Report 35

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the australian longitudinal study on women's health

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EXECUTIVE SUMMARY

1. This report covers the twelve-month period from January to December 2012.
2. Recruitment of a new cohort of young women (aged 18-23) began in October 2012. The survey is offered online, and participation is open to any young women 18-23 who have an Australian Medicare card. At 19 December, 501 surveys had been completed.
3. Survey 6 for the 1973-78 cohort was distributed to participants electronically and on paper on 26 April 2012. At 11 November, 7,202 surveys had been completed and returned (60% response).
4. Preparation has commenced for Survey 7 of the 1946-51 cohort, scheduled to be conducted in 2013. This survey will be offered online and in the traditional paper format, and piloting in both formats began in November 2012. Collection of pilot data will close in February 2013, when refinement of the survey questions for Survey 7 will begin.
5. A number of important methodological issues concerning the conduct of online surveys have been examined, along with changes to 1921-26 cohort data related to the follow-up surveys now being conducted every six months.
6. The team have continued to work on progressing linkage of ALSWH survey data with health information from the Medicare Benefits Schedule (MBS), the Pharmaceutical Benefits Scheme (PBS), and other administrative datasets without the need to ask for individual consent. Data linkage is also underway with the hospital data and cancer registry data from most States and Territories.
7. A major report has been prepared for the Department of Health and Ageing on adherence to health guidelines by Australian women. Forty-seven papers have been published or accepted for publication in national and international scientific journals during the reporting period. Forty-four presentations have been made to scientific and professional audiences both in Australia and internationally. Nineteen postgraduate students are currently working on aspects of the project.

1. Collaborative Research Activities

1.1 Scientific meetings and teleconferences among the research team

The Steering Committee is responsible for the overall direction of activities and resources to ensure that timelines and deliverables are met. Meetings and teleconferences are conducted at least once a month among the Steering Committee, with agendas, notes and minutes circulated to all investigators. Steering Committee membership is flexible and decided on an annual basis, so that a group of at least six investigators is involved at this level at any one time. The current Steering Committee members are:

- Professor Annette Dobson (Chair)
- Professor Julie Byles
- Professor Wendy Brown
- Professor Christina Lee
- Associate Professor Jayne Lucke
- Associate Professor Deborah Loxton
- Professor Gita Mishra
- Professor Nancy Pachana
- Professor David Sibbritt
- Dr Leigh Tooth
- Dr Deirdre McLaughlin
- Dr Meredith Tavener

Steering Committee meetings during the reporting period have been held by teleconference on 1st February, 7th March, 16th April, 2nd May, 6th June, 4th July, 1st August, 5th September, 3rd October, 7th November and 5th December.

The Data Management Group is responsible for all technical issues involving data quality, derivation of variables, checking and cleaning of data sets, linkage and archiving. The group is chaired by David Fitzgerald (Data Manager – The University of Queensland) and Anna Graves (Operations Manager - The University of Newcastle) and members in 2012 included Professor Annette Dobson (Study Director), Professor Julie Byles (Study Co-Director), Associate Professor Deborah Loxton (Study Deputy Director), project statisticians and other staff including Xenia Dolja-Gore, Richard Hockey, Jenny Powers, Cath Chojenta, Dr Samantha McKenzie, Ewan McKenzie and Ryan Tuckerman.

From November 2012, informal teleconferences on progress of recruitment of the new young cohort have been conducted weekly. Attendance is open to all ALSWH personnel at each university, and has included Professor Julie Byles, Associate Professor Deb Loxton, Dr Meredith Tavener, Anna Graves, Clare Rooney, Ashleigh O'Mara, Cath Chojenta, Ryan Tuckerman, and Stephanie Pease at Newcastle and Professor Annette Dobson, Professor Gita Mishra, Megan Ferguson, Leonie Gemmell, Katherine De Maria and Ewan MacKenzie at Herston.

An email update is periodically provided to all investigators, staff, students, collaborators and others with an interest in the progress of the project. Updates for 2012 are included in Appendix A.

1.2 Current research projects

1.2.1 Chronic conditions

Project: A133B	**Arthritis impact over time: A longitudinal exploration of burden of illness, comorbidities (especially depression), management, and healthcare costs in older Australian women.**
ALSWH Liaison:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Collaborative Investigators:	• A/Professor Lynne Parkinson (Health CRN, CQ University) • Richard Gibson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Glenn Salkeld (School of Public Health, University of Sydney) • Dr Michelle Cunich (School of Public Health, University of Sydney) • Thomas Lo (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Katia De Luca (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Amanda McGovern (University of Wisconsin-Madison) • Dr Fiona Blyth (The Sax Institute, Sydney) • Professor Lyn March, (Medicine, Northern Clinical School, The University of Sydney) • A/Professor Henry Pollard (Faculty of Health Science, Australian Catholic University) • Professor Isabel Higgins (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Chris Hayes (Hunter Integrated Pain Service, Royal Newcastle Centre) • Professor Gillian Hawker (Department of Medicine, University of Toronto) • Dr Jacqueline Hochman (Canadian Osteoarthritis Research Program, Women's College Hospital, Toronto) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland)

Arthritis is the most common cause of activity limitation and disability among older Australian women. In 2002, arthritis and musculoskeletal conditions were established as a National Health Priority Area, in recognition of the major health and economic burden these conditions place on our community. The broad aim of this project is to investigate the effect of arthritis, and comorbidities associated with arthritis, on health and quality of life for older Australian women. The combination of extensive

demographic, psychosocial and health survey data linked with Medicare and hospitalisations data means that the burden and economic costs of arthritis in Australia can be examined more rigorously than in any previous work. In 2012, Thomas Lo and Katie DeLuca successfully completed their PhD confirmations and substudies for their doctoral work are planned to commence in November.

Research outcomes in 2012:

- G. Peeters, L. Parkinson, E. Badley, W. J. Brown, A. Dobson, & G. Mishra. *Longitudinal variations in reporting doctor-diagnosed arthritis reflect contemporaneous severity of symptoms and disability*. The European League Against Rheumatism, Berlin, Germany, 6 - 9 June, 2012.

Project: A133D	**Incident Osteoarthritis in a cohort of "baby boomer" women: Management and outcomes in the Australian community**
ALSWH Liaison:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Collaborative Investigators:	• A/Professor Lynne Parkinson (Health CRN, CQ University) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Gillian Caughey (School of Pharmacy and Medical Sciences, University of South Australia) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Dr Michelle Cunich (School of Public Health, University of Sydney) • Professor Dimity Pond (School of Medicine & Public Health, The University of Newcastle) • Dr Fiona Blyth (The Sax Institute, Sydney) • Dr Parker Magin (School of Medicine & Public Health, The University of Newcastle)

Osteoarthritis (OA) is a leading contributor to disability in Australia. As demographic ageing is expected to greatly increase the number of Australian women with OA by 2020, due predominantly to the ageing of the “baby boomer” cohort, there is a critical need to understand the factors that enable women with OA to remain active and independent in the community as they age; the reduction of disability with age will reduce demand on residential care and community services and enable older people to live independently for longer. OA is most commonly reported by women, and is the most common chronic disease reported by older women. While there is good evidence to underpin how OA should be managed, we know very little about how OA is managed in the community, or the longer term outcomes of that management. From our past research we know that older women with new OA report rapidly reducing quality of life over a short time frame; that OA medicine guidelines may not be followed, such as in the case of Vioxx; and that women often use complementary therapies for OA. However, there are gaps in our knowledge around the immediate and ongoing therapies for new

onset OA, and related health outcomes, which is an obvious next step for our research. The NHMRC endorsed evidence-based guidelines for non-surgical management of OA in the Australian health care context, published by Royal Australian College of General Practitioners, emphasise the importance of self management to prevent repeated acute episodes, and prevent or delay functional limitations and disability. This project will examine the extent to which these guidelines are being applied among a large ageing "baby boomer" cohort of women with OA by examining onset of OA, immediate and ongoing management, and the related health outcomes. Given the burden of disease associated with OA, in terms of health, health services and social costs to community and government, this work is essential and overdue. The unsuccessful NHMRC proposal for this project will be worked up for other funding sources in 2012 and 2013.

Project: A282	**Experience of pain and analgesic use by Australian women: What do older women say?**
Collaborative Investigators:	• Professor Isabel Higgins (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Lynne Parkinson (Health CRN, CQ University) • Dr Jane Robertson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Sarah Jeong (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Sharyn Hunter (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Pamela Vanderiet (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)

First level analysis of data has commenced. However, several members of the research team have been unwell throughout the project, which has caused some delay to the analysis of the data sets.

Project: A307	**Risk factors for constipation**
Collaborative Investigators:	• Professor Nicholas Talley (Faculty of Health, The University of Newcastle) • Dr Natasha Koloski (School of Psychology, The University of Queensland and Faculty of Health, The University of Newcastle) • Peta Forder (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Michael Jones (Psychology Department, Macquarie University) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Gill Raghubunder (Gastroenterology Department, Royal Prince Alfred Hospital) • Dr Ronald Wai (School of Medicine & Public Health, The University of Newcastle)

We aimed to determine risk factors for new onset constipation in a large population based cohort of older Australian women over a 9 year period. Our participants were 12,762 women (aged 70-75 years) who participated in the first survey of the Australian Longitudinal Study on Women's Health in 1996. Of these women, n =3716, aged 79-84 years also completed a follow-up survey in 2005. Both the first and follow-up survey asked women "Have you had constipation in the past 12 months?" The following baseline variables were asked in the first survey. Demographic factors included nationality, educational, marital and socioeconomic status. Lifestyle factors assessed included smoking, alcohol intake, body mass index, number of live births and a history of a prolapse repair. The number of stressful life events in the past year was assessed, as was depression, using the Centre for Epidemiological Studies-Depression scale (CES-D). Domains of quality of life were assessed using the valid SF-36. Of the 3716 women who responded to the first and follow-up survey, we found 1501 (40.3%) developed constipation over the 9 year period. Univariately, we found an increased number of live births, increased number of stressful life events, lower socioeconomic status and reduced functioning in the following SF 36 domains: general health, bodily pain, mental health, physical and social functioning, role emotional and physical and vitality to be significantly associated with new onset constipation. However in a multiple regression model that included these significant variables we found the rate of constipation in those women who have given birth versus those who had not (43% vs. 34%;) and reduced functioning on the SF- 36 subscales for vitality (M=6.4 vs. M=6.8;) and bodily pain (M=6.8 vs. M=7.4;) were independent risk factors for developing constipation among women who did not report constipation on the first survey. Therefore we showed that constipation is an extremely common problem among older community dwelling women and causes decrement in health related quality of life. Our prospective data suggests factors related to childbirth and generally being unwell as reflected by poor quality of life are risk factors for developing new onset constipation among older women.

We have also looked at risk factors associated with a shorter time to constipation among older women and are preparing to submit this work as an abstract to Digestive Diseases Week in 2013 (with permission from ALSWH). We are also working on a manuscript focussing more on the risk factors associated with a shorted time to constipation as we feel this takes advantage of the several time points of data available. A draft of this manuscript is almost complete and will be circulated to authors during November 2012.

Research outcomes in 2012:

- Koloski NA, Jones M, Raghubinder GS, Forder P, Talley NJ. Long term risk factors for the development of constipation in older community dweling women. *Gastroenterology* 2011;140 (5) (Supplement) p359-360.

Project: A306	**The role of sitting time in the development of osteoporosis**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Professor Paul Lips, (VU University Medical Centre, Department of Internal Medicine)

Two research questions were proposed which would each result in a paper. The analyses for the first research question were done, but when writing up the results, we realised that it would be impossible

to turn it into a paper that would be of sufficient quality to be of interest to a decent journal. The associations were not significant, but, more importantly, there were too many limitations in the data which hampered meaningful interpretation of the results. We therefore decided to drop this paper.

The analyses for the second research question have been completed and written up as a full length paper. The paper is currently under review with *the European Journal of Ageing*.

Project: A323	**The relationships between activity patterns (physical activity and sitting time) and musculoskeletal health in mid-age and older women**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Nicola Burton (School of Human Movements Studies, The University of Queensland)

No work has been done on this project yet, as the research team have had some difficulty having any papers on arthritis accepted by quality journals. Geeske Peeters is currently working on validation of self-reported arthritis, and as it may be better to focus on joint pain and mobility limitations rather than self-reported arthritis, a new and more specific research plan is being drafted.

Project: A346	**Factors affecting survival among older women with asthma**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Peta Forder (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Tazeen Majeed (Research Centre for Gender, Health and Ageing, The University of Newcastle)

Among the 12,432 women in the 1921-26 cohort, 13% reported asthma at Survey 1 in 1996. Twelve years later in 2008, around 6% of the 5560 women completing the 5th survey reported asthma. Compared to women with no diagnosed asthma at survey 1, women with asthma were more likely to die. 42% of women with asthma died over the follow-up period, compared to 31.7% women without diagnosed asthma. After adjustment for comorbid conditions the association between asthma and mortality was reduced but remained statistically significant. The effect of asthma mortality remained stable and significant after adjustment for behavioural risk factors, demographic factors and social support.

A draft manuscript is in preparation.

Project: A349	**Cancer rates and risk factors among lesbian and bisexual women: an overlooked health disparity**
Collaborative Investigators:	• Dr Rhonda Brown (School of Nursing and Midwifery, Deakin University) • Dr Patricia Livingston (School of Nursing, Deakin University) • Dr Ruth McNair (Department of General Practice, University of Melbourne) • Professor Tonda Hughes (College of Nursing, University of Illinois) • Professor Christina Lee (School of Psychology, The University of Queensland)

Analysis of the data from mid-cohort Surveys 3, 4, 5 and 6 has now been completed. We have compared cancer rates and cancer risk factors among 10,451 of the participants who identified their sexual identity in Survey 3 as exclusively heterosexual (n=10,200) or mainly heterosexual, bisexual, mainly lesbian, lesbian (n=251; sexual minority women). Participants who indicated uncertainty about their sexual identity or declined to answer the question (n=394) we excluded from the analysis. We are currently preparing a paper for publication reporting findings.

In summary we found:

- Cancer incidence and screening - Almost 20% of the participants were recently diagnosed with a cancer. While rates of cancer screening were high in both groups, exclusively heterosexual women were significantly more likely to conduct self-breast exams, to have had a mammogram, and to ever having had a pap smear than sexual minority women. Sexual minority women were significantly more likely to have never had a mammogram and to have never had a pap smear.
- Behavioural cancer risk factors - Sexual minority women were significantly more likely to be high risk drinkers for exclusive heterosexual women) and were twice as likely to be smokers and while only a small number, to smoke more than 20 cigarettes a day. There were no significant differences in BMI or current hormone replacement therapy.
- Physical and mental health - While there were no significant differences in health by sexual identity in the main as measured by the mental health index, life satisfaction, stress or anxiety, sexual minority women reported significantly poorer social functioning, lower emotional role, and greater depression than did exclusively heterosexual women.
- Experiences of violence - Sexual minority women reported almost twice the level of violent experiences than did exclusively heterosexual women and reported significanlty higher reates of having been in violent relationship with a partner/spouse and being uncomfortable with a family member recently.

We are interested in tracking these women over time to see whether these higher rates of cancer risk factors among sexual minority women result in higher rates of cancer than heterosexual women as they age. Information about sexuality is not routinely collected in national cancer surveillance and indeed was only asked of the mid cohort of the ALSWH study in 2001. We would argue that it is important to identify sexual minority women in data collection to better understand the health and health risks in this underserved population.

A paper reporting the findings from this study is in preparation and abstracts have also been submitted to the Australian Women's Heath Conference in Sydney in May and the Health in Difference Conference in Melbourne in March 2013.

Project: A261A	**The Australian Cancer and Diabetes Collaboration**
Collaborative Investigators:	• Dr Dianna Magliano (Baker IDI Heart & Diabetes Institute) • A/Professor Jonathon Shaw (Baker IDI Heart & Diabetes Institute) • Jessica Harding (Clinical Diabetes & Epidemiology, Baker IDI Heart & Diabetes Institute) • Professor Annette Dobson (School of Population Health, The University of Queensland)

Data linkage to the National Death Index and Australian Cancer Database is now complete for all the cohorts in the project, pooling of cohort data is 75% complete and a website describing the project has been developed.

Project: A358	**Gastrointestinal problems in older adults**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Derrick Lopez (Centre for Health and Ageing, University of Western Australia) • Professor Leon Flicker (School of Medicine and Pharmacology, University of Western Australia) • A/Professor Kieran McCaul (University of Western Australia)

One paper from this research has been published, and a second is planned.

Research outcomes in 2012:

Lopez D, Flicker L & Dobson A (2012) Validation of the frail scale in a cohort of older Australian Women. *J Am Geriatrics Society*: 60(1): 171-173

Project: A422	**Predictors of stroke among mid-age and old-age women**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Dr Caroline Jackson (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Isobel Hubbard (School of Medicine & Public Health, The University of Newcastle)

The analyses for the relationship between socioeconomic status and mental health and stroke in the elderly cohort have been completed, using mortality data and hospital admission data from NSW to identify incident stroke events. With the receipt of hospital data from Queensland and Western Australia, these analyses will be upated in November/December 2012 to included women from these additional states, before the results will be written up in a scientific paper.

Similar analyses examining the relationship between socioeconomic status and mental health and stroke in the mid-age cohort are ongoing, using self-reported data on stroke (since there are insufficient stroke events from the hospital linked data to date). These analyses reveal associations between some socioeconomic indicators and stroke incidence, with at least part of the relationship mediated by lifestyle behaviours. Analyses will be completed by December 2012 and a paper will be drafted for submission to a peer-reviewed journal.

Project: A402	**Number of ALSWH participants who have had joint replacement surgery**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland)

Ethical clearance has been received from the Universities of Adelaide, Newcastle and Queensland, and datasets are now being preparing for linkage.

Project: A413	**Oestrogen exposure index (OEI) for post-menopausal women**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Danielle Herbert (School of Population Health, The University of Queensland) • Dr Gerrie-Cor Gast (School of Population Health, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)

The creation of the index is currently underway.

Project: A414	**InterLACE: International collaboration for a life course approach to reproductive health and chronic disease events.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Deborah Anderson (Queensland University of Technology) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Jemma Rowlands (School of Population Health, The University of Queensland) • Danielle Schoenaker (School of Population Health, The University of Queensland)

The InterLACE project will investigate the relationship of reproductive health, from menarche to menopause, with cardiovascular disease and Type 2 diabetes mellitus outcomes in later life, using data from longitudinal studies on women's health from several countries, including Australia, China, Japan, Sweden, UK, and USA.

The research questions are 1) Identify trajectories for reproductive health, formed by the relationships between markers, that best characterise lifetime reproductive health; 2) Investigate the relationship of markers and trajectories of reproductive health with subsequent risk of CVD and T2DM; and 3) Examine how the effects of reproductive health vary due to culture, lifestyle, and social and policy environments in different nations.

InterLACE commenced in 2012 and is funded by the National Health and Medical Research Council. Currently a manuscript outlining InterLACE is being prepared for the February issue of *Maturitas*.

1.2.2 Health service use and systems

Project: A081A	**Characteristics of CAM users and associated symptoms and conditions.**
Collaborative Investigators:	• Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Professor Jon Adams (School of Public Health, University of Technology Sydney) • A/Professor Alexander Broom (School of Social Science, The University of Queensland) • Dr Chi-Wai Lui (School of Population Health, The University of Queensland) • Jon Wardle (School of Population Health, The University of Queensland) • Dr Steven Bowe (Cancer Council Victoria) • Dr WenBo (Penny) Peng (School of Medicine and Public Health, The University of Newcastle)

This research conducted as part of this project continues to demostrate that the use of complementary and alternative medicine (CAM) is considerable and widespread amongst these Australian women. CAM is clearly a significant healthcare option, particularly for women with chronic illness.

2012 research outcomes:

- Sibbritt D. (invited) Public health research: Insights for acupuncture. *International Scientific Acupuncture and Meridian Symposium (iSAMS),* Sydney, Australia. 5-7 October 2012.
- Adams J, Sibbritt D & Lui C. Health service utilisation among persons with self-reported depression: A longitudinal analysis of 7,164 women. *Archives of Psychiatric Nursing*, 26(3); 181-191.
- Sibbritt D, Adams J, Chi Wai L & Broom A. Health services use among young Australian women with allergies, hayfever and sinusitis: A longitudinal analysis. *Complementary Therapies in Medicine*. (accepted)

Project: A101	**Change in health status and healthcare use for women who have and have not had Medicare health assessments**
ALSWH Liaison:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Collaborative Investigator:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle)

Survival and health-related quality of life scores for women who were eligible for the 75+ assessment were examined according to whether or not the women had a health assessment since 1999 and whether or not they had a major condition (heart disease, cancer, diabetes, asthma/bronchitis). Health assessments had no great impact on survival. While there was a slight trend for women who had a health assessment to have better survival than women who had no assessments, interpretation of these data is difficult since assessments are dependent on survival. Among women who were still alive in 2004, there was no statistically significant difference between physical function scores for women who did and did not have health assessment. However, there was a small trend towards a lesser decline in scores for women having more than one assessment. There were no differences in SF-36 Mental Health sub-scale score. Further analysis of these data will be undertaken to include data up to S6 and to identify the impact of time varying covariates (including health assessments at different time points) on survival and quality of life and over a longer follow-up period.

Project: A158B	**Use and costs of a polypill for primary and secondary prevention of cardiovascular disease in Australian women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Dr Jennifer Stewart Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Chris Doran (School of Medicine and Public Health, The University of Newcastle) • Dr Chris Wallick (School of Pharmacy, University of Washington) • Dr Andrew Searles (School of Medicine and Public Health- The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle)

A low cost "polypill" could theoretically be one way of improving medication affordability and compliance for secondary prevention of cardiovascular and cerebrovascular disease while also offering primary prevention at a population level. Although there are a number of clinical issues to be resolved before introducing a "polypill", this work addresses more fundamental questions concerning the use of individual medicines proposed for a cardio-protective "polypill". The objective is to describe association between patient characteristics (socio-demographic, health and behavioural) and the use of statins and anti-hypertensive medicines in mid-and older-aged Australian women aged 55 and over. Survey records from the Australian Longitudinal Study on Women's Health were linked to Pharmaceutical Benefits Scheme (PBS) claims for 7,116 mid-aged women (aged 56 to 61) and 4,526 older-aged women (aged 81 to 86). Associations between women's characteristics and use of statins and anti-hypertensive medicines were analysed using chi square and multivariate regression techniques. Prevalence of PBS claims for anti-hypertensive medications and statins increased with age. About 10% of mid-aged women and 30% of older-aged women used both types of medicines and were more likely to be in lower socioeconomic groups. Mid-aged women who reported having had a cardiac and/or cardiovascular related diagnosis were significantly more likely to be using statins. This study found that a substantial proportion of Australian women aged 55+ years many of whom were in lower socioeconomic groups, were prescribed the two main "polypill" component medicines either as primary or secondary cardiovascular prevention. The findings suggest that if an inexpensive single dose "polypill" were to be introduced there may be population-wide benefits in terms of improved adherence, better health outcomes and lower costs. Clearly there is a need in future to undertake robustly designed cohort studies to more fully investigate the potential benefits and costs that may arise were a "polypill" be introduced as proposed.

2012 research outcomes: A manuscript "Assessing patterns of use of cardio-protective polypill component medicines in Australian women" has been accepted for publication in *Drugs & Aging*

Project: A166	**Comparison of self-reported medications and PBS records**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Sabrina Pit (School of Public Health, University of Sydney) • A/Professor Lynne Parkinson (Health CRN, CQ University) • A/Professor Geoff Morgan (School of Public Health, The University of Sydney)

This study compared older women's self-reported medication use as recorded on Survey 4 with PBS data 4,687 participants that consented to the release of their MBS/PBS data. The agreement between these two sources of information was checked for particular classes of medication for common chronic conditions (insulin and analogues, oral blood glucose lowering drugs, anti-hypertensives, statins, aspirin and folic acid, anti-depressant medications, anxiolytics and hypnotics). For these medications prevalence of medication use was generally higher in PBS data except for Aspirin intake. This could be accounted for by over the counter purchases of Aspirin which will not appear in the PBS data. Specificity (the probability that a woman who is not taking a medication will not report this on her survey) was high for all medication use. Overall agreement and sensitivity (the probability that women identified as taking a medication according to PBS data reported this medication on the survey) were highest for glucose lowering drugs and lowest for nervous system medications. Positive and negative predictive values were generally high, except for Aspirin and folic acid which can be purchased over-the-counter without prescription.

In general, this analysis indicates good agreement between these two sources of medication information for most of the groups of medications assessed. Care must be taken when using PBS data as a source of information about drugs that can be bought over-the-counter or that are used as needed. Medications that are not covered under the PBS scheme will also be under-represented in PBS data and self-report is a better source of information on the use of these medicines.

Further analysis is now underway to compare agreement between self-reported medication use and PBS data for mid-age women. We expect there may be some differences in coverage of PBS data for these women. Write up of the analysis of the data for 1921-26 cohort is complete and a manuscript has been accepted for publication. Analysis of data for mid cohort is yet to be completed.

Project: A178A	**Tracking the impact of drug regulatory actions: Consumer health outcomes, risk-benefit issues and policy framework**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Lynne Parkinson (Health CRN, CQ University) • Dr Evan Doran (School of Medicine and Public Health, The University of Newcastle) • Dr Jane Robertson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Gibson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor David Henry (Institute of Evaluative Clinical Sciences, Toronto) • Andrew Searles (School of Medicine and Public Health, The University of Newcastle) • Dr Paul Kowal (World Health Organisation, Freshwater) • Professor Glen Salkeld (School of Public Health, University of Sydney)

	• Dr Jennifer Stewart-Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Melissa Harris (School of Medicine and Public Health, The University of Newcastle) • Alison Gibberd (Research Centre for Gender, Health and Ageing, The University of Newcastle)

In 2004, a prescribed medicine for the relief of arthritis pain and inflammation (Vioxx) was taken off the market due to safety concerns. Caution in the use of other related medicines was also advised. When a medicine such as Vioxx is withdrawn (or a whole class of medicines discredited), follow-up of impacts at consumer level can be difficult and costly. The Australian Longitudinal Study on Women's Health provided a rare opportunity to examine medicine use by individuals following this major discrediting event. When first marketed, Vioxx was expected to reduce the health problems related to arthritis medicine use; however, it was later found that this medicine could actually increase the risk of heart and kidney problems for some people. This study found that women who had frequently used Vioxx often switched to medicines related to Vioxx for their arthritis pain, once Vioxx was no longer available. This conflicted with public health advice at the time. Whether this choice was mostly made by women or by their prescribers depended upon their age group. Overall, we found little evidence that discrediting Vioxx resulted in harm for this group of Australian women, in terms of health outcomes and quality of life, and effect on perceptions of safety of medicines overall.

- The majority (over 80%) of continuous Vioxx users (nine or more scripts in previous 12 months) switched to another COX-2 medicine following Vioxx withdrawal.
- This typical switching behaviour suggests that the issues leading to the discrediting of Vioxx were not seen as a COX-2 class effect by many Australian prescribers or consumers.
- Withdrawal of Vioxx did not appear to have a negative impact on health related quality of life for those women using Vioxx at the time of discrediting.
- Women spoke of long histories of taking anti-inflammatories – over many years and taking many different medicines with much "chopping and changing."
- General practitioners (GPs) were a powerful source of information about medicines to women. Women had a general skepticism about the media but were prompted to further explore or validate the information they were exposed to, often through their GP.
- Glucosamine and fish oil were common complementary and alternative medicines (CAMs) used by women, and recommended by some GPs.
- GP behavior and attitude was impacted by the discrediting event, but COX-2s continued to be prescribed with caution, dependent on presenting inflammation and co-morbidity.
- While GPs generally believed "the evidence", some were sceptical of medicine recalls and considered them "knee jerk reactions".

These findings contribute to our understanding of how public safety concerns with medicines should be managed and communicated in future events, and provides important information for improvements in regulatory and provider responses when other medicines are discredited in the future.

Project: A256	**Agreement between self-reported cardiovascular disease and hospital admission records: What factors influence agreement and what are the differences in estimated prevalence?**
Collaborative Investigators:	• Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Dr Jennifer Stewart Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Tina Navin (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Lynne Parkinson (Health CRN, CQ University)

The aim of this study is to measure the conformity of information on physician diagnosed diabetes, hypertension, heart disease and stroke, reported by women in surveys administered by the Australian Longitudinal Study on Women's Health (ALSWH) with centralized hospital records. Records for two cohorts of women in the ALSWH born 1946-51 and 1921-26 were assessed. The study found that agreement was substantial for diabetes, moderate for heart disease and fair for hypertension and stroke. Sensitivities were higher when cases were ascertained using multiple survey time points. Higher education was associated with better agreement for heart disease for women in the 1946-51 cohort. A journal manuscript has been written, and is currently under review.

Project: A256A	**Identifying the predictors of hospitalisation for women with single and multiple comorbid chronic conditions**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Deb Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Jennifer Stewart-Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Lynne Parkinson (Health CRN, CQ University) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Gibson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Cath Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Allison Gibberd (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Michelle Cunich (School of Public Health, The University of Sydney) • Tina Navin (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Thomas Lo (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Nicole Mirjanich (The University of Newcastle) • Professor Chris Doran (School of Medicine and Public Health, The University of Newcastle) • Dr Lynn Francis (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This research aims to identify and test the policy modifiable predictors of acute hospital service utilisation, and costs accumulated over time by individuals with specified chronic conditions and comorbidities (cardiovascular disease, cerebrovascular disease, chronic obstructive airways disease, asthma, arthritis, diabetes, depression), and their associated risk factors. For these analyses, ALSWH survey data for NSW women have been linked with the NSW Admitted Patients Data Collection (APDC), through the NSW Centre for Health Record Linkage (CHeReL). The APDC provides detailed information on hospital admissions and costs, while the survey data provides longitudinal information on personal, health and function, behavioural, social, and lifestyle factors that may explain and predict cumulative hospital service usage and costs for people with chronic and complex diseases and associated risk factors. Only women resident of NSW are included and the linked data collection includes 2,836 women in the 1946-51 cohort and 2,278 women in the 1921-26 cohort.

Arthritis:

Analysis of the data collection using arthritis as the index condition of interest has been summarised in a technical report, (See also A133B) This work had four aims, to explore:

1. the socio-demographic, physical, psychological, behavioural, functional, psychosocial and lifestyle characteristics of mid aged and older women residents of NSW with arthritis;

2. the episodic and cumulative NSW acute hospital inpatient utilisation patterns for mid aged and older women residents of NSW with arthritis;

3. the policy modifiable predictors of accumulated inpatient resource utilisation in NSW acute hospitals by mid aged and older women residents of NSW with arthritis; and

4. the accuracy of self-reported arthritis relevant procedures using linked NSW hospitalisations data.

There were 4,074 participants from 1946-51 cohort (mids) and 4,214 participants 1921-26 cohort (olds) lived in NSW between at some stage between Survey 1 and 2010. After merging with APDC data from July 2000 to December 2008, over 11,000 records for mids, over 23,000 records for olds- 3,885 mids and 4,105 olds had real (or imputed) residential addresses in NSW.

Women were allocated to four groups based on presence/absence of arthritis and presence/absence of other National Health Priority Conditions (NHPC). Groups with arthritis were more likely to visit doctors, report more symptoms, score less for SF36 measures, be unemployed and have less formal education than the corresponding groups without arthritis. These patterns were also apparent when groups with other NHPCs and those without were compared.

For both cohorts, women with arthritis were more likely to be admitted to hospital than women without arthritis between July 2000 and December 2008. Women with another NHPC were also more likely to be admitted. Women with arthritis and women with another NHPC also had a higher average number of admissions, both for overnight admissions and day only admissions. The admission rate increased steadily over time for mids for both overnight and day only admissions. However, in 2005, the rate of day only admissions for the olds decreased, while the overnight admission rate climbed.

The procedures undertaken at hospital were similar for all groups, though different for the two cohorts. Hip replacement was one of the top 10 reasons for admission Group 4 of the mids. Knee replacement was in the top 10 for Groups 2 and 4 for the olds. For the mids, the rate of knee replacements was always equal to, or greater, to the rate of hip replacements. However, for the olds, in the final 4 years, the rate of hip replacements appears to be slightly greater than knee replacements.

For the mids, women who reported stroke and heart (grouped), arthritis or anxiety at S3 and women frequently visited medical practitioners, did not hold a Health Care card were more likely to subsequently be admitted to a NSW hospital at least once. Marital status was also influential.

For the olds, none of the logistic regression models were a good fit to the data. However, some factors that had some influence were alcohol status at S3, marital status, Veterans' Affairs, private health insurance (ancillary services), visits to medical practitioners, asthma, depression, anxiety, been injured as the result of a fall, arthritis and heart problems.

For both cohorts, the average cost to NSW hospitals of women with arthritis was higher than that of women without. Knee and hip procedures were in the top 10 most expensive ARDRGs for each cohort.

APDC records of joint replacement (mids) and knee and hip surgery (olds) were compared against participants reporting of these operations in the previous 3 years. Agreement was good with kappas around 0.7 for each survey and each cohort. The agreement is likely to be greater as some women who do not appear in the APDC records live close to the NSW border. A number of procedures declared as being in the past 3 years were undertaken over 3 years age, generally in the past 4 years. A number of women failed to declare procedures that clearly met the relevant definition and were in the past 3 years.

Cardiovascular disease:

Cardiovascular diseases (CVDs) include diseases of the heart, vascular diseases of the brain and diseases of blood vessels. Risk factors such as high blood pressure, high blood glucose, tobacco use and physical inactivity, are responsible for raising the risk of heart disease, diabetes and stroke all of which are predisposing factors for CVD. Analysis based on ALSWH survey data have been conducted to compare socio-demographic and health-related differences between groups of women in each of the 1921-26 and 1946-51 cohorts, who have self-reported CVD. (See also A279A).

We have also undertaken an agreement study in which we have compared self-reported CVD-related conditions and risk factors (diabetes, hypertension, heart disease and stroke) in the mid and older aged ALSWH cohorts with APDC records (2004-2008). Prevalence, agreement (kappa) and sensitivity were calculated. We found substantial agreement for diabetes (k=0.75 and 0.77 for the mid and older-aged women respectively), moderate agreement for heart disease (k=0.55 and 0.41), and fair agreement for hypertension (k=0.35 and 0.21) and stroke (k=0.39 for both cohorts). Agreement for diabetes, stroke and heart disease in the mid-aged cohort improved when we adjusted for prevalence. Sensitivities ranged from 66.7% for stroke to over 80% for diabetes, hypertension and heart disease in the mid-aged cohort and from 69.6% for stroke to 70-80% for diabetes and heart disease in the older cohort. A major strength of the study was the fact that the longitudinal ALSWH data made it possible to measure cases according to responses at Survey 5 and also according to responses at Surveys 1 to 5 inclusive. Sensitivities increased (particularly in the older-aged cohort) when self-report cases included the five survey time points. Cases in the APDC were also defined in two ways, for all admissions and for admissions excluding day only patients. The women in the older-aged cohort were equally likely to have chronic conditions recorded on their hospital discharge records, regardless of admission type (i.e. day-only or overnight). However the mid-aged women were less likely to have diabetes and hypertension recorded on their hospital discharge record if they have been admitted as a day-only patients.

We undertook logistic regression analysis of the association between socio-demographic characteristics and agreement for each of the four diagnosed conditions (diabetes, hypertension, heart disease and stroke) in each cohort of ALSWH women. There was significant positive association between agreement and education for heart disease in mid-aged women.

Our study showed that the reliability of self-report survey data can be measured using a number of methods that can be usefully applied for different purposes. For example, measuring the prevalence of chronic conditions at more than one survey time point increases the sensitivity of self-report when compared with hospital medical records. Hospital medical records with well-defined diagnostic criteria for illnesses that have frequent interactions with the health care system have the highest agreement with self-report. Prevalence, case definitions, record capture, data linkage and choice of reference groups all impact upon how we measure and interpret the reliability of population-based survey data.

2012 research outcomes:

- Agreement between Self-report of Cardiovascular Disease and Related Diagnoses in Hospital Records *Australasian Epidemiological Association Conference* Perth 19-21 Sept 2011
- Parkinson L, Curryer C, Gibberd A, Cunich M, Byles J. Agreement between self-reported arthritis related surgeries and centralised hospitalisations data Journal of Clinical Epidemiology (under review)
- Two papers are in preparation.

Project: A256B	**Policy pathways to reduce the burden of illness and costs of diabetes and hypertension in Australian women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Jennifer Stewart-Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Chris Doran (School of Medicine and Public Health, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Michelle Cunich (School of Public Health, University of Sydney) • Tina Navin (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Dr Dominique Cadilhac (Melbourne Brain Centre, National Stroke Research Institute) • Dr Kerry Inder (School of Medicine and Public Health, The University of Newcastle) • Professor Christopher Levi (Acute Stroke Services, Hunter New England Health) • Dr Dennis Petrie (Economic Studies, The University of Dundee)

	• Dr Rodney Ling (School of Medicine and Public Health, The University of Newcastle) • Dr Andrew Searles (School of Medicine and Public Health- The University of Newcastle)

This body of work involves comparing the health and social characteristics of groups of mid-and older-aged ALSWH women who reported having cardiovascular-related conditions, such as diabetes and hypertension, in their surveys. Analyses of ALSWH records individually linked to the NSW Admitted Patient Data Collection are being undertaken to assess patterns of health service use in these women. Specifically we are investigating the socio-demographic and health characteristics, health behaviours and health service use and costs of mid-aged Australian women with and without self-reported diabetes. A manuscript on this work will be submitted to a journal by 31 December 2012.

Project: A360	**Predictors of mental health services utilization and costs for Australian women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Catherine D'Este (School of Medicine and Public Health, The University of Newcastle)

The aim of this research is to investigate the impact and utilisation of the 'Better Access Scheme' on health services among Australian women with mental health conditions. The research has begun in-depth analysis on the differing social, economic and health characteristics for women with mental health conditions who do and do not use the 'Better Access Scheme'. The project at present is using the Behavioural Model(Andersen/Newman) amongst the three age cohorts of women from the ALSWH to predict access of the BAS services. Women are grouped as early adopters, late adopters, non-users of the BAS services and a baseline group. The project aims to identify and describe characteristics of the groups of women associated to use of the BAS and compare any difference between relationships among the three components (predisposing, enabling and need) in the Behavioural Model for each age cohort.

2012 research outcomes:

- A poster was presented at the 2012 Public Health Congress in Adelaide.

Project: A415	**Proton pump inhibitor use and subsequent prescribing of anti-osteoporosis medication.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland)

	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Susan Tett (School of Pharmacy, The University of Queensland)

A Masters student, Marielle van der Hoorn from VU University Amsterdam, The Netherlands, joined the project in October 2012. This project will serve as Marielle's Masters thesis and a paper is expected to be ready for submission as the end of her six month internship (March 31, 2013). Analyses are currently at the stage of data preparation.

Project: A417	**Changes in use of osteoporosis medication over the past decade: influence of guidelines, availability and policy.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Susan Tett (School of Pharmacy, The University of Queensland) • Dr Emma Duncan (Department of Endocrinology, Royal Brisbane and Women's Hospital)

Dr Emma Duncan from the UQ Diamantina Institute for Cancer, Immunology and Metabolic Medicine at the Princess Alexandra Hospital joined the project this year. Analyses for this project have been completed and writing is in progress. A first draft of a paper has been completed and is currently being circulated among co-authors for revision. We expect to submit the paper early 2013 for publication in a peer review journal.

1.2.3 Preventive health

Project: A362A	**Do breastfeeding women adhere to guidelines?**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Annette Dobson (School of Population Health, The University of Queensland)

	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland)

The proposed project will describe adherence to health behaviour guidelines for breastfeeding women. Guidelines vary considerably. Smoking guidelines are straightforward: do not smoke. However alcohol guidelines have changed over the duration of the study, from drink only small amounts of alcohol in the 2001 guidelines to not drinking is the safest option in 2009. Dietary guidelines are complex and involve five different food groups. In comparison, physical activity guidelines are simpler and advise that half an hour a day of physical activity on at least five days a week is recommended. Analyses are in progress.

Project: A362A	**Do breastfeeding women adhere to guidelines?**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland)

This project investigated what proportion of women breastfed their children to six months, one year or two years, and what factors related to breastfeeding. We found only three out of five children received breast milk for the first six months of their life. Less than one in three infants were breastfed for a year and less than 3% were breastfed for two years. Women were less likely to breastfeed to sixmonths if they were young, unmarried, less educated or had difficulty managing on their available income. A manuscript is under consideration for publication.

Project: A364A	**Do pregnant women adhere to behaviour guidelines?**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland)

The aims of this project are to describe adherence to behaviour guidelines by pregnant women at the 2003 and 2009 surveys, and describe who adheres and to which guidelines. The smoking guideline has consistently been do not smoke, however the drinking guidelines changed from drinking a small amount of alcohol in 2003 to not drinking is the safest option in 2009. Dietary guidelines cover five groups and women will only be considered adherent if they follow all the guidelines. Pregnant women should also exercise for about half an hour on five days of the week to fulfil the physical activity guidelines. Analyses are in progress.

Project: A364B	**Do young women adhere to behaviour guidelines?**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland)

The purpose of this study is to discover how women behave with regard to smoking, drinking, eating and exercising when pregnant, breastfeeding and neither pregnant or breastfeeding. In addition we will describe the patterns of adherence to these behaviour guidelines for each group of women. We will investigate differences in adherence to the different guidelines and whether one group is more or less adherent than the others. Analyses are progressing.

Project: A388	**Adherence to screening guidelines for mid-age women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Lucy Leigh (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle)

In Surveys 4, 5, and 6, participants in the 1945-51 cohort were asked if they had preventive health checks including blood pressure, cholesterol, blood sugar, mammography, pap test, bowel cancer screen. This study involves cross-sectional and longitudinal analyses of factors associated with these checks including demographic factors such as area of residence, highest education level attained, marital status, employment status; health care factors (private health insurance, health care concession status, frequency of GP visits, attending the same GP and GP practice, and whether the GP sent a reminder for health checks to be conducted); Health related factors including self-rated health, health conditions (diabetes, heart disease, hypertension, breast cancer, cervical cancer, skin cancer, chronic lung conditions), health behaviours (HRT, smoking status, BMI).

Apart from blood pressure checks, it appears that many women do not adhere to the full range of guidelines for screening procedures and routine health checks. However, rates for mammographic screening did increase over time, as women moved into the target age ranges for this test, with over 80% of women being screened within the recommended two year interval at the time of Survey 6. Cholesterol screening also increased over time and as the women aged, and Pap test coverage remained at around 80%.

Blood sugar checks and cholesterol were far more likely to be reported by women who also report having hypertension, diabetes or heart disease. This may suggest that these procedures are more commonly being undertaken to monitor existing conditions rather than to screen for previously undiagnosed conditions or as preventive procedures. However, it is also possible that some of this association is due to case finding on routine testing.

Project: A366	**Change in dietary guideline compliance in Australian middle-aged women**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Danielle Schoenaker (School of Population Health, The University of Queensland) • Johanna Rienks (The University of Wageningen, The Netherlands) • Liset Elstgeest (The University of Wageningen, The Netherlands)

Results from this project were reported in the study's major report for 2012, Adherence to health guidelines: Findings from the Australian Longitudinal Study on Women's Health. A manuscript that describes the diet of women who do not adhere to the food based dietary guideline is in preparation to be submitted by January 2013.

2012 research outcomes:

- Oral presentation at the 2012 Public Health Association of Australia Congress in Adelaide.

Project: A367	**Adherence to dietary guidelines in young Australian women over a six year period.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Danielle Schoenaker (School of Population Health, The University of Queensland) • Johanna Rienks (The University of Wageningen, The Netherlands) • Liset Elstgeest (The University of Wageningen, The Netherlands)

Results from this project were reported in the study's major report for 2012, *Adherence to health guidelines: Findings from the Australian Longitudinal Study on Women's Health*. A manuscript that describes the diet of pregnant women who do not adhere to the food based dietary guideline is in preparation to be submitted by January 2013. The manuscript is lead by Danielle Schoenaker.

2012 research outcomes:

- Oral presentation at the 2012 Public Health Association of Australia Congress in Adelaide.

1.2.4 Mental health

Project: A271A	**Dietary zinc intake, incident type 2 diabetes and depression in Australian women.**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Mark McEvoy (School of Medicine and Public Health, The University of Newcastle) • Dr Zumin Shi (Department of Health, Government of South Australia) • Dr Milton Hasnat (School of Medicine and Public Health, The University of Newcastle) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Dr Amanda Patterson (School of Health Sciences, The University of Newcastle) • Professor John Attia (School of Medicine and Public Health, The University of Newcastle) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Khanrim Vashum (The University of Newcastle) • Dr Rafiqul Islam (The University of Newcastle)

The primary aim of this project was to analyse measures of dietary zinc intake and dietary zinc to iron ratio in a random community based sample of women aged 45 to 50 years and determine if low zinc intake is associated with self-report incident type-2 diabetes and incident depression using CESD. A

manuscript regarding dietary zinc intake and it's association with type-2 diabetes has been prepared and is currently under review in PLOS one. The analysis for the depression component of the project is ongoing and this will be written as a manuscript that will be submitted to the *Journal of Affective* disorders.

Project: A359	**Late life decline in mental health: patterns, predictors and perspectives from older Australian women.**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Nancy Pachana (School of Psychology, The University of Queensland) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Lucy Leigh (Research Centre for Gender, Health and Ageing, The University of Newcastle)

The overall aim of this study is to gain understanding of changes in mental health as women age, and particularly the phenomenon of late life decline in mental health. We will analyse 17 years of prospective data from a large cohort of women across to determine patterns of change in mental health scores, and particularly the proportions of women who experience late life decline in mental health and the rate of decline in mental health scores. We will also study how mental health scores change during the years prior to death at different ages, as well as the sociodemographic, behavioural and health-related factors that are associated with different patterns of change.

The women's own views on the changes affecting their lives and mental well-being will be further examined through analysis of extensive qualitative data provided by the women at each survey.

We are currently analysing scores for women who have died, and particularly the relationship between mental health scores on the last survey they completed and the time to death. These analyses show a slightly negative slope with lower scores for women with shorter times between surveys and death. Further analysis of longitudinal data is underway to identify women with different patterns of decline in mental health and factors associated with different late life trajectories.

Some early data will be included in the study's major report for 2013.

Project: A421	**The role of sleeping difficulties in the subsequent development of depression and anxiety in young women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Melinda Jackson (Victoria University) • Professor Dorothy Bruck (School of Psychology, Victoria University) • A/Professor Neil Diamond (Victoria University) • Dr Ewa Sztendur (Victoria University)

Sleep disturbance and depression are more common in women than men. Sleeping difficulties such as insomnia have been associated with the development of depression and anxiety later in life in both young and older age groups of both genders. This project is examining the possible predictive relationship between sleeping difficulties and subsequent depression and anxiety across a 9 year follow up period in the young women cohort. A secondary aim of the study is to examine the prevalence of sleeping difficulty, depression and anxiety in young women over time, and the potential bidirectional relationship between sleep disturbance and mental health.

To date we have completed longitudinal analyses that involved calculation of prevalence ratios for diagnosis of depression, anxiety and sleep disturbance. The results indicate that depression rates have increased from survey to survey as too has the prevalence of sleep disturbance. However, the prevalence of episodes of anxiety has remained stable over the nine years, between Survey 2 and Survey 5. Generalised Linear Models have shown that women who were not diagnosed with depression or episodes of depression prior to Survey 2 were more likely to be diagnosed with depression atS 3, 4 and 5 if they had sleeping difficulties at Survey 2. This work will be extended to control for relevant covariates. We will also examine biodirectionality between sleeping difficulties and depression/anxiety using transition models.

Project: A308	**Life Control Scale**
Investigator:	• Professor Christina Lee (School of Psychology, The University of Queensland)

This project examines the role of Perceived Life Control in women's health. Progress to date has involved a cross-sectioal analysis of Survey 5 data from the Mid-age Cohort, showing that perceived control is significantly related to a range of measures of physical and mental health, including health service use (GP visits, Pap tests, mammography); physical health (major diagnoses, number of symptoms), health behaviours (smoking, physical activity, BMI), SF-36 (PCS and MCS), and psychological health (depression, anxiety and stress).

Mediation analysis indicates that Perceived Life Control significantly mediates socioeconomic gradients on all of these variables. The next phase of the project is to begin longitudinal analyses.

2012 research outcomes:

- Lee, C. (2012, August). Life Control mediates social gradients in health and wellbeing among middle-aged Australian women. Paper presented at the 12th International Congress of Behavioral Medicine, Budapest.
- Lee, C. (2012, October). Life control mediates social gradients in health and wellbeing among middle-aged Australian women. Paper presented at the 7th World Conference on the Promotion of Mental Health and the Prevention of Mental and Behavioural Disorders, Perth.

Project: A331A	**Emerging Adulthood, Life Transitions, and Wellbeing**
Collaborative Investigators:	• Professor Christina Lee (School of Psychology, The University of Queensland) • Dr Libby Holden (School of Population Health, The University of Queensland)

This project, funded by an ARC Discovery grant to Professor Christina Lee, examines trajectories of demographic change and emotional wellbeing amongst young Australian women.

Two sets of analyses are currently in progress:

1. Trajectories of emotional wellbeing (as indicated by Mental Health Index from SF-36) have been compared across groups categorised according to the Survey at which participants first reported having had a baby. Analyses show that women who had their first child by Survey 2, 3, 4 or 5 showed similar, and upward, trajectories of wellbeing over time; those who had had their first child before Survey 1, and those who have not (yet) given birth have poorer mental health and show less improvement over time.

2. Cross-sectional correlates of wellbeing (indicated by CESD scores) have been examined at Survey 2 and Survey 5. Similarities and differences in correlates are in the process of being explored.

2012 research outcomes:

- Holden. L., & Lee, C. (2012, October). Correlates of depression: Do they change with life stage? Paper presented at the 7th World Conference on the Promotion of Mental Health and the prevention of Mental and Behavioural Disorders.

Project: A377	**Suicidal ideation and suicide attempts in women providing unpaid care**
Collaborative Investigators:	• Siobhan O'Dwyer (School of Human Movements Studies, The University of Queensland) • Professor Wendy Moyle (Research Centre for Clinical & Community Practice Innovation, Griffith University) • Dr Susan Barrett (Griffith Health Institute, Griffith University) • Professor Nancy Pachana (School of Psychology, The University of Queensland)

The analysis of this data has been conducted and a manuscript is being prepared for publication. *2012 research outcomes*:

- A presentation was given at the International Meeting of the International Psychogeriatrics Association in Cairns in September 2012.

Project: A047	**Analyses of women's use of counselling services in the Mid cohort using Mid 1, 2 and 3 data.**
Collaborative Investigators:	• Professor Margot Schofield (School of Public Health, LaTrobe University) • Dr Asad Khan (School of Health and Rehabilitation, The University of Queensland)

This project examines associations between mental health indicators and consultations by Australian women with counsellors, psychologists or social workers over the past year.

Previous work on this project found that only 6.9% of women who participated in Survey 3 (2001) had consulted a Counsellor/Psychologist/Social Worker in the past year, with rates increasing significantly

among women with increasing levels of poor mental health: 18% of those diagnosed with anxiety, 24% diagnosed with depression, and 41% among those diagnosed with both anxiety and depression. Multivariable analysis showed that the odds of having counselling increased with the number of mental health diagnoses and decreasing SF-36 mental health scores. Women with both anxiety and depression diagnoses were seven times more likely to seek counselling in the past year compared to women with no diagnoses, and twice as likely as those with a single diagnosis.

The research will now be extended to include more recent surveys of the 1946-51 cohort. The third paper on mental health profiles of women who have sought counselling is being modfied to include longitudinal data as agreed in the MOU. It will be submitted to a journal in early 2013.

Project: A102A	**Use of medication for psychiatric disorders amongst mid-age women.**
Collaborative Investigators:	• Professor Margot Schofield (LaTrobe University) • Dr Asad Khan (School of Health and Rehabilitation Studies, The University of Queensland)

This project aims to predict change in self-reported use of medications over a three year period among mid-aged Australian women for each of four conditions: depression, anxiety, stress, and to help sleep. Data were drawn from the ALSWH third and fourth mail survey of 11,201 mid-aged women aged 50–55 (Survey 3) and 53-58 (Survey 4). Medication use was assessed by asking whether they had taken any medications over the past four weeks for: depression, nerves/anxiety/worries, stress (difficulty coping), and to help them sleep. Mental health was measured in two ways: self-reports of having been diagnosed in the last three years with anxiety, depression, or both anxiety and depression; the SF-36 MCS measuring mental health over the past four weeks. A range of demographic, health behaviour, mental and physical health, and health service use variables were also measured. Generalised estimating equation (GEE) analysis was undertaken to predict use of medication for each of the four health conditions at Survey 4, using 18 potentially explanatory health and socio-demographic variables as well as time.

Results: Medication use increased for each of the four health conditions from 2001 to 2004, with around 9% taking medication for depression, anxiety, and sleep in 2004, compared with 7-8% in 2001. Around 5% took medication for stress in 2001, and 5.7% in 2004. In all four GEE models, medication use significantly increased from 2001 to 2004. Other significant predictors of medication use in 2004 in all models included: mental health diagnoses in last three years, MCS, PCS, and use of counselling. A number of health and demographic variables were differentially predictive for specific types of medication use.

Conclusions: The strongest predictors of medication use for depression, anxiety, stress and sleep conditions were mental health status and use of counseling services, supporting the view that medication use is accurately targeted to those most in need. This is further supported by a finding of strong dose-response relationships and discriminating findings by type of disorder.

Analysis on the first paper has been completed, the paper is in preparation and is expected to be submitted for publication end of 2012.

Project: A281	**Precipitation over time and associated changes in women's health**
Collaborative Investigators:	• Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Anna Graves (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Hockey (School of Population Health, The University of Queensland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland)

A paper has been completed which showed a steady improvement in mental health for women in the mid-aged cohort, that was unaffected by periods of drought or prolonged dryness. The paper is now being submitted for publication.

Project: A302	**Chocolate and health**
Collaborative Investigators:	• Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Richard Hockey (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Samantha McKenzie (School of Population Health, The University of Queensland) • Janni Leung (School of Population Health, The University of Queensland) • A/Professor Geoff Marks (School of Population Health, The University of Queensland)

Analyses showed that more frequent and higher quantity of chocolate consumption was associated with stressed and depressed mood in women. We propose to publish these results in an appropriate peer reviewed journal.

2012 research outcomes:

- A paper, 'Chocolate and depression in 1946-51 cohort women', has been submitted to *Appetite.*

Project: A314	**Changes in SF-36 among the 1946-51 cohort**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Professor Nancy Pachana (School of Psychology, The University of Queensland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • David Fitzgerald (School of Population Health, The University of Queensland) • Richard Hockey (School of Population Health, The University of Queensland) • Dr Graciela Muniz-Terrera (MRC Biostatistics Unit, University of Cambridge)

All statistical analyses for this paper have been completed. Results on the mental health and menopausal transition will inform the study's major report for 2013.

Project: A151a	**Examining health risks across sexual identity groups**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Ruth McNair (Department of General Practice, The University of Melbourne) • Professor Tonda Hughes (College of Nursing, University of Illinois) • A/Professor Laura Szalacha (College of Nursing, University of Illinois) • Professor Sharon Wilsnack (Department of Clinical Neuroscience, University of North Dakota)

Our primary aim was to examine and compare prevalence rates of health status indicators (i.e., depression, anxiety, BMI, self rated health, abuse, stressful life events), and health risk behaviors (i.e., smoking, alcohol use, and illegal drug use), and barriers to health care (i.e., regular source of medical care, use of counselling, access to health care, satisfaction with health care provider) among women in five sexual identity categories (only heterosexual, mostly heterosexual, bisexual, mostly lesbian, only lesbian) to determine which groups are at greatest health risk.

We have completed these analyses of Survey 3 of th e1973-78 cohort, published two papers and submitted a third paper for publication. The findings confirm significant health inequalities for all

sexual minority women compared with heterosexual women, which have not been reported previously from Australian population-based data. A summary of these differences:

- Higher use of health services (apart from reproductive services)
- Lower continuity of care and satisfaction
- Higher levels of at-risk drinking & binge drinking and illicit drug use (stress the main predictor)
- Higher rates of anxiety & depression
- More experiences of violence
- More likely to experience suicidality

These findings are consistent with those from international studies conducted in USA, Canada, the Netherlands and UK.

We also found important differences across the sexual minority sub-groups. In brief, lesbian women were more likely to have:

- Lower levels of pap screening, but least likely to have abnormal pap
- Higher levels of dissatisfaction with health services
- Higher levels of binge drinking
- More severe physical abuse and sexual abuse

Bisexual and mainly heterosexual women had:

- Lowest levels of general health
- Higher rates of abnormal paps, STIs, Hep B, Hep C, UTIs
- Higher rates of asthma
- Higher levels of illicit drug use and harmful drinking
- Higher rates of suicidal ideation & self harm
- More experiences of all forms of violence, re-victimisation
- More disordered eating patterns
- Higher rates of depression and anxiety

Several questions arise from these findings that would benefit from empirical research in the future:

- Why do sexual minority women have higher rates of childhood abuse
- Direction of effect – substance use connected with mental health
- Sexual orientation-based discrimination – types, risks, impact
- What characteristics distinguish women who identitfy as mainly heterosexual (from those who identify as exclusively heterosexual or bisexual)
- Cancer prevalence and risk factors
    - Protective factors beyond social support

Policy implications of these findings include:

- Health policies should include specific mention of diverse sexual orientation and gender identity – (e.g. National women's health policy 2010 - now includes lesbian and bisexual women as a specific at-risk group)

- Healthcare provider training should include competencies for sexual minority sub-groups (e.g. headspaces national training in SSAGQY mental health 2011)
- Data collection –should include sexual orientation measures in representative datasets (e.g. 2010 National Drug Strategy Household Survey – 2.2% respondents were gay, lesbian or bisexual (GLB)

A secondary aim of the project was to examine changes in sexual identity at two time points and to determine whether changes in sexual identity are associated with changes in health risk and changes to health care access. We determined that approximately 10% of women changed their sexual identity selection between the Young survey 2 and 3, and that these changes occurred in any direction. We have not conducted analyses that examine associations between changes in identity and changes in health risk.

We have not conducted analyses of the mid surveys, however Ruth McNair is now involved in another research team (led by Rhonda Brown) that is analysing the mid cohort with regard to cancer risk factors and cancer prevelance.

We made the decision not to analyze changes to health risks associated with change in sexual identity given the short time span (three years between time points in which sexual identity was assessed). We determined that this time frame is likely too short to expect substantial changes in sexual identity to occur.

We had planned to compare the ALSWH findings with those from two U.S. longitudinal studies: the Chicago Health and Life Experiences of Women study (CHLEW - lead researcher Prof Hughes), and the National Study of Health and Life Experiences of Women (NSHLEW - lead researcher Prof Wilsnack). Although we have described similarities and differences in findings across these studies we have not conducted statistical analyses to formally compare data in the ALSWH, CHLEW and NSHLEW.

2012 research outcomes:

- November 2012 - Hughes, T.L. Social determinants of mental health among sexual minority women. Georgia Health Sciences University. Augusta, GA.
- October 2012 - Hughes, T.L. Mental Health Disparities among Sexual Minority Women. Grand Rounds presentation. New York Psychiatric Institute and Columbia University. New York City, New York.
- May 2012 - Hughes, T.L. Social determinants of sexual minority women's health: From invisibility to advocacy and empowerment. Center for Global Women's Health Inaugural Symposium, Empowerment, Safety, and Health: A Global Mandate for Women and Girls. University of Pennsylvania, School of Nursing. Philadelphia, PA.
- January 2012 - Lesbian health research forum, The University of Melbourne.

  a) Dr McNair - Lesbian and bisexual women's health – summary of inequalities and policy implications

  b) Hughes - Substance abuse and mental health disparities among sexual minority women: the potential role of victimisation.

- Dr McNair presents a lesbian, bisexual gay and transgender health talk three times per year within the sexual and reproductive professional development course at Family Planning Victoria. She includes data from the ALSWH study.

1.2.5 Ageing

Project: A260	**Trends in health related quality of life of women in their 70's and 80's**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Gibson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Professor Annette Dobson (School of Population Health, The University of Queensland)

This study assesses factors associated with survival and maintenance of physical well-being among a large cohort of women, and explores physical, social, and health care factors that distinguish women who live long and well. At Survey 1 in 1996, 26% of the women in the 1921-26 cohort described themselves as being in very good or excellent health, and 39% described their health as "good". Across five surveys, there has been increasing incidence of conditions such as arthritis, heart disease and diabetes, and a marked decline in physical health scores for the cohort, as measured by Short Form (SF-36) health related quality of life sub-scales. However, while average scores declined, a large proportion of the women experienced minimal change in physical health scores over the 12 years. Using latent profile analysis, we identified four main patterns in the scores among those who survived and stayed in the study at Survey 5: 1) Consistently high scores showing relatively stable high scores up to Survey 3 followed by a slow decline between Survey 3 and Survey 5 (61% of women); 2) Declining scores, showing high scores at Survey 1 falling to low scores by Survey 3 (11% of women); 3) Consistently low scores, showing low scores at Survey 1 and onwards (25% of women); and 4) Increasing scores, showing low scores at Survey 1 rising to high scores by Survey 2 (3% of women.) Factors associated with maintaining high physical function scores included clinical diagnoses, healthy weight, and a range of social, behavioural and health care factors. Women were more likely to have declining scores (Class2), consistently low scores (Class 3), or increasing scores (Class 4) if they were older and if they had lower education, and were more likely to have low scores (Class 3) if they were widowed. Findings emphasise the importance of maintaining healthy weight and physical activity, and not smoking. After adjustment for age, arthritis, heart disease, diabetes, stroke, bronchitis/emphysema/asthma and falls were all associated with not having consistently high scores. Comparison across groups showed continuously low scores (Class 3) were most likely in participants reporting arthritis, heart disease, stroke, bronchitis/emphysema/asthma, or falls. Continuously low or declining scores, were more likely if participants reported foot problems, vision problems, incontinence, or back pain. Hip and knee surgery were associated with consistently low scores, declining scores and increasing.

A paper is in preparation and Professor Gita Mishra has been asked to give expert feedback prior to submission to a high impact journal.

Project: A288	**Incontinence in older women: Impact on QOL and social functioning**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Peta Forder (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Pauline Chiarelli (Discipline of Physiotherapy, The University of Newcastle) • Janet Sansoni (Centre for Health Service Development, University of Wollongong) • Nick Marosszeky (Centre for Health Service Development, University of Wollongong) • A/Professor Graeme Hawthorne (Department of Psychiatry, The University of Melbourne) • Tazeen Majeed (Research Centre for Gender, Health and Ageing, The University of Newcastle)

While the causes of incontinence are largely physiological, the condition itself is often defined in terms of tits social impact. For example, a recent definition published by the International Continence Society describes incontinence as “accidental or involuntary loss of urine from bladder which is a social or hygienic problem”. Likewise , a large body of research from all over the world presents evidence that urinary incontinence is associated with problems in self-esteem, loneliness, psychological distress, poor life satisfaction, social isolation and low mental health-related quality of life. However, these studies are largely cross-sectional with few studies investigating the temporal sequence between incontinence and the associated physical and social limitations.

Although incontinence is a potentially socially debilitating condition, much of its impact on social settings may be due to the presence of coincident conditions or co-morbidities. Almost all of incontinence types are associated with presence of co-existing and chronic health problems that are common among older people e.g. diabetes, chronic coughing (linked to asthma, bronchitis, smoking), constipation, obesity, Parkinson’s disease, Alzheimer’s disease, neurological disorders, stroke , eye sight problems, dementia, or mobility problems. These co-existing or causative factors may also negatively impact the social and physical functioning for these women and would therefore confound the association between incontinence and social function.

This study will investigates longitudinal associations between continence status at each survey and quality of life (particularly social functioning as measured by the SF-36 social function scales). Associations between incontinence and participation in other roles (such as marital status, caring, grandparenting, volunteering, physical and leisure activities) are also be explored. Analyses have been completed, including data from Survey 6, and manuscript preparation is in progress.

Project: A384	**Salutogenesis and trajectories of ageing.**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Cassie Curryer (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Meredith Tavener (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Lucy Leigh (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This qualitative study follows previous research from the ALSWH that identified differing trajectories of ageing and health related improvement or decline in older women born between 1921- 1926. The study seeks to explore these different trajectories of ageing and women's narratives surrounding ageing and health, and to assess these themes against theories of salutogenesis (SOC) and ageing in older women. Salutogenesis theory holds that those with high sense of coherence (SOC) will have more positive physical and mental health outcomes and hence, will experience ageing more positively compared to those with low levels of sense of coherence (SOC). Data are currently being analysed and coded within the N-Vivo program. Preliminary analyses indicate some clear differences in attitude and outlook between women with different patterns of self-rated health.

2012 research outcomes:

- Sir Keith Wilson Oration, '2012 Ageing Odyssey. It's all about the Journey'. *South Australia Gerontology Conference 2012.* 14 September 2012. National Wine Centre, Adelaide.

Project: A248A	**Words women use: An exploration of the effects of ageing on language in Australian women**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Elizabeth Spencer (School of Humanities & Social Sciences, The University of Newcastle) • Professor Hugh Craig (School of Humanities & Social Sciences, The University of Newcastle) • A/Professor Alison Ferguson (School of Humanities & Social Sciences, The University of Newcastle) • Kim Colyvas (School of Mathematical & Physical Sciences, The University of Newcastle) • Bill Pascoe (The University of Newcastle) • Megan Vile (The University of Newcastle)

Plans are currently underway to alter the research plan as follows:

1. Request data access to the following categories

- Reported history of stroke (in view of its potential as a indicator of relevant health/cognitive status in relation to language function)
- We have also sought data as to the use of a proxy to complete the form (for the old cohort), in order to be able to exclude proxy written comments from the linguistic data.

2. Alter linguistic analyses (measures as dependent variables):

- Flesch-Kincaid Grade Levels

The analysis to be used by honours student, Megan Vile, *Systemic Functional Linguistic analysis of Transitivity, Modality and 'Theme',* will also be added. (Note that in this linguistic analysis 'Theme' involves analysis of Rhetorical Structure and salience, i.e. it identifies the way language users move important information to the start of sentences. It is a grammatical analysis, not a content analysis.)

2012 research outcomes:

- Spencer E, Ferguson A, Craig H, & Colyvas K. (2012). Language and ageing: Using propositional density as a measure over time. Poster presented at the *International Clinical Linguistics & Phonetics conference*, Cork, Ireland, June 27-30.
- Spencer E, & Ferguson A, & Craig H. (2012). Language and life stages. Paper presented at the *Digital Humanities Australasia 2012 conference*, Canberra, March 28-30.
- Spencer E, Craig H, Ferguson A, & Colyvas K. (2012). Language and ageing – exploring propositional density in written language – stability over time. Clinical Linguistics & Phonetics, 26 (9), 743-754.

1.2.6 Caring

Project: A328	**Can we recognise women's experiences of caregiving as a 'community practice'?**
Collaborative Investigators:	• Dr Leigh Tooth (School of Population Health, The University of Queensland) • Dr Meredith Tavener (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland) • Dr Samantha McKenzie (School of Population Health, The University of Queensland)

Providing informal care can represent an unexpected, and often unappreciated, vocation - particularly for women, who continue to provide the majority of care. The current research provides a fresh perspective on caregiving and examines the extent to which caregivers involve themselves in 'communities of practice' - groups of people who share a concern or passion for something they do, a commitment to that domain and a shared competence that distinguishes them from other people. This research explored 146 free-text comments written by women aged between 56 to 61 years, who provided care, for evidence of whether they involved themselves in 'communities of practice'. A thematic analysis explored three dimensions of communities of practice: (a) 'what it's about' i.e., evidence of a joint enterprise which is continually renegotiated by its members; (b) 'how it functions' i.e., recognition of associations which bind members together and (c) 'what capability it has produced' i.e., presence of shared repertoires which members develop over time.

This work has been submitted for consideration for an oral presentation at the Community, Work and Family Conference, in Sydney 17-19 July 2013. A paper is also currently being finalised for submission to a peer-reviewed journal.

Project: A303A	**Influence of socio-economic position on transitions in caring over 15 years for women born 1946-51 and 1973-78.**
Collaborative Investigators:	• Dr Leigh Tooth (School of Population Health, The University of Queensland) • Richard Hockey (School of Population Health, The

	University of Queensland) • Professor Christina Lee (School of Psychology, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland)

An application to ARC for funding in the 2013 round has been made. In the interim, preliminary analyses have begun. A paper is planned for submission by the end of 2012 which aims to describe trajectories of caring over 12 years by the younger and mid-aged ALSWH women, and to determine the demographic, socioeconomic and lifestyle factors that are associated with these trajectories.

1.2.7 Reproductive health

Project: A297	**Uptake of permanent or long-acting methods of contraception among Australian women**
ALSWH Liaison:	• A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland)
Collaborative Investigators:	• Dr Danielle Herbert (School of Population Health, The University of Queensland) • Suzanne Dixon (UQ Centre for Clinical Research, The University of Queensland)

At the last update we reported that there was inadequate uptake of novel contraceptive methods in the cohort so far to allow us to analyse the data in a useful way. We intend to postpone the examination of novel methods until data from a subsequent survey is available. However, we have been able to examine the uptake of permanent and long-acting methods in comparison with traditional methods of contraception.

An abstract has been submitted to the 12th National Rural Health Conference.

Authors: Jayne Lucke & Danielle Herbert

Title: Area of residence is associated with Australian women's uptake of long-acting contraception

Aims: This project examines uptake of permanent or long-acting reversible contraception (LARCs) among Australian women in rural areas compared to women in urban areas.

Method: Participants in the Australian Longitudinal Study on Women's Health born in 1973-78 reported on their contraceptive use at three surveys between 2003 and 2009. Contraceptive methods included permanent sterilisation (tubal ligation, vasectomy), non-daily or LARC methods (implant, IUD, injection, vaginal ring), and other methods including daily, barrier or "natural" methods (oral contraceptive pills, condoms, withdrawal, safe period). Sociodemographic, reproductive history and health service use factors associated with using permanent, LARC or other methods were examined using a multivariable logistic regression analysis.

Relevance: Several new types of contraception became available in Australia over the last twelve years (the implant in 2001, progestogen intra-uterine device (IUD) in 2003, and vaginal contraceptive ring in 2007). All methods of contraception (except "natural" methods and condoms) require access to health services. Permanent sterilisation and the insertion of an implant or IUD involve a surgical

procedure. Access to health professionals providing these specialised services may be more difficult in rural areas. Our study examined whether uptake of contraception types differed according to area of residence.

Results: Of 9,081 women aged 25-30 in 2003, 3% used permanent methods and 4% used LARCs. Six years later in 2009, of 8,200 women (aged 31-36), 11% used permanent methods and 9% used LARCs. The fully adjusted parsimonious regression model showed that the likelihood of a woman using LARCs and permanent methods increased with number of children. Women whose youngest child was school-age were more likely to use LARCs (OR=1.83, 95%CI 1.43-2.33) or permanent methods (OR=4.39, 95%CI 3.54-5.46) compared to women with pre-school children. Compared to women living in major cities, women in inner regional areas were more likely to use LARCs (OR=1.26, 95%CI 1.03-1.55) or permanent methods (OR=1.43, 95%CI 1.17-1.76). Women living in outer regional and remote areas were more likely than women living in cities to use LARCs (OR=1.65, 95%CI 1.31-2.08) or permanent methods (OR=1.69, 95%CI 1.43-2.14). Women with poorer access to GPs were more likely to use permanent methods (OR=1.27, 95%CI 1.07-1.52).

Conclusions: Location of residence and access to health services are important factors in women's choices about long-acting contraception in addition to the number and age of their children. There is a low level of uptake of non-daily, long-acting methods of contraception among Australian women in their mid-thirties.

At the last update we reported that there was inadequate uptake of novel contraceptive methods in the cohort so far to allow us to analyse the data in a useful way. We intend to postpone the examination of uptake of novel methods until data from a subsequent survey is available. We have refocused our current investigations to examine the uptake of permanent and long-acting methods of contraception in comparison with traditional methods. We are particularly interested in whether location of residence and access to health services are important factors.

Project: A403	**Exploring the antecedents and predictors of termination of pregnancy (TOP) in the 1973-78 cohort of ALSWH**
ALSWH Liaison:	• A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland)
Collaborative Investigators:	• Dr Angela Taft (Mother and Child Health Research, La Trobe University) • Professor Danielle Mazza (Department of General Practice, Monash University) • Paul Agius (Australian Research Centre in Sex Health and Society, La Trobe University) • Melissa Hobbs (Mother and Children's Health Research, La Trobe University) • Dr Safeera Hussainy (Center for Medicine Use and Safety, Monash University) • A/Professor Kay Stewart (Center for Medicine Use and Safety, Monash University) • Dr Kathleen McNamee (Family Planning Victoria and Sexual Health and Family Planning Australia)

Preliminary analysis is underway.

Project: A222	**Prescribed drug utilisation in women before, during and after pregnancy**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Jane Robertson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Michelle Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This project has examined prescribed drug utilisation in women before, during and after pregnancy. It has found that a large percentage of Australian women before, during and immediately after pregnancy take prescribed medications. The project has completed all analyses - findings were published in ALSWH's major report for 2009, *Reproductive health: Findings from the Australian Longitudinal Study on Women's Health,* and a paper has been submitted for peer review.

Project: A240A	**PCOS in Australian women: A chronic illness with psychological, reproductive and metabolic features**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Helena Teede (Faculty of Medicine, Monash University) • Dr Anju Joham (School of Public Health and Preventative Medicine, Monash University) • Eldho Paul (Faculty of Medicine, Monash University) • A/Professor Damian Jolley (Faculty of Medicine, Monash University) • Dr Lisa Moran (Faculty of Medicine, Monash University) • Melanie Gibson-Helm (Faculty of Medicine, Monash University) • Dr Sarah McNaughton (School of Exercise and Nutrition Sciences, Deakin University) • Sanjeeva Ranasinha (The Jean Hailes Clinical Research Unit, Monash University)

In this project, women with a self-reported diagnosis of PCOS will be compared to those not reporting PCOS in Survey 4. PCOS prevalence, the interaction with demographic features, BMI and lifestyle factors will be examined along with evaluating predictors of PCOS over the duration of the study to date. PCOS complications including fertility, GDM, T2DM, hypertension both in and outside of pregnancy and mood disturbance are being studied.

Progress to date:

<u>Prevalence and predictors of PCOS, including the impact of obesity.</u>

Manuscript submitted to Obesity is undergoing a third review.

PCOS and fertility

- Prevalence, natural history, predictors and health care utilisation
- Pregnancy rates and contraception use and requirements in Australian women with PCOS compared to a non PCOS cohort
- infertility and fertility treatments in Australia on women with PCOS

A manuscript is in final stages of preparation.

PCOS and metabolic complications

- Prevalence and predictors of glycaemic complications [gestational diabetes (GDM) and Type 2 Diabetes (T2DM)] in Australian women with PCOS
- Prevalence and predictors of hypertension (chronic and pregnancy related) in Australian women with PCOS

A manuscript is in preparation.

PCOS and psychological factors

- Mental health, depression/anxiety and use of psychotropic mediations in women with PCOS
- Health professional attendance in women with PCOS

Assessment of the relationship between diet and physical activity (Survey 5) with cross-sectional BMI and changes in BMI from Surveys 3-5 in women with and without PCOS.

Preliminary data analysis is complete and manuscript completion is anticipated by the end of 2012 with the manuscript to be submitted to peer-reviewed journals and conferences in 2013.

Project: A241	**Risk factors for emergency and non-emergency caesarean births among women in NSW**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Ian Symonds (School of Medicine and Public Health, The University of Newcastle) • Professor Kathleen Fahy (School of Nursing and Midwifery, The University of Newcastle) • Dr Jennifer Stewart Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Andrew Bisits (School of Medicine and Public Health, The University of Newcastle) • Ashleigh O/Mara (Research Centre for Gender, Health and Ageing, The University of Newcastle)

The prevalence of caesarean section is now over 30% in Australia, despite the reported risks caesarean section poses to both the mother and the baby. This project aims to identify factors that relate to subsequent caesarean births using data from the ALSWH surveys of the 1973-78 cohort and also from ALSWH data linked with the NSW Midwives Data Collection.

ALSWH data from the first five surveys of the 1973-78 cohort have been used to investigate risk factors for emergency and elective caesarean births. A paper is in progress.

ALSWH data have been successfully linked with the NSW Midwives Data Collection. These data will be used to further explore the full range of predictors of emergency and elective caesarean section.

Project: A241A	**Risk factors in childbirth interventions**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Ian Symonds (School of Medicine and Public Health, The University of Newcastle) • Professor Kathleen Fahy (School of Nursing and Midwifery, The University of Newcastle) • Dr Jennifer Stewart Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Ashleigh O/Mara (Research Centre for Gender, Health and Ageing, The University of Newcastle)

Few studies have examined differences in birth interventions by area of residence. Data from the 1973-78 cohort were used to examine differences in birth interventions between major cities and more rural and remote areas. Women living in major cities were more likely to have epidural analgesia, and an elective or emergency caesarean, but no more likely to have a prolonged labour. Differences in maternal age and private health insurance explained differences in caesarean section but not differences in epidural analgesia. A paper is in preparation.

Project: A276 & W068	**Perinatal mental health: Psychosocial assessment, service utilisation and maternal outcomes.**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Marie-Paul Austin (Perinatal and Women's Mental Health, University of New South Wales) • Nicole Reilly (Perinatal and Women's Mental Health, University of New South Wales)

	• Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Jeanette Milgrom (School of Behavioural Sciences, University of Melbourne) • Peta Forder (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Sheree Harris (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This Project aims to evaluate the impact of an early intervention approach to perinatal mental health on service utilisation and maternal health outcomes.

Specifically, the objectives of the Project are to:

1. Describe the extent of antenatal and postnatal psychosocial assessment, the content of these assessments, and the characteristics of women who are and are not assessed;

2. Evaluate the acceptability and perceived importance of perinatal psychosocial assessment to pregnant and postnatal women;

3. Evaluate the impact of perinatal mental health promotion and psychosocial assessment on health service utilisation, and maternal health outcomes;

4. Identify factors that support the health of mothers, including social inclusion factors such as the employment patterns of women having children, social support, neighbourhood and area of residence.

This study, which is being conducted in tandem with W068, will address a significant gap in the evidence-base using data from the Australian Longitudinal Study on Women's Health (ALSWH) Main Young Cohort Surveys and Project-specific sub-study survey. Financial support for the project is provided by a competitive research grant from the Bupa Foundation (2010-2012).

The Project has progressed in 2012 as planned. A series of analyses addressing Objectives 1-4 are now well underway and will continue into the first half of 2013.

Analyses relating to Objective 1 have been finalised and a manuscript prepared and submitted for peer-reviewed publication. These results showed that a large majority of women reported being asked questions about their emotional wellbeing during pregnancy (77.8%) and/or in the postnatal period (82.3%). Rates decreased markedly for reported assessment of mental health history (52.9% during pregnancy and 41.2% postnatally). Both pregnant and postnatal women were least likely to be asked about their experience of domestic violence or abuse (in total, 35.7% and 31.8%, respectively). In terms of equity of access to psychosocial assessment, maternity hospital sector exerted the strongest effect across all domains of assessment in the antenatal period. Compared with women who gave birth in the private sector, women who gave birth in the public hospital sector were two to five times more likely to report being assessed, after adjusting for other significant covariates (adjOR 2.35-5.49, $p<0.001$). These differences were less pronounced in the postnatal period. Women from non-English speaking backgrounds and women with more than one child were also at risk of not being assessed across various domains.

These results provide an important insight into the reported overall penetration of and access to perinatal psychosocial assessment among a national sample of women in Australia. Opportunities to minimise the current shortfall in assessment rates, particularly in the private sector, and for ongoing monitoring of assessment activity at a national level are discussed in the submitted manuscript (details below).

2012 research outcomes:

- Three presentations were made at the International Biennial Congress of The Marcé Society, 4 October 2012, Paris:
  - Disparities in reported psychosocial assessment during pregnancy and the postnatal period: a national survey of women in Australia
  - Adverse reproductive events and mental health and parenting outcomes.
  - Intimate partner abuse and perinatal mental health
  - These presentations took the form of a symposium titled 'Perinatal mental health in Australia: Outcomes from epidemiological and longitudinal survey based studies'.
- Loxton, D. 'Motherhood, health and the impact of psychosocial factors in high risk mothers' (Keynote speaker). St John of God Health Care Perinatal Mental Health Seminar, 'The challenges of service provision to high risk mothers and infants', 10 November 2012, Sydney.
- Reilly N, Harris S, Loxton D, Chojenta C, Forder P, Milgrom J, & Austin M-P. Disparities in reported psychosocial assessment across public and private maternity settings: A national survey of women in Australia. *BMC Public Health*. Submitted September 2012

Project: A312	**Assessing alcohol use in pregnant women using data from the Australian Longitudinal Study on Women's Health (ALSWH)**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Amy Anderson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Frances Kay-Lambkin (School of Medicine & Public Healh, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle)

The majority of Australian women report drinking some alcohol during pregnancy. The first analysis for this project, which investigated pregnant women's compliance with the 2009 NHMRC alcohol guidelines by using the 1973-1978 cohort data, found that most women (72%) were not complying with the latest national guidelines that recommend abstinence. Previous drinking behaviour was the largest predictor of whether or not women complied with the guidelines. The manuscript resulting from the analysis has been published by BMC Public Health. Further investigation into why women drink during pregnancy is currently being undertaken. Interviews with ALSWH women from the 1973-1978 cohort and focus groups with GPs will provide insight into the information about alcohol use being provided to and received by pregnant women. An understanding of what leads women to choose to consume alcohol during pregnancy will help to identify areas that need to be targeted by future interventions aiming to reduce the level of prenatal alcohol consumption.

2012 research outcomes:

- Anderson A, Hure A, Powers J, Kay-Lambkin F, Loxton D. Determinants of pregnant women's compliance with alcohol guidelines: a prospective cohort study. *BMC Public Health* 2012;12(1):777.

Project: A380	**A qualitative analysis of unplanned pregnancy and access to contraception among the 1973-78 cohort.**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland) • Dr Danielle Herbert (School of Population Health, The University of Queensland) • Suzanne Dixon (UQ Centre for Clinical Research, The University of Queensland)

"As many options as there are, there are just not enough for me": A qualitative analysis of contraceptive use and barriers to access among Australian women.

There is currently little information available about reasons for contraceptive use or non-use among young Australian women and the reasons for choosing specific types of contraceptive methods. A comprehensive life course perspective of women's experiences in using and obtaining contraceptives is lacking, particularly relating to women's perceived or physical barriers to access. This paper presents an analysis of qualitative data gathered from free-text comments provided by women born between 1973 and 1978 as part of their participation in the Australian Longitudinal Study on Women's Health. Written comments from 690 women across five surveys from 1996 (when they were aged 18-23 years) to 2009 (aged 31-36 years) were examined. Factors relating to contraceptive use and barriers to access were identified and explored using thematic analysis. Side-effects, method satisfaction, family timing, and hormonal balance were relevant to young women using contraception. Most women who commented about a specific contraceptive method wrote about the oral contraceptive pill. While many women were positive or neutral about their method, noting its convenience or non-contraceptive benefits, many others were concerned about adverse effects, affordability, method failure, and lack of choice. Negative experiences with health services, lack of information, and cost were identified as barriers to access. As the cohort aged over time, method choice, changing patterns of use, side-effects, and negative experiences with health services remained important themes. In conclusion, side-effects, convenience, and family timing play important roles in young Australian women's experiences of contraception and barriers to access. Further research is needed about how to decrease barriers to contraceptive use and minimise negative experiences in order to ensure optimal contraceptive access for Australian women.

The abstract outlined above has been submitted to the Women's Health Conference to be held in Sydney, 7-10 May 2013

Project: W085	**Women's perceptions of information they received about alcohol use during pregnancy**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Amy Anderson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Dr Frances Kay-Lambkin (School of Medicine & Public Healh, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle)

During their pregnancies, the majority of women from the ALSWH 1973-1976 cohort consumed alcohol. There has yet to be an investigation as to how these women perceive alcohol use during pregnancy, and how they make the decision of whether or not to consume alcohol during this time. This project will qualitatively examine women's perceptions of the information and advice they received about alcohol use during pregnancy. Participants are currently being recruited for this substudy and interviews will commence shortly.

Project: A386	**Causes of vasomotor menopausal symptoms in midlife.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Gerrie-Cor Gast (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Prof Yvonne van der Schouw (University of Utrecht)

The analysis for this project have been performed over a period of months. Progress and results were (bi)-weekly discussed with ProfessorMishra and Professor. Dobson. Dr Herber-Gast (the project leader) has drafted the manuscript, which has been critically revised by the other co-authors. The manuscript is currently under review for publication in the *American Journal of Public Health.*

Dr Herber-Gast (the project leader) gave a presentation of the findings at a face-to-face meeting of the research team of the Centre for Research Excellence in Women's Health in the 21st Century (CREWH21) in July 2012.

Project: A391	**Diet and risk of vasomotor menopausal symptoms**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Dr Gerrie-Cor Gast (School of Population Health, The University of Queensland)

The analyses for this project have been performed over a period of a couple of months. Progress and results were (bi)-weekly discussed with Professor Mishra. Dr Herber-Gast (the project leader) has drafted the manuscript, which is currently under review for publication in the American Journal of Clinical Nutrition. An abstract has also been submitted to the Women's Health Conference in Sydney in May 2013.

Dr Herber-Gast (the project leader) gave a presentation of the findings at a face-to-face meeting of the research team of the Centre for Research Excellence in Women's Health in the 21st Century (CREWH21) in July 2012

1.2.8 Methodology

Project: A058	**Use of ALSWH data to illustrate methodology for analyzing longitudinal data**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Dr Liliana Orellana (Faculty of Sciences, University of Buenos Aires) • Dr Mark Jones (School of Population Health, The University of Queensland)

Two different pieces of methodological work are being done under this project at present.

- An examination of the bidirectional association in longitudinal data using causal inference
- Estimating health in longitudinal studies with missing data due to participant withdrawal, loss to follow up and death.

Project: A332	**Mortality among the 1946-51 cohort**
Collaborative Investigators:	• Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Richard Hockey (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Professor Nancy Pachana (School of Psychology, The University of Queensland) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • David Fitzgerald (School of Population Health, The University of Queensland) • Richard Hockey (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Hanh Tran (School of Population Health, The University of Queensland)

Up to October 2010 there were 474 deaths among the women born 1946-51. The death rate was lower than for all Australian women at the same time: 2.5 compared to 3.0 deaths per 1000 women per year. The main causes of death were the same as those for all Australian women of this age: breast cancer, lung cancer, other cancers and cardiovascular disease. Poor self rated health, being unemployed or otherwise not in the labour force and being a heavy smoker were all associated with increased risk of death.

Tran Thi Duc Hanh submitted a report on this work for her Masters of Epidemiology degree.

Project: A233	**ALSWH: What can we learn from no contact?**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Anna Graves (Research Centre for Gender, Health and Ageing, The University of Newcastle)

People who cannot be contacted during a survey are often excluded from the study sample on the understanding that they are not different from the rest of the sample. in an attempt to determine whether this is valid we have used longitudinal data from surveys of the 1973-78 cohort to describe differences between women who could or could not be contacted at the second survey of the 1973-78 cohort. A paper is currently being written.

Project: A295	**An exploratory study. Using qualitative data to better understand the economics of personal health**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Meredith Tavener (Research Centre for Gender, Health and Ageing, The University of Newcastle)

Qualitative data from the mid-aged cohort was used to explore personal patterns of economic rationalization and allocation. Work such as this is difficult to identify in the literature. The aim of the work was to explore how individuals perceive health costs in relation to their own income, and the context of their own lives. The narrative based approach and thematic analysis results were recently written up as a short report for a peer reviewed journal.

At present a short report of 2000 words is under reviewed by the journal *Health Economics*.

Project: A382	**A descriptive analysis of those that write free text comments collected by the ALSWH**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jane Rich (Research Centre for Gender, Health and Ageing, The University of Newcastle)

The aims of this exploratory study were to identify the major themes that women write about in the free-text space at the end of the survey and to determine the differences, if any, in demographics and general health and wellbeing between women who wrtie comments in the ALSWH surveys and those who do not. Using the analytical software leximancer, the major themes identified for the 1973-78 cohort from 1996 data included time, health and family; 15 years later these same women wrote most frequently about work, pregnancy and about the survey. The 1946-51 cohort wrote most frequently about health, life and time; 11 years later the most frequent topic was that of work in relation to health and time. The 1921-26 cohort the most frequent concept that women wrote about was husband in 1996 and 2008. Women who wrote comments tended to have poorer health then those who did not. Results from this study are being written-up for submission to a peer reviewed journal and were presented in a poster during March 2012 at an international conference, where the poster received a conference Honorable Mention.

2012 research outcomes:

- Loxton, D. Is there anything you would like to add? Responses to open-ended survey questions as research data. Women's Health 2012: The 20th Annual Congress. NIH Office of Research on Women's Health. Grand Hyatt Hotel, Washington DC, March 16-18, 2012. (received a conference Honorable Mention Award.)

Project: A292	**Quality of life trajectories**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Graciela Muniz-Terrera (MRC Biostatistics Unit, The University of Cambridge) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Jessica Prasser (Ludwig Maximilans, University Munich) • Franca Kirchberg

Two papers have been prepared and submitted for publication - one is in press and the other is being reviewed. Two students from Germany also worked on the project this year. They investigated the use of pattern-mixture models to account for informative missing data.

2012 research outcomes:

- Dr Tooth will present some results at the Centre for Health Equity Studies, Stockholm in November 2012.

- Tooth L & Mishra G. Intergenerational educational mobility on general mental health and depressive symptoms in young women, *Quality of Life Research*. (accepted).

Project: A394	**Bidirectional association between smoking and depressive symptoms. Observational longitudinal data used to emulate randomized clinical trial.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Liliana Orellana (Faculty of Sciences, University of Buenos Aires)

Results from this project were presented by Professor Annette Dobson at the Australian Statistical Conference in July 2012.

1.2.9 Tobacco, alcohol and other drugs

Project: A135A	**Alcohol consumption and poor mental health among mid-aged Australian women 1996-2010.**
Investigator:	• Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This project aims to provide up-to-date findings on the relationship between alcohol consumption and many aspects of the physical and mental health of women between the ages of 45 and 64. The findings are that women who consistently drank in moderation had the best physical health. Poorer health was related to decreased alcohol intake in moderate drinkers. Non-drinkers, occasional drinkers and heavy drinkers all had poorer self-rated health than moderate drinkers. The self-rated physical health of recent abstainers was the same as longer-term abstainers. Further analyses will examine alcohol consumption and mental health.

Project: A329	**Mental health and alcohol**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Lucy Burns (National Drug and Alcohol Research Centre, University of New South Wales)

Mental health problems and heavy episodic alcohol consumption are major public health issues in Australia and both are common among young adults. This project aims to identify groups of women with distinct longitudinal trajectories of binge drinking between 16 and 21 years, and describe factors

associated with these tractories. The longitudinal relationship between binge drinking and poor mental health will be investigated. The NSW Department of Health has awarded a grant to conduct these analyses, which are ongoing.

Project: A353	**Long term risk from alcohol consumption across generations**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Amy Anderson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Gita Mishra (School of Population Health, The University of Queensland)

Alcohol guidelines for women who are neither pregnant nor breastfeeding have remained relatively consistent between the 1990s and 2010. The recommendations are to drink no more than 2 drinks a day to minimise long term harm, and no more than 4 drinks on a single occasion to decrease the risk of injury and other short-term harm. We investigated whether women across the three cohorts followed the recommendations and whether adherence to the guidelines changed with age. A report has been written for the Department of Health and Ageing and a paper is in progress.

Project: A354	**Binge drinking patterns among women aged 18 to 64**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This project aims to identify patterns of binge drinking among women aged 18-64 and factors associated with the identified patterns. Having identified patterns of binge drinking, we will determine which factors are associated with changes in binge drinking over time. Analyses are ongoing.

1.2.10 Medications

Project: A178B	**Tracking the impact of drug regulatory actions: consumer health outcomes, risk-benefit issues and policy framework - women's comments on Vioxx and medicine safety**
Collaborative Investigators:	• A/Professor Lynne Parkinson (Health CRN, CQUniversity) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• Dr Evan Doran (School of Medicine and Public Health, The University of Newcastle) • Dr Jane Robertson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Gibson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Paul Kowal (World Health Organisation, Freshwater) • Dr Jennifer Stewart-Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Cassandra Jean Lindsey (School of Pharmacy, University of Wisconsin-Madison)

The purpose of this study was to examine qualitative data from Women's Health Australia for women with arthritis and their experiences with discredited medicines. The end comments were reviewed from Survey 3 (both mid- and old- age cohorts) and Survey 4 (both mid- and old age- cohorts), to bridge the Vioxx withdrawal event. End comments were imported into NVivo9. Comments were then separated into two groups: Survey 3 and Survey 4. Surveys were separated by survey, not age, to better identify effect of the event (Vioxx removal from market). Comments were excluded if they mentioned arthritis, but did not mention concerns with medications. The main themes identified were:

- COX-2 Inhibitors: side effects experienced; pain relief vs. no pain relief; discontinued medication; recommended to stop; chose to discontinue prior to event.
- Pain not controlled
- Unable to take anti-inflammatories
- Pain controlled by meds other than COX-2 inhibitors

In general, women tend to refer to the struggles of arthritis in their day to day life more than a struggle with finding appropriate treatment.

1.2.11 Weight, nutrition and physical activity

Project: A171A	**Health costs of poor psychological health and inactivity**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Nicola Burton (School of Human Movements Studies, The University of Queensland) • Dr Asad Khan(School of Health and Rehabilitation Sciences, The University of Queensland) • Professor Kylie Ball (School of Exercise and Nutrition Science, Deakin University)

Output from this work is on hold after intial analyses indicated problems with the periods of the data requested: the survey data and MBS data did not match. Additional data will be requested to resolve this issue.

Project: A324	**The association between sedentary behaviour, physical activity and depression in Australian women**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Jannique van Uffelen (Institute of Sport, Exercise & Active Living (ISEAL), Victoria University and School of Human Movement Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Dr Nicola Burton (School of Human Movements Studies, The University of Queensland) • Yolanda van Gellecum (Institute for Social Science Research, The University of Queensland) • Dr Kristiann Heesch (School of Public Health, Queensland University of Technology)

A manuscript is currently being prepared for submission to the American Journal of Preventive Medicine in December 2012.

2012 research outcomes:

- van Uffelen JGZ, Burton NB, van Gellecum YR, Peeters G, Heesch K, Brown WJ. Concurrent and prospective associations between sitting time, physical activity and depression in mid-aged Australian women. Oral presentation: *4th International Congress on Physical Activity and Public Health*, Sydney, Australia, October 31 – November 3, 2012.

Project: A326	**Should household activities be included when measuring physical activity and health outcomes?**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Jannique van Uffelen (Institute of Sport, Exercise & Active Living (ISEAL), Victoria University and School of Human Movement Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Dr Nicola Burton (School of Human Movements Studies, The University of Queensland) • Yolanda van Gellecum (Institute for Social Science Research, The University of Queensland)

A paper has been accepted for publication in the British Journal of Sports Medicine.

2012 research outcomes:

- Peeters, G, van Gellecum YR, van Uffelen JG, Burton NW, Brown WJ (2012). Contribution of house and garden work to the association between physical activity and well-being in young, mid-aged and older women. British Journal of Sports Medicine. [Epub ahead of print 1 Sept 2012] doi: 10.1136/bjsports-2012-091103.

Project: A343	**Social support and physical activity in older Australian women**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Jannique van Uffelen (Institute of Sport, Exercise & Active Living (ISEAL), Victoria University and School of Human Movement Studies, The University of Queensland) • Dr Nicola Burton (School of Human Movements Studies, The University of Queensland) • Professor Nancy Pachana (School of Psychology, The University of Queensland)

This project is an ongoing review of previously published studies on social support and physical activity. The cross sectional analyses have been completed.

Project: A371	**What is the optimal approach for physical activity and sitting interventions aiming to reduce incidence rates of major health conditions?**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Richard Hockey (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland)

Analyses have been completed and apaper is currently under review with the *Journal of Physical Activity and Health*.

2012 research outcomes:

- Peeters G, Hockey R, Brown W. Should physical activity intervention efforts take a whole population, high risk or middle road strategy? 4th International Congress on Physical Activity and Public Health, Sydney Australia, October 31-November 3; 2012.

Project: A379	**Exploring the relationships between sitting time and symptoms in mid-age women**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland)

Analyses have been completed and a paper has been written. The paper is currently in revision for *Preventive Medicine*, which has expressed interest in publishing it.

Project: A390	**Stress as a mediator of socioeconomic inequalities in weight gain and obesity risk.**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Kylie Ball (School of Exercise and Nutrition Sciences, Deakin University)

Literature has been collated and a preliminary review undertaken. A draft data analytic protocol is being discussed. The co-authors have scheduled further writing time to progress the manuscript in November.

Project: A404	**Sitting, physical activity and direct health care and pharmaceutical costs in mid-age and older women.**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland)

Data analyses have commenced, but further analyses are needed. It is expected that analyses will be completed in 2013 and written up as a full length paper.

Project: A408	**The relationship between sitting time and mortality in mid-aged and older women.**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of

	Queensland) • Dr Toby Pavey (School of Human Movements Studies, The University of Queensland)

One paper has been accepted for publication and another, on sitting and mortality in the 1946-51 cohort, is on hold.

2012 research outcomes:

- 'Sitting-time and 9-year all cause mortality in older women', *British Journal of Sports Medicine* (accepted).

Project: A409	**The relationship between physical activity intensity and health in mid-aged women.**
Collaborative Investigators:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Dr Toby Pavey (School of Human Movements Studies, The University of Queensland)

A paper has been prepared and is currently in final revision before submission to a journal.

Project: A416	**A life-course perspective on physical functioning**
ALSWH Liaison:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland)
Collaborative Investigators:	• Dr Geeske Peeters (School of Population Health and School of Human Movement Studies, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Dorly Deeg (LASA, EMGO+ Institute, VU University Medical Centre)

Data analyses has been completed and the paper is currently being drafted. We expect to be able to submit this paper for publication in 2013.

Project: A338	**Diet and the incidence of diabetes in mid-aged women**
ALSWH Liaison:	• Professor Gita Mishra (The University of Queensland)
Collaborative Investigators:	• Danielle Schoenaker (School of Population Health, The University of Queensland) • Prof Annette Dobson (School of Population Health, The University of Queensland) • Dr Sabita Soedamah-Muthu (Division of Human Nutrition, Wageningen University)

A manuscript on 'Comparison of statistical approaches for deriving dietary patterns associated with risk of diabetes' has been submitted and is current under review by a peer-reviewed journal.

Project: A084A	**Health related outcomes of weight change in mid-aged women**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Gurshant Singh (School of Population Health, The University of Queensland)

Dr Gurshant Singh, a research assistant, has been working full time on this project. He has submitted one paper for publication (see detail below) and is working on another paper.

Singh G, Mishra GD, Dobson AJ. Contrasting associations of short-term weight change and the incidence of diabetes and hypertension among mid-aged women: A 15 year follow-up study (submitted to *Circulation*, Nov 2012).

Project: A183A	**Overweight, obesity and urinary incontinence: The effects of modest weight change: Results from the ALSWH**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Jemma Rowlands (School of Population Health, The University of Queensland)

We are in the process of finalising a paper that investigates the relationship between BMI and the incidence of urinary incontinence in young women.

Longitudinal profiles of urinary incontinence in young Australian women: the role of BMI across the life course (to be submitted to *International Journal of Obesity*). Jemma V. Rowlands, Gerrie-Cor M. Herber-Gast, Tim Hillard, Gita D. Mishra

Project: A083B	**Trajectories of weight change in relation to dietary patterns among mid-aged women in Australia**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Danielle Schoenaker (School of Population Health, The University of Queensland)

We have started statistical analyses - the body weight trajectories have been defined. The next step is to link the trajectories with dietary patterns. Danielle Schoneker has started work on this project and hopes to complete the manuscript by next April.

Project: A182	**Short term weight change and the incidence of hypertension: Results from the ALSWH**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Gurshant Singh (School of Population Health, The University of Queensland)

All parts of the project including literature review, data anlysis and manuscript writing are being completed and will be submitted to "*Circulation"* journal. This project examined the incidence of self-reported doctor diagnosed hypertension and diabetes from six surveys over 15 years. We found that the risk associated with high BMI increased more rapidly for diabetes than hypertension. The pattern of weight loss around the time of diagnosis was characteristically seen in case of diabetes than hypertension. Short-term weight gain increased the cumulative risk for hypertension whereas short-term weight loss increased cumulative risk for diabetes. Short-term weight loss increased the incidence of diabetes which was not seen for hypertension.

Publications: Singh G, Mishra G, Dobson A. Contrasting associations of weight change and the incidence of diabetes and hypertension among mid-aged women: a 15 year follow-up study. Submitted to *Circulation*.

Project: A337	**Diet and depression in mid-aged women**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Sabita Soedamah-Muthu (Division of Human Nutrition, The University of Wageningen) • Johanna Rienks (The University of Wageningen)

The paper has been submitted and rejected by several journals. It is currently it is in its second revision for European Journal of Clinical Nutrition and the revised manuscript is due on 2nd December 2012.

Project: A338	**Diet and the incidence of diabetes in mid-aged women**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Sabita Soedamah-Muthu (Division of Human Nutrition, The University of Wageningen) • Danielle Schoenaker (School of Population Health, The University of Queensland)

A manuscript on 'Comparison of statistical approaches for deriving dietary patterns associated with risk of diabetes' has been submitted and is current under review by a peer-reviewed journal.

Project: A356	**Trajectories of dietary patterns in young and middle aged women**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Danielle Schoenaker (School of Population Health, The University of Queensland) • Liset Elstgeest (The University of Wageningen) • Johanna Rienks (The University of Wageningen)

A paper was submitted to the *British Journal of Nutrition* for publicaton, and helpful comments were received from reviewers. The paper is currently being revised before re-submission.

Project: A397	**Differential contribution of fruit and vegetable intake to general health in ALSWH**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Seema Mihrshahi (School of Population Health, The University of Queensland)

The broad objective of this project is to evaluate the differential effects of fruit and vegetables on health status. Analysis is progressing well and a paper entitled "Fruit consumption is associated with lower risk of depression in midlife" has been drafted and will be submitted by the end of November to the *Journal of Nutrition*.

1.2.12 Health in rural and remote areas

Project: A310A	**Has access to health services changed for women in rural Australia?**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Jessica Greene (Centre for Health Economics Research & Evaluation, University of Technology Sydney) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Xenia Doja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Hockey (School of Population Health, The University of Queensland) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Kees van Gool (Centre for Health Economics Research and Evaluation, University of Technology Sydney) • A/Professor Elizabeth Savage (Centre for Health Economics Research and Evaluation, University of Technology Sydney) • Professor Jane Hall (Centre for Health Economics Research and Evaluation, University of Technology Sydney)

It has previously been shown that many people living in regional areas of Australia have limited access to medical services and particularly bulk-billed services.

The focus of this research is to quantify whether access to bulk billing has improved by analysis of longitudinal data across Australia. Data from all three cohorts (1973-78, 1945-51 and 1921-26) were examined to explore trends over time by ARIA+ in Medicare data 2002-2008 for GP services.

In 2002, 61% of older women in major cities had no out-of-pocket costs, and this proportion was lower for older women in regional and remote areas. From 2005, there was a marked increase in the

proportion of older women with no out-of-pocket costs across all areas, especially in remote and very remote areas (where 87% had no out-of-pocket costs in 2008). Older women from inner regional areas were most disadvantaged in terms of bulk-billing, even after the introduction of bulk-billing incentives. Mid-aged and younger women were less likely to have no out-of-pocket costs than older women but showed similar, albeit less dramatic, increases in bulk-billing. Our data show an overall improvement in access to bulk-billing, although some inequity remains for women in inner regional areas.

Further analyses will explore relationships between changes in bulk billing and health and socio-demographic characteristics for women in urban, rural and remote areas.

Project: A281	**Salinity and health**
Collaborative Investigators:	• Professor Philip Weinstein (Graduate Research Centre, University of South Australia) • A/Professor Peter Speldewinde (Centre of Excellence in Natural Resource Management, University of Western Australia) • Dr Emily Fearnley (School of Population Health, The University of Queensland) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Anna Graves (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Richard Hockey (School of Population Health, The University of Queensland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Professor Archie Clements (School of Population Health, The University of Queensland) • Ricardo Soares (School of Population Health, The University of Queensland)

A paper has been submitted and the authors were invited to revise and resubmit it. Accordingly it is currently being revised.

1.2.13 Social factors in health and well being

Project: A173	**Transport for women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Lucy Leigh (Research Centre for Gender, Health and Ageing, The University of Newcastle)

Among older women in the Australian Longitudinal Study on Women's Health, driving is the major form of transport, especially for those in rural and remote areas. In this project we examine trends in the proportion of women who drive themselves as their main means of transport, what factors are associated with giving up driving, and what alternative transport means older women adopt. The analyses involve six years of longitudinal data for 5560 women participants in the Australian Longitudinal Study on Women's Health who completed Survey 5. At each survey there was a decline in the proportions driving themselves as the main means of transport in all areas. However, after accounting for time and compared to major cities, the odds of driving were 52% higher in inner regional areas, 110% higher analyses have been completed and published up to survey 5. further final analyses will look at drivers in late life.in outer regional, and 117% higher in remote areas. The odds of driving were significantly lower if women reported diabetes, stroke, vision problems, and need for help with daily tasks, and better SF-36 Physical Function scores were associated with higher odds of driving after other effects were included in the model. Compared to women with no caring role, women who care for someone who lives with them were 32% more likely to drive, and women who care for someone who lives elsewhere were 69% more likely to drive.

Older women in more regional and remote areas are more likely to drive than urban women, despite the effects of age and other conditions that may limit their driving were other alternatives available to them. Women who have responsibility for caring for others are particularly likely to keep driving as they age.

Analyses have been completed and published up to Survey 5. Further final analyses will look at drivers in late life.

2012 research outcomes:

- Byles J and Gallienne L. Driving in older age: a longitudinal study of women in urban, regional and remote areas and the impact of caregiving. *Journal of Women & Aging*. 2012 Volume 24, Issue 2 pp. 113-125 | DOI: 10.1080/08952841.2012.639661

1.2.14 Abuse

Project: A291	**Australian women's experiences of violence and abuse**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle)

	• A/Professor Jan Coles (Department of General Practice, Monash University) • Adeline Lee (Monash University)

Analysis of qualitative data has just begun. Minimal progress made with this as work on project A361 is reaching completion and has been prioritised.

Project: A361	**The health effects of sexual violence for Australian women: A pilot study**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Jan Coles (Department of General Practice, Monash University) • Professor Danielle Mazza (Department of General Practice, Monash University) • Dr Angela Taft (Mother and Child Health Research, La Trobe University) • Adeline Lee (Monash University)

Three papers are currently in draft and are undergoing statistical review and input from ALWHS liason ALSWH (Deb Loxton) before final revisions and submission:

- Childhood Sexual Abuse and Perinatal Outcomes: Results from the Australian Longitudinal Study on Women's Health, (to be submitted to *British Journal of O&G*)
- Childhood sexual abuse and its association with adult physical and mental health: Results from a national cohort of young Australian women (to be submitted to *BMJ*)
- General Practice Service Use and Satisfaction among Female Survivors of Childhood Sexual Abuse and Adult Violence (to be submitted to *British Journal of GP*)

Project: A159A	**Health effects of intimate partner violence among Australian women**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • David Fitzgerald (School of Population Health, The University of Queensland) • Dr Angela Taft (Mother and Child Health Research, La Trobe University) • Dr Lindsay Watson (Mother and Child Health Research, La Trobe University) • Dr Kelsey Hegarty (Faculty of Medicine, University of Melbourne) • Peta Forder (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This study has examined the factor structure, reliability and validity of the modified Composite Abuse Scale that was included in the fourth survey of the 1973-78 cohort. The scale was found to measure intimate partner abuse (IPA) in three domains: physical abuse, emotional abuse and harassment. One item that measured sexual abuse was considered a stand alone item that did not load onto the three major factors. Concurrent validity was as predicted, with experiences of IPA having positive significant correlations with other measures of abuse included in the survey and significant negative correlations with health measures. The results are being written-up for submission to a peer reviewed journal.

Project: A237A	**The long term implications of intimate partner violence for health and social support**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Karly Furber (School of Medicine and Public Health, The University of Newcastle)

This study aimed to identify the long term implications for mental health associated with a history of intimate partner violence (IPV). Findings indicated that, compared with women who had never experienced IPV, women who had lived with violent partners experienced a deficit in mental health that lasted at least 12 years after the violence had ceased. However, the results also indicated that the mental health of women who had experienced IPV improved over time, once the violence had ceased. Furthermore, the presence of social support in women's lives was found to contribute to improvement in mental health. Results from this investigaation will beincluded in Major Report H (2013) and are the subject of a paper being prepared for submission to a peer reviewed journal.

Project: A269	**Elder abuse**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Margot Schofield (School of Public Health, La Trobe University)

This project's aims were to examine the disability and mortality associated with abuse experienced in older age. Findings indicated that women who experienced abuse at baseline in 1996 (aged 70-75 years) experienced increased mortality and were more likely to experience disability than women who did not report abuse at baseline. Findings have been reported at international conferences and the results have been written-up and submitted to the Journal the American Geriatrics Society.

2012 research outcomes:

- Loxton D, Powers J. Survival among women who have experienced abuse in older age. *Futures without Violence: National Conference on Health and Domestic Violence*. San Francisco Marriott Marquis Hotel, March 30 31, 2012.

Project: A269A	**Abuse and older Australian women**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Leigh Tooth (School of Population Health, The University of Queensland) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle)

This project's aims were to explore the ways in which older Australian women wrote about their experiences of abuse after the age of 60 years. Free-text comments provided at the end of the ALSWH surveys in response to the question that asks, 'Is there anything you would like to add?' were analysed. All comments were read and experiences of abuse were identified using recognised definitions of elder abuse. However, the analysis provided evidence that many definitions of elder abuse omit acts that could reasonably be considered abusive. The results of the research identified situations in which women became vulnerable to abuse. The results have been presented at three international conferences, which have assisted with the development of the results. A paper is currently being written-up for submission to a peer reviewed journal.

2012 research outcomes:

- Loxton D, Powers J. Survival among women who have experienced abuse in older age. Futures without Violence: National Conference on Health and Domestic Violence. San Francisco Marriott Marquis Hotel, March 30 31, 2012.

1.3 Completed research projects

Project: A149	**Self-rated health, age and gender in longitudinal ageing studies in Australia**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Kaarin Anstey (Centre for Mental Health Research, Australian National University) • Dr Richard Burns (Ageing and Research Unit, Australian National University) • Richard Gibson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Kim Kiely (Ageing and Research Unit, Australian National University

The DYNOPTA project includes data from Survey 1 to 4 of the 1921-26 and 1945-46 cohort, along with data from 8 other longitudinal studies of ageing. The data from these studies have been harmonised to create a new data set known as the DYNOPTA data set. By pooling and analysing data from these nine existing Australian longitudinal studies on ageing, this program of research aimed to analyse health and functional status for a large sample of older people. The harmonisation process created a new and entirely unique pooled data set of modified variables derived from the harmonisation procedures. Version 2 of this dataset has been released to DYNOPTA investigators and has been used in a variety of projects within the DYNOPTA research program.

The DYNOPTA research program focuses on four outcomes that contribute greatly to the burden of disease and disability, namely dementia and cognition, mental health, sensory disability, and mobility/activity limitations. Mortality is also included as a key outcome in the study.

Over 30 associated research project proposals have been received and approved by the DYNOPTA Scientific Committee http://dynopta.anu.edu.au/. Many epidemiological analyses of the DYNOPTA dataset have been completed, with some more analyses underway. The prevalence and incidence rates generated from these investigations have also been used in microsimulation models which will predict future health impacts of population ageing.

2012 research outcomes:

- Bielak AA, Byles JE, Luszcz MA, Anstey KJ Combining longitudinal studies showed prevalence of disease differed throughout older adulthood.. *J Clin Epidemiol*. 2012 Mar;65(3):317-24.
- Richard A Burns, Julie Byles, Paul Mitchell, Kaarin J Anstey. Positive mental health provides significant protection against likelihood of falling in women over a 13 year period. *International Psychogeriatrics* 14 March 2012, FirstView Articles: pp 1-10 DOI: 10.1017/S1041610212000154 Volume 24 / Issue 09 / September 2012 , pp 1419-1428
- Windsor TD. Burns RA. Byles JE. Age and physical functioning predict high and low arousal positive and negative emotions in middle and older adulthood. *Journals of Gerontology*: *Psych Sciences.* (Accepted 2012.)

Project: A158A	**Use of the polypill among Australian women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Chris Wallick (School of Pharmacy, University of Washington) • Dr Jennifer Stewart Williams (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Chris Doran (School of Medicine and Public Health, The University of Newcastle) • A/Professor Lynne Parkinson (Health CRN, CQUniversity)

A low cost "polypill" could theoretically be one way of improving medication affordability and compliance for secondary prevention of cardiovascular and cerebrovascular disease. This analysis examines utilization of polypill component medicines (statins and antihypertensive medications) in two population cohorts of Australian women who were aged 56 to 61 years and 81 to 86 years in 2007. Survey records from the Australian Longitudinal Study on Women's Health (ALSWH) were linked to 2007 Pharmaceutical Benefits Scheme (PBS) claims for 7,116 mid-aged women and 4,526 older-aged women. Associations between women's characteristics (self-reported in ALSWH surveys) and their use of statins and antihypertensive medicines (measured through PBS claims in 2007) were analysed using chi square and multivariate regression techniques. The results suggest that a polypill may provide an easy to take, cheaper alternative for Australian women already taking multiple CVD medications, with particular benefits for older and lower SES women. Future research is needed to quantify the potential social and economic benefits of the polypill.

2012 research outcomes:

- Stewart Williams J, Wallick CJ, Byles JE, Doran C. Assessing the public health advantages of a polypill for prevention of cardiovascular disease in Australian women (*Journal of Clinical Epidemiology* – accepted October 2012).

Project: A398	**Impact of persistent constipation on health related quality of life and mortality in older community dwelling women.**
Collaborative Investigators:	• Professor Nicholas Talley (Faculty of Health, The University of Newcastle) • Dr Natasha Koloski (School of Psychology, The University of Queensland and Faculty of Health, The University of Newcastle) • A/ Professor Michael Jones (Psychology Department, Macquarie University) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Dr Gill Raghubunder (Gastroenterology Department, Royal Prince Alfred Hospital) • Dr Ronald Wai (School of Medicine & Public Health, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle)

We aimed to determine the impact of persistent versus transient constipation on health related quality of life, depression and mortality in a large sample of older community dwelling women. Our participants were 5107 women who answered "Have you had constipation in the past 12 months?" in all five surveys of the Australian Longitudinal Study on Women's Health. These women were aged 70-75 years in 1996 and were followed up every 3 years over a 15 year period. Persistent constipation was defined as reporting constipation on at least 4 out of the 5 surveys. Transient constipation was defined as reporting constipation 1-3 times across the 5 surveys. We assessed eight domains of quality of life using the valid SF-36, self-reported depression at survey 5 and mortality over the 15 year period. Potential confounders included the number of chronic illnesses over the past 12 months and daily fluid intake as reported in the 5th survey. Of the 5107 women, we found 20.9% (n=1068), 54.1% (n=2763) and 24.7% (n=1276) reported having persistent, transient or no constipation over the 15 year time frame, respectively. Women who reported persistent constipation compared with transient constipation were significantly more impaired in all domains of quality of life except role-emotional and were significantly more depressed, even after adjusting for number of chronic illnesses

and fluid intake. Mortality rates did not significantly differentiate between transient and persistent constipation (9.2% vs. 10.9%, OR=1.20, 95% CI 0.95,1.52, P=0.12) but were increased when comparing no constipation with persistent (7.4% vs. 10.9%, OR=1.34, 95%CI 1.0-1.80, P=0.048) after controlling for confounders. We showed persistent compared with transient constipation affects about one fifth of older community dwelling women and is associated with greater impairment in quality of life and depression as well as higher mortality compared with no constipation.

2012 research outcomes:

- This work was presented as a poster at 2012 Digestive Diseases Week in the USA.
- Koloski N, Jones M, Wai R, Raghubinder SG, Talley NJ. Impact of persistent constipation on health related quality of life and mortality in older community dwelling women. *Gastroenterology* 2012; 142 (5) Supplement 1 S-819.

A manuscript was submitted to the American Journal of Epidemiology, but was rejected. It is now with the *American Journal of Gastroenterology*, which has requested some revisions.

Project: A296	**Birth outcomes after spontaneous or assisted conception among infertile Australian women aged 28-36 years**
ALSWH Liaison:	• A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland)
Collaborative Investigators:	• Dr Danielle Herbert (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland)

This study examined whether the odds of birth or other pregnancy outcomes are higher among women aged 28-36 years who use fertility treatment compared to untreated women. Women with prior births were less likely to use in vitro fertilisation (IVF) compared to nulliparous women. Women using either IVF or ovulation induction were more likely to have given birth or be pregnant compared to untreated women. Women using treatment were as likely to have ectopic pregnancies, stillbirths, premature or low birthweight babies as untreated women. Overall, one-in-four women with a history of infertility prior to age 36 years may still end up having a baby without treatment, indicating they are subfertile rather than infertile.

2012 research outcomes:

- Herbert DL, Lucke JC, Dobson AJ. Birth outcomes after spontaneous or assisted conception among infertile Australian women aged 28-36 years: A prospective, population-based study. *Fertility and Sterility* 2012; 97(3): 630-638. IF=3.958.
- Herbert DL, Lucke JC, Dobson AJ. Infertility resolved with or without fertility treatment in Australian women aged 31-36 years: a prospective, population-based study. [Abstract for 3rd North American Congress of Epidemiology, June 21-24, 2011 Montreal, Canada]. *American Journal of Epidemiology* 2011; 173(suppl 11): S236. IF=5.589.

Project: A298	Agreement between self-reported use of in vitro fertilisation or ovulation induction, and medical insurance claims in Australian women aged 28-36 years
ALSWH Liaison:	• A/Prof Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland)
Collaborative Investigators:	• Dr Danielle Herbert (School of Population Health, The University of Queensland) • Prof Annette Dobson (School of Population Health, The University of Queensland)

This study compared self-reported use of in vitro fertilisation (IVF), or ovulation induction (OI), and medical insurance claims by Australian women aged 28-36 years. Participants self-reported their use of IVF or OI when aged 28-33 and 31-36 years. There were low numbers of women using repeated fertility treatment therefore the statistical analysis of repeated treatment was unreliable and inappropriate. This study focussed on the level of agreement between self-reported use of fertility treatment and Medicare claims for treatment or medication. Self-reported use of IVF was compared to Medicare claims for superovulation cycles, egg collection, sperm preparation, intracytoplasmic sperm injection, embryo transfers and superovulation medication. Self-reported use of OI was compared to ovulation monitoring and medication. The self-reported use of IVF is quite likely to be valid however the use of OI is less well reported.

2012 research outcomes:

- Herbert DL, Lucke JC, Dobson AJ. Agreement between self-reported use of in vitro fertilisation or ovulation induction, and medical insurance claims in Australian women aged 28-36 years. Human Reproduction 2012: in press

Project: A330	**For women with chronic disease, how and in what ways does utilisation of allied health services change over time with different life stages and what is the relationship to health insurance coverage?**
Collaborative Investigators:	• Dr Michele Foster (School of Social Work and Human Studies, The University of Queensland) • A/Professor Michele Haynes (Institute for Social Science Research, The University of Queensland) • A/Professor Terry Haines (Allied Health Clinical Research Unit, Southern Health) • Professor Geoffery Mitchell (School of Medicine, The University of Queensland) • Martin O'Flaherty (Institute for Social Science Research, The University of Queensland) • Professor Nancy Pachana (School of Psychology, The University of Queensland)

The project was completed successfully in January 2012. The final reports for the project can be found at:

http://aphcri.anu.edu.au/research-program/aphcri-network-research/aphcri-network-research-completed/interdisciplinary-andor-cross-boundary-0

In addition to the final reports, the researchers expect to pursue academic publication using the ALSWH data, focussing on patterns of allied health care use among women at different stages of the life course.

2012 research outcomes:

- Researchers from the project participated in the Australian Primary Health Care Research Institute (APHCRI) policy roundtable at the Australian National University, presenting findings from the research to policy makers, APHCRI staff, and other research teams funded by APHCRI.

Project: A357	**Validation of self-reported assessment of osteoporosis**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Richard Hockey (School of Population Health, The University of Queensland) • Professor Susan Tett (School of Pharmacy, The University of Queensland)

This project has been completed and resulted in one publication.

2012 research outcomes:

- Peeters G, Tett S, Dobson A & Mishra G. Validity of self-osteoporosis in mid-age and older women. *Osteoporosis International, 2012.*

1.4 Substudies

Project: W059	**Longitudinal study of sleeping difficulty and medication use among older women**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Gita Mishra (School of Population Health, The University of Queensland) • Dr Margaret Harris (School of Nursing and Midwifery, The University of Newcastle) • David Fitzgerald (School of Population Health, The University of Queensland)

This study identifies sleeping difficulty among women in the 1921-26 cohort to determine trends in prevalence of self-reported sleeping difficulty among women as they age, and associations between sleeping difficulty and health-related quality of life and survival.

At Survey 2 (age 73-78 years), 35.4% of women had no sleeping difficulties, 33.9% had one problem, and 30.6% had two or more problems. Over time the proportion with sleeping problems increased. Women with two or more sleeping problems had a lower survival probability than those with no problems, but this difference was not statistically significant after adjustment for covariates. There was a strong consistent association between poorer quality of life on SF-36 component scores and increasing sleeping difficulty.

Sleeping difficulties are common and persistent concerns for older women, and are associated with poorer health-related quality of life. Self-reported sleeping difficulty at one survey point is not associated with increased risk of mortality after adjustment for other factors, but persistent sleeping difficulty is.

Project: W063	**Tracking the impact of drug regulatory actions: Consumer health outcomes, risk-benefit issues and policy framework**
Collaborative Investigators:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Lynne Parkinson (Health CRN, CQUniversity) • Dr Evan Doran (School of Medicine and Public Health, The University of Newcastle) • Dr Jane Robertson (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Xenia Dolja-Gore (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Margaret Harris (School of Nursing and Midwifery, The University of Newcastle) • Dr Annette Moxey (School of Medicine and Public Health, The University of Newcastle)

The aim of this project was to examine the impact of a medicine discrediting event (the withdrawal of rofecoxib [Vioxx], and issuing of safety warnings on other COX-2s) on the medicine behaviours and attitudes of women with arthritis.

Women who had been prescribed a COX-2 prior to the 2003 COX-2 discrediting event were drawn from the Australian Longitudinal Study on Women's Health (ALSWH). Qualitative in-depth telephone interviews were undertaken with women. Intensive analysis of interview transcripts was used to derive thematic codes, and discover emergent themes related to women's reactions to the withdrawal of rofecoxib and issuing of safety warnings regarding other COX-2s.

Interviews were conducted with ten women from the mid-aged (born 1946-51) and 15 from the older-aged (born 1921-26) ALSWH cohorts. Reactions to the discrediting event were largely undramatic. Women sought information from their GP (general practitioner) and made treatment decisions with the GP based on that information. The media was the key source of information of the withdrawal event. Women were sceptical of the long term use of prescribed medicine while they were happy to be using CAM (complementary and alternative medicines) and to manage CAM treatment on their own.

Results for women in the mid-aged cohort were highly similar to those for women in the older cohort. The older cohort voiced equal use of CAM but more reliance on the GP for decision making.

2012 research outcomes:

- Harris M, Parkinson L, Moxey A, Robertson J, Doran E, & Byles J. Crisis… What crisis? Women's experience of the withdrawal of Vioxx and discrediting of the COX-2s. *2nd Global Congress of Qualitative Health Research,* Milan, Italy, 28 - 30 June 2012.

Project: W061	**CAM use among mid age women: A national mixed-method study across the urban-rural divide**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Jon Adams (School of Public Health, University of Technology Sydney) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Dr Marie Pirotta (Faculty of Medicine, Dentisty and Health Sciences, University of Melbourne) • Professor Marc Cohen (Health Sciences, Royal Melbourne Institute of Technology) • A/Professor Alexander Broom (School of Social Science, The University of Queensland) • Professor John Humphreys (Faculty of Nursing and Health Science, Monash University) • Jon Wardle (School of Population Health, The University of Queensland) • A/Professor Joanne Barnes (School of Pharmacy, University of Auckland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Dr Gavin Andrews (Department of Health, Ageing and Society, McMaster University)

Our project was the first in-depth national, mixed methods study ever to be conducted in Australia examining women's CAM use across rural and urban health. This topic is underresearched internationally and our results are of interest and benefit to health practitioners, patients and policymakers in countries where the rural/urban divide is pronounced. Our research papers have been published in leading international journals for the rural health/CAM fields and our international conference presentations have also helped to introduce vital insights for practice and service provision relating to CAM use in rural and urban health settings. All fieldwork and study stages have now been successfully completed and NHMRC funding has ceased. We have already received extremely positive feedback and interest from practitioners and researchers.

2012 research outcomes:

- Sibbritt D. (invited) Public health research: insights for acupuncture. *International Scientific Acupuncture and Meridian Symposium (iSAMS)*, Sydney, Australia. 5-7 October 2012.

- Adams J, Sibbritt D, Broom A, Loxton D, Wardle J, Pirotta M, Lui C. (in press) High levels of CAM use in rural areas largely due to high levels of chiropractor use: A national survey. *Journal of Manipulative and Physiological Therapeutics* (accepted 1st Nov 2012).
- Broom A, Meurk C, Adams J, Sibbritt D. (in press) Bodies of knowledge: Nature, holism and women's plural health practices. *Health* (accepted June 2012)
- Wardle J, Lui C, Adams. (2012) CAM in rural communities: Current research and future directions. *Journal of Rural Health* 28(11): 101-112.
- Sibbritt D, Adams J. (2012) Developing public healthmethods for integrative medicine: Examples from the field in Australia. *Journal of Chinese Integrative Medicine* 9(3): 233-236.
- Broom A, Meurk C, Adams J, Sibbritt D. (in press) My health, my responsibility? Complementary medicine and self (health) care. *Journal of Sociology* (accepted Oct 2012)
- Andrews G, Adams J, Segrott J. (2012) The profile of CAM users and reasons for CAM use. In Adams J. et al (Eds) Traditional, Complementary and Integrative Medicine: An International Reader. Palgrave MacMillan: Basingstoke.
- Andrews G, Segrott J, Lui C, Adams J. (2012) The geography of CAM. In Adams J. et al (Eds) Traditional, Complementary and Integrative Medicine: An International Reader. Palgrave MacMillan: Basingstoke.
- Wardle J, Adams J, Broom A, Sibbritt D. (2012). Examining the relationship between complementary and integrative medicine and rural general practice. In Adams J. et al (Eds) Primary Health Care and Complementary and Integrative Medicine. Imperial College Press: London.
- Steel A, Frawley J, Adams J, Sibbritt D, Broom A, (2012) Primary health care, CAM and women's health. In Adams J. et al (Eds) Primary Health Care and Complementary and Integrative Medicine. Imperial College Press: London.

Project: W066	**The predictors, antecedents and efficacy of treatment of postnatal depression in Australian women**
Collaborative Investigators:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland) • Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle)

While the longitudinal study data offers a rich source of information to investigate both the long and short term predictors of post natal depression (PND), additional detailed information is required on the experience preceding a diagnosis of PND, which can be used in conjunction with previously collected survey data. For example, the events of childbirth have previously been related to the development of PND, such as mode of delivery (Brown et al., 1994), which is available in the survey data, however emotional coping through childbirth (Bloch, Rotenberg et al., 2006) and duration of labour (Johnstone, Boyce et al., 2001) are not available in the survey data. Furthermore, the longitudinal study does not gather information about the diagnosis, treatment and recovery from PND, all of which will be investigated in this substudy.

In-depth qualitative telephone interviews were conducted with women who had indicated in Survey 4 that they had been diagnosed or treated for PND in the past, as well as with women who did not indicate they had experienced PND. Around 60 participants were sent a letter of invitation, and 16 of those took up the invitation to participate. Participants were selected based on responses to Survey 4 in 2006. Those eligible were women who had given birth to a child in the four years prior to Survey 4. The sample was selected so that half of the women had answered positively to the PND diagnosis item, and half had answered negatively. Data analysis has been conducted, and results will be prepared for publication shortly.

Project: W062	**Depression and cardiovascular disease in a cohort of mid-aged Australian women.**
Collaborative Investigators:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Dr Janneke Berecki (Monash University) • Professor Sandy McFarlane (Centre for Military and Veterans Affairs, University of Adelaide) • Janni Leung (School of Population Health, The University of Queensland) • June Ling (School of Population Health, The University of Queensland)

Women from the 1946-1951 ALSWH cohort who had no reported history of CVD prior to Survey 4 (2004) or Survey 5 (2007) were selected for this sub-study. 407 women who potentially met the criteria for new cases of CVD, were mailed a questionnaire which included items that: (i) assessed the women's depression and measured other aspects of their mental health, (ii) sought to validate their CVD diagnosis, and (iii) obtained information on factors that may have helped or hindered them in coping with their CVD. 306 completed questionnaires were returned (75%).

The results of our analyses on the effect of comorbid anxiety and depression in women with angina were reported in 2010. In the past year we have further explored the effect of traumatic experiences on the new onset of coronary heart disease in women and the impact on quality of life. The results of longitudinal analyses indicate that women who reported experiencing violence or abuse at baseline (1998) were 1.4 times more likely to report new onset coronary heart disease at subsequent surveys. Cross sectional analyses indicated that there was a dose-response relationship between the number of types of traumatic events reported and quality of life. Women who reported experiencing 4 or more types of traumatic events had the lowest quality of life scores, compared to women who reported experiencing 2 to 3 types and women who experienced 1 type of traumatic event.

One paper has been submitted (, McLaughlin D, Ling J & Loxton D. The effect of abuse on risk of coronary heart disease among mid-aged women) to *Psychosomatic Medicine*.

Project: W081	**Vasomotor menopausal symptoms and risk of cardiovascular disease**
Collaborative Investigators:	• Professor Gita Mishra (School of Population Health, The University of Queensland)

	• Dr Gerrie-Cor Gast (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Dr Danielle Herbert (School of Population Health, The University of Queensland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland)

We have conducted a sub-study to collect additional data from the mid-aged women who reported heart disease in Surveys 1-6. Currently 546 women have completed the survey, and data has been received in a data file. The coronary heart disease cases were selected on the basis of affirmative answers to survey questions. However, since only 174 women have coronary heart disease, the statistical power to detect any difference is too low. We will therefore wait for the linked data from the hospital registries to arrive before continuing this project.

Project: W062	**Women's use of CAM for pregnancy and birthing: A natural mixed methods study**
Collaborative Investigators:	• Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Professor Jon Adams (School of Public Health, University of Technology Sydney) • Jon Wardle (School of Population Health, The University of Queensland) • A/Professor Alexander Broom (School of Social Science, The University of Queensland) • Professor Caroline Homer (Centre for Midwifery, Child and Family Health, University of Technology Sydney) • Professor David Ellwood (School of Clinical Medicine, Australian National University) • Professor Cindy Gallois (School of Social and Behavioural Sciences, University of Queensland) • Amie Steel (School of Population Health, University of Queensland) • Jane Frawley (The University of Newcastle)

This project has produced a rich dataset with which to explore the use of complementary and alternative medicine (CAM) by pregnant women. To date we have discovered that CAM use by pregnant women is considerable, particularly for the relief of common pregnancy-related symptoms. It also appears that women are avoiding certain CAMs known to adversely affect pregnant women, suggesting that the women are being educated about the safety aspect of CAM use, either by healthcare professionals or their own research.

PhD students on the project have produced 2 manuscripts currently under review, with six more in preparation.

Project: W070	**Navigating back pain: A sociological study of women's illness pathways within and between intersecting social worlds.**
Collaborative Investigators:	• Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney) • Professor Jon Adams (School of Public Health, University of Technology Sydney) • A/Professor Alexander Broom (School of Social Science, The University of Queensland) • Professor Kathryn Refshauge (School of Social Science, The University of Queensland) • Vijayendra Murthy (The University of Newcastle)

This project is in its earlier stages, but to date we have found that mid-aged women with back pain utilise a range of conventional and CAM treatments. Consultation with CAM practitioners or self-prescribed CAM was predominantly in addition to, rather than a replacement for, conventional care. Better communication is needed between patients, conventional and CAM practitioners to ensure the creation and maintenance of 'best' treatment plans for back pain sufferers.

2012 research outcomes:

- Kirby E, Broom A, Sibbritt D, Adams J, Refshauge K. A national cross-sectional survey of back pain care amongst mid-age Australian women. *European Journal of Integrative Medicine* (in press).
- Broom AF, Kirby ER, Sibbritt DW, Adams J, Refshauge KM. Back pain amongst mid-age Australian women: An analysis of provider use and self-prescribed treatments. *Complementary Therapies in Medicine* 2012; 20(5): 275-282.

1.5 Current student projects

Project: A176	**Predictors of post-natal depression**
PhD Candidate:	Catherine Chojenta (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Supervisors:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • A/Professor Jayne Lucke (UQ Centre for Clinical Research, The University of Queensland)

This research examines the risk factors for postnatal depression (PND) utilising longitudinal data in a representative Australian sample of Australian women. To date, an analysis using data collected up to Survey 4 has been conducted, and found that women with a history of depression were more likely to report being diagnosed for postnatal depression. A qualitative analysis of the open-ended responses to the question 'have we missed anything' has been conducted in order to examine the types of prior

experiences described by women who have experienced PND. A longitudinal analysis of data collected up to Survey 5 has also been conducted, and found that a history of poor mental health and experience of stress to be significantly related to PND.

Project: A179 & W079	**When life's a pain: The relationship between stress and modifiable psychological factors in arthritis** **Arthritis and women at midlife: The lived psychosocial experience**
PhD Candidate	Melissa Harris (School of Medicine and Public Health, The University of Newcastle)
Supervisors	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney)

Project A179 aims to examine the relationship between perceived stress, psychosocial factors and arthritis in women as they transition from midlife to older age. To date, analyses surrounding the relative importance of psychosocial factors in women with arthritis from the 1946-1951 cohort has been conducted and published. Cross-sectional analyses using data from survey 5 in 2007 revealed that the diagnosis of arthritis is characterised by widespread psychosocial concerns. In comparison to women without arthritis, univariate analyses revealed that self-reported arthritis was associated with a 1.6-fold increase in experiencing lower levels of stress, a 2.5-fold increase in experiencing moderate/high levels of stress and a 1.4-fold increase in experiencing negative interpersonal life events. Additionally, women with self-reported arthritis also experienced significantly reduced levels of optimism and perceived social support (all associations $p<0.001$). Having psychiatric comorbidity (depression and anxiety) was also predictive of arthritis status. Following the adjustment for behavioural, demographic and medical characteristics (using a backward elimination technique), being diagnosed with an anxiety disorder remained the only independent predictor of self-reported arthritis. Longitudinal analyses using data obtained from the third, fourth and fifth surveys have been undertaken in order to examine the role of perceived stress and psychosocial factors in contributing to arthritis risk. The findings from these analyses have been submitted for publication and are currently being revised. The findings from this project will help inform policy and practice regarding the role of psychosocial factors (particularly stress) in influencing disease risk and poor outcomes for women with arthritis.

Substudy W079 is designed to qualitatively explore the lived psychosocial experience of midlife women with arthritis, expanding upon, and clarifying findings from ALSWH quantitative analyses examining the relationship between stress and psychosocial factors in women with arthritis from the 1946-1951 cohort (project A179).

Qualitative in-depth semi-structured telephone interviews were conducted with women from the 1946-1951 cohort who indicated in survey 5 that they had been diagnosed with, or treated for arthritis in the previous three years. Approximately 45 women were invited to take part in this study and a total of 19 interviews were conducted over a three month period. Data has been analysed and is currently being written up for thesis submission and publication.

Project: A205	**The impact of health on lifetime earnings, labour force experience and retirement and the effects of all these factors on the degree of income and health inequalities post retirement**
PhD Candidate:	Joanne Flavel (National Institute of Labour Studies, Flinders University
Supervisors:	Professor Sue Richardson (National Institute of Labour Studies, Flinders University)

Complex econometric analysis for this project is now well underway and it is hoped that analysis will be completed either mid or late 2013. Results to date have been written up and the thesis is now approximately half written (subject to amendments).

Project: A265A & W077	**An interdisciplinary investigation into the relationship between drought and mental health in Australia** **An interdisciplinary investigation into the experience and impacts of living with drought for 3 generations of Australian women**
PhD Candidate:	Jane Rich (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Supervisors:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Sarah Wright (School of Environmental and Life Sciences, The University of Newcastle)

Project A265A is progressing well. All analyses are complete and final revisions to chapters are currently being conducted. There have been three analyses conducted to date, two of which involve the qualitative data collected by the ALSWH. The first of these was a thematic analysis of all comments made by women who stated they had experienced living in drought. The second analysis used Leximancer software to explore these women's stories over time. The third analysis was based on interview data from ALSWH participants. Jane has a paper accepted which will be in the December issue of the *Australian Journal of Rural Health*. Jane plans to submit her thesis mid 2013.

Substudy W077 has also progressed well. Interviews were conducted in early 2012 after receiving Ethics approval. The interviews asked women to talk about their experiences of rural life and drought in Australia. The interview aimed to gain an understanding of women's connectedness to their home towns, their social support systems and their lived-experiences of drought. The women interviewed were keen to tell their stories and this data has since been written up into three narratives, one per cohort. Final revisions of these analyses are to occur and it is planned that this work will be submitted as part of Jane's PhD thesis in mid 2013.

2012 research outcomes:

Rich J, Wright S, Loxton D (2012, inpress) “Patience, HRT and Rain” Women Ageing and Drought” *Australian Journal of Rural Health.*

Project: A267A	**Neighbourhood, geographic location and health.**
PhD student:	• Sue Conrad (School of Population Health, The University of Queensland)
Supervisors:	• Dr Leigh Tooth (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Deirdre McLaughlin (School of Population Health, The University of Queensland)

Two major analyses have been completed since 2011. These are reported in two thesis chapters titled "Associations between socio-demographic variables and neighbourhood cohesion", and "Psychosocial, health and health care utilisation factors associated with migration, and effects of migration on neighbourhood safety and cohesion". Two abstracts have been submitted to the 12th National Rural Health Conference to be held in 2013. These were titled "Neighbourhood cohesion among middle-aged women: The influence of psychosocial factors" and "Rural-urban migration and associations with health, psychosocial factors and neighbourhood cohesion". Work towards the results final chapter which examines associations between neighbourhood cohesion and health is underway.

Project: A312 & W085	**Assessing alcohol use in pregnant women using data from the Australian Longitudinal Study on Women's Health (ALSWH)** **Women's perceptions of information they received about alcohol use during pregnancy**
Honours Candidate:	Amy Anderson (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Supervisors:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Jenny Powers (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Frances Kay-Lambkin (School of Medicine & Public Healh, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle)

Project A312: The majority of Australian women report drinking some alcohol during pregnancy. The first analysis for this project, which investigated pregnant women's compliance with the 2009 NHMRC alcohol guidelines by using the 1973-1978 cohort data, found that most women (72%) were not complying with the latest national guidelines that recommend abstinence. Previous drinking behaviour was the largest predictor of whether or not women complied with the guidelines. The manuscript resulting from the analysis has been published by BMC Public Health. Further

investigation into why women drink during pregnancy is currently being undertaken. Interviews with ALSWH women from the 1973-1978 cohort and focus groups with GPs will provide insight into the information about alcohol use being provided to and received by pregnant women. An understanding of what leads women to choose to consume alcohol during pregnancy will help to identify areas that need to be targeted by future interventions aiming to reduce the level of prenatal alcohol consumption.

Substudy W085: During their pregnancies, the majority of women from the ALSWH 1973-1976 cohort consumed alcohol. There has yet to be an investigation as to how these women perceive alcohol use during pregnancy, and how they make the decision of whether or not to consume alcohol during this time. This project will qualitatively examine women's perceptions of the information and advice they received about alcohol use during pregnancy. Participants are currently being recruited for this substudy and interviews will commence shortly.

2012 research outcomes:

- Anderson A, Hure A, Powers J, Kay-Lambkin F, Loxton D. Determinants of pregnant women's compliance with alcohol guidelines: a prospective cohort study. *BMC Public Health* 2012;12(1):777.

Project: A316	**Pap screening in the 1973-78 cohort**
PhD Candidate:	Dr Elizabeth Crowe (Centre for Health Data Services, The University of Queensland)
Supervisors:	• Professor Annette Dobson (School of Population Health, The University of Queensland) • Professor Steve Kisely (Centre for Health Data Services, The University of Queensland) • Professor David Whiteman (Cancer Control Lab, Queensland Institute of Medical Research)

Analysis of these data will form part of my PhD. Initial work on this project involved exploration of the dataset and the production of summary statistics. Further work has been postponed because the priority of the research team has been to complete a complex analysis of another dataset. Once this is complete, we hope to return to analysing the ALSWH dataset.

Project: A317	**The effect of food in the development of Type-2 Diabetes Mellitus in mid-age Australian women**
PhD Candidate:	Amani Hamad Alhazmi (School of Health Sciences, The University of Newcastle)
Supervisors:	• Professor Wendy Brown (School of Human Movements Studies, The University of Queensland) • Mark McEvoy (School of Medicine and Public Health, The University of Newcastle) • Professor Manohar Garg (School of Biomedical Sciences & Pharmacy, The University of Newcastle) • Dr Elizabeth Stojanovski (School of Mathematical & Physical Sciences, The University of Newcastle)

This project aims to determine the effect of macronutrient in-take (fat, carbohydrate and protein) in the form of percentage energy distribution of on the risk of developing T2DM over 6 years in mid-age Australian women and examine the association between dietary pattern in the form of diet quality score and risk of developing T2DM over 6 years in mid-age Australian women.

Research questions are:

- What is the association between carbohydrate, protein and type of dietary fat (omega-3 , omega-6, Poly-unsaturated fat , Monounsaturated fat, and Saturated fat)intakes and the risk of developing T2DM over 6 years in mid-age Australian women?
- What is the association between diet quality score and the risk of developing T2DM over 6 years in mid-age Australian women?

The analysis will take two main forms:

1. Multivariate logistic regression will be used to model the association of the main explanatory variables with incident T2DM after adjusting for known confounders as describes above. Macronutrient ratios will be calculated for percentage combinations of each of the macronutrients (e.g. P and C; P and F, C and F) and these will be used as a explanatory variables in different regression models.

2. Decision tree analysis will be used to determine which combination of dietary macronutrients is associated with the lowest/highest risk of T2DM.

2012 research outcomes:

- Alhazmi, E. Stojanovski, M. McEvoy, M.L. Garg, Overall Diet Quality Score and Type 2 Diabetes, The Australian Diabetes Society (ADS) & Australian Diabetes Educators Association (ADEA) annual scientific meeting Gold Coast, Queensland, Australia, August 2012.
- Alhazmi,E. Stojanovski, M. McEvoy, M.L. Garg, ARFS Items and Type 2 Diabetes in Australian Women, The Australian Diabetes Society (ADS)& Australian Diabetes Educators Association (ADEA) annual scientific meeting Gold Coast, Qeensland, Australia, August 2012.

Project: A350	**The impact of pharmaceutical characteristics on the choice of treatments for osteoporosis**
PhD Candidate:	Bonny Parkinson (Centre for Heath Economics and Research, University of Technology Sydney)
Supervisors:	• A/Professor Rosalie Viney (Centre for Health Economics Research and Evaluation, University of Technology Sydney) • Professor Marion Haas (Centre for Health Economics Research and Evaluation, University of Technology Sydney) • Dr Stephen Goodall (Centre for Health Economics Research and Evaluation, University of Technology Sydney) • Professor Denzil Fiebig (School of Economics, University of New South Wales)

Unfortunately nothing has happened regarding the project since presentation at the Australian Health Economics Association Conference in September 2011. Bonny Parkinson hasbeen conducting a literature review on influences of clinician prescribing since then, which will inform the proposed re-analyses that are planned to begin soon.

Project: A351	**Urban rural differences in health care for women with colorectal, breast and lung cancer**
PhD Candidate:	Janni Leung (School of Population Health, The University of Queensland)
Supervisors:	• Dr Deirdre McLaughlin (School of Population Health, The University of Queensland) • Professor Annette Dobson (School of Population Health, The University of Queensland) • Dr Samantha McKenzie (School of Population Health, The University of Queensland)

This project will involve a series of studies comparing urban and rural differences in breast cancer screening, diagnosis, treatment, and survival. The project relies on linked data between the ALSWH data with hospital and cancer registry data from each state. It is expected that the investigators will gain access to the linked data and commence analyses early 2013. However, preliminary results for the first part of the study are available.

The aim of this first study was to identify and compare breast cancer screening patterns in women residing in rural and urban areas. Participants were drawn from the Australian Longitudinal Study on Women's Health and included 11,200 women who were aged 50-55 years at baseline (1996). Breast screening measures included mammography utilisation, clinical breast examinations, or breast self-examinations. Area of residence was defined in accordance to the accessibility remoteness index of Australia Plus (ARIA+). Covariates included country of birth, marital status, body mass index (BMI), difficulties in the management of income, education, and depression. Results showed that self-reported access to mammography services were poorer in women residing in rural areas. Nevertheless, mammography screening rates were similar between women residing in rural and urban areas. Women residing in rural areas were less likely to have clinical breast examinations, but more likely to conduct breast self-examinations. Patterns were similar over time. In conclusion, the poorer breast cancer survival among rural women is unlikely to be explained by differences in breast screening practices. Further research on other explanatory factors, such as disparities in breast cancer treatment, are required to determine the cause of the rural disadvantage. These preliminary results were presented that the 2012 School of Population Health Research Higher Degree Conference.

2012 research outcomes:

- Leung J, McLaughlin D, McKenzie S et al. Differences in breast cancer screening patterns between women residing rural and urban areas. 2012 School of Population Health Research Higher Degree Conference. Herston, Australia 2012.

Project: A368	Does diet quality before and during pregnancy predict pregnancy and birth outcomes?
PhD Candidate:	Ellie Gresham (Research Centre for Gender, Health and Ageing, The University of Newcastle)
Supervisors:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Clare Collins (School of Health Sciences (Nutrition and Dietetics), The University of Newcastle) • Professor Gita Mishra (School of Population Health, The University of Queensland)

Preliminary analyses have been conducted using FFQ/dietary data at Survey 3 and correlated with Survey 4 outcome data. Part of the preliminary results have been presented, demonstrating an association between diet quality and gestational hypertension. The second half of the analysis will take place following the collection of outcome data at Survey 6 (distributed in March 2012). The second half of the analysis is expected to take place towards the end of 2013/beginning of 2014.

2012 research outcomes:

- Poorer diet quality predicts gestational hypertension. International Congress of Dietetics, Sydney, Australia. 5-7th September 2012.

Project: A376	**Healthcare resources use in older Australian women with Arthritis**
PhD Candidate:	Thomas Lo (The University of Newcastle)
Supervisors:	• A/Professor Lynne Parkinson (Health CRN, CQUniversity) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Michelle Cunich (School of Public Health, University of Sydney)

Analyses commenced in September 2011. First stage of analysis involves validating survey (Australian Longitudinal Study on Women's Health) data by examining agreement between self-reported arthritis and: a) Medicare data; and b) arthritis symptoms. Preliminary results have been presented last year in international conferences including the 4th Pan American Congress of the International Association of Gerontology and Geriatrics (IAGG) in Ottawa and the 9th Asia/Oceania Regional Congress of Gerontology and Geriatrists in Melbourne. First stage analysis will be completed in December 2012; results will be presented at the 45th Australian Association of Gerontology National Conference later this year in Brisbane. Second stage analysis involves examining healthcare utilisation and costs attributable to managing arthritis using survey data and linked Medicare data. Analyses are scheduled to commence in January 2013.

Project: A401	Medication use and mental health in older Australian women.
PhD Candidate:	Maha Alsalami (School of Medicine and Public Health, The University of Newcastle)
Supervisors:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Milton Hasnat (School of Medicine and Public Health, The University of Newcastle) • Mark McEvoy (School of Medicine and Public Health, The University of Newcastle)

People use an increasing number of medications as they age: The use of multiple medications is known as 'polypharmacy' and is common amongst the elderly. Previous research has shown that for the older population polypharmacy is linked to a number of health problems such as adverse drug reactions and increased risk of disease. This research will examine how polypharmacy is related to mental health in older Australian women. In particular this research will examine the relationship between depression and medication use.

Project: A419	**What is the role of nurses in Primary Health Care?**
Candidate:	Rebecca Gaston (The University of Newcastle)
Supervisors:	• Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Jane Maguire (School of Nursing and Midwifery, The University of Newcastle)

At present the data analysis is being completed. The project is estimated to be completed by the end of January 2013.

Project: A352	**Relationship between diet stability, diet quality, body mass index and health utilisation over time.**
PhD student:	Haya Mohammedali Al-Jadani (The University of Newcastle)
ALSWH Liaison	• Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney)
Supervisors:	• Professor Clare Collins (School of Health Sciences (Nutrition and Dietetics), The University of Newcastle) • Dr Amanda Patterson (School of Health Sciences (nutrition), The University of Newcastle)

The current study will test the relationship between diet quality measured by Australian Recommended Food score at Survey 3 and weight change from Survey 3 to Survey 5 at mid-age and

young cohorts. Furthermore, we will investigate the relationship between fruit and vegetable consumption at survey 3 and weight change in six years of follow-up from survey 3 to Survey 5 in young women cohorts. The outcome for both cohorts will be absolute weight change in kg, developing overweight and/or obesity, weight- stable and gaining, losing weight. Participants will be excluded if they met any of the specific exclusion criteria. For statistical tests we will apply two different approhces:1) linear regression; 2) logistic regressions including three different models that include different number of confounders. In the models we will control for potential confounders including area of residence, physical activity, total energy intake and others. A paper is under review with the *Australian and New Zealand Journal of Public Health* and two others are in preparation.

2012 research outcomes:

- Diet quality does not predict 6 year weight change in mid-age women from Australian Longitudinal Study on Women's Health.Presented by Professor Clare Collins.*The 2012 ANZOS Annual Scientific Meeting.*

Project: A374	**A qualitative analysis of the use of Complementary & Alternative Medicine (CAM) in relation to health status and health service utilisation by women with back pain.**
PhD student:	• Vijayndra Murthy (The University of Newcastle)
Supervisors:	• Professor Jon Adams (School of Public Health, University of Technology Sydney) • Professor David Sibbritt (Faculty of Nursing, Midwifery and Health, University Technology Sydney)

So far, data analysis of women's consultations with complementary and alternative medicine (CAM) practitioners for back pain and women's use of self-prescribed CAM treatments for back pain has been completed. Two papers have been drafted for submission to a rheumatology journal and a complemenatay and alternative medicine journal. Currently, data analyis on what influences womens' decision to choose CAM and womens' communication with conventional medical practitioners and CAM practitioners regarding their use of CAM for back pian is being undertaken. A critical review of literature on use of chiropractic and massage therapy for back pain is also in progress.

The title of the research project has changed to: " The use of Complementary and Alternative Medicine for back pain by women across Australia"

1.6 Completed student projects

Project: A321	**Does physical activity contribute to better memory? Findings from the Australian Longitudinal Study on Women's Health?**
PhD Candidate:	Yirui Wang (School of Psychology, The University of Queensland)
Supervisors:	• Professor Nancy Pachana (School of Psychology, The University of Queensland) • Professor Wendy Brown (School of Human Movements Studies, The University of Queensland)

This research examined the prevalence of physical activity (PA) and sedentary behaviour (i.e., prolonged sitting) in a sample of 5470 middle-aged Australian women participating in the Australian Longitudinal Study on Women's Health. It also explored the relationship between PA and memory complaints. Participants included a large, national sample of community-dwelling, relatively healthy women who reported no difficulty walking 100 meters and had no missing values on the main outcome or explanatory variables. For this research, data collected at the surveys in 2004, 2007 and 2010 were used. The results indicated that a substantial proportion of the middle-aged Australian women achieved or exceeded the recommended 150 minutes per week of moderate-intensity PA (64.3% in 2004, 68.2% in 2007, and 65.7% in 2010). Contrary to expectation, the self-reported levels of leisure/transport PA increased from 2004 to 2010. Further investigation revealed that women with low education, low socio-economic status, high body mass index (BMI), and smokers may be less likely to meet the recommendation. The average sitting time among these women was high (42.60 hours per week in 2004, 45.80 hours per week in 2007, and 45.07 hours per week in 2010); working women and women with high BMI were more likely to report longer sitting time. The cross-sectional analyses indicated that a higher level of total PA (including leisure/transport and intense domestic PA) was associated with a lower rate of perceived decline in memory function. The association remained true following adjustment for a number of confounding variables in two of the three surveys. The research highlights the need for more empirical work, especially intervention studies, to understand the complex relationships between PA and memory complaints.

Project: A405	**Difference in dietary patterns amongst cancer survivors in rural versus metropolitan regions**
PhD Candidate:	Jennifer Potter (The University of Newcastle)
Supervisors:	• A/Professor Deborah Loxton (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Clare Collins (School of Health Sciences (Nutrition and Dietetics), The University of Newcastle) • Dr Alexis Hure (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Dr Leanne Brown (University Department of Rural Health and Rural Clinical School)

The thesis has now been submitted and is being examined. The results are summarised below:

Abstract: Purpose Evidence supports strong associations between healthy eating patterns and favorable health outcomes for breast cancer survivors (BCS). The purpose of the present study was to evaluate the diet quality of Australian BCS and determine if diet quality differed between BCS and age-matched healthy controls (HC) or by geographic location.

Methods: This cross-sectional study included 281 BCS and 4069 HC from the Australian Longitudinal Study on Women's Health (ALSWH) mid-aged cohort completing survey three in 2001. Data from the Dietary Questionnaire for Epidemiological Studies Food Frequency Questionnaire were used to calculate the Australian Recommended Food Score (ARFS), a validated summary estimate of overall diet quality based on adherence to the Australian dietary guidelines.

Results: The mean ARFS of the BCS group was 33.2 + 9.4 out of a maximum of 74. Higher ARFS amongst BCS was associated with higher nutrient density and lower percentage of energy from total

and saturated fat (P<0.01). Mean total ARFS and component scores of BCS did not differ from the HC group (P>0.05) and no differences were found in ARFS between urban and rural BCS (P>0.08).

Conclusions: This study is the first to describe diet quality of Australian BCS. Given known associations between higher diet quality, reduced risk of morbidity, breast cancer specific and all-cause mortality, the current data indicate there is a strong rationale to target improvements in diet quality of Australian BCS. Research targeting diet quality improvements on health outcomes of the Australian BCS population across their breast cancer journey is warranted.

A manuscript will be will be submitted to the journal *Cancer Causes and Control* later this year or early 2013 when feedback from the thesis examiner has been received and addressed.

Jennifer Potter presented the project now titled "Diet Quality of Australian Breast Cancer Survivors: A Cross Sectional Analysis from the Australian Longitudinal Study on Women's Health" for part requirement for assessment for the honours component for B.Nutrition and Dietetics (Hons) program at the University of Newcastle and was also scheduled to present at the Hunter Cancer Research Symposium on the 2nd November 2012.

Project: A419	**Stroke impact in older Australian women: A cohort study using self-reported longitudinal data.**
Honours student:	Claire Grennall (Faculty of Health, The University of Newcastle)
Supervisors:	• Isobel Hubbard (School of Medicine & Public Health, The University of Newcastle) • Professor Julie Byles (Research Centre for Gender, Health and Ageing, The University of Newcastle) • Professor Christopher Levi (Acute Stroke Services, Hunter New England Health)

The aim of this study is to describe experiences and outcomes for Australian women born between 1921 – 1926 who report.

The first phase of the analysis included comparison of the written comments for women who reported stroke at Survey 1 in 1996, and those who did not report stroke. This analysis is the basis of Clare Grenall's honours thesis: Stroke survival and lived experiences post stroke in older Australian women: A mixed methodology study. A parallel analysis involves qualitative analysis of the outcomes for women reporting stroke including survival and health related quality of life.

Compared to women with no history of stroke, women reporting stroke at Survey 1 were less likely to survive to Survey 5, those who did survive were more likely to experience difficulties in physical function, social function and mental health ($p < 0.001$).

2012 research activities:

- March 2012: University presentation given as part of course HLSC 4310. Presentation on overview of study including background information, study design and methods.
- October 2012: University presentation given as part of course HLSC 4310. Presentation on study results including background information, study design, methods, findings, discussion, conclusions and study strengths and limitations.

2. Conduct of surveys

2.1 Online survey infrastructure

Two new servers and DatStat Illume, a software package that provides a research platform for electronic data capture, were purchased towards the end of 2011 to facilitate the administration of online surveys. Each server provides a failover solution for the other server. Illume and the existing ALSWH Microsoft SQL Server database are hosted on the new servers. Illume integrates with the ALSWH MS SQL Server database to update survey completion status and participant details.

2.2 1921-26 cohort Survey 6 – Final response rate

Survey 6 of the 1921-26 cohort was mailed to 5,801 participants in 2011 when the women were aged between 85 and 90. The planning, development and piloting of this survey were previously described in Technical Report 33, while the mailout and collection of the surveys was described in Technical Report 34. Completed surveys were accepted until March 2012. Table 2-1 details the final response rates for Survey 6 of the 1921-26 cohort. Completed surveys were received from 4,055 women, which represents 70% of those mailed.

Table 2-1 Response rates for the 1921-26 cohort Survey 6

	N	%
Completed surveys	4,055	70
Deceased	159	2
Withdrawn	281	5
Not this time	273	5
Absent	1	0
No response	1,032	18
Total mailed	**5,801**	**100**

2.3 1973-78 cohort Survey 6 – Pilot mailout, data collection and response rates

The planning and development of the 1973-78 cohort Pilot Survey 6 was previously described in Technical Report 34 (December 2011). The survey was offered in two formats, online and paper, in a randomised control trial. Data collection began on 17th November, 2011 when the online survey was made available on the SurveyMonkey website, invitations (mailed and emailed) to complete the survey online were sent to an 'online' group, and paper surveys were mailed to a 'paper' group.

At the first follow-up, both groups were either mailed or emailed a reminder, and participants in each group who had provided a mobile phone number were sent an SMS message as a second follow-up reminder. The third follow-up became the crossover point where the online group were mailed a survey and the paper group were sent an invitation to participate online. Those who had a valid email address received an email invitation, while those who did not have an email address, or if the one on record bounced, received a letter inviting them to participate online. As a final follow-up telephone reminders were made from the end of February, 2012. The change in process meant that participants had the option of completing it either on paper or online.

The new mailing protocol was approved by ethics committees at both the University of Newcastle and the University of Queensland and is summarised in Figure 2-1, Figure 2-2, Figure 2-3 and Figure 2-4.

Figure 2-1 1973-78 cohort Pilot Survey 6 - paper survey group

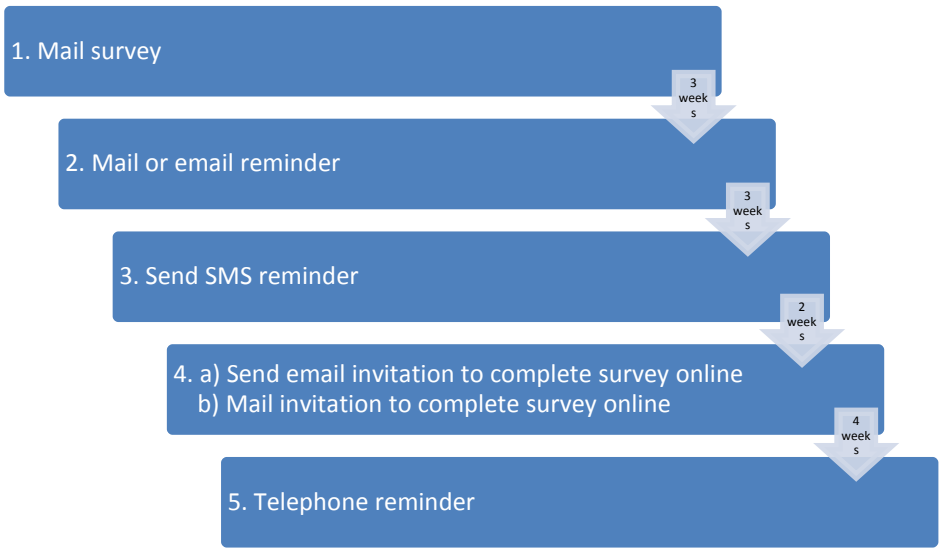


Figure 2-2 1973-78 cohort Pilot Survey 6 - online survey group

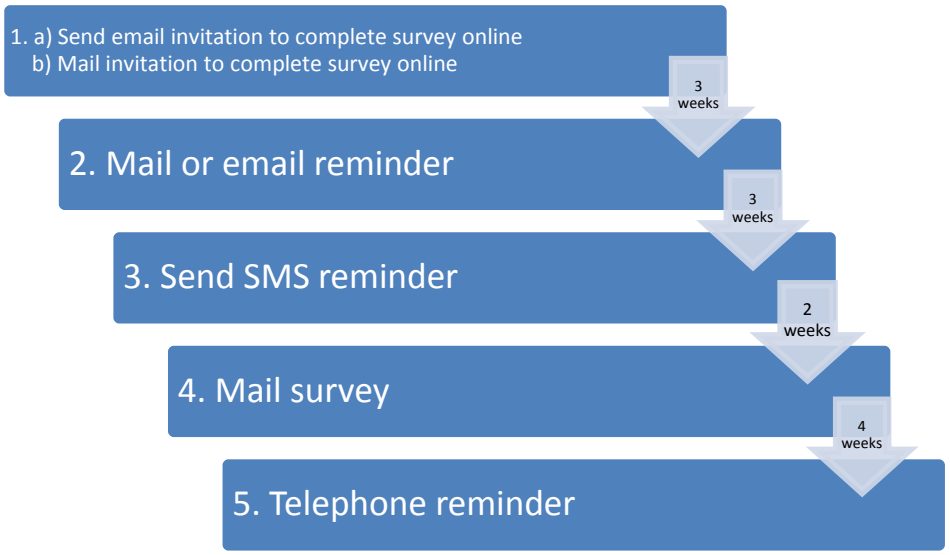


Figure 2-3 1973-78 cohort Pilot Survey 6 – protocol for reminders for incomplete surveys

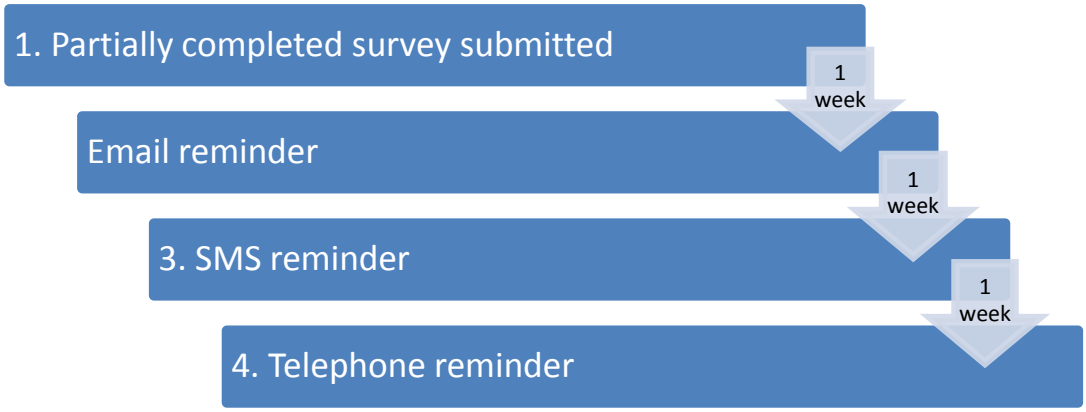
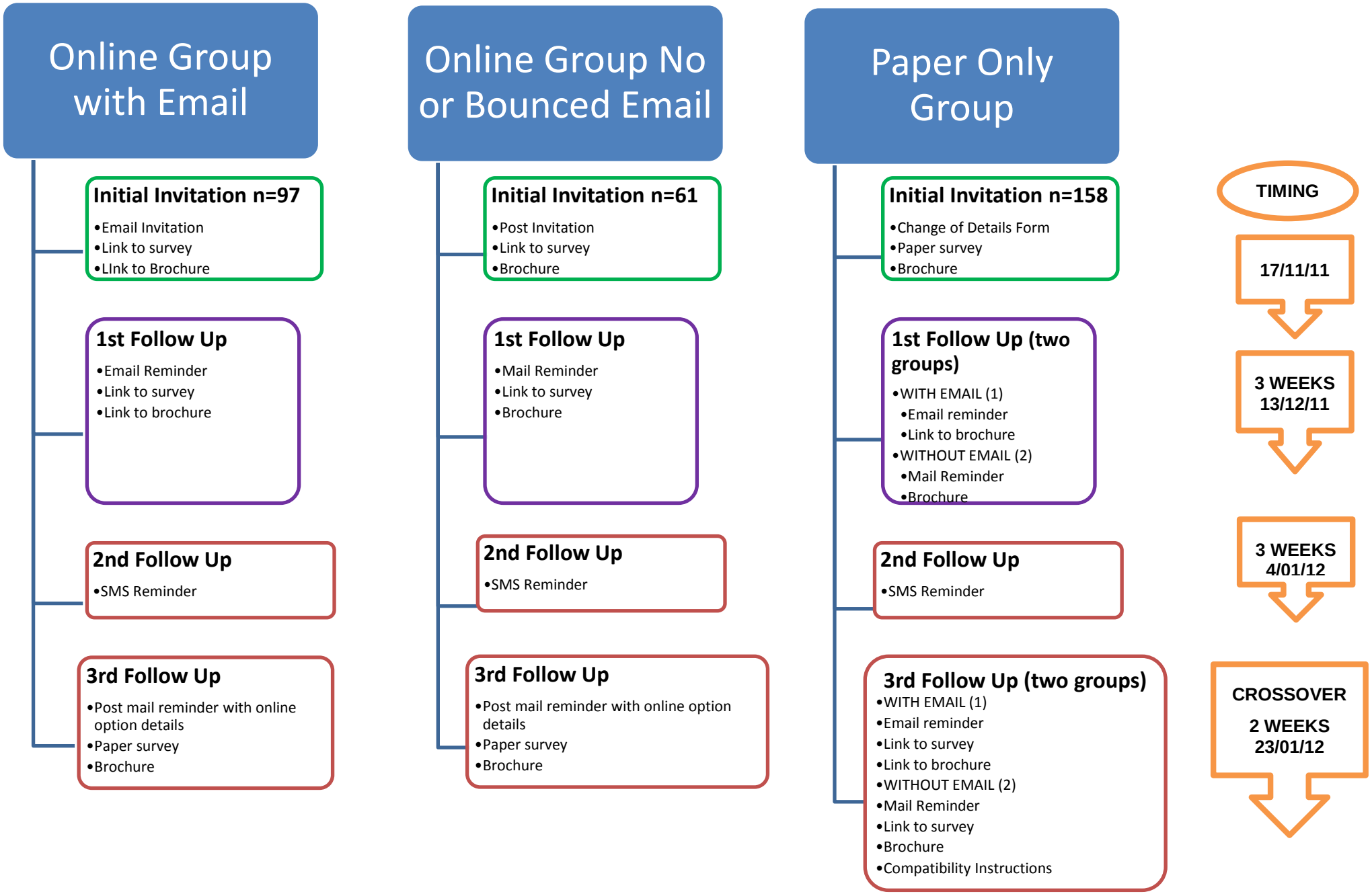


Figure 2-4 Pilot Survey 6 RCT flowchart for online & paper survey groups (overleaf)


Online Group with Email
Initial Invitation n=97
•Email Invitation
•Link to survey
•LInk to Brochure
1st Follow Up
•Email Reminder
•Link to survey
•Link to brochure
2nd Follow Up
•SMS Reminder
3rd Follow Up
•Post mail reminder with online option details
•Paper survey
•Brochure
Online Group No or Bounced Email
Initial Invitation n=61
•Post Invitation
•Link to survey
•Brochure
1st Follow Up
•Mail Reminder
•Link to survey
•Brochure
2nd Follow Up
•SMS Reminder
3rd Follow Up
•Post mail reminder with online option details
•Paper survey
•Brochure
Paper Only Group
Initial Invitation n=158
•Change of Details Form
•Paper survey
•Brochure
1st Follow Up (two groups)
•WITH EMAIL (1)
•Email reminder
•Link to brochure
•WITHOUT EMAIL (2)
•Mail Reminder
•Brochure
2nd Follow Up
•SMS Reminder
3rd Follow Up (two groups)
•WITH EMAIL (1)
•Email reminder
•Link to survey
•Link to brochure
•WITHOUT EMAIL (2)
•Mail Reminder
•Link to survey
•Brochure
•Compatibility Instructions
TIMING
17/11/11
3 WEEKS 13/12/11
3 WEEKS 4/01/12
CROSSOVER
2 WEEKS 23/01/12

The numbers involved and the items included in the invitation, survey mailout or follow-up activity are summarised in Table 2-2.

Table 2-2 Mailout timetable for the 1973-78 cohort pilot Survey 6

Date	Group	Activity	Items	Number
17 Nov 2011	Paper	Initial invite - mailed	Package mailed including survey, reply-paid envelope, brochure and change of details card	158
17 Nov 2011	Online	Initial invite – email	Email invitation to complete online survey	97
17 Nov 2011	Online	Initial invite - mailed	Mail invitation, including change of details card, to complete online survey	61
22 Nov 2011	Online	Initial invite - mailed	Mail invitation, including change of details card, to complete online survey to those email addresses that bounce from email on 17/11	20
22 Nov 2011	Online	Initial invite – email	Email invitation to those email addresses that bounce and are able to be corrected from email on 17/11	6
13 Dec 2011	Paper	1st follow-up	First reminder leaflet mailed to all non-respondents	48
13 Dec 2011	Paper	1st follow-up	First reminder emailed to all non-respondents	67
13 Dec 2011	Online	1st follow-up	First reminder leaflet mailed to all non-respondents	68
13 Dec 2011	Online	1st follow-up	First reminder emailed to all non-respondents	49
16 Dec 2011	Paper	1st follow-up	First reminder leaflet mailed to those email addresses that bounced from email on 13/12	14
16 Dec 2011	Paper	1st follow-up	First reminder leaflet re-emailed corrected email addresses that bounced from email on 13/12	1
16 Dec 2011	Online	1st follow-up	First reminder leaflet mailed to those email addresses that bounced from email on 13/12	1
4 Jan 2012	Both	2nd follow-up	Text message to all non-respondents with mobile phone numbers	123
Dec 2011 – 23 Jan 2012	Paper	Extra mailouts	Package mailed including survey, reply-paid envelope, brochure and change of details card	14
5 Jan 2012	Online	Initial invite – email	Email invitation to complete online survey	4
23 Jan 2012	**CROSSOVER**			

Date	Group	Activity	Items	Number
23 Jan 2012	Paper	3rd follow-up	Email reminder / invitation to complete online survey	24
23 Jan 2012	Paper	3rd follow-up	Mail reminder / invitation to complete online survey	50
23 Jan 2012	Online	3rd follow-up	Package mailed including survey, reply-paid envelope, brochure and change of details card	87
Feb - Mar 2012	Both	Extra emails	Email invitations to complete online survey	16
Feb - Mar 2012	Both	Extra mailouts	Package mailed including survey, reply-paid envelope, brochure and change of details card	17
2 Mar 2012	Both	1st follow-up	First reminder leaflet mailed to those email addresses that bounced from email on 13/12	4
23 Feb -2 Mar 2012	Both	Telephone reminder	Phone call to all non-respondents with a phone number (339 attempted calls)	139 non respondents. Telephone reminder 93% complete

Response rates for the online and paper groups at the time of the crossover of the randomised control trial (23rd January 2012) are given in Table 2-3 while the final response rates are given in Table 2-4. The results of the randomised control trial are currently being analysed and will be written up as a paper.

Table 2-3 Response rates for the 1973-78 cohort Pilot Survey 6 online and paper groups at crossover on 23rd January 2012

	Online		Paper	
	N	(%)	N	(%)
Completed survey	64	40	76	48
Partially completed online survey	4	3	N/A	N/A
Withdrawn	1	1	N/A	N/A
No response	89	56	82	52
Total	**158**	**100**	**158**	**100**

Table 2-4 Final response rates for the 1973-78 cohort Pilot Survey 6

	Online		Paper	
	N	(%)	N	(%)
Completed online survey	70	44	8	5
Partially completed online survey	5	3	0	0
Completed paper survey	31	20	102	65
Withdrawn	1	1	2	1
Not this time	2	1	2	1
Absent	1	1	0	0
No response	48	30	44	28
Total	**158**	**100**	**158**	**100**

2.4 1973-78 cohort Survey 6 – Mailout and data collection

Planning for the main survey of the 1973-78 cohort began in February 2012. As online surveys received a similar response to paper surveys in the pilot survey trial, and they are also considerably less expensive than paper surveys, online surveys were introduced as an option for the main cohort. The mailing and reminder protocol used for the main cohort varied slightly from that used for the online pilot group, as the first follow-up was sent by post to everyone who had not completed the online survey. In the pilot, those that had an email address received the first follow up by email and those that didn't have email were followed-up by post. This change was made to simplify the mailing process and provide another means of contact for those who had received the email invitation.

The pilot survey was revised for the main cohort group by removing questions which were poorly answered - for example waist circumference and time use; or which had very low response rates - for example deletion of 'HIV or AIDS' as a diagnosis. Other questions were reworded and restructured to improve clarity - for example the childbirth and breastfeeding questions. The life event questions were scaled down to concentrate on events that could be reported more objectively and to minimise ambiguity. The sexual orientation question had not been asked of this group for a long time and was included to monitor change. Table 2-9 lists all the changes to the main survey from the pilot survey and Table 2-10 lists the deleted items.

Ethical approval was obtained for the changes to the mailing and reminder protocol as well as the changes to the survey. On 26th April 2012, the survey was published on Illume and invitations to complete the online survey (version 1) were emailed to those participants who had email addresses, and mailed to those who did not. Version 2 of the online survey, published on 30th April, corrected a spelling mistake in the question on sexual orientation i.e. "maily" to "mainly" and enabled mobile phone numbers to be recorded in the database.

In the pilot survey, ethics approval was obtained to omit the 'matching' statement 'I consent to the researchers 'matching' the information provided in this survey with that given in previous surveys so that any change in my health can be noted' from the signature box on the consent form, and no 'matching' consent question was included in the online survey. Instead, the statement 'Researchers will be comparing the information provided in this survey with that of surveys you have completed in the past' was included in the instructions for both the online and the paper versions of the pilot survey.

However, just prior to mailout of the paper survey to the main cohort, it was discovered that the previously omitted 'matching' statement ('I consent to the researchers 'matching' the information provided in this survey with that given in previous surveys so that any change in my health can be noted. Yes/No') had been included (in error) on the online survey, but not the paper survey. The

'matching' statement was removed from the online survey on 6th June 2012 (after permission was granted by the University of Newcastle HREC), creating version 3 of the online survey. Six women had already answered 'No' to the 'matching' statement and an ethics variation will be submitted in 2013 proposing that these participants be contacted to clarify their intent when responding to the 'matching' statement.

A further change in version 3 of the online survey allows participants who went back to work after the birth of their child to skip the next question - i.e. if any number is entered in the number of months box for the question "If you went back to work after the birth of your last child, how soon did you go back?" then skip the following question "If you did not go back to work after the birth of your last child…". is skipped.

Table 2-5 1973-78 cohort Main Survey 6 – dates of online versions and completion numbers

Version number	Dates in operation	Completed	Partial/Incomplete
1	26/04/2012 to 30/4/2012	1,040	21
2	30/04/2012 to 6/06/2012	2,114	48
3	6/06/2012 to date	1,287	60
Total		**4,441**	**129**

In the online survey, Q102 'In general, how satisfied are you with what you have achieved in each of the following areas of your life?' included a 'not applicable' response field for each item, while this response ('not applicable') was only included for the 'motherhood / children' item on the paper survey. This difference was identified during a comparison of each item in the online survey against each item in the printed survey. At the time, the online survey had already been completed by some women, and the 'not applicable' response had been used. To remedy this error, two options were available:

- add 'not applicable' response categories to all items in the paper survey, or
- remove the 'not applicable' response categories from the online survey to match the paper survey.

The first option has been adopted, which will allow compatibility between survey administration modes for the current survey. However, there is expected to be an impact from this change, in terms of losing backwards comparability with earlier surveys for the questions affected.

The reminder protocol for those that partially completed the online survey was changed from that used in the pilot, and the first reminder to this group was delayed a week to allow those that had been mailed the link to the survey a chance to complete it. The reminder protocol was repeated at approximately four weekly intervals, or as required, to capture new partially completed surveys in the reminder cycle.

Figure 2-5 outlines the mailing protocol for the survey and Table 2-6 and Table 2-7 detail the actual mailout activity, showing dates and quantities. Changes to the online and paper survey and to the mailout protocol that required an ethics variation caused delays to the mailout dates of some activities.

Figure 2-5 Flowchart for the 1973-78 cohort Survey 6 protocol

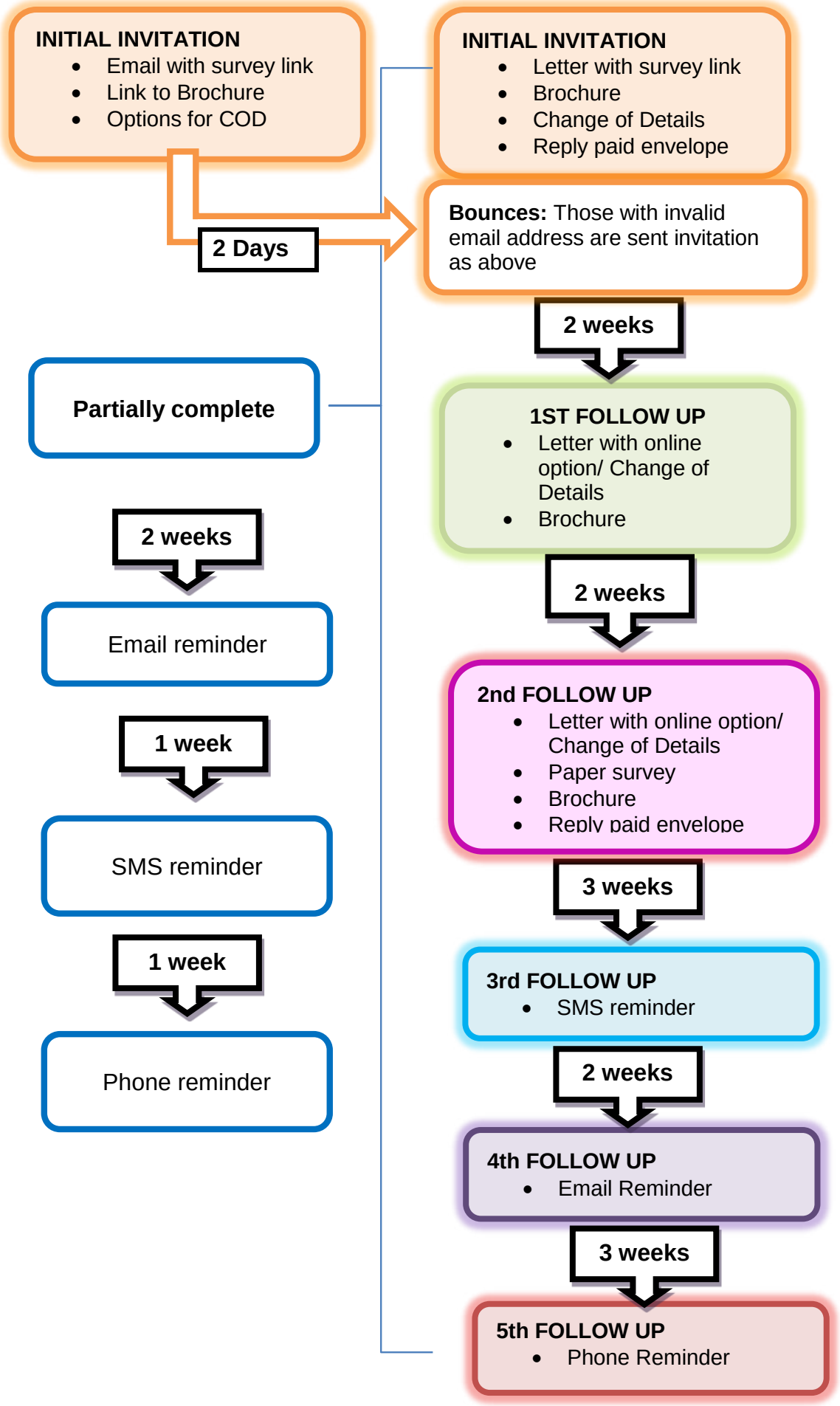


Table 2-6 Mailout timetable for the 1973-78 cohort Main Survey 6 at 21st November 2012

Date	Activity	Items	Number
26 Apr 2012	Initial invite – email	Emailed invitation to do online survey, including a link to the brochure	8,098
26 Apr 2012	Initial invite - mailed	Mailed invitation to do online survey, including brochure, change of details card and reply paid envelope	3,902
26 to 30 Apr 2012	Initial invite – email	Emailed invitation to do online survey, including link to the brochure, to email addresses that bounced and were able to be corrected from the email sent on 26 April	55
1 May 2012	Initial invite - mailed	Mailed invitation to do online survey, including brochure, change of details card and reply paid envelope, to email addresses that bounced from email sent on 26 April or who were going to be away from work for an extended time and to those who had been found during tracking since the initial invitation	1,565
2 May 2012	Email	Email to participants whose mobile phone number had not been captured by Illume	433
8 May 2012	Reminder letter	First reminder letter mailed, with change of details form and brochure, to all non-respondents	10,149
16 Jun 2012	Survey mailout	Package mailed including paper survey, online survey link, reply-paid envelope, brochure and change of details card	8,573
20 Jul 2012	SMS reminder	SMS reminder to do survey	4,551
3 Aug 2012	Extra emails	Email invitations to do online survey	2,314
5 Sep 2012	Extra emails	Email invitations to do online survey	1,674
Aug – Oct 2012	Telephone reminder	Phone call to all non-respondents with a phone number (4425 attempted calls)	4,629 non-respondents, telephone reminder 43% complete
As required	Extra mailouts	Package mailed including survey, reply-paid envelope, brochure and change of details card	741
As required	Extra email invitation	Emailed invitation to do online survey, including a link to the brochure	292

Table 2-7 Timetable for the 1973-78 cohort Survey 6 partial survey completers at 21st November 2012

Date	Mailout	Items	Number
10 May 2012	Email reminder	Email to partially completed more than one week ago	95
17 May 2012	SMS reminder	SMS reminder to partially completed more than two weeks ago	47
24 May 2012	Phone reminder	Phone reminder to partially completed more than three weeks ago	55
7 Jun 2012	Email reminder	Email to partially completed more than one week ago	76
14 Jun 2012	SMS reminder	SMS reminder to partially completed more than two weeks ago	64
21 Jun 2012	Phone reminder	Phone reminder to partially completed more than three weeks ago	As required
5 Jul 2012	Email reminder	Email to partially completed more than one week ago	12
12 Jul 2012	SMS reminder	SMS reminder to partially completed more than two weeks ago	12
2 Aug 2012	Email reminder	Email to partially completed more than one week ago	19
9 Aug 2012	SMS reminder	SMS reminder to partially completed more than two weeks ago	12
5 Sep 2012	Email reminder	Email to partially completed more than one week ago	21
10 Oct 2012	Email reminder	Email to partially completed more than one week ago	12

Table 2-8 gives the response rates for Survey 6 of the 1973-78 cohort at 16th November 2012. Completed surveys have been returned by 7,202 women, representing 59% of the 12,136 survey packages that were emailed or mailed.

Table 2-8 Response rates for the 1973-78 cohort Survey 6 (at 16th November 2012)

	N	%
Completed online survey	4,441	37
Completed paper survey	2,759	23
Completed telephone interview survey	2	0
Incomplete online survey	93	0.8
Deceased	5	0
Withdrawn	130	1
Not this time	72	0.6
Tracking	418	3
Lost to contact	82	0.6
No response	4,133	34
Total mailed	**12,136**	**100**

A mailed reminder, a mailed survey and an SMS reminder to non-respondents have been conducted. The telephone reminder to this cohort commenced in mid-August but was halted at the end of October 2012 due to staff shortages. Additional email and SMS reminders are planned, and an ethics variation requesting a change to the mailing and reminder protocol has been submitted.

Table 2-9 Changes table: 1973-78 cohort Survey 6 Pilot to 1973-78 cohort Survey 6 Main Survey

Main Survey 6 Item No	Topic	Source	1973-78 cohort Survey 6 Pilot to 1973-78 cohort Main Survey 6	
			Has the item changed? Why?	Is it an additional item? Why?
12	Diagnosis	Modified from Australian Bureau of Statistics (1991) 1989-1990 National health survey users' guide. Canberra: ABS. Cat No. 4363.0	Deleted answer option 'HIV or AIDS' as in all response rate has been 0% in all prior surveys.	
37	Ever given birth	ALSWH	Wording of item changed from 'Have you ever given birth to a child?' to 'Have you ever given birth?' as it is clear that the birth of a child is what is being referred to.	
38	DOB Children		Wording of item changed from 'If you have ever given birth to a child, please write the date of each birth in the box?' to 'If you have ever given birth, please write the date of each birth in the box?' as it is clear that the birth of a child is what is being referred to.	
39	Childbirth complications	ALSWH and Beyond Blue	The order of items was amended to group similar items together and more closely follow the timeline of events. i) Episiotomy was reworded from 'Episiotomy (cutting of vagina)' to 'Episiotomy (cut to perineum)' as prior wording was inaccurate. j) Forceps and ventouse suction (vacuum) were combined to become one answer option: instrumental delivery (forceps / vacuum). Instrumental delivery is the clinical classification for a delivery involving forceps or vacuum. k) Emotional distress was reworded to become 'emotional distress during labour' to ensure participants	

Main Survey 6 Item No	Topic	Source	1973-78 cohort Survey 6 Pilot to 1973-78 cohort Main Survey 6	
			Has the item changed? Why?	**Is it an additional item? Why?**
			understand the time period ALSWH are enquiring about. m) A high birth weight weighing more than 4000 grams or 81/2 pounds was added to allow birth weight classification (as low birth weight is an existing item). p) 'Death of a live born baby within the first month' was added to capture neonatal death. Answer options 'medical removal of placenta and / or blood clots by hand' and 'excessive blood loss requiring extra blood or fluid by drip (IV infusion)' were deleted. The accuracy of the reporting of these events is questionable and they are relatively infrequent occurrences.	
41	Ever breastfed	ALSWH		Yes. Additional item asking if participants have ever breastfed. This item allows participants who have not breastfed to skip the following sequence of questions on this topic that would not be applicable to them.
42	Breastfeeding	ALSWH		Yes. This item combines items asking which children had at least one breastfeed, length of time each child was breastfed and the currently breastfeeding item. Asking if a child had at least one breastfeed and how many months each child was breastfed captures information

Main Survey 6 Item No	Topic	Source	1973-78 cohort Survey 6 Pilot to 1973-78 cohort Main Survey 6	
			Has the item changed? Why?	**Is it an additional item? Why?**
				related to breastfeeding initiation and adherence to breastfeeding guidelines , which features in Major Report G.
68	Sitting	ALSWH	Item stem changed from 'How many hours in total…' to become 'In total, how much time…' as the prior wording was not well received by participants. Participants often answered in minutes, rather than hours. With the changed wording, this should no longer be an issue.	
77	Life events	Modified from Norbeck JS. (1984). Modification of live event questionnaires for use with female respondents. *Research in Nursing and Health*, 7, 61-71.	19 items in this question were deleted: - Birth of a child - Starting a new, close relationship - Problem or break up in a close personal relationship - Becoming a sole parent - Increased hassles with parents - Serious conflict between members of your family - Parents getting divorced, separated or remarried - Miscarriage - Death of a close friend - Difficulty finding a job - Return to study - Beginning / resuming work outside the home - Distressing harassment at work - Loss of job	

Main Survey 6 Item No	Topic	Source	1973-78 cohort Survey 6 Pilot to 1973-78 cohort Main Survey 6	
			Has the item changed? Why?	**Is it an additional item? Why?**
			- Partner losing a job - Decreased income - Major loss or damage to personal property - Legal troubles or involvement in a court case - Family member / close friend being arrested / in gaol - You or a family member involved in problem gambling The above answer options were deleted to reduce repetition and to allow concentration on objective stress causing events and minimise ambiguity. e) 'Getting married or starting to live with someone' was amended and became simply 'getting married' to focus on the bigger event. The 'divorce or separation' answer option was split into two answer options: f) Divorce g) Separation The splitting of answer options allows definition of the two situations as individual experiences that apply to varying situations and types of relationships. The split also replaces the deleted answer option 'problem or break up in a close personal relationship'. Answer option 'death of a partner or close family member' was split into two answer options: h) Death of a partner i) Death of a parent This change removes ambiguity about who has died and keeps the item specific.	

Main Survey 6 Item No	Topic	Source	1973-78 cohort Survey 6 Pilot to 1973-78 cohort Main Survey 6	
			Has the item changed? Why?	Is it an additional item? Why?
99	Sexual orientation	ALSWH		Item has not been included in surveys of this cohort for nine years. Sexual orientation may have changed for some participants in this time, additionally, sexual orientation can influence health.
102	Life satisfaction	ALSWH	Check boxes had to be included under “Not applicable” for all options i.e. a to g because online surveys require all boxes to be used for all options.	

Table 2-10 Items deleted from Pilot Survey 6 to Main Survey 6 - 1973-78 cohort

Pilot Survey 6 item number	Topic	Source	Reason for deletion
18	HPV Vaccine	ALSWH	The HPV vaccine was recommended and free for a period of time for women under 25. Consequently, a low number of women in the 1973-78 cohort received the vaccine and they will be unlikely to receive it in the future.
43	Currently breastfeeding	ALSWH	This item, along with 44 (below), were deleted and then incorporated into a new item (item 44 in Y6 Main).
44	How long breastfeed?	ALSWH	See above
55	Waist circumference	ALSWH	This item had very high levels of missing data in the past.

Pilot Survey 6 item number	Topic	Source	Reason for deletion
92-93	Time use	Modified from Australian Bureau of Statistics (1993) Time use survey, Australia, 1992: user's guide. Canberra: ABS. Cat No. 4150.0.	Item poorly answered in the past..
94	Sitting: work and non-work days	ALSWH	Item poorly answered in the past.
95	Sleep	ALSWH	Item poorly answered in the past.
105	Percentage of income on housing	ALSWH	Item was not answered well in the past, for example, in the Y6 Pilot, 13% missing responses for the paper survey and 14% missing responses using the online survey.

2.5 1946-51 cohort Survey 7 – Planning and development

Planning for the 1946-51 cohort Pilot Survey 7 began in May 2012. As for the previous 1973-78 cohort survey, participants will be able to complete the survey either online, or by the usual paper survey. The online survey will be offered using Illume software. The online and paper surveys have the same wording and question order and all changes from the sixth survey will apply to both methods.

In order to facilitate the online survey some changes to the instructions, consent form and the stress question were made. These changes align the text in this survey with that in the 1973-78 cohort Survey 6. The entire Food Frequency Questionnaire (as opposed to brief version included in Survey 6) was added to the survey, as it has been over 10 years since participants completed the full version. Some questions that were no longer relevant, like the menopause and menstrual frequency questions, were removed. Questions that are no longer used by researchers, for example the option “prayer or spiritual healing” in the complementary and alternative therapies question were removed. Other questions like the Life Events questions and the elder abuse questions have been cut down. Removing these questions helps reduce questionnaire burden on respondents. Changes from Survey 6 to Pilot Survey 7 are shown in Table 2-13, with deletions shown in Table 2-14.

The mailing and reminder protocol for Survey 7 is shown in Figure 2-6. It is the same as the protocol for Survey 6 of the 198-73 cohort, except for one change - a second email reminder to women who only partially completed the online survey will be made two weeks after the first email reminder, and one week after the first SMS reminder. The reminder protocol is repeated at approximately four weekly intervals, or as required, to capture new partially completed surveys in the reminder cycle.

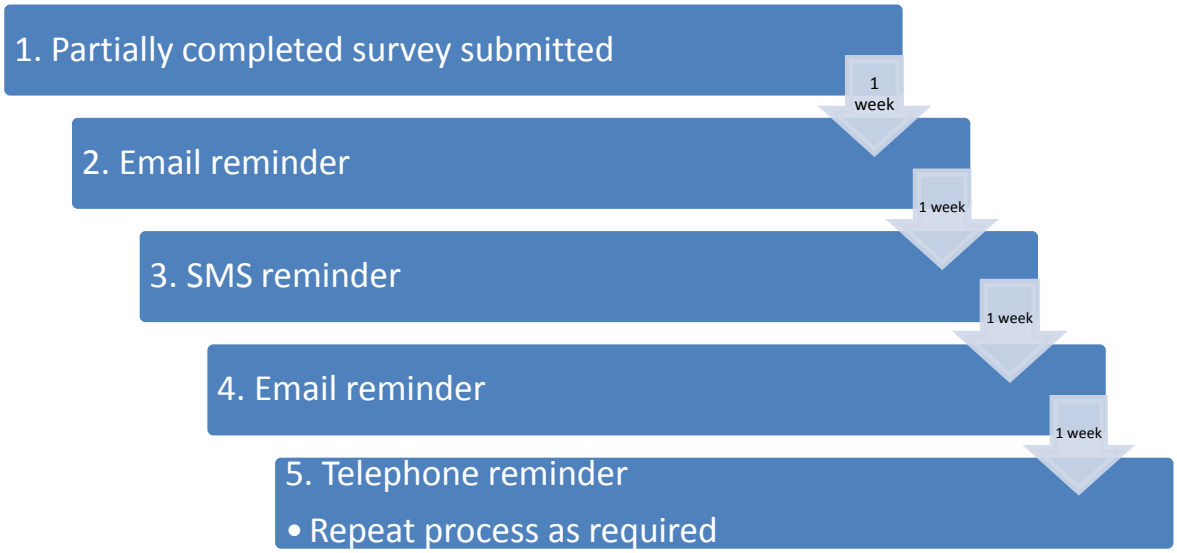


Figure 2-6 Reminder protocol for respondents who only partially completed the survey.

Ethics approval of changes proposed for the 1946-51 Pilot cohort Survey 7 was received in September, but the launch was postponed due to delays in receipt of the funding for the project. The funding was received in early November and the Illume online survey was published on 16th November 2012. Figure 2-7 outlines the planned mailing protocol for the survey and Table 2-11 and Table 2-12 provide details of mailout activity.

Figure 2-7 Flowchart for the 1946-51 cohort Survey 7 protocol

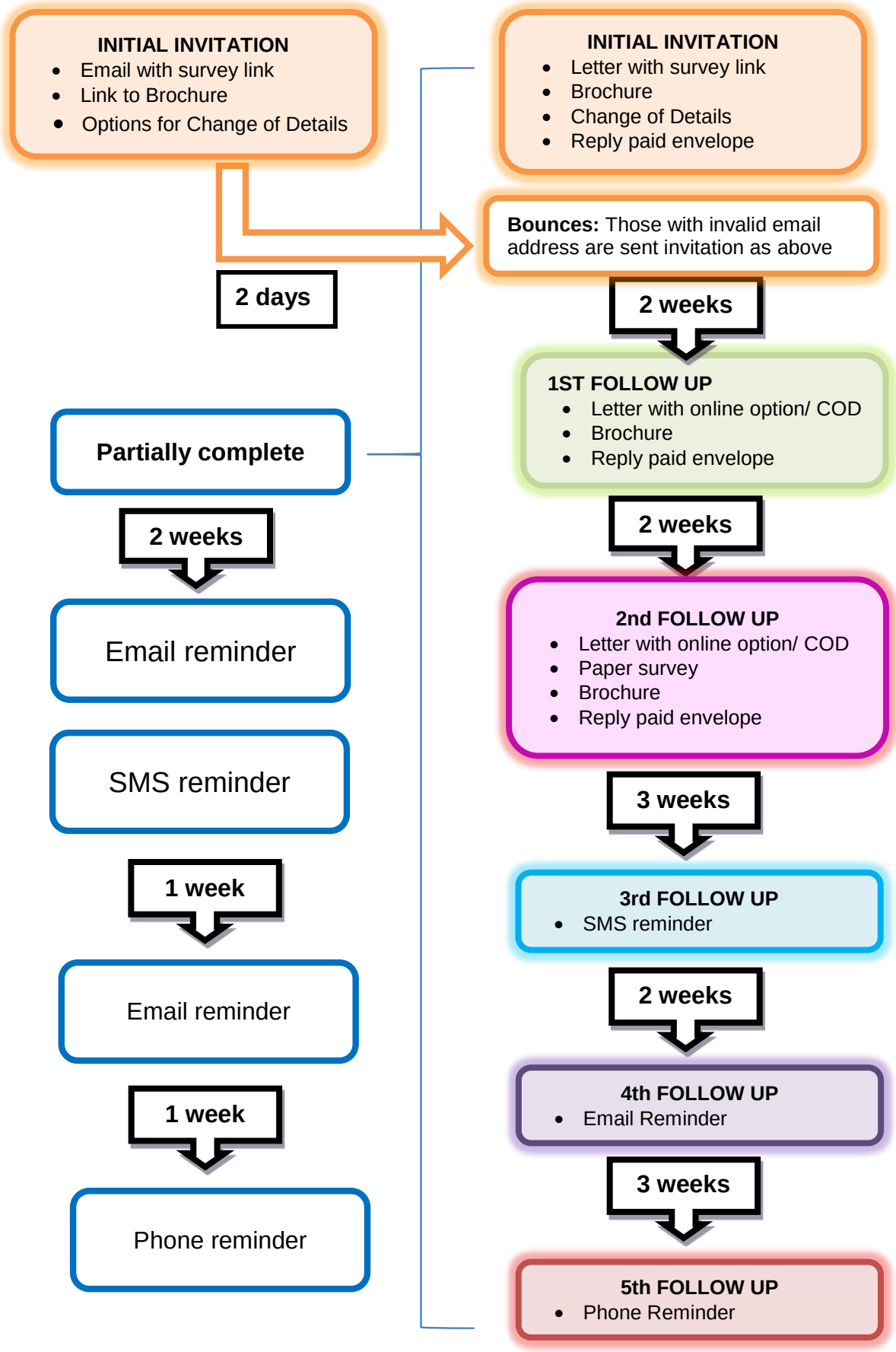


Table 2-11 Timetable for the 1946-51 cohort pilot Survey 6 (at 18th December 2012)

Date	Activity	Items	Number
16 Nov 2012	Initial invite – email	Emailed invitation to do online survey, including a link to the brochure	208
16 Nov 2012	Initial invite - mailed	Mailed invitation to do online survey, including brochure, change of details card and reply paid envelope	129
20 Nov 2012	Initial invite – email	Email invitation to do online survey, including a link to the brochure, to those email addresses that bounced and were able to be corrected from the email sent on 16 November.	2
20 Nov 2012	Initial invite - mailed	Mail invitation to do online survey, including brochure, change of details card and reply paid envelope, to those email addresses that bounced from the email sent on 16 November or who were going to be away from work for an extended time and to those who had been found during tracking since the initial invitation	57
30 Nov 2012	Reminder letter	Mail first reminder, with change of details form and brochure, to all non-respondents	277
14 Dec 2012	Survey mailout	Mail package including letter with online survey link, paper survey, brochure, change of details card and reply-paid envelope	240
4 Jan 2013	SMS reminder	SMS reminder to complete survey	As required
As required	Extra emails	Email invitations to do online survey	As required
As required	Extra mailouts	Mail package including letter with online survey link, paper survey, brochure, change of details card and reply-paid envelope	As required
7 Jan 2013	Telephone reminder	Phone call to all non-respondents with a phone number	As required

Table 2-12 Timetable for the reminders for women in the 1946-51 cohort who only partially completed Survey 7 (at 20th November 2012)

Date	Mailout	Items	Number
30 Nov 2012	Email reminder	Email to partially completed more than one week ago	As required
7 Dec 2012	SMS reminder	SMS reminder to partially completed more than two weeks ago	As required
14 Dec 2012	Email reminder	Email to partially completed more than three weeks ago	As required
7 Jan 2013	Phone reminder	Phone reminder to partially completed more than four weeks ago	As required

Table 2-13 Changes table: 1946-51 cohort Pilot Survey 6 to 1946-51 cohort Main Survey 6

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	Is it an additional item? Why?
p.2	Instructions/ linkage information	ALSWH	Top text box - added 'Researchers will be comparing the information provided in this survey with that of surveys you have completed in the past'. Sentence is a restructured version of the sentence deleted from the consent page. This change aligns the text in this current survey with the 2012 1973-78 cohort Survey 6, which was deemed more accurately worded.	
13	Specialist Consultations	ALSWH	Added Dentist answer option at h as other dental items were deleted from the survey for brevity and to minimise repetition	
14	Complementary and Alternative Therapies	ALSWH	Deleted answer option f) prayer or spiritual healing. This was not being utilised by researchers and due to the addition of the full Food Frequency Questionnaire (FFQ), space is limited.	
23	Screening – breasts, bowels, bones, vaccinations	ALSWH	Deleted: - e) 'Had a reminder from your general practice to have a screening test (e.g. blood pressure, cholesterol, blood sugar, skin)?' which suggests *thought* about action (having screening tests), whereas the answer options remaining in this item are action focused, e.g., 'in the past three years, have you had your skin checked...'. Added: e) 'been vaccinated for influenza (the 'flu') f) Had a pneumococcal vaccine (also called PPV, for pneumonia) upon recommendations from The Royal Australian College of General Practitioners Guidelines for Preventive Activities in General Practice (The Red Book) for women in this age group.	
24	HRT/Pill	Modified from Australian Bureau of Statistics (1991). *1989-1990 National Health Survey Users' Guide.* Canberra: ABS. Cat No. 4363.0	Added answer option c) other hormones? following feedback from participants in past 1946-51 cohort surveys to recognise that there are forms of hormones in use other than HRT and mini pill.	

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
30	Diagnoses	Modified from Australian Bureau of Statistics (1991). *1989-1990 National Health Survey Users' Guide.* Canberra: ABS. Cat No. 4363.0	New answer options: w) Macular degeneration x) Cataracts y) Glaucoma Added to align with National Health Survey and Australian Institute of Health and Welfare recommendations. The survey has not had many questions about vision and the conditions listed are common in women of this age group.	
32	Operations/ procedures	ALSWH	Added answer option: n) Gastric banding surgery Gastric banding was a stand-alone item in the last survey of this cohort. It has been added to operations and procedures for brevity and to group similar items together.	
35	Medications/ vitamins/ supplements	ALSWH	Added answer option: c) Medications to help you sleep? This answer option has been part of the sleep question in the most recent 1921-26 survey but never asked of the 1946-51 cohort.	
36	Medications/ vitamins/ supplements	ALSWH	Rather than open text boxes for participants to enter the medications and supplements they take, there is now a list of common medications and supplements to choose from in addition to extra lines to write 'others' not listed. The answer options are as follows: a) Glucosamine b) Paracetamol c) Omega 3 (eg fish oil) d) Calcium tablets / Caltrate e)Vitamin D f) Vitamin C g) St John's Wort (eg Hypericum perforatum) h) Vitamin B or Vitamin B Complex	

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
			i) Multivitamins j) Aspirin (eg Aspro Clear) k) Magnesium supplements l) Ventolin (salbutamol) m) Other (please specify) This list contains only over-the-counter (OTCs) medications/supplements/vitamins as prescribed medications will come from PBS data. The list is comprehensive to gain as much information as possible in the pilot. Participants can add anything else in the 'other' answer option. This will allow the compilation of the most common OTCs for the main survey. The list for the pilot survey was compiled using the top ten most common OTCs from ALSWH Survey 6 for the 1946-51 cohort, 45 and up survey data and recommendations from Professor David Sibbritt.	
39	Symptoms	ALSWH (survey 1) with revisions	Deleted column B as it has not been filled in well in past surveys and reduce burden on participants. Deleted answer option 'toothache' as this issue is covered by the broader answer option q) mouth, teeth or gum problems.	
40	Stress	ALSWH	Check boxes have been included under "Not applicable" for option "a) Own health", "d) Living arrangements" and "f) Money". These had to be included because online surveys do not have the option to leave boxes out.	
42	Happiness scale	National Social Life, Health and Ageing Project (NSHAP)		Yes. This item has been included in ALSWH 1921-26 cohort Survey 6. The 1946-51 cohort surveys did not have an item looking at happiness levels. It will be useful in combination with the depression, anxiety and

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
				stress scales in measuring well-being.
47	Weight control strategies	French, S.A., Story, M., Downes, B., Resnick, M.D., Blum, R.W. (1995) Frequent dieting among adolescents: Psychosocial and health behaviour correlates. American Journal of Public Health, 85(5): 695-701.	Added another example to answer option b – 'Tony Ferguson' as it is a popular weight loss method and to make our item more comprehensive.	
48-50	Alcohol status	Modified from National Heart Foundation of Australia (1990). Risk factor prevalence study Survey no. 3 1989. National Heart Foundation of Australia and Australian Institute of Health.	Wording of item was changed to include 'standard' when asking how many alcoholic drinks a participant consumes. 49) 'On a day when you drink alcohol, how many standard drinks do you usually have?' 50) 'How often do you have five or more standard drinks on one occasion?'	
52	Soft-drinks	ALSWH		Yes. This item has been included in surveys of the 1973-78 cohort. It has been included here to augment the FFQ. It is a more comprehensive item on this topic than past 1946-51 cohort surveys.
76	Time use	Modified from Australian Bureau of Statistics (1993) *Time use survey, Australia, 1992: user's guide.* Canberra: ABS. Cat No. 4150.0.	Added two answer options: k) Socialising l) Buying goods and/or services (eg paying bills, shopping) Socialising was added to recognise participants' comments that they have diverse ways to spend time and reflect the baby boomer image. Buying goods reflects generally how time is spent and the baby boomer as a consumer. Socialising has been part of Survey 3 for this cohort and both items were	

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
			included in the ABS Time Use Surveys (1992, 1997 and 2006).	
77	Time pressure	Modified from Statistics Canada, *Housing Family and Social Statistics Division* (1987) General social survey analysis series. Ottawa: Canadian Government Publication Centre. ISSN 0836-043X and Findings from 2006 ALSWH substudy on baby boomers by Meredith Tavener	Added four new answer options: c) That people ask too much of your time? d) That you can spend your time the way you want to? e) That you need more "me time"? f) That you have no control over how your time is spent? Participants in this cohort are either retired already or moving into retirement, which makes time use an important research area. The added answer options provide more detail on this topic. Qualitative data from a substudy on baby boomers conducted with ALSWH participants in 2006 showed women's time was not their own, and often expectations of having time were unable to be realised.	
88	Reason for care	2007 ALSWH Substudy 'Service utilisation and caregiving among mid-aged women'.		Yes. Item lists reasons for providing care and an 'other' option if response options provided are not appropriate. This question will provide greater detail in this area of ALSWH research. The list maybe reduced in the main survey, however in this pilot phase a comprehensive list is required to gain as much information as possible.
89	Stopping care	2007 ALSWH Substudy 'Service utilisation and caregiving among mid-aged women'.		Yes. Asking why a participant does not provide care or stopped providing care will provide information that we have

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
				not previously had and fulfil requests from participants that we ask about this.
91	Retirement status	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L2a.	Item stem has been simplified but answer options are the same.	
92	Ageism	Ageism survey developed by Palmore (2001).		Yes. New item that has been used in1921-26 Surveys 5 and 6. To make the item more appropriate to the 1946-51 cohort and explore ageism in the work place, answer option d) I was denied medical treatment because of my age, was added.
95	Current sources of income	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L22.	Added answer option 'other sources (please specify below)'. This is typical of ALSWH pilot surveys as it helps gain extra information to inform the items and in the main survey.	
96	Financial management	Original source: L23 in "Retirement" section of HILDA Wave 3 questionnaire and used in 2006 baby boomer retirement survey (ALSWH substudy).		Yes. Item replaces two questions in Mid 6 asking about sources of income when over 65 and how participants expect to manage when over 65. The item will allow

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
				ALSWH to learn if women have had to take specific action to manage financially since the last survey.
98	Elder abuse	Hwalek, M.A., & Sengstock, M.C. (1986). Assessing the probability of abuse of the elderly: Toward development of a clinical screening instrument. Journal of Applied Gerontology, 5(2), 153-173.	Six answer options have been deleted: - Are you sad or lonely often? - Can you take your own medication and get around by yourself? - Does someone in your family make you stay in bed or tell you you're sick when you know you are not? - Do you trust most of the people in your family? - Do you have enough privacy at home? - Does anyone in your family drink a lot of alcohol? Remaining eight answer options: - Do you feel uncomfortable with anyone in your family? - Do you feel that nobody wants you around? - Has anyone forced you to do things you didn't want to do? - Has anyone taken things that belong to you without your OK? - Has anyone close to you tried to hurt you or harm you recently? - Has anyone close to you called you names or put you down or made you feel bad recently? - Are you afraid of anyone in your family? - Have you ever been in a violent relationship with a partner/spouse? Modified to capture data most relevant for this cohort.	
99	Years when experienced	Modified from Hegarty KL, Sheehan M, Schonfeld C.		Yes. This item is an updated version of a

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
	violence	(1999) A multidimensional definition of partner abuse: development and preliminary validation of the Composite Abuse Scale. J Fam Violence, 14, 399-414.		similar question in the 5th survey for this cohort, to gain further information, particularly historic information, on abuse.
100	Life events	Modified from Norbeck, J.S. (1984). Modification of live event questionnaires for use with female respondents. Research in Nursing and Health, 7, 61-71. Revised in 2012 by ALSWH Data Management Group.	This question has been cut down to three items. The complete list is not used by many researchers, quality of items is not good and they contribute to questionnaire burden on respondents. Reported in Pachana, Brilleman & Dobson (2011), Reporting of Life Events over time: Methodological issues in a longitudinal sample of women. *Psychological Assessment, 23*(1); 277-281. The following were deleted: - Major personal illness -Major personal injury or involvement in a serious accident -Major personal achievement -Birth of a grandchild -Major surgery (not including dental work) - Going through menopause - Major decline in health of spouse or partner - Major decline in health of other close family member or close friend - Starting a new, close personal relationship - Infidelity of spouse or partner - Break up of close personal relationship - Divorce - Major conflict with teenage or older children - Child or other family member leaving home (due to marriage, to attend university etc) - Death of spouse or partner - Death of child - Death of other close family member - Death of close friend	

Pilot Survey 7 Item No	Topic	Source	1946-51 cohort Pilot Survey 7 to 1946-51 cohort Main Survey 7	
			Has the item changed? Why?	**Is it an additional item? Why?**
			- Changing your type of work/hours/conditions/responsibilities at work - Retirement - Your spouse or partner retiring from work - Being made redundant - Your spouse/partner being made redundant - Decreased income - Moving house - Natural disaster (fire, flood, drought, earthquake etc) - Major loss or damage to personal property - Being robbed - Legal troubles or involved in a court case - Family member/close friend being arrested/in gaol - You or a family member involved in problem gambling - Child or other family member returning home to live The remaining answer options are: -Being pushed, grabbed, kicked or hit - Being forced to take part in unwanted sexual activity - None of these events	
101	Childhood sexual abuse	ALSWH		Yes. Added to gain an estimation of childhood abuse in this cohort. It has also been used in the 4th survey of the 1973-78 cohort. Modified the item by adding an 'I prefer not to answer' answer option.
	Consent page	ALSWH	Maiden name deleted. We already have the information. Deleted wording 'I consent to the researchers 'matching' the information provided in this survey with that given in previous surveys so that any changes in my health can be noted' and added it to page 2 as per 1973-78 Survey 6 in 2012.	

Table 2-14 Deleted items from 1946-51 cohort Survey 6 Main to 1946-51 cohort Survey 7 Pilot

M6 item number	Topic	Source	Reason for deletion
26	Hysterectomy	ALSWH	Information on each of these topics has been collected in past surveys of this cohort. Participants will be aged 62-67 years at the time of the current survey, making it unlikely these events will occur again.
27	Menstrual frequency	Modified from Brambilla, DJ., McKinlay, SM., Johannes, CB. (1994) Defining the peri menopause for application in epidemiological investigations. *American Journal of Epidemiology*, 140(2), 1091-95	
28	Periods ceased	ALSWH	
29	Gestational diabetes	Modified from Australian Bureau of Statistics (1991). *1989-1990 National Health Survey Users' Guide.* Canberra: ABS. Cat No. 4363.0	
31	Dentists	Adapted from Anne Young's Health Care Access Substudy	This item has been added to question 13, specialist consultation, for survey brevity.
33-36	Oral health care	Modified from Carter, K.D., & Stewart, J.F. (2002). *National Dental Telephone Interview Survey 2002.* The AIHW Dental Statistics and Research Unit, University of Adelaide.	Deleted for brevity of the survey.
39	Memory	Crook III, T. M., Feher, E. P., & Larrabee, G. J. (1992). Assessment of memory complaint in age-associated memory impairment: The MAC-Q. International Psychogeriatrics, 4(2), 165-176. (Revised by ALSWH for Australian sample)	The MAC-Q was deleted as it has been found to be not useful as a specific screen of memory complaint for general population research - J Clin Epidemiol. Reid M, Parkinson L, Gibson R, Schofield P, D'Este C, Attia J, Tavener M, Byles J. (2012). Memory complaint questionnaire performed poorly as screening tool: validation against psychometric tests and affective measures. 65(2):199-205.
41	Sleep	ALSWH	Item has had a low response rate in past surveys and often not answered well.

M6 item number	Topic	Source	Reason for deletion
57	Weight loss or gain	ALSWH-modified from Mid phase 2	Deleted for brevity of the survey.
59	Gastric banding	ALSWH	Has been merged with operations/procedures item.
83	Frequency of sexual activity	ALSWH	Item has had a low response rate in past surveys. May be added back in at Survey 8 if space permits.
86	Share of tasks	ALSWH	Item has had a low response rate in past surveys. May be added back in at Survey 8 if space permits.
92	Paid work	ALSWH	This group of items have had a low response rate in past surveys and are often not answered well.
93-94	Paid and unpaid work	ALSWH	
95	Sitting	ALSWH	
97	Usual work/non-work day	ALSWH	
104	Retirement age choice	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L18.	The utility of the item was assessed and deemed to be not useful.
106	Expected sources of income	Modified from the Household, Income and Labour Dynamics in Australia (HILDA) Survey - Continuing Person Questionnaire, Wave 3, question L22.	Items have been replaced with 'financial management strategies' item and many participants are already 65 years (deleted items asked about plans after 65 years of age).
107	Retirement income management	ALSWH	
108	Highest level of education	GISCA. SEIFA Index of Education and Occupation.	Deleted to fit the FFQ in. It will return in the next survey of this cohort.

2.6 1921-26 cohort Six Month Follow-Up Survey 1

The questions in the Six Month Follow-Up (6MF) Survey remained the same as those in the pilot survey (see Tech Report 34), with the exception of an addition of a question on housing. The Six Month Follow-Up Survey 1 (6MF1) was mailed in batches, beginning on 11th November 2011, to 4,128 participants who had completed Survey 6. Participants who were unable to complete a paper survey, either by themselves or with the assistance of someone else, were phoned and the survey was completed over the phone with the interviewer, or an appointment was made to do the survey over the phone later. No paper reminders were mailed; instead a telephone reminder was conducted. On speaking to the participant, if she was doubtful that she would be able to complete the survey on paper a telephone interview was offered then or at a later date. A second mailout to 699 participants was sent on 15th February 2012 to participants who:

- completed Survey 6 late,
- did not complete Survey 6 at all,
- had said that they had mislaid their 6MF1 when reminded by telephone,
- or whose 6MF1 had been returned to sender and the correct address had now been found.

Table 2-15 Timetable for Six Month Follow-Up Survey 1

Date	Activity	Items	Number
Commenced 11 November 2011	Mailout 1	Package mailed including survey, reply-paid envelope, information letter and change of details card	4,128 mailed
Dec 2011 – May 2012	Phone call	Telephone interview	62 completed
Jan – Feb 2012	Phone call	Reminder phone calls to all non-respondents and phone surveys for those unable to complete themselves (1657 attempted calls)	1000 non-respondents telephone reminder 96% complete
15 Feb 2012	Mailout 2	Package mailed including survey, reply-paid envelope, information letter and change of details card	699 mailed

Table 2-16 shows the response rate to 6MF1.

Table 2-16 Response rates for Six Month Follow-Up Survey 1 at 21 November 2012

	N	%
Completed surveys	3,697	79
Deceased	161	3
Withdrawn	378	8
Not this time	135	3
No response	340	7
Total mailed	**4,711**	**100**

Participants who have not completed 6MF1 and who have not died, withdrawn or become lost to contact will continue to be sent a survey every six months. If they complete this survey, it will be counted as a survey completion of 6MF, even though it has been completed outside the period of the first survey. The process will be the same for subsequent surveys. If the participant does not wish to complete a survey at that time, but is prepared to complete one in six months' time, then the participant will be recorded as 'Not this time' for that survey.

2.7 1921-26 cohort Six Month Follow-up Survey 2

The 1921-26 cohort Six Month Follow-up Survey 2 (6MF2) commenced with the first mailout on 7th May 2012. Surveys were mailed to those participants who:

- had completed 6MF1 between five and six months ago,
- said that they did not want to do 6MF1 between five and six months ago, i.e. 'Not this time',
- had asked for a new survey to be sent,
- or who had not done 6MF1 and it had been mailed to them between five to six months ago.

This process was repeated each month for another five months.

Toward the end of the six month period, non respondents were phoned and reminded to complete their survey. If they had mislaid the survey they were added to the list of those to be sent a new survey, or if they were unable to complete a paper survey either by themselves or with the assistance of someone else, the survey was completed over the phone or an appointment was made to do the survey over the phone later.

Table 2-17 Timetable for Six Month Follow-Up Survey 2

Date	Activity	Items	Number
7 May 2012	Mailout 1	Package mailed including survey, information letter, change of details card and reply-paid envelope	3,079 mailed
5 Jun 2012	Mailout 2	Package mailed including survey, information letter, change of details card and reply-paid envelope	184 mailed
2 Jul 2012	Mailout 3	Package mailed including survey, information letter, change of details card and reply-paid envelope	142 mailed
6 Aug 2012	Mailout 4	Package mailed including survey, information letter, change of details card and reply-paid envelope	607 mailed
5 Sep 2012	Mailout 5	Package mailed including survey, information letter, change of details card and reply-paid envelope	204 mailed
5 Oct 2012	Mailout 6	Package mailed including survey, information letter, change of	426 mailed

Date	Activity	Items	Number
		details card and reply-paid envelope	
May 2012 to Oct 2012	Phone call	Telephone interview	150 completed
Sep to Oct 2012	Phone call	Reminder phone calls to all non-respondents of 6MF1 and phone surveys for those unable to complete themselves (838 attempted calls)	539 non-respondents, telephone reminder 77% complete
Sep to Oct 2012	Phone call	Reminder phone calls to all non-respondents of 6MF2 and phone surveys for those unable to complete themselves (1041 attempted calls)	927 non-respondents, telephone reminder 73% complete

Table 2-18 Response rates for Six Month Follow-Up Survey 2 on 21 November 2012

	N	%
Completed surveys	3,091	85
Deceased	90	2
Withdrawn	95	3
Not this time	25	1
No response	322	9
Total mailed	**3,623**	**100**

2.8 1921-26 cohort Six Month Follow-up Survey 3

The first mailout of the 1921-26 cohort Six Month Follow-up Survey 3 (6MF3) was posted on 12th November 2012. The planned timetable for the 6MF3 is outlined in Table 2-19. Surveys will continue to be mailed and telephone surveys and reminders will be conducted as for 6MF2.

Table 2-19 Timetable for Six Month Follow-Up Survey 3

Date	Activity	Items	Number
12 Nov 2012	Mailout 1	Package mailed including survey, reply-paid envelope, information letter and change of details card	1846 mailed
Dec 2012	Mailout 2	Package mailed including survey, information letter, change of details card and reply-paid envelope	As required
Jan 2013	Mailout 3	Package mailed including survey, information letter, change of details card and reply-paid envelope	As required

Date	Activity	Items	Number
Feb 2013	Mailout 4	Package mailed including survey, information letter, change of details card and reply-paid envelope	As required
Mar 2013	Mailout 5	Package mailed including survey, information letter, change of details card and reply-paid envelope	As required
Apr 2013	Mailout 6	Package mailed including survey, information letter, change of details card and reply-paid envelope	As required
Nov – May 2013	Phone call	Telephone interview	As required
Jan – May 2013	Phone call	Reminder phone calls to all non-respondents and phone surveys for those unable to complete themselves	As required

Table 2-20 Response rates for the 6MF3 on 21 November 2012

	N	%
Completed surveys	112	7
Deceased	15	1
Withdrawn	4	0
Not this time	1	0
No response	1,585	92
Total mailed	**1,717**	**100**

3. Methodological issues

3.1 How to create an online version of a past survey, and then upload data into it, using Illume software.

Ewan MacKenzie

3.1.1 Background

In 2012, ALSWH began offering surveys online using Illume software (produced by the company DatStat), which creates a database of survey information that can be downloaded. To create a comprehensive online database, data from surveys offered only on paper (i.e. all surveys prior to 2012) is now being uploaded into the Illume system. As well as expanding the data available to download, creation of a comprehensive online database of all ALSWH survey data will facilitate consistency in future survey creation, as existing coding and programs can be used when questions are repeated.

Here the process of building all pre-2012 ALSWH (or legacy) surveys in Illume and uploading the final datasets for each survey is described, and the steps taken to ensure all aspects of the data are available are documented.

There are three main steps involved:

- **Building the Survey in Illume** – A PDF copy of the survey, the Data Dictionary, and the Illume Survey Designer desktop application are used. When complete, the survey is published, and is then visible in the Illume Data Manager web application.
- **Creating the Illume Dataset** – A SAS program is downloaded from Illume, which, when run, creates an empty dataset with all variables created in the survey. This list of variables is then cross-checked with the variables in the current SAS dataset for that survey. Variables are renamed, added and deleted as necessary, and then a new SAS program is written to create a new dataset which assigns data from SAS into a dataset ready to be imported into Illume.
- **Importing the Dataset into Illume –** The Illume Import Data Tab (which must be enabled for each user who requires access to it) is used to repeatedly test the data import process until it is error-free. The data is then imported as production data in the survey.

These steps are outlined in detail below.

3.1.2 Building the Survey in Illume.

NOTE: This is not intended as a guide to building surveys in Illume - only important steps are outlined here.

There are two components to Illume – the desktop application Survey Manager, and the web interface Enterprise and Data Manager. For ALSWH, the Survey Manager (Figure 3-1) is used to design, build and publish the survey, while the Data Manager is used to import the data for the survey into Illume.

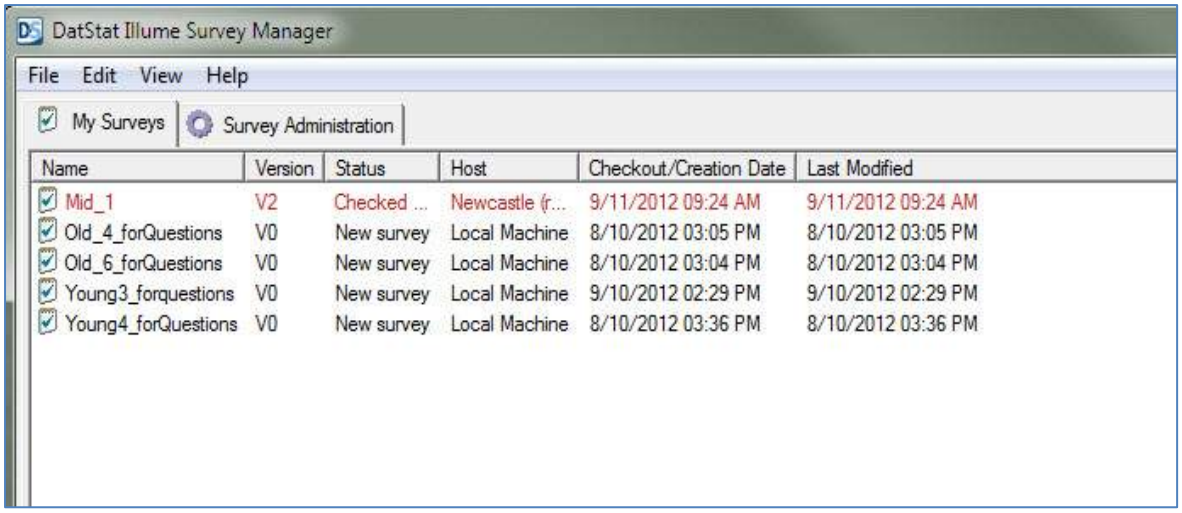


Figure 3-1: Illume Survey Manager (used to build the ALSWH surveys)

For each question in the survey, a search of the ALSWH Data Dictionary is done. Figure 3-2 shows the Data Dictionary search results for question 11 of the second survey of the 1946-51 cohort, or MID 2.

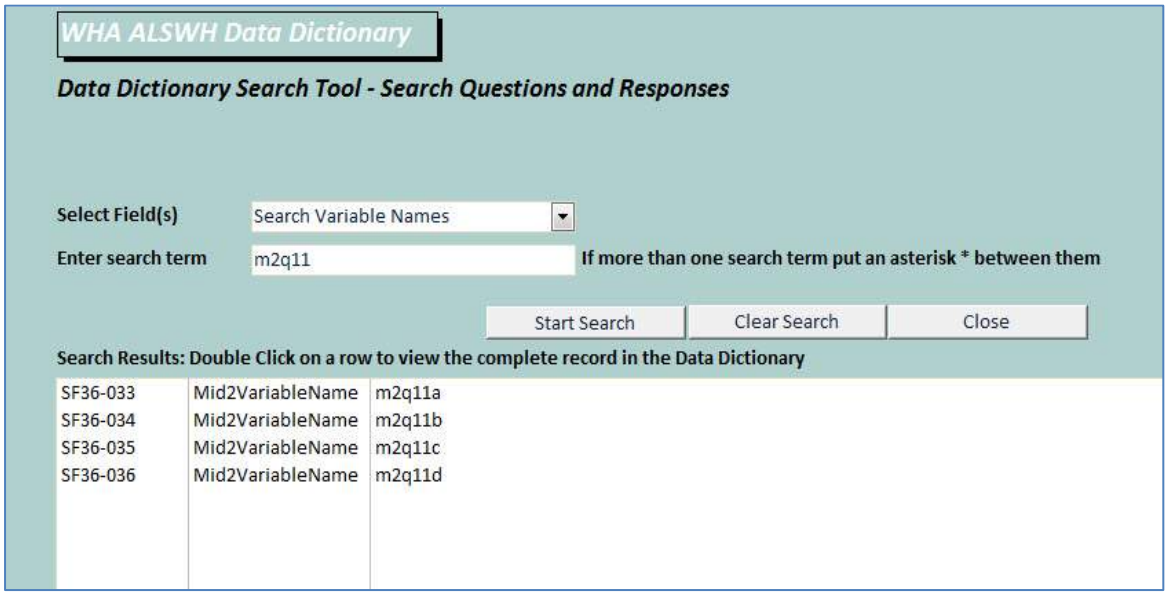


Figure 3-2: ALSWH Data Dictionary Search Results

For a single survey question, a new question is created in the Illume survey. The Index Number in the ALSWH Data Dictionary (without the dash) is assigned to the question in the Illume survey and becomes the variable name in the Illume Data Dictionary for that survey – e.g. m2q1 becomes SF36001 in the Illume version of the survey. The question description and responses are copied from the Data Dictionary into the Illume question.

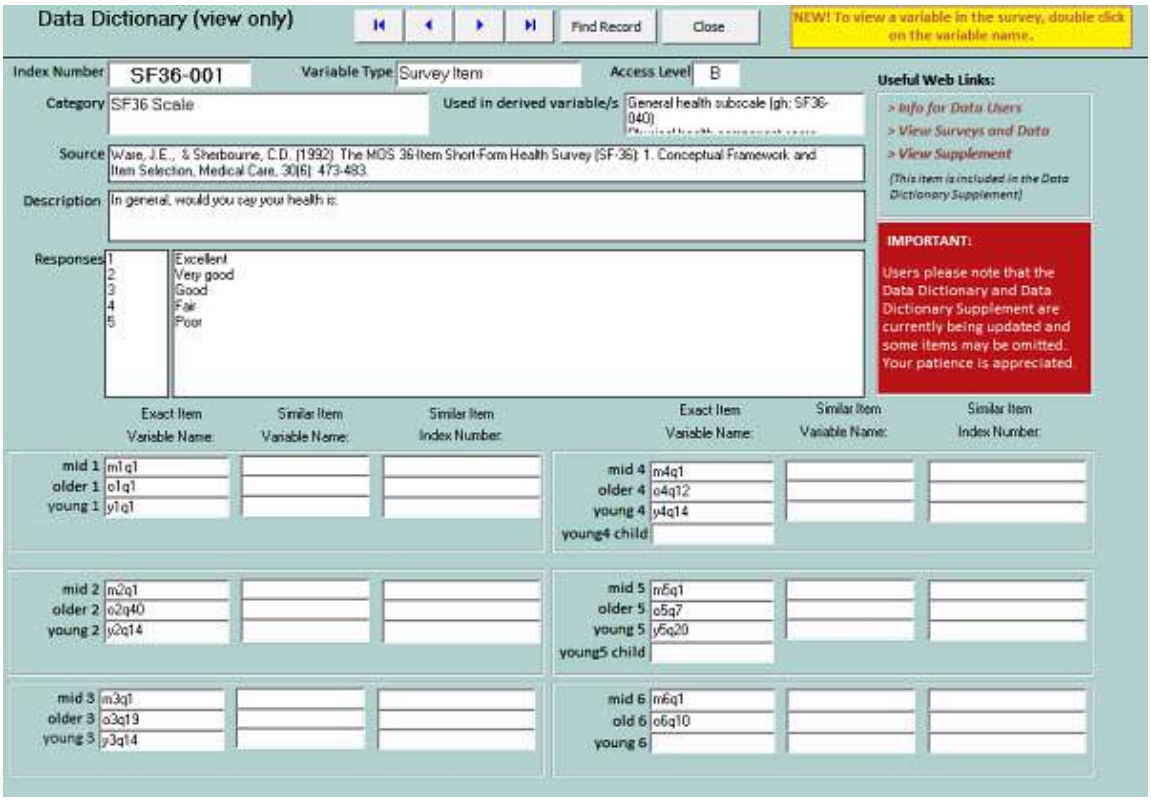


Figure 3-3: Data Dictionary record

For a survey question with multiple parts (a, b, c, etc.), a new question table is created in the Illume survey, and the question description and responses are copied from the ALSWH Data Dictionary into that question. In the prompts section, all the multiple sections of the question need to be entered. These then appear as subsections of the question table – Illume assigns identifiers such as Q1, Q2, etc. These should be changed for each sub-question to the Index Number for the part - e.g. m2q11 has four parts, a-d. The sub-questions in the Illume survey are given the identifiers SF36033, SF36034, SF36035, and SF36036. (Note that if the record for the variable in the ALSWH Data Dictionary shows that the question is in a survey previously built in Illume, it is possible to open that survey and copy the question into the current survey, updating any references to the previous survey to the current one).

These steps are repeated until the survey is complete. (Further changes to the survey may be necessary after subsequent steps).

Finally the survey is saved and published in the Illume Survey Manager. It will be empty and the next step is to create an Illume data set that will be used to populate the survey.

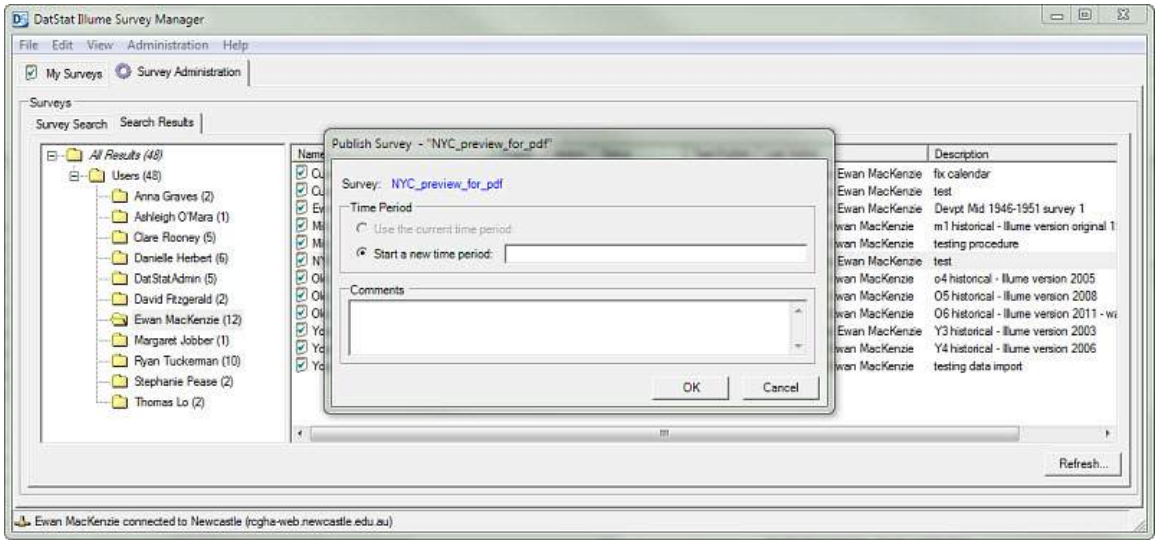


Figure 3-4: Publishing a Survey in Survey Manager

3.1.3 Creating the Illume Dataset.

The empty survey now needs to be populated with an Illume data set. The instructions below demonstrate how this can be done.

1. Login to the Illume Survey Data Manager website, and select Data Manager at the top right of the page. Click on the ALSWH project, then the Published Surveys tab. Click on the survey just published, then the Data Download tab. Choose raw data format and Include Value Labels. Select SAS as the File Format. Choose the time period entered when publishing the survey. Click the Download Data button.
2. Save the .sas file from your downloads into a personal folder. Start SAS, open the program and run it. In the Work library, there will be a dataset - called in this example Mid2 (the dataset name is defined in the sas program). Open a new program window and run a PROC Contents with ODS file output. Open the file and print it out.
3. In the Data Dictionary, create and run an SQL query that generates a list of variables, for example for Mid2, and the associated index numbers. Save the query and export the results to a text file. Open the text file and copy all content. Open a new SAS program that creates the Illume Import dataset with variables that match those in the survey. (This is done by using the RENAME statement in SAS). Examine each line of the RENAME statement, comparing it to the printout of Illume variables. The Index Number should match the Illume variable name. There will be two groups of non-matched names – those that are in the RENAME list and not in Illume, and those that are in Illume, but not in the SAS list (less likely). Make a note of both. One group will need to be added to the survey in Illume, and the other will either need to be deleted from the survey or added to the SAS list. To check each list, run a PROC FREQ for that variable in SAS on the SAS dataset. If there is data for that variable, it must be added to the Illume survey. If there isn't, it can be dropped. There will be inconsistencies, and the RENAME list will contain Derived Variables that need to be added to the survey.

4. To edit the survey in Illume, open the Survey Manager, go to the Administration tab, right-click the survey and select Unpublish. Click OK in the Caution alert. Check the survey out and make any edits necessary. Derived variables can be added as Pre-loaded or Calculated variables. Save the survey; check it in and publish again. In SAS, run the program that has been compiled above. This creates the Illume Import dataset. Next, use the EXPORT statement in SAS to create tab delimited text files ready for import into Illume.

These instructions will create the Illume dataset. The next step is to populate it with ALSWH data.

3.1.4 Importing the Dataset into Illume.

Importing is done within the Illume Data Manager website and in the Import Data tab (see Figure 3-5) and involves four steps:

- Testing for unknown column errors – these are variables not yet in the Illume survey that must added.
- Testing for missing column errors – these are variables defined in the Illume survey that are not in the import dataset – they can be removed from the survey.
- Testing for unknown scale value errors – these are errors in response values; the Illume survey must be amended to reflect the range of response values present for that variable in the import dataset.
- Testing for response guide validation errors - these are errors in data typing; the Illume survey must be amended to the correct type.

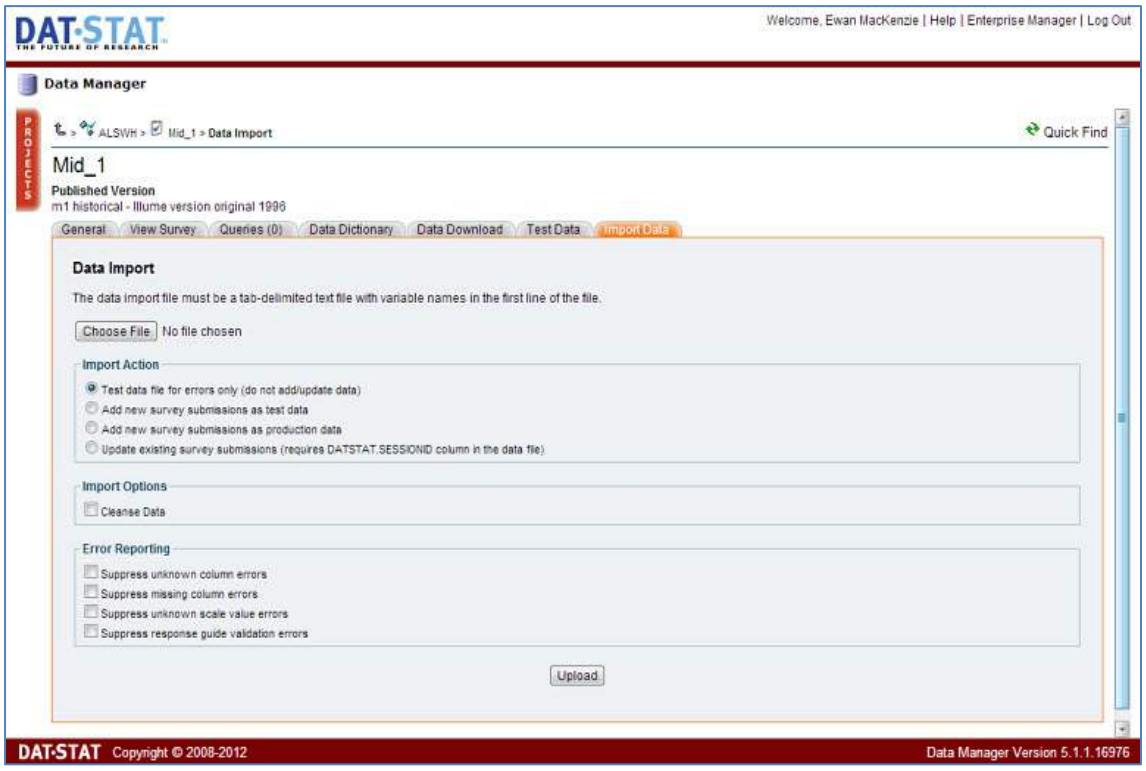


Figure 3-5: Import Data Screen in Data Manager

Instructions for importing SAS data into Illume.

1. Click Choose File and navigate to the text file (created above). Select it.
2. In Import Action, select test data file; in the Error Reporting section, check all but the first option. Click the Upload button. Note errors – these are variables in the import set that are not in the Illume survey. Close the data manager, unpublish the survey, check it out and edit it, adding the required variables – they will be derived variables that can be added to the preloaded or calculated sections. If a variable is not required, a DROP statement can be added to the SAS program. Repeat these steps – including re-creating the import dataset and exporting it to text files if changes are made to the SAS program - until no errors are found.
3. Choose file; select 'test' option; check 'Suppress unknown scale value errors' and 'Suppress response guide validation errors' only. Click 'upload'. Note errors – these are variables missing from the import set that are in the Illume survey. Edit the SAS program, adding the required variables. If not required, they can be deleted from the Illume survey. To do this, check the survey out, open it and set the Show-if option for that question to 'never shown'. Repeat these steps until no errors are found.
4. Choose file; select 'test' option; 'Suppress response guide validation errors' only. Click 'upload'. Note errors – these are variables where the response values in the import set differ from those defined in the Illume survey. Edit the Illume survey, correcting the responses for that question. Repeat these steps until no errors are found.
5. Choose file; select 'test' option; leave all Error Reporting options un-checked. Click 'upload'. Note errors – these are variables where the data type in the import set differs from that defined in the Illume survey. Edit the Illume survey, correcting the data type for that question. Repeat these steps until no errors are found.
6. Choose file; select 'Add new survey submissions as production data' option; leave all Error Reporting options un-checked. Click 'upload'. A 'data successfully imported' message will be shown. Click the back button. Choose the next file and click upload. Repeat until all data has been uploaded. In the General tab, verify that the number of submissions matches the number of observations in the original SAS dataset.

3.1.5 Summary

The three steps above describe the process of entering ALSWH data into Illume. A number of pre-2012 ALSWH surveys have now been entered into Illume and it is planned that eventually all surveys and data will be available in Illume, which will then provide the first comprehensive online database for the study.

3.2 Changes in 1921-26 Cohort Data due to Six-Month Follow Up

David Fitzgerald, Anna Graves

3.2.1 Background

In order to obtain more frequent information about the health of the oldest women in the ALSWH, surveys of the 1921-26 cohort have changed from being conducted every three years to being conducted every six months. The first six surveys (conducted from 1996 to 2011) of the cohort are now referred to as Surveys 1 to 6, while the subsequent six-monthly surveys are known as the Six-Month Follow Up (6MF) surveys.

3.2.2 Survey time lines

The first six surveys of the 1921-26 cohort were conducted at three yearly intervals from 1996 until 2011. The respondents were typically sent a survey in March of the survey year and had up to 18 months to complete it. For Survey 6, respondents had 12 rather than 18 months to complete the survey to allow the Six-Month Follow Up (6MF) survey to begin in 2012. The 6MF survey questionnaire is about half the length of Survey 6, and all questions on the 6MF survey have been used in the previous (sixth) survey.

3.2.3 Survey 6 early cut off

The earlier cut off for Survey 6 is unlikely to have affected the response rate since very few responses are usually received in the final six months of ALSWH surveys. Table 3-1 shows the responses broken into three-month, or quarterly, periods for all surveys except Survey 1.

Table 3-1 Survey response rates by quarter years

	Three-month period						
Survey	**First**	**Second**	**Third**	**Fourth**	**Fifth**	**Sixth**	**Total**
2	9,556	866	9	0	2	1	10,434
	91.6%	8.3%	0.09%		0.02%	0.01%	
3	7,823	598	165	36	7	1	8,630
	90.7%	6.9%	1.9%	0.4%	0.08%	0.01%	
4	6,525	356	242	32	2	1	7,158
	91.1%	5.0%	3.4%	0.5%	0.02%	0.01%	
5	4,921	522	66	50	1	0	5,560
	88.5%	9.4%	1.2%	0.9%	0.02%	0%	
6	3,565	216	245	29	NA	NA	4,055
	87.9%	5.3%	6.0%	0.7%			
Six-Month	3,079	346	NA	NA	NA	NA	3,425
Follow Up	89.9%	10.1%					

Survey 1 was not included in the table because the dates surveys were returned were recorded in batches rather than the actual date the individual surveys were returned.

It can be seen from Table 3-1 that in each survey about 90% of surveys were returned in the first three months. The second 3-month period saw most of the remaining responses come in, with very few responses in the final six months. Therefore the 12-month cut off for Survey 6 would not have

affected the response much at all. Assuming a similar rate of return for the 6MF survey, there should be enough time to receive about 95% of the responses usually obtained in an 18-month period.

3.2.4 Percentage of missing values in each question of Six-Month Follow Up

All the questions in the six-month follow up survey were also in Survey 6. Therefore a direct comparison of the proportion of missed questions could be done between these two surveys. Missed questions are a persistent feature of the ALSWH surveys. They reduce the quality of the data and efforts are made to keep the missing rate low.

Only those women who responded to both Survey 6 and the 6MF survey were included in this analysis. The rate of missing was recorded after all the standard survey recoding was done.

Although all questions on the 6MF survey were also on Survey 6, they were not all directly comparable. The questions that were not comparable were removed from this analysis. These were questions 13, 16, and 17 from the 6MF. Question 13 had only four of the 15 items in the equivalent question in the sixth survey. It is possible that a long list of items is more likely to have missing responses than a short list. Question 16 only asked for the number of times physical activity was undertaken, compared with Survey 6 where the number of hours and minutes were also asked. This extra information about hours and minutes was used to recode some missing values to zero in certain cases in Survey 6. And question 17 only had two response items, 'car' and 'other', while the item in the sixth survey had six response items. All the other questions in the Follow Up survey were directly comparable to the items in Survey 6. In total there were 93 similar items. All items were directly compared except for the heights and weights questions, for which a valid BMI value was used to determine a valid response rather than missing. This was because the questionnaire had options for metric and imperial units.

The percentage missing for each equivalent item in survey 6 and the follow up survey were calculated and shown in Table 3-2.

Table 3-2 Mean percentage of missing in common items of Survey 6 and 6MF survey

	Number of items	Mean Missing (%) (SD)	Minimum % missing	Maximum % missing
Survey 6	93	4.1 (2.9)	0.3	16.8
Follow-Up	93	3.4 (2.2)	0.4	13.9

The 6MF survey had a lower rate of missing. Overall, the mean missing rate for the 6MF survey was 3.4%, and for the sixth survey it was 4.1%. These were the same cohort responding in both surveys. The highest rate of missing was 13.9% in the 6MF survey and 16.8% for the sixth survey. This highest rate was for BMI, which was a combination of two items, height and weight.

These results suggest there will be an improvement in data quality for the 6MF survey. A possible explanation for this improvement in non-missing is that the shorter form of the questionnaire was less demanding and the respondents filled it in more thoroughly.

3.2.5 Data Changes in the Six Month Follow Up survey

Exercise status has been based on metabolic minutes, MetMins, in the longer surveys. The 6MF survey does not ask for 'hours, minutes', so the exercise status variable will not be able to be calculated as before.

Heights and weights

Heights and weights questions were asked the same way as in earlier surveys, so the main difference will be that these data will now be received every six months. Previously the height and weights were recorded every three years, so the protocols developed for editing and cleaning these data were based on the changes possible over the three year interval. Because the protocols were not designed for a six month period, the 6MF data will not be extensively cleaned the way the three-year data were.

The only editing of the data will be the cross-sectional editing that is described in the ALSWH Data Dictionary Supplement. In brief, these edits are conducted to see if non-standard height or weight responses can be interpreted as measurement written in the wrong questionnaire box. An example would be a height of 5 foot, 8 inches written as 58 in the inches box. Other editing involves setting to missing any extreme values that are probably impossible for this cohort. (To date any weight has been allowed, but heights have had to be between 130 and 180 centimetres).

Variable Prefix for the Six-Month Follow Up survey

This 6MF is the seventh survey for the 1921-26 cohort, so the variable prefix for the data will be 'o7' - i.e. the marital variable will be 'o7marital'. With each repeated wave of the survey, the variables will continue to have the 'o7' prefix responses. Each wave of data will be distinguishable by a variable, 'count', as well as the date the survey was completed.

3.3 Changes to survey processing procedures

Ryan Tuckerman

As many ALSWH surveys are now offered online, new procedures for processing online surveys have been developed. Procedures for processing both paper and online surveys are shown in Figure 3-6 and Figure 3-7. Conceptually, the new online processing procedures do not vary greatly from those used for paper surveys, with both types of processing maintaining a separation between participants' personal details and the answers they provide when completing a survey. However, a major online change has been the replacement of physical handling with virtual processes. Of particular importance is the removal of the need to convert hard copy data (from paper surveys) to soft copy. This has previously been done by an external data capture company, and its removal not only represents a significant cost saving for online surveys, but also reduces the conversion time between the receipt of the survey and usable data from an average of 3-4 months to virtually nil.

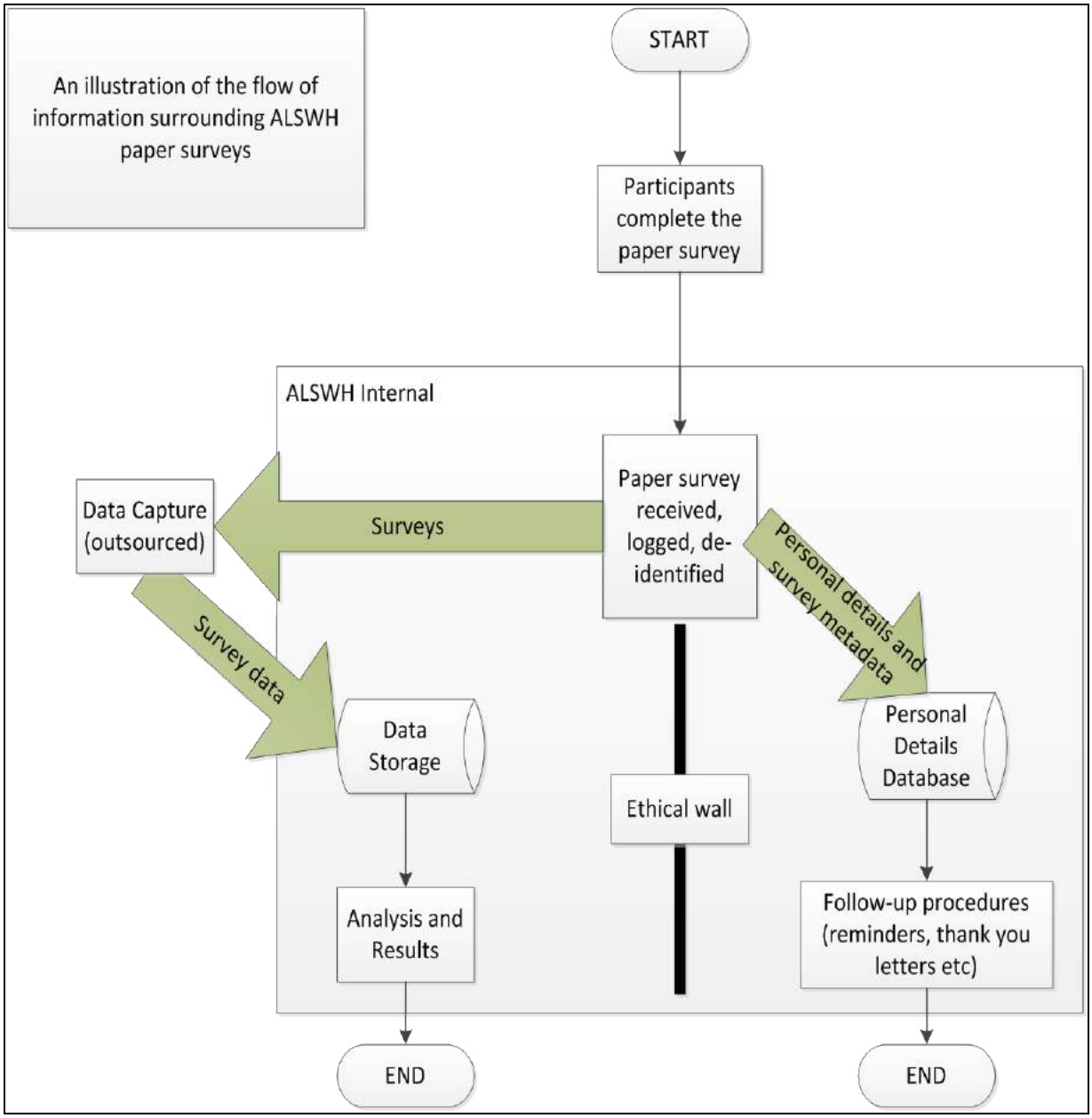


Figure 3-6: ALSWH processing procedure for paper surveys.

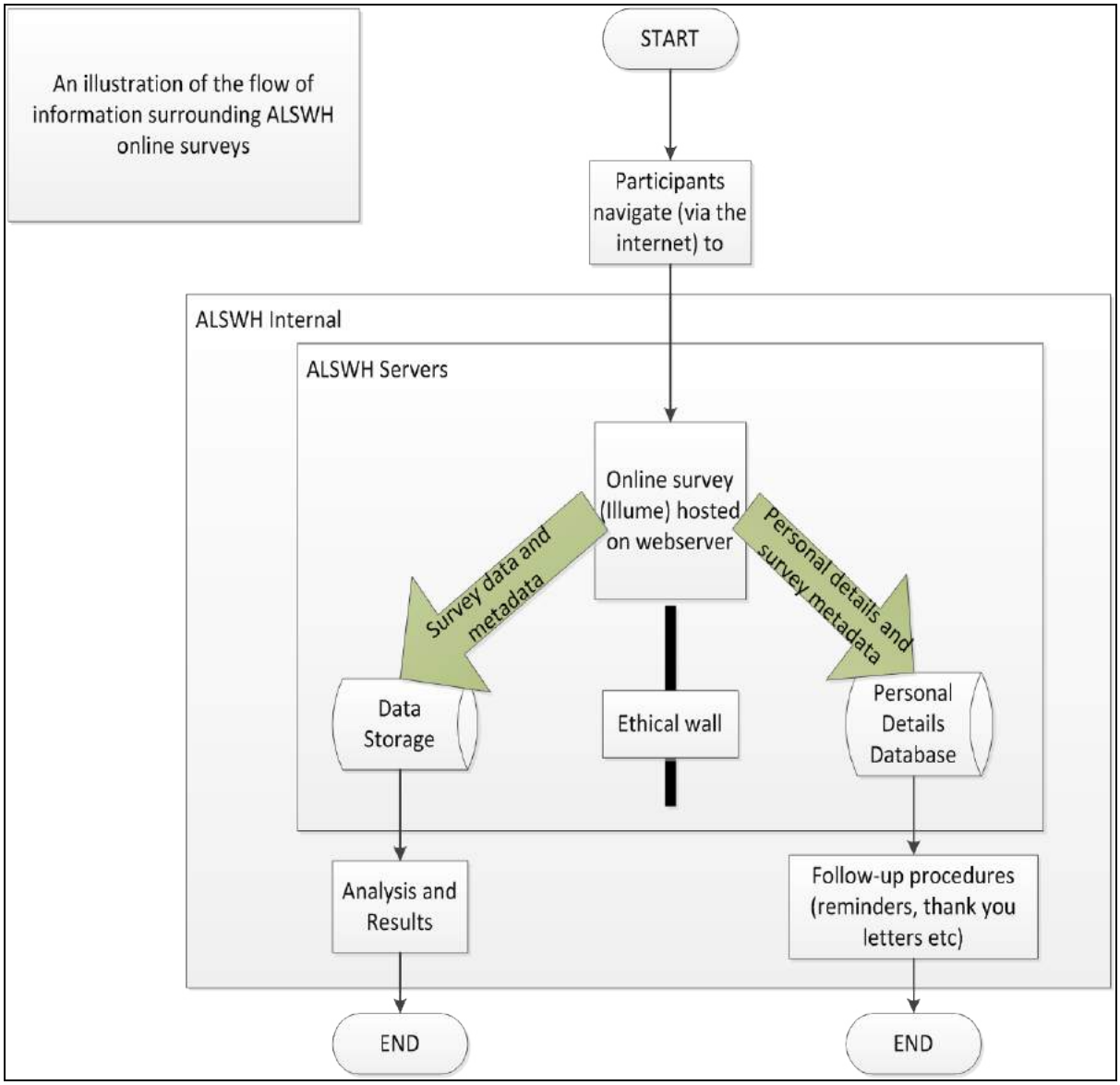


Figure 3-7: ALSWH processing procedure for online surveys.

4. Establishment of the New Young Cohort

4.1 Background to the establishment of a new young cohort

In 2011, ALSWH received funding from the Department of Health and Ageing to establish a new cohort of young women aged 18 to 23 (born 1989-94), who will comprise the fourth ALSWH cohort.

4.1.1 Objectives

The broad objectives for establishing a new young cohort are:

- To collect scientifically valid information about the current health and health service use of young women which will provide an evidence base for the development and evaluation of health policy and practice relevant to a new generation of Australian women;
- To add health information from young women to the information from existing cohorts, in order to create a dataset which can be used to examine the health and health service use of Australian women across the lifespan.
- To compare the health and use of health services by young women currently aged 18-23 (born 1989-94) with the health and use of health services by young women of that age in 1996 (i.e. the 1973-78 cohort when they were first surveyed at age 18-23). This will provide a measure of generational changes in health, as well as an opportunity to evaluate the effects of changes in health policy and practice.

Specific objectives of establishing a new young cohort are:

- To examine health risk factors including weight, physical activity, and use of tobacco and alcohol;
- To examine risk taking behaviour, such as use of illicit drugs, and sexual behaviour;
- To gather information about social experiences and environmental influences on young women, including information about families of origin, traumatic or stressful events, neighbourhood characteristics, and social inclusion;
- To examine patterns of contraceptive use, experiences of pregnancy and childbirth, and other reproductive health issues
- To examine young women's access to sources of information about, and use of health services and preventive health activities;
- To record the aspirations for the future and life goals of young women in relation to education, travel, area of residence, work, family and children.

Self-reported data from the new cohort will be linked with administrative data, particularly Medicare data, to provide an objective measure of health and health service use. The surveys are planned to continue longitudinally, so that as for existing cohorts, longitudinal survey data and longitudinal health service data for the same individuals can be linked. Findings will be translated into evidence that can be used for health policy and planning.

4.1.2 Original recruitment method

The existing ALSWH cohorts were recruited via the Health Insurance Australia (now Medicare) database with oversampling (by a factor of two) of women from rural and remote areas. A letter of invitation was sent to women randomly selected from the Health Insurance Australia database, and only after women had agreed to take part and complete the survey, were their personal details provided to ALSWH. The same method of recruitment was planned for the new young cohort, with sampling to continue until at least 10,000 participants had been recruited.

Selection criteria included being female, aged 18-23 years, in possession of a Medicare number (inclusion on either a family card or personal card), and agreeing to take part in ongoing surveys and consenting to data linkage with Medicare data (such as Medicare Benefits Scheme, and Pharmaceuticals Benefit Scheme) and other data related to health and medical services.

Recruitment of a pilot cohort of participants, with the same inclusion criteria as for the main study, was also planned, with letters of invitation to the pilot participants to be sent to them via Medicare.

4.1.3 The Contraceptive Use, Pregnancy Intention and Decisions of Australian Women (CUPID) project

Several ALSWH investigators (including the Director, Professor Annette Dobson and Deputy Director, Associate Professor Deborah Loxton) are also investigators on the CUPID (Contraceptive Use, Pregnancy Intentions and Decisions of Australian Women) project. CUPID is funded by the Australian Research Council and linkage partners Family Planning NSW and Bayer Australia. It was originally planned as a proof of concept study for recruiting 18-23 year old women for ALSWH, and as such, provided valuable information about the planned recruitment methods for the new ALSWH cohort.

In May 2012, the pilot survey of the CUPID project was conducted. A sample of potential participants was selected from the Medicare database and Medicare posted an invitation letter on behalf of the research team. This recruitment protocol was the same as that intended for the ALSWH new young cohort, the only difference being that CUPID recruitment was limited to New South Wales.

Of 900 women approached in the first CUPID Medicare mailout, only 40 (4.4%) responded. After reminders were sent, the total rose to 51 responses (5.6%). The cost for the Medicare mailouts totalled $4750, which equates to a cost of ~$93/participant. The CUPID response rate (<6% for the pilot study) was also considerably lower than the estimated response of 40% obtained when this same method was used to recruit the existing ALSWH cohorts in 1996.

4.1.4 Updated recruitment method

Due to the poor response rate obtained in the CUPID project, alternatives to using the same recruitment method were considered, and a new protocol, based on feedback from focus groups (discussed below) and current literature, was developed. The new procedure uses advertising, traditional media and social media to promote the survey, with an open invitation to any young women

who meet the eligibility criteria to participate. It should be noted that while the recruitment strategy changed, the eligibility criteria to participate did not, and remain the same as detailed above.

4.1.5 Timeline

Figure 4-1 shows the schedule of major activities relating to establishment of the cohort during 2011 – 2013. Several stages of information-gathering and feedback have been undertaken. These have included two phases of focus groups, pilot testing, the establishment of a reference panel, and consultation with experts regarding social media and new technologies.

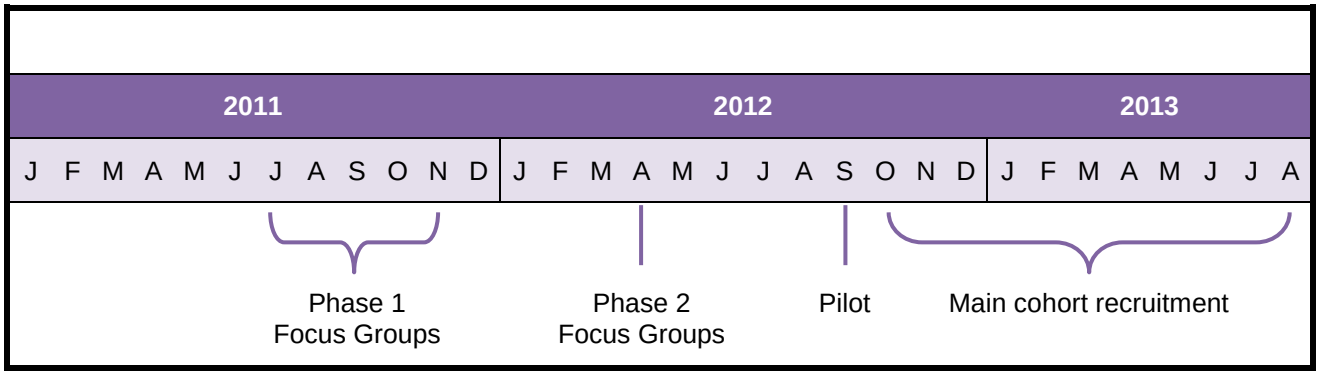


Figure 4-1: New Young Cohort - Major activities, 2011– 2013.

This report outlines progress at December 2012 towards establishing the new cohort, focussing on preparatory work undertaken in focus groups and pilot testing, development of the survey, recruitment strategies adopted and ethical review processes required.

4.2 Focus Groups

Focus groups were conducted in late 2011 and early 2012 to gain an understanding of how to recruit and retain a representative national sample of 18-23 year old women for a longitudinal study, and to assist with development of relevant content. The focus groups were held in both rural and urban settings in New South Wales and Queensland. To ensure a diverse range of young women, Australian Bureau of Statistics snapshot reports were used to identify potential locations for the groups, based on demographic, geographic, socio-economic and cultural characteristics. The CUPID project (mentioned above) conducted focus groups with the same demographic of young women prior to those conducted by ALSWH and found that snowballing (word of mouth) was suggested as the best way to recruit focus group participants. Accordingly, efforts were also made to conduct the ALSWH focus groups in areas where ALSWH staff had contacts who could distribute advertising posters and/or help spread the word about the focus groups.

Focus groups were held in two phases, and were conducted in community meeting/conference rooms. Inclusion criteria for the focus groups were:

- Female

- Aged 18-23 years
- Living in Australia
- Willing to volunteer to join a focus group discussion
- Proficient in the English language

Phase 1 focus groups primarily sought feedback on methodologies, how young women felt about privacy, mode of administration, and the types of topics that were appropriate and inappropriate for inclusion in the survey. Phase 2 focus groups sought feedback on a draft survey, including time taken to complete the survey and specific feedback on proposed questions. Each focus group was structured according to a schedule (see Appendices for schedules) and was audio recorded, transcribed and de-identified. The focus group discussions were used to develop the survey and recruiting methods. Participants were also asked to complete a short paper survey about their demographic characteristics and access to the internet

4.2.1 Results of Phase 1 Focus Groups

The majority of participants favoured the practicality of completing the survey online. Regarding the content of the survey questions, participants generally felt there were no questions that were off-limits as long as people were provided the option not to answer, that confidentiality was assured and the purpose for asking the questions was clear. Participants felt incentives (such as gift vouchers) were needed as motivation to complete the survey, but noted that prize values should not seem so large as to be unrealistic. By the end of each focus group, participants were supportive of the study and emphasised the importance of providing potential study participants with information about the impact of the study, in a form that reaches their demographic, in order to tap into altruism. The focus group participants believed that the more people who become aware of the study and understand its impact, the more people will participate. Social media, and in particular Facebook, were found to be important for connecting with this age-group. Participants consistently emphasised the preference for a link to the survey through social media.

4.2.2 Phase 2 Focus Groups

Phase 2 of the focus groups was conducted in early 2012. A total of 19 participants took part in six groups which were held in the Hunter region. Participants gave feedback on a draft survey, focussing on the types of questions they would be willing to answer and the length of the survey they would be willing to complete. Sources of items on the draft survey are shown in Table 4-1. The draft survey and other focus group materials are available in Appendix C.

Table 4-1 Sources of items for the draft Pilot Survey used in Phase 2 focus groups

TOPIC	SOURCE
Consent to participate	N/A
Consent to data linkage	N/A
Given name	N/A
Second name	N/A
Third name	N/A

TOPIC	SOURCE
Family name	N/A
Maiden name	N/A
Preferred name	N/A
Email address	N/A
Confirm email address	N/A
Date of Birth	N/A
Living overseas?	N/A
Overseas address	N/A
Postal address	N/A
Is residential the same as postal address?	N/A
Residential Address	N/A
Participant is asked to rate their general health (SF-1)	Ware, JE, & Sherbourne, CD. (1992). The MOS 36-Item Short-Form Health Survey (SF-36): 1. Conceptual framework and item selection, Medical Care, 30(6): 473-83.
Where participants get health information	ALSWH
Preference for seeing a female GP	ALSWH
Whether participant has own Medicare card	ALSWH
Whether participant has a Health Care Card	ALSWH
Highest level of education	Modified from *Census of population and housing: Nature & content of the census*. (1996) Canberra:ABS.Cat No.2008.0
Time use: Hrs per week: • Paid work • Study	Modified from *Time use survey, Australia: User's guide 1992*. (1993) Canberra: ABS. Cat No. 4150.0
Managing on available income	ALSWH
Current relationship status	Modified from *Census of population and housing: Nature and content of the census*. (1996) Canberra: ABS. Cat No. 2008.0.
Current living arrangements	ALSWH
Sexual orientation	ALSWH
Symptoms experienced over the past 12 months	ALSWH
Whether diagnosed or treated for the listed health conditions	Modified from *1989-1990 National health survey users' guide*. (1991) Canberra: ABS. Cat No. 4363.0
Whether participant has had a Pap Test, blood pressure check, skin check in the last two years	Modified from *1989-1990 National health survey users' guide*. (1991) Canberra: ABS. Cat No. 4363.0
Whether participant has had the HPV vaccination	ALSWH
Smoking habits	Modified from *National Health Data Dictionary, Version 6.0*. (1997) AIHW Standard questions on the use of tobacco among adults.

TOPIC	SOURCE
Alcohol consumption	Modified from *Risk factor prevalence study Survey No. 3, 1989*. (1990). National Heart Foundation of Australia and AIHW.
Illicit drug use	National Drug Strategy household survey: survey report 1995 (1996).
Mental health scale (K-10)	Kessler RC, et al. (2003) Screening for serious mental illness in the general population. *Archives of General Psychiatry*. 60(2), 184-189.
Stress scale	ALSWH
Age at first Menstrual period	ALSWH
Ever had sex	ALSWH
Age when first had sex	ALSWH
Contraceptive use	ALSWH
Ever been pregnant	ALSWH
Pregnant: Current status	ALSWH
Childbirth complications	ALSWH
Number of miscarriages	ALSWH
Number of abortions	ALSWH
Number of ectopic pregnancies	ALSWH
Number of live births	ALSWH
Number of still births	ALSWH
Height	ALSWH
Weight	ALSWH
Experience of abuse perpetrated by a partner	Modified from Hegarty KL, Sheehan M, Schonfeld C. (1999) A multidimensional definition of partner abuse: development and preliminary validation of the Composite Abuse Scale. *J Fam Violence*, 14, 399-414.
Experience of a violent relationship	Hwalek MA & Sengstock MC. (1986).Assessing the probability of abuse of the elderly: Toward development of a clinical screening instrument. *Journal of Applied Gerontology, 5*, 153-173.
Abuse events perpetrated by anyone	ALSWH, modified from Norbeck, JS (1984). Modification of life event questionnaires for use with female respondents. *Research in Nursing and Health,* 7, 61-71.
Feeling that life isn't worth living/Self-harm	Modified from Beck A, Schuyler D & Herman, I. (1974) *Development of the Suicide Intent Scale*. In AT Beck, HLP Resnick, & DJ Lettieri (Eds.) The prediction of suicide. Bowie, MD: Charles Press Publishers
Physical activity in the past week: frequency and intensity	Active Australia, Armstrong T, Bauman A, Davies J. *Physical activity patterns of Australian Adults: Results of the 1999 National Physical Activity Survey.* AIHW Canberra 2000.
Sitting time	ALSWH

TOPIC	SOURCE
Proxy: Did the participant need help filling out the survey?	ALSWH
Reason for needing help	ALSWH
Missed anything?	ALSWH

4.2.3 Results of Phase 2 Focus Groups

Length of time to complete survey

Focus group participants were asked to complete the draft survey using a variety of media. Figure 4-2 shows the average time taken to complete the survey on different devices. When asked to evaluate the length of time it took them to complete the survey, most (18/19) participants indicated that it was 'just right', and one participant felt it was 'too short'.

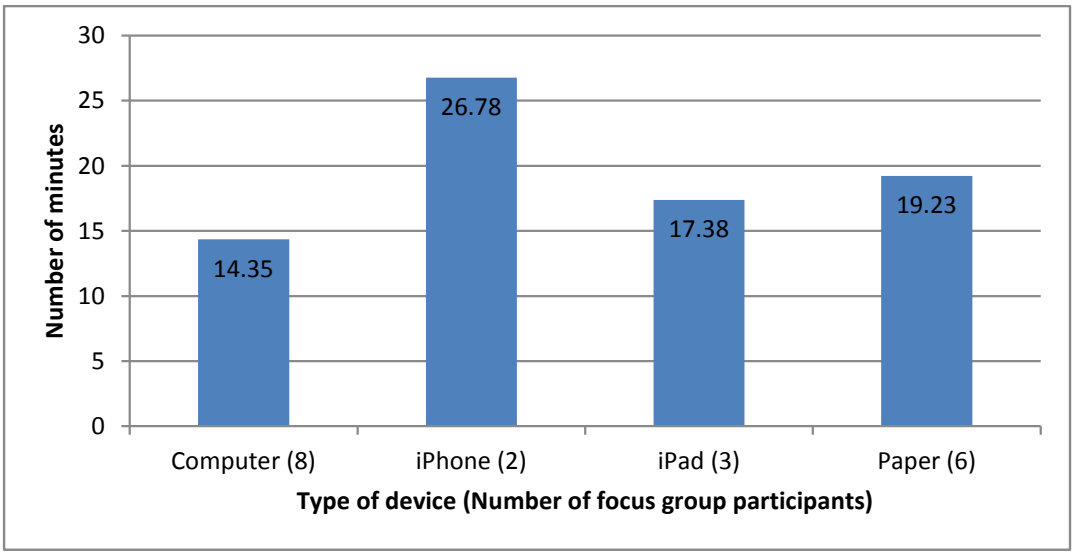


Figure 4-2 Length of time to complete survey (Phase 2 Focus Groups)

Feedback from Phase 2 Focus Groups

- **Were you happy with the way your device presented the survey? Why/Why not?**

While several participants were happy with the way that the survey was presented, some using an iPhone or an iPad were not, due to screen size, the large volume of information on the screen, and the need to zoom in and out to read information. Participants who liked the presentation were particularly happy with the percentage bar that kept track of progress through the survey and with the simple format of the survey.

- **Were there any questions you found difficult to answer on your device? If yes, which questions and why?**

Several participants described difficulty with questions in a tabular format that required scrolling across the screen. In addition, some participants had difficulty responding to items that required the alpha and numeric keyboard when responding on an iPad due to the need to switch on the iPad

keypad screen. Some participants also commented that questions on physical activity were difficult to answer.

- **What did you like about the survey? Why?**

When asked what they liked about the survey, participants most commonly described the ease of selecting response options, the range of questions, and the clear and concise structure and instructions. They also liked the short time required to complete the survey, and the ability to complete it online. Participants also enjoyed the way the questions were split into categories, and that there was an option to not answer if they felt uncomfortable.

- **What did you dislike about the survey? Why?**

A number of participants did not like particular questions because of difficulty answering them - such as the diagnoses items, the physical activity question and the alcohol and drugs questions. Other participants were uncomfortable with the personal information items, however they also commented that the privacy assurances helped with their concerns. Some participants commented on types of questions that they were uncomfortable answering, such as the abuse questions and the pregnancy termination questions. Other comments were on survey formatting – one participant recommended the use of colour and pictures to make the survey more visually appealing, and another participant suggested using a short URL to help with typing.

- **Do you have any other ideas, comments or concerns about the survey (wording, layout, privacy)?**

Participants raised several new ideas. One participant suggested headings to divide groups of questions for ease of completion. Another participant commented that including skips was useful for questions that were not relevant to them. Another participant commented on the personal details section and said that the ‘first’ ‘second’ and ‘third’ name fields were confusing.

4.3 Pilot Testing

In the original protocol, after focus groups were completed, it was planned to recruit a pilot sample in order to examine the response rate, the acceptability of survey questions and the overall methodology. After plans for recruitment of the main study cohort changed from a Medicare mailout to open access promoted through social and traditional media, it was no longer feasible to recruit a pilot cohort. Therefore, alternative pilot testing strategies were adopted. In order to pilot test the survey instrument and gain further feedback on the proposed recruitment strategies, a pilot survey and evaluation were conducted via an online market research organisation, MyOpinions, that had approximately 700 members who met the ALSWH new young cohort eligibility criteria (female, 18-23 years old, residing in Australia). All eligible members were invited to take part in the pilot testing, with participation capped at the first 200 respondents.

4.3.1 Pilot Survey including evaluation items

The draft survey used for Phase 2 Focus Groups was revised based on feedback from focus group participants, and the revised survey was then used in pilot testing. Details of the sources of the questions added to the pilot survey can be found in Table 4-2 below and the survey itself is included in Appendix C.

Table 4-2 Items included in the Pilot survey that were not included in the Focus group survey.

TOPIC	SOURCE	NOTES/Examples
Mobile phone	N/A	For future contact if necessary
Home Phone	N/A	For future contact if necessary
Work Phone	N/A	For future contact if necessary
Title	N/A	Response options: Dr, Miss, Mrs, Ms, Professor, Reverend, Sister.
Given names	N/A	In the focus group survey, participants were asked to provide their 1st, 2nd and 3rd names. Participant feedback said that this caused confusion so the fields were merged into one.
Speaking English fluently	ALSWH	Question is: Do you speak fluent English? Yes/No
Language spoken at home	Modified from Department of Immigration and Citizenship. (2008). The People of Australia: Statistics from the 2006 Census. Canberra: Commonwealth of Australia.	Reponse options: English, Arabic, Assyrian, Cantonese, Dari, Dinka, French, Indonesian, Italian, Japanese, Khmer, Korean, Macedonian, Mandarin, Persian (excl. Dari), Portugese, Serbian, Spanish, Thai, Turkish, Vietnamese, Other.
Need for care	Modified from Australian Bureau of Statistics (1993) Disability, Ageing and Carers Australia. Canberra: ABS. Cat. No. 4432.0	Question is: Do you regularly need help with daily tasks because of a long-term illness or disability (eg help with personal care, getting around, preparing meals etc)? Yes/No
Evaluation	ALSWH	Questions ask participants to evaluate various aspects of the pilot survey.

A soft launch of the survey was conducted by MyOpinions on 14th September 2012, and after a database error was discovered, the soft launch was repeated on 17th September, 2012. MyOpinions sent out an invitation email (see Appendix C) on 18th September directing interested members to the ALSWH web page containing a link to the survey (shown in Figure 4-3 below) and 200 participants were recruited that same day. Participants were given the pilot survey, which included the information statement in full, as well as some evaluation items at the end of the survey (see Appendix C). They were then redirected to the MyOpinions website in order to claim their credits for completion (from MyOpinions).

Figure 4-3 ALSWH website splash page for the new young cohort Pilot Survey.

4.3.2 Evaluation of pilot results

Overall, responses to the evaluation items at the end of the survey were positive, with participants reporting a high degree of satisfaction with the quality of the survey and ease of completion. A high proportion of participants also registered their willingness to take part in the main study when recruitment began.

4.4 Main Survey

4.4.1 Changes made from Pilot Survey to Main Survey

After receiving feedback from pilot participants and analysing the pilot data, minor changes were made to the survey and are shown in Table 4-3. The final Survey 1 can be found in Appendix C.

Table 4-3 Changes made from Pilot Survey to Main Survey of the New Young Cohort.

TOPIC	SOURCE	NOTES/Examples
Age criteria	N/A	Reference to being born 1989-94 has been removed from the log-in page of the survey Not all women born in 1989-94 will be eligible as recruiting will continue from 2012 to 2013 (see Section 4.5.1 for further details).
Personal details	N/A	A number of pilot participants stopped completing the survey at the personal details section, so non-essential personal details were moved to the end of the survey. Essential personal details (email, mobile phone number (for re-contacting and reminder emails), title, first name, surname, date of birth remain at the beginning of the survey.
Contraception	N/A	Implanon and Mirena were added as response options.
Employment	N/A	Unemployment question added: 'Are you currently unemployed and actively seeking work?' Response options: No OR Yes, unemployed for less than six months OR Yes, unemployed for six months or more.
Physical Activity		'Show-if' logic has been applied to the questions, so if the participant responds that they do not do a certain activity, then the "time spent doing the activity" question is not displayed.
Evaluation	ALSWH	Deleted, as questions were only included to collect information and feedback for development of the main survey, and are no longer required.

4.4.2 Survey Navigation Procedure

After logging into the survey, participants are presented with a series of choices. Their responses determine if they proceed, and if so, how they are navigated through the survey. Figure 4-4 shows the various navigation paths and possible outcomes.

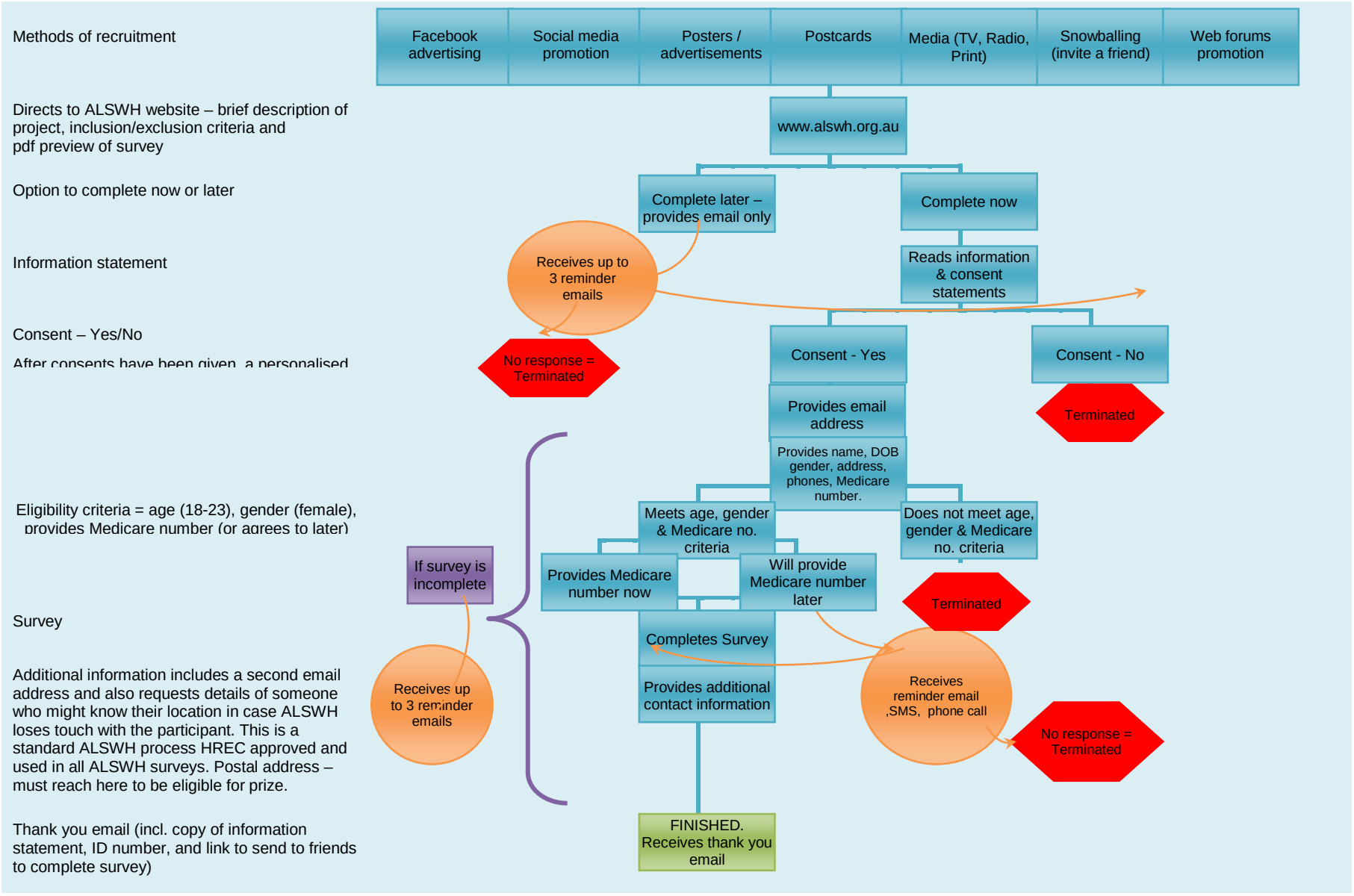


Figure 4-4 Navigation for Survey 1 of ALSWH new young cohort

4.5 Recruitment

Recruitment commenced in late October 2012 and is expected to continue until at least August 2013, depending on the rate of response. Before recruitment began and final modifications were made to the survey instrument and recruitment strategy based on Pilot feedback, approvals were obtained from all necessary ethics committees (including the University of Newcastle Human Research Ethics Committee, the University of Queensland Medical Research Ethics Committee, Department of Health and Ageing Ethics Committee and the Department of Human Services).

Using various social media such as Facebook and Twitter, as well as traditional media, eligible women are being encouraged to visit a web 'splash' page (see Figure 4-4) dedicated to the recruitment of the new cohort: www.alswh.org.au/survey. From this page, potential participants can preview the survey questions, view the information statement, and read the eligibility criteria. If they are interested, but would prefer to complete the survey later they can provide their email address and receive a reminder email at a later date to return and complete the survey. The online survey is accessed directly from the 'splash' page, and links to the 'splash' page are included at various locations across the ALSWH website.

4.5.1 Age at recruitment

In March 1996, when the existing cohorts were randomly selected, a five year age range for each cohort was used – so the youngest participants recruited would be aged 18-22 years, the mid-aged participants would be aged 45 – 49, and older participants would be 70-74 years of age. There was approximately a six month gap between sample selection and the mailout of the first survey so that respondents were aged 18-23, 45-50 and 70-75 when they responded. After recruitment closed, the range of birth years were established as 1973-78, 1946-51 and 1921-26 for the three cohorts.

For the new young cohort, a six-year age range was planned to match the original 18-23 year old cohort, with young women aged 18-23 years of age eligible to participate. The cohort has been referred to as the 1989-94 cohort, as it was anticipated that most participants would have been born during this period. However, it is important to note that the eligibility criterion for participation is that women are aged 18-23 at Survey 1, not that they are born during 1989-94. This is important, as some young women born at the end of the period (i.e. born in November or December of 1994) would not have been 18 years old when recruitment began, and would therefore have been ineligible to participate. Similarly, women born at the beginning of the 1989-94 period (i.e. born January to August 1989) will not be eligible to complete Survey 1 after their birthdates in 2013, when they turn 24.

As the existing cohorts were mainly recruited in 1996, the women could readily be compared with 1996 Census data for women of the same age in the general population. The new young cohort is currently being recruited and recruitment is expected to continue through 2013, making comparison with the 2011 Census more difficult. Potentially women in the new young cohort could be compared with data from the 2011 Census in two ways: firstly based on the age the women would have been at the 2011 Census (i.e. 16 to 21 years old) and secondly with 18-23 year olds at the 2011 Census. Clearly this is a time of considerable change, with a large number of younger women in the cohort moving from more rural areas to urban areas for study and employment, and the older women in the cohort completing their studies, taking up permanent employment, and becoming partnered. Given these changes, comparisons and weightings based on 18-23 year old women at the 2011 Census are likely to result in less biased estimates than weights based on 16-21 year olds.

4.5.2 Incentives

Incentives were not used in recruitment of previous ALSWH cohorts. However, feedback from focus groups strongly indicated that incentives would be necessary to gain the attention of young women in the target age range (18-23) for recruitment of the new young cohort. Accordingly, participants will be offered the opportunity to take part in a lottery draw to receive one of one hundred $50 prepaid eftpos gift vouchers after completion of the survey. A prepaid eftpos gift voucher was specifically selected after the focus groups indicated this type of voucher was preferred, as it can be used at any eftpos machine and does not discriminate against participants in regional or remote areas where access to shops is limited.

The effectiveness of this style of incentive has been subject to much research. A Cochrane review found that within six randomised controlled trials (17,493 participants) that specifically evaluated the effect of a non-monetary incentive (e.g. lottery participation and Amazon gift cards), the response odds were almost doubled when the incentive was used[1]. A study by Doerfling (2010) suggested that the effect of offering a cash lottery draw for internet-based research participation may be dependent upon the target population[2]. This suggestion was supported by the ALSWH focus groups, where it was found that within the target age cohort of participants (18-23 years of age), having a form of reward was seen as a way to illustrate the survey's legitimacy; if the project is able to reward participants, the project is seen as legitimate by women in the target age group. The women within this group also said that a chance to win a gift card made them feel valued as participants.

Draper and colleagues suggest that an individual's decision to participate within a study will not solely be influenced by the offer of reimbursements or incentives, but also by the participant's perceived feelings of obligations and benefits[3]. The survey materials for the new young cohort emphasise the benefit to the Australian community that is an expected outcome of the survey, and the opportunity to win a gift card has been included as a means to thank young women for their contribution.

4.5.3 Recruitment methods

At December 2012, social media, paid Facebook advertising, and some limited traditional media had been used for recruitment.

1. ALSWH social media

- **Facebook**

  Since early October 2012, a wide range of people and organisations, such as celebrities and athletes who may be considered positive role models for young women, federal politicians, and other research organisations, have been 'liked' on the ALSWH Facebook page. It is hoped that at least a few of those 'liked' will 'like' ALSWH in reciprocation, which will assist in promoting awareness of recruitment. In a two month period, over 240 'likes' have been received by the ALSWH page. Posts directly encouraging young women in the target group to take part in the survey started on Friday 26th October. Examples of posts include:

  - *20 mins of your day. Women aged 18-23, that's all that is needed to make a difference. http://www.alswh.org.au/survey*

- *http://www.alswh.org.au/survey is where it's at! Young Australian women - you are more than the sum of your parts*
- *Work, family, friends, work...what do you fit in your day? Women 18-23 tell us http://www.alswh.org.au/survey*
- *Daughter. Sister. Girlfriend. Niece. Friend. Cousin...aged 18-23? Get them involved – their health matters http://www.ow.ly/f8TMN*
- *Female + age 18-23 years + Medicare card number = new participant http://www.alswh.org.au/survey*

- **Twitter**

  As with the Facebook page, the ALSWH Twitter account (@ALSWH_Official) began following key stakeholders as well as high profile young women in early October, in order to encourage reciprocal followers. Tweets directly encouraging women in the target age group began on 26th October. Examples of tweets include:

  - *The ALSWH survey for Australian women aged 18-23 is up and running!! Get on board and RT http://www.alswh.org.au/survey*
  - *RT to show young women their past, present and futures are important. http://www.alswh.org.au/survey*
  - *RT to get 10 000 Australian women aged 18-23 shaping the future of women's health policy http://www.alswh.org.au/survey*
  - *Feeling good? Tell us about it...but only if you're female and aged 18-23. http://www.alswh.org.au/survey*
  - *There are health problems we know about, but what don't we know about you? Speak out ladies aged 18-23! http://www.alswh.org.au/surve y*

- **Youtube**

  An ALSWH YouTube channel was established in October 2012 and is linked to the ALSWH Facebook and Twitter accounts. An external video production company was contracted to work with the research team to develop a number of clips for the YouTube channel. Undergraduate drama students from the University of Newcastle assisted by performing in the clips and an undergraduate music student provided the soundtrack. When clips are posted to YouTube, links will also be posted to the social media platforms (Facebook, Twitter, etc.). The first clip was posted to the Youtube channel on the 7th November 2012.

2. Paid Facebook advertising

On the 31st of October, ALSWH began an advertising campaign on Facebook. The following advert was uploaded:

The cost of the advertisement is determined on a 'per click' basis. This means that although the advertisement may be visibly present on people's Facebook page, charges are only incurred when someone actively clicks on the advertisement. So unless someone clicks on the advert (showing interest), the 'impression' (number of times the advert has popped up on an individual's Facebook page) costs nothing.

Statistics at 15th Nov 2012:

- Impressions: 2,876,172
- Clicks: 742

3. Printed materials - posters and postcards and print advertisements

ALSWH enlisted the help of undergraduate graphic design students from the University of Newcastle to create several designs for posters and postcards for use in different advertising media. Posters were designed for display by businesses and networks, and for inclusion in magazines. Postcards were developed for distribution in shopping bags by retailers, or display by Avantcard, a national free postcard distribution company with distribution points across the country. Designs for postcards and posters will also be used for online advertising and distribution via email networks. A poster designed by ALSWH staff is currently being displayed on Facebook and Twitter and has been distributed to ALSWH networks. This poster will also be published as a full page advertisement in the February edition of CLEO magazine. All recruitment materials are subject to review by ethics committees of the University of Newcastle and the University of Queensland (please see Appendix C).

4. Traditional media

A media release announcing the launch of the new cohort has been prepared by ALSWH to be distributed to traditional media outlets throughout the country (television, radio, newspapers). Media offices of The University of Newcastle and The University of Queensland are expected to distribute the release in December 2012.

5. Ambassadors/Advocates

ALSWH staff have contacted Australians of note by email to invite them to become involved as recruitment ambassadors (see Appendix C for the correspondence sent). To date, active support has been received from Australian snowboarder Sami Kennedy-Sim. On advice from marketing consultant Brad Keeling (Hunter Medical Research Institute), ALSWH have also established a list of notable advocates who will be asked to support the recruitment of the new cohort by 're-tweeting' and 're-posting' recruitment messages (prepared by ALSWH) on their social media channels. This will enable the recruitment message to reach a larger audience and promote credibility and legitimacy in the eyes of the public.

6. Snowballing/word of mouth

Throughout the focus group process, successful recruitment was achieved through word of mouth, and accordingly this recruitment strategy will be used for the main study. Snowballing is promoted throughout all ALSWH recruitment methods including Facebook and Twitter messages. Participants receive a thank you email once they complete the survey which also encourages them to inform their friends about the study, encouraging them to participate (see Appendix C).

4.5.4 Monitoring uptake of recruitment

Recruitment of this cohort will be a dynamic process and ALSWH intend to employ a range of strategies (mentioned above) designed to be flexible and reactive to public response. Monitoring progress is a crucial element of the development of this cohort. See Table 4-4 below to review response to the survey at December 19th. Further details of the monitoring of recruitment strategies and results are provided in Appendix C (New Young Cohort Recruitment Record Keeping).

Table 4-4 New Young Cohort response rates

Date	Cumulative surveys completed	Cumulative surveys partially completed*	Cumulative surveys terminated**
October 31st	44	105	12
November 29th	237	378	87
December 19th	**501**	**730**	**174**

*Includes all visits to survey site that did not result in a completed or terminated survey.
**Includes those who enter the survey site and who either:

- Don't give consent to survey
- Do not meet age or gender criteria
- Do not provide Medicare number after reminder email, SMS, and phone call

Over-sampling in rural and remote areas has been an important component of all previous ALSWH recruitment. Although the previous sampling method cannot be exactly replicated in the current recruitment, over-sampling in rural and remote areas will be promoted by consistent monitoring of participant's location as they are recruited. Participant's residential address, collected in the online survey, can be quickly geocoded and plotted onto a map of Australia to give a visual picture of the spread of respondents across the country. Figure 4-5 shows location of participants recruited at 17 December, 2012. Participant's postcode can also be used to determine their remoteness area using

the ABS 2011 Postcode to Remoteness Areas 2006 index. These details for participants recruited at December 18, 2012 are shown in a cross tabulation of remoteness area by state in Table 4-5

If a specific area, for example, rural South Australia, is not accurately represented, advertising and promotion can be quickly adapted and targeted at areas in that region. For example, social media advertising, posts on Facebook and tweets on Twitter could appeal directly to women living in rural South Australia as follows: 'Calling all women of Smithtown/Port Lincoln/Lucindale, no-one in your town is taking part – help ensure young women in Smithtown/Port Lincoln/Lucindale are heard'. Traditional media can also be targeted to specific areas where recruiting might be lagging through approaches to rural press and radio, which have both previously been very accommodating in providing editorial space to assist with recruiting research participants.

4.5.5 Reference Panel

In order to collect feedback on draft promotional materials, recruitment strategies and other related items, a reference panel of 18-23 year old women has been established at Newcastle. The panel comprises a group of four young women who are able to provide feedback on a regular basis to recruitment materials provided to them for comment. Involvement of the reference group helps to ensure that promotional materials are suitably targeted to the 18-23 year age group, and that the viewpoints of this age group are considered.

Table 4-5 Cross-tabulation of Remoteness Area by State for New Young cohort participants at 18 December, 2012

	State								
Remoteness Areas of Australia	NSW	VIC	QLD	WA	SA	ACT	TAS	NT	TOTAL
Major Cities	156	76	139	33	19	33			456
Inner Regional	29	21	27		3		10		90
Outer Regional	4	4	3	6	2			3	22
Remote				2	1				3
Very Remote					1				1
TOTAL	189	101	169	41	26	33	10	3	572

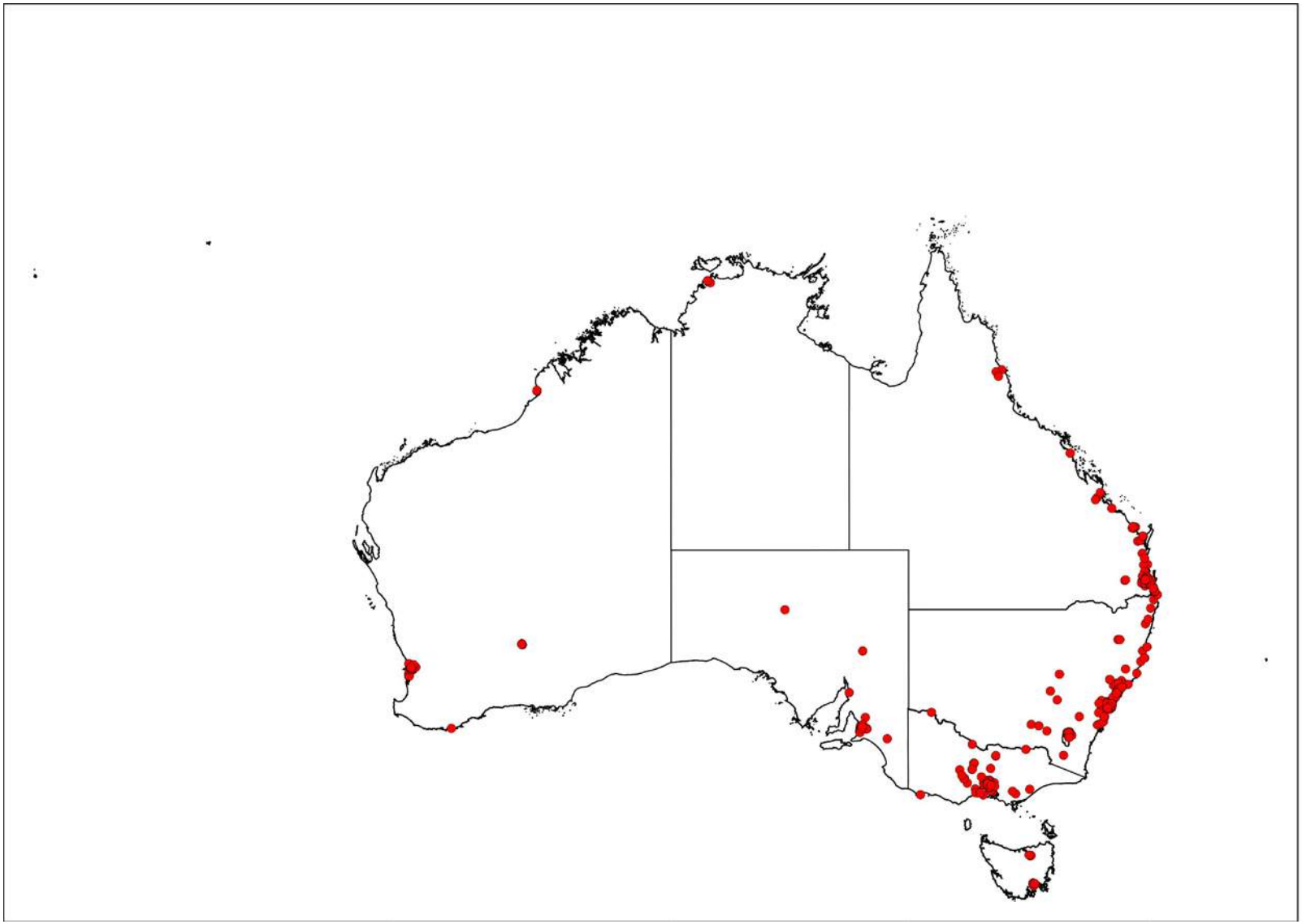


Figure 4-5 Remoteness area and location of new young cohort participants at December 18, 2012.

4.6 Ethics approvals

ALSWH activities are reviewed by ethics committees at The University of Newcastle, The University of Queensland, and the Department of Health and Ageing. The University of Newcastle Human Research Ethics Committee (HREC) acts as the primary ethics committee and reviews all activity or materials.

Ethical review of recruitment of ALSWH's new young cohort began in June 2011, when an application for approval for Phase 1 Focus Groups was made to The University of Newcastle HREC. Eighteen more formal applications have been submitted and approved since then - details are shown in Table 4-6.

Table 4-6 New Young Cohort formal ethics applications and approvals, 2011 – 2012.

Description	Ethics Committee	Submission date	Approval Date
Request to conduct Phase 1 Focus Groups	University of Newcastle HREC	1 June 2011	15 July 2011
	University of Queensland MREC	19 July 2011	27 July 2011
Reimbursement for focus group participants	University of Newcastle HREC	25 August 2011	4 October 2011
	University of Queensland MREC	5 October 2011	5 October 2011
Phase 2 Focus Groups (January amendment)	University of Newcastle HREC	8 December 2011	20 December 2011
	University of Queensland MREC	16 January 2012	18 January 2012
Phase 2 Focus Groups (March amendment)	University of Newcastle HREC	15 March 2012	29 March 2012
	University of Queensland MREC	20 March 2012	21 March 2012
Pilot Survey	University of Newcastle HREC	28 July 2012	23 August 2012
	University of Queensland MREC	27 August	30 August 2012
Cohort recruitment and Survey 1	University of Newcastle HREC	19 July 2012	19 July 2012
	Department of Health and Ageing Ethics Committee	25 July 2012	14 September 2012 (Conditional approval received 24 August 2012)
	University of Queensland MREC	20 August 2012	30 August 2012
	Department of Human Services External Review Committee	19 September 2012	12 October 2012

Description	Ethics Committee	Submission date	Approval Date
Documentation for Ambassadors	University of Newcastle HREC	10 September 2012	19 September 2012
Minor changes to questions on Survey	University of Newcastle HREC	10 October 2012	11 October 2012
	University of Queensland MREC	12 October 2012	25 October 2012
2nd recruitment poster + postcard	University of Newcastle HREC	17 October 2012 (submitted for noting, but required full review)	21 November 2012
	University of Queensland MREC	6 December 2012	Pending

4.6.1 Approval for online consent for data linkage

A key feature of the new young cohort is that at recruitment, participants are required to give consent for their data collected in administrative datasets (such as Medicare, the Pharmaceutical Benefits Scheme, and state-based records such as hospital separations data) to be accessed and linked to their ALSWH survey data.

In the original recruitment protocol, written consent to this linkage was to be obtained as part of the Medicare mailout. However, recruitment through Medicare was not adopted, and focus group and other feedback strongly indicated asking for online consent for data linkage would be most appropriate for this age group. To obtain online consent some alterations to the original consent process were required – details of the changes are provided in Appendix C. Approval was also required from ethics committees, with final approval required from the External Review Committee of the Department of Human Services (see Table 4-6 for dates of submissions and approvals).

4.7 References:

[1] Edwards PJ, Roberts I, Clarke MJ, DiGuiseppi C, Wentz R, Kwan I, Cooper R, Felix LM, & Pratap S. (2009). Methods to increase response to postal and electronic questionnaires. *Cochrane Database of Systematic Reviews*, Issue 3. Art. No.: MR000008. DOI: 10.1002/14651858.MR000008.pub4

[2] Doerfling P, Kopec JA, Liang MH, & Esdaile JM. (2010). The effect of cash lottery on response rates to an online health survey among members of the Canadian Association of Retired Persons: a randomized experiment. *Canadian Journal of Public Health*, 101:251-254.

[3] Draper H, Wilson S, Flanagan S, & Ives J. (2009). Offering payments, reimbursement and incentives to patients and family doctors to encourage participation in research. *Family Practice,* 26(3):231-8.

5. MAINTENANCE OF COHORTS

5.1 Update of sample and response rates

5.1.1 Survey 1, 1996

Information provided in early reports has been repeated and updated here for completeness. More than 40,000 women responded to Survey 1 of the main cohorts in 1996. Because of uncertainties about the accuracy of the Medicare database (which was used as the sampling frame for the stratified random samples), response rates cannot be exactly specified. We have estimated that 41-42%, 53-56%, and 37-40% of the 1973-78 cohort, the 1946-51 cohort, and the 1921-26 cohort of women, respectively, responded to the initial invitation to participate. Confidentiality restrictions meant that the names of the selected women were unknown to researchers. Usual methods of encouraging participation such as by telephone could not be used. The response rates were pleasing given that the invitation included a request for women to participate in the longitudinal study for up to 20 years.

In light of these response rates, it is important to assess any response bias so that the generalisability of the study findings can be determined. A comparison of the demographic characteristics of respondents and non-respondents was not possible because privacy guidelines prevented the researchers from having any information about women who were selected to receive an invitation but did not respond. We were able, however, to obtain aggregate data for non-respondents' use of health services (from the Australian Medicare database). These data suggest that there are small differences in use of health services among respondents and non-respondents, with non-respondents less likely, for example, to have visited a medical specialist in the last 2 years (The 1946-51 cohort, 49% versus 54%; the 1921-26 cohort, 65% versus 72%). There was not a significant difference in health service use between respondents and non-respondents from the 1973-78 cohort.

A proportion of this difference may be explained by the fact that some women who were selected may no longer be living in Australia or may have died, as the Medicare database is not routinely linked to emigration records or the National Death Index in Australia.

Although we were not able to ascertain reasons for non-response (because we were not allowed to know any details about the selected women), we were able, through comparison with the 1996 census data, to confirm that the participants in each of the cohorts are reasonably representative of the general population of women of the same age in Australia (see Table 5-1). There is some response bias in terms of overrepresentation of women with tertiary education and under-representation of some groups of immigrant women.

This information and Table 5-1 (below) are taken from Brown, W. J., Dobson, A. J., Bryson, L., & Byles, J. E., Women's Health Australia: On the progress of the main cohort studies. *Journal of Women's Health & Gender-Based Medicine,* 1999; 8(5): 681-688.

5.1.2 Sample for the longitudinal study

Retention and representativeness of the sample

Some participants who completed Survey 1 in 1996 did not provide any contact details (532 women in the 1973-78 cohort, 383 women in the 1946-51 cohort and 508 women in the 1921-26 cohort). Hence, the numbers of women actually enrolled in the study were 14,247 in the 1973-78 cohort, 13,716 in the 1946-51 cohort and 12,432 in the 1921-26 cohort of women.

Table 5-1 Socio-demographic characteristics of the 1973-78 cohort, the 1946-51 cohort and the 1921-26 cohort respondents, and for women of the same age in the general population (ABS Census, 1996).

	Young (18 - 23 years)		Mid-age (45 - 50 years)		Older (70-75 years)	
	WHA %	ABS %	WHA %	ABS %	WHA %	ABS %
Number	14,762	759,680	14,072	734,155	12,804	377,152
Main current employment status						
Employed full-time	31.3	32.4	36.1	36.0	NA	
Employed part-time	19.2	26.4	30.1	28.5	NA	
Worked (without pay)/employed (other)	1.9	1.3	7.0	2.0	NA	
Unemployed	6.4	10.5	1.9	4.0	NA	
Total not in labour force	39.4	26.3	21.6	27.0	NA	
Not stated	1.8	2.7	3.3	2.5	NA	
Highest qualification completed						
No post school qualification	69.8	69.3	63.1	61.8	79.8	70.4
Trade/Apprenticeship	2.4	7.9	3.5	7.0	3.7	2.7
Certificate/Diploma	15.1	6.0	15.9	8.7	7.3	3.3
University degree	12.1	7.7	16.3	11.6	4.0	2.4
Other (not stated, inadequately described)	0.6	9.1	1.2	10.8	5.2	21.2
Aboriginal/Torres Strait Islander						
Non Indigenous	97.9	94.9	98.1	96.7	91.6	93.7
Aboriginal or TSI	1.6	2.7	0.8	1.1	0.3	0.4
Not stated	0.5	2.5	1.1	2.1	8.1	5.9
Country of birth						
Australia	88.6	77.8	69.0	62.6	68.5	66.4
Other English speaking	3.5	4.1	13.9	11.6	12.4	11.0
Other Europe	1.3	1.6	8.7	11.0	9.7	12.7
Asia	3.6	10.6	4.3	8.2	1.8	3.3
Other/not stated	3.0	6.0	4.2	6.5	7.6	6.5

Present marital status						
Married	8.2	9.0	75.1	73.0	54.7	48.9
Separated/divorced	0.0	1.1	13.2	18.7	6.3	6.8
Widowed	0.0	0.2	2.1	2.7	35.2	39.9
Never married	79.0	89.8	3.9	5.6	3.2	4.4
De Facto (not collected by ABS)	12.0	-	5.7	-	0.6	-
Present housing situation						
House	74.3	79.4	84.7	89.2	76.7	79.3
Flat/apartment/unit	20.0	14.0	7.1	6.5	19.4	12.9
Other	5.7	6.6	8.2	4.3	3.9	7.9

Among the 1973-78 cohort, 69% responded to Survey 2 in 2000, 65% to Survey 3 in 2003, 67% responded to Survey 4 in 2006 and 61% to Survey 5 in 2009 (see Table 5-2). This retention compares well with other surveys of this highly mobile age group. The major reason for non-response among the 1973-78 cohort has been that the research team has been unable to contact the women (21% of eligible women at Survey 2, 28% at Survey 3, 21% at Survey 4 and 23% at Survey 5), despite using all possible methods of maintaining contact. Women in their twenties are characterised by high levels of mobility, change of surnames on marriage, often not having telephone listings, not being registered to vote, and making extended trips outside Australia for work, education, or recreation.

Table 5-2 Participation and retention of 14,247 women in the 1973-78 cohort of women who were 18-23 years old at the first survey in 1996

	Survey 2	Survey 3	Survey 4	Survey 5
Age in years	22-27	25-30	28-33	31-36
Eligible at previous survey	14,247	14,116	13,886	13,557
Ineligible				
Deceased between surveys	22	10	15	8
Frailty (e.g. intellectual disability)	3	6	4	3
Withdrawn before survey mailout	106	213	311	209
Total ineligible	131	229	330	220
Eligible at current survey	14,116	13,887	13,557	13,337
Non-respondents				
Withdrawn from the project	124	200	171	113
Contacted but no return to survey	1332	653	1371	1994
Unable to contact participant	2972	3953	2870	3030
Total non-respondents	4428	4806	4412	5137
Respondents completed survey	9688	9081	9145	8200
Retention rate as % eligible	68.6%	65.4%	67.5%	61.5

Demographic characteristics (country of birth, marital status, education, employment and lone person household) of the 1973-78 cohort respondents at Survey 1 (1996) and Survey 2 (2000) were compared with those of women of the same age in the Australian population, using data from the 1996 and 2001

Censuses respectively. The comparisons revealed few differences - however there was some under-representation of women from non-English language countries at both surveys, a not unexpected finding, given that Medicare routinely excludes overseas students. The disparity in education increased between 1996 and 2001. Whereas at the 1996 Census almost 70% of young women had no post school qualifications (ALSWH and the general population), 31% and 49% had no post school qualifications in the ALSWH sample in 2000 and the 2001 Census respectively. Some of these differences will be due to overseas graduates returning home and Australian graduates working overseas. ALSWH women were less likely to be employed compared with women of the same age in the 1996 Census (52% vs. 60%), but more likely to be employed than women of the same age in the 2001 Census (85% vs. 67%).

Retention has been much higher among the 1946-51 cohort of women; 91% responded to Survey 2 in 1998, 84% responded to Survey 3 in 2001, Survey 4 in 2004 and Survey 5 in 2007, and 82% responded to Survey 6 in 2010 (see Table 5-3). The major reasons for non-response among the 1946-51 cohort has been that the research team has been unable to contact the women (6% to 8% of eligible women between Survey 2 and Survey 6), and non-return of questionnaires by women who could be contacted (2% at Survey 2 and 7% to 9% of eligible women at subsequent surveys). Women in the 1946-51 cohort typically lead busy lives, often working as well as caring for parents and their children. The women who could not be contacted were more likely to be separated, divorced or widowed.

Table 5-3 Participation and retention of 13,715 women in the 1946-51 cohort who were aged 45-50 years at Survey 1 in 1996

	Survey 2	Survey 3	Survey 4	Survey 5	Survey 6
Age in years	47-52	50-55	53-58	56-61	59-64
Eligible at previous survey	13,715	13,605	13,310	12,979	12,694
Ineligible					
deceased between surveys	50	65	88	99	119
frailty (e.g. dementia, stroke)	7	14	14	19	28
withdrawn before survey mailout	53	216	229	167	277
Total ineligible	110	295	331	285	424
Eligible at current survey	13,605	13,310	12,979	12,694	12,270
Non-respondents					
withdrawn from the project	156	161	136	226	201
contacted but did not return survey	254	997	886	995	1153
unable to contact participant	857	926	1052	835	905
Total non-respondents	1268	2084	2074	2056	2259
Respondents					
completed survey	12,338	11,226	10,905	10,638	10,011
Retention rate as % eligible	90.7%	84.3%	84.0%	83.8%	81.6%

Data from the 1996 and 2001 Censuses were used to compare demographic characteristics (country of birth, marital status, education, employment and lone person household) of women of the same age in

the Australian population with the 1946-51 cohort respondents at Survey 1 (1996) and Survey 3 (2001). There were few differences, however there was some under-representation of women from non-English language countries and women who were separated or divorced at both surveys.

Of women from the 1921-26 cohort, 91% responded to Survey 2 in 1999, 85% to Survey 3 in 2002, 84% to Survey 4 in 2005, 79% to Survey 5 in 2008 and 77% to Survey 6 in 2011 (see Table 5-4). Among the 1921-26 cohort the major reason for non-response was non-return of the questionnaire (4%, 8%, 7%, 9%, 17% of eligible women at Surveys 2, 3, 4, 5 and 6 respectively), although increasingly the participant could not be contacted in Surveys 1 to 5 (3% at Surveys 2 and 3, 6% at Survey 4, 9% at Survey 5). Non-respondent women tended to report poorer self-rated health at Survey 1 than respondents.

Table 5-4 Participation and retention of 12,432 women in the 1921-26 cohort of women who were aged 70-75 years at Survey 1 in 1996

	Survey 2	Survey 3	Survey 4	Survey 5	Survey 6
Age in years	73-78	76-81	79-84	82-87	85-90
Eligible at previous survey	12,432	11,537	10,186	8,531	7,002
Ineligible					
deceased between surveys	529	569	770	866	914
frailty (e.g. dementia, stroke)	106	265	379	322	563
withdrawn before survey mailout	260	517	506	341	263
Total ineligible	895	1351	1655	1528	1740
Eligible at current survey	11,537	10,186	8,531	7,002	5,262
Non-respondents					
withdrawn from the project	313	384	269	159	228
contacted but did not return survey	481	860	592	640	883
unable to contact participant	309	294	512	643	96
Total non-respondents	1103	1539	1373	1442	1207
Respondents					
completed survey	10,434	8,647	7,158	5,560	4,055
Retention rate as % eligible	90.5%	84.9%	83.9%	79.4%	77.1%

Demographic characteristics (country of birth, marital status, education and lone person household) of the 1921-26 cohort respondents at Survey 1 (1996) and Survey 3 (2002) were compared with those of women of the same age in the Australian population, using data from the 1996 and 2001 Censuses respectively. Comparisons showed few differences. There was some under-representation of women from non-English speaking countries in the ALSWH sample at both surveys. Comparisons are difficult for marital status and educational qualifications due to the high level of missing data in the Census.

5.2 Maintenance strategies

Cohort maintenance and tracking of 'return to sender' mail continues. The office team continues to track all women who responded to Survey 1 in 1996 and who are not known to have died or withdrawn from the survey since then. This includes women who did not respond to Survey 2, through to Survey 6. Participants for whom we have no current contact details remain in the tracking system unless they are positively identified as found, deceased, withdrawn, permanently emigrated or otherwise ineligible or are unwilling to participate.

The denial of access to the Electoral Roll early in 2011 has resulted in a more time-consuming process with a less successful tracking outcome. Secondary contacts, mobile phone numbers and email addresses continue to be the main sources of information. Publically available information, published on various websites including White Pages, Facebook, Reverse Australia phone number listings and obituary notices assist in the process.

5.3 National Death Index

The National Death Index (NDI) is used on an annual basis to identify women who are recorded as being deceased. This not only adds to information provided by family members, but also provides administrative data on causes of death. A list of 35,605 participants' details, including unconfirmed deceased participants and participants who have withdrawn from the project, was sent to AIHW in December 2011 for matching against the NDI. This year maiden names were not included because the inclusion of these names has not previously resulted in many extra matches, but does incur a higher fee. A list of 10,583 record pairs for 1913 participants was returned by AIHW in January 2012 for clerical review.

Each record pair comparison received a weight that reflects the quality of the link: the higher the weight, the higher the quality (as determined by the linking algorithm).[1]

In general, the main contribution to the weight is made by the names. There are two factors that influence the weight that a name-pair contributes. The first is the frequency of the name in the portion of the NDI selected. For example, a link of John to John receives far less weight (about 6.5) than a link of Zbygniew to itself (about 20) because the former is much more likely to occur by chance. The second factor comes into play when the names are not the same. An algorithm is used to determine how 'close' the two names are. Names that are very similar receive almost the same weight as names that are exactly the same. As the difference grows, the weight diminishes until it reaches a maximum disagreement of about –10.[1]

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

The last and smallest contribution to the weight is for agreement or disagreement of sex.[1]

The record pairs can be divided into three regions – non-links (reject), possible links (review) and links (accept). The majority of the clerical review will be done in the 'possible links' region. These three regions are illustrated in Figure 5-1.[1]

[1] Australian Government, Australian Institute of Health and Welfare (AIHW), 2011. *User-guide to the NDI results file*

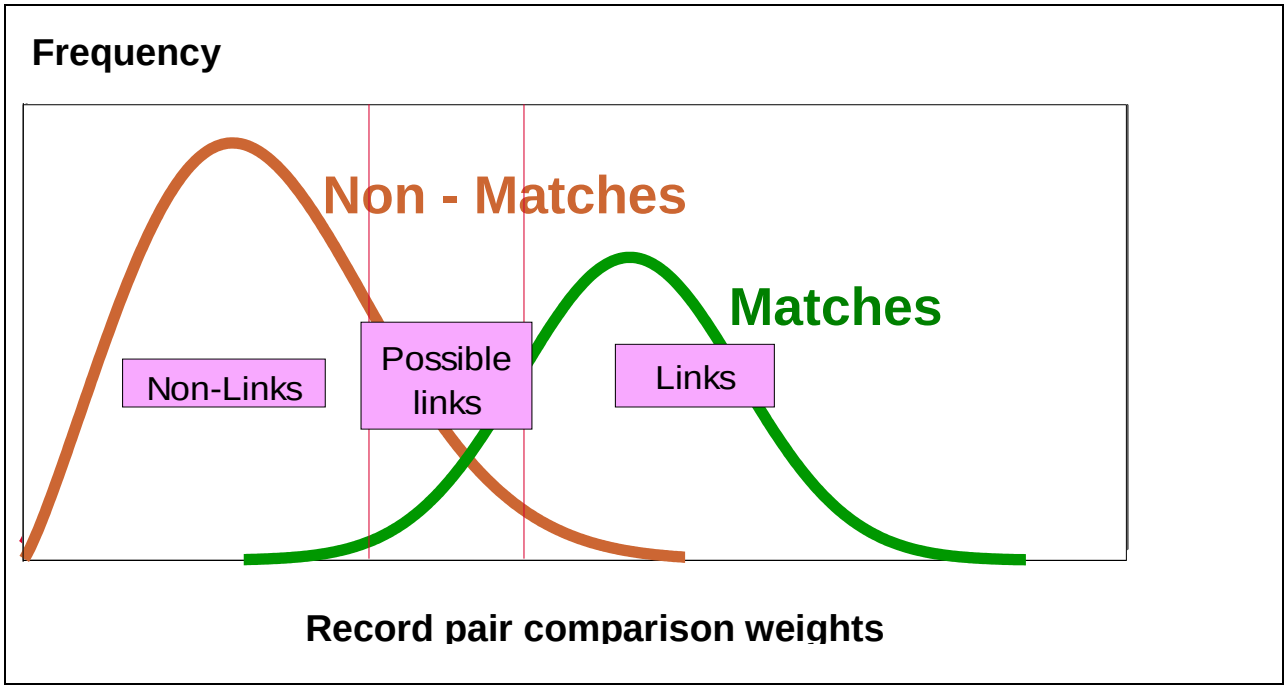


Figure 5-1 Idealised distribution of record pair comparison weights from a hypothetical linkage.

Quite often record pairs can be accepted or rejected from a certain weight onwards without having to clerically review the records beyond a certain cut-off weight. For example, if all links below a weight cut-off of 10 are to be rejected, a 'lower weight bound' of 10 can be applied to automatically reject any record pairs below that weight. The same applies for records that can be accepted above a weight cut-off of for example 25. An 'upper weight bound' of 25 can be applied to automatically accept all the record pairs above a weight of 25.[1]

Figure 5-2 shows a graph of the distribution of weights of record pairs in the clerical review file. In the clerical review of the ALSWH record pairs an upper weight bound of 35 was used to automatically accept record pairs greater than or equal to this value.

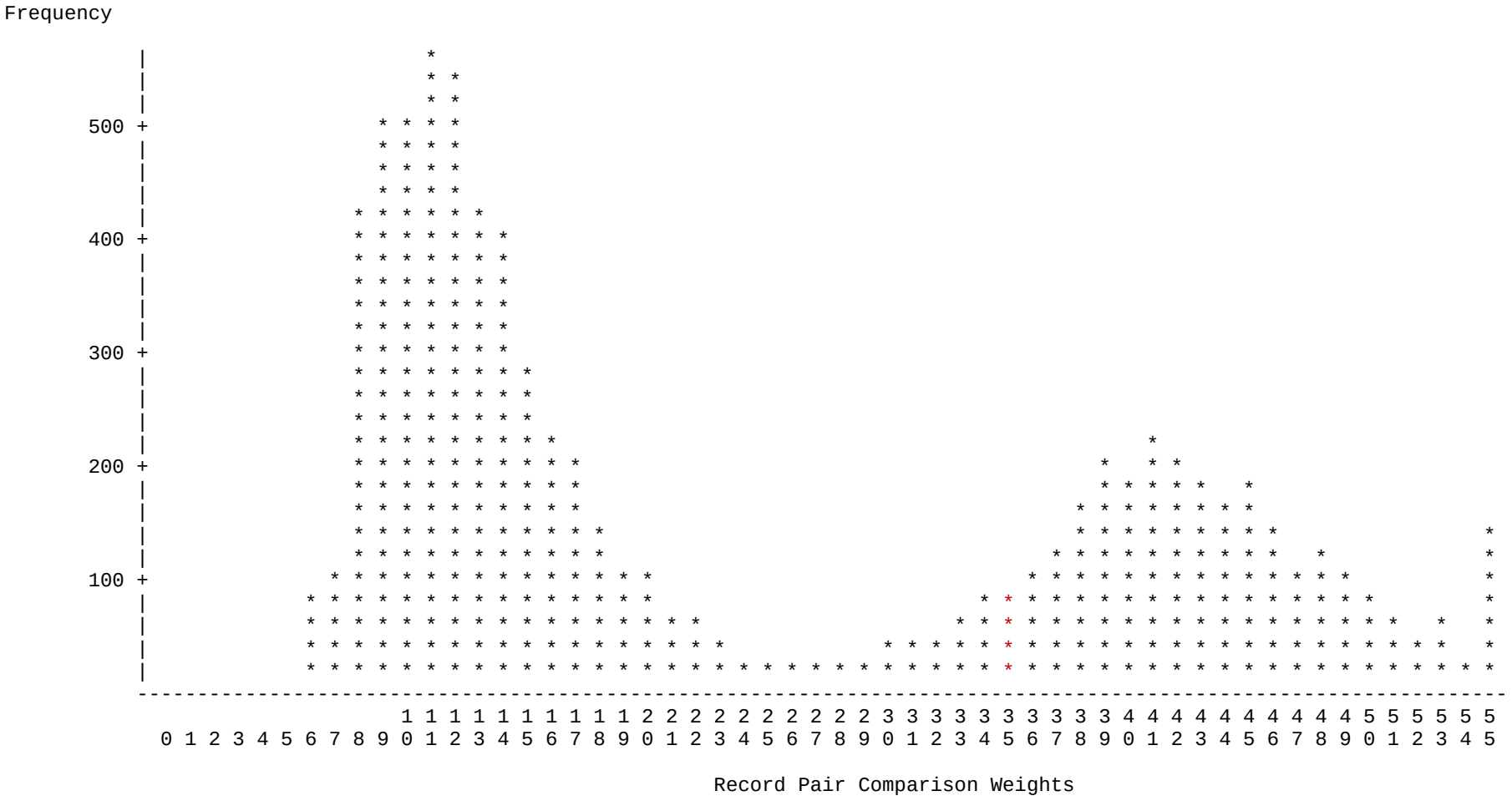


Figure 5-2 Distribution of record pair comparison weights for primary record pairs review file

The ALSWH record pairs were coded according to the closeness of the match of the ALSWH date of birth with the NDI date of birth and the closeness of the match of the project surname, first name and middle name with those recorded on the NDI. Those with exactly matching date of birth and surname, first name and middle name (Pass 1) were taken as deceased (432 records). Those with exactly matching date of death and surname, first name and middle name (Pass 2) were taken as deceased (5 records). Those with a weight greater than or equal to 35 (Pass 3) were automatically taken as deceased (68 records). Those with matching date of birth and date of death (Pass 4) were checked and all 10 record pairs were confirmed. Combinations of close date of birth matches and close name matches and weight greater than 25 were checked (Pass 5) and 17 matches were confirmed as deceased. Further records where the first name, middle name and date of birth matched with the weight greater than 20 (Pass 6) were checked. From the records checked, a further 4 deceased matches were identified and in cases where there was any doubt whether the deceased person was one of the ALSWH participants the record pair was rejected. Records where the participant was known to be deceased by ALSWH but had not been matched in Passes 1 to 6 were checked but no satisfactory matches were found. Each match accepted was checked to see if they were an ALSWH known deceased participant or a new deceased participant. A table showing the characteristics of each successive pass is shown in Table 5-5 and the results of each pass in shown in Table 5-6.

Table 5-5 Criteria for the clerical review passes

Pass	Surname	First name	Middle name	Deceased	DOB	DOD	Weight	Record as deceased
1	Same as NDI	Same as NDI	Same as NDI or is null		Same as NDI			Automatically
2	Same as NDI	Same as NDI	Same as NDI or is null			Same as NDI		Automatically
3							>35	Automatically
4					Same as NDI	Same as NDI		Check
5							>25	Check
6		Same as NDI	Same as NDI		Same as NDI		>20	Check
7				ALSWH known deceased			>10	Check

Table 5-6 Summary of National Death Index matching results

Pass	Known deceased	New deceased	**Total confirmed**	Doubtful match	Not checked	Duplicates	**Total**
1	182	250	**432**			22	**454**
2	5		**5**				**5**
3	29	39	**68**	2		3	**73**
4	10		**10**			1	**11**
5	8	9	**17**	66		1	**84**
6	1	3	**4**	13			**17**
7			**0**	90		115	**205**
Remainder			**0**		9219	515	**9734**
Total	**235**	**301**	**536**	**171**	**9219**	**657**	**10,583**

Of the 536 matches identified, for 235 deaths ALSWH had already been informed, 73 were new notifications and 229 were notification of deaths of participants who had withdrawn. The summary of results is shown in Table 5-7.

Table 5-7 Summary of National Death Index matching results

Confirmed deceased	235
New deceased	73
Withdrawn deceased	229
Doubtful match	171
Duplicate deceased record	657
Not checked	9,219
Total	**10,583**

Since 1996, a total of 5,983 participant deaths had been identified at the time of the clerical review - this number includes participants who have withdrawn. The number of participant deaths excluding participants who have withdrawn is 4,401 and 135 (3%) of these have never been confirmed with the NDI.

Figure 5-3 shows the majority of the confirmed deaths occur in the 1921-26 cohort, with a few in the 1946-51 cohort, and very few in the 1973-78 cohort. The graph shows a drop in 2011, against the trend of increasing numbers of 1921-26 cohort deaths over previous years.

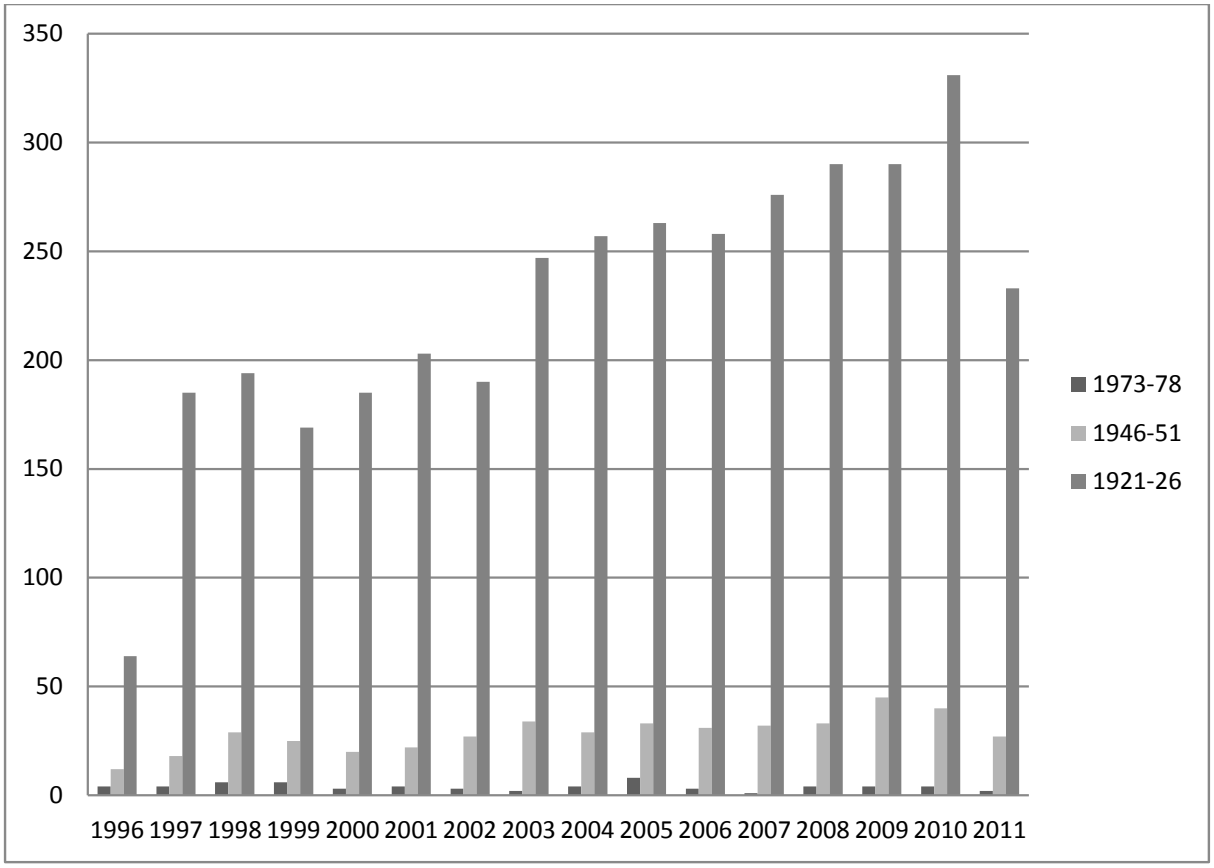


Figure 5-3 Number of confirmed deaths of ALSWH participants for each year by main cohort.

Figure 5-4, Figure 5-5 and Figure 5-6 below, graph the results for each year that matching to the NDI has been conducted. Additional contact with the 1921-26 cohort as a result of the six monthly follow-up has meant that many more of the deaths of this cohort have been known about than in previous years.

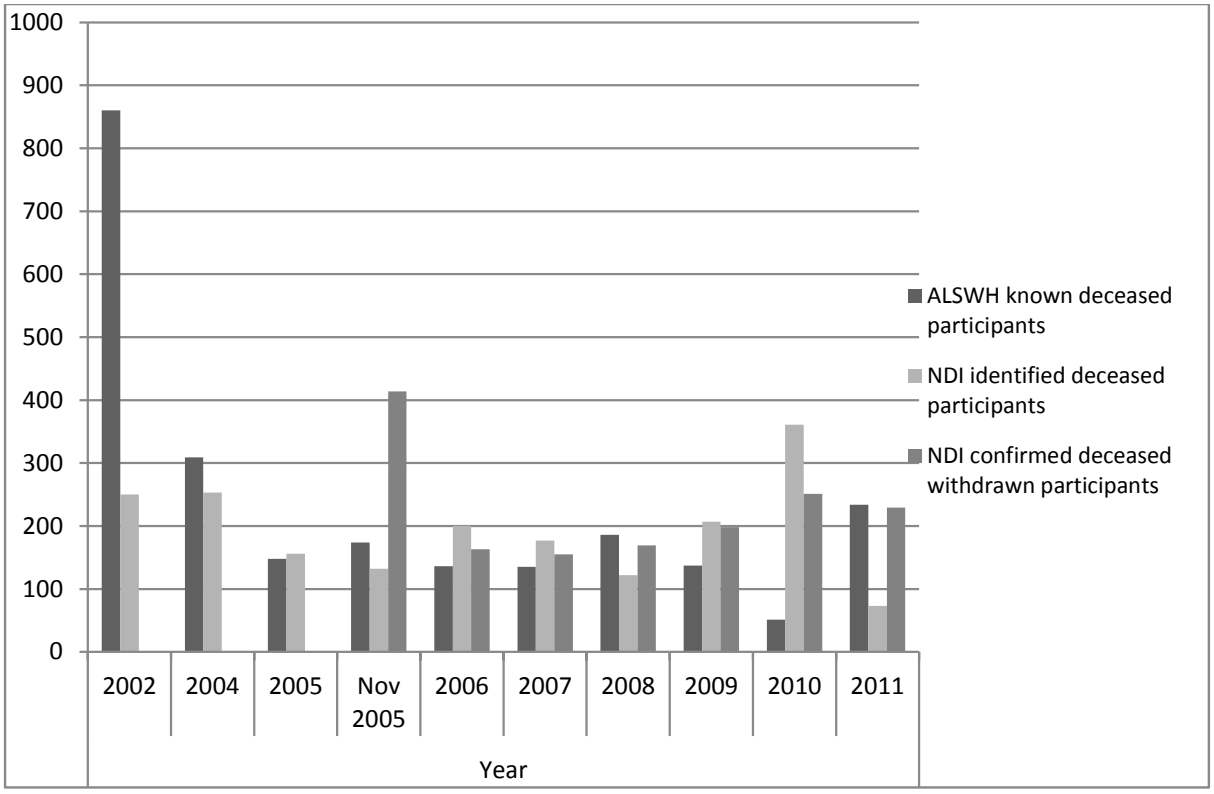


Figure 5-4 Number of matched deaths at each time matching has been conducted.

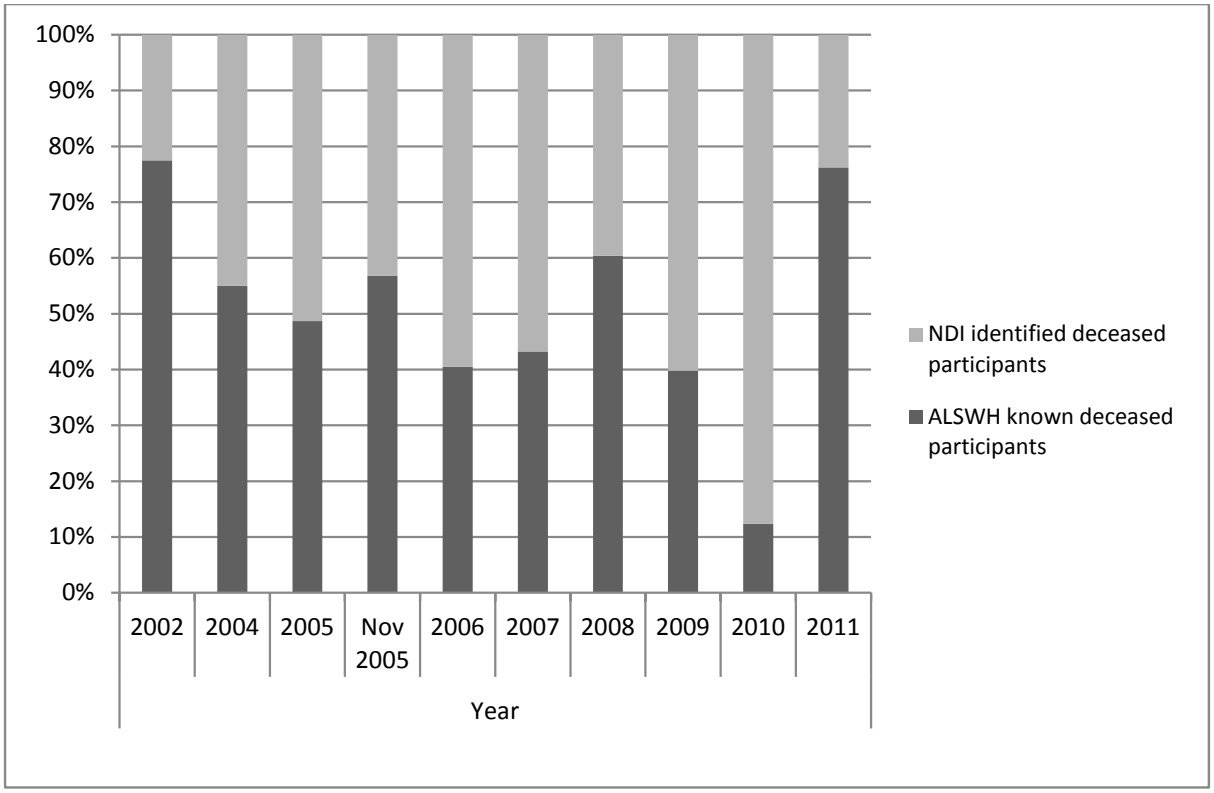


Figure 5-5 Percentage of ALSWH known and unknown deaths confirmed by NDI at each time of matching.

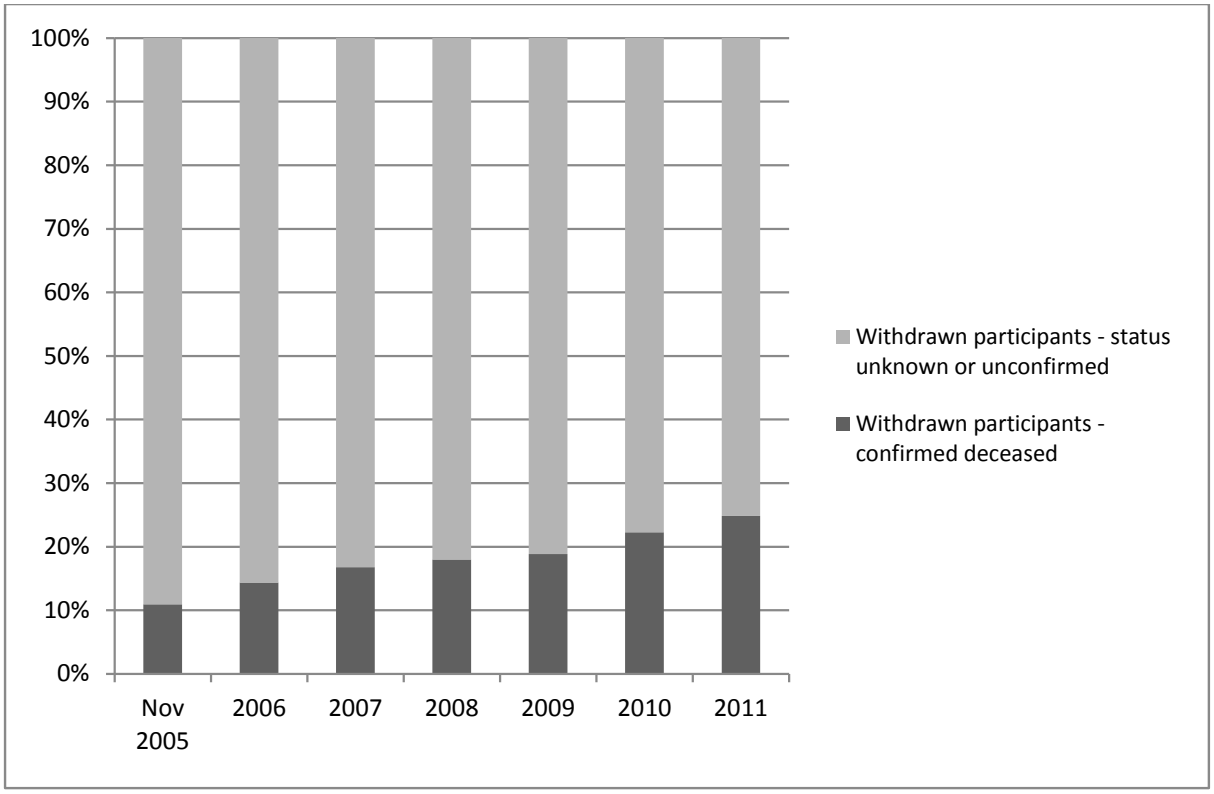


Figure 5-6 Percentage of withdrawn participants who are known to be deceased at each time of matching.

The next round of matching of ALSWH participants to the NDI will commence in November 2012.

5.4 Cause of Death Codes

Of the 5,847 deaths confirmed with NDI (including participants who have withdrawn) cause of death (COD) codes are available for 3,653. The 2,194 deaths for which there is no COD information occurred in the last four years. Availability of COD data from 2008 onwards has been delayed by changes in procedural processes within AIHW.

Table 5-8 Confirmed deaths with and without cause of death (COD) codes by year of matching

	Year of matching					
	Before 2008	2008	2009	2010	2011	**Total**
No COD Code	0	467	535	657	535	2194
COD Codes	3629	10	7	6	1	3653
Deceased	3629	477	542	663	536	5847

There can be up to 19 causes of death. The first cause of death is the underlying cause of death. All others are additional causes of death. Multiple cause of death coding was used from 1997 onwards.

The codes for causes of death depend on when the person died and when their record was placed on the NDI. Those deaths that were registered in or before 1996 are recorded in ICD-9, those registered in 1997 and 1998 are a combination of ICD-9 and ICD-10 and those registered in 1999 and onwards are recorded in ICD-10.

6. Data linkage

In 2012, approval was obtained from the Department of Health and Ageing Departmental Ethics Committee and the AIHW Ethics Committee for a revised data linkage protocol for linkage of Australian Longitudinal Study on Women's Health (ALSWH) survey data with Commonwealth datasets under the auspices of the AIHW as an Integrating Authority. As the Integrating Authority, the AIHW will ensure appropriate governance of the record linkage aspects of the project in accordance with the high level principles for data linkage involving Commonwealth data defined by the Cross Portfolio Statistical Integration Committee (CPSIC).

The approved protocol allows for linkages of de-identified ALSWH data from all participants, with the exception of those who have specifically refused consent, to data from the Medicare Benefits Scheme (MBS) and the Pharmaceutical Benefits Scheme (PBS), Aged Care Funding Instrument (ACFI), Community Aged Care Program (CACP), Extended Care at Home (EACH) Program, Extended Care at Home- Dementia (EACH-D) Program, Home and Community Care (HACC) Program – HACC minimum data set (MDS) including functional dependency items, Aged Care Assessment Program (ACAP) and the National Death Index (NDI).

The AIHW are currently negotiating access to historical (from 1996) MBS/PBS data with the Department of Health and Ageing and will then extract required data for provision to the ALSWH investigators.

This year, ALSWH has also progressed linkages between ALSWH data and State-based datasets. Approval has been gained from Human Research Ethics Committees (HREC) in Queensland, New South Wales, Western Australia and Victoria for access to Admitted Patients Datasets, Perinatal Data Collections and Cancer Registry, and data have been received from these States. South Australia and the Northern Territory HREC applications are in progress. Approval has been obtained for the State-based data to be updated annually so that all analyses are based on the most recent data.

A number of projects relying on State data are currently in progress.

7. Major Reports

7.1 Adherence to health guidelines: Findings from the Australian Longitudinal Study on Women's Health

Report prepared for the Australian Government Department of Health and Ageing

7.1.1 Introduction

This report used data from the Australian Longitudinal Study on Women's Health (ALSWH) to assess adherence to national guidelines for preventive health behaviours and selected health screening.

The guidelines used were those disseminated by the National Health and Medical Research Council, the Royal Australian College of General Practitioners, and/or the Australian Government Department of Health and Ageing, based on the best available evidence at the time.

The main findings over the period 1996-2011 are summarised in Table 7-1.

7.1.2 Smoking

The data from the women in the study show that women are responding to quit smoking messages. While around half the women in the cohorts had smoked at some time, the predominant change since the study began is that women have quit smoking. While some of the younger women took up smoking over the course of the study, the majority of these women quit by 2009 so that overall the prevalence of smoking halved and the prevalence of ex-smoking doubled. However some groups of women, particularly those with lower educational status and those in rural areas, remain at higher risk of continuing to smoke. Around half the smokers in 1946-51 cohort quit smoking by the sixth survey. Smoking rates among women in the 1921-26 cohort remained stable between Survey 1 and Survey 2, but smokers had much poorer survival. Moreover, there were clear benefits of quitting in terms of improved survival among women in this age group with ex-smokers having lower death rates than smokers.

7.1.3 Overweight and obesity

The overall trend was for women to gain weight, and for fewer women to meet the guidelines for healthy weight at each survey. The greatest increases were seen among the women in the 1973-78 cohort. By Survey 5 in 2009, around 45% of this cohort were overweight or obese. Few women lost weight.

The 1946-51 cohort started the study with around 47% overweight. This proportion increased over time but with some levelling off in later years. In contrast, women in the oldest cohort showed little change in the proportion who were overweight or obese. However the interpretation of the results for these women needs to consider loss to follow-up due to illness or death. Importantly, women who had a BMI < 18.5 had the highest rate of mortality. Also, current evidence suggests that a slightly higher BMI (around 27) can be considered to be "healthy" for women in this age group.

Table 7-1 Summary of major findings of report

Smoking guidelines	No-one should take up smoking and smokers should quit				
Cohort	Prevalence of current smoking				
1973-78	Decreased from 32% to 15%				
1946-51	Decreased from 18% to 9%				
1921-26	Only 8% at Survey 1				
Overweight and obesity	Healthy weight BMI<25 (kg/m^2)				
Cohort	Prevalence of overweight and obesity				
1973-78	Increased from 23% to 45%				
1946-51	Increased from 47% to 62%				
1921-26	Changed little, around 46% - percentage underweight increased				
Alcohol consumption	No more than 2 drinks per day and 14 per week; no more than 4 drinks on any one occasion				
Cohort	No more than 2 drinks per day				
1973-78	Increased from 39% to 72%				
1946-51	Increased from 81% to 87%				
1921-26	More than 90% at Survey 1				
Adherence to the guideline for no more than 4 drinks on any one occasion also increased					
Physical activity	30 mins of moderate activity on most days				
Cohort	Change for Survey 2 to Survey 6				
1973-78	Decreased from 47% to 44%				
1946-51	Increased from 46% to 58%				
1921-26	Decreased from 41% to 25%				
Diet	Percentages of women meeting the guidelines for different food groups				
Cohort	Cereals 4-9	Vegetables >=5	Fruit>=2	Dairy>=2	Meat>=1
1973-78	2%	<1%	21%	14%	71%
1946-51	10%	2%	47%	33%	83%
1921-26*	N/A	8%*	70%*	N/A	N/A
*Different data collection method. Due to the times and methods for measuring diet in ALSWH few changes can be detected over time.					
Screening health checks for 1946-51 cohort					
Blood pressure	>90%				
Cholesterol	Increased from 60% to 83% since Survey 3				
Mammography	Increased from 53% to 83% since Survey 1				
Pap smear	Steady, around 80% since Survey 3				
Bowel cancer	33% at Survey 6				

7.1.4 Alcohol

Most women in the study did not exceed more than 14 alcoholic drinks per week and most had at least one alcohol free day. Adherence to the guideline to drink no more than two drinks per day was lowest in the youngest cohort, but increased over time in all cohorts. By the time the youngest women were 31-26 years old over 70% were adhering to this guideline. Likewise the percentage adhering to the recommendation to have no more than four drinks on any one occasion increased as the women moved from their 20s into their 30s. Analysis of change across surveys among these younger women shows a high degree of fluctuation in their alcohol intakes, with around 80% being non-adherent to the advice to drink no more than two drinks a day on at least one of the surveys, and 10% not adhering to this advice across all surveys. Other cohorts were more adherent with the guidelines overall and more consistent in their drinking behaviours.

7.1.5 Diet

A majority of women did not meet dietary guidelines for most food groups. The only exception was for intakes of meat, where guidelines were met by 71% of the 1973-78 cohort and 83% of the 1946-51 cohort. Guidelines for consumption of at least 5 serves of vegetables per day were least likely to be met.

A further area of poor adherence to dietary guidelines was in relation to consumption of “extras” in the diet. These are typically nutrient poor high-energy foods and Australians adults are recommended no more than four serves of these foods per day. However, only 10% of the 1973-78 cohort and 30% of the 1946-51 cohort were adherent with this guideline, with most women consuming more than four serves of these foods.

7.1.6 Physical activity

The proportions of women who met guidelines for adequate physical activity declined with each survey among the youngest and oldest cohorts, but increased among the women born 1946-51. Among the 1973-78 cohort, only 18% of women maintained adequate levels of physical activity at all surveys. Women were less likely to stay physically active once they married, had children, or were divorced. Among the 1946-51 cohort, there was a great fluctuation in adherence from survey to survey, but the overall trend was that women moved from inadequate to adequate levels of physical activity so that 57% per cent could be considered to be meeting the guidelines by Survey 6. This increase in activity was associated with changes in work and death of spouse, but a decrease was associated with birth of a grandchild. Activity levels decreased overall in the 1921-26 cohort so that by Survey 6 only 24% met the guideline. Factors associated with decreasing activity included major illness, injury or surgery, and moving into institutional care.

7.1.7 Pregnancy

The message about not smoking during pregnancy was adhered to by most women and adherence increased with women's age, with around 95% of pregnant women aged 31-36 years adhering to this guideline. In contrast, most women continued to consume alcohol while pregnant, even when guidelines for abstinence were in place. However, women who continued to drink while pregnant mostly adhered to the low alcohol guidelines that were in place in 2001.

Few pregnant women were adherent to the general guideline for physical activity, and the proportion of pregnant women who had adequate physical activity declined with age from 40% for 18-23 year olds to around 30% for women having pregnancies at later ages.

Diets of pregnant women were similar to those of other women in the 1973-78 cohort except pregnant women were more likely to meet guidelines for intake of dairy products. A detailed analysis of diet quality revealed that pregnant women's diets were often deficient in important nutrients including fibre, folate, Vitamin E, iodine and iron. There is also potential tension between guidelines to avoid foods that are at high risk of listeria contamination and achieving adequate nutrition.

7.1.8 Screening

There is very high adherence to recommendations for women to have blood pressure, cholesterol and blood sugar checks and for mammograms and Pap testing, with over 80% of women meeting guidelines for these checks. Bowel cancer screening and skin checks appear to be less well covered. However there are some inequities in the coverage of these checks including some small differences according to area of residence, and lower rates of screening among women in full-time work, those who are not married and according to level of education. Screening was strongly associated with more frequent attendance to a GP and with continuity of care and with receiving a reminder from the GP. Checks for cholesterol and blood sugar were more common among women with poor health and with chronic conditions including heart disease and diabetes. Women who smoke were less likely to have all screening procedures.

7.1.9 Conclusion

Among participants in the ALSWH, adherence to guidelines about smoking, alcohol consumption and most health screens has steadily improved or has remained high since the beginning of the study.

The areas in which there are substantial differences between guidelines and actual behaviour relate to energy balance. The prevalence of overweight and obesity has increased, and around half the women do not report adequate physical activity and very few meet the dietary guidelines.

This finding brings into sharp focus the national importance of attaining healthy weight for the entire population, not just for children, and the challenges that are faced in changing diet and exercise levels.

8. Dissemination of study findings

8.1 Website

In 2011, ALSWH engaged KMO, a Brisbane web design company, to redevelop the study website. Major objectives were to improve navigation around the website and update the underlying technology to allow content to be accessed and managed by staff at both the University of Queensland and the University of Newcastle. The redesign was completed in August 2012. The website (location is unchanged at **www.alswh.org.au**) now has a new look and new features including:

- Separate sections for participants and researchers
- Drop-down menus to make navigation quicker
- Details of all projects, including the title, collaborators and, for recently approved projects, a lay summary of the research.
- Links to social media (Facebook, Twitter and YouTube)
- A page with links to all current online surveys is under construction

The website continues to be regularly updated with details of collaborators, ongoing and completed analyses, reports, and abstracts of all accepted and published papers. The website links to ALSWH online surveys and has been included on all promotional material used for recruitment of the new young cohort.

8.2 Publications

8.2.1 Papers published

Anderson A, Hure A, Powers J, Kay-Lambkin F & Loxton D. **Determinants of pregnant women's compliance with alcohol guidelines: A prospective cohort study**. *BMC Public Health*, 2012, 12(1); p. 777.

Powers J, Loxton D, Baker J, Rich J & Dobson A. **Empirical evidence suggests adverse climate events have not affected Australian women's health and well-being.** *The Australian and New Zealand Journal of Public Health*, 2012, 36(5); 452-457.

Adams J, Sibbritt D & Lui C. **Health service utilisation among persons with self-reported depression: A longitudinal analysis of 7,164 women**. *Archives of Psychiatric Nursing,* 2012, 26(3), 181-191.

Beatty L, Adams J, Sibbritt D & Wade T. **Evaluating the impact of cancer on complementary and alternative medicine use, distress and health related QoL among Australian women: A prospective longitudinal investigation.** *Complementary Therapies in Medicine,* 2012, 20(1-2); 61-69.

Bielak A, Byles J, Luszcz M & Anstey K. **Combining longitudinal studies showed prevalence of disease differed throughout older adulthood.** *Journal of Clinical Epidemiology,* 2012, 65(3); 317-324.

Broom A, Kirby E, Sibbritt D, Adams J & Refshauge K. **Back pain amongst mid-age Australian women: A longitudinal analysis of provider use and self-prescribed treatments.** *Complementary Therapies in Medicine,* 2012, 20(5); 275-282.

Brown W, McLaughlin D, Leung J, McCaul K, Flicker L, Almeida O, Hankey G, Lopez G & Dobson A**. Physical activity and all-cause mortality in older women and men.** *British Journal of Sports Medicine,* 2012, 46(9); 664-668.

Bruck D & Astbury J. **Population study on the predictors of sleeping difficulties in young Australian women.** *Behavioural Sleep Medicine,* 2012, 10(2); 84-95.

Burns R, Byles J, Mitchell P & Anstey K**. Positive components of mental health provide significant protection against likelihood of falling in older women over a 13-year period.** *International Psychogeriatrics*, 2012, 24(9); 1419-1428.

Chojenta C, Loxton D & Lucke J. **How do previous mental health, social support, and stressful life events contribute to postnatal depression in a representative sample of Australian women?** *Journal of Midwifery & Women's Health*, 2012, 57(2); 145-150.

Elstgeest L, Mishra G & Dobson A. **Transitions in living arrangements are associated with changes in dietary patterns in young women.** *The Journal of Nutrition,* 2012, 142(8); 1561-1567.

Heesch K, van Uffelen J, Gellecum Y & Brown W. **Dose response relationships between physical activity, walking and health-related quality of life in mid-age and older women.** *Journal of Epidemiology and Community Health,* 2012, 66(8); 670-677.

Herbert D, Lucke J & Dobson A. **Birth outcomes after spontaneous or assisted conception among infertile Australian women aged 28-36 years: a prospective, population-based study.** *Fertility and Sterility*, 2012, 97(3); 630-638.

Hure A, Powers J, Mishra G, Herbert D, Byles J & Loxton D. **Miscarriage, preterm delivery and stillbirth: large variations in rates within a cohort of Australian women.** *PLoS ONE,* 2012, 7(5); 1-8.

Leung J, Gartner C, Hall W, Lucke J & Dobson A. **A longitudinal study of the bi-directional relationship between tobacco smoking and psychological distress in a community sample of young Australian women.** *Psychological Medicine,* 2012, 42(6); 1273-1282.

Lopez D, Flicker L & Dobson A. **Validation of the Frail Scale in a cohort of older Australian women.** *JAGS,* 2012, 60(1); 171-173.

McLaughlin D, Leung J, Pachana N, Hankey G, Flicker L & Dobson A. **Social support and subsequent disability: It's not the size of your network that counts.** *Age & Ageing,* 2012, 41; 674-677.

Mishra D & Dobson A. **Using longitudinal profiles to characterize women's symptoms through midlife: results from a large prospective study.** *Menopause,* 2012, 19(5); 549-555.

Pachana N, McLaughlin D, Leung J, Byrne G & Dobson A**. Anxiety and depression in adults in their eighties: Do gender differences remain?** *International Psychogeriatrics,* 2012, 24(1); 145-150.

Pit S & Byles J. **The association of health and employment in mature women: A longitudinal study.** *Journal of Women's Health*, 2012, 21(3); 273-280.

Sibbritt D & Adams J. **Developing and promoting public health methods for integrative medicine: examples from the field in Australia.** *Journal of Chinese Integrative Medicine,* 2012, 9(3); 233-236.

Spencer E, Hugh C, Ferguson A & Colyvas K**. Language and ageing: Exploring propositional density in written language: Stability over time.** *Clinical Linguistics and Phonetics Journal,* 2012, 26(9); 743-754.

Tooth L, Hockey R, Treloar S, McClintock C & Dobson A. **Does Government subsidy for costs of medical and pharmaceutical services result in higher service utilization by older widowed women in Australia?** *BMC Health Services Research*, 2012, 12: 179.

van Uffelen J, Heesch K, van Gellecum Y, Burton N & Brown W**. Which older women could benefit from interventions to decrease sitting time and increase physical activity?** *Journal of the American Geriatrics Society*, 2012, 60(2); 393-396.

van Uffelen J, Heesch N & Brown W. **Correlates of sitting time in working age Australian women: who should be targeted with interventions to decrease sitting time?** *Journal of Physical Activity and Health,* 2012, 9(2); 270-287.

Wade T, Wilksch S & Lee C. **A longitudinal investigation of the impact of disordered eating on young women's quality of life.** *Health Psychology,* 2012, 31(3); 352-359.

Wardle J, Lui C, Adams. **CAM in rural communities: Current research and future directions.** *Journal of Rural Health,* 2012, 28(11); 101-112.

8.2.2 Papers accepted

Adams J, Sibbritt D, Broom A, Loxton D, Wardle J, Pirotta M & Lui C**. High levels of CAM use in rural areas largely due to high levels of chiropractor use: A national survey.** *Journal of Manipulative and Physiological Therapeutics.*

Au N, Hauck K & Hollingsworth B. **Employment, work hours and weight gain among middle-aged women.** *International Journal of Obesity.*

Berecki-Gisolf J, McKenzie S, Dobson A, McFarlane A, McLaughlin D. **A history of comorbid depression and anxiety predicts new onset of heart disease.** *Journal of Behavioral Medicine.*

Broom A, Meurk C, Adams J & Sibbritt D. **My health, my responsibility? Complementary medicine and self (health) care.** *Journal of Sociology.*

Jenkins L, Patterson A, McEvoy M & Sibbritt D. **Unprocessed red meat, chicken and fish intake is associated with a higher vegetable intake in mid-age non-vegetarian women.** *Nutrition & Dietetics Journal.*

Kirby E, Broom A, Sibbritt D, Adams J & Refshauge K**. A national cross-sectional survey of back pain care amongst Australian women aged 60–65**. *European Journal of Integrative Medicine.*

Liddle J, Parkinson L & Sibbritt D. **Painting pictures and playing musical instruments: Change in participation and relationship to health in older women.** *Australasian Journal on Ageing.*

Lucke J, Herbert D, Watson M, & Loxton D**. Predictors of sexually transmitted infection in Australian women: Evidence from the Australian Longitudinal Study on Women's Health.** *Archives of Sexual Behavior.*

McKenzie S, Tooth L, Lucke J, Hockey R & Dobson A. **Transitions into and out of providing informal care and their effects on use of community services in women born between 1921 and 1926: Results from the Australian Longitudinal Study on Women's Health.** *Ageing & Society.*

McLaughlin D, Adams J & Lu C. **Complementary and alternative medicine use among older Australian women – a qualitative study.** *BMC Complementary and Alternative Medicine.*

Meurk C, Broom A, Adams J & Sibbritt D. **Bodies of knowledge: Nature, holism and women's plural health practices.** *Health.*

Peeters G, Tett S, Dobson A & Mishra G**. Validity of self-reported osteoporosis in mid-age and older women**. *Osteoporosis International.*

Peeters G, van Gellecum Y, van Uffelen J, Burton N & Brown W. **Contribution of house and garden work to the association between physical activity and well-being in young, mid-aged and older women.** *British Journal of Sports Medicine.*

Pezdirc K, Hure A, Blumfield M & Collins C. **Listeria monocytogenes and diet during pregnancy; balancing nutrient intake adequacy versus adverse pregnancy outcomes.** *Public Health Nutrition.*

Powers J, McDermott L, Loxton D & Chojenta C. **A prospective study of prevalence and predictors of concurrent alcohol and tobacco use during pregnancy.** *Maternal and Child Health Journal.*

Rich J, Wright S, Loxton D. **Patience, HRT and Rain!" Women, ageing and drought in Australia – narratives from the mid-age cohort of the Australian Longitudinal Study on Women's Health.** *Australian Journal of Rural Health.*

Stewart Williams J, Wallick C, Byles J & Doran C. **Assessing patterns of use of cardio-protective polypill component medicines in Australian women: use of polypill component medicines in Australian women.** *Drugs and Ageing.*

Teede H, Joham, A, Eldho P, Moran L, Loxton D, Jolley D & Lombard C. **Longitudinal weight gain in women identified with Polycystic Ovary Syndrome: Results of an observational study in young women.** *Obesity.*

Tooth L & Mishra G. **Intergenerational educational mobility on general mental health and depressive symptoms in young women.** *Quality of Life Research.*

Windsor T, Burns R & Byles J. **Age, physical functioning, and affect in midlife and older adulthood.** *The Journals of Gerontology: Series B, Psychological Science, Social Science.*

8.2.3 Book chapters published

Andrews G, Adams J, Segrott J & Lui C**. The profile of complementary and alternative medicine users and reasons for complementary and alternative medicine use**. *Adams J. et al (Eds) Traditional, Complementary and Integrative Medicine: An International Reader. Palgrave* 2012 11-17 *MacMillan: Basingstoke.*

Andrews G, Segrott J, Lui C & Adams J**. The geography of complementary and alternative medicine**. Adams J. et al (eds) Traditional, Complementary and Integrative Medicine: An International Reader. Palgrave 2012 231-236. *MacMillan: Basingstoke*.

8.2.4 Book chapters accepted

Collins C, Hure A, Burrows T & Patterson A**. Diet quality and its potential cost savings**. *VR Preedy Diet Quality: An Evidence-Based Approach London: Springer.*

Steel A, Frawley J, Adams J, Sibbritt & Broom A**. Primary health care, CAM and women's health**. Adams J. Et al (eds) Primary Health Care and Complementary and Integrative Medicine Imperial College Press: 2012 London.

8.2.5 Conference proceedings published

van Uffelen J, Heesch K, van Gellecum Y, Burton N & Brown W**. Social interaction and physical activity in women in their seventies. 45th Australian Association of gerontology National Conference.** *Australasian Journal on Ageing*. 2012. 31(S 2):61

8.3 Conference presentations

Alhazmi A, Stojanovski E, McEvoy M, Garg M. **ARFS items and Type 2 diabetes in Australian women.** Annual scientific meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association 2012 Gold Coast, Queensland 29 - 31 August 2012.

Alhazmi A, Stojanovski E, McEvoy M, Garg M. **Overall diet quality score and type 2 diabetes.** Annual scientific meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association 2012 Gold Coast, Queensland 29 - 31 August 2012.

Anderson A. **Compliance with alcohol guidelines for pregnant women: Using data from the Australian Longitudinal Study on Women's Health (poster presentation)**. Women's Health 2012: The 20th Annual Congress, Washington, DC, USA, 16-18 March 2012.

Austin M. **Intimate partner abuse and perinatal mental health.** International Biennial Congress of The Marcé Society, Paris, France, 3 – 5 October 2012.

Austin M. **Adverse reproductive events and mental health and parenting outcomes.** International Biennial Congress of The Marcé Society, Paris, France, 3 - 5 October 2012.

Austin M**. Disparities in reported psychosocial assessment during pregnancy and the postnatal period: a national survey of women in Australia.** International Biennial Congress of The Marcé Society, Paris, France, 3 - 5 October 2012.

Byles J & Gibson R. **Living long and living well: Factors associated with maintenance of physical function among older women.** Gerontological Society of America 64th Annual Scientific Meeting, Boston, MA, USA 18 - 22 November 2012.

Byles J. **ACH Group Sir Keith Wilson Oration. Inspired by ageing: observations from 12432 women and one researcher.** SA Gerontology Conference 2012.The Ageing Odyssey. It's All About the Journey, Adelaide, South Australia 14 September 2012.

Chojenta C & Harris S. **Adverse reproductive events and mental health and parenting outcomes**. International Biennial Congress of The Marcé Society, Paris, France, 3 - 5 October 2012.

Collins C. **Diet quality does not predict 6 year weight change in mid-age women from Australian Longitudinal Study on Women's Health.** Australian and New Zealand Obesity Society Annual Scientific Meeting 2012 Auckland, New Zealand, 18 - 20 October 2012.

Craig H, Spencer E & Ferguson A. **Language and life stages.** Digital Humanities Australasia 2012 Conference Canberra, ACT, 28 - 30 March 2012.

Dobson A. **Using causal inference to examine bi-directional associations in longitudinal data: cigarette smoking and mental health.** Australian Statistical Conference 2012, Adelaide, SA, 9-12 September 2012.

Frawley J, Sibbritt D, Adams J, Broom A & Steel A. **Women's sources of information for CAM use during pregnancy.** IRCIMH Integrative Medicine and Health Congress, Portland, Oregon, USA 15 - 18 May 2012.

Gresham E, Byles J, Loxton D & Hure A. **Poorer diet quality predicts gestational hypertension.** 16th International Congress of Dietetics, Sydney, NSW, 5-9 September 2012.

Harris M, Parkinson L, Moxey A, Robertson J, Doran E & Byles J. **What crisis? Women's experience of the withdrawal of Vioxx and discrediting of the COX-2s.** 2nd Global Congress of Qualitative Health Research, Milan, Italy, 28 - 30 June 2012.

Hockey R, Jones M, Mishra G & Dobson A. **Visualising and modelling changes in categorical variables in longitudinal studies.** Statistical Challenges in Life Course Research Conference, 2012, Leeds, UK, 17 - 18 July 2012.

Holden L & Lee C. **Correlates of depression: Do they change with life stage?** 7th World Conference on the Promotion of Mental Health and the Prevention of Mental and Behavioural Disorders, Perth, WA, 17-19 October 2012.

Hughes T. **Social determinants of sexual minority women's health: From invisibility to advocacy and empowerment**. Center For Global Women's Health (CGWH) Inaugural Symposium, Empowerment, Safety, and Health: A Global Mandate for Women and Girls. Philadelphia, United States, 11 May 2012.

Hure A. **An overview of the developmental origins of health and disease: What should Dietitians know?** 16th International Congress of Dietetics, Sydney, NSW, 5-9 September 2012.

Koloski N, Jones M, Halland M, Byles J, Chiarelli P & Talley N. **Faecal incontinence in community dwelling older women- it's impact on quality of life and associated factors.** Digestive Diseases Week 2012, San Diego, USA, 19-22 May 2012.

Koloski N, Jones M, Raghubinder G, Forder P & Talley N. **Long term risk factors for the development of constipation in older community dwelling women.** Digestive Diseases Week 2012, San Diego, USA, 19-22 May 2012.

Koloski N, Jones M, Wai R, Raghubinder S & Talley N. **Impact of persistent constipation on health related quality of life and mortality in older community dwelling women.** Digestive Diseases Week 2012, San Diego, USA, 19-22 May 2012.

Lee C. **Life control mediates social gradients in health and wellbeing among middle-aged Australian women.** 12th International Congress of Behavioral Medicine, Budapest, Hungary, 29 August - 01 September 2012.

Lee C. **Life control mediates social gradients in health and wellbeing among middle-aged Australian women.** 7th World Conference on the Promotion of Mental Health and the Prevention of Mental and Behavioural Disorders, Perth, WA, 17-19 October 2012.

Liddle J, Parkinson L & Sibbritt D. **Environmental factors affecting participation in art and craft activities by older women.** Australian Association of Gerontology & Aged & Community Services Association of NSW & ACT Incorporated Rural Conference, Dubbo, NSW, 19 - 20 March 2012.

Loxton D & Chojenta C. **Intimate partner abuse and perinatal mental health**. International Biennial Congress of The Marcé Society, Paris, France, 3 - 5 October 2012.

Loxton D & Powers J. **Survival among women who have experienced abuse in older age.** National Conference on Health and Domestic Violence, San Francisco, USA, 29-31 March 2012.

Loxton D, Powers J & Byles J. **Aging and vulnerability to abuse: Findings on prevalence, experience and survival outcomes from the Australian Longitudinal Study on Women's Health**. International Network for the Prevention of Elder Abuse 7th World Conference, Prague, Czech Republic, 28 May 2012.

Loxton D, Rich J & Chojenta C. **Is there anything you'd like to add? Responses to open ended survey questions as research data.** Women's Health 2012: The 20th Annual Congress, Washington, DC, USA, 16-18 March 2012.

McLaughlin D. **Ageing through the gender lens: Evidence from Australia.** International Federation on Ageing, Prague, Czech Republic, 28 - 31 May 2012.

Mishra G. **The challenges of adherence to guidelines.** Population Health Congress 2012, Adelaide, SA, 9-12 September 2012.

Mishra G. **InterLACE: An international collaborative study of reproductive health in mid life.** ICOWHI 19th International Congress on "Women's Health 2012: Partnering for a Brighter Global Future", Bangkok, Thailand, 14-16 November 2012.

O'Dwyer S. **Suicidal ideation in women providing informal care: Cross-sectional evidence from the Australian Longitudinal Study on Women's Health**. International Psychogeriatric Association (IPA) International Meeting 2012, Cairns, Queensland 7 - 11 September 2012.

Parkinson L, Dolja-Gore X, Robertson J, Doran E & Byles J. **Rofexoxib withdrawal and health outcomes for Australian women.** National Medicines Symposium 2012, Sydney, NSW, 24 - 25 May 2012.

Parkinson L, Dolja-Gore X, Robertson J, Gibson R, Doran E & Byles J. **Health outcomes for older Australian women - is there a relationship with rofecoxib withdrawal?** International Data Linkage Conference 2012, Perth, WA, 2 - 4 May 2012.

Peeters G, Burton N & Brown W. **Associations between sitting time and a broad range of symptoms in mid age women.** 4th International Congress on Physical Activity and Public Health, Sydney, NSW, 31 October-03 November 2012.

Peeters G, Hockey R & Brown W. **Should physical activity intervention efforts take a whole population, high risk or middle road strategy?** 4th International Congress on Physical Activity and Public Health, Sydney, NSW, 31 October-03 November 2012.

Peeters G, Parkinson L, Badley E, Brown W, Dobson A & Mishra G. **Longitudinal variations in reporting doctor-diagnosed arthritis reflect contemporaneous severity of symptoms disability.** The European League Against Rheumatism, Berlin, Germany, 6 - 9 June 2012.

Reilly N, Austin M, Loxton D, Chojenta C, Forder P & Milgrom J**. Disparities in reported psychosocial assessment during pregnancy and the postnatal period: A national survey of women in Australia.** International Biennial Congress of The Marcé Society, Paris, France, 3 - 5 October 2012.

Sibbritt D. **Public health research: insights for acupuncture.** International Scientific Acupuncture and Meridian Symposium (iSAMS), Sydney, NSW, 5 - 7 October 2012.

Spencer E, Ferguson A, Craig H & Colyvas K. **Language and ageing: Using propositional density as a measure over time (poster presentation).** International Clinical Linguistics & Phonetics Conference, Cork, Ireland, 27 - 30 June 2012.

Teede H. **The need for a new name for PCOS.** 15th International Congress of Endocrinology, Florence, Italy, 5 - 9 May 2012.

van Uffelen J, Burton N, van Gellecum Y, Peeters G, Heesch K & Brown W. **Concurrent and prospective associations between sitting time, physical activity and depression in mid-aged Australian women.** 4th International Congress on Physical Activity and Public Health, Sydney, NSW, 31 October-03 November 2012.

van Uffelen J, Heesch K, van Gellecum Y, Burton N & Brown W. **Social Interaction and Physical activity in women in their seventies.** 45th Australian Association of Gerontology National Conference, Brisbane, Qld 20-23 November 2012.

8.4 Media

Month	Topic	Media
September	Women's adherence to guidelines for healthy eating and exercise. **Julie Byles**	ABC local radio Newcastle
	Funding to continue ALSWH. **Tanya Plibersek**	2HD Newcastle
	ALSWH, how well women follow advice on healthy behaviours and good health. **Julie Byles**	ABC News radio Sydney
	Australian women eat less healthy food and don't exercise. (**Major Report G**)	News.com.au
	Booze and smokes go, more exercise, diet needed. (**Major Report G)**	The Newcastle Herald
	Australian women fall short of health guidelines. (**Major Report G**)	Futurity.org
	Women's health is on the decline. (**Major Report G**)	Central Coast Express Advocate (Gosford)
	Study tracks female trends. (**Major Report G**)	Northern Daily Leader (Tamworth)
October	Incontinence is no laughing matter. **Pauline Chiarelli**	It'sMyHealth.com.au

8.5 Social media

ALSWH established a social media presence in September 2012, with the creation of accounts on Facebook and Twitter. The social media profile now also includes Youtube, Tumblr and Instagram. Social media can be accessed as follows:

- Facebook: http://www.facebook.com/alswh
- Twitter: https://twitter.com/ALSWH_Official
- Youtube: http://www.youtube.com/user/ALSWHinfo
- Tumblr: http://www.tumblr.com/tagged/alswh

To ensure transparency between ALSWH social media, the marketing and communications offices at the University of Newcastle and the University of Queensland, and ethics committees at each university, a high level of accountability is required. Social media sites used by the study (Facebook, Twitter, Youtube, Tumblr and Instagram) must meet the ethical conduct requirements of the study, and must also satisfy the aesthetic and structural requirements of the marketing and communications offices of each university.

Accordingly, a style guide for social media posts has been developed and approved by both the ALSWH Steering Committee and the ethics committees of both universities. The style guide contains guidelines which determine the suitability of posts for social media. The guidelines ensure social media posts maintain accountability and consistency internally (within ALSWH), and also comply with university policies on using social media channels. The style guide is intended to ensure all social media communication reflects a high standard of professionalism and all staff responsible for social media posts are required to be familiar with it. In addition, any social media posts that include a recruiting element must also be noted by the ethics committees at the University of Newcastle and the University of Queensland. The social media style guide is available in Appendix C.

Hootsuite

To assist with management of social media, Hootsuite, an online social media management tool, has been employed. This online program allows for social media posts to be preloaded and then automatically uploaded at a predetermined time. This allows for posting at times most suited to each social media site, which may differ greatly between site. Hootsuite then also provides a record of the impact of ALSWH social media activity (Figure 8-1, Figure 8-2 and Figure 8-3).

Twitter: Profile Summary

@ALSWH_Official

Followers: 157

Following 537

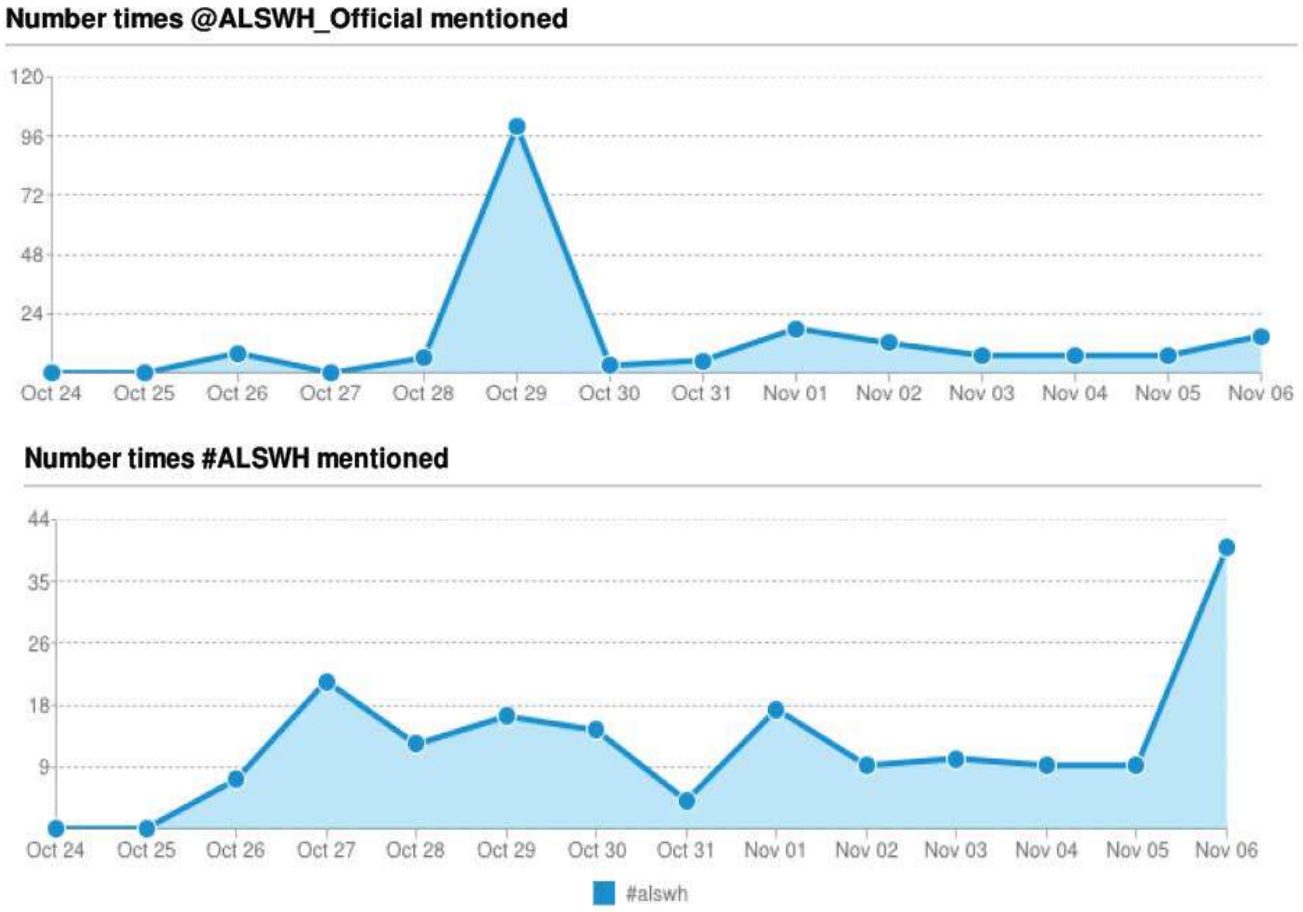


Figure 8-1 Hootsuite Twitter record from October 24 – November 7, 2012.

Facebook: Profile Summary

ALSWH Facebook Snapshot

Total Likes ?	Friends of Fans ?	People Talking About This ?	Weekly Total Reach ?
141	36,552	83	1,702
↑ 15.6%	↑ 21%	↑ 59.6%	↑ 97.9%

Likes by Demographic

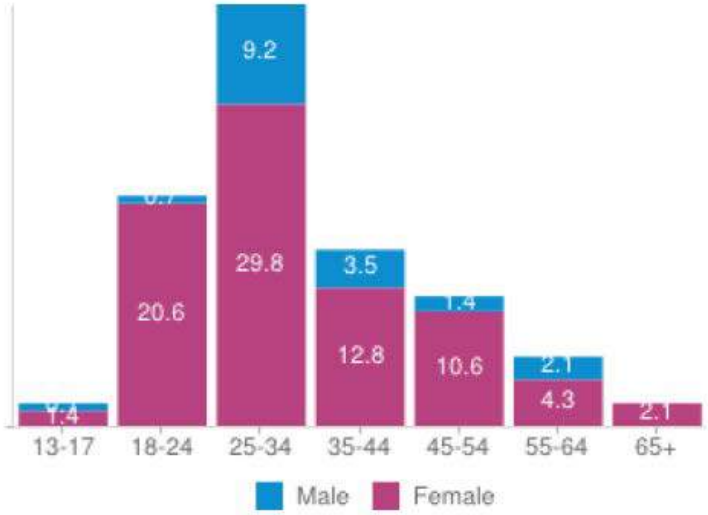


Figure 8-2 Hootsuite Facebook record

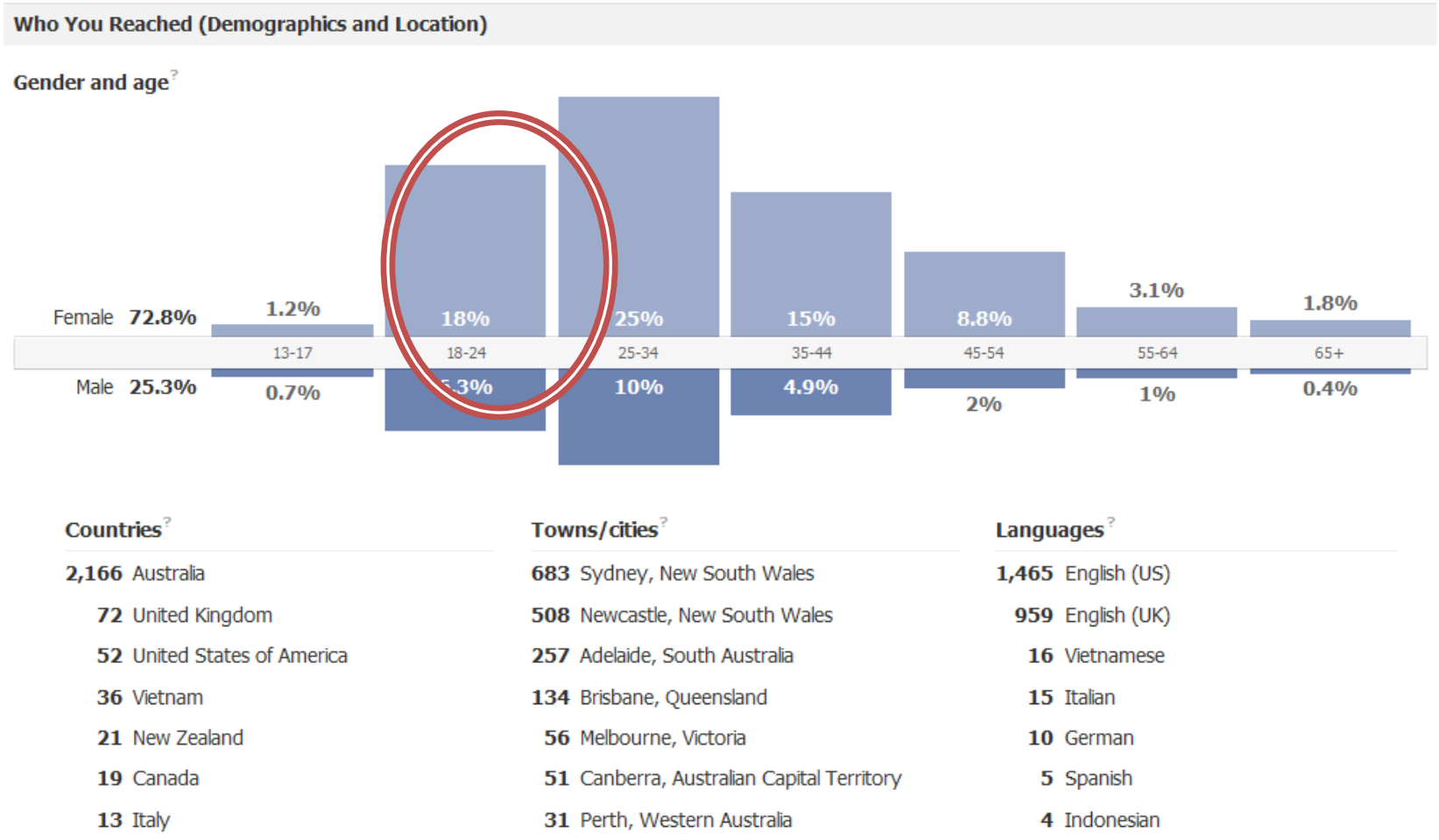


Figure 8-3 Facebook reach.

9. Archiving

ALSWH are required to archive data with the Australian Social Sciences Data Archive (ASSDA) at the Australian National University on an annual basis. Each year the most recently completed data set and any new data sets that have been created are archived.

The data for Survey 6 of the 1946–1951 cohort were archived in 2012. In 2012 the Survey 6 files from the 1946-1951 cohort deposited with ASSDA consisted of:

- Completed ASSDA Licence form and Deposit form
- 1946-1951 cohort Survey 6 Questionnaire
- 1946-1951 cohort Survey 6 level 'A' and 'B' analysis data sets in SAS format
- 1946-1951 cohort Survey 6 level 'A' and 'B' Child data sets in SAS format
- 1946-1951 cohort Survey 6 formats and labels in text format for the analysis data set
- 1946-1951 cohort Survey 6 list of variables in Excel format
- 1946-1951 cohort Participant file updated at November 2011 in SAS format
- Participant file Metadata file in Word format
- The latest version of the ALSWH Data Dictionary

In 2012 only SAS-formatted data were sent. The labels and format files were necessary for reading the data in SAS format. The Level 'A' survey data set has the survey identification numbers, IDs, included and the data set was sorted by this ID variable. The Level 'B' has another identification number, IDalias, which replaces the survey identification, ID. The Level 'B' data is sorted by the IDalias variable. Researchers accessing the data receive only the Level 'B' data.

The participant data file was included in the archiving this year along with its description file. This is necessary to understand the ALSWH data. It includes attrition, death status and date of responses. Also, an excel file including the list of variables in the 1946-51 Survey 6 data was included in the archiving. This is a useful brief description of the data.

In 2013 the data from Survey 6 of the 1921-1926 cohort will be archived.

As well as being a valuable and reliable off-site backup of all ALSWH data, archiving will make the data available for future use by other researchers, subject to certain conditions.

10. Project staff

School of Population Health University of Queensland	
• **ALSWH Director**	Professor Annette Dobson
• **Professorial Research Fellow**	Professor Gita Mishra
• **Senior Research Fellow/ Project Coordinator**	Dr Leigh Tooth
• **Senior Research Fellow**	Dr Deirdre McLaughlin
• **Research Fellow**	Dr Libby Holden
• **Statistician**	Richard Hockey
• **Research Assistants**	Janni Leung Jemma Rowlands Danielle Schoenaker Gurshant Singh
• **Data Manager**	David Fitzgerald
• **Data/Statistical Assistant**	Ewan Mackenzie
• **Research Project Manager**	Megan Ferguson
• **Administration Officers**	Leonie Gemmell Katherine De Maria

At the University of Queensland, Dr Leigh Tooth, Janni Leung, Jemma Rowlands and Ewan McKenzie have worked part-time on the project.

Research Centre for Gender, Health and Ageing University of Newcastle	
• **Co-Director ALSWH/ RCGHA Director**	Professor Julie Byles
• **Deputy Director**	Associate Professor Deborah Loxton
• **Statisticians**	Jenny Powers Xenia Dolja-Gore Lucy Gallienne
• **Operations Manager**	Anna Graves
• **Data Assistant/ Database Developer**	Ryan Tuckerman
• **Communication & Research Officer**	Catherine Chojenta
• **Research Assistants**	Jenny Helman Jane Rich Ashleigh O'Mara Clare Rooney Paula Bridge
• **Administrative Officer**	Melanie Moonen
• **Project Assistants**	Stephanie Pease Margaret Jobber Elisabetta Scarabelli
• **Casual Project Assistants**	Nicola Evans Laura Croger Natalie Townsend Sarah Casey Rachael Sales

11. Appendices

Appendix A: Update for research team and collaborators (November 2012)

Appendix B: Materials from Pilot Survey 7 of the 1946-51 cohort

- B1:Survey Mailout Flowchart
- B2:Pilot survey (paper version)
- B3:Invitation to participate – mailed
- B4: Invitation to participate - online
- B5: Survey evaluation sheet
- B6: First reminder - letter (paper group)
- B7: Second reminder - letter (paper group)
- B8: Third reminder - SMS_(paper group)
- B9: Fourth reminder – email (paper group)
- B10:Thank you
- B11:Invitation to participate – email
- B12: First reminder to finish incomplete online survey - email
- B13: Second reminder to finish incomplete online survey – SMS
- B14: Online survey example

Appendix C: Materials for recruitment of the new young cohort.

- C1: Data Linkage Electronic Consent: Differentiation of procedures
- C2: Phase 2 Focus Group Interview Schedule
- C3: Focus Group Participant Information Sheet
- C4: Focus Group Consent Form
- C5: Focus Group Survey
- C6: Focus Group Poster
- C7: Focus Group Evaluation Sheet
- C8: Focus Group Survey
- C9: Email from MyOpinion company sent to potential pilot participants
- C10: Pilot Group Survey
- C11: Main survey
- C12: Poster
- C13: Email to ambassadors
- C14: Completed survey email
- C15: Recruitment Record Keeping
- C16: Social Media Policies and Procedures

APPENDIX A: UPDATE FOR RESEARCH TEAM AND COLLABORATORS (NOVEMBER 2012)

Update for Research Team, Associates and Colleagues - November 2012

A lot has been happening at ALSWH over the past few months - here's a brief summary!

News:

New young cohort of women born 1989-94: Recruitment of a new cohort of young women aged 18-23 years has begun! All surveys of the new cohort will be conducted online, and the first survey is available at:

www.alswh.org.au/survey

Participation is open to any young women born from 1 January 1989 to 31 December 1994 who have an Australian Medicare card. All collaborators are invited to pass on the survey link to young women amongst their family, friends, and other networks who may be interested in taking part. Further details are available at the ALSWH website (www.alswh.org.au). A promotional poster is included at the end of this Update, and has also been attached for printing or emailing.*

Social media: ALSWH is now active on Twitter and Facebook. The survey for the new young cohort is available at both sites, and news about study activities and upcoming events are regularly posted. All collaborators are encouraged to follow/friend the study to keep up to date!

Facebook: www.facebook.com/alswh (Australian Longitudinal Study on Women's Health)
Twitter: www.twitter.com/alswh_official (@ALSWH-Official)

ALSWH website: The ALSWH website has been redesigned – it now has a new look and new features include:

- Separate sections for participants and researchers
- Drop-down menus to make navigation quicker
- Details of all analyses (EoIs), including the title, collaborators and, for recently approved projects, a lay summary of the research.
- Links to social media (Facebook, Twitter and YouTube)
- A page with links to all current online surveys (under construction)

We hope you like the new design and that it is easier to navigate around the website. Any feedback is most welcome and appreciated.

Major Reports: ALSWH's major report for 2012, *Adherence to health guidelines: Findings from the ALSWH*, was launched by the Minister for Health, Tanya Plibersek in September. The report compared women's lifestyles with national guidelines for good health behaviours and screening and a main finding was that fewer women than ever were meeting weight guidelines, with almost half of those surveyed considered overweight or obese. The full report is available at www.alswh.org.au/publications-and-reports/major-reports

Progress: Survey 6 of the 1973-78 cohort began in March and preparations are now underway for the Pilot of Survey 7 of the 1946-51 cohort to begin in November.

Survey	1973-78 cohort	1946-51 cohort	1921-26 cohort
Survey 1	1996 Age 18-23 N=14 247	1996 Age 45-50 N=13 715	1996 Age 70-75 N=12 432
Survey 2	2000 Age 22-27 N=9688	1998 Age 47-52 N=12 338	1999 Age 73-78 N=10 434
Survey 3	2003 Age 25-30 N=9081	2001 Age 50-55 N=11 226	2002 Age 76-81 N=8647
Survey 4	2006 Age 28-33 N=9145	2004 Age 53-58 N=10 905	2005 Age 79-84 N=7158
Survey 5	2009 Age 31-36 N= 8200	2007 Age 56-61 N=10 638	2008 Age 82-87 N=5561
Survey 6	2012 Age 34-39 *N=6804	2010 Age 59-64 N = 10 011	2011 Age 85-90 N=4055
Survey 7	↓ 2015 Age 37-42	↓ 2013 Age 62-67	↓ 2014 Age 88-93

**Survey intake will be finalised in August 2013.*

Other activities:

People: In February, Steering Committee member **David Sibbritt** was appointed Professor of Epidemiology at University of Technology Sydney (UTS) where he will continue to work on public health and health services research of complementary medicine and integrative healthcare.

In July, ALSWH Steering Committee member **Gita Mishra**, from the University of Queensland, was awarded an Australian Research Council Future Fellowship worth $927,168 over four years. Gita's project, titled *'Trajectories and turning points for women's reproductive health'* will analyse data from more than 10 cohort studies (including ALSWH) across six nations and it is anticipated findings will support a more tailored approach to women's health policy and strategies for healthy aging.

Congratulations David and Gita!

Conferences and events:

Call for papers: *2013 Australian Association of Gerontology (Hunter / NSW Division) Rural Conference: Living and belonging*. (21 -22 March 2013, Orange, NSW). Further details are available at www.aag.asn.au and also in the flyer below.

Date Claimer: *Australasian Epidemiological Association Annual Scientific Meeting 2013: Life Course Approach to Health and Wellbeing*, (20-22 October 2013, Brisbane Queensland). www.aea.asn.au

That's all for now - if you have queries, comments or suggestions, please let us know at sph-wha@sph.uq.edu.au, and remember to friend/follow ALSWH on social media to keep up to date on all the latest news!

Megan Ferguson
Research Project Manager
ALSWH-UQ www.alswh.org.au

*Materials for recruitment of the new cohort have been approved by Ethics committees at The University of Newcastle, The University of Queensland, The Department of Health and Ageing and the Department of Human Services. If you have any questions about the survey or recruitment, please do not hesitate to contact us at info@alswh.org.au or freecall 1800 068081.

women's health australia

australian longitudinal study on women's health

Hey Ladies aged 18-23! We need YOU!

participate in a nationally important survey on health

You are more than the sum of your parts. You are a complicated being.

Help us understand young Australian women's health by taking a 15-20 minute confidential online survey.

You will go in the draw to win one of 100 prizes valued at $50 each.

Tell me more you say?

www.alswh.org.au/survey
info@alswh.org.au
1800 068 081

CALL FOR PAPERS

2013 AAG & ACS Rural Conference

living *and* belonging

21 - 22 March 2013 Orange Ex-Services Club, Orange www.aag.asn.au www.agedservices.asn.au

The Australian Association of Gerontology (Hunter / NSW Division) in partnership with Aged & Community Services Association of NSW & ACT Inc, the University of Newcastle Centre for Rural and Remote Mental Health Orange, and Research Centre for Gender, Health and Ageing are hosting the 2013 Rural Conference at the Ex-Services Club in Orange, NSW on Thursday 21 and Friday 22 March, 2013.

The conference will be of interest to health and aged care practitioners, researchers, policy makers and planners, older people and anyone interested in current issues in ageing and aged care.

This year's theme is "**living and belonging**".

Australians living in regional and remote areas can experience poorer health than people living in larger urban areas. Issues of geographic isolation and dispersed communities can result in reduced access to services and vulnerability to environmental change. The good news is however, people in rural areas often enjoy very high levels of social connectedness.

The availability and sustainability of health and social services is important for all. With older people often representing a higher proportion of the population in rural communities, access to social networks and required support agencies can assist wellbeing, feelings of belonging and an enjoyable quality of life.

Aged & Community Services Association of NSW & ACT Incorporated

CALL FOR ABSTRACTS

We welcome submissions of papers and interactive sessions regarding these and other aspects of living and belonging, especially in rural areas. Share research and current practices that enable older Australians to live and age well.

- Care and service provision from afar
- Mental health
- Social connectedness
- Spirituality, mindfulness and ageing
- Transport and access to services
- Men's health issues
- Indigenous health
- Climate change and ageing
- Health & wellbeing
- Medicare Locals interface
- Allied health interactions and referrals
- Elder abuse in rural areas

SUBMISSIONS FORMAT

All submissions are to meet the following format and be emailed to events@agedservices.asn.au

- All submissions must include full contact details, including presenter's name, organisation, position, telephone, fax, postal address and email address
- An abstract of 350 – 450 words for oral presentation or workshop
- A 75 – 100 word biography of the speaker/s.

PRESENTER'S REGISTRATION

All presenters will be required to register for the Conference and pay the registration fee. Presenters will also need to meet their own travel and accommodation costs.

CONFERENCE ORGANISERS

Aged & Community Services Association of NSW & ACT Inc

PO BOX 3124
Rhodes NSW 2138

02 8754 0400

events@agedservices.asn.au

All this information must be submitted electronically to the email address above by Friday November 9 2012.

APPENDIX B: MATERIALS FOR PILOT SURVEY 7 OF THE 1946-51 COHORT

- **B1:Survey Mailout Flowchart**
- **B2:Pilot survey (paper version)**
- **B3:Invitation to participate – mailed**
- **B4: Invitation to participate - online**
- **B5: Survey evaluation sheet**
- **B6: First reminder - letter (paper group)**
- **B7: Second reminder - letter (paper group)**
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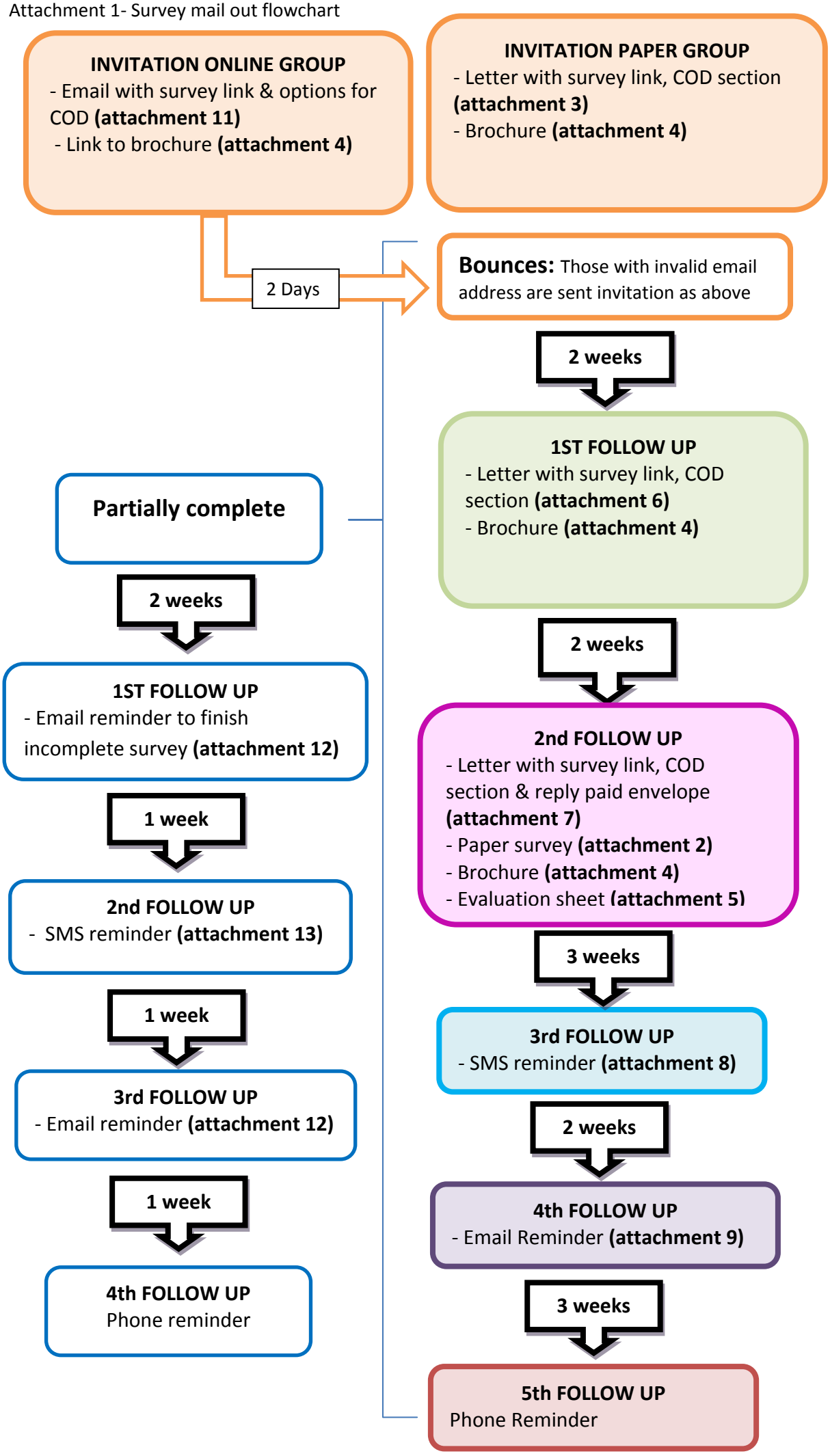
- **B9: Fourth reminder – email (paper group)**
- **B10:Thank you**
- **B11:Invitation to participate – email**
- **B12: First reminder to finish incomplete online survey - email**
- **B13: Second reminder to finish incomplete online survey – SMS**
- **B14: Online survey example**

Attachment 1- Survey mail out flowchart



Seventh survey for the women of the 1946-51 cohort

2012

How to complete this survey

This is the seventh "pilot" survey for the women of the 1946-51 cohort. As the purpose of the project is to look at changes over time, some of the questions are the same as those in previous surveys. Researchers will be comparing the information provided in this survey with that of surveys you have completed in the past.

Please answer every question you can. If you are unsure about how to answer a question, mark the response for the closest answer to how you feel.

Please read the instructions above each question carefully. Some require you to only answer those options which are applicable to you. Other questions require you to mark one answer on each line. The questions may also refer to different time periods.

INSTRUCTIONS:

- Use a black/blue biro
- Do not fold or bend this survey
- **Cross the boxes like this:**

In general, would you say your health is:
(*Mark one only*)

Excellent	☐
Very good	☐
Good	☒
Fair	☐
Poor	☐

You would mark this one if you think your health is good

- **Print clearly in the boxes like this:**

What is your postcode?
(PRINT clearly in the boxes)

2	3	0	8

- **Correct mistakes like this:**

When you go to a General Practitioner:
(*Mark one on each line*)

	Always	Most of the time	Some-times	Rarely or never
Do you go to the same place?	☐	☒	☒	☐

If you make a mistake simply scribble it out and clearly mark the correct answer with a cross

If you need help to answer any questions, please ring 1800 068 081
(This is a FREECALL number)

* *If you are concerned about any of your health experiences and would like some help you may like to contact:*
  - *your nearest Women's Health Centre or Community Health Centre;*
  - *your General Practitioner for advice about who would be the best person in your community for you to talk to.*

* *If you feel distressed NOW and would like someone to talk to, you could ring Lifeline on 131 114 (local call).*

Note: No commercial gain or sponsorship is provided to WHA for the inclusion of brand names in the survey.

The questions on the first page ask only about NOW - how your health is NOW and about how your health limits certain activities NOW.

1 In general, would you say your health is: *(Mark one only)*

Excellent	☐
Very good	☐
Good	☐
Fair	☐
Poor	☐

2 Compared to one year ago, how would you rate your health in general now?
(Mark one only)

Much better now than one year ago	☐
Somewhat better now than one year ago	☐
About the same now as one year ago	☐
Somewhat worse now than one year ago	☐
Much worse now than one year ago	☐

3 The following questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much? *(Mark one on each line)*

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	VIGOROUS activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b	MODERATE activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
c	Lifting or carrying groceries	☐	☐	☐
d	Climbing SEVERAL flights of stairs	☐	☐	☐
e	Climbing ONE flight of stairs	☐	☐	☐
f	Bending, kneeling or stooping	☐	☐	☐
g	Walking MORE THAN ONE kilometre	☐	☐	☐
h	Walking HALF a kilometre	☐	☐	☐
i	Walking 100 metres	☐	☐	☐
j	Bathing or dressing yourself	☐	☐	☐

The next 7 questions ask about your health IN THE LAST FOUR WEEKS

4 During the PAST FOUR WEEKS, have you had any of the following problems with your work *(including your work outside the home and housework)* or other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?
(Mark one on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	☐	☐
b	Accomplished less than you would like	☐	☐
c	Were limited in the kind of work or other activities	☐	☐
d	Had difficulty performing the work or other activities *(eg it took extra effort)*	☐	☐

5 During the PAST FOUR WEEKS, have you had any of the following problems with your work or other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS *(such as feeling depressed or anxious)*? *(Mark one on each line)*

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	☐	☐
b	Accomplished less than you would like	☐	☐
c	Didn't do work or other activities as carefully as usual	☐	☐

6 During the PAST FOUR WEEKS, to what extent have your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your normal social activities with family, friends, neighbours or groups? *(Mark one only)*

- Not at all ☐
- Slightly ☐
- Moderately ☐
- Quite a bit ☐
- Extremely ☐

7 How much BODILY pain have you had during the PAST FOUR WEEKS? *(Mark one only)*

- No bodily pain ☐
- Very mild ☐
- Mild ☐
- Moderate ☐
- Severe ☐
- Very severe ☐

8 During the PAST FOUR WEEKS, how much did PAIN interfere with your normal work *(including both work outside the home and housework)*? *(Mark one only)*

- Not at all ☐
- A little bit ☐
- Moderately ☐
- Quite a bit ☐
- Extremely ☐

9 For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST FOUR WEEKS: (*Mark one on each line*)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a	Did you feel full of life?	☐	☐	☐	☐	☐	☐
b	Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c	Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d	Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e	Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f	Have you felt down?	☐	☐	☐	☐	☐	☐
g	Did you feel worn out?	☐	☐	☐	☐	☐	☐
h	Have you been a happy person?	☐	☐	☐	☐	☐	☐
i	Did you feel tired?	☐	☐	☐	☐	☐	☐

10 **During the PAST FOUR WEEKS, how much of the time have your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities *(like visiting friends, relatives, etc)*?** *(Mark one only)*

All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

11 **How TRUE or FALSE is EACH of the following statements for you?**
(Mark one on each line)

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
b	I am as healthy as anybody I know	☐	☐	☐	☐	☐
c	I expect my health to get worse	☐	☐	☐	☐	☐
d	My health is excellent	☐	☐	☐	☐	☐

12 **How many times have you consulted the following people for YOUR OWN HEALTH in the LAST TWELVE MONTHS?**
(Mark one on each line)

		None	Once or twice	3 or 4 times	5 or 6 times	7-12 times	13-24 times	25 or more times
a	A family doctor or another General Practitioner (GP)	☐	☐	☐	☐	☐	☐	☐
b	A hospital doctor (*eg in outpatients or casualty*)	☐	☐	☐	☐	☐	☐	☐
c	A specialist doctor	☐	☐	☐	☐	☐	☐	☐

13 **Have you consulted the following people for YOUR OWN HEALTH in the LAST TWELVE MONTHS?** *(Mark one on each line)*

		Yes	No
a	Physiotherapist	☐	☐
b	Counsellor / Psychologist / Social worker	☐	☐
c	A community nurse, practice nurse, or nurse practitioner	☐	☐
d	Optician / Optometrist	☐	☐
e	Hearing specialist	☐	☐
f	Dietitian	☐	☐
g	Podiatrist	☐	☐
h	Dentist	☐	☐
i	Massage therapist	☐	☐
j	Naturopath / Herbalist	☐	☐
k	Chiropractor	☐	☐
l	Osteopath	☐	☐
m	Acupuncturist	☐	☐
n	Other alternative health practitioner *(eg aromatherapist, homeopath, reflexologist, iridologist)*	☐	☐

14 **How often have you used the following therapies for YOUR OWN HEALTH in the LAST TWELVE MONTHS?**
(Mark one on each line)

		Never	Rarely	Sometimes	Often
a	Vitamins / Minerals	☐	☐	☐	☐
b	Yoga or meditation	☐	☐	☐	☐
c	Herbal medicines	☐	☐	☐	☐
d	Aromatherapy oils	☐	☐	☐	☐
e	Chinese medicines	☐	☐	☐	☐
f	Other alternative therapies	☐	☐	☐	☐

15 **When you go to a General Practitioner:**
(Mark one on each line)

		Always	Most of the time	Some-times	Rarely or never
a	Do you go to the same place?	☐	☐	☐	☐
b	Do you usually see the same doctor?	☐	☐	☐	☐

16 **How would you rate the cost to you of your LAST visit to a General Practitioner?**
(Mark one only)

- No cost to me ☐
- Good ☐
- Fair ☐
- Poor ☐
- Don't know ☐

17 **Do you have a Health Care Card?**
This is a card that entitles you to discounts and assistance with medical expenses. This is not the same as a Medicare card. *(Mark one only)*

- Yes ☐
- No ☐

18a **Do you have private health insurance for HOSPITAL COVER?** *(Mark one only)*

- Yes ☐
- No – I am covered by Veterans' Affairs ☐
- No – other reason ☐

18b **Do you have private health insurance for ANCILLARY services (eg dental, physiotherapy)?**
(Mark one only)

- Yes ☐
- No – I am covered by Veterans' Affairs ☐
- No – other reason ☐

19 **Have you been admitted to hospital in the LAST TWELVE MONTHS?** *(Mark one only)*

- No ☐
- Yes, day only ☐
- Yes, spent at least one night ☐

20 When did you last have:
(Mark one on each line)

		In the last 2 years	2-5 years ago	More than 5 years ago	Never	Don't know
a	A Pap test?	☐	☐	☐	☐	☐
b	A mammogram?	☐	☐	☐	☐	☐

21 Have you EVER had an abnormal result from:
(Mark one on each line)

		Yes	No	Don't know
a	A Pap test?	☐	☐	☐
b	A mammogram?	☐	☐	☐

22 In the PAST THREE YEARS, have you: *(Mark all that apply on each line)*

		Doctor	Nurse	Other	Not checked
a	Had your blood pressure checked?	☐	☐	☐	☐
b	Had your cholesterol checked?	☐	☐	☐	☐
c	Had your blood sugar level checked?	☐	☐	☐	☐
d	Had your skin checked (eg spots, lesions, moles)?	☐	☐	☐	☐

23 In the PAST THREE YEARS, have you: *(Mark one on each line)*

		Yes	No
a	Had your breasts examined by a doctor or nurse?	☐	☐
b	Carried out *regular monthly* breast self examination?	☐	☐
c	Had a bone density test?	☐	☐
d	Had a test for bowel cancer?	☐	☐
e	Been vaccinated for influenza (the 'flu')?	☐	☐
f	Had a pneumococcal vaccine (also called PPV, for pneumonia)?	☐	☐

24 Are you CURRENTLY taking: *(Mark one on each line)*

		Yes	No
a	The oral contraceptive pill?	☐	☐
b	Hormone Replacement Therapy (HRT)?	☐	☐
c	Other hormones?	☐	☐

25 Do you regularly NEED help with daily tasks because of long-term illness, disability or frailty *(eg personal care, getting around, preparing meals etc)?* *(Mark one only)*

Yes ☐
No ☐

26 **In the LAST TWELVE MONTHS have you:**

(Mark all that apply)

		Yes
a	Slipped, tripped or stumbled?	☐
b	Had a fall to the ground?	☐
c	Been injured as a result of a fall?	☐
d	Needed to seek medical attention for an injury from a fall?	☐
e	Had any other injury from an accident at your home?	☐
f	Broken or fractured any bone/s?	☐
g	None of the above	☐

27 **Thinking about your own health care, how would you rate the following?**

(Mark one on each line)

		Excellent	Very good	Good	Fair	Poor	Don't know
a	Access to medical specialists if you need them	☐	☐	☐	☐	☐	☐
b	Access to a hospital if you need it	☐	☐	☐	☐	☐	☐
c	Access to medical care in an emergency	☐	☐	☐	☐	☐	☐
d	Access to after-hours medical care	☐	☐	☐	☐	☐	☐
e	Access to a GP who bulk bills	☐	☐	☐	☐	☐	☐
f	Access to a female GP	☐	☐	☐	☐	☐	☐
g	Hours when a GP is available	☐	☐	☐	☐	☐	☐
h	Number of GPs you have to choose from	☐	☐	☐	☐	☐	☐
i	Ease of seeing the GP of your choice	☐	☐	☐	☐	☐	☐
j	How long you wait to get a GP appointment	☐	☐	☐	☐	☐	☐
k	The outcomes of your medical care *(how much you are helped)*	☐	☐	☐	☐	☐	☐
l	Ease of obtaining a mammogram	☐	☐	☐	☐	☐	☐
m	Ease of obtaining a Pap test	☐	☐	☐	☐	☐	☐
n	Access to a counselling service if you need it	☐	☐	☐	☐	☐	☐

28 **In the PAST WEEK, have you been feeling that life isn't worth living?** *(Mark one only)*

Yes ☐
No ☐

29 **In the PAST 6 MONTHS, have you EVER deliberately hurt yourself or done anything that you knew might have harmed or even killed you?** *(Mark one only)*

Yes ☐
No ☐

If you answered YES to either of the last 2 questions, you might like to talk to someone about how you are feeling. You could ring Lifeline on 13 11 14 (local call).

30 In the PAST THREE YEARS, have you been diagnosed or treated for: *(Mark all that apply)*

		Yes, in the past 3 years
a	Diabetes *(high blood sugar)*	☐
b	Impaired glucose tolerance	☐
c	Osteoarthritis	☐
d	Rheumatoid arthritis	☐
e	Other arthritis	☐
f	Heart disease *(including heart attack, angina)*	☐
g	Thrombosis *(a blood clot)*	☐
h	Hypertension *(high blood pressure)*	☐
i	Stroke	☐
j	Low iron level *(iron deficiency or anaemia)*	☐
k	Asthma	☐
l	Bronchitis / emphysema	☐
m	Osteoporosis	☐
n	Breast cancer	☐
o	Cervical cancer	☐
p	Skin cancer *(including melanoma)*	☐
q	Other Cancer *(please specify on page 30)*	☐
r	Depression	☐
s	Anxiety / nervous disorder	☐
t	Other psychiatric disorder	☐
u	Chronic Fatigue Syndrome	☐
v	Sexually transmitted infection *(eg genital herpes or warts, chlamydia)*	☐
w	Macular degeneration	☐
x	Cataracts	☐
y	Glaucoma	☐
z	Other major illness or disability *(please specify below)*	☐
	……	
aa	None of these conditions	☐

31 Do you have any of these sleeping problems?
(Mark all that apply)

		Yes
a	Waking up in the early hours of the morning	☐
b	Lying awake for most of the night	☐
c	Taking a long time to get to sleep	☐
d	Worry keeping you awake at night	☐
e	Sleeping badly at night	☐
f	None of these problems	☐

32 In the PAST THREE YEARS, have you had any of the following operations or procedures?
(Mark all that apply)

		Yes in the past 3 years
a	Both ovaries removed	☐
b	Repair of prolapsed vagina, bladder or bowel	☐
c	Endometrial ablation *(removal of the lining of the uterus)*	☐
d	Joint replacement *(eg hip, knee)*	☐
e	Mastectomy *(removal of one or both breasts)*	☐
f	Lumpectomy *(removal of lump from breast)*	☐
g	Removal of skin cancer	☐
h	Any cancer surgery *(other than skin or breast)*	☐
i	Chemotherapy or radiotherapy for any cancer	☐
j	Breast biopsy *(taking a sample of breast tissue)*	☐
k	Hysteroscopy *(investigative procedure to examine the uterus)*	☐
l	Cholecystectomy *(gall bladder removed)*	☐
m	Gastroscopy / colonoscopy	☐
n	Gastric banding surgery	☐
o	None of these	☐

33 How would you rate the overall condition of your teeth, dentures or gums?
(Mark one only)

Excellent	☐
Very good	☐
Good	☐
Fair	☐
Poor	☐

34 What is your postcode?

Mark here if living overseas ☐

a What is your RESIDENTIAL postcode?
(where you live)

b What is the postcode of your POSTAL ADDRESS?
(if different from residential)

35 In the PAST FOUR WEEKS, have you taken any: *(Mark one on each line)*

		Yes	No
a	Medications prescribed by a doctor?	☐	☐
b	Medications / vitamins / supplements or herbal therapies bought without a prescription at the chemist, supermarket or health food shop?	☐	☐
c	Medications to help you sleep?	☐	☐

36 In the PAST FOUR WEEKS, have you taken any: *(Mark one on each line)*

		Yes	No
a	Glucosamine	☐	☐
b	Paracetamol	☐	☐
c	Omega 3 *(eg fish oil)*	☐	☐
d	Calcium tablets / Caltrate	☐	☐
e	Vitamin D	☐	☐
f	Vitamin C	☐	☐
g	St John's Wort (eg Hypericum perforatum)	☐	☐
h	Vitamin B or Vitamin B Complex	☐	☐
i	Multivitamins	☐	☐
j	Aspirin (eg Aspro clear)	☐	☐
k	Magnesium supplements	☐	☐
l	Ventolin (salbutamol)	☐	☐
m	Other vitamins, supplements or herbal therapies (*please specify below*)	☐	☐
	…….. …….		

37 Thinking about your current approach to life, please indicate how much you think each statement describes you:
(Mark one on each line)

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a	In uncertain times, I usually expect the best	☐	☐	☐	☐	☐
b	If something can go wrong for me, it will	☐	☐	☐	☐	☐
c	I'm always optimistic about my future	☐	☐	☐	☐	☐
d	I hardly ever expect things to go my way	☐	☐	☐	☐	☐
e	I rarely count on good things happening to me	☐	☐	☐	☐	☐
f	Overall, I expect more good things to happen to me than bad	☐	☐	☐	☐	☐

38 In general, are you satisfied with what you have achieved in your life so far in the areas of:
(Mark one on each line)

		Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
a	Work	☐	☐	☐	☐
b	Career	☐	☐	☐	☐
c	Study	☐	☐	☐	☐
d	Family relationships	☐	☐	☐	☐
e	Partner / closest personal relationship	☐	☐	☐	☐
f	Friendships	☐	☐	☐	☐
g	Social activities	☐	☐	☐	☐

39 **In the LAST 12 MONTHS, have you had any of the following:**
(Mark one on each line)

		Never	Rarely	Some-times	Often
a	Allergies, hay fever, sinusitis	☐	☐	☐	☐
b	Breathing difficulty	☐	☐	☐	☐
c	Indigestion / heartburn	☐	☐	☐	☐
d	Chest pain	☐	☐	☐	☐
e	Headaches / migraines	☐	☐	☐	☐
f	Severe tiredness	☐	☐	☐	☐
g	Stiff or painful joints	☐	☐	☐	☐
h	Back pain	☐	☐	☐	☐
i	Urine that burns or stings	☐	☐	☐	☐
j	Haemorrhoids *(piles)*	☐	☐	☐	☐
k	Other bowel problems	☐	☐	☐	☐
l	Vaginal discharge or irritation	☐	☐	☐	☐
m	Hot flushes	☐	☐	☐	☐
n	Night sweats	☐	☐	☐	☐
o	Eyesight problems	☐	☐	☐	☐
p	Leaking urine	☐	☐	☐	☐
q	Mouth, teeth or gum problems	☐	☐	☐	☐
r	Avoided eating some foods because of problems with your teeth, mouth or dentures	☐	☐	☐	☐
s	Hearing problems	☐	☐	☐	☐
t	Depression	☐	☐	☐	☐
u	Anxiety	☐	☐	☐	☐
v	Episodes of intense anxiety *(eg panic attacks)*	☐	☐	☐	☐
w	Palpitations *(feeling that your heart is racing or fluttering in your chest)*	☐	☐	☐	☐
x	Poor memory	☐	☐	☐	☐
y	Dizziness, loss of balance	☐	☐	☐	☐
z	Difficulty concentrating	☐	☐	☐	☐

40 **Over the LAST TWELVE MONTHS, how stressed have you felt about the following areas of your life:** *(Mark one on each line)*

		Not applicable	Not at all stressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed
a	Own health	☐	☐	☐	☐	☐	☐
b	Health of family members	☐	☐	☐	☐	☐	☐
c	Work / employment	☐	☐	☐	☐	☐	☐
d	Living arrangements	☐	☐	☐	☐	☐	☐
e	Study	☐	☐	☐	☐	☐	☐
f	Money	☐	☐	☐	☐	☐	☐
g	Relationship with parents	☐	☐	☐	☐	☐	☐
h	Relationship with partner / spouse	☐	☐	☐	☐	☐	☐
i	Relationship with children	☐	☐	☐	☐	☐	☐
j	Relationship with other family members	☐	☐	☐	☐	☐	☐

41 **How much do you agree or disagree with each of the following statements?** *(Mark one on each line)*

		Disagree strongly	Disagree	Disagree slightly	Agree slightly	Agree	Agree strongly
a	At home, I feel I have control over what happens in most situations	☐	☐	☐	☐	☐	☐
b	I feel that what happens in my life is often determined by factors beyond my control	☐	☐	☐	☐	☐	☐
c	Over the next 5-10 years I expect to have more positive than negative experiences	☐	☐	☐	☐	☐	☐
d	I often have the feeling that I am being treated unfairly	☐	☐	☐	☐	☐	☐
e	In the past 10 years my life has been full of changes without my knowing what will happen next	☐	☐	☐	☐	☐	☐
f	I gave up trying to make big improvements or changes in my life a long time ago	☐	☐	☐	☐	☐	☐

42 **If you were to consider your life in general these days, how happy or unhappy would you say you are on the whole?** *(Mark one only)*

Extremely happy ☐
Very happy ☐
Pretty happy ☐
Unhappy sometimes ☐
Unhappy usually ☐

43 Below is a list of the ways you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK.

(Mark <u>one on each line</u>)

		Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7 days)
a	I was bothered by things that don't usually bother me	☐	☐	☐	☐
b	I had trouble keeping my mind on what I was doing	☐	☐	☐	☐
c	I felt depressed	☐	☐	☐	☐
d	I felt that everything I did was an effort	☐	☐	☐	☐
e	I felt hopeful about the future	☐	☐	☐	☐
f	I felt fearful	☐	☐	☐	☐
g	My sleep was restless	☐	☐	☐	☐
h	I was happy	☐	☐	☐	☐
i	I felt lonely	☐	☐	☐	☐
j	I could not "get going"	☐	☐	☐	☐
k	I felt terrific	☐	☐	☐	☐

44 In the past month: *(Mark <u>one on each line</u>)*

		Yes	No
a	Have you felt keyed up or on edge?	☐	☐
b	Have you been worrying a lot?	☐	☐
c	Have you been irritable?	☐	☐
d	Have you had difficulty relaxing?	☐	☐
e	Have you been sleeping poorly?	☐	☐
f	Have you had headaches or neck aches?	☐	☐
g	Have you had any of the following: trembling, tingling, dizzy spells, sweating, diarrhoea or needing to pass urine more often than normal?	☐	☐
h	Have you been worried about your health?	☐	☐
i	Have you had difficulty falling asleep?	☐	☐

45 a How much do you weigh? *(no clothes or shoes)*

☐☐☐ **kgs** **<u>OR</u>** ☐☐ **stones** ☐☐ **pounds**

b How tall are you without shoes?

☐☐☐ **cms** **<u>OR</u>** ☐ **feet** ☐☐ **inches**

46 What is your waist measurement?

*Please measure your waist while in your underwear. If possible, get someone to help you take the measurement. Find your navel (belly button) and measure at that level. Be careful not to have the tape too tight. You should be able to slip your little finger under it comfortably. Write the measurement to the **nearest** centimetre (or inches if this is the only measure you have available).*

☐☐☐ **cms** **OR** ☐☐ **inches**

47 Have you used any of these methods to lose weight or to control your weight or shape in the LAST TWELVE MONTHS? *(Mark one on each line)*

		Yes	No
a	Commercial weight loss programs *(eg Weight Watchers®, Lite n' Easy®, Sureslim®, Jenny Craig®)*	☐	☐
b	Meal replacements or slimming products (*eg OPTIFAST®, Herbalife®, Tony Ferguson®)*	☐	☐
c	Exercise	☐	☐
d	Cut down on the size of meals or between meal snacks	☐	☐
e	Cut down on fats (low fat) and / or sugars	☐	☐
f	Low glycaemic index (GI) diet	☐	☐
g	Diet book diets (*eg Atkins, Zone, CSIRO diet, Liver Cleansing diet)*	☐	☐
h	Laxatives, diuretics or diet pills (*eg Xenical®, Reductil®*)	☐	☐
i	Fasting	☐	☐
j	Smoking	☐	☐

48 How often do you usually drink alcohol? *(Mark one only)*

I have never drunk alcohol in my life ☐
I never drink alcohol, but I have in the past ☐
} **Go to Q51**

I drink rarely ☐
Less than once a week ☐
On 1 or 2 days a week ☐
On 3 or 4 days a week ☐
On 5 or 6 days a week ☐
Every day ☐

49 On a day when you drink alcohol, how many drinks do you usually have? *(Mark one only)*

1 or 2 drinks per day ☐
3 or 4 drinks per day ☐
5 to 8 drinks per day ☐
9 or more drinks per day ☐

50 How often do you have five or more drinks of alcohol on one occasion? *(Mark one only)*

Never ☐
Less than once a month ☐
About once a month ☐
About once a week ☐
More than once a week ☐

51 How many glasses / cups of non-alcoholic drinks do you usually have each day *(eg juice, tea, coffee, water, milk etc)?* *(Mark one only)*

0 – 2 glasses ☐
3 – 5 glasses ☐
6 – 8 glasses ☐
9 or more glasses ☐

52 Over the *last 12 months*, on average, how often did you drink the following?
(Mark one on each line)

		Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
a	Cola drinks / not diet *(eg Coke)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Diet cola drinks *(eg Diet coke)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Other carbonated / not diet *(eg fizzy / soft drinks)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	Other carbonated / diet *(eg diet lemonade)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Non-carbonated / not diet cordials, fruit or sport drinks	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Non-carbonated / diet cordials, fruit or sport drinks	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g	Milk or soya milk *(including flavoured varieties)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h	Fruit or vegetable juices	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i	Tea	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j	Herbal tea	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k	Coffee	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l	Water *(including soda or plain mineral water)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Questions 52 to 69 are modified from the Cancer Council of Victoria Food Frequency Questionnaire and are used with permission.

*This section is about your **usual** eating habits over the **LAST 12 MONTHS**. Where possible, give only **one answer per question** for the type of food you eat **most often** (if you can't decide which type you have most often, answer for the types you usually eat).*

53 How many pieces of FRESH fruit do you usually eat per day? (Count ½ cup of diced fruit, berries or grapes as one piece)

- I don't eat fruit ☐
- Less than 1 piece of fruit per day ☐
- 1 piece of fruit per day ☐
- 2 pieces of fruit per day ☐
- 3 pieces of fruit per day ☐
- 4 or more pieces of fruit per day ☐

54 How many different vegetables do you usually eat per day? (Count all types, fresh, frozen or tinned)

- Less than 1 vegetable per day ☐
- 1 vegetable per day ☐
- 2 vegetables per day ☐
- 3 vegetables per day ☐
- 4 vegetables per day ☐
- 5 vegetables per day ☐
- 6 or more vegetables per day ☐

55 What type of milk do you usually use?

- **a** None ☐
- **b** Full cream milk ☐
- **c** Reduced fat milk ☐
- **d** Skim milk ☐
- **e** Soya milk ☐

56 How much milk do you usually use per day? (Include flavoured milk and milk added to tea, coffee, cereal etc)

- None ☐
- Less than 250 ml (1 large cup or mug) ☐
- Between 250 and 500 ml (1-2 cups) ☐
- Between 500 and 750 ml (2-3 cups) ☐
- 750 ml (3 cups) or more ☐

57 What type of bread do you usually eat?

- **a** I don't eat bread ☐
- **b** High fibre white bread ☐
- **c** White bread ☐
- **d** Wholemeal bread ☐
- **e** Rye bread ☐
- **f** Multi-grain bread ☐

58 How many slices of bread do you usually eat per day? (Include all types, fresh or toasted and count one bread roll as 2 slices)

- Less than 1 slice per day ☐
- 1 slice per day ☐
- 2 slices per day ☐
- 3 slices per day ☐
- 4 slices per day ☐
- 5-7 slices per day ☐
- 8 or more slices per day ☐

59 Which spread do you usually put on bread?

- **a** I don't usually use any fat spread ☐
- **b** Margarine of any kind ☐
- **c** Polyunsaturated margarine ☐
- **d** Monounsaturated margarine ☐
- **e** Butter and margarine blends ☐
- **f** Butter ☐

60 On average, how many teaspoons of sugar do you usually use per day? (Include sugar taken with tea and coffee and on breakfast cereal etc)

- None ☐
- 1 to 4 teaspoons per day ☐
- 5 to 8 teaspoons per day ☐
- 9 to 12 teaspoons per day ☐
- More than 12 teaspoons per day ☐

61 On average, how many eggs do you usually eat per week?

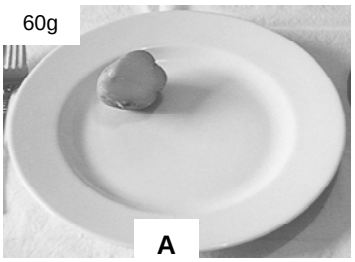
- I don't eat eggs ☐
- Less than 1 egg per week ☐
- 1 to 2 eggs per week ☐
- 3 to 5 eggs per week ☐
- 6 or more eggs per week ☐

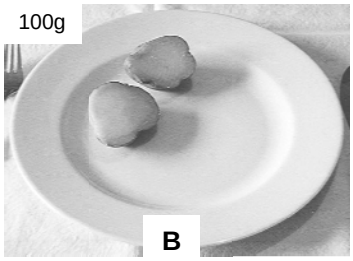
62 What types of cheese do you usually eat?

- **a** I don't eat cheese ☐
- **b** Hard cheeses, eg parmesan, romano ☐
- **c** Firm cheeses, eg cheddar, edam ☐
- **d** Soft cheeses, eg camembert, brie ☐
- **e** Ricotta or cottage cheese ☐
- **f** Cream cheese ☐
- **g** Low fat cheese ☐

For each food shown on this page, indicate **how much on average you would usually have eaten at main meals during the PAST 12 MONTHS**. When answering each question, think of the **amount** of that food you usually ate, even though you may rarely have eaten the food on its own. If you usually ate more than one helping, Choose the serving size closest to the **total amount** you ate.

63 When you ate potato, did you usually eat: I never ate potato ☐

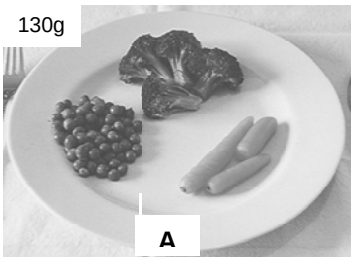


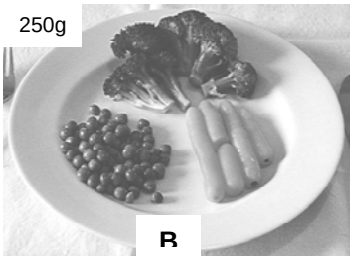


☐ ☐ ☐ ☐ ☐ ☐ ☐

Less than A A Between A & B B Between B & C C More than C

64 When you ate vegetables, did you usually eat: I never ate vegetables ☐

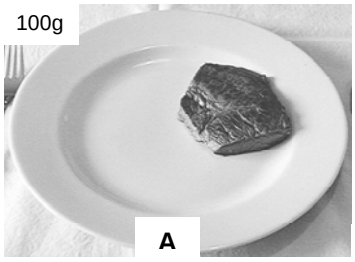


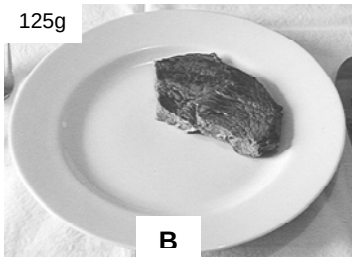


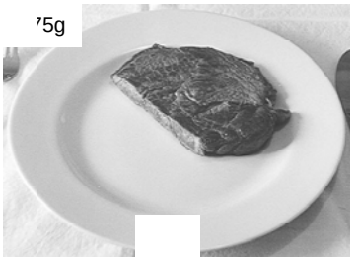
☐ ☐ ☐ ☐ ☐ ☐ ☐

Less than A A Between A & B B Between B & C C More than C

65 When you ate steak, did you usually eat: I never ate steak ☐



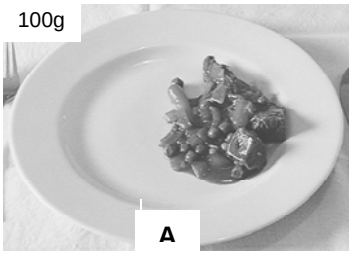


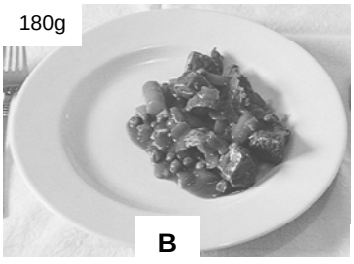


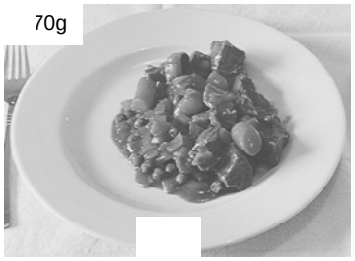
☐ ☐ ☐ ☐ ☐ ☐ ☐

Less than A A Between A & B B Between B & C C More than C

66 When you ate meat *or* vegetable casserole, did you usually eat: I never ate casserole ☐







☐ ☐ ☐ ☐ ☐ ☐ ☐

Less than A A Between A & B B Between B & C C More than C

67 Over the LAST 12 MONTHS, on average, how often did you eat the following foods?
(Mark one on each line)

	Times you have eaten	Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
	Cereal, Foods, Sweets & Snacks										
a	All Bran	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Sultana Bran™, FibrePlus™, Branflakes™	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Weet Bix™, Vita Brits™, Weeties™	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	Cornflakes, Nutrigrain™, Special K™	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Porridge	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Muesli	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g	Rice	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h	Pasta or noodles *(include lasagne)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i	Crackers, crispbreads, dry biscuits	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j	Sweet biscuits	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k	Cakes, sweet pies, tarts and other sweet pastries	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l	Meat pies, pasties, quiche, and other savoury pastries	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
m	Pizza	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
n	Hamburger with a bun	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
o	Chocolate	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
p	Flavoured milk drink *(cocoa, Milo™ etc)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
q	Nuts	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
r	Peanut butter or peanut paste	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
s	Corn chips, potato crisps, Twisties™ etc	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
t	Jam, marmalade, honey or syrups	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
u	Vegemite™, Marmite™ or Promite™	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
	Dairy Products, Meat & Fish										
a	Cheese	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Ice-cream	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Yoghurt	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	Beef	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Veal	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Chicken	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g	Lamb	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h	Pork	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i	Bacon	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j	Ham	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k	Corned beef, luncheon meats or salami	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l	Sausages or frankfurters	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
m	Fish, steamed, grilled or baked	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
n	Fish, fried *(include take-away)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
o	Fish, tinned *(salmon, tuna, sardines etc)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	Times you have eaten continued	Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
	Fruit										
a	Tinned or frozen fruit *(any kind)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Fruit juice	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Oranges or other citrus fruit	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	Apples	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Pears	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Bananas	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g	Watermelon, rockmelon *(cantaloupe)*, honeydew etc.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h	Pineapple	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i	Strawberries	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j	Apricots	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k	Peaches or nectarines	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l	Mango or paw paw	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
m	Avocado	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
	Vegetables (including fresh, frozen and tinned)										
a	Potatoes roasted or fried *(include hot chips)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Potatoes cooked without fat	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Tomato sauce, tomato paste or dried tomatoes	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	Fresh or tinned tomatoes	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Peppers *(capsicum)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Lettuce, endive, or other salad greens	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g	Cucumber	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h	Celery	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i	Beetroot	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j	Carrots	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k	Cabbage or Brussels sprouts	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l	Cauliflower	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
m	Broccoli	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
n	Silverbeet or spinach	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
o	Peas	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
p	Green beans	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
q	Bean sprouts or alfalfa sprouts	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
r	Baked beans	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
s	Soy beans, soy bean curd or tofu	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
t	Other beans *(include chick peas, lentils etc)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
u	Pumpkin	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
v	Onion or leeks	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
w	Garlic *(not garlic tablets)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
x	Mushrooms	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
y	Zucchini	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

68 Over the LAST 12 MONTHS, how often did you drink beer, wine and/or spirits?
(Mark one on each line)

If you do NOT drink alcohol, mark here → ☐ and go to Q71

	Times that you drank	Never	Less than once per month	1 to 3 days per month	1 day per week	2 days per week	3 days per week	4 days per week	5 days per week	6 days per week	Every day
a	Beer *(low alcohol)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Beer *(full strength)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Red wine	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	White wine *(include sparkling wines)*	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Fortified wines, port, sherry etc	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Spirits, liqueurs etc	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

When answering the next two questions, please convert the amounts you drink into glasses using the examples given below.

For spirits, liqueurs, and mixed drinks containing spirits, please count each nip (30 ml) as one glass.

1 can or stubby of beer = 2 glasses
1 large bottle beer (750 ml) = 4 glasses
1 bottle wine (750 ml) = 6 glasses
1 bottle of port or sherry (750 ml) = 12 glasses

69 Over the LAST 12 MONTHS, on days when you were drinking, how many glasses of beer, wine and/or spirits altogether did you *usually* drink? *(Mark one only)*

Total number of glasses per day	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten or more
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

70 Over the LAST 12 MONTHS, what was the *maximum* number of glasses of beer, wine and/or spirits that you drank in 24 hours? *(Mark one only)*

Maximum number of glasses per 24 hours	1-2	3-4	5-6	7-8	9-10	11-12	13-14	15-16	17-18	19 or more
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

71 How often do you currently smoke cigarettes or any tobacco products? *(Mark one only)*

Daily ☐ → **Go to Q72**

At least weekly *(but not daily)* ☐ → **Go to Q73**

Less often than weekly ☐
Not at all ☐
} **Go to Q74**

72 **If you smoke daily, on average how many cigarettes do you smoke EACH DAY?**

PRINT the number in the box

☐☐☐ cigarettes per day → **Go to Q76**

73 **If you smoke, but not daily, on average how many cigarettes do you smoke PER WEEK?**

PRINT the number in the box

☐☐☐ cigarettes per week

74 **Have you ever smoked DAILY?** *(Mark one only)*

Yes ☐

No ☐ → **If No, go to Q76**

75 **At what age did you finally stop smoking DAILY?**

PRINT age in the box

☐☐ years old

76 **In a usual week, how much time in total do you spend doing the following things?**
(Mark one on each line)

		I don't do this activity	1-15 hours	16-24 hours	25-34 hours	35-40 hours	41-48 hours	49 hours or more
a	Full time paid work	☐	☐	☐	☐	☐	☐	☐
b	Part-time paid work	☐	☐	☐	☐	☐	☐	☐
c	Casual paid work	☐	☐	☐	☐	☐	☐	☐
d	Home duties *(own / family home)*	☐	☐	☐	☐	☐	☐	☐
e	Work without pay *(eg family business)*	☐	☐	☐	☐	☐	☐	☐
f	Looking for work	☐	☐	☐	☐	☐	☐	☐
g	Unpaid voluntary work	☐	☐	☐	☐	☐	☐	☐
h	Active leisure *(eg walking, exercise, sport)*	☐	☐	☐	☐	☐	☐	☐
i	Passive leisure *(eg TV, music, reading, relaxing)*	☐	☐	☐	☐	☐	☐	☐
j	Studying	☐	☐	☐	☐	☐	☐	☐
k	Socialising	☐	☐	☐	☐	☐	☐	☐
l	Buying goods and/or services *(eg paying bills, shopping)*	☐	☐	☐	☐	☐	☐	☐

77 **Managing time is often difficult. How often do you feel**: *(Mark one on each line)*

		Every day	A few times a week	About once a week	About once a month	Never
a	That you are rushed, pressured, too busy?	☐	☐	☐	☐	☐
b	That you have time on your hands that you don't know what to do with?	☐	☐	☐	☐	☐
c	That people ask too much of your time?	☐	☐	☐	☐	☐
d	That you can spend your time the way you want to?	☐	☐	☐	☐	☐
e	That you need more "me time"?	☐	☐	☐	☐	☐
f	That you have no control over how your time is spent?	☐	☐	☐	☐	☐

Think about all of the time you spend sitting during EACH DAY while at home, at work, while getting from place to place or during your spare time

78 How many hours EACH DAY do you typically spend sitting down while doing things like visiting friends, driving, reading, watching television or working at a desk or computer?

a	On a usual **WEEK DAY**	☐☐ hours
b	On a usual **WEEKEND DAY**	☐☐ hours

The next two questions are about the amount of physical activity you did LAST WEEK

79 How many <u>times</u> did you do each type of activity LAST WEEK?
Only count the number of times when the activity lasted for 10 minutes or more.
*(If you did **not** do an activity, please write "0" in the box)*

a	**Walking briskly** *(for recreation or exercise, or to get from place to place)*	☐☐ times
b	**Moderate leisure activity** *(like social tennis, moderate exercise classes, recreational swimming, dancing)*	☐☐ times
c	**Vigorous leisure activity** *(that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming)*	☐☐ times
d	**Vigorous household or garden chores** *(that make you breathe harder or puff and pant)*	☐☐ times

80 If you add up all the times you spent in each activity LAST WEEK, how much time did you spend ALTOGETHER doing each type of activity?
*(If you did **not** do an activity, please write "0" in the box)*

a	**Walking briskly** *(for recreation or exercise, or to get from place to place)*	☐☐ hours	☐☐ minutes
b	**Moderate leisure activity** *(like social tennis, moderate exercise classes, recreational swimming, dancing)*	☐☐ hours	☐☐ minutes
c	**Vigorous leisure activity** *(that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming)*	☐☐ hours	☐☐ minutes
d	**Vigorous household or garden chores** *(that make you breathe harder or puff and pant)*	☐☐ hours	☐☐ minutes

81 How do you manage on the income you have available? *(Mark one only)*

- It is impossible ☐
- It is difficult all the time ☐
- It is difficult some of the time ☐
- It is not too bad ☐
- It is easy ☐

82 Are there people who do NOT live with you who are dependent on your household income? *(Mark one only)*

- No ☐
- Yes, one ☐
- Yes, more than one ☐

83 Do you regularly provide (unpaid) care for grandchildren or other people's children? *(Mark one only)*

- Yes, daily ☐
- Yes, weekly ☐
- Yes, occasionally ☐
- No, never ☐

84 Do you regularly provide care or assistance *(eg personal care, transport)* to any other person because of their long-term illness, disability or frailty? *(Mark one on each line)*

		Yes	No	
a	For someone who lives with you	☐	☐	**If No to both, go to Q89**
b	For someone who lives elsewhere	☐	☐	

85 How many people with a long-term illness, disability or frailty do you regularly provide care for? *(Mark one only)*

- One person ☐
- Two people ☐
- More than two people ☐

86 How often in total do you provide this care or assistance? *(Mark one only)*

- Every day ☐
- Several times a week ☐
- Once a week ☐
- Once every few weeks ☐
- Less often ☐

87 How much time do you usually spend providing such care or assistance on each occasion? *(Mark one only)*

- All day and night ☐
- All day ☐
- All night ☐
- Several hours ☐
- About an hour ☐

88 **Does the person you care for have any of the following major medical conditions or disabilities?** ***If you care for more than 1 person, please select the person you have cared for the longest and complete the question about that person. (Mark all that apply)***

a	Alzheimer's disease / dementia	☐
b	Autism spectrum disorder	☐
c	Autoimmune disorder	☐
d	Cancer	☐
e	Cerebral palsy	☐
f	Down syndrome	☐
g	Frailty in old age	☐
h	Head injury	☐
i	Heart condition	☐
j	Infectious disease	☐
k	Mental health problem *(eg depression, anxiety)*	☐
l	Musculoskeletal condition *(eg break / fracture)*	☐
m	Visual impairment	☐
n	Paralysis	☐
o	Respiratory condition *(eg asthma, emphysema)*	☐
p	Spinal cord injury	☐
q	Stroke	☐
r	Substance abuse / addiction	☐
s	Other neurological disorder *(eg multiple sclerosis, motor neurone disease)*	☐
t	Other reason *(please specify below)* …….	☐

89 **If you do NOT provide care or assistance to any person with a long term illness, disability or frailty, is it because you:** *(Mark one only)*

a	Used to care for someone in the last 3 years, but they passed away or moved into a nursing home or other residential care facility	☐
b	Used to care for someone in the last 3 years, but stopped caring for them for another reason *(please specify below)* ……..	☐
c	Have never provided care or assistance	☐
d	Other reason *(please specify below)* …….	☐

90 **We would like to know YOUR and YOUR PARTNER'S main occupation NOW:** *(Mark one in each column)*

	A self	B partner
Manager or administrator *(eg magistrate, farm manager, media producer, school principal)*	☐	☐
Professional *(eg registered nurse, allied health professional, teacher, artist)*	☐	☐
Associate professional *(eg office manager, branch manager, shop manager, retail buyer, youth worker, police officer)*	☐	☐
Tradesperson or related worker *(eg cook, dressmaker, hairdresser, gardener, florist)*	☐	☐
Advanced clerical or service worker *(eg credit officer, radio despatcher, personal assistant, flight attendant, law clerk)*	☐	☐
Intermediate clerical, sales or service worker *(eg accounts clerk, checkout supervisor, data entry operator, child care worker, nursing assistant, hospitality worker)*	☐	☐
Intermediate production or transport worker *(eg machine operator, bus driver)*	☐	☐
Elementary clerical, sales or service worker *(eg filing / mail clerk, parking inspector, sales assistant, telemarketer, housekeeper)*	☐	☐
Labourer or related worker *(eg cleaner, factory worker, kitchen hand, fast food cook)*	☐	☐
No paid job	☐	☐
Don't know or **no partner**		☐

91 **Please indicate the following description that best fits your life now. If you want to add more please write this on page 28.** *(Mark one only)*

I am not retired at all ☐

I am partially retired ☐

I am completely retired from paid work ☐

I gave up paid work over 20 years ago ☐

I have never been in paid work ☐

92 **Have you experienced the following events?** *(Mark one on each line)*

		Yes, in the last 12 months	Yes, over 12 months ago	No
a	I was ignored or not taken seriously because of my age	☐	☐	☐
b	I was patronised or "talked down to" because of my age	☐	☐	☐
c	I was denied medical treatment because of my age	☐	☐	☐
d	I was denied employment because of my age	☐	☐	☐

93 **When did you retire or give up work completely?**

(Print year in the box) ☐☐☐☐ Not applicable ☐

94 At what age do you expect to retire (completely) from the paid workforce?

(Print age, in whole years, in the box) | | | |

Do not expect to ever retire ☐

Have already retired ☐

Don't know ☐

95 What are your CURRENT sources of income? *(Mark all that apply)*

		Yes
a	Age pension / Service pension / Widow's pension / War Widow's pension	☐
b	Other government pension or allowance	☐
c	Lump sum superannuation payout	☐
d	A pension or annuity purchased with superannuation or some other funds	☐
e	Income from savings and investments *(such as shares and property)*	☐
f	Income from a business	☐
g	Income or pension from your spouse / partner	☐
h	Financial support from family	☐
i	Spouse / partner's superannuation	☐
j	Wage or salary	☐
k	Other sources *(please specify below)*	☐

……

96 Which of these things (if any) have you had to do in the last 3 years, to help manage financially? *(Mark all that apply)*

a	Sell your house or move to lower cost accommodation	☐
b	Sell something else you own, like a holiday house, or car or jewellery	☐
c	Share housing with relatives or friends	☐
d	Cut back on your normal weekly spending	☐
e	Cut back on less frequent expenditures such as holidays, new cars & large household goods	☐
f	Take on paid work	☐
g	Rely on your spouse / partner going out to work or increasing their working hours	☐
h	None of the above	☐
i	Other *(please specify below)*	☐

……

97 What is your present marital status? *(Mark one only)*

Married *(registered)* ☐

De facto relationship *(opposite sex)* ☐

De facto relationship *(same sex)* ☐

Separated ☐

Divorced ☐

Widowed ☐

Never married ☐

98 **These questions are about getting on with other people:**
(Mark one on each line)

		Yes	No
a	Do you feel uncomfortable with anyone in your family?	☐	☐
b	Do you feel that nobody wants you around?	☐	☐
c	Has anyone forced you to do things you didn't want to do?	☐	☐
d	Has anyone taken things that belong to you without your OK?	☐	☐
e	Has anyone close to you tried to hurt or harm you recently?	☐	☐
f	Has anyone close to you called you names or put you down or made you feel bad recently?	☐	☐
g	Are you afraid of anyone in your family?	☐	☐
h	Have you ever been in a violent relationship with a partner / spouse?	☐	☐

99 If you have ever lived with a violent partner or spouse, in which years did you experience violence? (*Mark all that apply*)

a	Before 2007	☐
b	2008	☐
c	2009	☐
d	2010	☐
e	2011	☐
f	2012	☐
g	None of these	☐

100 **Which of the following events have you experienced?** (*Mark all that apply*)

		Yes, in the last 12 months	Yes, more than 12 months ago
a	Being pushed, grabbed, shoved, kicked or hit	☐	☐
b	Being forced to take part in unwanted sexual activity	☐	☐
c	None of these	☐	☐

101 **As a child did you experience sexual abuse (eg forced to engage in unwanted sexual practices such as unwanted touching, exposure or penetration)?** *(Mark one only)*

Yes	☐
No	☐
I prefer not to answer	☐

If you answered YES to any of the last 4 questions, you might like to talk to someone about how you are feeling. You could ring Lifeline on 131114 (local call)

102 People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?
(Mark <u>one on each line</u>)

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
a	Someone to help you if you are confined to bed	☐	☐	☐	☐	☐
b	Someone you can count on to listen to you when you need to talk	☐	☐	☐	☐	☐
c	Someone to give you good advice about a crisis	☐	☐	☐	☐	☐
d	Someone to take you to the doctor if you need it	☐	☐	☐	☐	☐
e	Someone who shows you love and affection	☐	☐	☐	☐	☐
f	Someone to have a good time with	☐	☐	☐	☐	☐
g	Someone to give you information to help you understand a situation	☐	☐	☐	☐	☐
h	Someone to confide in or talk to about yourself or your problems	☐	☐	☐	☐	☐
i	Someone who hugs you	☐	☐	☐	☐	☐
j	Someone to get together with for relaxation	☐	☐	☐	☐	☐
k	Someone to prepare your meals if you are unable to do it yourself	☐	☐	☐	☐	☐
l	Someone whose advice you really want	☐	☐	☐	☐	☐
m	Someone to do things with to help you get your mind off things	☐	☐	☐	☐	☐
n	Someone to help with daily chores if you are sick	☐	☐	☐	☐	☐
o	Someone to share your most private worries and fears with	☐	☐	☐	☐	☐
p	Someone to turn to for suggestions about how to deal with a personal problem	☐	☐	☐	☐	☐
q	Someone to do something enjoyable with	☐	☐	☐	☐	☐
r	Someone who understands your problems	☐	☐	☐	☐	☐
s	Someone to love and make you feel wanted	☐	☐	☐	☐	☐

103 How many people live with you now? *(Mark <u>all that apply</u>)*

a	No one, I live alone	☐		
b	Partner or spouse	☐		
		One	**Two**	**Three or more**
c	Children under 16 years	☐	☐	☐
d	Children 16-18 years	☐	☐	☐
e	Children over 18 years	☐	☐	☐
f	Your parents or in-laws	☐	☐	☐
g	Other adult relatives	☐	☐	☐
h	Other adults (not family members)	☐	☐	☐

104 What is your date of birth?

					19		
Day		Month			Year		

105 Did someone help you fill in this survey? *(Mark <u>one only</u>)*

No ☐

Yes, but I told them the answers I wanted ☐

Yes, but the helper answered for me using his / her own judgement ☐

106 What was the MAIN reason for your needing help to fill in this survey? *(Please describe)*

……

Have we missed anything?

If there is ANYTHING else you would like to tell us about changes in your health (especially in the last three years) please write on the lines below.

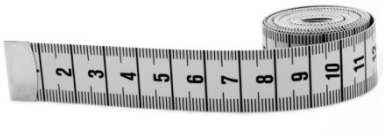
Consent

I agree to the research team following health and other records relating to me, including hospital and health service use records and cancer registers and other chronic conditions registers as described to me in the accompanying brochure. I also understand this means I agree to Medicare releasing information concerning services provided to me under Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, for the duration of the study, as outlined in the enclosed brochure.
(Mark <u>one only</u>)

Yes ☐ **No** ☐

Please sign below and send the completed survey back to us in the envelope supplied as soon as possible. We will detach the consent form and store it in a separate locked room.

Signature _____ **Date** / /



Have you remembered to measure your waist?
Page 15, Question 46.

Help us keep in touch

Sometimes we lose touch with our participants. It would be helpful if you could give us your mobile phone number and email address.

Mobile | | | | | | | | | | |

Email _____

It would be helpful also if you could give us details of **a relative or friend** who will be able to help us find you, after checking that the relative or friend is happy for you to provide these details.

Name _____

Address _____

Town / Suburb _____ State _____ Postcode | | | |

Phone (| |) | | | | | | | | | **Relationship to you** _____

Office use only - DO NOT DETACH.

Thank you for taking the time to complete this survey.

If you have any questions you can contact us by telephoning 1800 068 081 (freecall).

Please let us know your new details if you move, change your name or your telephone number.

Don't forget to sign the consent and post this back to us in the Reply Paid envelope provided!

Australian Longitudinal Study on Women's Health
The University of Newcastle, Callaghan NSW 2308.
Phone: 02 4913 8872 Fax: 02 4913 8888
Email: whasec@newcastle.edu.au
Web: www.alswh.org.au

«AddressBlock»
«AddressBlock»
«AddressBlock»
«AddressBlock»

Women's Health Australia
The Australian Longitudinal Study on Women's Health
Reply Paid 70
Hunter Region MC NSW 2310

Ph: 1800 068 081
Email: info@alswh.org.au
Web: www.alswh.org.au

Dear «FirstName»

Thank you for your continuing participation in the Australian Longitudinal Study on Women's Health. It is now sixteen years since you completed your first survey for this long-term study on the health and health care needs of Australian women.

This year we are offering the option to complete the survey online using the link found on the bottom tear-off section of this letter. Using your identification number, the information you contribute by completing this survey will be linked to the information you have given in the past. This will allow us to follow changes in women's health and their use of health services.

If you prefer, you can still complete the paper version of the survey. The paper survey will be mailed to you in a few weeks (along with the online completion details once more) if we have not received an online survey from you.

If you have changed address or contact details, or if you have any questions or concerns please

- call us on 1800 068 081 (freecall within Australia) **or**
- email us at: info@alswh.org.au **or**
- complete the change of details form overleaf **or**
- complete the change of details as part of the online survey.

Your participation is voluntary. If at any time you would like to discontinue your involvement in the project, please telephone, email or write to us. If we do not hear from you, we will continue to include you in the project.

Thank you again for all your help, we look forward to hearing from you soon.

Yours sincerely,

The Australian Longitudinal Study on Women's Health

University of Newcastle

Change of details form overleaf.
Keep the section below to complete survey online.

Prefer to complete the survey online?

1. Type the following link into the address bar of your web browser:

www.alswh.org.au/onlinesurveys

2. When prompted, enter this 9 digit personal ID number:

<ID NUMBER>

3. Follow the instructions on screen to complete the survey.

Your answers will automatically save as you complete the survey.

Please contact the Australian Longitudinal Study on Women's Health if you have any queries or difficulty completing the survey.
Freecall: 1800 068 081 **Email:** info@alswh.org.au

women's health australia

the australian longitudinal study on women's health

(«IDFull»)

HAVE YOUR DETAILS CHANGED?

If you have changed your name, address or contact details, please advise us by completing and returning this form in the reply paid envelope provided or by calling FREECALL 1800 068 081.

NAME:

TITLE *GIVEN NAME/S* *SURNAME*

POSTAL ADDRESS:

ADDRESS:

SUBURB *STATE* *POSTCODE*

RESIDENTIAL ADDRESS: ☐ SAME AS POSTAL ADDRESS

ADDRESS:

SUBURB *STATE* *POSTCODE*

PH (HOME): ( )

PH (WORK): ( )

PH (MOBILE):

EMAIL 1:

EMAIL 2:

✂ -

If you have any complaints about this project and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Research Ethics Officer (02) 4921 6333 or write to them at the University of Newcastle, University Drive, Callaghan, NSW, 2308. You could also contact the University of Queensland's Human Research Ethics Officer on (07) 3365 3924 or write to them at the University of Queensland, St Lucia, QLD, 4072. The proposed research using Medicare information will be conducted in accordance with relevant privacy requirements and other legislation protecting this information and is subject to final approval being granted by government and university ethics committees.

The Australian Electoral Commission (AEC) has supplied name, address, gender and age-range information for this medical research study in conformity with Item 2 of subsection 90B(4) of the Commonwealth Electoral Act 1918 and subregulation 9(a) of the Electoral and Referendum Regulations 1940. The information has been provided by the AEC on a confidential basis and will not be forwarded on or sold or otherwise disclosed or used for any purpose other than to contact participants for this medical research project.

Attachment 4

Hi again!

Your participation over the past sixteen years has contributed to the advancement of the understanding of the health trends and health care service use of all Australian women.

The Australian Longitudinal Study on Women's Health is the most comprehensive longitudinal study on women's health ever undertaken in Australia. The response rate from your age group at the last survey was amazing and we would like to take this opportunity to thank you all for your commitment to this project.

The current survey reflects the many differing lifestyles among all women of your generation. We hope that the new option to complete the survey online offers a convenient, quicker way to participate.

Yours sincerely,

Annette Dobson

Professor Annette Dobson
Project Director

Contact Us

Website
www.alswh.org.au

Email
info@alswh.org.au

Freecall
1800 068 081

Mail
Women's Health Australia
The Australian Longitudinal Study
on Women's Health
Reply Paid 70
Hunter Region MC
NSW 2310

Your participation is voluntary. If you would like to discontinue your involvement in the project, please phone, email or write to us.

If you have any complaints about this project and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Research Ethics Officer (02) 4921 6333 or write to them at the University of Newcastle, University Drive, Callaghan, NSW, 2308. You could also contact the University of Queensland's Human Research Ethics Officer on (07) 3365 3924 or write to them at the University of Queensland, St Lucia, QLD, 4072. The proposed research using Medicare information will be conducted in accordance with relevant privacy requirements and other legislation protecting this information and is subject to final approval being granted by government and university ethics committees.

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

women's health australia

the australian longitudinal study on women's health

" Participating in this sort of survey gives a good opportunity to review myself or my life from time to time. How amazing three years have gone by since the last one. "
1946-51 participant, Survey 5

Complete the survey Online

For the first time, the Australian Longitudinal Study on Women's Health is offering the 1946-51 cohort survey online! We are very excited about this. The survey has taken on this new form in response to your requests. We hope this will make it easier for you to complete.

If you prefer to complete the survey on paper, this option is still available.

Please do not hesitate to contact us using the details overleaf if you have problems or queries.

As the project heads further into the 21st century, the team at the Australian Longitudinal Study on Women's Health is assessing new ways to conduct research.

In the past, data from consenting participants has been linked to data sourced from Medicare. This has been most successful in providing policy makers with evidence of the need for changes to health services.

Changing technology means that in the future, the data may be linked with many different data collected from other sources such as hospital and pathology records, cancer registries, screening records and midwives registers to name a few. This linkage will reduce the number of questions in future surveys and provides a bigger picture of health trends and service usage of all Australian women.

Of course, we continue to take your privacy seriously. When we receive your completed survey online or by post, any information which could identify you is kept separately. As usual, only your ID number will be used to link this survey information to that from previous surveys. Only ID numbers are used when other data sets are linked. Analysts only ever see linked data with ID numbers, never names and addresses.

With both survey information and health service records information, the picture of women's health becomes clearer.

Attachment 5- Survey Evaluation sheet

EVALUATION SHEET

As mentioned at the beginning of the survey, you are one of our pilot group participants.
As well as completing the survey, we would like to know what you think of it.
We may make changes before sending it to others in your age group in 2013.
Please help by answering the questions below.

1. Were there any questions you found difficult to understand? Yes / No
   If Yes, which questions were they and why?

_____

_____

_____

_____

2. Were there any questions you didn't want to answer? Yes / No
   If Yes, which questions were they and why?

_____

_____

_____

_____

3. Were there any questions you found too personal or not relevant? Yes / No
   If Yes, which questions were they and why?

_____

_____

_____

_____

Please turn over ➔

4. In future, would you complete the survey online?

☐ **NO** Please tell us why not.

_____

_____

_____

What could we do to address these concerns?

_____

_____

_____

☐ **YES** What do you like about completing surveys online?

_____

_____

_____

5. How can we make this survey easier to complete?

_____

_____

_____

6. Do you have any other comments about the survey wording, layout or anything else?

_____

_____

_____

_____

Your feedback will help us improve the survey.
Thank you for taking the time to complete this evaluation sheet.

Attachment 6 – 1st paper group follow up (letter)

Women's Health Australia
The Australian Longitudinal Study on Women's Health
Reply Paid 70
Hunter Region MC NSW 2310

Ph: 1800 068 081
Email: info@alswh.org.au
Web: www.alswh.org.au

«AddressBlock»
«AddressBlock»
«AddressBlock»
«AddressBlock»

Dear «FIRST NAME»

You have been a participant in the Australian Longitudinal Study on Women's Health since 1996, filling in a survey from time to time. We recently sent you an invitation to complete the latest survey online but have not heard back from you (some invitations were sent by post and others by email). Perhaps you have changed postal / email address or the email may have been marked as spam.

If you would like to complete the survey online, please follow the instructions on the tear off section below.

If you prefer, you can complete the paper version of the survey. Simply ignore this reminder and the paper survey will be mailed to you in a few weeks.

If you have changed address or contact details, or if you have any questions or concerns please

- call us on 1800 068 081 (freecall within Australia) **or**
- email us at: info@alswh.org.au **or**
- complete the change of details form overleaf **or**
- complete the change of details as part of the online survey.

You are a unique and irreplaceable participant and we look forward to hearing from you.

Change of details form overleaf. **Keep the section below to complete survey online.**

Kind regards,

The Australian Longitudinal Study on Women's Health

University of Newcastle

✂----------

Prefer to complete the survey online?

1. Type the following link into the address bar of your web browser:

www.alswh.org.au/onlinesurveys

2. When prompted, enter this 9 digit personal ID number:

<ID NUMBER>

3. Follow the instructions on screen to complete the survey.

Your answers will automatically save as you complete the survey.

Please contact the Australian Longitudinal Study on Women's Health if you have any queries or difficulty completing the survey.
Freecall: 1800 068 081 **Email:** info@alswh.org.au

women's health australia

the australian longitudinal study on women's health

(«IDFull»)

HAVE YOUR DETAILS CHANGED?

If you have changed your name, address or contact details, please advise us by completing and returning this form in the reply paid envelope provided or by calling FREECALL 1800 068 081.

NAME: ____________________

TITLE GIVEN NAME/S SURNAME

POSTAL ADDRESS:

ADDRESS: ____________________

SUBURB STATE POSTCODE

RESIDENTIAL ADDRESS: ☐ SAME AS POSTAL ADDRESS

ADDRESS: ____________________

SUBURB STATE POSTCODE

PH (HOME): ( ) ____________________

PH (WORK): ( ) ____________________

PH (MOBILE): ____________________

EMAIL 1: ____________________

EMAIL 2: ____________________

✂ -

If you have any complaints about this project and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Research Ethics Officer (02) 4921 6333 or write to them at the University of Newcastle, University Drive, Callaghan, NSW, 2308. You could also contact the University of Queensland's Human Research Ethics Officer on (07) 3365 3924 or write to them at the University of Queensland, St Lucia, QLD, 4072. The proposed research using Medicare information will be conducted in accordance with relevant privacy requirements and other legislation protecting this information and is subject to final approval being granted by government and university ethics committees.

The Australian Electoral Commission (AEC) has supplied name, address, gender and age-range information for this medical research study in conformity with Item 2 of subsection 90B(4) of the Commonwealth Electoral Act 1918 and subregulation 9(a) of the Electoral and Referendum Regulations 1940. The information has been provided by the AEC on a confidential basis and will not be forwarded on or sold or otherwise disclosed or used for any purpose other than to contact participants for this medical research project.

«AddressBlock»
«AddressBlock»
«AddressBlock»
«AddressBlock»

Women's Health Australia
The Australian Longitudinal Study on Women's Health
Reply Paid 70
Hunter Region MC NSW 2310

Ph: 1800 068 081
Email: info@alswh.org.au
Web: www.alswh.org.au

Dear <FIRSTNAME>

Thank you for your continuing participation in the Australian Longitudinal Study on Women's Health. It is now sixteen years since you completed your first survey for this long-term study on the health and health care needs of Australian women. We recently sent you a letter inviting you to complete the latest survey online but have not heard back from you. Perhaps you have moved and did not receive the invitation.

You can still complete the survey online using the tear off section of this letter or you can complete the enclosed survey. Using your identification number, the information you contribute by completing this survey will be linked to the information you have given in the past. This will allow us to follow changes in women's health and their use of health services.

If you have changed address or contact details, or if you have any questions or concerns please

- call us on 1800 068 081 (freecall within Australia) **or**
- email us at: info@alswh.org.au **or**
- complete the change of details form overleaf **or**
- complete the change of details as part of the online survey.

Your participation is voluntary. If at any time you would like to discontinue your involvement in the project, please telephone, email or write to us. If we do not hear from you, we will continue to include you in the project.

Thank you again for all your help, we look forward to hearing from you.

Kind regards,

The Australian Longitudinal Study on Women's Health

University of Newcastle

Change of details form overleaf.
Keep the section below to complete survey online.

✂ -

Prefer to complete the survey online?

1. Type the following link into the address bar of your web browser:

www.alswh.org.au/onlinesurveys

2. When prompted, enter this 9 digit personal ID number:

<ID NUMBER>

3. Follow the instructions on screen to complete the survey.

Your answers will automatically save as you complete the survey.

Please contact the Australian Longitudinal Study on Women's Health if you have any queries or difficulty completing the survey.
Freecall: 1800 068 081 **Email:** info@alswh.org.au

Attachment 7 – 2nd paper group follow up (letter)

M7P 2012

women's health australia

the australian longitudinal study on women's health

(«IDFull»)

HAVE YOUR DETAILS CHANGED?

If you have changed your name, address or contact details, please advise us by completing and returning this form with your survey in the reply paid envelope provided or by calling FREECALL 1800 068 081.

NAME: ____________________

TITLE *GIVEN NAME/S* *SURNAME*

POSTAL ADDRESS:

ADDRESS: ____________________

SUBURB *STATE* *POSTCODE*

RESIDENTIAL ADDRESS: ☐ SAME AS POSTAL ADDRESS

ADDRESS: ____________________

SUBURB *STATE* *POSTCODE*

PH (HOME): ( ) ____________________

PH (WORK): ( ) ____________________

PH (MOBILE): ____________________

EMAIL 1: ____________________

EMAIL 2: ____________________

✂ -

If you have any complaints about this project and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Research Ethics Officer (02) 4921 6333 or write to them at the University of Newcastle, University Drive, Callaghan, NSW, 2308. You could also contact the University of Queensland's Human Research Ethics Officer on (07) 3365 3924 or write to them at the University of Queensland, St Lucia, QLD, 4072. The proposed research using Medicare information will be conducted in accordance with relevant privacy requirements and other legislation protecting this information and is subject to final approval being granted by government and university ethics committees.

The Australian Electoral Commission (AEC) has supplied name, address, gender and age-range information for this medical research study in conformity with Item 2 of subsection 90B(4) of the Commonwealth Electoral Act 1918 and subregulation 9(a) of the Electoral and Referendum Regulations 1940. The information has been provided by the AEC on a confidential basis and will not be forwarded on or sold or otherwise disclosed or used for any purpose other than to contact participants for this medical research project.

Attachment 8 – 3rd paper group follow up (SMS)

Paper group SMS follow up:

Hi Women's Health Australia Participant. We've not heard from you since sending our latest survey & online link. Please reply or call 1800 068 081. Thank you

Attachment 9 – 4th follow up paper group (email)

Dear «Firstname»,

You have been a participant in the Australian Longitudinal Study on Women's Health since 1996, filling in a survey from time to time. We sent an email to you earlier this year inviting you to complete the survey online but have not heard back from you. We also posted a paper version of the survey to your address in <Suburb/Town>.

If you would like to complete the latest survey online, please click on the link below.

www.alswh.org.au/onlinesurveys.html

Enter your unique ID number: **«ID»**

Then follow the instructions on screen. If the link does not work when you click on it, please copy and paste it into your browser. Your answers will automatically save as you complete the survey.

Please see this year's brochure below:

mid7brochurelink

If you require another paper survey, would like to update your details or if you have any questions or concerns please

- call us on 1800 068 081 (freecall within Australia) **or**
- email us at: info@alswh.org.au **or**
- complete the online change of details form on our website http://www.alswh.org.au/Infoparticipants/change-of-details-form.html **or**
- complete the change of details as part of the online survey.

You are a unique and irreplaceable participant in the project and we look forward to hearing from you.

Kind regards,

The Australian Longitudinal Study on Women's Health

University of Newcastle
Reply Paid 70
Hunter Region MC NSW 2310
Ph: 1800 068 081
info@alswh.org.au
www.alswh.org.au

Thank you

We have received your completed survey.

Congratulations on your continuing commitment to the Australian Longitudinal Study on Women's Health.

With your help we can continue to provide accurate information to the government about the health needs of women across Australia.

women's health australia

the australian longitudinal study on women's health

Did you know that...

76% of women in your age group take vitamins or minerals

43% of women your age rate their number of GPs to choose from as either excellent or very good

27% of women in your age group do unpaid voluntary work

Freecall number
1800 068 081

Email
info@alswh.org.au

Website
www.alswh.org.au

Address
Women's Health Australia
The Australian Longitudinal Study on Women's Health
Reply Paid 70
Hunter Region MC
NSW 2310

Attachment 11 – invitation email online group

Dear «Prefname»,

Thank you for your continuing participation in the Australian Longitudinal Study on Women's Health. It is now sixteen years since you completed your first survey for this long-term study on the health and health care needs of Australian women.

This year we are offering the option to complete the survey online using the link further down this email. Using your identification number, the information you contribute by completing this survey will be linked to the information you have given in the past. This will allow us to follow changes in women's health and their use of health services.

To complete the survey online, follow the link below:

www.alswh.org.au/onlinesurveys.html

Enter your unique ID number: **«ID»**

Then follow the instructions on screen. If the link does not work when you click on it, please copy and paste it into your browser. Your answers will automatically save as you complete the survey.

If you prefer, you can still complete the paper version of the survey. The paper survey will be mailed to you in a few weeks (along with the online completion details once more) if we have not received an online survey from you.

Please see this year's brochure below:

mid7 brochure link

If you have changed address or contact details, or if you have any questions or concerns please

- call us on 1800 068 081 (freecall within Australia) **or**

- email us at: info@alswh.org.au **or**
- complete the online change of details form on our website:

  www.alswh.org.au/Infoparticipants/change-of-details-form.html **or**
- complete the change of details as part of the online survey.

Your participation is voluntary. If at any time you would like to discontinue your involvement in the project, please telephone, email or write to us. If we do not hear from you, we will continue to include you in the project.

Thank you again for all your help, we look forward to hearing from you soon.

Yours sincerely,

The Australian Longitudinal Study on Women's Health

University of Newcastle
Reply Paid 70
Hunter Region MC NSW 2310
Ph: 1800 068 081
info@alswh.org.au
www.alswh.org.au

Attachment 12 – follow up email to finish incomplete online survey

Dear <Name>,

Thank you for your continuing participation in the Australian Longitudinal Study on Women's Health. You are unique and irreplaceable and with your help we can continue to provide accurate information to better assist in the provision of health services for women around Australia.

We recently emailed you a survey that you began but have not completed. We understand that the survey might take some time to do, but would really appreciate if you could complete it.

When you are ready to resume the survey, please click on the following link:

www.alswh.org.au/onlinesurveys.html

Then enter your unique ID number: <ID FIELD>

Your previous answers have been saved. Click the "Next" button onscreen until you get to the next unanswered question.

If you would prefer to complete the paper survey (as in previous years) or if you have any questions or concerns please don't hesitate to call us on 1800 068 081 (freecall within Australia) or email us at: info@alswh.org.au

Kind regards,

The Australian Longitudinal Study on Women's Health

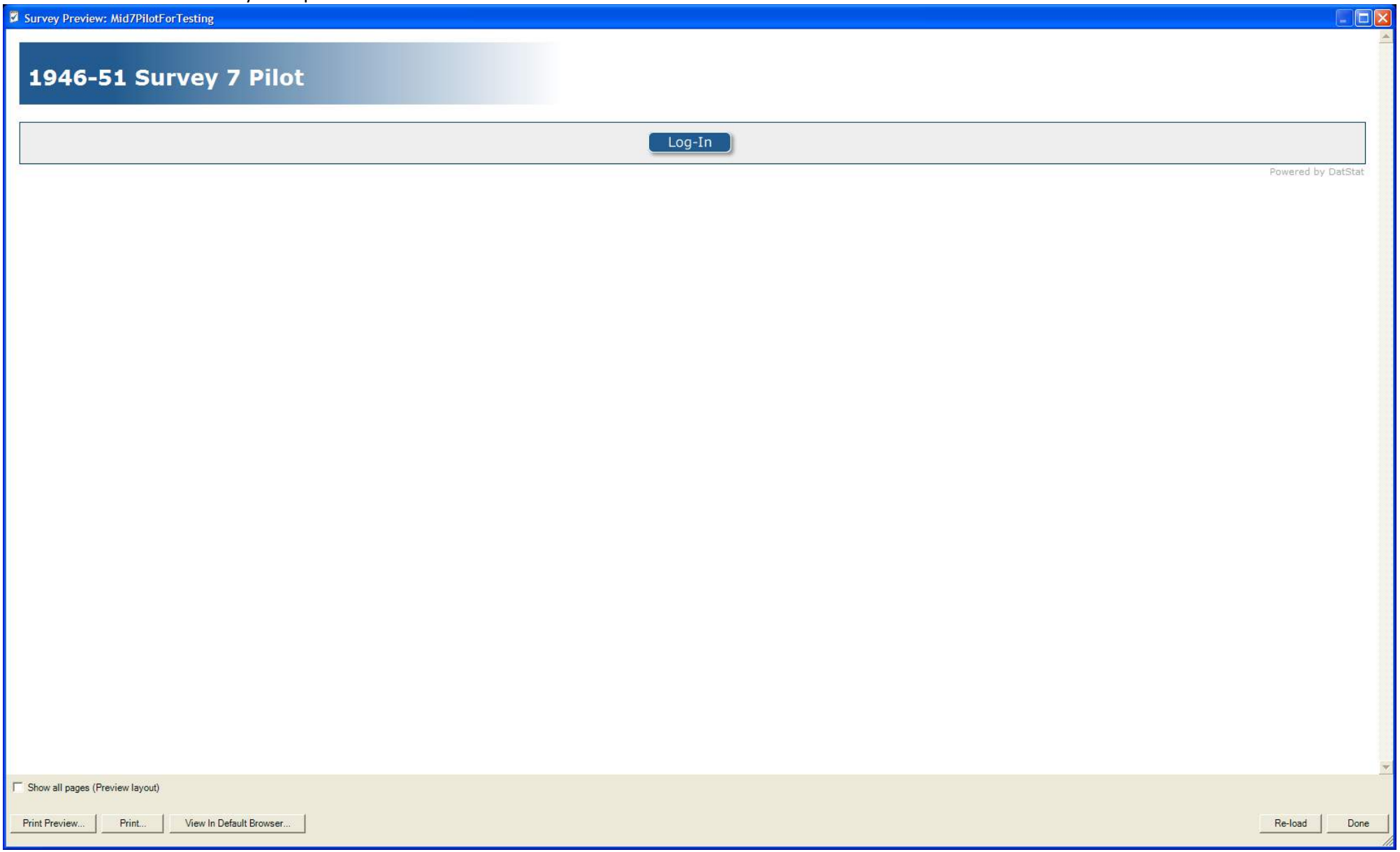
University of Newcastle
Reply Paid 70
Hunter Region MC NSW 2310
Ph: 1800 068 081
info@alswh.org.au
www.alswh.org.au

Attachment 13 – 2nd follow up for online incomplete survey (SMS)

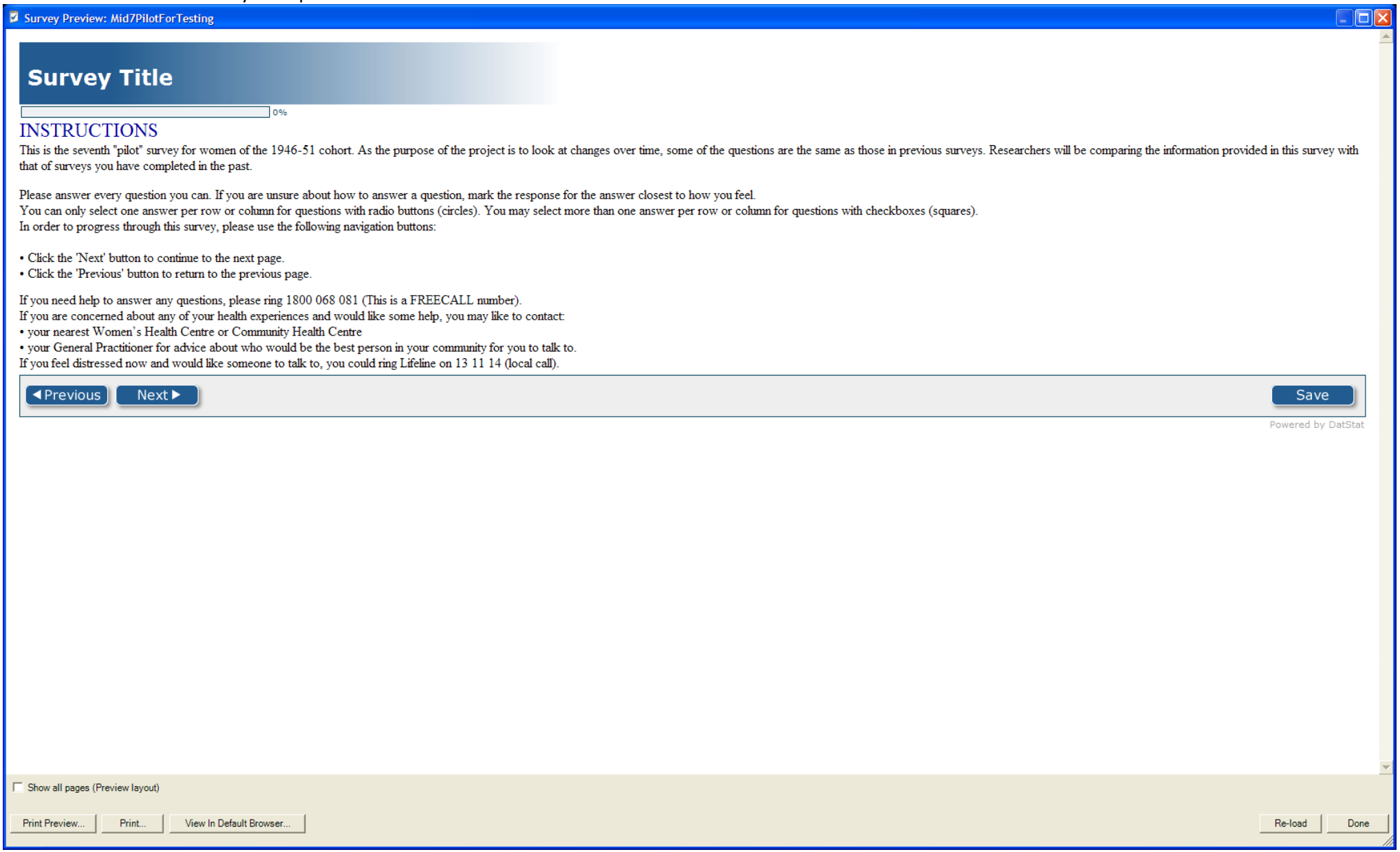
2nd follow up to finish incomplete online survey - SMS

Hi Women's Health Australia Participant. Just a reminder that you haven’t finished the latest online survey. Any problems reply or call 1800 068 081. Thank you

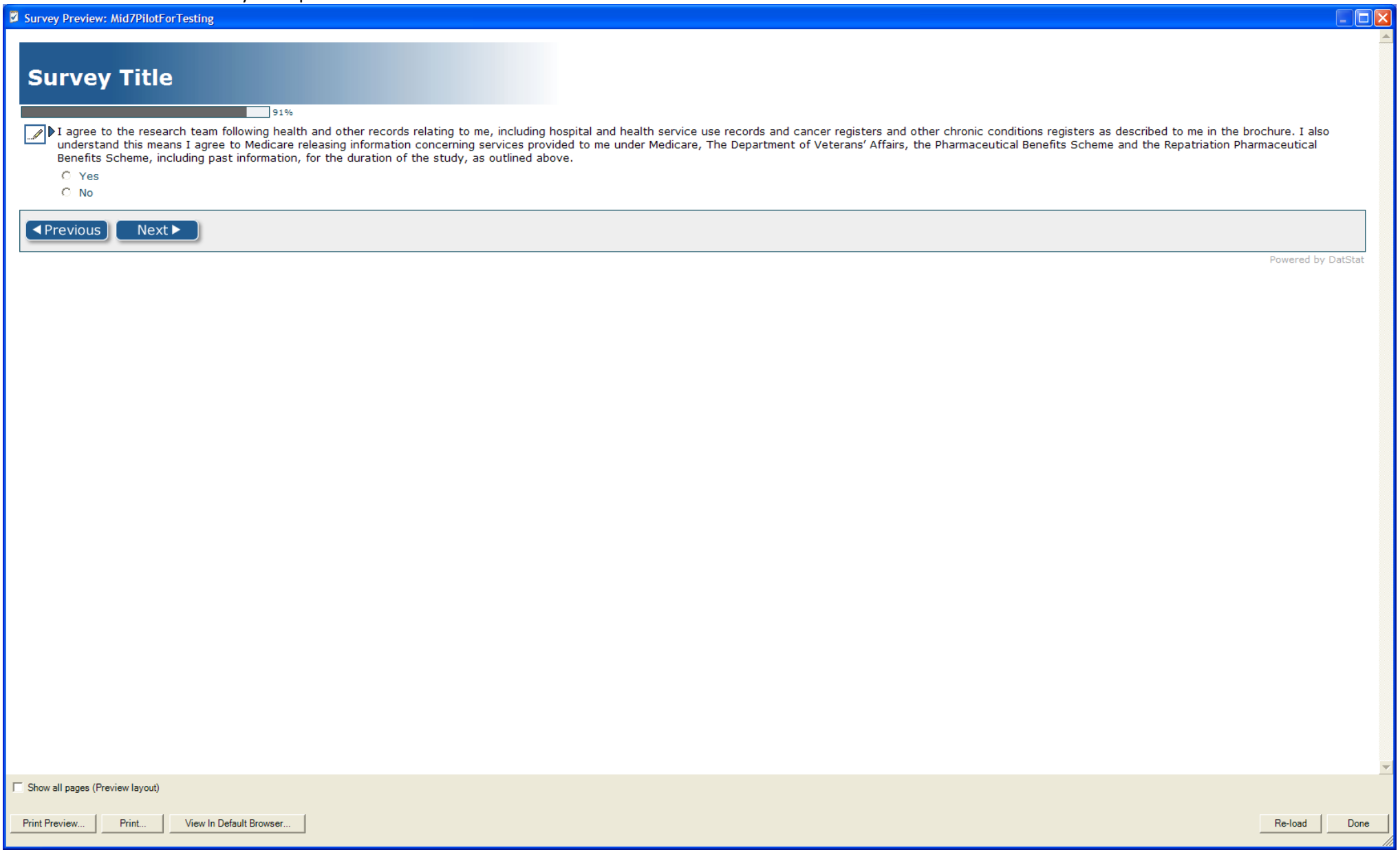
Attachment 14- Online Survey Example



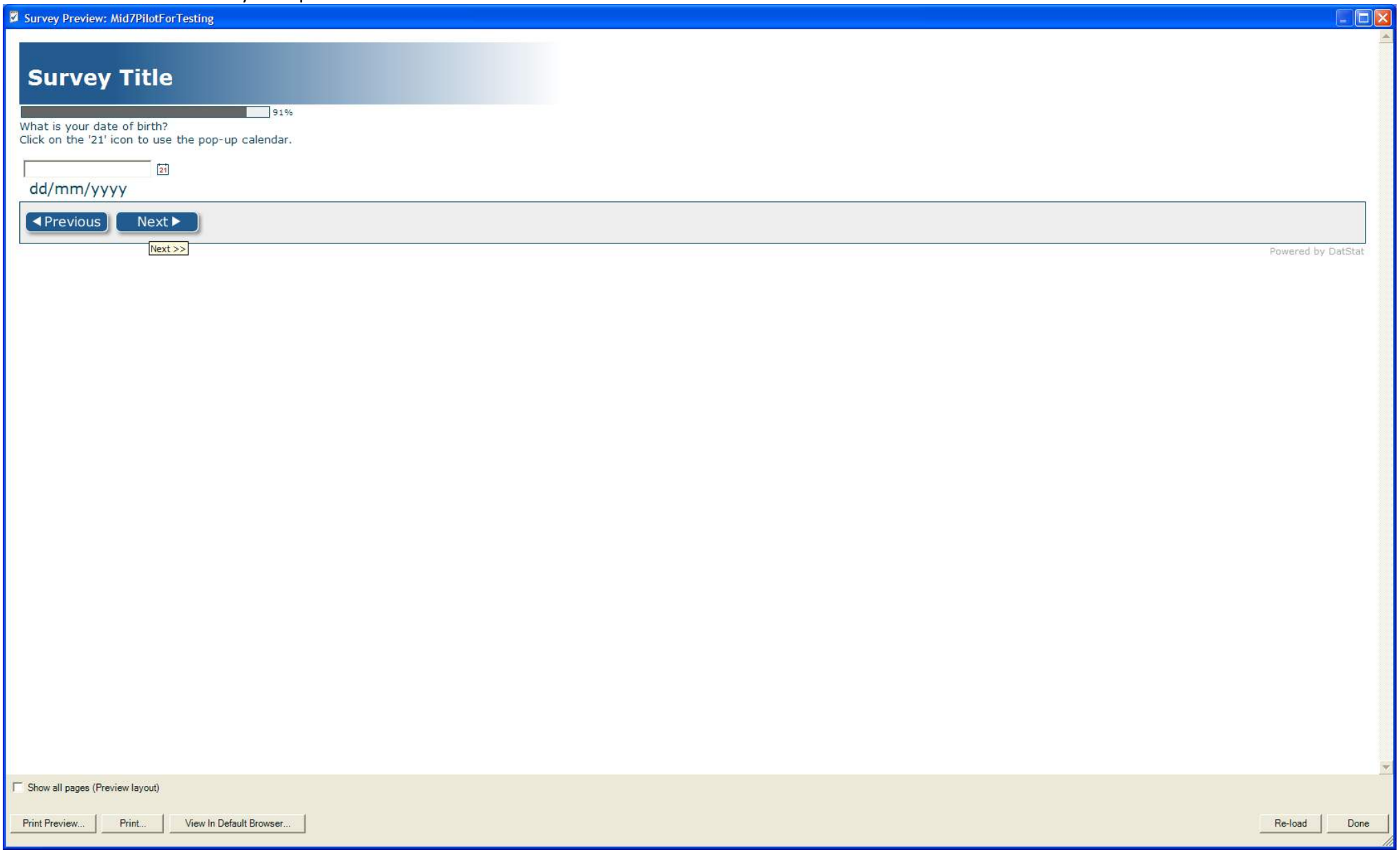
Attachment 14- Online Survey Example



Attachment 14- Online Survey Example



Attachment 14- Online Survey Example



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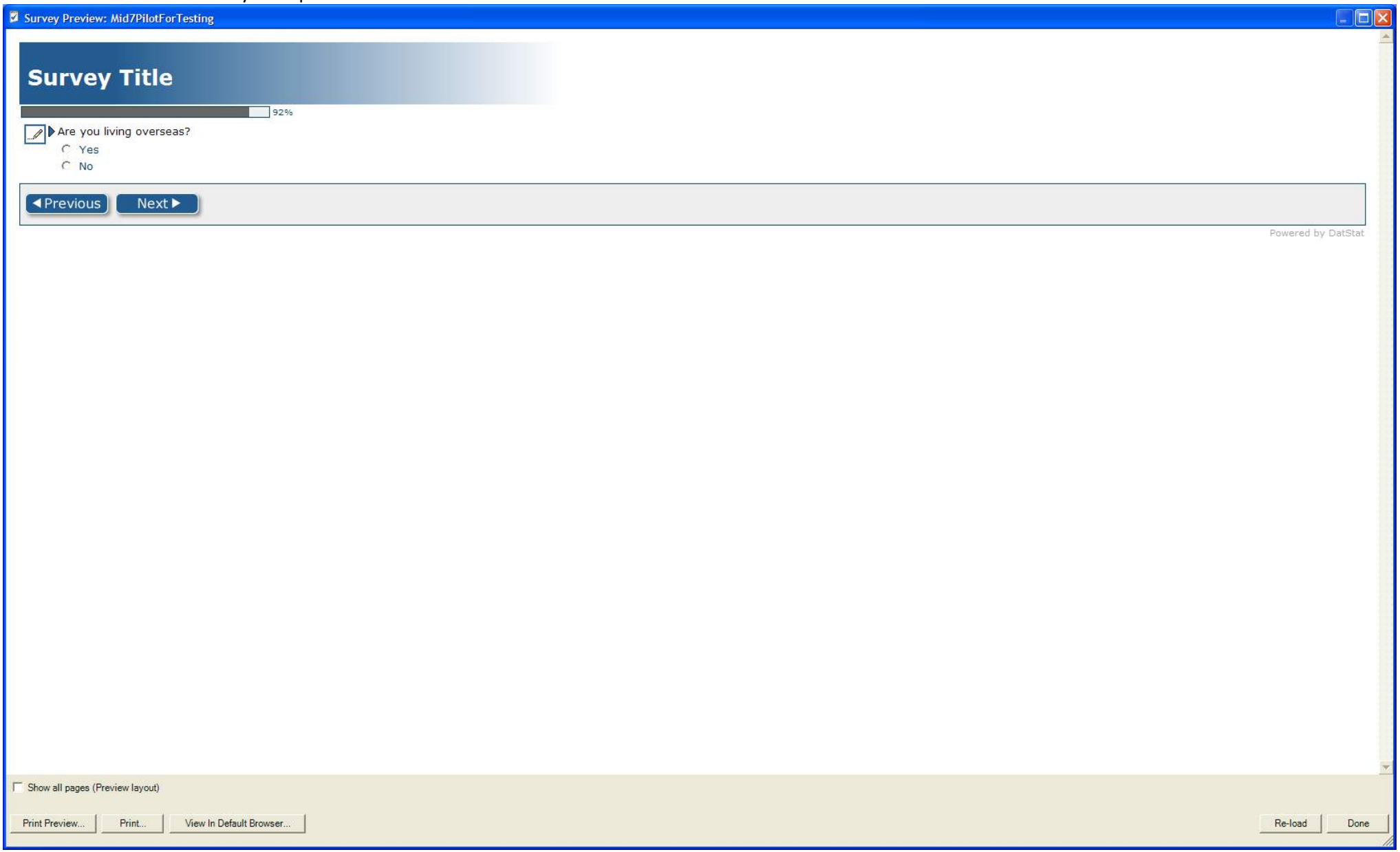

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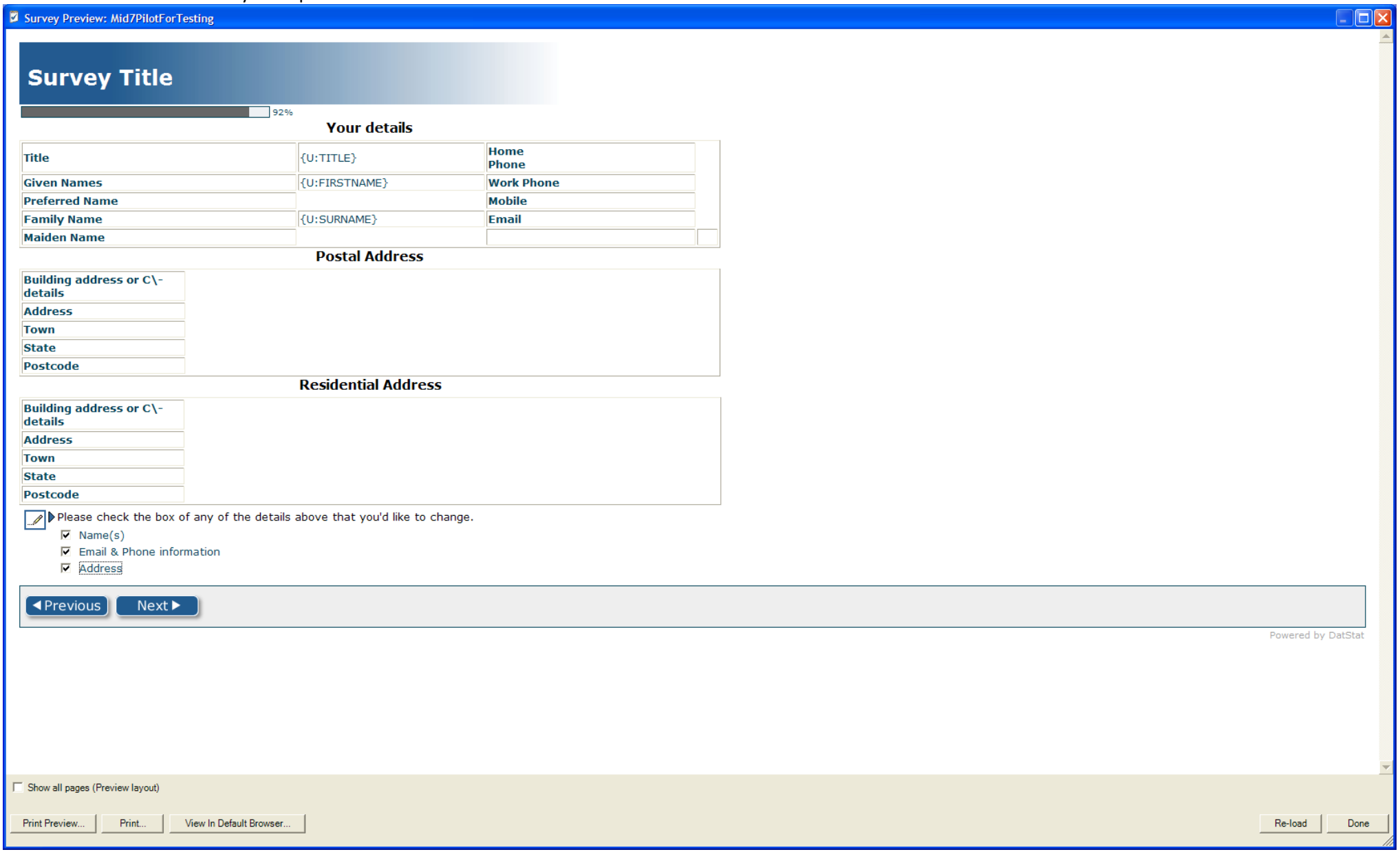

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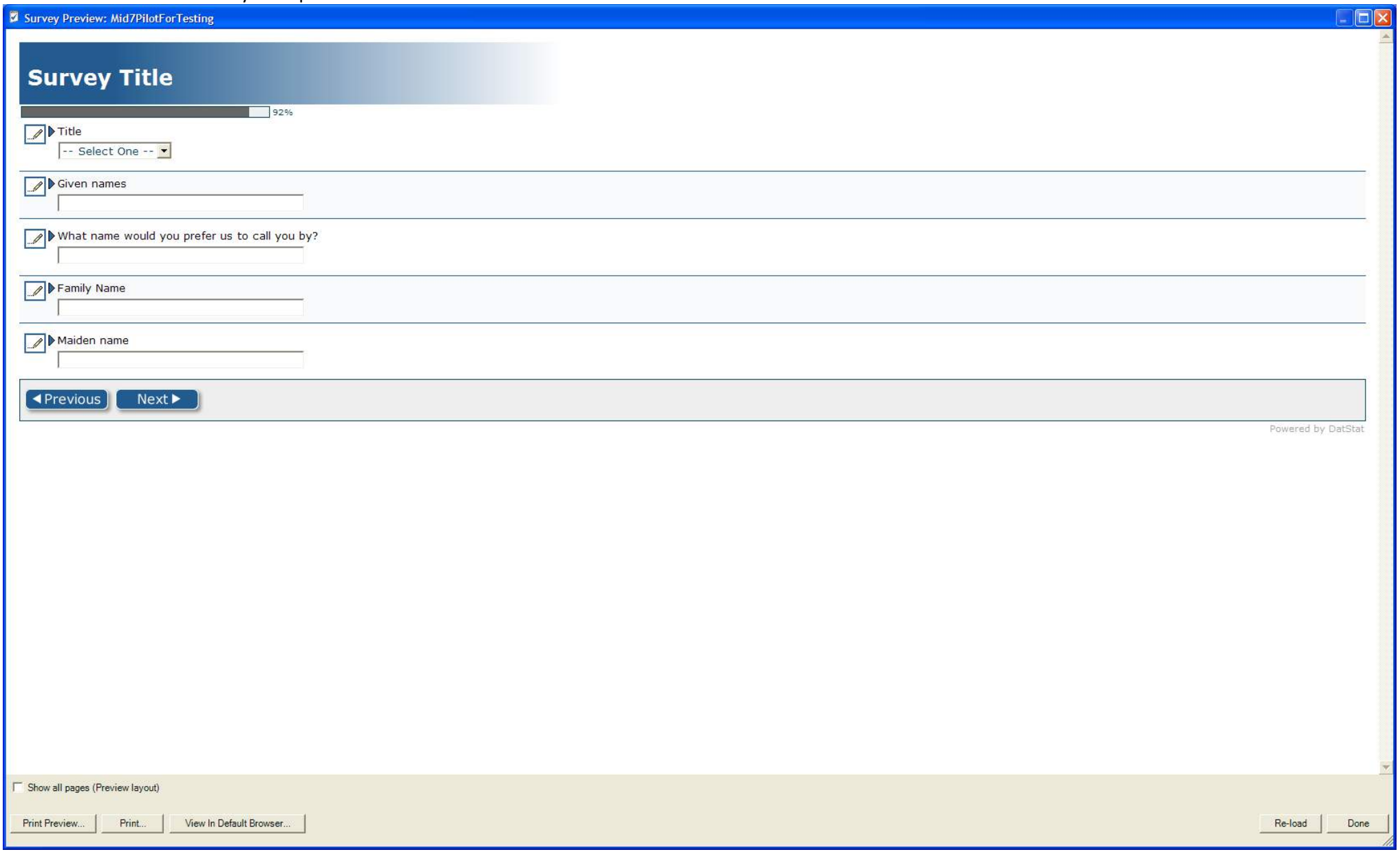

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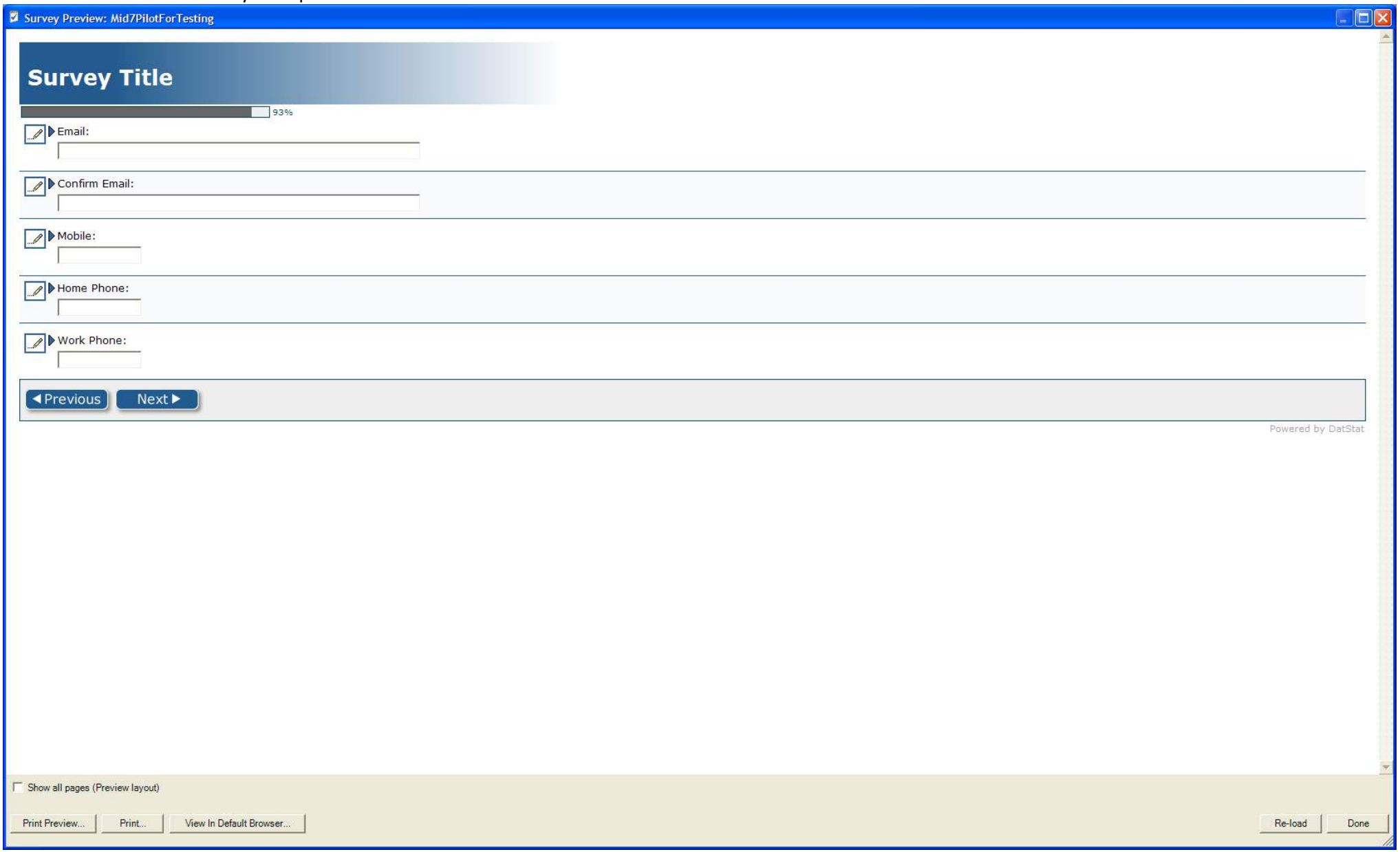

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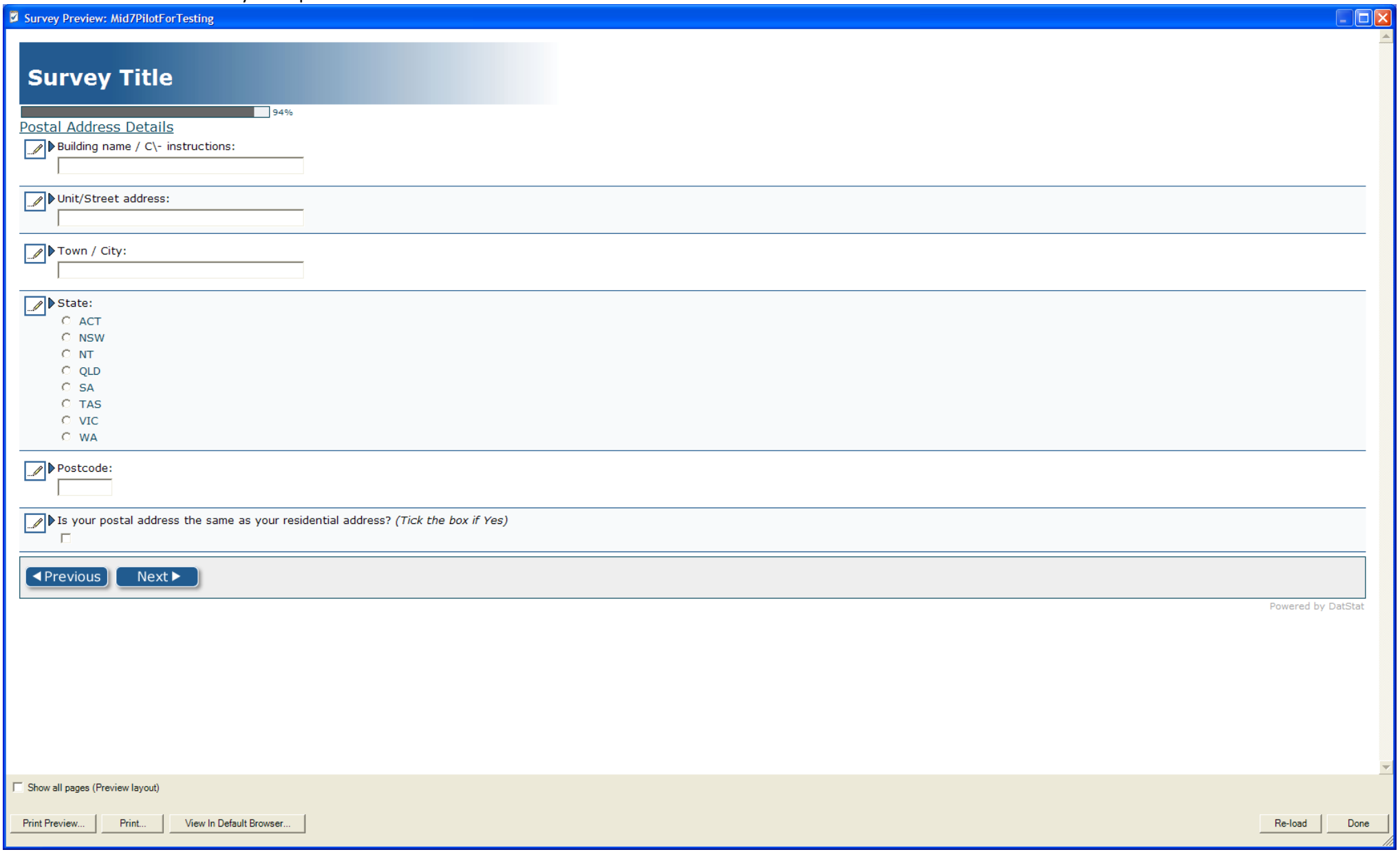

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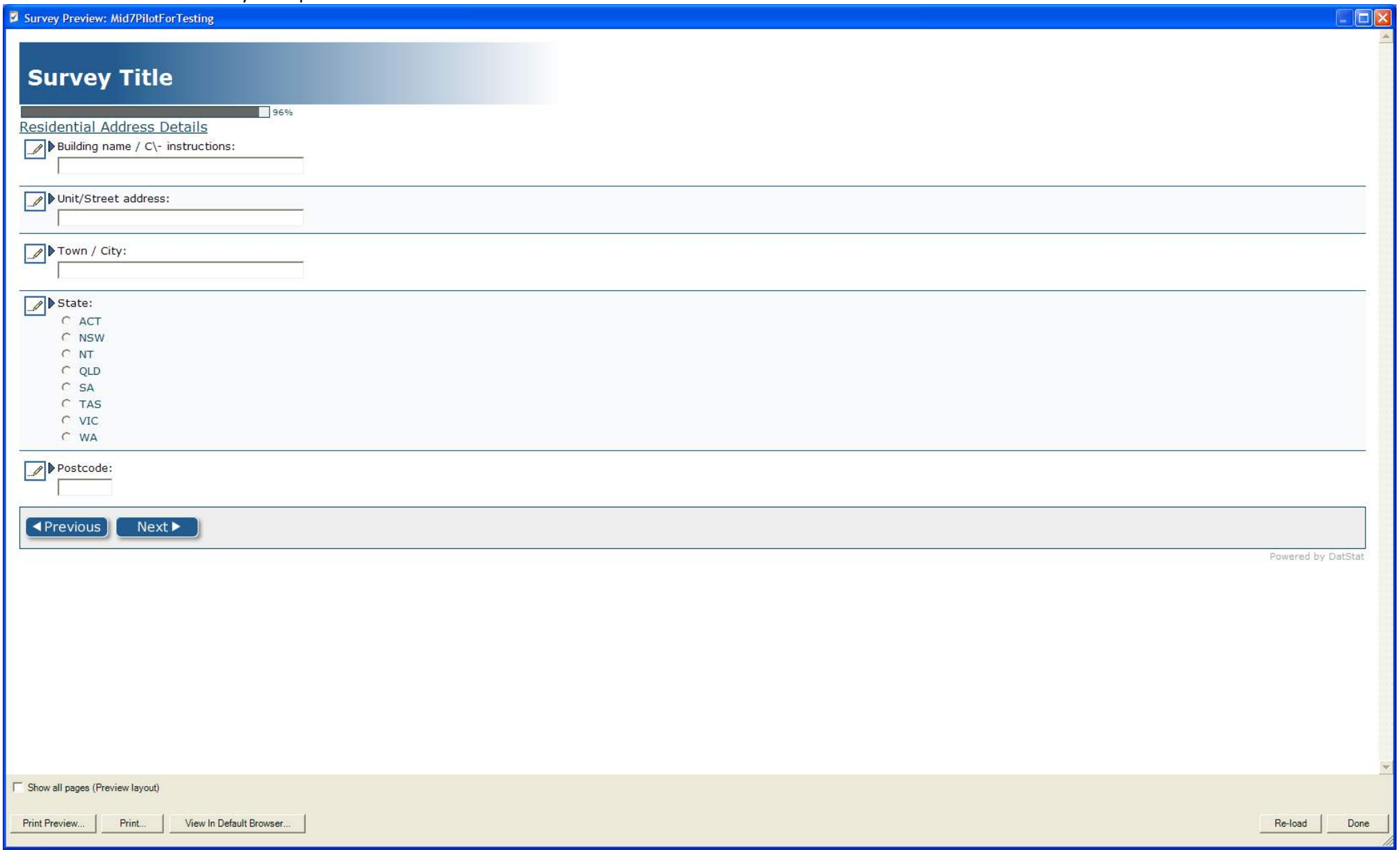

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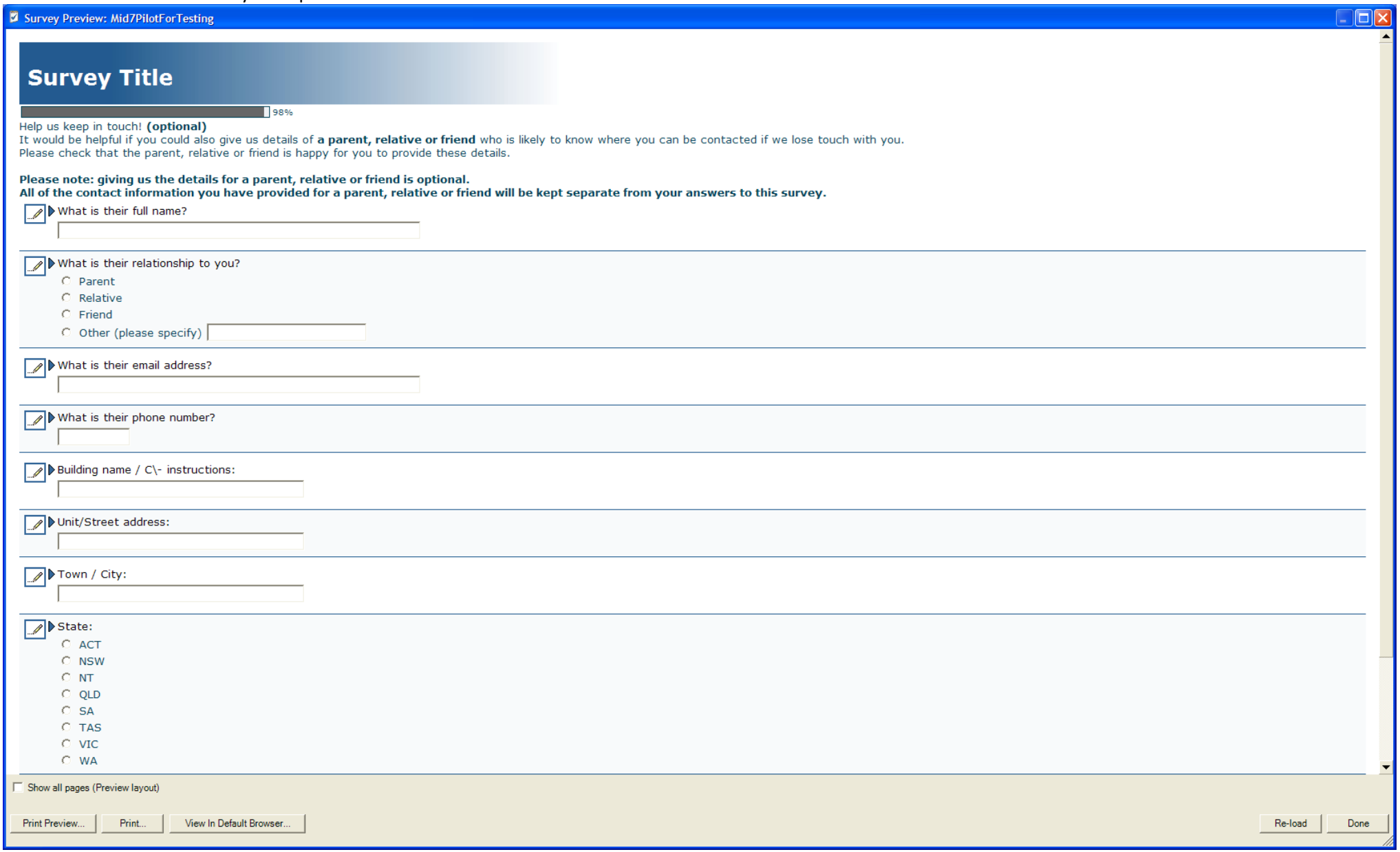

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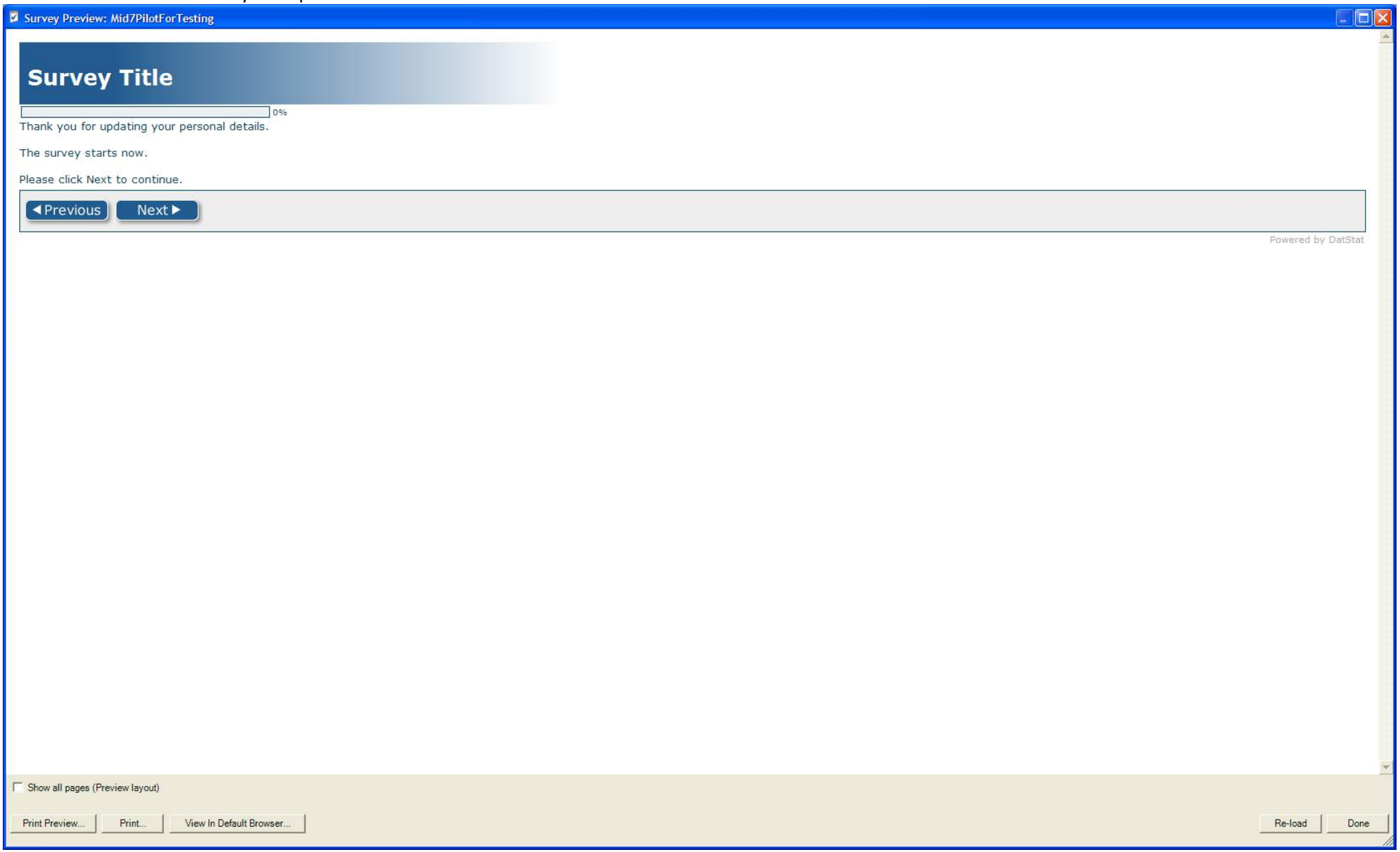

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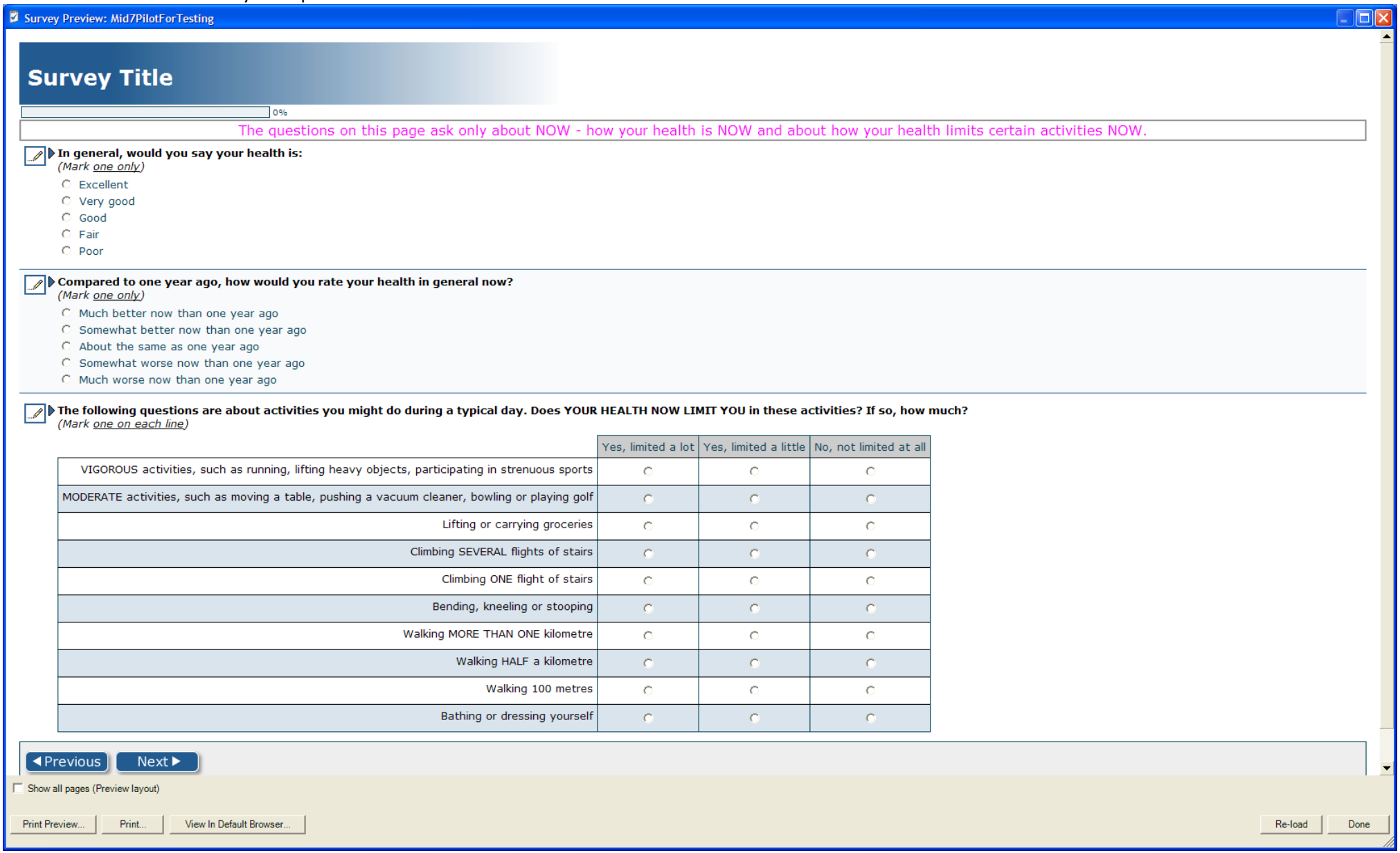

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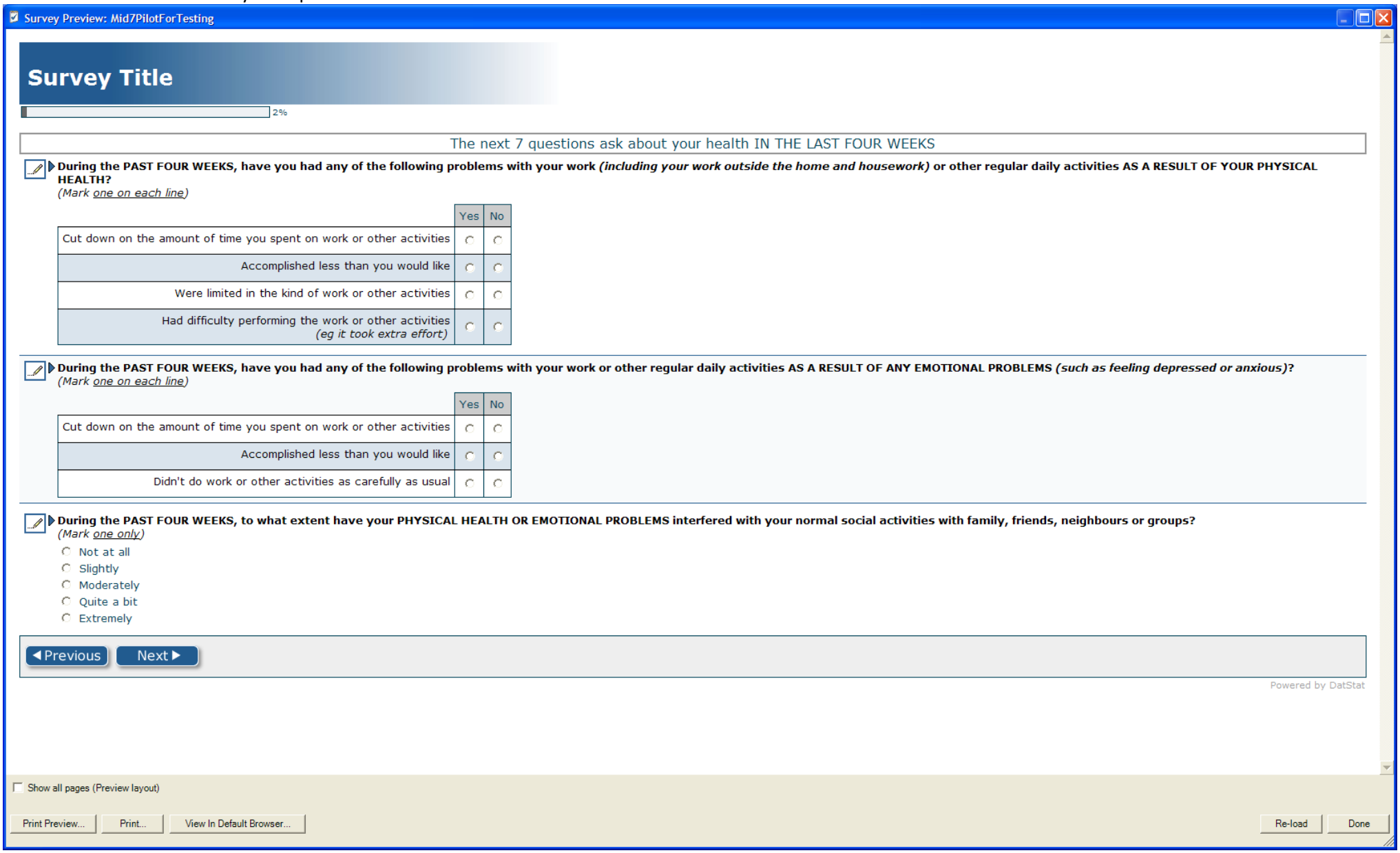

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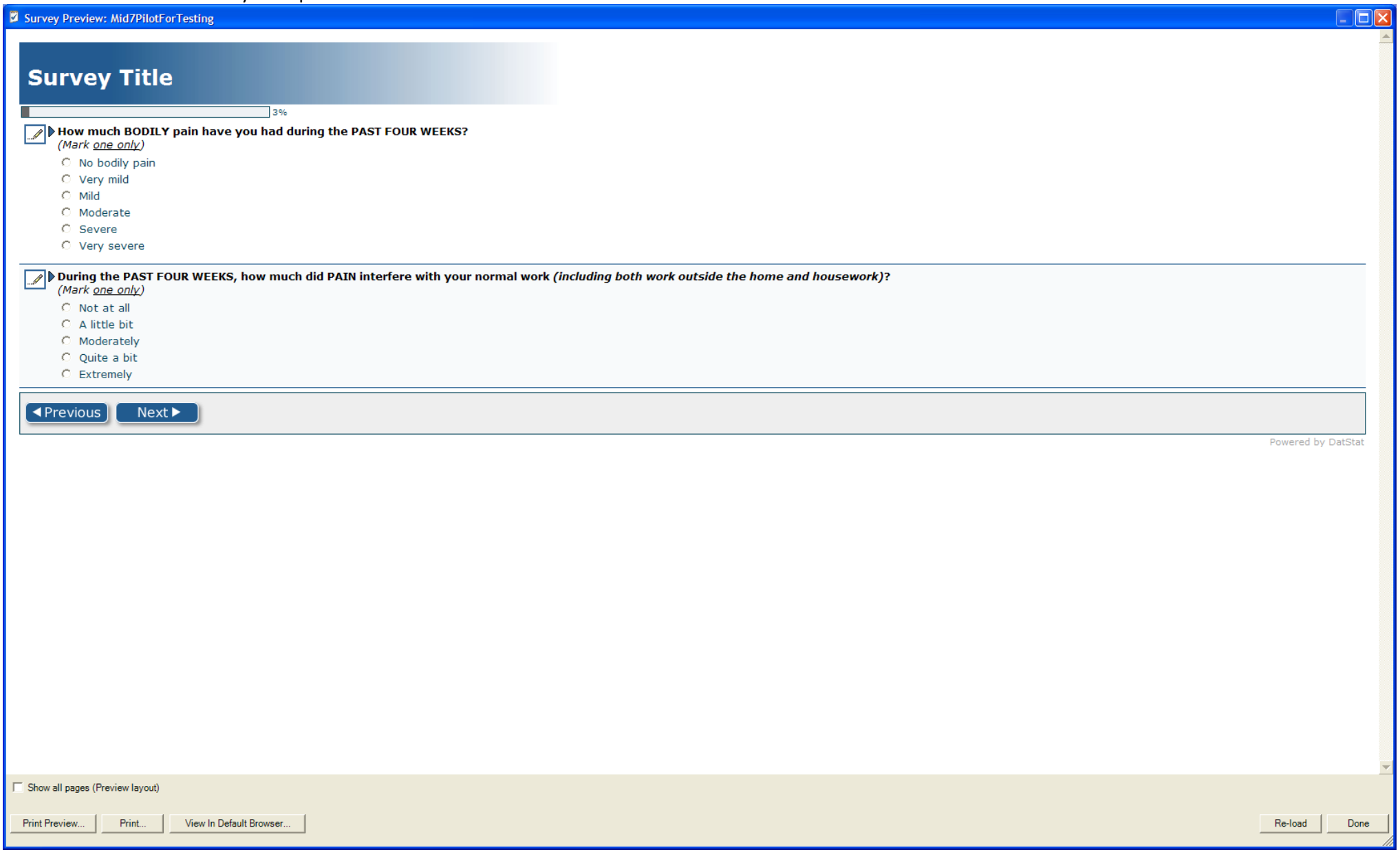

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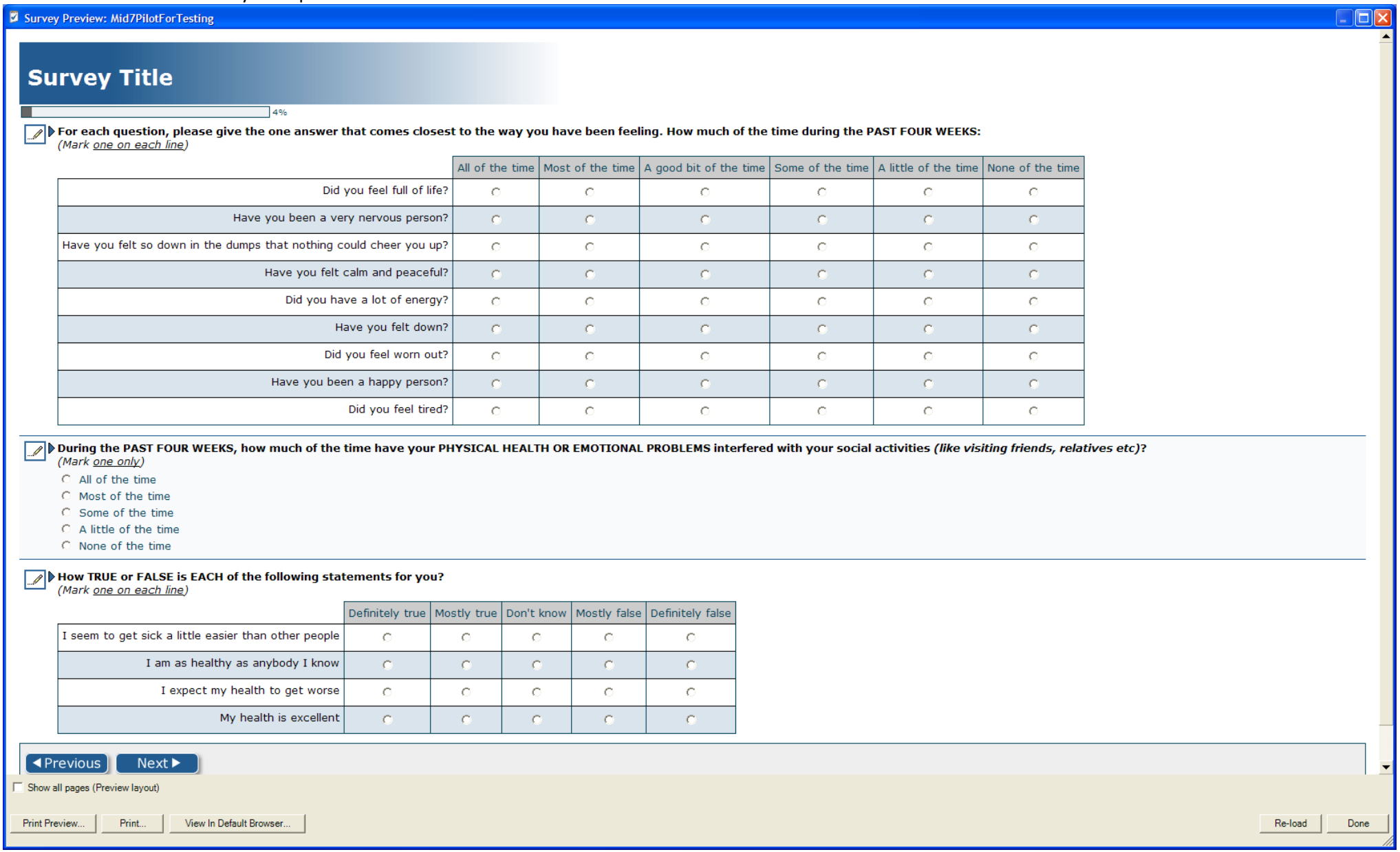

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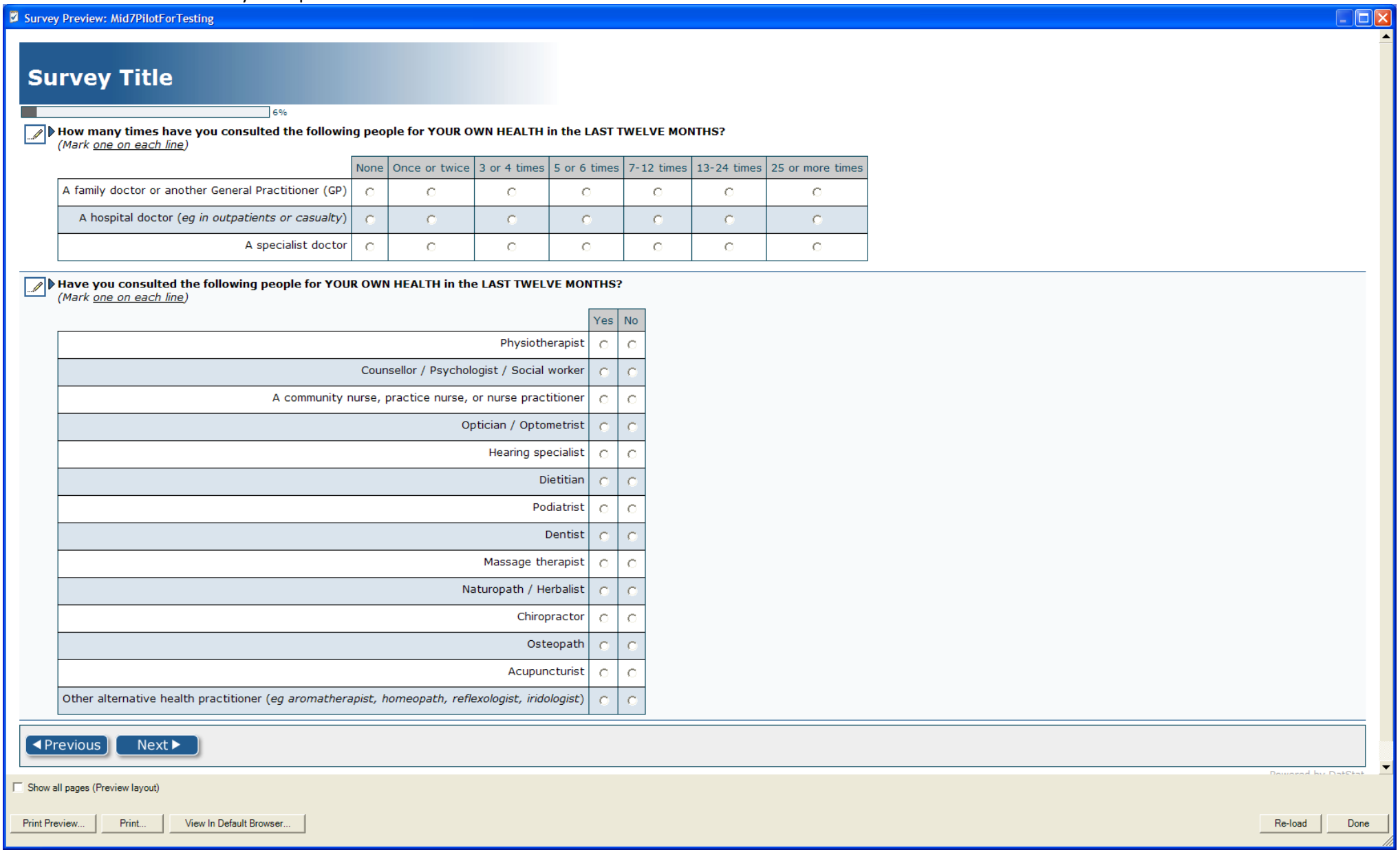

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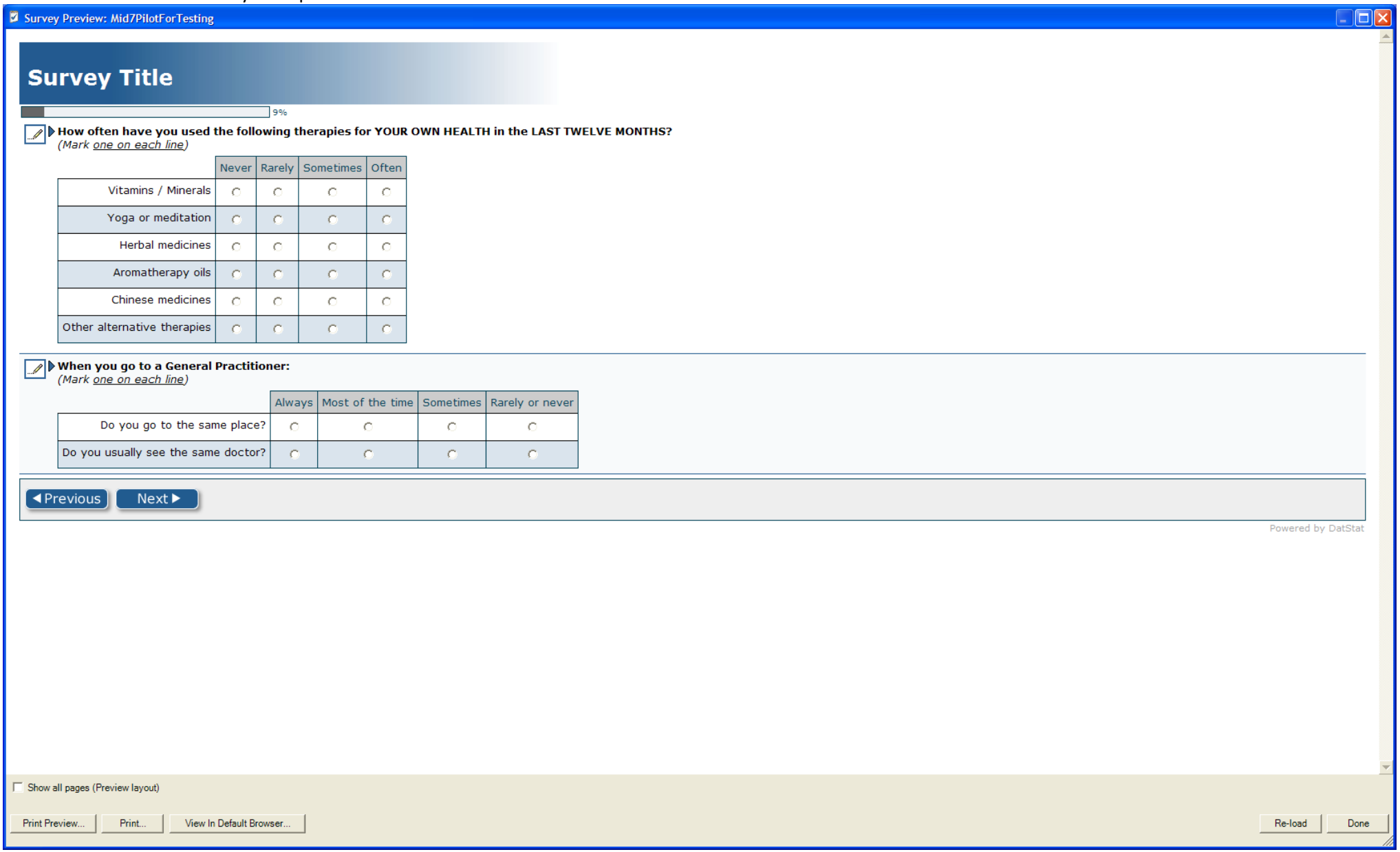

Attachment 14- Online Survey Example

Survey Preview: Mid7PilotForTesting

Survey Title

10%

How would you rate the cost to you of your LAST visit to a General Practitioner?
(*Mark one only*)

- No cost to me
- Good
- Fair
- Poor
- Don't know

Do you have a Health Care Card?
This is a card that entitles you to discounts and assistance with medical expenses. This is not the same as a Medicare card.

(*Mark one only*)

- Yes
- No

Do you have private health insurance for HOSPITAL COVER?
(*Mark one only*)

- Yes
- No - I am covered by Veterans' Affairs
- No - other reason

Do you have private health insurance for ANCILLARY services (eg dental, physiotherapy)?
(*Mark one only*)

- Yes
- No - I am covered by Veterans' Affairs
- No - other reason

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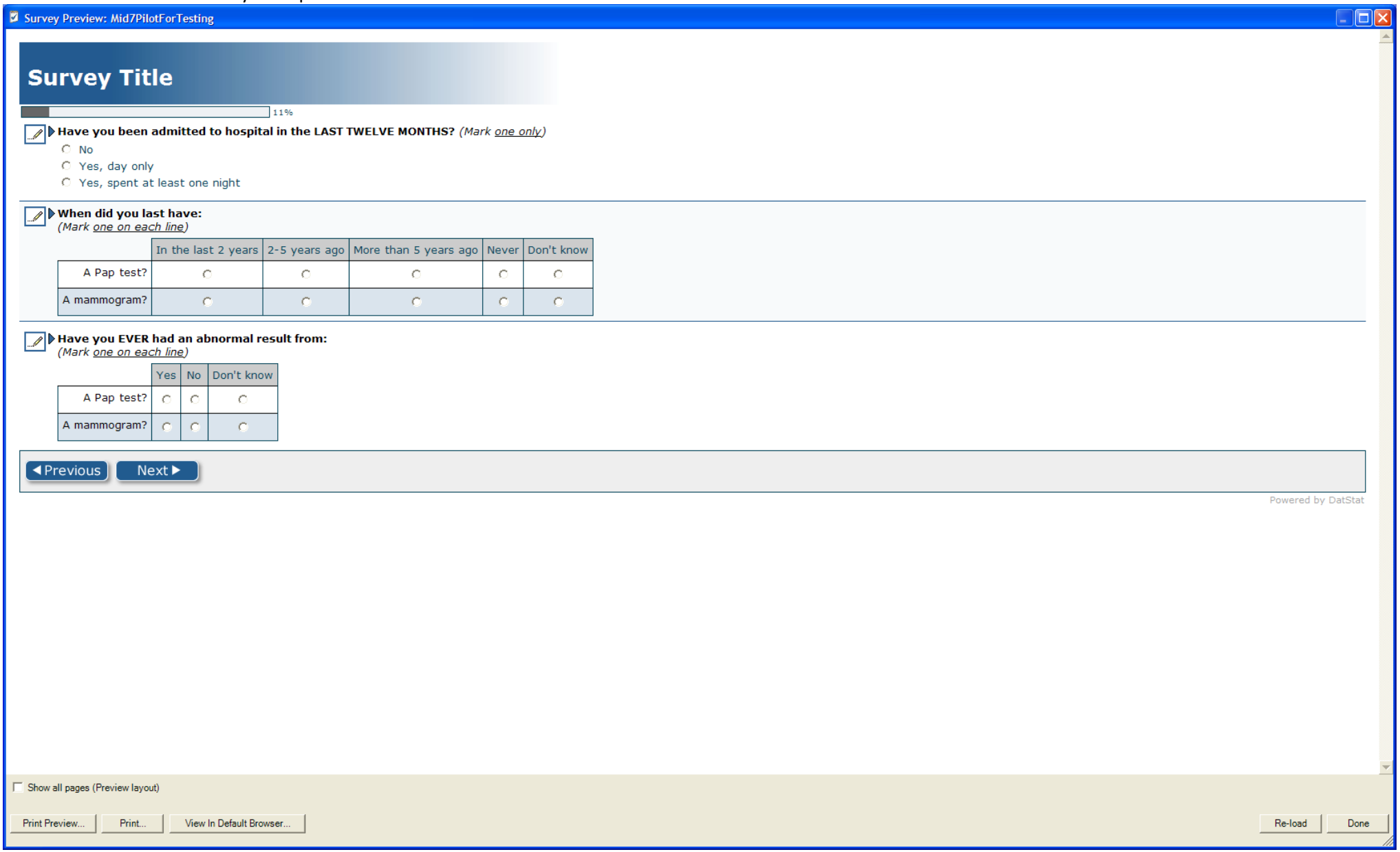
Attachment 14- Online Survey Example



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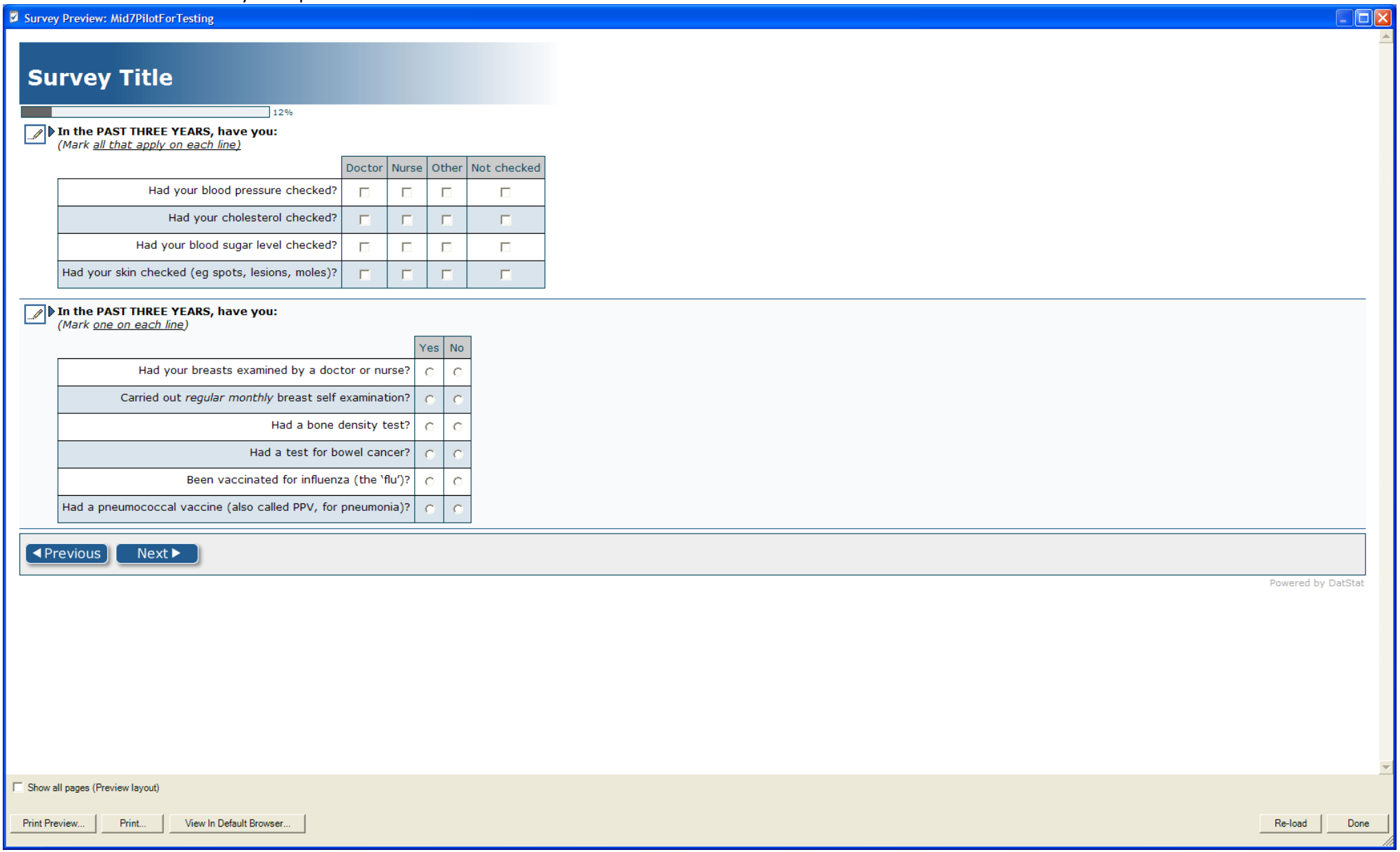

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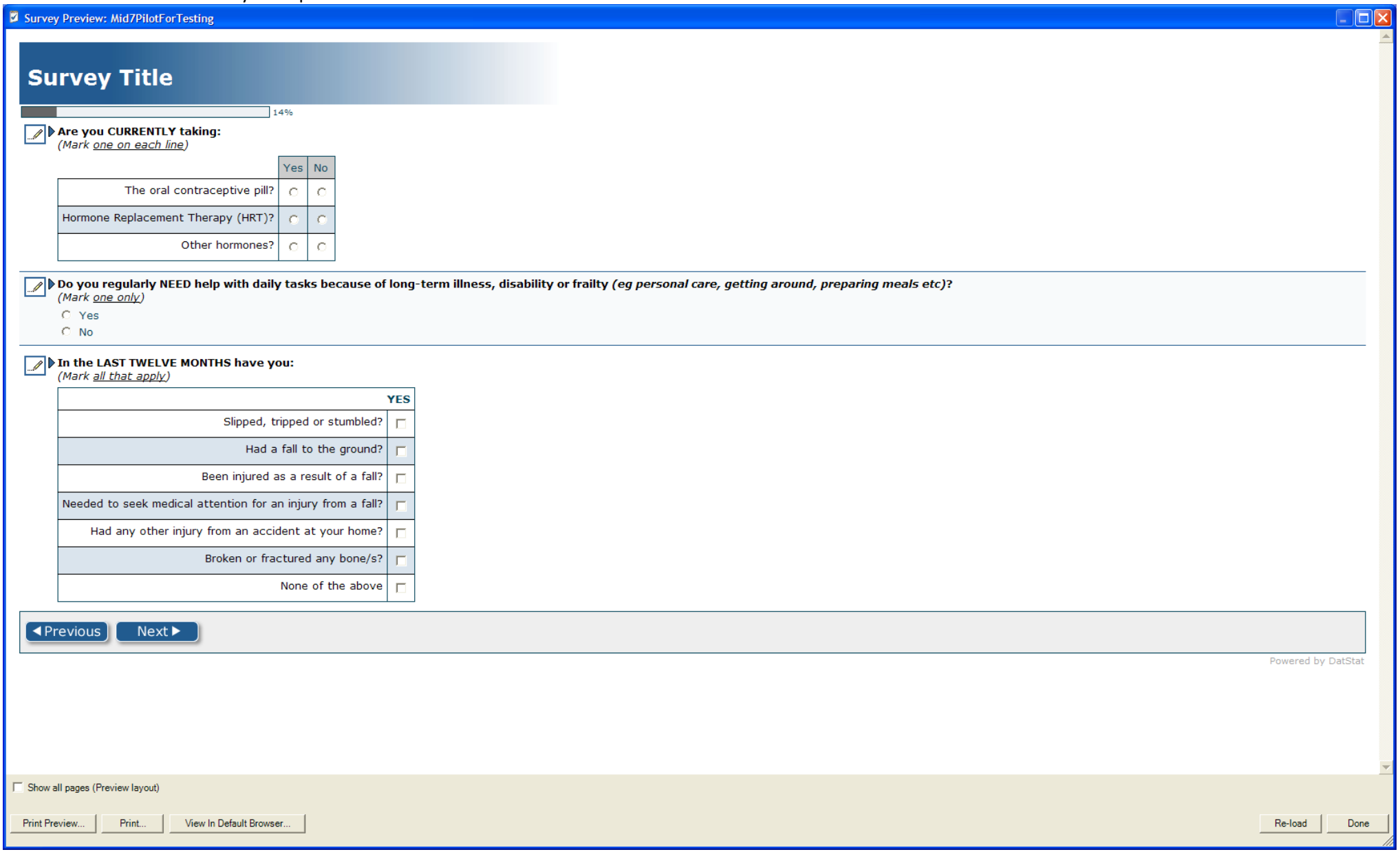

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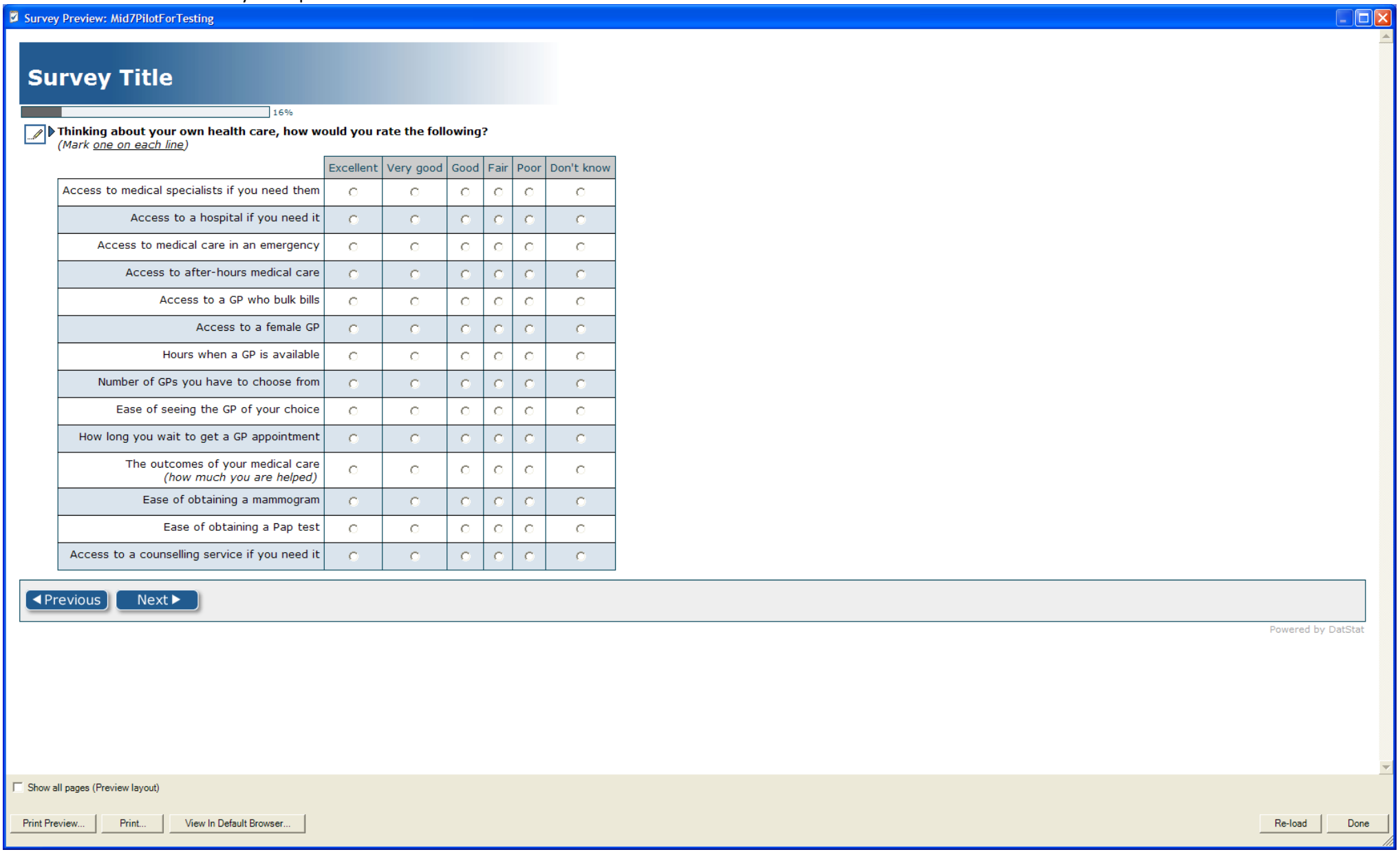

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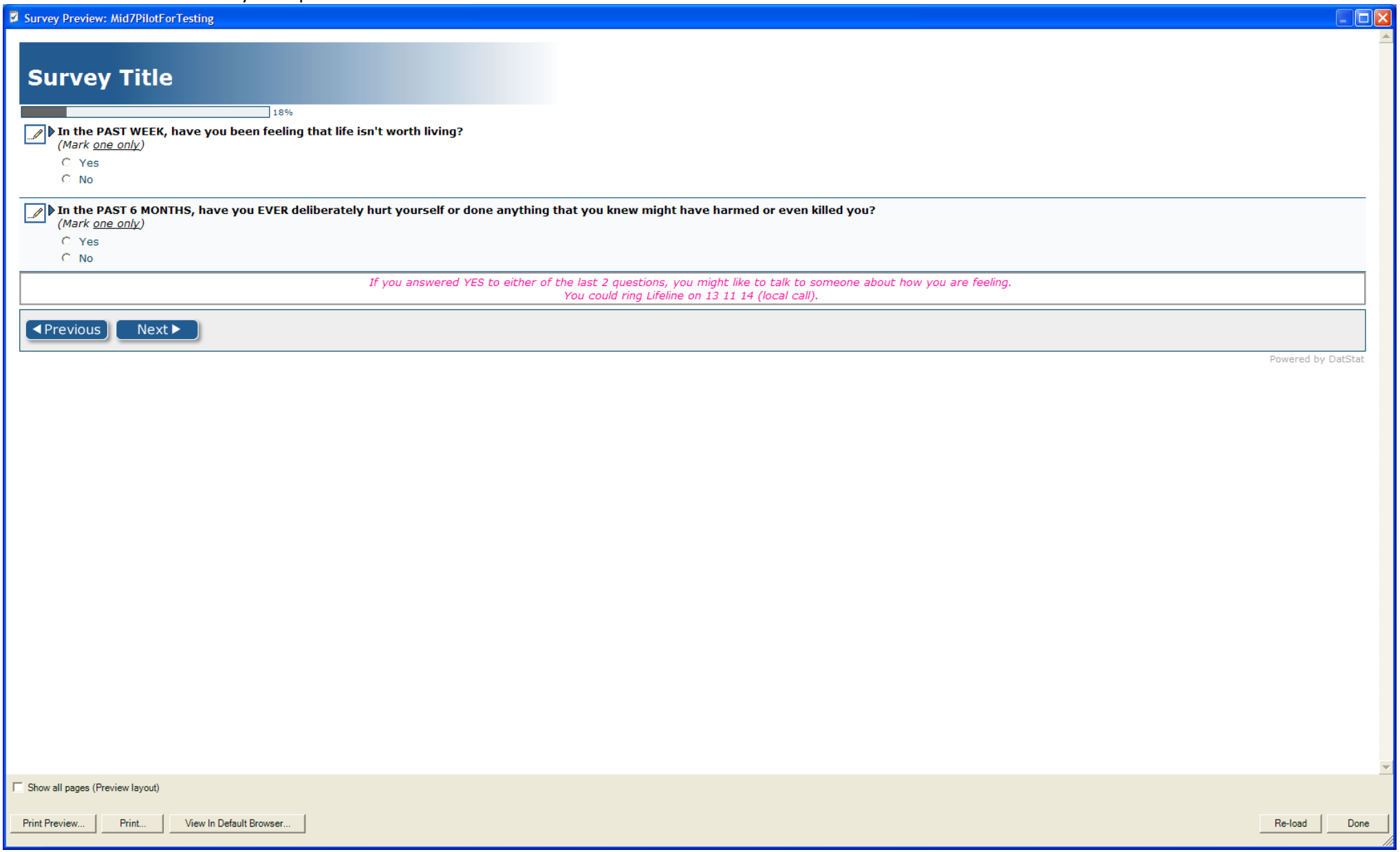

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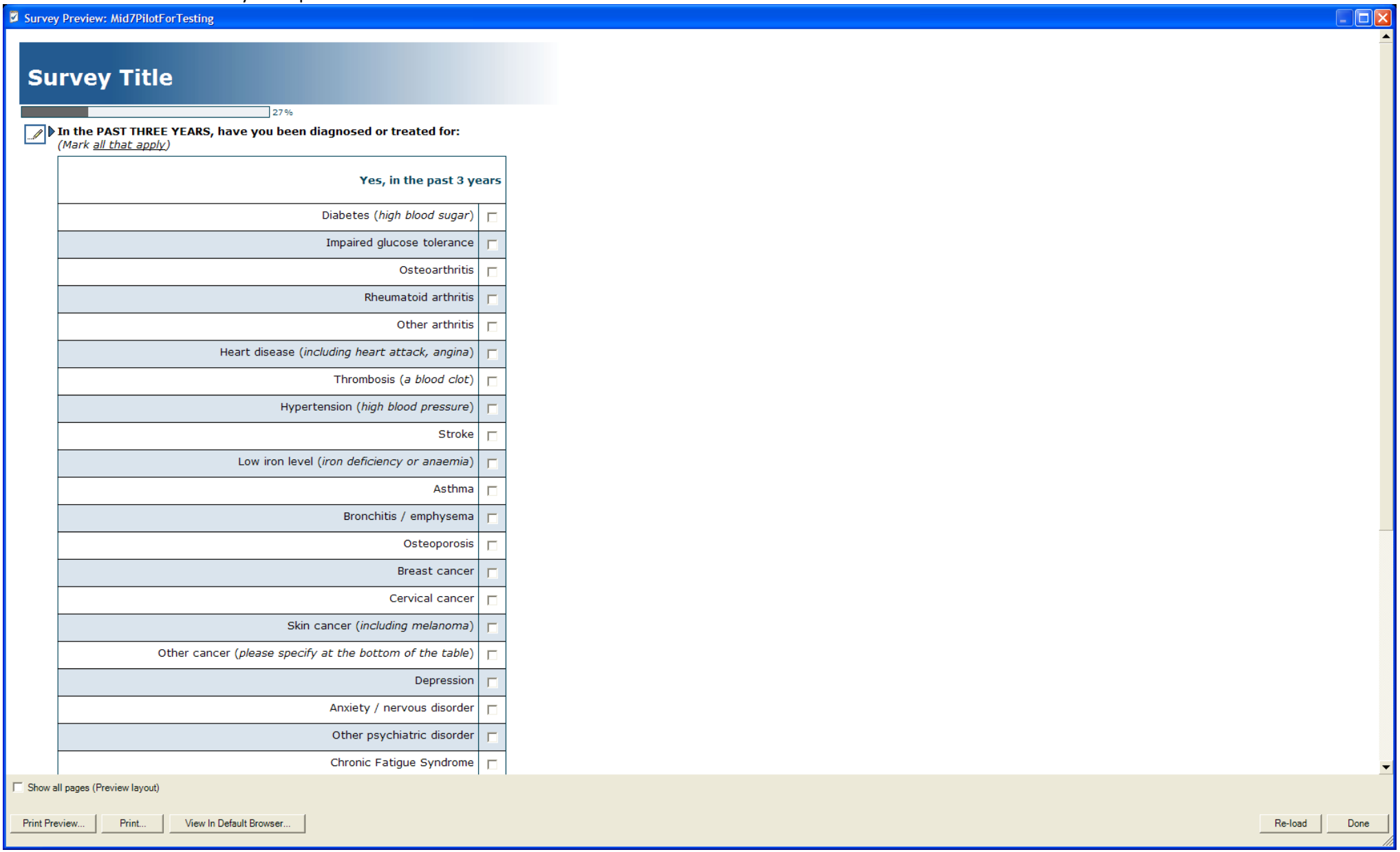

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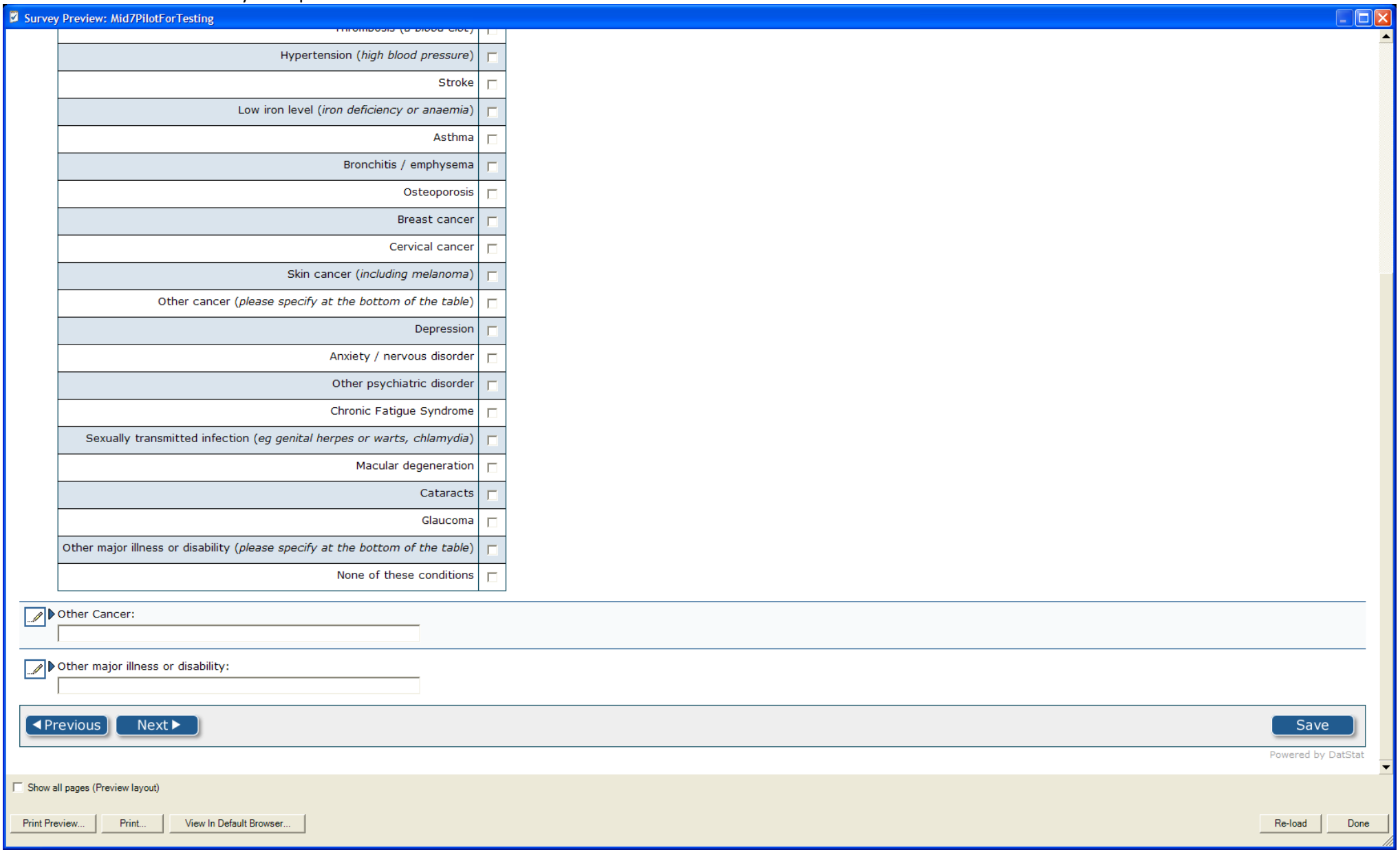

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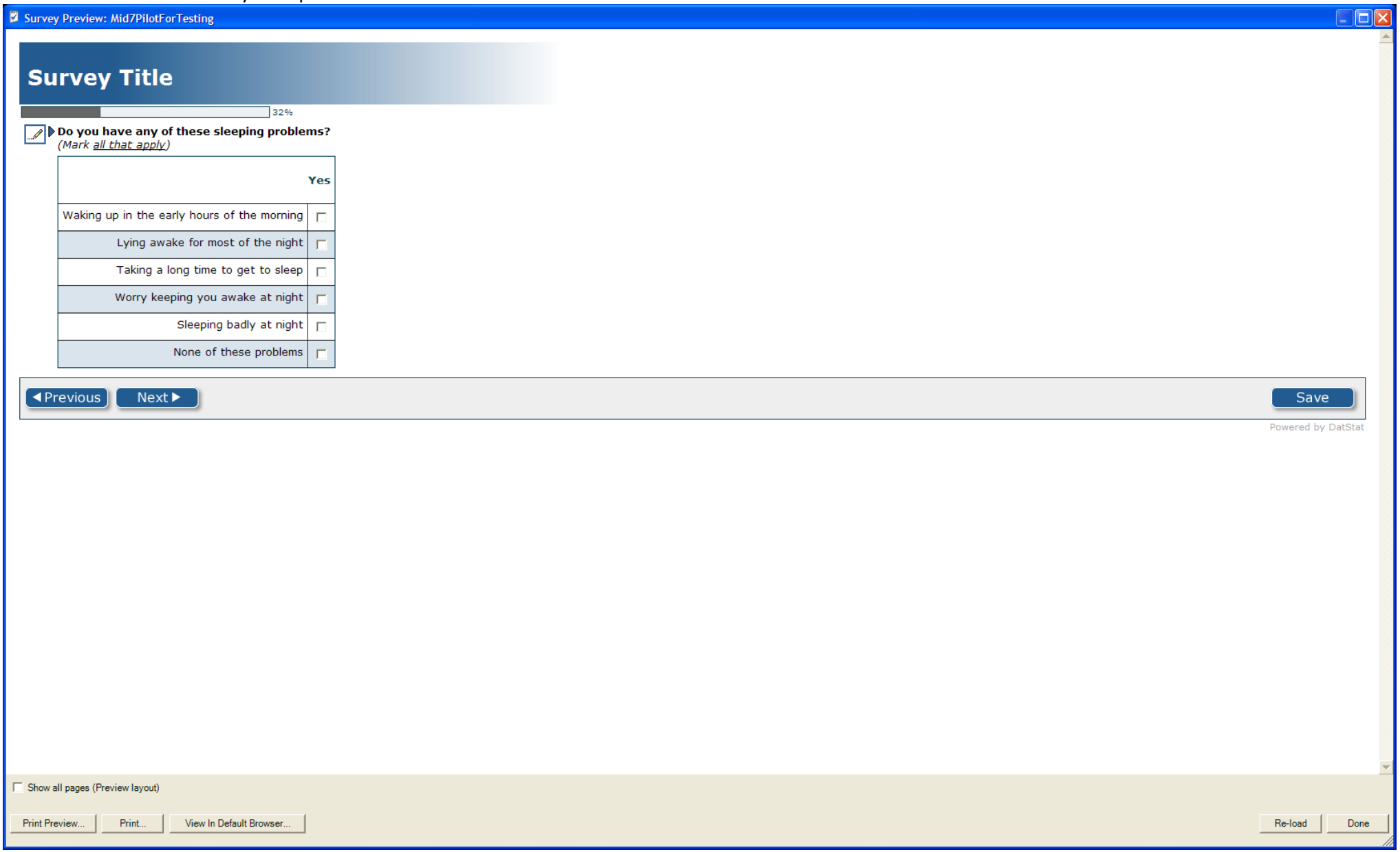

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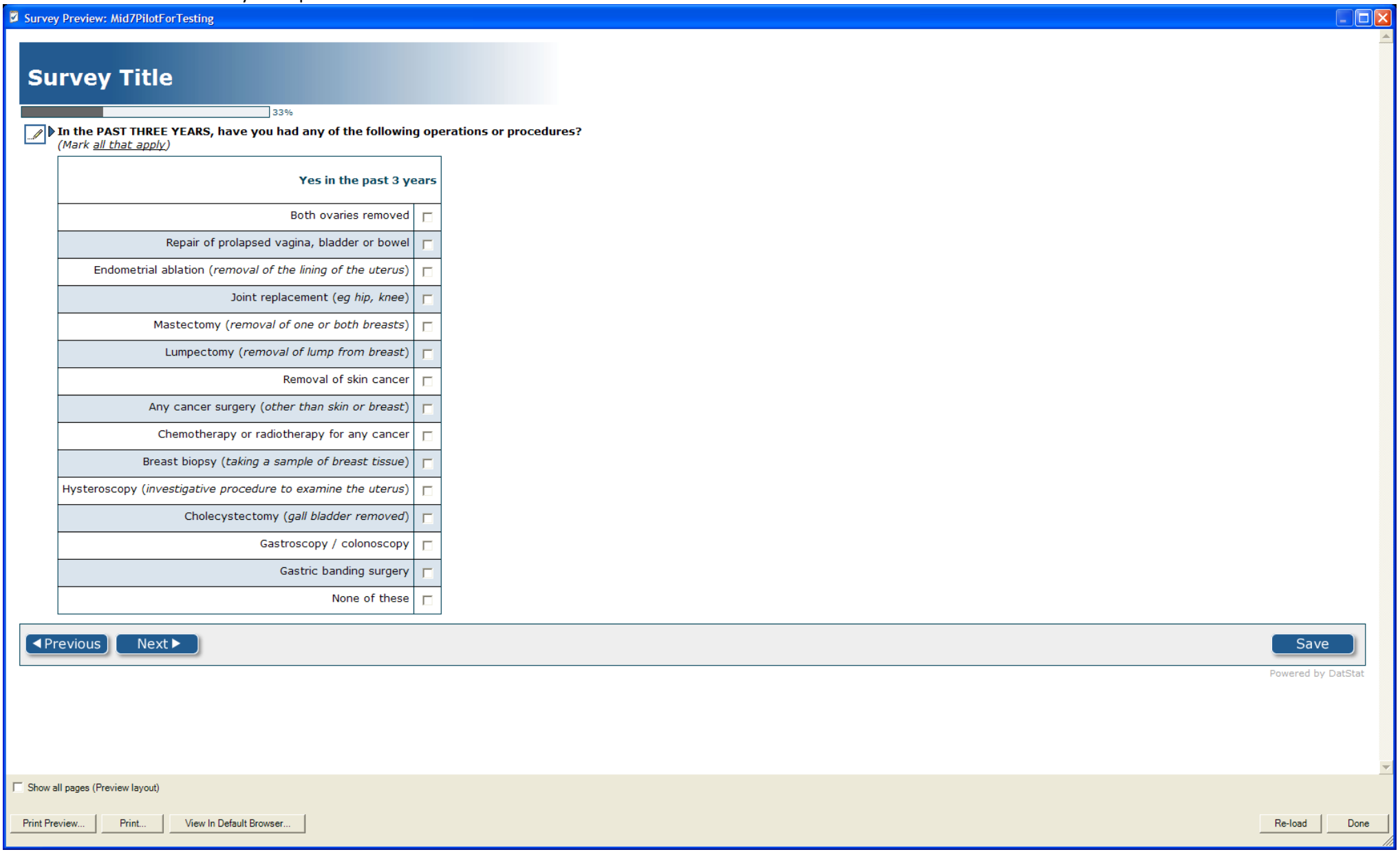

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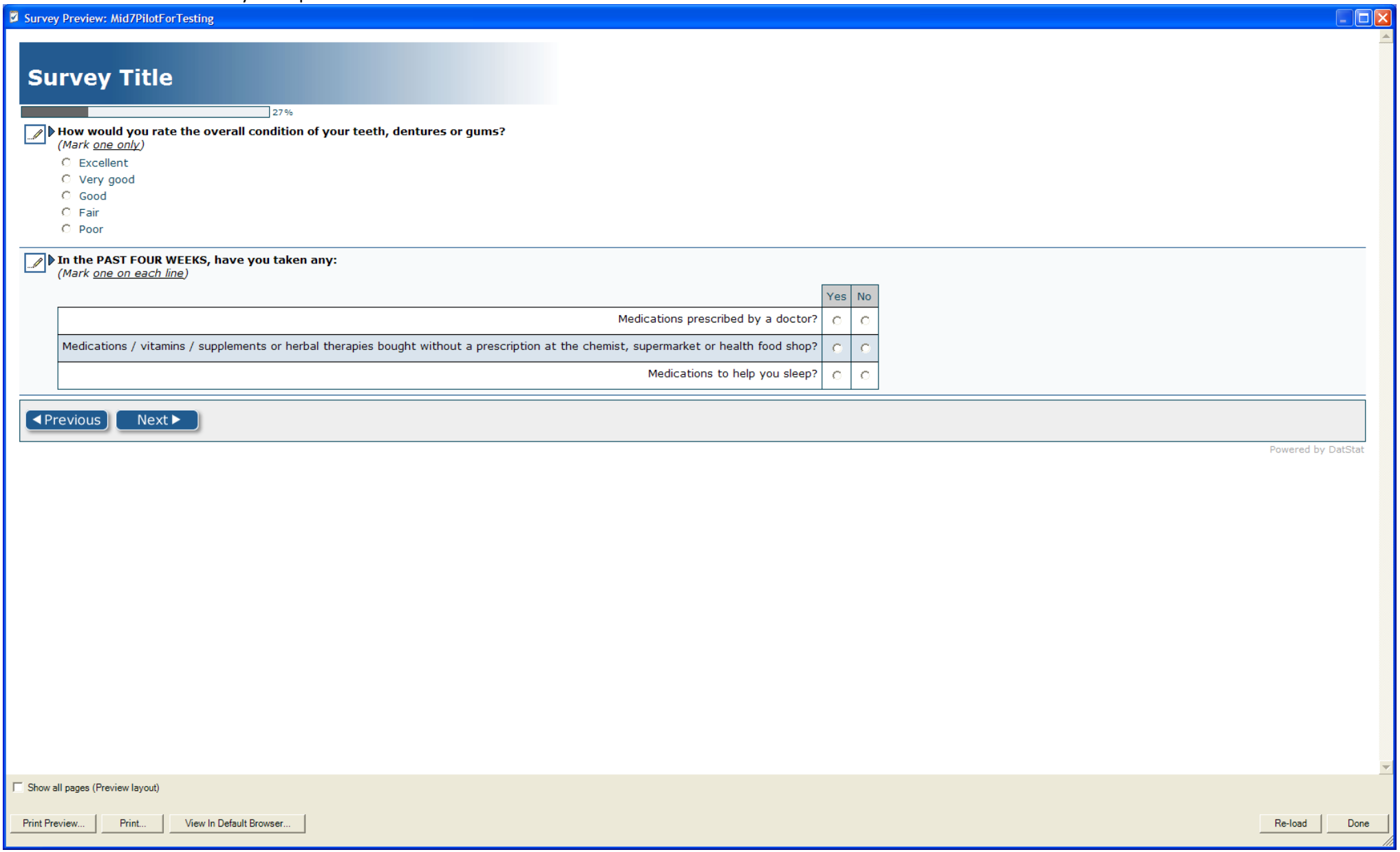

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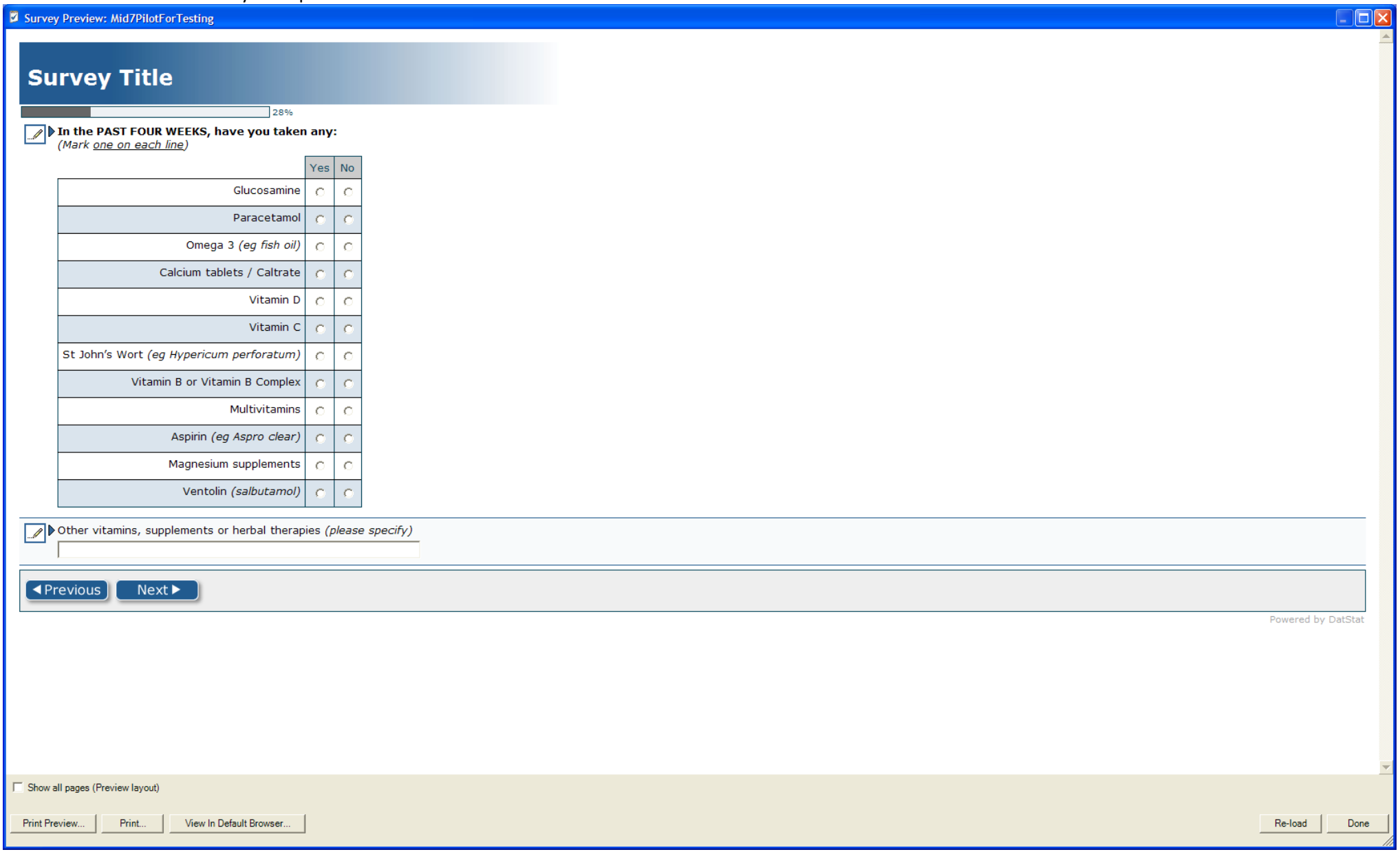

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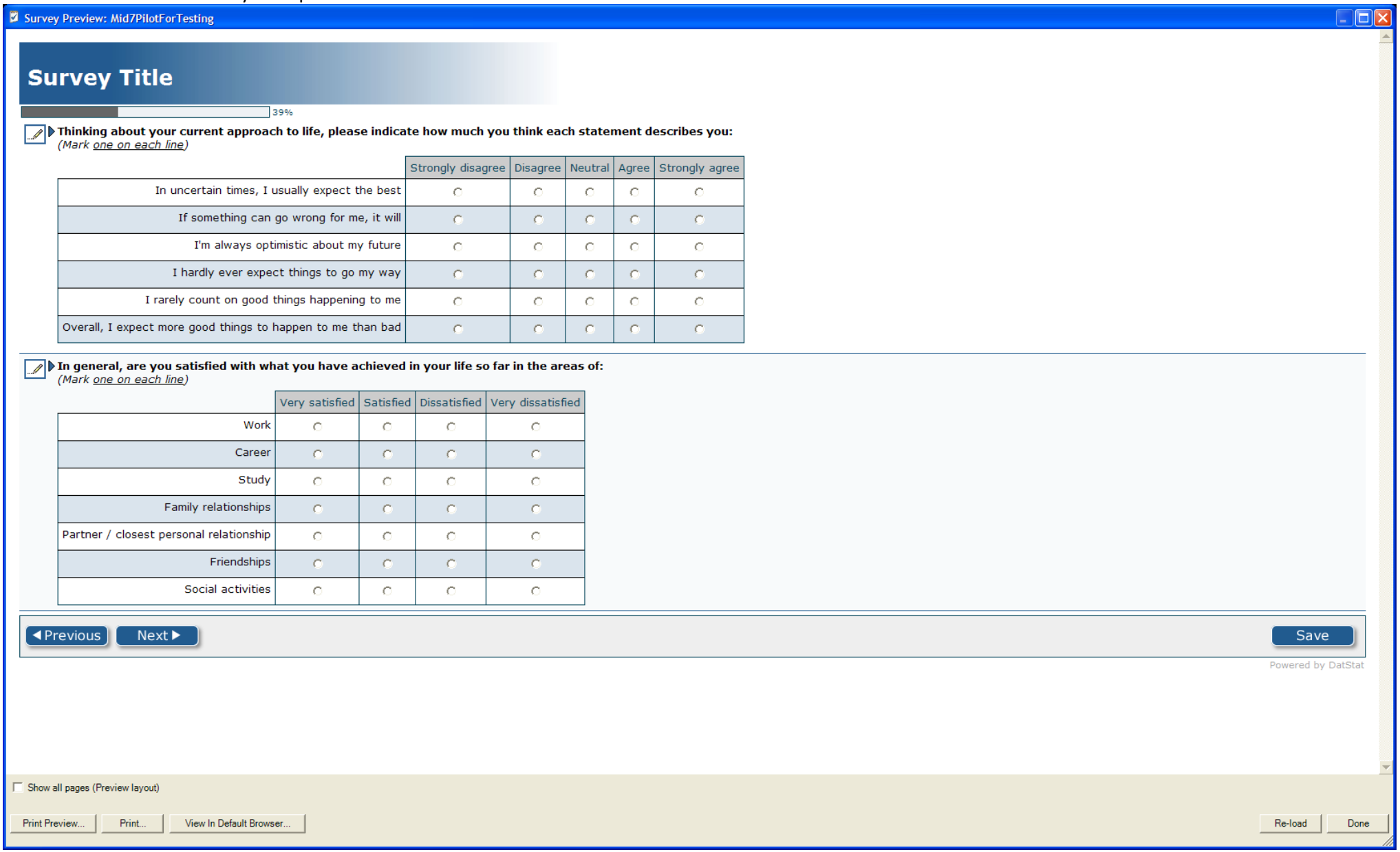

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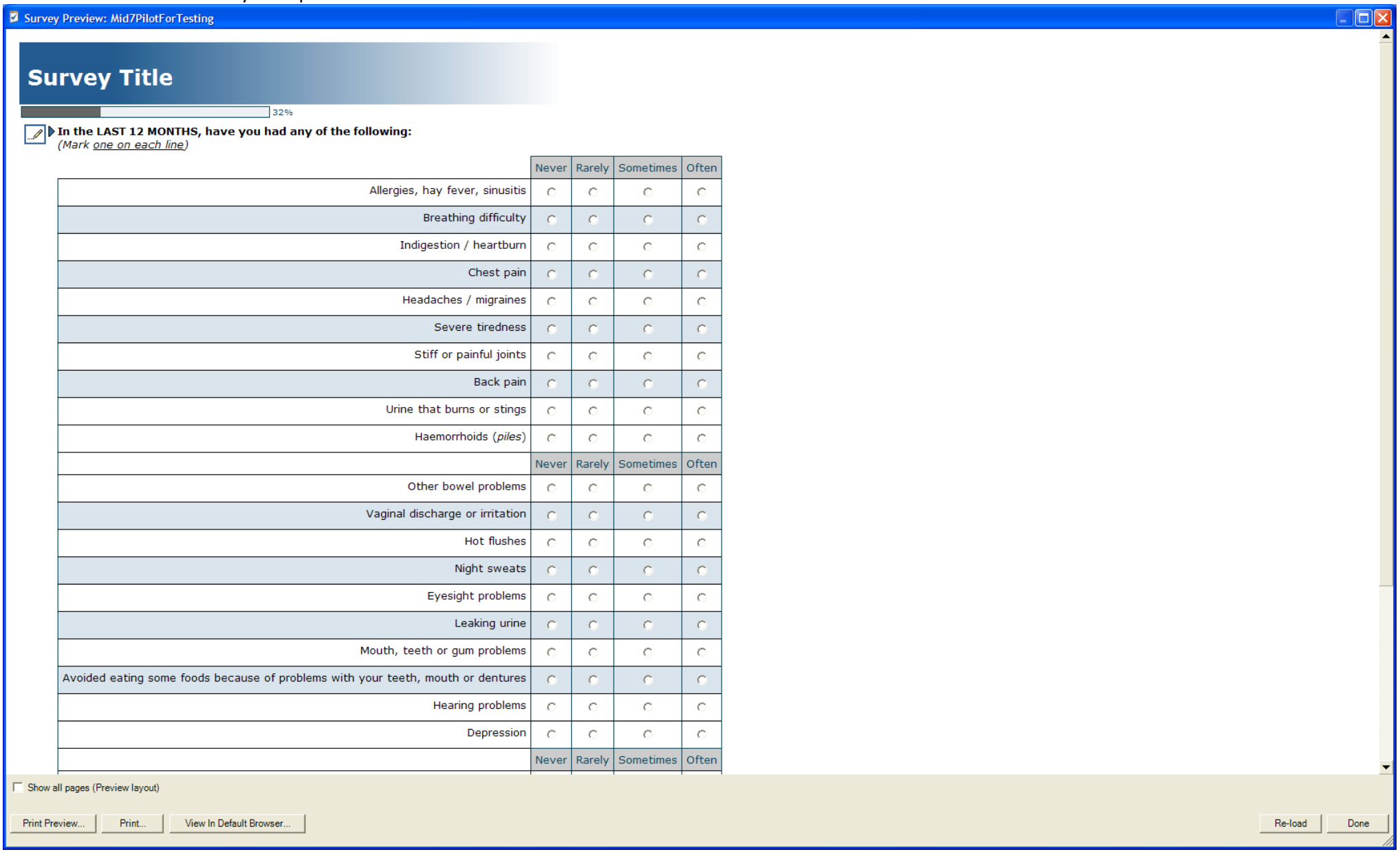

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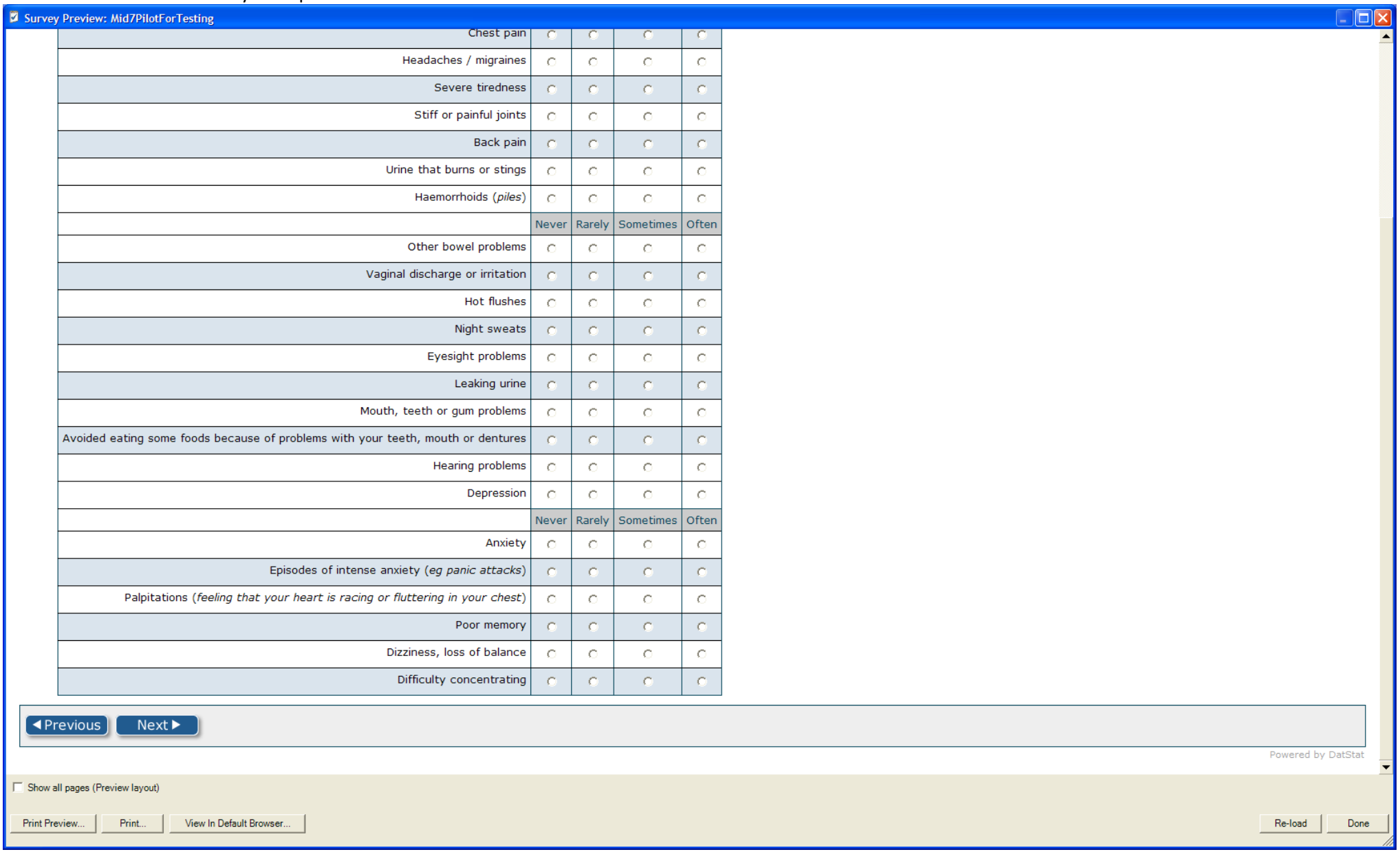

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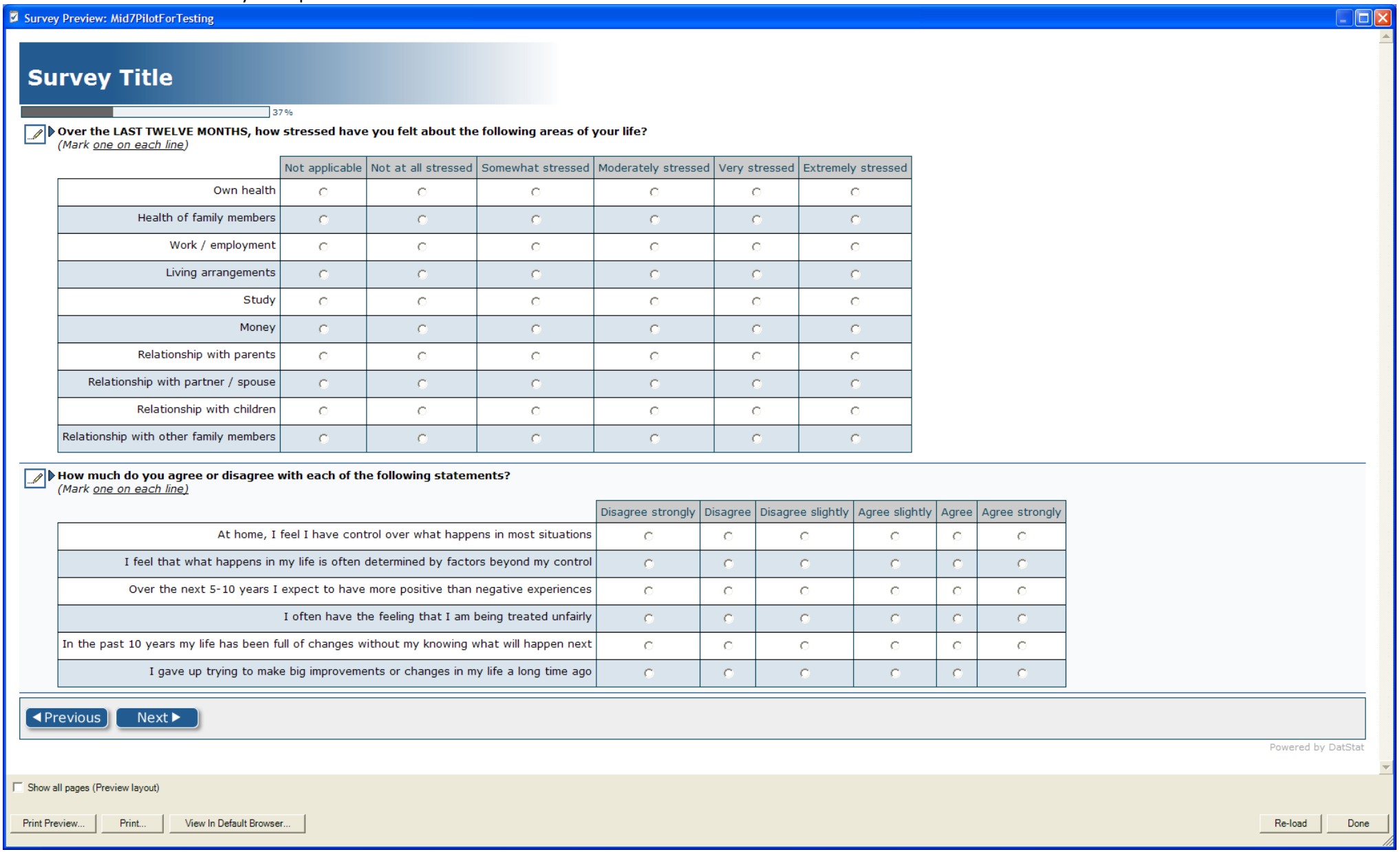

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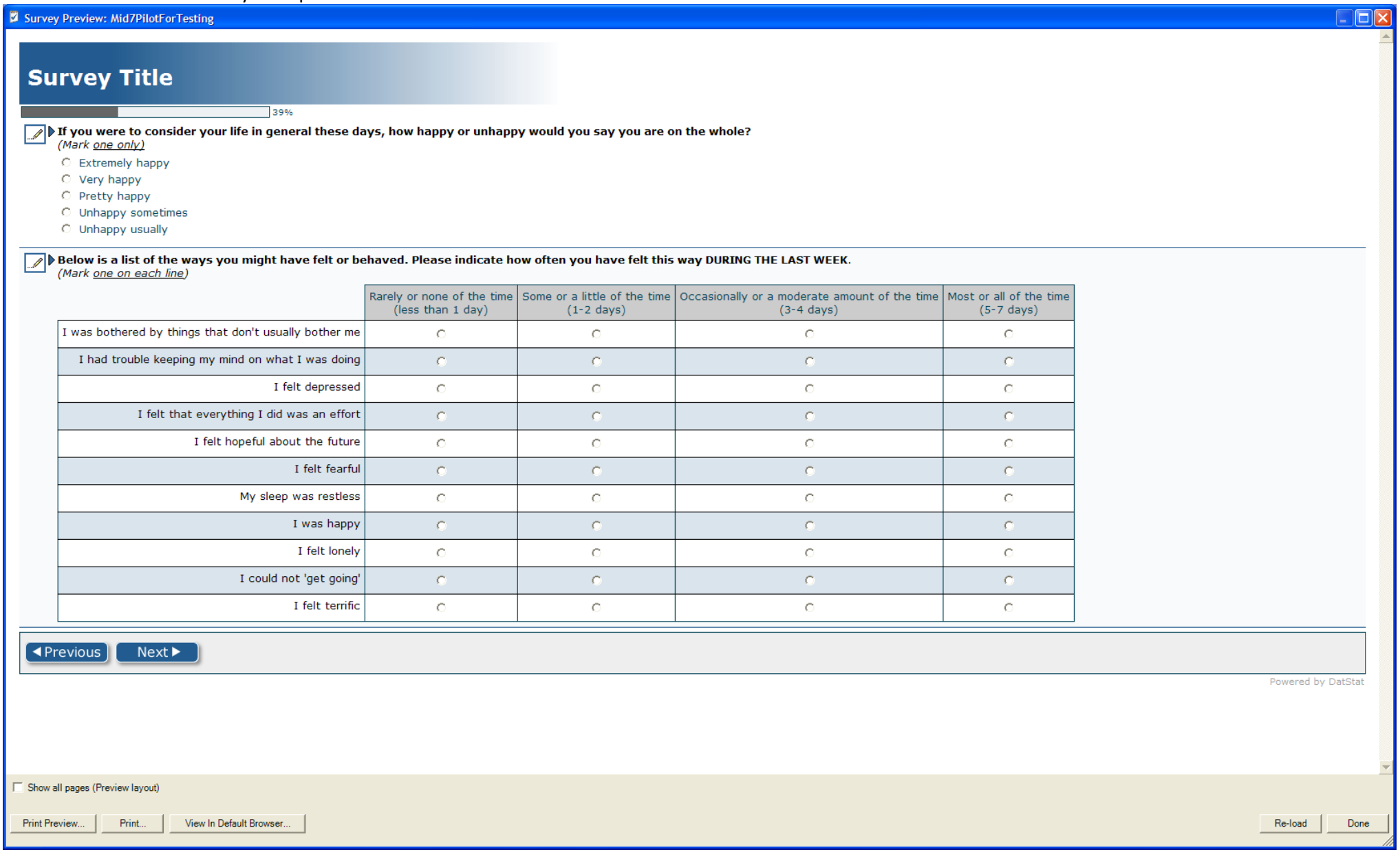

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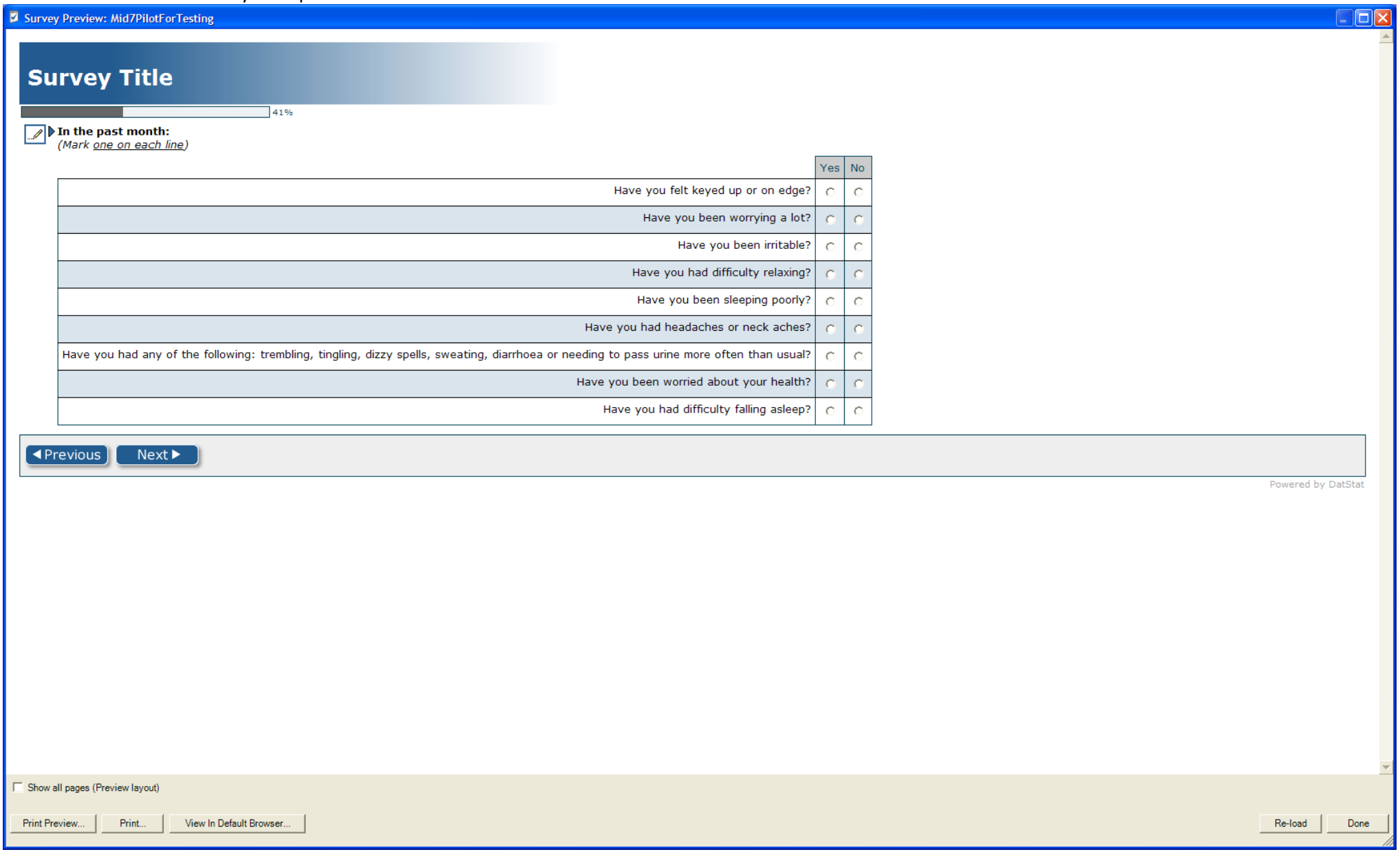

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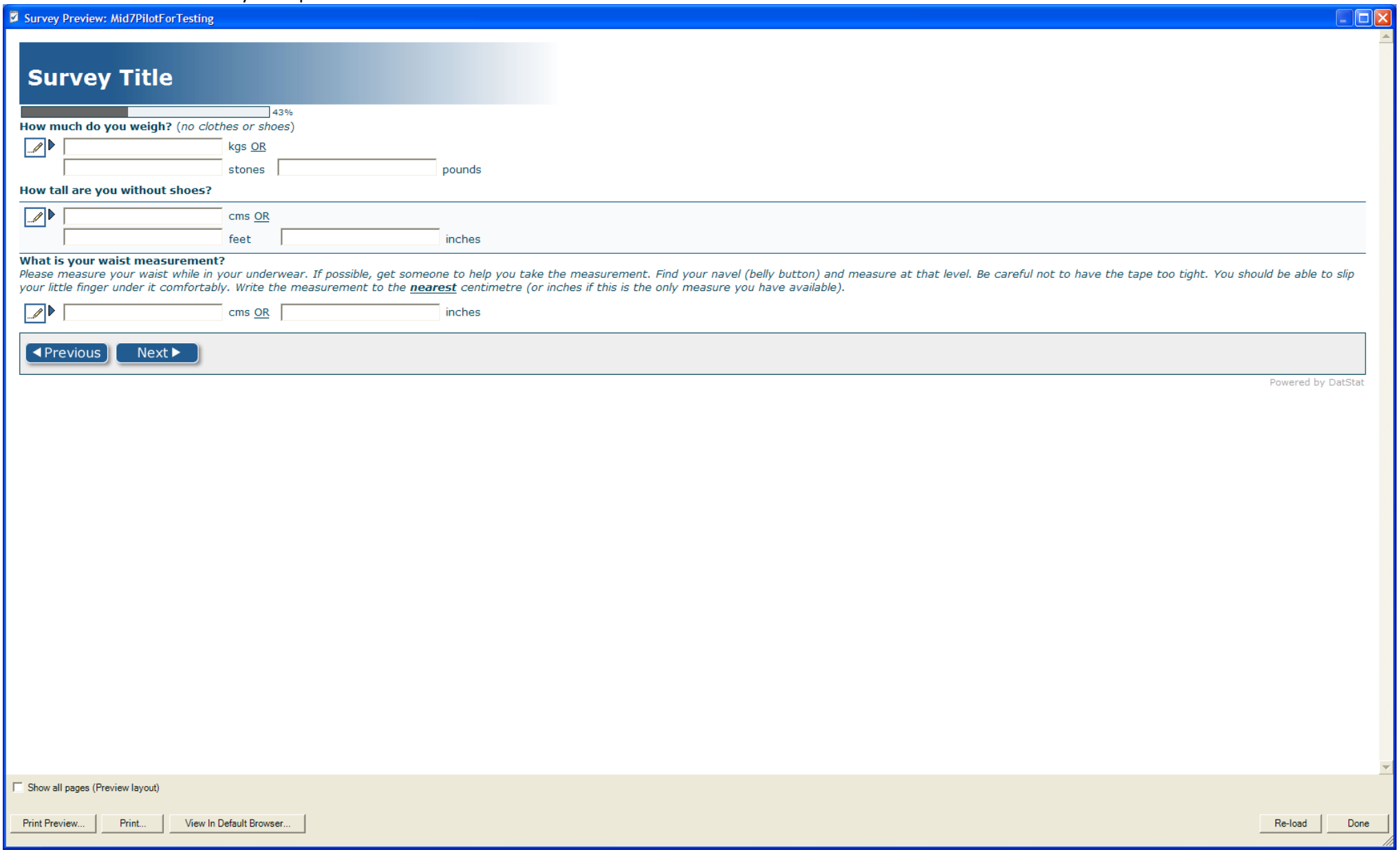

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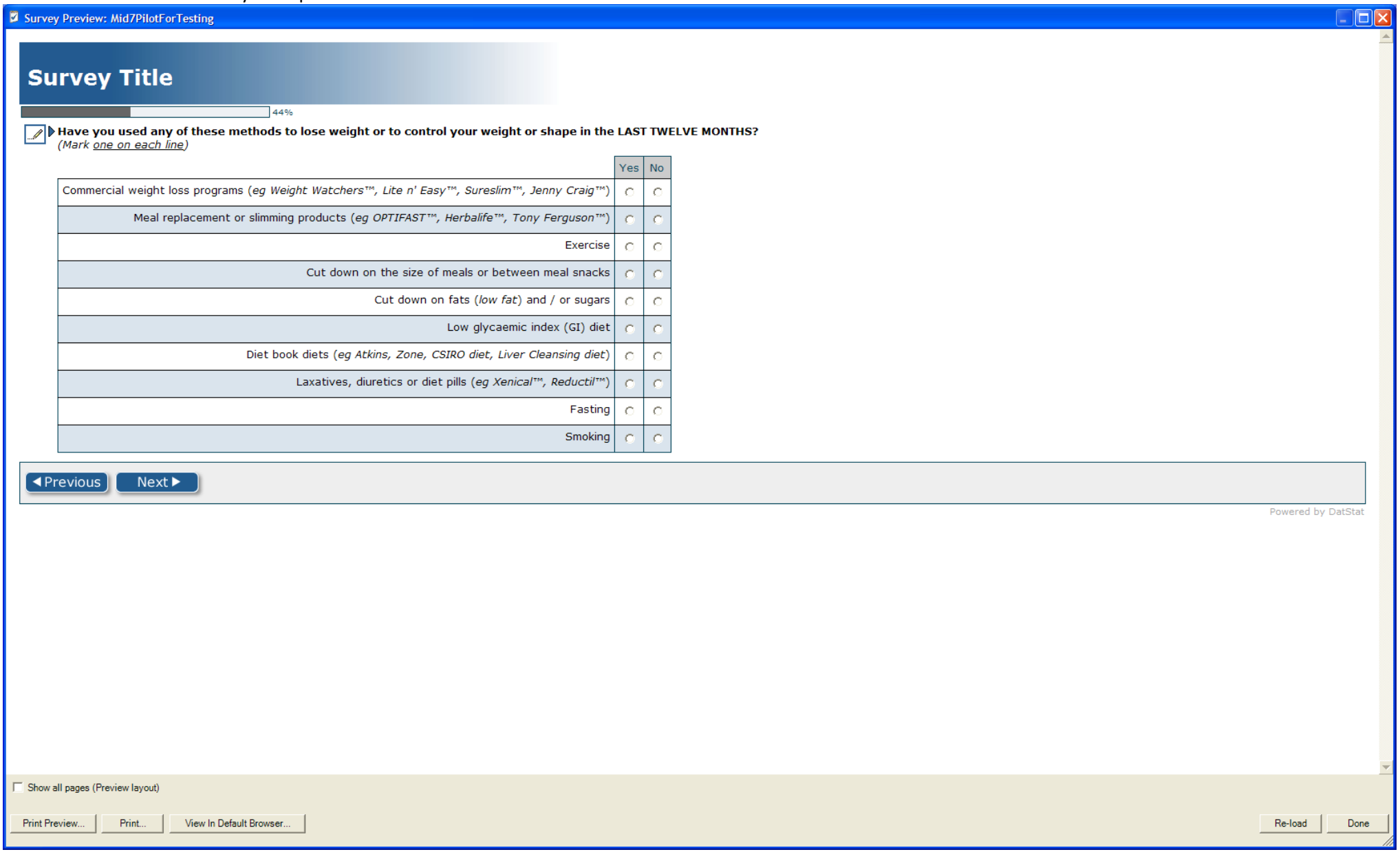

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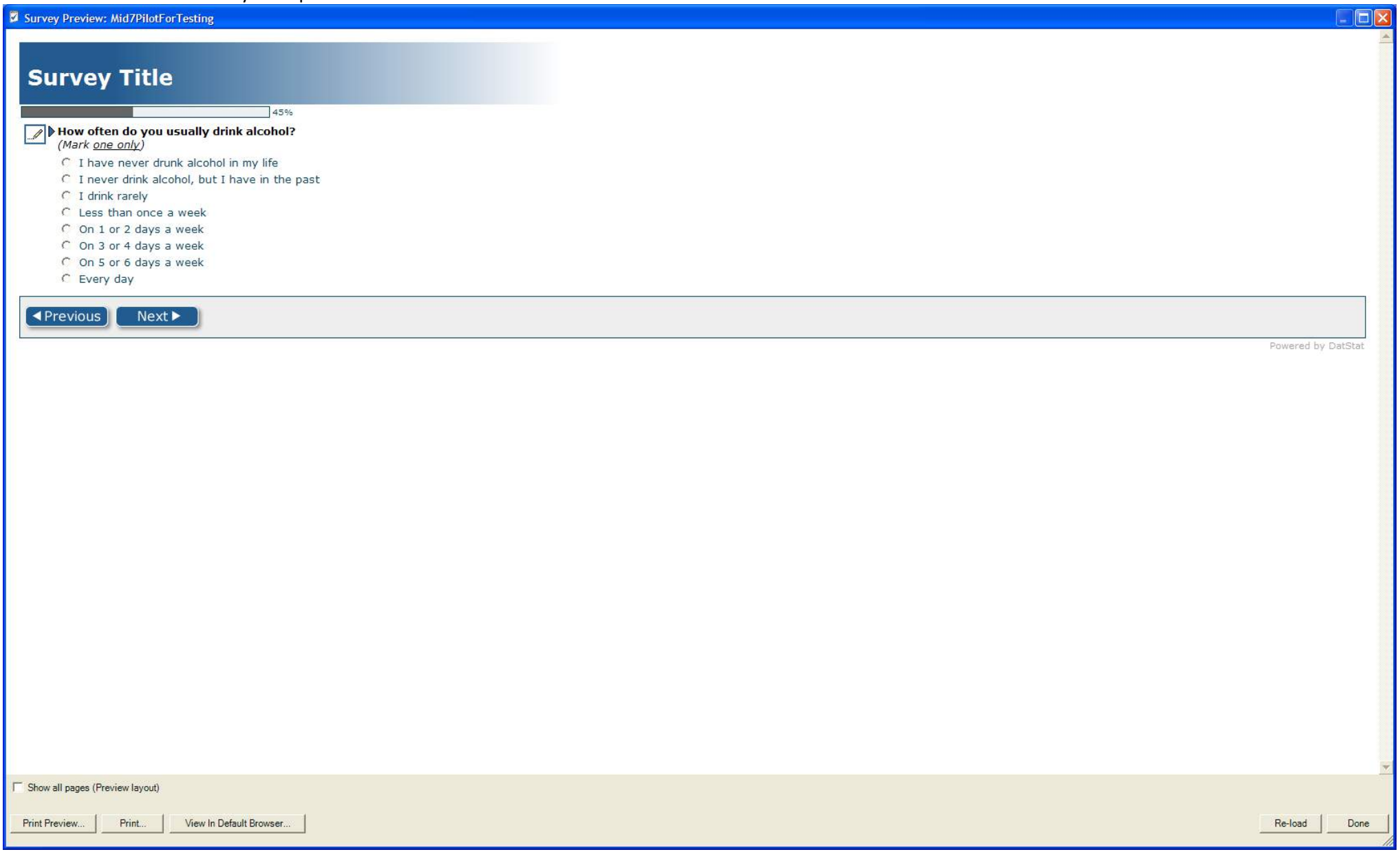

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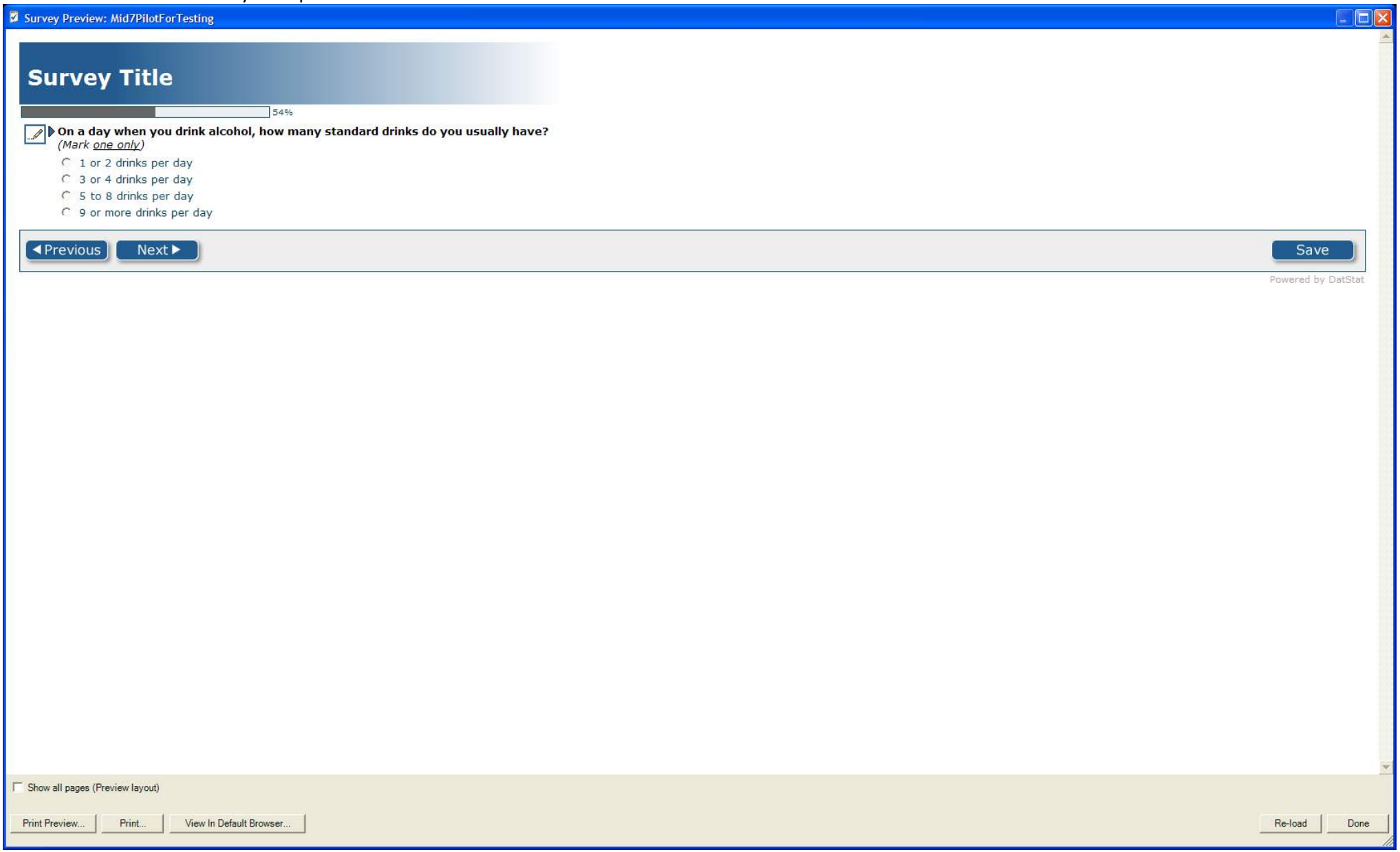

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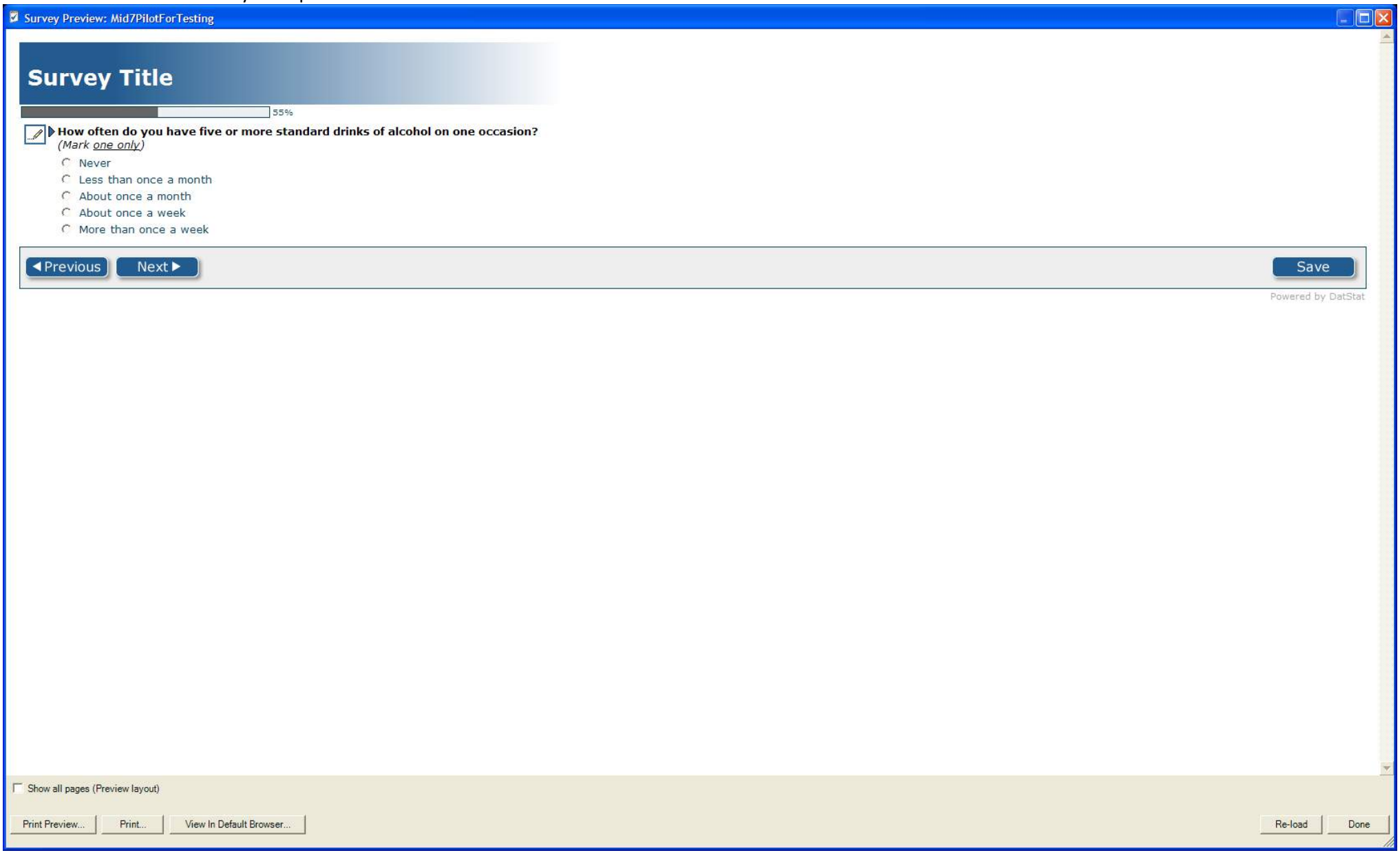

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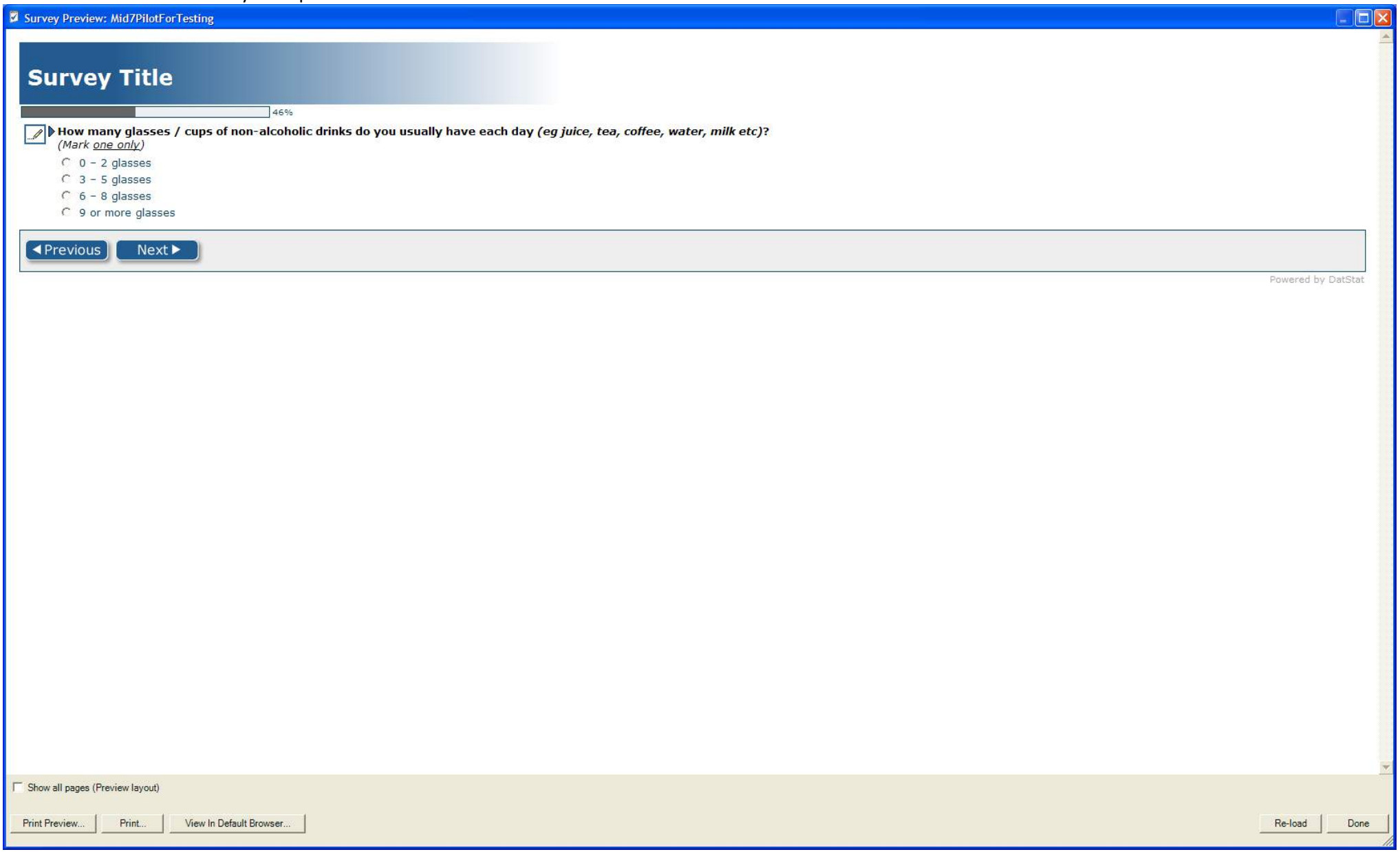

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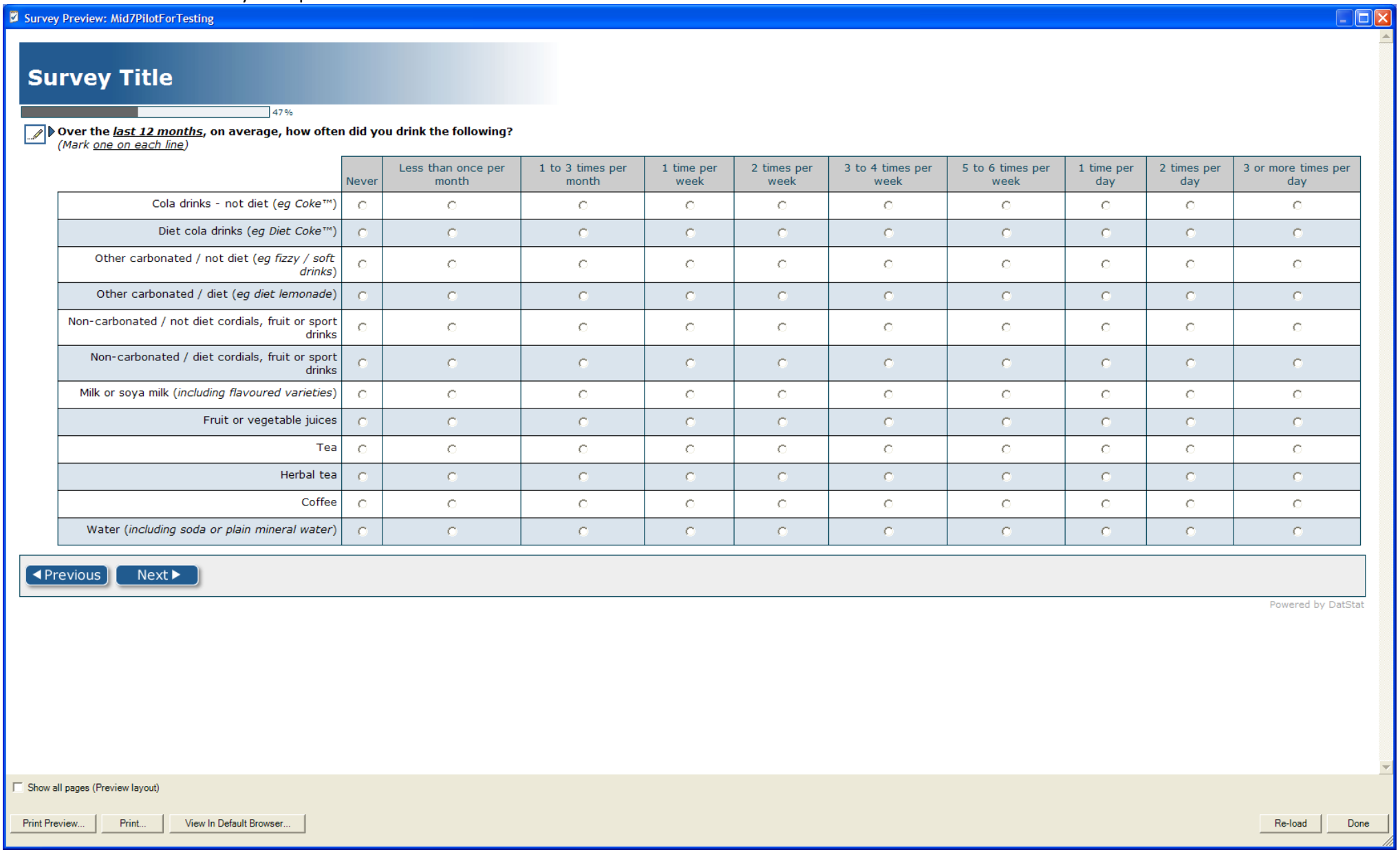

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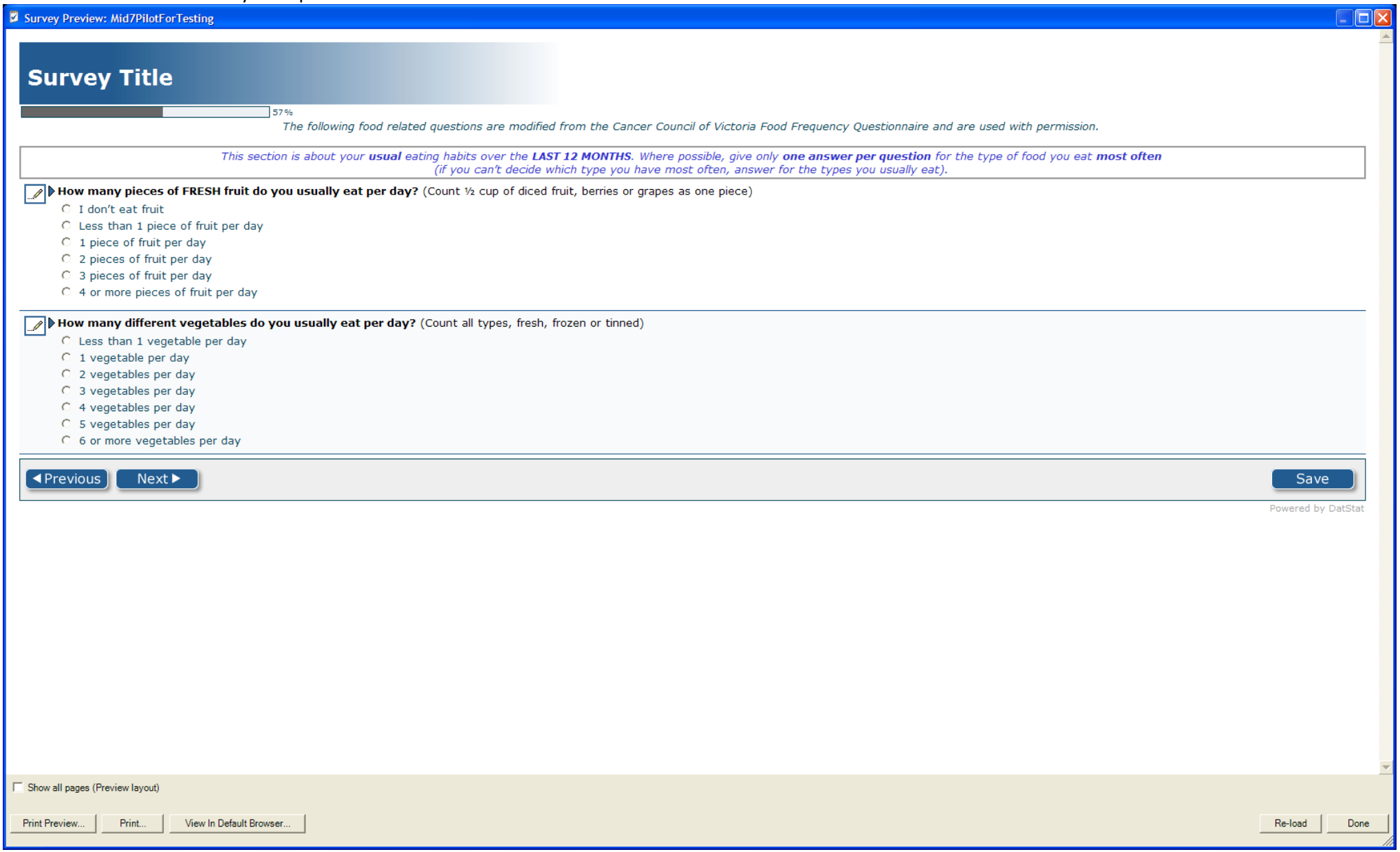

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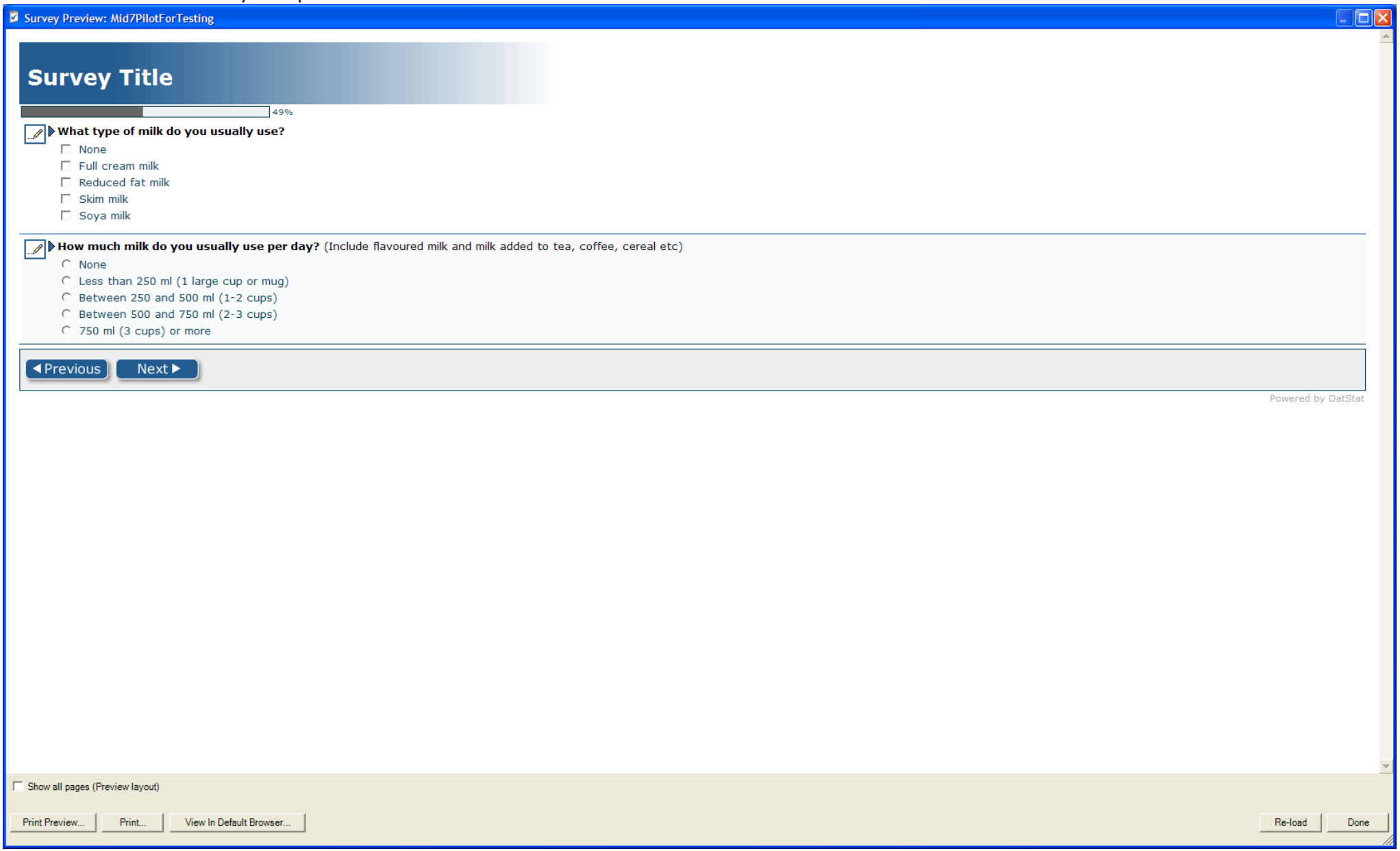

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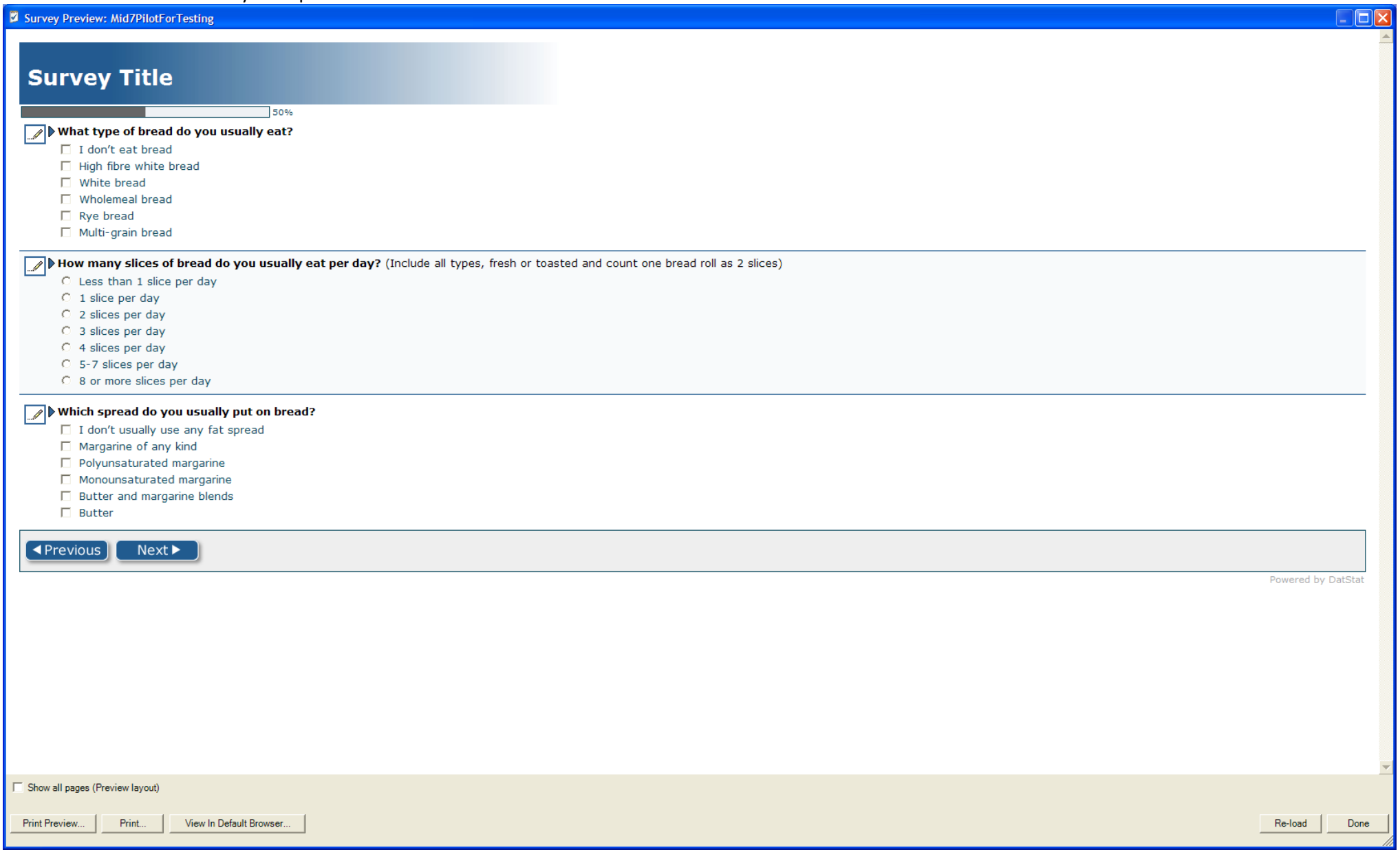

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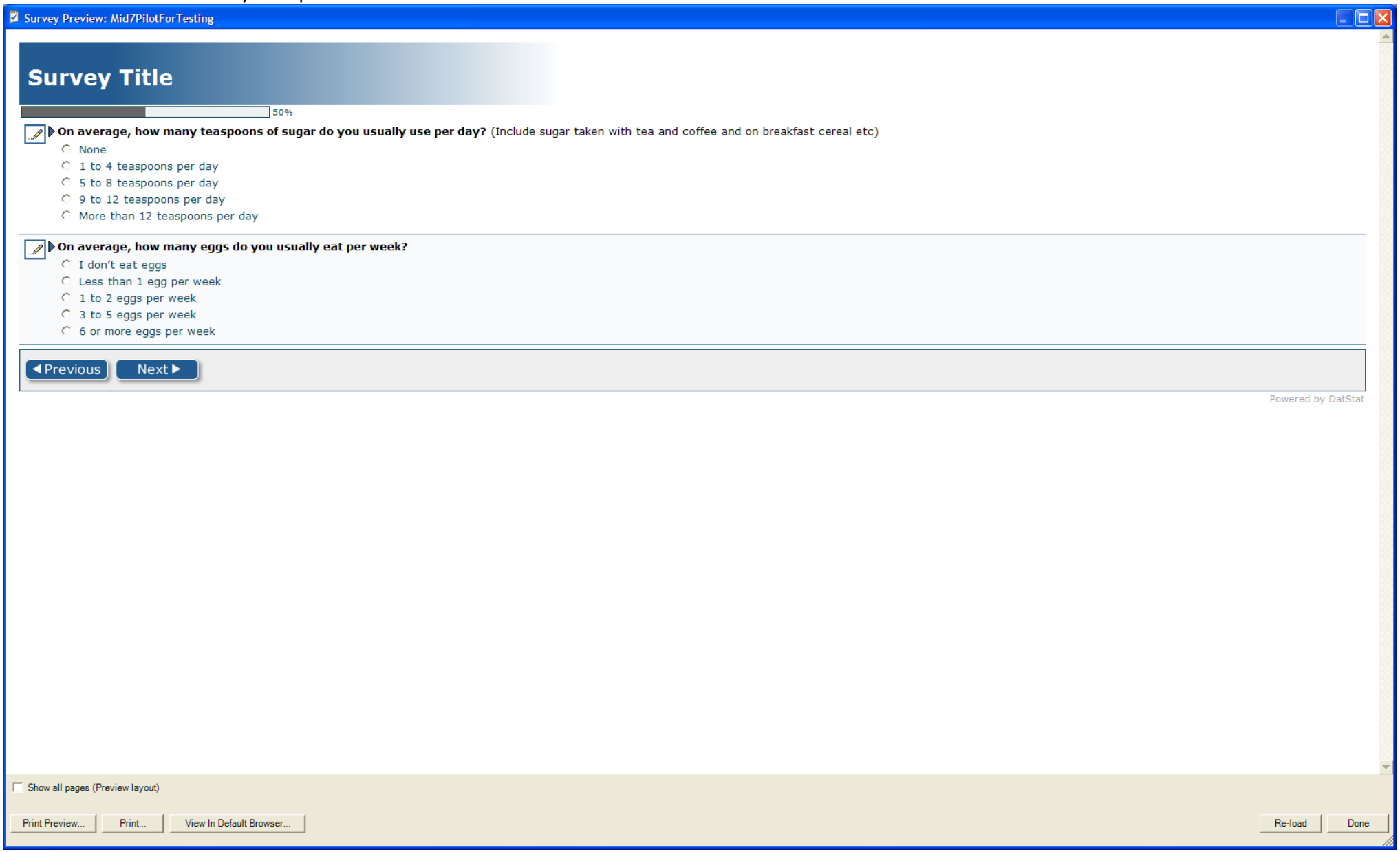

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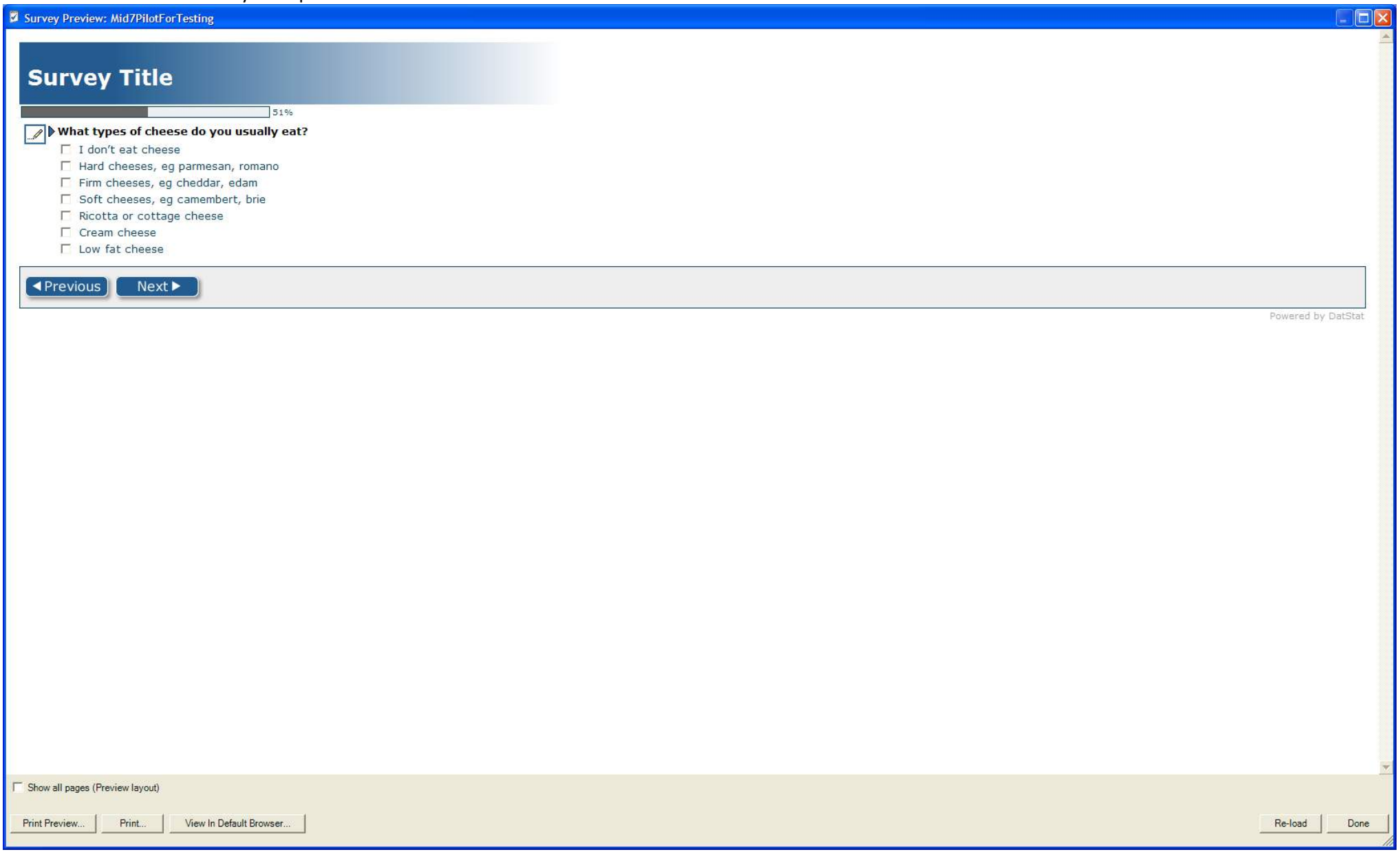


Attachment 14- Online Survey Example

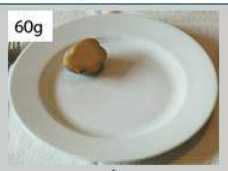
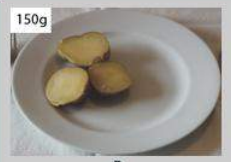
Survey Preview: Mid7PilotForTesting

Survey Title

60%

For each food shown on these pages, indicate **how much on average you would usually have eaten at main meals during the PAST 12 MONTHS**. When answering each question, think of the **amount** of that food you usually ate, even though you may rarely have eaten the food on its own. If you usually ate more than one helping, choose the serving size closest to the **total amount** you ate.

When you ate potato, did you usually eat:

Less than A	A	Between A & B	B	Between B & C	C	More than C	I never ate potato
							
○	○	○	○	○	○	○	○

When you ate vegetables, did you usually eat:

Less than A	A	Between A & B	B	Between B & C	C	More than C	I never ate vegetables
○	○	○	○	○	○	○	○

◀ Previous Next ▶ Save

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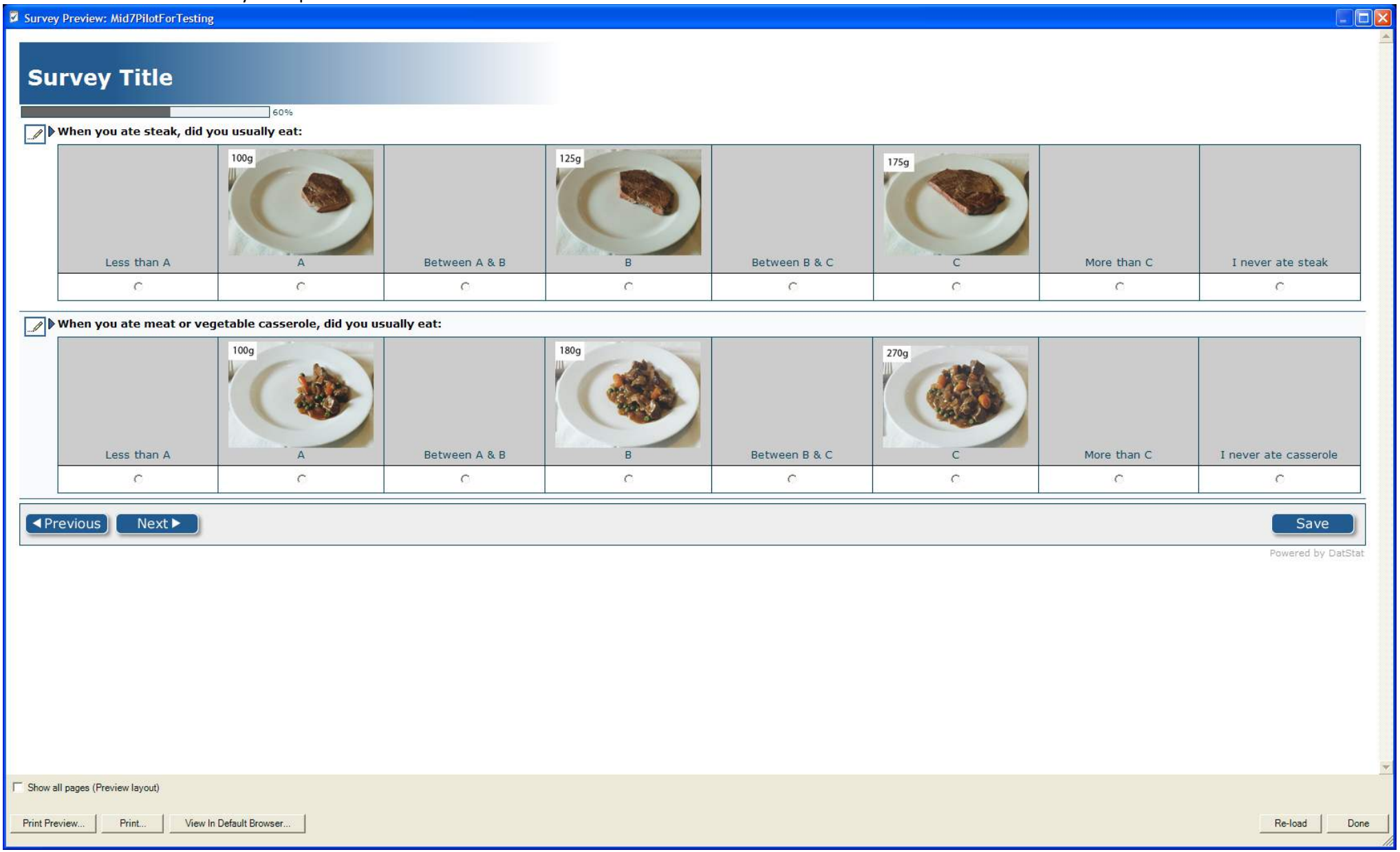
Attachment 14- Online Survey Example



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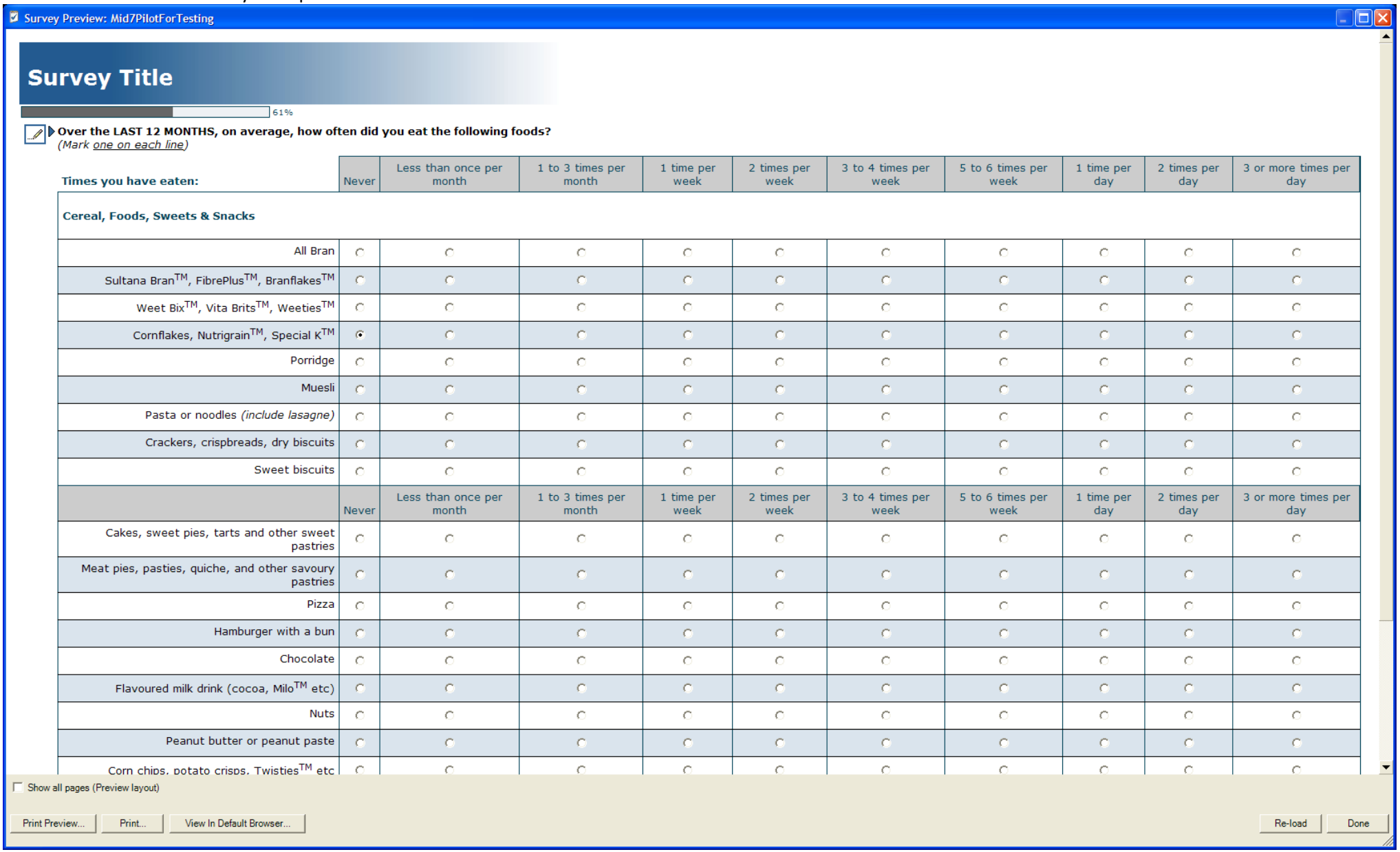
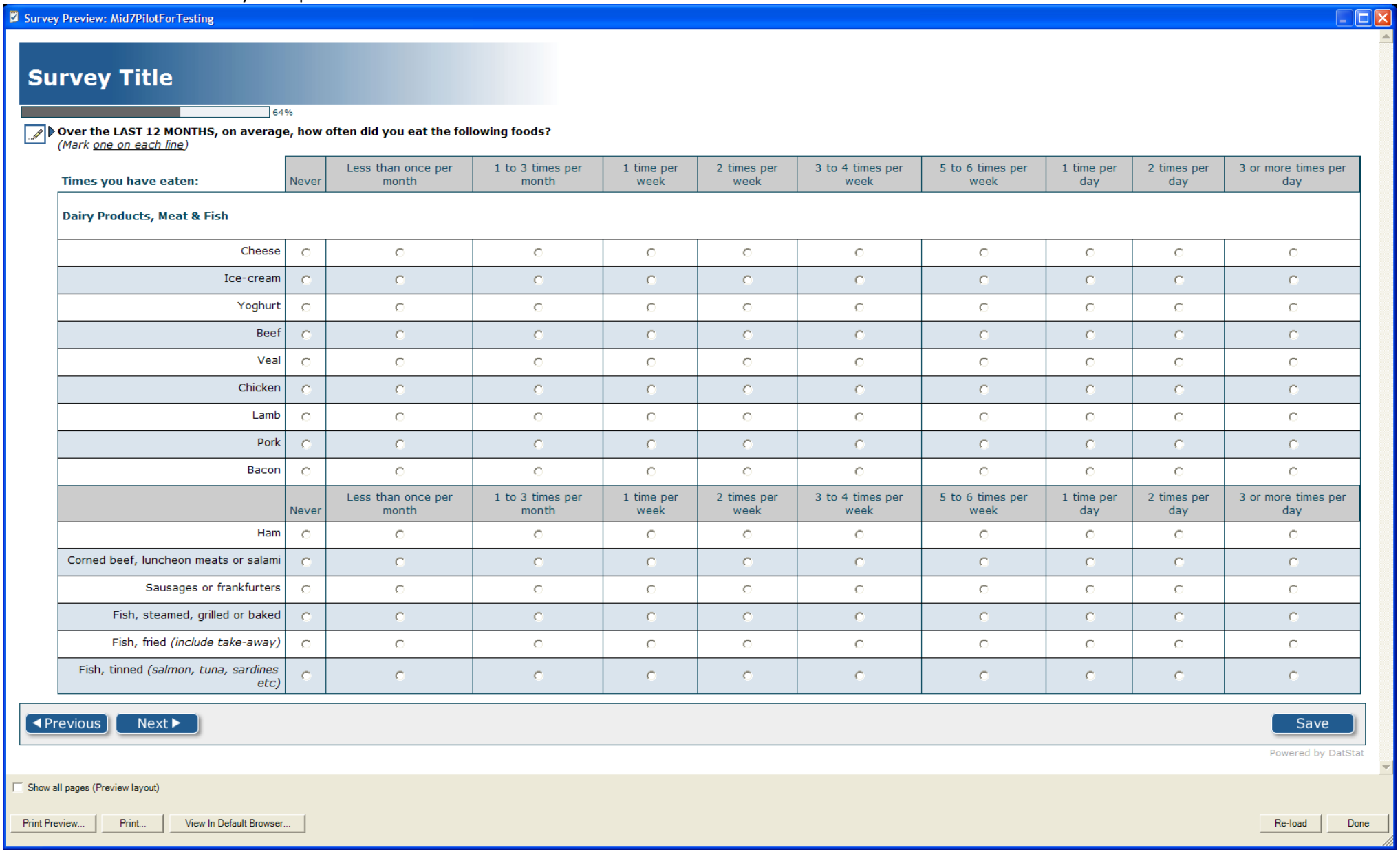


Over the LAST 12 MONTHS, on average, how often did you eat the following foods?
(Mark one on each line)

Times you have eaten:	Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
Cereal, Foods, Sweets & Snacks										
All Bran	○	○	○	○	○	○	○	○	○	○
Sultana Bran™, FibrePlus™, Branflakes™	○	○	○	○	○	○	○	○	○	○
Weet Bix™, Vita Brits™, Weeties™	○	○	○	○	○	○	○	○	○	○
Cornflakes, Nutrigrain™, Special K™	◉	○	○	○	○	○	○	○	○	○
Porridge	○	○	○	○	○	○	○	○	○	○
Muesli	○	○	○	○	○	○	○	○	○	○
Pasta or noodles *(include lasagne)*	○	○	○	○	○	○	○	○	○	○
Crackers, crispbreads, dry biscuits	○	○	○	○	○	○	○	○	○	○
Sweet biscuits	○	○	○	○	○	○	○	○	○	○
	Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
Cakes, sweet pies, tarts and other sweet pastries	○	○	○	○	○	○	○	○	○	○
Meat pies, pasties, quiche, and other savoury pastries	○	○	○	○	○	○	○	○	○	○
Pizza	○	○	○	○	○	○	○	○	○	○
Hamburger with a bun	○	○	○	○	○	○	○	○	○	○
Chocolate	○	○	○	○	○	○	○	○	○	○
Flavoured milk drink (cocoa, Milo™ etc)	○	○	○	○	○	○	○	○	○	○
Nuts	○	○	○	○	○	○	○	○	○	○
Peanut butter or peanut paste	○	○	○	○	○	○	○	○	○	○
Corn chips, potato crisps, Twisties™ etc	○	○	○	○	○	○	○	○	○	○

Attachment 14- Online Survey Example



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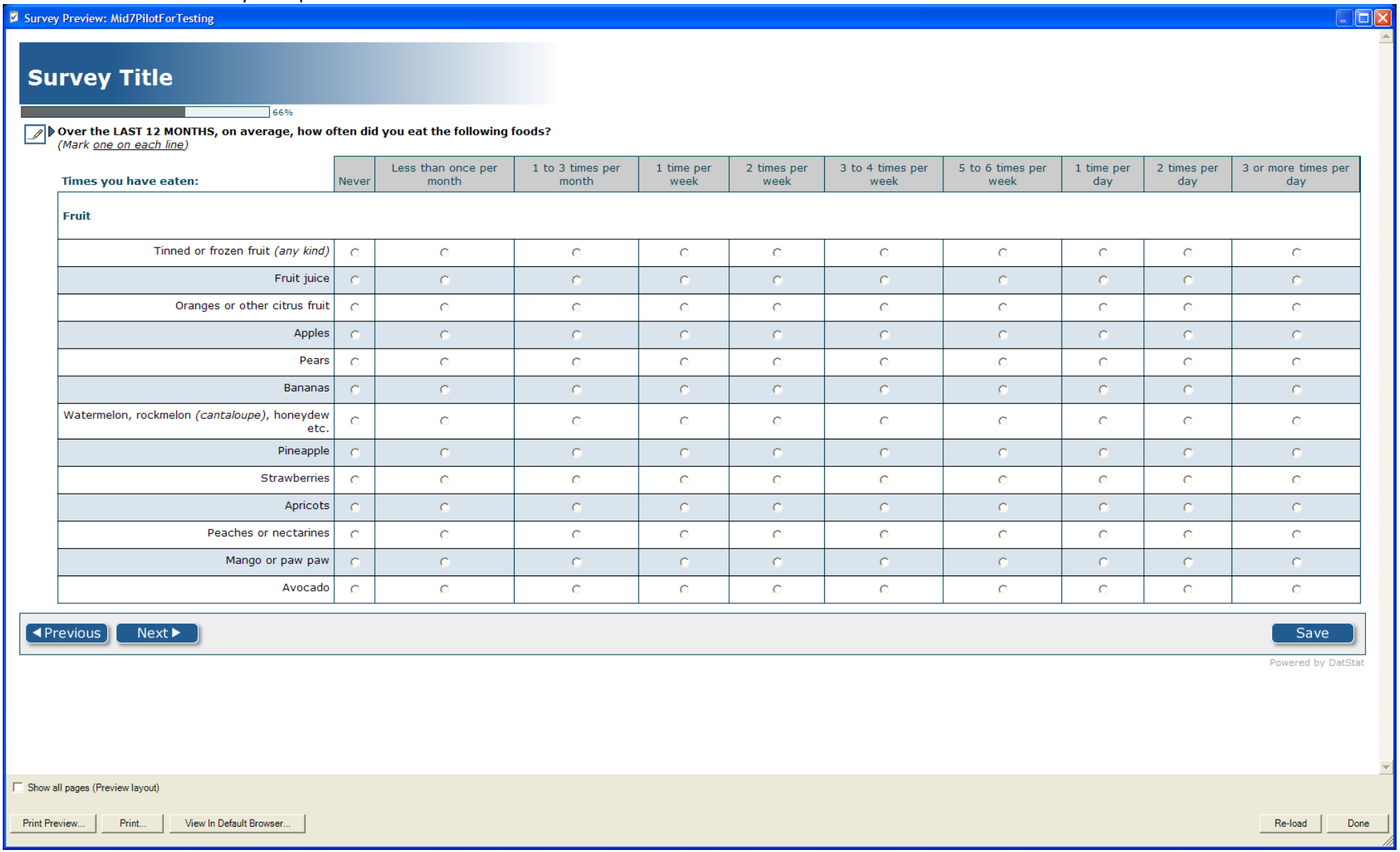

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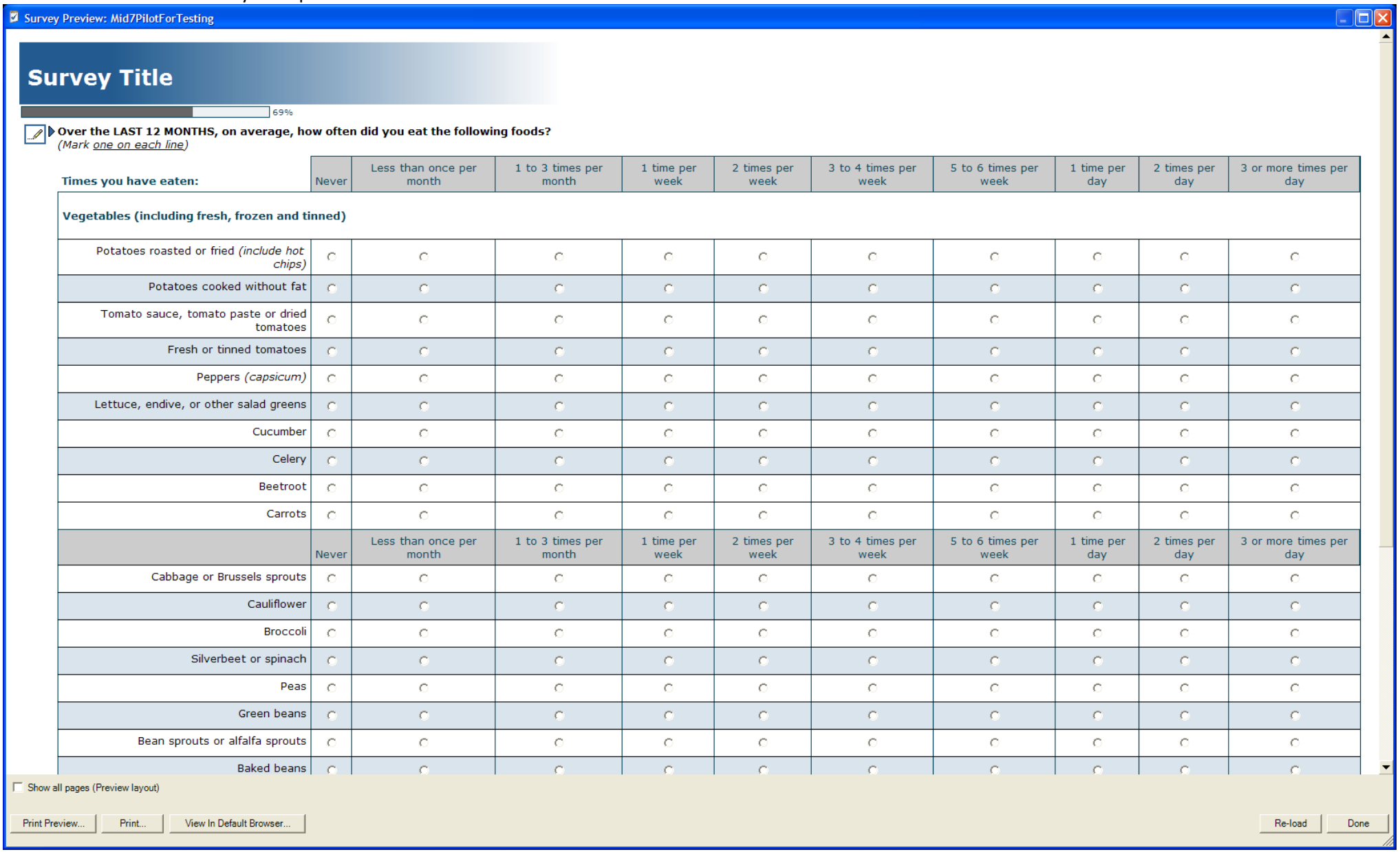

Times you have eaten:	Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
Vegetables (including fresh, frozen and tinned)										
Potatoes roasted or fried *(include hot chips)*	○	○	○	○	○	○	○	○	○	○
Potatoes cooked without fat	○	○	○	○	○	○	○	○	○	○
Tomato sauce, tomato paste or dried tomatoes	○	○	○	○	○	○	○	○	○	○
Fresh or tinned tomatoes	○	○	○	○	○	○	○	○	○	○
Peppers *(capsicum)*	○	○	○	○	○	○	○	○	○	○
Lettuce, endive, or other salad greens	○	○	○	○	○	○	○	○	○	○
Cucumber	○	○	○	○	○	○	○	○	○	○
Celery	○	○	○	○	○	○	○	○	○	○
Beetroot	○	○	○	○	○	○	○	○	○	○
Carrots	○	○	○	○	○	○	○	○	○	○
	Never	Less than once per month	1 to 3 times per month	1 time per week	2 times per week	3 to 4 times per week	5 to 6 times per week	1 time per day	2 times per day	3 or more times per day
Cabbage or Brussels sprouts	○	○	○	○	○	○	○	○	○	○
Cauliflower	○	○	○	○	○	○	○	○	○	○
Broccoli	○	○	○	○	○	○	○	○	○	○
Silverbeet or spinach	○	○	○	○	○	○	○	○	○	○
Peas	○	○	○	○	○	○	○	○	○	○
Green beans	○	○	○	○	○	○	○	○	○	○
Bean sprouts or alfalfa sprouts	○	○	○	○	○	○	○	○	○	○
Baked beans	○	○	○	○	○	○	○	○	○	○

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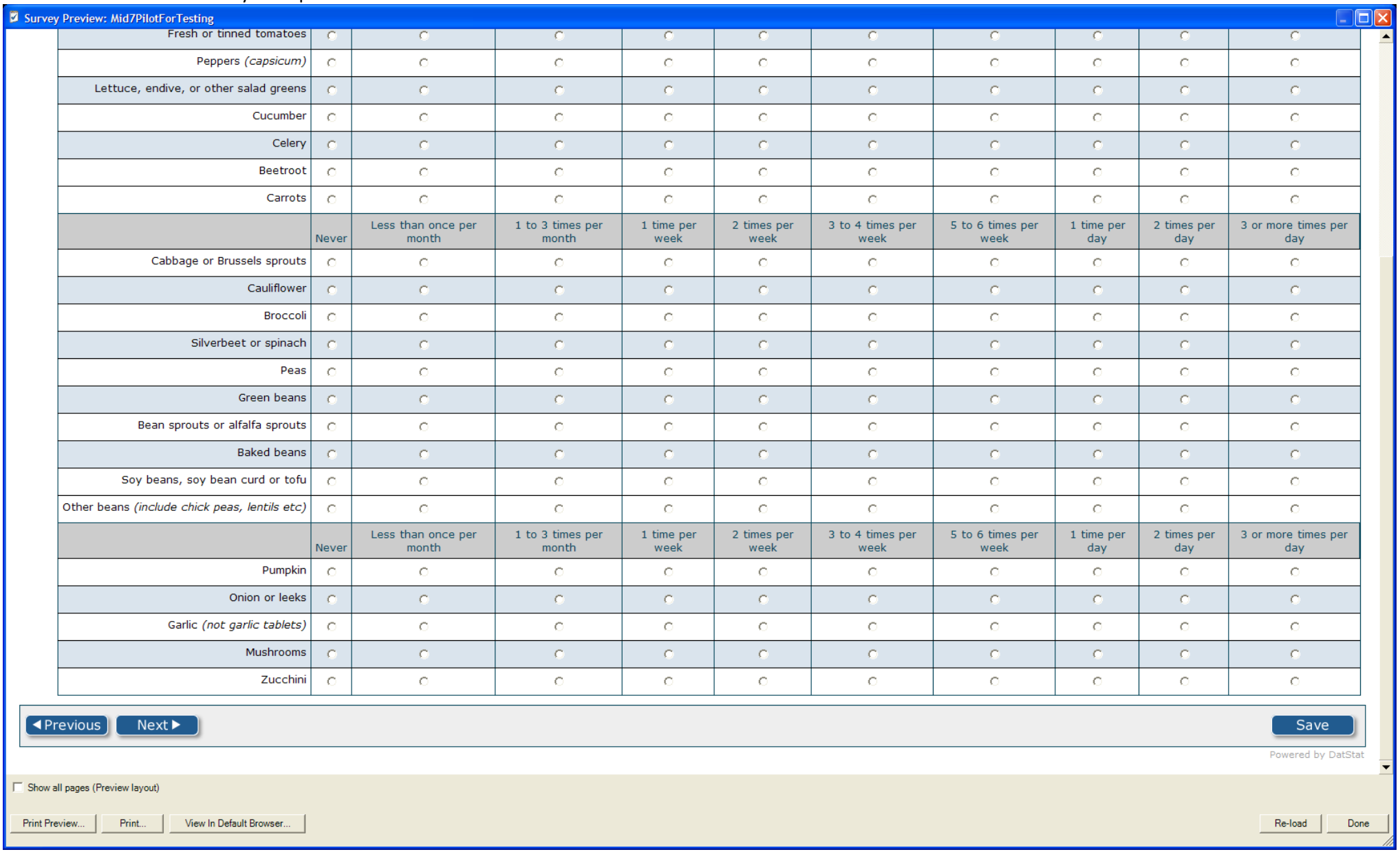

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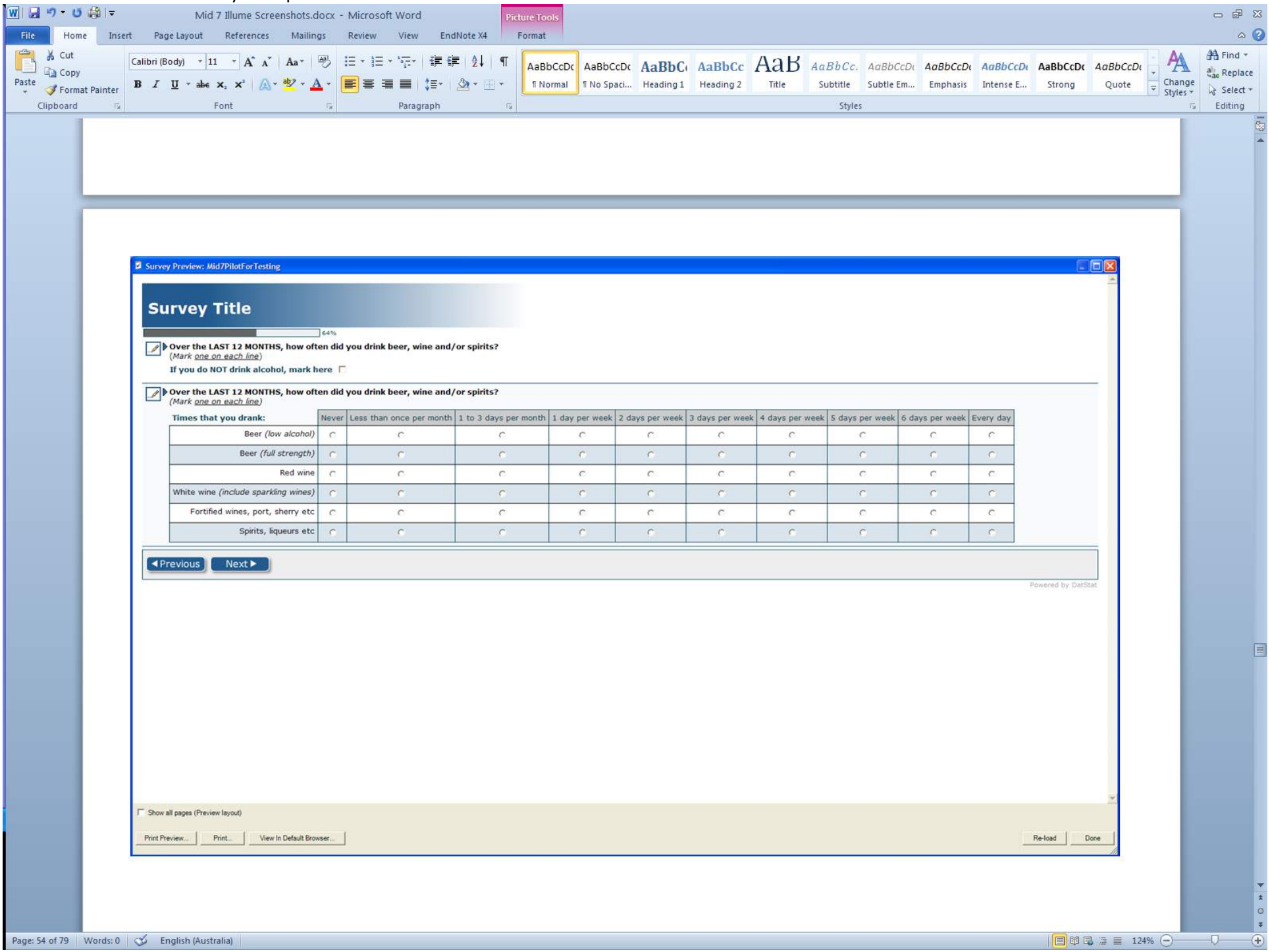

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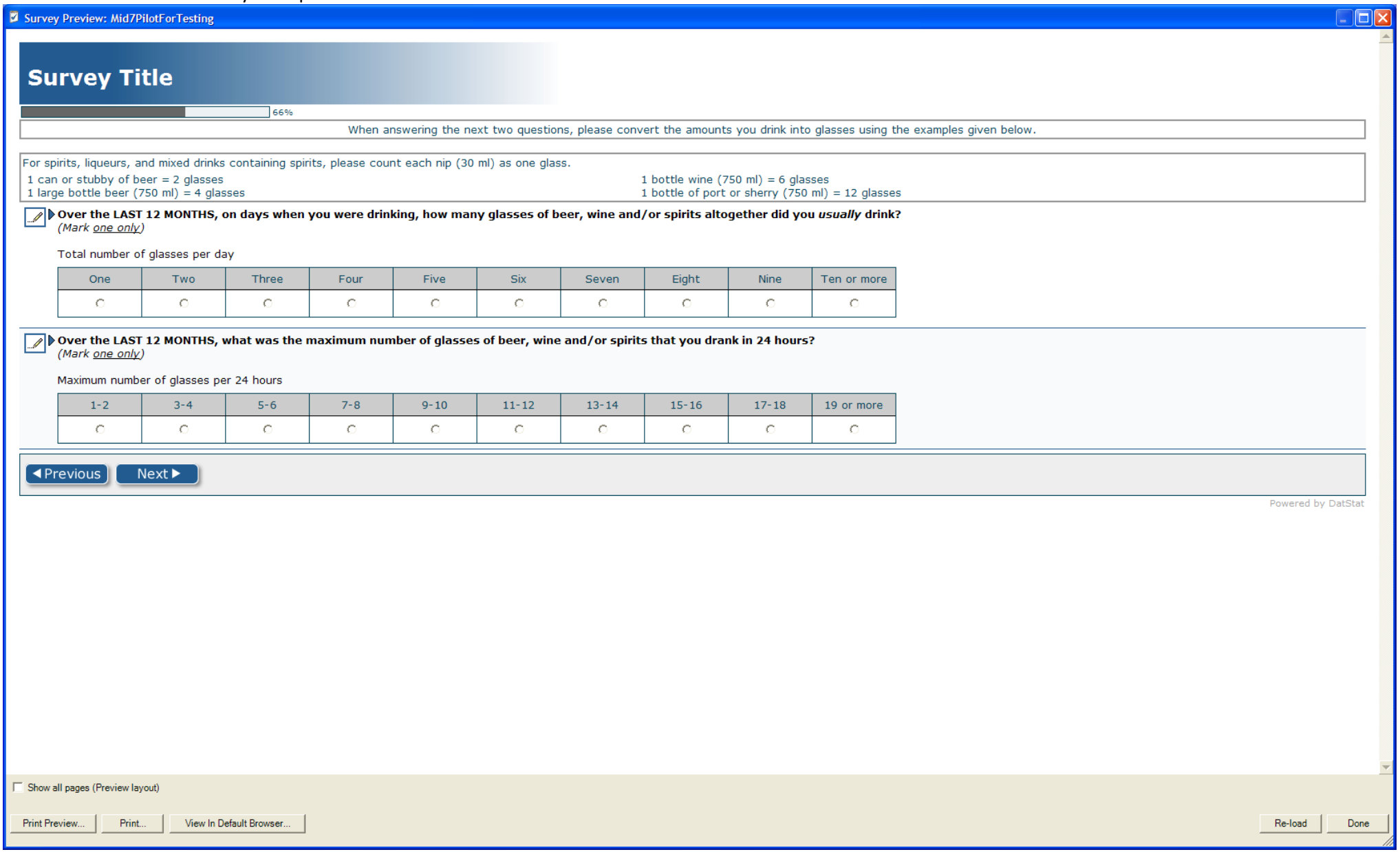

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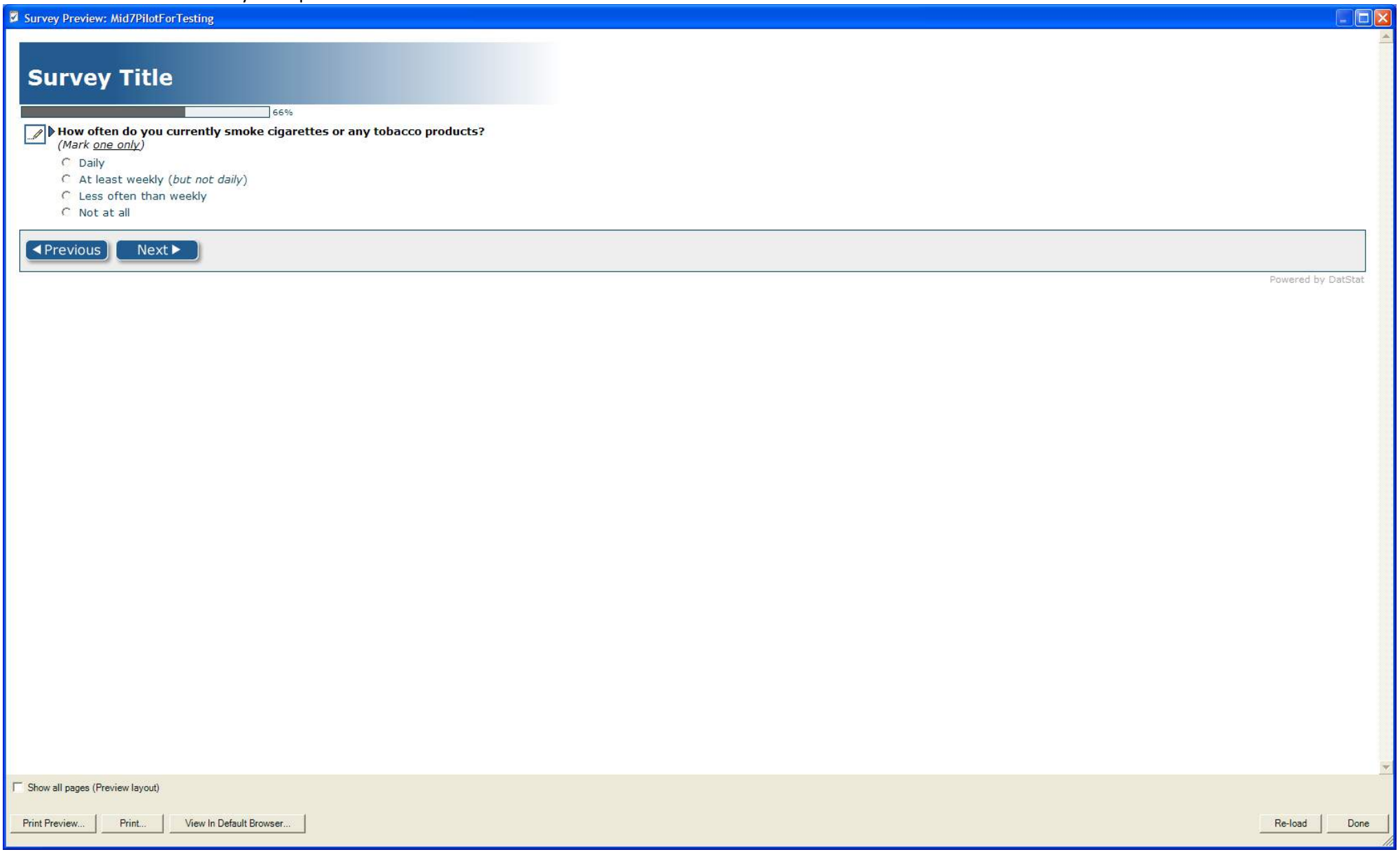

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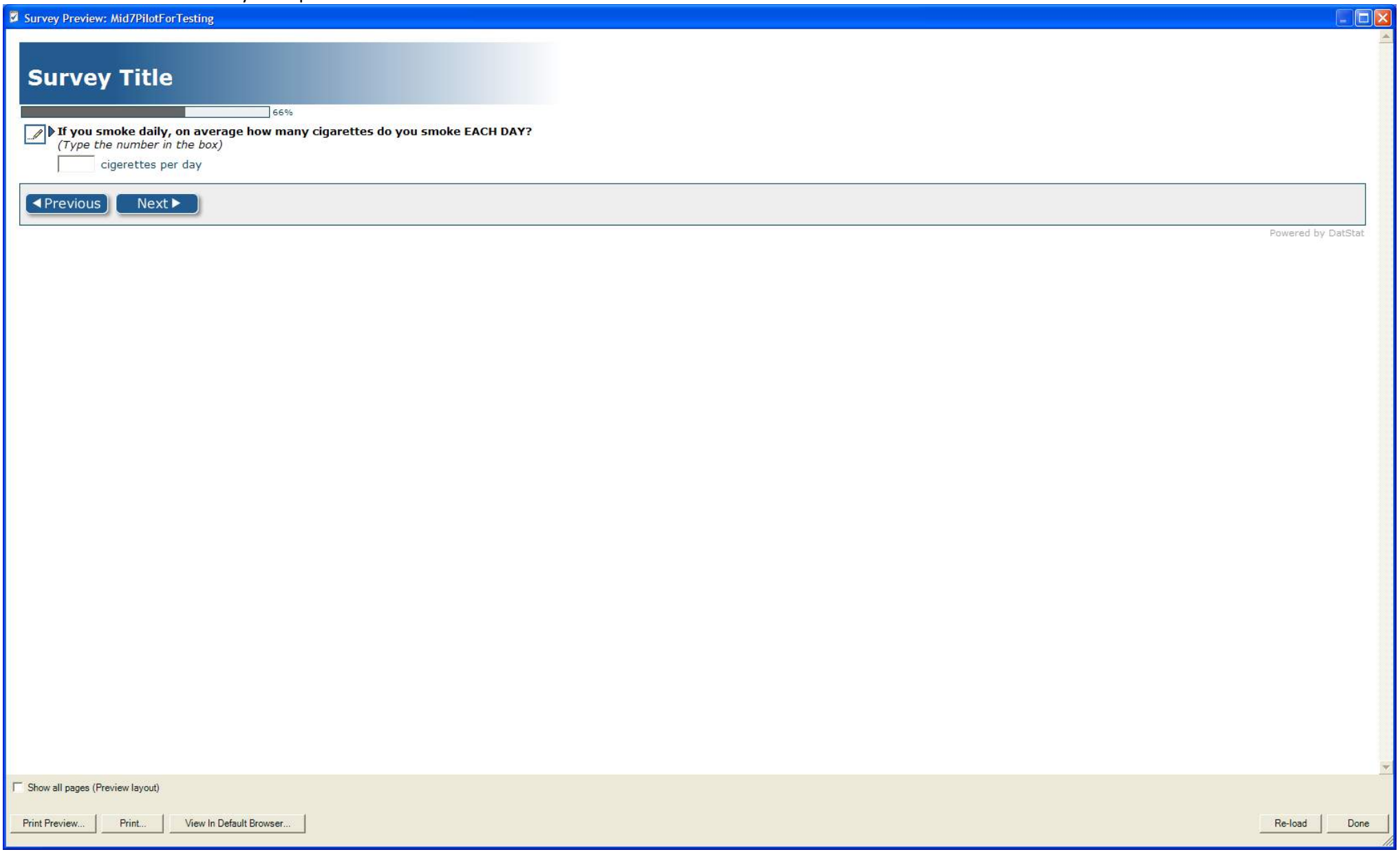

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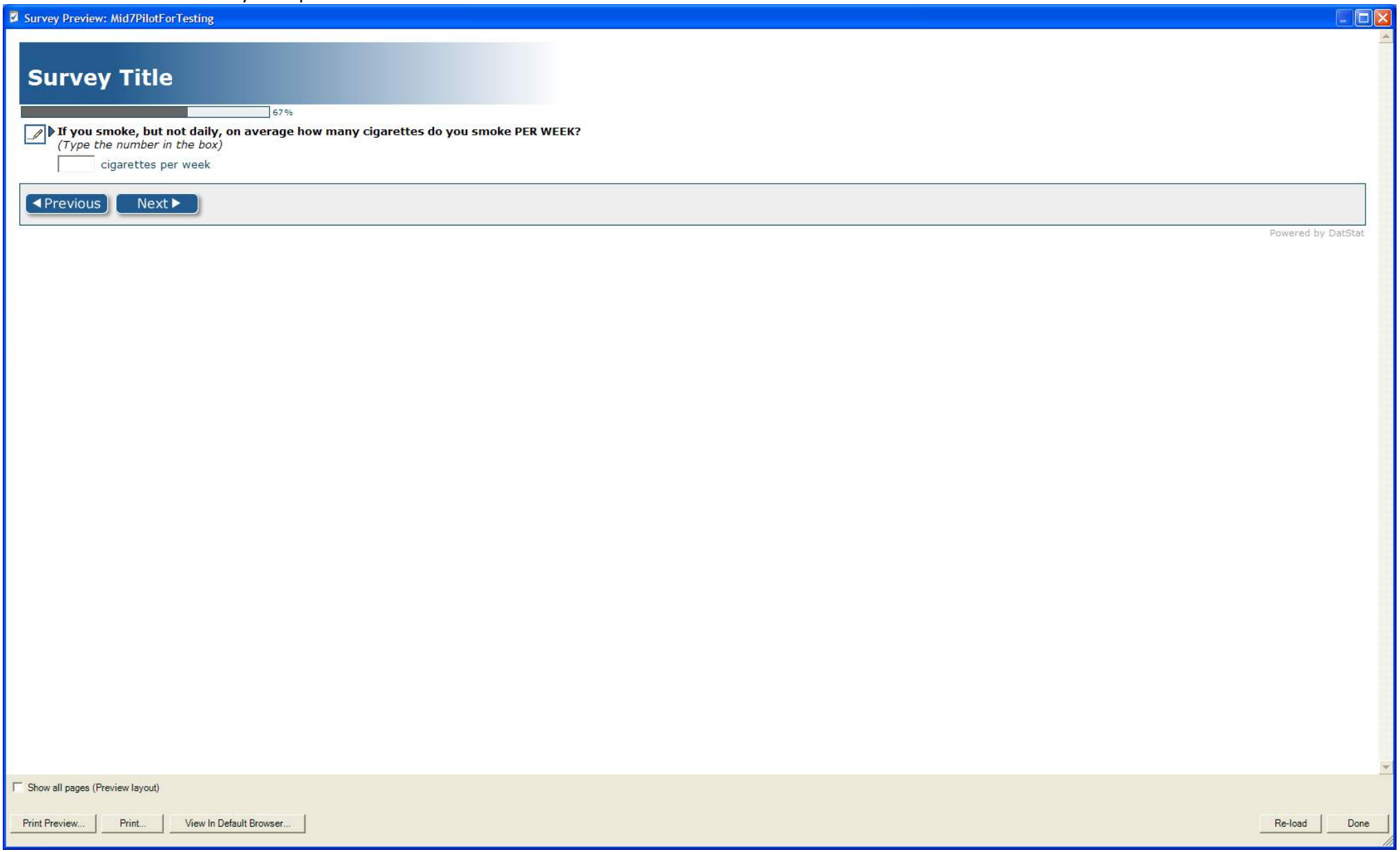

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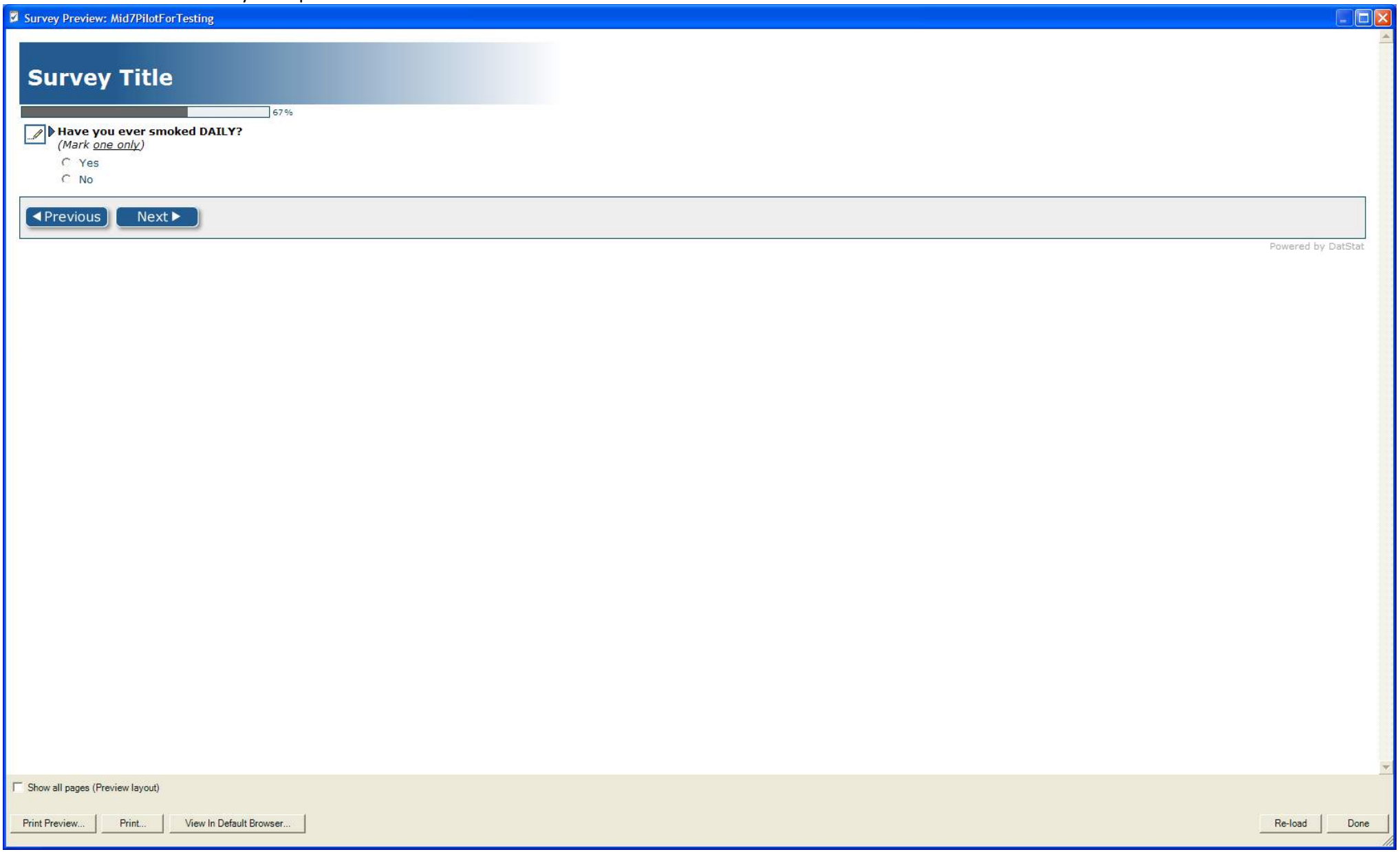

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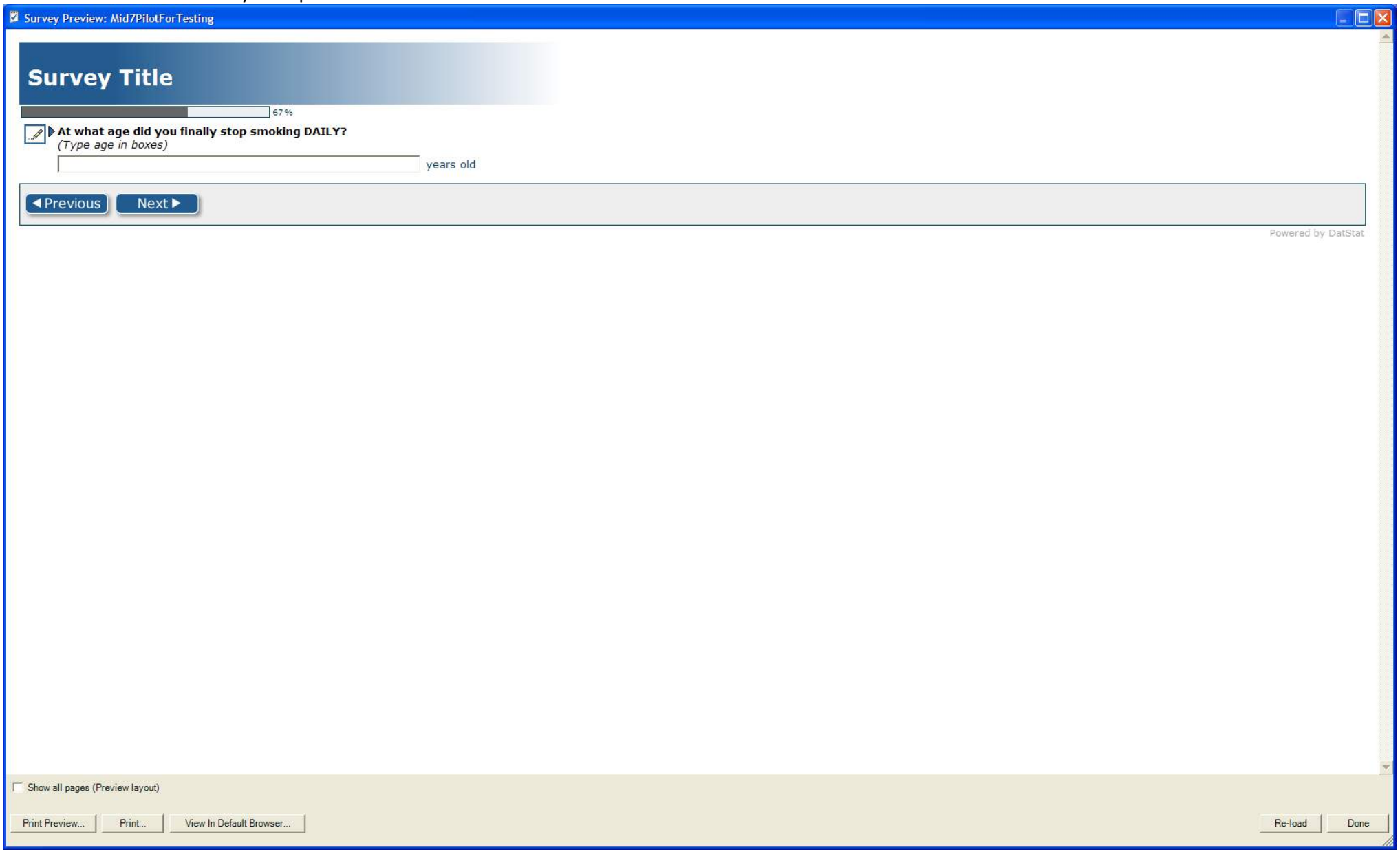

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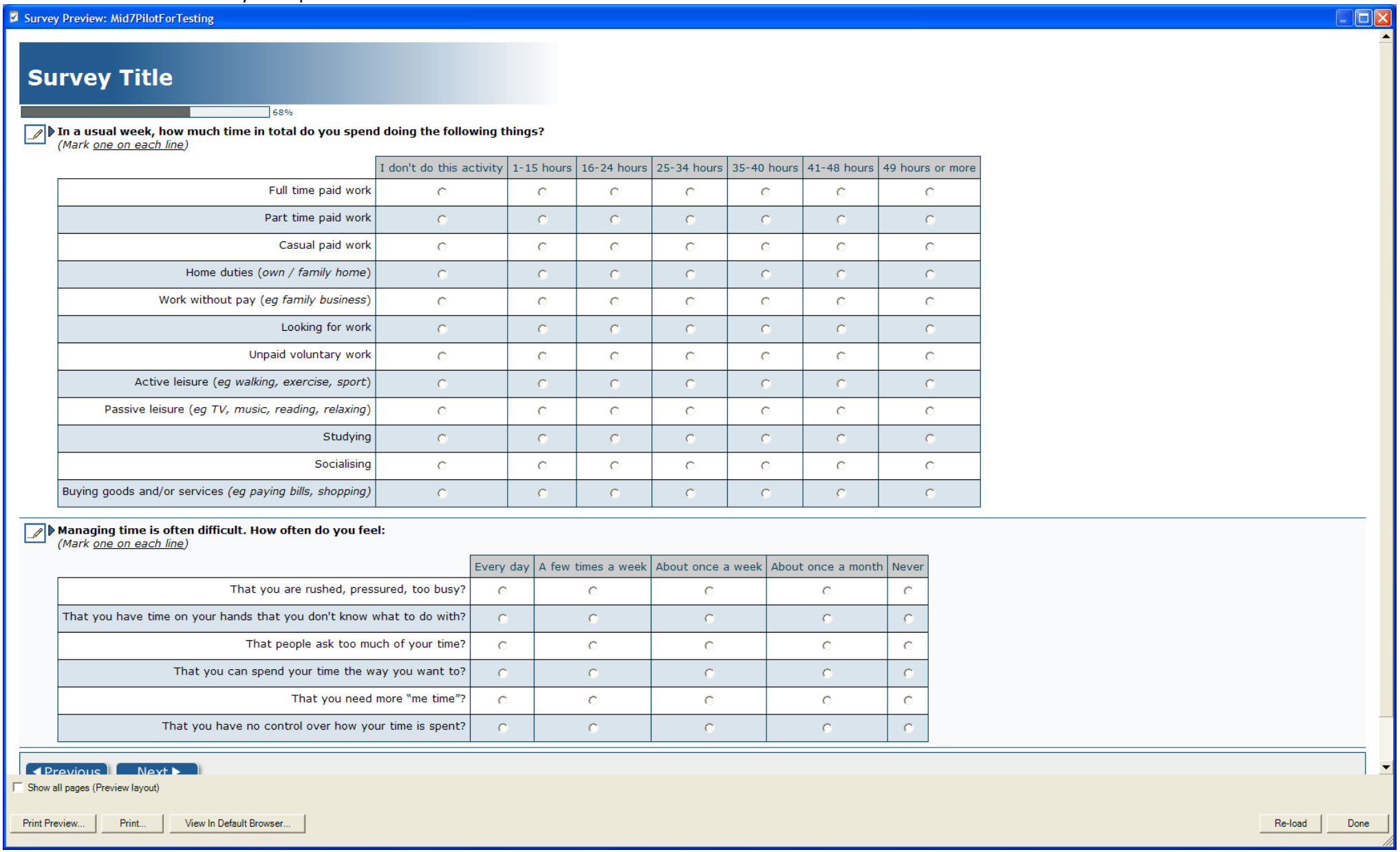

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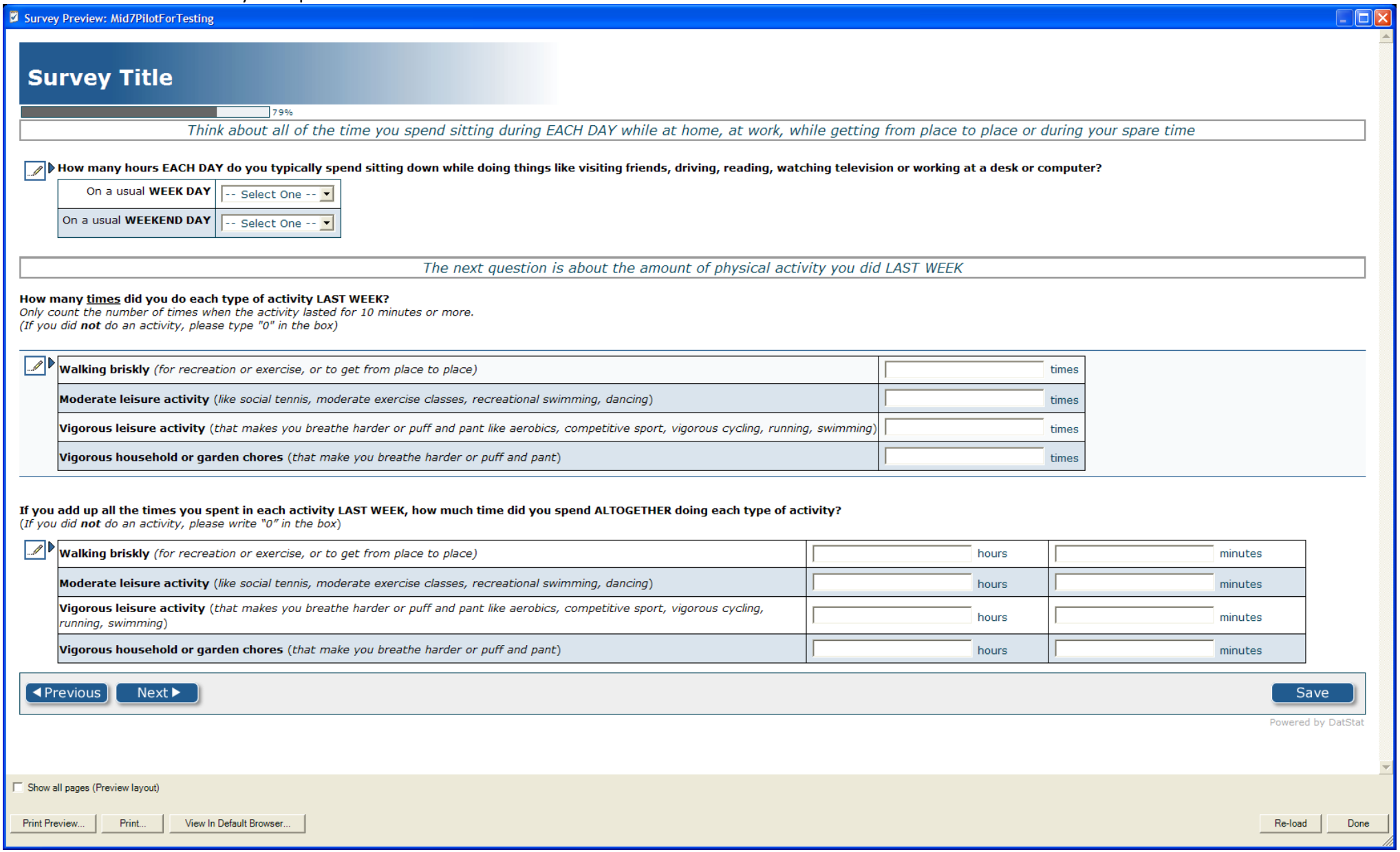

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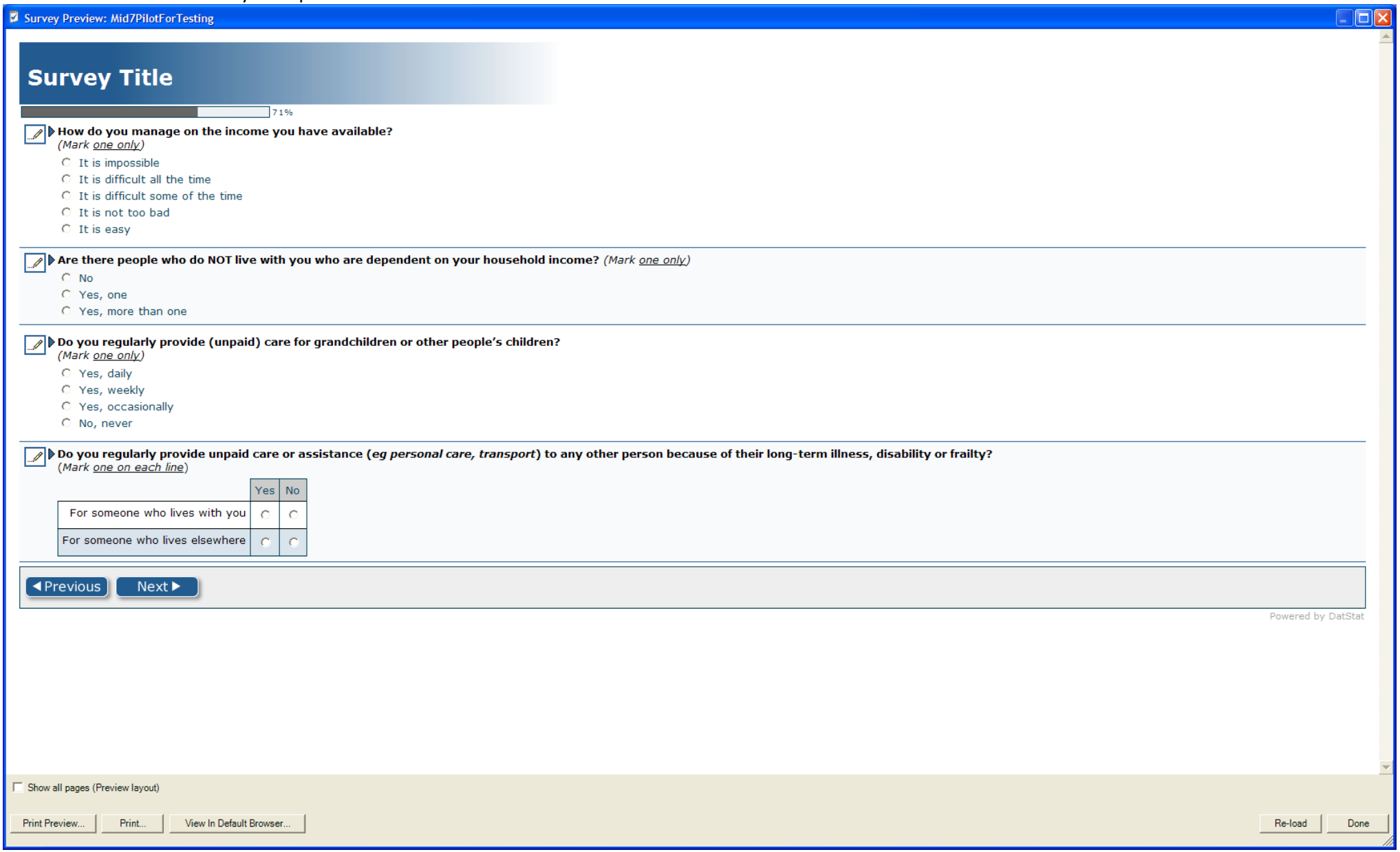

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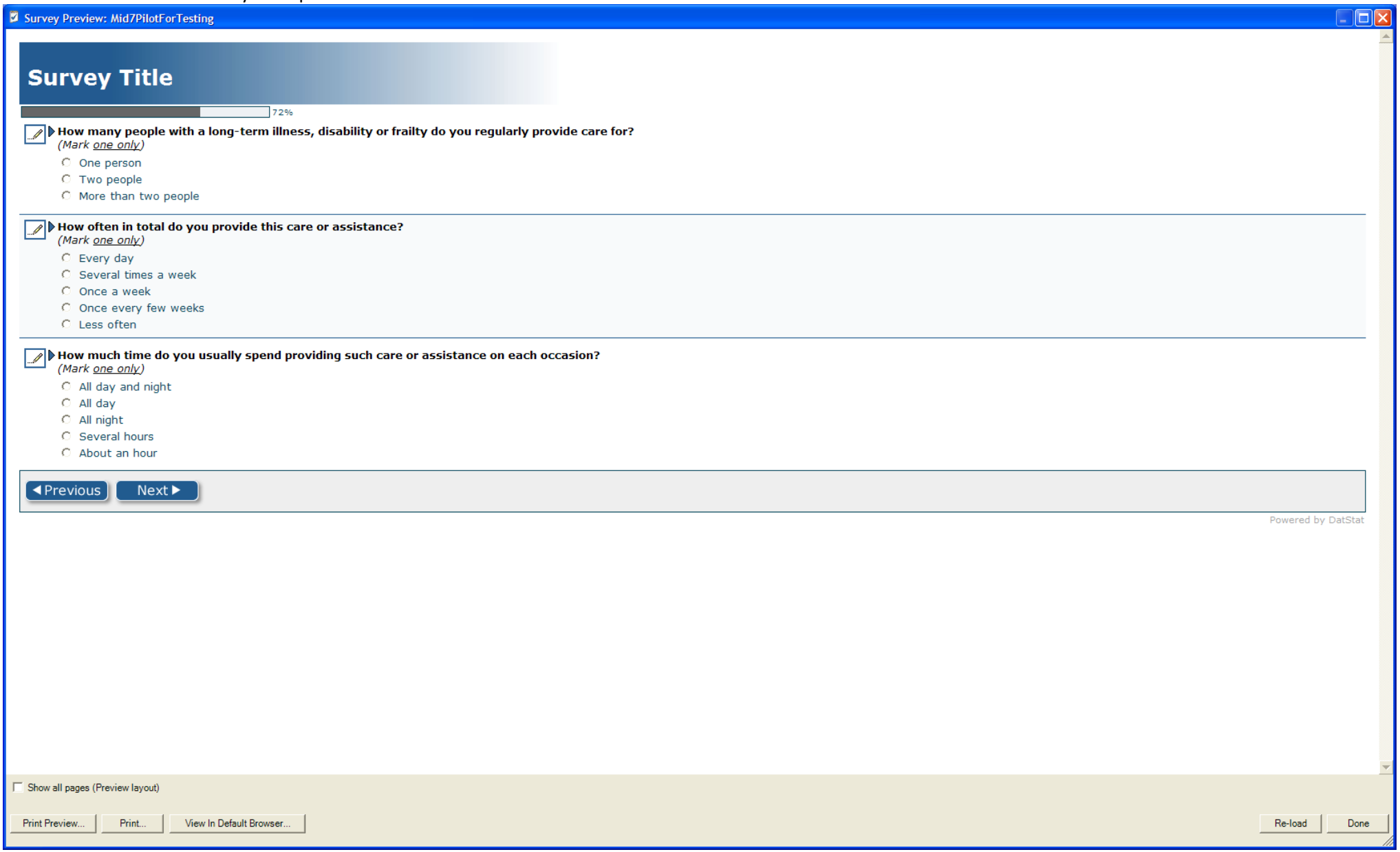

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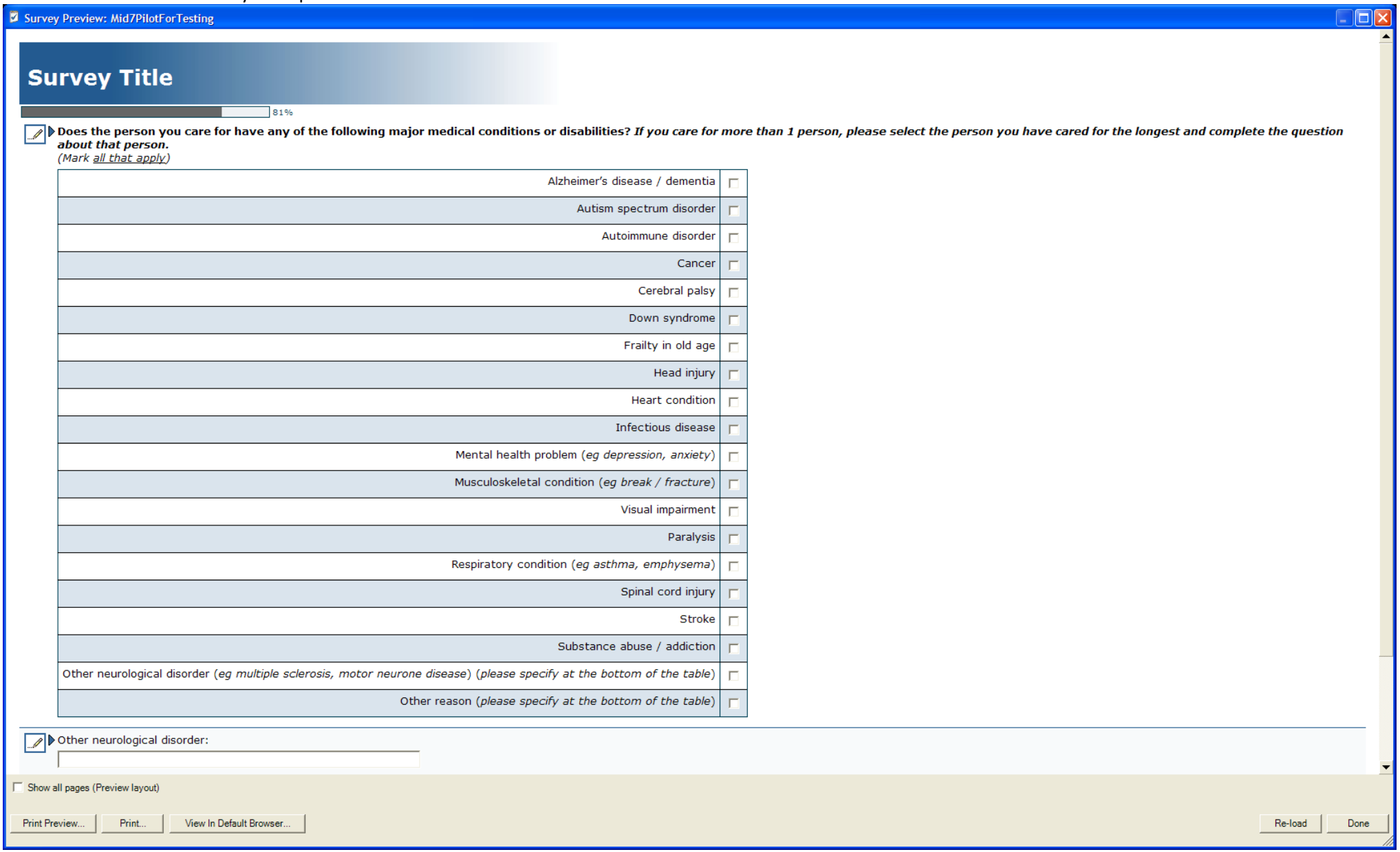

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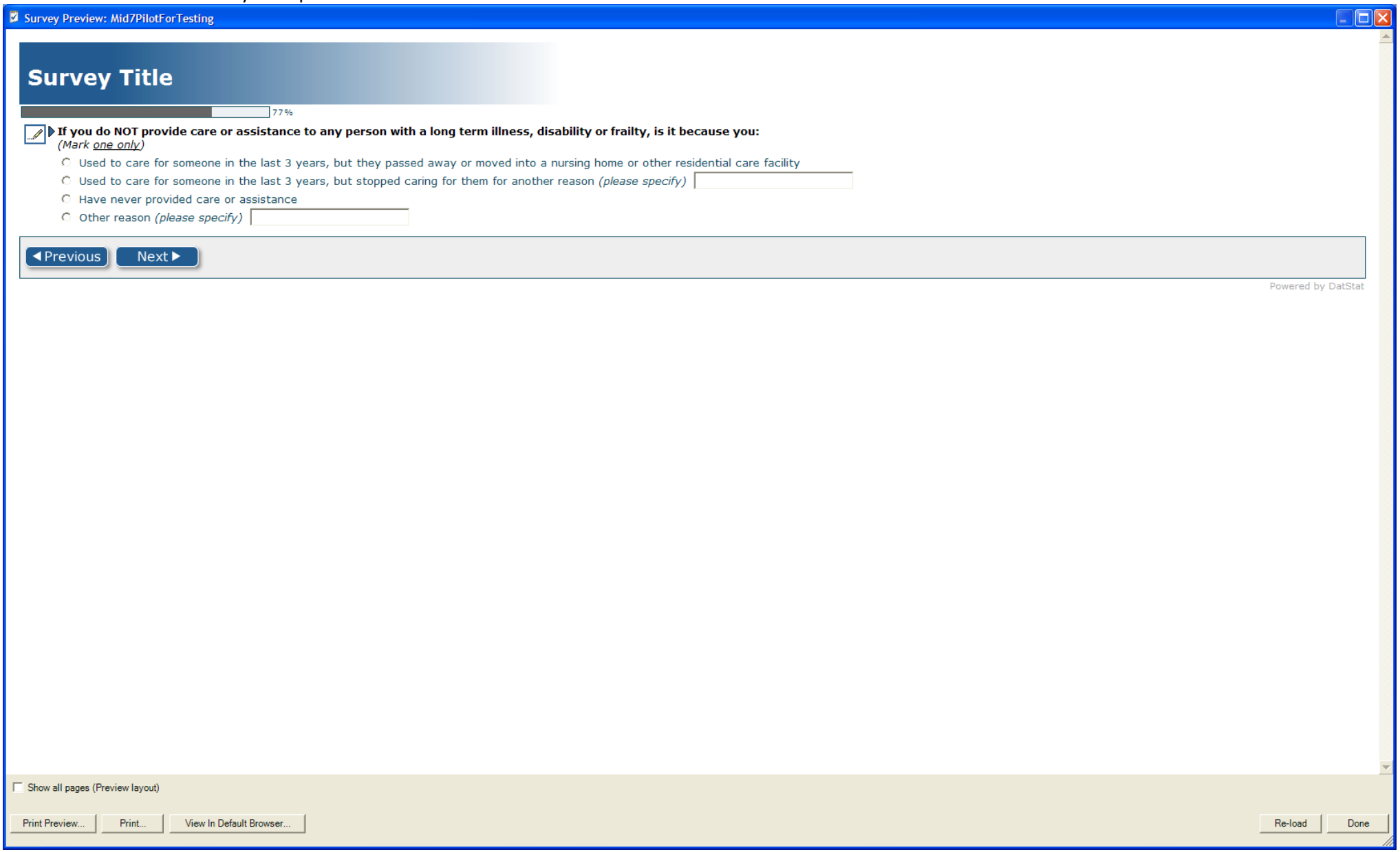

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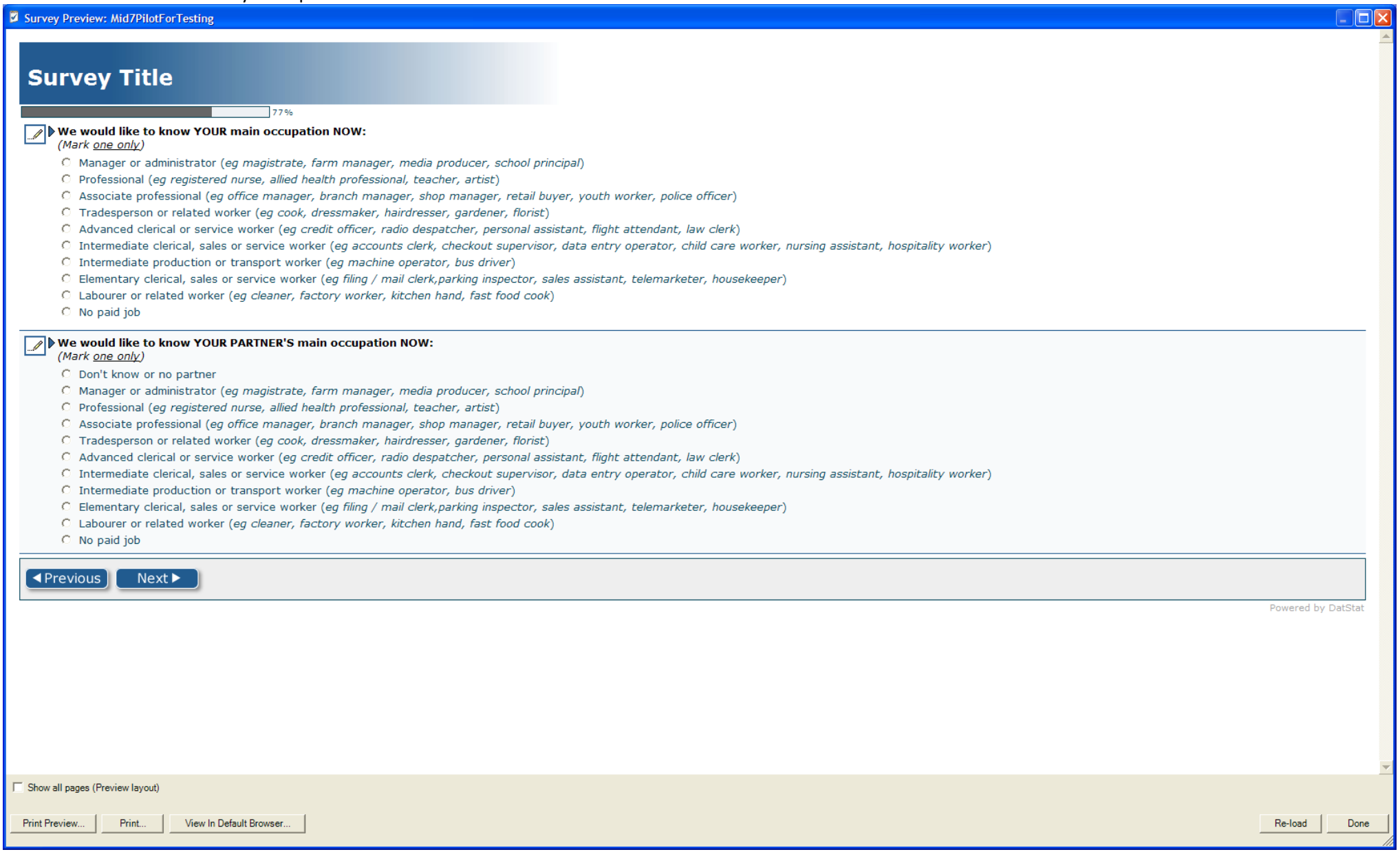

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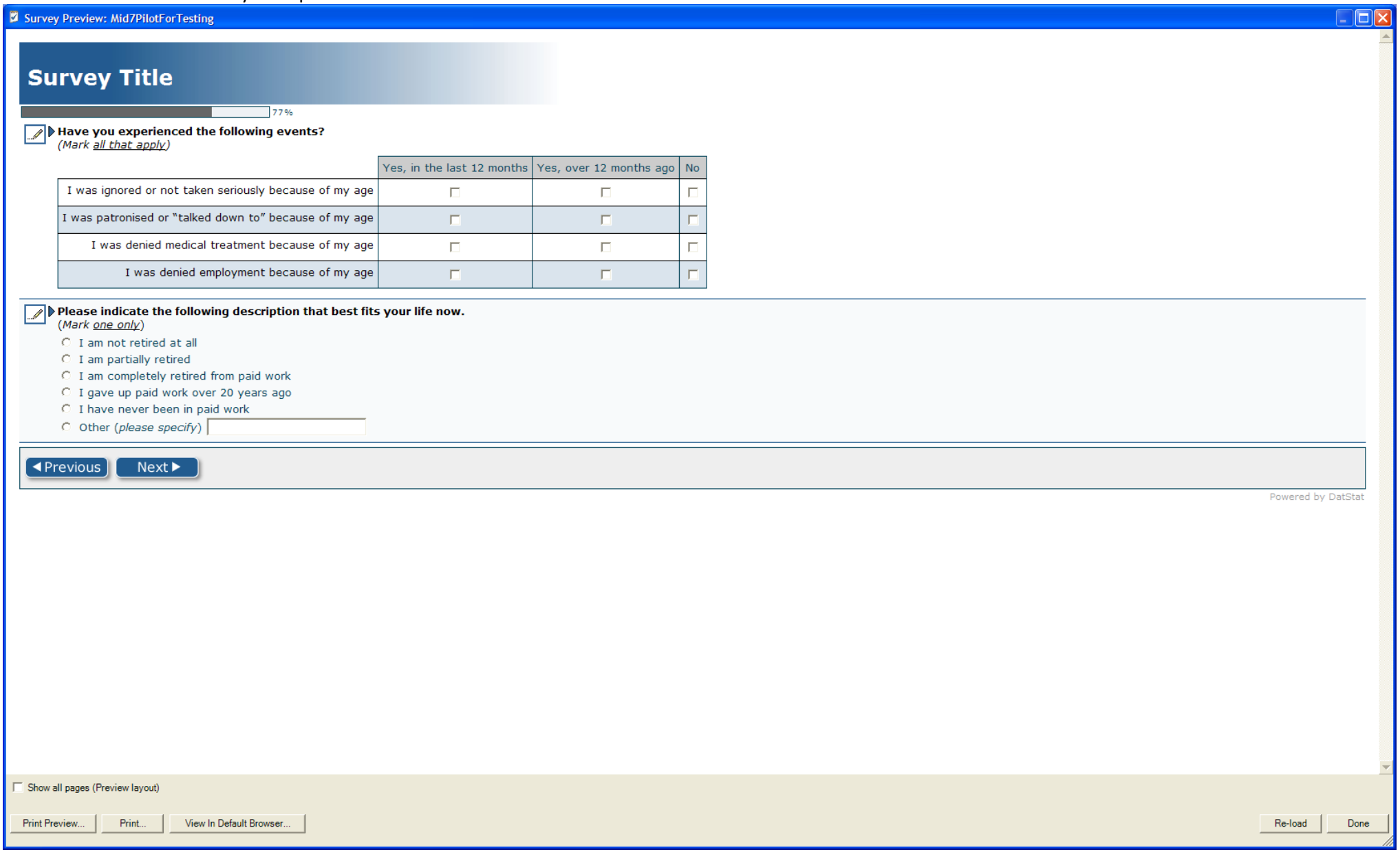

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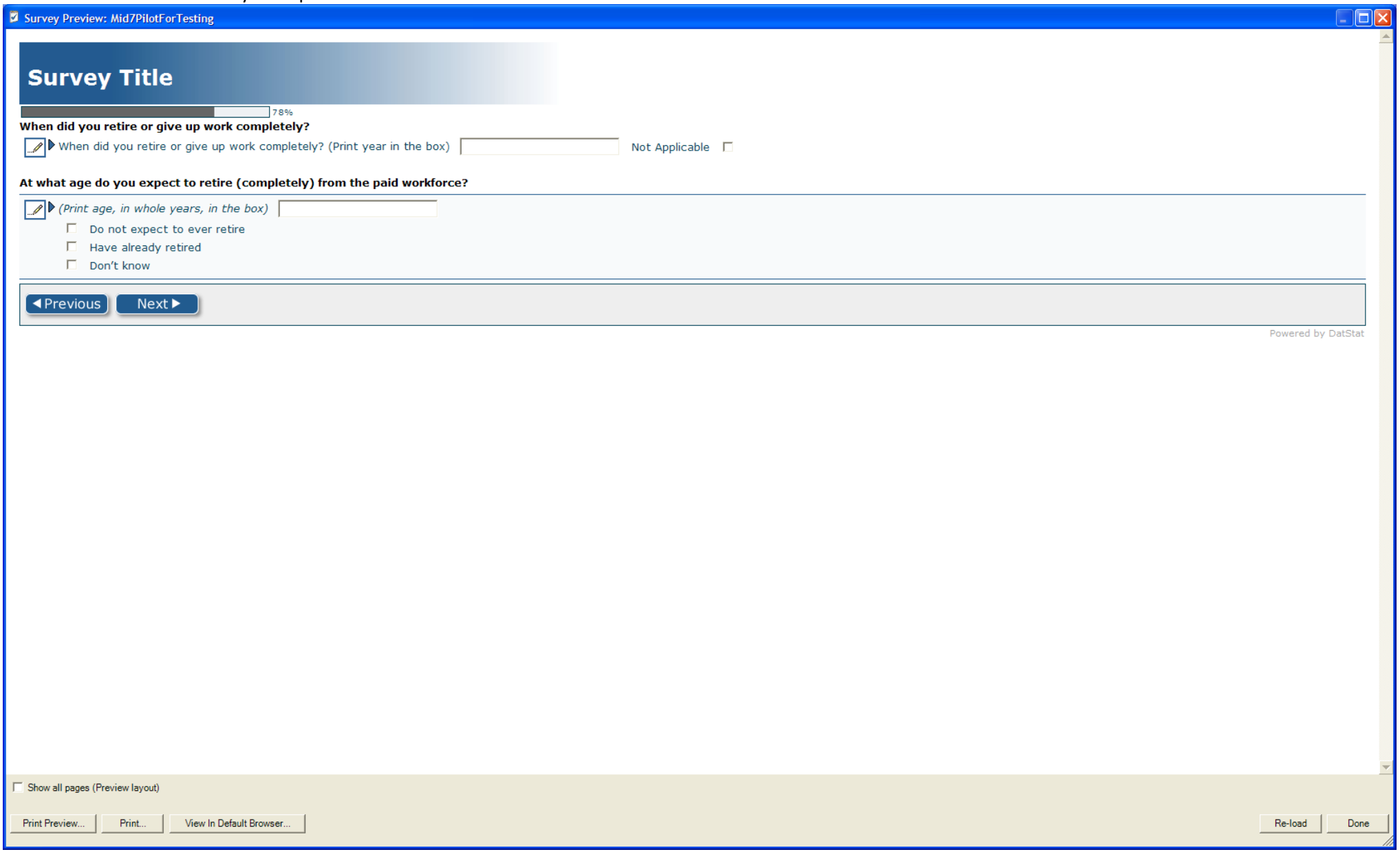

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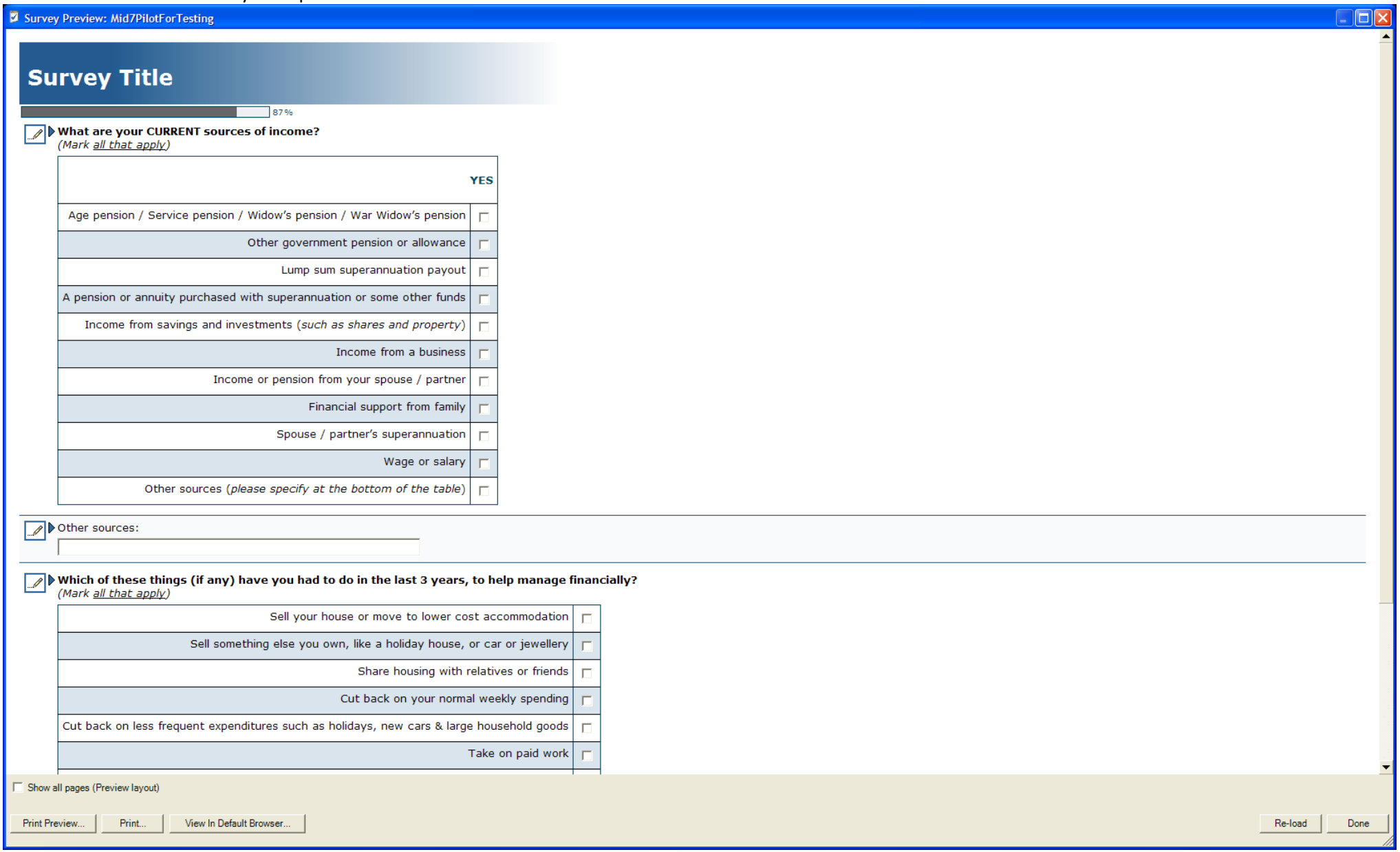

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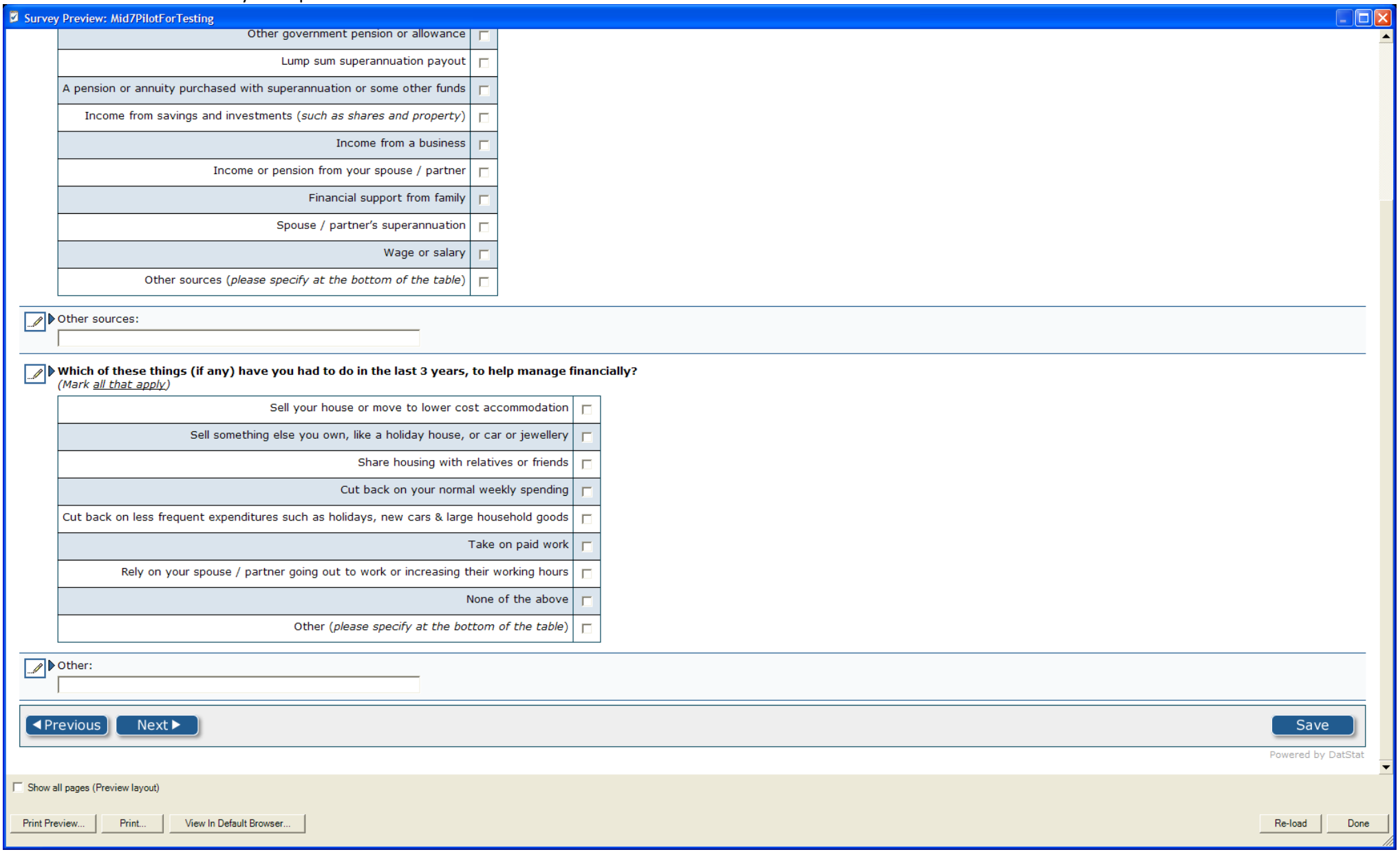

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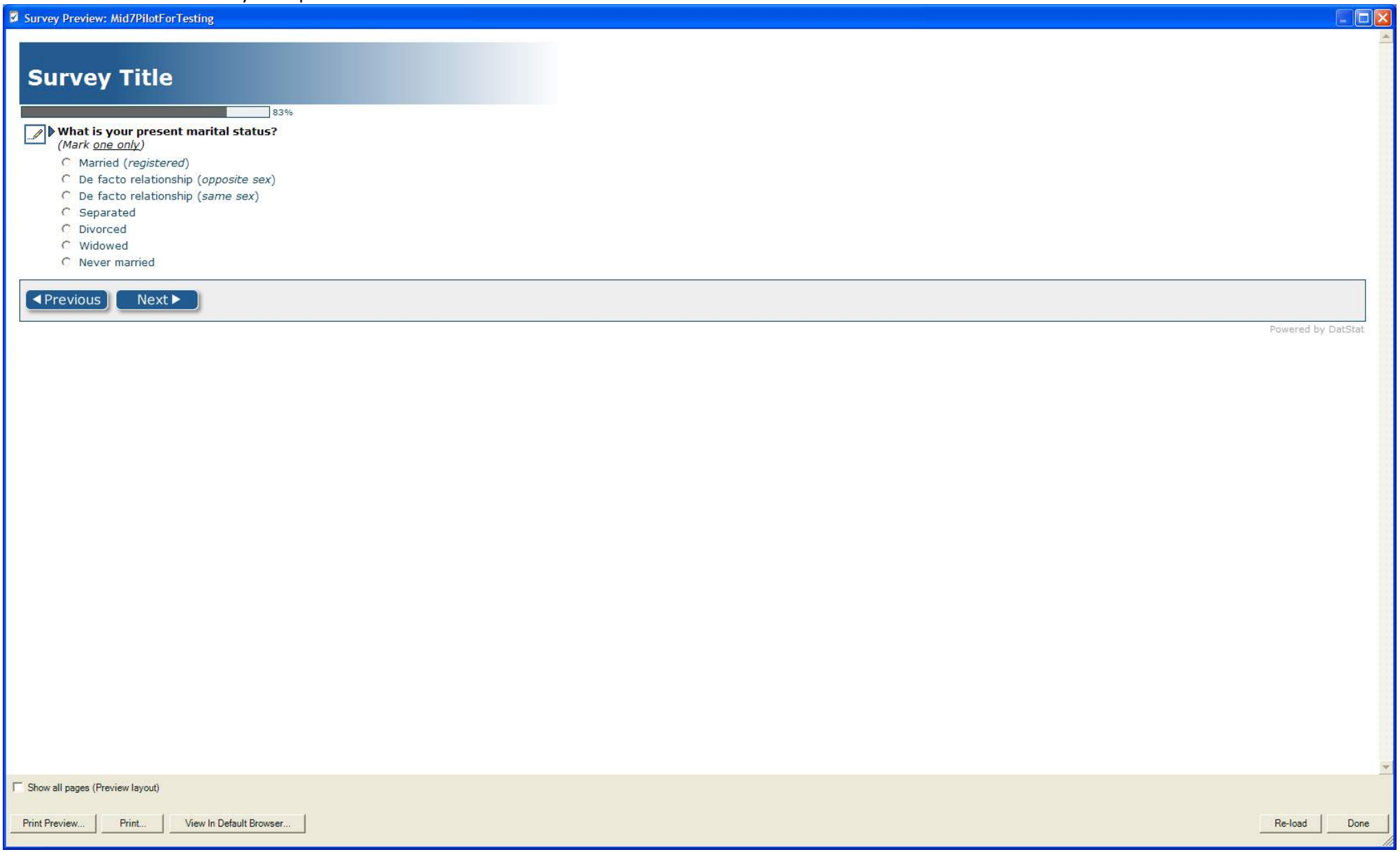

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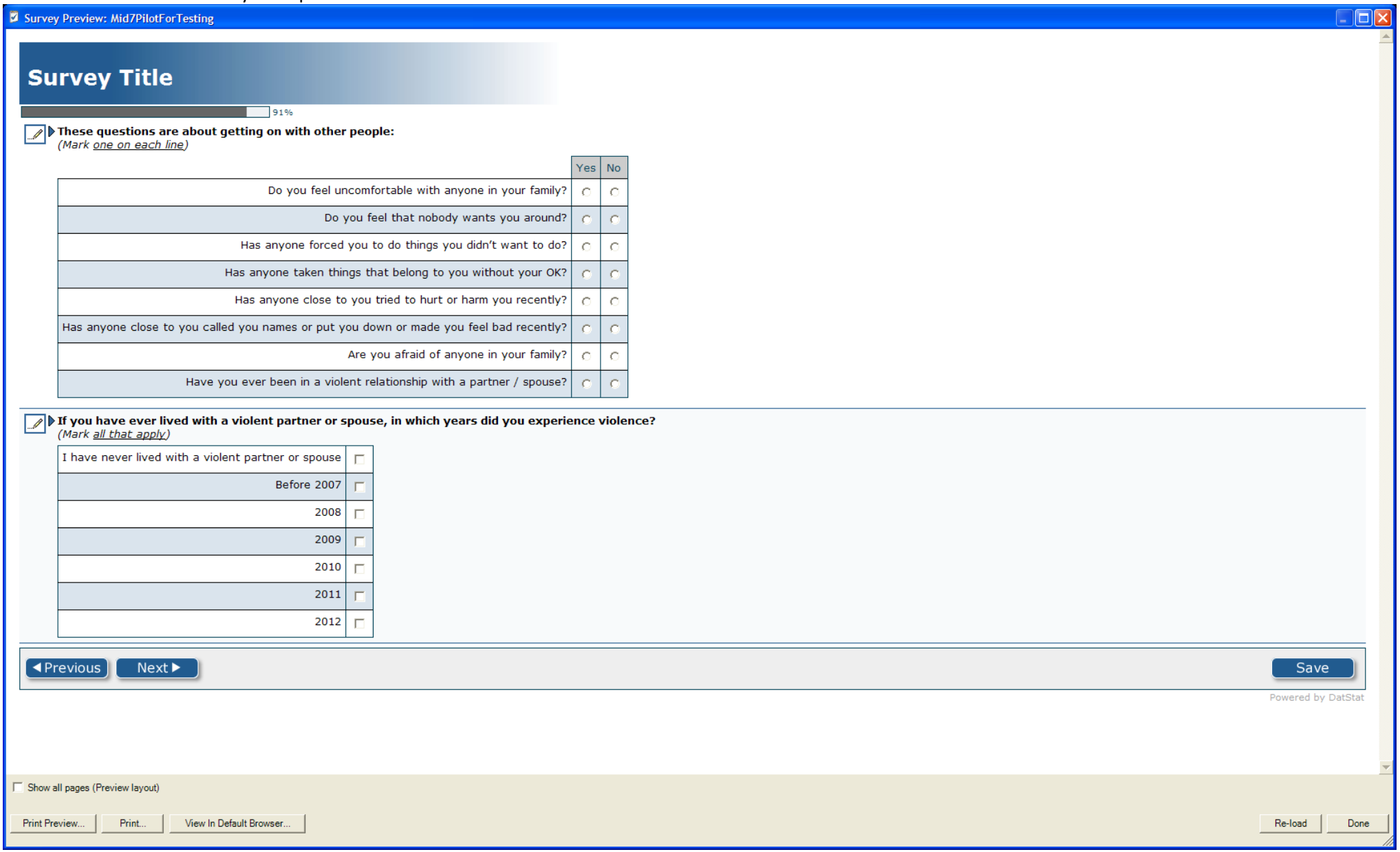

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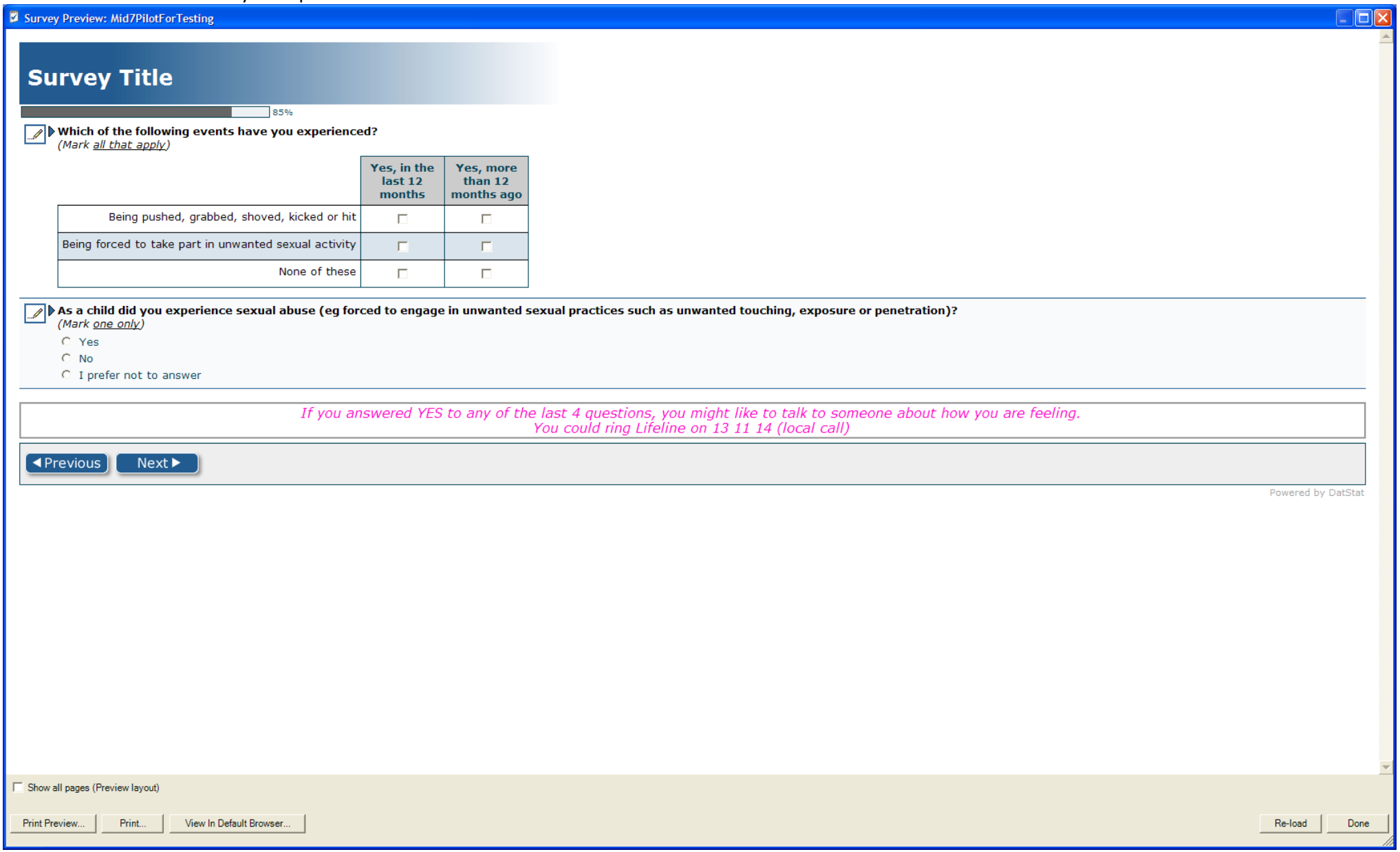

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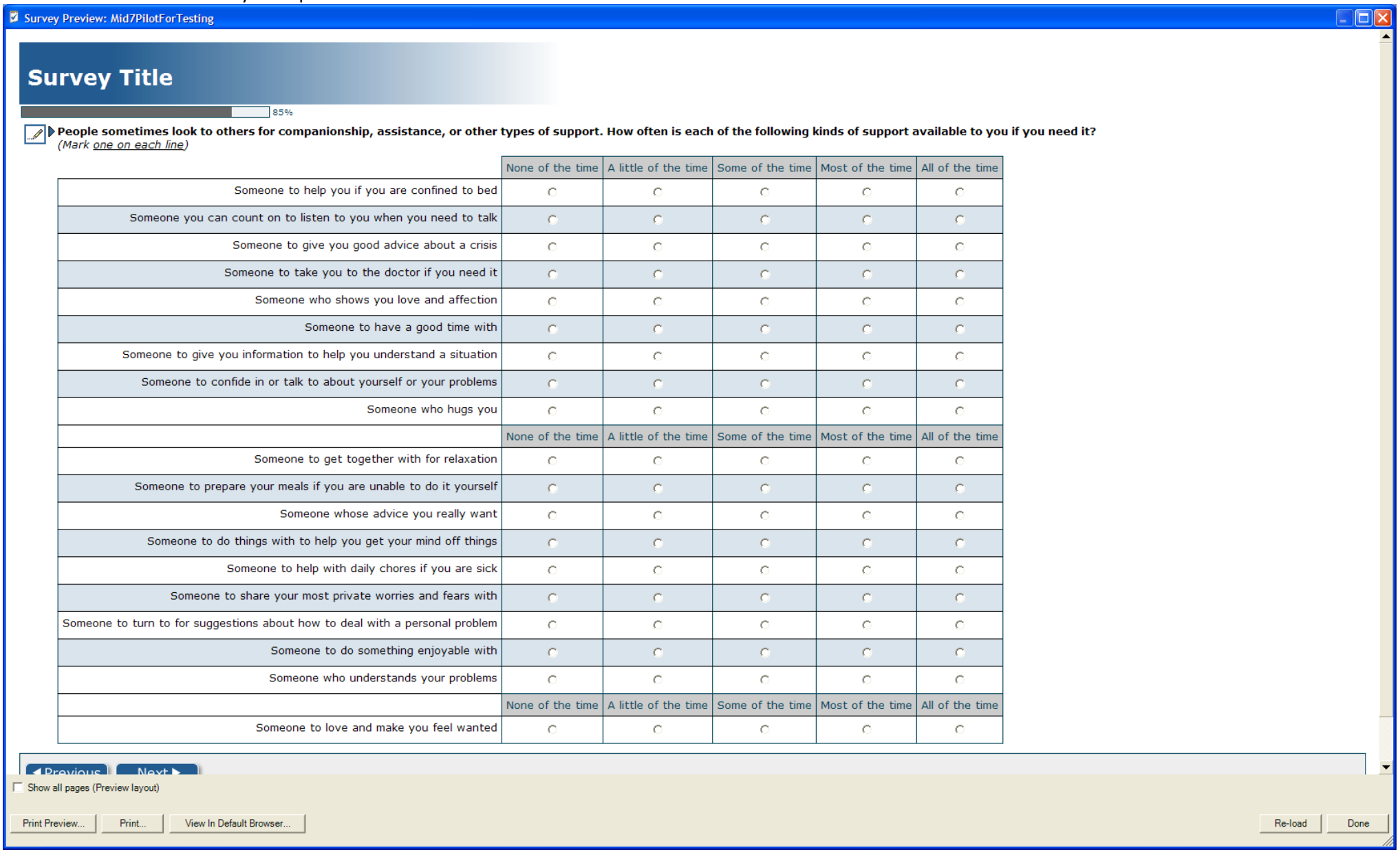

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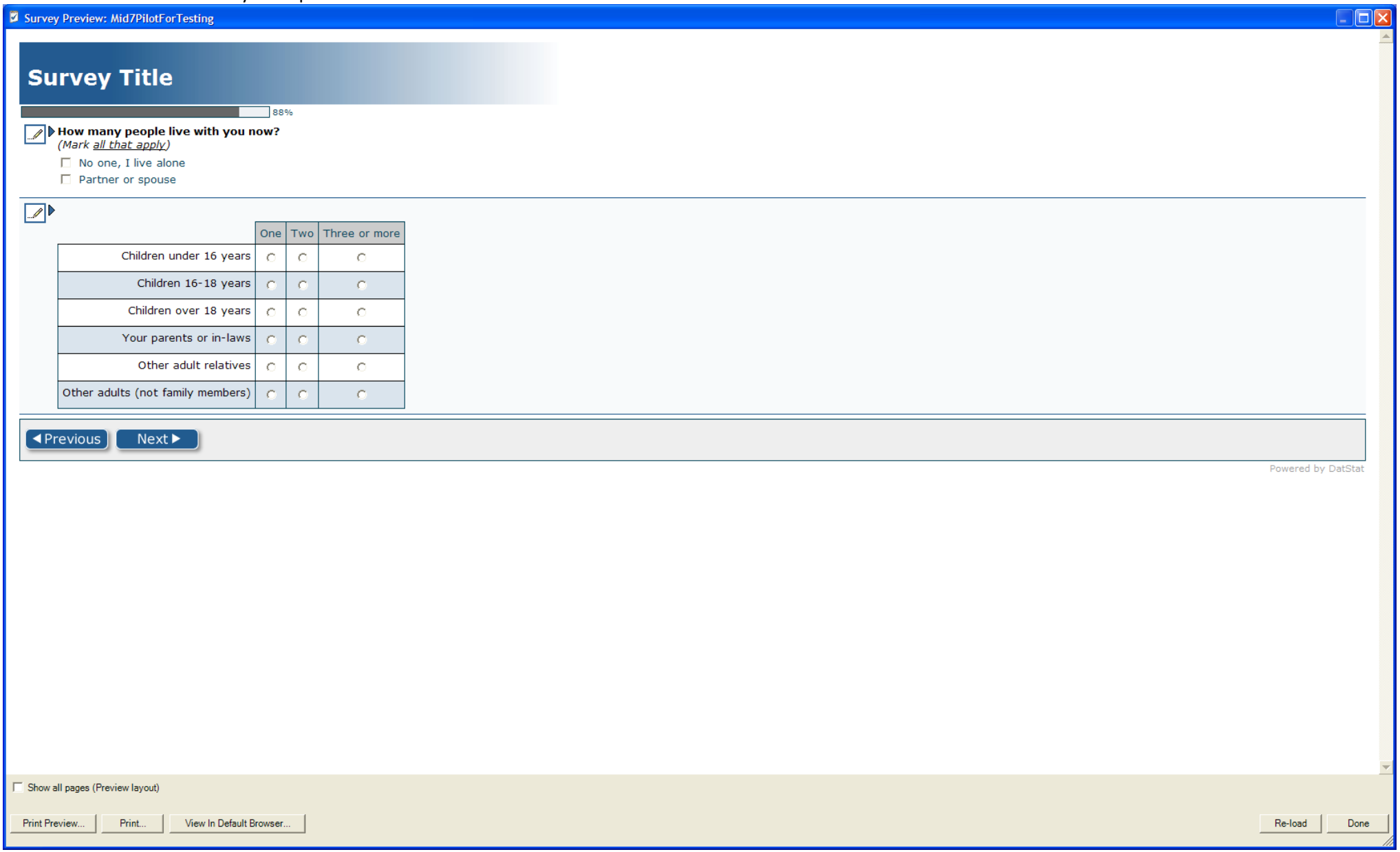

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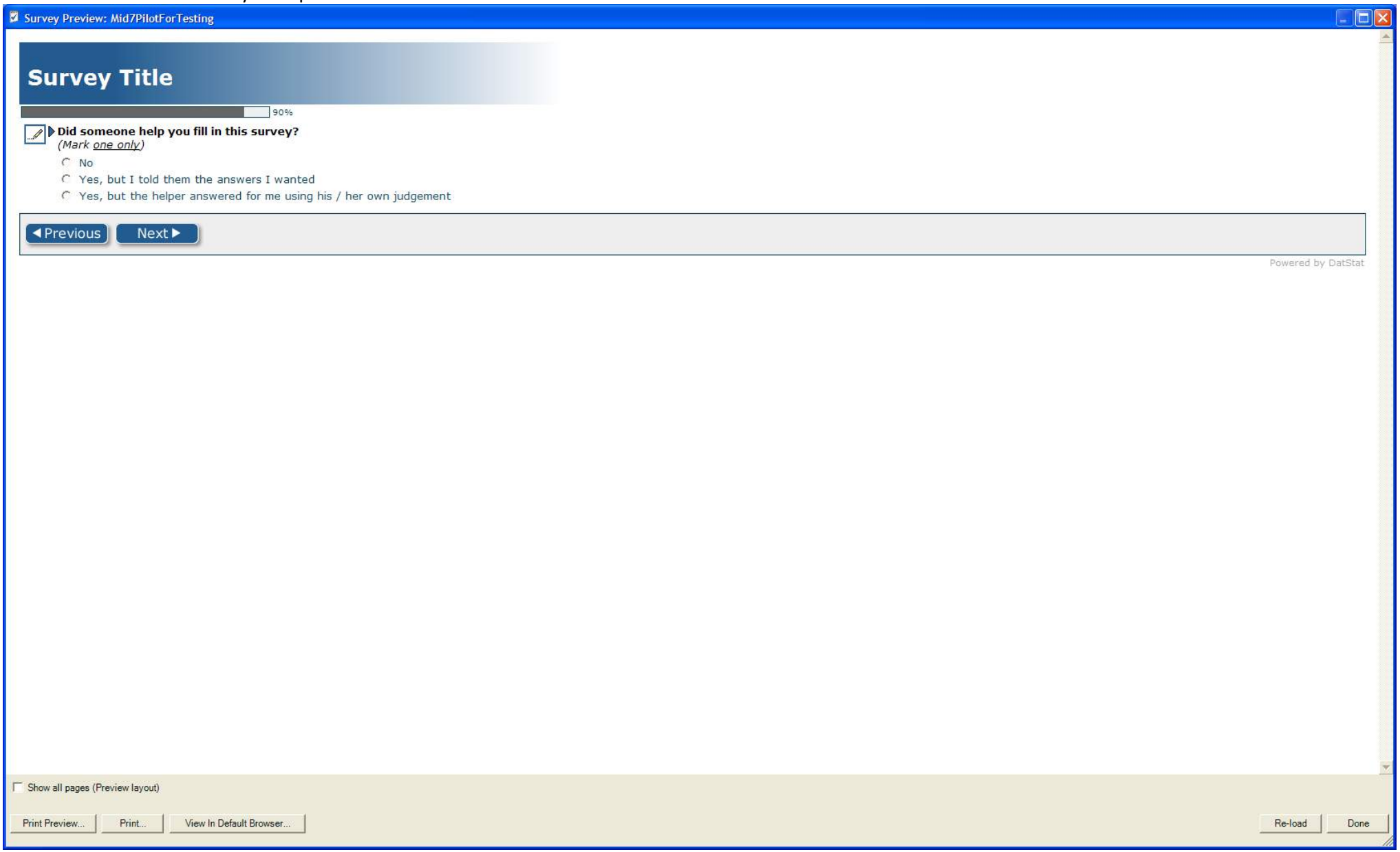

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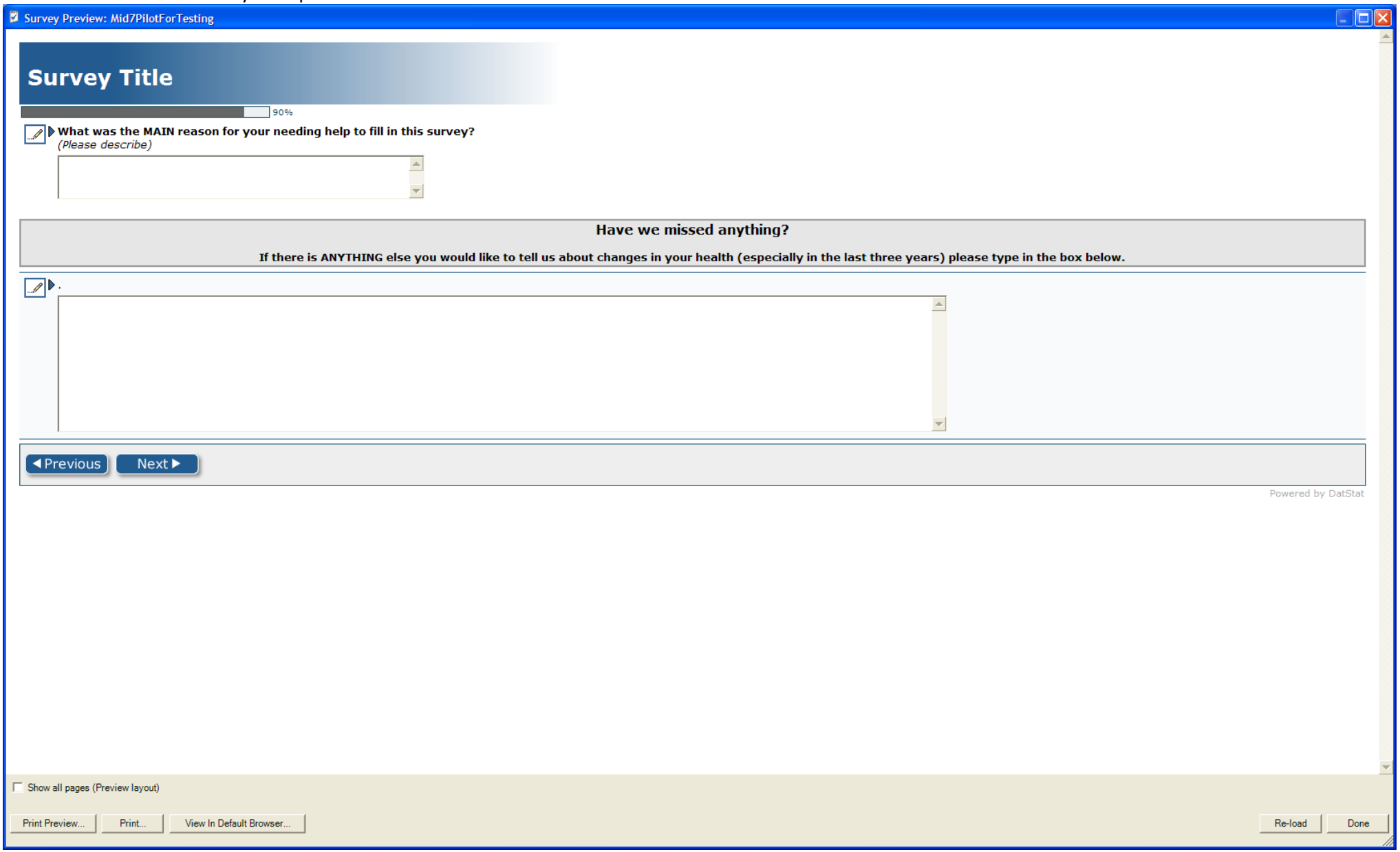

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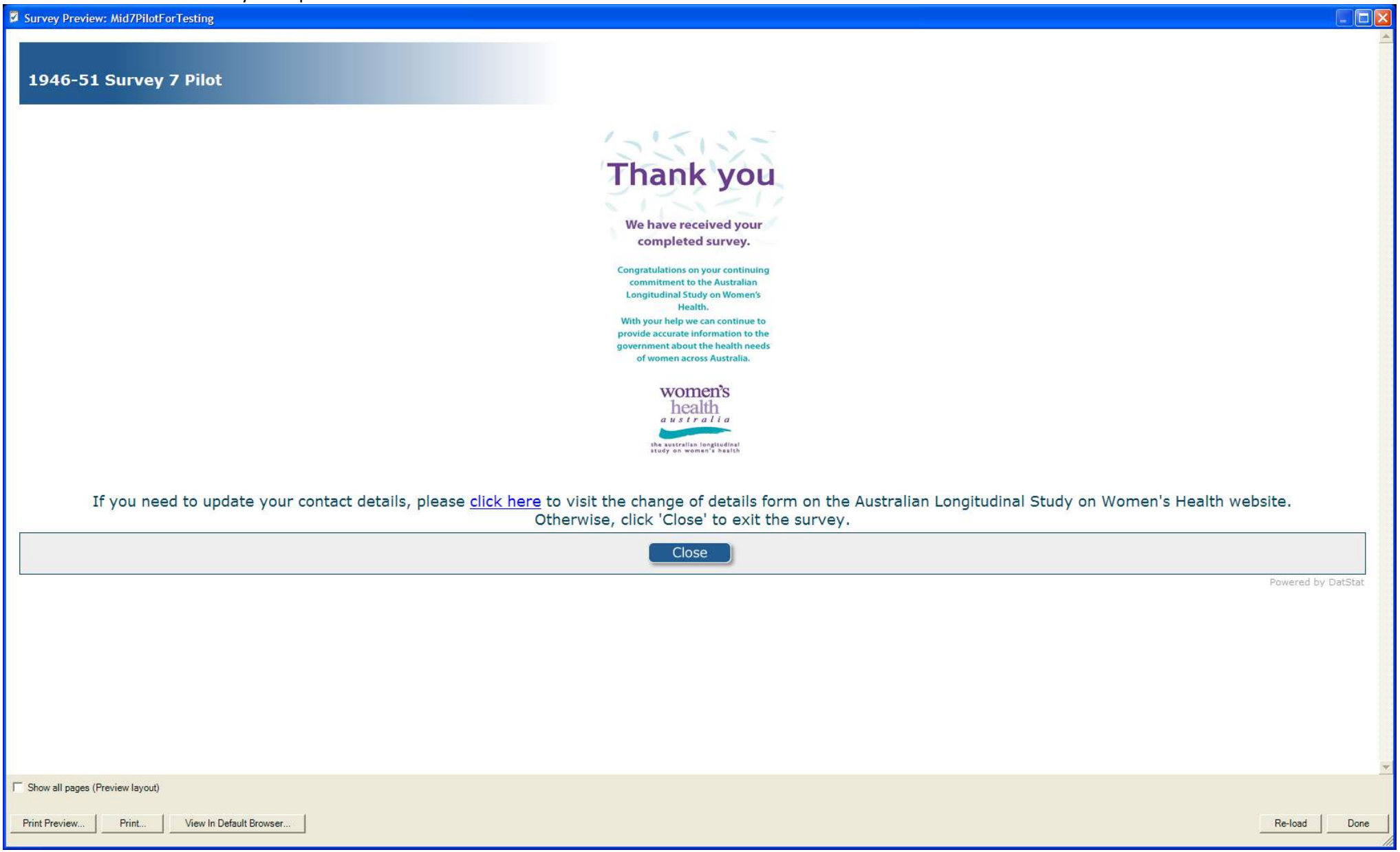

APPENDIX C: MATERIALS FOR RECRUITMENT OF THE NEW YOUNG COHORT

- **C1: Data Linkage Electronic Consent: Differentiation of procedures**
- **C2: Phase 2 Focus Group Interview Schedule**
- **C3: Focus Group Participant Information Sheet**
- **C4: Focus Group Consent Form**
- **C5: Focus Group Survey**
- **C6: Focus Group Poster**
- **C7: Focus Group Evaluation Sheet**
- **C8: Focus Group Survey**
- **C9: Email from MyOpinion company sent to potential pilot participants**
- **C10: Pilot Group Survey**
- **C11: Main survey**
- **C12: Poster**
- **C13: Email to ambassadors**
- **C14: Completed survey email**
- **C15: Recruitment Record Keeping**
- **C16: Social Media Policies and Procedures**

C1- Data Linkage Electronic Consent: Differentiation of procedures

Medicare consent procedure	ALSWH consent procedure
1. Navigates to a secure website managed by the study.	1. Navigates to a secure website managed by ALSWH where the participant clicks on a link to take them to the survey.
2. Is asked to provide their unique study identifier, surname, first name, DOB and email address.	2. The potential participant indicates their consent to participate in the study by clicking a button on the page, and then indicates consent to data linkage by clicking a button on the page (Please see attachment 3 entitled: **Consent and personal details** for the consent question as it has been altered to include other datasets). If consent is not acquired, for both of these steps, the participant will be navigated out of the study. The consent pages need to come prior to the personal details so that the ALSWH does not receive personal and identifying information for people who are not in the study in case a potential participant decides not to participate at this point.
3. Receives an email from the study which will contain a link to the study information page with the consent form.	*[DELETED STEP: An email linking participants to an information page and consent form separate from the survey is not required. Instead ALSWH will provide all the information required within the introduction of the survey then have the participant complete the consent pages, personal details page, and survey questions in one survey. Following this, the participant's consent and personal*

C1- Data Linkage Electronic Consent: Differentiation of procedures

	*details will be separated from survey responses (Refer to attachment 2 entitled: **Security precautions for the online survey process**).Upon completing and submitting the survey, each participant will receive an individual ID number that will be associated with them for the duration of the study. An ID alias will also be generated for each individual correlating to the participant ID, this allows researchers to differentiate between participant response data without having access to the ID that correlates back to the participant's identifying details.*
4. Logs into the site using their unique study identifier and nominates a password.	*[DELETED STEP: participant will already be logged into the site as the process is one continuous survey].*
5. Views a study information page and consent details, populated with details that the person has provided.	3. After a participant consents, they provide their email address, then answer some eligibility questions: • Gender • Date of birth Once they have entered eligible data here, they move on to provide their Medicare number. If they are unable to provide their Medicare number there and then, they can elect to continue and be reminded to provide their number later on. If they don't have a Medicare number, they will be thanked for their time and exited from the survey. After this, those that continue to participate will be asked to provide personal information including: names, residential address details and phone numbers. The opportunity will be provided at the end of the survey to enter: • Postal Address details

C1- Data Linkage Electronic Consent: Differentiation of procedures

	• Secondary email • Relative or friend's details for the purpose of follow-up in case we lose contact with the participant due to out-of-date details. Please see the questions laid out in attachment 3 entitled: **Consent and Personal details**. This document will show the questions as they will be seen by a participant. These questions cover the relevant fields required on the Medicare Participant Consent form provided to ALSWH. It is important to ask for the Medicare number prior to personal details as it is a required question and some may choose not to participate as a result. If participants do not wish to provide this number, they will be navigated away from the survey.
6. Indicates their consent to participate in the study by clicking a button on the page.	4. Participant clicks 'next' after entering personal information and continues on to complete the survey online.
7. Receives another email from the study containing a copy of their consent form and a link to the questionnaire.	5. Personal information entered by participant will be separated from survey responses and an identification number and ID alias will be allocated in order to de-indentify the data.
8. Clicks on the link and completes the questionnaire online.	**STEP COVERED** – see above step
9. Receives a third email from the study acknowledging completion of the form.	6. Receives an email from the study acknowledging completion of the survey and thanking them for taking part.
10. The study will then electronically forward the relevant details of each person who has consented to the release of the Medicare and PBS data to DHS	7. ALSWH will then electronically forward the relevant details of each person who has consented to the release of Medicare and PBS **and other dataset** data to DHS. The DHS will verify the participant details against their records to confirm each one

C1- Data Linkage Electronic Consent: Differentiation of procedures

	fits the ALSWH inclusion criteria (Female with a Medicare number born 1989-1994), reporting this back to the ALSWH.

C2

women's health australia
the australian longitudinal study on women's health

***Project Title*: The 1989-94 Cohort Of The Australian Longitudinal Study On Women's Health**

***Chief Investigators*:**

The University of Newcastle	**The University of Queensland**
Prof Julie Byles	Prof Annette Dobson
Dr Deborah Loxton	Prof Wendy Brown
Assoc Prof. David Sibbritt	Prof Christina Lee
Dr Meredith Tavener	A/Prof Jayne Lucke
	Prof Gita Mishra
	A/Prof Nancy Pachana
	Dr Leigh Tooth

FOCUS GROUP INTERVIEW SCHEDULE

Put out information sheets, consent forms, demographic survey, evaluation sheets and distribute devices and stop watches.

Identify facilitator/s, invite participants to have something to eat or drink as the group is conducted.

Ask: Has everyone read and understood the Information Sheet?

Ask: Does anyone have any questions?

If participants wish to take part, sign and hand in the consent form.
Complete the demographic survey. Collect and check that consent forms have been signed.
Collect the surveys.

DISCUSSION

Ask: Everyone to respect the confidentiality of the group, and not to divulge the specific content of the discussion to people outside of the group.

Please do not identify yourself or others in the group, during the audio recording of the discussion.

Remind participants they have the right not to respond to any questions that they do not wish to respond to.

Ask: Any questions?
Turn on tape recorder. The tape recorder is now switched on.

Thanks for volunteering to participate in this focus group. We are going to discuss the use of an internet survey on young women's health and wellbeing. The focus of our discussion is the online survey you are about to complete.

We don't need you to answer the online questionnaire truthfully; we just want to know your perceptions of the survey; the questions, the design, the structure and the method of delivery.

The online survey that you fill out will be destroyed within 24 hours without anyone assessing your responses. Until then, they will be stored on secure servers at the University of Newcastle. None of the questions are compulsory so you can leave them blank if you prefer.

Background
Potential participants will be approached by Medicare Australia, inviting them to take part in the online survey. Each participant will be provided with a URL link that will take them to the secure survey.

Participants to commence the survey
At this point, you are the potential participant. I would ask that you read through the evaluation sheet in front of you. When you are ready to trial the survey, please start the stop watch and begin.

Remember, if you prefer not to answer all the questions, leave them blank.
Please fill out the evaluation form. Notice that it asked specifically about the device on which you completed it. This form is completely anonymous and will not be associated with your personal details.

When all participants have completed the survey and the evaluation form, move on to the discussion.

Discussion
Thank you for completing the survey and evaluation form.

I would like to discuss a few aspects of the survey with you as a group. Please remember to respect the confidentiality of the discussion.

You were asked to consent if you wished to do the survey. What did you think about the consent to participate?

Prompt: Was it clearly explained?

In other studies we've conducted, we have linked survey information to information held by Medicare. We do this by removing names and personal details and just using identification numbers. The sort of information Medicare provides is only about services used, not about diagnoses.

Prompt: Is this aptly explained in the survey?

Once you had responded to the consent, you were asked to fill in your personal details.

How do you feel about giving your personal details?

Prompt: What concerns might you have?

After filling out your personal details, you are asked about your health and lifestyle.

How does everybody feel about these questions?

Prompt: Are there any concerns when answering the survey questions?

What do you feel about the conclusion of the survey?

Prompt: Does it finish well?

How did the survey present on the devices you each used to complete it.

Prompt: Was it easy or hard to complete, could you see the whole question, did the device discourage you from commencing/continuing the survey?

Thank you for your feedback.

I would like to ask you a question about social media use. We are aware that Facebook is a popular social media device. If Women's Health Australia was unable to have a Facebook page, what are some other strategies to create awareness with the general public?
Prompt: A website? Etc.

Is there anything you would like to add?

Prompt: Provide a summary of the main discussion findings and give participants the opportunity to change or delete anything they have said.

Collect evaluation sheets.

If anyone is feeling distressed after this discussion, please speak with us privately or you may wish to discuss your feelings with someone else at Lifeline on 13 1114.

Thank you for your time – you have been a great help to our research! If you have opted to receive a summary of the results, they will be posted or emailed shortly.

C3

women's health australia

the australian longitudinal study on women's health

***Project Title*: The 1989-94 Cohort Of The Australian Longitudinal Study On Women's Health**

Research team led by Project Director: Prof Annette Dobson

FOCUS GROUP PARTICIPANT INFORMATION SHEET

What is the focus group and project about?

We are setting up an internet survey to find out about young women's health and wellbeing. We would like your help to work out the best way to do this. The internet survey is part of a project funded by the Australian Government Department of Health and Ageing.

Why is this project important?

It is important to know about the health and wellbeing of young Australian women so that appropriate services and programs can be developed. The findings from women in their late teens and twenties can then be compared to older women so we know more about the changing health of young women.

What will you be asked to do?

You will be asked to participate in a focus group for about one hour. The focus group will be conducted in a community location convenient for you. At the start of the focus group you will be asked to read and sign a consent form. In the focus group you will be presented with a draft version of the survey on young women's health and wellbeing. We want to know what you think about its content, potential structure and design.

At the beginning of the focus group you will be asked to answer some short questions on your age, where you live, whether you are working or studying, and how you access the internet. You will not need to include your name on this survey.

What are the benefits and risks of joining this focus group?

The focus group is your opportunity to give your opinion and make a difference. We are working for better health experiences and services for young Australian women. You can help us by giving your views on an internet survey about women's health and wellbeing. **We don't need to know about your personal experiences, just your opinions about how we might ask about these issues.** There is a small risk you may feel uncomfortable discussing a survey on women's health. If you start to feel upset during the focus group, you can choose to leave the group or speak privately with the project staff after the focus group has ended.

You may also wish to discuss your feelings with someone else at Lifeline on 13 1114.

Will the focus group be recorded and can I change what I have said?

The focus groups will be audio recorded. After the focus group, the recording will be transcribed by qualified personnel. You can feel free to review and edit the recording or transcript of the focus group discussion. During transcribing, any information that might identify you or another participant will be removed. Your decision to take part or not will not affect you, or your access to health services, in any way.

This study adheres to the Guidelines of the ethical review process of The University of Queensland and The University of Newcastle. Dr Deborah Loxton is the Deputy Director of this project and whilst you are free to discuss the project with her (contactable on 1800 068 081), if you have any complaints about this project and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Research Ethics Officer (02) 4921 6333 or write to them at the University of Newcastle, University Drive, Callaghan, NSW, 2308. You could also contact the University of Queensland's Human Research Ethics Officer on (07) 3365 3924 or write to them at the University of Queensland, St Lucia, QLD, 4072.

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What are your rights?
If you agree to take part, you are free to withdraw from the study at any time without saying why. Your confidentiality and privacy will be maintained at all times, and all identifying information will be removed when the recording is transcribed. Any results will be presented in summary form and no individual will be able to be identified from any reports resulting from this study.

What will happen with your information?
All data will be securely stored on password protected computers at the University of Queensland and the University of Newcastle, while any hard copies will be securely stored in locked filing cabinets at the Research Centre for Gender Health and Ageing on the University of Newcastle premises for a minimum of five years. Any identifying information will be removed and replaced with a code.

Does the project have ethical approval?
This study adheres to the Guidelines of the ethical review processes of The University of Newcastle (Approval number H- 2011-0154). This project also has ethical approval from The University of Queensland (Approval number 2011000809). Whilst you are free to discuss your participation in this study with the Project staff on freecall 1800 068 081, email: whasec@newcastle.edu.au, if you would like to speak to an officer of the University not involved in the study, you may contact the University of Newcastle Ethics Officer on (02) 4921 6333.

Need further information?
The research staff will be able to discuss any questions you may have and will provide guidance on where to get further information or assistance. A copy of the research findings will be made available to you by email or post if you wish.

We greatly appreciate your help and cooperation in this important study. Thank you very much.

Annette Dobson

Professor Annette Dobson
Project Director

Research Team:

The University of Newcastle	**The University of Queensland**
Prof Julie Byles	Prof Wendy Brown
Dr Deborah Loxton	Prof Christina Lee
Assoc Prof. David Sibbritt	A/Prof Jayne Lucke
	Prof Gita Mishra
	A/Prof Nancy Pachana
	Dr Leigh Tooth

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women's health australia
the australian longitudinal study on women's health

***Project Title*: The 1989-94 Cohort Of The Australian Longitudinal Study On Women's Health**

***Chief Investigators*:**

The University of Newcastle	**The University of Queensland**
Prof Julie Byles	Prof Annette Dobson
Dr Deborah Loxton	Prof Wendy Brown
Assoc Prof. David Sibbritt	Prof Christina Lee
	A/Prof Jayne Lucke
	Prof Gita Mishra
	A/Prof Nancy Pachana
	Dr Leigh Tooth

FOCUS GROUP CONSENT FORM

I have read the participant information sheet for the focus group: **The 1989-94 Cohort of The Australian Longitudinal Study on Women's Health**, and the focus group has been explained to me**.** I have had the opportunity to ask questions about the focus group and they have been answered to my satisfaction.

I understand that:

- I will be asked to participate in a focus group and that this will be audio recorded for research use in a manner that does not reveal my identity.
- My confidentiality and privacy will be maintained at all times. The fact of my participation in this focus group and the information I provide will not be revealed to anyone except the research staff directly involved in this study.
- De-identified information (including direct quotes) and my completed survey containing unidentified demographic information may be used in project reports and publications.
- All data will be stored in a secure manner at The University of Newcastle and The University of Queensland. All identifying information will be removed and replaced with a code.
- My participation is voluntary and I am free to stop participating at any time without penalty and without stating a reason.
- I agree to participate in this focus group.

PLEASE PRINT YOUR NAME: _____

SIGNED: _____ DATE: _____

I would like to receive a summary of the research findings: YES☐ NO☐

If yes, please provide an email address: _____

Or, a postal address: _____

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women's health australia
the australian longitudinal study on women's health

***Project Title*: The 1989-94 Cohort Of The Australian Longitudinal Study On Women's Health**

FOCUS GROUP SURVEY

Thank you for taking part in the focus group discussion. This survey will be used to make sure that we have spoken with a range of young women from different parts of Australia. Please try and answer every question. There is no need to put your name on this survey.

If you have any questions about the survey, please ask.

1. What is your age? _____

2. What is your occupation? _____

3. How do you manage on the income you have available?
(Mark <u>one only</u>)

It is impossible	☐
It is difficult all the time	☐
It is difficult some of the time	☐
It is not too bad	☐
It is easy	☐

3. What is your highest level of education? (please circle)

Year 10 Year 11 Year 12 TAFE/Vocational University

4. Are you currently working? (please circle)

Yes, Full-time Yes, Part-time Yes, casual No, not working

5. Are you currently studying? (please circle)

Yes, Full-time Yes, Part-time No, not studying

6. How often do you use the internet? (please circle)

Daily Weekly Monthly Rarely Never

7. How do you use the internet? (please circle **all** that apply)

Computer Smartphone Tablet Other (please specify)_____

Thank you for your participation.

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C6

Are you a young woman aged 18 -23 years?

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YES!

Join a 1 hour discussion in your local area to help us create a survey that is relevant to you.

Help research by giving us your opinion about an internet survey on women's health and wellbeing.

Women who take part in a group will be reimbursed for travel expenses with a **$20 GIFT CARD.**

To get involved, contact us!
Email us: whasec@newcastle.edu.au
Phone toll free: 1800 068 081

Visit our website: www.alswh.org.au

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***Project Title*: The 1989-94 Cohort Of The Australian Longitudinal Study On Women's Health**

EVALUATION SHEET
We would like to know what you think about the survey.
We may make changes before sending it to others in your age group this year.
Please help by answering the questions below.

1. How long did it take to complete the survey? _____ MINS

2. Did you think the survey was:

Too short ☐

Just right ☐

Too long ☐

3. Which of the following devices did you use to view the survey? *(Circle device)*

Computer/Laptop Smartphone Tablet (iPad)

4. Were you happy with the way your device presented the survey? Yes / No
Why / Why not?

_____

_____

_____

_____

5. Were there any questions you found difficult to answer on your device? Yes / No
If Yes, which questions and why?

_____

_____

_____

_____

Please turn over ➔

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6. On a scale of 1 – 10 (1 being appalling and 10 being excellent) please rate:

Survey design and layout	☐
Survey instructions	☐
Question content	☐

7. What did you like about the survey?

   Why?

_____

_____

8. What did you dislike about the survey?

   Why?

_____

_____

9. Do you have any other ideas, comments or concerns about the survey (wording, layout, privacy)?

_____

_____

_____

_____

Thank you for your participation

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

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C8

Phase 2 Focus Groups Survey

Collection: LOGIN
Contains:

This is the first survey for women born between 1989-94

Thank you for participating in this important study

INSTRUCTIONS

• Please answer every question you can. If you are unsure about how to answer a question, mark the response for the closest answer to how you feel.

• Please answer the survey for the time period indicated even if you are pregnant or your circumstances are unusual in some way.

• Questions marked with a star are compulsory. Often this is because your response will alter the path of the survey, tailoring it so that unnecessary content is skipped.

• If you need help to answer any questions, please ring 1800 068 081 (This is a FREECALL number).

If you are concerned about any of your health experiences and would like some help, you may like to contact:

• your nearest Women's Health Centre or Community Health Centre

• your doctor for advice about who would be the best person in your community for you to talk to.

If you feel distressed now and would like someone to talk to, you could ring Lifeline on 131 114 (local call).

Page Break

C8

I HAVE READ THE INFORMATION SHEET THAT WAS MAILED TO ME WITH MY INVITATION.

I understand that:

• Confidentiality will be maintained at all times,

• My personal details will be stored safely on secure servers at the University of Newcastle and the University of Queensland,

• My answers will not be linked with my personal details and so will not be identifiable,

• This is a longitudinal survey which will be conducted annually,

• Only those staff members within the project that are given specific authorization will be able to access my personal details for the purpose of project upkeep and maintenance,

• My participation is voluntary and I am free to discontinue involvement at any time

Question: Q51

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

1. **As a result, I consent to participate**

● Yes ● No

Page Break

C8

I agree to the research team following health and other records relating to me, including hospital and health service use records and cancer registers and other chronic conditions registers. I also understand this means I agree to Medicare releasing information concerning services provided to me under Medicare, The Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, for the duration of the study, as outlined above.

Question: Q50

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

2. **I agree**

● Yes ● No

Page Break

C8

You have received a letter from Medicare on our behalf.

We don't receive any of your personal details from Medicare.

We need you to give us your name and contact details so we can let you know when it is time to do the next survey.

All of your personal information will be kept separate from your responses to the rest of the survey so your answers will be anonymous.

Question: Q269

3.GIVEN NAME

Question: Q43

4.SECOND NAME

Question: Q44

5.THIRD NAME

Question: Q271

6.FAMILY NAME

Page Break

C8

Question: Q105

7.MAIDEN NAME

Question: Q107

8.PREFERRED NAME

Page Break

Question: Q272

9.EMAIL ADDRESS

Question: Q273

10.CONFIRM EMAIL ADDRESS

Page Break

C8

Question: Q1

11.What is your date of birth?

(Type date as displayed)

dd/mm/yyyy

Question: Q4

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

12. Are you living overseas?

- Yes
- No

Auto Page Break

C8

Question: Q118
Show if: (Q4 = 1:[Yes])

13.Overseas Address

Line 1

Question: Q119
Show if: (Q4 = 1:[Yes])

14.*

Line 2

Question: Q120
Show if: (Q4 = 1:[Yes])

15.*

Line 3

Question: Q121
Show if: (Q4 = 1:[Yes])

16.Country

Line 4

Page Break

C8

Collection: POSTAL_ADDRESS
Contains: Q45, Q270, Q274, Q275, Q57
Show if: (Q4 = 2:[No])

What is your *postal* address?

Question: Q45

17.PRE-ADDRESS:

Question: Q270

18.ADDRESS:

Question: Q274

19.TOWN / SUBURB:

C8

Question: Q275

Scale Summary		
Code	Label	Show-If
1	NSW	
2	NT	
3	QLD	
4	SA	
5	TAS	
6	VIC	
7	WA	

20. STATE:

-- Select One --

Question: Q57

21.POSTCODE:

Auto Page Break

C8

Question: Q46
Show if: (Q57 was-answered)

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

22. Is your *residential* address the same as your postal address?

- ● Yes
- ● No

Auto Page Break

C8

Collection: RESIDENTIAL_ADDRESS
Contains: Q2, Q3, Q47, Q48, Q49
Show if: (Q46 = 2:[No])

What is your *residential* address?

Question: Q2

23.PRE-ADDRESS:

Question: Q3

24.ADDRESS:

Question: Q47

25.TOWN / SUBURB:

C8

Question: Q48

Scale Summary		
Code	Label	Show-If
1	NSW	
2	NT	
3	QLD	
4	SA	
5	TAS	
6	VIC	
7	WA	

26. STATE:

-- Select One --

Question: Q49

27.POSTCODE:

Page Break

C8

Question: Q5

Scale Summary		
Code	Label	Show-If
1	Excellent	
2	Very good	
3	Good	
4	Fair	
5	Poor	

28. In general would you say your health is: *(Mark one only)*

- Excellent
- Very good
- Good
- Fair
- Poor

C8

Question: Q6

29. Where do you get information about your health?
(Mark all that apply)

- [ ] School, University, TAFE
- [ ] Friends
- [ ] Internet (please expand)
- [ ] Mother / father, sister / brother or other family member
- [ ] Nurse
- [ ] Doctor
- [ ] Family planning or sexual health clinic
- [ ] Youth or community services (e.g. mother's group)
- [ ] TV / radio, magazines, poster / leaflet
- [ ] Other (please specify)
- [ ] **None of these**

C8

Question: Q10

Scale Summary		
Code	Label	Show-If
1	Yes, always	
2	Yes, but only for certain things, such as	
3	No	
4	Don't care	

30. In general, do you prefer to see a female doctor? *(Mark one only)*

- Yes, always
- Yes, but only for certain things, such as
- No
- Don't care

Page Break

C8

Question: Q11

Scale Summary		
Code	Label	Show-If
1	Yes, I have my own card	
2	Yes, I have a copy of my parent's card	
3	No, I need to borrow my parent's card	
4	No, I don't have one	
5	Don't know	

31. Do you have your own Medicare card? *(Mark one only)*

- Yes, I have my own card
- Yes, I have a copy of my parent's card
- No, I need to borrow my parent's card
- No, I don't have one
- Don't know

C8

Question: Q12

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

32. Do you have a Health Care Card? *This is a card that entitles you to discounts and assistance with medical expenses. This is not the same as a Medicare card.*
(Mark one only)

● Yes ● No

Page Break

C8

Question: Q15

Scale Summary		
Code	Label	Show-If
1	Year 10 or below	
2	Year 11 or equivalent	
3	Year 12 or equivalent	
4	Certificate I / II	
5	Certificate III / IV	
6	Advanced Diploma / Diploma	
7	Bachelor degree	
8	Graduate diploma / Graduate certificate	
9	Postgraduate degree	

33. What is the highest level of education you have completed? *(Mark one only)*

- Year 10 or below
- Year 11 or equivalent
- Year 12 or equivalent
- Certificate I / II
- Certificate III / IV
- Advanced Diploma / Diploma
- Bachelor degree
- Graduate diploma / Graduate certificate
- Postgraduate degree

C8

Question: Q7

Scale Summary		
Code	Label	Show-If
0	0	
1	1 - 15	
2	16 - 29	
3	30 - 34	
4	35 - 40	
5	41 - 49	
6	50 or more	

34. In a usual week, how many hours do you spend doing paid work?

-- Select One -- Hours

Question: Q52

Scale Summary		
Code	Label	Show-If
0	0	
1	1 - 15	
2	16 - 29	
3	30 - 34	
4	35 - 40	
5	41 - 49	
6	50 or more	

35. In a usual week, how many hours do you spend *studying*?

-- Select One -- Hours

C8

Question: Q17

Scale Summary		
Code	Label	Show-If
1	It is impossible	
2	It is difficult all the time	
3	It is difficult some of the time	
4	It is not too bad	
5	It is easy	

36. How do you manage on the income you have available? *(Mark one only)*

- It is impossible
- It is difficult all the time
- It is difficult some of the time
- It is not too bad
- It is easy

Page Break

C8

Question: Q18

Scale Summary		
Code	Label	Show-If
1	I am single	
2	I am engaged	
3	I am married	
4	I am living with a partner	
5	Other (please specify)	

37. What is your current relationship status? *(Mark one only)*

- ● I am single
- ● I am engaged
- ● I am married
- ● I am living with a partner
- ● Other (please specify)

C8

Question: Q8

38. What are your living arrangements? (Mark all that apply)

- [ ] I live alone
- [ ] I live with one or both parents
- [ ] I live with other adults
- [ ] I live with my male partner
- [ ] I live with my female partner
- [ ] I live with children
- [ ] Other (please specify)

Page Break

C8

Question: Q116

Scale Summary		
Code	Label	Show-If
1	I am exclusively heterosexual	
2	I am mainly heterosexual	
3	I am bisexual	
4	I am mainly homosexual (lesbian)	
5	I am exclusively homosexual (lesbian)	
6	I don't know	
7	I don't want to answer	

39. Which of these most closely describes your sexual orientation? *(Mark one only)*

- I am exclusively heterosexual
- I am mainly heterosexual
- I am bisexual
- I am mainly homosexual (lesbian)
- I am exclusively homosexual (lesbian)
- I don't know
- I don't want to answer

C8

Question **Block:** C2
Contains: Q19, Q20, Q21, Q22, Q23, Q24, Q25, Q26, Q27, Q28, Q29, Q30, Q31, Q32, Q33, Q34, Q35, Q36, Q37, Q38, Q39, Q40, Q41, Q42

Scale Summary		
Code	Label	Show-If
0	Never	
1	Rarely	
2	Sometimes	
3	Often	

40. In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
(a) Allergies, hay fever, sinusitis	●	●	●	●
(b) Headaches / migraines	●	●	●	●
(c) Severe tiredness	●	●	●	●
(d) Indigestion (heart burn)	●	●	●	●
(e) Breathing difficulties	●	●	●	●
(f) Stiff or painful joints	●	●	●	●
(g) Back pain	●	●	●	●
(h) Problems with one or both feet	●	●	●	●
(i) Urine that burns or stings	●	●	●	●
(j) Leaking urine	●	●	●	●
(k) Constipation	●	●	●	●
(l) Haemorrhoids (piles)	●	●	●	●

C8

	Never	Rarely	Sometimes	Often
(m) Other bowel problems	●	●	●	●
(n) Vaginal discharge or irritation	●	●	●	●
(o) Premenstrual tension	●	●	●	●
(p) Irregular periods	●	●	●	●
(q) Heavy periods	●	●	●	●
(r) Severe period pain	●	●	●	●
(s) Skin problems	●	●	●	●
(t) Difficulty sleeping	●	●	●	●
(u) Depression	●	●	●	●
(v) Episodes of intense anxiety (eg panic attacks)	●	●	●	●
(w) Other mental health problems	●	●	●	●
(x) Palpitations (feeling that your heart is racing or fluttering in your chest)	●	●	●	●

Page Break

C8

Question: Q9

41. Have you ever been diagnosed or treated for:
(Mark all that apply)

- [ ] Insulin dependent (Type 1) diabetes
- [ ] Non-insulin dependent (Type 2) diabetes
- [ ] Heart disease
- [ ] Hypertension (high blood pressure)
- [ ] Low iron (iron deficiency or anaemia)
- [ ] Asthma
- [ ] Bronchitis
- [ ] Depression
- [ ] Anxiety disorder
- [ ] Endometriosis
- [ ] Thrombosis
- [ ] Polycystic Ovary Syndrome
- [ ] Urinary tract infection
- [ ] Chlamydia
- [ ] Genital herpes

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- [ ] Genital warts (HPV)
- [ ] HIV or AIDS
- [ ] Hepatitis B or C
- [ ] Skin cancer
- [ ] Other cancer (please specify)
- [ ] Other major physical illness (please specify)
- [ ] Other major mental illness (please specify)
- [ ] Other sexually transmitted infection (please specify)
- [ ] Other (please specify)
- [ ] **None of these conditions**

Page Break

C8

Question **Block:** C4
Contains: Q67, Q68, Q69

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

42. Within the last two years, have you had:

(Mark one on each line)

	Yes	No
(a) A Pap test?	●	●
(b) Your blood pressure checked?	●	●
(c) Your skin checked (eg spots, lesions, moles)?	●	●

Question: Q70

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

43. Have you *ever* had a vaccination for HPV (genital warts, cervical cancer)? *(Mark one only)*

● Yes

● No

Page Break

C8

Question: Q128

Scale Summary		
Code	Label	Show-If
1	Daily	
2	Less than daily	
3	Not at all	

44. Do you *currently* smoke tobacco?
(Mark one only)

- Daily
- Less than daily
- Not at all

Question: Q129

Scale Summary		
Code	Label	Show-If
1	Daily	
2	Less than daily	
3	Not at all	

45. In the *past*, have you smoked tobacco?
(Mark one only)

- Daily
- Less than daily
- Not at all

Page Break

C8

Question: Q13

46.At what age did you start drinking alcohol?

☐ years old

Question: Q109

Scale Summary		
Code	Label	Show-If
0	I never drink alcohol	
1	Less than once a month	
2	Less than once a week	
3	On 1 or 2 days a week	
4	On 3 or 4 days a week	
5	On 5 or 6 days a week	
6	Every day	

47. How often do you usually drink alcohol? *(Mark one only)*

- ● I never drink alcohol
- ● Less than once a month
- ● Less than once a week
- ● On 1 or 2 days a week
- ● On 3 or 4 days a week
- ● On 5 or 6 days a week
- ● Every day

C8

Question: Q110

Scale Summary		
Code	Label	Show-If
1	1 or 2 drinks per day	
2	3 or four drinks per day	
3	5 to 8 drinks per day	
4	9 or more drinks per day	

48. On a day when you drink alcohol, how many standard drinks do you usually have? *(Mark one only)*

- 1 or 2 drinks per day
- 3 or four drinks per day
- 5 to 8 drinks per day
- 9 or more drinks per day

C8

Question: Q111

Scale Summary		
Code	Label	Show-If
0	Never	
1	Less than once a month	
2	About once a month	
3	About once a week	
4	More than once a week	

49. How often do you have five or more standard drinks of alcohol on one occasion? *(Mark one only)*

- Never
- Less than once a month
- About once a month
- About once a week
- More than once a week

Page Break

C8

Remember that any information you give us is kept confidential.

The following questions asks about the use of drugs for *non-medicinal* purposes. We want to know about general patterns of use. Please do not give details of specific instances of use. *(Mark all that apply).*

Question: Q53

50. Have you tried Marijuana?
(Cannabis, pot, grass, weed, ya(r)ndi, rope, mull, dope, skunk, bhang, ganja, hash, chronic, reefer, joint, cone or spliff).
(Mark all that apply)

- ☐ In the last 12 months
- ☐ More than 12 months ago
- ☐ Never

Question: Q55

51. Have you tried any other illicit drugs? (Ice, Speed, GHB, Amphetamines, LSD, Natural Hallucinogens, Tranquilisers, Ketamine, Cocaine, Ecstasy, Inhalants, Heroin or Barbiturates)
(Mark all that apply)

- ☐ In the last 12 months
- ☐ More than 12 months ago
- ☐ Never

Question: Q54

52. At what age did you first use Marijuana?

☐ years old

Question: Q56

53. At what age did you first use any other illicit drug?

☐ years old

Page Break

C8

Question Block: K10
Contains: Q73, Q74, Q75, Q76, Q77, Q78, Q79, Q80, Q81, Q82

Scale Summary		
Code	Label	Show-If
0	None of the time	
1	A little of the time	
2	Some of the time	
3	Most of the time	
4	All of the time	

54. In the past 4 weeks:
(Mark one on each line)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
(a) About how often did you feel tired out for no good reason?	●	●	●	●	●
(b) About how often did you feel nervous?	●	●	●	●	●
(c) About how often did you feel so nervous that nothing could calm you down?	●	●	●	●	●
(d) About how often did you feel hopeless?	●	●	●	●	●
(e) About how often did you feel restless or fidgety?	●	●	●	●	●
(f) About how often did you feel so restless you could not sit still?	●	●	●	●	●
(g) About how often did you feel depressed?	●	●	●	●	●
(h) About how often did you feel that everything is an effort?	●	●	●	●	●
(i) About how often did you feel so sad that nothing could cheer you up?	●	●	●	●	●
(j) About how often did you feel worthless?	●	●	●	●	●

Page Break

C8

Question Block: C6
Contains: Q83, Q84, Q85, Q86, Q87, Q88, Q89, Q90, Q91, Q92, Q93

Scale Summary		
Code	Label	Show-If
0	Not applicable	
1	Not at all stressed	
2	Somewhat stressed	
3	Moderately stressed	
4	Very stressed	
5	Extremely stressed	

55. Over the *last 12 months*, how stressed have you felt about the following areas of your life?
(Mark one on each line)

	Not applicable	Not at allstressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed
(a)Own health	●	●	●	●	●	●
(b)Health of family members	●	●	●	●	●	●
(c)Work / employment	●	●	●	●	●	●
(d)Living arrangements	●	●	●	●	●	●
(e)Study	●	●	●	●	●	●
(f) Money	●	●	●	●	●	●
(g)Relationship with parents	●	●	●	●	●	●
(h)Relationship with partner / spouse	●	●	●	●	●	●
(i) Relationship with other family members	●	●	●	●	●	●
(j) Relationship with friends	●	●	●	●	●	●
(k)Motherhood / Children	●	●	●	●	●	●

Page Break

C8

Question: Q96

56. At what age did you have your first menstrual period?
(Age in years)

☐ years old

Question: Q98

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	
3	I prefer not to answer	

57. Have you ever had vaginal sex?

- ● Yes
- ● No
- ● I prefer not to answer

Question: Q99

58. How old were you when you first had vaginal sex?
(Age in years)

☐ years old

Question: Q101

59. Thinking about the LAST TIME you had vaginal sex, did you use any of the following?
(Mark all that apply)

- ☐ The Pill
- ☐ Condoms
- ☐ Other contraceptive (please specify) ☐
- ☐ **None**

C8

Question: Q126

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

60. Have you ever been pregnant?

- Yes
- No

Question: Q127

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

61. Are you currently pregnant?

- Yes
- No

Page Break

Collection: PREGNANCY_EXPERIENCES
Contains: C9, Q97, Q100, Q112, Q113, Q114, Q115

Question **Block:** C9
Contains: Q131, Q132, Q133, Q134, Q14, Q16

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	
3	Don't know	
4	I prefer not to answer	

62. Have you ever had a:

(Mark one on each line)

	Yes	No	Don't know	I prefer not to answer
(a)Miscarriage	●	●	●	●
(b)Abortion or termination (for personal reasons)	●	●	●	●
(c)Abortion or termination (for medical reasons)	●	●	●	●
(d)Ectopic pregnancy (tubal pregnancy)	●	●	●	●
(e)Live birth	●	●	●	●
(f) Still birth	●	●	●	●

C8

Question: Q97

63.How many miscarriages have you had?

Question: Q100

64.How many abortions or terminations for personal reasons have you had?

Question: Q112

65.How many abortions or terminations for medical reasons have you had?

Question: Q113

66.How many Ectopic pregnancies (tubal pregnancies) have you had?

Question: Q114

67.How many live births have you had?

Question: Q115

68.How many still births have you had?

Page Break

C8

Question: Q135

69. How tall are you without shoes?
(If you are not sure , please estimate)

cms

Question: Q136

70. How much do you weigh without clothes or shoes?
If you are pregnant now, write in the weight you were in the month prior to pregnancy.
(If you are not sure, please estimate)

kgs

Page Break

C8

The following questions ask about difficult situations you may have experienced.
Some people prefer not to answer questions of this nature.
If this is true for you, please go to the next question.

Question Block: PARTNERABUSE
Contains: Q140, Q142, Q143, Q58, Q146, Q148, Q155, Q151, Q59, Q156, Q157, Q163

71. This question asks about situations you may have experienced with *current or past* partners.

(Mark as many as apply on each line)

My partner:	In the last 12 months	More than 12 months ago	Never
(a) Told me that I was ugly, stupid or crazy, or that I wasn't good enough or that no one would ever want me	☐	☐	☐
(b) Followed me or harassed me around my neighbourhood / work	☐	☐	☐
(c) Tried to turn my family, friends or children against me or tried to convince them I was crazy	☐	☐	☐
(d) Kicked, bit, slapped or hit me with a fist or tried to hit me with something	☐	☐	☐
(e) Forced me to take part in unwanted sexual activity	☐	☐	☐
(f) Tried to keep me from seeing or talking to my family, friends or children, or didn't want me to socialise	☐	☐	☐
(g) Pushed, grabbed, shoved, shook or threw me	☐	☐	☐
(h) Blamed me for causing their violent behaviour	☐	☐	☐
(i) Harassed me over the telephone, email, Facebook or internet	☐	☐	☐
(j) Used a knife or gun or other weapon or beat me up	☐	☐	☐
(k) Became upset if dinner / housework wasn't done when they thought it should be	☐	☐	☐
(l) Refused to let me work outside the home or took my wallet and left me stranded	☐	☐	☐

C8

Question: Q139

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	

72. Have you ever been in a violent relationship with a partner / spouse? *(Mark one only)*

- ● Yes
- ● No

Page Break

C8

Question **Block:** ABUSE
Contains: Q63, Q64, Q106

73. Which of the following events have you experienced?

(Mark as many as apply on each line)

	Yes, in the last 12 months	Yes, more than 12 months ago	Never
(a) Being pushed, grabbed, shoved, kicked or hit	☐	☐	☐
(b) Being forced to take part in unwanted sexual activity	☐	☐	☐
(c) Being bullied	☐	☐	☐

Page Break

C8

If you feel distressed about any experiences of violence and abuse and would like some help to deal with this, please consider contacting one of the following:

**** Your nearest Women's Health Centre or Community Health Centre***

**** Your General Practitioner for advice about who would be the best person in your community to talk to***

**** A Lifeline counsellor on 13 11 14 (local call)***

Page Break

C8

Question **Block:** C7
Contains: Q108, Q117

74.

Mark as many as apply on each line	Yes, in the last 12 months	Yes, more than 12 months ago	Never
(a) Have you been feeling that life isn't worth living?	☐	☐	☐
(b) Have you deliberately hurt yourself or done anything that you knew might have harmed or even killed you?	☐	☐	☐

If you answered yes to either of the last 2 questions, you might like to talk to someone about how you are feeling. You could ring Lifeline on 13 11 14 (local call).

Page Break

C8

Question **Block:** C1
Contains: Q62, Q65, Q66, Q71

75.Please state *how many times* you did each type of activity and *how much time* you spent altogether doing each type of activity *last week*.

*Only count activities that lasted for 10 minutes or more; add up all the times you spent in each activity to get the total time for each activity. (If you did **not** do an activity, please select option"0").*

(a)**Walking briskly** (for recreation or exercise, or to get from place to place) Number of times

(b)**Moderate leisure activity** (like social tennis, moderate exercise classes, recreational swimming, dancing) Number of times

(c)**Vigorous leisure activity** (that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming) Number of times

(d)**Vigorous household or garden chores** (that make you breathe harder or puff and pant) Number of times

Question **Block:** C3
Contains: Q72, Q94, Q95, Q102

76.Total time in this activity last week

(a)**Walking briskly** (for recreation or exercise, or to get from place to place) Hrs : Mins

(b)**Moderate leisure activity** (like social tennis, moderate exercise classes, recreational swimming, dancing) Hrs : Mins

(c)**Vigorous leisure activity** (that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming) Hrs : Mins

(d)**Vigorous household or garden chores** (that make you breath harder or puff and pant) Hrs : Mins

Now think about all of the time you spend sitting during *each day* while at home, at work, wile getting from place to place or during your spare time.

Question **Block:** C5
Contains: Q103, Q104

77.In total, how much time do you typically spend sitting down while doing things like visiting friends, driving, reading, watching television, or working at a desk or computer?

(a)On usual **weekday** Hrs : Mins

(b)On a usual **weekend day** Hrs : Mins

Page Break

C8

Question: Q219

Scale Summary		
Code	Label	Show-If
1	No	
2	Yes, but I told them the answers I wanted	
3	Yes, but the helper answered for me using his / her own judgement	

78. Did someone help you fill in this survey?
(Mark one only)

- ● No
- ● Yes, but I told them the answers I wanted
- ● Yes, but the helper answered for me using his / her own judgement

Question: Q220

79. What was the MAIN reason for your needing help to fill in this survey?
(Please describe)

Question: COMMENTS

80. ***Have we missed anything?***
If you have anything else you would like to tell us, please type in the box below.

C9

Email from MyOpinion company sent to potential pilot participants

Hi there!

You are invited by The Australian Longitudinal Study on Women's Health to take part in a pilot survey!

Since 1996, the Australian Longitudinal Study on Women's Health has been surveying over 40,000 women about their health and wellbeing. The youngest of these women is now aged 34, so we are about to start surveying a group of women aged 18-23.

What we would like you to do is to read the information about the survey, fill the survey in and then tell us how we could improve the survey and the information.

Please follow the link below for more information and to commence the survey!

www.alswh.org.au

Thank you,

The research team at The Australian Longitudinal Study on Women's Health.

C10

Pilot Copy of Survey

Collection: LOGIN
Contains:

Hello from MyOpinions

Thank you for agreeing to participate in this survey. To begin the survey, click on the button below. As you move through the survey please do not use your browser buttons - use the buttons at the bottom of each screen.

Please remember:

- Your views are important to us and your answers will be kept in the strictest confidence.
- None of the responses you give are directly linked to you as an individual. They are used purely for statistical purposes only.
- The survey incentives and expected length are outlined in the invitation e-mail.
- In order for us to reward you for your time and opinion, please complete this survey in one go unless specified otherwise.

Honest and thoughtful answers to this survey are vital to the integrity of the market research process. We, and our clients, require factual information in order to make important decisions that not only affect consumers like you; but other people as well.

Please click 'Login' if you agree to spend a reasonable amount of time completing this survey and to provide honest and thoughtful responses.

Jump-To: JMP6
Description:
Jump-To-Item: T44
Jump-If: (QUOTAFULL = 1)

women's health australia
australian longitudinal study on women's health

2012 survey of the 1989-94 cohort

Page Break

C10

This is the first survey for women born between 1989-94
Thank you for participating in this important study

Instructions

• Please answer every question you can. If you are unsure about how to answer a question, mark the response for the closest answer to how you feel.

• Please answer the survey for the time period indicated even if you are pregnant or your circumstances are unusual in some way.

• Questions marked with a star are compulsory. Often this is because your response will alter the path of the survey, tailoring it so that unnecessary content is skipped.

• You will be asked to provide your Medicare card number, so please have it ready. Please remember that your details will remain confidential.

• If you need help to answer any questions, please ring 1800 068 081 (This is a FREECALL number).

If you are concerned about any of your health experiences and would like some help, you may like to contact:
• your nearest Women's Health Centre or Community Health Centre
• your doctor for advice about who would be the best person in your community for you to talk to.

If you feel distressed now and would like someone to talk to, you could ring Lifeline on 131 114 (local call).

Page Break

C10

Collection: ELIGIBILITYGROUP
Contains: Q51, Q50, GENDER, DOBCONFIRM002
Show if: (ELIGIBLE ≠ 1)

I HAVE READ THE INFORMATION STATEMENT.

I understand that:

• Confidentiality will be maintained at all times

• My personal details will be stored safely on secure servers at the University of Newcastle and the University of Queensland

• My answers will not be linked with my personal details and so will not be identifiable

• This is a longitudinal survey which will be conducted annually. Researchers will be comparing the information provided in this survey to those completed in the future

• Only those staff members within the project who are given specific authorization will be able to access my personal details for the purpose of project upkeep and maintenance

• My participation is voluntary and I am free to discontinue involvement at any time

Question: Q51
Required

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

As a result, I consent to participate

Yes No

Page Break

C10

Jump-To: JMP2
Description:
Jump-To-Item: T19
Jump-If: (Q51 ≠ 1:[Yes])

I agree to the research team following health and other records relating to me, including hospital and health service use records and cancer registers and other chronic conditions registers.
I also understand this means I agree to Medicare releasing information concerning services provided to me under Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, for the duration of the study, as outlined above.

A sample of the information that may be included in your Medicare claims history:

[+]Sample Medicare Data

Date of service	Date of Processing	Item number	Item description	Provider charge	Schedule Fee	Benefit paid	Patient out of pocket	Bill type
20/04/09	03/05/09	00023	Level B consultation	$38.30	$34.30	$34.30	$4.00	Cash
22/06/09	23/06/09	11700	ECG	$29.50	$29.50	$29.50		Bulk Bill

Scrambled ordering Provider number*	Scrambled rendering Provider number*	Date of referral	Rendering Provider postcode	Ordering Provider postcode	Hospital indicator	Provider derived major speciality	Item category
	999999A		2300		N	General Practitioner	1
999999A	999999A	20/04/09	2300	2302	N	Cardiologist	2

A sample of the information that may be included in your PBS claims history:

[+]Sample PBS Data

Date of supply	Date of prescribing	PBS item code	Item description	Patient category	Patient contribution	Net Benefit	Scrambled Prescriber number*	Pharmacy postcode	Form Category
06/03/09	01/03/09	03133X	Oxazepham Tablet 30 mg	Concessional Ordinary	$5.30	$25.55	9999999	2560	Original
04/07/09	28/05/09	03161J	Diazepam Tablet 2 mg	General Ordinary	$30.85		9999999	2530	Repeat

ATC Code	ATC Name	Prescriber derived major speciality
N05 B A 04	Oxazepam	General Practitioner
N05 B A 01	Diazepam	Psychiatrist

Question: Q50
Required

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

I authorize access to my records

Yes No

Jump-To: JMP3
Description:
Jump-To-Item: T19
Jump-If: (Q51 ≠ 1:[Yes])

C10

Question: GENDER

Scale Summary		
Code	Label	Show-If
1	Male	
2	Female	

What is your gender?

- Male
- Female

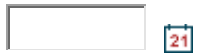
Page Break

C10

Jump-To:	JMP1
Description:	
Jump-To-Item:	T10
Jump-If: (GENDER ≠ 2:[Female])	

What is your date of birth?

Click on the '21' icon to use the pop-up calendar.



dd/mm/yyyy

Please provide your date of birth.

If you are experiencing errors, please type your date of birth instead.

Page Break

C10

Question: DOBCONFIRM002
Show if: (AGE < 18) or (BIRTHDATE < 01/01/1988)

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Are you sure your birth date () is correct?

- Yes
- No

Please press the "previous" arrow to amend your date of birth.

Page Break

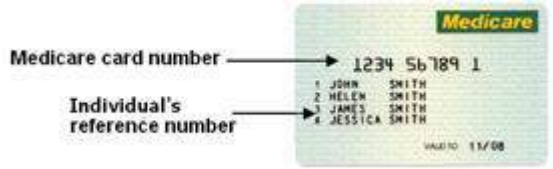
C10

Jump-To: JMP4
Description:
Jump-To-Item: T8
Jump-If: ((BIRTHDATE < 01/01/1989) or (AGE < 18)) and (DOBCONFIRM002 = 1:[Yes])

Collection: MEDICAREGROUP
Contains: MEDICARECARDNUMBER, MEDICARECARDREASON

Question: MEDICARECARDNUMBER

Please enter your Medicare Card number:
This number will remain confidential.



Question: MEDICARECARDREASON

OR
Choose one:

- [ ] I don't have a Medicare Card
- [ ] I don't have my Medicare Card with me at the moment.

Page Break

C10

Collection: ELIGIBILITYGROUP2
Contains: REDOEMAILPHONES, CONTACTDETAILS, REDONAMES, NAMEDETAIL, LIVINGOS, REDORES, RESADDRESS
Show if: (ELIGIBLE ≠ 1)

Question: REDOEMAILPHONES
Show if: (SUBMITTEDEMAILPHONES = 1)

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- ○ Yes
- ○ No

Page Break

C10

Collection: CONTACTDETAILS
Contains: EMAILPRIMARY, EMAILPRIMARYCONFIRM, MOBILEPHONE, HOMEPHONE, WORKPHONE
Show if: (SUBMITTEDEMAILPHONES = 0)

Question: EMAILPRIMARY

Email:

Question: EMAILPRIMARYCONFIRM

Confirm Email:

The email address and confirmation you have supplied do not match. Please try again.

Question: MOBILEPHONE

Mobile:

Question: HOMEPHONE

Home Phone:

Question: WORKPHONE

Work Phone:

Error:

Page Break

C10

Question: REDONAMES
Show if: (SUBMITTEDNAMES = 1)

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- Yes
- No

Page Break

Collection: NAMEDETAIL
Contains: TITLE, GIVENNAME, PREFNAME, SURNAME, MAIDENNAME
Show if: (SUBMITTEDNAMES = 0)

Question: TITLE

Scale Summary		
Code	Label	Show-If
DR	DR	
MISS	MISS	
MRS	MRS	
MS	MS	
PROF	PROF	
REV	REV	
SIS	SIS	

Title

-- Select One --

Question: GIVENNAME
Required

Given Names (in full)

Question: PREFNAME

What name would you prefer us to call you by?

Question: SURNAME
Required

Family Name

Question: MAIDENNAME

Maiden Name (if applicable)

Page Break

C10

Question: LIVINGOS
Required

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Are you living overseas?

- Yes
- No

Page Break

C10

Question: REDORES
Show if: (SUBMITTEDRES = 1)

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- Yes
- No

Page Break

C10

Collection: RESADDRESS
Contains: AUSRESADDRESS, OSRESADDRESS
Show if: (SUBMITTEDRES = 0)

Residential Address Details

Collection: AUSRESADDRESS
Contains: PREADDRESSRES, ADDRESSRES, TOWNRES, STATERES, POSTCODERES
Show if: (LIVINGOS = 2:[No])

Question: PREADDRESSRES

Building name / C\- instructions:

Question: ADDRESSRES
Required

Unit/Street address:

Question: TOWNRES
Required

Town / City:

C10

Question: STATERES
Required

Scale Summary		
Code	Label	Show-If
ACT	ACT	
NSW	NSW	
NT	NT	
QLD	QLD	
SA	SA	
TAS	TAS	
VIC	VIC	
WA	WA	

State:

- ACT
- NSW
- NT
- QLD
- SA
- TAS
- VIC
- WA

Question: POSTCODERES
Required

Postcode:

C10

Collection: OSRESADDRESS
Contains: OSRESLINE1, OSRESLINE2, OSRESLINE3, OSRESLINE4
Show if: (LIVINGOS = 1:[Yes])

Question: OSRESLINE1

Line 1:

Question: OSRESLINE2

Line 2:

Question: OSRESLINE3

Line 3:

Question: OSRESLINE4
Required

Line 4 (required):

Error:

Page Break

C10

Thank you for submitting your personal details.

The survey for our research starts here.

Page Break

C10

Women's health is about you and your life

Question: SF36001

Scale Summary		
Code	Label	Show-If
1	Excellent	
2	Very good	
3	Good	
4	Fair	
5	Poor	

In general, would you say your health is:
(Mark <u>one only</u>)

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor

C10

Question: Q6

Where do you get information about your health?
(Mark all that apply)

- [ ] School, University, TAFE
- [ ] Friends
- [ ] Internet (please expand)
- [ ] Mother / father, sister / brother or other family member
- [ ] Nurse
- [ ] Doctor
- [ ] Family planning or sexual health clinic
- [ ] Youth or community services (e.g. mother's group)
- [ ] TV / radio, magazines, poster / leaflet
- [ ] Other (please specify)
- [ ] **None of these**

C10

Question: HSRV015

Scale Summary		
Code	Label	Show-If
1	Yes, always	
2	Yes, but only for certain things, such as	
3	No	
4	Don't care	

In general, do you prefer to see a female doctor?
(Mark <u>one only</u>)

- ○ Yes, always
- ○ Yes, but only for certain things, such as _____
- ○ No
- ○ Don't care

Page Break

C10

Question Block: C2
Contains: CPRB001, CPRB002, CPRB022

Scale Summary		
Code	Label	Show-If
1	Never	
2	Rarely	
3	Sometimes	
4	Often	

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Allergies, hay fever, sinusitis	○	○	○	○
Breathing difficulties	○	○	○	○
Skin problems	○	○	○	○

C10

Question Block: C2B
Contains: CPRB005, CPRB084, CPRB007, CPRB008, Q24

Scale Summary		
Code	Label	Show-If
1	Never	
2	Rarely	
3	Sometimes	
4	Often	

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Headaches / migraines	○	○	○	○
Severe tiredness	○	○	○	○
Stiff or painful joints	○	○	○	○
Back pain	○	○	○	○
Problems with one or both feet	○	○	○	○

Page Break

C10

Question Block: C2C
Contains: CPRB025, CPRB085, CPRB238, CPRB276, CPRB239

Scale Summary		
Code	Label	Show-If
1	Never	
2	Rarely	
3	Sometimes	
4	Often	

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Difficulty sleeping	○	○	○	○
Depression	○	○	○	○
Episodes of intense anxiety (eg panic attacks)	○	○	○	○
Other mental health problems	○	○	○	○
Palpitations (feeling that your heart is racing or fluttering in your chest)	○	○	○	○

Page Break

C10

Question **Block:** C2D
Contains: CPRB015, CPRB016, Q32, CPRB018, CPRB019

Scale Summary		
Code	Label	Show-If
1	Never	
2	Rarely	
3	Sometimes	
4	Often	

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Vaginal discharge or irritation	○	○	○	○
Premenstrual tension	○	○	○	○
Irregular periods	○	○	○	○
Heavy periods	○	○	○	○
Severe period pain	○	○	○	○

Page Break

C10

Question **Block:** C2E
Contains: CPRB010, CPRB011, CPRB012, CPRB013, CPRB014

Scale Summary		
Code	Label	Show-If
1	Never	
2	Rarely	
3	Sometimes	
4	Often	

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Urine that burns or stings	○	○	○	○
Leaking urine	○	○	○	○
Constipation	○	○	○	○
Haemorrhoids (piles)	○	○	○	○
Other bowel problems	○	○	○	○

Page Break

Women's health is about coping with common problems

C10

Question: MEDH

Have you ever been diagnosed or treated for:
(Mark all that apply)

- ☐ Insulin dependent (Type 1) diabetes
- ☐ Non-insulin dependent (Type 2) diabetes
- ☐ Heart disease
- ☐ Hypertension (high blood pressure)
- ☐ Low iron (iron deficiency or anaemia)
- ☐ Asthma
- ☐ Bronchitis
- ☐ Endometriosis
- ☐ Thrombosis
- ☐ Polycystic Ovary Syndrome
- ☐ Skin cancer
- ☐ Other cancer (please specify)
- ☐ Other major physical illness (please specify)
- ☐ Other (please specify)
- ☐ **None of these conditions**

Page Break

Question: MEDHB

Have you ever been diagnosed or treated for:
(Mark all that apply)

- ☐ Urinary tract infection

- ☐ Chlamydia
- ☐ Genital herpes
- ☐ Genital warts (HPV)
- ☐ HIV or AIDS
- ☐ Hepatitis B or C
- ☐ Other sexually transmitted infection (please specify)
- ☐ **None of these conditions**

Question: MEDHC

Have you ever been diagnosed or treated for:
(Mark all that apply)

- ☐ Depression
- ☐ Anxiety disorder
- ☐ Other major mental illness (please specify)
- ☐ **None of these conditions**

Page Break

Women's health is about using health services

Question Block: C4
Contains: Q67, Q68, Q69

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Within the last two years, have you had:

(Mark <u>one on each line</u>)

	Yes	No
A Pap test?	○	○
Your blood pressure checked?	○	○
Your skin checked (eg spots, lesions, moles)?	○	○

Question: PHTH009

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Have you <u>ever</u> had a vaccination for HPV (genital warts, cervical cancer)?
(Mark <u>one only</u>)

- ○ Yes
- ○ No

Page Break

Question: Q11

Scale Summary		
Code	Label	Show-If
1	Yes, I have my own card	
2	Yes, I have a copy of my parent's card	
3	No, I need to borrow my parent's card	
4	No, I don't have one	
5	Don't know	

Do you have your own Medicare card?
(Mark <u>one only</u>)

- ○ Yes, I have my own card

- Yes, I have a copy of my parent's card
- No, I need to borrow my parent's card
- No, I don't have one
- Don't know

Question: HSRV079

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Do you have a Health Care Card? ***This is a card that entitles you to discounts and assistance with medical expenses. This is not the same as a Medicare card.***
(Mark one only)

- Yes
- No

Page Break

Women's health is about lifestyle choices

Question: Q128

Scale Summary		
Code	Label	Show-If
1	Daily	
2	Less than daily	
3	Not at all	

C10

Do you *currently* smoke tobacco?
(Mark one only)

- Daily
- Less than daily
- Not at all

Page Break

C10

Question: Q40
Show if: (Q128 ≠ 3:[Not at all])

On a day when you smoke, how many cigarettes do you usually smoke?
Type the number in the box

_____ cigarettes

Question: Q129
Show if: (Q128 is-none-of 1:[Daily] or 2:[Less than daily])

Scale Summary		
Code	Label	Show-If
1	Daily	
2	Less than daily	
3	Not at all	

In the *past*, have you smoked tobacco?
(Mark one only)

- ○ Daily
- ○ Less than daily
- ○ Not at all

Page Break

C10

Question: Q41
Show if: (Q129 ≠ 3:[Not at all])

At what age did you start smoking tobacco?
Print the number in the box

☐ years old

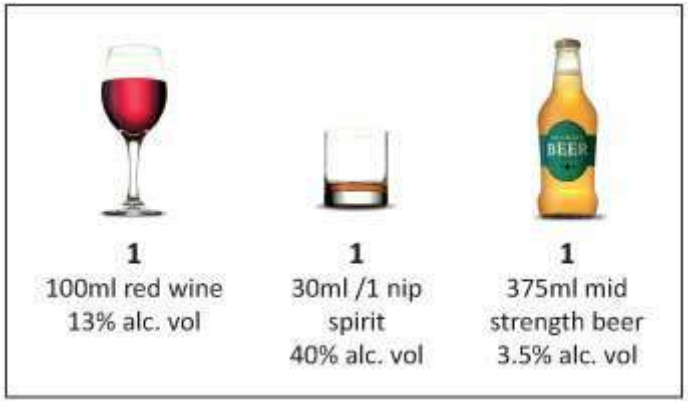
Page Break

C10

Question: Q60

Scale Summary		
Code	Label	Show-If
1	I have never drunk alcohol	
2	I started drinking alcohol at age	

At what age did you first have a standard drink of alcohol?
(Mark one only)



- ○ I have never drunk alcohol
- ○ I started drinking alcohol at age [ ]

Page Break

Question: ALCS009
Show if: (Q60 ≠ 1:[I have never drunk alcohol])

C10

Scale Summary		
Code	Label	Show-If
1	I never drink alcohol	
2	Less than once a month	
3	Less than once a week	
4	On 1 or 2 days a week	
5	On 3 or 4 days a week	
6	On 5 or 6 days a week	
7	Every day	

How often do you usually drink alcohol?
(Mark <u>one only</u>)

- I never drink alcohol
- Less than once a month
- Less than once a week
- On 1 or 2 days a week
- On 3 or 4 days a week
- On 5 or 6 days a week
- Every day

Page Break

C10

Question: ALCS010
Show if: (Q60 ≠ 1:[I have never drunk alcohol]) and (ALCS009 ≠ 1:[I never drink alcohol])

Scale Summary		
Code	Label	Show-If
1	1 or 2 drinks per day	
2	3 or four drinks per day	
3	5 to 8 drinks per day	
4	9 or more drinks per day	

On a day when you drink alcohol, how many standard drinks do you usually have?
(Mark one only)

- 1 or 2 drinks per day
- 3 or four drinks per day
- 5 to 8 drinks per day
- 9 or more drinks per day

C10

Question: ALCS011
Show if: (Q60 ≠ 1:[I have never drunk alcohol]) and (ALCS009 ≠ 1:[I never drink alcohol])

Scale Summary		
Code	Label	Show-If
1	Never	
2	Less than once a month	
3	About once a month	
4	About once a week	
5	More than once a week	

How often do you have five or more standard drinks of alcohol on one occasion?
(Mark one only)

- ○ Never
- ○ Less than once a month
- ○ About once a month
- ○ About once a week
- ○ More than once a week

Page Break

C10

Remember that any information you give us is kept confidential.

The following questions ask about the use of drugs for *non-medicinal* purposes.

We want to know about general patterns of use.

Please do not give details of specific instances of use (*mark all that apply*).

Page Break

C10

Question: MARIJTRY

Have you tried Marijuana? [+] (Expand for other names)

(Cannabis, pot, grass, weed, ya(r)ndi, rope, mull, dope, skunk, bhang, ganja, hash, chronic, reefer, joint, cone or spliff).

(Mark all that apply)

- ☐ In the last 12 months
- ☐ More than 12 months ago
- ☐ Never

Question: ILLICITTRY

Have you tried any other illicit drugs? [+](Expand for other names)

(Ice, Speed, GHB, Amphetamines, LSD, Natural Hallucinogens, Tranquilisers, Ketamine, Cocaine, Ecstasy, Inhalants, Heroin or Barbiturates)

(Mark all that apply)

- ☐ In the last 12 months
- ☐ More than 12 months ago
- ☐ Never

Page Break

Question: MARIJAGE
Show if: (MARIJTRY is-none-of [Never])

At what age did you first use Marijuana?

☐ years old

Question: ILLICITAGE
Show if: (ILLICITTRY is-none-of [Never])

At what age did you first use any other illicit drug?

☐ years old

Page Break

C10

The next question is about the amount of physical activity you did *LAST WEEK*.

Custom Layout Question: EXERCISE

Please state how many times you did each type of activity and how much time you spent altogether doing each type of activity *last week*.

*Only count activities that lasted for 10 minutes or more; add up all the times you spent in each activity to get the total time for each activity. (If you did **not** do an activity, please type "0")*

	Number of Times	Hours	Minutes
Walking briskly (for recreation or exercise, or to get from place to place)			
Moderate leisure activity (like social tennis, moderate exercise classes, recreational swimming, dancing)			
Vigorous leisure activity (that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming)			
Vigorous household or garden chores (that make you breathe harder or puff and pant)			

Page Break

C10

Question **Block:** K10
Contains: Q73, Q74, Q75, Q76, Q77, Q78, Q79, Q80, Q81, Q82

Scale Summary		
Code	Label	Show-If
1	None of the time	
2	A little of the time	
3	Some of the time	
4	Most of the time	
5	All of the time	

In the past 4 weeks:
(Mark <u>one on each line</u>)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
About how often did you feel tired out for no good reason?	○	○	○	○	○
About how often did you feel nervous?	○	○	○	○	○
About how often did you feel so nervous that nothing could calm you down?	○	○	○	○	○
About how often did you feel hopeless?	○	○	○	○	○
About how often did you feel restless or fidgety?	○	○	○	○	○
About how often did you feel so restless you could not sit still?	○	○	○	○	○
About how often did you feel depressed?	○	○	○	○	○
About how often did you feel that everything is an effort?	○	○	○	○	○
About how often did you feel so sad that nothing could cheer you up?	○	○	○	○	○
About how often did you feel worthless?	○	○	○	○	○

If you would like some help with any of the symptoms listed above, a link to MoodGYM, an interactive website, will be provided at the end of the survey.

Page Break

C10

Women's health is about coping with stress

Question Block: C6
Contains: STRS001, STRS002, STRS003, STRS004, STRS005, STRS006, STRS007, STRS008, STRS010, STRS030, STRS031

Scale Summary		
Code	Label	Show-If
1	Not applicable	
2	Not at all stressed	
3	Somewhat stressed	
4	Moderately stressed	
5	Very stressed	
6	Extremely stressed	

Over the *last 12 months*, how stressed have you felt about the following areas of your life?
(Mark one on each line)

	Not applicable	Not at all stressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed
Own health	○	○	○	○	○	○
Health of family members	○	○	○	○	○	○
Work / employment	○	○	○	○	○	○
Living arrangements	○	○	○	○	○	○
Study	○	○	○	○	○	○
Money	○	○	○	○	○	○
Relationship with parents	○	○	○	○	○	○
Relationship with partner / spouse	○	○	○	○	○	○
Relationship with other family members	○	○	○	○	○	○
Relationship with friends	○	○	○	○	○	○
Motherhood / Children	○	○	○	○	○	○

C10

Now think about all of the time you spend sitting during *EACH DAY* while at home, at work, while getting from place to place or during your spare time.

Custom Layout Question: SITTINGRC

In total, how much time do you typically spend sitting down while doing things like visiting friends, driving, reading, watching television, or working at a desk or computer?

	Hours	Minutes
On usual **weekday**		
On a usual **weekend day**		

Page Break

C10

Women's health is about reproductive health

There are some unanswered questions on this page.

We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Question: Q96

At what age did you have your first menstrual period?
(Age in years)

☐ years old

Question: Q98

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	
3	I prefer not to answer	

Have you ever had vaginal sex?

- ○ Yes
- ○ No
- ○ I prefer not to answer

Page Break

C10

Question: Q99
Show if: (Q98 ≠ 2:[No])

How old were you when you first had vaginal sex?
(Age in years)

☐ years old

Question: Q101
Show if: (Q98 ≠ 2:[No])

Thinking about the LAST TIME you had vaginal sex, did you use any of the following?
(Mark all that apply)

- ☐ The Pill
- ☐ Condoms
- ☐ Other contraceptive (please specify) ____
- ☐ **None**

Page Break

C10

Question: REPH179

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Have you ever been pregnant?

- Yes
- No

Question: REPH009

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Are you currently pregnant?

- Yes
- No

Page Break

C10

Collection: PREGNANCY_EXPERIENCES
Contains: C9, Q97, Q100, Q112, Q113, Q114, Q115
Show if: (REPH179 ≠ 2:[No])

Question Block: C9
Contains: Q131, Q132, Q133, Q134, Q14, Q16

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	
3	Don't know	
4	I prefer not to answer	

Have you ever had a:

(Mark <u>one on each line</u>)

	Yes	No	Don't know	I prefer not to answer
Miscarriage	○	○	○	○
Abortion or termination (for personal reasons)	○	○	○	○
Abortion or termination (for medical reasons)	○	○	○	○
Ectopic pregnancy (tubal pregnancy)	○	○	○	○
Live birth	○	○	○	○
Still birth	○	○	○	○

Page Break

C10

Question: Q97
Show if: (Q131 ≠ 2:[No]) and (Q131 ≠ 4:[I prefer not to answer])

How many miscarriages have you had?

Question: Q100
Show if: (Q132 ≠ 2:[No]) and (Q132 ≠ 4:[I prefer not to answer])

How many abortions or terminations for personal reasons have you had?

Question: Q112
Show if: (Q133 ≠ 2:[No]) and (Q133 ≠ 4:[I prefer not to answer])

How many abortions or terminations for medical reasons have you had?

Question: Q113
Show if: (Q134 ≠ 2:[No]) and (Q134 ≠ 4:[I prefer not to answer])

How many Ectopic pregnancies (tubal pregnancies) have you had?

Question: Q114
Show if: (Q14 ≠ 2:[No]) and (Q14 ≠ 4:[I prefer not to answer])

How many live births have you had?

Question: Q115
Show if: (Q16 ≠ 2:[No]) and (Q16 ≠ 4:[I prefer not to answer])

How many still births have you had?

Page Break

C10

Question: WTSH001

How tall are you without shoes?
(If you are not sure , please estimate)

cms

Question: WTSH002

How much do you weigh without clothes or shoes?
If you are pregnant now, write in the weight you were in the month prior to pregnancy.
(If you are not sure, please estimate)

kgs

Page Break

C10

The following questions ask about difficult situations you may have experienced.

Some people prefer not to answer questions of this nature.

If this is true for you, please go to the next question.

Page Break

C10

Question Block: ABUSE
Contains: LFEVPGSK, LFEVUNSEX, Q106

Which of the following events have you experienced?

(Mark as many as apply on each line)

	Yes, in the last 12 months	Yes, more than 12 months ago	Never
Being pushed, grabbed, shoved, kicked or hit	☐	☐	☐
Being forced to take part in unwanted sexual activity	☐	☐	☐
Being bullied	☐	☐	☐

Page Break

C10

Question Block: PARTNERABUSE
Contains: Q140, Q142, Q143, Q58, Q146, Q148, Q155, Q151, Q59, Q156, Q157, Q163

This question asks about situations you may have experienced with *current or past* partners[?]
For this question, partner can refer to a boyfriend or girlfriend that you have dated or lived with.
(Mark as many as apply on each line)

My partner:	In the last 12 months	More than 12 months ago	Never
Told me that I was ugly, stupid or crazy, or that I wasn't good enough or that no one would ever want me	☐	☐	☐
Followed me or harassed me around my neighbourhood / work	☐	☐	☐
Tried to turn my family, friends or children against me or tried to convince them I was crazy	☐	☐	☐
Kicked, bit, slapped or hit me with a fist or tried to hit me with something	☐	☐	☐
Forced me to take part in unwanted sexual activity	☐	☐	☐
Tried to keep me from seeing or talking to my family, friends or children, or didn't want me to socialise	☐	☐	☐
Pushed, grabbed, shoved, shook or threw me	☐	☐	☐
Blamed me for causing their violent behaviour	☐	☐	☐
Harassed me over the telephone, email, Facebook or internet	☐	☐	☐
Used a knife or gun or other weapon or beat me up	☐	☐	☐
Became upset if dinner / housework wasn't done when they thought it should be	☐	☐	☐
Refused to let me work outside the home or took my wallet and left me stranded	☐	☐	☐

C10

Question: FAMF023

Scale Summary		
Code	Label	Show-If
1	Yes	
0	No	

Have you ever been in a violent relationship with a partner / spouse?
(Mark <u>one only</u>)

- Yes
- No

Page Break

C10

If you feel distressed about any experiences of violence and abuse and would like some help to deal with this, please consider contacting one of the following:

- Your nearest Women's Health Centre or Community Health Centre
- Your General Practitioner for advice about who would be the best person in your community to talk to
- A Lifeline counsellor on 13 11 14 (local call)

Page Break

C10

Question **Block:** C7
Contains: PWEL001, PWEL002

Mark as many as apply on each line	Yes, in the last 12 months	Yes, more than 12 months ago	Never
Have you been feeling that life isn't worth living?	☐	☐	☐
Have you deliberately hurt yourself or done anything that you knew might have harmed or even killed you?	☐	☐	☐

If you answered yes to either of the last 2 questions, you might like to talk to someone about how you are feeling.

You could ring Lifeline on 13 11 14 (local call).

Page Break

C10

Women's health is about considering diversity

Question: Q1

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Do you speak fluent English?

- Yes
- No

Page Break

C10

Question: Q2
Show if: (Q1 ≠ 1:[Yes])

Scale Summary		
Code	Label	Show-If
0	English	
1	Arabic	
2	Assyrian	
3	Cantonese	
4	Dari	
5	Dinka	
6	French	
7	Indonesian	
8	Italian	
9	Japanese	
10	Khmer	
11	Korean	
12	Macedonian	
13	Mandarin	
14	Persian (excl. Dari)	
15	Portugese	
16	Serbian	
17	Spanish	
18	Thai	
19	Turkish	
20	Vietnamese	
21	Other	

What language do you speak at home?
(Mark the one *most commonly spoken*)

-- Select One --

C10

Question: Q15

Scale Summary		
Code	Label	Show-If
1	Year 10 or below	
2	Year 11 or equivalent	
3	Year 12 or equivalent	
4	Certificate I / II	
5	Certificate III / IV	
6	Advanced Diploma / Diploma	
7	Bachelor degree	
8	Graduate diploma / Graduate certificate	
9	Postgraduate degree	

What is the highest level of education you have completed?
(Mark <u>one only</u>)

- ○ Year 10 or below
- ○ Year 11 or equivalent
- ○ Year 12 or equivalent
- ○ Certificate I / II
- ○ Certificate III / IV
- ○ Advanced Diploma / Diploma
- ○ Bachelor degree
- ○ Graduate diploma / Graduate certificate
- ○ Postgraduate degree

Page Break

C10

Women's health is about juggling time

Question: Q7

Scale Summary		
Code	Label	Show-If
1	0	
2	1 - 15	
3	16 - 29	
4	30 - 34	
5	35 - 40	
6	41 - 49	
7	50 or more	

In a usual week, how many hours do you spend doing *paid work*?

-- Select One -- Hours

Question: Q52

Scale Summary		
Code	Label	Show-If
1	0	
2	1 - 15	
3	16 - 29	
4	30 - 34	
5	35 - 40	
6	41 - 49	
7	50 or more	

In a usual week, how many hours do you spend *studying*?

-- Select One -- Hours

C10

Question: DEMO013

Scale Summary		
Code	Label	Show-If
1	It is impossible	
2	It is difficult all the time	
3	It is difficult some of the time	
4	It is not too bad	
5	It is easy	

How do you manage on the income you have available?
(Mark <u>one only</u>)

- ○ It is impossible
- ○ It is difficult all the time
- ○ It is difficult some of the time
- ○ It is not too bad
- ○ It is easy

Question: FAMF126

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Do you regularly need help with daily tasks because of a long-term illness or disability (eg help with personal care, getting around, preparing meals etc)?

- ○ Yes
- ○ No

Page Break

C10

Question: REPH048

Scale Summary		
Code	Label	Show-If
1	I am exclusively heterosexual	
2	I am mainly heterosexual	
3	I am bisexual	
4	I am mainly homosexual (lesbian)	
5	I am exclusively homosexual (lesbian)	
6	I don't know	
7	I don't want to answer	

Which of these most closely describes your sexual orientation?
(Mark <u>one only</u>)

- I am exclusively heterosexual
- I am mainly heterosexual
- I am bisexual
- I am mainly homosexual (lesbian)
- I am exclusively homosexual (lesbian)
- I don't know
- I don't want to answer

C10

Question: Q18

Scale Summary		
Code	Label	Show-If
1	I am single	
2	I am in a relationship (not living together)	
3	I am living with a partner	
4	I am engaged	
5	I am married	
6	I am divorced	
7	I am separated	
8	Other (please specify)	

What is your current relationship status?
(Mark the response that best suits your current circumstances)

- I am single
- I am in a relationship (not living together)
- I am living with a partner
- I am engaged
- I am married
- I am divorced
- I am separated
- Other (please specify)

C10

Question: Q8

What are your living arrangements? (Mark all that apply)

- [ ] I live alone
- [ ] I live with one or both parents
- [ ] I live with other adults
- [ ] I live with my male partner
- [ ] I live with my female partner
- [ ] I live with children
- [ ] Other (please specify)

Page Break

C10

Question: Q219

Scale Summary		
Code	Label	Show-If
1	No	
2	Yes, but I told them the answers I wanted	
3	Yes, but the helper answered for me using his / her own judgement	

Did someone help you fill in this survey? *(Mark <u>one only</u>)*

- ○ No
- ○ Yes, but I told them the answers I wanted
- ○ Yes, but the helper answered for me using his / her own judgement

Page Break

C10

Question: Q220
Show if: (Q219 ≠ 1:[No])

What was the MAIN reason for your needing help to fill in this survey?
(Please describe)

Question: COMMENTS

Have we missed anything?
If you have anything else you would like to tell us, please type in the box below.

Page Break

C10

Question: MYOEMAILCONSENT

Scale Summary		
Code	Label	Show-If
1	Yes	
2	No	

Are you happy to allow MyOpinions to provide us with your email address so we can contact you when this survey is officially rolled out?

- Yes
- No

Page Break

C10

We have some evaluation questions to ask that will help us improve the survey for a national audience. Please fill them out to the best of your ability.

Question: Q13

What is the best way to contact women your age to ask them to do this survey?

- [ ] Facebook
- [ ] TV
- [ ] Radio
- [ ] Newspapers
- [ ] Magazines
- [ ] Billboard type advertising
- [ ] Posters in prominent locations
- [ ] Online forums
- [ ] Any other ways?

Question Block: C5
Contains: Q48, Q46, Q45, Q47

Scale Summary		
Code	Label	Show-If
1	Dislike a lot	
2	Dislike	
3	Not fussed	
4	Like	
5	Like a lot	

What did you think about the following aspects of the survey: (*Mark one on <u>each line</u>*)

	Dislike a lot	Dislike	Not fussed	Like	Like a lot
Information about the survey	○	○	○	○	○
Survey instructions	○	○	○	○	○
Survey Design and layout	○	○	○	○	○
Question content	○	○	○	○	○

C10

Question: Q43

Scale Summary		
Code	Label	Show-If
1	Too short	
2	Just right	
3	Too long	

I felt that the survey was:

- Too short
- Just right
- Too long

Question: Q44

Do you have any other ideas, comments or concerns about the survey?

If you would like to visit the MoodGYM website for mental health information and coping strategies click this link:

http://moodgym.anu.edu.au/welcome

Page Break

C10

2012 survey of the 1989-94 cohort

Thank you for your time, but we cannot continue without your consent. For more information on the Australian Longitudinal Study on Women's Health, please visit the website: www.alswh.org.au

Page Break

myopinions

We would like to thank you for taking the time to participate in our survey.

Your opinions and responses are gratefully received and extremely important to us.

The survey is now closed due to overwhelming responses from people like yourself.

Once again thank you for your interest. To ensure that you receive further relevant surveys, please make sure that your details are always up to date.

Please click the right arrow below to earn your points.

Page Break

C10

Jump-To: JMP5
Description:
Jump-To-Item: End and Submit
Jump-If: (ENDREASON is-any-of 1:[Date of birth is out of target cohort range] or 2:[Wrong gender] or 3:[Did not consent] or 4:[Quota Full])

Thank you for taking part in this survey

For more information on the Australian Longitudinal Study on Women's Health:

women's health australia
australian longitudinal study on women's health

www.alswh.org.au

find us on facebook

follow us on twitter

Page Break

C10

We would like to thank you for taking the time to complete our survey. Your opinions and responses are gratefully received and extremely important to us.

The insight which you have given us will be used to develop future products and others like it.

Your responses will be used at an aggregate level only, and as such we would like to assure you once again that your details will be used in the strictest of confidence and will not be passed on to any other party for any purpose other than that which it was intended.

Once again thank you for your interest. To ensure that you receive further relevant surveys, please make sure that your details are always up to date.

Please click the 'Submit' button below to earn your points.

MyOpinions Privacy Policy

Technical Problems? Contact Us

Powered by DatStat

C11

0%

2012 survey for women aged 18-23

Thank you for participating in this important study

Instructions

• Please answer every question you can. If you are unsure about how to answer a question, mark the response for the closest answer to how you feel.

• Please answer the survey for the time period indicated even if you are pregnant or your

circumstances are unusual in some way.

• Questions marked with a star are compulsory. Often this is because your response will alter the path of the survey, tailoring it so that unnecessary content is skipped.

• **You will be asked to provide your Medicare card number, so please have it ready. Please remember that your details will remain confidential.**

• If you need help to answer any questions, please ring 1800 068 081 (This is a FREECALL number).

If you are concerned about any of your health experiences and would like some help, you may like to contact:

• your nearest Women's Health Centre or Community Health Centre

• your doctor for advice about who would be the best person in your community for you to talk to.

If you feel distressed now and would like someone to talk to, you could ring Lifeline on 131 114 (local call).

Page Break

C11

I HAVE READ THE INFORMATION STATEMENT.

I understand that:

• Confidentiality will be maintained at all times

• My personal details will be stored safely on secure servers at the University of Newcastle and the University of Queensland

• My answers will not be linked with my personal details and so will not be identifiable

• This is a longitudinal survey which will be conducted annually. Researchers will be comparing the information provided in this survey to those completed in the future

• Only those staff members within the project who are given specific authorisation will be able to access my personal details for the purpose of project upkeep and maintenance

• My participation is voluntary and I am free to discontinue involvement at any time

As a result, I consent to participate

● Yes ● No

Page Break

• I agree to the research team following health and other records relating to me, including hospital and health service use records and cancer registers and other chronic conditions registers.

• I also understand this means I agree to Medicare releasing information concerning services provided to me under

Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, for the duration of the study, as outlined above.

A sample of the information that may be included in your Medicare claims history:

[+]Sample Medicare Data

Date of service	Date of Processing	Item number	Item description	Provider charge	Schedule Fee	Benefit paid	Patient out of pocket	Bill type
20/04/09	03/05/09	00023	Level B consultation	$38.30	$34.30	$34.30	$4.00	Cash
22/06/09	23/06/09	11700	ECG	$29.50	$29.50	$29.50		Bulk Bill

Scrambled ordering Provider number*	Scrambled rendering Provider number*	Date of referral	Rendering Provider postcode	Ordering Provider postcode	Hospital indicator	Provider derived major speciality	Item category
	999999A		2300		N	General Practitioner	1
999999A	999999A	20/04/09	2300	2302	N	Cardiologist	2

* Scrambled Provider number refers to a unique scrambled provider number identifying the doctor who provided/referred the service. Generally, each individual provider number will be scrambled and the identity of that provider will not be disclosed.

A sample of the information that may be included in your PBS claims history:

[+]Sample PBS Data

Date of supply	Date of prescribing	PBS item code	Item description	Patient category	Patient contribution	Net Benefit	Scrambled Prescriber number*	Pharmacy postcode	Form Category
06/03/09	01/03/09	03133X	Oxazepham Tablet 30 mg	Concessional Ordinary	$5.30	$25.55	9999999	2560	Original
04/07/09	28/05/09	03161J	Diazepam Tablet 2 mg	General Ordinary	$30.85		9999999	2530	Repeat

ATC Code	ATC Name	Prescriber derived major speciality
N05 B A 04	Oxazepam	General

C11

		Practitioner
N05 B A 01	Diazepam	Psychiatrist

* Scrambled Prescriber number refers to a unique scrambled prescriber number identifying the doctor who prescribed the prescription. Generally, each individual prescriber number will be scrambled and the identity of that prescriber will not be disclosed.

I authorize access to my records

- Yes
- No

Page Break

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- Yes
- No

Page Break

Please remember that your details will remain confidential.

Email:

Confirm Email:

The email address and confirmation you have supplied do not match. Please try again.

Page Break

What is your gender?

- Male
- Female

C11

Page Break

Please remember that your details will remain confidential.

What is your date of birth?

Click on the '21' icon to use the pop-up calendar.

dd/mm/yyyy

Please provide your date of birth.

If you are experiencing errors, please type your date of birth instead.

Page Break

Are you sure your birth date () is correct?

- Yes
- No

Please press the previous button to amend your date of birth.

Page Break

Please remember that your details will remain confidential.

IMPORTANT: Before we can finalise your responses, please provide your Medicare Card number

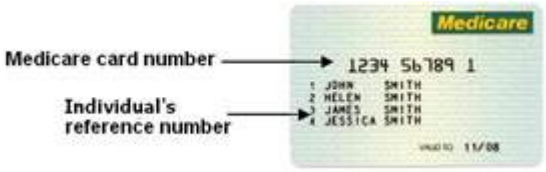
An email has been sent to you with a link so you can come back to this page when you have your Medicare card with you

Once you have provided your Medicare Card number, please click the "next" arrow. Otherwise, please close your browser.

Please enter your Medicare Card number:

This number will remain confidential.

C11



OR

Choose one:

- I don't have a Medicare Card (and am not on a card with someone else. eg with parents)
- I don't have a Medicare Card with me at the moment.

Page Break

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- Yes
- No

Page Break

Please remember that your details will remain confidential.

Title

(e.g. Mrs, Miss, Ms etc.)

C11

Given Names (in full)

What name would you prefer us to call you by?

Family Name

Page Break

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- Yes
- No

Page Break

Please remember that your details will remain confidential.

Mobile:

Page Break

Are you living overseas?

- Yes
- No

Page Break

C11

****These details have been removed from the survey to protect your confidentiality. You do not need to enter them again unless you wish to make a change.****

Do you wish to re-enter these details?

- Yes
- No

Page Break

Please remember that your details will remain confidential.

Residential Address Details

Building name / C\- instructions:

Unit/Street address:

Town / City:

State:

- ACT
- NSW
- NT
- QLD
- SA

- TAS
- VIC
- WA

Postcode:

Line 1:

Line 2:

Line 3:

Line 4 (required):

Page Break

Thank you for submitting your personal details.

The survey for our research starts here.

C11

Page Break

Women's health is about you and your life

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

In general, would you say your health is:
(Mark <u>one only</u>)

- Excellent
- Very good
- Good
- Fair
- Poor

Where do you get information about your health?

C11

(Mark all that apply)

- ☐ School, University, TAFE
- ☐ Friends
- ☐ Internet (please expand)
- ☐ Mother / father, sister / brother or other family member
- ☐ Nurse
- ☐ Doctor
- ☐ Family planning or sexual health clinic
- ☐ Youth or community services (e.g. mother's group)
- ☐ TV / radio, magazines, poster / leaflet
- ☐ Other (please specify)
- ☐ **None of these**

In general, do you prefer to see a female doctor?
(Mark one only)

- ● Yes, always
- ● Yes, but only for certain things, such as
- ● No
- ● Don't care

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often

C11

Allergies, hay fever, sinusitis	●	●	●	●
Breathing difficulties	●	●	●	●
Skin problems	●	●	●	●

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Headaches / migraines	●	●	●	●
Severe tiredness	●	●	●	●
Stiff or painful joints	●	●	●	●
Back pain	●	●	●	●
Problems with one or both feet	●	●	●	●

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Difficulty sleeping	●	●	●	●
Depression	●	●	●	●
Episodes of intense anxiety (eg panic attacks)	●	●	●	●
Other mental health problems	●	●	●	●
Palpitations (feeling that your heart is racing or fluttering in your chest)	●	●	●	●

C11

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Vaginal discharge or irritation	●	●	●	●
Premenstrual tension	●	●	●	●
Irregular periods	●	●	●	●
Heavy periods	●	●	●	●
Severe period pain	●	●	●	●

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

In the *last 12 months,* have you had any of the following:
(Mark one on each line)

	Never	Rarely	Sometimes	Often
Urine that burns or stings	●	●	●	●
Leaking urine	●	●	●	●
Constipation	●	●	●	●
Haemorrhoids (piles)	●	●	●	●
Other bowel problems	●	●	●	●

Page Break

Women's health is about coping with common problems

C11

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Have you ever been diagnosed or treated for:
(Mark all that apply)

- ☐ Insulin dependent (Type 1) diabetes
- ☐ Non-insulin dependent (Type 2) diabetes
- ☐ Heart disease
- ☐ Hypertension (high blood pressure)
- ☐ Low iron (iron deficiency or anaemia)
- ☐ Asthma
- ☐ Bronchitis
- ☐ Endometriosis
- ☐ Thrombosis
- ☐ Polycystic Ovary Syndrome
- ☐ Skin cancer
- ☐ Other cancer (please specify)
- ☐ Other major physical illness (please specify)
- ☐ Other (please specify)
- ☐ **None of these conditions**

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Have you ever been diagnosed or treated for:
(Mark all that apply)

- ☐ Urinary tract infection

C11

- ☐ Chlamydia
- ☐ Genital herpes
- ☐ Genital warts (HPV)
- ☐ HIV or AIDS
- ☐ Hepatitis B or C
- ☐ Other sexually transmitted infection (please specify)
- ☐ **None of these conditions**

Have you ever been diagnosed or treated for:
(Mark all that apply)

- ☐ Depression
- ☐ Anxiety disorder
- ☐ Other major mental illness (please specify)
- ☐ **None of these conditions**

Page Break

Women's health is about using health services

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Within the last two years, have you had:
(Mark one on each line)

	Yes	No
A Pap test?	●	●
Your blood pressure checked?	●	●
Your skin checked (eg spots, lesions, moles)?	●	●

C11

Have you *ever* had a vaccination for HPV (genital warts, cervical cancer)?
(Mark one only)

- Yes
- No

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Do you have your own Medicare card?
(Mark one only)

- Yes, I have my own card
- Yes, I have a copy of my parent's card
- No, I need to borrow my parent's card
- No, I don't have one
- Don't know

Do you have a Health Care Card? *This is a card that entitles you to discounts and assistance with medical expenses. This is not the same as a Medicare card.*
(Mark one only)

- Yes
- No

Page Break

Women's health is about lifestyle choices

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

C11

Do you *currently* smoke tobacco?
(Mark one only)

- Daily
- Less than daily
- Not at all

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

On a day when you smoke, how many cigarettes do you usually smoke?
Type the number in the box

[ ] cigarettes

In the *past*, have you smoked tobacco?
(Mark one only)

- Daily
- Less than daily
- Not at all

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

At what age did you start smoking tobacco?
Print the number in the box

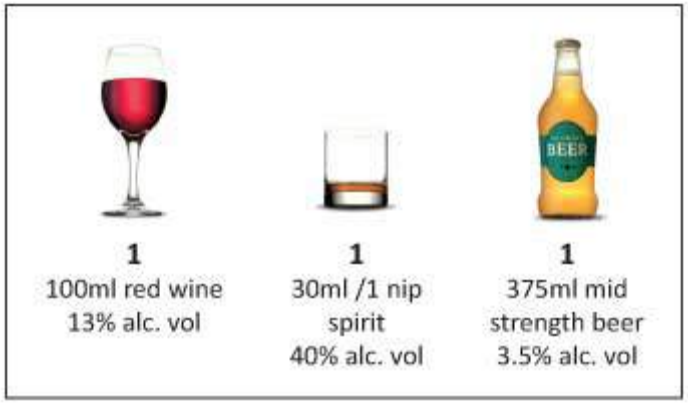
[ ] years old

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

C11

At what age did you first have a standard drink of alcohol?
(Mark <u>one only</u>)



- I have never drunk alcohol
- I started drinking alcohol at age

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

How often do you usually drink alcohol?
(Mark <u>one only</u>)

- I never drink alcohol
- Less than once a month
- Less than once a week
- On 1 or 2 days a week
- On 3 or 4 days a week
- On 5 or 6 days a week
- Every day

Page Break

C11

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

On a day when you drink alcohol, how many standard drinks do you usually have?
(Mark one only)

- 1 or 2 drinks per day
- 3 or four drinks per day
- 5 to 8 drinks per day
- 9 or more drinks per day

How often do you have five or more standard drinks of alcohol on one occasion?
(Mark one only)

- Never
- Less than once a month
- About once a month
- About once a week
- More than once a week

Page Break

Remember that any information you give us is kept confidential.

The following questions ask about the use of drugs for *non-medicinal* purposes.

We want to know about general patterns of use.

Please do not give details of specific instances of use (*mark all that apply*).

Page Break

C11

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Have you tried Marijuana? [+] (Expand for other names)
(Cannabis, pot, grass, weed, ya(r)ndi, rope, mull, dope, skunk, bhang, ganja, hash, chronic, reefer, joint, cone or spliff).

(Mark all that apply)

- ☐ In the last 12 months
- ☐ More than 12 months ago
- ☐ Never

Have you tried any other illicit drugs? [+](Expand for other names)
(Ice, Speed, GHB, Amphetamines, LSD, Natural Hallucinogens, Tranquilisers, Ketamine, Cocaine, Ecstasy, Inhalants, Heroin or Barbiturates)

(Mark all that apply)

- ☐ In the last 12 months
- ☐ More than 12 months ago
- ☐ Never

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

At what age did you first use Marijuana?

☐ years old

At what age did you first use any other illicit drug?

☐ years old

C11

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

The next two questions are about the amount of physical activity you did *LAST WEEK*.

Please state how many times you did each type of activity doing each type of activity *last week*.

Only count activities that lasted for 10 minutes or more.
*(If you did **not** do an activity, please type "0")*

Walking briskly (*for recreation or exercise, or to get from place to place*)

Moderate leisure activity (*like social tennis, moderate exercise classes, recreational swimming, dancing*)

Vigorous leisure activity (*that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming*)

Vigorous household or garden chores (*that make you breathe harder or puff and pant*)

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Please state how much time you spent altogether doing each type of activity *last week*.

Add up all the times you spent in each activity to get the total time for each activity.

	Hours	Minutes

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click "Next" to continue.

In the past 4 weeks:
(Mark one on each line)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time

About how often did you feel tired out for no good reason?	●	●	●	●	●
About how often did you feel nervous?	●	●	●	●	●
About how often did you feel so nervous that nothing could calm you down?	●	●	●	●	●
About how often did you feel hopeless?	●	●	●	●	●
About how often did you feel restless or fidgety?	●	●	●	●	●
About how often did you feel so restless you could not sit still?	●	●	●	●	●
About how often did you feel depressed?	●	●	●	●	●
About how often did you feel that everything is an effort?	●	●	●	●	●
About how often did you feel so sad that nothing could cheer you up?	●	●	●	●	●
About how often did you feel worthless?	●	●	●	●	●

If you would like some help with any of the symptoms listed above, a link to MoodGYM, an interactive website, will be provided at the end of the survey.

Page Break

Women's health is about coping with stres

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Over the *last 12 months*, how stressed have you felt about the following areas of your life?
(Mark one on each line)

	Not applicable	Not at all stressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed
Own health	●	●	●	●	●	●
Health of family members	●	●	●	●	●	●

C11

Work / employment	●	●	●	●	●	●
Living arrangements	●	●	●	●	●	●
Study	●	●	●	●	●	●
Money	●	●	●	●	●	●
Relationship with parents	●	●	●	●	●	●
Relationship with partner / spouse	●	●	●	●	●	●
Relationship with other family members	●	●	●	●	●	●
Relationship with friends	●	●	●	●	●	●
Motherhood / Children	●	●	●	●	●	●

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click "Next" to continue.

Now think about all of the time you spend sitting during *EACH DAY* while at home, at work, while getting from place to place or during your spare time.

In total, how much time do you typically spend sitting down while doing things like visiting friends, driving, reading, watching television, or working at a desk or computer?

	Hours	Minutes
On usual **weekday**		
On a usual **weekend day**		

Page Break

Women's health is about reproductive health

There are some unanswered questions on this page.

C11

We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

At what age did you have your first menstrual period?
(Age in years)

☐ years old

Have you ever had vaginal sex?

- ● Yes
- ● No
- ● I prefer not to answer

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

How old were you when you first had vaginal sex?
(Age in years)

☐ years old

Thinking about the LAST TIME you had vaginal sex, did you use any of the following?
(Mark all that apply)

- ☐ The Pill
- ☐ Condoms
- ☐ Implanon
- ☐ Mirena
- ☐ Other contraceptive ☐
- ☐ **None**

Page Break

There are some unanswered questions on this page.

C11

We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Have you ever been pregnant?

- Yes
- No

Are you currently pregnant?

- Yes
- No

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click "Next" to continue.

Have you ever had a:
(Mark one on each line)

	Yes	No	Don't know	I prefer not to answer
Miscarriage	●	●	●	●
Abortion or termination (for personal reasons)	●	●	●	●
Abortion or termination (for medical reasons)	●	●	●	●
Ectopic pregnancy (tubal pregnancy)	●	●	●	●
Live birth	●	●	●	●
Still birth	●	●	●	●

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click "Next" to continue.

C11

How many miscarriages have you had?

How many abortions or terminations for personal reasons have you had?

How many abortions or terminations for medical reasons have you had?

How many Ectopic pregnancies (tubal pregnancies) have you had?

How many live births have you had?

How many still births have you had?

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

How tall are you without shoes?
(If you are not sure , please estimate)
cms

How much do you weigh without clothes or shoes?
If you are pregnant now, write in the weight you were in the month prior to pregnancy.
(If you are not sure, please estimate)

C11

[ ] kgs

Page Break

The following questions ask about difficult situations you may have experienced.

Some people prefer not to answer questions of this nature.

If this is true for you, please go to the next question.

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Which of the following events have you experienced?
(Mark as many as apply on each line)

	Yes, in the last 12 months	Yes, more than 12 months ago	Never
Being pushed, grabbed, shoved, kicked or hit	☐	☐	☐
Being forced to take part in unwanted sexual activity	☐	☐	☐
Being bullied	☐	☐	☐

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

This question asks about situations you may have experienced with *current or past* partners[?]
For this question, partner can refer to a boyfriend or girlfriend that you have dated or lived with.
(Mark as many as apply on each line)

My partner:	In the last 12 months	More than 12 months ago	Never

C11

Told me that I was ugly, stupid or crazy, or that I wasn't good enough or that no one would ever want me	☐	☐	☐
Followed me or harassed me around my neighbourhood / work	☐	☐	☐
Tried to turn my family, friends or children against me or tried to convince them I was crazy	☐	☐	☐
Kicked, bit, slapped or hit me with a fist or tried to hit me with something	☐	☐	☐
Forced me to take part in unwanted sexual activity	☐	☐	☐
Tried to keep me from seeing or talking to my family, friends or children, or didn't want me to socialise	☐	☐	☐
Pushed, grabbed, shoved, shook or threw me	☐	☐	☐
Blamed me for causing their violent behaviour	☐	☐	☐
Harassed me over the telephone, email, Facebook or internet	☐	☐	☐
Used a knife or gun or other weapon or beat me up	☐	☐	☐
Became upset if dinner / housework wasn't done when they thought it should be	☐	☐	☐
Refused to let me work outside the home or took my wallet and left me stranded	☐	☐	☐

Have you ever been in a violent relationship with a partner / spouse?
(Mark one only)

- ● Yes
- ● No

Page Break

C11

If you feel distressed about any experiences of violence and abuse and would like some help to deal with this, please consider contacting one of the following:

- Your nearest Women's Health Centre or Community Health Centre
- Your General Practitioner for advice about who would be the best person in your community to talk to
- A Lifeline counsellor on 13 11 14 (local call)

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Mark as many as apply on each line	Yes, in the last 12 months	Yes, more than 12 months ago	Never
Have you been feeling that life isn't worth living?	☐	☐	☐
Have you deliberately hurt yourself or done anything that you knew might have harmed or even killed you?	☐	☐	☐

If you answered yes to either of the last 2 questions, you might like to talk to someone about how you are feeling.

You could ring Lifeline on 13 11 14 (local call).

Page Break

C11

Women's health is about considering diversity

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Do you speak fluent English?

- Yes
- No

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

What language do you speak at home?
(Mark the one *most commonly spoken*)

-- Select One --

What is the highest level of education you have completed?
(Mark one only)

- Year 10 or below
- Year 11 or equivalent
- Year 12 or equivalent
- Certificate I / II
- Certificate III / IV
- Advanced Diploma / Diploma
- Bachelor degree
- Graduate diploma / Graduate certificate
- Postgraduate degree

C11

Are you currently unemployed and actively seeking work?
(Mark one only)

- No
- Yes, unemployed for less than 6 months
- Yes, unemployed for 6 months or more

Page Break

Women's health is about juggling time

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

In a usual week, how many hours do you spend doing *paid work*?

-- Select One -- Hours

In a usual week, how many hours do you spend *studying*?

-- Select One -- Hours

How do you manage on the income you have available?
(Mark one only)

- It is impossible
- It is difficult all the time
- It is difficult some of the time
- It is not too bad
- It is easy

Do you regularly need help with daily tasks because of a long-term illness or disability (eg help with personal care, getting around, preparing meals etc)?

C11

- Yes
- No

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

Which of these most closely describes your sexual orientation?
(Mark one only)

- I am exclusively heterosexual
- I am mainly heterosexual
- I am bisexual
- I am mainly homosexual (lesbian)
- I am exclusively homosexual (lesbian)
- I don't know
- I don't want to answer

What is your current relationship status?
(Mark the response that best suits your current circumstances)

- I am single
- I am in a relationship (not living together)
- I am living with a partner
- I am engaged
- I am married
- I am divorced
- I am separated
- Other (please specify)

C11

What are your living arrangements?
(Mark all that apply)

- [ ] I live alone
- [ ] I live with one or both parents
- [ ] I live with other adults
- [ ] I live with my male partner
- [ ] I live with my female partner
- [ ] I live with children
- [ ] Other (please specify)

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

How did you hear about the Australian Longitudinal Study on Women's Health survey?

- ● Our Facebook page
- ● Facebook advertising
- ● Other online advertising or promotion. Please state what site/organisation
- ● Twitter
- ● Our website
- ● Another website. Please state what site
- ● Referral (e.g. friend or family)
- ● Poster, flyer or magazine advertising. Please record where
- ● Radio
- ● Television

Did someone help you fill in this survey?
(Mark one only)

- No
- Yes, but I told them the answers I wanted
- Yes, but the helper answered for me using his / her own judgement

Page Break

There are some unanswered questions on this page.
We would appreciate it if you could answer these or you can click the "Next" arrow to continue.

What was the MAIN reason for your needing help to fill in this survey?
(Please describe)

Have we missed anything?
If you have anything else you would like to tell us, please type in the box below.

Page Break

Please remember that your details will remain confidential.

Additional Personal Details

Maiden Name (if applicable)

Home Phone:

C11

Work Phone:

Page Break

In the event that you win our participation prize draw, please provide your postal address so we can send you your prize.

Is your postal address the same as your residential address? *(Tick the box if Yes)*

Page Break

Please remember that your details will remain confidential.

Postal Address Details

Building name / C\- instructions:

Unit/Street address:

Town / City:

State:

- ACT
- NSW
- NT

- QLD
- SA
- TAS
- VIC
- WA

Postcode:

Page Break

Please remember that your details will remain confidential.

Would you like to provide a second email address?
(If not, please leave blank)

Email:

Confirm Email:

The email address and confirmation you have supplied do not match. Please try again.

Page Break

Please remember that your details will remain confidential.

Help us keep in touch! **(optional)**
It would be helpful if you could also give us details of **a parent, relative or friend** who is likely to know where you can be contacted if we lose touch with you.
Please check that the parent, relative or friend is happy for you to provide these details.

Please note: giving us the details for a parent, relative or friend is optional.
All of the contact information you have provided for a parent, relative or friend will be kept separate from your answers to this

C11

survey.

What is their full name?

What is their relationship to you?

- Parent
- Relative
- Friend
- Other (please specify)

What is their email address?

What is their phone number (mobile preferred)?

Building name / C\- instructions:

Unit/Street address:

Town / City:

State:

- ACT
- NSW
- NT
- QLD
- SA
- TAS
- VIC
- WA

Postcode:

Would you like to provide another person's contact details?

- Yes
- No

Page Break

Please remember that your details will remain confidential.

What is their full name?

What is their relationship to you?

- Parent
- Relative
- Friend
- Other (please specify)

C11

What is their email address?

What is their phone number (mobile preferred)?

Building name / C\- instructions:

Unit/Street address:

Town / City:

State:

- ACT
- NSW
- NT
- QLD
- SA
- TAS
- VIC
- WA

C11

Postcode:

Page Break

If you would like to visit the MoodGYM website for mental health information and coping strategies click this link:
http://moodgym.anu.edu.au/welcome

Page Break

Jump-To: JMP5
Description:
Jump-To-Item: MEDICAREGROUP
Jump-If: (SUBMITTEDMEDICARE ≠ 1)

Powered by DatStat

C12

women's health australia

australian longitudinal study on women's health

Hey Ladies aged 18-23! We need YOU!

participate in a nationally important survey on health

You are more than the sum of your parts. You are a complicated being.

Help us understand young Australian women's health by taking a 15-20 minute confidential online survey.

You will go in the draw to win one of 100 prizes valued at $50 each.

Tell me more you say?

www.alswh.org.au/survey
info@alswh.org.au
1800 068 081

C13

To: {List} Converted from Ambassadors NYC mail merge 20121009.txt (18 recipients)
From: info@alswh.org.au (info@alswh.org.au / via SMTP)
Subject: Give back and help young Aussie women

women's health australia
australian longitudinal study on women's health

Women's Health Australia
Reply Paid 70
Hunter Region MC NSW 2310

1800 068 081
info@alswh.org.au
www.alswh.org.au

October 2012

Dear [[First_Name]] [[Surname]],

We would like to invite you to become an Ambassador for the Australian Longitudinal Study on Women's Health (ALSWH). ALSWH is one of the most prestigious, long running and comprehensive health surveys in Australia. It provides vital information to the Australian Government on the health and wellbeing of women in Australia and was used extensively in the development of the National Women's Health Policy 2010 (www.health.gov.au/womenshealthpolicy).

The role of an ALSWH Ambassador is new to the study. Ambassadors are being sought to raise the profile of the study while we recruit a new cohort of women. Young women aged 18-23 from all Australian states and territories, will be invited to join ALSWH in 2012 so that we can ensure that the opinions and experiences of young women are accounted for in future Government health initiatives.

Our Ambassadors will be prominent young women from sport, entertainment, arts and science who are called upon to raise awareness of the aims and objectives of ALSWH and to convey messages about its activities to the public. We have conducted focus groups around the country and feedback from young women has shown that those with a high public profile are very important to women aged 18-23. We are asking you to become an ALSWH Ambassador because of your profile and the attributes that you possess in being a positive role model for young women. We are seeking your help in raising our public profile in order to encourage more young women to participate in this study.

As an ALSWH Ambassador, we would ask you to:

- Provide a photo
- Prepare or endorse a short statement expressing your support for health and medical research, affirming your endorsement to encourage young women to take part in the study The photo and endorsement may be placed on ALSWH's website, Facebook, YouTube and Twitter pages, in information documents sent to participants as well as in magazine advertisements and the annual newsletter to participants
- Additionally, we may ask for a brief video expressing the importance of women's health issues and participation in research that will be available on YouTube and linked via ALSWH's website.

Your Ambassadorship would be for a limited duration of 6 months. In the future, we may wish to expand our publicity (such as television and radio spots). While there will be no obligation, should you choose to take part, any such activity would be arranged in consultation with you and your agent.

We hope that you will accept our invitation to become an ALSWH Ambassador, to help raise the profile of young women's health in Australia. It is an exciting time for our study, and we hope that you will join us and find it a rewarding journey! Further information about the study is attached. Should you have any questions concerning this proposal, please do not hesitate to contact us.

Kind regards

Deborah Loxton

Associate Professor Deborah Loxton
Deputy Director, ALSWH
On behalf of the ALSWH Research Team

Australian Longitudinal Study on Women's Health

Reply Paid 70, Hunter Region MC NSW 2310
1800 068 081
info@alswh.org.au
www.alswh.org.au
http://www.facebook.com/alswh
https://twitter.com/ALSWH_Official

C13

women's health australia

australian longitudinal study on women's health

Some more information about us

The Australian Longitudinal Study on Women's Health (ALSWH) is one of the most comprehensive national health studies in Australia, covering urban, rural, regional and remote areas, since 1996.

The study is run by researchers at The University of Newcastle and The University of Queensland, with funding from the Federal Department of Health and Ageing. ALSWH has produced 175 reports and ALSWH data have been used in 354 papers in peer reviewed journals, 607 conference presentations, 75 PhD, 20 Masters and 18 Honours projects. Over 430 collaborations with researchers from Australia, the USA, UK, Netherlands, Hong Kong, Argentina, Switzerland and New Zealand have conducted research using ALSWH data. The study was also cited 54 times in the 2010 National Women's Health Policy.

Three age groups of women have been participating in the study for the past 16 years. When the study first recruited participants in 1996 approximately 40,000 women opted in:

- 14,762 aged 18-23 - 14,072 aged 45-50 - 12,804 aged 70-75

With time passing, we now have a gap in the young adult age range.

This is where you come in...we are now preparing to recruit at least 10,000 Australian women aged 18 to 23 via a national social media and traditonal media campaign to join the study and follow the other participants.

They are the next generation of Australian women and

we need your help to make it happen!!

So why is this important?

- The data assists identification of social, psychological, physical and environmental factors influencing women's health throughout life
- This study is the largest of its kind ever conducted in Australia and has gained an international reputation
- It provides a national research resource on women's health issues
- Providing information on the long term health effects of life events
- Identifying when, if and how the health system meets the health needs of women
- ALSWH provides an evidence base to the Federal Department of Health and Ageing for the development and evaluation of policy and practice in many areas of service delivery that affect women

How can this influence change?

- Young Australian women will have a say about their health and health services
- Providing data will help motivate women to participate in decision making on health

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

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Email to be sent to participants who have submitted a survey

Dear [Name],

Thank you for completing the online survey for Australian Longitudinal Study on Women's Health. Your voice has been heard and your results will contribute to improving the health and wellbeing of all Australian women. For your information, we have included the information statement that you read before completing the survey as an attachment.

We will contact you during the year with a newsletter, updating you on the progress of the project. You will then hear from us in 2013 when your next survey becomes available.

For your information, your ID number is XXX-XXXXX-XX. You might like to keep this somewhere safe in case you need to contact the project at any time.

Refer a Friend:
Why don't you share the opportunity to participate in this project with your friends? Forward this link to them so that they can take part too: www.alwsh.org.au

Thanks again,

Kind Regards,

The Research Team at the Australian Longitudinal Study on Women's Health

University of Newcastle
Reply Paid 70
Hunter Region MC
NSW 2310

Ph: 1800 068 081 (Toll free number for questions or concerns)

C15

New Young Cohort Recruitment Record Keeping

HOW TO COMPLETE:

Enter a number (1 or more) in to the box if the task was conducted on that day. Leave blank if not conducted.			**OCT 2012**										**NOV 2012**														
			22nd	23rd	24 th	25 th	26 th	27 th	28 th	29 th	30 th	31 st	1 st	2nd	3rd	4th	05-Nov-12	06-Nov-12	07-Nov-12	08-Nov-12	09-Nov-12	10-Nov-12	11-Nov-12	12-Nov-12	13-Nov-12	14-Nov-12	15-Nov-12
SOCIAL MEDIA																											
Facebook post re. Recruitment			0	0	0	0	2	2	2	2	2	2	2	1	2	2	2	1	2	1	1	2	2	2	1	0	0
Facebook post re. Other				0	1	1	0	0	0	1	1	0	2	1	1	1	0	1	0	1	0	0	0	1	0	0	0
Facebook repost			0	0	0	1	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0
Twitter re. Recruitment			0	0	0	0	2	2	2	2	2	2	2	1	2	2	2	1	2	1	1	2	2	2	1	0	0
Twitter re. Other				0	1	1	1	0	2	1	1	1	0	1	1	1	0	1	0	1	4	1	3	1		1	0
Twitter RT							1			4	3	1		2	1	1	1	3		1	2			2	4	2	
Youtube video released																			1								
TRADITIONAL MEDIA																											
Media release			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0		0	0	0	0	0	0	0	0	0
Interview/news story			0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Ambassador interview/story/media release			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0
WEB-BASED ADVERTISING																											
Web forum post			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0
Facebook Ad													1	1	1	1	1	1									
Internet ad			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
POSTERS/POSTCARDS																											
Send to email networks for forwarding			0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0

C15

Send email to pilot group N=180													1														
Send to organisation for forwarding			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Placed on noticeboard (give details)			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Placed in shopping bags (give details)			0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
TOTAL RECRUITMENT HITS			***0***	***0***	***2***	***3***	***6***	***4***	***6***	***10***	***11***	***6***	***6***	***6***	***7***	***7***	***5***	***7***	***5***	***5***	***8***	***5***	***7***	***11***	***6***	***3***	***0***

C16

1. Social media policies and procedures: Streamlining posts and approvals

In the following list we are requesting permission to write some posts and tweets as they occur – e.g. posting or tweeting the arrival of visitors to UQ or UoN (eg the Minister's visit) or 'retweeting' relevant tweets from reputable sources (eg DOHA- who are very active Tweeters). This is labelled a 'global approval' request. If the global requests are approved then each individual post or tweet would not be put through the SC approval process.

If the global approvals are acceptable, the social media team will send around an invitation to all ALSWH staff and SC to provide information (about papers, conferences etc) that they may want uploaded on ALSWH social media.

The suggested procedure for uploading posts that have global approval:
ALSWH staff/SC emails a Post or Tweet and pictures (if available) to one of the social media team. The team check that the post and associated links and pictures meet the guidelines as set out in ALSWH Social Media Policy and the Style guide. The post will then be checked to ensure that it is the type of post that has global approval (ie is included on the list below). The post must be approved by the Director or the Co-Director or the Deputy Director prior to uploading.

Social media posts can be accepted by;

Ashleigh.omara@newcastle.edu.au
Clare.rooney@newcastele.edu.au

Posts and Tweets not included below will be put through the approval process as described in the ALSWH Social Media Policy.

Type of post/tweet	Notes
RETWEETS/ REPOSTS	Global approval request
Regular retweets from DoHA & other key collaborators/ organisations (see list)	
PAPERS	Global approval request
Every new paper can be tweeted/ posted upon publishing Brief description of paper followed by the link. The authors of the paper are required to write their own descriptions Some publisher's offer the option of tweeting/ posting directly with their share box	To be sent by the 1st author or liaison person.
CONFERENCE ATTENDANCE	Global approval request
Focus of tweets/posts is to be on the topic to be presented.	To be sent by the conference delegate.

Type of post/tweet	Notes
AMBASSADORS/ ADVOCATES	Global approval request
Acknowledge ALSWH advocates/ ambassadors Eg Thanks NAME for your support	(See Batch 5 for a full list)
Repost any involvement in health related endeavours e.g. if one of ambassadors/ advocates does a fun run, supports a health charity etc E.g: "Congratulations to the Aus Women's soccer team, the Matildas who handed England a 5:0 defeat today!"	
GUESTS to ALSWH	Global approval request
Also post on their home institution's facebook page if possible	
Welcome to "NAME" from INSTITUTION HASHTAG who is visiting today to [continue collaborating on the XX study/speak about XXX research]	
ALSWH VISITING OTHER INSTITUTIONS	Global approval request
Thanks @Hashtag for welcoming NAME to discuss TOPIC	
STUDENTS	Global approval request
"Welcome STUDENT from @hashtag [who will be working on xxx/looking at XXX]. Enjoy your experience working with ALSWH"	For visiting students eg the Dutch students at UQ
"Thanks to 3rd year design students for their contribution to ALSWH." Include links to the ads provided by the students.	These students have created poster/postcard/picture ads for Tumblr/Instagram which will be put through the approval process soon.
"Thanks to all drama students for donating their time for this video link"	Drama students participated in YouTube clips- which will also be put through the approval process soon.
"Thank you to NAMES, composers for ALSWH videos link"	For those who composed music, sound etc. for YouTube clips.
SURVEY UPDATES	Global approval request
Examples: "500 women have completed the new survey! Thank you for your help!" "This week 1247 phone calls were made to women reminding them to complete their survey- thanks for agreeing to fill them in!"	
New Young Cohort SURVEY UPDATES	
"Over 500 surveys completed online. What a great example of contributing to health information!"	
"Over 3000 young Aussie women care about the future of health policy."	
4000 Young Australian women are making a difference! Join them LINK	Recruitment requiring REC sign-off

C16

Type of post/tweet	Notes
Retweet if you care about the future of young women. SURVEY LINK	Recruitment requiring REC sign-off

2. Risk mitigation strategies re: Comments made by public users on ALSWH social media sites

A. Utilising security/permission settings on Facebook

See Figure 3 for a display of permission settings.

1. **Posting ability restricted**

   This restricts any user other than the administrator from making a post, adding a photo or tagging a photo on the timeline. This does not restrict users from commenting on posts that the administrator adds to the timeline – there is currently no way to do this as Facebook removed this function. See Part B for processes to minimise the risks associated with comments not being restricted.

2. **Private messages enabled**

   This allows users to send a private message only visible to themselves and the administrator. This does not appear on the timeline and is visible only to the administrator and the sender.

3. **Moderation blocklist automated**

   Keyword terms can be added here to block. When users include blacklisted keywords in a comment on the page, the content will be automatically marked as spam, which means the comment will not be displayed publicly. The comment can be unmarked as spam by the administrator.
   Words that will be included in the blocklist include ‘www’ or ‘com’ to restrict users from posting spam links. A lexicon of keywords will be compiled initially and added to over time using language used in unsuitable comments.

4. **Profanity blocklist automated**

   Profanity blocklist is set to ‘strong’, the most stringent setting available. “Facebook will block the most commonly repeated words and phrases marked as offensive by the broader community” (taken from Facebook information pop-up window on profanity blocklist).

5. **Reporting options for unsuitable comments**

   If a comment is determined to be unsuitable, the ‘mark as spam’ option can be selected by the administrator. This effectively deletes the comment from public view. The ‘report to facebook’ option is then available if the comment/user has been offensive or used profanity or determined to be a repeat-offender. Facebook investigates these reports of spam and will block and disable user accounts.

B. Proactively moderating comments made by other users

Moderators/administrators

The ALSWH team responsible for social media have administrator privileges on all ALSWH social media sites. Administrators have been rostered to monitor the sites during business hours, into the evening and on weekends. The administrator who is ‘on call’ will have primary responsibility for monitoring the social media sites (more detail below) and will be backed up by at least one other administrator who can take over the duty should the need arise.

Moderating process

1. **Immediate email notifications and online notifications for all comments**

   For Facebook and Twitter, email notifications and online notifications will be turned on (see Figure 1) to ensure that the administrator who is 'on call' is notified when any user makes a comment. Email notifications will be sent to alswh@alswh.org.au. In addition, 'Pages' will be utilised, which also notifies the administrator on call when a comment is made on Facebook. Notifications for any other social media utilised will also be turned on to facilitate monitoring. See Part C for the procedure for checking emails and online notifications.

Figure 1 Notification settings available for Facebook pages

2. **EVERY new comment will be reviewed using the review checklist (see Figure 2).**

   a. If a comment is determined to be unsuitable based on use of inappropriate language, content not suitable for the ALSWH audience, or because it is attempting to market or sell to viewers of the page, it will be removed. In Facebook this is achieved by 'marking as spam'. If the content is determined to also be offensive, it will be 'reported to Facebook' for investigation.

   b. If the comment is determined to be from a participant and/or risks the anonymity of that participant, a private message will be sent to them suggesting they remove the post. The message will read:

   "Hi. We noticed that you have made a comment about your participation in the Australian Longitudinal Study on Women's Health. Due to privacy concerns and upholding the anonymity of all participants, we recommend you remove your comment. If you would like to discuss this further, or have any questions or concerns please contact call 1800 068 081 (Freecall), via private message, or by email (info@alswh.org.au). Thank for you ongoing involvement in the study."

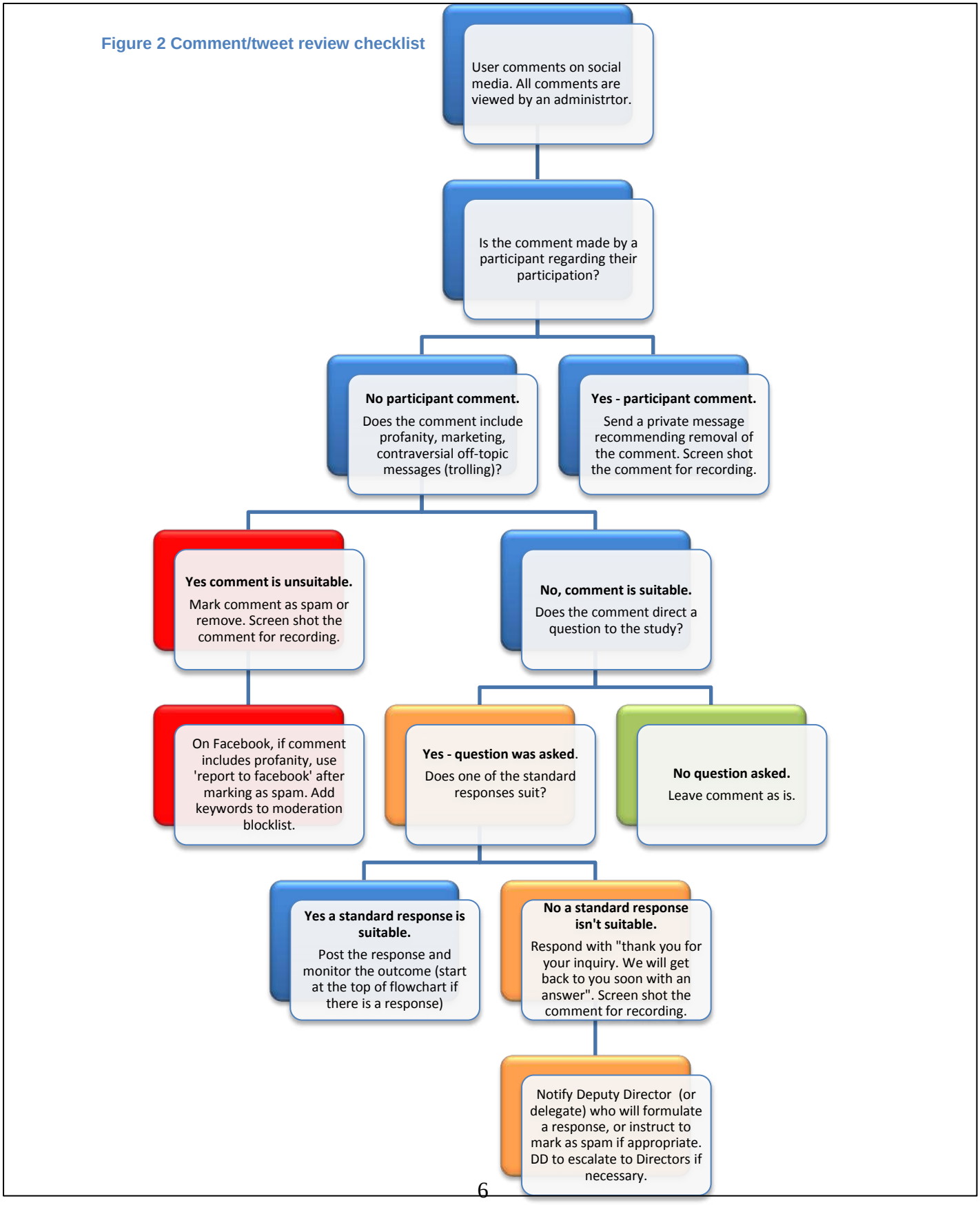
   If a comment contains a question directed at the study, these comments will receive a response that is in line with the standard and procedures currently used by ALSWH in responding to email, mail and telephone inquiries.

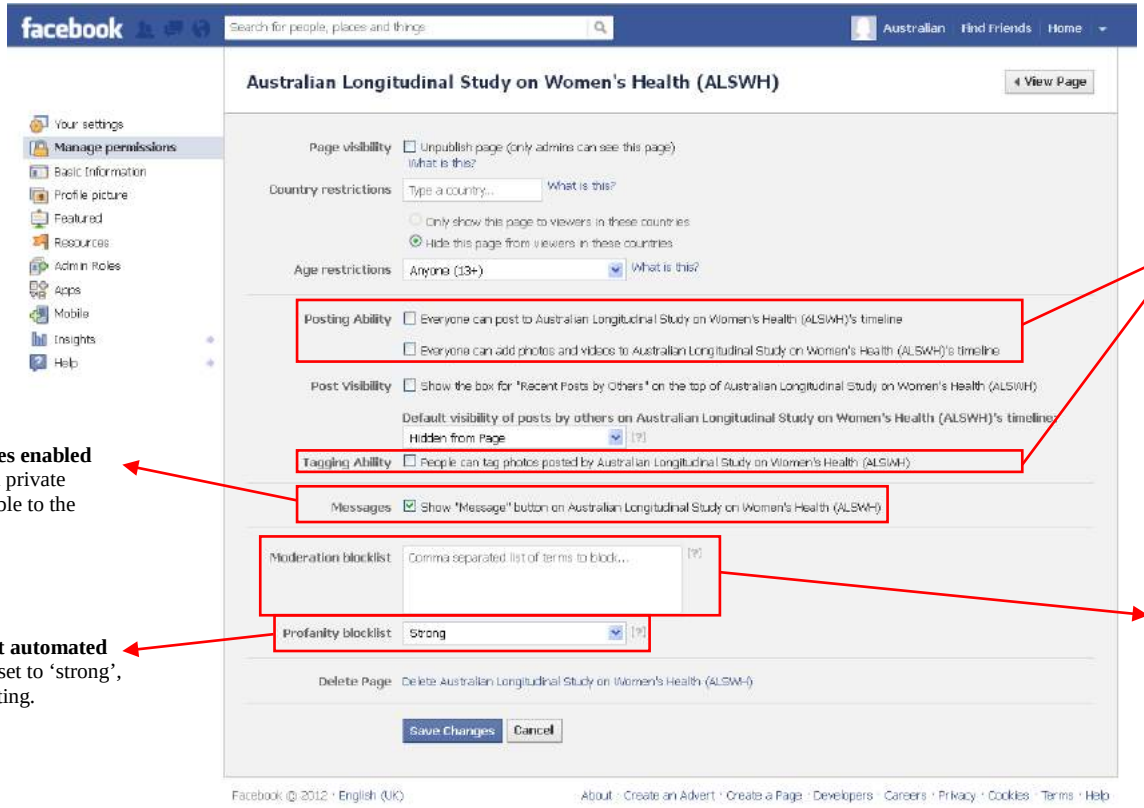
   Record keeping
   A record of the details of every comment that requires an action (ie is removed or marked as spam or recommended for removal or requires a response) will be kept by taking a screen shot of the media involved. This will be saved on the device (smart phone, iPad) and date stamped with the date and time that the screen shot was taken. Screen shots will then be archived (see below).

3. Backup

The iPad will be synchronised on a daily basis and routinely backed up to the network drive on a weekly basis. This will synchronise the photo album on the iPad that contains the screen shots of incidents.

Figure 2 Comment/tweet review checklist





1. Posting ability restricted
No person other than the administrator can post or add photos or tag photos on the ALSWH page.

2. Private messages enabled
Anyone can send a private message, only visible to the administrator.

3. Moderation Blocklist automated
Keyword terms can be added here to block. When users include blacklisted keywords in a comment on the page, the content will be automatically marked as spam. The comment can be unmarked as spam by the administrator.

4. Profanity blocklist automated
Profanity blocklist is set to 'strong', the most stringent setting.

Figure 3 Permission settings available for Facebook pages

3. ALSWH Disclaimers, Terms and Conditions

Note: This document will be held on the ALSWH website. A link to the document entitled "Disclaimers, terms and conditions of use" will be included on all ALSWH social media.

Disclaimers, terms and conditions of using and posting to ALSWH Social Media

By participating on ALSWH social media, you acknowledge that:

1. Information posted on this site, does not necessarily reflect the opinions and ideas of the University of Newcastle, the University of Queensland or he Department of Health and Ageing.
2. Except where expressly stated otherwise, material on ALSWH social media is provided as general information only. It is not intended as advice and must not be relied upon as such. You should make your own inquiries and take independent advice tailored to your specific circumstances prior to making any decisions.
3. ALSWH is not responsible for, and accepts no liability in relation to, any other users' use of, access to or conduct in connection with ALSWH social media pages in any circumstance.
4. Any medical information on this website is for general information only. It is not intended to be and should not be relied on as a substitute for specific medical or health advice.
5. This site may contain links to sites controlled or produced by organisations other than ALSWH. The links are provided for convenience only and are not an endorsement of any products, services or content at those other sites, which also may not remain current or be maintained.
6. Retweeting and reposting does not constitute endorsement of the subject matter or of the origin or originator of the original tweet or post.

ALSWH attempts to acknowledge and seek permission from content owners whenever possible. If you are the owner of any content that is posted on this site and would like it removed. Please contact us.

ALSWH post /tweet guidelines (applies to all ALSWH social media channels)

This is a guide for responsible social media use. If you ignore these guidelines, your posts/comments may be removed.

ALSWH will never disclose a name of a participant, if an individual chooses to disclose this information, it is their choice. However, this is not an action ALSWH recommends.

- Remain honest and transparent in your communications,
- Before you post or comment, make sure that your participation adds value to the discussion and does not solicit business,
- Be respectful when expressing an opposing opinion or engaging in debate.
- Never be aggressive or post content that is offensive or defamatory,
- When participating in online discussions relating to your area of expertise, always identify your standing at the University or your organisation and any relevant qualifications,
- Avoid commenting on unfamiliar topics and ensure your personal opinions are distinguished from professional communication,
- Protect sensitive and confidential information. Respect intellectual property and link to sources whenever possible.
- Always be upfront and take responsibility for your mistakes. An apology or correction can often rectify minor issues.
- Use common sense and always think twice before you publish. You are ultimately responsible for what you write.

Bullet points adapted from 'THINK BEFORE YOU POST' UoN
http://www.facebook.com/UoNStudents/app_293583394047144

Your conduct

You must not:

(a) use ALSWH social media pages in breach of any applicable laws or regulations;

(b) use ALSWH social media pages:

- to transmit (or authorise the transmission of) "junk mail," "chain letters," unsolicited emails, instant messaging, "spimming," or "spamming";
- to impersonate any person or entity;
- to solicit money, passwords or personal information from any person;
- to harm, abuse, harass, stalk, threaten or otherwise offend others; or
- for any unlawful purpose;

(c) use ALSWH social media pages to upload, post, transmit or otherwise make available (or attempt to upload, post, transmit or otherwise make available) any material that:

- is not your original work, or which in any way violates or infringes (or could reasonably be expected to violate or infringe) the intellectual property or other rights of another person;
- contains, promotes, or provides information about unlawful activities or conduct;

- is, or could reasonably be expected to be, defamatory, obscene, offensive, threatening, abusive, pornographic, vulgar, profane, indecent or otherwise unlawful, including material that racially or religiously vilifies, incites violence or hatred, or is likely to offend, insult or humiliate others based on race, religion, ethnicity, gender, age, sexual orientation or any physical or mental disability;
- exploits another person in any manner;
- contains nudity, violence, or sexual acts or references;
- includes an image or personal information of another person or persons unless you have their consent;
- poses or creates a privacy or security risk to any person;
- you know or suspect (or ought reasonably to have known or suspected) to be false, misleading or deceptive;
- contains restricted or password only access pages, or hidden content;
- contains viruses, or other computer codes, files or programs designed to interrupt, limit or destroy the functionality of other computer software or hardware;
- advertises, promotes or solicits any goods or services or commercial activities (except where expressly permitted or authorised by us); or
- contains financial, legal, medical or other professional advice;

(d) use code or other devices containing any reference to ALSWH social media pages to direct other persons to any other web page;

(e) except to the extent permitted by law, modify, adapt, sublicense, translate, sell, reverse engineer, decipher, decompile or otherwise disassemble any portion of ALSWH social media pages or cause any other person to do so; or

(f) delete any attributions or legal or proprietary notices on ALSWH social media pages.

Notifying ALSWH

If you think that any ALSWH social media pages have been accessed or used by another user in breach of the Conditions, please email info@alswh.org.au

4. ALSWH Social Media Policy

When composing, approving and posting public comment about or relating to the Australian Longitudinal Study on Women's Health (ALSWH) on Social Media Channels that belong to the ALSWH, or on personal channels, staff of the ALSWH will adhere to the guidelines laid out in the following governing bodyies' policies:

1. Australian Public Service Commission (the Department of Health and Ageing adhere to this policy):
   http://www.apsc.gov.au/publications-and-media/current-circulars-and-advices/2012/circular-20121

2. In the absence of a policy endorsed by the University of Queensland, the Queensland State Government policy:
   http://www.qld.gov.au/web/social-media/policy-guidelines/guidelines/documents/social-media-guideline.pdf

3. The University of Newcastle:
   http://www.newcastle.edu.au/policy/000955.html
   http://www.newcastle.edu.au/policy/000953.html
   http://www.newcastle.edu.au/policy/000954.html

The ALSWH Social Media Policy applies to: Twitter, Facebook, Tumblr and future social media site posts. Figure 1 shows the process for gaining approval to post to these and other internet based ALSWH media sites.

Timing/ Frequency

Posts are to be made at different times during the business day (9:00am-5:00pm)
In general, posts will be made on a cycle that will not exceed eight days. Posts will be made on different days of the week. Justification: allows us to capture different audiences depending on their internet traffic habits. Pages remain dynamic but without oversaturation.
Peak periods: During survey deployment posts will be made on a more frequent basis. This is to encourage participants to complete their surveys.

Principles for participation in social media

a. Be honest. Where possible, always use your real name.
b. Be respectful. Never be aggressive or post content that is offensive or defamatory.
c. Reference your area of expertise, if relevant to your discussions or comments. To speak as an expert, the University of Newcastle uses the rule that the speaker must have a peer-reviewed publication in the topic area.
d. Make sure your personal opinions are distinguished from professional communication.
e. Protect sensitive and confidential information. Respect intellectual property and link to sources whenever possible.
f. Always take responsibility for your mistakes. An apology or correction can often fix minor issues.
g. By engaging on the ALSWH official social media channels you also agree to comply with the host site's guidelines (i.e., Twitter Terms of Service). The terms and conditions of each channel will be assessed thoroughly by each ALSWH employee responsible for editing posts and posting on and maintaining the channels.
h. Use common sense and always think twice before you publish. You are ultimately responsible for what you write.

i. Information posted on associated sites by external parties, does not necessarily reflect the opinions of the ALSWH (This will be made clear on the ALSWH social media sites).

j. The more the ALSWH site is linked with other relevant material, the more contacts will be made and the more popular the ALSWH pages/sites will become.

Guidelines for Social Media Posts

- Evidence based posts
- Apolitical
- Personal opinion minimised
- No product placement
- No favouritism/ prejudicial posting
- Politically correct, inclusive posts assuming a diverse readership
- Plain language used
- Links to other sites/ videos – before links to other sites (including video sites) are posted on ALSWH social media the proposed sites will be checked for compliance with the ALSWH social media policy and will be subject to the ALSWH social media approval process.

Categories for Social Media Posts

Categories for posts can include but are not limited to:

a. Summaries of published findings (dot points and plain language).
b. Results from surveys
    a. E.g. number of completed surveys
    b. Results from previous surveys
c. Results from other studies that are relevant
    a. E.g. sharing a link of other interesting results; or giving a few dot points from a paper and sharing a link to the abstract.
        i. http://www.halifaxcourier.co.uk/news/health/new-breast-cancer-blood-test-1-4509088
d. Suggestions
    a. Occasionally posting health education information would be interesting. Such as dietary guidelines, minimum exercise recommendations-as published by other authoritative services/ medical sources.
e. Staff profiles
f. Conferences to be attended/ presented
g. Interactions with government bodies
h. National charity events *e.g. Breast Cancer Walk, Memory Walk*
i. Programmes- documentaries and news programs that are coming up
j. Calendar specific posts: e.g. Pink ribbon day, Daffodil Day, International Women's Day, Anniversary of achievements
k. Achievements of female health professionals e.g. Professor X wins award for X research.

l. Facts and explanations
    a. e.g., video about what a longitudinal study is.
m. Operational news- e.g. just deployed the 7th survey for women born between 1946-1951
n. Linking our other social media platforms- e.g. posting when we upload or 'favourite' a video to YouTube or make a Tumblr post.
o. Statistics explained by statisticians and other specialist points of interest explained by specialists (eg psychology by psychologists, gerontology by gerontologists)
p. Health myths and truths- dispelling myths and endorsing factual information- backing up with links to abstracts and published research
q. How ALSWH has had an effect on policy

Stylistic Principles

Language:

a. The language style must be conversational (not clinical)
b. Aim for a Year 6 communication level
c. Correct grammar and spelling

Remember the audience includes:

a. General public
b. Participants of all ages
c. Researchers
d. Media
e. Government
f. Health service providers

Rotate the group being targeted. This can be achieved by rotating themes.

Monitoring Procedure

The ALSWH must have a process in place to monitor social media presence. It is important to retain a historical log of all social media interaction to ensure that an audit can be done by the organisations ALSWH is accountable to (The University of Newcastle, The University of Queensland and the Department of Health and Ageing) and internally by the Steering Committee. It is also helpful to retain a log of topics and themes addressed to ensure variety and interest.

Web-Forum (Discussion Board):

The ALSWH social media web-forum will be a record of the internal justification for the posts made. This is where the approval process will be recorded. It will be the medium that enables the Steering Committee to participate in the Social Media approval process. All communication regarding social media posts must be communicated through the web-forum. This includes

A. Guidelines that govern posts
B. Potential posts
C. Comments about the posts by Steering Committee
D. Any modifications of posts
E. Final approval of posts

Monitoring

All internet based ALSWH sites will be monitored for feedback, messages, cross postings and to oversee the ways in which ALSWH is portrayed by users of the sites. While it may not be possible to monitor all such activity, it should be possible to monitor such things as shared posts. Responses to inquiries made as a result of the ALSWH social media presence will be made in line with existing ALSWH protocols (ie those used for telephone, written and email inquiries). An excel workbook will be maintained to log the monitoring of the social media channels.

It will contain multiple spreadsheets that log:

1. The published posts
2. Enquiries and responses
3. Monitoring of the different social media sites

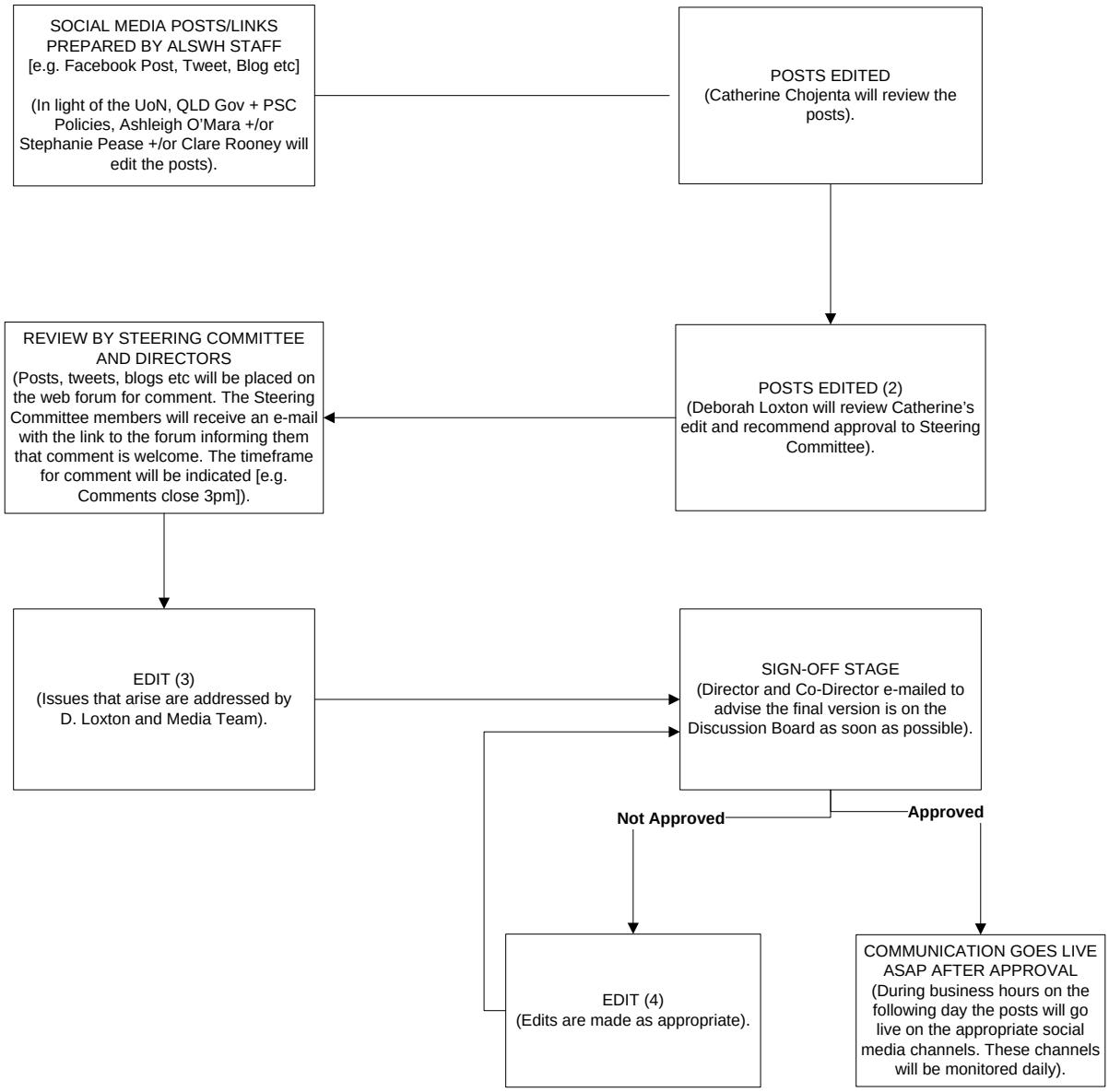


Figure 1: ALSWH Social media approval process

5. ALSWH Style Guide

Be informative, maintain professional but plain language.
Focus on the reasons for visitors, conference attendances etc rather than the people and places concerned.
In any post, focus on the research aspect of the event or topic.
Be aware of the diversity of the audience, which might include:

- Government departments
- Politicians
- Researchers
- Participants
- Potential NYC participants
- Media
- General public
- Service providers

Avoid personal possessive pronouns eg 'our' study, 'our participants', research 'we' conducted. Use the third person:

'ALSWH hosted Professors Smith, Jones and Allen from the University of Smithton who are collaborating on mental health research' [link to appropriate report/paper]
NOT
'WE welcomed Jane, Jenny and Joyce from Greece today to continue OUR work on mental health.'

<u>Use of the article 'The'</u>

1. Abbreviation (ALSWH): No article (the).
   Example: ALSWH data show that as you get older, you get more wrinkles.
   If you are an over-sharer, don't worry, ALSWH wants to hear it!
2. Unabbreviated with no article.
   Example: Australian Longitudinal Study on Women's Health data show that as you get older, you get more wrinkles.
3. Unabbreviated (Australian Longitudinal Study on Women's Health): permitted to use lower case article (the) **when necessary**.
   Example: If you are an over-sharer, don't worry, the Australian longitudinal Study on Women's Health wants to hear it!
4. In some rare cases, organisations use a capitalised article (The) as part of their name (eg The Age). In these cases, use the name as it is used by the organisation concerned.

www.alswh.org.au

women's health australia

December 2012