, duration, nature and type of activities and are used to measure trends in physical activity over time. The sample, stratified by S/T, is drawn from the EWP with one person randomly selected per household to complete the interview. Data from quarterly surveys (in February, May, August & November) are aggregated to produce an annual report.[215] From 2001-2004 the questionnaire covered two main areas: physical activity for exercise, recreation and sport over the last 12 months; and demographics: sex, age, marital status, number and age of children, educational qualifications, employment status, and postcode; from 2005 onwards the questionnaire was expanded to include a third section on physical activity for exercise, recreation and sport over the last two weeks; and the demographics expanded to include Indigenous status, and language/s spoken at home. 2003-2006: Response rate calculated as: the number of completed interviews divided by the number of contacts plus those where there was no answer after six calls.[No numbers given.[215-218] No response rate or calculation given for 2001 & 2002 surveys.[219,220]]
Other 6. National Sun Protection Survey – funded by The Cancer Council Australia and the Australian Government and managed by Cancer Australia	yes	?	?	?	?	Australia S/T (adults only)	The National Sun Protection Survey collected information on sun-related knowledge, attitudes and behaviours including sunburn and deliberate tanning through weekly telephone interviews conducted on Monday and Tuesday evenings over the summer of 2006-07.[221] It provides comprehensive national data on skin cancer preventive behaviours and risk assessment, enables comparisons of adolescents' and adults' behaviour, monitors changes over time and assists in the planning and evaluation of specific skin cancer prevention strategies, including assessment of the impact of the first national skin cancer prevention campaign implemented in spring/summer 2006-07. The baseline survey was conducted in the summer of 2003-04.[221]
Other 7. National Non-melanoma Skin Cancer Survey	yes	yes	-	yes COB	yes income and educat-ion levels	Australia latitudes (North, Central & South regions*)	Objectives of the 2002 survey were to measure the incidence of treated non-melanoma skin cancer (NMSC) and investigate trends since 1985 by histological type, sex, age group, latitude and skin type. Face to face household interviews throughout the year were used to identify people who had been treated for skin cancer in the previous 12 months. Self-reported diagnoses were confirmed with treatment providers: of 57,215 people interviewed, 4,098 reported being treated for skin cancer in the 12 months previous, and 3,198 gave permission for their diagnoses to be confirmed with their doctor.[222:6-10] Responses from the treating doctor were received for 2,502 (80% of requests), giving a response rate of 61% for access to confirmation of diagnosis for those reporting treatment within the previous 12 months. The three latitude-based regions were: North region (< 29ºS), Central (29ºS–37ºS), and South (> 37ºS).

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
NSW 1. NSW Population Health Survey * – NSW Health	yes	yes	yes collected but only reported when sample is representative	yes collected but only reported when sample is representative	yes	NSW area health regions & urban/ rural LGAs	The main aims of the survey are to provide detailed information on the health of the people of NSW, and to support the planning, implementation, and evaluation of health services and programs in NSW.[223:12] Topic modules (not all asked every year) include: Alcohol (frequency & consumption); Asthma 1 (prevalence & service use); Asthma 2 (medications & severity); Breastfeeding; Cancer screening 1 (breast & cervical); Cancer screening 2 (prostate & bowel); Cardiovascular disease (blood pressure & cholesterol); Childcare, school attendance & reading to child; Childhood personal health record; Demographics 1 (respondent); Demographics 2 (child proxy); Diabetes 1 (prevalence & management); Diabetes 2 (complications screening); Emergent issues; Environmental risks; Environmental tobacco smoke; Folate & pregnancy; Food handling; Food security; Family functioning & parental support; Health services access, use & satisfaction; Healthy environments; Height & weight (BMI); Hysterectomy rate; Incontinence; Immunisation 1 (influenza & pneumococcal); Immunisation 2 (access–attitudes to child immunisation); Injury 1 (adult &/or child injury & prevention); Injury 2 (falls in older people); Chronic health conditions; Mental health 1 (adult psychological distress); Mental health 2 (childhood strengths & difficulties); Nutrition 1 (adult dietary guidelines); Nutrition 2 (child dietary guidelines); Oral health; Physical activity 1 (leisure time); Physical activity 2 (household chores & gardening); Physical activity 3 (child activity & inactivity); Self-rated health status & disability; Sexual health risk behaviours; Sight, hearing & speech; Smoking 1 (prevalence); Smoking 2 (during pregnancy); Smoking 3 (policy); Social capital (safety, trust, reciprocity & participation); & Summer sun protection.[25] Area Health Services (AHS) may add topics. Current target sample ~1,500 people in each AHS annually; one person per randomly selected household, ~12,000 in total. Households contacted using list assisted random digit dialling, up to 7 calls made to establish initial contact with household and up to 5 calls to contact selected respondent. Carers/ parents of children aged 0-15 years are interviewed on the child's behalf.[223:12] Response rate calculated as: number of completed interviews divided by sum of the number of completed interviews & number of refusals. [2006: 10,345 / (10,345 + 7,100) = 59.3%.]
NSW 2. NSW School Students Health Behaviours (SSHB) Survey – NSW component of the Australian Secondary Schools Alcohol and Drug Survey (ASSAD)	Yes	yes	yes collected but not reported	yes collected but not reported	yes SEIFA IRSD	NSW area health regions & urban/ rural	The Survey collects information about the health behaviours and attitudes of secondary school students in NSW. The Survey instrument is composed of a national core from the Australian Secondary School Alcohol and Drug (ASSAD) Survey, and state supplementary questionnaires. 2005: The survey instrument was a self-administered questionnaire with a core component and 2 supplements. Each student completed the core module and one of the supplementary modules. The core module included questions on demographics, alcohol, tobacco, substance use, sun protection, sunburn experience, nutrition, physical activity, and sedentary behaviour. Supplementary A included questions on alcohol and psychological distress & additional questions on tobacco. Supplementary B included questions on nutrition, height and weight, perception of body mass, injury, use of solariums or sunbeds, & additional questions on physical activity. 2005: target sample was 126 secondary schools, 193 secondary schools were invited to participate; 120 participated. 2002: 424 schools were invited to participate of which 99 participated.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
NSW 3. The 45 and Up Study – auspiced by the Sax Institute in collaboration with The Cancer Council NSW, Heart Foundation, NSW Health, beyondblue, & DADHC	yes	yes	yes	yes	yes	postcode	Participants in the 45 and Up Study: (1) provide self-reported information about their background, lifestyle, health and health service use at baseline and then every five years; (2) consent to link to their medical records including data from the NSW Admitted Patient Data Collection, Medical and Pharmaceutical Benefits Schedule (MBS and PBS) datasets, NSW Central Cancer Registry and ABS mortality data. Data linkage will take place through the Centre for Health Record Linkage (CHeReL), which includes the 45 and Up Study in its Master Linkage Key (so that linkages with a core set of datasets, including hospital, cancer and death data, will be updated on a routine and ongoing basis, making these linked data available to researchers as soon as source datasets are updated), and through Medicare Australia; and (3) consent to be approached about sub-studies between the five year follow-ups to obtain extra information not collected in the baseline questionnaire. The collection of biological samples (e.g., blood for genotyping & examination of analytes) is also planned for as funding becomes available. The baseline questionnaire for the study includes: measures of health status and past medical and surgical history; known risk factors for major causes of morbidity and mortality; likely confounding factors; potential mediators of risk and some novel factors. Repeat questionnaires to all cohort members to update exposure data and health status are planned at 5-yearly intervals.[175] There is over-sampling of individuals from rural areas, and of those aged 80+ years; and all individuals in remote areas are sampled. Retention rate not calculated at this stage. Baseline response rate calculated as: number of eligible respondents divided by number of surveys mailed. Eligible respondents are individuals aged 45 or over living in NSW at the time of recruitment who sign the consent form.
NSW 4. NSW Centre for Health Record Linkage (CHeReL) – hosted at Cancer Institute NSW, supported by The Sax Institute, NSW Health, ACT Health, NSW Clinical Excellence Commission, and the Universities of Newcastle, NSW & Sydney	yes	yes	yes	yes	proxy SES of area of residence	yes	CHeReL includes the following eight core datasets: NSW Admitted Patients Data Collection, NSW Emergency Department Data Collection, NSW Central Cancer Registry, NSW Pap Test Register, NSW Midwives Data Collection, NSW Birth Defects Register, NSW Registry of Births, Deaths and Marriages birth and death registration data, and ABS mortality data and perinatal mortality data.[224] CHeReL holds coded personal identifiers only (pointers) and links records using a master linkage key (data stays with data custodians). Access requires ethics approval and the approval of all data custodians. Benefits include, for example, the ability to use recorded Indigenous status from one dataset to improve the quality of Indigenous identification overall.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
NSW 5. Schools Physical Activity and Nutrition Survey (SPANS) –	yes	yes	yes	yes language spoken most at home	proxy SES of area of residence	postcode, suburb, 3 ARIA remoteness categories	Student selection: primary schools - one class chosen at random from each of years K (Kindergarten), 2, 4 & 6; secondary schools - two classes chosen at random from each of years 8 & 10 (one to participate in the main study & one to participate in the physical activity sub-study). Sydney metropolitan secondary schools: a third year 10 class was chosen (anticipating lower response rates due to collection of blood in this group). Three additional secondary schools were recruited to increase the number of participating Year 10 students. 2004 SPANS had six components (variously administered to different classes of students of different ages): 1. main student survey: included demographic information (sex, date of birth, language spoken most at home, Aboriginal or Torres Strait Islander status, school year, suburb & postcode of residence [extracted from school records for years K & 2]), anthropometry (measured height, weight, & waist circumference), assessed fundamental movement skills (FMS; sprint run, vertical jump, side gallop, leap, catch, overhand throw, kick), cardiorespiratory endurance, and collected self-reported information, including: participation in physical activity (PA) (including travel to & from school) and in sedentary behaviours, food habits and eating behaviours (food intake, food preferences, influences on eating behaviours, dieting practices, & body image); 2. bio-marker sub-study: included objective measures of: blood pressure, blood samples (overnight fasting) tested for insulin and glucose, blood lipids (HDL & LDL cholesterol, & triglycerides), high sensitivity C-reactive protein, and liver function; 3. physical activity sub-study: used the PA questionnaire used in the Australian Health and Fitness Survey 1985[225] (instruments from this study also used to assess PA participation in the main student study enabling comparison with 1985 results); 4. school environment survey: information on facilities at/ near the school that might be used for sports/ other PAs, availability & frequency of use of those facilities (before school, lunchtimes, after school), time allocated for physical education (PE) lessons & sport, range of activities offered for PE, which members of school staff taught PE & sport, strength of support for sport & PE, barriers within the school to skill development & participation in sport & other PAs & extent to which different strategies were used to promote participation in physical activity among students; 5. school canteen questionnaire: information on what is sold in school canteens and vending machines, food-related school policies & procedures & factors that help or hinder canteens offering more healthy choices; and 6. response bias study: to determine if estimates of the prevalence of overweight & obesity (based on SPANS data), were biased due to any systematic response bias - methods used were validated in the response bias study & results indicated that SPANS data were not biased.[226] Time series: some comparability with (1) the 1985 Australian Health and Fitness Survey & (2) the 1997 NSW Schools Physical Activity and Fitness Survey, for students in Years 2-10, age range 7-16 years.[227:4] SPANS may be repeated in 2011. Disaggregations: ‘Language spoken most at home’ used to categorise students into four main cultural backgrounds: English-speaking, European, Middle-Eastern and Asian. Postcode of residence determined remoteness using ARIA: students living in ‘highly accessible’ & ‘accessible’ locations classed as ‘urban’, ‘moderately accessible’, and ‘remote’ areas classed as ‘rural’.[226]

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
Vic 1. Victorian Population Health Survey (VPHS) – Victorian Department of Human Services (DHS)	yes	yes	yes	yes	yes	Vic DHS health regions	The VPHS is based on a core set of question modules that provide information on: health and lifestyle, including physical activity, smoking, alcohol consumption, intake of fruit and vegetables, selected health screening, adult obesity, asthma and diabetes prevalence, psychological distress and social networks (social support, connectedness and participation). A representative state-wide sample of adults aged 18 years and over is randomly selected from households in each of the DHS health regions (currently eight, previously nine regions). Approximately 7,500 interviews are completed during the fieldwork period. Random digit dialling is used to generate the sample of telephone numbers that form the household sample for CATI. All residential households with landline telephone connections are considered in-scope for the survey. Recent response rates have been improved through intensive training of interviewers. Rural regions are oversampled as inequalities in health between urban and rural Victoria are a major interest. From 2008-09 the VPHS sample size will be expanded to collect information on health and risk factors at local government area level every three years. As well as reporting annually at a state-wide level[228-233], regional fact sheets for each DHS region have reported the major findings on physical activity, healthy eating and body mass index; and patterns of health, wellbeing and community strength (2003 data); and 2006 data on health status, obesity, nutrition, physical activity, health checks, eye protection and alcohol consumption; and on cardiovascular disease.[234] Response rate calculated as: number of completed interviews divided by the sum of the number of completed interviews and the number of refusals.
Vic 2. 2006 Victorian Child Health and Wellbeing Survey (VCHWS) - Department of Human Services	yes	yes	?	?	? proxy	metro/ rural; Vic DHS health regions	The aims of VCHWS are to: (1) provide baseline and trend data to inform and support planning, implementation and evaluation of child health, wellbeing, development and learning policies, services and programs; and (2) allow comparisons of how children are faring over time, between metropolitan and rural areas, and in major demographic groups. Children from rural Victoria were over-sampled to enable analysis of health inequalities between metropolitan and rural areas, with ~50% of the interviews for children in metropolitan areas and ~50% for those in rural Victoria.[235:4-5] Topics in the initial survey included: Special health care needs (children dependent on medication, requiring more services than most children of the same age, with functional limitations), General health status, Asthma status & management, Exposure to tobacco smoke, Nutrition (fruit & vegetable intake, drink tap water (fluoride question), consumption of fries, takeaways, milk; households that ran out of food in past 12 months & their coping strategies), Breastfeeding, Oral health, Child activity, Reading, Injury, Sun exposure, Sudden Infant Death Syndrome, Child behaviour, Family functioning, Parental social support, Parental health & mental health, Health in pregnancy, Adequate housing, Parental perceptions of neighbourhood safety, amenity & facilities. [235: 10-16] 2006 response rate calculated as: the number of completed interviews divided by the number of in-scope households contacted (5,000 / 5,774).

Data collection title	Disaggregations						Additional information:
	age	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
Qld 1. 2003 Omnibus Survey: Infant Nutrition	yes	by sex of child	yes p	no	yes	state, RaRA classification, ARIA classification	Additional survey details: A sample of households selected by randomly choosing telephone numbers from the last 5 editions of the electronic white pages (EWP). A small but unknown proportion of the target population was excluded from selection because their household did not have a fixed telephone. In 2003, it was estimated that 4.7% of Qld households had no fixed telephone connection.[74] Up to 6 calls were made to establish initial contact with household. No formal upper limit on the number of calls to contact the selected respondent. RaRA classification: Urban (1 & 2) / Rural and Remote (3, 4, 5 & 6). ARIA classification: Highly accessible/ Accessible/ Moderately accessible/ Remote or Very remote. Modules in the questionnaire included: breastfeeding, predictors of successful breastfeeding, fruit and vegetable intake, the introduction of solid foods and of a variety of types of fluids, and a number of related oral health issues, plus standard demographic module. Biological mothers of children aged less than 5 years were interviewed on the child's behalf. In 2008 the target group will change to biological mothers of children aged less than 13 months. The response rate for the survey was 92% of contacted in-scope people and the contact rate was 87% of telephone numbers.[62:17] Response rate calculated as: number of completed interviews divided by [number of completed interviews plus number of terminated interviews plus number of refusals from households with an eligible person plus (number of refusals from households of unknown eligibility times proportion of households found to have a person eligible to take part)].
Qld 2. 2003 Omnibus Survey: Child Health	yes	by sex of child and care-giver (respondent)	yes p	no	yes	state, RaRA classification, ARIA classification	Additional survey details: As for Qld 1. Modules in the questionnaire included: oral health, infant and child nutrition, caffeine awareness, skin cancer prevention and storage of poisonous substances. Principal caregivers of children aged less than 13 years were interviewed on the child's behalf. The response rate for the survey was 86% of contacted in-scope people and the contact rate was 87% of residential telephone numbers.[62:19] Response rate calculated as for Qld 1.
Qld 3. 2003 Older Persons Survey	yes	yes	yes p	no	yes	state, RaRA classification, ARIA classification	Additional survey details: As for Qld 1, except that the sample of households was selected by randomly choosing telephone numbers from the last 6 editions of the EWP. Females aged 50-74 years (n=908) were asked questions related to breast cancer screening behaviour, knowledge and attitudes. Other respondents were asked questions related to influenza vaccination only. Response rate calculated as for Qld 1.
Qld 4. 2004 Omnibus Survey: Risk Factors	yes	yes	yes p	no	yes	state, RaRA classification, ARIA classification	Additional survey details: As for Qld 3. Modules in the questionnaire included: asthma prevalence, diabetes prevalence, population knowledge about diabetes, general health, exercise, BMI, smoking, quit-smoking methods and motivations to quit smoking, public perceptions of medicines, installation of safety switches and hot water tempering devices plus standard demographic module. Response rate calculated as for Qld 1.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
Qld 5. 2004 SNAPS Data Collection (Filling the gaps) – funded by DoHA	yes	yes	yes p	no	yes	state, RaRA classific-ation, ARIA classific-ation	Up to 6 calls made to establish initial contact with household. Modules in questionnaire included: smoking, food and nutrition, alcohol consumption, physical activity, BMI and psychological distress (as measured by the Kessler-10 instrument), plus standard demographic module. Response rate calculated as: number of completed interviews divided by [all eligible contacts plus all non-contacts after 6 attempts].
Qld 6. 2005 Omnibus Survey: General Population	yes	yes	yes p	no	yes	state, RaRA classific-ation, ARIA classific-ation	Additional survey details: As for Qld 3. Modules in the questionnaire included: general health status, oral health, nutrition, mental health and colo-rectal cancer, plus standard demographic module. Response rate calculated as for Qld 1.
Qld 7. 2005 Omnibus Survey: Sunsafe	yes	yes	yes p	no	yes	state, RaRA classific-ation, ARIA classific-ation	Additional survey details: As for Qld 3. Modules in the questionnaire included: likelihood to use shade, concern about developing skin cancer or melanoma, skin cancer prevention behaviour, sun burn experienced by respondent in the past week, skin type, attitudes and behaviours in relation to tanning, weekday and weekend sun protection practices; and tattoo campaign awareness; plus standard demographic module. Response rate calculated as for Qld 1.
Qld 8. 2005 & 2006 Fruit & Vegetable Consumption (Go for 2&5) Surveys	yes	yes	yes p	no	yes	state, RaRA classific-ation, ARIA classific-ation	Additional survey details: As for Qld 3. Modules in the questionnaire included: recall of advertisements about food and health, about fruit and vegetables and health, and about the vegetable character/ Go for 2 and 5 advertisements; understanding of the meaning of the vegetable character/ Go for 2 and 5 advertisements; fruit and vegetable consumption; knowledge and attitudes regarding fruit and vegetable consumption; intention to increase fruit and vegetable consumption; promoters and barriers to increasing fruit and vegetable intakes; type of milk consumed and take-away food consumption; height, weight, and perceived acceptability of weight; controllers of the household’s food habits; plus standard demographic module. Response rate calculated as for Qld 1.
Qld 9. 2005 & 2006 Physical Activity (10,000 Steps) Surveys	yes	yes	yes p	no	yes	state, RaRA classific-ation, ARIA classific-ation	Additional survey details: As for Qld 3. Modules in the questionnaire included: awareness of messages about exercise or physical activity, physical activity in the previous week, walking & walking groups, motivators for & barriers to walking, whether increased activity levels recently, motivators for increasing activity levels, use of pedometers, exercise companions, awareness of pedometer library loan scheme, plus standard demographic module. NB Not all topics were included in both surveys. Response rate calculated as for Qld 1.

Data collection title	Disaggregations age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	Additional information:
Qld 10. 2006 Omnibus Survey: General Population	yes	yes	yes p	no	yes	state, RaRA classification, ARIA classification	Additional survey details: As for Qld 3. Modules in the questionnaire included: asthma, blood pressure and cholesterol, nutrition, smoking status, alcohol consumption, physical activity, height and weight, general health and quality of life and influenza, plus standard demographic module. Respondents 60 years and over were also asked about falls. Response rate calculated as for Qld 1.
Qld 11. 2007 Omnibus Survey: General Population	yes	yes	yes p	no	yes	state, RaRA classification, ARIA classification	Additional survey details: As for Qld 3. Modules in the questionnaire included: quality of life and health status, your neighbourhood, nutrition, shingles, back and joint problems, and diabetes, plus standard demographic module. Response rate calculated as for Qld 1.
Qld 12. 2006 National Oral Health Survey: Queensland Component	yes	yes	-	-	-	-	Anthropometric measurements taken: height, weight and waist circumference. Self-reported height and weight data collected in telephone interview. Aim to evaluate the validity of self-reported body size.
WA 1. WA Data Linkage System (WADLS) – Department of Health WA in collaboration with the University of WA School of Population Health, Telethon Institute for Child Health Research, & Curtin University	yes	yes	yes (dependent on availability in source data)	yes (dependent on availability in source data)	yes (dependent on availability in source data)	yes (dependent on availability in source data)	Core data sets include: Birth registrations from 1974 (& Midwives notifications from 1980), Death registrations from 1969, Hospital separations from 1970, Cancer notifications from 1981, Electoral roll from 1988. Other state data system records may also be linked, including: Road injury 1987-2004, Silver Chain (community, residential and health services) 1993-2001, Emergency Department presentations 2000-2003, Ambulance services 1990-2005, Next Step (drug & alcohol services) 1990-2000, and various other state Department datasets; as well as Commonwealth data systems (data holdings for WA residents only): Aged care 1990-2003, MBS 1984-2004, and PBS 1990-2004. Specific research databases may also be linked, including: Busselton Surveys 1966-1987, Monica (MONItor trends in Cardiovascular diseases project [WHO]) 1984-1993, National Heart Foundation Surveys 1978-1994, [WA] Crime Research 1984-1995, Fremantle Diabetes Study 1993-1999, Kimberley Survey 1987, Maternal and Child Health Research Data Base 1980-2001, and others that may be linked in an ad hoc fashion. Geographic area: data sources that incorporate address information can be assigned latitude and longitude, collector's district (CD), statistical local area (SLA), local government area (LGA) and radius values using purpose-built address parsing software linking to land-based reference datasets. Hospital Morbidity Data Collection, Midwives Notifications System and the WA Death Registrations are routinely geocoded for all records post 1993 using the 1996, 2001 and 2006 census boundaries.[174,181] Link quality: an internal quality audit performed in January 2002 estimated that the number of chains containing one or more false positive matches (mismatches) was 0.3% (based on manual scrutiny of a 1% random sample of chains derived from 1990 hospital admission records). This was significantly lower than the level of 0.6% estimated from a similar audit process in January 2001. The level of possible mismatches in the system is much lower than the underlying variation in reported details (e.g., name, address, data of birth) in the source datasets.[236:187]

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
WA 2. Hospital Morbidity Data Collection (HMDS) – Department of Health WA	yes	yes	yes	yes	yes	at postcode level, where sample size permits	The HMDS contains in-patient discharge summary data from all public and private hospitals in WA (hospital separations) from July 1969. An electronic form representing a statistical summary of a hospital separation is supplied for each in-patient event. Data is provided annually to the AIHW (National Hospital Morbidity Database) & DoHA, as mandated under the Australian Health Care Agreement (data items defined in National Minimum Data Sets). The HMDS comprises: ~20,000,000 inpatient records dating from July 1969 onwards, snapshots of waitlist data dating back to 1991, hospital survey data since 1993 (including information on available beds, specialised services and accreditation status), & monthly summary data since 1989-90 detailing hospital admissions (inpatient) and occasions of service for outpatient and emergency events.
WA 3. Western Australian Cancer Registry (WACR) – Department of Health WA	yes	yes	yes	yes (based on birthplace)	yes (based on address)	WA Health Districts - standard publicly-released area level. Geocoded to latitude/ longitude where quality permits.	The WACR was established in 1981 when the Health (Notification of Cancer) Regulations 1981 were proclaimed, to require mandatory reporting of cancer by pathologists and radiation oncologists. The Regulations (as amended, 1996) require the notification of *in situ* neoplasms and all non-melanoma skin cancers other than basal cell and squamous cell carcinomas, and all other invasive malignancies and benign central nervous system tumours. The WACR collects, collates, analyses and reports on the resulting information. Incidence is reported for all malignancies except primary squamous cell and basal cell skin cancers, and mortality for all malignancies and certain other tumours or tumour-like conditions. The WA Mesothelioma Register, a separate database maintained within the WACR is reconciled frequently with WACR data, and incorporates specific information for mesothelioma cases, relating to occupational, residential and asbestos exposure history, and the presumed most significant asbestos exposure.[237] Enumeration: ongoing reconciliation processes result in some WA cases being found to have been diagnosed elsewhere, or in earlier years, and case-counts necessarily change as new information arrives. Mortality information often sheds new light on a person's cancer history (for instance, while total cancers for 2004 were previously reported at 9,244, the total currently recorded for 2004 is 9,325, an increase of 0.9%; and corresponding figures are 1.8% for 2003 data re-examined at the time of the 2004 report, and 2.0% for 2002 data at the time of the 2003 report). A 2006 audit of 754 hospital-data-only cancer records from 2005 resulted in the confirmation of 348 new cancers on the WACR database (many diagnosed prior to 2005) while 219 could be confidently excluded.[237] A 2007 audit of 1,189 hospital-data-only tumour records from 2006 confirmed 744 cases, increasing the apparent WA cancer incidence records by over 6%. The results are being used in ongoing examination of the cancer notification process; and in supporting current initiatives to make 'non-pathological' diagnoses directly notifiable by hospitals, and to ensure haematological tests (e.g., flow cytometry) become part of the core notification stream received by the WACR.[238] Cases and populations are used for the main statistic - age standardised rates. There is no 'opt out' provision and notifications are not based on consent.

Data collection title	**Disaggregations**						**Additional information:**
	age	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
WA 4. Health & Wellbeing Surveillance System (HWSS) – Department of Health WA	yes	yes	yes p (not representative of the state-wide Aboriginal population due to collection mode)	yes	yes	WA health region level. Smaller geographic areas available with ethics approval.	Questionnaire topics include: demographics; quality of life (SF-12 up to 2002 and SF8 from then on); disability; selected chronic health conditions; injury; health service use; psychological distress (Kessler 10 scale); risk factors: physical activity, body mass index (BMI), alcohol consumption, smoking, nutrition; perceived control of life events; psychosocial events; mental health specific questions; group membership. Questionnaires are tailored to four age ranges (0-15 years – answered by parents/ carers on behalf of children, 16-24 years, 25-64 years, and 65 years and over) and questions change to reflect the life course of individuals. All four questionnaires have questions in common (e.g., weight and height, for estimating BMI), as well as those tailored to the age range. Respondents are also asked (1) whether or not they agree to being contacted again on health issues (>90% agree & give their first name as a point of contact); and (2) whether their survey information can be linked with other health data held by the Department of Health (~80% agree & provide their full name and date of birth for this purpose).[28] Annual sample frame (from 2002 to end 2004): up to six calls made to each household to establish initial contact, and up to eight calls made to obtain an interview with the selected respondent. Monthly sample frame (from Jan 2005 on): up to ten calls made to establish contact, and up to eight calls made to obtain an interview. Various areas and age groups have been over-sampled: Feb to June 2002 - rural and remote parts of WA; Sept to Dec 2002 - people aged 0-15 and 16-24 years; Feb to June 2003 - four areas of metropolitan Perth (SLA localities); Sept 2003 to Aug 2004 - new health region areas; Nov 2004 to Feb 2005 - new area health service areas. From 2006 the sampling strategy used Area Health Services rather than the metro/ rural/ remote. HWSS achieves a proportion of Aboriginal people that reflects the sampled population but is not representative of the state-wide Aboriginal population due to the use of telephone as the collection mode.
WA 5. Mental Health Information System (MHIS) – Department of Health WA	yes	yes			proxy, postcode	postcode	The MHIS has operated since 1st July 1966 and is the oldest continuous mental health information system in Australia. Information is collected about all people who use mental health services in WA & this information is used to support the planning and provision of mental health services and ongoing mental health research in WA. Processing, storage and provision of data are subject to strict security protocols & all data releases are guided by strict confidentiality rules. The MHIS currently collects information from two sources: (1) in-patient data from authorised psychiatric hospitals, designated psychiatric inpatient units, & acute general hospitals; and (2) ambulatory data (non in-patients) from public program: psychiatric clinics, community health centres, day centres, outreach programs, & rehabilitation programs.
SA 1. South Australian Cancer Registry (SACR) – Dept of Health	yes	yes	yes, with limitations	yes, with limitations (COB, race)	proxy, postcode	yes postcode SLA	Primary sources of information include pathology laboratories, hospitals, radiotherapy departments, the Registrar of Births, Deaths and Marriages and other supplementary sources such as clinicians. These notifications are mandated by the SA Cancer Regulations. The SACR collects a minimum data set for each cancer case, including: place of residence, sex, date of birth, date of diagnosis, cancer site and morphology, means of diagnosis, whether there were multiple primary sites of cancer, race, country of birth, and date, place and cause of death, where applicable. These data elements can be reported on in various combinations to meet special research requirements.[239:8-9] Annual reports are available.
SA 2. Integrated SA Activity Collection (ISAAC) – SA Dept of Health	yes	yes	yes	COB only	no	SLA & postcode	ISAAC is an admitted patient morbidity data collection designed to provide the Department of Health with the information resources necessary to effectively organise, evaluate and plan health services in SA. It provides Information on all admitted patient activity in public and private hospitals in SA. Information is supplied to ISAAC by all recognised public and private hospitals in SA as required under the SA *Health Commission Act 1976*.

Data collection title	Disaggregations						Additional information:
	age	sex	Indigenous status‡	ethnicity ** ‡	SES	geog area ‡	
SA 3. South Australian Monitoring and Surveillance System (SAMSS) – SA Dept of Health	yes	yes	yes	some	limited	yes	A core set of questions is asked every month with additional questions asked in alternate months (Dal Grande et al. 2004). Topics include: demographics, health conditions (arthritis / osteoporosis, asthma, chronic obstructive pulmonary disease, cardiovascular disease, diabetes, injury, depression/ mental health, disability), risk factors (body mass index, cholesterol, high blood pressure, alcohol consumption, immunisation, nutrition [breastfeeding, food consumption, food security], physical activity, smoking, sun protection, child development, health service utilisation, social capital, economic indicators, socio-demographics. A number of reports/ publications based on SAMSS data have been published. 2002-03 response rate calculated as: number of respondents completing the survey divided by number of eligible sample (2002-03: 6,145 / 8,873 = 69.3%). Eligible sample = original sample less sample loss (10,320 - [non-connected numbers (218) + non-residential numbers (218) + fax/modem connections (1420)] = 8,873 in 2002-03.).[240:17]
SA 4. Health Omnibus Survey (HOS) – SA Dept of Health	yes	yes	yes	some	limited	yes but initial coverage is limited*	The Health Omnibus Survey (HOS) is an annual survey on health, well-being and related issues that is a 'user-pays' service: participating organisations purchase questions and share the cost of the survey, with approximately ten background demographic questions included free of charge. Questions vary from year to year. HOS has included questions on telephone connections within the household (e.g., in 1994, 1998, 1999 and 2002).[60] A number of reports/ publications based on Health Omnibus Survey data have been published. Each survey (conducted in October/ November) samples 4,400 households with 77% selected from the Adelaide metropolitan area (340 CDs) and the remainder (100 CDs) drawn from country towns with a population of 1,000 or more (based on the ABS Census). The response rate of around 70% was achieved 1991-2000, resulting in a minimum 3,000 interviews per survey.[241] 2004 response rate calculated as: number of interviews completed divided by number of selected households remaining after sample loss (3,015 / 4,573 = 65.9). Selected households = 4,700 less vacant dwellings (127) = 4,573.[242:41]
SA 5. Health Monitor Survey (HMS) – SA Dept of Health	yes	yes	yes	some	limited	varies	Like HOS, the Health Monitor Survey (HMS) is a 'user-pays' service: participating organisations purchase questions and share the cost of the survey; up to 13 demographic questions are included free of charge (PROS 2007:5). HMS supplements the annual HOS and provides more frequent data in three regular, SA-wide surveys per year (in February/ March, June/ July and September/ October). Additional surveys into particular aspects of health may be conducted on an ad-hoc basis. A number of reports/ publications based on Health Monitor Survey data have been published. Response rates: approximately 65-70% of the eligible households sampled. The majority of HMS have sampled around 3,400 households, resulting in around 2,000 completed interviews per survey.[243:6]
SA 6. Social, Environmental and Risk Context Information System (SERCIS) – SA Dept of Health	yes	yes	yes	some	limited	varies	SERCIS is a flexible, timely survey system that conducts issue-specific population surveys on an ad-hoc basis and may survey households in specific areas or regions, on particular health matters, at any time of the year. Content varies according to need of customers, and the sample frame, sample size and sampling method vary with individual survey needs. A number of reports/ publications based on SERCIS data have been published. Sample size and participation rates vary from survey to survey, examples include: Older Persons 2000 – final sample 2,619, participation rate 70.5%; Gambling patterns 2001 – final sample 6,045, participation rate 73.1%.

	Disaggregations						Additional information:
Data collection title	**age**	**sex**	**Indigenous status‡**	**ethnicity ** ‡**	**SES**	**geog area ‡**	
Tas 1. Healthy Communities Survey	yes	yes	yes	yes	yes	state, LGA/ postcode	A one off survey with a strong focus on quality of life, risk factors and community capacity. Sample of 25,000 drawn from the electoral roll. Response rate calculated as: number of respondents divided by number in sample (18,680 / 25,000 = 75%).
Tas 2. SNAPS 'Filling the Gaps' CATI survey – funded by DoHA	yes	yes	yes	yes	yes SEIFA IRSD	state, LGA, rural/ urban based on ARIA	Commonwealth funded survey to provide risk factor data for inclusion in the national data pooling project so that the data from all jurisdictions are represented in national estimates.
ACT 1. ASSAD	yes	yes	yes, p	yes	no	q	See Other 2. above for the main entry on the Australian Secondary Schools Alcohol and Drug Survey (ASSAD).
ACT 2. Child Health NSW	yes	yes	yes	yes		no	ACT commissioned NSW Health to include an ACT sample in their Child Health Survey– refer NSW Health Child Health Survey 2001 for details.
ACT 3. SNAPS (Smoking, Nutrition, Alcohol & PA Survey)	yes	yes	yes	yes		no	Refer CATI TRG for details.
ACT 4. Older Persons (NSW)	yes	yes	yes	yes		no	ACT commissioned NSW Health to include an ACT sample in their survey – refer NSW Health Older Persons Survey 1999 for details.
ACT 5. Physical Activity & Nutrition Survey (ACTPANS)	yes	yes	yes	yes	no	yes	School based collection of measured height, weight plus questionnaire: self-reported information on a range of healthy weight priority areas including, weight status, participation in physical activity, eating patterns and environments, attitudes and psychosocial outcomes.
ACT 6. General Health (SA)	yes	yes	yes	yes	limited	no	ACT commissioned SA Health to administer the survey. The sampling frame was all households in the ACT with a telephone connected. The sampling methodology used was Random Digit Dialling (RDD). The survey was conducted over two months (April and September) with a response rate of 80% and 78% respectively.
ACT 7. General Health (NSW)	yes	yes	yes	yes	yes	not yet	ACT commissioned NSW Health to include an ACT sample in their continuous survey from 2007 – refer NSW 1. above for details
NT 1. NT Health and Wellbeing Survey (adult) 2000 – funded by DoHA	yes	yes	non-Indigenous (small Indigenous sample)	?	some detail	NT	Tristate survey (WA, SA & NT). CATI is not an appropriate method for the NT Aboriginal population because of lack of access to telephones.

Data collection title	Disaggregations age	 sex	 Indigenous status‡	 ethnicity ** ‡	 SES	 geog area ‡	Additional information:
NT 2. Risk factor survey, 2004 (Filling the Gaps) – funded by DoHA	yes	yes	non-Indigenous (small Indigenous sample)	?	some detail	NT	CATI is not an appropriate method for the NT Aboriginal population because of lack of access to telephones.
NT 3. National Aboriginal and Torres Strait Islander Survey (NATSIHS) 2004-05 – ABS	yes	yes	Indigenous only	Indigenous only, non-Indigenous available through NHS	yes	NT remote/ non-remote	See other details for NATSIHS at ABS 2. above.
NT 4. Chronic disease register – NT Dept. of Health and Community Services (DHCS)	yes	yes	yes	?	proxy - postcode	address	
NT 5. Central NT heath and community services data warehouse – NT DHCS	yes	yes	yes	?	proxy - postcode	address	
NT 6. Primary health care electronic record systems – NT DHCS	yes	yes	yes	?	proxy - postcode	address	Allows estimates of prevalence, incidence and future monitoring of population. Direct estimates are possible, but enhanced by statistical methods such as capture/ recapture.

Note that a number of additional, mostly non-government data collections were nominated but as details are not complete they have not been included here.

This concludes the Audit of Australian Chronic Disease and Associated Risk Factor Data Collections.

Please contact PHIDU to advice factual changes and/or amendments such as major changes in collections or to nominate additional collections of interest that could be incorporated in future versions.