

women's  
health  
a u s t r a l i a



**The Australian Longitudinal Study on  
Women's Health**

**Report 16**



*The* UNIVERSITY  
*of* NEWCASTLE  
AUSTRALIA

in association with



THE UNIVERSITY  
OF QUEENSLAND

**10 June 2001**

**REPORT 16**  
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## EXECUTIVE SUMMARY

1. The main surveys are continuing according to the timetable. The third survey of the mid-age cohort (now aged 50 to 55) began on 19 March 2001 with a mailout to 13,007 women. As usual, a thank you/reminder card was sent to all women after two weeks and a further reminder to non-respondents after another four weeks. Response rates to date have been considerably higher than those achieved in the same time period during 2000 with the young cohort, and reached 71.3% on 15 May (the comparable rate in 2000 was 46%). This reflects greater stability among mid-age women than among the younger women. Tracking of addresses of women whose surveys were returned to sender is under way. Further mailouts to new addresses, and telephone reminders to non-respondents, will commence in June.
2. The previous report on progress with the indigenous special cohorts was unavoidably delayed until April 2001. The short time period between that report and this one (June 2001) means that there is no additional report on that cohort.
3. Planning for Survey 3 of the older cohort, to be conducted in 2002, is under way. A preliminary telephone survey of older women indicated a definite willingness to continue with the project and a strong preference for mailed rather than telephone administration of surveys. A planning meeting was held in April, and a draft survey is currently being finalized for piloting later in 2001.
4. Individual consent must be sought for the study team to access participants' Medicare or DVA data held by the Health Insurance Commission. On previous occasions, Women's Health Australia (WHA) were required to place a time limit on the consent requested, and consent for those who had previously agreed will expire at the end of 2001. Therefore, it is necessary to approach all women who are still participating in WHA, during 2001 and invite them to consent to further data linkage. Requests for consent have been approved by institutional ethics committees and will be mailed with the annual newsletter in the second half of June. Those women who have previously given consent (53%) and those who have not explicitly refused consent (44%) will be invited to give consent. Those who have actually refused in the past (3%) will be given an opportunity to request a consent form if they wish to change their minds.
5. Substudies and subsidiary analyses currently under way focus on several aspects of women's health and well-being. Data from Survey 1 and from specific substudies are still being analyzed, but we are also beginning to explore changes in health and behaviour between Surveys 1 and 2 in order to examine predictors of changes towards healthier, or unhealthier, lifestyles. Current or recently completed projects focusing on health behaviour include an analysis of changes in smoking status among the young women between Surveys 1 and 2, with a focus on predictors of smoking cessation; and patterns of pap smear adherence and mammographic screening in the mid-age cohort, based on responses to questions in Surveys 1 and 2. Projects that examine women's health in the context of their personal and social lives include an analysis of young and mid-age women's access to, and choices about, leisure activities; an exploration of multiple social roles and health across all three age groups; a survey on coping with abusive relationships; and analyses of psychological predictors of healthy ageing. Projects focusing on diagnosis and health service use include a longitudinal analysis of the effects

of incontinence on changes in older women's health, and a validation of Health Needs Index models for predicting health service use in New South Wales.

6. Dissemination of study findings has been a strong component of the WHA work of the past six months. A highlight has been the publication of a book overviewing the first five years of the project. Publications and presentations in this period include seven papers published in peer-reviewed journals and a further seven accepted for publication. Investigators and students also presented nine papers at national and international conferences. Conference organization activities (which have replaced the requirement that we organize a specific conference) have also been successful. Investigators presented a highly successful one-day workshop at the Australian Women's Health Network conference in Adelaide in February and presented a well-received symposium at the Rural Health Conference in March. We are also playing a role in organization of conferences to be held later in the year.
7. The book, "Women's Health Australia: What do we know? What do we need to know?", was written to provide an overview of the project and summary of results to date. It was formally launched by Professor Anne Edwards at the Women's Health Network conference in Adelaide in February and generated a considerable amount of interest. Sales have been good and this appears to be a successful strategy for increasing awareness of the project among the broader professional community.
8. Statistical work has continued to be a major focus. In particular, the statistics team has been focusing on the validation of scales and the use of imputation methods to produce scale scores when some individual items are missing. Ad hoc analyses for the Department of Health and Aged Care include an assessment of missing data among women of ATSI and non-ATSI background, and ongoing work on smoking among young women. We are continuing to encourage members of the Department to make use of the data sets.
9. Data quality assurance activities are ongoing. These include the successful archiving of updated Survey 1 data for all cohorts, as well as Survey 2 data for the mid- and older cohorts. The Survey 2 dataset for the young cohort has been checked and cleaned, and is available for use. Data dictionaries are continuing to be updated. Medicare data for 1998 and 1999 have been obtained from the Health Insurance Commission and are in the process of being cleaned, checked, and linked to survey data.

# **1 COLLABORATIVE RESEARCH ACTIVITIES**

## **1.1 MEETINGS BETWEEN AND WITHIN THE UNIVERSITIES OF NEWCASTLE AND QUEENSLAND**

The ten Investigators on the main survey are now located at the University of Newcastle, the University of Queensland, the University of New England, RMIT University, and the Medical Research Council Human Nutrition Research Unit, Cambridge, UK. Teleconferences were held on 29 January and 26 February, a face-to-face meeting was held in Newcastle on 26 April (in conjunction with a workshop on the design of Survey 3 of the older cohort), and a further teleconference was held on 29 May. Minutes of these formal meetings appear in Appendix 1.1.

General meetings of those Investigators, Associate Investigators and project staff who were able to attend were also held at the University of Newcastle on 30 January, 27 February, 24 April and 22 May, and minutes of these meetings appear in Appendix 1.2.

Face-to-face meetings between special cohort researchers and those main study researchers located at the University of Queensland were held on 15 February, 13 March, 10 April and 15 May, and minutes on these meetings appear in Appendix 1.3.

Informal meetings were held between Professor Christina Lee, Project Manager, and Dr Gita Mishra and Associate Professor Margot Schofield at the Medical Research Council Human Nutrition Unit, Cambridge, UK, on Friday 30 March. Notes on these meetings appear in Appendix 1.4.

The research team is steadily growing and is spread across a large number of locations. As well as circulating agendas and meeting minutes, we are increasingly providing detailed notes in advance of all meetings so that those who are unable to participate in person can maintain their connection with the project.

## 1.2 SUMMARY OF COLLABORATIVE RESEARCH ACTIVITIES BETWEEN AND WITHIN UNIVERSITIES OF NEWCASTLE AND QUEENSLAND, AND WITH OTHER COLLABORATING INSTITUTIONS

### 1.2.1 Projects completed by WHA investigators and collaborators

<b>Project:</b>	Women and leisure towards 2000. Does all work and no play make Jill unwell?
<b>WHA Collaborators:</b>	Professor Wendy Brown, Emeritus Professor Lois Bryson & Dr Penny Warner-Smith
<b>Collaborator:</b>	Associate Professor Peter Brown (Dept of Leisure and Tourism Studies, The University of Newcastle)
<b>Funding source:</b>	ARC Small Grant

This substudy aimed to develop an understanding of the role of leisure in women's lives, and the relationships between leisure, well-being and gender relations. Key questions addressed by the study were: i) How do women divide their time between various types of leisure (e.g. active/passive, structured/unstructured, relational/non-relational leisure) ii) How are leisure patterns and outcomes mediated by age, location (rural, urban, remote), class, ethnicity, etc? iii) What patterns of leisure are associated with the greatest satisfaction for women and with the most efficacious outcomes for well-being including physical and mental health?

A series of 11 focus groups were completed involving 62 women recruited from the existing young and mid-age cohorts of the Australian Longitudinal Study on Women's Health (ALSWH). The focus groups were undertaken in a mix of 'urban' (Belmont, Dapto), 'large rural' (Dubbo, Mittagong) and 'other rural' (West Wyalong) areas. A semi-structured group interview explored issues relevant to women's perceptions of leisure, their current leisure patterns, leisure aspirations, and associations between leisure, personal health and well-being.

For many women, leisure was defined in terms of enjoyable activities undertaken in 'free time'. However, in the context of this and other studies of leisure it is clear that so called 'free choices' are generally undertaken within a framework of constraints and that, for women in particular, leisure is very much constrained or enabled by patterns of work and family circumstances. While the data captured some of the diverse ways in which women understand and experience leisure, the findings indicate broad generational differences in women's attitudes to leisure and leisure time, and the ways in which women use leisure as a form of stress relief (younger women) and risk management (mid-age women) in relation to their health.

A specific focus on the leisure and well-being of mid-age rural women also highlights how issues relating to women living in rural Australia (e.g. poor job opportunities, lack of public transport and other facilities, family transience) impact on both leisure and health. Looking specifically at young rural women, who proved to be particularly dissatisfied with the leisure time available to them, it seems that the construction of leisure in their lives can no longer be seen as 'free time' in the sense of time not needed to meet their commitments, but something which has to be constructed. It seems they attempt to control their lives to achieve an idealized notion of 'the balance'. This balance is characterised by their obligations to work, obligations to others and time for self.

Data from the focus groups have informed a follow-up study that uses time diaries and in-depth interviews to explore issues relating to constraints on women's leisure, and the ways in which constraints are negotiated within households. This follow-up is currently in the early stages of data collection.

### **1.2.2 Projects in progress by WHA investigators and collaborators**

**Project:** Age cohort, social roles, and well-being in three generations of Australian women

**WHA Investigators:** Professor Christina Lee & Ms Jennifer Powers

Understanding the nature of the relationship between social roles and health is relevant to the development of health policy and the provision of appropriate health services throughout the lifespan. While women's expectations concerning employment and equality have changed radically in the past few decades, at the same time women continue to take major responsibility for childcare and unpaid domestic labour. The extent to which women hold multiple social roles has profound impacts on their health and well-being, and at a broader level on the development of social policy which promotes healthy women, healthy families and healthy communities.

This analysis of Survey 1 data examines the relationship between multiple role occupancy, physical health, emotional health, and health service use in the three cohorts of women. Young and mid-age women were categorized according to their occupancy of five roles: paid worker (full or part time); partner (in a married or de facto relationship); mother (with a child at home); student (full or part time); and caregiver. Older women were categorized according to partner and caregiver variables only.

Young women were most likely to have only one role: those who had one role (59% of the total) were most likely to be students (50%) or workers (43%). Thirty per cent of young women had two roles, and these were most likely to be worker/student (37%) or worker/partner (28%). The parent role was the least frequently endorsed (7.5%), and the majority of those who had a parent role cared for one child of pre-school age.

Mid-age women were most likely to endorse three roles (40%), though two roles were also common (35%). The predominant triple role was partner/worker/parent (74%), while double roles included partner/worker (44%), partner/parent (28%), and worker/parent (18%). Those who were defined as having a parent role (ie had a child at home) were most likely to have a child over the age of 15, although 42% of mid-age parents cared for a younger child.

Older women only had the opportunity to endorse "partner" or "caregiver" roles. The major single role for older women was partner (88%), and by definition all those with two roles were combining partner and caregiver roles.

Among the young women, there was a consistent trend for more roles to be associated with poorer physical health, more symptoms, poorer emotional health, and higher health service use. Among the mid-age women, those with three or more roles tended to have better scores on the outcome variables than those with fewer. One role was associated with the best outcomes for the older group.

This suggests that there are important differences in the strategies which younger and mid-age women use to cope with multiple social roles. The implications of these differences for women’s health will be investigated in future analytical work.

**Project:** Quality and accessibility of health care for women in Australia with diabetes  
**WHA Investigators:** Dr Anne Young, Dr Amanda Patterson & Associate Professor Julie Byles  
**Associate Investigator:** Dr Julia Lowe  
**Funding:** Diabetes Australia

**Stage 1**

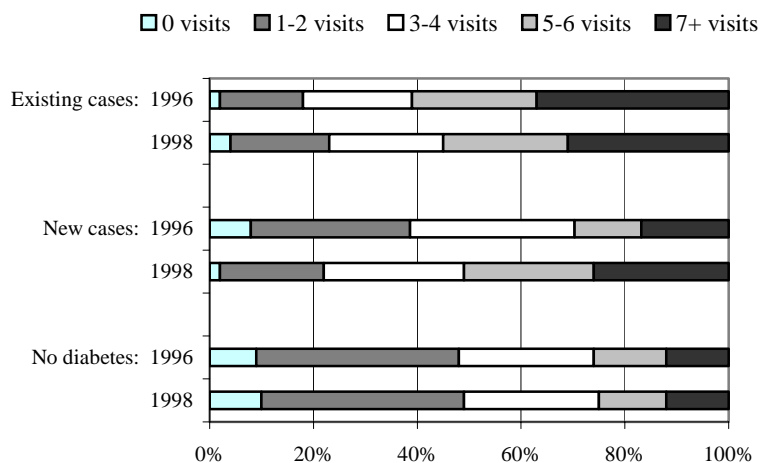
*Aim:* To report on the prevalence of diabetes; risk factors for diabetes (such as inactivity, overweight and obesity); and health, functional status and access to health care services for women with and without diabetes, by analysing data obtained from Survey 1 and Survey 2 of women in the ALSWH project.

*Progress:* Responses to the questions on diabetes in Survey 1 and Survey 2 were used to define diabetes status. Women who reported they had diabetes at the time of Survey 1 in 1996 were called ‘existing cases’. Women who reported having diabetes at the time of the Survey 2 in 1998, but not in Survey 1, were called ‘new cases’ and women who responded that they did not have diabetes at both Survey 1 and Survey 2 were called the ‘no diabetes’ group. The total number of women in each group for the mid and older cohorts is shown Table 1.

**Table 1 Women with and without diabetes in the mid-age and older cohorts**

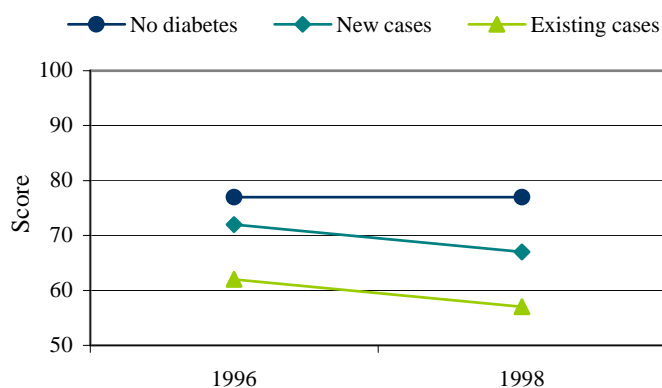
	Mid Cohort	Older Cohort
Existing cases	236	840
New cases	141	266
No diabetes	11,853	9,315
Total	12,230	10,421

The analysis of Survey 1 and Survey 2 data for women in the mid-age cohort showed differences in health and health service utilisation according to whether the women had diabetes. (Analysis of data for the older cohort is underway.) The number of general practitioner (GP) visits by women in the mid cohort for the year prior to each of the surveys is shown in Figure 1. Women with diabetes reported a higher number of GP visits than women without diabetes. Among women with diabetes, those who had diabetes at Survey 1 (existing cases) had a higher number of GP visits than the new cases of diabetes, but GP visits increased across the two surveys for the “new cases”.



**Figure 1** Reported number of GP visits in previous year at Surveys 1 and 2 for mid-age women with and without diabetes

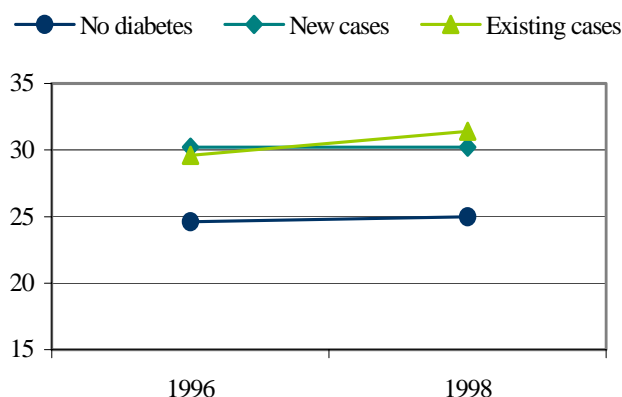
Women with diabetes tended to have lower scores on the general health subscale of the SF-36 than women without diabetes. Median general health scores were lowest among women who had diabetes in 1996 (existing cases), while “new cases” reported general health scores midway between existing cases and those without diabetes. General health scores for both existing and new cases of diabetes tended to decrease between 1996 and 1998, while scores for women without diabetes remained much the same over this time period. Thus, women with diabetes reported poorer general health than women without diabetes and also reported a reduction in general health between Survey 1 and Survey 2.



**Figure 2** Median General Health scores (SF-36 subscale) at Surveys 1 and 2 for mid-age women with and without diabetes

Median body mass index (BMI) scores for women with diabetes were higher than for women without diabetes. Women who were diagnosed with diabetes between Survey 1 and Survey 2 (new cases) had similar BMI scores as women who had diabetes at Survey 1. Higher body weight, or BMI above 25 kg/m<sup>2</sup>, has been shown to be associated with an increased risk of developing Type II diabetes (Colagiuri et al, 1998). The median BMI for women with diabetes (existing and new cases) was 29.6 kg/m<sup>2</sup> at Survey 1 and 31.4 kg/m<sup>2</sup> at Survey 2,

compared with 24.6 kg/m<sup>2</sup> at Survey 1 and 25.0 kg/m<sup>2</sup> at Survey 2 for women without diabetes.



**Figure 3 Median BMI at Surveys 1 and 2 for mid-age women with and without diabetes**

**Stage 2**

*Aim:* To examine the use of general practitioner and specialist services, out of pocket costs and use of best practice guidelines for HbA1c, lipids, microalbuminuria and retinal screening for women in the ALSWH with diabetes, using Medicare/Department of Veterans’ Affairs data.

*Progress:* The Medicare Benefit Schedule item numbers for diabetes-specific services have been identified and changes in definition or item number have been recorded for the period 1997-1999. Almost 70% of the mid-age and older women with Survey 1 and Survey 2 data have given consent for the Health Insurance Commission (HIC) to provide identified data on their service use. HIC data for 1997-1999 have been received by WHA and analysis is currently underway.

**Table 2 Number of women in the mid and older cohorts who have given consent for HIC to provide data for 1997-1999, by diabetes status**

	Mid Cohort		Older Cohort	
	Number	%	Number	%
Existing cases	158	67	551	66
New cases	94	67	156	59
No diabetes	8253	70	6418	69
<b>Subtotal</b>	<b>8505</b>	<b>70</b>	<b>7125</b>	<b>68</b>
No consent to linkage	3725	30	3296	32
<b>TOTAL</b>	<b>12230</b>		<b>10421</b>	



### **Stage 3**

**Aim:** To conduct a substudy of women with diabetes to assess diabetes-related health needs, access to and satisfaction with health care.

**Progress:** The substudy questionnaire has been developed and ethics approval granted. We are currently liaising with Diabetes Education and Stabilisation Centres to organise focus groups for piloting the substudy questionnaire. All women in the mid and older cohort who reported having diabetes in Survey 2 will receive a substudy questionnaire in August/September 2001.

A grant application to Diabetes Australia for financial support for 2002 is in preparation. Further research is planned to investigate the relationship between exercise, body mass index (BMI) and nutrition and the development of diabetes. This proposed research will include analysis of the food frequency questionnaire data from Survey 3 (mid cohort) for women with and without diabetes.

### **Reference**

Colagiuri S, Colagiuri R & Ward J. *National Diabetes Strategy and Implementation Plan*. Diabetes Australia, Canberra, 1998.

**Project:** The differential experience of ageing for women in urban, rural and remote parts of Australia

**WHA Investigators:** Associate Professor Julie Byles & Dr Gita Mishra

The main aim of this study was to explore three year changes in health outcomes for older women living in urban, rural and remote parts of Australia. A secondary aim was to identify the proportion of women who move to more urban areas during this period, and the factors associated with this change of residence with the hypothesis that those who move to more urban areas had poorer baseline health status.

At Survey 1 the majority (60%) of the 10,382 women in the older cohort lived outside capital cities or other metropolitan areas. At Survey 2, 275 (3%) women had moved to more urban areas based on the Rural, Remote and Metropolitan Areas (RRMA) classification of their reported postcodes. Women in remote areas were most likely to move, with 11% of the 72 women originally living in these areas having moved. After adjustment for other factors, several health and social factors were related to women's area of residence, or whether they had moved. There was a significant trend for women who moved to have more symptoms than women who remained in their original locational classification ( $p < 0.01$ ). Women who moved showed no significant change in Mental Health SF-36 subscale scores, while those who did not move showed significant increases in Mental Health. Among women who remained in their original classifications, there was a significant trend for the increase in Mental Health scores to be greater with increasing remoteness ( $p < 0.001$ ).

Predictably, perceived access to health care decreased with increasing remoteness, and those who moved to more urban areas recorded access scores that were consistent with women in capital cities and metropolitan areas. Similarly, satisfaction with general practitioner services was significantly higher for women in capital cities and other metropolitan areas. Conversely, women in rural and remote areas used more community services than women in capital cities or other metropolitan areas.

There was a significant trend for the neighbourhood satisfaction score to increase from urban to remote areas, and women who moved between Surveys 1 and 2 reported the lowest neighbourhood satisfaction at Survey 2. Similarly, while there was a mean decrease in perceived social support for all areas, the greatest decrease was among women who moved to more urban areas.

Women living in rural and remote areas at both times, were less likely to have post-school qualifications, and more likely to be born in Australia than women in capital cities. Those who moved, however, were similar to women in urban areas in their educational level.

Clearly, one advantage of “ageing in place” is the ability to retain social support networks. In this analysis, those women who moved had a greater reduction in their level of social support than women who remained in more rural areas. This difference in social support was not evident at Survey 1 and seems to be a consequence of moving rather than a cause of the move.

**Project:** An examination of the aspirations of a group of young Australian women in relation to work, education, relationships and children.  
**WHA Investigators:** Dr Deirdre Wicks & Dr Gita Mishra  
**Funding:** University of Newcastle Research Management Committee Project Grant (\$10,000)

### ***Aims***

To elicit information on the aspirations of the 14,762 young women who comprise the young cohort of the Australian Longitudinal Study on Women’s Health (ALSWH) in relation to work/career choice, hours of work, further educational qualifications, marriage, relationships and children.

To produce new data on the interactions between identity, aspirations and the role of situational factors (such as class background) in the formation and maintenance of aspirations.

To establish baseline data for follow-up studies at regular intervals that will provide information for a more comprehensive understanding of the factors involved in the process of aspiration formation over time and the long-term consequences for women’s health.

### ***Methods***

Stage 1 of the research consisted of the analysis of the Survey 1 data. The responses were analysed in relation to current sociological debates on women’s participation in the workforce and their aspirations regarding work, career and family life. In order to examine the effect of social class, the aspirations of groups of women from high and low income areas were compared.

Stage 2 of the research was designed to add both qualitative and longitudinal dimensions to the project. Four years after Survey 1, 57 of the young women agreed to participate in in-depth, telephone interviews in order to explore further issues surrounding their aspirations. Of these 57 women, 33 were from high income areas and 24 were from low income areas so that effects of social class on the formation and maintenance of aspirations could be examined.

Stage 1 is complete, Stage 2 is in the report-writing stage and has been presented at an international conference.

**Project:** Pap smear adherence and mammographic screening behaviour in middle aged women

**WHA Investigators:** Professor Annette Dobson & Ms Anne Russell

This study examines the patterns of pap smear adherence and mammographic screening behaviour in the mid-age cohort, based on responses to questions in Surveys 1 and 2 which indicate if and when women had undertaken screening. The study aims to determine associations between screening behaviour and age, socio-demographic variables (income, ethnicity, education, marital status), health status, health service use, access to health care, health insurance, medical history, time use, use of alcohol, smoking status, BMI, results of previous screening and previous history of cancer.

**Project:** Changes in cigarette smoking by young women

**WHA Investigators:** Professor Annette Dobson & Ms Anne Russell (Dept of Social and Preventive Medicine, University of Queensland)

Smoking prevalence for women peaks in their early twenties and then declines. The purpose of this project is to identify factors associated with continuing to smoke or with quitting among women in the young cohort. This is being done by comparing smoking data from Survey 1 and Survey 2. Overall about 25% of all young women who smoked in 1996 had quit by 2000. But this quitting rate was much higher among women who had been pregnant, reaching 6.7% for women who were pregnant for the first time when they completed Survey 2. Women who continued to smoke had relatively lower socio-economic status and were less likely to be married. The results of these preliminary analyses and further analyses will be provided to the Department of Health and Aged Care to assist the National Tobacco Strategy.

**Project:** Impact of miscarriages and abortions on well-being at midlife: Data from the Women's Health Australia study

**Collaborators:** Dr Rafat Hussain (School of Health, University of New England)

**WHA Collaborator:** Associate Professor Margot Schofield & Professor Christina Lee

This analysis examines the relationships between women's history of miscarriages and abortions, and their midlife physical and mental health, controlling for demographic, psychosocial and health factors. The study sample comprised 14,100 women aged 45-50 years who participated in Survey 1 of the Australian Longitudinal Study on Women's Health. The main outcome variables were physical and mental health (SF-36) and perceived stress. Women who responded to questions about miscarriages (84%) and abortions (79%) were included in the analyses. Overall, 36% of women reported at least one miscarriage and 22% at least one abortion. Multivariate analyses showed that, after controlling for sociodemographic variables, number of live births, number of children living at home, social support, life events, menopause status and HRT use, the effects of prior miscarriages and abortions on health outcomes were small. Having one miscarriage contributed to poorer physical health and greater stress at midlife; and poor mental health was associated with three or more miscarriages. Having three or more abortions was significantly related to poorer

midlife mental health, and having had any abortion to higher midlife stress. The statistically significant effects were small, suggesting that the majority of mid-age women do not continue to be distressed by earlier reproductive events, although a small minority may do so.

**Project:** Alcohol consumption by young Australian women: Patterns, harm, and influence  
**Collaborators:** Dr Helen Jonas (School of Health & Human Sciences, La Trobe University) & Professor Margaret Hamilton (Turning Point Alcohol and Drug Centre Inc, Fitzroy)  
**WHA Collaborator:** Professor Wendy Brown  
**Funding source:** Victorian Health Promotion Foundation (July 1999 – June 2002)

Despite concerted community efforts to highlight the risks and reduce the harm associated with heavy drinking, the proportions of young Australian women who drink at hazardous or harmful levels and who binge drink regularly remain high.

Most strategies aimed at reducing heavy drinking by young Australian women have failed because relevant information is lacking on the multiple factors that influence young women's drinking patterns, attitudes, behaviours and drinking-associated harm. The aim of this project is to provide such information.

In October 1999, we mailed a comprehensive survey to a sample 2,400 women aged 21-26 years participating in the WHA longitudinal study. The young women were asked about:

- their patterns of drinking, and any harm arising from their drinking;
- the cultural and societal influences on their drinking;
- the settings in which they were most likely to consume alcohol;
- the perceived consequences of drinking harmful amounts;
- the strategies that they used to monitor/control their alcohol consumption;
- the strategies that they used to minimise potential harm resulting from drinking to intoxication;
- the influences of external organisations on their drinking practices.

54% of the young women returned completed questionnaires. Another 30% could not be contacted. The "open-ended" responses from the returned survey forms have been coded, and all the responses entered on to a database. Preliminary analyses have begun, and will be followed by more extensive analyses involving structural equation modelling.

This study will provide up-to-date information to health and planning authorities on issues relevant to young women's drinking, and may contribute to the design and delivery of effective education and prevention programs.

**Project:** Sleep disturbance and sleeping medication use among older Australian women.

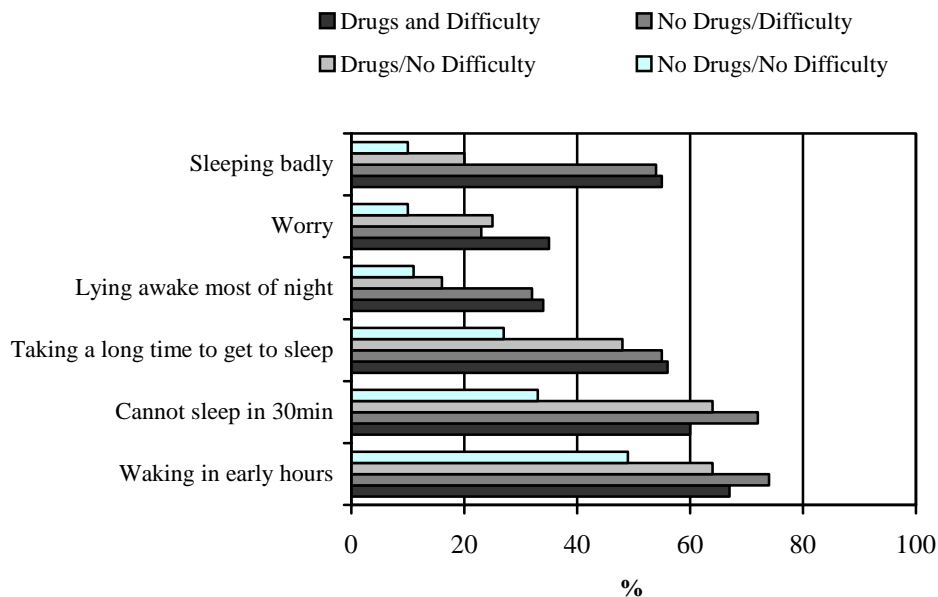
**WHA Investigators:** Associate Professor Julie Byles & Dr Gita Mishra

**Collaborators:** Dr Margaret Harris & Associate Professor Kichu Nair

**Funding:** Quality Use of Medicines Evaluation Program, Department of Health and Aged Care

This project has involved a detailed quantitative survey of 1,210 women. The women were selected from among participants in the older cohort of the ALSWH (aged 73-78 years when surveyed in 2000) and stratified according to whether or not they reported use of medications at Survey 2 and according to their scores on the Nottingham Health Profile sleep items. There were four groups: 1) no drugs and have no difficulty sleeping; 2) use drugs have no difficulty sleeping; 3) don't use drugs but have difficulty sleeping; 4) use drugs and have difficulty sleeping;

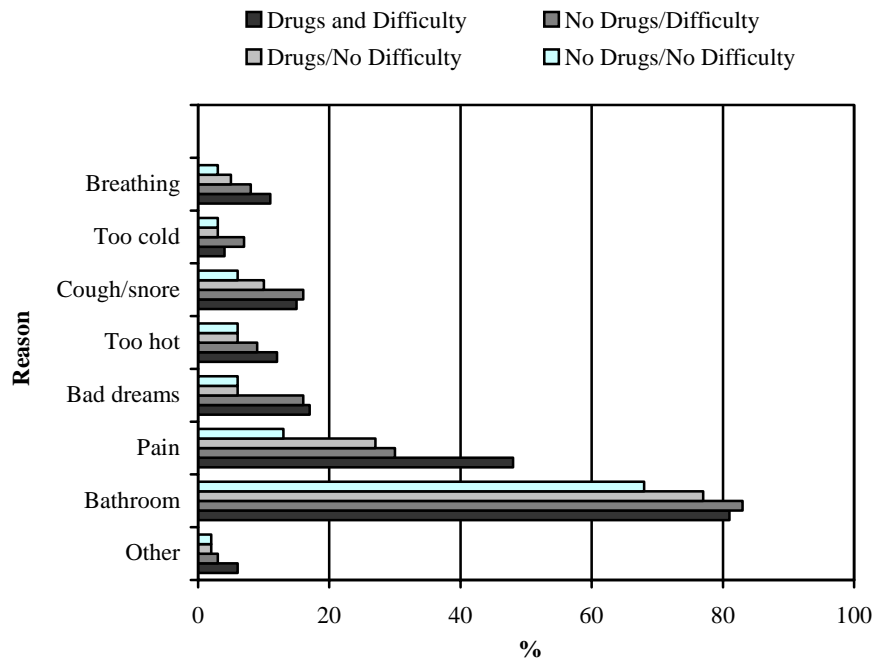
The survey was developed on the basis of structured telephone interviews with ALSWH women who reported sleeping difficulty, and also incorporated standard epidemiological measures of sleep disturbance and sleep quality (the Nottingham Health Profile Sleep Subscale, the Pittsburgh Sleep Questionnaire, and the Epworth Sleepiness Index).



**Figure 4 Percentage of women in each subgroup of the Older Sleep Substudy reporting sleeping difficulties**

A total of 1011 women returned the surveys, an 84% response rate for this sub-study. Regardless of group, most women responded positively to at least one of the Nottingham Health Profile Sleep Subscale items in the sub-study. Even in the “no drugs, no difficulty” group only 29% of women reported no sleeping difficulties at all. However, in the other groups less than 10% of women had no problems at the time of the sub-study. Waking in the early hours of the morning was common across all groups and so was not a good discriminator between them. Sleeping badly at night and lying awake most of the night were the best discriminating items (see Figure 4).

Among the group of women who had not used drugs, and had low sleep difficulty scores, 91% rated their sleep as fairly good or very good. In contrast, those who had used drugs and had high sleep difficulty scores were most likely to rate their sleep as fairly bad or very bad (53%).



**Figure 5 Percentage of women in each subgroup of the Older Sleep Substudy reporting reasons for sleeping difficulty**

Women who had sleeping difficulty at Survey 2 were more likely to report that they could not sleep because of pain, bad dreams, cough/snoring, or difficulty breathing than others (see Figure 5).

The most common behavioural strategies used to assist sleeping were reading, listening to the radio, and having a hot drink. Interestingly, a proportion of those in the sleeping difficulty group took tea or coffee as an aid to sleep, although both of these substances contain caffeine.

Very few reported using alcohol to help sleep, reflecting a very low use of alcohol in the older cohort overall.

Help for sleeping difficulty was most commonly sought from a doctor, and less commonly from a chemist. Those who used drugs to help them sleep had higher levels of seeking medical help, asking for sleeping medications, and being prescribed medications. Women who used drugs were most likely to have used medications 3 or more times per week over the past month.

There were distinct differences in the knowledge and attitudes of women who did and did not use sleeping medications. For instance, women who used medications were more likely to agree that medications improve sleep quality, and that “its OK to take sleeping medications as long as they are mild”, and more likely to get angry or frustrated about not sleeping; and less likely to agree that medications are habit forming, have side effects, make you “feel groggy”, or put “a glaze over life”.

Further analysis of these data is in progress. Combining the results of all three phases of the study so far, the following conclusions are emerging:

- Sleep disturbance is a common and persistent complaint;
- Use of sleeping medications is a common and persistent behaviour;
- These behaviours have independent effects on health although use of medications appears to have greater impact than sleeping difficulty per se.

**Project:** Validation of New South Wales Health funding models using WHA data  
**Collaborator:** Dr Anne Young (Women's Health Australia, University of Newcastle)  
**WHA Collaborators:** Associate Professor Bob Gibberd, Dr Barry McDonald (Health Services Research Group, University of Newcastle)

The Health Services Research Group at the University of Newcastle, in collaboration with the New South Wales Department of Health, is deriving a Relative Health Needs Index (HNI) for the 17 Area Health Services within NSW. The index may be used to advise the NSW Government in allocating funding to the Area Health Services. The index incorporates information relating to inpatient separation data, mortality data (Standardised Mortality Ratios for ages 0-69 years), measures of socioeconomic status (ABS education and occupation index, 1996), census information about percentage of Indigenous people and a measure of remoteness and accessibility (the ARIA score developed by GISCA – see section 3.7).

The WHA project has data on various aspects of health and health services utilisation. This project will explore whether WHA data, specifically the NSW subset, can be used to validate the Health Needs Index models being developed by the Health Services Research Group. The number of women from each age cohort of the WHA study living in the 17 health regions will be calculated. The extent to which SF-36 scores, medical conditions and symptoms for these women are consistent with the relative health needs index for their area of residence will be examined. Further stages of the project may be developed following this initial validation phase.

**Project 1:** Weight maintenance analyses: young cohort  
**WHA Collaborators:** Professor Christina Lee, Professor Wendy Brown  
**Collaborator:** Dr Kylie Ball (School of Health Sciences, Deakin University)  
**Project 2:** BMI and aspirations analyses: young cohort  
**WHA Collaborator:** Associate Professor Justin Kenardy  
**Collaborator:** Dr Kylie Ball (School of Health Sciences, Deakin University)

The data from Survey 2 of the young cohort have continued to be collected and cleaned, and so the final analyses for these projects have not yet been completed. Baseline analyses and preparatory analyses using a template of Survey 2 data have been conducted and these will be used to inform the final analyses once all data are available.

**Project:** Vegetarian style eating practices among young Australian women  
**Collaborators:** Dr Surinder Baines (Discipline of Nutrition and Dietetics, University of Newcastle)  
**WHA Collaborator:** University of Newcastle Early Career Researcher Grant

Vegetarian diets appear to have health benefits. Mortality rates for vegetarians are reported to be lower than those of the general population and research has shown a lower prevalence of a number of diseases that are common in Western countries, such as obesity, coronary heart disease, hypertension and some cancers. Decreased consumption of foods high in animal fat, salt and sugar and increased intake of cereals, fruits and vegetables is thought to be the major benefit of a vegetarian diet. However the health of vegetarians may not be simply related to their diet, but could be explained by a number of lifestyle differences such as limiting or refraining from tobacco and alcohol consumption.

Most vegetarians eat some foods of animal sources, such as dairy foods and/or fish and/or poultry and terms such as “partly vegetarian” and “semi-vegetarian” have been used to describe the extent of vegetarianism. However, vegetarian diets have no advantage over healthy omnivore diets unless they are planned appropriately and can meet all energy and nutritional requirements. Unbalanced diets can have long term detrimental effects to health. It is known that some vegetarian diets can be low in iron and zinc, and selenium and calcium content may also be low. Consequently, poorly balanced vegetarian diets could result in general malnutrition and cause anaemia, fatigue, poor wound healing and impaired immune function.

The vegetarians most likely to experience health problems as a result of their dietary practices are in the younger age group, especially women and those individuals who adopt extremely restrictive diets. Dietary practices relating to meat avoidance and vegetarianism have not been extensively studied and to date there are only fragmentary reports in Australia and overseas about these practices. Consequently, more research is required to investigate meat avoidance and various other forms of vegetarian dietary practices, in order to explore the extent of associated nutritional inadequacy and the impact on health of this increasingly popular trend in some groups in the Western world. This is especially true for young women, for whom there may be considerable effects on physical and mental health in both the short- and long-term.

This study plans to investigate the dietary practices and the impact on health of young Australian women who limit or avoid the consumption of meat and follow vegetarian style dietary practices. In addition the study will determine whether these dietary practices are used primarily to lose weight or for other reasons. A pilot survey of university students is currently in progress.



**Project:** Mid-aged women and heart disease: Understanding risks and prevention  
**Collaborator:** Dr Marilys Guillemin (Centre for the Study of Health & Society, University of Melbourne)  
**WHA Collaborator:** Professor Wendy Brown  
**Funding source:** Australasian Menopause Society Research Grant Scheme, Australasian Menopause Society Travel Grant Scheme, and University of Melbourne Research Career Establishment Grant Scheme

### ***Project aims***

The aims of this project were to investigate: 1) how mid-age women with reported heart disease understand their condition, 2) the impact of heart disease on their lives, 3) how they perceive their risks of heart disease, and 4) the strategies they employ (if any) to prevent further recurrences of heart disease.

### ***Methods***

The research has involved the following:

1. Analysis of WHA data for associations between reported heart disease and recognised biological, social and psychological risk factors in the mid-age cohort (n=319);
2. National questionnaire survey of women from the WHA mid-age cohort who reported having heart disease. 94 out of a possible 189 women responded to the survey (50% response rate);
3. Exploratory in depth, face to face interviews with 32 women (73% participation rate) from the WHA mid-age cohort in rural and urban Victoria who report having heart disease.

### ***Summary of findings***

The mid age women and heart disease study found that 2.3% (319 of 14, 011) of the ALSWH mid age cohort reported at Survey 1 that they had been told by a doctor that they had heart disease. However, very few of these mid-age women considered themselves as “at risk” of heart disease. This is despite 35% of the women interviewed reporting two or more recognised risk factors for heart disease. Although these women were very knowledgeable about prevention and heart disease, only a few reported actually having employed preventive strategies against heart disease either prior to, or since, diagnosis. Although the women were very aware of risk factors for heart disease and its prevention, they did not perceive these issues as being relevant to their lives at this time. This suggests that further efforts are required in the secondary and tertiary prevention of heart disease among mid-age Australian women, with a focus on strategies to help them put their health knowledge into practice.

### 1.2.3 Completed projects by postgraduate students (since December 2000)

**Project:** Female urinary incontinence in Australia: prevalence and prevention in postpartum women  
**PhD Candidate:** Ms Pauline Chiarelli (Faculty of Medicine and Health Sciences, University of Newcastle)  
**Supervisor:** Professor Jill Cockburn

Underpinning this PhD is an examination of the basic science of continence and a review of the international and Australian literature pertaining to the prevalence of urinary incontinence. Although there have been few studies that have evaluated the prevalence of female urinary incontinence in the Australian population, the available studies suggest that incontinence is a morbid and costly condition.

The Women's Health Australia project provided an opportunity to obtain current data on the prevalence of leaking urine and associated factors in a large representative sample of Australian women. The prevalence of leaking urine in cohorts of women aged 18-23, 45-50 and 70-75 years was estimated to be 12.8% (CI: 12.2 - 13.3), 36.1% (CI: 35.2 - 37.0), and 35% (CI: 34.1 - 35.9) respectively.

Despite the burden of illness imposed by urinary incontinence, to date there has been no evidence to support the concept of primary continence promotion as an effective method of preventing urinary incontinence. Therefore, a major aim of this thesis was to examine this. Given that trauma to the pelvic floor following childbirth appears to be related to the development of incontinence, postpartum women were chosen as the target group.

Evidence from the literature and expert opinion were combined with the conceptual framework of the Health Belief Model to develop the components of a continence promotion program. The effectiveness of an intervention delivered by physiotherapists to postpartum women was evaluated using a randomised controlled trial among 720 women. Multivariate analyses, that controlled for potential residual confounding effects of maternal, delivery, and continence variables, indicated that women in the intervention group were 40% less likely to report incontinence at three-months postpartum than women in the control group (Odds ratio=0.6, 95% CI: 0.5 - 0.9, p=0.01). Women in the intervention group were more likely than women in the control group to report that they were performing the recommended pelvic floor exercises (p=0.001).

The intervention was also found to be acceptable to women and its components were well utilised. This suggests that the intervention could feasibly be provided for women who deliver in hospitals where physiotherapists are employed.

**Project:** Predicting body dissatisfaction amongst young women  
**Degree:** Master of Health Science (Women's Health)  
**Candidate:** Ms Fiona Campbell (Discipline of Behavioural Science in Relation to Medicine, University of Newcastle)  
**Supervisor:** Dr Libby Campbell

### ***Objectives***

To estimate the prevalence of dissatisfaction with weight and shape amongst the 18-23 year old group (divided into underweight, average and overweight groups based on their reported Body Mass Index (BMI)) participating in Survey 1 of the Women's Health Australia project. The second aim was to develop a profile of women dissatisfied with either weight or shape for women in the three BMI categories, by assessing the relationship between dissatisfaction and the following variables: demographic information, perceptions of current weight and size, use of weight control methods, lifestyle behaviours and perceived health status variables. The project was a subsidiary analysis of Survey 1 data from 13,716 non-pregnant women in the younger cohort.

### ***Results***

40.2% of underweight women (BMI<20), 60.7% of average weight women (BMI 20-24.9) and 82.1% of overweight (BMI 25+), were dissatisfied with their weight and/or shape. Logistic regression modelling showed that for all BMI groups, women who considered themselves overweight, women who wanted to weigh less and women who had used dieting methods in the past month, were most likely to be dissatisfied. These models showed that a greater likelihood of dissatisfaction was also associated with: higher Sum of Life Events Score (underweight and average weight women); a poorer mental health status score (overweight women); rural rather than urban location (average and overweight women); and being an ex-smoker rather than a non-smoker (underweight women).

### ***Conclusion***

Body dissatisfaction is common among young Australian women within all BMI categories, but is most prevalent among those with a BMI of 25+. Associations with dieting behaviour, cognitions relating to weight and mental health are apparent.

## **1.2.4 Student projects in progress**

**Project:** Factors influencing weight change in mid-aged women  
**PhD Candidate:** Ms Lauren Williams (Discipline of Nutrition and Dietetics, University of Newcastle)  
**Supervisors:** Professor Wendy Brown & Dr Anne Young  
**Funding source:** Research Management Committee, University of Newcastle  
**Expected Completion:** 2002

This study is addressing the question of why women gain weight in mid-life (45-55 years) through analysis of the main WHA survey results and a nested cohort study of weight change in menopausal women. In the nested cohort study, 875 women completed a survey containing pre-validated instruments measuring dietary intake, physical activity, emotional eating and questions relating to lifestyle which might affect weight in mid-aged women. Differences between the "weight gainers" over the three year period 1996-1999 (51% of the

nested cohort) and non-weight gainers (49% of the nested cohort) are currently being investigated.

Emotional eating scores were calculated using the scale developed by Arnow, Kenardy and Agras (1995). In the nested cohort, the weight gainers had a significantly higher mean emotional eating score than the non-weight gainers. This would suggest that the development of non-food strategies for coping with negative affect might be an important means of preventing weight gain in women experiencing menopause. Analysis is continuing on other components of the survey, and is currently focused on the dietary intake measures collected by food frequency questionnaire (FFQ). The analysis is expected to be completed by the end of 2001.

### **Reference**

Arnow B, Kenardy J, Agras WS. The Emotional Eating Scale: The Development of a Measure to Assess Coping with Negative Affect by Eating. *International Journal of Eating Disorders*, 1995; 18(1): 79-90.

**Project:** The transition to adulthood and health  
**PhD Candidate:** Mrs Sandra Bell (Research Centre for Gender and Health, University of Newcastle)  
**Supervisor:** Professor Christina Lee  
**Funding source:** Faculty of Science and Mathematics & Women's Health Australia (University of Newcastle)  
**Expected Completion:** December 2003

### **Aim**

To examine the transition to adulthood in terms of role acquisition. The concepts of timing and spacing of role acquisitions with regard to social norms, and Erikson's psychosocial stages of development will be utilised to assess the extent to which these affect physical and emotional well-being.

### **Methods**

Initially secondary analysis of Survey 1 and Survey 2 data for the young cohort will be undertaken. Cluster analysis to determine groups of young women on the basis of health behaviours is the first step and is in progress. The social roles of women in these clusters, and the extent of change or stability across time, will be explored. A substudy is planned for 2002.

### **Outcomes**

The project is in the preliminary analysis and literature review stage.

**Project:** Young women, health, class and neighbourhood  
**PhD Candidate:** Ms Lisa Milne (Department of Sociology and Anthropology, University of Newcastle)  
**Supervisor:** Dr Gita Mishra, Dr Deirdre Wicks, Dr Pam Nilan  
**Funding source:** Australian Postgraduate Award scholarship, Department of Sociology and Anthropology  
**Expected Completion:** November 2002

It has recently been suggested that gender inequalities within labour markets may be largely a result of individual women's own choices and preferences for work and for family. Given debates surrounding the extent to which these choices and preferences can be conditioned by social contexts and processes, it is the aim of this study to broaden our understanding of what those social contexts and processes may be for young Australian women. In adopting class and gender as key concepts in the explanatory framework, we plan to look at how socio-economic structures may influence differential achievement of aspirations amongst groups of young women. Specifically, the aspirations for work, children and education held by two groups of young women (high and low SES) will be assessed in relation to their current opportunities for realising these aspirations during their early labour market experiences. Neighbourhood networks and locality are key dimensions of the social contexts considered, relevant to a consideration of the local labour market conditions of the two groups. The primary research instrument is a survey, to be completed by a sample of women. Analysis of the data will shed light on debates about women's workforce participation, as well as establishing baseline data for future research on the options chosen and available for this group of young women. The information will have significance for policy debates in several areas, including those concerned with worker entitlements, childcare, access to higher education and workforce planning. More particularly, it will make a contribution to current debates about women's supposed preference for part-time rather than full-time work.

This project investigates: (1) Survey 1 data from the young cohort; (2) substudy survey data from a sample of the original respondents from the ALSWH and (3) data from 57 qualitative interviews from a different sample of the original respondents from the ALSWH. The focus is on the aspirations of young women (aged 18-23) for work, their ideal job, relationships (including children) and further education, particularly in the context of gender inequality in labour markets. The results are expected to confirm the continued importance of social contexts and processes in shaping the decisions of individuals. It is expected that the rates of part time and full time work reported for young adult women will be shown to reflect the way that their positioning within social contexts can both enable and constrain the enaction of supposedly free and individualistic choices in this regard. Relationships between SES and health status are well documented in the literature, and it is expected that this study may shed light on the relatively un-explored relationships between health status, work status and aspirations. It is expected that frustrated or stalled aspirations may be related to socio-economic inequalities. A further relationship between mediated aspirations and health status is posited. The substudy questionnaire has been developed and is currently being piloted.

**Projects:** The physical and psychological health impact of domestic violence on mid-age women in Australia  
**PhD candidate:** Ms Deborah Loxton (School of Health, University of New England)  
**Supervisor:** Dr Rafat Hussain  
**WHA collaborator:** Associate Professor Margot Schofield & Dr Gita Mishra  
**Funding source:** APA Postgraduate Award with HECS Stipend  
**Expected Completion:** 1 February 2002

***The relationship between health, life factors, and domestic violence among mid-age Australian women***

The objectives of this research are to determine the health impact of domestic violence, to determine the life, lifestyle, and demographic factors that are related to domestic violence, and to investigate the status of these factors as mediators in the relationship between domestic violence and health. Analysis of Survey 1 data from the mid-age cohort comprised the first stage of the project. Having ever lived in a violent relationship was related to poorer general health, as measured by the SF-36; to an increased number of consultations with family and hospital doctors; to a higher likelihood of experiencing symptoms, specifically, allergies and breathing problems, pain, fatigue, bowel, eye and hearing problems, and hot flushes; an increased number of diagnoses, particularly diabetes, circulatory and lung disorders, low iron, and osteoporosis; and an increased number of surgical procedures, particularly gynaecological and cosmetic surgery, and cholecystectomies. Women who had ever lived in a violent relationship were more likely to binge drink, smoke, and to experience higher stress, more life events, less social support, have less formal education, and experience difficulty managing on their available incomes, relative to women who had never lived in a violent relationship. Furthermore, these life factors mediated the relationship between domestic violence and the health.

***Factors that mediate the relationship between psychological health and domestic violence in mid-age Australian Women.***

The aims of this research were to describe the psychological health impact of ever having lived in a violent relationship, and to determine the factors that may mediate the relationship between domestic violence and psychological health for mid-age Australian women. For the purposes of this investigation, the domestic violence and education level measures were taken from Survey 1, all remaining measures were taken from Survey 2. Women who had ever lived in a violent relationship were more likely to take medication for depression, ‘nerves’, and to help them sleep; were more likely to experience depression and anxiety both in the 12 months prior to the survey, and at some point in their lives; and were more likely to have experienced an ‘other’ psychiatric disorder and to have had difficulty sleeping. General psychological health, as measured by the SF-36, was negatively related to ever having lived in a violent relationship. Depression, as measured by the short form of the Centre for Epidemiologic Studies Depression Scale-10 (CESD-10), was positively related to ever having lived in a violent relationship. Both of these relationships were partially mediated by stress, number of life events, available social support, level of formal education, and income management.

***Current Status***

The above two studies form the majority of the quantitative analysis to be included in my thesis. The qualitative study that forms the final stage of the thesis has received ethics approval from the University of Newcastle and the University of New England, and is scheduled to begin in August.

**Project:** Iron deficiency and menstrual blood loss in Australian women  
**PhD candidate:** Ms Allison Schmidt (Research Centre for Gender and Health, University of Newcastle)  
**Supervisors:** Professor Christina Lee, Professor Wendy Brown & Dr Gita Mishra  
**Funding source:** ARC Small Grant & RMC Multi Year Scholarship Grant  
**Expected Completion:** Mid 2002

### *Aims*

To assess the relative roles of menstrual blood loss (MBL) and dietary factors in iron deficiency, and to assess the health outcomes of varying iron status in a population of working women.

### *Methods & outcomes*

MBL has been measured descriptively in a group of local working women. Attitudes towards menstruation, levels of general health and fatigue have also been assessed. Currently, MBL is being re-measured using an accurate, objective laboratory method. Dietary iron intake is also being recorded in this group of women using a twelve day weighed food diary. Serum ferritin and haemoglobin levels have also been recorded in order to make accurate comparisons between dietary intake, MBL and body iron levels. In the earlier stages of the study, no definite relationship was demonstrated between self-reports of excess menstrual blood loss and health outcomes.

**Project:** Coping with abuse in adult relationships: mid-age women's perspectives  
**PhD Candidate:** Ms Glennys Parker (Research Centre for Gender and Health, University of Newcastle)  
**Supervisor:** Professor Christina Lee  
**Expected Completion:** February 2003

The primary focus of this PhD thesis is to develop a framework for understanding women's experiences of abuse, the personal meanings ascribed to these experiences, and an evaluation of the range and effectiveness of coping strategies used by abused women. The WHA 1999 abuse survey for mid-age women has been useful in identifying the nature and scope of gendered abuse in Australia. Evaluation of the health-related practices, socioeconomic status, and ethnicity of women in the substudy, and a comparison of these women with non-abused women from the main cohort on these variables, is in progress. Qualitative analysis of respondents' open-ended responses from the 1999 survey is in progress. In November 2000, an additional questionnaire was mailed to 200 women who had participated in the initial abuse substudy and had indicated their willingness to take part in further research on the topic. The main purpose of this second survey is to assess individual differences in coping with abuse, and to identify positive strategies used by women to manage and deal with abuse experience. Response rate for that survey is 74%. Data have been entered and checked and analysis will begin in late 2001.

**Project:** Childlessness and the role of choice in childless women's reproductive outcome  
**PhD Candidate:** Ms Heather McKay (Key Centre for Women's Health in Society, University of Melbourne)  
**Supervisors:** Dr Jane Fisher & Professor Christina Lee  
**Funding source:** University of Melbourne Research Scholarship (Faculty-Based MRS)  
**Expected Completion:** October 2003

The fertility rate in Australia has been declining since the early 1970's due to women having fewer children and more women remaining childless. Childlessness, however, is not a new phenomenon. Rather the choice to reject motherhood is a result of social, economic and political change, including the availability of the contraceptive pill, that began in the 1960's. Women in Australia today experience increased opportunities in both education and employment. They have been amongst the beneficiaries of technological advancement and have also experienced diversity and change in relationships and family structure. Expanding opportunities and new possibilities have meant some women are now questioning whether they want to mother and some are remaining childless.

Little information is available on how women feel about being childless or why Australian women choose childlessness. This study aims to provide information on childlessness and the role of choice in childless women's reproductive outcome. Further, it seeks to better describe childless women's lives and how they feel about their childless status. Analysis of existing data from the mid-aged group in Women's Health Australia will be performed and an additional survey sent to those women who have indicated that they have never given birth to a child. This additional survey is planned for March 2002. The mid-aged group were chosen because although their childless status is unchangeable, they are young enough to have lived their childbearing years after the peak of the baby boom (1961) when economic, political and social changes significantly altered women's choices and affected fertility patterns in Australia.

**Project:** Psychological factors in coronary heart disease  
**PhD Candidate:** Mr Esben Strodl (School of Psychology, University of Queensland)  
**Supervisor:** Associate Professor Justin Kenardy  
**Expected Completion:** August 2002

The first part to the PhD aimed at identifying which psychosocial factors were significant predictors of the new manifestation of coronary heart disease (CHD) in elderly women over a 3 year period. The Mental Health Index (from the SF-36), social support (i.e. Duke Social Support Index) and Perceived Stress were all significant predictors of the new diagnosis of CHD. This variable remained significant even after controlling for the frequency of GP visits and other significant risk factors (BMI, alcohol status, nutritional risk and having hypertension).



**Project:** Yoga, leisure and women: A critical examination of the effects of sustained yoga practice on women's health and well-being  
**PhD Candidate:** Ms Julie Hodges (Leisure & Tourism Studies, University of Newcastle)  
**Supervisors:** Dr Penny Warner-Smith & Associate Professor Peter Brown  
**Funding source:** APA Postgraduate Award  
**Expected Completion:** March 2003

The proposed study aims to develop an understanding of the role of yoga as a form of therapeutic leisure activity and, specifically, its relationship to health and well-being. The proposed study will investigate the potential health benefits of regular yoga practice for women with specific physical and/or emotional needs, and, hence, the effects of yoga on their physical and mental well-being and overall quality of life.

**Project:** Lay perceptions of Queensland Women's asthma  
**PhD Candidate:** Ms Gabrielle Rose (School of Population Health, University of Queensland)  
**Supervisors:** Professor Lenore Manderson & Professor Jake Najman  
**Funding Source:** Partial funding from Merck Sharp and Dohme  
**Expected Completion:** June 2002

### *Aim*

The aim of the study was to describe women's personal experiences of asthma, how they diagnose and manage their asthma, their treatment strategies, and the impact of asthma on their quality of life.

### *Population*

The sub-study consisted of a sample population of 239 women aged between 45-50 years from urban, rural and remote areas of Queensland. The sample was drawn from the ALSWH mid-age cohort. Women who had answered positively to the question in Survey 1 "Have you ever been told by a doctor you have asthma?" were selected for the asthma sub-study.

### *Methods*

The study used a combination of qualitative and quantitative research techniques. The first stage involved conducting in-depth interviews with 10 women with asthma to ensure that the study was grounded in lay perceptions of asthma. From these interviews and with the use of existing asthma questionnaires, a new questionnaire was developed and sent to women (from the ALWSH Queensland sample) with asthma. Follow-up in-depth interviews were conducted with a smaller sample of the same women who had mild, moderate and severe asthma and who were from rural, remote and metropolitan regions. Four indigenous women with asthma were interviewed. The principal focus of the research was on women with asthma, however, people involved in asthma policy, practice and research were interviewed as well. Other specific methods included participant observation at hospitals, conferences, forums, critical reflexive journal entries, critical analysis of existing literature and, case presentations. The sub-study data are now entered on SPSS and NUD\*IST and the information from the Asthma questionnaire has been merged with Survey 1 data. This has ensured a rich data set of the overall health of women in the sub-study.

## ***Outcomes***

The results are now emerging and indicate that:

- 97% of women have taken asthma medication;
- 70% were over 20 years of age when first diagnosed with asthma;
- 88% were over 20 when they first took reliever medication;
- 30% were currently treating their asthma with alternative and complementary methods of treatment only.

The SF-36 means scores from the main ALWSH study were utilised to reveal some trends in women with asthma.

- When the SF-36 means of women with asthma were compared to the population norms (Australian Bureau of Statistics 1997), it revealed that overall health of the women with asthma was poorer than the rest of the population on every subscale.
- Of women with asthma, those who were married or in a partnership experienced better health than those who were single, divorced, separated, or widowed.
- Sixty two percent of the women with asthma were employed either on a full time or part time paid basis. Those who worked experienced better health than those who were in other categories (working without pay, in home duties, studying, unemployed, doing voluntary work, retired, sick or injured).

**Project:** Psychological predictors of successful ageing in a cohort of Australian women  
**Degree:** Master of Medical Statistics  
**Candidate:** Ms Nadine Smith (Research Centre for Gender and Health, University of Newcastle)  
**Supervisor:** Professor Christina Lee & Dr Anne Young  
**Funding:** Research Centre for Gender and Health Scholarship, University of Newcastle  
**Expected Completion:** 1 June 2001

The project's main aim is to examine the extent to which the intrapersonal factors of optimism, the inclination to anticipate the best possible outcome, and health-related hardiness (a composite of a sense of control over, commitment to maintain, and tendency to take direct action over one's health), allow us to explain the variance in older women's subjective health and well-being and perceived stress, over and above that which is explained by physical health, socioeconomic status, social support and healthcare access. On the basis of previous research, it was posited that, after controlling for physical health status (number of diagnoses, number of symptoms, falls needing medical attention, hospital admittance, sensory deficits), socioeconomic status (area of residence, educational qualifications, ability to manage on income, country of birth), social support (marital status, neighbourhood satisfaction, instrumental support), and access to healthcare (GP availability, private hospital insurance), optimism and health-related hardiness will be significantly related to subjective well-being and perceived stress. More specifically, it is hypothesized that optimism and hardiness will be related to individuals' ability to maintain high levels of subjective health and well-being, and low levels of stress in old age. The eight subdimensions of the SF-36 are being used as measures of subjective health.

The study sample was the 9501 women in the older cohort who completed the longer version of Survey 2. Women who completed the short version of Survey 2 were not included since this version did not include items on optimism or health-related hardiness. The main methods of analysis used were factor analysis, multiple regression and structural equation modeling. Positively phrased items tended to group together on the Life Orientation Test (optimism); the negatively phrased items also tended to group together (pessimism). This suggests that optimism and pessimism are related but distinct constructs, not opposite ends of an optimism continuum. Positively phrased items tended to group together on the Health-Related Hardiness Scale; the negatively phrased items also tended to group together. This suggests that the positively phrased items and the negatively phrased items on the Health-Related Hardiness Scale also measure related but distinct constructs. Optimism and health-related hardiness explained just over 10% of the variance in older women’s general health and mental health SF-36 scores, over and above that which is explained by physical health, socioeconomic status, social support and healthcare access. Optimism and health-related hardiness explained approximately 12% of the variance in older women’s general health and mental health SF-36 scores, over and above that which is explained by physical health, socioeconomic status, social support and healthcare access.

These findings suggest that psychological factors do play a role in the health and well-being of older women, and that strategies to promote and maintain optimism and a sense of personal control may help people to cope despite deficits in objective physical health.

## 2 CONDUCT OF SURVEYS

### 2.1 MAIN COHORTS

#### 2.1.1 Young Survey 2 (final stages)

Young Survey 2 was conducted during 2000, and the process was described in detail in Report 15. Table 3 below provides a summary of response rates to Young Survey 2 as at 1 June 2001. Three batches of completed surveys were sent from the Newcastle office to NCS in Melbourne for scanning. The resultant database has now been cleaned and checked by Jean Ball, the WHA data manager. Anomalies have been identified and resolved, and the data are available for analysis.

**Table 3 Response Rates for Young Survey 2 (as at 1 June 2001)**

	Freq	%
Surveys mailed March to October 2000	13,717	
Completed Surveys	9586	69.9
Completed short phone Surveys	85	0.6
Deceased	7	
Withdrawals	128	0.1
Overseas	136	0.1
Will not do survey this time	253	1.9
Return to sender	204	1.5

### 2.1.2 Mid-age cohort Survey 3 (in progress)

Following the process of development and piloting described in Report 15, mid-age Survey 3 was finalized in December 2000. The letter to participants, survey and reminder card are included in Appendix 2.1. These were approved by the University of Newcastle Human Research Ethics Committee, and NCS was selected following the tender process to print, pack, mail and scan the materials.

Table 4 below summarizes the timetable for Mid-Age Survey 3, and Table 5 the response rates as at 1 June 2001.

**Table 4 Timetable for mid-age Survey 3**

Date	Mailout	Items	Number
20 March 2001	Mailout 1	Package mailed including survey, reply-paid envelope, letter of invitation and change of details card	13,007 mailed
5 April 2001	Mailout 2	Thank you/reminder leaflet mailed to all in Mailout 1, except withdrawals, deceased and overseas	12,856 mailed
7 May 2001	Mailout 3	Reminder leaflet to all non-responders	3,891
28 May 2001	Extra mailout	Packages mailed (as Mailout 1) to: <ul style="list-style-type: none"> <li>those previously not sent surveys because of no current contact details, who have since have given new contact details;</li> <li>to those who elected to have telephone interviews;</li> <li>to those who rang to say they received a reminder but did not receive the first survey.</li> </ul>	Approx 250
12 June 2001	Phone reminder	Reminder phone calls to all non-respondents	Approx 2,500

**Table 5 Response Rates for Mid-Age Survey 3 (as at 1 June 2001)**

	Freq	%
Completed Surveys	9787	75.2
Deceased	15	0.1
Withdrawals	62	0.5
Overseas	3	
Will not do survey this time	13	
Return to sender (being tracked)	318	2.4

### **2.1.3 Older cohort Survey 3 (in development stages)**

Preparation for the third survey of the older cohort, which is scheduled to take place from March 2002, has begun. As the women will be aged 76-81 by this time, concerns were expressed as to whether a lengthy mailed survey continued to be an appropriate strategy, both in terms of acceptability to the women and in terms of data quality. The possibility of switching to telephone interviews was discussed, and a small pre-pilot survey was conducted by telephone, to explore participants' attitudes to continued participation and to mode of administration. The following section<sup>a</sup> summarizes the pre-pilot procedures and outcomes.

#### **Pre-pilot Survey of Participants' Preferences**

Public health research with vulnerable populations such as the elderly raises ethical and methodological questions, and raises questions as to the appropriateness of standard epidemiological methods with the old and very old. Ethically, the extent to which some members of this vulnerable section of the community are capable of giving informed consent has been questioned; so too has the extent to which elderly people are actually willing to refuse consent, even if they feel reluctant, when they receive official-looking surveys from government-sponsored researchers (Cassel, Meier & Traines, 1986).

Methodologically, the most appropriate mode of administration of surveys to older age groups must be considered. Deficits in vision and in fine motor coordination may mean that elderly people are unable to complete paper-and-pencil surveys accurately; hearing deficits and speaking problems may make telephone interviewing problematic; any method may be compromised by memory loss. Researchers who plan to compare age cohorts or to follow participants longitudinally must also make decisions about whether to use different modes of administration with different groups, or to change the mode of administration as participants age.

Mailed surveys are significantly cheaper per unit than telephone or face-to-face interviews (McHorney, Kosinski & Ware, 1994; O'Toole et al., 1986; Pruchno & Hayden, 2000) although they tend to have a greater proportion of missing data (O'Toole et al, 1986; Perkins & Sanson-Fisher, 1998; Pruchno et al., 2000), and the relative importance of these two factors for any particular project must be considered. Another important issue, the preferences of research participants, has received little systematic investigation. Longitudinal research in particular depends on high response rates and good retention across time. Feminist researchers (Riger, 1992) have argued that promoting a sense of shared research ownership between researchers and participants is not only compatible with values of respect and consideration, but is also likely to produce better retention rates and more careful responses.

The ALSWH uses mailed surveys which were chosen as the main mode of data collection because of their relatively low cost, appropriateness for a nationally representative cohort, and practicality. However, questions have been raised as to the appropriateness of mailed surveys for the oldest cohort. These women were aged 70 to 75 when first surveyed by mail in 1996; when they were re-surveyed by mail in 1999, it was found necessary to collect data

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<sup>a</sup> Based on Lee, C. (under review) Survey research with elderly women: Preferences of members of the Women's Health Australia older cohort.

by telephone from 9% of respondents. As part of the process of deciding on the mode of administration for Survey 3 in 2002, when they will be aged between 76 and 81, a small study was conducted of older participants, in order to seek their views on the appropriateness of mailed or telephone surveys, acceptable survey length, and related issues.

### ***Method and Results***

A sample was drawn from all women who completed Survey 2 of the WHA older cohort in 1999, excluding those who were interviewed by phone (8.7%) and those whose surveys had been completed by a third party on their behalf (3.0%). A total of 110 women were selected randomly, with stratification on the basis of their 1999 responses to the first item of the SF-36, measuring self-rated health: "In general, would you say your health is: Excellent/Very Good/Good/Fair/Poor". Women were sent a letter informing them that they would be contacted to discuss their views on the main survey, and then telephoned within 14 days. All calls were made during November 2000, by Ms Jenny Helman, a research assistant with experience in telephone interviews with women in this age group.

Two women had died since the last contact. Of the 108 eligible, 85 (79%) completed the interview. Eight telephones had been disconnected; nine could not be contacted after at least five calls; three were too ill to participate at that time, and three withdrew from the study because of failing health. Both women who were deceased, all three who were too ill to participate, and two of the three who withdrew, had rated their health as "Poor" in 1999.

### ***Responses***

The 85 women who participated were aged between 74 and 79, and came from all states and territories, with 31 living in urban areas and 54 in rural or remote areas. Three spoke a language other than English at home (Hungarian, Maltese, and Polish), but all considered themselves able to complete a survey in English either by phone or by mail.

All indicated that they were willing to complete Survey 3 in 2002, although six (7%) qualified this with a comment such as "if I'm still here" and three indicated they would need assistance. They were reminded that the previous main survey had been 24 pages in length and were asked what length of survey they would be willing to complete next time. Thirty-three (39%) specified 24 pages and 21 (25%) "any length"; 13 (12%) said that they would complete 24 pages if necessary but would prefer something shorter, while 16 (19%) definitely wanted a shorter survey. Twenty-three commented on the length of the main survey: nineteen commented that they enjoyed completing the survey, thought it was worthwhile, or were happy to help; two said they had health problems which would make completing a long survey difficult; and two thought the main survey was too long and irrelevant.

When asked whether they would prefer a mail survey or a telephone interview lasting about one hour for the next main survey, 79 (93%) preferred mail, six telephone (of these five said that it would need to be considerably shorter, while the other was visually impaired and unable to read), and one said "either". Overall, the most frequent comment was that a mailed survey was preferable because it enabled the respondent to answer the questions in her own time and to think about the answers, resulting in more accurate responses (56 women, 66%). Fifty-one (60%) said that an hour was too long to spend on the phone. Eleven suggested that they would need to see the questions first if they were to answer them over the phone, so that a survey would still need to be sent by mail; and six said that they would need to arrange an appointment for a telephone interview, meaning at least two calls. Eight said that they would refuse to complete the main survey by phone, with three adding that they would get flustered

with a complicated phone interview, and one said she stuttered when nervous. Five were concerned about the cost to the taxpayer of the phone calls.

When asked whether there were questions or topics that were not suitable for a survey of this nature or that they would not want to answer, the majority (77, 91%) were willing to be asked about any topic. Four would not answer questions about money or income, two about sex, and two about relationships.

A final question asked whether the participants had any other comments about the conduct of the WHA project as a whole. Responses were overwhelmingly favourable, the general message being that the respondents felt that the project was worthwhile and well run, were happy to be part of it, were pleased to see attention being paid to the needs of older women, and appreciated receiving newsletters and other feedback.

### **Conclusion**

This small survey shows that women in this cohort are willing to continue participating in WHA surveys, that the majority consider themselves capable of responding to written surveys, and that there is a clear preference for mail rather than telephone administration. The view that surveys such as WHA might be seen as bothersome, irrelevant, or too much of a burden for women in this age group received very little support. While two women did say they thought the main survey was long and irrelevant to them, they were both willing to complete the next survey. Almost all were positive about participating in public health research, and regarded the main survey as a legitimate and useful activity. The results overall suggest that the WHA research team should continue to survey the older cohort by mail, although shorter and simpler surveys may be needed as the women continue to age.

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### Development of Older Survey 3

Preparation for the third survey of the older cohort, to be administered in 2002, began in March 2001. In March and April 2001, the Investigators circulated and discussed the second Older survey and generated ideas for modifications and deletions. On 26 April a working party discussed principles for the development of Survey 3 for this age group, and a preliminary draft was prepared on the basis of this meeting.

It was pointed out this would be the last main survey for many women in this cohort. Survey 4 of this group is timetabled for 2005, when the surviving women will be aged between 79 and 84. Mean life expectancy for Australian women is currently 81.9 years, but mean life expectancy is actually higher among older age groups as a result of the “survivor effect”: current life expectancy for Australian women who have reached 65 is 85.3 years (Public Health Division, NSW Department of Health 2001). Increasingly, though, women who are still alive and contactable at Survey 4 will become unable or unwilling to complete surveys as a result of frailty or illness.

Because of this, a decision was made to focus primarily on those variables that were considered to be outcomes rather than on predictors of health. No new variables were considered for inclusion, except for a measure of memory problems to screen for early signs of cognitive deficit, which was identified as of central conceptual relevance. Decisions about content of Survey 3 were also based on the principle that it was important to maximize response rate and maximize the probability that women would be willing to continue for as long as possible. Ensuring that the survey was as short as possible and larger fonts were used, as suggested by the women in the pre-pilot phone interviews, was agreed to be important. A decision was taken to remove those items that:

- a. Were unlikely to have changed since Survey 1 or Survey 2;
- b. Had very low rates of endorsement (< 1%);
- c. Had rates of non-completion over 10%;
- d. Were not clearly related to the main study themes.

Exceptions were made in the case of variables that were central to the outcomes or were needed for face validity.

A further decision was made to explore strategies for improving the quality of completed returns. Accurate scanning of forms requires that surveys are completed precisely, and there are concerns that older women may be likely to experience problems such as arthritis and tremor which make this difficult. Office staff check and re-complete surveys by hand but this is expensive and time-consuming. The use of carpenters’ pencils has been explored but is impractical. Carpenters’ pencils are sold unsharpened in bulk and would need to be sharpened by staff before distribution. Trials in the Newcastle office, showed that the pencils quickly develop a point and thus produce a fine line. Various brands of felt-tipped pens have also been trialled, and also found impractical. The ink shows through the paper to the other side, making scanning impossible unless a thicker paper was used or printing was on one side only. The additional cost of printing, cost of felt-tipped pens, and additional mailing costs of heavier surveys and pens, would add an estimated \$30,000-\$45,000 to the costs of surveys. The office staff are continuing to explore strategies for making completion easier.



Consensus has been reached on the content of the pilot version of Survey 3 for the older women (see Table 6). The next stage of the process will be to decide on the ordering of items and finalize the layout. Piloting is scheduled for July/August 2001.

***Reference***

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**Table 6 Items in 2002 Older Survey 3 – May 2001 Draft of Pilot**

Survey 2 item	Question description	Source	Modification from Survey 2
<b>Health Service Use</b>			
1 a-r	Medical History	Modified from ABS (NHS) 1989-90, then revised and extended.	Heart disease divided into 3 (angina, heart attack, other heart problems) Wording for hypertension and iron deficiency changed to improve comprehension Breast cancer, bowel cancer and thrombosis removed because of low levels of endorsement (“other cancer” retained) Re-ordered with more frequent items first
2 a-k	Operations/ Procedures	WHA (Survey 1), then revised according to national estimates for females aged 72-76 in Quality in Australian Health Care Study database (1995)	Hysterectomy, oophorectomy, cholecystectomy removed because of low levels of endorsement Re-ordered with more frequent items first
3	Frequency of family doctor or GP visits	Modified from ABS (NHS) 1989-90, then revised according to data from “Availability and Use of Health Services Substudy”(AUHS) (WHA)	No change
4 a-i	HCP visits	Modified from ABS (NHS) 1989-90, then revised according to data from “Availability and Use of Health Services Substudy”(AUHS) (WHA)	Counsellor removed because of low levels of endorsement (retained at item 68)
5 a- g	Access to Health Care	AUHS Substudy (WHA)	“Access to female GP” and “How long you waited to get a GP appointment” added (from original scale and Mid 2 & 3 surveys).
6	Gender preference of GP	Modified from AUHS Substudy (WHA)	Deleted – no change expected.
7	Cost of GP	AUHS Substudy (WHA)	No change.
8	Falls	DVA trial.	No change.
9	Days in Hospital	AUHS Substudy	Upper four categories collapsed to “4 or more” to reduce missing data

Survey 2 item	Question description	Source	Modification from Survey 2
10 a-b	Insurance	Modified from ABS (NHS) 1989-90	Replaced with items 18 and 19 from Mid Survey 3 to separate DVA and private cover.
11	General Physical Ability	Medical Outcomes Study(MOS) Physical Functioning Measures (1992)	No change though will be re-positioned within survey.
12	Mobility	MOS Physical Functioning Measures (1992)	As above
13 a-b	Medication- general	WHA (Survey 1)	Replaced with 3 new items: Medications prescribed or recommended by a doctor for 13 specific purposes (see Mid 3 item 33), YES response only Number of different types of medications in past 4 weeks Currently using HRT YES/NO
14 a-c, e-f	Medication (specific)	WHA (Survey 1) revised and extended.	
14d	HRT	WHA	
<b>Health Conditions , Healthy Behaviour &amp; Life Events</b>			
15 a-aa	Life Events	Modified from Norbeck (1984), revised and extended	Shortened to 12 items (deleted those with low endorsement or little relevance to health)
16 a-w	Symptoms and Help-seeking	WHA (Survey 1) with revisions	“never” option added; otherwise no change
17 a-e	Specific Sensory deficits	Lambeth Disability Screening Questionnaire (1981)	Items on difficulty seeing and hearing (a and c) retained. Items on difficulty shopping and cooking/feeding added (from 251)
18 a-f	Sleeping	Nottingham Health Profile	No change.
19 a-j	Depression	CESD-10 (Mid Follow-Up)	Deleted because of high rates of missing data. Replaced with Goldberg Anxiety & Depression Scale (Goldberg D et al., Detecting anxiety and depression in general medical settings. BMJ, 1988, 297: 897-9.) 14 items, yes/no response.
20 a-d	Physical Activity-occasions	Modified from Commonwealth Department of the Arts, Sport, the Environment and Territories (1992)	No change

Survey 2 item	Question description	Source	Modification from Survey 2
21 a-d	Physical Activity – amount of time	Modified from Commonwealth Department of the Arts, Sport, the Environment and Territories (1992)	No change.
22	Date of Birth	WHA	No change.
23	Height	WHA	No change.
24	Weight	WHA	No change.
25 a-m	Nutrition	Australian Nutrition Screening Checklist (extended to include vegetarianism)	Deleted. High rates of missing data. Item 1 incorporated at item 17.
26	Alcohol-frequency	Modified from NHF (1980)	No change.
27	Alcohol - amount	Modified from NHF (1980)	No change.
28	Smoking	Modified from Australian Institute of Health and Welfare (AIHW) (1998)	Deleted. Low rates of endorsement, unlikely to change.
29 a-g	Stress	WHA	Deleted. High rates of missing data.
NEW	Memory change	Crook, T et al. Assessment of memory complaint in age-associated memory impairment: The MAC-Q. International Psychogeriatrics, 1992, 4: 165-75.	6 items about perceived change in memory
<b>Living Arrangements</b>			
30	Marital Status	Modified from ABS (1996) Census	No change.
31	Living Alone and no. living in household	Modified from ABS (1994) Social, Labour, & Demograph Stats	No change.
32	Pet Ownership	WHA	Delete fish and horse options – low endorsement.
33	Housing situation	Modified from ABS (1996) Census	No change.

<b>Survey 2 item</b>	<b>Question description</b>	<b>Source</b>	<b>Modification from Survey 2</b>
34	Time in present home	WHA	Delete.
35	Postcode	WHA	No change.
36 a-m	Feelings about Neighbours and Neighbourhood	Australian Living Standards Study (Aust Institute of Family Studies)	Delete. High missing data. Other measures of social support retained.
37	Income sources	WHA	Slight change of wording.
38	Managing on Income	WHA	No change.
<b>Quality of Life</b>			
39 a-f	Optimism	Revised and reduced Revised Life Orientation Test (LOT-R) (1994)	Delete.
40-50	Physical and Mental Health	SF36- Ware & Sherbourne (1992)	No change.
<b>Support (Providing and Receiving)</b>			
51-61	Social Support	Duke Social Support Index, Koenig et al, 1993.	Items 54 – 58 and 61 deleted on basis of factor analysis from Survey 2.
62	Need for Care	Modified from ABS (1993) Disability, Aging and Carers Australia.	No change.
63	Assistance for Travel	MOS Physical Functioning Measures (1992)	No change.
64	Ability to use Public Transport	MOS Physical Functioning Measures (1992)	No change.
65	Availability of Public Transport	WHA	No change.

<b>Survey 2 item</b>	<b>Question description</b>	<b>Source</b>	<b>Modification from Survey 2</b>
NEW	Usual mode of transport	From widowhood substudy	
66 a-g	Instrumental Support	Modified subscales D and E from Social Support Questionnaire for Transactions (SSQT)	Items b, c and f deleted on basis of factor analysis from Survey 2
67 a-m	Elder abuse	Validation of the Hwalek-Sengstock Elder Abuse Screening Test (Neale 1991).	No change.
68 a-i	Formal Support/ Service Use	Modified from Jorm et al (1993) using DVA data.	No change.
69	Care for Children	WHA	No change.
70	Care for Others	Modified from ABS (1993) Disability, Aging and carers Aust.	No change.
71	Caring for ill/frail	WHA : Developed from Survey 1	Deleted – unnecessary detail.
72	Frequency of Care for ill/frail	WHA : Developed from Survey 1	As above.
73	Time spent caring for ill/frail on each occasion	WHA : Developed from Survey 1	As above
74	Volunteering	WHA	No change.
75 a-b	Time pressure	Modified from Statistics Canada (1985)	Deleted.

Survey 2 item	Question description	Source	Modification from Survey 2
<b>Miscellaneous</b>			
76 a-b	Childhood Trauma	WHA	Deleted
77 a-o	Health-related hardiness	Health-Related Hardiness Scale (Pollock, 1990)	Deleted – predictor rather than outcome.
78 a-p	Erikson’s Stages of development	Revised Inventory of Psychosocial balance (IPB) (Domino & Affonso, 1990)- re-shuffled and terms defined.	Deleted.

## **2.2 INDIGENOUS COHORTS**

Reporting on progress on the indigenous special cohorts which was due in December 2000 was unavoidably delayed. A report was submitted to the Commonwealth in May 2001.

## **3 METHODOLOGICAL ISSUES: SOURCES AND DEVELOPMENT OF INSTRUMENTS, RELIABILITY AND VALIDITY**

The data management and analysis group within the project, led by Dr Anne Young, has been concentrating on validation issues over this six-month period. The group has developed a protocol for examining the validity of the scales that have been included in the surveys (see Appendix 3.1).

A summary of the scales currently under review is given below. Where reports are available, these are included as appendices to this report. Where possible, we have begun sharing SAS code within the group to make the analyses more streamlined. This ensures that we are working in a consistent manner, our methods are transparent and it also avoids the situation of re-writing the same or closely related programs.

### **3.1 THE CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE SHORTENED VERSION (CESD-10)**

Jennifer Powers, Anne Young, Anne Russell.

Working paper on missing data in a short form of the Center for Epidemiologic Studies Depression Scale in Women's Health Australia surveys

#### **3.1.1 Background**

##### ***Introduction***

Depression is an important problem in later life. It is associated with decreased life satisfaction, physical and mental decline, increased health service use and increased mortality (Henderson, 1997; Steffens, 2000). Assessing depression is complicated, particularly in the presence of disability, physical disease and other mental disorders (McCallum, 1995; Vahle, 2000). Various screening scales have been developed to improve recognition of depressive symptoms (Beekman, 1997; Mulrow, 1995). In epidemiological studies, screening scales can provide estimates of the prevalence of depression using consistent measurement criteria across samples and time (Vahle, 2000).

##### ***The Center for Epidemiologic Studies Depression Scale (CES-D)***



One of the most commonly used self-report depression screening scales is the 20-item Center for Epidemiologic Studies Depression Scale (CES-D), that was designed as a screening instrument for symptoms of depressed mood in older adults (Radloff, 1977). It has been validated across a range of ages making it appropriate for use in longitudinal studies (Ossip-Klein, 1997). The scale is suitable for self-administration, is easy to read and is easily scored (Mulrow, 1995). However, there have been reports that the elderly sometimes have problems with multiple-item, forced-choice scales (Vahle, 2000).

### *Shortened versions of the CES-D*

Shrout and Yager (1989) demonstrated that the length of the 20-item CES-D could be halved without appreciable loss to reliability and quartered without significantly affecting the validity. Various short and/or simplified forms of the 20-item CES-D have been evaluated (Andresen, 1994; Boey, 1999; Carpenter, 1998; Furukawa, 1997; Irwin, 1999). The most commonly used abbreviated forms are the Boston form (10 dichotomously scored items; Irwin, 1999), the Iowa form (11 items with three response options; Carpenter, 1998) and the four-category response 10-item form (CESD-10) developed by Andresen et al (1994) (Table 7). The Iowa form and CESD-10 have been found to perform as well as the original 20-item CES-D (Carpenter, 1998; Furukawa, 1997).

### **Table 7 Items in the CESD-10 Scale used for WHA**

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Below is a list of ways you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK.

---

- 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 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"
-

The response options for each item were: "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)" and "most or all of the time (5-7 days)" and are coded 0 to 3 respectively (Radloff, 1977). The scores for the positive mood items (e and h) are reversed and the score is the sum of all item scores. Following the conservative approach of Andresen et al (1994), one missing item can be replaced by mean imputation. Hence study participants are considered to have completed the CESD-10 if they completed 9 or more of the 10 items. The score is set to missing if fewer than nine items are completed. The range of scores is 0 to 30, with higher scores representing a more depressed mood.

Depression screening scales generally overestimate the prevalence of depression (Vahle, 2000; Zich, 1990). Most studies using the 20-item CES-D recommend a score of 16 or more to categorise individuals as positive for depressive symptoms, however higher cut-off scores have been used in different populations to decrease the number of false positives (Lyness, 1997; Ossip-Klein, 1997; Penninx, 1998). Validation of the CESD-10 against the 20-item CES-D using a cut-offs of 8, 9, 10 has shown the cut-off of 10 or more, minimises false positives with little loss of sensitivity (Andresen, 1994; Boey, 1999). In this study a cut-off of 10 was used to classify women as depressed. The mental health sub-scale of the SF-36, with a cut-off of 52 or below, has also been used to detect depression (Ware, 1994).

### 3.1.2 Use of the CESD-10 in WHA surveys

#### *Survey 2 for the mid cohort*

The CESD-10, as described in Table 7, was included in Survey 2 for the mid-age cohort in 1998. The women were aged 47-52 years. The full survey was completed by 11,648 women and 690 women completed the telephone administered sub-survey. The responses to the CESD-10 items are shown in Table 8. Proportions of missing data for the CESD-10 items were 1-2%. It should be noted that the CESD-10 and the two and a half pages of preceding questions all had the instruction "Mark one response per line".

An extra item (k), 'I felt terrific', was added at the end of the scale so that it finished with a positive item. This extra item was not included in the scale.

**Table 8 Percentage of mid age women (n=11,648) responding to each option of the CESD-10 items, and percentage not completed, in Survey 2 in 1998.**

**Below is a list of ways you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK.**

*(Mark one response per line)*

	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) %	<i>ITEM NOT COMPLETED</i> %	<i>TOTAL</i> %
a I was bothered by things that don't usually bother me	69	22	5	2	2	100
b I had trouble keeping my mind on what I was doing	57	31	8	3	1	100
c I felt depressed	64	23	7	3	2	100
d I felt everything I did was an effort	57	28	9	5	1	100
e I felt hopeful about the future	17	21	19	40	2	100
f I felt fearful	74	17	5	2	2	100
g My sleep was restless	36	37	15	10	1	100
h I was happy	6	16	22	54	2	100
i I felt lonely	68	20	7	4	1	100
j I could not "get going"	47	36	10	5	1	100
k I felt terrific	24	22	23	30	1	100

*Survey 2 for the young cohort*

Survey 2 for the young age cohort in 2000 included the CESD-10 as described in Table 7. Preliminary results are available for 9197 women aged 22-27 years who completed the full survey. The responses to the CESD-10 items are shown in Table 9. Proportions of missing data for the CESD-10 items were 1-3%. Questions immediately preceding the CESD-10 had the instruction “Mark one on each line”, however the previous page had the instruction “Mark all that apply”.

As for the mid age cohort, an extra positive item (k) was added at the end of the scale and was not included in the scale.

**Table 9 Percentage of young women (n=9197) responding to each option of the CESD-10 items, and percentage not completed, in the Survey 2 in 2000 (preliminary data only).**

**Below is a list of ways you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK.**

*(Mark one on each line)*

	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) %	ITEM NOT COMPLETED %	TOTAL %
a I was bothered by things that don't usually bother me	60	28	8	2	1	100
b I had trouble keeping my mind on what I was doing	45	37	12	4	1	100
c I felt depressed	54	29	11	5	2	100
d I felt everything I did was an effort	55	30	10	4	2	100
e I felt hopeful about the future	14	27	32	26	2	100
f I felt fearful	70	19	6	2	3	100
g My sleep was restless	36	35	18	10	2	100
h I was happy	5	19	36	40	1	100
i I felt lonely	55	28	11	5	2	100
j I could not "get going"	41	39	13	5	1	100

k	I felt terrific	23	30	32	14	1	100
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***Pilot Survey 2 for the older cohort***

The CESD-10, as described in Table 7, was used in the pilot Survey 2 for the older cohort. The women selected for pilot surveys are believed to be representative of Australian women aged 72-77 years and 202 of these women completed the full survey in the year prior to the main survey of the older cohort. Missing data for the CESD-10 items was three to five times higher than missing data for similar horizontally formatted multiple response questions in the SF-36 (Table 10). Missing response items for the CESD-10 were considered to be unacceptably high (11% to 19%). Following discussions amongst the investigators and experts in the field, various changes in format were made to the CESD-10. Firstly, the sub-heading, "...don't spend too much time on each question", was added to the format. Secondly, a vertical line was drawn between the first response category and the other response categories. Thirdly, the response options were altered to: "none of the time (less than 1 day)", "rarely (1-2 days)", "sometimes (3-4 days)" and "most of the time (5-7 days)".

In the pilot survey, the position of the CESD-10 items was at the bottom of page 8 following one and a half pages of questions which had the instruction "Mark one on each line". Despite this, some women may have only marked those that apply, as 44% (19/43) of women with missing data answered 'some ...', 'occasionally ...' or 'most ... of the time' and left the remaining items blank.

**Table 10 Proportions of missing data for CESD-10 and SF-36 sub-scales with horizontally formatted multiple response items in the pilot Survey 2 for the older cohort (n=202).**

Number of missing items	CESD-10 %	Physical functioning %	Mental health and vitality %	4 of 5 general health items %
0	73.3	90.1	92.1	93.1
1	5.9	5.0	6.4	2.5
2	2.5	1.0	0.5	1.0
3	0	1.5	0	2.5
4	2.0	0.5	0	1.0
5	0.5	0	0	
6	2.0	0.5	0.5	
7	1.5	0.5	0	
8	3.5	0	0	
9	3.5	0	0.5	

10	5.5	1.0		
Total items	10	10	9	4
Reversed items	2	0	4	2
Response categories	4	3	6	5
Single item percent missing	11% to 19%	1% to 4%	1% to 4%	3% to 4%

***Results of the CESD-10 in Survey 2 for the older cohort***

The responses of the 9,501 women who completed Survey 2 for the older cohort are shown in Table 11. Item completion percentages for the CESD-10 ranged from 53% (I felt fearful) to 68% (I was happy). Less than half the women (49%, 4630/9501) completed sufficient items (9 or 10) to have a CESD-10 score calculated. Ten percent of women had all items missing, 16% answered only one item, and a further 9% answered only two items (Table 12).

**Table 11 Percentage of older women (n=9501) responding to each option of the CESD-10 items, and percentage not completed, in Survey 2**

**Below is a list of ways you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK.**

*(Mark one on each line, but don't spend too much time on each question)*

	None of the time (less than 1 day) %	Rarely (1-2 days) %	Some- times (3-4 days) %	Most of the time (5-7 days) %	ITEM NOT COMPLETED %	TOTAL %
a I was bothered by things that don't usually bother me	42	10	5	1	43	100
b I had trouble keeping my mind on what I was doing	39	9	7	1	44	100
c I felt depressed	39	11	7	1	42	100
d I felt everything I did was an effort	33	12	11	4	40	100
e I felt hopeful about the future	13	4	10	30	43	100
f I felt fearful	40	7	4	1	47	100
g My sleep was restless	25	14	16	7	37	100
h I was happy	6	2	8	51	32	100
i I felt lonely	35	11	10	3	42	100
j I could not "get going"	30	15	12	3	39	100

***Why was the CESD-10 so poorly answered in Survey 2 for the older cohort?***

There are several possible explanations for the large amount of missing data in this scale with this population of women. Firstly the two and a half pages of questions in the survey preceding the CESD-10 items had the instruction: "Mark all that apply to you". It is possible that women may have answered the CESD-10 items in this way. Of the women who answered between one and nine of the CESD-10 items, 61% (2677/4365) had answered 'rarely', 'sometimes' or 'most of the time' to one or more items and left the remaining items blank. Hence, it might be inferred that their response to the missing items was "none of the time". Under this assumption, the level of missing data would be reduced to the level found in the pilot study (11% to 19%).

Secondly, it has been suggested that using a horizontal format with the response categories arranged across the page may lead to missing responses (Ossip-Klein, 1997). However, in the WHA survey, other sets of questions with a similar format were answered reasonably well. Other horizontally formatted multiple response questions included 23 items in several SF-36 sub-scales (physical functioning, mental health and vitality, and four of the five general health items). Missing values for these individual SF-36 items ranged from 1% to 6% compared to 32% to 47% for the CESD-10 items (Table 12). While fewer than half the participants completed the CESD-10, between 85% and 92% of the women completed the SF-36 sub-scales (Table 12).

Thirdly, it has been suggested that older people may not like completing items with *frequency*-based responses, such as the CESD-10 but rather prefer *intensity*-based responses. Like the CESD-10, the mental health and vitality sub-scales of the SF-36 require frequency-based responses. The response options for these sub-scales are “all of the time”, “most of the time”, “a good bit of the time”, “some of the time”, “a little of the time” and “none of the time”. In comparison, the physical functioning sub-scale and four of the five items of the general health sub-scale require intensity-based responses. The response options for the physical functioning sub-scale are “yes limited a lot”, “yes limited a little” and “no not limited at all” and those for the general health sub-scale are “definitely true”, “mostly true”, “don’t know”, “mostly false” and “definitely false”. Missing data for the frequency-based responses ranged from 1% to 4% (Table 12). For items with intensity-based responses, data were missing for 1% to 6% of women. Similar percent completion occurred for the frequency- (90%) and intensity-based SF-36 sub-scales (85% to 92%).

Finally, changes to the layout and responses and modification to the wording of the instructions that preceded the CESD-10 items ie. "don't spend too much time on each question" may have had an adverse affect on percent completion. In the pilot survey, missing data for CES-D items ranged from 11% to 19% in comparison to 1% to 4% for the physical functioning, mental health and vitality sub-scales and 3% to 4% for four of the five items in the general health sub-scale (Table 10). In Survey 2, similar proportions of “missingness” were observed for the SF-36 sub-scales, however missing proportions were considerably higher for the CESD-10 items (Table 12).

**Table 12 Percentages of missing data for CESD-10 and SF-36 sub-scales with horizontally formatted multiple response items in Survey 2 for the older cohort (n= 9501).**

Number of missing items	CESD-10	Physical functioning	Mental health and vitality	4 of 5 general health items
	%	%	%	%
0	44.0	84.6	90.0	91.5
1	4.8	8.1	5.6	3.1
2	2.0	3.1	1.8	1.2
3	1.3	1.5	0.5	3.8
4	1.5	0.8	0.4	0.6
5	2.2	0.5	0.3	



6	3.1	0.4	0.3	
7	5.4	0.4	0.3	
8	9.5	0.3	0.4	
9	16.4	0.3	0.4	
10	10.1	0.2		
Total items	10	10	9	4
Reversed items	2	0	4	2
Response categories				
Number	4	3	6	5
Type	Frequency-based	Intensity-based	Frequency-based	Intensity-based
Single item percent missing	32% to 47%	1% to 6%	1% to 4%	4% to 5%

### *Patterns of missing data*

Comparison of the total number of items missing for the CESD-10 in the pilot and final Survey 2 (Tables 10 and 12), show the increase in missing data from pilot to main survey occurred mainly where 8, 9 or 10 items were missing. The difference in percent missing was 23.5% (pilot 12.5%, main 36%). Of the women who answered only one or two items (i.e. 8 or 9 items missing), 76% (1858/2454) answered ‘rarely’, ‘sometimes’ or ‘most of the time’ to the items and left the remainder blank. Over two-thirds of the women answering one item in this way (820/1213), responded to one of the positive items (‘I was happy’ (n=518) or ‘I felt hopeful about the future’ (n=50)) or the item about sleep (n=252). A quarter of women answering two items (165/645) responded to the two positive items. Based on these answers, at least half the women with only one or two responses to CESD-10 items appear to not be depressed and to be only marking those items that apply.

The pattern of depressive symptoms appears to support this argument. Depressive symptoms are least frequent among those with none or one of the CESD-10 items missing or eight to ten items missing (Table 13). A similar pattern occurs for arthritis, with the highest percentages occurring in those missing responses to three to seven items.

**Table 13 Number of missing items for CESD-10, indicators of depression and arthritis in Survey 2 for the older cohort (n= 9501)\*.**

<b>Number of missing items</b>	<b>Diagnosis of depression %</b>	<b>Medication for depression %</b>	<b>Mental health score ≤52 %</b>	<b>Arthritis %</b>
0	5.2	4.1	5.8	39.7
1	6.6	4.6	9.3	41.3
2	11.8	9.1	13.9	48.1
3	18.3	9.2	24.2	58.3
4	17.0	15.6	15.6	49.7
5	18.5	11.7	24.9	58.1
6	12.7	8.3	18.9	55.3
7	9.3	5.5	11.7	51.2
8	5.1	4.8	8.9	44.9
9	2.6	3.5	4.8	39.9
10	4.4	3.1	6.6	40.4

\* Data missing for indicators of depression and arthritis for up to 266 women.

### *Implications of missing data*

Previous research studies have not fully investigated the characteristics of non-completers, the possible reasons for non-completion or the potential bias arising from non-completion of items on the CES-D. Regardless of the mode of administration, non-completion of the 20-item or shorter versions of the CES-D was 21% to 42% (Andresen, 1994; Callaghan, 1994; Furukawa, 1997; Kimberlin, 1998; Ying, 1988; Zich, 1990). Although some studies have used the mean of responses to answered items to impute scores for up to 25% of missing CES-D items (Zich, 1990), only a few have examined the possible effects of imputation on their findings. Respondents to the Boston form of the CES-D for whom data were imputed for up to two items were more likely to be female, older, widowed, have more functional limitations, lower self-reported health status and more depressive symptoms than those who completed all items on the CES-D (Kimberlin, 1998). Another study using the 20-item CES-D imputed data for nearly 40% of respondents (Callahan, 1994). Those with imputed scores were more likely to have cognitive impairment but not greater numbers of chronic illnesses or higher rates of depression.

The potential bias associated with missing responses to items in the CESD-10 was investigated using the WHA data. Specifically the socio-demographic and health profiles of women who did and did not have missing data on the CESD-10 were compared.

### **3.1.3 Analysis of completers and non-completers of the CESD-10**

#### *Socio-demographic and health measures*

Country of birth was classified as being of English-speaking background or not. The highest educational level completed was categorised into four groups: no formal qualifications, school, trade/certificate/diploma, and university. Marital status in 1999 was categorised as: married/de-facto, widowed, separated/divorced and never married. Capacity to manage on current income was measured in 1999 with response options categorised as: impossible/always difficult, difficult some of the time, not too bad and easy.

Indicators of health from the 1999 survey were: self-rated health; number of chronic conditions in the last 3 years from a list of 17; number of physical symptoms in the last year from a list of 22; number of visits to the general practitioner in the previous 12 months; the number of types of other health professionals (specialist doctor, dentist, physiotherapist, optician, podiatrist/chiropract, counsellor) seen in the last 12 months (referred to as 'other health professionals' in the remainder of the paper); days in hospital in the previous 12 months (categorised as none, 1 or 2, 3-7, 8 or more) and the eight dimensions of the SF-36. The SF-36 dimensions have missing data and so percent completion of SF-36, according to completion of the CESD-10, was investigated.

#### *Statistical analyses*

All statistical analyses were performed in SAS. Tests of association between CESD-10 completion and socio-demographic factors, health indicators and health service usage were made in PROC FREQ, based on the Chi-square statistic. Tests for differences in mean SF-36 scores between groups based on CESD-10 were made in PROC GLM, and crude and adjusted means estimated using the least squares mean option. Medians and quartiles were calculated in PROC UNIVARIATE and percentages calculated in PROC FREQ.

## Results

There were higher rates of CESD-10 completion among those born in countries with English as the first language, with higher levels of completed education and among women who had never married (Table 14). Percent completion increased with ability to manage on the available income. The women were aged from 73 to 78 years and there was no association between age or area of residence (urban/non urban) and percent completion (data not shown).

**Table 14 Percentage of women (n=9501) completing the CESD-10 by socio-demographic variables in Survey 2 for the older cohort**

	N*	Percent with complete CESD-10	p-value
<i>Country of birth</i>			
English speaking	8175	49.6	0.020
Non-English speaking	757	45.2	
<i>Highest education level</i>			
No formal qualifications	2821	44.1	<0.001
School	4768	48.9	
Trade/certificate/diploma	1093	55.9	
University	369	66.1	
<i>Marital status</i>			
Married/defacto	4868	48.8	0.024
Widowed	3856	48.2	
Separated/divorced	465	49.9	
Never married	272	57.7	
<i>Manage on income available</i>			
Impossible/Always difficult	525	42.3	<0.001
Difficult some of the time	1848	45.3	
Not too bad	4858	48.3	

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Easy	2155	54.9
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*\* Does not always total 9501 due to missing values*

Percent completion increased with self-rated health and declined with increasing number of chronic diseases and visits to the general practitioner (Table 15). There were statistically significant associations between CESD-10 completion, the number of physical symptoms and days in hospital in the previous 12 months, although the pattern of association was not consistent.

**Table 15 Percentage of women completing the CESD-10 at each level of a variety of health indicators and of health service usage (N=9501) in Survey 2 for the older cohort**

	N*	Percent with complete CESD-10	p-value
<i>Health indicators</i>			
Self rated health			
Excellent	430	59.5	<0.001
Very good	2497	52.9	
Good	3916	49.3	
Fair	2288	41.9	
Poor	333	44.7	
<i>Chronic conditions in last three years</i>			
None	1918	56.1	<0.001
One	2971	49.3	
Two	2236	46.2	
Three or more	2153	45.6	
<i>Physical symptoms in last year</i>			
None or one	1582	51.5	<0.001
Two to four	3414	47.6	
Five to seven	2272	46.6	
Eight or more	2150	51.5	
<i>Health service use in the last 12 months</i>			
Visits to general practitioner			
None	189	58.2	<0.001
1 or 2 times	1222	50.6	
3 or 4 times	2577	51.3	
5 to 8 times	2673	49.8	
9 to 12 times	1440	44.2	
13 or more times	1272	44.7	
<i>Other health professionals seen</i>			
None	1263	50.4	0.036
One	2776	49.2	

Two	2542	46.6	
Three	1669	50.8	
Four or more	1125	50.7	
<i>Days in hospital</i>			
None	6735	49.9	0.005
One or two	938	51.8	
Three to seven	829	45.1	
Eight or more	824	45.9	

\* Does not always total 9501 due to missing values

Women with incomplete CESD-10 scores were more likely to have incomplete scores for the dimensions of the SF-36 (Table 16). Using the cut-point of 10 or more, 18% (818/4630) of women with CESD-10 scores were classified as clinically depressed. Mean SF-36 scores were lower for these women than for women who were not depressed. Scores on the SF-36 for women not completing the CESD-10 were intermediate between the depressed and not depressed groups. Figure 6 shows the medians and first and third quartiles of each dimension of the SF-36 for women in the three groups defined by the CESD-10 scale scores (not depressed, depressed, incomplete).

There remains the question of the prevalence of depressive symptoms in the women who did not complete the CESD-10. Differences between scores on the SF-36 for women with incomplete CESD-10 scores and women without depression were obvious for some subscales, even after adjusting for differences in socio-demographic and health variables. The differences were most pronounced for sub-scales relating to role limitations due to emotional and physical problems and mental health, suggesting a greater load of depression among the non-completers. This idea is supported by the slightly higher prevalence of self-reported diagnosis of depression among those who did not complete in comparison to those who did complete the CESD-10 (6.8% versus 5.4%,  $p < 0.005$ ). Further evidence is provided by the higher proportions of women with a mental health score of 52 or less (9.8% versus 6.2%,  $p < 0.0001$ ) and those taking medications for depression (5.4% versus 4.2%,  $p < 0.005$ ).

**Table 16 Difference in mean SF-36 dimension scores for women with complete CESD-10 scores (n=818 depressed\*, n=3812 not depressed\*) and with incomplete CESD-10 scores (n=4871) in Survey 2 for the older cohort**

	% Missing SF-36	Crude Mean	95% CI	P-value <sup>#</sup>	Adjusted Mean <sup>+</sup>	95% CI	P-value <sup>#</sup>
<i>Physical functioning</i>							
Depressed	0.5	47.2	(45.4, 48.9)	<0.001	53.3	(51.3, 55.4)	<0.001
Incomplete	2.7	60.1	(59.4, 60.8)		58.3	(56.8, 59.9)	
Not depressed	0.3	67.6	(66.8, 68.4)		61.9	(60.3, 63.4)	
<i>Role physical</i>							
Depressed	2.2	29.1	(26.2, 31.9)	<0.001	36.4	(32.7, 40.1)	<0.001
Incomplete	7.7	49.3	(48.0, 50.5)		45.4	(42.7, 48.2)	
Not depressed	1.7	65.1	(63.7, 66.4)		55.9	(53.1, 58.6)	
<i>Bodily pain</i>							
Depressed	0.1	49.4	(47.6, 51.2)	<0.001	57.3	(55.1, 59.4)	<0.001
Incomplete	0.7	63.0	(62.3, 63.7)		61.4	(59.8, 63.0)	
Not depressed	0.2	71.0	(70.2, 71.8)		65.5	(63.9, 67.1)	
<i>General health</i>							
Depressed	2.6	50.0	(48.6, 51.4)	<0.001	54.7	(53.0, 56.4)	<0.001
Incomplete	6.9	64.8	(64.3, 65.4)		62.1	(60.8, 63.3)	
Not depressed	1.4	72.1	(71.5, 72.7)		66.1	(64.9, 67.4)	
<i>Vitality</i>							
Depressed	0.4	39.6	(38.3, 40.9)	<0.001	44.7	(43.0, 46.3)	<0.001
Incomplete	2.1	57.2	(56.7, 57.8)		55.8	(54.6, 57.0)	
Not depressed	0.5	64.5	(63.8, 65.1)		60.4	(59.2, 61.7)	
<i>Social functioning</i>							
Depressed	0.1	63.6	(61.9, 65.2)	<0.001	63.4	(61.3, 65.5)	<0.001
Incomplete	0.6	80.4	(79.7, 81.1)		74.1	(72.5, 75.7)	
Not depressed	0.2	89.2	(88.4, 89.9)		79.9	(78.3, 81.5)	
<i>Role emotional</i>							



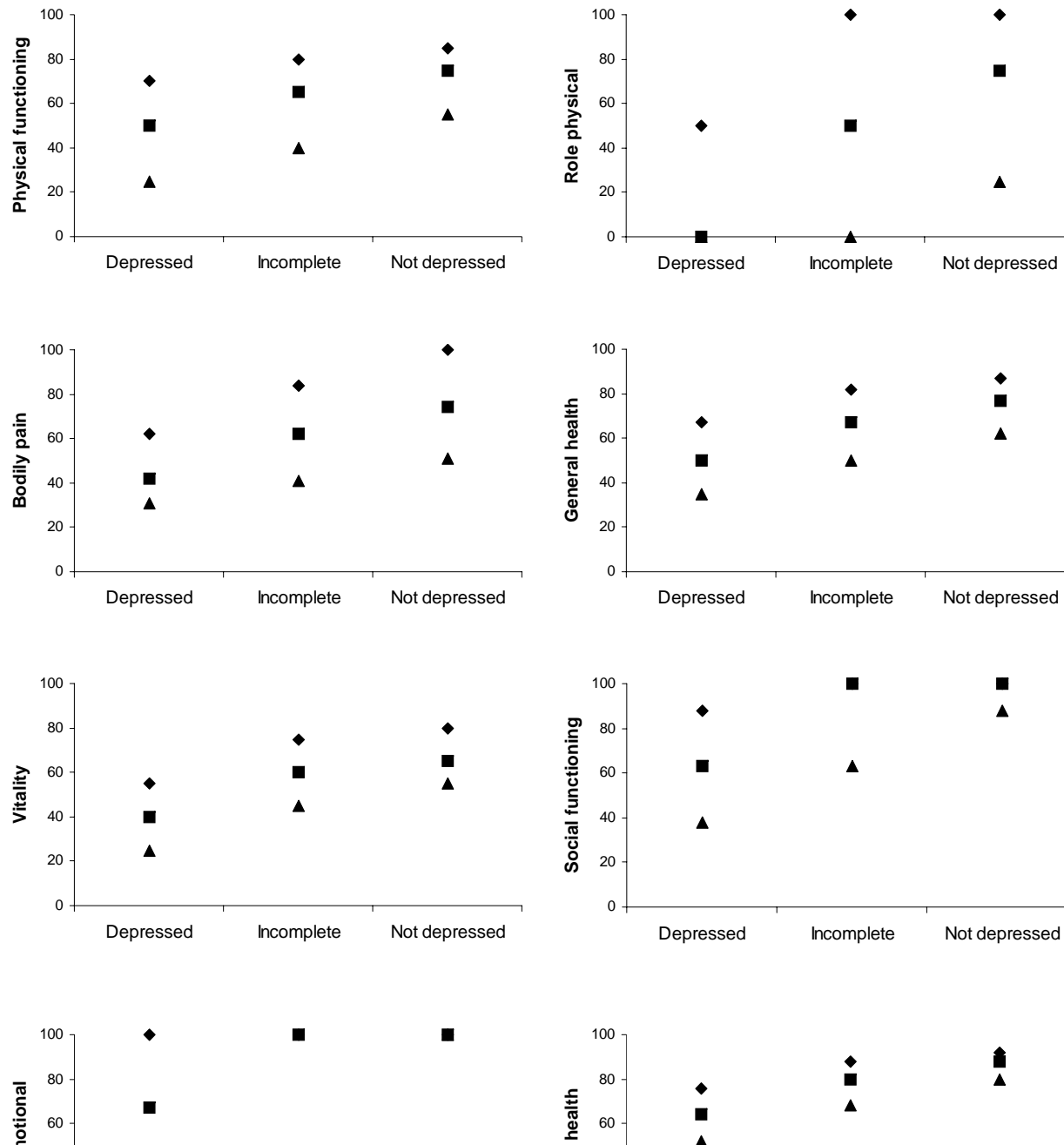
Depressed	3.4	54.5	(52.1, 56.9)	<0.001	56.5	(53.2, 59.8)	<0.001
Incomplete	10.4	72.2	(71.2, 73.2)		69.8	(67.3, 72.2)	
Not depressed	2.0	89.1	(88.0, 90.3)		83.5	(81.0, 86.0)	
<i>Mental health</i>							
Depressed	0.5	62.8	(61.8, 63.8)	<0.001	63.9	(62.6, 65.3)	<0.001
Incomplete	3.1	76.9	(76.5, 77.4)		74.8	(73.8, 75.8)	
Not depressed	0.5	84.7	(84.2, 85.2)		80.8	(79.7, 81.8)	

\* Not depressed if CESD-10 <10. Depressed if CESD-10 ≥10.

# p-value represents difference in mean scores between not depressed, depressed and incomplete

+ Adjusted for English speaking background, education, marital status, ability to manage on income, medical conditions and symptoms, visits to general practitioners and other health professionals, days in hospital.

**Figure 6 Median, 25<sup>th</sup> percentile (Q1) and 75<sup>th</sup> percentile (Q3) for the eight dimensions of the SF-36, by CESD-10 categories.**



### *Discussion for older cohort*

Previous studies using the CES-D have not reported the problems of missing data that we encountered. In response to the mailed questionnaire in our study, only 44% of women aged 73 to 78 years completed all items in the CESD-10 (Table 12). In comparison, reported non-completion was between 21% and 42% for various versions of the CES-D, administered by mail or interview in other studies (Andresen, 1994; Callahan, 1994; Furukawa, 1997; Kimberlin, 1998; Ying, 1988; Zich, 1990). The few studies reporting item non-response found non-response was highest for items measuring positive effect of which the highest non-response item was “I felt hopeful about the future” (Callahan, 1994; Radloff, 1977). In our study the highest non-response tended to be to the items measuring depressed mood (i.e. I felt fearful, depressed, lonely) (Table 11).

Previous studies have found that those who complete a version of the CES-D tend to be younger, male and married (Andresen, 1994; Furukawa, 1997; Kimberlin, 1998; Radloff, 1986). In our study of older women, age was not associated with completion of the CESD-10 and women who had never married were most likely to complete the CESD-10 (Table 14). However when married women, including those in defacto relationships, are compared to all other women the percent completion for both groups is the same. The lower percent completion in non-English background women and those with lower education levels could be due to poorer English reading skills. This would seem unlikely, however, as the CES-D has been classed as easy to read (Mulrow, 1995) and more than a third of women with higher levels of education also did not complete the CESD-10.

It has been reported that people completing all the CES-D items rate their health more positively, have fewer depressive symptoms and higher functional status (Andresen, 1994; Furukawa, 1997; Kimberlin, 1998) than those who left some or all the items blank. In their study of 3057 primary care patients, Callahan et al (1994) found no difference in the mean number of diagnoses among those with and without missing CES-D items. In our study women completing the CESD-10 had better self-rated health, fewer symptoms and chronic conditions including depression (Table 15). Their use of health services tended to be consistent with this pattern. However percent completion increased for women who rated their health as poor, had more than seven symptoms and saw more than two types of other health professionals. This finding suggests that a greater proportion of the very ill may be completing the CESD-10 than might be expected if percent completion declined monotonically with health.

Estimates for the prevalence of depressive symptoms vary depending on the methods and cut-off scores used. For the original CES-D and a cut-off score of 16, prevalence estimates were between 14% and 19% of community-based adults (Callahan, 1994; Lewinsohn, 1997; Radloff, 1977). Using a cut-off score of 10 or more for the CESD-10, prevalence estimates were 12% and 28% in well American and Chinese elderly respectively (Andresen, 1994; Boey, 1999). In this study, the prevalence estimate of 18% for those who completed the CESD-10 is remarkably consistent with the results obtained for other populations of community-based adults.

Although age was not associated with percent completion of the CESD-10 in the older cohort, an age effect does seem likely. Single item percents missing were considerably higher in the pilot for the older cohort than the young and mid age cohorts i.e. where the format of the CESD-10 was the same (Tables 8,9, &10). Compared to other horizontally formatted multiple response questions in each survey, the missing item percent for the CESD-10 was substantially higher in both the pilot and main surveys of older women (Tables 10 and 12). While the changes to the format for the CESD-10 in

the main survey seems to have had an adverse affect on percent completion, the format of the questions is unlikely to be the sole problem. It seems that a large percentage of older Australian women simply do not like to answer these types of questions.

Finally the pattern of missing data for the CESD-10 and the corresponding pattern of depressive symptoms suggest that many of the non-completers, particularly those with most missing CESD-10 items (8 to 10), were likely to not be depressed (Table 13). However those with two to seven items missing were more likely to be depressed than women who completed the CESD-10. Overall, the lower SF-36 scores, particularly in the sub-scales relating to role limitations due to emotional and physical problems (Table 16) suggest that non-completers have a greater burden of mental and physical illness than those who complete the CESD-10. Some form of imputation, which accounts for factors related to depression and other chronic conditions, may need to be used to replace missing data rather than risking bias by excluding women with incomplete data.

### ***Implications for future WHA surveys***

Changes, particularly to existing instruments, should not be incorporated into the main survey after the initial pilot unless sufficient time is available to pilot these changes again prior to sending out the main survey.

A thorough literature search and review of any new instruments should be done prior to including such instruments in future surveys. Particular emphasis should be placed on level of missing data and validation of instruments across a range of populations, particularly women of a similar age to those for whom the survey is planned.

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### **3.2 THE AUSTRALIAN NUTRITION SCREENING INITIATIVE (ANSI)**

Amanda Patterson, Anne Young, Jennifer Powers, Wendy Brown and Julie Byles.

A paper on the baseline results (Relationships between nutrition screening checklists and the health and well-being of older Australian women) is under review at Public Health Nutrition and a summary of the work was included in the Report 15, December 2000.

Responses to individual items in the ANSI checklist, and ANSI and Nutrition Screening Initiative (NSI) scores, were associated with measures of health and health service utilisation. Women with high ANSI and NSI scores had poorer physical and mental health, and higher health care use, and

were less likely to be in the acceptable weight range. The performance of an unweighted score (Total Score Index (TSI)) was also examined and showed similar results. Whereas ANSI classified 30% of the women as 'high risk', only 13% and 12% were classified as 'high risk' by the NSI and TSI respectively. Higher scores on both the ANSI and NSI were associated with poorer health. The simpler unweighted method of scoring the ANSI (TSI) showed better discrimination for the identification of 'at risk' women than the weighted ANSI method.

The predictive value of individual items and the checklist scores needs to be examined longitudinally. Analysis on the performance of ANSI in Older Survey 2 is planned but has not yet begun.

### **3.3 THE DUKE SOCIAL SUPPORT SCALE**

Jennifer Powers, Julie Byles, Brendan Goodger

Jennifer Powers is currently examining the performance of the DSSI among the older cohort at Surveys 1 and 2. The report will include results of factor analysis of the 11 items, whether our data confirm two subscales, the behaviour of the score over time, and correlates of the score and of changes over time in the score.

### **3.4 NEIGHBOURHOOD SATISFACTION**

Anne Young, Anne Russell & Jennifer Powers

#### **3.4.1 Background**

The relationships between neighbourhood quality, fear of crime, community participation, social support, and health are now being recognised as an important area of research into healthy ageing and well being. Policies aimed at promoting health and well being should take into account not only the socioeconomic characteristics of people but also the places where they live. After accounting for individual risk factors, neighbourhood characteristics have been shown to have an independent effect on mortality (Cubbin, LeClere & Smith, 2000; Yen & Kaplan, 1999) and to be associated with self-reported poor health (Malmstrom, Sundquist & Johansson, 1999).

The sense of community is hypothesised to be determined by the extent to which community members experience a sense of solidarity and a sense of significance and this should be assessed by asking community members how they feel (Clarke, 1973). The sense of solidarity refers to sentiments such as "feelings of belonging, togetherness, cohesion, and identification, so that members talk in terms of "we" and "our" in the absence of thoughts of

distinction or division" (Brownlee, 1993). The sense of significance entails members feeling that they are appreciated as important contributors to the group, thereby developing a sense of achievement, fulfillment and worth (Brownlee, 1993).

It is known that regular physical activity in older adults can facilitate healthy ageing, improve functional capacity, and prevent disease (Booth et al., 2000). However, concerns about neighbourhood safety may serve as a barrier to physical activity. Several studies have shown that people who perceive their neighbourhood to be unsafe are more likely to be physically inactive (Centers for Disease Control and Prevention, 1999). Safety is one dimension of neighbourhood satisfaction but there are other dimensions that may also be of interest in understanding health and health behaviours. These include having a sense of community and neighbourhood connectedness, community living standards and material resources. Neighbourhood deprivation, including measures of unemployment, overcrowding, social instability and cultural needs, has been shown to influence risk factors for cardiovascular disease, after adjustment for age and individual socioeconomic status (Sundquist, Malmstrom & Johansson, 1999). This has led to the suggestion that interventions that aim to increase the standard of living, provide more resources at a local level for primary health care and target health promotion activities at the community level should be beneficial (Sundquist et al., 1999).

A set of items to measure community participation and neighbourhood connectedness was included in the WHA Survey 2 (1999) of the older cohort to examine the importance of neighbourhood satisfaction as a predictor of health outcomes.

### **3.4.2 Source of the items**

#### ***(a) The Australian Living Standards Study, 1991***

In their 1991 survey the Australian Institute of Family Studies (AIFS) aimed to measure "sense of community" with eight items (WHA items: a, b, d, e, g, j, k, l) concerned with neighbourhood satisfaction within a population of Australian parents with at least one child under the age of twenty (Brownlee, 1993). Principal component analysis indicated that these items could be summed to yield a single "sense of community" index for each person. The scale had Cronbach alpha scores of 0.81 for men and 0.85 for women (Brownlee, 1993). However, items d and j had low communality estimates (unpublished results, personal communication).

#### ***(b) The Health and Participation Survey, Adelaide 1997***

The Department of Public Health at the Flinders University of South Australia conducted "The Health and Participation Survey" in the western suburbs of Adelaide in 1997. The survey included seven items that asked what the respondents thought about the neighbourhood in which they lived. The items included six of the eight AIFS items (WHA items: d, e, g, j, k, and l) and a question relating to language barriers.

#### ***(c) The Healthy Communities Survey, Tasmania 1998***

The purpose of this study was to assist the development of policy and services to promote healthy and supportive communities. The study included questions to measure feelings about neighbours and neighbourhood to examine the impact of neighbourhood connectedness on health and well being.



The thirteen items consisted of the eight items from the AIFS survey and five additional items (c, f, h, i, m) based on the theoretical literature concerning the link between social connectedness and health and well being. The response options were: Strongly disagree, Disagree, Neutral, Agree, Strongly agree, Not Applicable. An aggregate measure of neighbourhood satisfaction was created, based on the mean of scores across all items (Department of Health and Human Services, 1999). No other details of the analysis are available. The investigators found that subjective quality of life increased as the sense of neighbourhood satisfaction increased and declined as the sense of neighbourhood satisfaction declined (Department of Health and Human Services, 1999). A secondary analysis of the factor structure of the items for the Healthy Communities Survey data was conducted, with permission, by WHA and appears in Appendix 3.2.

### 3.4.3 The items

The items used in Survey 2 of the older cohort in 1999 are shown in Table 17 and are based on those used in The Healthy Communities Survey. (The minor differences in wording of the items in the four studies described above are shown in Table C in Appendix 3.2.) Participants (women aged 73-78 years) were asked to rate thirteen statements relating to neighbourhood satisfaction using a 5-point response scale (Strongly disagree, Disagree, Neutral, Agree, Strongly agree).

**Table 17 Items used to measure neighbourhood satisfaction in the WHA study**

- 
- a I would be really sorry if I had to move away from the people in my neighbourhood
  - b I have a lot in common with people in my neighbourhood
  - c I generally trust my neighbours to look out for my property
  - d People in my neighbourhood make it a difficult place to live
  - e I am good friends with many people in this neighbourhood
  - f I like living where I live
  - g I have little to do with people in this neighbourhood
  - h My neighbours treat me with respect
  - i Children are safe walking around the neighbourhood during the day
  - j I get involved with most local issues
  - k People in my neighbourhood are very willing to help each other out
  - l If I no longer lived here, hardly anyone around here would notice
  - m It is safe to walk around the neighbourhood at night
-

### 3.4.4 Statistical analysis

#### *Sample*

9501 women from the older WHA cohort completed the full version of Survey 2, which included neighbourhood satisfaction items. Evaluation of neighbourhood satisfaction items was based on data from 9445 women, after the exclusion of women living in nursing homes (n=13) and those whose housing situation was unknown (n=43). The short version of the survey, which was administered by phone, did not include the neighbourhood satisfaction items.

#### *Method*

Responses to the thirteen items were scored from 1 (strongly disagree) to 5 (strongly agree). Scores for the negatively worded items (d, g, l) were recoded so that for all items, a higher score reflected greater satisfaction.

The distribution of responses to the individual items was examined by univariate analyses. Secondly, factor analysis was used to determine whether the empirical data supported a single factor. This procedure was necessary, as the factor structure of the items may be sensitive to the population under study. The rotated factor pattern from principal components analysis (with varimax rotation) was used to check the groupings of the items and the contribution of each item to the factors. Items that are highly inter-related show high loadings on the same factor and items should load strongly on one factor rather than crossload on several factors.

Two equally sized groups were selected at random to allow split sample analysis (group 1: 4723 women, group 2: 4722 women). Factors were extracted and examined, based on complete cases (n=7677, group 1: 3846, group 2: 3831). The factor analysis was repeated, using the pairwise correlations for all cases, rather than using data for complete cases only. The results were compared for consistency across samples and methods.

To summarise the scale, composite factor scores were created based on the information provided by the factor analyses. For each woman with complete data, a composite factor score for neighbourhood satisfaction was calculated as the total of response scores, weighted by the standardised scoring coefficients on that factor from the factor analysis. A second score, the summed score for neighbourhood satisfaction, was calculated as the sum of response scores for the items that loaded together, with unit weighting. Up to 2 missing items were allowed in the calculation of the summed score, with the average of the non-missing data substituted for the missing items. The factor scores and the summed scores were then compared.

It was hypothesised that neighbourhood satisfaction would be positively related to physical (PCS) and mental health (MCS) component scores derived from SF-36, physical activity, social support (DSSI) and duration of living at the same address. Similarly, negative correlations were postulated for CES-D 10 scores, stress scores and certain life events, such as moving house. As a test of validity, a null association was proposed between neighbourhood satisfaction and height, as there are no substantive reasons why the two variables would be related. Associations with these factors were evaluated with the Pearson correlation coefficients, and differences in mean scores with t-tests and ANOVA. Results were used to assess construct

validity. The demographic characteristics, health and social support of women with high and low neighbourhood satisfaction scores were compared. To reduce the effects of inflated type 1 errors due to multiple comparisons and the large sample size, the level of statistical significance was set at 0.005. All analyses were performed using SAS (SAS Institute Inc., 1989).

### **3.4.5 Results**

#### ***Univariate analysis***

The percentage of women agreeing or strongly agreeing with each item is shown in Table 18. The women in the study were generally happy with where they lived, felt they were treated with respect, and had trust in their neighbours to help look out for their property. Women living in non-urban areas were more likely to get involved in local issues and felt they had more in common with people in their neighbourhood than women in urban areas. Less than one third of the women in urban areas felt that it was safe to walk around at night. It is of some concern that almost one quarter of the older women from all areas of residence had little to do with their neighbours and felt that it would not be noticed if they no longer lived there.

**Table 18 Percentage of older women agreeing or strongly agreeing with neighbourhood satisfaction items, by area of residence.**

	Urban (n=3942)	Large rural centre (n=1197)	Small rural centre (n=1456)	Other rural/ Remote (n=2906)
a I would be really sorry if I had to move away from the people in my neighbourhood	61	62	63	67
b I have a lot in common with people in my neighbourhood	54	59	62	65
c I generally trust my neighbours to look out for my property	82	87	87	85
d People in my neighbourhood make it a difficult place to live	5	5	6	4
e I am good friends with many people in this neighbourhood	74	78	82	84
f I like living where I live	89	91	91	91
g I have little to do with people in this neighbourhood	25	24	23	21
h My neighbours treat me with respect	90	91	91	91
i Children are safe walking around the neighbourhood during the day	77	84	85	89
j I get involved with most local issues	26	33	37	46
k People in my neighbourhood are very willing to help each other out	69	77	80	83
l If I no longer lived here, hardly anyone around here would notice	22	20	19	16
m It is safe to walk around the neighbourhood at night	29	34	40	53

### 3.4.6 Factor analysis

Results are given for the whole sample since factor analysis of the two split samples gave similar results.

***Stage 1 results***

Three factors were identified in the factor analysis and they accounted for 57% of the variance in the responses to the thirteen items. Items loading on the three factors for the complete set of responses (n= 7677) are shown in Table 19.

**Table 19 Factor loadings for neighbourhood satisfaction items for women with complete data (n=7677).**

		<b>Factor 1</b>	<b>Factor 2</b>	<b>Factor 3</b>	<b>Communality</b>	<b>% with item missing</b>
h	My neighbours treat me with respect	<b>0.75</b>	0.03	0.23	0.61	2.6
f	I like living where I live	<b>0.74</b>	0.004	0.15	0.57	2.2
c	I generally trust my neighbours to look out for my property	<b>0.72</b>	0.23	0.07	0.58	3.3
a	I would be really sorry if I had to move away from the people in my neighbourhood	<b>0.69</b>	0.23	0.03	0.54	3.7
e	I am good friends with many people in this neighbourhood	<b>0.68</b>	0.40	0.13	0.63	3.7
b	I have a lot in common with people in my neighbourhood	<b>0.65</b>	0.46	0.07	0.65	4.2
k	People in my neighbourhood are very willing to help each other out	<b>0.60</b>	0.37	0.25	0.56	3.8
d	People in my neighbourhood make it a difficult place to live	0.44	0.25	-0.02	0.26	7.5
g	I have little to do with people in this neighbourhood	0.31	0.75	-0.002	0.66	7.6
l	If I no longer lived here, hardly anyone around here would notice	0.16	0.75	-0.02	0.59	5.4
j	I get involved with most local issues	0.12	0.54	0.37	0.44	7.0
m	It is safe to walk around the neighbourhood at night	-0.00	0.11	<b>0.83</b>	0.70	3.2
i	Children are safe walking around the neighbourhood during the day	0.31	-0.03	<b>0.75</b>	0.65	5.1
Eigenvalue		5.09	1.29	1.06		
Cumulative percentage of variance explained		39%	49%	57%		

The results were similar for factors based on pairwise correlations. Items m and i clearly comprise a neighbourhood safety factor. In stage 2 of the analysis, these items were removed and the remaining 11 items were re-analysed to establish whether they supported 1 or 2 factors.

### *Stage 2 results*

Two factors were identified in the factor analysis of the 11 items. Seven of the items (a, b, c, e, f, h and k) loaded together in the analyses of split samples, based on both complete cases and pairwise correlations. The results of factor analysis for the complete set of responses (n= 7801) are shown in Table 20. The seven items that load on factor 1 have good face validity for measuring neighbourhood satisfaction. The remaining four items (d, g, j and l) had higher rates of missing data (5.4% to 7.6%), tended to have low communality scores or did not behave consistently across the various analyses (results not shown, but available upon request). These four items may be measuring other aspects of sense of community, such as involvement or community participation. These results are consistent with the findings from The Australian Institute of Family Studies survey and the Tasmanian Healthy Community Survey (see Appendix 3.2).

**Table 20 Factor loadings for the neighbourhood satisfaction items (excluding the two items relating to safety) for women with complete data (n=7801).**

		<b>Factor 1</b>	<b>Factor 2</b>	<b>Communality</b>	<b>% with item missing</b>
h	My neighbours treat me with respect	<b>0.77</b>	0.09	0.61	2.6
f	I like living where I live	<b>0.76</b>	0.05	0.58	2.2
c	I generally trust my neighbours to look out for my property	<b>0.71</b>	0.27	0.57	3.3
a	I would be really sorry if I had to move away from the people in my neighbourhood	<b>0.68</b>	0.26	0.53	3.7
e	I am good friends with many people in this neighbourhood	<b>0.67</b>	0.43	0.64	3.7
b	I have a lot in common with people in my neighbourhood	<b>0.64</b>	0.48	0.64	4.2

k	People in my neighbourhood are very willing to help each other out	<b>0.63</b>	0.41	0.56	3.8
d	People in my neighbourhood make it a difficult place to live	0.36	0.34	0.24	7.5
l	If I no longer lived here, hardly anyone around here would notice	0.07	<b>0.79</b>	0.63	5.4
g	I have little to do with people in this neighbourhood	0.23	<b>0.79</b>	0.67	7.6
j	I get involved with most local issues	0.22	0.50	0.30	7.0
Eigenvalue		4.9	1.1		
Cumulative percentage of variance explained		44%	54%		

The seven items (a, b, c, e, f, h and k) were subjected to a confirmatory factor analysis using the whole sample. The minimum communality was 0.53 and item-total correlations were high ( $>0.73$ ) for all items. The factor scores and the scores obtained by summing the responses had a correlation of 0.997. There were 8433 women (89%) with factor scores (no missing items) and 9171 women (97%) with summed scores (up to two items missing) for the neighbourhood satisfaction variable.

#### ***Distribution of the summed score***

The summed score ranged from 7 to 35 with women tending to report high levels of neighbourhood satisfaction. The median score was 28, the first quartile was 25 and the third quartile was 30. The mean score was 27.6, standard deviation 4.5, skewness  $-0.8$  and kurtosis 2.5.

#### ***Validity checks***

Neighbourhood satisfaction scores were positively but weakly correlated with PCS ( $r=0.07$ ,  $p<0.0001$ ) and MCS ( $r=0.151$ ,  $p<0.0001$ ); negatively correlated with mean stress ( $r=-0.135$ ,  $p<0.0001$ ); not significantly correlated with height ( $r = -0.0007$ ,  $p=0.95$ ) as hypothesised (Table 20). Correlation with DSSI was 0.33 ( $p<0.0001$ ) (Table 21).

**Table 21 Construct validity of the summed neighbourhood satisfaction score for 9171 women aged 73-78 years.**



<b>Variable</b>	<b>Correlation with Neighbourhood Satisfaction Score</b>	<b>p-value</b>
SF-36 Physical Health Component score	0.07	< 0.0001
SF-36 Mental Health Component score	0.15	< 0.0001
Stress score	-0.14	< 0.0001
DSSI – Social interaction and satisfaction score	0.33	< 0.0001
Height	Less than -0.01	0.95

*Note: Sample size varies from 8302 to 9089 due to missing data*

Women who had moved house in the previous three years reported lower levels of neighbourhood satisfaction (Table 22). Physical activity was also associated with neighbourhood satisfaction. Women who were sedentary or had low levels of physical activity had a lower mean satisfaction score than women who had moderate or high levels of physical activity (Table 22).

**Table 22 Differences in mean neighbourhood satisfaction scores by migration and amount of exercise.**

	<b>Mean</b>	<b>95% CI</b>	<b>p-value</b>
<i>Moved house in last 3 years</i>			<0.001
No	27.7	(27.6,27.8)	
Yes	26.7	(26.4,27.0)	
<i>Physical activity</i>			<0.001
None or sedentary	27.2	(27.0,27.4)	
Low	27.6	(27.5,27.8)	
Moderate	28.0	(27.8,28.2)	
High	28.0	(27.8,28.2)	

*Note: means not significantly different from one another are joined by a line*

### **3.4.7 Characteristics of women with high and low neighbourhood satisfaction scores**

There were 764 women (8.3%) who had the maximum neighbourhood satisfaction score of 35, defined as the 'high' neighbourhood satisfaction group. A similar percentage of women scored 21 or less for neighbourhood satisfaction (n=683, 7.5%). A score of 21 or less is equivalent to answering in a

neutral way or expressing dissatisfaction to all seven items (defined as the 'low' neighbourhood satisfaction group). For comparison, two other groups were defined, according to whether the score was below the median of 28 or not.

The characteristics of women in these four groups are shown in Table 23. Women who were less satisfied with their interaction with their neighbours and their neighbourhood tended to have poorer health, to live in urban areas and to have higher use of, but poorer access to, health services. Less satisfied women were also less able to manage on their income. Women who were more satisfied with their neighbours and neighbourhood tended to have lived at their present address for a longer period of time, were involved in volunteer work, were more satisfied with their physical ability, had fewer visits to general practitioners, had higher levels of social support, and higher physical activity scores. There were no significant differences between the groups of women in the use of services such as nursing care and food services.

**Table 23 Characteristics of older women by summed neighbourhood satisfaction score**

	Neighbourhood satisfaction score (nss)			
	Low: (nss ≤21) %	Below median: (21 <nss <28) %	Median or above: (28 ≤ nss <35) %	High: (nss = 35) %
Number of women	683	3507	4217	764
<i>Area of residence *</i>				
Urban	48	46	38	35
Large rural	12	13	12	14
Small rural	12	15	16	14
Other rural / remote	28	26	34	37
Total	100	100	100	100
<i>Marital status *</i>				
Married/defacto	48	53	52	47
Widowed	42	38	42	46
Separated/divorced	8	6	4	3
Never married	2	3	3	3
Total	100	100	100	100
<i>Living arrangements</i>				
Live alone (%) *	41	39	42	47
<i>Years in present home *</i>				
Less than one	7	7	4	6
2-5	18	15	12	10
6-10	19	17	15	15
11-20	23	27	26	25
21-30	11	11	15	12
31-40	9	9	11	10
41+	12	14	18	21
Total	100	100	100	100
<i>Manage on income *</i>				
Impossible/difficult most of the time	12	5	5	5
Difficult some of the time	24	21	18	19
Not too bad	50	53	52	46

Easy	14	21	25	29
<b>Total</b>	100	100	100	100
<i>Do voluntary work*</i>				
Daily/weekly	14	19	23	27
Monthly	10	15	21	22
Less than monthly	7	9	10	11
Not at all	69	57	45	41
<b>Total</b>	100	100	100	100
<i>Satisfaction with physical ability *</i>				
Completely satisfied	18	15	17	27
Very satisfied	24	34	36	32
Somewhat satisfied	30	33	31	27
Somewhat dissatisfied	17	12	11	9
Very/completely dissatisfied	11	6	5	5
<b>Total</b>	100	100	100	100

*table continues*

	<b>Neighbourhood satisfaction score (nss)</b>			
	<b>Low:</b> (nss ≤21) %	<b>Below median:</b> (21 <nss <28) %	<b>Median or above:</b> (28 ≤ nss <35) %	<b>High:</b> (nss = 35) %
Number of women	683	3507	4217	764
<i>Need help with daily tasks</i>				
% yes *	16	9	10	9
<i>Use of services</i>				
Food services	4	3	3	2
Nurses	12	9	8	10
<i>GP visits previous year *</i>				
None	2	2	2	1
1 or 2	12	13	13	13
3 or 4	25	27	28	30
5-8	24	29	29	28
9-12	16	15	15	16
13 or more	21	12	13	12
<b>Total</b>	100	100	100	100

<i>Specialist visit in previous year</i>	51	47	47	46
<i>Prescribed medications</i>				
<b>None</b>	11	12	13	13
One	15	17	17	16
Two	18	19	18	20
Three	16	17	16	16
Four	14	14	14	15
Five or more	26	20	21	20
Total	100	100	100	100
Medication to sleep (%) p=.0076	19	14	14	15
Medication for nerves (%) *	12	7	8	9
Medication for depression (%)	7	5	4	4
Medication for chronic illness (%)	28	24	23	21
<i>Access to medical specialists *</i>				
Excellent	23	21	25	35
Very good	29	37	37	33
Good	31	30	29	23
Fair	12	9	7	7
Poor	5	3	2	2
Total	100	100	100	100
<i>Access to hospital *</i>				
Excellent	26	23	29	42
Very good	31	35	37	31
Good	27	31	26	20
Fair	11	8	7	5
Poor	5	3	2	2
<b>Total</b>	100	100	100	100

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\* associated with neighbourhood satisfaction score, chi-square test,  $p < 0.005$

### 3.4.8 Discussion

Seven of the thirteen items included in Survey 2 of the older cohort appear to produce a valid measure of neighbourhood satisfaction. The dimension of satisfaction being measured is the sense of community and neighbourhood connectedness, rather than a measure of satisfaction with living standards, community resources or safety. The two items relating to neighbourhood safety and the remaining four items which did not load strongly with these items may be used in analysis of other aspects of neighbourhood involvement.

Among the older cohort of WHA, neighbourhood satisfaction was associated with demographic characteristics, health and social support. The finding that there were no significant differences in use of services such as nursing care and food services among these groups of women, suggests that there is an unmet need for support services for some women in poorer health who have little interaction with their community. The direct association between physical health and access to medical services also suggests that women in poor health with lower levels of community participation have more difficulty getting the medical services that they require. These hypotheses need to be explored further in multivariate analysis.

The importance of features of social life and community participation, such as neighbourhood satisfaction, as predictors of health outcomes will be explored in further research.

### 3.4.9 References

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Yen IH, Kaplan GA. Neighborhood social environment and risk of death: multilevel evidence from the Alameda County Study. *American Journal of Epidemiology* 1999; 149: 898-907.

### **3.5 OPTIMISM AND HARDINESS**

Nadine Smith, Christina Lee, Anne Young

Nadine Smith is examining these scales as part of the work towards the minor thesis of her Master of Medical Statistics degree. The analysis has followed the methodology for scale validation within the WHA project (Appendix 3.1). A detailed report of work in progress appears in Section 1.2.4 of this report.

### **3.6 PERCEIVED STRESS**

Jennifer Powers, Jean Ball, Sandra Bell

#### **3.6.1 Development and format of the stress questions**

The stress questions were first used in 1995 in one of the pilot surveys of the young cohort. The questions included items in specific life domains: own health, health of other family members, work/employment, living arrangements, study, money, relationship with parents, relationship with partner/spouse, relationships with children, relationship with other family members, relationships with boyfriends, and relationships with girlfriends. The items were developed on the basis of discussions with key informants, including psychologists, sociologists, and women of all ages. A final item,

'anything else', provided an opportunity for respondents to specify other life domains that had added to their stress levels in the last 12 months. Table 24 shows the questions that were asked of the three age cohorts in Survey 1.



**Table 24 Questions asked about stress of each of the cohorts in Survey 1 in 1996.**

Over the LAST 12 months, how stressed have you felt about the following areas of your life:  
*(Circle one number on each line)*

	Young	Mid	Old
Own health	a	a	a
Health of other family members	b	b	b
Work/Employment	c	c	
Living arrangements	d	d	c
Study	e	e	
Money	f	f	d
Relationship with parents	g	g	
Relationship with partner/spouse	h	h	e
Relationship with other family members	i	j	g
Relationships with boyfriends	j		
Relationships with girlfriends	k		
Relationship with children		i	f
Anything else ( <i>Please specify on line</i> )	l	k	h

Each item was rated on a scale from 1 to 6: not applicable; not at all stressed; somewhat stressed; moderately stressed; very stressed; extremely stressed.

### 3.6.2 Calculating mean stress

Each item was re-coded 0 for ‘not applicable’ or ‘not at all stressed’; 1 for ‘somewhat stressed’; 2 for ‘moderately stressed’; 3 for ‘very stressed’ and 4 for ‘extremely stressed’. The scores for all non-missing items were averaged to give a mean perceived stress score with a possible range of 0 to 4. Participants tended to use the ‘anything else’ item as a means of providing more information on items already marked and so responses to the ‘anything else’ item were excluded from the calculation of mean stress (see Report 15).

There was much discussion about whether it was valid to assign 0 to 'not applicable' and 'not at all stressed'. Is the meaning of 'not applicable' and 'not at all stressed' the same or different? Is the overall effect the same?

As part of her Honours thesis, Sandra Bell investigated the effect of conceptualising the mean stress score across the whole scale, or only those items that assess areas that are relevant to the respondent. This was done by comparing results when 'not applicable' was set to zero (equivalent to 'not at all stressed'), or set to missing (equivalent to no answer to this item). The analysis was undertaken on data provided by 85 female University of Newcastle students, aged 18 to 23. Mean stress scores were calculated in two ways for all participants with no missing items, as a "whole" mean score across the entire scale and as a "partial" mean stress score across only those items which were applicable. For example, if one item was answered 'not applicable', the 'whole' mean stress score was calculated for the 11 items, with 'not applicable' set to zero (i.e. equivalent to 'not at all stressed'). The 'partial' mean stress score was calculated using the 10 items answered other than 'not applicable'.

The 'whole' mean stress and 'partial' mean stress variables were correlated with mental health and other stress scales (Tables 25 and 26). The mental health variables measured were the General Health Questionnaire 12-item version (Goldberg, 1972) and a ten-item version of the Center for Epidemiologic Studies Depression Scale (CESD-10) (Andresen et al., 1994). The other scales were the Daily Hassles Scale (Revised) – DHS(R) (Holm & Holroyd, 1992), the life events scale from Young Survey 1, and the Feminine Gender Role Stress Scale (FGRS) (Gillespie & Eisler, 1992)..

**Table 25 Correlations between mental health variables and mean stress scores among a sample of 85 female University students (Bell, 1999)\***

Variable	'Whole' Mean Stress	'Partial' Mean Stress
GHQ	0.425	0.475
CESD-10	0.483	0.508

\*All correlations  $p < .001$ .

**Table 26 Correlations between other stress scales and mean stress scores among a sample of 85 female University students (Bell, 1999)**

Variable	'Whole' Mean Stress	'Partial' Mean Stress
DHS(R)	0.400***	0.424***
DHS(R) Mean Hassle Intensity	<b>0.599***</b>	<b>0.653***</b>
Life Events	0.505***	0.483***
FGRS	0.339*	0.375***

\*\*\* $p < .001$ , \* $p < .05$ .

Correlations with mental health and other stress scales were similar for ‘whole’ mean stress and ‘partial’ mean stress scores which were highly correlated with each other ( $r=.97$ ) It was decided to use the “whole” scale and to treat ‘not applicable’ as equivalent to ‘not at all’.

There was some discussion as to whether weights of 1, 2, 3 and 4 were appropriate for the verbal categories of somewhat, moderately, very, and extremely stressed. For example, it was questioned whether being somewhat stressed about four categories was equivalent to being extremely stressed about one category. Two scoring systems were tried with Survey 1 data. The first (Weighted Mean A) was the mean of scores of 0 for ‘not applicable’ or ‘not stressed’, 1 for ‘somewhat stressed’ or ‘moderately stressed’ and 4 for ‘very stressed’ or ‘extremely stressed’. The second (Weighted Mean B) was the mean of scores of 0 for ‘not applicable’, ‘not stressed’, ‘somewhat stressed’ or ‘moderately stressed’ and 1 for ‘very stressed’ or ‘extremely stressed’. In all cases, the mean stress score was calculated for all non-missing items and set to missing if half or more of the items were missing (i.e. 5 missing items for the younger and mid-age cohorts and 4 missing items for the older cohort).

The correlation was very high between ‘whole’ mean stress and Weighted Mean A (.97 for the younger and the mid-age cohorts, .96 for the older cohort). The correlations between ‘whole’ mean stress and Weighted Mean B were somewhat lower, .85 for the younger and mid-age cohorts, .79 for the older cohort. The next step was to compare scores on ‘whole’ mean stress and Weighted Mean A. Bland-Altman plots of the difference between the two scores against the average of the two scores (Figure 7) show that a small proportion of women with very high stress would have scores more than 0.5 higher using the Weighted Mean A score instead of the ‘whole’ mean stress score ( $n=16$  in the younger cohort). Similarly, a small proportion of women with low stress would have scores 0.5 lower using the Weighted Mean A score instead of the ‘whole’ mean stress score ( $n=65$  in the younger cohort). The bulk of the Weighted Mean A and ‘whole’ mean stress scores were within a range of  $\pm 0.5$  of each other. Hence it seems reasonable to continue to use the ‘whole’ mean stress variable, which has behaved well in analyses to date.



0                      2                      4  
Average of 'whole' mean stress and Weighted Mean A

**Figure 7 Bland-Altman plot of difference between Weighted Mean A and 'whole' mean stress against the average of the two scores, for Young Survey 1 (letters represent numbers of cases; A=1, B=2 ..... z=26+).**

### **3.6.3 Distribution of the mean stress score**

The distributions of the mean stress score for the three cohorts at Survey 1 are shown in Table 27. This score becomes progressively more skewed with each age cohort and probably needs to be transformed in the old cohort.

**Table 27 Distribution of the mean stress score in three cohorts at Survey 1**

	<b>Young N=14779</b>	<b>Mid N=14100</b>	<b>Old N=12939</b>
Mean	0.89	0.68	0.37
Standard deviation	0.57	0.53	0.44
Median	0.82	0.60	0.29
Q1 and Q3	0.45; 1.18	0.30; 1.00	0; 0.57
Skewness	0.9	1.2	2.3
Kurtosis	0.9	1.8	5.4
Missing	0.5%	0.7%	3.2%

### **3.6.4 Use of the stress items in published WHA papers**

Mean stress score has been used in the following published WHA papers.

Dobson A, Brown W, Ball J, Powers J & McFadden M. Women drivers' behaviour, socio-demographic characteristics and accidents. *Accident Analysis and Prevention*, 1999; 31: 525-535.

Brown WJ, Young AF & Byles JE. Tyranny of distance? The health of mid-age women living in five geographical areas of Australia. *Australian Journal of Rural Health*, 1999; 7: 148-154.

Brown WJ, Dobson AJ, Bryson L & Byles JE. Women's Health Australia: on the progress of the main cohort studies. *Journal of Women's Health & Gender-based Medicine*, 1999; 8: 681-688. (This paper also identified the main causes of stress).

Mishra GD, Dobson AJ & Schofield MJ. Cigarette smoking, menstrual symptoms and miscarriage among young women. *Australian and New Zealand Journal of Public Health*, 2000; 24: 413-420.

The stress questions have been used to construct a binary variable to estimate the prevalence of stress. Women who responded 'very stressed' or 'extremely stressed' to three or more items were classified as Very stressed. Individual items have also been classified as Stressed (very or extremely stressed) or Not stressed (not applicable, not at all stressed, somewhat or moderately stressed). These definitions have been used in the following WHA publications.

Brown W, Ball K & Powers J. Is life a party for young women? *The ACHPER Healthy Lifestyles Journal*, 1998; 45: 21-26.

Bryson L. The Women's Health Australia Project and policy development. *Australian Journal of Primary Health*, 1998; 4: 59-71.

Byles JE, Feldman S & Mishra G. For richer, for poorer, in sickness and in health: older widowed women's health, relationships and financial security. *Women and Health*, 1999; 29: 15-30.

### **3.6.5 References**

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## **3.7 MEASURING REMOTENESS**

Anne Young, Rachel Aylward, Errol Bamford

The measurement of remoteness is receiving a great deal of attention among researchers and government departments at present. In particular, there is a strong move in favour of the use of Accessibility/Remoteness Index of Australia (ARIA) scores rather than the previous RRMA system. Definitions of remoteness and the classification of areas have implications for health funding and research, and it is a general principle of this project that we should use the most up-to-date measures and definitions possible. Anne Young has been working with staff of National Key Centre for Social Applications of Geographical Information Systems (GISCA) in examining the implications of using ARIA scores and/or geocoding all localities with our databases. A summary of a meeting held recently to discuss these issues and the way that WHA might implement the new measures is included in Appendix 3.3.

## **4 MAINTENANCE OF COHORTS**

### **4.1 GENERAL PROCEDURES**

General procedures for cohort maintenance have been outlined in previous Reports and continue to be followed. Requests for secondary contacts (“someone who will always know where you are if you have moved”) are made on all consent forms, and these are the first line of inquiry if letters are returned to sender and telephone contact is unsuccessful. We have also begun requesting email addresses but are as yet uncertain of how permanent email addresses are likely to be and thus how useful they may be in the longer term. Efforts to track participants through electronic searches of email lists have been unsuccessful. These provide all email addresses that match a particular name, but there is no way of checking an individual’s sex, age or location (many young women, for example, have Hotmail or Yahoo addresses which are not specifically Australian, and they cannot be distinguished from women of the same name living anywhere in the world). Trials with known individuals and known email addresses show that at least some legitimate email addresses are not located through these searches. For example, none of Christina Lee’s three email addresses could be found. Staff continue to use Electronic White Pages and Electoral Rolls in attempts to locate participants with whom we have otherwise lost contact. As a general principle, we continue to track women who are “lost”, many of whom are travelling overseas and will return to Australia eventually.

## **4.2 USE OF MEDICARE END DATES**

An ongoing problem for the research team is establishing definitely whether a participant has died. It is potentially distressing for family members if surveys are sent to women who have died, and it is also a waste of staff time if efforts are put into tracking non-respondents who have died. Report 14 included a report on the use of National Death Index. This has proved a useful way of identifying members of the older cohort who have died, but it is not entirely up-to-date and matching is not perfect. In particular, it relies on the periodic collation of state-based records and thus lags several months behinds death notifications. Matches depend on the woman’s name and date of birth being recorded accurately on both databases, and inaccuracies may occur particularly with the older women (e.g. nobody may be entirely sure of a deceased woman’s year of birth). The practicalities and expense of running our entire data base of names and addresses against the NDI data base also mean that it is only feasible to do this with the older cohort.

The Health Insurance Commission will record an “end date” in an individual’s Medicare records if they become aware that that person is no longer eligible for Medicare benefits. This is normally because they have been notified of the person’s death but also encompasses permanent emigration or a change in Australian residency status. HIC do not record the reason for the end date. The participants were originally selected from the HIC database, and the HIC maintain a record of each participant’s Medicare PIN. Thus, it is possible for them to determine exactly which of our participants have been assigned end dates. The primary use of end dates for the research team is in analysis of the use of Medicare services. Women who were not eligible for services at the time of interest can be excluded from analysis (e.g. if a woman died or emigrated during 1999, her total use of Medicare services for 1999 cannot be compared with other women who were eligible for the full year).

This report examines the effectiveness of using the end dates to establish that participants have died. The use of unique Medicare PINs has a definite advantage over the NDI, which matches by name, address and date of birth, none of which is unique. There are also three main disadvantages: an end date assigned to a Medicare record does not necessarily mean that a woman has died, simply that HIC has been notified that she is no longer eligible;



we have access to end dates only for those women who have consented for us to access their Medicare records; and HIC records are not automatically linked to death registers, so that deaths are not recorded unless HIC are specifically notified.

Thus, with the National Death Index we can be sure that someone has died, but not necessarily that it was a WHA participant; with HIC end dates we can be sure that the WHA participant is no longer eligible for Medicare, but not necessarily that she has died.

In January 2001, HIC supplied us with a list of end dates and study ID numbers of those women who had consented for us to access their Medicare data and who had an end date. Lyn Adamson conducted an audit of our records, with the following results.

A total of 266 women, comprising 18 Young women, 27 Mid age women and 221 in the Older age group, had given consent and been issued end dates. The individual consent forms and participant database were checked for each participant with the following findings.

#### **4.2.1 Young age group**

Of the 18 end dated, 3 were already known to have died. 1 participant had advised us she was living overseas, and 2 had not had any contact with the project since giving permission to access their HIC data. The remaining 12 had had contact with the project in varying forms after their end date, including completing surveys, and advising address and name changes. A preliminary investigation showed that 2 of the 12 had had Medicare claims paid after the recorded end date.

#### **4.2.2 Mid age group**

Of the 27 mid-age women who were end dated 17 (63%) were already known to have died. Of the remaining 10, all of whom were sent Mid 3 surveys, their status will be checked based on whether a survey is returned or not.

#### **4.2.3 Older age group**

Of the 221 notified, 182 (82%) were known to have died. 3 had had invalid birthdates when first selected and were ineligible for the project. The current status of the remaining 36 remains unknown. The consent forms have been annotated by checking the white pages and electoral roll and will be compared with the National Death Index when it is next run for the project, in December 2001. Of the 36, 25 had completed Survey 2 in 1999. At that time, two-thirds had rated their health as “fair” or “poor”.

#### **4.2.4 Conclusion**

Medicare end dates are not good indicators of death among the youngest cohort. The very low death rate in this age group means that proportionately more end dates relate to notified absences overseas, or result from data errors. End dates are better indicators of death in the mid-age and older cohorts, but do not appear to provide information beyond what we are already able to obtain from other sources. While a small proportion of women are newly identified as possibly deceased, it is also possible that these women are overseas or have been identified in error, so they should not be removed from the database without independent verification.

The Medicare end dates continue to be extremely useful for their main purpose, which is improving the accuracy of analysis linking Medicare claims data with self-report data.

### **5 DATA LINKAGE**

#### **5.1 CONSENT TO ACCESS MEDICARE AND DVA DATA**

Women who participate in WHA have been invited on two previous occasions to give us an additional consent, allowing us to obtain unit records from the Health Insurance Commission (HIC), who hold records of individual Medicare and Department of Veterans' Affairs (DVA) health service claims, and to link their individual data with survey data from WHA. Legal protection means that HIC may not provide information at an individual level to any third party without signed consent of the person concerned. On the previous occasions, WHA were required to place a time limit on the consent requested, and consent for those who had previously agreed will expire at the end of 2001.

Because of this, it is necessary to approach all women who are still participating in WHA, during 2001, and invite them to consent to further data linkage. Requests for consent will be mailed with the annual newsletter in the second half of June. Copies of the materials, which are currently in the final stages of proof reading and printing, will appear in Report 17 (December 2001).

WHA staff have been working closely with staff of the Health Insurance Commission as well as staff from the Department for Veterans' Affairs, which handles health insurance for war veterans and eligible family members. Changes to procedures at HIC have meant that this time we are able to ask women to consent not only to access to the Medicare claims data but also to other administrative data including changes of address and "end dates" (see Section 4.2). We are also able to invite the participants to consent to access to Pharmaceutical Benefits Service (PBS) and Repatriation Pharmaceutical Benefits Service (RPBS) records which will give data on the majority of prescription medications.

On previous occasions, we have asked women to indicate their consent by signing and returning a form; those who chose not to consent did not need to respond at all, but a small number chose to contact us directly to inform us that they did not wish to consent to our accessing HIC data. Thus, we have three groups of women participating in the WHA survey: women who have consented to linkage on one or other of two previous occasions (53%); women who have chosen not to respond to previous requests for linkage (45%); and women who have informed us that they definitely did not want to consent to our access to HIC data (2%). This last group of women will be treated differently from the others.

### **5.1.1 Procedure for Seeking Consents**

The procedure outlined below is based on the modified Dillman method used for all WHA surveys and substudies.

#### ***Step 1 Initial request. Target mailout date 18 June 2001***

An initial request for updated consent will be included in the annual newsletter. The newsletter will include one page, headed “Medicare Information Update”, which outlines our request for renewed consent. Text for this page, based on letters and brochures sent on previous occasions following the necessary approvals, has been approved by the various ethics committees (see below). The rest of the newsletter will contain information about other aspects of WHA. Included with the newsletter will be a consent form based on those previously approved. The mailout package will also include a prepaid return envelope for the consent form, and a change-of-details prepaid card which is routinely included in all mailouts.

A small number of participants, as indicated above, have informed us that they definitely do not consent to our accessing their HIC data, although they are willing to participate in WHA. These women will receive a package containing the newsletter and change-of-details card, and a letter explaining that our records indicate that they had previously refused consent. This letter invites them to contact WHA on a Freecall number if they have changed their minds and would now like to receive a consent form. This group of women will not be included in any of the subsequent steps.

#### ***Step 2 Reminder Card to Non-Respondents. Target mailout date 16 July 2001***

Four weeks after mailing the newsletter and consent form, women who have not returned the consent form (and have not ever explicitly refused consent) will be sent a reminder card. This card asks them to return their consent form or to contact the WHA office if they have mislaid it and would like another.

#### ***Step 3 Second Mailout to Non-Respondents. Target mailout date 13 August 2001***

Four weeks after the reminder card (eight weeks after the initial mailout) women who have still not responded (and have never explicitly refused consent) will be sent a follow-up letter and a second consent form. There are two versions of the reminder letter, one to be sent to women who previously gave consent, and the other to women who have not previously consented (but have never refused consent).

***Step 4 Phone Follow-up of Non-Respondents (Previous Consenters Only). Target start date 17 September 2001.***

Four weeks after the second mailout, those who had previously consented to Medicare data access but have not responded to the present request will be identified. At this stage, all non-respondents will have received an initial invitation, a reminder and a second invitation. Women who had not previously consented have thus had three opportunities to change their minds. It seems unlikely that further contacts with these women will produce positive results, and it is possible that they may perceive further requests as harassment. Those who did previously give consent (and have not explicitly withdrawn it) are in a somewhat different category. It is difficult to guess why a person who had previously given consent might not return a second consent form, and we propose telephoning this group in order to determine whether they have overlooked the request; decided not to consent; have changed their address and not received the written communications; or have other circumstances. As a final step, we plan to telephone all women in this category and invite them one final time to consent to data linkage.

### 5.1.2 Permissions and Approvals

It is necessary to obtain approval from HIC, DVA, DHAC, and the University of Newcastle's Human Research Ethics Committee, and draft materials were sent to all these organizations in February 2001. Some minor changes were made in response to a variety of concerns, and revised materials were circulated in April 2001. Final approval has now been obtained from all bodies. Materials are currently in production and copies of all items will appear in the December 2001 report.

### 5.1.3 Cost estimates

Table 28 provides rough estimates, based on conservative estimates of response rates, of the costs of each phase of the consent procedure.

**Table 28 Approximate cost of obtaining Medicare/DVA consent**

<b>Item</b>	<b>Cost per unit</b>	<b>Est number</b>	<b>Total</b>
Newsletter and consent form layout and print, change of address card, return envelope, pack envelopes		40,000	\$17,000
Postage	0.45	40,000	\$18,000
Reminders print pack and post	1.40	30,000	\$15,000
Reminder letter and second consent form print pack and post	1.60	25,000	\$10,000
Return postage	0.45	25,000	\$11,000
Telephone follow-up (previous consenters only)	5.00	5,000	\$25,000
<b>TOTAL</b>			<b>\$96,000</b>

This is a major component of our budget and is considerably more costly than the normal newsletter mailouts, which do not include return postage or tracking of non-respondents. This additional cost is offset to some degree by the expectation that the task of tracking and phoning for the main survey will be considerably simpler this year than in 2000. Women in the mid-age cohort are substantially less likely to have moved house, and seem

generally easier to track, than those in the young cohort. Early indications are that the response rate to the Mid 3 survey is higher, and surveys returned more quickly, than for Young 2 in 2000.

## 5.2 SUMMARY OF INDIVIDUAL CLAIMS DATA FROM MEDICARE AND DVA (1997-1999)

In May 2001, the HIC extracted details of all services provided during 1997-1999 to women who consented for their information to be released to the research team ("consenters"). The file contained the following information, for each claim for each consenter:

- ALSWH study number of the consenter (to enable linkage to the ALSWH database);
- postcode of residence;
- the date of the service;
- whether the service was provided in hospital;
- the broad type of service category;
- the specific item number;
- the amount charged by the provider;
- the Medicare benefit for the service (the 'rebate');
- the method of payment;
- a unique number for the provider of the service;
- the age group, sex and state of residence of the provider;
- major specialty of the provider;
- a unique number for the provider who referred the patient (if applicable);
- date of referral (if applicable);
- whether Medicare or the DVA paid for the service.

Three files were received which in total contained 1,056,217 records of services provided through Medicare and the DVA to the 22,633 women (6219 young, 8883 mid-age, 7531 older) who consented for their information to be released. Of the services, 969,601 (92%) were provided outside hospital (services provided in hospital to public patients are not processed by the HIC). The HIC also provided three files with the ID numbers of consenters who made no claims through Medicare or the DVA for services in each calendar year (Table 29).

**Table 29 Number of women receiving services each year and number of services provided to the 22,633 women who gave consent for their HIC data to be released.**

	Year		
	1997	1998	1999
		<b>NUMBER OF WOMEN</b>	
Received services	21724	21652	21551
Received no services	909	981	1082
<b>Total number of women</b>	<b>22633</b>	<b>22633</b>	<b>22633</b>
		<b>NUMBER OF SERVICES</b>	
Outside hospital	311282	323695	334624
In-hospital	27739	28530	30347
<b>Total number of services</b>	<b>339021</b>	<b>352225</b>	<b>364971</b>
% of services outside hospital funded by DVA	4%	5%	6%
Number of GP attendances	145320	146473	147518

The HIC also provided a file with the Study ID numbers for women who had consented and had an end-date in the HIC enrolment file. An end-date for a woman indicates that the HIC has been notified that the woman is not eligible for Medicare benefits, either because they are deceased or out of the country. A report on the usefulness of that file appears at Section 4.2 of this report. The status of the women who gave consent for the release of their HIC data but made no claims (see Table 29) is also being checked. This group will include deceased participants. Analyses of the HIC data are ongoing and further results will be presented in later reports.

## **6 DATA ANALYSIS**

### **6.1 PROCEDURES FOR DATA CHECKING AND RELATED QUALITY ASSURANCE ACTIVITIES**



Procedures for the checking of raw data remain unchanged, and the accuracy of scanned data is extremely high. Staff are continuing to carry out and document strategies for recoding and imputing missing values.

## **6.2 DATA COLLECTION AND ENTRY, DATA BOOKS, DATA DICTIONARIES**

### **6.2.1 Data dictionary**

The data dictionary is a continually updated set of Access databases that describes and defines every item in every main survey, including its precise wording and response options, its sources, and its relationship to similar items in other main surveys. It also includes all created variables, i.e. those which are derived from combination or re-coding of items in the surveys. It is maintained in the Newcastle office and archived to SSSA along with the databases. Sandra Bell has taken primary responsibility for the data dictionary, and has produced the following brief description of its format.

The dictionary contains several parts:

1. Category – Broad classification of the item, allocated for simplicity of retrieval.
2. Index number – Unique number assigned to each item.
3. Access level – There are two access levels, Level A and Level B. Level A items are not available except as necessary by the data manager, in order to maintain individual confidentiality. Level B items are available to all approved researchers.
4. Description – Two types of items can be described. The first is of a survey item and the description is identical to the wording of the hard copy survey. The second type is created items and contains the full name of the created item.
5. Source – This contains a reference to an article or other source for the item. If the item was created by WHA, this is noted.
6. Responses – Scoring for the responses is given in the left-hand column, and the responses they represent are presented in the right hand column.
7. The item / variable name section has 3 main components:
  - a) The left-hand column indicates the survey in which the item can be found.
  - b) The next 4 columns are “exact item” columns (item and variable name) and “similar item” columns (item and variable name), where:
    - The “exact item” columns list survey or created items and variables from other surveys that are exactly the same, and have the same response options. The variable name is the unique notation for the item within a survey;
    - The “similar item” columns list survey or created items and variables from other surveys that differ in either the item wording, or in responses.
  - c) The “notes” column denotes whether the items are dissimilar in the question, the responses or both. When there is an entry in the “notes” column, but not in the “similar item” column, this means that the item was not dissimilar enough to have its own separate entry.

8. Cross reference – This section indicates the index numbers of records that are related to the current record. In brackets after the index numbers is either the survey which the related item is from, or the survey item number, whichever is more appropriate.
9. Used in created item/s – This section has the name and abbreviation of any items created from the current survey item.
10. Scoring of created item – Details how the created variables are formulated from the survey variables.
11. Notes – This section corresponds to the earlier notes section – here the question or response is expanded to describe the differences between the current item and the similar item.

### 6.3 USE OF DATA BY OTHER RESEARCHERS

The databases are a valuable national resource and we are continuing a policy of active collaboration with researchers outside the Women's Health Australia group. Reports on projects which are currently in progress appear in Section 1.2 of this report.

Considerable time and effort is spent in discussion and communication with other researchers before any specific project actually commences. Table 30 below lists potential collaborators with whom negotiations are currently in progress.

**Table 30 Potential collaborators**

Researcher	Institution	Research Topic	Cohorts	Current Status of project
Dr Ruth McNair	Dept of General Practice, University of Melbourne	Lesbians' health, health service use, health behaviours	Y2, M2	Sample sizes have been identified; Dr McNair has formed a research group in Melbourne and is seeking funding for the analysis
Dr Angela Taft	Centre for the Study of Mothers' and Children's Health, La Trobe University	Young women, reproductive health and intimate partner abuse	Y1, Y2	Dr Taft has developed and circulated a detailed proposal for analysis; WHA group are supportive of the project; Dr Taft is seeking funding for the analysis.
Dr Jane Fisher & Ms Heather McKay	Key Centre for Women's Health, University of Melbourne	Childlessness	Y1, Y2	This would form the basis for Heather's PhD, jointly supervised by Jane Fisher and Christina Lee from WHA. The intention is to examine the stability of intentions to remain childless and the extent to which women construe these intentions as caused by infertility choice, or circumstance. Jane and Heather visited Newcastle in January, and funding for a substudy is currently being sought.

Researcher	Institution	Research Topic	Cohorts	Current Status of project
Dr Barbara Pocock	Department of Social Inquiry, University of Adelaide	Work, health and well-being	Y1, Y2, M1, M2	A quantitative overview of the connection between paid work (and hours of work) and well-being for inclusion in a book on work in women's lives. Memorandum of Understanding has been signed, Research Assistant appointed, databases in the process of being prepared for analysis.
Ms Beverley Lloyd	Department of Public Health & Community Medicine, University of Sydney	Employment, motherhood & health among young women	Y1, Y2	A planned PhD project would involve a qualitative study of a subgroup of Young women to explore their own understandings of health in the context of their lives. Preliminary discussion is underway and a visit to Newcastle is planned.
<i>table continues</i> Professor Anne Edwards	Vice Chancellor, Flinders University of South Australia	Flinders Women's Health Research Group	All	Professor Edwards is drawing together a group of researchers to negotiate with WHA on the development of projects which use the data.
Dr Caroline Bolton-Smith	MRC Human Nutrition Research, Cambridge, UK	Nutritional predictors of obesity	M2	Early stages of plan to compare UK and Australian women at mid-life on dietary predictors of obesity. Currently exchanging questionnaires and exploring avenues for funding

## 6.4 AD HOC DATA ANALYSIS FOR THE DEPARTMENT OF HEALTH AND AGED CARE

### 6.4.1 Missing Data from ATSI and Other Respondents

The following brief report was prepared by Jennifer Powers and Christina Lee for Andrew Benson and Carey Smith in the Office of Aboriginal and Torres Strait Islander Health (OATSIH).

Women’s Health Australia (the Australian Longitudinal Study on Women’s Health) surveys 40,000 women across Australia to assess health, health care service use etc. The sample was selected from the Medicare database, with deliberate oversampling of women in rural and remote areas. There was no deliberate effort to include or exclude indigenous women (although there are also additional cohorts of Aboriginal women living in DoGiT communities in Queensland) – women who agreed to participate were asked whether they identified as Aboriginal or as Torres Strait Islander.

Table 31 looks at the extent to which women have left individual items in the 24-page questionnaire blank. It shows the percentage of “ATSI” and “non-ATSI” women who did NOT answer selected questions, from the Mid-age (45-50) and younger (18-23) cohorts only. There is also an older cohort (70-75) but there are too few ATSI women in this category for analysis to be useful.

The first set of six items below are ones which we felt were NOT likely to be particularly sensitive for women of ATSI background and were NOT concerned with mental health. You will notice that levels of missing data are relatively low for all items, but that ATSI women are approximately 2-3 times as likely to choose not to respond.

The second set of 11 items (SF-36 mental health summary and the 10 items from the CES-D depression scale) are directly concerned with mental health. Rates of missing data are much higher, especially for the mid-age women, but you will notice that this is true for non-ATSI as well as for ATSI women. Again, ATSI women are around 2-3 times as likely to choose not to respond.

These data suggest that ATSI women have higher rates of missing data than non-ATSI women regardless of the type of question. Mental health items do seem to produce higher rates of missing data for all women but the proportions are about the same for various items; there does not seem to be a relationship between ATSI status and question type.

We suspect that at least some of the overall difference may be explained by differences in education levels and general familiarity with form-filling. We do not believe that there is good evidence here to support the view that ATSI women are particularly reluctant to answer questions about mental health: ATSI women are 2-3 times as likely to leave items blank, whatever they are.

**Table 31 Percent missing answers to selected questions or scales, ATSI and non-ATSI women, Survey 1**

Question	Mid		Young	
	ATSI n=94	Non-ATSI n=12148	ATSI n=124	Non-ATSI n=9036
How is your general health	1	1	0	1
Vigorous exercise	1	0	0	0
Less vigorous exercise	2	0	0	0

Work related exercise	1	1	3	1
Paid shift work	7	2	4	1
How often rushed/too busy	5	2	12	5
Mean stress score	1	1	2	0
SF-36 Mental Component summary score	14	6	8	2
CESD-10 items (depression)				
Bothered by things	17	7	3	1
Trouble keeping mind on	18	7	3	1
Felt depressed	20	8	4	1
Everything was an effort	16	7	4	2
Hopeful about future	17	8	3	1
Felt fearful	17	7	4	2
Sleep restless	17	7	7	1
Happy	16	7	3	1
Felt lonely	17	7	2	2
Could not get going	17	7	4	2

*Note* Of the 134 mid-age ATSI women who answered the first survey, 94 answered the second. Allowing imputation of up to two missing items on the CESD-10, the depression scale could be calculated for 84% of mid-age ATSI women compared to 93% of mid-age non-ATSI women.

Of the 296 young ATSI women who answered the first survey, returns are only available for 124. CESD-10 could be calculated for 97% of young ATSI women compared to 98% of non-ATSI women.

### **Demographic characteristics of ATSI and non-ATSI women**

The following report was prepared by Jennifer Powers at the request of OATSIH in order to begin exploring possible analysis of data from the ATSI members of the main cohorts.

*ATSI and Non-ATSI mid-age women at Survey 1: Sociodemographic comparison.*

In 1996, 134 ATSI women and 13,870 non-ATSI women in the mid-age group returned Survey 1. The question on Aboriginal or Torres Strait Islander origin was not answered by a further 96 women. ATSI women were almost four times as likely to live in remote areas. They were less likely to live in Victoria and more likely to live in the Northern Territory and Tasmania.

**Table 32 Mid Survey 1: Area of residence**

	<b>ATSI</b>	<b>Non-ATSI</b>
	<b>%</b>	<b>%</b>
Urban	26	36
Rural	50	57
Remote	24	7
Total	133	13807

**Table 33 Mid Survey 1: State**

	<b>ATSI</b>	<b>Non-ATSI</b>
	<b>%</b>	<b>%</b>
New South Wales	31	29
Victoria	7	24
Queensland	24	22
South Australia	7	8
Western Australia	10	9
Tasmania	10	4
Northern Territory	10	2
Australian Capital Territory	1	1
Total	134	13809

ATSI women were less likely to have a formal education and more likely leave school at a younger age.

**Table 34 Mid Survey 1: Highest qualification**

	ATSI %	Non-ATSI %
No formal qualifications	41	18
School certificate	24	32
Higher school certificate	12	17
Trade/ apprenticeship	2	4
Certificate/ diploma	15	16
University degree	4	9
Higher university degree	2	5
Total	131	13771

**Table 35 Mid Survey 1: Age left school**

	ATSI %	Non-ATSI %
Never attended	1	0
14 years or under	20	11
15-16 years	65	56
17-18 years	11	26
19 years or older	4	7
Total	132	13845

Non-ATSI women were more likely to be married than ATSI women.

**Table 36 Mid Survey 1: Marital status**

	ATSI %	Non-ATSI %
Married	59	77



Defacto	10	6
Separated	2	4
Divorced	15	8
Widowed	4	2
Single	10	3
Total	134	13806

ATSI women were more likely to have three or more children than non-ATSI women.

**Table 37 Mid Survey 1: Times given birth**

	ATSI %	Non-ATSI %
Never	3	8
Once	11	9
Twice	22	39
Three	31	28
Four or more times	33	16
Total	123	13159

Non-ATSI women found it easier to manage on the income they had available.

**Table 38 Mid Survey 1: How do you manage on the income you have available**

	<b>ATSI</b>	<b>Non-ATSI</b>
	<b>%</b>	<b>%</b>
Impossible	6	3
Difficult all the time	17	12
Difficult some of the time	27	29
Not too bad	37	41
Easy	13	15
Total	132	13,788

ATSI women had more visits to general practitioners in the last 12 months.

**Table 39 Mid Survey 1: Number of visits to GPs**

	<b>ATSI</b>	<b>Non-ATSI</b>
	<b>%</b>	<b>%</b>
None	3	9
Once or twice	31	37
Three, four times	29	26
Five, six times	13	14
Seven or more times	24	14
Total	133	13800

Non-ATSI women were much more likely to have had a PAP smear in the last two years.

**Table 40 Mid Survey 1: Pap smear**

	<b>ATSI</b>	<b>Non-ATSI</b>
	<b>%</b>	<b>%</b>
In last two years	59	71
Not in last two years	41	29
Total	131	13780

Non-ATSI women were slightly more likely to have had a mammogram in the last two years.

**Table 41 Mid Survey 1: Mammogram**

	ATSI %	Non-ATSI %
In last two years	47	53
Not in last two years	53	47
Total	128	13822

Self-perceived health was worse for ATSI than non-ATSI women. The differences in mean physical and mental health summary scores were the equivalent of the presence of at least one serious physical condition (e.g. cancer, heart disease, diabetes, hypertension, asthma, arthritis).

**Table 42 Mid Survey 1: Physical and mental health summary scores**

	Physical health summary score			Mental health summary score		
	N	Mean (SD)	Median (IQR)	N	Mean (SD)	Median (IQR)
ATSI	115	43.3 (12.4)	48.0 (33.9;53.1)	115	44.1 (14.1)	44.8 (34.3;55.3)
Non-ATSI	13024	49.6 (9.2)	52.2 (46.2;55.5)	13024	47.1 (12.2)	50.0 (39.7;56.6)

At Survey 1, 383 women did not supply any contact details and therefore could not be contacted for the Survey 2. A further 50 non-ATSI women died between Surveys 1 and 2. Response rate for non-ATSI mid-age women at Survey 2 was 91% and for ATSI mid-age women was 74%. 94 mid-age ATSI women responded to Survey 2.

#### *ATSI and Non-ATSI Young Women at Survey 1: Sociodemographic comparison.*

In 1996, 296 ATSI women and 14,420 non-ATSI women returned Survey 1. The question on Aboriginal or Torres Strait Islander origin was not answered by a further 63 women. ATSI women were more than four times as likely to live in remote areas. They were less likely to live in Victoria and more likely to live in the Northern Territory and Queensland.

**Table 43 Young Survey 1: Area of residence**

	<b>ATSI</b>	<b>Non-ATSI</b>
	<b>%</b>	<b>%</b>
Urban	29	56
Rural	54	41
Remote	17	4
Total	293	14329

**Table 44 Young Survey 1: State**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
New South Wales	30	29
Victoria	10	26
Queensland	32	21
South Australia	6	8
Western Australia	9	9
Tasmania	7	4
Northern Territory	5	1
Australian Capital Territory	1	2
<b>Total</b>	<b>293</b>	<b>14330</b>

ATSI women were less likely to have HSC and post-school qualifications.

**Table 45 Young Survey 1: Highest qualification**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
No formal qualifications	13	3
School certificate	27	14
Higher school certificate	42	54
Trade/ apprenticeship	3	3
Certificate/ diploma	10	16
University/ higher degree	5	11
<b>Total</b>	<b>291</b>	<b>14364</b>

ATSI women were more likely to leave school at a younger age than non-ATSI women.

**Table 46 Young Survey 1: Age left school**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
14 years or under	4	1
15-16 years	30	16
17-18 years	53	65
19 years or older	18	12
Total	294	14383

Non-ATSI women were more likely to have never married than ATSI women.

**Table 47 Young Survey 1: Marital status**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
Married	6	9
Defacto	24	13
Separated/divorced/widowed	5	1
Never married	65	77
Total	293	14363

ATSI women were more likely to have children than non-ATSI women.

**Table 48 Young Survey 1: Times given birth**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
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Never	70	91
Once	21	7
Two or more times	9	2
Total	288	14146

Non-ATSI women found it a little easier to manage on the income they had available.

**Table 49 Young Survey 1: How do you manage on the income you have available?**

	ATSI %	Non-ATSI %
Impossible	5	3
Difficult all the time	19	15
Difficult some of the time	34	33
Not too bad	28	36
Easy	13	13
Total	295	14383

ATSI and non-ATSI women had a similar number of visits to general practitioners in the last 12 months.



**Table 50 Young Survey 1: Number of visits to GPs**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
None	6	6
Once or twice	31	32
Three, four times	27	28
Five, six times	16	18
Seven or more times	19	17
<b>Total</b>	<b>296</b>	<b>14364</b>

ATSI women had similar or were slightly better at having PAP smears in the last two years.

**Table 51 Young Survey 1: Pap smear**

	<b>ATSI</b> %	<b>Non-ATSI</b> %
In last two years	50	47
Not in last two years	50	53
<b>Total</b>	<b>290</b>	<b>14363</b>

Self-perceived health was worse for ATSI than non-ATSI women. The differences in mean physical and mental health summary scores were almost equivalent to the effect of at least one serious physical condition (e.g. cancer, heart disease, diabetes, hypertension, asthma, arthritis).

**Table 52 Young Survey 1: Physical and mental health summary scores**

<b>Physical health summary score</b>			<b>Mental health summary score</b>		
<b>N</b>	<b>Mean (SD)</b>	<b>Median (IQR)</b>	<b>N</b>	<b>Mean (SD)</b>	<b>Median (IQR)</b>

ATSI		44.6	47.7		43.5	44.5
	272	(11.2)	(36.8;52.8)	272	(13.0)	(33.6;53.5)
Non-ATSI		48.9	51.0		45.5	47.6
	14134	(8.7)	(45.4;54.4)	14134	(12.4)	(37.7;55.2)

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When Survey 1 was returned in 1996, 532 young women supplied no contact details and so could not be contacted for Survey 2 in 2000. Nineteen young non-ATSI women died between the Surveys 1 and 2. Retention rates for Survey 2 were 68% for young non-ATSI women and 48% for young ATSI women. 134 young ATSI women responded to Survey 2.

## **Smoking cessation in the young cohort**

A project is being undertaken for Tobacco and Alcohol Strategies to examine rates of smoking among the younger cohort. This has a particular focus on changes in smoking status between Survey 1 and Survey 2, and their relationship with reproductive events. The extent to which women stop smoking while pregnant, and the extent to which non-smoking is maintained after pregnancy, are being explored. This project is in the early stages (see page 18).

## **8 DISSEMINATION OF STUDY FINDINGS**

### **8.1 WEB SITE**

The web site (<http://www.fec.newcastle.edu.au/wha>) continues to be updated regularly with new publications and information. Most recently we have included information and an order form for the new book on the project (see Section 8.2.1). The site has an average of 26 hits per day with an overall total of 11,586 hits (since 9 March 2000).

### **8.2 PUBLICATIONS**

#### **8.2.1 Women's Health Australia Book, "Women's Health Australia: What do we know? What do we need to know?"**

The edited book, "Women's Health Australia: What do we know? What do we need to know?", was prepared specifically to be launched at the 4<sup>th</sup> Australian Women's Health Conference. The idea was to produce a single volume that summarized the first five years of the project. While aspects of the work of the project are disseminated through scientific papers, conference presentations, and published conference proceedings, six monthly and annual reports, newsletters for participants, media releases, and the website, there is a need for a single document which outlines the project and results to date.

The book, edited by Christina Lee, begins with an overview of the project as a whole, a general introduction to the methods, and a description of each of the three cohorts. The rest of the book consists of summaries of scientific papers which have appeared in peer-reviewed journals, grouped according to their relationships with the study's five main themes. The book is designed for service providers, community health centres, policy-makers in government and private health organizations, women's health nurses, students and international colleagues with an interest in women's health.

The book was launched at the 4th Australian Women's Health Conference by Professor Anne Edwards, Vice-Chancellor of Flinders University. Professor Edwards' remarks at the launch are included in Appendix 8.1. Copies of the book were sold at the conference, and order forms were included in conference materials. Order forms are available on our web site, and have been circulated through relevant professional groups including the Public Health Association (PHA). Complimentary copies have been distributed to key individuals.

The book was published by Australian Academic Press, with all costs met by Women's Health Australia. All proceeds from sales are returned directly to project funds. Table 53 below summarizes the current financial situation with regard to this book.

**Table 53 Expenditure and income (as at 21 May 2001) for Women's Health Australia: What do we know? What do we need to know?**

Expenditure		Income (ex GST)			
			number	rate	total
Typesetting and printing of 1000 copies	\$9,527.88	Conference Sales	90	20	\$1,800
		Sales Feb-Mar 2001	52	20	\$1040
		Sales April 2001	48		\$960
		Sales May 2001	30		\$600
TOTAL	\$9,527.88		220		\$4,400
Balance					(\$5,127.88)

## 8.2.2 Papers published

**McFadden M, Powers J, Brown W & Walker M. Vehicle and driver attributes affecting sitting distance from the steering wheel in motor vehicles. *Human Factors*, 2000; 42(4): 676-682.**

The current study was designed to confirm that female drivers sit closer to the steering wheel than male drivers and to investigate whether this expected difference in sitting position is due to differences in the physical dimensions of men and women. Driver body dimensions and multiple measures of sitting distance from the steering wheel were collected from a sample of 150 men and 150 women. The results confirmed that, on average, women sit closer to the steering wheel than men and that this difference was accounted for by variations in body dimensions, especially height. On the

basis of these findings consideration should be given to vehicle design that allows independent adjustment of the relative distance between the driver's seat, the steering wheel and the floor pedals. The results also suggest that height of drivers may provide a good surrogate for sitting distance from the steering wheel when investigating the role of driver position in real world crash outcomes.

**Brown WJ, Mishra G, Kenardy J & Dobson AJ. Relationships between body mass index and well-being in young Australian women. *International Journal of Obesity*, 2000; 24(10): 1360-1368.**

Objective: To explore relationships between body mass index (BMI, kg.m<sup>-2</sup>) and indicators of health and well-being in young Australian women.

Design: Population based longitudinal cohort study – baseline cross-sectional data.

Subjects: 14,779 women aged 18-23 who participated in the baseline survey of the Australian Longitudinal Study on Women's Health in 1996.

Measurements: Self-reported height, weight, medical conditions, symptoms and SF-36.

Results: The majority of women (68.2%) had a BMI in the range  $\geq 18.5 - < 25$ ; 12% had a BMI  $< 18.5$ ; 14.1% had a BMI in the range  $\geq 25 - < 30$  and 5.7% had a BMI  $\geq 30$ . After adjustment for area of residence, age, education, smoking and exercise, women in the highest BMI category ( $\geq 30$ ) were more likely to report hypertension, asthma, headaches, backpain, sleeping difficulties, irregular periods, and more visits to their medical practitioner. They were also more likely to have given birth at least once, and less likely to report 'low iron.' Women with low BMI ( $< 18.5$ ) were more likely to report irregular periods and 'low iron'. Mean scores on the SF-36 sub-scales for physical functioning, general health and vitality were highest for women with BMI in the range 18.5 – 25.

Conclusion: Acknowledging the limits of the cross-sectional nature of the data, the results show that the deleterious effects of overweight can be seen at a comparatively young age, and that BMI  $< 25$  is associated with fewer indicators of morbidity in young women. However, as BMI  $< 18.5$  is associated with some health problems, care should be taken when developing strategies to prevent overweight in young women, not to promote weight loss to those who already have a healthy BMI.

**Feldman S, Byles JE & Beaumont R. “Is anybody listening?”: The experiences of widowhood for older Australian women. *Journal of Women & Aging*, 2000; 12: 155-176.**

This paper discusses preliminary findings from participants in the baseline survey of the Australian Longitudinal Study on Women's Health who reported their marital status as widowed. A total of 12,624 women, aged 70-75 years, completed a self administered 260 item questionnaire, and 4355

of these women were widowed. Many of these women provided additional qualitative comments about their health, social and financial circumstances after the death of their spouse. This paper presents a thematic analysis of the qualitative comments and builds on the findings of the quantitative analysis of base-line data. The aims of this study are to examine the short and long term effects of widowhood on the health and wellbeing of older women and to explore the process of change that they experience after the death of a spouse. Preliminary findings suggest that, as a key life event, widowhood has an initial negative impact on the health and wellbeing of older women, but in the long term it may be accompanied by a positive shift into a new life phase.

**Rutnam R, Martin-Murray S & Smith N. Using research to assist women with disabilities in Australia. *Australian Social Policy*, 2000; 1: 91-99.**

The International Year of Older Persons 1999 focused national attention on meeting the needs of people with disabilities as they age, as well as those who acquire disability late in life.

In Australia to date, Women's Health Australia (WHA) is the only national longitudinal study with numbers large enough to allow for comparison between (some) people living with and without disability – in this case, women only.

The Office of Disability began analysis of the WHA survey because of its potential to illuminate factors that contribute to capacity-building and self-reliance in women with disability and to the development and evaluation of prevention and early intervention strategies. This note, however, provides only a very brief 'first cut' from the initial cross-sectional results for the older women's cohort.

This very preliminary appraisal of some data from the WHA shows that it is possible to draw out some useful pointers to policy initiatives that may help to improve the health and wellbeing of older women with chronic illness or disability.

**Markovic M & Manderson L. Nowhere is as at home: adjustment strategies of recent immigrant women from the former Yugoslav Republics in southeast Queensland. *Journal of Sociology*, 2000; 36(3): 315-328.**

This paper analyses adjustment strategies of women from the former Yugoslav Republics who have settled in Australia since 1991. The majority of these recent immigrants have been humanitarian settlers and refugees, and this has had specific implications for their adjustment strategies. In-depth interviews were conducted during 1996-1997 with 52 former Yugoslavian-born women who resided in southeast Queensland. The women's assessments of their decision to immigrate resulted in three adjustment strategies: 1) loss orientation, 2) ambivalence and 3) future orientation. Described separately, this typology delineates only ideal types, but is predictive of the kinds of settlement and coping issues that are faced by

individual immigrants. The adjustment strategies are primarily affected by the women's status as independent immigrants or refugees and humanitarian settlers, social capital and social constraints in the host country.

**Markovic M & Manderson L. European immigrants and the Australian labor market. A case study on women from the former Yugoslavia. *Journal of Ethnic and Migration Studies*, 2000; 26(1): 127-136.**

Labor market participation is one of the main indicators of immigrants' adjustment to a host country. This article explores the experience of immigrant women born in former Yugoslavia, with a focus on their socio-economic performance in Australia. Data collected from women from the former Yugoslavia confirms the continued placement of immigrants at the bottom of the social hierarchy of Australian society. Lack of recognition of immigrants' overseas qualifications and skills is a structural barrier which prevents them from entering the Australian labor market and acquiring commensurate employment. Immigrants who lack competitive attributes necessary for the labor market resort to informal networks to facilitate their employment.

**Hodge A, Patterson A, Brown W, Ireland P & Giles G. The Anti Cancer Council of Victoria FFQ. Relative validity of nutrient intakes compared with diet diaries in young to middle-aged women in a study of iron supplementation. *The Australian and New Zealand Journal of Public Health*, 2001; 24(6): 576-583.**

Objective: To assess the validity of the Anti Cancer Council of Victoria food frequency questionnaire (ACCVFFQ) relative to 7-day weighed diaries in 63 women of child-bearing age.

Method: The women completed diet diaries to assess iron intake as part of a study on iron deficiency, providing the opportunity to compare diaries with the ACCVFFQ. Nutrient intakes based on NUTTAB95 were computed independently for the diaries and the FFQs. Nutrient intakes were compared as group means, by correlation and by quintile classification, adjusting for day-to-day variation in intakes, and for energy intake. Individual differences in results were also examined.

Results: The strongest associations between diary and FFQ results were energy adjusted, log-transformed and adjusted for day-to-day variability in intake. Correlation coefficients ranged from 0.28 for vitamin A to 0.78 for carbohydrate. Mean intakes from diaries and FFQs were within +/- 20% for 21 of 27 nutrients. Poor agreement between FFQs and diaries for retinol intake was due to the inclusion of liver, which is not included in the FFQ, in two diaries.

Conclusion: The ACCVFFQ performs as well as other FFQs for which validation data are available. The relatively poor measurement of retinol is consistent with other data, and with the limited number of foods in which this nutrient is abundant.

Implications: The ACCVFFQ is an optically scannable instrument that can be used to assess intake in Australian populations. The availability of such an instrument will facilitate epidemiological studies of diet and disease, an area of current research priority.

**Hasan S, Byles JE, Mishra G & Harris MA. Use of sleeping medication, and quality of life, among older women who report sleeping difficulty. *Australasian Journal on Ageing*, 2001; 20(1): 29-35.**

Objective: To estimate the proportion of older women who report sleeping difficulties and/or use sleeping medication; and to identify associated factors.

Method: Cross sectional survey of Australian women aged 70-75 years. These women were participants in the Australian Longitudinal Study on Women's Health (ALSWH) randomly selected from the Australian Medicare database.



**Results:** Of the 12624 women aged 70-75 years who provided data for this analysis (36% response rate), 50% (n=6042) reported sleeping difficulty "never/rarely"; 33% (n=3979) "sometimes"; and, 17% (n=2011) of women reported to experience sleeping difficulty "often". Approximately 18% (n=2287) of women reported to use sleeping medication within the previous four weeks. Women reporting sleeping difficulty "sometimes" were over five times more likely to be taking sleeping medications than women who reported to "never/rarely" experience difficulties ( $p < 0.0001$ ); while women reporting difficulty sleeping "often" were over 15 times more likely to be using sleeping medications ( $p < 0.0001$ ). Mean scores for sub scales of the SF-36 health-related quality of life measure were significantly lower for women reporting sleeping difficulty and women using sleeping medication ( $p < 0.001$ ). Similarly, there was an inverse relationship between the SF-36 physical and mental health summary scores and difficulty sleeping or sleeping medication use.

**Conclusions:** Self-reported sleeping difficulty is significantly related to reduced quality of life, suggesting sleeping difficulty is not a benign complaint. After adjustment for other explanatory variables there were strong, clinically significant differences between the SF-36 scores of women reporting sleeping difficulty. However, while this association is statistically, and clinically significant, it is not clear whether sleeping difficulty reduces quality of life, or whether quality of life interferes with sleep, or whether both problems are a result of other associated conditions. Further longitudinal exploration of this relationship is necessary. Further, issues need to be explored with older women, with a view to identifying acceptable and effective alternatives to sleeping medication use.

### 8.2.3 Papers accepted for publication

**Patterson AJ, Young AF, Powers JR, Brown WJ, Byles JE. Relationships between nutrition screening checklists and the health and well being of older Australian women. *Public Health Nutrition*.**

**Objectives:** To examine associations between nutrition screening checklists and the health of older women.

**Methods:** The Australian Nutrition Screening Initiative (ANSI), adapted from the Nutrition Screening Initiative (NSI), was completed by 12,939 women aged 70-75 years as part of the Australian Longitudinal Study on Women's Health. Responses to individual items in the checklist, and ANSI and NSI scores, were compared with measures of health and health service utilization. The performance of an unweighted score (TSI) was also examined.

**Results:** Women with high ANSI, NSI and TSI scores had poorer physical and mental health, higher health care utilization and were less likely to be in the acceptable weight range. Whereas ANSI classified 30% of the women as 'high risk', only 13% and 12% were classified as 'high risk' by the NSI and TSI respectively.

Conclusions: Higher scores on both the ANSI and NSI are associated with poorer health. The simpler unweighted method of scoring the ANSI (TSI) showed better discrimination for the identification of 'at risk' women than the weighted ANSI method. The predictive value of individual items and the checklist scores need to be examined longitudinally.

**Patterson AJ, Brown WJ, Roberts DCK. Dietary and supplement treatment of iron deficiency results in improvements in general health and fatigue in Australian women of childbearing age. *The Journal of the American College of Nutrition.***

Objective: To examine the effects of iron deficiency, and its treatment by iron supplementation or a high iron diet, on fatigue and general health measures in women of childbearing age.

Design: Randomised controlled trial to compare supplement and dietary treatment of iron deficiency.

Subjects: 44 iron deficient (serum ferritin <15µg/L or serum ferritin 15-20µg/L, plus two of: serum iron <10 µmol/L; total iron binding capacity >68 µmol/L; or transferrin saturation <15%) and 22 iron replete (haemoglobin ≥ 120g/L and serum ferritin >20µg/L) women, aged 18-50 years were matched for age and parity.

Interventions: Iron deficient women were randomly allocated to either iron supplementation or a high iron diet for 12 weeks.

Measures of Outcome: Iron deficient and iron replete participants had iron studies performed and completed the Piper Fatigue Scale (PFS) and the SF-36 general health and well-being questionnaire at baseline (T0), following the 12 week intervention (T1) and again after a 6 month non-intervention phase (T2). The SF-36 includes measures of physical (PCS) and mental (MCS) health and vitality (VT).

Results: MCS and VT scores were lower, and PFS scores were higher for iron deficient women (diet and supplement groups) than iron replete women at baseline. Both intervention groups showed similar improvements in MCS, VT and PFS scores during the intervention phase, but mean increases in serum ferritin were greater in the supplement than the diet group. PCS scores were not related to iron status.

Conclusions: Treatment of iron deficiency with either supplementation or a high iron diet results in improved mental health and decreased fatigue among women of childbearing age.

**Miller YD, Brown WJ, Chiarelli P & Russell A. Urinary incontinence across the lifespan. *Neurourology and Urodynamics.***

The objectives of the current study were (1) to measure type and severity of urinary leakage and (2) to investigate the association between these factors and age-related life events and conditions in three groups of Australian women with a history of urinary leakage. Five-hundred participants were randomly selected from women in the young (aged 18-22 in 1996), mid-age (aged 45-50) and older (70-75) cohorts of the Australian Longitudinal Study of Women's Health (ALSWH) who had reported leaking urine in the 1996 baseline survey. Details about leaking urine (frequency, severity, situations) and associated factors (pregnancy, childbirth, Body Mass Index) were sought through self-report mailed follow-up surveys in 1999. Response rates were 50%, 83%, and 80% in the young, mid-age and older women respectively. Most women confirmed that they had leaked urine in the last month, and the majority of these were cases of 'mixed' incontinence. Incontinence severity tended to increase with BMI for women of all ages, and increased severity scores were associated with having urine that burns or stings. Additional independent risk factors for increasing incontinence severity were heavy smoking in young women, past or present use of hormone replacement therapy in older women, and BMI, births assisted with forceps or other delivery aids and history of hysterectomy in mid-age women.

**Schofield MJ, Reynolds R, Mishra G, Powers J & Dobson AJ. Vulnerability to abuse, powerlessness and psychological stress, among older women: women's health study. *Journal of Applied Gerontology*.**

This study represents the first large scale investigation of the validity of a brief self-report screening measure for elder abuse in a nationally representative sample of more than 12,000 older Australian women, from the baseline survey of the Australian Longitudinal Study on Women's Health (ALSWH). The screening instrument was a modification of the Hwalek- Sengstock Elder Abuse Screening Test (H-S/EAST), comprising the original 15 items and two additional items. Construct validity was examined using factor analysis and correlation with a wide range of socio-demographic, psychological and health related variables. Results failed to support the original three factors of the H-S/EAST. Four factors, each of three items, were identified representing the following domains: 'vulnerability', 'dependence', 'dejection' and 'coercion'. The four factors accounted for 50% of the variance, the sampling adequacy was MSA=0.71 and Cronbach's alpha coefficients ranged from 0.39 to 0.55. Construct validity of the scales (correlation between factor scores and hypothesised associations with other variables) was largely supported. 'Vulnerability' and 'coercion' had the highest face validity for abuse and demonstrated moderate to good construct validity. 'Dejection' was related to more variables, but demonstrated less discriminatory power and may be an indicator of depression. 'Dependence' showed poor construct validity and appeared to measure lack of autonomy rather than abuse. The sum of responses to the six items which comprise the factors 'vulnerability' and 'coercion' may provide a simple screening tool for elder abuse for use by health professionals. Follow-up surveys of the ALSWH will allow investigation of predictive validity of the revised instrument.

**Mishra GD, Ball K, Dobson AJ, Byles JE & Warner-Smith P. The measurement of socio-economic status: Investigation of gender-and age-specific indicators in Australia: National Health Survey '95. *Social Indicators Research*.**

Age- and gender-specific measures of socio-economic status (SES) in Australia were investigated using data from the 1995 National Health Survey. Factor analysis produced consistent results that were interpreted in terms of five conceptually meaningful domains (employment, housing, migration,

family unit and education). Age- and gender-specific SES scores based on these factors had stronger associations with physical and mental health, as measured by the component summary scores of SF-36, than either an area based index or scores derived only from males aged 40-45 years. Overall the results supported the hypothesis that SES measures composed of social and demographic items exhibit important age- and gender-specific differences which are relevant for health.

**Doran CM, Chiarelli P & Cockburn J. Economic costs of urinary incontinence in community-dwelling Australian women. *Medical Journal of Australia.***

Objective: To estimate the economic cost of urinary incontinence in community-dwelling Australian women for the year 1998

Design: Micro level costing approach

Setting: Urinary incontinent community dwelling Australian women

Patients, Participants: Urinary incontinent women 18 years of age and over

Interventions: The framework integrates evidence of the prevalence of urinary incontinence among Australian women aged over 18 years, together with the resource implications (both personal and treatment) of their incontinence, in an attempt to quantify the economic costs of urinary incontinence.

Main outcome measure: Australian dollar cost in 1998

Results: An estimated 1,835,628 community dwelling women over the age of 18 years were incontinent of urine in 1998. The total annual cost of urinary incontinence in 1998 is estimated at \$710.44 million or \$387 per incontinent woman that is comprised of \$338.47 million in treatment costs and \$371.97 million in personal costs. Extrapolating 20 years hence, holding constant both prevalence of incontinence and inflationary pressures, the total cost is projected to be \$1,267.85 million of which 93% (\$1.18 billion) will constitute costs associated with incontinent women aged over 40 years.

Conclusions: The results of this analysis demonstrate that: 1) urinary incontinence imposes a considerable drain on scarce health care resources in Australia; and, 2) there exists a need for research to facilitate a clearer understanding of the magnitude of the problem and potential gains from the pursuit of continence promotion.

**Patterson AJ, Brown WJ, Roberts DCK, Seldon MR. Dietary treatment of iron deficiency in women of childbearing age. *American Journal of Clinical Nutrition.***

**Background:** The Australian Iron Status Advisory Panel advocates the use of dietary intervention as the first treatment option in mild cases of iron deficiency (serum ferritin 10-15µg/L). However, there appear to be no studies examining the efficacy of dietary treatment of iron deficiency.

**Objective:** To compare the effects of iron supplementation and a high iron diet on serum ferritin (SF) and haemoglobin (Hb) in iron deficient women of childbearing age.

**Design:** 44 iron deficient (SF<15µg/L *or* SF 15-20µg/L, plus two of: serum iron <10 µmol/L; total iron binding capacity >68 µmol/L; or transferrin saturation <15%) and 22 iron replete (Hb ≥ 120g/L *and* SF >20µg/L) women, matched for age and parity categories, had iron studies performed and completed 7 day weighed food records (T0). Iron deficient women were randomly allocated to either iron supplementation (105mg/d) or a high iron diet (recommended intake of absorbable iron 2.25mg/d) for 12 weeks. Haematological and dietary assessments were repeated at the end of the intervention phase (T1) and again after a 6 month non-intervention phase (T2).

**Results:** Mean SF for the supplement group increased from 9.0±3.1µg/L to 24.8±10.0µg/L during the intervention phase and remained stable during the non-intervention phase (24.2±8.8µg/L), while increases in SF for the diet group were smaller during the intervention phase (8.9±3.1µg/L to 11.0±5.9µg/L), and continued to improve during the non-intervention phase to 15.2±9.5µg/L. Mean Hb improved similarly for both intervention groups but the change was only significant for the supplement group [Supplement: T0=125.2±9.1mg/L, T1=130.4±6.8mg/L, T2=131.4±6.6mg/L; Diet: T0=127.6±8.5mg/L, T1=130.6±7.1mg/L, T2=130.8±6.9mg/L].

**Conclusions:** A high iron diet produced small increases in SF and Hb relative to iron supplementation for iron deficient women of childbearing age during a 12 week intervention, but resulted in continued improvements in iron status during a 6 month non-intervention phase.

**Patterson AJ, Brown WJ & Roberts DCK. Dietary and lifestyle factors influencing iron stores in Australian women: An examination of the role of bioavailable dietary iron. *Australian Journal of Nutrition and Dietetics*.**

**Background:** Research to date has not been able to adequately describe the relative impact of dietary and lifestyle variables on iron status. While total iron intake appears unrelated to iron status, bioavailable dietary iron should correlate with iron stores, after adjustment for iron losses.

**Objective:** To determine dietary and lifestyle variables which are important in the determination of iron status for Australian women of childbearing age.

**Design:** Serum ferritin and body mass index were measured in 52 iron deficient and 24 iron replete women. Dietary data were collected using 7-day weighed food records and bioavailable dietary iron calculations were performed using the methods of Monsen et al and Tseng et al. Self-report data on

demographic characteristics, parity, breastfeeding, oral contraceptive pill (OCP), intrauterine device and hormone replacement therapy use, menstruation, smoking, alcohol intake, exercise, dieting, vitamin and mineral supplement use and blood donation were collected. Multiple linear regression was used to examine dietary and lifestyle factors associated with serum ferritin.

Results: Current OCP use (0.01) and alcohol intake (0.001) were positively associated and phytate intake was negatively associated (0.05) with serum ferritin in multiple linear regression. Total iron, heme iron and bioavailable dietary iron intakes were not associated with iron stores.

Conclusions: Factors other than dietary iron, such as alcohol and phytate intake, and use of the OCP may be important in the aetiology of iron deficiency.

## **8.3 CONFERENCES**

### **8.3.1 Conference organization**

The Project Advisory Committee decided that the project contract should be modified so that the requirement that ALSWH organize a conference be replaced with the requirement that ALSWH would organize a series of workshops, seminars and symposia at or in conjunction with existing conferences. The following organizational activities have taken place or are in the planning stages:

#### **Australian Women's Health Network 4<sup>th</sup> Australian Women's Health Conference "Women's Health: Politics, Action and Renewal" . 18 – 21 February 2001.**

Investigators from Women's Health Australia presented a one-day workshop entitled "Bridging the Research-Policy Gap in Women's Health" on 18 February 2001 (see programme in Appendix 8.2). The workshop was designed to provide an overview of the project and its findings, with a focus on strategies for translating research into policy. The aim was firstly to describe the study, its design, and results to date, and secondly to encourage participants to identify areas in which the project might usefully make a contribution to practice and policy. The workshop was attended by 37 participants, drawn from Universities, State Government Health Departments, Community Health Centres, and NGOs (Bessie Smyth Foundation, FPA, Jean Hailes Foundation, Women With Disabilities Australia). Presenters included Christina Lee, Lois Bryson, Anne Young, and Julie Byles from Women's Health Australia, as well as Dr Helen Keleher (convenor of Australian Women's Health Network and an Associate Investigator with Women's Health Australia), Dr Dorothy Broom, and Dr Angela Taft.

The morning programme included an overview of the project and five illustrative papers, dealing with specific aspects of the project which have clear application in policy and practice. The afternoon involved audience participation in group discussion and a panel discussion session.

### Outcomes:

The morning's presentations on aspects of Women's Health Australia were well received, with a sense that the presenters were reaching a new audience, particularly those who worked in service delivery and in policy areas.

Issues raised during the discussions held in the afternoon generally reflected the particular interests of the participants; many of these have already been discussed by Women's Health Australia researchers and members of the Project Advisory Committee, while others provide a slightly different perspective.

The possibility that Women's Health Australia might establish new special cohorts, now that research with the Filipina and former Yugoslav groups has been wound up, was raised, although it was acknowledged that additional funds and staff would be required.

A stronger focus on the needs of subgroups of women, including women with disabilities, women with psychiatric disorders, women in prisons, NESB women, and lesbians, was proposed. It was also pointed out that women who fall into two or more "minority" categories may have particular health needs, but it was agreed that a large representative population survey may not be the best strategy for approaching these issues. Following the conference, we have begun negotiations with Dr Ruth McNair over lesbians' health and Dr Angela Taft over violence and pregnancy among young women (see Section 6.3).

Other discussion themes included the importance of the biopsychosocial and gendered approach which the project takes to women's health, and the importance of widespread dissemination of results, consultation with stakeholders, and collaboration with the service delivery sector.

### **6<sup>th</sup> National Rural Health Conference, 4-7 March 2001, National Convention Centre, Canberra.**

Christina Lee, Anne Young and Penny Warner-Smith presented a symposium on the project and on some of the findings which reflect on the health and access to health services of rural Australian women. This symposium was well received, and the first of fifteen priority recommendations which emerged from the conference as a whole was that, "The Conference recommends that the Department of Health and Aged Care (DHAC) fund research on men's health which draws on the methods and strategies developed by the Australian Longitudinal Study on Women's Health (ALSWH). At the same time DHAC continue to provide funding for the ALSWH and that its results be further promoted."

### **Public Health Association of Australia 33<sup>rd</sup> Annual Conference, 23-26 September 2001, Sydney.**

This year's PHA conference highlights several themes, one of which is "Quantitative/ qualitative research methods: Can we achieve a balance?" Women's Health Australia has submitted a proposal for a symposium which highlights the ways in which quantitative and qualitative data complement each other in the project. The symposium is coordinated by Associate Professor Julie Byles and will feature the work of a number of current postgraduate students.

**Office of the Status of Women National Women's Conference, 26-28 August, National Convention Centre, Canberra.**

This conference is in the early planning stages but we have been invited to participate in programme planning and to present a workshop or symposium.

**The Australian Sociology Association Annual Conference, 13-15 December 2001, Sydney.**

We plan to offer a symposium or panel discussion as part of a day which will feature gender and health as a theme.

### **8.3.2 Conference presentations**

**Byles JE, Harris MA, Mishra G & Nair K. Older women's use of sleeping medications. *Australian Association of Gerontology Rural Conference Showcasing the Hunter and Beyond*. Morpeth, NSW. 16 February 2001.**

Difficulty sleeping is common in older people, particularly women, and often explained as a normal and physiological aspect of ageing. This set of studies explores the health implications of sleeping difficulty and associated use of sleeping medications, and the impact of sleeping difficulty on women's lives. As a first step, baseline data from 12624 community-dwelling women aged 70-75 years who were participants in the Australian Longitudinal Study on Women's Health (ALSWH) were analysed. Approximately 50% of these older women reported some degree of difficulty sleeping, and approximately 17% reported difficulty sleeping often.

At three year follow-up, 42.4% of women reported "waking in the early hours", 26.0% "taking a long time to get to sleep", 21.0% "sleeping badly at night", 10.84 "lying awake most of the night" and 11.0% "worry keeping you awake". There was a strong statistical association between reporting sleeping difficulty at baseline and at follow-up indicating that this was a persistent and long-term problem for these women. A total of 1532 (15%) women reported use of sleeping medication at follow-up and women were 6.5 times more likely to report use if they also reported any item of sleep difficulty.

On multivariate analysis, sleeping difficulty at baseline was negatively associated with general health perceptions, emotional role limitations and general mental health sub-scales of the Short-Form – 36 Health Survey (SF-36) at follow-up; the use of sleep medication at baseline was negatively



associated physical functioning, bodily pain, vitality, social functioning and general mental health SF-36 sub-scale scores. The use of sleep medication was also significantly associated with falls, accidents, and health care utilisation.

Qualitative and quantitative sub-studies were undertaken to further explore these negative health impacts from the women's perspective and to women's knowledge and attitudes in relation to sleep and sleeping medication use. These data also provide insight into the nature of women's sleeping difficulty, and the behaviours that women adopt to deal with this problem. Particularly they indicate clear differences in the help seeking behaviours, knowledge and attitudes of women who do and do not use sleeping medications.

**Mishra G, Dobson A & Richardson K. Multiple imputation for Body Mass Index: sensitivity analysis from the Australian Longitudinal Study on Women's Health. *Annual European Royal Statistical Society Meeting*. Belgium. 16 February 2001.**

The Australian Longitudinal Study on Women's Health (ALSWH) aims to explore the factors which promote good health and prevent ill-health for women. The study involves three cohorts of women: young women who were aged 18-23 years at the time of the Survey 1 in 1996 (N=14,762); mid-age women (45-50 at Survey 1, N=14,072) and older women (70-75 years at Survey 1, N=12, 767).

This paper describes the technique of multiple imputation for the case of missing BMI data from ALSWH. The reliability and sensitivity of the procedure is examined with a range of random vs selective deletions from variable categories. Results from sensitivity analysis, by examining the effects of different variables in the imputation model, will be discussed in terms of the appropriateness of the missing-at-random assumption.

**Lee C, Bryson B, Young A, Byles J, Keleher H, Broom D & Taft A. Bridging the Research-Policy Gap in Women's Health Workshop. *Australian Women's Health Network 4<sup>th</sup> Australian Women's Health Conference "Women's Health: Politics, Action and Renewal"*. Adelaide, South Australia. 18 February 2001.**

See Section 8.3.1.

**Graham M, Keleher H, James E & Byles J. Satisfaction with the outcomes of hysterectomy. *Australian Women's Health Network 4<sup>th</sup> Australian Women's Health Conference "Women's Health: Politics, Action and Renewal"*. Adelaide, South Australia. 19-21 February 2001.**

The impact of gynaecological disorders on women's health and well-being can be substantial, potentially affecting many aspects of a woman's quality of life. Hysterectomy is one of the most common gynaecological surgical procedures performed of a non-obstetric nature. Australian statistics indicate that just over one in ten women will undergo a hysterectomy by the age of 40, and around one in five women will undergo a hysterectomy before the age of 50. There is concern about the number of hysterectomies performed, the necessity of such surgery, and the appropriateness of hysterectomy to treat non-malignant conditions. This paper will describe preliminary results from a retrospective cohort study of 218 women who completed a self-administered questionnaire designed to collect information about their quality of life, factors influencing their decision to have a hysterectomy and satisfaction with hysterectomy as a treatment for menstrual symptoms. This project is a sub-study of the Women's Health Australia.

**Lee C. Women's Health Australia: Introduction. Symposium: Women's Health Australia: Focus on Rural Women Throughout the Lifespan. *6th National Rural Health Conference*. Canberra, Australian Capital Territory. 4-7 March 2001.**

Women's Health Australia (WHA) is a large-scale longitudinal project which was the initiative of the Commonwealth Department of Health and Aged Care. First funded in 1995, it involves a 20-year longitudinal survey of the health of Australia's women, with a strong emphasis on the needs of women in rural and remote areas. The project aims to clarify relationships between women's health and biological, psychological, social, economic and lifestyle factors, with the overall goal of providing information of value to the Department in the formulation of policy and the evaluation of health services.

The project involves three cohorts of women, randomly selected by HIC from the Medicare database, to represent young (aged 18-23 in 1996), mid-age (45-50), and older women (70-75). Over-sampling of women in rural and remote areas allows an examination of geographical variations in health and in access to health care. More than 41,000 women responded to mailed baseline surveys in 1996, and comparisons with 1996 census data suggest that they are reasonably representative of Australian women in these age groups. Over 50% have also agreed to linkage with their Medicare data. Each cohort will be followed up on a three-year rolling basis for twenty years; the middle-aged women were re-surveyed in 1998, with a response rate of 92%; the older women were surveyed in 1999 (91% response), and the young women were surveyed in 2000 with a much lower response rate of 63%.

This paper provides an overview of the project and presents descriptive data on geographical differences in health, with a particular emphasis on the oldest cohort. Compared to city women, rural women in their 70s appear to be in good health, with lower levels of commonly occurring symptoms and lower levels of stress and depression. Possible explanations for this health advantage are explored. These include self-selection, whereby unhealthy women may move to the city to be closer to services, differences in attitudes and expectations between rural and urban Australians, and differences in life experiences.

**Young A, Dobson A & Byles J. Access to health services in urban and rural Australia: a level playing field? Symposium: Women's Health Australia: Focus on Rural Women Throughout the Lifespan. 6th National Rural Health Conference. Canberra, Australian Capital Territory. 4-7 March 2001.**

Although the shortages of general practitioners (GPs) and specialists in rural and remote areas of Australia have been well documented, very few studies have been conducted to measure access to health services from a consumer perspective. There is also a lack of data to assess the effect that direct financial cost has on the use of health services.

Almost 20,000 women in the Australian Longitudinal Study on Women's Health gave consent for data from the Health Insurance Commission (which processes claims for services provided by Medicare and the Department of Veterans' Affairs) to be provided to the research project. Data on general practice consultations during 1995 and 1996 were linked with survey data to inform the debate about equity of access to health services.

Concerns about the geographical imbalance in the supply, distribution and affordability of GP services in Australia were confirmed by the findings of the study. Women living in rural and remote areas gave lower ratings for the availability, accessibility and affordability of health services than women living in urban areas. The shortage of female GPs in rural areas was reflected by the high proportion of women who rated their access to a female provider as poor. The problem of limited choice of GPs for women in rural areas is compounded by the difficulty they have seeing the GP of their choice. Women living in rural areas were also more likely than women in urban areas to report having poor access to after-hours care.

Older women were more likely to have their GP consultations "bulk billed" resulting in no out of pocket costs. However in all age groups, the proportion of women whose visits were bulk billed was lower in rural areas than in urban areas and the out of pocket costs were higher in rural areas.

The longitudinal study will be well placed to monitor the effectiveness any new programs aimed at improving the access to health care services of people living in rural and remote areas of Australia.

**Warner-Smith P & Lee C. Young rural women: life choices, aspirations, and well-being. Symposium: Women's Health Australia: Focus on Rural Women Throughout the Lifespan. 6th National Rural Health Conference. Canberra, Australian Capital Territory. 4-7 March 2001.**

Women's Health Australia data show that young rural women's life experiences and aspirations are very different from those of their city cousins, suggesting that national policies need to take rural women's needs into account. For example, data from the baseline survey show that women in the youngest cohort of this project (aged 18-23 in 1996) who live in rural and remote areas will have different needs in regard to gynaecological and family planning services. They are more likely to be married or in permanent relationships, more likely to have children and are also more likely than city women to want 3 or more children by the time they are 35 years old.

Young women living in rural areas have generally left school earlier than young women living in the city, and are more likely to be in paid work, either full- or part-time, rather than to be studying. Conversely, many young women living in the city are deferring motherhood and obtaining further educational qualifications with the aim of establishing themselves in a career. Given the earlier age at which they become mothers, and their relative lack of post-school qualifications, young rural women may be disadvantaged if they attempt to return to the workforce after childbearing and possibly a period spent at home with small children. While it is also the case that rural women have lower levels of stress than women in metropolitan areas, this presentation examines the possible implications of young rural women's life choices for their continued well-being in the current economic climate. Their situation is likely to be exacerbated by on-going processes of restructuring and the dismantling of infrastructure, which are disadvantaging people in rural areas. It is argued that there is a particular need for supportive social policies which enable rural women to make choices about parenting, relationships and paid work

**Young A & Byles J. A sense of belonging: how do you measure it and does it matter? Symposium: Women's Health Australia: Focus on Rural Women Throughout the Lifespan. 6th National Rural Health Conference. Canberra, Australian Capital Territory. 4-7 March 2001.**

As the population ages, women will be highly represented in the older age groups, as noted in the "Healthy Horizons" strategy. A goal of the Women's Health Australia project is to improve our understanding of how social, economic, environmental and psychological factors contribute towards "positive ageing" for women across Australia. However many concepts thought to be important, such as community participation and geographical remoteness, are difficult to measure.

Personal characteristics such as optimism and "hardiness", and contextual variables such as neighbourhood satisfaction and social support, may affect healthy ageing. This paper will present an overview of the methods used to include measures of these factors in the longitudinal study of women's health. The findings from the follow up survey of more than 10,000 women in their 70's, of whom 6,000 live in rural and remote areas of Australia, will be presented.

The Women's Health Australia project has the capacity to monitor the health status and health changes for older women living in different locations and report on the outcomes for rural women. The use of a new index of geographical remoteness will be discussed. This index, the Accessibility/Remoteness Index of Australia, was developed by the National Key Centre for Social Applications of Geographic Information Systems, in partnership with the Department of Health & Aged Care. The accessibility/remoteness index has been used to quantify migration over time, and to examine the relationship between migration and health status, for the older women in the longitudinal study.

**Lee C, Mishra G, Brown W & Dobson A. Symptoms during the menopausal transition: demographics, lifestyle, and country of birth in an Australian population survey. *Building Bridges from Science to practice and Policy: Behavioral medicine in the 21<sup>st</sup> Century. Society of Behavioral Medicine 22<sup>nd</sup> Annual Scientific Sessions. Seattle, Washington, USA. 21-24 March 2001.***

Reports of menopausal symptoms differ across countries, and there is debate on the extent to which such differences have a biological or cultural basis. Menopausal transitions and symptoms were assessed longitudinally as part of Women's Health Australia, a large-scale longitudinal survey of a nationally representative sample of women. The analysis explores relationships between country of birth and menopausal transition over a two-year period, focusing on 8,623 mid-age women (aged 45-50 at Survey 1) who had not had a hysterectomy. Approximately 25% were born outside Australia. Analysis focused on country of birth (Australia; other English-speaking; European; Asian; Other), menopausal status at Survey 1 and 2 and menopausal transition, and symptoms. Women born in Asian countries were twice as likely as Australian-born women to be post-menopausal at Survey 1. They were twice as likely to become post-menopausal between Surveys 1 and 2, less likely to remain peri-menopausal, and less likely to report hot flashes and night sweats. Logistic regression was used to determine odds ratios for symptoms at Survey 2 by country of birth. After adjustment for symptoms at Survey 1, menopausal transition status, demographics, and health behaviours, differences were small and non-significant. Women from Asian countries appeared to enter menopause at an earlier age and to pass through it more quickly, but women from different countries showed the same patterns of symptoms once menopausal transitions were taken into account. This suggests that there may be biological differences between ethnic groups which influence the timing of the onset and transition of menopause, but that subjective experience of menopause is similar regardless of ethnic background.

**Wicks D, Mishra G & Milne L. Young women, work and inequality: Is it what they want or what they get? An Australian contribution to research on women and workforce participation. *British Sociological Association Conference: 2001 A Sociological Odyssey. Manchester, United Kingdom. 9-12 April, 2001.***

The Australian Longitudinal Study on Women's Health was established to track the health of three age cohorts of Australian women - 40,000 in total - over a 20 year period. It provides opportunities for research into health and related issues for women. In this paper, we investigate (1) baseline data from the young cohort of 1400 survey participants and (2) follow up in-depth interview data from a small sample of 100 of the original respondents. The focus of the paper is on the aspirations of young women (aged 18-23) for work, their ideal job, relationships (including children) and further education, particularly in the context of gender inequality in labour markets.

Through an analysis of the data, we look at the extent to which gender inequalities are the result of free choices and preferences and to what extent they are conditioned by socio-economic structures and processes that reproduce inequalities over time. This issue is further explored through a classification of women by socio-economic status. In this way, we can analyse the gender dimension of labour market inequality in general as well as the relationship of gender inequality to class inequality in the areas of work, work choice and the ability to combine work and family responsibilities.

Analysis of the two data sets sheds light on debates about women's workforce participation as well as establishing baseline data for future research on the options chosen and available for this group of young women. The information will have significance for policy debates in several areas, including those concerned with worker entitlements, childcare, access to higher education and workforce planning. More particularly, it makes a significant contribution to current debates about women's alleged preference for part-time rather than full-time work.

**Lee C & Young A. Women's Health Australia. 25th Congress of the Medical Women's International Association. Sydney, New South Wales. 19-22 April 2001.**

Women's Health Australia (WHA) is a large-scale longitudinal project which was the initiative of the Australian Commonwealth Department of Health and Aged Care. First funded in 1995, it involves a 20-year longitudinal survey of the health of Australia's women. The purpose of the project is to clarify relationships between women's health and biological, psychological, social, economic and lifestyle factors.

The project involves 42,000 women in three nationally representative cohorts: young (aged 18-23 in 1996), mid-age (45-50), and older women (70-75). Each cohort will be followed up on a three-year rolling basis for twenty years; the mid-age women were re-surveyed in 1998, with a response rate of 92%; the older women were surveyed in 1999 (91% response); the young women in 2000 (71%), and we are returning to the mid-age women this year. Approximately 50% of women have also consented to linkage with data from Australia's universal health insurance system (Medicare), enabling us to link self-report with health service use.

The project addresses a broad range of issues in women's lives. This presentation focuses on women's self-reported access to, and satisfaction with, general practitioner (GP) services, with emphasis on differences across age groups and localities. Younger women are least satisfied with GP services and most likely to prefer a female practitioner; those who live in rural and remote areas make less use of services, are less satisfied, and are less likely to have access to female practitioners. The role of epidemiological data in guiding policy and in informing practitioners is discussed.

**Young A. Women's Health Australia: the Australian Longitudinal Study on Women's Health. National Benchmarking Group Meeting - Women's Hospital Australasia. Sydney, New South Wales, 17 May 2001.**

The Australian Longitudinal Study on Women's Health, also known as Women's Health Australia, is a large-scale longitudinal project funded by the Commonwealth Department of Health and Aged Care. The project began in 1995 and involves a 20-year longitudinal survey of the health of Australia's women, with a strong emphasis on the needs of women in rural and remote areas. The aim of the project is to collect scientifically valid information which is relevant to the formulation of health policy and the evaluation of health services.

The project involves three cohorts of women, randomly selected by the Health Insurance Commission from the Medicare database, to represent young (aged 18-23 in 1996), mid-age (45-50), and older women (70-75). Over-sampling of women in rural and remote areas allows an examination of geographical variations in health and in access to health care. More than 41,000 women responded to mailed baseline surveys in 1996, and comparisons with 1996 census data suggest that they are reasonably representative of Australian women in these age groups. Over 50% have also agreed to linkage with their Medicare data. Each cohort is being followed up on a three-year rolling basis for twenty years.

The project is strongly multidisciplinary with researchers from medicine, psychology, epidemiology, statistics, nutrition, sociology and health sciences. As well as collecting information about medical aspects of health, the effects of factors such as work, family, relationships, leisure time and the context of everyday life on women's health and well-being are being explored.

This paper provides an overview of the project and presents data from the baseline and first follow up surveys. It will also illustrate the diversity of substudies and analyses that are underway and suggest ways in which the project may provide useful information for the Women's Hospital Australasia group.

### **8.3.3 Other presentations**

Larson A, Bell M & Young A. No Place for a Sick Woman: Untangling the Relationship between Health and Rural Residence in Australia (Poster Presentation). Population Association of America Meetings. Washington DC, USA. 28-30 March 2001

Dobson A. Screening behaviour results from the Australian Longitudinal Study on Women's Health. Behavioural Science in Cancer Control, Queensland Cancer Fund. Brisbane, Queensland. 3-4 May 2001.

Larson A, Bell M & Young A. No Place for a Sick Woman: Untangling the Relationship between Health and Rural Residence in Australia (Poster Presentation). Combined Universities Centre for Rural Health Seminar Series. Geraldton Western Australia. 7 May 2001

Young A. Statistical modelling of psychosocial theory: Can we speak the same language? Biostatistics Group, Centre for Clinical Epidemiology and Biostatistics. Newcastle, New South Wales. 10 May 2001.

Feldman S. Widowed Older Women and well-being: A longitudinal study. National Ageing Institute Seminar program. Melbourne, Victoria. 21 May 2001.

a'Beckett J. A comparison of health service utilisation and health measures between women with and without diabetes in the Australian Longitudinal Study on Women's Health. 2<sup>nd</sup> 2001 Meeting of the Nutrition Society of Australia (Inc) – Newcastle Group. Newcastle, New South Wales. 23 May 2001.

Patterson A. Iron deficiency, general health and fatigue: results from the Australian Longitudinal Study on Women's Health. 2<sup>nd</sup> 2001 Meeting of the Nutrition Society of Australia (Inc) – Newcastle Group. Newcastle, New South Wales. 23 May 2001.

Williams L. Weight change in mid-age women: why does it affect some and not others. 2<sup>nd</sup> 2001 Meeting of the Nutrition Society of Australia (Inc) – Newcastle Group. Newcastle, New South Wales. 23 May 2001.

Schmidt. Iron status in Australian women – dietary intake versus menstrual blood loss. 2<sup>nd</sup> 2001 Meeting of the Nutrition Society of Australia (Inc) – Newcastle Group. Newcastle, New South Wales. 23 May 2001.

#### **8.4 DISSEMINATION OF METHODOLOGICAL EXPERTISE**

Over five years of the project, staff and investigators have developed and are continuing to develop substantial expertise in the conduct of large-scale survey research, and as a consequence we are increasingly asked to provide advice and input on an ad hoc basis to government departments and other agencies that are considering projects with related methodologies. In the six months January to June 2001, we have provided the following advice and services:

##### **Dr Mary Harris, Australian Medical Workforce Advisory Council (AMWAC)**

AMWAC are developing a longitudinal survey on Career Choice and Workforce Participation, focusing on the career choices of medical practitioners, their reasons for those choices, and the policy implications of these choices. Dr Harris visited the ALSWH office in 2000 to discuss practical aspects of such a project. In 2001 she has invited Dr Anne Young and Professor Christina Lee to join the working party overseeing the development of the project. Anne Young attended a committee meeting in March, and Christina Lee provided the committee with a detailed summary of the necessary resources and associated costs, and the decisions which need to be made, in planning a longitudinal survey.

##### **Department of Family and Community Services**

We have been in consultation with staff of FACS over the early development of the Longitudinal Survey of Australian Children (LSAC) and several of us (Annette, Christina, Wendy) are members of their advisory group. Newcastle office staff met with three of FACS' project staff – Stephen Horn,



Justine Gibbings, and Jean Gifford – on 2<sup>nd</sup> March. These people are responsible for overseeing both HILDA and the LSAC. We spent the day discussing researcher-department relationships and reporting systems, cohort recruitment and maintenance, data integrity, statistical issues including imputation, confidentiality, reporting methods and other practical aspects of longitudinal survey management.

### **South West Sydney Area Health Service (SWSAH)**

Staff from SWSAH, led by Margo Moore, are putting together a longitudinal survey on the health needs of women in the Villawood area. They have corresponded with us on several occasions on survey design, sample size and related matters. Five of the staff visited the office in January 2001 to talk through the practicalities of design, and statistical issues relating to measures and sample sizes. We provided them with a power analysis which suggested that they would need a sample of 360 women to detect a meaningful difference in SF-36 MCS, and have continued to provide input into survey design and clarification of aims and objectives.

### **Monash Institute of Reproduction and Development**

A coalition of endocrinological researchers, led by Professor David de Kretzer of the Monash Institute of Reproduction and Development, is proposing a longitudinal study on the health of middle-aged and older men. Christina Lee attended a planning meeting in Melbourne on 18<sup>th</sup> May 2001, to provide input from this project to help them to establish the detailed objectives and the optimum study design of a longitudinal study, develop the project outline and research plan, determine the budget and resource requirements for such a longitudinal study, assess the efficacy and cost effectiveness of the proposed longitudinal study and consider the long-term funding requirements for such a study and to establish potential sponsors for such a study. This meeting covered a range of topics, including the relative strengths and weaknesses of representative mailed surveys and targeted physiological research; relevant outcomes; social versus biological view of men's health; practicalities of organization. The process is in the early planning stages but we have agreed to continue to provide input on the basis of our experience.

## **8.5 MEDIA**

### **Newspaper articles**

- 19/2/01 Article in Adelaide Advertiser, "Why young women fail stress test" – Christina Lee.
- 20/2/01 Article in Adelaide Advertiser, "Young women's weight worry" – Anne Young. (Book Launch)
- 20/2/01 Article in MX Free News Ltd (Melbourne), "Image Eating at women" – Christina Lee.
- 02/3/01 Article in Medical Observer, "Young women stressed out" – Christina Lee.
- 28/3/01 Article in The Australian, "A changing world for women, mostly for the better", - Lois Bryson.
- 28/3/01 Article in The Age, "Women's liberation a thing for the future" – Lois Bryson.

- 28/3/01 Article in The Sydney Morning Herald, “Why women’s work is never done” – Lois Bryson.
- 28/3/01 Article in The Sydney Morning Herald, “Full-time motherhood an ambition of a tiny few” – Lois Bryson.
- 30/3/01 Article in Australian Doctor, “Younger female patients more likely to complain” – Christina Lee.
- 11/4/01 Article in The Age, “Young and stressed out” – Lois Bryson.
- 21/4/01 Study mention in article in The Age, “Does Fatherhood have a future”
- 10/4/01 Article in Newcastle Herald, “Young women stress heads” – Lois Bryson.
- 11/4/01 Article in Daily Telegraph, “It’s dollars, not sense that keeps Mums home” – Lois Bryson
- 1/5/01 Condensation of Chapter 7.1 of Women’s Health Australia, What do we know? What do we need to know? Article titled “Great Expectations”.
- 21/5/01 Article in Daily Telegraph, “The thin end on the edge” – Christina Lee.

### **Radio interviews**

- 26/3/01 ABC Radio Angela Katerns, “Women in 2001” – Lois Bryson
- 26/3/01 ABC Radio James Valentine, “Combining Family and Employment” – Lois Bryson.
- 15/3/01 New FM Newcastle, “Combining motherhood and work” – Lois Bryson
- 11/4/01 Macquarie Radio Network, “ Young women and Motherhood” – Chris Lee
- 22/4/01 ABC Radio 2NC Newcastle interview with Lindy Burns, “Body image and progress of Women’s Health Australia” - Christina Lee
- 23/4/01 ABC Radio 2NC Newcastle interview with Lindy Burns, “Iron Deficiency” – Amanda Patterson.
- 23/4/01 2HD (Newcastle) News grab, “Iron Deficiency” – Amanda Patterson
- 23/4/01 ABC Radio 2NC (Newcastle) News grab.
- 28/5/01 ABC Radio National interview with Dr Norman Swan for The Health Report, “Urinary Incontinence in Women” – Pauline Chiarelli
- 28/5/01 ABC News Radio with Dr Norman Swan for Health Minutes, “Urinary Incontinence” – Pauline Chiarelli

### **8.5.3 Television interviews**

- 13/2/01 ABC National Television News interview with Sophie Scott –“Book Launch” Chris Lee.
- 13/2/01 Channel 10 National News, “Book Launch”. - Chris Lee

## **9 ARCHIVING**

## 9.1 UPDATE ON ARCHIVING AT SOCIAL SCIENCE DATA ARCHIVES (SSDA)

The data from the main cohorts (Survey 1 of all cohorts and Survey 2 of mid-age and older cohorts) were archived according to the plans described in Report 15, in January 2001.

## 10 FINANCIAL STATEMENT

Total estimated expenditure for 2001 exceeds income from grant and other sources during this period by \$49,119. This is in line with the predicted deficit for this year, of \$43,451, which appears in Report 10 (December 1998). As stated in that report, the total income provided for the project for this funding period is considerably lower than that recommended by the reviewers. It is also the case that additional costs have become necessary that were not anticipated at that time; for example, this year's requirement that we contact every woman and request consent to access Medicare records was not costed in those forward projections. There have been other cost increases, including increased award rates for staff. The deficit will be made up by Research Quantum earnings saved from previous years, but this cannot be maintained indefinitely, and this is not the purpose of the Research Quantum funding. It is notable that the Medicare consent procedures make this an unusual and expensive year, but these figures illustrate the extreme care that must be exercised in order to keep the project running with the funds allocated. Funds from other sources are accessed whenever possible; for example, in this six-month period we have been successful in obtaining \$2,783 from the University of Newcastle's Research Infrastructure Block Funding to offset the costs of upgraded computers for statisticians, and \$2,400 from the University of Newcastle's Research Management Committee to offset the costs of international travel. There have also been significant contributions to the project this year from the University of Queensland, who have paid the salary of the statistician who is based there.

**Table 54 Expenditure January- June 2001, based on University of Newcastle Financial Reporting System 22/5/01. Account 593-1029.**

NB Excludes income and expenditure associated with book publication

INCOME			EXPENDITURE			
Source	Details	Income (includes July -Dec 01)	Items	Actual Expenditure 1/1/01- 22/5/01	Forward Estimate 23/5/01- 30/6/01	Forward Estimate 1/7/01- 31/12/01
DHAC	Contract	391,500	Shared research (UQ)	22,500	0	45,000c
		414,000 (July-Dec 01) <sup>c</sup>	Shared research (Principal Investigators)	7,421	3,000a	6,000a
			Surveys & data entry	35,615	36,183a	0

			Newsletters	0	0	50,000 <sup>d</sup>
			Data linkage (AEC, HIC)	0	5,528a	0
			Computer hardware, software	9,208	2,282a	3,000 <sup>b</sup>
			Equipment & maintenance	633	190b	850 <sup>b</sup>
			Postage & freight	994	8,548a	20,000 <sup>b</sup>
			Telephone	1,687	506b	9,000 <sup>b</sup>
			Printing, stationery, office supplies	1,383	415b	1,500 <sup>b</sup>
			General consumables/ Repairs	983	295b	1,100 <sup>b</sup>
			Travel/ Hospitality	7,544	2,000b	5,000 <sup>b</sup>
			Salaries	140,103	42,031a	182,000 <sup>a</sup>
			On-costs	34,421	10,326a	45,000 <sup>a</sup>
			Annual Report	0	3,033a	5,000 <sup>b</sup>
			University O'head charge	55,350	0	55,350 <sup>a</sup>
U of N	Research Contribution	50,000	Postgraduate scholarships/ fees	7,930	2,379a	11,000 <sup>a</sup>
	Research Infrastructure	2,783	Postdoctoral fellowship	22,239	6,672a	0
			On costs	1,291	388a	0
			Student research costs	95	90b	300 <sup>b</sup>
	Conference Travel Grants	2,400				
<b>TOTALS</b>		<b>850,683</b>		<b>349,397</b>	<b>123,654</b>	<b>443,100</b>

<sup>a</sup> firm commitment

<sup>b</sup> figures are estimates

<sup>c</sup> according to current contract

<sup>d</sup> estimate for newsletter and HIC consents

## **11 PROJECT STAFF JANUARY- JUNE 2001**

Staffing has been stable over the period of this report, with some turnover among research assistants and students but the situation remaining essentially unchanged since 2000. Dr Gita Mishra, Investigator, who has been with the project since its inception, has taken a position at the Medical Research Council Human Nutrition Research Unit, Cambridge, UK. She has been appointed an Honorary Senior Research Fellow with the Research Centre for Gender and Health, University of Newcastle, and continues to be closely involved with the project.

### **11.1 FULL-TIME STAFF LOCATED AT RESEARCH CENTRE FOR GENDER AND HEALTH**

Project Manager:	Professor Christina Lee
Data Manager:	Ms Jean Ball
Statistician:	Dr Anne Young
Statistician:	Ms Jennifer Powers
Postdoctoral Research Fellow:	Dr Amanda Patterson
Research Assistants:	Mrs Lyn Adamson Mrs Joy Goldsworthy
Secretary:	Ms Emma Threlfo/Ms Penny Knight (shared position)

### **11.2 INVESTIGATORS ON THE LONGITUDINAL SURVEY**

Professor Annette Dobson, School of Population Health, University of Queensland, Study Director  
Professor Wendy Brown, School of Human Movement Studies, University of Queensland  
Emeritus Professor Lois Bryson, Research Centre for Gender and Health, University of Newcastle, and RMIT University  
Associate Professor Julie Byles, Centre for Clinical Epidemiology and Biostatistics, University of Newcastle  
Associate Professor Justin Kenardy, School of Psychology, University of Queensland  
Professor Christina Lee, Research Centre for Gender and Health, University of Newcastle  
Dr Gita Mishra, Medical Research Council Human Nutrition Research Unit, Cambridge, UK  
Associate Professor Margot Schofield, School of Health, University of New England  
Dr Penny Warner Smith, Department of Leisure and Tourism, University of Newcastle  
Associate Professor Gail Williams, School of Population Health, University of Queensland  
Dr Anne Young, Research Centre for Gender and Health, University of Newcastle

### **11.3 ASSOCIATE INVESTIGATORS CURRENTLY WORKING WITH THE MAIN COHORTS**

Dr Surinder Baines, Discipline of Nutrition and Dietetics, University of Newcastle  
Dr Kylie Ball, School of Health Sciences, Deakin University  
Dr Martin Bell, Department of Geography, University of Adelaide  
Associate Professor Peter Brown, Department of Leisure and Tourism Studies, University of Newcastle  
Ms Pauline Chiarelli, Faculty of Medicine and Health Sciences, University of Newcastle  
Ms Susan Donath, Key Centre for Women's Health in Society, University of Melbourne  
Dr Susan Feldman, Alma Unit on Women & Ageing, University of Melbourne  
Dr John Germov, Department of Sociology and Anthropology, University of Newcastle  
Dr Marilys Guillemain, Centre for the Study of Health & Society, University of Melbourne  
Dr Rafat Hussain, School of Health, University of New England  
Dr Helen Jonas, School of Health and Human Sciences, La Trobe University, Bendigo  
Dr Helen Keleher, School of Health and Human Sciences, La Trobe University, Bendigo  
Dr Ann Larson, Combined Universities Centre for Rural Health, Geraldton  
Dr Julia Lowe, Discipline of Endocrinology, University of Newcastle  
Dr Ruth McNair, Department of General Practice, University of Melbourne  
Ms Sue Outram, Faculty of Medicine and Health Sciences, University of Newcastle  
Dr Nancy Pachana, School of Psychology, University of Queensland  
Dr Amanda Patterson, Research Centre for Gender and Health, University of Newcastle  
Dr Barbara Pocock, Discipline of Social Inquiry, University of Adelaide  
Dr Stewart Trost, School of Human Movement Studies, University of Queensland  
Ms Lauren Williams, Discipline of Nutrition and Dietetics, University of Newcastle  
Dr Deirdre Wicks, Department of Sociology, National University of Ireland, Galway

### **11.4 STUDENTS**

#### **11.4.1 PhD**

Mrs Sandra Bell, Research Centre for Gender and Health, University of Newcastle  
Ms Julie Brooks, Department of Sociology and Anthropology, University of Newcastle  
Ms Pauline Chiarelli, Faculty of Medicine and Health Sciences, University of Newcastle

Ms Julie Hodges, Department of Leisure and Tourism, University of Newcastle  
Ms Deborah Loxton, School of Health, University of New England  
Ms Lisa Milne, Department of Sociology and Anthropology, University of Newcastle  
Ms Heather McKay, Key Centre for Women's Health in Society, University of Melbourne  
Ms Glennys Parker, Research Centre for Gender and Health, University of Newcastle  
Ms Gabrielle Rose, School of Population Health, University of Queensland  
Ms Allison Schmidt, Research Centre for Gender and Health, University of Newcastle  
Mr Esben Strodl, School of Psychology, University of Queensland  
Ms Lauren Williams, Discipline of Nutrition and Dietetics, University of Newcastle

#### **11.4.2 Masters degrees**

Ms Fiona Campbell, Discipline of Behavioural Science in Relation to Medicine, University of Newcastle  
Ms Melissa Graham, School of Health and Human Sciences, La Trobe University, Bendigo  
Ms Nadine Smith, Research Centre for Gender and Health, University of Newcastle

### **11.5 PART-TIME AND CASUAL STAFF AT RESEARCH CENTRE FOR GENDER AND HEALTH, JANUARY-JUNE 2001**

Ms Jane a'Beckett  
Mrs Sandra Bell  
Ms Jenny Dannatt  
Ms Eliza Fraser  
Ms Alicia Frost  
Ms Sheree Gregory  
Ms Renay Grieg  
Mrs Vibeke Hansen  
Ms Jennifer Helman  
Mr Marc Howlett  
Mrs Claire Johnson  
Ms Natasha Matthews  
Ms Lisa Scobie  
Ms Zoe Turner

### **11.6 STAFF AT THE UNIVERSITY OF QUEENSLAND**

Ms Noela Baigrie, Research Officer, School of Population Health  
Ms Anne Russell, Senior Project Officer, School of Population Health



# **Appendix 1**

## **Collaborative research activities**

## **Appendix 1.1**

**Minutes of formal teleconferences (29 January, 26 February and 29 May) and face-to-face meeting (26 April) held among main study investigators**

**UN/UQ TELECONFERENCE  
Monday 29 January 2001**

**Present:** Annette Dobson, Christina Lee, Julie Byles, Penny Warner-Smith, Lois Bryson ,Wendy Brown, Margot Schofield

**Apologies:** Justin Kenardy, Anne Young, Peter Brown

**Minutes:** Emma Threlfo

**Gita Mishra will be sent minutes**

Item No	Item	Action	By whom/ due date
1	<p><b>Apologies</b> Anne Young, Justin Kenardy, Peter Brown</p>		
2	<p><b>Minutes from previous meeting</b> All on agenda for discussion</p>		
3	<p><b>Report from Christina - PAC/DRG meeting Dec 2000; Young 2; Mid 3; Newsletter and HIC; substudies and analyses 2001; office news</b></p> <p><b>PAC/DRG meeting</b> –Comments in notes circulated. Christina to finish changes to draft minutes of meeting and send to Wendy Fahy at DHAC.</p> <p><b>Y2</b> - reached 70% response rate, young demographics changed which explains why they were so hard to find. Everyone pleased with this effort.</p> <p><b>M3</b> - survey is finalised, has been piloted and circulated. One screening question added about mobile phone usage, because Annette has had some links with Anti Cancer Council who are interested in health outcomes of mobile phone users. Collecting this basic data will create a foundation for looking at exposure later on. Also possibility of a special study on exposure. Scheduled to run on the 19<sup>th</sup> March. Only received one tender, NCS (who ran y2 last year) estimate actually lower than last year, as we are not budgeting for as many second surveys to be sent out. Jean checked tender very carefully, and accepted tender. NCS have been sent the survey to get started on.</p>	Amend minutes	Christina asap

Item No	Item	Action	By whom/ due date
	<p><b>Newsletter &amp; HIC</b> - Decided to send out the consent form with the newsletter. Need consent from University of Newcastle, HIC, DHAC and DVA. Probably have to prepare draft materials and seek approval from individuals, at least at DVA and DHAC, full ethics committee at Newcastle University and HIC. Christina to write to each committee to remind them of the study and ask what we need to do to ask for consent again. Planning on mailing out in June.</p> <p><b>Substudies &amp; analyses - Postgraduate &amp; Honours students</b></p> <p>Margrette Young - Julie to check what she is doing this year. If she is not doing anything, she should really terminate the enrolment. We have never received any data from her survey. Unless there has been high level activity recently, Julie will contact graduate studies and terminate enrolment.</p> <p>Lisa Milne - Christina has met with Lisa a couple of time this year. She has developed a survey to be sent out in May 2001. Lisa sought advice from Gita about the sample to be drawn. She will discuss this with Jean closer to mailout.</p> <p>Alan Bolton - He was given 2<sup>nd</sup> semester 2000 leave of absence. Has made no progress at any time. Christina and Annette to find out if he is enrolled and terminate if so.</p> <p>Julie Hodges – new student - scholarship - interested in looking at Yoga. Peter and Penny jointly supervising Julie.</p> <p>Visitor today - a PhD student Heather McKay, supervised by Jane Fisher at Key Centre for Women's Health, University of Melbourne. Looking at women's fertility choices in both young and mid. Why women do not have children?</p> <p>Possibility of Margot having a PhD student next year, looking at domestic violence and cosmetic surgery. Rafat and Margot working on research proposal for February.</p> <p>Cathy Regan - PhD looking at risk and resilience in the elderly. Hasn't got any plans to go back to WHA participants at this stage. Julie will inform if there are any changes.</p>	<p>Christina starting to look at previous documentation and tracking down names of the chairs of committees</p> <p>Julie to contact her</p> <p>Check Alan's enrolment</p>	<p>Christina asap</p> <p>Julie</p> <p>Christina</p>

Item No	Item	Action	By whom/ due date
	<p><b>Substudies &amp; analyses - Substudies involving data collection 2001</b></p> <p>Surinder Baines - She has been conducting pilot study with university students on dietary choices, vegetarians, those who avoid meat. Has plans to survey young vegetarians, but may not be this year. Margot also submitting a proposal on surveying WHA vegetarians. Should not overlap.</p> <p><b>Substudies &amp; analyses - Subsidiary Analyses 2001</b></p> <p>Margot - writing up a paper with Rafat on cosmetic surgery in mid.</p> <p>Wendy - working with Stewart Trost in QLD. Would like to have a look at the data before writing an abstract. Wants to look at tracking health risk behaviour of the young cohort. Continuation of 'life's a party?' paper. Have to be careful about not overlapping with Helen Jonas - Drinking. Wendy and Stewart to submit an abstract, possibly 'Is life still a party for young women?'</p> <p>Nadine - visiting Annette to talk about her PhD</p> <p><b>Office news-</b> 2000 glossy reports and newsletters have been sent out</p> <p>Jean re-archived all of baseline, mid 2 and old 2 (4<sup>th</sup> January). Young 2 expected to be archived April</p>		
4 4.1	<p><b>Strategic issues</b></p> <p><b><i>Indigenous cohort</i></b></p> <p>After the advisory committee meeting there was a meeting in Brisbane attended by ATSI people from Canberra and Brisbane. Recommendation that the indigenous cohort is completely separated from the main cohort and the University of Newcastle. Annette to speak with and write to Janet Greely and Robyn Millthorpe to support this separation with reasons to reinforce this. Gail is required to put a proposal together by 1<sup>st</sup> March about future direction with the indigenous cohort. Deliverables had not been met in Dec and QLD cohort only received half the payment.</p>	Annette to report back with progress on separation	Annette

Item No	Item	Action	By whom/ due date
4.2	<p><b><i>Terms of reference for review</i></b></p> <p>When Annette spoke to Adele, she said that she would speak to senior people at NHMRC. Talked about possibility of NHMRC and DHAC jointly funding. We have to make sure the Department continue to put our funding in their budget. Ensure the Project Advisory Committee is aware of us. We are currently under the Public Health Division - Robyn Milthorpe. Office of NHMRC do the paperwork. Important to keep stronger links with other departments for refunding. Lois to try and keep integrated among various departments.</p> <p>Robyn Milthorpe has circulated previous set of terms of reference to the Project Advisory Committee</p> <p>PAC nomination suggestions: Prof Simon Chapman, Diana Kuh, Graham Coleman, Pat Kaufert (very first in the funding round), Sally Redman, Steve Leeder.</p>	<p>Lois to find out about the Department's budget cycle</p> <p>Any further suggestions to Christina</p>	<p>Lois</p> <p>Christina</p>
4.3	<p><b><i>Old 3 - preliminary progress, development process (JB to report)</i></b></p> <p>Should begin process by considering what items should be retained and removed. Julie thinks no new questions should be included in the survey, rather consolidate what we have previously asked. Suggestion that survey 2 be sent to investigators and returned to Julie with comments. Julie can then look at consistency, and report back. At some stage a workshop could be conducted. Investigators to identify: items for deletion, items that are essential and nominate additional items or concepts to be covered with a rationale and return to Julie. Essential to get some comparable data points at this stage.</p>	<p>Christina to arrange for old 2 to be circulated by email with a deadline</p>	<p>Christina</p>

Item No	Item	Action	By whom/ due date
5	<p><b>Any other business</b></p> <p>Budget - Christina to follow up on.</p> <p>Book launch - Lyn to work on promotions. Christina in the process on proof reading the second half of the book. Lois confirmed with Anne Edwards about the launch.</p> <p>Margot not available for the next 12 months, study leave in Cambridge with Gita for first 6 months. Margot will let us know her new contact details.</p>	Christina to provide investigators with budget overview	Christina

**Meeting closed: 12.30pm**

**Next meeting: 26<sup>th</sup> February 2001**

**UN/UQ TELECONFERENCE**  
**Monday 26 February 2001**

**Present:** Annette Dobson, Christina Lee, Anne Young, Lois Bryson, Wendy Brown, Justin Kenardy

**Apologies:** Margot Schofield, Peter Brown, Penny Warner-Smith, Julie Byles.

**Minutes:** Emma Threlfo

*Gita Mishra will be sent minutes*

Item No	Item	Action	By whom/ due date
1	<b>Apologies</b> Margot Schofield, Peter Brown, Penny Warner-Smith, Julie Byles.		
2	<b>Minutes from previous meeting</b> All on agenda for discussion		
3	<p><b>Report from Christina: PAC/DRG meeting Dec 2000; Young 2; Mid 3; Newsletter and HIC; substudies and analyses 2001; office news</b></p> <p><b>PAC/DRG meeting</b> - Annette and Christina have modified the minutes and sent them back. Haven't heard anything back. Christina has been invited to speak at the DHAC Research and Development committee meeting on the 24<sup>th</sup> May. Christina has asked Robyn Milthorpe to set up some meetings with other people from DHAC.</p> <p><b>Women's Health Network Conference - Adelaide</b> - workshop on Sunday - 37 participants, mostly from service delivery, some from universities. Presented on WHA, discussion on important issues. Lois thought the meeting went very well. At the end of the day, the presentation was wound up by Dorothy Broom, Angela Taft and Lois. Lois stressed that the study provides the base data, and it is up to others to make use of it. Some groups felt that the study was missing special groups. It was explained that WHA can collaborate with researchers by using WHA data as a basis for further research.</p> <p>Book launch held on Monday. Anne Edwards - VC of Flinders - spoke very highly of the WHA</p>		



Item No	Item	Action	By whom/ due date
	<p>project. Sold 90 copies of the book at the conference. Everyone got order forms. Publicity was good, ABC news, channel 10, local Adelaide newspapers and radio. Complimentary books also given to important people attending the conference. Also selling books at the Rural Health Conference. Lois spoke with Anne Edwards who is forming a group at Flinders to look at conducting collaborative analysis with WHA on feminist issues.</p> <p><b>Y2</b> - Sent final batch of surveys to NCS on Friday. Achieved response rate 70%. Data cleaning and checking will be done as soon as possible.</p> <p><b>M3</b> - Has been proof read, and colours chosen. Pilot FFQ data sent to ACCV, still waiting on results. Pilot data were entered and missing data looked at, changes were made on the basis of the pilot survey. On track to go out on the 19<sup>th</sup> March.</p> <p><b>Newsletter &amp; HIC</b> - Materials have been finalised. Jigsaw theme 'help us complete the picture'. Christina planning to send the materials to DVA and DHAC for approval asap.</p> <p><b>Substudies &amp; analyses</b> -  Marilys Guillemin - has already completed substudy with mid aged women on heart disease. Marilyns has put in an NHRMC application, with Christina as an Investigator to do the same study but with the old cohort in 2003.</p> <p>Esben Strodl - has completed draft of his paper</p> <p><i>See notes for other substudies and analyses</i></p> <p><b>Budget-</b> Budget tight (<i>see notes</i>) There is nothing we can cut, but Chris feels funds are ok. Other sums of money are possible. Chris putting in for Research Infrastructure Block Grant for two new computers and CD burner (\$6000). Chris successful in gaining travel grant for conference in Seattle. As much as possible, other sources of funds are being found.</p>	<p>Justin to ask Esben to circulate it.</p>	<p>Justin</p>

Item No	Item	Action	By whom/ due date
4 4.1	<p><b>Strategic issues</b> <b>Indigenous cohort</b> (AD to report)</p> <p>Annette talked with Janet Greeley and Adele Green, who were in favour of separating the main and indigenous cohorts. Annette drafted a letter on Janet's request and phoned Robyn Milthorpe. Robyn asked Annette not to send the letter for another fortnight, while Robyn discussed options with OATSIH. Annette to follow up on this. Request is for the indigenous to have a separate contract. Jackie Huggins - Deputy Director of the ATSI unit at the University of Queensland may be a good contact to speak with. Anne Edwards mentioned to Lois to speak with Jackie. Run it past Cindy Shannon first.</p>	<p>Documents to be sent to Chris</p> <p>Annette to follow up</p>	<p>Annette</p> <p>Annette</p>
4.2	<p>Substudies with older cohort</p> <p>Chris suggested that very soon, we should cease substudies with the old cohort. Need to be careful not to overload them so we can keep them in the main study. Possibly put in main study a question asking if they wish to participate in further substudies, as some really enjoy completing the surveys. Needs to be very clear to the participants.</p> <p>Old 3 Stage one - everyone was circulated old 2. Comments to be back to Julie by end of March. Chris and Julie will collate the comments and suggestions and organise an investigators' meeting to discuss. Annette suggests a question on screening for cognitive impairment. All extra questions have to have rationale to be included. Annette and Justin working with Nancy Pachana on finding a validated smaller scale. Old 3 has to be reduced, less questions and larger font will have to be used. CESD scale needs to be discussed to see if worth including in old 3. Need to measure depression accurately. All information to go to Julie by end of March.</p>	<p>Add question in old 3 about further substudies</p> <p>Justin to continue discussing this with Nancy</p> <p>Send comments on old 3 to Julie by March</p>	<p>Chris to look into</p> <p>Justin</p> <p>All</p>
5	<p><b>Any other business</b></p> <p>Wendy went to DVA last week, and met with the Head of Health Promotion Unit. Establish a cohort of Vietnam Veterans. Christina was asked about the WA Elderly cohort (data on older men, comparing with our data on older women). What's the feeling on bringing in new cohorts? Would</p>	<p>Wendy and Annette to discuss and report back to the group with any</p>	<p>Wendy</p>

Item No	Item	Action	By whom/ due date
	<p>have to have own budget, with own staff members. There are some problems working with vets: Legal consequences, reluctant to provide health information, may believe it would affect their current benefits. There are huge differences in three major cohorts; WWII, Vietnam, Gulf War. It is very difficult to extrapolate in comparison to each other. Justin heard DVA were very interested into research into family of veterans. If we were going to start a new cohort, we would need to employ a Senior Project Officer at UQ or UN (whichever location was chosen). Will have to put in a submission.</p> <p>PHA Conference - September – Sydney Would be good if WHA could do a symposium on qualitative/quantitative data. This is one of the themes of the conference. Anyone interested in attending, to email Chris.</p> <p>Lauren started work on the FFQ data she collected in her substudy (n=900). Anne asked her to put a report together on results.</p> <p>Anne putting together a databook on the HIC data, that we have just received. Anne asks if we need to do a report on statistical analysis to keep everyone up to date?</p> <p>Anne also putting together a report on the GISCA meeting last week. They are interested in collaborating with WHA. They work on location coding, using ARIA scores etc. ABS and Dept of Health now use ARIA scoring.</p> <p>Rural Health Conference - Canberra - Next week Chris, Anne and Penny presenting. Chris (general WHA and older women) , Anne (ARIA and RRMA) and Penny (young women and life choices).</p>	<p>developments</p> <p>Christina to send an email around to who would be interested in presenting</p> <p>Anne to circulate report on current statistical analysis.</p>	<p>Christina</p> <p>Anne</p>

**Meeting closed: 12.30pm**  
**Next meeting: 23<sup>rd</sup> April 2001**

**UN/UQ MEETING (in lieu of teleconference)  
Thursday 26<sup>th</sup> April 2001**

**Present:** Annette Dobson, Christina Lee, Anne Young, Wendy Brown, Penny Warner-Smith, Julie Byles, Nancy Pachana.

**Minutes:** Penny Knight

Item No	Item	Action	By whom/ due date
1	<p><b>Apologies</b> Margot Schofield, Lois Bryson, Justin Kenardy, Gita Mishra Peter Brown</p>		
2	<p><b>Minutes from previous meeting</b> All on agenda for discussion.</p> <p><b>Report back on Adelaide Conference:</b> It was a success. 195 copies of the book sold. We need to sell 450 to cover costs. Order forms to be handed to PI's for distribution at conferences, seminars etc. Include an item in newsletter about book, but soft sell. Perhaps a stall to sell books at PHA conference. Contact Judith Lumley at PHA.</p> <p>The conference led to a number of collaborations. Angela Taft raising funds to do a substudy on domestic violence and young women's reproductive health. Ruth McNair – Lesbian women and their health needs. Barbara Pocock – ACTU related project. Anne Edwards – getting together a group to explore women's health.</p> <p>Chris to email Anne re Wendy Brown's visit to Adelaide on Friday 18<sup>th</sup> May and possible seminar. Fran Baum is former president of PHA and should be contacted before this visit.</p> <p><b>BUDGET</b> 7 part timers at present, but the work will ease off and it won't cost as much to do the survey. HIC consents will generate cost, through need to send reminders, track, etc. Research overheads had been allocated but not actually transferred to the University since 1998, but this has now been rectified. Chris obtained a travel grant to go to Seattle. Two new computers were purchased, but a \$2700 grant covered the cost of one of them. \$10 000 ARC grant to Christina has been transferred to the Research Centre and this is being used to pay the part timers. Budget is tight but we are managing.</p>	<p>Contact Anne Edwards re possible visit</p> <p>Contact Fran Baum</p>	<p>Christina asap</p> <p>Wendy asap</p>
3	<b>STRATEGIC ISSUES:</b>		

Item No	Item	Action	By whom/ due date
	<p><b>INDIGENOUS COHORT:</b> THERE WAS A DISCUSSION ON THIS ISSUE. PROGRESS WITH THE INDIGENOUS COHORTS HAS BEEN SLOWER THAN HOPED. ANNETTE HAS BEEN DISCUSSING THIS ASPECT OF THE PROJECT WITH DHAC STAFF.</p> <p><b>TERMS OF REFERENCE:</b> THE DRAFT PREPARED BY CHRISTINA WAS DISCUSSED AND MODIFIED AND AN UPDATED DRAFT WILL BE CIRCULATED.</p> <p><b>Proposed meeting:</b> Christina, Annette and Wendy will attend 3 meetings in Canberra on Thursday 24<sup>th</sup> May.</p> <ol style="list-style-type: none"> <li>1 Meeting with OATSIH: two main issues – progress of special cohorts, use of existing data from indigenous women in main survey.</li> <li>2 Presentation to DHAC R&amp;D committee: Christina to prepare Powerpoint presentation and circulate to Annette and Wendy.</li> <li>3 Meeting with Alan Pettigrew, CEO of NHMRC: Christina reported that a package, including book, was recently sent to Alan Pettigrew. Annette reported that he was not well informed about ALSWH as yet. Christina to prepare a brief outline of items to be raised at meeting, including the Project Review, reviewers and terms of reference.</li> </ol> <p><b>PAC/DRG MEETING</b> Agenda items: terms of reference and how we manage the review process. June report in train.</p>	<p>Revise and circulate draft Terms of Reference</p> <p>Christina to ask Jenny Powers to extract some descriptive data. Christina to prepare presentation. Christina to prepare outline and circulate.</p>	<p>Christina asap</p> <p>Christina/Jenny asap</p>
4	<p><b>Report from Christina: Young 2; Mid 3; Old 3; Newsletter and HIC; substudies and analyses 2001; office news</b></p> <p><b>Y2</b> – 9597 surveys in. Jean now finalizing the database. Final report on response rates will be done once the database has been completed and checked.</p> <p><b>M3</b> - 7000 – 7500 surveys back. 4000 have been checked and logged. Reminder 2 is due to go out in the week of 7 May.</p>		

Item No	Item	Action	By whom/ due date
	<p><b>Old 3</b> – discussed at workshop this morning. Substudy question to be included.</p> <p><b>Newsletter &amp; HIC</b> – Approval for HIC consents received from the University of Newcastle. Joy Goldsworthy to include one and a half pages in the newsletter re the HIC consent. She will start today with the rest of the newsletter. No order form for book to go with newsletter but readers will be advised that the form is available on the website should they wish to order a book.</p> <p><b>Substudy &amp; Collaboration update</b> – We should be concentrating on the main surveys and getting substudy reports out and not starting new substudies. Good that the number of substudies has been reduced. Need to go back and see what we said we would do and compare that with what is currently done and planned.</p> <p><u>Vegetarian substudy</u> (Surinder) : iron, calcium deficiencies when someone becomes a vegetarian.</p> <p><u>PhD students</u>: Important that we keep numbers up to three full time students and as many part time/affiliated students as possible.</p> <p>Chris has been asked to co-supervise Heather McKay from the Key Centre for Women’s Health, in Melbourne, who is looking into women who don’t have children. <i>See table for more information on substudies.</i></p>		
5	<p><b>Strategic issues</b> Very important that we are ready for the meeting with Alan Pettigrew. Discussion of items from 1998 Report for Reviewers and the extent to which key research questions have actually been addressed. Need to explore strategies for funding additional statistics and data management positions.</p>	Christina to draw up table	Christina asap

**Meeting closed: 3:30 pm**  
**Next meeting: Teleconference 11am Tuesday 29<sup>th</sup> May**

**UN/UQ TELECONFERENCE**  
**Tuesday 29 May 2001**

**Present:** Annette Dobson, Wendy Brown, Christina Lee, Anne Young, Lois Bryson

**Apologies:** Julie Byles, Penny Warner-Smith, Gita Mishra, Margot Schofield, Justin Kenardy

**Minutes:** Emma Threlfo

Item No	Item	Action	By whom/ due date
1	<b>Apologies</b>		
2	<b>Minutes from previous meeting</b> All on agenda for discussion.		
3	<p><b>REPORT ON MEETING IN CANBERRA 24<sup>TH</sup> MAY</b> Annette, Chris and Annette attended 3 main meetings.</p> <p>First meeting with OATSIH. Purpose was to present the data from the main cohort on the indigenous and non indigenous women. Jenny Powers did preliminary analysis on comparisons of demographics and follow up rate. Presented what data we did have and the potential for doing additional analysis. Gail Williams and Noela Baigrie joined meeting by telephone.</p> <p>Second meeting involved presentation on the main study to DHAC Research and Development committee. All division heads attended plus NHRMC. Presentation went over extremely well.</p> <p>Third meeting was with NHMRC (Elspeth McLachlan). Talked about the review and reviewers. She suggested a number of NHMRC committees who she thought we should present to, because of their strategic importance. Robyn Milthorpe – Next time money be taken off the top of departments funding, instead of going to actual division. Spoke about refunding, and how much should be asked for. Suggested that Elspeth McLachlan should be invited to be a reviewer. Janet Greeley suggested some reviewers, but it was agreed they were not appropriate.</p> <p>Many things to do for the Department. Chris continuing to work with OATSIH about the main study data. Jenny having a look data in more detail. Request to look at mental health issues for</p>	Chris to add Elspeth to the list and email everyone the current list	Chris

Item No	Item	Action	By whom/ due date
	<p>indigenous women. Wendy to help develop a research plan for general practice in Australia. Annette to work on pap screening and monography estimates for Robyn Milthorpe. Chris also working on terms of reference and review with the department.</p> <p>Margaret McDonald now the Director of the Research and Quality at GP Branch and spoke to Chris about looking at ways of using their money to get more out of existing datasets. May have money to put into additional analysis (funding an additional position).</p>		
4	<p><b>STRATEGIC ISSUES:</b></p> <p><b>INDIGENOUS COHORT:</b> A NUMBER OF DISCUSSIONS IN CANBERRA, ABOUT WHAT MIGHT BE DONE. ONE OPTION BEING CONSIDERED IS SUPPLEMENTING THE MAIN COHORT. CANNOT CLOSE THE INDIGENOUS COHORT WITHOUT PUTTING SOMETHING IN PLACE. JANET GREELEY WISHES TO SEPARATE THE INDIGENOUS COHORT FROM THE MAIN STUDY. GAIL WILLIAMS REQUESTED TO VISIT CANBERRA TO EXPLAIN THE INDIGENOUS COHORTS PROGRESS. ROBYN SUGGESTED TO ANNETTE, THAT ANDREW BENSON SPEAK TO CINDY SHANNON. CHRIS INVOICING THE DEPARTMENT SOON, AND NEEDS TO KNOW WHETHER TO INCLUDE THE UQ MONEY. THEY HAVE NOT MET THE CONTRACTUAL OBLIGATIONS OF LAST DECEMBER YET, AND MONEY HAS BEEN WITHHELD BY THE COMMONWEALTH. THIS IS DAMAGING TO THE MAIN PROJECT. CHRIS SPOKE TO RON MACDONALD ABOUT IT IN JANUARY, AND HE SUPPORTS THE SEPARATION OF CONTRACT FOR THIS REASON. ROBYN WILL KEEP THINGS MOVING ALONG. ANNETTE TO FIND OUT FROM GAIL WHAT'S HAPPENING WITH THE INDIGENOUS WORK.</p> <p><b>TERMS OF REFERENCE:</b> TIMELINE TALKED THROUGH AT THE NHMRC MEETING AND IT HAS TO BE FULFILLED. ALL DOCUMENTS WILL BE GIVEN TO THE MINISTER. CHRIS BEGAN TO PULL OUT THE REPORT THAT THE GROUP PUT IN LAST TIME AND THE RESPONSE FROM THE REVIEWERS. SHOULD HAVE FACE-TO-FACE MEETING TO DETERMINE VISION AND PROPOSAL FOR THE NEXT 5 YEARS (AROUND EARLY NOVEMBER IN NEWCASTLE AFTER TEACHING</p>	Chris to outline what the study has achieved and issues in the last 5 years	Chris



Item No	Item	Action	By whom/ due date
	<p>PERIOD). SHOULD ALSO LIST ALL THE ISSUES RAISED AND CHANGES IN DIRECTION.</p> <p><i>PAC meeting : 13<sup>th</sup> June</i></p>		

Item No	Item	Action	By whom/ due date
5	<p><b>Report from Christina: Young 2; Mid 3; Old 3; Newsletter and HIC; substudies and analyses 2001; office news</b> (see additional notes)</p> <p><i>Y2</i> – finished, dataset on the G drive and Sandra starting to do a databook</p> <p><i>M3</i> – returns dropped off, starting phone reminders in 1-2 weeks</p> <p><i>Old 3</i> – draft developed from the workshop. Chris to make some changes and circulate again</p> <p><i>Newsletter &amp; HIC</i> – Waiting on tender documents, extra staff to assist</p> <p><i>Substudy &amp; Collaboration update</i> – Longitudinal study on men’s health – see notes</p>		
6	<p><b>Any other business</b></p> <p>Meetings every fourth Monday at 11am:</p> <ul style="list-style-type: none"> <li>• Monday 18<sup>th</sup> June</li> <li>• Tuesday 17<sup>th</sup> July (12 noon)</li> <li>• Monday 13<sup>th</sup> August</li> <li>• Monday 10<sup>th</sup> September</li> <li>• Monday 8<sup>th</sup> October</li> <li>• Monday 5<sup>th</sup> November</li> <li>• Monday 3<sup>rd</sup> December</li> </ul> <p>Anne presented to the Australasian Group of Women’s Hospitals and Children’s Hospitals – Conference in Sydney. ]</p>		

**Meeting closed:** 12.10pm

**Next meeting:** Teleconference 11am 18 June 2001

## **Appendix 1.2**

**Minutes of face-to-face meetings held among main study investigators, associate investigators and staff at the University of Newcastle (30 January, 27 February, 24 April and 22 May)**

**General Meeting  
30 January 2001**

**Present:** Christina Lee, Jenny Powers, Anne Young, Amanda Patterson, Peter Brown, Penny Warner-Smith, Julie Hodges, Glennys Parker, Heather McKay.  
**Apologies:** Lauren Williams  
**Minutes:** Penny Knight

<i>Item no</i>	<i>Item</i>	<i>Action</i>	<i>By whom/ due date</i>
1	<p><b>Welcome and apologies</b>            First general meeting for year 2001. Julie Hodges will be doing a PhD with Penny and Peter - Yoga and women's health and wellbeing - use of leisure to ensure wellbeing. Heather McKay (Melbourne) will be doing a PhD - women and childlessness, choices in child bearing decision making.</p>		
2	<p><b>Minutes &amp; matters arising</b>            All on agenda for discussion</p>		
3	<p><b>Young 2 update</b></p> <ul style="list-style-type: none"> <li>- Changes in demographics - see notes with agenda.</li> <li>- Two lots have been sent to NCS to be scanned. Another couple of hundred surveys will be sent once Jean gets back in mid February.</li> <li>- We have a 70% return.</li> <li>- Data available by end February and data book and archiving by April.</li> </ul>		
4	<p><b>Mid 3 pilot update</b></p> <ul style="list-style-type: none"> <li>- Ready to go</li> <li>- Accepted NCS bid to print, post, scan etc - no other tenders received. Cost is almost identical to last year and in fact ended up slightly lower because we will need smaller number of surveys for the mid cohort.</li> <li>- Time line: ethics done, Joy working on design for front cover and reminder cards.</li> </ul>		

<i>Item no</i>	<i>Item</i>	<i>Action</i>	<i>By whom/ due date</i>
	<ul style="list-style-type: none"> <li>- Have included an extra question in the survey about exposure to mobile phones. Use of mobile phones data being collected by the Cancer Council.</li> </ul>		
5	<p><b>Old 3</b></p> <ul style="list-style-type: none"> <li>- Going out 2002.</li> <li>- Pre pre-pilot was conducted on 110 old women to ask about preference to phone surveys or written surveys. 85 answered that they would not like a phone interview and would rather have time to answer the questions in writing without being under pressure.</li> <li>- Julie Byles taking the lead on Old 3.</li> <li>- No new questions will be inserted, and may have to cut down on the number of existing questions as the font size will have to be increased.</li> <li>- Chris to let everyone have a copy of the Old 2 survey, to read through and give opinions on what should stay and what should be left out. Chris to distribute and get back to Julie.</li> <li>- No new ethics approval required to use National Death Index again next year. Jenny to email them in December, to match in February.</li> <li>- The latest Medicare data include 'end dates' indicating that the person has died or emigrated permanently. These may be useful in identifying deceased and ineligible participants.</li> </ul>	<p>Chris to distribute and get back to Julie.</p> <p>Jenny to email Anne to research</p>	<p>Chris</p> <p>Jenny Anne</p>
6	<p><b>Newsletter and HIC consents</b></p> <ul style="list-style-type: none"> <li>- We have to seek consent to access Medicare data from everyone again this year. We got consent from 53% of the sample but have to go back and ask everyone again for their consent. We have decided to send out, with the newsletter, a brochure to sign and send back. We need to send out reminders and do tracking of people who do not respond. Make sure the mailing list is as comprehensive as possible before doing mailout.</li> <li>- Ethics clearance or approval from the University of Newcastle, DHAC, HIC and DVA. Formal applications to both DVA Ethics committee and the University of Newcastle. The Dept of Health and HIC - someone to authorise consent and does not have to go before a committee.</li> <li>- A month after initial mailout, reminders to be sent to between 20 000 and 30 000 women. After a further month, and send second mailout to any non-respondents. Thereafter women who previously gave consent and who have not responded will be phoned. Anyone who has previously expressed strong views of invasion of privacy will not be send a brochure.</li> <li>- Peter asked about the feasibility of using email addresses - this does not work well. We are however collecting email addresses and these will be used as a last resort in tracking.</li> </ul>		

<i>Item no</i>	<i>Item</i>	<i>Action</i>	<i>By whom/ due date</i>
	<ul style="list-style-type: none"> <li>- Penny suggested that the reminder form be a card rather than another piece of paper.</li> <li>- A new part time assistant for Jean has been appointed - Jenny Dannatt.</li> </ul>		
7	<p><b>Substudy update</b> Chris listed all the substudies for 2001.</p> <ol style="list-style-type: none"> <li>1 Young women - aspirations (Lisa Milne). Survey gone to ethics. She wants a sample of 400 high SES and 600 low SES who live in Sydney. Doubtful whether we have those numbers living in Sydney.</li> <li>2 Mid weight gain (Lauren). Data all in??</li> <li>3 Menstrual blood loss (Allison) - not using WHA women. 18 full sets of data collected.</li> <li>4 Coping with violence (Glennys) - survey sent out to 200 women in November 2000. 75% response rate.</li> <li>5 Menstrual problems - hysterectomy (Melissa) - took a long time to get through ethics, lots of delays - six month leave of absence from her degree and will do Survey 2 in the second half of the year.</li> <li>6 Leisure (Peter and Wendy). RMC grant. How leisure choices are negotiated in households. Conducting a time diary for two days with a follow up interview. Ethics approval obtained. Letter sent today and Vibeke will ring in two weeks to set project in context of main survey, check eligibility and answer questions. Never asked spouse to complete a survey before. Anne asked if there shouldn't be a question on pets included in the survey.</li> <li>7 Migration (Julie and Gita) - looking at telephone substudy of old women who have moved from rural to urban areas. Why do they move, and is it working out in the way they expected.</li> <li>8 Continence - (Julie) - follow up of national continence management strategy. RA to talk to Chris tomorrow.</li> <li>9 Diabetes - (Amanda). A RA to be employed to co-ordinate. Analyses of existing medical data. Looking at mid and old with diabetes. A substudy to ask about other services such as podiatrists, dietetics, medication etc. Looking at diabetes testing to see whether they are being tested in the correct way. Amanda gathering questions for substudy.</li> <li>10 Vegetarians - (Surinder) delays with Surinder's other commitments.</li> <li>11 Continence 2 - (Christina and Pauline) - not really a substudy. Pauline has a grant to look at early intervention project. Based on findings that mid women had some symptoms and did</li> </ol>		

<i>Item no</i>	<i>Item</i>	<i>Action</i>	<i>By whom/ due date</i>
	not seek help. Early intervention could have helped. Jean needs to know if a substudy is to be undertaken, all details to be given at least a month in advance, so that participants can be selected. Substudy surveys to be in different colours for ease of identification.		
8	<p><b>Conferences</b></p> <p>Next conference Australian Women's Health Network. The WHA book is to be launched on the Monday. Media release to coincide with launch. Target Universities which have women's health courses. Freebies to Journals.</p> <p>Order form on website? Order forms should be taken to all conferences attended to be distributed. Peter and Penny will take some to the ANZALS Conference in July. Exposure is very important. Database of purchasers to be set up - Jenny?</p> <p>Rural Health Conference in Canberra - lobby.</p> <p>Sociology conference at the end of the year. Presentation/workshop? Penny to talk to John Germov.</p> <p>Need someone to co-ordinate seminars this year.</p>		
9	<p><b>Reports</b></p> <p>Anyone who needs extra copies of the glossy report, to get from WHA office. Jon Boyages to get a copy - NSW Health.</p>		
10	<p><b>Any Other Business</b></p> <p>Seminars should be organised. Paper published, sent abstract to Rebecca Monk.</p> <p>Check with Emma that room has been booked for the year. Try and get W301B in the Human Sciences building for seminars.</p>	Emma to investigate	Emma

**Meeting closed: 2.25pm**

**Next meeting: Tue 27<sup>th</sup> February, 1 pm in V103**

## GENERAL MEETING

27 February 2001

**Present:** Christina Lee, Jenny Powers, Jean Ball, Anne Young, Amanda Patterson, Penny Warner-Smith, Julie Hodges, Lauren Williams, John Germov  
**Apologies:** Julie Byles  
**Minutes:** Emma Threlfo

Item no	Item	Action	By whom/ due date
1	<b>Welcome and apologies</b> See above		
2	<b>Minutes &amp; matters arising</b> All on agenda for discussion		
3	<b>Young 2 update</b> - Last 5 boxes sent to NCS for scanning on Friday. Should get data within 2 weeks. Jean will then clean up data for usage.		
4	<b>Mid 3 update</b> - Survey nearly finalised. Final proofs to be sent to NCS this week. Colours finalised. NCS will then start printing. Mailout proposed for 19 <sup>th</sup> March. - Lyn is starting to arrange part time staff		
5	<b>Old 3</b> - Old 2 sent out for comments and suggestions, mainly to cut questions not required. All surveys to be returned to Julie Byles. Chris and Julie will collate comments. Then a one day workshop will be held to finalise questions. - It was suggested that whilst editing main surveys, a list be kept of questions with problems. -	Send all comments to Julie by end of March	All
6	<b>Newsletter and HIC consents</b> - Joy has been working on layout and graphics - Chris sent to UN, DHAC and HIC for ethics approval. Will send to DVA this week. DVA		



Item no	Item	Action	By whom/ due date
	meeting on 6 <sup>th</sup> April for discussion. - Other 3 should be simpler as is a variation to current materials -		
7	<p><b>Substudy update</b></p> <ol style="list-style-type: none"> <li>1. Young women - aspirations (Lisa Milne). Waiting on ethics. Lisa has given Jean a list of postcodes to be drawn after she has completed work on mid 3.</li> <li>2. Mid weight gain (Lauren). Analysing and writing up.</li> <li>3. Menstrual blood loss (Allison) - proceeding.</li> <li>4. Coping with violence (Glennys) - data currently being entered.</li> <li>5. Menstrual problems - hysterectomy (Melissa Graham) - Second survey for mids, second half of the year. Presented at the Women's Health Network Conference.</li> <li>6. Leisure (Peter, Penny, Lois and Wendy). RMC grant. How leisure choices are negotiated in households. 10 participants have agreed to take part so far from first 30. Second sample drawn and were sent out package last week. All packages need to be sent out soon, as mid 3 will be mailed out in 3 weeks.</li> <li>7. Continence - (Julie) - follow up of national continence management strategy. Jean has been sent a list of post codes to see how many women fit the criteria.</li> <li>8. Diabetes - (Amanda/Anne). Amanda currently putting together questionnaire for ethics application. Will have to go to ethics in April. Anne working on Medicare data.</li> <li>9. Vegetarians - (Surinder) delays with Surinder's study. May try and recruit again now uni is back.</li> <li>10. Continence 2 - (Christina and Pauline) - Early stages of project. Working with FPA Health on intervention. FPA Health both nationally and locally happy to collaborate.</li> </ol>		

Item no	Item	Action	By whom/ due date
8	<p><b>Conferences</b>  <i>Women's Health Network Conference - Adelaide</i>  WHA organised a workshop which was very successful. 37 attended, with lots of discussion of future research topics. Lois, Chris, Julie and Anne presented. Other important people also presented; Dorothy Broom, Helen Keleher and Angela Taft.</p> <p>WHA book launch - Monday of the conference. Anne Edwards - VC of Flinders University spoke very highly of the project. Had lots of media attention and publicity; ABC, Channel 10, local newspaper and radio.</p> <p><i>Rural Health Conference in Canberra</i> - next week. Chris, Anne and Penny presenting.</p> <p><i>PHA in Sydney</i> - September. One theme on qualitative/quantitative data, how to combine? Suggestion that WHA could form a symposium. Some students like Glennys and Lauren as well as some investigators.</p> <p><i>The Australian Sociology Association conference (TASA)</i> - December. Interest is symposium.</p> <p><i>International Sociology Association conference in Brisbane</i> - 2002. Possible opportunity for symposium.</p>	<p>Emma to remind Lyn about uni news and dotpointers. Also send John the order form attachment</p> <p>Chris will email everyone to find out who would be interested in presenting</p> <p>John to look into</p> <p>John to look into</p>	<p>Emma</p> <p>Chris</p> <p>John</p> <p>John</p>
9	<p><b>Reports</b>  Next report due June 2001.</p>		
10	<p><b>Any Other Business</b>  3 NHMRC applications</p> <ul style="list-style-type: none"> <li>- Annette, Chris and Julie - analysis on widows, who has coped, who hasn't and what are the differences?</li> <li>- Marilys Guillemin - heart disease in old</li> </ul>		

Item no	Item	Action	By whom/ due date
	<ul style="list-style-type: none"> <li>- Margot and Rafat - relationship between domestic violence and cosmetic surgery</li> <li>Staff Excellence Awards - for office staff - Friday 16<sup>th</sup> March at 12.30pm</li> </ul>	Tell Emma if you wish to attend	

**Meeting closed - 2.00 pm**

**Next meeting - 24<sup>th</sup> April 2001 (w301b)**

**GENERAL MEETING**  
**24 April 2001**

**Present:** Christina Lee, Jenny Powers, Jean Ball, Anne Young, Lauren Williams, Julie Byles, Sue Outram, Surinder Baines  
**Apologies:** Penny Warner-Smith, John Germov  
**Minutes:** Emma Threlfo

Item no	Item	Action	By whom/ due date
1	<b>Welcome and apologies</b> See above		
2	<b>Minutes &amp; matters arising</b> All on agenda for discussion		
3	<b>Young 2 update</b> <ul style="list-style-type: none"> <li>- Final response rate is 70.8% - 9595 long surveys, 85 short surveys and a further 13 long surveys to be entered.</li> <li>- Data should be ready by next week</li> <li>- Databook to be created including frequencies and overall percentages. Need to decide whether to present by area of residence.</li> <li>- Data should also be added to the web page – including area of residence. Should weight them on where they were at baseline</li> </ul>	Sandra Bell will be asked to do databook To be discussed further at PI meeting. Chris to put on agenda	Jean Chris  Chris
4	<b>Mid 3 update</b> <ul style="list-style-type: none"> <li>- N=13,007</li> <li>- 7000-7500 surveys have been returned</li> <li>- 7 part time staff have been employed to open, edit and log surveys</li> <li>- Editing this year is a problem and very time consuming</li> <li>- Tracking has begun</li> <li>- Second reminder to go out 7<sup>th</sup> May</li> </ul>		

Item no	Item	Action	By whom/ due date
5	<p><b>Old 3</b></p> <ul style="list-style-type: none"> <li>- Workshop on Thurs 26<sup>th</sup> April (Canberra room, 9-12pm)</li> <li>- Julie has collated people's comments drawn from old 2</li> <li>- Julie also drawing up a list of principles for development, to be circulated before the workshop</li> <li>- Hopefully by the end of the workshop decisions will be made on what to include in the pilot</li> </ul>	All welcome to attend	
6	<p><b>Newsletter and HIC consents</b></p> <ul style="list-style-type: none"> <li>- UN ethics committee suggested revisions to the consent letter. These have been made and returned for approval</li> <li>- DHAC will approve materials if formal approval has been received from UN ethics committee</li> <li>- DVA have also approved materials</li> <li>- Anne has discussed including PBS and Repatriation PBS with HIC and decided to include in consent. DVA must now be informed and approval must be gained.</li> <li>- Anne discussed with Annette Hume what is required for consent form</li> </ul> <p>Newsletter</p> <ul style="list-style-type: none"> <li>- 1 ½ pages in the newsletter about HIC consent</li> <li>- Proposed mailout 18<sup>th</sup> June</li> <li>- First reminder 16<sup>th</sup> July</li> <li>- Second mailout 13<sup>th</sup> August</li> <li>- Phoning to begin 17<sup>th</sup> September</li> </ul>	Anne to ask for this in writing	Anne
7	<p><b>Substudy and collaboration update</b> (see notes for more detail)</p> <ol style="list-style-type: none"> <li>1. Leisure and health – (Peter Brown, Penny Warner-Smith, Wendy Brown, Lois Bryson). First mailout to 60 mids, 16 couples have agreed to take part from 60 and so far 7 diaries have been returned. Next mailout to youngs, going out next week.</li> <li>2. Menstrual problems (Melissa Graham). Follow up to go to mids, later this year.</li> <li>3. Young women - aspirations (Lisa Milne). Jean has drawn some more postcodes to increase numbers for study. Survey has ethics clearance.</li> </ol>		

Item no	Item	Action	By whom/ due date
	<p>4. Vegetarians (Surinder Baines). 120 surveys returned. Surveys will be data entered in second semester. Surinder also doing analysis on vegetarians from the main study data.</p> <p>5. Diabetes (Amanda Patterson, Anne Young, Julie Byles, Julia Lowe). Survey sent to ethics, waiting on approval decision. Jane a'Beckett working 2 days per week as an RA.</p> <p>6. Violence (Deb Loxton). Has received ethics approval to interview 30 women by phone. Mailout proposed for July/August. Phonecalls to be made from WHA office.</p> <p>7. Young and Alcohol (Helen Jonas). Ethics approval has been revoked, she is not allowed to phone anymore participants to return survey. Wants to put in revision to ethics to complete 25 face-to-face interviews.</p> <p><b>COLLABORATIVE ACTIVITIES (SEE NOTES FOR MORE DETAIL ON COLLABORATORS)</b></p> <p>1. Dr Ruth McNair – Department of General Practice, University of Melbourne (lesbian health). Currently seeking funds.</p> <p>2. Dr Angela Taft - Centre for the Study of Mothers' and Children's Health, LaTrobe University (Young women, reproductive health and intimate partner abuse).</p> <p>3. Dr Jane Fisher/Ms Heather McKay – Key Centre for Women's Health and Society, University of Melbourne (Childlessness). Christina has been invited to be an Associate Supervisor for Heather McKay.</p> <p>4. Dr Barbara Pocock – Department of Social Inquiry, University of Adelaide (Work, health and well-being). Jean sent data today for analysis.</p> <p>5. Beverley Lloyd – Department of Public Health and Community Medicine, University of Sydney (Employment, motherhood and health among young women). Beverley visiting next week.</p>	<p>Chris waiting on comments from Sue O'Connor</p>	<p>Chris</p>

Item no	Item	Action	By whom/ due date
	<p>6. Prof Anne Edwards – Vice Chancellor, Flinders University of South Australia.</p> <p>7. Dr Caroline Bolton-Smith – MRC Human Nutrition Research, Cambridge, UK (Dietary predictors of obesity across middle-aged Australian and British women). Lauren has expressed interest in being involved in collaboration.</p>		
8	<p><b>Conferences</b></p> <p>Conferences attended include:</p> <ul style="list-style-type: none"> <li>- Women’s Health Network Conference</li> <li>- Australian Rural health Conference</li> <li>- US Society for Behavioral Medicine meeting in Seattle</li> </ul> <p>(reports circulated with notes and agenda)</p> <p><b>UPCOMING CONFERENCES</b></p> <p><i>International Association of Gerontology Conference</i> - Julie, Margot and Susan Feldman presenting</p> <p><i>Australian Society of the Study of Obesity</i> – Lauren, Wendy, Justin all presenting</p>	Everyone presenting at conferences to send abstracts to Joy	All
9	<p><b>Reports</b></p> <p>Next report due June 2001. Chris and Joy have started on this.</p>	Everyone involved in a project should send Joy work in progress, abstracts, info on papers and presentations etc	All
10	<b>Any Other Business</b>		

Meeting closed - 2.05pm

Next meeting – Tues 22<sup>nd</sup> May (W301b)

**GENERAL MEETING**  
**22<sup>nd</sup> May 2001**

**Present:** Christina Lee, Jenny Powers, Jean Ball, Anne Young, Penny Warner-Smith, Amanda Patterson, Glennys Parker, Julie Hodges  
**Apologies:** Lauren Williams, John Germov, Julie Byles, Sue Outram, Surinder Baines  
**Minutes:** Emma Threlfo

Item no	Item	Action	By whom/ due date
1	<b>Welcome and apologies</b> See above		
2	<b>Minutes &amp; matters arising</b> All on agenda for discussion		
3	<b>Young 2 update</b> <ul style="list-style-type: none"> <li>- First version of the young 2 dataset on G drive</li> <li>- Will be some minor changes – due to late surveys etc</li> <li>- The young 2 databook will be compiled by Sandra Bell who will get started on this shortly</li> <li>- Archiving will be completed by the end of the year</li> </ul>	Sandra to begin y2 databook	Sandra  Jean
4	<b>Mid 3 update</b> <ul style="list-style-type: none"> <li>- N=13,007</li> <li>- 72% response rate and surveys are still arriving</li> <li>- Phone reminder to start in a few weeks</li> <li>- The last mailout prompted a response but not as much as expected</li> </ul>		
5	<b>Old 3</b> <ul style="list-style-type: none"> <li>- Workshop was successful and a draft compiled. Further changes were made and font increased to 14pt.</li> <li>- Currently survey stands at 27 pages, but will be cut to 24pages</li> <li>- Next step is piloting in the next couple of months</li> <li>- Given up on carpenter pencils as they would need sharpening before and during the survey</li> </ul>		



Item no	Item	Action	By whom/ due date
	<ul style="list-style-type: none"> <li>- Also given up on the idea of textas as the ink goes through the paper. Therefore we would need thicker paper and postage would be more expensive. It would almost double the cost of the mailout. The alternative is to make the bubbles flatter and possibly include a pencil.</li> </ul>	Emma to get quotes on pencils	Emma
6	<p><b>Newsletter and HIC consents</b></p> <ul style="list-style-type: none"> <li>- Consent form and Newsletter has been finalised and approved by Annette</li> <li>- Package went to tender 21/5 (Monday)</li> <li>- Proposed mailout 18<sup>th</sup> June</li> <li>- First reminder 16<sup>th</sup> July</li> <li>- Second mailout 13<sup>th</sup> August</li> <li>- Phoning to begin 17<sup>th</sup> September</li> </ul>		
7	<p><b>Substudy and collaboration update</b> (see notes for more detail)</p> <ol style="list-style-type: none"> <li>11. Leisure and health – (Peter Brown, Penny Warner-Smith, Wendy Brown, Lois Bryson). Still in the process of interviewing mid participants. Hope to be finished by the end of September.</li> <li>12. Menstrual problems (Melissa Graham). Follow up to go to mids, later this year.</li> <li>13. Young women - aspirations (Lisa Milne). Survey being printed, getting ready to pilot.</li> <li>14. Vegetarians (Surinder Baines). Ongoing</li> <li>15. Diabetes (Amanda Patterson, Anne Young, Julie Byles, Julia Lowe). Working on medicare data and graphs from mid and old data. Starting to pilot in Diabetes clinics around Newcastle to see if the questions are suitable. Then the survey will be piloted with WHA women. Jane a’Beckett is presenting WHA diabetes data at the Nutrition Society Meeting 23/5/01.</li> <li>16. Violence (Deb Loxton). Waiting until after school holidays. Phonecalls to be made from WHA office.</li> <li>17. Incontinence Intervention Project (Christina Lee, Pauline Chiarelli) – has to go back to ethics with revisions. Claire Johnson employed 3 days per week as a nurse and RA to help with the intervention in FPA clinics.</li> <li>18. Violence (Glennys Parker) – analysis stage.</li> <li>19. Menstrual Blood Loss (Allison Schmidt) – collecting data and analysing samples.</li> <li>20. Nadine Smith – finishing thesis.</li> </ol>		

Item no	Item	Action	By whom/ due date
	<p>21. Alan Bolton – Withdrawn from Masters.  22. Lauren Williams – analysing stage.  <b>COLLABORATIVE ACTIVITIES</b> (SEE NOTES FOR MORE DETAIL ON COLLABORATORS)</p> <p>8. Dr Ruth McNair – Department of General Practice, University of Melbourne (lesbian health). Waiting to see if we have enough women in the mids.  9. Dr Angela Taft - Centre for the Study of Mothers’ and Children’s Health, LaTrobe University ( Young women, reproductive health and intimate partner abuse).Went to Office of Status of Women for funding – pending.  10. Dr Jane Fisher/Ms Heather McKay – Key Centre for Women’s Health and Society, University of Melbourne (Childlessness). Christina has been invited to be an Associate Supervisor for Heather McKay.  11. Dr Barbara Pocock – Department of Social Inquiry, University of Adelaide (Work, health and well-being). Jean sent data two weeks ago for analysis. They are beginning to use the data.  12. Beverley Lloyd – Department of Public Health and Community Medicine, University of Sydney (Employment, motherhood and health among young women). Beverley visited the WHA office and is thinking about doing a PhD. Is writing up a proposal.  13. Prof Anne Edwards – Vice Chancellor, Flinders University of South Australia. Postponed for a couple of months.  14. Dr Caroline Bolton-Smith – MRC Human Nutrition Research, Cambridge, UK (Dietary predictors of obesity across middle-aged Australian and British women). Chris will contact Caroline.</p>		
8	<p><b>Conferences</b></p> <p>Anne– presented at Women’s Hospital Australiasia in Sydney on the 17<sup>th</sup> May</p> <p>Chris- visited Monash Institute for Reproductive Health and Development to discuss a Longitudinal Study on Men’s Health.</p> <p><b>UPCOMING CONFERENCES</b></p>		John

Item no	Item	Action	By whom/ due date
	<p>TASA – John is following up on.</p> <p>PHA – In September at Sydney. Julie submitted a proposal for a symposium on qualitative and quantitative data analysis. Students to be involved in presentation.</p> <p>Office of the Status of Women – Last week in August, still waiting on details.</p> <p>National Diabetes Conference – In August at Surfers Paradise.</p> <p>Australian Epidemiology Association – In September at Sydney. Jenny and Anne are submitting abstracts</p> <p>Nutrition Society Seminar – Lauren, Jane, Amanda, and Allison presenting tomorrow 23/5.</p>		
9	<p><b>Reports</b> June report nearly finished</p>		
10	<p><b>Any Other Business</b> Still looking for someone to assist Jean two days per week experienced in Access and statistical software.</p> <p>On the 14<sup>th</sup> June – a potential PhD student is visiting. Janette McCrow interested in childcare.</p> <p>Chris, Annette and Wendy attending meeting in Canberra with the research and development committee of DHAC. Also meeting with OATSI committee and the CEO of NHMRC. (24<sup>th</sup> May)</p>		

Meeting closed 1.55 pm

Next meeting Tues 19<sup>th</sup> June (W301b)

## **Appendix 1.3**

**Summary of regular face-to-face meetings held between University of Queensland main study and special cohort investigators (15 February, 13 March, 10 April and 15 May)**

## WHA-UQ MEETING

15 February 2001

**Present:** Annette Dobson, Justin Kenardy, Yvette Miller, Nancy Pachana, Esben Strodl  
**Apologies:** Wendy Brown, Gail Williams  
**Minutes:** Anne Russell

### Filipina Cohort

The 22 in-depth interviews on Filipina mental health have been coded and analysed using content and thematic analysis. The first draft of a paper is close to completion. The final manuscript will be prepared for submission to the International Migration Review mid-year.

### Indigenous Cohorts

Annette has drafted a letter to the DHAC proposing separation of the Main WHA Cohorts and the Indigenous Cohorts. DHAC requested a 2-week delay in sending the letter while they undertake negotiations with OATSIH.

Action: Annette to review progress of negotiations.

### Analysis

#### Missing CES\_D

- Nancy Pachana has spoken with colleagues in the US who have used the CES-D extensively. They observe that older people may not like completing items with frequency-based responses (such as CES-D) but rather prefer intensity-based responses.
- Annette recalls John McCallam being consulted about the problem of missed items after the Old 2 pilot.

Action: Anne Russell to ask Anne Young if she recalls his advice.

- One issue is that those most likely not to complete the CES-D are those not completing other items, such as the SF36.

Action: Anne Russell to stratify associations between missing CES-D and socio-demographic factors by completion of SF36 dimensions.

- Justin feels that the proximity of the 2 scales and placement of the CES-D soon after the SF36 may have promoted failure to complete.

Action: Justin/Annette to propose to Julie/Chris that placement be randomised to 2 locations on the Old 3 pilot.

- If failure to complete is high again in the Old 3 pilot there should be interview follow-up to ascertain reasons/problems.
- Nancy is interested in whether recent widowhood is associated with failure to complete.

Action: Anne to do

#### Neighbourhood Scale

- Annette concerned that using only 7 of the 14 items in Q36 of Old 2 to measure neighbourhood satisfaction may break up an existing scale. Anne does not think the 14 items have been validated as scale.

Action: Anne to check

#### Psychosocial Predictors of Recent CHD/Chest Pain

- Esben Strodl presented summaries of his analysis to date of women who did not report CHD at Old 1. His analyses suggest that mental stress (0,  $\leq 1$ ,  $> 1$ ) may be associated with CHD in the last 3 years.

**Next Meeting:** Venue and time to be notified

**WHA-UQ MEETING**  
**13 March 2001**

**Present:** Annette Dobson, Justin Kenardy, Nancy Pachana, Gail Williams, Noela Baigrie  
**Apologies:** Wendy Brown, Yvette Miller  
**Minutes:** Anne Russell

**Measuring Cognition on the Old 3 Survey**

Nancy Pachana has reviewed the rationale for inclusion and the availability of instruments to measure cognitive function.

Action: Anne Russell to compile a report from Nancy's notes and copy references for circulation to CIs and to the WHA office as background to discussions of the Old 3 Survey.

**Filipina Cohort**

Note received 15 March states:

- A draft of the manuscript based on in-depth interviews is expected to be available by April.
- Replies expected soon from the Australian and New Zealand Journal of Psychiatry regarding the 2 papers submitted November 2000.

**Indigenous Cohorts**

- Cherbourg: Noela has attended twice for scheduled meetings, which have been cancelled. The hospital may be closed and this may provide an opportunity for the project to discuss issues such as birthing. Next meeting scheduled for 28 March.
- Woorabinda: At a similar stage. Adam (SPH) to assist with the database run by the health service.
- Toowoomba: Pam has left the study. Gail Williams is now to prepare the report.
- Hopevale: Report in preparation.
- Sunshine Coast: Data entered but not cleaned.
- Progress report to DHAC due February.
- Karen Thurecht et al have prepared a methodological manuscript for submission to 'Women & Health'.
- OATSIH: Phone conference scheduled for tomorrow with Robyn Milthorpe and other departmental representatives. The objective is to resolve accountability requirements in a

way that allows the Indigenous component to function. It was noted that the issues raised in the June 2000 Report remain current.

## **Analysis**

### **Missing CESD & Neighbourhood Scale**

- Jenny Powers and Anne Young have today to discuss both of these analyses. Anne Young hopes to send updated reports to Anne Russell before Friday, and all 3 will discuss progress next Monday (19 March).
- The intention is to produce both an internal methodological report and a manuscript for each of these topics. Drafts of these will be circulated more widely soon.
- Having spoken with the a contact from the Tasmanian Healthy Communities Survey, Jenny Powers is optimistic that we will be able to their data for the 13 neighbourhood satisfaction items, age and sex. We hope to use these to compare factor structures in different age and sex groups.

### **Other Business**

Nadine Smith is to begin a PhD in second semester 2001. She is to be supervised by Annette Dobson and will be working on Old Cohort data.

**Next Meeting:** 3pm, Tuesday, 10 April 2001  
Room 228 in the Clinic  
Building 24A - McElwain Psychology Building  
St Lucia



## WHA-UQ MEETING

10 April 2001

**Present:** Annette Dobson, Wendy Brown, Nancy Pachana  
**Apologies:** Justin Kenardy  
**Minutes:** Anne Russell

### UN- Main Cohorts

- Planning day for Old 3 scheduled late April. Annette Dobson, Wendy Brown and Nancy Pachana to attend.  
  
Action: WB to contact Chris Lee to request Old 3 and the strategic planning meetings be held on the one day.
- The Hospital Anxiety and Depression Scale has been suggested as an alternative to the CESD for the Older cohort.  
  
Action: AR to look for references on its performance
- Mid 3 Survey response is very good. More than 3,000 surveys received.
- Chris Lee is compiling the June report for the PAC (13 June).
- Access to HIC data approved.

### Manuscripts

- SES: Accepted in Social Indicators Research
- Two papers on menopause rejected-to be submitted to International Journal of Behavioural Medicine.
- Wendy is revising a manuscript from Nadine Smith
- CESD: Nancy has relevant material on the theoretical basis for completion of survey items and has agreed to discuss the task of turning the report into a publishable paper with Jenny Powers and Anne Young when she visits Newcastle on 26 April
- Dieting habits and weight in the mid cohort: A manuscript was rejected some time ago. No one is sure of its current status.

Action: AR to contact JK

## UQ-Main Cohorts

- DHAC have requested a 3,000 word report on pregnancy and smoking on behalf of the National Tobacco Initiative. AD and AR are working on devising definitions across the Y1 and Y2 surveys for both smoking and pregnancy. AD is negotiating with DHAC.
- AD and AR have commenced work on analyses, describing cancer screening behaviours (Pap smear and Mammogram) among the Mid cohort, taking into account data from surveys 1 and 2.

Action: AR to forward proposals to Chris Lee.

- Stewart Trost is working on analysis of physical activity and social support in the older cohort.
- A woman from QUT (Nursing) has approached AD with a view to doing PhD research on the issue of late pregnancy.
- Nadine Smith to arrive in June.

## Filipina Cohort

Sam Thompson has reported that:

- Two papers submitted to ANZ journal of psychiatry. S.Thompson et al.

Both papers have been accepted (letter dated 29/03/01)- no revision required for the qualitative paper; revisions are required for the quantitative paper. ST is currently working on revision and response to reviewers in collaboration with co-authors.

- Mental Health Issues Paper. A.Cahill and S.Thompson

Still in progress. Methods- close to final. Results/Discussion- 2nd version reviewed by ST and reported back to AC at meeting on Sun 1 April. AC working on version 3. Intro - point form (AC currently reading and incorporating literature)

**Next Meeting:** 3pm, Tuesday, 8 May 2001  
Room 113, Public Health Building  
Herston

**WHA-UQ MEETING**  
**15 May 2001**

**Present:** Annette Dobson, Justin Kenardy, Nancy Pachana, Gail Williams  
**Apologies:** Wendy Brown, Yvette Miller  
**Minutes:** Anne Russell

**UN- Main Cohorts**

- The Old 3 planning day at University of Newcastle was very productive. The Australianised form of the cognition scale is currently being piloted. Ann Larson has criticised the migration questions in the survey.
- Christina, Annette and Wendy are to attend a meeting in Canberra on Thursday 24 May with the DHAC R&D committee. They will also meet with staff from OATSIH and with Alan Pettigrew, the CEO of NHMRC. Gail Williams may also attend
- \*
- The 6-monthly Project Advisory Committee meeting will be held in Canberra on Wednesday 13 June.

**UQ-Main Cohorts**

- Annette has completed negotiations with DHAC about 2 reports on smoking. A 3,000 word report looking at predictors of smoking and quitting in the young cohort will be prepared as part of the ad hoc analyses required under the ALWSH contract. An additional report, summarising the US Surgeon General's report Women and Smoking and supplementing it with relevant Australian data, will be prepared under a separate contract with the Commonwealth.

**Indigenous Cohorts**

- A report has been sent to OATSIH and the team is waiting for a response from Robyn Millthorpe. Gail noted that after meetings and reports in June 2000 she had believed that there was acknowledgment in Canberra that the Indigenous cohorts could not follow the same methods as the main cohorts, however recent discussions suggest that this is no longer the case.

Project progress requires a clear commitment to accept methodological differences. The Canberra meeting (24 May) should decide on how to deal with these issues, including a discussion of options and costs for closure of the projects.

**Next Meeting:** 3pm, Tuesday, 19 June 2001  
Room 228 in the Clinic  
Building 24A - McElwain Psychology Building  
St Lucia

## **Appendix 1.4**

**Notes on meeting of Investigators held in MRC Human Nutrition Research  
Centre, Cambridge, UK**

**COLLABORATION BETWEEN ALSWH & MRC HUMAN NUTRITION RESEARCH CENTRE**  
**30<sup>th</sup> March 2001**

**Present at various times:** Christina Lee, Project Manager, ALSWH  
Gita Mishra, Investigator, ALSWH, Senior Research Fellow,  
MRC Human Nutrition Research Centre  
Margot Schofield, Investigator, ALSWH, visiting scholar, MRC  
Human Nutrition Research Centre (on sabbatical from UNE)  
Caroline Bolton-Smith, Director of Nutritional Epidemiology,  
MRC Human Nutrition Research Centre

**Discussion:**

1. Prospects for collaboration between ALSWH and MRC Human Nutrition Research Centre. (CL, GM, CBS) Available data from the two centres were compared, and a decision made to explore a project comparing relationships between diet and obesity across Australian and UK samples of mid-age women. As a first step, CL will send CBS copies of the Food Frequency Questionnaire and sample output. A joint funding proposal to NHMRC and MRC (UK) was suggested, as was the possibility of seeking ARC International Linkages funding to cover travel.
2. Progress with research and plans for further subsidiary analysis. (CL, MS) Progress on a draft paper on history of terminations and miscarriages was discussed and plans made for the next stage of writing. MS outlined her plans for future subsidiary analyses.
3. Progress with research and plans for further subsidiary analysis. (CL, GM) Revisions on a report on ethnicity and menopause were planned. Preliminary analysis of data on HRT, hysterectomy, demographics and well-being was reviewed and plans made for the next stage of analysis.

# **Appendix 2**

## **Conduct of surveys**

## **Appendix 2.1**

### **Mid 3 package**

# **Appendix 3**

## **Reports on reliability and validity issues**



## **Appendix 3.1**

### **Scale validation protocol**

**Dr Anne Young**

## SCALE VALIDATION PROTOCOL

Dr Anne Young

### Strategy for validating scales

1. Document the source of the items and previous studies based on the items. In particular, document the scoring system (if any) and the populations on which it was used.
2. Psychometric evaluation of scales
  - (a) Examine the distribution of responses to individual items by univariate analyses.

(b) Determine whether the empirical data support the hypothesized groupings (if any) of the items, using factor analysis. This procedure is necessary, as the factor structure of the items may be sensitive to the population under study. Use the rotated factor pattern from principal components analysis (with varimax rotation) to check the groupings of the items and the contribution of each item to the factors. Items that are highly inter-related show high loadings on the same factor and items should load strongly on one factor rather than crossload on several factors. Factors can be extracted and examined, based on complete cases and also based on pairwise correlations, and the results can then be compared for consistency. Split sample analysis can also be performed if there are enough cases.

As a method to summarize the multi-item scales, composite factor scores can be created, based on the information provided by the factor analyses. Each item is weighted by the appropriate factor coefficient. These figures are summed to produce a new factor score for each woman with complete data. A second score is obtained by simply adding the response scores for the items that load together. The factor scores and the summed scores are then compared. High correlations suggest that the simpler additive method can validly be used. To overcome the problem of missing data for some of the items in a scale, a further set of scores for each factor can be calculated using the average of the non-missing data, after agreeing on the allowable number of missing items.

(c) The third way to evaluate multi-item scales is to calculate the reliability coefficient, Cronbach's alpha. Davies and Ware recommend a minimum standard of 0.50 for the reliability of scales to be used in comparing groups of consumers. Streiner and Norman suggest that alpha should be between 0.70 and 0.9 as very high values of alpha may indicate redundancy.

3. Types of validity checks (refer to Streiner DL and Norman GR (1995) "Health measurement scales: A practical guide to their development and use" Oxford University Press, for further detail)

(a) *Content validity* (or face validity)

This usually is done during the development of a scale.

(b) *Criterion validity* (also known as convergent validity, concurrent validity or criterion validity).

This involves testing whether the scale correlates with other measures. The other measures can be concurrent (at the same time) or predictive (validate with some future

event). We will be able to check predictive validity for scales that have been used for at least two phases of the survey. There should be clear hypotheses stating which variables will be related (and if which direction), or unrelated, to the new measure.

(c) *Construct* validity

This is an ongoing process that is not determined by one or two tests.

#### 4. Longitudinal analysis

Where possible, examine whether the factor structure is robust over time. As well as repeating the evaluation of the scale at both time points, examine the change over time in the scores (using linked data). Further validation can be conducted, such as checking whether subgroups of women show changes in their scores in the expected direction.

## **Appendix 3.2**

### **Results of factor analysis of the Tasmanian Healthy Communities Survey data**

## **RESULTS OF FACTOR ANALYSIS OF THE TASMANIAN HEALTHY COMMUNITIES SURVEY DATA**

In 1998, 25,000 Tasmanian men and women aged 18 years and older were mailed the Healthy Communities Survey. There were 15,112 respondents, yielding a response rate of approximately 60%. The survey included 13 questions relating to neighbourhood satisfaction, as well as age and sex of the respondent. The neighbourhood satisfaction items had the same wording as those in Survey 2 of the older cohort of WHA in 1999.

Data were received from the researchers in Tasmania to enable the WHA team to perform a secondary data analysis to test the factor structure of the neighbourhood satisfaction items in a different population. In the dataset, age was categorised into six groups: 18-24 years, 25-44, 45-54, 55-64, 65-74 and 75+ years. The items had five response options ranging from strongly disagree to strongly agree, as in the WHA survey (rated 1 to 5) but also had the response option 'not applicable', which was coded 9.

The percentage of respondents with missing data for at least one of the 13 items (including a response of 'not applicable') ranged from around 20% in men and women aged from 18 to 54 years, 34% for women aged 55-64 (24% for men), 46% for women aged 65-74 (33% for men) and 62% for women 75 years and older (52% for men). Of the missing data, approximately one third was due to a response of 'not applicable'.

As found in the analysis of the WHA data for the older cohort, the two items relating to neighbourhood safety (items i and m) loaded on a single factor (across all age groups, for men and women). Two other main factors were identified in all age groups. In women aged less than 55 years and men aged less than 65 years, the common items (a, b, e, g, j, k, l) are about interaction with people in the neighbourhood. For women aged 55 years and older and men aged 65 years and older, the seven items (a, b, c, e, f, h and k) loaded together. This is consistent with the results obtained from the older cohort of the Women's Health Australia project. Sometimes item d loaded with these items, however it did not load strongly (see Tables A and B).

**Table A Factors and loadings for neighbourhood questions by age for women in the Healthy Communities Survey, Tasmania, 1998.**  
**Cross-loadings shown only for values of 0.30 or greater.**

Item	18-24 Factor			25-44 Factor			45-54 Factor			55-64 Factor			65-74 Factor			75+ Factor			
	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	4
h		0.66			0.71			0.58	0.36	0.71			0.72				0.54		0.41
f		0.59			0.61			0.60	0.38	0.72			0.69				0.77		
c	0.38	0.61		0.37	0.64		0.41	0.67		0.75			0.72				0.72		
a	0.68	0.38		0.63	0.41		0.49	0.57		0.69	0.37		0.64	0.42			0.82		
e	0.70	0.36		0.74			0.65	0.35		0.63	0.40		0.65	0.42			0.71		
b	0.73			0.75			0.66	0.43		0.59	0.55		0.55	0.54			0.77		
k	0.45	0.42	0.42	0.61	0.37		0.57	0.44	0.36	0.60	0.39	0.31	0.57	0.49			0.48	0.41	0.38
d		0.71			0.77			0.71		0.40			0.60					0.38	-0.67
l	0.65			0.61			0.65				0.60			0.67				0.74	
g	0.75			0.73			0.71				0.74			0.70				0.83	
j	0.64		0.40	0.58		0.36	0.67				0.58	0.42		0.61					0.71
i		0.32	0.79			0.81			0.84		0.39	0.73	0.43		0.69				0.77
m			0.78			0.84			0.79			0.82		0.87					0.79
Eigenvalue	5.1	1.5	1.0	5.2	1.3	1.1	5.0	1.4	1.1	4.7	1.4	1.0	5.1	1.2	1.1	4.8	1.3	1.2	1.0
Cum % var	39%	51%	59%	40%	50%	59%	39%	50%	58%	36%	47%	55%	39%	49%	57%	37%	47%	56%	64%
Respondents	1069			1262			1306			1415			1731			1145			
Missing data	281 (26%)			235 (19%)			321 (25%)			481 (34%)			802 (46%)			710 (62%)			

**Table B Factors and loadings for neighbourhood questions by age for men in the Healthy Communities Survey, Tasmania, 1998. Cross-loadings shown only for values of 0.30 or greater.**

Item	18-24 Factor			25-44 Factor			45-54 Factor			55-64 Factor		65-74 Factor			75+ Factor			
	1	2	3	1	2	3	1	2	3	1	2	1	2	3	1	2	3	4
h		0.72		0.33	0.58	0.31	0.39	0.51	0.36	0.53	0.45	0.66		0.32	0.73			
f	0.30		0.53		0.54	0.41	0.32	0.53		0.40	0.49	0.72			0.72			
c	0.35	0.71		0.45	0.61		0.47	0.37	0.54	0.60	0.47	0.69			0.75			
a	0.71			0.63	0.32		0.58			0.69		0.71			0.69			
e	0.69	0.37		0.71	0.30		0.70			0.69	0.32	0.73			0.76			
b	0.76			0.74			0.70			0.79		0.68	0.46		0.70	0.36		
k	0.48	0.36	0.34	0.57	0.32	0.37	0.62	0.39		0.59	0.46	0.56	0.41		0.62			
d		0.81			0.78				0.82	0.34		0.46				0.32		0.72
l	0.68			0.70			0.66			0.66			0.72			0.74		
g	0.72			0.75			0.74			0.70			0.75			0.80		
j	0.60			0.64	-0.36		0.65		-0.36	0.49			0.68					-0.70
i			0.81			0.81		0.85			0.82	0.31		0.75	0.34		0.78	
m			0.86			0.83		0.81			0.80			0.84			0.85	
Eigenvalue	4.8	1.6	1.1	5.3	1.5	1.0	5.1	1.5	1.0	5.2	1.3	5.0	1.4	1.1	4.8	1.3	1.1	1.0
Cum % var	37%	50%	58%	41%	53%	60%	39%	50%	58%	40%	50%	38%	49%	57%	37%	47%	55%	63%
Respondents	802			1041			1166			1271		1378			1526			
Missing data	170 (21%)			193 (19%)			210 (18%)			307 (24%)		450 (33%)			792 (52%)			

**Table C Items used to measure neighbourhood satisfaction in four Australian studies**

<b>Women's Health Australia, 1999</b>	<b>Australian Living Standards Study, 1991</b>	<b>Health and Participation Survey, 1997 *</b>	<b>Healthy Community Survey, 1998</b>
a I would be really sorry if I had to move away from the people in my neighbourhood	this neighbourhood		same
b I have a lot in common with people in my neighbourhood	the people in this		same
c I generally trust my neighbours to look out for my property			same
d People in my neighbourhood make it a difficult place to live	this neighbourhood... to live in	same	My neighbours make it ...
e I am good friends with many people in this neighbourhood	same	same	with many people
f I like living where I live			same
g I have little to do with people in this neighbourhood	same	same	same
h My neighbours treat me with respect			same
i Children are safe walking around the neighbourhood during the day			same
j I get involved with most local issues	I seem to get ...	I seem to get ...	same
k People in my neighbourhood are very willing to help each other out	this neighbourhood	same	same
l If I no longer lived here, hardly anyone around here would notice	would even notice	If I moved ..	same
m It is safe to walk around the neighbourhood at night			same

*\* also contained a question relating to language barriers*



## **Appendix 3.3**

### **The measurement of remoteness**

## THE MEASUREMENT OF REMOTENESS

Notes on a meeting held at the National Key Centre for Social Applications of Geographic Information Systems (GISCA), University of Adelaide, 20 February 2001.

There have been two new reports recently released, which discuss the measurement of remoteness in Australia. The first is called "A comparison of the ARIA (Accessibility/Remoteness Index of Australia) and RRMA (Rural, remote and metropolitan areas classification) methodologies for measuring remoteness in Australia" December, 2000 and the other is called "ABS views on remoteness" January, 2001. The change from RRMA to ARIA has implications for remoteness funding of health and other services.

Both the ABS and DHAC are promoting the use of ARIA scores. The RRMA classification system is very outdated. It was designed in 1991 and based on coding SLAs to one of seven RRMA categories. However within the RRMA classification there are only three levels of remoteness (urban, rural, remote zones). Within these zones, the SLAs were split according to population size to produce the seven RRMA levels (*urban*: capital city, other metropolitan; *rural*: large rural centre, small rural centre, other rural area and *remote*: remote centre, other remote). Hence there are many localities in 'other rural areas' that may be less remote than localities in 'large rural centres'. The RRMA was not designed as an ordinal scale although it is widely used as such.

The GISCA report highlights these problems. Within WHA our allocation of RRMA is even more approximate and potentially invalid for many women. We use a postcode to RRMA concordance file which allocates an RRMA code, based on the SLA where most of the population of that postcode live. Postcodes were established to make postal deliveries easier. Postcodes in Australia cover very heterogeneous and sometimes physically disjoint areas, which have differing urban/rural characteristics and remoteness.

A better method is to contract GISCA to geocode the localities of woman in our cohorts. This has been done for the localities at baseline and at the beginning of 1999. GISCA used our address files to test their locality database (and added quite a few new localities that had previously not been coded). A report on this work was included in the WHA report to DHAC in June, 2000. GISCA can also provide any other levels of classification for a given locality, such as census CD, LGA, RRMA, SLA and State.

As GISCA already has on file most of the addresses and ARIA values etc for our respondents, they would anticipate that any updating would involve a process of determining who had changed address and reallocating the values. This should take around two to three days, depending on the error rates in transcription from the survey forms etc. This would be around \$1000 - \$1500. The main advantages in having them geocode the addresses would be that they would have on file a spatial reference for every one of our respondents, which would enable us to undertake a wide range of point-based spatial analyses of the data (ie aggregating to any larger areal unit of our choice, determining accessibility to various services, mapping etc) should we wish to at a later date. GISCA have also measured a range of variables for each locality such as access to many types of services eg. hospitals, doctors, pharmacies, schools, retail facilities and so on. GISCA has also calculated remoteness or 'isolation' scores for each locality for many types of professionals, such as GPs and specialists.

We can also use locality geocoding to measure the distances moved for women in our study, rather than estimate distance from weighted centroids of postcodes. It is crucial that we keep a record of the location of the women at the time they complete the follow-up surveys, even though it is impossible to geocode every move between surveys. We have not yet coded locality for Mid2 and Old2 (we only have codes for their locality in January 1999) but we have kept a database of locality for the women who recently completed Young 2. For women who do not actually live at their contact address or who use post office boxes, we will have to decide what to do. Future surveys are asking for residential and postal postcode and we can compare these to the address we have in the participant database.

GISCA is keen to see how we might collaborate further. For example, they have indices of remoteness and access to services by locality. We have self-reported access to services such as female GPs, hospitals, and measures of continuity of care. We could put the two sets of data together and see whether the 'objective' measures of access correlate with self-reported measures of access. GISCA was asked to help determine where the "fly in – fly out" female GP services were most needed, as they have the location of all female GPs and the age/sex distribution of the population in each locality. Perhaps we could get some funding to support this extension of the work we are each currently doing. GISCA have some great interactive web-based tools that demonstrate the data they have by locality (<http://www.gisca.adelaide.edu.au/gisca>).

# **Appendix 8**

## **Dissemination of study findings**

## **Appendix 8.1**

### **Book launch**

**BOOK LAUNCH AT  
4<sup>th</sup> AUSTRALIAN WOMEN'S HEALTH NETWORK CONFERENCE**

**Women's Health Australia: What Do We Know? What Do We Want To Know?**

The research project that which started life as the Australian Longitudinal Study on Women's Health and is now known as Women's Health Australia is, we believe, a world first. Its uniqueness lies in its size, scale and scope: the project is a study of Australian women spanning the full adult life-course from 18 to the 90's; utilising a multi-disciplinary framework informing its concepts and methodology; covering the broad spectrum of women's circumstances, roles, experiences and feelings and how these relate to physical and mental health, and over time. This last is the most ambitious and potentially by far the most valuable aspect of the study; it has been set up to be over a twenty-year period, 1996 to 2016. There is no comparable study in existence.

The overall goal of the study is to have information collected at regular intervals from members of a very large and representative sample of the total population of Australian women, who when first surveyed in 1996 were in three age cohorts, 18-23, 45-50 and 70-75, and who will be resurveyed six or seven times in the period to 2016, so the researchers can follow the same individuals as they move through the next twenty years of their lives. The brilliance of such a design is that the combination of the large numbers (over 40,000 women), the diversity across a range of socio-demographic factors - not only age but cultural background, education, employment, urban/rural, family and domestic relationships, and so on - and the longitudinal dimension permits the tracing of changes and the establishing of cause-effect relationships between events.

The book consists of a series of short chapters with descriptive data on five broad themes from the three cohorts: health service use; health-related behaviour; time use, work, leisure and women's health; life stages and key events; and violence and abuse. This is only a fraction of the data that the survey has generated but provides a good picture of some solid baseline data and some of the questions that the University of Newcastle research team will be pursuing. At the one-day research workshop run here in Adelaide yesterday by Women's Health Australia some of us were given an early taste of what can be expected from the next stage of the project.

We are coming to the point where these three cohorts of women have been revisited once each since the original survey in 1996, and the emerging findings demonstrate the capacity of this study to answer key policy and health intervention questions. Interesting hypotheses that could be posed on the basis of the first survey and research evidence from other studies can now be tested against the reported experience of these groups of women. One such that Lois Bryson talked about yesterday for the youth cohort were the relationships between education and having children in urban as compared with rural/regional areas. The added value that is brought to the analysis by resurveying the same population over time is the capacity to tease out the relationships between factors and events for different sub-categories within the population and to establish whether particular temporal sequences are also likely to be casual.

Credit for this very important and innovative study must go to a number of people and groups. First, to the previous Labor Government who, under the Minister of Health at the

time, Carmen Lawrence, initiated the idea of such an enormous and ambitious and therefore expensive study and launched the project with three years of funding in 1995. This was in the context of a significant amount of interest and effort associated with the development of a National Women's Health Strategy which involved large numbers of women, health providers and community groups across the country. Credit is also due to the Coalition Government under Minister Michael Wooldridge which renewed funding for a further five year period.

Secondly we must recognise the vision, creativity and courage of the original team of women at the University of Newcastle who took up the challenge of responding to the tender, who conceived the project in its current form with its broad inter-disciplinary character and took on the huge responsibility of such a massive project stretching far into the future, knowing that the personnel would inevitably change, as it has done, but with the confidence that there would be people able and willing to keep going.

With their commitment and the involvement of a growing number of researchers from other universities and agencies around the country in the whole project, the future of the project is critical. This means ongoing financial support being provided by future governments. This is essential if the momentum is to be maintained and the full potential of this study is to be realised. The longer the study continues, the more valuable it is, as the data become more and more unusual and more and more useful in answering major health and life style questions with important policy and service implications.

The project is entering a new and important phase, with the publication of this volume reporting on progress to date. The books makes available for the first time in a readily accessible form, information about the kinds of topics that are being investigated and gives to the wide range of people involved with women's health and related issues an understanding of the capability of this multi-disciplinary, large-scale, longitudinal study for informing policy, politics and practice. It helps get the research out into the public arena and opens up opportunities for input into the project from people and organisations working in the field.

This project and its data bank is a huge public resource and it is the desire of Women's Health Australia that it becomes a resource that is widely used for all sorts of purposes. To give one highly topical example. The broad conceptualisation of health and health issues and the wide diversity of the women in the sample, which included a deliberate oversampling of women living in rural, regional and remote areas to get adequate numbers for detailed analysis, at a time when the community concerns about the changes that are affecting these areas were only just beginning to make their impact means that many of the kinds of questions that are being asked about their relative disadvantages and their impact on women can be investigated.

I therefore commend the volume 'Women's Health Australia: What do we know? What do we need to know?' to you and would urge you to make sure that it and the information about the project Women's Health Australia are widely disseminated. This is something Australia should be justifiably proud of and should promote nationally and internationally. Looking at the participants at this conference and where they come from, this is an excellent start. Finally I should mention some of the key people associated with the project and the book. The editor is Christina Lee, the present project manager of the Research Team of Women's Health Australia. Other authors who are present at this conference include Lois Bryson, one of the original team that put together the successful submission back in 1995; Julie Byles also

in that original group; Anne Young, who joined the team as a postgraduate student and has remained as the team statistician.

Finally, on a personal note, for those of you who do not know me, I am a sociologist who has been engaged in research on women and health in the past and who has taken a keen interest in this project from the start. Had other changes not occurred in my career at around that time, I would have been trying to organise some way in which I could participate in the study and using whatever persuasive powers I might have with Lois and others to achieve this. As it happens, I have had to be satisfied with observing the progress of the study from a distance. In my estimation, they have well exceeded the expectations even of those like me who were favourably disposed to their project from the start. We all now have to work hard to ensure that the essential financial support is forthcoming so that the project does fulfil the original brief of a twenty-year study of Australian women's health.

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