Cohort Profile: The Australian Longitudinal Study on Women’s Health

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How did the study come about?
The Australian Longitudinal Study on Women’s Health (ALSWH), also known as Women’s Health Australia, has its history in the women’s movement of the 1980s. At that time, activists successfully pressured governments in Australia, at both the State and Federal levels, to develop women’s health policies. Part of the development process of the National Women’s Health Policy, which was launched in 1989, involved a national consultation with women’s organizations representing more than a million women.1 From this consultation the idea of a national longitudinal study on women’s health emerged. As with the National Policy generally, the longitudinal study was to be premised on a social rather than a narrowly focused medical approach to health. The study was envisaged as a strategy to enable women to gain greater power over shaping the nature of health care. This was given impetus by studies at the time showing that it was not major medical conditions that were of most concern to most women. Studies asking women to rate their main health concerns found these concerns to be tiredness, menstrual difficulties, overweight, depression, and anxiety.2,3

In the early 1990s the Labor government called for submissions for a study of the type recommended by the women’s health movement. It was to focus on women’s health and well-being across the life course, in keeping with a broad social view of health. In 1995 a contract was signed for the ALSWH. The project is now in its 10th year and is planned to continue for at least another 10 years. The research design involves the longitudinal study of three age cohorts, mainly using mailed surveys. Despite political and social changes, the Australian government has continued to fund the ALSWH, mostly with three-year contracts, each following rigorous review and reconsideration of the value of the study.

What does the study cover?
The ALSWH examines demographic, social, physical, psychological, and behavioural variables and their effect on major aspects of women’s health and well-being and health service use. The surveys cover major diagnosed diseases, symptoms, health behaviours, use of health services and medications, and a range of factors relating to psychological well-being, social roles, and life events.

The study began with the objective of exploring five key themes: health service use; health-related behaviours (e.g. diet and exercise); time use (paid work, unpaid work, and leisure); life stages and key events (e.g. childbirth, divorce, and widowhood); and violence against women.4 Changes in Australian government policy priorities and enhanced understanding of women’s needs resulting from earlier phases of the study have led to some modifications to the original emphases. Currently we identify four major research topics: chronic disease; health services and systems; social factors in health and well-being; and methodology for longitudinal studies. Continuing cross-cutting themes include rural and remote women’s health; intergenerational issues; tobacco, alcohol, and other drugs; weight, nutrition, and physical activity; and mental health.

Who is in the sample?
The ALSWH involves three age cohorts of Australian women (younger, born 1973–1978, aged 18–23 in 1996; mid-age, born 1946–1951, aged 45–50 in 1996; older, born 1921–1926, aged 70–75 in 1996) who were selected from the database of the Health Insurance Commission (HIC) that runs the national health insurance scheme, Medicare. The Medicare database includes all Australian citizens and permanent residents, regardless of age or income, and is believed to be the most complete and up-to-date population list in Australia. The age groups were selected so that participation would commence, for most women in the cohorts, before the occurrence of major life events, such as first pregnancy, menopause, retirement, or death of a partner, and so that, over 20 years, we would have data from women aged 18–95.

Sampling from the population was random within each age group, except that women living in rural and remote areas5 were sampled at twice the rate of women in urban areas. This strategy was selected in order to capture the heterogeneity of health experiences of women living outside metropolitan areas.

Following pilot testing to assess response rates and survey acceptability, in 1996 surveys and information packs were sent to 106 000 women. Confidentiality restrictions meant that names and contact details for the selected women were not available to the study team until they chose to participate. Hence the recruitment was based entirely on mailed materials.

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sent from the HIC on behalf of the research team and more
targeted methods of encouraging participation were not
possible. A reminder protocol was followed, based on the
methods of Dillman, and a freecall telephone number was
provided for women who required additional information. The
study methods are approved by the Human Research Ethics
Committees of the Universities of Newcastle and Queensland.
Response rates to the first mailed survey (Survey 1) cannot be
exactly specified, as some women selected for the sample may
not have received the invitation (e.g. if they had died or had
changed their address without notifying the HIC). An estimated
41–42% of the younger women (n = 14 247), 53–56% of the
mid-age women (n = 13 716), and 37–40% of the older women
(n = 12 432) agreed to participate in the longitudinal study. A
further 532 younger women, 383 mid-age women, and 508
older women completed Survey 1 but failed to sign the consent
form or provide contact information.
Recognizing that some minority groups are less likely than the
general population to respond to a mailed written survey,
several special cohorts were initially established. These included
women from the Philippines, recent immigrants from the former
Yugoslav Republic, and women from several rural indigenous
communities. After several years, these special cohorts managed
by a separate research group were wound up, after contributing
to the debate in Australia on research with indigenous and other
disadvantaged and culturally different communities.

How often have they been followed-up,
and what has been measured?

Two years after the initial survey of all three cohorts in 1996, a
second survey was sent to the mid-age cohort. Second surveys
were sent to the older women in 1999 (3 years after Survey 1)
and to the younger women in 2001 (4 years after Survey 1).
Since then, surveys have been sent to each cohort once every
3 years (see Table 1).

Where appropriate, standard questions validated for mailed
surveys are used and are further validated within the ALSWH.
These include the SF-36, Center for Epidemiologic Studies
Depression Scale, and measures of social support and
neighbourhood satisfaction. Demographics and health
behaviours are assessed using standard questions from the
Australian census or from other national surveys. Diagnoses,
symptoms, and health service use are measured using face-valid
lists of items. For some concepts, there are no appropriate
measures for women or for specific age groups, so the team has
developed and validated new measurement tools, including
measures of stress and life events. Some items and scales
are included in every survey for all three cohorts. Others are
group-specific or reflect policy relevant issues at the time.
For example, surveys of the younger cohort include detailed
questions about fertility, contraception, sexual health, childcare,
and illicit drugs. Surveys of the mid-age women include
questions on menopause and, in Survey 4, items about
retirement planning. For the older women the surveys have a
larger font and fewer questions; cohort-specific items include
falls, activities of daily living, hearing, vision, dental problems,
and access to transport. Each survey also provides space for
open-ended comments, which are transcribed and have been
used in qualitative analyses.

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<td>Younger</td>
<td>18–23 yrs</td>
<td>45–50 yrs</td>
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<td>53–58 yrs</td>
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<td>Mid-age</td>
<td>45–50 yrs</td>
<td>47–52 yrs</td>
<td>76–81 yrs</td>
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<td>79–84 yrs</td>
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<td>Older</td>
<td>70–75 yrs</td>
<td>93–97 yrs</td>
<td>73–78 yrs</td>
<td>73–78 yrs</td>
<td>79–84 yrs</td>
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<td></td>
<td></td>
<td>n = 14 247</td>
<td>n = 13 716</td>
<td>n = 12 338</td>
<td>n = 9074</td>
<td>n = 9690</td>
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<td>Survey 1</td>
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<td>Survey 2</td>
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<td>Survey 4</td>
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Table 1 Timetable for first four waves of data collection from main cohorts (pilot cohorts are surveyed in the preceding year), and respondent numbers at each wave to date.

The project is expected to continue for 20 years or more.

Additional data are obtained from the HIC for government
subsidized health services through Medicare, the Department of Veterans’ Affairs, and the Pharmaceutical Benefits Scheme. These records include information on >90% of all services provided by general practitioners, consultant physicians and specialists outside hospital, as well as government-subsidized medications. Data include the type of service or medication, date, charge, patient co-payment, and practitioner descriptors. Participant details are also linked annually to the National Death Index to obtain dates and causes of death.

Sub-studies of the ALSWH participants are also conducted; these are smaller, separately funded, and targeted surveys addressing specific topics in more detail. Methods for these studies have included face-to-face interviews with women in selected geographic areas, focus groups, detailed telephone surveys, and more focused postal surveys on specific health issues. For example, women with low scores on the SF-36 Mental Health subscale have been interviewed about their experiences in seeking help for mental health-related issues. Likewise, mid-age women who reported having been in violent relationships were invited to describe their experience of violence, and the outcomes for those who did and did not seek help have been described.

What is attrition like?

Despite intensive tracking and follow-up methods, loss of participants has occurred, particularly among the younger women. The younger cohort had retention rates of 68% (n = 9690) and 64% (n = 9074) at Surveys 2 and 3, respectively.
Retention rates for the mid-age cohort were 90 and 83%, respectively, while for the older cohort, once those who had died or were too ill to complete surveys had been excluded, rates were 89 and 80% (see Table 2). Attrition is related to having less education, not being born in Australia, and being a current smoker, in all cohorts, and with poorer health in the older cohort. The reasons for attrition differ markedly across the three age cohorts. The major reason for loss at Survey 2 among younger women was inability to contact the women (21%), despite using all possible methods of maintaining contact, whereas only 6% of the mid-age and 3% of the older women could not be contacted. The younger women are characterized by high levels of mobility, change of surnames on marriage, often not having telephone listings and not registering to vote (even though it is compulsory in Australia), and making extended trips outside Australia for work, education, or recreation.

What has it found?

Because the ALSWH does not focus on a specific exposure, disease outcome, or social problem, publications are highly diverse. Table 3 provides an illustrative, but by no means exhaustive, list of recent publications and analyses. A full listing of all publications, including abstracts, is available at http://www.newcastle.edu.au/centre/wha/public.html.

What are the main strengths and weaknesses?

The ALSWH's major strength is its inclusion of three different age cohorts within a longitudinal design. This enables us simultaneously to explore health trajectories and to address generational differences (e.g. cohort differences in opportunities for education and employment) as they affect women's health. A further strength is that it is based on a national sample, rather than being defined by a region or occupational group; participants come from the widest possible range of geographic, socioeconomic, and personal circumstances.

Another strength is the broad disciplinary range of the research team (encompassing epidemiology, physiology, psychology, medicine, sociology, nutrition, and biostatistics). Investigators bring expert knowledge from their disciplinary traditions to provide a multifaceted perspective that goes beyond the biomedical to take account of social and psychological factors affecting women's health. Additionally, the core group of researchers who began the study remain closely involved, as do the main administrative and support staff, thus ensuring strong institutional memory. Succession planning is a related issue which the ALSWH investigators are addressing, recognizing that this is integral to the efficiency of the project.

A further strength is the combination of the statistical power afforded by the large database in tandem with the insights added at the end of each survey by the participants themselves. The quantitative data may tell us that a large percentage of young women in rural areas are dissatisfied with their access to female health practitioners, but it is comments such as 'the male doctor lectures the girls about going on the pill because he is old-fashioned' that illustrate the problems for young women, which can arise from the culture of practice of the male-dominated and ageing rural primary practitioner workforce.

Close contact with the women in the study through regular newsletters, the project website, telephoning to maintain contact details, and ensuring that personal replies are sent to all letters from participants has resulted in a high level of trust, which works to maintain good retention rates and good response rates to potentially sensitive questions, such as sexuality or illicit drug use.

There are methodological disadvantages of the study design. A parallel study of men would have provided evidence on gender similarities and differences. Little is known about the experiences of men as users of health services or the influence of family composition, paid and unpaid work, family roles, and ageing on men's health and well-being. Another limitation is that the data are mainly gained through self-report or from the administrative databases of the HIC. To date we have not obtained physical measures or biological samples from the

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Table 2 Retention and attrition of women in the three age cohorts at Survey 2 and Survey 3

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<tr>
<th>Respondents at Survey 1</th>
<th>Respondents</th>
<th>Non-respondents</th>
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<tbody>
<tr>
<td>Respondents</td>
<td>Survey 2</td>
<td>Survey 3</td>
</tr>
<tr>
<td>Completed survey</td>
<td>9690</td>
<td>9074</td>
</tr>
<tr>
<td>Deceased between surveys</td>
<td>22</td>
<td>10</td>
</tr>
<tr>
<td>Unable to complete further surveys (e.g. stroke, dementia, trauma, travelling)</td>
<td>26</td>
<td>75</td>
</tr>
<tr>
<td>Withdrew (cumulative total by age)</td>
<td>211</td>
<td>433</td>
</tr>
<tr>
<td>Contacted but did not return survey</td>
<td>1312</td>
<td>653</td>
</tr>
<tr>
<td>Unable to contact participant</td>
<td>2986</td>
<td>3954</td>
</tr>
<tr>
<td>Total eligible</td>
<td>14 199</td>
<td>14 114</td>
</tr>
<tr>
<td>Retention as % eligible</td>
<td>68.2</td>
<td>64.3</td>
</tr>
</tbody>
</table>

a Number eligible at previous survey minus those who died since last survey or are unable to complete further surveys.
women, nor have we confirmed diagnoses from health care provider records.

Further, despite intensive efforts, we are aware that we have under-sampled, and lost to attrition, a number of minority groups with special needs. These include indigenous women; migrants who do not speak, read, or write English well; women with disabilities; and those living in institutions.

Can I get hold of the data? Where can I find out more?

The data are held by the ALSWH research team and archived annually at the Social Sciences Data Archive at the Australian National University. The ALSWH website http://www.newcastle.edu.au/centre/wha has copies of published and in-press papers, lists and information about administrative processes. Potential collaborators should discuss ideas informally with the study coordinator by email before completing a formal Expression of Interest (see website for contact details). Proposals are assessed for feasibility and potential overlap with other work underway or completed. Following approval, collaborators complete a Memorandum of Understanding and are provided with data, data dictionaries, and supplementary documentation.

Successful collaborative analyses to date have included cooperative projects between members of the research team and others with complementary expertise, independent work by groups of researchers on important topics, which are not of current policy relevance, joint supervision of post-graduate research students in other institutions across Australia, and provision of data to support policy recommendations. In addition, we have published a cross-cohort comparison study in collaboration with the British Birth Cohort and have other cross-cohort comparisons planned. We welcome new collaborative opportunities.

Acknowledgements

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References


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