



Australian Longitudinal Study
on Women's Health

Technical Report #46

November 2023

ISSN 2653-3235



TABLE OF CONTENTS

1	EXECUTIVE SUMMARY	1
2	INTRODUCTION.....	5
3	DATA COLLECTION PROCEDURES AND MATERIALS	7
3.1	1946-51 cohort.....	7
3.1.1	Main Survey 10	7
3.2	1989-95 cohort.....	7
3.2.1	Pilot cohort – Survey 7	8
3.2.2	Main cohort – Survey 7	24
3.3	1921-26 cohort.....	24
3.3.1	Six-Month Follow-Up Surveys	24
3.4	‘Refresh’ of the 1973-78 and 1989-95 cohorts with women from Asian backgrounds	28
3.4.1	Background	28
3.4.2	Changes to study design	28
3.4.3	Recruitment activities undertaken for the refresh of the 1973-78 and 1989-95 cohorts	53
3.4.4	1973-78 and 1989-95 cohort refresh progress update	54
3.4.5	Future plans.....	54
3.4.6	References.....	54
4	MAINTENANCE OF COHORTS	55
4.1	Survey participation over time	55
4.1.1	First survey of the 1973-78, 1946-51 and 1921-26 cohorts in 1996.	55
4.1.2	1921-26 cohort.....	55
4.1.3	1946-51 cohort.....	59
4.1.4	1973-78 cohort.....	59
4.1.5	1989-95 cohort.....	60
4.2	Maintenance strategies	61
4.3	References.....	61
5	DATA LINKAGE	63
5.1	ALSWH linked data holdings.....	63
5.1.1	National collections	63
5.1.2	State and Territory collections	66

5.1.3	Common Conditions from Multiple Sources (CCMS).....	68
5.1.4	Substudies, and the 1973-78 Cohort and 1989-95 Cohort Refresh.....	69
5.2	Data access procedures	70
5.2.1	Data user approvals.....	70
5.2.2	Access options.....	70
5.2.3	Data access conditions	71
5.3	Use of linked data	73
5.4	Legal and ethical considerations for health record linkage.....	73
5.4.1	Applicable legislation and guidelines.....	73
5.4.2	Consent status of ALSWH participants	74
5.4.3	Communicating with ALSWH participants about health record linkage	76
5.4.4	Current HREC approvals for health record linkage.....	76
6	ARCHIVING	78
7	METHODOLOGICAL ISSUES	79
7.1	Aged Care Data Notes for Researchers	79
7.1.1	Introduction	79
7.1.2	Brief summary of linked aged care datasets	79
7.1.3	Measuring at-home care in a longitudinally consistent way	82
7.1.4	Health conditions from Aged Care Assessments	85
7.1.5	Admissions to residential aged care	87
7.2	Summary of recently introduced scale instruments.....	88
7.2.1	Brief Resilience Scale.....	88
7.2.2	Social Wellbeing Scale	90
7.3	Key Longitudinal Variable Datasets	94
7.3.1	Overview	94
7.3.2	Issues to note with the KLV datasets	94
8	2023 MAJOR REPORT: COVID-19 AND ITS IMPACT ON HEALTH CARE USE .	102
8.1	Women’s health and access to health services during the COVID-19 pandemic in 2020: Results of the mini-surveys	102
8.2	Comparing women’s health service use before and during the COVID-19 pandemic	102
8.3	Changes in GP and specialist service use before and during the COVID-19 pandemic for women with common conditions and multimorbidity.....	103

8.4	Telehealth service use during the COVID-19 pandemic	103
8.5	Women’s experiences accessing health care during the COVID-19 pandemic in 2020-21 in their own words.....	104
8.6	Implications and recommendations	105
9	DISSEMINATION OF STUDY FINDINGS	106
9.1	Publications.....	106
9.2	Conference Presentations	109
9.3	Media	112
9.4	Social media.....	115
9.5	Website	115
9.6	Newsletters.....	116
10	COLLABORATIVE RESEARCH ACTIVITIES	117
10.1	Scientific meetings and teleconferences among the research team	117
10.1.1	Management Committee	117
10.1.2	Data Management Committee.....	117
10.1.3	Data Access Committee	118
10.2	Research projects.....	119
10.2.1	Full ALSWH datasets	119
10.2.2	Core dataset	119
10.2.3	Substudies.....	123
10.2.4	Student projects.....	123
11	PROJECT STAFF.....	124
12	DATA LINKAGE APPENDIX	126
13	APPENDICES: PROGRESS REPORTS FOR CURRENT AND COMPLETED PROJECTS	131

1 EXECUTIVE SUMMARY

This draft technical report covers the period from December 2022 to November 2023. 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 2022 – November 2023 contained in the relevant contracts with the Department of Health and Aged Care (DOHAC).

Conduct of surveys

During this period, surveys have been conducted as follows:

- **1989-95 cohort:** The pilot of Survey 7 was deployed to 412 women in July 2023, and by the end of August had been completed by 162 women, and partially completed by 12 women. The main survey of the cohort is expected to be sent out in the next couple of months.
- **1973-78 cohort:** Data collection for Main Survey 9, deployed in June 2021, closed in November 2022. 11,306 women were invited to participate, and of these 6,857 women returned surveys with valid data.
- **1946-51 cohort:** Main Survey 10 was deployed to 10,021 women in June 2022, when the women were aged 71 to 76 years. The survey closed on 31 August 2023, with surveys completed by 7,100 women, and partially completed by 63 women.
- **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. Currently, most women still participating in this cohort are completing 6MF Surveys 23 and 24. By August, 100 women had been sent 6MF Survey 23, and 47 had been sent 6MF Survey 24.

- Recruitment continued for the 'refresh' of the 1989-95 and 1973-78 cohorts with women from North-Eastern, South-Eastern and Southern Asian backgrounds. Due to low responses to initial recruitment strategies, revisions were undertaken (explained in detail in Section [3.4](#)) and a shortened introductory survey (Cohort Refresh Survey 1) was introduced in May 2023. By August 2023, 115 women across both cohorts had completed Cohort Refresh Survey 1 – 18 of these were from the target backgrounds. Recruitment for this 'refresh' will now continue into 2024.

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 28–34) and women born 1973-78 (now aged 45-50), and over 75% for the women born 1946-51 (now aged 72-77). 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 97-102 years, there are less than 500 women still participating, with approximately 150 returning six-monthly surveys in 2022.

Since November 2022, we have continued our recruitment of 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) to the 1973-78 cohort, and also began recruitment to the 1989-95 cohort. This initiative is being conducted to improve each cohort's representativeness of the general population.

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 280 projects are currently approved to use the linked data. We have also continued to maintain the ALSWH Common Conditions from Multiple Sources (CCMS) datasets, which contain indicator variables for 9 common chronic conditions (cancer, dementia, diabetes, ischaemic heart disease, depression/anxiety, eating disorders, 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 114 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 2023, recent data from Survey 10 of the 1946-51 cohort and 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 2023 including:

- how to use the various Aged Care datasets linked with ALSWH survey data
- documentation of recently introduced instruments and scales
- descriptions of key longitudinal variables

Major report 2022

The 2023 Major Report examined women's use of health services during the COVID-19 pandemic. A summary is included here in Section 8 – the full report is available on [the Study website](#).

Dissemination of study findings

Since November 2022, 26 papers have been published in national and international scientific journals, and 17 presentations have been made to scientific and professional audiences both in Australia and internationally. 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 2022, data access has been approved for 44 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
- Violence

29 postgraduate students are currently working on aspects of the project. Progress summaries of all collaborative research projects are provided in Appendixes 13 A, B and C.

Staff

ALSWH staff are located at the University of Newcastle and the University of Queensland. During 2023 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 DOHAC.

2 INTRODUCTION

The Australian Longitudinal Study on Women's Health (ALSWH) is a longitudinal population-based survey funded by the Australian Government (DOHAC) (previously the Department of Health and hereafter referred to as the DOHAC). 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 28 to 34. Survey 7 of this cohort will commence shortly.
- **The 1973-78 cohort:** aged 18 to 23 when first recruited in 1996 (N = 14,247) and aged 45 to 50 in 2023. Survey 9 of this cohort was completed in 2023, with 6,857 women participating.
- **The 1946-51 cohort:** aged 45 to 50 years in 1996 (N = 13,716) and now aged 72 to 77 years. Survey 10 closed in August 2023, and was completed by 7,157 women.
- **The 1921-26 cohort:** aged 70 to 75 years in 1996 (N = 12,432). Surviving women in this cohort are now aged 97 to 102 and are surveyed every six months (with an abbreviated questionnaire). The twenty-fourth abbreviated questionnaire was sent in May 2023, and by 31 August, had been returned by 83 women.

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 and quality of life, 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 27 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 draft technical report (#46) has been provided by the University of Queensland and the University of Newcastle as agreed in contracts between the DOHAC 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 DOHAC:

- 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 2023 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.

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

- For the 1989-95 cohort, Pilot Survey 7 was conducted. In the 1973-78 cohort, data from Survey 9 was archived, and in the 1946-51 cohort, data collection for Survey 10 closed. The twenty-third wave of the six-monthly follow-up surveys of the 1921-26 cohort continued and the twenty-fourth wave commenced in May. Recruitment also continued for the 'refresh' of the 1989-95 and 1973-78 cohorts with women from North-Eastern, South-Eastern and Southern Asian backgrounds.
- A total of 44 new or amended research projects were given approval to use ALSWH data. Results from previously approved projects have been published in 26 peer reviewed scientific journal articles and used in 17 conference presentations. Projects include analyses that:
 - clarify the cause and effect relationship between women's health and a range of biological, psychological, social and lifestyle factors;
 - assess the effects of changes in policy and practice;
 - explore the factors that influence health among women who are broadly representative of the entire Australian population;
 - investigate all aspects of health throughout women's lifespan and;
 - provide an evidence base of the development and evaluation of health policy, other relevant policies and practice.
- An Annual Report for 2022 and a Major Report (examining use of health services during the COVID-19 pandemic) were prepared for the DOHAC.
- 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 registries data, perinatal data and emergency services data.

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

3 Data collection procedures and materials

3.1 1946-51 cohort

3.1.1 Main Survey 10

Survey 10 of the 1946-51 cohort began in June 2022, when the women were aged 71-76 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 [Technical Report \(Report 45\)](#).

Table 1-1 details the response rates for the main survey. Completed surveys (online, paper or telephone) were received from 7,100 women, which was 73% of those invited; while another 57 (1%) had partially completed their survey online. Of the women who did not respond to the survey after invitation (n=1,863), 334 women (18%) are currently in tracking and 116 women (6%) are deemed lost to follow-up.

Table 3-1 Response rates for Main Survey 10 for the 1946-51 cohort, at 31st October 2023 (N = 9,764)

	Main Survey	
	N	%
Completed online survey	3,967	41.0
Completed paper survey	3,127	32.3
Completed phone survey	6	0.1
Partially completed online survey	57	0.6
Deceased	111	1.1
Withdrawn	392	4.1
Not this time	178	1.8
No response	1,836	19.0
Total	9,674	100.0

Data collection for this survey was closed on 31st August 2023.

3.2 1989-95 cohort

In 2023, the 1989-95 pilot and main cohort were due for their seventh ALSWH survey. This survey wave also includes survey items and materials that relate to the Mothers and their Children's Healthcare Experiences Study (MatCHES) – an ALSWH substudy collecting data from this cohort of women. In the first half of 2022, the MatCHES pilot survey was developed using findings from focus groups. To reduce

participant burden, it was decided that the MatCHES main survey would be presented as an optional secondary component of the 1989-95 main Survey 7. Participants from the 1989-95 main cohort are eligible to complete the MatCHES survey if they have completed the 1989-95 main Survey 7 and if they have a child/ren born after 31/12/2014 who lives with them at least part of the time. For more information on MatCHES, see <https://alswh.org.au/matches/>.

3.2.1 Pilot cohort – Survey 7

Development of survey materials

Several changes were made from the previous survey (Survey 6, deployed in 2019) for the pilot cohort Survey 7 of the 1989-95 cohort. For details about changes to existing survey items and the addition of new survey items from Main Survey 6 to Pilot Survey 7, please refer to Table 3-2. For details about the deleted items from Main Survey 6 to Pilot Survey 7 for the 1989-95 cohort, please refer to Table 3-3.

Table 3-2 Changes to existing items and additions of new items from Main Survey 6 to Pilot Survey 7 for the 1989-95 Pilot Cohort

Item No.	Topic	Source	Item change justification	New item justification
1	General Health (SF-1)	Ware, J. E., & Sherbourne, C. D. (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.		
2-3	Mental illness diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	The timeframe was updated from the last 2 years to the last 4 years to match the timeframe since the last survey.	
4-5	Physical illness diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	The timeframe was updated from the last 2 years to the last 4 years to match the timeframe since the last survey. The following response options were deleted and moved into a new item (Q6): endometriosis, polycystic ovary syndrome, chronic bladder pain	
6-7	Reproductive Health diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		The reproductive health diagnoses were removed from the previous question and two new items were added to ensure reproductive health issues were captured separate to physical illness diagnoses.
8-9	Sexually transmitted infection diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	The timeframe was updated from the last 2 years to the last 4 years to match the timeframe since the last survey.	

Item No.	Topic	Source	Item change justification	New item justification
10	Symptoms	ALSWH Symptoms Set		
11	Disability	Modified from Australian Bureau of Statistics (1993) Disability, Aging and Carers Australia. Canberra: ABS. Cat. No. 4432.0		
12	Screening	Modified from the Australian Bureau of Statistics (1991) 1989-1990 National Health Survey users' guide: Canberra: ABS Cat No. 4363.0	The wording was updated to align with the current screening options (self-collected and clinician collected samples not available).	
13	Abnormal cancer screening result	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	The timeframe was updated from the last 2 years to the last 4 years to match the timeframe since the last survey.	
14-18	Health service use	Modified from Davies, A.R., & Ware, J.E.J. (1991). GHAA's consumer satisfaction survey and user's manual (2nd Edn). Washington DC: The Group Health Association of America (GHAA).	The timeframe was updated from the last 12 months to the last 4 years in Q15 to match the timeframe since the last survey. Response options were reduced to assist with participant burden.	Q14 was added to capture data on where women source health information.
19-23	COVID-19	ALSWH		Q19-23 were added to capture women's experiences of COVID-19, vaccinations, and long COVID-19 symptoms.
24	Living arrangements	ALSWH	The response options were updated to be inclusive of gender diversity and allow for the range of living arrangements to be captured.	

Item No.	Topic	Source	Item change justification	New item justification
25-26	Partner level of education/ occupation	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		These questions were added to capture information on partner's qualifications and occupations.
27	Contraception	ALSWH		
28	Contraception Non-use	Modified from Contraceptive Use, Pregnancy Intention & Decision of Australian Women (CUPID) surveys		
29-53	Pregnancy	ALSWH	<p>Wording has been updated to ensure sensitivity regarding live births and stillbirths (now referred to as 'births'). Children's names to be piped into survey rather than 'child 1' being shown will help to reduce confusion for participants completing the survey.</p> <p>"Hyperemesis Gravidarum" has been added as a response option for Q53 as this is a common condition women can experience during pregnancy.</p>	<p>Q32 was added to capture information on unplanned pregnancy.</p> <p>Q40 was added to capture information on multiple births to ensure order or births and linkage of children's health information is accurate.</p> <p>Q41 was added to assist with piping children's names into survey questions. This will help to reduce confusion for participants completing the survey.</p> <p>Q42 was added to capture information on children's sex recorded at birth.</p>

Item No.	Topic	Source	Item change justification	New item justification
				Q47 was added to capture information on whether children are alive or deceased. This will assist with skipping questions where appropriate. Support services were also added for those who have had a child who is now deceased.
54-55	Maternity Leave	Modified from the Longitudinal Study of Australians Children (LSAC) 2005 Infant questionnaire.		
56	Child/ren	ALSWH		Added to capture whether child/ren live/s with the participant, to determine eligibility for Part 2 (MatCHES questions).
57	Partner	ALSWH		Added to assist with skip logic.
58	Partner's relationship to child/ren	ALSWH		Added to capture partner's relationship to child/ren for Part 2 (MatCHES questions).
59	Infertility	ALSWH		

Item No.	Topic	Source	Item change justification	New item justification
60	Pelvic Organ Prolapse diagnosed/ treated	ALSWH		This item was added to capture information on pelvic organ prolapse, as this is a common occurrence in this age group.
61	Pelvic symptoms	M.D. Barber, M.D. Walters, R.C. Bump. 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). https://doi.org/10.1016/j.ajog.2004.12.025 .		This item was added to capture information on pelvic symptoms which are common in this age group.
62	Health Care Card	ALSWH		
63-64	Private Health Insurance	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		
65-71	Smoking	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.		Q68-71 were added to capture information on vaping / electronic cigarette use, as the use of these products is increasing in this age group.
72	Marijuana	Modified from National Drug Strategy household survey: survey report 1995 (1996).		

Item No.	Topic	Source	Item change justification	New item justification
73	Illicit drug use	National Drug Strategy household survey: survey report 1995 (1996).		
74-77	Alcohol	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. ALSWH	The response options for Q74-75 were updated as NHMRC officially changed their alcohol guidelines. To compare with the new guideline recommendations, the quantity and frequency items needed to be split. The new items are still backwards compatible as they will be able to be recombined to compare to previous surveys.	
78-79	Physical activity	Active Australia Armstrong, T, Bauman A, Davies J. Physical activity patterns of Australian Adults: results of the 1999 National Physical Activity Survey. AIHW Canberra 2000		
80	Sitting	ALSWH		
81	Life events	ALSWH		
82	Ever had a partner/spouse	ALSWH		
83-85	Partner abuse	Modified from Hegarty KL, Sheehan M, Schonfeld C. (1999) A multidimensional definition of partner abuse: development and preliminary validation of the Composite Abuse Scale. J Fam Violence, 14, 399-414.	The response options were simplified to assist with skip logic.	Q84 was added to capture more information on when partner abuse occurred. This information is needed to assist with baseline and evaluation data for the Department of Social Services' National Plan.

Item No.	Topic	Source	Item change justification	New item justification
				Q85 was added to capture information on reproductive coercion.
86-87	Violent relationship	Hwalek, M.A., & Sengstock, M.C. (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.		Q87 was added to capture information on when participants were in a violent relationship. This information is needed to assist with baseline and evaluation data for the Department of Social Services' National Plan.
88-89	Year of start of violence	ALSWH		Q88-89 were added to capture information on when participants first experienced violence within the relationship, and also unwanted sexual activity. This information is needed to assist with baseline and evaluation data for the Department of Social Services' National Plan.
90-95	Childhood trauma	Modified from the Female Family Health History Questionnaire in the Adverse Childhood Experiences Study.		

Item No.	Topic	Source	Item change justification	New item justification
96	Life isn't worth living/Self-harm	Modified from Beck A, Schuyler D & Herman, I. (1974) Development of the Suicide Intent Scale. In AT Beck, HLP Resnick, & DJ Lettieri (Eds.) The prediction of suicide. Bowie, MD: Charles Press Publishers		
97	Depression (K-10)	Kessler, R.C., et al. (2003). Screening for serious mental illness in the general population. Archives of General Psychiatry, 60(2), 184-189.		
98	Depression and anxiety	Depression Anxiety Stress Scales (DASS) https://www.psytoolkit.org/survey-library/depression-anxiety-stress-dass.html		
99	Stress	ALSWH		
100	Self-esteem	Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press. https://socy.umd.edu/quick-links/using-rosenberg-self-esteem-scale		
101	Life orientation	Revised and reduced Revised Life Orientation Test (LOT-R) Scheier M.F., Carver, C.S., Bridges, M.W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self esteem): a reevaluation of the life orientation test. Journal of Personality and Social Psychology, 67, 1063-1078.		

Item No.	Topic	Source	Item change justification	New item justification
102	Weight	ALSWH		
103-104	Body image	Modified from French, SA, Story, M, Downes, B, Resnick, MD, Blum, RW (1995). Frequent dieting among adolescents: psychosocial and health behaviour correlates. American Journal of Public Health, 85(5): 695-701.		
105	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. Asia Pacific J Clin Nutr 1994; 3: 19-31.		
106	Vegetables	ALSWH		
107	Social support	Sherbourne, C.D., & Stewart, A.L. (1991). The MOS social support survey. Social Science and Medicine, 32(6), 705-714.		
108-109	Parents place of birth	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/		Q108-109 were added to capture information on parents' country of birth. This information will assist in determining the representativeness of the cohort.
110	Education	Modified from ABS (1993) 1996 Census of population and housing: Nature and content		

Item No.	Topic	Source	Item change justification	New item justification
		of the census. Canberra: ABS. Cat No. 2008.0.		
111-112	Employment	ALSWH		
113-115	Time use	Modified from Australian Bureau of Statistics (1993) Time use survey, Australia, 1992: user's guide. Canberra: ABS. Cat No. 4150.0.		
116	Manage on income	ALSWH		
117-118	Menstrual product affordability	Cardoso, L.F., Scolese, A.M., Hamidaddin, A. et al. Period poverty and mental health implications among college-aged women in the United States. BMC Women's Health 21, 14 (2021). https://doi.org/10.1186/s12905-020-01149-5		These questions were added at the request of the Department of Health and Aged Care, as they need data on period poverty.
119	Sexual orientation	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		This item was added based on feedback from participants that requested sexual orientation be captured.
120	Relationship status	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		This item was added to align with the measure used in the 1973-78 cohort.
121	Housing	ALSWH	A free text 'other' option was added to allow participants to describe more diverse housing options.	
122	Residential postcode	ALSWH		

Item No.	Topic	Source	Item change justification	New item justification
123	Postal postcode	ALSWH		
124	Occupation	Modified from Australian standard classification of occupations. Second Edition. (1997). Catalogue No. 1220.0		
125	Days at work	ALSWH		
126	Hours at work	ALSWH		
127	Proxy	ALSWH		
128	Reason for needing help	ALSWH		
129	Missed anything	ALSWH		

Table 3-3 Items from Survey 6 of the 1989-95 cohort deleted for Pilot Cohort Survey 7

Survey 6 Main Item Number	Topic	Source	Justification of deletion
2	Mental illness diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	This item was deleted and replaced with Q2-3 to assist with participant burden.
5	Physical illness diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	This item was deleted and replaced with Q4-5 to assist with participant burden.
66	Sexually active	ALSWH	This item was deleted as the majority of participants in this age group are now sexually active.
67	Ever had sex	ALSWH	This item was deleted as the majority of participants in this age group are now sexually active.
68	Contraception	ALSWH	This item was deleted as this information does not need to be captured at each survey.
70	Pregnancy	ALSWH	This item was deleted as this information does not need to be captured at each survey.
194	Extended Leave	ALSWH	This item was deleted as this information does not need to be captured at each survey.
208	Drink spiking	Alcohol Consumption Questionnaire http://www.createsurvey.com/c/16319-m1j2BI/	This item was deleted as this information does not need to be captured at each survey.

Survey 6 Main Item Number	Topic	Source	Justification of deletion
214-218	Stairs	Modified from Sesso, H.D., Paffenbarger, R.S., & Lee, I.-M. (2000). Physical Activity and Coronary Heart Disease in Men: The Harvard Alumni Health Study. <i>Circulation</i> , 102(9), 975-980.	This item was deleted as this information does not need to be captured at each survey.
244-245	Partner abuse	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.	This item was deleted and replaced with Q84 to capture more detailed information.
253-256	Happiness	Lyubomirsky, S., & Lepper, H. (1999). A measure of subjective happiness: Preliminary reliability and construct validation. <i>Social Indicators Research</i> , 46, 137-155. The original publication is available at www.springerlink.com .	This item was deleted as this information does not need to be captured at each survey.
319	Dieting	Modified from French, SA, Story, M, Downes, B, Resnick, MD, Blum, RW (1995). Frequent dieting among adolescents: psychosocial and health behaviour correlates. <i>American Journal of Public Health</i> , 85(5): 695-701.	This item was deleted as this information does not need to be captured at each survey.
350	Relationship status	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.	This item was deleted and replaced with Q120 to align with the measure used in the 1973-78 cohort.
355	Work	ALSWH	This item was deleted as this information does not need to be captured at each survey.

Approvals

A variation to the existing ethics protocols for the 1989-95 cohort was submitted and approved by the University of Newcastle Human Research Ethics Committee (HREC). This approval was ratified by the University of Queensland HREC.

Data collection

Pilot survey data collection began on 21 July 2023. The survey was offered online using the Research Electronic Data Capture (REDCap) platform.

Prizes

Three prize draws were offered for survey 7 participants, as detailed in Table 3-4 below. Prezzy gift vouchers were used for all prize draws, with electronic gift cards emailed to winners.

Table 3-4 Prize draws for Survey 7 for the 1989-95 cohort participants

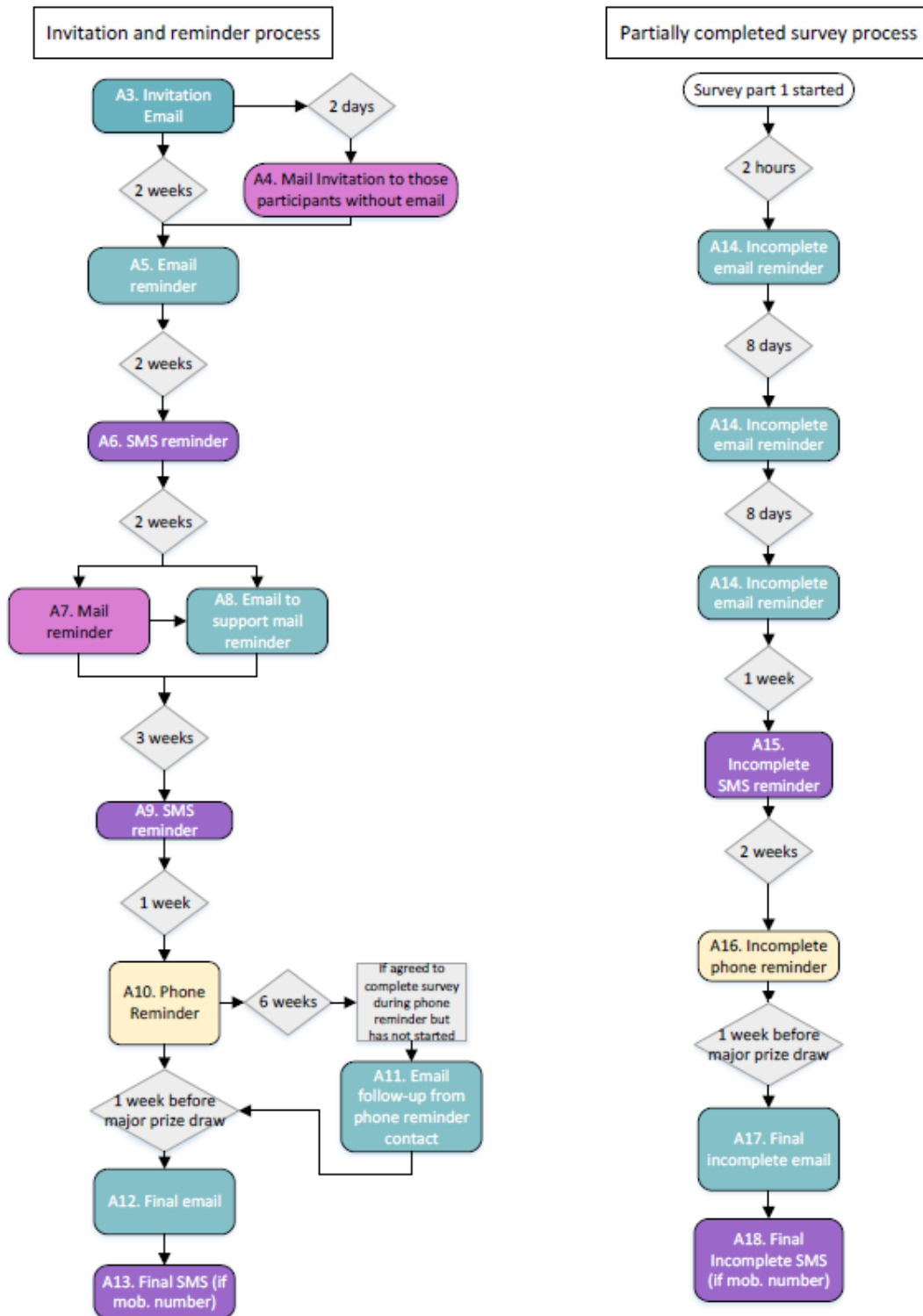
	Prize	Survey to be completed by:		
		5pm, 03 Sept 2023	5pm, 29 Oct 2023	5pm, 14 Apr 2024
Prize Draw 1	\$100 voucher (Five winners)	Eligible (1 entry)		
Prize Draw 2	\$100 vouchers (Five winners)		Eligible (1 entry)	
Prize Draw 3 (Major)	\$1000 voucher (One winner)			Eligible (1 entry)

Invitation and reminder protocol

The invitation and reminder protocol is presented in Figure 3-1.

Figure 3-1 Invitation and reminder protocol for Pilot Survey 7 for the 1989-95 Pilot Cohort.

1989 – 95 Cohort Pilot Survey 7 Part 1



Response rate

Table 3-5 details the response rates for Pilot Survey 7 for the 1989-95 pilot cohort as at 12 November 2023. Completed online pilot surveys have been received from 173 women (42% of those invited), while another 13 women (3%) have partially completed their survey online at this time.

Table 3-5 Response rates for Pilot Survey 7 for the 1989-95 pilot cohort (N=412)

	N	Pilot Survey %
Completed online survey	173	42.0
Partially completed online survey	13	3.2
Deceased	0	0.0
Withdrawn	2	0.5
Not this time	0	0.0
No response	224	54.3
Total	412	100.0

3.2.2 Main cohort – Survey 7

Development of survey materials

During August 2023, frequencies and comments from the 1989-95 cohort Pilot Survey 7 were reviewed, and recommendations for changes and improvements for the main survey were discussed.

Future plans

The main Survey 7 for the 1989-95 cohort will launch in the second half of 2023.

3.3 1921-26 cohort

3.3.1 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 23 and Survey 24. The survey content is the same as that for previous waves of the 6MF survey.

Each month, surveys were mailed to participants who had:

- Completed a survey approximately six months ago

- Asked for a new survey to be sent
- Requested to skip the previous survey, approximately six months ago.

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

Survey 23 was first sent to eligible participants on 7th November 2022, while Survey 24 was first sent to eligible participants on 5th May 2023. Surveys are administered via phone for eligible participants who have requested to complete the survey via phone due to difficulties completing a paper survey.

Mailouts

There have been 11 mailouts for 6MF-Survey 23 and 24 so far, as detailed below in Table 3-6. The packages mailed include a paper survey, information letter, change of details card, and a reply-paid envelope.

Table 3-6 Mailout for 6MF Surveys 23 and 24 from November 2022 to October 2023

Date	Mailout	6MF-23 and 6MF-24 mailed	Total 6MF-surveys mailed
November 2022	1	11	68
December 2022	2	8	63
January 2023	3	2	64
February 2023	4	14	37
March 2023	5	8	33
April 2023	6	3	46
May 2023	7	15	59
June 2023	8	4	32
August 2023	9	39	118
September 2023	10	9	27
October 2023	11	10	45

Response rates

Of the participants who have been sent the 23rd 6MF survey, 64% have responded to date (68/107, Table 3-7). Of the participants who have been sent the 24th 6MF survey, 41% have responded to date (26/64). The number of survey completions across all 6MF surveys for the 1921-26 cohort is presented in Figure 3-2, illustrating when the surveys have been returned.

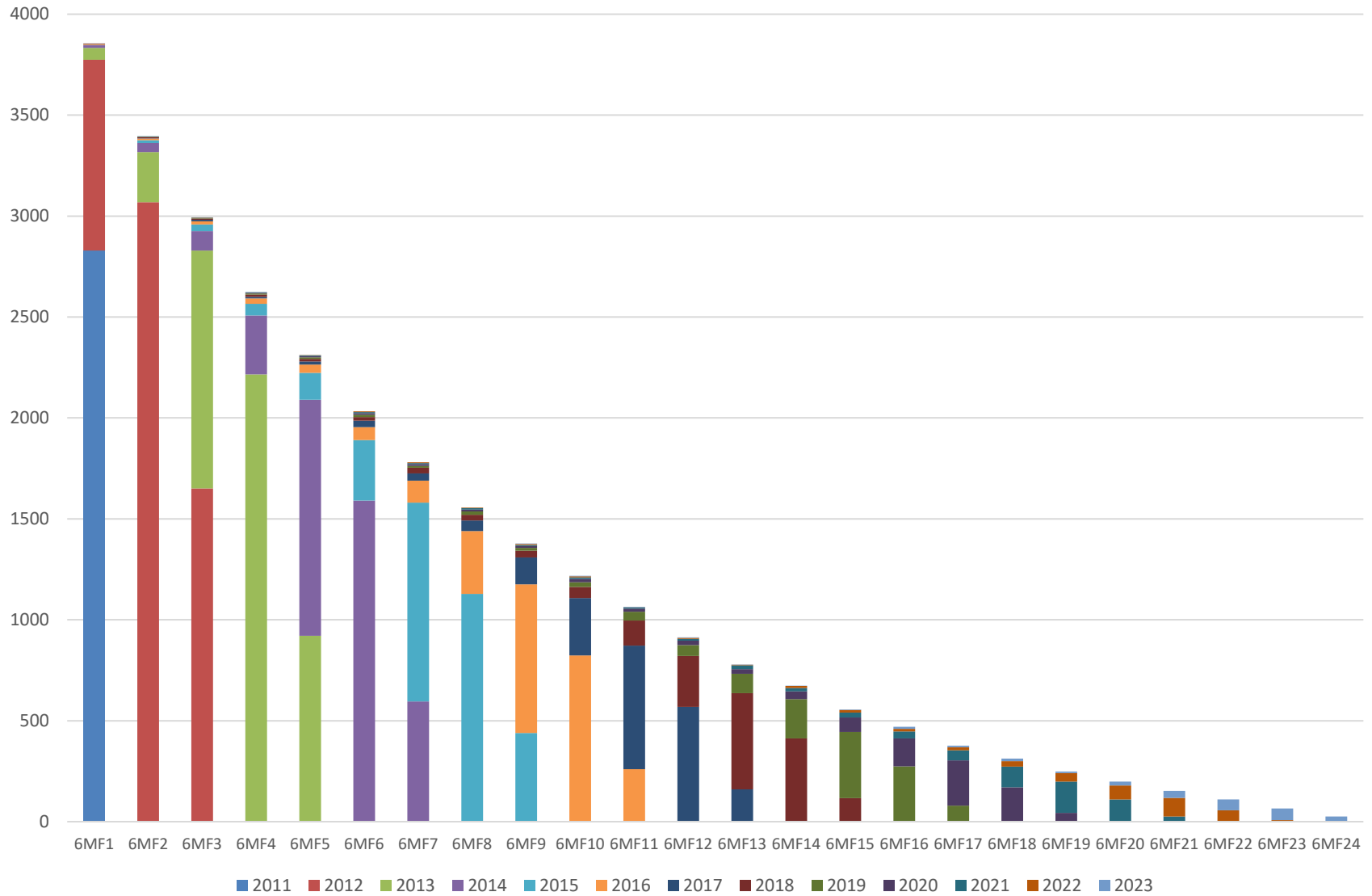
Table 3-7 Response rates for 6MF Surveys 23 and 24 (at 12 November 2023)

	6MF Survey 23 ^a		6MF Survey 24 ^b	
	N	%	N	%
Completed paper survey	68	64	26	41
Completed phone survey	0	0	0	0
Deceased	7	7	1	2
Withdrawn	1	1	2	3
No response	30	28	35	54
Total so far deployed	107	100	64	100

^a first deployed 7th November 2022

^b first deployed 5th May 2023

Figure 3-2 Number of completions for 1921-26 cohort Six-Month Follow-Up Surveys 1 to 24, at 31 October 2023.



3.4 'Refresh' of the 1973-78 and 1989-95 cohorts with women from Asian backgrounds

3.4.1 Background

ALSWH is currently undertaking a 'refresh' of participants in the 1973-78 and 1989-95 cohorts. This cohort refresh aims to improve the representativeness of the study, with a goal to recruit 1,000 women from South, Southeast and Northeast Asian countries into each of the 1973-78 and 1989-95 cohorts. As detailed in previous reports, 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).

Planning for the 1973-78 cohort refresh began in 2021, and recruitment to the 1973-78 cohort started in 2022. In 2023, the 1989-95 cohort refresh commenced. This report provides an update on the:

- changes to study design;
- recruitment activities undertaken;
- progress of the 1973-78 and 1989-95 cohort refresh recruitment; and
- future plans for this cohort refresh.

3.4.2 Changes to study design

Update to eligibility criteria and data linkage requirements

The 1973-78 and 1989-95 cohort refreshes are now occurring simultaneously, meaning the eligibility criteria have been updated to include those born 1973-78 and 1989-95. We are particularly seeking women with ancestry from Asian countries (where women were either born in South, Southeast and Northeast Asian countries, or have a parent born in these countries) but the survey is open to anyone who meets the eligibility criteria (female and born 1989-95 or 1973-1978).

The eligibility criteria of having a Medicare card and consenting to data linkage have been removed since the initial launch, due to extensive feedback from potential participants, the Multicultural Women's Health Centre, and other stakeholders suggesting this was not culturally appropriate and was a significant barrier to participation. Data linkage consent will be revisited once the Study has built trust with the new participants and consulted on the most appropriate way to seek this consent.

Split data collection

A new short survey has been created (Survey 1) that takes a few minutes to complete. Once eligible participants have completed Survey 1, they are later sent a second online survey (Survey 2), which is longer and more comprehensive. The short survey allows participants to be recruited at face-to-face

events, providing the necessary contact details for later follow-up. All surveys are built in REDCap™ and are only available online.

Survey 1 was developed by the ALSWH cohort refresh team in consultation with t DOHAC. Feedback was also sought from relevant stakeholders and community groups (e.g., Multicultural Centre for Women's Health). For details about included survey items, please refer to Table 3-8.

Survey 2 1973-78 Cohort Refresh

Women born 1973-78 and recruited as part of the refresh will receive a modified version of the ninth survey developed for the existing members of the 1973-78 cohort (and deployed in June 2021) as Survey 2. The refresh survey was developed by the ALSWH cohort refresh team in consultation with the DOHAC. For details about changes to existing survey items and the addition of new survey items from the 1973-78 cohort main Survey 9 to 1973-78 cohort refresh Survey 2, please refer to Table 3-9. For details about the deleted items from the 1973-78 cohort main Survey 9 to 1973-78 cohort refresh Survey 2, please refer to Table 3-10. This survey has received ethical approval by the University of Newcastle and University of Queensland HRECs

Survey 2 1989-95 Cohort Refresh

Women born 1989-95 recruited as part of the refresh will receive a modified version of the seventh survey developed for the existing members of the 1989-95 cohort (and deployed in July 2023) as Survey 2. The refresh survey was developed by the ALSWH cohort refresh team in consultation with the DOHAC. For details about changes to existing survey items and the addition of new survey items from the 1989-95 cohort pilot Survey 7 to the 1989-95 cohort refresh Survey 2, please refer to Table 3-11. For details about the deleted items from the 1989-95 cohort pilot Survey 7 to the 1989-95 cohort refresh Survey 2, please refer to Table 3-12. This survey is currently being assessed for ethical approval by the University of Newcastle and University of Queensland HRECs

Table 3-8 1973-78 and 1989-95 Cohort Refresh Survey 1 item inclusions, sources and justifications

Item No.	Topic	Source	Justification
Eligibility preferred name	Eligibility criteria	ALSWH	Eligibility criteria
Eligibility email	Eligibility criteria	ALSWH	Eligibility criteria
Eligibility confirm email	Eligibility criteria	ALSWH	Eligibility criteria
Personal details phone	Personal details	ALSWH	Personal details needed for follow up
Eligibility DOB	Eligibility criteria	ALSWH	Eligibility criteria
Personal details	Residential postcode	ALSWH	Personal details needed to calculate representativeness of sample
Eligibility sex	Eligibility criteria	ABS Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables 2020 https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release	Eligibility criteria
Eligibility Medicare card	Eligibility criteria	ALSWH	Eligibility criteria
1	Country of birth	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/	Added to capture Cohort Refresh participants' country of birth
2	Language spoken at home	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/	Added to capture Cohort Refresh participants' language spoken at home
3	Mother's country of birth	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/	Added to capture information on participants' mothers' country of birth

Item No.	Topic	Source	Justification
4	Father's country of birth	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/	Added to capture information on participants' fathers' country of birth
5	SF-1	Ware, J.E., & Sherbourne, C.D. (1992) The MOS 36-Item Short-Form Health Survey (SF-36):1. Conceptual framework and item selection, Medical Care, 30(6), 473-483	This item was included to capture overall general health.
6	Top 3 health concerns	ALSWH	This item was included to capture the top health concerns.
7	Top 3 health service concerns	ALSWH	This item was included to capture the top health service concerns.
8	Anything else about health and wellbeing	ALSWH	This item was included to capture any other information about health and wellbeing.

Table 3-9 Changes to existing items and additions of new items from 1973-78 Cohort Survey 9 Main to 1973-78 Cohort Refresh Survey 2

Item No.	Topic	Source	Item changes justification	New item justification
1-11	SF-36	Ware, J.E., & Sherbourne, C.D. (1992) The MOS 36-Item Short-Form Health Survey (SF-36):1. Conceptual framework and item selection, Medical Care, 30(6), 473-483		
12	Consultations	ALSWH	<ul style="list-style-type: none"> Added "A counsellor or other mental health worker" and "An alternative health practitioner (e.g., acupuncturist, naturopath / herbalist, aromatherapist etc.)", which were from Q14 Y9Main 	

Item No.	Topic	Source	Item changes justification	New item justification
			<ul style="list-style-type: none"> Simplified item to remove reference to “how many times”, to change item to a “have you consulted - Yes/No” format 	
13	Hospital admissions	ALSWH	Simplified to capture any hospital admission in last 12 months	
14	Screening – breasts and vaccinations	ALSWH	Removed item on Pneumococcal vaccination as not recommended for overall population of women in the age group. Added item “been vaccinated for COVID-19”.	
15	COVID-19 test	ALSWH		
16	Female GP	ALSWH		
17	Health care card	ALSWH		
18-19	Private health insurance	Modified from Australian Bureau of Statistics (1991). <i>1989-1990 National Health Survey Users' Guide</i> . Canberra: ABS. Cat No. 4363.0		
20	Diagnosis	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	<ul style="list-style-type: none"> Split option “Uterine polyps/Uterine fibroids” into two different items, as these are two different conditions 	
21	Health checks	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		
22	Abnormal health check	ALSWH	<ul style="list-style-type: none"> Changed timeframe to capture “ever” Simplified response category to “Yes/No” 	
23	Fertility	ALSWH		
24	Procedures	ALSWH	<ul style="list-style-type: none"> Added question asking about age at operation/procedure 	

Item No.	Topic	Source	Item changes justification	New item justification
			<ul style="list-style-type: none"> Reduced procedures to three items to simplify item 	
25	HRT	Developed for ALSWH and M-PreM		
26	Menstruation	Developed for ALSWH and M-PreM		
27	Skipping periods	Developed for ALSWH and M-PreM		
28	Period frequency	Developed for ALSWH and M-PreM		
29	Menopause age	Developed for ALSWH and M-PreM		
30	Height	ALSWH		Added to capture participants height – needed to calculate BMI
31	Weight	ALSWH		
32	Stress	ALSWH		
33	Time use	Modified from Australian Bureau of Statistics (1993) Time use survey, Australia, 1992: user's guide. Canberra: ABS. Cat No. 4150.0.		
34	Physical Activity	Active Australia. Armstrong, T., Bauman A., & Davies, J. Physical activity patterns of Australian Adults: results of the 1999 National Physical Activity Survey. AIHW Canberra 2000		
35	Symptoms	ALSWH	Shortened to simplify the first survey for the Cohort Refresh participants	
36	Drugs	National Drug Strategy household survey: survey report 1995 (1996)		
37-45	Smoking	Modified from Australian Institute of Health and Welfare (AIHW) (1997) National Health Data Dictionary, Version 6.0. Standard		Additional item added to identify the age participants started to smoke daily (where applicable)

Item No.	Topic	Source	Item changes justification	New item justification
		questions on the use of tobacco among adults.		
46-48	Alcohol	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.	Standard drinks chart to be displayed in online survey to help participants identify a standard drink	
49	Need for care	Modified from Australian Bureau of Statistics (1993) Disability, Ageing and Carers Australia. Canberra: ABS. Cat. No. 4432.0		
50	Conception/pregnancy	ALSWH		
51	Current contraception	ALSWH	Original contraception item replaced with a simplified "Yes/No" item assessing use of any form of contraception	
52	Currently pregnant	ALSWH		
53	Ever been pregnant	ALSWH		
54	Childbirth complications	ALSWH		
55	Ever given birth	ALSWH		
56	Live births and still births	ALSWH		
57	Details of birth	ALSWH	Shortened to simplify the first survey for the Cohort Refresh participants, detailed birth experiences removed (Y9Q63a-t)	
58	Pregnancy diagnosis	ALSWH		
59	Breastfed children	ALSWH		

Item No.	Topic	Source	Item changes justification	New item justification
60-61	Children living with you	ALSWH	Condensed response categories for Q59 to shorten and simplify survey for Cohort Refresh participants	
62	Partner	ALSWH		
63	Violent relationship	Hwalek, M.A., & Sengstock, M.C. (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.		
64	Occupation	Modified from M2 and Australian standard classification of occupations. Second Edition. (1997). Catalogue No. 1220.0		
65	Sources of income	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L22.		
66	Manage on income	ALSWH		
67	Fruit intake	Based on National Health and Medical Research Council (2013) Australian Dietary Guidelines. Canberra: National Health and Medical Research Council.		
68	Vegetable intake	ALSWH		
69	Residential and postal postcode			

Item No.	Topic	Source	Item changes justification	New item justification
70	Education	Modified from Australian Bureau of Statistics. (1993). 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		
71	Housing situation	ALSWH	Modified last two items to clarify meaning	
72	Marital status	Modified from Australian Bureau of Statistics. (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		
73	Who lives with you	Modified from Australian Bureau of Statistics. (1994) Australian Housing Survey: User Guide. Canberra: ABS. Cat No. 4180.0		
74	English proficiency	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/		Added to capture Cohort Refresh participants' English proficiency
75	Source of recruitment	ALSWH		Added to monitor the different recruitment methods
76	Proxy	ALSWH	Added skip instruction for participants who answer "no" to skip Q116	
77	Reason for assistance in completing survey	ALSWH		
	Have we missed anything?	ALSWH		
Personal details		ALSWH		Need participant personal details to include the participants into the 1989-95 and 1973-78 cohorts. Details will be kept separate from survey responses.

Table 3-10 Deleted items from 1973-78 Cohort Survey 9 Main to 1973-78 Cohort Refresh Survey 2

Item No.	Topic	Source	Reason for deletion
12	Brief Resilience Scale (BRS)	Smith, B.W., Dalen, J., Wiggins, K. et al. The brief resilience scale: Assessing the ability to bounce back. <i>Int. J. Behav. Med.</i> 15, 194–200 (2008). https://doi.org/10.1080/10705500802222972	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
14	Consultations (allied health)	Modified from Australian Bureau of Statistics (1991) 1989-1990 National Health Survey Users' Guide. Canberra: ABS. Cat No. 4363.0	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
17	GP visits	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
18	GP cost	Modified from Davies, A.R., & Ware, J.E.J. (1991). GHAA's consumer satisfaction survey and user's manual (2nd Edn). Washington DC: The Group Health Association of America (GHAA).	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
20	Health care satisfaction	Modified from Davies, A.R., & Ware, J.E.J. (1991). GHAA's consumer satisfaction survey and user's manual (2nd Edn). Washington DC: The Group Health Association of America (GHAA).	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
27	Life events	Modified from Norbeck, J.S. (1984). Modification of live event questionnaires for use with female respondents. <i>Research in Nursing and Health</i> , 7, 61-71.	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
38	Types of paid work	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.

Item No.	Topic	Source	Reason for deletion
39	Anxiety: Anxiety Scale from the DASS	Lovibond, S.H. & Lovibond, P.F. (1995). Manual for the Depression Anxiety Stress Scales. (2nd ed.). Sydney: Psychology.	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
41	Symptom severity	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
59	Pregnancy and emotional well-being information	Beyond Blue	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
65	Breastfeeding	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
68-69	Child care	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
70	CES-D	Andresen, E.M., Carter, W.B., Malmgren, J.A., & Patrick, D.L. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D. American Journal of Preventative Medicine, 10(2), 77-82.	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
71-74	Providing care	Modified from Australian Bureau of Statistics (1993) Disability, Ageing and Carers Australia. Canberra: ABS. Cat. No. 4432.0	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
75	Providing care	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
76	Social support	Sherbourne, C.D., & Stewart, A.L. (1991). The MOS social support survey. Social Science and Medicine, 32(6), 705-714	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.

Item No.	Topic	Source	Reason for deletion
79	Abuse	Modified from Hegarty, K.L., Sheehan, M., Schonfeld, C. (1999) A multidimensional definition of partner abuse: development and preliminary validation of the Composite Abuse Scale. J Fam Violence, 14, 399-414.	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
80	Economic abuse	Modified from: Australian Bureau of Statistics. (2017). 2016 Personal Safety Survey (PSS): Questions Specifications. https://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/C897D50E421A3E45CA2581D1000C3B49/\$File/4906055003%202016%20personal%20safety%20survey%20questionnaire.pdf	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
81	Reproductive coercion	Item created based on 3 subthemes of reproductive coercion (i.e. pregnancy coercion, abortion coercion, and birth control sabotage) listed in: Grace KT, Anderson JC. Reproductive Coercion: A Systematic Review. Trauma Violence Abuse. 2018;19(4):371-390. doi:10.1177/1524838016663935	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
82	Psychological distress (K10)	Kessler, R.C., et al. (2003). Screening for serious mental illness in the general population. Archives of General Psychiatry, 60(2), 184-189.	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.

Item No.	Topic	Source	Reason for deletion
83-84	Life isn't worth living/ Self harm	Modified from Beck, A., Schuyler, D., & Herman, I. (1974) Development of the Suicide Intent Scale. In Beck, A.T., Resnick, H.L.P., & Lettieri, D.J. (Eds.) The prediction of suicide. Bowie, MD: Charles Press Publishers	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
85	Managing time	Modified from Statistics Canada, Housing Family and Social Statistics Division (1987) General social survey analysis series. Ottawa: Canadian Government Publication Centre. ISSN 0836-043X	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
86-87	Employment	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
88	Job security	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
92-94	ABS Financial Stress Indicators	ABS, Household income, living standards and financial stress from 1998-99 Household Expenditure Survey (HES). https://www.abs.gov.au/ausstats/abs@.nsf/0/793D1402EE51BA8BCA256A5D0004F5D5?OpenDocument	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.

Item No.	Topic	Source	Reason for deletion
95-99	Food security (USDA HFSSM 6-item Short Form)	<p>Bickel, Gary, Mark Nord, Cristofer Price, William Hamilton, and John Cook: Guide to Measuring Household Food Security, Revised 2000. U.S. Department of Agriculture, Food and Nutrition Service, Alexandria VA. March, 2000.</p> <p>Australian wording: Ramsey, R., Giskes, K., Turrell, G., & Gallegos, D. (2012). Food insecurity among adults residing in disadvantaged urban areas: potential health and dietary consequences. <i>Public Health Nutrition</i>, 15(2), 227-237.</p> <p>McKechnie, R., Turrell, G., Giskes, K., & Gallegos, D. (2018). Single-item measure of food insecurity used in the National Health Survey may underestimate prevalence in Australia. <i>Australian and New Zealand Journal of Public Health</i>, 42(4), 389-395.</p>	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
100	Life satisfaction	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
101-102	Bushfires and/or bushfire smoke	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
104	COVID-19 stress	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
108	Sitting	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.

Item No.	Topic	Source	Reason for deletion
117-187	Diet	Commonwealth Scientific and Industrial Research Organisation (CSIRO). CSIRO Healthy Diet Score (minus the demographic questions)	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.
188	Date of birth (Food questionnaire)	ALSWH	Need to keep first survey for Cohort Refresh short to increase participation rates. Can be assessed at a later survey.

Table 3-11 Changes to existing items and additions of new items from 1989-95 Cohort Survey 7 Pilot to Cohort Refresh 1989-95 Cohort Survey 2

Item No.	Topic	Source	Item changes justification	New item justification
P1	Introduction and data linkage	NA	Wording change to Introduction to suit the Cohort Refresh sample born 1989-95. The Cohort Refresh cohort will not be asked to consent to data linkage until a later date and so the wording related to data linkage has been deleted.	
1	General Health (SF-1)	Ware, J. E., & Sherbourne, C. D. (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.		
2-3	Mental illness diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	This cohort has not been surveyed about these conditions and so the timeframe and wording have been adjusted to accommodate an 'ever' timeframe to collect baseline data.	

Item No.	Topic	Source	Item changes justification	New item justification
			Free text option added to allow participants who select 'Other' to specify other mental health condition.	
4-5	Physical illness diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	This cohort has not been surveyed about these conditions and so the timeframe and wording have been adjusted to accommodate an 'ever' timeframe to collect baseline data. Free text option added to allow participants who select 'Other' to specify other physical health condition.	
6-7	Reproductive Health diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	This cohort has not been surveyed about these conditions and so the timeframe and wording have been adjusted to accommodate an 'ever' timeframe to collect baseline data.	
8-9	Sexually transmitted infection diagnoses	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	This cohort has not been surveyed about these conditions and so the timeframe and wording have been adjusted to accommodate an 'ever' timeframe to collect baseline data. Free text option added to allow participants who select 'Other' to specify other sexually transmitted infection.	
10	Symptoms	ALSWH Symptoms Set	Headaches/migraines have been split into two different items. Recent research has demonstrated that these conditions are distinct, and therefore should be measured separately.	
11	Disability	Modified from Australian Bureau of Statistics (1993) Disability, Aging		

Item No.	Topic	Source	Item changes justification	New item justification
		and Carers Australia. Canberra: ABS. Cat. No. 4432.0		
12	Screening	Modified from the Australian Bureau of Statistics (1991) 1989-1990 National Health Survey users' guide: Canberra: ABS Cat No. 4363.0		
13	Abnormal cancer screening result	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		
14-15	Health service use	Modified from Davies, A.R., & Ware, J.E.J. (1991). GHAA's consumer satisfaction survey and user's manual (2nd Edn). Washington DC: The Group Health Association of America (GHAA).		Question added on preference to see a female doctor. It is important to capture this information for women from diverse cultural backgrounds to ascertain whether or not there are cultural differences in doctor preferences.
16-18	COVID-19	ALSWH		
19	Living arrangements	ALSWH		
20	Contraception	ALSWH		
21	Contraception Non-use	Modified from Contraceptive Use, Pregnancy Intention & Decision of Australian Women (CUPID) surveys		
22-45	Pregnancy	ALSWH		
46	Child/ren	ALSWH		
47	Infertility	ALSWH		
48	Health Care Card	ALSWH		
49-50	Private Health Insurance	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0		
51-57	Smoking	Modified from Australian Institute of Health and Welfare (AIHW) (1997) National Health Data Dictionary,		

Item No.	Topic	Source	Item changes justification	New item justification
		Version 6.0. Standard questions on the use of tobacco among adults.		
58	Marijuana	Modified from National Drug Strategy household survey: survey report 1995 (1996).		
59	Illicit drug use	National Drug Strategy household survey: survey report 1995 (1996).		
60-63	Alcohol	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. ALSWH		
64-65	Physical activity	Active Australia Armstrong, T, Bauman A, Davies J. Physical activity patterns of Australian Adults: results of the 1999 National Physical Activity Survey. AIHW Canberra 2000		
66	Sitting	ALSWH		
67	Ever had a partner/spouse	ALSWH		
68-69	Violent relationship	Hwalek, M.A., & Sengstock, M.C. (1986). Assessing the probability of abuse of the elderly: Toward development of a clinical screening instrument. Journal of Applied Gerontology, 5(2), 153-173.		
70	Year of start of violence	ALSWH		
71	Life isn't worth living/Self-harm	Modified from Beck A, Schuyler D & Herman, I. (1974) Development of the Suicide Intent Scale. In AT Beck,		

Item No.	Topic	Source	Item changes justification	New item justification
		HLP Resnick, & DJ Lettieri (Eds.) The prediction of suicide. Bowie, MD: Charles Press Publishers		
72	Stress	ALSWH		
73	Weight	ALSWH		
74	Height			This item has been added to allow for the collection of baseline measures that facilitate calculation of Body Mass Index (which indicates health and unhealthy weights according to World Health Organization criteria).
75	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. Asia Pacific J Clin Nutr 1994; 3: 19-31.		
76	Vegetables	ALSWH		
77	Education	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		
78-80	Time use	Modified from Australian Bureau of Statistics (1993) Time use survey, Australia, 1992: user's guide. Canberra: ABS. Cat No. 4150.0.		
81	Manage on income	ALSWH		
83-83	Menstrual product affordability	Cardoso, L.F., Scolese, A.M., Hamidaddin, A. et al. Period poverty and mental health implications among college-aged women in the United States. BMC Women's Health		

Item No.	Topic	Source	Item changes justification	New item justification
		21, 14 (2021). https://doi.org/10.1186/s12905-020-01149-5		
84	Sexual orientation	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		
85	Relationship status	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.		
86	Housing	ALSWH		
87	Residential postcode	ALSWH		
88	Postal postcode	ALSWH		
89	Occupation	Modified from Australian standard classification of occupations. Second Edition. (1997). Catalogue No. 1220.0		
90	Days at work	ALSWH		
91	Hours at work	ALSWH		
92	Proxy	ALSWH		
93	Reason for needing help	ALSWH		
94	Missed anything	ALSWH		
	Thank you	NA	MatCHES information removed. This was only applicable to 1989-95 Cohort Main participants.	

Table 3-12 Deleted items from 1989-95 Cohort Survey 7 Pilot to Cohort Refresh 1989-95 Cohort Survey 2

Survey 7 Main item	Topic	Source	Reason for deletion
14	Where do you get your health information?	ALSWH	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
16-18	Health service use	Modified from Davies, A.R., & Ware, J.E.J. (1991). GHAA's consumer satisfaction survey and user's manual (2nd Edn). Washington DC: The Group Health Association of America (GHAA).	These items have been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
22-23	COVID-19	ALSWH	These items have been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
25-26	Partner level of education/occupation	Modified from ABS (1993) 1996 Census of population and housing: Nature and content of the census. Canberra: ABS. Cat No. 2008.0.	These items have been deleted from this survey as they are not necessary at this stage of the Cohort Refresh.
47	Pregnancy – is your child still alive?	ALSWH	This item was added as a screening item for main ALSWH cohort participants (to determine eligibility for the MatCHES survey) and is not needed for the Cohort Refresh participants.
54-55	Maternity leave	Modified from the Longitudinal Study of Australians Children (LSAC) 2005 Infant questionnaire.	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
57-58	Partner and Partner's relationship to child/ren	ALSWH	These items were deleted as they pertained to the ALSWH main Survey 7 Parts 1 and 2, but not to the Cohort Refresh participants.
60	Pelvic Organ Prolapse diagnosed/ treated	ALSWH	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.

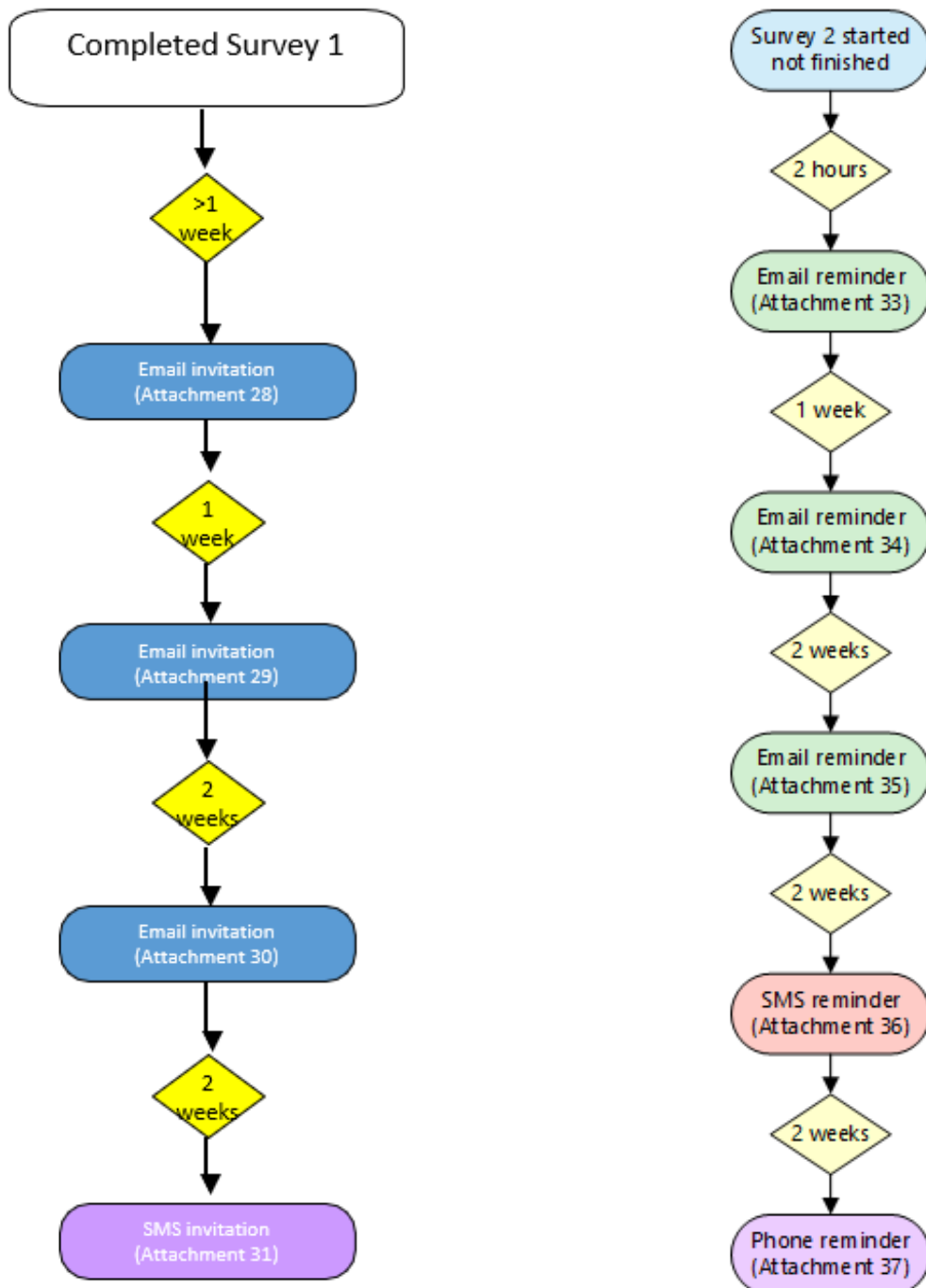
Survey 7 Main item	Topic	Source	Reason for deletion
61	Pelvic symptoms	M.D. Barber, M.D. Walters, R.C. Bump. Short forms of two condition-specific quality-of-life questionnaires for women with pelvic floor disorders (PFDI-20 and PFIQ-7). American Journal of Obstetrics and Gynecology 193, 103-113 (2021). https://doi.org/10.1016/j.ajog.2004.12.025 .	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
81	Life events	ALSWH	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
83-85	Partner abuse	Modified from Hegarty KL, Sheehan M, Schonfeld C. (1999) A multidimensional definition of partner abuse: development and preliminary validation of the Composite Abuse Scale. J Fam Violence, 14, 399-414.	Detailed items that ask about violence were deleted from this survey and will be asked at a later survey, in order to reduce the length of this survey.
87	Years experienced violence	ALSWH	The item that asked about the year sexual violence was first experienced was deleted, since the items that related to this question were deleted.
89	Years experienced violence	ALSWH	The item that asked about the year sexual violence was first experienced was deleted, since the items that related to this question were deleted.
90-95	Childhood trauma	Modified from the Female Family Health History Questionnaire in the Adverse Childhood Experiences Study	Detailed items that ask about violence were deleted from this survey and will be asked at a later survey, in order to reduce the length of this survey.
97	Depression (K-10)	Kessler, R.C., et al. (2003). Screening for serious mental illness in the general population. Archives of General Psychiatry, 60(2), 184-189.	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.

Survey 7 Main item	Topic	Source	Reason for deletion
98	Depression and anxiety	Depression Anxiety Stress Scales (DASS) https://www.psytoolkit.org/survey-library/depression-anxiety-stress-dass.html	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language
100	Self-esteem	Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press. https://socy.umd.edu/quick-links/using-rosenberg-self-esteem-scale	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
101	Life orientation	Life Orientation Test (LOT-R) Scheier M.F., Carver, C.S., Bridges, M.W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self esteem): a reevaluation of the life orientation test. Journal of Personality and Social Psychology, 67, 1063-1078.	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
103-104	Body image	Modified from French, SA, Story, M, Downes, B, Resnick, MD, Blum, RW (1995). Frequent dieting among adolescents: psychosocial and health behaviour correlates. American Journal of Public Health, 85(5): 695-701.	These items have been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.
107	Social support	Sherbourne, C.D., & Stewart, A.L. (1991). The MOS social support survey. Social Science and Medicine, 32(6), 705-714.	This item has been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.

Survey 7 Main item	Topic	Source	Reason for deletion
108-109	Parents' place of birth	Modified from Australian Bureau of Statistics. (2021) 2021 Australian Census of Population and Housing. https://www.census.abs.gov.au/	These items were deleted as the information has already been collected at Cohort Refresh short Survey 1.
111-112	Employment	ALSWH	These items have been deleted due to concerns about survey length, especially as this cohort may use English as a non-primary language.

The invitation and reminder protocol for Survey 2 of the cohort refresh is presented in Figure 3-3.

Figure 3-3 Invitation and reminder protocol for Survey 2 for the 1973-78 and 1989-95 Cohort Refresh



Reimbursement

Participants of the Cohort Refresh Survey 1 are offered a \$5 Prezzy Smart eGift Card as reimbursement for completing Survey 1. The voucher is distributed via email, which ensures no handling of a gift card. Participants are required to provide their email addresses to be eligible to receive the voucher.

Participants of the Cohort Refresh Survey 2 will be offered a \$30 Prezzy Smart eGift Card as reimbursement for completing Survey 2. The voucher will be distributed via email, which ensures no handling of a gift card. Participants are required to provide their email addresses to be eligible to receive the voucher. The addition of this reimbursement is currently being assessed for ethical approval by the University of Newcastle and University of Queensland HRECs.

Updated recruitment strategies

Recruitment strategies have been updated to include:

- Face-to-face activities to recruit potential participants (i.e., at cultural and community events) and engage with cultural organisations, community groups, and existing networks for assistance with recruitment; and
- Contact with all sitting members of parliament to ask them to share recruitment materials with their constituents.

All procedural changes were subject to ethics approvals, which were processed and granted by the Human Research Ethics Committees at the University of Newcastle and the University of Queensland.

3.4.3 Recruitment activities undertaken for the refresh of the 1973-78 and 1989-95 cohorts

Recruitment activities for the 1973-78 cohort refresh prior to 2023 are described in detail elsewhere. In May 2023, the simultaneous recruitment of new participants to both the 1989-95 and 1973-78 cohorts commenced. To date, the following recruitment activities undertaken include:

- Contact with existing ALSWH participants requesting they share recruitment information and materials through their networks;
- Contact with existing professional and personal networks, sharing recruitment information and materials;
- Following up with people who have expressed an interest in joining the Study both through the website and during other recruitment activities;
- Postal mailouts of materials to organisations and networks;
- Face-to-face recruitment at community organisations, networks, events, and festivals; and
- Face-to-face recruitment at cultural events and festivals.

3.4.4 1973-78 and 1989-95 cohort refresh progress update

Response rates

As 18 October 2023, 482 eligible participants have completed the Cohort Refresh Survey 1. Of the 205 women born 1973-78 who have completed the Cohort Refresh Survey 1, 17 have ancestry from the targeted countries. Of the 277 women born 1989-95 who have completed the Cohort Refresh Survey 1, 31 have ancestry from the targeted countries.

3.4.5 Future plans

Data collection is currently ongoing. Recruitment activities are continuing, with plans to attend additional face-to-face cultural events (e.g., Diwali, Chinese New Year) and engage with cultural organisations for assistance in reaching target participants.

The most recent changes to study design are currently being assessed for ethical approval. Once these are approved, Survey 2 for both the 1973-78 and 1989-95 cohorts will be launched and data collection and survey follow-up activities will commence.

3.4.6 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 Survey participation over time

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 1921-26 cohort

Among women born 1921-26, survey response rates remained relatively high through Surveys 2 to 6, with a response rate of 93% at the first follow-up survey in 1999 when the women were aged 73-78 and a response rate of 81% at the sixth survey in 2011 (Table 4-1). The percentage of women who did not complete the survey increased from 4% to 17% during the 12 years of follow-up between Survey 2 and Survey 6. Women who did not respond to the survey tended to report poorer self-rated health at Survey 1 compared to women who did respond to surveys. The effects of these losses were evaluated in terms of losses due to death and non-death reasons, with Brilleman and colleagues (2010) concluding that non-death losses were potentially a greater source of bias than the effect of death.

Table 4-1. Survey participation for women born 1921-26 (N=12,432) between 1996 and 2011

Survey	Year (Age)	Deceased	Withdrawn	Total Ineligible	No contact	Did not do survey	Respondent	Total Eligible	Response Rate (%)
1	1996 (70-75)	—	—	—	—	—	12,432	12,432	100.0%
2	1999 (73-78)	549	658	1,207	310	481	10,434	11,225	93.0%
3	2002 (76-81)	1,237	1,393	2,630	295	861	8,646	9,802	88.2%
4	2005 (79-84)	2,290	1,883	4,173	509	592	7,158	8,829	86.7%
5	2008 (82-87)	3,632	1,960	5,592	640	640	5,560	6,840	81.3%
6	2011 (85-90)	5,295	2,124	7,419	96	862	4,055	5,013	80.9%

* As at 31 August 2023

In 2011, the women were aged 85-95 and there was concern that the longer survey format every three years was no longer suitable for this cohort. Since November 2011, shorter surveys containing a set of core questions have been mailed to women born 1921-26 the 1921-26 cohort. These are known as the six-monthly follow-up surveys (6MF surveys) and are mailed 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 4-2 provides the number of women since November 2011 who are eligible to complete the shorter 6MF surveys, with the number of women who have responded to a 6MF survey in that six-month period.

By September 2023, the study has been notified of the deaths for 11,194 women (90% of the cohort). The remaining women (approximately 1,238 women) are now aged 97 to 102 years old, with 60% having withdrawn from active survey participation (n=747), typically citing reasons of ill health, frailty or diminishing capacity. Of the women who are still eligible to participate in the 6MF surveys, around 30% have sent back a survey in the last 12 months.

Table 4-2 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 (%)
1	01 May 2012	5,547	2,319	7,866	1,136	3,430	4,566	75.1%
2	01 Nov 2012	5,942	2,348	8,290	882	3,260	4,142	78.7%
3	01 May 2013	6,244	2,393	8,637	953	2,842	3,795	74.9%
4	01 Nov 2013	6,638	2,330	8,968	991	2,473	3,464	71.4%
5	01 May 2014	6,966	2,277	9,243	1,071	2,118	3,189	66.4%
6	01 Nov 2014	7,307	2,164	9,471	997	1,964	2,961	66.3%
7	01 May 2015	7,637	2,083	9,720	986	1,726	2,712	63.6%
8	01 Nov 2015	7,984	1,949	9,933	975	1,524	2,499	61.0%
9	01 May 2016	8,285	1,853	10,138	932	1,362	2,294	59.4%
10	01 Nov 2016	8,617	1,717	10,334	851	1,247	2,098	59.4%
11	01 May 2017	8,901	1,655	10,556	814	1062	1,876	56.6%
12	01 Nov 2017	9,237	1,505	10,742	711	979	1,690	57.9%
13	01 May 2018	9,481	1,423	10,904	652	876	1,528	57.3%
14	01 Nov 2018	9,783	1,281	11,064	601	767	1,368	56.1%
15	01 May 2019	10,025	1,177	11,202	594	636	1,230	51.7%
16	01 Nov 2019	10,288	1,040	11,328	524	580	1,104	52.5%
17	01 May 2020	10,488	961	11,449	493	490	983	49.8%

Wave #	Wave ending	Deceased	Withdrawn	Total ineligible	Non-Respondent	Respondent	Total eligible	Response rate (%)
18	01 Nov 2020	10,688	874	11,562	466	404	870	46.4%
19	01 May 2021	10,881	796	11,677	423	332	755	44.0%
20	01 Nov 2020	11,054	722	11,776	384	272	656	41.5%
21	01 May 2022	11,117	709	11,826	377	229	606	37.8%
22	01 Nov 2022	11,159	730	11,889	346	197	543	36.3%
23	01 May 2023	11,186	741	11,927	347	158	505	31.3%
24	01 Nov 2023	11,201	748	11,949	361	122	483	25.3%

NOTE: using 6MF questionnaires logged by 31 October 2023.

4.1.3 1946-51 cohort

Retention has been much higher among the 1946-51 cohort of women, where 92% of women responded to the first follow-up survey in 1998, with survey response rates slowly dropping over the next 25 years (See Table 4-3). The main reason for non-response among the 1946-51 cohort has been that the research team has been unable to contact the women (6% to 19% of eligible women between Survey 2 and Survey 10). The tenth survey for women born 1946-51 was deployed in mid-2022, with data collection closed at the end of August 2023. By mid-2023, around 11% of the cohort had died (n=1,468) while 17% (n=2,344) have opted to withdraw from active survey participation.

Table 4-3 Survey participation for women born 1946-51 (N=13,714)

Survey	Year (Age)	Deceased	Withdrawn	Total Ineligible	No contact	Did not do survey	Respondent	Total Eligible	Response Rate (%)
1	1996 (45-50)	—	—	—	—	—	13,714	13,714	100.0%
2	1998 (47-52)	50	216	266	856	254	12,338	13,448	91.7%
3	2001 (50-55)	119	447	566	925	997	11,226	13,148	85.4%
4	2004 (53-58)	216	656	872	1,051	886	10,905	12,842	84.9%
5	2007 (56-61)	329	920	1,249	832	995	10,638	12,465	85.3%
6	2010 (59-64)	475	1,177	1,652	903	1,148	10,011	12,062	83.0%
7	2013 (62-67)	675	1,749	2,424	1,088	1,051	9,151	11,290	81.1%
8	2016 (65-70)	878	2,121	2,999	1,379	714	8,622	10,715	80.5%
9	2019 (68-73)	1,173	2,209	3,382	1,658	718	7,956	10,332	77.0%
10	2022* (71-76)	1,468	2,344	3,812	1,921	824	7,157	9,902	72.3%

* As at 12 November 2023.

4.1.4 1973-78 cohort

Nearly 70% of women born 1973-78 (n=9,688) responded to the first follow-up survey (2000). From there, response rates among this cohort have slowly declined over time (Table 4-4), with a response rate of 56% at the last survey conducted in 2021-2022.

Retention compares well with other surveys of this highly mobile age group. The major reason for non-response among women born 1973-78 is that the research team has been unable to contact the women (between 21% and 39% of the cohort across all 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 and the study's ability to maintain contact.

Table 4-4 Survey participation for women born 1973-78 (N=14,247)

Survey	Year (Age)	Deceased	Withdrawn	Total Ineligible	No contact	Did not do survey	Respondent	Total Eligible	Response Rate (%)
1	1996 (18-23)	—	—	—	—	—	14,247	14,247	100.0%
2	2000 (22-27)	22	233	255	2,972	1,332	9,688	13,992	69.2%
3	2003 (25-30)	33	527	560	3,953	6,53	9,081	13,687	66.3%
4	2006 (28-33)	51	812	863	2,868	1,371	9,145	13,384	68.3%
5	2009 (31-36)	59	966	1,025	3,029	1,994	8,199	13,222	62.0%
6	2012 (34-39)	80	1,172	1,252	3,531	1,455	8,009	12,995	61.6%
7	2015 (37-42)	104	1,451	1,555	4,107	1,399	7,186	12,692	56.6%
8	2018 (40-45)	126	1,686	1,812	4,046	1,268	7,121	12,435	57.3%
9	2021 (43-48)	157	1,783	1,940	4,822	610	6,875	12,307	55.9%

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 was deployed in 2023 and is currently open for data collection.

Table 4-5 Survey participation for women born 1989-95 (N=17,010)

Survey	Year (Age)	Deceased	Withdrawn	Total Ineligible	No contact	Did not do survey	Respondent	Total Eligible	Response Rate (%)
1	2012-13 (18-23)	—	—	—	—	—	17,010	17,010	100.0%
2	214 (19-24)	1	682	683	2,621	2,362	11,344	16,327	69.5%
3	2015 (20-25)	6	694	701	3,469	3,879	8,961	16,309	54.9%
4	2016 (21-26)	8	1,745	1,753	4,400	1,850	9,007	15,257	59.0%
5	2017 (22-27)	13	1,944	1,957	4,745	1,813	8,495	15,053	56.4%
6	2019 (24-30)	22	2,049	2,071	5,264	1,329	8,346	14,939	55.9%

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.

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.

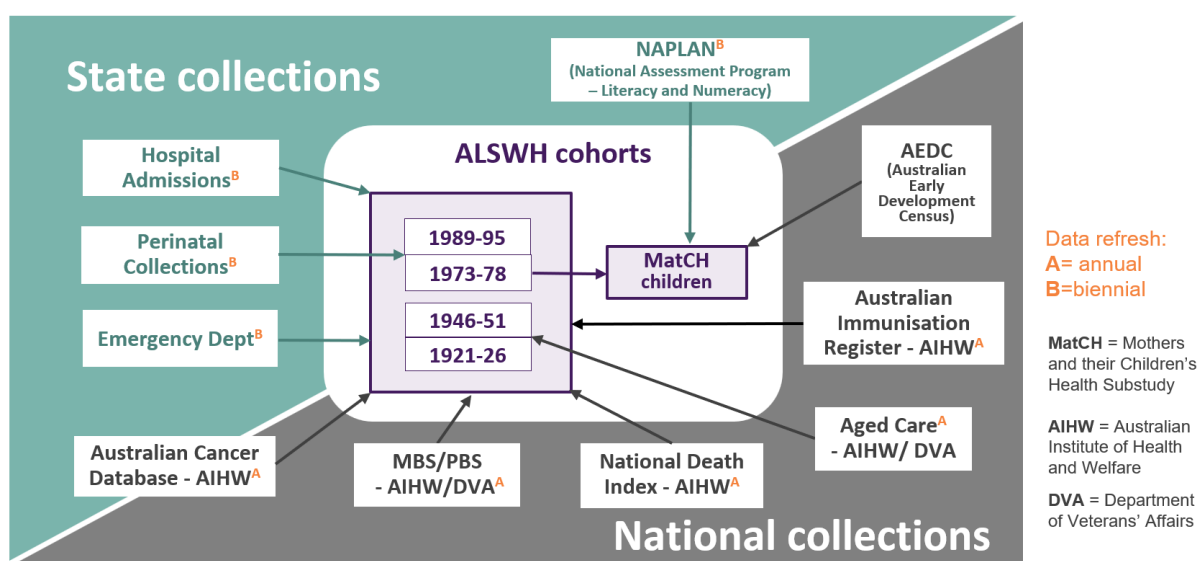


Figure 5-1 ALSWH Data Linkage Program.

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 1,881 (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.

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.

Table 5-1 ALSWH linked data holdings: National (at November 2023)

Data linkage unit	Data custodian	Collection name	Abbreviation used in this Chapter
Australian Institute of Health and Welfare (AIHW)	Australian Government	• Medicare Benefits Schedule	MBS
	Department of Health and Aged Care	• Pharmaceutical Benefits Scheme ¹	PBS
		• Australian Immunisation Register	AIR
	Department of Veterans' Affairs (DVA)	• Repatriation-MBS	R-MBS
		• DVA Aged Care Programs	DVA-AC
	AIHW	• National Aged Care Data Collection	AC
AIHW / State and Territory Death Registries	• National Death Index	NDI	
	• Cause of Death	COD	
AIHW / State and Territory Cancer Registries	• Australian Cancer Database	Cancer	

¹ Includes DVA PBS records

All national collections have been, or will be, updated in 2023, 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.

Table 5-2 ALSWH linked data coverage: National (at November 2023)

Collection	Updated MM/YYYY	Coverage MM/YYYY	Records N	Women Total N	Women, by cohort			
					1989-95 N	1973-78 N	1946-51 N	1921-26 N
MBS	03/2023	02/1984 - 12/2022	32,548,201	55,502	16,990	13,501	12,951	12,060
R-MBS	04/2021	01/1991 - 12/2020	1,968,285	2,828	-	-	114	2,714
PBS	03/2023	07/2001 - 12/2022	15,310,735	53,608	16,940	13,133	12,717	10,818
COD	06/2022	05/1996 - 12/2020	12,076	12,076	23	139	1278	10,636
Cancer	07/2023	01/1982 - 12/2019	8,073	7,166	104	460	2,749	3,856
AC	07/2022	*	†	14,333	-	-	3,935	10,98
DVA-AC	06/2021	*	26,484	2,396	-	-	32	2,289

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

† Multiple Aged Care component datasets, see Table 5.3 for details

Table 5-3 ALSWH linked data coverage: Aged Care Programs (at November 2023)

Program and content	Coverage MM/YYYY	Records N	Women Total N	Women, by cohort	
				1946-51 N	1921-26 N
Aged Care Assessment Program (ACAP) ¹ - Assessments	04/2003- 05/2016	17,230	7,562	311	7,251
Aged Care Funding Instrument (ACFI) ² - Assessments	04/2008 - 09/2021	13,009	5,111	196	4,915
Commonwealth Home Support Program (CHSP) ³ - Services	04/2016 - 06/2020	340,850	4,262	2,430	1,832
Home and Community Care (HACC) ³ - Services	01/2000 - 07/2015	166,109	11,216	2,118	9,098
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 Form - Assessments	04/2000 - 06/2020	7,237	4,167	2,163	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

Program and content	Coverage MM/YYYY	Records N	Women Total N	Women, by cohort	
				1946-51 N	1921-26 N
Resident Classification Scale (RCS) ⁴ - Assessments	10/1997 - 07/2008	6,209	1,907	24	1,883
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 2023: from Victoria and Western Australia. We will soon commence re-applying for the next state linkage round.

Table 5-4 ALSWH linked data holdings: State/Territory (at November 2023)

Data custodian	Data linkage unit	Collection Name
ACT Health	Centre for Health Record Linkage (CHeReL)	<ul style="list-style-type: none"> • ACT Admitted Patient Care • ACT Emergency Department Data Collection • ACT Perinatal Data Collection
NSW Ministry of Health	CHeReL	<ul style="list-style-type: none"> • NSW Admitted Patients Data Collection • NSW Emergency Department Data Collection • NSW Perinatal Data Collection
Queensland Health	Statistical Services Branch	<ul style="list-style-type: none"> • Queensland Hospital Admitted Patient Data Collection • Queensland Emergency Department Collection • Queensland Perinatal Data Collection

Data custodian	Data linkage unit	Collection Name
SA Department for Health and Wellbeing	SA NT Datalink	<ul style="list-style-type: none"> SA Public Hospital Separations SA Public Hospital Emergency Department Data Collection SA Perinatal Statistics Data Collection
Northern Territory Department of Health	SA NT Datalink	<ul style="list-style-type: none"> NT Public Hospital Inpatient Activity NT Public Hospital Emergency Department Data Collection NT Perinatal Trends Data Collection
Department of Health Tasmania	Tasmanian Data Linkage Unit (TDLU)	<ul style="list-style-type: none"> Tasmanian Public Hospital Admitted Patient Episodes Tasmanian Emergency Department Presentations Tasmanian Perinatal Data Collection
Department of Health and Human Services Victoria	Centre for Data Linkage Victoria (CVDL)	<ul style="list-style-type: none"> Victorian Admitted Episodes Dataset Victorian Emergency Minimum Dataset
Victorian Agency for Health Information (VAHI) ¹	CVDL	<ul style="list-style-type: none"> Victorian Perinatal Data Collection
Department of Health Western Australia	Data Linkage Branch	<ul style="list-style-type: none"> WA Hospital Morbidity Data Collection WA Emergency Department Data Collection WA Midwives Notification System

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

Table 5-5 ALSWH linked data coverage: State/Territory (at November 2023)

State and Collection		Updated MM/YYYY	Coverage MM/YYYY	Records		Women, by cohort			
				N	Women Total N	1989-95 N	1973-78 N	1946-51 N	1921-26 N
ACT	A	03/2022	07/2004 - 06/2020	3,521	1,061	416	257	174	214
	E	02/2022	05/2005 - 06/2020	4,937	1,346	706	281	185	174
	P		05/1997 - 11/2017	397	242	67	175	-	-
NSW	A	11/2021	06/2001 - 03/2021	120,540	15,465	4,148	3,680	3,697	3,940
	E		01/2005 - 03/2021	76,750	14,173	4,767	2,973	3,226	3,207
	P		01/1994 - 12/2020	8,003	3,861	917	2,944	-	-
NT	A	07/2021	06/2000 - 06/2019	2,755	501	148	168	156	29
	E		07/2000 - 06/2019	3,538	835	303?	213	274	45
	P		02/1986 - 12/2018	331	213	53	160	-	-

State and Collection		Updated MM/YYYY	Coverage MM/YYYY	Records Women		Women, by cohort			
						1989-95 N	1973-78 N	1946-51 N	1921-26 N
QLD	A	05/2021	06/2007- 06/2020	82,330	11,140	3,383	2,826	3,114	1,817
	E		07/2009 - 06/2020	36,746	8,306	3,091	1,881	2,098	1,236
	P		07/2007 - 12/2019	3,628	2,298	881	1,417	-	-
SA	A	03/2021	6/2000 - 06/2021	20,792	3,697	856	884	913	1,044
	E		7/2003 - 06/2021	17,038	3,598	1,122	794	875	807
	P	08/2021	03/1986 - 12/2018	2,570	1,211	243	899	69	-
TAS	A	11/2020	01/2007 - 12/2019	5,039	1,168	1,168	269	328	280
	E		01/2007 – 12/2019	1,498	1,469	482	306	401	280
	P		01/2005 - 12/2018	610	373	121	252	-	-
VIC	A	05/2021	01/2000 – 12/2020	113,146	12,643	3,355	3,573	2,941	2,774
	E		07/1999 – 12/2020	62,098	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	-	-
WA	A	04/2019	01/1970 - 12/2017	60,914	5,573	1,731	1,511	1,349	982
	E		01/2002 - 10/2018	29,351	4,725	1,624	1,162	1,117	822
	P		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 dataset composition (at November 2023)

CCMS dataset	External linked data collections used					
	Cancer	COD	MBS	PBS	AC	A
Asthma		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>
Chronic Obstructive Pulmonary Disease		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
Dementia		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CCMS dataset	External linked data collections used					
	Cancer	COD	MBS	PBS	AC	A
Depression/anxiety		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating Disorders		<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>
Essential Hypertension		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypercholesterolaemia		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ischaemic Heart Disease		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Musculoskeletal		<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory conditions		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stroke		<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>
Uterine Fibroids		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

A, hospital admissions/emergency.

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

For the cohort refresh, obtaining consent for linkage to MBS and PBS is currently on hold (the survey for the 1989-95 and 1973-78 cohort refresh is currently underway). Rather, consent for data linkage will be sought at a later stage. 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.

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.

ALSWH has a suite of substudies known as the 'ALSWH Intergenerational Studies' which include:

- Mothers and their Children's Health (MatCH1) Substudy
- Mothers and their Children's Health (MatCH2) Substudy – a follow-up of the children in MatCH1
- Mothers and their Children's Healthcare Experiences Substudy (MatCHES)
- Maternal and early life origins of Adolescent menstrual disorders and Pelvic Pain Substudy (MAPPS)

An application has been drafted for submission to AIHW HREC to link all child cohorts with national collections. Furthermore, an application has been submitted via the Australian Institute of Family Studies for data linkage of the ALSWH Intergenerational Studies with the Australian Early Development Census (AEDC). Data linkage will also be sought with the National Assessment Program – Literacy and Numeracy (NAPLAN). This will streamline the administrative process for data linkage. Table 5-7 details the current status of data linkage for MatCH. Linkage for AEDC and NSW NAPLAN was conducted by the AIHW.

Table 5-7 MatCH linked data coverage (at November 2023)

Data Collection	Data Custodians	Status
Australian Early Development Census (AEDC)	Australian Government Department of Education and Training	Linked data obtained in 2018 for AEDC 2009, 2012 and 2015 collections for N=946 children.
National Assessment Program – Literacy and Numeracy	<ul style="list-style-type: none"> • ACT Education Directorate • NSW Education Standards Authority • NT Department of Education • Queensland Curriculum and Assessment Authority • SA Department for Education • TAS Department of Education • VIC Curriculum and Assessment Authority • WA School Curriculum and Standards Authority 	Linked data obtained in 2019-20 from each State/territory. Coverage is from 2010 to 2018/19 for N=2,516 children. (NAPLAN was not collected in 2020 due to COVID-19).

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 Eoi round. The approval process is largely outside of our control - researchers are advised that for certain collections, gaining all the necessary approvals may take several months over and above ALSWH's internal Eoi processing time.

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 2023, 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 late 2023 and will provide an additional option for research collaborators using linked ALSWH data. Once 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.

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

Data Source	Approving body	Documents
AIHW Collections	AIHW HREC	<ul style="list-style-type: none"> • ‘AIHW s.29’ signed by all researchers • ALSWH Confidentiality Statement signed by all researchers • Updated Technical Assessment Form approved by AIHW Data Linkage Unit • HREC amendment through Ethics Online System (EthOS)
DVA	DDVA HREC	<ul style="list-style-type: none"> • Researcher CVs • Complete new application for every ALSWH Eol
NSW	CHeReL	<ul style="list-style-type: none"> • 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 Eols
NSW, QLD	NSW Population & Health Services Research Ethics Committee (PHSREC)	<ul style="list-style-type: none"> • Copy of Data Custodian approval (where use of SURE, or a new Substudy is involved) • Change in personnel form

Data Source	Approving body	Documents
		<ul style="list-style-type: none"> • Updated Study Protocol (where use of SURE, or a new Substudy is involved) • Copies of ALSWH Eols • HREC amendment through Research Ethics and Governance Information System (REGIS)
QLD	Qld Health Information, Investment and Research Office	<ul style="list-style-type: none"> • Copy of NSW PHSREC approval letter • Updated Public Health Act (PHA) form • Updated Project List
	Qld Health Statistical Services Branch	<ul style="list-style-type: none"> • Conditions of Disclosure document signed by all researchers
WA	Dept of Health WA HREC	<ul style="list-style-type: none"> • Researcher online registration and accepted invitation to join study project through WA Research Governance System (RGS) • WA Health Student Research and Confidentiality Declaration (signed by students) • Updated researcher and project list • HREC amendment through RGS
ACT, VIC, SA, NT	ACT Health HREC	<ul style="list-style-type: none"> • Researcher CVs • HREC amendment
VIC (except Perinatal)	CVDL	<ul style="list-style-type: none"> • Copy of ACT Health HREC approval letter • 'CVDL Schedule 2' signed by all researchers • Copies of ALSWH Eols with cover page summaries • Updated researcher and project list
VIC Perinatal	Austin Health HREC	<ul style="list-style-type: none"> • HREC amendment through Ethics Review Manager (ERM) • Researcher CVs
	VAHI	<ul style="list-style-type: none"> • Data request signed by all researchers • New Data Request lodged in VAHI Hub for every ALSWH Eol • Copy of Austin HREC approval letter • Copy of ALSWH Eol
SA/NT	SA NT Datalink	<ul style="list-style-type: none"> • SA Health Confidentiality Deed • 'NT Appendix B Deed 2' signed by all researchers

Data Source	Approving body	Documents
		<ul style="list-style-type: none"> • ‘Annexure B’ signed by all researchers • Copy of ACT HREC approval letter • Updated researcher list
TAS	Tas Health & Medical HREC	<ul style="list-style-type: none"> • HREC Amendment through Ethics Review Manager (ERM) • Copy of NSW PHSREC approval letter
	TDLU	<ul style="list-style-type: none"> • 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 280 projects have requested linked health record data to date and 114 ALSWH publications have used linked data.

5.4 Legal and ethical considerations for health record linkage

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

5.4.1 Applicable legislation and guidelines

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

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

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

- [NHMRC National Statement on Ethical Conduct in Human Research 2007](#) (Updated 2018; Chapters 2.2-3 and 3.2 are particularly relevant)
- [The Australian Code for the Responsible Conduct of Research 2018 – Management of Data and Information in Research \(2019\)](#)

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

- [Privacy public interest determination guide V1.0, June 2014](#).
- [Health Insurance Act 1973](#) (for MBS data).
- [Public Interest Disclosure Act 2013](#)
- [A Guide for Data Integration Projects involving Commonwealth Data for Statistical and Research purposes](#) (National Statistical Service).

ALSWH's [Participant Privacy Policy](#) is available on the web site and is regularly updated. All researchers and collaborators accessing linked data are also subject to ALSWH [Data Access Protocols](#) in addition to the Codes of Conduct and Privacy Policies of their home institutions. The University of Queensland and University of Newcastle Privacy Codes are:

- The University of Queensland Policy and Procedures library (<http://ppl.app.uq.edu.au/>), including: 1.60.01 Right to Information, 1.60.02 Privacy Management, 1.60.04 Records Management, 4.20 Research Conduct and Integrity, and 4.20.06 Research Data Management.
- The University of Newcastle Responsible Conduct of Research Policy (<https://policies.newcastle.edu.au/document/view-current.php?id=66>) and Privacy Management Plan (<https://www.newcastle.edu.au/privacy>)

ALSWH compliance with national guidelines was described in the [2019 Technical Report](#). The history of consent procedures is also detailed in that report, and is summarised Figure 5-2

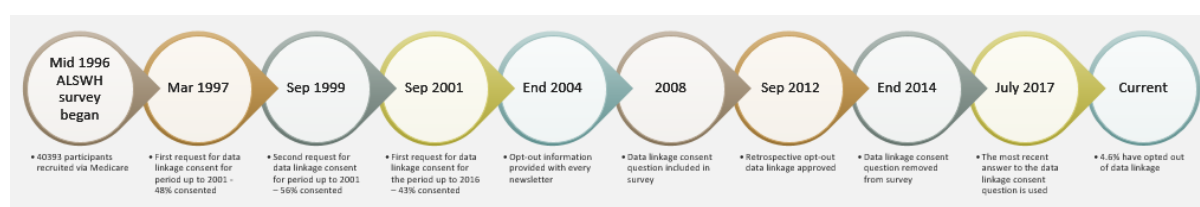


Figure 5-2 History of data linkage consent for ALSWH participants 1996-2018.

5.4.2 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.

Table 5-9 Health record linkage consent categories

Consent status	Relevant participants	Linkage
a) Declined	<ul style="list-style-type: none"> • Latest answer to the data linkage questions is 'No' • Explicitly declined data linkage by contacting ALSWH • Withdrawn from the Study because of privacy, confidentiality or Medicare data linkage concerns. 	NDI only; deterministic only (no personal information is to be transferred to/from AIHW)
b) Explicit consent*	Latest answer to the data linkage questions is 'Yes'.	All
c) Implicit consent	Not in category a) or b), who have completed ALSWH surveys since the introduction of opt-out consent (2005).	All except VIC Perinatal
d) Waived consent	Not in category a) or b), who have not completed a survey since the introduction of opt-out consent (2005).	All except VIC Perinatal; the Data Custodian for SA Cancer does not supply sensitive variables for this group

*This category was labelled as 'express consent' in previous Technical Reports.

Table 5-11 shows consent status for health record linkage, by cohort. We recently conducted a review of the definitions for different types of consent. The definitions of 'implicit' and 'waived' consent have been updated (refer to Appendix 13 for more details). Furthermore, 'express consent' has been relabelled as 'explicit consent' for clarity and consistency with other labels. Consequently, there are minor adjustments to the proportion of participants in each consent category and for each cohort.

Table 5-10 Health record linkage: Consent status of ALSWH participants

Cohort	Total N	Consent type							
		a) Declined		b) Explicit		c) Implicit		d) Waived	
1921-26	12,432	353	2.8%	9,131	73.4%	388	3.1%	2,560	20.6%
1946-51	13,714	763	5.6%	11,231	81.9%	434	3.2%	1,286	9.4%
1973-78	14,247	748	5.3%	9,893	69.4%	1,118	7.8%	2,488	17.5%
1989-95 ¹	17,010	17	0.1%	16,993	99.9%	N/A	N/A	N/A	N/A
TOTAL	57,403	1,881	3.3%	47,248	82.3%	1,940	3.4%	6,334	11.0%

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

5.4.3 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 DOHAC).

5.4.4 Current HREC approvals for health record linkage

Table 5-12 shows current HREC approvals for the ALSWH Data Linkage Project. The [National Mutual Acceptance Scheme](#) (NMA) aims to reduce duplication of coverage for cross-jurisdictional and/or multi-site projects. (There are some exceptions; we still require local approval for data linkage in WA, Tasmania and for the Victorian Perinatal Data Collection). In July, our ethics approval for Calvary Bruce Public Hospital (Reference 21-2020) was closed as this hospital (renamed North Canberra Hospital) is now part of Canberra Health Services. Consequently, ethical review is governed by the ACT Health HREC for which we have existing approval.

Table 5-11 Health record linkage: Current HREC approvals (at November 2023)

Ethics Committee	Reference	Approved	Expiry	Coverage
The University of Newcastle HREC (EC00144); ratified by The University of Queensland HRECs (EC00456/7)	H-2011-0371; 2012/HE000132	31/01/12	31/12/30	ALSWH Data linkage Project (subject to jurisdictional approvals)
	H-2014-0246; 2014/HE001213	07/08/14	31/12/25	MatCH Phase 1 Substudy (survey and record linkage)
	H-2021-0383; 2021/HE001641	15/12/21		MatCHES (survey and record linkage)
	H-076-0795; 2004/HE000224	26/07/95	31/12/30	ALSWH Survey program, original cohorts, (including COVID surveys and 1973-78 Cohort Refresh)
	H-2012-0256; 2012/HE000950	08/08/12	31/12/32	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
	RMS2001	17/02/22	none	MatCHES

Ethics Committee	Reference	Approved	Expiry	Coverage
Services Australia External Request Evaluation Committee				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)
Australian Institute of Health and Welfare HREC (EC00103)	EC2020/3/1115	17/08/20	31/12/30	All national collections
	EO2017/1/342	7/03/17	31/12/25	MatCH Phase 1 Substudy (child record linkage)
Defence/DVA HREC (EC00460)	EO14/022	19/12/14	30/06/24	DVA-AC & MBS
	E002/020	Oct 1996	none	Recruitment and consent (1946-51 & 1921-26 cohorts)
ACT Health HREC (EC00100)	ETH.6.13.148 - VIC collections - SA collections - NT collections	01/07/13 22/08/18 19/09/20 27/05/21	31/07/26	ACT, SA, NT and VIC collections (except VIC Perinatal).
Austin Health HREC (EC00204)	HREC/18/ Austin/163	17/07/18	none	VIC Perinatal
NSW Population and Health Services Research Ethics Committee (EC00410)	2019/ETH01837 (2011/11/357) - QLD collections	03/01/12 13/04/18	31/12/25	NSW & QLD collections
Tasmanian Health & Medical HREC (EC00337)	H0017192	19/04/18	24/03/24	TAS collections
Dept of Health WA HREC (EC00422)	RGS 2853 (2015/47) RGS 4844 (re-application)	15/12/15 16/08/21	31/12/21 16/08/24	WA collections

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 6 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, 2023, data from Survey 9 of the 1973-78 cohort will be archived, along with recent data from the six-month follow up survey of the 1921-1926 cohort.

7 Methodological issues

7.1 Aged Care Data Notes for Researchers

7.1.1 Introduction

The 2022 Aged Care data supplied to ALSWH from AIHW is complex. It consists of 32 datasets containing records of aged care service use for the 1921-26 and 1946-51 cohorts, describing aged care assessments and various types of aged care service use. The data documentation supplied with the data is comprehensive and is available when requesting aged care data from the ALSWH.

Three common research-based requirements when using the aged care data relate to:

- How to measure aged care at-home services in a longitudinally consistent way
- Identifying health conditions through the aged care assessments
- Identifying admissions to Permanent Residential Aged Care

The following sections will describe the current aged care datasets and provide a brief discussion around the above three points.

7.1.2 Brief summary of linked aged care datasets

The number of records and the time coverage of each data set is available on the ALSWH website (<https://alswh.org.au/for-data-users/linked-data-overview/national-data/metadata-for-alswh-aged-care-data-holdings/>).

Description of datasets

Table 7-1 lists the different service and assessment programs, the associated datasets, and provides a brief description of the type of information available in the dataset(s).

Table 7-1 Description of aged care datasets which were linked to ALSWH participants in 2022

Program	Dataset(s) name	Record information	Description
Aged Care Assessment Program (ACAP)	<i>acacap_2022</i>	Individual records of assessment	Records of individual assessments for participants. Multiple assessments per participant. Specifies details of each assessment relating to the individuals care needs, current services used, approvals for future services, demographics and health conditions.
Aged Care Funding Instrument (ACFI)	<i>acacfi_2022</i>	Individual records of assessment	Records of individual assessments. Multiple assessments per participant. Specifies health care needs of participants in residential aged care to allocate funding to providers. Records health conditions and functioning levels. This program replaced the RCS assessment program.

Program	Dataset(s) name	Record information	Description
Commonwealth Home Support Programme (CHSP) - Attendance	<i>acchsp_attend_2017_2022</i> <i>acchsp_attend_2018_2022</i> <i>acchsp_attend_2019_2022</i> <i>acchsp_attend_2020_2022</i>	Individual records of service	Part of the CHSP data. Relates the individual demographic lists (CHSP - Person) of participants to their records of service use (CHSP - Session). The CHSP programme replaced the HACC.
Commonwealth Home Support Programme (CHSP) - Person	<i>acchsp_person_2017_2022</i> <i>acchsp_person_2018_2022</i> <i>acchsp_person_2019_2022</i> <i>acchsp_person_2020_2022</i>	CHSP user characteristics	Part of the CHSP data listing all individuals who were CHSP users in that financial year. Includes some demographic and health status information. This file includes the ALSWH participant ID and is connected to the CHSP session information (that does not include the participant ID) through the CHSP - Attend datasets. The CHSP programme replaced the HACC.
Commonwealth Home Support Programme (CHSP) - Session	<i>chsp_session_2017_2022</i> <i>chsp_session_2018_2022</i> <i>chsp_session_2019_2022</i> <i>chsp_session_2020_2022</i>	Individual records of service	Part of the CHSP data listing all individual episodes of service, linking information on the service type, and date of service. This file does not include the ALSWH participant ID and is connected to the participant demographics (and ID) through the CHSP - Attend datasets. The CHSP programme replaced the HACC.
Commonwealth Home Support Programme (CHSP) - Provider	<i>chsp_provider_2017_20_2022</i>	CHSP provider characteristics	Lists the CHSP providers and gives their status (Not for profit, For profit, Government etc.) and the state they are in. Is linked to the CHSP - Session dataset, so for each episode of service, the provider can be identified. The CHSP programme replaced the HACC.
Home and Community Care (HACC)	<i>achacc_v1_2022</i> <i>achacc_v2_2022</i>	Total HACC use per calendar quarter	The HACC details hours of service use per quarter for all types of home care services (e.g., Domestic Assistance, Meals at Home, Home Maintenance). For some type of assistance, it details counts of items (meals received, linen services etc.), or the dollar cost of the service per quarter (e.g., home modifications). The HACC data is separated into two very similar datasets (Version 1: 2001 - 2005, Version 2: 2005 - 2015), with the newer dataset (Version 2) having more information about the participants functional status.
Home Care Package (HCP) - Assessments	<i>achcp_assessment_2022</i>	Individual records of service approval	Lists the HCP level of care approved from an individual's assessment (i.e., Home Care level 1, 2, 3 or 4.). Includes data from multiple historical (overlapping) home care programs i.e., CACP (1992-2013), EACH (2005-2013), EACHD (2008-2013) and HCP (2013-present). Includes information on the level of

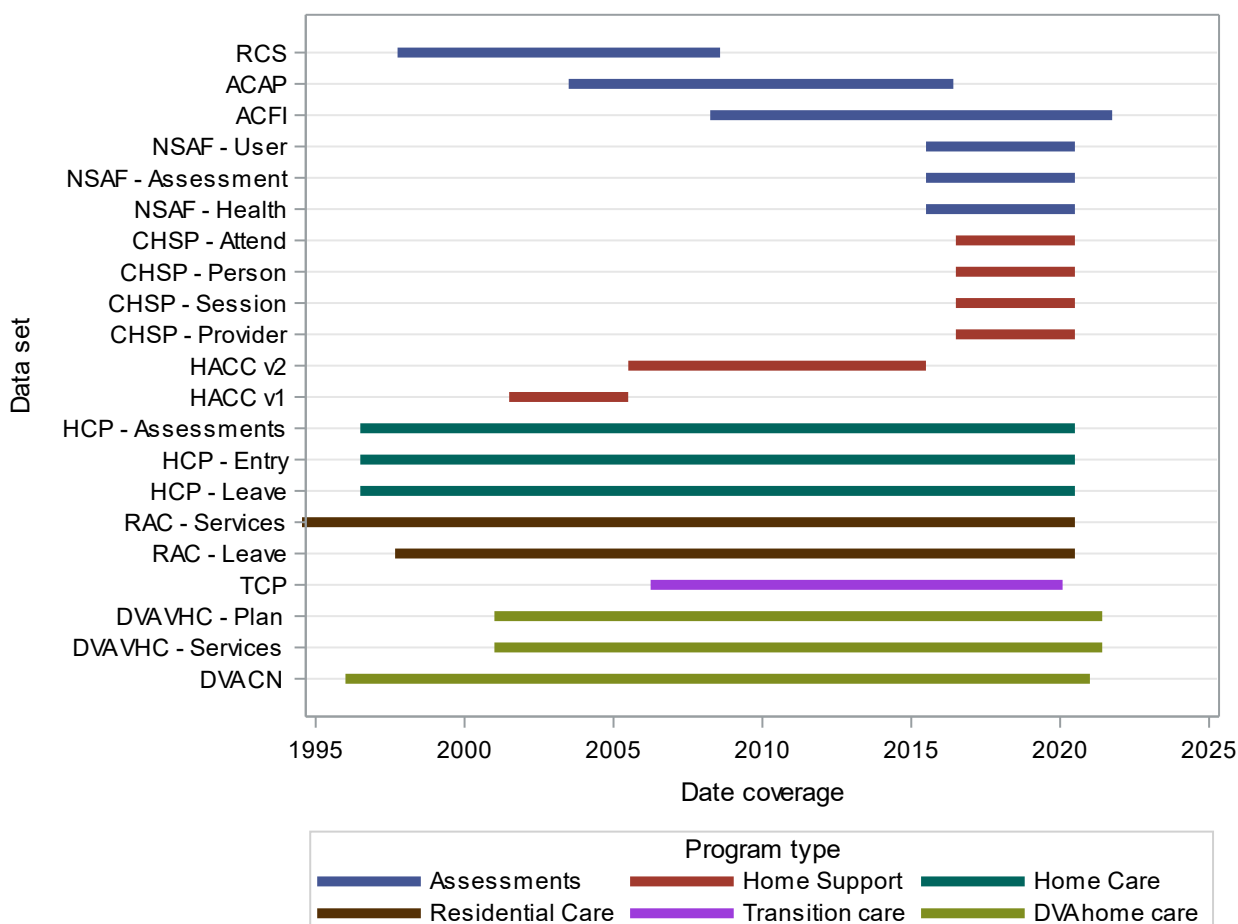
Program	Dataset(s) name	Record information	Description
			care approved and the start and end date of that approval - note that this is an approval for service use, not a record of service use i.e., even though a participant may have been approved for a service, they might not have actually used it.
Home Care Package (HCP) - Service Use	<i>achcp_entry_2022</i>	Individual records of HCP use	Lists the HCP service use of participants by care level. Includes dates of entry and exit to the care level as well as reasons for departure and some other basic participant demographics.
Home Care Package (HCP) - Leave	<i>achcp_leave_2022</i>	Individual records of leave from HCP	List of the episodes of leave taken from the HCP program. Includes the reason for the leave and the start and end date of the leave.
National Screening and Assessment Form (NSAF) - User	<i>acnsaf_ac_user_2022</i>	NSAF user characteristics	Participant details of those having an NSAF assessment. Contains some basic demographics and existing health conditions.
National Screening and Assessment Form (NSAF) - Assessment	<i>acnsaf_assessment_3006_2022</i> <i>acnsaf_assessment_wide_2022</i>	Individual records of assessment	Information on NSAF assessments. Note the two versions of this data ("3006" vs. "wide"), with the "wide" dataset containing more in-depth information about the assessment.
National Screening and Assessment Form (NSAF) - Health	<i>acnsaf_health_main_2022</i>	NSAF user health conditions	Lists all health conditions identified in the NSAF assessment for each participant.
Residential Aged Care (RAC) - Services	<i>acrac_2022</i>	Individual records of RAC admission	Lists all episodes of RAC (respite and permanent) care per individual. Includes information about the reason for discharge and some basic demographics.
Residential Aged Care (RAC) - Leave	<i>acrac_leave_2022</i>	Individual records of leave from RAC	Lists all episodes of leave from RAC, including the reason for the leave (Social, Hospital, Pre-entry leave etc.).
Resident Classification Scale (RCS)	<i>acracs_2022</i>	Individual records of assessment	Lists assessment information from the RCS (predecessor of the ACFI)
Transition Care Program (TCP)	<i>actcp_days_2022</i>	Number of days per calendar month using TCP	Records the number of days of transition care per participant per calendar quarter.
Department of Veterans Affairs - Veterans Home Care (DVA VHC) - Plan	<i>acvhc_plan_2021</i>	Individual records of care plans	Records details of Veterans Home Care received, including the type, period and frequency of service
Department of Veterans Affairs - Veterans Home Care (DVA VHC) - Services	<i>acvhc_integrated_client_2021</i>	Individual records of service	Records individual episodes of veteran's home care service, including descriptions of the type of service and cost.
Department of Veterans Affairs	<i>accommnursingdvambbs21mid</i>	Records of service use per 4-week period	Records 4 weekly periods of use of community nursing. The "Item

Program	Dataset(s) name	Record information	Description
(DVA) - Community Nursing			Numbers" are summaries of both the number and types of visits. The record start date is always the first date of service received, and then the end date is 28 days from that date. Therefore, the item numbers summarise the type of quantity of use in the 28 days from first use.

Time coverage of aged care datasets

It is important to be aware that the date coverage of each of the programs/datasets is different. Figure 7-1 shows the date coverage for each program listed in Table 7-1 above, grouped by program type.

Figure 7-1. Date coverage for the ALSWH 2022 aged care datasets by program type.



7.1.3 Measuring at-home care in a longitudinally consistent way

Programs providing at-home care in the available linked aged care data include:

- Home support programs:
 - Home and Community Care (HACC v1/v2)
 - Commonwealth Home Support Program (CHSP)

- Home Care (captured in the HCP dataset):
 - Community Aged Care Packages (CACP)
 - Extended Aged Care at Home (EACH)
 - Extended Aged Care at Home – Dementia (EACHD)
 - Home Care Packages (HCP)
- Department of Veterans Affairs (DVA) – Veterans Home Care
- Department of Veterans Affairs (DVA) – Community Nursing

Generally, the Home Support programs deliver 1 or 2 basic services to participants and represent lower levels of support compared to the Home Care packages which deliver a higher level of care. Similarly, the Veterans Home Care program is a low-level care program and DVA Community Nursing provides clinically required nursing and personal care services. Both DVA programs are only available to those participants with eligible DVA entitlements (veterans, war widows, widowers, Gold Card holders etc.). These programs provide different levels of care based on needs and entitlements, so participants can engage with a range of these services over their lifetime as their needs change.

i. At home care program descriptions:

The **HACC data records** the quantity of service use per HACC participant per calendar quarter. It contains no finer detail on when the services were delivered, or the number of events of service. The service quantity is measured by either hours of use (domestic assistance, care at centre, case management etc.), counts of use (linen service, meals at home, transport trips etc.) or the dollar cost of the services for the quarter (home modifications). There are two versions of the HACC dataset: Version 1 (2001 – 2005) and Version 2 (2005 - 2015). The two versions are similar, however version 2 collects information on more types of services received by participants, and also includes additional demographic and health measures.

The **CHSP data records** the dates on which individual ‘sessions’ of service were conducted. It contains no information on the quantity/length of services that each session entailed. It records the service type (General House Cleaning, Nursing, Home Modifications etc.) that comprised each session.

The **HCP data records** the dates of entry and exit from different care levels. It contains no information regarding individual dates on which services were used or the quantity of use. Prior to the introduction of the current Home Care Program (2013) the CACP, EACH and EACHD programs were used. Data on all four of these programs are included in the HCP datasets.

The **DVA veterans home care data** is similar to the CHSP data in that it identifies the dates of individual sessions of service, rather than quantity of service. It includes information on the type of service used, and the amount paid for that service. There is an additional table that records the start and end dates of approved plans from the DVA for veterans home care in a similar way to the HCP data. The DVA community nursing data is more complex in how it codes service use. It uses a set of predefined codes to indicate the (approximate) number and type of visits in a 28-day period (see [here](#) for a list of codes and associated fees). It does not provide exact dates of service.

Analysing these services in a consistent manner is challenging due to the different measures of use each program records. Based on which datasets are of interest, different approaches may be used to measure at home service use, however, the following notes may be worth considering.

ii. The time frame of the analysis

As indicated by Figure 7-1, the coverage of datasets differs. This has implications for which programs will need to be investigated. Considering a more restrictive time frame for analysis may reduce the number of datasets that need to be analysed, overall reducing analysis burden. This obviously comes at the cost of losing longitudinal data.

iii. 'Gaps' in the Home Support data

The HACC program ended in mid-2015 and was taken over by the CHSP. The first year of data for the CHSP is not provided in the datasets due to its low quality. Different states also began participating in the CHSP progressively, so there is not national coverage until WA began participating in 2018. Subsequently, there is a 1-year gap (mid 2015-2016) where there is no data available on Home Support services, and until 2018, the CHSP data is piecemeal by state. If analysing home support data, the choice of an appropriate analysis period should consider this missing data.

iv. Fact of service vs date of service vs frequency of service

The measure that is consistent across home care data is fact of service. This refers to a (potentially broad) time frame during which the participant is using the service. Individual dates of service are not available in all data sets (HACC, HCP, DVA nursing), neither is quantity of service (HCP, CHSP, HCP, DVA home care). If multiple programs of home service use are of interest in an analysis, a broad definition of use may be considered in order to guarantee each individual service can be captured accurately in the definition. This could take the form of calendar years/quarters where a participant used (at least some) service.

v. Level of care

Each at home care dataset provides (at least some) information regarding the program of care that the participant is receiving. This is a good way to differentiate users of care. For example, it may be reasonable to categorise use by whether a participant was receiving Home Support vs Home Care, and one is able to further categorise Home Care by its different levels of care (i.e., high versus low level care).

vi. Movement through levels of care/programs

Generally, aged care recipients can receive at home care from only one program at a time depending on their level of care. (Note: Participants who receive DVA benefits may also receive DVA home care support in addition to home care support at different points in time.) Categorization of the use of different levels of care/programs may wish to consider the *patterns* of service use over a period of time, rather than facts of use for each program. For example, a participant may be receiving Home Support (HACC/CHSP). Due to increasing needs they may require increased support and move into a Home

Care package (HCP/CACP). If an analysis looked at home support use only, this participant would go from a user to a non-user, while in reality they have moved to a higher level of care/use.

vii. DVA users

The 1921-26 ALSWH cohort has a significant proportion of women who are eligible for services through the Department of Veterans Affairs. These users may get some or all of their at-home care through the DVA. To reduce the potential of underreporting of service use, the Veterans Home Care and Community Nursing datasets should be considered for use in some circumstances, particularly for the older cohorts where use of DVA services may be quite high.

7.1.4 Health conditions from Aged Care Assessments

The Aged Care Assessment Programs record information that is relevant to measuring a participant's care needs. Included in parts of the aged care assessment datasets are condition level codes indicating relevant health conditions that have been identified during the assessment. These data can be highly useful to researchers wanting to identify chronic health conditions. As a result, these data form a key part of the ALSWH CCMS algorithm (<https://alswh.org.au/for-data-users/linked-data-overview/ccms-datasets/>) which identifies specific chronic conditions. However, researchers may wish to identify their own conditions of interest using all available data, including the aged care assessment datasets. Table 7-2 summarises how health conditions are recorded across the three aged care assessment datasets, including the relevant variables and codes.

In each of the programs, the health conditions are recorded based on whether they are having an impact on the person's need for assistance with activities of daily living and social participation at the time of the assessment, as evaluated by the assessor. The NSAF includes qualifying information regarding the "primary" health condition of a participant and how the condition was diagnosed (i.e., hospital confirmed, GP confirmed, other health practitioner diagnosis, self-reported). Not all pre-existing health conditions will be recorded in the assessment as this will depend on whether the condition is deemed to be impacting a person's need for assistance and will be constrained by the number of available variables to capture health conditions in the dataset.

Table 7-2 Details of Aged Care Assessment datasets linked to the ALSWH containing information on participant health conditions.

Assessment Program	Dataset Name	Variable(s) containing health condition codes	Coding scheme
ACAP	<i>acacap_2022</i>	HC1, HC2, HC3, HC4, HC5, HC6, HC7, HC8, HC9, HC10	The health conditions are coded using a four-digit numeric code that is based on the ICD-10 classifications. See ACAP MDS data dictionary Appendix H for the coding for specific conditions: https://www.aihw.gov.au/getmedia/f54990eb-6db0-4e4e-b3de-2f54b46c1508/acapdd.pdf.aspx?inline=true
ACFI	<i>acacfi_2022</i>	Q13_C1, Q13_C2, Q13_C3, Q14_C1, Q14_C2, Q14_C3	The health conditions are coded in the same way as the ACAP health conditions (above), with the addition of two other codes (550A – Depression / 550B – Psychoses/schizophrenia) Note that Q13_c1, Q13_c2, Q13_c3 exclusively list codes related to “Mental and Behavioral Disorders” while Q14_c1, Q14_c2, Q14_c3 lists all other conditions.
NSAF	<i>acnsaf_health_main_2022</i>	HEALTH_CONDITION_CDE	This uses a very similar 4-digit coding scheme as the ACAP but may include some additional codes. Refer to Appendix B of the NSAF user guide for the list of codes and their description: https://www.health.gov.au/sites/default/files/documents/2020/01/my-aged-care-national-screening-and-assessment-form-user-guide_0.pdf

The maximum number of conditions that are recorded in each dataset are:

- ACAP: 10 (one for each HC* variable)
- ACFI: 6 (one for each of the Q13_C*/Q14_C* variables)
- NSAF: No limit (This dataset is in long format so can have as many records per participant as there are recorded health conditions)

7.1.5 Admissions to residential aged care

Admissions to residential aged care (RAC) are recorded in the *acrac_2022* dataset. It lists the entry and exit dates from RAC, as well as the admission type (Respite / Permanent) and the discharge reason (Return to home, to another RACS, death etc.). This data is reasonably self-explanatory, however, there are a handful of issues to note, primarily around leave from RAC and the way the data is recorded.

i. Leave from RAC

Once admitted to RAC, a participant can take leave from aged care for several reasons. The *acrac_leave_2022* dataset records periods of leave from RAC, including start and end dates and the reason for the leave. Of note is the “pre-entry leave” category. This specifies a period right at the beginning of residential aged care where a participant has secured a spot in an aged care facility but is not yet a resident, potentially still living in the community, or a hospital/rehab facility. This period of leave should be considered when identifying dates of admission to RAC if exact days of entry to a facility are of interest.

Hospital leave is another leave category that may be of interest to researchers. While the reason and type of hospital admission is not recorded in the aged care data, it can be combined with the state hospital data that is linked to the ALSWH to get a fuller picture of the health status of women in RAC, and the services they are using/require.

ii. RAC data structure and data stitching

The *acrac_2022* is structured in “long” format where participants may have multiple records. These records can represent multiple periods of distinct use, e.g., multiple episodes of short-term respite care. Multiple records can also form individual parts of a single period of continual care/admission. These can be identified by sequential records that have the same end/start dates. This can indicate movement between different providers or facilities or may represent some other administrative change.

Of interest to researchers may be sequences of records for a participant that start with a respite admission and are immediately followed by admission to permanent care. If a researcher is interested in identifying the first date that a participant entered care permanently, it may be misleading to look at the first admission date for records that are flagged as permanent admissions if this admission was immediately preceded by a respite admission. “Stitching” the RAC admission records together for each participant may be worthwhile in these cases. This process would identify and combine records where the end date and start date of sequential records are the same into single periods of admission. This would give a better impression of continual periods of care and more accurate dates for initial admission to care.

7.2 Summary of recently introduced scale instruments

New instruments and scales may be introduced into ALSWH surveys through the evolution of survey development. Where possible, the ALSWH surveys include instruments which have been developed to measure a particular trait or behaviour which is appropriate for the cohort(s) and have been published or used elsewhere. These instruments typically have multiple items which are combined to obtain an overall score and/or several sub-scale scores. Table 7-3 provides a summary of scale instruments which have been included in recent surveys for the three younger cohorts.

Table 7-3 Scale instruments included in recent surveys for the three younger cohorts (born 1989-95, 1973-78, 1946-51)

	Cohort	1989-95		1973-78		1946-51	
	Year	2017	2019	2018	2021	2016	2019
	Wave	5	6	8	9	8	9
Instrument/Scale							
Brief Resilience Scale		—	—	—	✓	✓	✓
Subjective Happiness Scale		—	✓	—	—	✓	✓
Rosenberg Self Esteem Scale		✓	✓	—	—	—	
Social Wellbeing Scale		—	—	—	—	—	✓

Details concerning preliminary validation work is provided below for the Brief Resilience Scale and the Social Wellbeing Scale. It is anticipated that similar validation work will be carried out for the Subjective Happiness Scale and the Rosenberg Self Esteem Scale in the future.

7.2.1 Brief Resilience Scale

The Brief Resilience Scale (BRS) is intended to measure the ability to bounce back or to recover from stress, noting that this ability may be particularly important for people who are already ill or are dealing with ongoing health-related stresses.

Source reference

Smith, B.W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., Bernard, J. (2008) The Brief Resilience Scale: Assessing the Ability to Bounce Back. *International Journal of Behavioral Medicine*. 15: 194–200. <https://doi.org/10.1080/10705500802222972>.

Attributes and scoring

The scale comprises six items (Figure 7-2), with positive wording used for items (A), (C) and (E) and negative wording used for items (B), (D) and (F). Participants are asked to indicate the extent to which they agree with six statements by using the following scale: strongly disagree = 1, disagree = 2,

neutral = 3, agree = 4, strongly agree = 5. The BRS is scored by reverse coding items (B), (D), and (F) and finding the mean of the six items. The BRS score has a range from 1 to 5.

Figure 7-2 The Brief Resilience Scale

Please indicate the extent to which you agree with each of the following statements

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
(A) I tend to bounce back quickly after hard times	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(B) I have a hard time making it through stressful events*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(C) It does not take me long to recover from a stressful event	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(D) It is hard for me to snap back when something bad happens*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(E) I usually come through difficult times with little trouble	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F) I tend to take a long time to get over set-backs in my life*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* Item requires reverse scoring

Use in ALSWH surveys

The BRS has been included in three ALSWH survey waves so far:

- 1946-51 cohort - Wave 8 (2016) – Question 47
- 1946-51 cohort - Wave 9 (2019) – Question 55
- 1973-78 cohort - Wave 9 (2021) – Question 12

The wording for items and response options included in ALSWH surveys is unchanged from the original scale proposed by Smith and colleagues, although there were some minor differences in the instrument instruction between surveys. For the 1946-51 cohort Waves 8 and 9, the instruction was “Please respond to each item by marking one on each line”, while the instruction was “Please indicate the extent to which you agree with each of the following statements: (Mark one on each line)” for the 1973-78 cohort Wave 9. At each wave, the questions were identical between the two modes of delivery (i.e. were the same for online or paper options).

This question has been well answered by the women (Table 7-4). The mean overall scores range from 3.53 to 3.69, depending on the cohort and survey wave. More than 95% of women provided a response for all items. The rate of missing ranged from 0.99% to 2.29% across items, depending on the cohort and survey wave.

Table 7-4 A summary of the BRS mean score and missing patterns observed in three recent ALSWH surveys

Cohort Survey/wave (Year)	N	Mean Overall Score	Missing patterns (%)			Selected either 'Strongly agree' or 'Strongly disagree' for all items%	Selected 'Neutral' for all items %
			No missing items	Some items missing	All items missing		
1946-51 cohort Wave 8 (2016)	8,622	3.65	98.1	1.1	0.8	6.0	3.9
1946-51 cohort Wave 9 (2019)	7,956	3.69	95.9	2.6	1.4	6.0	4.4
1973-78 cohort Wave 9 (2021)	6,875	3.53	98.1	0.8	1.1	4.8	2.9

The behaviour and validation of this scale for use in the ALSWH setting is currently being investigated; it is anticipated that the results from this methodological work will be available soon.

7.2.2 Social Wellbeing Scale

This instrument intends to capture participants' positive social health status, measuring dimensions of social integration, social contribution, social coherence, social actualisation and social acceptance.

Source reference

Keyes, C. L. M. (1998) Social well-being. *Social Psychology Quarterly*. 61(2): 121-140. <https://doi.org/10.2307/2787065>

Attributes and scoring

Two scales were tested and presented by Keyes (1998) – a comprehensive 50-item instrument in Study 1, and a shorter 15-item instrument in Study 2. The shorter scale included three questions for each of the five social wellbeing dimensions, namely social integration, social acceptance, social contribution, social actualisation, and social coherence. The questions were presented in random order. In the shorter scale, each item had seven response options from *strongly disagree* (=1) to *strongly agree* (=7). Eight items required reverse scoring. For each social wellbeing dimension, the relevant item scores are summed, taking into account reverse scoring, with a higher score indicating more positive social wellbeing (total score range for each dimension 3 to 21). Scores are calculated only if all the items in each scale were answered.

The shorter instrument by Keyes (15 items) was chosen for inclusion in the 9th main survey for ALSWH women born 1946-51, although there were some differences in the delivery of the instrument. For the ALSWH survey, only six response options were included ranging from *strongly disagree* (=1) to *strongly agree* (=6), without the "Don't Know" option included in the Keyes study (total score range for each

dimension 3 to 18). The items in the ALSWH survey were presented in the order in which they appear in Appendix A of the Keyes paper, which grouped items by the scale dimension (see Table 7-5).

Table 7-5 Social Wellbeing Scale used by Keyes (1998, Study 2) and ALSWH (women born 1946-51)

Dimension	Item	Scoring ^a	Item Order ^b	
			Keyes	ALSWH
Social Integration	I don't feel like I belong to anything I'd call a community	-	2	1
	I feel close to other people in my community	+	6	2
	My community is a source of comfort	+	11	3
Social Acceptance	People who do a favour expect nothing in return	+	3	4
	People do not care about other people's problems	-	10	5
	I believe that people are kind	+	14	6
Social Contribution	I have something valuable to give to the world	+	4	7
	My daily activities do not produce anything worthwhile for my community	-	7	8
	I have nothing important to contribute to society	-	15	9
Social Actualisation	The world is becoming a better place for everyone	+	5	10
	Society has stopped making progress	-	9	11
	Society isn't improving for people like me	-	13	12
Social Coherence	The world is too complex for me	-	1	13
	I cannot make sense of what's going on in the world	-	8	14
	I find it easy to predict what will happen next in society ^c	+	12	15

^a The scoring direction (+/-) of the relevant item.

^b The order in which the items were presented to respondents for (i) Keyes, 1998, Study 2; and (ii) ALSWH - 9th main survey for women born 1946-51.

^c In the analysis in the Keyes paper this item was found to suppress the internal reliability of the scale and was dropped from the analysis

Use in ALSWH surveys

The Social Wellbeing scale has been included in one survey to date – the 9th main survey for ALSWH women born 1946-51.

This question was well answered by the women (Table 7-6). All items were answered by 88% of women, 10% of women were missing responses for some items, and 2% of women had missing responses for all items. The rate of missing across individual items ranged from 2% to 4%. Very few women responded 'Strongly disagree' to all items (n=5, >0.1%), and no-one answered 'Strongly agree' to all items.

Table 7-6 Response proportions for the Social Wellbeing scale among women born 1973-78 (Wave 9, 2021; n=7,956)

Item	Missing (%)	Strongly disagree (%)	Moderately disagree (%)	Slightly disagree (%)	Slightly agree (%)	Moderately agree (%)	Strongly agree (%)
Social Integration							
<i>I don't feel I belong to anything I'd call a community</i>	3.0	43.0	18.9	9.6	11.3	9.1	5.1
<i>I feel close to other people in my community</i>	3.2	6.0	7.5	8.2	17.1	32.8	25.2
<i>My community is a source of comfort</i>	3.7	6.8	8.0	8.6	22.3	29.8	20.8
Social Acceptance							
<i>People who do a favour expect nothing in return</i>	3.6	3.7	4.9	6.8	16.5	34.5	30.1
<i>People do not care about other people's problems</i>	3.9	25.8	27.0	15.7	15.8	8.7	3.1
<i>I believe that people are kind</i>	3.4	1.1	1.5	1.9	12.5	48.0	31.6
Social Contribution							
<i>I have something valuable to give the world</i>	4.2	3.0	4.0	5.6	23.2	37.8	22.2
<i>My daily activities do not produce anything worthwhile for my community</i>	3.4	24.6	23.7	14.6	17.7	11.3	4.6
<i>I have nothing important to contribute to society</i>	3.0	36.0	25.6	14.9	10.7	6.3	3.5
Social Actualisation							

Item	Missing (%)	Strongly disagree (%)	Moderately disagree (%)	Slightly disagree (%)	Slightly agree (%)	Moderately agree (%)	Strongly agree (%)
<i>The world is becoming a better place for everyone</i>	2.4	19.9	23.8	23.7	14.4	13.6	2.3
<i>Society has stopped making progress</i>	3.0	9.7	21.9	22.2	24.0	14.5	4.8
<i>Society isn't improving for people like me</i>	4.0	14.8	23.7	21.7	20.8	10.9	4.1
Social Coherence							
<i>The world is too complex for me</i>	3.8	18.8	21.2	17.0	25.2	10.6	3.4
<i>I cannot make sense of what's going on in the world</i>	2.9	20.4	21.9	13.2	23.9	12.3	5.4
<i>I find it easy to predict what will happen next in society</i>	2.8	17.2	24.1	22.9	18.8	11.4	2.8

For each social wellbeing dimension, scores were calculated for around 95% of women (Table 7-7).

Table 7-7 Descriptive statistics for the Social Wellbeing dimension scores among women born 1946-51 (n=7,956)

Dimension of social wellbeing	Missing n (%)	Mean Score	Std Dev	Observed Min/Max	Interquartile range (P ₂₅ , P ₇₅)
Social Integration	371 (4.7)	13.4	3.83	3/18	(11, 16)
Social Acceptance	425 (5.3)	14.1	2.66	3/18	(12, 16)
Social Contribution	393 (4.9)	13.5	3.39	3/18	(11, 16)
Social Actualisation	382 (4.8)	10.6	3.12	3/18	(9, 12)
Social Coherence	365 (4.6)	10.9	2.98	3/18	(9, 13)

The behaviour and validation of this scale for use in the ALSWH setting is currently being investigated; it is anticipated that the results from this methodological work will be available soon.

7.3 Key Longitudinal Variable Datasets

Authors: Nicholas Egan, Peta Forder, Paul McElwee

7.3.1 Overview

It can be a substantial undertaking to generate longitudinal datasets of selected variables ('long data') due to the number of survey waves and the different variable names at each survey wave for the original three cohorts. In order to reduce duplication of common work by data users, the **Key Longitudinal Variable (KLV) datasets** have been generated with frequently used variables and are now available for data users.

Each cohort has its own longitudinal KLV dataset, using available surveys waves as appropriate for each cohort:

- Born 1989-95: Waves 1-6
- Born 1973-78: Waves 1-9
- Born 1946-51: Waves 1-9
- Born 1921-26: Waves 1-6

Documentation on the KLV datasets has been added to the ALSWH website under 'Survey data'. The KLV datasets will be provided by the ALSWH Data Manager (alswhdata@uq.edu.au) alongside survey data requests for approved projects (in the same way as the participant status files). Data users who have already received data for their project can contact the ALSWH Data Manager to request the KLV datasets.

7.3.2 Issues to note with the KLV datasets

- ***Collapsed variables***
 - We have included commonly used collapsed versions of some variables; these are denoted by the variable suffix `_#gp` where `#` refers to the number of levels in the collapsed variable. All variables with original response values are retained in the survey datasets, in the event data users wish to use an alternative categorisation of a variable. The categories included in the collapsed versions of variables are provided in the table below.
- ***Missing values***
 - Missing values have been left unchanged. If the raw response value for survey variable was a missing value for a given survey, then the corresponding longitudinal response for that variable is also set to missing in the KLV dataset.
- ***Values applied across surveys***
 - Country of birth was only asked at one survey wave for each cohort, usually the first survey. As this variable is time-invariant, it has been applied across all survey waves. Note that in the 1989-95 cohort, country of birth was asked at Wave 2 and was

subsequently back-filled for Wave 1. Any 1989-95 cohort participants who did not respond to Wave 2 will have missing data for country of birth.

- Highest qualification was only asked at Wave 1 in the 1921-26 cohort and Wave 1 and Wave 6 in the 1946-51 cohort. As highest qualification is less likely to change in these older women, highest qualification is 'filled-in' for the later survey waves in the 1921-26 based on their response at Wave 1. Similarly, for the 1946-51 cohort, their Wave 1 response is used to fill-in Waves 1 to 5, and their Wave 6 response is used to fill-in Waves 7 to 9.

- **Available formats**

- The KLV datasets are available in SAS, Stata, and SPSS formats.

The KLV datasets include the following variables presented in the table below. Cells shaded in yellow denote collapsed categories of commonly used variables. SF-36 scores are not included in the 1989-95 KLV dataset as the SF-36 instrument is not routinely included in surveys for this cohort.

Table 7-8 Variable names, variable labels and categories in KLV datasets

KLV Variable	Label	Categories
idalias/idproj	ID number	NA
survey	Survey wave	1 to 9, depending on cohort
age	Participant age at time of survey return	NA
ariappg	Area of residence (original levels)	1='Major cities' 2='Inner regional' 3='Outer regional' 4='Remote' 5='Very remote' 6='Overseas'
marital	Marital status (original levels)	1='Married' 2='Defacto' 3='Widowed' 4='Separated' 5='Divorced' 6='Never married'
smokst	Smoking status (original levels)	1='Never-smoker' 2='Ex-smoker' 3='Smoker, less than 10 per day' 4='Smoker, 10-19 per day' 5='Smoker, 20 or more per day' 6='Smoker, unknown cigarettes per day'

KLV Variable	Label	Categories
alcnhmrc	Alcohol consumption (original levels)	1='Low risk drinker' 2='Non-drinker' 3='Rarely drinks' 4='Risky drinker' 5='High risk drinker'
mh	SF-36 Mental Health score	NA
pf	SF-36 Physical Functioning score	NA
srh	Self-rated health (original levels)	1='Excellent' 2='Very good' 3='Good' 4='Fair' 5='Poor'
hq	Highest qualification (original levels)	Varies by cohort see Data Dictionary.
moi	Ability to manage on available income (original levels)	1='Easy' 2='Not too bad' 3='Difficult sometimes' 4='Difficult always' 5='Impossible'
mnstrs	Mean stress score	NA
bmigroup	Body mass index (WHO categories for people of non-Asian ethnicity)	1='Underweight (<18.5 kg/m ²)' 2='Acceptable weight (>=18.5 to <25 kg/m ²)' 3='Overweight (>=25 to <30 kg/m ²)' 4='Obese (>30 kg/m ²)'
hcc	Health care card	0='No' 1='Yes'
cob	Country of birth (original levels)	Varies by cohort see Data Dictionary.
ariappg_3gp	Area of residence (3 levels)	1='Major cities/overseas' 2='Inner regional' 3='Outer regional/remote/very remote'
moi_3gp	Ability to manage on available income (3 levels)	1='Not too bad/easy' 2='Difficult sometimes' 3='Difficult always/impossible'
marital_2gp	Marital status (2 levels)	0='Partnered' 1='Non-partnered'
alcnhmrc_3gp	Alcohol consumption (3 levels)	1='Low risk drinker' 2='Non-drinker/rarely drinks' 3='Risky/high risk drinker'

KLV Variable	Label	Categories
smokst_3gp	Smoking status (3 levels)	1='Non-smoker' 2='Ex-smoker' 3='Current smoker'
srh_3gp	Self-rated health (3 levels)	1='Excellent' 2='Very good/good' 3='Fair/poor'
hq_3gp	Highest qualification (3 levels)	1='Year 12 or below' 2='Certificate/diploma' 3='University'
hq_4gp	Highest qualification (4 levels)	1='Less than Year 12' 2='Year 12 or equivalent' 3='Certificate/diploma' 4='University'
cob_3gp	Country of birth (3 levels)	1='Australian born' 2='Other English-speaking country' 3='Other'

The original survey variables used for each longitudinal variable are presented in Table 7-9.

Table 7-9 Survey variables used to derive longitudinal variables in KLV datasets

KLV Variable(s)	1989-95 Cohort	1973-78 Cohort	1946-51 Cohort	1921-26 Cohort
age	AGE	Y1AGE Y2AGE Y3AGE Y4AGE Y5AGE Y6AGE Y7AGE Y8AGE Y9AGE	M1AGE M2AGE M3AGE M4AGE M5AGE M6AGE M7AGE M8AGE M9AGE	O1AGE O2AGE O3AGE O4AGE O5AGE O6AGE
ariapgp ariapgp_3gp	ARIAPGP	Y1ARIAPGP Y2ARIAPGP Y3ARIAPGP Y4ARIAPGP Y5ARIAPGP Y6ARIAPGP Y7ARIAPGP Y8ARIAPGP Y9ARIAPGP	M1ARIAPGP M2ARIAPGP M3ARIAPGP M4ARIAPGP M5ARIAPGP M6ARIAPGP M7ARIAPGP M8ARIAPGP M9ARIAPGP	O1ARIAPGP O2ARIAPGP O3ARIAPGP O4ARIAPGP O5ARIAPGP O6ARIAPGP

KLV Variable(s)	1989-95 Cohort	1973-78 Cohort	1946-51 Cohort	1921-26 Cohort
marital marital_2gp	MARITAL	Y1MARITAL Y2MARITAL Y3MARITAL Y4MARITAL Y5MARITAL Y6MARITAL Y7MARITAL Y8MARITAL Y9MARITAL	M1MARITAL M2MARITAL M3MARITAL M4MARITAL M5MARITAL M6MARITAL M7MARITAL M8MARITAL M9MARITAL	O1MARITAL O2MARITAL O3MARITAL O4MARITAL O5MARITAL O6MARITAL
smokst smokst_3gp	SMOKST	Y1SMOKST Y2SMOKST Y3SMOKST Y4SMOKST Y5SMOKST Y6SMOKST Y7SMOKST Y8SMOKST Y9SMOKST	M1SMOKST M2SMOKST M3SMOKST M4SMOKST M5SMOKST M6SMOKST M7SMOKST M8SMOKST M9SMOKST	O1SMOKST O2SMOKST
alcnhmrc alcnhmrc_3gp	ALCNHMRC	Y1ALCNHMR C Y2ALCNHMR C Y3ALCNHMR C Y4ALCNHMR C Y5ALCNHMR C Y6ALCNHMR C Y7ALCNHMR C Y8ALCNHMR C Y9ALCNHMR C	M1ALCNHMR C M2ALCNHMR C M3ALCNHMR C M4ALCNHMR C M5ALCNHMR C M6ALCNHMR C M7ALCNHMR C M8ALCNHMR C M9ALCNHMR C	O1ALCNHMR C O2ALCNHMR C O3ALCNHMR C

KLV Variable(s)	1989-95 Cohort	1973-78 Cohort	1946-51 Cohort	1921-26 Cohort
mh	NA	Y1MH Y2MH Y3MH Y4MH Y5MH Y6MH Y7MH Y8MH Y9MH	M1MH M2MH M3MH M4MH M5MH M6MH M7MH M8MH M9MH	O1MH O2MH O3MH O4MH O5MH O6MH
pf	NA	Y1PF Y2PF Y3PF Y4PF Y5PF Y6PF Y7PF Y8PF Y9PF	M1PF M2PF M3PF M4PF M5PF M6PF M7PF M8PF M9PF	O1PF O2PF O3PF O4PF O5PF O6PF
srh srh_3gp	SF36001	Y1Q1 Y2Q14 Y3Q14 Y4Q14 Y5Q20 Y6Q18 Y7Q9 Y8Q9 Y9Q1	M1Q1 M2Q1 M3Q1 M4Q1 M5Q1 M6Q1 M7Q1 M8Q1 M9Q3	O1Q1 O2Q40 O3Q19 O4Q12 O5Q7 O6Q10
hq hq_3gp hq_4gp	DEMO154	Y1Q78 Y2Q26 Y3Q104 Y4Q89 Y5Q115 Y6Q97 Y7Q106 Y8Q125 Y9Q110	M1Q90 M6Q108	O1Q69

KLV Variable(s)	1989-95 Cohort	1973-78 Cohort	1946-51 Cohort	1921-26 Cohort
moi moi_3gp	DEMO013	Y1Q85 Y3Q110 Y4Q102 Y5Q118 Y6Q96 Y7Q105 Y8Q124 Y9Q90	M1Q97 M2Q72 M3Q89 M4Q79 M5Q95 M6Q99 M7Q95 M8Q79 M9Q91	O1Q76 O2Q38 O3Q44 O4Q56 O5Q48 O6Q44
mnstrs	MNSTRS	Y1MNSTRS Y2MNSTRS Y3MNSTRS Y4MNSTRS Y5MNSTRS Y6MNSTRS Y7MNSTRS Y8MNSTRS Y9MNSTRS	M1MNSTRS M2MNSTRS M3MNSTRS M4MNSTRS M5MNSTRS M6MNSTRS M7MNSTRS M8MNSTRS M9MNSTRS	O1MNSTRS O2MNSTRS
bmigroup	BMIGROUP	Y1BMIGROUP Y2BMIGROUP Y3BMIGROUP Y4BMIGROUP Y5BMIGROUP Y6BMIGROUP Y7BMIGROUP Y8BMIGROUP Y9BMIGROUP	M1BMIGROUP M2BMIGROUP M3BMIGROUP M4BMIGROUP M5BMIGROUP M6BMIGROUP M7BMIGROUP M8BMIGROUP M9BMIGROUP	O1BMIGROUP O2BMIGROUP O3BMIGROUP O4BMIGROUP O5BMIGROUP O6BMIGROUP
hcc	HSRV079	Y2Q9 Y3Q9 Y4Q9 Y5Q9 Y6Q9 Y7Q20 Y8Q20 Y9Q21	M3Q17 M4Q18 M5Q17 M6Q17 M7Q18 M8Q18 M9Q21D	NA

KLV Variable(s)	1989-95 Cohort	1973-78 Cohort	1946-51 Cohort	1921-26 Cohort
cob cob_3gp	DEMO167	Y1COBCAT	M1COBCAT	O1COBCAT

8 2023 Major Report: COVID-19 and its impact on health care use

The 2023 major report examined women's use of health services to assess the impact of the COVID-19 pandemic. It also considered the differential impact of health service use by women during the pandemic according to their health status (i.e., presence of chronic conditions), area of residence, financial status and domestic violence history. A summary of the report is included here – full details are available on the Study [website](#).

8.1 Women's health and access to health services during the COVID-19 pandemic in 2020: Results of the mini-surveys

Fourteen mini-surveys were conducted during 2020 - from April to October - to capture information about women's experiences of the pandemic and the actions taken to control COVID-19 transmission.

Results showed that young women (in their late 20s) were more likely to report poor health, high stress, and psychological distress than older women, and more likely to delay seeing a general practitioner (GP), mental health professional, or allied health professional than older women (in their early 70s). Young women were also more likely to access a mental health professional or helpline/chat services, and more likely to use telehealth for GP and mental health services than older women.

Women who lived alone were more likely to report high psychological distress than those who lived with others, and those who reported little or no pre-pandemic social support were more likely to report high psychological distress.

For screening tests (of the skin, breast, or cervix), up to one in ten women reported delaying the screening.

Three-quarters of women who used telehealth services during the pandemic had a positive experience with different types of health professionals.

8.2 Comparing women's health service use before and during the COVID-19 pandemic

Analysis of women's health service use was enabled by the linkage of ALSWH survey data to MBS data. Health service use – visits to GPs and specialists, obstetrician consultations, mental health treatment, and cervical screening – before the COVID-19 pandemic (March 2018 - August 2019) and during it (March 2020 – August 2021) were compared for women in their late 20s, mid 40s and early 70s.

Average yearly GP visits increased during the COVID-19 pandemic for women in their early 70s, but did not change for women in their late 20s and mid 40s. For all cohorts, out-of-pocket costs for GP visits did not change – the lack of increase for women in their early 70s is likely due to bulk billing of GP services for this cohort, and their eligibility for a Seniors Health Card. Medicare benefits paid for GP

visits during the pandemic were greater among women in their 70s who had difficulty managing on income, and among women in their late 20s and mid 40s with a history of domestic violence.

The average number of yearly specialist visits increased during the COVID-19 pandemic for women in their late 20s, but not for the older women. The increase was due to use of obstetric services and was more apparent among women living in metropolitan areas, who were entering peak childbearing years, than for women living in rural and remote areas, who were more likely to have had children at a younger age. Not surprisingly, during the pandemic the use of specialist services was higher for women in their late 20s due to increased access to obstetric services and for those who found it easy to manage on income. Increased specialist service use during the pandemic was associated with both higher Medicare benefits paid and out-of-pocket costs.

Mental health service use increased during the pandemic from pre-pandemic levels for women aged in their late 20s (but not for women in their mid 40s or early 70s) and this difference decreased with remoteness and difficulty managing income.

Cervical screening fell by 32-59% during the COVID-19 pandemic with the biggest reduction observed for women in their mid 40s.

8.3 Changes in GP and specialist service use before and during the COVID-19 pandemic for women with common conditions and multimorbidity

Health service use - visits to GPs and specialists, and obstetrician consultations - before the COVID-19 pandemic (March 2018 - August 2019) and during the pandemic (March 2020 – August 2021) by women with and without a history of specific common conditions were compared.

Conditions associated with a greater increase in GP service use during the COVID-19 pandemic compared to before the pandemic differed by age group: diabetes and cancer were associated with greater increases for women in their late 20s, asthma for those in their mid 40s, and stroke for women in their early 70s.

Two specific conditions were associated with a greater increase in specialist service use during the COVID-19 pandemic compared to before the pandemic: cancer for the women in their late 20s and mid 40s, and chronic obstructive pulmonary disorder for the women in their early 70s.

The rate of obstetric service use was higher during the COVID-19 pandemic than before the pandemic because the women in their late 20s had entered the peak childbearing years; however, there was no increase in obstetric service use for women who had a history of diabetes or cancer.

During the pandemic period, for all cohorts, GP telehealth service use increased with the number of common conditions experienced by women.

8.4 Telehealth service use during the COVID-19 pandemic

Telehealth services (medical consultations via telephone or video conferencing) were introduced at the start of the COVID-19 pandemic to minimise virus transmission in the community and to protect patients

and health care providers. MBS claims for telehealth services were examined for women in different age groups and subpopulations, and with various health conditions.

Telehealth services were predominantly delivered by phone, rather than video conferencing, for GP, specialist, and mental health consultations/therapies. Women in their late 20s and mid 40s were more likely to use telehealth services to consult GPs and specialists and obtain mental health treatment and less likely to use GPs for COVID-19 vaccinations than women in their early 70s.

GP telehealth services had the greatest uptake among women living in metropolitan areas and the least among women living in remote areas. Telehealth service use for both GP and specialist services was higher for women with common conditions than for those with no conditions across all cohorts. Women in their late 20s with a history of cancer and women in their 40s with a history of stroke or chronic obstructive pulmonary disorder (COPD) were more likely to use GP telehealth services than women without these conditions.

Specialist telehealth services varied by specific common conditions: mental health problems and musculoskeletal conditions were associated with greater uptake of telehealth services, as well as cancer, diabetes, and COPD, however the trends were not consistent across the three cohorts. Telehealth delivery of mental health services was least likely to be used by women in the 1973-78 cohort who lived in rural and remote areas, lived with children, or had a history of domestic violence.

8.5 Women's experiences accessing health care during the COVID-19 pandemic in 2020-21 in their own words

A thematic analysis of the qualitative free-text responses from the COVID-19 mini-surveys identified four major themes in relation to health service use during the pandemic:

- *Unmet needs and reduced quality of care* encompassed disruptions to routine care, difficulty accessing health services, and telehealth services being an inadequate alternative for certain conditions and health concerns.
- *Reluctance to seek care* described delays in treatment, screening, and attending medical appointments due to a fear of COVID-19, consideration of others with health needs, and concern for an overburdened health system.
- *Confusion and frustration surrounding health information* is a theme largely focussed on women's confusion about health messages in relation to the COVID-19 vaccine, particularly with regard to persistent encouragement of COVID-19 vaccine uptake during the early periods of low supply, perceived inconsistencies in information about who was eligible for vaccination and with information about where to get vaccinated. The theme also encompassed women's frustration when public discourse highlighted concerning side-effects of COVID-19 vaccines.
- *Convenience and improved choices for care* describes women's appreciation for the introduction of telehealth services across the wider community, compared with the more limited availability of the services prior to the pandemic.

8.6 Implications and recommendations

The COVID-19 pandemic highlighted a number of key areas of consideration when implementing strategies to minimise disease transmission in the community:

Younger women were more likely to be negatively impacted by the pandemic and policies designed to limit the transmission of COVID-19 than older women: they experienced more stress and sought more mental health services. Psychological distress during the pandemic was associated with low social support for all women, and with living alone for women in their 20s and 40s.

- **Recommendation:** Research is needed to determine who is most at risk of minimal social support, and to develop programs for promoting social connectivity. Furthermore, strategies implemented by local governments to promote social support, particularly for people who lived alone during the pandemic, need to be evaluated and, if required, improved to minimise the mental health impact of isolation.
- **Recommendation:** The pandemic can be viewed as a global stressor. The particular vulnerability of younger women to mental health issues warrants further examination and development of service and policy interventions.

Telehealth services were well-utilised by younger women, women who lived in areas that experienced more restrictions and stay-at home orders (metropolitan), and women who had common conditions. Phone consultations were the predominant mode of telehealth delivery. Additionally, most women who used telehealth services found it be a positive experience. Under some circumstances, uptake of telehealth was lower in non-urban compared to urban locations.

- **Recommendation:** Further research is needed to determine the barriers to using telehealth services and strategies to promote or facilitate the effective use of telehealth services, particularly for older women and women with certain conditions.
- **Recommendation:** A better understanding of the lower uptake of telehealth in non-urban areas would determine whether this was due to unmet need or other factors (such as service availability or telehealth connectivity).

Women delayed access to health care services and cancer screening programs during the COVID-19 pandemic.

- **Recommendation:** Research is needed to determine the short- and long-term impact of delays to health care and cancer screening on women's health. This is needed to help inform future responses to global pandemics.
- **Recommendation:** Development of a public health campaign to remind the community to 'get back on track' with preventive screening activities could be helpful. Consideration should be given to some women's reluctance to attend such appointments due to a fear of COVID-19 as a part of any such campaign.

9 DISSEMINATION OF STUDY FINDINGS

9.1 Publications

Since the last Technical Report (15 November 2022) there have been 26 publications recorded using ALSWH data. The most frequently published research themes were chronic conditions, weight, nutrition and physical activity and reproductive health (Table 9-1). Publications are listed below the table. A list of all ALSWH publications is available on the [Study website](#).

Table 9-1 ALSWH publications from November 2022 to November 2023 by research theme.

Theme	No. publications
Weight, nutrition and physical activity	12
Reproductive health	11
Chronic conditions	6
Mental health	5
Ageing and Aged Care	5
Social factors in health and wellbeing	4
Health service use	3
Violence	2
Child health and development	1
Environmental health	1
Caring	1
Methodology	1

Note: Publications can include more than one research theme.

Bizuayehu HM, Harris ML, Chojenta C, Cavenagh D, Forder PM & Loxton D. (2023) Patterns of labour interventions and associated maternal biopsychosocial factors in Australia: a path analysis. *Reproductive Sciences*. <https://doi.org/10.1007/s43032-023-01219-7>

Bedaso A, Adams J, Peng W & Sibbritt D. (2023). The direct and mediating effect of social support on health-related quality of life during pregnancy among Australian women. *BMC Pregnancy Childbirth*; 23: 372 <https://doi.org/10.1186/s12884-023-05708-0>

Byles J, Cavenagh D, Bryant J, Carey M, Mazza D, Sanson-Fisher R. (2023). Do health assessments affect time to permanent residential aged care admission for older women with and without dementia? *Geriatrics & Gerontology International*. <https://doi.org/10.1111/ggi.14631>

Dey T & Cebulla A. (2023). Mental health of single mothers in Australia. *Journal of Public Mental Health*. <https://doi.org/10.1108/JPMH-12-2022-0124>

Dingle SE, Bowe SJ, Bujtor M, Milte CM, Daly RM, Byles J, Cavenagh D & Torres S. (2023). Data-driven lifestyle patterns and risk of dementia in older Australian women. *Alzheimer's & Dementia*; 1-11 <https://doi.org/10.1002/alz.13467>

Harris ML, Egan N, Forder PM, Bateson D & Loxton DL. (2023) Patterns of contraceptive use through later reproductive years: A cohort study of Australian women with chronic disease. *PLOS ONE*; 18-5: e0268872. <https://doi.org/10.1371/journal.pone.0268872>

Hou L Chen L & Zhang W. (2023). The longitudinal predictive effect of self-reported frequency of premenstrual syndrome on depression: Findings from the Australian Longitudinal Study on Women's Health. *Frontiers in Public Health*; 11: <https://doi.org/10.3389/fpubh.2023.1126190>

Hutchinson M, Cosh SM & East L. (2023) Reproductive and sexual health effects of intimate partner violence: A longitudinal and intergenerational analysis. *Sexual & Reproductive Healthcare*; 35: 100816. <https://doi.org/10.1016/j.srhc.2023.100816>

Jin C, Tooth LR, Xu X & Mishra GD. (2023) Do mothers or females without children have better health-related quality of life across their reproductive years? *Quality of Life Research*. <https://doi.org/10.1007/s11136-022-03338-1>

Jin C, Tooth LR, Xu X & Mishra GD. (2023). Is being childless associated with a woman's risk of overweight and obesity? Results from a national longitudinal study. *International Journal of Obesity*; 1-7. <https://doi.org/10.1038/s41366-023-01329-x>

Khalesi S, Vandelanotte C, Irwin C, Vincent GE, Gupta C & Mishra GD. (2023). Symptoms of sleep problems and adherence to dietary guidelines in older women: Evidence from the Australian Longitudinal Study on Women's Health. *Public Health Nutrition*; 26(8): 1679-1685. <https://doi.org/10.1017/S1368980023001052>

Kwok WS, Dolja-Gore X, Khalatbari-Soltani S, Byles J, Oliveira JS, Pinheiro MB, Naganathan V, Tiedemann A & Sherrington C. (2023). Physical activity and injurious falls in older Australian women:

adjusted associations and modification by physical function limitation and frailty in the Australian Longitudinal Study on Women's Health. *Age and Ageing*; 52(6): 1-10.

<https://doi.org/10.1093/ageing/afad108>

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. (2023). Thyroid cancers potentially preventable by reducing overweight and obesity in Australia: A pooled cohort study. *International Journal of Cancer*; 150(8) 1281-1290. <https://doi.org/10.1002/ijc.33889>

Lauche R, Anheyer D, Uebelacker LA, Sibbritt D, Adams J & Cramer H. (2023). Do yoga and meditation moderate the relationship between negative life events and depressive symptoms? Analysis of a national cross-sectional survey of Australian women. *Frontiers in Psychology*; 14: <https://doi.org/10.3389/fpsyg.2023.1218976>

Lee M, Bradbury J, Yoxall J & Sargeant S. A longitudinal analysis of Australian women's fruit and vegetable consumption and depressive symptoms. (2023). *British Journal of Health Psychology*. <https://doi.org/10.1111/bjhp.12656>

Lewandowski S, Neale E, D'Arcy E, Hodge AM & Schoenaker DAJM. (2023). Quality of low-carbohydrate diets among Australian post-partum women: Cross-sectional analysis of a national population-based cohort study. *Maternal and Child Nutrition*. <https://doi.org/10.1111/mcn.13502>

Makama M, Earnest A, Lim S, Skouteris H, Hill B, Teede H, Boyle JA, Brown WJ, Hodge AM & Moran LJ. (2023). Assessing patterns of change in lifestyle behaviours by parity: a longitudinal cohort study. *International Journal of Epidemiology*; 52(2), 589-599 <https://doi.org/10.1093/ije/dyac139>

Makama M, Brown WJ, Lim S, Skouteris H, Harrison CL, Joham AE, Mishra GD, Teede H, Moran LJ. (2023). Levels of physical activity and sitting time in women with infants, toddlers and preschoolers: a population-based cross-sectional study. *Public Health*; 214: 1-9. <https://doi.org/10.1016/j.puhe.2022.10.016>

Mielke GI, Doust J, Chan HW, Mishra GD. (2023). Physical activity accumulated across adulthood and resting heart rate at age 41-46 years in women: Findings from the Menarche to Premenopause Study. *Journal of Physical Activity Health*. <https://doi.org/10.1123/jpah.2023-0082>

Moss KM, Loxton D & Mishra GD. Does Timing Matter? Associations Between Intimate Partner Violence Across the Early Life Course and Internalizing and Externalizing Behavior in Children. *Journal of Interpersonal Violence*. <https://doi.org/10.1177/08862605231174505>

Mouly TA, Mishra GD, Hystad P, Nieuwenhuijsen M & Knibbs L. (2023). Residential greenspace and anxiety symptoms among Australian women living in major cities: A longitudinal analysis. *Environment International*; 178: 108065. <https://doi.org/10.1016/j.envint.2023.108110>

Nohr EA, Taastrom KA, Kjeldsen ACM, Wu C, Pedersen FH, Brown WJ & Davis DL. (2023). Parity, mode of birth, and long-term gynecological health: A follow-up study of parous and nonparous women in the Australian Longitudinal Study on Women's Health cohort. *Birth Issues in Perinatal Care*; <https://doi.org/10.1111/birt.12781>

Shebeshi DS, Dolja-Gore X & Byles J. (2023). Validation of Frail Scale and comparison with hospital frailty risk score to predict hospital use in a cohort of older Australian women. *The International Journal of Health Planning and Management*, 38(5), 1510-1519. <https://doi.org/10.1002/hpm.3684>

Wei, L, Ahmadi, MN, Chan, H-W, et al. (2023). Association between device-measured stepping behaviors and cardiometabolic health markers in middle-aged women: The Australian Longitudinal Study on Women's Health. *Scandinavian Journal of Medicine & Science in Sport*; 33(8): 1384-1398. <https://doi.org/10.1111/sms.14363>

Wilson LF, Doust J, Mishra GD & Dobson AJ. (2023). Symptom patterns and health service use of women in early adulthood: a latent class analysis from the Australian Longitudinal Study on Women's Health. *BMC Public Health*; 23: 147. <https://doi.org/10.1186/s12889-023-15070-7>

Xu X, Mishra GD, Holt-Lunstad J & Jones M. (2023). Social relationships satisfaction and accumulation of chronic conditions and multimorbidity: A national cohort of Australian women. *General Psychiatry*; 36(1): e100925. <http://dx.doi.org/10.1136/gpsych-2022-100925>

9.2 Conference Presentations

Seventeen presentations using ALSWH data have been recorded since the last Technical Report.

Conference Presentations

- Bizuayehu HM. **Labour interventions patterns and associated biopsychosocial factors: path analysis of cohort study**. *Australasian Epidemiological Association (AEA) 2023 Annual Scientific Meeting, Hybrid Conference*, Melbourne, VIC, 18-20 October 2023
- Fang H-F. **Early natural menopause and risk of incident type 2 diabetes mellitus**. *Australasian Epidemiological Association (AEA) 2023 Annual Scientific Meeting, Hybrid Conference*, Melbourne, VIC, 18-20 October 2023
- Collins C, Baldwin J & Clarke E. **Reduction in diet quality is associated with greater healthcare claims and charges over 21-years in Australian Women**. *International Society of Behavioural Nutrition and Physical Activity*, 14-17 June 2023

- Gete D. **Risk of iron deficiency in Women with Endometriosis: A population-based prospective cohort study.** *Nutrition 2023*, Boston, USA, 22-25 July 2023
- Jin C. **Is childlessness associated with the risk of overweight and obesity in women?** *Australasian Epidemiological Association (AEA) 2023 Annual Scientific Meeting*, Jin C. 18-20 October 2023
- Jones A, Ebeling PR, Mishra G, Teede H, Enticott J & Vincent AJ. **Bone health in Australian women with early menopause: a 23-year longitudinal analysis.** *European Society of Human Reproduction and Embryology (ESHRE) 39th Annual Meeting*, Jones A, Ebeling PR, Mishra G, Teede H, Enticott J & Vincent AJ. 25-28 June 2023
- Jones A, Ebeling PR, Mishra G, Teede H, Enticott J, Vincent AJ. **Geographical variation in osteoporosis care: A longitudinal analysis over 23 years.** *World Congress on Osteoporosis, Osteoarthritis and Musculoskeletal Diseases*, Barcelona, Spain, 4-7 May 2023
- Kwok W, Khalatbari-Soltani S, Dolja-Gore X, Byles J, Oliveira J, Pinheiro M, Sherrington C. **Exploring bi-directional prospective relationship between physical activity (PA) and falls and long-term relationship between PA and falls in Australian women.** *World Physiotherapy Congress 2023*, Dubai, UAE, 2-4 June 2023
- Mielke G. **Emergence of socioeconomic disparities in physical activity across the lifespan in women.** *Australian Public Health Conference 2023*, Hobart, TAS, 26-28 September 2023
- Mishra G. **How the collaborative and expanded use of telehealth can support research to inform more equitable health policy and practice for all women and girls.** *67th Session Commission on the Status of Women: Women's Health and Well-Being: Integrating Information and Communication Technologies, Universal Health Coverage, NCDs, and Policy*. 9 March 2023
- Nguyen B, Clare P, Mielke G, Brown W & Ding D. **Could it ever be too late to adopt an active lifestyle? Longitudinal patterns of physical activity and health-related quality of life in a cohort of middle-aged Australian women.** *International Behavioral Nutrition and Physical Activity Annual Meeting*, Uppsala, Sweden, 14-17 June 2023
- Pant A. **Association of Ultra-processed Foods with Cardiovascular Disease and Hypertension in middle-aged Women.** *European Society of Cardiology Congress 2023*, 25th-28th August 2023

- Peeters G, de Munck I & Melis R. **Physical functioning 12 years before and after knee or hip surgery in older women.** *Annual Meeting of the Gerontological Society of America*, Tampa, Florida, USA, 7-12 November 2023

Poon E, Donald M, van Driel M, Pache D, Dolja-Gore X, Hollingworth S & McGuire T. **Prevalence and patterns of long-term antidepressant use in older Australian women.** *FIP Brisbane 2023*, Brisbane, QLD, 24-28 September 2023

- Rahman MM, Byles J, Steinberg J, David M, Yu X, Cust A, Canfell K. **Trajectory of health-related quality of life among women cancer survivors in Australia.** *COSA Survivorship Conference*, 10 March 2023
- Tooth L. **Parental resources on children's screen use ignore a challenge many families face.** *Australian Public Health Conference 2023*, 26-28 September 2023
- Tooth L. **Screen use in young children. Screen use habits in early childhood.** *International Congress on Evidence-based Parenting Support*, online, 6-8th June 2023

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). Both organisations use the Meltwater media monitoring system. From September 2022 to November 2023, media coverage mentioning ALSWH or research based on ALSWH data covered by the media included:

620 mentions in news media*

39 Topics

28 Countries

Topics covered included:

- Representation of Indian-Australian women in research
- The health impact of violence
- Childhood exposure to intimate partner violence and the risk of behavioural problems
- The 2023-24 Federal Budget
- Endometriosis – prevalence, links to gastrointestinal disorders
- Rates of physical and sexual violence
- Satisfying relationships are good for health
- Menopause
- Weight loss
- Depression as a warning sign for stroke
- The National Women's Health Advisory Council
- Nutrition and depressive symptoms
- Having conversations about contraception
- Premature birth and nutrition
- Adequate Medicare rebates lead to optimal care
- 'Banking' exercise for future heart health

Table 9-2 ALSWH media highlights from December 2022 – November 2023

Date	Topic	Collaborator and Institute	Highlights
February 2023	National Women’s Health Advisory Council	Prof Gita Mishra, UQ Prof Deb Loxton, UON	The Mandarin
February – March 2023	Satisfying mid-life relationships linked to lower multiple chronic disease risk in older age	Prof Gita Mishra, UQ Dr Xiaolin Xu, UQ	450+ media mentions across 21 countries including: ABC News Australia & ABC Radio Australia Yahoo! News and Lifestyle MSN France, MSN Korean Pourquoi Docteur (France) Nation World News (India) The Sun (UK) Daily Mail (UK) Sky News (UK)
May 2023	Women’s Budget	ALSWH	Women’s Agenda MSN.com
May 2023	Exposure to Intimate Partner Violence puts children’s development at risk	Dr Katrina Moss (MatCH data)	Triple M Radio Education HQ The Mirage The National Tribune

Date	Topic	Collaborator and Institute	Highlights
September 2023	Banking exercise for future Heart Health	Dr Gregore Mielke, UQ (Menarche to Pre-Menopause data)	Triple M Radio Healthnews.com Yes Punjab
September 2023	1 in 7 Women have endometriosis	Australian Institute of Health and Welfare (ALSWH data)	ABC SBS Women's Agenda 9 News News.com.au
October 2023	Preventative health checks are reaching women in need	Prof. Jenny Doust, Dr Louise Wilson, UQ	RACGP MedicalXpress
October 2023	Endometriosis linked with gastrointestinal disorders	Prof. Grant Montgomery, UQ	The Guardian

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. ALSWH relies on organic (free) social media exposure and does not advertise or pay to promote its posts. Engaging with stakeholders on these channels is increasingly challenging. We continue to assess the relevancy of X (Twitter) and new media (e.g., Threads).

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 [Facebook](#) has around 9,606 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 400 and 2,000 accounts.

X (Twitter): The [Twitter account](#) 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 1,841 followers and its Tweets receive between 400 to 2,000 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 479 followers and posts receive between 90 and 150 impressions.

LinkedIn: The [ALSWH LinkedIn page](#) 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 138 followers.

9.5 Website

The ALSWH website (www.alswh.org.au) 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 2022-23 year the website team have focused on major upgrades to the site's hosting infrastructure, content management system, and analytics.

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 has shifted towards a mid-year distribution. It is emailed to participants in the 1989-95 and 1973-78 cohorts as well as those participants in the 1946-51 cohort who have provided email addresses. A print version is made available to the 1921-26 cohort and members of the 1946-51 cohort who prefer to receive hard copies.

The 2023 newsletter is online at: <https://alswh.org.au/participants-newsletter/2023/>

Copies of all participant newsletters are available at: <https://alswh.org.au/for-participants/newsletters/>

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

The Study News is sent to a list of over 670 subscribers, at least once 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

In the 2022-23 year, the Data Updates newsletter was distributed in December 2022, and June 2023. The Study News was delivered in December 2022.

Copies of the Data Update newsletter are available at: <https://alswh.org.au/newsletter/data-update-newsletter/>

Copies of the Study News are available at: <https://alswh.org.au/about/newsletters/alswh-study-news/>

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 2023, the SMC have met once face-to-face (in July), with all other meetings conducted as videoconferences (Zoom).

10.1.2 Data Management Committee

The Data Management Committee (DMC) is responsible for all technical issues involving ALSWH data. The group's primary tasks include:

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

This year, the DMG has reviewed all items for Pilot Survey 10 of the 1973-78 cohort and has provided advice on preparation of the 'Common conditions from multiple sources (CCMS)' datasets. The DMC meets monthly by teleconference or videoconference and is chaired by Paul McElwee (Acting Data Manager – The University of Queensland) and Peta Forder (The University of Newcastle). Members in 2023 have included:

- Paul McElwee
- Peta Forder
- Professor Gita Mishra
- Professor Deborah Loxton
- Associate Professor Leigh Tooth
- Richard Hockey
- Dominic Cavenagh

- Professor Annette Dobson
- Dr Hsiu-Wen Chan
- 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 2023 have included:

- Associate Professor Leigh Tooth
- Professor Gita Mishra
- Professor Wendy Brown
- Professor Annette Dobson
- Professor Deborah Loxton
- Peta Forder
- Dr Michael Waller

- Dr Katrina Moss
- Dominic Cavenagh

Data linkage projects were also reviewed by the ALSWH Data Analyst, Richard Hockey and the ALSWH Data Linkage Coordinators, Colleen Loos and Dr Hsiu-Wen Chan.

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. Thirty-five new or amended projects have been approved since the last Technical Report (November 2022). 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 2023 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
- Violence
- 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. Thirteen applications to use the 'core' datasets have been approved in 2023 (Table 10-1).

Table 10-1 Applications approved in 2023 to use the ALSWH core datasets (accessed through the Australian Data Archive)

Title	Project Leader	Institution/Organisation
Social inequalities in oral health among Australian working age adults	Ankur Singh	The University of Melbourne
An epidemiological study of hysterectomies in India and Australia	Jesty Varghese	The University of Queensland
Association between Polycystic Ovary Syndrome and incidence of non-communicable diseases among women in Australia: Analysis of the Australian Longitudinal Study on Women's Health	Joel Komakech	Mississippi State University
Trajectories and predictors of life satisfaction and mental health in Australian women	Anastasia Ejova	The University of Adelaide
The excruciating price of the quest for motherhood	Natasha Poularikas	Oklahoma State University
Trajectories of physical activity and health outcomes after major life events in Australian women	Yuta Nemoto	The University of Queensland
Risk factors in women and CVD outcomes	Glen Wiesner	Heart Foundation
Understanding physical activity and sedentary behaviour in women with endometriosis	Luana De Giorgio	University Of Exeter
The impacts of a healthy lifestyle on the physical and mental health of female stroke survivors in Australia.	Sazedur Rahman	University of Technology Sydney

Title	Project Leader	Institution/Organisation
Social inequalities in oral health among Australian working age adults	Ankur Singh	The University of Melbourne
Identifying health behaviours as key targets for lifestyle modification and pre pregnancy intervention	Paige van der Pligt	Deakin University
The relationship between optimism and work experience	Weiwen Yang	The Chinese University of Hong Kong
Trajectories of physical activity across the lifespan in Australian women: correlates and health consequences	Yuta Nemoto	The University of Queensland

10.2.3 Substudies

During 2023, data collection (to date) has been conducted for:

- **Genetic variants, Early Life exposures, and Longitudinal Endometriosis symptoms Study (GELLES)** (EoI 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

29 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
Professorial Research Fellow	Professor Annette Dobson
Research Fellow	Dr Katrina Moss*
Statisticians	Richard Hockey Professor Reza Baneshi
Data Manager	Paul McElwee (Acting)
Data Linkage Coordinator	Colleen Loos Dr Hsiu-Wen Chan (Acting)
Research Project Manager	Megan Ferguson
Communications and Engagement Officer	Helen Gray
Senior Research Assistant	Dr Hsiu-Wen Chan
Principal Project Coordinators	Carla Shield (MatCH 2)* Reema Naresh (Cohort Refresh)*
Database Developer	Chamila Pathigoda
Data Access and Liaison Officer	Leonie Gemmell
Research Support Officer	Christine Coleman*
Administration Officer	Alison Manley

*Dr Moss ceased working for ALSWH in February. Christine Coleman ceased working for ALSWH in July. Carla Shield started work in April and Reema Naresh started work in May.

Centre for Women's Health Research The University of Newcastle	
Director ALSWH	Professor Deborah Loxton
Research Executive Manager	Natalie Townsend
Statistics and Data Operations Coordinator	Peta Forder
MATCH 2 Coordinator	Dr Melissa Harris
Statistics and Data Operations Team	Dominic Cavenagh Nick Egan Liam Dowling
Research Team	Isabelle Barnes Emma Byrnes Clare Thomson Dr Caitlyn Mitchell Jemma Henderson Zoe Crittendon Layla Solomon
Administration Team	Katherine Tuckerman Kacey Johnston
Project Assistants	Tara Barrington Haylee Ferov Ella McConnochie Teghan O'Beirne Daisy Pike

12 Data Linkage Appendix

Participant consent status was first formalised in July 2017 (ref 2017 ALSWH Major Report) and the corresponding statistics have been presented in the ALSWH Technical Reports since then. The four categories and definitions of data linkage consent used in previous reports is shown in Table 12-1.

Table 12-1 Consent status definitions described in the previous ALSWH technical reports.

Consent status	Relevant participants
e) Declined	<ul style="list-style-type: none"> • Latest answer to the data linkage questions is 'No' • Explicitly declined data linkage by contacting ALSWH • Withdrawn from the Study because of privacy, confidentiality or Medicare data linkage concerns.
f) Express consent	Latest answer to the data linkage questions is ' Yes '.
g) Implicit consent	Not in category a) or b), who have completed ALSWH surveys since the introduction of opt-out consent (2005).
h) Waived consent	Not in category a) or b), who have not completed a survey since the introduction of opt-out consent (2005).

'Declined' and 'express' consent definitions are self-explanatory and primarily relate to the most recent response to data linkage questions that were included in ALSWH surveys. In contrast, the 'implicit' and 'waived' consent definitions are more complicated, and thus a review was conducted in July 2023. In this chapter, we first describe the historical definitions used to categorise 'implicit' and 'waived' consent and how they were implemented. Following this, we detail a new method to accurately define these categories.

12.1 Survey completion codes and definition of 'completed a survey'

Historically, both 'implicit' and 'waived' consent definitions rely on the criteria 'completed a survey since the introduction of the opt-out consent (2005)' (see Table 1). When surveys are launched, participants are designated a survey completion status code for tracking purposes. These codes provide an indication of whether or not a participant has started or completed a survey, withdrawn from the survey or study overall, been in contact with the ALSWH team, amongst other useful operational information. Only one code can be assigned to a participant at any time, and it can be changed based on circumstance.

The definition 'completed a survey since the introduction of opt-out consent (2005)' is slightly misleading as it is not only the completion of the survey that matters, but whether or not the participant has been given the data linkage information and had a chance to review it. This information is distributed with all ALSWH survey invitations and reminders. The primary question is: which survey completion status codes should be used to define 'completed a survey?' Since 2017, this has changed over the years.

12.2 Comparison of historical survey completion statuses used to define the term 'completed a survey'

12.2.1 2017-2019

The consent status table shown in Table 2 was included in the ALSWH Technical Reports from 2017 to 2019. The 'implicit' and 'waived' consent categories were reported together as a single category and included participants who never explicitly agreed or disagreed to consent. Using this method, the following consent status frequencies were generated when applied to the current participant database (see Table 12-2).

Table 12-2 Consent status of participants based on 2017-19 definition, as of 14/07/23.

	Total	Consent type					
		<i>Declined</i>		<i>Express</i>		<i>Implicit/waived</i>	
		<i>N</i>	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Cohort							
1921-26	12432	353	2.8	9131	73.4	2948	23.7
1946-51	13714	763	5.6	11231	81.9	1720	12.5
1973-78	14247	748	5.3	9893	69.4	3606	25.3
1989-95	17010	17	0.1	16993	99.9	0	0
Total	57403	1881	3.3	47248	82.3	8274	14.4

12.2.2 2020 and 2021

In the 2020 and 2021 ALSWH Technical Reports, the following survey completion status codes were used to define participants as having completed an ALSWH survey:

Code	Description
C	Completed survey
Y	Incomplete
P	Completed phone survey (do not use)
S	Completed short phone survey
A	Absent
YN	Incomplete, won't do more
CW	Completed, substudy withdrawn
L	No data

Thus, if a participant had a survey record in the survey log with one of the completion statuses above, a completion date after 31st December 2004, and had never explicitly declined or agreed to linkage then they were considered as giving 'implicit' consent. Otherwise, they were considered to have given

'waived' consent. Using this method, the following consent status frequencies were generated when applied to the current participant database (Table 12-3).

Table 12-3 Consent status of participants based on the 2020/21 definition, as of 14/07/23.

2020/21 definition	Consent type								
	Total	a) Declined		b) Express consent		c) Implicit consent		d) Waived consent	
	N	n	%	n	%	n	%	n	%
Cohort									
1921-26	12432	353	2.8	9131	73.4	381	3.1	2567	20.6
1946-51	13714	763	5.6	11231	81.9	401	2.9	1319	9.6
1973-78	14247	748	5.3	9893	69.4	921	6.5	2685	18.8
1989-95	17010	17	0.1	16993	99.9	0	0	0	0
Total	57403	1881	3.3	47248	82.3	1703	3	6571	11.4

12.2.3 2022 report

In the 2022 Technical Report, all completion statuses except 'No response' (Z) were used to define participants as having completed an ALSWH survey:

Code	Description
A	Absent
B	Booking made
C	Completed survey
CW	Completed, substudy withdrawn
D	Deceased
I	Ineligible
L	No data
N	Will not do survey this time
O	Overseas
P	Completed phone survey (do not use)
R	Returned Too Late
S	Completed short phone survey
T	Terminated (online only)
W	Withdrawn
WD	Withdrawn, data deleted
X	Not returned, no contact
Y	Incomplete
YN	Incomplete, won't do more
Z	No response

This is a more descriptive list of codes and results in more people being included in the implicit consent, rather than the waived consent. Using this method, the following consent status frequencies were generated when applied to the current participant database (Table 12-4).

Table 12-4 Consent status of participants based on the 2022 definition, as of 14/07/23.

2022 definition	Consent type								
	Total	a) Declined		b) Express consent		c) Implicit consent		d) Waived consent	
	<i>N</i>	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Cohort									
1921-26	12432	353	2.8	9131	73.4	389	3.1	2559	20.6
1946-51	13714	763	5.6	11231	81.9	444	3.2	1276	9.3
1973-78	14247	748	5.3	9893	69.4	1385	9.7	2221	15.6
1989-95	17010	17	0.1	16993	99.9	0	0	0	0
Total	57403	1881	3.3	47248	82.3	2218	3.9	6056	10.5

12.2.4 Comparison of historical methods

There are 515 records with different consent statuses based on the 2020/21 and 2022 definitions (when applied to the participant database as at 14/07/23). For the majority of these participants, the most recent survey completion status was 'X' – 'Not returned, no contact' (53%), 'N' – 'Will not do survey this time' (23%) or 'W' – 'Withdrawn' (22.5%). This indicates that the discrepancies between the two methods in terms of the number of participants in the waived and implicit consent categories is primarily driven by participants we have not been able to contact or participants may or may not have reviewed the consent information in the survey invitations and associated materials.

12.3 Proposed method for 2023 and onwards

After a review of the previous methods of consent status derivation and possible survey completion codes, the following list of completion status were selected to indicate that a participant had an opportunity to review the consent information when invited to complete an ALSWH survey.

Code	Description
B	Booking made
C	Completed Survey
CW	Completed, substudy withdrawn

I	Ineligible
L	No data
N	Will not do survey this time
P	Completed phone survey (do not use)
R	Returned too late
S	Completed short phone survey
W	Withdrawn
WD	Withdrawn, data deleted
Y	Incomplete
YN	Incomplete, won't do more

Participants with at least one survey with one of these completion statuses during or after 2005 are considered to have provided implicit consent. Using this list of codes to define the difference between implicit and waived consent results in the following table (based on data as at 14/07/23).

Table 12-5 Consent status of participants based on the proposed 2023 definition, as of 14/07/23.

Proposed 2023 definition	Total	Consent type							
		<i>a) Declined</i>		<i>b) Express consent</i>		<i>c) Implicit consent</i>		<i>d) Waived consent</i>	
		<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Cohort									
1921-26	12432	353	2.8	9131	73.4	388	3.1	2560	20.6
1946-51	13714	763	5.6	11231	81.9	434	3.2	1286	9.4
1973-78	14247	748	5.3	9893	69.4	1118	7.8	2488	17.5
1989-95	17010	17	0.1	16993	99.9	0	0	0	0
Total	57403	1881	3.3	47248	82.3	1940	3.4	6334	11

13 Appendices: Progress reports for current and completed projects

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

www.alswh.org.au



November 2023