ACIL Allen Consulting

Report to Department of Health

19 June 2015

AUSTRALIAN LONGITUDINAL STUDY ON WOMEN'S HEALTH

EVALUATION

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Key findings

The key findings from this evaluation are reported here as they relate to each of the evaluation objectives. Further detail on the findings, and recommendations resulting from the findings can be found in the body of the report.

OBJECTIVE 1: ASSESS THE QUALITY OF THE STUDY IN TERMS OF ITS RELEVANCE, TIMELINESS ACCURACY, COHERENCE, INTERPRETABILITY AND ACCESSIBILITY

- Joint hosting of the ALSWH by the University of Queensland and the University of Newcastle brings substantial research expertise, objectivity and resources, including support for secondary research
- The breadth of the ALSWH as scoped by the key themes to be addressed allows for wide ranging relevance of the data and the potential to accommodate continuing inquiry from new perspectives
- The funding agreement for the ALSWH has enabled regular input from the Commonwealth to priority analysis of the ALSWH data
- There is no 'gold standard' for the timeliness of longitudinal studies. The frequency of the ALSWH survey waves are largely determined by the likely rate of change influencing the health of participants, and data collection occurs over an extended period to maximise the response rate
- The technical reports and data books describe the accuracy of the ALSWH data and provide evidence of study coherence
- The ALSWH is seen as a robust and accurate source of data
- There is a diversity of data products of the ALSWH designed to support interpretability that also serve to promote the accessibility of the information
- There is a general sense that the ALSWH is an underutilised source of data
- Data cubes are provided to AIHW and ABS although the level of awareness and familiarity with the data in these agencies appears to be limited
- A dedicated website is a key source of information about the ALSWH data and products
- There is some concern by users and non-users of the ALSWH data that access is restrictive and the process for obtaining data is difficult.

OBJECTIVE 2: ASSESS THE CONTRIBUTION TO THE EVIDENCE BASE ON WOMEN'S HEALTH IN AUSTRALIA

- The majority of the ALSWH research collaborators and NGOs surveyed reported that the ALSWH had made a large contribution to the evidence base for women's health
- Recent policies informed by the evidence established by the ALSWH include a number of national and state policies guiding strategic directions on women's health
- Scientific articles using the ALSWH data have appeared predominantly in high ranked journals

- Feedback from potential data users suggests there continues to be scope to promote the ALSWH data, including to clinicians
- There was a common view that as publicly funded research it should be more widely known that the ALSWH is a public resource and available for secondary analysis
- There was an interest amongst leaders in the Commonwealth in discussing the opportunities for the ALSWH to contribute to their policy questions
- There were different views about the policy areas most influenced by the ALSWH among collaborators and NGOs, which demonstrates the different priorities for these groups and reinforces the value of including NGOs in discussions about the ALSWH survey design and analysis.

OBJECTIVE 3: ASSESS THE CONTRIBUTION TO PUBLIC HEALTH RESEARCH PRACTICE

- The technical reports of the ALSWH have shared the considerable expertise developed in the conduct of longitudinal research and generally in good practice in research design and methods
- Collaborating with researchers has been an important approach to increasing the power of the longitudinal data, the resources available to analyse the data, and the breadth of research perspectives applied to data that crosses a wide range of domains
- The ALSWH researchers and the ALSWH data are capable of attracting new funds, partners and taking advantage of new research capabilities in driving public health research practice
- There is evidence that the ALSWH has influenced research practice, notwithstanding the opportunities that improved awareness of the initiative, and wider sector engagement could bring to this area.

OBJECTIVE 4: ASSESS THE EFFECT OF THE STUDY ON PARTICIPANTS

- Based on a sample of qualitative feedback, there was little evidence of a causal relationship between participating in the survey and changed behaviour towards the participant's health
- Participation in the survey had provided markers of life events and health behaviour that gave cause for reflection about the journey
- Some feedback suggested that assessment of their responses had led to participant intention to change but there was little evidence of acting on that intention
- The ALSWH cohorts have a higher representation of tertiary educated women than exists in the wider comparable population. Education is known to have a positive influence on health status
- Participant relationship to the ALSWH has been important in obtaining accurate responses, maintaining the cohorts and achieving a desirable response rate
- Respondents used a range of strategies to allow them to complete the survey. While there was evidence of frustration with the length and complexity of the questionnaire this was not likely to be attributable to the longitudinal nature of the study.

Executive summary

ACIL Allen Consulting was commissioned by the Commonwealth Department of Health (DoH) to conduct an evaluation of the Australian Longitudinal Study on Women's Health (ALSWH). The evaluation began in June 2014 and concluded in June 2015.

Background on the Study

The ALSWH is a longitudinal population-based survey that assesses the physical and mental health of over 50,000 women across Australia. It is designed to provide government and other decision-making bodies within Australia with an evidence base from which to develop and evaluate women's health policy and practice and a scientific basis from which to plan for the future.

The ALSWH was launched in 1995 and currently follows four cohorts of women – each representing generations at differing key stages of life. The University of Queensland and the University of Newcastle are funded by the Commonwealth to conduct the ALSWH.

The objectives of the ALSWH are to:

- Collect scientifically valid information about the current health and health service use of women which will provide an evidence base for the development and evaluation of health policy and practice relevant to Australian women
- Gather information about social experiences and environmental influences on women, including information about families of origin, traumatic or stressful events, and social inclusion
- Examine patterns of contraceptive use, experiences of pregnancy and childbirth, and other reproductive health issues
- Examine women's access to sources of information about, and use of health services and preventive health activities.

The evaluation

The evaluation focused on assessing four objectives for the ALSWH including:

- Its quality – through consideration of the institutional environment, relevance, timeliness, accuracy, coherence, interpretability and accessibility of the ALSWH data and results
- Its contribution to the evidence base on women's health in Australia
- Its contribution to public health research practice
- Its effect on participants.
- In addition, ACIL Allen also conducted a Value for Money assessment of the ALSWH.

Key findings

Quality

Overall, the ALSWH is a longitudinal survey of high quality. Its methodology is sound and is seen by users of the data as rigorous and accurate. ALSWH researchers are technical experts and leaders in the field. They are recognised nationally and internationally as leading the way in innovative approaches to longitudinal studies (e.g. data linkage, on-line survey methodology, cohort preservation).

The quality of the ALSWH benefits from the relationship between academia and government providing a meld of direction on policy priorities, application of research rigour, and opportunity to continually explore new ways of leveraging further research from the data set. There is an impressive program of research collaboration and there are data outputs that recognise a wide range of information needs and technical skills.

Consultation feedback suggests that there is new potential within government to explore the use of longitudinal surveys, including the ALSWH, in providing greater clarity about cause and effect, and tracking the impact of policy changes. This evaluation found a low level of use of ALSWH data to inform policy, most likely because of low awareness of the ALSWH rather than a reflection its quality. Increased promotion of the ALSWH initially within government is warranted and could be achieved through enhanced governance arrangements, and improved mechanisms for researchers to discuss information needs with key leaders within government.

Additionally, feedback from current users and potential users of the data suggests that access to the dataset is restrictive and the process for obtaining data is difficult. The ALSWH researchers have recognised that their strict access protocols have limited the utilisation of the data and have begun to take steps to allow greater access to the data while at the same time continuing to protect the integrity of the data and the participant cohorts.

Contribution to the evidence base on women's health in Australia

The ALSWH is seen by research collaborators and NGOs as making a strong contribution to the evidence base for women's health policy and programs. Indeed, several national and state policies guiding strategic directions on women's health have utilised ALSWH data as evidence to inform their policy position (e.g. National Women's Health Policy 2010, Health Framework for Women's Health NSW). However, this evaluation found that many key leaders within and outside government are either unaware of the existence of the ALSWH or are not accessing ALSWH findings or using the data to inform policy. Most leaders who were consulted inside government were interested in exploring ways for the ALSWH to contribute to their policy questions and were open to utilising it more fully to inform policy development and as a source of valid information from which to measure the impact of policy. Without addressing the low level of awareness of, and engagement with, the ALSWH, the potential for the data to have a bigger impact on policy and program decisions will not be realised.

Contribution to public health research practice

The impact of the ALSWH on public health research practice comes in part from dissemination of information about implementation, analysis and maintenance of the ALSHW, and in part from working with researchers and students to utilise ALSWH data for secondary analysis. This evaluation found that current users of the data and NGO leaders felt that the ALSWH had an impact on the development of other research, but that there was an opportunity for strengthened engagement both in the government and non-government sectors to influence research practice related to women's health. Additionally, consultations with practicing and academic clinicians (as opposed to public health researchers) revealed some concern that there wasn't enough clinical information included in the ALSWH and they expressed a desire to be more involved in priority setting for the study.

The ALSWH has contributed to public health research practice in leading innovative work to build research capacity through building record linkage capabilities, and by building on ALSWH cohorts to adopt a family centred approach to researching child health outcomes. The technical reports of the ALSWH have shared the considerable expertise developed in the conduct of longitudinal research and generally in good practice in research design and methods. Scientific articles using ALSWH data have appeared predominantly in highly ranked journals and over 40 PhD projects have been supported utilising ALSWH data.

As stated previously, there is concern among current and potential ALSWH data users that the process for accessing the data is restrictive and difficult. Reviewing access to ALSWH data might serve to not only increase the use of the data but also to offer benefits to the role of the ALSWH in shaping future research practice.

Study effects on participants

Participating in the survey appears to have generated a great deal of loyalty to the ALSWH that has resulted in accurate responses, a willingness to complete the questionnaire, and a genuine interest in remaining part of the initiative. The response rates have remained high - this was cited by numerous researchers as being a very positive finding and one that demonstrates the care taken by the ALSWH team to protect and engage the cohorts along with the robust nature of the methodology.

This evaluation found little evidence of a causal relationship between participating in the ALSWH and changed behaviour towards the participant's health. While many participants indicated an intention to change there was little evidence of actually acting on that intention.

The length and complexity of the ALSWH questionnaire was cited as a frustration for some participants, however, they used a range of strategies to allow them to complete the survey. This frustration was tempered by the longitudinal nature of the survey and the fact that it is conducted infrequently.

Value for money

The ALSWH represents good value for money. The ALSWH was compared to HILDA, LSAC and LSAY for the value for money component of the evaluation. The analysis of the four longitudinal study's outputs and costs revealed that HILDA and LSAC require significantly more funding, when compared to LSAY, and, to a lesser extent, ALSWH. The ALSWH produces less outputs when compared to HILDA and LSAC but a greater number than LSAY.

The cost per participant is less for the ALSWH (estimated at $114 per person) than HILDA ($834 per person) and significantly less than LSAC ($2,251 per person). It is slightly higher than the cost per participant for the LSAY ($104 per person).

The research output/cost ratio and cost per output for ALSWH and comparator studies shows that overall, the ALSWH represented the greatest value for money among the four comparator longitudinal studies, given it had the lowest cost to the Commonwealth per research output.

Improvements and recommendations

The ALSWH is a public resource of great value to Australia. To reach its full potential three areas for improvement should be addressed including; 1) to raise the profile of the ALSWH among key stakeholder groups and the community more generally; 2) to improve access to ALSWH data; and 3) to enhance the ALSWH by improving the translation between research findings and application to policy and explore the possibility of including objective measures (e.g. weight and height) into the survey.

The recommendations from this evaluation directly address the three areas for improvement outlined above. They are:

- That a communication and marketing strategy be developed and implemented to raise awareness of the ALSWH in government (Commonwealth and states/territories), NGO and academic sectors.
- That governance arrangements for ALSWH be reviewed to assure the ALSWH addresses contemporary issues, incorporates the perspectives of NGOs, clinicians, state/territory governments, and provides for an external scientific advisory group.
- That a 'champion' be identified to promote ALSWH amongst policy leaders and to leverage from networks and collaborations supported by government to increase the awareness of the ALSWH.
- That the protocol be reviewed for access to ALSWH data for secondary research with the aim of achieving open access and greater utilisation of the data.
- That the value of increasing the capability of the ALSWH be investigated for the opportunity to include objective measures in the survey and for a specific focus on translation of research into policy and practice to provide additional support in acting on the evidence base for women's health.
- That consideration be given to commissioning and overview of the research and policy implications of the ALSWH after 20 years.

1. INTRODUCTION

In June 2014 ACIL Allen Consulting was commissioned by the Commonwealth Department of Health (DoH) to conduct an evaluation of the Australian Longitudinal Study on Women's Health (ALSWH). The purpose of the evaluation was to ascertain if the ALSWH is meeting the objectives set forth at its inception and to measure its quality and contribution.

The evaluation was conducted over a 12-month period concluding in June 2015.

The Australian Longitudinal Study on Women's Health

The ALSWH assesses the physical and mental health of over 50,000 women across Australia and is designed to support understanding of the many factors that influence the health of Australia's women. The ALSWH is funded through the DoH's Health Social Surveys Fund (HSSF) whose aim is to establish (and maintain) a comprehensive evidence base to provide a foundation for the development, implementation and evaluation of relevant health policies.

The ALSWH is a longitudinal population-based survey designed to provide government and other decision-making bodies within Australia with an evidence base from which to develop and evaluate women's health/general health policy and practice and a scientific basis from which to plan for the future. The ALSWH specifically aims to assess, and provide evidence on women's:

- Physical and emotional health
- The use of health services (GP, specialist and other visits, access, satisfaction)
- Health behaviours and risk factors (including diet, exercise, smoking, alcohol, and other drugs)
- Time use (including paid and unpaid work, family roles and leisure)
- Socio-demographic factors (location, education, employment, family composition)
- Life stages and key events (e.g. childbirth, divorce, widowhood).

The ALSWH was launched in 1995 and has been undertaken jointly by the University of Queensland and the University of Newcastle since its inception. The study currently follows four cohorts of women with each cohort representing different generations at differing key stages of life. The four cohorts included in the ALSWH are as follows:

- Women born in 1921-26 (N=2,750 in 2013)
- Women born in 1946-51 (N=9,151 in 2013)
- Women born in 1973-78 (N=8,010 in 2012)
- Women born in 1989-94 (N= 17,096 in 2013)

The study collects a wide range of health and social data across the four cohorts and has recently begun to augment the survey data by linking with other data sources such as the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme.

The original (and current) objectives of the ALSWH are to:

- Collect scientifically valid information about the current health and health service use of women which will provide an evidence base for the development and evaluation of health policy and practice relevant to Australian women
- Gather information about social experiences and environmental influences on women, including information about families of origin, traumatic or stressful events, and social inclusion
- Examine patterns of contraceptive use, experiences of pregnancy and childbirth, and other reproductive health issues
- Examine women's access to sources of information about, and use of health services and preventive health activities.

The evaluation objectives

The objectives for the evaluation of the ALSWH were set out in the RFQ and required the ACIL Allen team to assess the ALSWH's:

- Quality–through consideration of the relevance, timeliness, accuracy, coherence, interpretability and accessibility of the ALSWH data and results
- Contribution–to the evidence-base on women's health in Australia and to public health research practice
- Effect on participants.

The RFQ also required the evaluation report to include a set of recommendations for improvements to maximise the value of the data collected through the ALSWH.

The focus of the evaluation was on the core activity of the ALSWH funded by the DoH and described in funding agreements. The ALSWH has also attracted research funding from other sources, such as the NHMRC, however, these activities were not in scope for this evaluation.

The methodology for this project involved a mix of qualitative and quantitative research methods. Specifically, it involved: key informant interviews, desktop research and literature review, consultations with four distinct stakeholder groups, and an on-line survey with current data users and women's health leaders

The report

This document is the evaluation report presenting key findings in response to each of the evaluation objectives.

The report comprises the following sections:

- Section 2: Methodology
- Section 3: The quality of the ALSWH (relevance, timeliness, accuracy, coherence, interpretability and accessibility)
- Section 4: Contribution to the evidence base on women's health in Australia

- Section 5: Contribution to public health research practice
- Section 6: Study effect on participants
- Section 7: Value for money of the ALSWH
- Section 8: Conclusion (improvements to the ALSWH and recommendations)
- Appendices
  - Appendix A: Evaluation framework
  - Appendix B: Discussion guides
  - Appendix C: Online survey questionnaires
  - Appendix D: Consultation report
  - Appendix E: Organisations consulted
  - Appendix F: Participant impact
  - Appendix G: Value for money analysis.

2. METHOD

Overview of the methodology

The methodology for this project comprised five key stages as summarised in Table 2.1, and explained in more detail below.

TABLE 2.1: METHODOLOGY OVERVIEW

Stage	Activities
Stage 1 Project Inception and project planning	• Inception meeting • Project plan – including: • Risk management plan • Stakeholder consultation plan • Key informant interviews (n=12)
Stage 2 **Evaluation framework**	• Desktop research • Development of an evaluation framework • Development of data collection tools
Stage 3 **Data collection**	• Ethics submission and approval • Stakeholder consultations (n=18) • Online survey (n=82) • Review a sample of ALSWH qualitative responses across cohorts • Collection of financial data
Stage 4 **Analysis**	• Qualitative data analysis • Quantitative data analysis • Value for money analysis
Stage 5 **Reporting**	• Monthly progress reports • Presentation of preliminary findings to DoH and ALSWH steering committee • Draft report • Final report • Presentation of findings and recommendations

SOURCE: ACIL ALLEN CONSULTING

Stage 1: Projection inception and project planning

The first stage of the project involved:

- An inception meeting between ACIL Allen and DoH
- Development and delivery of a project plan including a risk management plan and a stakeholder consultation plan
- Twelve interviews with key informants including:
  - ALSWH researchers
  - other longitudinal surveys (HILDA, LSAC, Ten to men)
  - individual experts
  - ALSWH funders.

Key informants interviewed in the early stages of this project were identified in consultation with DoH. They were selected because of their knowledge and involvement in women's health both from a research and a policy perspective. The purpose of the key informant interviews was to gain a thorough understanding of the ALSWH and to assess, from the key informants' perspective, whether the study was attaining its primary objectives.

Stage 2: Evaluation framework

The second stage of the project involved desktop research, the development of an evaluation plan and development of data collection tools.

- The desktop research involved two activities – a desktop review and a literature review. The desktop review included:
- historical documents
- administrative information
- comparator studies
- policy documents.

The literature review included:

- relevant published national and international literature related to quality and attributes of longitudinal studies
- national and international literature and presentations that used the ALSWH data.

An evaluation framework (see Appendix A) was developed that guided the assessment of the performance of the ALSWH in terms of the key evaluation objectives, and set out areas of inquiry, research questions, and measurement in response to the research questions. Additionally, data collection tools (stakeholder discussion guides, stakeholder survey, and financial data collection template) were developed during this stage of the project (see Appendices B and C).

Stage 3: Data collection

This stage included both qualitative and quantitative data collection. The project team used a variety of methods (telephone, face to face, and survey) to gain qualitative input from key stakeholders. Discussion guides were developed for each key stakeholder category and consultations were conducted using these guides to provide for consistency in documentation and reporting. An online survey was also developed and sent to current data users and women's health agencies (leaders) outside government.

KEY STAKEHOLDERS CONSULTING

Leaders inside government

Four interviews (1 face to face and 3 telephone) were conducted with leaders inside government. One stakeholder declined to be interviewed on the basis that the ALSWH had not been used within their Division. The purpose of these consultations was to assess the degree to which leaders inside government used the ALSWH for informing policy development, building the evidence base around women's health issues in Australia, and seeking ideas on how the ALSWH could be improved to maximise the value of the data collected.

Leaders outside government

The number of potential consultations with leaders outside government was quite large and beyond the capacity of the project to complete via personal interview. Therefore, a decision was made and approved by DoH to conduct three interviews and deploy a survey for the remaining 20 organisations. Surveys were sent to 20 organisations on 17 November with 14 responding within the timeframe. The purpose of these consultations was to get a sense of how/if ALSWH was used to inform their policy and or research activities and to explore ways in which it could be improved to maximise the value of the data collected.

Current data users

Five current data users (defined as using ALSWH data within the last 3 years) were interviewed as part of the consultation strategy – these five were chosen randomly from the list of current users. Additionally, surveys were sent to approximately 200 current users with 68 responding within the timelines. The purpose of these consultations was to explore whether the ALSWH is meeting its objectives, the quality of the data, the contribution to building the evidence base around women's health, the contribution to public health research practice and how it could be improved to maximise the value of the data collected.

Potential users

Four telephone consultations were conducted with 'potential' users of ALSWH data. These participants were selected based on a search of organisations/institutions that focus on women's health and then matched to the list of current users. If the organisations/institutions were not included as a current user they were included in the list of 'potential' users. From this list, four organisations/institutions were chosen for inclusion in the consultation. The purpose of including

potential users in the consultation strategy was to explore the reasons that ALSWH was not being used by an organisation/institution that would be expected to be interested in the information included in the ALSWH. These consultations were also an opportunity to educate people about the ALSWH and to explore ideas to improve visibility, knowledge and thus utilisation of the ALSWH.

National government statistical agencies

Two face to face interviews were conducted with the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. The purpose of these interviews was to determine the extent to which the agencies were familiar with the ALSWH, had utilised ALSWH data to inform their work, and their perspectives on the contribution longitudinal data can make to their work.

Qualitative data collection

A report which details the consultation process is included as Appendix D. Qualitative information was collected from the four distinct stakeholder groups outlined above in order to get input that related to both policy and research. Discussion guides were developed for each of the four groups and were sent to participants approximately one week prior to their scheduled consultation session. The ACIL Allen team conducted a total of 18 interviews with key stakeholders and received survey responses from 82 individuals/organisations.

An ethics application was submitted and approved for the project team to review a sample of qualitative ALSWH survey responses across all cohorts in order to assess its effect on participants. Extraction of data for this review occurred at the ALSWH offices at the University of Newcastle and involved a Principal Consultant from ACIL Allen and ALSWH research staff. The methodology for this review is detailed in Appendix F.

Quantitative data collection

Quantitative financial data was collected from the University of Newcastle, the University of Queensland, and the DoH for the value for money assessment.

Stage 4: Analysis

The analysis of both the quantitative and qualitative data was guided by the evaluation framework developed in Stage 2 (Appendix A). Analysis of the data focused on the key themes (quality, contribution, effect on participants, and value for money) – results of the analysis are included in Chapters 3 – 7 of this report.

Stage 5: Reporting

The reporting for the project included the following:

- Monthly progress reports – a report template was developed for this purpose and was updated monthly to reflect progress and to also provide a forum to discuss outstanding issues. These reports were sent to the DoH on the 15th of each month.

- Presentation of preliminary findings –on 9 April 2015 ACIL Allen presented preliminary findings on the quality, contribution, effect on participants, and value for money of the ALSWH to the advisory committee, which included ALSWH researchers, an independent chairperson and other relevant Commonwealth government stakeholders. This presentation provided a forum to test and validate the preliminary findings and resulted in a request to conduct 4 additional consultations with leaders inside government. This request was actioned and 3 of the additional consultations conducted.
- Draft report – the structure of the draft and final reports was agreed with DoH and both reports were written to this structure. The draft report was submitted to DoH on 3 June 2015.
- Final Report – consolidated comments on the draft report were incorporated into the final report which was submitted on 19 June 2015.
- Presentation of findings and recommendation–ACIL Allen will provide two presentations on the findings of the evaluation. The first presentation will be conducted on 30 June to DoH staff, and the second will be conducted on 1 July as part of a DoH sponsored conference on longitudinal studies.

Limitations

There are a number of limitations which may have an effect on the findings presented in this report. These include the following:

- The consultations with key women's health leaders both inside and outside government posed a challenge in that many potential participants were unaware of the ALSWH and did not want to engage in a discussion about it. In several cases the project team were able to conduct interviews with policy representatives who were unaware of the ALSWH and used the opportunity to raise awareness about the Study and its relevance to their work along with discussing ways in which the ALSWH might be better utilised within government.
- Consistent with the scope of this evaluation, the value for money analysis focused on the DoH funding for the core activities of ALSWH. Additional research activities involving the ALSWH and funded from other sources, were not included in consideration of the value of the ALSWH. In addition, the comparative analysis for the value for money component of the evaluation was restricted to use of publicly available data from the comparator groups. Potentially, there are more data available which is not in the public domain, however, this was not requested or accessed in this project.

KEY FINDINGS – QUALITY OF THE ALSWH

INSTITUTIONAL ENVIRONMENT

- Joint hosting of the ALSWH by the University of Queensland and the University of Newcastle brings substantial research expertise, objectivity and resources, including support for secondary research.

RELEVANCE

- The breadth of the ALSWH as scoped by the key themes to be addressed allows for wide ranging relevance of the data and the potential to accommodate continuing inquiry from new perspectives
- The ALSWH cohorts are considered to be broadly representative of the Australian adult women population
- The funding agreement for the ALSWH has enabled regular input from the Commonwealth to priority analysis of ALSWH data
- The governance structure for the ALSWH could be enhanced to include the perspectives of states/territories, non-government organisations, clinicians, and the general community
- The low level of awareness of the ALSWH among leaders in government may reflect more on the relatively low use of longitudinal data sets to inform policy than on the potential relevance of the ALSWH.

TIMELINESS

- There is no 'gold standard' for the timeliness of longitudinal studies. The frequency of the ALSWH survey waves are largely determined by the likely rate of change influencing the health of participants, and data collection occurs over an extended period to maximise the response rate.

ACCURACY

- Actions taken to address accuracy of the ALSWH include oversampling in the original sample selection, derivation of sample weights to obtain population estimates, and rigorous strategies to maintain the cohort groups
- Processes are in place to encourage completion of survey questions and to provide for regular review and feedback on data quality
- The ALSWH is seen as a robust and accurate source of data.

COHERENCE

- The technical reports and data books describe the accuracy of the ALSWH data and provide evidence of study coherence.

INTERPRETABILITY

- There is a diversity of data products of the ALSWH designed to support interpretability that also serve to promote the accessibility of the information.

ACCESSIBILITY

- There is a general sense that the ALSWH is an underutilised source of data
- Data cubes are provided to AIHW and ABS although the level of awareness and familiarity with the data in these agencies appears to be limited
- A dedicated website is a key source of information about the ALSWH data and products
- There is some concern by users and non-users of the ALSWH data that access to the data is restrictive and the process for obtaining data is difficult.

3. QUALITY OF THE ALSWH

3.1 Performance against key measures of quality

A key requirement of the evaluation is to assess the quality of the ALSWH. The data quality is critical to achievement of the ALSWH objectives that include the collection of 'scientifically valid' information to provide an 'evidence base' for 'health policy and practice'. The Australian Bureau of Statistics (ABS) describes the concept of data quality as multidimensional that can be defined by seven dimensions to assess whether the collection and products are fit for purpose (ABS Data Quality Framework 2009). The importance of each of the dimensions will vary according to the purpose. The following assesses the ALSWH against these dimensions comprised of the institutional environment, relevance, timeliness, accuracy, coherence, interpretability and accessibility. The assessment draws from the Data Quality Statement (2014) prepared by ALSWH researchers, information on the ALSWH website, and from stakeholder feedback.

Institutional environment

The ALSWH is jointly implemented and managed by the University of Queensland and the University of Newcastle. This arrangement brings substantial expertise, objectivity and resources including access to research infrastructure. The roles and responsibilities of each of the partners is clearly defined, supporting: participant confidentiality; a focus on building capacity and good practice in key areas of data collection, storage and manipulation; and a breadth of research interest to inform the evidence base for women's health as well as the conduct of longitudinal studies. The ALSWH team at the University of Newcastle includes statisticians, researchers, and cohort management. The University of Queensland ALSWH team focuses on data management, statistical analysis, data access and outcomes, and includes a mental health research fellow.

The organisational context for management of the ALSWH has provided the contemporary research infrastructure of protocols and ethical review, and a research skills set that includes a continually evolving technical capacity to manage and manipulate large databases.

This arrangement has also enhanced the opportunity both internal and external, for secondary use of ALSWH data, and increased the value of the longitudinal data through data linkage research. Similarly, the ALSWH cohort has provided the sample population for other research, including extending the cohort to capture their children for separate research. The approach used to support secondary research and access to the ALSWH cohort has involved close liaison with ALSWH researchers to foster quality outputs and preserve the ALSWH sample.

Relevance

Governance and priorities

The ALSWH is managed through a series of contracts between the Commonwealth and the research institutions. The periodic review of the contract for services has enabled the outputs and design of the ALSWH to be reviewed, refreshed and agreed in ensuring its continuing relevance.

The current contracts cover the period 2013 to 2015 for the original cohort, and into 2016 for the new young cohort and changed survey arrangements for the older cohort. The contracts include the requirement to consult with DoH on the content of each survey, to present research findings to DoH every two years, and host an annual meeting with DoH for 'scientific and research planning'. A list of research themes (see Box 3.1) is provided for inclusion in surveys as appropriate to the cohort, and there is a further requirement of the researchers to investigate potential new content areas.

BOX 3.1: KEY RESEARCH THEMES FOR ALSWH

The following are the current agreed research themes relevant to ALSWH, to be incorporated in surveys as deemed relevant to the cohort.

- Chronic disease
- Health service use and systems
- Social factors in health and well-being
- health in rural and remote areas
- Women and mental health
- Roles and relationships
- Intergenerational issues
- Tobacco, alcohol and other drugs
- Weight, nutrition and physical activity
- Mental health
- Ageing
- Health service usage
- Formal and informal work patterns and work-family balance
- Caring
- Reproductive health.

SOURCE: CONTRACT FOR SERVICES BETWEEN THE COMMONWEALTH AND ALSWH RESEARCH ORGANISATIONS, 2013 - 2015.

The research themes capture the priorities identified in the National Women's Health Policy 2010, and have been sufficiently broad (for example, 'social factors in health and well-being') to accommodate current priorities, such as, prevention of violence against women (also the subject of ALSWH thematic analyses and sub-studies), and to reflect a range of ways in which violence can manifest, such as psychological abuse of older women (Department of Health, 2010). In some instances, there is a new language used to frame issues, such as the impact of 'climate change' on women's health (Australian Women's Health Network), however, this impact can be tracked in a number of ways through the ALSWH, including changes in working and living options, and understanding the vulnerabilities of women in a changing environment, such as those with a carer role. The extent to which diversity, such as cultural and gender, can be accommodated has some limitations, which can in part be addressed through the capacity to introduce new content areas, to link datasets, and combine studies. Using the examples of recent women's health policy statements in New South Wales (NSW Government, 2013) and Western Australia (Department of Health Western Australia, 2013), the ALSWH remains a relevant source of information about all areas of nominated health priorities, and a strong potential contributor to achievement of policy outcomes.

Under the Commonwealth contracts, the major outputs of the ALSWH include:

- An Annual Report - including ALSWH highlights, new findings and analytical review of the research themes, with a copy provided to interested parties in consultation with DoH, including to the Office for Women
- Major Reports - addressing a topic agreed annually and selected from the research themes (for example, mental health (2013), and comparison of health and wellbeing of women aged 18 to 23 in 2013 and 1996 (2014))
- Technical Reports - covering methodology, new research findings, and dissemination activities
- Annual submission of ALSWH de-identified data to the Australian Social Sciences Data Archive (replaced by the Australian Data Archive) to facilitate other research
- Production and dissemination of a Newsletter to survey participants
- Maintaining a website for the ALSWH.

The contract also provides for the input of the ALSWH Project Advisory Committee established to provide 'strategic, policy and technical advice...on the long term directions and future priorities and the implementation, content, operation and analysis of [ALSWH]'. Governance arrangements provide an important mechanism for ensuring the quality of the ALSWH products, including informing and assessing the relevance. The governance of the ALSWH captures selected Commonwealth Government Departments through the Project Advisory Committee convened by the DoH, and researchers through the Research Steering Committee convened by the ALSWH.

There is scope to widen the engagement of Commonwealth agencies in providing stronger linkages to key stakeholders. This could be achieved through review of the Advisory Committee membership, either to expand standing members or invite occasional participation, and/or through an enhanced process for canvassing priority information needs. This process should `stimulate discussion about the policy questions that can make best use of the existing data set, and leverage additional resources for new analyses. There is also scope for direct representation of state and territory government on the Advisory Committee. Rotating membership of the Committee for a state/territory government representative(s), and an occasional national forum to discuss existing and emerging policy information gaps would bring stronger links to local issues as they might inform national priorities. This could also provide an opportunity to review progress against the National Women's Health Policy 2010 and the key planks of advancing women's health through targeted health services and prevention programs, and addressing health inequities.

Other governance models that might strengthen the relevance, and awareness, of the ALSWH include representation from non-government agencies, clinicians, and extension of the governance structure to include a community reference group and external scientific advisory group.

Coverage

There is detailed analysis of the survey sample populations to establish the extent to which findings can be generalised to the comparable broader population. Comparison with 1996 census data suggested some bias in the ALSWH sample with over-representation of women with tertiary education and under-representation of certain groups of immigrant women. Later census data

comparisons also suggested that ALSWH women were more likely to be married, be employed and working longer hours. These differences are thought to be partly attributable to differences in survey questions and sampling for the original cohorts that drew from Medicare cardholders. The new younger cohort recruited in 2012 and 2013 were required to hold a Medicare card, and when compared with the 2011 census data, were found to be broadly representative for area of residence, marital status, and distribution across states and territories, and age. As for the original cohorts, there was an over-representation of women with tertiary education.

The over representation of people with 'higher intelligence and socioeconomic status' has been associated with sample selection of longitudinal studies arising from the voluntary nature of participation (Baltes, 1968). The Australian Longitudinal Study on Male Health (Ten to Men), commissioned in 2011, used a household recruitment method in preference to a mail-out based on the Medicare database because of concerns about the low response rate. Comparison of the Ten to Men sample with ABS 2011 Census data found that adult participants tended to have higher levels of education, workforce participation and household income than for the general population (Ten to Men, 2014). The Household, Income and Labour Dynamics in Australia (HILDA) Survey, which recruited households through private dwellings, also found differences between the HILDA sample and the general population using the ABS Labour Force Survey, with higher estimates for the variables of hours worked and highest level of education (Watson, 2012). As for the ALSWH, it is argued that the comparison may not be valid because the difference could be attributable to the data collection method or the questions asked.

In relation to Aboriginal and Torres Strait Islander women, the ALSWH Indigenous DATA Policy clarifies that the ALSWH was not designed to be used as a source of data about Indigenous health, and cautions that data provided by Aboriginal and Torres Strait Islander women in the ALSWH is not representative of this population more generally. The ALSWH is promoted as 'broadly representative of the entire Australian population of adult women'.

Stakeholders interviewed generally recognised that the ALSWH is not likely to be able to meet all needs and that its strength, in tracking changes over time through repetition of questions, in part accounted for its limitations. There was support also for focusing on the strengths of longitudinal studies in researching variability in populations rather than establishing the representative nature of the survey population.

Utilisation

Stakeholder feedback from leaders within and external to government suggests that longitudinal studies are generally poorly used as an input to policy, despite the establishment of a number of longitudinal studies by Commonwealth agencies. This support has been in recognition of the 'valuable contribution' of longitudinal studies to show 'what matters and works' over time and domains, providing 'a unique and cross-portfolio perspective for understanding the often complex and interacting issues facing policy-makers' (A guide to Australian longitudinal studies, FaHCSIA 2013). There is a growing awareness of the potential of longitudinal data and an enthusiasm for engaging with the ALSWH and other longitudinal studies to address policy challenges.

In contributing to the understanding of the physical and mental health of Australian women, the ALSWH has a broad scope that encompasses the social and environmental influences, and the specific priority issues of reproductive health, health service usage, and preventative health. While there is continual contextual change, the issues remain pertinent to health priorities for women. In addition, the increasing capacity for data linkage and the emerging science together with the high regard for the reliability and consistency of ALSWH data, have extended the relevance and power of the data collection. For example, ALSWH data contributed to the international collaboration of 20 existing longitudinal studies investigating the link between reproductive health and subsequent chronic disease events (InterLACE 2012-2015), and the application of record linkage capabilities to combine data from the ALSWH with administrative health services data (for example, cancer registries and hospital admission datasets), focussing on the priority areas of reproductive health, mental health, cardiovascular conditions and musculoskeletal problems (CREWH21 2010-2015).

Amongst the research community, respondents to the survey of current collaborators indicated that 35 per cent (n=68) used ALSWH data for over 70 per cent of their research. Of the 25 per cent of respondents who indicated that they rarely used ALSWH data, alternative data sources cited included their own research, state databases and ABS Census data. Current users of ALSWH data thought that it was an underutilised database.

Outputs

The key data users of the ALSWH are broadly defined as government and non-government agencies, researchers, advocacy groups and women in general. The diversity of outputs recognise the range of users but also highlights the challenge in distilling and analysing information to meet user needs and do justice to the database. Consultation feedback from a number of senior government officials involved in the development of national policy suggests that the ALSWH remains relevant to informing the response to women's health needs, but generally, is not well known, both to agencies responsible for highlighting the statistical evidence base, and in areas of government concerned with population health and wellbeing. There would also appear to be opportunity to better connect to key areas of government health and welfare where policy questions emerging from debates within and between governments provide a modern context for research that is responsive to the policy needs of government. Some of the thinking about emerging and future policy questions related to: societal issues such as the mental health of the 'sandwich generation' of women dealing with child care and ageing parents; preventative health measures such as tracking the cohort of women who received Gardasil vaccine and their long term outcome in relation to cervical cancer; productivity associated with extending working life, the science around onset of dementia, and tracking interventions to avert the dementia pathway; and to tracking reforms to health financing mechanisms that better reflected the challenges of chronic disease as opposed to acute care. These examples provided in consultation feedback fit within the scope of the ALSWH key themes (see Box 3.1), but provide specificity about policy issues and challenges. There was interest within government in engaging with the DoH to discuss cohort design and policy questions, as well as sub-studies using the ALSWH and the capacity to develop bespoke questions and analysis. There was a view that there would be an increasing need to leverage off the ALSWH as part of data collection, and longitudinal studies in general,

‘Government needs to get better at understanding the value of longitudinal data in informing policy’.

The ALSWH data was influential in shaping aspects of the National Women's Health Policy released in 2010. Since then, the ALSWH's contribution to government policy is reported to include influencing recommendations of the Australian Government's Physical Activity Guidelines 2014, and the NSW Government's Health Framework for Women's Health in 2013.

Belying the continued investment in the ALSWH and analytical direction provided, there was a perception among leaders external to government, that the reduced capacity of DoH and detachment from women's health had undermined confidence in the continuing relevance of the ALSWH.

TIMELINESS

Wave frequency

The funding agreement for the ALSWH establishes the agreed frequency of survey waves and the timeframe for reporting. While there is no 'gold standard' for the timeliness of longitudinal studies, the reliability of the data requires regard for the likely occurrence of change, including change peculiar to a cohort, maintenance of the cohorts and concession to achievement of a high response rate.

Two of the first three ALSWH cohorts are currently surveyed every three years, with the third and oldest cohort surveyed every six months. The fourth and youngest (new young) cohort is surveyed annually. The majority of the surveys are paper-based, with some surveys conducted by telephone on request, while the new young cohort complete the survey online. The timing of the surveys for the youngest and oldest cohorts is sensitive to the rate of change in life events for these participants, while the survey waves for the remaining cohorts anticipate greater stability.

Other longitudinal surveys range from one to five years between survey waves, for example, the NSW based 45 and Up Study, which has a single large cohort, conducts five yearly follow up surveys, while the UK based Million Women Study of women aged 50 and over, has conducted follow up surveys at irregular intervals, the first follow up at three years, with subsequent surveys at five and 4 year intervals. The time between surveys may be influenced by the dynamics of the issues (for example the Household Income and Labour Dynamics in Australia (HILDA) survey conducted annually), the resources required to collect data (for example the inclusion of biometric measures in the Australian Diabetes, Obesity and Lifestyle (AusDiab) Study conducted three times in a period of 12 years), the demand for the information (for example the Longitudinal Study of Indigenous Children (LSIC) conducted annually), and the complexity of the cohorts (for example the Australian Longitudinal Study on Male Health (Ten to Men Study) conducted every two to three years with four cohorts comprised of boys (aged 10 to 14 years), parents of boys, adolescents (15 to 17 years) and adult males (18 to 55 years)).

Regardless of the frequency of survey waves, the 'currency' of longitudinal data is extended by linkages to other datasets that provide both prospective and retrospective information, and the ability for ongoing research based on the longitudinal data, such as through sub-studies.

Data availability

Data books for each of the ALSWH surveys are published online approximately four months after closure of the survey period, which extends to 18 months. Data from the six-month follow up surveys of the oldest cohort are updated regularly and available on request. The importance of follow up to the validity of the longitudinal survey justifies the lengthy period to closure of the survey wave.

ACCURACY

Sample weights

The accuracy of the data influences 'how useful and meaningful the data will be'. A number of actions are taken in the ALSWH to address accuracy. In the original sample selection, oversampling was conducted in rural and remote areas, and sample weights based on the original samples are provided for use in deriving population estimates.

Key informants commented on good retention rates of ALSWH particularly in the original cohorts. A range of strategies are employed by the ALSWH to maintain the cohorts with continuous tracking of all enrolled women including those who may have failed to respond to a follow up survey (ALSWH 2014). It is difficult to compare retention rates across longitudinal studies as loss can be affected by a number of factors including time between survey waves, time available for data collection, the cohort population, the content of the study, and resources available to maintain the cohort. Generally, however, the highest loss of participants in cohort studies is considered to occur between the first and second survey waves, with ALSWH, HILDA and the Melbourne Collaborative Cohort Study recording between 10 to 30 per cent attrition (Ten to Men 2014). The ALSWH is at the high end of this range for the 1973-78 youngest original cohort (approximately 69 per cent retention rate at wave 2 as a proportion of eligible women in the cohort (and 65 per cent for the 1989-95 new young cohort)), noting that ALSWH modelling suggests no serious bias for the cohort due to this rate of loss. The ALSWH is at the low end of the range for the two older original cohorts (approximately 92 per cent for the 1946-51 cohort and 93 per cent for the 1921-26 cohort) (ALSWH 2014).

Over a longer period of time, HILDA (a household, annual survey commenced in 2001) reported that almost 63 per cent of persons in the original interview were re-interviewed in the tenth follow up survey (wave 11), or approximately 69 per cent of those 'in scope' (Watson & Wooden 2012). The ALSWH achieved similar results for the 1946-51 cohort after five follow up surveys (wave 6 - approximately 73 per cent of the original cohort or 83 per cent of those eligible) with a longer time between survey waves. 'Eligibility' excluded loss to death, frailty and withdrawal. The comparable ALSWH results for the youngest original cohort, of approximately 56 per cent of the original cohort or 62 per cent of those eligible, and oldest original cohort, of approximately 33 per cent of the original cohort or 81 per cent of those eligible, reflect the loss attributable to a mix of

factors including the mobility of the youngest cohort, and the high incidence of death and frailty among the oldest cohort.

Testing of survey questions

ALSWH follow up survey questions are tested and evaluated prior to each survey wave. A similar process precedes survey waves for other longitudinal studies, such as HILDA, or has been undertaken 'as necessary', such as LSAC. Testing allows review and refinement of questions, having regard also for current literature and feedback from survey respondents. This also enables testing of sensitive questions and the impact on response rates. The Technical Reports document the operational aspects of ALSWH including survey planning and development, and details of the outcome of pilot surveys, such as question inclusion or modification and rationale.

Follow up survey testing includes opportunity for ALSWH staff and researchers to nominate questions for deletion and propose new questions for inclusion in the next survey cohort wave. The pilot survey includes an evaluation questionnaire to provide feedback on survey items, and is tested on a pilot sample recruited from the cohort. An internal Data Management Group and Steering Committee agree the final questionnaire content for the cohort pilot survey, following feedback from DoH. The pilot survey is also subject to usual ethics approval.

Survey completion

ALSWH data books are published for completed surveys with respondent numbers, mean and standard error, and missing responses for each survey question. Missing data is reported to be less than 5 per cent for most items, with a notable exception being reporting of Body Mass Index with 10 per cent missing data. A number of processes are in place to encourage completion of the survey questions.

Data revisions

The ALSWH Data Management Group meets monthly to consider data issues, and any necessary revisions to the data. Data users are encouraged to provide feedback on data quality.

Coherence

The coherence of the ALSWH relies in large part on the consistency of questions over time and the ability for the study to incorporate changes in guidelines, for example, in order to be consistent with related studies.

Internal

As mentioned above, changes to each of the ALSWH surveys are kept to a minimum, but may need to respond, for example, to technical improvements, new evidence of influences on/predicators of behaviour, changes to the delivery of health services, consistency with other studies, and participant feedback from the previous survey.

Baseline data or other periods for the cohort are used to make statistical comparisons, and cohort response summaries are produced showing changes in responses over time. A number of stakeholders commented that ALSWH data is not replicated in any other data sets.

Changes to the mode of administration of the survey were investigated with the adoption of internet surveys for the new young cohort. This research used a randomised controlled trial of internet and paper surveys for the pilot of wave 6 for the 1973-78 cohort (women aged in their thirties). The research concluded that there was no significant impact on response rates and completion of survey questions in moving from paper survey to online survey in a longitudinal study (ALSWH 2014).

External

In relation to external coherence, ALSWH data has been pooled with Australian and international studies, although the sampling method and mode of collection (i.e. self-reporting rather than measured) has led to some differences with other studies.

Interpretability

Supporting documentation

Interpretation of ALSWH data is supported in a number of ways that takes account of the technical skills of the enquirer and the different purposes for accessing the data. Detailed explanation of the data is contained in the standard outputs of survey data books, data dictionary, technical and major reports providing selected thematic analysis. More concise information is contained in newsletters to cohorts and 'quick grabs' or fact sheets that may be featured on the ALSWH website.

Findings of patterns in ALSWH data have been highlighted through themed major reports, cohort summaries and achievement reports.

Scientific papers using ALSWH data foster an accurate understanding of the information. The ALSWH researchers estimate that since survey commencement in 1996, more than 650 researchers have collaborated on projects using ALSWH data and more than 470 papers have been generated for publication in peer reviewed journals.

A descriptive file, the data dictionary, and a description of the variables in the data set accompany archived ALSWH data.

Accessibility

Data availability and formats

The ALSWH website is a key source of information about the study data and products, tailoring information to three categories of enquirers: participants, researchers, and policy makers. Published papers by research collaborators extend access to ALSWH data with 130 papers in peer-reviewed journals between 2010 and 2014 using ALSWH data. In addition, book chapters have been prepared using ALSWH data with five books incorporating chapters since 2010. Conferences

also provide an important medium to raise awareness and improve access to research findings. ALSWH researchers' presentations at conferences have served to engage the communities of interest and generate media interest.

Data cubes are provided to the ABS and the Australian Institute of Health and Welfare (AIHW) although the level of awareness and familiarity with the data in these agencies appears to be limited.

A protocol, contact details and a committee are available to promote shared data by external researchers. Of current collaborators surveyed, 67 per cent (n= 60) strongly agreed or agreed that ALSWH data is easy to access. Almost half of respondents (n= 67) indicated that the ALSWH liaison person (designed to ensure correct use of the data and coordination of projects) was extensively involved in all aspects of accessing and interpreting the data, and was cited as a collaborator/author.

Consultation feedback suggested that while access procedures and supports were clear, data access could be improved through increased promotion of the data and less tightly controlled data access, which could act as a deterrent to data use. ALSWH staff have reported that they have been making improvements to accessibility requirements, but it is not known whether consultation feedback takes account of these improvements. A range of protocols exist for other longitudinal studies offering potential options for more flexible, and self-directed access.

3.2 Summary

The quality of the ALSWH has benefited from the relationship between academia and government providing a meld of direction on policy priorities, application of research rigour, and opportunity to continually explore new ways of leveraging further research from the data set. There is an impressive program of research collaboration and there are data outputs that recognise a wide range of information needs and technical skills.

Consultation feedback suggests that there is new potential within government to explore the use of longitudinal surveys in providing greater clarity about cause and effect, and tracking the impact of policy changes. Generally, there is a low level of use of ALSWH data to inform policy, which can probably be attributed to low awareness of ALSWH rather than a reflection on the quality including coverage of ALSWH. Increased promotion of ALSWH initially within government is warranted and could be achieved through enhanced governance arrangements and improved mechanisms for researchers to discuss information needs with key leaders in government.

From the researcher’s perspective, there may be a better balance between safeguards to ensure ALSWH data is appropriately used, and facilitating an easier process to access the data.

4. CONTRIBUTION TO THE EVIDENCE BASE

KEY FINDINGS – CONTRIBUTION TO THE EVIDENCE BASE

- The majority of ALSWH research collaborators and NGOs surveyed reported that the ALSWH had made a large contribution to the evidence base for women's health
- Recent policies informed by the evidence established by ALSWH include a number of national and state policies guiding strategic directions on women's health
- Scientific articles using ALSWH data have appeared predominantly in high ranked journals
- Feedback from potential data users suggests there continues to be scope to promote ALSWH data, including to clinicians.
- There was a common view that as publicly funded research it should be more widely known that the ALSWH is a public resource and available for secondary analysis
- There is an interest amongst leaders in the Commonwealth in discussing the opportunities for the ALSWH to contribute to their policy questions
- There were different views about the policy areas most influenced by the ALSWH among collaborators and NGOs, which demonstrates the different priorities for these groups and reinforces the value of including NGOs in discussions about the ALSWH survey design and analysis.

4.1 Strategies to build the evidence base

A key objective of the ALSWH is to provide an evidence base to government for decision making about policy and practice in women's health. The extent to which this objective is being met is assessed through the use of the ALSWH to inform research papers and government policy, and the approaches taken to promote data usage in building the evidence. The previous discussion about the quality of ALSWH data is an important enabler to providing confidence around the data and its accuracy, however, a range of strategies will be necessary to highlight the data findings and their relevance to policy and practice issues.

Influence of the ALSWH

The majority of current ALSWH research collaborators (87 per cent; n=60) and NGO leaders (90 per cent; n=10) surveyed strongly agreed or agreed that 'ALSWH had played a key role in identifying relevant women's health issues and needs since its inception 20 years ago'. The respondents further agreed that the ALSWH had contributed to a very large or large extent, to the evidence base around women's health (80 per cent of collaborators and NGOs).

ALSWH data has influenced national and state policies, most significantly the strategic priorities of the National Women's Health Policy 2010. Other areas of national influence have included

incontinence management, respite for carers and a physical activity guide for older Australians. Additional policies informed by the ALSWH in 2010 through to 2014 are set out in Table 4.1 below, and include state policies for Victoria and New South Wales.

TABLE 4.1: ALSWH'S CONTRIBUTION TO GOVERNMENT POLICY (2010-2014)

Commonwealth Government Policy	Year	Contribution
The Australian Government's Physical Activity Guidelines	2014	ALSWH research impacted recommendations regarding: prevalence and predictors of weight gain, sedentary behaviours and health; and new domains of physical activity
Australian Government National Women's Health Policy	2010	ALSWH research was used extensively to develop this policy. Specifically, ALSWH research/data influences recommendations covering a range of topics include: • Sexual and reproductive health • Mental health • Chronic conditions
Australian Government National Women's Health Policy	2010	ALSWH data/research was used to inform findings on access to health services and lesbian and bisexual women.
STATE / TERRITORY		
The NSW Government's Health Framework for Women's Health	2013	Published research utilising ALSWH data was utilised to develop key recommendations (e.g. accessing health services).
New South Wales Women's Health Plan	2010	ALSWH data/research assisted in developing short term objectives to advance women's health priorities.
Victorian Women's Health and Wellbeing Strategy 2010-2014	2010	ALSWH data was used for contextual purposes.
Improving women's access to health care services and information: A strategic framework 2010-2015	2010	ALSWH data/research was used as evidence for 'key drivers of change' in health service demand.

SOURCE: BASED ON SELECTED CONTRIBUTIONS TO GOVERNMENT POLICIES AVAILABLE AT: HTTP://WWW.ALSWH.ORG.AU/PUBLICATIONS-AND-REPORTS/POLICIES-AND-GUIDELINES

Scientific articles largely generated by the collaborating research community extend the value of ALSWH data and increase its capacity to contribute to a wider evidence base. In the period 2010-2014, there were 130 peer-reviewed journal articles that drew upon ALSWH data, delivered to between 36 and 44 conferences annually. Excluding 14 articles that were published in a journal not ranked by SCImago (medical journal rank), the majority (78 per cent; n=90) of these articles were published in a high ranked journal, and the remainder (22 per cent of n=26) in a medium ranked journal. ALSWH data was exclusively used in 61 per cent of articles (n=79), and included in a further 36 per cent of articles (n=47).

Promotion of ALSWH data

The reach of the ALSWH has been actively pursued through dissemination of the findings of survey waves through the ALSWH website, support for research collaborators in undertaking secondary analysis of the ASWH data, and presenting research findings at conferences. The different avenues for dissemination of information about the findings reflect the website categorisation of potential interest, that is, participants, researchers and policy makers. This could be further developed to include the general public and advocacy bodies. Examples of ALSWH survey outputs include the analysis represented by reports and papers outlined in Box 4.1. These outputs align with the products of other longitudinal studies, although HILDA includes 'public lectures' and is able to reference other publications such as Grattan Institute and Productivity Commission Reports, and Reserve Bank Bulletins.

BOX 3.1: KEY RESEARCH THEMES FOR ALSWH

Survey outputs reflect a range of resources and purposes:

- Annual report: reporting on surveys and dissemination
- Major report: an annual report focusing on an agreed theme drawn from ALSWH priority areas
- Technical report: outlining how ALSWH is progressing
- Peer reviewed article: between 2010 and 2014, 130 articles were published using ALSWH data
- Miscellaneous report: covering a range of health issues and methodological issues, not published in peer-reviewed journal
- Achievement report: produced in 2005 to mark a decade of ALSWH and covered issues such as paid work and women's health, ageing, alcohol consumption, weight, mental health, violence and rural health.
- Synthesis report: summarising technical reports and produced in 2003 and 2004
- Book chapter: focusing on aspects of ALSWH research with five chapters produced since 2010
- Cohort summaries: for each of the original cohort from initial survey through to 2013.
- Newsletter: for cohorts providing feedback on findings of survey waves
- Fact Sheets: providing a 'quick grab' on women, work and retirement.

Additional survey outputs include:

- Data books, data dictionary, and data cubes.health in rural and remote areas
- Reproductive health.

SOURCE: (ALSWH, 2015A)

A consistent theme in consultation for the evaluation, was the low level of awareness of the ALSWH which was noted above for leaders in government and national statistical agencies. Feedback from potential data users suggests there continues to be scope to promote ALSWH data, including to clinicians. There was interest in an opt-in newsletter style communication and a pro-active approach that made use of the networks of medical professional associations, similar to the regular reports provided by the Australian Institute of Health and Welfare. There was a common view that as publicly funded research it should be more widely known that the ALSWH is a public resource and available for secondary analysis.

4.2 Contribution to the ALSWH areas of priority

The key research themes for the ALSWH are listed in Box 3.1 and summarised in section 1.1 as related to the aims to assess and provide evidence on women's:

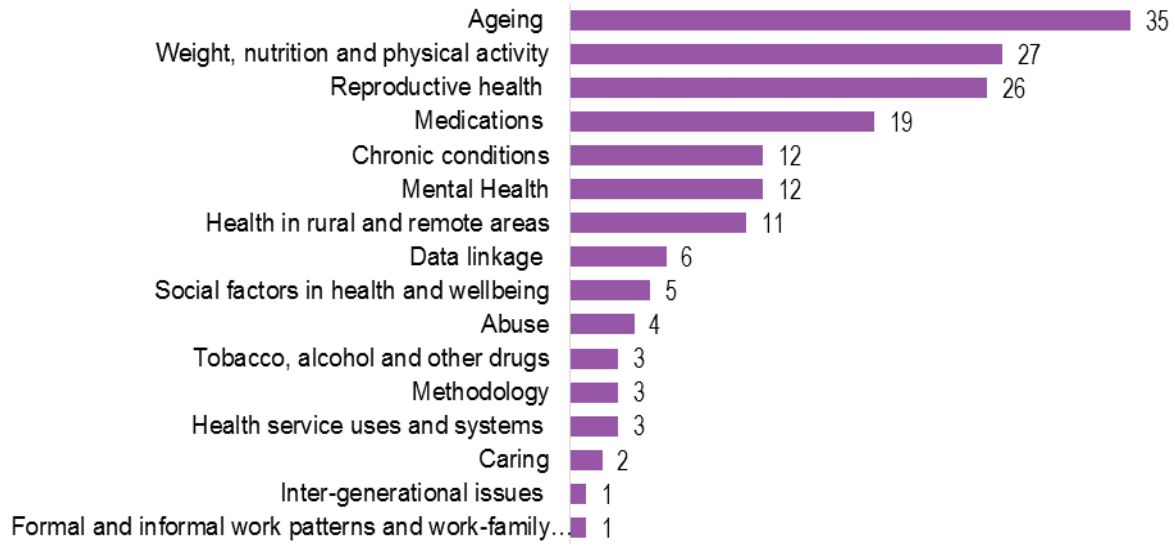
- Physical and emotional health
- Use of health services
- Health behaviours and risk factors
- Time use
- Socio-demographic factors
- Life stages and key events.

Major annual reports produced by the ALSWH in the period 2010-2014 have canvassed most aspects of these research themes combining and comparing cohorts in reporting on:

- Ageing and chronic conditions
- Health in rural and remote areas
- Reproductive health
- Health behaviours and risk factors
- Mental health
- Access to health services
- Psychological distress and violence
- Physical health.

Thematic analysis of the peer-reviewed articles using ALSWH data between 2010 and 2014 shows an emphasis on ageing; health risk factors and reproductive health (see Figure 4.1). Together, these issues account for 65 per cent of the 130 articles.

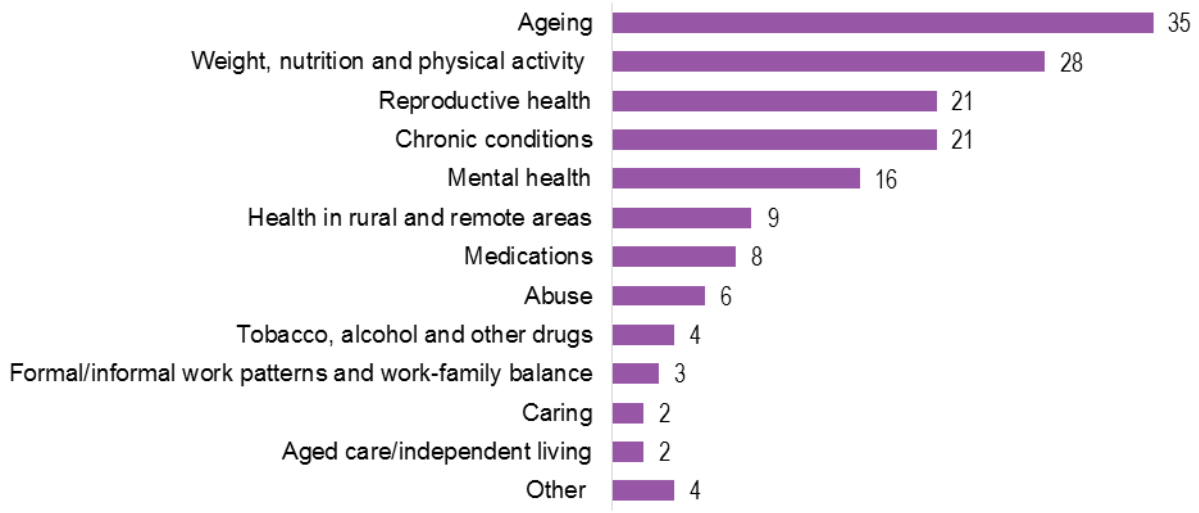
FIGURE 4.1: ALSWH PEER REVIEWED ARTICLES 2010-14 BY THEME



SOURCE: ARTICLES PROVIDED BY ALSWH

These results align with the findings from the current collaborator survey in relation to perception of the areas of largest impact of the ALSWH on women's health research, evidence base, and policy development. The single greatest area of influence was considered to be related to ageing, with eating and exercise behaviours, reproductive health, chronic conditions and mental health also resonating strongly (see Figure 4.2).

FIGURE 4.2: CURRENT COLLABORATOR SURVEY RESPONSES: WHAT AREAS OF WOMEN'S HEALTH RESEARCH EVIDENCE BASE AND POLICY DEVELOPMENT HAS ALSWH HAD A PARTICULAR IMPACT ON? (N=58)



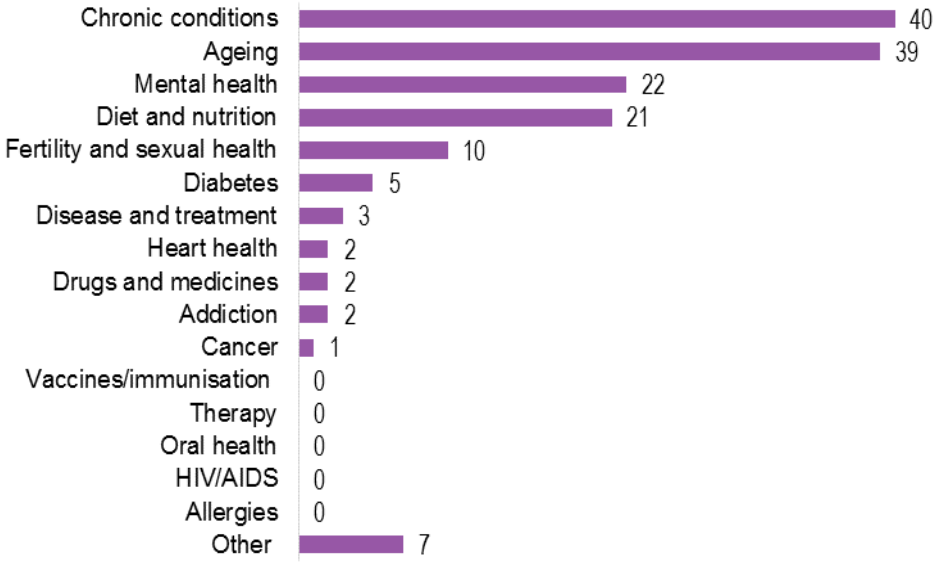
NOTE: RESPONSES ARE GREATER THAN 58 GIVEN RESPONDENTS COULD CHOOSE MORE THAN ONE RESPONSE

SOURCE: CURRENT COLLABORATOR SURVEY 2015

While the sample size is small, the NGO respondents (n=11) to the same question prioritised reproductive health, followed by work patterns and work-family balance on equal footing with abuse. This difference reflects the different policy issues at the NGO level and the value of this group in bringing different perspectives to discussions about the ALSWH priorities and analysis.

Differences in emphasis were recorded for the ALSWH's contribution to general health with stronger support from collaborators for chronic conditions and reduced perception of the value of reproductive health ('fertility and sexual health') (see Figure 4.3). Conversely, reproductive health was identified most frequently by NGO respondents (n=9) as the area of general health most influenced by ALSWH data.

FIGURE 4.3 – **CURRENT COLLABORATOR SURVEY RESPONSES: WHAT AREAS OF GENERAL HEALTH RESEARCH EVIDENCE BASE AND POLICY DEVELOPMENT HAS ALSWH HAD A PARTICULAR IMPACT ON? (N=56)**



NOTE: RESPONSES ARE GREATER THAN 56 GIVEN RESPONDENTS COULD CHOOSE MORE THAN ONE RESPONSE

SOURCE: CURRENT COLLABORATOR SURVEY 2015

There was strong agreement from collaborators and NGOs that ALSWH plays a key role in informing public health policy at both a state/territory and national level.

> *"I think the ALSWH is a very important resource for informing women's health policy in Australia. The ALSWH also helps to raise awareness of how health and other social indicators such as childbirth, education, caring for others, and employment over the life-course impacts on women's health."*
>
> *ALSWH current collaborator 2014*

4.3 Summary

The ALSWH is seen by research collaborators and NGOs as making a strong contribution to the evidence base for women's policy and programs. There are a range of methods used to build the evidence base and the products are of high quality. However, there are key leaders within and outside government, and potential data users who are not presently accessing ALSWH findings or taking the opportunity to undertake secondary analysis of the data. Without addressing the low level of awareness of, and engagement with, the ALSWH, the potential for the data to have a bigger impact on policy and program decisions will not be realised.

5. CONTRIBUTION TO THE PUBLIC HEALTH RESEARCH PRACTICE

KEY FINDINGS – CONTRIBUTION TO PUBLIC HEALTH RESEARCH PRACTICE

- The technical reports of the ALSWH have shared the considerable expertise developed in the conduct of longitudinal research and generally in good practice in research design and methods
- Collaborating with researchers has been an important approach to increasing the power of the longitudinal data, the resources available to analyse the data, and the breadth of research perspectives applied to data that crosses a wide range of domains
- The ALSWH researchers and ALSWH data are capable of attracting new funds, partners and taking advantage of new research capabilities in driving public health research practice.
- There is evidence that the ALSWH has influenced research practice, notwithstanding the opportunities that improved awareness of the initiative, and wider sector engagement could bring to this area.

5.1 Strategies to influence public health research practice

The ALSWH is able to influence research practice in a number of ways. These include in the conduct of quality longitudinal research, the development of research questions that are informed by the findings of the ALSWH, the conduct of secondary analysis of ALSWH data that focuses on the broad research themes that frame ALSWH data collection, and attracting research grants and collaborators for continuing analysis of the large ALSWH database.

Technical capacity

Over the 20 year life of the ALSWH there has been considerable expertise developed in the conduct of longitudinal research and generally in good practice in research design and methods. The ALSWH has explored these issues through occasional data technical reports and in the regular technical reports that document the operations and progress of the ALSWH. The technical reports describe, for example, the annual conduct of surveys, strategies for maintenance of cohorts, data linkage, data archiving and methodological issues related to survey data capture including the results of investigation of these issues. Dissemination practices and collaborative research activities are also canvassed. There have been 37 technical reports to date which are publicly available on the ALSWH website.

A number of data technical reports were produced in 2004 to 2006. These reports discussed aspects of survey design and analysis drawing from the ALSWH experience, for example, transition or change variables, analysing longitudinal data, and exclusion of survey items.

Secondary data analysis

The research community focus of the ALSWH is a strong component that serves multiple purposes. The community fosters research networking, and dissemination of information about research findings, and characteristics of the ALSWH including variables, cohorts and data collection. This encourages collaboration, an important approach to increasing the power of the longitudinal data, the resources available to analyse the data, and the breadth of research perspectives applied to data that crosses a wide range of domains.

The ALSWH has an established method for inviting interest in further analysis of the database that centres on allocation of an ALSWH liaison person to work through the research question, and as appropriate, to access the data and continue to collaborate on the analysis and reporting. Whilst this approach is viewed by some stakeholders as an overly restrictive model, and potentially a deterrent to using the data, it does respect the integrity of the longitudinal data, including the purposes for which it was collected, and can rationalise the allocation of research effort to similar areas of inquiry.

Leading research innovation

The ALSWH represents a national repository of information about the causes and influences on health outcomes of four generations of Australian women. This is a substantial data collection that is amenable to linking to administrative datasets, and to being pooled with other longitudinal data for more complex and layered investigation. The ALSWH researchers and ALSWH data are capable of attracting new funds, partners and taking advantage of new research capabilities in driving public health research practice.

5.2 Evidence of influence on research practice

There is evidence that the ALSWH has influenced research practice, notwithstanding the opportunities that improved awareness of the initiative, wider sector engagement, and easier access to the data could bring to this area.

Technical capacity

Research collaborators surveyed agreed or strongly agreed (72 per cent; n=57) that the ALSWH had an impact on development of research methodologies for other related studies. Amongst NGO leaders surveyed, a majority (60 per cent; n=10) agreed with the statement that ‘ALSWH has played a significant role in informing my organisation’s research, policy and other work’, while 20 per cent strongly disagreed.

The establishment of the Ten to Men longitudinal study had received support from the ALSWH during design to ensure the data corresponded with ALSWH data and shared information about survey method, cohort maintenance, data storage, access and management, and data linkage. This advice had influenced the Ten to Men research strategies including recruitment and data access.

The ALSWH researchers also have considerable technical expertise in data linkage and have provided training to numerous other researchers who are attempting to link large datasets.

Secondary data analysis

A majority (78 per cent, n=59) of current collaborators agreed or strongly agreed that the ALSWH has been useful in providing opportunities for current users to undertake sub-studies to inform women's health and general health, research and policy. The top three reasons provided by current collaborators for using ALSWH data related to the longitudinal nature of the survey, its relevance to research work, and the quality of the data. The majority (85 per cent; n=66) of current collaborators were university based, with 8 per cent and 3 per cent respectively from non-government and government sectors. Respondent organisations were a mix of national (34 per cent; n=62) and state/territory bodies (53 per cent). In the past 5 years, collaborators surveyed had produced papers/policies using ALSWH data for 1-3 projects (71 per cent, n=60), 4-6 projects (15 per cent), or 7 or more projects (14 per cent). Just over a third of collaborators indicated that 71 per cent or more of their research on women's health as based on ALSWH data.

The ALSWH also has an active program of student research (a proportion (28 per cent; n=67) of current collaborators had previously worked under supervision of ALSWH staff). There have been 40 PhD projects working on ALSWH data and 24 current PhD projects. Masters and Honours projects have also been supported. Student research not only makes good use of ALSWH data and assists in research dissemination, but also transfers research skills with the potential for influencing future public health research practice.

Leading research innovation

Current large scale multi-year research funded by the National Health and Medical Research Foundation utilises the ALSWH to explore a range of research questions through three associated studies that represent innovation in research practice. The approaches used in these studies include:

- The developing record linkage capabilities of the NCRIS funded Population Health Research Network
- Undertaking cross-cohort research by combining data at the individual level for more than 240,000 participants with the capability of generating evidence not possible from any single cohort study
- A family-centred approach to child health outcomes that support a more integrated and targeted approach to delivery of preventative and primary health care.

5.3 Summary

The impact of the ALSWH on public health research practice comes in part from dissemination of information about implementation, analysis and maintenance of the ALSWH, and in part from working with researchers and students to utilise ALSWH data for secondary analysis.

The ALSWH is also leading by example in the innovative work to build research capacity through building record linkage capabilities, and by building on the ALSWH cohorts to adopt a family centred approach to researching child health outcomes.

While collaborators and NGO leaders surveyed agreed that ALSWH had an impact on the development of other research, there is opportunity for strengthened engagement both in the government and non-government sectors to influence research practice related to women's health. Reviewing access to ALSWH data might also serve to increase the use of this data with benefits to the role of ALSWH in shaping future research practice

6. THE ALSWH EFFECT ON PARTICIPANTS

KEY FINDINGS – THE ALSWH EFFECT ON PARTICIPANTS

Impact on behaviour

Based on a sample of qualitative feedback, there was little evidence of a casual relationship between participating in the survey and changed behavour

A number of sources of information were used to determine the effect on women of participating in the ALSWH. The approach to this assessment is outlined in Appendix F and received ethics approval through the ALSWH ethics clearance processes, supported by ALSWH researchers. The areas investigated were whether the data had been effected by:

1. Participant lifestyle changes attributable to participation

2. Participant survey fatigue

3. Participant relationship with the ALSWH.

The key sources of information were:

- Qualitative information extracted from a sub-sample of surveys
- Records of outcomes of reminder calls and feedback on non-participation
- Sub-study activity and response rates
- Pilot survey feedback on sensitive nature of questions
- Data books for missing data
- Data linkage for withdrawn participants
- Major Reports providing comparison to broader population.

Qualitative information provided under the 'Have we missed anything?' section of the survey questionnaire which invites respondents to write anything else they 'would like to tell us about changes in your health (especially in the last three year)', was extracted for a sub-sample of ALSWH surveys completed in the last 10 years by the Young (1973-78) and Mid-age (1946-51) cohorts (see Table 6.1). These cohorts were chosen because of the length of time in the study, and the likely exposure to a diversity of life events.

TABLE 6.1: – SUB-SAMPLE OF RESPONSES TO 'HAVE WE MISSED ANYTHING' BY COHORT, SURVEY WAY, SURVEY YEAR, AND RESPONDENT AGE

Cohort	Survey wave	Survey year	Respondent age
1973-78 (Young)	Survey 4	2006	28-33 years
	Survey 5	2009	31-36 years

	Survey 6	2012	34-39 years
1946-51 (Middle)	Survey 4	2004	53-58 years
	Survey 5	2007	56-61 years
	Survey 6	2010	59-64 years

SOURCE: ALSWH WEBSITE

Information was searched for reference to changes to lifestyle, intention to change, awareness of need to change, and improvement to lifestyle. In addition, where available and appropriate, comments from the same respondent over time were extracted to provide additional insight about the likely impact of the ALSWH on the participant's lifestyle. Information about survey responses reviewed and information extracted that forms the basis of the findings that follow are set out in Table 6.2.

TABLE 6.2: **NUMBER OF RESPONDENT REVIEWED BY COHORT AND SURVEY WAVE**

Cohort	Number of respondent extracts	Extracts by survey wave		
		Survey 4	Survey 5	Survey 6
1973-78 (Young)	152	89	91	66
1946-51 (Mid)	345	122	103	120

SOURCE: ACIL ALLEN CONSULTING 2014

6.1 Survey impact on behaviour

Generally, themes emerging from participant comment on recent changes to their health, can be summarised as:

- Reflective about their health and circumstances: *'The questions you asked helped me to reflect on my situation and the choices I have made in my life..', 'I continue to look forward to this survey as I evaluate my life!' and later from the same respondent, 'As I say every time I fill this in – I really enjoy the opportunity to reflect on my life', another respondent commented that 'Generally, I definitely agree that completing this survey triggers us to reflect on where we are in life, where we have been and what we hope for in the future. Not the present state of our health…*'
- Documenting acute health episodes and health interventions: '*I had surgery last week…[but] I stuck to the survey and answered what I was asked, I didn't change it to be a "typical week" '*
- Linking health and their responses to life events: some respondents contextualised their responses to demonstrate the snapshot influence of a death in the family, overseas holiday, miscarriage – *'I hope this helps to frame my questionnaire – I felt it was a bit inconsistent, but*

could only answer the questions as they appeared'; 'My general lifestyle has been affected significantly due to time and money constraints – but mostly due to being unable to do many things because I'm pregnant….'

- Explaining factors that had precipitated lifestyle change: 'I manage this with exercise now but will….always be prone to severe lower back pain and back injury'*; 'Recently I was diagnosed with anxiety/panic disorder ...and high blood pressure…..which led me to a lot of lifestyle changes, such as exercise, diet, alternative therapies, and other help..'*
- Using the response similar to an entry in a personal diary, describing health challenges and sometimes rating their success, *'Overall I think I am doing a good job.', 'In completing this form it reaffirms how miserable and sad my life is and I really want to change but don't know if I can.', 'I am determined to get my life back on track'*

For a small number of the sub-sample there was a suggestion that resolve to improve their lifestyle was triggered by the questionnaire, which had served to:

- Broaden reflection on their health: *'I am someone who often reflects on my health and how I can improve it, but this survey always brings up something I have not thought of'*
- Better understand personal behaviour: *'The questions relating to food/drink….made me think about what I actually eat'*
- Take action: *'Filling out these surveys years ago made me aware that I may have been suffering from depression and caused me to seek help…'*
- Highlight opportunities: *'The mere act of completing this survey has drawn my attention…to some areas for improvement!'*

Based on a sample of qualitative feedback making reference to lifestyle and change, generally, participating in the survey had prompted reflection about their personal health journey, the impact of life events and the personal choices made. There was some evidence that the questionnaire provided a benchmark of good health behaviour/status and had effectively educated the participant:

'The questions relating to food/drink were good in that they made me think about what I actually eat – ie more "bad" things than I thought'

'The questionnaire serves as a good way on all aspects of my life…it has also helped me make some decisions (positive) about my lifestyle, and since filling this out I'm living a much healthier & energetic life! Thanks, and I hope the results of these surveys have a positive impact on the health of other women too.'

The prevalence of lifestyle risk factors for study cohorts compared to patterns in the general population were also considered in terms of the impact participation in the ALSWH may have had on adherence to health guidelines or changes to health behaviours. The ALSWH analysis of compliance with health guidelines for smoking, alcohol consumption and most health screening by the original three study cohorts shows that participant adherence had steadily improved over the period to 2012, or had remained high. Substantial departure from guidelines was found for weight, physical activity and diet, with increased prevalence of overweight and obesity. (ALSWH, 2012) No comparison is drawn between the performance of ALSWH cohorts and similar ages in

the general population, however, it had previously been established by the ALSWH that the cohorts shared similar socio-demographic characteristics when compared to censuses for 2001, 2006 and 2011, with the exception of over-representation of Australian born and tertiary educated women. Education attainment is known to have an impact on health status.

Recent investigation by the ALSWH of the representativeness of the new Young cohort included comparison to women of the same age range in 1996, by using baseline data from the original Young (1973-78) cohort. It was concluded that the groups were not dissimilar but appeared more physically active and to have higher levels of psychological distress. When compared to the general population of the same ages using the 2011 census, differences included a higher proportion with university degrees, while the cohort was broadly representative for geographical and age distribution, and marital status (ALSWH, 2014).

6.2 Relationship with the ALSWH

The feedback from participants reviewed above, suggests that respondents are respectful of the direction to respond honestly, rather than to reflect what they consider to be their usual circumstances/behaviour. This suggests an appreciation of the value of the research and the importance of accurate responses to tracking health over time.

Participant relationship to ALSWH has been important in maintaining the cohorts and achieving a desirable response rate. Some indicators of the strength of the relationship with the ALSWH is provided by:

- The willingness for some of the cohort to participate in sub-studies. Over the period 2010-2014, the response rate has ranged from 25 per cent to 96 per cent with the median 71 per cent
- A preparedness to respond to difficult questions with a small number of respondents indicating in recent pilot cohort surveys that there were questions they did not want to answer, despite the fact that some questions could be regarded as highly personal and of a potentially sensitive nature
- Survey withdrawal numbers which are relatively low, with withdrawal on the basis of 'not interested' accounting for less than half of the reason for withdrawal for the 1946-51 cohort survey 7 (280/692).

Of the three original cohorts, linked data remains available for approximately 90 per cent of those who have withdrawn, suggesting an ongoing commitment to the objectives of the ALSWH despite their personal reasons for withdrawal.

6.3 Survey fatigue

Qualitative data was also reviewed to see if response rates were influenced by survey fatigue. The feedback indicated that respondents used a range of strategies to allow them to complete the questionnaire despite the demands on their time. Any difficulty with the survey appeared to relate

to interpretation rather than burden, and there was evidence of enthusiasm for the survey where additional areas of inquiry were suggested. Review of a sample of respondent feedback shows:

- References to 'difficulty' in answering reflected on personal circumstances and the way in which questions were worded rather than survey burden
- Some respondents conveyed their enthusiasm for participation and sharing findings around common issues: *"I love being a part of this survey and look forward to contributing every time a survey comes around!"* and "*I am surprised to find this is the sixth survey!...Having little children I also have very little time to exercise, relax or even think. I hope this has changed by survey 7!"*
- Other respondents prompted additional questions to probe other aspects that they considered influenced their health and wellbeing, such as single parenthood, emotional abuse
- Despite significant demands on their time, or major health crises, respondents were able to complete the survey in stages and online save function facilitated completion, "*Great to be able to save this and return to complete it."* One respondent indicated that the pain she suffered meant that completing surveys was problematic, *"..I hope this is almost the last of them. The only reason I bother still is that I do understand how important it is to you."*
- In one instance, the demands of family and especially children with special needs necessitated withdrawal from the survey *"Time to complete this survey is now a concern for me."*

In some instances, concern was expressed about the length of the questionnaire. As the survey is repeated several years apart, this is more likely to be an issue with the questionnaire rather than the longitudinal nature of the survey:

- Frustration with the survey was noted*, "This survey is too time consuming and a few of the questions are poorly framed."* And "*Your survey takes too long to complete and I haven't got around to it. My only gripe."* And "*This survey in parts are too detailed…(and) a very time consuming exercise."* And *"This survey is too repetitive, tedious and time consuming."*

6.4 Summary

Participating in the survey waves would appear to have generated a loyalty to the ALSWH that has resulted in accurate responses, a willingness to complete the questionnaire, and a genuine interest in remaining part of the initiative. Based on the sources used for this assessment it is difficult to determine the extent to which health behaviours for ALSWH cohorts differ from the general population, however, recent analysis of the newly recruited Young cohort suggests that they are not dissimilar to the original Young cohort, and to the general population of the same ages other than for education attainment.

7. VALUE FOR MONEY OF THE ALSWH

KEY FINDINGS – VALUE FOR MONEY ANALYSIS

The ALSWH:

- has significantly lower costs when compared to HILDA and LSAC, but greater than LSAY
- produces less outputs when compared to HILDA and LSAC, but greater than LSAY
- represents the greatest value for money when compared to three similar longitudinal studies in Australia.

7.1 Assessing value for money

A key consideration for this evaluation is whether funding for the ALSWH is being utilised in a cost-effective manner and producing outputs that justify government funding.

To assess the value for money (VFM), costs to the Australian Government (i.e. funding, excluding the National Health and Medical Research Council) and outputs between 2010-14 were collected for the ALSWH and three comparator studies, namely the Household, Income and Labour Dynamics in Australia Survey (HILDA), the Longitudinal Study on Australian Children (LSAC) and the Longitudinal Survey of Australian Youth (LSAY) (see Appendix G further details on these studies). These surveys were chosen given they are all longitudinal, based in Australia and are funded by the Commonwealth Government.

The overall cost-effectiveness (i.e. outputs generated, given the funding provided) of all studies were then compared to determine which represented the most efficient use of government funds.

7.2 Costs and outputs of the ALSWH and comparator studies

Costs

The costs incurred by the Commonwealth Government associated with the ALSWH were drawn from financial statements provided by the UoQ and UoN.[1] The total cost to the Commonwealth Government of ALSWH between 2010 and 2014 was calculated to be $7.9 million (in 2013-14 dollars, GST exclusive), of which 60 per cent related to UoN costs and 40 per cent to UoQ costs.

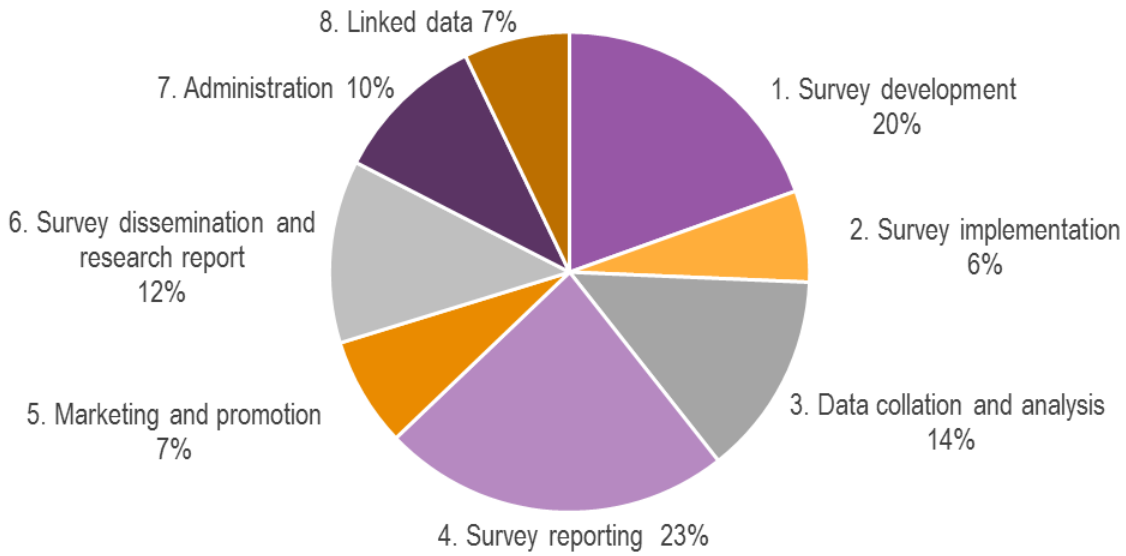
Allocation of ALSWH funding to expenditure

A detailed breakdown of expenditure by activity was also provided by UoQ and UoN, and is presented in Figure 7.1. The results show that *survey development* (20 per cent) and survey reporting (23 per cent) are the primary expenditure drivers, comprising just under half of all expenditure. Of this expenditure, the vast majority (92 per cent) is associated with employee-

[1] This analysis does not include costs incurred by the Commonwealth Government in administering funding for ALSWH or comparator studies.

related costs, other expenditure (8 per cent) included specialist software, geocoding, printing, and website hosting and maintenance costs.

FIGURE 7.1: ALSWH COST BREAKDOWN BY ACTIVITY



SOURCE: DATA PROVIDED BY UNIVERSITY OF NEWCASTLE AND THE UNIVERSITY OF QUEENSLAND 2015

Comparing the cost to the Commonwealth Government of the ALSWH and comparator studies

A comparison of Commonwealth Government funding for the ALSWH and the three comparator studies over the years 2010-14 (in 2013-14 dollars) is as follows:

- ALSWH: $7.9 million[2]
- HILDA: $44.4 million
- LSAC: $41 million
- LSAY: $3.8 million (University of Newcastle 2011-14 & University of Queensland 2011-14).

The results show that HILDA and LSAC are funded at a significantly higher level when compared to the ALSWH and LSAY. Appendix G provides further details on how comparator study costs to the Commonwealth Government were developed.

Estimates of the cost to the Commonwealth Government per participant contact has also been undertaken. Cost per participant contact refers to the number of surveys completed by participants, not simply the number of survey participants. Compared to LSAC and HILDA, the ALSWH has a relatively low cost per participant contact at $114. However, this cost is approximately 9 per cent greater than LSAY at $104. The method for calculating the cost per participant can be found at Appendix G.

[2] ALSWH costs were calculated by adding the 'income' of UoN and UoQ in financial years 2010-11 to 2013-14. Financial statements were provided by both of the universities.

The results indicate that costs are not necessarily driven by number of participant contacts, but through survey methodologies employed. For example, 82 per cent of interviews undertaken for the latest HILDA survey wave were done via face-to-face, which involves significant labour costs. The remaining 18 per cent were completed over the phone (HILDA, 2014). The ALSWH, on the other hand, primarily uses mailed surveys (83 per cent) and to a lesser extent online interviews (16 per cent), both of which are relatively cheaper methods of data collection (ALSWH, 2014).[3]

TABLE 7.1: COST PER PARTICIPANT FOR ALSWH AND COMPARATOR STUDIES: 2010-14

Costs / number	ALSWH	HILDA	LSAC	LSAY[a]
(a)Total survey cost	$7.9 million	$44.4 million	$41.0 million	$3.8 million
(b)Total number of participant contacts	65,997	53,215	18,236	61,843
Cost per participant contact (=a/b)	**$114**	**$834**	**$2,251**	**$104[b]**

Note: [a]Further details on how the number of participants was calculated can be found at Appendix G. [b]The cost per participant contact does not equal a/b for LSAY, as advice on cost per participant was provided by relevant National Centre for Vocational Education Research (NCVER) staff.
SOURCE: (UNIVERSITY OF NEWCASTLE, 2012) (UNIVERSITY OF NEWCASTLE, 2013) (UNIVERSITY OF NEWCASTLE, 2014) (UNIVERSITY OF QUEENSLAND, 2012) (UNIVERSITY OF QUEENSLAND, 2013) (UNIVERSITY OF QUEENSLAND, 2014) (UNIVERSITY OF NEWCASTLE, 2011); TOTAL SURVEY COSTS FOR HILDA, LSAC AND LSAY WERE PROVIDED BY RELEVANT CONTACT PERSONNEL WITHIN EACH OF THE STUDIES.

Research outputs

Three research output measures have been used for the value for money analysis, however, only two are consistent across all four studies. Although not directly comparable, the third output measure was chosen based on degree of similarity across the studies.

The output measures comprise:

- ***Peer-reviewed journal articles*:** This output refers to the number of peer-reviewed journal articles that utilise study data. The contribution of the data towards the article's methodology and findings have not been explored. Neither have subsequent citations of the published research.
- ***Conferences:*** This output relates to the number of conferences where study findings have been presented (for example, presentation of peer-reviewed articles).
- ***Reports/papers:*** The following outputs have been used for each study: ALSWH–major reports; HILDA–working/discussion/research papers; LSAC–government/research reports: and, LSAY–research reports.

[3] ALSWH also involves telephone interviews, however, these only comprise 0.4 per cent of interviews.

The total number of outputs between 2011 and 2014 for each study are presented in Table 7.2.[4] The results show that HILDA and LSAC produce between 1.7 and 2.5 times the number of outputs when compared to the ALSWH. It is unclear why LSAY produces a significantly lower number of research outputs.

TABLE 7.2: **ALSWH AND COMPARATOR STUDY RESEARCH OUTPUTS: 2011-14**

Output	ALSWH	HILDA	LSAC	LSAY
Journal articles	83	319	185	15
Conferences	143	127	189	7
Reports/papers	4	161	25	20
Total	**230**	**607**	**399**	**42**

SOURCE: ALSWH JOURNAL ARTICLES PROVIDED BY ALSWH (2014); (ALSWH, 2015B); (ALSWH, 2015C); (HILDA, 2015); (HILDA, 2015A); (HILDA, 2015B); (LSAC, 2013); (LSAC, 2012); (LSAC, 2011); (LSAY, 2013)

7.3 Overall value for money assessment

To assess whether the ALSWH represents a comparatively good use of Commonwealth Government funds, output/cost ratios were developed for all four studies. In order to calculate this ratio, total weighted output figures have been developed for the studies. The weighted output figure were developed by providing each output with a percentage weighting (which add to 100 per cent), whereby a higher weighting places a greater emphasis on an output. Both the peer-reviewed articles and conferences where allocated a high weighting of 45 per cent, given these outputs are comparable across the study and therefore more reliable outputs for the analysis. Research reports/papers was provided with a relatively low weighting of 10 per cent, for reasons provided above (row *a* of Table 7.3). From here, the weighted output figures are provided with a ranking between 1 and 4, with 4 representing the highest weighted output score (row b). The same method has been used to rank total study costs (row d). Lastly, an output/cost ratio is calculated by dividing the weighted output ranking by the cost ranking. A higher output/cost ratio is desired.

Another way to assess value for money is to look at the cost per output as seen in the last row of Table 7.3. This figure is calculated by dividing the total cost (row c) by the total weighted output (row a). A lower cost per output represents greater value for money.

The output/cost ratio is equal to one for all studies, therefore the value for money analysis is reliant on the cost per output ratios. It is evident therefore that the ALSWH comparatively

[4] The cost data for this analysis comprises four years (2010-11 to 2013-14), therefore, only four years of output data is required. For this reason, years 2011-14 have been used for output data as opposed to 2010-14.

represents the best use of Commonwealth Government funds given it has the lowest cost per output at $77,778 (see Table 7.3).

TABLE 7.3 **– RESEARCH OUTPUT/COST RATIO AND COST PER OUTPUT FOR ALSWH AND COMPARATOR STUDIES: 2010-14**

Output/cost	ALSWH	HILDA	LSAC	LSAY
(a) Total weighted output[a]	102	217	171	12
(b) Weighted output ranking[b]	2	4	3	1
(c) Total cost (million)	$7.9	$44.4	$41.0	$3.8
(d) Cost ranking[b]	2	4	3	1
Research output / cost ratio (=b/d)	**1**	**1**	**1**	**1**
Cost per research output (=c/a)c	**$77,778**	**$204,884**	**$239,941**	**$326,344**

Note: [a] Further details on how the total weighted output was calculated can be found in Appendix G, [b]4=very high, 3=high, 2=medium and 1=low. [c]Cost comprises cost to the Commonwealth Government.

SOURCE: (UNIVERSITY OF NEWCASTLE, 2012) (UNIVERSITY OF NEWCASTLE, 2013) (UNIVERSITY OF NEWCASTLE, 2014) (UNIVERSITY OF QUEENSLAND, 2012) (UNIVERSITY OF QUEENSLAND, 2013) (UNIVERSITY OF QUEENSLAND, 2014) (UNIVERSITY OF NEWCASTLE, 2011); ALSWH JOURNAL ARTICLES PROVIDED BY ALSWH (2014); (ALSWH, 2015B); (ALSWH, 2015C); (HILDA, 2015); (HILDA, 2015A); (HILDA, 2015B); (LSAC, 2013); (LSAC, 2012); (LSAC, 2011); (LSAY, 2013); TOTAL SURVEY COSTS FOR HILDA, LSAC AND LSAY WERE PROVIDED BY RELEVANT CONTACT PERSONNEL WITHIN EACH OF THE STUDIES.

7.1 Summary

An analysis of the four studies' outputs and costs revealed that HILDA and LSAC require significantly more funding, when compared to LSAY, and, to a lesser extent, the ALSWH. However, the increased costs are reflected by a greater number of outputs.

Overall, a comparison of costs and benefits across the studies revealed that the ALSWH represented the greatest value for money, given it had the lowest cost to the Commonwealth Government per research output.

8. CONCLUSION: IMPROVEMENTS TO THE ALSWH AND RECOMMENDATIONS

8.1 Improvements to the ALSWH

The following summarises areas of potential improvement to the ALSWH, drawn from consultations with key stakeholders and the evaluation more broadly. There are three major action areas.

Profile of the ALSWH

Across all categories of stakeholders included in this evaluation, with the exception of current research collaborators, there was low awareness of the ALSWH. This was especially notable for leaders in government and the non-government sector. Most stakeholders expressed genuine interest in finding out more about the ALSWH and looking at ways in which the research might be relevant to their work. In some instances, stakeholders knew of the ALSWH but did not know that ALSWH data was publicly available.

Increasing the profile of the ALSWH amongst key stakeholder groups and the community more generally was considered to be a necessary and important initial step to increasing the reach of ALSWH findings and their consideration in the development of policy and practice in women's health.

Access to ALSWH data

There were a range of experiences in accessing ALSWH data for secondary analysis. Whilst appreciating the role of ALSWH staff as custodians of the data, and the desirability of 'controlling the traffic' of inquiries about data access and research, there was a preference for a less restrictive process in providing access, and a view that current arrangements could act as a deterrent to researchers. A number of different models exist that strike a better balance in facilitating access, including that for the LSAC.

Enhancement of the ALSWH

A number of additional activities were suggested to increase the value of the ALSWH outputs. These included a dedicated role for translational research to bridge the gap between research findings and application to policy and programs, and consideration of the opportunity for inclusion of objective measures into the survey, such as weight and height.

8.2 Recommendations

That a communication and marketing strategy be developed and implemented to raise awareness of the ALSWH in government (Commonwealth and states/territories), NGO and academic sectors.

That governance arrangements for ALSWH be reviewed to assure the ALSWH addresses contemporary issues, incorporates perspectives of NGOs, clinicians, state/territory governments, and provides for an external scientific advisory group.

That a 'champion' be identified to promote the ALSWH amongst policy leaders and to leverage from networks and collaborations supported by government to increase the awareness of ALSWH.

That the protocol be reviewed for access to ALSWH data for secondary research with the aim of achieving open access and greater utilisation of the data.

That the value of increasing the capability of the ALSWH be investigated for the opportunity to include objective measures in the survey and for a specific focus on translation of research into policy and practice to provide additional support in acting on the evidence base for women's health.

That consideration be given to commissioning an overview of the research and policy implications of the ALSWH after 20 years.

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Appendix A: EVALUATION FRAMEWORK

TABLES A.1 – EVALUATION FRAMEWORK OF THE AUSTRALIAN LONGITUDINAL STUDY ON WOMEN'S HEALTH (THE STUDY)

1. **Quality of the ALSWH - Area of inquiry – 1.1 Relevance**

Research question	**Indicator**	**Data source/approach –Primary**	**Data source/approach – Secondary**
What arrangements are in place to ensure the Study remains relevant to data user needs?	Process for regular review of the Study Arrangements to obtain input from stakeholders about information needs Proportion of stakeholders utilising Study findings and/or data Adoption of good practice in meeting information needs through research	Key informant interviews Stakeholder interviews and surveys	Literature review considering robustness of longitudinal surveys in responding to information needs including emerging issues Contractual arrangements describing Study expectations and deliverables Study protocols and documented practices
What is the current scope and coverage of the Study? Does the scope appropriately capture the main health issues affecting Australian women?	Type of health issues included in surveys by age cohort compared to main health issues affecting Australian women Geographical and socio-demographic coverage of survey	Key informant interviews Cohort profiles	Mapping of survey topics by age cohort and survey wave Socio-demographic information extracted for survey participants and comparisons to general

Research question	Indicator	Data source/approach –Primary	Data source/approach – Secondary
What are the main data item outputs of the Study?	cohorts Consistency with good practice in longitudinal survey design to measure change over time Type of survey data outputs		population of women in Australia Literature review reflecting on 'representativeness' versus 'variability' Desktop review of data bank fields and data cubes Comparison to data outputs for selected comparator studies
What flexibility has there been to expand/modify existing questions?	Number and type of changes to survey questionnaires to enhance relevance	Key informant interviews	Desktop review of selection of recent survey questionnaires
Has it been possible to make new inquiries of the existing database?	Number of new analyses responding to current information needs that draw on data bank Number of sub-studies that draw on data bank		Desktop review of Study papers and sub-studies

Quality of the ALSWH - Area of inquiry – 1.2 Timeliness

Research question	Indicator	Data source/approach – Primary	Data source/approach – Secondary
What has been the frequency of survey waves? Is this frequency appropriate to measure changes in health status over time?	Number of years between survey waves for each cohort	Stakeholder interviews and surveys	Literature review of how often surveys need to be conducted to measure changes in health status Desktop review of timing of survey waves Supplementary information from Study staff, as necessary
How timely has been the release of findings following survey close?	Average length of time between close of survey and production of major themes reports		Literature review of how often surveys need to be conducted to measure changes in health status Desktop review of timing of survey waves Supplementary information from Study staff, as necessary
How timely has been the release of data cubes following survey waves?	Average length of time to release of data cubes to key stakeholders and frequency of release		Literature review of how often surveys need to be conducted to measure changes in health status Desktop review of timing of survey

Research question	Indicator	Data source/approach – Primary	Data source/approach – Secondary
			waves Supplementary information from Study staff, as necessary
How satisfied are stakeholders with the time to availability of Study findings and data?	Stakeholder feedback on timeliness of information release		Literature review of how often surveys need to be conducted to measure changes in health status Desktop review of timing of survey waves Supplementary information from Study staff, as necessary

Quality of the ALSWH - Area of inquiry – 1.3 Accuracy

Research question	Indicator	Data source/approach-Primary	Data source/approach-Secondary
What procedures are followed to optimise response rates?	Number and type of measures to encourage response and follow up non-response Process for dealing with missing data	Key informant interviews	Desktop review of Study procedures and protocols Desktop review of practices in selected comparator studies

Research question	Indicator	Data source/approach-Primary	Data source/approach-Secondary
What checking is undertaken to ensure accuracy of data?	Types of error measurement undertaken Measures to test questions for clarity and sensitivity		Desktop review of standard Study measures undertaken to check data accuracy

Quality of the ALSWH - Area of inquiry – 1.4 Coherence

Research question	Indicator	Data source/approach-primary	Data source/approach-Secondary
How much variation is there in reporting of findings across survey periods?	Proportion of common reporting items across survey waves		Desktop review of reporting topics over the life of the Study
How consistent are the Study methods with similar longitudinal studies	Use of standard variables and classifications, where available	Key informant interviews	Desktop review of Study methods and commentary on consistency with standards of good practice

Quality of the ALSWH - Area of inquiry – 1.5 Interpretability

Research question	Indicator	Data source/approach-Primary	Data source/approach-Secondary

Research question	Indicator	Data source/approach-Primary	Data source/approach-Secondary
How well documented is information about the statistical measures and processes of data collection for external data users?	Type and format of publicly available information about statistical measures and processes/methods of the Study		Desktop review of information available detailing Study statistical methods and processes

Quality of the ALSWH - Area of inquiry – 1.6 Accessibility

Research question	Indicator	Data source/approach - Primary	Data source/approach - Secondary
How accessible is the Study information to a range of end users, including appropriateness of the meta-data?	Number and type of approaches used to provide access to the Study findings and summary data by target audience Measures to facilitate data user independent management and interrogation of the data bank, including processes for gaining access Resources required for external users to access data	Key informant interviews Stakeholder interviews and surveys	Desktop review of the Study products designed to allow access to findings and data bank Desktop review of how other study data are available and accessible

Contribution of the Study to the evidence base for women's health in Australia – 2.1 Building the evidence base

Research question	Indicator	Data source/approach – Primary	Data source/approach – Secondary
To what extent is the information collected through the Study contributing to the evidence base for women's health in Australia?	Number of peer-reviewed articles using Study data and number of citations relating to these articles Women's health policy at a state/territory and/or federal level that utilise Study data and/or reports Number of conferences using Study data and/or reports		Desktop review of ALSWH and government website information
What strategies are in place to promote data usage for building an evidence base?	Type of approaches designed to embed data outputs in recognised evidence base to inform decisions Proportion of stakeholders who consider the Study is a recognised contributor to the evidence base	Stakeholder interviews and surveys	Desktop review of Study approaches to ensure findings contribute to the evidence base Literature review for success factors in establishing research findings as part of the evidence base to inform decisions

Contribution of the Study to the evidence base for women's health in Australia:

- **2.2 Development and evaluation of women's health policy and practice;**
- **2.3 Social experiences and environmental influences on women**
- **2.4 Reproductive health issues**
- **2.5 Access to information and use of health services and preventative health activities**

Research question	Indicator	Data source/approach – Primary	Data source/approach – Secondary
To what extent is the information collected through the Study contributing to the evidence base in areas of priority defined by the objectives of the Study?	Number and type of major reports, conference papers and other publications based on Study findings that address key issues identified for women's health in the Study objectives Quality of peer-reviewed articles derived from journal quality, number of citations relating to these articles and the degree of relevance to areas of priority defined by the objectives of the Study Proportion of stakeholder survey respondents utilising the Study as an evidence base for development and evaluation of policy and practice	Key informant interviews Stakeholder interviews and surveys	Desktop review of publication and topics aligned to Study objectives, over time based on Study website information Desktop review of peer reviewed and government published papers/documents on women's health in Australia referencing the Study findings to assess the weight of evidence attributed to the findings

Research question	Indicator	Data source/approach – Primary	Data source/approach – Secondary
	Proportion of stakeholder survey respondents utilising the Study as an evidence base for external influences on women Proportion of stakeholder survey respondents utilising the Study as an evidence base for reproductive health behaviours Proportion of stakeholder survey respondents utilising the Study as an evidence base for women's access to information about, and use of health services and preventative activities Utilisation of Study findings by key informants as part of the evidence base in informing policy decisions Utilisation of Study data by researchers contributing to the evidence base in areas of priority defined by the objectives of the Study.		

Contribution of the ALSWH to public health research practice – 3.1 Public health research practice

Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
What strategies are in place for influencing public health research practice?	Documented processes for disseminating findings to the wider public health research community in Australia Number and reach of research conferences attended to present on Study findings Established avenues for influencing research agendas/strategies of government and research grants bodies Contribution of the Study to quality public health research practice, including: Number of student projects completed using ALSWH data Reports of other studies that have adopted ALSWH research methods or that ALSWH informed their study design	Key informant interviews Stakeholder interviews and surveys	Desktop review of approaches to engage public health researchers in Australia in awareness of Study findings Desktop review of external researchers accessing Study data bank Desktop review of methods used to add to the quality of public health research practice through sharing of information about conduct of the Study Literature review for success factors in promoting longitudinal study findings, and research findings more broadly, to influence research practice

How the Study has affected participants

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach – Secondary
4.1 Lifestyle changes	Has the Study data been affected through lifestyle changes precipitated by involvement of participants in the Study?	Prevalence of lifestyle risk factors in the general population compared to Study Participant feedback over time on their lifestyle	Analysis of qualitative information related to lifestyle changes from a sub-sample of surveys for selected cohorts over the last 10 years Key informant interviews	Desktop review of major reports produced from the Study on adherence to health guidelines, health behaviour changes over time
4.2 Survey fatigue	Has Study participation been affected by survey fatigue?	Rates of survey attrition Participant feedback on ability to complete the survey Number, size and frequency of additional survey requests (sub-studies) utilising Study sample	Analysis of qualitative information in sample of surveys completed in last survey wave for all cohorts for reference to survey burden Study staff interviews relating to outcome of first reminder call for key themes relating to delay in responding Key informant interviews	Review of attrition rates and rationale for all cohorts over life of Study Review of information on withdrawal from Study contained in the participant database Desktop review of sub-studies undertaken, response rates and strategies to avoid disruption of Study sample

4.3 Relationship with the Study	Has the participant's relationship with the Study had an impact on their engagement?	Proportion of respondents completing free text area of survey to volunteer additional information Extent of change over time in participant engagement in Study Proportion of women withdrawing from Study who allow ongoing access to their information	Review of free text section of selected surveys for key themes, utilisation, evidence of sensitivity about questions/privacy Key informant interviews	Desktop review of related sub-studies Review of data books on proportion of questions not responded to for all cohorts for the last survey; proportion of 'prefer not to say' responses and the nature of the question Review of pilot evaluation results for feedback on questions regarded as too personal or sensitive Review of Study data on women who have withdrawn from the Study and whose information remains accessible for the data linkage component

5. Value for money of the ALSWH

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
5.1 Measurement of Study costs	What are the costs associated with the Study for the last 3-5 years?	Operating expenses Labour costs Other costs Capital costs Activity expenses Survey development Implementation of survey Survey analysis Reporting Marketing and Promotion	Information requests of Study staff	Desktop review of annual reports
5.2 Measurement of Study outputs	What outputs does the Study deliver?	Number of peer-reviewed articles using Study data and number of citations relating to these articles Women's health policy at a state/territory and/or federal level that utilise	Key informant interviews Stakeholder surveys	Desktop review of relevant previously collected secondary data under Key Theme 2.

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
		Study data and/or reports		
5.3 Measurement of selected comparator survey costs	What are the costs associated with delivering selected comparator studies?	See 'Measure of Study costs'		Desktop review of annual and financial reports for selected comparator studies
5.4 Measurement of selected comparator study outputs	What outputs do selected comparator studies deliver?	Number of publications using study data Number of citations for publications using study data Number of state/territory and/or federal health policy documents utilising study data Consideration of survey length, funding, topics(s) and size		Desktop review (e.g. publications on selected comparator study websites, number of citations)
5.5 Efficiency of the Study compared to selected similar longitudinal studies	How does the cost to output ratio compare between the Study and selected comparator	Study outputs as a proportion of total costs for ALSWH and selected comparator studies		Desktop review using secondary data previously collected within the Value for Money analysis

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
	studies?	including: Cost per participant Cost per publication		

SOURCE: ACIL Allen 2014

6. Improvements that could be made

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
6.1 Wider range of researcher perspectives	What opportunities exist to increase the value of the data collected through the data collected through the Study?	Increased number of external researchers utilising Study data bank	Key informant interviews Stakeholder interviews and surveys	Literature review for evidence of - Enhanced approaches to utilisation of longitudinal data to optimised the value of the Study - Optimal frequency of data collection - Scope of data collection - Effective data

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
				collection methods Desktop review of selected comparator studies Desktop review of organisational arrangements to support and inform Study outputs Desktop review of IT infrastructure and facilitation of more complex analysis utilising existing and new data Desktop review of processes to encourage researcher access to data bank
6.2 IT capability		IT capability to maximise ongoing inquiry of data bank and improve timeliness and accuracy of outputs		As listed above

Area of inquiry	Research question	Indicator	Data source/approach – Primary	Data source/approach - Secondary
6.3 Communication		Frequency, nature and reach of communication about Study findings		As listed above
6.4 Survey frequency	Do surveys need to be conducted more or less frequently? Do more or less questions need to be asked? Should the cohorts continue to be surveyed in their current form?	Optimal frequency of data collection		As listed above
6.5 Questionnaire coverage	As listed above	Size of questionnaire commensurate with data utilisation		As listed above
6.6 Data collection methods	As listed above	Good practice in survey data collection methods relevant to ALSWH		As listed above
6.7 Other	As listed above	Other indicators of improved value arising from evaluation findings		As listed above

Appendix B: DISCUSSION GUIDES

This Appendix provides discussion guides used for current data users, potential data users, government health leaders and non-government health leaders.

A cover page, which was provided to each stakeholder group, is provided below followed by specific questions for each stakeholder group.

B.1 Discussion guide cover page

Evaluation of the Australian Longitudinal Study on Women's Health (ALSWH)

Discussion guide: current users of ALSWH data

The Study

The Australian Longitudinal Study on Women's Health (ALSWH) assesses the physical and mental health of over 50,000 women from across Australia and is designed to support understanding of the many factors that influence the health of Australia's women. ALSWH is funded through the Department of Health's Health Social Surveys Fund with the aim to establish (and maintain) a comprehensive evidence base to provide a foundation for the development, implementation and evaluation of relevant health policies.

Since its inception 20 years ago, ALSWH has aimed to provide scientifically valid information, based on current and accurate data, for use as a tool to help shape the future of women's health in Australia. For example, the Study is designed to:

- Identify social, psychological, physical and environmental factors which determine good health and ill-health amongst women
- Identify whether the current health system meets the needs of women
- Guide future policy and planning of women's health care services
- Provide a national research resource on women's health issues
- Provide data to help motivate women to participate in decision making in health.

The ALSWH is jointly hosted by the University of Queensland and the University of Newcastle.

The evaluation

ACIL Allen Consulting has been engaged by the Australian Government Department of Health to undertake an evaluation of ALSWH. The evaluation will assess whether ALSWH is meeting its objectives; measure its quality and contribution to the evidence base on women's health and public health research practice; and identify opportunities to improve the data collected through ALSWH.

As part of the evaluation, members of the ACIL Allen project team will undertake consultations with a range of stakeholders including leaders in women's health and general health policy, representatives of relevant areas of government, and researchers.

Stakeholder consultations are being undertaken in October through to early December 2014. Current users of data from ALSWH have been included amongst the stakeholders to better understand the extent to which their needs have been met.

B.2 Current data users

The following questions are provided as a guide to areas for discussion. Note that the information provided by stakeholders will be de-identified when collating responses for the purposes of reporting on the evaluation.

1. What is your/your organisation's interest in women's health or general health research or policy?
2. What other areas of research/policy are you/your organisation currently involved in?
3. How long have you been utilising ALSWH data?
4. What other information sources do you draw upon for your research and/or policy work on women's health and general health in Australia?
5. Are you aware of fellow researchers and colleagues that utilise ALSWH data?
6. Have you supervised students to utilise ALSWH data?
7. Are ALSWH data easily accessible for current users?
8. Can data from ALSWH be easily interpreted and analysed?
9. Are the data provided by ALSWH of good quality?
    a) Are they relevant
    b) Are they timely
    c) Are they accurate
    d) Do they have coherence
10. If you have undertaken a sub-study drawing from the ALSWH sample, did you find the process for conducting the sub-study appropriate?
11. Does the ALSWH play a key role in shaping:
    a) public policy regarding women's health?

b) public health research regarding women's health? If so, what areas has the ALSWH had a significant impact on?

12. Are there relevant areas of women's health or general health research the ALSWH is not involved in which you believe it should be?
13. Do you have any suggestions on how the ALSWH could be improved to strengthen its contribution to the evidence base and increase its impact on public health research and policy?

14. How could the ALSWH better support your work on women's or general health?
15. Do you have any other comments you would like to make about the ALSWH?

THANK YOU for agreeing to participate in consultations. Your views are important to a robust evaluation of the ALSWH.

B.3 Potential data user

1. What areas of research/policy are you (your organisation) currently involved in?
2. Do you or your organisation have an interest in women's health-related policy or research?
3. What sources of data and information do you draw upon for your research and/or policy development concerning health, and more specifically women's health or general heath in Australia?
4. Have these data and information sources been sufficient for your research and policy needs?
5. Are you aware of the ALSWH? If so, how long have you known about the Study?
6. Why have you chosen not to draw upon ALSWH for your work?
7. What would need to change with the ALSWH in order for you to use it?
8. Does your decision to not use ALSWH have anything to do with its quality in terms of:
   a) Relevance
   b) Timeliness
   c) Accuracy
   d) Coherence
   e) Interpretability
   f) Accessibility
9. Do you have any suggestions on how the ALSWH could increase its utilisation by researchers, governments and women's health advocates?
10. Do you have any suggestions on how the ALSWH could increase its exposure among researchers and policy makers in Australia?
11. Do you have any other comments you would like to make about the ALSWH?

THANK YOU for agreeing to participate in consultations. Your views are important to a robust evaluation of the ALSWH.

B.4 Government health leaders

1. What area of Government do you work in? And, what is its role?
2. What is your current role within Government?
3. Are you aware of the ALSWH and the data and information available?
4. Have you accessed ALSWH reports and/or data and if so, what information was used?

5. In your work do you draw upon ALSWH for information on emerging health issues in Australia? If so:

a) Has this information been of a high quality? E.g. relevant, easy to interpret and informing.

b) Has the information been easily accessible?

6. Has the ALSWH been used to inform Government policies for women, women's health or general health issues? If not, what types of information and data does the Government draw upon?

7. What do you think the key issues in women's health and general health are for the next 5-10 years? How could the ALSWH contribute to addressing these issues?

8. Do you have any suggestions on how ALSWH could be improved to increase its influence on public health policy in Australia?

THANK YOU for agreeing to participate in consultations. Your views are important to a robust evaluation of the ALSWH.

B.5 Non-government health leaders

1. What is the role of your organisation?
2. What are your organisation's interests in women's health-related issues?
3. What is your role within the organisation?
4. Is your organisation aware of the ALSWH and the information available?
5. Does the organisation draw upon ALSWH reports and/or data for information on emerging health issues in Australia? If so:
   a) What information is used?
   b) Have the reports and/or data been of a high quality? E.g. relevant, easy to interpret and informing.
   c) What ways does the organisation use the reports and/or data? E.g. policy development, advocacy and workforce development.
6. Does the organisation extract data directly from the ALSWH?
   a) If yes, were the data easy to access, query and interpret?
   b) If no, was the organisation aware that ALSWH data are available upon request? Would you consider this option in the future?
7. Does the organisation see value in accessing ALSWH data to support its work?
8. Has the ALSWH played a role in informing the organisation's research and policies on women's health-related issues and other general health issues?
   a) If yes, please provide details.
   b) If no, what sources of information does the organisation draw upon?
9. Has the ALSWH had a significant impact on women's health and general health policy in Australia? If so, what areas?

10. Are there relevant areas of women's or general health that the ALSWH has had little to no impact on?
11. What do you think the key issues in women's health and general health are for the next 5-10 years? How could the ALSWH contribute to addressing these issues?
12. Do you have any suggestions on how the ALSWH could be improved to increase its influence on public health policy in Australia?

THANK YOU for agreeing to participate in consultations. Your views are important to a robust evaluation of the ALSWH.

Appendix C: ONLINE SURVEY QUESTIONNAIRES

Two online surveys were undertaken for current ALSWH data users and health leaders outside of government. The cover page and survey questions for each stakeholder group are provided below.

C.1 Current data user survey

The Study

The Australian Longitudinal Study on Women's Health (ALSWH) assesses the physical and mental health of over 50,000 women from across Australia and is designed to support understanding of the many factors that influence the health of Australia's women. ALSWH is funded through the Department of Health's Health Social Surveys Fund with the aim to establish (and maintain) a comprehensive evidence base to provide a foundation for the development, implementation and evaluation of relevant health policies.

Since its inception 20 years ago, the ALSWH has aimed to provide scientifically valid information, based on current and accurate data, for use as a tool to help shape the future of women's health in Australia. For example, the Study is designed to:

- Identify social, psychological, physical and environmental factors which determine good health and ill-health amongst women
- Identify whether the current health system meets the needs of women
- Guide future policy and planning of women's health care services
- Provide a national research resource on women's health issues
- Provide data to help motivate women to participate in decision making in health.

The ALSWH is jointly hosted by the University of Queensland and the University of Newcastle.

The evaluation

ACIL Allen Consulting has been engaged by the Australian Government Department of Health to undertake an evaluation of the ALSWH. The evaluation will assess whether the ALSWH is meeting its objectives; measure its quality and contribution to the evidence base on women's health and public health research practice; and identify opportunities to improve the data collected through the ALSWH.

As part of the evaluation, members of the ACIL Allen project team will undertake consultations with a range of stakeholders including leaders in women's health and general health policy, representatives of relevant areas of government, and researchers.

This survey is designed for people who currently draw upon ALSWH data to undertake research within Australia. This survey will provide respondents with an opportunity to provide feedback on the ALSWH including how the study is performing and how it could improve.

Completion of the survey is voluntary. The information you provide will be treated as confidential and will only be used for the purpose of conducting the evaluation.

The survey will take approximately 20 minutes to complete.

If you have any questions about the survey or the evaluation please contact the project manager, Karen Roger, at: alswhdata@allenconsult.com.au.

Background

1. What best describes your relationship with the ALSWH study, the assigned liaison person and/or ALSWH staff while accessing the data?
   a) I worked under direct supervision by ALSWH staff members at the time of applying for, and using, ALSWH data (e.g. while undertaking a PhD)
   b) An ALSWH person was extensively involved in the application process for, and the interpretation analysis of, the data. The ALSWH liaison person is included as a collaborator / author on the respective paper(s).
   c) An ALSWH liaison person was involved in the application process for the data but was not, or only to a minor extent, involved in the interpretation/analysis of the data. The ALSWH liaison person is not included as a collaborator / author on the respective papers(s).
   d) I applied for and used ALSWH data independently, i.e. at no point in time was an ALSWH liaison person or any other person affiliated with ALSWH involved in my research.
2. Does you work involve research/policy in women's health? (y/n)
3. Does you work involve research/policy in general health (eg obesity, chronic disease)? (y/n)
4. What type of organisation do you currently work for?
   a) Non-governmental / not-for-profit
   b) Government department / organisation
   c) University
   d) Private sector organisation
   e) Other
5. Is your organisation a community, state/territory, national or international body?
   a) State / territory
   b) National
   c) International
6. What area(s) of research and/or policy does your organisation specialise in?

Utilisation

7. Over what time period have you been using ALSWH data? Please select one of the following:
   a) Under one year
   b) 1-5 years
   c) 5 years or more
8. How many research or policy projects (resulting in published and unpublished papers/policies) have you conducted using ALSWH data in the last five years?
   a) 1-3 projects
   b) 4-6 projects
   c) 7+ projects
9. Approximately what proportion of your research/policy work relating to women's health is based on ALSWH data? (Please select one of the following)
   a) 10 per cent or less
   b) 11-20 per cent
   c) 21-40 per cent
   d) 41-70 per cent
   e) 71 per cent or more
   f) Not applicable
10. Approximately, what proportion of your research/policy work relating to general health is based on ALSWH data? Please select one of the following:
    a) Under 10 per cent
    b) 11-20 per cent
    c) 21-40 per cent
    d) 41-70 per cent
    e) 71 per cent or more
11. Do you have any suggestions on how the ALSWH could be promoted to other researchers/policy makers who are currently not using it in order to increase utilisation? (open text)
12. What other sources of information and data do you use to inform your work on women's health and/or general health issues? (open text)
13. How do these sources complement ALSWH data? Please describe
14. For your research/policy work, how often do you use information contained in any of the reports produced based on ALSWH Data that are published on the ALSWH website, such as Major Reports, Technical Reports, Other/Miscellaneous Reports?
    a) Always

b) Usually

c) Often

d) Sometimes

e) Rarely

f) Never

15. Is there anything else you would like to say in regards to the use of ALSWH data or information?

Usefulness and accessibility

16. How useful are ALSWH data for you research/policy work on women's health issues?

a) Extremely useful

b) Useful

c) Moderately useful

d) Somewhat useful

e) Not very useful

f) I'm not sure / I don't know

17. How useful are ALSWH data for you research/policy work on general health issues?

a) Extremely useful

b) Useful

c) Moderately useful

d) Somewhat useful

e) Not very useful

f) I'm not sure / I don't know

18. Question 18. What are the top three reasons for using ALSWH data in your research/policy work? Please select up to three reasons:

a) Quality of the data

b) Rigorous methodology used in collecting and reporting the data

c) Familiarity with the database

d) Relevance to research work

e) Study liaison person assigned to work with you

f) Longitudinal nature of the data

g) Only or best source of data for your specific research/policy

h) Ease of use

i) Ease of accessibility

Other (please specify)

19. ALSWH data are easy to access . Please select one of the following:
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
20. Do you have any suggestions on how access to ALSWH could be improved? (open text)
21. ALSWH data are easy to query and interpret (Please select one of the following)
    a) Strongly agree
    b) Agree
    c) Neither agree not disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
22. Do you have any suggestions on how to improve the way in which the data are queried and interpreted? (open text)
23. ALSWH data are of high quality (Please select one of the following)
    a) Strongly agree
    b) Agree
    c) Neither agree not disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
24. Is there anything else you would like to say in regards to the usefulness and accessibility of ALSWH data? (open text)

Performance

25. The ALSWH has played a key role in identifying relevant women's health issues and needs since its inception 20 years ago Please select one of the following:
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree

d) Disagree

e) Strongly disagree

f) I'm not sure / I don't know

26. To what extent has the ALSWH contributed to the evidence base around women's health in Australia? Please select one of the following:

a) To a very large extent

b) To a large extent

c) To a moderate extent

d) To a small extent

e) Not at all

f) I'm not sure / I don't know

27. What areas of women's health research evidence base and policy development has the ALSWH had a particular impact on? (Respondents are able to choose up to three options)

a) Ageing

b) Weight, nutrition and physical activity

c) Reproductive health

d) Chronic conditions

e) Mental health

f) Health in rural and remote areas

g) Medications

h) Abuse

i) Tobacco, alcohol and other drugs

j) Formal and informal work patterns and work-family balance

k) Caring aged care / independent living

l) Other

28. The ALSWH has played a key role in identifying relevant general health issues and needs since its inception 20 years ago

a) Strongly agree

b) Agree

c) Neither agree nor disagree

d) Disagree

e) Strongly disagree

f) I'm not sure / I don't know

29. To what extent has the ALSWH contributed to the evidence base around general health in Australia?

a) To a very large extent
b) To a large extent
c) To a moderate extent
d) To a small extent
e) Not at all
f) I'm not sure / I don't know

30. What areas of general health research evidence base and policy development has the ALSWH had a particular impact on? (Respondents are able to choose up to three options)
    a) Chronic conditions
    b) Ageing
    c) Mental health
    d) Diet and nutrition
    e) Fertility and sexual health
    f) Diabetes
    g) Diseases and treatments
    h) Heart health
    i) Drugs and medicine
    j) Addiction
    k) Cancer
    l) Vaccines / immunisation
    m) Therapy
    n) Oral health
    o) HIV/AIDS
    p) Allergies
    q) Other
31. The ALSWH plays a key role in informing public health policy at both a state/territory and national level (Please select one of the following)
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
32. The ALSWH had an impact on development of research methodologies for other related studies (Please select one of the following)

a) Strongly agree
b) Agree
c) Neither agree nor disagree
d) Disagree
e) Strongly disagree
f) I'm not sure / I don't know

33. The ALSWH has been useful in providing opportunities for current users to undertake sub-studies to inform women's health and general health research and policy
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
34. Do you have any suggestions on how the ALSWH could be improved to increase its impact on public health research and policy? (open text)
35. Is there anything else you would like to say in regards to the contribution of ALSWH data or information to the evidence base around women's or general health in Australia or any topic in this section of the survey (open text)

THANK YOU FOR CONTRIBUTING TO THE EVALUATION

C.2 Non-government health leader survey

ACIL Allen undertook a desktop review to identify contact details for national and international leaders in non-government health organisations. A total of 20 non-government health organisation leaders were identified, all of whom received a link to the ALSWH evaluation survey from ACIL Allen's project email, alswhdata@acilallen.com.au.

One non-government organisation (NGO) leader requested permission to invite relevant partner organisations to complete the survey. It is unknown how many additional NGO leaders received the ALSWH evaluation survey.

NGO leaders were given the opportunity to complete the survey between 17 November and 8 December 2014. A reminder email to complete the survey was sent on 1 December 2014. A total of 15 NGO leaders completed the survey.

The survey was hosted by the online survey tool, Survey Monkey.

The NGO survey was broadly designed to gather feedback from leading health organisations on their awareness of ALSWH, the relevance of ALSWH to their organisation, and the impact of ALSWH on women's and general health policy and research.

Background

1. What is the focus of your organisation's work? (Please choose up to 3 responses)
    a) Women's health
    b) Rural health
    c) Economic wellbeing
    d) Aboriginal and Torres Strait Islander health
    e) Abuse
    f) Ageing
    g) Nutrition
    h) Chronic disease
    i) Other
2. What activities does your organisation primarily engage in? (Please choose up to 3 responses)
    a) Advocacy
    b) Policy development
    c) Public education
    d) Applied/transnational research
    e) Basic research
    f) Other
3. What is your role in the organisation?
    a) Management
    b) Researcher
    c) Other
4. Is your organisation a community, state/territory, national or international body?

Awareness of ALSWH

5. Are you aware of the Australian Longitudinal Study on Women's Health (ALSWH)? (y/n)
6. How long have you been aware of the ALSWH?

Use of primary ALSWH data

7. Has your organisation accessed ALSWH data for your work (through a formal request to make use of the data and permission by the Publications, Analyses and Sub-studies Committee of ALSWH)? (y/n)
8. Over what period of time have you been using ALSWH data?
    a) Less than one year
    b) 2-5 years

c) 5 years or more

9. How many projects have you conducted using ALSWH data in the last five years?
   a) 1-3 projects
   b) 4-6 projects
   c) 7+ projects
10. Approximately what proportion of your research/policy/other work relating to women's health is based on ALSWH data?
   a) 10 per cent or less
   b) 11-20 per cent
   c) 21-40 per cent
   d) 41-70 per cent
   e) 71 per cent or more
   f) Not applicable
11. Approximately what proportion of your research/policy/other work relating to general health is based on ALSWH data?
   a) 10 per cent or less
   b) 11-20 per cent
   c) 21-40 per cent
   d) 41-70 per cent
   e) 71 per cent or more
   f) Not applicable

Data usefulness and accessibility

12. How useful are ALSWH data for your research/policy/other work on women's health issues?
   a) Extremely useful
   b) Useful
   c) Moderately useful
   d) Somewhat useful
   e) Not very useful
   f) I'm not sure / I don't know
13. How useful are ALSWH data for your research/policy/other work on general health issues?
   a) Extremely useful
   b) Useful
   c) Moderately useful
   d) Somewhat useful

e) Not very useful

f) I'm not sure / I don't know

14. What are your top three reasons for using ALSWH data in your work? (Please choose up to 3 responses)

a) Quality of the data

b) Rigorous methodology used in collecting and reporting the data

c) Familiarity with the database

d) Relevance to research work

e) Study liaison person assigned to work with you

f) Longitudinal nature of the data

g) Only or best source of data for your specific research/policy

h) Ease of use

i) Ease of accessibility

Other (please specify)

15. ALSWH data are easy to access

a) Strongly agree

b) Agree

c) Neither agree nor disagree

d) Disagree

e) Strongly disagree

f) I'm not sure / I don't know

16. Do you have any suggestions on how access to ALSWH data could be improved?

17. ALSWH data are easy to query and interpret

a) Strongly agree

b) Agree

c) Neither agree nor disagree

d) Disagree

e) Strongly disagree

f) I'm not sure / I don't know

Comment

18. Do you have any suggestions on how to improve the way in which the data are queried and interpreted?

19. ALSWH data are of high quality (e.g. relevant, accurate and/or coherent)

a) Strongly agree

b) Agree

c) Neither agree nor disagree

d) Disagree

e) Strongly disagree

f) I'm not sure / I don't know

20. Is there anything else you would like to say in regards to the usefulness, accessibility and quality of ALSWH data?

Use of ALSWH reports and information

21. Has your organisation used any of the reports generated from the data that are published on the ALSWH website? (y/n)
22. Which of the ALSWH reports are most useful to your work?

    a) Major reports

    b) Cohort summaries

    c) Other/miscellaneous reports

23. For your work, how often do you/does your organisation draw upon such ALSWH reports/information?

    a) Always

    b) Usually

    c) Often

    d) Sometimes

    e) Rarely

    f) Never

24. ALSWH report findings are easy to access

    a) Strongly agree

    b) Agree

    c) Neither agree nor disagree

    d) Disagree

    e) Strongly disagree

    f) I'm not sure / I don't know

25. Do you have any suggestions on how access to ALSWH reports and information could be improved?
26. The reports generated from ALSWH data that are published on the ALSWH website are of good quality (e.g. relevant, accurate and/or coherent)

    a) Strongly agree

    b) Agree

    c) Neither agree nor disagree

d) Disagree

e) Strongly disagree

f) I'm not sure / I don't know

Performance

27. The ALSWH has played a key role in identifying relevant women's health issues and needs since its inception 20 years ago

    a) Strongly agree

    b) Agree

    c) Neither agree nor disagree

    d) Disagree

    e) Strongly disagree

    f) I'm not sure / I don't know

28. To what extent has the ALSWH contributed to the evidence base around women's health in Australia?

    a) To a very large extent

    b) To a large extent

    c) To a moderate extent

    d) To a small extent

    e) Not at all

    f) I'm not sure/ I don't know

29. What areas of the women's health research evidence base and policy development has the ALSWH had a particular impact on? (Please choose up to 3 responses)

    a) Ageing

    b) Weight, nutrition and physical activity

    c) Reproductive health

    d) Chronic conditions

    e) Mental health

    f) Health in rural and remote areas

    g) Medications

    h) Abuse

    i) Tobacco, alcohol and other drugs

    j) Formal and informal work patterns and work-family balance

    k) Caring aged care / independent living

    l) Other

30. The ALSWH has played a key role in identifying relevant general health issues and needs in Australia
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
31. To what extent has the ALSWH contributed to the evidence base around general health in Australia?
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
32. What areas of general health research evidence base and policy development has the ALSWH had a particular impact on? (Please choose up to 3 responses)

Chronic conditions

    a) Ageing
    b) Mental health
    c) Diet and nutrition
    d) Fertility and sexual health
    e) Diabetes
    f) Diseases and treatments
    g) Heart health
    h) Drugs and medicine
    i) Addiction
    j) Cancer
    k) Vaccines / immunisation
    l) Therapy
    m) Oral health
    n) HIV/AIDS
    o) Allergies

33. The ALSWH plays a key role in informing public health policy at both a state/territory and national level
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
34. The ALSWH has played a significant role in informing my organisation's research, policy and other work
    a) Strongly agree
    b) Agree
    c) Neither agree nor disagree
    d) Disagree
    e) Strongly disagree
    f) I'm not sure / I don't know
35. Do you have any suggestions on how the ALSWH could be improved to better support your organisation's work on women's health or general health issues? (open text)
36. Do you have any suggestions on how the ALSWH could be improved to increase its impact on the public health research evidence base and policy? (open text)

Other questions

37. Do you have any suggestions on how the ALSWH could be promoted to non-governmental health organisations who are currently not using it in order to increase utilisation? (open text)
38. What other sources of data and information to inform your work on women's health and/or general health issues does your organisation routinely access? (open text)
39. In your view, what are the key issues/emerging trends in women's health over the next 5-10 years? (open text)

Appendix D: CONSULTATION REPORT

Completion of consultations

ACIL Allen Consulting have completed the consultation phase of the evaluation of the consultation strategy called for qualitative data collection from a number of stakeholders including:

- Key informants
  - ALSWH researchers
  - Other longitudinal surveys
  - Individual experts
  - ALSWH funders.
- Key stakeholders
  - Leaders in women's health and general health and ageing policy and programming inside government
  - Leaders in women's health and general health and ageing policy and programming outside government (NGOs)
  - Current ALSWH data users
  - Potential ALSWH data users.

The project team used a variety of methods (telephone, face to face, and survey) to gain input from the key informants and key stakeholders. Discussion guides were developed for each key stakeholder category and consultations were conducted using these guides to provide for consistency in documentation and reporting. The following narrative provides a description of the major components of the consultation strategy along with a description of the number of consultations undertaken and the methods used.

A full list of organisations that were consulted is included as Appendix A.

Key informants

Prior to the consultation all key informants were provided with a short information sheet which described the evaluation, the study, and contact information for the ACIL Allen Project Director.

The purpose of the key informant interviews was to gain a thorough understanding of the ALSWH and to assess, from the key informants perspective, whether the study was attaining its primary objectives. All of the key informants were knowledgeable about the study and were chosen because they had a valuable perspective to offer the evaluation.

ALSWH researchers

The ACIL Allen team conducted several telephone meetings with ALSWH researchers. Additionally, face to face meetings were also held with the researchers on-site in Brisbane and Newcastle.

In addition to the researchers, a telephone interview was conducted with the Chair of the Advisory Committee for the ALSWH.

Other longitudinal surveys

ACIL Allen consulted with staff from three other longitudinal surveys:

- Ten to Men (University of Melbourne)
- Household, Income and Labour Dynamics in Australia (HILDA)
- Longitudinal Study on Australia's Children (LSAC).

The interviews with the HILDA and LSAC project directors were conducted as telephone interviews while the Ten to Men consultation was done face to face at the University of Melbourne.

ALSWH funders

A face to face interview was conducted with representatives of the Population Health Division which oversees the contract for ALSWH. This meeting was held early in the consultation process which allowed an exploration of pertinent issues prior to broader consultation.

Other experts

Telephone interviews were held with experts from the University of Melbourne and the Public Health Information Development Unit. These key informants are considered experts in their field and they provided the ACIL Allen project team an objective viewpoint of the ALSWH as it pertains to their area of expertise.

Key stakeholders

Qualitative information was collected from four distinct stakeholder groups in order to get input that related to both policy and research. Discussion guides were developed for each of the four groups and were sent to participants approximately one week prior to their scheduled consultation session. The ACIL Allen team did a total of 16 interviews with key stakeholders and received survey responses from 82 individuals/organisations.

Leaders inside government

Face to face and telephone consultations were conducted with leaders inside government. These consultations included representatives from the following areas:

- Office of Women, Department of Prime Minister and Cabinet
- Australian Bureau of Statistics
- Australian Institute of Health and Welfare
- Medicare Benefits Division, Department of Health
- Strategic Policy Unit, Department of Health
- Policy and Strategy Branch, Department of Social Services.

The purpose of these consultations was to assess the degree to which leaders inside government used the ALSWH for informing policy development, building the evidence base around women's health issues in Australia, and seeking ideas on how the Study could be improved to maximise the value of the data collected.

Leaders outside government

The number of potential consultations with leaders outside government was quite large and beyond the capacity of the project to complete via personal interview. Therefore, a decision was made and approved by DoH to conduct three interviews and deploy a survey for the remaining 20 organisations.

Telephone interviews were conducted with three organisations including:

- Multi-cultural Centre for Women's Health
- National Heart Foundation Australia
- Australian Women Against Violence Alliance.

Surveys were sent to 20 organisations on 17 November with 14 responding within the timeframe.

The purpose of these consultations was to get a sense of how/if the ALSWH was used to inform their policy and or research activities and to explore ways in which the study could be improved to maximise the value of the data collected.

Current data users

Five current data users (defined as using the ALSWH data within the last 3 years) were interviewed as part of the consultation strategy – these five were chosen randomly from the list of current users. Additionally, surveys were sent to approximately 200 current users with 68 responding within the timelines.

Telephone interviews with conducted with researchers currently using the data from the following institutions:

- Flinders University
- Macquarie University
- University of Sydney
- LaTrobe University
- Southern Cross University.

The purpose of these consultations was to explore whether the Study is meeting its objectives, the quality of the data, the contribution to building the evidence base around women's health, the contribution to public health research practice and how the Study could be improved to maximise the value of the data collected.

Potential users

Four telephone consultations were conducted with 'potential' users of the ALSWH data. These participants were selected based on a search of organisations/institutions that focus on women's health and then matched to the list of current users. If the organisations/institutions were not included as a current user they were included in the list of 'potential' users. From this list, four organisations/institutions were chosen for inclusion in the consultation and included:

- Monash University
- Jean Hailes Research Unit
- Women's Health and Research Institute of Australia
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

The purpose of including potential users in the consultation strategy was to explore the reasons that ALSWH wasn't being used by an organisation/institution that would be expected to be interested in the information included in the Study. These consultations were also an opportunity to educate people about the study and to explore ideas to improve visibility, knowledge and thus utilisation of the Study.

Appendix E: ORGANISATIONS CONSULTED

TABLE E.1: KEY INFORMANT ORGANISATIONS CONSULTED

KEY INFORMANT ORGANISATIONS
University of Newcastle
University of Queensland
ALSWH advisory group
Ten to Men, University of Melbourne
Australian Institute of Family Studies
University of Melbourne
Public Health Information Development Unit (PHIDU)
Household, Income and Labour Dynamics in Australia (HILDA) Survey, University of Melbourne

TABLE E.2: KEY STAKEHOLDER ORGANISATIONS CONSULTED

STAKEHOLDER GROUP	ORGANISATION
Current data users	Flinders University
	Macquarie University
	University of Sydney
	La Trobe University
	Southern Cross University
Potential data users	Monash University
	Jean Hailes Research Unit
	Women's Health and Research Institute of Australia
	The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
National government statistical agencies	Australian Bureau of Statistics (ABS) Australian Institute of Health and Welfare (AIHW)

Leaders in women's health policy and programming (inside government)	
	Office for Women, Department of Prime Minister and Cabinet
	Medicare Benefits Division, Department of Health
	Strategic Policy Unit, Department of Health
	Policy and Strategy Branch, Department of Social Services
Leaders in women's health policy and programming (outside government)	
	Multicultural Centre for Women's Health
	National Heart Foundation Australia
	Australian Women Against Violence Alliance

Appendix F: PARTICIPANT IMPACT METHOD

F.1 Revision to methodology to evaluate the Australian Longitudinal Study on Women's Health (ALSWH)

Assessing impact of the ALSWH on participants

It was originally proposed to sample up to 30 ALSWH survey participants drawn from the three cohorts recruited in 1996, to interview them about how participating in the survey has affected them. The survey would consider both potential positive and negative impacts of the study.

Alternative method

Greater understanding of the ALSWH cohort and data capture suggests that a more robust investigation of survey impact on participants could be achieved through data analysis rather than a small and selective sub-study from which it would be difficult to generalise. We also understand that seeking approval for the sub-study from the ALSWH host universities' ethics committees is unlikely to succeed as, within the context of the evaluation, it would not be regarded as health research.

An alternative method will be implemented that involves analysis associated with the following areas of investigation to provide a comprehensive approach to assessing the impact of the survey on participants, that:

- Maximises available sources of secondary information
- Better meets the requirements of the ALSWH's ethics committees for access to raw data for research purposes
- Will generate a stronger evidence base for establishing the way in which the ALSWH has affected participants.

Areas for investigation include:

1. Study data affected through lifestyle change - The extent to which there is any evidence of a change in lifestyle or approach to health that might be attributable to heightened awareness of health issues prompted by responding to the ALSWH survey and ongoing involvement with the study

2. Survey data affected due to participants' survey fatigue – The extent to which there is any evidence of 'survey fatigue' associated with either the breadth and depth of questions or the requirement for an ongoing commitment to ALSWH

3. Survey data affected due to participant's relationship to study – Assessment of the way in which the ALSWH is perceived by participants and their level of engagement.

Approach

The approach to investigate the possible impact of involvement in ALSWH has been developed in discussions with ALSWH researchers at the University of Newcastle and University of Queensland. The specific research questions for this component of the evaluation are:

- What do women write about their experiences of participating in ALSWH?
- What has been reported about ALSWH participant lifestyle behaviours over time and how does this compare to the wider population? How has any difference between the sample and the wider population been accounted for in the analysis of the data?
- How do women describe their relationship with the ALSWH?
- What do the free-text comments suggest about the relationship women have with the ALSWH?
- What is the burden of participating?

The following table outlines the area of investigation, analysis and proposed data sources.

TABLE F.1: ASSESSING STUDY IMPACT ON PARTICIPANTS

Potential impact	Approach	Data source
Study data affected through lifestyle changes	• Investigate prevalence of lifestyle risk factors for the study cohort and compare to patterns in the general population, such as differences in socio-demographic groups • Review participant feedback on their lifestyle over the last 10 years	Major Reports produced from the ALSWH survey data on: • G. Adherence to health guidelines (2012) • I. Changes over time including comparison with youngest cohort and with National Health Survey (2014, not yet released). • Qualitative information from a sub-sample of surveys undertaken over the last 10 years for the 1973-78 and 1946-51 cohorts for reference to changes to lifestyle, intention to change, awareness of need to change, improvement to lifestyle.
Study data affected due to participants' survey fatigue	• Investigate formal and informal feedback on the survey to determine participant level of tolerance or ability to complete the survey, through: • Attrition • Feedback in free text section	• Attrition rates and rationale for all cohorts over life of study • Qualitative information provided in a sample of surveys completed in the last survey wave for all cohorts for any reference to survey burden (retrieved through search terms including but not limited to: survey, questions, late, future, unable)

Potential impact	Approach	Data source
	of survey form • Feedback provided to liaison staff • Review additional research requests of participants to gauge extent of potential 'burden', level of response and strategies to avoid jeopardising ALSWH cohort	• Record of outcome of first reminder call for the most recent survey wave to determine key themes for delay in completing • Information on reasons for not participating and extent to which no reason provided for withdrawal, from record of feedback provided to ALSWH staff contained in the participant database • Summary request from ALSWH researchers of number of sub-studies undertaken, number of sub-studies undertaken by year of cohort, strategies to avoid disruption to ALSWH cohort; and response rates for a subset of sub-studies ensuring that each cohort has been included.
Study data affected due to participants' relationship with the study	• Investigate how the participant engages in the study to determine the way in which participation is perceived and any change in this perception over time • Willingness for ongoing access to their information from women withdrawing from the ALSWH	• Related sub-studies • Proportion of respondents completing the free text area of the survey • Key themes covered in free text • Any discomfort expressed in free text about the nature of questions or concerns about data privacy • Evaluation survey results for the most recent pilot of surveys for all cohorts for feedback on questions regarded as too personal or sensitive. • Data books for proportion of questions not responded to for all cohorts for the last survey • Data books for proportion of 'prefer not to say' responses and the nature of the question • Proportion of women from all cohorts who have withdrawn from the ALSWH but whose information remains accessible for the data linkage component
Study data affected through lifestyle changes	• Investigate prevalence of lifestyle risk factors for the study cohort and compare to patterns in the general population, such as differences in socio-demographic groups • Review participant feedback on their lifestyle over the last 10 years	• Major Reports produced from the ALSWH survey data on: • G. Adherence to health guidelines (2012) • I. Changes over time including comparison with youngest cohort and with National Health Survey (2014, not yet released). • Qualitative information from a sub-sample of surveys undertaken over the last 10 years for the 1973-78 and 1946-51 cohorts for reference to changes to lifestyle, intention to change, awareness of need to change, improvement to lifestyle.

SOURCE: ACIL ALLEN CONSULTING

Appendix G: VALUE FOR MONEY ANALYSIS

This Appendix provides further details on the value for money analysis undertaken in Chapter 7.

G.1 Comparator studies

The Household, Income and Labour Dynamics in Australia (HILDA) Survey

Description and purpose

The Household, Income and Labour Dynamics in Australia (HILDA) Survey collects longitudinal information from a large nationally representative sample of Australian households through both face-to-face interviews and self-completion questionnaires, for a sample of household members aged 15 years and older. A total of 13,969 individuals in 7,682 households were interviewed in wave 1 of the HILDA survey. By wave 11, this figure had increased by 2,153 households and 5,477 individuals (HILDA, 2014).

The HILDA Survey is a broad, general-purpose panel survey designed to obtain detailed information about the dynamics of household structure and formation, income and economic well-being, as well as employment and labour force participation (HILDA, 2014).

Methodology

HILDA surveys were initially collected only through face-to-face interviews, however, in survey wave 12, this figure decreased to 82 per cent, with the remaining 18 per cent being collected through telephone interviews (HILDA, 2014).

Funding and implementation

Funding from the Commonwealth Department of Social Services has been guaranteed for 16 survey waves, a total of 12 waves have been completed to date. Responsibility for the design and management of the survey rests with the Melbourne Institute of Applied Economic and Social Research at the University of Melbourne. Data collection for waves 9 to 16 is being undertaken by Roy Morgan Research, a private market research company, The Nielsen Company collected waves 1 to 8 (HILDA, 2015c).

The Longitudinal Study of Australian Children (LSAC)

Description and purpose

The Longitudinal Study of Australian Children (LSAC) aims to examine the impact of Australia's social and cultural environment on children born in the late 1990s and early 2000s. The study has a broad, multi-disciplinary base, and examines policy-relevant questions about children's and adolescents' development and wellbeing.

LSAC involves a representative sample of children from urban and rural areas of all states and territories of Australia. Data are collected from two cohorts every two years. The first cohort of 5,000 children was aged 0-1 years in 2003-04, and the second cohort of 5,000 children was aged 4-5 years in 2003-04. Study informants include the child (when of an appropriate age) and parents (both resident and non-resident), carers and teachers.

The Study addresses a range of research questions about parenting, family relationships, childhood education, non-parental child care and health. By tracking children over time, the study aims to determine the individual, family, and broader social and environmental factors that are associated with consistency and change in developmental trajectories. The study provides information on child and adolescent development, informs social policy debate, and is used to identify opportunities for early intervention and prevention strategies in policy areas concerning children and families.

Methodology

Face-to-face interviews are the principal method of collecting data from the primary caregiving parent. The first contact with the primary respondent is either by letter or by phone. If by phone, there will be an initial 20-minute interview followed by a 40-minute face-to-face discussion. If by letter, the face-to-face interview may be extended.

Data collection from a second parent will primarily be undertaken through a face-to-face interview (of approximately 15 minutes duration), however, if this is not possible data will be collected either by phone or through a mailed questionnaire (LSAC, 2015).

Other administrative data bases used to complement primary survey data include Medicare Australia database, the National Childcare Accreditation Council data, ABS Census data, and National Assessment Program Literacy and Numeracy scores (LSAC, 2015).

Funding and implementation

The Study is funded by the Australian Government Department of Social Services. The Study is being undertaken in partnership with the Australian Institute of Family Studies and the ABS, with advice from researchers, research institutions and universities (LSAC, 2013).

Longitudinal Surveys of Australian Youth (LSAY)

Description and purpose

The Longitudinal Surveys of Australian Youth (LSAY) track young people annually as they move from school into further study, work and other destinations. LSAY provides information to help better understand young people and their transitions from school to post-school destinations, as well as exploring social outcomes, such as wellbeing (LSAY, 2013).

Information collected as part of LSAY covers a wide range of school and post-school topics, including: student achievement, student aspirations, school retention, social background, attitudes to school, work experiences and what students are doing when they leave school. This includes

vocational and higher education, employment, job seeking activity, and satisfaction with various aspects of their lives (LSAY, 2013).

Methodology

LSAY uses large, nationally representative samples of young people, in a range of age cohorts, to collect information about education and training, work, and social development. Each cohort starts with approximately 14,000 students. Survey participants enter the Study when they are 15 years old or, when they reach Year 9. To date, there have been five cohorts, the first started in 1995, followed by cohorts in 1998, 2003, 2006 and 2009 (LSAY, 2013).

Up until 2012, all survey interviews were collected via computer assisted telephone interviewing (CATI), which lasts between 15-20 minutes per interview. Today, interviewees have the option to complete the survey online. All interviews are undertaken by the Wallis Consulting Group (LSAY, 2015).

Funding and survey implementation

LSAY is managed and funded by the Australian Government Department of Education and Training, with support from state and territory governments. On 1 July 2007, the National Centre for Vocational Education Research (NCVER) was contracted to provide analytical and reporting services for LSAY (LSAY, 2015).

G.2 Costs

Comparator study costs

One annual funding figure for each comparator study was available. These are provided below and are GST exclusive:

- HILDA: $9.3 million in 2007-08
- LSAC: $7.2 million in 2001-02
- LSAY: $1.0 million in 2014-15.

In order to provide the most accurate figure for each year between 2010-11 and 2013-14, these funding figures were adjusted to take into account inflation over the years. The total dollars presented between 2010 and 2014 are presented in 2013-14 figures. The cost calculations assumes no changes in base year funding.

Costs per participant contact

In order to determine the cost per participant, the number of participants between 2010 and 2014 was required.

ALSWH

The number of survey participants for the ALSWH survey between 2010 and 2014 were collected from the ALSWH website, which provided a schedule of surveys for the ALSWH by age cohort and year (ALSWH 2015f).

HILDA

Waves 7-11 within the HILDA survey fit within the time period 2010-14, however, only figures from 2011-14 have been used. This is because cost data have been collected over four financial years, whereas, 2010-14 represents five years of data. For a robust VFM analysis, the same number of years across costs and outputs is needed.

The total number of participant contacts between 2011-14 was 53,215, which comprises:

- 12,785 participants in 2011
- 13,310 participants in 2012
- 13,526 participants in 2013
- 13,603 participants in 2014.

Given HILDA produce surveys each year, the total number of participants interviewed is used for the cost per participant calculation.

LSAC

Publically available data did not reveal study participant numbers within the analysis time period. However, participant numbers were recorded for survey waves undertaken between 2004 and 2010. The average number of participants over these survey waves has been used to determine the cost per participant.

Between 2004 and 2010 there were four survey waves, which involved 36,472 participant interviews. Therefore, the average number of participants per survey wave is 9,118 (36,472 divided by four).

LSAC produce surveys every two years, therefore the number of participants for two survey waves has been used for the cost per participant calculation–specifically, 18,236 (9,118 multiplied by 2).

LSAY

LSAY undertake surveys each year, however, number of participant contacts was only available for years 2011-13, which were:

- 17,475 in 2011
- 15,156 in 2012
- 13,751 in 2012.

Given participant contacts were not available for 2014, the average number of participants contacts between years 2011-13 was used, specifically 15,461. Therefore, the total number of participant contacts over the analysis period is 61,843.

G.3 Research outputs

Research output data

The number of publications, conferences and reports/papers by study between 2011 and 2014 are outlined in the table below. There is no apparent trend within any study and/or output measure across the chosen time period.

TABLES G.1: RESEARCH OUTPUTS BY STUDY AND YEAR: 2011-2014

Peer-reviewed journal articles

YEAR	ALSWH	HILDA	LSAC	LSAY
2011	22	115	38	3
2012	19	70	51	4
2013	24	70	50	3
2014	18	64	46*	5
Total articles	**83**	**319**	**185**	**15**

Conferences

YEAR	ALSWH	HILDA	LSAC	LSAY
2011	26	26	47	1
2012	39	38	74	1
2013	44	39	21	3
2014	34	24	47*	2
Total conferences	**143**	**127**	**189**	**7**

Research reports/papers

YEAR	ALSWH	HILDA	LSAC	LSAY
2011	1	44	2	7
2012	1	41	4	4
2013	1	42	13	4
2014	1	34	6*	5
Total research reports/papers	**4**	**161**	**25**	**20**

Note: * No data was available for 2014, therefore, the average of the previous three years has have been used.
SOURCE: ALSWH JOURNAL ARTICLES PROVIDED BY ALSWH (2014); (ALSWH, 2015B); (ALSWH, 2015C); (HILDA, 2015); (HILDA, 2015A); (HILDA, 2015B); (LSAC, 2013); (LSAC, 2012); (LSAC, 2011); (LSAY, 2013)

Total weighted research output calculation

The total weighted research output was calculated in order to place a greater emphasis on outputs that were comparable across all four studies. In order to weight the outputs, percentages (that add to 100 per cent) were allocated across the three outputs. For this analysis, journal articles and conferences each received 45 per cent of the weighting, which left 10 per cent for the research reports/papers.

The formula used for calculating total weighted outputs figures is:

= 0.45(Number of articles) + 0.45(Number of conferences)
+ 0.1(Number of research reports or papers)

Calculations for the total weighted output values are provided in the table below.

TABLE G.2: TOTAL WEIGHTED RESEARCH OUTPUT SCORES

	ALSWH	HILDA	LSAC	LSAY
Calculation	=0.45(83) + 0.45(143) +0.1(4)	=0.45(319) + 0.45(127) + 0.1(161)	=0.45(185) + 0.45(189) + 0.1(25)	=0.45(15) + 0.45(7) + 0.1(20)
Total weighted output score	**102**	**217**	**171**	**12**

SOURCE: ALSWH JOURNAL ARTICLES PROVIDED BY ALSWH (2014); (ALSWH, 2015B); (ALSWH, 2015C); (HILDA, 2015); (HILDA, 2015A); (HILDA, 2015B); (LSAC, 2013); (LSAC, 2012); (LSAC, 2011); (LSAY, 2013)