women's health australia

The Australian Longitudinal Study on Women's Health

Report 4

The University of Newcastle

&

The University of Queensland

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AUSTRALIAN LONGITUDINAL STUDY ON WOMEN'S HEALTH

JUNE 1996 REPORT

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INTRODUCTION

This is the fourth report on the Australian Longitudinal Study on Women's Health, provided by the University of Newcastle and the University of Queensland, due 10 June 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 content of report four is to include

A For the main cohort studies:

- sampling and recruitment of the main cohort
- project operation and management issues
- plans for the next six months

B For the special cohort studies:

- the establishment of the special cohorts and collection of baseline data from these groups
- the operations of the reference groups
- communications with participants
- 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, including communications with study participants and the wider community and publications of study findings.

This report is presented in four parts:

PART A -	Progress at the University of Newcastle
PART B -	Progress at the University of Queensland

PART A: UNIVERSITY OF NEWCASTLE

EXECUTIVE SUMMARY

The Women's Health Australia research group at the University of Newcastle is responsible for the main (age) cohort studies of the Australian Longitudinal Study of Women's Health. Part A of this report describes the activities and outcomes of the main cohort studies during the period January - June 1996.

1 Pilot studies: During the first three months of 1996, three further pilot studies were completed. These studies, together with those undertaken during 1995, (and reported in the December 1995 report) were used to inform and finalise the development of the questionnaires for the baseline study of the three age cohorts. Details of the content of the baseline questionnaires are included in this report (see appendix L). Five papers relating to these pilot studies are currently in preparation for publication in scientific journals.

2 Publicity: A comprehensive publicity plan was developed to coincide with the launch of the main baseline surveys in April and May 1996. Information about the study was disseminated to women throughout Australia through press releases to all national, metropolitan, regional, suburban, rural and ethnic news publications, and through 28 radio interviews which were broadcast nationally, and regionally in the six states and two territories. Limited publicity was also achieved through television and women's magazines.

3 Baseline surveys: During April 1996, the names of 28,000 women aged 45 - 49 were randomly selected from the Medicare data base, and sent invitations to participate in the study. The sample includes women from urban (40%), rural (54%) and remote (6%) areas, with intentional over-representation of women from non-metropolitan areas. To date 12,500 surveys have been returned and 1900 women have indicated that they do not wish to participate. Reasons for non-participation are included in this report.

During May 1996, 39,000 invitations were sent to women in the older age group (70 -74). This randomly selected sample also includes women from urban (43%), rural (54%) and remote (3%) areas, with over-representation of rural and remote women. Telephone

interviews have been conducted with 50 women who have literacy, eyesight or language difficulties.

4 Research Students: Three PhD and one MSc student have commenced work on sub-studies relating to the main cohorts. Areas of research include psychological stress and disordered eating, seeking help for emotional distress, iron deficiency and use of health care services.

5 Collaborative links and research activities: Links with other research centres in Australia and the USA continue to be developed, with a view to collaborative work on sub-studies in 1997. Details of research activities, including publications, conference presentations, seminars and additional research grants are included in this report.

1. ADMINISTRATIVE ARRANGEMENTS

1.1 PROJECT MANAGEMENT

Since the last report a full-time project manager and statistician, a part-time research fellow and three PhD students have joined the Newcastle research team. This brings the number of staff in the Women's Health Australia (Newcastle) group to ten (project manager, statistician, research fellow (0.4), data manager, secretary, two research assistants and three PhD students. Another PhD student (funded by a PHRDC grant) is expected to join the group before 30 June 1996. One of the research assistants is now acting as the project's media liaison and publicity officer.

The Women's Health Australia office is now fully established with 10 work stations and networked computer systems with access to electronic mail, the university library and the world wide web. To accommodate additional staff, expansion to shared space in the MONICA office has been necessary. Office procedures have been established for the following issues: communication; resource library; purchasing; computers, and task distribution. Procedures for publication of the study results are under review, and new procedures for conference presentation have been developed.

A general meeting of all researchers is held fortnightly to discuss operational issues. The investigators also meet once a month to plan strategic directions, and to discuss financial and human resource management issues.

There is regular communication with the researchers at the University of Queensland, through monthly teleconference meetings and by circulation of minutes of all meetings. Two of the Newcastle researchers travelled to Brisbane for a face-to-face project meeting in March 1996.

1.2 BUDGET

The estimated income and expenditure for 1996 are shown in Table 1.2.1. The funds carried forward from 1995 reflect the fact that the main baseline study was not completed during 1995 as suggested in the original submission, but to the new timetable, as agreed in December, 1995. Because of the high cost of printing, packaging and posting the required number of questionnaires for the baseline study, it is anticipated that these funds will be expended during 1995. In March 1996, the University of Newcastle reimbursed the project for the cost of furniture and computers which was expended during the establishment of the office in 1995.

TABLE 1.2.1

ALSWH - Estimated Budget for 1996 - University of Newcastle

INCOME		EXPENDITURE	
Item:	**$**	**Item:**	**$**
Carried forward (1995)	449110	University of Queensland	1900
Department of Health & Family Services	875000	**Core Salaries (inc on-costs)**	
		Project Manager	622
		Statistician	498
		Data Manager	475
		Research Fellow (0.4)	276
		Secretary	320
		Research Assistants (2.3)	735
		Casual research staff (eg telephone interviewers)	265
		Scholarships	600
		University Overheads (eg library info technology, power, cleaning etc)	1027
University of Newcastle	99131	Furniture and Computers	254
		Office running costs (eg consumables, photocopier, fax, phone, etc)	334
		Pilot projects	129
		PhD projects	160
		Main Survey	
		Printing	1175
		Packing	834
		Post	2000
		Data entry	890
		1800 telephone number	98
		Publicity	
		Publicity for baseline survey	160
		Newsletter	500
		Travel	
		Project/staff establishment & visitors	190
		Uni of Q'land meetings	35
		Advisory Group	157
		Conference travel	65
		Sub-studies	530
TOTAL	**1423241**		**14232**

2. PROJECT STAFF

2.1 WOMEN 'S HEALTH AUSTRALIA TEAM

Investigators

Professor Annette Dobson, BSc, MSc, PhD (Professor, Biostatistics)
Professor Lois Bryson, BA, Dip Soc Stud, Dip Ed, PhD (Professor, Sociology & Anthropology)
Dr Margot Schofield, BA, Dip Sc, M Clin Psych, PhD (Senior Research Fellow, WHA)
Dr Julie Byles, B Med, PhD (Senior Lecturer, Clinical Epidemiology & Biostatistics)
Dr Wendy Brown, BSc (Hons), MSc, PhD (Project Manager & Senior Lecturer, WHA)
Associate 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
Joy Ellem, BA (Hons)	Research 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)
Ms Niki Saroco, BA (University of Newcastle)
Mrs Anne Young, BMath(HonsI), DipMedStat (University of Newcastle)

Associate Investigators

Dr Justin Kenardy, PhD (University of Queensland)
Ms Deborah Lloyd, BA (Hunter Centre for Health Advancement)
Dr Julia Lowe, MBChB, FRCP(UK), M.Med.Sci. (John Hunter Hospital; Univ. of Newcastle)
Dr Rhonda Reynolds, BA (Hons), PhD (University of Western Sydney Macarthur)

3. REPORTS ON PILOT STUDIES

3.1 QUALITATIVE DATA FROM PILOT STUDY 1

Pilot study 1 was sent to 1,000 women in each of the three age groups in the Illawarra and Central West districts of New South Wales. The aim was to pilot questions and format for the baseline study. These surveys provided respondents with an opportunity to comment on any aspect of their health and/or the survey itself. This facilitated the respondents' discussion of issues which are important to them, but which were not necessarily addressed in the structured questionnaire, or not given as much weight as respondents would have wished.

Approximately one third of all respondents wrote comments on their survey forms. Initial analysis of these comments suggests that they contain useful and valuable information about women's perceptions and understanding of the health issues which affect them. They provide insights into women's perceptions of the health care system, and the ways in which they relate health issues to broader social, political and economic factors. For example, two women linked their current health problems to financial difficulties:

> *the only thing with my health which bothers me is that shortage of money causes such stress I can't believe it*

> *I feel my high blood pressure is the result of stress due to financial pressures on the family*

Preliminary investigation suggests that the women's comments fall into five broad categories: health services: including access issues for rural women; personal relationships; a specific personal health issue or stress, and compliments about the survey.

Women who made comments about health services wrote about their dissatisfaction with both general practitioners and specialists, missed diagnoses and mis-diagnoses, and alternative therapies and women's health centres. Several women commented on the cost of health services. Women from rural areas, in particular highlighted isolation and marginalisation as key issues in determining their health. As one woman stated:

> *I cannot take time off work to travel 8 hours to see a specialist*

When one women with ongoing back pain did see a specialist, she reported that he asked:

> *Are you going to be another burden on Medicare?*

Many women wrote in great detail about personal relationships - especially childhood abuse and violence. Although we received feedback from many other women (through our 1800 telephone number) protesting that the questions were too personal, the fact that some women were able to tell us details of past and present abuse suggests that for some women at least, the survey provided an avenue for them to disclose these very personal problems.

The issues mentioned by women who wanted to tell us more about a personal health problem, or about factors perceived to cause stress, included:

physical health - including chronic pain, mobility impairment, family history, nutrition, contraception, reproductive issues, sexually transmissible diseases, sleep and dental problems;
emotional and mental health issues - including loss of memory, loss of confidence, loneliness and death of a partner or child;
social issues - including paid and unpaid work, unemployment, need for outside help, poverty, maintenance of independence;
religious and moral issues;
sexuality;
behavioural issues related to health - including use of illicit drugs, alcohol and exercise.

There were recurring comments from many woman about chronic pain:

> *My pain has caused financial pressure, depression, loss of fitness, insomnia, stress, conflict with my employers, and problems with my personal relationships*

Women in the middle age group tended to be more concerned with menopause and with the impact of family relationships and responsibilities on their own health. Some women highlighted a lack of information and education about menopause:

> *I was totally unprepared for the physical and psychological changes that occurred during menopause*

> *I am not sure about this change of life thing. I do know that I don't have the same confidence or memory that I used to have*

Others commented on the problems of motherhood in middle age:

> *I feel that worries about adult children and THEIR social and health problems have a great effect on women's health*

In contrast, many of the older women identified loneliness and loss of self-confidence relating to ageing as important to them. Others thought their views would not be of interest to the researchers:

> *At 74 years of age I doubt if my contribution is much good to you*

> *I really feel that I am too old (73 years of age) to be included in your survey*

Overall, the comments highlight the fact that concepts of health and health-care represent different things to different groups of women, and that these differences are mediated by age, social and geographic location, and health status.

Further analyses of the comments made by women will provide an additional interpretive framework for the quantitative data, and will be used to suggest further areas of research for

inclusion in sub-studies It is already clear that issues such as access to health services, menopause and healthy ageing should be explored in more depth, and that there are some women who are willing to provide information about issues relating to violence and abuse. The general tenor of the comments is summed up by one women's view:

> *I feel sorry that our doctors don't take the time or don't have the time to ask many of the questions asked in this survey*

3.2 PILOT STUDIES 4 AND 5

The rationale, methods and results of pilot studies 1-3 were reported in the December 1995 report. The main issues which arose from studies 1-3 were :

1 Low consent rates, especially for the old and young samples;
2 Need to ensure that issues addressed in the questionnaires were relevant to the particular age groups;
3 Need for the questionnaire for older women to be shortened and made more relevant;
4 Need to make the questionnaire for younger women more relevant;
5 Concern about the high education level of participants in the Pilot studies 1-3, and lack of representativeness of the general population;
6 Omission of some important issues for specific age groups.

Pilot studies 1-3 had been designed to use the same questions for the three age groups as far as possible in order to allow for comparisons across age groups and to develop a picture of generational effects. However, analysis of the findings from Pilot studies 1-3, as well as interviews with non-responders and age-specific focus groups, suggested that the questionnaires needed to be more specifically targeted to each of the three age groups. The young group in particular seemed to feel that some questions were not relevant to them. As a result of this feedback, two further pilot studies were designed, Pilot 4 for older women, and Pilot 5 for younger women.

3.2.1 Pilot 4

Aim

To determine whether two different mailing strategies resulted in different consent rates for the older sample, and whether they improved the consent rates recorded in Pilots 1-3. The two strategies were:

1 Sending the complete questionnaire at the first contact (12 pages, 134 items);
2 Sending a very brief questionnaire (3 pages; 22 items) at initial contact followed by a longer questionnaire (9 pages; 113 items) after the first questionnaire was returned.

Methods

Pilot 4 was a survey of 200 women from the 70-74 age group, randomly selected from the Medicare database in the following proportions: 40% urban women, 30% rural and 30% remote (n=80, 60, 60 respectively). (This classification was based on the description used by the Department of Primary Industries & Energy, and the Department of Health and Human Services (1994), with the 1991 Census statistical local area postcode concordance (ABS, 1991). The categories are as follows: urban: other metropolitan; rural: large and small rural; remote: other rural, remote centres and other remote.)

Half the sample were randomised to receive the full questionnaire and the other half to receive the two-stage questionnaire. The follow-up reminder procedure followed the protocol specified by Dillman (1978) (see table 3.2.1).

Questionnaire

The questions used in the survey were modified based on the findings of the first three pilot studies. All questions related to employment were deleted. Additions included mammography screening, years on the oral contraception pill and hormone replacement therapy, and feeling rushed/pressured. Other questions were modified, including questions on height and weight, weight change and social support. The Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991) was replaced by the Duke Social Support Survey (Koenig et al., 1993) which was developed specifically for older people. The life events scales were modified as discussed in the section on the life events substudy.

3.2.2 Pilot 5

Aims

1 to determine issues of relevance to young people, using focus groups;

2 to revise the questionnaire for the younger age group, on the basis of Pilot 1-3 results and the focus groups;

3 to determine whether the revised questionnaire and Dillman mailing protocol resulted in a more acceptable consent rate than earlier pilot studies of young samples.

Methods and Results

Aim 1: Focus groups for young sample

Two focus groups were used to identify particular issues of concern for young women. One was held in a private home and comprised 10 members, mainly university and final year school students, recruited from networks of the research team. A second focus group was held at the Family Care Cottage, a Department of Health facility for adolescent and disadvantaged mothers, to sample a group who were likely to identify different issues and priorities. The results of the focus groups were transcribed and analysed.

One issue which emerged strongly was stress. Particular forms of stress raised by the young women were financial, part-time work, harassment at work, study, being "worthless" university students, and exercise and body image issues. Other matters raised were interactions with health care providers and parents, and issues to do with living at home versus independently, relationship issues, excessive drinking, dieting, overeating, violence, and particular health problems such as migraines.

The focus group members were asked to provide specific comments on the draft questionnaires. They discussed the format and content of the questionnaire and survey procedures. Some young women expressed concern about some sensitive issues such as contraception and termination, sexually transmitted diseases, and drug use. The focus groups also suggested deleting less relevant health issues such as major illness.

Members suggested some possible incentives to encourage completion of the questionnaire such as providing tea bags or perfume. They felt that mail was far more acceptable than

telephone as a survey method. Members also commented on the need to allow participants to write comments to open-ended questions. They suggested appropriate publicity and media sources for young people including women's magazines, Triple J, Channel 10, and prominent role models such as Georgie Parker, Kate Ceberano, Helen Raiser and Jane Kennedy. They emphasized the need to use "ordinary" women, not models with perfect bodies.

Aim 2: Revision of questionnaire and further pre-testing

The questionnaire for the young sample was revised on the basis of the focus group findings and by elimination of issues which were shown to have very low prevalence in Pilots 1 to 3. Modified questions on stress and coping strategies from the Adolescent Life Stress Scale developed by Yeaworth et al. (1980; 1992) were added. The revised questionnaire was then pre-tested with a small group of young women and refined further, especially in format.

Aim 3: Mailout survey

Pilot 5 involved a mailout survey of 200 women from the 18-22 age group, randomly selected from the Medicare database in the following proportions: 40% urban women, 30% rural and 30% remote (n=80, 60, 60 respectively).

The full version (only) of the questionnaire was mailed to the women; it was 13 pages in length and comprised 204 items. The follow-up reminder procedure followed the protocol specified by Dillman (1978) (see table 3.2.1).

The mailing protocols and consent rates obtained for Pilot studies 4 and 5 are detailed in table 3.2.1.

Table 3.2.1

Response and Consent rates at each mail out stage in each geographical area for Pilots 4 and 5

	Pilot 4				Pilot 5			
Mail protocol	**Date mailed**	**# sent**	**Completed n**	**%**	**Date mailed**	**# sent**	**Completed n**	**%**
Mail 1	5 Jan	200			19 Feb	200		
Remind card	12 Jan	200	57	28.6	26 Feb	200	48	24.0
Remind Quest.	29 Jan	135	25	12.6	11 Mar	148	21	10.5
Remind Quest	26 Feb	69	4	2.0	8 Apr	127	5	2.5
Consent rate: Total			**86**	**43.2**			**74**	**37.0**
Urban		80	36	45.0		80	20	25.0
Rural		60	30	50.0		60	32	53.3
Remote		60	20	33.3		60	22	36.7
Total		200	86	43.2		200	74	37.0

Results & Implications for main baseline survey of older women

The mailing protocol trialed in Pilot 4 led to a response rate of 43%, which is better than that achieved in previous pilots of this age group. Questionnaire length did not have a significant effect on response rates. However, the two-stage procedure of sending out a short questionnaire and a later longer questionnaire resulted in loss of respondents at the second questionnaire and was more expensive. It was therefore decided to use one longer questionnaire only for the baseline survey.

Comments on the revised questionnaire were also received from the Older Women's Network Health group. These included suggestions about wording of certain items, exclusion of items that were perceived to be irrelevant to older women; additions to certain questions (eg alternative health care providers), and questions which required further clarification. These issues were considered in the final revision of the survey.

Implications for main baseline survey of young women

The mailing protocol trialed in Pilot 5 led to a response rate of 37% which was comparable with results from Pilot 3.

General issues for all age groups

The Dillman Protocol (1978), as used in Pilot studies 3, 4 and 5, was adopted for the main baseline survey for all three age groups with the exception that the time between first mailout and reminder 1 was increased by one week to allow more time for the questionnaires to be returned. In addition, the third reminder package was replaced by a reminder card, as this would result in considerable cost-savings and would be unlikely to make a major difference to the overall response rates.

Demographic questions were standardised across age groups where possible, with slight modifications in response options to reflect age differences. Any questions which were clearly irrelevant to the younger or older cohorts were deleted, and response options to questions where there were likely to be age-specific differences were carefully considered. Following a request from Professor Doreen Rosenthal from the Australian National Council on AIDS, questions about specific sexually transmissible diseases were added to the questionnaire for the younger age-group, with an optional response of "do not wish to answer".

3.3 LIFE EVENTS SUBSTUDY

The life events items used in pilot studies 1 - 3 originated from the Norbeck Life Events Questionnaire (Norbeck, 1984). This list (82 items), which was developed in the USA, was selected because it attempted to produce items appropriate for women. Most other life events

lists have been developed for women and men. No life events lists have been validated for Australian women or for women in specific age groups. The results of pilot studies 1 - 3 suggested that the life events lists required modification to make them more age and gender specific and to shorten them. Pilot studies 1 - 3 provided data about the frequency of specific life events in each of the age groups. However, it was considered that a further study was needed to obtain information on the perceived severity of the life events in each of the three age groups of Australian women.

Aims

1. Using a sub-sample of participants from Phase 1, to obtain data on the perceived severity of specific significant life events, in each of the 3 age groups;

2. To construct short lists of major life events relevant for women in three age groups, based on prevalence (from pilot studies 1 - 3) and perceived severity.

Phase 2: Perceived severity of life events

Methods

A sub-sample of 210 women from Phase 1 (70 in each age group) was randomly selected to participate in this substudy. They were asked to complete a mailed survey on their perceptions of the severity of life events.

The life events lists used in Phase 1 were modified by deleting 23 items for the younger age groups and 24 items for each of the middle and the older age groups. Four items were added for the younger age group, 2 for the middle age group and 7 for the older age group. Some of the Norbeck items were bi-directional and these were separated to include both directions; there were 10 such items for the younger and middle age group, and 8 for the older group. The word "major" was added to 8 of the items for the younger and older age group and 10 for the middle age group, in order to emphasise only serious events. The questionnaire for the younger age group contained 77 items; for the middle group, 76 items, and for the older women, 52 items.

The instructions were "Below is a list of events that happen to women. Please would you think about each event and decide how much effort it would take to adjust if that event

happened to you at this stage in your life. In general, adjustment means adapting or changing so that you can live easily under the new conditions. Some events on this list, such as death, are upsetting and naturally require a lot of adjustment. Other events such as getting married (or starting to live with someone) may be pleasant, but still require a great deal of adjustment. Still other events may not affect women's lives greatly. Please use your own experience to help you make your decision. Below each event is a line that starts at 0: '*requires no adjustment*' and ends on 10: '*requires most adjustment*'. Place an 'X' on the line to show how much adjustment each event would need. For instance, if you decide it would require a lot of adjustment, place an 'X' near a high number; alternatively if you decide it would not require much adjustment, place an 'X' near a low number. You can put an 'X' between the numbers if that seems more appropriate for you. If you feel you cannot answer a question because you honestly do not know how much adjustment it would take, simply put an 'X' at 0. Please be sure to put an 'X' for *every* event. Remember, for each event, think about how much adjustment it would take for **you** if you experienced that event at this stage of your life."

Completed surveys were received from 63 (93%) young women, 68 (99%) middle-aged women and 69 (100%) older women. Mean response rates were calculated for each item for each age group, as a measure of perceived severity of the items.

Modification of the three age-specific lists of life events

The three life events lists were modified by consensus among the research group, based on the data collected, on frequency of events and perceived severity. The following criteria were used: items with greater prevalence; items rated as requiring greater adjustment, and researchers' subjective assessment of the importance of the event. The final lists contained 35 items for the younger age group, 28 items for the middle age group, and 24 items for the older age group. Five items from the Adolescent Life Change Event Scale (Yeaworth, McNamee & Pozehl, 1992) were also included on the younger age group scale due to the perceived relevance and importance of these events to young women. The final scales are included in the baseline questionnaire (see Appendix L).

A paper is currently being drafted for publication based on this work to develop age-specific lists of life events relevant for Australian women in the 1990's.

4. MEDIA COVERAGE FOR BASELINE SURVEY

4.1 BACKGROUND

During 1995 it was agreed that the main focus for publicity preceding recruitment of the main cohorts would be women's magazines. Approaches were made to the magazine editors of the Packer Group (Women's Weekly, Women's Day, Cosmopolitan, She and Cleo) but there was little enthusiasm for the project in the absence of results from the baseline study. The communications consultant developed a press release which was sent to 12 women's magazines. This was followed up by telephone calls from the Women's Health Australia office, resulting in coverage in one magazine (Appendix M) and the possibility of mention in the health sections of two others in July. The other magazines indicated we should contact them again once the baseline results were available. An offer was made by *Women's Day* to publish some of the questions for their readers to submit (as a separate cohort). This offer was rejected by the research team on the grounds that it might cause confusion for women who received invitations to participate in the study.

In light of the difficulties experienced with gaining publicity through women's magazines, and the long lead time needed for magazine coverage, a revised publicity strategy for the main cohort study was developed during March 1996. It was agreed that publicity for the main study would be coordinated from the WHA office at the University of Newcastle.

4.2 PUBLICITY PLAN FOR THE RECRUITMENT PHASE FOR THE BASELINE SURVEY

Following focus group discussions with women in each age group it was decided that the main media outlets to be targeted for each of the baseline surveys would be as follows:

1	Middle aged cohort	National print media (including national metropolitan, suburban, rural, regional and local papers). National radio
2	Older Cohort	National 'seniors' press National print media (regional papers) ABC radio Community radio
3	Younger cohort	ABC Radio Triple J Community radio National magazines with "young" readership

4.3 REPORT ON PUBLICITY FOR THE RECRUITMENT PHASE FOR THE MIDDLE AND OLDER COHORTS

4.3.1 Television coverage

Television coverage is not seen as interesting by producers until the results of the study are available. However, local television stations, NBN and Prime (which broadcast to Central, Northern and country New South Wales) have broadcast interviews with Professor Lois Bryson, Dr Julie Byles and Dr Wendy Brown. Dr Julie Byles was interviewed on NBN's Morning Show and Professor Lois Bryson and Dr Wendy Brown on Prime Television's Regional News program. (Tapes of all of these interviews are available).

Following a program about the risks of lack of confidentiality in surveys on the television show, *Better Homes and Gardens*, the producer was approached and agreed to promote the study in its bulletin board section.

Further television publicity was achieved when Channel 7's National Morning News program *11am* joined us for a day at Women's Health Australia. The resultant 10 minute segment gave accurate coverage of the project, and included interviews with Professor Lois Bryson, Associate Professor Christina Lee and PhD student Kylie Ball. Dr Deidre Wicks was filmed facilitating a focus group and researcher Deborah Lloyd and her children were filmed in a variety of situations relating to time use and working women's multiple roles. (A copy of this tape is available).

Negotiations are continuing with several TV programmes (including *A Current Affair*) for dissemination of the results of the study.

4.3.2 Women's magazines

Women's magazines will be approached again once the main findings of the baseline studies are known. The possibility of using magazines as a major channel for communication of the study findings to the general population will continue to be pursued.

4.3.3 Newspaper coverage

Several health writers from metropolitan daily newspapers were approached by telephone, resulting in national press coverage on page 3 of the Australian (Appendix M) for the middle aged cohort, and 26 x 26 cm article in the Herald Sun (Victoria) for the older cohort. Both generated further interest from other papers and radio stations. The banner to advertise the April 20 edition of the Australian related to the article (title *Women - How They Cope*), and was displayed outside newsagents throughout Australia.

A press release (Appendix M) was faxed to 774 print, television and media outlets during the week beginning 22nd April. (The day of the initial 'middle' mail-out). These media outlets included:

1	Current Affairs	including AAP info service, ABC Radio, TCN Channel 9, Bulletin/Newsweek (13 faxes sent).
2	Women's Health	including women's writers at the Australian, Herald Sun, Country Women, and Magazines (Cleo, Australian Family Circle etc) (60 faxes sent).
3	Ethnic Languages	including Ethnic language newspapers covering 28 languages. (82 faxes sent).
4	Regional Newspapers	Newspapers covering areas outside the large metropolitan areas. (eg. Central West Sun, Byron News). (175 faxes sent).
5	Suburban Newspapers	Local weeklies (eg Wittlesea Post, Liverpool Leader) (167 faxes sent).
6	General Metropolitan	eg. Brisbane Sun, Katherine Times (277 faxes sent).

Response to the 'fax frenzy ' was widespread. The WHA office received 23 follow-up calls in the 3 days following the media release.

A second press release (Appendix M) was faxed to 300 print and media outlets during the week beginning 27 May to coincide with the initial mail-out for the older group. These media outlets focussed particularly on rural women and included:

1	Current Affairs & Women's Health	eg. Australian Associated Press
2	Regional Newspapers	eg. North Central News, Coonabarabran Times
3	Age specific publications	eg. Pensioners Voice, Action Network
4	Rural	The Land, Queensland Country Life, The Victorian
5	Medical publications	Medical Observer, Australian Doctor Weekly

It is not possible to estimate how many of the targeted outlets used the "fax frenzy" material. We did however receive many calls requesting further information and have received copies of some of the articles (Appendix M) which appeared in local publications. A number of our 'special intelligence' women around the country reported that they had seen articles about the study in their local paper.

Following the initial mail-outs to the middle and older cohorts we received several enquires from General Practitioners about the study. As a result we approached the two national GP publications, resulting in a feature article in the Medical Observer and the sending of a press release and information package to the Australian Doctor Weekly.

4.3.4 Radio coverage

Over 300 information packages have been sent to Community Radio Stations throughout Australia. These packages were prepared by 2NUR (the Newcastle University Community Radio Station) and Women's Health Australia, and contained a personal letter from the manager of the radio station, a response form, reply paid envelope and project brochure (Appendix N). The letter offered 30 second promotional spots and/or a 30 minute feature on the project itself, to target the older and younger age groups, according to the profile of the station. Initial response to this initiative has been excellent, with 63 stations (to 31 May) throughout Australia requesting these promotional spots and 5 minute regular updates on the project.

During April and May, the Newcastle researchers were interviewed by 28 radio stations from around Australia. These included:

Australian Associated Press
Perth ABC, and Commercial 6PR
Brisbane ABC and 4QR
Adelaide 5PR, 5DN
Sydney 2UE and ABC
Newcastle ABC, 2HD, 2NUR
National SBS

ABC Regional Radio NSW, VIC, WA

Additional radio publicity has been achieved through interviews with Lindy Burns on ABC Radio's the *Sunday Show* (Dr Wendy Brown) on Easter Sunday and with Geraldine Doogue (Dr Deidre Wicks) and Dr Norman Swan (Dr Julie Byles) on National Radio's *Life Matters*. All three interviewers encouraged women who received an invitation to participate in the study.

Women who had already completed their surveys (middle cohort) were thanked on ABC's *Australia All Over*, on 3 June, and women receiving the "older" survey were encouraged to participate.

4.4 OTHER COMMUNICATION STRATEGIES IN THE LAST SIX MONTHS

Members of Parliament

A letter was sent to all the recently elected women members of Federal Parliament to congratulate them on their election, and to raise awareness of the study. To date encouraging replies have been received from six members (3 from the Senate and 3 from the House of Representatives).

Internet

Internet address:
http://econ-www.newcastle.edu.au/statistics/womens_health

Women's Health Australia has its own home page on the World Wide Web. It currently contains photos and brief cv's of the researchers at Women's Health Australia. It is intended to expand this site and include information such as the newsletter, update bulletins of progress and abstracts of papers. The web site is currently averaging 33 calls a day from throughout the world.

Country Women's Association (CWA) State Conference

The NSW CWA's Annual General Conference was held in Newcastle in May, just before the initial mail-out to the older cohort. Information brochures outlining the study were distributed to each group delegate attending the conference and an announcement was made publicising the project.

5. THE BASELINE SURVEYS

5.1 ETHICS APPROVAL FOR THE MAIN STUDY

Approval to proceed with the baseline study was granted by the University of Newcastle ethics committee in March 1996 (Appendix O).

5.2 DEVELOPMENT OF THE BASELINE QUESTIONNAIRES

Following review of the pilot study results, a core set of questions was developed for the baseline survey. The following principles were used to decide which questions would be included in the baseline surveys:

- The surveys for each age cohort will include questions on each of the study's themes. This will allow cross-sectional comparisons and generation differences in issues to be explored.
- The themes to be covered (with headings used in the surveys) will be as follows:

  General well-being ("how you are feeling")

  Health service utilisation ("using health services")

  Symptoms and satisfaction with help ("coping with common problems")

  Stress, smoking and alcohol ("coping with stress")

  Weight, exercise and eating ("healthy weight and shape")

  Time use ("juggling time")

  Social support ("family and friends")

  Demographics ("you and your life")

  Aspirations (young only, "you and your future")

  (Each age-cohort survey will include every theme in the same ordered sequence, with the exception that "aspirations" will be included in the young cohort only.)

- Within each theme, questions for which the pilot studies indicated a very low prevalence in any age group will not be included. (There are some exceptions to this, where important issues with low prevalence are the subject of sub-studies, eg eating disorders).
- For each age cohort, only questions which are relevant to that particular age group will be included. Wherever possible core questions will be modified to make them appropriate to specific age groups.
- Questions on potentially sensitive issues will not be included in the baseline survey.

Table 5.2.1 provides a summary of the number of questions and the number of items in each survey, and table 5.2.2 provides a summary of the source of each question. The baseline survey for the middle cohort has 100 questions (272 items), for the older cohort 78 questions (251 items), and for the younger cohort 94 questions (252 items).

Table 5.2.1

Number of questions and items (by theme) in each of the baseline questionnaires

	Young (18 - 22)		**Middle (45 - 49)**		**Older (70 - 74)**	
Theme:	Questions	Items	Questions	Items	Questions	Items
Well-being	11	36	11	36	11	36
Health & health services	14	44	22	66	15	51
Symptoms	1	17	1	25	1	23
Stress	11	64	11	56	12	49
Weight	19	24	20	22	10	20
Time use	10	20	11	21	5	15
Family & friends	8	23	10	27	12	39
Demographics	14	14	13	14	13	13
Achievements	1	5	1	5	1	5
Aspirations	5	5	-	-	-	-
TOTAL	94	252	100	272	80	251

Table 5.2.2
Question source and number for the main survey questionnaires

THEME Women's health is about -	Questions	Source	Question number		
			Old	Mid	Young
1. "How you are feeling"	SF 36	Ware & Sherbourne (1992)	1-11	1-11	1-11
2. "Using health services"	Service uitlisation*	Modified from ABS (NHS) 1989-1990	15	12	12
	GP visit	Modified from Davies & Ware (1991)	14	13	13
	Gender preference	WHA	17	14	14
	Medical History*	Modified from ABS (NHS) 1989-1990	16	15	15
	Operation/procedures*	WHA	18	16	-
	Sexually transmissible diseases	Australian National Council on AIDS (ANCA)	-	-	16
	Hospital and insurance	Modified from ABS (NHS) 1989-1990	12	17	17
	Hospital waiting list	WHA	13	-	-
	Medication- general*	WHA	19	18	18
	Medication (benzoids and chronic illness)	WHA	20	19	-
	Oral contraceptive pill (OCP)	Modified from NCEPH (1992)	-	20	-
	Duration of OCP use*	Modified from NCEPH (1992)	21	21	24
	HRT and duration	WHA	22-23	22-23	-
	Pap test	Modified from ABS (NHS) 1989-1990	24	24	19
	Abnormal pap	WHA	-	25	20
	Mammogram	Modified from ABS (NHS) 1989-1990	25	26	-
	Abnormal mammogram	WHA	-	27	-
	Currently pregnant	WHA	-	28	21
	Reproductive history*	WHA	26	29	22
	Contraception*	WHA	-	30	23
	Condoms	WHA	-	-	25
	Menstrual status	Modified from Brambilla et al. (1994)	-	31-33	-
3. "Coping with common problems"	Symptoms and satisfaction with available help*	WHA	27a/b	34a/b	26a/b
4. "Coping with stress"	Sources of stress*	WHA	28	35	27
	Coping with stress	Modified from Groer et al. (1992)	29	36	28
	Life events*	Modified from Norbeck (1984)	30	37	29
	Smoking	Modified from NHF (1980)	34-39	38-42	30-34
	Alcohol	Modified from NHF (1980)	31-33	43-45	35-37

5. "Healthy weight and shape"	Height/weight	WHA	40-41	46-47	38-39
	Satisfaction with weight	WHA	42	48	42
	Disatisfaction with weight	WHA	-	-	48
	Highest weight and reason	WHA	-	49-50	-
	Lowest weight and reason	WHA	-	51-52	-
	Weight description at 10	WHA	-	54	41
	Weight description now	WHA	-	55	40
	Ever dieted	WHA	-	-	43
	Dieted in last year	French et al. (1995)	43	53	44
	Age first dieted	WHA	-	-	45
	Dieting now	WHA	44	56	-
	Binge behaviour	Fairburn & Beglin (1994) EDEQ and French et al. (1995)	-	60	49
	Loss of control	Modified from Fairburn & Beglin (1994) EDEQ	-	-	50
	Age started bingeing	WHA	-	-	51
	Unhealthy weight loss	Modified from Fairburn & Beglin (1994) EDEQ and French et al. (1995)	-	61	52
	Bulimic behaviour	French et al. (1995)	-	62	-
	Lost 5 kg	WHA	45	57	46
	Gained 5 kg	WHA	46	58	-
	Regained lost weight	WHA	-	-	47
	Normal eating habits	Australian Nutrition Screening Checklist	49	-	-
	Take away food	WHA	49	59	56
	Exercise - vigorous	Commonwealth Department of the Arts, Sport, the Environment	47	63	53
	- less vigorous	and Territories (1992)	48	64	54
	- work related		-	65	55
6. "Juggling time"	Employment status	Modified from ABS (1992) Time Use Survey	-	66	57
	Hours in paid work	ABS (1996) Census	-	67	58
	Shift work	WHA	-	68	59
	Night work	WHA	-	69	60
	Work at home	WHA	-	70	61
	Rushed/pressured*	Modified from Statistics Canada (1985)	50a/51	71-72	62
	Time on hands	Statistics Canada (1985)	50b	73	63
	Satisfaction with time use	Modified from ABS (1992) Time Use Survey	52	74	64
	Satisfaction with work share	WHA	53	75	65
	Main occupation self/spouse*	ABS ASCO (1987)	54	76	66

7. "Family and friends"	Who lives with you*	Modified from ABS (1994) Social, Labour, & Demograph Stats	55	77	67
	Children at home	WHA	-	78	-
	Child care	WHA	-	79	68
	Care for others	Modified from ABS (1993) Disability, Aging and Carers Aust	56	80	69
	Need for care (self)	Modified from ABS (1993) Disability, Aging and Carers Aust	57	81	70
	Satisfaction with care*	WHA	58	82	71
	Relationships*	Hwalek & Sengstock (1986)	59/60	83	72
	Social support*	Koenig et al. (1993) Duke Social Support Index	61-66	84-86	73-74
8. "You and your life"	Date of birth	ABS (1994) Social, Labour, & Demographic Statistics	67	87	75
	Age left school	ABS (1996) Census	68	88	76
	Currently studying	ABS (1996) Census	-	89	77
	Highest qualification	Modified from ABS (1996) Census	69	90	78
	ATSI Origin	ABS (1996) Census	70	91	79
	Country of birth	ABS (1996) Census	71	92	80
	Arrival in Australia	Modified from ABS (1996) Census	72	93	81
	Language at home	ABS (1996) Census	73	94	82
	English ability	ABS (1996) Census	74	95	83
	Marital status	Modified from ABS (1996) Census	75	96	84
	Manage on income	WHA	76	97	85
	Housing situation	WHA modified from ABS (1996) Census	77	98a	86
	Ownership etc	WHA	78	98b	87
	Employment at 35	Modified from Hakim (1991)	-	-	89
	Job at 35	Modified from Hakim (1991)	-	-	90
	Relationship at 35	Modified from Hakim (1991)	-	-	91
	Children at 35	Modified from Hakim (1991)	-	-	92
	Qualifications at 35	WHA	-	-	93
	Postcode	WHA	79	99	88
	Satisfaction with life	WHA	80	100	94

* Exact question varies across age groups

5.4 SAMPLING AND RECRUITMENT FOR THE MAIN STUDY

A random sample of women in each group was drawn from the HIC (Medicare) data base. (All women in the selected age group in the "current" Medicare file were included in the sampling frame.)

The sample was designed so that women from rural and remote areas were over-represented. They were selected in twice the proportions which exist in the general rural and remote population for women of that age (see Table 5.3.1). Women from capital cities and other metropolitan areas made up the balance of the sample.[1]

Table 5.3.1
Representation of women from different geographic areas in the baseline sample (based on postcode classification) [1]

		Capital city & other metropolitan %	Large/small/ other rural %	Remote major & other remote %
45 - 49 years	Population	70	27	3
	WHA sample	40	54	6
70 - 74 years	Population	72	27	1.5
	WHA sample	43	54	3
18 - 22 years	Population	73	24	3
	WHA sample	46	48	6

Procedure

1. In light of lower than expected response rates, and the high costs of the revised (Dillman, 1978) protocol, the original sample size of 20,000 was reduced to 12 - 15,000. The size of the initial mail out was calculated from pilot study response rates, to give a final sample size of 12 - 15,000 in each age group (see Table 5.3.2).

Table 5.3.2
Calculation of sample size for the initial mail-out

Age cohort	Expected response rate	Sample size required	Initial mail-out

[1] These classifications were taken from the sources listed on page 7. The subclassifications are however different from those used in the pilot studies in that "other rural" areas were classified as "rural" rather than "remote".

	(from pilot studies)		
18-22 years	35%	12 - 15,000	39,000
45-49 years	48%	12 - 15,000	28,000
70-74 years	35%	12 - 15,000	39,000

2. Contracts for printing, packaging, mailing and data entry for the baseline survey were developed after a competitive tendering process. The successful tenders were:

Printing - Paragon Printers, Canberra
Packaging and Mailing - The Practical Group, Canberra
Data Entry - Harrisons Data Capture, Parramatta

Australia Post gave approval for mail lodged in Canberra to be credited to a Newcastle University bulk postage account, and our application for bulk mail discount was approved.

3. HIC mailed a survey package to randomly selected women in each group. Each package contained:
    - an introductory letter;
    - an information brochure;
    - a consent form;
    - a questionnaire;
    - a reply paid envelope.

   Mailing was carried out through a mailing company in Canberra, who packaged the materials and delivered them (pre-sorted, bagged and tagged) to Canberra Post Office according to the schedule shown in Table 5.3.3.

4. One week after the initial mail out, all women in the sample were sent a card designed to thank those who had completed the survey and to act as a prompt for those women who had not yet returned their questionnaires.

5. A 1800 telephone number was provided for women to ring if they did not wish to participate in the survey. Women who used this number were asked to give their main reason for not wishing to participate in the study. The number was also available for women who wanted additional information about the study.

6. Three weeks after the initial mail out, identification numbers of all women who had either
    - returned their survey
    - informed the researchers they did not wish to participate
    - or whose initial package had been "returned to sender"

   were sent to the mail company for deletion from the mailing list.

7. Four weeks after the initial mail out, women whose identification number was still on the mailing list were sent a replacement package. This package was identical to the first except that the letter was modified to reflect the fact that this was a reminder/replacement.

8. Four weeks after the replacement package was posted, all women who had still not responded, or whose packages had not been returned, were sent a final reminder card.

The times for mailing each of the surveys are shown in Table 5.3.3., and a summary of the logistic operation of the surveys is shown in Chart 1. Survey materials are included in Appendix L.

Table 5.3.3
Main study mail-out timetable (including number of packages/cards to be mailed at each stage)

Age group	22/4	29/4	6/5	13/5	20/5	27/5	3/6	10/6	17/6	24/6	1/7	8/7	15/7	22/7	29/7	5/8	12/8	19/8	26/8	2/9	9/9
45 - 49 (M)	M1 28000	M2 28000			M3 18000				M4 15000												
70 - 74 (O)							O1 39000	O2 39000			O3 30000				O4 26000						
18 - 22 (Y)													Y1 39000	Y2 39000			Y3 30000				Y4 26000

M1, O1, Y1 = initial mail-out (package)
M2, O2, Y2 = first reminder/thank you card
M3, O3, Y3 = replacement package
M4, O4, Y4 = final reminder/thank you card

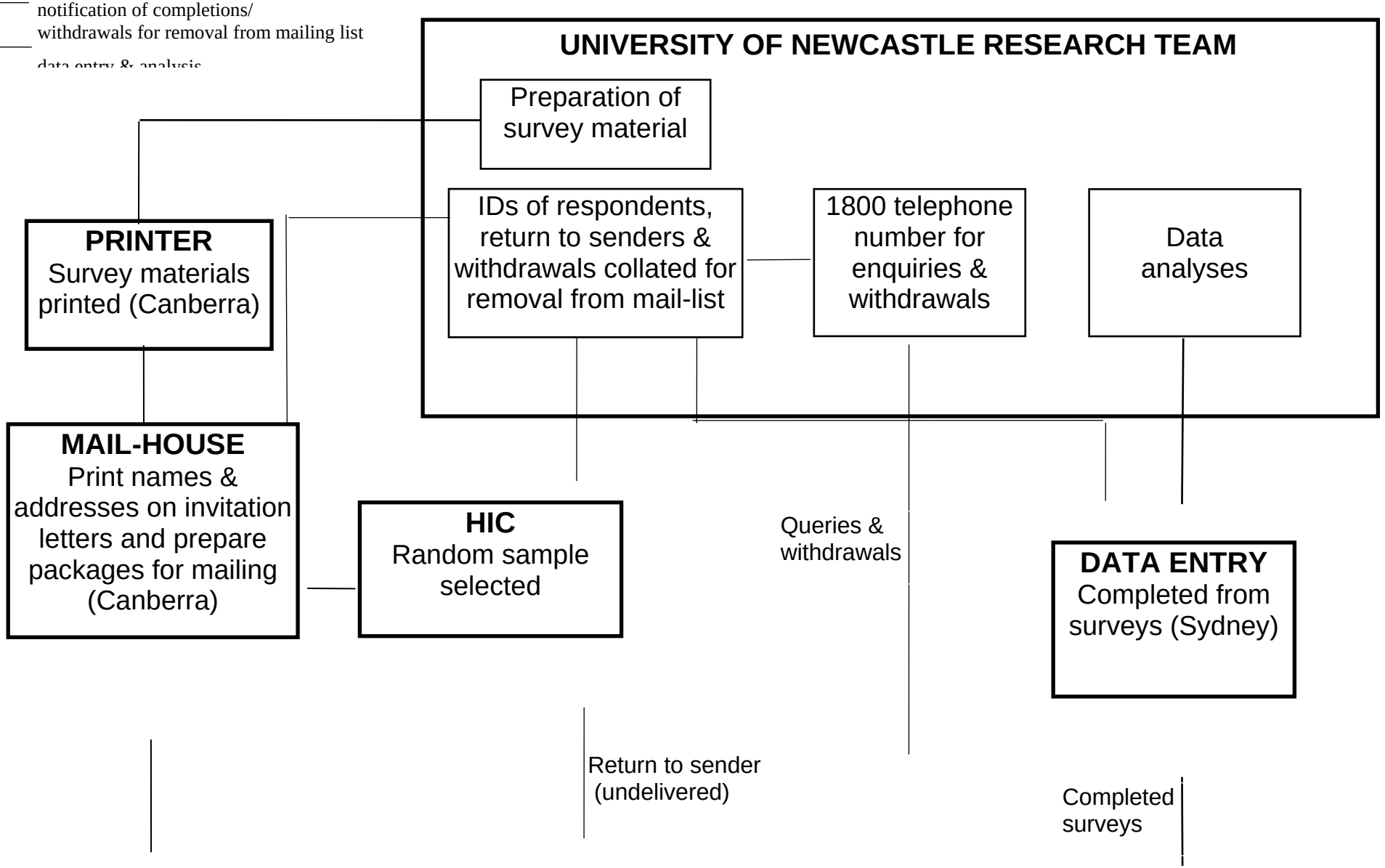
Key

delivery of surveys to women

notification of completions/ withdrawals for removal from mailing list

data entry & analysis

CHART 1: Flowchart of logistic operation of the baseline surveys




CANBERRA
MAIL CENTRE
SURVEY DELIVERED TO WOMEN THROUGHOUT AUSTRALIA

5.4 1800 TELEPHONE NUMBER

A 1800 telephone number was provided in the project materials, to enable women who required more information or who did not wish to participate, to contact the research team.

During April and May 1996, we received 3,026 calls on this number. Of these 2,186 were "withdrawals" and 840 were from women seeking clarification/information or who required assistance with the survey.

Fifty interviews were completed by telephone with women who were unable to complete the survey themselves (see table 5.4.1). Hunter Area Health service translators were employed to conduct interviews in languages other than English.

Table 5.4.1

Record on telephone interviews (April - May 1996)

Language/Reason	**Number**
English (unable to read/write or needed assistance)	27
Other language - Chinese	8
- Greek	4
- Italian	7
- Serbian	1
- Vietnamese	1
- Croatian	2

Each woman who rang to decline the offer to participate in the study was invited to offer her main reason for non-participation. A summary of responses is shown in table 5.4.2

Table 5.4.2

Main reasons given by women in the middle age cohort who declined the invitation to participate (April - May 1996; N = 1900 withdrawals; N = 286 ineligible)

Reasons for non-participation		N	%
General reasons	Too busy/no time	359	18.9
N = 1039 (54.7%)	No reason (including messages on answering machine and HIC)	259	13.6
	Just don't want to	208	10.9
	Not interested	134	7.1
	Don't feel like it/can't be bothered	71	3.7
	I don't want to give a reason	8	0.4
Privacy/confidentiality	Questions are too personal	160	8.4
issues	Invasion of privacy	122	6.4
N = 339 (17.8%)	Concerns about confidentiality	44	2.3
	Concerns about Medicare	8	0.4
	Not comfortable with the whole study	5	0.3
Questionnaire issues	Doesn't like/doesn't do surveys	87	4.6
N = 259 (13.6%)	Questions are boring/pointless/irrelevant	55	2.9
	There are too many issues	35	1.8
	Too difficult to fill in	26	1.7
	Has completed too many in the past (sick of surveys)	19	1.0
	Waste of time/money	18	0.9
	Disapproves of sampling/reminder process	10	0.5
	Stupid idea/tore it up	9	0.5
Personal issues	Personal issues	45	2.4
N = 198 (10.4%)	Don't feel up to it	41	2.2

	Family reasons	30	1.6
	Too distressing	25	1.3
	Too healthy	25	1.3
	Husband rang to say that wife does not want to take part	23	1.2
	Woman rang to say that husband would not allow her to do it	9	0.5
Barriers	Language problems	31	1.6
N = 65 (3.4%)	Constantly moving	29	1.5
	Nomadic (Aboriginal)	4	0.2
	Wants to be paid	1	0.1
Ineligible/unable to complete	Overseas/travelling	150	
	Too sick/disabled	79	
N = 286	Deceased	35	
	Woman has never lived at that address/moved but do not know where	14	
	Outside the age group/wrong gender	8	
Returned to sender		750	

6. POSTGRADUATE STUDENT PROJECTS

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: Associate Professor Christina Lee

Background

Dieting and disordered eating have in recent years become the focus of increased research, clinical and public interest. Researchers have examined, for example, factors which may be important in the etiology of disordered eating, and various factors are documented in the literature as being possible precursors. These include psychological factors such as poor body image, low self-esteem and depression. One factor which has recently received increased attention is psychological stress. However, there are several problems which remain to be addressed. Firstly, which types of psychological stress are most frequently associated with disordered eating? For example, are negative life events more likely to be associated with disordered eating than general levels of stress, or daily hassles? Is the role of coping skills significant in mediating different types of stress among individuals with eating disorders? In addition, previous studies have used a multitude of different assessment instruments, with inadequate regard for precision or consistency in the assessment and quantification of stress. An additional problem is that the majority of studies which have suggested an association between psychological stress and eating disorders are correlational in nature, and many utilize retrospective, self-report methods. This makes it difficult to determine the importance of stress processes in the onset of disordered eating, and to establish conclusively the direction of causality of this effect.

The proposed study

The proposed study will investigate the temporal relationship between psychological stress and disordered eating, in a cohort of young women (aged 18-22 years). A longitudinal study design will enable an examination of the temporal order of these

factors, which should establish conclusions about the role of stress in the onset of disordered eating. It is anticipated that the study will comprise several smaller sub-studies, including:

1. An analysis of data from pilot studies;
2. A study to establish the efficacy of assessment instruments/questionnaires;
3. A longitudinal study examining stress and disordered eating at baseline and over time;
4. An intervention study based on the findings of the longitudinal study.

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: Dr Margot Schofield

Background

The rate of mental illness and psychological distress in the Australian community is potentially a health problem of national significance. Some studies have shown that women have up to three times more minor psychiatric disturbance than men. There are no published Australian studies which describe help seeking for psychological distress in middle-aged women, and their experience with this help (or lack of it). This study explores the significance of psychological distress in women's lives, the expectations of women seeking help from formal sources such as medical practitioners and psychologists, and their satisfaction with this help. The study utilises a feminist ethnographic framework.

Research aims

1. To describe the help seeking behaviour for psychological distress in a community sample of women.
2. To describe in detail the knowledge, beliefs, attitudes and experiences of women who seek help about psychological distress from formal sources compared to those who do not.

Methodology

Study 1 Three hundred and fifty NSW women who scored in the poorer 20% of the MHI-5 (5 item mental health scale in the SF36) in the baseline survey of the Australian Longitudinal Study on Women's Health will be randomly selected. These women will be asked to complete a structured telephone interview asking them about psychological distress in the past year and ever. Details will be obtained about the most recent and the most significant distress including who they talked to, what help they received, what they did for themselves, how helpful these things were and reasons for not seeking help.

Study 2 Qualitative Case Comparison Study. In depth open-ended face-to-face interviews will be carried out with 40 women from Study 1 who live within 300 kms of the University of Newcastle. Women who did seek formal help and women who did not, will be chosen for interview until 20 in each category have been recruited. Concepts to be explored include the woman's own explanation for her distress, stigma, beliefs about the

nature of mental illness and mental health, recognition of gender issues and relationships, knowledge about services and beliefs about the most appropriate sources of help.

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)

Background

Iron deficiency is the most prevalent nutritional deficiency in the world. The detrimental effects of anaemia have long been recognised but morbidity can be demonstrated in the following areas long before iron deficiency develops into anaemia.

1. Physical Work Capacity - work performance is known to be reduced in people with iron deficiency. These effects are not due to anaemia per se but to a tissue iron deficiency.
2. Behaviour - mental development and cognition are affected in people with iron deficiency. Most studies have been done during the period of brain development (ie infants and young children), however, studies done beyond this period also show a adverse effect on mental performance and psychomotor development.
3. Immunity - non-specific immunity and cellular immunity are both reduced in people with iron deficiency. Studies on infection in humans generally show a positive relationship between iron deficiency and rates of infection.
4. Thermoregulation - maintenance of body temperature is impaired in people with iron deficiency and metabolic rate is reduced.

Pre-menopausal women are at particular risk of iron deficiency due to increased losses (menstrual), increased requirements (during pregnancy and lactation), and poor dietary intake (weight reduction and avoidance of red meat). Although few studies have been done on these morbidity factors in developed countries, it is possible that all may affect general well-being.
The overall aim of this study will be to determine the importance of this issue for Australian women and to develop an appropriate dietary intervention with General Practitioners (ie those assessing and treating this condition).

Proposed Study

<u>Factors Associated with Iron Deficiency</u>

- "Does iron deficiency matter?" Using the baseline survey, data will be analysed to determine whether women who have suffered from iron deficiency score worse on the Physical Functioning, Vitality and General Health Scales from the SF-36.
- Data will also be analysed to determine associations of iron deficiency with proposed causal factors (eg. heavy periods, oral contraceptive use, alcohol intake, dieting pattern, number of children born).

Knowledge, Attitudes and Behaviour to Iron Deficiency among GP's and Women

- GP's will be surveyed about their knowledge, attitudes and treatment of iron deficiency.
- Women who have had low iron in the last 12 months will be surveyed regarding the treatment they received from their doctor.
- Women who have had low iron, and another random sample who have never had low iron, will be asked about their knowledge, attitudes and behaviour towards iron in their diet.

Exploration of Dietary Iron Intake and Iron Status

- Women with iron deficiency (and controls) will be recruited from local GP's to explore the relationship between dietary iron intake and iron status.

Intervention Study to determine the Best Practice for Management of Iron Deficiency

- The best treatment method for correcting and maintaining iron status will be determined by investigating the roles of supplements, haem and non-haem iron and inhibiting and enhancing agents.
- The question "Does iron deficiency matter?" will be investigated by getting iron deficient women to complete SF-36, a fatigue scale and a test of cognitive performance before and after restoration of iron status.

6.4 WOMEN'S USE OF HEALTH CARE SERVICES

PhD candidate: Anne Young BMath(Hons), DipMedStat
Supervisor: Professor Annette Dobson, Dr Julie Byles

Background

It is well documented that women account for a large proportion of users of the health care services in Australia. However, there is some evidence that there are inequalities in access to health care services and that, despite frequent encounters with the health care system, many women's health needs remain unmet. A study of health service utilisation using the national Medicare claims data file, linked with self reported information on perceived health status, medical conditions and satisfaction with care, has the potential to

yield benefits in the investigation of issues of equity and access to care for Australian women.

Aims

- to describe the health care utilisation of women who participate in the ALSWH project and compare the results of those who consent to access to Medicare information and those who do not
- to examine health care utilisation in relation to geographic location and self reported health care needs
- to describe the patterns of screening for breast and cervical cancer and to compare women's self report of cervical cancer screening with the claims for this service in the Medicare data file.

Research plan

The participants in the ALSWH project will be asked to allow the study team to access their Medicare claims data. These data can be used to calculate, for each woman, the number of visits to GPs and specialists, the number of different providers seen and which tests and procedures were performed eg Pap tests. The date of each service is also available, so that patterns of use of professional services and diagnostic tests over time can be studied. For the women who provide consent, their Medicare data will be linked to their ALSWH survey data. For the women who do not consent to record linkage, information from the Medicare database can be obtained in aggregated form. There are issues of privacy and confidentiality to be considered and focus groups will be used to identify the concerns women have about consenting to record linkage. Pilot study groups will be used to test strategies to request consent to Medicare access, prior to contacting the main survey group.

7. RESEARCH ACTIVITIES (see Appendix P for abstracts)

7.1 VISITS TO OTHER RESEARCH CENTRES

PROFESSOR LOIS BRYSON

May 1996

Dr Duncan Ironmonger, Director, Households Research Unit, University of Melbourne

DR MARGOT SCHOFIELD

Washington DC 12 - 14 March 1996

Dr Loretta Finnegan, Director & Dr Joanne Odenkirchen, Policy Analyst, Women's Health Initiative, National Institute of Health, USA.

Dr Dolores Parron, Assistant Director, Special Populations, National Institute of Mental Health.

Boston 18 - 20 March 1996

Kate Kalan, Site Project Coordinator, Women's Health Initiative, Brigham and Women's Hospital, Chestnut Hill, Massachusetts.

Dr Susan Hankinson, Epidemiologist, Harvard Medical School, Boston, Massachusetts. (Boston Nurses Study).

Dr John Ware, Dr Barbara Gandek & Dr Cathy Bungay, The Health Institute, New England Medical Centre. [Measurement of quality of life (SF36)].

Dr Avron Spiro III, Veterans Affairs, Normative Aging Study.

Henry A Murray Research Centre, Radcliffe College.

Dr Nancy Avis, Director & Principal Research Scientist, New England Research Institute, Watertown, Massachusetts. (Massachusetts Women's Health Study)

Dr Judith Ockene, Professor of Medicine, University of Massachusetts Medical Centre, Worcester, Massachusetts. (Study of Women's Health Across the Nation).

Dr Wayne Velicer, Dr James Prochaska, Dr Gabrielle Reed & Dr Bob LaForge. Cancer Prevention Research Centre, University of Rhode Island.

Jody Brown, Family Violence Research Program, University of Rhode Island.

7.2 PRESENTATIONS

7.2.1 Papers presented

BYLES JE, BROWN W, WILLIAMS G & MANDERSON, L. Women's Health Australia. International Women's Day Launch, Parliamentary Annexe, Alice Street, Brisbane. 8 March, 1996.

BRYSON L. The Australian Longitudinal Study on Women's Health. Paper presented to The Australian Sociology Association Conference. December, 1995.

LEE C. Exercise and hormone replacement therapy: Effects on mood in middle-aged women. Paper presented at the third New Zealand Health Psychology Conference, Okoroire. February, 1996.

Slaven L & LEE C. Acute effects of aerobic exercise on mood and menopause-related symptoms among users and non-users of hormone replacement therapy. Paper presented at the fourth International Congress of Behavioural Medicine, Washington, DC. March, 1996.

SCHOFIELD MJ. The Australian Longitudinal Study on Women's Health: the first year. Seminar presented to the Cancer Prevention Research Center, University of Rhode Island, Kingston, Rhode Island. March 1996.

SCHOFIELD MJ. The Australian Longitudinal Study on Women's Health: methodological issues in the design of cohort studies. Seminar presented to the Faculty of Nursing Post-Graduate Program, University of Newcastle. April 1996.

SCHOFIELD M, France K & LEE C. Knowledge, attitudes, well-being and hormone replacement therapy use among mid-aged Australian women. Poster presented at the 4th International Congress of Behavioral Medicine, Washington DC, March 1996.

SCHOFIELD M & Redman S. Menstrual problems among Australian women: prevalence and impact of symptoms and health care experiences. Paper presented at the 4th International Congress of Behavioural Medicine, Washington DC, March 1996.

WICKS D. 1996. Have women found the secret of happy ageing. Presented to Aged Services Association of NSW & ACT.

7.2.2 Abstracts accepted for presentation

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. The XXVI International Congress of Psychology, Montreal, Canada, August 1996.

7.2.3 Abstracts submitted for presentation

Public Health Conference (Perth, September, 1996)

BROWN WJ, DOBSON AJ & MISHRA G. The changing weight of Australian women.

BYLES JE, SCHOFIELD M, BROWN WJ & Tiller K. Variation in gynaecological procedure rates.

YOUNG A, BYLES J & DOBSON A. The tyranny of distance: Health care utilisation by women living in rural and remote Australia

7.3 PUBLICATIONS 1996

7.3.1 Papers published

Associated Projects

BROWN WJ & Doran FM. Women's Health: consumer views for planning local health promotion priorities. *Australian and New Zealand Journal of Public Health.* 1996. 20 (2): 149-154.

BROWN WJ, LEE C & Oyomopito R. Exercise and dietary modification with women of non-English speaking background: A heart health program for Greek-Australian women. *Health Promotion International*. 1996. 11(2): 117-125.

BRYSON L. Revaluing the Household Economy. *Women's Studies International Forum.* 1996. 19: No 3.

BRYSON L, Lazzarini V & Winter I. An Australian Newtown Revisited: Employment , Change and Poverty, 1966 and 1991. *Family Matters.* 1996. 43: 28-30.

BRYSON L. A Letter from Australia: Transforming Australia's Welfare State. *SPANews* May/June 1996: 11-13.

7.3.2 Papers accepted for publication

Associated Projects

BROWN WJ, MacDonald B, Alexander J, Mills-Evers T. The Health of Filipinas in the Hunter Region. *Australian and New Zealand Journal of Public Health.*

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

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.*

Davis T & LEE C. Sexual assault: Myths and stereotypes among Australian adolescents. *Sex Roles.*

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

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

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

Nagle A, SCHOFIELD MJ & Redman S. Smoking in hospital grounds and the impact of outdoor smokefree zones. Accpeted for publication in *Tobacco Control.*

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.*

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

7.3.3 Papers submitted for publication

Women's Health Australia

BROWN WJ, BRYSON L, BYLES JE, DOBSON AJ, MANDERSON L, SCHOFIELD M & WILLIAMS G. Establishment of the Australian Longitudinal Study on Women's Health. *Submitted to Journal of Women's Health.*

DOBSON A, MISHRA G, BROWN WJ & REYNOLDS R. Food habits of young and middle-aged women living outside the capital cities of Australia. *Submitted to Australian and New Zealand Journal of Public Health.*

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. *Submitted to the Medical Journal of Australia.*

Bates L & BROWN WJ. Nurses and doctors: Knowledge, attitudes and treatment of domestic violence. *Submitted to the Journal of Advanced Nursing Practice.*

BROWN WJ & BYLES JE. A collaborative approach to cervical cancer screening. *Submitted to the British Medical Journal.*

BROWN WJ, LEE C & Nasstasia J. Heart health for migrant women: Interventions with Dutch-Australian and Macedonian-Australian women. *Submitted to the Australian and New Zealand Journal of Public Health.*

BRYSON L, Lazzarini V & Winter I. (1996) 'An Australian Newtown Revisited: Employment , Change and Poverty, 1966 and 1991' *Family Matters* No. 43: 28-30 (with Viviana Lazzarini and Ian Winter).

BRYSON L. 'Is the Household Economy Emerging from Obscurity?: Implications for Women' *Refractory Girl* (forthcoming)

BRYSON L. 'The ABS: Informing Social Policy ', *Just Policy* (forthcoming)

BRYSON L. (1996) 'A Letter from Australia: Transforming Australia's Welfare State' *SPANews* May/June 1996: 11-13.

BRYSON L. (1996) 'Revaluing the Household Economy' *Women's Studies International Forum.*Volume 19, No 3.

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. *Submitted to the Medical Journal of Australia.*

BYLES JE, Harris M, Butler J, Kanagarajah S & Nair K. Preventive health programs for older Australians. *Submitted to the Health Promotion Journal of Australia.*

BYLES JE. Research involving patients of general practitioners. *Submitted to Australian Family Physician.*

France K, SCHOFIELD MJ & LEE CL. Hormone replacement therapy use among mid-aged Australian women. *Submitted to the Journal of Health Psychology.*

France K, SCHOFIELD MJ & Lee CL. Menopausal symptoms reported by mid-life Australian women: a random community survey. *British Journal of Health Psychology.*

Girgis A, Sanson-Fisher RW & SCHOFIELD MJ. Breaking bad news: is there consensus between breast cancer patients and providers on guidelines? *Submitted to the Journal of Clinical Oncology.*

LEE C & BROWN WJ. Australian migrant women and physical activity: Attitudes, barriers, preferences and participation. *Australian and New Zealand Journal of Public Health.*

Lynagh M, SCHOFIELD MJ & Sanson-Fisher R. School health promotion programs over the past decade: a review of smoking, alcohol and sun protection literature. *Submitted to the Health Promotion International.*

SCHOFIELD MJ, Walkom S & Sanson-Fisher R. Patient-provider agreement on guidelines for preparation for breast cancer treatment. *Submitted to the Behavioural Medicine.*

7.3.4 Additional research grants

Additional Research Grants

J BYLES, N Higginbotham, M Coory & B Goodger. 1996. Social Support for Older Persons

Funded by the Commonwealth Department of Human Services and Health. Health and Human Services Research and Development Grants. $18,962

R Heller, J BYLES, N Higginbotham, L Lim, K Nair, J Butler & C Jackson. 1996-1999. Preventive Care for Older Australian Veterans and War Widows.

Funded by Commonwealth Department of Veterans' Affairs. $1.6 million

MJ SCHOFIELD, AL Nagle, MJ Hensley & M Rowley. 1996-98. Nurse provided smoking cessation for inpatients: effectiveness of three models. $248,000

MJ SCHOFIELD, R Sanson-Fisher, T Hazell & L Hancock. 1995-97. Evaluation of the Health Promoting Schools Program in NSW High Schools. *Funded by NHMRC-PHRDC.* $178,500

RW Sanson-Fisher, JA Bowman, MJ SCHOFIELD & EM Campbell. Optical mark reader scanner and software. 1996. *Funded by NHMRC Equipment Grant.* $ 10,000

S OUTRAM, MJ SCHOFIELD & L BRYSON. 1996. Women's experience of seeking help for emotional distress. *Funded by University of Newcastle Research Management Committee.* $ 5,000.

7.4 WOMEN'S HEALTH AUSTRALIA MONTHLY SEMINAR SERIES

A series of monthly seminars has been organised at the Callaghan campus for 1996. Topics and speakers for the first five months of 1996 were as follows.

23 JAN	Dr Marilynne Bell, Dalhousie University, Nova Scotia, Canada
	Medicalization of woman abuse: its implications for medical education
27 FEB	Associate Professor Christina Lee, Department of Psychology
	Dr Margot Schofield, Women's Health Australia
	Menstrual and menopause issues for mid-aged Australian women
26 MARCH	Professor John McCallum,
	Dean, School of Health, University of Western Sydney
	Who uses health services? Models from the Record Linkage Study
	Dr Julie Byles and Ms Anne Young, Women's Health Australia
	Record Linkage for the Australian Longitudinal Study on Women's Health
30 APRIL	Professor Lois Bryson, Department of Sociology
	Time use and women's health
28 MAY	Professor Annette Dobson, Director, Women's Health Australia
	Gender issues in cardiovascular disease
	Presentation by WHA postgraduate students:
	Sue Outram
	Women's experiences of seeking help for emotional distress
	Amanda Patterson
	Iron deficiency in Australian women
	Kylie Ball
	The role of psychological stress in the aetiology of disordered eating
	Anne Young
	The use of Health Insurance Commission data in women's health research

7.5 VISITORS

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

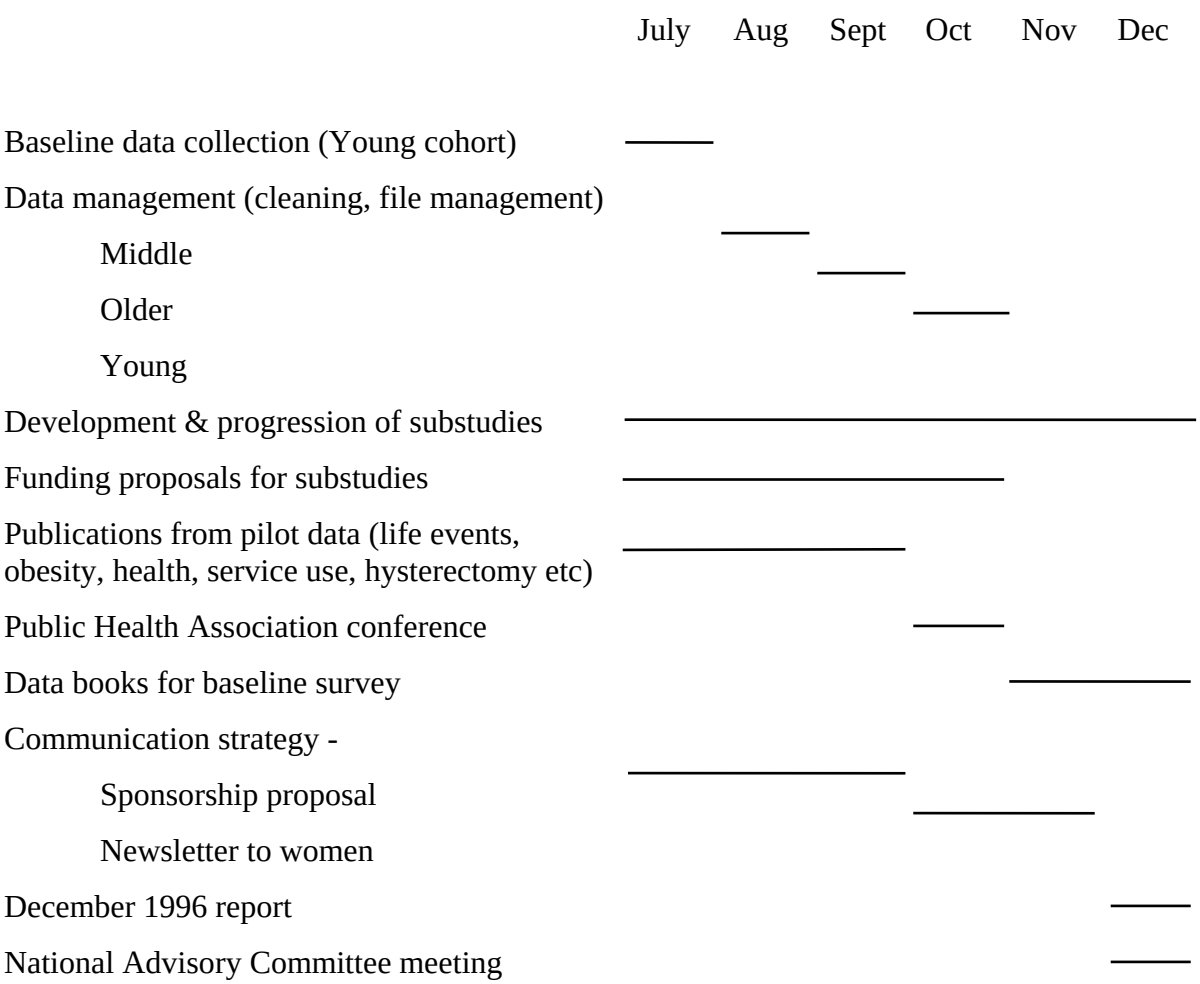
Dr Marilynne Bell, Assistant Professor, Department of Family Medicine, Dalhousie University, Canada

Professor Allen Dietrich, Department of Community and Family Medicine, Darmouth Medical School, Hanover, New Hampshire, USA.

Professor John McCallum, Dean, School of Health, University of Western Sydney Macarthur

Dr Sharon Buehler, Associate Professor of Epidemiology, Health Research Unit, Memorial University of Newfoundland, St Johns, Canada

8. PLANS FOR THE NEXT SIX MONTHS



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