women's health australia

The Australian Longitudinal Study on Women's Health

The First Decade

Background

In 1996 over 40,000 Australian women were invited take part in a long term project which would survey the health of women across the nation, over time. The participants were selected in three age cohorts: younger women aged 18-23, mid-age women aged 45-50, and older women aged 70-75. These groups were deliberately chosen in order to recruit women before they passed through major turning points in women's lives.

The participants remain the same for the duration of the study - intended to be at least 20 years. Women in each age group complete a comprehensive survey on their health every three years, enabling comparisons over time and between age groups.

To date, three surveys have been undertaken and analysed and a fourth is in progress. The results have established the Australian Longitudinal Study on Women's Health (ALSWH, also known as Women's Health Australia) as a valuable national and international research resource providing evidence-based information on women's health issues.

The study is funded by the Australian Government Department of Health and Ageing. Until now, availability of the ALSWH results has been limited to the Department of Health and Ageing, other federal and state government agencies, the Office for Women and relevant non-government organisations such as State Cancer Councils and the National Rural Health Network. The study has given a more solid information base for policy and practice in many areas of health services for Australian women.

With eight years of change now tracked in the surveys, the study is providing insights into major trends in the lives of Australian women.

Did you know?

The project provides the most comprehensive information ever collected on the health and well-being of Australian women.

The combination of a longitudinal design, with comparative data across three age groups, and access to information on health service use, makes the project a world first.

The project has the lowest cost per participant of any current major survey in Australia, or in other comparable countries.

The Survey

The survey covers the main issues that affect the health of women in contemporary Australian society. Questions are chosen to reflect National Health Priorities and social and policy concerns, as well as to add to knowledge of women's well-being throughout the lifespan. The survey takes a comprehensive view of health throughout life, encompassing:

- Physical health
  (including health-related quality of life, diseases, conditions, symptoms)
- Emotional health
  (including depression and anxiety, psychotropic medications, stress, positive well-being)
- Use of health services (GPs, specialists)
- Ease of access to health services, and satisfaction with services
- Health behaviours and risk factors
  (such as nutrition, physical activity, smoking, alcohol, other drugs)
- Gynaecological health (including contraception, fertility problems, menopause)
- Time Use
  (including paid and unpaid work, family roles, leisure)
- Socio-demographic factors
  (including education, employment, household composition)
- Life stages and key events
  (such as childbirth, divorce, widowhood)

Standard validated questions from both Australian and overseas sources, such as the Australian Census and National Health Survey, are used in the surveys. This allows findings to be compared directly with information from other studies, which is a major strength of the project. The research team has also at times had to develop specific survey items when there were no suitable existing questions, thus contributing further to the international research literature.

Data Linkage

The women who participate in the project were recruited from the name and address database of the Australian Health Insurance Commission (Medicare). This allows routinely collected data on health care services (including Medicare, Pharmaceutical Benefits Scheme records and Department of Veterans' Affairs entitlements) to be linked with the survey data.

The combination of administrative records with self-reports of health and personal circumstances means the study can provide a unique richness of information on factors underlying patterns of health service use.

Linkage to the National Death Index provides information on dates and causes of death which is increasingly valuable as the study progresses.

Sampling

Over 70% of Australian women live in major coastal cities, but rural health is an important policy issue. The project was designed to ensure adequate inclusion of women living in rural and remote areas, by intentional over-sampling of women living in these areas.

Timelines

After Survey 1 of all three cohorts in 1996, the survey is operating on a three-year cycle (see Figure 1). Each year, one cohort receives a survey, while at the same time the survey for the following year is developed and piloted and the responses from the previous year are scanned, cleaned and checked for analysis.

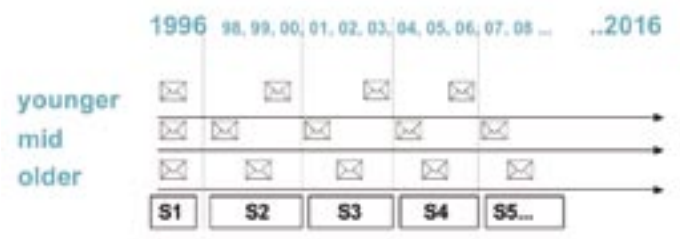

Figure 1. Project Timeline

Three Generations

When the younger women were recruited in 1996 they were aged 18 to 23. The majority of these women were single and still living with one or both parents. The study tracks changes in the health of these women as they make the transitions of early adulthood to independent living, adult relationships, work and motherhood.

The mid-age women were initially aged between 45 and 50. As well as passing through menopause, they are now experiencing changes in household structure, family caregiving and planning for retirement. Some women are showing early signs of age-related physical decline of later life, while others are adopting new health behaviours in preparation for a healthy old age.

The older women were aged between 70 and 75 years when first recruited. They were generally still in good health and able to manage independently. The information they are contributing provides an opportunity to examine predictors of continued healthy and independent living, and conversely to assess factors which lead to disability, dependence and the physical, emotional and social challenges of old age.

Comparisons between the three age cohorts reflect not only the changes associated with ageing, but also the very different life circumstances of three generations of Australian women.

"I think this is very worthwhile. 3 generations of women in my family (me, my mum and her mum) were all selected in the process at the start - what a coincidence, hey! After 16 years you guys will seem like old friends."

Staying Involved

The longitudinal design of the study means that the health and lifestyle changes of the same women are documented as they move through major life transitions (such as moving into or out of the workforce, or becoming mothers), change their lifestyles (giving up smoking, cutting back on drinking), or go through physical changes (such as menopause, or developing arthritis). It is vital to the success of the study that the women who were initially selected in 1996 remain involved, and that up-to-date contact details for them are maintained.

Some strategies to ensure that participants are retained include:

- Annual newsletters to thank participants and inform them of study findings
- An up-to-date website with pages specifically designed for participants
- Requests for contact details of family members or others who will know where the participants are if they have moved
- Postal reminders and follow up telephone calls to those who do not respond
- A Freecall number to encourage telephone contact
- Rapid follow-up of returned mail through the White Pages and online electoral rolls
- Use of the National Death Index to identify women who have died between surveys.

By international standards, maintenance of the cohorts has been very successful (see Figure 2).

The mid-age cohort has the highest retention rate, with 90% of participants responding at Survey 2 and 83% at Survey 3.

The younger cohort of women are considerably more difficult to track, and the retention rate is much lower with 68% at Survey 2 and 64% at Survey 3. This reflects aspects of their lifestyle such as higher mobility, living in shared housing, travelling overseas or within Australia, and name changes on marriage.

> *"Thanks must go to you guys who have tracked me down three times now despite my moving about. It's a strangely satisfying feeling to know that I am part of something bigger than me and my world. Also that has lasted longer than any project, job, study or relationship of mine. Keep finding me."*
>
> - Younger woman, Survey 3.

The retention rate amongst the women in the older age group reflects their advancing age as there has been a significant death rate. Excluding these women, the retention rate for this age group was 88% at Survey 2 and 79% at Survey 3.

Younger 18-23 in 1996	N=14,247 at S1 68% retention at S2 64% retention at S3
Mid 45-50 in 1996	N=13,716 at S1 90% retention at S2 83% retention at S3
Older 70-75 in 1996	N=12,432 at S1 88% retention at S2 79% retention at S3

Figure 2. Age Cohorts

Substudies

Some topics have been researched in greater depth by conducting smaller studies. A number of participants have been invited to complete an additional survey on a specific topic.

Substudies have been undertaken in a variety of ways. They have involved mailed surveys, focus groups, telephone surveys and most recently, palm pilots (hand held digital computers). Substudy topics have included:

- Urinary incontinence
- Weight, nutrition, physical activity and well-being
- The effects of family caregiving on women's health and well-being
- Women's understanding of mental health and preferred treatments.
- The aspirations of younger women for work and family
- Weight gain at menopause
- Time use
- Smoking uptake in younger women
- Falls among older women
- Cardiovascular disease
- Domestic violence
- Sleeping difficulties and sleeping medication use
- Diabetes

Dissemination

Findings of the research are provided to the Department of Health and Ageing, and by arrangement to other Federal and State Departments and Offices such as the Office for Women.

Findings are presented at conferences and workshops for academics, professionals and policy-makers, both in Australia and overseas. They are also published in national and international scientific journals.

Policy Issues

The ability to explore changes in individual women's lives has enabled the provision of important information and recommendations.

- Younger women are gaining weight rapidly, and the health problems associated with being overweight will start to appear much earlier than in previous generations, especially in rural areas.
- Being in a violent relationship has adverse effects on younger women's reproductive health. For example, there is greater risk of unplanned pregnancy or miscarriage.
- Younger women, particularly in the cities, want to combine motherhood with paid work. The challenge is to create situations to allow them to manage this.
- Poor mental health is associated with higher use of all drugs. While sorting out the order of causation requires more longitudinal data, recognition of the strong link should be taken into account in public health action.
- The high rate of relationship breakdown among mid-age women suggests that around a quarter will reach retirement age without partners. The implications of this for finances and lifestyle in older age have important policy implications.
- Many rural women have no access to female medical staff, or to bulk billing doctors, and this may reduce their willingness to seek help for potentially treatable conditions.
- Data collected over six years from a large sample of older women show there is no evidence to support different guidelines for alcohol consumption for older women.
- Hypertension and arthritis are the most common conditions affecting older women. While not life-threatening, stiff and painful joints cause most disability. Prevention and management of bone and joint problems should be regarded as a high priority for public health. Importantly, women should be encouraged to maintain safe and appropriate levels of physical activity.
- Widowhood is associated with poor health and high health service use in the first year or so, after which the health of widowed women becomes comparable with that of other women.
- Although there are relatively fewer providers of specialist care in rural areas, this does not translate into increased patient fees.

"

Thank you for allowing me to take part. I do appreciate the opportunity the survey gives to help all women receive the very best of medical care. You are I believe fulfilling a much needed service for Australian women's health and wellbeing.

"

- Younger woman, Survey 3.

Ensuring Privacy

All staff and collaborators on the Australian Longitudinal Study on Women's Health are bound by confidentiality agreements. The project abides by the requirements of the National Health and Medical Research Council and the Privacy Act. Access to Medicare records is done under strict control and personally identifying information regarding participants and service providers is not made available.

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Find out more

The Australian Longitudinal Study on Women's Health is funded by the Australian Government Department of Health and Ageing and is conducted by a team of researchers at the University of Newcastle and the University of Queensland.

Information, including surveys and details of scientific publications, may be found at the project website:
http://www.newcastle.edu.au/centre/wha

or by calling the research team at:

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