****Australian Longitudinal Study on Women’s Health
1921-26 Cohort Summary
1996–2018

October 2018

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# Executive Summary

The Australian Longitudinal Study on Women’s Health (ALSWH) is a longitudinal population-based survey of over 60,000 Australian women in four cohorts. This report is a summary of data for 12,432 women in the cohort born 1921-26 who completed the baseline survey in 1996 (aged 70-75 years), and surviving women for each survey point up to May 2018 (aged 92-97). The data therefore represent changes in the population for women who survive to different ages.

**Sociodemographic characteristics:** Over the 20+ years of the study, the majority of women in this cohort have resided in cities or inner regional areas, with less than 10% living in outer regional or remote/very remote areas. In 1996, when the women were aged 70 to 75 years, some 35% were widowed, with this proportion rising to over 80% by 85 to 90 years. Women who were married or in a defacto relationship at Survey 1 had a small but statistically significant survival advantage over other women.

**Lifestyle:** Most women were in the healthy weight (50%) or overweight (33%) BMI categories at the start of the study. These proportions did not change greatly over time, with some women becoming underweight, replacing previously underweight women who died. Underweight women had a much greater mortality rate (lower survival) than healthy weight or overweight women. Survival was also lower among women who were obese in comparison to those who started the study with a BMI in the healthy weight range.

At Survey 1, most women were lifetime non-smokers (62%), with 30% classified as ex-smokers, and 8% as current smokers. There were large differences in survival for smokers compared to non-smokers. Non-smokers were around twice as likely to survive 20 years from the start of the study, compared to smokers. In addition, ex-smokers continued to have a survival disadvantage even after 20 years.

Physical activity declined over the course of the study as the women aged. In terms of survival, any level of physical activity was better than none, with some additional advantage for high levels.

**Self-rated health:** The percentage of the women who rated their health as fair or poor increased over the study period. Women who rated their health as “fair” or “poor” at Survey 1 had much worse survival than women who rated their health as “good”. Women who rated their health as “very good” or “excellent” at Survey 1 had the best survival with around 50% of these women surviving at least 20 years (to age 90-95). Likewise higher scores on physical functioning were associated with better survival. Low mental health scores, indicating psychological distress, were associated with lower survival rates.

**Functional abilities and caring:** The percentage of women who reported needing help from others for daily tasks due to long-term illness rose fourfold, from less than 10% at age 70 to 75 years to around 40% by age 90-95. However women were also likely to be caring for someone else due to that person’s illness, disability or frailty. At age 70-75, women were twice as likely to be caring for someone else than needing care for themselves. Later in life this ratio was reversed first as women’s own needs for help increased, and then as their role in caring for others diminished. Those who needed help with daily activities at the start of the study had a much higher mortality rate than those who did not report such needs. The relationship between providing care to others and survival is more complex due to the periodic and varying nature of caregiving across later life.

**Potential policy implications:** Data from earlier surveys highlight that most older women were in good, very good or excellent health during this part of their lives (when they were in their seventies), with high or moderately high levels of physical functioning and low rates of psychological distress. The women were also making important contributions to their families and communities, shown here in relation to their roles in caring for others. These data have implications for policies concerning healthy and active ageing which look to optimise quality of life in older age and develop social and physical environments that support older people and allow them to maximise their activity and participation. Good health in older age is a significant resource not only for the woman herself, but also for her family and community. The economic contributions of these women must not be underestimated.

Healthy behaviours are key drivers of health in older age, and significant determinants of longevity. This cohort entered adulthood prior to the global rise in the incidence of obesity. Few women were obese, and women’s BMI tended to decrease over time. Underweight is a potential issue for this cohort, particularly as they age and may represent a loss of lean body mass and poor nutrition. These underweight women are less likely to have survived.

The findings also underscore the importance of physical activity for older women, with even small levels conferring survival benefit. There is however a strong trend for women to become increasingly inactive in later life, with such sedentary behaviour heralding a poor prognosis. Physical activity programs for older people can be tailored to their functional capacity, and can help improve strength and balance, reduce falls and improve independence and overall wellbeing.

The women who remain in the study at age 92-97 represent exceptional members of their cohort who have survived to very old age, and who still have good prospects for survival into their late 90’s and to 100 years or more.

# Introduction

## Background

The Australian Longitudinal Study on Women’s Health (ALSWH) is a longitudinal population-based survey examining the health of around 60,000 Australian women. The Study follows women in four age cohorts, and a summary of selected data from the cohort born 1921-26 (now aged 92-97) who were first surveyed aged 70-75 in 1996 is presented here.

The 12,432 women in the 1921-26 cohort were recruited from the name and address database of the Australian Health Insurance Commission (now Medicare Australia). Sampling was random, except that women living in rural and remote areas were sampled at twice the rate of women in urban areas, in order to capture the heterogeneity of health experiences of women living outside metropolitan areas. The cohort was surveyed six times between 1996 and 2011, and has been surveyed every six months since November, 2011. These women are now in their nineties, and bi-annual surveys provide insight into the factors affecting the longevity and on-going health and health care needs of those who are still alive.

This report contains two sections: the first discusses factors associated with survival of women in this cohort and their trajectories over time on a range of health-related measures, and the second part outlines the key research achievements. Details of publications, reports and cohort participation rates are included as appendices.

## Surveys

The 1921-26 cohort receive mailed pen and paper surveys. Some participants elect to complete their surveys over the telephone. Telephone interviews are conducted with trained project assistants based at the University of Newcastle.

The surveys conducted between 1996 and 2011 were sent to the women every three years and contained questions on a broad range of health-related themes, including:

* Physical, social and emotional functioning (SF-36 Health related quality of life measure)
* Medically diagnosed conditions and symptoms
* Use of health care services
* Degree of difficulties with activities of daily living and need for assistance with activities of daily living
* Sight and hearing difficulties
* Falls
* Physical activity, height and weight
* Demographics and living circumstances

Information is also collected as to whether the women had help to complete the survey (based on the participant’s answers), or if the survey was completed by another person on behalf of the participant (by proxy).

The six monthly follow-up (6MF) of the 1921-26 cohort commenced November 2011. Subsequent surveys are sent on a rolling basis, six months after the return of the previous survey. So if a participant returned the first six monthly survey in December 2011, their second six monthly follow-up survey was mailed in June 2012.

The six monthly follow-up surveys contain a set of core questions to minimise participant burden. As far as possible, the survey questions are not subject to change, which ensures longitudinal integrity. The survey content and format are approved by the Human Research Ethics Committees at the University of Newcastle and the University of Queensland.

## Retention

Numbers are declining in the 1921-26 cohort due to death and increasing frailty. Between 1996 and May 2018, 9,304 (75%) of the original 12,432 participants in the cohort died, and 1,570 (13%) have requested no more surveys (mainly due to frailty as reported to the research team by the participant or proxy). To ensure the best possible retention in this cohort, intensive follow-up and tracking procedures are used, including use of the National Death Index to identify those participants who have died. The Australian Life Tables for 2014-161 show that women aged 92 will live, on average, a further 4.1 years and women aged 97 will live, on average, a further 2.8 years. Of the 1558 participants who are currently alive and still eligible to receive surveys, some will turn 100 between 2021 and 2026.

To date, each six month follow up (6MF) survey has been completed by over 80% of the eligible participants (See Table 2). At 6MF Survey 1, 9% withdrew from further surveys and a further 3% withdrew at each of 6MF Survey 2 or 6MF Survey 3. At each subsequent survey 1-3% of women have withdrawn or indicated that they would prefer to skip the survey and do the next one, and between 2-4% have died since the previous survey.

Details of survey dates and response rates for the main Surveys and the six-month surveys are shown in Table 2‑1 and Table 2‑2 respectively.

Table 2‑1 ALSWH 1921-26 cohort schedule of surveys and response rates 1996 to 2011

|  | **Survey 1**  | **Survey 2**  | **Survey 3**  | **Survey 4**  | **Survey 5**  | **Survey 6**  |
| --- | --- | --- | --- | --- | --- | --- |
| Year (YYYY) | 1996 | 1999 | 2002 | 2005 | 2008 | 2011 |
| Age range (years) | 70-75 | 73-78 | 76-81 | 79-84 | 82-87 | 85-90 |
| Response Rate (N) | 12,432 | 10,434 | 8,647 | 7,158 | 5,561 | 4,055 |

Table 2‑2 ALSWH 1921-26 cohort six-month follow up (6MF) survey completions 2011 to 2018

| **Year** | **Survey (close)\*** | **Age range** | **Deceased** | **Withdrawn** | **Total ineligible** | **Total eligible** | **Surveys completed** | **Response (%)** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **2012** | 6MF 1 (May)  | 86-91 | 5532 | 2334 | 7866 | 4566 | **3430** | **75.1** |
| **2012** | 6MF 2 (Nov) | 86-91 | 5927 | 2363 | 8290 | 4142 | **3260** | **78.7** |
| **2013** | 6MF 3 (May) | 87-92 | 6227 | 2409 | 8636 | 3796 | **2842** | **74.9** |
| **2013** | 6MF 4 (Nov) | 87-92 | 6620 | 2347 | 8967 | 3465 | **2473** | **71.4** |
| **2014** | 6MF 5 (May) | 88-93 | 6947 | 2294 | 9241 | 3191 | **2118** | **66.4** |
| **2014** | 6MF 6 (Nov) | 88-93 | 7288 | 2181 | 9469 | 2963 | **1964** | **66.3** |
| **2015** | 6MF 7 (May) | 89-94 | 7617 | 2102 | 9719 | 2713 | **1726** | **63.6** |
| **2015** | 6MF 8 (Nov) | 89-94 | 7962 | 1967 | 9929 | 2503 | **1524** | **60.9** |
| **2016** | 6MF 9 (May) | 90-95 | 8261 | 1875 | 10,136 | 2296 | **1362** | **59.3** |
| **2016** | 6MF 10 (Nov) | 90-95 | 8591 | 1740 | 10,331 | 2101 | **1247** | **59.4** |
| **2017** | 6MF 11 (May) | 91-96 | 8873 | 1678 | 10,551 | 1881 | **1062** | **56.5** |
| **2017** | 6MF 12 (Nov) | 91-96 | 9203 | 1534 | 10,737 | 1695 | **979** | **57.8** |
| **2018** | 6MF 13 (May) | 92-97 | 9302 | 1546 | 10,848 | 1584 | **877** | **55.4** |
| **2018** | 6MF 14(Nov^)  | 92-97 | 9304 | 1570 | 10,874 | 1558 | **403** | **25.9^** |

\*This is the nominal closing date, and is also when the next 6MF survey is deployed (however, if a participant returns their survey after this date, it is still accepted).

^ This survey period is still open, and death data are incomplete.Complete data for every survey, including questions and responses, are listed in the ALSWH data books, available at: [here](http://www.alswh.org.au/for-researchers/data/data-books)

ALSWH will continue to provide support for women to complete six-monthly follow-up surveys. These support activities include:

* The option to complete the survey by telephone in one or two sessions. It is anticipated that the proportion of telephone interviews will increase over time.
* The option for the participant to ask a family member, carer or other trusted person to complete the survey on their behalf (a proxy completion).
* Provision of a ‘not this time’ option, whereby participants who are not feeling well enough at one survey time point can elect to skip a survey and do the next.
* Provision of surveys to women living in residential aged care, wherever possible.

# SURVIVAL CURVES AND COHORT TRAJECTORIES 1996 – 2018

## Explanation of survival curves

Survival curves for women grouped according to characteristics recorded at Survey 1 in 1996 show the associations between these characteristics and how much longer the women lived, on average. For example, Figure 3-1 shows the survival curves for women with different levels of education.

Figure 3‑1 Survival curves for the period 1996-2016 for groups of women defined by the highest level of education reported at Survey 1.

At Survey 1 100% of the women were alive, but gradually over time some died. Twenty years later about 30% of those with no formal qualifications (the lowest dashed line) were still alive and 70% had died. This compares with 40% alive (and 60% had died) among the women with university education (top line with long dashes). In this example, the difference in survival was only statistically significantly different for the women with no formal qualifications; the other groups were more similar.

The survival curves were produced using the Kaplan Meier method and are shown for a period of twenty years from Survey 1.

## Explanation of cohort trajectories

The cohort trajectories reflect the women’s responses to questions asked in the three-yearly surveys during the years 1996 to 2013 and the six-monthly follow-up (6M FU) surveys since then. The trajectories are only shown for those questions that were asked at all these surveys.

Two trajectories are shown. One is based on the responses from women who responded to every survey, that is, they were still alive and completing surveys up until the most recent one. The other is based on the responses from every woman who completed that survey. These two trajectories are illustrated in Figure 3-2 which shows the percentage of women who were married or in a de-facto relationship, as opposed to those who were widowed, divorced or separated.

**Figure 3‑2 Percentages of women who were married or in a de-facto relationship (as opposed to those who were widowed, divorced, separated or never married) for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

The open circles and plus signs show the percentages at each survey and the vertical lines are 95% confidence intervals. At Survey 1 in 1996 57% of the women were married (while 35% were widowed and the others were divorced, separated or never married). Among the much smaller group who continued to participate until the most recent survey (n=640), 64% were married and (28% were widowed) at Survey 1. Both trajectories go down over time as fewer women remain married (as more are widowed). The lines converge as many of the women who completed the early surveys die or cease to participate in the surveys, and those who survive and continue to complete the surveys provide the data.

For some other survey variables, data from the six-month follow-up surveys are different from and more variable than the data from Surveys 1-6. This may be due to the surveys being shorter and more frequent as well as changes in the format.

With each survival curve or cohort trajectory, an example survey question has been included – however, the wording of questions has sometimes changed from survey to survey, and the example question is intended as a guide only. Full surveys and summary data for each follow-up are available at alswh.org.au

Some questions were only asked at Survey 1 as they could not change (e.g. country of birth) or were unlikely to change (e.g. highest level of education). Others were asked at several surveys but the responses did not change much over time (e.g. [area of residence](http://www.alswh.org.au/images/content/pdf/Cohort_summaries/ALSWH_1921-2_%20cohort_summary.pdf)). For these characteristics, only survival curves are presented (for groups based on Survey 1 responses). For other characteristics which varied over time, both cohort trajectories and survival curves are presented.

## Sociodemographic factors

### Area of residence

QUESTION: What is your residential postcode?

From their Survey 1 responses women were categorised as living in a major city (68%), an inner regional area (21%), an outer regional area (9%), or a remote of very remote area (1%) according to the ARIA+ classification. The percentages of women living in these area of residence categories [remained stable over time](http://www.alswh.org.au/images/content/pdf/Cohort_summaries/ALSWH_1921-2_%20cohort_summary.pdf), so no trajectories are shown. **Figure 3‑3** shows the survival curves for these women.

**Figure 3‑3 Survival curves for the period 1996-2016 for groups of women defined by area of residence at Survey 1.**

Women living in major cities had slightly higher survival rates and those in remote or very remote areas had poorer survival, but the differences were not large.

### Country of Birth

QUESTION: In which country were you born?

The responses were categorised as: Australian born (73%), born in another English-speaking country (14%), and born elsewhere (13%). **Figure 3‑4** shows the survival patterns over the subsequent 20 years.

**Figure 3‑4 Survival curves for the period 1996-2016 for groups of women defined by area of residence at Survey 1.**

Survival rates were similar for all country of birth categories.

### Education

QUESTION: What is the highest qualification you have completed?

Survey 1 responses were grouped as follows: no formal qualification (33%), school certificate or higher school certificate (51%), certificate or trade qualification (12%), and university degree (4%). The survival curves are shown in **Figure 3‑5**.

**Figure 3‑5 Survival curves for the period 1996-2016 for groups of women defined by highest qualification at Survey 1**

Women with no formal qualifications (lowest dotted line) had significantly lower survival rates than those in the other groups. While survival rates improved with increasing levels of education, the differences between the groups were not statistically significant.

### Marital Status

QUESTION: What is your present marital status?

* Married
* De facto
* Widowed
* Separated
* Divorced
* Never married

These categories were combined into two groups: women with partners (married or de facto), and those without partners (widowed, separated, divorced or never married). **Figure 3‑6** shows the percentages of women in each of these groups at each survey.

**Figure 3‑6 Percentages of women who were married or in a de-facto relationship (as opposed to those who were widowed, divorced, separated or never married) for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

At Survey 1 in 1996, 57% of the women were married (while 35% were widowed and the others were divorced, separated or never married). Among those who continued to participate until the most recent survey (n=640), 64% were married and (28% were widowed) at Survey 1. Both trajectories go down over time as fewer women remain married (as more are widowed). The trajectories converge as many of the women who completed the early surveys die or cease to participate in the surveys, and those who survive and continue to complete the surveys provide the data.

Figure 3‑7 shows the survival curves, comparing partnered women with those who were already widowed at Survey 1, or were never married, or separated or divorced.



Figure 3‑7 Survival curves for the period 1996-2016 for groups of women defined by marital status at Survey 1

Women who were partnered at survey 1 had significantly higher survival rates than women in the other groups.

### Manage on Income

QUESTION: How do you manage on the income you have available?

* It is impossible
* Difficult all the time
* Difficult some of the time
* Not too bad
* It is easy

At Survey 1 in 1996, when the women were aged 70-75, 22% responded ’easy’, 51% ‘not too bad’, 20% ‘difficult some of the time’ and 7% said ‘difficult all of the time’ or ‘impossible. Over time these proportions did not vary greatly, so trajectories over time are not shown.

**Figure 3‑8** shows the survival curves, comparing women who responded ‘easy/not too bad’, ‘sometimes difficult’ or ‘difficult always/impossible’ at Survey 1.

**Figure 3‑8 Survival curves for the period 1996-2016 for groups of women defined by their responses at Survey 1 to the question about managing on their available income.**

Women who reported ‘easy/not too bad’ (the top dashed-dotted line) had significantly better survival rates than those in the other categories.

## Lifestyle

### Weight and Body Mass Index (BMI)

QUESTION: How tall are you without shoes?

QUESTION: How much do you weigh without clothes or shoes?

BMI [weight (kg)/height (m)2] is calculated from responses to both questions and categorised (according to the World Health Organisation classification) as: underweight, BMI < 18.5; healthy weight, 18.5<= BMI < 25; overweight 25 <= BMI < 30; or obese BMI>=30.

At Survey 1 in 1996, 3% of the women were underweight, 50% were in the healthy weight range, 33% were overweight, and 14% were obese. These proportion did not change much over time and the mean BMI remained constant, so trajectories over time are not shown.

**Figure 3‑9** shows the survival curves, comparing women in each of the BMI categories at Survey 1.

**Figure 3‑9 Survival curves for the period 1996-2016 for groups of women defined by their BMI category at Survey 1.**

Underweight women (long dashed lines) had significantly poorer survival than the other groups. However women in the obese category (short dashed lines) also had poorer survival than the other two groups (healthy weigh and overweight) who had similar survival rates.

### Smoking

QUESTIONS: Women were asked a series of questions including: whether they had ever smoked; if they have ever smoked, at what age they started; if they used to smoke when they had given up; if they currently smoked, how many cigarettes they smoked and how frequently.

From their answers to these questions at Survey 1 women were classified as current smokers, ex-smokers or never smokers. At Survey 1, 62% of women reported never smoking, 30% were ex-smokers and 8% smoked regularly or occasionally. The questions were not asked at every survey, but among those women who responded to Survey 6 the percentages were: 71% never smokers, 27% ex-smokers and 2% current smokers. **Figure 3‑10** shows that earlier deaths among smokers could explain these changes as those who never smoked became a larger proportion of those alive and able to respond to Survey 6.

**Figure 3‑10 Survival curves for the period 1996-2016 for groups of women defined by their smoking status at Survey 1.**

Survival rates were lowest for women who smoked at Survey 1, higher for ex-smokers and significantly higher for never smokers.

### Physical Activity

QUESTION: How many times did you do each type of activity last week? Only count the number of times when the activity lasted for 10 minutes or more.

* Walking briskly (for recreation or exercise, or to get from place to place)
* Moderate leisure activity (like social tennis, moderate exercise classes, recreational swimming, dancing), or more vigorous leisure activity (that makes you breathe harder or puff and pant)
* Vigorous work in the house or garden (like vacuuming, mopping, cleaning windows, digging, mowing, etc.)

Questions were asked consistently from Survey 2 and the responses were used to categorise women as: inactive, low level of physical activity, moderate level, or high level of physical activity. Physical activity questions are not asked in the six-monthly surveys. The percentage of women in each category over Surveys 2 - 6 are shown in Figure 3‑11 (from the 2014 summary for this cohort).

**Figure 3‑11 Physical activity from Survey 2 to Survey 6.**

The percentage of women classified as inactive increased from 34% at age 73 to 78 years (Survey 2) to 59% by 85 to 90 years (Survey 6). Although the figure for moderate or high levels of physical activity declined over the study period, almost 20% of women were still in this category at age 85 to 90 years.

Figure 3‑12 shows the survival curves for women classified by their level of physical activity at Survey 2.

**Figure 3‑12 Survival curves for the period 1996-2016 for groups of women defined by their level of physical activity at Survey 2.**

Women who were inactive (the nil/sedentary group) at Survey 2 has substantially lower survival rates than women in the other groups, and those in the high activity group had slightly higher survival than women in the intermediate groups.

## Health

### Self-Rated Health

QUESTION: In general, would you say your health is:

* Excellent
* Very good
* Good
* Fair
* Poor

These categories were grouped into: excellent/very good, goof, fair/poor. At Survey 1, 33% of women rated their health as ‘excellent’ or ‘very good’, 39% as ‘good’, and 28% as ‘fair’ or ‘poor’. By the most recent follow-up survey these percentages were 18%, 41% and 41% respectively.

**Figure 3‑13** shows the trajectories for the women who rated their health as ‘fair’ or ‘poor’.

**Figure 3‑13 Percentages of women who rated their health as ‘fair’ or ‘poor’, for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

The percentage of women who classified their health as ‘fair’ or ‘poor’ increased steadily over the study period, with a sharp increase in the percentage “fair/poor” between Survey 6 and Six-month follow-up 1. Compared to all the women who completed Survey 1, women who went on to complete every survey were less likely to report ‘fair’ or ‘poor’ health.

Self-rated health is a very good predictor of survival, as shown in **Figure 3‑14**.

 **Figure 3‑14 Survival curves for the period 1996-2016 for women grouped by their self-rated health at Survey 1.**

Women who rated their health as ‘fair’ or ‘poor’ at Survey 1 had the significantly lowest survival rates, and those who rated their health as ‘excellent’ or ‘very good’ had significantly higher survival rates.

### Health-related Quality of Life – physical functioning and mental health scores

Scores on the SF-36 are used to measure Health-related quality of life, with two of the main sub-scales being physical functioning (as a marker of physical health) and mental health (Ware et al, 1993). All scales are positively scored so that higher scores represent better outcomes.

**Physical functioning**

QUESTION: The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

* Vigorous activities such as running, lifting heavy objects, participating in strenuous sports
* Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf
* Lifting or carrying groceries
* Climbing several flights of stairs
* Climbing one flight of stairs
* Bending, kneeling or stooping
* Walking more than one kilometre
* Walking half a kilometre
* Walking 100 metres
* Bathing or dressing yourself

(Response options: Yes, limited a lot; Yes, limited a little; No, not limited at all).

The responses are used to calculate a summary score ranging from 0 to 100 with higher scores indicating better physical functioning. **Figure 3‑15** shows the trajectories for mean scores over time.

**Figure 3‑15 Mean scores for physical functioning for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

Mean scores for physical functioning declined at each survey and also over time for women who responded to every survey. Women who completed all surveys had better physical functioning at earlier surveys when compared to all women who commenced the study.

 **Figure 3‑16** shows the survival curves for women grouped into quintiles based on their scores at Survey 1.

 **Figure 3‑16 Survival curves for the period 1996-2016 women grouped by quintiles of their physical functioning scores health at Survey 1 (1 = lowest 20% of scores, and 5 = highest 20% of scores).**

Survival rates strongly reflected the physical functioning scores with each quintile group having statistically significantly poorer survival than the higher quintile group (except that groups 3 and 4 were not significantly different.

**Mental health**

QUESTION: For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks:

* Have you been a very nervous person
* Have you felt so down in the dumps that nothing could cheer you up
* Have you felt calm and peaceful
* Have you felt down
* Have you been a happy person

 (Response options: All of the time, most of the time, a good bit of the time, some of the time, a little of the time, none of the time)

The responses are used to calculate a summary score ranging from 0 to 100. Scores <= 52 indicate psychological distress2,3. The trajectories are shown in **Figure 3‑17**.

**Figure 3‑17 Percentages of women with low mental health index scores; for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

Over time the percentages of women with low mental health scores (i.e. scores ≤52 which indicate psychological distress) increased. Notably, women who completed every survey were much less likely to have low mental health scores at the early surveys.

**Figure 3‑18** shows the survival curves for women categorised by their mental health scores at Survey 1.

**Figure 3‑18 Survival curves for women with mental health scores <= 52 and >52 at Survey 1.**

Women with mental health scores < 52 at Survey 1 had poorer survival rates.

## Needing help and providing care to others

### Needing help

QUESTION: Do you regularly NEED help with daily tasks because of long-term illness, disability or frailty (e.g., personal care, getting around, preparing meals etc.)?

**Figure 3‑19** shows the trajectories for the percentages of women needing help with daily tasks. The reason for the increase associated with the change to six-monthly surveys is unknown but possibly relates to the change in format.

**Figure 3‑19 Percentage of women needing help with daily tasks because of long term illness, disability or frailty; for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

The percentage of women who reported needing help for daily tasks due to long-term illness, disability or frailty rose from 9% at Survey 1 when they were aged 70 to 75 years to 39% at the most recent six-monthly survey. Women who completed all surveys had less need for help when compared to all women in the cohort.

Women who needed help with daily tasks at Survey 1 had much poorer survival than other women, as shown in **Figure 3‑20**.

**Figure 3‑20 Survival curves for the period 1996-2016 for women grouped according to whether or not they needed help with daily tasks because of long term illness, disability or frailty at Survey 1.**

### Providing care for others

QUESTION: Do you regularly PROVIDE care or assistance (e.g., personal care, transport) to any other person because of their long-term illness, disability or frailty?

* Yes, for someone who lives with me
* Yes, for someone who lives elsewhere
* No, I do not provide care

Over time the percentage of women who reported regularly providing for someone because of their long-term illness, disability or frailty increased and then declined – see **Figure 3‑22** and 3-22.

**Figure 3‑21 Percentage of women who reported caring for another person because of long term illness, disability or frailty who lives with them; for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

The percentage of women who reported caring for another person living with them increased from 7% at Survey 2 to 13% at Survey 4 when they were aged 79 to 84 years, followed by a consistent decrease in later years.

**Figure 3‑22 Percentage of women who reported caring for another person because of long term illness, disability or frailty; for all women who completed each survey (open circles) and for the women who completed every survey (+ signs).**

The percentage of women who reported caring for another person increased from 17% at Survey 2 to 26% at Survey 4 when they were aged 79 to 84 years, followed by a consistent decrease in later years.

Survival curves for women who did or did not provide care to someone else at Survey 1 are shown in **Figure 3‑23** and **Figure 3‑24**.

**Figure 3‑23 Survival curves for the period 1996-2016 for women grouped according to whether or not at Survey 2 they provided care to someone because of long term illness, disability or frailty, who lived with them.**

**Figure 3‑24 Survival curves for the period 1996-2016 for women grouped according to whether or not at Survey 2 they provided care to someone because of long term illness, disability or frailty, who lived elsewhere.**

There is a slight, but statistically significant, survival advantage for women who were carers for someone living elsewhere at Survey 2. There was no difference in survival for women caring for someone living with them. However given the large amount of change in carer role over the women’s later lives, these comparisons do not reflect the true differences in survival for carers and non-carers.

# KEY RESEARCH ACHIEVEMENTS

## Publications using data from the 1921-26 cohort

Since 1996, over 200 papers using data from the ALSWH 1921-26 cohort have been published. The major themes in these publications are:

* Survival, frailty, and physical health (68 papers)
* Non-communicable disease (chronic conditions) (49 papers)
* Health service use and systems (49 papers)
* Mental health (44 papers)
* Linked data (41 papers)
* Social factors in health and wellbeing (39 papers)
* Methodology (35 papers)
* Weight, nutrition and physical activity (32 papers)
* Intergenerational issues (29 papers)
* Medications (22 papers)
* Quality of Life (16 papers)
* Health in rural and remote areas (15 papers)
* Tobacco, alcohol and other drugs (13 papers)
* Social determinants of health (8 papers)
* Comorbidity/multimorbidity (7 papers)
* Abuse (6 papers)
* Caring (6 papers)

 (*Note:* A publication may reflect more than one major theme).

Themes with high rates of citations (i.e., in peer reviewed journals, reports for government etc., as recorded by Google Scholar) were *Social factors in health* (14 papers cited more than 40 times); *Health service use and systems* (12 papers cited more than 40 times); *Mental health* (10 papers with more than 40 citations); Weight, nutrition and physical activity (8 papers cited more than 40 times); and Survival, frailty and physical health (7 papers with more than 40 citations).

### Highly cited publications since 1996:

Leaking urine: Prevalence and associated factors in Australian women. 1999. Neurourology and Urodynamics, 18(6); 567-577. Citations = 243.

This paper presented data on the prevalence of urinary incontinence across the original three cohorts of women. The proportion of women with reporting leaking urine was 13% (18-23 years), 36% (45-50 years), 35% (70-75 years). Subsequent papers have looked at the incidence and impact of urinary incontinence.

Updating the evidence on physical activity and health in women. 2007. American Journal of Preventive Medicine, 14(4); 380-391. Citations = 199

This paper reviewed findings on physical activity and prevention of cardiovascular disease, diabetes and cancer in women from prospective cohort studies conducted 1997-2006. They found strong evidence that physical activity has a role in prevention, but no evidence of additional benefits of vigorous intensity physical activity.

The World report on ageing and health: A policy framework for healthy ageing. The Lancet, 2016, 2145-2154. Citations = 194

This paper highlights key findings and recommendations from the 2015 WHO report on ageing and health. Four priority areas for action are noted – aligning health systems to the older populations they serve, ensuring the systems are developed to provide long-term care, providing opportunities for growing old in age-friendly environments, and improving measurement, monitoring and understanding of healthy ageing.

Attrition in longitudinal studies: Who do you lose? 2006. Australian and New Zealand Journal of Public Health, 30(4); 353-361. Citations = 182.

This paper examined loss to follow-up in the three original cohorts. The findings were used to target follow-up procedures, and to understand the effect of non-death attrition on the representativeness of the cohort. The analyses have been repeated and updated to provide good characterisation of the cohort over time and to reduce the effects of bias in study findings.

Disorders of breathing and continence have a stronger association with back pain than obesity and physical activity. 2006. Australian Journal of Physiotherapy, 52(1); 11-16. Citations = 172.

This paper examined associations between back pain, breathing difficulty and incontinence, with the suggestion of a common pathophysiological link between these three common symptoms.

The profile of women who consult alternative health practitioners in Australia. 2003. Medical Journal of Australia, 179(6); 297-300. Citations = 158.

This study identified the high prevalence use of complementary and alternative practitioners by women across Australia. Many subsequent studies have provided more in-depth analyses of how and why women use these services.

Validity of self-report screening scale for elder abuse: Women's Health Australia study. The Gerontologist, 2003; 43(1): 110-120. Citations = 123.

This paper established the methods for assessing vulnerability to elder abuse which are used in ALSWH.

Self-rated health and a healthy lifestyle are the most important predictors of survival in elderly women. 2008. Age & Ageing, 37(2); 194-200. Citations = 127.

This paper showed that current health and health related behaviours were stronger predictors than social factors of relatively early mortality among older women. The results underscored the importance of adopting a healthier lifestyle, by doing more exercise and not smoking, and showed how these health behaviours can continue to be of benefit even in later life. Subsequent papers further quantified the mortality risks for particular conditions and comorbidities and modifiable health behaviours in later life.

The problems of sleep for older women: Changes in health outcomes. 2003. Age and Ageing, 32(2); 154-163. Citations = 79.

This paper is one in a series which examined the prevalence, incidence and health impacts of sleeping difficulties among older women. The paper underscored the importance of sleeping difficulties for older women and the impact on their health-related quality of life. Further studies of the association between sleeping difficulty and mortality suggest that much of the mortality risk associated with sleeping difficulty can be explained by comorbid conditions.

### Highly cited publications in the last five years include:

* van der Hoorn M, Tett S, de Vries O, Dobson A & Peeters G. The effect of dose and type of proton pump inhibitor use on risk of fractures and osteoporosis treatment in older Australian women: A prospective cohort study. Bone, 2015, 81, 675-682. (31 citations)
* Brown W, Pavey T & Bauman A. Comparing population attributable risks for heart disease across the adult lifespan in women. British Journal of Sports Medicine, 2015, 49(16); 1069-1076. (33 citations)
* Schofield M, Powers J & Loxton L. Mortality and disability outcomes of self-reported elder abuse: A 12-year prospective investigation. Journal of the American Geriatric Society, 2013; 61(5): 679-685. (57 citations)
* Rich J, Chojenta C & Loxton D. Quality, rigour and usefulness of free-text comments collected by a large population based longitudinal study - ALSWH. 2013. PLoS ONE, 8; Art. No e68832. (34 citations)
* Koloski N, Jones M, Wai R, Gill R, Byles J & Talley N.Impact of persistent constipation on health related quality of life and mortality in older community dwelling women. 2013. American Journal of Gastroenterology, 108(7); 1152-1158. (52 citations)
* Peeters G, Dobson A, Deeg D & Brown WJ. A life-course perspective on physical functioning in women. 2013. Bulletin of the World Health Organization, 91(9): 661-670. (42 citations)

All publications using data from the 1921-21 cohort are listed in in Appendix A.

## Reports prepared using data from the 1921-26 cohort

### Major Reports:

Since 2001, ALSWH has prepared over 30 reports for the Department of Health that have used data from the 1921-26 cohort, including 11 major reports. One major report in 2010, focussed on the health of older women in Australia. These reports, listed in full in Appendix B, have included the following research areas:

**Informal caregiving:** This report examined patterns of caregiving across the lifecourse. Older women (from the 1921-26 cohort) provided care for grandchildren, as well as providing care to another because of illness, disability or frailty. The socio-demographic factors associated with patterns of care giving across women’s later life, and the impact of caregiving on the wellbeing of caregivers and their health service use was also presented. (This report will be formally released in October 2018).

**Future health service use and cost:** Data from the cohort was used to identify trends in women’s health status, risk and behaviour over the next twenty years, and to predict need for care and potential health service use in 2013. A summary of the report is available [here](https://www.alswh.org.au/images/content/pdf/major_reports/ResearchSummary_2016-Major-Report.pdf)

**Use, access to, and impact of Medicare services for Australian women:** Understanding how Medicare services are used at different life stages can guide and improve the provision of health services. In this report, women’s survey data were linked to Medicare Benefits Scheme (MBS) data to provide detailed information on how and when women use health services, and the costs of these services, throughout the life course. A summary of the report findings is available [here](https://www.alswh.org.au/images/content/pdf/major_reports/Major_Report_2017_Lay_Summary_Web.pdf).

**Chronic conditions, physical function and health care use:** Presented data on the increasing prevalence of several major chronic conditions as women age, including arthritis, asthma, diabetes, and cardiovascular conditions. The relationship between chronic disease and decline in women’s physical and mental health related quality of life was examined, as well as related increases in use of general practice consultations. The report also considered the prevalence or comorbidities and the increased rate of death associated with some chronic conditions. The report is available [here](http://www.alswh.org.au/images/content/pdf/major_reports/2015%20ALSWH%20MRJ%20Final.pdf)

**Women, health and ageing:** This report examined changes in women’s health as they aged from their 70s to their 80’s. Over this time, more than half of the women maintained good physical health. Women whose health started low and continued low had lower socio-economic status, were more likely to be overweight or obese, undertook little physical activity, and were current or ex-smokers. These women also had multiple chronic conditions and were heavy users of health services. A small group of women had clear improvements in their physical health, and many of these women had restorative surgery, or were recovering from acute conditions or events. The report also contrasted the effects of different chronic conditions on physical and mental health, social engagement, and health care use. The report is available [here](http://www.alswh.org.au/images/content/pdf/major_reports/2010_women_health_and_ageing_r161.pdf)

**Mental health:** The prevalence of psychological distress decreased with age, except in later old age when it increased slightly. Most (80%) of the 1921-1926 cohort reported ongoing good mental health. While there had been a steady increase in the use of the Better Access Scheme (BAS) to manage psychological distress among all cohorts, by December 2010, only about 3% of the 1921-1926 cohort had claimed for at least one BAS item. The experience of widowhood was associated with a decline in mental health up to four years prior to bereavement, with the lowest mental health reported in the year immediately after the loss. However, within four years of date of widowhood, the women’s mental health had returned to pre-loss levels. Poor mental health in the 1921-1926 cohort was associated with an increased risk of cardiovascular disease and with diabetes and arthritis. The report is available [here](http://www.alswh.org.au/images/content/pdf/major_reports/2013_major%20report%20H.pdf)

**Weight and physical activity:** Both weight and physical activity are important contributors to healthy ageing and the prevention and management of chronic conditions. ALSWH has examined these issues for the 1921-1926 cohort in four major reports in 2006, 2007, 2011 and 2012. The main findings of the reports were that over time, BMI of women in this cohort remained stable, although the percentage of those who were underweight increased. A slightly higher BMI was associated with better survival among older women. Physical activity which met guidelines of 30 minutes of moderate activity on most days decreased as the women aged. Both BMI and physical activity were associated with chronic conditions such as hypertension, heart disease, diabetes, asthma, osteoporosis and arthritis in this cohort. The report is available [here](http://www.alswh.org.au/images/content/pdf/major_reports/2007_major_report_b.pdf)

**Medications:** The prevalence of medication use increased with age and as chronic conditions became more common. The 1921-1926 cohort used more medications than the younger ALSWH cohorts, and were more likely to be using two or more medications in combination. The most common PBS claims were for cardiovascular medications (75% of the 1921-1926 cohort in 2005); alimentary tract medications (57% in 2005); drugs for musculoskeletal conditions (43% in 2005); respiratory system medications (20% in 2005) and antidepressant medications (18% in 2005). The report is available [here](http://www.alswh.org.au/images/content/pdf/major_reports/2008_major_report_c_r144.pdf)

**Area of residence:** Women in the 1921-1926 cohort living in regional and remote areas of Australia had higher death rates than those living in major cities. These higher death rates were associated with lung cancer, chronic obstructive pulmonary disease and ischaemic heart disease, which are often associated with smoking. However, very few of the older women were current smokers, so the higher mortality rate ascribed to these conditions may have been the result of past smoking, exposure to passive smoking or greater exposure to other hazards, such as environmental toxins. The health risk factor that was consistently higher with increasing distance from major cities was obesity. Thus, the prevalence and incidence of conditions associated with obesity, such as diabetes and hypertension, were also consistently higher among women living in regional and remote areas. Use of most health services was higher in major cities than in regional and remote areas. Visits to specialist medical practitioners decreased with increasing distance from major cities, however, there were few differences in hospital admissions. The report is available [here](http://www.alswh.org.au/images/content/pdf/major_reports/2011_rural_remote_and_regional_differences_r163.pdf)

### Other reports

ALSWH data from the 1921-1926 cohort have also been used by researchers to produce reports for various sections of the Department of Health, as well as for other agencies. Recent examples include:

**Health service use at the end of life by older Australian women with chronic conditions.** Dobson A, Waller M, Forder P, Dolja-Gore X, Hockey R, Byles J & Mishra G. Report prepared for the Australian Government Department of Health. May 2018.

This report was prepared for the Palliative Care Section, and used ALSWH survey data and linked administrative data to assess health service and aged care use in the last two years of life for women with dementia, heart disease, stroke or chronic lung disease. The report examined a range of aged care services (including permanent residential care, respite care, and community care) as well as hospital admissions, GP services, specialist services, and pharmaceuticals, and found that use of these services did increase in the last two years of life, particularly the last few months. Dementia was a strong driver of use of residential aged care and GP services, but lower use of community care, hospital and specialist services.

Some other examples include five reports on incontinence (2000, 2001, 2002, 2003 and 2004) and three reports on data provision, paid work and retirement and physical activity and health for the Office for Women, Department of Families, Community Services and Indigenous Affairs (2005 and 2007). A full list is available in Appendix B.

### Other information for women in the 1921-26 cohort

In addition to survey data, data for most women in the cohort can be obtained from administrative data sets through a data linkage authority. This method provides detailed information on women’s health and aged care service use across their later life, and for ascertainment of conditions such as dementia which are difficult to determine from a postal survey.

## Contributions to Government Policy

Findings from the 1921-26 cohort have directly influenced Federal and State Government Policy in several areas. We briefly feature recent notable contributions:

* **2013 New South Wales Government’s Health Framework for Women’s Health** (NSW Ministry of Health, 2013).

Published research from the ALSWH 1921-26 cohort contributed to recommendations for healthy ageing, including accessing health services, managing dementia, osteoarthritis and falls. Key strategies included supporting healthy lifestyles, appropriate mental health services, support for women with a disability or those who are caring for a person with a disability.

* **2010 Australian Government National Women’s Health Policy** (Australian Government Department of Health and Ageing, (now the Australian Government Department of Health) 2010)

Published research from the ALSWH 1921-1926 cohort was cited 18 times in the policy. Evidence from the ALSWH contributed to recommendations concerning chronic conditions (such as asthma and arthritis); health behaviours (physical activity, smoking, alcohol and weight); use of mental health services (such as counselling); the experience of widowhood and the availability of services to assist with older bereaved women’s health, financial and social needs; the impact of comorbid conditions on physical and psychological health and social function; the ability of older women with chronic conditions to manage on their available income; and physical and psychological abuse of older women.

The Policy states that evidence from the ALSWH has confirmed the importance of taking a whole of life approach to women’s heath, preventing the accumulation of health risk factors. Informed by the ALSWH, the Policy identifies the importance of controlling risk factors to prevent chronic disease, as well as promoting physical activity and healthy in later life and targeting mental health and well-being. Arthritis, a condition highlighted by the study as having a particular impact on women’s wellbeing, participation and health care use, is emphasised in the Policy. The Policy also emphasises the social and economic contexts in which women age, with consideration for the experiences of widowed women, women with lower levels of social support, and women ageing in rural areas, as identified in various publications and reports arising from the study. The Policy recognises the study’s role in defining different health needs of older women in rural areas, their poorer access to health care, and their higher mortality rates when compared to urban women. The Policy quotes the study as identifying the importance of homes, social support and active participation in the community as fundamental to older women’s well-being. The policy on older women and violence is also informed by ALSWH data on the prevalence, vulnerabilities and impacts of violence for older Australian women. Extensive research into the needs of older women as carers, the care women receive, and the health of those who care for them, has informed Policy in relation to carers. Research into women’s healthcare use provided rich data to inform Policy on access to primary care, chronic disease management, and Medicare incentives.

* **Choose Health: Be Active. A physical activity guide for older Australians** (Australian Government Department of Veteran’s Affairs and the Department of Health and Ageing (now the Australian Department of Health), 2008).

This guide was prepared by ALSWH Chief Investigator Professor Wendy Brown to provide an evidence-based guide for optimal physical activity for older adults.

* **National Continence Management Strategy**

The study informed the strategy with respect to prevalence, incidence and risk factors for urinary incontinence, the effects of ageing on incontinence, and the impacts of incontinence on the lives of older women. Information from the study informed the preparation of information brochures available on www.bladderbowel.gov.au

Data from the study also informed the development of **“Best practice in the prevention and treatment of constipation in adults under 65 years”.** Available[here](http://www.health.gov.au/internet/main/publishing.nsf/content/continence-ncms-faecalmgmt.htm/%24file/pjt23clinical.pdf)

* **National physical activity recommendations for older Australians: Discussion document** (Australian Government Department of Health and Ageing, 2006)

Published research from the ALSWH 1921-1926 cohort was cited in this discussion document which was commissioned from the National Ageing Research Institute.

Data have also been used in numerous submissions by other agencies, for example:

* Older Women’s Network: Older Women’s Network NSW notes on a submission to ALRC Grey Areas—Age Barriers to Work in Commonwealth Laws (IP 41) 28 May 2012
* Mental Health Council of Australia Submission to: The Productivity Commission Inquiry into Aged Care July 2010
* Submission to House of Representatives Standing Committee on Health and Ageing, Inquiry into Obesity in Australia

The study was featured in a special edition of the Australasian Journal of Ageing “Ageing well in Australia”:

[Byles JE](http://www.ncbi.nlm.nih.gov/pubmed?term=Byles%20JE%5BAuthor%5D&cauthor=true&cauthor_uid=22032764), [Dobson A](http://www.ncbi.nlm.nih.gov/pubmed?term=Dobson%20A%5BAuthor%5D&cauthor=true&cauthor_uid=22032764); [Australian Longitudinal Study on Women's Health](http://www.ncbi.nlm.nih.gov/pubmed?term=Australian%20Longitudinal%20Study%20on%20Women's%20Health%5BCorporate%20Author%5D). (2011). **The value of time in longitudinal studies of ageing. Lessons from the Australian Longitudinal Study on Women's Health.** *Australasian Journal of Ageing*. S2; p 6-12. doi: 10.1111/j.1741-6612.2011.00531.x.

This special edition was produced by the Australian Association of Gerontology (AAG) to showcase the latest evidence in ageing research, with a particular emphasis on research funded through the Ageing Well Ageing Productively (AWAP) research grants and the Australian Longitudinal Study of Women's Health, and on contributions to policy and practice outcomes benefiting older Australians in their everyday lives.

## Capacity building activities in women’s health research

Between 1996 and 2018, 21 researchers who based their research on the ALSWH 1921-26 cohort have graduated with a masters or PhD degree. Table 4‑1 outlines these research topics, and highlights the subsequent careers of a few of the researchers. Ten Masters or PhD research students are currently enrolled and undertaking projects using data from the ALSWH 1921-26 cohort

Table 4‑1 ALSWH RESEARCH HIGHER DEGREE STUDENTS COMPLETED USING 1921-26 COHORT DATA

| Student | Topic | Institution | Degree | Completion date | Current position |
| --- | --- | --- | --- | --- | --- |
| Anne Young | General Practitioner utilisation among women in Australia. | The University of Newcastle | PhD | 1999 |  |
| Brendan Goodger | Social support, health status and health care utilization in women aged 70-76 years. | The University of Newcastle | PhD | 2000 | Head of Population Health and Chronic Disease at Central Eastern Sydney Primary Health Care Network. |
| Esben Strodl | Psychological factors associated with frequency of angina and the role of mediating variables | The University of Queensland | PhD | 2002 | Senior lecturer in health psychology and psychotherapy at Queensland University of Technology. Serves as national chair of the APS College of Health Psychologists. |
| Emma Harley | Social support in later life: Cross-sectional and longitudinal analysis of inter-relationships between psychosocial variables in the Women’s Health of Australia study. | Flinders University | PhD | 2004 | Practicing Clinical Psychologist working across the public and private sectors with a range of different clients, including remote indigenous communities, soldiers, peacekeepers and refugees. |
| Karen Furlong | Epidemiology of osteoporosis in Australian women | The University of Queensland | Masters | 2006 |  |
| Dr Sally Price | Carers and psychosocial correlates over time: A longitudinal analysis. | The University of Queensland | Doctor of Psychology | 2006 |  |
| Leah Collins | Investigating quality of life and depression in middle aged and older Australian women with cancer | The University of Melbourne | Doctor of Psychology | 2008 | Clinical and Health Psychologist in private practice in Melbourne. |
| Nadine Smith | Psychological predictors of successful ageing in a cohort of Australian women | The University of Newcastle | Masters | 2001 |  |
| Biopsychosocial correlates of women’s mental health: A longitudinal analysis of self-reported mental health across three generations of Australian women | The University of Queensland | PhD | 2008 | Senior researcher with the New South Wales Bureau of Crime Statistics and Research. |
| Afsoon Hassani Mehraban | An application of the International Classification of Functioning Disability and Health for understanding falls risks among older community women in Australia | The University of Newcastle | PhD | 2008 | Associate Professor, Department of Occupational Therapy, School of Rehabilitation Sciences, Iran University of Medical Sciences, Tehran, Iran. |
| Nur Hafidha Hikmayani | Cardiovascular medication use and health related Quality of Life in older women with diabetes | The University of Newcastle | Master Clinical Epi | 2009 | Member of the Faculty of Medicine, Sebelas Maret University, Indonesia. 2014-17 PhD University College London (explored the dynamics and variations in diabetes care over time in the UK, and the factors associated with glycaemic, blood pressure and lipid target attainment using linked electronic health records)  |
| Emma Poulsen | Complementary and alternative medicine use in the Australian baby boomer and older adult populations | The University of Queensland | Doctorate Clinical Health | 2012 | Clinical psychologist and clinical health psychologist with the Ageing Mind Initiative at The University of Queensland. |
| Jeannine Liddell | Participation in the arts and its relation to healthy ageing | The University of Newcastle | PhD | 2012 |  |
| Melissa Harris | When life’s a pain: The relationship between stress and modifiable psychological factors in arthritis | The University of Newcastle | PhD | 2013 | Postdoctoral research fellow at the Research Centre for Generational Health and Ageing |
| Jane Rich | An interdisciplinary investigation into the relationship between drought and mental health in Australia | The University of Newcastle | PhD | 2014 |  |
| Thomas Lo | Arthritis impact over time | The University of Newcastle | PhD | 2015 | Health Economist with the Institute of Health Economics, Edmonton, Canada. |
| Janni Leung | Urban rural differences in health care for women with colorectal, breast and lung cancer | The University of Queensland | PhD | 2015 | Global Addiction Epidemiology Research Fellow at the National Drug and Alcohol Centre (NDARC) at UNSW. |
| Xenia Dolja-Gore | Predictors of mental health services utilisation and costs for Australian women | The University of Newcastle | PhD | 2016 | Research Fellow with the HMRI Public Health Capacity Building Group at the University of Newcastle. |
| Tazeen Majeed | Workforce participation patterns over the life course and the association with chronic diseases – A gendered approach  | The University of Newcastle | PhD | 2016 | Postdoctoral research fellow with the Research Centre for Generational Health and Ageing, University of Newcastle |
| Katie de Luca | Arthritis impact over time: A longitudinal exploration of burden of illness, comorbidities (particularly depression), management, and health care costs in older Australian women. | The University of Newcastle | PhD | 2016 | Postdoctoral research fellow in the Department of Chiropractic at Macquarie University. |
| Maha Alsalami | Medication use and mental health in older Australian women | The University of Newcastle | PhD | 2017 |  |
| Robyn Kennaugh | “It’s not how old we are; it’s how we are old”; A salutogenic approach to how older Australian women experience ageing and respond to life stressors | The University of Newcastle | PhD | 2017 |  |

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2. Silveira E, Taft C, Sundh TV, Waern M, Palsson S, & Steen B. (2005). Performance of the SF-36 Health Survey in screening for depressive and anxiety disorders in an elderly female Swedish population. Quality of Life Research, 14, 1263-1274.

3. Rumph H-J, Meyer C, Hapke U &John U. (2001). Screening for mental health: Validity of the MHI-5 using DSM-IV Axis 1 psychiatric disorders as gold standard. Psychiatry Research, 105, 243-253.

4. Australian Longitudinal Study on Women’s Health. (2013). [1921-26 Cohort Summary 1996-2013](https://www.alswh.org.au/images/content/pdf/Cohort_summaries/ALSWH_1921-2_%20cohort_summary.pdf). Report prepared for the Australian Government Department of Health.

# APPENDIX A: PUBLICATIONS USING 1921-26 COHORT DATA (from 1998 to 2018)

(\*Citation details are from Google Scholar, September 2018).

## Abuse

| **Details** | **Authors** | **Citations\*** |
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| Intimate partner violence adversely impacts health over 16 years and across generations: A longitudinal cohort study. PLoS One, 2017, 12(6); e0178138. | Loxton D, Dolja-Gore X, Anderson A & Townsend N. | 10 |
| Mortality and disability outcomes of self-reported elder abuse: A 12-year prospective investigation. Journal of the American Geriatric Society, 2013; 61(5): 679-685. | Schofield M, Powers J & Loxton L. | 57 |
| 'There's more to life than just walking': Older women's ways of staying healthy and happy. Journal of Aging and Physical Activity, 2006; 14(4): 380-391.  | Adamson L & Parker G. | 27 |
| Three year health outcomes among older women at risk of elder abuse: Women's Health Australia. Quality of Life Research, 2004; 13(6): 1043-1052. | Schofield MJ & Mishra G. | 40 |
| Validity of self-report screening scale for elder abuse: Women's Health Australia study. The Gerontologist, 2003; 43(1): 110-120. | Schofield MJ & Mishra GD. | 123 |
| Screening for vulnerability to abuse among older women: Women's Health Australia study. Journal of Applied Gerontology, 2002; 21(1): 24-39. | Schofield MJ, Reynolds R, Mishra G, Powers J & Dobson AJ. | 69 |

## Ageing: Survival, frailty, physical health

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# APPENDIX B: REPORTS PREPARED USING 1921-26 COHORT DATA

## Major Reports (2006 – 2018)

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# APPENDIX C: 1921-26 cohort participation details, Six Monthly Follow-Up Survey (to May 2018).

Table 8‑1 Response rates for six monthly follow-up surveys at 22nd August 2018

| Survey | Total Completed (N) | Total Completed (%) | Total Mailed (N) | Total Mailed (%) |
| --- | --- | --- | --- | --- |
| First | 3,855 | 82 | 4,707 | 100 |
| Second | 3,390 | 90 | 3,778 | 100 |
| Third | 2,987 | 90 | 3,324 | 100 |
| Fourth | 2,609 | 90 | 2,905 | 100 |
| Fifth | 2,289 | 90 | 2,532 | 100 |
| Sixth | 2,003 | 89 | 2,240 | 100 |
| Seventh | 1,745 | 89 | 1,959 | 100 |
| Eighth | 1,512 | 90 | 1,681 | 100 |
| Ninth | 1,336 | 91 | 1,464 | 100 |
| Tenth | 1,150 | 89 | 1,288 | 100 |
| Eleventh | 978 | 89 | 1,098 | 100 |
| Twelfth | 774 | 88 | 883 | 100 |
| Thirteenth | 551 | 88 | 632 | 100 |
| Fourteenth | 257 | 87 | 306 | 100 |