

Australian Longitudinal Study on Women's Health

Technical Report #45

November 2022





Australian Longitudinal Study on Women's Health

Technical Report #45

Final prepared November 2022. (ISSN 2653-3235)

TABLE OF CONTENTS

1	EXECUTIVE SUMMARY				
2	INTRODUCTION9				
3	COND	UCT OF SURVEYS11			
3.1	1973-7	8 cohort			
	3.1.1	Main Survey 911			
	3.1.2	1946-51 Pilot Cohort - Survey 1012			
	3.1.3	Main Survey 1031			
3.2	1921-2	6 cohort			
	3.2.1	Six-Month Follow-Up Surveys48			
3.3	COVID	-19 surveys			
	3.3.1	COVID-19 Surveys - Vaccination survey52			
	3.3.2	References			
3.4	'Refres	h' of the 1973-78 cohort with women from Asian backgrounds54			
	3.4.1	Background			
	3.4.2	1973-78 cohort 'refresh' development and progress54			
	3.4.3	Future plans56			
	3.4.4	References			
4	MAINT	ENANCE OF COHORTS			
4.1	Update	of cohorts and response rates57			
	4.1.1	First survey of the 1973-78, 1946-51 and 1921-26 cohorts in 199657			
	4.1.2	1973-78 cohort			
	4.1.3	1946-51 cohort			
	4.1.4	1921-26 cohort			
	4.1.5	1989-95 cohort			
4.2	Mainte	nance strategies63			
4.3	Refere	nces64			
5	DATA LINKAGE				
5.1	ALSW	۲ linked data holdings65			
	5.1.1	National collections			
	5.1.2	State and Territory collections68			
	5.1.3	Common Conditions from Multiple Sources (CCMS)70			
	5.1.4	Substudies, and the 1973-78 Cohort and 1989-95 Cohort Refresh71			

5.2	Data access procedures72				
	5.2.1	Data user approvals72			
	5.2.2	Access options72			
	5.2.3	Data access conditions73			
5.3	Use of	linked data74			
5.4	Other a	activities75			
5.5	Legal a	and ethical considerations for health record linkage			
	5.5.1	Applicable legislation and guidelines76			
	5.5.2	Consent status of ALSWH participants77			
	5.5.3	Communicating with ALSWH participants about health record			
		linkage78			
	5.5.4	Current HREC approvals for health record linkage78			
6	ARCH	IVING			
7	METH	DDOLOGICAL ISSUES			
7.1	Mean s	stress derived variable in ALSWH82			
	7.1.1	Introduction82			
	7.1.2	Mean stress in ALSWH82			
	7.1.2.1	The change in 2021 / 2022			
	7.1.2.2	Implications85			
7.2	Measu	ring sexual violence in ALSWH Surveys86			
	7.2.1	Introduction86			
	7.2.2	Measures of sexual violence in ALSWH86			
	7.2.3	Issues with measuring sexual violence using ALSWH data88			
	7.2.4	References			
7.3	SEIFA	percentiles in ALSWH91			
	7.3.1	Introduction91			
	7.3.2	SEIFA in ALSWH91			
	7.3.3	Quantiles replacing index values92			
	7.3.4	SEIFA Quantiles in the ALSWH data92			
	7.3.5	References			
8	2021 N	IAJOR REPORT			
8.1	Overvi	ew of the four ALSWH cohorts across the life course			
8.2	Then a	nd now: Comparing two generations of women during midlife94			

8.3	Social and personal circumstances95				
8.4	Abuse and violence in midlife96				
8.5	Then and now: Comparing two generations of women in their early 70s	96			
8.6	Women's attitudes to ageing and their outlook for the future	97			
8.7	Implications and recommendations	97			
9	DISSEMINATION OF STUDY FINDINGS	99			
9.1	Publications	99			
9.2	Conference Presentations	110			
9.3	Media 112				
9.4	Social media	113			
9.5	Website	117			
9.6	Newsletters	117			
10	COLLABORATIVE RESEARCH ACTIVITIES	118			
10.1	Scientific meetings and teleconferences among the research team	118			
	10.1.1 Management Committee	118			
	10.1.2 Data Management Group	118			
	10.1.3 Data Access Committee	119			
10.2	Research projects	120			
	10.2.1 Full ALSWH datasets	120			
	10.2.2 Core dataset	120			
	10.2.3 Substudies	123			
	10.2.4 Student projects	123			
11	PROJECT STAFF	124			
12	APPENDICES: PROGRESS REPORTS FOR CURRENT AND COMPLET	ED			
	PROJECTS	126			

1 EXECUTIVE SUMMARY

This draft technical report covers the period from December 2021 to November 2022. The purpose of the report is to document the annual operational aspects of the Australian Longitudinal Study on Women's Health (ALSWH), as well as the progress and outcomes of the preceding year. The 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 surveys (mailed or online) that ask about diverse aspects of their health, wellbeing, life experiences and demographics. ALSWH has met all of the obligations and deliverables for the period December 2021 – November 2022 contained in the relevant contracts with the Department of Health and Aged Care

Conduct of surveys

During this period, surveys have been conducted as follows:

- 1973-78 cohort: Data collection for Main Survey 9, deployed in June 2021, continued throughout the year, with 12,318 women invited to participate. By 31 October 2022, the survey had been completed by 6,510 women, and another 363 women had partially completed it. Data collection for Survey 9 was closed in December 2022.
- 1946-51 cohort: Planning for Survey 10 began with deployment of the Pilot Cohort Survey to 303 women in the Pilot Cohort in December 2021. The Pilot Survey was completed by 219 women, and partially completed by 4 women. Main Survey 9 was subsequently deployed to 10,021 women in June 2022, when the women were aged 71 to 76 years. At 31 October 2022, surveys had been completed by 5,915 women, and partially completed by 65 women. Main Survey 10 is scheduled to close in the second half of 2023.
- 1921-26 cohort: Women in this cohort receive a survey every 6 months. The six-monthly follow-up (6MF) surveys are conducted on a rolling basis, so that women receive a survey 6 months after they have completed their previous survey. Thus, both the numerator and denominator of the

response rate are dynamic. The twenty-first round of survey distribution started in November 2021, and the twenty-second in June 2022.

 Recruitment commenced for the 'refresh' of the 1973-78 cohort with women from North-Eastern, South-Eastern and Southern Asian backgrounds. By early November 2022, 70 women from these backgrounds had completed the survey. Of these women, 38 (about 55%) met all the eligibility criteria for participation (i.e., provided contact details and Medicare information). An additional 584 women have completed the survey but are not from the target backgrounds. Similarly, only 304 (just over 50%) of these women met all the eligibility criteria for participation in the cohort.

Maintenance of cohorts

Retention of participants in the 3 youngest cohorts has remained stable, at approximately 60% for the women born 1989-95 (now aged 27–33) and women born 1973-78 (now aged 44-49), and over 75% for the women born 1946-51 (now aged 71-76). Women in the oldest cohort, born 1921-26, received their last full survey in 2011, when they were aged 85-90, which was completed by just over 4,000 women. Since then, this cohort have received shortened surveys at six-monthly intervals. Now aged 96-101 years, there are less than 500 women still participating, with approximately 150 returning six-monthly surveys in 2022.

Since the initial ALSWH participants were recruited, their representativeness of the Australian population has declined due to immigration. This is particularly apparent for women from North-East Asia (mainly China, Hong Kong, Taiwan, Japan and Korea), South-East Asia (e.g., Vietnam, Indonesia and the Philippines) and South Asia (including India, Sri Lanka and Pakistan) in the 1989-95 and 1973-78 cohorts. According to the 2016 Census, about 10-15% of the general population of women were born in these countries, but for women in the two youngest ALSWH cohorts, only about 1-2% were born in these regions. To address this imbalance, recruitment of at least 1,000 women with ancestry from North-Eastern, South-Eastern and Southern Asia to the 1973-78 cohort began this year. Recruitment for the 1989-95 cohort is expected to begin in 2023.

Data linkage

Data linkage has continued to be an important component of the Study. Thirty-four administrative datasets are linked with survey data (including data from the Mothers and their Children's Health sub study) and 264 projects are currently approved to use the linked data. This year we updated and expanded the ALSWH Common Conditions from Multiple Sources (CCMS) datasets, which contain indicator variables for 8 common chronic conditions (cancer, dementia, diabetes, ischaemic heart disease, mental health, musculoskeletal conditions, respiratory conditions, and stroke) derived from both survey and linked health record data. These datasets have been made available to research collaborators, subject to standard ethics/data custodian approvals for linked data. Analyses using linked data have been included in over 110 publications (journal articles and reports). Planning also continued this year to access a Secure e-Research Platform (SERP).

Archiving

ALSWH data are routinely archived with the Australian Data Archive (ADA). In 2022, recent data from the ongoing six-month follow-up surveys of the 1921-26 cohort was archived.

Methodological issues

A number of important methodological issues have been considered during 2022 including:

- changes to how the mean stress variable is derived
- measurement of sexual violence in ALSWH surveys
- calculation of SEIFA percentiles

Major report 2021

The 2022 Major Report focused on women's health and risk factors at mid-life. A summary is included here in <u>Section 8</u> – the <u>full report</u> is available on the Study website.

Dissemination of study findings

Since November 2021, 42 papers have been published in national and international scientific journals, and 26 presentations have been made to scientific and professional audiences both in Australia and internationally (conference attendance has continued to be somewhat 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. Newsletters have been distributed to participants, research collaborators, and other stakeholders. Social media continued to be used as a communication tool.

Collaborative research activities

Since December 2021, data access has been approved for 32 new or amended 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

67 postgraduate students are currently working on aspects of the project. Progress summaries of all collaborative research projects are provided in Appendixes A, B and C.

Staff

ALSWH staff are located at the University of Newcastle and the University of Queensland. During 2022 over 35 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 and Aged Care.

2 INTRODUCTION

The Australian Longitudinal Study on Women's Health (ALSWH) is a longitudinal population-based survey funded by the Australian Government Department of Health and Aged Care (previously the Department of Health and hereafter referred to as the Department of Health and Aged Care). The project began in 1996 and involves 4 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 now aged 27 to 33. Their most recent survey (Survey 6; 2019) was completed by 8,346 women.
- The 1973-78 cohort: aged 18 to 23 when first recruited in 1996 (N = 14,247) and aged 44 to 49 in 2022. Survey 9 of this cohort is underway, and by November 2022 had been completed by 6,510 women.
- The 1946-51 cohort: aged 45 to 50 years in 1996 (N = 13,716) and now aged 71 to 76 years. 7,956 women completed Survey 9 in 2019.
- The 1921-26 cohort: aged 70 to 75 years in 1996 (N = 12,432). Surviving women in this cohort are now aged 96 to 101 and are surveyed every six months (with an abbreviated questionnaire). We estimate approximately 200 women are still participating in 2022.

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 26 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 (#45) 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 Aged Care 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 and Aged Care:

- 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 2022 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 2022 are provided in a separate appendix.

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

- For the 1946-51 cohort, Pilot Survey 10 was conducted, and Main Survey 10 began. In the 1973-78 cohort, Survey 9 continued. The nineteenth wave of the six-monthly follow-up surveys of the 1921-26 cohort continued and the twentieth wave commenced in May. Recruitment commenced for the 'refresh' of the 1989-95 cohort with women from North-Eastern, South-Eastern and Southern Asian backgrounds.
- A total of 32 new or amended research projects have been given approval to use ALSWH data. Results from previously approved projects have been published in 42 peer reviewed scientific journal articles and used in 26 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;
 - o 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;
 - o investigate all aspects of health throughout women's lifespan and;
 - provide an evidence base of the development and evaluation of health policy, other relevant policies and practice.
- An Annual Report for 2021 and a Major Report (examining women's health and risk factors at midlife) 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.

3 Conduct of surveys

3.1 1973-78 cohort

3.1.1 Main Survey 9

Survey 9 of the 1973-78 cohort began in June 2021, when the women were aged 43-48 years old. The survey was offered in two formats, both as an online survey and as a paper survey. For details concerning development of this survey and processes for data collection, please refer to the previous <u>Technical Report</u> (Report 44).

Table 3-1 details the interim response rates for the main survey and the CSIRO food intake survey (which was included in the main survey). By 31 October 2022, completed (online or paper) main surveys had been received from 6,510 women, which is 53% of those invited; while another 363 (3%) had partially completed their survey online. Of the women who have not yet responded (n=5,145), active follow-up and contact has been made with 2,893 (56%). Another 535 women (10%) are in tracking, and 795 women (15%) are lost to follow-up.

	Main Survey		CSIRO Food	I Intake Survey
	N	%	N	%
Completed online survey	5,390	43.8	5,042	40.8
Completed paper survey	1,120	9.1	1,078	8.8
Partially completed online survey	363	2.9	281	2.3
Deceased	9	0.0	9	0.0
Withdrawn	137	1.1	145	1.2
Not this time	154	1.3	9	0.0
No response	5,145	41.8	5,772	46.9
Total	12,318	100	12,318	100

Table 3-1 Response rates for Main Survey 9 and the CSIRO Food Intake Survey for the 1973-78 cohort, at 31 October 2022 (N = 12,318)

Data collection for this survey closed in mid-December 2022, and the dataset will be made available to researchers in the first half of 2023. The Databook for Survey 9 of the 1973-78 cohort, (prepared with an interim sample in November 2022), will also be updated on the Study website.

3.1.2 1946-51 Pilot Cohort - Survey 10

Development of survey materials

Several changes were made from the previous survey (Survey 9, deployed in 2019) for the Pilot Cohort Survey 10 of the 1946-51 cohort.

As the women in this cohort are now aged 71-76, the font size was increased throughout the entire survey to accommodate the increased risk of deteriorating vision. Font size was increased to be a similar size to that used in Survey 2 for the 1921-26 Cohort (when those women were aged 73-78).

Changes, additions and deletions

Five new items were introduced into the pilot survey, including:

- COVID-19 positive test: To capture the prevalence of women within the cohort who had received a positive test for COVID-19
- COVID-19 vaccination status: To measure the prevalence of COVID-19 vaccination status
- *Pelvic Organ Prolapse diagnosed/ treated*: To measure the prevalence of women with prolapse who may not have had an operation or procedure to correct it
- Pelvic Organ Prolapse Inventory 6 (POPDI-6): To measure the prevalence of prolapse symptoms
- Adopted status: To measure the prevalence of women who were adopted as children

While many of the existing survey items from Main Survey 9 remained unchanged, 14 items were modified slightly to provide better clarity or instruction. The increased font size meant that there was less room to accommodate all previous questions from Main Survey 9. As a result, 20 items that were included in Main Survey 9 were removed for Pilot Survey 10. The CSIRO Food Intake Survey is not required in all surveys, so was also removed. These items have been reserved for inclusion at a later survey, as appropriate.

For details about changes to existing survey items and the addition of new survey items from Main Survey 9 to Pilot Survey 10, please refer to Table 3-2. For details about the deleted items from Main Survey 9 to Pilot Survey 10 for the 1946-51 Cohort, please refer to Table 3-3.

Item No.	Торіс	Source	Item change justification	New item justification
All	Text size		Text font size increased for entire survey (similar to 1921-26 Cohort Survey 2) to account for increased risk of deteriorating vision.	
1	Date of birth	ALSWH		
2	Postcode	ALSWH		
3-13	SF-36	Ware JE & Sherbourne CD. (1992). The MOS 36-Item Short-Form Health Survey (SF- 36): 1. Conceptual Framework and item selection, <i>Medical Care</i> , 30(6): 473-483.		
14	GP Consultations	Modified from Australian Bureau of Statistics. (1991). <i>1989-1990 National Health Survey</i> <i>Users' Guide.</i> Canberra: ABS. Cat. No. 4363.0		
15	Specialist Consultations	ALSWH		
16	Complementary and Alternative Therapies	ALSWH		
17	GP Continuity of Care	ALSWH		

Table 3-2 Changes to existing items and additions of new items from Main Survey 9 to Pilot Survey 10 for the 1946-51 Pilot Cohort

Item No.	Торіс	Source	Item change justification	New item justification
18	GP Costs	Modified from Davies AR & Ware JEJ. (1991). <i>GAA's consumer satisfaction survey</i> <i>and user's manual</i> (2 nd Edn). Washington DC: The Group Health Association of America (GHAA)		
19	Private Health Insurance (hospital)	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users' Guide</i> . Canberra: ABS. Cat No. 4363.0	Reverted back to two items (as in Survey 8), due to high missing values in Survey 9 when using combined item	
20	Private Health Insurance (ancillary)	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey</i> <i>Users' Guide</i> . Canberra: ABS. Cat No. 4363.0	Reverted back to two items (as in Survey 8), due to high missing values in Survey 9 when using combined item	
21	Health Cover (including Health Care Card)	ALSWH		
22	Hospital Admissions	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users' Guide</i> . Canberra: ABS. Cat No. 4363.0		
23	Screening	ALSWH		
24	Abnormal pap test / mammogram	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		

Item No.	Торіс	Source	Item change justification	New item justification
25	Screening – breasts, bowels, bones, vaccinations	ALSWH		
26	HRT/Pill	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users' Guide</i> . Canberra: ABS. Cat No. 4363.0		
27	COVID-19 positive test	ALSWH		To capture prevalence of women who received a positive test for COVID-19
28-30	COVID-19 vaccination status	ALSWH		To measure prevalence of COVID-19 vaccination status among the cohort
31	Goldberg Anxiety and Depression Scale	Anxiety and depression scales from: Goldberg D, Bridges K, Duncan-Jones P & Grayson D. (1988). Detecting anxiety and depression in general medical settings. British Medical Journal, 297, 897-899.		
32	Life isn't worth living	Modified from Beck A, Schuyler D & Herman, I. (1974) Development of the Suicide Intent Scale. In AT Beck, HLP Resnick, & DJ Lettieri (Eds.) <i>The prediction of suicide</i> . Bowier, MD: Charles Press Publishers		
33	Health service utilisation	Modified from Davies AR & Ware JEJ. (1991). <i>GHAA's consumer satisfaction survey</i> and user's manual (2nd Edn). Washington		

Item No.	Торіс	Source	Item change justification	New item justification
		DC: The Group Health Association of America (GHAA).		
34	Falls	Modified from DVA (Dept of Veterans' Affairs) trial (1997)		
35a-35b	Falls	Modified from: MacKenzie LA. Home Hazards and Falls prevention in home-based health assessments for older people in the community. PhD Thesis. The University of Newcastle. 2002. Daejin Kim & Sherry Ahrentzen (2017). Environmental and behavioral circumstances and consequences of falls in a senior living development, <i>Journal of Housing For the Elderly</i> , 31:3, 286-301. Stevens JA, Mahoney JE & Ehrenreich H. Inj. Circumstances and outcomes of falls among high risk community-dwelling older adults. <i>Epidemiology.</i> (2014) 1: 5. Bleijlevens MHC, Diederiks JPM, Hendriks MRC, et al. Relationship between location and activity in injurious falls: An exploratory study. <i>BMC Geriatrics</i> , 2010;10:40 Milat AJ, Watson WL, Monger C, Barr M, Giffin M & Reid M. (2011) Prevalence, circumstances and consequences of falls among community-dwelling older people: Results of the 2009 NSW Falls Prevention	Added instructions to Q34b: "Mark all that apply"	

Item No.	Торіс	Source	Item change justification	New item justification
		Baseline Survey. <i>NSW Public Health Bulletin</i> 22, 43-48.		
36	Sleeping problems	Baum FE & Cooke RD. (1989). Community- health needs assessment: Use of the Nottingham health profile in an Australian study. <i>The Medical Journal of Australia</i> , Vol. 150, pp 581-590.		
37	Diagnoses	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users' Guide.</i> Canberra: ABS. Cat No. 4363.0	Additional conditions added to investigate prevalence of "ovarian cancer" and "Interstitial cystitis (or Painful Bladder Syndrome)"	
38	Operations/ procedures	ALSWH		
39	Hysterectomy	ALSWH		
40	Weight	ALSWH		
41	Height	ALSWH		
42	Waist measurement	ALSWH		
43	Medications	ALSWH	Broke up question grid to make it easier to read. Deleted response "Lysine" due to high missing values in Survey 9.	
44	Symptoms	ALSWH		
45	Oral Health	Modified from Carter KD & Stewart JF. (2002). <i>National Dental Telephone Interview</i>		

Item No.	Торіс	Source	Item change justification	New item justification
		<i>Survey 2002.</i> The AIHW Dental Statistics and Research Unit, University of Adelaide.		
46	Ageism	Ageism survey developed by Palmore (2001).		
47	Pelvic Organ Prolapse diagnosed/ treated	ALSWH		To measure prevalence of women with prolapse who may not have had an operation or procedure to correct it
48	Pelvic Organ Prolapse Inventory 6 (POPDI-6)	MD Barber, MD Walters & RC Bump. Short forms of two condition-specific quality-of-life questionnaires for women with pelvic floor disorders (PFDI-20 and PFIQ-7). <i>American</i> <i>Journal of Obstetrics and Gynecology</i> 193, 103-113 (2021).		To measure prevalence of prolapse symptoms among women
49-51	Urine leakage	Sansoni J, Hawthorne G, Fleming G, Owen E and Marosszeky N. (2011). Technical Manual and Instructions: Revised incontinence and Patient Satisfaction Tools. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.		
52	Resilience	Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P & Bernard J. (2008). The brief resilience scale: Assessing the ability to		

Item No.	Торіс	Source	Item change justification	New item justification
		bounce back. <i>International journal of behavioral medicine</i> , <i>15</i> (3), 194-200.		
53	Depression (CESD- 10)	Andresen EM, Carter WB, Malmgren JA & Patrick DL. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D. <i>American Journal of</i> <i>Preventive Medicine</i> , 10(2), 77-82.		
54-55	Exercise status (physical activity)	ALSWH Substudy on weight gain at mid-life		
56a-56b	Exercise status (physical activity)	ALSWH	Revised Q55a to enable skip logic	
57	Sitting	ALSWH		
58	Stress	ALSWH		
59	Control and autonomy	Wiggins RD, Netuveli G, Hyde M, Higgs P & Blane D. (2008). The evaluation of a self- enumerated scale of quality of life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches. <i>Social Indicators Research</i> , 89(1), 61-77	Altered response format and instructions to align closely with the original scale	
60	Life Control Scale	Bobak M, Pikhart H, Hertaman C, Rose R & Marmot M. (1998) Socioeconomic factors, perceived control and self-reported health in Russia. A cross-sectional survey. <i>Social Science Medicine</i> , 47(2), 269-279.		

Item No.	Торіс	Source	Item change justification	New item justification
61-63	Alcohol status	Modified from National Heart Foundation of Australia (1990). Risk factor prevalence study Survey no. 3 1989. National Heart Foundation of Australia and Australian Institute of Health.	Response options modified slightly for Q62 and Q63 to account for new alcohol guidelines from NHMRC (2020)	
64	Fruit	Ireland P, Jolley D, Giles G, O'Dea K et al. Development of the Melbourne FFQ: A food frequency questionnaire for use in an Australian prospective study involving an ethnically diverse cohort. <i>Asia Pacific J Clin</i> <i>Nutr</i> 1994;3:19-31.	Wording modified to align with updated Australian Dietary Guidelines	
65	Vegetables	ALSWH		
66-69	Smoking	Modified from National Heart Foundation of Australia (1990). Risk factor prevalence study survey no.3 1989. National Heart Foundation of Australia and Australian Institute of Health. Also: Modified from Australian Institute of Health and Welfare (AIHW) (1997) National Health Data Dictionary, Version 6.0. Standard questions on the use of tobacco among adults.		
70	Elder abuse	Hwalek MA & Sengstock MC. (1986). Assessing the probability of abuse of the elderly: Toward development of a clinical screening instrument. <i>Journal of Applied</i> <i>Gerontology</i> , 5(2), 153-173.		

Item No.	Торіс	Source	Item change justification	New item justification
71	Life events	Modified from Norbeck JS. (1984). Modification of live event questionnaires for use with female respondents. <i>Research in</i> <i>Nursing and Health</i> , 7, 61-71.		
72	Years when experienced violence	Modified from Hegarty KL, Sheehan M, Schonfeld C. (1999) A multidimensional definition of partner abuse: Development and preliminary validation of the Composite Abuse Scale. <i>J Fam Violence</i> , 14, 399-414.	Updated years to adjust for time since the previous survey	
73	Needs help with daily tasks	Modified from Australian Bureau of Statistics (1993) Disability, Aging and Carers Australia. Canberra: ABS. Cat. No. 4432.0		
74	Time use	Modified from Australian Bureau of Statistics (1993) Time use survey, Australia, 1992: User's guide. Canberra: ABS. Cat No. 4150.0.		
75	Volunteer work	ALSWH		
76-79	Care for other people	Modified from Australian Bureau of Statistics (1993) <i>Disability, Aging and Carers Australia.</i> Canberra: ABS. Cat. No. 4432.0		
80	Reason for care	2007 ALSWH Substudy 'Service utilisation and caregiving among mid-aged women'.		
81	Relationship to person you care for	ALSWH		

Item No.	Торіс	Source	Item change justification	New item justification
82	Retirement status (self)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2a.		
83	Expect to retire (self)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L17.		
84	Date of retirement (self)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2b.		
85	Manage on income	ALSWH		
86	Financial stress indicators	McColl R, Pietsch L & Gatenby J. (2001) Household Income, Living Standards and Financial Stress, <i>Australian Economic</i> <i>Indicators</i>		
87	Financial stress indicators	McColl R, Pietsch L & Gatenby J. (2001) Household Income, Living Standards and Financial Stress, <i>Australian Economic</i> <i>Indicators</i>		
88	Current sources of income	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L22.		

Item No.	Торіс	Source	Item change justification	New item justification	
89	Sources of funding for future care	ALSWH			
90	Financial management	Original source: L23 in "Retirement" section of HILDA Wave 3 questionnaire and used in 2006 baby boomer retirement survey (ALSWH substudy).			
91	Housing	ALSWH; 45 & Up (SEEF and HAIL); HILDA (wave 15 household questionnaire)			
92-93	Housing	Modified from Byles et al. (2011). Housing and Independent Living: Environmental and built factors for maintaining independence in older age.	Changed timeframe for Q93 to "last 3 years" to capture time since last survey		
94	Housing	ALSWH; 45 & Up (SEEF and HAIL); HILDA (wave 15 household questionnaire)			
95	Transport	ALSWH			
96	Adopted status	ALSWH		To measure prevalence of women from the cohort that were adopted as children	
97	Social support	Sherbourne CD & Stewart AL. (1991). The MOS social support survey. <i>Social Science</i> <i>and Medicine</i> , 32(6), 705-714			
98	Caring for children	ALSWH			
99	Hobbies	Nair B, Byles J, Tavener M and Heinze, R (2000). Immunisation rates in older veterans	Deleted response option "Other" due to high missing values in Mid9 Main Survey,		

Item No.	Торіс	Source	Item change justification	New item justification
		and war widows, <i>Australasian Journal on Ageing</i> , 19(3):136-138.	and to align with what was done for the 1921-26 cohort.	
100	Marital status	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.	Modified response options to allow for non-binary response. This change aligns with that in the 1973-78 survey 9 Main based on the Department of Health request to add the additional non- gendered responses.	
101	Date of Bereavement	ALSWH		
102	Who lives with you	Modified from ABS (1994) Australian Housing Survey: User Guide. Canberra: ABS. Cat No. 4180.0		
103	Achievements	ALSWH	Deleted response option "Study" due to high missing values in Mid9 Main Survey, and to align with what was done for the 1921-26 cohort.	
104	Proxy	ALSWH		
105	Reason for needing help	ALSWH		
	Have we missed anything?	ALSWH		
Consent Page	Statement	ALSWH		

Survey 9 Main Item Number	Торіс	Source	Justification of deletion
22b	Screening	ALSWH	Does not need to be asked at each survey.
37-38	Number of remaining teeth	Modified from Carter KD & Stewart JF. (2002). National Dental Telephone Interview Survey 2002. The AIHW Dental Statistics and Research Unit, University of Adelaide.	Does not need to be asked at each survey.
39	Sense of taste	ALSWH	Does not need to be asked at each survey.
40	Sense of smell	Pusswald G, Auff E & Lehrner J. (2012). Development of a brief self-report inventory to measure olfactory dysfunction and quality of life in patients with problems with the sense of smell. <i>Chemosensory Perception</i> , 5(3-4), 292-299.	Does not need to be asked at each survey.
41	Sight (impairments)	Modified from Charlton JRH, Patrick DL & Peach H. (1983). Use of multivariate measures of disability in health surveys. <i>Journal of Epidemiology and Community Health</i> , 37, 296- 304.	Does not need to be asked at each survey.
43	Life Orientation Test – Revised	Revised and reduced Revised Life Orientation Test (LOT-R) Scheier MF, Carver CS, Bridges MW. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self esteem): A re-evaluation of the life orientation test. <i>Journal of Personality and Social Psychology</i> , 67, 1063- 1078.	Does not need to be asked at each survey.

Survey 9 Main Item Number	Торіс	Source	Justification of deletion	
44	4-item Subjective Happiness Scale	Lyubomirsky S & Lepper H. (1999). A measure of subjective happiness: Preliminary reliability and construct validation. <i>Social Indicators Research, 46,</i> 137-155. The original publication is available at www.springerlink.com.	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
57	Sex life satisfaction	Department of Mental Health and Substance Dependence World Health Organization (2002). <i>WHOQOL-HIV</i> <i>Instrument: The 120 questions with response scales and 38</i> <i>importance items</i> .	Need to reduce length of Survey 10 to allow for additimeasures and increased font size. Does not need to be asked at each survey.	
65	Marijuana use	National Drug Strategy household survey: Survey report 1995 (1996).	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
77	Pets	ALSWH	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
88	Partner status	ALSWH	Was used as a screener question for partner retirement status, so removed.	
89	Retirement status (partner)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2a.	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
90	Date of retirement (partner)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2b.	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	

Survey 9 Main Item Number	Торіс	Source	Justification of deletion	
100	Housing (changes to current home)	Modified from Byles et al. (2011). Housing and Independent Living: Environmental and built factors for maintaining independence in older age.	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
102	Housing	ALSWH; 45 & Up (SEEF and HAIL); HILDA (wave 15 household questionnaire)	Need to reduce length of Survey 10 to allow for additio measures and increased font size. Does not need to be asked at each survey.	
104	Transport aids	ALSWH	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
105	Problems with transport	ALSWH	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
106	Legal arrangements	ALSWH	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
109	Indicators of social well-being	Modified from Keyes CLM. (1998). Social well-being. <i>Social Psychology Quarterly</i> , 61(2), 121-140	Need to reduce length of Survey 10 to allow for additional measures and increased font size. Does not need to be asked at each survey.	
114-184	Diet	CSIRO Healthy Diet Score (minus the demographic questions)	Does not need to be asked at each survey.	

Approvals

Approval from the Department of Health and the University of Newcastle Human Research Ethics Committee (HREC) was applied for and was ratified by the University of Queensland HREC in November 2021.

Data Collection

Data collection began on 10 December 2021. The survey was offered in 2 formats, online and paper. As is usual for pilot surveys, an evaluation questionnaire was included with both forms of the survey. The online surveys were programmed using the Research Electronic Data Capture (REDCap) platform. Paper surveys were printed in-house and were entered into the online survey manually.

Prizes

Three prize draws were offered for the Pilot Survey 10 participants, as detailed in Table 3-4 below. Prize draws 1 and 2 were to encourage participants to complete the survey online rather than on paper. Prezzee gift vouchers were used for all prize draws, with electronic gift cards emailed to winners. By using electronic gift cards as prizes, participants were encouraged to ensure their email contact details were current.

		Survey to be completed by:				
	Prize	5pm, 10 Jan 2022	5pm, 14 Feb 2022	5pm, 11 Apr 2022		
Prize Draw 1	\$100 voucher (Two winners)	Eligible (1 entry)				
Prize Draw 2	\$100 vouchers (Two winners)		Eligible (1 entry)			
Prize Draw 3 (Major)	\$300 voucher (One winner)			Eligible (1 entry)		

Table 3-4 Prize draws for Pilot Survey 10 for the 1946-51 Cohort participants

Invitation and Reminder protocol

The invitation and reminder protocol is presented in Figure 3-1, while the follow-up survey activities are presented in **Table 3-5**.



Figure 3-1 Invitation and reminder protocol for Pilot Survey 10 for the 1946-51 Pilot Cohort.

Date	Activity	Step No.	Items
Dec 2021	Mailout	A1	Mail invitation to do online survey
	Email	A2	Email invitation to do online survey
	SMS	A3	SMS invitation to do online survey (if email bounces)
Jan 2022	Prize Draw 1		
	Email	A4	Email reminder to do online survey
	SMS	A5	SMS reminders to do survey
Feb 2022	Prize Draw 2		
	Mailout	A6	Mailed package (letter with online survey link, paper survey, change of details card, reply-paid envelope
Mar 2022	Phone call	A7	Phone call reminder to do survey
	Email	A8	Email reminder about completing survey & prize draw 3
	Email	A9	Email survey link following request during phone call
Apr 2022	SMS	A10	SMS reminder about completing survey & final prize draw
	Prize Draw 3		
	Email	A11	Final email reminder to complete survey
	SMS	A12	Final SMS reminder to complete survey
PARTIALLY	COMPLETED ON	ILINE SURV	EYS (triggered from first incomplete survey attempt)
Dec 2021 to Apr 2022	Email	A13	Automated email reminder to complete online survey (3 reminders, one week apart)
	SMS	A14	Automated SMS reminder to complete online survey
	Phone call	A15	Phone call reminder to complete online survey
	SMS	A16	Final SMS reminder to complete online survey
	Email	A17	Final email reminder to complete online survey

Table 3-5 Survey follow-up activity for the 1946-51 pilot cohort Survey 10

Response rate

Table 3-6 details the response rates for pilot survey 10 for the 1946-51 pilot cohort. Completed (online or paper) pilot surveys were received from 219 women, which was 72% of those invited; while another 4 (1%) partially completed their survey online.

		Pilot Survey
	N	%
Completed online survey	119	39
Partially completed online survey	4	1
Completed paper survey	100	33
Deceased	5	2
Withdrawn	3	1
Not this time	8	3
No response	64	21
Total	303	100

Table 3-6 Response rates for Pilot Survey 10 for the 1946-51 pilot cohort (N=303)

3.1.3 Main Survey 10

Planning and Development

During March and April 2022, frequencies, evaluation question responses and comments from the 1946--51 cohort Pilot Survey 10 were reviewed, and recommendations for changes and improvements to the main survey were proposed and decided on.

Development of survey materials

Two new items were introduced into the main survey, including:

- COVID-19 free text comment: A free text item was added based on participant feedback to allow participants a space to qualify the impact COVID-19 has had on their health and wellbeing
- *Diagnosis of endometriosis*: To measure the prevalence of endometriosis in the cohort, added at the request of the Department of Health and Aged Care

While many of the existing survey items from Pilot Survey 10 remained unchanged, eight items were modified slightly to provide better clarity or instruction (Table 3-8). Two items from Pilot Survey 10 were removed for Main Survey 10, as presented in Table 3-8.

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
1	Date of birth	ALSWH		
2	Postcode	ALSWH		
3-13	SF-36	Ware JE & Sherbourne CD. (1992). The MOS 36- Item Short-Form Health Survey (SF-36): 1. Conceptual Framework and item selection, <i>Medical Care,</i> 30(6): 473-483.		
14	GP Consultations	ALSWH Item Inspired by Australian Bureau of Statistics (1991) 1989-1990 National Health Survey Users' Guide. Canberra: ABS. Cat No. 4363.0		
15	Specialist Consultations	ALSWH Item Inspired by Australian Bureau of Statistics (1991) 1989-1990 National Health Survey Users' Guide. Canberra: ABS. Cat No. 4363.0	Response options reduced based on frequencies in pilot data and to reduce burden on participants.	
16	GP Continuity of Care	ALSWH		
17	GP Costs	Modified from Davies AR & Ware JEJ. (1991). <i>GHAA's consumer satisfaction survey and user's</i> <i>manual</i> (2 nd Edn). Washington DC: The Group Health Association of America (GHAA)		
18	Private Health Insurance (hospital)	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users'</i> <i>Guide.</i> Canberra: ABS. Cat No. 4363.0		

Table 3-7 Changes to existing items and additions of new items from Pilot Survey 10 to Main Survey 10 for the 1946-51 Cohort

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
19	Private Health Insurance (ancillary)	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users'</i> <i>Guide.</i> Canberra: ABS. Cat No. 4363.0		
20	Health Cover (including Health Care Card)	ALSWH		
21	Screening	ALSWH		
22	Abnormal pap test / mammogram	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		
23	Screening – breasts, bowels, bones, vaccinations	ALSWH		
24	Hospital Admissions	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users'</i> <i>Guide.</i> Canberra: ABS. Cat No. 4363.0		
25	Goldberg Anxiety and Depression Scale	Anxiety and depression scales from: Goldberg D, Bridges K, Duncan-Jones P & Grayson D. (1988). Detecting anxiety and depression in general medical settings. <i>British Medical Journal</i> , 297, 897-899.		
26	Life isn't worth living	Modified from Beck A, Schuyler D & Herman, I. (1974) Development of the Suicide Intent Scale. In AT Beck, HLP Resnick, & DJ Lettieri (Eds.) <i>The</i> <i>prediction of suicide</i> . Bowier, MD: Charles Press Publishers		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
27	HRT/Pill	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users'</i> <i>Guide.</i> Canberra: ABS. Cat No. 4363.0		
28	Health service utilisation	Modified from Davies AR & Ware JEJ. (1991). <i>GHAA's consumer satisfaction survey and user's</i> <i>manual</i> (2nd Edn). Washington DC: The Group Health Association of America (GHAA).		
29	COVID-19 positive test	ALSWH		
30-32	COVID-19 vaccination status	ALSWH	Q33- Novavax added as vaccination option to cover currently approved vaccines for Australians Q32- Number of doses modified, and reference to booster shot removed, to cover current ATAGI recommendations for COVID-19 vaccination.	
33	COVID-19 impacts (free text)	ALSWH		A free text item was added based on participant feedback to allow participants a space to qualify the impact COVID-19 has had on their health and wellbeing.
34	Falls	Modified from DVA (Dept of Veterans' Affairs) trial (1997)		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
35-36	Falls	Modified from: MacKenzie LA. Home hazards and falls prevention in home-based health assessments for older people in the community. PhD Thesis. The University of Newcastle. 2002. Daejin Kim & Sherry Ahrentzen (2017) environmental and behavioral circumstances and consequences of falls in a senior living development, <i>Journal of Housing For the Elderly</i> , 31:3, 286-301. Stevens, J.A., Mahoney, J.E. & Ehrenreich, H. Inj. Circumstances and outcomes of falls among high risk community-dwelling older adults. <i>Epidemiology</i> . (2014) 1: 5. Bleijlevens MHC, Diederiks JPM, Hendriks MRC, et al. Relationship between location and activity in injurious falls: an exploratory study. <i>BMC</i> <i>Geriatrics</i> , 2010; 10:40 Milat AJ, Watson WL, Monger C, Barr M, Giffin M, Reid M. (2011) Prevalence, circumstances and consequences of falls among community-dwelling older people: Results of the 2009 NSW Falls Prevention Baseline Survey. <i>NSW Public Health</i> <i>Bulletin</i> 22, 43-48.		
37	Diagnoses	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users'</i> <i>Guide</i> . Canberra: ABS. Cat No. 4363.0		
38	Weight	ALSWH		
Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
------------------------------	---	--	----------------------------	---
39	Height	ALSWH		
40	Operations/ procedures	ALSWH		
41	Hysterectomy	ALSWH		
42	Diagnosis – endometriosis	ALSWH		Added as a request from the Department of Health
43	Waist measurement	ALSWH		
44	Medications	ALSWH		
45	Symptoms	ALSWH		
46	Oral Health	Modified from Carter KD & Stewart JF. (2002). <i>National Dental Telephone Interview Survey</i> <i>2002</i> . The AIHW Dental Statistics and Research Unit, University of Adelaide.		
47	Ageism	Ageism survey developed by Palmore (2001).		
48	Pelvic Organ Prolapse diagnosed/ treated	ALSWH		
49	Pelvic Organ Prolapse Inventory 6 (POPDI-6)	Barber MD, Walters RC, Bump J. Short forms of two condition-specific quality-of-life questionnaires for women with pelvic floor disorders (PFDI-20 and PFIQ-7). American Journal of Obstetrics and Gynecology 193, 103- 113 (2021).		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
50	Sleeping problems	Baum FE & Cooke RD. (1989). Community-health needs assessment: Use of the Nottingham health profile in an Australian study. <i>The Medical Journal</i> <i>of Australia</i> , Vol. 150, pp 581-590.		
51-53	Urine leakage	Sansoni J, Hawthorne G, Fleming G, Owen E and Marosszeky N (2011), Technical Manual and Instructions: Revised incontinence and Patient Satisfaction Tools. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.		
54	Depression (CESD- 10)	Andresen EM, Carter WB, Malmgren JA & Patrick DL. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D. <i>American Journal of Preventive Medicine</i> , 10(2), 77-82.		
55-56	Exercise status (physical activity)	ALSWH Substudy on weight gain at mid-life		
57-58	Exercise status (physical activity)	ALSWH		
59	Sitting	ALSWH		
60	Stress	ALSWH		
61	Resilience	Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P & Bernard J. (2008). The brief resilience scale: assessing the ability to bounce back. <i>International journal of Behavioral Medicine</i> , <i>15</i> (3), 194-200.	Instructions reworded to align with the original instructions recommended for the Brief Resilience Scale	

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
62	Life Control Scale	Bobak M, Pikhart H, Hertaman C, Rose R & Marmot M. (1998) Socioeconomic factors, perceived control and self-reported health in Russia. A cross-sectional survey. <i>Social Science</i> <i>Medicine</i> , 47(2), 269-279.		
63-65	Alcohol status	Modified from National Heart Foundation of Australia (1990). Risk factor prevalence study Survey no. 3 1989. National Heart Foundation of Australia and Australian Institute of Health.		
66	Fruit	Ireland P, Jolley D, Giles G, O'Dea K et al. Development of the Melbourne FFQ: A food frequency questionnaire for use in an Australian prospective study involving an ethnically diverse cohort. <i>Asia Pacific J Clin</i> Nutr 1994;3:19-31.		
67	Vegetables	ALSWH		
68-71	Smoking	Modified from National Heart Foundation of Australia (1990). Risk factor prevalence study survey no.3 1989. National Heart Foundation of Australia and Australian Institute of Health. Also: Modified from Australian Institute of Health and Welfare (AIHW) (1997) National Health Data Dictionary, Version 6.0. Standard questions on the use of tobacco among adults.		
72	Elder abuse	Hwalek MA, & Sengstock MC. (1986). Assessing the probability of abuse of the elderly: Toward development of a clinical screening instrument. <i>Journal of Applied Gerontology</i> , 5(2), 153-173.		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
73	Life events	Modified from Norbeck JS. (1984). Modification of live event questionnaires for use with female respondents. <i>Research in Nursing and Health</i> , 7, 61-71.		
74	Years when experienced violence	Modified from Hegarty KL, Sheehan M, Schonfeld C. (1999) A multidimensional definition of partner abuse: development and preliminary validation of the Composite Abuse Scale. <i>J Fam Violence</i> , 14, 399-414.	Timeframes modified after longitudinal audit of the item to make sure it accurately captured when violence was experienced across the longitudinal study. Slight reduction in wording of the information blurb after the item due to formatting constraints.	
75	Needs help with daily tasks	Modified from Australian Bureau of Statistics (1993) Disability, Aging and Carers Australia. Canberra: ABS. Cat. No. 4432.0		
76	Time use	Modified from Australian Bureau of Statistics (1993) Time use survey, Australia, 1992: user's guide. Canberra: ABS. Cat No. 4150.0.		
77	Volunteer work	ALSWH		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
78-81	Care for other people	Modified from Australian Bureau of Statistics (1993) <i>Disability, Aging and Carers Australia.</i> Canberra: ABS. Cat. No. 4432.0	Q77 wording modified to clarify participants still need to answer both a and b before skipping ahead. To address higher missing values in paper survey vs online.	
82	Reason for care	2007 ALSWH Substudy 'Service utilisation and caregiving among mid-aged women'.		
83	Relationship to person you care for	ALSWH		
84	Retirement status (self)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2a.		
85	Expect to retire (self)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L17.		
86	Date of retirement (self)	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2b.		
87	Manage on income	ALSWH		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
88	Financial stress indicators	McColl R, Pietsch L & Gatenby J. (2001) Household Income, Living Standards and Financial Stress, <i>Australian Economic Indicators</i>		
89	Financial stress indicators	McColl R, Pietsch L & Gatenby J. (2001) Household Income, Living Standards and Financial Stress, <i>Australian Economic Indicators</i>		
90	Current sources of income	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L22.		
91	Sources of funding for future care	ALSWH		
92	Financial management	Original source: L23 in "Retirement" section of HILDA Wave 3 questionnaire and used in 2006 baby boomer retirement survey (ALSWH substudy).		
93	Housing	ALSWH; 45 & Up (SEEF and HAIL); HILDA (wave 15 household questionnaire)		
94-95	Housing	Modified from Byles et al. (2011). Housing and Independent Living: Environmental and built factors for maintaining independence in older age.		
96	Housing	ALSWH; 45 & Up (SEEF and HAIL); HILDA (wave 15 household questionnaire)		
97	Transport	ALSWH		
98	Adopted status	ALSWH		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
99	Social support	Sherbourne CD & Stewart AL. (1991). The MOS social support survey. <i>Social Science and Medicine</i> , 32(6), 705-714		
100	Caring for children	ALSWH		
101	Hobbies	Nair B, Byles J, Tavener M and Heinze, R (2000). Immunisation rates in older veterans and war widows, <i>Australasian Journal on Ageing</i> , 19(3):136-138.		
102	Marital status	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		
103	Date of Bereavement	ALSWH	Due to high level of missing data from the pilot survey, the item was slightly reworded to clarify the question for participants.	
104	Who lives with you	Modified from ABS (1994) Australian Housing Survey: User Guide. Canberra: ABS. Cat No. 4180.0	Due to high level of missing data from the pilot survey, the item was slightly reformatted with a skip introduced to clarify the question for participants and reduce burden for participants living alone.	
105	Achievements	ALSWH		
106	Proxy	ALSWH		

Survey 10 Main Item No	Торіс	Source	Item changes justification	New item justification
107	Reason for needing help	ALSWH		
	Have we missed anything?	ALSWH		
Consent Page	Statement	ALSWH		

Table 3-8 Items deleted from Pilot Survey 10 to Main Survey 10 of the 1946-51 Cohort

Survey 10 Pilot item number	Торіс	Source	Justification of deletion
16	Complementary and Alternative Therapies	ALSWH	Does not need to be asked at every survey round.
58	Control and autonomy	Wiggins RD, Netuveli G, Hyde M, Higgs P & Blane D. (2008). The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches. <i>Social</i> <i>Indicators Research</i> , 89(1), 61-77	Comparison of the CASP-12 control and autonomy subscale with the Life Control Scale did not result in a high correlation. Therefore, the CASP-12 CA subscale is not considered a suitable replacement for the Life Control Scale as a measure of perceived control. It was agreed that only one of these measures should be kept to reduce participant burden, so the CASP-12 CA subscale was deleted.

Approvals

Approval of survey materials for Main Survey 10 for the 1946-51 cohort was granted by the Department of Health and Aged Care and from the University of Newcastle Human Research Ethics Committee (HREC) in May 2022, and was ratified in the same month by the University of Queensland HREC.

Data collection

In June 2022, when they were between 71 to 76 years old, 10,021 women from the 1946-51 cohort were invited to complete the online survey (Survey 10). The online survey was programmed using the REDCap survey platform.

The survey is also offered in paper format, with mailed invitations and paper surveys sent out in September 2022 to eligible participants who had not yet completed the survey online. The printing and mailing of the invitations and paper surveys was contracted to New Data Solutions Pty Ltd who subcontracted to Dual Print Solutions Pty Ltd trading as Valiant Press. A scanning application for the paper survey has been developed in-house by ALSWH staff using the ScanTools Plus program with the Scantron iNSIGHT 4ES OMR scanner. Paper surveys are returned to ALSWH at the University of Newcastle where the survey questions/answers are logged, checked, visually audited and scanned, while the consent page is removed, scanned and securely stored. Hand entered data is verified when duplicate fields do not match.

It is anticipated that Main Survey 10 for the 1946-51 cohort will close during the second half of 2023.

Prizes

As with the pilot survey, three prize draws are also offered for Main Survey 10, using Prezzee electronic gift cards (Table 3-9). Prize draws 1 and 2 aim to encourage participants to complete the survey online rather than on paper.

		Survey to be completed by:			
	Prize	5pm, 17 July 2022	5pm, 21 Aug 2022	5pm, 11 June 2023	
Prize Draw 1	\$100 voucher (Five winners)	Eligible (1 entry)			
Prize Draw 2	\$100 vouchers (Five winners)		Eligible (1 entry)		
Prize Draw 3 (Major)	\$1,000 voucher (One winner)			Eligible (1 entry)	

Table 3-9 Prize draws for Main Survey 10 for the 1946-51 Cohort participants

Invitation and reminder protocol

The invitation and reminder protocol is presented in Figure 3-2, while the follow-up survey activities are presented in Table 3-11.

Response rate

Table 3-10 details the response rates for Main Survey 10 for the 1946-51 cohort. By October 2022, completed (online and paper) main surveys have been received from 5,915 women (59% of those invited). Another 65 women (0.6%) have partially completed their survey online).

		Main Survey
	N	%
Completed online survey	3,793	36.8
Completed paper survey	2,122	21.2
Partially completed online survey	65	0.6
Deceased	107	1.0
Withdrawn	61	0.6
Not this time	19	0.2
No response	3,854	38.5
Total	10,021	100



Figure 3-2 Invitation and reminder protocol for Main Survey 10 for the 1946-51 Cohort.

Date	Activity	Step No.	Items
June 2022	Email	A2	Email invitation to do online survey
July 2022	Mailout	A1	Mail invitation to do online survey (when no valid email address is available)
	SMS	A3	SMS invitation to do online survey (if email bounces)
	Prize Draw 1		
	Email	A4	Email reminder to do online survey
Aug 2022	SMS	A5	SMS reminders to do survey
	Prize Draw 2		
Sept 2022	Mailout	A6	Mailed package (letter with online survey link, paper survey, change of details card, reply-paid envelope
	Phone call	A7	Phone call reminders to do survey
	Email	A9	Email survey link following request during phone call
June 2023	Email	A8	Email reminder about completing survey & prize draw 3
	SMS	A10	SMS reminder about completing survey & final prize draw
	Prize Draw 3		
July 2023	Email	A11	Final email reminder to complete survey
	SMS	A12	Final SMS reminder to complete survey
PARTIALLY		ILINE SURV	EYS (triggered from first incomplete survey attempt)
June 2022 onwards	Email	A13	Automated email reminder to complete online survey (3 reminders)
	SMS	A14	Automated SMS reminder to complete online survey
	Phone call	A15	Phone call reminder to complete online survey
	SMS	A16	Final SMS reminder to complete online survey
	Email	A17	Final email reminder to complete online survey

Table 3-11 Survey follow-up activity for 1946-51 Main Cohort Survey 10

3.2 1921-26 cohort

3.2.1 Six-Month Follow-Up Surveys

Since the last Technical Report, the six-month follow-up (6MF) surveys have continued for eligible participants from the 1921-26 cohort - specifically Survey 21 and Survey 22. The survey content is the same as that for previous waves of the six-monthly survey.

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. The surveys were scanned in-house using the Scantron iNSIGHT 4ES OMR scanner.

Survey 21 was first sent to eligible participants on 2 November 2021, while Survey 22 was first sent to eligible participants on 2 June 2022. Eligible participants who have indicated that they are unable to complete a paper survey (either by themselves or with the assistance of someone else), but have indicated they would still like to participate are phoned and the survey is administered over the phone by ALSWH staff.

Response rates

Of the participants who have been sent the 21st 6MF survey, 62% have responded to date (111/180,Table 3-12). Of the participants who have been sent the 22nd 6MF survey, 43% have responded to date (48/113).

The number of survey completions across all 6MF surveys for the 1921-26 cohort is presented in Figure 3-3, illustrating when the surveys have been returned. For example, the first survey (6MF Survey 1) began in November 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. For this reason, analysis of data from these surveys tends to be based on the date of return rather than the survey sequence

	6MI	F Survey 21ª	6MF Survey 22 ^b		
	N	%	N	%	
Completed paper survey	111	62	48	43	
Completed phone survey	4	2	3	3	
Deceased	9	5	5	4	
Withdrawn	8	4	2	2	
No response	48	27	58	51	
Total so far deployed	180	100	113	100	

Table 3-12 Table Response rates for 6MF Surveys 21 and 21 (at 31 October 2022)

^a first deployed 2 November 2021

^b first deployed 2 June 2022

Mailouts

There have been eleven mailouts for 6MF-Survey 21 and 22 so far, as detailed below in Table 3-13.

Date	Activity	Items	Number
Nov 2021	Mailout 1	Package mailed including survey, information letter, change of details card and reply-paid envelope	22 mailed
Dec 2021	Mailout 2	Package mailed including survey, information letter, change of details card and reply-paid envelope	13 mailed
Jan 2022	Mailout 3	Package mailed including survey, information letter, change of details card and reply-paid envelope	13 mailed
Feb 2022	Mailout 4	Package mailed including survey, information letter, change of details card and reply-paid envelope	10 mailed

Date	Activity	Items	Number
Apr 2022	Mailout 5	Package mailed including survey, information letter, change of details card and reply-paid envelope	7 mailed
May 2022	Mailout 6	Package mailed including survey, information letter, change of details card and reply-paid envelope	46 mailed
Jun 2022	Mailout 7	Package mailed including survey, information letter, change of details card and reply-paid envelope	23 mailed
July 2022	Mailout 8	Package mailed including survey, information letter, change of details card and reply-paid envelope	31 mailed
Aug 2022	Mailout 9	Package mailed including survey, information letter, change of details card and reply-paid envelope	17 mailed
Sept 2022	Mailout 10	Package mailed including survey, information letter, change of details card and reply-paid envelope	28 mailed
Oct 2022	Mailout 11	Package mailed including survey, information letter, change of details card and reply-paid envelope	54 mailed



Figure 3-3 Number of completions for 1921-26 cohort Six-Month Follow-Up Surveys 1 to 22, at 31 October 2022.

3.3 COVID-19 surveys

3.3.1 COVID-19 Surveys - Vaccination survey

As with the rest of the population, the women in ALSWH have never lived through anything like the current pandemic. Fourteen fortnightly online surveys were deployed in 2020, with invitations to participate sent via email to women in the three youngest ALSWH cohorts (born 1989-95, 1973-78, and 1946-51). These surveys were all short succinct surveys, typically with ten questions or less. There were no reminder or follow-up procedures for these COVID-19 surveys. The purpose of the surveys was to ascertain women's experiences with COVID-19 testing, their overall wellbeing, and the impact of COVID-19 and associated policies, such as lockdowns, on their lives. Details about these fourteen COVID-19 surveys were provided in the previous Technical Report (Report 44).

A follow-up survey (Survey 15) was deployed in late August 2021 to examine women's concerns about the pandemic and their risk of being infected with the virus. The survey also explored access to COVID-19 vaccines and women's intentions and concerns about getting a COVID-19 vaccine. As the purpose of this survey was to specifically investigate factors influencing vaccine uptake and vaccine hesitancy, questions were sourced with permission from the COVID-19 vaccination adult survey tool used by the World Health Organisation. This tool contains items examining the behavioural and social drivers of vaccine uptake and were adapted for use within the ALSWH context.

At the time of this survey, New South Wales (NSW), Victoria and the Australian Capital Territory (ACT) were in lockdown. None of the other states or territories were in lockdown, reporting zero cases or a handful of cases each day. NSW was seeing around 1,000-1,500 new COVID cases a day while the survey was open. Victoria saw around 70 new COVID cases a day at the beginning of the data collection period but were recording approximately 500 cases a day by mid-September. At the beginning of the survey period, Australia had had reported that 34% of people aged 16 or older had received two doses of the COVID-19 vaccine, predominantly in older ages.

Invitations to participate in this survey were emailed on 30 August 2021, and the survey was subsequently closed a fortnight later, on 13 September 2021. Email invitations were sent to a total of 27,587 women: 13,527 from the 1989-95 cohort (aged 26-32 years), 8,246 from the 1973-78 cohort (aged 43-48 years), and 5,814 from the 1946-51 cohort (aged 70-75 years). In total, 6,563 (24%) women completed Survey 15: 2,126 (16%) from the 1989-95 cohort, 1,966 (24%) from the 1973-78 cohort, and 2,471 (43%) from the 1946-51 cohort.

A report of findings from this survey is available on the ALSWH website. This report investigates:

- Women's feeling of stress about the ongoing COVID-19 crisis
- testing for COVID-19

- uptake of COVID-19 vaccine
- factors influencing vaccine uptake, including
 - o practical considerations (availability, ease of access, preferred locations);
 - o personal motivations (intention to vaccinate);
 - thoughts and perceptions about the COVID-19 vaccines (importance of vaccine benefits and confidence in vaccine safety); and
 - o social processes (influence from family, friends, and community, and benefit to self).

3.3.2 References

Brewer NT, Chapman GB, Rothman AJ, Leask J & Kempe A. 2017. Increasing vaccination: Putting psychological science into action. *Psychological Science in the Public Interest* 18(3):149–207. doi: 10.1177/1529100618760521.

World Health Organization. (2021). Data for action: Achieving high uptake of COVID-19 vaccines: gathering and using data on the behavioural and social drivers of vaccination: a guidebook for immunization programmes and implementing partners: interim guidance, 1 April 2021. World Health Organization. https://apps.who.int/iris/handle/10665/340645. License: CC BY-NC-SA 3.0 IGO

3.4 'Refresh' of the 1973-78 cohort with women from Asian backgrounds

3.4.1 Background

A key ALSWH objective is to provide an evidence base for Government to underpin development, implementation and evaluation of women's health policies. To achieve this objective, it is important that the women participating in the Study are representative of the general population. While the cohorts were reasonably representative of the general population of women of the same age at recruitment (in 1995 and 2013), there was some under-representation of immigrants from non-English speaking countries (Brown, et al. 1999; Mishra et al., 2014; Loxton et al., 2015). Recent increases in immigration to Australia from these countries, especially by young people, has further increased these differences. Table 3-14 shows comparisons of country/region of birth of the 1973-78 ALSWH cohort, and women of the same age for the 2016 Australian Census.

Table 3-14 Comparison of region of birth for the ALSWH 1973-78 cohort (at Survey 7 in 2015) and women of the same age in the general population (as recorded in the 2016 Australian Census).

	ALSWH (a	ge 37-42)	2016 Australian Census (age 38-43)		
	No. women	%	%		
Australia	6,636	92.95	61.53		
Other English speaking country	270	3.78	9.14		
Europe	67	0.94	3.00		
Asia	114	1.6	15.47		
Other	52	0.73	4.50		
Not Specified			6.36		

To redress this imbalance, ALSWH have embarked on a 'refresh' of the 1973-78 cohort and plan a refresh of the 1989-95 cohort with 1,000 women from South, Southeast and Northeast Asian countries. Planning for the 1973-78 cohort 'refresh' began in 2021, and recruitment to the 1973-78 cohort started this year. The 1989-95 cohort 'refresh' will commence in 2023.

3.4.2 1973-78 cohort 'refresh' development and progress

Cultural consultation

We have followed three main processes for cultural consultation. The first was interviews with women from the target group (born 1973-78, from a South, Southeast or Northeast Asian country) who were recruited via social media. Interviews were conducted with seven women in April and May of 2021 and

focused on: most appropriate survey mode (i.e., paper or online); use of English and overcoming language barriers; how to encourage women to participate (intrinsic and extrinsic incentives); social media platforms; areas of inquiry that could be culturally sensitive or taboo; and women's thoughts about providing Medicare card details. The second round of cultural consultation involved engaging with a national organisation representing migrant and refugee women, the Multicultural Centre for Women's Health, who provided advice on initial study design, methods, recruitment materials, and survey content. Further cultural consultation is currently underway, which involves engaging with targeted community groups and organisations for advice on reaching specific communities.

Ethics approvals

Human Research Ethics Committees at the University of Newcastle and the University of Queensland have ethical oversight of the survey for the new cohort members and all recruitment materials (e.g., information statements, factsheets, social media posts, emails, SMS text etc.). The University of Newcastle HREC is the primary committee, with all approvals subsequently ratified by the University of Queensland HREC. Services Australia's Human Research Ethics Committee also has oversight of this protocol so data linkage for new participants can be established.

Ethics approval for the survey content, recruitment process and materials was first sought on 27 October 2021 and initially approved by the University of Newcastle on 4 November 2021 and by the University of Queensland on 15 November 2021. A variation requesting changes to approved materials to address feedback received from the Department of Health and Aged Care, Services Australia and the Multicultural Centre on Women's Health was submitted on 28 January 2022. Final approval from both universities and Services Australia was granted on the 1 March 2022.

Who is eligible to participate?

Participation is open to females born 1973-78 with a Medicare card and who consent to data linkage. However, consistent with the aim to improve ALSWH representativeness of women from South, Southeast and Northeast Asian countries, women from those backgrounds have been the focus of recruitment strategies.

Survey development and deployment

Women recruited as part of the 'refresh' receive a modified version of the ninth survey developed for the existing members of the 1973-78 cohort (and deployed in June 2021). The 'refresh' survey was developed by the ALSWH cohort refresh team in consultation with the Department of Health and Aged Care. Feedback was also sought from relevant stakeholders and community groups (e.g., Multicultural Centre for Women's Health). Surveys are built in REDCap[™] and are only available online. Recruitment materials (e.g., social media posts, newsletter stories) contain a link to the study landing page, and this page is also accessible from the main ALSWH website. Participants are provided with an information statement, FAQs and a link to initiate the survey.

Recruitment activities

Recruitment began on 11 April 2022, with a soft launch to existing contacts. The culturally specific recruitment strategy began on 13 May 2022 after consultation with the Multicultural Centre for Women's Health, and after ethical approval for culturally specific recruitment materials was received (10 May 2022). To date, we have launched recruitment campaigns on social media (Facebook, Twitter, Instagram, and LinkedIn), engaged with traditional media (radio, newspapers), contacted more than 300 community and religious organisations to share recruitment materials through their networks, distributed information through personal and professional networks, and emailed existing ALSWH participants requesting they share recruitment materials through their networks. We have translated the recruitment materials into 6 different languages (Mandarin, Cantonese, Tamil, Hindi, Singhalese and Vietnamese). We have also reconnected with some of the women we interviewed in 2021 to discuss barriers and challenges and potential solutions and strategies.

Response rates

At 9 November 2022, 342 women have completed the survey and provided sufficient information for data linkage, and 38 of these women are from the targeted countries.

3.4.3 Future plans

We have taken an iterative approach to recruitment, where we trial strategies, reflect on what has and has not worked, and use those learnings to adapt existing strategies and trial new approaches. In addition to the recruitment strategies outlined above, we are currently pilot testing contacting community organisations in their language (for example, Chinese ALSWH staff are contacting Chinese organisations in Mandarin or Cantonese). Once this strategy has been trialled and modified as needed, we plan to expand this to other communities (e.g., Indian organisations). We are also focusing on making personal connections with community leaders. For example, we have connected with an Indian community leader in Brisbane who has agreed to facilitate contact with his network. In addition, we are in the process of organising face-to-face meetings with local multicultural organisations and planning to attend relevant festivals (e.g., Diwali, Chinese New Year) where appropriate.

3.4.4 References

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 and Gender-based Medicine*, 1999; 8(5): 681-688

Mishra GD, Hockey R, Powers J, Loxton D, Tooth L, Rowlands I, Byles J & Dobson A. Recruitment via the internet and social networking sites: The 1989-1995 cohort of the Australian Longitudinal Study on Women's Health. *Journal of Medical Internet Research*, 2014; 16(12): e279.

Dobson A, Hockey R, Brown W, Byles J, Loxton D, McLaughlin D, Tooth L & Mishra G. Cohort Profile Update: Australian Longitudinal Study on Women's Health. International Journal of Epidemiology, 2015; 44(5): 1547a-1547f

4 Maintenance of cohorts

4.1 Update of cohorts and response rates

4.1.1 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 et al; 1999). 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 official numbers of women 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 et al; 2005).

4.1.2 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, and 57% responded to Survey 7 in 2015 and to Survey 8 in 2018 (See Table 4-1). The ninth survey for this cohort was deployed in 2021, with data collection due to close in 2022.

Retention compares well with other surveys of this highly mobile age group. The major reason for nonresponse 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. Although the women in this cohort are now in their late forties, the impact of high mobility in their younger years remains an influence on the response rate. 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 & Loxton, 2010).

Year	2000	2003	2006	2009	2012	2015	2018
Survey	Survey 2	Survey 3	Survey 4	Survey 5	Survey 6	Survey 7	Survey 8
(age range)	(22-27)	(25-30)	(28-33)	(31-36)	(34-39)	(37-42)	(40-45)
Deceased	22	33	51	59	80	104	126
Frail	3	9	12	15	16	16	16
Withdrawn	230	518	800	951	1,156	1,435	1,670
TOTAL INELIGIBLE	255	560	863	1,025	1,252	1,555	1,812
Did not do survey	1,332	6,53	1,371	1,994	1,455	1,399	1,268
No contact	2,972	3,953	2,868	3,029	3,531	4,107	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	12,692	12,435
RESPONSE RATE (%)	69.2%	66.3%	68.3%	62.0%	61.6%	56.6%	57.3%

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*

*as at 27 July 2022

4.1.3 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, 80% responded to Survey 8 in 2016, with 77% responding to the ninth survey deployed in 2019 (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 16% of eligible women between Survey 2 and Survey 9).

The tenth survey for this cohort was deployed in mid-2022, with data collection anticipated to close in 2023.

1998	2001	2004	2007	2010	2013	2016	2019
Survey 2	Survey 3	Survey 4	Survey 5	Survey 6	Survey 7	Survey 8	Survey 9
(47-52)	(50-55)	(53-58)	(56-61)	(59-64)	(62-67)	(65-70)	(68-73)
50	119	216	329	475	675	878	1,173
7	23	34	51	70	100	120	128
209	424	622	869	1,107	1,649	2,001	2,081
266	566	872	1,249	1,652	2,424	2,999	3,382
254	997	886	995	1148	1051	714	718
856	925	1,051	832	903	1,088	1,379	1,658
12,338	11,226	10,905	10,638	10,011	9,151	8,622	7,956
13,448	13,148	12,842	12,465	12,062	11,290	10,715	10,332
91.7%	85.4%	84.9%	85.3%	83.0%	81.1%	80.5%	77.0%
	1998 Survey 2 (47-52) 50 7 209 266 254 856 12,338 13,448 91.7%	1998 2001 Survey 2 Survey 3 (47-52) (50-55) 50 119 7 23 209 424 266 566 254 997 856 925 12,338 11,226 13,448 13,148 91.7% 85.4%	199820012004Survey 2Survey 3Survey 4(47-52)(50-55)(53-58)50119216723342094246222665668722549978868569251,05112,33811,22610,90513,44813,14812,84291.7%85.4%84.9%	1998200120042007Survey 2Survey 3Survey 4Survey 5(47-52)(50-55)(53-58)(56-61)5011921632972334512094246228692665668721,2492549978869958569251,05183212,33811,22610,90510,63813,44813,14812,84212,46591.7%85.4%84.9%85.3%	19982001200420072010Survey 2Survey 3Survey 4Survey 5Survey 6(47-52)(50-55)(53-58)(56-61)(59-64)501192163294757233451702094246228691,1072665668721,2491,65225499788699511488569251,05183290312,33811,22610,90510,63810,01113,44813,14812,84212,46512,06291.7%85.4%84.9%85.3%83.0%	199820012004200720102013Survey 2Survey 3Survey 4Survey 5Survey 6Survey 7(47-52)(50-55)(53-58)(56-61)(59-64)(62-67)501192163294756757233451701002094246228691,1071,6492665668721,2491,6522,424254997886995114810518569251,0518329031,08812,33811,22610,90510,63810,0119,15113,44813,14812,84212,46512,06211,29091.7%85.4%84.9%85.3%83.0%81.1%	1998200120042007201020132016Survey 2Survey 3Survey 4Survey 5Survey 6Survey 7Survey 8(47-52)(50-55)(53-58)(56-61)(59-64)(62-67)(65-70)501192163294756758787233451701001202094246228691,1071,6492,0012665668721,2491,6522,4242,999254997886995114810517148569251,0518329031,0881,37912,33811,22610,90510,63810,0119,1518,62213,44813,14812,84212,46512,06211,29010,71591.7%85.4%84.9%85.3%83.0%81.1%80.5%

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*

*as at 27 July 2022

4.1.4 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-death. Brilleman and colleagues (2010) concluded that non-death losses were potentially a greater source of bias than effects of death.

Year	1999	2002	2005	2008	2011
Survey	Survey 2	Survey 3	Survey 4	Survey 5	Survey 6
(age range)	(73-78)	(76-81)	(79-84)	(82-87)	(85-90)
Deceased	549	1,237	2,290	3,632	5,295
Frail	95	303	524	593	788
Withdrawn	563	1,090	1,359	1,367	1,336
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%

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*

*as at 27 July 2022

From November 2011, shorter surveys containing a set of core questions have been mailed to the 1921-26 cohort every 6 months after the return of the previous survey, with some participants opting for a phone interview with ALSWH staff if they are unable to complete the paper survey. Table 4-4 shows the numbers of eligible participants and respondents at the end of each 6 month period.

By 2022, around 90% of the cohort had died. The remaining women who are still alive (approximately 1,320 women) are now aged 96 to 101 years old, with 54% having withdrawn from active survey participation, typically citing reasons of ill health, frailty or diminishing capacity.

Wave #	Wave ending	Deceased	Withdrawn	Total ineligible	Non-Respondent	Respondent	Total eligible	Response rate (%)
1	01 May 2012	5,546	2,321	7,867	1,135	3,430	4,565	75.1%
2	01 Nov 2012	5,941	2,350	8,291	881	3,260	4,141	78.7%
3	01 May 2013	6,243	2,395	8,638	952	2,842	3,794	74.9%
4	01 Nov 2013	6,637	2,332	8,969	990	2,473	3,463	71.4%
5	01 May 2014	6,965	2,279	9,244	1,070	2,118	3,188	66.4%
6	01 Nov 2014	7,306	2,166	9,472	996	1,964	2,960	66.4%
7	01 May 2015	7,636	2,085	9,721	985	1,726	2,711	63.7%
8	01 Nov 2015	7,983	1,949	9,932	976	1,524	2,500	61.0%
9	01 May 2016	8,284	1,855	10,139	931	1,362	2,293	59.4%
10	01 Nov 2016	8,616	1,718	10,334	851	1,247	2,098	59.4%
11	01 May 2017	8,900	1,654	10,554	816	1,062	1,878	56.5%
12	01 Nov 2017	9,236	1,507	10,743	710	979	1,689	58.0%
13	01 May 2018	9,480	1,425	10,905	651	876	1,527	57.4%
14	01 Nov 2018	9,782	1,282	11,064	601	767	1,368	56.1%
15	01 May 2019	10,024	1,177	11,201	595	636	1,231	51.7%
16	01 Nov 2019	10,287	1,041	11,328	524	580	1,104	52.5%
17	01 May 2020	10,487	962	11,449	493	490	983	49.8%

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

Wave #	Wave ending	Deceased	Withdrawn	Total ineligible	Non-Respondent	Respondent	Total eligible	Response rate (%)
18	01 Nov 2020	10,687	874	11,561	467	404	871	46.4%
19	01 May 2021	10,880	798	11,678	422	332	754	44.0%
20	01 Nov 2020	11,053	722	11,775	385	272	657	41.4%
21	01 May 2022	11,113	710	11,823	380	229	609	37.6%
22	01 Nov 2022	11,124	722	11,846	392	194	586	33.1%

NOTE: using 6MF questionnaires logged by 31 Oct 2022.

4.1.5 1989-95 cohort

Over 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 survey online and provided consent to linkage of their survey data with administrative databases such as Medicare.

Unlike the original cohorts, the 1989-95 cohort were surveyed annually from 2013 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 seventh survey for this cohort is planned for deployment by the first half of 2023.

· · · · · · · · · · · · · · · · · · ·		·		·	•
Year	2014	2015	2016	2017	2019/20
Survey	Survey 2	Survey 3	Survey 4	Survey 5	Survey 6
(age range)	(19-24)	(20-25)	(21-26)	(22-27)	(24-30)
Deceased	1	6	8	13	22
Frail	1	1	1	1	1
Withdrawn	681	694	1,744	1,943	2,048
TOTAL INELIGIBLE	683	701	1,753	1,957	2,071
Did not do survey	2,362	3,879	1,850	1,813	1,329
No contact	2,621	3,469	4,400	4,745	5,264
Respondent	11,344	8,961	9,007	8,495	8,346
TOTAL ELIGIBLE	16,327	16,309	15,257	15,053	14,939
RESPONSE RATE (%)	69.5%	54.9%	59.0%	56.4%	55.9%

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*

*as at 27 July 2022

4.2 Maintenance strategies

Cohort maintenance and tracking of 'return to sender' mail is ongoing. The ALSWH team continues to track all participants who have (a) not withdrawn from active survey involvement and (b) are not known to have died. This includes women who may not have responded to all surveys over time. 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 involving considerably more salary hours. 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.

4.3 References

Brilleman 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

Brown WJ, Dobson AJ, Bryson L, & Byles JE. (1999). Women's Health Australia: On the progress of the main cohort studies. *Journal of Women's Health & Gender-Based Medicine*, 8(5): 681-688.

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.

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.

5 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 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.

5.1 ALSWH linked data holdings



Figure 5-1 is an overview of ALSWH's data linkage program.

Figure 5-1 ALSWH Data Linkage Program.

The following sections provide details of coverage, by cohort, for national and state collections held by ALSWH. However, when considering these metadata, it is important to also note the number of participants who have declined (or opted-out) of health record linkage. The total number of declined participants is currently 1,873 (details of consent are reported in Section 5.4.2 and Table 5.11).

5.1.1 National collections

Current national linked data collections are listed in Table 5-1. The Australian Institute of Health and Welfare (AIHW) conducts these linkages. From 2022, all linkage is deterministic, with AIHW holding the concordance file between ALSWH Participant IDs and Medicare PINS, and maintaining enduring PPNs (Project Person numbers) for our participants, and linked to their enduring master linkage spine. AIHW also extracts the data, except for DVA collections (extracted by that Department). This ensures highly accurate linkage and obviates the need for much of the clerical checking of death data which was previously required.

The ALSWH Data linkage Team liaise closely with the AIHW Data Linkage Unit, including an annual meeting (held 27/06/2022). At this meeting, we discussed our regular linkage request schedule, new ALSWH sub studies, and the 1973-78 and 1989-95 cohort refresh, and new national collections which may be available to us (such as the Australian Immunisation Register), as well as developments in the National Integrated Health Services Information (NIHSI; <u>https://www.mja.com.au/journal/2019/national-data-linkage-asset-boost-health-services</u>) and LINked Data Asset for Australian Health Research (LINDAHR; <u>https://ardc.edu.au/project/linked-data-asset-for-australian-health-research-lindahr/</u>).

As ALSWH is a national study, national linked data collections are preferred, if available. The creation of single national minimum dataset by AIHW (for example, for Hospital Admissions, and Emergency Department collections) takes time, hence national data will tend to be both less current and less rich, than the collections sourced directly from state jurisdictions. However, from ALSWH's perspective, both the access and the analyses of national minimum datasets is likely to be more accurate and efficient.

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

Table 5-1 ALSWH linked data holdings: National (at November 2022)

¹ Includes DVA PBS records

All national collections have been, or will be, updated in 2022, except for DVA collections. As the number of participants in the 1921-26 cohort reduces, the number of women with new records in DVA collections is also rapidly diminishing. In 2025 a final reconciliation will be conducted to finalise these collections. Table 5-2 shows metadata for national collections; aged care collections also detailed in Table 5-3. For aged care, the new aged care assessment data collection, or National Assessment Screening Form (NSAF) which replaced the Aged Care Assessment Program (ACAP) from 2015, was linked for the first time.

	Undated	Coverage	Records	Women	V	Women, by cohort			
Collection		MM/VVVV	N	Total N	1989-95	1973-78	1946-51	1921-26	
			N	Total N	Ν	Ν	Ν	Ν	
MBS	12/2021	02/1984 - 08/2021	30,959,636	55,506	16,990	13,503	12,953	12,060	
R-MBS	04/2021	01/1991 - 12/2020	1,968,285	2,828	-	-	114	2,714	
PBS	12/2021	07/2002 - 08/2021	14,342,252	53,554	16,924	13,102	12,710	10,818	
COD	06/2022	08/1996 - 01/2022	9,517	9,517	30	86	1099	8302	
Cancer	09/2021	01/1982 - 12/2017	7,472	6,661	79	380	2,432	3,770	
AC	07/2022	*	*	14,333	-	-	3,935	10,98	
DVA-AC	06/2021	*	26,484	2,396	-	-	32	2,289	

Table 5-2 ALSWH linked data coverage: National (at November 2022)

* Dates vary among component datasets, see Table 5.3 for details

Table 5-3 ALSWH linked data coverage	: Aged Care Programs	(at November 2022)
Tuble o o Aloutit initice dute coverage	n Agea Gaie i Tograms	

	Coverage	Records	Women	Women, by cohort	
Program and content	MM/YYYY	N	Total N	1946-51	1921-26 N
				N	N
Aged Care Assessment Program	04/2003- 05/2016	17,230	7,562	311	7,251
(ACAP) ¹ - Assessments					
Aged Care Funding Instrument	04/2008 00/2021	12 000	5 111	106	4 015
(ACFI) ² - Assessments	04/2008 - 09/2021	13,009	5,111	190	4,915
Commonwealth Home Support	04/2016 06/2020	340.850	4 262	2 430	1 832
Program (CHSP) ³ - Services	04/2010 - 00/2020	540,050	4,202	2,430	1,002
Home and Community Care (HACC) ³	01/2000 - 07/2015	166 109	11 216	2 118	9 098
- Services	01/2000 - 01/2013	100,100	11,210	2,110	0,000
Home Care Program (HCP) ³ and					
predecessor programs					
- Assessments	01/1996 - 06/2020	5,606	2,942	344	2,598
- Care level	07/1995 - 06/2020	3,425	2,788	265	2,523
- Leave	08/1997 - 06/2020	7,469	2,041	143	1,898
National Screening and Assessment	04/2000 - 06/2020	7 237	4 167	2 163	2 004
Form - Assessments	04/2000 00/2020	1,201	4,107	2,100	2,004
Residential Aged Care (RAC)					
- Services	11/1982 - 06/2020	16,393	7,297	274	7,023
- Leave	09/1997 - 06/2020	19,799	4,914	124	4,790
Resident Classification Scale (RCS) ⁴	10/1997 - 07/2008	6.209	1.907	24	1.883
- Assessments		0,200	.,		.,

Program and content	Coverage MM/YYYY	Records N	Women Total N	Women, b 1946-51 N	y cohort 1921-26 N
Transition Care Program (TCP) - Services	04/2006 - 01/2020	3,622	1,064	116	948
DVA Veterans' Home Care - service plans	01/2001- 01/2021	31,791	2,156	52	2,104
DVA Community Nursing - services	05/1998- 12/2020	55,974	1,713	17	1,696

¹ ACAP was replaced by NSAF from 2016

² ACFI was introduced in 2008

³ HACC was replaced by CHSP from 2015

⁴ RCS was replaced by ACFI in 2008

5.1.2 State and Territory collections

Current State and Territory linked data collections are listed in Table 5-4; coverage is shown in Table 5-5. We expect to update State-based collections 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). In late 2021/ early 2022 we received NSW and ACT collections. There are two outstanding collections in 2022: we are waiting on sign-off of governance documents for WA linkage; and, while our re-application for the Victorian Perinatal Data Collection was approved by the custodians in late 2021, the source dataset is not yet available to the Centre for Data Linkage Victoria to effect linkage. In 2022 we will commence re-applying for the next state linkage round.

Data custodian	Data linkage unit	Collection Name
ACT Health	Centre for Health	ACT Admitted Patient Care
	Record Linkage	 ACT Emergency Department Data Collection
	(CHeReL)	ACT Perinatal Data Collection
NSW Ministry of	CHeReL	NSW Admitted Patients Data Collection
Health		 NSW Emergency Department Data Collection
		NSW Perinatal Data Collection
Queensland Health	Statistical Services	Queensland Hospital Admitted Patient Data Collection
	Branch	 Queensland Emergency Department Collection
		Queensland Perinatal Data Collection

Table 5-4 ALSWH linked data holdings: State/Territory (at November 2022)

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

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

Table 5-5 ALSWH linked data	coverage: State/Territory	(at November 2022)
	outorage. Otater remittery	

State	and	Updated	Coverage	Records	Women	W	omen, I	oy coho	rt
Collec	rtion		MM/YYYY	N	Total N	1989-95	1973-78	1946-51	1921-26
Conce				n rotain		Ν	Ν	Ν	N
	А	03/2022	07/2004 - 06/2020	3,521	1,061	416	257	174	214
ACT	Е	02/2022	05/2005 - 06/2020	4,937	1,346	706	281	185	174
	Р	02/2022	05/1997 - 11/2017	397	242	67	175	-	-
	А		06/2001 - 03/2021	120,540	15,465	4,148	3,680	3,697	3,940
NSW	Е	11/2021	01/2005 - 03/2021	76,750	14,173	4,767	2,973	3,226	3,207
	Ρ		01/1994 - 12/2020	8,003	3,861	917	2,944	-	-
	А		06/2000 - 06/2019	2,753	501	148	168	156	29
NT	Е	07/2021	07/2000 - 06/2019	3,538	835	303?	213	274	45
	Р		02/1986 - 12/2018	331	213	53	160	-	-

State	and	Updated	Coverage	Records	Women	W	omen, l	by coho	rt
Coller	rtion		MM/YYYY	N	Total N	1989-95	1973-78	1946-51	1921-26
Conce				N Total N		N	Ν	Ν	Ν
	А		06/2007- 06/2020	82,330	11,140	3,383	2,826	3,114	1,817
QLD	Е	05/2021	07/2009 - 06/2020	36,746	8,306	3,091	1,881	2,098	1,236
	Р		07/2007 - 12/2019	3,628	2,298	881	1,417	-	-
	Α	02/2021	6/2000 - 06/2021	20,792	3,697	856	884	913	1,044
SA	Е	03/2021	7/2003 - 06/2021	17,038	3,598	1,122	794	875	807
	Р	08/2021	03/1986 - 12/2016	2,306	1,061	172	889	-	-
	Α		01/2007 - 12/2019	5,039	1,168	1,168	269	328	280
TAS	Е	11/2020	01/2007 – 12/2019	1,498	1,469	482	306	401	280
	Р		01/2005 - 12/2018	610	373	121	252	-	-
	Α	05/2021	01/2000 - 12/2020	113,146	12,643	3,355	3,573	2,941	2,774
VIC	Е	03/2021	07/1999 – 12/2020	62,608	11,480	3,686	2,979	2,428	2,387
	P^1	09/2019	01/1999 - 12/2016	5,083	2,525	404	2,122	-	-
	Α		01/1970 - 12/2017	60,914	5,573	1,731	1,511	1,349	982
WA	Е	04/2019	01/2002 - 10/2018	29,351	4,725	1,624	1,162	1,117	822
	Р		07/1989 - 12/2017	2,989	1,442	296	1,146	-	-

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.

5.1.3 Common Conditions from Multiple Sources (CCMS)

ALSWH's Common Conditions from Multiple Sources (CCMS) datasets continue to be updated and expanded to include more conditions (not all of which are "chronic", hence the change of name since last year's report). These datasets contain indicator variables for common conditions, derived from both survey and linked health record data. They are made available to research collaborators, subject to the usual ethical and data custodian approvals apply (see Section 5.2.1). Table 5-6 shows which linked data collections contribute to each CCMS dataset.

Table 5-6 CCMS dat	aset composition	(at November 2022)
--------------------	------------------	--------------------

CCMS dataget	External linked data collections used							
CCMS dataset	Cancer	COD	MBS	PBS	AC	Α		
Cancer								
Dementia								
Diabetes								
Ischaemic Heart Disease								

CCMS dataset	External linked data collections used					
CCWS dataset	Cancer	COD	MBS	PBS	AC	Α
Mental health						
Musculoskeletal						
Respiratory conditions						
Stroke						

5.1.4 Substudies, and the 1973-78 Cohort and 1989-95 Cohort Refresh

In 2021, we applied to Services Australia's External Request Evaluation Committee for approval of data linkage protocols for the new MatCHES (Mothers and their Children's Healthcare Experiences) Substudy, and also for the 1973-78 and 1989-95 cohort refresh, as both of these activities will involve linking new cohort members to their collections (among others). Both requests were approved early in 2022.

For the cohort fresh, completing consent for linkage to MBS and PBS is mandatory upon enrolment (the survey for the 1973-78 cohort refresh is currently underway, with the 1989-95 survey to be rolled out in 2023). For mothers in the 1989-95 cohort, who will be invited to take part in MatCHES in 2023, child record linkage to MBS, PBS and the Australian Immunisation Register (AIR) will be optional.

Permission will also be sought to add the new members to other data requests, once they are enrolled. Likewise, we are currently updating all our data linkage protocols to integrate the Menarche to pre-Menopause (M-PreM) and Genetic variants, Early Life exposures and Longitudinal Endometriosis symptoms (GELLES) substudy datasets with our linked collections.

Data linkage is also conducted, with maternal consent, for children of women who participated in the MatCH Substudy (funded from 2014-2019 by the National Health and Medical Research Council). A total of 3,702 women took part in MatCH in 2016/17, reporting on the health and wellbeing of 5,842 children, then aged 0-12 years. Seventy-five per cent of mothers consented to linkage of education records for 4,300 children. Now that the original MatCH research team have published key results, access to MatCH data will also be offered to external collaborators. Table 5-7 details the current status of data linkage for MatCH. Linkage for AEDC and NSW NAPLAN was conducted by the AIHW. Linkage for NAPLAN in other jurisdictions was conducted by the relevant authority. We are applying to update these collections in 2022.

Data Collection	Data Custodians	Status		
Australian Early	Australian Government Department of	Linked data obtained in 2018 for		
Development	Education and Training	AEDC 2009, 2012 and 2015		
Census (AEDC)		collections for N=946 children.		
National	ACT Education Directorate	Linked data obtained in 2019-20		
Assessment	NSW Education Standards Authority	from each State/territory.		
Program –				

Table 5-7 MatCH linked data coverage (at November 2022)
Data Collection	Data Custodians	Status
Literacy and	NT Department of Education	Coverage is from 2010 to 2018/19
Numeracy	Queensland Curriculum and Assessment	for N=2,516 children.
	Authority	(NAPLAN was not collected in
	SA Department for Education	2020 due to COVID-19).
	TAS Department of Education	
	• VIC Curriculum and Assessment Authority	
	WA School Curriculum and Standards	
	Authority	

5.2 Data access procedures

5.2.1 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. ALSWH research collaborators apply 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 also review and approve new EoIs. These arrangements are subject to change at the direction of the agencies involved. 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 Eol 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 Eol processing time.

5.2.2 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 Centre for Women's Health Research, HMRI, 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.

From late 2021 to 2022, the ALSWH Team at UQ has also been collaborating in the Queensland Cyber Infrastructure Foundation's development of a SURE-type remote access platform, known as KeyPoint. KeyPoint is expected to be deployed in 2023 and will provide an additional option for research

collaborators using linked ALSWH data. As soon as the security features of the system are available, we will seek approval from linked data custodians to use their datasets in KeyPoint.

5.2.3 Data access conditions

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

Data Source	Approving body	Documents
AIHW	AIHW HREC	'AIHW s.29' signed by all researchers
Collections		 Updated Technical Assessment Form
		approved by AIHW Data Linkage Unit
		HREC amendment through Ethics Online
		System (EthOS)
DVA	DDVA HREC	Researcher CVs
		Complete new application for every ALSWH
		Eol
NSW	CHeReL	Necessary when use of SURE, or a new
		Substudy is involved
		 Copy of draft HREC amendment through
		Research Ethics and Governance Information
		System (REGIS)
		Change in Personnel form
		Updated Study Protocol
		Copies of ALSWH EoIs
NSW, QLD	NSW Population & Health	Copy of Data Custodian approval (where use
	Services Research Ethics	of SURE, or a new Substudy is involved)
	Committee (PHSREC)	Change in personnel form
		Updated Study Protocol (where use of SURE,
		or a new Substudy is involved)
		Copies of ALSWH EoIs
		HREC amendment through Research Ethics
		and Governance Information System (REGIS)
QLD	Qld Health Information,	Copy of NSW PHSREC approval letter
	Investment and Research Office	Updated Public Health Act (PHA) form
		Updated Project List
	Qld Health Statistical Services	Conditions of Disclosure document signed by
	Branch	all researchers

 Table 5-8 Approval procedures for researchers and projects using linked health records

Data Source	Approving body	Documents
WA	Dept of Health WA HREC	 Researcher online registration and accepted invitation to join study project through WA Research Governance System (RGS) HREC amendment through RGS
ACT, VIC, SA, NT	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 Eols Updated researcher and project list
VIC Perinatal	Austin Health HREC	 HREC amendment through Ethics Review Manager (ERM) Researcher CVs
	VAHI	 Data request signed by all researchers New Data Request lodged in VAHI Hub for every ALSWH EoI Copy of Austin HREC approval letter Copy of ALSWH EoI
SA/NT	SA NT Datalink	 SA Health Confidentiality Deed 'NT Appendix B Deed 2' signed by all researchers 'Annexure B' signed by all researchers Copy of ACT HREC approval letter
TAS	Tas Health & Medical HREC	 HREC Amendment through Ethics Review Manager (ERM) 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

5.3 Use of linked data

A total of 264 projects have requested linked health record data to date and 111 ALSWH publications have used linked data. Table 5-9 shows the numbers of approved ALSWH projects, and researchers who have requested linked data for their analyses.

	Pro	jects	Us	ers	Publications			
Collection type	Total	Since last report	Total	Since last report	Total	Since last report		
MBS	156	16	162	31	59	5		
PBS	166	24	168	26	56	6		
COD*	90	12	93	13	8	1		
Date of Death	22	6	39	10	0	0		
Cancer	36	8	55	12	6	1		
Aged Care	42	3	62	1	22	4		
Hospital Admissions	113	14	140	12	43	5		
Perinatal Collections	49	5	74	8	7	2		
Emergency Department	32	10	58	10	1	0		
TOTAL^	264	39	225	22	111	14		

Table 5-9 Linked health record data requested in approved ALSWH Eols (at 5 September 2022)

*The total number of projects (EoIs), users, and publications that have requested, used, and reported (respectively) Cause of Death data have increased beyond the number of new instances since the last report. This resulted from a review of previously closed EoIs that revealed instances not previously reported in this table.

^Projects (EoIs), Users, and Publications can each request, use, and report on multiple linked health record datasets. Therefore, the total value does not equal the sum of the values above.

5.4 Other activities

In 2022, ALSWH was the only project invited to present a webinar at the Population Health Research Network (PHRN) Client Services Forum. The objectives of the PHRN of the session were:

- To give client services officers, data linkers and data custodians the opportunity to hear the outcomes and impact of research that they have supported.
- To increase the understanding of client services officers, data linkers and data custodians of the researcher experience of applying for and obtaining cross-jurisdictional linked data.
- To highlight research findings and their impact.

The ALSWH presenters were Gita Mishra, Colleen Loos and Leigh Tooth. The participants in the session included members of the PHRN Project Office, Client Services staff, data linkage staff, data outputs team staff, data custodians, and managers from each of the PHRN jurisdictions (WA, SA, NT, QLD, NSW, ACT, Commonwealth, VIC, TAS). (In 2021, ALSWH also participated in the PHRN Linkage Luminaries Webinar series <u>https://www.youtube.com/watch?v=EZ3uF27z968</u>).

5.5 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 <u>2019 Technical Report.</u>

5.5.1 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.

- <u>NHMRC Guidelines approved under Section 95 of the Privacy Act 1988</u> (November 2014)
- <u>Australian Privacy Principles (APP) guidelines</u> (Version 1.2 July 2019) as well as Privacy principles operating in Australian States and Territories.
- Australian Government <u>Best Practice Guide to Applying Data Sharing Principles (</u>15 March 2019)

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

- <u>NHMRC National Statement on Ethical Conduct in Human Research 2007</u> (Updated 2019; Chapters 2.2-3 and 3.2 are particularly relevant)
- <u>The Australian Code for the Responsible Conduct of Research 2018</u> <u>Management of Data and</u> <u>Information in Research (2019)</u>

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

- Privacy public interest determination guide V1.0, June 2014.
- <u>Health Insurance Act 1973 (</u>for MBS data).
- <u>Public Interest Disclosure Act 2013</u>
- <u>High Level Principles for Data Integration Involving Commonwealth Data for Statistical and</u>
 <u>Research Purposes</u> (February 2010)
- <u>A Guide for Data Integration Projects involving Commonwealth Data for Statistical and</u> <u>Research purposes</u> (National Statistical Service).

ALSWH's <u>Participant Privacy Policy</u> is available on the web site and is regularly updated. All researchers and collaborators accessing linked data are also subject to ALSWH <u>Data Access Protocols</u> 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 (<u>http://ppl.app.uq.edu.au/</u>), 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 (<u>https://policies.newcastle.edu.au/document/view-current.php?id=66</u>) and Privacy Management Plan (https://www.newcastle.edu.au/privacy)

ALSWH compliance with national guidelines was described in the <u>2019 Technical Report</u>. The history of consent procedures is also detailed in that report, and is summarised Figure 5-2.



Figure 5-2 History of data linkage consent for ALSWH participants 1996-2018.

5.5.2 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 **website**. Table 5-10 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.

Consent status	Relevant participants	Linkage
a) Declined	• Latest answer to the data linkage questions is 'No'	NDI only; deterministic
	Explicitly declined data linkage by contacting	only (no personal
	ALSWH	information is to be
	• Withdrawn from the Study because of privacy,	transferred to/from
	confidentiality or Medicare data linkage concerns.	AIHW)
b) Express	Latest answer to the data linkage questions is 'Yes'.	All
consent		

Table 5-10	Health	record	linkage	consent	categories
					Jungoinge

Consent status	Relevant participants	Linkage			
c) Implicit	Not in category a) or b), who have completed ALSWH	All except VIC P			
consent	surveys since the introduction of opt-out consent (2005).				
d) Waived	Not in category a) or b), who have not completed a	All except VIC P; the			
consent	survey since the introduction of opt-out consent (2005).	Data Custodian for SA			
		Cancer does not supply			
		sensitive variables for			
		this group			

Table 5- shows consent status for health record linkage, by cohort. There have been no further opt-outs from health record linkage since the last report.

Cohort	Total		nod	Consent type								
Conort	N	a) Deci	neu	b) Ex	oress	c) Imp	licit	it d) Waived				
1921-26	12,432	353	2.8%	9,131	73.4%	389	3.1%	2,559	20.6%			
1946-51	13,714	758	5.5%	11,236	81.9%	439	3.2%	1,281	9.3%			
1973-78	14,247	745	5.2%	9,896	69.5%	1,382	9.7%	2,224	15.6%			
1989-95 ¹	17,010	17	0.1%	16,993	99.9%	N/A	N/A	N/A	N/A			
TOTAL	57,403	1,873	3.3%	47,256	82.3%	2,210	3.8%	6,064	10.6%			

Table 5-11 Health record linkage: Consent status of ALSWH participants (at July 2022)

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

5.5.3 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. This information was updated in 2020 (with approval from the Department of Health and Aged Care).

5.5.4 Current HREC approvals for health record linkage

Table 5- shows current HREC approvals for the ALSWH Data Linkage Project. The <u>National Mutual</u> <u>Acceptance Scheme</u> (NMA) aims to reduce duplication of coverage for cross-jurisdictional and/or multisite projects. (There are some exceptions; we still require local approval for data linkage in WA, Tasmania and for the Victorian Perinatal Data Collection). In 2021, our NT data linkage protocol was transferred to the ACT Health HREC. We were also granted approval by the Calvary Bruce Public Hospital HREC (ACT) which will allow Emergency Department records for this hospital to be included in future ACT data linkage requests.

Ethics Committee	Reference	Approved	Expiry	Coverage				
The University of Newcastle HREC (EC00144); ratified by	H-2011-0371; 2012/HE000132	31/01/12; 9/02/12	31/12/25	ALSWH Data linkage Project (subject to jurisdictional approvals)				
The University of Queensland HRECs	H-2014-0246; 2014/HE001213	07/08/14; 10/09/14	31/12/25	MatCH Phase 1 Substudy (survey and record linkage)				
(EC00456/7)	H-2021-0383; 2021/HE001641	15/12/21; 23/08/21		MatCHES (survey and record linkage)				
	H-076-0795; 2004/HE000224	26/07/95; 2/04/04	31/12/30	ALSWH Survey program, original cohorts, (including COVID surveys and 1973- 78 Cohort Refresh)				
	H-2012-0256; 2012/HE000950	08/08/12; 31/12/23	31/12/23	ALSWH Survey program, 1989-95 cohort				
	H-2019-0191; 2017/HE001745	04/06/19	15/05/24	Menarche to Menopause (M-PreM) Substudy				
	H-2021-0246; 2020/HE002968	31/08/21	17/08/22	Genetic variants, Early Life exposures, and Longitudinal Endometriosis Symptoms (GELLES) Substudy				
Services Australia External Request Evaluation Committee	RMS2001	17/02/22	none	MatCHES MBS, PBS and Australian Immunisation Register (child record linkage including validation of Medicare PINs and transfer of concordance file to AIHW)				
	RMS2107	01/03/22	none	1973-78 Cohort refresh MBS and PBS (including validation of Medicare PINs and transfer of concordance file to AIHW)				
	EC2020/3/1115	17/08/20	31/12/30	All national collections				

Table 5-12 Health record linkage: Current HREC approvals (at November 2022)

Ethics Committee	Reference	Approved	Expiry	Coverage
Australian Institute of	EO2017/1/342	7/03/17	31/12/25	MatCH Phase 1 Substudy
Health and Welfare				(child record linkage)
HREC (EC00103)				
Defence/DVA HREC	EO14/022	19/12/14	30/06/24	DVA-AC & MBS
(EC00460)	E002/020	Oct 1996	none	Recruitment and consent
				(1946-51 & 1921-26
				cohorts
ACT Health HREC	ETH.6.13.148	01/07/13	31/07/26	ACT, SA, NT and VIC
(EC00100)	- VIC collections	22/08/18		collections (except VIC P).
	- SA collections	19/09/20		
	- NT collections	27/05/21		
Calvary Bruce Public	21-2020	24/11/20	none	ACT E
HREC (EC00105)				
Austin Health HREC	HREC/18/ Austin/163	17/07/18	none	VIC P
(EC00204)				
NSW Population and	2019/ETH01837	03/01/12	31/12/25	NSW & QLD collections
Health Services	(2011/11/357)			
Research Ethics	- QLD collections	13/04/18		
Committee (EC00410)				
Tasmanian Health &	H0017192	19/04/18	19/04/22	TAS collections
Medical HREC				
(EC00337)				
Dept of Health WA	RGS 2853 (2015/47)	15/12/15	31/12/21	WA collections
HREC (EC00422)	RGS 4844 (re-	16/08/21	16/08024	
	application)			

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

6 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 9 of the 1946-1951 cohort, Surveys 1 to 8 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 ongoing data from the six-month follow up survey of the 1921-1926 cohort.

This year, 2022, only the recent data from the six-month follow up survey of the 1921-1926 cohort was archived. Due to extension of the data collection period for the ninth survey of the 1973-78 cohort, which would usually have been archived in 2022, this survey's data will be archived in 2023.

In 2022, the following were deposited with ADA:

• Completed ADA licence form

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
- 1921–1926 cohort comments file in SAS format

7 Methodological issues

7.1 Mean stress derived variable in ALSWH

Author: David Fitzgerald

7.1.1 Introduction

ALSWH asks questions about the stress the participants have felt in various areas of their life. These questions are used to derive the Mean Stress variable for analysis. These series of questions were developed by ALSWH on the basis of discussions with key informants, including psychologists, sociologists, and women of all ages.

7.1.2 Mean stress in ALSWH

Mean stress variables have been derived for all the waves in the 1946-51 and 1973-78 cohort surveys, most of the 1989-95 cohort waves and the first two waves of the 1921-26 cohort.

The questions have slightly changed over the cohorts and waves, as shown in Table 1. The introduction to the questions - "Over the last 12 months, how stressed have you felt about the following areas of your life:" - has not changed.

Table 7-1 shows the mean stress questions asked across the cohorts and waves. The oldest cohort were not asked about stress from their parents and the 1973-78 cohort were not initially asked about stress from their children. Note that in Survey 2 of the 1921-26 cohort and Surveys 3 and 4 of the 1946-51 cohort there was no 'Not Applicable' option for some questions. The other surveys did have the 'Not Applicable' option for all questions.

The stress questions were only asked in Surveys 1 and 2 of the 1921-26 cohort.

Cohort			1989-95 1973-78 1946-51							1921-															
Survey wave	1	2	3	4	5	6	1	2	3	4	5	6	7	8	1	2	3	4	5	6	7	8	9	1	2
Own health	NA	NA	NA	NA	NA	NA	NA	NA				NA	NA	NA	NA	NA								NA	
Money	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA								NA	
Living arrangements	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA								NA	

Table 7-1 Availability of 'Not Applicable' (NA) in three stress questions for all cohorts and waves

Note: Not Applicable was available for all other items in all cohorts and waves.

Derivation of Mean Stress score

The mean stress score is calculated from the responses to all the questions and is a mean average of the non-missing responses. The survey responses that are initially valued as 1 to 6 are recoded to 0 to 4 (shown in Table 7-2). These values are then added up and divided by the number of non-missing responses to produce the mean stress value. If there are fewer than 5 non-missing values, then the mean stress value is set to missing. The mean stress score can possibly range from 0 (not stressed to all options) to 4 (extremely stressed to all options).

	Response Category												
	Not applicable	Not at all stressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed							
Code	1	2	3	4	5	6							
Score	0	0	1	2	3	4							

Table 7-2 Response	categories	and scoring	of stress	scale items
--------------------	------------	-------------	-----------	-------------

7.1.2.1 The change in 2021 / 2022

In 2021, ALSWH staff queried the recoding of 'Not Applicable' to zero rather than missing. A 'Not at all stressed' response is a definitive statement of no stress while 'Not Applicable' may not be (e.g., in response to questions about relationship with parents or children it may be simply because there are no parents or children in the participant's life). The Data Management Group in late 2021 decided the 'Not Applicable' response is not considered equivalent to 'Not at all stressed', and so should be set to missing (Table 7-3). It was decided to update all the mean stress variables using the new derivation method.

Table 7-3 New response categories a	nd scoring of stress scale items
-------------------------------------	----------------------------------

	Response Category											
	Not applicable	Not at all stressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed						
Code	1	2	3	4	5	6						
Score		0	1	2	3	4						

This change affected the value of the mean stress variable in two ways. Firstly, some non-missing values were set to missing where there were now five or more missing values. Secondly, where there were some 'Not Applicable' values set to missing, but still fewer than five missing in total the mean stress value is larger. This is because the numerator total is same, but the denominator number of non-missing values is smaller. Figure 7-1 below shows the means of the existing and new mean stress values in the 1973-78 (YNG) and 1946-51 (MID) cohorts. The 1973-78 cohort is shown from ages 20 to 40 and the 1946-51 cohort from ages 45 to 70. The new values are higher because the denominator is smaller.



Figure 7-1 Previous and re-calculated mean stress scores for the 1973-78 and 1946-51 cohorts.

7.1.2.2 Implications

The change was made in early 2022 to all relevant datasets at the same time. Anyone receiving ALSWH data from 2022 will receive the new mean stress values in all datasets. The values are used in comparison to other values at different waves so the absolute value does not have any intrinsic meaning. Previous ALSWH advice regarding interpretation of mean stress (0 to <.25 not stressed; .25 to <.50 somewhat stressed; .50 to <1.0 moderately stressed; 1.0 to 4.0 very stressed) may no longer be valid, as the values have changed. Data users will be informed of these changes to calculation of the mean stress values in the next ALSWH data user newsletter.

7.2 Measuring sexual violence in ALSWH Surveys

Authors: Nicholas Egan, Peta Forder, Deborah Loxton

7.2.1 Introduction

ALSWH surveys include measures of different types of sexual violence that a woman may experience in her lifetime. Sexual violence is a complex issue, and the survey instruments used to measure it are also complex. This section seeks to provide an overview of these measures, their subtleties, and practical advice on using these measures based on past research.

Much of this work draws on the lessons learnt in writing an <u>ALSWH report</u> commissioned by the Australian National Research Organisation for Women's Safety (ANROWS), which was published in August 2022. These ideas were developed in concert with the report's team, which was led by Natalie Townsend and Deborah Loxton and included Peta Forder, Nicholas Egan and Isabelle Barnes.

7.2.2 Measures of sexual violence in ALSWH

There are three main measures of sexual violence included in the ALSWH surveys. These included measures of (A) sexual violence during childhood, (B) sexual violence perpetrated by a partner, and (C) sexual violence perpetrated by an unspecified person. The availability of these measures is summarised in Table 7-4.

		1989-95							19	97:	3-7	78			1946-51							1921-26							
Survey	1	2	3	4	5	6	1	2	3	4	5	6	7	8	1	2	3	4	5	6	7	8	9	1	2	3	4	5	6
Sexual violence																													
During childhood					*	*																							
By partner																													
By unspecified person																													

Table 7-4 Summary of collection of sexual violence data across ALSWH cohorts and surveys

* Captured at this survey if not captured at previous surveys

Sexual violence during childhood

Sexual violence during childhood was measured by four items within the Adverse Childhood Experiences Scale (Felitti et al., 1998) in the 1989-95, 1973-78 and 1946-51 cohort surveys (Table 7-5). Participants were asked to indicate which items applied to them, from which a total score between zero and four was calculated. A score of one or more indicated a history of sexual violence during childhood.

Table 7-5 Childhood sexual violence items from the Adverse Childhood Experiences Scale

While you were growing up during your first 18 years of life, did an adult or person at least 5 years older than you: <i>(mark all that apply)</i>					
Touch or fondle you in a sexual way?					
Have you touch their body in a sexual way?					
Attempt oral, anal or vaginal intercourse with you?					
Actually have oral, anal or vaginal intercourse with you?					

Sexual violence by a partner

As part of the Community Composite Abuse Scale (Hegarty, Sheehan & Schonfeld, 1999) instrument used to evaluate intimate partner violence (IPV), a single item was included to detect sexual violence experienced within a relationship. This was first included in Survey 4 (2006) of the 1973-78 cohort, with the following lead: "*This question asks about situations with your partner. We would like to know if you have experienced any of the actions listed below and how often it happened during the past twelve months: Being forced to take part in unwanted sexual activity*". Response options included: 'Never', 'Only once', 'Several times', 'Once/month', 'Once/week', or 'Daily'. Due to low frequencies for the affirmative responses, these options are typically collapsed to indicate 'In the last 12 months' or 'Never'.

From Survey 5 (2009) onwards of the 1973-78 cohort and from Survey 2 (2014) onwards of the 1989-95 cohort, the question item was worded, '*This question asks about situations you may have experienced with current or past partners: Being forced to take part in unwanted sexual activity*'. Women were directed to mark all that apply with response options of: 'In the last 12 months', 'More than 12 months ago', or 'Never'.

Sexual violence by an unspecified person

Sexual violence was measured in all cohorts by the question, '*Have you experienced any of the following events*: *Being forced to take part in unwanted sexual activity*' with response options: 'In the last 12 months', 'More than 12 months ago', or 'Never'. Note that at Survey 1 of the 1973-78, 1946-51 and 1921-26 cohorts, the question was phrased slightly differently: '*In the last 12 months, have you experienced any of the following events: being forced to take part in unwanted sexual activity*' with response options 'Yes' and 'No'. At Survey 2 of the 1921-26 cohort, the question was the same but with a timeframe of the last three years instead of the last 12 months.

Additional measures of sexual violence in the 1973-78 cohort

The other isolated measures of sexual violence have not been included consistently across cohorts or across surveys. These measures may be useful for cross-sectional analyses or for analyses which don't span across cohorts.

The 1973-78 and 1946-51 cohorts were asked a stand-alone question about sexual violence during childhood in Survey 4 (2006) and Survey 7 (2013), respectively. The question was worded: 'As a child, did you experience sexual abuse (e.g., forced to engage in unwanted sexual practices such as unwanted touching, exposure or penetration)?' with response options 'Yes', 'No', and 'I prefer not to answer'.

The 1973-78 cohort were also asked additional sexual abuse questions at earlier surveys. At Survey 2 in 2000, participants were asked a screening question, 'Have you ever experienced any form of physical, mental, emotional or sexual abuse or violence, either as a child, in an adult relationship, or at any other time?' with response options: 'Yes', 'No', and "Don't want to answer'. If the participant indicated 'Yes' to this question, they were asked several follow up questions and had the opportunity to indicate if they had experienced any of the following: 'Sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual assault, forced to engage in unwanted sexual practices)'. At Survey 3 in 2003, the women from the 1973-78 cohort were asked to indicate if they had experienced any of the following in the last three years: Sexual abuse (e.g., rape or attempted rape, sexual assault, forced to engage in unwanted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, forced to engage in unwanted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual abuse (e.g., rape or attempted rape, sexual assault, fear of sexual assault, forced to engage in unwanted sexual practices)'.

Sexual violence over the lifetime

It may be useful for some research purposes to define a composite variable that measures lifetime experiences of sexual violence. This can be readily achieved by creating a dichotomous indicator variable for lifetime sexual violence, which is set to true if the participant indicated 'yes' to any of the available questions on sexual violence. Note that this does not indicate when the sexual violence itself occurred.

7.2.3 Issues with measuring sexual violence using ALSWH data

There are several key issues to be aware of when analysing sexual violence data from ALSWH.

Determining severity and frequency of sexual violence

The sexual violence measures included in ALSWH do not capture severity or frequency of sexual violence. Looking at the quantitative data, it is not possible to distinguish between someone who experienced one incident of sexual violence from someone who has experienced many incidents of sexual violence. Nor do these questions quantitatively capture severity of the sexual violence. ALSWH had determined as part of its survey development consultation processes that it is not appropriate to collect explicit details of sexual violence in a self-complete health survey with no immediate support resources available, due to the triggering nature of more detailed questions.

Determining when sexual violence occurred

The measures which have a specific time frame included as a response option (e.g., "In the last 12 months") will allow investigation of recent sexual violence. For experiences of sexual violence beyond this time frame (e.g., "More than 12 months ago") or when a time frame is not specified, it is difficult to determine when these experiences of sexual violence occurred. For the child sexual abuse measures, it can only be assumed that the sexual violence occurred prior to age 18.

Furthermore, data users should not assume that if sexual violence is reported for the first time that the violence occurred since the last completed survey. Women may have many reasons why they disclose or do not disclose experiences of violence, it may take a number of surveys before they report such experiences in an ALSWH survey (Loxton et al., 2013).

Potential overlap between sexual violence variables

In the course of using multiple sexual violence measures longitudinally, it was discovered that there is some potential overlap between measurements which was not anticipated when the measures were introduced into the surveys.

Experiences of sexual violence by a partner were reported by participants who were only 18 years old at the time of survey completion (specifically women from the 1989-95 cohort). This leads to some overlap between the 'sexual violence by a partner' questions and the 'sexual violence during childhood' questions, such that the same experience of sexual violence may be captured by both of these questions. In a similar way, there is also overlap between the 'sexual violence by an unspecified person' questions and the 'sexual violence during childhood' questions, such that the same experience during childhood' questions, such that the same experience of sexual violence by an unspecified person' questions and the 'sexual violence during childhood' questions, such that the same experience of sexual violence may be captured by both questions. The overlap between these questions makes it difficult in practice to isolate experiences of sexual violence that occurred during adulthood and not in childhood.

Inconsistent reporting of sexual violence

Reporting of violence (sexual or otherwise) is not always consistent over time. For example, there are women who indicated 'yes' to having ever experienced sexual violence at Survey 2, but at Survey 3 they indicated 'no' to having ever experienced sexual violence. This may be due to changed perception of past experiences, emotional costs associated with disclosure, fear of reprisal, an attempt to forget the past, misremembering, or other reasons (Loxton et al., 2017). For some analyses, it may be appropriate to set all future values for 'ever experienced sexual violence' to 'true' once sexual violence has been reported for the first time to account for this inconsistent reporting.

Under-reporting of sexual violence

Keep in mind for all analyses that sexual violence tends to be under-reported due to triggering unwanted emotions, stigma, shame, guilt, or fear of reprisal from perpetrators. This may lead to an underestimate of prevalences or attenuation of associations between variables.

7.2.4 References

Felitti VJ, RF Anda, D Nordenberg, et al. (1998). *Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACES) Study.* American Journal of Preventive Medicine, 14(4): 245-258.

Hegarty K, Sheehan M, & Schonfeld C. (1999). *A multidimensional definition of partner abuse: Development and preliminary validation of the Composite Abuse Scale*. Journal of Family Violence 14: 399-415.

Loxton D, Powers JR, Fitzgerald D, Forder PM, Anderson AE, Taft A & Hegarty K. (2013). *The Community Composite Abuse Scale: Reliability and validity of a measure of intimate partner violence in a community survey from the ALSWH*. Journal of Women's Health, Issues and Care, 2: 1-7.

Loxton D, Townsend N, Cavenagh D & Green L. (2017). *Measuring domestic violence in longitudinal research*, Australian Government Department of Social Services

Townsend N, Loxton D, Egan N, Barnes I, Byrnes E & Forder P. (2022). A life course approach to determining the prevalence and impact of sexual violence in Australia: Findings from the Australian Longitudinal Study on Women's Health. (Research report 14/2022). ANROWS.

7.3 SEIFA percentiles in ALSWH

Author: David Fitzgerald

7.3.1 Introduction

ALSWH data currently include the geo-coded variables ARIA+, Modified Monash Model (MMM), and SEIFA. (Other geo-coded variables have been used previously). This document describes how ALSWH has changed the way SEIFA variables are presented in the ALSWH datasets.

The Australian Bureau of Statistics (ABS) produces the SEIFA variables (ABS, 2016) and describes them as follows:

Socio-Economic Indexes for Areas (SEIFA) is a product developed by the ABS that ranks areas in Australia according to relative socio-economic advantage and disadvantage. The indexes are based on information from the five-yearly Census.

SEIFA consists of four indexes:

- The Index of Relative Socio-Economic Disadvantage (IRSD)
- The Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD)
- The Index of Education and Occupation (IEO)
- The Index of Economic Resources (IER).

Each index is a summary of a different subset of Census variables and focuses on a different aspect of socio-economic advantage and disadvantage. Some common uses of SEIFA include:

- determining areas that require funding and services
- identifying new business opportunities
- research into the relationship between socio-economic disadvantage and various health and educational outcomes.

7.3.2 SEIFA in ALSWH

The geo-coded variables are added to the ALSWH datasets after the dataset is initially released because they take some time to be produced from the geo-coding process. The SEIFA variables are based on the census values – censuses used for each survey are shown in Table 7-6.

	Cohort										
Wave	1921-26	1946-51	1973-78	1989-95							
1	1996	1996	1996	2011							
2	1996	1996	1996	2011							
3	2001	1996	2001	2011							
4	2001	2001	2006	2011							
5	2006	2006	2006	2016							
6	2006	2006	2011	2016							
7		2011	2011								
8		2011	2016								
9		2016									

 Table 7-6 Censuses used in the SEIFA indices by cohort and wave

The four SEIFA indices mentioned above – IRSD, IRSAD, IEO and IER – have been in the ALSWH datasets since 2002. Before 2002, different SEIFA indices, including Urban Advantage and Rural Advantage, were used. Up until 2022 the full SEIFA index values were on the ALSWH datasets and available to researchers. From 2022 the actual values will be replaced by SEIFA quantiles.

7.3.3 Quantiles replacing index values

The ABS give guidelines on the appropriate use of SEIFA and clarify that the indices are assigned to areas, not to people. They indicate the average socio-economic characteristics of the people, families, and households in the area.

SEIFA are best interpreted as ordinal measures. The scales are arbitrary; they do not represent some quantity. For example, an index value of 1000 does not necessarily mean the area is twice as advantaged as one with a value of 500.

The ABS recommend rankings and quantiles, such as deciles and percentiles, are used rather than the index values. The ABS also note the indexes are designed to compare area characteristics at a given time and longitudinal analysis can be difficult to interpret. Therefore, the use of quantiles is recommended, rather than scores.

Further to the ABS recommendations for using quantiles, it was noticed that the actual SEIFA scores could be potentially identifying of individual participants especially where there only one participant in the statistical area unit.

7.3.4 SEIFA Quantiles in the ALSWH data

Each SEIFA index has been replaced by four quantile variables in the ALSWH datasets. These are deciles, quartiles, tertiles and binary variables. The quartiles and tertiles can be combined to produce 12-point quantiles. The variable names are shown in Table 7-7.

Quantile	Label
SEO11_deciles	Deciles, SEIFA index of Education and Occupation, Census 2011
SEO11_quartiles	Quartiles, SEIFA index of Education and Occupation, Census 2011
SEO11_tertiles	Tertiles, SEIFA index of Education and Occupation, Census 2011
SEO11_high1low0	High-Low, SEIFA index of Education and Occupation, Census 2011
SAD11_deciles	Deciles, SEIFA index of Socio-economic Adv/Disadv, Census 2011
SAD11_quartiles	Quartiles, SEIFA index of Socio-economic Adv/Disadv, Census 2011
SAD11_tertiles	Tertiles, SEIFA index of Socio-economic Adv/Disadv, Census 2011
SAD11_high1low0	High-Low, SEIFA index of Socio-economic Adv/Disadv, Census 2011
SER11_deciles	Deciles, SEIFA index of Economic resources, Census 2011
SER11_quartiles	Quartiles, SEIFA index of Economic resources, Census 2011
SER11_tertiles	Tertiles, SEIFA index of Economic resources, Census 2011
SER11_high1low0	High-Low, SEIFA index of Economic resources, Census 2011
SD11_deciles	Deciles, SEIFA index of Socio-economic Disadvantage, Census 2011
SD11_quartiles	Quartiles, SEIFA index of Socio-economic Disadvantage, Census 2011
SD11_tertiles	Tertiles, SEIFA index of Socio-economic Disadvantage, Census 2011
SD11_high1low0	High-Low, SEIFA index of Socio-economic Disadvantage, Census 2011

Table 7-7 SEIFA Quantile variable names and labels

7.3.5 References

Australian Bureau of Statistics. Socio-Economic Indexes for Areas. (2016; accessed July 2022).

8 2021 Major Report

The 2022 Major Report used the longitudinal data collected across the four cohorts of women in the ALSWH to focus on health and risk factors in midlife. In 2021, when the report was prepared, the women in the 1973-78 cohort were just entering their middle years (aged 43-48), and the 1946-51 cohort were in their 70s, while the 1989-95 cohort were in their late 20s. Consequently, while the report concentrates on changes for women in the 1946-51 cohort as they age from their 40s to their 70s, the report also contrasts the experience of these women with those of the 1921-26 cohort (who may shed light on these women's future health expectations) and those of the younger cohorts as they move into their middle years. The report findings aim to improve understanding of midlife for women in Australia and the implications for health and wellbeing in midlife and beyond. They can help identify intervention points at earlier stages of women's lives to reduce risk of adverse outcomes and inform preventive health policy and targeted intervention strategies to improve women's health and wellbeing over the medium and long term. A summary of the report is included here – the <u>full report</u> is available on the Study website.

8.1 Overview of the four ALSWH cohorts across the life course

The initial analysis used longitudinal data from ALSWH collected since the baseline survey in 1996 to the most recent data points. These data provide an overview of health and key factors across the four cohorts, essentially covering the life course from early adulthood to old age. This overview clarifies the changes across the course of women's lives, often showing progress in health states, but also highlighting areas of rising concern, with each generation of Australian women:

- Successive cohorts of women are: better educated, less likely to smoke, more likely to undertake sufficient physical activity for health benefit, but more likely to be overweight or obese.
- The 1989-95 cohort, the youngest in ALSWH, have poorer self-rated health and poorer mental health, as is clearly evident in comparison with the 1973-78 cohort.
- Rates of obesity have increased rapidly in the 1989-95 cohort compared with previous generations. Over 20% were obese by their late 20s, a rate not seen in the 1973-78 cohort until their late 30s, and not until women in the 1946-51 cohort were aged in their 50s.

8.2 Then and now: Comparing two generations of women during midlife

Longitudinal data for women in the 1973-78 and 1946-51 cohorts were compared across midlife, with a specific comparison point used for when women in the 1973-78 cohort were aged 40-45 in 2018 with the 1946-51 cohort when women were aged 45-50 in 1996. This showed that:

The prevalence of overweight and obesity increased over time for women in both cohorts. The increase was greater among the 1973-78 cohort who were more likely to be overweight or obese at the age of 40-45 in 2018 than the older women were when they were aged 45-50 in 1996 (57% compared with 45%).

- The 1946-51 cohort were more likely than the 1973-78 cohort to meet Australian Guidelines for fruit and vegetable consumption, physical activity and sitting time, and alcohol consumption.
- Both cohorts, showed a decline in smoking over time, with less than 10% of the 1973-78 cohort being smokers in their 40s, a rate substantially lower than for 1946-51 cohort around that age. While smoking in the 1946-51 cohort has continued to decline to less than 5% by their 70s, in the 1973-78 cohort the rate of decline in smoking has slowed in recent surveys.
- Most chronic conditions considered in this report increased with age. These included diabetes, arthritis, cancer, heart disease, urinary incontinence, and difficulty sleeping, together with more doctor visits and poorer self-rated health.
- Consistent with the higher rates of obesity for the 1973-78 cohort in their 40s, the prevalence of diabetes at age 40-45 is already around 5% and is on the rise. This prevalence only occurred for the 1946-51 cohort when they were in their 50s. Similarly, there are early indications that women in the 1973-78 cohort in their 40s are tracking higher than expected for both heart disease and urinary incontinence when compared with the 1946-51 cohort.
- The mental health of women in the 1946-51 cohort improved with age, with measures of depression, anxiety, and stress all showing a consistent decline. For the 1973-78 cohort, however, after an initial decline there was a sharp rise in depression, anxiety and stress scores, since their mid-30s or since around 2010, that has yet to show a shift to a decline again.
- There were some other notable differences between cohorts, possibly reflecting changes in medical practice. Asthma prevalence increased over time but was much more common overall in the 1973-78 cohort. For hysterectomy less than 5% of the 1973-78 cohort had the procedure by age 40-45 years, compared with more than 20% of women in the 1946-51 cohort by age 45-50.

8.3 Social and personal circumstances

We compared the patterns of change in the social and personal circumstances of women in the 1946-51 cohort as they age from their mid-40s to their 70s with those in the 1973-78 cohort (from their 20s to their early 40s). This showed that:

- In terms of employment, women in the 1946-51 cohort were not in the workforce most of the time and had the lowest 36-Item Short Form Survey (SF-36) scores for mental health and physical functioning at each age point compared with other employment categories that showed little difference. Similarly for the 1973-78 cohort, though here the category combined part-time employment and not in the workforce.
- For relationship status, those in the 1946-51 cohort who were always partnered had the highest SF-36 scores mental health and physical functioning scores, while those were single or were no longer in a partnership had the lowest. Again, similar differences were evident in the 1973-78 cohort (with the differences being clearest for physical functioning as the women approached their 40s).
- Social needs and roles of women are a key factor in women's lives, with women in both cohorts who reported lower levels of social support having the lowest mental and physical functioning

score across the age range. This was similarly the case for women who needed help with daily tasks and for those who had a caring role related to mental health.

 Women in the 1946-51 cohort at age 68-73 who reported a fall to the ground in the previous 12 months were found to have markedly lower social and physical function and mental health scores and a higher percentage were stressed about different aspects of their lives (from relationships with spouse and children to health and managing on their income). The same findings were seen for those who ever had reported a fall to the ground.

8.4 Abuse and violence in midlife

Interpersonal violence reported by the women in the ALSWH surveys includes experiences of childhood abuse, domestic violence, and sexual abuse.

- At age 45, half of the women (52%) in the 1973-78 cohort reported experiencing interpersonal violence compared with 36% of women at that age in the 1946-51 cohort.
- On average, women in midlife who have reported interpersonal violence also experience poorer physical functioning, poorer mental health, worse social functioning, and consistently higher levels of stress.
- Among mid-aged women, use of health services (GP visits, specialist consultations, etc.) was higher for women who had experienced interpersonal violence, which was consistent with women in the 1973-78 cohort at age 45 years.

8.5 Then and now: Comparing two generations of women in their early 70s

Women in the 1946-51 cohort, aged 70-73 in 2019 were compared with women at the same age in 1996 in the 1921-26 cohort:

- In their early 70s, women in the 1946-51 cohort generally had better scores across the domains
 of SF-36 Health Related Quality of Life than the older generation of women in the 1921-26
 cohort at the same age. This was clear for *general health* and *vitality*, but particularly so for *physical functioning* and *role physical* (limitations in activity or participation in terms of physical
 functioning) and similarly for *role emotional*.
- The 1946-51 cohort were also less likely to smoke but had a higher prevalence of obesity than the 1921-26 cohort.
- Women in the 1946-51 cohort had better self-reported general health and lower prevalence of a range of symptoms, from poor memory and eyesight problems, to breathing difficulties. The exceptions were stiffness or painful joints (which were the same across cohorts) and a higher prevalence of leaking urine in the 1946-51 cohort compared to the 1921-26 cohort, which is consistent with the higher rates of obesity in the younger generation.
- The relationship with health service use by the 1946-51 cohort in their early 70s is not straightforward. These women had a higher prevalence of specialist and hospital doctor attendances, but with a lower proportion having seven or more GP visits in the previous year, when compared with the 1921-26 cohort. These differences may reflect changes in the health system and policy since 1996.

8.6 Women's attitudes to ageing and their outlook for the future

A qualitative analysis of the free-text responses from women in the 1946-51 cohort when aged in their late 60s and early 70s has provided a rich narrative on their diverse perceptions of ageing. Five major themes were identified:

- Attitudes towards health with ageing were expressed as an anticipation of worsening health over time, attention to activities that support health, and perceptions of (both positive and negative) changes to mental health with age.
- *The experience of slowing down* that included acceptance and reflection on past experiences and achievements.
- Loss of independence and reduced capability due to ageing with views expressed on the implications and limitations, including on forming relationships and the need for support.
- The impact of financial security on life choices and health, including concerns about the future and managing on their income, and the difficulty of undertaking paid work, that contrasted with others who felt financially secure.
- Life transitions and changes in purpose and identity, including experiences of both positive adjustment to and the difficulties of coping with life events such as retirement or bereavement

 ranging from a loss of purpose and social isolation, to taking on new opportunities for work, study, and caring roles with grandchildren.

8.7 Implications and recommendations

Compared to women in the 1946-51 cohort, women in the 1973-78 cohort in their early 40s are generally better placed in terms of their physical and mental health and across various aspects of their lives including education levels and participation in the workforce, than the previous generation. However, there are a number of key areas of concern, that have important implications for their health and wellbeing going forward:

The comparatively higher rates of overweight and obesity in the 1973-78 cohort already appear to correspond with the higher trajectory of diabetes prevalence (and possibly with higher rates of leaking urine) compared with the older generation. Further research on cancers and cardiovascular disease will confirm if these are also on a higher trajectory than seen in the 1946-51 cohort.

• **Recommendation:** Further research and interventions are needed to reverse the rising obesity rates that risk undoing the current health and wellbeing advantage this generation has otherwise gained, with increased risk of chronic conditions going forward and their associated demand on health services.

Progress on smoking cessation, which shows the 1973-78 cohort has a lower prevalence of current smokers than the older generation, which appears to have slowed. If this slowing continues, then smoking rates may by higher than the older generation by their 60s.

• **Recommendation:** Smoking cessation research and preventive health policy needs to focus on women in the late 30s and early 40s (in addition to initiatives directed at younger women) to

support them quitting before the major health consequences of later midlife develop, such as cardiovascular disease and cancer.

The rise in depression, anxiety, and stress scores since around 2010 in the 1973-78 cohort are yet to show signs of a return to the expected trajectory of improvements with age as seen in the 1946-51 cohort. With the challenges posed in recent years by major life-events, including those related to the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic and major disasters, such as bush fires, we may see a further rise in these markers of poor mental health.

• **Recommendation:** research should continue to focus on the depression, anxiety, and stress levels seen in these women, which if worsening further due to recent events, would underscore the importance of initiatives to return the trajectory to improving mental health with age.

The high prevalence of women in the 1973-78 cohort who reported the experience of interpersonal violence by their early 40s, with the poorer physical functioning, mental health, social functioning, and consistently higher levels of stress.

 Recommendation: interpersonal violence is a major issue that remains unresolved for women; one that requires on-going policy initiatives and research to evaluate progress and to help mitigate the substantial health and wellbeing consequences going forward.

The low participation in the workforce in the 1973-78 cohort (and supported by similar findings in the older generation) is consistently linked with poorer mental health and physical functioning scores.

• **Recommendation:** further research is needed on the direction and causal pathways for these relationships and initiatives are needed to focus on increased workforce participation across midlife.

If there are clear warning signs on overweight and obesity in the 1973-78 cohort, then there should be alarm bells ringing on the rapid increase for the 1989-95 cohort. These women in their late 20s already have overweight and obesity rates not seen in previous generations until much later, even decades older in the 1946-51 cohort.

• **Recommendation:** Intervention studies and preventive health strategies are needed that are targeted at women prior to midlife with corresponding research evaluation of their efficacy, if we are to mitigate the increased risk of chronic diseases and burden on health service use in the decades ahead.

Compared to the 1921-26 cohort, there is some evidence that women in the 1946-51 cohort may have better self-reported health and health-related quality of life scores. However higher rates of obesity in this cohort may limit gains in healthy ageing.

9 DISSEMINATION OF STUDY FINDINGS

9.1 Publications

Since the last Technical Report (15 November 2021) there have been 42 publications recorded using ALSWH data. The most frequently published research themes were chronic conditions, weight, nutrition and physical activity and reproductive health (**Error! Reference source not found.**).

Table 9-1 ALSWH publications from November 2021 to November 2022 by research theme.

Theme	No. publications
Chronic conditions	15
Weight, nutrition and physical activity	15
Reproductive health	13
Mental health	10
Ageing and Aged Care	6
Social factors in health and wellbeing	6
Health service use	5
Tobacco, alcohol and other drugs	4
Child health and development	4
Physical health	3
Methodology	2
Environmental health	2
Abuse	1
Formal and informal workpatterns and work/family balance	1
Medications	1

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 <u>Study website</u>.

Chronic conditions

- Abdulbasit M. Seid, Gita D. Mishra, Annette J. Dobson. (2022). The association between childhood sexual abuse and historical intimate partner violence with body mass index and diabetes: Evidence from the Australian Longitudinal Study on Women's Health. *Preventive Medicine*; 161: 107134. <u>https://doi.org/10.1016/j.ypmed.2022.107134</u>
- Botteri E, Xu Z, Støer NC & Mishra GD. (2022). Menopausal hormone therapy and melanoma risk in the Australian longitudinal study on women's health. *Maturitas*; 160: 1-3. https://doi.org/10.1016/j.maturitas.2022.01.004
- Engel RM, de Luca K, Graham PL, Farshchi MK, Vemulpad S & Byles J. (2022). Predictors of chronic obstructive pulmonary disease in women who have never smoked: A cohort study. *ERJ Open Research*; 8(2). <u>https://doi.org/10.1183/23120541.00532-2021</u>
- Gribbin S, Enticott J, Hodge AM, Moran L, Thong E, Joahm A & Zaman S. (2022). Association of carbohydrate and saturated fat intake with cardiovascular disease and mortality in Australian women. *Heart*;108(12): 932-939. <u>http://dx.doi.org/10.1136/heartjnl-2021-319654</u>
- Harris ML, Egan N, Forder PM, Bateson D, Sverdlov AL, Murphy VE & Loxton D. (2022). Patterns of contraceptive use among young Australian women with chronic disease: Findings from a prospective cohort study. *Reproductive Health*; <u>https://doi.org/10.1186/s12978-022-</u> 01413-x
- Kicono S, Teede HJ, Earnest A, Loxton D & Joham AE. (2022). Menstrual cycle regularity as a predictor for heart disease and diabetes: Findings from a large population-based longitudinal cohort study. Clinical Endocrinology, 96(4); 605-616. <u>https://doi.org/10.1111/cen.14640</u>
- Laaksonen MA, MacInnis RJ, Canfell K, Shaw JE, Magliano DJ, Banks E, Giles GG, Byles JE, Gill TK, Mitchell P, Hirani V, Cumming RG & Vajdic CM. (2022). Thyroid cancers potentially preventable by reducing overweight and obesity in Australia: A pooled cohort study. *International Journal of Cancer*, 150(8): 1281-1290. <u>https://doi.org/10.1002/ijc.33889</u>
- Liang C, Chung H-F, Dobson A, Hayashi K, van der Schouw Y, Kuh D, Hardy R, Derby CA, El Khoudary SR, Janssen I, Sandin S, Weiderpass E & Mishr GD. (2022). Infertility, recurrent pregnancy loss, and risk of stroke: Pooled analysis of individual patient data of 618,851 women. *BMJ*; 377: e070603. <u>https://doi.org/10.1136/bmj-2022-070603</u>
- Mishra SR, Waller M, Chung H-F & Mishra GD. (2022). Association between reproductive lifespan and risk of incident type 2 diabetes and hypertension in postmenopausal women:

Findings from a 20-year prospective study. *Maturitas*; 159: 52-61. https://doi.org/10.1016/j.maturitas.2022.01.001

- Oorschot T, Adams J & Sibbritt D. (2022). Is mental health co-morbidity an influencing factor in the health service utilisation of women with diabetes mellitus? *PLoS One*; <u>https://doi.org/10.1371/journal.pone.0272041</u>
- Rahman M, Jagger C, Princehorn EM, Holliday EG, Leigh L, Loxton D, Beard J, Kowal P, & Byles JE. (2022). Onset and progression of chronic disease and disability in a large cohort of older Australian women. Maturitas; 158(1): 25-33. https://doi.org/10.1016/j.maturitas.2021.11.007
- Rowlands I, Hockey R, Abbott J, Montgomery G & Mishra G. (2022). Body mass index and the diagnosis of endometriosis: Findings from a national data linkage cohort study. *Obesity Research and Clinical Practice*; <u>https://doi.org/10.1016/j.orcp.2022.04.002</u>
- Rowlands I, Hockey R, Abbott J, Montgomery G & Mishra G. (2022). Longitudinal changes in employment following a diagnosis of endometriosis: Findings from an Australian cohort study. *Annals of Epidemiology*; 69: 1-8. <u>https://doi.org/10.1016/j.annepidem.2021.10.005</u>
- Tay CT, Loxton D, Khomami MB, Teede H & Joham AE. (2022). Negative associations of ideal family size achievement with hypertension, obesity and maternal age in women with and without polycystic ovary syndrome. *Clinical Endocrinology*; <u>https://doi.org/10.1111/cen.14736</u>
- Xu Z, Hockey R, McElwee P, Waller M & Dobson A. (2022). Accuracy of death certifications of diabetes, dementia, and cancer in Australia: a population-based cohort study. *BMC Public Health*; 22(1): 902. <u>https://doi.org/10.1186/s12889-022-13304-8</u>

Weight, nutrition and physical activity

- Abdulbasit M. Seid, Gita D. Mishra, Annette J. Dobson. (2022). The association between childhood sexual abuse and historical intimate partner violence with body mass index and diabetes: Evidence from the Australian Longitudinal Study on Women's Health. *Preventive Medicine*; 161: 107134. https://doi.org/10.1016/j.ypmed.2022.107134
- Awoke MA, Earnest A, Joham AE, Hodge AM, Teede HJ, Brown WJ & Moran LJ. (2022). Weight gain and lifestyle factors in women with and without polycystic ovary syndrome. *Human Reproduction*, 37(1): 12-141. <u>https://doi.org/10.1093/humrep/deab239</u>
- Bennett CJ, Mansfield DR, Mo L, Joham AE, Cain SW, Blumfield ML, Hodge A & Moran LJ. (2022). Sleep disturbances may influence lifestyle behaviours in women with self-reported polycystic ovary syndrome. *British Journal of Nutrition*, 127(9); 1395-1403. <u>https://doi.org/10.1017/S0007114521002361</u>

- Dharmayani PNA, Mishra GD & Mihrshahi S. (2022). Fruit and vegetable consumption and depression symptoms in young women: Results from 1973 to 1978 cohort of the Australian Longitudinal Study on Women's Health. *European Journal of Nutrition*; <u>https://doi.org/10.1007/s00394-022-02926-8</u>
- Gete DG, Waller M & Mishra GD. (2022). The role of child diets in the association between pre-pregnancy diets and childhood behavioral problems: A mediation analysis. *Public Health Nutrition*; <u>https://doi.org/10.1017/S1368980022001410</u>
- Gribbin S, Enticott J, Hodge AM, Moran L, Thong E, Joahm A & Zaman S. (2022). Association of carbohydrate and saturated fat intake with cardiovascular disease and mortality in Australian women. *Heart*;108(12): 932-939. <u>http://dx.doi.org/10.1136/heartjnl-2021-319654</u>
- Laaksonen MA, MacInnis RJ, Canfell K, Shaw JE, Magliano DJ, Banks E, Giles GG, Byles JE, Gill TK, Mitchell P, Hirani V, Cumming RG & Vajdic CM. (2022). Thyroid cancers potentially preventable by reducing overweight and obesity in Australia: A pooled cohort study. *International Journal of Cancer*, 150(8): 1281-1290. <u>https://doi.org/10.1002/ijc.33889</u>
- Lee M, Bradbury J, Yoxall J & Sargeant S. (2022). Is dietary quality associated with depression? An analysis of the Australian longitudinal study of women's health data. *British Journal of Nutrition*; https://doi.org/10.1017/S0007114522002410
- Magnus MC, Hockey RL, Haberg SE & Mishra GD. (2022) Pre-pregnancy lifestyle characteristics and risk of miscarriage: The Australian Longitudinal Study on Women's Health. BMC Pregnancy and Childbirth; 22:169. <u>https://doi.org/10.1186/s12884-022-04482-9</u>
- Makama M, Earnest A, Lim S, Skouteris H, Hill B, Teede H, Boyle JA, Brown WJ, Hodge AM & Moran LJ. (2022). Assessing patterns of change in lifestyle behaviours by parity: A longitudinal cohort study. *International Journal of Epidemiology*; <u>https://doi.org/10.1093/ije/dyac139</u>
- Rahman M, Jagger C, Leigh L, Holliday E, Princehor E, Loxton D, Kowal P, Beard J & Byles J. (2022). The impact of education and lifestyle factors on disability-free life expectancy from mid-life to older age: A multi-cohort study. *International Journal of Public Health*; 67. https://doi.org/10.3389/ijph.2022.1605045
- Rowlands I, Hockey R, Abbott J, Montgomery G & Mishra G. (2022). Body mass index and the diagnosis of endometriosis: Findings from a national data linkage cohort study. *Obesity Research and Clinical Practice*; <u>https://doi.org/10.1016/j.orcp.2022.04.002</u>

- Tay CT, Loxton D, Khomami MB, Teede H & Joham AE. (2022). Negative associations of ideal family size achievement with hypertension, obesity and maternal age in women with and without polycystic ovary syndrome. *Clinical Endocrinology*; <u>https://doi.org/10.1111/cen.14736</u>
- Tolhurts T, Princehorn E, Loxton D, Mishra G, Mate K & Byles J. (2022). Changes in food and drink consumption patterns of Australian women during the COVID-19 pandemic. *Australian and New Zealand Journal of Public Health*, https://doi.org/10.1111/1753-6405.13295
- Wilson LF, Dobson AJ, Doust J & Mishra GD. (2022). Socioeconomic, behavioural and health factors associated with chlamydia testing in sexually active young women: An Australian observational cohort study. Sexual Health; <u>https://doi.org/10.1071/SH21230</u>

Reproductive health

- Awoke MA, Earnest A, Joham AE, Hodge AM, Teede HJ, Brown WJ & Moran LJ. (2022). Weight gain and lifestyle factors in women with and without polycystic ovary syndrome. *Human Reproduction*, 37(1): 12-141. <u>https://doi.org/10.1093/humrep/deab239</u>
- Bagade T, Thapaliya K, Breuer E, Kamath R, Li Z, Sullivan E & Majeed T. (2022). Investigating the association between infertility and psychological distress using Australian Longitudinal Study on Women's Health (ALSWH). *Scientific Reports*, 12, 10808. <u>https://doi.org/10.1038/s41598-022-15064-2</u>
- Bennett CJ, Mansfield DR, Mo L, Joham AE, Cain SW, Blumfield ML, Hodge A & Moran LJ. (2022). Sleep disturbances may influence lifestyle behaviours in women with self-reported polycystic ovary syndrome. *British Journal of Nutrition*, 127(9); 1395-1403. <u>https://doi.org/10.1017/S0007114521002361</u>
- Bizuayehu HM, Harris ML, Chojenta C, Forder PM & Loxon D. (2022). Biopsychosocial factors influencing the occurrence and recurrence of preterm singleton births among Australian women: A prospective cohort study. *Midwifery*; 110: 103334. <u>https://doi.org/10.1016/j.orcp.2022.04.002</u>
- Botteri E, Xu Z, Støer NC & Mishra GD. (2022). Menopausal hormone therapy and melanoma risk in the Australian longitudinal study on women's health. *Maturitas*; 160: 1-3. https://doi.org/10.1016/j.maturitas.2022.01.004
- Harris ML, Egan N, Forder PM, Bateson D, Sverdlov AL, Murphy VE & Loxton D. (2022). Patterns of contraceptive use among young Australian women with chronic disease: Findings from a prospective cohort study. *Reproductive Health*; https://doi.org/10.1186/s12978-022-01413-x

- Kicono S, Teede HJ, Earnest A, Loxton D & Joham AE. (2022). Menstrual cycle regularity as a predictor for heart disease and diabetes: Findings from a large population-based longitudinal cohort study. Clinical Endocrinology, 96(4); 605-616. <u>https://doi.org/10.1111/cen.14640</u>
- Liang C, Chung H-F, Dobson A, Hayashi K, van der Schouw Y, Kuh D, Hardy R, Derby CA, El Khoudary SR, Janssen I, Sandin S, Weiderpass E & Mishr GD. (2022). Infertility, recurrent pregnancy loss, and risk of stroke: Pooled analysis of individual patient data of 618,851 women. *BMJ*; 377: e070603. https://doi.org/10.1136/bmj-2022-070603
- Magnus MC, Hockey RL, Haberg SE & Mishra GD. (2022) Pre-pregnancy lifestyle characteristics and risk of miscarriage: The Australian Longitudinal Study on Women's Health. *BMC Pregnancy and Childbirth*; 22:169. https://doi.org/10.1186/s12884-022-04482-9
- Mishra GD, Baneshi MR, Dobson AJ & Tooth LR. (2022). Maternal factors associated with interbirth intervals in Australia: Results from a population-based longitudinal study. *Birth*; https://doi.org/10.1111/birt.12638
- Mishra SR, Waller M, Chung H-F & Mishra GD. (2022). Association between reproductive lifespan and risk of incident type 2 diabetes and hypertension in postmenopausal women: Findings from a 20-year prospective study. *Maturitas*; 159: 52-61. https://doi.org/10.1016/j.maturitas.2022.01.001
- Tapp C, Mishra GD, Dobson AJ, Moss KM & Tooth LR. (2022). History of pre-pregnancy maternal symptoms of binge eating and childhood behavioral problems in girls and boys. *Journal of Eating Disorders*, 1-10 <u>https://doi.org/10.1002/eat.23783</u>
- Wilson LF, Dobson AJ, Doust J & Mishra GD. (2022). Socioeconomic, behavioural and health factors associated with chlamydia testing in sexually active young women: An Australian observational cohort study. *Sexual Health*; https://doi.org/10.1071/SH21230

Mental health

- Bagade T, Thapaliya K, Breuer E, Kamath R, Li Z, Sullivan E & Majeed T. (2022). Investigating the association between infertility and psychological distress using Australian Longitudinal Study on Women's Health (ALSWH). *Scientific Reports*, 12, 10808. <u>https://doi.org/10.1038/s41598-022-15064-2</u>
- Campbell A, Perales F, Hughes TL, Everett BG & Baxter J. (2022). Sexual fluidity and psychological distress: What happens when young women's sexual identities change? *Journal of Health and Social Behavior*; <u>https://doi.org/10.1177/00221465221086335</u>
- Dharmayani PNA, Mishra GD & Mihrshahi S. (2022). Fruit and vegetable consumption and depression symptoms in young women: Results from 1973 to 1978 cohort of the Australian

Longitudinal Study on Women's Health. *European Journal of Nutrition*; https://doi.org/10.1007/s00394-022-02926-8

- Dolja-Gore X, Loxton D, D'Este C & Byles JE. (2022). Transitions in health service use among women with poor mental health: A 7-year follow-up. *Family Medicine and Community Health*; 10 2: e001481. <u>http://dx.doi.org/10.1136/fmch-2021-001481</u>
- Freak-Poli R, Ryan J, Tran T, Owen A, McHugh Power J, Berk M, Stocks N, Gonzalez-Chica D, Lowthian J, Fisher J & Byles J. (2022). Social isolation, social support and loneliness as independent concepts, and their relationship with health-related Quality of Life among older women. *Aging and Mental Health*, 26(7); 1335-1344. https://doi.org/10.1080/13607863.2021.1940097
- Lam J & Campbell A. (2022) Life events and loneliness among older women of diverse sexual identities: Application of the Stress Process Model. *Research on Aging*; https://doi.org/10.1177/01640275221090681
- Lee M, Bradbury J, Yoxall J & Sargeant S. (2022). Is dietary quality associated with depression? An analysis of the Australian longitudinal study of women's health data. *British Journal of Nutrition*; <u>https://doi.org/10.1017/S0007114522002410</u>
- Oorschot T, Adams J & Sibbritt D. (2022). Is mental health co-morbidity an influencing factor in the health service utilisation of women with diabetes mellitus? *PLoS One*; <u>https://doi.org/10.1371/journal.pone.0272041</u>
- Tapp C, Mishra GD, Dobson AJ, Moss KM & Tooth LR. (2022). History of pre-pregnancy maternal symptoms of binge eating and childhood behavioral problems in girls and boys. *Journal of Eating Disorders*, 1-10 <u>https://doi.org/10.1002/eat.23783</u>
- Tay CT, Loxton D, Khomami MB, Teede H & Joham AE. (2022). Negative associations of ideal family size achievement with hypertension, obesity and maternal age in women with and without polycystic ovary syndrome. *Clinical Endocrinology*; https://doi.org/10.1111/cen.14736

Ageing and Aged Care

Freak-Poli R, Ryan J, Tran T, Owen A, McHugh Power J, Berk M, Stocks N, Gonzalez-Chica D, Lowthian J, Fisher J & Byles J. (2022). Social isolation, social support and loneliness as independent concepts, and their relationship with health-related Quality of Life among older women. *Aging and Mental Health*, 26(7); 1335-1344. https://doi.org/10.1080/13607863.2021.1940097

- Lam J & Campbell A. (2022) Life events and loneliness among older women of diverse sexual identities: Application of the Stress Process Model. *Research on Aging*; https://doi.org/10.1177/01640275221090681
- Hambisa MT, Dolja-Gore X & Byles J. (2022). Determinants of driving among oldest-old Australian women. *Journal of Women and Aging*, 34)3): 351-371. <u>https://doi.org/10.1080/08952841.2021.1937012</u>
- Tay CT, Loxton D, Khomami MB, Teede H & Joham AE. (2022). Negative associations of ideal family size achievement with hypertension, obesity and maternal age in women with and without polycystic ovary syndrome. *Clinical Endocrinology*; <u>https://doi.org/10.1111/cen.14736</u>
- Thiruchelvam K, Byles J, Hasan SS, Egan N & Kairuz T. (2022). Impact of medication reviews on potentially inappropriate medications and associated costs among older women in aged care. *Research in Social and Administrative Pharmacy*; <u>https://doi.org/10.1016/j.sapharm.2022.05.003</u>
- White J, Hambisa M, Cavenagh D, Dolja-Gore X & Byles J. (2022). Understanding the relationship between eye disease and driving in very old Australian Women: A longitudinal thematic evaluation. *BMC Ophthalmology*; 22:277. <u>https://doi.org/10.1186/s12886-022-02506-8</u>
- Byles J, Tavener M & Princehorn E. (2022). Healthy Ageing at very old ages perspectives from women in the oldest cohort of the Australian Longitudinal Study on Women's Health. *International Handbook on Contemporary Ageing Issues: Various Narratives*. (Accepted book chapter)

Health service use

- Dolja-Gore X, Loxton D, D'Este C & Byles JE. (2022). Transitions in health service use among women with poor mental health: A 7-year follow-up. *Family Medicine and Community Health*; 10 2: e001481. http://dx.doi.org/10.1136/fmch-2021-001481
- Hambisa MT, Dolja-Gore X & Byles J. (2022). Application of Anderson-Newman model to assess cataract surgery uptake among older Australian women: Findings from the Australian Longitudinal Study on Women's Health. *Aging Clinical and Experimental Research*, 34(7): 1673-1685. <u>https://doi.org/10.1007/s40520-022-02091-2</u>
- Oorschot T, Adams J & Sibbritt D. (2022). Is mental health co-morbidity an influencing factor in the health service utilisation of women with diabetes mellitus? *PLoS One*; <u>https://doi.org/10.1371/journal.pone.0272041</u>

- Thiruchelvam K, Byles J, Hasan SS, Egan N & Kairuz T. (2022). Impact of medication reviews on potentially inappropriate medications and associated costs among older women in aged care. Research in Social and Administrative Pharmacy; <u>https://doi.org/10.1016/j.sapharm.2022.05.003</u>
- Wilson LF, Dobson AJ, Doust J & Mishra GD. (2022). Socioeconomic, behavioural and health factors associated with chlamydia testing in sexually active young women: An Australian observational cohort study. Sexual Health; <u>https://doi.org/10.1071/SH21230</u>

Tobacco, alcohol and other drugs

- Engel RM, de Luca K, Graham PL, Farshchi MK, Vemulpad S & Byles J. (2022). Predictors of chronic obstructive pulmonary disease in women who have never smoked: a cohort study. *ERJ Open Research*; 8(2). <u>https://doi.org/10.1183/23120541.00532-2021</u>
- Magnus MC, Hockey RL, Haberg SE & Mishra GD. (2022) Pre-pregnancy lifestyle characteristics and risk of miscarriage: The Australian Longitudinal Study on Women's Health. BMC *Pregnancy and Childbirth*; 22:169. <u>https://doi.org/10.1186/s12884-022-04482-9</u>
- Rahman M, Jagger C, Leigh L, Holliday E, Princehor E, Loxton D, Kowal P, Beard J & Byles J. (2022). The impact of education and lifestyle factors on disability-free life expectancy from mid-life to older age: A multi-cohort study. *International Journal of Public Health*; 67. https://doi.org/10.3389/ijph.2022.1605045
- Wilson LF, Dobson AJ, Doust J & Mishra GD. (2022). Socioeconomic, behavioural and health factors associated with chlamydia testing in sexually active young women: An Australian observational cohort study. Sexual Health; <u>https://doi.org/10.1071/SH21230</u>

Social factors in health and wellbeing

- Campbell A, Perales F, Hughes TL, Everett BG & Baxter J. (2022). Sexual fluidity and psychological distress: What happens when young women's sexual identities change? *Journal of Health and Social Behavior*; <u>https://doi.org/10.1177/00221465221086335</u>
- Freak-Poli R, Ryan J, Tran T, Owen A, McHugh Power J, Berk M, Stocks N, Gonzalez-Chica D, Lowthian J, Fisher J & Byles J. (2022). Social isolation, social support and loneliness as independent concepts, and their relationship with health-related Quality of Life among older women. *Aging and Mental Health*, 26(7); 1335-1344. https://doi.org/10.1080/13607863.2021.1940097
- Lam J & Campbell A. (2022) Life events and loneliness among older women of diverse sexual identities: Application of the Stress Process Model. *Research on Aging*; <u>https://doi.org/10.1177/01640275221090681</u>
- Mishra GD, Baneshi MR, Dobson AJ & Tooth LR. (2022). Maternal factors associated with interbirth intervals in Australia: Results from a population-based longitudinal study. *Birth*; <u>https://doi.org/10.1111/birt.12638</u>
- Rahman M, Jagger C, Leigh L, Holliday E, Princehor E, Loxton D, Kowal P, Beard J & Byles J. (2022). The impact of education and lifestyle factors on disability-free life expectancy from mid-life to older age: A multi-cohort study. *International Journal of Public Health*; 67. https://doi.org/10.3389/ijph.2022.1605045
- Wilson LF, Xu Z, Doust J, Mishra GD & Dobson AJ. (2022). Associations of socioeconomic and health factors with dental non-attendance: A comparison of three cohorts of women. *Community Dentistry and Oral Epidemiology*. <u>https://doi.org/10.1111/cdoe.12776</u>

Children's health and development

- Ahmed SM, Knibbs LD, Moss KM, Mouly TA, Yang IA & Mishra GD. (2022). Residential greenspace and early childhood development and academic performance: A longitudinal analysis of Australian children aged 4-12 years. Science of The Total Environment; 833: 155214. <u>https://doi.org/10.1016/j.scitotenv.2022.155214</u>
- Ahmed SM, Mishra GD, Moss KM, Mouly TA, Yang IA & Knibbs LD. (2022). Association between greenspace and health-related quality of life in children aged 0-12 years. *Environmental Research*, 214(1): 113759. <u>https://doi.org/10.1016/j.envres.2022.113759</u>
- Gete DG, Waller M & Mishra GD. (2022). The role of child diets in the association between pre-pregnancy diets and childhood behavioral problems: A mediation analysis. *Public Health Nutrition*; <u>https://doi</u>.org/10.1017/S1368980022001410
- Tooth LR, Moss KM & Mishra GD. (2022). Adherence to screen time guidelines among families in Australia with children of different ages. *JAMA Pediatrics*; <u>https://doi.org/10.1001/jamapediatrics.2021.6382</u>

Methodology

- Rahman M, Jagger C, Princehorn EM, Holliday EG, Leigh L, Loxton D, Beard J, Kowal P, & Byles JE. (2022). Onset and progression of chronic disease and disability in a large cohort of older Australian women. Maturitas; 158(1): 25-33. https://doi.org/10.1016/j.maturitas.2021.11.007
- Xu Z, Hockey R, McElwee P, Waller M & Dobson A. (2022). Accuracy of death certifications of diabetes, dementia, and cancer in Australia: a population-based cohort study. *BMC Public Health*; 22(1): 902. <u>https://doi.org/10.1186/s12889-022-13304-8</u>

Abuse

 Abdulbasit M. Seid, Gita D. Mishra, Annette J. Dobson. (2022). The association between childhood sexual abuse and historical intimate partner violence with body mass index and diabetes: Evidence from the Australian Longitudinal Study on Women's Health. *Preventive Medicine*; 161: 107134. <u>https://doi.org/10.1016/j.ypmed.2022.107134</u>

Environmental health

- Ahmed SM, Knibbs LD, Moss KM, Mouly TA, Yang IA & Mishra GD. (2022). Residential greenspace and early childhood development and academic performance: A longitudinal analysis of Australian children aged 4-12 years. Science of The Total Environment; 833: 155214. <u>https://doi.org/10.1016/j.scitotenv.2022.155214</u>
- Ahmed SM, Mishra GD, Moss KM, Mouly TA, Yang IA & Knibbs LD. (2022). Association between greenspace and health-related quality of life in children aged 0-12 years. *Environmental Research*, 214(1): 113759. <u>https://doi.org/10.1016/j.envres.2022.113759</u>

Formal and informal work patterns and work-family life balance

 Rowlands I, Hockey R, Abbott J, Montgomery G & Mishra G. (2022). Longitudinal changes in employment following a diagnosis of endometriosis: Findings from an Australian cohort study. *Annals of Epidemiology*; 69: 1-8. <u>https://doi.org/10.1016/j.annepidem.2021.10.005</u>

Medications

 Thiruchelvam K, Byles J, Hasan SS, Egan N & Kairuz T. (2022). Impact of medication reviews on potentially inappropriate medications and associated costs among older women in aged care. *Research in Social and Administrative Pharmacy*; <u>https://doi.org/10.1016/j.sapharm.2022.05.003</u>

Physical health

- White J, Hambisa M, Cavenagh D, Dolja-Gore X & Byles J. (2022). Understanding the relationship between eye disease and driving in very old Australian women: A longitudinal thematic evaluation. *BMC Ophthalmology*; 22:277. <u>https://doi.org/10.1186/s12886-022-02506-8</u>
- Hambisa MT, Dolja-Gore X & Byles J. (2022). Application of Anderson-Newman model to assess cataract surgery uptake among older Australian women: Findings from the Australian Longitudinal Study on Women's Health. *Aging Clinical and Experimental Research*, 34(7): 1673-1685. <u>https://doi.org/10.1007/s40520-022-02091-2</u>
- Wilson LF, Xu Z, Doust J, Mishra GD & Dobson AJ. (2022). Associations of socioeconomic and health factors with dental non-attendance: A comparison of three cohorts of women. *Community Dentistry and Oral Epidemiology*. <u>https://doi.org/10.1111/cdoe.12776</u>

9.2 Conference Presentations

Due to COVID-19, conference participation in 2022 has continued to be mainly online. Twenty-six presentations using ALSWH data have been recorded in our database since the last Technical Report.

Conference Presentations

- Baneshi MR, McElwee P & Dobson A. Exploring the association between causes of death listed in Part II of death certificates by comparison of the observed and expected frequency of pairs and triads of diseases: a Bayesian approach. 5th Meeting of the MultiCause Network, Bonn Germany, 19-20 May 2022
- Baneshi, MR, McElwee P & Dobson A. Exploring the underlying patterns among causes of death listed in Part II of death certificates using Social Network Analysis. 5th Meeting of the MultiCause Network, Bonn, Germany, 19-20 May 2022
- Byles J. **100** and not out: Health and healthy ageing for women approaching **100** years of age. *IAGG 2022: 22nd World Congress of Gerontology and Geriatrics*, Virtual, 12-16 June 2022
- Francis L & Stulz V. Finding a life without domestic violence: Analysing free text data from the ALSWH. Stop Domestic Violence Conference 2022, Gold Coast, QLD, 30 November - 2 December 2022
- Gete D. The role of child diets in the association between pre-pregnancy diets and childhood behavioral problems: A mediation analysis (poster presentation). *Nutrition 2022*, Online, 14-16 June 2022
- Hambisa M. Application of Andersen-Newman model to assess cataract surgery uptake among older Australian women: Findings from the Australian Longitudinal Study on Women's Health (ALSWH). Australian Society for Medical Research (ASMR) Hunter Region Annual Scientific Meeting, Newcastle, NSW, 6 June 2022
- Koller-Smith L. Estimating the prevalence of rheumatoid arthritis in Australia (poster presentation). Australian Rheumatology Conference ASM 2022, Perth, WA, 6-9 May 2022
- Kwok W. Falls and physical activity in older Australian women from two different generations. Safety 2022: 14th World Conference on Injury Prevention & Safety Promotion, Adelaide, SA, 27-30 November 2022

- Kwok W. Associations between different amounts and types of physical activity (PA) and injurious falls in older Australian women (poster presentation). *IAGG 2022: 22nd World Congress of Gerontology and Geriatrics*, Virtual, 12-16 June 2022
- Kwok W. Are there any differences in falls, physical activity (PA) and the associations between PA and falls in older women from two different generations? IAGG 2022: 22nd World Congress of Gerontology and Geriatrics, Virtual, 12-16 June 2022
- Kwok W. Understanding physical activity and falls in Australian women. *NSW Fall Prevention and Healthy Ageing Network Annual Forum*, Sydney, NSW, 27-May 2022
- Lithgow S. The terminology of abuse among older Australian women from the Australian Longitudinal Study on Women's Health. National Elder Abuse Conference, Hobart, TAS, 14-15 February 2022
- McElwee P, Baneshi MR, Nguyen K-H & Dobson A. A new data driven weighting method for Multiple Cause of Death analysis. 5th Meeting of the MultiCause network, Bonn, Germany, 19-20 May 2022
- McElwee P, Baneshi MR, Nguyen K-H & Dobson A. Development of an Australian categorisation for Multiple Cause of Death analysis. 5th Meeting of the MultiCause Network, Bonn, Germany, 19-20 May 2022
- Mena G. The role of physical activity in fertility. FACTS Conference 2022 For the Future of Women's Health, Virtual, 23 July 2022
- Mielke G. Magic mirror on the wall who is the most inactive of them all? 9th International Society for Physical Activity and Health (ISPAH) Congress, Abu Dhabi, 23-26 October 2022
- Mielke G. Physical activity during pregnancy: guidelines, patterns and interventions. 9th International Society for Physical Activity and Health (ISPAH) Congress, Abu Dhabi, 23-26 October 2022
- Moss K. What is the best fertility treatment for women with endometriosis IUI or IVF? Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) Annual Scientific Meeting 2022, Gold Coast, QLD, 10-12 October 2022

- Moss K. Making a difference after natural disasters reducing the influence of prenatal flood-related stress on pregnancy and childhood outcomes. 2022 SOMANZ Annual Scientific Meeting, Hobart, TAS, 14-16 October 2022
- Pan K, Charlton BM, Chavarro JE, Gunderson EP, Hart J, Jukic AM, Ley S, Mishra GD, Mumford SL, Shaffer JG, Wise LA & Harville EW. Preconception cannabis use and gestational diabetes (GDM): The PrePARED consortium. 35th Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research (SPER), Chicago, USA, 13-14 June 2022
- Pan K, Charlton BM, Chavarro JE, Gunderson EP, Hart J, Jukic AM, Ley S, Mishra GD, Mumford SL, Shaffer JG, Wise LA & Harville EW. Preconception cannabis use, gestational hypertension, and pre-eclampsia: The PrePARED consortium. 35th Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research (SPER), Chicago, USA, 13-14 June 2022
- Paudel S. Does the prevalence of overweight/obesity, physical activity and sitting time differ by CALD background? A secondary analysis of the Australian Longitudinal Study on Women's Health. International Congress on Obesity (ICO) 2022, Melbourne, VIC, 18-22 October 2022
- Tooth L. Delayed health care access during the pandemic. *Queensland Women's Health Forum*, Toowoomba, QLD, 12-13 September 2022.
- Tooth L, Moss K, Hockey R, Mishra G. Are screen time guidelines actually working for Australian families? *Population Health Congress*, Adelaide, SA, 21-23 September 2022
- William J & Parkinson B. The lifetime health system costs of women who experience domestic violence. *Australian Gender Economics Workshop 2022*, Virtual, 10-11 February 2022
- Xu Z, McElwee P, Hockey R & Dobson A. Accuracy of death certifications of diabetes, dementia, and cancer in Australia. 5th Meeting of the MultiCause Network, Bonn, Germany, 19-20 May 2022.

9.3 Media

Media monitoring is carried out for the Study by The University of Queensland and the Hunter Medical Research Institute (in collaboration with the University of Newcastle), using the Meltwater media monitoring system. In addition to Study media that mentions the host universities, this system picks up media generated by collaborating researchers at other universities, or independently by journalists and bloggers. From 1 October 2021 to 31October 2022, there were 948 mentions of the Study and major

projects using Study data in news media, encompassing 37 topics and across 45 countries. Details of some major media items are shown in Table 9-2.

9.4 Social media

During the year, details of Study outcomes and activities have been posted on the Study's social media accounts on Facebook, Twitter, Instagram and LinkedIn. Content is repurposed and reformatted so that it can be efficiently shared across multiple social media platforms where appropriate.

Facebook: Content posted to Facebook continues to be aimed at a lay audience - particularly participants. The Facebook page is used to post reminders about open surveys and substudies and to inform participants of research outcomes. The Study's <u>Facebook</u> has around 9,711 followers. Roughly 97% of the audience is female. Over 80% are likely to be participants from the 1989-95 cohort, less than 10% from the 1973-78 cohort, and 2% from the 1946-51 cohort. Posts made to the Facebook page reach between 200 and 1,400 followers.

Twitter: The <u>Twitter account</u> 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 1,829 followers and its Tweets receive between 2,500 to 5000 impressions each month.

Instagram: 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 430 followers and posts receive between 90 and 150 impressions.

LinkedIn: The <u>ALSWH LinkedIn page</u> was started in 2020 with the aim of providing professionals in policy, advocacy, and research with updates on ALSWH research outcomes and impact. The Study's LinkedIn following has grown to over 200 followers.

Date	Торіс	Collaborator and Institute	Highlights
August-Sept 2022	ANROWS report – A life course approach to determining the prevalence and impact of sexual violence in Australia	Australia's National Research Organisation for Women's Safety (ANROWS) Natalie Townsend, Deborah Loxton, Nicholas Egan, Isabelle Barnes, Emily Byrnes & Peta Forder, University of Newcastle	 National print, radio, and digital coverage including: <u>The Australian</u> <u>The Conversation</u> <u>Junkee</u> <u>The Guardian</u> <u>Women's Agenda</u> <u>Australian Women's Health</u>
Jun – Aug 2022	Psychological toll lasts long after fertility issues resolved.	Dr Tanmay Bagade, Hunter Medical Research Institute	<u>8 media placements</u>
Jul 2022	Menopause weight loss	NA	Syndicated on <u>MSN</u> <u>https://www.msn.com/en-ie/health/fitness/menopause-weight-loss-</u> <u>diet-changes-to-help-beat-menopausal-weight-gain/ar-AAZYvy3</u>
Jul 2022	Recurrent miscarriage increases the risk of stroke	Prof Gita Mishra, The University of Queensland	75+ media mentions including <u>ABC TV</u> , ABC radio interviews, and digital news stories in mainstream media and <u>The Conversation</u> .

Table 9-2 ALSWH media highlights from December 2021 – November 2022

Date	Торіс	Collaborator and Institute	Highlights
		(ALSWH data used in the InterLACE collaboration)	
Jun 2022	Young women's psychological distress increases when they change their identity away from the heterosexual norm	Dr Alice Campbell, The University of Queensland	19 mentions stemming from an interview with <u>PsyPost</u> .
May - Jun 2022	Migrant women needed to join ALSWH	Prof Gita Mishra, The University of Queensland	Featured on local radio, digital news sites as well as translated coverage on <u>SBS news websites</u> and podcasts.
		Prof Deborah Loxton, University of Newcastle	
Mar 2022	Endometriosis can end women's careers	Dr Ingrid Rowlands, The University of Queensland Prof Gita Mishra, The University of Queensland	Article from <u>The Conversation</u> republished 17 times. <u>https://theconversation.com/endometriosis-can-end-womens-careers-and-stall-their-education-thats-everyones-business-179846</u>

Date	Торіс	Collaborator and Institute	Highlights
		Prof Jason Abbot, University of New South Wales	
Mar 2022	Managing screen time is harder in families with multiple children	A/Prof Leigh Tooth, The University of Queensland	
Jan 2022	Prof Julie Byles awarded an Order of Australia	Professor Julie Byles, University of Newcastle	Prof Byles award and her achievements, including the Study, were mentioned 47 times on <u>radio and digital media</u> , mostly in the Newcastle region.
Dec 2021	Irregular periods may signal a heart disease and diabetes risk	Sylvia Kiconco, Monash University	An Australian exclusive in <u>The Australian</u> , and international pickup on health and wellness and diabetes related <u>websites</u> . <u>https://www.healio.com/news/endocrinology/20211215/irregular-</u> <u>menses-may-signal-heart-disease-diabetes-risk</u>

9.5 Website

The ALSWH website (<u>www.alswh.org.au</u>) continues to be an important portal for communication of ALSWH activities to the wider community. The website is the main gateway for information about ALSWH data, data applications, and also provides updates on Study news, events, publications and similar items. During the 2021-22 year the website team have focused on improving access to information and the user experience for collaborating researchers with updates to the Data User Portal and For Data Users sections of the site.

9.6 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 ALSWH participant newsletter (2021 year in review) was distributed in August 2022. 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 <u>here</u>.

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 is sent to a list of over 670 subscribers, at least 3 times per year and 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 is sent as relevant information becomes available. It includes:

- details of recent data releases including ALSWH surveys and linked data
- details of current and forthcoming surveys
- updates on recent publications, presentations and seminars and upcoming conferences

Since November 2021, the Data Updates newsletter has been distributed once, in December 2021, and the Study News newsletter twice, in December 2021 and June 2022.

10 Collaborative Research Activities

10.1 Scientific meetings and teleconferences among the research team

10.1.1 Management Committee

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 2022, SMC meetings have been conducted as videoconferences (Zoom)

10.1.2 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 Survey 10 of the 1946-51 cohort and has provided advice on preparation of the 'Common conditions from multiple sources (CCMS)' datasets. The DMG meets monthly by teleconference or videoconference and is chaired by David Fitzgerald (Data Manager – The University of Queensland) and Ryan Tuckerman (Database Manager - The University of Newcastle). Members in 2022 have included:

- David Fitzgerald
- Anna Graves
- Ryan Tuckerman
- Professor Gita Mishra
- Professor Julie Byles
- Professor Deborah Loxton
- Associate Professor Leigh Tooth

- Richard Hockey
- Dominic Cavenagh
- Professor Annette Dobson
- Peta Forder
- Dr Michael Waller
- Colleen Loos
- Nick Egan

10.1.3 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 2022 have included:

- Associate Professor Leigh Tooth
- Professor Gita Mishra
- Professor Julie Byles
- Professor Wendy Brown
- Professor Annette Dobson

- Professor Deborah Loxton
- Peta Forder
- Dr Amy Anderson
- Dr Michael Waller
- Dr Katrina Moss

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

10.2 Research projects

10.2.1 Full ALSWH datasets

ALSWH data has now been provided to collaborators for use in over 1,100 research projects. Fortythree new or amended projects have been approved since the last Technical Report (November 2021). Fifty 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 2022 are included in Appendixes A, B and C. Topics under investigation include:

- Chronic conditions such as musculoskeletal problems, cardiovascular conditions, 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
- Abuse
- Environmental health
- Physical health
- Child health and development

10.2.2 Core dataset

To facilitate streamlined access to ALSWH data, confidentialised subsets of the full datasets for each ALSWH cohort are available through the Australian Data Archive. These datasets are designed to be used:

- for simple, descriptive analyses
- for simple longitudinal investigations

- as a first step to using and becoming familiar with the full datasets
- to test the potential of research questions.

The 'core' datasets include total scale scores, with a reduced number of single survey items; sensitive variables have been omitted; and in some cases, response categories have been collapsed. Seven applications to use the 'core' datasets have been approved in 2022 (Table 10-1).

Project Title	Project Leader	Institution/Organisation
The role of stress in the relationship between premenstrual tension and postpartum depression	Sophia Bracken	The University of Newcastle
The economic cost of violence, abuse, neglect and exploitation for people with disability	Dennis McCarthy	The Centre for International Economics
The harms and benefits of sun exposure: striking the right balance	Namal Nishantha Balasooriya Mudiyanselage	The University of Queensland
The influencing factors of premenstrual tension and its influence on other mental disorders	Lulu Hou	Shanghai Normal University
Pregnancy intentions and subsequent fertility and contraceptive behaviors among australian women	Otobo Ujah	University of South Florida
Partnering patterns associated with polycystic ovary syndrome (PCOS) in Australian women	Yoobin Park	University of Toronto
Adverse childhood experiences and the risk of pregnancy complications and adverse pregnancy outcomes	Tuhin Biswas	The University of Queensland

Table 10-1 Approved applications to use the ALSWH core datasets (accessed through the Australian Data Archive)

10.2.3 Substudies

During 2022, data collection (to date) has been conducted for:

• Genetic variants, Early Life exposures, and Longitudinal Endometriosis symptoms Study (GELLES) (Eol W105) which is investigating endometriosis

HRECs 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 GELLES study involves collection of biosamples, collected by post.

Reports on all substudies currently collecting data, as well as research being conducted using data from other substudies, are included in Appendix B.

10.2.4 Student projects

76 postgraduate students are currently working on aspects of their projects, 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.

11 Project staff

Australian Women and Girls' Health Research Centre The University of Queensland		
Director ALSWH	Professor Gita Mishra	
Deputy Director ALSWH	A/Professor Leigh Tooth	
Research Fellow (s)	Professor Annette Dobson Dr Katrina Moss	
Statisticians	Richard Hockey Dr Reza Baneshi	
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	

Centre for Women's Health Research The University of Newcastle		
Director ALSWH*	Professor Julie Byles/Professor Deborah Loxton	
Research Program Manager	Natalie Townsend	
Senior Research Officer	Amy Anderson	
Manager, Statistics and Data/ Senior Statistician	Peta Forder	
Statistics Team	Dominic Cavenagh	
	Nick Egan	
Research Officers	Isabelle Barnes	
	Emma Byrnes	
Operations Manager	Anna Graves (ret. March 2022)	
Database manager	Ryan Tuckerman	
Administration Officers	Clare Thomson (Ethics)	
	Katherine Tuckerman	
	Kacey Johnston	
Project Assistants	Cathy Seberry	
	Alyse Berrigan	
	Belinda Jackson	
	Brianna Barclay	
	Megan Son Hing	
	Sarah Morris	
	Ursula Horton	

*Professor Julie Byles retired in June 2022. Professor Deborah Loxton is now ALSWH Director at the University of Newcastle.

12 Appendices: Progress reports for current and completed projects

Please see separate document for Appendixes A, B and C.

www.alswh.org.au



November 2022