



Overview of ALSWH Project and Data

I. Description of the Australian Longitudinal Study on Women's Health (ALSWH)

The Australian Longitudinal Study on Women's Health (ALSWH) – also previously known as Women's Health Australia – is a longitudinal population-based survey that examines the health of four large cohorts of Australian women (see <http://www.alswh.org.au>). It has been continually funded by the Australian Government since 1995. The project explores factors that influence health among women who are broadly representative of the entire Australian population. The project goes beyond a narrow perspective that equates women's health with reproductive and sexual health, and takes a comprehensive view of all aspects of health throughout women's lifespan.

Research for the ALSWH is conducted at the University of Newcastle and the University of Queensland. The ALSWH is a national research resource providing information on women's health issues. The project is one of the largest longitudinal studies conducted in Australia and has an international reputation for its multidisciplinary methodology.

Aims

The aim of the study is to collect scientifically valid information that is relevant to the development of health policy, so that Commonwealth and State Government Departments of Health can base policy and practice in women's health on current data and accurate information. The study was a key resource used by the Australian Government Department of Health for its 2010 Women's Health Policy (see <http://www.health.gov.au/womenshealthpolicy>) and findings from the study have been used in other policies and guidelines (see <http://www.alswh.org.au/publications-and-reports/policies-and-guidelines>).

By examining the needs, views, lifestyles, health and factors affecting the physical and emotional health of individual women in Australia, the ALSWH is able to provide evidence to assist Commonwealth and State Departments to plan for the future and to develop policies that are most appropriate to Australians of all ages in the twenty-first century.

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

The study addresses a wide range of themes which are available at:
<http://www.alswh.org.au/about/aims>

The study also links social, environmental and personal factors in women's lives to health service use, by record linkage with administrative datasets.

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, we are continuing to develop valuable relationships with international research teams, and increasing the growing bank of national and international knowledge about women's health. For example, we are comparing menopause experiences for Australian women with women in England; we have compared Australian women's patterns of work and leisure with Canadian women; and we are comparing Australian women's use of complementary and alternative medical services with women in Norway. For details on current projects see the web link: <http://www.alswh.org.au/substudies-and-analyses/analyses>

The ALSWH has become a key foundation study for other studies, including the Centre for Research Excellence in Women's Health in the 21st Century (CREWH21), the International Collaboration for a Life Course Approach to Reproductive Health and Chronic Disease Events (InterLACE), and the Mothers and their Children's Health Study (MatCH) (see <http://www.alswh.org.au/about/associated-studies>).

Methods

Original cohorts recruited in 1996

In April 1996, women in the original three cohorts aged 18-23 years (the 1973-78 cohort), 45-50 years (the 1946-51 cohort) and 70-75 years (the 1921-26 cohort) were invited to take part in the study. The sample was selected from the Medicare database that was then maintained by the Health Insurance Commission (now called Medicare Australia) and contains the name and address details of all Australian citizens and permanent residents. These women were sent an invitation to participate in a 20 year project of health and health service use. Over 40,000 women responded to this initial invitation and agreed to participate in the project for at least 20 years.

The three original age groups were selected in order to follow women through life stages that are critical to women's health and well-being. We began tracking the 1973-78 cohort when they were in the early stages of transition from late adolescence to full adulthood; over time, most of them have moved into the workforce, entered adult relationships, and many have become mothers. The 1946-51 cohort was selected to examine menopausal transitions and the social and personal changes of middle age. The 1921-26 cohort was 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 well-being and independence in older adult life.

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. The ALSWH is

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the one of the largest studies of health issues in rural and remote parts of Australia.

The longitudinal study design, by which the same women are followed for 20 years, means that the project is able to clarify cause-and-effect relationships and to assess the effects of changes in policy and practice. From 1996-2011 each age cohort was surveyed once every three years via surveys sent in the mail. In 2011 the older cohort began receiving a shortened survey every six months and the younger and mid-aged cohorts were given the option of completing surveys online.

The cohorts were originally named the Young, Mid-age and Old cohorts. Some years later, these were changed to the Younger, Mid-age and Older cohorts. However, in 2008 the decision was made to rename the cohorts of women in the Study according to their birth years. These cohort names are more precise and informative, do not rely on their relationship with the other cohorts, and will not change their meaning or relevance over time.

| Previous cohort name | New cohort name based on years of birth |
|-----------------------------|--|
| Younger | 1973-1978 |
| Mid-aged | 1946-1951 |
| Older | 1921-1926 |

Surveys

All cohorts were mailed surveys when the study first collected data in 1996. Surveys were then staggered so that one cohort is surveyed each year so that cohorts are now surveyed on a triennial basis.

| | Year | 1973-78 cohort | 1946-51 cohort | 1921-26 cohort |
|-----------------|-------------|-----------------------|-----------------------|-----------------------|
| Survey 1 | 1996 | 18-23 years | 45-50 years | 70-75 years |
| | 1997 | | | |
| Survey 2 | 1998 | | 47-52 years | |
| | 1999 | | | 73-78 years |
| | 2000 | 22-27 years | | |
| Survey 3 | 2001 | | 50-55 years | |
| | 2002 | | | 76-81 years |
| | 2003 | 25-30 years | | |
| Survey 4 | 2004 | | 53-58 years | |
| | 2005 | | | 79-84 years |
| | 2006 | 28-33 years | | |
| Survey 5 | 2007 | | 56-61 years | |
| | 2008 | | | 82-87 years |
| | 2009 | 31-36 years | | |
| Survey 6 | 2010 | | 59-64 years | |
| | 2011 | | | 85-90 years |
| | 2012 | 34-39 years | | |
| Survey 7 | 2013 | | 62-67 years | |
| | 2014 | | | 88-93 years* |
| | 2015 | 37-42 years | | |

*After the 6th Survey of the 1921-26 cohort these women were surveyed every 6 months.

Surveys are available at <http://www.alsw.org.au/for-researchers/surveys>

New cohort recruited in 2012/13

In 2012, ALSWH began annual surveys of a new cohort of over 17,000 young women born 1989-95. This cohort completes an annual online survey.

| | Year | 1989-95 cohort |
|-----------------|-------------|---------------------------|
| Survey 1 | 2013 | 18-23 years |
| Survey 2 | 2014 | 19-24 years |
| Survey 3 | 2015 | 20-25 years |

Additional research

As well as these main surveys, women may be invited to participate in substudies. These substudies target particular areas of health, and have covered a wide range of topics including sleeping difficulties and disturbances, domestic violence, menopausal problems, urinary incontinence, caregiver service use, pregnancy, childbirth, retirement, falls risk, cardiovascular disease, smoking, health service use, leisure and time use, diabetes and the future plans of young women. A list of current substudies is available at <http://www.alswh.org.au/substudies-and-analyses/analyses>

Women are also invited to consent to linkage of their survey responses with records from administrative databases including hospital and health service use records, cancer registers and other chronic conditions registers, and services provided under Medicare. The Medicare data include information such as number of GP visits and service costs, but no clinical or diagnostic information.

Progress

More than 58,000 women in the original and new cohorts responded to the initial invitations to participate. The response for surveys completed from 1996 onwards is available at <http://www.alswh.org.au/about/sample>

Information on Data File Setup is available at

<http://www.alswh.org.au/images/content/pdf/Notes-compiled-for-collaborators-April2018.pdf>