

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



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

Report 14



&



10 June 2000

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APPENDICES (Number relates to relevant section of the report)**1 COLLABORATIVE RESEARCH ACTIVITIES**

- 1.1 Minutes of formal teleconferences held among Main Study Investigators
- 1.2 Minutes of formal teleconference held between Main Study and Special Cohort Investigators, and summary of regular face-to-face meetings held between University of Queensland Main Study and Special Cohort Investigators

2 YOUNG SURVEY 2

- 2.1 Letter to participants, questionnaire, change of address card and reminder cards

3 METHODOLOGICAL ISSUES

- 3.3 Identification of multi-collinearity in the mid-age cohort at baseline
- 3.4 Databook for the Filipina cohort

4 MAINTENANCE OF COHORTS

- 4.1 Flow charts for tracking of return to senders
- 4.2 Letters to the Health Insurance Commission staff requesting information on archiving of databases
- 4.3 Letter and reply form sent to women identified as probable Main Survey participants through the Australian Electoral Roll
- 4.4 Letter and reply form sent via the Health Insurance Commission to women's current addresses as identified in Medicare database

8 DISSEMINATION OF STUDY FINDINGS

- 8.1 Feedback letter sent to mid-aged women who participated in substudy on experiences of violence

9 ARCHIVING AT SOCIAL SCIENCES DATA ARCHIVE

- 9.1 Licence form
- 9.2 Study description form

EXECUTIVE SUMMARY

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1 COLLABORATIVE RESEARCH ACTIVITIES

1.1 MEETINGS BETWEEN UNIVERSITIES OF NEWCASTLE AND QUEENSLAND

1.1.1 Main Survey Meetings

Teleconferences were held on 11 February and 4 April and minutes of these formal meetings appear as Appendix 1.1. A working party was held on 12 May to begin development of the third survey of the mid-age cohort. A report on progress appears as Section 2.1.2.

1.1.2 Main Study/Special Cohort meetings

A teleconference was held on 22 February, and face-to-face meetings (with Annette Dobson representing the main study researchers) on 29 March, 4 April and 21 May. Minutes of the teleconference and notes on the face-to-face meetings appear in Appendix 1.2.

1.1.3 Comments on Collaborative Meetings between University of Newcastle and Queensland, and between the Main Survey and Special Cohorts Researchers

The relocation of Wendy Brown and Annette Dobson to the University of Queensland has meant that the scientific management of the main cohorts has become considerably less centralized, while simultaneously the relationships between the "main survey" and "special cohorts" teams have become closer and more collaborative. This, together with the appointment of Anne Russell as Senior Project Officer at the University of Queensland, has had a substantial effect on the relationships between the two components of the project, and on the need for formal meetings.

The ten Investigators on the main survey are now located at the University of Newcastle (Byles, Lee, Mishra, Warner-Smith, Young), the University of Queensland (Brown, Dobson, Kenardy), the University of New England (Schofield) and Royal Melbourne Institute of Technology (Bryson). This has necessitated a series of formal and minuted meetings (see Appendix 1.1), as well as close informal collaboration through email and telephone contact, and a monthly face-to-face meeting at the University of Newcastle, in order to maintain team coherence and good communication links.

The "main survey" and "special cohort" Investigators located at the University of Queensland have developed closer collaborative links, involving informal collaboration on a day-to-day basis. While one formal and minuted teleconference has been held (see Appendix 1.2), close proximity and a developing working relationship have meant that these have largely been replaced by weekly working meetings. Annette Dobson and Anne Russell are working collaboratively with Gail Williams and Cindy Shannon. They will produce a data book which summarises data obtained from the special cohorts, including the precise wording of questions, coding processes, and processes for translation or modification for specific groups, and then develop strategies for comparing data obtained from the special cohorts with that available from ATSI and Filipina members of the main cohorts (see Section 3.3 below). This will formalise the quantitative data from the special cohorts and enable the research team to collaborate on analyses comparing data from "special" and "main" cohorts.

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

1.2.1 Project Summaries

1.2.1.1 Completed investigator projects (in last 6 months)

Project: The Real Australian Woman
WHA Investigator: Dr Amanda Patterson
Funding Source: Hestia Pty Ltd.

This project was an examination of the current size and shape of Australian women, how this has changed in the last 73 years, and the difficulties associated with purchasing clothes and lingerie.

450 women (150 each from Newcastle, Melbourne and Brisbane) were recruited through university campuses, workplaces, community groups and shopping centres. They had their height, weight, waist, hip and bust measurements taken by trained researchers, and completed a questionnaire about health, exercise, body image and issues surrounding the purchasing of clothing and lingerie.

Size and shape data were compared with similar data from a study of 6,000 women performed by Berlei Pty Ltd in 1926. On average, women in 1999 were taller, bigger and heavier than their 1926 counterparts. Mean height had increased by about 3 cm (to 164.5) and mean weight by 4.5kg (to 66.0kg). Waist and hip measurements both increased by about 3.5cm (to 76.5cm and 101.6cm respectively), but over bust measurements increased by almost 6cm (to 93.5cm).

Over 70% of the women reported having difficulties buying clothes to fit at least some of the time, despite the most popular sizes being 12 and 14. The most commonly reported difficulties were 'too tight around the hips, bottom and thighs' and 'too loose around the waist', and these correlated with the most common desired body changes of the women: smaller and firmer stomachs, bottoms, thighs and hips. Chi square analysis showed an association between 'difficulties finding clothes to fit' and body image which was independent of BMI.

Thus, it appears clothing manufacturers may be an important influence on Australian women's body image and should consider the typical female form (larger hips, bottom and thighs and smaller waist) more closely in their designs.

1.2.1.2 Investigator projects in progress

Project: Sleeping difficulty and sleeping medication use among older women.
WHA Investigator: Dr Julie Byles, , Dr Gita Mishra
Collaborators: Ms Margaret Harris, Ass Prof Kichu Nair
Funding: Quality Use of Medicines Evaluation Program, Department of Health and Aged Care

The aims of this study are:

- 1) to identify the consequences of sleeping difficulty in terms of health-related quality of life, falls and accidents, medication and health service use;
- 2) to explore the women's experience of and response to sleeping difficulty using in depth interviews;
- 3) to describe the prevalence of sleep disturbance and related behaviours;
- 4) to work with women to develop appropriate health promotion materials for sleep disturbance.

Cross sectional analysis of the baseline data for women aged 70-75 years indicated that self-reported sleeping difficulty is significantly related to reduced quality of life. Of the 12,624 women aged 70-75 years who provided data for this analysis (32% of eligible sample), 50% (n=6,042) reported sleeping difficulty "never/rarely"; 33% (n=3979) "sometimes"; and, 17% (n=2,011) of

women reported to experience sleeping difficulty "often". Approximately 18% (n=2,287) 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 ($p<0.0001$). After adjustment for other explanatory variables there were strong, clinically significant differences between the SF-36 scores of women reporting sleeping difficulty. Mean scores for sub scales of the Medical Outcomes Study 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. However, while these associations are both clinically and statistically 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.

To enable such longitudinal analysis all women in the older cohort were re-surveyed about sleeping difficulty in 1999 (when they were aged 73-78 years). The Nottingham Health Profile sleep subscale was used to provide a quantitative estimate of the degree of sleeping problems. The subscale also allows better differentiation between the types of problems experienced. These data are currently being analysed to determine the association between sleeping difficulty and/ or sleeping medication use at baseline and subsequent effects on quality of life, falls and health service use.

Follow-up data for relevant items are provided below. Women are grouped according to area of residence to account for over-sampling of women in rural and remote areas.

Table 1 Follow-up data for the sleep sub-study

Item	Capital City/other metropolitan area N=3866	Large rural area N=1145	Small rural area N=1415	Other rural/ Remote area N=2858
Use medication to help sleep within past 4 weeks	16.6%	15.6%	15.4%	13.2%
Waking in early hours of morning	43.1%	44.5%	42.9%	40.3%
Lying awake for most of night	10.8%	12.9%	10.4%	10.3%
Taking a long time to get to sleep	25.7%	25.8%	28.5%	25.5%
Worry keeping you awake at night	11.8%	12.6%	9.8%	9.6%
Sleeping badly at night	22.1%	21.7%	21.4%	19.2%
No sleep problems	34.6%	33.4%	34.0%	36.7%

To gain a more in-depth understanding of the problem of sleeping difficulty, selected women reporting sleeping difficulty with or without medication use were interviewed. These interviews were to gain an insiders' view of sleep difficulty and factors associated with medication use.

The data are currently being analysed using a qualitative framework.

Major themes identified during the interviews were used to identify dimensions and items to be included in the detailed follow-up study involving 1,300 women with and without sleep disturbance, and who do and do not use sleeping medication. This survey is currently in progress.

The final phase of the project will involve a workshop where women will consider the findings of the study, and develop ways to most appropriately incorporate key messages regarding sleeping difficulty management and prevention into a health promotion strategy.

1.2.1.3 Completed postgraduate student projects (in past 6 months)

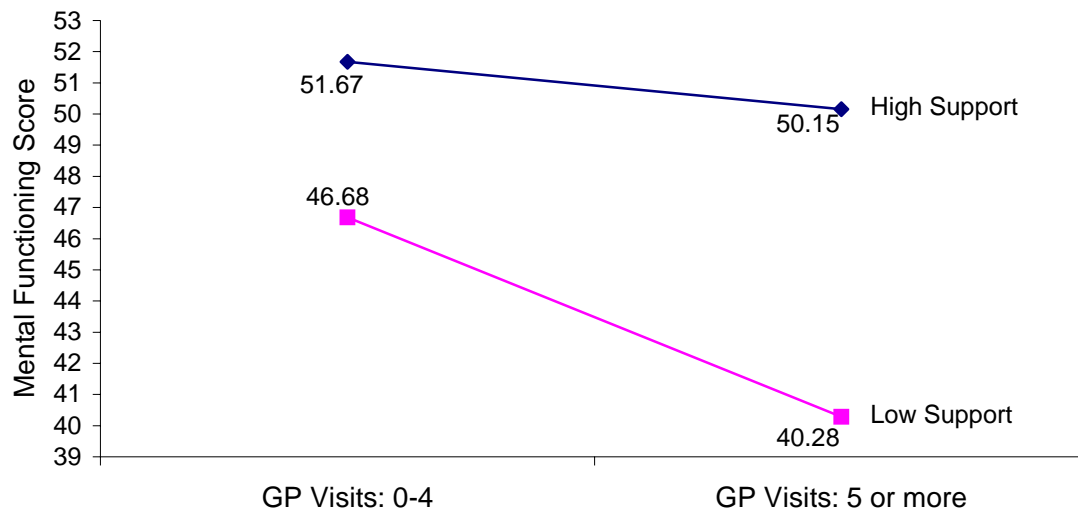
Project: Social support, health status and health care utilisation in women aged 70-76 years
PhD candidate: Mr Brendan Goodger (CCEB, University of Newcastle)
Supervisors: Dr Julie Byles & Dr Gita Mishra
Funding source: Public Health Research Development Committee Scholarship provided by the NHMRC

This substudy involved a two-year prospective survey (with annual follow up) of those older women with low and higher levels of social support who responded to the WHA baseline survey. Out of the 840 participants selected for this substudy, 573 completed all three-time periods. After exclusion of 27 ineligible participants, an overall response rate of 70.5% was obtained. This study had three major aims. Firstly, to identify changes in social support among older women. Secondly, to assess the effects of social support on health-related quality of life, and thirdly to investigate the potential for social support to moderate the relationship between quality of life and the number of visits to general practitioners. Multivariate statistical techniques were used with adjustment for the effect of potential confounders.

Results

Of participants classified as having high support at baseline only 4% changed to low support at time three. However of those with low support at baseline, 57% still had low support at time three with a further 22% shifting up one category to fair support. Despite these changes, those with low support at baseline still had significantly worse physical and mental related quality of life scores than those with high support that persisted over all time points of this substudy. Among all older women in this study with a higher number of visits to general practitioners (four or more) those with low support had mean physical and mental functioning scores (see Figure 1) that were significantly lower than those with high support. This research clearly reveals the adverse consequences of low social support on the health of older women.

Figure 1: Mean level of Year Three Physical Functioning for Groups Differing in Visits to General Practitioners by Level of Social Support



1.2.1.4 Student projects in progress

Project: Violence in mid-age women
PhD candidate: Ms Glennys Parker (RIGH, University of Newcastle)
Supervisor: Prof Christina Lee
Funding: Postgraduate Research Scholarship in Women's Health, Research Institute for Gender and Health.

Epidemiological evidence suggests that Australia conforms to global prevalence rates of gender-based violence and results from the second major survey for the mid-aged cohort of the Women's Health Australia project indicated that approximately one-third of respondents had experienced abusive or violent episodes. In May 1999, 1,500 questionnaires were mailed to a random selection of the 2,498 abused women who had agreed to participate in a written survey on the topic. There was a response rate of 77% and a preliminary analysis was undertaken of descriptive summaries together with regression assessment of primary physical and psychological criteria. The longer time frame of a PhD is beneficial in allowing for a more in-depth examination of the responses. Many women gave details of their encounters with violence and abuse.

Qualitative analysis of these subjective experiences, feelings, and attitudes will be valuable in contributing to a more holistic understanding of the impact of aggressive behaviour on individual and social functioning. Further empirical analyses are also planned to define at-risk populations, determine specific intervening psychological variables, assess environmental elements, quantify cumulative effects, and examine path trajectories. However, the primary research focus will be directed towards an understanding of individual differences in coping. For example, are these differences related to demographic factors, socio-economic status, the type of abuse experienced, personal attributes, or certain combinations of these or other unspecified elements? The issues are undoubtedly complex and this investigation has the potential to significantly enhance current understanding of the phenomenon as well as positively impact on women's general health and well-being.

Project: Iron deficiency and menstrual blood loss in Australian women

PhD candidate: Ms Allison Schmidt (RIGH, University of Newcastle)
Supervisor: Prof Wendy Brown
Funding source: ARC Small Grant and University of Newcastle Postgraduate Scholarship

Stage one of this project involved obtaining an approximate measure of menstrual blood loss in a large group of Australian women. The general health, well-being and levels of tiredness of this group of women were also examined. Stage two of the project will involve a more detailed study of menstrual blood loss in a smaller group of women. Body iron status and dietary iron intake will also be accurately measured. The first stage of this project was completed in 1999. We are currently awaiting ethics approval to begin stage two which will take place in 2000.

Project: Factors influencing weight change at menopause
PhD candidate: Ms Lauren Williams (RIGH, University of Newcastle)
Supervisors: Prof Wendy Brown, Dr Anne Young
Funding source: ARC Small Grant

As reported previously (in Report 13, see Section 7.4.3), this study is attempting to answer the question of why women gain weight in the menopausal years (45-55). Focus group discussions with women in regional and metropolitan areas allowed the development of a twenty page survey, containing pre-validated instruments measuring dietary intake, exercise and emotional eating and lifestyle related questions which might affect weight in mid-aged women. The survey was mailed to 1,164 women in the mid-age cohort of the ALSWH whose menopausal status altered between the mid baseline survey (M1) in 1996, and the first follow-up survey (M2) in 1998. Reminder notices were mailed to 531 women who had not responded four weeks after mailing. Telephone reminders were conducted for the 284 women who had not responded after a further six weeks. To date 915 surveys have been received, in giving a response rate of 78.6%. Preliminary analysis shows 51.1% of the women reported weight gain since completing the mid-age baseline survey three years previously. 13.7% reported to have lost weight, and 35.1% reported to weigh about the same as three years previously. Analysis of the questionnaire results will elucidate why some women gained weight, while others lost or maintained weight. Recommendations can then be made for avoiding weight gain at menopause.

Project: The effectiveness of legal protection in the prevention of domestic violence amongst young Australian women
PhD candidate: Ms Margrette Young (RIGH, University of Newcastle)
Supervisors: Prof Annette Dobson, Dr Julie Byles
Funding source: Criminology Research Council and NHMRC Scholarship

A retrospective study was conducted in 1998 in a national sample of almost 500 women aged 20-25 years who had been subjected to physical violence by a male partner. Violence had stopped for 90% of the women at least 12 months before the interview, whether or not they had obtained legal protection. Women who sought legal protection (police help and/or a court order) were more likely to have been injured or experienced more severe levels of physical violence, to have children and to have had a partner with a history of violence, than women who did not seek legal protection. Legal protection was effective in reducing the severity of physical violence and there were few women who experienced any increase in violence. About half the women who sought legal protection only obtained police help. Although they had experienced less severe violence before obtaining help than those who obtained court orders the improvement following legal protection was not as marked. Two thirds of the women who had both police and court protection experienced reductions in physical violence and none suffered an exacerbation. The results of the study provide

information for evidence-based policy and practice for preventing violence to young women. Although the prevalence of partner violence has been reported to be 3-4 times higher for young women than older women it can be reduced. Legal protection, especially through court orders, is effective even against severe levels of physical violence.

Project: Women and emotions
Masters candidate: Ms Barbara Reen (CCEB, University of Newcastle)
Supervisors: Assoc Prof Nick Higginbotham
Funding source: Part funding by CCEB

The preliminary pilot section of this study, involving qualitative open-ended taped telephone interviews of one hour's duration with 6 women has been completed. The women, who were randomly selected from the mid-age cohort, were from rural and remote areas of Australia whose survey scores indicated that they had experienced feelings of depression, but had not received any treatment for depression. Tapes of these interviews have been transcribed and entered into Ethnograph v. 4.0, and are currently being coded. A further 10 women have been invited to participate in the study, and the remaining data will be collected from those women who agree to participate during June/July 2000. The process of transcribing and coding this data will take place during July/August 2000. The analysis and writing up of the study will take place during September/October, for submission (in the form of a journal article) as a minor thesis for the Masters in Medical Science (Health Social Science), by November 1, 2000.

1.2.2 Summary of other collaborative research activities

Project: Incontinence In Australian Women: Following Up Participants In The Australian Longitudinal Study On Women's Health
Collaborator: Ms Pauline Chiarelli (Faculty of Medicine and Health Sciences, The University of Newcastle)
WHA Collaborators: Prof Wendy Brown, Prof Annette Dobson
Funding source: Department of Health and Aged Care

Initial analysis of baseline data found the proportion of women reporting 'leaking urine' was 13.8% in the young cohort, 36.1% in the mid-age cohort and 35% in the older cohort. Lower scores on the physical and mental component summary scores of the SF-36 suggest lower quality of life among women who report leaking urine, compared with those who do not. However, fewer than half of those who reported leaking urine had sought help for the problem. Five-hundred participants were selected randomly from those in each cohort who reported leaking urine 'often' at baseline. In the young cohort, women who reported leaking urine 'sometimes' were included in the sampling frame as insufficient women reported leaking urine 'often'. A survey measuring severity and type of leakage, help-seeking and treatment outcomes, and awareness of treatment and prevention strategies was completed by 50%, 83%, and 80% of sampled women in the young, mid-aged, and older cohorts respectively. A data book based on their responses has been compiled, and several papers highlighting essential findings are currently being developed.

Project: A longitudinal investigation of weight maintenance: implications for weight gain prevention strategies.
Collaborator: Dr Kylie Ball (Faculty of Health and Behavioural Sciences, Deakin University)
WHA Collaborators: Prof Christina Lee

Funding source: Deakin University, 2000 Faculty Research Development Grants

The proposed research project focuses on the public health problem of overweight from a unique perspective, examining weight maintenance rather than weight gain. Using existing longitudinal data from the Women's Health Australia project, the research study will describe the weight change/maintenance patterns of young adult women over a four-year period; investigate determinants of weight maintenance in young women over time; and quantify relationships between weight maintenance and physical activity and diet. These findings will be used to develop a weight gain prevention program to be evaluated in subsequent studies.

Project: The measurement of socio-economic status of Australian women.
Collaborator: Dr Kylie Ball (Faculty of Health and Behavioural Sciences, Deakin University)
WHA Collaborators: Dr Gita Mishra, Prof Annette Dobson, Dr Penny Warner-Smith
Funding source: Research Management Committee Project Grant, The University of Newcastle

Following our derivation and initial validation of age- and gender-specific indicators of socio-economic status (SES), we plan to further validate the indicators by comparing the performance of the proposed indicators for several age- and gender-sensitive health outcomes. The Australian Longitudinal Study of Women's Health provides an opportunity for this research to be conducted. From the longitudinal data it will be possible to investigate women's health in the context of personal, social and economic factors which affect SES as these change over time and throughout the women's life stages.

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

This sub-study aims 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 include: i) How do women divide their time between various types of leisure, including active/passive, structured/unstructured, relational/non-relational? 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 have now been completed with women from the existing 'young' and 'mid-age' WHA cohorts in a mix of 'urban' (Belmont, Dapto), 'rural' (Dubbo, Mittagong) and 'other rural' (West Wyalong) areas. Data are currently being analysed with particular reference to generational differences between women's leisure patterns and well-being, and the degree to which women use leisure as a form of risk management in relation to their health.

Project: Alcohol consumption by young Australian women: patterns, harms, and influences

Collaborator: Dr Helen Jonas (School of Health & Human Sciences, La Trobe University), Prof Margaret Hamilton (Turning Point Alcohol and Drug Centre Inc, Melbourne)

WHA Collaborators: Prof Wendy Brown

Funding source: Victorian Health Promotion Foundation

A comprehensive survey based on earlier questionnaires devised for the Carlton Women's Survey and for young women drinking in hotel environments, was distributed during October 1999 to 2,400 young women (21-26 years) already participating in the WHA longitudinal study. This survey asked young WHA women about their patterns of drinking, any drinking-related consequences, and their attitudes, behaviours and beliefs about alcohol. Fifty four percent of the young women have mailed back their questionnaires, and their responses have been coded and entered in a database. Further follow-up of those who did not respond, or who were uncontactable in late 1999, is planned for June 2000.

This data, combined with information from the baseline survey (conducted in 1996), will be used to predict alcohol consumption and related consequences, using regression analyses and structural equation modelling. This will be the first longitudinal study in Australia to generate comprehensive information on young women's knowledge, attitudes, beliefs and behaviours to alcohol, and the multiple factors that influence their drinking patterns and related consequences. Such information is vital for the design of effective education and prevention programs.

Project: Mid age women and heart disease: understanding risks and prevention

Collaborator: Dr Marilys Guillemin (Centre for the Study of Health & Society, University of Melbourne)

WHA Collaborator: Prof Wendy Brown

Funding source: University of Melbourne & Australian Menopause Society

This research examines 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.

Since 1998 when this project commenced, the following research has been undertaken:

1. Analysis of previously collected WHA data for associations between reported cardiovascular 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 to have cardiovascular disease to examine the type of heart disease they have and their associated risk factors (n=189).
3. Exploratory in depth, face to face interviews of a small group of women from the WHA mid age cohort in rural and urban Victoria (n=25) who report to have cardiovascular disease.

The research outlined above is nearing completion. Preliminary analysis of risk factors has been completed, with further analysis of more recently collected data still to be undertaken. The data collection phase of the national questionnaire survey is complete with 91 submitted surveys to be analysed. Approximately half of the in depth interviews have been completed and transcribed, and the remaining interviews are to be conducted in the next few weeks.

It is envisaged that the research outlined above will be completed by the end of this year.

2 CONDUCT OF SURVEYS

2.1 MAIN COHORTS

2.1.1 Young Survey 2 (in progress, commenced March 2000)

Young Survey 2: Piloting

The second survey for the young cohort was developed and piloted during 1999 and is described in detail in Report 13 (December 1999). A copy of the pilot questionnaire and related materials appears as Appendix 2 of Report 13. Tables 2 and 3 below provide an updated summary of response rates to the pilot survey.

Table 2 Piloting Young Survey 2: Response rates at each contact stage

	Date	Number sent/phoned	Response rate up to each stage (%)	Cumulative response rate (%)
Package	31 August 1999	372	0	0
Thank you reminder	21 September 1999	369	6.3	6.3
Reminder 2	18 October 1999	168	34.6	40.9
Phone reminder	1 November 1999	153	4.7	45.6
	February 2000		16.1	61.7

Table 3 Piloting Young Survey 2: Summary of response rates

Status	Number	%
Packages sent	372	100.0
No responses	89	23.9
Completed	227	61.0
Ineligible	4	1.1
Not this time	12	3.2
RTS	39	10.5
Withdrawal	2	0.5

The very large number of participants who were not located (return to sender or no response) is a matter for concern. This may be explained by the very high level of mobility among young Australian women. Of those pilot participants who did return surveys, 171 (79.5%) reported having moved house at least once in the previous 3 years. Overall, 45 (20.9%) had moved once, 48 (22.3%) had moved twice, and 78 (36.2%) had moved three or more times.

Further evidence of the mobility of this group was produced when WHA staff sought to contact 43 young women from the pilot sample to invite them to participate in focus groups. Young women living in Dapto and Mittagong who had responded to the pilot survey between September and December 1999 (and whose addresses could have been assumed to be current at that time) were telephoned in March 2000. Six (14%) were uncontactable. Of the 37 for whom information was obtained, six (16%) were currently overseas; five (14%) had changed address (though for 4 of these the previous address was their parents'), and one had changed her surname.

Extensive efforts were made during January and February of 2000 to track as many participants of the young main cohort as possible; all those whose newsletters (sent out in August 1999) had been returned to sender were tracked using the procedures outlined in Section 4.

Young Survey 2: Development Of Main Questionnaire

Pilot survey data and open-ended comments were collated, and summary statistics were prepared. On the basis of response rates, missing data, and comments on questionnaire design, minor modifications to the pilot questionnaire were made. The Chair of the University of Newcastle Human Research Ethics Committee reviewed and approved the final questionnaire. Table 4 summarizes the changes made and reasons for those changes. Table 5 summarizes the final content of the questionnaire and the derivation of each item. It also notes which items were included in a short version, designed for telephone administration with those young women who were unwilling or unable to complete the entire survey. The questionnaire, letter to participants, and reminder card appear in Appendix 2.1.

Table 4 Differences between the pilot (1999) and the main (2000) survey for Young Survey 2

No. In Main	Question Description	Change Made	Reason for change
1 & 2 a-b	No. of times consulted a family doctor/specialist doctor Part a - Routine pregnancy checks, Pap tests, contraception	The options "1-2 times" and "3-4 times" were separated into 4 different options: "Once", "Twice", "3 times" and "4 times". The order of these changed to Pap test, contraception, routine pregnancy tests.	The 1-2 times option had response rates of 32.6 - 45.6%, so it was separated into two items to spread responses. The 3-4 times option had response rates of 23.3 - 27.4%, so was also separated to spread responses. Pap tests and contraception would be more common than the pregnancy checks.
9	Health Care Card	Explanation of what a Health Care Card was added.	A couple of participants did not understand the distinction between a Medicare Card and a Health Care Card.
10 & 11	Health Insurance for hospital cover/ancillary services	"If not, mark the main reason why" was added to the end of the question.	Discourage participants responding to more than one option. 3 participants wanted to circle more than one option.
25	Serious illness/condition/disability	This question now asks "If you have a serious illness..., please write in the box below" rather than asking in Part a, if they have a serious illness... (yes/no) and Part b, if yes, write it in the box.	As 89.3% said no to Part A in the pilot, it seemed unnecessary to ask this question. Instead, only the ones who had a serious illness... were asked to respond.
28a-d	Help with first baby	The "adequate" option was replaced by "very good", "good" and "fair" .	Responses for "adequate" ranged from 6.5 - 11.6%, so more options were added to spread responses further.
33	Years taken OCP	The "1 year" option was replaced by "1 or less".	Enabled participants to respond if they had been on the OCP for less than 1 year.
35 a-e	Reproductive history	The "none" option was deleted and instructions changed to "mark all that apply".	The missing values were high for this question (4.2 - 11.6%) because they didn't respond if the item wasn't applicable.
50A	Methods of losing weight Part b	The words "to lose" was deleted so that the question was the same as in the baseline survey. "Vomited" changed to "Vomited on purpose after eating"	For comparability between baseline data and follow-up. For comparability between baseline data and follow-up.
54a	No. of cigarettes smoked each day	"Each day" was capitalized.	To emphasise that this question referred to daily smoking.
54b	No. of cigarettes smoked per week	"Per week" was capitalized.	To emphasise that this question referred to weekly smoking.
55 & 56	Ever smoked 100 cigarettes or	The "skip" box now reads, "If no, go to	To make it clearer that only those who answer "no" should skip the next

No. In Main	Question Description	Change Made	Reason for change
	smoked daily	Q59".	few questions.
62	Use of drugs for non-medicinal purposes	The sentence "We want to know about general patterns of use. Please do not give details of specific instance of use." was added to the question. Delete Column IV in the pilot "Do you think that you are addicted".	Legal advice from University of Newcastle Human Research Ethics Committee. Legal advice from University of Newcastle Human Research Ethics Committee.
67 a-b	Hours spent sitting	The word "day" was bolded and capitalized	To emphasis that the time frame was on a usual day, as 6.5% answered for a week not a day, e.g. 60 hours.
70	Life events	Now has 2 columns to respond to. A - "Yes - in the last 12 months" and B - "Yes - more than 12 months ago". "Partner or parent losing a job" was separated into two separate items.	To cover the entire time between baseline and follow-up. 48.4% are living with a partner, so items needed to be separated.
73 & 74	Life isn't worth living and self harm	Lifeline number provided just below these questions.	For access to help/advice. On request from University of Newcastle Human Research Ethics Committee.
75	Time use	Part-time and casual work were separated into two items.	Suggestion from FACs that these were conceptually distinct
82	Satisfaction with child care	"Go to Q84" was added to the "not applicable" option.	If not applicable, the participant was not required to answer Q83 (use of child care).
83 a-b	Use of child care	The "None" option was deleted for a and b.	88.9% of those who answered "not applicable" in Q82, answered "none", so this option was almost repetitive.
80 - 83	Provide care/ managing time/ satisfaction with child care/ use of childcare	These questions were reordered.	In the pilot, the order of the questions were satisfaction with child care/ use of childcare/ provide care/ managing time. These questions were reordered so that the satisfaction question, which had a "skip" option, would finish the page, reducing the chance of failure to answer the rest of the questions on that page.

No. In Main	Question Description	Change Made	Reason
84	Who lives with you?	Item "I live in group accommodation (eg hall of residence, hostel etc)" was added.	The question without this item was hard to answer for those who lived in group accommodation.
85	No. of children living with you.	The words "your own or your partner's" were added. The items "Preschoolers" and "School age" were replaced with "12 months - 5 years", "6-12 years" and "13 - 16 years".	This question was aimed at those who had children under their care, but three participants answered this for siblings living with them. In the pilot, 27% answered that they had at least one child, so items were changed to spread the responses further.
89-91	Social support/ violence/ type of violence	These questions were reordered.	In the pilot, the order of the questions were violence/type of violence/social support. Because the violence question had a "skip", 1.4 - 1.9% failed to answer the social support question. These questions were reordered so that the "skip" would fall at the bottom of the page.
95	Occupation	The word "now" was added so that the question asks "We would like to know YOUR main occupation NOW...." The option "Don't know or not applicable" was added	3.7% responded for all the occupations they have had, rather than their main occupation. This enabled those who were unsure of parents' occupations to respond.
96	Highest qualification of parents	The "Not applicable" and "Don't know" options were combined. The words "or equivalent" were added to the "Up to year 10" and "Up to year 12" options.	The differences between "not applicable" and "don't know" were felt to be unimportant and layout was improved. Those who have studied overseas may not have experienced the same school system.
101 in pilot	Priorities in life	Question deleted.	44 - 46% gave invalid responses. Layout was difficult and the majority considered all options to be important; decided that useful info would not be obtained.
101	Employment at 35	The "Other" option was replaced by "self-employed / own business".	Most responses in the "Other" option related to self-employment or owning their own business. Providing this as an option reduces the amount of write-in responses.

No. In Main	Question Description	Change Made	Reason
103	Relationship at 35	The "Other" option was deleted.	The majority of responses in this "Other" option could be answered in the already existing options.
104	Children at 35	The options "4", "5", and "6 or more children" were deleted. The options are now "No children", "1 child", "2 children" and "3 or more children".	Only 7.4% wanted more than 3 children.
106 h	Satisfaction with motherhood/children	"Not applicable" option added.	28.8% left this item blank and 8.4% wrote in "not applicable"
Consent		"Help us keep in touch" box added.	Space provided for participant to provide details of 2 people that we can contact in the event that we might lose contact with them. Aids tracking.

Table 5 Summary of items in Young Survey 2, derivation, and list of those included in short telephone version.

✓ Item included in the short telephone survey

No.	Question description	Source	Short survey
1 a-b	No. of times consulted a family doctor or a GP	WHA	✓
2 a-b	No. of times consulted a specialist doctor	WHA	✓
3 a-f	No. of times consulted health care professionals	Modified from ABS. 1989-1990 National Health Survey. Summary of results, Australia. Canberra: ABS, 1991; Catalogue No. 4364.0.	✓
4	Admitted to hospital in the last 12 months	WHA	✓
5 a-b	Consistency of GP visit	WHA "Availability and Use of Health Services Substudy" (AUHS)	✓
6 a-j	GP satisfaction	Modified from Davies AR, Ware JE. GHAA's Consumer satisfaction survey and user's manual, Second edition. Washington, DC: The Group Health Association of America (GHAA), 1991. Then revised according to data from AUHS.	
7	GP preference	WHA	✓
8 a-k	Access to health care	WHA - AUHS	
9	Health care card	WHA	✓
10	Health insurance for hospital cover	WHA - AUHS	
11	Health insurance for ancillary services	WHA - AUHS	
12 a-v	Medical History	Modified from ABS 1989-1990 NHS	✓
13 A/B/C a-t	Symptoms and help seeking	WHA (baseline) with revisions	✓
14 - 24	SF-36	Ware JE & Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. <i>Medical Care</i> , 1992; 30: 473-483.	✓
25	Serious illness/condition/disability	WHA	✓
26	Need for care	Modified from ABS. Disability, Aging & Carers, Australia: Summary of Findings. Canberra: ABS, 1993; Catalogue No. 4430.0.	
27 a-c	Age of first period, sexual intercourse, baby	WHA	✓
28 a-d	Help with first baby	WHA	
29	Frequency of period in past 3 months	WHA	✓
30	Sexual orientation	WHA	
31 a-b	No. of sexual partners	WHA	
32 a-g	Contraception	WHA	✓
33	Years taken OCP	WHA	✓
34	Currently pregnant	WHA	✓
35 a-e	Reproductive history	WHA	✓
36	Pap test	Modified from ABS 1989-1990 NHS	✓
37	Abnormal pap test	WHA	✓
38	Infertility problems	WHA	
39	Height	WHA	✓
40	Weight	WHA	✓

No.	Question description	Source	Short survey
41	Birth weight	WHA - substudy on weight gain at mid life	
42	Weight preference	WHA	✓
43	Dieting in last year	French SA, Story M, Downes B, Resnick MD, Blum RW. Frequent dieting among adolescents: psychosocial and health behaviour correlates. <i>American Journal of Public Health</i> , 1995; 85(5): 695-701.	✓
44 a-c	Lost/gained 5 kg	WHA	✓
45 a-b	Dissatisfaction with weight or shape	WHA	✓
46	Binge behaviour	Fairburn CG & Beglin SJ. Assessment of eating disorders: Interview or self-report questionnaire? <i>International Journal of Eating Disorders</i> , 1994; 16: 363-370.	✓
47	Loss of control over eating	Modified from Fairburn & Beglin (1994).	✓
48	No. of times of loss of control	WHA	✓
49	How long...loss of control	WHA	✓
50 A/B a-j	Methods of losing weight	Modified from Fairburn & Beglin (1994) and French et al. (1995).	✓
51A/B a-e	Exclusion of foods from diet	WHA	
52 a-f	Medications	WHA	
53-58	Smoking questions	Australian Institute of Health & Welfare. Standard questions on the use of tobacco among adults. (1998)	✓
59-61	Alcohol questions	Modified from National Heart Foundation of Australia. Risk factor Prevalence Study NO. 1 (1980). Woden: NHF of Australia, 1981.	✓
62 a-l	Use of drugs for non-medicinal purposes	The Drug Offensive: A federal and state initiative. National Drug Strategy Household Survey 1995.	
63 a-b	Have you ever injected yourself?	The Drug Offensive: A federal and state initiative. National Drug Strategy Household Survey 1995.	✓
64 a-b	Used drugs with alcohol/marijuana	The Drug Offensive: A federal and state initiative. National Drug Strategy Household Survey 1995.	✓
65-66 a-d	Exercise questions	WHA	
67 a-b	Hours spent sitting	WHA - Substudy on weight gain at mid life	
68 a-p	Erikson's stages of development	Domingo G & Affonso DD. A personality measure of Erikson's life stages: the Inventory of Psychosocial Balance. <i>Journal of Personality Assessment</i> , 1990; 54(3&4): 574-580.	
69 a-f	Optimism - approach to life	Modified from Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety, self-mastery and self-esteem): a reevaluation of the Life Orientation Test. <i>Journal of Personality & Social Psychology</i> , 1994; 67(6): 1063-1078.	
70 a-ll	Life events	Modified from Norbeck JS. Modification of life event questionnaire for use with female respondents. <i>Researching in Nursing & Health</i> , 1984; 7: 61-71.	
71 a-j	Sources of stress	WHA	✓

No.	Question description	Source	Short survey
72 a-k	Depression - CES-D	Andresen EM, Carter WB, Malmgren JA & Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D. <i>American Journal of Preventive Medicine</i> , 1994; 10: 77-84.	
73	Life isn't worth living	WHA	
74	Self-harm	Modified from Beck A, Schuyler D & Herman I. Development of the Suicide Intent Scale. In Beck AT, Resnick HLP & Lettieri D. The prediction of suicide. Bowie PA: Charles Press, 1974.	
75 a-i	Time use	WHA but items modified from ABS (1992) Time use survey.	✓
76 a-e	Types of work	WHA	
77	Satisfaction with hours in paid work	Modified from ABS (1992) Time use survey. Canberra: ABS, 1993.	
78	Reason for wanting fewer hours of work	WHA	
79	Reason for not doing more hours of work	WHA	
80	Caring for others	Modified from ABS (1993) Disability, Aging and Carers Australia	
81 a-b	Rushed/pressured	Modified from Statistics Canada (1985)	✓
82	Satisfaction with child care	WHA	
83 a-b	Use of child care	WHA	
84 a-k	Who lives with you?	Modified from ABS (1994) Social, Labour and Demographic Statistics	✓
85 a-d	No. of children living with you	WHA	✓
86 a-i	Elder abuse	Neale AV, Hwalek MA, Scott RO & Stahl C. Validation of the Hwalek-Sengstock elder abuse screening test <i>Journal of Applied Gerontology</i> , 1991; 10(4): 406-418.	
87	Living arrangements	ABS Census dictionary. 1996 Catalogue No. 2901.0	✓
88	Marital status	ABS Census dictionary. 1996 Catalogue No. 2901.0	✓
89 a-f	Social support available - MOS SSS	Sherbourne CD & Stewart AL. The MOS Social Support Survey. <i>Social Science & Medicine</i> , 1991; 32(6): 705-714.	
90	Violence	WHA - Violence substudy	
91 a-e	Type of violence	WHA - Violence substudy	
92	Number of moves in past 3 years	WHA	
93	Postcode	WHA	✓
94	Highest qualification	Modified from ABS Census. 1996.	✓
95 a-c	Occupation	ABS. Australian Standard Classification of Occupations Second Edition. 1997. Catalogue No. 1220.0. From the Web page.	✓
96 a-b	Highest qualification of parents	WHA	
97	History of unemployment	WHA	✓
98 a-b	Income	WHA	
99	Number dependent on this income	WHA	
100	Date of birth	Modified from ABS. A Directory of Concepts and Standards: for Social, Labour and Demographic Statistics. Canberra: ABS, 1994.	✓

No.	Question description	Source	Short survey
101	Employment at 35	Modified from Hakim C. Grateful slaves and self made women: fact and fantasy in women's work orientations. <i>European Sociological Review</i> , 1991; 7(2): 101-121.	
102	Job at 35	Modified from Hakim (1991)	
103	Relationship at 35	Modified from Hakim (1991)	
104	Children at 35	Modified from Hakim (1991)	
105	Qualifications at 35	WHA	
106 a-h	Satisfaction with life	WHA	

Young Survey 2: Procedure

Following tendering procedures, the contract for preparation, printing, mailing and optical scanning of the survey was let in January 2000 to NCS Australia. The timetable for survey distribution, number of surveys distributed at each stage are shown in Table 6, and response rates to date are shown in Table 7.

Table 6 Timetable for Young Survey 2

Date	Mailout	Items	Number
21 March 2000	Mailout 1	Package mailed including survey, reply-paid envelope, letter of invitation and change of details card.	13,516 mailed
5 April 2000	Mailout 2	Thank you/reminder leaflet mailed to all in mailout 1, except withdrawals, deceased and overseas.	13,066 mailed
8 May 2000	Mailout 3	Reminder leaflet to all non-responders.	6,312 mailed.
12 Jun 2000	Phone reminder	Reminder phone calls to all non-responders.	Approximately 5,500 expected to be phoned.

Table 7 Response rates for Young Survey 2 (as at 15 May 2000)

	Freq	%
Completed surveys	6460	48%
Deceased	4	
Withdrawals	26	
No current address	10	
Overseas	32	
Will not do survey this time	3	
Return to senders (being tracked)	846	6%

2.1.2 Mid-age Survey 3 (March 2001, in planning stages)

Preparation for the third survey of the mid-age cohort began in March 2000. As a general principle, the Investigators decided that this survey should maintain questions from the second Mid-age survey as much as was appropriate, so that the longitudinal strengths of the survey design would be maximised. Changes would generally be limited to the updating of standardised risk measures (e.g., alcohol consumption) if consensus within the scientific community had changed; adding questions within existing categories (eg, life events, symptoms, diagnoses) that would be more appropriate to the current age group of the women (50-55 in 2001); removal of questions which are no longer appropriate to the age group (eg, childbirth), which are peripheral to the main survey themes, have not been used in analysis, or do not need to be measured again.

Specific additions include: nutritional measures (we are currently negotiating with the Anti-Cancer Council of Victoria to examine the possibility of including their Australian validated Food Frequency Questionnaire); experience of infertility (included in Young Survey 2 2000); question on sexual orientation (included in second Young Survey 2 2000).

In March and April 2000, the Principal Investigators circulated and discussed the second Mid-age survey, compared it with the second Young and Older surveys, and generated ideas for modifications, additions and deletions. On 12 May 2000 a working party discussed the inclusion or exclusion of items, wording of items, response formats, and issues to be developed further. A preliminary draft has been prepared on the basis of this day's discussions and is currently being circulated for debate. The proposed timeline after May 2000 is outlined in Table 8.

Table 8 **Timeline for development of Mid-age Survey 3**

Month	Task
June 2000	Finalise questionnaire
July 2000	Pilot questionnaire: print, ethics clearance
Aug/Sept/Oct 2000	Mail, process, data entry and analysis of pilot
Nov 2000	Revise, finalise, ethics clearance
Dec 2000	Call for tenders for main survey
Jan 2001	Select tenderer and work on development of materials
Feb 2001	Production
March 2001	Begin Mid 3 main survey
April 2001	NB Easter break is Fri 13/4/01- Tue 17/4/01

2.2 INDIGENOUS COHORTS

2.2.1 Progress with existing cohorts

The Women's Health Australia, Indigenous Women's Cohort Project aims to investigate health issues among indigenous women in remote, rural and urban communities in Queensland. Baseline data have been collected from 5 communities, forming a platform for future surveys within the same communities. Progress to date has relied on extensive community consultation, allowing the establishment of a sustainable and trusting relationship with potential partner communities.

2.2.1.1 Community Based Research

One of the major principles of community based research is the focus on community issues, rather than on individual issues. In indigenous communities, the issues of transience of community membership and the desire for individual privacy also place the research focus at the community level. Thus the project has developed a culturally appropriate and practical method, which involves returning to the same communities, but not necessarily including the same individuals in it's follow-up survey.

Successful community research also depends upon reciprocity. Indigenous communities maintain that for too long researchers have taken information away from communities while returning very little benefit to the community from that research. Communities are beginning to develop formal protocols for incoming researchers that reach beyond those set by the NH&MRC guidelines. These community-initiated protocols invariably include elements of reciprocity, such as:

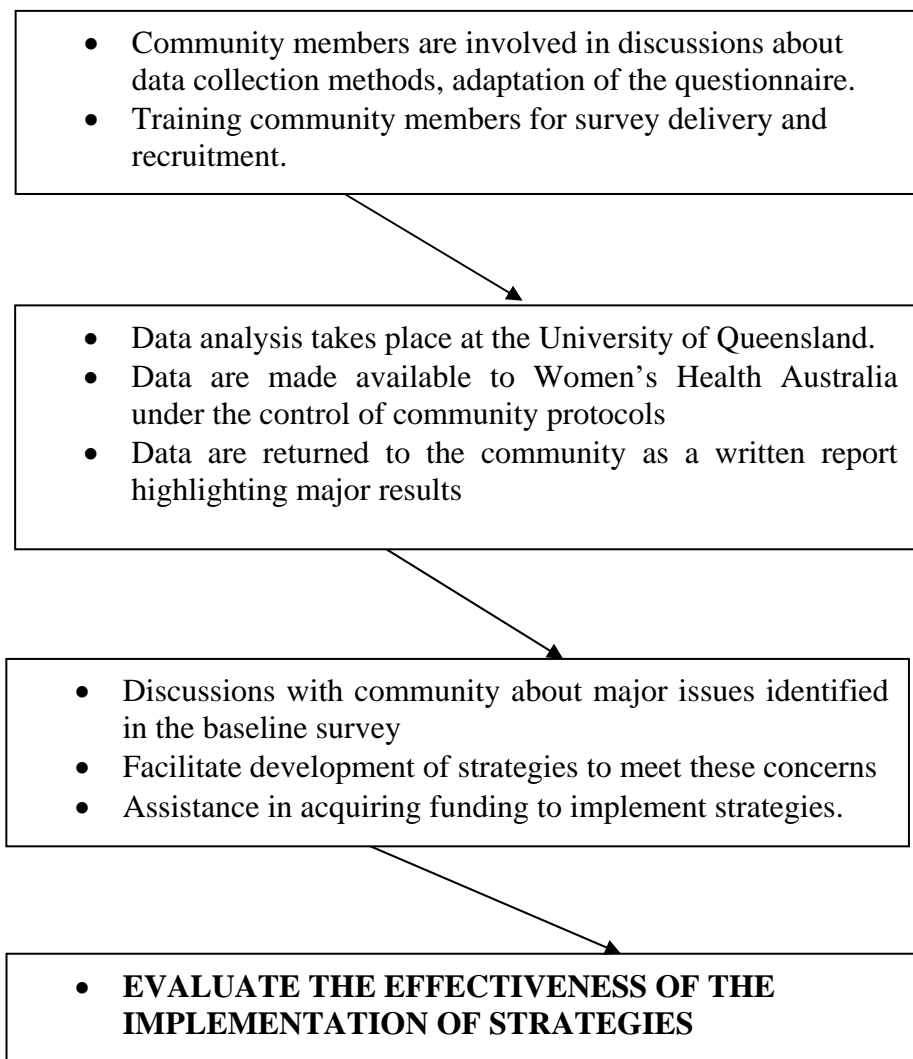
- The research is expected to return a direct and tangible benefit to the community;
- The research is expected to incorporate an element of training to build skills within the community;
- The research is expected to establish an initial relationship with the community which is ongoing and involves responsibilities and obligations on the part of the research team that continue over time, and strengthen in intensity and complexity.

Another pressing issue for communities in relation to research is the question of ownership. This issue is currently under discussion within communities and is increasingly included in formal community based protocols. In essence, Indigenous ownership is defined by communities as meaning that permission to gather data does not automatically grant the research team, or their organising institution, or the funding body, ownership over that data. The issue of ownership, and how data may or may not be used, is a matter of negotiation in each instance.

With the above in mind, the Women's Health Australia, Indigenous Project Team have developed a research model which has met with approval from communities already involved in the project and those currently negotiating involvement. The model has been fully implemented in the Cherbourg community and is currently in the process of implementation in Woorabinda, Hope Vale, Toowoomba and North Brisbane.

2.2.1.2 Women's Health Australia: Indigenous Women's Projects Research Model.

The model involves a process, which begins with negotiation regarding the baseline survey.



The baseline phase is then complete and the process begins again in relation to the second phase.

2.2.1.3 Cherbourg

As has been reported in previous documents, the baseline phase has been fully implemented in Cherbourg. Consultation was carried out over 12 months, followed by the identification of the Health Action Group as the community organisation accepting ownership of the project on behalf of the community. The Health Action Group then led community consideration and adaptation of the survey. Local community members were then trained in data collection methods and employed as interviewers by WHA to gather the data. Results were then presented back to the community via the Health Action Group. The Women's Health Australia Team spent time with the Health Action Group assisting them to identify strategies that might meet some of the concerns arising from the survey, facilitated implementation of these strategies and monitoring progress.

As a consequence of the successful completion of this process, and the strong ties built between the University and the community during the process, the community is eager, three years after the initial baseline survey, to participate in the second phase of the longitudinal data collection. The development of this model has been lengthy and costly, however now that it has been refined, the cost of repeating the process is less in each community.

Major issues identified in the Baseline Survey

Exercise and Fitness

Women identified the need for a fitness program in Cherbourg and Women's Health Australia successfully obtained Queensland Health funding for gym equipment and fitness trainers. The gym equipment is now housed in the newly developed gymnasium, funded by the Queensland Government. When Queensland Health funding expired, the Community Council took over funding of the fitness trainer and the Healthy Lifestyle Program. The project is now fully sustained by the Community Council and participation of community members remains high. Early anecdotal evidence suggests that smoking and alcohol consumption are lower among those participating in the Healthy Lifestyle Program, because of the increased awareness of the value of fitness. Women realised they were unable to keep up their exercise program while they smoked heavily, they began to reduce their smoking.

Birthing

Women also identified the need to return birthing to the Cherbourg community. Since 1987 expecting mothers have been transported to Kingaroy Hospital for delivery of their babies. Women find this unacceptable and express a desire to give birth in the community. To this end they have realised a need for risk data on birthing and for an antenatal risk assessment tool that is appropriate to their circumstances and culture. Women's Health Australia supported this research by the Health Action Group to an Aboriginal researcher currently undertaking a Masters Degree in Epidemiology at the Australian National University.

This student is carrying out the risk assessment research as part of the requirement for her Masters Degree. The WHA Team has agreed to assist the Health Action Group in using these data to write a proposal to Queensland Health for the return of birthing to Cherbourg.

Data Comparison

During meetings between researchers working on the national Women's Health Australia component and the Indigenous women's study, it was suggested that comparisons could be made between the data from Indigenous communities and from the 480 Indigenous participants in the national survey. There are difficulties inherent in such a comparison as methods varied so greatly between the major study and the community studies. In addition ethical issues arise, relating to the way such comparisons should be implemented and how they might be interpreted

Discussions with women from the study communities have taken place about this proposal over several meetings. A number of viewpoints have been put forward by the various participants in the discussion. The major points voiced are outlined below:

- Indigenous women selected at random from Medicare records will be generally different in demographic characteristics from Indigenous women selected within communities. There is no way of describing these differences precisely, and of considering their impact on the data.
- Indigenous women selected randomly within the national study are likely to be from a diverse range of circumstances themselves.
- As the impact of demographic and social circumstance has such a dramatic impact on Aboriginal and Torres Strait Islander health, there seems little value in statistical comparisons which allow no consideration of these variables, beyond the assumption that they will differ between sets in an unknown way.
- Data sets have been selected according to such vastly different methods that comparisons will have little value.

- Such comparisons once made, however clearly qualified according to their limitations, open possibilities for misleading interpretations that may be based on stereotypical assumptions.

Once researchers had highlighted their concerns it was decided to put the issue of data comparison to the communities.

A series of bar graphs and histograms, based on the Indigenous women in the national survey, were established to demonstrate to the community members what is intended in terms of comparisons. These were presented to the Health Action Group members in Cherbourg, along with explanation of their meaning and information about how they would appear in relation to the final text. Health Action Group members appreciated the opportunity to learn more about statistical presentations of data and applauded the training component embedded within the project, as well as the commitment to true Indigenous ownership of the data. Their response to the proposal is presented below:

- The Health Action Group had concerns about the comparison of a group of women selected from across the nation with their Cherbourg data.
- They asked for specific ways in which this comparison is likely to improve health in their community, or for Aboriginal people as a whole.
- They did not want their data compared with the data collected from other communities because this could lead to bitterness between communities and inappropriate interpretation.
- They did not want their data compared to the major study data because this could lead to racist assumptions.

As has already been stated, this project is committed to maintaining strong relationships with the participating communities and to the principles of Indigenous ownership. At this stage the project does not have agreement to carry out data comparisons or make data public. It is of course possible that further negotiation and consultation may lead to a change of position from the community. It may be best to work through a staged process of selective data release, rather than expect an open unconditional agreement.

Agreements and Consent

The consultation process itself forms the basis for a fully informed agreement from the community or organisation to participate in the research. Although the NH&MRC ethical guidelines recommend the use of a formal written contract between researchers and community to provide evidence of consent, such a written document has not been used in all cases relating to the WHA Indigenous women's projects.

A final agreement may be made formal and in writing if the community prefers this option. In this case, the community may draft the agreement themselves setting out names of individuals, organisations or groups involved and their roles, the nature and scope of the project, and in particular conditions. It may take the form of a contract or letter, to be co-signed by those taking responsibility.

However, there are reasons why a community or organisation, which supports the project and wishes to be involved, may prefer not to have a written agreement. Reasons put forward by people participating in this project include:

- the importance of a traditionally oral culture and respect for that tradition;
- a fear of written contracts, based on negative past experience;

- fear that a written agreement will prevent the community from re-considering their involvement at some point in the future.

The insistence on a written agreement can have the paradoxical effect of alienating a community since it may be interpreted as a lack of trust. This research team has found that building a trust relationship through the consultation phase and maintaining that relationship throughout the process of the project is much more complex than can be represented in a written contract.

Without a written agreement, there is still ample evidence of a positive relationship between the project and the community. This evidence includes documentation of continuing consultation, active and voluntary support from the community through their attendance at meetings, training workshops, evaluation sessions, and their participation in the preparation of reports and publications.

2.2.1.4 Toowoomba

The Area

Toowoomba is Australia's largest inland city after Canberra. The city sits on the edge of the Great Dividing Range and the Darling Downs at around 700 meters above sea level. Toowoomba is 138 km, or about 90 minutes drive, from Brisbane. The city is the major education centre of the region with 23 private schools, a technical and Further Education College and the University of Southern Queensland.

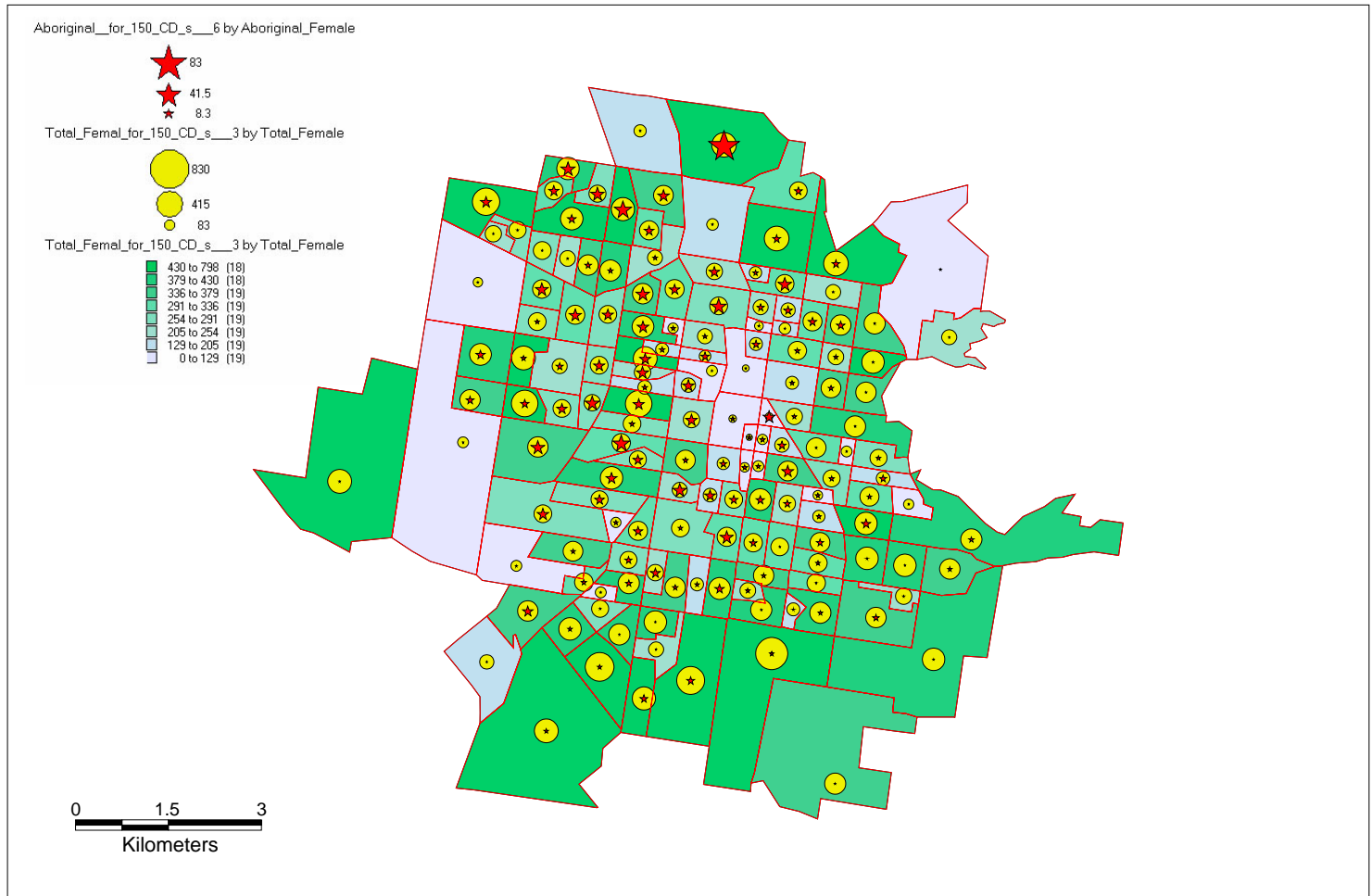
Of the population of approximately 90,000, there are 2,200 Indigenous Australians (1996 Census). Of these 1,084 are female.

Consultation

Community consultation, while an important phase of Indigenous research, is also an aspect of that is often vaguely defined. The term 'community consultation' may refer, in different reports, to a broad range of interpretations and activities. These might vary from a phone call to someone working in a health service, to extensive contact over a period of years. Both the words 'community' and 'consultation' can be broadly interpreted. When working in Deed-of-Grant-in-Trust (DOGIT) communities, the label community is less problematic than in the urban setting. Historically DOGIT communities have their origins in church or government mission settlements formed by the relocation of Aboriginal and Torres Strait Islander peoples to areas designated by the Government of the day. These communities have a high percentage (95%) of Indigenous residents and are more easily geographically defined and compact than other areas. Aboriginal councils control DOGIT communities and these councils usually represent the community position on issues of research in a formal sense. If true consultation has not occurred, individuals within the community will remain reluctant to participate. There are methodological difficulties even in DOGIT communities, for example census figures for Cherbourg (1996) are only half those estimated by the Community Health Service (approximately 2 000). This may reflect under-enumeration of the census, or may be related to high mobility of people across communities.

Within an urban environment such as Toowoomba, the label 'community', when attached to the Indigenous population, is somewhat less easy to define. The 2.6% of Toowoomba's population who are Indigenous are spread across the city and outlying suburbs (see Figure 2). It is difficult to select a sample, but it is also difficult to identify a representative body for consultation. The most common response is to work through the Community Controlled Health Service. However this body is not always recognised by the local Indigenous community as representing their needs. In terms of sampling the Community Health Services provide access to a limited number of local Indigenous people who utilise that service. There is an obvious bias in this, particularly when researching issues relating to health. It is tempting to conclude that the term community does not apply in the urban setting and that representation is simply too difficult. Indeed, this is a reason given for the paucity of Indigenous research in urban centres. The Indigenous people of urban centres do, however, identify themselves as belonging to the community of that centre. This is true in Toowoomba.

Figure 2 Distribution of Aboriginal Females in Toowoomba



Through discussions with a range of Indigenous people living in Toowoomba we found a consensus that the area covered by the Shire Council of Toowoomba was a relevant geographic boundary for their community. While they acknowledged their diversity within that boundary they felt strongly that they constituted a Toowoomba Aboriginal and Torres Strait Islander Community.

Consultation within that diverse community then became an issue of representation. There are always a number of Aboriginal organisations within an urban setting and these can provide a practical way to access a wide range of Indigenous residents. Organisations often have resident lists covering a sector of the population they service and even if these lists are not formal there will be informal knowledge of individuals and families linked to those organisations. As organisations service different sectors of the population, for example: the aged; women's groups; men's groups; youth groups; housing and so on, they provide a varied series of access points to the population. Once a relationship of trust and respect is established between the research Team and the organisations, this trust will form the basis for access to broader circles of community consultation.

Consultation was carried out with the Indigenous community of Toowoomba over a period of two years. Initially consultation began with the Aboriginal Health Service and then broadened to include the Down's Women's Support Group in Toowoomba. At the suggestion of the Health Service, the Down's Women's Support Group became the community organisation accepting ownership of the Women's Health Australia, Indigenous Women's Project Baseline Survey. A Women's Health Forum was organised in November 1996 as an opportunity to introduce the project

aims to the community. Professional women spoke on health issues at the Forum and the WHA Team presented the background to the project and the proposal to carry out baseline research in Toowoomba and the surrounding communities.

Following the forum, interested women took part in evaluation of the baseline questionnaire and discussion of potential recruitment and research strategies. This consultation took place over a period of twelve months and involved women from a number of age groups and geographical areas within Toowoomba. There was a period of time following this early consultation in which no further progress could be made. Issues of continued funding for the project blocked progress, as did major staff changes within the Down's Women's Group. In August 1999, consultation resumed and new staff at both the community organisation and within WHA were introduced to the project and the consultations that had already taken place. At this point the questionnaire was revisited by women linked to the Down's Women's Group and a number of adaptations (see below) were approved by the organisation.

Sampling

As there is no formal register of Indigenous peoples living in Toowoomba, it was not possible to select a sample from a pre-established population frame. Given that the population of Indigenous women living in Toowoomba is spread across the geographical area it did not seem appropriate to rely on housing clusters. Instead the geographical boundaries of the study were defined as the boundaries of the Toowoomba Shire Council plus the township of Oakey, 30 kilometres north west of Toowoomba. Selection into the survey was based on networking within seven geographic sectors- six sectors within the Toowoomba Shire Council, and a seventh in Oakey. Indigenous women known to the Down's Women's Group and living in each of these sectors were identified and invited to participate. This form of networking has been well established as appropriate in Indigenous research. It allows for discussion of the survey to precede the request to fill in a questionnaire and for the interviewer to be recommended to the respondent prior to their first meeting. In this way trust is maintained and response rates remain high.

Of the 1,084 Indigenous women identified by the 1996 Census as living within the Toowoomba boundary, approximately 400 were expected to be over the age of 16 years and eligible to participate in the survey. The final sample included 190 women.

The age distribution (Table 9) shows broad coverage, with women aged between 16 and 89 years. Participant numbers are low in the older age groups, reflecting the age distribution of indigenous residents. Twenty participants did not wish to reveal their age.

Table 9 **Age distribution of sample**

Age in Years	Number of Women
16 - 20 yrs	31
21 - 25 yrs	28
26 – 30 yrs	30
31 - 35 yrs	20
36 - 40 yrs	22
41 - 45 yrs	13
46 - 50 yrs	16
51 – 55 yrs	7

56 – 89 yrs	3
Total	170
<i>Missing</i>	20

The sample included women spread across each of the six grids (Table 10).

Table 10 **Geographic distribution of sample**

Area	Number of Women
Oakey	36
Sector 1	35
Sector 2	52
Sector 3	35
Sector 4	12
Sector 5	19
Sector 6	1
Total	190

Interviewers

The Down's Women's Group was asked to nominate local Indigenous women who would like to work as interviewers on the project. There was no prerequisite for the training, however we asked that both younger and older women be trained. All women who were nominated attended training workshops, with was no obligation to continue as an interviewer after the workshop. Women were paid for the time they spent at the training workshop. In all five women attended the workshops and participated in the data collection process. Interviewers were all local community women. Three women were aged less than 45 years and two were more than 45 years of age.

Training

The training workshop aimed to familiarise the women with basic research processes and the key principles of survey interviewing. Participants had no research experience, nor did they have any health worker experience. An essential element of the training was to help them feel comfortable with the process of introducing themselves and the project to potential study participants, and increase their comfort with the questionnaire. It was also intended that the training workshop would build a team spirit among the interviewers and set up the foundation for regular meetings to discuss among themselves any difficulties as they might arise.

Interviewers were informed of the importance of gaining consent and ensuring that women were truly comfortable with participating before survey questions were asked. Basic survey techniques such as asking questions in the same way for each participant, were covered (see the Training Manual in the Appendix). It was stressed, however, that the interview process should be enjoyable rather than grueling and that the feeling of a “yarn” over a cup of tea would gain the best results in terms of accuracy and honesty in the data.

Interviewers were also informed of the processes of employment within the University system. They became familiar with appointment forms, time sheets and expense claim forms and discussed the number of interviews they might gather and the time it was expected to take. They gained an

initial sense of how many surveys they were expected to collect and the time schedule of the project.

This discussion was important at this stage because it quickly became apparent that some interviewers would be able to gather more data than others. At two weekly intervals the interview team met with research staff to hand in their completed surveys and discuss their experiences. When interviewers were able to discuss their experiences with one another, they could re-evaluate the amount of time they were spending on each interview and the techniques they were using. Women learned best from one another and only minimal input was required from the research team.

The initial training workshop took place at Aida's Hostel, and took about five hours. Fortnightly meetings lasted for about two hours of intense discussion relating to the project. They were followed by morning tea and social discussion. There was great value in these meetings, in terms of monitoring the progress of the data collection, and in providing ongoing support for the interviewers.

The Questionnaire

The baseline survey that had been used in Cherbourg, Wooroobinda and Hope Vale was discussed with the women of Toowoomba during the consultation phase. Women did not find any problem with the range of questions or with individual questions asked, however they did request that there be two versions of the survey, one for women between the ages of 16 and 45 and one for women over 45 years. The difference between the two was that the older age group was asked questions about reproduction and birthing in the past tense.

Initially, women thought the survey was too long, but after the data collection had begun, interviewers reported that it did not take as long to deliver as they had expected. In the consultation phase there was discussion about whether interviewers should ask the questions and write down answers, or whether women would prefer to read the questions and answer them alone. It was decided that face to face interviews would reveal the most comprehensive results. However as some questions are highly sensitive this approach needed to be taken with caution.

Photocopies of the two versions of the survey (16 to 45 years and >45 years) were left at Aida's Haven for interviewers to collect as they needed them. Completed surveys were returned at the fortnightly meetings. (A copy of the survey is included in the Appendix). These were checked for completeness and accuracy and any problems were discussed with interviewers.

Data Management

Completed forms were returned to the project office at the Royal Brisbane Hospital. Data entry is currently being organised. When this step is complete, the surveys will be stored in a locked filing cabinet in the project office. Master data files are stored on a password-protected section of the central file server within the Tropical Health Program. Up to date back up copies are held on CD-ROM's in a locked cabinet. Codebooks, field diaries and other data management documentation are kept up to date in a locked cabinet at the Project Office.

2.2.1.5 Hope Vale

The Area

Hope Vale Aboriginal community is approximately 62 kilometers north of Cooktown in Cape York Peninsula. The mission was first established in 1855 at Cape Bedford as a mission set up to help the Gugu Yimidirr people, as they were battle-wearies, dispossessed and disheartened survivors of the Palmer River gold rush. During World War II the Cape Bedford people were evacuated to Woorobinda, southwest of Rockhampton. There they suffered many deaths in a strange climate and environment. In 1949 the survivors returned to a new mission some 25 kilometers from the previous site of Cape Bedford, and called it Hope Vale. Hope Vale became one of the Aboriginal communities in Queensland to receive land under the new Deed of Grant in Trust (DOGIT) system. With the DOGIT system community members were given a few hectares of land where they established farms in surrounding areas. Most have pastoral land for stock; others have farms that produce their own fruit and vegetables, while others were found to move out of the areas to avoid community stress.

In December 1997, the Federal Courts in Cairns granted native title over 110,000 hectares of land to the Hope Vale community. The 1996 census shows that the population of Hope Vale is approximately 669 with a total of 359 males and 312 females.

Consultation

In March 1998, Audrey Deemal conducted a pilot of the baseline survey in Hope Vale Project. At that time women expressed interest in having the survey carried out on a wider scale in Hope Vale. In November 1999 the research team returned to Hope Vale to discuss the baseline survey. A Women's Forum was held on November 22 and women were nominated for training to carry out data collection in the community.

Sampling

A household survey of all residences in the Hope Vale community was planned. Women were eligible for inclusion if they were Indigenous, aged 15 years or older, and were permanent residents of Hope Vale. Interviewers recorded the number of eligible women in each house, 150 in total, and interviewed those agreeing to participate. A single return visit was made to houses where residents were not home at the first visit.

Thirty eight (38) women were away at the time of the survey and 24 declined the invitation to participate. Those women who did not want to participate in the survey said that it was because it was "too wet" and they did not want visitors. Throughout the period of the survey it rained heavily in Hope Vale and this made it difficult for interviewers to move around the community and restricted the times they could call on people. Twenty eight (28) women had completed the survey during the 1998 pilot and a further 60 completed the survey in early 2000.

Interviewers

Three local women were trained to carry out interviews in Hope Vale. The training workshop consisted of a three-hour session focussing on the basic principles and techniques of data gathering, the survey itself and issues of consent and confidentiality. A training manual was supplied. Interviewers were chosen on the basis of their knowledge of the community and because they were respected by women living in Hope Vale.

Results

The Hope Vale data is currently being analysed. Data from the pilot study was merged with data from the wider survey to create a data set of 90 questionnaires from Hope Vale. Only preliminary results are available at this stage.

In summary, participants ranged between 16 and 69 years of age and approximately half the women surveyed had lived in Hope Vale most of their lives. Half the women were unemployed and a further 17% were employed through the CDEP scheme. The health issues women identified as having the greatest impact on the community were drugs and alcohol, violence and grief and loss. A report is currently being prepared and is scheduled to be ready for return to the community for feedback, by the end of June.

2.2.1.6 Woorabinda

Discussions with the Health Team in Woorabinda have continued. This community will be visited soon in order to develop the research plans for the next phase.

Census data for Woorabinda and Cherbourg (both DOGIT communities) have been extracted and mapped (see figures: Women in Duaringa Shire and Women in Murgon Shire), with a view to making estimates of past and future coverage. The distinction between the distributed Indigenous population in urban centers (Figure 2) and these communities is striking (Figures 3 and 4).

Figure 3 Women in Duaringa Shire

Census year	Number of Indigenous women 15 years or over	Number of women 15 years or over
1986	313 (10.1%)	3105
1991	348 (11.3%)	3080
1996	368 (12.9%)	2845

Area	Number of Aboriginal females in 1996	Number of females in 1996
Woorabinda	489 (91.2%)	536
Duaringa	93 (3.4%)	2755
Elsewhere	36 (4.0%)	901
Total	618 (14.7%)	4192

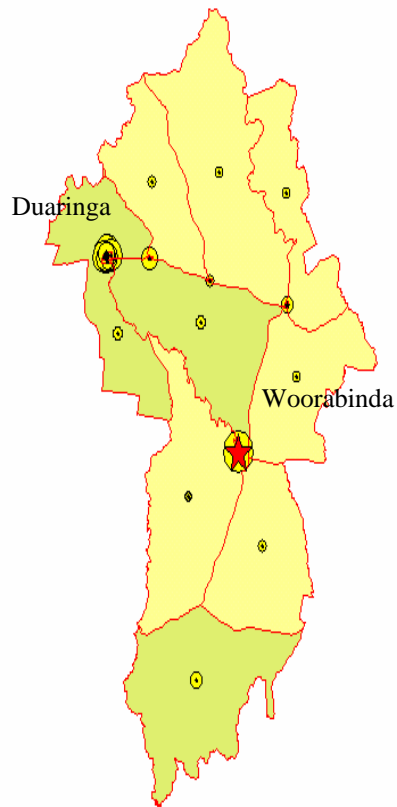
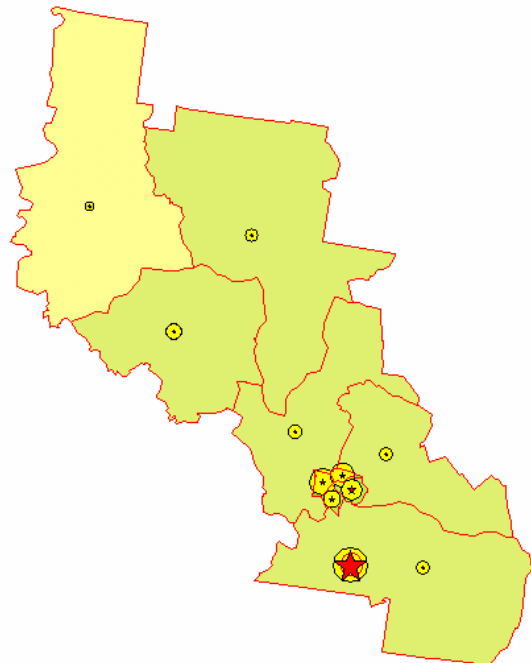


Figure 4 Women in Murgon Shire

Census year	Number of Indigenous women 15 years or over	Number of women 15 years or over
1986	309 (20.0%)	1548
1991	336 (21.6%)	1555
1996	402 (25.1%)	1604

Area	Number of Aboriginal females in 1996	Number of females in 1996
Cherbourg	554 (97.0%)	571
Murgon	126 (11.8%)	1066
Elsewhere	10 (1.7%)	582
Total	690 (31.1%)	2219



2.2.2 Establishment of urban indigenous cohorts

Brisbane

During the last six months, consultation regarding a baseline survey in the northern suburbs of Brisbane has been carried out. Keribah Wangunn, an Aboriginal Corporation for women, and Sandgate Aboriginal Corporation, which has a women's group meeting once a week, have both been involved. We have also visited Aboriginal and Torres Strait Islander Corporations in Caloundra and Nambour regularly. Ngawudinum Community Care and Nalingu, Brighton and Redcliffe Community Centres have also been visited. On 21 February we hosted a Women's Gathering at Nunjeena in the Glasshouse Mountains and invited women to discuss the baseline survey. This gathering was well attended by representatives from all the above organisations, who expressed their interest in taking ownership of the baseline survey in this area. A plan for recruitment similar to that used in Toowoomba is being developed.

2.3 FILIPINA COHORT: STRATEGY FOR FINALISATION

After the decision was made to close the migrant cohorts of Women's Health Australia, a small qualitative study of mental health was approved at the Project Advisory Committee meeting (October 28, 1999) and was conducted with a subset of the Filipina cohort from February to May 2000. The strategy was for the study to follow-up on a health issue that was both a major finding of the longitudinal study and of direct concern to the Filipina women involved. In this way finalisation of the cohort would have the potential to lead to both direct and indirect benefits beyond the closure of the cohort to the women participating. This was important as the women comprising the Filipina cohort were anticipating a longitudinal study of 20 years duration with the potential benefits resulting from this.

The pilot study was restricted to Brisbane and environs to keep within a modest budget. Members of the Filipina reference group from the other regions of Queensland participating in the cohort (Cairns, Townsville and Mt Isa) were involved in the meetings for the study through teleconferencing, with all members receiving the meeting minutes. Meetings with the reference group were held on March 16 and April 10, 2000. A final meeting is scheduled for June 20, 2000. At this meeting a thank-you card and letter outlining the closure of the cohort will be presented to the reference group members for their review and will then be posted to all 346 women participating in the first follow-up survey in 1998. Outlined below is a brief description of the study that was conducted and plan for direct community-benefit based on the results of the study following the closure of the cohort.

2.3.1 Qualitative sub-study: Mental health of Filipina women in Brisbane and environs

Aims and objectives

The main aim of the study was to illicit the meaning of mental health and the social and cultural context of its associated determinants in Brisbane and environs for;

- a) Instrument development for screening, research and measurement of mental health,
- b) Application to policy and mental health service provision for Filipina women.

The overall objectives were to:

1. Explore community concepts of mental health/illness,
2. Investigate the way in which mental illness is experienced by Filipina women,

3. Describe the social and cultural context of Filipina women's everyday experience of the factors that have a negative impact on mental health,
4. Describe the ways in which Filipina women connect to people and place in Brisbane and environs and the role these connections play in stress and coping.

Methodology

Sampling was purposive based on the results of the longitudinal surveys. Characteristics of women in the sample are shown in Table 11.

Table 11 Sampling frame for the Filipina women

Brisbane				Sunshine Coast			
GHQ * <4		GHQ ≥ 4		GHQ <4		GHQ ≥ 4	
Age <50	Age ≥ 50	Age <50	Age ≥ 50	Age <50	Age ≥ 50	Age <50	Age ≥ 50
n=3	n=3	n=3	n=3	n=3	n=3	n=3	n=3

*GHQ-28 was used at the follow-up survey as a measure of mental health status. The threshold of 4 was used as the cut-off.

Women selected from the participant list of the 1998 survey were contacted by a local reference group member and by a Women's Health Australia researcher and were invited to participate in the study. A letter of confirmation of interview date and time and an information sheet and consent form was sent to each woman prior to interview. Individual in-depth interviews were conducted with a total of 24 women from March to May 2000. The interviews were 1-1 ½ hours in duration and were conducted either in the woman's home or an office on the University campus at their request. A semi-structured questionnaire was used which included four main areas of focus: 1) Problems and coping strategies; 2) Experience of mental health problems; 3) Community and family networks; and 4) How women connect with place in Australia. Interviews were tape-recorded after gaining consent from the women.

The interviews are currently being fully transcribed, with about half of them completed at the time of this report. In-depth analysis of the interviews will take place from mid June. The study will then be written up for publication.

One of the potential community-based needs outcomes identified from preliminary analysis and ongoing analysis of the qualitative research is an information booklet in both English and Tagalog to assist Filipina women in coping with problems in their everyday lives and in linking them with local mental health services. Funding is currently being sought for the development and production of this booklet based on the results of the qualitative research. This is important so that there is direct community benefit from the five years of research in the Filipina communities of Queensland.

3 METHODOLOGICAL ISSUES

3.1 SOURCES AND DEVELOPMENT OF INSTRUMENTS

3.1.2 Measuring remoteness – The development and use of ARIA

Background

The need for a standard classification and index of remoteness for service planning and research in Australia has long been recognised. To address this issue the Accessibility/Remoteness Index of Australia (ARIA) was developed by the National Key Centre for Social Applications of Geographic Information Systems (GISCA) in partnership with the Department of Health & Aged Care. (Department of Health and Aged Care, and the National Key Centre for Social Applications of Geographical Information Systems (GISCA) (1999) Measuring remoteness: accessibility/remoteness index of Australia (ARIA) Canberra: Dept. of Health and Aged Care. Occasional Paper No. 6, www.health.gov.au)

The Index and Classification supersede the Rural, Remote & Metropolitan Areas classification (RRMA), produced in conjunction with the Department of Primary Industry and Energy (DPIE) in 1994. The categorical RRMA classification, although widely used, has two main limitations:

- the large and varying sizes of the statistical areas forming the unit of analysis in RRMA, and
- the use of straight line distance measurements which do not reflect the reality of travel by road.

ARIA is designed to be comprehensive and simple, stable over time and is an unambiguously geographical approach to defining remoteness. This approach uses distances to service centres as the basis for quantifying service access and hence remoteness. It uses GIS technology to combine road distances to population centres of various sizes, as a measure of service access, to develop a standard measure of remoteness at community level that is suitable for a broad range of applications. Socioeconomic, urban/rural and population size factors are excluded.

The ARIA scores range from 0 to 12 on a continuous scale. However, for ease of reporting, discrete categories have also been defined, based on natural breaks in the data, balance across categories and broad comparability with RRMA (DHAC, 1999). See table below for the categories.

Table 12 Categories of ARIA scores

Category	ARIA score	Description
Highly accessible	0 - 1.84	Relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction
Accessible	1.85 - 3.51	Some restrictions to accessibility of some goods, services and opportunities for social interaction
Moderately accessible	3.52 - 5.80	Significantly restricted accessibility of goods, services and opportunities for social interaction
Remote	5.81 - 9.08	Very restricted accessibility of goods, services and opportunities for social interaction
Very Remote	9.09 - 12	Locationally disadvantaged - very little accessibility of goods, services and opportunities for social interaction

As the Department of Health and Aged Care is proposing ARIA for adoption as a national standard, the use of the ARIA score in the Women's Health Australia project is currently being assessed. The distribution of ARIA scores and the agreement between ARIA scores and RRMA categories have been investigated and are reported below.

Method

Using the consent database, the study ID number, locality and postcode for women in the young, mid-age and older cohorts, both in 1996 and 1999, were sent to GISCA for coding. Only records with non-missing postcodes were sent. The number of records sent for coding were:

1996		1999	
Young	14260	Young	14233
Mid	13641	Mid	13698
Old	2502	Old	12432

In December 1999 the records were run against comprehensive dataset of localities and scores. The large number of incorrectly spelt or inaccurate addresses caused some delays in coding. These errors had to be dealt with manually by GISCA staff and were time consuming. A database was created and sent to WHA for analysis. For each participant in the cohorts the following details were obtained (see Table 13).

Table 13 Information from GISCA regarding ARIA coding

Field	Description	
Study ID number	Study ID number of respondent.	
Locality	Residential town, state and postcode of respondent (as a checking mechanism for the ID number).	
Join field	The town and state used to derive an ARIA value for the respondent. In the majority of cases, it is the same as that listed in their address (in metropolitan areas it reverts to the capital city).	
Method	This is an important field which describes how the ARIA score was determined for the respondent and has five categories:	
1	Actual (89.6% of respondents)	the respondent's address directly corresponded with an existing ARIA locality, so a straight match was possible.
2	Estimated (9.8% of respondents)	the respondent's address was within 10km of an ARIA locality, and so the score of the ARIA locality is allocated to the respondent.
3	Interpolated (0.1% of respondents)	the respondent's address was greater than 10km from an ARIA locality, and as such their score was derived from the weighted ARIA scores of the 6 nearest localities.
4	Approximated (0.4% of respondents)	the address could not be located geographically - the address was verified through other means (eg the Internet) and a judgement was made as to the nearest town or region to which it belongs.
5	Unmatched (0.1% of respondents)	it was not possible to give an ARIA score as the address was incorrect or the respondent lives on an island (ARIA scores have not yet been calculated for most Australian islands as yet). NB: When using the dataset for analysis, it is very important to omit those respondents with addresses listed as 'unmatched' as the results will be misleading if you include them.
Aria Score	The ARIA score for the respondent	
Estimator Town	The ARIA locality situated within 10km of the respondent's address and used to give an ARIA score. (Only applies to those respondents whose method was 'Estimated')	
Distance From Locality	The distance of the ARIA locality used to give an ARIA score from the respondent's address (in kilometres). (Only applies to those respondents whose method was 'Estimated')	

The ARIA scores were merged with the baseline survey data for each woman. The ARIA scores were also categorised according to the definitions suggested by the Department of Health and Aged Care. The WHA dataset already contained an RRMA code, based on the postcode on the survey form. The RRMA codes and the ARIA codes were then compared for the 38,242 women with complete information.

Results

The results for the baseline data are summarised in the following tables and figures. When interpreting the information it is important to note that there are several reasons why discrepancies occur.

- Firstly, RRMA codes are based on survey data (the postcode field) whereas ARIA codes are based on locality of residence, according to the consent database. In some instances these will differ because respondents have given a postal address that differs from their residential address. This is more common among young women who are mobile and keep their parent's address on the consent database.
- Secondly, the RRMA codes and ARIA codes may be discordant when the postcode has been written or keyed incorrectly in the survey database, resulting in an inaccurate RRMA code being allocated. In this instance, the ARIA code, which is based on locality, will be more accurate.

However, the main factor accounting for the differences between ARIA scores and RRMA categories, particularly in rural and remote areas, is the use of GIS technology to define new measures of accessibility of services and to allocate scores to smaller geographical units. In this way, a single postcode area may contain localities with differing ARIA scores.

Table 14 RRMA categories and ARIA scores for women at baseline

RRMA category	ARIA CATEGORY					Total	(%)
	Highly accessible (0-1.84)	Accessible (1.85-3.51)	Moderately accessible (3.52-5.80)	Remote (5.81-9.08)	Very Remote (9.09-12)		
Capital city	14749	269	53	15	2	15088	(39)
Other metropolitan	1744	222	12	2	0	1980	(5)
Large rural centre	3719	1003	262	5	0	4989	(13)
Small rural centre	2792	2038	50	66	2	5128	(13)
Other rural area	3989	3758	1627	72	11	9457	(25)
Remote centre	6	5	299	301	13	624	(2)
Other remote	27	79	254	349	267	976	(3)
Total (%)	27206 (71)	7374 (19)	2557 (7)	810 (2)	295 (1)	38242	
Australian population in each category (%)*	80.8	12.1	4.3	1.4	1.5		

* From figures supplied by DHAC (Excel file sla_aria.xls)

The disadvantage of using the discrete categories is apparent from Table 14. The distribution of the population across ARIA categories is very skewed, even in the WHA study which oversampled in rural and remote areas of Australia. The raw ARIA scores and their concordance with the RRMA categories are shown in Figure 5 to Figure 11.

Figure 5 Raw ARIA scores for women at baseline in RRMA category 1 - capital city, n=15,088

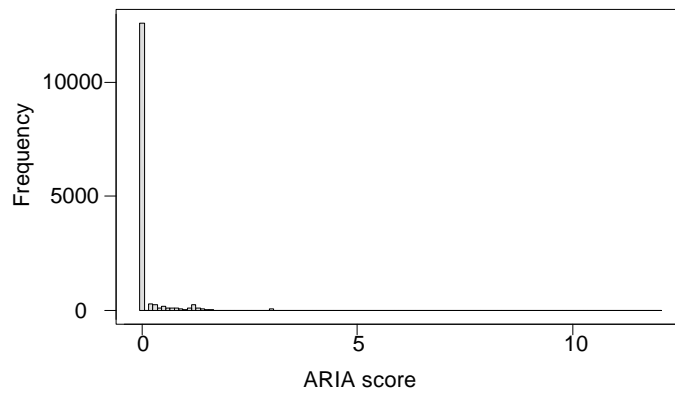


Figure 6: Raw ARIA scores for women at baseline in RRMA category 2 – other metropolitan, n=1980

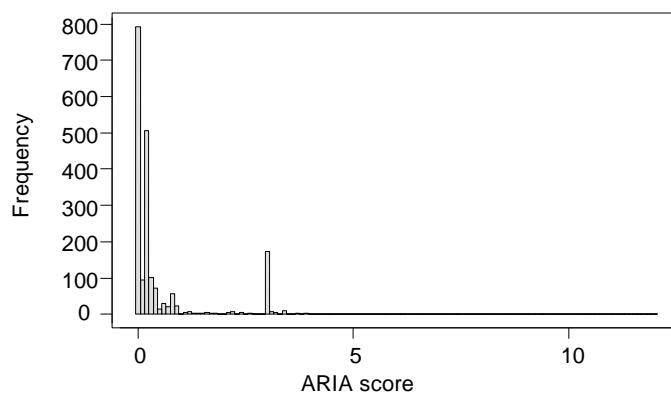


Figure 7: Raw ARIA scores for women at baseline in RRMA category 3 – large rural centre, n=4989

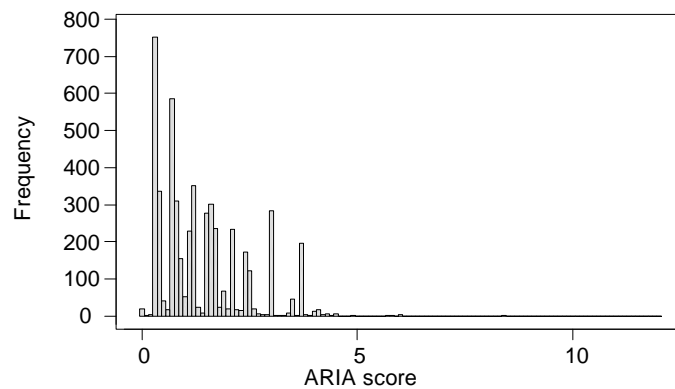


Figure 8: Raw ARIA scores for women at baseline in RRMA category 4 – small rural centre, n=5128

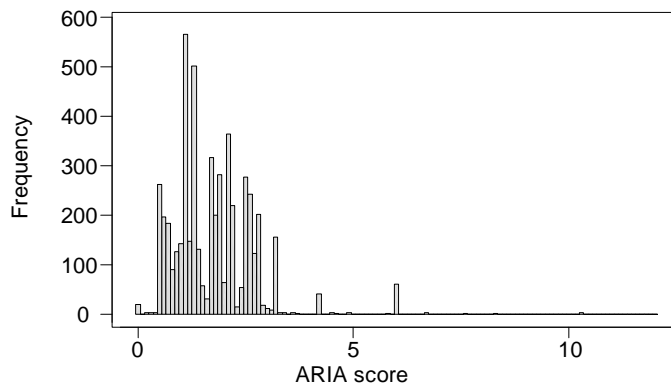


Figure 9: Raw ARIA scores for women at baseline in RRMA category 5 – other rural area, n=9457

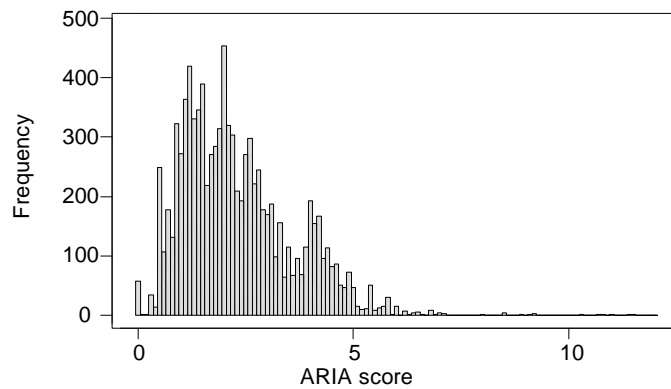


Figure 10: Raw ARIA scores for women at baseline in RRMA category 6 – remote centre, n=624

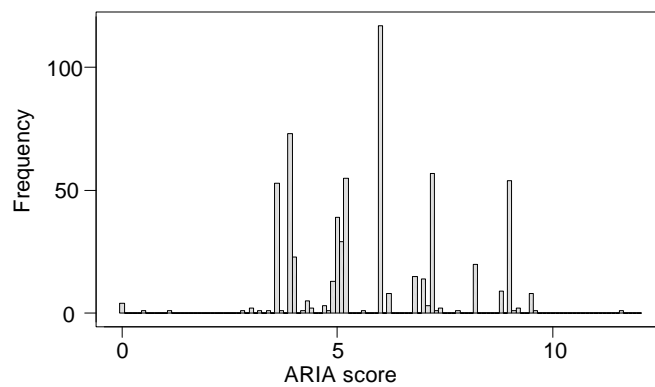
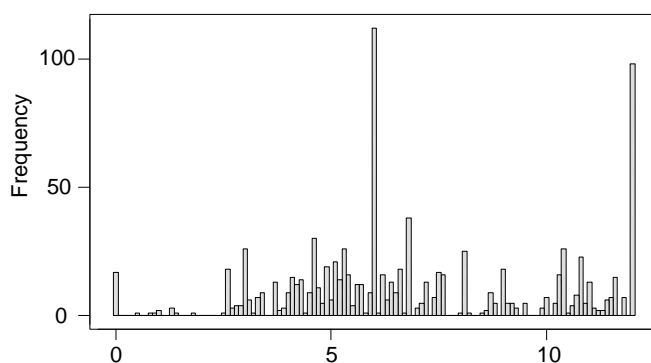


Figure 11: Raw ARIA scores for women at baseline in RRMA category 7 – other remote area, n=976



Discussion

This work has provided an opportunity to examine the use of ARIA scores in a large population survey. By coding the locality of residence, rather than the postcode, a more accurate measure of remoteness should be obtained. The problems with using postcode to allocate scores are that it is easy to make an error in writing or key-entering the postcode, some women don't know their postcode or have an incorrect memory of it, postcode boundaries change and new postcodes are introduced. Many postcode areas are a heterogeneous mix of localities and a single score, such as an RRMA category, may not be representative.

The allocation of ARIA scores in this exercise was very labour intensive, since many of the localities of women in the study had previously not been included in the GISCA database. The cooperation and effort of the staff at GISCA in determining scores for these localities is appreciated. Hence the database has now been expanded and the allocation of scores should be easier in the future.

The discrepancies between ARIA scores and RRMA categories were very marked for the rural and remote areas of Australia. For example, using the RRMA method all remote centres have the same score of remoteness. However using the ARIA methodology, each locality was allocated a score based on their access to services (Figure 10). The ARIA scores also provide much more information about the level of access to services for women living in "other rural areas" RRMA category 5 - the WHA study has more than 9,000 women in these areas (Figure 9).

The next step in this analysis will be to identify the localities with greatest discrepancy in RRMA/ARIA scores (to check for errors in the database) and then to discuss the features of these localities. This work is continuing in collaboration with GISCA and DHAC staff. The concordance between ARIA scores and women's reported access to health services (from the follow up surveys) will also be examined. The ARIA scores can also be used to quantify migration over time and to look at the relationship between migration and health status.

3.1.2 Assessment of new measures in the older cohort follow up survey (O2)

The first follow-up of the older cohort included many new items to help investigate research questions such as:

1. How important are individual (physical and psychological) characteristics in promoting and maintaining health-related quality of life in older women?
2. How important is the social environment (social interaction and satisfaction, instrumental support, participation in clubs and organisations, neighbourhood satisfaction) in promoting and maintaining health related quality of life in older women?
3. How important is access to health and community services in maintaining and promoting health-related quality of life?

Analysis is underway to assess how well the items performed. A total of 114 items measuring aspects of social interaction and satisfaction, instrumental support, participation in clubs and organisations, neighbourhood satisfaction, access to health and community services and demographic variables from the older cohort follow up survey were selected for study. Exploratory factor analysis using the method of principal components and varimax rotation was performed. Firstly, cases with complete data for the 114 items were included in the analysis. To assess whether the factors were robust, the analysis was repeated using pairwise correlations to create the correlation matrix, hence reducing the amount of missing data. About 30 factors were consistently identified among the items in both analyses, based on their eigenvalues, and they explained about 54% of the variance. The items which loaded most strongly on each factor are shown in the table below, along with a tentative name for the factor and some comments on the items which comprise the factor.

In some factors, the items which loaded together were the same as those found in previous research e.g. three of the subscales of the elder abuse scale. For other factors, the items came from various parts of the survey but had good face validity as measuring a similar concept e.g. community participation (Factor 9).

Further analysis of the factors identified in this analysis, such as assessing the degree of intercorrelations among the items in the factors and the amount of variance explained by the factors, is underway. The robustness of the factors will further be tested using split sample analysis. To assess construct validity, scores on each of the identified factors will be compared to other variables plausibly related to the concept.

These factors will be used to define new scores which reduce the collinearity among variables or alternatively, to choose one item to represent a concept from those items that are highly correlated.

Table 13 Results of factor analysis of items selected from old follow-up survey

FACTOR NAME AND ITEMS	COMMENTS
<p>1. Neighbourhood satisfaction</p> <p>O2q36b I have a lot in common with people in my neighbourhood</p> <p>O2q36e I am good friends with many people in this neighbourhood</p> <p>O2q36c I generally trust my neighbours to look out for my property</p> <p>O2q36k People in my neighbourhood are very willing to help each other out</p> <p>O2q36a I would be really sorry if I had to move away from the people in my neighbourhood</p> <p>O2q36h My neighbours treat me with respect</p>	<p>Ten of the thirteen items in question 36 relating to neighbourhood satisfaction load together and can be used to form a score.</p> <p>Items O2q36i and O2q36m relate to neighbourhood safety and load together (see factor 20).</p> <p>Item O2q36j loads with community participation items (see factor 9).</p>

<p>O2q36g I have little to do with people in this neighbourhood (reversed)</p> <p>O2q36f I like living where I live</p> <p>O2q36l If I no longer lived here, hardly anyone around here would notice (reversed)</p> <p>Oq2-36d People in my neighbourhood make it a difficult place to live (reversed)</p>	
<p>2. Marital status/living arrangements</p> <p>O2q31a Live alone</p> <p>O2q25I Eat alone most of the time Widow</p> <p>O2q29e Stress about relationships with spouse/partner (negative loading)</p> <p>O2q31b Live with spouse (negative loading) Married (negative loading)</p>	<p>Questions about living alone, eating alone, living with a partner and stress with partner are correlated with marital status.</p>
<p>3. Access to health care</p> <p>O2q5e Hours when a GP is available</p> <p>O2q5g Ease of seeing the GP of your choice</p> <p>O2q5c Access to after-hours medical care</p> <p>O2q5a Access to medical specialists if you need them</p> <p>O2q5f Number of GPs you have to choose from</p> <p>O2q5b Access to a hospital if you need it</p> <p>O2q5d Access to a GP who bulk bills</p>	<p>All seven measures of access to health care services are correlated and so can be used to form a single score.</p>
<p>4. Social support</p> <p>O2q58 Do you feel you have a definite role (place) in your family and among your friends?</p> <p>O2q57 When you are talking with your family and friends, do you feel you are being listened to?</p> <p>O2q54 Does it seem that your family and friends (people who are important to you) understand you?</p> <p>O2q56 Do you know what is going on with your family and friends?</p> <p>O2q55 Do you feel useful to your family and friends (people important to you)?</p> <p>O2q59 Can you talk about your deepest problems with at least some of your family and friends?</p>	<p>These six items are part of the Duke Social Support satisfaction subscale. The other item in the subscale is O2q61 which did not load with the items in this analysis.</p>
<p>5. Housing</p> <p>Live in a house</p> <p>O2q34 How long at present address</p> <p>O2q15o Moving house in past 3 years (negative loading) Live in other than house (negative loading)</p>	<p>These four items are correlated and measure type of housing and continuity of residence.</p>
<p>6. Elder abuse 1</p> <p>O2q67i Do you have enough privacy at home?</p> <p>O2q67h Do you trust most of the people in your family?</p> <p>O2q67c Can you take your own medication and get around by yourself?</p>	<p>These three items are the dependence subscale of the elder abuse scale, as identified in an analysis of baseline data (see Schofield et al, Section 6.7).</p>

<p>7. Service use</p> <p>O2q68a Food services (eg. Meals on Wheels)</p> <p>O2q68c Homemaking services (eg. home care service, heavy laundry service)</p> <p>O2q68b Nurses (community or district), Community health services (eg. Rehabilitative services, providing equipment, etc.) or Respite services (in home, day centre, or inpatient)</p> <p>O2q68d Home maintenance services (eg. Odd jobs, gardening)</p>	<p>These four items from the same question are correlated and can be used to form a service use score.</p>
<p>8. Instrumental support 1</p> <p>O2q66e Do people help you if you call upon them to do so unexpectedly?</p> <p>O2q66g Do people help you, for example, when you are sick, when you have transport problems or when you need them to accompany you somewhere?</p> <p>O2q66d Do people give you information or advice?</p> <p>O2q66a Do people help you to do odd jobs?</p>	<p>These four items from the question about assistance received from others load together and can be used to define a score for help and assistance.</p>
<p>9. Participation</p> <p>O2q74 Do you do any volunteer work for any community or social organisations? (eg. Fundraising, community welfare, church activities, organising groups or classes)</p> <p>O2q53 About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?</p> <p>O2q36j I get involved with most local issues</p>	<p>These three items are from different parts of the questionnaire but all relate to community participation and they load together.</p>
<p>10. Money</p> <p>O2q29c Stress about money</p> <p>O2q38 Difficulty managing on the income available</p> <p>O2q15n Decreased income (in past 3 years)</p>	<p>These three items are from different parts of the questionnaire but all relate to financial matters and are correlated.</p>
<p>11. Family conflict</p> <p>O2q29f Stress about relationship with children</p> <p>O2q15h Major conflict with children (in last 3 years)</p> <p>O2q29g Stress about relationship with other family members</p> <p>O2q67b Do you feel uncomfortable with anyone in your family?</p>	<p>Four correlated measures of family conflict</p>
<p>12. Area of residence</p> <p>Rural, Remote, Metropolitan Area (RRMA)</p> <p>O2q65 Is public transport available when you need it?</p>	<p>Availability and use of public transport is associated with remoteness of residence</p>
<p>13. Health care use</p> <p>O2q4b A specialist doctor (consulted in past 12 months)</p> <p>O2q3 How many times have you consulted a family doctor or another general practitioner in the last 12 months?</p>	<p>These items are all correlated and measure health care use in the past 12 months.</p>

O2q4f	A podiatrist or chiropodist (consulted in past 12 months)	
O2q4d	A physiotherapist (consulted in past 12 months)	
14. Friendship		The Duke Social Support social interaction subscale consists of items O2q51, O2q52 and O2q53 and O2q60.
O2q51	How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?	
O2q52	How many times did you talk to someone (friends, relatives or others) on the telephone in the past week (either they called you, or you called them)?	
15. Stress/loneliness		These three items are from different parts of the questionnaire but all measure aspects of stress and loneliness. The association between these items and other measures of mental health, such as the CESD and the SF-36, will be investigated.
O2q29b	Stressed about living arrangements	
O2q67a	Are you sad or lonely often?	
O2q78l	I often feel lonely even when there are others around me	
16. Counsellor		Use of counselling services (only 1% of women used these services)
O2q4g	Consulted a counsellor (or other mental health professional) in the last 12 months	
O2q68e	Advice from counselling services	
17. Pets		Living with own children is associated with having a pet.
	Dog Other pet Cat	
O2q31c	Live with own children	
18. Death		These three life events items deal with experiences of declining health and death among friends/family
O2q15e	Major decline in health of other close family member or family friend (in last 3 years)	
O2q15k	Death of other close family member (in last 3 years)	
O2q15l	Death of close friend (in last 3 years)	
19. Spouse health		These three life events items deal with the health of spouse
O2q15z	Spouse/partner moving into institutionalised care (in last 3 years)	
O2q15d	Major decline in health of spouse or partner (in last three years)	
O2q15i	Death of spouse or partner (in last three years)	
20. Neighbourhood safety		Two items from the neighbourhood satisfaction question relating to neighbourhood safety, which loaded together.
O2q36i	Children are safe walking around the neighbourhood during the day	
O2q36m	It is safe to walk around the neighbourhood at night	

<p>21. Elder abuse 2</p> <p>O2q67e Does someone in your family make you stay in bed or tell you you're sick when you know you're not?</p> <p>O2q67g Has anyone taken things that belong to you without your OK?</p> <p>O2q67f Has anyone forced you to do things you didn't want to?</p>	<p>These three items form the coercion subscale of the elder abuse scale (see Schofield et al, Section 6.7)</p>
<p>22. Emergency/outpatient service use</p> <p>O2q4a A hospital doctor (eg. in outpatients or casualty)</p> <p>O2q68f Help/advice from ambulance service</p>	<p>Two items indicating use of emergency or outpatient health care services</p>
<p>23. Instrumental support 2</p> <p>O2q66b Do people lend you small things (eg. sugar, screwdriver, etc)?</p> <p>O2q66f Do people lend you valuable things?</p> <p>O2q66c Do people lend you small amounts of money?</p>	<p>These three items can be used to create a score for 'lending' as a form of instrumental support.</p>
<p>24. Caring</p> <p>O2q70 Provide care to others</p> <p>O2q29d Stress about health of family members</p>	<p>Providing care to another person and being stressed about health of family members are correlated</p>
<p>25. Support groups</p> <p>O2q68g Help/advice from social groups (eg. CWA, Senior Citizen's Centre, friendship groups, craft or exercise groups, church groups)</p> <p>O2q68h Help/advice from support and advisory groups (eg. Arthritis Foundation, Pensioner Advisory service, Older Women's Network)</p>	<p>These items are correlated and measure use of support groups</p>
<p>26. Elder abuse 3</p> <p>O2q67l Are you afraid of anyone in your family?</p> <p>O2q67j Has anyone close to you tried to hurt you or harm you recently?</p> <p>O2q67k Has anyone close to you called you names or put you down or made you feel bad recently?</p>	<p>These three items form the vulnerability subscale of the elder abuse scale (see Schofield et al in Section 6.7)</p>
<p>27. Institution</p> <p>O2q31e Living with non-family members</p> <p>O2q15y Moving into institutionalised care (in last 3 years)</p>	<p>Both items indicate living in institutional care</p>
<p>28. Allied health care use</p> <p>O2q4e An optician</p> <p>O2q4c A dentist</p>	<p>Use of opticians and dentists is correlated</p>
<p>29. Living with other family members</p> <p>O2q31d Live with other family members</p>	<p>Women who live with other family</p>

O2q69	Do you regularly provide (unpaid) care for grandchildren or other people's children?	members are more likely to provide babysitting.
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3.2 RELIABILITY AND VALIDITY

The Australian Nutrition Screening Initiative (ANSI) is a modification of the original, American, Nutritional Screening Initiative (NSI). Development and evaluation of the NSI has suggested that its sensitivity and specificity are moderate to good, and that the scale may be more useful as a tool for educating and raising awareness than as a screening instrument. Expert opinion was used as the basis for modification of the NSI for Australian populations. The ANSI was developed from the NSI on the basis of expert panel discussion, but as yet there is little empirical evidence addressing its validity. An analysis is being conducted to examine the relationship between ANSI items and general health and well-being, and to assess the usefulness of ANSI overall.

3.3 IDENTIFICATION OF MULTI-COLLINEARITY IN THE MID-AGE COHORT AT BASELINE

A combination of cluster and factor analyses of three samples identified 18 groups (of correlated variables), comprising 122 items measured for the mid-age cohort at baseline. These groups of variables related to five broad areas - perceived physical and mental health, health service use, gynaecological health, lifestyle and demographics. By reducing each group of correlated variables to either a single variable, index or score. The problem of multi-collinearity can be avoided. These groups can also be used to identify redundancy and imputation of missing values. See Appendix 3.3 for a full copy of the paper.

3.4 COMPARABILITY OF METHODS: MAIN SURVEY, INDIGENOUS AND FILIPINA SPECIAL COHORTS

Table 16 Comparability of methods between main and special cohorts

	Main	Indigenous	Filipina
Sample frame	HIC (Medicare)	Selected communities	Regions of high population density in Queensland
Sample method	Random sample with over-representation of rural and remote areas	Personal networks	Extensive snowball sampling
Eligibility	Age in 1996: 18-23, 45-50,70-75	All women	All women
Data collection methods	Mailed survey (some by phone)	Face-to-face interview by trained members of indigenous communities	Baseline: Face-to-face interviews. Follow-up: Face-to-face and phone interviews

Selection of items	By researchers in consultation with DHAC	Consultation with communities	By researchers in consultation with a Filipina Reference Group, established prior to data collection
Wording of items	Standard instruments if possible, modified by focus groups and pilots		Standard instruments if possible, modified by consultation with reference group and qualitative research
Follow-up surveys - subjects - content	extensive tracking some continuing, some new	Not yet done	extensive tracking some continuing, some new

Table 17 Response rates for the special cohorts

Cohort	Surveys sent out	Surveys completed	Estimated response rate
Main			
Baseline-1996			
Young	39,000	14 792	41-44%
Mid-age	28,000	14 200	53-56%
Older	39,000	12 624	37-40%
Indigenous			
Baseline			
Hope Vale 1998		29	
Hope Vale 2000		60	
Cherbourg		171	
Woorabinda		65	
Toowoomba			
Filipina			
Baseline-1996		487	
Follow-Up-1998	403 (who consented to follow-up)	346	86%

3.4.1 Data book for the baseline surveys of the Filipina special cohort and Filipina women in the main cohorts

A data book (Appendix 3.4) has been assembled comparing responses to identical and similar items from baseline surveys of the main and Filipina special cohorts. It demonstrates differences in the age structure of the cohorts, survey items and responses.

4 MAINTENANCE OF COHORTS

4.1 GENERAL PROCEDURES

The following report on our general tracking procedures was prepared by Annette Dobson and Christina Lee and submitted to the Australian and New Zealand Journal of Public Health. It provides an overview of the strategies developed over several years of trial and error. More detail on specific techniques is provided in the following subsections.

4.1.1 Tracking participants: Lessons from the Women's Health Australia project

Women's Health Australia (WHA) is a large-scale multidisciplinary project which aims to explore the health of Australia's women over twenty years. The overall goal is to clarify relationships between women's health and use of health services and biological, psychological, social and lifestyle factors. It involves collection of quantitative and qualitative data, as well as record linkage with other data sources. The participants for the main part of the study are three age cohorts of women, selected by the Health Insurance Commission (HIC) through Medicare records, to represent young (aged 18-23 in 1996), mid-age (45-50) and older women (70-75). Stratified random sampling was used, with over-sampling of women in rural and remote areas. The study design involves surveying each main cohort every three years for twenty years as well as conducting nested sub-studies. More than 41,000 women (14,792 young women, 14,200 mid-age women and 12,624 older women) responded to baseline surveys in 1996. Comparisons with 1996 census data suggest that the participants are reasonably representative of Australian women as a whole¹.

Clearly, maintaining contact with participants is essential to the quality of any longitudinal project. A population-based survey of women ranging in age from 18 to (eventually) 95 years raises particular problems for maintaining contact. Young women frequently move location (our 1999 pilot survey showed that 35% of respondents had moved house three or more times in the past three years), and many of them change their surnames when they marry. While the mid-age women move less often, similar problems arise when they divorce or separate. Younger women may not be registered on the electoral roll, and if they are, their addresses there may be out of date. In tracking older women, the main problems occur when they move to a retirement village or nursing home, or to live with a relative; the identification of those who have died is also important.

4.1.2 How to avoid losing contact with participants

The most important and cost-effective strategy for cohort maintenance is, obviously, to avoid losing contact with participants in the first place. The following strategies are generally well recognised², but are worth reiterating in this context.

1. Contact details for participants: Since signed consent forms are required for most surveys, it is opportune to confirm correct address and telephone details at this stage. - Each subsequent contact with participants provides an opportunity to update contact details, and since 1998 we have begun asking specifically for mobile phone and email contacts as well as more traditional sources.
2. Secondary contacts: Invite participants to provide details of a secondary contact - "someone who will always know where you are if you move". For WHA we now ask for secondary contact details every time we contact the participants, and these contacts are proving to be very useful for tracking.
3. Newsletters: encourage loyalty and a sense of belonging to the project. We are committed to providing newsletters at least once a year to all participants, giving feedback on the study findings. The newsletters remind participants that they are important contributors to the project, and emphasise that it is producing interesting results that may have implications for health care policy.³
4. Media coverage: has the potential to enhance participants' sense that the project is important and valuable, and enhance its perceived legitimacy. Seeing or hearing news of the project in the media can prompt women who have moved to let us know where they are.
4. Reminders: Newsletters, surveys, sub-studies and any other contact provide an opportunity to send a reply-paid change-of-details form that may prompt participants to notify us of changes. All documents also show our Freecall 1800 number and email address, and invite participants to inform

us of changes. This year we are distributing fridge magnets printed with our logo and Freecall number; this increases familiarity with the logo and may again serve as a reminder to notify us of changes.⁴

4.1.3 How to trace 'lost' participants

Since 1995 the staff in the WHA office in Newcastle have developed a general procedure for tracking. Many of these strategies have been reported by others^{2,3,4,5} but are described here for the Australian context.

The first step is to establish that a woman has been "lost" to the project; we generally discover this when mail is 'returned to sender'. We then proceed through the following steps, in order, until she is located (see Appendix 4.1 for flow charts on tracking of return to senders).

1. Start a 'tracking sheet' for this woman so that a record of all tracking attempts can be made.
2. Check all known details. Go back to the consent form and check the original handwritten contact details - transcription errors do occur.
3. Try all phone numbers for the woman herself. Care is needed when trying to contact the woman by phone in case there has been a change of circumstances, such as a divorce or separation (in the case of a home number) or a less than amicable change of work circumstances (in the case of a work number). Telephoning secondary contacts supplied by the woman is often less problematic.
4. Check Telstra White Pages. If none of the contact numbers helps us to find the woman, we try the web-based telephone directory. Using this is not as simple as it sounds. Many women are listed under a male partner's surname or (if they have the same surname) under their partner's initials. Single women, in particular, often have mobile phones that are not listed, live in shared households in which the phone listing is in someone else's name, or have silent numbers. The electronic White Pages database is set up so that one has to search a single State or Territory at a time, which adds to the complexity of the process. This step is most successful if the woman has an unusual surname, or if we know the surname and initials under which she was previously listed.

Sometimes when searching the white pages for an unusual surname, especially in rural areas, we have inadvertently contacted a relative of the missing woman. Consistent with the ethical and confidentiality requirements, our protocol in this case is to ask the relative to pass on a request for the 'lost' woman to contact us.

5. Search the electoral rolls. Enrolment data are maintained by the Australian Electoral Commission (AEC). Microfiche films of the electoral rolls, separately by State of residence, are public documents and are held at local offices of the AEC for use with microfiche readers. The system is cumbersome, often outdated and unergonomic. Recently we were granted approval to obtain from the AEC a file of the names and addresses of all female electors in the age range 20-29 years. This is considerably more up-to-date than the microfiche version and it enables us to search the whole of Australia for electors in the correct age range. Since it is possible to search by given name (rather than visually scan a microfiche in alphabetical order of surname), we have also been able to locate women with unusual given names even if they have changed their surnames after marriage.

If this method identifies a possible match, we contact the woman (by mail) to confirm that she is a participant in the project, and ask whether she wishes to continue. As there have been cases where women have confused involvement with the WHA project with something else, we cross check date of birth and previous post-code to ensure we have really found a study participant.

6. HIC address database. The HIC maintains a database of names and addresses of people with Medicare cards, which is protected by Commonwealth privacy legislation. In cases where all our search attempts have failed, the HIC has agreed to forward a letter from WHA to the address on the woman's current Medicare record. In principle, this system could be applicable with other government agencies but, of course, there is no way of knowing that the addresses they hold will be any more up-to-date than those known to the research team.

7. National Death Index. This is a comprehensive list of registered deaths in Australia and has proved to be useful for identifying deaths in the older cohort. We have used it *before* sending out a survey to avoid distressing family members of women who have died, and to reduce the time spent attempting to track women who have not responded.

4.1.4 What we don't use and why not

We have investigated and rejected the following strategies

1. Email searches. There are several Web-based search engines which search for email and phone contacts (these are available on home pages of Netscape, Microsoft Explorer, Yahoo, Hotmail etc). We tried these to search for our young participants but without success. A search for a specific name will frequently yield three or four email addresses, and there is no way of determining whether any or all of them is correct. These search engines are also very incomplete; for example, CL couldn't find any of the research team on any of them.

2. Births, Deaths and Marriages. The Attorney General's Department in each State maintains records of births, marriages and deaths. While for each State there is a Web page and query facilities, these are of little use for our purposes. In NSW, for example, the databases are searchable only for births occurring before 1905 and marriages and deaths before 1945, and full name and range of years need to be entered for each one. More recent marriages and deaths may be requested only by the persons involved or their next of kin, there is a fee payable for every search, and information must be provided on names, dates and place of marriage or death. (If we knew that we wouldn't be tracking!)

3. Genealogical Databases. Many genealogical databases are available on the Web. The largest of these is the project coordinated by the Church of Jesus Christ of Latter Day Saints; one of the Church's activities is the compilation of the names and genealogical details of every person who has ever lived. This database, in common with all the others we tried, however, is almost exclusively American, restricts itself to historical data that provide no direct information about living persons, and is relatively incomplete. For example, CL tried the births and deaths of all her grandparents without success.

4. Health and medical sources. These are not relevant for WHA as the women do not provide any identifying information about their health care providers. These sources may however be useful for other research projects, especially for people needing regular medical treatment, provided appropriate consent is obtained from all concerned.

5. Legal sources, including police records, drivers' licences and migration records, are not usually accessible for public health research.

6. Real Estate Databases. These are usually based on the Electronic White Pages so cannot provide additional information.

7. Debt Collectors and Private Investigators. Credit companies are in the business of tracing persons, and we consulted an experienced credit manager for additional ideas. Tightening of privacy legislation has meant that their traditional avenues of exploration – drivers' licences, council rates databases, and so forth, are now not legally accessible. Of course, using such agents for research purposes is also expensive and would almost certainly raise ethical questions.

4.1.5 Conclusion

Tracking is essential for the success of any longitudinal study. It is a time consuming and expensive process, which requires patience, professionalism, and, at times, extreme sensitivity. For WHA, the first follow-up of the mid-age cohort in 1998 achieved a response rate of 92%, and for the 1999 follow-up of the older cohort the response rate was 90%. These data show that it *is* possible, with persistence and hard work, to maintain contact with large numbers of study participants.

4.1.6 Acknowledgements

The Australian Longitudinal Survey of Women's Health, also known as Women's Health Australia, is funded by the Commonwealth Department of Health and Aged Care, conducted by researchers located mainly at the Universities of Newcastle and Queensland. The tracking strategies and protocols were developed and refined by the research group at the University of Newcastle, with particular help from Jean Ball, Jenny Powers, Bev Simmons and Anne Young.

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4.2 LIAISON WITH GOVERNMENT DEPARTMENTS TO ENHANCE COHORT MAINTENANCE PROCEDURES

Staff at the Department of Health and Aged Care, the Health Insurance Commission and the Department of Veterans' Affairs have contributed in many ways to the ongoing success of the study. As part of a commitment to improve communication between the study team and these agencies a joint meeting was held at the University of Newcastle on November 25-26, 1999. The meeting began with a brief history and overview of the study as well as a summary of the key findings to date and work in progress. Methods used to retain the cohorts were also discussed. Procedures for documenting and archiving the Study ID numbers, Medicare PIN numbers, claims data, consent forms and computer programs held by the Health Insurance Commission were agreed upon and minuted.

The key decisions made at the meeting, and actions taken since then, are listed below:

1. *HIC staff agreed to back up and archive all files related to the WHA project, in liaison with Ross Saunders at the DHAC. These datasets include the file of Medicare PINs and study ID numbers for the 106,000 women initially selected and a file with the HIC consent status for the 40,000 women in the study. The latter file will need to be updated as new consent forms are approved and withdrawals occur (including the date of withdrawal).*

Action: Christina Lee wrote to HIC staff in March 2000, seeking an assurance that these procedures had been carried out (see Appendix 4.2). A reply was received early April indicating that some progress had been made, but more information was needed, so letters were written to Annette Hume and Lannie Pomazak requesting more detailed information on archiving (see Appendix 4.2).

2. *All data sets and programs created by the HIC for the project in the future will be named and coded so that they will not be erased.*

Action: No further data sets have been created, so no action is required at this stage.

3. *The HIC offered to assist with tracking women with whom WHA had lost contact, by forwarding a letter on our behalf to their current address on the Medicare enrolment file.*

Action: A letter was drafted and a trial set of 200 addresses of members of the Young cohort was sent to HIC in February 2000. The outcomes of this procedure are described in Section 4.4.

4. *Margaret McKenzie (Privacy, FOI and Data Access Branch, HIC) offered to find out whether the project could be notified of the enrolment details of women who had consented to the release of their claims data.*

Action: Margaret McKenzie informed WHA that the consent forms signed by WHA participants, which referred specifically to Medicare claims data, could not legally be interpreted as consent to release of personal information such as current address, Medicare eligibility status, or death. Margaret McKenzie has offered to prepare a submission to the Delegate of the Minister recommending that the study be advised of women for whom the HIC has a new address and individuals whose Medicare records have been end-dated (no longer eligible for Medicare benefits), provided they consented in 1997 to the release of their data to the study researchers, but no action will be taken until the outcomes of the trial mailout to 200 women have been assessed by WHA and HIC.

WHA will explore possible changes to the wording of future consent forms that would explicitly provide consent for personal information to be made available to WHA. University of Newcastle Human Research Ethics Committee requires that all consents are re-sought in 2001, so this issue will be pursued then.

5. *The availability of an electronic version of the electoral roll to assist in tracking should be investigated.*

Action: Anne Young followed this possibility up with the Australian Electoral Commission and in February 2000 WHA were able to purchase a CD-ROM containing a searchable database of names and addresses of all Australian women in the 20-29 age group who are currently enrolled to vote. The usefulness of this in tracking is described in Section 4.3.

6. *HIC data cannot be archived with the survey data at the ANU or given to any other researchers.*

Action: For noting.

7. *WHA should advise the HIC of the names of all participants who have withdrawn from the study and the date of withdrawal.*

A list of all IDs of participants who have withdrawn from the study will be sent to HIC in June 2000, a week before the next batch of HIC consents is sent for processing.

8. *There should be an annual meeting of HIC and WHA staff to discuss ongoing collaborative research activities.*

Action: No action has been taken at this stage but we plan to arrange a meeting in October/November 2000.

4.3 AUSTRALIAN ELECTORAL COMMISSION

Enrolment data held by the Australian Electoral Commission (AEC) under the Electoral and Referendum Regulations are one source of information for tracking persons aged over 18 years who are eligible to vote. Voter registration is compulsory under Australian law for all citizens who are 18 years of age or over and have lived at their current address for at least one month. Microfiche films of the electoral rolls, separately by State of residence, are public documents and are held at local offices of the AEC for use with microfiche reader machines. From June 1999 to December 1999 the microfiche copies of the electoral rolls were searched to look for 925 missing participants. It is possible that this had a 20% success rate (ie. found possible matches), but it is hard to estimate as other tracking methods were being used. Where names and addresses were located, the Electronic White Pages were then used to search for a contact phone number and to phone to check whether the person identified was a study participant. In many cases, addresses were found but no phone number could be located. Approval was received from the University of Newcastle Human Research Ethics Committee in December 1999 to write these addresses. The letter asked whether they were participants in the study and if so, invited them to contact the study office, either by completing a pre-printed reply paid form or by telephoning the study freecall number. Copies of the letter and form appear in Appendix 4.3.

A trial of 124 letters were sent out to these possible matches.. As the women were asked to either return the reply letter or call the 1800 number, the success rate cannot really be estimated as it is not possible to monitor the freecall number specifically for the reply to these letters. A total of 10 reply letters were returned, 21 letters were returned as RTS's and 4 letters were sent back as they were not the participant.

The AEC is now able to supply electronic copies of enrolment data for use in medical research, subject to certain privacy conditions. Each application must be accompanied by a copy of the ethical approval for the study and researchers must agree in writing to protect the data from unauthorised use. Under the provisions of the Commonwealth Electoral Act 1918, the name, address, gender and decade age-range of electors can be supplied but not date of birth or occupation. To assist in tracking young participants, the ALSWH applied to the AEC to obtain a file of the name and address of electors in the age range 20-29 years in Australia. This application was successful and the file was received in February 2000 for a cost of \$430.96. The electronic version of the elector data is considerably more up-to-date than the microfiche copies held in the regional office, and the electronic form enables research assistants to search the whole of Australia for

electors in the correct age range by name. Since it is possible to search by given name (rather than visually scan a "hard" microfiche in alphabetical order of surname), it is also possible to search for women who may have changed their names after marriage. For example, if a woman has two relatively unusual given names, it may be possible to establish that there is only one woman with those two given names in the right age range listed on the Australian Electoral Roll, and thus one can be relatively sure that it is the same woman. The electronic system also obviates the need to travel to the Electoral Commission regional office, queue for use of microfiches and readers, and deal with cumbersome, outdated, and unergonomic microfiche systems. We are able to search more efficiently and inexpensively and in considerably more comfort.

A random sample of 24 return to senders were tracked using this electronic system. Of these, 14 were possible matches with new addresses, 6 had the same address as on the WHA database, and 4 were not found at all on the electronic system.

4.4 HEALTH INSURANCE COMMISSION (HIC)

The HIC agreed to assisting in tracking women in the study with whom the study had lost contact. However, Section 130 of the Health Insurance Act 1973 (the legislation which governs the administration of the Medicare Program) prevents staff of the HIC from divulging information about a person, to a third party, except with the consent of the individual to whom the information relates or where an exception to these secrecy provisions applies. As mentioned above, the consent form signed by WHA participants specifically refers to Medicare claims data and not to personal information such as current address. The HIC agreed to undertake a mailout, on WHA's behalf, to women with whom the study has lost contact and to forward a letter to their current address as shown on Medicare records. Once searches have been made, Margaret McKenzie (Privacy, FOI and Data Access Branch, HIC) has offered to prepare a submission to the Delegate of the Minister recommending that the study be advised of women for whom the HIC has a new address and individuals whose Medicare records have been end-dated (no longer eligible for Medicare benefits), provided they consented in 1997 to the release of their data to the study researchers.

As a pilot test of this method of tracking, the names and study ID numbers of 200 young women with whom the study had lost contact were forwarded to the HIC in January 2000. Using the study ID number each woman's Medicare PIN number was found from the master file created in 1996 when the sample was selected. This PIN number was then matched to a name and address in the current enrolment file for Medicare and a letter sent to each woman from the HIC on behalf of the study. A copy of the letter and reply form are in Appendix 4.4. Unfortunately, this trial suggested that the strategy is of little value as an effective means of contacting participants that are lost to follow-up. From the 200 letters sent, only 20 replies were obtained. Of these, 18 women had already been tracked by other means. Thus, the success rate stands at 1%.

4.5 NATIONAL DEATH INDEX

The National Death Index (NDI) is a database maintained by the Australian Institute for Health and Welfare, which records demographic details and causes of death for all Australians. While many family members do inform us of the deaths of survey participants, it was decided that the name and address database for our Older cohort should be checked against the NDI before mailouts occurred in March 1999. Because this was a relatively costly and time-consuming process, it was not conducted again in 2000 for the Young cohort, among whom the death rate is very small. However, effort was put into an evaluation of the usefulness of the National Death Index for identifying women enrolled in the Older cohort who had died.

Ethical approval was obtained from the AIHW and University of Newcastle to match the ALSWH and NDI databases before mailing the 1999 follow-up survey of older women. Matching the ALSWH cohort with NDI identified 410 potential matches for 409 participants. Two possible matches were identified for one woman. The linkage of the NDI and ALSWH databases identified 178 women whose deaths were not previously known to ALSWH. Twenty-three matches were considered doubtful because full details of name, address, date of death did not match completely. Responses to the follow-up survey confirmed six of these women had died, 16 were alive and the vital status of one woman remained unconfirmed at 30 June 1998 (Table 16).

Table 18 Outcomes of linkage of NDI and ALSWH databases.

Outcomes of linkage before Survey 2 in March 1999	
NDI match and death known to ALSWH	208
NDI match, death not known at ALSWH	178
Doubtful matches	23
<i>Total before follow-up survey in 1999</i>	<i>409</i>
Outcomes for doubtful matches after Survey 2 in March 1999	
Alive at March 1999	15
Died before July 1998	6
Died in April 1999	1
Uncontactable during follow-up survey in 1999	1
<i>Total doubtful matches</i>	<i>23</i>
Deaths known to ALSWH and not matched to the NDI	
Died before 1 July 1998	12
Died between 1 July and 31 December 1998	20
Died possibly in 1998, exact date of death unknown	2
<i>Total deaths known to ALSWH and not matched to the NDI</i>	<i>34</i>

Matching with the NDI successfully identified 95% of the deaths known to ALSWH and found another 178 deaths about which ALSWH had not been notified. We concluded that using surname, all given names, gender, date of birth, State of residence and age at last contact as matching variables, the NDI was an effective tool for identifying women who had died. In this particular instance, we were able to avoid potential distress to 178 families and reduce time spent in attempting to trace women who had died. We intend to repeat use of the NDI before the third main survey of older women, planned for 2002.

4.6 OTHER STRATEGIES FOR IMPROVING TRACKING OF PARTICIPANTS

Participant tracking has continued throughout the reporting period, using all of the methods described above. Other methods have included an intensive media campaign focusing on the young cohort, launched in March 2000, which targeted rural and regional radio and print media and which emphasised the mobility of young women and encouraged them to call the Newcastle office if they had changed their address or surname. As a further reminder to those women who were still contactable, a total of 40,000 fridge magnets bearing the Women's Health Australia logo and Freecall phone number were ordered. Magnets were distributed to all participants in the young

cohort with the thank you/reminder card in early April; and magnets will be included with the newsletters sent to Mid-aged and older women in August/September 2000.

A continuing problem which is particularly relevant with the younger cohort is that many women change their surnames on marriage. This not only makes them difficult to track but also raises questions concerning the validity of consents to access Medicare files, if consents are signed in a different name to that in which the records are held. We are continuing to explore with the HIC strategies for dealing with this potential problem.

4.7 ANALYSIS OF THOSE LOST TO FOLLOW-UP

A concerted effort at contacting all of the women in each of the cohorts occurs before each main survey, that is once every three years for each age-group. If women cannot be contacted during the follow-up survey, they are classed as temporarily lost to follow-up. Previously we have reported on these women in the mid and older cohorts. The current status of the younger cohort is presented in Table 7, but it should be borne in mind that we are currently part way through their second survey, and tracking efforts are still being pursued vigorously.

5 DATA LINKAGE

5.1 UPDATE ON CONSENTS TO ACCESS MEDICARE AND DEPARTMENT OF VETERANS' AFFAIRS DATA

In March 1997 all participants were asked to give their consent for the Health Insurance Commission to provide linkable information to the researchers on use of medical services funded by Medicare and the Department of Veterans' Affairs (DVA). At that time about 20,000 women provided written consent, and data relating to those women's service usage for the two-year period 1995-1996 have been extensively analyzed.

In September and October 1999, all participants who had not yet consented were invited to consider the request again. A summary of responses to this second request was presented in Report 13 (December 1999) but at that time consent forms were still being received and Return to Senders were being 'tracked'.

Table 19 below shows an updated summary of responses to this second request, as at 25 May 2000.

Table 19 Summary of responses to second request to access Medicare or DVA data

	Young	Mid-age	Older	Total
Number of requests sent	8,334	4,759	4,763	17,856
Number of consents given	951	998	1,012	2,961

5.2 LINKAGE WITH OTHER SOURCES

Data linkage with the National Death Index, for the Older Cohort only, was trialed in 1999. Section 4.5 above reports on the success of this strategy.

6 DATA ANALYSIS

6.1 PROCEDURES FOR DATA CHECKING AND RELATED QUALITY ASSURANCE ACTIVITIES

6.1.1 Recoding of missing values for WHA baseline survey data

It was decided that missing data in selected variables be recoded according to the following methods.

Method a

Due to the way some questions are phrased we can assume that participants have only responded to those items that are applicable to them.

This method is used on questions with multiple parts and is based on the assumption that participants have only responded to the applicable items and left out not applicable answers, even though a 'no' response category was available. This method applies to questions with only 'yes' and 'no' responses and is explained as follows:

- if all missing, leave as missing;
- if some responses are 'yes', no responses are 'no' and there are missing values then recode response to 'no' for missing;
- if answered some as 'yes', others as 'no' then leave missing.

Method b

This is a logical reasoning approach, which uses answers to other questions to recode a missing question. For example, if the participant answered 'limited a lot' to walking 100m, then a missing value in either of the questions 'walking half a kilometre' and 'walking more than one kilometre' is recoded to 'limited a lot'.

Method c

This is an extension of method a, which applies to questions with multiple parts and with response options other than 'yes' and 'no'. For example, a question may have response options 'none', 'once or twice', 'three to four times', 'five to six times' and 'seven or more times'. The method is as follows;

- if all missing, leave as missing;
- if some responses are 'once or twice' to 'seven or more', no responses are 'none' and there are missing values then recode missing to 'none';
- if answered some as 'once or twice' to 'seven or more', others as 'none' then leave missing.

6.2 DATA COLLECTION AND ENTRY

We are currently in the process of surveying the participants in our young cohort. In March, 13,516 surveys were mailed with a covering letter, a change of address card, and a reply paid envelope.

The survey is 32 pages long, containing 106 questions and a page for general comments. The 106 questions comprise 533 single items. Most of the questions are answered by marking the appropriate response option and there are a handful of questions requiring hand written, open-ended responses.

Thank you/reminder leaflets were mailed two weeks later to all who received an initial package (minus deceased, withdrawals and those overseas). Four weeks after that, a reminder leaflet was mailed to all non-respondents. Finally, it is planned to begin phone reminders to non-responders in mid June. During the phone reminder, the participant will be encouraged to complete and return the

survey. If the participant appears reluctant, a shortened version of the survey will be offered via a telephone interview immediately or at an agreed time in the very near future. This will be used as a last resort and is expected to increase the response rate by about 10%.

The surveys are returned to the University of Newcastle, where they are opened, checked, logged, edited and batched for scanning. The first wave of surveys (approximately 6,500) will be sent to the contractor for scanning in June. Late surveys and telephone surveys will be sent at a later date for scanning. It may be necessary to send a third wave of surveys for scanning, depending on the progress of the phone reminders and the return of late surveys.

6.3 POLICIES FOR ACCESS TO DATA

Policies for data access have not changed since the last report (see section 6.2 in Report 13). This policy can now be viewed on the web page under the data book section.

6.4 DATA BOOKS

6.4.1 Main cohorts

Data books for the baseline surveys (@ \$20.00), the first follow-up of the mid-age cohort (@ \$10.00) and the first follow-up for the older cohort (@ \$10.00) are available. Baseline data books with the overall percentages weighted for area, are also downloadable on the web page.

6.5 USE OF DATA BY OTHER RESEARCHERS

Project:	No place for a sick woman: untangling the relationship between health and rural residence
Collaborators:	Martin Bell (Dept of Geography, University of Adelaide), Ann Larson (Combined Universities Centre for Rural Health, Geraldton)
WHA Collaborator:	Dr Anne Young

Indicators of mortality and morbidity for most causes suggest that there is little difference between urban, rural and remote populations after controlling for age structure and the proportion of the Indigenous population. This is a somewhat surprising finding in light of other evidence that rural and remote populations have much less access to health services, heightened risk factors due to greater consumption of tobacco and alcohol and typically lower levels of education and income. This study explores the hypothesis that rural and remote populations are selective of good health, through a combination of in-migration of healthy persons from urban areas and the out migration of unhealthy rural and remote residents.

At present, the WHA baseline and follow up surveys for the mid age group have been used to identify the type of migration data collected in the surveys, to summarise the migration measures in terms of simple frequencies, to assess the reliability of the data in terms of internal consistency and to identify issues which need to be considered in using the data. There has been some initial exploration of bivariate predictors of moving house prior to the baseline and follow up surveys.

The WHA survey collects two main forms of data that can be used to analyse migration. These are self-reported responses to questions on whether the subject had moved house in specified periods prior to each survey and comparison of place of residence at the time of each survey to identify whether a move has occurred. The self-reported questions on moving house provide a series of

indicators of the overall propensity to move that might be employed to test the association between migration and other events. While the self-reported questions and the comparison of postcodes measure different aspects of migration, the two sets of measures should be broadly consistent with each other.

Three methodological problems have been identified. Firstly, inconsistencies between these two sets of mobility measures need to be addressed prior to further data analysis. Secondly, the question in the follow up survey on moving house more than 2 years ago appears to have been poorly understood and the proportion of women reporting a move 1-2 years prior to the follow-up appears to be very low and is probably prejudiced by recall errors. Thirdly, the sample covered in the follow-up survey may have suffered attrition of its more mobile members, resulting in substantially lower apparent rates of movement and distortions in the predictors of propensity to move. These issues are currently being investigated further.

Project: Connecting leisure and health in the lives of Australian women of mid age.
Collaborator: Assoc Prof Peter Brown (Dept of Leisure and Tourism, The University of Newcastle)
WHA Collaborators: Prof Wendy Brown, Ms Jenny Powers

There is a growing body of evidence that leisure participation contributes to individual health and well-being and may serve to moderate levels of stress. Explorations of associations between satisfaction levels with the time spent in active, passive and social leisure, and measures of physical and mental health, may provide insights into the role of leisure in promoting good health, and moderating stress levels associated with increased time pressure for Australian women. Data from the baseline survey with the 'mid' WHA cohort are currently being used to examine the associations between leisure and health in the lives of Australian women of 'mid-age'.

Projects: Psychosocial problems of sufferers of intractable angina
PhD candidate: Mr Esben Strodhl (Dept of Psychology, University of Queensland)
Supervisor: Assoc Prof Justin Kenardy
Funding source: Australian Postgraduate Research Award

Psychosocial variables have repeatedly been found to be associated with the presence of heart disease. Analysis of data from the 70 to 74 year old WHA cohort will form the first of three studies to further examine these relationships. This PhD is looking specifically at angina (chest pain) and psychological distress in those with and without medical conditions that would correlate with chest pain. It is specifically looking for evidence to support the hypothesis that angina is, at least in part, determined by distress, and is therefore remediable, at least in part, via psychosocial intervention.

Projects: The prevalence of domestic violence among mid-age women and the health and psychological factors associated with the experience of domestic violence
PhD candidate: Ms Deborah Loxton (Dept of Psychology, University of New England)
Supervisor: Assoc Prof Margot Schofield
Funding source: APA University of New England Scholarship

The current analysis concerning the health impact of domestic violence on mid-aged women is nearing its conclusion. As expected, associations were found between domestic violence, and physical and psychological health. Generally, women who had experienced domestic violence were more likely to visit their doctor, to experience major illnesses, to undergo surgical procedures, and

to experience various symptoms of ill health. The results of these analyses are currently being written up in two separate articles, one concerning the physical health, and one concerning the psychological health of mid-aged women who have experienced domestic violence.

The preliminary mediation analysis concerning factors that may mitigate the health impact of domestic violence on mid-aged women appears promising. The addition of 'stress' as a mediating variable in this analysis would be appropriate, and is not currently included in the relevant abstract on file with WHA ("The lifetime prevalence of, and factors associated with reporting of domestic violence by mid-age women in Australia"). It is too early to draw conclusions from this analysis, however it appears as though some factors do act to mitigate the impact of domestic violence on the health of mid-aged women. Some factors, however, appear to act as moderators rather than as mediators, and it is this facet of the investigation that is currently being reviewed. It is anticipated that this analysis will take longer than expected, and will probably require the use of Structural Equation Modelling.

At the conclusion of the mediation analysis, one further analysis will be conducted using the Baseline Survey (1996), the Second Survey (1998), and one question from the Follow-up Survey (1999; *Have you ever left a violent relationship?*). The purpose of this investigation will be to identify those participants who have left violent relationships, and when they left the violent relationships, in order to track their psychological and physical health over time.

Project: Predicting body dissatisfaction amongst young women
Masters candidate: Ms Fiona Campbell (Discipline of Behavioural Science in Relation to Medicine, University of Newcastle)
Supervisor: Dr Libby Campbell
Funding source: Discipline of Behavioural Science, University of Newcastle

This project focuses on the young cohort of women in the WHA project and is in the final stages of statistical analysis and is currently being written up for submission at the end of June 2000. This project has taken the option available to it to be written as a Journal Article rather than a conventional length thesis.

It examines prevalence rates of dissatisfaction with weight and/or shape amongst women aged 18-23 years and also creates a model of predictors of body dissatisfaction amongst this group. From the results gathered to date it appears that there are a significant number of participants who describe themselves as being moderately dissatisfied with their weight and/or shape. The second stage of the analysis (creating a profile of predictors for body dissatisfaction) is currently being undertaken.

6.6 AD HOC DATA ANALYSIS FOR DEPARTMENT

No requests have been received.

6.7 ANALYSES CONDUCTED

Project: Ethnicity, Weight and Shape in young cohort
Investigator: Assoc Prof Justin Kenardy

Weight and shape dissatisfaction, dieting and disordered eating was examined in relation to ethnicity. It was found that young women who migrated from Asian countries reported the lowest

mean body mass index compared to women who migrated from Western and other countries, and non-migrant women, however dissatisfaction with their weight and body shape was not commensurate with this. This suggests that across migrant groups, body dissatisfaction is not related to actual weight and shape. Also dieting behaviours, shape and weight dissatisfaction, and actual weight are related to time since arrival in Australia in migrant women generally. The longer migrant women stay in Australia the more similar their weight and shape attitudes and dieting behaviours are to non-migrant women.

Project: Dieting and Health in mid cohort
Investigator: Assoc Prof Justin Kenardy

Dieting in women of the mid sample is very frequent. Furthermore there are strong relationships between frequency of dieting to lose weight and poorer mental health. Complex relationships are found between successful and unsuccessful dieting and physical and mental health.

Project: Life events and health in all cohorts
Investigator: Assoc Prof Justin Kenardy

Generally adverse life events are related to poorer scores on SF-36. Across age cohorts there are life events which have similar impact, however there are also events which do not have the same impact within each age cohort. It may be that certain events are more salient for particular ages, for example physical illness, loss of a partner.

Project: GP satisfaction, disordered eating, and depression
Investigator: Assoc Prof Justin Kenardy

In order to examine satisfaction with GP care in women with mental health problems, specifically eating disorder and depression, three groups were compared, non-depressed, depressed (defined by MHI), and depressed plus with symptoms of disordered eating. In general level of satisfaction with care was high, with no differences found across urban, rural, or remote regions. There were state-specific differences found though, with women with disordered eating symptoms in Queensland reporting significantly lower levels of satisfaction with GP care.

Project: Falls and serious injury among older women in Australia
Investigators: Dr Julie Byles, Dr Gita Mishra & Ms Lynette MacKenzie

Issue Addressed: This project describes factors associated with falls resulting in serious injury among women in Australia aged 70-75 years.

Methods: Cross-sectional data from 12,900 community-dwelling women participating in the baseline postal survey of the Australian Longitudinal Study on Women's Health, were analysed to estimate the proportion reporting a fall with serious injury and factors associated with these serious falls. Multiple stepwise logistic regression models were used to identify statistical associations between serious falls and a wide range of health-related and social variables.

Results: Six hundred and fifty-five women (4.9%) reported a fall with serious injury within the twelve months before the survey. On multivariate analysis, four variables were significantly associated with these reports of serious falls. Physical health summary score was inversely associated with the odds of having had a serious fall (OR: 0.95; 95% CI:0.94-0.96). A greater number of life events (OR: 1.32; 95% CI: 1.24-1.4); higher scores on the 'feeling dejected' subscale

of an elder abuse scale (OR: 1.96; 95% CI: 1.45-2.65) and taking medications for nerves (OR: 1.4; 1.09-1.92) were positively associated with reporting a fall with serious injury.

Conclusions: Physical, medical and psychological factors are significantly associated with falls with serious injury.

So what? These results highlight the need to consider psychological factors both in terms of falls prevention and in assisting people to recover from a fall-related injury.

Project: Experiences of family caregiving among older Australian women

Investigator: Prof Christina Lee

This project used quantitative and qualitative methods to examine the effects on family caregiving on physical and emotional well-being, finances, and leisure among the older cohort, using baseline data from 1996. A total of 11,939 women, of whom 10% (N=1,235) identified themselves as caregivers for frail, ill or disabled family members and 168 made open-ended comments about their experiences, was examined. Unlike other surveys with younger respondents, the data failed to demonstrate any differences in physical health between caregivers and others. They were, however, significantly more likely to have low levels of emotional well-being and to feel stressed, rushed and pressured. Qualitative analysis supported the value of the concept of the "ethic of care" in understanding the social and individual forces which propel vulnerable older women into providing family care despite its demonstratively negative effects on their wellbeing. A report has been submitted to the Journal of Health Psychology.

Project: Experiences of family caregiving among middle-aged Australian women

Investigators: Prof Christina Lee & Ms Jenny Porteous

This project used quantitative and qualitative methods to examine the impact of family caregiving in the mid-aged cohort - a sample of 13,888 women aged 45 to 50, of whom 12.8% (N=1,775) responded to specific items at baseline about caring for a frail, ill or disabled family member and 185 made open-ended comments about their experiences. Quantitative analyses showed that caregivers were less likely to be employed full-time and more likely to have financial difficulties. Caregivers rated their health lower than did non-caregivers, reported more physical symptoms, and scored lower on both the physical and the mental components of the SF-36. They also reported higher levels of stress and perceived pressure, were more likely to have been admitted to hospital in the previous year, to be taking medication for "nerves", and more likely to smoke, though less likely to drink alcohol. The qualitative analysis supported these findings, and in addition identified several new themes including difficulties with travel; inadequacies in health and welfare systems; a sense of exploitation; and fear for the future. These findings support the view that interventions to assist family caregivers must address systemic in addition to individual factors.

Project: Sexually transmitted infections and use of sexual health services among young Australian women: Women's Health Australia study

Investigator: Assoc Prof Margot Schofield, Assoc Prof Victor Minichiello, Dr Gita Mishra, Assoc Prof David Plummer, & Ms Jan Savage

Objective: To examine associations between self-reported sexually transmitted infections (STI) and socio-demographic, lifestyle, health status, health service use and quality of life factors among young Australian women; and their use of family planning and sexual health clinics and associations with health, demographic and psychosocial factors.

Method: The study sample comprised 14,762 women aged 18-23 years who participated in the mailed baseline survey for the Australian Longitudinal Study on Women's Health, conducted in 1996. The main outcome measures are self report of ever being diagnosed by a doctor with a sexually transmitted infection, including chlamydia, genital herpes, genital warts or other STI, and use of family planning and sexual health clinics.

Results: The self-reported incidence of STI was 1.7% for chlamydia, 1.1% genital herpes, 3.1% genital warts, and 2.1% other STI. There were a large number of demographic, health behaviour, psychosocial and health service use factors significantly and independently associated with reports of having had each STI. Factors independently associated with use of family planning clinic included unemployment current smoking, having had a Pap Smear less than two years ago, not having ancillary health insurance, having consulted a hospital doctor and having higher stress and life events score. Factors independently associated with use of a sexual health clinic included younger age, lower occupation status, being a current or ex-smoker, being a binge drinker, having had a Pap Smear, having consulted a hospital doctor, having poorer mental health and having higher life events score.

Conclusion: This study reports interesting correlates of having an STI among young Australian women aged 18-23. The longitudinal nature of this study provides the opportunity to explore the long-term health and gynaecological outcomes of having STIs during young adulthood.

Project: Vulnerability to abuse, powerlessness and psychological stress among older women: women's health study

Investigators: Assoc Prof Margot Schofield, Dr Rhonda Reynolds, Ms Jenny Powers, Prof Annette Dobson

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-SIEAST), 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-SIEAST. 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.

8 DISSEMINATION OF STUDY FINDINGS

8.1 COMMUNICATION WITH STUDY PARTICIPANTS

8.1.1 Newsletters

The next newsletter is scheduled to be mailed in August/September 2000.

8.1.2 Feedback on substudies

The research team are developing policy guidelines for communicating the results of substudies to participants. Current substudies focusing on particular subpopulations include surveys of women who have experienced heart disease, incontinence, or domestic violence, and provide an opportunity to focus on service delivery and other policy-relevant issues for specific health needs. Feedback to participants on the general outcomes of these substudies provides a strategy for emphasising the relevance of the overall project to women's health needs, and may help to maintain women's involvement with the longitudinal survey.

During the report period, feedback was provided to women who participated in a substudy on mid-aged women's experiences of violence (see Appendix 8.1)

8.1.3 Communication with Special Cohorts

Monthly meetings of all researchers and staff based within the University of Queensland commenced in April 2000.

The WHA-UQ Project Officer contributes to the Special Cohorts study through co-ordination of data entry, preliminary data analyses and the preparation of reports and to Main Cohorts by liaison with Newcastle team and data analyses.

8.2. DISSEMINATION OF FINDINGS

8.2.1 Web Site

The web site is regularly updated to give useful and easily accessible information to the general public. There are six main sections: general information about the study; the investigators and staff; current events; publications; information for participants; databooks and feedback. A counter was put on the web page on 9 March 2000 to monitor the popularity of the site. It has had an average of 168 hits per week with a total of xxx "hits" (as of xxxx).

8.2.2 Publications

Published

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

The purpose of this study was to examine factors which affect driving behaviour and accident rates in women in Australia. Two groups of women (18-23 and 45-50 years) participating in the Australian Longitudinal Study on Women's Health, completed a mailed questionnaire on driver behaviour and road accidents. Self reported accident rates in the last 3 years were 1.87 per 100,000km for the young drivers (n=1204) and 0.59 per 100,000km for the mid-age drivers (n=1565); most accidents involved damage only, not injury. Mean scores for lapses obtained using the Driver Behaviour Questionnaire, were similar in the two age groups and similar to those found in other studies. In contrast, scores for errors and violations for the young women were higher than for the mid-age group and previous reports using the same instruments.

Riskier driving behaviour among young women was associated with stress and habitual alcohol consumption. In the mid-age group, poorer driver behaviour scores were related to higher levels of education, feeling rushed, higher habitual alcohol consumption and lower life satisfaction scores. Accident rates in both groups were significantly related to lapses. Women born in non-English speaking countries had significantly higher risk of accidents compared to Australian-born women: relative risk = 3.40, 95% confidence interval (1.93, 5.98) for the young drivers; relative risk = 1.77, 95% confidence interval (1.11, 2.83) for mid-age drivers.

Lee C. Health habits and psychological functioning among young, middle-aged and older Australian women. *British Journal of Health Psychology*, 1999; 4: 301-314.

Objectives: To assess health habits, and their relationship with psychological well-being among Australian women; in particular to examine the relationship between health habits and the Women's Health Questionnaire.

Design: A cross-sectional postal survey of women in three age groups was carried out.

Methods: Questionnaire responses from a representative sample of 612 women from three age groups (18-23, 45-50, and 70-75) were analysed. Data included the WHQ, 12-item General Health Questionnaire, Medical Outcomes Study SF-12, and self-reports of smoking, height and weight, alcohol use, and exercise status.

Results: Young women had the highest rates of smoking and drinking, and were most likely to be underweight, while middle-aged and older women were most likely to be overweight or obese. Psychological distress was highest in the youngest group; the middle-aged were most likely to report vasomotor symptoms and difficulties with memory and concentration, and the older women difficulty sleeping. Health habits were related to psychological well-being; smoking, unhealthy body weight, and lack of exercise were most closely related to the depression sub-scale of the GHQ.

Conclusions: Young adulthood appears the time of greatest distress for women. Distress, particularly depression, is associated with behaviours which predispose to later disease, suggesting that psychological interventions with young women may be particularly important for long-term physical health. The WHQ appears a useful measure of well-being and a good predictor of health-related behaviour across a range of ages.

Ball K & Lee C. Relationships between psychological stress, coping and disordered eating: a review. *Psychology and Health*, 2000; 14: 1007-1035.

Objective: Psychological stress and inadequate coping skills have been hypothesised to play important roles in the etiology of disordered eating. This paper reviews the empirical evidence which has emerged regarding the proposed relationships among stress, coping skills and various forms of disordered eating.

Method: A search of psychological and medical databases was conducted to identify studies examining life events, and other types of psychological stress and coping strategies, in relation to the onset of disordered eating.

Results: Despite methodological limitations such as the use of non-representative samples and retrospective methodologies, evidence of relationships between stress, coping and disordered eating was obtained in the majority of studies reviewed.

Discussion: The implications of these findings are discussed and suggestions for future research, including the utilisation of longitudinal, prospective studies, are presented.

Jonas HA, Dobson AJ & Brown WJ. Patterns of alcohol consumption in young Australian women: associations with sociodemographic factors, health related behaviours and physical health. *The Australian and New Zealand Journal of Public Health*, 2000; 24(2): 185-191.

Objective. To determine which sociodemographic factors, health related behaviours and physical health conditions are associated with non-drinking, binge drinking and hazardous/harmful drinking

in young Australian women.

Methods. Cross-sectional data were obtained from the baseline survey of 14,762 young women (aged 18-23 years) enrolled in the Women's Health Australia study in 1996. Drinking patterns were categorized as "non-drinkers", "low risk", "low intake/binge drink weekly", and "hazardous/harmful". Associations between these drinking patterns and sociodemographic factors, health related behaviours and health conditions were examined.

Results. Half the women were "low intake" drinkers, a third "rarely drank" and 9% were non-drinkers; however, 70% reported binge drinking with one quarter of the binge drinkers doing so at least weekly. Non-drinkers were more likely than drinkers to be married, pregnant, non-smokers, born in non-English speaking countries, to live in the Northern Territory, and to have lower levels of education, employment, and private health insurance. "Low intake/binge weekly" drinkers (12%) and "hazardous/harmful" drinkers (5%) were more likely than "low risk" drinkers to be unmarried; to live in shared accommodation, alone or with their parents; to live in rural or remote areas; to have ever had any sexually transmitted infection; to be current smokers or ex-smokers, and to have used unhealthy weight-control practices. "Hazardous/harmful" drinkers were also more likely to report difficulties in managing their incomes.

Implications. These results confirm findings from other countries about the importance of social conditions as determinants of alcohol consumption by young women. Health promotion to reduce their alcohol consumption needs to be carefully targeted to take account of their demographics, living environments and beliefs.

Chiarelli P, Brown W & McElduff P. Constipation in Australian women: Prevalence and associated factors. *International Urogynecology Journal*, 2000, 11(2): 71-78.

14,762 young women aged 18-23 years; 14,200 mid-age women (45-50 years) and 12,893 older women (70-75 years) completed a mailed health survey. The prevalence of constipation was estimated to be 14.1% (CI: 13.5-14.7) in young women, 26.6% (CI: 25.9-27.4) in mid-age women and 27.7% (CI: 26.9-28.5) in the older women. The prevalence of haemorrhoids was 3.2% (CI: 2.9-3.4; young), 17.7% (CI: 17.1-18.4; mid-age) and 18.3% (CI: 17.6-19.0; older). In the mid-age and older women, those who reported gynaecological surgery were between 18 and 63% more likely to report constipation, while in the younger cohort women with one or two children were also more likely to report constipation (adjusted OR 1.43-1.46). One third of the young women and half of the mid-age and older women had sought help for constipation, and the majority indicated that they were satisfied with the help available to them.

Accepted

Brown WJ, Lee C, Mishra G, Bauman A. Leisure time physical activity in Australian women: relationship with well-being and symptoms. *Research Quarterly for Exercise and Sport*, 1998.

This paper explores the association between moderate levels of physical activity and health benefits in well-being and symptoms such as tiredness, back pain and constipation. 14,502 young women (18-23 years), 13,609 mid-age women (45-50) and 11,421 older women (70-75), participants in the Australian Longitudinal Study on Women's Health, answered questions about vigorous and less vigorous exercise (used to determine a physical activity score), well-being (SF-36), symptoms and medical conditions. There were significant associations between PA score and SF-36 in each cohort. Odds ratios for a range of symptoms and conditions were lower for women who reported low -- moderate activity (eg for young women, OR for constipation = 0.76 (CI 0.65-0.89), for mid-age women, OR for tiredness = 0.70 (0.63-0.78)) than for sedentary women. There was no threshold of PA at which health benefits increased significantly. Although cross-sectional, the findings suggest that low to moderate levels of exercise are associated with a range of health benefits for women of all ages. These preliminary findings will be followed up during the longitudinal study.

McFadden M, Powers J, Brown W & Walker M. Vehicle and driver attributes affecting sitting distance from the steering wheel in motor vehicles. *Human Factors*, 1999.

Past research suggests that variations in sitting distance from the steering wheel between male and female drivers may partially account for the higher rate of injury sustained by women drivers. The current study investigated whether women sit closer to the steering wheel because they are physically smaller. Driver body dimensions and multiple measures of sitting distance from the steering wheel were collected from a sample of 150 males and 150 female subjects. The results confirmed that women on average sit closer to the steering wheel than men and that this difference was accounted for by variations in body dimensions, especially height. The implications for vehicle design are discussed. In addition, drivers of large cars sat marginally closer than drivers of small cars. The results also suggest that height of drivers may provide a good surrogate of sitting distance from wheel when investigating the role of driver position in real world crash outcomes.

Lee C, Dobson A, Brown W, Adamson L & Goldsworthy J. Tracking Participants: Lessons From The Women's Health Australia Project. *The Australian and New Zealand Journal of Public Health*, 2000.

No abstract - Practice Notes.

8.2.3 Conference Presentations (related to Women's Health Australia)

Warner-Smith P & Imbruglia C. Child care and the health and well-being of young mothers. Population, Gender and Reproductive Health: the Motherhood Questions. Adelaide, SA, 10-11 February 2000.

This paper is set in the context of the 'deepening divide' among young Australian women, which is characterised by the age at which young women are having children, and the differences in the socio-economic background of the group of women who are having children in their late teens and early twenties compared to the group of those who are deferring motherhood. The issue of deferral of childbearing is particularly relevant to current debates around falling fertility rates.

The main focus is the health and wellbeing of young mothers. This group is compared firstly to young childless women and secondly to older mothers, using quantitative data from the Australian longitudinal Study on Women's Health, now known as Women's Health Australia (WHA). The discussion then centres on specific issues around child care which have been raised in focus groups with young mothers. Selected data from the WHA project concerning associations between mid age women's employment and leisure and measures of physical and mental health are also presented in the context of what may lie ahead for today's young women.

Bryson L. Motherhood in the new millenium: policy implications of recent social change. Population, Gender and Reproductive Health: the Motherhood Questions. Adelaide, SA, 10-11 February 2000

Despite falling birth rates evidence from the Women's Health Australia Study shows that the vast majority of women aspire to motherhood, with most (68%) wanting one or two children. The data also raise some of problems that can be associated with optimal circumstances for women to control their fertility. These relate to access to appropriate information and services in respect to contraception, reproductive health and the negotiation of sexual relationships. These problems are especially felt by young women and those in rural and regional Australia. The evidence also

suggests that if motherhood choices are to be understood, a broad range of issues must be taken into account

The social context in which such decisions are made is one in which conventional expectations about having children have been weakened. The paper places these in their broad sociological context, with a focus on processes of individualisation and the way these raise issues of risk. When more individual, rather than conventional, choices are made and risks are carefully weighed, it is important that the circumstances for free choice be optimal. The analysis suggests that costs to individual families can be eased by the ready availability of support structures including family friendly employment policies.

Dobson A, Lee C, Brown W, Byles J, Young A & Warner-Smith P. Women's Health Australia FACS Panel Data and Policy Conference. Canberra, ACT, 1-3 May 2000.

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. The purpose of the project is 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 will be surveyed in 2000.

Part of our research strategy is to build on our initial findings to identify questions that can only be answered with a longitudinal study. For example, young women who were mothers at baseline were more depressed, more stressed and had lower scores on the SF-36 than those without children. Examination of the follow-up data and of those participants who have become mothers in the interim will allow an understanding of which variables may predict successful and unsuccessful transition to motherhood. Among the mid-aged women, those in part- or full-time paid employment had good physical health, but those in full-time work with dependent children had lower levels of mental health. Causality can only be understood longitudinally, by exploring the health effects of moving in and out of the workforce over a number of years. Among older women, widowhood is a common life transition. The dynamics of the early health, social and economic effects of widowhood and how these resolve over time, including the role of family and social support, can only be properly investigated prospectively in a longitudinal study. A final example is the differential access to health services of women in rural and remote areas compared to urban women, which was evident from our baseline survey. In subsequent work we will be able to evaluate the effectiveness of government initiatives (eg. flying visits by women doctors, and improved conditions for rural GPs) in terms of women's use of and satisfaction with services.

The project raises several methodological challenges. For example, we use many standard instruments to collect data of health and social issues, but these are closely inter-related. We need to understand the underlying factors or dimensions and ensure that our statistical analyses are robust

against multicollinearity. Secondly, there is an ongoing issue of maintaining the cohorts and achieving complete data. In a longitudinal study the biases due to missing data accumulate and can jeopardize the generalisability of any findings. The second issue is reducing the dimensionality of the data. The value of longitudinal studies is crucially dependent on data quality. Achieving this requires continuing resources and a clear-long-term vision and commitment.

Williams L & Brown W. How do women explain weight change at menopause. Dietitians Association of Australia Annual Conference. Canberra, ACT, 19-21 May 2000

Weight gain in women is most marked during the menopausal years, and the NH&MRC have recognised this problem by identifying women in the menopausal years (45-55) as a key target group for prevention of weight increase. Baseline data from the Australian Longitudinal Study on Women's Health (ALSWH) found 22% of women in the mid-age cohort (45-50 in 1996) reported gaining more than 5 kilograms, without wanting to, in the six months prior to the survey. To understand why women gain weight at this life stage, behavioural and environmental determinants of weight change at menopause will be explored by questionnaire with a nested cohort of approximately 1,200 menopausal women from the ALSWH mid-age cohort. A qualitative technique was first employed to develop an appropriate questionnaire for the study.

Methods: Focus group discussions were held to discuss with women their own experiences and perceptions of why their weight did or did not change during menopause. Five focus group discussions were held; three in a rural area and two in a metropolitan area of NSW. Sessions lasted between 90 and 120 minutes, with food and drinks served in an effort to create a less formal atmosphere. A trained facilitator used open-ended questions to prompt discussion. The sessions were audiotaped, with a scribe also present to attribute quotes. The typed transcripts from all five sessions were combined, and analysed by sorting the discussion into themes.

Results: Many participants had experienced mid-life weight gain, which they attributed to ageing, menopause or lifestyle related factors. There was a widespread belief that hormone replacement therapy causes weight gain. While the women recognised the benefits of optimal diet and physical activity, they elucidated several barriers to achieving these goals. Common barriers to physical activity cited were physical and health problems, decreased motivation, social factors or some combination of these. Barriers to improving dietary intake included changes to who lived at home, and emotional eating in response to menopausal symptoms.

Conclusions: The focus group method provided information for the development of a comprehensive and relevant questionnaire to quantify factors influencing weight change within a cohort of menopausal women.

8.2.4 Other Presentations

Lee C. Women's Health Australia Project – Preliminary results from the Young 2 Pilot. Research Institute for Gender and Health Seminars, The University of Newcastle, 22 February 2000.

Lee C. Women's Health Australia Study. NSW Public Health Network: Epidemiology Special Interest Group. Royal Prince Alfred Hospital, Sydney, 25 February 2000

Warner-Smith P. Child care and the health and wellbeing of young mothers. Research Institute for Gender and Health Seminars, The University of Newcastle, 7 March 2000.

Brown P & Hansen V. Identifying and addressing constraints to active leisure for mothers of young children: The 'Pro-active Mums' Project. Research Institute for Gender and Health Seminars, The University of Newcastle, 21 March 2000.

Patterson A. The Real Australian Woman Project – Changes in women's size and shape since the 1930's. Research Institute for Gender and Health Seminars, The University of Newcastle, 4 April 2000.

Lee C. Report on Australian Longitudinal Survey of Women's Health. NSW Women's Health Nurses' Professional Days. Morpeth, 4 April 2000.

Byles J. Research for an older, healthier Australia. Research Institute for Gender and Health Seminars, The University of Newcastle, 18 April 2000.

Schmidt A. Assessment of menstrual blood loss in Australian women. Research Institute for Gender and Health Seminars, The University of Newcastle, 16 May 2000.

Patterson A. The Real Australian Woman Project – Size, shape and body image issues. Research Institute for Gender and Health Seminars, The University of Newcastle, 30 May 2000.

8.2.5 Media

- 25/2/00 Article in The Newcastle Herald, "Mystery of Young Mothers"
- 28/2/00 2NUR Community Radio, Christina Lee interview on transition to motherhood
- 2/3/00 ABC Morning Program, Surinder Baines interview on vegetarian diets
- 7/3/00 2NUR Community Radio, Christina Lee Wellbeing Program on WHA
- 7/3/00 Article in The Australian, "Life begins at forty something for mothers who choose" featuring Penny Warner-Smith's work
- 7/3/00 2BL James Valentine, Lois Bryson interview on motherhood and women's health
- 8/3/00 4ZZZ Regional Radio, Christina Lee interview on young women and mental health
- 8/3/00 NBN TV Today Extra 9.00 am, Christina Lee interview with Nat Jeffrey on the WHA study
- 8/3/00 ABC Canberra, Penny Warner-Smith on young women and motherhood
- 8/3/00 ABC Tasmania, Penny Warner-Smith on young women and motherhood
- 8/3/00 2UE Sydney, Penny Warner-Smith interview with Malcolm Elliot on young women and motherhood

9 ARCHIVING

9.1 UPDATE ON ARCHIVING AT SOCIAL SCIENCES DATA ARCHIVES (SSDA)

In December 1999, the three baseline data sets which were collected in 1996, were archived with the Social Sciences Data Archive (SSDA) at the Australian National University. The Licence Form and the Study Description Form were also sent with the data sets (see Appendix 9.1 and 9.2).

As well as being a valuable and reliable off-site backup of all Women's Health Australia data, archiving will make the data available for future use by other researchers, subject to certain conditions. Each data item was assigned an Access level – level A or level B. Level A items are not available to other researchers due to privacy issues. Level B items are available to all approved applicants. For this reason the data were sent as two files per age group – a level A data set and a level B data set.

9.1.1 Baseline Data Schedule Of Materials Deposited

1. Data dictionary in Microsoft Access 97
2. Users guide to using data dictionary (text file)

Young Cohort

3. Whal yngA.txt tab-delimited text file with level A data
4. Whal yngB.txt tab-delimited text file with level B data
5. Young dataset levelA.txt text file with level A variable descriptions
6. Young dataset levelB.txt text file with level B variable descriptions
7. Young freqs.txt text file with raw frequencies of level B data
8. Young formats.txt text file with formats for level B data
9. Young labels.txt text file with labels for level B data

Mid cohort

10. Whal midA.txt tab-delimited text file with level A data
11. Whal midB.txt tab-delimited text file with level B data
12. Mid dataset levelA.txt text file with level A variable descriptions
13. Mid dataset levelB.txt text file with level B variable descriptions
14. Mid freqs.txt text file with raw frequencies of level B data
15. Mid formats.txt text file with formats for level B data
16. Mid labels.txt text file with labels for level B data

Old cohort

17. Whal oldA.txt tab-delimited text file with level A data
18. Whal oldB.txt tab-delimited text file with level B data
19. Old dataset levelA.txt text file with level A variable descriptions
20. Old dataset levelB.txt text file with level B variable descriptions
21. Old freqs.txt text file with raw frequencies of level B data
22. Old formats.txt text file with formats for level B data
23. Old labels.txt text file with labels for level B data

Table 20 Details of baseline data files

File	No. of obs	No. of variables	File size (Mbs)
Whal yngA.txt	14,779	320	20.0
Whal yngB.txt	14,779	303	18.7
Whal midA.txt	14,100	354	20.8
Whal midB.txt	14,100	331	19.1
Whal oldA.txt	12,939	334	18.2
Whal oldB.txt	12,939	317	17.0

9.1.2 Follow-up Data

The first follow-up data for the Mid and Old age groups, which were collected in 1998 and 1999 respectively, will be archived with the SSDA in June 2000. At this time, the revised baseline data will be archived again to replace the data sent in December. These revised data are necessary, due to recent efforts made in recoding missing values in some questions.

It is planned in the future that, each year in June, the data collected in the previous year will be archived along with updates of previously archived data, if they have had revisions.

9.2 USE OF DATA BY OTHER RESEARCHERS

9.2.1 Through SSDA

To date there have been no requests to access WHA data through the SSDA.

9.2.2 Through University of Newcastle

<i>Collaborator/Student</i>	<i>Data set</i>	<i>Date given</i>	<i>Additional user</i>
Ann Larson	M2	2/00	
Susan Donath	Y1, M1, O1 M2, O2	2/00	
Nadine Smith	O1, O2	2/00	
Anne Russell	Y1, M1, O1 M2, O2	4/00	
Margot Schofield	M1, M2	5/00	Rafat Hussein
Rachel Aylward	O1, O2	5/00	

A document is currently being finalised that lists all of the collaborators who have current data sets.

9.3 ARCHIVING OF SPECIAL COHORT DATA

9.3.1 Indigenous Cohorts

- There is no contractual requirement for these data to be archived.
- Agreements made with indigenous communities regarding data collection and use require the communities to approve any distribution of the data, including archiving.
- Although the same survey instrument has been used in Hope Vale, Cherbourg and Woorabinda, the data files for each community are not directly comparable. Each data file contains differences in variable names, types and coding. No formal documentation of these data exists yet, other than copies of surveys and SAS file formats.
- Independently of archiving requirements, these data require unified formatting and documentation. Preparation of coding manuals has commenced.
- The methodology, including details of consultations, is to be documented as a potential model for research processes with indigenous communities.
- Using data from the main cohorts, the research team will discuss with the indigenous communities the possibility of using community data in comparative analyses.

9.3.2 Filipina Cohort

- Baseline and follow-up data from the main Filipina cohort are stored in a single SAS file. Coding manuals have been prepared. The compatibility of the coding manuals and the data set would need to be confirmed prior to archiving.
- The Filipina youth data are not as advanced and, given the small numbers involved (n=43), may not be worth attempting to archive.
- Approval is to be obtained from the Filipina Reference Group; discussions should include where the data are to be held, who should have access and under what conditions.

10 FINANCIAL STATEMENT

10.1 EXPENDITURE FROM DHAC SOURCES

Table 21 Financial Statement January- June 2000 (based on University of Newcastle Financial Reporting System 29/5/00)

Account 593-1029 (ALSWH)

INCOME			EXPENDITURE		
Source	Details	Income	Items	Expenditure 1/1/00 – 29/5/00	Commitment 30/5/00- 30/6/00
DHAC	Contract	414,000	Shared research (UQ)	70,000	28,000 ^a
	Additional funds for UQ	28,000	Surveys & data entry	3,014	96,482 ^a
			Computer h'ware, s'ware	5,966	0
			Equipment & maintenance	0	4,093 ^a
			Postage & freight	4,284	1,000 ^b
			Telephone	2,098	800 ^b
			Printing, stationery, office supplies	2,352	900 ^b
			General consumables/ repairs	1,007	400 ^b
			Travel/ hospitality	3,293	3,000 ^b
			Salaries	105,817	21,163 ^b
			On-costs	24,057	4,811 ^b
			Annual Report	5,153	0
			University O'head charge		62,100 ^a
TOTALS		\$442,000		\$227,041	\$222,749

^a firm commitment

^b figures are estimates

All Other Accounts

10.2 ADDITIONAL SOURCES OF FUNDING

CL to do both of these from Finance One files – to end May

11 PROJECT STAFF 2000

Staffing has remained relatively stable over the period of this report. The main change has been the resignation of Wendy Brown from the position of Project Manager and Director of the Research Institute for Gender and Health to take up the position of Professor of Human Movement, University of Queensland. Wendy remains a Principal Investigator but her position has been taken over by Christina Lee, seconded out of the Department of Psychology, University of Newcastle, for the term of the current contract. Annette Dobson has shifted her substantive position from Professor of Statistics, University of Newcastle to Professor of Biostatistics, University of Queensland, but maintains her role as Director of the Women's Health Australia Project. Other changes have included the appointment of a postdoctoral research fellow at Newcastle to work on assessment of nutritional status, and the appointment of a senior project officer at the University of Queensland to assist Professor Dobson.

11.1 FULL-TIME STAFF LOCATED AT RESEARCH INSTITUTE FOR GENDER AND HEALTH

Project Manager	Prof Christina Lee
Data Manager	Ms Jean Ball
Statistician	Dr Anne Young
Statistician	Ms Jenny Powers
Postdoctoral Research Fellow	Dr Amanda Patterson
Research Assistants	Mrs Lyn Adamson Mrs Joy Goldsworthy
Secretary	Ms Emma Threlfo

11.2 CURRENT INVESTIGATORS WORKING ON THE LONGITUDINAL SURVEY

Prof Annette Dobson, Department of Biostatistics, University of Queensland, *Study Director*
 Prof Wendy Brown, Department of Human Movement, University of Queensland
 Emeritus Prof Lois Bryson, Research Institute for Gender and Health, University of Newcastle
 Dr Julie Byles, Centre for Clinical Epidemiology and Biostatistics, University of Newcastle
 Assoc Prof Justin Kenardy, Department of Psychology, University of Queensland
 Dr Gita Mishra, Department of Statistics, University of Newcastle
 Assoc Prof Margot Schofield, Department of Health Studies, University of New England
 Dr Penny Warner-Smith, Department of Leisure and Tourism, University of Newcastle
 Assoc Prof Gail Williams, Australian Centre for International and Tropical Health and Nutrition,
 University of Queensland
 Dr Anne Young, Research Institute for Gender and Health, University of Newcastle

11.3 ASSOCIATE INVESTIGATORS WHO ARE CURRENTLY WORKING WITH THE MAIN COHORTS

Dr Surinder Baines, Discipline of Nutrition and Dietetics, University of Newcastle
 Assoc Prof Peter Brown, Department of Leisure and Tourism, University of Newcastle
 Ms Pauline Chiarelli, Medicine and Health Sciences, University of Newcastle
 Dr Marilyns Guillemin, Centre for the Study of Health & Society, University of Melbourne
 Dr Helen Jonas, School of Health and Human Sciences, La Trobe University
 Ms Sue Outram, Medicine and Health Sciences, University of Newcastle
 Ms Lauren Williams, Department of Nutrition and Dietetics, University of Newcastle

Dr Deidre Wicks, Department of Sociology and Anthropology, University of Newcastle
 Dr Rafat Hussain, Department of Health Studies, The University of New England

11.4 STUDENTS

11.4.1 PhD

Ms Julie Brooks, Department of Sociology, University of Newcastle
 Ms Pauline Chiarelli, Faculty of Medicine and Health Sciences, University of Newcastle
 Ms Lauren Williams, Department of Nutrition and Dietetics, University of Newcastle
 Ms Emilee Gilbert, School of Sociology, Macquarie University
 Mr Brendan Goodger, Centre for Clinical Epidemiology and Biostatistics, University of Newcastle
 Ms Deborah Loxton, Department of Health Studies, University of New England
 Ms Yvette Miller, Department of Human Movement, University of Queensland
 Ms Lisa Milne, Department of Sociology and Anthropology, University of Newcastle
 Ms Glennys Parker, Research Institute for Gender and Health, University of Newcastle
 Ms Allison Schmidt, Research Institute for Gender and Health, University of Newcastle
 Ms Margrette Young, Research Institute for Gender and Health, University of Newcastle
 Mr Esben Strodhl, Department of Psychology, University of Queensland
 Ms Cathy Regan, Royal Australian College of General Practitioners, Wallsend Campus

11.4.2 Masters degrees

Ms Jenny Powers, Research Institute for Gender and Health, University of Newcastle
 Ms Nadine Smith, Research Institute for Gender and Health, University of Newcastle
 Ms Barbara Reen, Centre for Clinical Epidemiology and Biostatistics, University of Newcastle

11.5 PART-TIME AND CASUAL STAFF AT RESEARCH INSTITUTE FOR GENDER AND HEALTH, JAN- JUNE 2000

Ms Renay Grieg
 Ms Kate Bell
 Ms Alicia Frost
 Mrs Ruth Gay
 Ms Vibeke Hansen
 Ms Jenny Helman
 Ms Melinda Lang
 Ms Catherine McCabe
 Ms Sandra Bell
 Mrs Beverley Parker
 Ms Nadine Smith

11.6 STAFF AT UNIVERSITY OF QUEENSLAND

Dr Samantha Thompson, Research Fellow, Migrant Cohorts, Australian Centre For International And Tropical Health And Nutrition
 Ms Noela Baigrie, Project Manager, Indigenous Cohorts, Australian Centre For International And Tropical Health And Nutrition
 Ms Anne Russell, Senior Projects Officer, Department of Biostatistics, University of Queensland