women's health australia

The Australian Longitudinal Study on Women's Health

Report 13

The University of Newcastle

10 December 1999

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EXECUTIVE SUMMARY

1. Data from the first follow-up survey of the mid-age cohort, which was conducted during 1998, are now available. There were delays due to problems with data entry, which have now been resolved. The final response rate was 91.6%.

2. The first follow-up survey of the older cohort was conducted this year. At the time of writing, data collection is almost complete and the response rate is 90.7%. 8% of older women completed a 'short' survey by telephone, as they were unable to complete the long (mailed) survey. A comparison of the demographic characteristics and health care use of those who completed the short and long surveys has been conducted.

3. During 1999, the survey for the first follow-up of the young cohort has been developed and pilot tested. Details of the questions are provided in this report. It is apparent that intensive efforts to 'track' young women who have changed address since the 1996 baseline survey, will be required early in 2000.

4. During 1999, women who did not give consent for the researchers to 'link' their HIC/Medicare data with data from the Australian Longitudinal Study on Women's Health (ALSWH) in 1997, were asked again for their consent to do this. Only 14% of the 17,856 women who were invited to do so, gave their consent.

5. Policies for archiving the ALSWH data, and for researchers from other organisations to gain access to the data, or to request specific analyses, have been developed. Data from the 1996 baseline surveys will be deposited in the Social Science Data Archive at the Australian National University in Canberra, before the end of 1999.

6. During 1999, the three foundation PhD students at The University of Newcastle completed their research and submitted their theses. They will graduate in April 2000. Two students working on the project completed their honours theses this year.

7. Twenty one sub-studies involving the collection of additional data were conducted this year. All were funded by sources external to the longitudinal study.

8. The researchers presented 18 papers at major national or international conferences this year. A highlight this year was presentations at a symposium on the ALSWH project at the Second International Interdisciplinary Conference on Women and Health in Edinburgh, Scotland. It is likely that there will be international collaboration as a result of this.

9. Ten papers have been published in peer reviewed journals this year, and another seven have been accepted for publication. Ten papers are currently being reviewed for publication.

10. A new NHMRC Project Advisory Committee has been established and has held two meetings this year.

11. Briefing meetings have been held with the Commonwealth Department of Health and Aged Care to report findings from the project and consider the policy implications for Australian women.

1. ADMINISTRATIVE ARRANGEMENTS

1.1 PROJECT STAFF

Investigators working on main cohort studies are currently:

Professor Annette Dobson, project director, Statistics, University of Newcastle;

Professor Wendy Brown, project manager, Women's Health Australia, University of Newcastle;

Emeritus Professor Lois Bryson, Research Institute for Gender & Health (RIGH), University of Newcastle;

Dr Julie Byles, Centre for Clinical Epidemiology & Biostatistics (CCEB), University of Newcastle;

Associate Professor Christina Lee, Psychology, University of Newcastle;

Associate Professor Justin Kenardy, Psychology, University of Queensland;

Dr Gita Mishra, Statistics, University of Newcastle;

Associate Professor Margot Schofield, Health Studies, University of New England;

Dr Penny Warner-Smith, Leisure & Tourism Studies, University of Newcastle;

Dr Anne Young, statistician, Women's Health Australia, University of Newcastle.

Associate investigators who have worked with the main cohorts in 1998 include:

Dr Deidre Wicks, Sociology & Anthropology, University of Newcastle;

Ms Lauren Williams, Nutrition & Dietetics, University of Newcastle;

Mr John Germov, Sociology & Anthropology, University of Newcastle;

Ms Sue Outram, Medicine & Health Science, University of Newcastle;

Ms Susan Feldman, Alma Unit on Women & Ageing, University of Melbourne;

Dr Helen Jonas, School of Health and Human Sciences, La Trobe University;

Dr Marilys Guillemin, Centre for the Study of Health & Society, University of Melbourne;

Ms Pauline Chiarelli, Medicine & Health Sciences, University of Newcastle;

Dr Surinder Baines, Nutrition & Dietetics, University of Newcastle.

Office staff at The University of Newcastle

Ms Lyn Adamson, research assistant/publicity officer;

Ms Jean Ball, data manager;

Ms Joy Goldsworthy, research assistant;

Ms Jenny Powers, research assistant/statistician;

Ms Emma Threlfo, secretary.

Students

Ms Allison Schmidt, RIGH, University of Newcastle;
Ms Lauren Williams, Nutrition & Dietetics, University of Newcastle;
Ms Margrette Young, RIGH, University of Newcastle;
Mr Brendan Goodger, CCEB, University of Newcastle;
Ms Barbara Reen, CCEB, University of Newcastle;
Ms Lisa Milne, Sociology & Anthropology, University of Newcastle;
Ms Melissa Graham, School of Health & Human Sciences, La Trobe University;
Ms Kerrilie Rice, Faculty of Human Development, Victoria University of Technology;
Ms Sandra Hickling, Psychology, University of Newcastle;
Ms Glennys Parker, Psychology, University of Newcastle;
Ms Fiona Campbell, Discipline of Behavioural Science in Relation to Medicine, University of Newcastle;
Mr Esben Strodl, Department of Psychology, University of Queensland;
Ms Jenny Powers, RIGH, University of Newcastle;
Ms Elizabeth Stojanovski, Statistics, University of Newcastle.

1.2   BUDGET 1999 - ACCOUNTS 593-1001 AND 593-1029

Income: 1 July 1998 - 30 June 1999
Expenditure: 1 January 1999 - 19 November 1999

	Income		Expenditure YTD	Approximate commitments to 31 Dec
DHAC	821,000	Shared research UQ	117,000	
		Shared research (UNE)	4,000	5,000
		AIHW (NDI)	2,410	
		HIC data		5,000
		Surveys and data entry	61,455	23,500
		Computer h'ware, s'ware	2,325	500
		Equipment & maintenance	4,689	1,500
		Postage	38,082	2,500
		Telephone	16,140	2,500
		Printing, stationery	8,509	13,000
		General consumables/repairs	4,616	3,000
		Travel/hospitality	11,754	500
		Salaries	280,775	46,000
		On-costs	51,962	12,000
		Scholarships	26,474	
		Annual report		5,000
		University overhead charge	105,600	
TOTAL	**821,000**		**735,791**	**120,000**

DHAC -   Department of Health and Aged Care
UQ -   University of Queensland
UNE -   University of New England
NDI -   National Death Index
HIC -   Health Insurance Commission

2 UPDATE ON THE FIRST FOLLOW-UP SURVEY OF THE MID-AGE COHORT

BASELINE (1996)	N	
Numbers of respondents	14,093	
Numbers with invalid birthdays	52	
TOTAL NUMBER	14,145	
Number with no participant details	385	
Number with participant details	13,760	
Not mailed	304	12 Deceased
		54 Withdrawn
		4 Overseas
		234 Lost

FOLLOW-UP (1998)		
Surveys mailed out	13,456	13,405 Mailed surveys
		51 Telephone interviews

	N	%
Surveys returned early	11,469	85.2
Surveys returned late (after phone reminder)	170	1.3
Surveys returned late (short surveys by phone)	689	5.1
Completed surveys in dataset	12,328	91.6
Will not do survey this time, but remain in study	224	1.7
Not returned, unsuccessful contact	859	6.4
Still invalid birthdays	45	0.3
TOTAL	13,456	100.0

3 FIRST FOLLOW-UP SURVEY OF THE OLDER COHORT (MARCH-OCTOBER 1999)

3.1 SUMMARY OF RESPONSES TO DATE

A summary of the results of each stage of the follow-up survey is shown in Table 1.

Table 1: Results of the follow-up survey (as of 16 November 1999)

Date started	Stage	Sent	Surveys returned	Deceased or too ill	Response rate cumulative (%)
26 March	Mail out surveys	11,677			
16 April	Reminder/thank you card	11,473	2,563	28	22.0
14 May	Second reminder (card)	3,130	5,675	48	71.0
1 June	Follow-up phone calls started		536	20	75.8
6 August	Follow-up phone calls finished		1,656	76	90.7
16 November	Total to date	11,677	10,430	172	90.7

Almost 13,000 women responded to the baseline survey for older women in 1996 (Figure 1). The Health Insurance Commission (HIC) mailed consent forms and surveys (without any identifying information) to the selected women. Unfortunately 507 surveys were returned without consents. As a result we had insufficient identifying information to allow us to contact these women for the follow-up survey in 1999.

Yearly newsletters have been sent to participating women to provide feedback on the information they have given us in the surveys and also to keep in touch with them. Many women phoned or wrote to tell us how much they enjoyed the newsletters. Approximately 200 newsletters were "returned to sender" after the 1998 newsletter. The research assistants searched the Telstra White Pages on the Internet and also used the electoral roll to successfully track two thirds of the women for whom newsletters were marked "return to senders". However the 1999 survey was not sent to 64 women who remain lost to follow-up.

As we had already been notified of 224 deaths since the baseline survey and did not wish to upset the relatives of the participants unnecessarily, in February 1999, it was decided to match the older cohort to the National Death Index (NDI). Identifying information (full name, date of birth, state and postcode and last known contact date) for 12,939 women was sent to the NDI. Of the 409 possible matches identified, 212 were already known to be deceased, an extra 174 were identified as deceased. A further 12 known deaths were not identified by NDI. As the vital status of the remaining 23 was uncertain, they were sent a copy of the older follow-up survey. Responses to the survey showed that 15 of these women were still alive, one woman could not be contacted and 7 had died.

The mailing company posted the follow-up survey to 11,516 women in March 1999. A further 161 surveys were mailed from the WHA office to women who had requested telephone interviews at baseline due to physical, cognitive or language difficulties. The survey and a covering letter were posted to the women at least two weeks prior to the telephone interview so they would know the questions they would be asked.

For varying periods between April and August 1999, 13 additional casual staff were employed to work on the older follow-up survey. All returned surveys including information about consent forms, proxies, change of address and date of phone calls to the WHA office were recorded in the computer log for older women. Withdrawals and deaths, including date and cause of death, were also recorded. Women were classified as "too ill" if they had a severe chronic illness or disability, such as dementia, stroke, debilitating pain, deafness, that prevented them from answering the questionnaire. The reasons for withdrawal were recorded as one of the following: general (don't want to do it, someone else withdrew her, no reason); concern about privacy/confidentiality; questionnaires or study issues (questions irrelevant, too personal); personal issues (husband very ill, husband died recently). A further 207 women, while happy to remain in the study, felt they could not complete the survey at this time. The main reasons were the health of their spouse or other family members, their own health, moving house or otherwise too busy.

The casual staff checked each returned survey to see if it required major editing (e.g. if most of the ovals on the survey were ticked instead of filled in as required for optical scanning). If data were missing for one page or more pages, these staff made a follow-up phone call to obtain answers to the missed questions. The women sent us letters, books, x-rays and sometimes asked for help or information. Letters were sent to 36 women in response to items returned with the survey or comments in the survey. Women were also given information

when they phoned our 1800 number; over 500 calls were taken, mainly in April and May 1999.

Two casual staff and 11 interpreters made telephone calls to 189 women who could not complete the survey on their own due to physical, cognitive or linguistic impairment; 134 surveys were completed. The majority spoke English and mainly required interviews because of eyesight or writing problems. Interviews were also conducted in Arabic (1), Cantonese (3), Croatian (1), Greek (3), Italian (9), Korean (1), Macedonian (2), Maltese (1), Polish (5), Russian (2) and Ukranian (1). We are still trying to find Tamil and Portuguese interpreters. A further 309 surveys were filled in by someone on behalf of the participant, usually by her husband or daughter. Most commonly, this was due to difficulty with English, poor eyesight, difficulty writing or memory problems.

After the success of reminder phone calls for the mid-age follow-up in 1998, a similar protocol was used for non-responders in the older cohort. Between 1st June and 6th August 1999, interviewers offered older women the chance to complete a full-length or shorter survey over the phone. Phone calls were attempted to 2,194 women. If there was no answer, the interviewers made a minimum of six attempts to contact the participant. The results of this stage are shown in Figure 1. While some women were tracked relatively easily (by referring to information on the consent form, including alternative contacts or checking on the Telstra White Pages), 406 women required intensive tracking and still 283 could not be contacted. New surveys were sent to 488 women and the majority of these have since been returned.

By 16 November 1999, full-length surveys have been received from 9510 women and short surveys have been completed over the phone by a further 920 women. This short survey is included in Appendix 1. 1,770 of the full-length surveys required editing or had at least a page of missing data. Follow-up phone calls were made to 1,186 women whose surveys had missing data; 1078 (91%) of these women answered questions on the missing data over the phone, 97 (8%) could not be contacted and 21 women refused to answer any more questions.

Image scanning was used to enter data for 10,404 surveys. Surveys which arrived after 30th August 1999, have been entered at the WHA office. Scanned images of the 10,404 surveys are stored on 10 CDs. The final page of the survey, "Have we missed anything?" was used by 4,721 of these women. The scanning company set up a database to view the images of these pages, which are stored on the same 10 CDs.

An overall summary of the outcome of the first follow-up survey for the older cohort after excluding women who had died (n=92) or were too ill to complete the survey (n=80) is shown in Table 2.

Figure 1: Outcomes of the follow-up (1998) surveys for the older cohort who had participated in the baseline survey in 1996 (as of 16 November 1999).

Table 2: **Outcomes of the first follow-up survey for the older cohort as at 16 November 1999.**

	N	Total (%)
Survey received	9,510	} 90.7
Short survey by phone	920	
Returning survey, not yet received	123	1.1
Sent new survey, not yet returned	151	1.3
Will not do this time (but will stay in study)	207	1.8
Withdrawn from study	311	2.7
No contact yet	283	2.5
Total eligible	**11,505**	**100**

The approximate cost of the printing, packing, mailing and data entry processes for the older follow-up survey is given in Table 3. Excluding the cost of a full time data manager to develop and maintain the computerised tracking system, and the costs of the research assistants who tracked the women whose addresses had changed, the estimated cost of printing, packing, mailing, phoning and data entry for the follow-up survey was around $124,000. This is an overall cost of approximately $12 per returned survey. The cost per returned survey, for early respondents who did not require a phone call reminder, was estimated to be $10.70. This figure included the costs of surveying women who had physical, cognitive or language impairment (almost $34 per completed survey). During the final stage of the process, reminder telephone calls were made to 90% of the 2,194 women who had not responded. The average cost of completed surveys at this stage was $14.50 per survey returned. Follow-up telephone calls to earlier responders whose surveys had missing data cost $10.50 per survey.

The overall cost of $124,000 for the entire process was quite low, considering that none of these additional costs for editing and telephoning was included in the original budget. This reflects the ongoing attempts by the researchers to ensure high quality but cost-efficient data collection.

Table 3:   Approximate cost of follow-up survey for the older cohort

Stage	Cost ($)	Approximate cost per returned survey
Mail out surveys and reminders		(n=10,430)
Print, pack and post surveys	41,660	
Print, pack and post reminder/thank you cards	7,230	
Print, pack and post second reminder cards	2,870	
Total print, post and pack	*51,760*	$4.96
Return mail and prepare for scan		(n=9,510)
Return mail and 1800 calls	7,560	
Telephone interviews (language, etc)	4,540	
Data editing	7,500	
Wages and telephone calls for missing data	12,400	
Total return mail and prepare for scan	*32,000*	$3.36
Data logging and scan		(n=10,430)
Data logging	4,700	
Data entry/ scanned images	20,450	
Total log and scan surveys	*25,150*	$2.41
Follow-up phone calls/ short surveys and full-length surveys received after 31st May		(n=2,094)
Telephone calls	4,600	
Salaries of casual staff	8,200	
Print short surveys	1,830	
Postage for new surveys	390	
Total	*15,020*	$7.17
COSTS OF OLDER FOLLOW-UP SURVEY (excluding salaries for data managers and research assistants, and costs of office supplies, computers, etc)	123,930	(n=10,430) $11.88

3.2   COMPARISONS OF DEMOGRAPHIC CHARACTERISTICS IN BASELINE SURVEY OF RESPONDENTS TO FULL FOLLOW-UP SURVEY, RESPONDENTS TO SHORT SURVEYS AND NON RESPONDENTS

The following tables provide a comparison of the socio-demographic characteristics of respondents to the full-length survey, respondents to the short survey and non-respondents as at September 1999.

Table 4:   Area of residence (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
Urban	3829	40.3	351	38.2	511	47.4	4691
Rural	5462	57.5	543	59.0	547	50.7	6552
Remote	216	2.3	24	2.6	21	2.0	261
Missing	0	0	2	0.2	0	0	2
Total	9,507	100	920	100	1,079	100	11,506

Table 5:   State of residence (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
NSW	3315	34.9	301	32.7	366	33.9	3982
VIC	2403	25.3	238	25.9	286	26.5	2927
QLD	1717	18.1	172	18.7	186	17.2	2075
SA	914	9.6	96	10.4	105	9.7	1115
WA	723	7.6	73	7.9	90	8.3	886
TAS	362	3.8	34	3.7	33	3.1	429
NT	12	0.1	2	0.2	3	0.3	17
ACT	61	0.6	4	0.4	10	0.9	75
Missing	0	0	0	0	0	0	0
Total	9,507	100	920	100	1,079	100	11,506

Table 6:   Marital status (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
Married	5314	55.9	491	53.4	570	52.8	6375
Defacto/separated/divorced	590	6.2	64	7.0	80	7.4	734
Widowed	3177	33.4	325	35.3	378	35.0	3880
Never Married	272	2.9	12	1.3	27	2.5	311
Missing	154	1.6	28	3.0	24	2.2	206
Total	9,507	100	920	100	1,079	100	11,506

Table 7: Country of birth (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
Australia	7036	74.0	644	70.0	667	61.8	8347
Other English speaking	1143	12.0	101	11.0	120	11.1	1364
Europe	616	6.5	79	8.6	162	15.0	857
Asia	88	0.9	11	1.2	38	3.5	137
Other	55	0.6	4	0.4	13	1.2	72
Missing	569	6.0	81	8.8	79	7.3	729
Total	9,507	100	920	100	1,079	100	11,506

Table 8: Level of education (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
Trade/diploma/uni/etc	1463	15.4	70	7.6	98	9.1	1631
Higher school certificate	1177	12.4	82	8.9	116	10.8	1375
School or intermediate certificate	3596	37.8	309	33.6	331	30.7	4236
No formal qualifications	2821	29.7	381	41.4	466	43.2	3668
Missing	450	4.7	78	8.5	68	6.3	596
Total	9,507	100	920	100	1,079	100	11,506

Table 9: Manage on income (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
Impossible	103	1.1	10	1.1	23	2.1	136
Difficult always	451	4.7	72	7.8	79	7.3	602
Difficult sometimes	1763	18.5	191	20.8	262	24.3	2216
Not too bad	4803	50.5	450	48.9	519	48.1	5772
It is easy	2209	23.2	165	17.9	166	15.4	2540
Missing	178	1.9	32	3.5	30	2.8	240
Total	9,507	100	920	100	1,079	100	11,506

Table 10: Number of symptoms in last 12 months (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
None	525	5.5	53	5.8	67	6.2	645
1-2	1320	13.9	107	11.6	140	13.0	1567
3-4	1653	17.4	130	14.1	155	14.4	1938
5-6	1707	18.0	148	16.1	181	16.8	2036
7 or more	4120	43.3	456	49.6	502	46.5	5078
Missing	182	1.9	26	2.8	34	3.2	242
Total	9,507	100	920	1001	1,079	100	11,506

Table 11:   Number of diagnoses (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
0	1404	14.8	146	15.9	166	15.4	1716
1	2577	27.1	234	25.4	288	26.7	3099
2	2408	25.3	232	25.2	246	22.8	2886
3	1548	16.3	136	14.8	161	14.9	1845
4 or more	1525	16.0	160	17.4	204	18.9	1889
Missing	45	0.5	12	1.3	14	1.3	71
Total	9,507	100	920	100	1,079	100	11,506

Table 12: SF-36 physical health score (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
<35	606	6.4	70	7.6	101	9.4	777
35-<55	4419	46.5	432	47.0	484	44.5	5335
55-<80	3320	34.9	239	26.0	275	25.5	3834
Missing	1162	12.2	179	19.5	219	20.3	1560
Total	9,507	100	920	100	1,079	100	11,506

Table 13: SF-36 mental health score (1996)

	Respondents full-length survey		Respondents short survey		Non-respondents		Total
	n	%	n	%	n	%	N
<35	680	7.2	103	11.2	119	11.0	902
35-<55	4093	43.1	405	44.0	452	41.9	4950
55-<80	3572	37.6	233	25.3	289	26.8	4094
Missing	1162	12.2	179	19.5	219	20.3	1560
Total	9,507	100	920	100	1,079	100	11,506

From these data it is apparent that the additional strategy of offering a short survey to the women who had not responded after the two mailed reminders was successful. For example, in relation to area of residence, approximately 50% of the rural and remote area women, and 40% of the urban women, who did not respond to the mailouts, have now completed a survey (Table 4).

There was also a higher initial rate of loss to follow-up among women who are in defacto relationships, separated or divorced, and those who have no formal qualifications (Tables 6 and 8). The additional telephone reminders resulted in surveys being completed by 44% of the separated/divorced non-respondents, and 45% of the 'no formal qualifications' non-respondents. There was limited success in finding non-respondents who were born in overseas non-English speaking countries; 33% of non-respondents who were born in Europe, and 22% of those born in Asia have now completed a survey (Table 7). Further surveys are still being done with non-English speaking women. Among those women who reported finding it difficult (always) or impossible to manage on their income, the additional telephone contact resulted in 45% completed surveys (Table 9).

In terms of general health and well-being, more than 40% of the initial non-respondents who had lower scores on the SF36 have now completed a survey. (41% of those with lower (<35) physical health scores and 46% of those with lower (<35) mental health scores) (Tables 12 and 13).

Non-respondents are more likely to be from urban rather than rural or remote areas; they are also more likely to be from non-English speaking countries. Women with lower levels of education and those who had difficulty managing on their income are also more likely to be non-respondents. It was interesting that there was little difference in number of symptoms and diagnoses between respondents and non-respondents (Tables 10 and 11). This was in contrast to perceived health; non-respondents were more likely to have lower SF-36 scores for both mental and physical health.

3.3   DEVELOPMENT OF NEW MEASURES

During 1999, the researchers have been working on two new measures - elder abuse in the older cohort, and stress in the young cohort. Details of these can be found in section 8.2.3 and section 7.3.2 respectively.

4   FIRST PILOT FOLLOW-UP SURVEY OF THE YOUNG COHORT

4.1   DEVELOPMENT OF THE SURVEY

Preparation for the pilot survey for the first follow-up of the young cohort began in March 1999. A number of steps were undertaken to identify questions and items for this survey. Initially, a broad and inclusive collection of themes, items and questions was collated from the following sources:

1. The themes identified in the original study proposal;
2. Questions and themes from the baseline questionnaire;
3. Variables and research questions listed in the document prepared for the Review of the WHA project which was conducted in 1998;
4. Some preliminary ideas which had been put forward by a working group who were considering an application for a Special Research Centre grant;
5. The qualitative and open-ended responses from the young participants in the baseline survey;
6. Comments and suggestions raised by the research team.

An exhaustive list of topics, ranging from broad concepts through to specific variables and individual questions, was collated. These 102 items were categorised into 15 main themes:

1. Life stages/key events/life transitions
2. Violence
3. Time Use
4. Physical health
5. Psychological health
6. Gynaecological health
7. Personal/family context
8. Social Context
9. Sexuality
10. Weight, exercise & health behaviour
11. Health service use
12. Demographics
13. Aspirations
14. Have we missed anything
15. Miscellaneous

These items were circulated for critical comment to all members of the research team during April/May 1999. On the basis of the resulting feedback, a refined summary consisting of 68 items under 10 main themes, was generated:

1. Life stages/key events
2. Gynaecological health
3. Work transition
4. Time use
5. Physical health
6. Psychological health
7. Weight, exercise & health behaviours
8. Health service use
9. Demographics
10. Aspirations
11. Have we missed anything?

The next step was to conduct literature searches and invite members of the research team to provide items, scales, and sources of questions. Where possible, standardised measures were selected.

A one-day intensive working session was held in early June 1999, to consider the concepts and scales. At this stage, decisions were made regarding scales and items, and their exact wording and response formats. Some further work was then carried out in accessing standardised measures. Following this, decisions were made about the grouping of questions and preliminary drafts of the questionnaire were produced. A further process of circulation and refinement was carried out; at this stage, women in the target age range (research assistants and their friends and acquaintances) were invited to complete the questionnaire and comment on any aspect of layout, wording, question content, or any other issues.

On this basis, a pilot questionnaire was finalised in August 1999 (see below for the list of items) ,and has been administered with the "young pilot" sample in the Bathurst and Illawarra districts.

4.2   ITEMS IN PILOT FOLLOW-UP SURVEY FOR THE YOUNG COHORT 1999

No.	Question description	Source	Question in baseline	Modifications from baseline
Health Service Use				
1 a-b	No. of times consulted a family doctor or a GP	WHA	12a	Now a separate question, split into 2 items & more response options given
2 a-b	No. of times consulted a specialist doctor	WHA	12c	Now a separate question, split into 2 items & more response options given
3 a-f	No. of times consulted health care professionals	Modified from ABS. 1989-1990 National Health Survey. Summary of results, Australia. Canberra: ABS, 1991; Catalogue No. 4364.0.	12b,d-g	Yes/no responses rather than number of times
4	Admitted to hospital	WHA	17	Response options differed

No.	Question description	Source	Question in baseline	Modifications from baseline
5 a-b	Consistency of GP visit	WHA Health Services Substudy (HSS)		
6 a-j	GP satisfaction	Modified from Davies AR, Ware JE. GHAA's Consumer satisfaction survey and user's manual, Second edition. Washington, DC: The Group Health Association of America (GHAA), 1991. Then revised according to data from AUHS.	13	Some items deleted, some added
7	GP preference	WHA	14	
8 a-k	Access to health care	WHA - HSS		
9	Health care card	WHA		
10	Health insurance for hospital cover	WHA - HSS	17b	Reworded and response options differed
11	Health insurance for ancillary services	WHA - HSS	17c	Response options differed
12 a-v	Medical History	Modified from ABS 1989-1990 NHS	15	Items added and response options differed
Coping with common problems				
13 a/b/c a-t	Symptoms and help seeking	WHA (baseline) with revisions	26	Items added and response options differed
How you are feeling?				
14 - 24	SF-36	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.	1-11	
25 a-b	Serious illness/condition/ disability	WHA	15g	Reworded.
26	Need for care	Modified from ABS. Disability, Aging & Carers, Australia: Summary of Findings. Canberra: ABS, 1993; Catalogue No. 4430.0.	70	
Sexual and reproductive health				
27 a-c	Age of first period, sexual intercourse, baby	WHA		
28	Help with first baby	WHA		
29	Freq. of period in past 3 months	WHA		
30	Sexual orientation	WHA		
31 a-b	No. of sexual partners	WHA		
32 a-g	Contraception	WHA	23, 25	Combined into 1 question

No.	Question description	Source	Question in baseline	Modifications from baseline
33	Years taken OCP	WHA	24	More response options given
34	Currently pregnant	WHA		
35 a-e	Reproductive history	WHA	22	Some items reworded and some items added
36	Pap test	Modified from ABS 1989-1990 NHS	19	
37	Abnormal pap test	WHA	20	
38	Infertility problems	WHA		
Health habits				
39	Height	WHA	38	
40	Weight	WHA	39	
41	Birth weight	WHA - substudy on weight gain at mid life		
42	Weight preference	WHA	42	
43	Dieting in last year	French SA, Story M, Downes B, Resnick MD, Blum RW. Frequent dieting among adolescents: psychosocial and health behaviour correlates. *American Journal of Public Health*, 1995; 85(5): 695-701.	44	
44 a-c	Lost/gained 5 kg	WHA	46	Time restriction of last 4 years. More response options given. Gained 5 kg item added.
45 a-b	Dissatisfaction with weight or shape	WHA	48	
46	Binge eating	Fairburn CG & Beglin SJ. Assessment of eating disorders: Interview or self-report questionnaire? *International Journal of Eating Disorders,* 1994; 16: 363-370.	49	
47	Loss of control over eating	Modified from Fairburn & Beglin (1994).	50	
48	No. of times of loss of control	WHA		
49	How long…loss of control	WHA		
50 a/b a-j	Methods of losing weight	Modified from Fairburn & Beglin (1994) and French et al. (1995).	52	Items added, and part b (how often in the last month did you use these methods) has been added.
51a/b a-e	Exclusion of foods from diet	WHA		

No.	Question description	Source	Question in baseline	Modifications from baseline
52 a-f	Medications	WHA	18	Same question but completely different items
53-58	Smoking questions	Australian Institute of Health & Welfare. Standard questions on the use of tobacco among adults. (1998)		
59-61	Alcohol questions	Modified from National Heart Foundation of Australia. *Risk factor Prevalence Study No. 1* (1980). Woden: NHF of Australia, 1981.	35-37	
62-64	Drugs for non-medicinal purposes	The Drug Offensive: A federal and state initiative. National Drug Strategy Household Survey 1995.		
65-66 a-d	Exercise questions	WHA		
67	Hours spent sitting down	WHA - Substudy on weight gain at mid life		
Feeling good about yourself				
68 a-p	Erikson's stages of development	Domingo G & Affonso DD. A personality measure of Erikson's life stages: the Inventory of Psychosocial Balance. *Journal of Personality Assessmen*t, 1990; 54(3&4): 574-580.		
69 a-f	Optimism - approach to life	Modified from Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety, self-mastery and self-esteem): a reevaluation of the Life Orientation Test. *Journal of Personality & Social Psychology*, 1994; 67(6): 1063-1078.		
70 a-kk	Life events	Modified from Norbeck JS. Modification of life event questionnaire for use with female respondents. *Researching in Nursing & Health*, 1984; 7: 61-71.	29	Some items added, some deleted
71 a-j	Sources of stress	WHA	27	The 2 friend items were combined into one.
72 a-k	Depression - CESD	Andresen EM. Carter WB, Malmgren JA & Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D. *American Journal of Preventive Medicine*, 1994; 10: 77-84.		
73	Life isn't worth living	WHA		

No.	Question description	Source	Question in baseline	Modifications from baseline
74	Self-harm	Modified from Beck A, Schuyler D & Herman I. Development of the Suicide Intent Scale. In Beck AT, Resnick HLP & Lettieri D. *The prediction of suicide*. Bowie PA: Charles Press, 1974.		
Juggling time				
75 a-h	Time use	WHA, items modified from ABS (1992) Time use survey.		
76	Types of work	WHA	59-61	Combined into 1 question rather than 3 separate questions and item added.
77	Satisfaction with hours in paid work	Modified from ABS (1992) Time use survey. Canberra: ABS, 1993.	64	Only used one item out of the baseline question
78	Reason for wanting fewer hours of work	WHA		
79	Reason for not doing more hours of work	WHA		
80	Satisfaction with child care arrangements	WHA	68	
81 a-f	Use of child care	WHA		
82	Care for others	Modified from ABS (1993) Disability, Aging and Carers Australia	69	
83 a-b	Rushed/pressured	Modified from Statistics Canada (1985)	62-63	Combined into 1 question rather than 2 separate questions.
Family and friends				
84 a-j	Who lives with you	Modified from ABS (1994) Social, Labour and Demographic Statistics	67	Parent item split into 3 separate items.
85 a-c	No. of children at home	WHA		
86 a-i	Getting on with other people	Modified from Neale AV, Hwalek MA, Scott RO & Stahl C. Validation of the Hwalek-Sengstock elder abuse screening test *Journal of Applied Gerontology*, 1991; 10(4): 406-418.	72	
87	Living arrangements	ABS Census dictionary. 1996 Catalogue No. 2901.0		
88	Marital status	ABS Census dictionary. 1996 Catalogue No. 2901.0	84	Different version of ABS question.
89	Violence	WHA - Violence substudy		
90 a-e	Type of violence	WHA - Violence substudy		

No.	Question description	Source	Question in baseline	Modifications from baseline
91	Social support available - MOS SSS	Sherbourne CD & Stewart AL. The MOS Social Support Survey. *Social Science & Medicine*, 1991; 32(6): 705-714.		
You and your life				
92	Number of moves in past 3 years	WHA		
93	Postcode	WHA	88	
94	Highest qualification	Modified from ABS Census. 1996.	78	
95	Main occupation of self and parents	ABS. Australian Standard Classification of Occupations Second Edition. 1997. Catalogue No. 1220.0. From the Web page.	66	Updated items, and responses for mother/stepmother and father/stepfather.
96	Education level of parents	WHA		
97	Ever been unemployed	WHA		
98	Income	WHA		
99	Number dependent on this income	WHA		
100	Date of birth	Modified from ABS. A Directory of Concepts and Standards: for Social, Labour and Demographic Statistics. Canberra: ABS, 1994.	75	
You and your future				
101 a-e	Priorities in life	Modified from Youth Research Centre. ARC Questionnaire 1999. University of Melbourne.		
102	Employment at 35	Modified from Hakim C. Grateful slaves and self made women: fact and fantasy in women's work orientations. *European Sociological Review*, 1991; 7(2): 101-121.	89	
103	Job at 35	Modified from Hakim (1991)	90	
104	Relationship at 35	Modified from Hakim (1991)	91	
105	Children at 35	Modified from Hakim (1991)	92	More response options given
106	Qualifications at 35	WHA	93	
107 a-h	Satisfaction with life	WHA	94	Work/career/study now 3 separate items. Motherhood/children item added.

See Appendix 2 for the materials used in the young pilot follow-up.

4.3 SUMMARY OF RESPONSES TO EACH STAGE OF THE SURVEY (at 2 December 1999)

Table 14: Response to the pilot follow-up survey for the young cohort.

	Date sent 1999	Number Sent/Phoned	Surveys Received (Cumulative)	Response Rate (Cumulative)
Mail out of surveys	31 August	372		
Thank you/reminder	21 September	369	70	18.9%
Second reminder card	18 October	168	167	45.1%
Telephone reminder	1 November	153	212	57.6%

4.4 SUMMARY OF QUALITY ASSURANCE CHECK FOR NON-RESPONDERS

On 2 October 1999, a 'quality assurance' check on non-responders was conducted, as only 121 surveys (33% response rate) had been returned. Twenty participants were randomly selected and telephoned, firstly to see whether they received the package, and secondly to ascertain whether there was any particular reason for not completing it.

From these 20 participants, 12 needed "tracking" as the contact details for them had changed. Below is a breakdown of the results.

4	Had completed the survey but had not yet posted it
4	Had moved and never received the survey (surveys were resent)
4	Have moved and we have not yet been able to contact them
2	Said that they would complete it
2	Participant is "lost". Cannot find new details.
1	Was ineligible as participant was 52 years of age
1	Withdrawal - too busy
1	Currently overseas
1	No answer on the original number

Since running the quality assurance check, 11 surveys (55% of the 20 women who were telephoned) have been received. The whereabouts of five (25%) of these non-respondents is still unknown.

As this resulted in an extra 55% response rate, a telephone reminder for the rest of the non-responders (153 of the 372 participants) was conducted on 1 November 1999.

5 SECOND REQUEST FOR CONSENT TO ACCESS MEDICARE/ DEPARTMENT OF VETERANS' AFFAIRS DATA

In March 1997 the participants in the longitudinal study were asked to give their consent for the Health Insurance Commission to provide linkable information to the researchers on use of medical services funded by Medicare and the Department of Veterans' Affairs. At that time

about 20,000 women provided written consent. Data relating to services for the two-year period 1995-1996 for these women have been received, linked to WHA survey data and analysed (see Section 7.2.2).

In September and October 1999, all participants who had not yet consented for the release of their Medicare/DVA data were invited to consider the request again. The request accompanied the regular newsletter to these participants. The letter, information sheet and consent form used in 1997 were revised, based on comments from the Department of Health and Aged Care, the Health Insurance Commission, the Department of Veterans' Affairs and The University of Newcastle Human Research Ethics Committee. The period of time covered by the consent form was 1995 to 2001, in keeping with the consent period for the women who responded at the first request.

The revised letter, information sheet and consent form are shown in Appendix 3.

A summary of responses to this second request is shown in Table 15.

Table 15: Response to the second request for consent to access Medicare/DVA data in the three cohorts.

	Young	Mid age	Older	Total
Requests sent	8,334	4,759	4,763	17,856
Number (%) returned (as of 2 December 1999	792 (9.5%)	893 (18.8%)	959 (20.1%)	2644 (14.8%)
Return to Sender	722	203	82	1007

Consent forms are still being received and the Return to Senders are currently being 'tracked'.

6   DATA ARCHIVING AND ACCESS TO DATA

6.1   DATA ARCHIVING

The baseline datasets for the three cohorts will be archived at the Social Science Data Archives (SSDA) at the Australian National University by the end of 1999. Archiving will preserve the data as a valuable resource and will make the data available for future use by other researchers, subject to the access conditions described below.

Access Conditions
All researchers who seek access to data sets supplied by the SSDA will be asked to sign and return an Undertaking Form in which they agree:

1   to acknowledge the original depositor and distributor in any work based on the data;
2   to deposit, with the Archives, two copies of any published work based on the data (to assemble information about the use of archival resources and to facilitate the exchange of information about users' research activities); and
3   to refrain from redistributing the data to others without the permission of the Archives.

The Research Institute for Gender and Health (RIGH) plans to impose additional access conditions on use of the data. RIGH wants to be informed of each request to use the data, in order to give or withhold permission. Permission must be granted by any two of Study Director, Project Manager and Study Statistician prior to the data being released. In addition, the user will be required to obtain permission in writing from RIGH before publishing any interpretation of such materials. This policy will ensure that RIGH is informed of the use being made of the data, to comment on that use and to make contact with colleagues with similar interests.

RIGH is to receive a copy of each piece of research based on the data.

It will further be specified that all manuscripts based in whole or in part on these data should:

1   Identify the data, original investigators and data distributors, by including the bibliographic reference for the data file given below:

Research Institute for Gender and Health, University of Newcastle, Australian Longitudinal Study on Women's Health baseline data, 1996 [computer file]. Canberra: Social Science Data Archives, The Australian National University, 1999.

2   Declare that those who carried out the original analysis and collection of the data and provided the data (the Research Institute for Gender and Health and the Social Science Data Archives) bear no responsibility for the further analysis or interpretation of them,

3   Acknowledge the Commonwealth Department of Health and Aged Care as the funding agency for the project.

Material to be deposited
A User's Guide containing a description of the study, copies of the questionnaires and coding frame, and a description of the data file format has been compiled for each data set. The User's Guides also refers interested researchers to the WHA website for further information about the study.

A data dictionary has been developed that describes the source of each item in each questionnaire, the exact wording of the item and the responses, the coding scheme and gives a reference to similar items in the baseline and follow-up surveys for each age cohort. This data dictionary will be archived as an Access 97 database.

The data files for the baseline data for each age cohort will be archived as text files. Files containing the labels and formats for each variable and a file of raw frequencies for each variable will also be archived.

The set of forms that are required by the SSDA to accompany each data set deposited at the SSDA include:

1.   Licence Form – which determines how the data and associated materials may be used;
2.   Schedule of Materials Deposited – a list of all the materials that are being sent to the SSDA that acts as an inventory of the deposit;
3.   Study Description Form – the information is used to write a standard SSDA Study Description and Catalogue Entry for the data set;

4. Data Deposit Form – this form documents the details of all computer-readable files that are being deposited at the SSDA and is used by SSDA programmers to read and check the files.

6.2 DATA ACCESS POLICY

Overview

Data collected by researchers associated with the project are held by The University of Newcastle or The University of Queensland. Data may be made available to collaborating researchers and requests for specific data analyses will be considered, provided that a formal request is submitted. The procedures for requesting access to data and data analysis are described below.

Access to datasets

A researcher who seeks access to the ALSWH data sets (a 'client') must submit a formal application in writing to the project manager, stating the purpose of the proposed research and the justification for the research. If the submission is approved, the client is asked to agree (in writing) to the terms and conditions for collaboration on the project, as described in the Memorandum of Understanding (MOU - see Appendix 4). An investigator from the ALSWH team will be assigned to collaborate with the client.

The terms of the MOU refer to the "Guidelines to ownership and access to data and publications" document and the privacy protocol for the project (see Appendix 4), which detail the requirements for authorship, publication, acknowledgement, data storage and security. Clients are also required to agree (in writing) to the terms set out in the confidentiality agreement, which describes their obligations of confidentiality (see Appendix 4).

Once approved, the ALSWH collaborator is responsible for monitoring the progress of the analysis and should document this in the 'collaborators' folder which is held in the RIGH office. Copies of all papers and reports arising from this collaboration, as well as statistical programs and analyses relating to these, are to be provided to the ALSWH data manager on completion of the project.

Data analysis

Requests for ad hoc data analysis are received from time to time from government agencies, academic and non-academic institutions, and other interested parties. An ad-hoc data analysis service will be provided to clients from the Department of Health and Aged Care (to a maximum of 400 hours per year, as part of the contract for the current funding period). Requests for data analysis from other researchers will be undertaken on a full cost recovery basis, provided that resources to perform the analysis are available. The cost of the task will be provided in writing before any analysis is performed.

All requests for analysis must be made in writing and should include:
- aim of the research
- brief background/rationale
- specific analyses required
- preferred method of presentation (eg. excel tables, text file)
- time frame
- details of person to contact for further information

The ALSWH statistician, or a person nominated by her, will liaise with the client to ensure optimal outcomes from this process.

6.2.1 DRAFT PROTOCOL FOR DATA ANALYSIS REQUESTS FROM THE DEPARTMENT OF HEALTH AND AGED CARE

Background
The contract between The University of Newcastle and the Department allows for up to 400 hours of adhoc analysis of the data sets as requested by the Department. This section outlines some of the issues for discussion in developing an agreed approach to requesting such data analysis.

Objectives
The objectives of having the facility of adhoc data analysis are to maximise the use of the existing data and to highlight areas where further study and/or analysis may be required. A streamlined process is required making effective use of the hours available.

Possible processes
The following points outline a possible approach:

a) The Departmental Reference Group (DRG) establishes a coordination person(s). This could be one nominee from DRG or a small group.

b) Division, branch or program area identifies the questions or data items for which analysis is required. This could be cross tabulations from the survey questions or a program related question (eg injury prevention).

c) The request is sent to the coordinator(s) whose role would be to assess the priority of the request, keep a log of the requests and monitor the use made of the responses.

d) The coordinator sends the request to the Study Manager in an agreed format. This could include contact details of person requesting, questions of data, time when response required, purpose of the request etc. The Study Manager would check if such analysis has already been undertaken (eg by PhD or honours student) or if this has been a subject of study (eg via the Data Archive).

e) Study Manager provides (to the coordinator):
   - an estimate of the time to undertake the analysis;
   - contact details of researchers who have already looked at this issue (if appropriate); &
   - any other issues that need to be considered (eg ethics, data validity etc).

f) Work proceeds according to priority accorded to it.

Priority criteria
What criteria should be used to prioritise requests? This issue may not arise if there is limited interest in adhoc data analysis, however, it would be useful to be clear on the criteria in the event that the requests exceed the 400-hour limit.

Some of the criteria could be:
- the Minister or his/her office requested information that could be obtained from the data sets;
- the Departmental executive requested the analysis;
- the analysis is required for program development or evaluation;
- the request will take less than 10? hours;
- no other researchers have looked at this particular issue from the data sets.

Monitoring

The 'request' arrangements will need to be monitored to check if the processes are operating well and that the information received is used. This could be a role for the coordinator.

Recommendation

It is recommended that the Reference Group discuss the issues outlined above and agree on a process for requesting adhoc data analysis from the Study.

7 REPORTS ON SUB-STUDIES

Most of the sub-studies outlined in this section involve additional data collection.

7.1 PROTOCOL FOR THE CONDUCT OF SUB-STUDIES

The following table provides a summary of the steps which are required to conduct a sub-study.

PI =   Proposed investigator
WHAC =   WHA collaborator
PM =   Project manager
RA =   Research assistant
UN =   University of Newcastle
DM =   Data manager
CDHAC = Commonwealth Department of Health and Aged Care

Substudy: ....

PI: ....

WHAC: ....

STAGE	STEPS	WHO	CHECK LIST
Preparation	1. Proposal to UN team.	PI	
	2. Circulate to UN team for discussion.	PM/RA	
	3. Appoint nominated WHA collaborator.	PM/WHAC	
	4. Copy of proposal to be filed in sub-study proposal folder.	RA	
	5. Feedback to proposer/modify/resubmit.	WHAC	
	6. Develop MOU, sign and send to proposer.	WHAC/PM	
	7. Signed MOU to WHA office.	PI	
	8. File MOU and revised proposal.	RA	

Ethics	1. Prepare UN ethics proposal and project materials - submit to WHA for review (ethics for PI's institution may also be required). The ethics statement must be put on the letter to the participants.	PI
	2. Check main study and sub-study timetable - advise PI.	WHAC
	3. Feedback to PI - modifications.	WHAC/PI
	4. Submit ethics application to UN ethics committee.	WHAC/PI
	5. Provide copy of ethics application to RA for WHA.	WHAC
	6. Respond to ethics committee comments.	WHAC/PI
	7. Provide ethics approval form to RA for WHA.	WHAC
Sample	1. Draw sample for sub-study (excluding those in previous sub-studies).	DM
	2. All project materials to PM for final check/approval.	WHAC/PM
	3. Sample details to PI.	DM
Implement	1. PI to brief research staff on all protocols for conduct of sub-study.	PI
	2. Provide written information and log files for 1800 telephone at WHA office at UN.	PI / PI
	3. Provide all change of address details, names of "Return to Sender" subjects to RA within one week of receipt of this information. Check phone log regularly.	PI
	4. Provide regular feedback to WHAC on progress/problems with sub-study.	
Reporting and data	1. Provide copies of all reports, papers, thesis (if applicable) etc to WHA office.	PI
	2. Provide hard and electronic copies of all data analyses to DM in WHA office.	PI
	3. Provide summary of sub-study for UN reports to CDHAC, and for newsletters as requested.	PI
	4. Produce a fact sheet of the findings for the participants.	PI

7.2   COMPLETED PHD THESES

7.2.1   IRON DEFICIENCY IN WOMEN OF CHILDBEARING AGE

Dr Amanda Patterson (RIGH, University of Newcastle)
Supervisors: Dr Wendy Brown (principal supervisor);
                    Professor David Roberts (associate supervisor)

The current prevalence of iron deficiency for Australian women of childbearing age is unknown, but baseline data from the Australian Longitudinal Study of Women's Health

(ALSWH) suggest that one in three women have had diagnosed iron deficiency by the age of 45-50 years. Despite this, dietary and lifestyle factors which are important in the development of iron deficiency have not yet been clearly defined for Australian women, and the public health impact of this condition remains unclear. In addition, while the Australian Iron Status Advisory Panel (AISAP) currently recommends dietary intervention as the first line of treatment for iron deficiency in adults, the efficacy of dietary treatment has not been evaluated. This thesis describes a series of studies which examine the development, implications and treatment of iron deficiency for Australian women of childbearing age.

A detailed literature review provides background information on the physiology of iron, the biochemical and haematological variables used to assess iron status, and the current definitions used for the diagnosis of iron deficiency. Iron deficiency has been shown to adversely affect work performance, immunity, thermoregulation and cognitive functioning, and the research describing these relationships is reviewed. Dietary and lifestyle factors thought to be important determinants of iron status, and the current strategies used in the prevention and treatment of iron deficiency are also discussed.

The PhD work included two preliminary studies. The first was a general practitioner (GP) survey and pathology audit which examined the knowledge, attitude and behaviour of GPs in relation to the diagnosis and treatment of iron deficiency. While diagnosis practices were generally in accordance with AISAP recommendations, treatment practices were not. Supplementation was the preferred treatment option in even mild cases of iron deficiency, and this preference may reflect the poor dietary knowledge of GPs in relation to enhancers and inhibitors of iron absorption. The second preliminary study was an epidemiological analysis of baseline and follow-up data from the ALSWH to determine the impact of self-reported iron deficiency on general health and well-being (measured using the Short Form-36 General Health and Well-being questionnaire; SF-36) for two large cohorts of Australian women. Baseline and longitudinal analysis of these data showed reduced vitality and physical and mental health for women who reported iron deficiency.
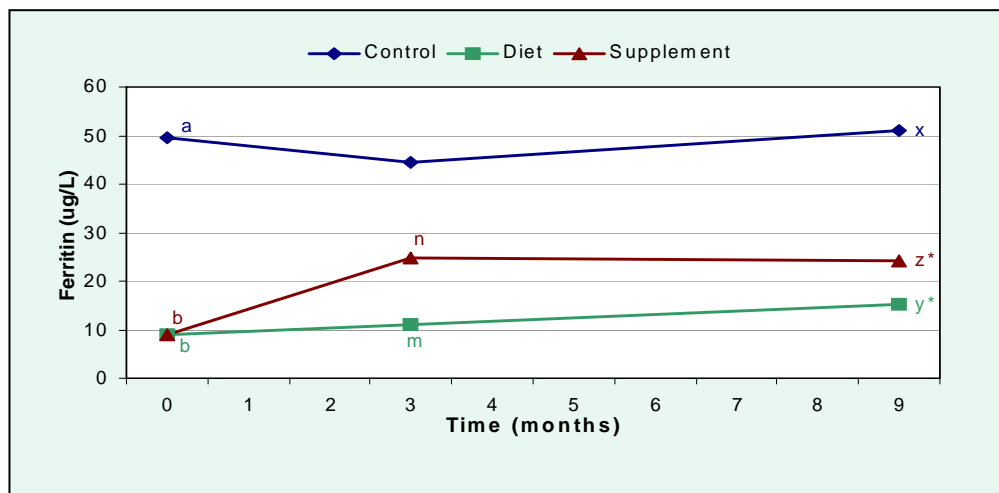
The major component of this research was a randomised control trial which compared dietary and supplement treatment for iron deficiency. Baseline dietary, lifestyle and morbidity data were examined for iron deficient and iron replete women. Multivariate analyses were used to investigate the relative importance of dietary and lifestyle factors in the development of iron deficiency for women of childbearing age. Iron status was positively associated with oral contraceptive pill use and alcohol consumption and negatively associated with phytate intake. The effects of iron deficiency on general health and well-being, fatigue and cognitive functioning were examined using the SF-36 general health questionnaire, the Piper Fatigue Scale and four subscales of Wechsler Adult Intelligence Scale-Revised (WAIS-R), respectively. Iron deficiency was associated with decreased mental health, vitality and cognitive functioning, and increased fatigue in the baseline data.

Dietary and supplement treatment for iron deficiency and the relative effects of each on general health and well-being, fatigue and cognitive functioning were compared. Both dietary and supplement treatment resulted in significant improvements in haemoglobin and serum ferritin, but changes in serum ferritin were seen more quickly for the supplement group. Women in both the diet and the supplement intervention groups showed significant improvements in general health and well-being, fatigue and cognitive functioning during the trial. Improvements in mental health were more marked among women in the diet intervention group, while vitality and fatigue improved similarly for women in both groups.

Women in both groups also improved similarly on two subscales of the WAIS-R which assess reasoning and perceptual organisation.
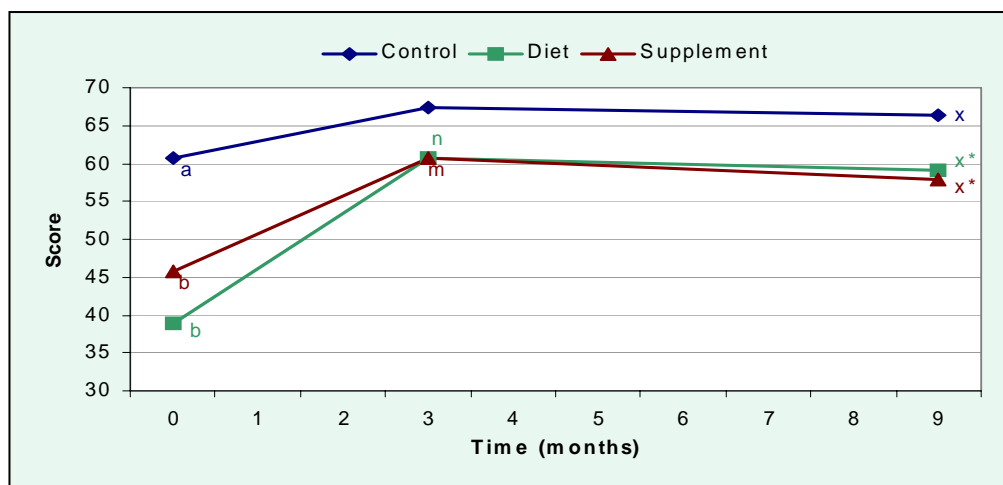
From this research it is clear that women who suffer from iron deficiency experience major morbidity in terms of vitality, fatigue and general health and well-being. Dietary intakes of alcohol and phytate have been highlighted as possible factors in the determination of iron status, and dietary treatment of iron deficiency has been shown to be effective.

Figure 2: **Mean (sd) serum ferritin results for the control, diet and supplement groups at baseline (time=0 months), following the three month intervention and after the six month follow-up.**

*   Diet or Supplement group changes significantly over time
a,b   Comparison of Control, Diet and Supplement groups at T0 (different letters = significantly diff.)
x,y,z   Comparison of Control, Diet and Supplement groups at T2 (different letters = significantly diff.)
m,n   Comparison of Diet and Supplement groups at T1 (different letters = significantly diff.)

Figure 3: **Mean (sd) Vitality (VT) scores from the SF-36 for the control, diet and supplement groups at baseline (time = 0 months), following the three month intervention and after the six month follow-up.**

*   Diet or Supplement group changes significantly over time
a,b   Comparison of Control, Diet and Supplement groups at T0 (different letters = significantly diff.)
x,y,z   Comparison of Control, Diet and Supplement groups at T2 (different letters = significantly diff.)
m,n   Comparison of Diet and Supplement groups at T1 (different letters = significantly diff.)

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7.2.2 GENERAL PRACTITIONER UTILISATION AMONG WOMEN IN AUSTRALIA

Dr Anne Young (RIGH, University of Newcastle)
Supervisors: Professor Annette Dobson & Dr Julie Byles

General practice is the first point of contact for the provision of health care services in Australia and is the gateway to more intensive and specialised services. Despite the existence of a national health insurance scheme (Medicare) there is growing debate about the equity of access to health services, especially for people living in rural and remote areas of Australia.

This study examined the use of general practitioner (GP) services during 1995 and 1996. The framework for the study was the behavioural model of health service utilisation which includes measures of medical need and other individual and societal factors that may predispose, enable or impede use of services. Survey data for 20,000 participants in the Australian Longitudinal Study on Women's Health were linked with data from the Health Insurance Commission which administers Medicare. The survey data included a range of questions designed to explore social and environmental aspects of women's lives as well as the psychological and biological determinants of health and health care utilisation. The Health Insurance Commission data provided a measure of GP utilisation and the out of pocket cost associated with each consultation (for services funded by Medicare and the Department of Veterans' Affairs), for each woman who gave written consent to record linkage.

Using the linked database, the demographic characteristics, medical history and health service utilisation of very frequent attenders and non-attenders to general practice were described. These data provided insights into the use of GP services that could not be determined from either source alone. Although some findings were consistent across age groups, the profile of frequent attenders differed according to life stages such as pregnancy and menopause. The difficult personal and social circumstances of some women were demonstrated in case studies which highlighted the importance of considering the context in which use of health services takes place.

A third source of data for the research was a substudy to provide additional measures of individual and environmental determinants of health service use and satisfaction with GPs among a sample of almost 5,000 mid age and older women participating in the longitudinal study. This substudy provided strong quantitative evidence to support the qualitative reports of the problems faced by women living in country areas. The availability, accessibility and affordability of services were rated lower by women living in rural and remote areas than by women living in urban areas (Figure 4 and Figure 5).

Many studies have adapted the behavioural model to examine the utilisation of a variety of types of health services, but the model requires more complex analysis than the traditional statistical techniques employed by most researchers. Insights were gained by using structural equation modelling, in addition to multiple linear regression and Poisson regression modelling, and by including out of pocket costs in the model.

The use of GP services was shown to be determined primarily by medical need. Also the out of pocket cost per visit tended to be lower for women with lower socioeconomic status. These findings suggest that the system is equitable in these dimensions. However the out of pocket

cost for GP services increased with distance from urban centres, which shows that the charges imposed by GPs are not equitable across place of residence. Higher cost was associated with lower use of services, even among women considered to have high levels of need for care.

The findings from these cross-sectional data suggest a need to regulate the costs of GP services to patients, particularly in rural areas. The study also highlights the need to improve the delivery of GP services especially in rural and remote areas. The longitudinal study will be well placed to monitor access to health services from the viewpoint of women throughout Australia and to assess the effectiveness of policy changes. For example, if the number of medical practitioners in rural and remote areas increases, especially female GPs, the negative relationship between geographical isolation and perceived access to care shown in this study should be reduced. Improved access should also be reflected by better ratings of satisfaction with GP services.

The long-term impact of the geographical inequity in services on health outcomes for women remains to be determined. The results of this research provide the rationale for the continued monitoring of the use of GP services among women in Australia and provide a mechanism for the evaluation of strategies designed to achieve equity of access to health care. In addition, longitudinal analysis of linked databases will enable the outcomes of use of health services to be examined and should be considered a priority for research in Australia.

Figure 4:   Percentage of mid age women in the Health Services sub-study (n=2,445) who rated items as 'fair' or 'poor' (on a scale of excellent/very good/good/fair/poor) by area of residence (within NSW).
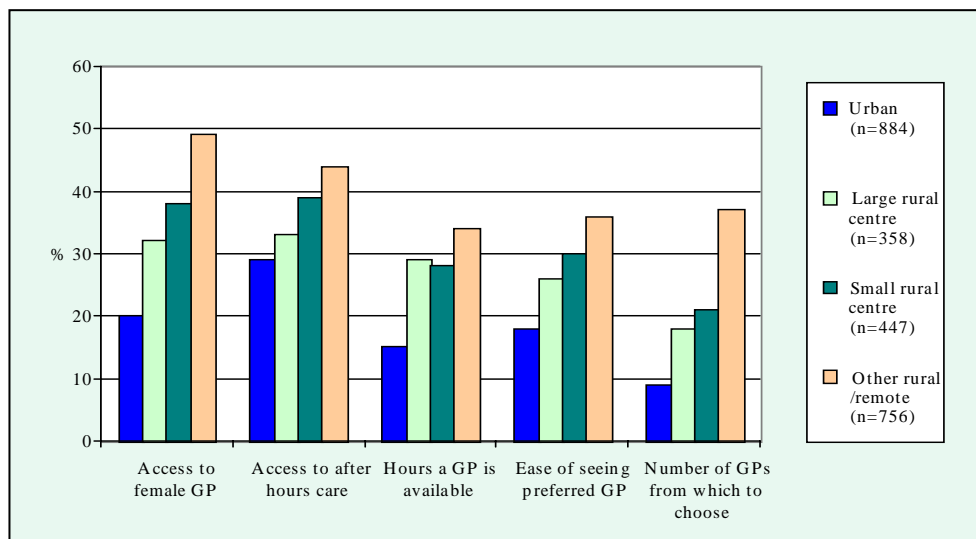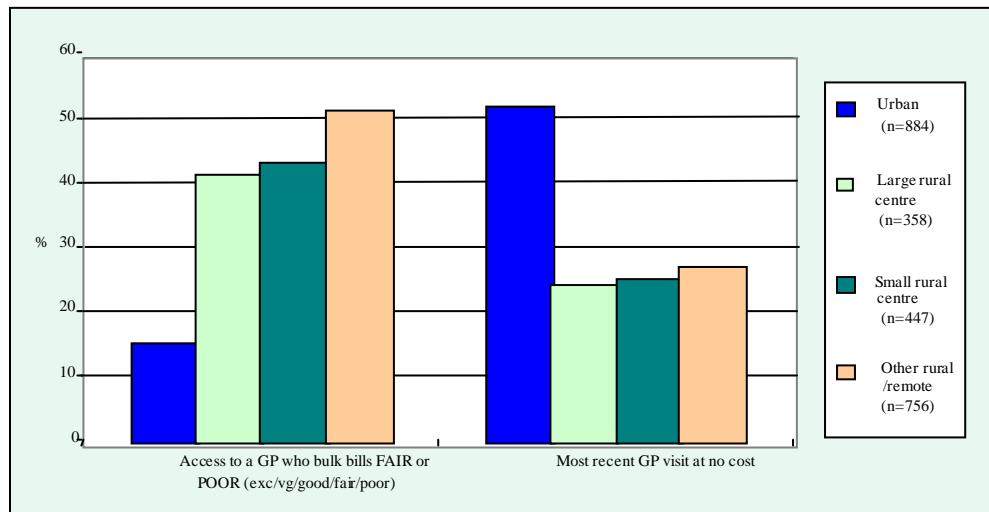
Figure 5:   Financial aspects of GP care reported by mid age women in the Health Services sub-study (n=2,445) by area of residence (within NSW).

7.2.3   DISORDERED EATING, PSYCHOLOGICAL STRESS AND COPING IN YOUNG WOMEN

PhD candidate: Ms Kylie Ball (RIGH, University of Newcastle)
Supervisor: A/Professor Christina Lee

While disordered eating among young women is generally believed to be multifactorially determined, two factors frequently implicated for their hypothesized etiological importance are psychological stress, and a reliance on maladaptive coping strategies. A review of empirical evidence indicated strong support for the concept that stress and inadequate coping strategies were major precursors of disordered eating, but also identified a number of conceptual and methodological limitations.   Most significantly, prior research was characterized by a reliance on cross-sectional methodologies, from which no conclusions regarding causal relationships can be made. A series of interconnected research studies was therefore designed to address these issues and investigate in detail the relationships between stress, coping and disordered eating in young Australian women. Firstly, the relationships between these variables were assessed cross-sectionally in two community surveys. Results of these quantitative surveys were supplemented with those of several qualitative studies, assessing young women's perceptions of relationships among stress, coping and disordered eating. Finally, a longitudinal study, targeting women with reported eating pathology, was conducted, with multiple regression and structural equation modelling used to investigate causal relationships between the study variables. Overall, the cross-sectional data indicated strong relationships between stress, coping and disordered eating; this was supported by qualitative findings suggesting a strong perception among young women that stress triggered subsequent eating pathology. However, results of longitudinal analyses, demonstrating only tenuous relationships between the study variables, did not support the hypothesis that stress and coping strategies predict disordered eating over time. These findings, while contrary to general opinion in the eating disorders literature, are consistent with those of the few previous longitudinal studies reported, and suggest that stress, coping and disordered eating may be closely intertwined, occurring concurrently among young women. Future studies replicating and extending these results could help to further clarify our knowledge of the mechanisms

underlying these relationships, and, ultimately, to increase our understanding of the complex etiology of disordered eating.

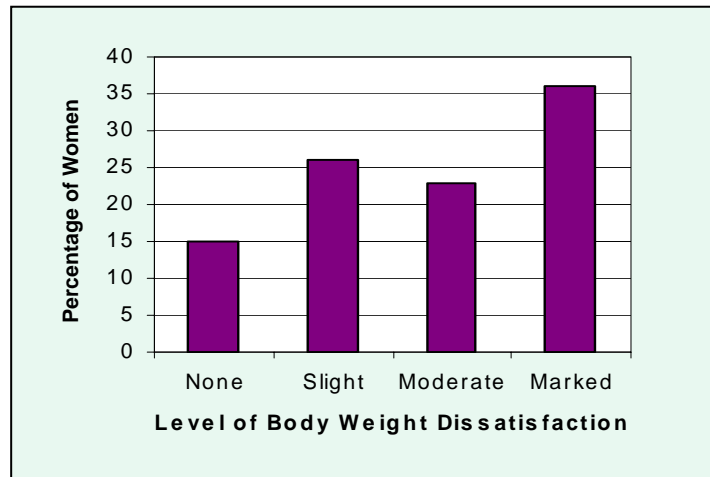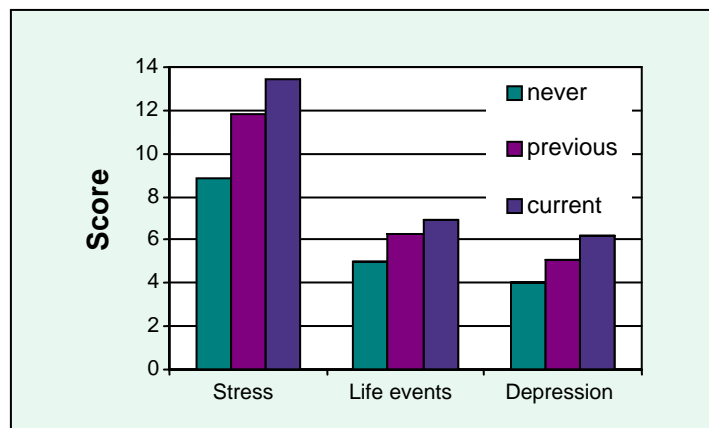**Figure 6: Body weight dissatisfaction among young women.**

Figure 7: Eating disorders and psychological well-being

7.3 COMPLETED HONOURS PROJECTS

7.3.1 VIOLENCE AND ABUSE: AN ASSESSMENT OF MID-AGED WOMEN'S EXPERIENCES

Honours candidate: Ms Glennys Parker (Psychology, University of Newcastle)
Supervisor: Associate Professor Christina Lee

Little systematic research has been conducted in Australia to develop a picture of mid-aged women's experiences of violence and abuse across their lifetime. The present study was designed to address this deficiency by assessing the prevalence rates of different types of

abuse, the situations in which they occur, how women coped, and the effect of abusive encounters on general health and well-being. Measures included descriptive variables, the SF-36 physical and mental health summary measures, the GHQ-12 instrument for psychological distress, and the CES-D depression scale. Using self-report questionnaires, data were obtained from 1159 mid-aged women previously recruited in the Women's Health Australia longitudinal project. The most frequently reported forms of abuse were emotional, physical and sexual. These overwhelmingly occurred in the home across all life stages, but mostly in adulthood and on an occasional or weekly basis. Almost all perpetrators were persons known to the victim and many women were afraid for their personal safety. Most abusive encounters persisted over time and were attributed to the personality of the perpetrator, alcohol, relationship problems, or financial concerns. The majority of women had discussed their circumstances with close relatives, friends, or professional persons, and one-third of respondents had reported abusive episodes to the police. Criterion measures of poorer physical and mental health, psychological distress, depression, and subjective perception of negative effects were predicted by frequent, but non-recent, abuse in adulthood that had continued over time and was most likely to be physical mistreatment or harassment. Other predictors were perpetrators being a blood relative, spouse, partner, or some other known person, wanting to leave the situation but not being able, and talking to professional counselling providers but not intimate confidants. It is recommended that wider recognition of gendered abuse and its impact on psychological functioning would be useful for sensitive intervention strategies implemented by social welfare agencies and private consultants.

7.3.2   EXAMINATION OF THE PSYCHOMETRIC PROPERTIES OF THE WHA STRESS SCALE: A MEASURE OF PERCEIVED STRESS FOR YOUNG AUSTRALIAN WOMEN.

Honours candidate: Ms Sandra Hickling (Psychology, University of Newcastle)
Supervisor: Associate Professor Christina Lee

This study examined the psychometric properties of validity and internal reliability for the WHA 'Young' Stress Scale, designed to measure perceived stress among young Australian women. Data from the 'young' baseline survey of the Women's Health Australia (WHA) study, and additional data collected from University of Newcastle undergraduates, were used for this purpose. There were 14,779 young women participants in the baseline study, and 111 in The University of Newcastle study, all aged between 18 and 23. The validity of the scale was determined by examining its relationships with other stress measures, mental health, physical symptoms, and health behaviours. The University of Newcastle data were also examined with two different scoring methods, and the differences between using a 6 and 12 month time frame was also assessed. Results provided evidence that the scale is internally reliable, with a single stable factor. The scale was found to he related to mental health, physical symptoms, smoking, and alcohol consumption. Convergent validity was found with life events, feminine gender role stress, and daily hassles. The scoring method that takes into account only those items that respondents consider to be relevant to their lives, was found have the highest correlations with the concurrently measured variables. It was concluded that the use of the WHA 'Young' Stress Scale to measure stress levels in young women in Australia, was both a valid and appropriate use of the data. Due to the small numbers in the validation study, future research should entail a repetition of this study to strengthen the findings, and a re-test reliability study to determine the extent to which the construct measured by the scale is best seen as a state or trait characteristic.

7.4 SUB-STUDIES FUNDED BY OTHER SOURCES CONDUCTED THIS YEAR

7.4.1 SOCIAL SUPPORT, HEALTH STATUS AND HEALTH CARE UTILISATION IN WOMEN AGED 70-76 YEARS
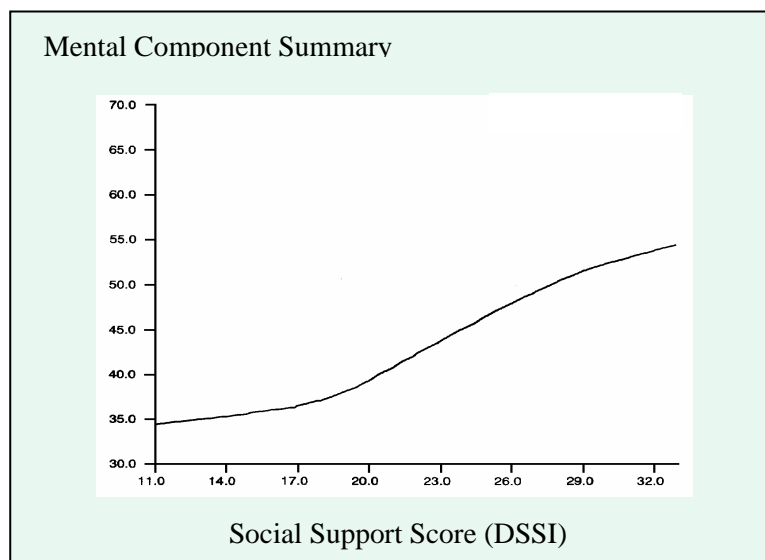
PhD candidate: Mr Brendan Goodger (CCEB, University of Newcastle)
Supervisors: Dr Julie Byles & Dr Gita Mishra
Funding source: Public Health Research Development Committee Scholarship provided by the NHMRC

This substudy has two main stages. The first stage involved analysis of social support, measured by the Duke Social Support Index amongst older women who responded to the WHA baseline survey. Higher social support was associated with increased health-related quality of life, medication use, use of general practitioner services and life satisfaction. By contrast those with lower social support had higher scores for nutritional risk and elder abuse scores. The relationship between social support and the mental health summary score of the SF-36 can be seen in Figure 8. Higher social support scores were associated with higher mental health scores. In addition, those older women with low support had significantly worse mean scores on a range of health measures. It is estimated that 8% of older participants in WHA have low support, 14% have fair support and 78% have high or very high support. The second stage involves a three year prospective study (with annual follow up) of a stratified sample of women with low and high social support. Data for this second stage have been collected and are being analyzed.

Figure 8:   Mental health and social support among women in the older cohort (aged 70-76 years in 1996).

7.4.2 THE EFFECTIVENESS OF LEGAL PROTECTION IN THE PREVENTION OF DOMESTIC VIOLENCE AMONGST YOUNG AUSTRALIAN WOMEN

PhD candidate: Ms Margrette Young (RIGH, University of Newcastle)
Supervisors: Prof Annette Dobson, Dr Julie Byles
Funding source: Criminology Research Council and NHMRC Scholarship

In the 1996 baseline survey, 12% of women in the youngest WHA cohort reported they had been in a violent relationship with a boyfriend, partner or spouse. To obtain information about the relative effectiveness of police assistance, court orders and other forms of help, an in-depth telephone interview survey has been conducted.

Due to difficulties locating these young women, only 56% were contacted; of those contacted 87% participated in the interviews. The study focused on physical rather than emotional or psychological abuse.

For most of the women the violence had ceased regardless of whether or not they had obtained legal protection. However those women who did seek help from the police or courts had experienced more severe levels of violence and they also experienced the greatest improvements - in no case was violence worse after legal intervention. Court orders tended to be more effective than police assistance alone, but as the availability of alternative forms of protection may vary in different parts of Australia, this finding needs further analysis. The results so far suggest that for most young women (and their children), separation is effective for reducing violence and legal assistance is beneficial.

7.4.3 FACTORS THAT INFLUENCE WEIGHT CHANGE AT MENOPAUSE

PhD candidate: Ms Lauren Williams (RIGH, University of Newcastle)
Supervisor: Dr Wendy Brown
Funding source: ARC Small Grant

The menopausal years (ages 45-55) are a recognised time of weight gain in women. The baseline survey of the Australian Longitudinal Study on Women's Health showed that 48% of 13,431 women aged 45-50 in 1996 (mid-age cohort) were overweight or obese, and 22% reported gaining more than 5kg without wanting to in the six months prior to the survey. To prevent weight gain, and associated health consequences, we need to understand why women gain weight at this life stage. A study of factors influencing weight change at menopause will firstly examine changes in health status for the entire mid-aged cohort according to menopausal status in the interval between the baseline and first follow-up surveys. Next a nested cohort study of the mid-aged WHA women who have experienced menopause between the baseline survey in 1996 and the first follow-up in 1998 will be conducted. Focus group discussions have already been held with groups of women who have experienced menopause to examine their experiences of weight change and factors which influence that change. Results from the focus groups were used to compile a survey instrument measuring weight change and factors which influence weight. This survey instrument was sent to 1164 women who had changed menopausal status between 1996 and 1998. 811 completed surveys have been returned (69.7% as of 2 December 1999). Results from this study will have the potential to help prevent weight gain in women as they become menopausal.

7.4.4 IRON DEFICIENCY AND MENSTRUAL BLOOD LOSS IN AUSTRALIAN WOMEN

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

This study will examine the factors that underlie iron deficiency in Australian women. Data from the baseline surveys of the ALSWH suggest a lifetime prevalence of iron deficiency of 33%. Despite this high prevalence it is not clear whether iron deficiency occurs as a result of inadequate intake of iron from the diet, or excess loss of iron from menstrual blood. In this study, menstrual blood loss (mbl) will be measured in a large group of working women. In order to clarify the relationships between mbl, diet and iron status, a dietary study will be undertaken with subsamples of women with low to very high mbl. The effect of iron status on cognitive functioning, immunity, tiredness, vitality and well-being will be determined. These factors will then be re-examined after an intervention study involving iron supplementation. This study will answer important questions about the determinants of iron deficiency and it's physical and social sequelae in Australian women.

7.4.5 COGNITIVE FUNCTIONING AND HORMONE REPLACEMENT THERAPY IN POSTMENOPAUSAL WOMEN

PhD candidate: Ms Kerrilie Rice (Faculty of Human Development, Victoria University of Technology)
Supervisor: Professor Carol Morse
Funding source: Royal Melbourne Institute of Technology University Allowance

The sub-study aims to provide a methodologically sound investigation that will allow a better understanding of the possible relationship between the physical, psychological and cognitive symptoms of menopause and circulating oestrogen in HRT users and non-HRT users. This collaborative project between Professor Carol Morse and Kerrilie Rice (both of Victoria University of Technology) and WHA will target urban Victorian women in the "middle-age" cohort. The sub-study will provide important information as to how changes in oestrogen levels, as measured objectively, may influence physical, psychological and cognitive functioning in postmenopausal Australian women.   It will also provide invaluable information regarding a possible relationship between oestrogen levels, HRT use and the risk of dementia states in a population of Australian women and help establish a database of information for future research in older women's mental functioning.

7.4.6 PSYCHOSOCIAL PROBLEMS OF SUFFERERS OF INTRACTABLE ANGINA

PhD candidate: Mr Esben Strodl (Psychology, University of Queensland)
Supervisor: Assoc Prof Justin Kenardy
Funding source: Australian Postgraduate Research Award

Psychosocial variables have repeatedly been found to be associated with the presence of heart disease. Analysis of data from the 70 to 74 year old WHA cohort will form the first of three studies to further examine these relationships. In particular the data will be analysed to examine the following questions:

1) What proportion of women aged 70-74 years participating in WHA have heart disease compared with the proportions of women with other chronic conditions?

2) How do the measures of pain, stress, health behaviours, time pressure, social support, mental health and social functioning compare among women with heart disease and the next most prevalent chronic conditions (excluding those with heart disease)?

3) Of those who have heart disease, is there a difference in psychosocial factors between those who have no or minimal chest pain and those who have moderate or severe chest pain?

4) Of those who have heart disease which psychosocial factors best predict mental health?

7.4.7 ASPIRATIONS OF A GROUP OF YOUNG AUSTRALIAN WOMEN IN RELATION TO WORK, EDUCATION, RELATIONSHIPS AND CHILDREN

PhD candidate: Ms Lisa Milne (Sociology & Anthropology, University of Newcastle)
Supervisors: Dr Deidre Wicks
 Dr Gita Mishra
Funding source: ARC Small Grant

Broadly, this project attempts to increase our understanding of young women's aspirations regarding paid work and relationships, and the role of situational factors in the formation and maintenance of aspirations. Accordingly, the aspirations of young women reported in the baseline WHA survey and changes between the baseline and follow-up surveys will be explored. The key factors which influence the formation and development of aspirations will be investigated, and participants will be asked how hopeful they are about the realisation of these aspirations. Semi-structured telephone interviews carried out with approximately fifty women drawn from the young cohort will provide the primary data for this analysis.

7.4.8 ASSESSING THE PREVALENCE OF BODY DISSATISFACTION AND FACTORS ASSOCIATED WITH BODY DISSATISFACTION IN THE YOUNG COHORT

Masters candidate: Ms Fiona Campbell (Discipline of Behavioural Science in Relation to Medicine, University of Newcastle)
Supervisor: Dr Libby Campbell
Funding source: Discipline of Behavioural Science, University of Newcastle

This project is being undertaken as part of the Masters of Health Science (Women's Health). It will use data from the baseline survey from the WHA Project . The aims of this project are to:
1. Assess the prevalence of body dissatisfaction (with weight and shape) amongst Australian women 18-23yrs in 1996;
2. Assess whether demographic variables, self-reported weight, perceived "weight status", the use of weight control methods, lifestyle behaviours and level of satisfaction with personal achievements are associated with level of body dissatisfaction.

7.4.9 A LONGITUDINAL STUDY OF WOMEN WITH MENSTRUAL SYMPTOMS, TREATMENTS TRIED, HYSTERECTOMY AND SATISFACTION WITH OUTCOMES

Masters candidate: Ms Melissa Graham (School of Health & Human Sciences, La Trobe University)
Supervisors: Dr Helen Keleher
    Dr Erica James
Funding source: Internal staff grant, La Trobe University

Hysterectomy is one of the most common gynaecological surgical procedures performed of a non-obstetric nature. Australian statistics indicate that just over one in ten women will undergo a hysterectomy by the age of 40, and around one in five women will undergo a hysterectomy before the age of 50. The appropriateness of hysterectomy to treat non-malignant conditions has been debated in recent years. Current literature suggests that there are many gaps in the research about the impact of hysterectomy on women's lives. A variety of procedures, less traumatic than hysterectomy, are available to treat menstrual symptoms successfully. Factors such as socio-economic status, social support, geographical location and education, menopause and emotional and sexual consequences of menstrual symptoms, may influence choice of treatment and satisfaction with treatment. To investigate some of these issues, two studies are being conducted. Both involve women in the mid-age cohort (45-49 years of age in 1996) who indicated that they experienced menstrual symptoms. The first study is a prospective cohort study which aims to determine women's satisfaction with the outcomes of hysterectomy compared to alternative treatments. The second study is a retrospective cohort study and aims to determine women's reasons for having a hysterectomy. Women in the second study are those who have had a hysterectomy since 1996, as identified in the first follow-up survey of these women in 1998.

7.4.10 WOMEN AND EMOTIONS

Masters candidate: Ms Barbara Reen (CCEB, University of Newcastle)
Supervisors: Assoc Prof Nick Higginbotham
                 Dr Carla Treloar
Funding source: Part funding by CCEB

The experience of emotions such as anxiety or unhappiness has been recognised in Australia and world-wide, as imposing a significant health burden on women. Overseas studies have pointed to the importance of economic, cultural and social factors in contributing to the experience of these emotions. To gain insight into the complex ways in which these factors influence women's emotional experiences, this project will move beyond the written questionnaire to collect more detailed and in-depth information through telephone interviews lasting from 35 - 60 minutes. Approximately 20 women from the WHA mid-age group who live in small rural and remote areas of Australia will be randomly selected and invited to talk about the ways in which their emotional experiences affect their lives. The project will build up a picture of the pressures placed on women living in isolated rural and remote areas and it will explore the ways the women respond emotionally to these pressures. By listening to the women talking about their experiences, about their own strengths and weaknesses and about the ways they cope it is hoped that the project will identify needs for care which are not being met adequately and generate ideas for practical ways of responding to these needs.

7.4.11 HEALTH CARE SEEKING AND HEALTH CARE EXPERIENCE IN RURAL AND URBAN NSW

Collaborator: Dr Margaret Harris (CCEB, University of Newcastle)
WHA Collaborator: Dr Julie Byles
Funding source: NSW Health

A series of focus group discussions and in-depth interviews was conducted to explore: 1) the health care seeking behaviours of mid-aged men and women in rural and urban New South Wales (NSW); and, 2) health care access for older women in rural and urban NSW.

Focus group discussions and in-depth interviews were conducted to collect the data. Women were recruited through the WHA data base and clubs such as Senior Citizens associations, and men through service clubs and contacts known to the researchers. Preliminary results for the mid-aged participants (part one of the study) indicate three major themes: access to health care; satisfaction with health care; and approaches to health care. Each major theme consists of several minor themes. The most striking differences between men and women were evident in the minor themes relating to attitudes towards waiting to see a general practitioner (GP), and to health care obtained from GPs in general. Time was a stronger influence on GP choice for men than for women. Motivators, influences to seek care and choice of who to see differed according to gender. Expectations of health care for men were more outcome oriented, while women focussed more on the process. Indirect costs associated with consulting a GP seemed more important to men. Approaches to health care presented the most striking differences based on gender, for example, the theme of scepticism towards medical care was strong for men, but absent for women. Also, themes related to prevention such as diet and exercise were only identified in data from women. Data for the older participants (part two of the study) are still being analysed.

The final analysis of these data will cast more light on these similarities and differences in men's and women's attitudes to GP services, and indicate the role, if any, of area of residence.

7.4.12 ALCOHOL CONSUMPTION BY YOUNG AUSTRALIAN WOMEN: PATTERNS, HARMS, BEHAVIOURS AND PREDICTORS

Collaborator: Dr Helen Jonas (School of Health & Human Sciences, La Trobe University)
WHA Collaborators: Dr Wendy Brown, Prof Annette Dobson
Funding source: Victorian Health Promotion Foundation

A comprehensive survey based on earlier questionnaires devised for the Carlton Women's Survey and for young women drinking in hotel environments was distributed during October 1999 to a sample of young women (21-26 years) already enrolled in the WHA longitudinal study. The 1999 sub-study survey asked young WHA women about their patterns of drinking, any drinking-related consequences, and their attitudes, behaviours and beliefs about alcohol. These data, combined with information from the WHA baseline survey (conducted in 1996), will be used to examine alcohol consumption and related consequences, using regression analyses and structural equation modelling. Qualitative analyses will also be conducted on a further sub-sample of Victorian women. This will be the first longitudinal study in Australia to generate comprehensive information on young women's knowledge, attitudes, beliefs and behaviours in relation to alcohol, and the multiple factors that influence their drinking patterns and related consequences. Such information is vital for the design of effective education and prevention programs.

7.4.13 MID AGE WOMEN AND HEART DISEASE: UNDERSTANDING RISKS AND PREVENTION

Collaborator: Dr Marilys Guillemin (Centre for the Study of Health & Society, University of Melbourne)
WHA Collaborator: Dr Wendy Brown
Funding source: University of Melbourne & Australian Menopause Society

There is a paucity of research examining how women perceive their risk of heart disease and the strategies that they employ to prevent heart disease in later life. Indeed, there is little research examining how women understand heart disease and its relative importance for their current and future health. This is despite the fact that cardiovascular disease is one of the major causes of mortality and morbidity in women in Australia. The *Mid-age women and heart disease* sub-study seeks to understand better the relationship between heart disease in mid-age women and its associated risk factors. Furthermore, the sub-study will examine how women with heart disease understand their illness and its impact on their lives.

The mid-age cohort of the WHA study comprises over 14,000 women. Results of the 1998 follow-up survey indicate that 319 women from this group report having been told by a doctor that they have heart disease. A selection (n~230) of these women will comprise the sample for the first component of this sub-study. This first component will analyse the existing data from the WHA 1996 baseline data and the 1998 follow up data on self-reported

prevalences of heart disease and established risk factors, including smoking, high blood pressure, elevated blood cholesterol, diabetes, physical inactivity and obesity as well as social and psychological factors, including self-reported stress. In addition, a questionnaire survey will be administered to ask women about: details of their heart disease, awareness of heart disease prior to being diagnosed, process of diagnosis, perceived risk factors of heart disease, and the management and preventive strategies they employ. The second component of the sub-study is a qualitative study on how mid age women understand heart disease and their perceptions of risk of heart disease. This will involve in depth interviews with 25 mid-age women from the WHA mid-age cohort from urban and rural Victoria who have been diagnosed with heart disease.

The sub study is currently under way. Pilot interviews are being carried out and the questionnaire survey is undergoing final refinement before being distributed nationally.

7.4.14 WOMEN'S LEISURE? WHAT LEISURE?

Collaborator: Dr Peter Brown
WHA Collaborators: Dr Penny Warner-Smith, Dr Wendy Brown,
                             Emeritus Prof Lois Bryson
Funding source: ARC Small Grant

What do women do for leisure? How much time do women have for leisure – if any? What constraints are there on women's leisure? How do women's experiences of leisure change as they get older? How does leisure for women in the bush differ from that of women in the city? And – very importantly - what kind of impact do these experiences and constraints have on women's health? While the WHA baseline surveys showed that a large proportion of women felt rushed, pressured, busy or stressed, and would like more active and passive leisure time for themselves, little is known about women's leisure in Australia.

Within the longitudinal study, there is (intentional) over representation of women from rural and remote areas of Australia. With funding from a small ARC grant for a preliminary substudy research, data on women's leisure are being gathered by means of focus groups in different geographical areas. Focus groups with WHA participants have already been conducted in Newcastle, West Wyalong and Dubbo, in order to take account of women's locational diversity.

Separate meetings have been held for young women and mid-age women, and already it seems fairly clear that there are (not surprisingly) major differences between these age groups. But there are also differences within each group, depending on factors such as family stage and relationships. For example, a widow whose children are in their late teens feels that she has too much leisure time, while another woman of the same age whose children are still at school says that she has about one hour a week, at the most, which she can call her own. For her, leisure is not about wanting to 'do' things, but about having time on her own, perhaps away from her family, when she can relax. A number of women in these discussion groups have pointed to strong associations between leisure and their mental health, rather than just their physical health and fitness.

There are also great differences in leisure opportunities and experiences for women in the country compared with those in the city. For example, our Newcastle based participants, who

are used to being able to see a film whenever they fancy, were surprised to learn that women in West Wyalong have to travel to Wagga to go to the movies. A community venture in West Wyalong is 'The Bland Bizarre' (sic), which is a co-operative of local craftspeople, mainly women, who sell their produce through the shop and take turns two or three days a month behind the counter. Profit above a certain commission goes to charity. The woman who was working there when the Newcastle team visited said that she likes doing community work, as long as it doesn't involve 'taking a plate'. On the previous day she had done the recording for a golf competition in which her husband was playing. "I don't mind what I do, but I'm not going to take a plate ever again," she said. Her comments raise the question of differences between the city and the country in the persistence of cultural expectations of women's role in facilitating men's leisure.

The research team hope to build on this preliminary research to conduct the first national study of women, leisure and health in Australia.

7.4.15 PROMOTING PHYSICAL ACTIVITY THROUGH CHILD CARE CENTRES: A RANDOMISED CONTROL TRIAL

Collaborators: Dr Peter Brown, Dr Wendy Gunthorpe
WHA Collaborator: Dr Wendy Brown
Funding source: NSW Health

Young adult women are less likely to be sufficiently physically active than their male counterparts. Furthermore, data from the Australian Longitudinal Study on Women's Health indicate that, among young women with children, only 46 % are adequately active, compared with 56 % of young women without children. The aim of the current study is to determine the efficacy of two strategies which aim to increase the level of habitual physical activity among women, compared with no intervention. A randomised cluster design was used with 7 centres in each of the three clusters. 542 women were recruited from the 21 randomly selected child care centres in the Hunter region. They completed a baseline survey about their patterns of, and attitudes towards, physical activity. Women in cluster 1 received no further information. Women in cluster 2 received written information about the importance of physical activity and a directory outlining local contacts for physical activity participation. Cluster 3 participants were invited to attend a meeting at which the investigators facilitated talk about strategies for increasing participation in physical activity. The strategies explored at each meeting were followed up with short-term community development interventions in each local community. Each participant who completed a baseline survey will be invited to complete further surveys in November and March in order to explore changes in physical activity over time.

7.4.16 INCONTINENCE IN AUSTRALIAN WOMEN: FOLLOWING UP PARTICIPANTS IN THE AUSTRALIAN LONGITUDINAL STUDY ON WOMEN'S HEALTH

Collaborator:　　　　Ms Pauline Chiarelli
WHA Collaborators:　Dr Wendy Brown, Prof Annette Dobson
Funding source:　　　Department of Health and Aged Care

Initial analysis of baseline data found the proportion of women reporting 'leaking urine' was 13.8% in the young cohort, 36.1% in the mid-age cohort and 35% in the older cohort. Lower scores on the physical and mental component summary scores of the SF-36 suggest lower quality of life among women who report leaking urine, compared with those who do not. However, fewer than half of those who reported leaking urine had sought help for the problem. 500 participants were selected randomly from those in each cohort who reported leaking urine 'often' at baseline. In the young cohort, women who reported leaking urine 'sometimes' were included in the sampling frame as insufficient women reported leaking urine 'often'. This substudy aims to explore issues relating to urinary leakage in more detail. These include the frequency, severity and type of leakage, help-seeking and treatment outcomes, coping strategies, and awareness of treatment and prevention strategies.

7.4.17 VEHICLE AND DRIVER ATTRIBUTES AFFECTING SITTING DISTANCE FROM THE STEERING WHEEL IN MOTOR

Collaborators:　　　Dr Michael McFadden, Michelle Walker
WHA Collaborators:　Dr Wendy Brown, Jenny Powers
Funding source:　　　Australian Transport Safety Bureau

Past research has demonstrated that women sit closer to the steering wheel than men. Variations in sitting distance from the steering wheel between male and female drivers may partially account for the higher rate of injury sustained by women drivers. The current study investigated whether women sit closer to the steering wheel because they are physically smaller. Driver body dimensions and multiple measures of sitting distance from the steering wheel were collected from a sample of 150 men and 150 women. The results confirmed that, on average, women sit closer to the steering wheel than men and that this difference was accounted for by variations in body dimensions, especially height. Consideration should be given to vehicle design that allows independent adjustment of the distances between the drivers seat, the steering wheel and the floor pedals. The results also suggest that height of drivers may provide a good surrogate of sitting distance from the steering wheel when investigating the role of driver position in real world crash outcomes.

7.4.18 THE MEASUREMENT OF SOCIO-ECONOMIC STATUS OF AUSTRALIAN WOMEN

Collaborator: Ms Kylie Ball
WHA Collaborators: Dr Gita Mishra, Prof Annette Dobson, Dr Penny Warner-Smith
Funding source: Research Management Committee Project Grant, University of Newcastle

There is an increasing need to find a better method of determining socio-economic status (SES) level, since it often has an important influence on the results of studies in many fields. In terms of improved reliability, and revealing new associations more clearly in the WHA study, the results may contain important implications for conclusions and ultimately health policy.

This research project will develop a more accurate and reliable measure of SES than those currently available, using statistical techniques to address many existing limitations. The method will be tested using National Health Survey data for the general population, and the SES index applied as a predictor of social and health outcomes in Australian women. In terms of improved reliability and revealing new associations more clearly, the results may contain important implications for policy arising from these and other studies.

7.4.19 CHANGES IN HEALTH DURING THE MENOPAUSAL TRANSITION

WHA Investigators: Dr Wendy Brown, Dr Gita Mishra
Funding source: Lilly Asia Pacific Ongoing Research Grant

The aim of the proposed study is to analyse mid-life changes in health and well-being among four groups of mid-age women (including women who are pre-menopausal, peri-menopausal and post-menopausal who are not taking HRT and a fourth group of women who are taking HRT).

It is hypothesised that: there will be significant differences in health indicators between these groups of women at baseline (1996 survey); health indicators for women whose menopausal status changes between 1996 and 1998 (follow-up) will show significantly greater deterioration than health indicators for those whose menopausal status remains constant, or those who are taking HRT; and that changes in BMI during the period 1996-1998 will be significantly associated with changes in health indicators during this period.

7.4.20 THE REAL AUSTRALIAN WOMEN

WHA Investigators: Dr Wendy Brown, Dr Amanda Patterson
Funding source: Hestia Pty Ltd

The project aims to determine what size and shape Australian women really are, how this varies from what clothing and lingerie manufacturers believe, and what effect this has on women's body image and self-esteem. Body shape data are available from a study of more than 6000 women in 1926, so we can determine how women's body shape has changed over

the last 73 years, with improvements in health and nutrition, and an increasing focus on the 'thin ideal'.

Four hundred and fifty women will be assessed in three states (NSW, Victoria and Queensland). They will complete a questionnaire and have their height, weight, waist, hip and bust measurements taken.

Preliminary results will be released to the media on the 7 December 1999.

This project will enable us to gain a better understanding of the size and shape of Australian woman in 1999 and to use this information to help clothing manufacturers understand what women want and need. We believe that being able to buy clothes and lingerie that fit properly and look good can do a lot to improve women's own body image and self-esteem and have an indirect effect on health and well-being.

7.4.21 DO LIFE EVENTS REALLY AFFECT HEALTH?

WHA Investigators: Prof Annette Dobson, Dr Gita Mishra, Ms Elizabeth Stojanovski
Funding source: ARC Small Grant

The experience of negative life events has been recognised to bear an association with onset of physical and mental illness. This study examined the relationship between negative life events and health by examining data from women in the mid-age group who participated in both the baseline and the first follow up surveys.

The longitudinal data allowed health at both times as well as possible mediating factors to be considered. Such mediating factors included age, smoking habits, marital status, occupation and social support. Structural equation modelling was used to model the data allowing repeated measures of the same items at different times to be examined.

Negative life events were found to bear a significant association with health when prior levels of health and mediating variables were not considered. However after these factors were taken into account, the association between negative life events and health was considerably weakened.

8 DISSEMINATION

8.1 ABSTRACTS OF PRESENTATIONS 1999

Lee C, Brown WJ, Mishra G & Bauman A. Physical Activity Among Three Age Cohorts Of Australian Women: Relationship With Well-Being And Symptoms. US Society of Behavioural Medicine. San Diego, USA, 3-6 March 1999.
It is well established that moderate physical activity is a causal factor in the reduction of coronary heart disease and all-cause mortality, as well as the promotion of physical and psychological wellbeing. Until recently, most epidemiological research has focused on men. Baseline data from the Women's Health Australia project, a large-scale longitudinal survey of factors influencing the health of Australian women, were used to explore the hypothesis that exercise which equates with moderate physical activity on most days of the week will be

associated with increased well-being and decreased symptoms. Baseline surveys of women in three age groups, selected from the Australian national health insurance database, and conducted by mail in 1996, recruited 14,762 young women (18-23 years), 14,065 mid-aged women (45-50 years) and 13,023 older women (70-75 years). Comparison with census data showed these cohorts to be largely representative of Australian women in those age groups.

Self-reported vigorous and less vigorous activity were used to determine a physical activity (PA) category, and logistic regression was used to examine PA's relationship with physical and mental summary scores of the SF-36 (PCS, MCS), symptoms (e.g., tiredness, back pain, stiff joints) and medical conditions (hypertension, osteoporosis).

Significant associations were found between PA and PCS and MCS in each age group (p<.001). Odds ratios for a range of symptoms were lower for women who reported low/moderate activity (for example, for young women, OR for constipation = 0.76 (CI 0.65-0.89); for mid-aged women, OR for tiredness = 0.70 (0.63-0.78); for older women, OR for clumsiness = 0.72 (0.64-0.81) compared with sedentary women). There was no threshold level of PA at which health benefits appeared to increase significantly. The findings suggest that low/moderate levels of exercise are associated with a wide range of health benefits for women of all ages.

Jonas HA & Brown WJ. Alcohol Consumption Patterns In Australian Women: Influences Of Lifestyle, Physical Health And Emotional Well-Being. Alcohol and Gender in Europe: Trends, patterns and problems. Berlin, Germany, 24-26 March 1999.
During 1996, over 40,000 women in three age-groups (18-23 years, N=14762; 45-50 years, N=14071; 70-75 years, N=13022) completed mailed baseline questionnaires for the population-based Women's Health Australia (WHA) longitudinal study on women's health. These questionnaires provided self-reported data on a range of demographics, physical characteristics, lifestyle patterns (smoking, alcohol consumption, diet and exercise), stressful life events, stress levels, and a variety of physical and emotional health measures (e.g., SF-36 Health survey, illnesses, common complaints, operations and medications). Women were asked how often they usually drank alcohol, how many drinks they usually had when they drank alcohol, and how often they drank 5 or more drinks on one occasion.

The responses for usual patterns of drinking were categorised as "non-drinker", "rarely drink", and the three National Health and Medical and Research Council (NHMRC) categories of "low harm" (up to 2 standard drinks/day), "hazardous" (2.01-4.00 drinks/day) and "harmful" (4+ standard drinks/day). "Binge drinking" (5 or more drinks/occasion) was categorised as "never", "monthly or less" and "weekly or more".

In the WHA study, <5% and <1% of the women in all three age groups reported drinking at hazardous and harmful levels. However, the young women drank less frequently than the mid-age and older age groups and drank greater amounts on their drinking days. "Binge drinking" was far more prevalent in the younger women (weekly or more: 17%; monthly or less: 53%). A third of the older women were abstinent. The rates of abstinence and higher risk drinking were associated with higher levels of mental and physical health problems, stress and stressful life events, and these associations varied between each of the age-groups.

Williams L & Brown W. How Do Women Explain Weight Change At Menopause. International Menopause Society Congress. Cairns, Queensland, 27-30 June 1999.

<u>Objective:</u>   Baseline data of the Australian Longitudinal Study on Women's Health (ALSWH) found 22% of women in the mid-age cohort (45-50 in 1996) reported gaining more than 5kg without wanting to in the six months prior to the survey. To understand why women gain weight at this life stage, behavioural and environmental determinants of weight change at menopause will be explored by questionnaire with a nested cohort of approximately 1200 menopausal women from the ALSWH mid-age cohort. In order to develop an appropriate questionnaire for the study, focus group discussions were held to discuss with women their own experiences and perceptions of why their weight did or did not change during menopause.

<u>Findings:</u> Three focus group discussions were held in a rural area and two in a metropolitan area of NSW. Participants discussed physical changes and symptoms associated with menopause which varied between individuals. Many participants had experienced weight gain, which they explained by aging or lifestyle related factors rather than an effect menopause per se. However each group raised the belief that hormone replacement therapy causes weight gain. While the women recognised the benefits of optimal diet and physical activity, they elucidated several barriers to achieving these goals, most notably role changes as children left home and some degree of emotional eating in response to menopausal symptoms.

<u>Conclusions:</u>   The focus group method provided information for the development of a comprehensive and relevant questionnaire to quantify these factors within the cohort of menopausal women.

Bryson L. Three Generations Of Women's Health In The New Millenium. Health for all: Primary Health Care Research & Evaluation in the 21st Century. Adelaide, SA, 30 June - 1 July 1999.

Drawing of the Women's Health Australia project the paper is concerned with key issues for the health of three generations of women in Australia into the new millenium. Against a background of their broad life course characteristics, the Women's Health Australia project (funded by the Department of Health and Aged Care) plans to track the health of a national sample of around 41,000 women for 20 years. The women, in 1996, were in the age cohorts 18-22, 45-49 and 70-74 years. Early findings highlight diversity, with significant differences in the health issues for the three age groups (and sub-groups within) which require tailored approaches, services and policy. In terms of general well-being and service appropriateness, the young are the most problematic, followed by the mid-group. Despite age related poorer general health, the older women indicate fewest problems, while the young women report the highest levels of stress, are often tired, are over concerned with their weight and body shape and are the most dissatisfied with GP services. Another issue for women's well-being, particularly young women's, is that of contraception. While virtually all the young women do, or intend to, control their fertility, available forms of contraception (and safe sex) remain problematic for health and other reasons.

The evidence also suggests that a combination of paid and family work has been normalised for women. Over 90 per cent of the young women aspire to be combining family and paid work at the age of 35 years. Findings from the mid cohort show that such a combination is

generally associated with better health. However there can also be strains which become issues that must be addressed in the pursuit of health for all.

Brown W & WHA researchers. Workshop - Determining Priorities For Women's Health Promotion. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.

<u>Aims</u>: To demonstrate a method which can be used by health workers who have responsibility for policy, planning or delivery of services, to determine priorities for health promotion action.

<u>Format</u>: The workshop will begin with an overview of the available empirical evidence about women's health, from both standard data collections (eg hospital records) as well as population based surveys (including the Australian Longitudinal Study on Women's Health). Participants will be invited to identify additional issues which are experienced by women in other areas. There will then be a discussion about the criteria which might be used to prioritise issues for health promotion action, in light of limited resources which are often available for such work. Having agreed on the criteria, participants will be invited to take part in a nominal group process (modified Delphi technique) to try to identify priorities for health promotion action. (If there are participants from very different cultural backgrounds we may not be able to develop consensus - but will identify a broad range of priorities.

Brown W & WHA researchers. Symposium: The Australian Longitudinal Study On Women's Health. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.

<u>Background</u>: The Australian Longitudinal Study on Women's Health was established in 1996. It aims to explore the sociological, biological, psychological and environmental determinants of good health for Australian women. The study involves three cohorts of women (young women (N=14,762) who were aged 18-23 at the time of the baseline data collection in 1996; mid-age women (N=14,072) 45-50 years; and older women (N=12,767) 70-75) who were selected randomly from Australia's national Medicare database. The aim is to track the health of the same women over twenty years, so that by 2016 we will have data from women of all ages between 18-95, a span of 77 years.

The aim of this symposium is to provide an overview of the initial years of this longitudinal study, focusing specifically on:

- Recruitment - problems in trying to achieve a representative sample
- Developing survey materials with an interdisciplinary perspective
- Conducting nested cohort studies
- Keeping in touch with participants
- Statistical analyses and data linkage, integrating statistics with qualitative data.

The symposium will begin with an overview of the study (20 minutes). This will be followed by three individual 20 minute presentations, selected to illustrate three of the study's main themes, as well as inter-disciplinary nature of the project:

- Health Service Utilisation (Anne Young, Annette Dobson, Julie Byles) - Statistics
- Healthy weight and exercise (Wendy Brown, Christina Lee) - Health behaviours

- Juggling time - time use and women's health (Penny Warner-Smith, Lois Bryson, Peter Brown) - Sociology.

Following these presentations there will be the opportunity for participants to discuss any aspects of the study, and to ask questions of a panel of researchers. The symposium will be valuable for any groups who are considering establishing longitudinal and/or interdisciplinary women's health research.

Brown W, Mishra G & Dobson A. Healthy Weight And Exercise. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.
This paper will explore the associations between weight, exercise and health and well-being in mid-age Australian women. 13,341 women who participated in the baseline surveys of the Australian Longitudinal Study on Women's Health provided information about height, weight, physical activity and a range of indicators of health and well-being.

Women who reported healthy weight (BMI = 20-25 kg.m^2) and physical activity on two-three days per week had higher scores on the physical and mental components summary scale of the SF-36 well-being scale and lower use of health care services, than women who were underweight, or who reported inactivity or very low levels of physical activity.

The results provide empirical evidence that maintenance of healthy weight and low-moderate levels of physical activity have benefits in terms of general health and well-being. The implications of these findings will be discussed in relation to the development of health promotion strategies.

Young A, Byles J & Dobson A. Determinants Of General Practitioner Utilisation Among Women In Australia. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.
In Australia, women account for a large proportion of the health care services used, with some evidence of inequalities in use, particularly for women in rural areas. This study examined the use of general practitioner services, employing survey data linked with Medicare (national health insurance) data for 20,000 participants in the Australian Longitudinal Study on Women's Health.

The framework for the study was the Andersen-Newman model, which includes measures of medical need and other individual and societal factors, which may predispose, enable or impede use of services. This model requires more complex analysis than offered by most traditional statistical techniques and so structural equation modelling was used.

Although medical need was shown to have the strongest association with use of general practitioner services, insights were gained in to the complex relationships between other variables in the model, including access to care and satisfaction. The findings will help to inform health policy

Bryson L & Warner-Smith P. Hours Of Work And Women's Health. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.

In this paper we examine the links between hours of work and women's health, with a view to contribution got broader debates relating to women, work and social policy. Our empirical data are from the survey responses of a cohort of women in the longitudinal Women' s Health Australian (WHA) project. These women were aged between 45-50 years at the time of collection of the baseline data in 1996. There we investigate links between the hours the women are employed and their health, and we point to a strong association between better health and employment for women.

Patterson A, Brown W & Roberts D. Will Eating Steak And Spinach Make Olive's Iron Status The Same As Popeye's? Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.

Aim: To determine dietary, health and lifestyle variables which are important in the development of iron deficiency in Australian women of childbearing age.

Methods: Self-reported data on parity, lactation, oral contraceptive pill (OCP) use, menstrual blood loss, smoking, alcohol consumption, exercise, dieting and blood donation, and dietary assessments (7-day weight food records) were collected from 52 iron deficient women (serum ferritin $\leq$ 15μg/L, haemoglobin $\geq$ 95 g/L) and 26 iron replete controls (serum ferritin > 20μg/L, haemoglobin > 120g/L.

Results: (Iron deficient women reported lower current OCP use (p=0.049), fewer years taking the OCP (p=0.05) and less regular consumption of alcohol (p=0.001). Dietary phytate intakes were higher (p=0.02) and measured alcohol intakes were lower (p=0.0002) for iron deficient compared with iron replete women, but there were no differences in total iron, haem iron or calculated bioavailable iron intakes. A multiple regression model to explain iron status in these women will be presented.

Brown P & Brown W. Women Working At Leisure: Juggling Time In The Interests Of Good Health. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.

Leisure time is characterised by liberation from the constraints of employment, domestic work and other social obligations. Leisure is also an avenue for the promotion of health, through physical activity and the psychological benefits associated with enjoyable leisure activities and sociability. It is highly likely that recent changes in patterns of women's work may also have affected women's leisure, and that attempts to balance work and leisure may impact on women's health.

Some insight into these issues is provided through a review of selected data taken from the Australian Longitudinal Study on Women's Health. Baseline surveys were completed in 1996 by more than 41,000 young, mid-age and older women. Among the mid-age women (45-50 years, N=14,011) one in five felt rushed, pressured or too busy every day, and 38% felt more rushed than five years ago. About half the women said they would like more time for passive (43.9%) and active (52%) leisure; while only 2% reported no passive leisure, 18.7% reported no active leisure.

These findings will be reviewed in the context of interrelationships between work and leisure in women's lives and the practical and ideological significance of changes in patterns of labour market involvement on women's leisure and health.

Ball K & Lee C. Stress, Disordered Eating And Psychological Distress In Young Australian Women. Second International Interdisciplinary Conference on Women and Health. Edinburgh, Scotland, 12-14 July 1999.

Cross-cohort comparisons within the Women's Health Australia research programme indicate that young women (aged 18-23) have significantly greater psychological distress, body dissatisfaction, and disordered eating than the middle-aged and older cohorts. This paper draws on a subsample of 554 young women, to examine predictors of disordered eating, as measured by the Eating Disorders Inventory (EDI) and psychological distress, as measured by the 12-item General Health Questionnaire (GHQ-12).

Multiple regression analyses indicated that disordered eating was best predicted by perceived stress, preference for solitary coping strategies when stressed, and weight-related variables: weight dissatisfaction, actual-ideal weight discrepancy, and restrictive dieting. Perceived stress was also the strongest predictor of GHQ-12, but life events in the past year and use of emotional-focused coping strategies such as wishful thinking and time out added significantly to the variance.

These analyses suggest that disordered eating is not simply an age-and-gender-specific manifestation of general psychological distress, although there are overlaps between the two constructs. The findings add to existing evidence to suggest firstly that there is a need for interventions which promote psychological well-being among young women, and secondly that such interventions should be targeted to specific issues including weight concerns, perceived stress, and appropriate coping.

Goodger B, Byles J, Mishra G, Higginbotham N. Social Support: A Three Year Longitudinal Study Of Older Australian Women. The Aged Care Australia & Australian Association of Gerontology National Conference. Sydney, Australia, 5-8 September 1999

Background: Social support is now acknowledged as an important contributor to the wellbeing of older people. Despite increasing numbers of older women there has been no dedicated longitudinal study focussing exclusively on the relationship between social support and personal wellbeing of community dwelling older women living in urban rural and remote areas of Australia.

Design: A stratified random sample of 1000 participants were selected from over 12000 older women aged 70-75 who completed a baseline survey as part of the Women's Health Australia project. This subsample contained two groups of 500 women who had either low or higher levels of social support as measured by the 11 item Duke Social Support Index and were living in urban, rural and remote environments. The subsample was followed up for a period of four years with annual postal surveys which included measures on health related quality of life, health care utilisation, life satisfaction, health status and social support.
Analysis: To analyse trends in social support and other measures such as health related quality of life over time statistical techniques employed involved multilevel modelling. In the analysis we wanted to determine potential causative changes which influence levels of

social support and the impact of any such changes on health related quality of life, health care utilisation and health status.

Implications: This study will assist in identifying risk factors contributing to the maintenance of low support and secondly how changes in health influence patterns of social support. If amelioration of harmful environments is the outcome of public health research then these results will be of interest to those offering health promotion and clinical care to older people.

Graham M. Four Women's Experiences: A Longitudinal Study Of Women With Menstrual Symptoms, Treatments Tried, Hysterectomy And Satisfaction With Outcomes - A Substudy Of The Australian Longitudinal Study On Women's Health. 31st Annual Public Health Association Conference: Our place, our health: Local values and global directions. Darwin, Northern Territory, 26 - 29 September 1999.

Recent literature indicates that more than 20% of women in Australian have had a hysterectomy by the age of 50. However, there is very little research on women's satisfaction with the outcomes of hysterectomy in comparison to alternative treatments that are widely available. 'Four women's experiences' is an in-depth look at four women who had been experiencing menstrual problems and the implications for quality of life. The women's satisfaction with the outcomes of various treatments, including hysterectomy, were considered in relation to the social support they received, the amount of information provided to them about treatment options, and their experience with medical practitioners in the decision making process.

The purpose of conducting in-depths interviews was to aid in the development of a questionnaire for a an epidemiological sub-study of the Australian Longitudinal Study of Women's Health entitled 'A longitudinal study of women with menstrual symptoms, treatments tried, hysterectomy and satisfaction with outcomes'.

Rutnam R. Living With The Disadvantage Of Long Term Illness Or Disability – A Comparison Of Some Characteristics Of The Older Women's Cohort Of The Australian Longitudinal Study Of Women's Health (ALSWH). 31st Annual Public Health Association Conference: Our place, our health: Local values and global directions. Darwin, Northern Territory, 26 - 29 September 1999.

The new Commonwealth Department of Family and Community Services works towards a fair and cohesive Australian society.

The International Year of Older People 1999 is focusing attention on the implications of an ageing population. One of this Department's challenges is to assist in meeting the needs of people with disabilities as they age, as well as those with late onset disability.

Given the lack of national longitudinal data on aspects of living with disability, the Department is analysing baseline data from the ALSWH to determine its usefulness in filling this gap.

This presentation provides results of an analysis of responses from the older women's cohort (aged 70-75 in 1996). It looks at characteristics of women who did and did not need help with daily activities, in areas such as self-rated health, SF36 physical and mental functioning scores, use of preventive medicine, and social networks.

Brown WJ, Dobson AJ & the WHA Research Team. Women's Health Australia: On The Progress Of The Main Cohort Studies. 31st Annual Public Health Association Conference: Our place, our health: Local values and global directions. Darwin, Northern Territory, 26-29 September 1999.

More than 40,000 women aged 18 - 23, 45 - 50 and 70 - 75 years in 1996 are participating in the Australian Longitudinal Study on Women's Health. Baseline surveys were conducted for all three cohorts in 1996, with the first follow-up surveys of the mid-age group in 1998 and the older age group in 1999. In addition to the main surveys, there have been 14 nested sub-studies which aim to investigate selected issues in more detail. The main findings so far reflect the large differences in the life experiences of the three generations of women.

This paper will provide an update of the main findings, reflecting the interactions between social roles, life events and women's health, as well as the potential of the study to inform the development of improved health policies and services.

Brown W & Powers J. Managing a large population-based cohort study. 31st Annual Public Health Association Conference: Our place, our health: Local values and global directions. Darwin, Northern Territory, 26-29 September 1999.

The Australian Longitudinal Study on Women's Health is a multi-disciplinary study designed to determine the social, psychological, physical and environmental factors which effect the health of women throughout their adult life. In 1996, approximately 42,000 women in the young (18-23), mid (45-50) and older (70-73) age groups completed a baseline survey. A study of this size and complexity requires strategic planning, the development of policy and protocols, and management of people, funds and data. Data management issues include documentation of data items, the collection and quality of the data and allocation of space for the secure storage of the data. Finally, it is important to disseminate the information provided by the data to a wide audience including government departments, health providers, other researchers and most importantly the women who have participated in the project.

Powers J & Dobson A. Factors related to the health of Australian women aged 45-50. 31st Annual Public Health Association Conference: Our place, our health: Local values and global directions. Darwin, Northern Territory, 26-29 September 1999.

In 1996, Women's Health Australia sent a letter of invitation and questionnaire to a random sample of women registered on the Medicare database. Approximately 14,000 women aged 45-50 completed the baseline survey which consisted of 298 items covering perceived health, use of health services, common health problems, life style, weight and shape, juggling time, family and friends, and demographics. The aim of this presentation is to explore methods to identify the main concepts or dimensions in the data.

Forty questions were excluded from the analysis as they related only to subsets of the cohort (eg number of cigarettes smoked by ex-smokers), answers to questions such as other major illness which had already been included in the list of diagnoses, or too many values were missing (eg miscarried pregnancy). After recoding there was a total of 266 variables. Factor analysis and cluster analysis were used to identify the main factors, clusters or dimensions. These dimensions were considered relatively stable if they were identified by both methods in the complete data set and split data sets.

Less than 20 dimensions were identified. The major dimensions related to the eight sub-scales of the SF-36, which measures perceived health related quality of life. Other dimensions included menstruation, contraception and HRT, satisfaction with GP visit, weight and dieting, tobacco and alcohol consumption, marital status and children, employment and leisure.

In conclusion, the bulk of the variation was accounted for by the SF-36 dimensions and demographics. Other psychological variables such as stress, feeling sad and lonely, etc also loaded on these factors.

8.2 PUBLICATIONS 1999

8.2.1 Papers published

Byles JE, Feldman S & Mishra G. For richer, for poorer, in sickness and in health: older widowed women's health, relationships and financial security. *Women and Health*, **1999; 29(1): 15-29.**
Aim: This study contrasts the health and social needs of widowed older women with needs of married older women.
Method: 12,624 women aged 70-75 years across Australia completed baseline questionnaires for the Australian Longitudinal Study on Women's Health: 34.5% of the women were widowed, and 13.5% of these widowed women had lost their spouse within the past 12 months (recently widowed).
Results: Recently widowed women had particular physical and mental health needs as well as financial and practical needs relating to managing on their income. They had the lowest self-rated health, were most likely to report they were stressed about their health, and scored significantly lower than married women on all 8 sub-scales of the SF-36. Women were more likely to say they make their own decisions about their life if they were widowed than if they were married. However, stress with relationships with children or other family members was more likely to be reported by widows than other women.

Chiarelli P & Brown W. Leaking urine in Australian women: Prevalence and associated conditions. *Women and Health*, **1999; 29(1): 1-12.**
The paper aims to (1) assess the prevalence of leaking urine and to (2) explore associations between leaking urine and a variety of other symptoms, conditions, surgical procedures and life events in three large cohorts of Australian women, who are participants in the Australian Longitudinal Study on Women's Health. Young women aged 18-23 (N = 14,000), rnid-age women, 45-50 (N = 13,738) and older women, 70-75 (N = 12,417), were recruited randomly from the national HIC/Medicare database.

Leaking urine was reported by approximately one in eight young women [estimated prevalence 12.8% (95% Cl: 12.2-13.3)l and one in three mid-age women [36.1% (Cl: 35.2-37.0)l and older women [35.0% (Cl: 34.1-35.9)1. Leaking urine was significantly associated with parity, conditions which increase the pressure on the pelvic floor such as constipation and obesity, past gynecological surgery and conditions which can impact on bladder control. The study showed that fewer than half the women had sought help for the problem and that younger women were less likely to be satisfied with the help available for this problem.

Strategies for continence promotion, including opportunistic raising of the issue at the time of cervical screening and pregnancy care are suggested, so that the health and social outcomes of untreated chronic incontinence in women might be improved.

Ball K, Lee C, & Brown W. Psychological stress and disordered eating: An exploratory study with young Australian women. *Women and Health*, **1998; 29(1): 1-15.**
An exploratory study was conducted to examine whether the relationships between psychological stress and disordered eating, reported in many studies using American samples, would be found in a sample of young Australian women. A total of 212 women aged 18-22 years completed a questionnaire assessing a number of women's health issues, including life event stress levels, psychological distress, disordered eating behaviours, and concerns about weight and eating. While results showed few strong relationships between stress and eating variables for the sample overall, those women with high psychological stress levels appeared to be more likely to engage in disordered eating behaviours than women with low levels of stress. Results suggest that further investigation, targeting subgroups of women scoring highly on measures of psychological stress or disordered eating, may help clarify our understanding of the relationships between these factors in young Australian women.

Brown P & Brown WJ. Women and leisure: does all work and no play make Jill unwell? *World Leisure and Recreation*, **1999; 41(1): 11-14.**
Leisure time is characterised by liberation from the constraints of employment, domestic work and other social obligations. It affords time and space to relax and recuperate from the stresses and fatigue of daily activities; offers opportunities to express individuality and creativity; and provides an important context for the establishment and maintenance of social networks. It is also an avenue for the promotion of health, through physical activity and the psychological benefits of social leisure activities.

The Australian Longitudinal Study on Women's Health aims to clarify the relationships between biological, psychological, social and lifestyle factors and women's physical health and emotional well-being. Baseline surveys were completed in 1996 by more than 41,000 young, mid-age and older women. Among the mid-age women (45-50 years, N=13,595) one in five felt rushed, pressured or too busy every day, and 38% felt more rushed than five years ago. About half the women said they would like more time for passive (43.9%) and active (2%) leisure; while only 2% reported no passive leisure, 18.7% reported no active leisure.

These findings will be reviewed in the context of interrelationships between work and leisure in women's lives and the practical and ideological significance of changes in patterns of labour market involvement on women's leisure and health.

Brown WJ, Young AF & Byles JE. Tyranny of distance? The health of mid-age women living in five geographical areas of Australia. *Australian Journal of Rural Health,* **1999; 7: 148-154.**
Over 14 000 women aged 45-50 are participating in the Australian Longitudinal Study on Women's Health, which is designed to track the health of Australian women for 20 years, and to understand lifestyle and healthcare factors that influence women's health. The study deliberately overrepresents women from rural and remote areas. This analysis of baseline data from the study compares the responses of women living in urban areas (capital city, other metropolitan), large rural centres, small rural centres, other rural areas and remote areas

(remote centres, other remote areas) of Australia. The data show that while women in this age group who live in rural and remote areas have similar levels of self-rated health, they have significantly fewer visits to general practitioners and specialists (P < 0.001) and more visits to alternative healthcare providers than women living in urban areas. Rural and remote area women were also more likely to undergo gynaecological surgery than women living in urban areas (P < 0.001). Other results suggest that being overweight is more common among women from rural and remote areas, and that these women also report lower levels of stress than women from urban areas (P < 0.001). Further follow up will allow any divergence in health and healthcare equity to be explored as these women get older.

Bryson L, Brown W & Strazzari S. Shaping families: women, control and contraception. *Family Matters*, **1999; 53: 31-38.**
'I consider the oral contraceptive pill to be the one discovery which has brought about the most change in society. Control in women has changed it all'. These are the words of one of the young women in a large national study of women's health and well-being across the life course (the Women's Health Australia project). While effective contraception has become normalised and the capacity to shape their life course is much appreciated by women, the study also reveals that many problematic issues remain.

Brown WJ, Dobson AJ, Bryson L & Byles JE. Women's Health Australia: on the progress of the main cohort studies. *Journal of Women's Health & Gender-based Medicine*, **1999; 8(5): 681-688.**
More than 41,000 women aged 18-23, 41-50, and 70-75 years in 1996 are participating in the Australian Longitudinal Study on Women's Health (Women's Health Australia). Baseline surveys were conducted for all three cohorts in 1996, and the first follow-up survey of the mid- age group in 1998 has achieved a response rate exceeding 90%. The main findings so far reflect the large differences in the life experiences of the three cohorts. The young women report high levels of stress. The physical and mental health of those with young children is worse than for those without children, but confounding by sociodemographic characteristics may account for the differences. Two thirds of young women in the healthy weight or underweight range would like to weigh less, and early onset of dieting is associated with poorer physical and mental health. Most of the women in the mid-age group have multiple roles-in paid work, home duties, and caring for children and other dependents. The potential of the study to investigate the long-term impact of such busy lives on health outcomes is considerable. At this stage, the main health issues for these women relate to tiredness, weight gain, and menopause. The older cohort presents a picture of positive aging. These women are heavier users of health services than the mid-age and younger women, and they are also more satisfied with these services. Although their physical health is poorer, their mental health is better, and they report less stress than women in the other two cohorts. The follow-up survey of this group, planned for 1999, will focus on the coping strategies used by these women. An overall goal of the project is to understand the interactions among social roles, life events, and women's health in order to provide a basis for improved health policies and services. Analysis of these interactions, which relies on both quantitative and qualitative data, poses many challenges that will be addressed as the longitudinal data become available.

Ball K, Kenardy J & Lee C. Relationships between disordered eating and unwanted sexual experiences: a review. *Australian Psychologist*, 1999; 34(3): 166-176.

It is frequently suggested that unwanted sexual experiences (USE), particularly childhood sexual abuse, are a major risk factor for the development of disordered eating. A review of published literature indicates that, while several studies find no relationship between a history of USE and eating pathology, many report that the hypothesised relationship is evident in at least some circumstances or subpopulations. It is argued that researchers should now attempt to explain this relationship by linking these research findings to a clear conceptual model which can be tested in future studies. In particular, longitudinal studies are required in order to test whether the relationship between these factors is causal or an artifact of other psychological processes. A conceptual model of the relationships among USE and disordered eating is currently lacking in the literature and the establishment of such a model should be a priority of future research in this area, in order to enable a thorough understanding and minimisation of the effects of USE on later psychological disturbance such as disordered eating.

Brown WJ, Fuller B, Lee C, Cockburn J & Adamson L. Never too late: older people's perceptions of physical activity. *Health Promotion Journal of Australia*, 1999, 9(1): 55-63.

Issue Addressed. A series of focus groups was conducted to explore older people's attitudes to, practices, and perceptions of physical activity, in order to inform the development of appropriate strategies to encourage participation among this population group.

Methods. Thirty five men and 46 women aged over 60, recruited through the Australian Longitudinal Study on Women's Health, seniors' organizations and personal contacts in urban and rural areas of the Hunter Valley, participated in 11 focus groups. A semi-structured group interview explored relevant issues including current patterns of activity and understanding of the terms used in activity promotion, motivations and barriers, and appropriateness of current promotion strategies, including the 'Active Australia' campaign.

Results. The participants described a wide range of current activities. The most common were walking, gardening and housework. Participants were unsure about what constituted 'adequate' activity but showed good understanding of the terms vigorous, moderate and light activity. Health, social support, doing something useful, environmental factors and avoiding the negative stereotypes of ageing were the main motivations for activity. Barriers included poor health; no-one to exercise with; inappropriate or unsafe environments and facilities; and lack of interest. Participants found existing media messages confusing, but supported the idea of campaigns encouraging older people to be active.

Conclusions. These older people were interested in a wide range of physical activities, but suggested that lack of social support, poor facilities and concerns about safety were the major barriers to participation.

So What? This project identified factors which are pertinent for the promotion of physical activity among older people. The issues identified, to maintain good health, a sense of social connectedness, and an ability to contribute, as well as the need for safe environments and appropriately trained exercise leaders, suggest strategies for the development of physical activity promotion campaigns for this group.

Chiarelli P, Brown WJ & McElduff P. Leaking urine – prevalence and associated factors in Australian women. *Neurourology and Urodynamics*, 1999, 18(6): 567-577.

The Women's Health Australia project provided the opportunity to examine the prevalence of leaking urine and associated variables in three large cohorts of Australian women aged 18- 23 ('young' N= 14761), 45 - 50 ('mid-age' N=14070) and 70 - 75 ('older' N= 12893) years. The proportion of women reporting leaking urine was 12.8% (95% CI: 12.2 - 13.3), 36.1% (35.2 - 37.0) and 35% (34.1 - 35.9) in each of the three cohorts respectively. Logistic regression analysis showed significant associations between leaking urine and parity in the young and mid-age women, and between leaking urine and constipation, other bowel symptoms, body mass index and urine that burns or stings, in all three groups. In the mid-age and older cohorts, women who reported having both hysterectomy and prolapse repair, or prolapse repair alone, were also more likely to report leaking urine. Lower scores on the physical and mental component summary scores of the SF-36 suggest lower quality of life among women who report leaking urine, compared with those who do not.

8.2.2   Papers accepted

Chiarelli P, Brown W & McElduff P. Constipation in Australian women: Prevalence and associated factors. *International Urogynecology Journal*, 1998.

A postal health survey was completed by 14761 young women (aged 18-23 years), 14070 middle-aged women (45-50 years) and 12 893 older women (70-75 years). The prevalence of constipation was 14.1% (Cl 13.5-14.7) in young women, 26.6% (Cl 25.9-27.4) in middle-aged women, and 27% (Cl 26.9- 28.5) in the older women. The prevalence of hemorrhoids was 3.2% (Cl 2.9-3.4 young), 17.7% (Cl 17.1- 18.4 middle-aged) and 18.3% (Cl 17.6-19.0 older). In the middle-aged and older women, those who reported previous gynecologic surgery were between 18% and 63% more likely to report constipation; in the younger cohort, women with one or two children were also more likely to report constipation (adjusted OR 1.43-1.46). One-third of the young women and half the middle-aged and older women had sought help for constipation; the majority indicated that they were satisfied with the help available to them.

Schofield M, Mishra G & Dobson A. Risk of multiple prior miscarriages among middle aged women who smoke. *Conference Proceedings of the 10th World Conference on Tobacco or Health*, 1999.

We present retrospective self-reported data from the baseline survey of the Australian Longitudinal Study on Women's Health on the relationship between smoking and history of miscarriages among 14 200 women aged 45-49 at the time of the survey. The sampling frame was the database of the national health insurance system. Participants were randomly selected, with over-sampling from rural and remote areas, and are broadly representative of Australian women in this age group. Polychotomous logistic regression analyses were used to test the hypotheses that current smoking status and age at starting to smoke are associated with the number of miscarriages reported. There was a strong positive relationship between smoking status and the number of reported miscarriages. Ex-smokers were 1.25 times more likely to have had two or more miscarriages, light smokers (1-19 cigarettes per day) were 1.39 times more likely, and women who smoked 20 or more per day were 1.78 times more likely compared with women who had never smoked. An inverse relationship was also found between age at starting to smoke and a history of miscarriages. The findings provide strong

evidence of a link between smoking and miscarriages and suggest that new initiatives are needed to prevent smoking among women of child-bearing age.

Schofield M, Mishra G & Dobson A. Risk of early menopause among Australian women who smoke. *Conference Proceedings of the 10th World Conference on Tobacco or Health*, **1999.**

We examined the relationship between smoking status and self-reported natural menopause among 14 200 women aged 45-49 years in the Australian Longitudinal Study on Women's Health. The sampling frame was the database of the national health insurance system. Participants were randomly selected, with over-sampling from rural and remote areas and are broadly representative of Australian women in this age group. Polychotomous logistic regression analyses were used to estimate the association between current smoking status and early menopause and peri-menopausal status after adjustment for potentially confounding factors. Smokers of 1-19 cigarettes per day were 1.48 times mor3e likely to be peri-menopausal, and women who smoked $\geq$ 20 per day were 1.74 times more likely to be peri-menopausal in comparison with never smokers. Both groups of smokers were 1.8 times more likely to report post-menopausal status than women who had never smoked. For ex-smokers, the risk for earlier onset of menopause declined rapidly after quitting. The results extend earlier evidence of a link between smoking and early menopause by estimating the effects of quitting and by controlling for a wide range of potential confounders.

Byles J. Over the hill and picking up speed: older women of the Australian Longitudinal Study on Women's Health. *Australian Journal on Ageing*, **1999.**

<u>Objective:</u> The aim of the Australian Longitudinal Study on Women's Health is to explore the physical, psychological, social and environmental factors that affect the health of women in Australia. In this paper, we identify key health issues for the 12,900 women in the oldest cohort c)f the study and highlight issues to be explored longitudinally.

<u>Method:</u> Women aged 70-75 years registered with the Health Insurance Commission were sent a postal questionnaire (response rate 40%). The questionnaire included 260 items on health, health related behaviours and health care use, and social circumstances.

<u>Results:</u> Despite the high proportion of women reporting chronic medical conditions and recent symptoms, only 4% of the women rated their health as poor. Scores on the SF-36 health-related quality of life measure indicate that while physical health scores were lowest for the older cohort, mental health scores were higher than for the youngest (18-23 years) and mid-age (45-50 years) cohort. In their comments, the older women emphasised the importance of their homes, social support and their active participation in their community as fundamental to their well-being.

<u>Conclusion:</u> This analysis highlights areas for follow-up in the longitudinal study, importantly the older women in the study do not equate disease with poor health and a broader social view of health is justified.

Feldman S, Byles JE & Beaumont R. "Is anybody listening?": The experiences of widowhood for older Australian women. *Journal of Women & Ageing*, **1999.**

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

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

Schofield MJ, Minichiello V, Mishra G, Plummer D & Savage J Sexually transmitted infections and use Of sexual health services among young Australian women: Women's Health Australia study. *International Journal of STD & AIDS,* **1999.**

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

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

Results: The self-reported incidence of STI was 1.7% for chlamydia, 1.1% genital herpes, 3. 1 % genital warts, and 2. 1 % other STI. There were a large number of demographic, health behaviour, psychosocial and health service use factors significantly and independently associated with reports of having had each STI. Factors independently associated with use of family planning clinic included unemployment current smoking, having had a Pap Smear less than two years ago, not having ancillary health insurance, having consulted a hospital doctor and having higher stress and life events score. Factors independently associated with use of a sexual health clinic included younger age, lower occupation status, being a current or ex-smoker, being a binge drinker, having had a Pap Smear, having consulted a hospital doctor, having poorer mental health and having higher life events score.

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

Byles JE, Mishra G & Schofield M. Factors associated with hysterectomy among women in Australia. *Health and Place: An International Journal,* **1999**

Objectives: To identify differences in hysterectomy rates across urban, rural and remote areas of Australia and across states; to separate these geographic differences from the effect of sociodemographic influences (such as education, parity, religion); to assess whether women who have hysterectomy have different quality of life and levels of health care utilisation than women who have not had this procedure.

Methods: Data were collected from 14205 women aged 45-49 years participating in the baseline survey of the Australian Longitudinal Study on Women's Health (Women's Health Australia project), a large-scale national study of factors affecting the health of women. Proportions were weighted to account for deliberate over-representation of women in rural and remote areas.

Results: The estimated prevalence of hysterectomy was 22%. Factors significantly associated with hysterectomy in a multiple logistic regression model included living in a remote area, state of residence (highest prevalence in Western Australia, and lowest rates in the Australian Capital Territory and Victoria), having private health insurance, lower levels of education, being currently or previously married, having had other gynaecological procedures, and other (non-gynaecological) surgical procedures. Compared with women who had not had hysterectomy, women who had had hysterectomy had significantly poorer physical and mental health as measured by the SF-36 quality of life profile (mean PCS = 47.07 vs 50.26, p < 0.0001; mean MCS = 44.75 vs 47.29, p<0.0001). There were also significant differences between women who had and had not had a hysterectomy in terms of the number of visits to a general practitioner in the past year.

Conclusions: High hysterectomy rates, regional variations, and associated demographic characteristics indicate a need for more careful evaluation of gynaecological care for women in Australia, particularly those living in remote areas and those with lower levels of education.

8.2.3 Papers submitted

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

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

Patterson AJ, Brown WJ, Powers JR & Roberts DCK. Iron deficiency, general health and fatigue: results from the Australian Longitudinal Study on Women's Health.

Associations between self-reported 'low iron', general health and well-being, vitality and tiredness in women, were examined using Physical (PCS) and Mental (MCS) Component Summary and Vitality (VT) scores from the MOS Short-form survey (SF-36). 14764 young (18-23yrs) and 14200 mid-age (45-50yrs) women, randomly selected from the national

Health Insurance Commission (Medicare) database, completed a baseline mailed self-report questionnaire and 8869 mid-age women completed a follow-up questionnaire two years later.

Young and mid-age women who reported (ever) having had 'low iron' reported lower mean PCS, MCS and VT scores, and greater prevalence of 'constant tiredness' at baseline than women with no history of iron deficiency [Young - PCS: 47.2 and 49.3 respectively, Difference=2.2 (95% CI: 1.9-2.5); MCS: 41.9 and 46.8, Difference=4.8 (95%CI: 4.4-5.2); VT-1.6); MCS: 45.1 and 48.1, Difference=3.1 (95% CI: 2.7-3.4); VT: 54.7 and 60.6, Difference=5.9 (95% CI: 5.3-6.5); Constant tiredness: 63% and 48%, Difference=15% (95% CI: 13-17%)].

After correcting for number of children, chronic conditions, symptoms and hours worked, mean PCS, MCS and VT scores for mid-age women at follow-up were lowest for women who reported recent iron deficiency (in the last two years) and highest for women with no history of iron deficiency [PCS – Recent: 47.8 (95% CI: 47.3-48.3); Past: 49.4 (95% CI: 49.0-49.8); Never: 49.0 (95% CI: 47.8-49.2)] [MCS – Recent: 45.7 (95% CI: 45.0-46.4); Past: 47.3 (95% CI: 46.7-47.9); Never: 47.9 (95% CI: 47.6-48.2)] [VT – Recent: 54.2 (95% CI: 53.0-55.4); Past: 56.7 (95% CI: 55.8-57.6); Never: 58.2 (95% CI: 57.7-58.7)].

Longitudinal analyses showed that mean PCS, MCS and VT scores were significantly reduced among mid-age women who reported iron deficiency in the follow-up survey but not at baseline (ie recent iron deficiency) [Mean change- PCS: –2.2 (95% CI: -2.7- -1.7); MCS: -2.3 (95% CI: -3.0- -1.6); VT: –5.7 (95% CI: -6.9- -4.5)].

The results suggest that iron deficiency is associated with decreased general health and well-being and increased fatigue.

Brown WJ, Mishra G, Kenardy J & Dobson AJ. What is a healthy weight for young women.

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

<u>Design:</u> Population based longitudinal cohort study – baseline cross-sectional data.

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

<u>Measurements:</u> Self-reported height, weight, medical conditions, symptoms and SF-36.

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

<u>Conclusion:</u> Acknowledging the limits of the cross-sectional nature of the data, the results show that the deleterious effects of overweight can be seen at a comparatively young age, and that BMI <25 is associated with fewer indicators of morbidity in young women. However, as BMI <18.5 is associated with some health problems, care should be taken when developing

strategies to prevent overweight in young women, not to promote weight loss to those who already have a healthy BMI.

Mishra GD, Dobson AJ & Schofield MJ. Cigarette smoking, menstrual symptoms and miscarriage among young women.

Objective: To examine associations between cigarette smoking and menstrual symptoms and miscarriage among young women.

Method: The study sample consists of 14,762 women aged 18-23 years who participated in the mailed baseline survey for the Australian Longitudinal Study on Women's Health, conducted in 1996. The main outcome measures are self reported menstrual symptoms and miscarriages.

Results: Current smokers and ex-smokers had an increased risk of menstrual symptoms and miscarriages compared with women who had never smoked, with the highest risk occurring in heavy smokers (adjusted odds ratios for those smoking $\geq$ 20 cigarettes per day: premenstrual tension 1.43 (95% confidence interval 1.27 to 1.60), irregular periods 1.32 (1.17 to 1.52), heavy periods 1.47 (1.28 to 1.69), severe period pain 1.41 (1.24 to 1.58), one or more miscarriages 2.66 (1.91 to 3.70)). The odds ratios generally increased with numbers of cigarettes smoked and younger age of starting to smoke.

Conclusion: This study suggests that young women who smoke are at higher risk of a range of menstrual problems and miscarriage than those who have never smoked. The immediacy of this risk (in contrast to the longer term risks of chronic disease) can be used to improve the relevance of anti-smoking campaigns targeted to young women.

Goodger B, Mishra G, Byles J & Higginbotham N. Social support and older women in Australia: What is a healthy level?

Objectives: To estimate and describe the prevalence and effects of differing levels of social support (as measured by the Duke Social Support Index) on selected indicators of health and wellbeing among older women.

Methods: Population based study using cross-sectional baseline data from 12,458 women aged 70-75 who completed a baseline survey for the Australian Longitudinal Study on Women's Health.

Results: Trend curves constructed using locally weighted regression between the Duke Social Support Index and health measures such as the SF-36 were monotonic. Higher social support scores were associated with increased scores on the SF-36. A plateau effect was not found between social support and any of the selected health measures. Four levels of social support were identified and found to reflect differential health benefits on analysis of covariance. Older women who were defined as having low support in comparison to those with very high support had significantly worse scores on the SF-36 and on other health measures. The prevalence of those with low and fair social support was estimated to be 22%.

Discussion: Despite the limitations imposed by the cross-sectional nature of these data, results suggest that differing levels of social support can be defined and that they are associated with older women's health experiences. Applying these levels of the Duke Social Support Index may be useful in clinical care, epidemiological research, and health promotion activities.

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

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

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

Design: Serum ferritin and body mass index were measured in 52 iron deficient and 24 iron replete women. Dietary data were collected using 7-day weighed food records and bioavailable dietary iron calculations were performed using the methods of Monsen et al and Tseng et al. Self-report data on demographic characteristics, parity, breastfeeding, oral contraceptive pill (OCP), intrauterine device and hormone replacement therapy use, menstruation, smoking, alcohol intake, exercise, dieting, vitamin and mineral supplement use and blood donation were collected. Multiple linear regression was used to examine dietary and lifestyle factors associated with serum ferritin.

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

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

Feldman S, Byles J, Mishra G & Powers J The health and social needs of recently widowed older women in Australia.

Objective: To identify women's health and social needs immediately following the death of their husbands.

Methods: Follow-up survey of 430 widowed women participating in the Australian Longitudinal Study on Women's Health.

Results: Surveys were returned by 340 women (78%) and 231 of these women had been widowed for three years or less. While 82% of the 231 women still lived in their own homes, almost one-fifth had moved house since being widowed for financial or social reasons. Needs for legal services (75%), and home maintenance (63%) were common. Assistance obtained from medical practitioners included understanding (64%), support (38%) and information (23%). Thirty-five percent said they had received medication to assist their bereavement, and 35% had taken medication to help them sleep or 'for their nerves' within the four weeks prior to survey. Most women (90%) felt they had maintained or increased their level of social contact since becoming widowed.

Discussion: Widowed women have broad needs for practical help and advice. Appropriate services for widowed women need to encompass the social context in which widowed women are attempting to reconstruct their lives.

Lee C & Porteous J. Experiences of family caregiving among middle-aged Australian women.

Family caregiving is an unpaid activity which falls inequitably on women. As one component of the Women's Health Australia survey, this paper uses quantitative and qualitative methods to examine the impact of family caregiving in a sample of 13,888 women aged 45 to 50, of whom 12.8% (N=1,775) responded to specific items about caring for a frail, ill or disabled

family member and 185 made open-ended comments about their experiences. Quantitative analyses showed that caregivers were less likely to be employed full-time and more likely to have financial difficulties. Caregivers rated their health lower than did non-caregivers, reported more physical symptoms, and scored lower on both the physical and the mental components of the SF-36. They also reported higher levels of stress and perceived pressure, were more likely to have been admitted to hospital in the previous year, to be taking medication for "nerves", and more likely to smoke, though less likely to drink alcohol. The qualitative analysis supported these findings, and in addition identified several new themes including difficulties with travel; inadequacies in health and welfare systems; a sense of exploitation; and fear for the future. These findings support the view that interventions to assist family caregivers must address systemic in addition to individual factors.

Brown WJ & Bauman A. Misclassification biases in assessing population levels of physical activity using two measures of energy expenditure.
Objective: To determine levels of 'adequate activity' for health benefit in different population groups using the 'traditional' method of estimating energy expenditure using Kilocalories (Kcals), and a newer method of estimating energy expenditure using Mets.mins.
Methods: 10,464 mid-age women (47-52 years) who participated in the second survey of the Australian Longitudinal Study on Women's Health (ALSWH, 1998) and 2,500 men and women (18-75 years) who participated in the 1997 *Active Australia* national survey, answered questions about physical activity. Kcals and Mets.mins were calculated from self-reported time spent in walking, moderate and vigorous activity, and self reported body weight. 'Adequate activity' was defined as a minimum of 800 Kcals or 600 Mets.mins.
Results: There were differences in the estimates of 'adequate activity' using the two methods among women participants in both the ALSWH and *Active Australia* surveys, but not among the male participants in the *Active Australia* survey. A significant proportion of the women in both surveys (6.4% of the ALSWH women and 8.5% of the *Active Australia* women, mean weight 60kg) were misclassified as *inactive* when the Kcals method was used despite reporting levels of activity commensurate with good health. Fewer than 1% were misclassified as *active* using Kcals when reporting lower than recommended levels of activity (mean weight 105 kg). Agreement between the two methods was better among men; only 3% were misclassified because of low or very high weight.
Conclusions: The Mets.mins method of estimating 'adequate' activity assesses physical activity independently of body weight and is recommended for use in future population surveys.
Implications: Using this method to assess adequate activity, women and men aged 45-59, and women aged >60 have the lowest levels of activity and should be the target of specific health promotion strategies for increasing population levels of physical activity.

Hasan S, Byles JE, Mishra G & Harris MA. Use of sleeping medication, and quality of life, among older women who report sleeping difficulty.
Objective: To estimate the proportion of older women who report sleeping difficulties and/or use sleeping medication; and to identity associated factors.
Method: Gross sectional survey of Australian women aged 70-75 years. These women were participants in the Australian Longitudinal Study on Women's Health (ALSWH) randomly selected from the Australian Medicare database.
Results: Of the 12624 women aged 70-75 years who provided data for this analysis (36% response rate), 50% (n=6042) reported sleeping difficulty "never/rarely"; 33% (n=3979)

"sometimes"; and, 17% (n=201 1) of women reported to experience sleeping difficulty "often". Approximately 18% (n=2287) of women reported to use sleeping medication within the previous four weeks. Women reporting sleeping difficulty "sometimes" were over five times more likely to be taking sleeping medications than women who reported to "never/rarely" experience difficulties (p=<0.0001); while women reporting difficulty sleeping "often" were over 15 times more likely to be using sleeping medications (p=<0.0001). Mean scores for sub scales of the SF-36 health-related quality of life measure were significantly lower for women reporting sleeping difficulty and women using sleeping medication (p=<0.001). Similarly, there was an inverse relationship between the SF-36 physical and mental health summary scores and difficulty sleeping or sleeping medication use. Conclusions: Self-reported sleeping difficulty is significantly related to reduced quality of life, suggesting sleeping difficulty is not a benign complaint. After adjustment for other explanatory variables there were strong, clinically significant differences between the SF-36 scores of women reporting sleeping difficulty. However, while this association is statistically, and clinically significant, it is not clear whether sleeping difficulty reduces quality of life, or whether quality of life interferes with sleep, or whether both problems are a result of other associated conditions. Further longitudinal exploration of this relationship is necessary. Further, issues need to be explored with older women, with a view to identifying acceptable and effective alternatives to sleeping medication use.

8.3   ANNUAL BRIEFING

Members of the research team (Prof Annette Dobson, Emeritus Prof Lois Bryson, Dr Wendy Brown, A/Prof Christina Lee, A/Prof Gail Williams, and Ms Noela Baigrie) presented an "update" of the project to staff from the Commonwealth Department of Health and Aged Care, and the Commonwealth Department of Family and Community Services on 27 October 1999. In the afternoon of the same day the researchers met with members of the Departmental Reference Group. See Section 10.1 for the minutes from this meeting.

9   COMMUNICATION

9.1   COMMUNICATION WITH PARTICIPANTS - 1999 NEWSLETTER

The main communication with participants in this period has been the 1999 newsletter, which was sent out in September (see Appendix 5). The newsletter contains a summary of findings from the 1996 baseline surveys. Change of address cards were included in the mail-out. This mail-out generated 1557 Return to Senders (RTS: 1099 young, 333 mid-age and 125 older) and over 1820 new addresses, as of 2 December 1999. Our priority is to track down current contact details for the young cohort RTSs, ready for the first follow-up questionnaire for the young cohort which will be sent out in March 2000.

9.2 COMMUNICATION BETWEEN RESEARCHERS AT THE UNIVERSITY OF NEWCASTLE AND THE UNIVERSITY OF QUEENSLAND

During 1999, researchers from the two universities have had several opportunities for face-to-face discussion of the project's progress. The first was in May when Dr Brown met with A/Prof Williams in Brisbane. On 4 October, Prof Dobson, A/Prof Lee and Dr Brown travelled to Brisbane for a strategic planning meeting. The minutes of this meeting are included in Appendix 6. Following this meeting, Prof Dobson has had several follow-up discussions in Brisbane relating to plans for closer co-operation of the two groups in 2000.

10 UPDATE ON THE PROJECT ADVISORY COMMITTEE (PAC) OF THE NHMRC RESEARCH COMMITTEE

10.1 MEETING HELD IN CANBERRA ON 22 APRIL 1999.

Present
Dr Janet Greeley (Chair)
Dame Margaret Guilfoyle
Professor Christine Ewan
Professor Adele Green
Dr Helena Britt

Department
Brendan Gibson
Margaret Curran

Secretariat
Therese Manson
Jeanette Pedlow

Investigators
Professor Annette Dobson
Professor Lois Bryson
Associate Professor Gail Williams

Apologies
Marilyn Hatton
Dr David Roder

1 Introduction

Dr Greeley thanked members and investigators for their agreement to be involved in the Project Advisory Committee (PAC) and participate at the meeting. She stated that NHMRC's role in the Study is to ensure that the Study moves ahead in an expeditious and appropriate manner and that the PAC develops processes and sets priorities to allow this to happen. This is consistent with the recommendation of the Review to provide scientific rigour and excellence. Such an end will be achieved by the PAC working with the Study team, the Department and non-government sectors. The PAC will also address the issue of funding priorities.

The Committee and Study team members then introduced themselves.

2 History of project

Action Item: Professor Dobson to provide sign-off letter to original committee

The Australian Longitudinal Study on Women's Health had its origins in a series of consultations in the nineteen eighties during which time there was pressure for a longitudinal study. Funding was committed in 1994 after a two stage process which resulted in The Newcastle University and The University of Queensland tendering together. A large cohort of 100,000 women from the HIC database, to be contacted by mail, was established, as were two smaller cohorts. The smaller cohorts consisted of indigenous women and Filipina women. Later separate funding was given to establish a cohort from the former Yugoslav Republics. The original phase had a Steering Committee which will be superseded by the PAC for this phase. Professor Dobson will write to members of the Steering Committee to thank them for their involvement.

3 Progress to date

The Study Team provided the meeting with a comprehensive up-date on progress to date including work with the smaller communities and a list of publications resulting from the Study. The mid-age cohort has had its first follow-up with a reasonable response rate and the team is now starting on a follow-up for the older cohort.

Professor Williams explained that the smaller cohorts were set up because it was not possible to obtain quality information about them from the larger cohorts. The indigenous cohorts are from the communities of Cherbourg and Woorabinda. Considerable hard work went into gaining the trust of these communities and thus a reasonable response rate. The report for this work indicated that overweight and unfitness is a considerable concern for the Cherbourg community. An outcome has been that a gym has been set up at Cherbourg with a $10,000 grant from the Queensland Department of Health. The team would like to set up cohorts in Rockhampton and Toowoomba with urban Aboriginal women but are hampered by lack of funding. They would also like to employ an indigenous liaison officer but funding hampers them in this regard also.

Professor Dobson also summarised a list of publications which have resulted from aspects of the Study picked up by researchers and doctoral students. These extra publications have added considerable value.

4 The Review of the Study

Professor Ewan and Dr Adele Green reviewed the Study in 1998. After this Review, the Minister decided that the Study should be continued and that, on the grounds of ensuring scientific merit, it should be managed by NHMRC.

5   Relationship of various groups

The meeting was keen to clarify the nexus between the PAC, the Departmental Reference Group, the Research Committee and the Department. Reporting linkages have been established between the PAC and the Study Team and the Departmental Reference Group. The PAC reports to the Research Committee who ultimately reports to the National Health and Medical Research Council.

6   Role of PAC

The role of the PAC will be to provide ongoing advice on the selection of research priorities, future directions and research direction within the context of the Department's priorities. The PAC will report to the Research Committee and NHMRC. The Departmental Reference Group will need to provide information to the PAC on Departmental priorities to facilitate the PAC in its decision making.

The PAC will monitor:

- Scientific worth;
- Advice from the Department;
- Advice from the Study Team.

Scientific merit includes qualitative and quantitative research. For quantitative research indicators include outcomes, samples size, impact, retention and validity.

Qualitative research methodologies will be employed for the special cohorts. The qualitative research strategies employed with the NESB and Indigenous cohorts are essential to capture the special needs of these groups. The methodologies of indepth interviewing and participant observation provide the researchers with the level of information required to understand the cultural relevance and significance of different health care and social needs of these groups who may not experience the same level of access to existing health care and social programs as women in the larger cohort. In addition, results from the qualitative studies will enhance the interpretation of quantitative data gathered in the larger cohort from individuals from culturally and linguistically diverse backgrounds and indigenous backgrounds

7   Terms of reference for the Project Advisory Committee

Action Item: *The Terms of Reference for the Project Advisory Committee are as follows:*

1.   *Assess and provide advice to the NHMRC, the Research Committee and the Department on the progress of the Study;*
2.   *Provide advice to the Study team on activities to raise additional funds from appropriate sources for core and special cohorts as well as nested sub-studies;*
3.   *Provide ongoing advice on the selection of research priorities, future directions and research questions – especially emerging issues in women's health – within the context of the Department's priorities and through liaison with the Departmental reference group.*

4. *Advise the Study team on avenues to effectively disseminate the research findings to maximise uptake within policy and programs;*

5. *Assist with inter-disciplinary and inter-sectoral collaborations to progress the research directions and breadth of analysis.*

The Project Advisory Committee reports to the Research Committee and provides feedback to the Departmental Reference Group. The meeting agreed that the selection of research priorities (Term of Reference 3) was crucial although a difficult task.

8   Role of Departmental Reference Group

Action Item: The revised draft terms of reference for the Departmental Reference Group are as follows:

1. *Evaluate the Study outputs in terms of quality and relevance to government policy;*
2. *Provide input and advice on priority areas for research questions and analysis.*
3. *Formulate Departmental advice on emerging policy issues relevant to the Study;*
4. *Provide input and advice on the development of performance indicators, reporting mechanisms and dissemination activities relevant to the contract;*
5. *Actively disseminate findings within the Department and advise on strategies for dissemination more broadly.*

The Departmental Reference Group will disseminate information both to the PAC and hence to the Study team and to the programs within the Department. The Departmental Reference Group is essential to ensure Departmental involvement in the Study but will need to work with the general direction and timeframe of the PAC. The PAC would like the Departmental Reference Group to focus on clarifying outputs of the Study.

9   Role of the Department

The role of the Department is to examine the reports from the Study and inform the PAC of their policy value and strategic direction for the Department. It will also study outputs with a view to quality and relevance and disseminate them. The Department will also be involved in identifying priorities for research which will be a particularly relevant role if there is a need to cut aspects of the Study.

10   Name of committee

The meeting decided that the most appropriate name for the Committee was the Project Advisory Committee.

11   Work to be done with industry

Action Item: Study team, PAC and Secretariat to undertake further research into private funding and whether the government may seek it.

<u>Discussion</u>

Discussion centred around the need for the Study Team and for the PAC to examine how funding and sponsorship can be obtained from industry. Dr Greeley explained that while this type of work is done frequently in the United States and the United Kingdom, such an approach is not as common in Australia, and there is a need to develop expertise to do this. Private contributions could be considered to sponsor the newsletter and to make up the $200,000 shortfall in funding. Members had differing views as to the political sensitivity of sponsorship. The pros were that some members had experienced sponsorship where all the sponsor required was acknowledgment for their financial support to a project. It was suggested that companies such as pharmaceutical companies, Kimberley Clarke or women's magazines could provide sponsorship that was value free. The cons were that it is possible that some academic journals will not accept articles that are sponsored privately and that consumers may doubt that the research is completely objective.

Dr Greeley told the meeting that organisations such as Soroptimists and Rotary International are now putting money into medical research and mental health in particular. Whilst Professor Dobson and Professor Williams had tried these organisations before, it was agreed that it was worthwhile to make another approach now that funding has been approved. The meeting also agreed that it is difficult for projects that have already been funded to attract outside sources because there is a conception that they do not truly need the money as it could be found within the existing budget.

12   Budget

Action Item: 1   Professor Dobson and Professor Williams will write a letter explaining the aspects of the Study which will need to be cut and the impact this might have on the overall quality and outcomes of the project, alluding to the situation and sensitivity of the Yugoslav cohort.
2   Professor Williams and Professor Dobson to write to Department regarding the impact of the $20,000 cuts to existing funding of the migrant cohort for the 1999 Budget.
3   When this information is obtained PAC will establish scientific priorities for any necessary cuts.
4   PAC to investigate possibility of obtaining research quantum from DEETYA

<u>Discussion</u>

The Budget was of considerable concern to the meeting given the immediacy of the impact on the indigenous and migrant cohort in particular. Cuts represent about 16% of the budget. The meeting decided that in order to progress this matter it needed explicit information from the Study team as follows:

- What will be the impact on overall quality?
- How will the cuts impact on the outcomes of the project?
- What aspects of the Study can be let go?

Professor Gail Williams faces particular concerns as she has no guarantee of funding and thus The University of Queensland cannot give her permission to hire needed staff. She would require a letter from The University of Newcastle to The University of Queensland to allow this to happen and at the moment, this has not occurred.

Professor Manderson, who has worked with the Yugoslav cohort, and Professor Dobson will formulate budgets to demonstrate what can be done with maximum and minimum funding. While the meeting discussed the possibility of contracting occurring in a manner where funds go directly to The University of Queensland, members were aware that ultimately that the form the contract would take was a decision that the Office of NHMRC would take. Dr Greeley stressed that it would not be possible to make decisions around the budget at the meeting, only to construct a process that would lead to decision making.

Professor Dobson and others stated that there were real costs around winding down the Yugoslav cohort if that is necessary. In addition, if the migrant cohort had to be cut, it would not be possible to reinstate it if funding was gained at a later stage as the trust would be gone.

13   Reporting requirements and performance indicators

Action Item: Sub-committee consisting of member of Committee, possibly Dr Britt, Dr Greeley and a member of the secretariat to be set up to progress performance indicators

Papers from the Department and the Study Team containing draft performance indicators were tabled. To a large extent they followed the development of recommendations made in the Review. It was decided to set up a sub-committee to progress the performance indicators. It is likely that special indicators may be necessary for the special cohorts. The sub-committee will need to meet quickly by teleconference so that the contract can be progressed.

The meeting was satisfied with the idea of six monthly summary reports against performance indicators and twelve monthly reports of scientific outcomes and progress and publications in the previous year. Reports will also need to include budgetary reporting.

The meeting closed at 3.25 pm

10.2   ACTIONS ARISING FROM THE PAC MEETING - 22 APRIL 1999.

ACTION ITEM	RESPONSIBILITY	PROGRESS TO DATE
Write to Steering Committee to thank them for their involvement with the Study.	Professor Dobson	Task completed
Undertake further research into private funding and whether the government may seek it.	Study team, PAC and Secretariat	
A letter to be produced, explaining the aspects of the Study which will need to be cut, the impact on the overall quality and outcomes etc.	Professor Dobson and Professor Williams	Task completed
A letter to be sent to the Department regarding the impact of the $20,000 cuts to existing funding of the migrant cohort for the 1999 Budget.	Professor Dobson and Professor Williams	Task completed
Establish scientific priorities for any necessary cuts	PAC	Agreed at follow-up teleconference on 21 May 1999
Investigate the possibility of obtaining research quantum from DEETYA	PAC	
Progress performance indicators	Sub-committee, consisting of Dr Britt and Dr Greeley and member of secretariat	Performance indicators agreed at teleconference on 21 May 1999

10.3   MEETING HELD IN CANBERRA ON 28 OCTOBER 1999.

Present
Dr Janet Greeley (Chair)
Dame Margaret Guilfoyle
Professor Christine Ewan
Professor Adele Green
Dr David Roder

Department
Jean Douglass
Teressa Ward

Observer
Romaine Rutnam (DFACS)

Secretariat
Premala Walsh

Investigators
Professor Annette Dobson
Professor Lois Bryson
Associate Professor Gail Williams
Mrs Noela Baigrie
Dr Wendy Brown
Associate Professor Christina Lee

Apologies
Dr Helena Britt
Mr Brendan Gibson

1   Introduction

The Chair, Dr Greeley, welcomed members and investigators to the meeting. She introduced the new Committee member Teressa Ward, who had replaced Margaret Curran as the OATSIH representative and informed those present that Brendan Gibson had been re-nominated as the Population Health Division representative.

Dr Helena Britt and Brendan Gibson were unable to attend and had forwarded their apologies to the Chair. Jean Douglass of Population Health Division (PHD) represented Brendan Gibson at the meeting. The Chair also introduced Romaine Rutnam from the Department of Family and Community Services (FACS) who attended the meeting in the capacity of an observer.

Dr Greeley also welcomed the six investigators from The Universities of Newcastle and Queensland who had attended the meeting, and introduced them to the others present at the meeting. Professor Greeley gave a brief summary of PAC's role and the NHMRC's role in relation to the ALSWH.

1.1 Minutes from previous meeting held on 22 April 1999

A change was proposed to page 2 concerning the section under the heading "History of project". The amended sentence was to read "A large sample of 106,000 women from the HIC database, were contacted by mail and three age based cohorts were established, as were two smaller cohorts".

On the basis that this amendment would be incorporated, the minutes were accepted by the PAC.

1.2 Action Items arising from the previous meeting

All action items had been completed apart from those dealing with funding issues. Members decided to discuss this action item in conjunction with the main agenda item relating to funding issues.

Concerns were expressed in relation to the additional funding needed for the Study. In response to a query as to whether further funding could be found through the university 'research quantum' system, Professor Dobson said that universities already had funding distributions systems in place. The opportunities for funding were reflected in the DEETYA green paper.

2 Presentation from the researchers – overview of the project (history, funding, goals, design, progress to date, main findings from baseline surveys)

The researchers expressed their willingness and commitment to assist the Department in its goal of developing policy that will improve the health of Australian women.

The researchers gave an overview of the Study that included details of its history, funding, goals, design, progress to date and main findings from baseline surveys.

The overall goal of the Study is to identify the factors that determine women's health and those that cause ill health in later life, including social, psychological, economic, historical, physical and environmental factors. The main cohort studies are based at The University of Newcastle. The universities and institutes involved in the Study or its nested sub –studies now include The University of Queensland (UQ), and in addition, The University of New England, La Trobe University, The University of Melbourne, Royal Melbourne Institute of Technology, VUT, CSU, The University of Adelaide and The University of Western Australia. The nested sub-studies had their own funding and were not funded through the Department

The Study is a twenty-year cohort study, comprising three cohorts in the main study, (young cohort, 18-23 years of age, mid age cohort, 45-50 years, and an older cohort,70-75 years). In addition, there are now two special cohorts comprising Indigenous and Filipina women and a small study with a group of women from the Former Yugoslav Republic has also been completed. Data are collected from the main cohorts through mail-out questionnaires and from the special cohorts through consultation. The main cohort includes urban, rural and remote women, randomly selected from the Health Insurance Commission (HIC) database. There was over sampling of rural and remote women in the selection process.

Over one hundred thousand self complete 24 page survey questionnaires were mailed out to the women selected. The surveys contained more than 100 questions with approximately 300 items relating to 5 main themes:

- Health service utilisation;
- Healthy weight and exercise;
- Time use and social roles;
- Life stage and key events;
- Violence against women.

Interpreters were available to those requiring assistance with language. Baseline data were collected from April to September 1996. A year after the baseline data collection, the women were also asked to consent to their HIC data being provided to the Study

Of the initial groups contacted for baseline data, 48% of the young cohort, 54% of the mid age cohort and 41% of the older cohort responded. These response rates compare favourably with other longitudinal studies. Participants in the Study come from all walks of life, from every State and Territory. They are reasonably representative of women in these age groups, when compared with the 1996 census data.

The first follow up surveys for the mid age cohort were conducted in 1998, and for the older cohort in 1999. Response rates for these surveys was >90%. It is intended to carry out the follow up survey for the young cohort in 2000. Following this, it is intended to have three yearly surveys, one per year on a rolling basis.

Sub-studies carried out by PhD students have investigated specific issues in greater depth. They are generally conducted through additional mail-outs, telephone surveys or focus groups.

The foundation PhD studies have focussed on:

- The link between well being and iron deficiency;
- Health service use;
- Eating Disorders;
- Legal protection and violence.

Some of the other sub-studies, supported by additional funds, have included investigations into social support, widows, physical activity, help for emotional problems, binge eating, menopausal weight gain, binge drinking and leisure.

3   Update on the conduct/progress of the main cohort studies, including nested sub-studies.

The first follow up surveys were conducted in 1998 for the mid age cohort. There was a response rate of approximately 92% from this cohort.

Issues that were found to be of specific importance in the case of the mid age cohort included:

- Links between Body Mass Index and Menopause and the impact of a hysterectomy on BMI;
- Links between Tiredness and Iron deficiency;
- Stress and life events seem to be of greater significance in any statistical analysis than the effects of the better known risk factors for poor health;
- The long-term impact of violence on women's health.

In the case of the older cohort, the first follow up cohort was conducted in 1999, with a response rate of 90%. The responses are yet to be fully processed and analysed.

Key research questions included issues concerning:

- Healthy ageing, optimism, community access, geography and location;
- Widowhood;
- Chronic disease and disability.

Older women tended to have poorer physical health than the young or mid age cohort. However they tended to have very good mental health.

Additional measures that were explored in the follow up survey 1999 were issues that included:

- Transport and access to health care;
- Falls, mobility, sleep, depression and trauma;
- Neighbourhood satisfaction
- Instrumental and formal support
- Optimism, hardiness
- Volunteering and caring.

Researchers associated with the Study were interested in these issues as they might, over a long term, predict better health outcomes.

There has been no follow up of the young cohort yet. The survey questionnaire is to be sent out to participants in this group next year.

Key research questions for this age group will include:

- Parenting, particularly parenting and mental health. It had been observed that having a child under the age of five was a good predictor of mental health;
- Stress – this cohort appear to be far more stressed than the mid age and older cohorts; young urban women appear to be particularly stressed;
- Health risks, including illicit drug use. Participants from the young cohort have expressed the view that further investigation of these issues should be undertaken;
- Body image and eating disorders – these factors are associated with morbidity in young women; sub-studies to date indicate links between eating disorders and psychological well being.

4 Methodological issues for the main cohort studies (maximising response rates, minimising attrition, short vs long surveys, maintaining contact with participants)

The investigators informed the meeting that research assistants employed by the Study use telephone communication to carry out a major part of their work. Tracking "lost" participants is largely done by telephone and phone contact, and is a major means of communication with participants in the Study. Research assistants verbally assist participants through the survey when necessary. A number of participants in the older follow-up survey had turned over two pages of the survey together and missed filling in the questions on those pages. The research assistants then contacted those participants by phone and filled in the missing responses.

In cases of non-response to the longer survey, participants in the older cohort were asked to complete a shortened version of the survey. Data entry typically takes about six months from collection to completion of data entry. For the baseline surveys, data were entered manually, but for the follow-ups the researchers had moved to optical scanning. The advantages of this process include the fact that both the page and background notations can be scanned and stored on CDs. Such a process enables researchers to easily access a particular page of data and even view any notations on it, if required.

Major problems had been discovered earlier this year with the mid follow-up data. The researchers had been forced to employ a number of additional casual staff members to check every survey response prior to re-forwarding the information for optical scanning. Another difficulty this year was that a proportion of materials sent to the women, particularly in the young cohort, did not reach the women selected due to their no longer being at the same address. The researchers then have to track down where these women might be, and this had resulted in a successful tracking of approximately 60% of the women with whom the Study had previously lost contact.

Several methods of tracking are being used to track women who had been lost to the Study. These include:

- attempting to contact women at initial contact phone numbers they had given;
- asking participants when they joined the Study, to supply in addition to their own phone number, the phone number belonging to a close personal contact. If the participant could not be contacted, the contact could be phoned to find out how the participant might be contacted;
- phoning the area post office to inquire if a forwarding address was available;
- whenever a participant contacted the Study, checking their current name and contact details;

5 Report on data linkage with the Health Insurance Commission and National Death Index

The Health Insurance Commission (HIC) requires written, informed consent from participants, in order to provide data linkages for the Study. If this does not occur, aggregate data only will be provided for the women who did not give their consent.

A second request for consent to linkage was sent out with this year's newsletter. It is envisaged that data linkages for the previous two years and the two years prior to that will be established. In 2001, written informed consent will need to be given again, and another request for all participants to again provide this will need to be forwarded to them.

The investigators have previously contacted officers in the HIC in order to seek their assistance in tracking women who had been lost to the Study. A process had suggested whereby letters written by the researchers to women who were lost to the Study, might be channelled through the HIC to their last recorded address as per HIC records. Such letters would ask the women concerned to respond to the researchers.

It was stated that a range of item numbers could be requested from the HIC concerning women who had given their consent. In response, Professor Dobson stated that the Study needed to be very careful about the information it requested. Should information be requested concerning items over which there could be some sensitivity, a backlash from participants might prove detrimental to the Study.

Another issue concerned the role of ethics committees. It would appear that decisions not to make item numbers available to the Study had been made by ethics committees on behalf of women participants. A question was raised whether ethics committees were entitled to make such a decision on behalf of someone else.

Prior to sending out the survey questionnaires, through data matching with the National Death Index, it was possible to establish if participants in the 70-76 year group had died in the time period following the initial survey. This enabled the Study to avoid sending out survey questionnaires to deceased participants. The data matching process had worked very effectively, and had also met both the AIHW's and The University of Newcastle's ethical standards for data matching procedures. It was envisaged that the NDI would be used for future linkage. Due to the comparatively high cost of approximately $3000 for carrying out this process, it was considered most useful to use it to identify deaths occurring in the older cohort.

6 Update on the conduct and progress of the Indigenous cohort studies

When the Study was initially proposed, one of the factors required of it was that it had to be relevant to groups of women in Australian society who were considered to be especially disadvantaged. Two such groups were identified, Indigenous women and Migrant women.

A number of important Indigenous issues needed to be taken into account when conducting surveys with Indigenous Australians.

Aboriginal women and Torres Strait Islander women were very clearly disadvantaged in terms of health issues. The rationale for a special cohort for Indigenous women included:

- Indigenous women would be under represented if they were part of the national study;
- There would probably be a low response from Indigenous women to mail-out questionnaires;

- The age groups in the main cohort were not appropriate for Indigenous women; since their rates of mortality and morbidity were high, deaths occurred at younger ages and health issues also affected quality of life at earlier ages;
- Indigenous research needed to be owned and controlled by Indigenous communities.

The consultation process was a crucial issue for the Indigenous cohort. It was considered to be the foundation stone on which a project should be built. Collaboration and negotiation with the community, together with community participation was necessary for successful outcomes. It was important to develop a partnership with the community, with the community acknowledging that the researcher brings knowledge and expertise to the project and the researcher acknowledging that the community brings knowledge and culture to the same.

It was necessary to build up trust between the researcher and the community, a process that will take time. Since the Study was to be held over a period of time, it was considered to be possible to achieve this.

Viewing Indigenous communities in terms of urban and rural communities may result in misconceptions as Indigenous communities had links based on relationships rather geographical location. The Study had set up working groups or reference groups in each community because each community is so different. The working group in each community directs the project and process of that project in the community.

Researchers associated with the Study had commenced work in Woorabinda, Cherbourg, Brisbane, Stradbroke Island, Toowoomba and Hope Vale.

At Cherbourg, baseline surveys had been conducted and outcomes obtained. Surveys had also been conducted in Woorabinda and Hope Vale.

It is planned to consult with the Brisbane community and conduct a further baseline survey in Hope Vale. Toowoomba had expressed an interest in conducting a survey as well. Researchers were also due to meet with Torres Strait Islander communities in the near future.

7   Update on incorporation of the NESB cohorts into the main cohort studies

In May 1999, PAC decided that the $50,000 originally allocated for a third follow up of the Filipina cohort be best allocated in the following manner:

- $25,000 in 1999 to determine the feasibility and willingness for the Filipina and Former Yugoslav Republic cohorts to be recruited into the main cohorts.
- The remaining $25,000 to be allocated in the year 2000 on the most appropriate option based on the 1999 work with the migrant cohorts.

From June to August 1999, the future options for the migrant cohorts were explored, including the principal option of recruiting these cohorts into the main study. A teleconference based in Brisbane was held on 11 June with Professor Lenore Manderson, Dr Samantha Thompson, Ms Nicole Stirling and Dr Margaret Kelaher participating. A symposium on migrant health to which members of the Filipina reference group and

Former Yugoslav Republic were invited, was held on 26 August. Future options for the Filipina migrant cohort were discussed following the symposium.

Concerns were expressed over the scientific value of merging the Migrant cohorts into the main cohorts of the ALSWH. Issues of concern that were mentioned included:

- The low percentage of Filipina and FYR women eligible to participate in one of the main cohorts of the ALSWH. Less than 25% of participants in the Filipina cohort fitted into either of the three age groupings of the main cohort. Similarly, only 21.5% of the participants in the FYR cohort fitted into one of the main cohorts;
- The possibility of low response rates to a request for a written survey. High response rates had been achieved in the Filipina cohort as a result of intensive and personal follow-up through the assistance of the Filipina community throughout Queensland;
- An issue of how drop out rates would be calculated when the migrant samples were added to the next follow-up;
- The fact that some of the themes explored in the first two Filipina surveys and the first FYR survey were specific to those communities and differed from the issues explored in the baseline surveys of the main cohort.

7.1   Response of the Migrant cohorts to the option of joining the main cohort

Filipina cohort:
The members of the Filipina cohort expressed concern and disappointment over the closure of the special cohort. They stated:

- They were concerned at losing the "personal touch" that had attracted them to the Study;
- They would lose their unique status, the link with migration and health would be lost and they would get 'lost' in the main study;
- They were concerned about privacy issues if they were part of the main Study, which was a larger project;
- People get tired of questionnaires.

However, the women agreed that middle-aged Filipinas could be given the option to participate in the questionnaire in 2001. They requested that appropriate safeguards and assurances of safeguards in relation to privacy issues be provided. They also stipulated that the data already collected remain with the original investigators.

Closure of the cohort was discussed, but the women did not want this. The women wanted to remain as a Queensland cohort even if some of the cohort members agreed to participate in the main Study. An option was raised to conduct a Brisbane and environs focused study on mental health issues.

It was proposed to put the remainder of the 1999 funds for the migrant cohorts ($17,000), plus an additional $7000 of the $25,000 to be allocated in the year 2000, to conduct a qualitative study of Filipina mental health in Brisbane and environs from January to June 2000, and to close the Filipina cohort. The results of this qualitative study will be relevant to public health practitioners working with Filipinas, the prevention of mental health problems in this group and to the design of quantitative instruments for measuring mental

health in culturally and ethnically diverse groups. The investigators stated that it was important to obtain cross-cultural views on what constituted mental health.

All investigators involved in the Migrant cohorts fully supported this proposal and would be involved in designing and conducting this study.

<u>Former Yugoslav cohort:</u>

Some of the participants in this cohort expressed the view that:

- they felt that by virtue of completing the questionnaire, they have fulfilled their role in enabling a researcher to develop policy recommendations;
- Difficulties with the English language and a lack of control in choosing the areas they wanted to talk about inhibited their participation in the national survey on women's health;
- They were proud of their coping strategies and successful settlement in Australia and they liked the idea that the qualitative methodology enabled researchers to talk specifically about this group.

It was expected that FYR women would be recruited in Victoria and the data collected in Queensland used for comparative analysis, rather than involve a follow-up of women from Queensland.

Dr Markovic had closed the cohort in Queensland and thanked the women for participating.

Action Items: 1 *The investigators will send appropriate letters to all participants, thanking them, clarifying any issues of concern, ensuring outstanding obligations are met and providing them with a summary of researchers' findings;*
2 *PAC to receive copies of what is sent out to the participants;*
3 *A copy of the correspondence to be included in the 6 monthly report;*
4 *The Committee and the Department to convey their thanks through the Study to all participants;*
5 *The investigators to provide a report on the closure of the FYR cohort study, and copies of any relevant publications.*

8   Variation to contract

Members discussed the contract variation and any proposed changes to the contract and its Schedules.

The Study will be providing information and data in response to ad hoc requests for information from Departmental officers. Details concerning the processing of such requests within the Department and liaison with researchers associated with the Study to obtain this information were yet to be finalised, however possible processes and procedures had been discussed at the Departmental Reference Group meeting held on the previous day.

It was suggested that the wording in two areas of the contract be amended to reflect the fact that the Study was intended to be a longitudinal study covering a long (20 year) period of time.

The current contract for the Study is to end on 30 June 2003. Members agreed that a Review of the Study should be conducted well in advance of this date, with a view to ensuring the Commonwealth had ample time in which to assess such a review and determine future funding for the Study. Members commented that such a Review should be completed prior to budget planning commencing for the year 2003, to ensure that funding proposed for the Study would be then be allocated in the 2003 budget.

Action Item: *The secretariat to explore the possibility of including details of the Review of the contract in the contract variation, or alternatively, providing a letter to The University of Newcastle containing details of the proposed Review.*

9   Fund raising issues

Members discussed the possibilities for fund raising for the Study. The investigators have already had requests for data from a range of firms, and they have asked these firms to donate funds for the Study. There were also opportunities to do sub-studies for commercial purposes, one of which had been taken up by the Study. Possibilities existed for the Study to ask firms to fund the newsletter or pay the stipend for a postgraduate student involved with the Study, in return for assisting them with data. Concerns were expressed about ensuring there was no appearance of a conflict in interest between the research and analysis being done within the Study and the private organisation providing funding.

Members discussed methods used by other organisations to raise funds. A leading insurance organisation had recently given $1.1 million to the National Breast Cancer Centre, but the organisation is said to be associated with the project, not its sponsor.

Insurance companies would be particularly suitable as a sponsor for the Study. Health Insurance Companies and private hospitals were also possible sponsors.

There was the possibility of funding being provided through partnership grants, particularly in relation to longitudinal and clinical trials.

There was the opportunity to collect blood, buccal cells and hair cells through the Study. This could enable a range of studies to be done, including those of interest to venture capital companies interested in biotechnology. In addition to these investigations, the Study has done a considerable amount of investigation into Body Mass Index, which has been identified as the biggest predictor of a range of cancers.

Action Items: 1   *Secretariat to organise a teleconference to brainstorm fund-raising issues;*
2   *Secretariat to draft letters to appropriate individuals and peak women's organisations, seeking further funding for the Study.*

Researchers were asked what were the shortfalls in funding and what were the impacts of such a shortfall. A brief discussion of the budget occurred. They were also asked to estimate what funding was needed and what projects would be carried out with such funding.

Action Item: *Researchers to provide an estimate as to how much funding is required for additional projects through the Study and brief details on the projects that are proposed with this funding.*

10   Report on deliverables for 1999

A priority for the Study was the data access policy and data archiving. Data collected by researchers associated with the project, are held by The University of Newcastle or The University of Queensland. Data may be made available to collaborating researchers and requests for specific data analyses will be considered, provided that a formal request is submitted. All applicants must meet requirements to ensure that:

- Any data provided remains confidential; and
- Any proposed study using the data provided does not duplicate or overlap with studies already being carried out by post-graduate students associated with the Study.

The baseline data-sets for the three cohorts will be archived at the Social Science Data Archives (SSDA) at the Australian National University by the end of 1999. Archiving will preserve the data as a valuable resource and will make the data available for future use by other researchers, subject to the same access conditions as existed previously. Requests for data will be directed through the Newcastle researchers, who can veto access to data.

Members expressed the view that a condition of access to data should include an undertaking that researchers using the data include the proviso that the data were not analysed by the Study.

Members also discussed the possibility of closer relationships with the Australian Institute of Health and Welfare (AIHW) and the HIC. The Study already has good relationships with AIHW, with AIHW using the Study data in its current work. Hence collaboration in research with AIHW already exists and members expressed a view that further action was unnecessary.

In the case of the HIC, a closer relationship may assist the Study obtain improved access to HIC data, due to improved HIC understanding of the Study's aim, objectives and value.

Action Item: Secretariat to invite the HIC to send a representative to the next PAC meeting.

Communication with participants occurred through the newsletters. Members were provided with a copy of the latest newsletter.

There were many publications and abstracts which provide information on the projects being carried out by researchers associated with the Study. Researchers have also given many presentations and liaised with groups such as general practitioners to provide data and information concerning women's health issues.

Twenty nine project reports concerning the Study had been provided over a five year period. The reports were produced on a six monthly basis and were painstakingly created, with considerable detail in them. Despite the work involved in producing them, the investigators themselves appreciated their usefulness and found themselves frequently referring to these reports for their own purposes. PAC members decided that project reports should be scientific, with copies of survey questionnaires, publications and other relevant information.

PAC members decided that the annual report should appeal to a broad audience and be easily and quickly read. Graphics and graphs should be included, together with personal photographs of participants if permitted.

The investigators provided information concerning the Study's budget to members. A document detailing spending was provided to all present. About half the funds went on salaries for research staff. This included support for a part of the Project Manager's salary, the Data manager's salary and three research officers' salaries. The main investigators themselves who were working on the Study, were not being paid anything by the Study but were funded by their respective universities.

Action Item: The investigators to circulate an amended budget sheet to all members.

11   Priorities for 2000 and future directions (including staff changes)

The meeting was informed that Professor Annette Dobson will be moving to Queensland, in order to take up the Chair in Biostatistics at The University of Queensland. The University of Newcastle has agreed that Professor Dobson will remain as Director of the Study.

Dr Wendy Brown will move to Queensland, in order to take up the Chair of Physical Activity and Health at The University of Queensland. Dr Brown will cease to be the Manager of the Study. It is likely that Associate Professor Christina Lee will be seconded to succeed her as the Manager of the Study. The investigators acknowledged the importance of retaining researchers with background knowledge and expertise concerning the Study at The University of Newcastle.

It is envisaged that there will be a strengthened node in Queensland as a result of Professor Dobson and Dr Brown moving to Queensland, with more opportunities being provided for statistical analysis of data and development and publication of papers. The University of Queensland has allocated $80,000 to the Study, which will be used to fund additional positions at The University of Queensland. This will strengthen the links between the main study and the special cohort studies.

The Chair expressed the view that the PAC was charged with the task of ensuring that the excellence of the Study was maintained, and through liaison with the Department and the consultant, who is currently The University of Newcastle, will endeavour to carry out this task.

Priority directions for the Study included meeting the Department's policy needs, archiving data, developing and refining a system for responding to Departmental requests for data, working with the Department to identify needs to be met, gathering resources for the Study and fund-raising.

The next PAC meeting will be held in the first week of April, possibly at Newcastle.

10.4   ACTIONS ARISING FROM THE PAC MEETING - 28 OCTOBER 1999.

AGENDA ITEM	TASK	RESPONSIBILITY	PROGRESS
7	Send appropriate letters to all participants, thanking them, clarifying any issues of concern, ensuring outstanding obligations are met and providing them with a summary of researchers' findings. Copies of what is sent out to the participants to be sent to PAC. A copy of the correspondence to be included in the 6 monthly report.	The Investigators	
7	A separate letter thanking all participants to be sent on behalf of the Committee and the Department.	The Secretariat	
7	Reports and copies of any relevant publications on the FYR cohort study that has been wound up, to be provided to PAC.	The Investigators	
8	Explore the possibility of including details of the Review of the Study in the contract variation, or alternatively, providing a letter to The University of Newcastle containing details of the proposed Review.	The Secretariat	
9	Organise a teleconference to brainstorm fund-raising issues.	The Secretariat	
9	Draft letters to appropriate individuals and peak women's organisations, seeking further funding for the Study.	The Secretariat with assistance from the Investigators	
9	Provide an estimate to PAC members as to how much funding is required for additional projects through the Study and brief details on the projects that are proposed with this funding.	The Investigators	
10	The HIC to be invited to send a representative to the next PAC meeting.	The Secretariat	
10	An amended budget sheet to be circulated to all PAC members.	The Investigators	