

A guide to Australian eye health data

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A guide to Australian eye health data

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Australian Institute of Health and Welfare
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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CATI	computer-aided telephone interviewing
CURF	confidentialised unit record file
DoHA	Australian Government Department of Health and Ageing
DVA	Department of Veterans' Affairs
ICD-9-BPA	International Statistical Classification of Diseases and Related Health Problems, Ninth edition, British Paediatric Association
ICD-9-CM	International Statistical Classification of Diseases and Related Health Problems, Ninth edition, Clinical Modification
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
ICF	International Classification of Functioning, Disability and Health
ICO	International College of Ophthalmologists
ICPC	International Classification of Primary Care
NDS-IS	National Data Standard for Injury Surveillance
NHPC	National Health Performance Committee
RANZCO	Royal Australian and New Zealand College of Ophthalmologists
SEIFA	Socio-Economic Indexes for Areas
SLA	statistical local area
WHO	World Health Organization

1 Introduction

1.1 Purpose of this report

The Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare (AIHW) to compile details of key Australian data sources that are relevant to assessing prevalence and outcomes of eye diseases and injuries and eye health-care utilisation.

1.2 Structure of this document

This report is divided into four sections. Following this introduction, Section 2 presents a brief analysis of the current key eye health data sources in Australia, in addition to presenting detailed listings of each key eye health data source.

Section 3 presents a discussion on the key definitional issues surrounding eye health terminology and includes a summary of eye health definitions in use in Australia.

Section 4 presents useful background information for the development of future performance indicators in eye health.

1.3 Eye health in Australia

It is estimated that in excess of 161 million people are visually impaired worldwide. This includes people with significant loss of function and disability due to the impact of vision loss. The leading cause of this visual impairment worldwide is cataract. Other major causes of visual impairment worldwide are glaucoma, age-related macular degeneration, diabetic retinopathy and trachoma (Resnikoff et al. 2004).

As in other developed countries, the most prevalent causes of blindness and vision loss in Australia are those related to ageing. *Eye health in Australia*, the background paper to the *National framework for action to promote eye health and prevent avoidable blindness and vision loss* (the *National eye health framework*), reported that age-related macular degeneration, cataract, glaucoma, diabetic retinopathy, uncorrected or under-corrected refractive error, eye trauma and trachoma are the most prevalent causes of blindness and vision loss in Australia (Commonwealth of Australia 2005a).

In a recent analysis of pooled eye health data from population-based clinical studies, conducted both in Australia and internationally, it was estimated that 9.4% of Australians aged 55 or older are visually impaired and about 1.2% are blind (AIHW 2005a). The combined impact of an ageing Australian population and the high age correlation of causes of vision loss indicates that the prevalence of visual impairment is set to increase over time in a policy-neutral environment (Access Economics 2004).

Self-reported data on the prevalence of loss of sight is available through the Australian Bureau of Statistics (ABS) National Health Survey 2004–05. The survey indicates that 52% of the Australian population report eyesight problems, including long and short sightedness, as a long-term medical condition (ABS 2006).

Certain groups within the Australian population are at greater risk of developing eye disease. These groups include Aboriginal and Torres Strait Islander peoples, older people, people with a family history of eye disease, people with diabetes and marginalised to disadvantaged people (Commonwealth of Australia 2005a).

People with diabetes have an increased risk of developing eye disease. The Australian Diabetes, Obesity and Lifestyle Study found that 15.3% of people with known diabetes and newly diagnosed diabetes had developed retinopathy (Tapp et al. 2003).

Eye disease and vision loss have considerable financial and social costs to the Australian community. Visual impairment can shorten life, increase the risk of other conditions, restrict social participation and independence, and impair physical and mental health. In addition, people with visual impairment have a higher use of social services and higher admission rate to nursing homes. It has been calculated that the total financial costs of visual impairment, both direct and indirect, were over \$5.0 billion in 2004 (Access Economics 2004).

1.4 Context of the project

In response to the World Health Assembly resolution WHA56.26 on the elimination of avoidable blindness in member states, the Australian Health Ministers' Advisory Council endorsed the *National eye health framework*. The framework focuses on the elimination of avoidable blindness and vision loss in Australia, providing an outline for nationally coordinated action by governments, health professionals, non-government organisations, industry and individuals to work in partnership (Commonwealth of Australia 2005b).

In the 2006 Federal Budget, the Australian Government allocated \$13.8 million over 4 years to a new National Eye Health Initiative. This initiative will support a range of activities to raise public awareness of eye health issues and to strengthen the delivery of eye health care. The National Eye Health Initiative represents the Australian Government's contribution to the implementation of the *National eye health framework*.

The Australian Government Department of Health and Ageing (DoHA) commissioned the AIHW through the National Eye Health Initiative to undertake the Eye Health Data Project. This follows on from work performed for an earlier publication, *Vision problems among older Australians*, released in July 2005.

The key areas for action within the *National eye health framework* provide a brief outline of the challenges to be addressed and a series of actions that might be utilised to meet these challenges.

The Key area for action 5—*Improving the evidence base* outlines, among other actions, a need to examine existing health data sets for relevance to eye health. The project informs this action area by compiling details of key Australian data sources that are relevant to assessing prevalence and outcomes of eye diseases and injuries and eye health-care utilisation. Refer to the Methodology section of this report (Section 2.1) for more information on the process of collating these data sources. The project assesses the set of key data sources in terms of their capacity to address questions which emerge from the key areas for action, as outlined in the *National eye health framework*.

The Key area for action 5—*Improving the evidence base* also outlines a need to develop performance indicators. The project informs this action area firstly at a preliminary level by presenting useful information for the development of future eye health performance indicators. Secondly, the project informs this action area through the preliminary examination of key definitional issues surrounding eye health terminology.

2 Key data sources

This chapter describes the key data sources available that are relevant to assessing the prevalence and outcomes of eye diseases and injuries and eye health-care utilisation in Australia. The data sources contain information collected nationally, in a state or territory or regionally when the information included is not available elsewhere.

2.1 Methodology

Consultations with stakeholders and an extensive search of information provided a wide range of eye health data sources which indicate the prevalence and outcomes of eye diseases and injuries and eye health-care utilisation. A greater understanding of the data sources and their application to the monitoring of eye health issues was gained through consultation with the data sources' primary contact officers.

While identification of these data sources mainly focused on those within the health and welfare areas, relevant data collections in the areas of income, education and workforce were also explored. Data sources from these areas provide additional information to describe people with eye diseases and injuries. This report focuses predominately on population-survey-based and administrative national data collections within the public domain, that is, those that are available to the public either through published reports or via access to the data for research. However, the focus is not restricted exclusively to this domain. Jurisdictional or local-level data sources have also been included, depending on their relevance and quality.

It is recognised that the eye health sector is dynamic. The key Australian eye health data sources, as presented in this report, are those that are current or effective at the time of publication.

Key data sources were documented individually according to a standard template. The template was designed to gather information on the purpose, collection methodology, data content, scope and details concerning eye health specific data, along with data custodian contact details.

Noted eye health researcher Prof. Hugh Taylor was asked by the AIHW to verify the breadth and relevance of data sources referenced in this publication and to provide comments on eye health definitions used in this report. The ABS also provided valuable comments.

2.2 Key Australian eye health data sources

Lists of national and regional data sources

National

Australian Congenital Anomalies System
Australian Corneal Graft Registry
Australian Diabetes, Obesity and Lifestyle Study (AusDiab)
Australian Longitudinal Study on Women's Health
Australian National Diabetes Information Audit & Benchmarking
Bettering the Evaluation and Care of Health
Commonwealth State/Territory Disability Agreement National Minimum Data Set
Disability Support Pension collection
Disease Expenditure Database
Growing Up in Australia: the Longitudinal Study of Australian Children
Higher Education Student Collection
Home and Community Care Program Minimum Data Set
Macular Degeneration Foundation Database
Medicare Australia data
National Aboriginal and Torres Strait Islander Health Survey
National Cancer Statistics Clearing House
National Data Set for Compensation-based Statistics
National Elective Surgery Waiting Times Data Collection
National Health Survey
National Hospital Morbidity Database
National Mortality Database
Optometrists Association Australia Optometrists Database
Optometrist registration boards
Outpatient Care Data Collection
Pharmaceutical Benefits Scheme data
Royal Australian and New Zealand College of Ophthalmologists Ophthalmology workforce database
Survey of Disability, Ageing and Carers
Treatment Accounts System

Regional

The 45 and Up Study

Association for the Blind of Western Australia Register of Blindness and Vision Impairment

Australian Longitudinal Study of Ageing

Blue Mountains Eye Study

Cataract Surgery and Age-related Macular Degeneration Study

Central Australia Ocular Health Study data/hospital records/ Regional Eye Health Coordinator records

Dubbo Study

Florey Adelaide Male Ageing Study

International Centre for Eyecare Education/Aboriginal Health and Medical Research Council/Visioncare New South Wales Aboriginal project data sheets

Katherine Region Diabetic Retinopathy Study

Melbourne Longitudinal Studies in Healthy Ageing program

Melbourne Visual Impairment Project

New South Wales Population Health Survey

North West Adelaide Health Study

Queensland Injury Surveillance Unit Database

Royal Society for the Blind Client Database

South Australian Health Monitor survey

South Australian Health Omnibus Survey

South Australian Monitoring and Surveillance System

Spectacle assistance schemes

Sydney Myopia Study

Sydney Older Persons Study

Victorian Emergency Minimum Dataset injury surveillance collection

Victorian Population Health Survey

Western Australian Aboriginal Child Health Survey

National data sources

Australian Congenital Anomalies System

Description of data source

The Australian Congenital Anomalies System contains information on congenital anomalies notified to birth defect registers and other data collections of Australian states and territories.

Purpose(s)

The purposes of the Australian Congenital Anomalies System are to monitor congenital anomalies at a national level, to fulfil international reporting requirements and to work towards the standardisation of definitions, classifications and collection methods among the states and territories.

Collection methodology

Data on congenital anomalies are collected in state and territory birth defect registers, perinatal data systems, hospital systems and other sources. These data are reported to the AIHW National Perinatal Statistics Unit.

Data content

For the mother, the following variables are collected: age, country of birth, Indigenous status, area of usual residence, place of birth, hospital of birth, hospital sector, admitted patient elected accommodation status, parity, gestation, and plurality.

For the baby/infant, the following variables are collected: sex, birth weight, outcome and congenital anomaly(ies). Anomalies are classified differently among the states and territories using either the International Statistical Classification of Diseases and Related Health Problems, 9th Revision, British Paediatric Association (ICD-9-BPA), International Statistical Classification of Diseases and Related Health Problems, 9th Revision, Clinical Modification (ICD-9-CM) or International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM).

Data content related to eye health

Congenital anomalies of the eye.

Eye health-related data are medically verified.

Indigenous identification

Yes, however the quality has not been determined.

Socioeconomic identification

Area of usual residence.

Scope/target population

Included within the collection are births of at least 20 weeks gestation or 400 grams birth weight with a major congenital anomaly notified up to 1 year of age, and terminations of pregnancy less than 20 weeks gestation and less than 400grams birth weight with a major congenital anomaly.

The period of notification of a congenital anomaly varies among the states and territories. For some jurisdictions, the period of notification is the perinatal period, or the birth episode. For others, the period of notification is up to 1, 5, 6 or 15 years of age. Only four jurisdictions provide data on terminations of pregnancy less than 20 weeks gestation or 400 grams birth weight.

Geographical coverage

All states and territories, Australia.

Time period covered

Data have been compiled for 1998 to 2001. Data for 2002 and 2003 are to be compiled in 2007.

Publications and other outputs

- Congenital anomalies in Australia publication series. Congenital anomalies in Australia 1998–2001 and Congenital anomalies in Australia 2002 and 2003 will be published in 2007. Congenital anomalies in Australia will be published annually or biannually in future years.)
- Data from the Australian Congenital Anomalies System also contributes to research projects.

Access

Access to the Australian Congenital Anomalies System can be requested through the Director, AIHW.

Data management agency

AIHW National Perinatal Statistics Unit

Level 2 McNevin Dickson Building

Randwick Hospital's Campus

Gate 6 Avoca St

Randwick NSW 2031

<www.npsu.unsw.edu.au>

(02) 9382 1014

Australian Corneal Graft Registry

Description of data source

The Australian Corneal Graft Registry operates an Australia-wide register of human corneal transplants.

Purpose(s)

The purpose of the Australian Corneal Graft Registry is to collect information on corneal transplants performed in Australia, to measure graft and visual outcomes that will inform clinical practice and to identify risk factors for poor patient outcomes.

Collection methodology

Proformas completed by the treating ophthalmologist or other medical professional are returned by mail at the time of corneal transplantation and at follow-up.

Registration is one-off for a given corneal transplant. Follow-up is at approximately yearly intervals thereafter until recipient death, loss-to-follow-up or graft failure.

Data content

The initial register collects information including de-identified information on the corneal transplant recipient, the corneal donor, the eye bank procedures and the operative procedure.

The follow-up collects information on graft survival, post-operative course and management, complications and visual outcome.

Data content related to eye health

Corneal transplants performed in Australia, along with graft and visual outcomes. Eye health-related data are medically verified.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

Any person in Australia with a corneal transplant.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 5 May 1985 to present (ongoing collection).

Publications and other outputs

- Williams KA, Hornsby NB, Bartlett CM, Holland HK, Esterman A & Coster DJ 2006. The Australian corneal graft registry 2004 annual report. Snap printing: Adelaide.
- Annual presentations at specialist meetings.
- Occasional papers in international literature.

Access

Access to the Australian Corneal Graft Registry is restricted.

Data management agency

Australian Corneal Graft Registry

Department of Ophthalmology

Flinders Medical Centre

Bedford Park SA 5042

(08) 8204 5321

Australian Diabetes, Obesity and Lifestyle Study

Description of data source

The Australian Diabetes, Obesity and Lifestyle study (AusDiab) is the largest Australian longitudinal population-based study examining the natural history of diabetes, pre-diabetes (in which glucose metabolism is impaired but not to the level to cause diabetes), heart disease and kidney disease.

Purpose(s)

The results provide a picture of the incidence of diabetes, cardiovascular disease and kidney disease, as well as the factors that increase the risk of these conditions.

Collection methodology

AusDiab is a field survey involving both physical testing as well as questionnaires. A team of researchers went to each of the 42 randomly selected testing sites around Australia to individually test each of the 11,247 individuals who participated in the baseline study in 1999–2000. Of these original participants, around 6,500 came back to participate in similar survey five years later in 2004–2005. In addition, self-reported health information was obtained from more than 2,000 of those who could not attend the survey site.

Data content

AusDiab collects data in the following categories: biochemistry, demographic, medical history, disease status, survey procedures, anthropometric, smoking, exercise, clinical observations, self efficacy, knowledge and opinion, socioeconomic, family medical history, alcohol and diet.

Data content related to eye health

Participants are asked the following questions:

- Do you think eye trouble or blindness is likely to occur in people with diabetes?
- Have you ever been treated for or suffered from trouble with the back of your eyes or retinopathy?
- Have you ever had the back of your eyes (retina) examined? Who conducted the eye examination? How long has it been since you last had the back of your eyes checked?

Eye health-related data are self-reported.

Indigenous identification

Yes, participants are recorded as Aboriginal/Torres Strait Islander or neither.

Socioeconomic identification

Participants provide information about accommodation, education, income and employment.

Scope/target population

The baseline AusDiab (1999–2000) study was a population-based national survey of the Australian general population aged 25 years or older residing in 42 randomly selected urban and rural areas (census collector districts) in six states and the Northern Territory. AusDiab was designed to be representative of the general Australian population aged over 25 years.

Geographical coverage

Forty-two randomly selected urban and rural areas of Australia. A stratified cluster sample was used involving seven strata (the six states and the Northern Territory) and clusters were based on census collector districts.

Time period covered

Surveys were conducted in 1999–2000 and 2005. Pending further funding, a follow-up to AusDiab and a new cross-sectional survey will be conducted in 2009–10.

Publications and other outputs

- Refereed publications, including those relevant to eye health:
 - Tapp R, Shaw J, Harper A, de Courten M, Balkau B, McCarty D, Taylor H, Welborn T & Zimmet P on behalf of the AusDiab Study Group 2003. The prevalence of and factors associated with diabetic retinopathy in the Australian population. *Diabetes Care* 26: 1721–1727.
 - Tapp RJ, Zimmet PZ, Harper CA, de Courten MD, Balkau B, McCarty DJ, Taylor H, Welborn TA & Shaw JE on behalf of the AusDiab Study Group 2004. Diabetes care in the Australian population: frequency of screening examination for eye and foot complications of diabetes. *Diabetes Care* 27:688–693.
- Presentations.

Access

The AusDiab team welcomes approaches from research workers for access to the accumulated data and biological materials and for participation in ongoing and new data collection activities. Access will generally not be granted to research groups/institutions or individuals who are receiving support from the Australian Tobacco Research Foundation or other bodies associated with the tobacco industry.

Data management agency

International Diabetes Institute
250 Kooyong Road
Caulfield Vic 3162
<www.diabetes.com.au>
(03) 9258 5050

Australian Longitudinal Study on Women's Health

Description of data source

The Australian Longitudinal Study on Women's Health, also known as Women's Health Australia, is a longitudinal population-based survey that examines the health of three large cohorts of Australian women over a 20-year period. It was first funded in 1995. The project was designed to explore factors that influence health among women who are broadly representative of the entire Australian population. The project goes beyond a narrow perspective that equates women's health with reproductive and sexual health, and takes a comprehensive view of all aspects of health throughout women's lifespan.

Purpose(s)

The aim of the project is to collect scientifically valid information that is relevant to the development of health policy, so that the Australia Government and state/territory government departments of health can base policy and practice in women's health on current data and accurate information.

An overall goal of the project is to clarify cause-and-effect relationships between women's health and a range of biological, psychological, social and lifestyle factors. Another goal is to assess the effects of changes in health policy and practice.

Collection methodology

Participants were initially selected by simple random sampling from the Medicare Australia database, with over-sampling for rural and remote areas. Three cohorts were recruited, with each cohort resurveyed every 3 years. The questionnaire is self-completed, however a telephone interview is provided for non-English-speaking respondents or when requested by participants.

Data content

The project assesses each participant's:

- physical and emotional health (including wellbeing, major diagnoses, symptoms)
- use of health services (general practitioner, specialists and other visits, access, satisfaction)
- health behaviours and risk factors (diet, exercise, smoking, alcohol, other drugs)
- time use (including paid and unpaid work, family roles and leisure)
- sociodemographic factors (location, education, employment, family composition)
- life stages and key events (such as childbirth, divorce, widowhood).

Data content related to eye health

Participants are asked the following questions:

- In the past 12 months have you had eyesight problems?
- For the eyesight problems you had, did you seek help?

- Have you had eye surgery? In last three years? More than three years ago?
- In the last three years have you had cataract surgery?
- In the last three years have you had any other eye surgery?
- In the last three years have you been on a waiting list for cataract surgery?
- In the last three years have you been on a waiting list for other eye surgery?
- Do you have difficulty seeing print, even with glasses?
- Do you have difficulty recognising people across the road, even with glasses?

Eye health-related data are self-reported.

Indigenous identification

Yes, participants are recorded as Aboriginal, Torres Strait Islander or neither.

Socioeconomic identification

Participants provide details of their postcode, highest educational qualification achieved and household income.

Scope/target population

Three age groups were selected in order to follow women through life stages that are critical to women's health and wellbeing. Ages at recruitment were 18–23 years of age (younger), 45–50 years of age (mid-aged) and 70–75 years of age (older). The younger age group began to be tracked when they were in the early stages of transition from late adolescence to full adulthood; over time, most of them are moving into the workforce, entering adult relationships, and becoming mothers. The mid-age group was selected to examine menopausal transitions and the social and personal changes of middle age. The older group was selected in their early 70s, to recruit older women who are generally still active, involved members of the community.

Geographical coverage

Urban, rural and remote areas, all states and territories, Australia.

Time period covered

Since 1996 to 2016.

Publications and other outputs

A number of annual reports and technical reports are available on the Women's Health Australia website, www.alsw.org.au/reports.html (viewed 20 March 2007).

Access

Data may be made available to collaborating researchers where there is a formal request to make use of the material. Permission to use the data must be obtained from the Publications, Analyses and Substudies Committee of the Australian

Longitudinal Study on Women's Health. Where data are collected in collaboration with, by or for a community, community permission to use data is also necessary. Rules relating to data concerning Aboriginal and Torres Strait Islander communities, as set out by the National Health and Medical Research Council, apply.

Data management agency

Women's Health Australia

Research Centre for Gender, Health and Ageing

University of Newcastle

Callaghan NSW 2308

<www.alsw.org.au>

(02) 4923 6872

whasec@newcastle.edu.au

Australian National Diabetes Information Audit & Benchmarking

Description of data source

The Australian National Diabetes Information Audit & Benchmarking (ANDIAB) project involves the collection of de-identified data on individuals with diabetes seen in diabetes centres and by specialist endocrinologists in private practice over a one-month period.

Purpose(s)

The purpose of ANDIAB is to collect information on individuals diagnosed with diabetes.

Collection methodology

Information is collection in survey format predominantly plus some data from established databases.

Data content

Collected information includes:

- demographic details (date of birth, sex, Indigenous);
- diagnosis details (year of diagnosis, type of diabetes, management method, current smoker, weight, height, blood pressure); and
- comorbidity/complication details; contact with health care providers (optometrists, ophthalmologists, podiatrists, diabetes educators and dieticians).

Data content related to eye health

Participants are asked the following questions:

- Have you seen an optometrist in the last 12 months?
- Have you been referred to an ophthalmologist in the last 12 months?
- Have you had a fundus examination in the last 12 months?
- Do you have a cataract currently present or previously removed?

They also have their visual acuity measured and are asked about comorbidities.

Eye health-related data are self-reported and medically verified.

Indigenous identification

The patient is recorded to be either Aboriginal/Torres Strait Islander or neither.

Socioeconomic identification

No.

Scope/target population

Individuals diagnosed with diabetes who attend specialist diabetes services.

Geographical coverage

All state and territories, Australia, excluding Western Australia and the Northern Territory in 2004.

Time period covered

Since 1998 to present (ongoing collection).

Publications and other outputs

- Flack JR & Colagiuri S 2005. ANDIAB 2004: Australian national diabetes information audit benchmarking. Canberra: National Association of Diabetes Centres.

Access

By application, contact:

Assoc. Prof. JR Flack FRACP MM

Bankstown-Lidcombe Hospital

Eldridge Road

Bankstown NSW 2200

Data management agency

Diabetes Centre, Bankstown-Lidcombe Hospital (managed on behalf of National Association of Diabetes Centres)

Bettering the Evaluation and Care of Health

Description of data source

The Bettering the Evaluation and Care of Health (BEACH) program continuously collects information about the patients seen, reasons people seek medical care, problems managed and treatments provided in general practice in Australia.

Purpose(s)

BEACH aims to:

- collect reliable and valid data about general practice which is responsive to the ever-changing needs of information users
- establish an ongoing database of general practitioner (GP)/patient encounter information
- assess patient-based risk factors and the relationship these factors have with health service activity
- provide accurate and timely data to a wide variety of users.

Collection methodology

BEACH uses a cross-sectional, paper-based data collection system developed over the past 27 years at the University of Sydney.

Data content

BEACH collects the following information from each GP/patient encounter:

- encounter characteristics
- GP characteristics – age, gender, years in general practice, number of sessions per week, country of graduation, size of practice, computer use, hours worked and on call each week, rurality of practice
- patient characteristics – age, sex, Indigenous status, Health Care Card and Veteran's Affairs status, status to the practice (new/seen before)
- patient reasons for encounter (up to three)
- problems managed at encounter (up to four)
- management for each problem (pharmacological and non-pharmacological)
- referrals, tests and investigations for each problem.

Data content related to eye health

All problems managed by GPs that are labelled as eye problems and therefore classified in Chapter F of the International Classification of Primary Care (ICPC), version 2.

Eye health-related data are medically verified.

Indigenous identification

Yes, a patient may self-report as Aboriginal and/or Torres Strait Islander.

Socioeconomic identification

Postcode of usual residence.

Scope/target population

Patients attending a GP who has been randomly selected for the study. The sample represents patients who see their GP. About 85% of the population visit the GP in any given year. However, the sample over-represents those people who attend more frequently, as they have more chance of being included.

Geographical coverage

All states and territories, Australia.

Time period covered

Since April 1998 to present (ongoing collection).

Publications and other outputs

A full list of publications can be found through the BEACH project website, <www.fmrc.org.au/beach.htm> (viewed 20 March 2007).

Access

The general public and researchers may request ad hoc analyses of BEACH data to be performed, a charge is made for access to the data and for work undertaken. Contact A/Prof. Helena Britt at the Australian General Practice Statistics and Classification Centre.

Data management agency

Australian General Practice Statistics and Classification Centre

Family Medicine Research Centre, Acacia House

Westmead Hospital

Westmead NSW 2145

<www.fmrc.org.au/agpscc/>

(02) 9845 8151

gpsc@med.usyd.edu.au

Commonwealth State/Territory Disability Agreement National Minimum Data Set

Description of data source

The Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) and its national collection provide information relating to all services funded under the CSTDA and the people receiving these services. The collection consists of a set of nationally significant data items that are collected in all Australian jurisdictions, with an agreed method of collection and transmission.

Purpose(s)

The purpose of the CSTDA NMDS collection is to facilitate the annual collation of nationally comparable data about CSTDA-funded services, and to obtain reliable, consistent data with minimal load on the disability services field. Under the CSTDA, the disability administrators in all Australian jurisdictions are responsible for ensuring 'that CSTDA NMDS information will be comparable across all jurisdictions and years'.

Collection methodology

The CSTDA NMDS is an administrative data set. Data are collected by disability support service agencies and forwarded to the appropriate state/territory or Australian Government department. All data are then forwarded to the AIHW on an annual basis for collation of a national data set.

Data content

Information collected on service users includes date of birth; sex; Indigenous status; country of birth; interpreter services required; communication method; living arrangements; postcode; residential setting; disability group (primary and 'other significant'); support needs; informal carer arrangements; receipt of carer allowance; labour force status; main source of income; individual funding status; receipt of service variables.

Information collected on service type outlets includes service type; postcode; statistical local area (SLA); funding jurisdiction; agency sector; full financial year of CSTDA funding; operation times (weeks, hours, days); staff hours; number of service users.

Data content related to eye health

'Vision' is included as a disability group for two data items.

- Primary disability group is the disability group that most clearly expresses the experience of disability by a person. The primary disability group can also be considered as the disability group causing the most difficulty to the person (overall difficulty in daily life, not just within the context of the support offered by the service).

- Other significant disability group(s): disability group(s) (other than that indicated as being 'primary') that also clearly express the experience of disability by a person and/or cause difficulty for the person.

Eye health-related data are medically verified.

Indigenous identification

Yes, the standard ABS classification for Indigenous identification is used.

Socioeconomic identification

No.

Scope/target population

Under the CSTDA, 'people with disabilities' means people with disabilities attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self care/management
- mobility
- communication.

requiring significant ongoing and/or long-term episodic support and which manifests itself before the age of 65.

Geographical coverage

All states and territories, Australia.

Time period covered

Since October 2002 to present (ongoing collection).

Previously data were collected on a 'snapshot day' basis under the former Commonwealth State Disability Agreement Minimum Data Set, implemented in 1995 and conducted at a national level from 1996 to 2002.

Publications and other outputs

- Annual reports, most recently:
 - AIHW 2006. Disability support services 2004–05: national data on services provided under the CSTDA NMDS. AIHW cat. no. DIS 46. Disability Series. Canberra: AIHW.
 - National Disability Administrators 2006. CSTDA annual public report 2004–05.
- Indicators from this data set are also reported in the annual report on government services:

- Steering Committee for the Review of Commonwealth/State Service Provision. Report on Government Services, Volume 2. Melbourne: Commonwealth of Australia.
- Previous AIHW publications relating to the CSTDA NMDS data can be found on the AIHW website (viewed 20 March 2007):
<<http://www.aihw.gov.au/publications/index.cfm/subject/7>>.
- CSTDA NMDS data collection materials, including the national *Data guide*; *Data transmission and technical guide*; collection forms; and *Data dictionary* can be accessed from the following link (viewed 20 March 2007):
<http://www.aihw.gov.au/disability/csda_public/index.cfm>.
- AIHW also publishes on-line, interactive data cubes for the CSTDA NMDS. These can be accessed from
<<http://www.aihw.gov.au/disability/datacubes/index.cfm>> (viewed 20 March 2007).

Access

The AIHW is the custodian of the national data set; jurisdictions are custodians of their own data. Therefore any jurisdiction-specific data analyses must be approved by the appropriate jurisdiction(s). Access to the CSTDA NMDS data can be requested through the AIHW.

Data management agency

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

<www.aihw.gov.au>

(02) 6244 1000

info@aihw.gov.au

Disability Support Pension collection

Description of data source

The Disability Support Pension collection is an administrative database.

Purpose(s)

The purpose of the Disability Support Pension collection is to collect information about recipients of the pension.

Collection methodology

Updated quarterly in Centrelink's SuperStar database.

Data content

General demographic details including age, gender, geographical location by state (also including those currently overseas) and postcode.

Data content related to eye health

Recipients identified as receiving the Disability Support Pension who are legally blind.

Eye health-related data are medically verified.

Indigenous identification

Yes, recipients are identified as being Indigenous, Non-indigenous or unknown.

Socioeconomic identification

Information is collected about recipients' postcode, country of birth, relationship status, home ownership and rent status.

Scope/target population

Australians who meet the eligibility requirements and are receiving the Disability Support Pension.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 1999 to present (ongoing collection).

Publications and other outputs

Not applicable.

Access

Disability Support Pension data is available by request to Centrelink (datarequests@centrelink.gov.au).

Data management agency

Centrelink

<<http://www.centrelink.gov.au/>>

Disease Expenditure Database

Description of data source

The report provides an overview of total health system expenditures on disease and injury in Australia during 2000–01, based on the best possible estimates from currently available data sources.

Purpose(s)

To provide a systematic analysis of Australian health expenditure by disease.

Collection methodology

The basic approach for direct costs of health services has been to take known aggregate expenditures on health care and apportion these to disease categories using Australian data.

Data content

Expenditure data are collected on hospitals, aged care homes, out-of-hospital medical services, pharmaceuticals, other professional services, dental, and research (by age and sex).

Data content related to eye health

Expenditure data related to conditions of the eye and services relating to the treatment of these conditions.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

General Australian population.

Geographical coverage

All states and territories, Australia.

Time period covered

1993–94 and 2000–01.

Publications and other outputs

- Publications, available on the AIHW website (viewed 20 March 2007), <<http://www.aihw.gov.au/publications/index.cfm>>.

- Online data cubes (viewed 20 March 2007),
<<http://www.aihw.gov.au/expenditure/datacubes/index.cfm>>.

Access

Access is available through the AIHW or through the online data cubes.

Data management agency

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

<www.aihw.gov.au>

(02) 6244 1000

info@aihw.gov.au

Growing Up in Australia: the Longitudinal Study of Australian Children

Description of data source

The Growing Up in Australia study has been initiated and funded by the Australian Government Department of Families, Community Services and Indigenous Affairs as part of its Stronger Families and Communities Strategy.

Purpose(s)

Growing Up in Australia: the Longitudinal Study of Australian Children aims to examine the impact of Australia's unique social and cultural environment on the next generation to gain a further understanding of early childhood development, inform social policy debate, and be used to identify opportunities for early intervention and prevention strategies in policy areas concerning children.

The longitudinal nature of the study aims to enable researchers to determine critical periods for the provision of services and welfare support, and to identify the long-term consequences of policy innovations.

Collection methodology

Data are being collected over seven years from two cohorts every two years. The first main wave of data collection occurred in 2004, and 2 waves of data collection have now been completed. The first cohort (Infant or B cohort) of approximately 5,000 children aged 0 to 1 years, when the sample was recruited in 2004, will be followed until they reach 6 to 7 years of age. The second cohort (Child or K cohort) comprising approximately 5,000 children aged 4 to 5 years, when the sample was recruited, will be followed until they reach 10 or 11 years of age. Study informants include the child (when of an appropriate age) and their parents, carers and teachers.

Data content

Participants provide information on child care; child care provider; child's development; child's diet and nutrition; child's health; conception, pregnancy and birth; education; family demographics; finances; housing; neighbourhood; non-resident parent; paid work; parental health; parenting and social capital.

Data content related to eye health

Participants are asked to respond to the following:

- Does the study child have sight problems that have lasted, or are likely to last, for six months or more?
- Do the study child's parents have sight problems that have lasted, or are likely to last, for six months or more?
- Are there concerns about study child's development, with regards to vision problems? (B cohort only)
- Do the study child's siblings, in the household, have sight problems?
- Does the study child have ongoing problems with eyes or seeing properly?

Eye health-related data are self-reported.

Indigenous identification

Yes, according to the ABS standard.

Socioeconomic identification

Information is collected about the finances of the study child's parents, their educational qualifications, their current work status and occupation, home ownership, and the ABS Socio-Economic Indexes for Areas (SEIFA) indices and other indicators are added to the data file for their neighbourhood.

Scope/target population

Children born from March 2003 to February 2004 (B cohort) and children born from March 1999 to February 2003 (K cohort). Children in about 40 per cent of remote postcodes were excluded.

Geographical coverage

All states and territories, Australia.

Time period covered

2003–04 to 2009–10.

Publications and other outputs

Publications and other products can be found on the Growing Up in Australia website <<http://www.aifs.gov.au/growingup/pubs.html>>.

Access

Data from Growing Up in Australia is warehoused at the Australian Institute of Family Studies and is available to researchers approved by the Department of Families, Community Services and Indigenous Affairs who must abide by strict security and confidentiality protocols. More information can be found on the Growing Up in Australia website, <<http://www.aifs.gov.au/growingup/data.html>> (viewed 20 March 2007).

Data management agency

Australian Institute of Family Studies

Level 20 485 La Trobe Street

Melbourne Vic 3000

<www.aifs.gov.au/growingup>

(03) 9214 7888

lsacweb@aifs.gov.au

Higher Education Student Collection

Description of data source

The Higher Education Student Collection collects data from higher education providers in Australia.

It is a condition under the *Higher Education Support Act 2003* (ss. 19–70) that a higher education provider must provide statistical information in respect of the provision of higher education by the provider.

Purpose(s)

The Higher Education Student Collection provides information required by the Australian Government Department of Education, Science and Training as well as the Australian Tax Office (in relation to student loans). The collection provides data for analysis by government and non-government researchers which drives higher education policy formulation.

Collection methodology

Higher education providers report data in a series of data sets specified by the Australian Government Department of Education, Science and Training.

Data content

The Higher Education Student Collection collects data on enrolments, student load, courses, unit of study completions and course completions.

Data content related to eye health

The number of students studying the fields of study of optometry, optical technology and optical science not elsewhere classified, as classified by the Australian Standard Classification of Education (ASCE).

Indigenous identification

Yes, the standard ABS classification for Indigenous identification is used.

Socioeconomic identification

No.

Scope/target population

Higher education students from public and private higher education institutions that receive Higher Education Loan Programme funding on behalf of students in the form of student Higher Education Loan Programme loans from the Australian Government Department of Education, Science and Training.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 1989 to present (ongoing collection).

Publications and other outputs

Available on the Department of Science, Education and Training website (viewed 22 March 2007):

<http://www.dest.gov.au/sectors/higher_education/publications_resources/statistics/publications_higher_education_statistics_collections.htm>.

Access

Data from the most recent student collection are available on the Department of Education, Science and Training's website in aggregated data sets (viewed 22 March 2007):

<http://www.dest.gov.au/sectors/higher_education/publications_resources/statistics/higher_education_statistics_collection.htm>.

Tabulations can also be generated to meet the needs of data users. Charges are incurred for these products.

Data management agency

Department of Education, Science and Training

14 Mort Street

Braddon ACT 2602

<www.dest.gov.au>

(02) 6240 9788

university.statistics@dest.gov.au

Home and Community Care Program Minimum Data Set

Description of data source

The Home and Community Care (HACC) Minimum Data Set (MDS) is a collection of data about HACC clients (such as their age and living arrangements) and the amount and types of assistance being provided to them.

Purpose(s)

The objectives of the HACC MDS are to:

- provide HACC program managers with a tool to access data required for policy development, strategic planning and performance monitoring against agreed output/outcome criteria
- assist HACC service providers to provide high quality services to their clients by facilitating improvements in the internal management of HACC-funded service delivery
- facilitate consistency and comparability between HACC data and other aged, community and health data collections.

Collection methodology

Quarterly submission of data by service providers.

Data content

The HACC MDS collects information which includes: HACC linkage key, basic sociodemographic data (age, sex, country of birth, Indigenous status, main language spoken at home), care recipient circumstances (living arrangements, accommodation setting, carer details, pension status, state, suburb) and information about the service episode.

Data content related to eye health

The data element 'Assistance with goods and equipment' describes the number of goods/equipment received by the client during the HACC reporting period. It refers to the loan or purchase of goods and equipment to assist the person to cope with a disabling condition and/or maintain their independence. The data domain categories applicable to eye health are:

- support and mobility aids (white cane; sonic beam, laser cane, optacon; guide dog)
- aids for reading (contact lenses, reading/magnifying glasses; Braille books/items/watch; books, large print/talking, cassette recorders/players; reading frame, page turners, reading aids not associated with loss of sight; other reading or sight aids; dwelling modification to aid communication-intercom; other aids for communication).

However, data specifically relating to eye health are limited as data are available only at the level of the aid categories above and are not further specified to indicate

the specific aids provided. Data on support and mobility aids for the blind are only one component of the support and mobility category and therefore this category is not useful in its current form for identifying assistance that is solely related to eye health, as the collection does not distinguish an aid for a blind person from an aid for a sighted person. While the same is true for the category 'Aids for reading', the majority of aids in this category are aids to help people with impaired vision.

Indigenous identification

Yes, the standard ABS classification for Indigenous identification is used.

Socioeconomic identification

Area of residence (SLA) is collected.

Scope/target population

Elderly, frail or younger disabled people and their carers. The data collection covers all service recipients whether care recipient or clients with the exception of those who may be assisted anonymously or if unknown to the agency (for example, general advocacy for a group rather than a client, or group activities such as an information session where the agency does not have information about the participants).

Geographical coverage

All states and territories, Australia.

Time period covered

Since 2001-02 to present (ongoing collection).

Publications and other outputs

Annual reports of HACC MDS data are available on the Australian Government Department of Health and Ageing (DoHA) website (viewed 22 March 2007), <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub_mds_sb.htm>.

Access

Data are available as either aggregated data or unit record data. The conditions and protocols for access to HACC data are available on the DoHA website (viewed 22 March 2007), <<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-mds-protocol.htm>>.

Data management agency

Australian Government Department of Health and Ageing
<www.health.gov.au>

Macular Degeneration Foundation Database

Description of data source

The Macular Degeneration Foundation Database is a source of contact details for people within the community diagnosed with macular degeneration, their family, friends or carers, people with a general interest in macular degeneration and health-care professionals. The database is for the internal purposes of the Macular Degeneration Foundation. Within earlier collected data, it is not able to be determined whether a client has been diagnosed with macular degeneration or not.

Purpose(s)

The Macular Degeneration Foundation Database is an avenue through which people within the community diagnosed with macular degeneration or their carers/family can be contacted with educational information and invited to participate in surveys.

Collection methodology

People are placed on the database via phone enquiry, filling out a form at education seminars or by writing to the Macular Degeneration Foundation.

Data content

The information collected includes name and contact information, preferred choice of newsletter format, where they heard about the Macular Degeneration Foundation, if they have macular degeneration or if they are a family member, a friend or a person with a general interest. Specific details, such as the stage or type of the disease or treatment, is not collected. Health-care professionals are categorised into their field such as ophthalmologists, optometrists, GPs, aged care facilities.

Data content related to eye health

Clients registered with the Macular Degeneration Foundation who have been diagnosed with macular degeneration.

Eye health-related data are self-reported.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

Australians diagnosed with macular degeneration, their carers/family or people with a general interest.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 2001 to present (ongoing collection).

Publications and other outputs

- Macular Degeneration in Australia February 2006. Macular Degeneration Foundation. Viewed 30 November 2006, <<http://www.mdfoundation.com.au/resources/10/Report%20For%20website.pdf>>.

Access

The Macular Degeneration Foundation Database is for internal purposes of the Macular Degeneration Foundation only. The data are not released externally under any circumstances.

Data management agency

Macular Degeneration Foundation Limited

Suite 302, 447 Kent Street

Sydney NSW 2000

<www.mdfoundation.com.au>

(02) 9261 8900

info@mdfoundation.com.au

Medicare Australia data

Description of data source

Medicare Australia statistics cover services rendered on a 'fee-for-service' basis for which Medicare benefits were paid.

To be eligible for a Medicare rebate, the service must be listed in the Medicare Benefits Schedule (MBS).

Purpose(s)

Medicare statistics are a by-product of processing claims for Medicare benefits. The statistics are used by DoHA in undertaking policy development and review and program administration in relation to Medicare.

Collection methodology

Administrative by-product as a result of assessing Medicare claims.

Data content

Statistics can be compiled on the number of services, fees charged, Schedule fees, benefits paid, bulk billing and Schedule fee observance down to MBS item level, by gender, age range, specialty of provider and by region of provider and region of patient.

Data content related to eye health

Eligible services provided by ophthalmologists and optometrists.

Indigenous identification

There is a voluntary Indigenous identifier in the Medicare claim record.

Socioeconomic identification

Statistics can be compiled by SEIFA index range, subject to availability of a postcode to SEIFA concordance file.

Scope/target population

All Australian residents are eligible for Medicare benefits. Medicare covers most medical and optometrical services, and selected dental and allied health services. Excluded are details of services to public patients in hospital, to Veterans' Affairs patients and some compensation cases.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 1984 to present (ongoing collection).

Publications and other outputs

Medicare statistics are published quarterly by the Department of Health and Ageing and monthly by Medicare Australia (viewed 22 March 2007),
<<http://www.health.gov.au/internet/wcms/publishing.nsf/content/medicare+statistics-1>>.

Access

Access to Medicare data is available through Medicare Australia.

Data management agency

Medicare Australia

PO Box 1001

Tuggeranong ACT 2901

<www.medicareaustralia.gov.au>

National Aboriginal and Torres Strait Islander Health Survey

Description of data source

The National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) is a health survey of Indigenous Australians conducted by the ABS. This survey, which was conducted in remote and non-remote areas throughout Australia, was designed to collect a range of information from Indigenous Australians about health-related issues, including health status, risk factors and actions, and socioeconomic circumstances.

Purpose(s)

The survey aims were to:

- provide broad information about the health of Indigenous Australians, by remoteness, and at the national and state/territory levels
- allow for the relationships across the health status, risk factors and health-related actions of Indigenous Australians to be explored
- provide comparisons over time on the health of Indigenous Australians
- provide comparisons with results for the non-Indigenous population.

Collection methodology

Data collection was undertaken by ABS interviewers using either computer-assisted interviewing (with a laptop) or pen and paper interviewing (paper questionnaire). Persons aged 18 years or more were interviewed personally, with the exception of persons who were too sick or otherwise unable to respond personally. Persons aged 15–17 years were interviewed (with consent from a parent or guardian) or their information was obtained from a parent or guardian. Information about children under 15 years of age was provided by a responsible adult. A nominated household spokesperson was interviewed about household-level information.

While some information (for example, long-term conditions) was collected about Indigenous people of all ages, other data were only collected for relevant subpopulations, for example, self-assessed health for Indigenous people aged 15 years or over, and smoking and alcohol consumption for Indigenous people aged 18 years or over.

Data content

Information was collected about:

- health status, including long-term medical conditions and recent injuries
- use of health services such as consultations with health practitioners and visits to hospitals, health insurance (non-remote only), financial stress and other health related actions
- health-related aspects of lifestyle, such as smoking, diet, exercise (non-remote only), substance use (non-remote only), alcohol consumption and financial stress

- demographic and socioeconomic characteristics.

Data content related to eye health

In the 2004–05 survey respondents provided the following information with regards to eye health:

- long term eye and sight problems (including cataract, glaucoma, astigmatism, macular degeneration, presbyopia, short sightedness, long sightedness, blindness and other disorders, disturbances or diseases of the eye and adnexa)
- whether conditions were correctable by glasses or contact lenses
- whether they wear glasses or contact lenses
- whether eye/sight problem(s) were due to diabetes/high sugar level
- time since last consulted eye specialist or optometrist for diabetes-related eye condition
- time since last consulted eye specialist or optometrist for any eye/sight condition
- recent injuries to the eye (including type of injury, activity at time of injury, location of injury event and hospital/medical attendance).

Eye health-related data are self-reported.

Indigenous identification

Respondents are identified as being of Aboriginal, Torres Strait Islander or both Aboriginal and Torres Strait Islander origin.

Socioeconomic identification

The 2004–05 NATSIHS contains a range of socioeconomic indicators for persons and households.

Scope/target population

The NATSIHS 2004–05 was conducted on a sample of 10,439 Indigenous Australians (or about 1 in 45 of the total Indigenous population). The sample covered usual residents of private dwellings only.

Geographical coverage

Remote and non-remote areas of Australia.

Time period covered

The NATSIHS is to be repeated on a six yearly cycle. Previous surveys have been conducted for 1995, 2001 and 2004–05. In 2004–05 the NATSIHS was conducted over an eleven month period so that seasonal variations were captured. 1995 and 2001 data were collected as Indigenous components of the National Health Survey.

Publications and other outputs

- ABS (Australian Bureau of Statistics (ABS) 2006. National Aboriginal and Torres Strait Islander health survey 2004–05. Cat. no. 4715.0. Canberra: ABS.
- ABS 2006. National Aboriginal and Torres Strait Islander health survey 2004–05: users' guide. Cat. no. 4715.0.55.004. Canberra: ABS.
- ABS 2006. National Aboriginal and Torres Strait Islander health survey, 2004–05, expanded confidentialised unit record file. Cat. no. 4715.0.55.001. Canberra: ABS.
- ABS 2006. National Aboriginal and Torres Strait Islander health survey, 2004–05, expanded confidentialised unit record file, technical manual. Cat. no. 4715.0.55.002. Canberra: ABS.
- ABS 2006. National health survey and National Aboriginal and Torres Strait Islander health survey, 2004–05: data reference package. Cat. no. 4363.0.55.002. Canberra: ABS.

Access

For users who wish to undertake more detailed analysis of the survey data, microdata from the 2004–05 NATSIHS are available in the form of an expanded confidentialised unit record file (CURF), National Aboriginal and Torres Strait Islander Health Survey, 2004–05, Expanded Confidentialised Unit Record File (cat. no. 4715.0.55.001). The expanded CURF is available via the ABS Remote Access Data Laboratory, which is a secure Internet-based data query service.

Data management agency

Australian Bureau of Statistics

PO Box 10

Belconnen ACT 2612

<www.abs.gov.au>

client.services@abs.gov.au

National Cancer Statistics Clearing House

Description of data source

The National Cancer Statistics Clearing House (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 the compilation of statistics on cancer types by sex, age group and other variables.

Purpose(s)

The aim of the NCSCH is to foster the development and dissemination of national cancer statistics for Australia and specifically to:

- enable computation and publication of national statistics on cancer
- allow tracking of interstate movement of cancer cases via record linkage
- facilitate exchange of scientific and technical information between cancer registries and promote standardisation in the collection and classification of cancer data
- facilitate cancer research both nationally and internationally.

Collection methodology

It is a legal requirement for doctors to report new cases of cancer to state and territory cancer registries, who supply the data annually to the AIHW.

Data content

The main variables collected are names, sex, date of birth, date of diagnosis, basis of diagnosis, SLA at time of diagnosis, site of cancer and cell type.

Data content related to eye health

Case information about people diagnosed with cancer of the eye and adnexa.

Eye health-related data are medically verified.

Indigenous identification

Indigenous status is collected, however ascertainment is only satisfactory for Western Australia, Northern Territory and Queensland.

Socioeconomic identification

No.

Scope/target population

All residents of Australia.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 1982 to present (ongoing collection).

Publications and other outputs

The NCSCH produces reports of national incidence and mortality data. Periodically, analyses are undertaken of specific cancer sites, cancer histology, differentials in cancer rates by country of birth, geographical variation, trends over time and survival. The most recent publications are:

- AIHW 2005. Cancer incidence projections Australia 2002 to 2011. AIHW Cat. no. CAN 25. Canberra: AIHW.
- AIHW 2004. Cancer in Australia 2001. AIHW Cat no. CAN 23. Canberra: AIHW.

The cancer interactive data cubes include the number of new cases and age-specific rates for all registrable cancers by year of diagnosis, sex and 5-year age groups: <<http://www.aihw.gov.au/cancer/datacubes/index.cfm>> (viewed 22 March 2007).

Access

The NCSCH can make available a broad range of statistical data to researchers after a strict scientific and ethical review process. Research database linkage with the NCSCH requires approvals from the AIHW Ethics Committee and all the state and territory cancer registries, including their ethics committees.

Data management agency

Australian Institute of Health and Welfare (commissioned by Australasian Association of Cancer Registries)

GPO Box 570

Canberra ACT 2601

<www.aihw.gov.au>

(02) 6244 1000

info@aihw.gov.au

National Data Set for Compensation-based Statistics

Description of data source

The National Data Set for Compensation-based Statistics is a national data set which provides details of accepted, pending and rejected workers' compensation claims.

Purpose(s)

The purpose of the data set is to provide uniform, comparable national workers' compensation data.

Collection methodology

Data are collected by jurisdictions on an ongoing basis, extracted annually and sent to the Office of the Australian Safety and Compensation Council.

Before 1 July 2006, only records on accepted workers' compensation claims were collected.

Data content

As of 1 July 2006, the following information is collected: record identifier; claim process details; claimant details; occurrence details; outcome of occurrence; compensation payments; payments for goods and services; non-compensation payments; premiums and remuneration; scheme assets and liabilities; scheme cost and disbursements; dispute and legal costs.

Data content related to eye health

Details of accepted, pending and rejected workers' compensation claims for injuries or diseases affecting the eye.

Eye health-related data are medically verified.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

All new accepted, pending and rejected workers' compensation claims made by or for an employee and which involved a death, a permanent incapacity, or a temporary incapacity for which payments were made. It includes injuries and disease claims. It does not represent self-employed workers or employees of the defence forces.

Geographical coverage

Australia and New Zealand.

Time period covered

Since 1991 to present (ongoing collection).

Publications and other outputs

- Workplace Relations Ministers Council (various dates). Comparative performance monitoring reports. Viewed 22 March 2007, <<http://www.workplace.gov.au/cpm>>.
- Australian Safety and Compensation Council (various dates) Compendiums of workers' compensation statistics Australia. Viewed 22 March 2007, <<http://www.ascc.gov.au/ascc/AboutUs/Publications/StatReports/>>.

Access

External access is available at <www.ascc.gov.au> through the National Occupational Health and Safety Commission Online Statistics Interactive.

Data management agency

Office of the Australian Safety and Compensation Council

Data and Analysis Section

Department of Employment and Workplace Relations

GPO Box 9879

Canberra ACT 2601

<www.ascc.gov.au>

(02) 6121 9115

National Elective Surgery Waiting Times Data Collection

Description of data source

The National Elective Surgery Waiting Times Data Collection (NESWTDC) is a collection of electronic confidentialised summary records for patients on elective surgery waiting lists and patients removed from waiting lists (for admission or another reason) in Australian public acute hospitals.

Purpose(s)

The NESWTDC is used to provide national information about the experience of patients on public hospital elective surgery waiting lists.

Collection methodology

Data are collected at each applicable hospital from patient administrative systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (for example, monthly). State/territory health authorities forward these data to the AIHW annually.

Data content

The NESWTDC collects the following information about each elective surgery listing: listing date, removal date, waiting time at removal from elective surgery waiting list, indicator procedure, specialty of surgeon, clinical urgency, reason for removal from elective surgery waiting list, overdue patient, extended wait patient.

Data content related to eye health

Elective surgery waiting time statistics where the indicator procedure is elected as 'cataract extraction' or the surgeon's specialty is 'ophthalmology'.

Eye health-related data are medically verified.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

The NESWTDC covers people added to elective surgery waiting lists in public acute hospitals only. However, some public patients treated under contract in private hospitals are included.

Geographical coverage

All states and territories, Australia, serviced by public acute hospitals.

Time period covered

Since 1995–96 to present (ongoing collection).

Publications and other outputs

For a full list of elective surgery publications produced by the AIHW visit:
<http://www.aihw.gov.au/hospitals/waitingtime_data.cfm>, (viewed 22 March 2007).

Access

The AIHW provides extracts of data from the NESWTDC on request. A charge may apply depending on the requirements and the complexity of the analysis undertaken. To utilise this data consultancy, email: hospitaldata@aihw.gov.au.

Data management agency

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

<www.aihw.gov.au>

(02) 6244 1000

info@aihw.gov.au

National Health Survey

Description of data source

The National Health Survey (NHS) is a triennial health survey which collects information about the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle.

Purpose(s)

The survey is designed to obtain national benchmarks on a wide range of health issues, and to enable changes in health to be monitored over time.

Collection methodology

Trained ABS interviewers conduct personal interviews with selected residents in sampled private dwellings. Persons included may vary from survey to survey: in the 2004–05 survey, one person aged 18 years and over in each dwelling was selected and interviewed about their health characteristics. Information was also collected about one child aged less than 18 years in sampled households; selected children aged 15–17 may have answered for themselves with parental consent; otherwise an adult, nominated by the household, was interviewed on behalf of the selected child.

Data content

The information collected in the NHS may vary from survey to survey. Information was collected in the 2004–05 survey about:

- the health status of the population, including long-term medical conditions experienced and recent injuries
- health-related aspects of people's lifestyles, such as smoking, diet, exercise and alcohol consumption
- use of health services such as consultations with health practitioners, visits to hospital, days away from work, health insurance (non-remote only) and other actions people have recently taken for their health
- demographic and socioeconomic characteristics.

Data content related to eye health

In the 2004–05 survey respondents were specifically asked about:

- long-term eye and sight problems (including cataract, glaucoma, astigmatism, macular degeneration, presbyopia, short sightedness, long sightedness, blindness and other disorders, disturbances or diseases of the eye and adnexa)
- whether conditions are correctable by glasses or contact lenses
- whether they wear glasses or contact lenses
- whether eye/sight problem(s) was due to diabetes/high sugar level
- time since last consulted eye specialist or optometrist for diabetes-related eye condition

- time since last consulted eye specialist or optometrist for any eye/sight condition
- recent injuries to the eye (including type of injury, activity at time of injury, location of injury event and hospital/medical attendance).

Eye health-related data are self-reported.

Indigenous identification

No, data are unable to be disaggregated by Indigenous identification. A National Aboriginal and Torres Strait Islander Health Survey was conducted at the same time as the 2004–05 NHS.

Socioeconomic identification

The 2004–05 NHS contains a range of socioeconomic indicators for persons and households.

Scope/target population

The NHS 2004–05 was conducted on a sample of 25,906 people in urban and rural areas in all states and territories; very remote areas were excluded.

The sample is designed to be representative of the population living in private dwellings other than those in very remote areas.

Geographical coverage

For the 2004–05 NHS, both urban and rural areas in all states and territories were included, but very remote areas of Australia were excluded.

Time period covered

The NHS is performed periodically: 1977–78, 1983, 1989–90, 1995, 2001, 2004–05. In 2004–05 the NHS was conducted over a ten month period so that seasonal variations were captured.

Publications and other outputs

National Health Survey 2004–05:

- ABS 2006. 2004–05 National health survey: summary of result. ABS cat. no. 4364.0. Canberra: ABS.
- ABS 2006. National health survey 2004–05: users' guide. ABS cat. no. 4363.0.55.001. Canberra: ABS.
- ABS 2006. 2004–05 National health survey: summary of results: state tables. ABS cat. no. 4362.0. Canberra: ABS.

Other topic-specific publications and snapshot articles may be produced and released through the ABS website.

Access

For users who wish to undertake more detailed analysis of the survey data, two CURFs are available. A Basic CURF is available on CD-ROM, while an expanded CURF (containing more detailed information than the basic CURF) is accessible through the ABS Remote Access Data Laboratory (RADL) system.

Data management agency

Australian Bureau of Statistics

Locked Bag 10

Belconnen ACT 2616

<www.abs.gov.au>

client.services@abs.gov.au

National Hospital Morbidity Database

Description of data source

The National Hospital Morbidity Database (NHMD) is a collection of electronic confidentialised summary records for patients admitted in public and private hospitals in Australia.

Purpose(s)

The purpose of the NHMD is to provide information about care provided to admitted patients in Australian hospitals.

Collection methodology

Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (for example, monthly). State/territory health authorities forward these data to the AIHW annually.

Data content

The information collected falls into the following categories:

- Establishment data (state/territory of the hospital; sector; rural; remote and metropolitan areas; accessibility/remoteness index of Australia; remoteness area)
- demographic (sex; date of birth, age at admission, country of birth; Indigenous status; state and local area of residence; remoteness area of residence)
- administrative variables (funding source; mode of admission; mode of separation; patient election status; urgency of admission)
- length of stay data (admission and separation dates; leave days; number of patient days; intended length of stay; same day flag)
- clinical variables (care type; principal diagnosis; additional diagnoses; morphology of neoplasm; procedures; external cause of injury or poisoning; place of occurrence of external cause; activity when injured; diagnosis-related group; major diagnostic category).

Data content related to eye health

Hospital separations with diagnoses for diseases and disorders of the eye, and procedures performed on the eye, in Australian hospitals.

Eye health-related data are medically verified.

Indigenous identification

Indigenous identification is based on the ABS standard for Indigenous status.

Socioeconomic identification

SEIFA based on provided SLA of individual.

Scope/target population

Episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and in Australia's off-shore territories may also be included. Hospitals specialising in dental, ophthalmic aids and other specialised acute medical or surgical care are included.

Geographical coverage

Data are collected for almost all public and private hospitals for all states and territories of Australia.

Time period covered

Since 1993–94 to present (ongoing collection).

Publications and other outputs

- Australian hospital statistics has been published annually since 1995–96. To see a full list of publications visit:
<http://www.aihw.gov.au/hospitals/nhm_database.cfm> (viewed 22 March 2007).
- Interactive data cubes are available on the AIHW's website at:
<<http://www.aihw.gov.au/hospitals/datacubes/index.cfm>> (viewed 22 March 2007).
- Data sourced from the NHMD contributes to many publications, reports and articles, both within the AIHW and by external researchers.

Access

The AIHW provides extracts of data from the NHMD on request. A charge may apply depending on the requirements and the complexity of the analysis undertaken. To utilise this data consultancy, email: hospitaldata@aihw.gov.au.

Data management agency

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

(02) 6244 1000

<www.aihw.gov.au>

info@aihw.gov.au

National Mortality Database

Description of data source

The National Mortality Database contains cause-of-death information for all deaths in Australia registered in Australia from 1965 onwards.

Death registration has been compulsory in all states and territories since the mid-1850s and this information is registered with the respective Registrars of Births, Deaths and Marriages.

Purpose(s)

To monitor the cause of all deaths in Australia and to hold a minimum of the last 10 years of mortality data.

Collection methodology

Information about a death is recorded on the Death Certificate and the Death Information Form. Information is provided to the AIHW by the Registrars of Births, Deaths and Marriages in each state and territory and coded nationally by the ABS.

Additional demographic and administrative information is collected by funeral directors, usually through the next of kin, or a person known to the deceased.

Data content

The collection includes data elements such as date of death, date of birth, underlying cause of death, multiple causes of death (1997 onwards), place of death by state and local government area and Indigenous status (for later years).

Data content related to eye health

Cases where a cause of death is associated with infections, cancers, disorders or injury of the eye.

Eye health-related data are medically verified.

Indigenous identification

Based on the ABS standard for Indigenous identification. The quality of Indigenous identification is not reliable for all states and territories.

Socioeconomic identification

SEIFA based on provided SLA of deceased.

Scope/target population

All deaths occurring in Australia. Deaths of Australians occurring overseas are not within scope of the collection.

Geographical coverage

All states and territories, Australia.

Time period covered

Since 1964 to present (ongoing collection).

Publications and other outputs

- AIHW 2006. Mortality over the twentieth century in Australia. Cat. no. PHE 73. Canberra: AIHW.
- Dunn C, Sadkowsky K & Jelfs P 2002. Trends in deaths: analysis of Australian data 1987–1998 with updates to 2000. Cat. no. PHE 40. Canberra: AIHW.
- AIHW (various dates). General record of incidence of mortality (GRIM) books. Viewed 22 March 2007, <www.aihw.gov.au/mortality/data/grim_books.cfm>.
- Data available as consultancy, email: mortality_info@aihw.gov.au.

Access

Summary-level data are available publicly in the AIHW General Record of Incidence of Mortality: Interactive Excel workbooks (GRIM Books), online at: <www.aihw.gov.au/mortality/data/grim_books.cfm>.

Data management agency

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

<www.aihw.gov.au>

(02) 6244 1000

info@aihw.gov.au

Optometrists Association Australia Optometrists Database

Description of data source

The Optometrists Association Australia Optometrists Database (OAAOD) includes both members and non-members of the Optometrists Association Australia and is continually updated with information received from registration boards, state divisions of the association and optometrists. The database is able to be manipulated to eliminate duplications, accounting for optometrists who are registered in more than one state, and to determine how many optometrists registered in Australia are in clinical practice.

Purpose(s)

The purpose of the OAAOD is to provide information about the workforce of the optometric sector.

Collection methodology

Approximately every 2 years, the association mails a survey form to all optometrists registered in Australia to correct errors and omissions in the database.

Data content

The most recent survey collected information on age, gender, practice addresses, hours spent practising optometry, states where registered, employment type (clinical practice/academia/research etc.) and employment status (employee, sole owner or partner).

Data content related to eye health

Statistics on the optometric labour force.

Indigenous identification

Not applicable.

Socioeconomic identification

Not applicable.

Scope/target population

Optometrists registered to practice in Australia.

Geographical coverage

All states and territories, Australia.

Time period covered

Studies have been conducted in 1988, 1992, 1996 and 2005.

Publications and other outputs

- Horton P, Kiely P & Chakman J 2006. The Australian optometric workforce 2005. *Clinical and Experimental Optometry* 89(4):229–240.
- Kiely P, Horton P & Chakman J 2007. The Australian optometric workforce 2005, analysed by local government areas (in press).

Access

The OAAOD is for the internal purposes of the Optometrists Association Australia and is not for public access.

Data management agency

Optometrists Association Australia

PO Box 185

Carlton South Vic 3053

<www.optometrists.asn.au/home>

(03) 9663 6833

oaanat@optometrists.asn.au

Optometrist registration boards

Description of data source

State/territory optometrist registration boards are established under legislation in their state/territory. In order to practice as an optometrist in a state/territory, an optometrist must comply with the conditions of registration for that particular state/territory. Renewal of registration occurs every financial year.

Purpose(s)

State/territory optometrist registration boards, among many things, have the functions to:

- administer the registration of optometrists
- keep a register of, and records relating to, registrants
- supervise the practice of optometry in a particular state/territory
- monitor standards of optometrical education and training.

Collection methodology

Optometrists wishing to apply for registration to practice optometry in a state/territory must apply through the state/territory's board and comply with the board's conditions of registration. The board verifies the applicant's identity and qualifications and officially registers the applicant. A registered optometrist must renew their registration annually. An optometrist may be registered to practice in more than one state/territory.

Data content

Name, address, phone number, qualifications, employment status.

Data content related to eye health

The number of optometrists registered to practice in each state/territory.

Indigenous identification

Not applicable.

Socioeconomic identification

Not applicable.

Scope/target population

A graduate of an institution accredited by the Council of Optometry Registration Authorities or overseas-registered optometrists who have undertaken a qualifying examination conducted by the Optometry Council of Australia and New Zealand.

Geographical coverage

All states and territories, Australia.

Time period covered

Varies among states/territories.

Publications and other outputs

Not applicable.

Access

Not applicable.

Data management agency

Each registration board has an individual state/territory office.

Outpatient Care Data Collection

Description of data source

The Outpatient Care Data Collection (OCDC) is a collection of electronic aggregate records of the number of services provided in non-admitted non-emergency departments of principal referral and specialist women's and children's hospitals and large hospitals.

Purpose(s)

The OCDC is used to provide national information about the volume of services provided by non-admitted non-emergency departments of principal referral and specialist women's and children's hospitals and large hospitals.

Collection methodology

Data are collected at each applicable hospital from patient administrative systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (for example, monthly). State/territory health authorities forward these data to the AIHW annually.

Data content

The OCDC collects the follow information: organisation identifier, outpatient clinic type, number of group sessions and number of occasions of service.

Data content related to eye health

Outpatient statistics are available where the outpatient clinic service is elected as 'ophthalmology'.

Eye health-related data are medically verified.

Indigenous identification

Not applicable.

Socioeconomic identification

Not applicable.

Scope/target population

The scope includes all arrangements made to deliver specialist care to non-admitted, non-emergency department patients whose treatment has been funded through the hospital, regardless of the source from which the hospital derives these funds.

Geographical coverage

All states and territories, Australia, serviced by principal referral and specialist women's and children's hospitals and large hospitals.

Time period covered

Since 2005–06 to present (ongoing).

Publications and other outputs

The first available year of data is expected for release in the publication Australian hospital statistics 2005–06, due to be released in May 2007 by the AIHW.

Access

The AIHW will be able to provide extracts of data from the OCDC on request. A charge may apply, depending on the extract requirements and the complexity of the analysis undertaken. To utilise this data consultancy, email: hospitaldata@aihw.gov.au.

Data management agency

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

<www.aihw.gov.au>

(02) 6244 1000

info@aihw.gov.au

Pharmaceutical Benefits Scheme data

Description of data source

The Pharmaceutical Benefits Scheme (PBS) is an Australian Government initiative that subsidises around 80% of prescriptions dispensed in Australia through 'community pharmacies'. It does not cover pharmaceuticals delivered to most inpatients in hospitals or delivered through alternative means such as through Aboriginal medical services.

Purpose(s)

Payment system.

Collection methodology

Data are collected on a bill payment basis and patient refund through Medicare Australia.

Data content

The PBS collects the following data:

- dates of prescription, supply and processing
- identifiers for doctors, patients and pharmacists
- basic patient demographic details (date of birth, gender, postcode and patient eligibility)
- pharmacy details
- prescriber details (main specialty)
- drug item number, benefit paid, patient contribution etc.

Data content related to eye health

Data on medicaments used in treating ophthalmological problems. It is also possible to identify other drugs throughout the schedule that may be related to eye health and identify the specialty of the prescribing doctor or optometrist.

Eye health-related data are medically verified.

Indigenous identification

Indigenous people can elect to have their data used for research and statistical purposes. Currently, approximately 160,000 indigenous people have given their consent.

As stated above pharmaceuticals delivered through aboriginal medical services are not included in PBS. These amounted to \$23 million expenditure across all drug types.

Socioeconomic identification

There is the potential to match the postcode to the SEIFA index.

Scope/target population

All Australians, though the difference in subsidy depending on eligibility means that data for health-care card holders is likely to be more complete than for other Australians.

Geographical coverage

All states and territories, Australia.

Time period covered

While the PBS has been in place since 1949, the data are only available in machine readable form from July 1990 (ongoing collection).

Publications and other outputs

- Online statistics related to the PBS at Medicare Australia,
<http://www.medicareaustralia.gov.au/providers/health_statistics/statistical_reporting/pbs.htm> (viewed 22 March 2007).
- Various DoHA publications, for example:
 - Australian statistics on medicines 2003. Viewed 22 March 2007,
<<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/pbs-pubs-asm2003>>
 - PBS publications webpage, which gives access to many papers on this topic. Viewed 22 March 2007,
<<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/PBS+Publications-1>>

Access

Access to the data is controlled by the *National Health Act 1953* (as amended). Data can be requested through the Data and Estimates Unit, Department of Health and Ageing.

Data management agency

Pharmaceutical Benefits Division, Department of Health and Ageing

GPO Box 9848

Canberra ACT 2601

<www.health.gov.au>

(02) 6289 7945

pbsstats@health.gov.au

Royal Australian and New Zealand College of Ophthalmologists ophthalmology workforce database

Description of data source

The ophthalmology workforce database provides statistics on the numbers and distribution of the ophthalmology workforce in Australian and New Zealand, as collected by the Royal Australian and New Zealand College of Ophthalmologists (RANZCO).

Purpose(s)

The database is used for the purposes of planning, continuing professional development, referral and membership services.

Collection methodology

Information is collected from members of RANZCO.

Data content

Name, address, age, gender, qualifications, activities.

Data content related to eye health

Service provision.

Indigenous identification

Not applicable.

Socioeconomic identification

Not applicable.

Scope/target population

Australian and New Zealand ophthalmologists. The database represents 95% of the Australian and New Zealand ophthalmological workforce.

Geographical coverage

Australia and New Zealand (including some overseas members).

Time period covered

Since 2004 to present.

Publications and other outputs

Statistical analysis of the database is published in the membership journal.

Access

Access to the ophthalmology workforce database may be obtained through RANZCO.

Data management agency

RANZCO

94-98 Chalmers St

Surry Hills NSW 2010

<www.ranzco.edu>

(02) 9690 1001

ranzco@ranzco.edu

Survey of Disability, Ageing and Carers

Description of data source

This survey collects information on three population groups: people aged 60 and over, people with disabilities and their carers. There are other sources of information about services provided to these groups, but this survey is the only source of information on the assistance requirements of those groups, the extent to which these requirements are met, and the characteristics of those with unmet need; It also provides information on participation in economic and community activities. The survey is the major source of national statistics on carers and primary carers: numbers and characteristics of carers, care relationships, activities for which informal care is provided, and, for primary carers, support available and required, and the effects of the caring role on their lives.

Purpose(s)

The aims of the survey undertaken in 2003 were to:

- measure the prevalence of disability in Australia
- measure the need for support of older people and those with a disability
- provide a demographic and socioeconomic profile of people with disabilities, older people and carers compared with the general population
- estimate the number of and provide information about people who provide care to older people and people with disabilities.

Collection methodology

Different collection methodologies were used for people in households and people in care accommodation:

- Trained interviewers conducted computer-assisted personal interviews for the household component of the survey. A set of screening questions was asked of a responsible adult in the household to establish whether the household included people with a disability, people aged 60 years or over, or people who were carers. Individuals identified as being in one of these populations were interviewed personally, where possible. Proxy interviews were conducted for children aged less than 15, children aged 15–17 whose parents did not permit them to be personally interviewed, and those whose disability prevented them from having a personal interview.
- The care accommodation component of the survey was collected in two steps using a mail-based methodology sent to directors of selected establishments. First, the name of a contact officer, the current number of occupants and the type of establishment were established in a contact information form. Second, the contact officer selected occupants, based on provided instructions. A separate questionnaire was completed for each selected occupant meeting the coverage requirements. The range of data collected in this component was smaller than in the household component.

Data content

The survey collected the following information:

- People with a disability were asked about their long-term health conditions, need for and receipt of assistance for self-care, mobility, communication, cognition or emotion, health care, housework, property maintenance, meal preparation, paperwork and transport activities; use of aids; and equipment such as wheelchairs and hearing aids, and participation in community activities. They were also asked questions relating to computer and Internet use and participation in community activities. Those aged 5–20 years (or their proxies) were asked about schooling restrictions, and those aged 15–64 years about employment restrictions.
- Older people (i.e. those aged 60 years and over) were asked about their need for and receipt of assistance with housework, home maintenance, meal preparation, paperwork, and transport activities; and participation in community activities. They were also asked questions relating to computer and internet use and participation in community activities.
- People who care for persons with a disability and older people were asked about the type of care they provide, the support available to them, and the characteristics of carers and some effects that the caring role has on their lives. A self-enumeration form was completed by these people during the interview which collected information about their attitudes to, and experience of, their caring role.
- Basic demographic and socioeconomic information was collected for all other people. Most of this information was provided by a responsible adult in the household rather than by each person individually.

Data content related to eye health

Participants provided information about the following issues:

- whether person has loss of sight – no loss; loss of sight corrected by wearing glasses or contact lenses; partial loss of sight not corrected by wearing glasses or contact lenses; total loss of sight
- disability type/main disability/disability that causes most problems – loss of sight
- disability type as a result of head injury – loss of sight
- disability type as a result of stroke – loss of sight
- disability type as a result of other brain damage – loss of sight
- type of long-term condition reported – retinal disorders/defects, glaucoma, sight loss, other diseases of the eye and adnexa
- condition(s) producing main disability (multiple response) – retinal disorders/defects, glaucoma, sight loss, other diseases of the eye and mastoid
- main condition causing loss of sight

- type of difficulty experienced at school or institution because of condition – hearing or sight problems
- Reasons for inability to use some or all forms of public transport – sight problems.

Eye health-related data are medically verified and self-reported.

Indigenous identification

Not included. Detailed data on disability in the Australian Aboriginal and Torres Strait Islander population are contained in the National Aboriginal and Torres Strait Islander Social Survey 2002.

Socioeconomic identification

Data items related to socioeconomic factors: main source of income, cash income amount (personal, family, income unit and household level), cash income decile, receipt of government benefits (such as Disability Support Pension, Carers Allowance or Parenting Payment), labour force participation, education levels achieved.

Scope/target population

The survey included people in both private and non-private dwellings, including people in care accommodation establishments but excluding those in jails and correctional institutions. The sample comprised of 36,241 people in households (both private and non-private) and 5,145 people in cared accommodation. Visitors to private dwellings, certain diplomatic personnel of overseas governments, overseas residents in Australia, and members of non-Australian defence forces stationed in Australia (and their dependants) were also excluded.

Geographical coverage

Covered people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia.

Time period covered

June to November 2003, the next survey is expected to be conducted in 2009.

Publications and other outputs

- ABS 2004. Disability, ageing and carers, Australia: summary of findings 2003. ABS cat. no. 4430.0. Canberra: ABS.
- AIHW 2005. Australia's Welfare 2005. Cat no. AUS 65. Canberra: AIHW.
- AIHW 2006. Australia's Health 2006. Cat no. AUS 73. Canberra: AIHW.
- AIHW 2006. Life expectancy and disability in Australia, 1988 to 2003. Cat. no. DIS 47. Canberra: AIHW.

- AIHS 2006. Disability updates: children with disabilities. AIHW bulletin no. 42. Cat. no. AUS 79. Canberra: AIHW 2006.

Access

All organisations and individuals within organisations who wish to access the CURF are required to read the Responsible Access to ABS CURFs Training Manual and sign an undertaking to abide by the legislative restrictions on use. These documents are available to read or download on the access to ABS CURFs page on the ABS website <www.abs.gov.au>. The Australian Statistician's approval is required for release of the CURF to an organisation and individuals. Use of the data for unauthorised purposes may render the organisation and/or user liable to severe penalties. Advice about the propriety of any particular intended use of the data is available from curf.management@abs.gov.au.

Data management agency

Australian Bureau of Statistics

Locked Bag 10

Belconnen ACT 2616

<www.abs.gov.au>

client.services@abs.gov.au

Treatment Accounts System

Description of data source

The Treatment Accounts System is administered by Medicare Australia on behalf of the Department of Veterans' Affairs (DVA). It is the system which will pay accounts for most medical and hospital services. A major exclusion is public hospital expenditure. It captures all relevant details of the services rendered.

Purpose(s)

Payment of health services for veterans with Treatment Cards, i.e. Gold, White or Orange cards. It is DVA's primary source of health services data.

Collection methodology

Data on services rendered and paid are collected from payment invoices and associated documentation, following accepted health data standards.

Data content

The list of data content is available through metadata and data dictionaries. It covers the full spectrum of data on health services.

Data content related to eye health

In addition to the data gathered through the claims, which use service type, item type and description codes, DVA also records the medical condition in respect of its Disability Pension claims using the ICD-10 codes.

Eye health-related data are medically verified.

Indigenous identification

No.

Socioeconomic identification

It can be linked to DVA's beneficiary population which contains some socioeconomic data (for example, income and assets).

Scope/target population

As covered under the *Veterans' Entitlements Act 1986*, veterans with Treatment Cards, i.e. Gold, White or Orange cards.

Geographical coverage

All states and territories, Australia.

Time period covered

Available from the late 1980s. However, the recent database holds readily accessible information since 2001.

Publications and other outputs

No external publications. However, the data are made available to researchers (for example, the AIHW) for health studies.

Access

Access to the Treatment Accounts System is available, subject to privacy principles and the consent of DVA's Ethics Committee.

Data management agency

Department of Veterans' Affairs

PO Box 21

Woden ACT 2606

<www.dva.gov.au>

Regional data sources

The 45 and Up Study

Description of data source

The 45 and Up Study is a long-term health study in Australia of men and women aged 45 and over. A key feature of the 45 and Up Study is its linkage to a range of established health data sets such as GP services, medication use, procedures and hospitalisations.

Purpose(s)

The primary aim of the 45 and Up Study is to investigate the main factors that determine healthy ageing in the population.

Areas that will be investigated in depth include questions relating to common diseases and health conditions that we may encounter as we grow older, including cancer, cardiovascular disease, obesity, arthritis, diabetes and depression.

Collection methodology

Over 250,000 men and women aged 45 and over will be randomly selected across New South Wales (NSW) and invited to join the 45 and Up Study. They receive an information leaflet and a 45 and Up Study questionnaire for either men or women.

Both men's and women's questionnaires have the same number and type of questions about health, lifestyle and experience. All questions have been carefully selected by leading NSW health professionals and researchers.

Participants are asked to complete the questionnaire as accurately as possible and to sign the accompanying consent form before enclosing it in the provided envelope and returning it. A follow-up questionnaire will then be sent to participants within about 5 year's time to update information about their health and lifestyle. In addition, their health will be followed via linkages to already routinely collected data sources such as records of hospital admissions and medical and surgical procedures, registers of deaths, cancers and infectious diseases, and use of medications and aged care facilities.

Participation in the study is entirely voluntary.

Data content

The 45 and Up Study questionnaire contains demographic, social, health, lifestyle, screening and other variables. Copies of questionnaires are available on the 45 and Up web site at <www.45andup.org.au>. A wide range of other variables is available via data linkage. Biological samples will be collected and relevant data will be stored in Study records. In addition, participating studies will be required to send key data collected or analysed by them to the 45 and Up Study for storage.

Data content related to eye health

The baseline questionnaire gathers information on:

- self-rated eyesight (excellent, very good, good, fair or poor)
- any operations
- serious illnesses
- medication use.

Records are able to be linked to relevant eye-related data on GP services, medication use, procedures and hospitalisations.

Note that, due to the nature of the self-administered questionnaire, it could be more difficult for people with significant vision problems to participate in the 45 and Up Study.

Eye health-related data are medically verified and self-reported.

Indigenous identification

Participants are asked if they are of Aboriginal and/or Torres Strait Islander origin.

Socioeconomic identification

Participants are asked about their address, highest educational qualification achieved, household income and current work status.

Scope/target population

Men and women aged 45 or over, living in New South Wales and on Medicare Australia's records. The eligible population is highly representative of the Australian population aged 45 and over.

Geographical coverage

All of New South Wales.

Time period covered

The recruitment of participants commenced in February 2006 and will continue for a period of at least 5 years.

Publications and other outputs

Papers are to be published in the future by the 45 and Up Study and by participating studies.

Access

There are plans to make certain data available via a website interface. A more complete data set will be available directly from the 45 and Up Study, following appropriate approvals.

Data management agency

The Sax Institute

PO Box 123

Broadway NSW 2007

<www.saxinstitute.org.au>

(02) 9514 5950

director@.saxinstitute.org.au

Association for the Blind of Western Australia Register of Blindness and Vision Impairment

Description of data source

A collection of demographic and diagnostic information relating to vision loss in adults who are referred to the Association's Low Vision Clinic.

Purpose(s)

To collect data on the incidence of blindness and vision impairment in Western Australia.

Collection methodology

Referring specialists provide the diagnostic information. The Association supplements this with data from the initial assessment process.

Data content

Information is collected on basic demographic data, bilateral diagnosis, other medical conditions, visual acuity, visual field, pension eligibility and name of referring specialist.

Data content related to eye health

Bilateral diagnosis, visual acuity, visual fields, associated ocular and medical conditions.

Eye health-related data are medically verified.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

Adults referred to the Association's Low Vision Clinic.

Geographical coverage

Western Australia.

Time period covered

Data have been collected since 1987 and is an ongoing collection. There have been recent changes in the data content.

Publications and other outputs

Yong VK, Morgan WH, Cooper RL, Shaw M, Bremner AP, Bulsara M & Yu D 2006. Trends in registered blindness and its causes over 19 years in Western Australia. *Ophthalmic Epidemiology* 13:35–42.

Access

For access to the data, contact the Association for the Blind of Western Australia Inc.

Data management agency

Association for the Blind of Western Australia Inc.

PO Box 101

Victoria Park WA 6978

<www.guidedogswa.com.au>

(08) 9311 8202

mailbox@abwa.asn.au

Australian Longitudinal Study of Ageing

Description of data source

The Australian Longitudinal Study of Ageing is a population-based bio-psycho-social and behavioural study of older adults. The longitudinal data collected in the course of the study comprise the most comprehensive longitudinal database yet assembled on ageing Australians.

Purpose(s)

The research has a number of specific objectives. These include:

- determination of levels of health and functional status of an older population and to track the changes in these characteristics over time
- identification of factors which promote and maintain health and wellbeing in an ageing population
- identification of risk factors for major morbid conditions and social, behavioural and other problems among an ageing population
- assessment of the effects of disease processes on functional status and the demand for health-care services and both informal and formal long-term care.

Collection methodology

Data from older people residing in South Australia in the community and residential care are collected using a mixture of personal and telephone interviews.

Waves 1 and 3 used comprehensive home interviews, functional assessments and optional mail-back questionnaires. Waves 2, 4 and 5 used short telephone interviews of about 20 minutes duration examining major life events, accommodation changes, health and daily living activities. Data were also gathered during Wave 1 from medical practitioners and service providers (for example, domiciliary care, Meals on Wheels).

Data content

Demographic characteristics, health, formal and informal support systems, chronic conditions, mental health, housing, living arrangements, social activities, lifestyles, labour force participation and economic circumstances, nutrition, psychological wellbeing.

Physical tests measured included anthropometric parameters, blood pressure, visual and auditory acuity, tremor sway, grip strength, respiratory function and dental health. Neuropsychological tests assessed memory, language and speed of information processing.

Laboratory investigations covered basic haematology, 20 channel biochemical analysis, lipid profiles and hormone analysis. Urine samples were tested for calcium, phosphate, sodium and creatinine.

Data content related to eye health

Data are collected about a participant's chronic conditions as well as a measurement of visual acuity taken (both using the Snellen and LogMar charts).

Eye health-related data are medically verified and self-reported.

Indigenous identification

No.

Socioeconomic identification

Information is collected concerning housing, labour force participation, highest level of education achieved and economic circumstances.

Scope/target population

South Australian residents aged 70 years and over at wave 1 of the study.

Geographical coverage

South Australia.

Time period covered

1992 (wave 1) to 2006 (wave 8); further waves of the study are dependent on future funding.

Publications and other outputs

A full list of publications can be found on the Centre for Ageing Studies website (viewed 22 March 2007): <<http://www.cas.flinders.edu.au/alsapub.html>>.

Access

Access to the Australian Longitudinal Study of Ageing can be obtained through the Centre for Ageing Studies.

Data management agency

Centre for Ageing Studies

Flinders University Campus, Mark Oliphant Building

Laffer Drive

Bedford Park SA 5042

<www.cas.flinders.edu.au>

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Blue Mountains Eye Study

Description of data source

The Blue Mountains Eye Study was a large population-based assessment of visual impairment and common eye diseases of a representative older Australian community sample.

Purpose(s)

To determine the prevalence of eye disease in older Australians.

Collection methodology

In late 1992 the target population was identified by a door-to-door census of all dwellings in the two postcode areas. A total of 3,654 residents, aged 49–97, were examined during the period 1992–1994 (an overall response of 82.4% of non-institutionalised residents).

During 1997–1999, all surviving participants were invited to attend a 5-year follow up examination, for which 2,334 persons returned (75% of survivors).

A second census of the same postcode areas was conducted in 1999, identifying a further 1,510 residents now eligible to participate of which 1,206 were examined as part of an extension study during 1999–2000.

In 2002, participants were invited to return for 10-year follow-up exams, and during 2002–2004 1,952 original participants were re-examined.

Data content

Data collected included medical history (self-reported), socio-economic status, food frequency questionnaire, quality of life, eye examination, hearing examination, smell test (for wave three only).

Data content related to eye health

The prevalence of eye disease in older Australians.

Eye health-related data are medically verified.

Indigenous identification

Information not provided.

Socioeconomic identification

Data was collected on marital status, income source and housing.

Scope/target population

All residents aged 49 years or older at baseline.

Geographical coverage

The project was conducted in an area that included Katoomba, Leura, Medlow Bath (postcode 2780) and Wentworth Falls (postcode 2782), NSW.

Time period covered

The first wave of the study, with the initial recruitment of participants, was conducted over 1992–1994. Wave two was conducted over 1997–1999 and wave three over 2002–2004. A 15-year follow-up is currently being conducted over 2007–2008.

Publications and other outputs

- In excess of 250 peer-reviewed papers have been published to date, and abstracts regularly presented at conferences.
- Data from the Melbourne Visual Impairment Project and the Blue Mountains Eye Study have been combined and extrapolated to the entire Australian population. Results of this study were presented in the paper, Taylor HR, Keeffe JE, Vu HTV, Wang JJ, Rochtchina E, Pezzullo ML & Mitchell P 2005. Vision loss in Australia. Medical Journal of Australia. 182:565–568.

Access

Information not provided.

Data management agency

Centre for Vision Research

Department of Ophthalmology, University of Sydney

Westmead Millennium Institute

Westmead NSW 2145

<www.cvr.org.au>

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paul_mitchell@wmi.usyd.edu.au

Cataract Surgery and Age-related Macular Degeneration Study

Description of data source

The Cataract Surgery and Age-related Macular Degeneration Study is a longitudinal follow up study.

Purpose(s)

The purpose of the study is to determine whether the risk of age-related macular degeneration increases following cataract surgery.

Collection methodology

Patients are examined pre-operatively and then re-examined at specified intervals post-operatively to determine whether the risk of age-related macular degeneration increases following cataract surgery.

Data content

Information is collected on medical history and quality of life data. An eye examination is conducted, including retinal photographs to document the state of the macula.

Data content related to eye health

The risk of age-related macular degeneration following cataract surgery.
Eye health-related data are medically verified.

Indigenous identification

Yes, but very small proportion of Indigenous participants.

Socioeconomic identification

No.

Scope/target population

Patients undergoing cataract surgery at a large public hospital (Westmead Hospital) and in private ophthalmologists rooms.

Geographical coverage

West Sydney suburban area.

Time period covered

Recruitment for the study was initiated in 2004; the study is currently on-going.

Publications and other outputs

- The first paper is currently in press.

Access

Access to the data is not yet available as data collection is on-going.

Data management agency

Centre for Vision Research

Department of Ophthalmology, University of Sydney

Westmead Millennium Institute

Westmead NSW 2145

<www.cvr.org.au>

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paul_mitchell@wmi.usyd.edu.au

Central Australia Ocular Health Study data/hospital records/ Regional Eye Health Coordinator records

Description of data source

Data sheets and clinical records summaries.

Purpose(s)

Data is used for coordination purposes and reporting.

Collection methodology

Completed by optometrists and ophthalmologists on bush visits, hospital clinics and town Aboriginal Medical Service clinics.

Data content

Data collected include demographic, diagnosis, referral and follow-up information.

Data content related to eye health

Summary screen of eye assessment parameters.

Eye health-related data are medically verified.

Indigenous identification

Yes.

Socioeconomic identification

No.

Scope/target population

Any patient seen by the Regional Eye Team or Visiting Optometrist.

More than 90% of remote community patients are Indigenous, while 50% of hospital clinic patients are Indigenous.

Geographical coverage

All of Central Australia and the Barkly region.

Time period covered

Since 2001 to present; summary data from 2001 and detailed data sheets from 2004 (ongoing collection).

Publications and other outputs

Some publications have followed specific research projects on central corneal thickness and optic disc appearances. However, there is extreme sensitivity about publishing any data without fully informed consent or ethical committee approval.

Access

Access to the data collected is restricted to clerical and administrative staff only.

Data management agency

NT Department of Health and Community Service/Regional Eye Program

Alice Springs Hospital

(08) 8951 7777

Dubbo Study

Description of data source

The Dubbo Study is a longitudinal community study of people born before 1930 living in the town of Dubbo, NSW.

Purpose(s)

The study has classic epidemiological goals, namely to identify patterns and predictors of mortality, hospitalisation and need for residential care. It is a biomedical and social science investigation of healthy ageing, service use, delay of disability and diseases like cardiovascular diseases and dementia.

Collection methodology

A group of 2,805 residents (1,233 men and 1,572 women) were first interviewed in 1988 and have been followed to the present with continuous 'cold pursuit' of death, hospitalisation and residential care data. There have been one-off collections of community services and other data as part of separately funded projects. From 1987, eligible subjects were identified through a reconciliation of GP and electoral records. They attended a centrally located office for medical and psychosocial assessment. The examinations extended from late August 1988 over a period of 13 months.

Survivors were re-interviewed in 2001 as part of the Asset and Health Dynamics phase of the study. At the end of 2000, there were 1,767 survivors of whom 1,537 remained in Dubbo and 230 lived outside Dubbo. Both groups were re-interviewed and there were 989 full interviews and 314 short interviews completed. Those missed in the follow-up interviews were generally unable to participate in interviews because of dementia and serious health limitations.

Data content

Briefly, the baseline examinations comprised demographic, psychosocial and standard cardiovascular risk assessments.

The medical examination included anthropometry; blood pressure (mean of two readings, phase V diastolic, after 10 minutes' seated rest); resting electrocardiography; peak expiratory flow rate (best of two attempts, measured by a Wright peak flow meter); and 12-hour fasting levels of plasma lipids, lipoproteins and glucose.

A questionnaire explored measures of social support; depression status; education level; cognitive function (Short Portable Mental Status Questionnaire); alcohol and tobacco use; medications; medical history; myocardial infarction and chest pain; physical activity (walking, gardening and sporting activity, coded as daily, weekly or less often); self-rated health; and physical disability.

Data content related to eye health

Participants answered the following questions:

- Do you wear glasses?
- Do you have good sight?
- Do you have poor sight?

Eye health-related data are self-reported.

Indigenous identification

No.

Socioeconomic identification

Participants provided information on education and economic status.

Scope/target population

The eligible study population comprised all non-institutionalised residents of the Dubbo local government area who were born before 1 January 1930 (i.e. those 60+ years) and who attended for baseline assessment.

The study population was broadly representative of the Australian population born before 1930 by gender, age, employment, socioeconomic status, housing tenure, tobacco usage, mean blood pressure and other variables. However, 90% of the study population were Australian-born compared to 73% in NSW.

Geographical coverage

Dubbo, NSW.

Time period covered

1987–1988 to 2001.

Publications and other outputs

A list of publications can be found on the Dubbo Study website (viewed 22 March 2007), <<http://www.dubbostudy.org/dubbostudy.nsf/main/Publications>>.

Access

Access to the Dubbo Study can be requested through the study directors.

Data management agency

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Florey Adelaide Male Ageing Study

Description of data source

The Florey Adelaide Male Ageing Study (FAMAS) is a major study into the health and ageing of Australian men. It is believed to be the first of its kind in Australia to attempt to identify the wide range of factors that contribute to Australian men's health (reproductive, physical and emotional), and their relationship with the ageing process. It is a longitudinal study involving biomedical assessments, self-reported measures and data linkage with established national databases.

Purpose(s)

FAMAS aims to identify the causes of men's poorer physical and mental health in an effort to develop and implement measures to promote a healthy and active lifestyle, prevent diseases and guide the development of appropriate health services and policy.

Collection methodology

Random sampling using the Electronic White Pages (telephone directory) was used to recruit 1,200 men aged 35–80 from Adelaide's north-west suburbs.

Biomedical clinic investigations occur every 5 years, beginning in 2002. Follow-up questionnaires are completed annually. Participants are invited on occasion to participate in substudies with selected collaborators.

Data content

Data collected includes utilisation of health services, including preventive and early intervention services; endocrinology of ageing, especially male sex hormones and the insulin growth factor axis; and prostate health and function in relation to the hormonal changes of ageing.

Chronic medical and psychological conditions such as obesity, cancer, diabetes, cardiovascular disease and mental health are also investigated.

Data content related to eye health

Information collected includes the following:

- vision-based quality-of-life (self-report)
- ophthalmic-based history (includes previous ocular trauma or surgery, topical medication use and ocular symptoms)
- ophthalmic examination (approx. 45 mins) involving
 - visual acuity testing (using a Snellen chart, photographs of eyes and adnexae)
 - slit-lamp examination of the anterior segment and lens, and tonometry
 - fundus photographs (pupils are dilated with tropicamide 1%)
 - automated refraction

- A-scan ocular ultrasound
- keratometry
- pachymetry
- optical coherence tomography.

Eye health-related data are medically verified and self-reported.

Indigenous identification

As per ABS Census 2001.

Socioeconomic identification

As per ABS Census 2001 and other statutory sources.

Scope/target population

Males aged 35–80 years, residing in the northern and western regions of Adelaide.

Participants' data were compared with the 2001 Australian Census in order to assess, where possible, the representativeness of the cohort with the local and national populations. Overall, FAMAS participants were comparable to men in the same age group from the north-west Adelaide and Australian regions. The men in our cohort were found to be under-represented in the younger age group and over-represented in the older bracket, a common finding in studies of this type. In addition, there was an under-representation of men who had never married, reflecting previous findings that men without live-in support systems tend not to participate in health studies. The FAMAS cohort displayed both a higher proportion of men with some form of post-school qualification (specifically, trade and tertiary qualifications) as well as men from the lowest income bracket, both previously demonstrated as predictors of study involvement.

Geographical coverage

The ABS Northern and Western Statistical Divisions of Adelaide.

Time period covered

Initial investigations began in 2002. Funding dependent, the study will continue for 15–20 years.

Publications and other outputs

Data analysis for the initial cross-sectional data is continuing. A baseline/methodological paper and a cohort description paper have been submitted for the broader FAMAS study. Results from the ophthalmology substudy are due to be published around mid-2007.

Access

Submissions for collaboration are reviewed at FAMAS Investigator meetings as appropriate. A final decision on collaboration is made by the FAMAS Executive Committee.

Data management agency

Data Management and Analysis Centre

A joint data management centre of The University of Adelaide's departments of Public Health and General Practice

<www.dmac.adelaide.edu.au>

(08) 8303 3465

International Centre for Eyecare Education / Aboriginal Health and Medical Research Council/Visioncare NSW Aboriginal project datasheets

Description of data source

International Centre for Eyecare Education (ICEE)/ Aboriginal Health and Medical Research Council (AHMRC)/Visioncare NSW Aboriginal project data sheets comprise the data collected from the project to deliver culturally appropriate eye-care services to Aboriginal people through Aboriginal controlled communities.

Purpose(s)

For Aboriginal Medical Services internal utilisation and ICEE/AHMRC/Aboriginal Medical Services planning activities.

Collection methodology

Eye health coordinators complete standard forms.

Data content

Demographical data, eye conditions, and spectacle wear history.

Data content related to eye health

Records incidence of diabetic retinopathy, glaucoma, cataract, trachoma, spectacles (whether had them before/Visioncare NSW spectacles), referrals to GP, optometrist or ophthalmologist. Self-reported diabetes.

Eye health-related data are medically verified.

Indigenous identification

Clients of the service are Aboriginal only.

Socioeconomic identification

No.

Scope/target population

Aboriginal people presenting at an ICEE/AHMRC Eyecare clinic, approximately 75 locations in New South Wales.

Geographical coverage

New South Wales, where there are ICEE/AHMRC Eyecare clinics.

Time period covered

Since 2000 to present (ongoing collection).

Publications and other outputs

Data are used for internal purposes only (e.g. planning). Data may be used on occasion in media reports (e.g. numbers seen).

Access

Access to the data is restricted.

Data management agency

International Centre for Eyecare Education

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University of New South Wales NSW 2052

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(02) 9385 7435

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Katherine Region Diabetic Retinopathy Study

Description of data source

The Katherine Region Diabetic Retinopathy Study was carried out in the lower top end of the Northern Territory between 1993 and 1996 as part of the Northern Territory Eye Health Program. It investigated diabetic eye conditions and its determinants in the Aboriginal Australian population of the region.

Purpose(s)

The study's primary objectives were to:

- describe diabetic eye disorders in Aboriginal people living in the Katherine region by documenting the prevalence and incidence of diabetic eye disease in the known diabetic population of the region and monitoring the progression of diabetic retinopathy
- describe the visual acuity in the known diabetic population of the Katherine region and describe the effect of various ocular pathologies (both diabetic and non-diabetic eye disorders) on vision
- address the issue of service delivery in the Katherine region of the Northern Territory.

Collection methodology

The study population consisted of all known Aboriginal diabetic patients who were residents at the time of community visits in Katherine region. An initial study was performed by the Mobile Eye Unit in 1993 and then followed up in 1996.

Data content

- Personal section: data on the personal section were of primary importance in identifying the Aboriginal patients. This could only be done by filling in of all the information requested in the personal section. Name, date of birth, sex, community seen in, community patient lived in, date of examination, Medicare number and ethnicity were recorded.
- Medical history section: the medical records of the patients and all relevant past eye history and past medical history were recorded and reviewed. The diabetic medications actually taken by the patient, not necessarily those prescribed, were recorded. The presence of hypertension was also recorded.
- Ophthalmological examination:
 - visual acuity
 - intraocular pressure
 - anterior segment and posterior segment examinations.
- Collection of biochemical data.

Data content related to eye health

Diabetic eye conditions and its determinants.

Eye health-related data are medically verified.

Indigenous identification

The study population was limited to Aboriginal peoples. Aboriginal identification was accepted on the basis of the patient viewing him/herself as such.

Socioeconomic identification

No.

Scope/target population

The study population consisted of all known Aboriginal diabetic patients who were residents at the time of community visits in Katherine region.

Geographical coverage

Katherine region, Northern Territory.

Time period covered

Strictly, the data collection was covered between 1993 and 1996. For cultural reasons, the denominator data could not be compiled until 2001.

Publications and other outputs

- Jaross N, Ryan P & Newland H 2003. Prevalence of diabetic retinopathy in an Aboriginal Australian population: results from the Katherine Region Diabetic Retinopathy Study (KRDRS). Report no. 1. Clinical Experiment Ophthalmology 31(1):32-39.
- Jaross N, Ryan P & Newland H 2005. Progression of diabetic retinopathy in an Aboriginal Australian population: results from the Katherine Region Diabetic Retinopathy Study (KRDRS). Report no. 2. Clinical Experiment Ophthalmology 33(1):26-33.

Access

Not applicable.

Data management Agency

Not applicable.

Melbourne Longitudinal Studies on Healthy Ageing program

Description of data source

The Melbourne Longitudinal Studies in Healthy Ageing (MELSHA) program was conducted initially by La Trobe University in partnership with The University of Sydney. Monash University now houses the study in collaboration with the University of Sydney. It was a series of three linked studies that formed a large longitudinal study on healthy ageing.

Purpose(s)

The three studies that form the program are:

- Study 1: the aim of this baseline study was to investigate the health, health behaviours and service use of a representative group of older people living in Melbourne.
- Study 2: this study was a follow-up of the Study 1 sample and focused on biannual health behaviour change and continued annual measurements of functional ageing, health, and service outcomes.
- Study 3: this study continued the follow-up of the Study 1 sample and aimed to provide a comprehensive knowledge base on ways in which functional ageing, medical conditions, and health behaviours influence the health, wellbeing, and service use and survival of older people. It will be used to describe annual changes in these outcomes areas and test hypotheses that explain improvement or deterioration in multiple aspects of ageing. The large sample and long duration will identify rare outcomes and gender, socioeconomic, and other sources of variability.

Collection methodology

Data collected for Study 1 form the baseline for the MELSHA program. Data collection involved a face-to-face interview (with a proxy if necessary) to gather data on health, health behaviours and service use; a self-completed questionnaire covered attitudes and life histories; a clinical examination measured variables such as weight, height, eyesight and hearing; a brief mail-out questionnaire (with a phone call or visit, where necessary) to collect change and limited outcome variables and CATI to collect follow-up data on core variables.

Study 2 focused on biannual health behaviour changes and continued annual measurements of functional ageing, health, and service outcomes including follow-up, where necessary, through home visits, proxies, and/or death registry checks. It also included CATI and a brief mail-out questionnaire.

Study 3 continued the follow-up of the original Study 1 sample.

Data content

Medical conditions including continence, musculoskeletal and cardiovascular disease, falls and injuries, confusion, pain, medication use, depression and mental

health, health behaviours (nutrition, exercise, social activity), wellbeing and service use (health services, community services, and residential care), functional ageing, health and service outcomes.

Data content related to eye health

The program collected the following information: cataracts, glaucoma, self-reported eyesight, eyesight check by optometrist, as well as visual acuity as measured by a Snellen chart.

Eye health-related data are medically verified and self-reported.

Indigenous identification

There were no Indigenous participants in the program.

Socioeconomic identification

A full range of socioeconomic participants were involved in the program.

Scope/target population

Participants aged 65 and over (average age 73) living in Melbourne.

Geographical coverage

Melbourne, Victoria.

Time period covered

Study 1 occurred 1994–1997, Study 2 occurred 1998–2000, and Study 3 occurred 2003–2005.

Publications and other outputs

- Journal articles, including:
 - Marino R, Browning C & Kendig H (2007). Factors associated with self-reported use of oral health services among older Melbournians. *Australasian Journal on Ageing*. (in press).
 - Browning CJ, Kendig H, Thomas SA & Yang H 2006. Healthy ageing in Australia: policy responses and research opportunities. *Chinese General Practice* 19:1575–1578.
 - Yang H, Browning C & Thomas S 2006. Healthy, active and productive ageing: strategic themes for policy and community services in Australia. *Chinese General Practice* 19:1571–1575.
- Books, book chapters and research reports, including:
 - Quine S & Browning C (in press). Methodological and ethical issues in conducting research with older people. In M. Pitts & A. Smith (Eds.), *Research in marginalised populations*. Palgrave Macmillan: Basingstoke, Hampshire UK.

Access

Access is currently restricted to investigators only. Data will be archived for restricted access in the future.

Data management agency

Prof. Colette Browning

Health Ageing Research Unit

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Melbourne Visual Impairment Project

Description of data source

The Melbourne Visual Impairment Project was a population-based study of urban, rural and institutionalised residents of Victoria aged 40 years or older.

Purpose(s)

To determine the prevalence study of eye disease.

Collection methodology

Participants completed a standardised questionnaire covering sociodemographic characteristics, symptoms of eye disease, medical history and medication use. They were also invited to a local examination centre for a standard ophthalmic examination. Home visits were conducted for participants unable to attend the local examination centre.

Data content

The examination included presenting visual acuity (which is measured with participant's spectacles, if usually worn for distance viewing), visual field, intraocular pressure, slit-lamp examination, dilated ophthalmoscopy and photography of the lens and fundus. Best-corrected visual acuity was measured for those with vision less than 6/6, using a standardised refraction.

Data content related to eye health

The prevalence of eye disease.

Eye health-related data are medically verified.

Indigenous identification

No.

Socioeconomic identification

No.

Scope/target population

Participants (4,744) were recruited from randomly selected pairs of adjacent census collector districts – nine in urban Melbourne and four in rural communities in Victoria who had lived in their homes for at least 6 months and were aged 40 years and older. A further 403 participants were recruited from 12 nursing homes and 2 hostels randomly selected from 104 nursing homes and hostels located within a 5 km radius of the nine selected urban pairs of census districts.

Geographical coverage

Urban and rural Victoria.

Time period covered

The urban study was carried out from 1992 to 1994, the nursing home and hostel study in 1995, and the rural study in 1996.

Publications and other outputs

Data collected from the Melbourne Visual Impairment Project have been published in many papers.

Data from the Melbourne Visual Impairment Project and the Blue Mountains Eye Study have been combined and extrapolated to the entire Australian population. Results of this study were presented in the paper, Taylor H R Keefe J E Vu H T V Wang J J Rochtchina E Pezzullo M L & Mitchell P 2005. Vision loss in Australia. Medical Journal of Australia. 182:565-568.

Access

Access to the Melbourne Visual Impairment Project can be obtained through the Centre for Eye Research Australia.

Data management agency

Centre for Eye Research Australia

Department of Ophthalmology

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Locked Bag 8

East Melbourne Vic 8002

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New South Wales Population Health Survey

Description of data source

The New South Wales Population Health Survey is an ongoing telephone survey of state residents that is one of the main mechanisms through which NSW Health monitors population health and reports on performance indicators.

Purpose(s)

The New South Wales Population Health Survey objectives are to:

- monitor changes over time in self-reported health behaviours, health status, health service use, satisfaction with health services, and other factors that influence health
- support the planning, implementation, and evaluation of health services
- collect health information that is not available from other sources
- respond quickly to emerging needs for health information
- promote research.

Collection methodology

The New South Wales Population Health Survey is conducted continuously between February and December each year and covers the whole state population from birth upwards.

Households are contacted using list-assisted random digit dialling. One person from the household is randomly selected for inclusion in the survey. Carers or parents of children aged 0–15 years are interviewed on their behalf.

Trained telephone interviewers carry out the interviews. Most interviews are conducted in English but the survey is also conducted in five other languages: Arabic, Chinese, Greek, Italian and Vietnamese.

The sample is weighted to adjust for differences in the probabilities of selection among subjects, and for differences between the age and sex structure of the sample and ABS mid-year population estimates for NSW. This enables calculation of prevalence estimates for the state population rather than for the respondents selected.

Data content

The survey collects information in modules in the areas of alcohol, asthma, cancer screening (breast and cervical), cancer screening (colorectal), community health centres, demographics, diabetes, difficulties getting health care, emergency departments, hearing, hospitals, immunisation, injury (youth violence), injury prevention, mental health, nutrition, oral health, overweight and obesity, physical activity, public dental services, self-rated health, sexual health, smoking, sun protection, and vision.

Data content related to eye health

A vision module asks respondent the following questions:

- When did you last have your eyesight checked? (Less than one year ago/1 year ago to less than 2 years ago/2 years ago to less than 5 years ago/5 or more years ago/Never/Don't know/Refused)
- As far as you know, do you have normal vision in both eyes? (Yes/No/Don't know/Refused)
- Do you currently wear glasses or contact lenses? (Yes/No/Don't know/Refused)
- Are you wearing glasses for reading or close work, distance or both? (Reading/Distance vision/Both/Don't know/Refused)
- Even when wearing glasses or contact lenses, do you have any difficulty reading or doing close work? (Yes/No/Don't know/Refused)

Eye health-related data are self-reported.

Indigenous identification

Indigenous status is collected according to the ABS standard.

Socioeconomic identification

Socioeconomic details are collected, including the highest achieved education level, employment, household income and postcode.

Scope/target population

The target population is all NSW residents living in households with private telephones. The target sample is approximately 1,500 people in each area health service (a total sample of 12,000).

Geographical coverage

New South Wales.

Time period covered

The New South Wales Population Health Survey is a continuous survey which commenced in January 2002 (ongoing collection).

Publications and other outputs

The survey reporting plan includes:

- an annual report on adult health for the whole state
- a monthly report on adult health for the whole state
- an annual report on adult health for each health area
- a biennial report on child health for the whole state
- a triennial report on adult health for each division of general practice

- occasional reports on the health of older people, indigenous people, people from culturally and linguistically diverse backgrounds, and other specific populations.

Survey reports, which contain an analysis of the collected data, can be downloaded from <www.health.nsw.gov.au>.

Access

Survey data sets are available for further analyses. The NSW Department of Health encourages as many people as possible to access these data sets through the Health Outcomes Information Statistical Toolkit (HOIST). For users who do not have access to HOIST, data sets are available through specific requests to the Chief Health Officer. Any publication that reports survey data must be approved by the Chief Health Officer before publication.

Data management agency

New South Wales Health Survey Program

(02) 9424 5759

catiadmin@doh.health.nsw.gov.au

North West Adelaide Health Study

Description of data source

The North West Adelaide Health Study is a representative biomedical population cohort study of approximately 4,000 adults aged 18 years and over in the northern and western regions of Adelaide. It is an ongoing epidemiological research collaboration between the South Australian Department of Health, the University of Adelaide, the University of South Australia, The Queen Elizabeth Hospital and Health Service, the Lyell McEwin Health Service and the Institute of Medical and Veterinary Science.

Purpose(s)

Its primary aim is to improve the regional conditions that help people maintain and promote health. It achieves these goals through the mobilisation of existing and new resources, the formation of new health partnerships, and applied research that monitors and identifies community health activity to improve health outcomes for specific groups.

Collection methodology

Stage 1 of the study established baseline self-reported and biomedically measured information on those who were at risk of these conditions; previously undiagnosed with these conditions; and diagnosed with these conditions.

The longitudinal nature of the study (Stage 2 onwards) allows examination of: incidence of these conditions; changes in patterns of severity, management costs and utilisation of resources; the impact of existing and future guidelines; and the potential for other health researchers to access a database for value-added chronic disease or related research.

Data content

Issues covered in the recruitment questionnaire included various health conditions, mental health, smoking status, reason for not wanting to participate in the study (if applicable), and demographics. The clinic tests conducted included blood pressure measurement, height and weight measurement, waist and hip measurement, blood test (fasting plasma glucose, lipids, glycated haemoglobin), allergy skin test and spirometry breathing test.

Data content related to eye health

Participants are asked: How many times in the last 12 months have you used the health services of an eye specialist/ophthalmologist in South Australia?

Indigenous identification

Yes.

Socioeconomic identification

Education, household income, occupation, pension/benefit, work status.

Scope/target population

Residents, aged 18 years and over, of the northern and western regions of Adelaide.

Geographical coverage

North-west suburbs of Adelaide.

Time period covered

Since 1999 to present (ongoing collection).

Publications and other outputs

Reports available online (viewed 26 March 2007):

<<http://www.nwadelaidhealthstudy.org/results.asp>>.

Access

Access to the North West Adelaide Health Study can be obtained through the Population Research and Outcome Studies Unit.

Data management agency

Population Research and Outcome Studies Unit

Department of Health, Government of South Australia

PO Box 287

11 Hindmarsh Square

Adelaide SA 5000

<www.health.sa.gov.au/pros>

(08) 8226 7042

pros@health.sa.gov.au

Queensland Injury Surveillance Unit database

Description of data source

The Queensland Injury Surveillance Unit (QISU) currently collects data from 16 hospitals in Queensland which comprise three sample regions: metropolitan (Brisbane); regional (Mackay and Moranbah Health Districts) and remote (Mt Isa). These data characterise and measure the frequency of injuries, provide demographic information and detail activity, location and main product or factor involved.

Purpose(s)

QISU's core business is injury data collection, data analysis and data dissemination. QISU supports injury prevention through the provision of injury surveillance data collected from metropolitan, regional and remote areas of Queensland. QISU's data provide a unique database of intentional and unintentional, all age injury presentations. The QISU database provides information to develop and evaluate injury prevention programs at a state level.

Collection methodology

Participating emergency departments provide data either electronically or on standardised forms which are then coded in accordance with the National Data Standard for Injury Surveillance (NDS-IS) and stored on the QISU database.

Data content

Data items include:

- age, sex, postcode
- country of birth, language
- time and date of injury event
- injury text description
- cause of injury (e.g. fall, poisoning)
- intent of incident (unintentional, assault etc.)
- place of injury (e.g. bedroom in boarding house)
- activity (e.g. playing cricket)
- nature of injury and body location or ICD-10 code
- mechanism and major injury factor (e.g. grinder)
- triage category (indication of severity)
- admission status.

Data content related to eye health

Injuries occurring to the eye, coded according to the NDS-IS.

Eye health-related data are medically verified.

Indigenous identification

Indigenous status is collected. However identification of these cases is reliant upon participating hospitals.

Socioeconomic identification

Postcode.

Scope/target population

Patients presenting to participating emergency departments in Queensland with an injury.

Geographical coverage

Areas of Queensland serviced by the participating hospitals.

Time period covered

Since 1998 to present (ongoing collection).

Publications and other outputs

The QISU Injury Bulletin is available on the QISU website (viewed 26 March 2007):
<<http://www.qisu.org.au/modcore/PreviousBulletin/frontend/index.asp>>.

Access

Access to the QISU database can be obtained through QISU.

Data management agency

Queensland Injury Surveillance Unit

Level 2, Mater Children's Hospital,

Raymond Terrace

South Brisbane Qld 4101

<<http://www.qisu.org.au/modcore/HomePage/frontend/index.asp>>

(07) 3840 8569

mail@qisu.org.au

Royal Society for the Blind client database

Description of data source

The Royal Society for the Blind client database is a client collection which holds information about the client and services provided to them.

Purpose(s)

The purpose of the Royal Society for the Blind client database is to collect data on clients of the Royal Society for the Blind. In addition, to monitor staff productivity and service delivery.

Collection methodology

Information is captured and input directly in to the database.

Data content

Demographic details, eye impairments, additional health information, carer details, referrals and services delivered.

Data content related to eye health

Eye impairments, including primary and secondary eye conditions, degree of vision impairment and visual acuity.

Eye health-related data are medically verified.

Indigenous identification

Yes, the standard ABS classification for Indigenous identification is used.

Socioeconomic identification

Postcode and pension details are collected.

Scope/target population

South Australian residents with vision impairment. It has been estimated that the total vision-impaired population of South Australia (SA) to be 0.75% of the total SA population, equating to 11,660 people. The Royal Society for the Blind current active client base is approximately 10,480. Therefore, 90% of the total estimated vision-impaired population is included. These calculations have been figures estimated from various ABS and Royal Australian and New Zealand College of Ophthalmologists reports.

Geographical coverage

South Australia.

Time period covered

Since 1993–94 to present (ongoing collection).

Publications and other outputs

- Royal Society for the Blind strategic planning reports.
- Royal Society for the Blind annual reports.
- Reports to management and board, on topics including key performance indicators, service delivery and staff productivity.
- Benchmarking projects.
- Internal and external research projects.
- Government and Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Access

Permission to access to the Royal Society for the Blind client database must be made through the Royal Society for the Blind management and board.

Data management agency

The Royal Society for the Blind
Knapman House
230 Pirie Street
Adelaide SA 5000
<www.rsb.org.au>
(08) 8232 4777 or (08) 8232 2444

South Australian Health Monitor survey

Description of data source

Health Monitor is telephone survey system that conducts large representative surveys of the South Australian population. It is a survey of 2000 South Australian households that will be conducted three times a year. The Health Monitor supplements the Health Omnibus Survey which is conducted annually. The reason for this is that some health planners need to collect information at other times of the year. World-class epidemiological techniques are applied in the process, including sample selection, interview methodology and data analysis. Health Monitor can be used by health professionals and policy makers for planning and to develop strategies.

Purpose(s)

The goal of the Health Monitor survey is to collect, analyse and interpret data, which can be used to plan, implement and monitor health programs and other initiatives. Health Monitor is a 'user-pays' service. Each organisation pays only for survey questions that have direct relevance to their information requirements. Alternatively, surveys that focus on a specific topic may be commissioned by a sole organisation.

Collection methodology

Health Monitor uses a computer-aided telephone interviewing (CATI) system.

Households to be included in the survey are randomly selected from the Electronic White Pages (telephone directory). Within households, the person who was last to have a birthday (aged 18 years or over) is usually selected to participate in the survey. Selected persons are non-replaceable, hence, if the selected person is not available, interviews are not conducted with alternative household members. At least six callbacks are made to each household before the selected individual is classified as a non-contact.

Data content

The Population Research and Outcome Studies Unit of the Department of Health assists clients to formulate questions and coordinates the preparation of the survey questionnaire. Each questionnaire includes approximately 60 questions. Ten background demographic questions are included free of charge to users.

Data content related to eye health

The following questions were included in the March 2000, July 2000, and March 2002 Health Monitor surveys:

- When did you last see an optometrist [who does eye testing for glasses]?
- Who referred you to the optometrist?
- When did you last see an ophthalmologist [an eye specialist]?
- Who referred you to the ophthalmologist?

Indigenous identification

Yes.

Socioeconomic identification

Employment status, pension received, education, household income.

Scope/target population

South Australian residents, aged 18 years and over living in a household listed in the Electronic White Pages.

The survey represents the population of South Australia aged 18 years and over.

Geographical coverage

South Australia.

Time period covered

Since 1999 to present (ongoing collection).

Publications and other outputs

Visit the Population Research and Outcome Studies Unit website (see below) for full details of publications and reports.

Access

Access to the Health Monitor survey can be obtained through the Population Research and Outcome Studies Unit.

Data management agency

Population Research and Outcome Studies Unit

Department of Health, Government of South Australia

PO Box 287

11 Hindmarsh Square

Adelaide SA 5000

<www.health.sa.gov.au/pros>

(08) 8226 7042

pros@health.sa.gov.au

South Australian Health Omnibus Survey

Description of data source

The Health Omnibus Survey is a face-to-face survey conducted annually since 1991 for government and non-government organisations responsible for servicing the health needs of the South Australian community.

Purpose(s)

The goal of the Omnibus is to collect, analyse and interpret data that can be used to plan, implement and monitor health programs and other initiatives. The idea of an omnibus survey is that several organisations share the cost of conducting a survey, with each organisation paying only for those questions that are of direct relevance to their information requirements.

The Health Omnibus provides organisations in the health sector with an opportunity to generate social statistics indicating prevalence rates, program impacts and other important data at an affordable cost.

Collection methodology

A particular advantage of the Health Omnibus Survey is that an extremely rigorous sampling procedure is adopted for the survey. A sample of 4,400 households is selected. One adult (non-replaceable) is interviewed in each household, on a face-to-face basis. The Health Omnibus aims to achieve a response rate of 70% or higher.

Data content

Approximately 10 background demographic questions (for example, age, gender, household income, marital status, education, country of birth) are included without charge and all clients' data can be cross-tabulated against these. This, in fact, means that an organisation with only one or two questions will have access to a great deal of data and can conduct a meaningful study.

Data content related to eye health

The following questions were included in the 2004 Spring Survey:

- Have you ever been told by a doctor that your vision has been affected because of your diabetes?
- Have you ever had laser therapy on your eyes because of your diabetes?
- Have you ever had cataract surgery?

Eye health-related data are self-reported.

Indigenous identification

Yes.

Socioeconomic identification

Household income, education, occupation.

Scope/target population

South Australian residents, aged 15 years and over.

Geographical coverage

South Australia.

Time period covered

Since 1991 to present (ongoing collection).

Publications and other outputs

Visit the Population Research and Outcome Studies Unit website (see below) for full details of publications and reports.

Accessen

Access to the Health Omnibus Survey can be obtained through the Population Research and Outcome Studies Unit.

Data management agency

Population Research and Outcome Studies Unit

Department of Health, Government of South Australia

PO Box 287

11 Hindmarsh Square

Adelaide SA 5000

<www.health.sa.gov.au/pros>

(08) 8226 7042

pros@health.sa.gov.au

South Australian Monitoring and Surveillance System

Description of data source

The South Australian Monitoring and Surveillance System (SAMSS) was established in 2002 by the Population Research and Outcome Studies Unit of the South Australian Department of Health. SAMSS monitors population trends in state and national risk factors and chronic diseases so that the Department of Health has appropriate, timely and valid population health information to monitor health status, respond to population changes and support planning, implementation, and evaluation of health services and programs.

Purpose(s)

The objectives of SAMSS are to:

- provide representative data
- characterise the problem or topic by time
- detect epidemics or changes in the topic occurrence
- identify high-risk groups or risk factors associated with the problem or topic and to suggest hypotheses for further investigation
- estimate the burden of the problem or topic
- highlight gaps in information and services that affect South Australians' general health and wellbeing
- disseminate findings to professionals and administrators within the Department of Health, and other human services professionals or organisations in South Australia and Australia
- project future health-care needs
- set priorities for allocation of resources
- strengthen the network for surveillance and monitoring of issues relevant to the Department of Health to improve information gathering and exchange.

Collection methodology

SAMSS is a relatively simple, efficient and timely system. That is, data collection is quick without compromising the quality of the information collection. The system is flexible to accommodate the changing characteristics of the population and needs of health professionals, administrators and policy makers.

The survey is conducted by telephone utilising the CATI system. The advantages of CATI surveys are that they are flexible, quick, efficient, relatively cost-effective and timely.

SAMSS collects data each month. Approximately 600 interviews are conducted each month with people of all ages.

Data content

Data collected include demographics, health conditions, physiological risk factors, behaviours, health service utilisation, medication usage, social capital, quality of life, economic indicators and sociodemographics.

Data content related to eye health

Participants respond to the following question: in the last four weeks, how many times [have you/has child's name] used the health services of an optometrist in South Australia?

Indigenous identification

Yes.

Socioeconomic identification

Economic indicators and sociodemographics are collected.

Scope/target population

South Australian residents of all ages.

Geographical coverage

South Australia.

Time period covered

Data collection started in June 2002 and as of May 2006, over 26,000 interviews had been conducted in South Australia for all ages.

Publications and other outputs

The following SAMSS reports have been published by the South Australian Department of Health, Population Research and Outcome Studies Unit:

- Avery J, Dal Grande E, Taylor A & Gill T 2004. Which South Australians experience psychological distress? Kessler distress 10-item scale, July 2002–June 2004.
- Dal Grande E, Taylor A, Hurst B, Kenny B & Catcheside B 2004. The health status of people living in the South Australian divisions of general practice, July 2002–December 2003.
- Dal Grande E, Taylor A, Hurst B, Kenny B & Catcheside B 2004. The health status of people living in the South Australian health regions, July 2002–December 2003.
- Dal Grande E, Taylor A, Hurst B, Kenny B & Catcheside B 2004. The health of status of South Australian by socio-economic status (SEIFA).
- Population Research and Outcome Studies Unit 2006. The health status of people living in South Australian health regions: overweight and obese, physical activity and nutrition, July 2004–June 2005.

Access

Access to SAMSS can be obtained through the Population Research and Outcome Studies Unit.

Data management agency

Population Research and Outcome Studies Unit

Department of Health, Government of South Australia

PO Box 287

11 Hindmarsh Square

Adelaide SA 5000

<www.health.sa.gov.au/pros>

(08) 8226 7042

pros@health.sa.gov.au

Spectacle assistance schemes

Description of data source

Spectacle assistance schemes exist in each Australian state and territory to provide assistance with the purchase of spectacles to residents who satisfy particular eligibility requirements. Availability of data from these schemes is not standard across states and territories.

Purpose(s)

The schemes provide low cost spectacles (or other vision correction) to low income and disadvantaged residents. Each state/territory has different eligibility requirements and provides a different level of benefit.

Collection methodology

Collection of information differs between states and territories. Generally, information is collected at the dispensing point and then forwarded to be processed centrally in each jurisdiction.

Data content

While each state and territory differ, generally the following are collected: name, date of birth, Medicare number, pension details, prescription provider details, details of prescription.

Data content related to eye health

The number of people receiving assistance to purchase spectacles and the cost of providing this assistance.

Indigenous identification

Some schemes collect information concerning Indigenous status.

Socioeconomic identification

Not strictly, however benefits of the scheme are restricted to eligible residents according to their low income status.

Scope/target population

Generally, residents of the applicable state and a recipient of the Commonwealth pension.

Geographical coverage

States and territories, Australia.

Time period covered

Varies.

Publications and other outputs

Reports are generally produced for internal purposes.

Access

Access availability differs from state to state.

Data management agency

Arrangements vary between states and territories, please contact the relevant state/territory health department.

Sydney Myopia Study

Description of data source

Funded by the National Health and Medical Research Council, the Sydney Myopia Study looks at factors contributing to the development of myopia.

Purpose(s)

The Sydney Myopia Study aims to document the prevalence of myopia in a large, representative sample of Sydney school children aged 6 and 12 (school years 1 and 7).

Collection methodology

The first phase of the Sydney Myopia Study was completed during the period June 2003 to September 2004. A comprehensive eye examination was conducted of 1,740 6-year old children attending Year 1 from 34 schools, with an overall response of 78.9%. The second phase exams of 12-year old children attending Year 7 was completed in December 2005, and saw 2,353 children from 21 schools, an overall response of 75.3%.

Data content

A complete eye test was conducted on each student. A questionnaire was used to collect information on students' demographics, self-reported vision and hearing problems, utilisation of eye-health services, use of glasses, general medical details, medications, birth history, home environment, activities and family history.

Data content related to eye health

Prevalence of myopia in school aged children.

Eye health-related data are medically verified.

Indigenous identification

The ethnic origins of the student's biological parents are recorded, with the ability to indicate as Indigenous Australian.

Socioeconomic identification

Yes.

Scope/target population

All year 1 (6-year-old) and year 7 (12-year-old) children from a random selection of primary and high schools in Sydney, balanced by socioeconomic status.

Geographical coverage

Sydney metropolitan area.

Time period covered

Baseline data was collected over 2002–2004. Follow up studies will continue in the future, pending further funding.

Publications and other outputs

- Over 25 peer-reviewed papers have been published to date

Access

Information not provided.

Data management agency

Centre for Vision Research

Department of Ophthalmology, University of Sydney

Westmead Millennium Institute

Westmead NSW 2145

<www.cvr.org.au>

(02) 9845 6852

paul_mitchell@wmi.usyd.edu.au

Sydney Older Persons Study

Description of data source

This study was conceived in 1988 as the Sydney Older Veterans Health and Services Project to investigate the health of community-dwelling veterans of World War II. The study was funded and commenced in 1991. At this stage, non-veteran members of the community were included as well.

Purpose(s)

The purpose of the Sydney Older Persons Study (SOPS) was to investigate the relationships between neurodegenerative ageing in people aged 75 and over, and a range of other health factors including systemic diseases, disability, social supports and self-rated health and coping.

Collection methodology

Stage 1 of the study (which ran from 1991–1993) involved visiting 647 people in their homes and conducting medical and neuropsychological assessments. Participants were also asked questions concerning their health and lifestyle, and often a spouse, relative or friend was interviewed to provide further information.

The second wave of the study – SOPS Stage 2 – involved interviews in the homes of the original study participants. SOPS Stage 3 did not have the broad aims of the first two stages. Rather, it was based on the SOPS population and involved taking a blood sample and completing a medication history.

SOPS Stage 4 was a further follow-up of the original SOPS population using the same methodology and instruments used in Stages 1 and 2. This allowed a broader time frame over which to study the correlates of successful and unsuccessful ageing and the possible risk factors and protective factors for these. By this wave, 462 people remained in the sample. Of the people who participated in SOPS Stage 4, 128 took part in a further phase that consisted of a magnetic resonance imaging (MRI) scan of the brain and more detailed neuropsychological assessments.

In 2001, SOPS Stage 5 commenced and data collection was completed in 2003. This study focused on the subgroup of subjects who had a MRI scan at SOPS 4. These people were invited to participate in a further MRI scan, detailed neuropsychological assessment and medical review. In addition, we re-interviewed the informants (such as a family member or a close friend) to measure the presence of health changes and their impact over time. It is anticipated that these data will provide invaluable information about the correlates and predictors of cognitive decline, with the potential to assist in the diagnosis of dementia and its subtypes. Data analysis is in progress.

Data content

Over 1,000 variables including information collected on demographics, level of difficulty associated with activities of daily living, medical conditions and disabilities.

Data content related to eye health

The following information was collected:

- self-reported incidence of cataracts, glaucoma, macular degeneration
- need for glasses
- inability to read an eye chart
- clinical qualitative assessment of the degree of visual impairment (none, mild, moderate, severe)
- assessment of the degree to which visual impairment was contributing to functional impairment (none, mild, moderate, severe).

Eye health-related data are medically verified and self-reported.

Indigenous identification

No.

Socioeconomic identification

Income, education, occupation and retirement details.

Scope/target population

Community-dwelling people aged 75 years and over in the inner west of metropolitan Sydney, NSW.

Geographical coverage

The inner western municipalities of metropolitan Sydney including Concord, Drummoyne, Strathfield, Burwood, Ashfield, Leichhardt, Marrickville and South Sydney.

Time period covered

Since 1991 to 2003.

Publications and other outputs

A number of papers have been published, most recently:

- Bennett H, Piguet O, Grayson D, Creasey H, Waite L, Lye T, Corbett A, Hayes M, Broe GA & Halliday G 2006. Cognitive, extrapyramidal and other MRI predictors of functional impairment in non-demented older community dwellers: The Sydney Older Person Study. *Journal of the American Geriatrics Society (JAGS)* 54: 3–10.

- Piguet O, Bennett H, Waite L, Kril J, Creasey H, Broe GA & Halliday GM 2006. Preserved cognition and functional independence after a large right posterior cerebral artery infarct: longitudinal, clinical and neuropathological findings. *Neurocase* 12:81–90.
- Piguet O, Cramsie J, Bennett HP, Kril JJ, Lye TC, Corbett AJ, Hayes M, Creasey H & Broe GA 2006. Contributions of age and alcohol consumption to cerebellar integrity, gait and cognition in non-demented very old individuals. *European Archives of Psychiatry and Clinical Neuroscience* 256(8):504–511.

Access

Access to SOPS data can be gained directly through the Prince of Wales Medical Research Institute/ Ageing Research Centre or through the Australian Social Science Data Archive at the Australian National University.

Data management agency

The Prince of Wales Medical Research Institute
 cnr of Barker Street and Easy Street
 Randwick NSW 2031
 <www.powmri.edu.au>
 (02) 9399 1000

Victorian Emergency Minimum Dataset injury surveillance collection

Description of data source

The Victorian Injury Surveillance Unit centralises and manages data from 38 Victorian public hospital emergency departments as part of the Victorian Emergency Minimum Dataset injury surveillance collection of emergency department presentations in Victoria.

Purpose(s)

Deliver and maintain a Victorian injury surveillance program for injuries to all persons in Victoria with the following specific objectives, to:

- promptly identify the emergence of new hazards, or the existence of previously unrecognised hazards
- give special focus to injuries and hazards aligned to state and nationally identified priority areas for action
- monitor secular trends in indicator injury rates
- provide support to primary care partnerships and local government supporting injury prevention activities
- assist in the evaluation of injury prevention interventions.

Collection methodology

Each hospital collects the required information for each presentation of an emergency department patient through a software package. If the presenting diagnosis is an injury, further related information is required. This information may be completed by the treating doctor, the triage nurse or clerical staff. Emergency department data are extracted monthly from the individual hospitals to Victoria's Department of Human Services. Quarterly, the Department of Human Services extracts a subset of the Victorian Emergency Minimum Dataset, only presenting injury cases, and passes this to the Victorian Injury Surveillance Unit.

Data content

Variables collected include: age, sex, injury cause, location, activity, nature of main injury, body region, human intent, birthplace, preferred language, address postcode, departure status, referral on departure and a 250-character text description of the injury event.

Data content related to eye health

Injuries occurring to the eye, coded according to the National Data Standard for Injury Surveillance (NDS-IS).

Eye health-related data are medically verified.

Indigenous identification

Indigenous status is collected, but not utilised.

Socioeconomic identification

Postcode.

Scope/target population

Patients presenting to monitored emergency departments with an injury.

Geographical coverage

Rural, remote and metropolitan Victoria, with 13 of the 37 hospitals in rural/remote Victoria.

Time period covered

Since October 1995 to 2005.

Publications and other outputs

Short reports are available on the Victorian Injury Surveillance Unit (VISU) website.

Access

The VISU data and information request service is open to government and non-government organisations, the higher education and schools sector, industry and business and community members. We are not able to provide a direct service to primary and secondary school students.

Data management agency

Victorian Injury Surveillance Unit

Accident Research Centre

Building 70

Monash University Vic 3800

<www.monash.edu.au/muarc/VISU/>

(03) 9905 1805

visu.enquire@general.monash.edu.au

Victorian Population Health Survey

Description of data source

The Victorian Population Health Survey is based on a core set of question modules that inform decisions about public health priorities. It measures the relevance and responsiveness of public health programs to current and emerging health issues.

Purpose(s)

The aim of the Victorian Population Health Survey is to provide quality, timely data to inform indicators of population health that are intended to have direct application to evidence-based policy development and strategic planning across the department and the wider community.

Collection methodology

The survey is conducted via CATI. The content of the survey was determined after reviewing the determinants of chronic disease states that are most likely to have an impact on Victorians. Priority has been given to areas in which a public health response is likely to be effective in improving health and, importantly, reducing inequalities in health for all Victorians.

Interviews are conducted in the major non-English languages in Victoria to ensure people of culturally and linguistically diverse backgrounds are represented.

Data content

The survey collects data on areas including demographics, screening, health-care use, self-reported height and weight, alcohol, smoking, asthma, blood pressure, diabetes, social capital measures, physical activity, self-reported health status, Kessler 10 measure of psychological distress, health conditions and eye care.

Data content related to eye health

The following information is collected:

- change in vision over the last 12 months
- the use of eye protection
- consultation with an eye-care specialist or attendance at an eye clinic
- type of eye problem including cataract, glaucoma, diabetic eye disease or diabetic retinopathy and macular degeneration.

Eye health-related data are self-reported.

Indigenous identification

Yes.

Socioeconomic identification

Information is provided on a participant's highest level of education, household income and residence area of state.

Scope/target population

A representative state-wide sample of adults aged 18 years or over is randomly selected from households in each of the eight departmental health regions.

Geographical coverage

Victoria.

Time period covered

Since 2003 to present (ongoing collection).

Publications and other outputs

Annual report:

- Victorian population health survey 2005, Department of Human Services, Victoria 2006.

Access

Access can be granted to the Victorian Population Health Survey data via licence deed with the Department of Human Services: contact Loretta Vaughan, manager Victorian Population Health Surveys, (03) 9096 5826.

Data management agency

Health Surveillance and Evaluation Section, Rural and Regional Health and Aged Care Services Division, Department of Human Services

50 Lonsdale Street

Melbourne Vic 3000

<<http://www.health.vic.gov.au/healthstatus/vphs.htm>>

(03) 9096 0000

public.health@dhs.vic.gov.au

Western Australian Aboriginal Child Health Survey

Description of data source

The Western Australian Aboriginal Child Health Survey (WAACHS), a large-scale epidemiological survey of the health and wellbeing of 5,289 Western Australian Aboriginal and Torres Strait Islander children, was undertaken in 2001 and 2002 by the Telethon Institute for Child Health Research, under the direction of the project's Aboriginal Steering Committee. The survey was designed to build an epidemiological knowledge base from which preventive strategies can be developed to promote and maintain healthy development and the social, emotional, academic and vocational wellbeing of young people.

Purpose(s)

The specific aims of the WAACHS were to:

- describe and define the health and wellbeing of Western Australian (WA) Aboriginal and Torres Strait Islander children and young people aged 0–17 years
- estimate the prevalence and distribution of commonly occurring chronic medical conditions and disabilities (for example, asthma, cerebral palsy, visual and hearing impairments, intellectual disability) and describe how they may affect a child's wellbeing and functioning
- estimate the prevalence, distribution and functional impact of common health and mental health problems in Aboriginal and Torres Strait Islander children and young people aged 0–17 years and their families
- estimate the prevalence and distribution of adverse health behaviours (for example, smoking, alcohol, drug and volatile substance misuse)
- estimate the prevalence and distribution of other psychosocial problems such as early school leaving, conduct problems, and juvenile offending
- describe Aboriginal and Torres Strait Islander children, adolescents and their families' access to, effective use of and satisfaction with health care, education, juvenile justice, housing and social services
- identify markers resulting in protection from, and amelioration of, poor health and wellbeing (mental health), adverse health behaviour(s) and other psychosocial problems
- develop estimates of risk and markers identifying Aboriginal and Torres Strait Islander children and young people at increased risk for various health, educational and vocational outcomes.

Collection methodology

Survey methodology and instrumentation were developed in consultation with Aboriginal leaders, key Aboriginal bodies (the Aboriginal and Torres Strait Islander Commission regional council, the Aboriginal Council of Elders, the Aboriginal Justice Council, and the Western Australian Aboriginal Community Controlled

Health Organisation), and through extensive community consultations throughout the state.

Dwellings were selected for screening using an area-based clustered multi-stage sample design. From 166,290 dwellings in 761 census collection districts, 139,000 dwellings were approached to determine if residents were eligible to participate in the survey. Using this method, a random sample of 2,386 families with 6,209 eligible children was identified throughout metropolitan, rural and remote regions of Western Australia. A total of 1,999 of these families (84%) with 5,513 eligible children consented to participate in the survey. Interviewers gathered useable data on 5,289 (96%) of these participating children.

Data were collected from interviews with the carers in the household who were the most knowledgeable about the survey children. In addition to the information collected on children, separate interviews were undertaken with up to two carers per child to gather information about the demographic and social characteristics of the household and family and to ask questions about the dwelling, neighbourhood and community.

In addition to the data gathered on children, data were also gathered on families.

Data content

Questionnaire content covered child and youth development; health and wellbeing; functional impairment and disability; use and access to health, education and social services; and a selected number of questions about diet; demographic and social characteristics of the household and family; information about the dwelling, neighbourhood and community.

The survey was subsequently linked to records of hospital admissions, diagnoses, procedures, and transfers through the Western Australia Record Linkage System.

Data content related to eye health

The following questions were asked:

- Does the respondent have normal vision in both eyes?
- Does the respondent use prescribed glasses or contact lenses?
- What access does the respondent have to vision services?

Eye health-related data are self-reported.

Indigenous identification

Yes.

Socioeconomic identification

Employment, education, remoteness.

Scope/target population

The survey was based on area sample of dwellings. Families in selected dwellings who reported that there were 'Aboriginal or Torres Strait Islander children or teenagers living at this address who are aged between 0 and 18 years' were eligible to be in the survey.

Children living within group homes, institutions and non-private dwellings were not in the scope of the survey. However, where a selected household had a child temporarily living away from home (for example, in a boarding school or hostel), these children were included in the scope of the survey.

Geographical coverage

Western Australia.

Time period covered

Commenced in May 2000 and was completed in June 2002.

Publications and other outputs

- Zubrick SR, Lawrence DM, Silburn SR, Blair E, Milroy H, Wilkes T, Eades S, D'Antoine H, Read A, Ishiguchi P & Doyle S 2004. The Western Australian Aboriginal child health survey: the health of Aboriginal children and young people. Perth: Telethon Institute for Child Health Research.
- Zubrick SR, Silburn SR, Lawrence DM, Mitrou FG, Dalby RB, Blair EM, Griffin J, Milroy H, De Maio JA & Li J 2005. The Western Australian Aboriginal child health survey: the social and emotional wellbeing of Aboriginal children and young people. Perth: Curtin University of Technology and Telethon Institute for Child Health Research.
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Access

General enquiries about the WAACHS and enquiries seeking statistical clarification of any of the topics covered should be directed to the Telethon Institute for Child Health Research at waachs@ichr.uwa.edu.au.

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2.3 Analysis

There is a large number of data sources which can be used to indicate the prevalence and outcomes of eye diseases and injuries and eye health-care utilisation in Australia. Some of these data sources have been developed for the specific purposes of collecting information on eye health while others have been developed with a broader purpose. Many of these data sources are based on nationally agreed standards that enable information to be compared across different service-delivery settings and sectors.

There is no comprehensive information framework that can assess the utility of these data sources. It is possible, however, to apply the analysis of data sources in this document to the information needs of the *National eye health framework*.

The *National eye health framework* outlines five key areas for action in preventing avoidable blindness and vision loss. These are:

1. reducing the risk
2. increasing early detection
3. improving access to eye health-care services
4. improving the systems and quality of care
5. improving the evidence base.

The objective of the first key area for action is to prevent eye disease and vision loss where possible through addressing known modifiable risk factors. The first key area for action is well informed by a number of the eye health data sources identified in Section 2.2. The monitoring of this key area for action may be informed by data sources that measure prevalence and incidence of eye diseases, injuries and risk factors. The identified data sources which inform this area include population-based surveys, clinical-based studies and national monitoring systems. Many of these data sources also include risk factor-related data, Indigenous status, comorbidity and socioeconomic status.

The objective of the second key area for action is to detect treatable eye conditions early so that interventions can be applied to preserve vision and prevent any further vision loss. Key area for action 2 is only moderately informed by the key Australian eye health data sources identified. Data sources that may inform this area are restricted in availability to those that collect information on eye examinations.

The objective of the third key area for action is to ensure that all Australians have equitable access to appropriate eye health care when required. This is an area well informed by a number of the eye health data sources identified. The monitoring of this area may be informed by data sources that measure encounters with the health-care sector or those that collect information about the eye health workforce. The identified data sources which inform this area include national administrative data collections, surveys and professional registration collections.

The objective of the fourth key area for action is to ensure eye health care is safe, affordable, well-coordinated, consumer-focused and consistent with internationally

recognised good practice. Key area for action 4 is the least informed of the five areas with few collections contributing to this area's information needs. A small number of data sources have limited information about referral pathways.

The objective of the fifth key area for action is to ensure that eye health-care policy, planning and programs are supported by high quality research and data collection systems. Virtually by definition, key area for action 5 is successfully informed by the identified data sources. To varying degrees, each data source informs this area.

In summary, the information needs of the *National eye health framework* are informed by a number of data sources, as identified in Section 2.2. Key area for action 5 – *Improving the evidence base* is the area most informed by the identified data sources. Key areas for action 1 – *Reducing the risk* and 3 – *Improving access to eye health-care services* are both well informed by the identified data sources, while Key area for action 2 – *Increasing early detection* is only moderately informed and Key area for action 4 – *Improving the systems and quality of care* is the least informed of the five areas.

Through the monitoring of data sources that inform the key areas for action, achievements over time can be measured. Monitoring of the prevalence and outcomes of eye diseases and injuries and eye health-care utilisation is necessary to improve Australia's ability to make decisions for cost-effective allocation of resources, to plan preventive and treatment services, and to target priority population groups. Monitoring of these data sources will also allow the impact of risk factors, health promotion and prevention strategies to be measured.

3 Terminology in eye health

Statistics on the prevalence of vision loss in Australia are available from a number of sources. Confident comparisons of these statistics both nationally and internationally rely on uniformity in the terms and definitions used to describe vision loss.

Examination of these sources indicates that the most common terms used to refer to vision loss in Australia are vision impairment, low vision, blindness and legal blindness. Full details of the variety of definitions currently used to describe vision loss in Australia are outlined in the following pages.

3.1 Visual impairment and low vision

Definitions of visual impairment and low vision are less established than the definition of blindness. The terms are used regularly, but are frequently used interchangeably. While the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) definition of low vision relates to reduced vision excluding blindness, Vision Australia defines visual impairment according to the same criteria. Other versions of both visual impairment and low vision use the same definition, a significant reduction in vision, including blindness.

The visual acuity upper limit which constitutes a significant reduction in vision is also a point of difference among definitions. Visual acuity limits vary between less than 6/12 and less than 6/18. Definitions of visual impairment and low vision in use in Australia are presented on pages 132 and 133.

3.2 Blindness and legal blindness

The most commonly adopted definition of blindness in Australia is classified in ICD-10-AM. This definition is based on the World Health Organization's (WHO) standard definition of blindness which has been internationally accepted and incorporated into the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10). The ICD-10-AM and ICD-10 classification systems are widely accepted by many Australian studies and data collections, including the Australian Corneal Graft Registry, the Florey Adelaide Male Ageing Study, the National Hospital Morbidity Database and the National Mortality Database.

Some definitions of blindness employ variants of the ICD-10-AM definition, including those used by the Blue Mountains Eye Study, the AIHW, the Department of Veterans' Affairs and the Australian National Diabetes Information Audit and Benchmarking. Full details of variations of the definition of blindness are presented on page 133.

Variations in definitions relate to the use of different levels of visual acuity loss. While the internationally aligned ICD-10-AM definition imposes a visual acuity of less than 3/60, a number of definitions of blindness maintain a visual acuity level of less than 6/60. Although a visual acuity of less than 3/60 aligns with internationally recognised definitions, it has been documented that the increased complexity of daily tasks requires a less severe level of visual acuity, that is, less than 6/60 (Dandona & Dandona 2006).

The concept of legal blindness arose with the introduction of social security systems. The term legal blindness is generally used by governments to determine the criteria by which a person is deemed eligible for government concessions, such as income assistance and disability support. In Australia the criteria for legal blindness is established under Section 95 of the *Social Security Act 1991* (Commonwealth of Australia 2006). The definition of legal blindness is widely and consistently adopted by researchers and community organisations. Details of the definition for legal blindness and the organisations and studies which have adopted this definition are presented on page 134.

Definitions of visual impairment used in Australia

- The ICD-10-AM classification, 'visual impairment' includes 'blindness' and 'low vision'. Therefore a visual acuity with best possible correction of less than 6/18 and/or a corresponding visual field loss of less than 10 degrees around central fixation or no light perception (National Centre for Classification in Health 2006)
- Adopted by:
 - National Mortality Database (Dunn et al. 2006)
 - National Hospital Morbidity Database (AIHW 2006b).
- An individual has some degree of sight loss (Royal Blind Foundation Queensland 2006)
- Visual acuity <6/12 in both eyes, established by Eye Research Australia (Access Economics 2004)
- Visual acuity <6/18, established by the Katherine Region Diabetic Retinopathy Study.
- Best corrected visual acuity <6/18 and/or visual field constriction to within 20° of fixation, established by the Melbourne Visual Impairment Project (Livingston et al. 1997)
- Best-corrected visual acuity of 6/12 or worse, established by Blue Mountains Eye Study (Wang et al. 2000)
- A person with visual acuity of less than 6/18 (0.3) but equal to or better than 6/60 (0.05) in the better eye with the best possible correction and/or a visual field of less than 20 degrees, referred to as 'vision impaired' (Vision Australia 2006c)
- People who are visually impaired include those who are blind, who have vision significantly less than normal (which is usually taken as acuity less than 6/18) but are not classified as blind (Fred Hollows Foundation 2006)

- 'Visual Impairment' to be used when the condition of vision loss is characterised by a loss of visual functions (such as visual acuity, visual field etc.) at the organ level. Many of these functions can be measured quantitatively, established by International Council of Ophthalmology (ICO), as endorsed locally by the Royal Australian and New Zealand College of Ophthalmologist (ICO 2002).

Definitions of low vision used in Australia:

- Visual acuity with best possible correction of less than 6/18, but equal to or greater than 3/60 (National Centre for Classification in Health 2006)
Adopted by:
 - National Mortality Database (Dunn et al. 2006)
 - National Hospital Morbidity Database (AIHW 2006b).
- A person is said to have low vision when their eyesight is limited or impaired and cannot be corrected with conventional glasses or contact lenses (Vision Australia 2006b)
- Low vision is an impairment to vision that significantly interferes with the functioning of a person and cannot be adequately corrected with medical, surgical, therapy, conventional eyewear or contact lenses. It is often a loss of sharpness or acuity but may present as a loss of field of vision, light sensitivity, distorted vision or loss of contrast. Low vision may occur as a result of birth defects, injury or as a complication of disease (Macular Degeneration Foundation 2006)
- 'Low vision' is to be used for lesser degrees of vision loss, where individuals can be helped significantly by vision enhancement aids and devices. International Council of Ophthalmology (ICO), as endorsed locally by the Royal Australian and New Zealand College of Ophthalmologist (ICO 2002).

Definitions of blindness used in Australia:

- Visual acuity with best possible correction of less than 3/60, and/or a corresponding visual field loss of less than 10 degrees around central fixation or no light perception (National Centre for Classification in Health 2006)
Adopted by:
 - Australian Corneal Graft Registry
- Florey Adelaide Male Ageing Study
- National Mortality Database (Dunn et al. 2006)
- National Hospital Morbidity Database (AIHW 2006b)
- Presenting visual acuity less than 6/60 in the best eye, established by the Blue Mountains Eye Study and Melbourne Visual Impairment Project combined study (Taylor et al. 2005)
- Visual acuity of less than 3/60 or corresponding visual field loss in the better eye with best possible correction (Fred Hollows Foundation 2006)

- Whether the individual has become legally blind in either or both eyes. Blindness is less than 6/60 vision in the better eye with glasses. Vision 6/60 is the ability to see only at 6 metres what the normal eye can see at 60 metres. An indicator of the presence or development of a visual impairment or inability to see (AIHW 2005b)
- Visual acuity < 6/60 in both eyes established by the Australian National Diabetes Information Audit and Benchmarking (National Association of Diabetes Centres 2005)
- 'Blindness' to be used only for total vision loss (that is, no light perception) and for conditions where individuals have to rely predominantly on vision substitution skills, established by the International Council of Ophthalmology (ICO), as endorsed locally by the Royal Australian and New Zealand College of Ophthalmologist (ICO 2002)
- There is total loss of sight; or corrected visual acuity is less than or equal to 6/60 in both eyes; or where, in the written opinion of an ophthalmologist, the visual fields deficits; and/or combination of deficits results in a visual impairment which is the equivalent of a corrected visual acuity measure of less than or equal to 6/60 in both eyes established by the Australian Government for the purposes of determining permanent blindness pensions paid by the Department of Veterans' Affairs (Australia Government, Department of Veterans Affairs 2006)

Definitions of legal blindness used in Australia

- Visual acuity on the Snellen scale after correction by suitable lenses must be less than 6/60 in both eyes; or constriction to within 10 degrees of fixation in the better eye irrespective of corrected visual acuity; or a combination of visual defects resulting in the same degree of visual impairment as that occurring in the above points, established by the Australian Government for the purposes of determining permanent blindness for Disability Support Pension or Age Pension – Blind under Section 95 of the Social Security Act 1991 (Australian Government 2006)
- Adopted by:
- Blind Citizens Australia, used as determining criteria for full and junior membership (Blind Citizens Australia 2006); referred to a 'permanent blindness'
- Eye Research Australia (Access Economics 2004)
- Queensland Blind Association Inc. Used as a basis for membership and purchase of white canes (Queensland Blind Association Inc. 2001)
- Royal Blind Foundation Queensland (2006)
- Retina Australia (2001)
- The Katherine Region Diabetic Retinopathy Study
- Vision Australia, as stated in the Constitution (Vision Australia 2006a)

3.3 Other definitional considerations

Presenting visual acuity versus corrected visual acuity

Corrected visual acuity is visual acuity measured according to the most appropriate refractive correction. Presenting visual acuity, however, is a measurement of an individual's acuity with the refractive correction which is currently in use by the individual; for example, spectacles or contact lenses (Dandona & Dandona 2001).

An individual may qualify as 'not blind' because their vision improves with refractive correction. However, in their daily living, their vision may be poor enough, due to uncorrected or under-corrected refractive error, that they qualify as 'blind' when measured according to their presenting visual acuity.

Although easily managed, uncorrected refractive error remains a major cause of vision impairment (Vennewkirk et al. 2001). A study has determined that nearly 300,000 of the 480,000 Australians who are visually impaired are so because of under-corrected refractive error (Access Economics 2004). In 2006, WHO recognised uncorrected refractive error as an important cause of vision loss. Broadening the definition of visual impairment, to include uncorrected refractive errors, effectively doubled the estimated total number of visually impaired people worldwide (WHO 2007). Defining vision loss according to corrected visual acuity would therefore have a substantial statistical impact on measuring the burden of vision loss.

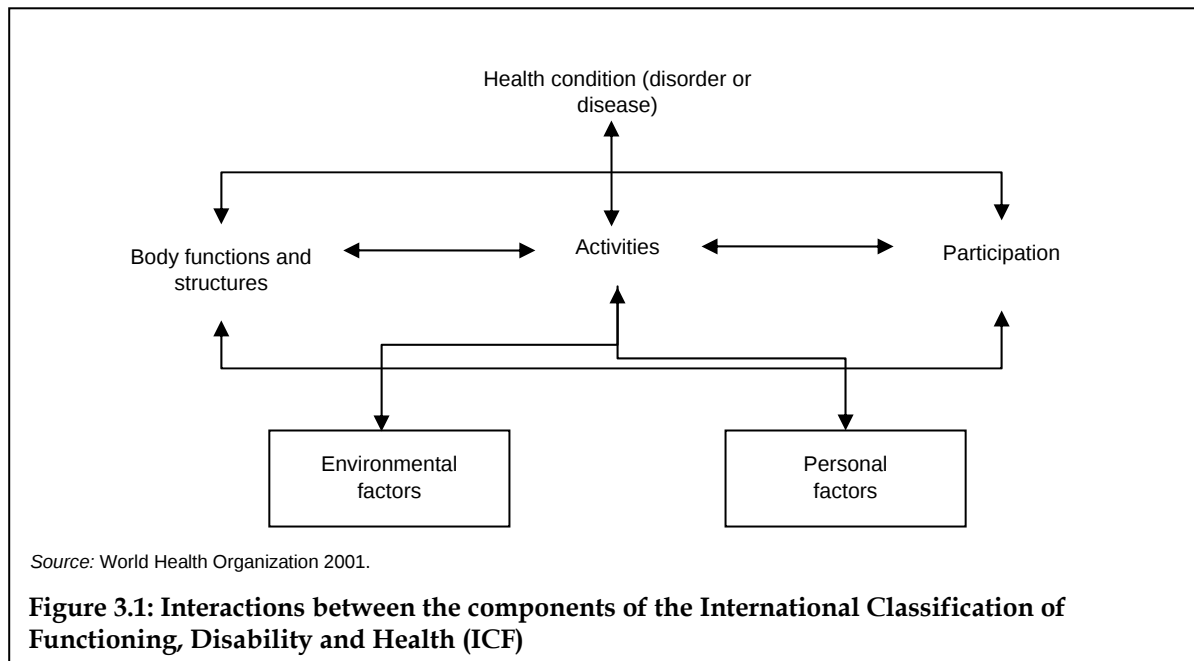
Visual field

Vision loss is generally measured according to visual acuity, visual field or both. Despite visual field loss being a major component of vision loss, second to visual acuity loss (ICO 2002), many of the definitions associated with vision loss do not utilise this measure. As visual field loss can exist independent to visual acuity loss (ICO 2002), prevalence estimates determined exclusively on visual acuity may underestimate the true prevalence rate of blindness.

Functional vision

One of the difficulties of limiting the measure (and hence definition) of vision loss terms to visual acuity and visual field is that they are objective measurements that do not take in to account an individual's ability to use vision in activities of daily living.

The International Classification of Functioning, Disability and Health (ICF) provides a multi-perspective approach to the classification of functioning and disability as an interactive and evolutionary process (WHO 2001). Figure 3.1 illustrates the various components and interactions of the ICF. By qualifying vision loss according to the component of body functions and structures only, in terms of visual acuity and visual field, many other important components of measuring visual functionality are ignored.

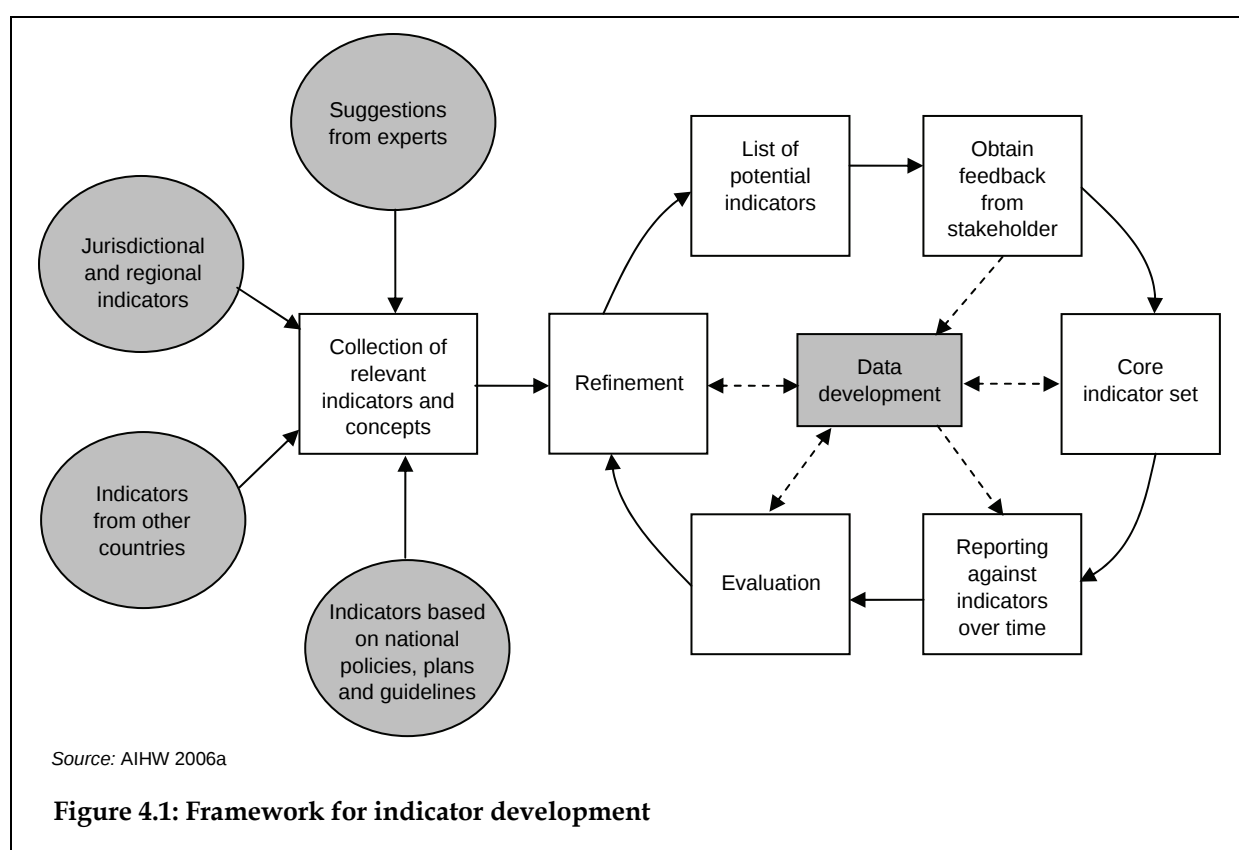


In summary, there are a number of key definitional issues surrounding vision loss terminology. While the definition of legal blindness is well established, other terms associated with vision loss lack the same uniformity.

4 Considerations for future indicator development

The use of indicators is central to monitoring eye health within Australia. Performance indicators are a valuable tool to identify trends, inform decision making and policy and evaluate the implementation of various interventions. Indicators have several levels of relevance. Assessments can be made at regional levels, through to national and international comparisons.

The AIHW has a history of involvement in the development of national performance indicators for many health areas. The typical process for indicator development is an iterative one, as illustrated by Figure 4.1.



Based on the process used to develop national indicators for monitoring osteoarthritis, rheumatoid arthritis and osteoporosis, indicator development begins with the identification of potential indicators. These are gathered from a number of sources, including existing indicators used regionally or internationally, those that flow from policy, and through consultations with experts. There are several areas from which to source potential indicators within the area of eye health. The WHO has developed a framework and indicators for monitoring VISION 2020 – The Right

to Sight (WHO 2003). Countries are encouraged to employ indicators from the basic set that are the most appropriate for their epidemiological and disease pattern and intervention strategy.

A number of potential indicators were suggested through the consultation process for the development of the *National eye health framework*. These may be used as a catalyst for further development through the formal channels of stakeholder consultation or through a national expert workshop. Potential indicators can also flow from the key areas of action expressed in the *National eye health framework*.

The next step in the indicator development process is to assess and refine the list of potential indicators. The National Health Performance Committee (NHPC) was established by the Australian Health Ministers' Conference and is attended by representatives from each state and territory, the Australian Government and national bodies. The NHPC is responsible for the development and maintenance of a national health performance framework, the support of benchmarking for health system improvement and the provision of information on national health system performance (NHPC 2004). The NHPC's criteria for indicator development (Box 1) may be used as a tool to assess the utility of potential indicators.

The NHPC's National Health Performance Framework aims to facilitate the use of data for benchmarking purposes. The list of potential indicators may also be organised within the tiers of the NHPC's National Health Performance Framework (NHPC 2001). The three tiers are health status and outcomes, determinants of health and health system performance. By organising indicators within the National Health Performance Framework a whole of system approach can be taken to developing indicators and measuring eye health.

Box 1: Selection criteria for health performance indicators

Indicators should have all or some of the following qualities. They should:

1. *be worth measuring*
2. *be measurable for diverse populations*
3. *be understood by people who need to act*
4. *galvanise action*
5. *be relevant to policy and practice*
6. *measurement over time will reflect results of actions*
7. *be feasible to collect and report*
8. *comply with national processes of data definitions.*

Source: NHPC 2001.

The NHPC recommends that indicators should have some or all of the qualities outlined in the selection criteria for sets of performance indicators (Box 2).

Following the assessment and refinement of indicators, feedback may be sought from experts and stakeholders. Any further short-listing of indicators should take this input into consideration.

Box 2: Selection criteria for sets of performance indicators

Sets of indicators or composite indices should:

1. *cover the spectrum of the health issue*
2. *reflect a balance of indicators for all appropriate parts of the framework*
3. *identify and respond to new and emerging issues*
4. *be capable of leading change*
5. *provide feedback on where the system is working well, as well as areas for improvement.*

Source: National Health Performance Committee 2001.

Further to the criteria outlined above, the NHPC recommends that indicators should be specified in technical terms to ensure consistency of reporting. The committee also recommends that indicators should conform with existing data definitions.

Therefore, to support the short-listed indicators, formalised definitions are required where existing data definitions do not exist. Again, this development stage is perhaps best done through a consultation process. If necessary, the indicators may be refined at a later stage to meet future information needs and priorities.

It is also important to seek the agreement of stakeholders on the nature and form of indicators to ensure wide acceptance.

Glossary

ASCED	The Australian Standard Classification of Education (ASCED) was developed by the ABS for use in the collection, storage and dissemination of statistical and administrative data relating to educational activity undertaken in Australia. The classification system includes two component classifications Level of Education and Field of Education.
ICD-9-BPA	ICD-9-BPA is an adaptation of WHO's International Statistical Classification of Diseases, 9 th Revision by the British Paediatrics Association (the Royal College of Paediatrics and Child Health)
ICD-9-CM	ICD-9-CM is based on WHO's 9 th Revision, International Classification of Diseases (ICD-9). ICD-9-CM is the official system of assigning codes to diagnoses and procedures associated with hospital utilisation in the United States.
ICD-10	ICD-10 is a classification system in the WHO Family of International Classifications. It is the international standard diagnostic classification for all general epidemiological and many health management purposes. It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records.
ICD-10-AM	ICD-10-AM is the Australian modification of the international standard ICD-10. It consists of a tabular list of diseases and accompanying index, a tabular list and index of procedures and Australian Coding Standards for the selection of codes. The ICD-10-AM disease component is based on the WHO ICD-10. It uses an alphanumeric coding scheme for diseases. It is structured by body system and aetiology. The ICD-10-AM procedures component is based on the MBS. The classification is structured by body system, site and procedure type. Procedures not currently listed in MBS have also been included (for example, allied health interventions, cosmetic surgery).
ICF	ICF is a classification system in the WHO Family of International Classifications. It describes how people live with their health condition. ICF is a classification of health and health-related domains that describe body functions and structures, activities and participation. The domains are classified from body, individual and societal perspectives. Since an individual's functioning and disability occurs in a context, ICF also includes a list of environmental factors.

ICPC	Internal Classification of Primary Care (ICPC) has been incorporated in to the WHO Family of International Classifications. It classifies patient data and clinical activity in the domains of general/family practice and primary care, taking into account the frequency distribution of problems seen in these domains. It allows classification of the patient's reason for encounter (RFE), the problems/ diagnosis managed, interventions, and the ordering of these data in an episode of care structure.
K-10 measure	The Kessler measure is a 10-item self-report questionnaire intended to yield a global measure of 'psychological distress' based on questions about the level of anxiety and depressive symptoms in the most recent 4-week period.
MBS	Medicare Benefits Schedule (MBS) is a listing of the Medicare services subsidised by the Australian Government.
NDS-IS	National Data Standard for Injury Surveillance (NDS-IS) describes data items and classifications designed to support public health surveillance of injury.
PBS	Pharmaceutical Benefits Scheme (PBS) is listing of all the pharmaceuticals subsidised by the Australia Government.
Visual acuity	Measurement of the finest details that an eye can distinguish, often estimated using LogMar or Snellen charts.
Visual field	Measurement of the ability to detect objects to either side, or above or below, the direction of central fixation.

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