**Australian Longitudinal Study on Women’s Health**

Technical Report #43

Prepared for the Australian Government Department of Health, November 2020

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# EXECUTIVE SUMMARY

This report covers the period from December 2019 to November 2020. The purpose of the Australian Longitudinal Study on Women’s Health (ALSWH) technical report is to document the annual operational aspects of the ALSWH, as well as the progress and outcomes of the preceding year. Content includes data collection procedures and materials; the outcomes of data collection procedures in terms of retention and attrition (including that due to deaths) and cohort maintenance strategies used to mitigate attrition; reports on data linkage and archiving activities; reports on methodological issues that have arisen and the resolutions that were applied; the executive summary of the annual major report; summaries of dissemination activities including publications, conference presentations and media; and information about collaborations and staffing. This executive summary includes the main findings of each section of the report.

***Introduction***

This section introduces the ALSWH by briefly describing the four cohorts (born 1989-95, 1973-78,

1946-51, and 1921-26) and the aims of the study. The women who comprise the cohorts regularly complete mailed or online surveys that ask about diverse aspects of health, wellbeing, life experiences and demographics. The ALSWH has met all of the obligations and deliverables for the period December 2019 – November 2020 contained in the relevant contracts with the Department of Health.

***Conduct of surveys***

During this period, surveys have been conducted as follows:

* *1989-95 cohort:* Survey 6 closed in August 2020. 14,939 women were emailed invitations to participate and 8,349 women completed or partially completed the survey.
* *1973-78 cohort*: Planning for Pilot Survey 9 began in July 2020, and deployment is expected before the end of the year.
* *1946-51 cohort:* Survey 9, which began in 2019, closed on 11 August 2020. 10,438 women were invited to participate, and 7,958 women completed or partially completed the survey.
* *1921-26 cohort:* Women in this cohort receive a survey every six months. The six-monthly follow-up (6MF) surveys are conducted on a rolling basis, so that women receive a survey six months after they have completed their previous survey. Thus, both the numerator and denominator of the response rate are dynamic. The eighteenth round of survey distribution started in May 2020.
* *COVID-19**mini-surveys:* A series of short on-line surveys were sent to women in the 1989-95, 1973-78 and 1946-51 cohorts to track their health during the pandemic.

***Maintenance of cohorts***

Retention of participants in each cohort has remained stable, at over 80% for the older cohorts and between 57% and 70% for the younger cohorts. While the ALSWH cohorts are broadly representative of the general population of Australian women of the same age, detailed comparison with recent Australian Censuses showed that women with Asian ancestry are under-represented due to recent migration, underrepresentation in the original sampling frame, or participation bias. To correct this under-representation, a targeted campaign to recruit women from Asia to improve representativeness will be conducted over the next three years.

***Data linkage***

Data linkage has continued to be an important component of the Study. 32 administrative datasets are linked with survey data and 130 projects are currently approved to use the linked data. Analyses using linked data have been included in over 81 publications (journal articles and reports).

***Archiving***

ALSWH data are routinely archived with the Australian Data Archive (ADA). In 2020, data from Survey 8 of the 1973-78 cohort and from the ongoing six-month follow-up surveys of the 1921-26 cohort will be archived with the ADA.

***Methodological issues***

A number of important methodological issues have been examined during 2020, including:

* creation of ‘core datasets’ of ALSWH survey data, to be accessed through the Australian Data Archive
* validation of the ALSWH income management survey question
* comparison of the DASS-21 and the GADS anxiety subscales in the 1973-78 cohort
* assessment of agreement between the K-10 and the MHI-5 measures of psychological wellbeing

***Major report 2020***

The ALSWH major report for 2020 examined the impact of multiple chronic conditions (musculoskeletal conditions, mental health conditions, coronary heart disease, respiratory disease, cancers, diabetes, dementia and stroke) on women’s health. A summary is included here – the full report is available on the Study [website](https://www.alswh.org.au/publications-and-reports/major-reports).

***Dissemination of study findings***

Since December 2019, 55 papers have been published in national and international scientific journals, and 28 presentations have been made to scientific and professional audiences both in Australia and internationally. (Conference attendance in 2020 has been affected by COVID-19 restrictions). During the year, the Study website has been updated regularly with new reports and published journal articles, and new factsheets have been made available on the resources page. Social media continued to be used as a communication tool. In addition to ongoing posts on Study outcomes, women’s health events and initiatives, social media was used to inform participants and the general public of ALSWH activity during the COVID-19 pandemic.

***Collaborative research activities***

Since December 2019, data access has been approved for 50 new research projects conducted by researchers at institutions across Australia and overseas. Progress reports have been provided for existing projects investigating the following topics:

* Chronic conditions (such as arthritis, cardiovascular conditions, cancer and diabetes)
* Health service use and systems
* Mental health
* Ageing and aged care
* Reproductive health
* Methodological issues
* Tobacco, alcohol and other drugs
* Medications
* Weight, nutrition and physical activity
* Social factors in health and well-being
* Caregiving
* Abuse

56 postgraduate students are currently working on aspects of the project.

***Staff***

ALSWH staff are located at the University of Newcastle and the University of Queensland. During 2020 over 30 individuals have been employed by ALSWH in casual, part-time, and full-time positions. All staff are employed on fixed-term contracts with their respective universities and none are in tenured (ongoing) positions. Positions are directly tied to the funding provided by the Department of Health.

# INTRODUCTION

The Australian Longitudinal Study on Women’s Health (ALSWH) is a longitudinal population-based survey funded by the Australian Government Department of Health. The project began in 1996 and involves four large, nationally representative cohorts of Australian women representing four generations:

* The 1989-95 cohort, aged 18 to 23 when first recruited in 2012/2013 (N = 17,015) and aged 25 to 31 in 2020
* The 1973-78 cohort, aged 18 to 23 years when first recruited in 1996 (N = 14,247) and aged 42 to 47 years in 2020
* The 1946-51 cohort, aged 45 to 50 years in 1996 (N = 13,716), aged 69 to 74 years in 2020
* The 1921-26 cohort, aged 70 to 75 years in 1996 (N = 12,432), aged 94 to 99 years in 2020

ALSWH takes a comprehensive view of all aspects of women’s health and aims to provide scientifically valid information based on current, accurate data that are relevant to the development of health policy and practice in women’s health. The surveys cover social and demographic variables, health behaviours, diagnoses, symptoms, general measures of health, such as the Health Survey 36 Short Form (SF-36), and access to, and use of, a range of health services. Survey data can be linked to administrative data on doctor visits, pharmaceutical prescriptions, hospital admissions, aged care services, cancer registries and death records.

Women participating in the Study have now been surveyed repeatedly over the past 24 years, providing a large amount of data on their lifestyles, use of health services, and health outcomes. Continuing participation is encouraged through regular newsletters, the Study website and social media, and opportunities to participate in focused sub-studies and other activities.

This technical report (#43) has been provided by the University of Queensland and the University of Newcastle as agreed in contracts between the Australian Government Department of Health and the two universities. The report is presented in sections, with information on data collection and related activities provided first, followed by details of how ALSWH data have been used during the year.

This report includes the following items, as required in contractual agreements with the Department of Health:

* Sources and development of instruments used for data collection are included in Section 3: Conduct of Surveys.
* Response rates are provided in Section 4: Maintenance of cohorts.
* Methodological issues relating to the surveys and data collection, as well as work relating to reliability, validity, and statistical issues for all cohorts are included in Section 7: Methodological Issues.
* Key new research findings for 2020 and details of dissemination activities, such as publications in scientific journals and presentations at conferences during the year are found in Section 8: Major Reports, and Section 9: Dissemination of Study Findings.
* Project materials and related items produced during 2020 are provided in a separate appendix.

All objectives, outcomes, and timeframes were met as required:

* Main Survey 6 of the 1989-95 cohort was completed.
* Planning for Pilot Survey 9 of the 1973-78 cohort began.
* Survey 9 of the 1946-51 cohort closed.
* The seventeenth wave of the six-monthly follow-up surveys of the 1921-26 cohort continued and the eighteenth wave commenced in May.
* A total of 50 new research projects have been given approval to use ALSWH data. Results from previously approved projects have been published in 55 peer reviewed scientific journal articles and used in 28 conference presentations. Projects include analyses that:
  + clarify the cause and effect relationship between women’s health and a range of biological, psychological, social and lifestyle factors,
  + assess the effects of changes in policy and practice,
  + explore the factors that influence health among women who are broadly representative of the entire Australian population,
  + investigate all aspects of health throughout women’s lifespan,
  + provide an evidence base of the development and evaluation of health policy and practice.
* An Annual Report for 2019 and a Major Report (examining the impact of multiple chronic conditions on women’s’ health) were prepared for the Department of Health.
* The Data Access Committee oversaw access to linked data for: Medicare Benefits Schedule (MBS)/Pharmaceutical Benefits Scheme (PBS) data, hospital admissions data, aged care data, cancer data, perinatal data and emergency services data.

*Note:* Percentages used in this report may not add up to 100 due to rounding.

# Conduct of surveys

In late 2019 and during 2020, survey activity was recorded for every ALSWH cohort. The 1989-95 cohort main Survey 6 was conducted and finalised and details are included in Section 3.1. The 1946-51 cohort main Survey 9 was conducted and finalised, and details are described in Section 3.2. The pilot survey for the 1973-78 cohort was planned, and details of these activities are in Section 3.3. For the 1921-26 cohort, the seventeenth and eighteenth six-monthly surveys were distributed (described in Section 3.4), and the nineteenth six-monthly survey will be distributed in November 2020. In early 2020, in response to the COVID-19 pandemic, fortnightly short online surveys were administered to women in the 1989-95, 1973-78 and 1946-51 cohorts who had email addresses. A brief outline of the COVID-19 mini surveys is included in Section 3.5.

## 1989-95 cohort

### Pilot Survey 6

Planning and development of the 1989-95 cohort Pilot Survey 6 is described in Technical Report 42. Data collection for this survey closed at 5pm 6th December 2019.

Table ‑ Final response rates for the 1989-95 pilot cohort Survey 6 (N=493)

| **Outcome** | **N** | **(%)** |
| --- | --- | --- |
| Completed online survey | 260 | 53 |
| Complete online survey – after cut-off | 2 | 0 |
| Partially completed online survey | 29 | 6 |
| Withdrawn | 2 | 0 |
| Not this time | 7 | 2 |
| No response | 146 | 30 |
| Withdrawn or Deceased prior to survey launch | 47 | 9 |
| **Total** | **493** | **100** |

### Survey 6

Planning and development of 1989-95 cohort Survey 6 are described in Technical Report 42. Data collection for Survey 6 closed at the end of August 2020.

#### Incentives

The major prize draw as detailed in Technical Report 42 was drawn on 13 December 2019. In 2020, an additional incentive was offered to participants who had not responded by June. For completion of the survey between 15 June 2020 and 16 August 2020, participants were eligible to win one $1,000 PrezeeTM gift card. The prize was drawn and awarded on 19 August 2020.

#### Distribution

The reminder protocol for this survey is shown in Figure 3‑1. The actual distribution of correspondence with participants is shown in Figure 3‑1 1989-95 main cohort Survey 6 reminder protocol.

Table 3‑2.

Diagram

Description automatically generated

Figure ‑ 1989-95 main cohort Survey 6 reminder protocol.

Table ‑ Actual distribution timetable for Survey 6 of the 1989-95 cohort

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Date** | **Activity** | **No** | **Items** | **Number Sent** |
| 30 May 2019 | Email | 1 | Email invitation | 14,574 |
| 3 Jun 2019 | Mail | 2 | Invitation letter to those without email | 361 |
| 14 Jun 2019 | SMS | 3 | SMS reminder | 9,286 |
| 25 Jun 2019 | Mail | 4 | Reminder letter | 10,162 |
| 10 Jul 2019 | Email | 5 | Reminder email to support mail | 10,275 |
| 31 Jul 2019 | SMS | 6 | SMS reminder | 7,357 |
| Sep 2019 to Aug 2020 | Phone | 7 | Phone reminder | 12,184 attempted calls |
| Aug 2019 to Aug 2020 | Email | 8 | Email follow-up after phone call | 2,006 |
| 20 Nov 2019 | Email | 10 | Email reminder - upcoming prize draw | 8,521 |
| 29 Nov 2019 | Email | 10 | Email reminder - upcoming prize draw | 6,273 |
| 15 Jun 2020 | Email | 10 | Email notifying participants of 2nd major prize draw | 6,765 |
| 22 Jun 2020 | SMS | 9 | SMS - 2nd major prize draw | 4,292 |
| 7 Aug 2020 | Email | 10 | Email reminder - upcoming prize draw | 5,965 |
| 14 Aug 2020 | SMS | 9 | Final SMS - 2nd major prize draw | 4,158 |
| May 2019 to Aug 2020 | Email | 11 | Email reminder to complete survey | 3,687 |
| June 2019 to Aug 2020 | SMS | 12 | SMS reminder to complete survey | 650 |
| July 2020 to Aug 2020 | Phone call | 13 | Phone reminder to complete survey | 713 attempted calls |
| 12 Aug 2020 | Email | 15 | Email reminder to those who haven’t completed the survey regarding upcoming prize draw | 371 |

Table ‑ Final response rates for the 1989-95 cohort Survey 6 (N=17,010)

| **Outcome** | **N** | **(%)** |
| --- | --- | --- |
| Completed online survey | 7,926 | 53 |
| Partially completed online survey | 423 | 3 |
| Deceased | 2 | 0 |
| Withdrawn | 236 | 1 |
| Not this time | 316 | 2 |
| No response | 6,036 | 41 |
| **Survey Total** | **14,939** | **100** |
| Withdrawn or Deceased prior to survey launch | 2,071 |  |
| **Cohort Total** | **17,010** |  |

## 1946-51 cohort

### Main Survey 9

#### Finalisation

Planning, development, mailout and data collection of the 1946-51 cohort Survey 9 was previously described in Technical Report 42 (2019).

The online survey closed on 5 August 2020, but paper surveys continued to be received until 11 August 2020. The reminder protocol for this survey is shown in Figure 3‑2. The numbers and dates of reminders and other activity for this survey which occurred in the period August 2019 to July 2020 are detailed in Table 3‑4.

A screenshot of a cell phone

Description automatically generated

**Figure 3‑2 1946-51 main cohort Survey 9 reminder protocol.**

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Table ‑ **Timetable of activity for the 1946-51 cohort Survey 9**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Date** | **Activity** | **No** | **Items** | **Number** |
| Aug 19 | Mailout | 5 | Mail package including letter with online survey link, paper survey, brochure, change of details card and reply-paid envelope | 7,498 |
| Aug 19 | Email | 3 | Email reminder to do the survey | 2,714 |
| Sep 19 | SMS | 6 | SMS reminder to do the survey | 2,313 |
| Oct 19 – Aug 20 | Phone call | 7 | Phone call to those who have not responded to the survey invitations and reminders | 3,244 added to phone reminder, 4499 attempted calls |
| Sep 19 onwards | Email | 8 | Extra email invitation to do online survey from the phone reminder | Currently 439 email reminders sent |
| Sept 19 onwards | Mailout | 5 | Extra mailed package including letter with online survey link, paper survey, brochure, change of details card and reply-paid envelope from the phone reminder | Currently 592 mailed packages sent |
| Jul 20 | SMS | 9 | Final SMS to do the survey | 1,080 |
| Jul 20 | Email | 9 | Final email to do the survey | 650 |
| **PARTIALLY COMPLETED ONLINE SURVEYS** | | | | |
| Jun 19 onwards | Email | 10 | Automated email reminders to participants who partially completed their survey | 1,557 |
| Jul 19 onwards | SMS | 11 | SMS reminders to participants who partially completed their survey | 95 |
| Nov 20 onwards | Phone call | 12 | Phone call to those who partially completed their survey | 114 added to phone reminder 2 attempted calls |
| Jul 20 | Email | 10 | Final email to do the survey | 107 |

Email and SMS reminders were sent to participants, who had not started the survey and to those who had started the survey but had not completed it, before the phone reminder commenced.

3,244 participants were included in the telephone reminder. Project assistants attempted to call each participant. 4,499 attempted calls were made. From these, 1,101 participants were spoken to, 148 (13%) withdrew, 113 (10%) did not want to do the survey this time, one said that they would not do the survey but partially completed it, and 839 (76%) said that they would do the survey - but only 412 (49%) of these completed the survey, 18 (2%) started the survey, and 409 (49%) did not start the survey.

439 extra email invitations and 592 mailed survey packages were sent to those requesting these through the telephone reminders.

A final SMS and a final email reminder were sent to all participants who had not started or completed their survey advising them that the survey was about to close.

Overall, 10,438 participants were invited to complete Survey 9 online or on paper. Completed surveys were received from 7,844 women (75% of those invited), while another 114 (1%) partially completed their online survey. Of the 7,958 who attempted the survey, 3,459 (43%) returned an online survey, and 4,498 (57%) completed a paper survey. Table 3‑5 details the final response rates.

**Table 3‑5 Final response rates for the 1946-51 cohort Survey 9 (N=10,438)**

|  | **N** | **(%)** |
| --- | --- | --- |
| Completed online survey | 3,347 | 32 |
| Partially completed online survey | 112 | 1 |
| Completed paper survey | 4,496 | 43 |
| Partially completed paper survey | 2 | 0 |
| Completed telephone survey | 1 | 0 |
| Deceased | 61 | 1 |
| Withdrawn | 240 | 2 |
| Not this time | 145 | 1 |
| No response | 2,034 | 20 |
| **Total** | **10,438** | **100** |

## 1973-78 cohort

### Pilot Survey 9

#### Planning and Development

Preparation for Pilot Survey 9 of the 1973-78 cohort began in July 2020. Frequencies, evaluation question responses and comments from 1973-78 cohort Survey 8 were reviewed, and recommendations for changes, additions and deletions to the survey were proposed. A discussion board was set up on SharePoint and items for discussion, change, additional items, and items for deletion were reviewed. A second discussion board was set up and further items for addition, change and deletion were reviewed. Final decisions on survey items were approved by the ALSWH Study Management Committee in August 2020. Approval from the Department of Health and the University of Newcastle Human Research Ethics Committee will be applied for once the survey design is finalised, and will be ratified by the University of Queensland Human Research Ethics Committee thereafter. Once ethics approvals are received, the online survey will be launched, to be followed six weeks later by the mailing of the paper survey.

## 1921-26 cohort

### Six-Month Follow-up Survey 17

The seventeenth Six-Month Follow-up Survey (6MF17) of the 1921-26 cohort commenced on 6 November 2019. The survey content is the same as that for previous waves of the 6MF surveys.Surveys were mailed to participants who had:

* Completed a survey between five and six months ago
* Asked for a new survey to be sent
* Not done the last survey and it had been mailed to them between five and six months ago
* Selected ‘Not this time’ when sent the previous survey, between five and six months ago.

This process was repeated each month for another five months. Upon receipt at the University of Newcastle, completed surveys were scanned in-house using the Scantron iNSIGHT 4ES OMR scanner.

Participants who were unable to complete a paper survey, either by themselves or with the assistance of someone else, were phoned and the survey was administered over the phone. The mailout activity for 6MF17 is detailed in Table 3‑6.

**Table 3‑6 Timetable for Six Month Follow-Up Survey 17**

| **Date** | **Activity** | **Items** | **Number** |
| --- | --- | --- | --- |
| November 2019 | Mailout 1 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 275 mailed |
| December 2019 | Mailout 2 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 107 mailed |
| January 2020 | Mailout 3 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 104 mailed |
| February 2020 | Mailout 4 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 171 mailed |
| March 2020 | Mailout 5 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 128 mailed |
| April 2020 | Mailout 6 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 83 mailed |
| November 2019 to April 2020 | Phone call | Telephone interview | 24 completed |

### Six Month Follow-up Survey 18

The eighteenth Six-Month Follow-up Survey (6MF18) commenced on 5 May 2020. The survey content remained the same as for previous 6MF surveys. Surveys were mailed in the same manner as for previous 6MF surveys, and the process will be repeated each month for six months, until the next round of follow-up survey begins. Those unable to complete the survey on paper will be offered a telephone survey. The mailout activity is detailed in Table 3‑7.

**Table 3‑7 Timetable for Six Month Follow-Up Survey 18 at 4 November 2020**

| **Date** | **Activity** | **Items** | **Number** |
| --- | --- | --- | --- |
| May 2020 | Mailout 1 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 219 mailed |
| June 2020 | Mailout 2 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 88 mailed |
| July 2020 | Mailout 3 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 104 mailed |
| August 2020 | Mailout 4 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 139 mailed |
| September 2020 | Mailout 5 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 163 mailed |
| October 2020 | Mailout 6 | Package mailed including survey, information letter, change of details card and reply-paid envelope | 45 mailed |
| May to October | Phone call | Telephone interview to those unable to complete the survey by themselves | 16 completed |

**Table 3‑8 Response rates for six-monthly follow-up surveys at 4 November 2020**

| First Survey | N | % |
| --- | --- | --- |
| Total Completed | 3,855 | 82 |
| Total Mailed | 4,707 | 100 |
| Second Survey | N | % |
| Total Completed | 3,394 | 90 |
| Total Mailed | 3,781 | 100 |
| Third Survey | N | % |
| Total Completed | 2,993 | 90 |
| Total Mailed | 3,332 | 100 |
| Fourth Survey | N | % |
| Total Completed | 2,621 | 90 |
| Total Mailed | 2,915 | 100 |
| Fifth Survey | N | % |
| Total Completed | 2,306 | 90 |
| Total Mailed | 2,548 | 100 |
| Sixth Survey | N | % |
| Total Completed | 2,024 | 90 |
| Total Mailed | 2,259 | 100 |
| Seventh Survey | N | % |
| Total Completed | 1,770 | 89 |
| Total Mailed | 1,982 | 100 |

|  |  |  |
| --- | --- | --- |
|  |  |  |
| Eighth Survey | N | % |
| Total Completed | 1,544 | 90 |
| Total Mailed | 1,715 | 100 |
| Ninth Survey | N | % |
| Total Completed | 1,364 | 91 |
| Total Mailed | 1,502 | 100 |
| Tenth Survey | N | % |
| Total Completed | 1,202 | 91 |
| Total Mailed | 1,328 | 100 |
| Eleventh Survey | N | % |
| Total Completed | 1,054 | 91 |
| Total Mailed | 1,163 | 100 |
| Twelfth Survey | N | % |
| Total Completed | 895 | 88 |
| Total Mailed | 1015 | 100 |
| Thirteenth Survey | N | % |
| Total Completed | 757 | 89 |
| Total Mailed | 852 | 100 |
| Fourteenth Survey | N | % |
| Total Completed | 643 | 93 |
| Total Mailed | 695 | 100 |
| Fifteenth Survey | N | % |
| Total Completed | 515 | 89 |
| Total Mailed | 578 | 100 |
| Sixteenth Survey | N | % |
| Total Completed | 406 | 91 |
| Total Mailed | 444 | 100 |
| Seventeenth Survey | N | % |
| Total Completed | 286 | 86 |
| Total Mailed | 331 | 100 |
| Eighteenth Survey | N | % |
| Total Completed | 150 | 75 |
| Total Mailed | 199 | 100 |

The responses for the 6MF surveys can also be shown graphically (Figure 3‑3). The graph also shows when the surveys have been returned – for example, the first survey (6MF Survey 1) began in Nov 2011 and some were still being returned in 2018, the second survey (6MF Survey 2) began in May 2012 and similarly, some were still being returned in 2020, and so on. We would therefore expect numbers to continue to increase for some of the more recent survey rounds. It should also be noted that mail outs for Survey 18 have not been completed at this time.

Figure ‑ Number of completions for 1921-26 cohort six-month follow-up surveys 1 to 18, at 4 November 2020.

## COVID-19 Mini Surveys

The advent of the COVID-19 pandemic has resulted in changes to every aspect of life, including massive loss of employment, closure of schools, the movement of employment and education into the home, cancellation of all public gatherings, and limitations on personal movement. The level of stress experienced by the public has been demonstrated by panic purchasing and hoarding, and anti-social behaviour. This impact has been counterbalanced by neighbours reaching out to one another, innovative techniques used for social support, and the overall willingness of the community to dramatically change the way life is lived in a short term. The impact on the individual and how this will evolve over the course of 2020 is unknown. The long-term impact of COVID-19 and resultant life changes is also unknown.

The COVID-19 mini surveys offer a very brief regular survey to women in the three youngest ALSWH cohorts throughout the pandemic. The purpose of the mini surveys is to ascertain who has experienced COVID-19, who has been tested (or not), their general health, stress level, and the impact of COVID-19 on their lives. Each mini survey will also focus on an additional topic of interest. The purpose of collecting these data is to ascertain changes in wellbeing as the pandemic, and responses to it, evolve. The collected data will permit tracking of wellbeing over the short-term, and will also allow for in depth analyses in the years that follow the pandemic. By collecting minimal data now, recall bias regarding the pandemic is avoided in the future.

Over the period 29 April 2020 to mid-October 2020, 14 COVID-19 mini surveys have been administered to participants in the 1946-51 main, 1973-78 main, and 1989-95 main and pilot cohorts who had a valid email address. Detailed activity for the COVID-19 mini surveys will be reported in the 2021 Technical Report.

The COVID-19 mini surveys were funded independently of core ALSWH activities.

# Maintenance of cohorts

## Introduction

This section provides updates on retention of participants in each of the ALSWH cohorts. Maintenance strategies, including updating of the National Death Index, are also outlined.

## Update of sample and response rates

### First survey of the 1973-78, 1946-51 and 1921-26 cohorts in 1996.

More than 40,000 women responded to the first survey of the original ALSWH cohorts in 1996. Due to uncertainties about the accuracy of the Medicare database (which was used as the sampling frame for the stratified random samples), response rates for this first survey cannot be exactly specified. However, it is estimated that 41-42% of the 1973-78 cohort, 53-56% of the 1946-51 cohort and 37-40% of the 1921-26 cohort responded to the initial invitation to participate. (Brown WJ, Dobson AJ, Bryson L, & Byles JE, Women's Health Australia: On the progress of the main cohort studies. *Journal of Women's Health & Gender-Based Medicine,* 1999; 8(5): 681-688). Confidentiality restrictions meant that the names of the selected women were unknown to researchers and usual methods of encouraging participation (e.g., by telephone) could not be used.

Some participants completed Survey 1 in 1996 and did not provide any contact details (532 women from the 1973-78 cohort, 383 women from the 1946-52 cohort, and 508 women from the 1921-26 cohort). Also, a very small number of women have since alerted the study that they were not eligible by their birth date, and they have been removed. Hence the numbers of women actually enrolled in the study were 14,247 women in the 1973-78 cohort, 13,714 women in the 1946-51 cohort and 12,432 women in the 1921-26 cohort (Lee C, Dobson AJ, Brown WJ, Bryson L, Byles J, Warner-Smith P & Young AF. (2005). Cohort Profile: the Australian Longitudinal Study on Women's Health. *International Journal of Epidemiology, 34*(5), 987-991).

### 1973-78 cohort

Among the 1973-78 cohort, 69% responded to Survey 2 in 2000, 66% to Survey 3 in 2003, 68% responded to Survey 4 in 2006, 62% to Survey 5 in 2009, 62% to Survey 6 in 2012, 57% responded to Survey 7 in 2015, and 57% responded to Survey 8 in 2018 (See Table 4‑1). This retention compares well with other surveys of this highly mobile age group. The major reason for non-response among the 1973-78 cohort is that that the research team has been unable to contact the women (between 21% and 33% of the cohort at subsequent surveys), despite using all possible methods of maintaining contact. Women in their twenties and thirties are characterised by high levels of mobility, change of surnames on marriage, often not having telephone listings, not being registered to vote, and making extended trips outside Australia for work, education, or recreation. Despite these losses, modelling has shown that there is no serious bias in estimates of associations between risk factors and health outcomes in longitudinal models (Powers J & Loxton D. 2010, The impact of attrition in an 11-year prospective longitudinal study of younger women. *Annals of Epidemiology, 20*(4), 318-321). The next survey for this cohort will be deployed in 2021.

**Table 4‑1 Participation and retention of 14,247 women in the 1973-78 cohort of women who were 18-23 years old at the first survey in 1996\***

| **Year**  **Survey**  **(age range)** | **2000**  **Survey 2**  **(22-27)** | **2003**  **Survey 3**  **(25-30)** | **2006**  **Survey 4**  **(28-33)** | **2009**  **Survey 5**  **(31-36)** | **2012**  **Survey 6**  **(34-39)** | **2015**  **Survey 7**  **(37-42)** | **2018**  **Survey 8**  **(40-45)** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Deceased | 22 | 33 | 51 | 59 | 79 | 104 | 125 |
| Frail | 3 | 9 | 12 | 15 | 16 | 16 | 16 |
| Withdrawn | 230 | 518 | 800 | 951 | 1,157 | 1,436 | 1,671 |
| **TOTAL INELIGIBLE** | **255** | **560** | **863** | **1,025** | **1,252** | **1,556** | **1,812** |
| Did not do survey | 1,332 | 653 | 1,371 | 1,994 | 1,455 | 1,399 | 1,268 |
| No contact | 2,972 | 3,953 | 2,868 | 3,029 | 3,531 | 4,106 | 4,046 |
| Respondent | 9,688 | 9,081 | 9,145 | 8,199 | 8,009 | 7,186 | 7,121 |
| **TOTAL ELIGIBLE** | **13,992** | **13,687** | **13,384** | **13,222** | **12,995** | **12,691** | **12,435** |
| **RESPONSE RATE (%)** | **69.2%** | **66.3%** | **68.3%** | **62.0%** | **61.6%** | **56.6%** | **57.3%** |

\*as at 23 November 2020

### 1946-51 cohort

Retention has been much higher among the 1946-51 cohort of women: 92% responded to Survey 2 in 1998, 85% responded to Survey 3 in 2001, Survey 4 in 2004 and Survey 5 in 2007, 83% responded to Survey 6 in 2010, 81% responded to Survey 7 in 2013, and 80% responded to Survey 8 in 2016 (See

Table **4‑2**). The major reason for non-response among the 1946-51 cohort has been that the research team has been unable to contact the women (6% to 13% of eligible women between Survey 2 and Survey 8). The 9th survey was released to participants in 2019, and the survey closed at the end of August 2020.

**Table 4‑2 Participation and retention of 13,714 women in the 1946-51 cohort of women who were 45-50 years old at the first survey in 1996\***

| **Year**  **Survey**  **(age range)** | **1998**  **Survey 2**  **(47-52)** | **2001**  **Survey 3**  **(50-55)** | **2004**  **Survey 4**  **(53-58)** | **2007**  **Survey 5**  **(56-61)** | **2010**  **Survey 6**  **(59-64)** | **2013**  **Survey 7**  **(62-67)** | **2016**  **Survey 8**  **(65-70)** | **2019**  **Survey 9**  **(68-73)** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Deceased | 50 | 119 | 216 | 328 | 474 | 673 | 875 | 1,168 |
| Frail | 7 | 23 | 34 | 51 | 70 | 100 | 120 | 129 |
| Withdrawn | 209 | 424 | 622 | 870 | 1,108 | 1,651 | 2,003 | 2,084 |
| **TOTAL INELIGIBLE** | **266** | **566** | **872** | **1,249** | **1,652** | **2,424** | **2,998** | **3,381** |
| Did not do survey | 254 | 997 | 886 | 995 | 1,148 | 1,051 | 714 | 718 |
| No contact | 856 | 925 | 1,051 | 832 | 903 | 1,088 | 1,380 | 1,659 |
| Respondent | 12,338 | 11,226 | 10,905 | 10,638 | 10,011 | 9,151 | 8,622 | 7,956 |
| **TOTAL ELIGIBLE** | **13,448** | **13,148** | **12,842** | **12,465** | **12,062** | **11,290** | **10,716** | **10,333** |
| **RESPONSE RATE (%)** | **91.7%** | **85.4%** | **84.9%** | **85.3%** | **83.0%** | **81.1%** | **80.5%** | **77.0%** |

\*as at 23 November 2020

### 1921-26 cohort

Of women from the 1921-26 cohort, 93% responded to Survey 2 in 1999, 88% to Survey 3 in 2002, 87% to Survey 4 in 2005, 81% to Survey 5 in 2008, and 81% to Survey 6 in 2011 (See Table 4‑3). The major reason for non-response among the 1921-26 cohort was the non-return of the questionnaire, rising from 4% at Survey 2 to 17% at Survey 6, although up to 9% of participants could not be contacted. Non-respondent women tended to report poorer self-rated health at Survey 1 than respondents. The effects of these losses were evaluated in terms of losses due to death and non-death1. Brilleman and colleagues concluded that non-death losses were potentially a greater source of bias than effects of death.

**Table 4‑3 Participation and retention of 12,432 women in the 1921-26 cohort of women who were aged 70-75 years at Survey 1 in 1996\***

| **Year**  **Survey**  **(age range)** | **1999**  **Survey 2**  **(73-78)** | **2002**  **Survey 3**  **(76-81)** | **2005**  **Survey 4**  **(79-84)** | **2008**  **Survey 5**  **(82-87)** | **2011**  **Survey 6**  **(85-90)** |
| --- | --- | --- | --- | --- | --- |
| Deceased | 549 | 1,237 | 2,289 | 3,630 | 5,292 |
| Frail | 95 | 303 | 525 | 594 | 789 |
| Withdrawn | 563 | 1,090 | 1,359 | 1,368 | 1,338 |
| **TOTAL INELIGIBLE** | **1,207** | **2,630** | **4,173** | **5,592** | **7,419** |
| Did not do survey | 481 | 861 | 592 | 640 | 862 |
| No contact | 310 | 295 | 509 | 640 | 96 |
| Respondent | 10,434 | 8,646 | 7,158 | 5,560 | 4,055 |
| **TOTAL ELIGIBLE** | **11,225** | **9,802** | **8,259** | **6,840** | **5,013** |
| **RESPONSE RATE (%)** | **93.0%** | **88.2%** | **86.7%** | **81.3%** | **80.9%** |

\*as at 7th August 2020

1Brilleman SL, Pachana NA & Dobson AJ. (2010). The impact of attrition on the representativeness of cohort studies of older people. *BMC Medical Research Methodology, 10*. doi: 7110.1186/1471-2288-10-71).

### Six-month follow-up surveys of the 1921-26 cohort

From November 2011, shorter surveys containing a set of core questions were mailed to the 1921-26 cohort every six months after the return of the previous survey. Table 4-4 shows the numbers of eligible participants and respondents at the end of each six month period.

**Table 4‑4 Participation in 6-month follow up surveys of the 12,432 women in the 1921-26 cohort (from November 2011 onwards)**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Wave**  **#** | **6-Month follow-up wave ending** | Deceased | Withdrawn | **Total ineligible** | Non-Respondent | Respondent | **Total eligible** | **Response rate (%)** |
| **1** | **30APR2012** | 5,543 | 2,324 | **7,867** | 1,182 | 3,430 | **4,612** | **74.4%** |
| **2** | **31OCT2012** | 5,938 | 2,353 | **8,291** | 885 | 3,303 | **4,188** | **78.9%** |
| **3** | **30APR2013** | 6,239 | 2,398 | **8,637** | 962 | 2,880 | **3,842** | **75.0%** |
| **4** | **31OCT2013** | 6,633 | 2,335 | **8,968** | 1,004 | 2,507 | **3,511** | **71.4%** |
| **5** | **30APR2014** | 6,960 | 2,282 | **9,242** | 1,089 | 2,148 | **3,237** | **66.4%** |
| **6** | **31OCT2014** | 7,301 | 2,169 | **9,470** | 1,016 | 1,993 | **3,009** | **66.3%** |
| **7** | **30APR2015** | 7,631 | 2,089 | **9,720** | 1,006 | 1,753 | **2,759** | **63.6%** |
| **8** | **31OCT2015** | 7,978 | 1,953 | **9,931** | 1,004 | 1,544 | **2,548** | **60.6%** |
| **9** | **30APR2016** | 8,279 | 1,859 | **10,138** | 956 | 1,385 | **2,341** | **59.2%** |
| **10** | **31OCT2016** | 8,609 | 1,724 | **10,333** | 879 | 1,267 | **2,146** | **59.1%** |
| **11** | **30APR2017** | 8,893 | 1,660 | **10,553** | 847 | 1,079 | **1,926** | **56.1%** |
| **12** | **31OCT2017** | 9,228 | 1,513 | **10,741** | 741 | 997 | **1,738** | **57.4%** |
| **13** | **30APR2018** | 9,472 | 1,430 | **10,902** | 682 | 895 | **1,577** | **56.8%** |
| **14** | **31OCT2018** | 9,769 | 1,291 | **11,060** | 636 | 783 | **1,419** | **55.2%** |
| **15** | **30APR2019** | 10,005 | 1,188 | **11,193** | 634 | 652 | **1,286** | **50.8%** |
| **16** | **31OCT2019** | 10,264 | 1,057 | **11,321** | 567 | 591 | **1,158** | **51.0%** |
| **17** | **30APR2020** | 10,342 | 1,072 | **11,414** | 566 | 499 | **1,065** | **46.8%** |
| **18\*** | **31OCT2020\*** | 10,377 | 1,104 | **11,481** | 586 | 412 | **998** | **41.3%** |

NOTE: 6MF questionnaires logged by 18 November 2020.

\*this 6MF collection period is still open for respondents.

### 1989-95 cohort

In 2012 and 2013, 17,010 women aged 18-23 years old were enrolled in the 1989-95 cohort. Women were mainly recruited using the internet and social media platforms. Consistent with the other cohorts, women were required to have a Medicare card. Women completed the online survey and provided consent to linkage of survey data with administrative databases such as Medicare.

Unlike the original cohorts, the 1989-95 cohort were surveyed annually through to 2017. There was a steep decline in response at the cohort’s second survey in 2014 (down to 70% of respondents from the baseline survey), but the response rate appears to have plateaued at around 55%-60% for subsequent surveys (Table 4‑5). The 6th survey was deployed in 2019, with survey closure planned for the end of August 2020.

**Table 4‑5 Participation and retention of 17,010 women in the 1989-95 cohort of women who were aged 18-23 years at Survey 1 in 2013\***

| **Year**  **Survey**  **(age range)** | **2014**  **Survey 2**  **(19-24)** | **2015**  **Survey 3**  **(20-25)** | **2016**  **Survey 4**  **(21-26)** | **2017**  **Survey 5**  **(22-27)** |
| --- | --- | --- | --- | --- |
| Deceased | 1 | 6 | 8 | 13 |
| Frail | 1 | 1 | 1 | 1 |
| Withdrawn | 681 | 694 | 1,744 | 1,943 |
| **TOTAL INELIGIBLE** | **683** | **701** | **1,753** | **1,957** |
| Did not do survey | 2,362 | 3,879 | 1,850 | 1,813 |
| No contact | 2,621 | 3,469 | 4,400 | 4,745 |
| Respondent | 11,344 | 8,961 | 9,007 | 8,495 |
| **TOTAL ELIGIBLE** | **16,327** | **16,309** | **15,257** | **15,053** |
| **RESPONSE RATE (%)** | **69.5%** | **54.9%** | **59.0%** | **56.4%** |

\*as at 7th August 2020

## Maintenance strategies

Cohort maintenance and tracking of ‘return to sender’ mail is ongoing. The office team continues to track all women from the original three cohorts who responded to Survey 1 in 1996 and from the new cohort of young women who responded to Survey 1 in 2012/13 and who are not known to have died or withdrawn from the survey since then. This includes women who did not respond to Survey 2, through to the latest survey for all cohorts. Participants for whom we have no current contact details remain in the tracking system unless they are positively identified as found, deceased, withdrawn, permanently emigrated or otherwise ineligible, or are unwilling to participate.

Before 2011 the Australian Electoral Commission (AEC) supplied the study with age range extracts of women on the Electoral Roll. These were used to look up a participant’s residential and postal addresses. The AEC stopped allowing this in 2011, although an electronic copy of the current Electoral Roll is available for public inspection at any AEC office. This has resulted in a more time-consuming tracking process. Despite this, the Electoral Roll has been found to be effective in tracking participants who have become lost to contact. Participants found in this way are sent a survey or reminder for their current or next survey by mail.

Secondary contacts, mobile phone numbers, and email addresses continue to be important in reconnecting with participants who become lost to contact. Publicly available information, published on various websites including White Pages, Facebook, Reverse Australia phone number listings, and obituary notices assist in the process.

## National Death Index

Participants in the study have been linked to the National Death Index (NDI) on an annual and, sometimes, on a bi-annual basis to identify women who are recorded as being deceased. This not only adds to information provided by family members, but also provides data on causes of death.

A list of 47,653 participants’ details, including unconfirmed deceased participants and participants who have withdrawn from the project, was sent to AIHW in November 2019 for matching against the National Death Index. Additional records with maiden names were not included on this occasion. A list of 1,871 unique record pairs were returned by AIHW in February 2020 for clerical review.

Each record pair comparison received a weight, ranging between 88.6 and 15.0, that reflects the quality of the link: the higher the weight, the higher the quality (as determined by the linking algorithm).

In general, the main contribution to the weight is made by the names. There are two factors that influence the weight that a name-pair contributes. The first is the frequency of the name in the portion of the NDI selected. For example, a link of Jane to Jane receives far less weight (about 6.5) than a link of Zipporah to itself (about 20) because the former is much more likely to occur by chance. The second factor comes into play when the names are not the same. An algorithm is used to determine how ‘close’ the two names are. Names that are very similar receive almost the same weight as names that are exactly the same. As the difference grows, the weight diminishes until it reaches a maximum disagreement of about –10.

Day, month and year of birth also contribute to the weight. The agreement and disagreement weights are not based on frequency and consider only exact agreement or disagreement on each field. In passes where the DOB is used and an error is allowed to occur in the year value, a weight penalty of -1 applies for each year that the pair’s DOBs disagree by. The last and smallest contribution to the weight is for agreement or disagreement of sex1.

1. Australian Government, Australian Institute of Health and Welfare (AIHW), 2013. User-guide to the NDI results file.

The record pairs can be divided into three regions – non-links (reject), possible links (review) and links (accept). The majority of the clerical review will be done in the ‘possible links’ region. These three regions are illustrated in Figure 4‑1.

**Record pair comparison weights**

**Matches**

**Non - Matches**



Figure ‑ Idealised distribution of record pair comparison weights from a hypothetical linkage.

Quite often record pairs can be accepted or rejected from a certain weight onwards without having to clerically review the records beyond a certain cut-off weight. For example, if all links below a weight cut-off of 10 are to be rejected, a ‘lower weight bound’ of 10 can be applied to automatically reject any record pairs below that weight. The same applies for records that can be accepted above a weight cut-off of for example 25. An ‘upper weight bound’ of 25 can be applied to automatically accept all the record pairs above a weight of 25.

Figure 4-2 shows a graph of the distribution of weights of record pairs in the clerical review file. In the clerical review of the ALSWH record pairs an upper weight bound of 35 was used in the past to automatically accept record pairs greater than or equal to this value, however it has been found

necessary to check those matches with a weight greater than or equal to 35 where the names, sex or date of birth do not agree or if the date of death is before the date of last contact.

Figure ‑ Distribution of weights of record pairs in the clerical review file.

The ALSWH record pairs were coded according to the closeness of the match of the ALSWH project date of birth with the NDI date of birth and the closeness of the match of the project surname, first name and middle name with those recorded on the NDI. Those with exactly matching date of birth and surname, first name and middle name, and with a weight greater than or equal to 35 (Pass 1) were taken as deceased (393 records). There were 3 records with exactly matching date of death and surname, first name and middle name, and weight greater than or equal to 35 (Pass 2): these records were taken as deceased. The 143 remaining records with a weight greater than or equal to 35 (Pass 3) were checked and 135 were found to be deceased. The remainder were doubtful matches and were not accepted. The one record with matching date of birth and date of death (Pass 4) were checked and was confirmed as deceased. Records with the weight greater than 25 were checked (Pass 5) and 56 matches were confirmed as deceased. Further records where the first name, middle name and date of birth matched with the weight greater than or equal to 20 (Pass 6) were checked and all 3 deceased matches were rejected as doubtful matches. Records where the participant was known to be deceased with a weight greater than or equal to 10 (Pass 7) were checked and one extra deceased match was found. Records where the surname and the date of birth matched with a weight greater than or equal to 15 (Pass 8) were checked and one matches was confirmed. Records where the last known participant address matched the NDI record with a weight greater than 10 (Pass 9) were checked and one extra match was identified. In cases where there was any doubt whether the deceased person was one of the ALSWH participants the review pair was rejected. Each match accepted was checked to see if they were an ALSWH known deceased participant or a new deceased participant. A table showing the characteristics of each successive pass is shown in Table 4-6 and the results of each pass is shown in Table 4-7.

**Table 4‑6 Criteria for the clerical review passes**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Pass** | **Surname** | **First name** | **Middle name** | **Deceased** | **DOB** | **DOD** | **Address** | **Weight** | **Make deceased** |
| **1** | Same as NDI | Same as NDI | Same as NDI or is null |  | Same as NDI |  |  |  | Automatically |
| **2** | Same as NDI | Same as NDI | Same as NDI or is null |  |  | Same as NDI |  |  | Automatically |
| **3** |  |  |  |  |  |  |  | >=35 | Check |
| **4** |  |  |  |  | Same as NDI | Same as NDI |  |  | Check |
| **5** |  |  |  |  |  |  |  | >=25 | Check |
| **6** |  | Same as NDI | Same as NDI |  | Same as NDI |  |  | >=20 | Check |
| **7** |  |  |  | ALSWH known deceased |  |  |  | >=10 | Check |
| **8** | Same as NDI |  |  |  | Same as NDI |  |  | >=15 | Check |
| **9** |  |  |  |  |  |  | First 10 characters of the addresses match | >+10 | Check |

**Table 4‑7 Summary of National Death Index matching results**

| **Pass** | Known deceased | New deceased | **Total confirmed** | Doubtful match | Not checked | Duplicates | **Total** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **1** | 88 | 305 | **393** |  |  |  | **393** |
| **2** | 3 |  | **3** |  |  |  | **3** |
| **3** | 35 | 100 | **135** | 8 |  |  | **143** |
| **4** | 1 |  | **1** |  |  |  | **1** |
| **5** | 3 | 53 | **56** | 78 |  |  | **134** |
| **6** |  |  | **0** | 3 |  |  | **3** |
| **7** | 1 |  | **1** | 13 |  |  | **14** |
| **8** |  | 1 | **1** | 13 |  |  | **14** |
| **9** |  | 1 | **1** | 3 |  |  | **4** |
| **Remainder** |  |  | **0** | 0 | 1,159 |  | **1,162** |
| **Total** | **131** | **460** | **591** | **121** | **1,159** | **0** | **1,871** |

Of the 591 matches identified, 131 deaths ALSWH knew about, 145 were new notifications and 315 were notification of deaths of participants who had withdrawn (Table 4‑8).

**Table 4‑8 Summary of National Death Index matching results**

|  |  |
| --- | --- |
| Confirmed deceased | 131 |
| New deceased | 145 |
| Withdrawn deceased | 315 |
| Doubtful match | 121 |
| Duplicate deceased record | 0 |
| Not checked | 1,159 |
| **TOTAL** | **1,871** |

A total of 11,947 participant deaths had been identified at the time of the clerical review, this number includes participants who have withdrawn (4,917). Four deaths occurred overseas and 67 other deaths (0.6%) have never been confirmed with the NDI. Figure 4‑3 shows the confirmed deaths by cohort – the majority of the confirmed deaths occur in the 1921-26 cohort, with a few in the 1946-51 cohort, very few in the 1973-78 cohort and even less in the 1989-95 cohort.

Figure ‑ Number of confirmed deaths of ALSWH participants for each year by main cohort.

**Figure 4‑4 Number of matched deaths at each time matching has been conducted.**

Figure 4‑5 Percentage of ALSWH known and unknown deaths confirmed by NDI at each time of matching.

Figure 4‑6 Percentage of withdrawn participants who are known to be deceased at each time of matching.

## Cause of Death Codes

Of the 11,876 deaths confirmed with NDI (including participants who have withdrawn) cause of death (COD) codes are available for 10,611. There are 1,265 deaths for which there is currently no COD information.

**Table 4‑9 Confirmed deaths with and without cause of death (COD) codes by year of matching**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | | **Year of matching** | | | | | |  | |  |  | |
|  | **Before 2013** | **2013** | | **2014** | **2015** | **2016** | **2017** | **2018** | | **2019** | | | **Total** |
| **No COD Code** | 18 | 1 | | 7 |  | 5 | 2 | 670 | | 562 | | | 1,265 |
| **COD Codes** | 6,688 | 592 | | 1,015 | 722 | 813 | 731 | 21 | | 29 | | | 10,611 |
| **Deceased** | 6,706 | 593 | | 1,022 | 722 | 818 | 733 | 691 | | 691 | | | 11,876 |

There can be up to 19 causes of death. The first cause of death is the underlying cause of death. All others are additional causes of death. Multiple cause of death coding was used from 1997 onwards. The classification system used for causes of death depends on when the person died and when their record was placed on the NDI. Those deaths that were registered in or before 1996 are recorded in ICD-9, those registered in 1997 and 1998 are a combination of ICD-9 and ICD-10 and those registered in 1999 and onwards are recorded in ICD-10.

# Data linkage

ALSWH arranges and manages linkages with major national and state datasets. Each external dataset has its own Data Custodian, and there is also one or more specific Human Research Ethics Committee (HREC) in each jurisdiction. ALSWH submits applications at both levels, requesting approval to link ALSWH data. If approval is granted, the linkage is conducted, data is extracted and the linked dataset is stored with ALSWH, for integration with other datasets for approved analysis projects.

## ALSWH linked data holdings

### National collections

Current national linked data collections are listed in Table 5-1. The Australian Institute of Health and Welfare (AIHW) performs data linkage for all national collections. MBS/PBS linkage is deterministic, with AIHW holding the concordance file between ALSWH Participant IDs and Medicare PINS (Personal Identification Numbers from the Medicare Consumer Directory, formerly the Medicare Enrolment File). Due to AIHW’s recent development of the master linkage file for the National Integrated Health Services Information (NIHSI) Analysis Asset, wherever possible, linkage for other national collections is now also based on Medicare PINS. AIHW also perform the data extraction for all the collections listed below (from 2029 this will include DVA). ALSWH aims to update national collections annually, except for aged care data (due to the more complex nature of these data).

Table ‑ ALSWH linked data holdings: National (at 31 October 2020)

|  |  |  |  |
| --- | --- | --- | --- |
| **Data linkage unit** | **Data custodian** | **Collection name** | **Abbreviation used in this Chapter** |
| Australian Institute of Health and Welfare (AIHW) | Australian Government Department of Health | * Medicare Benefits Schedule | MBS |
| * Pharmaceutical Benefits Scheme1 | PBS |
| Department of Veterans’ Affairs (DVA) | * Repatriation-MBS | R-MBS |
| * DVA Aged Care Programs | DVA-AC |
| AIHW | * National Aged Care Data Collection | NACDC |
| AIHW / State and Territory Death Registries | * National Death Index | NDI |
| * Cause of Death | COD |
| AIHW / State and Territory Cancer Registries | * Australian Cancer Database | Cancer |

1 *Includes DVA PBS records*

Table 5-2 shows metadata for national collections, with aged care collections also detailed in Table 5-3. When considering data linkage results, it is important to note that participants who decline health record linkage are excluded from linkage (with the exception of NDI). The total number of declined participants is currently 1,871 (details of consent are reported in Section 5.4.2 and Table 5.9).

Table ‑ ALSWH linked data coverage: National (at 31 October 2020)

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Collection** | **Update**  **MM/YY** | **Coverage** | | **Records**  **N** | **Women**  **Total N** | **N by cohort** | | | |
| **from**  **MM/YY** | **to**  **MM/YY** | **1921-26** | **1946-51** | **1973-78** | **1989-95** |
| MBS | 10/20 | 01/96 | 06/120 | 24,492,541 | 55,311 | 16,989 | 13,500 | 12,944 | 11,878 |
| R-MBS | 09/19 | 05/95 | 06/19 | 1,895,575 | 2,820 | 2,709 | 111 | - | - |
| PBS | 10/20 | 05/02 | 06/20 | 13,589,883 | 53,581 | 16,915 | 13,086 | 12,700 | 10,880 |
| CoD | 04/20 | 05/96 | 12/17 | 10,324 | 10,324 | 9,238 | 958 | 116 | 12 |
| Cancer | 08/20 | 01/82 | 12/16 | 6,777 | 6,085 | 3,609 | 2,112 | 302 | 62 |
| NACDC | 05/17 | \* | \* | 77,602 | 11,657 | 9,941 | 1,716 | - | - |
| DVA-AC | 02/17 | \* | \* | 26,484 | 2,321 | 2,289 | 32 | - | - |

\* *Dates vary among component datasets, see next table for details*

Table ‑ ALSWH linked data coverage: Aged Care Programs (at 31 October 2020)

| **Program and content** | **Coverage** | | **Records**  **N** | **Women**  **Total N** | **N by cohort** | |
| --- | --- | --- | --- | --- | --- | --- |
| **from**  **MM/YY** | **to**  **MM/YY** | **1921-26** | **1946-51** |
| ACAP (Aged Care Assessment Program) - assessments | 07/03 | 06/14 | 19,158 | 6,806 | 6,598 | 208 |
| ACFI (Aged Care Funding Instrument) - appraisals | 08/03 | 12/14 | 7,829 | 3,615 | 3,552 | 63 |
| RCS (Resident Classification Scale) - appraisals | 10/97 | 07/09 | 6,435 | 2,026 | 2,000 | 26 |
| RAC (Residential Aged Care) – admission / discharge | 10/97 | 08/15 | 14,125 | 6,035 | 5,909 | 126 |
| RAC - Periods of leave | 10/97 | 08/15 | 20,420 | 4,560 | 4,469 | 91 |
| TCP (Transition Care Program) - Admission / discharge | 04/06 | 07/14 | 850 | 690 | 661 | 29 |
| HCP (Home Care Packages) - care level changes | 08/13 | 06/15 | 385 | 383 | 364 | 19 |
| HACC(Home and Community Care) - service provision | 07/01 | 06/14 | 176,258 | 10,525 | 8,751 | 1,774 |
| All events file (all NACDC programs) | 05/97 | 09/15 | 77,602 | 11,657 | 9,941 | 1,716 |
| DVA Veterans’ Home Care - assessments | 01/01 | 01/17 | 23,671 | 2,075 | 2,046 | 29 |
| DVA Veterans’ Home Care - service plans | 01/01 | 01/17 | 26,484 | 2,021 | 1,992 | 29 |
| DVA Community Nursing - treatment accounts | 05/98 | 08/17 | 40,609 | 1,662 | 1,651 | 11 |

### State and Territory collections

Current national linked data collections are listed in Table 5-4; coverage is shown in Table 5-5. State-based collections are be updated approximately every two years. Probabilistic linkage is performed by designated Data Linkage Units for each jurisdiction, with data extracted by the relevant Department. Access to South Australian, Northern Territory, Tasmanian and Victorian collections is facilitated by the Population Health Research Network (approvals for other collections pre-date this facility). HREC and Data Custodian COVID-19 priorities have impacted timelines for some collections in 2020.

Table ‑ ALSWH linked data holdings: State/Territory (at 31 October 2020)

| **Data custodian** | **Data linkage unit** | **Collection Name** |
| --- | --- | --- |
| ACT Health | Centre for Health Record Linkage (CHeReL) | * ACT Admitted Patient Care |
| * ACT Emergency Department Data Collection |
| * ACT Perinatal Data Collection |
| NSW Ministry of Health | CHeReL | * NSW Admitted Patients Data Collection |
| * NSW Emergency Department Data Collection |
| * NSW Perinatal Data Collection |
| Queensland Health | Statistical Services Branch | * Queensland Hospital Admitted Patient Data Collection |
| * Queensland Emergency Department Collection |
| * Queensland Perinatal Data Collection |
| SA Department for Health and Wellbeing | SA NT Datalink | * SA Public Hospital Separations |
| * SA Public Hospital Emergency Department Data Collection |
| * SA Perinatal Statistics Data Collection |
| Northern Territory Department of Health | SA NT Datalink | * NT Public Hospital Inpatient Activity |
| * NT Public Hospital Emergency Department Data Collection |
| * NT Perinatal Trends Data Collection |
| Department of Health Tasmania | Tasmanian Data Linkage Unit (TDLU) | * Tasmanian Public Hospital Admitted Patient Episodes |
| * Tasmanian Emergency Department Presentations |
| * Tasmanian Perinatal Data Collection |
| Department of Health and Human Services Victoria | Centre for Data Linkage Victoria (CVDL) | * Victorian Admitted Episodes Dataset |
| * Victorian Emergency Minimum Dataset |
| Victorian Agency for Health Information (VAHI)1 | CVDL | * Victorian Perinatal Data Collection |
| Department of Health Western Australia | Data Linkage Branch | * WA Hospital Morbidity Data Collection |
| * WA Emergency Department Data Collection |
| * WA Midwives Notification System |

1 *on behalf of the Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity*

Table ‑ ALSWH linked data coverage: State/Territory (at 31 October 2020)

| **State and Collection** | | **Update**  **MM/YY** | **Coverage** | | | **Records**  **N** | **Women**  **Total N** | **N by cohort** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **from**  **MM/YY** | **to**  **MM/YY** | | **1921-26** | **1946-51** | **1973-78** | **1989-95** |
| ACT | A | 01/20 | 07/04 | 06/17 | | 2,197 | 741 | 179 | 116 | 177 | 269 |
| P | 05/97 | 12/16 | | 373 | 228 | - | - | 175 | 53 |
| E | 05/05 | 06/17 | | 4,197 | 1,229 | 170 | 162 | 263 | 634 |
| NSW | A | 09/19 | 03/01 | 03/19 | | 109,294 | 14,956 | 3,936 | 3,577 | 3,612 | 3,831 |
| P | 01/94 | 12/17 | | 7,326 | 3,474 | - | - | 2,917 | 557 |
| E | 01/05 | 03/19 | | 67,134 | 13,452 | 3,185 | 2,974 | 2,812 | 4,481 |
| NT | A | 02/19 | 07/00 | 07/18 | | 2,414 | 496 | 29 | 160 | 170 | 137 |
| P | 01/86 | 12/15 | | 271 | 167 | - | - | 146 | 21 |
| E | - | *Approval in place; data to be delivered* | | | | | | | | |
| QLD | A | 04/18 | 07/07 | 12/17 | | 64,234 | 10,326 | 1,789 | 2,888 | 2,665 | 2,984 |
| P | 07/07 | 12/17 | | 3,106 | 2,004 | - | - | 1,395 | 609 |
| E | - | *Approval in place; data to be delivered* | | | | | | | | |
| SA | A | 12/18 | 01/01 | 03/18 | | 17,748 | 3,437 | 1,006 | 826 | 847 | 758 |
| P | 01/19 | 03/86 | 12/16 | | 2,306 | 1,127 | - | 66 | 889 | 172 |
| E | - | *Approval in place; data to be delivered* | | | | | | | | |
| TAS | A | 10/18 | 01/07 | 12/17 | | 4,272 | 1,065 | 274 | 296 | 244 | 251 |
| P | 01/05 | 12/14 | | 461 | 295 | - | - | 233 | 62 |
| E | - | *Approval in place; data to be delivered* | | | | | | | | |
| VIC | A | 03/19 | 07/93 | | 06/18 | 118,327 | 12,967 | 3,137 | 2,944 | 3,638 | 3,248 |
| P1 | 09/19 | 01/99 | | 12/16 | 5,083 | 2,525 | - | - | 2,122 | 404 |
| E | - | *Approval in place; data to be delivered* | | | | | | | | |
| WA | A | 04/19 | 01/70 | | 12/17 | 60,914 | 5,573 | 982 | 1,349 | 1,511 | 1,731 |
| P | 07/89 | | 12/17 | 2,989 | 1,442 | - | - | 1,146 | 296 |
| E | 01/02 | | 10/18 | 29,351 | 4,725 | 822 | 1,117 | 1,162 | 1,624 |

A *= Hospital Admissions;* P *= Perinatal;* E *= Emergency Department*

1 *Linkage is with explicit consent only, due to specific legislative requirements for this collection; see Section 5.4.2 for a description of consent in ALSWH.*

### Derived datasets: Chronic conditions from multiple sources

Work is currently underway to make key indicator variables, derived from linked health record data, available to research collaborators. Harmonising and analysing linked data from multiple sources is a time-consuming task, especially as data sources may differ on coverage (type of hospital, time periods), linkage procedures (matching sensitivity), context of collection (funding and policy changes), and the variables supplied. There are frequently other important caveats around the use of the data. Considerable time and expertise is therefore required to produce valid and reliable results, with sufficient power to detect the effects in question. To streamline analysis, ALSWH is now offering derived variables to research collaborators, for example, fact of diagnosis for certain conditions, such as dementia (which may have been identified from ALSWH surveys or from one or more available linked data sources). Current ethical requirements for linked data still apply to derived data – collaborators require HREC approval for all contributing datasets before they can access the derived data.

## Data access procedures

### Data user approvals

Collaborating researchers from other Centres/Institutions can access the ALSWH linked datasets, subject to the approval of the relevant Data Custodians and HRECs. This means that instead of an individual researcher having to make their own separate applications to Data Custodians and HRECs to use linked data held by ALSWH, they apply instead to the ALSWH Data Access Committee by submitting an Expression of Interest (EoI). Upon approval of the EoI, ALSWH submits amendments and data user agreements to the relevant HRECs and Data Custodians. In some cases HRECs and/or Data Custodians must also review and approve new EoIs. These arrangements are subject to change at the direction of the agencies involved. Please note that substudies (projects which collect new survey data), or analysis projects which link with collections not covered by ALSWH, require individual approval of the HREC/s and the Data Custodian.

Table 5‑4 shows the current external approval processes required to add new researchers and projects (subsequent to approval by the ALSWH Data Access Committee). For ease of administration, ALSWH batches the new applications for submission to external agencies at the close of each EoI round. The approval process is largely outside of our control - researchers are advised that for certain collections, gaining all the necessary approvals may take several months over and above ALSWH’s internal EoI processing time. Table 5-10, at the end of this chapter, gives details of current ALSWH HREC record linkage protocols.

### Access options

Research datasets containing linked health records cannot be passed on to third parties. They can only be accessed:

* At ALSWH sites (School of Public Health, University of Queensland; or the Research Centre for Generational Health and Ageing, University of Newcastle). Visits must be booked; access depends on the facilities and resources available.
* Remotely through the SURE facility, at the researcher’s expense.

### Data access conditions

Information about data access conditions, including acknowledgements and review requirements for research outputs, is available on the ALSWH web site.

Table ‑ Approval procedures for researchers and projects using linked health records

| **Data Source** | **Approving body** | **Documents** |
| --- | --- | --- |
| AIHW Collections | AIHW HREC | * ‘AIHW s.29’ signed by all researchers * HREC amendment |
| DVA | DVA HREC | * Researcher CVs * HREC amendment * Project specific application\* * Evidence of DVA sponsor\* |
| NSW | CHeReL | * Draft HREC amendment and ALSWH EoIs (where use of SURE is involved) |
| NSW, QLD | NSW Population & Health Services Research Ethics Committee (PHSREC) | * Copy of Data Custodian approval (where use of SURE is involved) * Change in personnel form * Updated Study Protocol (where use of SURE is involved) * Copies of ALSWH EoIs * HREC amendment |
| QLD | Qld Health Information, Investment and Research Office | * Copy of NSW PHSREC approval letter * Updated Public Health Act (PHA) form |
| Qld Health Statistical Services Branch | * Conditions of Disclosure document signed by all researchers |
| WA | Dept of Health WA HREC | * Researcher online registration * HREC amendment |
| ACT, VIC, SA | ACT Health HREC | * HREC amendment |
| VIC (except Perinatal) | CVDL | * Copy of ACT Health HREC approval letter * ‘CVDL Schedule 2’ signed by all researchers * Copies of ALSWH EoIs |
| VIC Perinatal | Austin Health HREC | * HREC amendment * Researcher CVs |
| VAHI | * Data request signed by all researchers * Amended Data Request * Copy of Austin HREC approval letter * Copies of ALSWH EoIs |
| SA/NT | SA NT Datalink | * ‘Annexure B’ signed by all researchers * Copy of SA and NT HREC approval letters |
| SA | SA Health | * Confidentiality Deed * Copy of SA HREC approval letter |
| NT | NT Health & Menzies HREC | * HREC Amendment |
| NT Health | * ‘NT Appendix B Deed 2’ signed by all researchers * Copies of ‘Annexure B’ signed by all researchers * Copy of NT HREC approval letter |
| TAS | Tas Health & Medical HREC | * HREC Amendment * Copy of NSW PHSREC approval letter |
| TDLU | * Copies of TAS & NSW HREC approval letters * TDLU ‘Deed of Confidentiality and Compliance’ signed by all researchers * TDLU Security Checklist for Researchers completed by all researchers |

\*for analyses which distinguish DVA clients and/or services

## Use of linked data

A total of 213 projects have requested linked health record data to date. Of these, 130 are current projects. 81 ALSWH publications have used linked data. Table 5-7 shows the numbers of approved ALSWH projects, and researchers who have requested linked data for their analyses.

Table ‑ Linked data use in approved ALSWH EoIs (at 25 August 2020)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Collection type** | **Projects** | | **Users** | | **Publications** | |
| **Total** | **Since last report** | **Total** | **Since last report** | **Total** | **Since last report** |
| MBS | 75 | 8 | 87 | 18 | 29 | 4 |
| PBS | 81 | 20 | 110 | 20 | 33 | 4 |
| CoD | 27 | 11 | 48 | 4 | 7 | 3 |
| Cancer | 13 | 7 | 28 | 5 | 2 | 0 |
| Aged Care | 26 | 8 | 42 | 10 | 10 | 3 |
| Hospital Admissions | 56 | 14 | 83 | 21 | 26 | 8 |
| Perinatal Collections | 28 | 9 | 50 | 8 | 3 | 0 |
| Emergency Department | 17 | 7 | 41 | 6 | 0 | 0 |
| TOTAL | 130 | 28 | 130 | 26 | 81 | 11 |

## Legal and ethical considerations for health record linkage

This section outlines ALSWH compliance with legal and ethical requirements for health record linkage. Data security measures are as described in the 2019 Technical Report.

### Applicable legislation and guidelines

ALSWH is bound by the Australian Privacy Act 1988 under its contractual obligations to the Commonwealth Department of Health, which funds the Study. The Universities of Queensland and Newcastle are also subject to privacy legislation in their respective States (which is substantially similar to the national legislation). Further, to ensure best practice on our own behalf, and to maintain the compliance of organisations from which ALSWH accesses linked health records, ALSWH must adhere to the following national regulations, as well as to State and Territory privacy and health privacy legislation.

* [*NHMRC Guidelines approved under Section 95 of the Privacy Act 1988*](https://www.nhmrc.gov.au/about-us/publications/guidelines-under-section-95-privacy-act-1988) *(November 2014)*
* [*Australian Privacy Principles (APP) guidelines*](https://www.oaic.gov.au/resources/agencies-and-organisations/app-guidelines/APP_guidelines_complete_version_2_March_2018.pdf) *(Version 1.2 July 2019)* as well as Privacy principles operating in Australian States and Territories.
* *Australian Government* [*Best Practice Guide to Applying Data Sharing Principles*](https://www.pmc.gov.au/sites/default/files/publications/data-sharing-principles-best-practice-guide-15-mar-2019_0.pdf) (15 March 2019)

The universities and researchers conducting ALSWH are also ethically bound by:

* [*NHMRC National Statement on Ethical Conduct in Human Research 2007*](https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#block-views-block-file-attachments-content-block-1) *(Updated 2018; Chapters 2.2-3 and 3.2 are particularly relevant)*
* [*The Australian Code for the Responsible Conduct of Research 2018*](https://www.nhmrc.gov.au/sites/default/files/documents/attachments/grant%20documents/The-australian-code-for-the-responsible-conduct-of-research-2018.pdf) *–* [*Management of Data and Information in Research (2019)*](https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Management-of-Data-and-Information-in-Research.pdf)

The following also apply to Commonwealth agencies disclosing health records to ALSWH:

* [*Privacy public interest determination guide*](http://www.oaic.gov.au/agencies-and-organisations/guides/privacy-pid-guide) *V1.0, June 2014.*
* [*Health Insurance Act 1973*](https://www.comlaw.gov.au/Details/C2015C00207)(for MBS data).
* [*Public Interest Disclosure Act 1973*](https://www.health.gov.au/about-us/corporate-reporting/public-interest-disclosure)
* [*High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes*](https://toolkit.data.gov.au/files/High_Level_Principles_for_Data_Integration_Involving_Commonwealth_Data_for_Statistical_and_Research_Purposes.pdf) (February 2010)
* [*A Guide for Data Integration Projects involving Commonwealth Data for Statistical and Research purposes*](https://statistical-data-integration.govspace.gov.au/)(National Statistical Service).

ALSWH’s [Participant Privacy Policy](https://www.alswh.org.au/for-participants/participant-information/participant-privacy-policy/) is available on the web site and is regularly updated. All researchers and collaborators accessing linked data are also subject to ALSWH [Data Access Protocols](https://www.alswh.org.au/for-data-users/applying-for-data/full-dataset-and-linked-data/) in addition to the Codes of Conduct and Privacy Policies of their home institutions. The University of Queensland and University of Newcastle Privacy Codes are:

* The University of Queensland Policy and Procedures library (<http://ppl.app.uq.edu.au/>), including: 1.60.01 Right to Information, 1.60.02 Privacy Management, 1.60.04 Records Management, 4.20 Research Conduct and Integrity, and 4.20.06 Research Data Management.
* The University of Newcastle Responsible Conduct of Research Policy (<https://www.newcastle.edu.au/research-and-innovation/resources/policies-procedures-and-codes/overview>) and Privacy Management Plan (<https://www.newcastle.edu.au/privacy>)

ALSWH compliance with national guidelines was described in the [2019 Technical Report](https://www.alswh.org.au/images/content/pdf/technical_reports/Report_42_alswh.pdf). The history of consent procedures is also detailed in that report, and is summarised Figure 5‑1

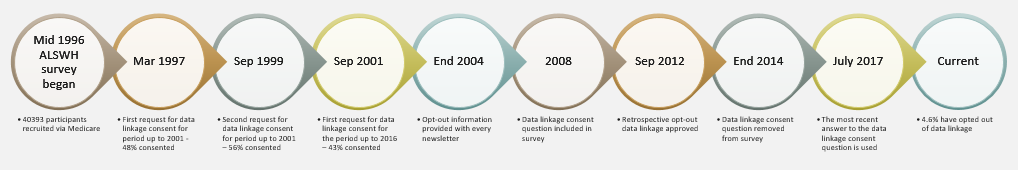


Figure ‑ History of data linkage consent for ALSWH participants 1996-2018.

### Consent status of ALSWH participants

Consent for health record linkage applies to all collections, apart from the National Death Index, which is conducted for all participants as an integral part of longitudinal tracking. ALSWH operates bundled opt-out consent due to the number and complexity of the record collections involved. Participants are informed of details of the collections accessed via the Study [web site](https://www.alswh.org.au/for-participants/participant-information/participant-privacy-policy/). Table 5-8 shows the definitive health record linkage consent categories. Participants who were active in the Study from 2005 are covered by the opt-out consent provisions which were introduced from that time, while participants who have never explicitly responded to health record consent communications,and have not been active in the study since 2005, are covered by waived consent.

Table ‑ Health record linkage consent categories

|  |  |  |
| --- | --- | --- |
| **Consent status** | **Relevant participants** | **Linkage** |
| 1. Declined | * Latest answer to the data linkage questions is ‘**No**’ * Explicitly declined data linkage by contacting ALSWH * Withdrawn from the Study because of privacy, confidentiality or Medicare data linkage concerns. | NDI only; deterministic only (no personal information is to be transferred to/from AIHW) |
| 1. Express consent | Latest answer to the data linkage questions is ‘**Yes**’. | All |
| 1. Implicit consent | Not in category a) or b), who **have** completed ALSWH surveys since the introduction of opt-out consent (2005). | All except VIC P |
| 1. Waived consent | Not in category a) or b), who **have not** completed a survey since the introduction of opt-out consent (2005). | All except VIC P; the Data Custodian for SA Cancer does not supply sensitive variables for this group |

Table 5‑9 shows the health record linkage consent status of the cohorts.

Table ‑ Health record linkage: Consent status of ALSWH participants (July 2020)

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Cohort** | **Total**  **N** | 1. **Declined** | | **Consent type** | | | | | |
|  | | | | | |
| 1. **Express** | | 1. **Implicit** | | 1. **Waived** | |
| 1921-26 | 12,432 | 353 | *2.8%* | 9,131 | *73.4%* | 381 | *3.1%* | 2,567 | *20.6%* |
| 1946-51 | 13,713 | 757 | *5.5%* | 11,236 | *81.9%* | 395 | *2.9%* | 1,325 | *9.7%* |
| 1973-78 | 14,247 | 744 | *5.2%* | 9,897 | *69.5%* | 873 | *6.1%* | 2,733 | *19.2%* |
| 1989-951 | 17,007 | 17 | *0.1%* | 16,990 | *99.9%* | N/A | *N/A* | N/A | *N/A* |
| **TOTAL** | 57,399 | 1,871 | *3.3%* | 47,254 | *82.3%* | 1,649 | *2.9%* | 6,625 | *11.5%* |

1 *Note that the 1989-95 cohort expressly consented on enrolment in 2012/13, therefore, qualified consent is not applicable*.

### Communicating with ALSWH participants about health record linkage

ALSWH participants have been informed about health record linkage and opt-out consent in annual newsletters since 2005. In 2020, the Department approved the updating of this content, to improve the currency and readability of this important information. Updated information was provided in the [2019 ALSWH participant newsletter](https://www.alswh.org.au/participants-newsletter/2019/).

### Current HREC approvals for health record linkage

Table 5‑10 shows current Human Research Ethics Committee (HREC) approvals for the ALSWH Data Linkage Project. In 2020, our three separate AIHW HREC protocols covering national data collections were updated and subsumed into a single protocol. The [National Mutual Acceptance Scheme](https://www.medicalresearch.nsw.gov.au/national-mutual-acceptance/) (NMA) aims to reduce duplication of coverage for cross-jurisdictional and/or multi-site projects. In May 2020 the scheme was revised to better support the requirements of researchers undertaking multi-jurisdiction data linkage studies, however, WA and NT are not party to this scheme, which also only covers locally-held Tasmanian data collections. ALSWH continues to pursue opportunities to streamline HREC monitoring, where feasible. From 2018, the NSW Population Health Services Research Ethics Committee (PHRSEC) covers data linkage in both NSW and Queensland; while Victorian (Hospital and Cancer) collections were added to our ACT Health HREC protocol. (Data custodians for the Victorian Perinatal Data Collection require approval of a Victorian Hospital HREC, therefore, this collection has its own protocol). In 2020, SA collections were also added under the ACT HREC.

Table ‑ Health record linkage: Current HREC approvals

| **Ethics Committee** | **Reference** | **Approved** | **Expiry** | **Coverage** |
| --- | --- | --- | --- | --- |
| University of Newcastle HREC (EC00144);  ratified by University of Queensland Human Research Ethics Committees (EC00456/7) | H-2011-0371;  2012000132 | 31/01/12;  9/02/12 | 31/12/25 | ALSWH Data linkage Project (subject to jurisdictional approvals) |
| H-2014-0246;  2014001213 | 07/08/14;  10/09/14 | 31/12/25 | MatCH Phase 1 Substudy (survey and record linkage) |
| H-076-0795;  2004000224 | 26/07/95;  2/04/04 | 31/12/30 | ALSWH Survey program, original cohorts |
| H-2012-0256;  2012000950 | 08/08/12;  31/12/23 | 31/12/32 | ALSWH Survey program, 1989-95 cohort |
| Australian Institute of Health and Welfare HREC (EC00103) | EC2020/3/1115  Replaces: | 17/08/20 | 31/12/30 | All national collections |
| EC 2012/1/12 | 12/04/12 | Closed | MBS (non-DVA), PBS |
| EO2013/1/7 | 7/01/13 | NACDC, DVA-AC,  R-MBS, Cancer |
| EO2014/3/110 | 31/10/14 | NDI |
| EO2017/1/342 | 7/03/17 | 31/12/25 | MatCH Phase 1 Substudy (child record linkage) |
| Defence/DVA HREC (EC00460) | EO14/022 | 19/12/14 | 31/12/21 | DVA-AC, R-MBS |
| ACT Health HREC (EC00100) | ETH.6.13.148 | 01/07/13 | 31/07/21 | ACT A, P, E, Cancer |
| Amendment – VIC collections | 22/08/18 | VIC A, E, Cancer |
|  | Amendment – SA collections | 19/09/20 |  | SA A, P, E, Cancer |
| Austin Health HREC (EC00204) | HREC/18/ Austin/163 | 17/07/18 | none | VIC P |
| NSW Population and Health Services Research Ethics Committee (EC00410) | 2011/11/357 | 03/01/12 | 31/12/20 (extension requested) | NSW A, P, E, Cancer |
| Amendment – QLD collections | 13/04/18 | QLD A, P, E, Cancer |
| HREC for the NT Dept of Health and Menzies School of Health Research (EC00153) | 2018-0371 | 16/04/18 | 31/12/21 | NT A, P, E, Cancer |
| SA Health HREC (EC00304) | HREC/12/ SAH/91 | 14/06/16 | Closed 24/09/20 |  |
| Tasmanian Health & Medical HREC (EC00337) | H0017192 | 19/04/18 | 19/04/22 | TAS A, P, E, Cancer |
| Dept of Health WA HREC (EC00422) | 2015/47 | 15/12/25 | 31/12/21 | WA A, P, E, Cancer |

*Shaded cells show coverage of the ALSWH survey program, rather than the data linkage component.*

# Archiving

ALSWH data are annually archived at the Australian Data Archive (ADA) at the Australian National University. To date, data have been archived for Surveys 1 to 8 of the 1946-1951 cohort, Surveys 1 to 7 of the 1973-1978 cohort, Surveys 1 to 5 of the 1989-1995 cohort, Surveys 1 to 6 of the 1921-1926 cohort, and the incomplete data from the six-month follow up survey of the 1921-1926 cohort. This year, 2020, the eighth wave of the 1973-78 cohort was archived along with recent data from the six-month follow up survey of the 1921-1926 cohort.

## Archiving Notes

In 2020, the following were deposited with ADA:

* Completed ADA licence form.
* The ALSWH Data Dictionary in MS Access format.

The data archived for the 1973-1978 cohort consisted of:

* 1973-1978 cohort survey level ‘A’ and ‘B’ analysis datasets in SAS format.
* 1973-1978 cohort survey CHILD dataset updated with wave 8 data in SAS format.
* 1973-1978 cohort participant status file in SAS format.

The data archived for the 1921-1926 cohort consisted of:

* 1921–1926 cohort 6-month follow up survey level ‘A’ and ‘B’ analysis datasets in SAS format.

1921–1926 cohort participant status file in SAS format.

# Methodological issues

## Creation of ADA-Accessed (Core) data

*Author: David Fitzgerald*

During the year, a core version of the ALSWH survey data was prepared and made available for release via the Australian Data Archive (ADA). These datasets are known as the ADA-Accessed (Core) data, and can be accessed from the [ADA](https://dataverse.ada.edu.au/dataverse/alswh) through a simplified procedure, usually within a week of application (provided applicants meet specific criteria). Full details of how to access the core datasets, and all supplementary information, are provided on both the ADA and ALSWH websites. The following is a description of how these core datasets were produced, and what was and was not included.

### Differences between the ALSWH data and the ADA-Accessed (Core) data

Some items have been removed from the Core datasets. Survey questions and derived variables/scales were removed if they were considered to be sensitive (e.g., questions involving criminality), not relevant for analysis, or if their release requires oversight of the ALSWH Data Access Committee. Some minor recoding of variables to avoid small cell sizes was also conducted. All the removed and recoded variables are outlined below.

The [ALSWH Data Dictionary](https://www.alswh.org.au/for-data-users/data-documentation/data-dictionary/) (available on the ALSWH website), has been updated to include all the ALSWH variables with an indicator showing whether they are in the Core datasets or not.

### Items not included in the Core Dataset

#### Age

Most age related variables were not included in the Core datasets. There is an AGE variable which is age in integer years at time the survey was returned. Other age variables, such as ‘age first starting smoking’, ‘came to Australia’, were not included.

#### Date variables

There are no exact dates in the Core datasets, although the respondents’ year of birth and year of response are available. All other dates, such as ‘date first came to Australia’, have been removed.

#### Geographic variables

The only geographic and geo-coded variables in the Core data are state of residence and ARIA+ grouped (ARIAPGP). For ARIAPGP, the ‘very remote’ and ‘remote’ categories were collapsed into a single category. The geo-coded variables ARIAPLUS and MMM were not included.

#### States / Territories

There were some small frequencies in the Australian Capital Territory (ACT) and Northern Territory (NT). To assist with de-identification, New South Wales and ACT have been collapsed together and so have South Australia and NT.

#### Exercise variables

The exercise status variable, EXSTAT, was removed from Survey 1 because this version was different from subsequent surveys. The exercise variables begin from Survey 2.

#### Short Surveys

The Short Surveys records are kept within the main datasets in the Core data, as they are with the main ALSWH datasets. The SURVEY variable, such as M2SURVEY, has value 1 for a full survey and value 2 for short survey. The Short Surveys were not continued after Survey 3.

#### Cell size greater than 10

The core data does not include any categorical variables with fewer than 10 responses in any category. Variables which had fewer than 10 responses in a category were either collapsed into fewer categories (to ensure at least 10 values in every category) or removed from the Core data. For example, in the 1989-95 cohort there were very few widowed women, so the Marital Status variable has a combined category of widowed and divorced.

#### Time use / Labour Force participation

The individual survey items for time use and labour force participation were removed from the Core datasets where they were used to derive other variables. The derived Labour Force Status variables are LABF, HRS, HRSWORK, and these are included in the Core datasets.

#### Child dataset

Child datasets items are not included in the Core data. The only child variable is the ‘children’ variable, which is number of children (0, 1, 2, 3 or more). All variables counting reproductive variables such as number of miscarriages were also removed.

#### Others

Other items not included are:

* The Complete Food Frequency datasets
* All text variables
* All qualitative data
* All Aboriginal and Torres Strait Islander questions
* Domestic and child abuse questions
* Illicit drug questions
* Medications free text data
* Cause of death
* Linked data
* Six-month follow-up data from the 1921-26 cohort

### Participant Status File

There is a participant status file for each cohort for the Core data. These files have year of response for each survey. This year of response variable has a value of 1 for did not respond, and a value of 2 where the respondent had died by the time of the survey.

### Recoded variables

There are a few variables in the Core dataset that have been recoded from the main ALSWH variables. These differences are described below.

#### Recodes common to all cohorts:

* ID Core - each woman in the Core datasets has an identifier ‘IDcore’. This identifier is different from the ‘IDalias’ identifier used in the full ALSWH datasets.
* As noted previously, ‘State of residence’, ‘ARIA+ grouped’, and ‘Age’ were recoded similarly for all cohorts.

#### Recodes by cohort:

Some items were recoded only for specific Surveys of each cohort. In particular, the 1946-51 cohort data had a number of recodes. All are described below.

* ***1946-51 Cohort***

| **Survey(s)** | **Question/variables** | **Recode details** |
| --- | --- | --- |
| Survey 2 | m2q71: Number people dependent on income | Capped at 7 (i.e., any value above 7 was recoded to 7). |
| Survey 3 | M3q49 a – j: How often drink cola, etc. | Category ‘3 or more times a day’ was collapsed with ‘2 times a day’. |
| M3q88: How many dependent on household income | Capped at 7 |
| Surveys 3 - 8 | How many times have you consulted GP/hospital doctor/ specialist in the last 12 months | The category ‘25+ times’ was collapsed with ‘13-24 times’ |
| Number of people living with you | Category ‘3 or more’ combined with ‘2’ |
| Survey 6 | m6q70: How many slices of bread eat per day | Category ‘8+ slices per day’ was collapsed with ‘5-7 slices per day’ |
| Survey 7 | M7q77 a – l: Number of drinks | Category ‘3 or more’ was collapsed with ‘2 times per day’ |
| Survey 8 | M8q57 a – l: Number of drinks | Category ‘3 or more’ was collapsed with ‘2 times per day’ |
| M8q82: Which best describes your housing situation’ | Category ‘Nursing home / residential aged care’ was collapsed with ‘Retirement village / self-care unit’, and ‘Hostel / boarding house’ was collapsed with ‘Other’. |
| M8q83: How many bedrooms | Capped at 8 |
| M8q85: Years lived in current home | Capped at 50 |
| M8q87: Where living in 10 years | Category ‘Hostel/ boarding house’ collapsed with ‘Have no idea’ |
| M8q76 a/b: Retirement of self/partner | Category ‘Never been in paid work’ was collapsed with ‘Other’ |

* ***1921 – 1926 cohort***

|  |  |  |
| --- | --- | --- |
| **Survey(s)** | **Question/variables** | **Recode details** |
| All | Marital status | ‘De facto’ was collapsed with ‘Married’ |
| Alcohol status (NHMRC) variables | ‘High risk drinker’ was collapsed with ‘Risky drinker’ |

* ***1973 – 1978 cohort***

|  |  |  |
| --- | --- | --- |
| **Survey(s)** | **Question/variables** | **Recode details** |
| All | Number of children | Capped at 3 for all surveys |
| Survey 1 | y1q76: Age left school | ‘Never attended school’ recoded to missing |
| y1q83: Speak English | Speak English ‘not at all’ was collapsed with ‘Not well’ |

* ***1989 – 1995 cohort***

|  |  |  |
| --- | --- | --- |
| **Survey(s)** | **Question/variables** | **Recode details** |
| All | Marital status | ‘Divorced’ and ‘Widowed’ were collapsed with ‘Separated’ |

## Validation of the ALSWH income management survey question

*Authors: Nicholas Egan, Peta Forder, Annette Dobson, Richard Hockey*

### Income within the context of socioeconomic status

Socioeconomic status (SES) refers to ‘the social and economic position of a given individual, or group of individuals, within the larger society’ (ABS, 2011). Socioeconomic status is viewed as a relative state (individual advantage/disadvantage compared to others) and is often difficult to quantify. SES is most commonly operationalised as education, social class or income, but other elements such as employment, wealth, location, health, consumption and household structure also contribute towards measurements of SES (ABS, 2011).

Income is often considered to be a clear indicator of material resources, and is strongly associated with higher/better SES (Darin-Mattson et al, 2017). Income is associated with better health outcomes (higher income increases the ability to access more services and resources to aid health) as well as indirectly influencing social participation and opportunities to improve life circumstances, which influence long-term health (Marmot, 2002). As such, income resources are often measured within the context of health surveys, such as ALSWH.

### Ability to manage on available income

Many ALSWH surveys include an income management question, which is phrased as ‘How do you manage on the income you have available?’ with the following response options: ‘It is impossible’, ‘It is difficult all of the time’, ‘It is difficult some of the time’, ‘It is not too bad’ and ‘It is easy’ (Figure 7‑1). This question has been used in many published papers based on ALSWH data, but its provenance is unclear, and it has never been validated within ALSWH. This investigation seeks to address these concerns.

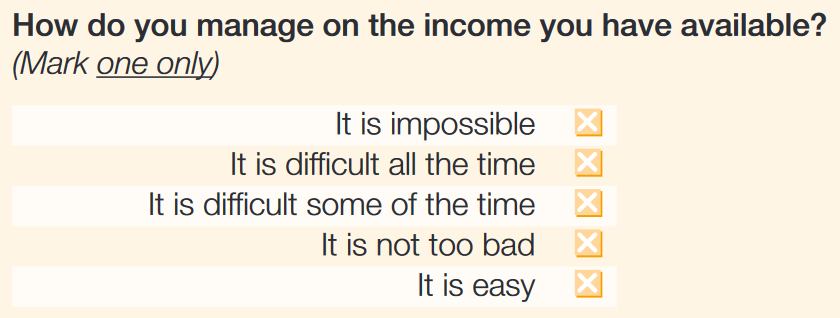


Figure ‑ Example of ALSWH questionnaire item on the ability to manage on available income, (Survey 8 of the 1973-78 cohort, 2018).

A search of the literature for use of this income management question predominantly returned results from studies based on ALSWH data. We found three papers that used other surveys where the income management question was used with the same wording (Ashman et al., 2017, Gregorevic et al., 2018, Gregorevic et al., 2020), but these did not provide references that might indicate the origin of the question.

A similar question which asks respondents about their ease in meeting health care costs was included in the Australian Living Standards Study Berwick Report published in 1993 (McDonald, 1993). The Australian Living Standards Study (ALSS) was conducted by the Australian Institute of Family Studies (AIFS), with the relevant question included in Part 2 of the questionnaire on page 35. The question is phrased as ‘How easy or difficult is it for you to meet the total health care costs of your family?’. Respondents could select one of the following options: ’Easy or very easy’, ‘Moderate/OK’ or ‘Difficult or very difficult’ (Figure 7‑2).

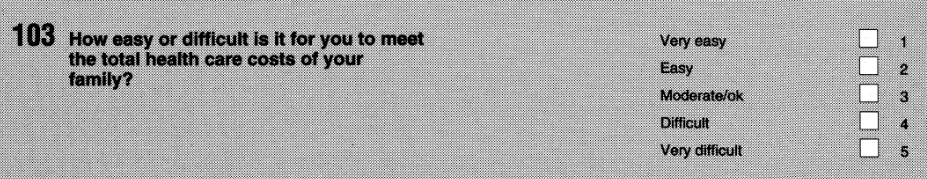


Figure ‑ Ease of meeting health care costs question from the Australian Living Standards Study (part 2, question 103, page 35).

This question is similar in content and structure to the ALSWH income management question, and predates the first ALSWH survey in 1996. It has been suggested that this question may have been modified for use in ALSWH, although this has not been confirmed.

Another similar question was included in the Poverty in the United Kingdom survey conducted in 1968 and 1969 in each of fifty-one constituencies in the United Kingdom (Townsend, 1979). The question was posed as ‘Do you find it especially difficult to manage on your income?’ with dichotomous response options yes and no. An AIFS report (Brownlee, 1990) on the development of the ALSS extensively references and analyses the Townsend study, suggesting that the Townsend study may have been used to inform the development of the income questions used in the ALSS.

### Financial resource questions under consideration

This investigation considers four questions that seek to measure financial resources within ALSWH, although there is a primary focus on the income management question that is regularly used across surveys in all four ALSWH cohorts. Table 7‑1 outlines the phrasing of the questions under consideration. The Question column contains shorthand names for the questions that will be used throughout this document for brevity (e.g. ‘Income management’ refers to the question that asks about participant’s ability to manage on the income that they have available to them).

Table ‑ Summary of financial resource and education questions under consideration

| **Question** | **Phrasing of question** |
| --- | --- |
| Income management | How do you manage on the income you have available? |
| Household income | What is the average gross (before tax) income of your household (e.g. you and your partner, or you and your parents sharing a house)? |
| Highest qualification | What is the highest qualification you have completed? |
|  | What is the highest level of education you have completed? |
| Stress about money | Over the last 12 months, how stressed have you felt about the following areas of your life: Money |

ALSWH survey data also includes the Socioeconomic Indices for Area (SEIFA) Economic Resources score, but this was not included in this analysis as it is an ecological variable that did not exhibit strong correlation with individual-level measures of financial resources.

### Surveys that measure financial resources and education

Table 7‑2 shows that the income management question has been regularly included in surveys in all cohorts. Although not shown in

Table 7‑2, the income management question is also included in each of the six-monthly follow-up surveys of the 1921-26 cohort. The highest qualification question has been sparingly included in the 1921-26 and 1946-51 cohorts, but has been regularly included in the 1973-78 and 1989-95 cohorts. The household income question has only been included in two surveys of the 1946-51 cohort and three surveys for the 1973-78 cohort. The stress about money question has been regularly included in all cohorts except the 1921-26 cohort, where it was only included at Survey 1.

Table ‑ Inclusion of financial resource and education questions across cohorts and surveys

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | **Survey Wave** | | | | | | | | | | | | | | |
| **Cohort** | **Question** | **1** | | **2** | | **3** | | **4** | | **5** | | **6** | | **7** | | **8** |
| 1921-26 | Income management | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | |  | |  |
|  | Household income |  | |  | |  | |  | |  | |  | |  | |  |
|  | Highest qualification | Yes | |  | |  | |  | |  | |  | |  | |  |
|  | Stress about money | Yes | |  | |  | |  | |  | |  | |  | |  |
| 1946-51 | Income management | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes |
|  | Household income |  | | Yes | | Yes | |  | |  | |  | |  | |  |
|  | Highest qualification | Yes | |  | |  | |  | |  | | Yes | |  | |  |
|  | Stress about money | Yes | | Yes | |  | |  | | Yes | | Yes | | Yes | | Yes |
| 1973-78 | Income management | Yes | |  | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes |
|  | Household income |  | | Yes | | Yes | | Yes | |  | |  | |  | |  |
|  | Highest qualification | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes |
|  | Stress about money | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes |
| 1989-95 | Income management | Yes | | Yes | | Yes | | Yes | | Yes | |  | |  | |  |
|  | Household income |  | |  | |  | |  | |  | |  | |  | |  |
|  | Highest qualification | Yes | | Yes | | Yes | | Yes | | Yes | |  | |  | |  |
|  | Stress about money | Yes | | Yes | | Yes | | Yes | | Yes | |  | |  | |  |
|  |  |  |  | |  | |  | |  | |  | |  | |  | |
| Yes | Question available |  |  | |  | |  | |  | |  | |  | |  | |
|  | Question not available |  |  | |  | |  | |  | |  | |  | |  | |
|  | Survey does not exist |  |  | |  | |  | |  | |  | |  | |  | |

### A note on the household income variable

The household income questions for the 1946-51 and 1973-78 cohorts are split into two parts: personal income and household income. The exception is Survey 2 in the 1946-51 cohort where the question was split into personal income and partner’s income. We generated a derived household income variable that was the sum of the personal income and partner’s income for this investigation to allow comparison with the other surveys. The mid-points of each category were used as estimates in the summation. For example, if the personal income was reported as being in the $120 to $300 per week category and the partner’s income was in the $700 to $999 per week category, then the total was $210 + $850 = $1,060, and the resulting category for household income was the $1,000 to $1,500 per week category.

### Missing data for financial resource and education variables

Responses to the household income question of don’t know and don’t want to answer were treated as missing, in addition to any actual missing responses. Missing data for all questions, excluding the household income question, ranges from 0.36% to 5.37%. Missing data for household income ranges from 16.77% to 36.07% (Table 7‑3 and Figure 7‑3).

With respect to the income management question, very low rates of missing were observed, with

* 0.7-2.1% missing observed across six surveys for the 1921-26 cohort;
* 0.6-1.4% missing observed across eight surveys for the 1946-51 cohort;
* 0.3-5.1% missing observed across seven surveys for the 1973-78 cohort; and
* 1.1-3.7% missing observed across five surveys for the 1989-95 cohort.

There was a noticeable increase in the proportion of missing observed for the income management question for the 1973-78 cohort at Survey 6 (1.27%), Survey 7 (5.13%) and Survey 8 (4.93%). We hypothesise that this increase may have been due to the ordering of the questions in the survey. In Survey 6, the income management question was included alongside other SES questions, but in Surveys 7 and 8, the income management question was included following a series of dietary questions.

There have been four ALSWH surveys where a small number of women were offered a short survey instead of the complete survey. These shortened surveys were offered at Survey 2 for the 1921-26, 1946-51 and 1973-78 cohorts, and Survey 3 for the 1946-51 cohort. The short surveys were restricted to the questions deemed most important and not all financial resource questions were included. Cells shaded yellow in Table 7‑3 indicate that the question was not included in these short surveys, and so women who completed the short survey have been excluded from the denominator in the missingness calculation (as they did not have the opportunity to respond to that particular question). The values in Table 7‑3 are presented graphically in Figure 7‑3.

Table ‑ Missing data (%) for financial resource and education questions

|  | | **Survey Wave** | | | | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Cohort** | **Question** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |
| 1921-26 | Income management | 2.14 | 1.21 | 0.74 | 1.29 | 1.08 | 1.09 |  |  |
|  | Household income |  |  |  |  |  |  |  |  |
|  | Highest qualification | 5.34 |  |  |  |  |  |  |  |
|  | Stress about money | 3.47 |  |  |  |  |  |  |  |
| 1946-51 | Income management | 0.63 | 1.28 | 1.21 | 0.75 | 0.63 | 0.90 | 1.37 | 1.25 |
|  | Household income |  | 36.07 | 27.55 |  |  |  |  |  |
|  | Highest qualification | 1.01 |  |  |  |  | 5.37 |  |  |
|  | Stress about money | 0.89 | 1.51 |  |  | 2.47 | 3.41 | 0.75 | 0.74 |
| 1973-78 | Income management | 0.36 |  | 0.52 | 0.45 | 0.43 | 1.27 | 5.13 | 4.93 |
|  | Household income |  | 24.65 | 21.17 | 16.77 |  |  |  |  |
|  | Highest qualification | 0.57 | 3.61 | 2.36 | 0.37 | 2.17 | 1.87 | 5.37 | 4.84 |
|  | Stress about money | 0.53 | 1.23 | 0.67 | 0.37 | 0.32 | 1.29 | 2.05 | 2.33 |
| 1989-95 | Income management | 1.11 | 1.80 | 3.25 | 3.69 | 2.61 |  |  |  |
|  | Household income |  |  |  |  |  |  |  |  |
|  | Highest qualification | 1.08 | 1.75 | 3.20 | 2.82 | 2.54 |  |  |  |
|  | Stress about money | 1.08 | 1.75 | 3.11 | 3.69 | 2.01 |  |  |  |

|  |  |
| --- | --- |
| XX.XX | Percent missing data |
|  | Question not available |
|  | Short survey respondents excluded |
|  | Survey does not exist |

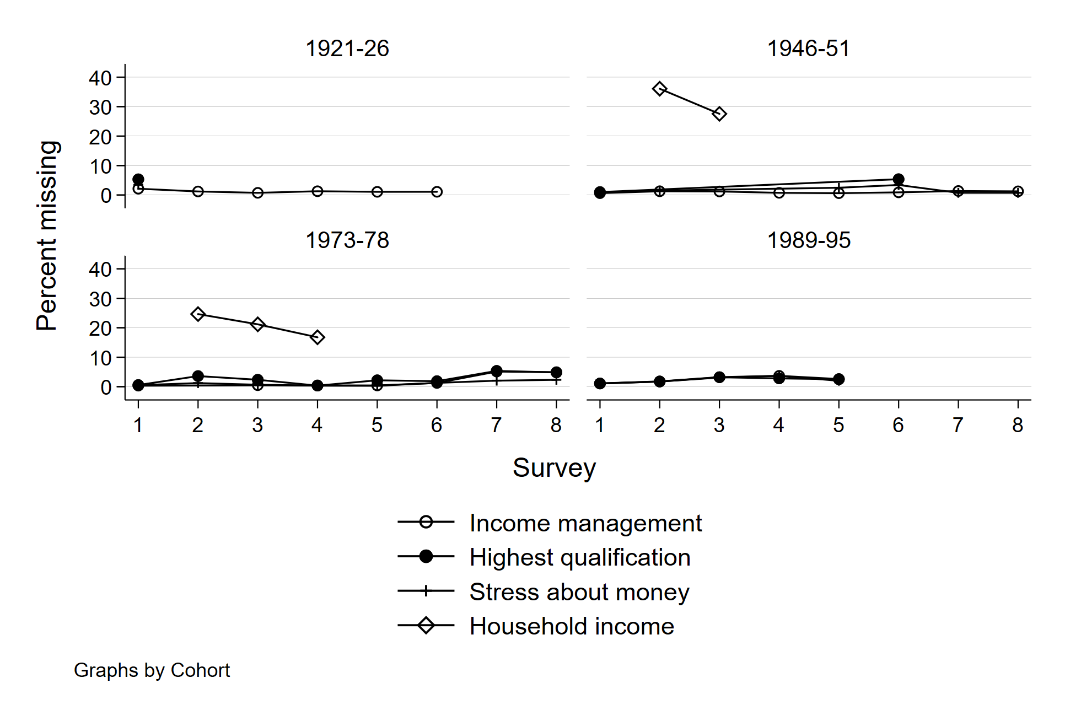
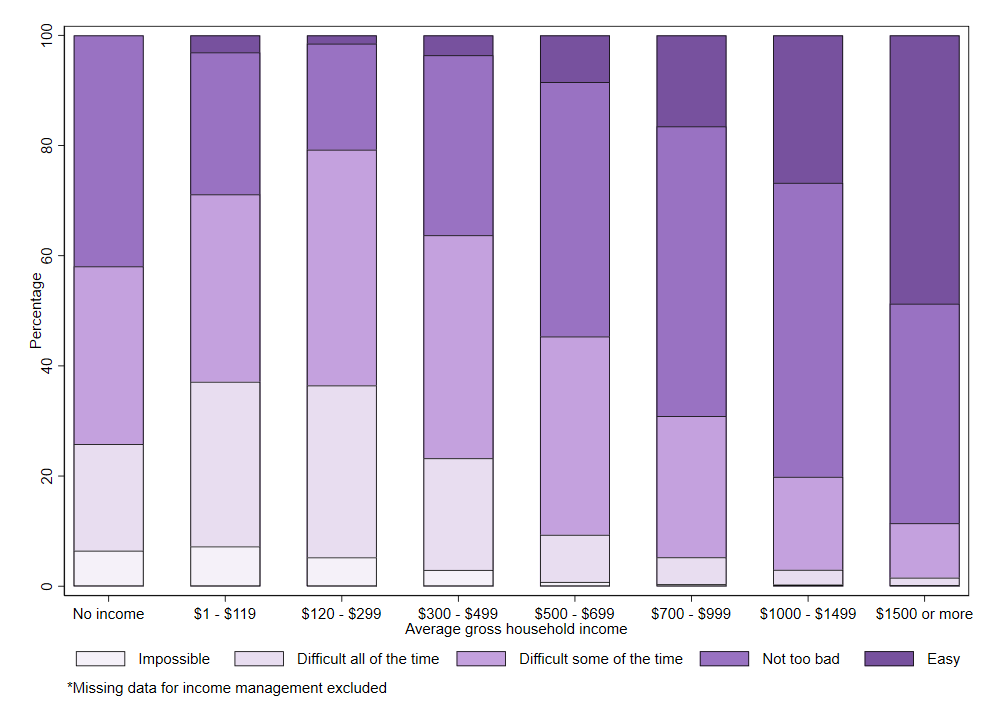
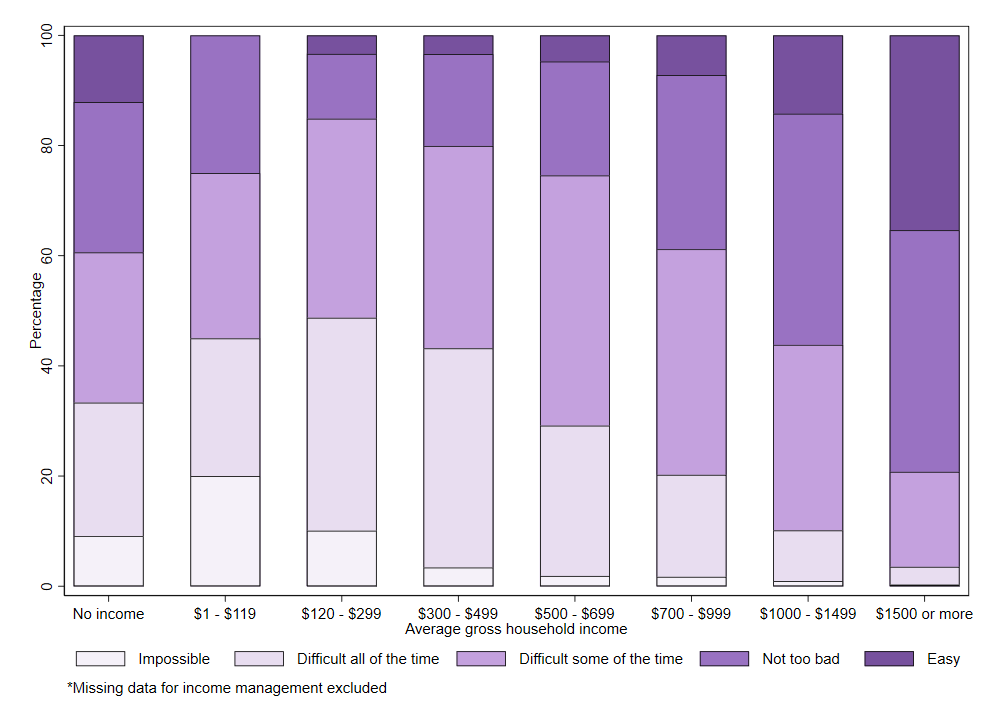


Figure ‑ Missing data for financial resources and education questions for each cohort.

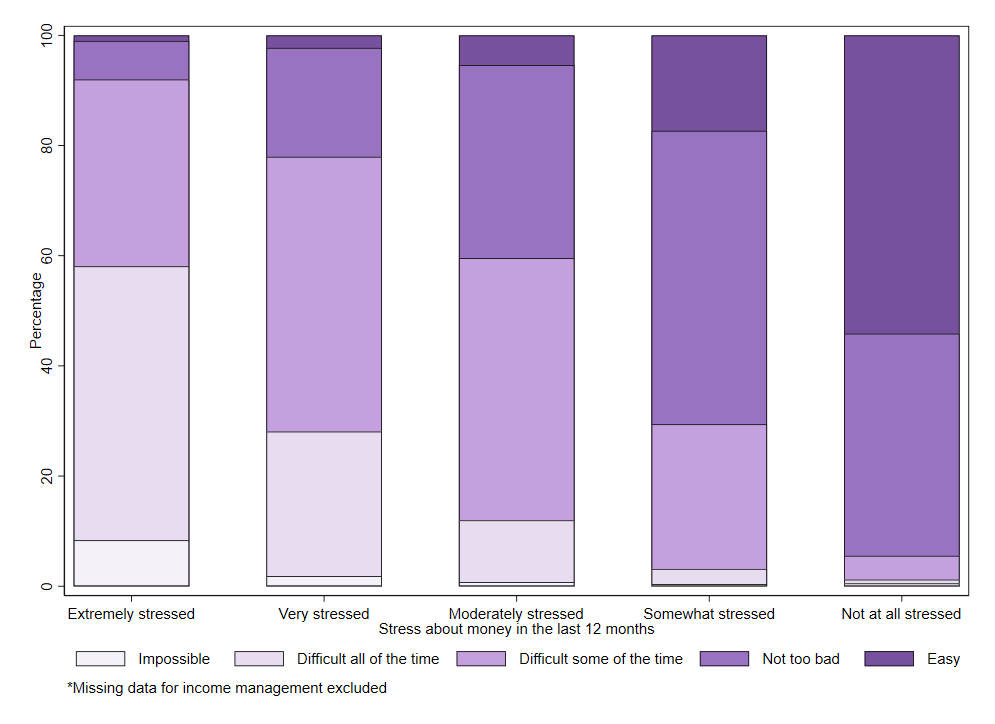
### Income management according to household income and stress about money

As expected, a higher proportion of women respond that they find it easier to manage on their available income when their household income is higher. Figure 7‑4 shows an increasing proportion of women in the 1946-51 cohort describe their ability to manage on available income as ‘Easy’ as their household income increases from ‘$1 to $119 per week’ (3.1%) through to ‘$1,500 or more per week’ (48.7%). The opposite trend holds true for the ‘Difficult all of the time’ and the ‘Impossible’ categories. Figure 7‑5 shows similar trends for the 1973-78 cohort, with an increasing proportion of women who describe their ability to manage on available income as ‘Easy’ with household incomes of ‘$1 to $119 per week’ (0%) through to ‘$1,500 or more per week’ (35.4%).

**Figure 7‑4 Responses for income management among women from the 1946-51 cohort (Survey 3, 2001), according to household income.**

**Figure 7‑5 Responses for income management among women from the 1973-78 cohort (Survey 4, 2009), according to household income.**

**Figure 7‑6** presents an increasing proportion of women in the 1989-95 cohort who describe their ability to manage on available income as ‘Easy’ as stress levels concerning money move from ‘Extremely stressed’ (1.0%) to ‘Not at all stressed’ (54.1%).

**Figure 7‑6 Responses for income management among women from the 1989-95 cohort (Survey 5, 2017), according to household income.**

### Spearman’s rank-order correlation coefficient

Spearman’s rank-order correlation coefficient, also known as Spearman’s rho, measures the strength and direction of association between two ordinal categorical or continuous variables. Here, we present the strength and direction of association between the income management question and the other measures of financial resources. Like Pearson’s correlation coefficient, Spearman’s rho is measured on a scale of minus one to one, with values nearer plus or minus one indicating greater correlation.

Table 7‑4 present Spearman’s rho for income management and each of the other financial resources and education questions. These coefficients were computed for both the first and last survey where each combination of questions was included. For example, income management and highest qualification were both included at Survey 1 and Survey 6 for the 1946-51 cohort, so the Spearman’s rho was computed separately for Survey 1 and Survey 6.

These coefficients show that the income management question exhibits greater correlation with the household income and stress about money questions, and less correlation with the highest qualification question.

Table ‑ Spearman’s correlation coefficients for income management and highest qualification, household income and stress about money

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Cohort** | **Survey** | **Highest qualification** | **Household income** | **Stress about money** |
| 1921-26 | 1 | 0.09 | - | 0.40 |
| 1946-51 | 1 | 0.11 | - | 0.59 |
|  | 2 | - | 0.47 | - |
|  | 3 | - | 0.50 | - |
|  | 6 | 0.18 | - | - |
|  | 8 | - | - | 0.59 |
| 1973-78 | 1 | 0.12 | - | 0.53 |
|  | 3 | - | 0.47 | - |
|  | 4 | - | 0.46 | - |
|  | 8 | 0.23 | - | 0.66 |
| 1989-95 | 1 | 0.06 | - | 0.57 |
|  | 5 | 0.26 | - | 0.64 |

### Cronbach’s alpha and Zumbo’s ordinal alpha

Cronbach’s alpha is a numerical measure of internal consistency, or reliability, of a set items on a scale. Conceptually, and mathematically, we can think of the income management question, the stress about money question and, where available, the household income question as items that make up a two-item or three-item scale that seeks to measure the underlying latent construct of financial resources. The financial resources construct is latent because it cannot be directly measured. The highest qualification question was excluded from these conceptual constructs as it was not as strongly related to financial resources as the other two questions either conceptually or statistically (using Spearman’s rank-order correlation coefficients).

We can then use Cronbach’s alpha to measure the internal consistency between the income management question and the other questions that seek to measure the financial resources construct. Cronbach’s alpha is measured on a scale of zero to one. A higher value for Cronbach’s alpha suggests the items have more shared covariance and are more likely to be measuring the same underlying construct (Hinton, 2004). Additional tests are required to test for unidimensionality.

We also present Zumbo’s ordinal alpha as an alternative measure of internal consistency. Zumbo’s ordinal alpha is a modified form of Cronbach’s alpha that relies on a polychoric correlation matrix, rather than Pearson’s correlation matrix, and is preferred over Cronbach’s alpha when handling ordinal item response data that is skewed or contains few item response levels (Gadermann, Guhn & Zumbo, 2012). We performed each Cronbach’s alpha and Zumbo’s ordinal alpha calculation for the first survey where the two or three items were all included.

There is good internal consistency across all four cohorts for the combinations of questions used to measure financial resources. Cronbach’s alpha and Zumbo’s ordinal alpha estimates ranged from 0.61 to 0.80, with higher values observed when using Zumbo’s ordinal alpha (Table 7‑5). The high degree of shared covariance suggests that the two or three questions intended to measure financial resources in each cohort are likely to be measuring the same underlying construct.

Table ‑ Cronbach's alpha and Zumbo’s ordinal alpha for conceptual financial resources scale

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | | | **Items included in conceptual financial resources scale** | | | | | | |  | |  |
| **Cohort** | | **Survey** | | **Item 1** | | **Item 2** | | **Item 3** | | **Cronbach’s alpha** | | **Zumbo’s ordinal alpha** | |
| 1921-26 | | | 1 | | Income management | | Stress about money | | - | 0.61 | | 0.80 | |
| 1946-51 | | | 2 | | Income management | | Stress about money | | Household income | 0.68 | | 0.74 | |
| 1973-78 | | | 3 | | Income management | | Stress about money | | Household income | 0.67 | | 0.73 | |
| 1989-95 | | | 1 | | Income management | | Stress about money | | - | 0.70 | | 0.76 | |

### Conclusion

The observed internal consistency between the items for income management, stress about money and household income indicate that these items are measuring the same latent construct of individual’s financial resources. Given that the household income question has not been asked at many surveys and when it has been included, it has high rates of missing data, it is reasonable to include the items of income management and stress about money as alternative measures of available financial resources. This is preferable as participants seem more willing to respond to these questions, resulting in less missing data while still adequately measuring their financial resources. We believe that the income management item is a consistent and valid measure.

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## Comparison of the DASS-21 and GADS anxiety subscales in the 1973-78 cohort

*Authors: Dominic Cavenagh, Amy Anderson, Richard Hockey*

### Introduction

The Depression Anxiety and Stress Scale (DASS) is a 42-item questionnaire that contains three subscales that measure depression, anxiety, and stress1,2. There is also a short 21-item version of the scale which has been found to give similar results to the longer form of the scale3. The anxiety subscale of the DASS-21 contains seven questions and was administered in Surveys 6-8 of the 1973-78 cohort.

Table ‑ DASS-21 anxiety subscale as presented in the ALSWH

|  |  |
| --- | --- |
|  | **Please read each statement below and indicate how much the statement applied to you over the past week** |
| a | I was aware of dryness in my mouth |
| b | I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion) |
| c | I experienced trembling (e.g. in the hands) |
| d | I was worried about situations in which I might panic and make a fool of myself |
| e | I felt I was close to panic |
| f | I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat) |
| g | I felt scared without any good reason |

With possible response options ‘Did not apply to me at all’ (0 points), ‘Applied to me to some degree, or some of the time’ (1 point), ‘Applied to me to a considerable degree, or a good part of the time’ (2 points) and ‘Applied to me very much, or most of the time’ (3 points). The scale is scored by summing the points for each question and multiplying by 2.

The Goldberg Anxiety and Depression Scale (GADS) is an 18-item self-report questionnaire that was developed from items in the Psychiatric Assessment Schedule4. The GADS contains two subscales (depression and anxiety) each with 9 items. The GADS anxiety subscale has nine questions and has been administered across cohorts and in multiple surveys in the ALSWH.

Table ‑ GADS anxiety subscale as presented in the ALSWH

|  | **Next are some specific questions about your health and how you have been feeling in the past month** |
| --- | --- |
| a | Have you felt keyed up or on edge? |
| b | Have you been worrying a lot? |
| c | Have you been irritable? |
| d | Have you had difficulty relaxing? |
| e | Have you been sleeping poorly? |
| f | Have you had headaches or neck aches? |
| g | Have you had any of the following: trembling, tingling, dizzy spells, sweating, diarrhoea or needing to pass urine more often than usual? |
| h | Have you been worried about your health? |
| i | Have you had difficulty falling asleep? |

With either a Yes or No response. The scale is scored by counting the number of positive (‘Yes’) responses (max score = 9, min score = 0). Note that in the original paper, Goldberg proposed that if a participant does not score 2 or more on the first 4 questions then the next five do not have to be administered. This seems mainly to be relevant in a situation where someone is administering the scale to a patient (i.e., it is not self-administered as in the ALSWH). Using this alternative scoring results in more people with scores of 1 or 2 but does not significantly change the numbers of people with a score of five or more (the proposed cut-off score). For the rest of this document the continuous GADS anxiety score is considered based on scoring all 9 questions.

As both scales measure anxiety levels, a comparison of them in Surveys 6, 7 and 8 of the 1973-78 cohort was undertaken to see if one of them was preferred, with a view to only include one of the scales in future surveys.

### Internal validity of the DASS and GADS

Internal consistency of the scales was calculated using Cronbach’s alpha at each survey (1973-78 cohort Surveys 6-8) where both scales were administered.

Table ‑. Internal validity of the DASS-21 and GADS anxiety subscales in the ALSWH

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | **Survey** | | |
| **6** | **7** | **8** |
| **Cronbach’s alpha** | *DASS-21 anxiety* | 0.78 | 0.79 | 0.79 |
|  | *Goldberg’s Anxiety* | 0.78 | 0.80 | 0.80 |

There was little change in the internal validity of either scale across time points, and little difference between scales.

### Correlation between DASS-21 anxiety and GADS anxiety subscales

DASS-21 anxiety and GADS anxiety scores were compared using scatter plots and Spearman correlation coefficients at each survey (1973-78 cohort Surveys 6-8) where both scales were administered (Figure 7‑7). Note that points are slightly jittered to prevent overlap in the plots.

| **Survey** | **Plot DASS-21 anxiety vs GADS anxiety** | **Spearman correlation coefficient** |
| --- | --- | --- |
| 6  (2012) |  | 0.47963 |
| 7  (2015) |  | 0.50311 |
| 8  (2018) |  | 0.52892 |

Figure ‑ Correlation between DASS-21 and GADS anxiety subscales in the ALSWH.

In all three surveys, there was only a medium level of correlation between the scores. On inspection of the graphs, it can be noted that it seems possible to score low on the DASS-21 anxiety scale while scoring middle to high on the GADS anxiety scale - however the opposite does not seem to be true. This may be due to the difference in time scales of the two subscales (DASS-21: past week, GADS: past month).

### Score thresholds

Five threshold values have been proposed for the DASS-21 anxiety subscale1 (0-6, 7-9, 10-14, 15-19, 20-42) to signify ‘normal’, ‘mild’, ‘moderate’, ‘severe’ and ‘extremely severe’ anxiety, although it is recommended by the scale authors to use the score value rather that these threshold values if possible. A single threshold of 5 was proposed for the GADs anxiety subscale – a score of 5 or more indicating a 50% chance of having a clinically significant disturbance4.

Table ‑. Percentage of DASS and GADs categorisations at each survey

|  |  |  |  |
| --- | --- | --- | --- |
| **Item** | **Survey 6** | **Survey 7** | **Survey 8** |
| **DASS-21 anxiety** |  |  |  |
| *Normal* | 88.59 | 83.82 | 81.45 |
| *Mild* | 3.88 | 5.12 | 5.85 |
| *Moderate* | 5.02 | 7.36 | 8.46 |
| *Severe* | 1.11 | 1.84 | 1.99 |
| *Extremely Severe* | 1.4 | 1.86 | 2.25 |
| **GADs Anxiety** |  |  |  |
| *<5* | 59.16 | 56.43 | 53.55 |
| *≥5* | 40.84 | 43.57 | 46.45 |

Table 7‑10 paints a very different picture depending on which scale is used based on the original scale authors threshold values. Use of the DASS-21 as a continuous measurement (as is recommended) is slightly problematic in a general setting (such as the ALSWH), as there is a very high percentage of 0 values (50.5%, 60.9% and 64% for surveys 6, 7 and 8 respectively). It is also unclear whether Goldberg intended his anxiety score to be used as a continuous measure, or whether it should only be used as a dichotomous score based on the 5 point cut level.

### DASS-21 and GADS anxiety subscales as predictors/correlates of anxiety/mental health

Three other anxiety related measures are administered through the ALSWH: self-report of diagnosed/treated for anxiety in the last 3 years (Yes/No); frequency of episodes of intense anxiety (Never, rarely, sometimes, often); and SF-36 mental health subscale score. Each of these were compared with both the GADS and DASS-21 anxiety subscale scores at Surveys 6-8 for the 1973-78 cohort. The Area Under the Curve was computed using both measures as predictors of anxiety diagnosed/treated, and Spearman correlation coefficients were calculated between the measures and the anxiety symptom and SF-36 measure.

Table ‑ Comparisons of the DASS-21 and GADS anxiety subscales to other mental health measures in the ALSWH

| **Comparison method/measure** | **Anxiety measure** | **Survey 6** | **Survey 7** | **Survey 8** |
| --- | --- | --- | --- | --- |
| **ROC AUC for predicting diagnosed/treated for anxiety**  *(Yes/No diagnosed/treated for anxiety in last 3 years)* | *DASS-21 anxiety score* | 0.745 | 0.753 | 0.753 |
| *GADS anxiety score* | 0.733 | 0.716 | 0.730 |
| **Correlation with anxiety symptom (Spearman)**  *(frequency of episodes of intense anxiety in last year)* | *DASS-21 anxiety score* | 0.422 | 0.490 | 0.514 |
| *GADS anxiety score* | 0.390 | 0.411 | 0.449 |
| **Correlation with SF36 mental health subscale score (Spearman)**  *(How have you been feeling in the last 4 weeks)* | *DASS-21 anxiety score* | -0.440 | -0.482 | -0.491 |
| *GADS anxiety score* | -0.649 | -0.637 | -0.634 |

Interestingly the DASS-21 anxiety score has higher predictive ability/correlation with self-reported diagnosis/treatment and anxiety symptoms, while the GADS anxiety score correlates higher with the SF-36 mental health subscale score. It should be noted that the SF-36 mental health score does not measure only anxiety, but a more general mental health aspect. Again, note the difference in time scales of the comparison items - specifically that the SF-36 mental health score has a similar time frame to the GADS anxiety subscale.

### Summary

Both the DASS-21 and GADs anxiety subscales have reasonable internal validity in the ALSWH, with the DASS-21 performing better against measures of diagnosed anxiety and anxiety symptoms, and the GADs correlating better with the general SF-36 mental health subscale score. Comparisons between the scales are difficult due to the different time frames of the questions. Difficulty is also present due to the lack of a ‘gold standard’ measure for anxiety amongst the ALSWH cohorts. Use of threshold scores produces vastly different categorisations between scales. There is evidence that the DASS-21 (and DASS-42) is in more common usage in the literature (Lovibond & Lovibond (1995) has 7,066 citations in Google Scholar and 3,573 in Web of Science, compared to Goldberg et al. (1988) being cited 1,217 times in Google Scholar and 681 times in Web of Science). This may be in part due to the entire DASS scale being in the public domain.

In summary, it seems that these scales are quite different, and have very different interpretations (based on time frame, use of cut-points, severity of measure etc.) and thus it is not possible to definitively choose between them in the current context. In deciding which scale to use, the authors recommend careful consideration of the research question in which the scales will be used, how they will be employed in any analysis, the fact that the scales are self-administered and if there is any previous research to indicate which of the scales would suit the research question/domain better.

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## Assessing agreement between the K10 and MHI-5 measures of psychological wellbeing

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During the year, agreement between the K10 and MHI-5 as measures of psychological wellbeing was examined. A paper has been published in *Applied Research in Quality of Life* and the abstract is included below - the full paper is available [online](https://link.springer.com/article/10.1007/s11482-020-09843-0).

Responses to the Kessler Psychological Distress Scale (K10) and the Mental Health Index-5 (MHI-5) mental health subscale of the Medical Outcomes Study Short Form (SF-36) survey cover broadly similar constructs. The aim of this paper is to use the equipercentile method to produce a concordance between K10 and MHI-5 across the whole score distribution.

Comparisons were made using survey data from the ALSWH and the Household, Income and Labour Dynamics in Australia (HILDA) survey, which used both the K10 and the MHI-5 measures at the same time for the same participants. Agreement was assessed with Bland-Altman plots. The differences between MHI-5 scores and transformed K10 scores were assessed with paired t-tests. For the ALSWH data there is good agreement between MHI-5 scores and scores equated from the K10. The mean of the differences ranged from 0.43 to 3.38 with corresponding standard deviations of 11.1 to 9.9. The concordance table was very similar to one obtained by the more complicated item response theory method.

These results suggest that longitudinal surveys of the same respondents that previously used MHI-5 could adopt the K10 (or vice versa) without loss of compatibility.

# Major Report: The effect of multiple chronic conditions – Findings from the Australian Longitudinal Study on Women’s Health

The 2020 Major Report examined the development of multi-morbidity (two or more chronic conditions) across the four ALSWH cohorts. The impact of multimorbidity on women’s quality of life, and the use of health services were also examine, and qualitative data available from the women’s comments on their surveys were also included to give voice to the experience of women with multimorbidity. A summary is included here – the [full report](https://www.alswh.org.au/publications-and-reports/major-reports) is available on the Study website.

## Main findings and recommendations

In order to examine multimorbidity, we focussed on identifying eight groups of common conditions affecting different body systems. These are:

* Musculoskeletal conditions – including osteoarthritis, rheumatoid arthritis, back pain, osteoporosis and joint replacements
* Mental health conditions – mostly anxiety and depression
* Coronary heart disease – including heart failure
* Respiratory disease – asthma and chronic obstructive pulmonary disease
* Cancers – all types except non-melanotic skin cancer
* Diabetes – types 1 and 2
* Dementia – all types
* Stroke – excluding transient ischaemic attack

Women who had conditions in two or more of these groups were considered to have multimorbidity, with morbidity counts representing the number of groups involved. Consequently, a woman with arthritis and asthma would be counted as having conditions in two groups (musculoskeletal and respiratory), whereas a woman with arthritis and back pain would be considered to have morbidity in only one group (musculoskeletal). It should also be noted that we did not identify all conditions that may affect women, but instead concentrated on conditions that are common and which are known to contribute strongly to women’s morbidity and mortality burden.

The prevalence of most conditions increased with age, and across the cohorts. Consequently, most conditions were most common in the 1921-26 cohort, increasing from when these women were in their 70s until surviving women were in their 90s. However, the prevalence of many conditions was higher among the 1946-51 cohort when they were in their 70s, compared to when the 1921-26 cohort were the same age. This disconnect may represent an increased prevalence of chronic conditions across the different cohorts. Alternatively, there may be a healthy survivor effect whereby women who joined the 1921-26 cohort at the start of the study had less chronic conditions than those who did not join the study. Another possible explanation is that there are better methods for diagnosis, and more treatments for women in the younger cohorts and so we are more aware of their conditions. Earlier diagnosis and survival with chronic disease will also affect prevalence. Another factor is availability of data; for example, where the identification of cases relied heavily on Medicare items such as the Better Access Scheme prevalence would be underestimated before the items were introduced. On the other hand, there are potentially more opportunities to identify chronic conditions in the oldest cohort, as more have been admitted to hospital and many have records from aged care and cause of death data.

* The prevalence of musculoskeletal conditions increases with age, but is higher in the 1946-51 cohort in their 70s than in the 1921-26 cohort when in their 80s; and higher in the 1989-95 cohort than in the 1973-78 cohort when they were of comparable ages. These data suggest musculoskeletal diseases are increasing with successive cohorts, though they could also be affected by data availability.
* Mental health conditions are markedly more common among women in the younger cohorts than in the older cohorts.
* Heart disease shows a steady increase across the cohorts, with a marked increase in prevalence from age 55 in the 1946-51 cohort to age 90 in the 1921-26 cohort.
* Respiratory conditions increase with age in all cohorts but the type of condition differs. Asthma is more common among the younger cohorts and chronic obstructive pulmonary disease is more common among the older cohorts. Some of the increase may be due to temporal changes in health services or prescribing for women with asthma, and with most of the cases identified from prescription medicines.
* Cancer increases with age in all cohorts, but is much more common among women in the 1946-51 cohort when aged 70 than in the 1921-26 cohort when they were aged 70. This may reflect earlier detection, better diagnosis, better survival, or increased incidence.
* Diabetes increases with age in all cohorts, but is much more common among women in the 1946-51 cohort when aged 70 than in the 1921-26 cohort when they were aged 70. This may reflect earlier and better diagnosis, better survival, or increased incidence.
* Dementia was only ascertained for the 1921-26 cohort. There is a rapid increase with age, partially representing onset of these conditions at older ages, and also partially representing the greater use of hospital and aged care services which were a major source of information on dementia.
* Stroke also increases rapidly with age. There is no evidence that women in the 1946-51 cohort have more stroke than women in the 1921-26 cohort, and some suggestion of lower prevalence of stroke among the younger cohort (which is consistent with national trends).

Multimorbidity was assessed by counting whether women had conditions across two or more of these disease groups. Taking a snap shot at the time of the most recent full survey for each cohort, the most common pairs of condition groups are shown in Table 8‑1.

Table ‑ Most common pairings of chronic conditions for women in each ALSWH cohort, at the time of their most recent survey.

|  |  |  |
| --- | --- | --- |
| **Cohort** | **Most recent full survey** | **Pairs of conditions groups** |
| 1989-95 | Survey 6, 2018  (age 23-28) | Musculoskeletal and mental health conditions  Mental health and respiratory conditions  Musculoskeletal and respiratory conditions |
| 1973-78 | Survey 7, 2016  (age 38-43) | Musculoskeletal and mental health conditions  Mental health and respiratory conditions  Musculoskeletal and respiratory conditions |
| 1946-51 | Survey 8, 2017  (age 66-71) | Musculoskeletal and mental health conditions  Musculoskeletal conditions and heart disease  Musculoskeletal conditions and diabetes |
| 1921-26 | Six-monthly follow-up surveys (2015)  (age 89-94) | Musculoskeletal conditions and heart disease  Musculoskeletal and mental health conditions  Mental health conditions and heart disease |

The progression of multimorbidity was reviewed over time for each cohort. Most of the women in the 1921-26 cohort had conditions from two or more of the groups of conditions, with more than 75% having two or more, and 50% having three or more by the time women were in their mid 80s. For the 1946-51 cohort, 25% of the women had two or more groups of conditions when they were in their 50s, and 50% had two or more when they were in their 60s. In the 1973-78 cohort, 20% had two or more groups of conditions when they were in their 40s. In comparison, in the 1989-95 cohort, 20% of the women had two or more groups of conditions when they were in their mid 20s. The higher incidence of multimorbidity at earlier ages in the 1989-95 cohort, compared to the 1973-78 cohort is largely due to mental health conditions.

The more multimorbidity a woman has the greater the impact on her physical and mental health related quality of life. In the 1921-26 cohort, women in their 90s with none of the conditions considered in this report had median physical functioning scores indicating they have few difficulties with most of the physical activities assessed by this scale. However, there was great variation in the range of scores even for women with none of the conditions. Women with more conditions had markedly lower mean scores, and while there was still great variability across the range of scores, most women with conditions in two or more of the groups had scores that suggest they would have difficulty on most of the physical activities assessed by the SF-36 physical functioning scale.

While the median scores tended to be higher overall, the relationship between multimorbidity and physical functioning was also strongly apparent in the 1946-51 cohort. The effect was less strong for the younger cohorts - however women with conditions in two or more groups had lower median physical functioning scores than women with no conditions or a condition(s) in only one group. The association between more multimorbidity and worse mental health was apparent in all cohorts. Higher levels of multimorbidity are also associated with much higher levels of health service and aged care use in the most recent periods considered in this report.

For the 1921-26 cohort (from ages 86-91 to 89-94):

* The one-year prevalence of admission to hospital increased from 40% for women with no conditions, to 80% or higher for those with conditions across four or more of the groups.
* The median number of general practitioner visits increased from 6 per year for women with no chronic conditions to 17 per year for women with conditions across seven or more of the condition groups.
* The median number of specialist visits increased from just over 1 per year for women with no chronic conditions to 3 or 4 per year for women with conditions across seven or more of the condition groups.
* The median number of prescriptions increased from 22 per year for women who had none of the groups of conditions assessed in this report, to over 70 per year if they had conditions across four or more groups.
* The percentage of women in permanent residential aged care was close to zero for women with none of the conditions assessed in this report, and increased to over 20% for women with conditions across four or more of the condition groups.
* The percentage of women using home and community care nursing and allied health services almost doubled from around 10% for women with no conditions, to over 20% for women with one or more of the conditions. However, the increase in the percentage was not consistent across the range of multimorbidities, potentially due to higher percentages in permanent residential aged care in the group with multiple morbidities. Likewise, the use of other home and community care services increased from no conditions up to conditions across two or three groups, but did not increase further with more complex multimorbidity.

For the 1946-51 cohort (from ages 62-67 to 65-70):

* The one-year prevalence of admission to hospital increased from less than 30% for women who had none of the conditions considered in this report, to over 70% for women who had conditions across four or more of the groups.
* The median number of general practitioner visits increased from 4 per year for women with no chronic conditions to 12 per year for women who had conditions across five or more of the groups.
* The median number of specialist visits increased from just over 1 per year for women with no chronic conditions to 3 or 4 per year for women who had conditions across five or more of the groups.
* The median number of prescriptions increased from 6 per year for women who had no conditions assessed in this report, to over 50 per year if they had conditions across four or more of the groups.

For the 1973-78 cohort (from ages 35-40 to 38-43):

* The one-year prevalence of admission to hospital increased from around 30% for women who had none of the conditions, to around 70% for women who had conditions across three or more of the groups (noting that some of these women may have been admitted for obstetrics care).
* The median number of general practitioner visits increased from 4 per year for women with no chronic conditions to 6 per year for women who had conditions across three or more of the groups.
* The median number of specialist visits increased from 0 per year for women with no chronic conditions to 1-2 per year for women who had conditions across three or more groups.
* The median number of prescriptions increased from 2 per year for women who had none of the conditions assessed in this report, to around 11 per year for women who had conditions across three or more of the groups.

For the 1989-95 cohort (from ages 18-24 to 21-27):

* The one-year prevalence of admission to hospital increased from less than 30% for women who had none of the conditions considered, to over 60% for women who had conditions across three or more of the groups.
* The median number of general practitioner visits increased from 4 per year for women with none of the chronic conditions to 8 per year for women who had conditions across three or more of the groups.
* The median number of specialist visits increased from 0 per year for women with none of the chronic conditions to 1-2 per year for women who had conditions across four or more of the groups.
* The median number of prescriptions increased from 2 per year for women who had none of the conditions assessed in this report, to around 12 per year if they had conditions across four or more of the groups.

The women’s written comments on the ALSWH surveys illustrate the effects of multiple conditions on their lives. They underscore the importance of having access to good health professionals they can trust, a lack of financial barriers to accessing health care, the importance of self-management, and the need for strong social support systems.

## Conclusion

Overall, this report shows that multimorbidity is common with most women having more than one chronic condition across more than one group. Moreover, many women had conditions across three or more groups, representing complex multimorbidity. While levels of morbidity increase with age, multimorbidity is also common among younger women, and may increase across successive cohorts. Regardless of whether this increase is due to better diagnosis, better survival, or increased disease risk, the presence and prevalence of multimorbidity poses particular challenges to the health system. The first challenge is meeting the demand for health care, with associated costs, infrastructure and skilled personnel in the health care system. The second challenge is the complexity of effectively managing multiple conditions where treatments may interact, and where the progress of one condition may affect the onset or progress of another. However, this challenge must also be considered from the perspective of the individual woman, and in the context of her life. A person-centred approach to health and wellbeing is needed to enable women to access health services in a timely and cost-efficient way. The system needs to provide consistent and coordinated care across the range of physical and mental health needs. Additionally, there is a need for instrumental and social supports for people with chronic conditions and ongoing needs for care.

# DISSEMINATION OF STUDY FINDINGS

## Publications

Since the last Technical Report (15 November 2019) there have been 55 publications recorded using ALSWH data. The most frequently published research themes were chronic conditions, reproductive health, mental health, and weight, nutrition and physical activity (Table 9‑1 ).

Table ‑ ALSWH publications from November 2019 to November 2020 by research theme.

|  |  |
| --- | --- |
| **Theme** | **No. publications** |
| [Chronic conditions](#Chronicconditions) | 21 |
| [Reproductive health](#Reproductivehealth) | 20 |
| [Weight, nutrition and physical activity](#WeightnutritionPA) | 16 |
| [Mental Health](#Mentalhealth) | 13 |
| [Social factors in health and wellbeing](#Socialfactors) | 10 |
| [Health service use](#Healthserviceuse) | 9 |
| [Ageing and Aged Care](#Ageing) | 7 |
| [Methodology](#Methodology) | 5 |
| [Formal and informal work patterns and work life balance](#Formalandinformalworklifebalance) | 3 |
| [Abuse](#Abuse) | 3 |
| [Tobacco, alcohol and other drugs](#Tobaccoalcoholdrugs) | 2 |
| [Medications](#Medications) | 2 |

Publications in each theme are listed below – please note, publications often encompass more than one theme, so may be appear in more than one category. A list of all ALSWH publications is available on the [Study website](https://www.alswh.org.au/publications-and-reports/published-papers).

**CHRONIC CONDITIONS**

* Abbas SS, Majeed T, Nair BR, Forder P, Weaver N & Byles J. (2020). Patterns of medications for atrial fibrillation among older women: Results from the Australian Longitudinal Study on Women’s Health. *Journal of Cardiovascular Pharmacology and Therapeutics*; [https://doi.org/10.1177/1074248420947278](https://doi.org/10.1177%2F1074248420947278)
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* Tay CT, Moran LJ, Harrison CL, Brown WJ & Joham AE. (2020). Physical activity and sedentary behaviour in women with and without polycystic ovary syndrome: An Australian population-based cross- sectional study. *Clinical Endocrinology*; 93(2):154-162. <https://doi.org/10.1111/cen.14205>
* Tay CT, Teede HJ, Loxton D, Kulkarni j & Joham AE. (2020). Psychiatric comorbidities and adverse childhood experiences in women with self-reported polycystic ovary syndrome: An Australian population-based study. *Psychoneuroendocrinology*; 116: 104678. <https://doi.org/10.1016/j.psyneuen.2020.104678>
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Rowlands IJ, Abbott JA, Montgomery GW, Hockey R, Rogers P & Misrha GD. Prevalence and incidence of endometriosis in Australian women: A data linkage cohort study. *Journal of Obstetrics and Gynaecology*

**REPRODUCTIVE HEALTH**

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Rowlands IJ, Abbott JA, Montgomery GW, Hockey R, Rogers P & Misrha GD. Prevalence and incidence of endometriosis in Australian women: A data linkage cohort study. *Journal of Obstetrics and Gynaecology*

**WEIGHT, NUTRITION AND PHYSICAL ACTIVITY**

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**MENTAL HEALTH**

* Aulike IA, Dobson AJ, Egwunye J, Fitzgerald DM & Mishra GD. (2020). Assessing agreement between the K10 and MHI-5 measures of psychological wellbeing. *Applied Research in Quality of Life*; <https://rdcu.be/b6y4h>
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**Accepted publication**

Hendryx M, Luo J, Chojenta C & Byles JE. Air pollution increases depression risk among young women: Possible natural world resiliencies. *Ecopsychology*

**SOCIAL FACTORS IN HEALTH AND WELLBEING**

* Callender D, Mooney-Somers J, Keen P, Guy R, Duck T, Bavinton BR, Grulich AE, Holt M & Prestage G. (2020). Australian 'gayborhoods' and 'lesborhoods': A new method for estimating the number of adult gay men and lesbian women living in each. *International Journal of Geographical Information Science*, <https://doi.org/10.1080/13658816.2019.1709973>
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**Accepted publication**

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**HEALTH SERVICE USE**

* Abbas SS, Majeed T, Nair BR, Forder P, Weaver N & Byles J. (2020). Patterns of medications for atrial fibrillation among older women: Results from the Australian Longitudinal Study on Women’s Health. *Journal of Cardiovascular Pharmacology and Therapeutics*; [https://doi.org/10.1177/1074248420947278](https://doi.org/10.1177%2F1074248420947278)
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**AGEING AND AGED CARE**

* Abbas SS, Majeed T, Nair BR, Forder P, Weaver N & Byles J. (2020). Patterns of medications for atrial fibrillation among older women: Results from the Australian Longitudinal Study on Women’s Health. *Journal of Cardiovascular Pharmacology and Therapeutics;* [https://doi.org/10.1177/1074248420947278](https://doi.org/10.1177%2F1074248420947278)
* Abbas SS, Majeed T, Nair BR, Forder P, Weaver N & Byles J. (2020). Burden of atrial fibrillation and stroke risk among octagenarian and nonagenarian women in Australia. *Annals of Epidemiology*; 44: 31-37. <https://doi.org/10.1016/j.annepidem.2020.02.004>
* Dobson AJ, Waller MJ, Hockey R, Dolja-Gore X, Forder PM & Byles JE. (2020). Impact of dementia on health service use in the last 2 years of life for women with other chronic conditions. *Journal of the American Medical Directors Association*; <https://doi.org/10.1016/j.jamda.2020.02.018>
* Rahman M & Byles J. (2020). Older women’s patterns of home and community care use and residential transition: An Australian cohort study. *Maturitas*; 131:28-33. <https://doi.org/10.1016/j.maturitas.2019.10.004>
* Shebeshi DS, Dolja-Gore X & Byles J. (2020). Estimating unplanned and planned hospitalization incidents among older Australian women aged 75 years and over: The presence of death as a completing risk. *Health Planning and Management*; <https://doi.org/10.1002/hpm.3030>
* Thapaliya K, Harris ML & Byles JB. Use of medication reviews among older women with dementia, 2003-2015: A longitudinal cohort study. *Australasian Journal on Ageing*; <https://doi.org/10.1111/ajag.12836>
* Wubishet BL, Byles JE, Harris ML & Jagger C. Impact of diabetes on life and healthy life expectancy among older women. *The Journals of Gerontology: Series A*; <https://doi.org/10.1093/gerona/glaa172>

**METHODOLOGY**

* Aulike IA, Dobson AJ, Egwunye J, Fitzgerald DM & Mishra GD. (2020). Assessing agreement between the K10 and MHI-5 measures of psychological wellbeing. *Applied Research in Quality of Life;* <https://rdcu.be/b6y4h>
* Campbell A, Perales F & Baxter J. (2020). Sexual minority women in longitudinal survey research: Is attrition a problem? *Archives of Sexual Behaviour*; 49(5): 1443-1461. <https://doi.org/10.1007/s10508-020-01669-z>
* Dobson A, Hockey R, Chan HW & Mishra G. (2020). Flexible age-period-cohort modelling illustrated using obesity prevalence data*. BMC Medical Research Methodology*, 20:16. https://doi.org/10.1186/s12874-020-0904-8
* Liverani S, Leigh L, Hudson IL & Byles JE. (2020). Clustering method for censored and collinear survival data. *Computational Statistics*; <https://doi.org/10.1007/s00180-020-01000-3>
* Shebeshi DS, Dolja-Gore X & Byles J. (2020). Estimating unplanned and planned hospitalization incidents among older Australian women aged 75 years and over: The presence of death as a completing risk. *Health Planning and Management*; <https://doi.org/10.1002/hpm.3030>

**FORMAL AND INFORMAL WORK PATTERNS AND WORK/LIFE BALANCE**

* Doiron D & Kettlewell N. (2020). Family formation and the demand for health insurance. *Health Economics*; 29(4): 523-533. <https://doi.org/10.1002/hec.4000>
* Gao N, Ryan M, Krucien N, Robinson S & Norman R. (2020). Paid work, household work, or leisure? Time allocation pathways among women following a cancer diagnosis. *Social Science & Medicine*; 246. <https://doi.org/10.1016/j.socscimed.2019.112776>
* Johnstone M, Lucke J & Hewitt B. (2020). Life transitions and women’s desired number of children: The impact of motherhood, relationships and employment. Community, Work and Family; <https://doi.org/10.1080/13668803.2020.1744526>

**ABUSE**

* Cations M, Keage HAD, Laver KE, Byles J & Loxton D. (2020). Intimate partner violence and risk for mortality and incident dementia in older women. *Journal of Interpersonal Violence*. <https://doi.org/10.1177/0886260520943712>
* Consistency and inconsistency of young women’s reporting of intimate partner violence in a population-based study. Rowlands IJ, Holder C, Forder P, Hegarty K, Dobson AJ & Loxton D. *Violence Against Women*, 2020. [https://doi.org/10.1177/1077801220908324](https://doi.org/10.1177%2F1077801220908324)
* Tay CT, Teede HJ, Loxton D, Kulkarni j & Joham AE. (2020). Psychiatric comorbidities and adverse childhood experiences in women with self-reported polycystic ovary syndrome: An Australian population-based study. *Psychoneuroendocrinology*; 116: 104678. <https://doi.org/10.1016/j.psyneuen.2020.104678>

**TOBACCO, ALCOHOL AND OTHER DRUGS**

* Anderson AE, Cavenagh D, Forder P, Loxton D & Byles J. (2020). Alcohol-related risk from pre-loading and heavy episodic drinking (HED) among a cohort of young Australian women: A cross-sectional analysis. *Australian and New Zealand Journal of Public Health*; <https://doi.org/10.1111/1753-6405.13018>
* Melka AS, Chojenta CL, Holliday EG & Loxton DJ. (2020). E-cigarette use and cigarette smoking initiation among Australian women who have never smoked. *Drug and Alcohol Review*; <https://doi.org/10.1111/dar.13131>

**MEDICATIONS**

* Abbas SS, Majeed T, Nair BR, Forder P, Weaver N & Byles J. (2020). Patterns of medications for atrial fibrillation among older women: Results from the Australian Longitudinal Study on Women’s Health. *Journal of Cardiovascular Pharmacology and Therapeutics;* [https://doi.org/10.1177/1074248420947278](https://doi.org/10.1177%2F1074248420947278)
* Thapaliya K, Harris ML & Byles JB. Use of medication reviews among older women with dementia, 2003-2015: A longitudinal cohort study. *Australasian Journal on Ageing*; <https://doi.org/10.1111/ajag.12836>

## Conference Presentations

Due to COVID-19 restrictions some conferences in 2020 have been cancelled, and others offered online. 28 presentations using ALSWH data had been recorded in our database since the last Technical Report.

* Baldwin JN, Forder P, Haslam R, Hure A, Loxton DJ, Patterson AJ & Collins CE. **Change in diet quality and 15-year healthcare costs in the mid-age cohort of the Australian Longitudinal Study on Women’s Health**. *2020 International Society of Behavioural Nutrition and Physical Activity (ISBNPA)*, XChange, Auckland, New Zealand (online), 17 - 20 June 2020.
* Bennet CJ, Mansfield D, Mo L, Hodge A, Joham J Cain S, Blumfield M, Teede H & Moran L. **Sleeping behaviour in women with and without polycystic ovary syndrome (PCOS) and their association with lifestyle factors (diet, physical activity and sitting time).** Poster presentation. *ENDO 2020*, San Francisco, USA 28-31 March 2020.
* Byles J. **A decade of healthy ageing? What good looks like and how we get there**? *International Longevity Centre UK Webinar*. 23 July 2020.
* Byles J. **Promoting prevention across the life course: The role of policymakers and civil society**. *Prevention in an ageing world – G20 side event*. (Invited speaker). ANA Crowne Plaza Hotel, Okayama, Japan, 18 October 2019.
* Byles J. **Six essential aspects for LTC: An evidence-based evaluation of the Australian LTC system.** *2019 Asia-Pacific Policy Forum for Long-term Care in Aging: Facing the Aged Society and Future of Long-term Care*. (Invited speaker). Kaoshiung Medical University, Kaoshiung, Taiwan, 21 October 2019.
* Byles J. **Health and wellbeing: Golden assets in a silver world**. *IAGG 11th IAGG Asia/Oceania Regional Congress 2019.* (Keynote speaker). Taipei, Taiwan, 23-27 October 2019.
* Byles J. **Integrating prevention in policy (Australian perspective).** *IAGG 11th IAGG Asia/Oceania Regional Congress 2019*. Taipei, Taiwan, 23-27 October 2019,
* Byles J, Rahman M, Princehorn E, Holliday E, Leigh L, Loxton D, Beard J, Kowal P, Jagger C. **Successful ageing from old to very old: Findings from a longitudinal study of 12,432 women from Australia.** *52nd AAG conference*, ICC Darling Harbour, Sydney, Australia. 5-8 November 2019.
* Byles J. **Six essential aspects for LTC: An evidence-based evaluation of the Australian LTC system.** *International Longevity Centre Global Alliance long-term care and care giving symposium.* The Benevolent Society, Glebe, NSW, Australia, 5 November 2019.
* Byles J. **Healthy Ageing: A multi-dimensional perspective contrasting measures of older people’s abilities against their own experiences**. *Centre for Excellence in Population Ageing Research (CEPAR)*. (Invited Speaker)University of New South Wales Business School. Sydney, 28 January 2020.
* Byles J. *6th Annual MARC Symposium: From Cells to Society – The most recent trends in Research and Ageing*. Virtual symposium. 15 and 17 July, 2020.
* Campbell A, Perales F & Baxter J. **Patterns and prevalence of sexual identity change: Evidence from two cohorts of Australian women**. *International Academy of Sex Researchers 2020 Virtual Meeting*, 29 July 2020.
* Gete DG, Waller M & Mishra GD. **Pre-pregnancy diet quality and its association with offspring behavioural problems.** *Nutrition 2020 Live Online*, 30 May - 2 June 2020.
* Melka A, Chojenta C, Holliday E & Loxton D. **Adverse childhood experiences and electronic cigarette use among young Australian women** (Poster presentation*). Australian Society of Behavioural Health and Medicine (ASBHM) Annual Scientific Meeting*, Sydney, NSW 5 - 7 February 2020.
* Mishra GD. **A life course approach to preconception health and pregnancy planning**. *9th International Conference on Birth Defects and Disabilities in the Developing World*, Colombo, Sri Lanka, 23 - 26 February 2020.
* Mishra G. **Causes and consequences of premature and early menopause: Results from the InterLACE consortium.** *European Menopause and Andropause Society*, Berlin, Germany,15 May 2019.
* Mishra G. **Epidemiology of endometriosis**. *Australasian Gynaecological Endoscopy & Surgery Society (AGES) and The World Endometriosis Society (WES) meeting*, Melbourne, 2-3 August 2019.
* Mishra G. **Epidemiology of endometriosis**. Society for Reproductive Biology Meeting, Sydney, 17 August 2019.
* Mishra G. **Long term health outcomes after hysterectomy**. *Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) Annual Scientific Meeting*, Melbourne,13 -16 October 2019.
* Mishra G. *Jean Hailes Women’s Health symposium* (keynote speaker), Canberra, 22-23 October 2019.
* Mishra G. *Norwegian Epidemiological Association*. Oslo, Norway,13 -14 November 2019.
* Mishra G. **Seminar**. The Centre for Fertility and Health at the Norwegian Institute of Public Health, Oslo, Norway, 15 November 2019.
* Mishra G. 2019 *International Conference for Intelligence and Big Health* (Plenary speaker), Zhejiang University & the Second Affiliated Hospital of Zhejiang University School of Medicine, Hangzhou, China, 5-8 December 2019.
* Rahman M, Byles JE, Holliday E. **Association between patterns of community care use and RAC admission**. *52nd AAG conference*, ICC Darling Harbour, Sydney, Australia, 5-8 November 2019.
* Shehzad S, Byles JE, Nair K, Majeed T, Weaver N. **Atrial fibrillation – Medication patterns in older women in Australia**. *52nd AAG conference*, ICC Darling Harbour, Sydney, Australia, 5-8 November 2019.
* Thapaliya K, Byles JE, Harris M. **Prevalence of drugs use before and after dementia diagnosis**. *52nd AAG conference*, ICC Darling Harbour, Sydney, Australia, 5-8 November 2019.
* Thiruchelvam K, Hasan SS, Wong PS, Byles J, Kairuz T. **Uptake of medication reviews among older women in the Australian Longitudinal Study of Women’s Health**. *52nd AAG conference*, ICC Darling Harbour, Sydney, Australia, 5-8 November 2019.
* Tollosa D. **A 15-year follow-up study on long-term adherence to health behaviour recommendations in women diagnosed with breast cancer** (poster presentation). *2020 International Society of Behavioural Nutrition and Physical Activity (ISBNPA)*, XChange, Auckland, New Zealand (online), 17 - 20 June 2020.
* Wubishet B, Byles J, Harris M, Jagger C. **Impact of diabetes on life expectancy and healthy life expectancy among older Australian women.** 18th National Conference of Emerging Researchers in Ageing, Sydney, Australia, 4-7 November 2019.

## Media

Research from the Study has been reported in a range of mainstream media throughout the year. Details are shown in Table 9‑2.

Table ‑ ALSWH media from October 2019 – November 2020

| **Date** | **Media** | **Media Source** | **Topic** | **Investigator Details** |
| --- | --- | --- | --- | --- |
| **2019** | | | | |
| 28 October  31 October | Online | Mercola (USA) | Fermented dairy lowers heart disease | [Amée Buziau](javascript:;)  Prof [Gita Mishra](javascript:;) |
| 26 November | Online | 137 local online news sites around the US including: Northwest Georgia News, Pittswburge Post-Gazette, The Punxsutawney Spirit | Vifor Pharma raises awareness on Iron Deficiency Day 2019 for people around the world to take iron seriously (ALSWH cited) |  |
| 21-26 December | Online | Malaysia News  NewKerala.com (India)  Malay Mail  The International Business Times Singapore  The Shillong Times (India)  Yahoo Malaysia  Yahoo Singapore | Longer exposure to obesity linked to high diabetes risk | A/Prof Juhua Luo  Prof Julie Byles |
| **2020** | | | | |
| 08 January  30 January |  | Gulf News (UAE)  Healio (USA)  Bariatric News  Pharmacy Times |  | A/Prof Juhua Luo  Prof Julie Byles |
| 20 – 25 January | Online | Yahoo News UK  Medical Xpress  Medindia  Aged Care Insite (Australia)  Health Medicine Network (USA)  Yahoo News Singapore  MSN Health UK  Medical News Bulletin (India)  MD Alert (USA)  Australian Doctor  Medscape (USA) | Premature menopause increases the risk of chronic disease | Dr Xaolin Xu  Prof Gita Mishra |
| 25 January | Online | Midwives (UK) | Honesty in perinatal screening | Peta Forder |
| 8 April | Online | Medscape (USA) | PCOS impacts on diet, physical activity and Contraceptive use | Tessa Copp |
| 16 April | Online | Medical Express  Xinhua News (China)  The Courier Mail (QLD)  The Medical News (Australia)  Physician Briefings (USA)  Physicians Weekly (USA)  MSN India news  Healio USA | Traditional vegetable diet lowers the risk of preterm birth | Dereje Gete  Prof Gita Mishra |
| 17 April | Online /Podcast | The Conversation  Player FM (USA)  Daily Bulletin (Australia) | Childhood, adolescence, pregnancy, menopause, 75+: how your diet should change with each stage of life | Prof Clare Collins |
| 28 May  29 May | Print  Online  Radio | The Age  The Sydney Morning Herald  Brisbane Times  WA Today  936 ABC Hobart | COVID-19 Reports – Young women affected worst by stress in the COVID era | Prof Deborah Loxton |
| 4 – 14 June | Online | The Sun (UK)  National Tribune (Australia)  Mirage News (Australia)  Brisbane Times  The Age  WA Today  The Sydney Morning Herald  Daily Mail Online (UK)  MSN (Ireland)  Yahoo Singapore  Yahoo UK  MSN UK  Australian Doctor | Breast is best push out of touch | Dr Katrina Moss |
| 9-12 June  9 June  10 June  11 June  12 June | Online  Radio  Online  Radio | Medical Xpress (UK)  Medindia  Daily Bulletin  The Conversation  Baby Gaga (Canada)  Eveningreport.NZ  ABC Capricornia FM  ABC Northwest Queensland  ABC Tropical North FM  ABC Far North Qld  Essential Baby (Australia)  Babyology  Australian Doctor  1233 ABC Newcastle  ABC Upper Hunter AM | 1 in 5 new mums do not receive mental health screening | Dr Katrina Moss  Dr Nicole Reilly |
| 15 – 24 June | Online | 67 articles including:  Hindustan Times (India)  Punjab Tribune (India)  Medical Express (UK)  The Medical News (Australia)  Health Medicine Network (USA)  Yahoo India | Maternal Depression – seeking help sooner is best for mums and kids | Dr Katrina Moss |
| 23 July | Online | Parent Herald (USA) | Early menstruation linked to hot flashes during menopause | Prof Gita Mishra |
| 11 August | Online  Radio | Mirage News  National Tribute  1233 ABC Newcastle  ABC Upper Hunter AM | Recognising the hazardous effects of pre-loading with alcohol | Dr Amy Anderson |
| 11 November | Online | Hunerheadline.com.au  National Tribune  Mirage News | $8.5 million secured to continue longest women’s health study | Prof Julie Byles  Prof Deborah Loxton |

## Social media

During the year, details of Study outcomes and activities have been posted on the Study’s social media accounts on Facebook, Twitter and Instagram. In the early period of the COVID-19 pandemic the Study used these social media channels to provide information about changes in the Study’s activity and to support distribution of official messaging developed through the Australian Government’s HealthDirect.gov.au website.

As in previous years, content posted to Facebook continued to be aimed at a lay audience - particularly participants. The Study’s [Facebook](https://www.facebook.com/womenshealthaustralia) has around 9, 812 followers. Roughly 95% of the audience is female and is most likely to be participants from the 1989-95 cohort, with some from the 1973-78 cohort, and a few from the 1946-51cohort. We share lay summaries, news releases, media and important updates from the study on Facebook, with each post reaching between 400 and 2000 people.

The [Twitter account](https://twitter.com/ALSWH_Official) promotes engagement with collaborators, other researchers, media professionals, policy makers, and non-government organisations (NGOs) as well as the general public. Tweets highlight study news, data releases, journal papers, lay summaries and attendance at conferences. The account currently has 1,663 followers.

This year, the Study took advantage of recent changes to Instagram, and restarted its [Instagram account](https://www.instagram.com/alswh_official/) to share infographics and brief lay summaries. This account is aimed at a lay audience and is promoted to participants. It also acquires new followers and post views from people following specific hashtags. The Instagram account currently has 337 followers.

## Website

The ALSWH website ([www.alswh.org.au](http://www.alswh.org.au)) continues to be an important portal for communication of ALSWH activities to the wider community. During this year, the website has been redeveloped to incorporate a new design, improved site navigation, and the introduction of a portal for data users to monitor their projects online. The website is the main gateway for applications for data, and regular update on Study news, events, publications and similar items.

## Newsletters

Every year a newsletter is produced for Study participants. The participant newsletter describes current events at ALSWH and features results on prominent issues arising from information about themselves that the participants have provided to ALSWH. The 2019 ALSWH participant newsletter was distributed in April 2020. It was provided online to all participants in the 1989-95 cohort, as well as to those participants in the 1973-78 and 1946-51 cohorts who have provided email addresses. Participants in the 1973-78 and 1946-51 cohorts who have not provided email addresses, or who prefer to receive hard copies, and all members of the 1921-26 cohort were provided with printed copies of the newsletter. Copies of all participant newsletters are available [here](https://www.alswh.org.au/for-participants/newsletters).

The Study also prepares two electronic newsletters - ‘Study News’ which is for all stakeholders with an interest in women’s health policy and practice, and ‘Data Updates’ which is for data users. The Study News includes:

* links to lay summaries or media coverage of noteworthy publications and reports
* updates on upcoming noteworthy seminars, presentations and conferences that will make use of ALSWH data
* other related items of interest.

The Data Update includes:

* details of recent data releases
* details of current and forthcoming surveys
* updates on recent publications, presentations and seminars and upcoming conferences

This year, Data Updates have been distributed in March, September and November, and the Study News was delivered in September.

# Collaborative Research Activities

* 1. **Scientific meetings and teleconferences among the research team**
     1. **Management Committees**

The Study Management Committee (SMC) oversees all aspects of ALSWH, ensuring that all contractual obligations are fulfilled and leading strategic planning for the Study (beyond contractual obligations). Membership of the SMC comprises the ALSWH Directors and Deputy-Directors. During 2020, SMC meetings have been conducted as videoconferences (Zoom). Due to COVID-19 restrictions, all face-to-face meetings were cancelled.

The Strategic Advisory and Stakeholder Committee (SASC) advises and supports the SMC on strategic and scientific issues and promotes ALSWH and the use of its research and data. Membership of the committee comprises the four members of the ALSWH SMC, four ALSWH collaborators and up to six stakeholders including people with expertise in research translation, policy implementation. Members are:

Chair:

**Professor Sally Redman**

Chief Executive Officer

Sax Institute, Sydney, New South Wales

ALSWH Directors and Deputy Directors:

**Professor** **Gita Mishra**

Director, ALSWH (The University of Queensland)

Professor of Life Course Epidemiology & NHMRC Principal Research Fellow

School of Public Health, Faculty of Medicine, The University of Queensland

**Professor Julie Byles**

Director, ALSWH (The University of Newcastle)

Director, Priority Research Centre for Generational Health and Ageing

Global Innovation Chair in Responsive Transitions in Health and Ageing

School of Medicine and Public Health, The University of Newcastle

**A/ Professor Leigh Tooth**

Principal Research Fellow and Deputy Director, ALSWH (The University of Queensland)

School of Public Health, Faculty of Medicine, The University of Queensland

**Professor** **Deb Loxton**

Deputy Director ALSWH (The University of Newcastle)

Director, Priority Research Centre for Generational Health and Ageing

School of Medicine and Public Health, The University of Newcastle

ALSWH collaborators:

**Professor** **Wendy Brown**

Director, Centre for Research on Exercise, Physical Activity and Health

School of Human Movement and Nutrition Sciences

Faculty of Health and Behavioral Sciences, The University of Queensland

**Professor** **Jayne Lucke**

Director, Australian Research Centre in Sex, Health and Society

College of Science, Health and Engineering, School of Psychology and Public Health

La Trobe University

Stakeholders:

**Professor Louisa Jorm**

Director, Centre for Big Data Research in Health

University of New South Wales, Sydney

**Janet Michelmore**

Executive Director, Jean Hailes

**Professor Marie-Paul Austin**

Director, St John of God Burwood Hospital

Chair, Perinatal and Women’s Mental Health Research Unit

University of New South Wales Sydney

**Professor Catherine D’Este**

Chair in Biostatistics, National Centre for Epidemiology and Population Health

Australian National University

**Professor Leon Flicker**

Professor of Geriatrics & Director, Western Australia Centre for Health and Ageing

University of Western Australia

**Professor** **John Attia**

Academic Director, School of Medicine and Public Health

The University of Newcastle

**Professor Helena Teede**

Director, Monash Centre for Health Research and Implementation (MCHRI)

Monash University

**Kelly Bannister**

Deputy Chair, Australian Women’s Health Network

Representative from the Department of Health:

Assistant Director, Preventive Policy Section, Preventive Health Policy Branch

Population Health & Sport Division, Department of Health

* + 1. **Data Management Group**

The Data Management Group (DMG) is responsible for all technical issues involving ALSWH data. The group’s primary tasks include:

* Providing a forum for discussion of all aspects of data management within ALSWH
* Disseminating summaries of current data management activities to the research team and collaborators
* Assessing the validity, reliability and responsiveness of new survey items
* Maintaining scale evaluation procedures
* Evaluating and documenting the validity and reliability of new scales included on surveys
* Developing and documenting definitions for derived variables in survey and other data sets
* Documenting datasets through the preparation of variable labels and formats, and the maintenance of the Data Dictionary and its Supplement
* Maintaining archival procedures for all datasets

This year, the DMG has reviewed all items for Pilot Survey 9 of the 1973-78 cohort and has provided advice on preparation of the ‘core datasets’ (accessible through the Australian Data Archive). The DMG meets monthly by teleconference or videoconference, and is chaired by David Fitzgerald (Data Manager – The University of Queensland) and Anna Graves (Operations Manager - The University of Newcastle). Members in 2020 have included:

* Anna Graves
* David Fitzgerald
* Professor Gita Mishra
* Professor Julie Byles
* Professor Deborah Loxton
* Associate Professor Leigh Tooth
* Richard Hockey
* Dominic Cavenagh
* Professor Annette Dobson
* Ryan Tuckerman
* Peta Forder
* Dr Michael Waller
* Colleen Loos
* Nick Egan

**Data Access Committee**

The Data Access Committee assesses and monitors all applications to use ALSWH data and linked data. The committee’s primary tasks are to:

* Assess each application for use of ALSWH data (and where required, linked data from external datasets) on merit for whether:
  + It is a reasonable and appropriate use of ALSWH data (and linked data where applicable)
  + It is a feasible project which will lead to scientifically valid findings
  + The research team have the necessary skills and resources to conduct the research.
  + The research team members who require access to the linked data have the necessary ethical permissions.
* Assess each application to conduct an ALSWH substudy on merit for whether:
  + The relevant ALSWH cohort/s is/are an appropriate target population for the research
  + The substudy will be an acceptable burden on ALSWH participants
  + It is a feasible project which will lead to scientifically valid findings
  + The research team have the necessary skills, resources and funding to conduct the research.
* If requested by an ALSWH liaison person, review outcomes (publications, conference abstracts, reports) from research using ALSWH data.

The Data Access Committee is chaired by Associate Professor Leigh Tooth, and members in 2020 included:

* Associate Professor Leigh Tooth
* Professor Gita Mishra
* Professor Julie Byles
* Professor Wendy Brown
* Professor Annette Dobson
* Professor Jayne Lucke
* Professor Deborah Loxton
* Peta Forder
* Dr Melissa Harris
* Dr Amy Anderson

Data linkage projects were also reviewed by the ALSWH Data Manager, David Fitzgerald and the ALSWH Data Linkage Coordinator, Colleen Loos.

* 1. **Research projects**

ALSWH data has now been provided to collaborators for use in over 850 research projects. 50 projects have been approved since the last Technical Report (November 2019), and five more are currently under review. 50 per cent of projects approved this year also requested access to the linked administrative datasets. Researchers who receive ALSWH data are required to provide regular reports on progress of their projects - reports for 2020 are included in Appendix A. Topics under investigation include:

* Chronic conditions such as musculoskeletal problems, cardiovascular conditions, diabetes.
* Health service use and systems
* Mental health
* Ageing
* Reproductive health
* Methodological issues
* Tobacco, alcohol and other drugs
* Medications
* Weight, nutrition and physical activity
* Health in rural and remote areas
* Social factors in health and well-being
* Abuse
  1. **Substudies**

During 2020, data collection has been conducted for three substudies:

* **M-PreM study** (EoI W103), which is examining reproductive factors from menarche to premenopause, and the risk of cardiometabolic and respiratory conditions
* **Living beyond expectations study** (EoI W102), which is looking at successful and healthy ageing in older women
* **Tracking the short-term impacts of COVID-19 on the health and wellbeing of Australian** **women** (EoI A840)

Human Ethics Research Committees at the University of Newcastle and the University of Queensland have oversight of all ALSWH substudies, and those involving additional institutions/facilities (e.g., hospital clinics) may also require ethical oversight from relevant associated HRECs. The M-preM study involves collection of biosamples, either through the mail or during a participant visit to a hospital clinic. In March, consistent with HREC guidelines, all data collection for this substudy was suspended due to COVID-19. HREC approval has since been given for resumption (in mid-September) of collection of biosamples by mail.

Reports on the the M-preM substudy, and the Living beyond expectations substudy, as well as research being conducted using data from other substudies, are included in Appendix B.

* 1. **Student projects**

56 postgraduate students are currently working on aspects of the project, investigating a wide range of topics, including mental health, arthritis, cancer, nutrition, pregnancy, menopause, and ageing. Detailed reports on student projects are available in Appendix C.

# Project staff

|  |  |
| --- | --- |
| **Centre for Longitudinal and Life Course Research**  **The University of Queensland** | |
| Director ALSWH | Professor Gita Mishra |
| Deputy Director ALSWH | A/Professor Leigh Tooth |
| Research Fellow (s) | Professor Annette Dobson |
| Statisticians | Richard Hockey  Dr Ingrid Aulike |
| Data Manager | David Fitzgerald |
| Data Linkage Coordinator | Colleen Loos |
| Research Project Manager | Megan Ferguson |
| Communications  and Engagement Officer | Helen Gray |
| Senior Research Assistant | Dr Hsiu-Wen Chan |
| Database Developer | Chamila Pathigoda |
| Administration Officer(s) | Leonie Gemmell  Christine Coleman |

At the University of Queensland, Professor Annette Dobson, Associate Professor Leigh Tooth, Richard Hockey, Colleen Loos, Helen Gray, Chamila Pathigoda and Christine Coleman have worked part-time on the project.

|  |  |
| --- | --- |
| **Research Centre for Generational Health and Ageing**  **The University of Newcastle** | |
| Director ALSWH | Professor Julie Byles |
| Deputy Director ALSWH | Professor Deborah Loxton |
| Research Managers | Dr Amy Anderson  Natalie Townsend |
| Senior Statistician | Peta Forder |
| Statistics Team | Dominic Cavenagh  Nick Egan |
| Research Assistants | Isabelle Barnes  Emma Byrnes |
| Operations Manager | Anna Graves |
| Database Developer | Ryan Tuckerman |
| Research Assistance Manager | Natalie Townsend |
| Administration Officers | Clare Thomson  Katherine Tuckerman |
| Project Assistants | Cathy Seberry  Alyse Berrigan  Belinda Jackson  Brianna Barclay  Jenny Helman  Megan Son Hing  Sarah Morris  Ursula Horton |