

Longitudinal studies of ageing

Implications for future studies

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Australian Institute of Health and Welfare
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Preface

In 2003, the Prime Minister's Science, Engineering and Innovation Council (PMSEIC) produced a report *Promoting Healthy Ageing in Australia* which argued that a large and comprehensive national study is needed to investigate the many influences on ageing outcomes for Australian people (PMSEIC 2003). It recommended that an Australian Longitudinal Study of Older People (ALSOP) be established, and suggested that the study give priority to areas potentially improvable and important for the health, functioning and wellbeing of older people. These include:

- the behavioural determinants of health in older age (particularly mental activity, physical activity and good nutrition);
- work environments, retirement, social involvement including family and community contributions; and
- housing, land use and assistive technology.

In January 2004, the Australian Government Department of Health and Ageing (DoHA) commissioned the Australian Institute of Health and Welfare (AIHW) to produce this report, *Longitudinal Studies of Ageing: Implications for Future Studies*, which describes and compares existing and proposed Australian longitudinal surveys relevant to ageing, in respect of their methodological features and data collection scope. The report also compares these features of Australian studies with some well-established overseas longitudinal projects.

The report is a mapping exercise intended to be a practical resource for informing future efforts to address ageing research needs in Australia

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Finally, we acknowledge and appreciate the information and comments provided by investigators associated with the longitudinal studies that have been included in this report.

Abbreviations

45 and Up	45 and Up Study
ABS	Australian Bureau of Statistics
ACER	Australian Council for Educational Research
ACSPRI	Australian Consortium for Social and Political Research Incorporated
ACT	Australian Capital Territory
ADAMS	The Aging, Demographics and Memory Study
ADL	Activity of Daily Living
AHEAD	Study of Assets and Health Dynamics Among the Oldest Old
AIFS	Australian Institute of Family Studies
AIHW	Australian Institute of Health and Welfare
ALSA	Australian Longitudinal Study of Ageing
ALSWH	Australian Longitudinal Study of Women’s Health
ANU	Australian National University
ApoE	Apolipoprotein E
ARC	Australian Research Council
ARO	Ageing Research Online
ASSDA	Australian Social Science Data Archive
ATP	Australian Temperament Project
AUSDIAB	AusDiab Follow-up Study
BLM	A Longitudinal Study of Bone Loss in Men
BLSA	Baltimore Longitudinal Study of Aging
CAPI	Computer Assisted Personal Interviewing
CATI	Computer Assisted Telephone Interviewing
CERA	Centre for Education and Research on Ageing
CES-D	Center for the Epidemiologic Studies – Depression
CLSA	Canberra Longitudinal Study of Ageing
CMHR	Centre for Mental Health Research
CSIRO	Commonwealth Scientific and Industrial Research Organisation
DEST	Australian Government Department of Education, Science and Training
DIMA	Australian Government Department of Immigration and Multicultural Affairs
DIMIA	Australian Government Department of Immigration and Multicultural and Indigenous Affairs

DNA	Deoxyribonucleic acid
DoHA	Australian Government Department of Health and Ageing
DSRU	Dental Statistics and Research Unit
DUBBO	The Dubbo Study of the Health of the Elderly
ECG	Electrocardiogram
ECHIDNAs	Epidemiology of Chronic Disease, Health Interventions and DNA studies
ELSA	English Longitudinal Study of Ageing
FaCS	Australian Government Department of Family and Community Services
FAHS	Functional Ageing and Health Services Project
FAMAS	Florey Adelaide Male Aging Study
GHQ	General Health Questionnaire
GP	General Practitioner
HBOA	Health, Behaviour and Outcomes of Older Adults Project
HIC	Health Insurance Commission
HILDA	Household, Income and Labour Dynamics in Australia Survey
HRP	Healthy Retirement Project
HRS	Health and Retirement Study
HSE	Health Survey for England
HSOP	Health Status of Older People Project
IADL	Instrumental Activity of Daily Living
ICPSR	Inter-university Consortium for Political and Social Research
IFS	Institute for Fiscal Studies
IHR	Institute for Health Research
IUSSP	International Union for the Scientific Study of Population
LSAC	Growing Up in Australia – The Longitudinal Study of Australian Children
LSAY	Longitudinal Surveys of Australian Youth
LSIA	Longitudinal Survey of Immigrants to Australia
MCCS	Melbourne Collaborative Cohort Study
MELSHA	Melbourne Longitudinal Studies on Healthy Ageing Program
METs	Metabolic equivalent tasks
MNRF	Major National Research Facilities
MRI	Magnetic Resonance Imaging
MU	Migrating Unit Spouse
NHMRC	National Health and Medical Research Council
NIA	National Institute on Aging
NIDR	National Institute of Dental Research

NIH	National Institute of Health
NLC	Negotiating the Life Course
NSW	New South Wales
OECD	Organization for Economic Co-operation and Development
OHIP	Oral Health Impact Profile
PA	Primary Applicant
PATH	The Personality and Total Health Through Life Project
PISA	Programme for International Student Assessment
PMSEIC	Prime Minister's Science, Engineering and Innovation Council
RSSS	Research School of Social Sciences
SA	South Australia
SADLS	The South Australian Dental Longitudinal Study
SoA	Stories of Ageing: A Longitudinal Study of Women's Self-Representation
SOPS	Sydney Older Persons Study
SPIRT	Strategic Partnerships with Industry-Research and Training
UCL	University College London
UK	United Kingdom
US	United States
VicHealth	Victorian Health Promotion Foundation
WA	Western Australia
XI	Xerostomia Inventory
—	no information provided

1 Introduction

1.1 'Ageing' as an area of research

Australia is experiencing considerable demographic change, particularly as the first cohort of Australia's baby-boomers reach the age of 65 over the next decade. In 1991, 11% of the population were aged 65 and over (2.0 million) and by 2021 this is projected to increase to 18% (4.2 million) (AIHW 1999:5). The increasing proportion of older Australians in the population has potentially significant implications for the nation's welfare services and health care system.

On the one hand, older Australians in the future are generally expected to be in better health than current seniors due to changes in lifestyle, working conditions and developments in health care. This cohort is also more highly educated than previous ones, and may have different expectations and needs than today's older Australians. However, while life expectancy at 65 has increased dramatically over the last century – by seven years for women and five years for men (AIHW 2003:279), life expectancy without disability has not increased proportionately, and disability levels appear to have remained relatively stable in Australia¹. This means that as people live longer, chronic diseases such as dementia, cerebrovascular disease and congestive heart failure may develop and require treatment at levels that may place pressures on the health care system.

There is increasing consideration of the range of policy and program responses that may be necessary in order to meet the challenges of population ageing. For example, the Intergenerational Report (Commonwealth of Australia 2002), tabled with the 2002–03 Commonwealth budget, explored the economic implications of these demographic pressures on future public expenditure. The Productivity Commission has recently been given a reference to examine the economic implications of an ageing Australia and expects to report in 2005. This activity is coupled with a recognition that the development of appropriate policy and program responses must be informed by a high-quality evidence base. This is a key principle of the government's *National Strategy for an Ageing Australia: An Older Australia, Challenges and Opportunities for All* (Andrews & DoHA 2001), and is reflected in the identification of the key research goal 'Ageing well, ageing productively' among the National Research Priorities (DEST 2003), developed through broad consultation with the research and policy making community throughout 2002.

Academic interest in this area is also growing, as evidenced by events such as the Dynamic Processes in Ageing Symposium 2003, sponsored by the Centre for Mental Health Research at the Australian National University (ANU), which identified the importance of integrating research on age-related changes from a range of disciplines, including psychology, neuropsychiatry, epidemiology, sociology and statistical modelling. The importance of this area of academic research has also been recently recognised through the success of the newly

¹ There is some debate internationally on this issue, though in Australia, the proportion of people over 65 with a severe or profound activity restriction has varied only marginally: from 18.4% in 1988, to 17.5% in 1993, to 19.6% in 1998. Moreover, age and sex specific rates within the older population have remained essentially stable. See Australia's Welfare 2001, Chapter 6 for a discussion.

formed Ageing Well Network in gaining an Australian Research Council (ARC) Network Grant. 'Ageing' has emerged, through numerous academic and government processes, as a high-priority area for research, both now and into the future.

1.2 Longitudinal studies as part of the evidence base

The evidence base used to address issues of ageing is usually derived from a broad range of multidisciplinary studies involving different study designs, of which longitudinal studies are only one type. These various designs are briefly described below to provide a context for the focus of this report. The most common primary data collection methods used are cross-sectional surveys, case-control studies, randomised control trials and cohort (longitudinal) studies. Administrative data are also extensively used in ageing research, sometimes linked with different study designs.

Cross-sectional studies

Typically, cross-sectional studies take a 'snap-shot' in time by measuring the prevalence of factors of interest and how that prevalence varies by demographic, social and other factors. Measures of 'exposure' and 'outcome' are made at the same time, which makes it difficult to demonstrate causality. Cross-sectional studies are useful for investigating associations with factors that are fixed characteristics of individuals, such as ethnicity or gender. They can also raise hypotheses for testing in other studies. Several countries conduct regular cross-sectional surveys on representative samples of their populations. Repeat cross-sectional surveys can permit some analysis across time for sub-groups but not at the individual level as each repeat survey is conducted on an independent sample of people.

Case-control studies

Case-control studies investigate the prior exposure of individuals with a particular outcome (cases) and individuals without it (controls) but who are otherwise comparable, to infer why certain individuals have the outcome and others do not. The occurrence of the possible cause is compared between cases and controls. Case-control studies incorporate longitudinal design elements by looking back in time from the outcome to a possible cause. They are relatively simple and economical to carry out and are especially useful for investigating the occurrence of rare events. The most difficult task is to avoid bias in the selection of cases and controls.

Randomised controlled trials

Randomised controlled trials (or randomised clinical trials) are experiments used to study new preventive or therapeutic regimens. Subjects are randomly allocated to groups, usually called treatment and control groups, and the results are assessed by comparing the outcomes between groups. These trials are one of the most powerful methods for testing specific interventions and demonstrating some causal relationship; however, practical and ethical considerations can limit their usefulness. Also, like case-control studies, they are generally restricted in the range and number of variables that can be examined simultaneously.

Cohort (longitudinal) studies

Cohort studies measure exposures of interest among a group of people (a cohort) who are initially free of the outcome of interest. The cohort is followed-up to see whether those who were exposed develop the outcome of interest at a different rate than those not exposed. The cohort is usually defined by a common characteristic, often age. The time interval between each follow-up data collection varies between studies and is usually determined by the research questions, the population of interest and available resources. Cohort studies allow investigation of causation of the outcome of interest and provide the most direct measurement of risk of the outcome. However, these studies are major undertakings and require long periods of follow-up when the outcome occurs a long time after exposure or after prolonged exposure.

The most common longitudinal study design is a single-cohort design in which a sample of a defined age is recruited at one point in time and followed-up at subsequent intervals. However, with this design, age effects, cohort effects and time-of-measurement effects are confounded and cannot be distinguished. Also, these studies are relatively slow at producing results on long-term or later-life outcomes, which can reduce the relevance of their findings for current policy and practice. There are alternative longitudinal designs involving multiple cohorts which overcome these problems but they can be more expensive, complex and challenging to execute. Nevertheless, longitudinal research is critical to understanding issues associated with ageing and developing the evidence base.

Administrative data

Administrative by-product data are frequently used to generate information relevant to ageing issues. Such studies are typically restricted to data about a single program or set of programs, such as income support, or a type of intervention, such as an episode in hospital. Administrative data are designed to produce information that will assist program-based service delivery and can be a rich source of information about program clients, such as residents in an aged care facility. However, they do not capture data about the population who do not receive such assistance. Nor do they generally collect data that are not directly relevant to the particular service delivery.

Record linkage

Record linkage can be used to introduce a longitudinal component into studies undertaken at a point in time, such as cross-sectional surveys, by linking with registers or databases that contain outcome data, such as the National Death Index or the Cancer Registries. Since there is no unique identifier for Australians, records may be linked, subject to ethical considerations, on the basis of common identification data, primarily name, sex and date of birth. By linking factors measured at one point in time with outcome data measured sometime later, the linked datasets can provide information on the ageing process. However, outcomes measures are limited to those available in registries and databases and the strength of the matching process depends upon the variables that are available for linkage.

Longitudinal data may also be generated from within administrative data collections by linking individual records over time. Linkage may also occur between administrative data systems. For example, several states have established linked datasets with matched records from local hospital, morbidity, mortality and other health records. In Western Australia

(WA), such data have been used to examine hospital use of older people during the last year of life.

Linkage may also occur between longitudinal surveys and administrative data with respondent consent. For example, the Australian Longitudinal Study of Women's Health (ALSWH) links social, environmental and personal factors in women's lives to health care use data, by record linkage with the Medicare database following specific consent from participants. The WA Aboriginal Child Health Survey will be linked to other datasets such as the WA Linked Database.

1.3 The scope and purpose of this report

Studies incorporating, or based primarily on, record linkage to registers or administrative datasets are a valuable way of constructing a longitudinal study which utilises existing data. There are particular ethical and technical issues associated with these kinds of studies which are deserving of consideration in their own right. This report instead focuses on an examination of cohort (longitudinal) studies, and documents recent, current and planned longitudinal cohort studies of ageing in Australia, as well as a selection of international studies.

As a guide to existing studies, it is intended that the report and associated documentation will be a practical resource supporting future efforts to address ageing research needs in Australia. For example, researchers may be able to ascertain whether existing data already exist that may suit their research purposes; research funding bodies may be able to determine whether funding proposals duplicate earlier work or build on it; policy-analysts can use it to identify research studies (and researchers), which can provide relevant information in respect of key policy issues.

This guide also complements and contributes to the Information Development Plan currently being developed by the National Ageing Statistics Unit at the Australian Bureau of Statistics (ABS). The Information Development Plan is a framework that scopes the field of statistics in a given subject area; identifies significant requirements for statistical information in that field; documents the availability of statistics to partially or fully meet that need; and identifies the areas where new statistics need to be developed to more fully satisfy that need.

2 Longitudinal studies and ageing

The longitudinal nature of cohort studies means they are particularly appropriate for obtaining high-quality evidence about ageing across the lifespan. Their advantages over other study designs include their ability to examine multiple exposures, determinants and outcomes, and to measure time relationships. In particular, longitudinal studies can:

- track patterns of development and change over time;
- examine causal relationships between early exposures or determinants and later outcomes;
- identify sequences and pathways;
- identify critical periods in human development for exposures and risks and inform the timing of preventive measures; and
- measure the relative contributions of the multitude of factors that affect development.

An example of the importance of longitudinal research as a means to better understanding these causal relationships is taken from research being conducted by the Australian Government Department of Family and Community Services (FaCS). It has been demonstrated that more than 30% of income-support recipients have a diagnosable mental health disorder compared to 18.6% for non-recipients. However, it is unclear whether this relationship exists because unemployed income recipients are more likely to develop a mental health disorder such as depression, or whether those with existing mental health disorders are more likely to find themselves unemployed and in need of income support. An appropriate understanding of the direction of causation is crucial to targeting effective intervention strategies (at people in society with mental disorders or at income-support recipients) (Butterworth 2003). The information needed to understand this relationship is best gathered over time for both of these groups using longitudinal research methods.

The relevance of longitudinal studies for research into ageing was particularly noted in the 2003 report *Promoting Healthy Ageing in Australia* prepared by an independent working group of PMSEIC. While recognising the value of evidence generated from the analysis of existing data sets, economic modelling and intervention studies, the report states that 'more useful information can be obtained by following a group of people over a period of time, surveying them or taking measurements at regular intervals' through longitudinal research (PMSEIC 2003). The report also suggests that this kind of research is internationally recognised to be at the forefront of multi-disciplinary research on ageing.

Against these advantages of longitudinal studies must be set their cost. Longitudinal research, which demands a long-term commitment of funding over the course of a study, is expensive. This issue has been identified in a number of recent reviews and reports on ageing research in Australia (Kendig et al. 2001). The *Promoting Healthy Ageing in Australia* report recognised the difficulty faced by longitudinal studies in securing adequate funding, when the 'long-term funding required does not fit well into the shorter range funding cycles of most Australian research bodies' (PMSEIC 2003). Similarly, the funding requirements of longitudinal research programs often extend beyond the immediate political and policy-making environment, which can make it difficult to secure long-term financial commitment.

An associated issue for longitudinal research programs is that without adequate resources, it can be difficult to establish an analytical program to run alongside a data-collection program. Some longitudinal research programs generate a wealth of data, yet do not have the

complementary resources to carry out regular analysis, reporting and dissemination of research findings, with the result that the data remain underutilised.

An alternative approach to directly funding data analysis is to make confidential data available for independent research. This ensures a wider utilisation of the data and is the approach adopted by studies such as the Household, Income and Labour Dynamics in Australia (HILDA) Survey, the Longitudinal Surveys of Australian Youth (LSAY)², the Longitudinal Survey of Immigrants to Australia (LSIA) and the United States (US) Health and Retirement Study (HRS). This approach still requires significant resources for the development of adequate technical documentation, appropriate data management structures and a user-support system that ensures appropriate use of the data.

An issue for both approaches to analysis is the investment required to develop the type of research skills among the research community in sufficient quantity and depth, so that the wealth of longitudinal data is exploited to its full extent.³

2.1 Studies included in the overview

There are a large number of longitudinal studies, both in Australia and overseas, that are relevant to ageing issues. The range of studies considered for inclusion in this report was potentially broad, encompassing research on particular cohorts, diseases or social issues as well as those focused on ageing as a process.

The main factor used to identify relevant studies for this overview was whether the population of interest was of immediate relevance to the concerns of an ageing Australia.

Attempts to define the relevant population for ageing research purposes usually involve the designation of a particular age group. A line drawn at age 65 (traditionally thought of as retirement age) is often used to delineate the older proportion of the population. Statistics about the population structure tend to report the number or proportion of the population aged over 65. An additional marker at 85 years is sometimes used to speak about the very old. Older people's services and policies typically target these age groups, and certain health and wellbeing issues are specific to the needs of these age groups (AIHW 2003). Issues associated with workforce participation and retirement may focus on a younger age group; older workers in the paid labour force are usually defined as those aged 45 and over, while early retirees are typically described as those aged in their fifties.

Ageing can also be seen as spanning the whole of life, from birth to death. This lifecourse view of ageing is interested in the impact on older people of cumulative experience over a lifetime. The health and wellbeing of many older people is to some extent affected by demographic, social, economic and health factors operating at younger ages. Current concern about childhood obesity is based, in part, on the recognition that this has long-term impacts.

However, for the purposes of this report, whether a study included respondents aged 45 and over was used to guide decisions about including the study for review. Studies with

² LSAY combines direct funding of an analytic program with making data available for independent researchers. In recent years, a small grants program has facilitated use by independent researchers.

³ These funding implications were also noted by the *Promoting Healthy Ageing in Australia* report (PMSEIC 2003)..

participants in this age bracket encompass the experiences and outcomes of people aged 65 and over, and also include mature workers and people approaching retirement.

However, some well-established Australian studies are primarily focused on younger age groups and these are of interest from a lifecourse perspective. A few of these studies were therefore included for comparative purposes, especially in respect of methodological issues.

Longitudinal studies relevant to the project were identified from Internet searches, electronic databases such as the Australian Social Science Data Archive (ASSDA)⁴ and references offered by colleagues, researchers, policy-makers and research funding organisations. Information on these studies was compiled from publicly available Internet sites, publications, reports and other review projects.

Twenty-one Australian longitudinal studies were selected. Three international studies were included in the report to provide a benchmark against which the Australian longitudinal studies could be considered.

The information collected on the final 24 included studies was used to construct an overview of each study, varying in the level of detail provided according to the availability of information. To ease comparison, these overview documents were hyperlinked to a matrix designed to allow for scanning across a number of studies. While this report had to necessarily limit its scope, the matrix has been designed in such a way as to permit the addition of other studies and the updating of information as necessary.

The principal investigators or nominated representatives were then contacted and provided with a draft copy of the information collected on their respective study. This information included a draft print-out of the matrix demonstrating the scope of other studies included in the report. Investigators or their nominees were given the opportunity to update or correct existing information and to provide any additional details on their study for inclusion in the overview document. The matrix is at Appendix A.

2.2 Comparing the studies

In order to assist comparison of the 24 studies in this report, the studies were grouped together according to the age of the participants and the extent to which data are collected on topics that have a primary focus on the ageing process and associated policy priorities.

Ageing was considered to be primary focus of a study if the ageing process defined investigated topics. For example, a number of studies collect information on housing type (e.g. private dwellings, community housing or institutional settings), housing composition, and living arrangements (e.g. single person or couple households, or households with children). When mapped against age, these questions provide valuable information about housing conditions for the older population. However, these questions do not investigate housing with a specifically ageing focus in mind. In comparison, questions investigating ageing-specific housing requirements, home alterations, and the use of assistive technologies

⁴ The ASSDA located at the Research School of Social Sciences (RSSS) at the ANU, collects and preserves computer-readable data on a broad range of studies and makes it available for further analysis. This resource is not specific to ageing or longitudinal research. The database yielded four studies for inclusion in this report including Negotiating the Life Course (NLC), the ALSWH, the LSIA and the LSAY.

developed for older people, represent a primary focus both on ageing and housing conditions for the older population.

A number of examples can be drawn from studies which have been included in this report. The ALSWH is able to provide a wealth of information on health issues affecting older women, such as a recent report discussing health outcomes among older women at risk of elder abuse (Schofield & Mishra 2004). The primary focus of the study as a whole, however, is on women's health across all ages. Thus it also provides information on the prevalence of illicit drug use in young Australian women, and a profile of women who use complementary and alternative medicine. In contrast, the Dubbo Study of the Health of the Elderly (DUBBO) has identified a set of issues that are particularly salient to the older population, including service use, delay of disability and age-related disease. It also brings an ageing-specific focus to a number of health issues affecting the broader population, such as cardiovascular disease. However, the age of its sample means that it cannot analyse cardiovascular disease among younger people.

Based on these criteria, the grouping of studies is therefore as follows:

1. Studies which predominantly include participants aged 45 and over, and ageing is a primary focus of data collection (Group I).
2. Studies which include participants aged 45 and over, but may also include younger participants. The primary focus of these studies is not necessarily ageing, but they are able to provide valuable information about a broad range of issues affecting various age groups, including older people (Group II).
3. Studies which do not include any participants aged 45 and over, and do not have a data collection focus on ageing in older people. These studies have relevance within a lifecourse perspective on ageing and are also of methodological interest (Group III).

These groups are not hierarchical either in their importance to building the field of knowledge on ageing, their methodological quality or potential usefulness to the policy agenda. Like-studies are grouped simply to facilitate comparisons across the 24 included studies.

2.2.1 Group I studies

Group I studies specifically investigate topics with an ageing focus and include participants mostly over the age of 45. This group includes three international studies.

International studies (Group I—Int)

English Longitudinal Study of Ageing (ELSA)

ELSA investigates the economic position, health, social circumstances, and quality of life of approximately 12,000 people aged 50 and over (and any partners who are under 50) who participated in the 1998, 1999 or 2001 Health Survey for England (HSE). Beginning data collection in 2002, ELSA aims to influence policy as well as to explain how people's expectations and plans for retirement are changing.

The study is a collaborative effort between the Department of Epidemiology and Public Health, University College London (UCL), the Institute for Fiscal Studies (IFS), the National Centre for Social Research and other United Kingdom (UK) university departments. Co-principal investigators are Professor Sir Michael Marmot and Professor James Nazroo. The

National Institute on Aging (NIA) in the US provided approximately half the funding for the first five-year cycle of the study; other funding comes from UK government departments.

Baltimore Longitudinal Study of Aging (BLSA)

The NIA conducts research to learn about the changes that take place as people age and to help understand medical problems that are common in older people. The BLSA was developed to investigate what happens as people age and aims to identify and separate changes due to ageing from those due to disease or other causes. The study began in 1958 and continues to collect information on participants every two years. Sociodemographic, functional health, bio-clinical, psychological, cognitive ability and lifestyle data are collected on over 1,200 men and women aged 20–96 years old.

Prior to the founding of the NIA, which presently resources the BLSA, the project was funded initially by a grant from the Macy Foundation and then the National Institute of Health (NIH) through congressional appropriation. The study was founded by Nathan W Shock, Arthur H Norris and William W Peter and continued under the guidance of Jordan D Tobin, MD and Dr James L Fozard. The present director of the BLSA is Dr Luigi Ferrucci.

Health and Retirement Study (HRS)

The HRS surveys more than 22,000 Americans over the age of 50 every two years. The study paints an emerging portrait of an ageing America's physical and mental health, insurance coverage, financial status, family support systems, labour market status and retirement planning. The HRS is intended to provide data for researchers, policy analysts, and program planners who are making major policy decisions that affect retirement, health insurance, savings and economic wellbeing. The study began in 1998, combining Wave 4 of the original HRS, Wave 3 of the Study of Assets and Health Dynamics Among the Oldest Old (AHEAD), as well as two new sub-samples. An additional sub-sample was included in 2004. The merger preserves the original HRS and AHEAD cohort linkages, allowing longitudinal analysis over all interview years.

The study is supported by the NIA and is run by the University of Michigan's Institute for Social Research in the US. Principal investigator of the study is Dr Robert Willis.

Australian studies (Group I—Aust)

Australian Longitudinal Study of Ageing (ALSA)

ALSA began in 1992, collecting data from 2,087 participants in South Australia (SA). The study allows assessment of the effects of social, biomedical, psychological, behavioural and environmental factors on changes in health, development of disability, general wellbeing, economic security, use of acute and long-term care services, morbidity, mortality, and 'successful' ageing in people aged 70 and over.

ALSA is funded by the NIA in the US, the SA Health Commission, the Australian and SA governments, the Australian Rotary Health Research Fund, the National Health and Medical Research Council (NHMRC) and the Elderly Citizens Home PL. Limited funds were also provided by Flinders University. Principal investigator of the study is Professor Gary Andrews.

The 45 and Up Study (45 and Up)

45 and Up is expected to commence in 2005 and collect data over the next 15 years. The study will look at the general health of more than 250,000 people aged 45 and over in New

South Wales (NSW) and report on health problems and areas of concern. The information will then be used to direct future medical research and health care policy. The study aims to address eight key research priority areas that include socioeconomic determinants of healthy ageing; obesity, overweight and physical activity; cancer; cardiovascular disease; environmental health; mental health; health services; and health in people aged 80 and over.

45 and Up is being carried out under the auspices of the Institute for Health Research (IHR) and will be funded by a consortium of organisations. The study is a collaborative effort between researchers and the wider community in NSW, with about 70 researchers expected to contribute throughout the course of the study. Dr Freddy Sitas is the chair of the study, and Dr Emily Banks is the scientific director.

The Dubbo Study of the Health of the Elderly (DUBBO)

DUBBO is a 15-year study of people born before 1930 living in the town of Dubbo, NSW. A group of 2,805 non-institutionalised citizens aged 60 and over were first interviewed in 1988. The study is a biomedical and social science investigation of healthy ageing, service use, delay of disability and age-related disease, including cardiovascular disease and dementia. DUBBO aims to contribute to policies and programs that improve the quality of life and services for older Australians. A new phase to the study began in 2000 to investigate how income and assets, government entitlements and informal care services modify expected changes in health or family circumstances in later life.

Funding for the study has come from various NHMRC project grants, an ARC Strategic Partnerships with Industry-Research and Training (SPIRT) Grant, the Department of Family and Community Services and Southern Cross Homes. Principal investigators are Professor Leon Simons and Professor John McCallum.

Melbourne Longitudinal Studies on Healthy Ageing (MELSHA) Program

The MELSHA Program consists of a series of three linked studies that form a large longitudinal study on healthy ageing. These studies are: Functional Ageing, Health and Services: A Longitudinal Outcomes Study (FAHS); Health, Behaviours and Outcomes of Older Australians (HBOA); and Health Status of Older People (HSOP). Beginning in 1994, the HSOP formed the baseline for the MELSHA Program and involved 1,000 people aged 65 and over living in Melbourne. HBOA and FAHS involved follow-ups of the original HSOP sample.

Funding for the MELSHA Program has come primarily from Victorian Health Promotion Foundation (VicHealth) and NHMRC Project Grants, but also from ARC Small Grants and the Faculties of Health Sciences at La Trobe University and the University of Sydney. Program directors are Professor Colette Browning and Professor Hal Kendig.

Sydney Older Persons Study (SOPS)

SOPS was conceived in 1988 by the Sydney Older Veterans Health and Services Project to investigate the health of community dwelling veterans of World War II. The study commenced in 1991, and included 327 war veterans and widows and 320 non-veterans aged 75 and over. The five stages of the study consist of medical and neurological assessments of the participants, and data collection on health and lifestyle, and medication history.

SOPS has received funding from the Research and Development Grants Advisory Council, PH and RDC, RFBI, Sir Zelman Crown Foundation and NHMRC over the course of its existence. Research is conducted by the Centre for Education and Research on Ageing

(CERA) of Concord Hospital and at the Prince of Wales Medical Research Institute. The principal investigator is Professor Tony Broe.

Healthy Retirement Project (HRP)

The HRP examined preparation for retirement and its immediate impacts, the ways in which people adjust to retirement and the relationship between health, health behaviours and retirement planning and adjustment. Health and Wellbeing in Retirement built on the HRP by examining the medium-term outcomes of retirement. The longitudinal component of the HRP, which began in 1998, contacted 590 workers aged 50 and over twice before retirement and twice after retirement. Health and Wellbeing in Retirement began in 2000 and followed-up the same individuals two and three years after retirement.

Funding for the studies was provided by VicHealth. Principal investigators are Professor Hal Kendig, Professor David de Vaus, and Dr Yvonne Wells from the Lincoln Gerontology Research Centre, Faculty of Health Sciences, La Trobe University.

Stories of Ageing: A Longitudinal Study of Women's Self-Representation (SoA)

SoA is a longitudinal case study investigating the change in the lives and concerns of approximately 40 women aged 70–85 living outside of institutional care. From 1997 to 1999, the project team worked collaboratively with older women to explore the ways in which their stories of ageing contributed to new understandings of later life and citizenship, and counteracted ageist and debilitating ways of viewing older women.

Funding was provided by the ARC Large Grant Awards for 1997. Principal investigator of the study is Professor Barbara Kamler.

Canberra Longitudinal Study of Ageing (CLSA)

The CLSA is a four-wave 12-year longitudinal study of 1,000 people aged 70 and over living in Canberra and Queanbeyan. Commencing in 1990, the study aims to identify predictors of memory decline and dementia and provide epidemiological data on mental disorders in older Australians.

Funding for the study was provided by a NHMRC Project Grant. Investigators included Professor Scott Henderson, Professor Anthony Jorm, Professor Helen Christensen, Dr Bryan Rodgers and Ailsa Kortten from the Centre for Mental Health Research (CMHR) at the ANU.

Florey Adelaide Male Aging Study (FAMAS)

The FAMAS attempts to identify the wide range of factors that contribute to Australian men's reproductive, physical and emotional health, and their relationship with the ageing process. The study 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. Five hundred and ninety men aged 35–80 in Adelaide's north-west suburbs were recruited in 2002–03; recruitment of a further 600 men will begin in 2004.

A Florey Research Grant awarded for three years provides the funding for the study. The FAMAS involves a collaborative research team headed by Professor Gary Wittert from the University of Adelaide's Department of Medicine.

2.2.2 Group II studies

These studies investigate social, economic, health, psychological or life-choice issues that affect people of all ages, including older people. This group was further divided into studies that include older participants as a single or separate older cohort, and studies that include older participants as part of a mixed age cohort. There was some flexibility in the application of these criteria, however, as studies such as the Melbourne Collaborative Cohort Study were included in the former group even though the cohort is aged 40–69 years.

Older cohort studies (Group II—Older)

Melbourne Collaborative Cohort Study (MCCS)

MCCS (or Health 2000) is a longitudinal study that investigates the role of diet, health and other lifestyle factors in causing common chronic diseases, including cancer, cardiovascular disease and diabetes. It is also designed to investigate possible interactions between common chronic disease and common genetic variants. The study aims have been broadened to include ageing, vision, and depression. A total of 41,528 Australians aged 27–75 (99.3% aged 40–69), were recruited from Melbourne between 1990 and 1994. Follow-up of baseline participants occurs every three to four years.

The study is one of three major research programs operated by The Cancer Council Victoria. Funding is provided predominantly by The Cancer Council Victoria and VicHealth. MCCS is now encompassed by the broader Epidemiology of Chronic Disease, Health Interventions and DNA Studies (ECHIDNAs). The principal investigators are Professor Graham Giles and Dr Dallas English.

A Longitudinal Study of Bone Loss in Men (BLM)

BLM is a longitudinal study of bone mass at forearm, hip, spine and whole body in men. Effects of diet, exercise, genetic polymorphisms, calcium absorption and excretion, bone resorption and bone formation were investigated to determine the rate of bone loss. The study, which occurred between 1990 and 2003, involved 146 ‘healthy white men’ aged 20–83 in Adelaide.

Funding for the study is through divisional funds from the Division of Clinical Biochemistry at the Institute of Medical and Veterinary Science and the Department of Nuclear Medicine and Bone Densitometry at the Royal Adelaide Hospital. Funding for the last wave of the study was received from the University of Adelaide. Principal investigator of the study is Associate Professor Allan Need.

The South Australian Dental Longitudinal Study (SADLS)

SADLS is a longitudinal study of the oral health of older adults. Data collection on 1,650 adults aged 60 and over living in Adelaide or Mt Gambier commenced in 1991, with follow-ups in 1993, 1996 and 2002. Data were collected on dental health status, use of dental services, preventive oral health practices, residential history, sociodemographic characteristics, medical history, mediations, use of tobacco and alcohol and chewing capacity for specific foods. Dentures and oral mucosal tissues were assessed.

Funding was provided by the NHMRC and the US NIH. The study involved a collaborative effort from the AIHW Dental Statistics and Research Unit (DSRU) and Social and Preventative Dentistry, Department of Dentistry, The University of Adelaide. Principal investigators are Professor Gary Slade and Professor A John Spencer.

Australian Longitudinal Study of Women's Health (ALSWH)

Beginning data collection in 1996, the ALSWH (or Women's Health Australia) provides information on women's health issues. The study observes the needs, views, lifestyles, health and factors affecting the health of individual women in Australia. In doing so, the ALSWH is able to provide an accurate and current evidence base to DoHA for the development and evaluation of policy and practice in areas of service delivery that affect women. Over 40,000 Australian women in three age cohorts (18–23, 45–50 and 70–75) were selected from the Australian National Health System Database, and are surveyed every three years.

The study is funded by the Australian Government through DoHA. Investigators include researchers from the University of Newcastle and University of Queensland. The principal investigator is Professor Annette Dobson.

The Personality and Total Health (PATH) Through Life Project

The PATH Project is a 20-year longitudinal study of 7,500 adults in the Canberra and Queanbeyan area. The three age cohorts (20–24, 40–44 and 60–64) were first interviewed in 1999, 2000 and 2001 respectively. The PATH Project aims to investigate the three classes of common mental health problems: anxiety and depression; alcohol and other substance abuse; and cognitive ageing and dementia.

Funding is provided by a NHMRC Program Grant and the Rotary Health Research Fund. Sub-studies have been funded by the NHMRC, CSIRO and Brewer's association. Professor Anthony Jorm, Professor Helen Christensen, Dr Bryan Rodgers, Dr Kaarin Anstey and Dr Keith Dear from the CMHR at the ANU are principal investigators of the project.

Mixed age cohort studies (Group II—Mixed)

Negotiating the Life Course (NLC)

NLC is designed to study the changing lifecourses and decision-making processes of Australian men and women as families and society move from a male-breadwinner orientation to greater gender equity. Detailed information is collected regarding lifetime experiences of paid employment, education and training, relationships and childbearing. The study began in 1996 with subsequent waves in 2000 and 2003. It consists of a national sample of 2,231 people aged 18–54 years randomly selected from the telephone directory.

Funding is provided by the RSSH at the ANU, and the ARC. The study is carried out by the Centre for Social Research in RSSH at the ANU and the School of Social Science at the University of Queensland. Investigators include Dr Janeen Baxter, Professor Peter McDonald, Dr Deborah Mitchell, Dr Ann Evans, Dr Edith Gray and Dr Trevor Breusch.

Household, Income, and Labour Dynamics in Australia (HILDA) Survey

The HILDA Survey is a household-based panel survey which collects data in three main areas: income dynamics; labour market dynamics; and family dynamics. Interviews were conducted with a nationally representative sample of 19,914 adults and children (excluding those living in remote or sparsely populated areas) in 7,682 responding Wave 1 private households. 13,939 of these permanent participants were aged 15 and over and were offered a full interview. The sample is extended over time by including new household members as temporary participants.

The HILDA Survey is funded by the Australian Government through FaCS. Responsibility for the design and management of the survey rests with a group comprising the Melbourne

Institute of Applied Economic and Social Research (University of Melbourne), the Australian Council for Educational Research (ACER) and the Australian Institute of Family Studies (AIFS). Principal investigator of the HILDA Survey is Professor Mark Wooden.

Longitudinal Survey of Immigrants to Australia (LSIA)

LSIA aims to provide reliable data for the Australian Government and other agencies to monitor and evaluate immigration and settlement policies, programs and services. The data can also be used for developing future policies. The LSIA consists of two cohorts: LSIA1 selected 5,192 primary applicants (PAs) aged 15 and over from offshore visa-holding immigrants who arrived between September 1993 and August 1995. Waves of interviews commenced in March 1994, March 1995 and March 1997, each taking place over a two-year period. LSIA2 selected 3,124 primary applicants from offshore visaed immigrants arriving between September 1999 and August 2000. Waves of interviews commenced in March 2000 and March 2001, each taking place over a one-year period.

The study is funded by the Australian Government through the Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) and also received some funding through trusts managed by the states during the initial wave of the study. The study is managed by investigators from the Research and Statistics Section, DIMIA; David Osborne is the LSIA Data Manager.

AusDiab Follow-up Study (AUSDIAB)

AUSDIAB will follow-up the 11,247 participants of the original Australian Diabetes, Obesity and Lifestyle Study, which took place in 1999–2000 and included adults aged 25 and over. AUSDIAB began in June 2004, and will include demographics, anthropometrics, blood pressure, blood and urine testing (for diabetes, lipids and renal function), clinical testing for diabetes complications, self-reported disease status, diet, physical activity and health service utilisation.

The study has received a NHMRC Project Grant for four years, with further funding from Kidney Health Australia (matched by hospital funding), Diabetes Australia and a variety of charities, foundations and pharmaceutical companies. Principal investigator of the study is Professor Paul Zimmet, from the International Diabetes Institute.

2.2.3 Group III studies

These studies investigate a range of issues affecting younger participants (under the age of 45). While studies specifically related to ageing and/or specifically sampling older participants have more immediate relevance to this project in respect of content, sampling and results, it was recognised that this group of longitudinal studies could provide useful insights in respect of design, methodology and data analysis, and ageing from a lifecourse perspective.

Australian Temperament Project (ATP)

The ATP is a longitudinal study of the psychosocial development of a large, representative sample of Australian children born in Victoria between September 1982 and January 1983. The study aims to trace the pathways of psychosocial adjustment and maladjustment across the lifespan, and to investigate the contribution of personal, familial and environmental factors to development and wellbeing. The ATP began in 1983 with an initial sample of 2,443

infants aged 4–8 months and their parents. The fourteenth survey wave is planned to take place when participants are in their mid-twenties.

The AIFS, in collaboration with researchers from the University of Melbourne and the Royal Children's Hospital, now houses the project. The project is presently funded by the AIFS, but has received support from NHMRC and ARC grants as well as the Murdoch Foundation of the Royal Children's Hospital. Investigators include Professor Ann Sanson, Mrs Diana Smart, Professor John Toumbourou, Professor Margot Prior and Professor Frank Oberklaid.

Growing Up in Australia – The Longitudinal Study of Australian Children (LSAC)

LSAC aims to examine the impact of Australia's unique social and cultural environment on the next generation. Beginning in 2004, LSAC will collect data on family functioning, education, health and non-parental child care as well as data on core measures. At least four waves of data will be collected from 5,000 infants and 5,000 children aged 4–5, every two years.

The Australian Government allocated \$20.2 million for four waves of data collection at the start of the study, as part of the Stronger Families and Communities Strategy. Principal investigator of the study is Professor Ann Sanson from the AIFS.

Longitudinal Surveys of Australian Youth (LSAY)

LSAY includes a series of data sets collected in Australia starting in the 1970s. The program concentrates on the transitions made by young people from school into further education and training, the labour force and adulthood. The size of the samples from each cohort ranges from 5,000 to 14,000 students. First contact is made in schools, just prior to the end of compulsory schooling. Young people are followed until about age 25. Current data collection activity is occurring for three cohorts of young people. The 1995 and 1998 cohorts included 13,613 and 14,117 Year 9 students, and the most recent cohort comprised 10,447 15-year-olds in 2003.

Funding for current data collection is provided by the Australian Government through the Department of Education, Science and Training (DEST) and state and territory governments. The LSAY research program is managed jointly by ACER and DEST. Principal investigator of the study is Dr Sheldon Rothman from ACER.

3 Comparing methodology

The design features and methodological approaches used in any longitudinal study will be influenced by the study's purpose and constrained by available funding. Methodological features examined in this chapter include sampling, cohort design, duration of study, frequency of data collection and data collection methods. The level of analysis that can be undertaken is limited by the level of detail that is available on each of the studies.

3.1 Sampling

Information about the sampling methods used by each of the studies is presented in the matrix in Appendix A and accompanying documents.

3.1.1 Sample size and age composition

In single-cohort study designs, sample size clearly refers to the size of the cohort. However, for multiple-cohort designs, it is the size of individual cohorts which is perhaps more important than the combined sample size of all cohorts.

Figure 3.1 is a graphical representation of the age and size of each cohort for each of the 24 studies included in this report.

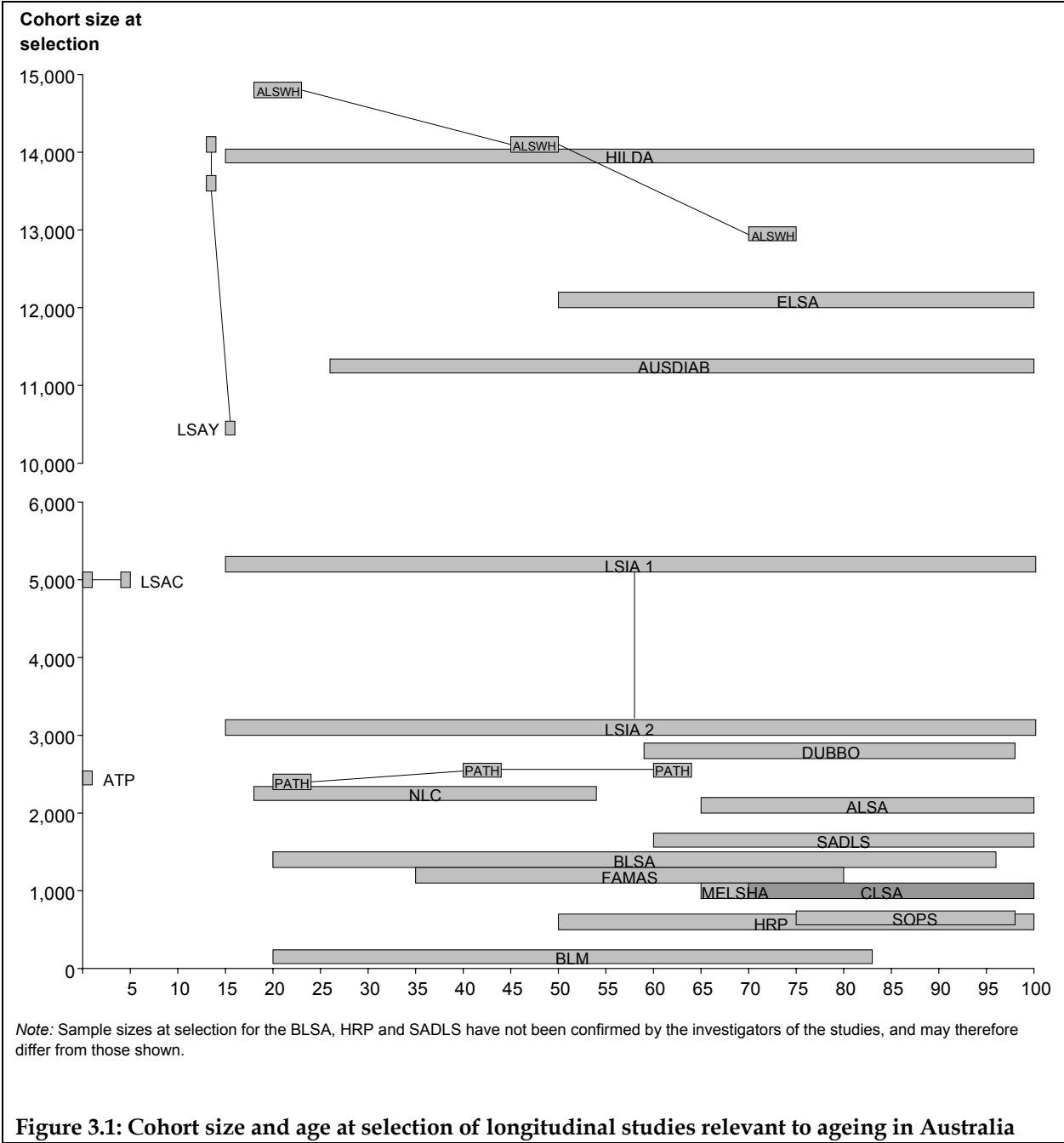
The achievement and maintenance of adequate sample sizes for the purposes of the study is an important consideration for longitudinal studies. Sample attrition is a major issue for longitudinal research as participants may choose to discontinue their participation, or may no longer be able to participate due to relocation, illness or death. A larger baseline sample size offers some protection for the viability of the study over time in the face of such sample loss. At the same time, sample size issues must be related to the purpose and design of the study, and how the population of interest is defined.

Large sample sizes can improve the ability of a study to investigate issues at a sub-population level (e.g. different age groups) and/or adjust for sample loss over time. Large cohorts also increase the capacity of a study to investigate rare conditions or events. They also increase the statistical capacity of the study to disentangle causal relationships. However, large cohorts may not always be necessary. A study investigating a very specific event or condition may not need a large sample size if the condition is very prevalent or if the population of interest can be easily identified and targeted for inclusion in a study.

Figure 3.1 displays only sample size **at selection**. Information is often more readily available about sample size at selection than current sample size. Information about the latter is often only available through project reports or discussions with the researcher(s).

There are a number of other caveats that need to be made about the sample size information displayed in Figure 3.1. Firstly, the available information does not always make it clear, even in a single-cohort design, whether the cohort is being built up over time (e.g. 500 in the first year and an additional 500 in the second year). Information is available in some cases about total sample size over a period of years. This does not necessarily give an indication of the numbers at initial selection.

Secondly, sample size at selection can be defined in a number of ways. The issued sample, the sample that is approached for interview or data collection, or the achieved sample, may be interpreted as the sample at selection. A study may also exclude a few ineligible participants from the achieved sample. For the purposes of this report, the sample size at selection is defined as the eligible achieved sample size (or the achieved sample size where information on the eligible sample size is not provided).



The interpretation of sample size at selection is further complicated with a number of studies performing full or partial interviews with other household or family members. Such participants were not included in the sample size presented in Figure 3.1, unless they were considered to be permanent participants in the study and were offered a full interview:

1. ALSA is therefore shown to collect baseline interview data from 2,087 people, consisting of participants aged 70 and over and any partners that are over 65 years of age.

2. ELSA conducted 12,100 full interviews with participants aged 50 and over and their partners. As information on the age of the partners in the sample was not provided, Figure 3.1 simply represents the age of the sample at selection as 50 years and over.
3. LSIA is displayed as collecting data from 5,196 PAs in LSIA1 and 3,124 PAs in LSIA2, though data are collected on all members of the migrating unit, with the partner of the PA also completing a partial interview.
4. The HILDA Survey consists of permanent Wave 1 participants and temporary sample members recruited at Wave 2. Only the 13,969 permanent participants aged 15 and over (that were therefore offered a full interview) are shown in Figure 3.1.
5. A sample of 2,443 infants are shown to participate in the ATP, although some information is also gathered from and about their parents.

Finally, several studies have not been included in Figure 3.1 because their size extends beyond the scale of this figure. The HRS (22,000 respondents), 45 and Up (planned to reach 250,000 respondents), and MCCA (over 40,000 respondents) consist of single cohorts that are much larger than the individual cohorts of any other study included in this report. On the other hand, SoA includes approximately 40 participants aged 70–85.

As the figure illustrates there is a wide variation in the size of samples included in the 24 studies. Eight of the studies include cohorts of more than 10,000 respondents. Two studies are located in the 3,000–5,000 sample size range, while the bulk of the studies (14) have initial samples of less than 3,000 for each cohort, with three of them being quite small (less than 1,000).

Studies located to the right of the figure are obviously those which include older age groups (Group I and II studies). There are three Group I studies with samples in excess of 10,000 respondents. These include two international studies (ELSA and HRS) and one planned Australian study (45 and Up). The remaining eight Group I studies have samples of less than 3,000 respondents. The BLSA, ALSA, DUBBO, MELSHA Program, CLSA, FAMAS have sample sizes of between 1,000 and 5,000 participants. Noticeably small Group I studies include HRP of 590 retirees and SOPS with 647 participants.

Four Group II studies have samples of over 10,000 respondents (ALSWH, HILDA, MCCA and AUSDIA). LSIA has cohorts of approximately 3,000 and 5,000 participants, while the PATH Project and SADLS have between 1,000 and 3,000 participants. The BLM is a small Group II study with 146 participants.

The three Group III projects also range in size from ATP with less than 3,000 participants, through LSAC with each cohort comprising about 5,000 participants to LSAY with cohorts ranging from 10,000 to approximately 14,000 in size.

3.1.2 Sample population

While age is an obvious characteristic used to define samples for research into ageing, a number of other variables may be used to define the population of interest, such as region, gender and health conditions.

A number of Australian studies focus on respondents from a particular geographic region. DUBBO is a study of people living in a regional centre in western NSW. The CLSA and PATH Project recruited people from the Canberra and Queanbeyan electoral rolls. Other studies with regional samples include the ALSA, FAMAS, SOPS and MCCA. Broader state-level studies include 45 and Up (NSW), and the SADLS (SA). There is no Group I Australian study with a national sample.

The HILDA Survey, ALSWH, LSAY and LSAC are national-level studies, although the ALSWH focuses only on women, and LSAY and LSAC survey younger participants.

Studies where the population is defined by a specific health condition include the BLSA, AUSDIAB and BLM. BLSA entered only healthy subjects into the study, AUSDIAB investigates diabetes in adults aged 25 and over, and BLM recruited husbands of women attending the Royal Adelaide Hospital's osteoporosis clinic, drawing on existing networks to sample.

Among the overseas studies, the ELSA (and possibly the HRS) include both genders, are nationally based and are not restricted to people with particular conditions.

Geographic, health condition, gender, and other restrictions may serve the research purpose of the study. If the scope of a study is already quite limited, the available population from which the sample can be drawn may be quite small. Funding constraints may also affect this design element.

3.2 Cohort design

3.2.1 Single-cohort studies

A range of cohort designs are evident among the studies. These are summarised in Table 3.1. The single-cohort study design is used in at least 13 of the studies, including seven of the Australian Group I studies. SoA, FAMAS, HILDA and the three international studies appear to also involve a single-cohort design. It is the simplest design allowing for the introduction of new measures and settings for all subjects at the same time and under the same conditions.

However, age effects, cohort effects and time-of-measurement effects cannot be distinguished from each other if the cohort is all of the same age. It can therefore be difficult to determine whether an outcome of interest is caused by the age of the cohort, specific experiences and conditions experienced by this cohort and not others (e.g. a Depression-era childhood) or particular influences occurring at the time the data are collected.

An alternative approach is to use a single-cohort, multiple-age design, which recruits a single sample spanning a broad age range allowing for the age stratification and follow-up of the one cohort. This design allows for some disentangling of age, cohort and period effects. While this form of design is run as a single-cohort study, the data can be analysed in a similar way to that generated by a cross-sequential design, provided the cohort is large enough to support age disaggregation. Such studies include ALSA, 45 and Up, MCCS, SADLS, NLC and AUSDIAB.

Single-cohort studies are slower to yield longitudinal results as the population must be followed through a number of data collection waves before analysis of change over time can be made.

3.2.2 Cross-lagged studies

Cross-lagged studies involve an initial cohort recruited at the baseline age of interest and followed forward. At a subsequent time, a second cohort is recruited at the baseline age of interest and followed simultaneously. Additional cohorts may also be recruited at further

assessments. This design makes it possible to distinguish between age effects and cohort or period effects as data are available for more than one cohort at the same age but from different points in time. It is a more expensive design than single-cohort studies.

This design is used in the LSIA and LSAY studies. The three international studies, FAMAS, and HILDA, may also include a cross-lagged component to their design.

3.2.3 Cross-sequential studies

In a cross-sequential design, two or more cohorts of differing ages are recruited at the beginning of the study and followed forwards. This design can allow some accelerated results, providing data on all age groups of interest in the early stages of research. It can also extend the effective timeframe of the study with some limitations. For example, three cohorts may be selected at ages 45, 50 and 55 years. If each cohort is followed for five years, at the end of the period the respondents are aged 50, 55 and 60 years. This effectively provides data about a 15-year age bracket with five years of data collection.

Cross-sequential studies require a long development time as assessment measures for all cohorts and sample ages must be developed and administered at baseline and all subjects must be recruited at the same time. Studies with a cross-sequential design include the ALSWH, PATH Project, and LSAC. The HRS appears to use a variation of this design.

Table 3.1: Cohort design of longitudinal studies relevant to ageing in Australia

Study	Single	Cross-lagged	Cross-seq	Notes
Group I—Int				
ELSA	✓			50+ from 3 years of HSE—HSE may be used to refresh sample as it ages
BLSA	✓	?		1,200 people aged 20–90 years
HRS		✓	✓	22,000+ participants through merging of 1931–41 HRS, 70+ AHEAD & new CODA & WB cohorts, new BB cohort added later
Group I—Aust				
ALSA	✓			2,087 participants aged 70+ (& partners aged 65+), age-stratified
45 and Up	✓			250,000 people aged 45+ recruited 2005–2009, age-stratified
DUBBO	✓			2,805 people aged 60+ in 1988, age-stratified
MELSHA	✓			1,000 people aged 65+ in 1994
SOPS	✓			647 WWII veterans & non-veterans aged 75+
HRP	✓			590 workers aged 50+
SoA	✓			Approximately 40 women aged 70–85
CLSA	✓			1,000 people aged 70+
FAMAS	✓	?		590 men aged 35–80 years recruited 2002–03, a further 600 recruited 2004
Group II—Older				
MCCS	✓			41,528 people aged 27–75 (99.3% 40–69 years), age-stratified
BLM	✓			146 men aged 20–83 years
SADLS	✓			1,650 adults aged 60+, age-stratified
ALSWH			✓	3 cohorts (18–23, 45–50 & 70–75 years), off-year assessment from Wave 2
PATH			✓	3 age cohorts (20–24, 40–44 & 60–64 years)

(continued)

Table 3.1 (continued): Cohort design of longitudinal studies relevant to ageing in Australia

Study	Single	Cross-lagged	Cross-seq	Notes
Group II—Mixed				
NLC	✓			2,231 persons aged 18–54, age-stratified
HILDA	✓	?		13,969 respondents aged 15+, other household members included at Wave 2, stratified by state
LSIA		✓		2 cohorts of immigrants aged 15+ arriving 1993–95 and 1999–2000
AUSDIAB	✓			Follow-up of 11,247 adults aged 25+, age-stratified
Group III				
ATP	✓			2,443 infants aged 4–8 months & their parents
LSAC			✓	2 cohorts (<12 months & 4–5 years)
LSAY		✓		Year 9 students in 1995 & 1998, 15-year-olds in 2003

Key: AHEAD Study of Assets and Health Dynamics Among the Oldest Old; BB Baby Boomers CODA Children of the Depression; HRS Health and Retirement Study; HSE Health Survey for England; WB War Babies WWII World War II.

There is a mix of cohort designs used in the longitudinal studies that have been included in this report, although the single-cohort design appears to be the most common. There is a predominance of single-cohort designs among the Group I studies; most Group II studies are also single-cohort designs, although cross-sequential and cross-lagged designs are also used. The three Group III studies each have a different cohort design.

3.3 Timeframes

Timing issues for longitudinal studies have a number of dimensions, including: the length of the study (starting and finishing dates); the number, length, frequency of and interval between each data collection wave; the interval between cohort selections; and the length of time each cohort remains in the study. A summary of this information is presented in Figure 3.2. Previous, current, and planned waves that occur between 1985 and 2020 are shown for each cohort in the 24 longitudinal studies included in this project.

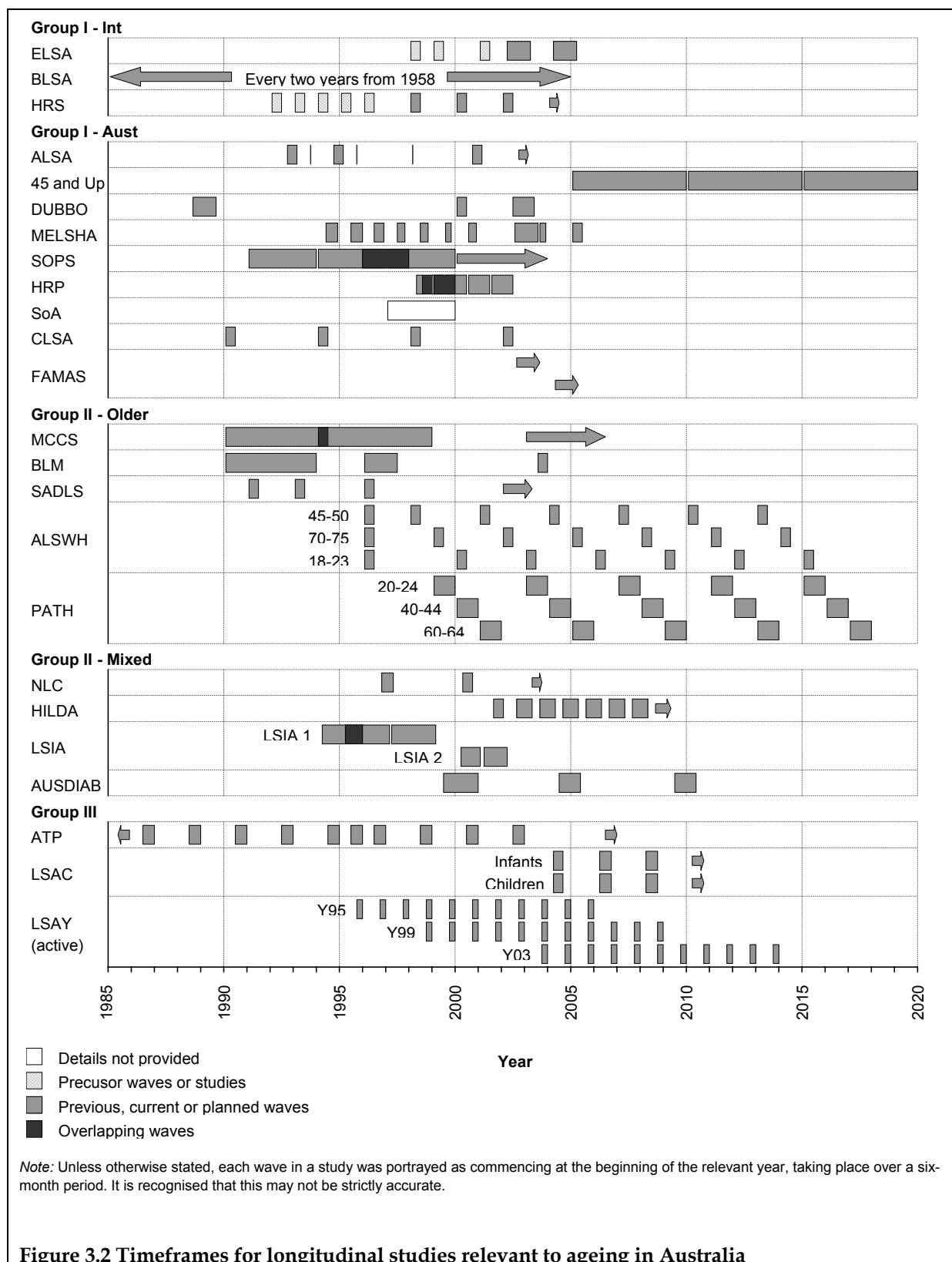


Figure 3.2 Timeframes for longitudinal studies relevant to ageing in Australia

Arrows represent previous waves that do not appear on the scale used in Figure 3.2, or the continuation of a study where details of planned waves are yet unknown. For example, the BLSA and ATP include waves that occurred before 1985, and the BLSA, ALSA, FAMAS, MCCS, NLC, HILDA, ATP, and LSAC plan for future waves but do not provide starting and

finishing dates for these waves. However, this does not exclude the possibility that studies such as the DUBBO, SOPS, and HRP will continue past the dates shown; publicly available information does not indicate the conclusion nor the continuation of these studies.

Approximate dates for the conclusion of the 45 and Up Study, MELSHA, CLSA, BLM, ALSWH, PATH, LSIA and LSAY have been identified and are demonstrated in Figure 3.2.

ALSA and MELSHA are the only Australian Group I studies that currently have more than five waves of data. 45 and Up and DUBBO appear to be the only studies in this group that have spanned (or expect to span) 15 years or more. Beginning in 1988, DUBBO is also the longest running study in this group. In comparison, BLSA (Group I–Int) commenced in 1958 and provides data across a number of decades. ELSA and HRS are both recent but complex studies that have drawn upon existing data and cohorts (these are represented as a single cohort in Figure 3.2).

The MCCS is currently the longest running Group II–Older study, and has commenced the third wave of data collection and has plans for future waves. The ALSWH and PATH Project plan for seven and five waves of data for each of three cohorts. These three studies are also the only studies in this group that expect to span 15 years or more. The MCCS commenced data collection in 1990 and expects to continue past 2005. The ALSWH and the PATH Project identify, as part of their study aim, the continuation of the studies to 2016 and 2019 respectively. HILDA is the only Group II–Mixed study that expects five or more waves of data collection, spanning over ten years.

Commencing in 1983, ATP (Group III) is the longest running active Australian study. Although LSAY brings together a number of studies conducted in Australian schools from the 1970s to the present decade, the most recent active study conducted as part of the LSAY project began data collection in 1995. Both these studies expect more than ten waves of data for each cohort over a period of 20 years or more.

3.4 Data collection methods

There are three principal data collection methods used in longitudinal research:

- survey questionnaire (including self-completed or interviewer-administered);
- clinical measurements, which provide independent and objective measures of health variables in contrast to the self-reporting through a survey questionnaire; and
- researcher observation, such as assessment of outside influence on survey responses, or general mobility in the home.

Decisions about methodology are strongly linked to the content that needs to be collected, the analysis that researchers would like to be able to undertake and the resources that are available to conduct the research.

Table 3.2 summarises the data collection methods used by each study.

Table 3.2: Data collection methods of longitudinal studies relevant to ageing in Australia

Study	Clinical measures	Researcher observation	Survey/Questionnaire		
			Self-completed	Personal	Phone
Group I—Int					
ELSA	✓ HSE nurse visit to collect biometric measures. ELSA nurse visit for anthropometric measurements, blood pressure, lung function, grip strength, lower body strength, balance & blood samples from Wave 2	✓ walking speed test & assessment of cognitive function	✓ self-completion questionnaire	✓ HSE personal interview. ELSA baseline taken from 1998, 1999 & 2001 HSE & interviewed biennially	
BLSA	100+ physiological assessments		Demographics, Physical Activity, Pulmonary Disease, Activities & Attitudes etc.	Diet Interview, Autopsy Study Interview etc.	
HRS	✓ lung function, hand strength & blood test for glycosylated haemoglobin, in-home clinical assessment of a sub-sample to determine dementia status & severity	✓ relationships between household residents, influence of others on respondents answers & respondents level of understanding at initial interview	✓ Off-Year Mail-Out Survey, Human Capital Mail Survey, Consumption & Activities Mail Survey & Diabetes Mail Survey	✓ initial face-to-face interview	✓ biennial follow-up interviews primarily by phone
Group I—Aust					
ALSA	✓ information on medication, blood pressure, physical & mental disabilities, self-report of conditions & symptoms, blood samples collected for Waves 1 & 3	✓ home-based assessment of physiological functions (anthropometry, grip strength, sight, hearing, psychological testing, performance base measures of physical function)	✓ conducted with full assessment personal interview at Waves 1, 3 & 6	✓ full CAPI at Waves 1, 3, 6 & 7	✓ CATI at Waves 2, 4 & 5
45 and Up	✓ saliva, blood & other biological samples may be collected to measure markers of susceptibility, exposure to harmful factors & disease occurrence		✓ brief mail-out questionnaire on socioeconomic factors, health & lifestyle factors at baseline, 5 & 10 years		
DUBBO	✓ medical examination including anthropometry, blood pressure, resting ECG, peak expiratory flow, blood testing for lipids & glucose			✓ questionnaire explored service use, social support, health, depression, past medical history, chest pain, alcohol & tobacco use, education & medication	✓ phone interviews for approx. 100 participants who had moved from the local area in 2002–2003

(continued)

Table 3.2 (continued): Data collection methods of longitudinal studies relevant to ageing in Australia

Study	Clinical measures	Researcher observation	Survey/Questionnaire		
			Self-completed	Personal	Phone
MESLHA	✓ HSOP—in-home examination of weight, height, eyesight, hearing etc. at baseline HBOA follow-up	? HSOP possibly involved researcher observations at baseline	✓ HSOP—brief baseline mail-out covering attitudes & life history with follow-up in 1995 & 1997 HBOA—brief mail-out in 1999 FAHS—brief mail-out in 2003 & 2005	✓ HSOP—health, health behaviours & service use at baseline	✓ HSOP—CATI core variable follow-up in 1996 HBOA—CATI core variable follow-up in 1998, 2000 & 2002 FAHS—CATI follow-up in 2004
SOPS	✓ medical & neuropsychological assessments, blood samples & medication history. MRI scanning & hippocampal measurements of a sub-sample at Stages 4 & 5 with additional follow-up for health changes			✓ extensive in-home interviews of participants & informants (such as family member or close friend) for health changes & impact over time	
HRP			✓ survey administered through employers & by mail		
SoA		✓ researcher observations	✓ researchers worked with women to produce stories of ageing in writing & video diary workshops		
CLSA	✓ measures of physiological functioning, collection of genetic samples & cognitive tests			✓ e.g. Canberra Interview for the Elderly, MMSE, NART, Symbol-Letter Modalities Test, Episodic Memory Test, Informant Questionnaire on Cognitive Decline	
FAMAS	✓ androgens, IGF1, lipids, glucose, LFTs, PSA, body composition, muscle strength, urine flow rate/LUTS. Repeat clinic visit at 5 years		✓ initial mail-out questionnaire & annual follow-up—SF-36, cognitive function, disease status, medication use, lifestyle factors etc.	? qualitative methodology used to evaluate health service utilisation	✓ initial phone interview
Group II—Older					
MCCS	✓ baseline & 2003 follow-up—height, weight, waist & hip measurements, lean & fat mass by bioelectric impedance & blood pressure. Blood samples for analysis of DNA & other molecules. Retinal photographs in 2003 follow-up		✓ lifestyle exposures & self-reports of non-cancer & non-fatal health events updated every 3–4 years by mail or phone	✓ face-to-face interviews at baseline & 2003 follow-up—diet, physical activity, medical history, social support, alcohol & tobacco use	✓ lifestyle exposures & self-reports of non-cancer & non-fatal health events updated every 3–4 years by mail or phone use

(continued)

Table 3.2 (continued): Data collection methods of longitudinal studies relevant to ageing in Australia

Study	Clinical measures	Researcher observation	Survey/Questionnaire		
			Self-completed	Personal	Phone
BLM	✓ bone density in forearm, spine, femoral neck, Ward's triangle, & trochanter measured by absorptiometry		✓ self-report of time spent on physical & sporting activities		
SADLS	✓ clinical oral examination at baseline & at 5 years for all subjects, dentate subjects also re-examined at 2 years. Clock Drawing test & saliva samples at 5 years		✓ Oral Health Impact Profile at baseline, 2 & 5 years. Xerostomia Inventory at 5 years	✓ initial face-to-face interview	✓ telephone interview at 2 & 5 years
ALSWH			24 page mail-out survey including core questions + specific questions for each of 3 age cohorts—rolling 3 year cycle of surveying each cohort		✓ option of completing the survey by phone in English or in the respondent's own language
PATH	✓ cheek swabs taken for genetic analysis. Physical testing carried out by interviewer. Sub-studies include neurocognitive assessments & MRI scans		✓ interview on hand-held computer in presence of interviewer every 4 years for 20 years	✓ memory tests completed by interviewer	
Group II—Mixed					
NLC			✓ PS99 mail-out questionnaire in NLC sub-studies		✓ national random CATI including GHQ with follow-up every 3 years. 3 additional sub-study follow-ups between Waves 1 & 2
HILDA		✓ assessment made of interview situation	✓ annual Self Completion Questionnaire including SF-36	✓ Household Form, Household Questionnaire & (new & continuing) Person Questionnaire administered annually	? CATI may be used in later waves
LSIA				✓ Principal Applicant & Migrating Unit Spouse (subset) questionnaires at 5/6 months, 1 year & 2 years	

(continued)

Table 3.2 (continued): Data collection methods of longitudinal studies relevant to ageing in Australia

Study	Clinical measures	Researcher observation	Survey/Questionnaire		
			Self-completed	Personal	Phone
AUSDIAB	✓ blood & urine testing, clinical testing for diabetes complications, height, weight, waist & hip circumference, retinal photographs, blood pressure		✓ General Health & Wellbeing Questionnaire + 4 questionnaires covering medical history, utilisation of health services, physical activity & diet	✓ short interview covering demographics & some health-related questions	
Group III					
ATP	✓ clinical measurements such as DNA in sub-studies	✓ assessment of child & home in sub-studies	✓ mail-out surveys to parents, teachers, nurses & children aged 11+. Data collected annually from infancy to 3–4 years, then biennially with an additional survey at 1 st year of high school		
LSAC	✓ physical markers & direct assessment tasks when child is an appropriate age	✓ interviewer observation of the external environment	✓ mail-out survey to parents between Waves 1 & 2. Teacher completed Australian EDI in Waves 3 & 4	✓ biennial face-to-face interviews of parents, teachers & child care providers	
LSAY	✓ tests in reading, mathematical & scientific literacy		✓ annual surveys		✓ annual follow-up interviews

Key: CAPI Computer Assisted Personal Interviewing; CATI Computer Assisted Telephone Interviewing; DNA Deoxyribonucleic acid; ECG Electrocardiogram; EDI Early Development Index; ELSA English Longitudinal Study of Ageing; FAHS Functional Ageing and Health Services Project; GHQ General Health Questionnaire; HBOA Health, Behaviour and Outcomes of Older Adults Project; HSE Health Survey for England; HSOP Health Status of Older People Project; IGF1 Insulin Growth Factor 1; LFTs Liver function tests; LUTS Lower urinary tract symptoms; MMSE Mini Mental State Examination; MRI Magnetic Resonance Imaging; NART National Adult Reading Test; PSA Prostate-specific antigen PS99 Parenting Survey 1999.

It is evident that a number of methods of investigation and data collection are used in these studies. While surveys and questionnaires were the most commonly used method of investigation (used in all studies), many of the studies supplemented this information with clinical measures and researcher observations. In addition, many of the studies adopted more than one mode of collecting survey responses and used varying methodologies for the different waves of the study in order to meet specific research objectives.

For example, the HRS involved an initial face-to-face interview, took clinical measures of lung function, hand strength and haemoglobin and had the interviewer make a number of observations about the participant's level of understanding and outside influence. Biennial follow-up surveys were delivered by phone interview and off-year mail-out surveys were administered on specific modules (human capital, consumption and activities and diabetes).

Other studies drawing on all three methods of investigation and data collection include ELSA, ALSA, and LSAC.

A number of studies used only questionnaires to collect data – for example, the HRP, ALSWH, NLC, LSIA, and ATP. However, the ALSWH links records with the Medicare database following specific consent from participants. Other studies which also link data with administrative data sources include the HRS, ALSA, DUBBO, MCCS and PATH. Such linkage is also expected to be a key feature of the 45 and Up study.

Many studies used both clinical measures and questionnaires. Studies in this group include BLSA, 45 and Up, DUBBO, MELSHA, SOPS, CLSA, FAMAS, MCCS, BLM, SADLS, PATH, AUSDIAB, and LSAY. Information gathered through clinical measures or researcher observations can help to validate self-reported data collected by questionnaires, provide an independent measure of health or mental state, and provide information that cannot be collected by any other means.

A final group including SoA and the HILDA Survey collect survey data and some additional information from observation of the interview situation.

Clinical measures are quite expensive and time consuming, involving a visit to a clinic or an in-home nurse visit. Similarly, researcher observations must be made directly and so can only be made during a personal interview, which is also a costly data collection methodology. As such, it is likely that levels of resourcing, as well as the research questions themselves, have an impact on the final design and methods of investigation and data collection that is adopted.

4 Comparing content

The research questions and topics investigated by the 24 studies included in this report were diverse and often complex. A set of key policy themes was therefore used to catalogue and compare the content covered by each study.

4.1 Key policy themes

Recent reports that have identified key policy issues for ageing research include the *National Strategy for an Ageing Australia: An Older Australia, Challenges and Opportunities for All* (Andrews & DoHA 2001), the Intergenerational Report (Commonwealth of Australia 2002) and the *Commonwealth, State and Territory Strategy on Healthy Ageing* (Healthy Ageing Task Force 2000). The priority research topics identified in these reports were further refined in the *Framework for an Australian Ageing Research Agenda: A Background Paper to the National Symposium on Ageing* (AIHW & DoHA 2003) which identified the following areas as requiring additional evidence for service development and policy decision-making:

- maintaining economic growth in the face of an ageing workforce and reduction in the supply of younger workers;
- achieving adequate, sustainable retirement income over lengthening periods of retirement;
- developing positive images of ageing and supporting continued social participation;
- developing age-friendly infrastructure and built environment;
- achieving healthy ageing to maintain health and independence; and
- providing accessible, appropriate, high-quality health and aged care (DoHA 2001).

A number of important issues for healthy ageing in Australia were also identified in the *Promoting Healthy Ageing in Australia* report that was released by PMSEIC in June 2003. The report identified physical activity and nutrition as significant contributors to physical and mental health, also affecting the risk and treatment of chronic diseases associated with ageing. Elements of work and the social environment, such as labour force participation and the contributions to community and family, were recognised as important factors influencing continued social participation. Additionally, aspects of the built environment, such as mobility, independence and autonomy in old age, were linked to facilitation and impediments to healthy choices about physical activity (PMSEIC 2003).

A composite framework incorporating these priority areas and research themes was constructed and is used in the following sections to demonstrate the scope of content covered in ageing-related longitudinal research.

4.2 Comparing content by priority policy themes

Data items collected by each of the 24 studies included in this report were grouped under general sub-headings within the six identified themes. The information is presented in a tabular format, with further detail about data coverage provided for studies that appear to have a major focus on one or more topics within a theme. Details for all studies are provided

in the matrix and accompanying documents. Group III studies which do not focus on ageing issues or include older participants are not considered in this section.

The amount and depth of data collected on each topic, were difficult to determine, due to the absence of detailed information on all studies. Where questionnaire materials were made available for review, this information was used to determine coverage of content. Otherwise, decisions were based on general descriptions of study aims and content which were provided by researchers. Studies are not shown to collect data on a topic if information on that topic appeared to be collected only as a demographic or explanatory variable, as it is assumed that all studies include at least some of these data items.

4.2.1 Theme 1: Maintaining economic growth in the face of an ageing workforce and reduction in the supply of younger workers

Topics within this theme include employment status, barriers to employment, and reasons for unemployment and/or retirement. Challenges facing the paid workforce are included under this theme.⁵ The topics within this theme are strongly linked to those within Theme 2: Achieving adequate, sustainable retirement income over lengthening periods of retirement. As Table 4.1 shows, three international studies, five Australian Group I studies and five Group II studies collect data about employment and retirement. Studies for which these topics appear to be a major focus include ELSA, HRS, HRP, NLC and HILDA.

Table 4.1: Investigation of an ageing workforce across Group I and II studies

	Group I—Int			Group I—Aust							Group II—Older					Group II—Mixed					
	ELSA	BLSA	HRS	ALSA	45 and Up	DUBBO	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB
Employment	✓	✓	✓	✓	✓	✓		✓	✓							✓	✓	✓	✓	✓	
Retirement	✓		✓	✓	✓	✓		✓	✓							✓		✓	✓		

English Longitudinal Study of Ageing

One of the 12 modules focuses on work and pensions, collecting details on employment, job characteristics, earnings, occupational pension contributions or receipts, and retirement decisions. It includes information about job search, training, voluntary activities and medical insurance where relevant. The module collects sufficient information to establish individual pension contributions and pension rights for those not currently drawing pensions and to determine how these will change with employment or retirement decisions.

Health and Retirement Study

Although the data items vary between waves, modules specifically investigating employment and/or retirement are included in each wave of the study. Data items include but are not restricted to employment status, main job description (income and earnings,

⁵ Issues affecting the volunteer workforce are covered in Theme 3: Developing positive images of ageing and supporting continued social participation.

hours, benefits), job requirements, impairments or injuries at work, description of previous or other work, job seeking activities, current retirement status, attitude towards retirement, pension and retirement plans, and exposure to health hazards.

Healthy Retirement Project

The HRP examined preparation for, and the immediate impacts of, retirement; the ways in which people adjust to retirement; and the relationship between health, health behaviours, and retirement planning and adjustment. Health and Wellbeing in Retirement built on the HRP by examining the medium-term outcomes of retirement, including the ways in which pre-retirement and early post-retirement intentions regarding health and health behaviours shape the ways in which people build their lives after retirement; and the ways in which different retirement styles and pathways affect medium-term health and health-related behaviour.

Negotiating the Life Course

One of the five NLC research areas focuses on work and family life, and how these two spheres interact. There are three specific research aims:

- to investigate what changes take place in the management and organisation of domestic labour as a result of women's movement into paid employment and to examine how these changes vary across differing socioeconomic groups and lifecycle stages;
- to identify the mechanisms associated with men's and women's employment that might lead to changes in household organisation; and
- to examine the relationship between work identities and domestic identities.

Household, Income and Labour Dynamics in Australia Survey

The HILDA Survey collects data in three main areas, including labour market dynamics, in an attempt to answer questions such as:

1. What are the patterns and correlates of employment, unemployment and non-participation?
2. What does the distribution of completed employment or unemployment spells look like?
3. How much cycling in and out of employment occurs around retirement?
4. What factors (e.g. the age pension) determine or distort decisions regarding retirement?

HILDA also includes additional research questions on job search, and considers the association between economic outcomes such as poverty and unemployment, and health (including disability), family break-up and neighbourhood.

4.2.2 Theme 2: Achieving adequate, sustainable retirement income over lengthening periods of retirement

Income and assets, superannuation, taxation and benefits, expenses and insurance are issues that are central to the independence and self-provision of older people, and which significantly affect retirement and lifestyle choices in older age. As mentioned, the topics within this theme are often discussed in relation to issues of employment and retirement. All three international studies, five Australian Group I studies, and four Group II studies collect data about retirement incomes and related financial issues. Further detail about ELSA, HRS, DUBBO, NLC and HILDA illustrates the type of data items collected under this theme.

Table 4.2: Investigation of retirement incomes across Group I and II studies

	Group I—Int			Group I—Aust							Group II—Older					Group II—Mixed					
	ELSA	BLSA	HRS	ALSA	45 and Up	DUBBO	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB
Income and assets	✓	✓	✓	✓	✓	✓		✓	✓							✓		✓	✓	✓	
Superannuation	?		?			✓		✓	?									✓	✓	✓	
Taxation and benefits	✓		✓			✓			?							✓		✓	✓	✓	
Expenses	✓		✓			✓			?										✓	✓	
Insurance	✓		✓					✓											✓	✓	

Note: ? is used where available information suggests, but does not verify, that data may be collected in this area.

English Longitudinal Study of Ageing

One of the 12 modules of ELSA focuses on income and assets. The module is modelled fairly closely on the Health and Retirement Survey, and collects data on:

- sources of income, including pensions, annuity income, health and disability benefits, intra-family transfers, income from savings or assets, and rent;
- assets including value of money accounts, stocks and shares, premium bonds, life insurance, value of real assets such as property, inheritance or works of art;
- information on debts from credit cards, purchase order agreements, and formal and informal loans; and
- organisation of family finances.

Health and Retirement Study

The HRS aims to examine the relationships between health, income and wealth over time. Although the data items vary between waves, modules specifically investigating income and assets, net worth, insurance and/or capital gain are included in each wave of the study. Topics include but are not restricted to current assets, expenses, income, net worth, wills, pensions and benefits, supplemental security, health and life insurance, workers compensation, financial assistance and provisions for children.

Dubbo Study of the Health of the Elderly

A new phase to DUBBO (commenced in 2000), aims to model how three kinds of resources, income and assets, government entitlements and informal care services modify expected changes in health or family circumstances in later life. The specific objectives were to model hospital use, residential care admission, informal community care, pension and benefit receipt, pharmaceutical benefit use and income and assets in an older cohort. Data were linked to pensions and assets records. The study also collected data on superannuation, taxation and expenses.

Negotiating the Life Course

One of the five NLC research areas focuses on income inequality. This area explores the dynamics of income between waves and relates the observed income changes to movements

in and out of the labour market, and other lifecourse events such as marriage, divorce and childbirth. Wave 3 of the study also includes questions regarding superannuation.

Household, Income and Labour Dynamics in Australia Survey

The HILDA Survey collects data in three main areas, including income dynamics, which focuses on income, wages and pay, savings, and taxes and benefits. Questions regarding income from superannuation, life insurance, and/or allocated pensions are included in each wave of the study. Wave 2 included a specific module on household wealth, and private health insurance questions are planned for Wave 4. HILDA also considers the association between economic outcomes such as poverty and unemployment, and health (including disability), family break-up and neighbourhood.

4.2.3 Theme 3: Developing positive images of ageing and supporting continued social participation

Topics within this theme include social involvement and support (e.g. organisation membership, leisure activities), family and community contributions (e.g. family care, volunteer activities), elder abuse and age discrimination (including attitudes towards older people), and education and training. The issues within this theme are often associated with those identified in Theme 1: Maintaining economic growth in the face of an ageing workforce and reduction in the supply of younger workers. For example, paid and unpaid workforce participation and training may significantly impact social involvement, while negative images of ageing and age discrimination may present barriers to employment and encourage early retirement. As Table 4.3 indicates, almost all studies included in this overview collect some data relevant to this theme, including all three international studies, seven Australian Group I studies and six Group II studies. Details for studies including ELSA, ALSA, DUBBO, SoA, ALSWH, and LSIA are provided below.

Table 4.3: Investigation of attitudes, lifestyle and community support across Group I and II studies

	Group I—Int			Group I—Aust							Group II—Older					Group II—Mixed					
	ELSA	BLSA	HRS ^a	ALSA	45 and Up	DUBBO	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB
Social involvement and support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓		✓	✓			✓	✓	
Family/community contributions	✓		✓	✓		✓		✓	✓	?						✓		✓	✓		
Elder abuse and age discrimination										✓						✓					
Education and training	✓		✓	✓		✓			✓							?		✓	✓	✓	
Religion, ethnicity, language, culture		✓	✓	✓	✓					✓						?	✓	?	✓	✓	

(a) The HRS includes experimental modules that examine social involvement and support; family and community contributions; and religion, ethnicity, language and culture.

Note: ? is used where available information suggests, but does not verify, that data may be collected in this area.

English Longitudinal Study of Ageing

The ELSA includes a module on social participation, which assesses levels of social integration and exclusion. Participants are asked questions regarding caring responsibilities, various social and cultural activities, membership of organisations, and satisfaction with their level of social activity. A number of related items are covered in other modules (particularly the self-completion questionnaire). Specifically, participation in education and voluntary activities is found in the work and pensions module.

Dubbo Study of the Health of the Elderly

The DUBBO is a biomedical and social science investigation of healthy ageing, service use, delay of disability and age-related diseases such as cardiovascular diseases and dementia. One of the strengths of DUBBO is the inclusion of questionnaires examining life satisfaction, self-esteem and social support. Social involvement and family and community contributions (including voluntary work) are major foci of the study.

Stories of Ageing: A Longitudinal Study of Women's Self-Representation

SoA investigates the change in the lives and concerns of an increasingly dominant social group in Victoria – women aged 70–85 living outside of institutional care. The project team worked with older women to produce alternative images and stories of ageing that contribute to new understandings of later life and an active sense of citizenship, and counteract ageist and debilitating ways of viewing older women. Workshops with Vietnamese women aged 55–74 allowed researchers to explore issues concerning cross-cultural communication and interpretation.

Australian Longitudinal Study of Women's Health

The ALSWH includes a theme on time use, which includes questions about paid and unpaid work, family roles and leisure. Questions regarding education and training, family composition, and religion, ethnicity and culture are included in the sociodemographic factors theme. A number of sub-studies cover topics including social isolation in the elderly and violence and abuse.

Longitudinal Survey of Immigrants to Australia

Both LSIA surveys cover similar topics, including support services, ancestry, religion and ethnicity, language, qualifications, and education and training. For example, information is collected on English proficiency, changes in English proficiency, main languages spoken at home, spoken and written languages required for work, main methods of learning English (e.g. AMEP or TAFE courses), main reasons for learning English (e.g. work or survival English), whether English courses improved English proficiency, and ways that current language courses improved English proficiency. Particular attention is given to how outcomes and activities vary across five visa eligibility categories.

4.2.4 Theme 4: Developing age-friendly infrastructure and built environment

This theme includes topics on housing, land use, assistive technology (including information and communication technology), and access to public transport and other key facilities. Access to assistive technology and transport may have significant impacts on employment, social involvement, and utilisation of health and welfare services. Three international

studies, five Australian Group I studies, and four Group II studies collect data on these topics. No Australian study addresses assistive technology.

Table 4.4: Investigation of infrastructure and built environment across Group I and II studies

	Group I—Int			Group I—Aust							Group II—Older					Group II—Mixed					
	ELSA	BLSA	HRS	ALSA	45 and Up	Dubbo	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB
Housing and land use	✓	?	✓	✓	?	✓	✓	✓	✓							✓		✓	✓	✓	
Assistive technology	?	✓	✓																		
Access to transport and key facilities	✓					✓		✓	✓							✓					

Note: ? is used where available information suggests, but does not verify, that data may be collected in this area.

English Longitudinal Study of Ageing

ELSA includes a module on housing, where the financial respondent is asked questions regarding:

- current tenure of main home, details of rent payments, mortgage arrangements and any loans or other financial measures taken to pay for the accommodation;
- housing type and quality, such as facilities and services included in rent, number of rooms, adjustments done to the accommodation and special features;
- ownership of durables, such as telephones, deep freezes or computers, and access to private vehicles; and
- subjective perceptions of housing, such as difficulties with paying the rent or mortgage, and problems with the housing, such as noise, dirt or decay.

Questions on access to key facilities and questions about the neighbourhood that provide a measure of social capital are covered in the self-completion questionnaire. The module on social participation covers available transport options.

Health and Retirement Study

Although the specific data items collected vary between waves, modules specifically investigating housing are included in each wave of the study. Data items include type of housing (any income or age limits, entry fees or association payments), services offered to residents, special features for the physically impaired, ownership status, home value or rental information, information on secondary residences and vacation homes, other housing costs including utilities, insurance, mortgage costs, taxes, and neighbourhood. In-home care and special facilities are addressed in modules on health care and activities of daily living (ADLs).

4.2.5 Theme 5: Achieving healthy ageing to maintain health and independence

This theme includes topics on disability and ADLs, sensory information, men’s and women’s health (including sexual health), mental health and cognitive ageing, oral health, lifestyle

and risk factors, and medications. Clinical health measures include data items such as height and weight, blood pressure, cholesterol, glucose tolerance, hormone levels and other biochemical measurements and biomarkers. Eighteen of the 24 studies collect data on topics in this area, and most of these collect data about many topics. Almost all studies include questions on general health and wellbeing, although studies such as LSIA are not shown to collect data on any particular aspect of health in the table below.

Table 4.5: Investigation of healthy ageing across Group I and II studies

	Group I—Int			Group I—Aust								Group II—Older					Group II—Mixed				
	ELSA	BLSA	HRS	ALSA	45 and Up	DUBBO	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB
Clinical health measures	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓	✓		✓				✓
Disability and ADLs	✓	✓	✓	✓	✓	✓	✓	✓				✓	?		✓	✓			✓		
Disease	✓	✓	✓	✓	✓	✓	✓	✓				✓	✓	?	✓	✓			✓		✓
Hearing and vision	✓	✓	✓	✓	✓	✓	✓	✓			✓		✓				✓				✓
Men's/women's health		✓		✓	✓	✓						✓				✓		?			
Mental health	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓				✓	✓			
Psychology and cognitive ageing	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓			✓		✓		✓		
Oral health		✓		✓	✓			✓							✓						
Physical activity	✓	✓	✓	✓	✓	✓	✓	✓	?			✓	✓	✓		✓	✓		✓		✓
Obesity		?	✓	✓	✓		✓					✓	?			✓	✓				✓
Nutrition		✓	?	✓	✓	✓	✓		?			✓	✓	✓	✓	✓	✓				✓
Drug, tobacco and alcohol use	✓		✓	✓	✓	✓	?	✓	?			✓	✓		✓	✓	✓		✓		✓
Pharmaceutical interventions	?			✓	?	✓	✓	✓				✓			✓		✓				?
Medical/family history	?	✓		✓	✓	✓	?	✓				✓	✓		✓						✓

Note: ? is used where available information suggests, but does not verify, that data may be collected in this area.

English Longitudinal Study of Ageing

The ELSA includes a substantial module on health. Topics include: self-reported general health; longstanding illness; diagnosed conditions; eyesight and hearing; cardiovascular disease and hypertension; diabetes; stroke; respiratory symptoms and chronic lung disease; chest pain; asthma; arthritis and osteoporosis; cancer; Parkinson's disease; mental illness; dementia; falls, fractures and joint replacements; pain and symptoms; dizziness; disability and functioning including ADLs/IADLs; mobility aids; incontinence; and health behaviours including smoking, alcohol, and physical activity. In Wave 1 and Wave 2 the self-reported mobility questions are complemented by a timed walking-speed test. A nurse visit from Wave 2 will involve the collection of blood samples and anthropometric and blood pressure

measurements. Other modules cover several different aspects of cognitive functioning (e.g. memory, language and executive function), and psychological health and perceived age.

Baltimore Longitudinal Study of Aging

The BLSA investigates what happens as people age and attempts to sort out changes due to ageing from those due to disease (e.g. dementia, arthritis, prostate cancer, cardiovascular disease and depression) or other causes. Topics include:

- functional health: self-reported health, hearing loss, taste sensations, vision testing, muscle strength and timed gait;
- bio-clinical: blood pressure, medical history and physical examination, immunological assays, ability to perform aerobic exercises, arterial stiffness, echocardiography; cardiac Magnetic Resonance Imaging (MRI); vascular medications; blood cholesterol levels; prostate-specific antigens measures, alcohol metabolism in men, glucose tolerance, plasma lipids, lipoproteins, body-fat distribution, diabetes predictors, renal function, pulmonary function, oestrogen levels, neurological exam, bone and joint osteoporosis and osteoarthritis and brain imaging; prostate imaging;
- psychological: stability of personality; temperament and coping mechanisms;
- cognitive abilities: visual recall, vocabulary and memory/reaction time; and
- lifestyle: nutrition, diet trends and physical activity.

Health and Retirement Study

The HRS includes modules on health and cognition. Data items include: falls and fractures; ADLs/IADLs; conditions including arthritis, diabetes, cancer, incontinence, lung disease, hypertension, stroke and heart problems; pain and symptoms; vision and hearing; height and weight; physical activity; alcohol, drug and tobacco use; preventive procedures; self-rated health; depression and mental health; and cognition. Clinical measures include lung function, hand strength, and a self-administered blood test for glycosylated haemoglobin.

Australian Longitudinal Study of Ageing

Among other topics, data relating to ADL/IADL performance, cognitive function, comorbidity, cardiovascular disease and risk factors, dental health, diet and nutrition, diabetes, exercise and physical activity, injuries and falls, mortality, and hearing and sensory function, are being analysed. Data are also collected on medication, health history, and physical and mental disabilities. Clinical measurements include anthropometry, grip strength, blood pressure, blood samples, hearing, sight, psychological testing and performance base measures of physical function.

45 and Up

45 and Up will focus on the burden of disease in NSW requiring active treatment; socioeconomic determinants of healthy ageing; the health effects of lifestyle factors such as overweight, obesity and physical activity on cancer, cardiovascular disease and diabetes; risk factors, detection and management of cancer (e.g. prostate cancer); impact of environmental factors on healthy ageing; mental health (e.g. depression) and the use of psychiatric health services; the use of health services, including determinants of use of residential care; and health in people aged 80 and over. Later waves of the study may involve clinical measurements such as saliva and blood tests.

Dubbo Study of the Health of the Elderly

Broad outcomes of interest in DUBBO were mortality, hospitalisation and placement in long-term care, while the specific objectives were cardiovascular disease, osteoporosis, disability and dementia. These were related to baseline characteristics such as lifestyle and dietary exposures (e.g. vitamin supplements), pharmaceutical interventions, medical/family history, social class, income, education, physical activity and physical measurements. Data were also collected on hearing and vision, women's health and mental health (e.g. depression).

Melbourne Longitudinal Studies on Healthy Ageing Program

The MELSHA Program consists of three linked studies which examine healthy ageing from biomedical, psychological, behavioural and social perspectives. Among other topics, HSOP collected data on medical conditions, including continence, musculoskeletal and cardiovascular disease, falls and injuries, confusion, pain, medication use, depression and mental health, health behaviours (e.g. nutrition, physical activity and social activity) and wellbeing. HBOA focused on biannual health behaviour change, wellbeing, social interaction and continued annual measurements of functional ageing, health and service outcomes. FAHS attempted to identify the factors that precipitate disability onset, service use, duration of care at home after disability onset, and predictors of entry to residential care.

Sydney Older Persons Study

Stages 1, 2 and 4 of SOPS involved visiting people in their homes and conducting medical and neuropsychological assessments. Participants were also asked about their health and lifestyle (e.g. exercise, smoking and alcohol consumption). Stage 3 involved taking a blood sample and completing a medication history. Stages 4 and 5 involved MRI scanning of the brain. Previous SOPS findings have focused on disease, disability and service use; prediction of dementia; prediction of mortality; life satisfaction and depression; medication use; alcohol; and laboratory results.

Canberra Longitudinal Study of Ageing

The CLSA aims to identify predictors of memory decline and dementia and provide epidemiological data on mental disorders in older Australians; relationships with apolipoprotein E (apoE) e4, personality, education level and activity levels have been investigated. Although the study focuses primarily on depression and cognitive impairment, extensive data on physical health and mortality are also available.

Florey Adelaide Male Aging Study

The FAMAS attempts to identify the wide range of factors that contribute to Australian men's reproductive, physical and emotional health, and their relationship with the ageing process. In addition to a range of chronic medical and psychological conditions, such as obesity, cancer, diabetes, cardiovascular disease and mental health, the study will focus on endocrinology of ageing (e.g. male sex hormones, insulin growth factor axis); and prostate health and function in relation to the hormonal changes of ageing.

Melbourne Collaborative Cohort Study

MCCS aims to investigate the role of diet, health, lifestyle factors (e.g. alcohol and tobacco use, and physical activity) and common genetic variants in causing diseases such as cancer, cardiovascular disease and diabetes. The aims of the study have been broadened to include ageing, vision and depression. Measurements include height, weight, hip circumference,

lean body and fat mass, blood pressure, retinal photographs, and blood samples for deoxyribonucleic acid (DNA), glucose, fatty acid and hormone analysis.

South Australian Dental Longitudinal Study

The SADLS is a longitudinal study of the oral health of older adults. Interviews contained 72 questions concerning dental health status, use of dental services, preventive oral health practices, residential history, sociodemographic characteristics, medical history, medications, use of tobacco and alcohol, and chewing capacity for specific foods. Clinical examinations included an assessment of any dentures and the oral mucosal tissues. Oral disorders were scaled as causing functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability or handicap. Self-perceptions of dry mouth, eyes and throat, difficulties with swallowing and eating, and the use of sweets to relieve dry mouth were examined, and cognitive status was also assessed.

Australian Longitudinal Study of Women's Health

ALSWH looks at the needs, views, lifestyles, health and factors affecting the health of Australian women. The study has five main themes. Weight and exercise examines the impact of weight and exercise, dieting and eating disorders on health outcomes. Life stages and key events includes questions on childbirth, menopause, major illness, falls and fractures in the elderly, and dementia. Data are also collected on general wellbeing, emotional health and on smoking, alcohol and drug use.

PATH Through Life Project

PATH aims to investigate the three classes of common mental health problems: anxiety and depression; alcohol and other substance abuse; and cognitive ageing and dementia. The project investigates four broad themes that are relevant to each of these problems: ageing versus cohort effects; social, psychological, nutritional and genetic risk factors; and comorbidity of mental health problems. Measurements include physical testing and memory tests, cheek swabs for genetic analysis, and neurocognitive assessments and MRI scans.

AusDiab Follow-up Study

AUSDIAB will include demographics; anthropometrics (e.g. measurements of height, weight, waist and hip circumference); blood pressure; blood and urine testing (for diabetes, lipids and renal function); clinical testing for diabetes complications (e.g. neuropathy and retinopathy, including a retinal photograph); self-reported disease status; and questionnaires on medical history, diet, physical activity and health service utilisation.

4.2.6 Theme 6: Providing accessible, appropriate, high-quality health and aged care

Utilisation of health services (including mental health services), welfare services, entry to residential care, and carer information are included within this theme. Fourteen studies, including seven Group I and four Group II – Older studies, collect data on topics under this theme. SOPS is the only study to address carer support/stress. Further details about some of the studies are provided below.

Table 4.6: Investigation of health and aged care across Group I and II studies

	Group I—Int					Group I—Aust					Group II—Older					Group II—Mixed					
	ELSA	BLSA	HRS	ALSA	45 and Up	DUBBO	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB
Health services			✓	✓	✓	✓	✓	✓			✓	✓	✓		✓	✓	✓			✓	✓
Welfare services	?			✓	?	✓	✓	✓								?				✓	
Residential care			✓	✓	✓	✓	✓								?						
Carer support/stress								✓													

Note: ? is used where available information suggests, but does not verify, that data may be collected in this area.

Health and Retirement Study

The HRS includes an expenditure sequence on health services in the module on health status. Respondents were asked about hospital, nursing home or General Practitioner (GP) visits and the use of prescription medications, and the associated costs. Earlier waves included a module on health care utilisation and costs (previous 12 months) which addressed hospitalisations, nursing home stays, doctor visits, outpatient surgery, dental care, prescription drugs, bed days, whether covered by Medicare, and out-of-pocket costs.

Australian Longitudinal Study of Ageing

ALSA aims to investigate the effects of health care provision and utilisation on transitions in health and functional status; assess the demand for health care services and both informal and formal long-term care; and examine the patterns of, the need for, and the utilisation of, informal and formal sources of long-term care as they relate to social-support networks, economic and housing conditions, care-giving arrangements and the availability of appropriate services.

45 and Up

45 and Up aims to address eight research areas, which include: the examination of risk factors for mental health problems in later life, and the use of psychiatric health services; and the use of health services in relation to ageing, including determinants of use of residential care. Further information may be provided by record linkage with NSW hospitalisation data (e.g. hospital admission and medical and surgical procedures), ambulance data, Emergency Department attendances, the Pharmaceutical and Medical Benefits Schemes, Australian and New Zealand dialysis and transplantation register, BreastScreen NSW, NSW Pap test register, NSW Midwives' data collection, Radiotherapy Management Information System, and use of aged care facilities.

Dubbo Study of the Health of the Elderly

DUBBO aims to identify patterns and predictors of mortality, hospitalisation and need for residential care. The newest phase of the study aims to model how income and assets, government entitlements and informal care services modify expected changes in health or family circumstances in later life. The specific objectives were to model hospital use, residential care admission, informal community care, pension and benefit receipt, pharmaceutical benefit use and income and assets in an older cohort.

Melbourne Longitudinal Studies on Healthy Ageing Program

HSOP collected data on service use (e.g. health services, community services and residential care). HBOA focused on biannual health behaviour change and continued annual measurements of functional ageing, health and service outcomes. FAHS attempted to identify the factors that precipitate disability onset, service use, duration of care at home after disability onset, and predictors of entry to residential care.

Sydney Older Persons Study

Previous SOPS research findings have identified disability as the strongest predictor of service use within the study population. Other findings include symptoms of stress and depression among carers who provide greater levels of assistance to study participants with illness or disability.

Florey Adelaide Male Aging Study

In addition to a range of chronic medical and psychological conditions, FAMAS will focus on men's utilisation of health services, including preventive and early intervention services, and guide the development of appropriate health services and policy.

South Australian Dental Longitudinal Study

Interviews contained questions concerning use of dental services, preventive oral health practices and residential history.

Australian Longitudinal Study of Women's Health

ALSWH has five main themes. Use and satisfaction with health care services investigates availability of, access to, and utilisation of health care services (e.g. GPs, specialists), cultural appropriateness and women's perceptions of the quality of care provided. Linkage of survey responses provides information about types of service, characteristics of providers, and out-of-pocket costs of Medicare-eligible services. The study aims to identify when, if and how the health system meets the health needs of women, and help guide future policy and planning of women's health care services.

PATH Through Life Study

PATH examined the types of factors that were associated with young adults aged 20–24 visiting GPs, by linking sociodemographic and health data with Medicare records of GP visits. The impact of pet ownership on health and health service use by adults aged 40–44 was also examined.

AusDiab Follow-up Study

AUSDIAB aims to provide information on Diabetes mellitus, heart disease and health-related behaviour, in order to develop ways of improving people's health and the provision of health services. Participants complete four short questionnaires, one of which specifically investigates health service utilisation.

4.3 Summary

Table 4.7 summarises information about the data collected by the 24 studies included in this report. If the range of data coverage by each study is considered, Table 4.7 shows that most studies collect data relevant to more than one theme. Exceptions to this would appear to be

SoA and BLM. Thirteen of the 21 Group I and Group II studies collect data across at least four themes.

Table 4.7 Content coverage by priority policy theme

Study	Theme 1 ^(a)	Theme 2 ^(b)	Theme 3 ^(c)	Theme 4 ^(d)	Theme 5 ^(e)	Theme 6 ^(f)	Total
Group I—Int							
ELSA	✓	✓	✓	✓	✓	?	5–6
BLSA	✓		✓	✓	✓		4
HRS	✓	✓	✓	✓	✓	✓	6
Group I—Aust							
ALSA	✓	✓	✓	✓	✓	✓	6
45 and Up	✓	✓	✓	?	✓	✓	5–6
DUBBO	✓	✓	✓	✓	✓	✓	6
MELSHA			✓	✓	✓	✓	4
SOPS	✓	✓	✓	✓	✓	✓	6
HRP	✓	✓	✓	✓	?		4–5
SoA			✓				1
CLSA					✓	✓	2
FAMAS					✓	✓	2
Group II—Older							
MCCS			✓		✓	✓	3
BLM					✓		1
SADLS			✓		✓	✓	3
ALSWH	✓	✓	✓	✓	✓	✓	6
PATH	✓		✓		✓	✓	4
Group II—Mixed							
NLC	✓	✓	✓	✓	✓		5
HILDA	✓	✓	✓	✓	✓		5
LSIA	✓	✓	✓	✓		✓	5
AUSDIAB					✓	✓	2
Total	13	11	17	12–13	18–19	14–15	85–88

(a) Maintaining economic growth in the face of an ageing workforce and reduction in the supply of younger workers.

(b) Achieving adequate, sustainable retirement income over lengthening periods of retirement.

(c) Developing positive images of ageing and supporting continued social participation.

(d) Developing age-friendly infrastructure and built environment.

(e) Achieving healthy ageing to maintain health and independence.

(f) Providing accessible, appropriate, high-quality health and aged care.

International studies that collect data across all six themes include the HRS and possibly ELSA, while among the Australian Group I studies ALSA, DUBBO, SOPS and possibly 45 and Up collect data across all themes. Among the Group II studies ALSWH covers all six themes. In other words, very few studies have a narrow focus.

Secondly, if we consider which themes are covered more extensively than others through the data collection activity of these studies, we can note the following:

- every theme is covered by at least ten studies;
- the second theme of retirement income is covered by the fewest number of studies (11). Other themes studied by relatively fewer studies include those concerning the ageing workforce (13 studies) and age-friendly infrastructure (12 studies); and
- the theme area of healthy ageing is covered by almost all (18) studies.

In summary, no theme is entirely neglected, although some topics within themes appear to have more limited coverage, including carer stress, assistive technology and elder abuse.

Our intention in this report is to identify those themes and topics which **are** covered by these studies rather than those which are not. In addition, as noted earlier, some studies obtain respondent consent to link their survey data to administrative data, which obviously supplements the range and type of data available for study. This report's focus on the primary data collection activity of the study does not include this information.

Taking these caveats into account, it nevertheless appears that the health/ageing interface has been the subject of most data collection activity among these studies, and that data coverage in respect of age-friendly infrastructure and the built environment appears to be less comprehensive.

5 Funding longitudinal research into ageing

Current sources of funding for longitudinal studies relevant to ageing include grants, government departments, state/territory governments, universities and other institutions and organisations. However, given the long time frame of many longitudinal research projects, funding may come from a number of different sources and/or change over time.

5.1 Types of funding

5.1.1 NHMRC and ARC grant funding

Grants from the major research councils are a consistent source of funding for longitudinal research into ageing-related issues and many of the projects reviewed in this report have received all or part of their funding through grant schemes. Both NMHRC and ARC have provided grant funding for a number of longitudinal studies relevant to ageing in Australia.

The NHMRC is a statutory body which provides research funding and development of advice to, among others, the Minister for Health and Ageing. The NHMRC brings together and draws upon the resources of all components of the health system and seeks to: raise the standard of individual and public health throughout Australia; foster the development of consistent health standards between the various states and territories; foster medical and public health research and training; and foster consideration of ethical issues relating to health. Funding is appropriated by Parliament each year, primarily via the Medical Research Endowment Reserve (including donations by private benefactors) and is then provided to researchers on a competitive basis through the funding schemes (NHMRC 2003).

The ARC is an independent body reporting to the Minister for Education, Science and Training which acts as a primary source of advice to the government on investment in the national research effort. ARC's mission is to advance Australia's capacity to undertake quality research that brings economic, social and cultural benefit to the community. ARC funding programs come under the umbrella of the National Competitive Grants Program. The 2001 innovation action plan, *Backing Australia's Ability*, sees ARC funding for research doubling by 2006 (ARC 2003).

5.1.2 Government funding

Government is a major source of funding for longitudinal research programs relevant to ageing. For a number of the Australian and international ageing research projects reviewed in this report, government funding, either directly or indirectly, comprised the total of their research resources.

The Australian Government funds longitudinal research through grants schemes such as those administered by the NHMRC and ARC, and through funding provided by government departments. Some of the latter funding is provided as part of broad policy

initiatives such as the Stronger Families and Communities Strategy, under which LSAC is supported. In other cases (e.g. LSIA and LSAY), departmental funding sources are used.

The NIA in the US is a principal source of funding for both US and international longitudinal studies relevant to ageing. The NIA, which is part of the NIH, was granted Congressional authority to lead a broad scientific effort to understand the nature of ageing; extend the healthy, active years of life; provide leadership in ageing research, training, health information dissemination, and other programs relevant to ageing and older people. The NIA supports research and research training, including basic biological, neuroscientific, behavioural and social research on ageing as well as intervention studies and clinical geriatric research. Although the NIA conducts research in its own laboratories in the US, the largest part of NIA's funding for research is extramural. This funding goes to research institutions, e.g. universities, hospitals, or similar organisations, through a variety of research funding models. Studies assessed in this report funded wholly or in part by the NIA include ELSA, BLSA, HRS and ALSA (NIA 2004).

5.1.3 State and territory government funding

Like the Australian Government, state and territory governments support longitudinal research into ageing-related issues through both research allocations and by funding organisations who then conduct or sponsor research projects. Such funding often involves projects concerning specific locations or populations within the interest of the state or territory. These projects may also be more likely to have a service or service delivery focus, as states and territories are the primary suppliers of general social services like health, transport and care needs. For example, the SA Government partially funds ALSA which, while providing general information on ageing issues, is particularly relevant to the SA context. Similarly, 45 and Up receives funding from the NSW Government through the IHR, and focuses on people aged 45 and over in NSW.

5.1.4 University funding

Universities are a primary supporter of ageing research and act as both a source of funding and host for longitudinal research projects and researchers. Universities involved in funding Australian longitudinal projects reviewed in this report include La Trobe University, The University of Sydney, ANU, The University of Adelaide, The University of Melbourne and Flinders University.

While universities themselves, and more specifically departments and/or research institutions within universities, often rely on the financing generated by research projects, such projects are also funded out of divisional allocations and other departmental resources. For example, NLC receives funding from RSSH at the ANU as well as an ARC grant.

In the housing and human resourcing of longitudinal studies, however, universities make an even greater contribution to longitudinal research by providing researchers with a base of operations. For example, the HRS study, while funded by the NIA, is housed at the Institute for Social Research at the University of Michigan, which staffs, coordinates, researches and manages data (including the maintenance of the web site) for the project.

5.1.5 Other funding

Private organisations and charitable foundations also contribute to the funding of longitudinal research projects either directly or indirectly by giving to bodies which then fund research. Examples of other funding sources for projects assessed in this report include the SA Health Commission, the Australian Rotary Health Research Fund, the Elderly Citizens Home PL, Cancer Council Victoria, the Murdoch Foundation and Southern Cross Homes.

Table 5.1: Sources of funding

	Group I—Int			Group I—Aust							Group II—Older					Group II—Mixed				Group III					
	ELSA	BLSA	HRS	ALSA	45 and Up	DUBBO	MELSHA	SOPS	HRP	SoA	CLSA	FAMAS	MCCS	BLM	SADLS	ALSWH	PATH	NLC	HILDA	LSIA	AUSDIAB	ATP	LSAC	LSAY	
NHMRC				✓		✓	✓	✓			✓		✓		✓		✓				✓	✓			
ARC						✓	✓			✓								✓				✓			
Govt departments	✓	✓	✓	✓		✓									✓	✓	✓		✓	✓	?	✓	✓	✓	✓
State/territory govt				✓	✓		✓		✓				✓												✓
University				✓			✓	✓				✓	?	✓				✓							
Other				✓	✓	✓	✓	✓					✓	✓			✓				✓	✓			

5.2 Funding issues in longitudinal research

The funding of longitudinal research can be expensive and requires the participation, organisation and commitment of many groups over time. Long time frames require that the needs of all stakeholders be assessed against realistic production criteria and that the patience required by this type of research is fully appreciated. Funding challenges identified include the finite nature of funding types, multiple funding sources, changes in the research environment, continuity in funding and research, and analytical and administrative needs.

The finite nature of grant and allocated funding affects the collection, continuation, production and dissemination of information by longitudinal research projects. This has implications for research programs whose time frames and funding needs often extend beyond that allocated by a grant. For example, although the NHMRC and ARC provide substantial support for a variety of research programs across many fields, grant money is by nature a limited resource and the sourcing of additional funding can significantly affect longitudinal research agendas. The AUSDIAB and FAMAS studies, for instance, have grant funding of four and three years respectively and will need to source other funding for the continuation of their project agenda.

Multiple sources of funding are not uncommon for longitudinal research projects as long-term, evolving research needs require extensive commitments of time by researchers and financial resources. Often multiple funding sources are needed from the inception of a project to ensure that costs are covered and research can be undertaken. Many projects must seek out new sources of funding as initial resources are exhausted. As an example of a study

with multiple funding sources, MELSHA has at least four funding sources across several university faculties and including multiple grants.

Lack of continuity in funding from any source is also a potential problem for longitudinal studies, resulting in changes in funding sources (and consequently accountability requirements) over the life of a project. Though singly funded at present, the BLSA, which is the longest-running study in this review, started with a grant from the Macy Foundation and received Congressional funding until the creation of the NIA who now house and run the project.

Changes over time to political, social and administrative environments such as government or university structures can put longitudinal research projects at risk of losing their funding. Continuity of both financing and researchers has been identified as essential to productive and functional longitudinal projects.

An AIFS report titled *Longitudinal Studies of Children and Youth* identified that changes to the culture of modern Australian tertiary institutions raise potential funding issues critical for future longitudinal studies (Nicholson et al. 2002). In particular, this report highlights the importance of funding that includes ongoing support, including time, for researchers and administrative staff. Lack of adequate resources can lead to a high turnover of researchers in a study, which in turn can limit the research potential of longitudinal data collections. Retention of researchers who have participated in the earliest stages of design and collection has been identified as an important factor in the long-term success of a project, particularly with regard to publications.

Funding arrangements also need to consider some particular requirements of longitudinal studies, such as the costs associated with sample maintenance, technical documentation of data collection waves, and the possible advantages of establishing an analytic program that reports on the study results.

6 Conclusions

6.1 Main features of longitudinal studies

This report is a comprehensive mapping of a number of significant longitudinal studies which are being developed and/or undertaken in Australia and compares them to some key overseas studies. Longitudinal studies are an important element in the evidence base for understanding the processes involved in ageing, from both a health and a social perspective. As already noted in this report, they have particular advantages in their ability to examine multiple exposures, determinants and outcomes, and to measure relationships over time.

As an example, longitudinal data would make a unique contribution to understanding and analysing the burden of disease for individuals and the implications this has for their experience of ageing and their need for care or other health measures. This type of understanding can be used to inform policy, planning and service delivery so that it can more effectively identify both the appropriate type as well as the timing of interventions.

Longitudinal studies can yield relatively quick returns in the form of cross-sectional results from the early waves of a study, although the longitudinal benefits of the project take longer to materialise. Many studies included in this overview have been collecting data over the past ten years, and longitudinal analysis should be increasingly possible where there are sufficient resources to support it.

The major conclusions that can be drawn from the evidence available about the included studies are that there is a wide variety of study types and designs among the Australian studies. However, many are relatively small, are not national in focus and may be further limited in their scope by an interest in particular health conditions.

Some Australian studies included in this review report have large cohorts (10,000 participants or more). However, most have less than 5,000 participants, and a few were noticeably smaller. There are no Group I studies with national-level samples. Of the Group II studies, ALSWH, HILDA, NLC, LSIA and AUSDIAB have national samples, as does LSAC and LSAY (Group III studies). ALSWH is of course restricted to a female sample. Many of the regionally based studies are also focused on participants with particular health conditions of interest.

The studies included in this report encompassed a diverse array of design features, although single-cohort designs were predominant among Group I studies. All studies reviewed in this report used surveys to collect demographic, health, and/or wellbeing data on participants. Relatively few of the studies used researcher observations, while clinical measures are used in a number of studies with a strong health focus. Most studies reviewed in this report used more than one method of investigation. It is possible that resources are a driver of methodological choices made in longitudinal research. Large and well funded and resourced studies such as HRS and ELSA make use of a broad spectrum of methods of research investigation and data collection and so have a diverse and detailed pool of information from which to build their analysis. The ALSA and LSAC are the only Australian longitudinal studies to use all three of the methods of investigation identified in this report.

Healthy ageing issues, mental health, and condition specific research are a prominent focus in the ageing research field. This predominance of health-related research may in part reflect

the importance of the NHMRC as a funding source for many studies, as well as the importance of the health and ageing/aged care interface.

All six policy and research themes identified in government priority-setting processes appear to be covered to some extent by at least ten Australian studies. On the basis of the information available to this overview, data coverage may be least comprehensive in the area of age-friendly infrastructure and the built environment. Certain sub-topics were also noted as having limited coverage, including assistive technology, carer stress and elder abuse and age discrimination.

The absence of research in some areas by the longitudinal studies included in this project does not necessarily mean there is a national data gap in these areas. These topics may be investigated by longitudinal studies that were not included in this project, or may be investigated by other age-stratified studies without a longitudinal component.

6.2 Potential for international comparison

There is wide recognition among researchers and policy-makers of the value in internationally comparable longitudinal data. The potential for international comparisons is therefore a factor that might be considered in designing or supporting longitudinal surveys in Australia.

At the International Union for the Scientific Study of Population (IUSSP) Conference on Population Ageing in Industrialized Countries: Challenges and Issues, the conclusions of a report identifying new opportunities for research were presented. *Data needs for an ageing world* (IUSSP 2001), prepared by 17 experts from six countries, suggested that the following were particularly valuable areas for international comparison of ageing issues:

- labour force participation and retirement;
- patterns of income and savings;
- family structures and intergenerational transfers;
- health and disability; and
- subjective assessments of wellbeing (other than health and wealth).

A number of cross-cutting issues were also identified as important for international ageing research, including the applicability and interrelatedness of subject matter, record linkage and privacy, diversity and socioeconomic differences, as well as the need to deal with changes to the ageing experience over time and the need for dialogue between policy-makers and researchers. Lastly, a recommendation was made by the panel that mirrors the impetus of this review – the development and use of multi-disciplinary, longitudinal research designs for ageing-related issues. Model studies were noted to be: the Berlin Ageing Study; the Taiwan Study on the Elderly; and the US HRS (reviewed in this paper).

In particular, comparisons made among Australian studies and UK and US studies could elicit valuable indicators for research of and policy for Australia's ageing population. Studies from the US and UK, with whom Australia shares cultural and demographic similarities, identified in this report for potential comparison are the HRS and ELSA. The NIA provides funding for these parallel international studies, as well as the ALSA. Differences in design and content may prevent comparisons between international studies and much of the longitudinal ageing research carried out in Australia. However, a full assessment of this issue was beyond the scope of this study and requires more detailed information.

6.3 Contribution of this report

This report is intended to provide a resource for researchers, research funders and policy-makers who have an interest in longitudinal studies of ageing. Together with the accompanying matrix, this report may facilitate development of thematically targeted projects by researchers, improve communication between existing researchers, promulgate general awareness about existing data resources and aid in decision-making by funding bodies such as the ARC and NHMRC.

As the usefulness of the report clearly depends on its availability, accuracy and currency, the report and the matrix of existing studies will be available on both the AIHW and the Ageing Research Online (ARO) web sites. Additional studies can be built into the existing matrix structure as more longitudinal studies are initiated, greater multidisciplinary and collaborative research is undertaken and information demands continue to grow.

A number of additional studies that were not reviewed in this report have already been identified for possible inclusion in the matrix. They include the Australian Multiple Sclerosis Longitudinal Study, the Busselton Health Study projects and a series of a vascular epidemiology follow-up studies conducted in Perth. CERA also contributes to a range of longitudinal epidemiological studies concerning ageing and age-related disease; those that are particularly relevant include the Concord Health and Ageing in Men Project, the Blue Mountains Eye Study and the Fracture Risk Epidemiology in the Elderly Project.

The report and matrix are also preliminary resources for those considering whether Australia should support and undertake a national comprehensive longitudinal study of ageing. As such, the report has identified relevant studies and noted their key features. At a very broad level, it has identified areas where there appears to be less comprehensive coverage in the research focus of existing studies, while also noting the variety of methodological approaches employed, and the extent of existing expertise in Australia in conducting these types of studies.

In addition, the international studies included in this overview offer useful models for any Australian consideration of a national and comprehensive longitudinal survey; however, much more detailed information would be required if a capacity to compare results was required.

In considering whether Australia needs an additional, different or more comprehensive longitudinal study of ageing, it would be valuable to investigate the potential for existing studies to form the building blocks for the development of national survey. This might occur through the extension of existing studies, e.g. to include a national sample. Pooling data from a number of longitudinal studies where definitions and methodological approaches can be reconciled might be another approach to utilising the existing longitudinal work in Australia.

However, any consideration of an additional or different longitudinal study needs to take account, not only of the studies covered by this review, but also of other types of longitudinal data which are being developed in Australia, particularly the construction of longitudinal administrative data sets. These types of data have not been included within the scope of this particular review, but they represent a potentially rich source of data about Australians' use of various health and welfare services as they age. The potential for linking these data with other longitudinal survey data is also worthy of further consideration, and is already employed by a number of longitudinal studies.

Before any additional studies are initiated, it is also critical that a clearer understanding of research needs and gaps is developed. While this study identified some apparent limitations

in data coverage compared with research priority areas in the Framework for an Australian Ageing Research Agenda, these research priority areas are described in very broad terms. In addition, this study was only able to assess data coverage on the basis of mostly quite broad information from each study. A more thorough analysis of data gaps would require detailed investigation of questionnaires and other data collection instruments for each study mapped against a more rigorously defined set of possible research topics.

The next stage in this process would therefore require additional investigation of the substance of existing longitudinal research, along with an attempt to define more carefully the new and emerging research questions for ageing research. The 'fleshing out' of research questions for longitudinal research should also involve reference to the wealth of supporting data and information that already exists.

Finally it needs to be recognised that the process of establishing and undertaking a longitudinal study is complex, a significant time commitment and a demanding resource investment. It is also true that data collection is only part of the task of realising the particular benefits of longitudinal research. Other critical elements include high-quality data analysis and interpretation, the production of accessible research outputs, and dissemination of research findings in ways that translate research findings into an evidence base for policy, planning and service delivery. In other words, there is the large and complex task of also building and supporting research capacity in Australia in this field; a task consistent with work being undertaken through the Building Ageing Research Capacity initiatives supported by DoHA, and with efforts being jointly undertaken by NHMRC and the ARC in terms of building health research capacity within a broader social context.

This has resource implications over the medium to long-term. Resources are needed not only to support data collection, but to also support appropriate access to data and associated documentation by researchers, the development of researchers' skills in working with longitudinal data, a capacity to analyse, interpret and report on the data collected and appropriate dissemination strategies.

There is obviously already a large investment in longitudinal research relevant to ageing in Australia, as evidenced in the number and scope of studies which have been included in this report. There is also a growing body of researchers with experience in this type of study.

In sum, future decisions about adoption of longitudinal research strategies to address ageing issues need to be made with reference to and awareness of what has gone before, and take account of the particular benefits, issues and costs associated with longitudinal studies. This report takes the first step in mapping and documenting existing longitudinal studies in Australia, and provides a basis for future consideration of the need for a national strategy on the future of longitudinal studies of ageing in Australia that meets the needs of the scientific, government, health and community sectors.

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Appendix A Matrix of longitudinal studies relevant to ageing in Australia

The matrix is a two-dimensional tabular structure that allows for quick comparison of relevant studies across specific fields. The horizontal axis of the matrix includes the 24 studies reviewed in the report; the vertical axis includes fields such as study aims, content, investigators, funding and a number of methodological items. Each cell in the matrix is hyperlinked to the corresponding section in an accompanying text document that provides further details on the study, thus providing a third dimension to the matrix. Descriptive fields such as Content and Methods and data collection particularly benefit from the capacity to expand and provide supplementary information. Print-outs of the matrix and accompanying text documents are below. There is no accompanying text document for the HRS, as the web site includes all the relevant information. However, basic details including the HRS web site address are included in the matrix.

In developing the matrix, several existing reports were considered as potential models for presenting and comparing information on a range of longitudinal research projects. The 17 fields used in the matrix and accompanying documents were based upon the more specific 71 fields used in *Keeping Track: A Guide to Longitudinal Resources*, an index of longitudinal studies compiled by researchers at the Institute for Social and Economic Research (2004) in the UK. However, this index emphasised the technical aspects of the studies and did not capture all information relevant to this report under such detailed and specific fields. Furthermore, including such a large number of fields in the matrix was considered to be an ineffective way of displaying the information for comparative purposes. The *Inventory of International Surveys on Children and Youth*, an index of international surveys compiled by researchers at Human Resources Development (2002), displays information in a similar tabular format to that used in this project and provided some direction in the development of the current model.

	English Longitudinal Study of Ageing	Baltimore Longitudinal Study of Aging	Health and Retirement Study
Study aims	Investigates the economic position, health, social circumstances & quality of life of people aged 50+ (& their partners) in England. The study seeks to influence policy & to explain economic, health & social inequalities as people age	Investigates what happens as people age & sorts these changes into those due to ageing & those due to disease or other causes	Paints an emerging portrait of an ageing America's physical & mental health, insurance coverage, financial status, family support systems, labour market status & retirement planning
Contact details	Michael Marmot or James Nazroo Email: elsa@natcen.ac.uk or elsa@public-health.ucl.ac.uk or m.marmot@public-health.ucl.ac.uk or j.nazroo@ucl.ac.uk Web: www.ifs.org.uk/elsa or www.natcen.ac.uk/elsa/faq/about.htm	Email: blsa@grc.nia.nih.gov Web: www.grc.nia.nih.gov/branches/blsa/blsa.htm	Email: hrsquest@isr.umich.edu Web: hrsonline.isr.umich.edu
Location of research	England, London	US, Maryland, Baltimore	US, Michigan
Principal Investigators	UCL, IFS, National Centre for Social Research —Professor Michael Marmot, Professor James Nazroo	NIA	University of Michigan Institute for Social Research —Robert J. Willis
Content	Modules include Household Demographics; Individual Demographics; Health; Social Participation; Work & Pensions; Income & Assets; Housing; Cognitive Function; Psychosocial Factors; Expectations; Self Completion Questions; Final Questions; & Walking Speed Measurement. Content of each module is at <www.ifs.org.uk/elsa/content.html>	Study variables categorised as sociodemographic; functional health; bio-clinical; psychological; cognitive abilities; & lifestyle. Focus on biomarkers of ageing	Cognition; health; disability; income (pensions) & assets; employment & job history; retirement; expectations; health & life insurance; family structure & transfers; care-giving; demographics; housing & access to services; health care utilisation/costs; widowhood; experimental modules
Funding agencies/budget	The NIA provided approximately half the funding for the first 5-year cycle of the study; other funding comes from UK Government Departments	NIA, although the BLSA was initially funded by the Macy Foundation & the NIH	NIA & US Government departments
Data availability	Anonomised data will be made available with no restrictions on its use as long as the confidentiality of the respondent is preserved. Contact sheema.ahmed@ucl.ac.uk (ELSA administrator) or elsa@public-health.ucl.ac.uk	Data are kept confidential, & participants are not identified by name in any publication or presentation of research	HRS data products are available without cost to researchers (see ssl.isr.umich.edu/hrs/). For a listing of public datasets available to registered users see <hrsonline.isr.umich.edu/data/avail.html>
Sampling	12,100 people aged 50+ (& their partners) living in private households who took part in the 1998, 1999 or 2001 HSE. HSE may be drawn upon to boost sub-populations of interest or to refresh ELSA sample as it ages	Over 1,200 men & women ranging in age from their 20s to their 90s. Only healthy subjects are entered into the study	More than 22,000 Americans aged 50+ from merging Wave 4 of original HRS, Wave 3 of AHEAD & 2 new sub-samples in 1998, with an additional sub-sample added in 2004. Oversamples of Blacks, Hispanics & Florida residents

Response rate	Household response rate of 70% with approximately 96% of individuals responding within households. This equates to an overall response rate of 67%	—	Detailed information on response rates available at hrsonline.isr.umich.edu/intro/sho_uinfo.php?hfyle=sample&xtyp=2
Incentives	Participants were offered vouchers as incentives. Refusals were taken as final. Also see Section 9.4 www.ifs.org.uk/elsa/report03/ch9.pdf	Volunteers are given a physical exam & medical screening tests every 2 years free of charge	—
Timeframes	Wave 0: 1998, 1999 & 2001 HSE, Wave 1: March 2002–March 2003, Wave 2: June 2004, Wave 3: 2006, Wave 4: 2008	Began in 1958. Data are collected on participants every 2 years	Original HRS & AHEAD which began in 1992 & 1994, were combined with 2 new sub-samples in 1998. Participants are surveyed every 2 years. For a detailed data collection path see hrsonline.isr.umich.edu/intro/dataflow.html
Methods and data collection	HSE involved fieldwork & biomedical tests. ELSA draws on blood samples, morbidity, lifestyle & diet data collected by HSE. From Wave 2 data are collected via an interview, a self-completion questionnaire & a nurse visit (which collects measurements such as blood pressure, lung function, grip strength, lower body strength & balance). Also see www.ifs.org.uk/elsa/report03/ch9.pdf	Volunteers participate in 100+ physiological assessments. Questionnaires covering Demographics, Physical Activity, Pulmonary Disease & Activities & Attitudes; Diet Interview; Autopsy Study Interview. For details on the measurement of study variables see blswww.grc.nia.nih.gov/infos.htm	Clinical measures (e.g. blood test, lung function, hand strength, dementia status); observation of household residents, influence of others on respondents' answers, respondents' level of understanding; mail-out questionnaires; initial face-to-face interview with biennial follow-up phone interviews; linkage with Employer Pension Study, National Death Index, Social Security Administration data & Medicare files
Data analysis	Following each round of data collection a report containing key analyses will be published, together with a commentary	—	—
Results	Wave 1 results for sociodemographic characteristics; socioeconomic position; work & retirement; social activity; health; physical & cognitive function; physical & social environment, available at www.ifs.org.uk/elsa/report.htm	The first 20 years of findings are outlined in <i>Normal Human Aging</i> . Findings on heart, brain, personality, prostate, senses & diet available at www.grc.nia.nih.gov/branches/blsa/blsafindings.pdf	—
Outputs	<i>Health, wealth and lifestyles of the older population in England: The 2002 English Longitudinal Study of Ageing</i> —see www.ifs.org.uk/elsa/report.htm	800+ scientific papers published 1958–1998. 1980–2002 publications available at www.grc.nia.nih.gov/php2/blsapub.php	For a listing of publications see hrsonline.isr.umich.edu/papers/index.html
Related Studies	NIA also funds the HRS—additional information may be provided by comparing results across the 2 countries. There are a series of parallel studies being developed in Europe—Surveys of Health, Ageing & Retirement in Europe	ELSA	ELSA

Australian Longitudinal Study of Ageing	45 and Up	The Dubbo Study of the Health of the Elderly
Studies how social, biomedical, psychological, behavioural & environmental factors are associated with age-related changes in health & wellbeing of persons aged 70+	To study the general health of the ageing population & report on health problems & areas of concern, in order to direct future medical research & health care policy	A biomedical & social science investigation of healthy ageing, service use & delay of disability & age-related diseases. The aim of a new phase to the study was to model how income & assets, government entitlements & informal care services modify expected changes in health or family circumstances in later life
<p align="center">Gary Andrews Email: cas@flinders.edu.au or g.andrews@flinders.edu.au or gary.andrews@unisa.edu.au Web: www.cas.flinders.edu.au/alsa.html</p>	<p align="center">Emily Banks Email: directorate@ihr.org.au or Emily.Banks@anu.edu.au Web: www.ihr.org.au</p>	<p align="center">John McCallum or Robyn Maddern Email: j.mccallum@uws.edu.au or r.maddern@uws.edu.au Web: www.dubbostudy.org/dubbostudy.nsf/main/main</p>
Australia, SA, Adelaide	Australia, NSW	Australia, NSW
<p align="center">CAS—Professor Gary Andrews, Professor Mary Luzcz, Dr Michael Clark & others</p>	<p align="center">Collaborative effort carried out under the auspices of the IHR—Dr Freddy Sitas (chair), Dr Emily Banks (scientific director)</p>	<p align="center">A/Professor Leon Simons, Professor John McCallum</p>
Ageing & older people; demography & migration; income, wealth & spending; sex & gender; health & disability; cognition; behaviour; living conditions; social care & welfare	8 key priority research areas burden of disease (e.g. cardiovascular disease); socioeconomic determinants of healthy ageing; obesity, overweight & physical activity; cancer; environmental health; mental health; health services; old old (80+)	Mortality, hospitalisation, residential care, informal care services, cardiovascular disease, osteoporosis, disability, dementia, lifestyle & dietary exposures, medication use, medical history, physical activity, physical measurements, income & assets, employment & retirement, education, government entitlements, social involvement & support, life satisfaction
SA Health Commission; Australian Rotary Health Fund; US NIA	Core funding provided by a consortium of organisations. Funding for the development of the program & pilot studies was provided by the IHR	NHMRC project grants, ARC SPIRT Grant, FaCS, Southern Cross Homes
The data are available for scientific research which will not compromise the identity of the respondents. Researchers wishing to use this data should contact the CAS team	The study is designed as a collaborative research resource which is available for use by the wider research community. All information given to the study will be treated with absolute confidentiality & will only be used for health research	Data will be available subject to privacy constraints by direct request to the study director
2,087 people aged 70+ randomly selected from within the Adelaide Statistical Division. Both community & institutionalised individuals were included. Spouses aged 65+ of specified persons were also invited to participate, as were other household members aged 70+	Broadly random sample of more than 250,000 people aged 45+ in NSW, identified using the electoral roll. Oversampling of those born overseas & of rural residents	Single cohort of non-institutionalised residents of the Dubbo local government who were born before 1 Jan 1930 (those aged 60+) & who attended for baseline assessment. 2,085 Dubbo residents (1,233 men & 1,572 women) were first interviewed in 1988

Baseline: 53.4%, Wave 2: 90.0%, Wave 3: 90.0%, Wave 4: 86.8%, Wave 5: 79.8%, Wave 6: 69.9%	—	2,805 residents participated in the study—73% of those eligible
—	Where studies are meaningful to participants, confidentiality is safeguarded & only a small amount of time & effort is required, large numbers of people are happy to participate in this kind of research	No incentives were provided to participants
Wave 1: Sep 1992–Feb 1993, Wave 2: Sep 1993, Wave 3: Sep 1994–Feb 1995, Wave 4: Sep 1995, Wave 5: Feb 1998, Wave 6: Sep 2000–Feb 2001, Wave 7: Sep 2002–Feb 2003	15-year study with 3 waves of data collection (follow-up questionnaires every 5 years). Recruitment of participants planned to begin in late 2004/early 2005 & to be completed in 2009	A 15-year longitudinal study with 3 data collections: 1988, 2000 & 2002/2003
The sample was randomly generated using the State Electoral Database & was stratified by gender & by the age groups 70–74, 75–79, 80–84 & 85+. Personal interviews, self-enumerated questionnaires & clinical and home-based assessments	Electoral roll will be used to identify potential participants. Self-administered questionnaires, possibly saliva & blood tests & cross-linking with death & cancer registry records & medical & pharmaceutical records	Phone & personal interviews, a medical examination & record linkage to service provider databases. Methods & measures employed have been described in detail in the early publications
Data being analysed relating to ADLs/IADLs, cognitive function, comorbidity, cardiovascular disease, dental health, diet, diabetes, exercise, family, formal service use, hearing, injuries & falls, sensory function, social activities	Following initial analyses of cross-sectional data, the main means of investigating relationships between exposure & outcome will be through a series of case-control studies nested within the cohort	Analysis of hospital & residential care has been completed. Pension & assets data, as well as data on GP & pharmaceutical usage, are being analysed. Analysis of Wave 3 data will be undertaken in conjunction with the record linkage data. Also see publications
Data is released approximately one year after collection	—	Various—see publications
Researchers have cited ALSA in almost 200 publications including reports, book chapters, refereed journal articles, abstracts, conference proceedings & theses. ALSA Bibliography available at < www.cas.flinders.edu.au/alsapub.html >	—	A list of publications is available at < www.dubbostudy.org/dubbostudy.nsf/main/Publications >
ALSA: Psychological Aspects; ALSA: The Intersection of Sensory and Cognitive Functioning; ALSA: Determinants of Formal Service Use in an Aged Population	Links to UK Million Women Study, the UK Biobank & European Prospective Investigation into Cancer & Nutrition	There have been one-off collections of community & post-acute care services & other data as part of separately funded projects

The Melbourne Longitudinal Studies On Healthy Ageing Program	Sydney Older Persons Study	Healthy Retirement Project
3 linked studies that form a large longitudinal study on healthy ageing—FAHS, HBOA & HSOP	Conceived in 1988 as the Sydney Older Veterans Health & Services Project to investigate the health of community dwelling veterans of WWII. The study commenced in 1991 & also included non-veteran members of the community	The HRP contacted retirees twice before retirement & 6 & 12 months after retirement, to examine preparation for & the immediate impacts of retirement. Health & Well-being in Retirement builds on the HRP by examining the medium-term outcomes 2 & 3 years after retirement
<p>Colette Browning or Hal Kendig Email: c.browning@latrobe.edu.au or H.Kendig@fhs.usyd.edu.au Web: www.latrobe.edu.au/public/health/research/specialist_research.htm#MELSHA</p>	<p>Tony Broe Email: BroeT@sesahs.nsw.gov.au Web: www.powmri.edu.au/research/pdda/ageing/sydneyops.htm or www.sesahs.nsw.gov.au/powh/arc</p>	<p>Yvonne Wells E-mail: Y.Wells@latrobe.edu.au</p>
Australia, Victoria, Melbourne	Australia, NSW, Sydney	Australia
La Trobe University—Professor Colette Browning, Professor Hal Kendig	CERA of Concord Hospital & the Prince of Wales Medical Research Institute—Professor Tony Broe	Lincoln Gerontology Research Centre—Professor Hal Kendig, Professor David de Vaus, Dr Yvonne Wells
HSOP: medical conditions, fall & injuries, confusion, pain, medication, mental health, health behaviours, wellbeing, service use; HBOA: health behaviour change, functional ageing, health, service outcomes; FAHS: disability onset, service use, entry to residential care	Medication use; disease; disability; service use; dementia; mortality; life satisfaction & depression; carer distress; alcohol, smoking & physical activity; laboratory results	HRP examined retirement (preparation, immediate impacts & adjustment) & the relationship to health & health behaviours. Health & Well-being in Retirement examined how pre-retirement intentions regarding health behaviours shape the way people build their lives after retirement; & the ways in which different retirement styles affect medium-term health & health behaviours
HSOP 1994–1997: \$532,743 VicHealth; HBOA 1998–2000: \$161,500 NHMRC; FAHS 2003–2005: \$215,465 NHMRC	SOPS 1: \$389,000 PH & RDC, Research & Development Grants Advisory Council, RFBI; SOPS 2: \$193,245 PH & RDC; SOPS 3: \$80,000 Sir Zelman Cowan Foundation; SOPS 4: \$251,560 PH & RDC; SOPS 5: \$825,000 NHMRC	Funded by VicHealth. \$373,174 received for 1997–1999. \$225,058 received for 2000–2002
—	Data are available to approved researchers & the SOPS study has shared research in Australia & overseas	—
1,000 people aged 65+ living in Melbourne in 1994	327 community dwelling war veterans & widows & 320 non-veterans aged 75+	Older workers were recruited through employers, unions, superannuation funds & the media. The longitudinal component of the HRP contacted 590 workers aged 50+. Health & Well-being in Retirement followed up the same individuals

Sample size at each wave: 1000 → 906 → 796 → 718 → 649 → 611 → 541 → 424 → 386	The initial sample size (& sample size) at each stage of the study was: 647 (647), 462 (449), 367 (367), 346 (299) & 185 (123)	—
—	No incentives were offered at any stage of the research	—
Wave 1: May 1994–Nov 1994, Wave 2: Jun 1995–Dec 1995, Wave 3: Jun 1996–Nov 1996, Wave 4: Jun 1997–Oct 1997, Wave 5: Jun 1998–Oct 1998, Wave 6: Jul 1999–Oct 1999, Wave 7: Jul 2000–Nov 2000, Wave 8: Jul 2002–Jul 2003, Wave 9: Aug 2003–Nov 2003	SOPS 1: 1991–1993, SOPS 2: 1994–1996, SOPS 3: 1996–1997, SOPS 4: 1997–1999, SOPS 5: 2000–2003	Wave 1: Apr 1998–Dec 1998, Wave 2: Jul 1998–Jun 1999, Wave 3 : Jan 1999–Dec 1999, Wave 4: Jul 1999–Jun 2000, Wave 5: Jul 2000–Jun 2001, Wave 6: Jul 2001–Jun 2002
Face-to-face interviews to gather data on health, health behaviours & service use; clinical examinations to measure height, weight, eyesight & hearing; brief follow-up mail surveys & CATI	Medical & neuropsychological assessments, blood samples & medication history. MRI scanning & hippocampal measurements of a sub-sample at SOPS 4 & 5 with additional follow-up for health changes. Extensive in-home interviews of participants & informants (such as family member or close friend) for health changes & impact over time	96-item survey administered by employers & by mail
—	—	Statistical analyses employed chi-square tests & logistic regression as categorical variables were examined
—	Disease, disability & service use; Prediction of dementia; Prediction of mortality; Life satisfaction & depression; Carer distress; Alcohol; Australian norms for the Boston Naming Test; Laboratory results in the community	—
—	See < www.cera.usyd.edu.au/CERA%20Pub.htm > for a list of CERA publications	—
MELSHA is a series of 3 linked studies	Data from SOPS have been used to develop, in collaboration with a number of research partners & data sets, a model of the accumulation of deficits in relation to ageing & mortality & the development of an index of frailty	US HRS

Stories of Ageing	Canberra Longitudinal Study of Ageing	Florey Adelaide Male Aging Study
To bring theoretical perspectives to the study of ageing which challenge existing research & policy directions; to understand the key factors that determine quality of life & needs of non-institutionalised women aged 70–85; & to work with older women to produce stories of ageing from their perspective	A 12-year study into the health & memory of older people. CLSA aims to identify predictors of memory decline & dementia & provide epidemiological data on mental disorders in older Australians	To identify factors that contribute to men's reproductive, physical & emotional health & their relationship with the ageing process. To develop & implement measures to promote a healthy & active lifestyle, eventually prevent diseases & guide the development of appropriate health services & policy
<p align="center">Barbara Kamler Email: brk@deakin.edu.au</p>	<p align="center">Helen Christensen or Kaarin Anstey Email: Helen.Christensen@anu.edu.au or Kaarin.Anstey@anu.edu.au Web: www.anu.edu.au/cmhr/ cls.php</p>	<p align="center">Gary Wittert Email: gary.wittert@adelaide.edu.au</p>
Australia, Victoria	Australia, ACT, Canberra	Australia, SA, Adelaide
<p>Deakin University—Professor Barbara Kamler, Professor Terry Threadgold, Ms Susan Feldman</p>	<p>ANU CMHR—Professor Scott Henderson, Professor Anthony Jorm, Professor Helen Christensen</p>	<p>University of Adelaide, Royal Adelaide Hospital, SA Department of Human Services, Institute of Medical & Veterinary Science, Hanson Institute, CSIRO, Glenside Hospital—A/Professor Gary Wittert</p>
Stories of ageing that contribute to new understandings of later life & citizenship & counteract ageist & debilitating ways of viewing older women	The study focuses primarily on depression & cognitive impairment, but also has extensive data on physical health & mortality	Utilisation of health services, endocrinology of ageing & prostate health & function in relation to the hormonal changes of ageing. Chronic medical & psychological conditions such as obesity, cancer, diabetes, cardiovascular disease & mental health will also be investigated
ARC Large Grant 1997: \$36,002; 1998: \$14,028; 1999: \$16,954	NHMRC Project Grant	\$450,000 Florey Research Grant awarded for 3 years. Florey Research Grant is jointly funded by the Florey Medical Research Fund & University of Adelaide Deputy Vice Chancellor (Research)
—	Contact Professor Helen Christensen	Microsoft Access database—file may be available on request
Approximately 40 women aged 70-85 living outside institutionalised care	Single cohort of approximately 1,000 people aged 70+. 897 participants were from the community & the remaining 103 were oversampled from nursing home residents & the older age group	1,000 men aged 35–80 in Adelaide's north-west suburbs. Random sampling using electronic white pages. Initial cohort of 590 men enrolled August 2002–August 2003. Recruitment of next 600 men (to allow for drop-outs) will begin April 2004

—	Approximately 69%	Of the initial 2,500, 77 ineligible due to participation in other studies, 1,313 households could not be contacted or did not include an eligible subject. Of 1,116 eligible men 482 refused. Of 634 that participated in the initial interview a further 65 refused clinic visits
The women learnt new strategies for crafting & developing writing & the researchers gained new understandings of ageing from their writing	—	—
A 3 year longitudinal study 1997–1999	A 12-year study which commenced in 1990, with waves in 1994, 1998 & 2002.	Florey Research Grant awarded in 2003 for 3 years. Initial cohort enrolled between August 2002 & August 2003. Annual follow-up questionnaire. Repeat clinic visit at 5 years. Recruitment of next cohort in April 2004
The stories that women told were produced in both writing & video diary workshops using a collaborative pedagogy which positioned the women as co-researchers	Instruments used in the collection of data include questionnaires, cognitive tests, various measures of physiological functioning & genetic samples	Introductory letter & brochure, telephone interview, questionnaire mail-out & 2 clinic appointments. Annual follow-up questionnaire mail-out. Repeat clinic visit at 5 years. Qualitative methodology used to evaluate health service utilisation in a stratified random subset
—	Cross-sectional analyses involved one-way analysis of variance, Fisher's exact test & hierarchical multiple linear regression. Longitudinal analyses involved regression analysis, one-way analysis of variance & Fisher's exact test	Linear regression, correlation coefficients, non-linear relationships, t-tests, log-binomial regression, mixed model analysis of variance, log-binomial Generalized Estimating Equations, Cox's proportional hazards regression, structural equation modeling
—	Prevalence of depressive disorders & the distribution of symptoms; self-reported health; cognitive functioning & relationships with personality, education level, activity levels & dementia. Other studies have investigated GP visits	Preliminary data now available but not yet submitted for publication
<i>Women's Stories of Action and Reflection: Counter-Narratives of Ageing</i> —other publications listed at < www.research.deakin.edu.au/performance/pub/reports/database/dynamic/output/person/person.php?person_code=kamleba >	For a list of publications outlining study methods & data analysis see < www.anu.edu.au/cmhr/cls.php >	—
—	Canberra & Queanbeyan Survey of Health in Later Life (1990–1991)	—

Melbourne Collaborative Cohort Study (Health 2000)	A Longitudinal Study of Bone Loss in Men	SA Dental Longitudinal Study
To investigate the role of diet & other lifestyle factors in causing common chronic diseases (cancer, cardiovascular disease & diabetes) & to investigate possible interactions between these exposures & common genetic variants. Its aims have been broadened to include ageing, vision & depression	A longitudinal study of bone mass at forearm, hip, spine & whole body in men	A longitudinal study of the oral health of older adults
<p align="center">Graham Giles Email: graham.giles@cancervic.org.au</p>	<p align="center">Allan Need Email: allan.need@imvs.sa.gov.au</p>	<p align="center">Professor John Spencer Email: aihw.dsru@adelaide.edu.au or john.spencer@adelaide.edu.au Web: www.adelaide.edu.au/spdent/dsru/</p>
Australia, Melbourne	Australia, SA, Adelaide	Australia, SA, Adelaide
<p align="center">Cancer Council Victoria—Professor Graham Giles</p>	<p align="center">Institute of Medical & Veterinary Science, Royal Adelaide Hospital, University of Adelaide—A/Professor Allan Need</p>	<p align="center">Collaborative effort between AIHW DSRU & University of Adelaide Social & Preventative Dentistry—Professor A John Spencer, Dr Jane Chalmers, Dr Kaye Roberts-Thomson</p>
<p>Main measures: anthropometric measurements, blood pressure, diet, alcohol, tobacco, physical activity, medical history, social support, DNA & plasma stored</p> <p>Main outcomes: cancers of the prostate, breast & bowel, heart disease, stroke, Type 2 diabetes & all causes of mortality (plus many others including health service use)</p>	<p>Effects of diet, exercise, genetic polymorphisms, calcium absorption & excretion, bone resorption & bone formation on the rate of bone loss at forearm, hip, spine & whole body</p>	<p>Social impact of oral disorders; dental health status; use of dental services; preventive oral health practices; residential history; sociodemographic characteristics; medical history; medications; tobacco & alcohol use; chewing capacity for specific foods; self-perceptions of dry mouth; cognitive status; dentures/oral mucosal tissues</p>
<p align="center">Cancer Council Victoria, VicHealth, NHMRC</p>	<p align="center">Divisional funds from the Institute of Medical & Veterinary Science & Royal Adelaide Hospital funding for the last wave was received from the University of Adelaide</p>	<p align="center">NHMRC 1991–93: \$145,876; 1996–97: \$140,524; 2002–03: \$225,000 & US NIH 1992–94: US\$338,547</p>
<p>Access to the MCCS data & materials is available via collaborative proposals that are congruent with the study design. Data access guidelines & data books are available from the Executive Officer</p>	<p align="center">Data available as a Minitab file</p>	<p>Data is available in SPSS format. Providing data on request is an important DSRU function</p>
<p>Single cohort of 41,528 people (17,049 men) aged 40–69 at baseline. Approximately 1/3 are southern European migrants to Australia, who were deliberately over-sampled</p>	<p>146 healthy white men aged 20–83 (mean age at selection was 48 years) in Adelaide</p>	<p>Stratified random sample of older adults aged 60+ who were listed on the SA Electoral Database. Subjects chosen from Adelaide & Mt Gambier. In 1991 1,650 took part in a face-to-face interview</p>

N/A—volunteer sample	At each wave the sample sizes were 146, 123 & 59	In 1991 2,751 people were sampled & 1,650 (60%) took part in a face to face interview
None	—	—
Wave 1: 1 Jan 1990–30 Jun 1994, Wave 2: 1 Jan 1994–31 Dec 1998, Wave 3; 1 Jan 2003–30 Jun 2006. The study expected to run indefinitely	Wave 1: Jan 1990–Dec 1993, Wave 2: Jan 1996–Jun 1997, Wave 3: Jul 2003–Dec 2003	The study is ongoing—Wave 1: 1991, Wave 2: 1993, Wave 3: 1996, Wave 4:2002
Recruitment via ethnic clubs, churches, social events & written invitations using the electoral roll. Extensive information collected at baseline & 2003 follow-up in face-to-face interviews, phlebotomy & physical measurements. Follow up at 3–4 years after baseline by phone or mailed questionnaire. Regular matching to cancer registries & death indices	In the study described by Need et al. (1995), subjects listed their regular physical activities. Bone density in the forearm was measured by single photon absorptiometry & measured by dual x-ray absorptiometry in the spine, femoral neck, Ward's triangle	Baseline—initial face-to-face interview, OHIP & clinical oral examination for all subjects; 2 years—OHIP & phone interview for all subjects, re-examination of dentate subjects; 5 years—re-examination, OHIP, phone interview, XI questionnaire, Clock Drawing Test & saliva sample for all subjects; 11 years—same data collection methods plus extra questionnaires, ADL/IADL scales & Global Deterioration Scale
Analysis is usually either a classical cohort analysis when data are available on the entire cohort, or a case-cohort analysis when data are only available on a subset. Occasional nested case-control designs are also used	Data in the study by Need et al. (1995) were analysed using student's t-test & multiple linear regression with age expressed as a quadratic function	Least squares regression and ordinal logistic regression techniques are being used in the development of predictive models of risk. Also see SADLS publications
See MCCA publications (website under development)	Need et al. (1995) reported a continuous positive relation between physical activity & bone density in normal white men the data suggest that any exercise is beneficial to bone & that, within the normal range, the more the better	See SADLS publications
List of 30+ publications from (or based on) MCCA soon to be on website (website under development)	<i>Effect of physical activity on femoral bone density in men ; Effect of age on bone density and bone turnover in men ; Vitamin D receptor genotypes are related to bone size and bone density in men</i>	Publications include: <i>Oral health status and treatment needs of non-institutionalised persons aged 60+ in Adelaide SA ; Trends and fluctuations in the impact of oral conditions among older adults during a one-year period ; Variations in the impact of oral conditions among older adults in SA</i>
There are a growing number of sub-studies supported by the MCCA. Also see other ECHIDNAS projects	—	Oral Health of Community-dwelling Adults with Dementia & the Adelaide Dental Study of Nursing Homes. SADLS was established in affiliation with two major North American studies

Australian Longitudinal Study of Women's Health	PATH Through Life	Negotiating the Life Course
By looking at the needs, views, lifestyles, health & factors affecting the health of individual women in Australia, ALSWH is able to provide an accurate & current evidence base to DoHA for the development & evaluation of policy & practice in many areas of service delivery that affect women	To investigate the causes of 3 common mental health problems anxiety & depression; alcohol & other substance abuse; & cognitive ageing & dementia	To study the changing life courses & decision-making processes of Australian men & women as the family & society move from male breadwinner orientation in the direction of higher levels of gender equity
<p align="center">Christina Lee Email: whasec@newcastle.edu.au or c.lee@psy.uq.edu.au Web: www.newcastle.edu.au/centre/wha/</p>	<p align="center">Kaarin Anstey Email: Kaarin.Anstey@anu.edu.au Web: www.anu.edu.au/cmhr/path.php</p>	<p align="center">Liana Leach Email: nlc@anu.edu.au or Liana.Leach@anu.edu.au Web: lifecourse.anu.edu.au/</p>
Australia, NSW, Newcastle	Australia, ACT & NSW, Canberra & Queanbeyan	Australia, ACT, Canberra
<p>Research Centre for Gender and Health, University of Newcastle, University of Queensland—Professor Annette Dobson, Professor Christina Lee, Dr Penny Warner-Smith</p>	<p>ANU CMHR—Professor Anthony Jorm, Professor Helen Christensen, Dr Bryan Rodgers, Dr Kaarin Anstey, Dr Keith Dear</p>	<p>Centre for Social Research, ANU Demography & Sociology Program, University of Queensland School of Social Science—Dr Janeen Baxter, Professor Peter McDonald, Dr Deborah Mitchell, Dr Ann Evans, Dr Edith Gray, Dr Trevor Breusch</p>
5 main themes: use of & satisfaction with health care services; life stages & key events; time use; weight & exercise; violence	The project investigates ageing vs. cohort effects; social, psychological, nutritional & genetic factors; & comorbidity of mental health problems, relevant to the 3 classes of common mental health problems	Income Inequality, Family Formation, Work & Family Life—careers, children & child care, education & training, employment, caring & voluntary work, fertility & childbearing, health, mental health, home economics, housing & household composition, human relations, income, superannuation, relationships & marriage, occupations, religion
DoHA first funded the study in 1995	Funded until 2006 by an NHMRC Program Grant, with additional funding from the Rotary Health Research Fund, CSIRO & Brewer's association	Wave 1 (1997) by the RISS, ANU; Waves 2 & 3 (2000 & 2003) by ARC
Researchers seeking access to the data must submit an application to the project coordinator. Data books of percentages & responses to individual items are available. Data are released approximately 1 year after data collection. See <www.newcastle.edu.au/centre/wha/infodata.html>	Contact Professor Anthony Jorm	Data from the NLC project are available from ASSDA. See <lifecourse.anu.edu.au/data/> for online codebooks, ASSDA access form, data updates & status scales. For more info on data access, email NLC
Australian women in 3 age cohorts (18–23, 45–50 & 70–75) randomly selected from the Medicare database. Wave 1 included 14,739, 12,762 & 14,011 participants. Oversampling in rural & remote areas	3 cross-lagged age cohorts (20–24, 40–44, 60–64) of 2,404, 2,528 & 2,551 participants, randomly selected from the Canberra & Queanbeyan electoral rolls	Single cohort of 2,231 Australians aged 18–54. Households were randomly selected from the White Pages. Within each selected household, respondents were chosen on the basis of having the next birthday

41%, 54% & 36% for the young, mid & old cohorts in Wave 1; 71%, 92% & 91% in Wave 2; 70%, 85% & 84% in Wave 3	58.6%, 64.5% & 58.3% in the 20–24, 40–44 & 60–64 age groups	2,231 persons were interviewed from a sample of 7,721 randomly selected phone numbers. 97% of respondents in the first wave agreed to participate in following rounds of the survey
Reminder letters, a publicity campaign, information brochures & the option of completing the survey by phone were used to encourage participation	—	—
All cohorts first surveyed in 1996. Wave 2 occurred in 1998, 1999 & 2000 for the mid, old & young cohorts. Cohorts are then surveyed every 3 years for Waves 2–7	The 3 age cohorts were interviewed in 1999, 2000 & 2001. These cohorts will be followed up at 4-yearly intervals for 20 years	Indefinite life panel survey. Wave 1: October 1996–November 1996 & February 1997–April 1997; Wave 2: April 2000–September 2000; Wave 3 2003
Each age cohort is surveyed once every 3 years, via surveys sent in the mail (with the option of completing the survey by phone). Each cohort receives a different survey & the number of questions & items vary somewhat. Previously validated questions or scales are used where possible. Women are invited to write about any additional issues, which are coded according to major themes & key words	Interviews done on hand-held computer in the presence of trained interviewers. Physical testing & memory tests are completed by the interviewer. Cheek swabs taken for genetic analysis	Single cohort stratified by age. CATI was the preferred data collection method and included a GHQ. A mail-out questionnaire was used in NLC sub-studies
Data analysis is carried out according to the needs of particular reports. A list of approved analyses will be available on the website. Requests for ad hoc data analysis are received from government agencies & academic & non-academic institutions	List of publications discussing methods, data analysis & the latest research findings available at < www.anu.edu.au/cmhr/path.php >	A weighting factor was provided to take account of bias in the unweighted sample. Also see NLC publications
Reports on ageing, rural health, chronic disease, physical activity, mental health & violence against women, have been produced. Reports on work & ageing, & alcohol use are in preparation. Also see Outputs	Results concerning sexual orientation & mental health, obesity & mental health, substance abuse, depression, anxiety, head injury, reaction time, & psychological wellbeing have already been reported	Available from NLC publications
113 papers, 3 book chapters & 1 book have been published, with another 21 submitted papers. Abstracts of publications are available at < www.newcastle.edu.au/centre/wha/public.html >. Annual & technical reports are available at < www.newcastle.edu.au/centre/wha/reports.html >	List of publications discussing methods, data analysis & the latest research findings available at < www.anu.edu.au/cmhr/path.php >	For a list of publications including discussion papers, journal articles, conference papers & book chapters see < lifecourse.anu.edu.au/publications/dps.html >
Many participants are invited to take part in sub-study surveys. Menopause experiences are compared with English women, patterns of work & leisure are compared with Canadian women, use of alternative medicine is compared with women in Norway	PATH Through Life Project sub-studies—Nutritional intake data; Study of the brain using MRI; Health & memory in the 60–64 year old cohort	Analyses of the Michigan Panel Study of Income Dynamics & the British Household Panel Survey. The Australian Family Formation Decisions Project sub-study

HILDA	Longitudinal Survey of Immigrants to Australia	AusDiab Follow-up Study
First Australian longitudinal survey on income, labour market & family characteristics of all members of a household. It will provide sound evidence for policy development & help address the root causes of disadvantage & develop measures that build stronger families & communities	Provides reliable data for the government & other agencies to monitor & evaluate immigration & settlement policies, programs & services	The AusDiab Follow-up Study will follow-up the participants of the original AusDiab study. AusDiab aims to provide information on Diabetes mellitus, heart disease & health-related behaviour, in order to develop ways of improving people's health & the provision of health services
<p align="center">Mark Wooden Email: m.wooden@unimelb.edu.au Web: www.melbourneinstitute.com/hilda</p>	<p align="center">David Osborne Email: research@immi.gov.au Web: www.immi.gov.au/research/lsia/index.htm</p>	<p align="center">Paul Zimmet Email: research@diabetes.com.au Web: www.diabetes.com.au/research/prospective.htm</p>
Australia, Victoria, Melbourne	Australia, ACT, Canberra	Australia, Victoria
University of Melbourne Institute of Applied Economic & Social Research, ACER, AIFS—Professor Mark Wooden	Research & Statistics Section, DIMIA—David Osborne	International Diabetes Institute—Professor Paul Zimmet
Economic & subjective wellbeing; labour market dynamics; & family dynamics. Research questions available at <www.melbourneinstitute.com/hilda/POverview-9.pdf>. Survey instruments available at <www.melbourneinstitute.com/hilda/sinstruments.html>	Pre-migration experience; immigration process; initial settlement; sponsorship activity; perceptions of Australia; support services; return migration; ancestry, religion & ethnicity; citizenship; views on immigration; English proficiency & learning; qualifications; education; employment; health; housing; household budgets; financial support; transferal of assets; pensions; income	The study will be a repeat of the baseline study & will include demographics, anthropometrics, blood pressure, blood & urine testing (for diabetes, lipids & renal function), clinical testing for diabetes complications (e.g. neuropathy & retinopathy), self-reported disease status, diet, physical activity & health service utilisation
Waves 1–8 funded by FaCS	Funded by the Australian Government through DIMIA. The initial wave of the study also received funding through trusts managed by the states	NHMRC project grant for 4 years with further funding from Kidney Health Australia (matched by hospital funding), Diabetes Australia, & a variety of other sources
A moderately confidentialised unit-record data file is available for research purposes. Provided on CD-ROM, the latest release provides data from Waves 1 & 2 in SPSS & SAS formats	De-identified unit record data available on request. Results from LSIA1 available on CD-ROM. For more info see <www.immi.gov.au/research/lsia/lsia07.htm>	Data will be confidentialised before the information is given to researchers for future use
The initial sample comprised 12,252 households from 488 neighbourhood regions across Australia. 11,693 were identified as within scope. Interviews were conducted with 13,969 members aged 15+ of 7,682 households	Offshore visaed immigrants aged 15+ & accompanying spouse. LSIA 1 & LSIA 2 had 5,192 & 3,124 Primary Applicants respectively	Follow-up of the 11,247 participants of the original AusDiab study which included adults aged 25+ from 6 randomly selected districts within each of the states & the Northern Territory

Wave 1 household response rate of 66%	Response rates for LSIA1 & LSIA2 were Wave 1: 60%, 60%; Wave 2: 86%, 85%; Wave 3: 72%	—
\$50 is offered to households where all members participate & \$20 is offered where only part of the household participates	—	Participants receive information & comments relating to their physical measurements
An indefinite life panel with 8 waves of funding. Wave 1: Aug 2001–Jan 2002, Wave 2: Aug 2002–Apr 2003, Wave 3: Aug 2003–Apr 2004, Wave 4+: annual interviews Aug–Apr	LSIA1 Wave 1: Mar 1994–Dec 1995, Wave 2: Mar 1995–Feb 1997, Wave 3: Mar 1997–Feb 1999; LSIA2 Wave 1: Mar 2000–Jan 2001, Wave 2: Mar 2001–Mar 2002	Original AusDiab study took place in 1999/2000—the AusDiab follow-up began in June 2004. A 10 year follow-up is being considered
Household Form & Household Questionnaire (personal interview) completed by an adult household member; Person Questionnaire (personal interview) & Self-Completion Questionnaire completed by all members 15+; subsequent waves included a separate instrument for new sample members	Random sample stratified by Visa eligibility categories & region of birth. The principal applicant & migrating unit spouse were interviewed. Demographics for other household members were obtained from the primary applicant	Clinical measures include blood & urine testing, height, weight, waist & hip circumference & blood pressure. 4 short questionnaires covering medical history, utilisation of health services, physical activity & diet administered at initial health check
Data file includes population weights & derived variables. Missing values have generally not been imputed. Technical papers on coding framework, survey methodology & weighting are available at <www.melbourneinstitute.com/hilda/hdps.html>	Data were weighted & considered the effects of stratification & sample loss	—
See annual reports, discussion papers, HILDA bibliography & data. Limited results given in <i>FaCS Research News</i>	Results from LSIA1 on CD-ROM & also discussed in publications. Sample reports available at <www.immi.gov.au/research/lisia/lisia05.htm> & <www.immi.gov.au/research/lisia/lisia06.htm>	—
Annual reports, discussion papers & technical papers on website. HILDA bibliography is available at <www.melbourneinstitute.com/hilda/hbiblio.html>	Publications based on LSIA data are at <www.immi.gov.au/research/publications/index.htm>. Sample reports available at <www.immi.gov.au/research/lisia/lisia05.htm> & <www.immi.gov.au/research/lisia/lisia06.htm>	—
British Household Panel Study, German Socio-Economic Panel Study, US Panel Study of Income Dynamics, Swiss Household Panel Survey	The Longitudinal Survey of Immigrants to Canada, The Longitudinal Immigration Survey: New Zealand	The Australian Diabetes, Obesity & Lifestyle Study

Australian Temperament Project	Longitudinal Study of Australian Children (Growing Up in Australia)	Longitudinal Surveys of Australian Youth
A study of children born between September 1982 & January 1983 that aims to trace the pathways to psychosocial adjustment & maladjustment across the lifespan, & to investigate the contribution of personal, familial & environmental factors to development & wellbeing	To examine the impact of Australia's unique social & cultural environment on the next generation. Will further understanding of early childhood development, inform social policy debate, & identify opportunities for early intervention	Studies the progress of several groups of young Australians as they move from school into further education & training, the labour force & adulthood
<p style="text-align: center;">Diana Smart</p> <p>Email: atp@aifs.gov.au or diana.smart@aifs.gov.au Web: www.aifs.gov.au/atp/home.html</p>	<p style="text-align: center;">Ann Sanson</p> <p>Email: growingup@aifs.gov.au or lsac@facs.gov.au Web: www.aifs.gov.au/growingup or www.facs.gov.au/internet/facsinternet.nsf/aboutfacs/respubs/research-lsac_nav.htm</p>	<p style="text-align: center;">Sheldon Rothman</p> <p>Email: lsay@acer.edu.au or rothman@acer.edu.au Web: www.acer.edu.au/research/LSAY/overview.html</p>
Australia, Victoria, Melbourne	Australia, VIC, Melbourne	Australia, Victoria
<p style="text-align: center;">AIFS—A/Professor Ann Sanson, Mrs Diana Smart, A/Professor John Toumbourou, Professor Margot Prior, Professor Frank Oberklaid</p>	Consortium of researchers led by the AIFS —A/Professor Ann Sanson	<p style="text-align: center;">ACER, DEST—Dr Sheldon Rothman</p>
Impact of family, environment & child character on emotional & behavioural adjustment; progression of childhood behaviour problems to adult adjustment difficulties; genetic influences on temperament; development of healthy, socially competent functioning; development of social responsibility; transition to young adulthood	The study will collect data addressing 14 specific research questions that span 4 research domains family functioning, education, health & non-parental child care as well as data on core measures (e.g. demographic questions about the child & family)	Transition from school to work; education & training; employment & labour markets; income; health & wellbeing; household & family formation; housing; living conditions; young people; attitudes & aspirations
The project is presently funded by the AIFS, but has received support from NHMRC & ARC grants as well as the Murdoch Foundation of the Royal Children's Hospital	\$20.2 million for first 4 waves of data collection as part of the Stronger Families & Communities Strategy	DEST plus other state & territory government funding
—	Data will be warehoused at AIFS & will be available for research purposes, with the release of Wave 1 data in April 2005. A paper discussing data management issues (& access) is available at < www.aifs.gov.au/growingup/pubs.dp3/dp3.html >	The data are available to researchers working at Australian institutions. Researchers can respond to DEST calls for research submissions or apply to ACER with ad hoc requests to use the data
Australian children born in Victoria between September 1982 & January 1983. 2,443 infants & their parents from urban & rural areas	The Medicare database is being used to select 5,000 infants aged 4–13 months & 5,000 children aged 4 years 4 months–5 years 1 month at selection	Nationally representative cohorts of school children. 13,613 & 14,117 Year 9 students in the 1995 & 1998 cohorts; 10,447 15 year-olds in the 2003 cohort

Approximately 2/3 of families are still participating after 21 years	Expect less than 15% attrition between each wave efforts are being made to improve the Wave 1 response rate which is slightly lower than expected	Response rates vary by individual data set
—	—	—
Began in 1983 with Waves 1–4 at annual intervals. Waves 4–13 have been at 2-yearly intervals, with an additional assessment during the first year of secondary school. 13th wave of 20 year olds completed in 2002, with the 14th wave planned for when participants are in their mid-twenties	Wave 1: Mar 2004–Aug 2004, Wave 2: Mar 2006–Sep 2006, Wave 3: Mar 2008–Sep 2008, Wave 4: Mar 2010–Sep 2010. Study is funded until 2010 but will continue past this point with additional funding	Wave 1: Sep 1995–Dec 1995, Sep 1998–Dec 1998 & Sep 2003–Dec 2003 for 1995, 1998 & 2003 cohorts. Annual interviews until 2005/2006, 2008/2009 & 2013 respectively
Mail surveys with waves 1–4 at annual intervals & biennial intervals thereafter. An additional assessment during the first year of secondary school. Questionnaires completed by parents, nurses, teachers & children 11 & over	Cross-sequential design. Data collected via biennial personal interviews & a mail-out survey. Informants will include the child, parents, carers & teachers. Some data will also be collected via physical markers & direct assessment tasks & interviewer observation of the external environment	Data collected from 3 cross-lagged cohorts via annual phone interviews & surveys. Data include reading & numeracy tests, adolescent self-reports & school based information about curricula, school climate & school organisation
—	The study will provide a public good data resource a discussion paper outlining data management issues is available at < www.aifs.gov.au/growingup/pubs.dp3/dp3.html >	See LSAY publications
Results given in publications & information on related studies. See Outputs & Related Studies for details	No results currently available	The LSAY website provides links to LSAY research reports, cohort reports, technical reports & briefing papers
Project book & reports on survey waves; collaborative Crime Prevention Victoria project; young novice driving behaviour & experiences; numerous papers in national & international scientific literature. For a list of publications see < www.aifs.gov.au/atp/pubs.html >	A list of publications including discussion papers (introduction & overview, study design, data management), conference papers, journal articles, newsletters & brochures is available at < www.aifs.gov.au/growingup/pubs.html >	37 research reports have been published as at March 2004, & are available for downloading at < www.acer.edu.au/research/LSAY/research.html >. Cohort reports, technical reports & briefing papers are also available
Collaborative Crime Prevention Victoria project; Transport Accident Commission of Victoria/Royal Automobile Club of Victoria collaborative project; Australian National University collaborative project; & other ATP sub-studies	National Longitudinal Study of Children & Youth in Canada, Millennium Cohort Study in the UK	Youth in Transition, Australian Youth Survey & the Australian Longitudinal Survey are part of the LSAY project. Initial sample for 2003 cohort drawn from OECD PISA

Appendix B English Longitudinal Study of Ageing

Study aims

ELSA investigates the economic position, health, social circumstances and quality of life of people who are aged 50 and over (and any partners who are under 50) in England. The study seeks to both influence policy and to explain how people's expectations and plans for their retirement are changing. It will provide information about how people's experiences vary and how their circumstances change over time.

The survey covers a broad set of topics relevant to a full understanding of the ageing process. The study aims to answer questions such as:

1. What is the relationship between health and wealth?
2. What determines the nature and timing of retirement?
3. How important are household and family structures to health, wealth and quality of life?
4. How adequate are financial provisions for retirement, and how can policy help?
5. How should the government design the use and quality of health services?
6. What is the nature and structure of social networks, support and participation?
7. What would improve the quality of life for people aged 50 and over?

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Location of research

UK, England, London

Investigators

Collaborating institutions

University College London, Department of Epidemiology and Public Health
Institute for Fiscal Studies
National Centre for Social Research
University of Cambridge, Department of Psychiatry
University of Nottingham, School of Economics

Principal investigator

The co-principal investigators for ELSA are Professor Sir Michael Marmot (Head of the Department of Epidemiology and Public Health and Director of the International Centre for Health and Society, UCL) and Professor James Nazroo (UCL).

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Mike Wadsworth, Department of Epidemiology and Public Health, UCL
Bob Wallace, Department of Epidemiology, University of Iowa
David Weir, Institute for Social Research, Michigan
Bob Willis, Institute for Social Research, University of Michigan

Also involved in the study are academic researchers from Cambridge University, Oxford
University, University of East Anglia, Exeter University and the University of Nottingham.

Content

Main topics covered: ageing and older people; demography and migration; education and
training; employment and labour markets; ethnicity and national identity; income, wealth
and spending; sex and gender; health and disability (including biomedical, anthropometric
and physical performance measures); household goods and technology; households and
families; housing; leisure; living conditions; welfare; and social and civic participation.

Other topics covered: retirement; inter-family transfers; life expectancy; disability; social
networks; psychological health and cognitive function; diet and nutrition; and pensions.

The first wave questionnaire and the pilot version for Wave 2 are available at
<www.ifs.org.uk/elsa/documentation.html>. The survey questionnaire was developed over
a period of time – initially themes were outlined which then developed into working
modules.

These modules include Household Demographics; Individual Demographics; Health; Social Participation; Work and Pensions; Income and Assets; Housing; Cognitive Function; Psychosocial Factors; Expectations; Self-Completion Questions; and Final Questions. A Walking Speed Measurement was also conducted. The purpose and content of each module can be found at <www.ifs.org.uk/elsa/content.html>, and some details are below:

1. Household Demographics collects basic demographic information such as sex, age, and relationships between everyone in the household.
2. Individual Demographics collects details from respondents about their legal marital status, whether their parents are alive or dead, number of living children, grandchildren and great-grandchildren, number of siblings and the respondents' circumstances in childhood.
3. Health covers self-reported general health, long-standing illness or disability, eyesight and hearing, specific diagnoses of physical and mental diseases, symptoms such as pain, difficulties with activities of daily living and instrumental activities of daily living, and health behaviours. Respondents aged 60 and over are asked about falls and fractures.
4. Social Participation covers the frequency with which respondents participate in social activities, whether they are limited from participating, and questions about care-giving and use of public transport.
5. Work and Pensions collects data on respondents' current work activities and provision made for pensions.
6. Income and Assets collects the income that respondents received from a variety of sources over the past 12 months, including wages, state pensions, private pensions, and other annuity income and state benefits. It also collects the amount of financial and non-financial assets held, any income from these assets, regular transfers from non-household members and one-off payments in the past year.
7. Housing collects information about current housing situation (including size and quality), housing-related expenses, ownership of durable goods and cars, and expenditure on food. Owners and mortgagors are asked about the value of their property, and questions are asked about mortgages, rent etc.
8. Cognitive Function measures different aspects of the respondents' cognitive function, including memory, speed and mental flexibility. Numeracy alternates with literacy in successive fieldwork waves.
9. Expectations measures people's expectations in a number of dimensions. The level of certainty respondents felt about the future, financial decision-making within households and optimal planning horizons.
10. Psychosocial Health measures how the respondent viewed his or her life across a variety of dimensions. Quality of life is measured using an instrument known as CASP.
11. Final Questions collects demographic information, a stable contact address and consent to obtain health and economic data from administrative sources.
12. Walking Speed times a walk of eight feet at the respondents' usual walking pace. It is completed for all individuals aged 60 and over who respond to the survey in person, where it is judged safe to do so.

Funding agencies/budget

The NIA in the US provided approximately half the funding for the first five-year cycle of the study (NIA also runs a parallel study in the US). Other funding was provided by UK Government departments involved in areas that are related to the ageing process: Department of Health; Department for Work and Pensions; Office for National Statistics; Department of Transport for Local Government and the Regions; Department for Education and Skills; Department of Culture, Media and Sport; HM Treasury; Department for Environment, Food and Rural Affairs.

Data availability

No survey results based on small geographical areas that may risk being identified with a participant or their household, will be made available to councils, the media or members of the public. Anomised data will be made available with no restrictions on its use as long as the confidentiality of the respondent is preserved. Access procedures are under development. Data are released approximately one year after collection. The data from Wave 1 was deposited in the UK Data Archive during August 2004. Once it is available, a link will be posted at <www.ifs.org.uk/elsa/data.html>. Contact Sheema Ahmed (ELSA Administrator) at sheema.ahmed@public-health.ucl.ac.uk or ELSA@public-health.ucl.ac.uk for further information.

Sampling (cohorts/sample size)

The survey sample was drawn from respondents to the HSE, a study conducted jointly by the Department of Epidemiology and Public Health, UCL and the National Centre for Social Research, on behalf of the Department of Public Health. Approximately 13,000 respondents from the 1998, 1999 and 2001 HSE were recruited to provide a representative sample of the English population (living in private households) aged 50 and over. In addition, partners under the age of 50, and new partners who had moved into the household since the HSE, were also given a full interview. Sample members who move into institutions are being followed from Wave 2. The HSE may later be drawn upon again to boost particular sub-populations of interest, or to refresh the ELSA sample as it ages.

The major advantage of the HSE sampling source is that baseline data on respondents' health (details of morbidity, lifestyle, diets and blood samples) have already been collected. The health data will be supplemented by the collection of baseline economic data in the first wave of ELSA. Future rounds of ELSA will then track changes in health and economic position.

The Wave 1 sample of 11,392 respondents included 204 partial and 158 proxy responses. In addition, 636 partners under 50 and 72 new partners were interviewed, equating to a total sample of 12,100.

Each of the main HSE samples was designed to be representative of the English population living in private households, and was drawn in two stages. Postcode sectors were selected from the Postcode Address File, stratified by health authority and proportion of households in the non-manual socioeconomic groups. Addresses were then selected systematically from each sector and a specified number of adults and children in each household were deemed eligible for interview.

Also see <www.ifs.org.uk/elsa/report03/ch9.pdf>, which includes issued and achieved sample numbers by age and sex.

Response rate

The survey achieved a household response rate of 70%, with approximately 96% of individuals responding within households. This equates to an overall response rate of 67%. The individual response rate for younger and new partners was 63% and 68%, respectively. The main reason for non-response was refusal.

Also see <www.ifs.org.uk/elsa/report03/ch9.pdf>.

Incentives

Participants were offered vouchers as incentives. Refusals were taken as final. Other methods of encouraging response included strategies for tracing and contacting eligible participants who had moved since their last interviews, interviews with proxy informants where eligible individuals were unable to participate in the interview due to a physical or mental impairment, and reminder letters and phone calls to chase up Self-Completion Questionnaires. Also see <www.ifs.org.uk/elsa/report03/ch9.pdf>.

Timeframes

ELSA was launched by an interdisciplinary consortium in October 2000. The designing of the questionnaire began in January 2001, and piloting took place in August and November 2001.

In March and April 2002, researchers briefed ELSA interviewers about the questionnaire. Interviewers collected data until March 2003. The first ELSA report available at <www.ifs.org.uk/elsa/report_wave1.html> was published in December 2003 and data analysis is ongoing.

Data is collected every two years, also drawing on HSE data which will have been collected before the first wave of ELSA.

Wave 0: 1998, 1999 and 2001 HSE (fieldwork and biomedical tests), Wave 1: March 2002 – March 2003 (ELSA fieldwork, face to face interview), Wave 2: June 2004 (ELSA fieldwork, face to face interview and nurse visit), Wave 3: 2006, Wave 4: 2008.

Methods and data collection

The 1998, 1999 and 2001 HSE consisted of fieldwork and biomedical tests. ELSA draws on blood samples, morbidity, lifestyle and diet data collected by the HSE by linking via a common respondent number. This allowed ELSA to focus more on economic information than on health information in Wave 1. From Wave 2 this information will be updated and combined with further health, economic and social data.

From Wave 1 data is collected every two years via a structured interview and a self-completion questionnaire. A nurse visit (to collect clinical measurements such as blood

pressure, lung function, grip strength, lower body strength and balance) is planned for alternate waves.

A common core of information is regularly collected in modules, using instruments and measures such as Standard Occupational Classification 2000, General health Questionnaire (GHQ) 12, Rose angina questionnaire, Medical Research Council respiratory questionnaire, and Strengths and difficulties questionnaire. Additional questions and modules are decided after extensive consultation with interested parties.

ELSA has developed new approaches where tried-and-tested measures do not exist. Examples include: unfolding brackets to mitigate non-response problems on financial variables (first developed for the HRS in the US and adapted by the IFS for ELSA.); concurrent interviewing where there was more than one eligible respondent per household (with a period of the interview spent privately with each respondent for the collection of sensitive data); and the use of 'percentage chance' questions to understand people's expectations of the future.

For more information see <www.ifs.org.uk/elsa/report03/ch9.pdf>.

Data analysis

Following each round of data collection, a report containing key analyses will be published, together with a commentary.

The equal probability sample design of the HSE samples eliminates the need for weights to account for selection probabilities. However, a thorough analysis of non-response found that households that did not contain an age-eligible individual who agreed to be re-interviewed beyond HSE, and household-level of non-response at ELSA Wave 1, were significant enough to justify calculating a non-response weight to account for differences between respondents and non-respondents. See <www.ifs.org.uk/elsa/report03/ch9.pdf> for further information on weighting strategies.

Results

Following each round of data collection, a report containing key analyses will be published, together with a commentary. Data are released approximately one year after collection. A summary of findings using Wave 1 data, under the headings of sociodemographic characteristics; socioeconomic position; work and retirement; social activity; health; physical and cognitive function; and physical and social environment, is available at <www.ifs.org.uk/elsa/report03/app1.pdf> with more detailed information provided in subsequent chapters.

In England the Department of Health and Department for Work and Pensions will use the results to help plan the spending of their budgets. Other government departments will be using results to design policies targeted towards older people. Academic researchers will use the data to help understand important questions in health, economics and ageing. Their results will then be used to advise policy-makers on policies for health and pensions, and for comparison with results from similar studies in other countries.

Outputs

Marmot M, Banks J, Blundell R, Lessof C & Nazroo J (eds) 2003. Health, wealth and lifestyles of the older population in England: The 2002 English Longitudinal Study of Ageing. London: Institute for Fiscal Studies. Viewed 19 August 2004, <www.ifs.org.uk/elsa/report_wave1.html>.

The Wave 1 technical report will be published in 2004, and will include key survey documents, including the Wave 1 questionnaire.

Related publications

Attanasio O, Banks J, Blundell R, Chote R & Emmerson C 2004. Pensions, pensioners and pension policy: financial security in UK retirement savings? IFS briefing note 48 prepared for the ESRC seminar series. Mapping the policy landscape.

Banks J, Emmerson C & Oldfield Z 2004. Not so brief lives: longevity expectations and wellbeing in retirement. In: Economic and Social Research Council. Seven ages of man and woman: a look at life in Britain in the second Elizabethan era.

Related studies

There are currently no data in the UK that cover and connect the full range of topics necessary to understand the economic, social, psychological and health elements of the ageing process. ELSA has been designed to fill that gap.

Related international studies include the Baltimore Longitudinal Study of Ageing. The NIA also funds a parallel study, the HRS, in the US – additional information may be provided by comparing results across the two countries. ELSA and HRS have become models for a series of parallel studies being developed in Europe (Surveys of Health, Ageing and Retirement in Europe), as well as studies of ageing in Mexico, Czech Republic, Poland, and Russia.

References

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Institute for Social and Economic Research: Fisher K, Ajayi J, Akhmadov R, O'Hanlon C, Pogorelis R & Watkins-Wright E 2004. Keeping track: a guide to longitudinal resources. London: Office for National Statistics; Colchester: University of Essex. Viewed 19 August 2004, <iserwww.essex.ac.uk/ulsc//keeptrack/results/results.php>.

Marmot M, Banks J, Blundell R, Lessof C & Nazroo J (eds) 2003. Health, wealth and lifestyles of the older population in England: the 2002 English Longitudinal Study of Ageing. London: IFS. Viewed 19 August 2004, <www.ifs.org.uk/elsa/report_wave1.html>.

National Centre for Social Research 2004. Ageing. London: National Centre for Social Research. Viewed 3 April 2004, <www.natcen.ac.uk/natcen/pages/or_ageing.htm>.

National Centre for Social Research 2003. English Longitudinal Study of Ageing. London: National Centre for Social Research. Viewed 19 August, <www.natcen.ac.uk/elsa/faq/about.htm>.

Appendix C Baltimore Longitudinal Study of Aging

Study aims

The NIA conducts research to learn about the changes that take place as we age. One goal of NIA research is to help understand medical problems that are common in older people. BLSA investigates what happens as people age and aims to sort out changes due to ageing from those due to disease or other causes.

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[<www.grc.nia.nih.gov/branches/blsa/blsa.htm>](http://www.grc.nia.nih.gov/branches/blsa/blsa.htm)

Location of research

US, Maryland, Baltimore

Investigators

Prior to the founding of the NIA, which presently resources the BLSA, the project was funded initially by a grant from the Macy Foundation and then the NIH through congressional appropriation. The study was founded by Nathan W Shock, Arthur H Norris and William W Peter and continued under the guidance of Jordan D Tobin, MD and Dr James L Fozard. The present director of the BLSA is Dr Luigi Ferrucci.

Content

BLSA focuses on biomarkers of ageing, but has also been used for the investigation of age on many diseases, including dementia, arthritis, prostate cancer, cardiovascular disease and depression, as well as functional parameters such as mobility, muscle strength and respiratory function.

Study variables include:

- Sociodemographic: sex, ethnicity, income/job status;
- Functional health: self-reported health, hearing loss, taste sensations, vision testing, muscle strength, timed gait;
- Bio-clinical: blood pressure, medical history and physical examination, laboratory variables and immunological assays, ability to perform aerobic exercises, ambulatory electro-cardio, arterial stiffness, exercise Thallium scan, echocardiography, cardiac MRI, vascular medications, blood cholesterol levels, prostate specific antigens measures, percentage of free prostate-specific antigen to predict treatable cancer, alcohol metabolism in men, glucose tolerance, plasma lipids and lipoproteins, body fat distribution in both sexes with concentration on waist, diabetes predictors, renal function, pulmonary function, oestrogen levels vis-à-vis memory, neurological exam, bone and joint osteoporosis and osteoarthritis, brain imaging, prostate imaging;
- Psychological: stability of personality, Temperament Survey, California Q-Set, Computer Assisted Test, Revised NEO Personality Inventory, coping mechanisms, personality tests to predict psychological wellbeing;
- Cognitive abilities: visual recall, vocabulary test, memory/reaction time, sustained vigilance task, Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological SS. Battery; and
- Lifestyle: nutrition, diet trends, physical activity and other, physical activity questionnaire.

Funding agencies/budget

Prior to the founding of the NIA, which presently resources the BLSA, the project was funded initially by a grant from the Macy Foundation and then the NIH through congressional appropriation.

Data availability

All data are kept confidential, and participants are not identified by name in any publication or presentation of research.

Sampling (cohorts/sample size)

Over 1,200 men and women ranging in age from their 20s to their 90s. Only healthy subjects are entered into the study.

Response rate

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Incentives

Volunteers are given a thorough physical examination and several medical screening tests every two years free of charge. More important is the chance to contribute to the knowledge about how people age.

Timeframes

Began in 1958. Data are collected on participants every two years. The BLSA Women's Program was initiated in 1978. See <www.grc.nia.nih.gov/branches/blsa/timeline.html> for a BLSA timeline.

Methods and data collection

Volunteers participate in more than 100 physiological assessments intended to yield a scientific understanding of the processes in human ageing. Data is also collected via self-completed questionnaires (e.g. Demographics, Physical Activity, Pulmonary Disease and Activities and Attitudes) and personal interviews (e.g. Diet Interview and Autopsy Study Interview). See <www.fhs.mcmaster.ca/clsa/LongStudies_DB_Working_pdf.pdf> for details on measurement of study variables. For other details on study variables see <blswww.grc.nia.nih.gov/infos.htm>.

Data analysis

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Results

Selected findings from 1978 to 1998 on the heart and arteries; the brain and memory; personality; the prostate; the senses; and diet and metabolism are available at <www.grc.nia.nih.gov/branches/blsa/blsafindings.pdf>. An overview of the first 20 years of findings can be found in the 1984 article *Normal Human Aging: The Baltimore Longitudinal Study of Aging*. Also see Outputs below.

Outputs

Over 800 scientific papers were published between 1958 and 1998. For a searchable list of publications (1980–2002) see <www.grc.nia.nih.gov/php2/blsapub.php>. Also see Results above.

Related studies

Related studies include ELSA.

References

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Appendix D Australian Longitudinal Study of Ageing

Study aims

ALSA is a population-based bio-psycho-social and behavioural study of older adults. The longitudinal data collected in the course of the ALSA study comprise the most comprehensive longitudinal database yet assembled on ageing Australians and the findings of the ALSA are directly relevant to policy formulation and planning of health and social services for an ageing population.

The study allows assessment of the effects of social, biomedical, psychological, behavioural, economic and environmental factors on changes in health, development of disability, general wellbeing, economic security, use of acute and long-term care services, morbidity, mortality, and 'successful' ageing in people aged 70 and over, particularly in a South Australian context. The research has a number of specific objectives. These include:

1. Determination of levels of health and functional status of an older population and to track the changes in these characteristics over time.
2. Identification of factors which promote and maintain health and wellbeing in an ageing population.
3. Identification of risk factors for major morbid conditions and social, behavioural and other problems among an ageing population.
4. Analysis of the effects on transitions in health and functional status of age, gender, different patterns of comorbidity, availability and nature of informal and formal support arrangements, social and economic circumstances, health care provision and utilisation and other variables of interest.
5. 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.
6. Examination of the patterns of the need for and the utilisation of informal and formal sources of long-term care as they relate to social support networks, economic and housing conditions, care-giving arrangements and the availability of appropriate services.
7. Examination of mortality outcomes in the light of changes in health and functional status, medical interventions, self-assessed health, social networks and individual characteristics.

The inclusion of both survey and clinical components makes it possible to link objective clinical measures with details of the lifestyle, attitudes and personal histories of respondents.

Contact details

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Other contacts

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Location of research

Australia, SA, Adelaide

Investigators

The Centre for Ageing Studies is the unit responsible both for the study and for data collection. Investigators include Professor Gary R Andrews (Director), Professor Mary Luszcz, Dr Michael Clark and others.

Content

Interviews include demographic, medical, psychological, social and economic components.

Main topics covered: ageing and older people; demography and migration; income, wealth and spending; sex and gender; health and disability; cognition, behaviour, living conditions; and social care and welfare.

Other topics covered: clinical health measures; general satisfaction; medication; and sleep.

Funding agencies/budget

Australian Rotary Health Research Fund \$50,000; SA Health Commission, \$76,900; US NIA \$967,521; SA Government (with contributions from the Australian Government via the Home and Community Care program) \$50,000; Elderly Citizens Homes PL \$50,000. Funds were also provided by the NHMRC (Wave 7 data collection and analysis of transitions) and limited funds were provided by Flinders University.

Data availability

The data are only available for scientific research that will not compromise the identity of the respondents. Researchers wishing to use this data should contact the Centre for Ageing Studies to discuss the way they potentially wish to use the research. Data are released approximately a year following collection. Eight data files, PDF documentation, LRECL with SAS and SPSS data definition statements and SPSS export files are available. Data from ALSA have been progressively archived with the Inter-university Consortium for Political and Social Research (ICPSR).

Sampling (cohorts/sample size)

Cohort consists of people aged 70 and over living in the Adelaide metropolitan area in 1992. Both community and institutionalised individuals were included. Initially, one person was selected per dwelling. Spouses aged 65 and over of specified persons were also invited to participate, as were other household members aged 70 and over. The sample was randomly generated from within the Adelaide Statistical Division using the State Electoral Database as the sampling frame.

Baseline interview data were collected from 2,087 people, including 566 elderly couples (where at least one partner was aged 70 or more and the spouse was aged at least 65); 1,620 baseline participants also provided clinical assessment data. 1,779 people were reinterviewed in Wave 2; and 1,679 reinterviews and 1,423 clinical assessments were conducted in Wave 3. 1,504 interviews were conducted in Wave 4, 1,171 were completed in Wave 5, and 791 were completed in Wave 6.

Response rate

Wave 1: 2,087 participants were interviewed. 53.4% of baseline sampled names participated at baseline. 56.3% of people who could be contacted completed a baseline interview.

Wave 2: 1,779 participants were interviewed (111 were deceased, 27 were not contactable and 170 refused since Wave 1). Response rate for eligible participants was 91.3% and 90.0% of survivors were reinterviewed.

Wave 3: 1,679 participants were interviewed (240 were deceased, 43 were not contactable and 125 refused since Wave 1). Response rate for eligible participants was 93.1% and 90.9% of survivors were reinterviewed.

Wave 4: 1,504 participants were interviewed (354 were deceased, 53 were not contactable and 176 refused since Wave 1). Response rate for eligible participants was 89.5% and 86.8% of survivors were reinterviewed.

Wave 5: 1,171 participants were interviewed (620 were deceased, 97 were not contactable and 199 refused since Wave 1). Response rate for eligible participants was 85.5% and 79.8% of survivors were reinterviewed.

Wave 6: 791 participants were interviewed (956 were deceased, 64 were not contactable and 276 refused since Wave 1). Response rate for eligible participants was 74.13% and 69.9% of survivors were reinterviewed.

Wave 7: 487 participants (including 72 proxies) were interviewed (1,287 were deceased (to be verified), 51 were not contactable and 169 refused (to be verified) since Wave 1).

Incentives

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Timeframes

Data collected yearly from 1992–1996 and biennially thereafter. Data are released approximately a year following collection. Another complete follow-up is planned (Wave 8) but the study will generally continue until the last participant survives.

Wave 1: September 1992–February 1993, Wave 2: September 1993, Wave 3: September 1994–February 1995, Wave 4: September 1995, Wave 5: February 1998, Wave 6: September 2000–February 2001, Wave 7: September 2002–February 2003.

Methods and data collection

The sample was randomly generated from within the Adelaide Statistical Division using the State Electoral Database as the sampling frame. The sample was stratified by gender and by the age groups 70–74, 75–79, 80–84 and 85 and over.

The initial baseline data collection for ALSA began in 1992 with information being collected for 2,087 participants. Components of this first wave included a comprehensive personal interview conducted via CAPI instruments, a home-based assessment of physiological functions, self-completed questionnaires (e.g. self-report of conditions, symptoms), and additional clinical studies. Personal interviews were carried out at this first wave for 2,087 participants and clinical assessments were obtained for 1,620 of the participants. Clinical measurements included anthropometry, grip strength, blood pressure, hearing, sight, psychological testing and performance-based measures of physical function. Blood samples were also collected for Waves 1 and 3.

After an interval of one year from the initial interview, respondents were recontacted by telephone. These interviews included questions regarding changes in domicile, current health and functional status, new morbid conditions, changes in medication, major life events, general life satisfaction, and changes in economic circumstances. In Waves 4 and 5, follow-up surveys were also conducted over the telephone.

Waves 3, 6 and 7 involved a full reassessment, again including comprehensive CAPI, home-based assessments of physiological functions, self-completed questionnaires, and additional clinical studies of most respondents. However, from Wave 3, shorter proxy instruments were used to gather information on some respondents. In Part 2, Wave 6 Clinical Data, information about the health histories of the respondents was elicited, including information on medication, blood pressure, and physical and mental disabilities. Wave 7 included additional information on significant transitions and responses.

Ancillary data collection has been ongoing since the initiation of the study. Data have been collected from secondary providers, including Domiciliary and Rehabilitation Services,

Meals on Wheels, and The Royal District Nursing Society. Lists of ALSA participants are compared periodically with the agencies' lists to determine the prevalence and incidence of receipt of services from these organisations.

Data analysis

Active groups of collaborators are analysing data relating to ADL/IADL performance, cognitive function, comorbidity, cardiovascular disease and risk factors, dental health, diet and nutrition, diabetes, exercise and physical activity, family relationships and support, formal service use, hearing function, injuries and falls, mortality, sensory function, social activities, social interactions between couples, 'successful' ageing and other parameters.

Also see publications.

Results

Data are released approximately a year following collection. See publications.

Outputs

Researchers have cited the ALSA in almost 200 publications including reports, book chapters, refereed journal articles, abstracts, conference proceedings and theses. A selected list of publications (excluding publications such as theses, conference papers and data files) is below:

Andrews G 2001. Australian Longitudinal Study of Ageing. In: Maddox GL (ed.). The Encyclopedia of Aging, 3rd edition. New York: Springer, 107-9.

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Related studies

Sub-studies include the Australian Longitudinal Study of Ageing: Psychological Aspects and the Australian Longitudinal Study of Ageing: The Intersection of Sensory and Cognitive Functioning.

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Appendix E 45 and Up

Study aims

45 and Up will look at the general health of the ageing population and report on health problems and areas of concern. The information will then be used to direct future medical research and health care policy. The study aims to address the following priority research areas and questions and to provide a long-term resource for public health research:

1. Provision of reliable information on the burden of disease in NSW, including the prevalence of cancer and cardiovascular diseases requiring active treatment.
2. Examination of the socioeconomic determinants of healthy ageing, including rural/urban inequalities, effect of retirement, social capital and variations in healthy ageing by ethnicity and social class.
3. Investigation of the health effects of obesity, overweight and physical activity, with a particular focus on the risk of cancer, cardiovascular disease, diabetes mellitus and all-cause mortality.
4. Investigation of risk factors for and the detection and management of cancer, including investigation of prostate cancer and prostate cancer screening.
5. Investigation of impact of environmental factors on healthy ageing.
6. Examination of risk factors for mental health problems later in life, including depression, and use of mental health services.
7. Investigation of use of health services in relation to ageing, including the determinants of use of residential aged care.
8. Investigation of health in people aged 80 and over (the 'old old').

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Location of research

Australia, NSW, Sydney

Investigators

45 and Up will be carried out under the auspices of the IHR. The study is a collaborative effort between researchers and the wider community in NSW, with about 90 researchers expected to contribute throughout the course of the study. Members of the Steering Group include:

Dr Freddy Sitas (chair)
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The Cancer Council NSW

Professor Bruce Armstrong
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Professor Adrian Bauman
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Content

Eight key research priority areas were listed in Study aims above: the burden of disease in NSW requiring active treatment; socioeconomic determinants of healthy ageing; the health effects of lifestyle factors such as overweight, obesity and physical activity on cancer, cardiovascular disease and diabetes; risk factors, detection and management of cancer (e.g. prostate cancer); impact of environmental factors on healthy ageing; mental health (e.g. depression) and the use of psychiatric health services; use of health services, including determinants of use of residential care; and health in people aged 80 and over.

Funding agencies/budget

Core funding for 45 and Up is provided by a consortium of organisations. The project has previously received seed funding for the development of the program and pilot studies from

the IHR, which is funded by NSW Health for a three-year period, July 2002 to June 2005, at \$1 million per annum.

Data availability

45 and Up is designed as a collaborative research resource which is available for use by the wider research community. Researchers will contribute to the design, development and conduct of the study through membership of approximately eight committees spanning the key research priority areas. Researchers will apply to use data from the study via a pre-defined and rigorous process of peer review, and will also be in a position to set up specific sub-studies within the framework of the cohort. By making data available to the scientific community, the project will serve as a means to develop national expertise and infrastructure in large-scale health research. It will provide a focus and resource for high-quality research over the coming decades.

All information given to the study will be treated with absolute confidentiality. It will be used for health research only and treated in strict accordance with current privacy legislation. All identifying details will be stored separately from the other data recorded for each participant and linkage of participant identifying information with their other study data will take place only when strictly necessary. Guidelines for such linkage will be drawn up by the Steering Group prior to the commencement of the study. Data released for analyses will not contain identifying information and no publication from the study will identify individuals taking part. Participation in the study will be purely voluntary.

Sampling (cohorts/sample size)

A broadly random sample of more than 250,000 people aged 45 and over in NSW (equal to around 10% of the general population of NSW in this age group). Potential participants aged 45 and over will be identified using the electoral roll and sent study information and a recruitment questionnaire. Those wishing to join the study will complete and return the questionnaire and a consent form for follow-up (including access to their medical and other records). There will be some oversampling of those born in countries other than Australia and of rural residents.

Response rate

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Incentives

Similar projects in Australia and other countries have found that, where studies are relevant and meaningful to participants, where confidentiality is safeguarded and where only a small amount of time and effort is required, large numbers of people are happy to participate in this kind of research. The 45 and Up Study is designed to address questions about health which many people in this age group are already asking. It is also very simple to

participate – participants are required to fill out an initial questionnaire (which should take approximately half an hour) and then another questionnaire every five years or so.

Timeframes

The study is expected to run for 15 years with follow-up questionnaires every five years or so. Project launched January 2004, with initial pilot studies planned for mid 2004.

Recruitment of participants is planned to begin late in 2004/early in 2005 and to be completed in 2009. The first wave of follow-up will then start and take five years, then the second wave of follow-up will start and take another five years. Studies using available data will commence one to two years after recruitment.

Methods and data collection

The institute will use the electoral roll to identify possible potential participants in the research. Participants will be asked to join the study by returning a brief self-administered questionnaire on their current health, their health and reproductive history, and lifestyle factors such as exercise levels and smoking, and providing written consent for follow-up (including access to their medical and other records).

Participants will be followed for incident cancer diagnoses and cause-specific mortality through the NSW cancer registry, the National Cancer Statistics Clearing House, the National Death Index, Geographical Information Systems and NSW births, deaths and marriages data.

Opportunities for other types of data linkage will be explored and used where practicable. Such linkage may include NSW hospitalisation data (e.g. hospital admissions and medical and surgical procedures), ambulance data, Emergency Department attendances, the Pharmaceutical and Medical Benefits Schemes, Australian and New Zealand dialysis and transplantation register, BreastScreen NSW, Department for Veteran's Affairs, National Coronal Information System, National diabetes register, NSW Pap test register, NSW Midwives' data collection, Radiotherapy Management Information System, use of aged care facilities and Road Traffic Authority data sources.

There will be follow-up questionnaires every five years or so to ascertain incident and self-reported morbidity and current health status, to update exposure data and to gather new exposure data. Participants' reports of incident morbidity will be validated and additional evidence of disease will be sought to allow classification of diseases status according to standard criteria.

Longer-term plans include the ability to gather biological samples (such as blood and saliva) to measure markers of susceptibility, exposure to harmful factors and disease occurrence.

Data analysis

Following initial analyses of cross-sectional data, the main means of investigating relationships between exposure and outcome will be through a series of case-control studies nested within the cohort. For conditions yielding at least 3,500 incident cases or deaths (e.g. diabetes mellitus, myocardial infarction, stroke, colorectal cancer, prostate cancer, breast

cancer, hip fracture, dementia) the study will be able to detect a minimum relative risk of 1.3 for exposures affecting 10–90% of controls and 1.4 for exposures affecting 5–95% of controls, with 95% power and 1% significance. With the same power, significance and ratio of cases to controls, for outcomes with 1,000 or more events (e.g. ischaemic heart and cerebrovascular diseases deaths and incident Parkinson’s disease, non-Hodgkin’s lymphoma, lung cancer) the study should be able to detect minimum relative risks of 1.4–1.5 for exposures affecting 20–80% of the population and 1.6 for exposures affecting 10–90% of the population.

Results

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Outputs

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Related studies

Steering group members Emily Banks (Scientific Director) and Valerie Beral have also worked on the UK Million Women Study and the UK Biobank. There are also strong links to the European Prospective Investigation into Cancer and Nutrition.

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Appendix F The Dubbo Study of the Health of the Elderly

Study aims

The Dubbo Study began as a longitudinal community study of people born before 1930 living in the town of Dubbo, NSW. 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 age-related diseases such as cardiovascular diseases and dementia. The objective of the Dubbo Study is to contribute for policies and programs to improve the quality of life and quality of services for older Australians. Generally the research project will enable Australians to increase longevity and improve wellbeing in later life.

A new phase to the study began in 2000 to investigate Assets and Health Dynamics in an 'old' old population. The aim of this new phase was to model how three kinds of resources – income and assets, government entitlements and informal care services – modify expected changes in health or family circumstances in later life. The specific objectives were to model hospital use, residential care admission, informal community care, pension and benefit receipt, pharmaceutical benefit use and income and assets in an older cohort.

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Location of research

Australia, NSW

Investigators

Directors of the study are Associate Professor Leon Simons and Professor John McCallum. Co-investigators are Ms Judith Simons and Professor Yechiel Friedlander.

Content

Broad outcomes of interest were mortality, hospitalisation and placement in long-term care, while the specific outcomes were cardiovascular disease, osteoporosis, disability and dementia. These were related to baseline characteristics such as lifestyle and dietary exposures (including doctor and self-prescribed vitamin supplements), pharmaceutical interventions and medical/family history (major foci), social class, income, education, physical activity and physical measurements. Data were also collected on hearing and vision, women's health and mental health (e.g. depression).

One of the strengths of the Dubbo study was the inclusion of questionnaires examining life satisfaction, self-esteem and social involvement and support. Family and community contributions (including voluntary work) was also a major focus of the study.

AHEAD modelled hospital use, residential care admission, informal community care, pension and benefit receipt, pharmaceutical benefit use and income and assets in an older cohort. Data were also collected on employment, retirement, superannuation, expenses, housing and access to (and knowledge of) transport and other services.

Funding agencies/budget

Various NHMRC project grants since 1988 and private company research grants, an ARC Strategic Partnership with Industry Research and Training Grant for \$498,707 from 1999, FaCS and industry partner Southern Cross Homes.

Data availability

Data will be available subject to privacy constraints by direct request to the study director.

Sampling (cohorts/sample size)

At baseline, from 1987, eligible subjects were identified through a reconciliation of GP and electoral records. The eligible study population was a single cohort of non-institutionalised residents of the Dubbo local government area who were born before 1 January 1930 and who attended a centrally located office for baseline medical and psychosocial assessment. A group of 2,805 residents (1,233 men and 1,572 women) aged 59–98 were first interviewed in 1988 and have been followed to the present with continuous ‘cold pursuit’ of death, hospitalisation and residential care data.

The study population are 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 the state of NSW as a whole.

Response rate

Based on a reconciliation of family doctor and electoral records, it is estimated that 73% of those eligible (2,805 people) participated in the study. At Wave 2, 1,089 participants completed face-to-face interviews, with 401 of these participants completing a reduced version of the questionnaire. The remaining participants were either deceased, unable to be contacted or were too ill to participate.

Incentives

No incentives have been provided to participants.

Timeframes

A 15-year longitudinal study with data collections in 1988, 2000 and 2002–2003. At baseline, from 1987, eligible subjects were identified through a reconciliation of GP and electoral records. Examinations and interviews extended from late August 1988 over a period of 13 months.

Methods and data collection

The Dubbo Study adopted an epidemiological approach to identifying risk factors and predictors of service use. The measures of risk factors were taken at a baseline point in time rather than proximate to admission.

Hospital, hostel and nursing home admissions in Dubbo were routinely collected as a part of the research program since late 1988 and this is ongoing. Services provided outside Dubbo

were tracked by two-yearly questionnaires and data collected from other hospitals, health and aged care services.

The medical examination included anthropometry, blood pressure, resting electrocardiogram (ECG), peak expiratory flow, and blood testing for lipids and glucose. A questionnaire explored social support, self-rating of health, functional health as ADLs and depression status (Center for the Epidemiologic Studies – Depression (CES-D)) and was administered by trained interviewers. It also covered demographics, education, alcohol and tobacco use, medications, past medical history and chest pain among other things.

In 2002–2003 approximately 100 interviews were conducted by phone, where participants had moved from the local area.

A unique feature of the Dubbo Study was gaining participants' consent to undertake record linkage to service provider databases. DoHA and the Health Insurance Commission (HIC) are currently compiling a dataset of records from the Pharmaceutical Benefits Scheme and Medicare. The Department of Veterans' Affairs has permitted the identification of veterans within the study population, and FaCS has provided information pertaining to pensions and assets records. The NSW Probate Registry has also given access to the records of the deceased for the purposes of the study.

Methods and measures employed have been described in detail in earlier publications:

Simons LA, McCallum J & Simons J et al. 1990. The Dubbo Study: An Australian prospective community study of the health of the elderly. *Australian and New Zealand Journal of Medicine* 20:783–89.

Simons LA, McCallum J & Friedlander Y et al. 1991. The Dubbo study of the elderly: Sociological and cardiovascular risk factors at entry. *Australian and New Zealand Journal of Medicine* 21:701–09.

Data analysis

Analysis of hospital and residential care has been completed. Pension and assets data, as well as data on GP and pharmaceutical usage, are currently being analysed. Analysis of Wave 3 data will be undertaken in conjunction with the record linkage data.

See publications for more information on data analyses.

Results

Various – see publications.

Outputs

See <www.dubbostudy.org/dubbostudy.nsf/main/Publications> for a list of Dubbo publications.

Related studies

There have been one-off collections of community and post-acute care services and other data, such as on organic depressions, as part of separately funded projects.

AHEAD is set within the Dubbo cohort, and is a comparative study of Australia, the European Community, Japan, US and UK, modelling what older people do with their income and assets when their health and family circumstances change.

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Appendix G Melbourne Longitudinal Studies on Healthy Ageing Program

Study aims

La Trobe University in partnership with The University of Sydney is conducting a series of three linked studies that form a large longitudinal study on healthy ageing: The MELSHA Program. The three studies that form the program are:

- HSOP Project – 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.
- HBOA Project – this study was a follow-up of the HSOP sample and focused on biannual health behaviour change and continued annual measurements of functional ageing, health, and service outcomes.
- FAHS Project: A Longitudinal Outcomes Study – this study continues the follow-up of the HSOP sample and aims 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 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.

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Location of research

Australia, Victoria, Melbourne

Investigators

The Program Directors are Associate Professor Colette Browning, School of Public Health, La Trobe University and Professor Hal Kendig, Dean and Professor, Faculty of Health Sciences, University of Sydney and Adjunct Professor, La Trobe University. The multidisciplinary research team for the three related studies has included psychologists, sociologists, medical researchers, occupational therapists, physiotherapists and public health researchers.

Principal investigators of HSOP included Professor Hal Kendig, Associate Professor Colette Browning, Professor Rob Helme (Associate, National Ageing Research Institute, The University of Melbourne). Associate investigators included Professor Leon Flicker (Geriatric Medicine Unit, Royal Perth Hospital) and Ms Karen Teshuva (Australian Institute for Primary Care, La Trobe University).

Principal investigators of HBOA included Professor Hal Kendig, Associate Professor Colette Browning, Professor Meg Morris (School of Physiotherapy, La Trobe University) and Professor Birgitta Lundgren-Lindquist (School of Health Sciences, Jönköping University, Sweden).

Principal investigators of FAHS include Professor Hal Kendig, Associate Professor Colette Browning, Professor Maria Fiatarone Singh (School of Exercise and Sports Medicine, University of Sydney), Associate Professor Susan Quine (Department of Public Health and Community Medicine, University of Sydney), Professor Shane Thomas (School of Public Health, La Trobe University), Associate Professor Carolyn Unsworth (School of Occupational Therapy, La Trobe University) and Dr Yvonne Wells (Australian Institute for Primary Care, La Trobe University).

Content

HSOP collected data on 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).

HBOA focused on biannual health behaviour change and continued annual measurements of functional ageing, health and service outcomes.

FAHS attempted to identify the most important factors that precipitate disability onset, service use, duration of care at home after disability onset, and predictors of entry to residential care.

Funding agencies/budget

The program has received funding primarily from VicHealth and the NHMRC over the period 1994–2005. However, in 2002 the Faculties of Health Sciences at La Trobe University and The University of Sydney contributed \$20,000 of matched funding for data collection on core variables (follow-up telephone survey) that year.

HSOP 1994–1997: \$532,743 VicHealth Project Grant, HBOA 1998–2000: \$161,500 NHMRC Project Grant, FAHS 2003–2005: \$215,465 NHMRC SRDC Healthy Ageing Project Grant.

ARC Small Grants were received to fund add-on components of the main study – 1994–1996: \$39,000; 1997: \$12,000; 1999–2000: \$10,000.

Data availability

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Sampling (cohorts/sample size)

HSOP included 1,000 participants aged 65 and over (average age 73) living in Melbourne. HBOA and FAHS were follow-ups of the original HSOP sample. All subjects first surveyed ten years earlier will have entered the critical age group of 75 years and over by 2004. See Response rate for the number of participants included in each wave of the project.

Response rate

The following number of participants were included in each wave of the study – Wave 1: 1,000, Wave 2: 906 Wave 3: 796, Wave 4: 718, Wave 5: 649, Wave 6: 611, Wave 7: 541, Wave 8: 424, Wave 9: 386.

Incentives

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Timeframes

The study is funded until 2005, which may be the last year. HSOP occurred 1994–1997, HBOA occurred 1998–2000, and FAHS runs from 2003–2005.

Wave 1: May 1994–November 1994, Wave 2: June 1995–December 1995, Wave 3: June 1996–November 1996, Wave 4: June 1997–October 1997, Wave 5: June 1998–October 1998, Wave 6: July 1999–October 1999, Wave 7: July 2000–November 2000, Wave 8: July 2002–July 2003, Wave 9: August 2003–November 2003.

Dates for waves in 2004 and 2005 have not been provided.

Methods and data collection

HSOP – This data collection formed the baseline for the MELSHA Program. Wave 1 included 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 (and possibly researcher observations) conducted in the home measured variables such as weight, height, eyesight and hearing. Waves 2 and 4 involved a brief mail-out questionnaire (with a phone call or visit where necessary) to collect change and limited outcome variables. Wave 3 used Computer Assisted Telephone Interviewing (CATI) to collect follow-up data on core variables.

HBOA – Focused on biannual health behaviour change 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. Waves 5 and 7 used CATI, and Wave 6 involved a brief mail-out questionnaire. Another CATI on core variables was conducted in Wave 8 using funding received from La Trobe University and The University of Sydney.

FAHS – This study continues the follow-up of the original HSOP sample. Wave 9 involved a brief mail-out questionnaire. Waves in 2004 and 2005 will involve CATI and a brief mail-out questionnaire, respectively.

Data analysis

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Results

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Outputs

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Related studies

MELSHA is a series of three linked studies.

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Faculty of Health Sciences, School of Public Health 2004. School of Public Health: current research. Melbourne: La Trobe University. Viewed 19 August 2004, <www.latrobe.edu.au/publichealth/research/specialist_research.htm#MELSHA>.

Appendix H The Sydney Older Persons Study

Study aims

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. SOPS commenced in 1991. At this stage, non-veteran members of the community were included as well.

SOPS Stage 4: MRI correlates of memory functioning in normal ageing

The aim of this study was to define cognitive and structural correlates of 'normal' brain ageing, with the specific purpose of investigating whether volumes of the hippocampus are selectively correlated with age-related memory performance.

SOPS Stage 4: Neuropsychology of ageing and cognition: changes in executive functions

The aims of this study were to provide a better understanding of the impact of age, environmental factors and illnesses on these executive functions in older people. The participants who took part in the MRI phase of the study were recruited for this study. They underwent extensive neurological and neuropsychological assessment, and were asked questions about their medical history, current and past health and lifestyle.

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Location of research

Australia, NSW, Sydney

Investigators

Research is conducted by the CERA of Concord Hospital and at the Prince of Wales Medical Research Institute. Principal investigator is Professor Tony Broe from the Prince of Wales Medical Research Institute. Other investigators from the Prince of Wales Medical Research Institute include Professor Glenda Halliday, Dr Bill Brooks, Dr Tony Harding, Dr Hayley Bennett and Dr Olivier Piguet. Investigators from CERA include Dr Louise Waite and Dr Helen Creasey. Associate Professor Dave Grayson is from the University of Sydney. Other investigators include Dr Jillian Kril.

Content

Medication use; disease; disability; service use; dementia; mortality; life satisfaction and depression; carer distress; alcohol, smoking and physical activity; and laboratory results.

Funding agencies/budget

The study has received regular funding since 1992. Submissions are still being made for funding for ongoing work and analysis relating to the SOPS study sample and accumulated results. There has also been some matched funding.

SOPS 1 1991–1993: \$389,000 PH and RDC, Research and Development Grants Advisory Council and RFBI; SOPS 2 1994–1996: \$193,245 PH and RDC; SOPS 3 1996–1997: \$80,000 Sir Zelman Cowan Foundation, University of Sydney; SOPS 4 1997–1999: \$251,560 PH and RDC; SOPS 5 2000–2003: \$825,000 NHMRC.

Data availability

Data are available to approved researchers and the SOPS study has shared research in Australia and overseas.

Sampling (cohorts/sample size)

The sampling design involved two random samples: a Department of Veterans' Affairs listing yielded 327 subjects (133 females and 194 males, response rate 82.4%) and a community area-probability sampling scheme yielded 320 subjects (193 females, 127 males, response rate 69.9%). Both samples were obtained from the same geographic base delineated by the Central Sydney Area Health Service. Participants were aged between 75 and 98 years (mean age 80.9) in SOPS 1.

Response rate

Initial response rates for the veteran and non-veteran samples were 82.4% and 69.9% respectively. The research subjects have a high rate of ongoing participation in the project. The initial sample size (and sample size) at each stage of the study was: 647 (647), 462 (449), 367 (367), 346 (299) and 185 (123). SOPS 5 only interviewed people who had an MRI – a constrained sample of the 185 were available for interview.

Incentives

No incentives were offered at any stage of the research.

Timeframes

SOPS involves 5 waves of data collection, though specific with sub-groups of the surviving sample are expected to continue for the next three to five years.

SOPS 1: 1991–1993, SOPS 2: 1994–1996, SOPS 3: 1996–1997, SOPS 4: 1997–1999, SOPS 5: 2000–2003.

Methods and data collection

SOPS involves 5 waves of data collection, though specific projects such as functional MRI studies, annual clinical follow-ups by questionnaire and related smaller-scale projects on gait disorder with sub-groups of the surviving sample are expected to continue for the next three to five years. Issues associated with frail ageing and the oldest old are now the primary focus of the study.

SOPS Stage 1

Stage 1 of the study involved visiting people in their homes and conducting medical and neuropsychological assessments. Participants were also asked questions about their health and lifestyle, and often a spouse, relative or friend was interviewed to provide further information.

SOPS Stages 2 and 3

The second wave of the study, SOPS Stage 2, involved extensive 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 a specific study based on the SOPS population that involved taking a blood sample and completing a medication history.

SOPS Stage 4

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 has allowed a broader timeframe over which to study the correlates of successful and unsuccessful ageing and the possible risk factors and protective factors for these.

MRI correlates of memory functioning in normal ageing

As part of the MRI study, 102 community-dwelling individuals aged over 80 years underwent MRI scanning of the brain as well as neurological and neuropsychological assessment. Volumes of the hippocampus, whole brain and intracranial region were calculated using a three-dimensional technique on an advanced software program developed in the US. Visual ratings of hippocampal size were also performed.

SOPS Stage 5

SOPS Stage 5 focused on the sub-group of subjects who had a MRI scan at SOPS 4. These people were re-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 sub-types.

Data analysis

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Results

Previous SOPS research findings

Disease, disability and service use

An increase in the number of diseases with increasing age is well recognised. The SOPS study found that this increase in disease was accounted for by the neurodegenerative illnesses, including disorders of gait and cognition, rather than conditions such as heart and lung disease, which did not increase in prevalence with advancing age. In our studies of

disability it was found that it was these neurodegenerative diseases which contributed most significantly to higher levels of disability. Furthermore, disability was the strongest predictor of service use within the study population. These findings highlight the significance of identifying neurodegenerative illnesses in older populations.

Prediction of dementia

When treatments become more readily available, the early detection of dementia will be increasingly important. Using the longitudinal data from the SOPS population, it has been found that the presence of mild cognitive deficits and abnormalities of gait can predict the subsequent development of dementia. Furthermore, when changes in both gait and memory are present there appears to be an even greater risk of developing dementia than when each is present singly. People with these mild changes in gait and memory also have an increased mortality and are more physically disabled. As identified in other studies the status of a gene called apoE also predicted the development of dementia.

Prediction of mortality

Many predictors of mortality have been identified using the longitudinal data from the SOPS study. These include the total number of illnesses, age, male gender, number of medications, number of falls and the presence of dementia and early cognitive deficits.

Life satisfaction and depression

Participants who had greater levels of disability and who had abnormalities of gait reported more depression and lower satisfaction with their lives. Disability was the strongest longitudinal predictor of depression. Levels of depression and life satisfaction remained relatively stable over time, reflecting both the chronicity of disease in this population and long-term personality traits.

Carer distress

Some study participants had significant disability, necessitating the need for a carer. Study participants who had carers had more illnesses and were more physically disabled. Carers providing greater levels of assistance were more likely to report symptoms of stress and depression. However, the main determinant of satisfaction with their caring role was determined by the nature and characteristics of their relationship with the study participant. Where the participant was perceived to be more controlling or domineering, the carer reported lower levels of satisfaction.

Alcohol

Around 10% of the study population drank alcohol in amounts that are defined as hazardous. While these people were not more disabled when seen at SOPS 1, they were longitudinally more likely to have an impaired ability to perform their day-to-day tasks. In contrast to other studies which have identified a protective effect from drinking alcohol, no reduction in mortality was identified in SOPS.

Australian norms for the Boston Naming Test

Another important result arising from the SOPS project is the publication of norms of naming ability in elderly Australians for a test known as the 'Boston Naming Test'. Until now, most available norms had been obtained from overseas studies using objects not necessarily familiar to Australians. The publication of these norms specific to Australian elderly will help clinicians identify more accurately people who are developing a naming difficulty, which can be a sign of dementia, and who may therefore require further intervention.

Laboratory results in the community

Using the blood samples collected in SOPS 3 it was found that, in keeping with other international studies, a higher prevalence of Alzheimer's disease was associated with the presence of the apoE e4 allele. Abnormalities in other biochemical and haematological parameters tested for were found to be due to disease and were not abnormal due to 'age'. This suggests that in the presence of abnormal laboratory test results, a cause needs to be identified and that abnormalities cannot be attributed to age.

SOPS Stage 4: MRI correlates of memory functioning in normal ageing

The hippocampus is a curved structure extending through the temporal lobes of the brain, and is intimately involved in the neural processing of memory. It is known to be one of the brain structures most vulnerable to degeneration in Alzheimer's disease. A decline in memory functioning is also a common complaint among healthy individuals of advanced age, and this is thought to be associated with an age-related decrease in hippocampal volume.

The hippocampus and memory in normal ageing

All hippocampal measures were identified as effective predictors of memory performance such that increasing hippocampal size was reflected in the form of superior memory function. This positive association between hippocampal size and memory persisted even when the influence of age-related illnesses (e.g. hypertension) and sociodemographic variables (e.g. education) was taken into account. Age and intelligence were also identified as significant predictors of verbal and visual memory in the study group. Importantly, the size of the hippocampus was not predictive of performance on non-memory tasks (i.e. information processing, language, visuospatial and executive tasks). This suggests that hippocampal size is not merely a marker of generalised cognitive decline, but rather is specifically related to the integrity of memory systems in individuals of advanced age.

The hippocampus and memory in successful ageing

Successful ageing is a term that has been used to describe optimally healthy older persons who remain cognitively intact and fail to exhibit signs of cognitive decline with advancing age. Using information collected from an informant, those individuals who had demonstrated evidence of mild cognitive decline over the previous three years were identified and excluded from the sample so that a subset of unambiguously healthy older persons could be defined. Analyses carried out on this sub-group of high-functioning

community dwellers provided further compelling support for the association between hippocampal size and memory function in the ninth and tenth decades of life. The findings of this study are thus at odds with previous suggestion in the literature that there is insufficient variation in hippocampal volumes in normal ageing for such structural-functional relationships to be demonstrated. Instead, our research suggests that the hippocampus is a critical structure for memory processing in both normal and successful ageing.

SOPS Stage 4: Neuropsychology of ageing and cognition: changes in executive functions

Increasing variability in performance on tests of cognitive functions with ageing is well documented. The current literature further suggests that the executive functions, which include aspects of cognition such as decision-making, planning, problem-solving and reasoning abilities, appear to be more sensitive to the ageing process with an earlier and more rapid decline. However, the underlying causes to this faster decline remain unclear.

In this group of non-demented elderly individuals, changes in executive functioning were mostly accounted for by the presence of signs and symptoms associated with the most common neurodegenerative diseases of ageing, such as Alzheimer's disease, dementia associated with vascular-related disorders and dementia associated with movement disorders. When these 'markers' were taken into account, the portion of change in performance due to chronological age was very small. These results suggest that getting old is not synonymous with a decline in executive functions efficiency. In contrast, such a decline would indicate the possible presence of a neurodegenerative process which becomes more common as we get older.

Executive functions rely in part on the integrity of frontal-subcortical brain circuits for their activation. These circuits are also commonly affected by vascular dementia and dementia associated with movement disorders. Interestingly, in this study, although we hypothesised that the presence of 'markers' associated with these disorders would give rise to poorer executive functioning, this was not to be the case. It appears that, in addition to the specific frontal circuits, the integrity of the brain as a whole is as important a component for the successful activation of these very complex abilities.

Outputs

A list of CERA publications is available at <www.cera.usyd.edu.au/CERA%20Pub.htm>. Current clinical information about the study and areas of ongoing research is available at <www.powmri.edu.au/research/pdda/ageing/sydneyops.htm>. Information on current social research and analysis activity is available at <www.sesahs.nsw.gov.au/powh/arc>.

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Waite LM, Grayson DA, Piguet O, Creasey H, Bennett HP & Broe GA 2004 (in press). Gait slowing as predictor of incident dementia: 6 year longitudinal data from the Sydney Older Persons Study. *Journal of Neurological Sciences*.

Related studies

Data from SOPS has been provided to Professor Kenneth Rockwood at Dalhousie University in Canada. This data have been used to develop, in collaboration with a number of research partners and data sets, a model of the accumulation of deficits in relation to ageing and mortality and the development of an index of frailty. The results are being presented for publication in 2004.

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Appendix I Healthy Retirement Project

Study aims

Health and Well-being in Retirement builds on the HRP by examining the medium-term outcomes of retirement. The HRP examined preparation for retirement and the immediate impacts of retirement, the ways in which people adjust to retirement and the relationship between health, health behaviours, retirement planning and retirement adjustment.

A fundamental aim of Health and Well-being in Retirement is to improve the health and wellbeing of people in retirement. In order to do this, the project has the following aims:

1. Determine the medium-term impact of retirement on health, health behaviours and wellbeing, and to determine the impact of pre-retirement health habits and intentions on medium-term adjustment to retirement.
2. Identify the diversity of retirement experiences and pathways.
3. Examine the relative importance of personal, situational and structural factors for health outcomes.
4. Identify whether there are identifiable phases or stages in adjustment to retirement and locate factors associated with these phases.
5. Determine how long post-work improvements or deterioration in health behaviours persist, and what predicts maintenance or 'recidivism'.
6. Determine outcomes for discernible groups or types on attitudes which are discernible pre-retirement (Optimists, Pessimists, Ambivalent and Indifferent).
7. Provide useful information to the Council on the Ageing and participating organisations on retirement issues which will assist in the development of programs to assist people as they retire and two to three years after leaving work.
8. Inform the development of appropriate health promotion strategies for retirees.

More information on study aims (and the significance of the research) is available at users.bigpond.net.au/david-devaus/My-Research/retirement23.htm.

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Location of research

Australia

Investigators

The study was undertaken by the Lincoln Gerontology Research Centre for Education and Research, Faculty of Health Sciences, La Trobe University. Investigators include Associate Professor David de Vaus, Professor Hal Kendig, and Dr Yvonne Wells (Project Coordinator). The HRP was designed and carried out in collaboration with the Council on the Ageing (Victoria), a consumer organisation for older Australians.

Content

The HRP examined preparation for retirement and the immediate impacts of retirement, the ways in which people adjust to retirement and the relationship between health, health behaviours, retirement planning, and retirement adjustment. Health and Well-being in Retirement examined the medium-term outcomes of retirement – the ways in which pre-retirement and early post-retirement intentions regarding health and health behaviours shape the ways in which people build their lives after retirement; and the ways in which different retirement styles and pathways affect medium-term health and health-related behaviour.

Funding agencies/budget

Funded by VicHealth. The HRP received \$373,174 (1997: \$129,319, 1998: \$164,233, 1999: \$79,622). Health and Well-being in Retirement received \$225,058 (approximately \$75,000 per annum 2000–2002).

Data availability

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Sampling (cohorts/sample size)

The HRP consisted of two components: a cross-sectional survey of 6,821 individuals aged 50 and over (mean age 54 years), and a longitudinal survey of 590 of these individuals. Health and Well-being in Retirement followed-up the 590 participants, although only 380 remained retired throughout the three-year follow-up.

Older workers were recruited through employers, unions, superannuation funds and the media. Non-probability multi-stage cluster sample with quotas, including: a range of diverse sampling points; clustering of sample elements to facilitate the distribution of questionnaires; and the capacity to fill minimum quotas for categories including men and women, workers in both high-status and low-status occupations, and employees in both the public and private sectors. Although the sample is not random or representative, it is sufficiently large to represent a diverse range of people.

Response rate

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Incentives

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Timeframes

The HRP ended in December 1999 – retirees were contacted twice before retirement and again at six months and 12 months after retirement. Health and Well-being in Retirement followed-up the same individuals two and three years after retirement.

Wave 1 (baseline): April 1998–December 1998, Wave 2 (at retirement): July 1998–June 1999, Wave 3 (six months post retirement): January 1999–December 1999, Wave 4 (one year post retirement): July 1999–June 2000, Wave 5 (two years post retirement): July 2000–June 2001, Wave 6 (three years post retirement): July 2001–June 2002.

Methods and data collection

Survey of 96 items administered by employers and by mail.

Data analysis

Statistical analyses employed chi-square tests and logistic regression as categorical variables (not continuous variables) were examined.

Results

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Outputs

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Related studies

Related studies include the US HRS.

References

De Vaus D 2003. Healthy retirement: 2–3 years on. Viewed 19 August 2004, <users.bigpond.net.au/david-devaus/My-Research/retirement23.htm>.

Merkes M. Chapter 5 – Study 3. In: 'A longer working life for Australian women of the baby boom generation? – Women's voices and the social policy implications of an ageing female workforce'. PhD thesis. Bundoora: LaTrobe University, 185–221. Viewed 19 August 2004, <member.melbpc.org.au/~monika/part5.pdf>.

Appendix J Stories of Ageing

Study aims

Stories of Ageing: A Longitudinal Study of Women's Self-Representation is a longitudinal case study which investigates change in the lives and concerns of women aged 70–85 living outside institutional care. The project team worked with ageing women to explore the ways in which their stories of ageing counteract ageist and debilitating ways of viewing older women, and contribute to new understandings of later life and an active sense of citizenship. The project aims to bring new theoretical perspectives to the study of ageing which challenge existing research and policy directions. The innovative pedagogies developed for working with ageing women will have practical applications for health care professionals, service providers and literacy educators.

Aims and expected outcomes are:

- to understand the key factors that determine the quality of life and needs of an increasingly dominant social group in Victoria – women between 70–85 years of age who live outside of institutional care and in their community;
- to work with older women as collaborative research partners to produce alternative images and stories of ageing from their perspective;
- to produce data in the form of videos, published stories and research reports that have national applicability and will contribute to the National Women's Health Policy; and
- to develop innovative pedagogies which can be used by health care professionals, service providers and educators in adult education, and secondary and tertiary literacy settings.

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Location of research

Australia, Victoria

Investigators

Professor Barbara Kamler (Deakin University), Professor Terry Threadgold (Cardiff University) and Ms Susan Feldman (Melbourne University). Possibly some involvement from Dr Kate Cregan (RMIT University).

Content

Women aged 70–85 worked in writing and video workshops to explore how their stories might challenge and disrupt conventional storylines of women and ageing. In order to construct new narratives, the research project sought stories of ageing from the perspective of the ageing woman herself.

The workshops were structured so that each week the women brought a piece of writing which they read aloud for response and critique. Reading aloud gave the women distance from the experience that was written about. Asking critical questions helped the women see that her text is only a representation of experience. Some of these questions included:

1. What was powerful in the writing? Identify an image, line, metaphor or representation of person that was powerful.
2. What was omitted? Who/what was absent and/or hinted at or over-generalised?
3. What clichés have been used to gloss over experience, facts, feelings?
4. What doesn't fit? What contradictions, if any, emerge?
5. What aspects/issues of ageing are constructed/concealed?
6. What common issues, experiences, storylines do the texts have in common?

Workshops with Vietnamese women aged 55–74 also allowed the researchers to explore issues of cross-cultural communication and translation.

Funding agencies/budget

ARC Large Grant (\$166,000?) – 1999: \$16,954; 1998: \$14,028; 1997: \$36,002.

Data availability

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Sampling (cohorts/sample size)

Approximately 40 women aged 70–85 living outside institutional care. The women brought to the project a mix of histories, both personal and professional, and represented a predominantly white, middle to lower-middle class population from a range of Eastern European and Anglo Celtic origins, with one Philippine participant.

Response rate

–

Incentives

Their participation in the project was understood by the women as part of a collaborative exchange: they would learn new strategies for crafting and developing writing, and the researchers would gain new understandings of ageing from their writing.

Timeframes

Between 1993 and 1996 the pilot projects were conducted by Barbara Kamler and Susan Feldman. From 1997–1999 the work was extended and redeveloped as a three-year longitudinal study with Terry Threadgold.

Methods and data collection

The stories the women told were both written and filmed – produced in both writing workshops and video diary workshops using a collaborative pedagogy which positioned the women as co-researchers. Typically, the researchers met with groups of ten to twelve women weekly in two-hour workshops over a six to eight-week period.

Data analysis

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Results

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Outputs

Feldman S, Kamler B & Threadgold T 1998. *Women's Stories of Action and Reflection: Counter-Narratives of Ageing*. International Sociology Conference, Montreal.

A list of other publications authored by Barbara Kamler (with links to lists of publications authored by Terry Threadgold and Susan Feldman) is available at www.research.deakin.edu.au/performance/pubs/reports/database/dynamic/output/person/person.php?person_code=kamleba.

Related studies

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References

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- Threadgold T & Kamler B 1999. *Translating difference: cross cultural and multimodal research dialogue*. Coldstream: Australian Association for Research in Education. Viewed 19 August 2004, <www.aare.edu.au/99pap/kam99149.htm>.

Appendix K Canberra Longitudinal Study of Ageing

Study aims

CLSA is a 12-year study into the health and memory of older people. It aims to identify predictors of memory decline and dementia and provide epidemiological data on mental disorders in older Australians.

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Location of research

Australia, Australian Capital Territory (ACT), Canberra

Investigators

CMHR at the ANU – Professor Scott Henderson, Professor Anthony Jorm, Professor Helen Christensen, Dr Bryan Rodgers and Ailsa Korten.

Content

The study focuses primarily on depression and cognitive impairment, but also has extensive data on physical health (e.g. vision) and mortality.

Funding agencies/budget

NHMRC Project Grant. Additional funding may have been provided by the Australian Rotary Health Research Fund.

Data availability

Contact Professor Helen Christensen.

Sampling (cohorts/sample size)

The sample consists of a single cohort of approximately 1,000 people (531 males) aged 70 and over collected in 1990–1991. 897 participants were selected from the community using Canberra and Queanbeyan electoral rolls; the remaining 103 participants were oversampled from older age groups and from nursing home residents.

Response rate

Approximately 69%.

Incentives

–

Timeframes

CLSA is a 12-year study which commenced in 1990, with subsequent waves in 1994, 1998 and 2002. The 2002 wave is the last time that participants were approached for interviews – the youngest participant in 2002 was 82 years of age.

Methods and data collection

The study includes a single cohort. Instruments utilised in the collection of data include questionnaires, cognitive tests, various measures of physiological functioning and genetic samples.

A study by Jorm et al. (1998), involved interviews carried out by a professional social survey interviewers with an informant (where available) as well as the subject. Interviews

incorporated the Canberra Interview for the Elderly which provides diagnoses of dementia and depression, and the following cognitive tests: Mini Mental State Examination, National Adult Reading Test, Symbol-Letter Modalities Test, Episodic Memory Test, and the Informant Questionnaire on Cognitive Decline.

Data analysis

A study by Jorm et al. (1998), involved both cross-sectional and longitudinal data analysis. Cross-sectional analyses involved one-way analysis of variance, Fisher's exact test, and hierarchical multiple linear regression. Longitudinal analyses involved regression analysis, one-way analysis of variance and Fisher's exact test.

Results

Although there is still work in progress, there have been many studies published, which include investigations into the prevalence of depressive disorders and the distribution of symptoms, self-reported health in an elderly community sample, cognitive functioning among the elderly and relationships with personality, education level, activity levels, and dementia. Yet other studies have investigated GP visits and attendance by GPs.

For example, Hofer (2003) reports findings relating to apoE e4 and cognitive function in the elderly:

In Hofer et al. (in press), the influence of apoE e4 variant was assessed in a community sample of older adults aged 70 to 94. Previous findings relate apoE e4 to an increased risk for Alzheimer's disease and risk for lower performance and greater decline in samples of individuals not diagnosed with Alzheimer's disease. Results from latent growth curve analyses of cognitive abilities, based on three occasions over a seven-year period, are reported for individuals genotyped for apoE at the second occasion (n=601) and a sub-sample of individuals not diagnosed with probable or definite dementia during the first or second measurement occasions (n=434). ApoE e4 status was a significant predictor of both level and change in memory performance, and change in speed performance in the full sample. ApoE e4 status remained predictive of initial level and change in memory performance in the non-demented sub-sample. While it is possible that some members of the non-demented sub-sample will develop dementia later, these findings support previous findings that apoE e4 is associated with accelerated memory deterioration in individuals without clinical dementia. Other research shows that education has an effect on initial status but not on change (Christensen et al. 2000), and that the structure of change in functioning among cognitive and physiological indicators is not well understood in terms of common-factor aging models (Mackinnon et al. submitted).

To access listings of published studies outlining study methods and data analysis, see <www.anu.edu.au/cmhr/cls.php>.

Outputs

For a list of publications specifically from the CLSA see <www.anu.edu.au/cmhr/cls.php>. Additional publications include:

Publications

Christensen H, Mackinnon A, Korten A, Hofer SM & Jorm AF (submitted May 2001). A common cause for the common cause factor? *Journals of Gerontology: Psychological Sciences*.

Mackinnon A, Christensen H, Hofer SM, Korten A, & Jorm AF (submitted July 2001). Use it and still lose it? The association between activity and cognitive performance established using latent growth techniques in a community sample. *Psychological Medicine*.

Presentations

Christensen H, Korten AE, MacKinnon AJ, Jorm AF & Hofer SM 2000. Changes in sensory disability, reaction time, grip and strength as determinants of changes in memory and CIQ in a community sample. Atlanta: Biennial Cognitive Aging Conference.

Hofer SM 2001. Change in cognitive functioning associated with apoE genotype in a community sample of older adults. Gerontology Center Colloquium Series. The Pennsylvania: Pennsylvania State University.

Related studies

Canberra and Queanbeyan Survey of Health in Later Life (1990-1991).

References

Centre for Mental Health Research 2004. Canberra Longitudinal Study. Canberra: The Australian National University. Viewed 19 August 2004, <www.anu.edu.au/cmhr/cls.php>.

Hofer SM 2003. Laboratory for lifespan developmental research. Pennsylvania: The Pennsylvania State University. Viewed 19 August 2004, <www.personal.psu.edu/faculty/s/m/smh21>.

Jorm AF, Rodgers B, Henderson AS, Korten AE, Jacomb PA, Christensen H & Mackinnon A 1998. Occupation type as a predictor of cognitive decline and dementia in old age. *Age and Ageing* 27:477-83.

Appendix L Florey Adelaide Male Aging Study

Study aims

FAMAS is believed to be the first study of its kind in Australia to attempt to identify the wide range of factors that contribute to Australian men's reproductive, physical and emotional health, and their relationship with the ageing process.

Compared with women, Australian men of all ages are less healthy and therefore do not enjoy as good a quality of life as they should. Chronic conditions such as obesity, cancer, diabetes and cardiovascular disease occur more frequently in men and their life expectancy is five years less than that of women. Men are less likely to use health services, especially in relation to preventive services and early intervention, and the quality of their mental health is below that of women. Some diseases that exclusively affect men, such as prostate cancer, are also insufficiently understood – screening remains controversial and there is little data regarding prevention.

The study therefore 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.

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Location of research

Australia, SA, Adelaide

Investigators

The study involves a collaborative research team headed by Associate Professor Gary Wittert from the University of Adelaide's Department of Medicine. The research team also involves researchers from the university's Department of Public Health (Professor Janet Hiller and Dr

Megan Warin) and the School of Molecular and Biomedical Science, as well as the Royal Adelaide Hospital, SA Department of Human Services, Institute of Medical and Veterinary Science (Dr Peter O'Loughlin), Hanson Institute, CSIRO and Glenside Hospital.

Content

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 will also be investigated.

Funding agencies/budget

\$450,000 Florey Research Grant awarded for three years. The Florey Research Grant is jointly funded by the Florey Medical Research Fund, the major fundraising arm of the University of Adelaide's Medical School, and the university's Deputy Vice Chancellor (Research). The grant aims to support research teams that are looking for better solutions to major health problems in SA, and promotes stronger partnerships between researchers in different disciplines in Adelaide.

Data availability

Microsoft Access database – file may be available on request.

Sampling (cohorts/sample size)

1,200 men aged 35–80 in Adelaide's north-west suburbs. Random sampling using the electronic white pages. Initial cohort of 590 men were enrolled between August 2002 and August 2003. Recruitment of next 600 men (to allow for drop-outs) will begin April 2004.

Response rate

The study initially included a sample of 2,500. Of these 77 were ineligible due to participation in other studies. 1,313 were lost because initial telephone contact could not be made or because there was no eligible subject in the household. Of 1,116 eligible men, 482 refused (43.4%). Of 634 that participated in the initial interview a further 65 (5.8%) refused the clinic visits.

Incentives

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Timeframes

Florey Research Grant awarded in 2003 for three years. Initial cohort of 590 men were enrolled between August 2002 and August 2003. Annual follow-up questionnaire mail-out. Repeat clinic visit at five years. Recruitment of next 600 men (to allow for drop-outs) will begin April 2004.

Methods and data collection

Random sampling. Introductory letter and brochure, telephone interview, questionnaire mail-out and clinic appointment. Second clinic appointment for dual-energy X-ray absorptiometry and urine flow. Annual follow-up questionnaire mail-out. Repeat clinic visit at five years. Qualitative methodology used to evaluate health service utilisation in a stratified random subset.

Measurements include androgens, insulin growth factor 1, lipids, glucose, liver function tests, prostate-specific antigen, body composition, muscle strength, urine flow rate/lower urinary tract symptoms, mood and cognitive function, erectile dysfunction, sexual desire, presence of chronic disease, prior disease and surgery, medication use, energy/nutrient intake, alcohol intake, smoking, physical activity, SF-36, and social and demographic data.

Data analysis

Cross-sectional data

Linear regression and correlation coefficients, non-linear relationships are also explored. T-tests and analysis of variance. Regression and analysis of variance with main effects and interactions. Log-binomial regression (to give a relative risk metric) will be used to determine if, for example, particular factors (e.g. testosterone level) predict disease status, both with and without adjusting for other factors such as lifestyle.

Cohort study

Mixed model Analysis of Variance to look at changes in the variable of interest versus other variables. Also, log-binomial Generalised Estimating Equations to look at disease state at various time points in relation to current, past and changes in a particular variable and other factors. The relationship variables to the age at which a particular problem appears will be analysed by Cox's proportional hazards regression. Structural equation modelling may be used to determine causal pathways.

Results

Preliminary data now available but not yet submitted for publication.

Outputs

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Related studies

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References

The University of Adelaide, Marketing and Strategic Communications Office 2003. Men's health study wins \$450,000 Florey grant. Adelaide: The University of Adelaide. Viewed 19 August 2004, <www.adelaide.edu.au/pr/media/releases/2003/floreygrant.html>.

The University of Adelaide, Marketing and Strategic Communications Office 2003. \$450,000 Florey grant awarded to health study. Adelaide: The University of Adelaide. Viewed 19 August 2004, <www.adelaide.edu.au/pr/publications/adelaidean/2003/issue10/page4/>.

Appendix M Melbourne Collaborative Cohort Study (Health 2000)

Study aims

Following careful planning, instrument development, pilot studies and extensive review by international experts, the MCCS or Health 2000 was set up in the early 1990s to investigate prospectively the role of diet and other lifestyle factors in causing common chronic diseases – especially cancers of the prostate, breast and bowel, heart disease, stroke, diabetes and all causes of mortality – and to investigate possible interactions between these exposures and common genetic variants. Its aims have been broadened to include ageing, vision (e.g. macular diseases) and depression. Health 2000 is now encompassed by the broader ECHIDNAs.

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Web address

Web site under development

Location of research

Australia, Melbourne

Investigators

One of three major research programs operated by The Cancer Council Victoria.

Content

Main measures: anthropometric measurements, blood pressure, diet, alcohol, tobacco, physical activity, medical history, social support, DNA and plasma stored.

Main outcomes: cancers of the prostate, breast and bowel, heart disease, stroke, Type 2 diabetes and all causes of mortality (plus many others including health services use).

Funding agencies/budget

Cohort recruitment was funded by VicHealth (\$1,430,000) and The Cancer Council Victoria (\$3,570,000). Continuing data management and follow-up has been funded by The Cancer Council Victoria (\$300,000 per annum since 1995).

ECHIDNAS is funded by a NHMRC Program Grant part of which is being used to fund Wave 3 of the MCCA. The NHMRC or other government sources have not provided any funding for recruitment or follow-up of MCCA participants.

Some funding possibly received from The University of Sydney and The University of Melbourne.

Data availability

Access to the MCCA data and materials is available via collaborative proposals that are congruent with the study design. Data access guidelines and data books are available from the Executive Officer.

Sampling (cohorts/sample size)

Single cohort of 41,528 Australians (24,479 women and 17,049 men) aged 27 to 75 (99.3% aged 40–69) at baseline recruited from Melbourne between 1990 and 1994. Approximately 33% of this sample is southern European migrants to Australia (including 2,419 Italian men and 3,008 Italian women, and 2,073 Greek men and 2,461 Greek women), which were deliberately over-sampled to extend the range of lifestyle exposures and to increase genetic variation.

Response rate

N/A – volunteer sample.

Incentives

None.

Timeframes

Recruitment took place 1990–1994. Follow-up every three to four years by phone with the most recent follow-up commencing in 2003. The study expected to run indefinitely. Wave 1: 1 January 1990–30 June 1994, Wave 2: 1 January 1994–31 December 1998, Wave 3: 1 January 2003–30 June 2006.

Methods and data collection

Recruitment of participants was a combination of direct approaches via ethnic clubs, churches and social events and written invitations using the electoral roll.

Extensive information was collected at baseline and at current follow-up in 2003–2006, in face-to-face interviews that included questionnaires (diet, physical activity etc.) and physical measurements of height, weight, waist and hip circumferences, including lean and fat mass by bioelectric impedance, and blood pressure. Blood samples were drawn and whole blood and plasma stored for analysis of DNA and other molecules of interest (e.g. glucose, sex hormones and growth factors, carotenoids and fatty acids involved in disease pathways). Retinal photographs were taken in the 2003 follow-up.

At three to four years after baseline, the cohort was followed-up by mailed questionnaire and by telephone to update lifestyle exposures and self-reports of non-cancer and non-fatal health events. The MCCS is regularly matched to cancer registries and death indices to capture cancer incidence and deaths.

Data analysis

Analysis is usually either a classical cohort analysis when data are available on the entire cohort, or a case-cohort analyses when data are only available on a subset (e.g. a case series and a random sample of approximately 5,000 chosen for this purpose). Occasional nested case-control designs are also used.

Results

See MCCS publications (web site under development).

Outputs

Publications from (or based on) MCCS:

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Related studies

There are a growing number of sub-studies supported by the MCCS. Also see other ECHIDNAs projects.

Risk and Determinants of Fatal and Non-Fatal Coronary Heart Disease in the Melbourne Collaborative Cohort Study is a collaborative research effort with Cancer Council Victoria and Dr Dianne Maglianno and Dr Danny Liew from Monash University. The study plans to follow-up fatal and non-fatal episodes of coronary heart disease within the 40,000 participants of the MCCS. The aims are to characterise determinants of coronary risk in a contemporary Australian population and to quantify it in risk prediction equations. These will be used to model coronary heart disease in Australia, providing the basis for determining the best available preventive strategies (Department of Epidemiology & Preventive Medicine 2003b).

The Cardiovascular Component of the Melbourne Collaborative Cohort Study involves an investigative team headed by Professor Andrew Tonkin from Monash University. Other investigators include Margaret Stebbing and Linton Harriss. In 2002, the sub-study was awarded a NHMRC Program Grant to re-survey surviving participants and to expand the

outcomes of interest to include cardiovascular disease and the metabolic syndrome. All participants of the cohort were invited to attend the study centre to repeat the baseline measures and health survey at which they were asked about any episodes of cardiovascular disease. Self-reported events were followed both actively and passively and finally adjudicated using an event verification committee. The study aims to investigate the determinants of heart disease, in order to develop prediction tools applicable to the current Australian population. Results from this study will allow future patterns of heart disease to be accurately forecasted, and permit preventive strategies to be utilised in a more effective manner (Department of Epidemiology & Preventive Medicine 2003a).

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Appendix N A Longitudinal Study of Bone Loss in Men

Study aims

A Longitudinal Study of Bone Loss in Men is a longitudinal study of bone mass at forearm, hip, spine and whole body in 150 normal men in Adelaide. Effects of diet, exercise, genetic polymorphisms, calcium absorption and excretion, bone resorption and bone formation were investigated to determine the rate of bone loss.

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Location of research

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Content

Effects of diet, exercise, genetic polymorphisms, calcium absorption and excretion, bone resorption and bone formation on the rate of bone loss at forearm, hip, spine and whole body in men.

Funding agencies/budget

Funding for the last wave was received from the University of Adelaide. All other work was done with existing funds, e.g. divisional funds from the Division of Clinical Biochemistry, the Institute of Medical and Veterinary Science and the Department of Nuclear Medicine and Bone Densitometry at the Royal Adelaide Hospital. There was no matched funding and no international links.

Data availability

Data available as a Minitab for Windows file.

Sampling (cohorts/sample size)

The initial sample size was 146 men aged 20–83 years (mean age at selection was 48 years). At each subsequent wave, participants were aged 23–83 years (mean 51) and 30–72 years (mean 58).

The cross-sectional component of the study described by Need et al. (1995), consisted of 137 healthy white men, comprising husbands of women attending Royal Adelaide Hospital's osteoporosis clinic, laboratory staff, and hospital workers who were enrolled in a normal bone study. Subjects taking drugs or with diseases likely to affect calcium metabolism were excluded.

Response rate

At each wave the sample sizes were 146, 123 and 59.

Incentives

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Timeframes

Start and end dates for each wave were January 1990 to December 1993, January 1996 to June 1997, and July 2003 to December 2003. The study is no longer running.

Methods and data collection

In the cross-sectional study described by Need et al. (1995), subjects listed their regular physical and sporting activities. The time spent on each activity was multiplied by the energy expenditure for that activity and expressed in metabolic equivalent tasks (METs) per week; 56 METs per week were subtracted for sleeping time. Bone density in the forearm was measured by single photon absorptiometry. Bone density in the spine, femoral neck, Ward's triangle and trochanter was measured by dual x-ray absorptiometry.

Data analysis

Data in the cross-sectional study described by Need et al. (1995) were analysed using student's t-test, linear regression, and multiple linear regression. Age was expressed as a quadratic function. Measurements were evaluated separately in men aged 50 and over and in those aged under 50.

Results

The article by Need et al. (1995) reports a major new finding of a continuous positive relation between physical activity and bone density in normal white men. The data suggest that any exercise is beneficial to bone and that, within the normal range, the more the better.

A lower forearm bone density in those aged 50 and over than in those aged under 50 was reported, although energy expenditure was similar in the two groups. In the whole set, activity was related to age-corrected bone density in the femoral neck. Activity and bone density were not related in men aged 50 and over, but were significantly related in the spine, femoral neck, Ward's triangle and trochanter in those aged under 50. These relations were unaffected by adjustment for age. There was a significant difference in the femoral neck bone density between joggers and sedentary men. Note that these results were based on cross-sectional data included as part of the longitudinal data set.

Outputs

Need AG, Wishart JM, Scopacasa F, Horowitz M, Morris HA & Nordin BEC 1995. Effect of physical activity on femoral bone density in men. *British Medical Journal* 310:1501-2.

Wishart JM, Need AG, Horowitz M, Morris HA & Nordin, BEC 1995. Effect of age on bone density and bone turnover in men. *Clinical Endocrinology* 42:141-6.

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Related studies

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References

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Appendix O The South Australian Dental Longitudinal Study

Study aims

SADLS is a longitudinal study of the oral health of older adults

Stage 1

The purpose of the first stage was to examine the distribution and determinants of oral disease and its social impact among older South Australians. This was addressed through three specific aims:

1. to ascertain the extent and distribution of the social impact of oral disease in a representative sample of adults aged 60 and over. A modification of the World Health Organization's concepts of functional limitation, discomfort and handicap was used to provide descriptive epidemiological data;
2. to assess the distribution and determinants of oral disease among older adults, particularly tooth loss, denture deterioration, dental caries and periodontal disease. Prevalence and incidence data were collected so that the effects of sociodemographic characteristics (particularly age) and potential preventive factors (particularly water fluoridation) on the development of oral disease could be assessed; and
3. to examine the associations between oral disease and social impact. The information from the study will be used to determine the oral disorders and sociodemographic characteristics which contribute to or prevent the development of functional limitation, discomfort, disability and handicap.

Stage 2

The purpose of the five-year follow-up was to evaluate oral disease incidence and its social impact among a random sample of people aged 60 and over, already followed over two years. The project aimed to:

1. to determine five-year incidence rates and develop risk prediction models for coronal and root caries, periodontal attachment destruction and occlusal wear;
2. to observe the social impact of oral conditions over five years and determine which forms of incident oral disease are associated with changes in social impact; and
3. to examine relationships between clinical oral disease, its impact and general health status on older adults' quality of life.

Stage 3

The purpose of the 11-year follow-up was to evaluate the incidence of oral diseases in a community-dwelling random sample of dentate older adults (initially aged 60 and over),

residing in urban Adelaide and rural Mt Gambier, who were previously followed up at two and five years. The project aims to:

1. determine and compare the 11-year incidence (baseline to 11 years) and six-year incidence (five years to 11 years) of oral diseases and conditions (e.g. coronal caries, root caries, periodontal diseases, tooth loss) in community-dwelling dentate older South Australians residing in urban Adelaide and rural Mt Gambier;
2. identify the sociodemographic, medical, medication, functional, cognitive, nutritional, dental history, oral hygiene care, financial, social and carer support, dry mouth (xerostomia and salivary gland hypofunction), residential type and oral social impact characteristics that were associated with the five-year and 11-year incidence of oral diseases and conditions (e.g. coronal caries, root caries, periodontal diseases, tooth loss) in community-dwelling dentate older South Australians residing in urban Adelaide and rural Mt Gambier; and
3. develop risk prediction models for coronal caries, root caries, periodontal diseases and tooth loss in community-dwelling dentate older South Australians residing in urban Adelaide and rural Mt Gambier.

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Location of research

Australia, SA, Adelaide

Investigators

Collaborative effort between the AIHW DSRU and Social and Preventative Dentistry, Dental School, The University of Adelaide. Principal investigators are Professor John Spencer, Dr Jane Chalmers, and Dr Kaye Roberts-Thomson. Other investigators are Professor Gary Slade and Associate Professor Murray Thomson.

Content

The OHIP questionnaire was a 49-item scaled index of social impact of oral disorders with seven subscales: functional limitation; physical pain; psychological discomfort; physical disability; psychological disability; social disability; and handicap. Interviews contained 72 questions concerning dental health status, use of dental services, preventive oral health practices, residential history, sociodemographic characteristics, medical history, medications, use of tobacco and alcohol, and chewing capacity for specific foods. The XI questionnaire was a 19-item inventory of subject's self-perceptions concerning dry mouth, dry eyes, dry throat, difficulties with swallowing and eating, and use of sweets to relieve dry mouth.

Clinical examinations included an assessment of any dentures and the oral mucosal tissues. The Clock Drawing Test assessed cognitive status.

The 11-year follow-up included more comprehensive assessments of participants' functional status, cognitive status, nutritional status (including swallowing problems and dietary type), dental history, oral hygiene care provision, residential location, social support and carer support.

Funding agencies/budget

The SADLS project has received support from the NHMRC (1991-93: \$145,876; 1996-97: \$140,524; 2002-03: \$225,000) and the US NIH (1992-94: US\$338,547).

Data availability

Data are available as an SPSS for Windows file. Providing data on request is an important DSRU function.

Sampling (cohorts/sample size)

Subjects were selected at baseline in 1991 using a stratified random sample of older adults aged 60 and over who were listed on the SA Electoral Database, a compulsory register for all citizens. Subjects were chosen in two SA cities, Adelaide and Mt Gambier. In Adelaide there were 18 strata defined by three age groups, two sexes and three locality categories, and in Mt Gambier there were six strata defined by three age groups and two sexes. Each sampled person at baseline was visited at their residence by a trained interviewer and a fourth level of stratification was used to select all dentate people in Mt Gambier and in Adelaide dentate and a random subset of edentulous people. An additional criterion was used at the time of

contact to exclude persons residing in nursing homes or hospitals (but not hostels for older adults).

In 1991 2,751 people were sampled and 1,650 (60%) took part in a face-to-face interview. Among those interviewed, 1,205 were dentate and 445 were edentulous. Clinical examinations were conducted with 853 dentate subjects (347 from Mt Gambier and 506 from Adelaide) and 313 edentulous Adelaide subjects. OHIP questionnaires were completed by 1,218 of the interviewed baseline subjects, with 1,018 completing both OHIP and the baseline examination. At two years, 1,224 subjects completed a telephone interview, with 693 dentate subjects participating in a clinical examination and 991 completing an OHIP questionnaire. In 1993, 498 of the baseline dentate participants completed the follow-up interview, OHIP and clinical examination. In 1996 at five years, 939 subjects completed a telephone interview, with 709 subjects (530 dentate and 179 edentulous) participating in a clinical examination and 792 completing an OHIP questionnaire. The XI questionnaire was completed by 639 five-year subjects and saliva samples were collected from 676 of the examined subjects.

Response rate

In 1991, 2,751 people were sampled and 1,650 (60%) took part in a face-to-face interview. Among that group 1,205 were dentate of whom 913 (75.8%) were examined. Of the 445 edentulous people interviewed, 313 (70.3%) were examined. Retention and participation rates were higher than projected at all data collection rounds.

Data for the 11-year follow-up were collected for 363 dentate older adults. Participation rates were very high with only 50 participants deceased, 11 edentulous, 6 moved interstate, 7 not contactable and 15 participants refusing to participate in one or more data collection activities, from those examined in the five-year follow-up.

Incentives

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Timeframes

An ongoing study with baseline data collection in 1991, a two-year follow-up in 1993, a five-year follow-up in 1996 and an 11 year follow-up in 2002. The 11-year follow-up was completed in April 2003.

Methods and data collection

All 1991 baseline subjects were interviewed face-to-face and then invited to complete a questionnaire concerning the social impact of oral diseases (the OHIP), and to take part in a clinical oral examination, conducted by calibrated dentists, which followed the US National Institute of Dental Research (NIDR) protocol. Dental inspections were conducted at dental clinics and at participants' homes.

At two years and five years, participating subjects completed a mail-out OHIP questionnaire and were interviewed by telephone. At two years, dentate subjects only were re-examined,

and at five years participating dentate as well as baseline edentulous subjects were re-examined and also completed a mail-out XI questionnaire, Clock Drawing Test and provided a saliva sample.

The 11-year collection collected the same data as the previous three rounds with additional questions concerning any assistance required with oral hygiene care, location of the last dental visit, diet type and social support. Swallowing problems were assessed using a four-item questionnaire. Following the completion of the dental inspection, an assessment of functional status was conducted using ADL and IADL scales. An interviewer-based assessment of cognitive status was completed using the Global Deterioration Scale and a clock drawing test administered.

The OHIP questionnaire was a 49-item scaled index of social impact of oral disorders with seven subscales. Interviews contained 72 questions. The XI questionnaire was a 19-item inventory of subject's self-perceptions of dry-mouth. The Clock Drawing Test was a standardised screening tool for cognitive status in which the subject was asked to draw a specified time onto a pre-drawn circle representing a clock face.

Clinical examinations included an assessment of any dentures and the oral mucosal tissues. For dentate subjects, the status of teeth and periodontal tissues was assessed using the NIDR examination protocol. Examiners categorised teeth as present or missing, with tooth roots being coded separately if there was more than three-quarters of the crown missing. Surfaces of tooth crowns were categorised by examiners as decayed, recurrent decay, filled, filled unsatisfactorily, or sound. Teeth with full crowns were categorised separately. Five surfaces were coded for molars and premolars and four surfaces were coded for canines and incisors. Root caries experience for the four root surfaces of each tooth were recorded separately as decayed, filled or sound (for visible root surfaces only). For the periodontal assessment, measurements of gingival recession and periodontal pocket depth were made using the NIDR periodontal probe at three sites – mesio-buccal, buccal and disto-buccal. Any bleeding upon probing was recorded for each tooth, and a plaque index recorded for the buccal surfaces of six teeth – the most anterior molar in each quadrant and an upper and lower central incisor.

Data analysis

Disease outcomes have been dichotomised to enable risk prediction models to be developed using multivariate models with logistic regression analysis. Least squares regression and ordinal logistic regression techniques are being used in the development of predictive models of risk. These analyses will produce models of both risk of disease and for risk of incidence of disease.

Also see Sampling and Methods and data collection above.

Results

The baseline data collection enabled the description of the prevalence of edentulism and tooth loss, caries experience, social impact of oral conditions and periodontal disease. Associations of these conditions with sociodemographic factors have been published.

The two-year data collection was used to investigate tooth loss in evidence and incidence of periodontal attachment loss.

The five-year data have been used to investigate relationships between medication, xerostomia and hyposalivation and dental caries in a population of older adults.

The main oral epidemiological outcome variables at the 11-year follow-up are the incidence between baseline and 11-years, and five-years and 11-years, of coronal caries, root caries, Plaque Index scores, periodontal loss-of-attachment and tooth loss. The analyses will also investigate overall risk profiles for oral diseases, incorporating baseline and 5-year oral health status and participant characteristics.

Outputs

Refereed publications:

Baseline

Slade GD, Hoskin GW & Spencer AJ 1996. Trends and fluctuations in the impact of oral conditions among older adults during a one-year period. *Community Dentistry and Oral Epidemiology* 24:317-21.

Slade GD & Spencer AJ 1994. Development and evaluation of the Oral Health Impact Profile. *Community Dental Health* 11:3-11.

Slade GD & Spencer AJ 1994. Social impact of oral conditions among older adults. *Australian Dental Journal* 39:358-64.

Slade GD & Spencer AJ 1995. Periodontal attachment loss among adults aged 60+ in South Australia. *Community Dentistry and Oral Epidemiology* 23:237-42.

Slade GD & Spencer AJ 1997. Distribution of coronal and root caries experience among people aged 60+ in South Australia. *Australian Dental Journal* 42(3):178-84.

Slade GD, Spencer AJ, Gorkic E & Andrews G 1993. Oral health status and treatment needs of non-institutionalised persons aged 60+ in Adelaide South Australia. *Australian Dental Journal* 38:373-80.

Slade GD, Spencer AJ, Locker D, Hunt RJ, Strauss RP & Beck JD 1996. Variations in the impact of oral conditions among older adults in South Australia. Ontario and North Carolina, *Journal of Dental Research* 75:1439-50.

Slade GD, Spencer AJ & Roberts-Thomson K 1996. Tooth loss and chewing incapacity among older adults in Adelaide. *Australian and New Zealand Journal of Public Health* 20:76-82.

Thomson WM, Slade GD & Spencer AJ 1995. Dental caries experience and use of prescription medications among people aged 60+ in South Australia. *Gerodontology* 12:104-10.

2-year follow-up

Slade GD, Gansky SA & Spencer AJ 1997. Two-year incidence of tooth loss among South Australians aged 60+ years. *Community Dentistry and Oral Epidemiology* 25:429-37.

5-year follow-up

Thomson WM 1997. A medication capture and analysis system for use in epidemiology. *Drugs and Aging* 10:290-8.

Thomson WM, Chalmers JM, Spencer AJ & Ketabi M 1999. The occurrence between xerostomia and salivary gland hypofunction in a population-based sample of older South Australians. *Special Care Dentistry* 19:20-3.

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Related studies

The oral health of older Australians is being investigated in three longitudinal studies.

- SADLS: an epidemiological study of persons aged 60 and over in Adelaide and Mt Gambier, which commenced in 1991. A particular aspect of this study is the collection of clinical and oral quality-of-life data. The third round in 1996-97 focused on dry-mouth and oral diseases;
- Oral Health of Community-dwelling Adults with Dementia: a study of oral health changes among persons with dementia (identified with assistance from the Alzheimer's Association of SA) and without dementia (from SADLS). Baseline information from this study has revealed the poor oral health of older adults with dementia; and
- the Adelaide Dental Study of Nursing Homes: a study of the oral health of older adults in nursing homes began in 1998 in Adelaide and involves follow-up of oral health changes over one to two years. This study has revealed the increasing number of nursing home residents who are dentate (i.e. have their own natural teeth) and who require maintenance care to avoid dental pain and infection.

SADLS was established in affiliation with two major North American studies.

References

South Australian Network for Research on Ageing 2001. The South Australian Dental Longitudinal Study. Adelaide: Flinders University, Centre for Ageing Studies. Viewed 28 January 2004, <www.cas.flinders.edu.au/sanra/research/proj0110.html>.

Appendix P Australian Longitudinal Study on Women's Health

Study aims

ALSWH (or Women's Health Australia) is a national research resource providing information on women's health issues. The study began in June 1995 in response to initiatives arising from the National Women's Health Policy.

By looking at the needs, views, lifestyles, health and factors affecting the health of individual women in Australia, ALSWH is able to provide an accurate and current evidence base to DoHA for the development and evaluation of policy and practice in many areas of service delivery that affect women.

The study was designed to explore factors that influence health among women who are broadly representative of the entire Australian population. ALSWH 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 lifespans.

The study assesses:

- physical and emotional health (including wellbeing, major diagnoses, symptoms);
- use of health services (GP, 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); and
- life stages and key events (such as childbirth, divorce, widowhood).

Goals for the next 20 years

The project is helping to shape the future of women's health in Australia by:

1. identifying the social, psychological, physical and environmental factors which determine good health, and those which cause ill-health, in women throughout adult life;
2. identifying when, if and how the health system meets the health needs of women and helping to guide future policy and planning of women's health care services;
3. providing information on the long-term health effects of events in women's lives and on the factors that modify these effects;
4. giving an opportunity for Australian women to have a say about the health and health services;
5. providing a national research resource on women's health issues; and
6. providing data which will help motivate women to participate in decision-making on health.

An overall goal of the project is to use the longitudinal study design to clarify cause-and-effect relationships between women's physical health, emotional wellbeing, and their use of and satisfaction with health care, and a range of biological, psychological, social and lifestyle factors. Another goal is to assess the effects of changes in health policy and practice.

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Location of research

Australia

Investigators

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Professor Wendy Brown
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School of Health
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Dr Anne Young
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Content

Participants respond to questions related to the study's five main themes:

- Use of and satisfaction with health care services: includes availability of, access to and utilisation of health services (e.g. GPs, specialists), cultural appropriateness and women's perceptions of the quality of care provided. Linkage of survey responses with Medicare

records provides information about types of service, characteristics of providers, and out-of-pocket costs of Medicare-eligible services;

- Life stages and key events: identifies factors that help women to maintain the highest level of health and quality of life following key events such as birth of first child, divorce, menopause, widowhood, major illness, moving house, changing job, falls and fractures in the elderly, dementia and bereavement;
- Time use: provides an indicator of women's roles in paid and unpaid work and providing care for others. There are questions about social support, overload, independence, leisure, feeling rushed, aspirations and financial resources;
- Weight and exercise: includes the impact of weight and exercise, dieting and eating disorders on health outcomes. Questions include items about perceptions of body image, as well as general wellbeing and quality of life, dieting and weight change; and
- Violence: explores issues surrounding women's experiences of physical and sexual abuse harassment, as well as issues of psychological and social abuse of older women.

Main topics covered: Ageing and older people; crime and justice; demography and migration; education and training; employment and labour markets; ethnicity and national identity; income, wealth and spending; sex and gender; health and disability; household goods and technology; households and families; housing; leisure; living conditions; social care and welfare; young people.

Other topics covered: Access to health services.

Surveys and data books, as well as information on analyses and sub-studies on specific topics, are available at <www.newcastle.edu.au/centre/wha/surveys.html>.

Funding agencies/budget

First funded in 1995 by DoHA.

Data availability

Data are released approximately one year after each phase of data collection.

Data books

All users can purchase data books at a low-cost for Surveys 1 and 2 for all three aged cohorts (also available online). These data books contain percentages of responses for individual items, divided into urban, rural and remote status.

Access to data sets

A researcher who seeks access to the ALSWH data sets (a 'client') must submit a formal application in writing to the project coordinator, stating the purpose of the proposed research and the justification for the research. If the submission is approved, the client is asked to agree (in writing) to the terms and conditions for collaboration on the project, as described in the Memorandum of Understanding. An investigator from the ALSWH team will be assigned to collaborate with the client.

The terms of the Memorandum of Understanding refer to the 'Guidelines to ownership and access to data and publications' document and the privacy protocol for the project, which detail the requirements for authorship, publication, acknowledgement, data storage and security. Clients are also required to agree (in writing) to the terms set out in the confidentiality agreement, which describes their obligations of confidentiality.

Copies of all papers and reports arising from this collaboration, as well as statistical programs and analyses relating to these, are to be provided to the ALSWH data manager on completion of the project.

See <www.newcastle.edu.au/centre/wha/infodata.html> for further information on data access and use.

Sampling (cohorts/sample size)

Women in three age cohorts 18–23, 45–50 and 70–75 (in April 1996) were randomly selected from the Medicare Database by the HIC. There were 14,739 in the younger cohort, 12,762 in the mid-age cohort and 14,011 in the older cohort. See Response rate below for more information.

Sampling from the population was random within each age group, except that women from rural and remote areas were sampled at twice the rate of women in urban areas. This oversampling meant that the numbers living outside major urban areas were large enough to allow statistical comparisons of the circumstances and health of city and country women, an important issue for Australia now and in the future. ALSWH is the largest study of health issues in rural and remote parts of Australia.

The study also included several smaller cohorts of approximately 500 subjects comprising women from Indigenous, Philipino and Yugoslavian origins.

Comparison with Australian census data indicated that the Wave 1 samples are reasonably representative of Australian women in the three age groups, except for a higher representation of women who are married or in a de facto relationship, and of women with post-secondary education.

The three age groups were selected in order to follow women through life stages which are critical to women's health and wellbeing. The study began when the younger age group were in the early stages of transition from late adolescence to young adulthood, so that they could be tracked as they move into the workforce, enter adult relationships, and become mothers. The mid-age group was selected to examine menopausal transitions and the social and personal changes of middle-age, including work and retirement. The older group were selected in their early 70s, to recruit older women who are generally still active, involved members of the community. These women are being tracked to obtain information on predictors of continuing wellbeing and independence in older adult life.

The study is designed to run for 20 years, by which time the women initially aged 18–23 will be 38–43 years old, the 45–50 year olds will be 65–70 years and the 70–75 year olds will be 90–95 years. In this way the study will develop a profile of the health of women from ages 18 through to 94.

Response rate

In the first round, 54% of the mid-aged cohort completed the survey (N=14,099), 36% of the older aged cohort (N =12,939) and 41% of the younger cohort (N = 14,779). For the second wave the response rates were 92% (N=12,338), 91% (N=10,434) and 71% (N=9,685), while for the third round they were 85% (N=11,202), 84% (N=8,640) and 70% (N=8,680).

Approximately half the women have consented to linkage of their survey data and their records from the Medicare database of the HIC.

Incentives

Reminder letters, a nation-wide publicity campaign, information brochures, a free call number for inquiries, and the option of completing the survey by telephone in English or in the respondent's own language, were used to encourage participation (statutory regulations precluded telephone follow-up of non-respondents). The most common reason for non-participation was lack of interest or time.

Timeframes

All three cohorts were first surveyed in 1996. Wave 2 of data collection occurred in 1998, 1999 and 2000 for the mid, old and young cohorts. From Wave 2, the cohorts are surveyed every three years. The study is designed to run for 20 years, and will involve seven waves of data collection.

Methods and data collection

106,000 women in three age cohorts were randomly selected from the Medicare Database, which is maintained by the HIC and contains the name and address details of all Australian citizens and permanent residents. This is widely regarded as the most up-to-date and complete database of Australians in existence.

These women were sent an invitation to participate in the study and 24 page self-complete survey. Over 41,000 women responded to this initial invitation and agreed to participate in the study. Each age cohort is surveyed once every three years, via surveys sent in the mail (with the option of completing the survey by telephone in English or in the respondent's own language), to see how their health has changed.

A core set of questions for each age cohort was developed and pilot-tested by the research team. Each age cohort receives a different survey and the number of questions and items vary somewhat. Wherever possible, previously validated questions or scales were used. At the end of each survey, women are invited to write about any additional issues they felt affected their health and wellbeing. ALSWH research staff code the replies according to major themes and key words.

As well as these main surveys, women are invited to participate in a variety of sub-studies (see Related studies below). Participants are also invited to consent to linkage of their survey responses with Medicare records, which provide information about type of service, characteristics of provider, and out-of-pocket costs of Medicare-eligible services, but no clinical or diagnostic information. Although specific consent from participants is currently

needed for this, investigators are exploring possibilities of complete de-identified linkage for specific analyses.

To date, more than 22,000 women (59% of the mid-aged cohort, 53% of the older-aged cohort and 37% of the younger cohort), have consented to record linkage, allowing researchers to conduct valuable analyses which explore the health service use of women in different regions of Australia, and their satisfaction with access to services. For example:

- Do women in remote areas of Australia have different patterns of use of health services than women in the cities?
- How far do women have to travel for health services?
- Do they tend to visit male or female doctors?
- How many women have tests such as Pap tests, or services such as Health Assessments, and do these tests help improve their health?

Data analysis

Data analysis is carried out according to the needs of particular reports. A list of approved analyses currently in progress using ALSWH data, will be available at www.newcastle.edu.au/centre/wha/Surveys%20&%20data/analyses.htm.

Requests for ad hoc data analysis are received from time to time from government agencies, academic and non-academic institutions, and other interested parties. Requests for data analysis will be undertaken on a full cost-recovery basis, provided that resources to perform the analysis are available. The cost of the task will be provided in writing before any analysis is performed.

All requests for analysis must be made in writing and should include the aim of the research, a brief background/rationale, the specific analyses required, preferred method of presentation, time frame and contact details. The ALSWH statistician, or a person nominated by her, will liaise with the client to ensure optimal outcomes from this process.

Results

See the web site for results. Reports synthesising project findings in key areas of women's health, including ageing, rural health, chronic disease, physical activity, mental health and violence against women, have been produced. Reports on work and ageing, and alcohol consumption are currently in preparation. Summary brochures of these syntheses are available at www.newcastle.edu.au/centre/wha/Reports/syntheses_reports.html.

Outputs

From 1996 to April 2004, ALSWH has had accepted/published 113 papers, three book chapters, and one book, while 21 papers are currently submitted for publication. Abstracts of all papers published, accepted or submitted for publication, and submitted to or presented at conferences are available at www.newcastle.edu.au/centre/wha/public.html. Annual reports, biannual technical reports, discussions of methodology, newsletters, and reports covering key findings are available at www.newcastle.edu.au/centre/wha/reports.html.

Related studies

Many participants are invited to help by participating in additional surveys. These sub-study surveys target particular areas of health, and cover a wide range of topics, including sleeping difficulties and disturbances; domestic violence; menopausal problems; urinary incontinence; leisure and time; diabetes; eating disorders; dieting and weight gain; out-of-pocket costs of GP services; measures of socioeconomic status for women in different generations and their relationship to health; impact of family care-giving; and the future plans of young women. A listing of ALSWH sub-studies conducted between 1998 and 2004, is available at <www.newcastle.edu.au/centre/wha/substud.html>.

See <www.newcastle.edu.au/centre/wha/Staff/students.html> for a listing of student research projects.

In addition to supplying valuable information about women's health and their use of health services to governments and other decision-making bodies within Australia, ALSWH is developing valuable relationships with international research teams, and increasing the growing bank of national and international knowledge about women's health. For example, menopause experiences among Australian women are compared with those of women in England, Australian women's patterns of work and leisure are compared with those of Canadian women, and Australian women's use of complementary and alternative medical services are compared with those of women in Norway.

References

ASSDA (Australian Social Science Data Archive). Australian Longitudinal Study on Women's Health. Canberra: The Australian National University. Viewed 19 August 2004, <assda.anu.edu.au/studies/D1017.html>.

Institute for Social and Economic Research: Fisher K, Ajayi J, Akhmadov R, O'Hanlon C, Pogorelis R & Watkins-Wright E 2004. Keeping track: a guide to longitudinal resources. London: Office for National Statistics; Colchester: University of Essex. Viewed 19 August 2004, <iserwww.essex.ac.uk/ulsc//keeptrack/results/results.php>.

Women's Health Australia 2004. The Australian Longitudinal Study on Women's Health. Callaghan: The University of Newcastle. Viewed 19 August, <www.newcastle.edu.au/centre/wha/>.

Appendix Q PATH Through Life Project

Study aims

The PATH Through Life Project is a 20-year longitudinal study of 7,485 adult community residents randomly selected from the Canberra and Queanbeyan electoral rolls. It aims to investigate the causes of three classes of common mental health problems: anxiety and depression; alcohol and other substance abuse; and cognitive ageing and dementia.

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Location of research

Australia, ACT and NSW, Canberra and Queanbeyan

Investigators

Organisations involved with the PATH through Life Project include CMHR, John Curtin School of Medical Research and the National Centre for Epidemiology and Population Health at the ANU; the Division of Nutrition at the CSIRO; and the University of New South Wales.

Investigators include Professor Anthony Jorm, Professor Helen Christensen, Dr Bryan Rodgers, Dr Kaarin Anstey, Dr Keith Dear, Karen Maxwell (Survey Manager) and Trish Jacomb (Data Manager) from the Centre for Mental Health Research at the ANU.

Team members on the additional studies include Stephen Rosenman, Chantal Meslin, Rajeev Kumar, June Cullen, Karen Maxwell, Trish Jacomb, Ruth Parslow, Peter Butterworth, Tim Windsor, Kathy Griffiths, Jerome Maller, Karen Mather and Alisa Korten.

Interviewers include Barbara Banvill, Elizabeth Parkes, Brian McNamara, Carolan Marstin, Bruce Hoogendoorn, Denise Melville, Jenny Stewart, Margaret Chapman, Jean Bennett, David Fryer, Betty Smith and Nick Newman.

Content

The project aims to investigate the causes of three classes of common mental health problems: anxiety and depression; alcohol and other substance abuse; and cognitive functioning and dementia. The project investigates four broad themes that are relevant to each these problems: ageing versus cohort effects; social, psychological, nutritional and genetic risk factors; and comorbidity of mental health problems.

Also see Results, Outputs and Related studies below.

Funding agencies/budget

The study is funded until 2006 by an NHMRC Program Grant. Other funding comes from the Rotary Health Research Fund. Smaller grants from the NHMRC and CSIRO have been used to fund the MRI and Nutritional intake sub-studies, with additional sub-study funding from the Brewer's association .

Data availability

Contact Professor Anthony Jorm.

Sampling (cohorts/sample size)

Data were obtained from three cross-lagged age cohorts aged 20–24, 40–44 and 60–64 years selected at random from the Canberra and Queanbeyan electoral rolls (enrolment is compulsory for Australians aged 18 and over). The achieved sample sizes for the three cohorts were 2,404, 2,528 and 2,551 giving a total of 7,485 participants.

Response rate

In the 20–24 years age group 4,102 potential participants were contacted and 2,404 were interviewed (participation rate was 58.6%). For the 40–44 years age group 3,919 potential participants were contacted and 2,528 were interviewed (64.5% participation rate). In the 60–64 years age group 4,378 potential participants were contacted and 2,551 were interviewed (58.3% participation rate).

Incentives

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Timeframes

Data were obtained from three age cohorts aged 20–24, 40–44 and 60–64 years selected at random from the electoral roles of Canberra and Queanbeyan and interviewed in 1999, 2000 and 2001 respectively. It takes a full three years to interview all participants. These cohorts are followed-up at four-yearly intervals for a total of 20 years, so that the study gives both cross-sectional and longitudinal assessments over the same age span.

Methods and data collection

Interviews are done on hand-held computers with participants entering their answers on the computer in the presence of trained interviewers. Some parts of the interview (such as physical testing and memory tests) are completed by the interviewer. Cheek swabs are taken for genetic analysis. Sub-studies involve more detailed physical and neurocognitive assessments by a doctor and MRI scans. Also see <www.anu.edu.au/cmhr/path.php> for a list of publications discussing methods, data analysis and the latest research findings.

Data analysis

See <www.anu.edu.au/cmhr/path.php> for a list of publications discussing methods, data analysis and the latest research findings.

Results

Although much work is yet to be done in analysing the PATH Through Life studies, results have already been reported in a number of areas. The PATH web site provides further details on:

- childhood parental affection as a depression/anxiety risk factor;
- childhood adversity as an adult mental health risk factor;
- sexual orientation and mental health;
- factors associated with young adults' obtaining GP services;
- substance use and mental health;
- alcohol consumption and cognitive functioning;
- gender differences in cognitive abilities;
- identification of individuals at risk of Alzheimer's disease;
- structure of cognitive functioning and intelligence in older age numerous; and
- head injury.

PATH publications (see Outputs below) also include results regarding pet ownership and health (particularly risk factors for cardiovascular disease), seasonality, religiosity and personality, work and health, medication use and memory, treatment of depressive and anxiety symptoms, and forced expiratory volume in one second and cognitive performance.

From the MRI sub-study some of the papers have covered topics on memory complaints, depression and white matter hyperintensities, intracranial volume and cognition, hippocampal volumes and incidental abnormalities.

Jorm et al. (2003) reports findings relating to the association of obesity with anxiety, depression and emotional wellbeing:

There is conflicting evidence in the literature about the relationship of obesity to anxiety and depression. Some studies show an association between obesity and depression, while other studies find that obese participants are less depressed. However, the previous research has had some limitations, such as including underweight individuals in the non-obese group.

Data from the PATH Through Life 20+ and 40+ samples was used to investigate the issue. It was found that obese females, but not obese males, tended to have more anxiety and depression and lower emotional wellbeing. Because obese people tend to have worse physical health and are less active, we also controlled for these factors, which removed the association between obesity and worse mental health. In conclusion, obesity has a weak association with anxiety, depression and wellbeing in women only. This association can be explained in terms of reduced physical activity and poorer physical health. Reducing the prevalence of obesity in the community is important for reducing physical morbidity, but there are unlikely to be major benefits to mental health or wellbeing.

Outputs

See <www.anu.edu.au/cmhr/path.php> for a list of publications discussing methods, data analysis and the latest research findings. Additional publications (that are not listed) include:

Rodgers B, Blewitt K, Jacomb P & Rosenman S 2003. Childhood adversity and abuse and mental in adult life. Paper Presented at the 8th Australian Institute of Family Studies Conference. Available: <www.aifs.gov.au/institute/afrc8/rodgers.pdf>.

Parslow RA & Jorm AF 2003. Pet ownership and risk factors for cardiovascular disease: another look. *Medical Journal of Australia* 179:466–8. Available: <www.mja.com.au/public/issues/179_09_031103/par10103_fm.html#elementId-1085189>.

Related studies

Sub-studies include:

1. PATH Through Life Project: Nutritional intake data

This project collects and analyses nutritional intake data from PATH participants. The data will allow investigations of the associations between nutritional intake, cognitive performance and psychological wellbeing both cross-sectionally and longitudinally, between and within age groups. Project researchers include Dr Janet Bryan, Dr Katherine Baghurst, Ms Ann-Marie Wordley, and Ms Donna Hughes, in conjunction with the NHMRC Psychiatric Epidemiology Research Unit at the ANU. For more information see <www.cas.flinders.edu.au/sanra/research/proj0183.html>.

2. Study of the brain using Magnetic Resonance Imaging

A sub-study of the 60–64 year-old cohort involves participants having a brain MRI scan (used to identify white matter hyperintensities as well as the size and shape of brain matter) and providing a blood sample. The research is being undertaken in collaboration with Professor Perminder Sachdev from the University of New South Wales. The purpose of the study is to examine relationships between certain brain characteristics and health measures such as blood pressure, depression and memory problems. The MRI team has completed all of the volumetric tracings, as well as ratings of atrophy and white matter lesions in the over 500 MRI brain scans. Data analysis has begun and findings will soon be reported.

3. Health and memory in the 60–64 year-old cohort

Participants were selected into this sub-study on the basis of the physical and memory test results in the first interview. They were then invited to have a more detailed physical and neurocognitive assessment from a medical doctor. Participants of this study are also asked to have an MRI. The aim of this study is to examine relationships between health and memory and to look at memory change over time.

References

Centre for Mental Health Research 2004. PATH Through Life Project. Canberra: The Australian National University. Viewed 19 August 2004, <www.anu.edu.au/cmhr/path.php>.

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Appendix R Negotiating the Life Course

Study aims

NLC is designed to study the changing life courses and decision-making processes of Australian men and women as the family and society move from male breadwinner orientation in the direction of higher levels of gender equity. The project has six aims:

- to extend the theories of human capital and new home economics in explaining women's and men's labour force participation;
- to map women's and men's work trajectories over their lifecourse, from career entry into retirement, and to develop explanatory models of career trajectories;
- to identify those aspects of the family-household system and the labour market that facilitate or impede women's involvement with the labour market;
- to investigate the interrelationships between labour force decisions about family formation and household arrangements;
- to identify the portfolio of resources that women and men draw upon throughout their lives when making decisions about career and family; and
- to assess the policy implications of the findings of the project for the institutions of the welfare state, the labour market and the family.

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Location of research

Australia, ACT, Canberra

Investigators

NLC is a longitudinal study undertaken by the Australian Consortium for Social and Political Research Incorporated (ASCPRI) Centre for Social Research and the Demography and Sociology Program of RSSS at the ANU and the School of Social Science, University of Queensland. Investigators include Dr Janeen Baxter, Professor Peter McDonald, Dr Deborah Mitchell, Dr Ann Evans, Dr Edith Gray and Dr Trevor Breusch. For more information see lifecourse.anu.edu.au/staff/.

Wave 1 of data was collected by the AIFS. Wave 2 of data was collected by telephone interviewers from the University of Queensland using the CATI facility.

Content

Careers, children and child care, education and training, employment, attitudes and expectations, caring and voluntary work, fertility and childbearing, health, mental health, home economics, housing and household composition, human relations, income, superannuation, relationships and marriage, occupations and religion, under the broad research areas of:

Income inequality

Research in this area explores the dynamics of income between waves and relates the observed income changes to movements in and out of the labour market, and other lifecourse events such as marriage, divorce and childbirth. Researchers include Dr Deborah Mitchell and Dr Trevor Breusch.

Family formation

NLC research in this area explores the issues of change and dispersion in the pattern and timing of individual lifecourse transitions, by focusing on five key lifecourse events (leaving home, cohabitation, marriage, fertility and relationship breakdown), and comparing the experience of four birth cohorts (those born in the 1940s, 1950s, 1960s and 1970s). Researchers include Professor Peter McDonald and Dr Ann Evans.

Work and family life

Researchers in this area include Dr Janeen Baxter and Dr Edith Gray. There are three specific research aims:

1. To investigate what changes, if any, take place in the management and organisation of domestic labour as a result of women's movement into paid employment and to examine how these changes vary across differing socioeconomic groups and lifecycle stages.
2. To identify the mechanisms associated with men's and women's employment that might lead to changes in household organisation. For example, is the amount of time that men and women spend in paid employment the key factor in bringing about change in household organisation, or is change dependent on women moving into particular kinds of jobs such as managerial or executive positions? By change here, we mean not just changes in men's levels of involvement in domestic labour, but also in women's levels of involvement in domestic labour, including their identity as homemakers, the employment of paid help, or the involvement of other family members.
3. To examine the relationship between work identities and domestic identities. For example, how does women's identity change as a result of their movement into paid work? Does this pattern vary across the lifecourse or for women in different kinds of jobs? In particular we will assess how women's perceptions of the fairness of the domestic division of labour vary in relation to labour force participation and lifecourse stage.

Also see the NLC web site for information on Student Research Topics, and Related studies below for information on the Australian Family Formation Decisions Project.

Funding agencies/budget

Wave 1 (1997) was funded by the RSSH at the ANU, and Waves 2 and 3 (2000 and 2003) were funded by the ARC. The Australian Family Formation Decisions Project is funded by an ARC Large Grant.

Data availability

Data from the NLC project are available for secondary analysis from the ASSDA. See lifecourse.anu.edu.au/data/ for online codebooks, ASSDA access form, data updates and status scales. For more information on data access, email NLC. All users of these data are strongly encouraged to publish their findings in the Life Course Project Discussion Paper Series. Contact the series editor Dr Ann Evans. Data files for Waves 1 and 2 include 2,231 unweighted cases with 1,297 variables per case, and 1,768 unweighted cases with 835 variables per case, respectively.

Sampling (cohorts/sample size)

The survey is a national random telephone survey using the electronic White Pages as its sampling frame. Within each selected household, respondents aged 18–54 years were chosen on the basis of having the next birthday. 2,231 persons were interviewed in Wave 1. Where

the respondent was married or in a cohabiting relationship, a wide range of information about the partner was provided by proxy by the respondent.

The NLC sample is broadly representative of the Australian population. However, there is some over-representation of employed persons, under-representation of young persons, over-representation of persons living alone and lone parents, and a bias towards English speaking respondents. The strongest bias was towards women. McDonald et al. (2000), provide details on the comparison of various indicators from the NLC with the general Australian population.

The selection of only one eligible person per household means that a system of weights needs to be applied to the sample population when the sample is used to obtain population estimates.

Response rate

A total of 2,231 persons were interviewed from a sample of 7,721 randomly selected phone numbers. 97% of respondents in the first wave agreed to participate in following rounds of the survey.

The study found that regular contact with respondents, contact information of a relative or friend, and other contact sources such as the White Pages, electoral roll and workplaces, assisted in maintaining contact with respondents. For example, making contact with the respondents receiving a mail-out questionnaire in NLC sub-studies increased the response rate.

See <lifecourse.anu.edu.au/publications/Discussion_papers/NLCDP001.pdf> for further information on response rates, including numbers by state and territory.

Incentives

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Timeframes

NLC is set up as an indefinite life, panel survey. The study began in 1996 with subsequent waves in 2000 and 2003 (Wave 1: October 1996–November 1996 and February 1997–April 1997; Wave 2: April 2000–September 2000).

Between rounds, two small and one large follow-up survey were conducted for specialised sub-samples of the original sample.

Methods and data collection

Single cohort stratified by age. CATI was the preferred data collection method and included a GHQ. Respondents proxy reported for their partner. To overcome difficulties in the collection of business income in Wave 1, respondents in Wave 2, were offered the opportunity of a call-back to enable them to look at their tax returns for the previous year. A

mail-out questionnaire (Parenting Survey 1999) was used in NLC sub-studies. Also see NLC publications.

Data analysis

Because only one person per household was interviewed, the unweighted sample under-represents households with more than one eligible respondent relative to households where there is only one eligible respondent. A weighting factor was provided to take account of bias in the unweighted sample when population estimates are being made. Weighting makes no difference to the distribution by sex. The main impact of weighting is in the distribution of the sample by living arrangement. Weighting shifts about 5% of respondents not in a relationship to married. Also see NLC publications.

Results

Available from NLC publications.

Outputs

For a list of publications including discussion papers, journal articles, conference papers and book chapters see <lifecourse.anu.edu.au/publications/dps.html>.

Related studies

Analyses of the Michigan Panel Study of Income Dynamics and the British Household Panel Survey.

The Australian Family Formation Decisions Project

The Australian Family Formation Decisions Project seeks to enhance understanding of the historically low and declining level of fertility in Australia. In-depth interviews are conducted with approximately 120 selected NLC respondents resident in the eastern states, to allow respondents to identify what they perceive to have been, or to be likely in future to be, the significant influences on their family formation experience. Investigators include Gordon Carmichael (National Centre for Epidemiology and Population Health, ANU), Andrea Whittaker (University of Melbourne) and Peter McDonald (NLC Project Team, ANU). See <lifecourse.anu.edu.au/research/affd_project.html> for further information.

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<lifecourse.anu.edu.au/publications/Discussion_papers/NLCDP001.pdf>.

Appendix S The Household, Income and Labour Dynamics in Australia Survey

Study aims

The HILDA Survey is a nationally representative household-based panel survey which aims to track all members of an initial sample of households over an indefinite life. By collecting data on economic and subjective wellbeing, labour market dynamics and family dynamics, HILDA can then give information on issues such as:

- how and why the composition of households change;
- how and why relationships form and break up;
- the relationship between education levels and labour market experience for different groups and generations; and
- the life satisfaction and health status of different group and generations.

The HILDA Survey represents the start of the first Australian longitudinal survey on income, labour market and family characteristics of all members of a household. It will provide sound evidence for policy development and help address the root causes of disadvantage and develop measures that build stronger families and communities. The longitudinal nature of the data enables analysis of the changes in socioeconomic circumstances of families and individuals over time, which is not possible with cross-sectional data.

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Location of research

Australia, Victoria, Melbourne

Investigators

The HILDA Survey is funded by the Australian Government through FaCS. Responsibility for the design and management of the survey rests with a group comprising the Melbourne Institute of Applied Economic and Social Research (University of Melbourne), ACER and the AIFS. Data collection has been sub-contracted to ACNielsen, a private market research company.

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Content

The HILDA Survey collects data in three main areas: economic and subjective wellbeing, labour market dynamics and family dynamics.

- Information on income from superannuation, life insurance and allocated pensions, SF-36 questions, and questions on smoking, drinking and physical activity are included in each wave of the study. Questions on social interaction (e.g. the amount of social support from other people, and social interaction with family and friends), are included in the self-completion questionnaires.
- In Wave 1 data were collected on a wide range of issues including: household structure, family background, marital history, family formation, education, employment history, current employment, job search, income, savings, taxes and benefits, health and wellbeing, child care and housing/locations.
- In Wave 2 a dedicated module on household wealth was included.
- Wave 3 included additional questions on retirement and the transition to retirement. From Wave 3 types of disabilities and health limitations are addressed.
- A new module on young people (aged less than 30 years) and a disability module have been developed for Wave 4, along with questions on private health insurance, religion (e.g. attendance at religious services and the importance of religion), parental education and visa category of immigrants. Note: ethnicity and culture are not addressed aside from what can be gleaned from country of birth, year of arrival to Australia, and whether the respondent speaks a language other than English at home. However, the study does identify Indigenous Australians.

Research questions compiled by FaCS, that guide the development of modules for the HILDA Survey, are available at <www.melbourneinstitute.com/hilda/POverview-9.pdf>. Also see <www.melbourneinstitute.com/hilda/sinstruments.html> for HILDA survey instruments.

Funding agencies/budget

Funded by the Australian Government through FaCS. The study was initially funded for three waves. Additional funding was then obtained for Wave 4, and more recently for Waves 5–8.

Data availability

A moderately confidentialised unit-record data file is available for research purposes. Provided on CD-ROM, the latest release provides data from both Waves 1 and 2 in SPSS and SAS formats. An order form and Deed of License can be accessed on the data page at

www.melbourneinstitute.com/hilda/data.html>. The Deed of License constitutes a legal contract between the user and the Australian Government and specifies conditions that users of the HILDA unit-record data agree to abide by. Apart from a fee to cover handling costs (\$77 if based in Australia), the data are free to approved users. More information is available on the data page of the HILDA web site.

Data from Wave 3 is expected to be available to researchers in December 2004.

Sampling (cohorts/sample size)

The target population for the first wave of the HILDA Survey is all Australian residents who live in private households. Persons living in remote and sparsely populated areas (about 80,000 persons) were outside the coverage of the survey.

The initial sample selected for the first wave comprised 12,252 households selected from 488 different neighbourhood regions across Australia, of which 11,693 were subsequently identified as in-scope. Interviews were sought with all adult (persons over 15 years of age) members of these households.

The achieved sample included 19,914 adults and children in 7,682 responding Wave 1 households. 13,939 of these respondents were aged 15 and over, and were offered a full interview.

All people in Wave 1 are permanent sample members. The sample is extended over time by use of the following rules to include newborn and adopted children (and their parents if they are not already part of the sample). Anyone living with a permanent sample member is included in the sample as a temporary sample member, and remains in the sample for as long as they share a house with a permanent sample member.

Interviews are conducted with sample members aged 15 and over. A small amount of data is collected about children aged 0-15 years within the household.

Response rate

Wave 1: 19,914 adults and children in 7,682 responding households. Interviews were successfully conducted with 13,969 adults aged 15 and over, giving a household response rate of 66%.

Wave 2: 18,925 adults and children in 7,245 responding households. Interviews were conducted with 13,041 adults aged 15 and over. The wave-on-wave response rate, after adjustments for deaths, was 87%.

Wave 3: 17,693 adults and children in 7,098 responding households. Interviews were conducted with 12,731 adults aged 15 and over.

Wave 3 interviewing finished in March 2004 with 12,722 respondents over 15 years of age completing personal interviews. 93% of the Wave 2 respondents provided an interview in Wave 3, resulting in an attrition rate of 9.7%, compared to the Wave 2 attrition rate of 13.2%.

Incentives

All responding households are offered a payment of either \$50 or \$20. The \$50 payment is made where all household members participate. The \$20 payment is made in cases where only part of the household cooperates.

Timeframes

Wave 1: August 2001–January 2002, Wave 2: August 2002–April 2003, Wave 3: August 2003–April 2004, Wave 4 onwards: annual interviews from August–April. Three waves have been conducted with data available from the first two. Funding has been received until the end of Wave 8, though the study is set up as an indefinite life panel.

Methods and data collection

Wave 1 of the survey involved administration of four questionnaires. Two of these – the Household Form and the Household Questionnaire – were administered by personal interview to at least one adult member of the household. A Person Questionnaire was then administered, again via personal interview, to all household members aged 15 and over. Finally, a Self-Completion Questionnaire was provided to all persons completing the Person Questionnaire and collected by the interviewer at a later date.

For subsequent waves, a separate instrument was introduced for new sample members. Subsequent waves may also include CATI. All survey instruments can be viewed and downloaded from www.melbourneinstitute.com/hilda/sinstruments.html.

Technical papers on the Wave 1 coding framework, Wave 1 and Wave 2 survey methodology and Wave 1 weighting are now available on the HILDA web site.

Data analysis

The publicly available data file includes a detailed set of derived variables which provide many commonly used variables following ABS conventions. Examples here include: relationship in household, labour force status, education (Australian Standard Classification of Education), occupation (Australian Standard Classification of Occupations), and industry (Australian and New Zealand Standard Industry Classification). Missing values have generally not been imputed. The notable exception is income and wealth data. An additional set of income and wealth variables have been constructed which impute missing cases using a nearest neighbour regression method. The data set also includes a detailed set of population weights.

Technical papers on the Wave 1 coding framework, Wave 1 and Wave 2 survey methodology and Wave 1 weighting are available on the HILDA web site, at: www.melbourneinstitute.com/hilda/hdps.html.

Results

The data are released annually. Most questions are identical each year. Some questions, however, are rotated to allow for inclusion of questions on special topics. See annual reports, discussion papers, HILDA bibliography and data.

HILDA has already shown that:

- women are more likely than men to work in ‘family-friendly jobs’;
- women are more often in permanent part-time work (81% of women and 58% of men);
- women work in jobs with better access to unpaid maternity leave (78% of women and 55% of men);
- women work in jobs with better access to paid maternity leave (51% of women and 40% of men);
- there appears to be no association between fertility and access to family-friendly entitlements;
- men (particularly younger men) are more likely than women to expect childlessness;
- women who remain childless are more likely to have high employment, occupational and education status – however, men who remain childless are more likely to have low employment, occupational and education status;
- 15% of all children aged 17 years or less have another parent who does not reside with them at least half the time; and
- according to resident parents who live with their children at least half the time, 39% of the youngest children in the family aged 17 years or less have had no contact in the past 12 months with their other parent who lives somewhere else.

Outputs

Annual reports on the HILDA Survey are released each year and are available at www.melbourneinstitute.com/hilda/areport.html. HILDA discussion papers and technical papers are available at www.melbourneinstitute.com/hilda/hdps.html.

There are also a growing number of papers that are being written using the HILDA Survey data. A bibliography is being maintained which lists this body of work as well as providing links to the actual papers wherever possible. This bibliography can be found at www.melbourneinstitute.com/hilda/hbiblio.html.

Related studies

The HILDA Survey is most closely aligned with the practices of the British Household Panel Study and the German Socio-Economic Panel Study. It is a member of a small group that comprises these studies as well as the Panel Study of Income Dynamics in the US and Swiss Household Panel Survey.

Social participation among income-support recipients: evidence from HILDA – Chris Ryan and Danielle Venn. This study will assess the strength of the relationship between social participation and subsequent outcomes among a representative sample of Australia income-support recipients. It will build on the analysis and results of the From Social to Economic

Participation, Social Policy Evaluation Analysis and Research project, which used data from the Welfare Reform Pilots. This analysis will use a more representative group of income-support recipients, analyse their outcomes over a longer time period and encompass a broader range of outcome measures.

References

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Appendix T Longitudinal Survey of Immigrants to Australia

Study aims

LSIA is the most comprehensive survey of immigrants to be undertaken in Australia. It aims to provide reliable data for the Australian Government, private agencies and community groups to monitor and evaluate immigration and settlement policies, programs and services (as usually only detailed demographic data are readily available). The data can also be used for developing future policies.

The benefit of using a longitudinal approach is that it provides a better picture of settlement progress than would be captured from a cross-sectional survey. For example, a longitudinal survey can answer questions such as:

- How long is it taking migrants to find work?
- How has the English proficiency of migrants improved when they have been in Australia for 18 months compared with six months after they arrived?
- How is the use of support services by migrants varying over time?

The LSIA was conducted as two separate surveys. LSIA1 was conducted for migrants arriving in Australia between September 1993 and August 1995, and LSIA2 was conducted for migrants arriving in Australia between September 1999 and August 2000 for the purpose of evaluating the effects of immigration policy change.

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Location of research

Australia, ACT, Canberra

Investigators

The study is managed by investigators from the Research and Statistics Section, DIMIA. Data are collected by Reark Research, who were later taken over by ACNielsen. David Osborne is the LSIA Data Manager.

Content

LSIA1 and LSIA2 cover similar topics, including: pre-migration experience; the immigration process; initial settlement and location; sponsorship activity; perceptions of Australia; support services (government and non-government); return migration and visits; ancestry, religion and ethnicity; citizenship; views on immigration; English language proficiency and learning; qualifications and skills assessment; education and training; labour force activity; health; housing arrangements; household budgets; financial support given/received; transferral of assets/remittances; pensions and allowances; income and finances.

Although they cover similar topics, the questions that make up the two surveys are slightly different. Questions vary because of the emergence of important new issues (e.g. the use of the Internet in the settlement process). Questions also vary between different collection waves. This is because different issues are relevant at different stages of the migration and settlement process. For more information see LSIA Questionnaires at www.immi.gov.au/research/lsia/lsia08.htm.

The PA answers questions relating to their direct settlement experience and questions relating to couple, family and household experiences and circumstances – the Migrating Unit Spouse (MU) spouse answers questions relating to their direct settlement experiences. Basic demographic information on the PA, MU and other household members, was obtained from the PA, and included age, sex, relationship to PA, whether they were in the same migrating unit as the PA, country of birth, marital status, employment, visa and citizenship status, and income. Additional information about the PAs and MUs occupation, expenses and languages spoken was collected.

Funding agencies/budget

The study is funded by the Australian Government through DIMIA and also received some funding through trusts managed by the states during the initial wave of the study.

Data availability

Anonimised LSIA unit record files are available free of charge as fixed format ASCII, SAS, DBASE, and SPSS files. An erratum, application form and user guide are available at www.immi.gov.au/research/lsia/lsia07_1.htm. The unit record data are also available for

a small administration fee through the ASSDA (see <assda.anu.edu.au> for more information).

A LSIA1 CD-ROM is available free of charge, and contains an introduction by the Minister for Immigration and Multicultural and Indigenous Affairs (Hon. Philip Ruddock, MP), an overview of the LSIA, an ad hoc query module allowing production of reports, a series of 33 standard reports, a report tutorial explaining how to generate standard reports and use the ad hoc query module, and an electronic copy of *New Settlers Have Their Say – How Immigrants Fare in their Early Years of Settlement: An Analysis of Data from the Three Waves of the Longitudinal Survey of Immigrants to Australia*. A CD-ROM disclaimer and contacts details for obtaining the CD-ROM are available at <www.immi.gov.au/research/lisia/lisia07_2.htm>.

Clients who are interested in some aspect of the LSIA, but do not have access to the LSIA unit record files, may contact the data manager and provide details of their request. Request are serviced at the rate of \$105 per hour including GST, with an additional surcharge that varies depending on the number of cells of data that are ordered (clients within DIMIA are serviced free of charge).

Sampling (cohorts/sample size)

Stratified random sample – the samples were stratified by Visa eligibility categories and region of birth. The sampling unit for the LSIA is the PA. The PA is the person upon whom the approval to immigrate was based.

The LSIA consists of two cohorts: LSIA1 had a sample size of 5,192 PAs who arrived between September 1993 and August 1995, and LSIA2 had a sample size of 3,124 PAs who arrived between September 1999 and August 2000.

Both samples were drawn from PAs on DIMIAs Settlement Database. To be eligible for inclusion in the samples, PAs had to meet the following criteria:

- they were at least 15 years of age;
- they were offshore visaed immigrants;
- they did not have special eligibility visas (e.g. persons who applied for visas while in Australia);
- they were not New Zealand Citizens (who do not require visas); and
- they had an identifiable country of birth.

Only persons settling in capital cities or nearby major urban areas such as Newcastle and Wollongong, were interviewed. Immigrants settling in Cairns were included in LSIA1, but were not included in LSIA2.

Migration policy changes mean that the composition of the LSIA2 sample is different from the LSIA1 sample. For example, for the period covered by the LSIA2, skilled migrants made up a greater proportion of the migration program. Therefore, the LSIA2 sample has a greater proportion of skilled migrants. Because of this change in sample composition, some care must be exercised when comparing the experiences of migrants from LSIA1 with those from LSIA2.

The main concern of the LSIA is to collect detailed information about the PA. However, the PA is also asked for basic demographic information for everyone in the household (all persons living at the same address as the PA), and for the migrating unit as a whole (all persons in the household who migrated to Australia as part of the same migration

application as the PA). If the PAs spouse is a MU, the spouse will be also be interviewed for detailed information. Otherwise, only basic information on the spouse will be collected from the PA.

Response rate

Approximately 60% of PAs selected for interview were actually interviewed in the first wave of both LSIA1 and LSIA2. 86% of PAs interviewed in LSIA1 Wave 1 were reinterviewed in LSIA1 Wave 2 and 72% of PAs interviewed in LSIA1 Wave 1 were reinterviewed in LSIA1 wave 3. 85% of PAs interviewed in LSIA2 Wave 1 were reinterviewed in LSIA2 Wave 2.

Reasons for non-interview varied; predominant reasons were respondent could not be tracked or respondent was overseas during the scheduled interview period. See Section III.3 and Appendices C and D in the LSIA user documentation for more information.

Incentives

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Timeframes

A three-wave prototype study was conducted between 1991 and 1995.

In LSIA1, immigrants were interviewed three times. The first interview was conducted approximately five or six months after arrival, the second interview one year later and the third interview a further two years later. The first wave of interviews commenced in March 1994–December 1995. The second wave of interviews commenced in March 1995–February 1997, and the third wave of interviews commenced in March 1997–February 1999. Each wave of interviews was spread over a two-year period.

In LSIA2, immigrants were interviewed twice. The first interview was conducted approximately five or six months after arrival, and the second interview one year later. The first wave of interviews commenced in March 2000–January 2001 and the second wave of interviews commenced in March 2001–March 2002. Each wave of interviews occurred over a one-year period.

Methods and data collection

The PA and their MU were personally interviewed using a printed questionnaire, and information was collected about other household members at each wave. The MU questionnaire contained a subset of the questions asked of the PA. Wave 1 interviews covered the period prior to arrival and approximately the first six months since migration; Wave 2 covered the period six to 18 months after migration; and Wave 3 covered the period 18 to 42 months after migration. For more information see LSIA questionnaires.

Approximately one-third of the LSIA1 interviews were conducted in languages other than English. The use of over 50 languages by respondents led to a mix of interpreting methods during interviews. Of these, more than half were conducted with the assistance of friends or

members of the respondent's family. The remaining non-English interviews were conducted with the assistance of an accredited interpreter or through a bilingual interviewer.

Both LSIA samples were stratified by visa eligibility category and region of birth.

Data analysis

As the LSIA used only a sample of settler arrivals, the raw figures had to be weighted to represent the total population of immigrants arriving in Australia during the time of the survey. In developing these weights, effects of stratification and sample loss had to be addressed.

Results

Results from three waves of the LSIA are available in the LSIA CD-ROM. Unit record data and tabulations are available upon request from the LSIA Data Manager. See Data availability above for more information. Results are also discussed in the sample reports and publications (see Outputs below).

Tables based on LSIA1 data include labour force status at time of interview, and how well English is spoken at time of interview. Tables and charts from LSIA2 are arranged under ten themes: migrant counts; demographic characteristics; education and qualifications; income and expenditure; health; housing; Internet use; the labour market; language; and settlement.

Outputs

Sample reports are available at <www.immi.gov.au/research/lsia/lsia05.htm> and <www.immi.gov.au/research/lsia/lsia06.htm>. A listing of publications based on LSIA data (with links where available) is at <www.immi.gov.au/research/publications/index.htm>. Publications include:

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Murphy J 1997. Initial location decisions of immigrants. Canberra: DIMA.

Plimer D & Candlin CN 1996. Language services for non-English-speaking-background women. Canberra: AGPS.

Richardson S, Miller-Lewis L, Ngo P & Ilsley D 2001. The labour force experience of new migrants. Canberra: DIMA.

Richardson S, Robertson F & Ilsley D 2002. The settlement experience of new migrants. Canberra: DIMIA.

Richardson S, Robertson F & Ilsley D 2002. Life in a new land: the experience of migrants in Wave 1 of LSIA1 and LSIA2 (unabridged).

Rod T & Murphy J 1997. Immigrant transfers and remittances. Canberra: DIMA.

VandenHeuvel A & Wooden M 1999. New settlers have their say – how immigrants fare in their early years of settlement: an analysis of data from the three waves of the Longitudinal Survey of Immigrants to Australia. Canberra: DIMA.

Williams LS, Murphy J & Brooks C 1997. Initial labour market experiences of immigrants. Canberra: DIMA.

Related studies

A three-wave prototype study was conducted between 1991 and 1995.

Related longitudinal surveys of immigrants include The Longitudinal Survey of Immigrants to Canada, and The Longitudinal Immigration Survey: New Zealand.

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ABS (Australian Bureau of Statistics). Longitudinal Survey of Immigrants to Australia. Canberra: ABS. Viewed 10 February 2004, <www.abs.gov.au/websitedbs/d3110120.nsf/23e66fc7516724c2ca256984001c53d0/c8b7bc30b2c68cd2ca256988001f9dd0!OpenDocument>.

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DIMIA (Department of Immigration and Multicultural and Indigenous Affairs) 2004. Longitudinal Survey of Immigrants to Australia. Canberra: DIMIA. Viewed 19 August 2004, <www.immi.gov.au/research/lisia/index.htm>.

Appendix U AusDiab Follow-up Study

Study aims

The AusDiab Follow-up Study will follow-up the participants of the original Australian Diabetes, Obesity and Lifestyle Study (AusDiab) study. AusDiab aims to provide information on Diabetes mellitus, heart disease and health-related behaviour (e.g. smoking, drinking and exercise), in order to develop ways of improving people's health and the provision of health services. The AusDiab Follow-up Study will be essentially a repeat of the baseline study.

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www.diabetes.com.au/research/prospective.htm (currently being updated)

Location of research

Australia, Victoria

Investigators

Principal investigator of the study is Professor Paul Zimmet from the International Diabetes Institute Inc. Other investigators include Professor Robert Atkins, Professor Timothy Welborn and Dr Jonathan Shaw.

Core field staff involved in the baseline AusDiab study include Dr David Dunstan (International Diabetes Institute) Project Coordinator, Ms Marita Dalton (International Diabetes Institute) Field Coordinator, Ms Alison Stewart (International Diabetes Institute), Ms Robyn Tapp (International Diabetes Institute), Ms Fay Wilson (International Diabetes Institute), Ms Clare Reid (Hitech Pathology) and Ms Annie Allman (Hitech Pathology).

Additional Research Staff include Mr Adrian Cameron (International Diabetes Institute) and Mr Adam Meehan (International Diabetes Institute).

Content

The AusDiab Follow-up Study will be essentially a repeat of the baseline study, and will include demographics, anthropometrics, blood pressure, blood and urine testing (for diabetes, lipids and renal function), clinical testing for diabetes complications (e.g. neuropathy and retinopathy), medical history, self-reported disease status, diet, physical activity, and health service utilisation. Personal details such as age, sex, country of birth and occupation were also included in the baseline study.

Funding agencies/budget

The study received a NHMRC Project Grant for four years (\$2,600,000) in 2003, with further funding from Kidney Health Australia (matched by hospital funding), Diabetes Australia, and a variety of charities, foundations and pharmaceutical companies.

Data availability

Only researchers who work on the survey will use participant's answers. Personal information such as names and addresses are removed before the information is given to researchers for future research use. Any information obtained will be strictly confidential and no individual will be identified in any reports. Participant's answers will be combined with those from thousands of other households and the results will be reported in such a way that answers cannot be identified individually.

Sampling (cohorts/sample size)

The AusDiab Follow-up Study will follow-up the 11,247 participants of the original AusDiab study, which invited all adults aged 25 and over from six randomly selected Census Collector Districts within each of the states and the Northern Territory to participate. See www.diabetes.com.au/research/ausdiab.htm for a listing of the suburbs that were surveyed in each state.

Response rate

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Incentives

Participants of the AusDiab survey received a results letter containing brief comments relating to their physical measurements collected on the testing day. The letter also reported

the participants' category of risk for these measurements, according to internationally accepted classification standards.

Timeframes

The original AusDiab study took place in May 1999–December 2000. The AusDiab Follow-up Study began in June 2004 with current data collection continuing into 2005. A ten-year follow-up is being considered.

Methods and data collection

The baseline study included a short interview conducted by survey staff, covering basic questions related to age, sex, country of birth, occupation and some health-related questions. After the interview, a visit to the local survey centre for a health check and clinical testing was arranged. Participants were required to complete a General Health & Well Being Questionnaire to be returned at their health check. Participants completed a further four short questionnaires on medical history, diet, physical activity and health service utilisation at their initial health check.

The AusDiab Follow-up Study will be essentially a repeat of the baseline study, and will include an interview covering demographics, anthropometrics (e.g. measurements of height, weight, waist & hip circumference), blood pressure, blood and urine testing (for diabetes, lipids and renal function), clinical testing for diabetes complications (e.g. neuropathy and retinopathy, including a retinal photograph), self-reported disease status, diet, physical activity and health service utilisation.

Data analysis

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Results

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Outputs

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Related studies

The Australian Diabetes, Obesity and Lifestyle Study.

References

International Diabetes Institute 2000. Australian Diabetes, Obesity and Lifestyle Study (AusDiab). Caulfield: International Diabetes Institute. Viewed 19 August 2004, <www.diabetes.com.au/research/ausdiab.htm>.

Appendix V Australian Temperament Project

Study aims

ATP is a longitudinal study of the psychosocial development of a large and representative sample of Australian children born in Victoria between September 1982 and January 1983. The study aims to trace the pathways to psychosocial adjustment and maladjustment across the lifespan, and to investigate the contribution of personal, familial and environmental factors to development and wellbeing.

The study addresses issues including temperament, behavioural and school adjustment, academic progress, substance use, antisocial behaviour, depression, health, social competence, civic mindedness and engagement, peer and family relationships, family functioning, parenting style and family sociodemographic background and environment.

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Location of research

Australia, Victoria, Melbourne

Investigators

The project began in 1983 as an interdisciplinary collaboration between researchers from the fields of Paediatrics and Psychology, namely Frank Oberklaid, Margot Prior and Ann Sanson. Diana Smart joined the research team in 1988 and is now the Project Manager. As the children entered the teenage years, John Toumbourou joined the team. As the cohort neared

adulthood early in 2000, the AIFS became a major collaborator in the project, and is now housing the project and taking the leading role in it. The AIFS is in collaboration with researchers from the University of Melbourne and the Royal Children's Hospital in developing the project.

Investigators currently include Associate Professor Ann Sanson (Acting Director, AIFS), Mrs Diana Smart (Research Fellow, AIFS), Associate Professor John Toumbourou (Centre for Adolescent Health, Royal Children's Hospital), Professor Margot Prior (Departments of Psychology and Paediatrics, University of Melbourne), and Professor Frank Oberklaid (paediatrician and Director of the University of Melbourne's Centre for Community Child Health, located at the Royal Children's Hospital).

See <www.aifs.gov.au/atp/investigators.html> for more information on the investigators.

Content

The broad issues addressed include:

1. the contribution of temperament to a child's emotional, behavioural and school adjustment;
2. the impact of family and environmental factors, together with child characteristics, on emotional and behavioural adjustment;
3. the factors and processes involved in the progression of childhood behaviour problems (e.g. aggression, hyperactivity, anxiety) to adolescent and adult adjustment difficulties (e.g. antisocial behaviour, substance use, depression);
4. genetic influences on temperament and behaviour;
5. the development of healthy, socially competent functioning;
6. the development of civic-mindedness and social responsibility; and
7. the transition to young adulthood: pathways to occupational and educational participation, the development of interpersonal relationships, and family formation.

The thirteenth survey wave of 20-year-old young adults and their parents focused on aspects of the young people's lives, including their living arrangements; educational, occupational and financial circumstances; relationships with parents, friends and romantic partners; parenthood and aspirations for parenthood; social skills and life satisfaction; civic engagement and religious commitment; health; temperament style; experience of anxiety, depression and stress; and engagement in antisocial behaviour, substance use and other risk taking behaviours.

Also see Related studies below.

Funding agencies/budget

The project is presently funded by the AIFS, but has received support from NHMRC and ARC grants as well as the Murdoch Foundation of the Royal Children's Hospital.

Data availability

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Sampling (cohorts/sample size)

The cohort includes Australian children born in the state of Victoria between September 1982 and January 1983. The initial sample comprised 2,443 families (2,443 infants aged 4–8 months and their parents) from urban and rural areas of the state. Participants have been followed into adulthood.

Response rate

Approximately two-thirds of the families are still participating in the study after 21 years.

Incentives

Reminder letters and phone calls during data collections and annual newsletters were used to keep participants informed of current findings and future initiatives and to maintain engagement.

Timeframes

The ATP began in 1983. The first four waves of data were collected at annual intervals from infancy to three to four years of age. Subsequent data collections have been at biennial intervals, with an additional assessment completed during the first year of secondary school.

The thirteenth survey wave of 20-year-old young adults and their parents was completed in 2002. The fourteenth survey wave is planned to take place when participants are in their mid-twenties.

Methods and data collection

Thirteen waves of data have been collected by mail surveys from 4–8 months of age to 19–20 years of age. The first four waves of data were collected at annual intervals from infancy to three to four years of age. Subsequent data collections, dating from the commencement of primary school, have been at two-yearly intervals, with an additional assessment completed during the first year of secondary school in order to track development over this important developmental transition. Age-appropriate measures have been used.

Parents, Maternal and Child Health nurses, primary school teachers, and from the age of 11 years, the children themselves, have completed questionnaires about the young people's development and wellbeing. There have also been a number of smaller, in-depth studies addressing specific developmental and clinical themes in which sub-samples of families have been visited at home and the children individually assessed. For example, in recent years, the project has collected DNA from many participants.

Data analysis

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Results

Information on various web pages (e.g. media releases, sub-studies). Also see Outputs and Related studies below.

Outputs

Over 70 publications have risen from the study. Findings from the study have been published in numerous papers in the national and international scientific literature. For a list of publications see <www.aifs.gov.au/atp/pubs.html>.

A book designed to give an accessible, non-technical overview of the study, its methods and findings may be purchased from the AIFS – Prior M, Sanson A, Smart D & Oberklaid F 2000. Pathways from infancy to adolescence: Australian Temperament Project 1983-2000.

Analyses of the data collected in the thirteenth survey wave of 20-year-old young adults and their parents have commenced and a report on the trends emerging will be completed in 2004. One aspect investigated – social skills at 20 years of age – was reported in *Social Competence in Young Adulthood, its Nature and Antecedents* (Smart & Sanson 2003).

A collaborative project with Crime Prevention Victoria, exploring a range of issues about adolescent antisocial behaviour, has produced two reports with a third report due for completion in 2004. The executive summaries and complete versions of the first two reports can be accessed on the ATP web site and Crime Prevention Victoria's site. Also see Related studies below.

A collaboration with the Transport Accident Commission of Victoria and the Royal Automobile Club of Victoria is nearing completion. The collaboration aims to investigate patterns and antecedents of differing driving behaviours among young novice drivers. The research team is currently preparing a report on learner driver experiences and current driving behaviours (e.g. time spent on the road, driving patterns, risky driving, involvement in accidents and speeding), which will be released in 2004.

Related studies

There have been a number of smaller, in-depth studies addressing specific developmental and clinical themes in which sub-samples of families have been visited at home and the children individually assessed. These include: connections between behaviour problems and learning difficulties; the impact of a chronic health condition on adjustment and wellbeing; temperamental and family influences on adjustment and maladjustment; negotiation of the transition to adolescence; risk and resilience for adolescent antisocial behaviour, substance use and depression; and genetic influences of development.

The collaborative project with Crime Prevention Victoria, exploring a range of issues about adolescent antisocial behaviour, has produced two reports with a third report due for completion in 2004:

1. The First Report describes the across-time patterns of antisocial behaviour from 13–18 years, and investigated risk factors for persistent and experimental antisocial behaviour.
2. The Second Report investigates four distinct issues: antecedents of violent and non-violent antisocial behaviour; resilience from the development of antisocial behaviour among at-risk children; connections between local area characteristics and antisocial behaviour; and patterns of antisocial behaviour at 19–20 years.
3. The Third Report will address six separate themes: connections between adolescent substance use and antisocial behaviour; pathways to persistent antisocial behaviour among low-risk children; a comparison of official records and self-report; the transition to adulthood and its impact on antisocial behaviour; rates of and risks for victimisation in young adulthood; and civic-mindedness and perceptions of the fairness of the justice system among young adults.

See <www.rch.org.au/cah/research/index.cfm?doc_id=1079> for information on *Longitudinal Pathways to Adolescent Antisocial Behaviour, Substance Use and Anxiety/Depression* – a sub-study conducted by the Royal Children’s Hospital Centre for Adolescent Health and the University of Melbourne’s Department of Psychology.

See <www.genomenewsnetwork.org/articles/10_00/Anxiety_serotonin_gene.shtml> for information on *Anxiety from Infancy to Adolescence: Polymorphisms in the Serotonin Transporter Gene and Temperament in Children* – a sub-study conducted by researchers at the ANU and the Australian Temperament Project team.

A new sub-study is planned to commence in 2004. This ongoing study will focus on the circumstances and experiences of the young people in the study who have, and will in the future, become parents. Their parents’ grand-parenting experiences will also be studied.

Several other smaller sub-studies are planned for 2004. These will explore the range of life styles and activities of young men and women; the way they handle social situations; and their views about relationships with boyfriends/girlfriends.

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Appendix W Growing Up in Australia

Study aims

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. It will further understanding of early childhood development and wellbeing, inform social and family policy debate, and be used to identify opportunities for early intervention and prevention strategies in policy areas concerning children. The study has a broad, multi-disciplinary base and will explore a range of individual, family, social and environmental factors relevant to children's development, and will address research questions about family functioning, health, non-parental child care and education.

Among the many issues which will be able to be addressed with the data set, 14 key research questions have been identified:

1. What are the impacts of family relationships, composition and dynamics on child outcomes, and how do these change over time?
2. What can be detected of the impacts and influences of fathers on their children?
3. How are child outcomes affected by the characteristics of their parents' labour force participation, their educational attainment and family economic status, and how do these change over time?
4. Do beliefs and expectations of children (parental, personal and community, in particular the parents' and child's expectations of the child's school success, workforce participation, family formation and parenting) impact on child outcomes, and how do these change over time?
5. How important are broad neighbourhood characteristics for child outcomes? Does their importance vary across childhood? How do family circumstances interact with neighbourhood characteristics to affect child outcomes?
6. How important are family and child social connections to child outcomes? How do these connections change over time and according to the child's age? Does their importance vary across childhood?
7. What is the impact over time of early experience on health, including conditions affecting the child's physical development?
8. What is the impact on other aspects of health and other child outcomes of poor mental health, including infant mental health and early conduct disorder? How does the picture change over time?
9. How do socioeconomic and sociocultural factors contribute over time to child health outcomes?
10. What are the patterns of children's use of their time (e.g. outdoor activities, unstructured play, watching television, reading) and how do these relate to child outcomes, including family attachment, physical fitness level and obesity, social skills and effectiveness over time?

11. What is the impact of non-parental child care on the child's developmental outcomes over time, particularly those relating to social and cognitive competence, impulse control, control of attention and concentration, and emotional attachment between child and family?
12. What early experiences support children's emerging literacy and numeracy?
13. What factors over the span of the early childhood period ensure a positive 'fit' between child and school and promote a good start in learning literacy and numeracy skills in the first years of primary education?
14. What are the interactions among factors in family functioning, health, non-parental care and education that affect child outcomes?

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Location of research

Australia, Victoria, Melbourne

Investigators

Growing Up in Australia is being designed and implemented by a large consortium led by the AIFS. The consortium brings together significant research and management expertise. It includes researchers from a wide range of disciplines, including child development, sociology, epidemiology, public health, family studies, psychology, paediatrics and child health, early childhood education, services and social policy research, and economics. This breadth of expertise ensures comprehensive coverage of influences on child development.

A small project team in the Longitudinal Data Section, Strategic Policy and Analysis Branch, at FaCS is managing the project on behalf of the Australian Government. State and territory

governments and the community and research sectors are represented on an advisory Steering Committee.

Consortium members

The consortium involves nine leading research organisations with expertise in child development. Consortium members are all associated with the Australian Research Alliance for Children and Youth, and include the AIFS (lead agency); ACER; the Telethon Institute for Child Health Research; Queensland University of Technology; Macquarie University; Charles Sturt University; Murdoch Children's Research Institute; the National Centre for Epidemiology and Population Health and CMHR at the ANU; and the Social Policy Research Centre at the University of NSW.

Project Operations Team

Day-to-day management of the study is undertaken by a Project Operations Team, including the Project Director (Associate Professor Ann Sanson, Acting Director, AIFS), a Project Manager (Carol Soloff), a Design Manager, Survey Officer, Data Manager and other research staff.

Consortium Advisory Group

The Project Operations Team is supported by a Consortium Advisory Group which includes members of each of the Consortium partners. The Consortium Advisory Group is chaired by Professor Steve Zubrick. See <www.aifs.gov.au/growingup/consortium.html> for a list of members.

Scientific Policy and Advisory Group

An additional advisory group, the Scientific Policy and Advisory Group, provides high-level strategic, scientific and policy input. It consists of national and international experts in all the aspects of child development covered by the study as well as longitudinal research methodology and policy research. See <www.aifs.gov.au/growingup/consortium.html> for Australian and overseas members.

Design teams

The study covers four broad research domains: health, education, non-parental child care and family functioning, and also taps sociodemographic factors. Five design teams have been formed around these research domains. Each team comprises members from the Consortium Advisory Group as well as others who have expertise in the area. Consultants have also been assigned to complement the composition in each of the teams. The design process is managed by the Project Operations Team at the AIFS. See <www.aifs.gov.au/growingup/consortium.html> for members of each design team.

Content

Growing Up in Australia is collecting data on a range of factors influencing children's developmental outcomes at each data collection point. These factors relate to the child (e.g. health, temperament and literacy experiences), the child's parents (e.g. socioeconomic status, parenting style and health), and the environment (e.g. neighbourhood resources, child care provider and school).

In addition to collecting data on a broad range of child outcomes, data are being collected relevant to the five research domains referred to above. The five research domains are outlined briefly below.

Family functioning

This domain includes such factors as family relationships, family composition, family size, extended family involvement, parental relationships (including non-resident parents), parenting practices, the experience of poverty, the effect of workforce participation on family life, and the connectedness of families to wider social networks and community resources.

Education

The education domain includes child (pre)literacy and (pre)numeracy, communication between children and their parents and teachers, exposure to home literacy resources, child participation in out-of-home early education programs, the characteristics of (pre)schools, child's skills and abilities, and an assessment of development provided by the child's teacher/carer.

Health

The health area includes gestation and birth, nutrition, immunisation, the experience of chronic illness or injury, parental health (including mental health), child mental health problems, and physical activity and fitness.

Non-parental child care

Non-parental child care includes type of child care (including home-based and centre-based), availability and access, current usage, past arrangements, affordability, age at entry, quality of care (including child-staff ratios, group sizes, etc.), accreditation, parental satisfaction, reasons for use, the carer-child relationship and family involvement in the program.

Sociodemographic measures

Sociodemographic information collected includes details on household members, family structure, parents' work status, parents' income, parents' education, ethnic and religious background, housing characteristics and neighbourhood profile.

Funding agencies/budget

The Australian Government provided \$20.2 million for four waves of data collection at the start of the project in 2000–2001, as part of the Stronger Families and Communities Strategy. The study is currently funded until 2010, though continued funding will be sought after this point.

Data availability

Growing Up in Australia will provide a 'public good' data resource for Australian governments, researchers, service providers, parents and communities to draw on. The first wave of data collection is occurring in 2004, with data to be publicly released in April 2005. Data will be warehoused at the AIFS and will be widely available for research purposes.

A third discussion paper that outlines data management issues, including recommendations on file structure, data security, data access and data release, and confidentialising of data is available at <www.aifs.gov.au/growingup/pubs/dp3/dp3.html>.

Sampling (cohorts/sample size)

Data will be collected from two cohorts every two years. The first cohort includes 5,000 children born between March 2003–February 2004 (aged 4–13 months in 2004), and the second cohort includes 5,000 children born between March 1999–February 2000 (aged between four years four months and five years one month in 2004). The samples of children and their families from a large number of postcodes across Australia are selected from HICs Medicare database. HIC sends letters to selected families with children of the right age, inviting them to take part in the study. Families can opt out by phone or mail.

Response rate

The sample size will be reduced by attrition—less than 15% attrition between each wave is expected. However, current response rates in Wave 1 have been slightly lower than expected. About 15% of families are choosing to opt out after receiving the HIC letter, and a further 2% of letters are 'returned to sender'. The opt out rate is slightly higher than that found in the dress rehearsal in 2003.

Contact details for the remaining families are then passed to I-view, the data collection agency, and a further letter is sent indicating when an interviewer will be calling. About 3–4% of families chose to withdraw from the study at this stage.

Once the interviewers are able to make contact, they are achieving good response rates (over 80% of selected families with whom contact is made agree to an interview), but about 12% of families are still being lost at this stage. In addition, quite a number of contact details are turning out to be out of date (around 15% on average).

Hence the final response rate is likely to be around 53% of those initially sent a letter by HIC. Efforts are being made to improve the response rate by:

1. checking the Medicare database for updated addresses for the 'return to senders' and other families whom interviewers identify as having moved. New addresses were located for about 25% of families in these situations;
2. organising another round of publicity via media releases to local papers and other media; and
3. active refusal follow-up by more experienced interviewers and supervisors (though interviewer refusal rates are improving).

In addition, the recruitment rate for families in the four-year-old cohort is lower than for the infants. Allowance was made for a lower rate of recruitment in the sample design, but even this rate has not been achieved (the design allowed for 56% recruitment rate for infants and 53% for four-year-olds. The infant recruitment is on target but the current rate for four-year-olds is about 51%).

As a result, HIC has been asked to select additional families in Phases 3 and 4 to ensure final numbers of about 5,000 in each cohort are obtained.

Incentives

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Timeframes

Wave 1: March 2004–August 2004, Wave 2: March 2006–September 2006; Wave 3: March 2008–September 2008, Wave 4: March 2010– September 2010. A dress rehearsal was conducted between August and October 2003.

Data will be collected from two cohorts every two years. The first cohort of children aged less than 12 months in 2004 will be followed until they reach six to seven years of age in 2010, and the second cohort of four-year-olds in 2004 will be followed to 10–11 years of age. With continued funding, there is potential for data collection to continue until the children in the survey are older, even into adulthood.

Methods and data collection

Cross-sequential cohort design. Stage 1 of the study involved a full study development program, including identification of data items, pre-tests, and a dress rehearsal in late 2003.

Letters of invitation to participate were sent out by HIC in four phases (late-January, early-March, mid-April and late-May), with each phase followed by a four-week opt out period. Interviewing will also occur in four fieldwork periods (mid-March, late-April, late-May and mid-July). There is some variation as to when each fieldwork period starts and finishes, to fit in with school holidays in various states and territories.

Data is collected by biennial face-to-face interviews in the child's home, and through one additional mail-out survey between Waves 1 and 2 (mainly as a sample maintenance tool).

Multiple informants will provide comprehensive information on the child and their environment. The informants for Wave 1 will include:

- the primary care-giving parent (Parent 1, usually the mother);

- other resident parent or step parent (Parent 2);
- child care providers;
- pre-school or school teachers;
- the child her/himself once they have reached an appropriate age (physical markers and direct assessment tasks); and
- some interviewer observation of the external environment.

The mail-out survey between Waves 1 and 2 will involve updates on the child's progress and changes to their family and child care/schooling arrangements. As part of this mail-out, negotiations are underway for the infant cohort to be sent additional questions on work and family, as part of a study being conducted by Dr Gillian Whitehouse of the University of Queensland.

An Australian version of the Canadian Early Development Index is being developed. The index measures readiness to learn at school in five domains (physical health and wellbeing, social competence, emotional maturity, language and cognitive development, and communications skills and general knowledge). This teacher-completed checklist will be validated by including it as part of the mail-out to the teachers of children recruited in three states in Waves 3 and 4, with approximately 1,000 returns expected.

Data analysis

Growing Up in Australia will provide a 'public good' data resource for Australian governments, researchers, service providers, parents and communities to draw on.

A third discussion paper that outlines data management issues, including recommendations on file structure, data security, data access and data release, and confidentialising of data are available at <www.aifs.gov.au/growingup/pubs/dp3/dp3.html>.

Results

A dress rehearsal conducted between August and October 2003 comprising 500 participants from Victoria, NSW and Queensland has shown:

- 96% of parents rated their child's health as being good, very good or excellent;
- 96% of four-year-olds are read to by someone in their family at least once a week, with 59% reporting that this happened daily;
- 89% of parents of four-year-olds who have educational or child care arrangements for their child reported satisfaction with these arrangements;
- 82% of parents rated their neighbourhood as either a good or very good place to raise children; and
- 59% of four-year-olds spend time with their grandparents weekly or more frequently.

Outputs

Links to newsletters, discussion papers, conference papers, journal articles and brochures, flyers and posters, are available at <www.aifs.gov.au/growingup/pubs.html>. The

discussion papers introduce and provide an overview of the study, concentrate on proposed study design and Wave 1 data collection, and discuss data management issues.

A Policy Analysis Report and Outcome Index using Growing Up in Australia data to address key policy issues will accompany the data release in April. This report will be a 40–50 page document containing simple analysis including graphs, tables and descriptive text and organised into key themes of direct relevance to policy makers.

This publication will feature an ‘outcome index’ which is being developed as a single composite measure of a child’s development at a particular time. This index will provide a means of summarising the complex information from the study for policy-makers, the media and the general public, as well as potential data users. Information on the structure of this index will be available later in the year.

Related studies

National Longitudinal Survey of Children and Youth (Canada) and the Millennium Cohort Study (UK).

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Appendix X Longitudinal Surveys of Australian Youth

Study aims

One of the major policy thrusts of Australian governments in recent years has been the creation of flexible pathways between education, training and paid employment. Understanding the transitions made by young people from school into further education and training, the labour force and adulthood, is greatly facilitated by longitudinal surveys of cohorts of young people such as the LSAY. This collection of data sets also permits the monitoring of educational outcomes and some trends in the Australian education system.

The LSAY project includes a series of data sets collected in Australia since the 1970s:

1. The Youth in Transition study conducted by ACER involved four cohorts of adolescents born in 1961, 1965, 1970 and 1975, contacted initially in school at 17, 16, 15 and 14 years of age respectively, and then by mail. The cross-lagged design allowed analysis of changing patterns of participation in education and the labour force, and transitions between education and work.
2. The Australian Youth Survey and its predecessor, the Australian Longitudinal Survey, were conducted by DEST, but the data are now held at ACER and the ASSDA. They involved nationally representative multiple-aged samples of young people aged 16–19, augmented by the addition of four new groups of 16-year-olds at annual intervals. The focus of research is on the causes and consequences of educational participation among different groups in the Australian population, and how these patterns have changed over time.
3. In 1995, the Youth in Transition study and the Australian Youth Survey were subsumed in a new study, the Longitudinal Surveys of Australian Youth, which introduced new cohorts with larger samples and with a broader research focus. However, the Australian Youth Survey continued data collection until 1997, and the Youth in Transition study collected a final wave of data from the 1975 cohort in 2002.

Unless otherwise specified, this document will focus on active data collection as part of the Longitudinal Surveys of Australian Youth.

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[<www.acer.edu.au/research/LSAY/overview.html>](http://www.acer.edu.au/research/LSAY/overview.html)

Location of research

Australia

Investigators

The LSAY research program is managed jointly by ACER and DEST.

Staff and committee

The LSAY program operates with a Steering Committee that advises on overall policy and the annual research program. The Committee has members representing national authorities concerned with education, training and employment in Australia, as well as academic experts. The LSAY Management Group, comprising representatives from ACER and DEST, oversees regular operations of the project.

LSAY Steering Committee

Ms Liz Tehacos, DEST (chair)

Mr Abdul Fattah, Department of Employment and Workplace Relations

Ms Renata Rustowski, Department of Family and Community Services

Ms Judy Hebblethwaite, Department of Education, Tasmania

Dr Sue Foster, Office of Employment, Training and Tertiary Education, Victoria

Ms Caroline Miller, National Council of Independent Schools' Associations

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Ms Julie Zubrinich

Further information and contact details are available from the ACER staff information page.

Content

Issues investigated in the LSAY project include school achievement and school completion, participation in vocational and university education, gaining and maintaining employment, and household and family formation. More detailed investigations look at the links between sociodemographic characteristics, education and training, and employment. Data include reading and numeracy test results, adolescent self-reports, and school-based information about curricula, school climate and school organisation.

Main topics covered: transition from school to work; education and training; employment and labour markets; income; health and wellbeing; household and family formation; housing; living conditions; young people.

Other topics covered: attitudes and aspirations.

Funding agencies/budget

Active data collection is funded by the DEST, and state and territory governments. Current data collection and analysis program contracts continue through to the end of 2005.

The Youth in Transition study and the Australian Youth Survey were previously funded by ACER and DEST, respectively.

Data availability

The data are available to researchers through the ASSDA at the ANU. DEST periodically commissions research using the LSAY data sets. Interested researchers can respond to DEST calls for research submissions to gain funding to use this data, or apply to ACER with ad hoc requests to use the data.

Sampling (cohorts/sample size)

Nationally representative cohorts of school children. The sizes of the samples from each study range between approximately 5,000 and 14,000 students. The oldest group in the project comprised people born in 1961. Sample selection procedures vary, but generally

students are sampled by age or year level in school from student records. Young people are followed until about age 25.

The three active cohorts included 13,613 Year 9 students (modal age 14 years) in 1995, 14,117 Year 9 students (modal age 14 years) in 1998, and 10,447 students aged 15 years in 2003. The 2003 cohort comprises students who also participated in Organization for Economic Cooperation and Development Programme (OECD) for International Student Assessment (PISA), an international study of student achievement in more than 40 countries.

Response rate

Response rates vary by individual data set. Response rates for active 1995, 1998 and 2003 cohorts are below.

Response rate for active 1995, 1998 and 2003 cohorts

Year	1995 Cohort	1998 Cohort	2003 Cohort
1995	13,613		
1996	9,837		
1997	10,307		
1998	9,738	14,117	
1999	8,783	9,289	
2000	7,889	9,584	
2001	6,876	8,777	
2002	6,095	7,762	
2003	5,354	6,905	10,447

Incentives

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Timeframes

1975–present. Some of the data sets included in LSAY are ASSP 1975, ASSP 1980, YIT 1989, LSAY 1995, LSAY 1998 and LSAY 2003 (based on PISA 2003). Data are released annually.

Wave 1 of data collection for the three active cohorts (LSAY 1995, LSAY 1998, and LSAY 2003) occurred in September 1995–December 1995, September 1998–December 1998, and September 2003–December 2003. Data will be collected annually until 2005 or 2006, 2008 or 2009, and 2013, respectively.

Methods and data collection

Cross-lagged cohorts. Using annual telephone interviews, the LSAY project studies the progress of several cross-lagged groups of young Australians as they move from school into post-secondary education and work. Data include reading and numeracy test results,

adolescent self-reports, and school-based information about curricula, school climate and school organisation.

Annual surveys provide information on what young Australians are doing and how they manage the many transitions they make after school. By incorporating data from older longitudinal studies within the LSAY program, it is possible to compare the current cohorts' pathways and outcomes to older cohorts' when they were the same age.

Data analysis

In LSAY publications.

Results

The LSAY web site provides links to LSAY research reports, cohort reports, technical reports and briefing papers.

Outputs

37 research reports, by ACER researchers and DEST analysis grant recipients, have been published as at March 2004. These are available for downloading from the LSAY Research Reports page at <www.acer.edu.au/research/LSAY/research.html>. The LSAY web site also provides links to LSAY cohort reports, technical reports and briefing papers.

Related studies

Youth In Transition study, Australian Youth Survey, and the Australian Longitudinal Survey (part of the LSAY project). The initial LSAY 2003 cohort was drawn from OCED PISA.

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