



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

Report 5

**The University of Newcastle
3rd December 1996**

**AUSTRALIAN LONGITUDINAL STUDY ON WOMEN'S
HEALTH
DECEMBER 1996 REPORT**

Table of Contents

INTRODUCTION	3
PART A: UNIVERSITY OF NEWCASTLE	4
PROJECT STAFF	4
EXECUTIVE SUMMARY	5
1. ADMINISTRATIVE ARRANGEMENTS	7
1.1 PROJECT MANAGEMENT.....	7
1.2 BUDGET	7
2. RECRUITMENT	9
2.1 PUBLICITY FOR RECRUITMENT OF THE YOUNGER COHORT	9
2.2 RECRUITMENT FOR THE MAIN STUDY.....	10
2.3 RESPONSE RATES	13
2.4 REASONS FOR NON-PARTICIPATION	18
2.5 DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS	19
2.6 EFFECTIVENESS OF THE MAILOUT STRATEGY AND COST OF RECRUITMENT.....	20
3. PILOT STUDY FOR MEDICARE CONSENT	31
4. QUALITATIVE DATA: MID COHORT	33
4.1 INTRODUCTION	33
4.2 METHODOLOGY	33
4.3 COMMENTS AND SUGGESTIONS ABOUT THE QUESTIONNAIRE.....	35
5. DATA QUALITY	40
5.1 DATA QUALITY ASSURANCE AND DATA MANAGEMENT.....	40
6. POSTGRADUATE STUDENT PROJECTS - UPDATES	41
6.1 PSYCHOLOGICAL STRESS PROCESSES IN THE ETIOLOGY OF DISORDERED EATING	41
6.2 EXPERIENCES OF WOMEN (AGED 45-49) SEEKING HELP FOR PSYCHOLOGICAL DISTRESS	42
6.3 IRON DEFICIENCY IN MIDDLE-AGED AUSTRALIAN WOMEN	43
6.4 USE OF AND SATISFACTION WITH HEALTH CARE SERVICES.....	45
6.5 LEGAL PROTECTION AND DOMESTIC VIOLENCE IN WOMEN'S LIVES	46

7.	RESEARCH ACTIVITIES	47
7.1	COLLABORATIONS WITH OTHER RESEARCH CENTRES	47
7.2	VISITS TO OTHER RESEARCH CENTRES	47
7.3	PRESENTATIONS.....	48
7.4	PUBLICATIONS.....	49
7.5	CONFERENCES ATTENDED.....	51
7.6	WORKSHOPS PRESENTED	52
7.7	ADDITIONAL RESEARCH GRANTS	53
7.8	COMMITTEES.....	53
7.9	WOMEN'S HEALTH AUSTRALIA MONTHLY SEMINAR SERIES	54
7.10	VISITORS.....	55
8.	PLANS FOR THE NEXT SIX MONTHS	56
9.	REFERENCES	56
 PART B: NATIONAL ADVISORY COMMITTEE		58
1.1	MINUTES OF THE LAST MEETING.....	58

APPENDICES

DECEMBER 1996 REPORT

INTRODUCTION

This is the fifth report on the Australian Longitudinal Study on Women's Health, provided by the University of Newcastle and the University of Queensland, due 10 December 1996, as agreed in the contract between the former Commonwealth Department of Human Services and Health (now known as the Commonwealth Department of Health and Family Services) and the University of Newcastle.

The contract states that the content of report five is to include:

A For the main cohort studies:

- data books of basic tabulations of all variables and reports on data quality
- project operation
- plans for the next six months

B For the special cohort studies:

- report on the special cohort studies
- project operation
- plans for the next six months

C For the study as a whole:

- the operations of the National Advisory Committee
- the communication strategy

This report is presented in three parts, with two data books:

PART A -	Progress at the University of Newcastle
PART B -	The National Advisory Committee
PART C -	Progress at the University of Queensland

DATA BOOKS: -	Main Cohorts
	Special cohort - Filipina women

PART A: UNIVERSITY OF NEWCASTLE

PROJECT STAFF

Investigators

Professor Annette Dobson, BSc, MSc, PhD (Professor, Biostatistics)

Professor Lois Bryson, BA, Dip Soc Stud, Dip Ed, PhD (Professor, Sociology & Anthropology)

A/Professor Margot Schofield, BA, DipSc, M Clin Psych, PhD (Honorary Associate, WHA)

Dr Julie Byles, B Med, PhD (Senior Lecturer, Clinical Epidemiology & Biostatistics)

Dr Wendy Brown, BSc (Hons), MSc, PhD (Project Manager & Senior Lecturer, WHA)

A/Professor Christina Lee, BA, PhD (Associate Professor, Psychology)

Dr Deidre Wicks, BA, PhD (Senior Lecturer, Sociology & Anthropology)

Dr Gita Mishra, BSc, MSc, PhD (Statistician & Lecturer, WHA)

Office Staff

Lyn Adamson	Research Assistant/Publicity Officer
Jean Ball, B.Math, Dip Med Stat	Data Manager
Phoebe Bissett, BA (Psych)	Secretary/Research Assistant
Joy Ellem, BA (Hons)	Research Assistant
Judy Alexander B.Math	SAS Programmer
Susan Walkom, BA, Dip.Ed, MAppEthics	Research Assistant
Beverly Parker	Administrative Assistant

Postgraduate students

Ms Kylie Ball, BA (Psych) (University of Newcastle)

Ms Julie Brookes, DipAppSc (Nursing), BA (Hons) (University of Newcastle)

Ms Sue Outram, BA, RN (University of New South Wales)

Ms Amanda Patterson, BSc (University of Newcastle), MND (University of Sydney)

Mrs Anne Young, BMath(HonsI), DipMedStat (University of Newcastle)

Mrs Margrette Young, BA(HonsI) (University of Sydney), MSc (Keele University)

Associate Investigators

Dr Justin Kenardy, PhD (Department of Psychology, University of Queensland)

Dr Julia Lowe, MBChB, FRCP(UK), M.Med.Sci. (John Hunter Hospital)

Dr Rhonda Reynolds, BA (Hons), PhD (University of Western Sydney Macarthur)

Professor Dave Roberts PhD (Professor of Nutrition and Dietetics, University of Newcastle)

Ms Susan Feldman BA MA (Alma Unit on Women & Ageing, University of Melbourne)

EXECUTIVE SUMMARY

1 Recruitment

During the second half of 1996, recruitment of the three main cohorts was completed. At the time of writing, 40832 women have agreed to participate in the study, and have completed baseline surveys.

2 Response rates

Response rates were estimated to be at least 38% for the younger cohort, 53% for the middle group and 35% for the older group. It is not possible to accurately determine response rates because it is not possible to establish the number of unreached respondents at this stage. The response rates compare favourably with those of previous similar studies.

3 Representation

The demographic characteristics of the study participants indicate that participants are broadly representative of Australian women in these three age groups. The data suggest that there may be some over-representation of married women, and, in the middle group, of women in the workforce. While 60-80% of the women in each group have no post-school qualifications, there may also be slight over-representation of women with tertiary qualifications. There is generally good representation of women from non-English speaking backgrounds, with at least 80 different languages being spoken at home. There is also good overall representation of Aboriginal and Torres Strait Islander women, although representation of this group in remote areas is lower than in the general population.

4 Reasons for non-participation

The main reasons given for non-participation (by those who contacted the study team) were “I don’t want to” “I’m not interested” “I’m too busy” and “I can’t be bothered.” Other reasons for non-participation related to issues of privacy and confidentiality, issues relating to the questionnaire or surveys in general and personal reasons.

5 Consent to access HIC data

Methods to be used for requesting consent to access Medicare records have been piloted with women in the middle and older cohorts. To date, more than half the participants in these pilot studies have given their consent for the researchers to receive information about health care service utilisation from the Health Insurance Commission or the Department of Veterans’ Affairs.

6 Qualitative data

Qualitative data from the middle cohort have been entered into a separate database, and will be reported with the quantitative data when reports on specific health issues are compiled.

7 Postgraduate students

Four PhD students and one master's student are continuing to work on specific sub-studies. The master's student has almost completed her data collection on the experiences of women seeking help for psychological distress.

8 Collaborative links and research activities

The researchers are continuing to develop collaborative links with other research centres. During the last six months we have hosted visitors from 11 Universities in Australia, the USA and New Zealand. Details of other research activities are included in this report.

9 Launch of the baseline data books

Baseline data books for the three main cohorts will be launched by the Minister for Health and Family Services at Parliament House on December 3, 1996.

1. ADMINISTRATIVE ARRANGEMENTS

1.1 PROJECT MANAGEMENT

Since the last report three additional research assistants have been employed to assist with data entry and analysis of the baseline data. One of our investigators, A/Professor Margot Schofield has left the University of Newcastle to take up the position of Program Director - Counselling in the Department of Health Studies at the University of New England, Armidale. Margot will continue to be a senior researcher with this project. Our fourth PhD student, funded by PHRDC, joined the study team in July 1996. This brings the number of staff in the Women's Health Australia (Newcastle) office to thirteen (project manager, statistician, data manager, secretary, five research assistants and four PhD students).

1.2 BUDGET

Supplementary funding of \$48,000 was received from the Department of Health and Family Services in August. These funds will be used to support the sub-study on Balkan women (\$20,000) and to assist with unforeseen costs of data storage (\$9,000) and entry of the qualitative data (\$19,000).

A summary of the 1996 budget is shown in Table 1.1.

**TABLE 1.1: ALSWH - 1996 BUDGET - UNIVERSITY OF NEWCASTLE
(REVISED NOVEMBER 1996)**

INCOME		EXPENDITURE	
Item:	\$	Item:	\$
Carried forward (1995)	449110	University of Queensland	210000
Department of Health & Family Services	875000	Core Salaries (inc on-costs)	
Supplementary funding	48000	Project Manager	60000
		Statistician	50000
		Data Manager	49000
		Research Fellow (0.4)	14000
		Secretary/RA	34000
		Research Assistants	90000
		Casual research staff (eg interviewers)	30000
		Scholarships	55000
		University Overheads (eg library, info technology, power, cleaning etc)	102750
University of Newcastle	99131	Furniture and Computers	30000
		Compactus	9500
		Office running costs (eg consumables, photocopier, fax, phone, photocopier etc)	30000
		Pilot projects	15000
		PhD projects	6000
		Main Survey	
		Printing	110000
		Packing	80000
		Post	210000
		Data entry	90000
		1800 number	12000
		Publicity	
		Pre-publicity	10000
		Newsletter/HIC consent	55000
		Travel	
		Project (staff establishment/visitors)	20000
		Uni of Queensland meetings	3500
		Advisory Group	20000
		Conference travel	6500
		Sub-studies	60000
TOTAL	1471241		1462250
		to be carried forward for 1997	8991

2. RECRUITMENT

2.1 PUBLICITY FOR RECRUITMENT OF THE YOUNGER COHORT

2.1.1 Newspaper Coverage

To coincide with the mailout of invitations to the young cohort, a press release (See Appendix 1) was faxed to 250 media outlets with emphasis being placed on the free suburban newspapers and women's health writers. As with the "fax frenzy" undertaken with the two other cohorts it is not possible to estimate how many of the targeted outlets used the material. We did however receive 11 requests for radio interviews from across Australia.

Advertisements encouraging young women to respond to the invitation to participate were also placed in six free "youth" orientated publications in major cities. (See Appendix 1). These free newspapers have wide distribution and some reach rural areas. Each publication was telephoned prior to the insertion of the advertisement and offered the press release. This resulted in editorial coverage in some of the targeted publications (See Appendix 1).

Presentations by the research team at the Public Health of Australia conference resulted in several requests by the press for interviews and information.

2.1.2 Radio Coverage

With the assistance of the University of Newcastle's local community radio station 2NUR FM, 73 community radio stations across Australia received 30 second promotional spots to target women in the older and younger age groups. The promotional spots for the younger age group were developed in conjunction with communication students from the University of Newcastle, who were working on placements with the radio station. The students collaborated with Women's Health Australia and wrote and produced three, promotional tapes (See Appendix 1 for scripts). It is difficult to estimate the 'air time' they received across Australia.

Over 200 Commercial radio stations received a "Community Radio Bulletin Announcement" with a request that it be read out as part of their free community service to prompt young women who received the invitation to respond to it. We are aware that many radio stations complied with this request (See Appendix 1).

Triple J, Australia's foremost national radio station for young people, was approached by telephone and subsequently broadcast a 5 minute segment about Women's Health Australia on the very popular The Morning Show. The interview was conducted by well known journalist Sarah McDonald and was slightly different in its approach as it involved excerpts of interviews with a participant in the project, as well as with the communication students who had volunteered to make our radio promotional spots (Tape available).

In total 10 radio interviews were carried out by researchers at the time of recruitment for the young cohort. Some of these interviews were with one of the PhD students, who is researching eating disorders in the younger cohort.

2.1.3 Print and Radio Strategies

To coincide with the mailout to young women, personal faxes were sent to 24 journalists throughout Australia who had previously provided coverage for the middle and/or older cohorts. The fax advised of the impending mailout to young women and updated the journalists on the progress of the study. This initiative resulted in several radio interviews and excellent coverage in a major Sunday newspaper.

2.1.4 Other Communication Strategies in the Last 6 Months

Presentations by the research team at the National Conference of the Australian Public Health Association resulted in requests from the press for interviews and information. Six radio interviews took place on topics directly relating to the presentations, and stories appeared in at least two major metropolitan newspapers.

During the entire mailout period several general reminders to participants have been broadcast. The most recent was on national commercial TV, when a prominent TV personality, Dr Feelgood, encouraged the return of the survey forms during her segment on Bert Newton's Morning Show, Channel 10 (tape available). This was targeted specifically at the older age group who may have felt it was too late to return their forms.

2.2 RECRUITMENT FOR THE MAIN STUDY

2.2.1 Background

In contrast with many previous longitudinal studies, which have focused on women from specific geographic areas or from particular occupation groups, this study was designed to explore the factors which promote and reduce good health in three age cohorts of women in the entire national population. It was important therefore to establish cohorts of women who were broadly representative of the Australian population in these age groups. Few other studies have attempted to recruit from such a wide geographic area. For example, the Longitudinal Study of Socio-Economic Health Differences (LS-SEHD) drew from population registers in a geographically restricted area around the city of Eindhoven in the Netherlands (Mackenbach et al., 1994), the Iowa Women's Health Study used the Iowa register of women driver's license holders as a sampling frame (Steinmetz et al., 1994) and the Massachusetts Women's Health Study recruited from census registries in 38 cities and towns in Massachusetts (Avis & McKinlay, 1991). The only other large cohort study of women's health to recruit from a geographic area as large as Australia is the Boston Nurses Study (Barton et al., 1980). Women were recruited to this, the largest and longest ongoing cohort study of women's lifestyle and health, from 11 states, including California in the west, Florida in the east, Michigan in the north and Texas in the south.

However, as the name implies, the Boston Nurses Study does not include women from all walks of life, and it was initially funded to examine a fairly specific women's health issue (the relationships between contraceptive use, smoking and the risk of major illness) (Colditz, 1995). Similarly, the Iowa Women's Health Study has a strong focus on a particular health concern (associations between diet and cancer) (Steinmetz et al., 1994), and the Massachusetts Women's Health Study focuses predominantly on menopause and the health of middle aged women (Avis & McKinlay 1995).

In contrast, the Women's Health Australia project is initially designed to focus on a wide range of health and health related issues, ranging from well-being, weight and exercise and health behaviours, to time-use, social support and health care utilisation, and will include young, middle aged and older women. This study is also unique because it provides the first opportunity in Australia to link social, environmental and personal factors in women's lives to health care utilisation data, by record linkage with the Medicare data base. While other research projects, such as the Manitoba Longitudinal Study on Aging, have retrospectively linked survey information with health insurance claims (Roos et al., 1987), this is the first attempt to provide accurate and detailed prospective longitudinal data on women's patterns of health service utilisation, and link this information to self report data in three national population based age cohorts.

2.2.2 Sampling frame

As it was important to the researchers to establish cohorts of women who were broadly representative of the Australian female population, the Medicare data base was selected as the sampling frame for this study. Almost all women in Australia (including immigrant and refugee women) are registered with this government health insurance agency. However, statutory restrictions on the use of the Medicare data base require that the selected participants' identity is concealed from researchers until consent is given by the individuals themselves; the names and addresses of the selected subjects were therefore not known to the researchers until responses and consents were returned to them. While this method had clear advantages with respect to protection of individual privacy, a disadvantage was that methods of encouraging participation (eg by telephone contact) were impossible.

2.2.3 Sample selection

The aim was to recruit between 12,000 and 15,000 women in each cohort. The sample sizes required to achieve this aim were based on results of the 1995 pilot studies which suggested that response rates would be around 48% for the mid age cohort, and 35% for the young and older cohorts. Consequently, invitations to participate were sent to 28,000 women in the mid age group and 39,000 in each of the younger and older age groups.

Women were randomly selected by the Health Insurance Commission, with deliberate over-representation of women from rural and remote areas. Women from these areas were selected in twice the proportion which exists in the Australian rural and remote

population in each age group. Women from capital cities and other metropolitan areas made up the balance of the samples.

2.2.4 Questionnaires

The research brief specified the need to consider the social and environmental aspects of women's lives as well as the psychological and biological determinants of health. These issues were addressed by grouping the questions into eight sections, each headed "*WOMEN'S HEALTH IS ABOUT*" "*...how you are feeling*"; "*...using health services*"; "*...coping with common problems*"; "*...coping with stress*"; "*...healthy weight and shape*"; "*...juggling time*"; "*...family and friends*" and "*...you and your life*." Wherever possible, validated questions or scales (for example, the SF36, the Duke Social Support Scale, the Australian Nutrition Screening Inventory and the Hwalek-Sengstock Elder Abuse Screening Test) were used. The self complete, closed item baseline questionnaires included 252 items for the younger group, 285 items for the middle-age group, and 260 items for the older-age group. A variety of question formats was included, ranging from "yes/no" or a choice of pre-coded responses, to up to six point Likert-type scales. At the end of the questionnaire women were invited to add additional comments in an open format.

2.2.5 Mailing Protocol

A mailing protocol based closely on the methods recommended by Dillman (1978) was used. This involved sending a series of items to each woman. The first mail-out included an introductory letter, an information brochure, a consent form, a questionnaire and reply paid envelope. One week after the initial mail out, all women were sent a card which thanked those who had completed the survey, and acted as a reminder for those who had not yet returned their questionnaire.

Three weeks after the initial mail out, identification numbers of all women who had either returned their survey, completed the survey by telephone, informed the researchers they did not wish to participate, or whose initial package had been 'returned to sender' were deleted from the mailing list. One week later, the remaining women were sent a replacement package. This package was the same as the first except that the letter was modified to indicate that this was a reminder/replacement for lost packages. Four weeks after the replacement package was mailed, all women who had still not responded, or whose packages had not been returned, were sent a final reminder card. All surveys were mailed between April and September 1996.

2.2.6 Telephone responses

A freecall number was provided for women to ring if they required additional information, or if they did not wish to participate in the survey. Women who rang to decline their invitation were asked their main reason for not wishing to participate. Women who experienced difficulties with reading or understanding the questionnaire were also invited to ring the freecall number to organise for the survey to be completed by telephone, in any language of their choice. All telephone surveys were conducted by experienced telephone interviewers and qualified health service interpreters.

2.2.7 Confidentiality

Confidentiality for participants is ensured by storing all data by identification number. Names and addresses are stored separately from the main data files, and all staff are bound by the provisions of the Privacy Act. The recruitment process was approved by the University of Newcastle Human Research Ethics Committee.

2.3 RESPONSE RATES

Overall response rates for the three cohorts were calculated by dividing the number of respondents (both self complete and telephone) by the estimated number of women who were eligible to complete the survey. The denominator was calculated using figures shown in Table 2.1 which include the number of surveys which were 'returned to sender' and the number of recipients who were judged ineligible to participate (see Table 2.1 for reasons). After adjustment for those who were known to be uncontactable or ineligible, response rates were 39% for the young group, 54% for the middle group, and 36% for the older group.

2.3.1 Telephone responses

13,500 calls were received on the freecall number. Almost 90% of these calls were from women who were ineligible (N= 3325, or 3.1% of those on the initial mailing list, see Table 2.1), or who wished to decline the invitation to participate in the study (N=8836, or 8.3% of those on the initial mailing list). Reasons for non-participation are summarised in Table 2.2.

201 calls were received from women requesting to do the survey by telephone, either because they had difficulty reading or understanding the survey (N=138), or because of language difficulties (N=63). Telephone interviews were subsequently conducted in 17 different languages (see Table 2.3). The remaining calls (N=1140) were from women seeking clarification about aspects of the study, such as confidentiality, the involvement of Medicare, how names were selected, clarification of the commitment which would be required, or the duration of the study.

TABLE 2.1: CALCULATION OF RESPONSE RATES

	YOUNG	MIDDLE	OLDER
Number sent out	39000	28000	39000
Returned to sender	2373	1060	1100
Surveys completed	14018	14200	12614
Provisional response rate	38.3%	52.7%	33.3%
KNOWN TO BE INELIGIBLE:			
Deceased	20	37	448
Male, outside age group, not known at address	99	31	64
Too ill to complete (eg nursing home, Alzheimer's, dementia, stroke, nervous breakdown)	24	53	414
Travelling (eg overseas/itinerant/ nomadic) - not contactable	366	164	354
Unable to complete (eg blind/illiterate/hearing impaired)	23	9	110
Too sick to do it now (in hospital, having surgery)	16	57	763
Language difficulties (declined interpreter)	7	35	205
Not allowed to complete (husband/partner or doctor)	5	11	10
TOTAL INELIGIBLE	560	397	2368
RESPONSE RATE	38.9%	53.5%	35.5%

TABLE 2.2: REASONS GIVEN BY WOMEN WHO DECLINED THE INVITATION TO PARTICIPATE

		YOUNG		MIDDLE		OLDER	
		N	%	N	%	N	%
General reasons							
	don't want to do it	266		232		1131	
	not interested	275		282		766	
	too busy/no time	142		137		458	
	can't be bothered	274		404		338	
	husband rang to say she doesn't want to	38		74		394	
	I can't help you	-		24		56	
	I don't want to give a reason	4		-		37	
		1		8		21	
	TOTAL	1000	70.0	1161	57.4	3201	59.4
Privacy and confidentiality							
	Invasion of privacy/health is my own business	64		151		174	
	Questions too personal	129		165		143	
	concerned about confidentiality	22		47		35	
	not comfortable with idea/study	11		7		25	
	Medicare concerns	4		8		8	
	TOTAL	230	16.1	378	18.7	385	7.2
Questionnaire Issues							
	too many surveys/dislikes longitudinal nature	42		62		160	
	doesn't like surveys	16		87		154	
	too long/too many questions	17		38		156	
	too difficult/confusing/complicated	6		26		162	
	questions are boring/pointless/irrelevant	17		58		84	
	disapproves of sampling/reminder process	8		10		13	
	waste of time/money/stupid idea/tore it up	11		30		70	
	TOTAL	117	8.2	311	15.4	799	14.8
Personal Issues							
	personal reasons	26		47		87	
	too distressing/too many problems	9		26		160	
	family reasons	-		30		54	
	too healthy	2		25		86	
	too old	-		-		232	
	caring for husband/another person	-		11		220	
	constantly moving/moving now	38		31		63	
	spouse died recently	-		1		92	
	services don't need improvement	-		-		4	
	having a baby/has baby to care for	6		-		-	
	wants to be paid	-		1		-	
	poorly educated	-		-		3	
	TOTAL	81	5.7	172	8.5	1001	18.6
TOTAL		1428	100	2022	100	5386	100
Proportion of invited sample			3.7		7.2		13.8

TABLE 2.3: NUMBER AND LANGUAGE OF TELEPHONE INTERVIEWS FOR THE THREE COHORTS

LANGUAGE:	YOUNG	MIDDLE	OLDER
English	17	34	87
Italian	-	6	14
Greek	-	6	7
Chinese (Mandarin/Cantonese)	3	9	-
Arabic/Turkish	3	-	-
Vietnamese/Thai/Cambodian	4	1	-
Serbian/Macedonian	1	2	-
Polish/Ukrainian/Hungarian	-	-	4
Spanish/Portuguese/Maltese	-	-	3

2.3.2 Discussion of Response rates

For the Women's Health Australia project we aimed to establish three age cohorts, each with between 12,000 and 15,000 women. This aim was achieved using a modified Dillman protocol, but without telephone contact to encourage follow-up.

We chose to use the Medicare data base as a sampling frame for this project because it had the potential to reach a wider cross section of women than either the electoral roll, telephone directories, or random digit dialling. Having decided to use this sampling frame, we were then bound to use a mail survey, because statutory regulations precluded the release of the selected women's personal details to the researchers. Invitations were therefore sent on behalf of the researchers by the Health Insurance Commission, which administers Medicare from Canberra. The researchers were unable to contact non-respondents, to determine their demographic characteristics, or their reasons for not wishing to participate. However, all women who contacted the researchers by telephone to decline the invitation to participate were asked their main reason for not wishing to take part in the survey.

Studies of recruitment for mailed surveys suggest that response rates to unsolicited mail surveys can be remarkably low. Response rates of between 10 and 30% are not uncommon. (Landy & Bates, 1973; Etzel & Walker, 1974). For example, the Rural Health Promotion project in Pittsburgh achieved a response rate of 13.5% to its mail only recruitment of 65-79 year olds from a health insurance data base. (Greenblatt-Ives et al., 1992), and a US Coronary Primary Prevention trial achieved a 12.7% recruitment rate, using voter lists as the sampling frame (Levenkron & Farquhar, 1982).

Some researchers have however shown that it is possible to attain higher rates of response to mail surveys. In general response rates appear to depend on a variety of factors including repeated contacts, inclusion of a reply-paid return envelope, and

monetary incentives (Yammarino et al., 1991). In an Australian mailed social science survey in 1985, Graetz achieved response rates ranging from 38% to 67% in 8 geographically distinct Federal electoral divisions (Graetz 1985). In general, response rates were lower in rural areas, but the relatively high overall response rate may have been attributable to the inducement of entry into a prize draw for those who returned their surveys (Yammarino et al., 1991).

Previous researchers have found that response rates are maximised when there is telephone contact and when the survey is marketed through the mass media, (Greenblatt-Ives et al., 1992). For health related surveys, response rates can also be enhanced when there is support from local health professionals (Greenblatt-Ives et al., 1992). Telephone contact was impossible in the WHA project, because the identity of the selected women could not be released to the researchers. Attempts were made to publicise the survey prior to the initial mail-outs, but it is difficult to know whether our publicity efforts reached every corner of Australia. Similarly, it was not possible to engage the support of health professionals from the entire country.

Our highest response rate was in the middle age group, where the response was a little lower than that of the Boston Nurses Study, which achieved a response rate of 58% in response to its mailed surveys. (A further 12% was achieved after telephone follow up). The Boston study had the advantage however of using nurse registration records, which may be more up to date than our Medicare data base. They also had the advantage of being able to market the study specifically through nursing journals which were targeted directly to the research population. The issue of marketing seems to be very important in this type of study. The relatively high response rate of the Netherlands LS-SEHD study (70%) was achieved only following an intense media campaign in the local geographic area of the study (Mackenbach et al., 1994). It was not possible to achieve the same depth of coverage for this project in which the potential participants were located across the whole of Australia.

Previous studies have found that response rates to mailed questionnaires are lower in the elderly (Kaldenberg et al., 1994). Researchers who mailed a 4 page questionnaire to 1000 retirees in a large US city found that the response rate fell by more than 0.5% for each year of age over 60 (Kaldenberg et al., 1994). This is not surprising, given that memory problems and confusion increase with age. Despite our attempts to simplify the questions and the use of a larger font in the older questionnaire, we would expect that some older women would have had difficulty reading, comprehending and answering the questions, and these factors may have contributed to the lower response rate in this group. Those who rang us to explain difficulties of this nature were offered the opportunity to complete the questionnaire by telephone, and the majority (about 90%) of these women accepted this offer.

The response rate in our older cohort was much lower than that achieved in the middle cohort, and a little lower than that achieved in the Iowa women's health study (42.6%), which targeted women in the 55-69 years age group. Once again the researchers in Iowa had the advantage of working in a defined geographic area, and their register of drivers' licences was likely to be a reliable and up-to-date source of names and addresses.

This raises the issue of one of the biggest problems with this type of mail survey, that is, the inability to establish clear cut categories of reached and unreached respondents (Sosdian & Sharp, 1979). As researchers, we knew the number of surveys sent, and the number returned, either completed, or marked 'return to sender.' However, we had no way of ascertaining the number of surveys which never reached the intended respondent, because they were incorrectly delivered. However, previous researchers who followed up non-respondents to a survey by telephone found that 28% of those contacted said they had never received the survey (Sosdian & Sharp, 1979). A more recent study of the destination of incorrectly addressed envelopes in the USA found that while 87% were returned to sender, 13% were never returned as undeliverable (Sandler & Holland, 1990). It is likely therefore that our 'return to sender' records underestimate the number of participants who never received the invitation, either because the addressee had moved without leaving a forwarding address, or the selected woman was unknown at the address to which the survey was sent.

Given the methodological limitations and ambitious scope of this project, the response rates compare favourably with previous longitudinal studies. Perhaps more important than the response rates, is the issue of whether the women recruited to this study are representative of the general Australian population (see Section 2.5 below).

2.4 REASONS FOR NON-PARTICIPATION

Many researchers have assumed that burdensome survey instruments, respondent scepticism about the usefulness of the research, issues of informed consent, invasion of privacy and confidentiality have been major factors in increasing respondent resistance to surveys (Sosdian & Sharp, 1979). However, provided the callers on our freecall number were typical of all non-respondents, the main reason for non-participation in this study, across all three age groups, was that women simply "did not want" to participate. They were either not interested, too busy or "couldn't be bothered." This was particularly true in the younger women (See Table 2.2).

In contrast to the findings of Sosdian & Sharp, who found there to be no concerns about privacy and confidentiality in 1979, many of our callers, particularly in the young and middle age groups, said worries about these issues were their main reason for not wishing to participate. This probably reflects a general change in the population's perceptions of data confidentiality since 1979. Callers in the mid and older groups were also concerned about issues relating to surveys in general ("I don't like surveys," "I'm sick of doing surveys") or to specific issues relating to this survey ("it's too long/too difficult/too complicated") (See Table 2.2).

We received many more calls from the older women, or their families, and this group were much more likely to offer a personal reason for non-participation. Some older callers said they found the questionnaire too distressing, because of their own or their family's health problems, or said that they were too busy caring for another person to complete a survey about their own health. Interestingly, there were also a few calls from husbands who were full time carers for invalid wives, who offered to complete the survey on behalf of their spouse. Proxy responses completed by these full time carers, or by parents on behalf of their severely disabled daughters, were accepted.

While lack of motivation appeared to be the major reason for non-participation, we did encounter some overt resistance from our callers. Most of this hostility was from women who were concerned that records entered on a confidential file had apparently been accessed without their prior consent. These callers were reassured that their names and addresses had not been released to the researchers.

We also received calls from some women who had received the second (replacement) package, to say that their initial package had never been received. Some claimed it was never delivered, while others suggested that it may have been “screened” by their partner, who had “decided not to pass it on to them”. Other women admitted that they had discarded the first package in error, with the ever increasing amount of “junk” mail they received. These calls confirm our view that an unknown proportion of surveys may never have reached the selected study participants.

2.5 DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

Demographic characteristics of the respondents were compared with those of women of the same age in the Australian population, by obtaining corresponding data from the latest available national census, which was conducted in 1991 (ABS, 1991). Similarities and differences in these demographic characteristics between the study participants and the general population are shown in Table 2.5.

Because there was over-sampling of women from rural and remote areas, it was necessary to weight observations to produce frequencies which are representative of the reference population (Australian women in the chosen age groups, see Table 2.4). The formula used to do this was:

$$\text{weight} = \frac{\text{No in urban/rural/remote population}}{\text{No in total population}} \times \frac{\text{No in total baseline sample}}{\text{No in urban/rural/remote sample}}$$

TABLE 2.4: WEIGHTS FOR EACH AREA OF RESIDENCY, FOR WOMEN AGED 18-22, 45-49 AND 70-74

	URBAN	RURAL	REMOTE
18-22	1.378494656	0.514301049	0.750776658
45-49	1.991388700	0.437170756	0.390580302
70-74	1.742017122	0.482636931	0.741746453

In all age groups there is good representation of women from non-English speaking backgrounds, but slight over-representation of women from Australia and other English speaking countries in the young and middle groups. (See Table 2.5). In the older group, women from non-English European backgrounds are slightly over-represented. ATSI representation was good overall, but remote Aboriginal women are under-represented.

Other minor differences between the cohort and the general population include a greater representation of married women in all age groups, and women who are employed in the middle group. In the young cohort, fewer are in the workforce, perhaps indicating that they may be full time students. It is difficult to compare the education qualifications since a high proportion of the population census data was classified as 'other/not stated' for this variable. It would appear however that there is greater representation of women with tertiary qualifications in all three cohorts.

The participants include women who speak (between them) 80 different languages at home, including the sign language, Auslan (see Table 2.6). The most common languages spoken by women in each group are shown in Table 2.7.

2.6 EFFECTIVENESS OF THE MAIL OUT STRATEGY AND COST OF RECRUITMENT

The number of packages and cards mailed at each stage of the mailing process is shown in Table 2.8. By adding the cost of printing, packing, mailing, postage, and the 1800 number, it is estimated that the cost of recruitment, in terms of each completed questionnaire was approximately \$12. This estimate does not include the cost of salaries of the research team for development of the questionnaires, pilot studies, computer hardware and software for data management and analysis, and office consumables. If included, these costs would increase the cost of the baseline survey to around \$23.60 per person.

Analysis of the returns at each stage of the mailing process indicates that the response to the final reminder card was very low (see Table 2.9). While the final reminder card increased the response rate in the middle group by 4.3%, it resulted in increases of less than 2% in the overall response rate for the younger and older groups. Based on the number of reminder cards sent, it is estimated that the *additional* cost of recruiting these final respondents was \$44 for each respondent in the young group, \$10.50 for each in the middle group, and \$22 for each of the older respondents. In addition to the added cost, previous researchers have found that the last mail out "may excessively strain the goodwill and forbearance of determined non-respondents" (Sosdian & Sharp, 1979), and judging from some of the telephone calls we received following the final mail out, we would conclude that many women who had already decided not to respond were angered by the apparent insistence of this approach. In hindsight we would probably recommend that the final stage of the mailing strategy be omitted from future surveys.

Conclusion

We have achieved the aim of recruiting three large cohorts of women using the Medicare data base as a sampling frame. The cohorts include women from all walks of life, and include women from those rural and remote communities which are often neglected in research of this nature. Importantly, the cohorts include women from many different non-English speaking backgrounds, and 60-80% of all participants have no post-school qualifications. The women who have agreed to participate in this longitudinal study have expressed their support for and interest in the study. Most appear to be pleased to have been selected to participate, and many have already asked when we will need their next contribution.

TABLE 2.5: a) SOCIO-DEMOGRAPHIC CHARACTERISTICS FOR YOUNG-AGE RESPONDENTS (N= 13442) AND OF THE GENERAL POPULATION (N= 683145)

	Urban		Rural		Remote		Australia	
	Cohort %	Population %	Cohort %	Population %	Cohort %	Population %	Cohort %	Population %
Main current employment status								
Full-time paid	30.0	35.5	32.7	33.9	42.9	34.1	30.9	35.1
Part-time/casual	18.4	20.8	19.9	17.2	22.3	17.0	18.8	20.0
Worked without pay	0.2	0.3	0.7	0.5	0.2	0.7	0.3	0.3
Employed not stated	0.0	3.2	0.0	2.8	0.0	2.8	0.0	3.1
Unemployed	5.8	13.3	8.6	16.6	6.8	12.7	6.4	13.9
Total labour force	54.3	73.0	61.9	70.9	72.2	67.2	56.4	72.4
Total not in labour force	43.3	24.8	35.8	26.9	24.7	28.7	41.2	25.3
Not Stated	2.4	2.2	2.3	2.2	3.2	4.1	2.4	2.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Highest qualification completed								
No Post-School Q	69.0	75.6	72.5	78.0	66.4	75.4	69.7	76.1
Trade/Apprentice	1.9	7.5	3.5	7.9	5.6	7.4	2.3	7.6
Certificate/Dipl	14.6	3.6	15.7	3.2	18.3	3.9	15.0	3.5
Uni degree	13.1	3.2	7.1	1.7	8.6	2.8	11.7	2.9
Higher degree	0.9	0.3	0.5	0.3	0.4	0.6	0.8	0.3
Other (Not stated/ Inadequately described)	0.5	9.8	0.7	8.8	0.8	9.9	0.5	9.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Aboriginal/Torres Strait Island

No	99.0	99.0	97.5	96.7	91.4	77.9	98.4	97.9
Aboriginal	0.9	0.9	2.2	3.0	7.4	20.7	1.4	1.9
Torres Strait Is	0.2	0.1	0.4	0.3	1.2	1.5	0.2	0.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

COB: Country of Birth

Australia	87.7	80.1	96.5	92.5	96.6	88.8	89.8	83.0
United Kingdom	2.2	3.4	1.0	1.8	0.4	2.9	1.9	3.1
New Zealand	1.5	2.0	1.2	1.2	1.6	2.5	1.4	1.9
Other Europe	1.7	2.2	0.3	0.7	0.0	1.0	1.4	1.8
Asia	4.5	5.8	0.4	1.0	0.6	0.8	3.5	4.7
Others	2.4	6.4	0.6	2.8	0.8	4.0	2.0	5.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Present Marital Status

Married/Defacto	17.2	10.5	27.1	13.4	44.0	20.2	20.1	11.4
Separated	0.7	0.7	1.1	0.9	1.2	1.2	0.8	0.8
Divorced	0.0	0.4	0.0	0.4	0.0	0.5	0.0	0.4
Widowed	0.0	0.3	0.0	0.3	0.0	0.6	0.1	0.3
Single	82.0	88.1	71.7	85.0	54.8	77.6	79.0	87.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Present housing situation

House	74.7	78.8	74.3	78.8	70.2	73.7	74.5	78.7
Flat/unit/apartment	20.5	16.6	19.2	12.1	21.4	9.8	20.2	15.5
Caravan/tent	0.5	0.5	1.2	2.0	3.6	5.6	0.7	0.9
Other	4.4	4.1	5.3	7.2	4.8	10.9	4.6	4.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

b) SOCIO-DEMOGRAPHIC CHARACTERISTICS FOR MIDDLE-AGE RESPONDENTS (N= 14200) AND OF THE GENERAL POPULATION (N= 489965)

	Urban		Rural		Remote		Australia	
	Cohort %	Population %	Cohort %	Population %	Cohort %	Population %	Cohort %	Population %
Main current employment status								
Full-time paid	38.5	34.7	29.3	30.6	37.0	33.3	36.1	33.7
Part-time/casual	30.2	26.5	30.3	25.5	24.7	23.1	30.0	26.2
Worked without pay	3.8	0.6	9.4	1.6	13.4	1.6	5.4	0.9
Employed not stated	0.0	2.9	0.0	2.8	0.0	3.4	0.0	2.8
Unemployed	2.0	4.5	1.8	4.7	1.4	3.7	1.9	4.5
Total labour force	74.3	69.3	70.9	65.2	76.4	65.1	73.4	68.1
Total not in labour force	22.4	27.5	25.6	31.7	21.0	30.9	23.3	28.6
Not Stated	3.3	3.3	3.5	3.2	2.6	4.0	3.3	3.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Highest qualification completed								
No Post-School Q	60.6	63.7	69.0	69.3	72.4	71.7	63.0	65.3
Trade/Apprentice	3.4	6.8	3.5	5.7	3.3	4.5	3.4	6.5
Certificate/Dipl	16.5	8.5	15.1	9.6	13.3	8.1	16.1	8.8
Uni degree	11.0	5.6	8.0	3.5	6.2	3.4	10.1	5.0
Higher degree	7.2	2.8	3.6	1.5	3.4	1.0	6.2	2.4
Other (Not stated/ Inadequately described)	1.3	12.5	0.9	10.4	1.4	11.2	1.2	12.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Aboriginal/Torres Strait Island

No	99.3	99.6	99.2	98.7	96.7	89.7	99.2	99.1
Aboriginal	0.6	0.4	0.7	1.1	2.8	9.5	0.7	0.8
Torres Strait Is	0.1	0.0	0.2	0.1	0.5	0.8	0.1	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

COB: Country of Birth

Australia	65.1	60.1	82.4	82.6	79.8	78.6	69.8	66.2
United Kingdom	13.4	11.4	8.3	7.7	8.0	8.6	12.0	10.4
New Zealand	2.2	1.9	1.7	1.3	3.2	1.9	2.1	1.7
Other Europe	10.7	14.4	4.9	4.8	4.8	4.9	9.1	11.8
Asia	5.3	3.9	1.1	0.7	2.3	1.4	4.2	3.1
Others	3.3	8.3	1.5	2.9	1.9	4.6	2.8	6.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Present Marital Status

Married/Defacto	79.1	76.0	84.5	80.2	88.4	78.6	80.7	77.1
Separated	5.3	4.2	3.7	3.7	2.9	4.0	4.8	4.1
Divorced	9.0	11.4	7.1	8.9	4.3	8.1	8.4	10.7
Widowed	2.2	3.0	1.9	3.2	1.8	4.3	2.1	3.1
Single	4.5	5.3	2.7	4.0	2.7	4.9	4.0	5.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Present housing situation

House	89.3	88.5	93.1	91.1	87.3	81.2	90.2	88.9
Flat/unit/apartment	8.8	9.0	4.0	3.9	6.7	3.7	7.5	7.6
Caravan/tent	0.5	0.5	1.1	2.0	3.3	7.8	0.7	1.1
Other	1.4	2.0	1.9	2.9	2.7	7.3	1.6	2.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

c) **SOCIO-DEMOGRAPHIC CHARACTERISTICS FOR OLDER-AGE RESPONDENTS (N= 12624) AND OF THE GENERAL POPULATION (N= 276614)**

	Urban		Rural		Remote		Australia	
	Cohort %	Population %	Cohort %	Population %	Cohort %	Population %	Cohort %	Population %
Highest qualification completed								
No Post-School Q	78.7	68.7	81.9	70.4	79.3	69.8	79.6	69.2
Trade/Apprentice	4.0	2.3	2.8	1.6	4.0	1.3	3.7	2.1
Certificate/Dipl	7.7	3.5	6.9	3.7	7.7	4.2	7.5	3.6
Uni degree	3.5	1.4	2.3	1.0	1.7	1.2	3.1	1.3
Higher degree	1.3	0.4	0.5	0.2	0.0	0.3	1.1	0.3
Other (Not stated/Inadequately described)	4.8	23.6	5.5	23.1	7.3	23.1	5.0	23.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Aboriginal/Torres Strait Island								
No	99.6	99.8	99.6	99.6	99.3	92.6	99.6	99.6
Aboriginal	0.2	0.1	0.3	0.4	0.4	6.5	0.3	0.3
Torres Strait Is	0.2	0.0	0.1	0.0	0.4	0.9	0.1	0.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
COB: Country of Birth								
Australia	69.3	67.5	82.8	82.8	83.9	81.7	73.3	72.0
United Kingdom	12.8	11.8	9.9	8.2	7.2	8.1	11.9	10.7
New Zealand	1.1	1.0	1.0	0.7	1.8	1.1	1.1	0.9
Other Europe	12.9	9.6	5.1	3.8	6.1	3.0	10.6	7.9
Asia	2.0	2.4	0.5	0.3	1.1	0.5	1.6	1.8
Others	1.9	7.7	0.7	4.1	0.0	5.6	1.5	6.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Present Marital Status

Married/Defacto	54.5	47.9	58.5	52.5	51.9	51.6	55.5	49.2
Separated	1.5	1.6	1.5	1.3	1.7	1.8	1.5	1.5
Divorced	5.3	4.5	3.5	2.8	2.4	2.7	4.8	4.0
Widowed	35.1	40.2	34.1	38.7	42.0	39.0	34.9	39.7
Single	3.7	5.9	2.4	4.7	2.1	4.9	3.3	5.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Present housing situation

House	73.7	77.4	83.3	83.9	89.6	69.6	76.7	79.1
Flat/unit/apartment	22.2	15.6	13.0	7.8	6.7	3.9	19.4	13.2
Caravan/tent	0.7	0.8	0.9	2.7	0.7	12.1	0.7	1.5
Other	3.3	6.2	2.8	5.6	3.0	14.4	3.2	6.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

TABLE 2.6: LANGUAGES SPOKEN AT HOME BY WHA RESPONDENTS

GEOGRAPHIC AREA	CODE	LANGUAGE
English	01	Australian, American
Southern Europe	02	Armenia, Creole, Italian, Greek, Spanish, Portuguese, Maltese
Northern Europe	03	Danish, Dutch, Finnish, French, German, Austrian, Scandinavian, Flemish, Swiss, Swedish
Eastern Europe	04	Bulgarian, Beloruss, Czech, Estonian, Hungarian, Romanian, Albanian, Latvian, Lithuanian, Slovak, Slovenian, Ukrainian, Polish, Russian
South-East Asia	05	Malay, Japanese, Korean, Indonesian, Laotian, Burmese, Cambodian, Vietnamese, Thai, Hakka, Cocos
North Asia	06	Fukkian, Punjabi, Hindi, Indian, Bengali, Chinese, Hokkien, Mandarin, Cantonese, Sri Lankan, Singalese, Urdu
Middle East	07	Arabic, Assyrian, Afghan, Turkish, Farsi, Hebrew, Lebanese, Yiddish
Africa	08	Africaans, Swahili
South America	09	
Pacific Islands	10	Fijian, Maori, Samoan, PNG, Pidgin, Tongan, Twi, Norfolk
Filipino	11	Tagalog, Filipino
Yugoslav	12	Croatian, Bosnian, Serbian, Macedonian, Yugoslavian
Auslan	13	Sign language
Aboriginal	14	

TABLE 2.7: LANGUAGE SPOKEN AT HOME BY RESPONDENTS IN EACH AGE GROUP

LANGUAGE SPOKEN AT HOME	AGE GROUP		
	<i>Young</i>	<i>Middle</i>	<i>Older</i>
English	10875	13090	10558
Italian	161	135	177
Greek	99	71	48
Cantonese	83	60	24
Mandarin	30	22	5
German	33	59	164
Arabic	60	22	18
Other	539	525	446
Missing	105	216	1174
Total	11985*	14200	12614

*data entry incomplete at time of printing

TABLE 2.8: NUMBER OF PACKAGES AND REMINDER CARDS SENT AT EACH STAGE OF THE MAILING PROCESS

COHORT		Week 1 Initial mail out	Week 2 Reminder/ thank you	Week 3	Week 4	Week 5 Replacement package	Week 6	Week 7	Week 8	Week 9 Reminder/ thank you	Remainder received	Total received
YOUNG	Number mailed	39000	38986			29262				21592	1166	14018
	Surveys completed and returned				6479				6342			
	Telephone interviews				16				15			
	Withdrawals/returns				3229				1313			
MIDDLE	Number mailed	28000	28000			17853				12090	1528	14200
	Surveys completed and returned				7915				4701			
	Telephone interviews				42				14			
	Withdrawals/returns				2190				1048			
OLDER	Number mailed	39000	39000			24518				15061	808	12614
	Surveys completed and returned				7132				4560			
	Telephone interviews				67				47			
	Withdrawals/returns				7283				4850			

TABLE 2. 9: RETURNS ACCORDING TO THE DILLMAN MAILOUT STRATEGY

AGE GROUP	ESTIMATED RESPONSE TO:		PERCENTAGE RETURNED
YOUNG	Initial package and reminder	10115	27.7
	Replacement package	3411	9.3
	Final reminder card	492	1.3
	TOTAL	14018	38.3
MIDDLE	Initial package and reminder	11052	41.0
	Replacement package	1993	7.4
	Final reminder card	1155	4.3
	TOTAL	14200	52.7
OLDER	Initial package and reminder	10248	27.0
	Replacement package	1686	4.5
	Final reminder card	680	1.8
	TOTAL	12614	33.3

3 PILOT STUDY FOR MEDICARE CONSENT

Pilot studies are currently in progress to test recruitment procedures for obtaining consent from study participants to allow Women's Health Australia to gain access to statistical information from Medicare. Pilot tests have been carried out for middle and older cohorts and are currently being designed for the younger cohort. In addition to requesting Medicare consent, participants were sent an age-specific newsletter designed to thank women for their participation in the project. This newsletter provided important feedback to women in the form of frequencies and basic results from the initial survey.

Women from the middle and older cohorts were mailed an age-specific information sheet and a consent form (See Appendix 2). The content of the information sheet was based on the brochure sent to pilot 1 participants, and suggestions from focus groups of women living in the local area. The content was reviewed by the Health Insurance Commission and the University of Newcastle's Ethic Committee. On the back of the consent form was a section for change of address or contact details, and a box for women to tick if they did not want Women's Health Australia to notify Medicare of their change of details.

For the middle cohort, 115 participants from pilots 2 and 3, were mailed a Medicare consent package on 13 September 1996 and a reminder card on 4 October 1996. To date, 75 (65.2%) women have consented to allow access to Medicare information and

4 have refused. Eleven women from the middle cohort were telephoned and asked what their reactions to the package were. Most women said that they were happy to consent but had not 'got around to posting it yet'.

For the older cohort, 170 participants from pilots 2, 3 and 4, were mailed an information sheet and consent form (See Appendix 2) on 4 October 1996. To date, 83 (48.8%) women have consented and 9 have refused.

The package for the younger cohort is currently being re-designed, based on findings from the middle and older cohort pilot tests. Because some women from the middle and older cohorts signed the Medicare consent form but did not tick one of the yes/no boxes, they had to be telephoned to check whether they had intended to give consent. All said that they meant to tick the 'yes' box. The 'yes' and 'no' tick boxes from the consent form have therefore been removed from the young consent letter. Also for the young cohort, a thank you letter with a brief explanation about the Medicare consent request will be included on the back of the consent form. This aims to provide a more personal approach to the invitation. The change of address form will not be included on the back of the consent form. A separate change of address card will be included to encourage women to keep in touch.

Another modification for the young cohort is that the information sheet has been replaced with an information brochure. The brochure is designed to make it easier to read, whilst retaining all necessary information about the request. Feedback from a few women suggested that the original information sheet may have been overwhelming, as it contained a lot of information. The revised brochure and consent form have been approved by the University's Research Ethics Committee and will be sent to the Health Insurance Commission for approval. If there are no problems with the next pilot phase, which involves sending consent packages to 166 young women from pilots 2, 3 and 5, the same packages will be used to seek consent from women in the three main cohorts early in 1997.

As the Medicare package is being sent as a separate package from the initial invitation to participate in the study, the cost of postage for this part of the study was not anticipated. In order to save additional costs, we have decided not to send a reminder card to women who do not respond to the request for Medicare consent. Participants who do not initially consent to Medicare access could be asked to consider the request again in association with future newsletters. However, a sub-sample of women will be selected to trial more intensive consent-seeking efforts, so that health care utilisation patterns can be established for a representative sub-sample of each cohort. It is also proposed that a business card with the Freecall 1800 telephone number and a statement about notifying Women's Health Australia of change of contact details, will be sent to women in the main cohorts.

4. QUALITATIVE DATA: MID COHORT

4.1 INTRODUCTION

In response to the question:

“Have we missed anything? If you have anything else you would like to tell us, please write on the lines below”,

2465 women from the mid cohort provided additional and valuable insight into their experiences of health. Therefore, in addition to the information provided from the quantitative data, we now have important qualitative data about specific health experiences, and recommendations for topics to be covered in future questionnaires for this age group.

Many women were grateful for the opportunity to express their views and reflect on their own health, with recognition that the stresses and demands placed on women at this particular life stage require considerable inner resources. Some women appear to cope well with these pressures but others identified particular areas of need which should be addressed in order to preserve and increase their well-being.

These comments may or may not bear out the quantitative data received through the questionnaire, depending on whether the comments are made by representative sub-groups of the respondents. In later analyses we will have the capacity to explore relationships between the comments and demographic variables, such as geographic location and socio-economic status of women who responded to this part of the survey, and to see whether the comments were made by women who are typical of the entire cohort.

4.2 METHODOLOGY

It is recognised that the qualitative data provide significant potential to augment the quantitative survey data. These data also provide perspectives which may not have been covered within the framework of the questionnaire and could provide direction for future research. The comments received were however complex and lengthy. For this reason we decided it was vital to establish a separate data base to record and analyse this valuable information.

Based on the major themes identified for the Australian Longitudinal Study on Women’s Health and the five priority areas of the National Women’s Health Policy, a program (in Microsoft Access) was designed to enable research assistants to enter and code the comments according to fourteen themes (See Appendix 3). Separate lists of key words were also provided for each age cohort.

As it was possible for the comments provided by any respondent to cover a number of health issues, up to eight themes and nine keywords could be entered for each respondent’s comments (See Appendix 3). The number of responses in each theme is shown in Table 4.1.

TABLE 4.1: NUMBER OF RESPONSES FOR EACH THEME IN THE MID COHORT

Total number of comments received, by Theme:

Ageing	18
Caring	331
Emotional and mental health	848
Family relationships	655
Health services	738
Individual health problems	880
Questionnaire	913
Reproductive health	360
Social policy	221
Stress	407
Time use	558
Violence	102
Weight and exercise	216
Other	17
Total	2465

The following information was entered into the database: Respondent's ID, "bundle" ID, area classification, the operator's name, whether the comments were descriptive, evaluative, or both, the comments themselves and the appropriate themes and keywords (See Appendix 3).

4.2.1 Quality Control

A coding manual was developed and followed by each of the operators. Quality control was provided by checking every 20th entry of each of the four operators. Operators asked for assistance from each other or the Project Manager in coding qualitative data where major themes/keywords could not be easily identified. Daily discussion and weekly brief meetings were held to ensure that any new major keywords were added to the list. A monthly meeting with the principal investigators, program manager and other staff was held to discuss progress and to ensure that linking of comments with themes was addressing the principal areas of research.

In compiling reports on specific health issues, the comments made in the final section of the questionnaire will be used to augment or illustrate the findings of the quantitative data. These qualitative findings will therefore be included in reports on specific health issues.

Following is a brief report on specific *question* issues raised by women. These issues include

- (1) comments on the clarity of individual questions and
- (2) omissions of specific issues from the questionnaire, or suggestions for changes for future surveys.

4.3 COMMENTS AND SUGGESTIONS ABOUT THE QUESTIONNAIRE

913 women commented on issues relating to the *structure* or other aspects of the questionnaire. 534 of these women commented on issues relating to specific questions, and 205 expressed support for the project or said the questionnaire was comprehensive and easy to complete.

The remainder of the comments (174 women) related to administrative information such as change of address. Two respondents felt that the questionnaire should be in languages other than English. (Provision has been made throughout the study for translators to be available to help NESB women contribute to the study. These translators have interviewed women by phone in 17 different languages). Many women commented on the potential value of the research, and welcomed the opportunity to participate. Some suggested this type of research should also be carried out with men.

In relation to the general *structure* of the questionnaire, a number of women suggested that the questions should be more specific, with fewer ‘grey’ areas. Some had difficulty answering ‘yes’ or ‘no.’ Several women also commented on the time frame associated with specific questions, especially in relation to the SF 36 (questions 1- 11) and the life events questions.

“It was a bit hard to answer some of the questions as you only wanted history over the last 12 months. But actually a lot of my problems started when my dad died nearly three years ago, and a nephew was killed.”

“Seemed to me that going back only 12 months didn’t capture the present impact on my life of events which happened in the previous 18 months, ie. major operation, mother dying and being retrenched in a few months period.”

4.3.1 *What have we missed? Suggestions for inclusion in future surveys (middle cohort only)*

The aim of the baseline survey was to collect information about a range of health issues, as defined by the major themes of the project. It was not possible to include every aspect of health in the survey. Several women recognised ‘gaps’ in the survey and took the opportunity to suggest areas which they perceive to be important in terms of their own health. These are listed below for consideration for inclusion in future surveys or sub-studies.

In general the comments received in relation to specific question issues (n = 534) were most informative and will provide us with direction for the development of future questionnaires. Most responses to specific question issues were raised in relation to the following areas of the questionnaire.

Question numbers	No. of women who commented.
------------------	-----------------------------

Individual Health Problems:	1, 2, 6, 7, 8, 10, 15, 16, 18, 19, 34, 38 - 45	171
Emotional and Mental Health:	5, 6, 9, 10, 37, 77, 83 - 86	141
Health Services:	12 - 15, 17, 34(b)	122
Time Use:	66 - 75	121
Reproductive Health:	20 - 33	80

Section One: “Women’s health is about how you are feeling”

Questions 1 - 11 relate to the SF-36 scale of physical and mental well-being. Several women commented that they found it difficult to distinguish between ‘physical’ and ‘emotional’ health in these questions.

“I was confused by the first few questions on health.”

“There was some confusion - my health limits me. When I have a migraine I am unable to function normally but it is not on a daily basis.”

Section Two: “Women’s health is about using health services”

The beginning of this section focussed on health care utilisation and satisfaction with GP services. Some women commented that the questions on GP satisfaction may not have related to their *usual* GP.

“. . . my response would have been very different owing to the fact that I saw a different GP.”

Others said that they would like to be asked more about specialists (doctors attitudes/negligence, fear of doctors, assertiveness in coping with doctors), allied health professionals (including dental and other ancillary services), and alternative health services (eg natural therapies, homoeopathy, acupuncture, herbalists, naturopaths, massage, acupuncture). Others would have liked us to include questions about satisfaction with hospitals (shortened stay, early discharge, high cost) and women’s health centres. Isolation and availability of services was repeatedly raised by rural women, and several women commented on the importance of nurses in maintaining services in rural areas.

In relation to health history, many women asked for more questions or some questions on their specific individual health problems. The following were explicitly mentioned: osteoarthritis; arthritis; back pain; eyesight; migraine; sporting injuries and accidents. Several women commented that they would like to see more questions about cancer, specifically about treatment, follow up, specialist care, about *fear* of breast cancer, and about the importance of family history.

In the section on contraception, hormone replacement and screening, there were suggestions for more questions on contraception (eg the reasons *why* a particular method was chosen) and on sexuality. Many women expressed surprise that there were no questions in the survey on this issue. Suggestions for inclusions in this area

in future surveys included: sexuality, libido, sexual health, venereal disease, HIV/AIDS prevention, pelvic inflammatory disease, infertility (assistance available and cost), sexual orientation/habits.

In relation to menopause, many women wanted to say more about more about HRT and menopausal symptoms.

“These symptoms can go on for several years prior to the cessation of menstruation. A yes/no answer is not entirely appropriate . . . for those people in this stage of their life.”

Also relating to this section were comments about births and miscarriages.

“You asked how many pregnancies and miscarriages, but no questions about how many surviving children.- eg we lost a son aged one through terminal illness.”

One woman suggested that finding out how many women hold first aid certificates would be interesting.

Section Three: “Women’s health is about coping with common problems”

One woman commented that it is not possible to suffer from ‘constant tiredness’ ‘rarely or sometimes’.

Section Four: “Women’s health is about coping with stress”

There were few queries or comments on the stress questions. In relation to the stressors induced by life events, many women commented that they felt the time frame of ‘the last twelve months’ did not give them the opportunity to disclose life events which happened earlier, but which continued to have significant impact on their health.

It is likely that the women were unaware of the study design, whereby women with *recent* life events (eg birth of a baby, widowhood) will be selected for sub-studies to assess the impact of these events. However, the suggestion that life events which may have occurred several years ago may have significant impact on subsequent health is acknowledged, and consideration will be given to how this might be addressed in future surveys.

“It might be useful to ask about major events in the last say, 3 - 4 years”

Several women commented that they would like us to add additional life events to the list (eg needed Lifeline, had psychiatric counselling, had debt problems, had an affair, had a proper holiday) and to explore the health effects of grief, particularly following the loss of a child, or an elderly person after long term illness or suffering.

In the smoking and alcohol section, women questioned why there were not more questions on smoking (eg attempts to quit, strength of cigarettes), cannabis, illegal drugs, and on the impact of living with an alcoholic, or having children who are drug users.

Section Five “Women’s health is about healthy weight and shape”

Several women commented in relation to weight and exercise that they felt they could be healthy (free of illness) but unfit.

"My health is good but I know that my fitness level (in particular in relation to sports) is not what I would like. Does health equate with fitness? My answers to some of the questions may seem inconsistent if this premise is accepted."

Some women found it difficult to answer the weight questions because they did not know their weight.

"Sorry it's taken so long to answer, but I found it very difficult to get on the bathroom scales to see how much overweight I am. I'm definitely depressed now, so next time I'll be the one using all those terrible methods to get down to the models weight."

"I never like to admit to the lack of exercise, eating habits or weight. Who does? Had to go and weigh myself as I sold the scales 2 years ago. I hope the results of this research go a long way towards the improvement of services for women. No scales at home. Will call with weight when I manage to get near a chemist and weigh myself."

This woman was one of several who rang to advise their weight after checking with the local pharmacy.

Some women found questions relating to weight intrusive and of a personal nature and decided not to answer some of the questions.

Section Six “Women’s health is about juggling time”

Many women found it difficult to answer the first question in this section. Because of their multiple roles it was difficult to say which was their *main* status, as many spend approximately equal hours in parenting, part-time work, studying etc. One woman said she did not include the number of hours spent in an (unpaid) family business in her response to question 67 (60 - 90 hours) as she received no pay for this.

In relation to paid work, there were suggestions for questions on unemployment, resumption of work after injury or illness, and getting into and managing debt. There were also suggestions for more focus on women’s and their families’ views on women’s traditional roles, and more exploration of issues of ‘free’ time spent with spouse or grandchildren.

“effect of ageing parents on women’s health could be an issue, particularly as our own children are leaving home, but ageing parents take their place so [there is] no free time with spouse or partner as expected.”

Section Seven “Women’s health. . . . is about family and friends”

While there were no specific difficulties with this section, women suggested we might like to ask more about a range of issues in this area. These suggestions included the health effects of: living with chronic mental illness (someone else’s), living with someone who is terminally ill, living with someone who is disabled (children with autism/intellectual disability), or living with one’s own chronic illness (arthritis, diabetes, asthma).

There were also suggestions for more questions on sole parenting, the effects of children leaving home, the importance of pets, the value of female friendships, and community involvement.

In relation to the final part of this section, some women suggested more questions around issues of emotional health, including self esteem, spirituality, religion, beliefs, and control over one’s life, as well as specific issues such as stuttering and suicide.

Section Eight “Women’s health is about you and your life”

The final question generated more comments than any other (is this because it was at the end?!).

In general women found it difficult to generalise their answers to this question. Many women commented that work/career and study could not be considered as one item

“the dissatisfaction relates only to my lack of education and study, not to my work which I am reasonably satisfied with.”

Some were happy with *some* family relationships but not with others. Others had no close personal relationships, and were happy with that situation.

“I have no partner nor close personal relationship and am very happy with the situation. . . I didn’t think I could circle any of the answers”

Some women suggested the range of responses to this question could be extended,

“I feel that is hard to accurately answer question 100 - not enough range of choice of answers.”

“putting ‘would like to improve’ in the middle of the options would help to give truer answers.”

5. DATA QUALITY

5.1 DATA QUALITY ASSURANCE AND DATA MANAGEMENT

Data entry for the baseline studies was done by Harrison Data Capture. The consent forms were verified on entry which guarantees an accuracy rate of 99%. Even though the survey forms were not verified, an estimated accuracy rate of 95% was achieved.

Further checks on data quality include:

1. There are two checks on the ID during data entry - that the ID is valid according to the check digit and that the two IDs (consent and survey) are the same.
2. There is a tight range and logic check on each field. All new variables that are created during the analyses are also checked for out of range values and outliers. When necessary, the questionnaires are retrieved to check for data entry errors.
3. As correct identification is crucial for the longitudinal follow-up, consent forms are checked manually by staff at WHA. A protocol has been devised to process notification of change of name/address of participants.
4. At the WHA office, programs are in place to:
 - allocate missing IDs to the correct age group.
 - check for non unique IDs.
 - find the correct postcode from the consent database, matching by ID, for records with missing postcodes.
 - correct minor programming errors, detected after the data have been entered.
5. A group of staff meet regularly to discuss data management issues. As a result of these meetings, the following procedures have been established:
 - A master file has been created for each cohort, which contains all the documented SAS data management programs, demographic characteristics, data entry protocols, SAS programs for analyses and the latest frequency tables. This enables other staff members to cross-check their work.
 - The creation and definition of new variables is discussed and consensus reached prior to using these variables in the analyses.
 - A review of both hardware and software requirements is undertaken regularly.
 - The need to purchase additional datasets (and the required format of these) is discussed eg. our requirements from both the 1991 and 1996 Census from ABS.

6. POSTGRADUATE STUDENT PROJECTS - UPDATES

6.1 PSYCHOLOGICAL STRESS PROCESSES IN THE ETIOLOGY OF DISORDERED EATING

PhD candidate: Kylie Ball BA (Psych) (e-mail: whkb@cc.newcastle.edu.au)
Supervisor: A/Professor Christina Lee

My PhD study examines the relationships between psychological stress, coping strategies and disordered eating in a cohort of women aged 18-22 years, drawn from the WHA sample of young women. During the course of this year, the following activities have been undertaken as part of this study:

1. An extensive review of the existing literature in this area. Based on this review and reading, I have written both a review paper, which will soon be submitted for publication to the *International Journal of Eating Disorders*, and a review chapter which will, with future modification, serve as an introductory chapter to my thesis. This review also highlighted a number of problems and inconsistencies in the current research, and a number of contradictory findings regarding the stress-disordered eating relationship which I plan to follow up.
2. An analysis of existing WHA pilot data. Results of these analyses showed no significant relationships between psychological stress and disordered eating in a sample of women aged 18-22 years. These analyses and findings have been written up as a thesis chapter. While this pilot study was very preliminary and exploratory, these findings, which contradict many previous findings in the literature, suggest that further investigation into the relationships between stress and disordered eating in Australian samples of young women, is required. Based on both these pilot findings, and the literature review, I have designed a general overview of the thesis research.
3. After successfully applying for ethics approval, a focus group was conducted in order to explore possible reasons for the lack of significant findings in the analyses of WHA pilot data. The participants were seven young women (aged 18-22). Qualitative data collected during this focus group are currently being analysed, and the results of this analysis will assist in guiding further quantitative research to be conducted during 1997.
4. I attended a NSW Department of Health Ministerial Summit on body image and eating disorders in Sydney on 19th August, during which I was given the opportunity to contribute to developing recommendations to guide future research in this area. These recommendations included the implementation of more interdisciplinary research, including further qualitative research; research into preventative strategies; and the establishment of a foundation with links to the media.
5. I have applied for two scholarships to undertake part of my PhD research at a University in the United Kingdom. If my application is successful, this will entitle me to spend 3 months studying in the UK, during which time I would hope to conduct some comparative research (qualitative and/or quantitative) with a British sample of young women.

In addition, I have worked with Dr Justin Kenardy of the University of Queensland on a paper examining the relationships between unwanted sexual experiences and disordered eating in the WHA young and mid pilot samples. This paper has been submitted for publication to the *Journal of Psychosomatic Research*.

6.2 EXPERIENCES OF WOMEN (AGED 45-49) SEEKING HELP FOR PSYCHOLOGICAL DISTRESS

MSc candidate: Sue Outram BA, RN (email: sueo@wallsend.newcastle.edu.au)
Supervisor: A/Professor Margot Schofield and Professor Lois Bryson

As at 21 November:

Four hundred (400) women aged 45 - 49 who scored equal to or less than 52 on the Mental Health Index of the SF36 and who live in NSW were randomly selected. The women were sent a letter outlining the research and asking them to take part in a telephone interview, of 20 to 30 minutes duration.

The majority of the interviews were carried out by the investigator, assisted by two part time interviewers with extensive interviewing experience. These women were trained in delivering the structured telephone interview and in support and referral for women who may need further assistance.

The required number of interviews was 350. To date 266 interviews have been completed, with another 60 anticipated in the next 2 weeks.

The response from the women contacted has been overwhelmingly positive. As would be expected, some women found the prospect of talking to someone about personal issues uncomfortable. Fifteen (15) women declined to take part, giving a refusal rate of 3.75%. When a reason was given (sometimes a telephone message was left on the answering machine). it was usually that they did not want to talk about their difficulties.

The main difficulties in interviewing the anticipated number of participants were 1) the number who had silent telephone numbers (which had not been written on the main questionnaire (10)), and 2) women who had moved and not left a forwarding address, or had their telephone disconnected (up to 40 women). Five women had moved out of NSW (all to Queensland therefore not lost to the larger study but ineligible for this sub-study). Eleven women indicated they did not speak English well enough to be interviewed and we are considering the feasibility of using interpreters given the sensitive nature of the study, the complexity of the questionnaire to an untrained interviewer and the high per unit cost of interpreters.

Eighty four of these women had written comments on their main questionnaire and relevant comments will be incorporated into this study. Qualitative data from the main study will be coded and entered into Ethnograph 3.0.

The Data collection for Part One of the study will be completed in December. Data will be entered in January and in February. After reviewing the results, a decision

will be made about further indepth interviews - the necessity for these and the themes to be explored.

6.3 IRON DEFICIENCY IN MIDDLE-AGED AUSTRALIAN WOMEN

PhD candidate: Amanda Patterson BSc. MND

(email: c9035844@alinga.newcastle.edu.au)

Supervisor: Dr Wendy Brown (principal supervisor); Professor David Roberts (associate supervisor)

There are four separate arms to the proposed research studies for my PhD. The progress on each is listed below -

GP Survey

- The aim is to survey Hunter GP's regarding knowledge, attitudes and behaviours to iron deficiency and it's treatment.
- A succinct questionnaire has been developed .
- Ethics approval has been obtained.
- On the advice of GP's involved with the Hunter Region General Practice Research and Development Group (HRGPRDG), the distribution of the questionnaires has been postponed until after the intervention study, to maximise the goodwill of Hunter GP's for the recruitment process.

ALSWH Women's Study

- The aim is to use ALSWH baseline data, linked to Medicare data, to identify women with recent iron deficiency in the mid cohort.
- Baseline data from these women will be used to examine the relationship between iron deficiency and SF36 scores, and to look for associations of iron deficiency with proposed causal factors (parity, menstrual blood loss, contraceptive use, alcohol intake and dieting pattern).
- This study is awaiting Medicare consent and linkage.

Women's Survey

- The aim is to survey ALSWH mid cohort women (iron deficient and iron replete) regarding their knowledge, attitudes and behaviours towards iron deficiency, its development and treatment.
- Also awaiting Medicare linkage to identify iron deficient group.

Intervention

- A number of questions will be examined in this study:
 1. What dietary patterns are associated with high/low iron status in Australian women?
 2. Can dietary intervention successfully improve and maintain iron status in iron deficient Australian women?
 3. What is the effect of iron deficiency on general health, fatigue levels and cognitive functioning in Australian women?
- A detailed research protocol has been established.
- Ethics application has been submitted.
- Recruitment has been discussed in meetings with the HRGPRDG.

Additional

- Iron study results from Hampson Pathology have been obtained for June-September 1996. These data are being analysed to examine the relationship between a clinical report of tiredness and a positive result for iron deficiency.
- The study proposal was presented at the Faculty of Medicine's Postgraduate Research Seminars. It was well received and attracted some interest for collaboration.
- Networks have been formed with the Australian Iron Status Advisory Panel, who have provided positive feedback.

Literature Review

- A literature review has been written, which will form a chapter of the final thesis, and is being modified for publication.

Funding

- Unsuccessful grant applications were submitted to Rotary and ARC for the GP and Women's Surveys. These studies, however, will not be expensive.
- The intervention study will require significant funds, and a grant application is currently being reviewed by the Meat Research Corporation. If funding is not received for this study, it may proceed at a pilot level, with limited numbers.

6.4 USE OF AND SATISFACTION WITH HEALTH CARE SERVICES

PhD candidate: Anne Young B Math (Hons1). Dip Med Stat.

(email: stafy@cc.newcastle.edu.au)

Supervisor: Professor Annette Dobson, Dr. Julie Byles

A major component of this research project involves linking the participants' survey data with their Medicare claims data. In order to do this, individual informed written consent must be obtained. As part of this process, I conducted a review of the literature concerning record linkage in epidemiological research, including concerns relating to confidentiality, security and privacy. Following this review, focus groups were conducted with women in the age groups being studied, to discuss their concerns about data matching and to draft an information sheet detailing the process and a consent form. This information sheet and consent form were pilot tested with around 300 women from the mid and old age groups. The forms have now been revised, and are being sent to a group of young women for further testing.

Around 600 women from Pilot 1 have consented to give access to their Medicare data and the Health Insurance Commission has sent a file containing claims for services received under Medicare for these women for the period 1994-1995. Programs to analyse and describe the patterns of health service utilisation in these claims are being developed. An ethics application was submitted to the Department of Veterans' Affairs to obtain information about medical services funded by Veterans' Affairs to women in the study. Many research issues of relevance to this project were discussed at the First Australian Conference on Record Linkage and Health Research, which I attended in Perth in October and several areas of potential collaborative research were identified. Many of the current record linkage projects in Australia lack detailed health survey data. A major strength of this part of the WHA project, is the ability to link Medicare data with self-reported survey data to answer research questions such as: *Are the women who have one main provider more satisfied with the care they receive and do they have better health outcomes? What are the characteristics of the frequent attenders and what symptoms and conditions do they report?* This research will compliment the work being done by the General Practice Branch which looks at the use of health services from the perspective of the provider. The WHA project will add information from the perspective of the consumer.

The utilisation of health services, as reported in the surveys by women in the middle- and older age groups, has been investigated. I presented a summary of these results at the Public Health Association of Australia conference in Perth in October, 1996. Although the self rated health was similar in women from urban, rural and remote areas, there was a considerable difference in use of general practitioner and specialist services. There was also a trend towards lower satisfaction with the cost of the services in the rural and remote areas. A more detailed investigation and modelling of the factors that affect the use of health services is currently being conducted. Following this, research questions which require further sub-studies will be identified.

6.5 THE USE AND EFFECTIVENESS OF LEGAL PROTECTION AS A SECONDARY PREVENTION STRATEGY TO REDUCE

FREQUENCY AND SEVERITY OF REPEAT DOMESTIC VIOLENCE IN WOMEN'S LIVES

PhD candidate: Margrette Young BA(Hons 1 Psych), M.Sc (Neuroscience)
(email: hmjy@cc.newcastle.edu.au)
Supervisor: Professor Annette Dobson, Dr. Julie Byles

Background

The goal of the research is to inform policy and practice on secondary prevention in relation to domestic violence, specifically the impact of legal protection on domestic violence and its relation to change in repeat domestic violence frequency and severity and associated health outcomes.

Specific legislation as a means of protecting women from domestic violence, and as a deterrent to offenders, has been introduced in Australia and overseas.

The results of a randomised controlled trial in USA, showing a significant reduction in repeat domestic violence following arrest, had a major effect on policy and practice both inside and outside USA. The results, however, have not been replicated in later studies.

The applicability of the USA results to Australian conditions is questionable in any case. While arrest and protection orders are two legal options available both in Australia and USA, the conditions and emphases are different in the two countries. For example, Australian conditions do not include mandatory arrest. Nor do they provide the integrated legal and counselling package (whereby the criminal court directs the perpetrator to attend an abuser counselling program) which is part of the USA model.

In Australia, protection orders are equally as likely to be used in cases of domestic violence as arrest is, and orders are increasingly sought and granted, possibly in response to their promotion as an appropriate legal and social tool by legal, health and social policy-makers and commentators.

Despite this, there is apparently no empirical data in Australia upon which current policy and practice can be based, on either the effectiveness of arrest or protection orders on reducing repeated domestic violence.

The current study will address the question of the effectiveness of legal protection in reducing frequency and severity of repeat domestic violence.

Study design.

The study will be a longitudinal study looking at legal protection and other factors associated with reduction of repeat domestic violence in women's lives. The sampling frame is women from the WHA national cohort of young women 18-22 years who reported in the WHA baseline survey that they are or have been in a violent relationship with a partner or spouse.

There are three components to the study: cross-sectional nested baseline survey; longitudinal survey 12 months later; reference back to the WHA survey.

This study will provide cross-sectional descriptive data on domestic violence characteristics, legal protection and associated social and health factors, and longitudinal data on changes in domestic violence comparing three groups - women with legal protection, women without legal protection but with other external help and women with no external help. It will also provide longitudinal data on changes over time in health and health care usage.

It is hypothesised that women with legal protection will experience a reduction in domestic violence (frequency and severity) compared to women with no protection. The study will also look at whether DV escalates in frequency and severity over time in women without (external) protection, and underlying policy for the management of domestic violence.

7. RESEARCH ACTIVITIES

7.1 COLLABORATIONS WITH OTHER RESEARCH CENTRES

The Director of the Alma Unit on Ageing at the University of Melbourne, Susan Feldman, will join with the Women's Health Australia team to find out more about women's experience of widowhood. Some women in the study will be sent a questionnaire to provide us with more specific information about how their lives have changed, and Susan will interview some women allowing these women to tell their own stories.

During October - December 1996, we have been working with Professor Dave Roberts, Head of the discipline of Nutrition and Dietetics, at the University of Newcastle to evaluate the Australian Nutritional Screening Initiative (ANSI), using data from the older cohort. We have also established collaborative links with Associate Professor Adrian Bauman of the University of NSW, Department of Community Health. A/Prof Bauman is assisting with evaluation of the exercise questions in the baseline study.

7.2 VISITS TO OTHER RESEARCH CENTRES

ASSOCIATE PROFESSOR CHRISTINA LEE visited and gave seminars on Women's Health Australia to:

Department of Psychology, Massey University;
Department of Psychology, Tamaki Campus, Auckland University;
Department of Psychiatry and Behavioural Science, Auckland University;
Department of Community Health, Auckland University.

MARGARETTE YOUNG visited the Bureau of Crime Statistics and Research.

7.3 PRESENTATIONS

7.3.1 Papers presented

Women's Health Australia

BROWN WJ, DOBSON AJ & MISHRA G. The changing weight of Australian women. *28th Annual Conference of the Public Health Association of Australia Inc. Perth, Western Australia. 29 September - 2 October, 1996.*

BYLES JE, SCHOFIELD M, BROWN WJ & Tiller K. Variation in gynaecological procedure rates. *28th Annual Conference of the Public Health Association of Australia Inc. Perth, Western Australia. 29 September - 2 October, 1996.*

DOBSON A, MISHRA G, BROWN, W & REYNOLDS, R. Food habits of young and middle-aged women outside the capital cities of Australia. Poster presentation at *Sydney International Congress, Sydney. July 8 - 12, 1996.*

SCHOFIELD, M, BYLES J, DOBSON A, BRYSON L, MANDERSON L & WILLIAMS G. Women's Health Australia: Progress on the Australian Longitudinal Study on Women's Health 1995-96. Poster presented at the XXVI International Congress of Psychology, Montreal, Canada, August 1996.

SCHOFIELD MJ. The Australian Longitudinal Study on Women's Health: Establishment of the main cohorts of women. Research seminar presented to the Faculty of Education, Health and Professional Studies, University of New England, November 1996.

YOUNG A, BYLES J & DOBSON A. The tyranny of distance: Health care utilisation by women living in rural and remote Australia. *28th Annual Conference of the Public Health Association of Australia Inc. Perth, Western Australia. 29 September - 2 October, 1996.*

Associated Projects

Slaven L & LEE C. Aerobic exercise and hormone replacement therapy: Effects on mood and menopausal symptoms in middle-aged women. *European Health Psychology Conference, Dublin, September 1996.*

7.4 PUBLICATIONS

7.4.1 *Papers published*

Women's Health Australia

BROWN WJ, BRYSON L, BYLES JE, DOBSON AJ, MANDERSON L, SCHOFIELD M & WILLIAMS G. Women's Health Australia: Establishment of The Australian Longitudinal Study on Women's Health. *Journal of Women's Health*. 1996. 5 (5):467-472. (For abstract, see Appendix 4).

Associated Projects

BYLES JE & Sanson-Fisher RW. Mass mail campaigns to promote screening for cervical cancer: Do they work and do they continue to work? *Australian and New Zealand Journal of Public Health*. 1996. 20(3):254-260.

BYLES JE, Harris M, Nair K & Butler J. Preventive health programs for older Australians. *Australian Journal of Health Promotion*. 1996. 6(2):37-43.

Davies T & LEE C. Sexual assault: Myths and stereotypes among Australian adolescents. *Sex Roles*. 1996.34:787-803.

France K, LEE C & SCHOFIELD, M. Hormone replacement therapy: Knowledge, attitudes and well-being among mid-aged Australian women. *International Journal of Behavioral Medicine*. 3:202-220.

Nagle A, SCHOFIELD MJ & Redman S. Smoking in hospital grounds and the impact of outdoor smokefree zones. *Tobacco Control*, 1996, 5, 1-6.

Pit SW, Schurink J, Nair BR, BYLES JE & Heller RF. Use of the Short-Form-36 Health Survey to assess quality of life among Australian elderly. *Australian Journal on Ageing*. 1996. 15(3):132-135.

SCHOFIELD MJ & Sanson-Fisher RW. How to prepare patients for potentially threatening medical procedures: consensus guidelines. *Journal of Cancer Education*, 1996, 11, 1-6.

7.4.2 *Papers accepted for publication*

Women's Health Australia

BRYSON L. A comment on 'Bureaucracy to Adhocracy' by Cahill, Birch and Goodier. *Australian Health Review*. 1996. 19(4).

Associated Projects

BROWN WJ & BYLES JE. A collaborative approach to screening for cancer of the cervix.. *Journal of Medical Screening*.

BYLES JE, Hanrahan P & SCHOFIELD MJ. "It would be good to know you're not alone": The health care needs of women with menstrual symptoms. *Family Practice*.

BYLES JE, Sanson-Fisher RW & Redman S. Promoting screening for cervical cancer: Realising the potential for recruitment by general practitioners. *Health Promotion International*.

France K, LEE CL & SCHOFIELD MJ. Hormone replacement therapy: Knowledge, attitudes and well-being among mid-aged Australian women. *International Journal of Behavioral Medicine*, in press.

France K, SCHOFIELD MJ & LEE CL. Patterns of hormone replacement therapy use among mid-aged Australian women. *Women's Health: Research on Gender, Behaviour, and Policy*.

Harris M, BYLES J & Higginbotham N. Preventive health programs for the elderly: A critical review of their effectiveness. *Australian Journal of Ageing*.

LEE C & BROWN WJ. Changing exercise and diet. In: *Medical Consultation Skills: A Practical Handbook*. Sanders M, Mitchell C & Byrne G (editors).

LEE C & White SW. Controlled trial of a minimal-intervention exercise programme for middle-aged working women. *Psychology and Health*.

SCHOFIELD MJ, WALKOM S & Sanson-Fisher R. Patient-provider agreement on guidelines for preparation for breast cancer treatment. *Behavioral Medicine*, in press.

Slaven L & LEE C. Mood and symptom reporting among middle-aged Australian women: The relationships between menopausal status, hormone replacement therapy and exercise participation. *Health Psychology*.

7.4.3 Papers submitted for publication

Women's Health Australia

KENARDY J & BALL K. Disordered eating, weight dissatisfaction and dieting in relation to unwanted childhood sexual experiences in a community sample. *Journal of Psychosomatic Research*.

Associated Projects

Bastian G, Connors H, Danko A, Duffy T, Leung N, Payne M, Rathborne R, Vallender L, Wood R & SCHOFIELD M. Cervical cancer screening among Australian women aged 50-70 years: knowledge, attitudes, and practices. *Health Promotion Journal of Australia*.

BROWN WJ & LEE C. Heart health for migrant women: an intervention with Macedonian Australian Women. *Health Promotion Journal of Australia*.

BROWN WJ & BROWN PR. Children, Physical Activity And Better Health. *ACHPER Healthy Lifestyles Journal*.

BYLES JE, SCHOFIELD M & Hanrahan P. Yes the tablets help, but its more important for someone to listen: the special needs of women with menstrual symptoms. *Family Practice*.

Girgis A, Sanson-Fisher RW & SCHOFIELD MJ. Breaking bad news: is there consensus between breast cancer patients and providers on guidelines? Under review

LEE C & BROWN WJ. Australian Migrant Women and physical activity: attitudes, preferences and participation. *Journal of Health Psychology*.

Perkins J, Sanson-Fisher RW, BYLES J & Tiller K. An examination of the predictors of cervical screening rates in Australia. *Preventative Medicine*.

Tiller K, BYLES J & SCHOFIELD MJ. Regional hysterectomy rates: socio-demographic and health care correlates. *Social Science and Medicine*.

7.5 CONFERENCES ATTENDED

ANNE YOUNG

July 1996: The Sydney International Statistical Congress 1996 Workshop on Survey Design and Analysis. Sydney.

September 1996: The Australasian Epidemiological Association Annual Scientific Meeting. Perth.

October 1996: The First Australian Conference on Record Linkage and Health Research. Perth.

GITA MISHRA

July 1996: The Sydney International Statistical Congress. Sydney.

August 1996: Integrating Health Outcomes Measurement in Routine Health Care Conference. Canberra.

CHRISTINA LEE

February 1996: Third New Zealand Health Psychology Conference, Okoroire.

March 1996: Fourth International Congress of Behavioural Medicine, Washington DC.

September 1996: Tenth Annual Conference of the European Health Psychology Society, Dublin.

WENDY BROWN

July 1996: NHF Cardiac Rehabilitation Workshop. Sydney (invited chair).

August 1996: Ministerial Summit on Eating Disorders Sydney maritime Museum.

September 96: "Bringing Education and Health Together" Health Promotion and Schools Conference - Newcastle - invited address: "Physical Activity and Children".

September 1996: National Conference of the Australian and New Zealand Public Health Association. Perth.

November 1996: International Menopause Conference. Sydney.

7.6 WORKSHOPS PRESENTED

ADAMSON L & PATTERSON A. Women's Health Australia. *Probus, Nelson Bay. 14 August, 1996.*

BALL J. Women's Health Australia. *NSW Health Department, Women's Health Coordinators. 15 November, 1996.*

BROWN W. Women's Health Australia. *John Hunter Hospital Grand Rounds. 8 August, 1996.*

BROWN W. Women's Health Australia. *Hunter Centre for Health Advancement Staff Development Day. 21 October, 1996.*

BROWN W. Update on Women's Health. *Hunter Medical Post-graduate Institute, Professional Development. 16th November, 1996.*

BYLES J. Putting yourself forward: a workshop for women presenters. *28th Annual Conference of the Public Health Association of Australia Inc. Perth, Western Australia. 29 September - 2 October, 1996.*

BYLES J. Reaching women: meeting the challenge. *Recruitment workshop for the National Breast and Cervical Screening Program. Adelaide, South Australia. 14-15 November, 1996.*

MISHRA G. Conducting a large trans-disciplinary health study. *University of Auckland, NZ. 1 August, 1996.*

MISHRA G. Canonical Variate Analysis of Generally Balanced Design. *Department of Statistics, University of Newcastle. 13 June, 1996.*

SCHOFIELD MJ. Invited participant in the Global Futures Forum: Capturing the Voice of a New Spirituality. *Asia-Pacific Event: University of Sydney, October 1996.*

SCHOFIELD MJ. NSW representative at the Australian Women's Health Network meeting in Melbourne, October, 1996.

7.7 ADDITIONAL RESEARCH GRANTS

BROWN W & DOBSON A Co-consultants with Lori Rubenstein and Jan Sansoni. Development of outcomes and indicators for women's health.

BROWN W. University of Newcastle, Research Management Committee Travel Grant. To attend Public Health Association (PHA) Annual Conference Perth, October 1996. Total funding: \$1,112.

BYLES J. University of Newcastle, Research Management Committee Travel Grant. To attend PHA Annual Conference Perth, October 1996. Total funding: \$1079.

GOODGER B. Social support of older persons. PHRDC scholarship.

Roberts D. Validation of the ANSI screening test for nutrition in the elderly. ABBOTT Australia: \$5000.

Stephens C (chief investigator) & LEE C (consultant). Hormone replacement therapy in New Zealand: Knowledge, attitudes and decision-making among middle-aged women. Massey University.

WICKS D. Aspirations and health in young women. RMC grant. University of Newcastle.

YOUNG M. Domestic violence. PHRDC scholarship.

7.8 COMMITTEES

ANNETTE DOBSON & WENDY BROWN

Department of Health & Family Services - Committee for the development of outcomes and indicators for women's health.

WENDY BROWN

NSW Health Steering Committee for the Evaluation of the National Women's Health Program.

National Heart Foundation - National Advisory Committee on physical activity.

JULIE BYLES

National Cervical Screening Program - Chair of Recruitment Working Party.

7.9 WOMEN'S HEALTH AUSTRALIA MONTHLY SEMINAR SERIES

- 30 JULY Dr John Lynch, University of California - Berkeley
Why do poor people behave poorly - variations in adult health behaviours by psycho-social characteristics by stage of the socio-economic lifecourse
- 27 AUGUST Dr Deidre Wicks, Department of Sociology
The Social Construction of Health
Ms Niki Sorocco, Department of Sociology
A Sociological Approach to Bulimia
- 11 SEPTEMBER Associate Professor Adrian Bauman, University of NSW
Physical Activity & Health
Dr Wendy Brown
The changing weight of Australian women
- 24 SEPTEMBER Julie Byles, Clinical Centre for Epidemiology & Biostatistics
Variation in gynaecological procedures
Ms Anne Young, Women's Health Australia
The tyranny of distance: Health care utilisation by women living in rural and remote Australia
- 25 OCTOBER Dr Ruth Bonita, Associate Professor & Masonic Senior Research Fellow, Department of Geriatric Medicine, University of Auckland
Women's Health & Ageing: Medicalisation of the Menopause
- 6 NOVEMBER Professor Sonya McKinlay, New England Research Institute, Boston
Massachusetts Women's Health Study

7.10 VISITORS

The Women's Health Australia researchers have welcomed the following visitors during the last five months of 1996:

Kamira Barron, Sociology student from UCLA. August.

Ms Susan Feldman, Project Director, Key Centre for Women's Health in Society, University of Melbourne. 19 November.

Professor Lorraine Dennerstein, Director, Key Centre for Women's Health in Society, University of Melbourne. 28 - 29 November.

Dr Stevi Jackson, Senior Lecturer and Co-ordinator of Postgraduate Women's Studies at the University of Strathclyde, Glasgow. Interests - feminism theory, sexuality and women's family lives. November 18.

Dr Sue Scott, Head of Sociology and Social Policy, University of Stirling, Scotland. Presented joint seminar with Dr Stevi Jackson - Rationality, irrationality and sexuality: gut reactions to matters of the heart. November 18.

Professor Sonya McKinlay, Massachusetts Women's Health Study, New England Research Institute, Boston. 6 November, 1996.

Associate Professor Adrian Bauman, University of NSW. 11 September.

Professor Jonathon Lomas, Professor of Health Policy Analysis, Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario, Canada. October.

Dr Ruth Bonita, Associate Professor and Senior Research Fellow in the Department of Geriatrics, University of Auckland. Delivered 1996 RM Gibson Oration. Positive Ageing: possibility or pipedream? 24 October.

Dr John Lynch, Human Population Laboratory, California Public Health Foundation, Berkely, California, USA. July.

Ms Susan Feldman, Project Director, Key Centre for Women's Health in Society, University of Melbourne. 25 June.

8. PLANS FOR THE NEXT SIX MONTHS

The next step in this study is to maintain the cohort for the first follow up survey in 1998. During 1997, each participant will be sent a newsletter which will provide feedback about the results of the baseline survey, and some women will be selected to participate in specific sub-studies, which will explore some of the issues raised in the baseline survey in more depth. In addition to the PhD studies described in this report, a specific sub-study planned for 1997 will explore the health of women who are carers. Other sub-studies are likely to be in the area of social support, the health of lesbian women, weight and exercise, aspirations of young women, use of contraceptives, women and heart disease, and healthy ageing. Separate funding has been sought by Susan Feldman to allow collaboration in a study of women who have been recently widowed. This sub-study will be coordinated from the University of Melbourne.

The baseline data books for the main cohorts will be launched by the Minister for Health and Family Services at Parliament House on 3 December 1996. Following the launch, several papers detailing the methodology and main findings of the baseline survey will be prepared and submitted for publication.

9. REFERENCES

- Australian Bureau of Statistics. *1991 Census customised matrices*. ABS; 1991: Catalogue No 2714.0.
- Avis NE, McKinlay SM. A longitudinal analysis of women's attitudes toward the menopause: results from the Massachusetts Women's Health Study. *Maturitas* 1991; 13: 65-70.
- Avis NE, McKinlay SM. The Massachusetts Women's Health Study: An epidemiologic investigation of the Menopause. *Journal of the American Medical Women's Association* 1995; 50: 45-49.
- Barton J, Bain C, Hennekens CH et al. Characteristics of respondents and non-respondents to a mailed questionnaire. *American Journal of Public Health* 1980; 70: 823-825.
- Colditz GA. The Nurses' Health Study: A cohort of US women followed since 1976. *Journal of the American Medical Women's Association* 1995; 50: 40-44, 63.
- Dillman DA. *Mail and telephone surveys: The Total Design Method*. New York, Wiley. 1978; 1-325.
- Etzel MJ, Walker BJ. Effects of alternative follow-up procedures on mail survey response rates. *Journal of Applied Psychology* 1974; 59: 219-221.
- Graetz B. The potential of mail surveys. *Australian New Zealand Journal of Sociology* 1985; 21: 445-455.

- Greenblatt-Ives D, Kuller LW, Schulz R, Traven ND, Lave JR. Comparison of recruitment strategies and associated disease prevalence for health promotion in rural elderly. *Preventive Medicine* 1992; 21: 582-591.
- Kaldenberg DO, Koenig HF, Becker BW. Mail survey response rate patterns in a population of the elderly. *Public Opinion Quarterly* 1994; 58: 68-76.
- Koenig HG, Westlund RE, George LK, Hughes DC, Blazer DG, Hybels C. Abbreviating the Duke Social Support Index for use in chronically ill elderly individuals. *Psychosomatics* 1993; 34: 61-69.
- Landy FI, Bates F. The noneffect of three variables on mail survey response rate. *Journal of Applied Psychology* 1973; 58: 147-148.
- Levenkron JC, Farquhar JW. Recruitment using mass media strategies. *Circulation* 1982; 66: 32-36.
- Lipski PS. Australian Nutrition Screening Initiative. *Australian Journal of Aging* 1996; 15: 14-16.
- Mackenbach JP, Van de Mheen H, Stronks K. A prospective cohort study investigating the explanation of socio-economic inequalities in health in the Netherlands. *Social Science and Medicine* 1994; 38: 299-308.
- Neale AV, Hwalek MA, Scott RO, Sengstock MC, Stahl C. Validation of the Hwalek - Sengstock Elder Abuse Screening Test. *The Journal of Applied Gerontology* 1991; 10: 406-418.
- Roos LL, Nicol JP, Cageorge SM. Using administrative data for longitudinal research: Comparisons with primary data collection. *Journal of Chronic Diseases* 1987; 40: 41-49.
- Sandler RS, Holland KL. Fate of incorrectly addressed mailed questionnaires. *Journal of Clinical Epidemiology* 1990; 43: 45-47.
- Sosdian CP, Sharp LM. Nonresponse in mail surveys: Access failure or respondent resistance. *Public Opinion Quarterly* 1980 ??
- Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 1992; 30: 473-483.
- Yammarino FJ, Skinner SJ, Childers TL. Understanding mail survey response behaviour. *Public Opinion Quarterly* 1991; 55: 613-639.

PART B: NATIONAL ADVISORY COMMITTEE

1.1 MINUTES

Minutes of the second meeting of the National Advisory Committee for the Australian Longitudinal Study on Women's Health

Monday 17 June, 1996, 10.15 am - 3.30 pm
The Chancellery, University of Newcastle

Present: Sally Redman (Acting Chair), Dorothy Broom, Fidelma Doran, Lorna Fejo, Gwen Seru, Gloria Sutherland, Jeanette Ward, Renata Watkinson, Agnes Whiten, Wendy Brown, Julie Byles, Lois Bryson, Annette Dobson, Margot Schofield, Margaret Kelaher, Lenore Manderson, Gail Williams.

Apologies: Rhonda Galbally

In attendance: Phoebe Bissett

1. Welcome
Sally Redman introduced herself as acting chair and welcomed everyone to the second meeting of the National Advisory Committee (NAC) of the Australian Longitudinal Study on Women's Health.
2. Apologies
Rhonda Galbally (Chair) has sent her apologies.
3. Minutes of last meeting and matters arising
The a/chair asked if anyone would like to make any changes to the minutes of the last meeting. Julie Byles moved to accept the minutes as a true record of the last meeting.
4. Progress at the University of Newcastle
Staff/student appointments
Annette Dobson reported new staff appointments were project manager, Dr Wendy Brown and statistician, Dr Gita Mishra. Several research students and four PhD students are now working on the project. Research interests of students are shown on page 28 of the report.

Pilot studies 4 and 5

Julie Byles reported the findings of pilot studies 4 and 5. Different mailing strategies were used to compare the use of express post versus normal post. No significant difference was found between mailing strategies, so normal post is being used in the baseline study. Different strategies were used to test impact on response rates of the length of the questionnaire. There was no significant difference in sending a short (4 page) or longer (28 page) questionnaire, so a longer questionnaire is being used in the baseline study.

Response rates for Pilots 4 and 5 are shown on page 11 of Report 4.

A life events survey was sent to 210 participants from the pilot studies. The response rates to this follow-up survey were very high (100% in the older cohort). These are shown on page 12 of Report 4.

Focus groups with the younger age group showed that young women are concerned about stress. Several questions about stress have not been incorporated into the baseline surveys.

JW questioned the response rate. AD said that a literature review carried out revealed that the response rates in the pilot studies aren't all that low. Most previous studies have response rates less than 34%. FD asked if there is a minimum response rate for the main study. AD explained that it is important that the sample is representative. MS said that maintaining the cohort will be important. The harder we work to recruit women, the more likely that we will lose them at a later date.

Media coverage for the baseline surveys

WB said that UN has raised awareness of the study within the community by a number of media strategies. Faxes were sent to media outlets the night before posting each first survey. Several radio, television and newspaper interviews were held (see page 14 & Appendix M of Report 4). The women's magazines said that they will be interested in publishing reports of the project when the data are available, and they can focus on specific issues for women in the different age groups.

It was agreed that it will be important to inform the participants of the results of the study to maintain their interest.

Main baseline surveys

The methodology for the baseline surveys is reported on page 17 of Report 4. AD said that the goal is to achieve 12,000 - 15,000 women in each age group. The original plan of 20,000 in each age group had to be changed due to the cost of the extensive reminder strategy used to recruit participants. Response rates as of Thursday 13 June were reported and are -

	Middle-aged	Older
Urban	4,624 (41.3%)	1,728 (10.3%)
Rural	7,462 (49.4%)	2,010 (9.5%)
Remote	903 (53.8%)	45 (3.8%)
Total	12,989 (46.4%)	3,783 (9.7%)

AD reported that the 1800 telephone number is constantly busy, with thousands of women ringing to withdraw or enquire about the study (see page 26 of Report 4). Analysis of the data from the 1800 number will be included in the next report.

5. Progress at the University of Queensland
Appointments and staffing

Recent staff appointments are statistician, Zakia Hossain; research assistant, Jenny Phillips and ATSI project officer, Joyce Mitchell. There are 4 PhD students working on the project.

Publicity

Some publicity has been conducted from UQ. A flyer for indigenous women and a brochure for Filipinas have been produced. Some radio interviews have been conducted but media links have been discouraged until links with the community have been established.

Consultation and preliminary work with indigenous Australians

GW reported that the special projects aim to provide a longitudinal broad-based view of women's health for groups of women whose health issues aren't addressed in the national survey. A complex negotiation process is currently under way to establish links with Aboriginal and Torres Strait Islander communities. Also a review of existing data collections is being conducted.

Discussions with community groups have been held in Toowoomba and the Gold Coast. Reports from these workshops are on page 61 of Report 4.

GW said that it is important to gain acceptance from peak bodies and to keep them informed (eg with a newsletter). UQ aim to utilise existing information from previous research because many communities feel over researched and if the information is available they will use it instead of contacting the communities.

The proposed methodology is to conduct a series of community based projects and use a cohort of communities rather than individuals.

GS suggested that it is very important to provide feedback to the communities and create a partnership with them so that they have a sense of control and ownership of the research. Communities are different in their holistic approach to health and this will have to be considered. Many women in Aboriginal communities are afraid to be examined by a doctor. Many women want to give birth on their own land, but there are no facilities to do this.

LS said that women in the "Top End" are "sick of being researched" and it is important that feedback is given to the community if people are to allow research to continue.

Community consultation and preliminary research with immigrant Australians

MK reported that Filipina consultations have been carried out in Brisbane and the Gold Coast area. Results of these workshops are shown on 51 of Report 4. UQ are currently analysing preliminary results of the pilot questionnaire (shown on page 57 of Report 4) tested on women attending the workshops. Alternative strategies for recruitment will have to be developed, especially for contacting young women.

FD asked why the question on domestic violence was removed from the Filipina survey. LM said it was not identified as a major issue in the consultation process, although mental health was raised as a major concern. AD said in the UN survey, several screening questions were used for sensitive issues. Information relating to violence will be obtained but it may take time to get the participants to give details.

AW said that the only way to succeed with this kind of research is to have good community links.

6. Development of sub-studies and collaboration with other groups

LB asked the Committee for ideas about which areas should be given priority for sub-studies and collaborative work. The group had the following suggestions:

- NESB women in other states and also older populations
- Arab and Muslim women
- Specific Aboriginal groups (eg in Central Australia)
- Measures of women's health status and 'outcomes' (Liz Eckerman)
- International collaboration
- Key Centre - widowhood
- Stress/suicide in younger women
- Gender comparisons: tiredness, body image, ageing, morbidity, income and access to medical services
- Database of studies (similar questions, methodology etc)
- Access to health services (rural/remote and state differences)
- Relationships and social support (including Balkan population)

JW suggested that a document should be developed to clarify procedures for collaboration with other groups.

7. Update on Department of Health & Family Services

FD reported that there are three major vehicles for changes to funding and administration of Commonwealth programs. These are: The Commonwealth Budget; the Commission of Audit processes and the COAG process. The Commonwealth has a signed contract with the University and would be unlikely to withdraw from it.

These changes and the foreshadowed cuts to programs administered by the Commonwealth will have an impact on the way Commonwealth programs will be administered for the future. With the development of a public health partnership and public health agreements between the Commonwealth and the States, it is expected that the Commonwealth will become more involved in public health generally at a national level and in developing and monitoring outcomes, rather than concentrating on inputs as at present. This will see a move away from program administration by the Commonwealth and a greater focus on measuring progress towards agreed targets.

The Coalition policy on Women's Health notes that women have specific needs and the Commonwealth will continue to play a role in this area within the context of the public health agreements.

Beyond 1998 (when the current contract finishes) FD said she is hopeful that the Department will nurture the study. LM suggested that this time next year we write a report to justify continued funding and support for the project. WB suggested we invite the Minister to visit the ALSWH project, or the team visit Canberra to present results of the project. FD said that these suggestions would be best implemented when results from the study are available.

WB said that UN had sent a letter to the new women MP's to inform them about the study. FD suggested that update letters be sent when interesting findings can be reported.

8. General funding issues

WB asked the Committee whether it would be appropriate to have corporate sponsorship. WB met with the PVC (External Relations) and a corporate sponsorship consultant from ADSHAN, who suggested that we make links with a large corporation to produce a newsletter and then approach them later for subsequent funding, eg for staffing, students etc. The consultant suggested approaching banks, mortgage brokers and insurance companies. We would not approach drug or health insurance companies for ethical reasons.

JW suggested that we should not consider this option unless it achieves a lot of financial support. RW said that corporate sponsorship is a sign of the times, and women would most probably not be offended by it. A small statement at the bottom of a newsletter should not affect responses.

The Committee thought it would be more appropriate if a group of sponsors was obtained, instead of just one single sponsor. They could be acknowledged in a list on the newsletters etc. GS suggested that a focus group be run to ask women how they would feel about corporate sponsorship. No objections were raised about the companies that UN are planning to approach. Other suggestions are the Body Shop, SBS, Angus & Robertson. The group agreed that seeking sponsorship does not weaken the study.

It was suggested that in NSW, Women's Health Managers may be able to assist in obtaining State support for the study. Also groups such as View clubs and the CWA may be able to assist at a local level. FD suggested applying to States under National Women's Health Program as they may have unspent funds.

9. Any other business

Health Policy

AD asked FD how she foresaw the study changing health policy. FD said that for example, if the study shows that women from NESB have particular trouble accessing services, the Commonwealth could negotiate with the States about ways of changing health services to improve access. At this stage, the Department of Health & Family Services is not sure what the new government's priorities are, and as findings from the study become apparent, they can be put on the agenda for the AHMAC sub-committee, which will help to get the information to the States.

WB asked whether there is a problem with releasing data to State Health Departments. FD said it is fine, as long as the Commonwealth gets all the information as well. SR asked if there are any specific issues that are important to the Commonwealth. FD said that women's interactions with the health system is a very important issue eg are the interactions satisfactory, if not why not. The Commonwealth Department could use the findings to develop, define and validate outcomes and to negotiate with States.

The committee agreed the following should be given preference:

- women's interaction with the health system
- mental health issues (especially for young women)
- health outcomes
- health needs of indigenous Australians
- needs of older women
- linkage of health care data sets
- generational changes
- policy change, access by new migrants to Medicare cover
- carers
- comparisons between the States

Balkan cohort

LM said that this study is a PhD study which will use similar methodology to that of the Filipina cohort. Social networks will be a particular focus of this project. The group is also working with Queensland Health to explore mental health issues in NESB groups. In relation to all special cohort studies the emphasis is on pursuing sound methodology which may then be applied to different communities.

Meeting closed 3.15 pm