



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

**Report 3 for the
Commonwealth Department of
Human Services and Health**

**The University of Newcastle
and
The University of Queensland**

10 December 1995

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This is the third report provided by the University of Newcastle and the University of Queensland, due 10 December, 1995 as agreed in the contract between the Commonwealth Department of Human Services and Health and the University of Newcastle.

The content of Report 3 is to include:

- a) A report on the pilot study including:
 - the sampling and recruitment progress;
 - the consent and response rates achieved for the pilot study;
 - analysis of the pilot study data including a data book of basic tabulations of all variables;
 - progress with the compilation and comparison of data for participants and non-participants for the pilot sample.
- b) A detailed protocol for the selection and recruitment of the main cohort, based on the results of the pilot study.
- c) A report on the establishment and operations of the National Advisory Committee and the reference groups.
- d) A detailed Communications Strategy.

This report is presented in three parts; from the Management Committee (part A), the University of Newcastle (part B) and the University of Queensland (part C), together with Data Books and Appendices.

PART A - MANAGEMENT COMMITTEE

1. MANAGEMENT COMMITTEE

The Management Committee has met through teleconferences (19 July 1995; 5 October 1995; 8 November 1995; 6 December 1995) and face to face meetings (27 June 1995; 28 July 1995). In addition, the minutes of each team's local meetings have been circulated by electronic mail for information and comment by the other group.

MEMBERSHIP OF THE MANAGEMENT COMMITTEE

The Women's Health Australia Management Committee comprises of the Women's Health Australia Principal Investigators and Project Manager from the University of Newcastle and the Principal Investigators and Study Co-ordinator from the University of Queensland.

The University of Newcastle

Professor Annette Dobson

Professor Lois Bryson

Dr Margot Schofield

Dr Julie Byles

Dr Wendy Brown

The University of Queensland

Professor Lenore Manderson

Dr Gail Williams

Ms Margaret Kelaher

TERMS OF REFERENCE FOR THE MANAGEMENT COMMITTEE

- 1. To co-ordinate the Australian Longitudinal Study on Women's Health (ALSWH) undertaken by researchers at the University of Newcastle and the University of Queensland and to ensure that the project is conducted in accordance with the terms of *Schedule 1 of the Agreement between the Commonwealth of Australia and the University of Newcastle***
- 2. To ensure that the study:**
 - 2.1 Addresses the priorities of the National Women's Health Policy**
Particularly those areas relevant to the five main study themes:
 - Time use
 - Weight, exercise and health
 - Violence against women
 - Life stage and key events
 - Use of and satisfaction with health care services
 - 2.2 Is undertaken in a methodologically sound fashion**
With attention to:
 - Recruitment of a representative samples of women in Australia and retention of these women in the study
 - Use of appropriate and valid measures

- Employment of adequate methods for controlling data quality
- Application of appropriate statistical analyses

2.3 Provides pertinent data to the Commonwealth Department of Human Services and Health to inform health policy for women

Providing information on:

- 2.3.1 those factors that promote and those that reduce good health in women, and
- 2.3.2 the interaction between the health system and the health needs of women, in particular the experiences of women in receiving health care and their attempts to have their continuing needs met by the health system

2.4 Communicates findings to women in Australia to assist them to make better health choices

2.5 Operates as a national resource, encouraging collaboration between researchers throughout Australia

2.6 Provides an opportunity for postgraduate training in women's health research

3. **To approve proposed substudies connected with ALSWH, whether these substudies are funded from ALSWH core funds or from external sources.**
4. **To identify and implement strategies to secure appropriate funding for the continuation of the study.**
5. **To co-ordinate access to data collected by the ALSWH according to the *Guidelines to Publication and Ownership and Access to Data*.**
6. **To authorise proposed publications and authorship according to the *Guidelines to Publication and Ownership and Access to Data*.**

OPERATING PRINCIPLES OF THE MANAGEMENT COMMITTEE

1. Face to face meetings will be held twice each year, at six-monthly intervals. Teleconferences will be held once a month.
2. The venue for each meeting will usually be at Newcastle or Brisbane.
3. Costs of airfares and incidental expenses are the responsibility of the Women's Health Australia project at the University of Newcastle.
4. Secretariat services for the meetings will be provided by the Women's Health Australia staff at the University of Newcastle or the Women's Health Australia staff at the University of Queensland.
5. The main business of the Management Committee will be conducted at the meetings and at teleconferences. The Women's Health Australia team at the

University of Newcastle will act as central co-ordination point between meetings.

2. GUIDELINES TO OWNERSHIP OF AND ACCESS TO DATA AND PUBLICATION

I. Guidelines to Ownership of and Access to Data

1. Data associated with the project collected by researchers at the University of Newcastle or the University of Queensland are held in trust by the respective University. The same principle applies for data associated with the project and collected by investigators at any affiliated institution. For data collected in collaboration with, by or for Aboriginal and Torres Strait Islander communities, rules set out by the NHMRC apply.
2. Data may be made available to collaborating researchers where there is a formal request to make use of the material. Permission to use the data must be obtained from the Principal Investigators of the project. Where data are collected in collaboration with, by or for a community, community permission to use data will also be necessary.
3. Full acknowledgement of the source of data must be provided in any publications that arise from access to and use of the data. This acknowledgement should appear in addition to the standard acknowledgement set out in II.5 (Guidelines to Publication).
4. Where data have been collected by an individual researcher, or are regarded as of primary interest to that researcher, and are made available to a second scholar, the original researcher, if available should be invited to participate in any publications that follow from use of the data. The original researcher is not bound to accept co-authorship.
5. Numerical data may be continually edited, and those who are responsible for the data (see 1 above) are obliged to ensure that the data are regularly reviewed and edited. Publications must use the most up-to-date information available, and should include the date and source of all data used.

II. Guidelines to Publication

1. Researchers wishing to write papers using study data should draft an abstract summarising the paper or other proposed publication and specifying intended authorship, define the deadline for the paper, and establish whether others on the team wish to participate in a substantial manner that would entitle them to be co-authors. Primary authorship may be renegotiated if the deadline is not met.
2. Where there is more than one author of a publication, one author - by agreement among the authors - should formally accept overall responsibility for the publication. Such formal acceptance, as the "responsible author", must be in

writing and kept on file in the department or unit of that author, together with the names and signatures of all other authors.

3. The minimum requirement for authorship is participation in a substantial way in conceiving and/or executing and/or interpreting at least part of the publication in the person's field of expertise, sufficient for her or him to take public responsibility for it. There will be no honorary or courtesy authorship.
4. Each co-author must acknowledge her/his co-authorship, in writing, and this must be kept in the department or unit of the responsible author. This requirement must be met by all authors signing an agreement that they are "authors" of a specified publication in the terms defined in 3 above. Such a statement must include an indication that there are no other authors of the publication, according to this definition. If one or more co-authors are unavailable or otherwise unable to sign the statement of authorship, the head of department or unit may sign on their behalf, noting the reason for their unavailability (see III).
5. All publications must include the following acknowledgement:

The research on which this paper (book, monograph, abstract, or report) is based was conducted as part of the Australian Longitudinal Study on Women's Health, The University of Newcastle and The University of Queensland. The Study was funded by the Department of Human Services and Health.

Additional funding agencies should also be acknowledged if this is applicable.

6. Due to recognition of all participants is a part of a proper research process. Authors should ensure that research assistants, technical officers, and other work of non-authors, including community members involved in supporting the project, are properly acknowledged.
7. The acknowledgement may refer to any members of the project who have provided comments, advice, support or other input to the paper, who are not already listed as authors.
8. Publication of multiple papers based on the same set(s) or subset(s) of data is improper unless full cross-referencing occurs within the papers, for example, by reference to a preliminary publication from which the complete work grew.
9. The Principal Investigators at the responsible Universities will maintain libraries of publications arising from the project, and ensure that copies of all publications are lodged with the collaborating University.
10. Prior to submitting a paper for publication, the paper must be submitted to the Principal Investigators at both the University of Newcastle and University of Queensland for comments with a two week turn around allowed. Researchers are also encouraged to circulate papers to members of the study team for comment. The paper must then be sent to the Department of Human Services and Health at

least four weeks before submission to a journal. If there is no reply, the paper may be submitted to the selected journal for publication.

III. Statement of authorship

A statement of authorship should include the following wording:

Australian Longitudinal Study on Women’s Health,
The University of Newcastle and The University of Queensland

Name of author(s):

Affiliations(s):

Title of published work:

Form of work:

Submitted to:

I certify that I am an author of this work and have participated in conceiving and/or executing and/or interpreting the data that are reported in this work. I am able to take public responsibility for this work.

I confirm that there are no other authors of the publication, according to this definition, and that the appropriate acknowledgements have been made.

Signed:

Date:

OR

I certify that.....is unavailable/unable to sign
this statement of authorship for the following reason:.....

.....
.....

Signed:

Head of department:

Date:

3. NATIONAL ADVISORY COMMITTEE

The first meeting of the National Advisory Committee was held on Monday 27 November, 1995 from 10 am to 4 pm at Vic Health, Carlton, Victoria.

TERMS OF REFERENCE FOR THE NATIONAL ADVISORY COMMITTEE

To provide advice to the Research Management Team on:

- how women may be involved in various phases of the research activity;
- how the Study might achieve an appropriate public profile;
- strategies to secure appropriate funding for the continuation of the Study;
- any other issue referred to it by the Research Management Team.

MEMBERSHIP OF THE NATIONAL ADVISORY COMMITTEE

Ms Rhonda Galbally AO	Chief Executive Officer, Vic Health, Melbourne (Chair)
Dr Dorothy Broom	National Centre for Epidemiology and Population Health, Australian National University, Canberra
Ms Liz Furler	Head, Primary Health Care Group Department of Human Services and Health, Canberra
Dr Sally Redman	Director National Breast Cancer Centre, Sydney
Ms Gloria Sutherland	Vice President Public Health Association, Perth
Mrs Renata Watkinson	Older Women's Network, Sydney Representing Australian Consumer's Health Forum
Dr Jeanette Ward	Needs Assessment and Health Outcomes Unit Camperdown, Representing NH&MRC
Mrs Agnes Whiten	Women's Advisor to the Archbishop The Catholic Centre, Brisbane

(ATSI representative - pending)

Women's Health Australia Management Committee

Professor Annette Dobson

Professor Lois Bryson

Dr Margot Schofield

Dr Julie Byles

Professor Lenore Manderson

Associate Professor Gail Williams

PART B - UNIVERSITY OF NEWCASTLE

1. ADMINISTRATIVE PROCEDURES

The Australian Longitudinal Study on Women's Health will be sited within the proposed Research Institute for Women's Health. This institute will be a cross-faculty organisation to facilitate multidisciplinary research into women's health. Details of the organisational structure are presently being finalised with the University administration.

2. TRANSDISCIPLINARY TEAM MEETING

Principal Investigators, Associate Investigators and general staff at the University of Newcastle meet every Tuesday at 2pm to discuss the project. These meetings encourage transdisciplinary collaboration of the project.

3. PROJECT STAFF

Jean Ball (Data Manager), Phoebe Bissett (Secretary), Lyn Adamson, Beverly Arnold and Joy Ellem (Research Assistants) have been working on the pilot studies and development of the survey instruments.

Dr Wendy Brown has accepted the position of Project Manager and will commence on 1 February, 1995.

The University advertised the following positions: Statistician, PhD scholarships; vacation scholarships (see Appendix A for advertisements and other material)

The table below summarises the outcome to date.

Position	Number of applicants	Number interviewed	Appointment
Statistician	17	5	Offer made
PhD scholarships	7		3 offers made
Vacation scholarships	2		1 offer made

4. OFFICE ESTABLISHMENT

The Women's Health Australia office is established. Furnishings and equipment have been purchased and are in use. The office comprises ten work stations in room V202, the Project Manager's office in room V203 and a resource area in room V203a in the Mathematics building at the Callaghan campus.

Room V202 has a reception, meeting room area and large collating table. Six work stations have personal computers, additional personal computers will be purchased ready for use by new staff when they commence. A laser printer, fax machine and photocopier are in use.

5. DEVELOPMENT OF NAME AND LOGO

Peach Advertising was contracted to develop the name and logo for the study. The name Women's Health Australia was selected. There are several versions of the logo; colour (2 shades of purple and green) and black and white. The logo has been incorporated on letterheads, brochures and business cards.

6. MEDIA

Kate Tully from CommuniKate has been contracted to develop and implement communication strategies and liaise with the media about Women's Health Australia. To date media coverage has been conducted in the pilot areas, Illawarra and Central West of New South Wales (see Appendix B for detailed report).

7. PRESENTATIONS

Women's Health Committee, Health Research Council of New Zealand, 1 August 1995. Auckland, New Zealand. Professor Annette Dobson informal presentation - background, current state, goals

Public Health Officers Training Program, NSW Department of Health, 1 September 1995, North Sydney. Professor Annette Dobson - talk on background, current state, study design and themes, methodology, current state, goals

Centre for Clinical Epidemiology and Biostatistics Weekly Seminar Series, 8 September 1995. Case Study Theatre, David Maddison Building, Royal Newcastle Hospital - Dr Julie Byles.

Department of Psychology Seminar, 14 September 1995
Behavioural Sciences Building, The University of Newcastle
Professor Annette Dobson, Drs Margot Schofield, Julie Byles, Christina Lee, Deidre Wicks - presentation on background, study themes, methodology, progress, goals

Public Health Association of Australia 27th Annual Conference 1995, 25-27 September 1995. Cairns International Hotel, Cairns, Dr Julie Byles. ALSWH

Clinical Centre for Epidemiology and Biostatistics Distance Learning Workshop, 11 October 1995. David Madison Building, Royal Newcastle Hospital, Newcastle
Professors Annette Dobson, Lois Bryson, Drs Margot Schofield, Julie Byles, Deidre Wicks - presentation on backgrounds, study themes, methodology, progress, goals

Newcastle West Business and Professional Women's Association, 18 October 1995
Bimet Lodge, Newcastle. Dr Julie Byles - background, study themes, methodology, progress, goals

Department of Psychology Seminar, 10 November 1995
University of Cape Town, Cape Town, South Africa. Dr Margot Schofield - overview of the Australian Longitudinal Study on Women's Health

3rd National Conference on Women's Health, 17-19 November 1995
Manning Clark Centre, Australian National University, Canberra. Dr Julie Byles - poster presentation: background, study themes, methodology, progress, goals

The Australian Sociological Association Health Sociological Day, 5 December 1995,
University of Newcastle
Forum: Social Research and Community Action in the Hunter
Professor Lois Bryson - background, study themes, progress, goals of ALSWH.

8. REFERENCE GROUPS FOR THE MAIN COHORTS

Three reference groups are currently being established, one for each of the age groups for the main cohort studies (women aged 18-22 years, 45-49 years and 70-74 years). Each group will include a maximum of 10 women who will be nominated by a wide range of organisations within the Hunter Region. An explanatory letter inviting the organisations to nominate a representative and brochures outlining the study have been forwarded to each of the groups (see Appendix C). The organisations are age specific and include groups such as: the Business and Professional Women's Club, the Commonwealth Employment Service, the Country Women's Association, Parents without Partners, Neighbourhood Centres, the Aboriginal Awabakal Co-operative, Students Associations, Seniors Citizens groups, Bowling Clubs, Probus Clubs, the Netball Association and the Ethnic Community Council.

The reference groups will take the form of focus groups with a maximum of four Principal or Associate Investigators in attendance. One researcher will consistently work with each group of women allowing them to develop rapport with this researcher. Each of the groups will operate under the following terms of reference:

1. To provide feedback and information to the Principal Investigators on the Australian Longitudinal Study on Women's Health undertaken by researchers at the University of Newcastle and the University of Queensland.
2. To work with the Principal Investigators on the Australian Longitudinal Study on Women's Health to ensure that the study and any proposed sub-studies use methodology which is acceptable to Australian women.
3. To provide feedback on the interpretation of study findings.
4. To advise on means to communicate study findings to women in Australia.

The meetings will be organised with the following arrangements:

1. Meetings will be held at least twice a year at a location in the Newcastle area.
2. Secretariat services for the meeting will be provided by the Women's Health Australia staff at the University of Newcastle.
3. The main business of the reference groups will be conducted within the meetings. The Women's Health Australia staff at the University of Newcastle will act as a central co-ordination point between the meetings.

9. SAMPLING AND RECRUITMENT PROCEDURES

9.1. RECRUITMENT OPTIONS

There are two main needs in conducting this longitudinal study on women's health. The first is the need for the study to represent all women in Australia. The second is the need to be able to make meaningful comparisons between women who are in the study who report various circumstances.

To meet the first need, the study participants need to be similar to other women who are not part of the study in terms of

- socioeconomic status (education, employment, occupation, financial circumstances)
- health status
- health care utilisation
- health risk behaviours
- geographical location (state, urban/rural/remote status)

A high survey response rate is usually desired as a means of ensuring that women participating in the study are truly representative.

The second need is not dependent on high response rates, but requires the collection of all relevant information, using valid and reliable measures, from a sufficient number of women.

In meeting these two needs, there are obviously trade offs in that more intensive recruitment methods (such as household surveys or telephone interviews) can achieve higher response rates but are more expensive. To employ these methods, the study will need to either: recruit fewer women, restrict the study to urban areas where doorknocking is more feasible or use a combination of these two options. These trade offs are presented in Table 1.

Another option is to recruit volunteer subjects who are more motivated to participate in and continue with the study. The disadvantages of this strategy are that the response bias is not quantified, and that women who volunteer are even less likely to be representative than women who agree to fill in a survey sent to them. The relative

advantages and disadvantages of volunteers versus probability sampling are also provided in Table 1.

For the Australian Longitudinal Study on Women's Health the preferred option is to recruit a random sample of women from the Health Insurance Commission providing a satisfactory response rate and an unbiased sample can be achieved. This strategy has been trialled in two pilot studies described below. An alternative strategy of selecting a random sample of women using the Telstra White Pages (Pilot 3) is also described. This strategy was trialled so that the response rates achieved from telephone recruitment could be estimated.

Table 1
Recruitment Options

		Advantages	Disadvantages
Random sample	HIC	Representative if good response rate Good geographical coverage (urban/rural/remote, states/territories) Good information on non-respondents	Unrepresentative if poor response Lack of personal contact
	Electoral roll	Personal contact (telephone) possible - but expensive Limited information for non-respondents	Limited coverage (some states/territories) Difficulties in obtaining access
	Telstra white pages	Good geographic coverage possible Some personal contact (telephone)	No information on non-respondents Contact households not selected women Difficult to define response rate Expensive smaller sample Unrepresentative
	Households	Personal contact Good response rate Good representativeness Some information on non-responders?	Maybe limited geographical coverage Very ? expensive so smaller sample size
Volunteers	Recruited by randomly selected sample (mixed method recruitment)	Sample size easily recruited Geographic coverage Personal contact	Unrepresentative No information on non-respondents for volunteer component, can't define response rates
	Media recruitment	Sample size easily recruited ? Geographical coverage Personal contact if phone in (maybe not rec) Cheap	Unrepresentative No information on non-respondents can't define response rate
	GP network	Geographic coverage possible Personal contact	Bias towards unhealthy and carers

10. PILOT STUDIES

A series of three pilot studies was carried out to identify and test sampling and recruitment procedures which would maximise response rates and test questionnaire items. All three pilot studies were conducted in two NSW statistical divisions: Illawarra and Central West, and were backed up by a media campaign. The media coverage conducted by CommuniKate for Illawarra and Central West during August 1995, is summarised in Table 2 and more details are given in Appendix B.

Table 2
Media Coverage

Statistical Division	Newspaper	Radio	Television
Illawarra	8	5	2
Central West	8	3	2

The first pilot study yielded a low response rate. Samples of both responders and non-responders were contacted by the study team and Health Insurance Commission (HIC) respectively, to identify possible reasons - results shown in Appendix D. Briefly, the non-responders attributed their non-response to the length of the questionnaire and their perception that the questions were too personal and/or intrusive. In general, the young women consulted said that they were “not interested”, women aged 45-49 said they had “no time” and older women did not think it was personally relevant. Giving consent to access their Medicare information may also have contributed to non-response. Women may also have felt ‘overloaded’ by the number of items they received in the mailed package. As a result, two more pilot studies (Pilot 2 and Pilot 3) were conducted testing the effects on response rates of a modified shorter questionnaire with less intrusive questions, not requesting consent to Medicare information at the same time and receiving fewer survey items in the package. The same modified questionnaire was used for Pilots 2 and 3 but they were based on different sampling frames and used different recruitment procedures.

10.1 SAMPLING FRAMES AND SAMPLE SELECTION

10.1.1 *Pilot 1*

The Health Insurance Commission (HIC) data base was used as the sampling frame. This database is one of the most accurate population lists in Australia as it is updated automatically each time a Medicare claim is lodged. HIC randomly selected samples of 1000 women in each age group who held a current Medicare card - 3000 women in total.

To ensure sufficient numbers of women from rural and remote areas, the sample was stratified in the following way: 40% of each age group was from the “Metropolitan” areas, 30% from the “Large or Small Rural” areas, and 30% from the “Other Rural or

Remote” areas. This represented oversampling, by a factor of about 1.5 from the “Other Rural and Remote” areas and undersampling from “Metropolitan” areas.

10.1.2 Pilot 2

The sampling frame was the HIC database with the same sampling fractions as for Pilot 1, except that only 200 women in each age group were selected - 600 women in total.

10.1.3 Pilot 3

The sampling frame was the Telstra Electronic White Pages. A sample of 500 households was randomly selected within the Illawarra and Central West statistical divisions. Simple random sampling was used with this sampling frame with no consideration of urban, rural or remote areas.

10.2 RECRUITMENT PROCEDURES

10.2.1 Pilot 1

This pilot study was designed to assess the relative merits of a single, long questionnaire against a two stage questionnaire - a short questionnaire at the time of consent followed by a longer questionnaire. It also tested the alternative timings for the offer of a telephone administered version of the questionnaire, instead of the pencil - and - paper version.

The women who were sent the single long questionnaire were randomly allocated to **Strategy 1** or **2**, with women in Strategy 2 not being offered an interview by telephone. This questionnaire will be referred to as the ‘full’ questionnaire. The women who received the two stage questionnaire were randomly allocated to **Strategy 3** or **4**, with women in Strategy 4 not being offered an interview by telephone. This first stage of the questionnaire will be referred to as the ‘short’ and the second stage as the ‘long’ questionnaire.

HIC posted the initial package to the women selected. In each package, the women received:

- a) a personally addressed letter from the HIC and the Department of Human Services and Health, explaining the involvement of the HIC in the study
- b) an open letter from the study team (signed by the principal investigators)
- c) a pamphlet on the study
- d) cards for names and addresses of friends or relatives through whom the subject could be recontacted if contact was lost through moving
- e) change of address notification cards
- f) an identification numbered consent form
- g) an identification numbered age-appropriate questionnaire - either the full questionnaire (1995 Survey) or the short questionnaire (1995 Survey A).

- h) a reply paid envelope for returning the completed consent form and questionnaire to the study team.

See Appendix L for materials used in Pilot 1.

Separate signed consent was required for participation in the survey and authorisation to release Medicare data to the study team.

For those women in Strategies 3 or 4 who returned the short questionnaire, the second part - the long questionnaire was sent a few weeks later.

It was planned that reminders would be sent three weeks after the first package was sent, and three weeks after that a replacement package would be sent. Looking at the results in section 10.4.1, it would have been a waste of resources and time to carry this out for the full sample. Instead a subsample of 90 women in strategy 1 and 90 in strategy 3 who had not responded were sent reminder cards to see the effect of these on response rates.

Later 34 responders and 20 non-responders were telephoned to discuss their reactions to the survey, and incentives and barriers to responding (see Appendix D for the summary of this).

10.2.2 Pilot 2

This pilot was based closely on the methods recommended by Dillman (1978) for maximising response rates for mailed surveys. Express postage was used with the intent of making the package seem more important and also more distinctive and memorable. Dillman indicates that certified mailing instead of bulk mailing will significantly increase response rate. However, certified mail was not used due to the impracticality for Australian conditions. For instance, if women are not at home at the time of delivery, a signature at the post office is needed. Express post has the advantage of having greater impact without this disadvantage, and is also more likely to be delivered to the correct address than ordinary post.

This second pilot study using the HIC database, was undertaken to compare the effects of different types of postage on response rates. Two mailing protocols were adopted (see Table 2).

HIC posted the initial package to the women selected. In each package the women received:

- a) an open letter from the principal investigators of the study
- b) an explanatory pamphlet
- c) an identification numbered consent form
- d) an identification numbered age-appropriate questionnaire
- e) a reply paid envelope for returning the completed consent form and questionnaire to the study team.

See Appendix M for materials used in Pilot 2.

This package was a lot simpler than that sent in Pilot 1. A shorter, less intrusive questionnaire was used. Medicare consent was not requested at this stage in the study. The words “statistical information” from Medicare were used rather than “Medicare records” as this was thought to be less off-putting. Contact cards for friends and relatives and change of address cards were omitted.

Table 3
Mailing protocols for Pilot 2

Mailout	Mailing protocol 1	Mailing protocol 2	Survey items in package
1st	Express	Regular	All of the items listed above
2nd (1 week later)	Regular	Regular	Signed thankyou/reminder card
3rd (3 weeks later)	Regular	Express	2nd letter, items c, d, e (listed above)
4th (6 weeks later)	Express	Express	3rd letter, items c, d, e

The wording of the letter and thank you/reminder card were also based on the recommendations of Dillman (1978).

10.2.3 Pilot 3

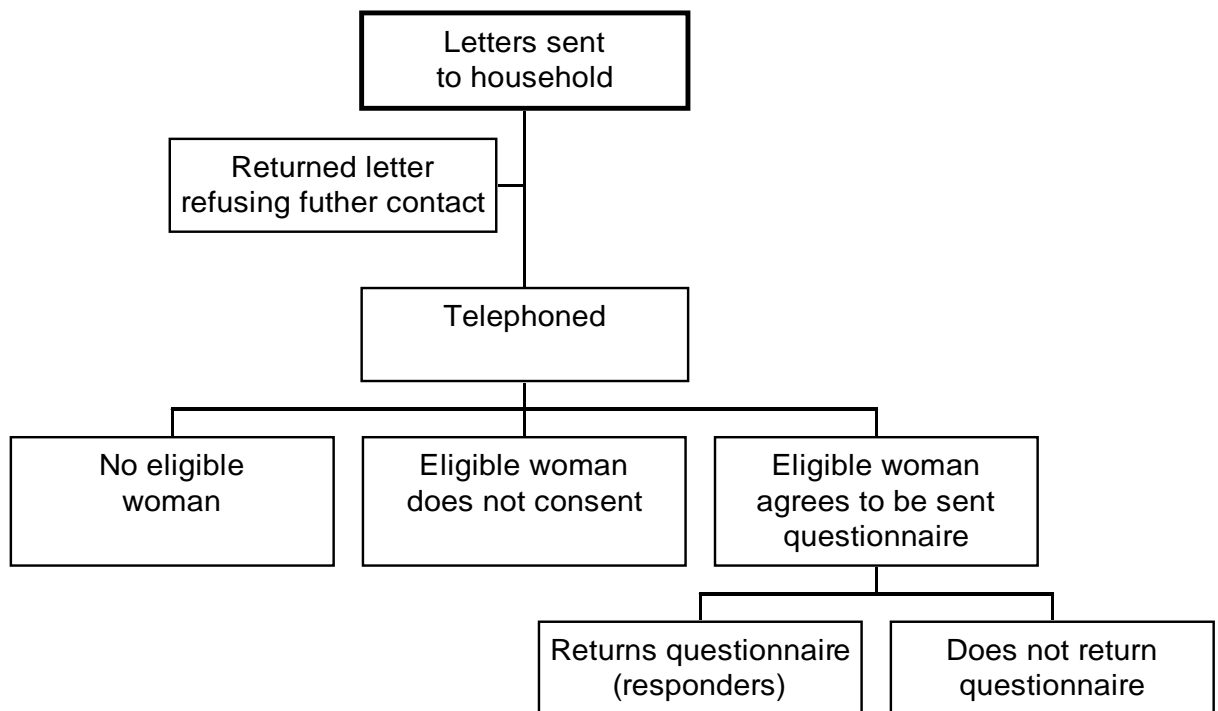
Telstra Electronic White Pages were used as an alternative sampling frame to the HIC so that women could be contacted personally by telephone. This strategy offers an opportunity to establish rapport with the women before sending them the questionnaire, which is especially important considering the nature of the longitudinal project.

Initial contact with the selected households was obtained by sending a letter explaining the project, stating that they would be called in the next couple of days unless they returned the non-contact form to the study team. This step was required by the University of Newcastle Human Research Ethics Committee, so that the women or the household knew the phone call was legitimate and could ask not to be phoned.

The telephone contact was made by the Hunter Valley Research Foundation 5 days after the letter had been sent (provided refusal had not been received). A trained interviewer, following a prepared script explained the project, asked if there were any women in one of the selected age groups and invited the woman having the next birthday to take part. Up to six call-back attempts were made if no-one was at home.

A summary of this procedure is shown in Figure 1. See Appendix M for materials used in Pilot 3.

Figure 1
Pilot 3 procedure for telephone recruitment



The mailout protocol conducted by the Hunter Valley Research Foundation was the same as for Pilot 2 mailout protocol 2 (see Table 3).

10.3. QUESTIONNAIRES FOR THE PILOT STUDIES

The main differences between the questionnaire in Pilot 1 and in Pilots 2 or 3 was that each section was condensed, questions were re-ordered, and the more intrusive and personal questions were removed. Following Dillman's (1978) suggestions, the responses for each question were moved to the left hand side if possible. The two stage questionnaire used in Pilot 1 was not used in Pilots 2 and 3.

The major specific changes are listed below:

- a simpler title page was used without a detailed description of the questionnaire
- the IQOLA SF-36 English (Australia) (adapted from Ware 1992) was used at the beginning of the questionnaire (replacing SF12 which had been at the end of the questionnaire for Pilot 1)
- the life events list was modified and reduced from 80 items to 22 items
- the violence section was reduced to two items in the list of life events
- the General Health Questionnaire (GHQ 12; Goldberg & Hiller 1979) was removed, as was the depression subscale of the Women's Health Questionnaire (Hunter 1992)
- the section on satisfaction with GP services was reduced from 25 items to 12 items
- the demographic items were asked last, with the income and some demographic questions about spouse/partner removed.

10.4 RESPONSE RATES FOR THE PILOT STUDIES

10.4.1 Pilot 1

The responses to the initial mailout for each strategy by age group and urban/rural/remote areas are shown in Table 4. The return to sender and ineligibility rates for each are also included.

Sending out reminders to the 180 women only increased the response rate by 19 responses (10.5%). This was not large enough to warrant sending out reminders to the remainder of the women.

Table 4
Eligibility and response rate by age group and questionnaire for Pilot 1

Age in years	18-22		45-49		70-74		
Questionnaire	Full	Short	Full	Short	Full	Short	Total
Sample	500	500	500	500	500	500	3000
RTS	25	28	9	15	16	13	106
Ineligible	0	1	0	0	6	4	11
Total eligible	475	471	491	485	478	483	2883
%	95.0%	94.2%	98.2%	97.0%	95.6%	96.6%	96.1%
Responders	103	106	131	139	58	69	606
%	21.7%	22.5%	26.7%	28.7%	12.1%	14.3%	21.0%

Only one woman requested a telephone interview.

The women who received the short questionnaire consistently had higher response rates than the women who received the full questionnaire (although the differences were not statistically significant). The highest response rate (28.7%) was obtained for the 45-49 age group who received the short questionnaire. This age group consistently had significantly higher response rates than the other age groups ($\chi^2 = 0.359$; $df = 2$; $p = 0.835$).

Table 5
Response rates (%) by age group, questionnaire
and geographic region for Pilot 1

Age in years	Questionnaire	Urban	Rural	Remote
18- 22	Full	22.7%	26.2%	15.7%
	Short	18.4%	21.7%	28.7%
45-49	Full	25.8%	28.1%	26.5%
	Short	30.4%	29.7%	25.3%
70-74	Full	11.5%	13.9%	11.2%
	Short	10.8%	15.4%	17.8%

There was no consistent trend across urban, rural or remote areas.

Table 6
Response rates(%) by age group, questionnaire and region for Pilot 1

Age in years	Questionnaire	Illawarra	Central West
18- 22	Full	24.0%	16.0%
	Short	24.6%	20.4%
45-49	Full	28.9%	20.0%
	Short	33.8%	22.3%
70-74	Full	15.1%	7.5%
	Short	20.3%	7.5%

10.4.2 Pilot 2

The responses for Pilot 2, for both statistical divisions together, are shown in Table 7.

Table 7
Eligibility and response rates by age group and strategy for Pilot 2

Age in years	18-22		45-49		70-74		Total
	1	2	1	2	1	2	
Mailout protocol							
Sample	100	100	100	100	100	100	600
RTS	9	7	6	3	8	6	39
Ineligible	2	1	3	2	7	9	24
Total eligible	89	92	91	95	85	85	537
%	89.0%	92.0%	91.0%	95.0%	85.0%	85.0%	89.5%
Responders	34	43	48	50	33	30	238
%	38.2%	46.7%	52.7%	52.6%	38.8%	35.3%	44.3%

In general, this pilot had higher response rates than Pilot 1. This result may indicate that the simpler survey package and the type of postage affected the response rate. As for Pilot 1, the highest response rates were observed for women aged 45-49 years.

The response rates for Pilot 2 for each age group and for urban, rural and remote areas are shown in Table 8. Response rates for each age group and for Illawarra and Central West are shown in Table 9.

Table 8
Response rates (%) by age and geographical area for Pilot 2

Age in years	Urban	Rural	Remote	Total
18- 22	49.7%	33.1%	42.4%	42.5%
45-49	53.8%	48.4%	55.6%	52.7%
70-74	33.8%	45.1%	33.3%	37.1%
Total	46.1%	42.2%	44.1%	44.3%

Table 9
Response rates (%) by age and region for Pilot 2

Age in years	Illawarra	Central West	Total
18- 22	49.7%	35.4%	42.5%
45-49	47.3%	58.1%	52.7%
70-74	38.8%	35.3%	37.1%
Total	45.4%	43.2%	44.3%

10.4.3 Pilot 3

Letters were sent to 500 households in the Illawarra and the Central West statistical divisions to introduce the project and notify that telephone calls would be made. Of these, 52 non-contact forms were returned. However, some households were contacted before the refusal letter was received and 4 women from these households agreed to be sent the questionnaire. The remaining households received up to six telephone calls and from these 89 eligible women were identified and 58 (65.2%) agreed to be sent the questionnaire. (Based on population figures about 25% of households would be expected to include a woman in one of the age groups). In total, 51.7% of these women returned the questionnaire. A summary of these results is shown in Table 10. Table 11 provides a summary of the eligibility of people in households contacted in Pilot 3.

Table 10
Eligibility and response rates by age group for Pilot 3

Age in years	18-22	45-49	70-74	Total
Eligible				89
Quest. sent	10	23	22	58
% agreed				65.2%
Returned	5	12	13	30
% returned	50.0%	52.2%	59.1%	51.7%

Of those who are eligible, age groups will be determined when the questionnaires are returned.

Table 11
Eligibility for Pilot 3

Eligible	89
Ineligible (no females in age group, business, disconnected, fax, unavailable, non-English speaking)	369
Unknown eligibility (engaged, no answer, answering machine)	31
Received non-contact forms	52

The response rate for Pilot 3 does not appear to be better than for Pilot 2 and caution is needed as the response rates may be spuriously high since a number of eligible women may not have identified themselves. The true denominator was unknown. However Pilot 3 is not feasible as the cost of writing to and phoning approximately 10 households per participant is unreasonable. An alternative sampling frame would be required if this approach was used.

10.5 REPRESENTATIVENESS OF PILOT STUDY RESPONDENTS

To determine the representativeness of the sample in each age group both in Pilot 1 and Pilot 2, demographic statistics were obtained from Clib 91 (cdrom census data) for the Illawarra and Central West statistical divisions.

Percentages were calculated for marital status, country of birth, level of income and highest level of education using the Clib 91 data and are shown in the following tables with percentages of responses from the Pilot populations. Further comparisons by employment status and occupation are underway.

The study population appear to be representative of the population generally.

10.6. CONCLUSIONS FROM THE PILOT STUDIES

Based on these results, it was decided that aspects of the recruitment procedures of Pilot 2 and 3, would be best for the main study. Combining these would produce the highest response rate while attempting to restrict costs.

In general, when the shorter questionnaire was used, the response rates were higher which indicates that reducing it even more for the main study would advantageous. From the telephone calls to the non-participants, it can be seen that interest levels need to be increased for the young women and personal relevance needs to be increased for the older women.

From the pilot studies, it is evident that different recruitment methods are required for the different age groups. While the highest overall response rate was achieved through telephone recruitment (65% of women identified as being in the eligible age groups) few women in the young and middle age groups returned questionnaires.

Consequently the main survey will need to employ different sampling and recruitment strategies (as well as different questionnaire content) for the different age groups. Protocols for these strategies are provided in Section 12 below. Since each strategy deviates from the strategies trialled in the pilot studies (being a compilation of approaches) these strategies will need to be pilot-tested to review the methods and to ensure that anticipated response rates can be achieved.

11. QUESTIONNAIRE DEVELOPMENT

11.1 QUESTIONNAIRE CONTENT

A number of existing validated scales were used in this questionnaire, the sources of these scales are shown below in Table 12. Where it was believed that existing validated scales did not cover the topic adequately, study specific questions were developed by the research team. These were then piloted to test for comprehensibility of each question (see 11.2 below).

Table 12
Scales and measures used in the questionnaire

Scale or items	Source
Items on health and illness	Australian Bureau of Statistics 1989-1990 National Health Survey.
Items on health	National Heart Foundation of Australia, Risk Factor Prevalence Study. 1980. No. 1.
Items on health care	Australian Institute of Family Services - Australian Living Standards Study. Part 2 Household Information.
Items on health care	National Centre for Epidemiology and Population Health Project Health Check. Reark Research Telephone Manual.
Items on health care utilisation	Australian Bureau of Statistics Population Survey 1989-1990 National Health Survey.
General Health Questionnaire	Goldberg DP & Hillier VS 1979. A scaled version of the General Health Questionnaire. <i>Psychological Medicine</i> , 9: 139-145.
Women's Health Questionnaire	Hunter M 1992. The women's health questionnaire measure of mid-aged women's perceptions of their emotional and physical health. <i>Psychology and Health</i> , 7: 45-54.
Nutrition screening checklist	Australian Nutrition Screening Initiative: Determine your nutritional health.
Items on diet	Dobson AJ, Alexander HM, Lloyd DM, Gibberd RW, Gillett RS & Leeder SR 1983. <i>Hunter Region Heart Disease Prevention Programme Risk Factor Prevalence Study</i> . 1983 Data Book.
Food frequency questions	Willet W 1990. Nutritional epidemiology, food and frequency methods. In Willet W (Ed) 1990, <i>Monographs in Epidemiology and Biostatistics, Vol 15</i> . New York: Oxford University Press.
Demographic items	Australian Bureau of Statistics: A Directory of Concepts and Standards. For Social, Labour and Demographic Statistics April 1994. Published ABS.
Selected demographic items	Australian Bureau of Statistics 1996 Census of Population and Housing. ABS Views on content and procedures. ABS Catalogue No. 2007.0
Selected items on time use	Housing Family and Social Statistics Division. General Social Survey - Time Use Questionnaire (Aged 15 Years and over).
Selected items on	Australian Bureau of Statistics Disability, ageing and carers

disability and caring/assistance	Australia, 1993. Catalogue No. 4432.0.
Elder abuse screening test	Neale AV, Walek MA, Scott RO, Senstock MC & Stahl C 1991. Validation of the Walek-Senstock elder abuse screening test. <i>The Journal of Applied Gerontology</i> , 10(4): 406-418.
Item on relationships	Spanier GB 1976. Measuring dyadic adjustment: new scales for assessing the quality of marriage and similar dyads. <i>Journal of Marriage and the Family</i> , 38(1): 15-38.
Life events	Norbeck JS 1984. Modification of life event questionnaires for use with female respondents. <i>Research in Nursing and Health</i> , 7: 61-71.
Social support survey	Sherbourne CD & Stewart AL 1991. The MOS social support survey. <i>Social Science and Medicine</i> , 32(6): 705-714.
SF-12	PILOT 1 Ware JE, Keller SD & Kosinski M. <i>Scoring guidelines for the SF-12 Physical and Mental Health Summary Scales</i> . Boston MA: New England Medical Centre - The Health Institute, in press. Ware JE, Kosinski M & Keller SD 1995 (in review). A 12-Item Short-Form Health Survey (SF-12): construction of scales and preliminary tests of reliability and validity. <i>Medical Care</i> .
SF-36	PILOT 2 Ware JE & Sherbourne CD 1992. The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. <i>Medical Care</i> , 30(6): 473-483.

11.2 QUESTIONNAIRE DEVELOPMENT

11.2.1 Pilot 1 Questionnaire

Face-to-face piloting of the draft questionnaire was conducted with 10 women in each of the three different age groups from the Newcastle area. This was a very constructive exercise and provided excellent feedback to the research team. In general the comments were very positive. There was general concern in all of the age groups that the draft questionnaire may have been too long. All age groups also commented on possible repetition of questions, appropriateness of the questions for each age group and the ordering of the items in the questionnaire. Women in all the age groups suggested possible questions that have been overlooked. Another concern was the overall formatting, resulting in enlarging the font for the older cohort. The

research team took into account all of the comments and used these to modify the questionnaire for Pilot 1.

11.2.2 Pilot 2/3 Questionnaire

Questionnaires completed for Pilot 1 were reviewed to identify specific items which were completed poorly. Where these problems occurred, the questionnaire was reviewed to identify possible causes to modify the items accordingly. Reasons identified included insufficient instructions for some questions or the position of items on the page. Some women had made specific comments on their questionnaires relating to their inability to respond accurately to some of the questions. These were noted and taken into account when modifying the questionnaire for Pilot 2/3.

The frequency distributions of the responses in Data Book 1 for Pilot 1 were analysed, and questions with a large number of missing values were identified. These items were highlighted for further modifications for the questionnaire used in Pilot 2 and 3, which resulted in the removal of some scales. This is still an ongoing process to refine and shorten the questionnaire for the baseline study. The results from telephoning the responders and non-responders of Pilot 1 (see Appendix D) were also helpful in modifying the questionnaire.

12. PROTOCOL FOR SAMPLING RECRUITMENT AND SURVEYING WOMEN IN THE MAIN COHORTS

12.1 WOMEN IN OLDER COHORT (70-74 YEARS)

Previous research indicated that mail survey response rates deteriorate with increasing age of the sample (Kaldenburg et al 1994) such decline is likely to be more marked for longitudinal studies, where older invitees may question their capacity to give a long term commitment to the study. Very few longitudinal studies have been undertaken with population samples of older women. Those that have been reported have recorded response rates as low as 8% (Cauley 1995). Best response rates (around 60%) have been achieved from samples drawn from specific populations such as retirement communities (Paganini-Hill et al 1989).

Cross-sectional surveys, which require a more immediate short-term commitment have achieved response rates as high as 85% when the survey is related to some highly relevant issue such as hospitalisation in the previous 48 hours (Victor 1988). Surveys of more general health issues achieved lower response rates of around 40-50% (Strayer et al 1993, Ives et al 1992, Kaldenburg et al 1994).

Survey length may also reduce the response rates for older women. In our first pilot study, there was a trend towards higher response rates for the shorter questionnaire. Importantly, and encouragingly, the majority of these women returned the second part of the questionnaire when it was mailed at a later date.

More personalised recruitment through either telephone contact or doorknock does seem to be associated with higher response rates. The Massachusetts Health Care

Panel Study conducted a household survey of people aged 65 years and over and achieved a consent rate of 79% (Jette & Branch 1992). Similarly the Dubbo study achieved response rate of 76% through a combination of written and phone request and personal visits (Simons et al 1990). One other study found that the addition of a telephone prompt to return a mailed survey resulted in significantly higher response rates than mail alone (Ives et al 1992). These findings support the results of our own pilot studies. While the addition of a telephone call would improve recruitment rates, the costs and practicalities of such an approach to recruit 20, 000 women need to be considered carefully.

At this stage the most cost effective approach for recruiting older women appears to be to send a very brief questionnaire, focussing on a limited range of issues which are highly and immediately relevant to older women. These questionnaires would be followed-up with reminders and replacement questionnaires as for Pilot 2. This modified approach will need to be pilot tested.

Only if a satisfactory response rate is not achieved, the following procedure will be trialled for older women.

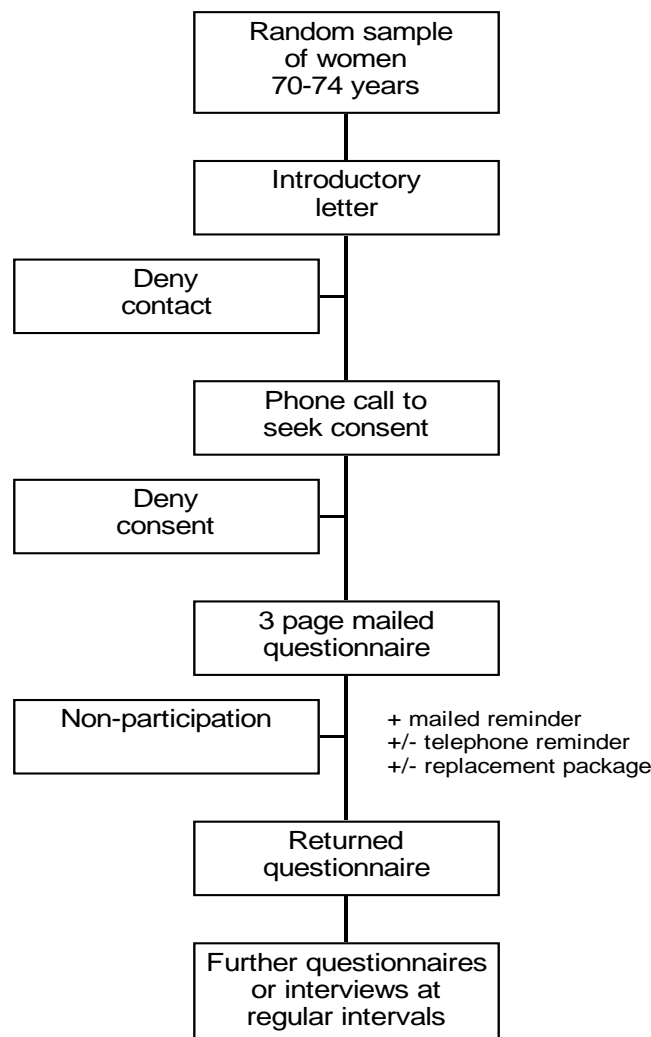
1. A random sample of women aged 70-74 years will be drawn from HIC lists, with oversampling of women from rural and remote areas as described previously.
2. These randomly selected women will be mailed a letter informing them of the study and that they will be telephoned within one week. The letter will allow women to refuse the telephone call (by returning the letter) and provide a reference point and credible source for the call when they do receive it.
3. Women who do not deny contact by returning the letter will be telephoned by an interviewer employed by HIC. This interviewer will explain the study, answer questions and concerns, counter self-exemptions and encourage women to agree to having a questionnaire mailed to them.
4. Women who agree will be sent a brief (3 page) questionnaire, information brochure and consent form.
5. Women who gave verbal agreement but who failed to return the consent form and questionnaire will be sent a postal reminder after 1 week and telephoned after a further 1 week. Replacement survey materials will be sent by express post if requested, or if women have not returned their surveys after a further 2 weeks (4 weeks after receipt of the original questionnaire).
6. Participants will be sent additional questionnaires at regular intervals to collect a broader range of baseline information and to collect follow-up data.
7. Survey items which are deemed unsuitable for a self-administered questionnaire (either because women in the pilot studies have had difficulty completing them, or because they require open responses) will be administered via telephone or face-to-face interviews.

Steps 3, 4, 5 and 6 of this procedure are identical to the steps used in pilot 3. Steps 1 and 2 differ in that the HIC sampling frame will be used to identify women in the reference age range, to enhance the efficiency of the recruitment process. Steps 6 and 7 are added, to allow for a shorter questionnaire and to provide for interviewer administration of the survey instrument if required. To avoid bias from the use of

different data collection methods, data on particular items will be collected from all women using the same method (a self administered questionnaire, or an interview).

Collection of data using telephone or face-to-face interviews will increase the data collection costs and require a reduction of the sample size (with resultant loss of study power).

Figure 2
Procedure for recruitment
of women in the older cohort



12.2 WOMEN IN MIDDLE COHORT (45-49 YEARS)

For women aged 45-49 the response rates to mail surveys were better than for the other two age groups, exceeding 50%. Further, mail surveys do appear to be the best method for recruiting women in this age group. While higher response rates may be achieved through telephone interview, the non-contact rates would be considerably higher introducing equally important threats to the representativeness of the study

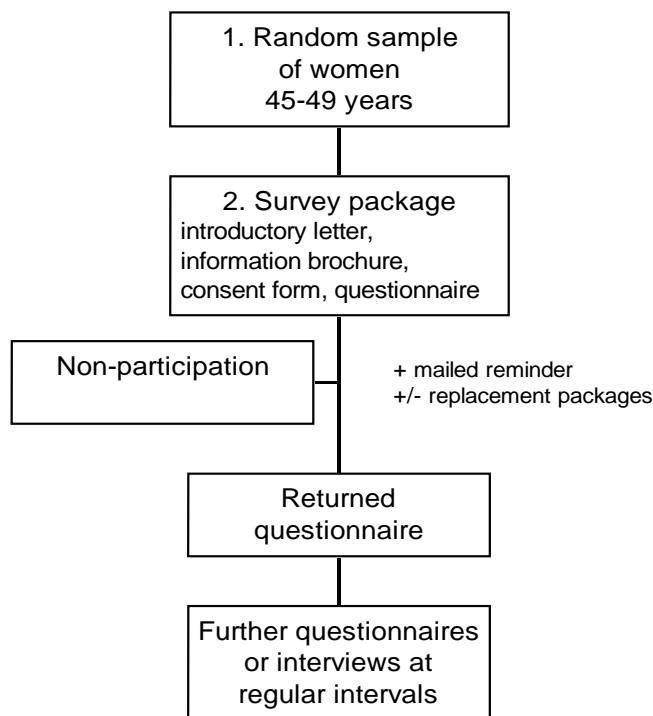
participants. This concern about non-contact rates is based on the results of pilot 3, where only 23 women aged 45-49 were recruited despite up to six phone calls to 500 households. Based on census data it would be expected that approximately 120 women would have been contacted. Initial telephone contact for this group appears to be counter productive.

The proposed procedure for recruiting women in the 45-49 year age group is as follows:

1. A random sample of women aged 45-49 will be drawn from the HIC lists with oversampling of women from rural and remote areas.
2. These randomly selected women will be mailed a survey package containing an introductory letter, and information brochure, consent form and questionnaire. The full baseline survey will be sent since there is no evidence from our pilot studies, or from previous research, that survey length has any impact on response rates for this age group.
3. One week after the initial mail out, all women in the sample will be sent a postcard designed to both thank women who have returned questionnaires and prompt those women who have not yet returned their questionnaires.
4. 4 weeks after the initial mail out, women who have still not returned their questionnaires will be sent a replacement survey package. This package will be sent by express mail.
5. 6 weeks after the initial mail out, women who have still not returned their questionnaires will be sent a replacement survey package. This package will be sent by express mail.
6. Sub-groups of participating women reporting particular characteristics will be asked to complete further surveys or participate in telephone interviews on specific issues.
7. Participating women will be re-surveyed after two years to collect the first follow-up information.

These procedures are identical to Strategy 2 of Pilot 2.

Figure 3
Procedure for recruitment
of women in the middle cohort



12.3 WOMEN IN YOUNGER COHORT (18-22 YEARS)

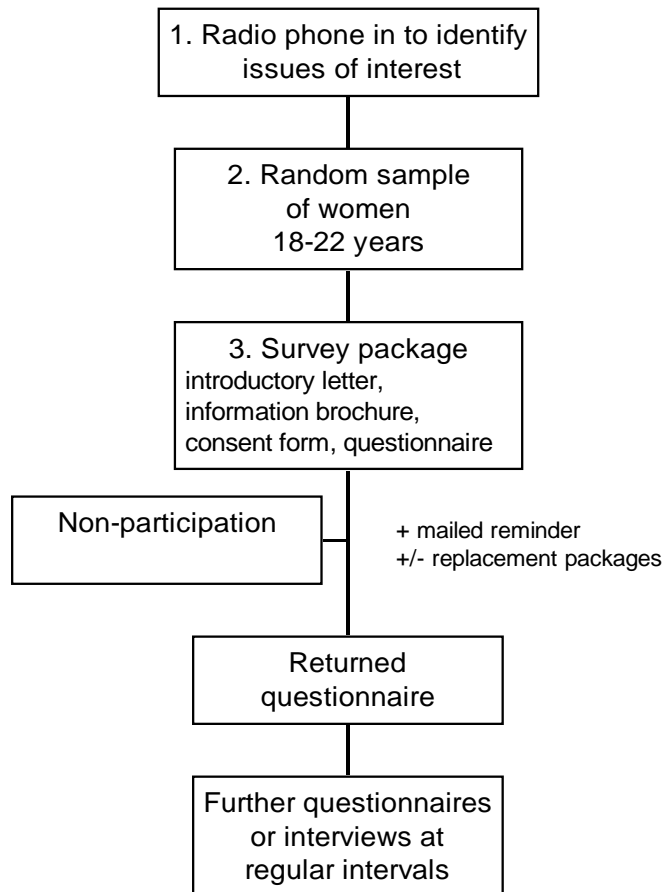
There appear to be many difficulties encouraging younger women to take an interest in health issues. The interviews with non-participants in Pilot 1 suggest that these women were 'not interested' in the study. Strategies to interest these women in participating need to be developed and trialled. The way forward in developing a recruitment strategy for these younger women is as follows.

1. Qualitative research to identify issues of interest to young women will be conducted via a radio program phone in. A national radio program such as Dr Feelgood's "Pillow Talk" or one of the ABC-JJJ programs will be used for this purpose. Issues identified from this program will allow the initial questionnaire and the recruitment methods to be targeted to the needs and interests of young women. Focus groups of women in this age group will also be conducted.
2. A random sample of women aged 18-22 will be drawn from the HIC lists with oversampling from rural and remote areas.
3. These randomly selected women will be mailed a survey package which will be designed for this specific target group; issues of interest to young women will be paramount. In addition, a popular personality may be used to attract young women to the study and to endorse it as relevant to them.

4. One week after the initial mail out, all women in the sample will be sent a postcard designed to thank women who have returned questionnaires and prompt those women who have not yet returned their questionnaires.
5. 4 weeks after the initial mail out, women who have still not returned their questionnaires will be sent a replacement survey package. This package will be sent by express mail.
6. 6 weeks after the initial mail out, women who have still not returned their questionnaires will be sent a replacement survey package. This package will be sent by express mail.
7. Sub-groups of participating women reporting particular characteristics will be asked to complete further surveys or participate in telephone interviews on specific issues.
8. Participating women will be resurveyed after two years to collect the first follow-up information.

Steps 2, 4, 5 and 6 of these procedures are identical to Strategy 2 of Pilot 2. Step 1 is added to tailor the questionnaire to the interests of young women. Step 3 is similar to procedures trialled in previous pilots except that a popular media personality may be used to endorse the study and arouse the women's interest.

Figure 4
Procedure for recruitment
of women in the younger cohort



13. ADDITIONAL PILOT STUDIES

These revised procedures for recruiting women for the main cohorts will need to be pilot tested. The proposal is:

- to conduct further developmental work, particularly with the young and older cohorts.
- to pilot the revised procedures with 100 people in each age group prior to the end of February 1996. This will necessitate postponing the main study by 3 months.

14. FURTHER WORK

The following additional methodological studies are already being incorporated into the project.

1. Development and testing of a scale to assess satisfaction with General Practitioner visits.
2. Comparison of food habits of younger and middle aged women in urban, rural and remote areas.
3. Identification of important life events as perceived by Australian women in the study age groups and the relationship between experiencing these events and health outcomes.
4. Analysis of the impact of questionnaire length on survey response rates.

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PART C: THE UNIVERSITY OF QUEENSLAND

SUMMARY

The special cohorts section of the Australian Longitudinal Study of Women's Health (ALSWH) was established because it was felt that some groups of women would be relatively inaccessible using the methodology of the main study conducted by the University of Newcastle, in particular Aboriginal and Torres Strait Islander and non-English speaking background women would be under represented. In addition it was felt that the health issues relevant in such populations may well differ from those in the main study.

Researchers from the University of Queensland (UQ) are responsible for establishing cohorts of Aboriginal and Torres Strait Islander women and women from non-English speaking backgrounds. The special cohort studies must be community based and owned so as to reflect the needs of the relevant communities and in turn, improve the health of those communities. An important aim is to ensure that the health-related concerns of Aboriginal and Torres Strait Islander and non-English speaking background women are more explicitly represented in protocols for the next phase of the study in 1998.

Consultation with Aboriginal and Torres Strait Islander communities has begun and reference groups should be established early in 1996. Background social, demographic and health data are being collated. In collaboration with community representatives, the final research techniques and their specific objectives will be developed. Data gathering is expected to begin in mid-1996, with analysis scheduled to occur in 1997.

The Filipino Community Co-ordinating Council has agreed to collaborate with researchers at UQ. The council is formally associated with 20 Filipino organisations and informally with an additional 20. Areas in Queensland which represent an appropriate range of migration experiences (e.g. marriage versus other; recent vs established), demographics (age, socio-economic status), degrees of facility with English and access to services and community support (remote vs urban) among Filipinas are currently being identified. Key women representatives of Filipina organisations in these areas will then be consulted and asked to provide a link between ALSWH and the community in their area. The Filipino Co-ordinating Council will facilitate this process by writing to affiliated organisations to inform them of the study and the council's endorsement of it. The consultation process and the development of methodology should be complete by March 1996 and data collection should commence at this stage. Analysis is scheduled to begin in March 1997.

1. ADMINISTRATIVE ARRANGEMENTS

The Queensland component of the Australian Longitudinal Study on Women's Health is situated within the Australian Centre for International and Tropical Health and Nutrition (ACITHN), and the University of Queensland Medical Faculty. The principal investigators and project staff are responsible to the central management of the ACITHN.

As reported earlier the management structure consists of a Working Group and a Steering Committee. The Steering Committee consists of all investigators and staff and provides overall supervision of the research. It has met regularly (5 times in all). In line with the need for appropriate community involvement at all levels of this component, it is proposed that representatives from the communities be sought for the Steering Committee.

The Working group consists of the principal investigators, staff; and associates involved in active research components. It has met a total of 5 times.

Regular contact with the University of Newcastle has been maintained. These have included 3 telephone conferences, 2 face-to-face meetings.

2. PROJECT STAFF

Ms Margaret Kelaher has been appointed full-time Research Fellow and co-ordinator of the UQ component of the study. Duties associated with this position include working to the principal investigators to establish study infrastructure, research background material, including analysing secondary data, assist in developing methodology, and coordinate and liaise with reference groups.

Dr Zakia Hossain has been appointed as Statistician/Data Manager (0.5-time) and will commence work on 1 February 1996.

Ms Nicole Woelz is Research Assistant/ Secretary (0.3 time) to the study.

Ms Sarah Handford and Ms Milica Markovic will commence PhD Scholarships on 2 January 1996.

The table below summarises the process of staff appointments.

Position	Number of applicants	Number Interviewed	Appointment
Research Fellow/ Special Cohorts Co-ordinator	4	2	accepted
Statistician	8	3	accepted
ATSI Liaison Officer	3	in process	in process
PhD scholarships	3	2	two accepted

3. OFFICE ESTABLISHMENT

The Women's Health Australia (UQ) office is established in the Edith Cavell Building, Royal Brisbane Hospital. The office comprises four work stations in Room 122 for the project staff and two work stations in Room 120 for the PhD scholarships.

Furnishings and equipment have been purchased, including one pentium computer, three lap top computers, one laser jet printer, filing cabinets and four work stations.

4. PRESENTATIONS

Kelاهر, M. (1995). Australian Longitudinal Women's Health Study. Queensland Women's Health Centre Forum. Logan, 14-15 November.

Kelاهر, M. (1995). Australian Longitudinal Women's Health Study. Centre for Mothers and Babies. Melbourne, 28 November.

Manderson, L. Kelاهر, M. and Allotely, P. (1995). Accessing difficult to reach populations. Australian Tropical Health and Nutrition Conference. Brisbane, 18-20 September.

5. ESTABLISHING REFERENCE GROUPS

5.1 ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN

National Health and Medical Research Council guidelines state that research which addresses the health of Aboriginal and Torres Strait Islander people can only proceed with full consultation, community support and community ownership of data. One of the original concerns about the implementation of the guidelines was that requiring researchers to respect the right of indigenous people to make their own decisions would prevent research from being conducted (Maddocks, 1992). Community consultation with Aboriginal and Torres Strait Islander communities can not proceed on the basis of externally imposed time frames (Aboriginal co-coordinating council, 1995). Designing and implementing effective health research depends on developing processes which take this into account.

It imperative for the success of the Australian Longitudinal Study of Women's Health (ALSWH) that sufficient time is allowed for community consultation and the establishment of reference groups. Initial community consultation for research generally proceeds through elected Aboriginal Councils and organisations, such as the Aboriginal Co-ordinating Council. These organisations are not appropriate starting points for women's health research because they predominantly consist of men. The Aboriginal Co-ordinating Council protocol for approaching indigenous communities specifically states that elected councils not be a useful source of information on the views of women (Aboriginal co-coordinating council, 1995 see Appendix E). Under law/lore, "women's business" is the prerogative of women and men can not discuss it. Consequently, there is no existing infrastructure to support community consultation with indigenous women.

Consultation commenced in June 1995 when four University of Queensland (UQ) ALSWH Steering Committee members met with female Aboriginal and Torres Strait Islander health care workers from regional Queensland. Although Aboriginal and Torres Strait Islander women attending the meeting generally supported a women's health study a number of concerns were expressed. Firstly, it was felt that the cohorts defined for the main studies were not appropriate for Aboriginal and Torres Strait Islander women because of differences in the timing of life stage events, morbidity and mortality. Secondly, it was felt that Aboriginal and Torres Strait Islander women should have control over the research, its implementation and who should have access to the data. The latter particularly applied to males. It was felt that the research would not benefit Aboriginal and Torres Strait Islander communities if the agenda was determined by either governments or academics rather than indigenous women themselves.

In response to this initial consultation, meetings have been conducted with Aboriginal and Torres Strait Islander women working in health to discuss ways of developing an appropriate process for addressing these concerns. It appeared that reservations about the research process could be addressed by developing a team which consisted of academics, government representatives and Aboriginal and Torres Strait Islander community members and health care workers. This would allow an exchange of skills and ideas between indigenous and non-indigenous team members and would reduce any distinctions between researchers and the researched. The women consulted included; Leanne Bell, Aboriginal and Torres Strait Islander Adviser to Queensland Sport, Tourism and Racing; Cindy Shannon, co-ordinator of the Indigenous Primary Health Care Program, University of Queensland; Sue Morgan, Brisbane North Aboriginal and Torres Strait Islander Health unit and Rhonda Kelly, Senior Policy Officer, Women's section, Aboriginal and Torres Strait Islander Policy Branch.

During this time the Aboriginal and Torres Strait Islander Policy Unit within Queensland Health began establishing a women's reference group, primarily to discuss birthing issues. The reference group is representative of different regions of Queensland. Senior Aboriginal community members advised that any independent attempt to establish yet another reference group could cause confusion and fragment efforts. It was decided that the most appropriate response would be to gain consent to access the reference group established by the Aboriginal and Torres Strait Islander Policy unit. This approach has many benefits but it obviously reduces the ability of researchers from ALSWH to determine the time frame of consultation.

With recent restructuring of Queensland Health, the women's reference group is now under the auspices of the Women's Policy Unit. Dr Jane Thomason, head of the Women's Policy Unit has agreed to jointly fund an additional meeting of the reference group. It has also been decided that the ALSWH will be the subject of one of a series of forums conducted by the women's health policy unit.

5.2 NON-ENGLISH SPEAKING BACKGROUND WOMEN

5.2.1 Filipina women

The initial proposal indicated that reference groups of Filipinas would be established using networks of community and church organisations. Preliminary discussions with Agnes Whiten, Adviser to the Catholic Archbishop, Member of The Queensland University Senate, and Chairperson of the Ethnic Affairs Advisory Committee, led to consultation with the Filipino Community Co-ordinating Council. The Filipino Community Co-ordinating Council is formally associated with 20 Filipino organisations and informally with an additional 20. A list of the organisations is included in Appendix F. Professor Manderson and A/Professor Williams met with Queenie Balabo, secretary of the council in August. It was agreed that researchers from the longitudinal women's study would attend the October meeting of the council. The aim of the meeting was to get permission to use the councils networks to establish a Filipina reference groups and to contact Filipinas. The council agreed to collaborate with University of Queensland researchers.

An additional meeting was conducted with Queenie Balabo to develop terms of reference and a structure for reference groups. It was decided that an initial strategy would be to identify areas in Queensland which would represent an appropriate range of migration experiences (e.g. marriage versus other; recent vs established), demographics (age, socio-economic status), degrees of facility with English and access to services and community support (remote vs urban) among Filipinas. Key women representatives of Filipina organisations in these areas would then be consulted and asked to provide a link between ALSWH and the community in their area. The Filipino Co-ordinating Council would facilitate this process by writing to affiliated organisations to inform them of the study and the council's endorsement of it. ALSWH would provide feedback about the progress and process of the study at monthly meetings of the council.

5.2.2 *Former Yugoslavian Women*

Budgetary limitations meant that plans for a cohort of women from the former Yugoslavia had to be abandoned. However a number of researchers and community organisations have expressed concerns about the fact that the longitudinal women's study now only includes a special cohort representing women from one language group. These concerns are reflected in the resolutions of the Third National Women's Health Conference. In response to this a PhD scholarship, part funded by the study, has been granted to Milica Markovic, a Bosnian researcher to conduct a smaller scale study on women from the Former Yugoslavia in Victoria. She will commence in January 1996.

The proposed research would provide a basis for planning the establishment of a cohort of former Yugoslavian women and would ensure that if funding became available the research could be completed by 1998.

6. ETHICS

The NH&MRC guidelines on ethical matters in Aboriginal and Torres Strait Islander research (1991) make it clear that full consultation must precede the development of research proposals and therefore applications for ethical approval. This process involves seeking advice from relevant Aboriginal and Torres Strait Islander agencies, providing proof that the research will have specific benefits for Aboriginal and Torres Strait Islander people, consent from participating communities, community involvement and clarification of ownership of data (NH&MRC, 1991 see Appendix E). Once this process has been completed a full submission will be made to the UQ institutional ethics committee. This is expected to occur in early 1996.

There are no ethical guidelines which specifically address the conduct of research in migrant communities. However the communities interests can not be accurately reflected in any research proposal not derived through consultation. Accordingly once consultation has been undertaken a full submission will be made to the UQ institutional ethics committee in early 1996

7. DEFINING THE COHORTS

7.1 ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN

Consultations with indigenous women suggest that community support and involvement is contingent upon Aboriginal and Torres Strait Islander women determining the agenda of the research. The initial proposal by the University of Queensland recognised the need for the Aboriginal and Torres Strait Islander section of the ALSWH to be community based and owned. It was originally envisaged that the cohort structure of the Aboriginal and Torres Strait Islander research would parallel that of the main study. This strategy is being reviewed for three main reasons. First, pre-determined restriction of the participant population will be viewed as undermining indigenous women's ownership of any results and will jeopardise community involvement. Second, the age distribution of the Aboriginal population and the age of onset of many health problems do not reflect general population patterns. Third, the structure of Aboriginal and Torres Strait Islander society and in particular the role of elders in shaping community opinions mean that it would be difficult and counterproductive to attempt to exclude women from the study on the basis of age.

The following sections expand on the background of these issues.

7.1.1 *The role of self-determination in the success of health research and health initiatives among Aboriginal and Torres Strait Islanders*

Since the 1970s activism among Aboriginal and Torres Strait Islanders has enhanced both general awareness of health problems among Australia's indigenous people and the political will to do something about them. Despite many community and government based health initiatives and considerable investment in infrastructure the health of Aboriginal and Torres Strait Islander women in 1995 is still far worse than their non-indigenous counterparts (Runciman & Ring, 1994). The impact of health initiatives on

the health status of Aboriginal and Torres Strait Islanders has been limited by failure to develop appropriate mechanisms for self determination by indigenous people (Rowse, 1992). Consequently, developments in health, housing and community services have often not reflected community needs and priorities. This has undermined the ability of indigenous people to determine where and how they should live and the ability to choose how money designated for indigenous health should be spent. The need to develop models of indigenous health and health care which avoid welfare colonialism and paternalism is a consistent theme among indigenous health forums (eg. Third National Women's Health Conference, 1995).

The importance of self-determination to indigenous people has also been reflected in health related research. Health research among Aboriginal and Torres Strait Islander people in the 1970s and 1980s was largely driven by a (government) perceived need to develop health information systems (Gray, 1985). This led to a proliferation of research *about* and *on* Aboriginal and Torres Strait Islander communities but not research *with* or *for* Aboriginal and Torres Strait Islander communities. Consequently, indigenous people expressed increased reluctance to become involved in health related research because research did not appear to have any benefit for their communities and only appeared to address other's agendas (Aboriginal Co-ordinating Council, 1995). This is particularly true for women who were often excluded from any consultation process because of poor representation on elected bodies (Aboriginal Co-ordinating Council, 1995).

In order to ensure that future health research better met the needs of Aboriginal and Torres Strait Islander people the NH & MRC developed new guidelines for research among indigenous people. These guidelines consisted of four major points (Maddocks, 1992): 1. Consultation 2. Scientific merit 3. Community involvement 4. Ownership of data and publication. These guidelines aimed to enhance the benefits of research for Aboriginal communities without impeding scientific rigour.

It is fundamental to community consultation and community ownership of research that communities rather than governments or academics determine its process and scope. This process is obviously undermined if indigenous communities are simply expected to approve a pre-determined agenda (Aboriginal Co-ordinating Council, 1995).

7.1.2 *Differences in the relationship between age and health in indigenous and non-indigenous populations*

The demographic composition of indigenous Australians is very different from non-indigenous Australians. In general, the population distribution of indigenous Australians is skewed towards younger ages compared to other Australians. Figure 1 shows the age distribution of indigenous and non-indigenous women in Queensland. Age cohorts developed for the non-indigenous population will not be equally representative or appropriate for indigenous women. This issue has already been discussed in relation to the need to reduce the age of 'older' women in the Aboriginal and Torres Strait Islander cohort to reflect earlier mortality among indigenous populations.

Health problems and life stage events tend to occur at different ages among Aboriginal and Torres Strait Islander women and non-indigenous women. Indigenous women tend to have their first babies earlier than non-indigenous women. For example, almost 30%

of Aboriginal women have babies at less than 19 years of age compared to 5.8% of other women (Thomson, 1991). Babies tend to be much more closely spaced among indigenous women and there is some evidence that parity is higher among Aboriginal women in some states (Wesley-Wise, 1994). Consequently, the ages which constitute 'child bearing years' and the ages at which women become mothers and grandmothers are different for indigenous women and non-indigenous women. Indigenous women tend to have earlier mortality than non-indigenous women. Diseases such as hypertension and non-insulin diabetes tend to have earlier ages of onset among indigenous women (Runciman & Ring, 1994). Determining age specific levels of risk for different diseases among indigenous women is difficult because of problems in the identification of Aboriginality in health statistics collections (Thomson, 1991).

7.1.3 The appropriateness of applying age cohorts to indigenous populations

Both traditional and detribalised indigenous communities tend to be matrifocal (Franklin, 1989). Mothers and grandmothers, particularly elders, play an important role in shaping the knowledge, opinions and behaviour of communities. Excluding women from the study because they do not fit into a particular age range may mean that important information about the context of health behaviours is not addressed. More importantly imposing age based selection criteria may be seen as a lack of respect for the social structure of Aboriginal and Torres Strait Islander communities. Involvement of all women should be sought in ways that respect the social structure of indigenous communities.

7.1.4 Overview

Overall, using less specific cohorts would allow indigenous communities to determine an appropriate structure for the study rather than having a structure imposed. This would enhance acceptance of the study by indigenous communities without compromising the scientific validity of the study.

7.2 NON-ENGLISH SPEAKING BACKGROUND WOMEN

The Australian Government has identified immigrants and especially newly arrived immigrants from non English speaking backgrounds (NESB) as people with special health needs. Except for indigenous people, immigrants are the most disadvantaged with respect to health status and access to health care (Manderson, 1990). Over the past two decades, there have been many calls by concerned ethnic communities, health professionals, policy makers, and public health researchers to give greater recognition to the health needs and experiences of immigrants in health service planning and delivery. This longitudinal study into the health needs of Australian women recognises these concerns.

In a multicultural society such as Australia, where individuals may recognise and respond to perceived ill health in a variety of ways, and as a consequence of very different understandings of the 'normal' and the pathological, the possibilities for misunderstanding are manifold. In the past 40 years, Australian immigrants have come from increasingly diverse countries, yet recognition of the heterogeneity of immigrant Australia is not reflected in the literature. Much of the work to date has made light of

differences within groups, dissolving cultural specificity under general terms (e.g. Southern Europeans, Indochinese), and concentrating on particular health issues whilst others are disregarded.

Ethnicity, class and geographic differences are themselves a short-hand for major differences in native and second languages, cultural practice, belief systems, familiarity with, access to, and use of health services, education levels, income and prior and present class position. These factors are all relevant to how people think of illness and health, and what they do - in terms of diagnosis, treatment advice and medication - when they are sick (Manderson & Reid, 1994). Frequently in the literature and in discussion by health professionals and policy makers about migrant health, greater attention has been given to cultural difference than to other factors that may also be significant in understanding patterns of sickness such as social isolation, poverty, age, gender or immigrant status (Manderson & Reid, 1994). Social class inequalities affecting migrants politically and economically in Australia all have a significant influence on their health. Poverty, which affects many new Australian migrants, can produce a lifestyle which also produces profound repercussions for the health of adults and children (Najman, 1994).

Present understanding of immigrants is largely politically and socially constructed, built upon presumptions of what a particular people are like rather than on empirical data of the experience and behaviour of those people. The way in which health status is influenced by social and economic and cultural factors needs to be addressed (Manderson & Reid, 1994). Each culture has its own 'language of distress' or means by which the experience of pain or discomfort are communicated to others, and the form of this pain behaviour, as well as response to it, are culturally determined (Helman, 1984; Parsons & Wakeley, 1991; Wolff & Langley, 1977). Cross-cultural interactions between health professionals and their clients often highlight the problems of communication, with both parties making certain assumptions about the other's perceptions and interpretation of symptoms within their own cultural or professional frame of reference (Manderson & Reid, 1994).

An extensive literature search has revealed a considerable amount of literature on the health status, health beliefs, attitudes and practices, and health service utilisation for women from Vietnamese, Lebanese, Italian, and Greek backgrounds. In comparison, the literature on women from Filipino and Bosnian backgrounds is virtually non-existent consequently research about these groups is a priority. The following data bases were searched: MEDLINE; APAIS (Australian Public Affairs Information Service); CINAHL (Cumulative Index of Nursing and Allied Health); and SOCIOFILE.

In delivering health care to people of diverse backgrounds, it is critical for the Australian health service providers to understand and appreciate the health values, beliefs and behaviours disease aetiology, prevention, treatment and traditional theories of achieving and maintaining good health.

8. DEVELOPING THE METHODOLOGY

8.1 ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN

In the past health research has not benefited indigenous Australians because of inadequate community consultation and failure to allow time for Aboriginal and Torres Strait Islander communities to reach their own decisions. The research team is currently working within the necessary guidelines to ensure that an appropriate foundation be built for these processes to occur.

The overall research strategy occurs within the framework of a three phase plan to ensure that indigenous women have control over the research, its implementation and the results. This is crucial to the success of the project and its acceptability to Aboriginal and Torres Strait Islander women.

Phase 1: Initiate contact with communities and establish reference groups

This initial phase involves establishing a reference group representing Aboriginal and Torres Strait Islander women throughout Queensland. This group will form the basis for the development of a research team consisting of academics, government and Aboriginal and Torres Strait Islander community representatives and health care workers. The reference group will develop research protocols and provide a first point of contact with communities. The activities of the reference group will be developed by a two person team, comprising an Aboriginal and Torres Strait Islander Liaison Officer and a research assistant, visiting Aboriginal and Torres Strait Islander communities and community groups throughout Queensland. This model has been successfully used by the Indigenous Primary Health Care Program at UQ to develop a nutrition policy for Aboriginal and Torres Strait Islanders in Queensland

Phase 1 has three objectives:

- 1) Discuss the project with communities
- 2) Determine community's terms of reference for
involvement in the project
- 3) Identify community's priority areas in women's health

Phase 2: Develop Community Based Protocol

Phase 2 will use information from phase 1 to develop a study protocol. The protocol will outline the purpose and scope of the study and processes of information gathering and analysis. Agreements will be developed on community participation, selection procedures and training of staff, community entitlement to results and community feedback. This will then be referred back relevant communities for discussion and approval.

Phase 3: Implementation of Protocol

Phase 3 will involve implementing the protocol developed in Phase 2.

Sampling strategies will be finalised when reference groups are established and communities who want to be involved give their consent. In parallel with these discussions, available baseline data on population distribution, health outcomes and social indicators have been collected for all health regions in Queensland, in order to inform the research design. These data will be supplemented with information based on the sampling strategy from the National Aboriginal Torres Strait Islander survey (see Appendix G). An overall summary of the demographic and health profile of Aboriginal and Torres Strait Islanders in each Queensland health region follows. These data will provide the background data for a community based sampling approach. Figure 2 shows the geographic location of health regions in Queensland. Raw data is attached (see Appendix H).

The following section presents a secondary analysis of available data on the health of Aboriginal and Torres Strait Islander women in Queensland. These analyses have been conducted since July 1995 and will be an ongoing component of the study, in order to help shape the design of the Aboriginal and Torres Strait Islander special cohorts study. This will be supplemented by a planned secondary data analysis disaggregating Aboriginal and Torres Strait Islander data from the 1994 National Aboriginal and Torres Strait Islander Survey. Further analysis of the latter survey will allow a national perspective to be obtained.

8.1.1 *Geographical distribution of Aboriginal and Torres Strait Islander women in Queensland*

Health Regions

Brisbane South

There are 2,131 Aboriginal and Torres Strait Islander women in Brisbane South. This represents 1.2% of the regions total female population and 7.1% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Acacia Ridge, Inala, Kingston, Marsden, Redland, Slacks Creek and Woodridge.

Brisbane North

There are 495 Aboriginal and Torres Strait Islander women in Brisbane North. The number of women in this region appears to be under reported. This represents 0.7% of the regions total female population and 1.7% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are New Farm, Zillmere, Kallangur and Brighton.

Central Region

There are 2,498 Aboriginal and Torres Strait Islander women in Central region. This represents 3.3% of the regions total female population and 8.4% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with

concentrations of Aboriginal and Torres Strait Islander people are Banana, Duaringa, Gladstone, Livingstone, Mount Morgan and Rockhampton.

Central West Region

There are 193 Aboriginal and Torres Strait Islander women in Central West region. This represents 0.06% of the total female Aboriginal and Torres Strait Islander population of Queensland.

Darling Downs

There are 1,051 Aboriginal and Torres Strait Islander women in Darling Downs region. This represents 1.4% of the regions total female population and 3.5% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Dalby, Jondaryan, Toowoomba and Warwick.

Northern

There are 6,617 Aboriginal and Torres Strait Islander women in Northern Region. This represents 6.1% of the regions total female population and 22.2% of the total female Aboriginal and Torres Strait Islander population of Queensland.

Peninsula and Torres Strait

There are 11,921 Aboriginal and Torres Strait Islander women in Peninsula and Torres Strait region. This represents 11.5% of the regions total female population and 39.9% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Aurukun, Cairns, Cardwell, Cook, Douglas, Johnstone, Mareeba, Mulgrave and Torres.

South Coast

There are 586 Aboriginal and Torres Strait Islander women in South Coast. This represents 0.6% of the regions total female population and 1.9% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Beaudesert, Eagleby, Palm Beach and Southport.

South West

There are 891 Aboriginal and Torres Strait Islander women in South West. This represents 7.7% of the regions total female population and 3.0% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Balone, Murweh, Paroo, and Roma.

Sunshine Coast

There are 942 Aboriginal and Torres Strait Islander women in Sunshine Coast Region. This represents 0.7% of the regions total female population and 3.2% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Caboolture part A, Maroochy part A and Redcliffe.

West Moreton

There are 997 Aboriginal and Torres Strait Islander women in West Moreton region. This represents 1.6% of the regions total female population and 3.3% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Carole Park, Ipswich and Moreton.

Wide bay

There are 1,527 Aboriginal and Torres Strait Islander women in Wide bay. This represents 2.2% of the regions total female population and 5.1% of the total female Aboriginal and Torres Strait Islander population of Queensland. SLAs in the region with concentrations of Aboriginal and Torres Strait Islander people are Bundaberg, Hervey Bay, Maryborough, Murgon, Woongarra and Eidsvold.

8.1.2 Regional Analysis of the Health of Aboriginal and Torres Strait Islander Women in Queensland

The absence of reliable baseline data on the health of indigenous women has prompted researchers from the UQ to collaborate with other organisations to conduct analyses on the health of Aboriginal and Torres Strait Islander women. Dr Ian Ring, head of Health Information Services Queensland Health Department, has agreed to collaborate on an analysis of hospital separation and mortality data for Aboriginal and Torres Strait Islander women and health service utilisation among women in Aboriginal and Torres Strait Islander communities. Discussions are presently underway with the Director of Aboriginal and Torres Strait Islander Unit of the Australian Bureau of Statistics to form a collaboration with ACITHN to further analyse the 1994 National Aboriginal and Torres Strait Islander survey data. The first proposed analysis would be a disaggregation of Aboriginal and Torres Strait Islander health outcomes for women. These data will provide a valuable resource for comparisons of health outcomes among Aboriginal and Torres Strait Islander women at a national level.

Hospital morbidity

Current data for hospital separations is not differentiated by sex. Other than for pregnancy and child birth, the largest number of hospitalisations among Aboriginal and Torres Strait Islanders in most regions were for injuries and poisoning and for diseases of the digestive, circulatory and respiratory systems. Hospitalisations for diseases of the genito-urinary tract were also high in West Moreton and Northern regions. Hospitalisations for mental disorders were high in Brisbane North and Wide bay regions. It should be noted that the ICD-9 diagnostic category, mental disorders, includes admissions related to substance use. In the Sunshine Coast region injury and poisoning alone were the greatest reason for hospitalisations.

In general hospitalisations were higher among Aboriginal and Torres Strait Islanders than other Queenslanders in almost all regions. There was excess morbidity in the age standardised rates of endocrine, nutritional and metabolic diseases, circulatory and respiratory disorders. In Central, Central West, Peninsula and Torres Strait and Wide Bay regions there was also excess morbidity due to mental disorders and skin diseases. In addition, there was excess morbidity associated with injuries and poisoning in Central region. In Peninsula and Torres Strait regions separations associated with infectious and

parasitic diseases among indigenous people were higher than for other members of the population. In the Central west region there was also greater morbidity due to genito-urinary diseases and injury and poisoning in the indigenous population than non-indigenous population.

Specific conditions with high excess morbidity rates in almost all regions included diabetes, heart disease and violence. In the Central, Central west, Peninsula and Torres Strait and Wide Bay regions pneumonia and chronic respiratory, renal disease and skin disease were also associated with high excess morbidity. In the West Moreton region only circulatory disease was associated with high excess morbidity.

In Brisbane South and Brisbane North rates of hospital separations among Aboriginal and Torres Strait Islander people are lower than for the rest of the state. This is likely to reflect poor recording of Aboriginality on admission forms rather than real differences in the separation rate. Despite this in Brisbane South the rate of admission for circulatory and respiratory diseases was higher than for all Queenslanders. In Brisbane North the rate of admission for mental disorders was higher than the all Queensland rate. Age specific morbidity could not be calculated for the Sunshine Coast due to inadequate data.

Maternal and Child Health

The age of Aboriginal and Torres Strait Islander mothers is generally lower than for non-indigenous mothers. The proportion of mothers under twenty is 28% for Aboriginal and Torres Strait Islanders, 20% for Torres Strait Islanders and 7% for other Queenslanders (Runciman & Ring, 1994). The proportion of teenage motherhood varies considerably between regions ranging from less than a third in North Brisbane to 60% in Northern region (see Appendix H).

Perinatal mortality is twice as high among indigenous Queenslanders compared to non-indigenous Queenslanders. Small numbers of births and concerns about the reliability of data make it difficult to make meaningful comparisons of neonatal deaths, still births and perinatal mortality among regions. However in almost all regions being indigenous was associated poorer perinatal outcomes (see Appendix H).

Aboriginal mothers had a higher proportion of low birth weight babies than non-indigenous mothers in almost all regions although there was some variability (see Appendix H). For example, the proportion of low birth weight babies in the Central West was 1.4 times greater for indigenous than non-indigenous women but 2.5 times greater for indigenous women in the Sunshine Coast. Differences between the proportion of low birth weight babies born to indigenous and non-indigenous mothers appeared to be greater in urban regions.

Socio-economic indicators

The socio-economic status of indigenous people in all regions is lower than that of non-indigenous people. Despite the fact that the indigenous population is younger than the non-indigenous population only 7.0% of Aboriginal and Torres Strait Islander people have achieved post secondary qualifications compared to 24.0% of non-indigenous people (Census, 1991). Two-thirds of females in the labour force are unemployed (Census, 1991). Unemployment is particularly high among young Aboriginal women, with 20.9% of females being unemployed.

Table F in Appendix H shows regional populations divided up into economic quintiles. The Aboriginal and Torres Strait Islander population was skewed towards lower economic quintiles in all regions compared to the non-indigenous population. The distribution of wealth among Aboriginal and Torres Strait Islander people varied considerably between regions. For example, 23.6% of indigenous people in Brisbane North were in the highest economic quintile compared to 0.2% in Wide Bay. The proportion of the indigenous population in the lowest economic quintile varied from 14.1% in Brisbane North to 80.5% in the Central West.

8.2 NON-ENGLISH SPEAKING BACKGROUND WOMEN

The Filipino Co-ordinating Council of Queensland Inc. has affiliations throughout Queensland. It is proposed that women would become involved throughout the state using this organisation and its affiliates as a first point of contact. The methodology will reflect the same three phases as the Aboriginal and Torres Strait Islander cohorts.

The first stage of this strategy would be to identify areas in Queensland which would represent an appropriate range of migration experiences (e.g. marriage versus other; recent vs established), demographics (age, socio-economic status), degrees of facility with English and access to services and community support (remote vs urban) among Filipinas. Key women representatives of Filipina organisations in these areas would then be consulted and asked to provide a link between ALSWH and the community in their area. Demographic details of organisation membership will be compared to census data to determine the extent to which samples recruited by this method are likely to be representative of the Filipina population of Queensland and are an appropriate method of contacting women in the age groups nominated for the cohorts. The addresses of Filipina organisations are included in Appendix F and the geographic distribution of Filipinas are included in Appendix I.

There is little data currently available on patterns of morbidity and mortality among Filipinas. Hospital separations for Filipinas in Queensland by age are included in Appendix J. Queensland Health has agreed to provide mortality and hospital separations data for Filipinas by age and geographic location where appropriate.

Consultation with the Bosnian community has not yet commenced but it is proposed that a similar strategy would be adopted. It was initially proposed that the Bosnian cohort would be established in Victoria. Census data on the distribution of women from the Former Yugoslavia in Victoria is included in Appendix K.

9. BUDGET

Expenditure for 1995 is shown below, as is the budget for 1996-1998. Expenditure in 1995 is below target due to the time necessary for preparing contracts and appointing staff. Research costs are indicative at this stage.

10. BACKGROUND PAPER ON ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN'S HEALTH

In 1978, the Honourable R.J. Ellicot, Minister for Home Affairs indicated that in preparation for the UN decade of women and in line with the establishment of an Aboriginal health service special provision would be made to improve Aboriginal and Torres Strait Islander women's health by improving health education and services, sanitation, nutrition, family education and family planning and other welfare services. In 1995 the health of Aboriginal and Torres Strait Islander women is still worse than any other group of Australian women (Thomson, 1991). This inequity is largely due to the social, cultural, environmental and nutritional consequences of alienating of Aboriginal and Torres Strait Islander people from their lands. Women have played a powerful role in advocacy for Aboriginal health, reflecting the importance of Aboriginal women in caring for the health of their communities and high priority of women's health issues to indigenous people. This has increased both recognition of health problems among Aboriginal and Torres Strait Islanders and the political will to do something about them. Failure to develop appropriate mechanisms for self-determination has meant that advances in the provision of health services and development of infrastructure have had minimal impact in reducing inequities between Aboriginal and Torres Strait Islander women and other Australian women.

The objective of this review is to consolidate existing research on the health of Aboriginal and Torres Strait Islander women (collectively referred to as indigenous). Achieving this aim is difficult for two reasons. Firstly, data on the health of indigenous populations is often inaccurate or absent particularly at the specific disease level because the recording of Aboriginality in health statistics collections is unreliable and incomplete. Second, there has been a tendency to discuss the health of indigenous people as though it was static and independent from its political and social context. This has resulted in reports consisting of long lists of illnesses and discrepancies between the health of indigenous populations and other Australians without discussing the reasons that such differences exist. This review will attempt to discuss health status in its social and cultural context where such information is available.

It is clear that the health status of Aboriginal and Torres Strait Islander women is ubiquitously low compared to their non-indigenous counterparts, however specific problems vary between communities. Adequately characterising health problems and health status among different Aboriginal communities is difficult because of the absence of accurate data. The 1984 Federal task force on Aboriginal statistics reached agreements with all states (except Queensland) on the identification of Aboriginality on priority statistics (Thomson, 1991). However Aboriginality is still often not indicated on health records or where it is indicated Aboriginals and Torres Strait Islanders are wrongly identified as non-indigenous and people who are not Aboriginal or Torres Strait Islanders are identified as such. Consequently, even where statistics are collected their validity may be questionable.

10.1 MORTALITY

10.1.1 *Total Mortality*

Death rates among Aborigines are almost 4 times higher (Thomson, 1991) and life expectancy is 15 to 17 years less at birth than for non-indigenous Australians (Australian Institute of Health and Welfare, 1992 cited in Gray & Saggars, 1994:119). Lower expectations at birth are largely due to an excess of mortality in Aboriginal young adults. Table 1 shows death rates and ratios for Aboriginal women. Thomson (1991) suggests that death rates for young and middle aged Aboriginal Australians have increased over the past 20-30 years.

Table 1
Aboriginal and total Australian age-specific death rates and rate ratios for women, 1985

Age in Years	Aboriginal	Total Australian	Rate ratio
0-4	9.2	2.2	4.3
5-9	0.2	0.2	1.0
10-14	0.4	0.2	2.5
15-24	2.7	0.5	5.7
25-34	3.3	0.6	5.9
35-44	6.9	1.0	6.8
45-54	22.5	3.0	7.4
55-64	38.3	7.6	5.0
65+	75.9	45.6	1.7

Since the 1970s the major causes of morbidity and mortality are heart disease and diabetes mellitus type II, infectious diseases such as diarrhoea, respiratory infections and malnutrition. The most frequent causes of death are diseases of the circulatory system, respiratory disease and external causes such as violence and accidents (Australian Institute of Health and Welfare, 1992).

The most common causes of death among Aboriginal women are the diseases of the circulatory system, neoplasms, endocrine and metabolic disorders (primarily diabetes mellitus type II), diseases of the respiratory system, and poisoning and injuries. The mortality rate for Aborigines is 2.3 and 4.6 times greater than for non-indigenous people.

Additionally, there are several other categories of diseases of which Aboriginal women die at far higher rates than do non-indigenous women, which include:

- . mental disorders (primarily alcohol and drug related conditions), which is the tenth leading cause of mortality for Aboriginal women, at die at a rate 5.5 times more than non-indigenous women;
- . diseases of the genitourinary system (particularly kidney disease) which is the sixth leading cause of mortality for Aboriginal women and die at a rate 16.9 times greater than non-indigenous women (Gray & Saggars, 1994:120)

Although not one of the major causes of mortality, Aboriginal women die from infectious and parasitic diseases at rates 7.5 times more than non-indigenous women. Thomas & Honari (1988) found that in South Australia and Western Australia, the hospital admission rates were three times higher of Aborigines compared to non-indigenous and remain longer in hospital (Thomson & Honari, 1988; Waddell & Dibley, 1986; cited in Gray & Saggars, 1994:120) Thus Thomson (1991) states, "Aborigines are between six and nine times more likely to be admitted to hospital than non-Aborigines for non-life threatening diseases of the skin and sub-cutaneous tissues and infectious and parasitic diseases" (Thomas, 1991 cited in Gray & Saggars, 1994:120-21). Although mortality from infectious diseases have decreased in the past twenty years, infectious disease among Aboriginal people still remains dangerously high.

10.1.2 *Perinatal and Infant Mortality*

Although perinatal and infant mortality among indigenous people has dropped dramatically since the 1970s mortality rates are still two to three times higher than the non-indigenous population (Thomson, 1991). For example, in Queensland in 1989 there were 21 still births and 14 neonatal deaths among babies born to Aboriginal women, 7 still births and 7 neonatal deaths among babies born to Torres Strait Islanders compared to 239 still births and 175 neonatal deaths among babies Australian Caucasians (Epidemiology and health information services Queensland Health, 1989). The rates were 24.3, 28.7 and 11.3 per 1000 for Aboriginal, Torres Strait Islander and Caucasian babies respectively.

10.1.3 *Maternal Mortality*

Maternal mortality decreased for all Australian women in the period from 1970-72 to 1982-84 (Thomson, 1988). Although all maternal deaths declined the proportionate decline has been less for indigenous women than non-indigenous women. The indigenous/non-indigenous ratio was 4.6 for direct maternal deaths and 3.2 for indirect maternal deaths (Thomson, 1988). There were only 5 maternal deaths from 1982-84 however these deaths indicate a greater degree of gynaecological disadvantage experienced by Aboriginal and Torres Strait Islander women (Thomson, 1988).

10.2 MORBIDITY

10.2.1 Overall Morbidity

There is a paucity of data on morbidity among Aboriginal and Torres Strait Islander women. The National Aboriginal and Torres Strait Islander survey 1994 measured self reported morbidity among Aboriginal and Torres Strait Islander people. Data from the National Aboriginal and Torres Strait Islander health survey are limited by the usual caveats concerning self report data and because they are not comparable to general population studies (eg. National Health survey, 1989/90).

The following section lists data on morbidity from the National Aboriginal and Torres Strait Islander Health survey. The survey contained data on recent illnesses and long term conditions. Recent illnesses were defined as conditions which had occurred in the two weeks preceding the survey. Long term conditions were defined as conditions which lasted 6 months or more.

15-24 years of age

A total of 21.4 per 1000 Aborigines and Torres Strait Islanders had an illness in the 2 weeks preceding the survey. The most common types of recent illnesses (all sexes); Diseases of the respiratory system (8.0/1000), ill defined (5.1/1000), injury and poisoning (3.9/1000), diseases of the skin and subcutaneous tissue (1.7/1000) and diseases of the nervous system and sense organs (1.4/1000).

The most commonly reported long term conditions among females were; Asthma (4.4/1000), ear or hearing problems (2.3/1000), skin problems (1.7/1000), kidney problems (1.1/1000), heart problems (0.9/1000) and kidney problems (0.7/1000).

25-44 years of age

The most common types of recent illnesses (all sexes); Diseases of the respiratory system (9.3/1000), ill defined (8.1/1000), injury and poisoning (5.1/1000), diseases of the circulatory system (4.0/1000) and diseases of the musculoskeletal system and connective tissue (3.7/1000).

The most commonly reported long term conditions among 25-44 year old females were; Asthma (3.6/1000), ear or hearing problems (2.2/1000), skin problems (1.5/1000), high blood pressure (1.6/1000) and chest problems (1.4/1000).

Over 45 years of age

The most commonly reported recent conditions were 45-54 year olds: Diseases of the circulatory system (3.5/1000), diseases of the respiratory system (2.5/1000), endocrine, nutritional and metabolic and immunity disorders (2.4/1000), congenital anomalies (2.4/1000) and diseases of the musculoskeletal system and connective tissue (2.0/1000). The most commonly reported recent conditions among Aboriginal and Torres Strait Islanders over 55 are: Diseases of the circulatory system (5.4/1000), diseases of the respiratory system (3.6/1000), endocrine, nutritional and metabolic and immunity

disorders (2.2/1000), congenital anomalies (1.9/1000) and diseases of the musculoskeletal system and connective tissue (1.7/1000).

The most commonly reported conditions for women aged over 45 were: High blood pressure (6.2/1000), diabetes (4.5/1000), asthma (4.2/1000), heart problems (2.8/1000) and ear or hearing problems (2.8/1000).

10.2.2 Hospital separations

Thomson (1991) states that Aboriginal and Torres Strait Islanders are 2 to 3 times more likely to be admitted to hospital than non-Aborigines and once admitted tend to stay longer. Higher frequency of admission may reflect higher prevalence of illness in Aboriginal communities or different patterns of health care utilisation or both. Data on hospitalisations among Aboriginals and Torres Strait Islanders must be interpreted with caution because of problems in identifying who is Aboriginal and who is not. Table X shows the rate for hospital admission for Aboriginal and Torres Strait. Separation rates were highest among older non-indigenous whereas for Aboriginal and Torres Strait Islanders the highest separation rates occurred among 0-4 year olds.

Table 2 shows hospital separations by age for Aboriginal and non-indigenous women in Northern Territory (1984), Western Australia (1986) and South Australia (1986).

Table 2
Age specific hospital separation rates and rate ratios for Indigenous and non-Indigenous women

Age	Indigenous	Non-Indigenous	Rate ratio
0-4	826	173	4.8
5-14	160	76	2.1
15-24	589	219	2.7
25-34	684	306	2.2
35-44	494	185	2.7
45-54	735	191	3.9
55-64	592	224	2.6
65+	741	359	2.1

Source: Thomson (1991), Australian Institute of Health.

Table 3 shows the causes of hospital separations for Aboriginal and Torres Strait Islander women in South Australia, Northern Territory and Western Australia. The supplementary classification includes a number of conditions associated with normal reproduction, including antenatal screening and healthy live births. The rate of hospitalisation of

indigenous women was higher in all categories than non-indigenous women. This is particularly true for hospitalisations for infectious and parasitic diseases and diseases of the skin and subcutaneous tissue which were 8.3 and 6.7 times greater respectively in indigenous women.

10.2.3 Fertility and Birth outcomes

Despite a major decreases in the fertility of since the 1970s fertility among indigenous women remains much higher than that of non-indigenous women. The fertility rate among all Australian women was 1873/1000 and for indigenous women was 3000/1000 (Thomson, 1991). This is largely due to much higher levels of motherhood among young women and teenagers. Almost 30% of Aboriginal and Torres Strait Islander women have babies at less than 19 years of age compared to 5.8% of all Australian women (Thomson, 1991).

It has been suggested that higher fertility among young Aboriginal women reflects the lack of culturally relevant information about family planning and cultural taboos about the discussion of birth control. Evidence of traditional methods of family planning (Gracey, 1991) in conjunction with a decrease in fertility associated with the uptake of family planning (Gray, 1989) suggest that other factors are involved.

Table 3
Causes of female hospital separations: Indigenous and non-indigenous
standardised separation rates and rate ratios

Cause	Indigenous	Non-Indigenous	Rate ratio
Supplementary classification	94.1	23.4	4.0
Complications of pregnancy	75.0	38.1	2.0
Injury and poisoning	64.7	17.6	3.7
Respiratory system	62.1	14.3	4.4
Symptoms, signs and ill defined conditions	47.3	14.0	3.4
Genito-urinary system	42.2	20.6	2.0
Infectious and parasitic	33.9	4.1	8.3
Skin and subcutaneous tissues	22.8	3.4	6.7
Nervous system and sense organs	22.9	8.8	2.6
Other causes	93.3	56.8	1.6
All causes	562.6	199.9	2.8

Source: Thomson (1991), Australian Institute of Health.

Motherhood and womanhood are synonymous in some Aboriginal communities. The birth of first child enhances young women's social status and enables them to be accepted as adults (Franklin, 1989; Parker & Williams, 1990; Toussaint, 1989). It has also been argued that beliefs about the appropriate number of children vary between indigenous and non-indigenous people (Franklin, 1989). Parity is generally higher among indigenous women (Wesley-Wise, 1994) it has been argued that this reflects the importance of children to communities and male beliefs about the association between virility and large families (Franklin, 1989). This has resulted in a tendency to use family planning to stop having children rather than a way of delaying motherhood and spacing children (Parker & Williams, 1990). The value of birth control in appropriately spacing children is acknowledged in many communities however the value of birth control in delaying motherhood or reducing family size is regarded with some ambivalence (Parker & Williams, 1990).

10.2.4 *Birth weight*

Babies born to Aboriginal women are 150-350 grams lighter than those born to non-Aboriginal women (Thomson, 1991). Data from South Australia 1983-1986 and the Northern Territory 1986-1987 suggests that only 5.7% of babies born to non-Aboriginal mothers were low birth weight (under 2500g) compared to 13.5% of babies born to Aboriginal mothers. In Queensland in 1989, 14.1% of babies born to Aboriginal mothers, 7.4% of babies born to Torres Strait Islander mothers and 3.7% of babies born to Caucasian mothers were low birth weight.

Lower birth weight and a higher proportion of low birth weight infants among Aboriginal babies may reflect a number of factors; Younger age of mothers, poorer nutrition, higher degree of smoking and alcohol consumption during pregnancy and late or absent antenatal care. It should be noted that most statistics on low birth weight do not distinguish between babies who are low birth weight because they were premature and babies who are small for their gestational age.

Low birth weight is typically emphasised because it is generally associated with poorer maternal health and worse outcomes for infants. High birth weight is also a problem because it is associated with more complications during the birth although not necessarily with worse outcomes for infants (Gray, 1985). A greater proportion of indigenous women tend to have high birth weight babies which can exacerbate generally higher levels of complications during birth. This may reflect differences in maternal nutrition and perhaps a tendency to overemphasise problems associated with low birth weight at the expense of problems associated with high birth weight.

10.2.5 *Maternal outcomes*

Rates of obstetric complications are higher among some groups of Aboriginal and Torres Strait Islander women are higher than for non-indigenous women (eg. Wesley-Wise, 1994; Fitzpatrick & Ford, in press). Rates of gestational diabetes among Aboriginal women in NSW from 1987-1991 were 1.4 times those for non-Aboriginal women. Threatened premature labour and premature rupture of membranes were 1.5 times higher. Fitzpatrick and Ford (in press) found that gestational diabetes was 1.3 times more likely in Aboriginal mothers and 3 times more likely in Torres Strait Islander mothers.

Aboriginal and Torres Strait Islander mothers tend to have lower rates of intervention (eg. elective caesarean section) than non-Aboriginal mothers. This may reflect higher parity among indigenous mothers and differences in health service provision.

Wesley-Wise (1994) found that in NSW indigenous women were less likely to give birth in specialist obstetric hospitals than other women. In other states indigenous women have little choice about where they give birth, particularly in far North Queensland. Pregnant women in Cape York and Peninsula area are routinely evacuated to Cairns base hospital to give birth and pregnant women in the Torres Strait are evacuated to Thursday Island. Proponents of this policy argue that it has improved both maternal and infant outcomes. However mothers are removed from their families and social support networks for the duration of the birth. Fitzpatrick (1993) suggests that Aboriginal and Torres Strait Islander women believe that the evacuation policy weakens infants cultural and legal ties with their land. The lack of adequate alternatives, such as giving birth in local hospitals, means that indigenous women in far North Queensland are forced to choose between tradition and adequate health care.

10.2.6 Nutrition

Many Aboriginals continue to experience poor nutrition. In recent years clinically evident malnutrition has decreased (except among some groups of children) but health problems associated with obesity remain high. Obesity is a health risk for coronary heart disease, hypertension and diabetes mellitus type 2 (Jones & White, 1994).

The level of obesity in a population is usually determined using criteria based on body mass index. The applicability of these criteria to Aboriginal populations has been questioned. Standard body mass index cut-offs were developed based on mortality among samples of white Americans (Norgan, 1994). Australian Aborigines tend to be fatter for their body mass than would be expected based on these standards, partly due to differences in body shape (Norgan, 1994). Applying standard body mass index cut-offs to Aboriginal populations is likely to over-estimate malnutrition and under-estimate obesity.

Despite the fact that obesity may be underestimated in indigenous populations the proportion of women classified as obese in many Aboriginal and Torres Strait Islander communities is higher than in the non-Aboriginal population. The National Aboriginal and Torres Strait Islander survey (1994) found that 38% of women were obese or overweight, 25% were an acceptable weight, 11% were underweight and 26% were unknown. The National Health Survey 1989-90 found that 9% of all Australian women were obese, 27% were overweight, 47% were an acceptable weight, 13.2% were underweight and 4% had unknown weight. However levels of obesity vary widely depending on area of residence and community. For example, 51% of Central Australian Aboriginal women (Ntaria: Phillips & Kubish, 1985), 17% of West Kimberley Aboriginal women (Bayulu, Junjuwa, Looma, Mowanjum & Wangkatjunka: Rutihauer & Mackay, 1986) and 4.3% of Arnhem land Aboriginal women (Yolungu: Jones & White, 1994) were classified as obese because their body mass indexes exceeded 30 kg/m². O'Dea, Hopper, Patel, Trainedes & Kubisch (1993) found that 45% of Central Australian women over 35 years old were obese. Obesity in Aboriginal communities

tends to increase with the shift from traditional lifestyles to western lifestyles (Jones & White, 1994; O'Dea et al, 1993)

The relationship between morbidity and obesity may differ between non-Aboriginal and Aboriginal populations because of differences in trends in adiposity due to age and the distribution of body fat. Adiposity decreases with age among some groups of Aboriginal women (Jones & White, 1994; White, 1985) in contrast to non-Aboriginal women where adiposity increases to old age. Reduced adiposity in elderly Aboriginal women may reflect disadvantage in the distribution of food in traditional communities and a tendency to distribute money to their children in cash-based economies (Jones & White, 1994; Bolger, 1991). Age related trends in adiposity may vary across communities. Smith, Spargo, Craig and Nestel (1991) found that there was a sharp increase in hypertension among Aboriginal women older than 35 in the Kimberley was primarily due to the high prevalence of obesity among women in the 30-60 year age group. O'Dea, Hopper, Patel, Trainedes & Kubisch (1993) found that adiposity was greater in central Aboriginal women over 35 years than aged 15-35 years. It is difficult to determine whether observed differences in the relationship between age and adiposity reflect actual population differences or inconsistencies in the way age groups are defined between studies.

A central distribution of body fat (ie. an accumulation of fat around the trunk of the body) is associated with greater risk of heart disease and diabetes mellitus type 2. Several studies suggest that Aboriginal women tend to have a central fat distribution (Jones & White, 1994; O'Dea, 1987; Norgan, 1994; O'Dea, Lion, White Lee, Trainedes, Hopper & Rae, 1990; Rutishauser & McKay, 1986; Thomson, 1991) although the extent varies between populations (O'Dea et al, 1993).

10.2.7 Diabetes

O'Dea et al (1993) found that the prevalence of type II diabetes among Central Australian Aboriginal women was 5.3% in women under 35 years and 28.8% in women over 35 years. Guest, O'Dea, Hopper, Nankervis and Larkins (1992) found that the prevalence of non-insulin dependent diabetes was 7.2% among Aboriginal females rural Victoria. The standardised prevalence for Aborigines in this sample was 8.1% compared to 1.9% in a European comparison group. Impairment in glucose tolerance and fasting insulin was more common in Aboriginals with no known non-Aboriginal ancestry than in Aboriginals with known non-Aboriginal ancestry (O'Dea et al, 1993). Impairment in glucose tolerance and fasting insulin are both consistent with higher insulin resistance, a characteristic of populations at higher risk for type 2 diabetes. There is evidence that young Australian Aboriginals with a family history of type 2 diabetes have peripheral and hepatic insulin resistance relative to controls even though fasting glucose levels were the same in both groups (Proietta, Nankervis, Trainedes, Rosella & O'Dea, 1992). O'Dea et al (1993) suggest that the westernisation of diet in combination with chronic risk factors are likely to have contributed to the high incidence of diabetes in the Aboriginal and Torres Strait Islander populations.

Not only is diabetes more common among Aboriginals and Torres Strait Islanders than non-Aboriginals it is also a greater cause of morbidity. Phillips, Patel and Caboron (1993) found that diabetes-specific admissions accounted for 10% of male and 11% of

female hospital separations from 1984 to 1986 for adult Aboriginals. The most common cause of admission was bacterial infection.

10.2.8 Sexual health

Notification rates for infectious diseases are notoriously inaccurate for estimating the prevalence of diseases. The cumbersome nature of notification in most states means that geographic and temporal variability in the number of notifications are more likely to reflect differences in reporting rather than differences in prevalence. These problems would be expected to be exacerbated when reporting the number of notifications for indigenous people because of poor or absent reporting of Aboriginality. The notification rate for syphilis among Aborigines in the Northern Territory is some 60 times greater for Aborigines than non-Aborigines (Thomson, 1991). The disease is also known to be more common among Aborigines in the Kimberley and some Queensland communities. Aboriginality is not included in notifications for infectious diseases in New South Wales however higher notification rates in areas with large Aboriginal populations, particularly in western NSW suggest that syphilis rates may also be higher among Aboriginals in these communities. Higher rates of congenital syphilis and cases where infants may be at risk of developing symptoms associated with congenital syphilis have also been detected in western NSW. This would suggest a higher prevalence among Aboriginal women.

Rates of notifications for gonorrhoea are also higher among indigenous people than non-indigenous people in the Northern Territories (Thomson, 1991). Infections with herpes and chlamydia trachomatis are lower among Aboriginal communities than non-Aboriginal communities.

Rates of Hepatitis B among Aboriginal and Torres Strait Islander communities are far higher than in the rest of the population. The prevalence of serological markers for hepatitis B ranges from 23 to 90 per cent (Thomson, 1991). The prevalence of chronic carriers varies from around 3 to 26% (Thomson, 1991). Fitzpatrick and Ford (in press) found that 0.8% of Caucasian, 2.8% of Aboriginal and 10.9% of Torres Strait Islander mothers had positive hepatitis B serology. It should be noted that antenatal screening is generally more thorough among indigenous women which may increase prevalence estimates in indigenous populations compared to non-indigenous populations.

Higher rates of sexually transmitted disease among Aboriginal communities may reflect a higher degree of sexual activity, more unprotected sex or a high degree of sexual mixing within populations with high baseline levels of infection. Parker and Williams (1990) suggest that one of the reasons for the high incidence of STDs among Aboriginal and Torres Strait Islander women in some communities is failure to stock condoms at local stores. They suggest that lack of knowledge about contraception and breakdown of cultural beliefs are responsible both for early motherhood and high prevalence of STDs.

Issues around STDs are not usually discussed within families which may place young women at risk (Parker & Williams, 1990). Social taboos around women exposing their pelvic regions may increase women's reluctance to approach medical services about STDs leading to late detection and increased complications. These problems are exacerbated when Aboriginal women have to deal with male doctors (Hill, 1994; Shannon, 1994; O'Connor, 1994). Hill (1994) points out that objections to the

involvement of male medical practitioners in women's health is not universal or indiscriminate. For example, although Aboriginal women far North Queensland preferred female attendants during pregnancy the majority were accepting ultrasound from male doctors (Fitzpatrick, 1993). Similarly it can not be assumed that the traditions and taboos of one group of indigenous women generalise to other groups (O'Connor, 1994).

Hill and Murphy (1992) argue that STD rates can be decreased through the use of culturally appropriate health education materials. They stress the importance of placing educational material in context by emphasising the role of social relationships in STD transmission, incorporating Aboriginal beliefs about sex and sexuality and using same-sex/kin educators. Hill and Murphy (1992) argue that successful education programs are characterised by their ability to use traditional means of communication (paintings, visual aids, stories) to discuss modern messages.

10.2.9 *Drug and Alcohol Problems*

Excessive use of alcohol and its role in increased morbidity and mortality among indigenous people is well documented. For example 15% of deaths among Aboriginal women in NSW in 1980-81 were alcohol related (Thomson & Smith, 1981). Excess mortality was especially high in the 35-44 year age group. A 1986-87 survey of alcohol consumption in the top end of Australia found that although only 20% of females consumed alcohol, two-thirds of female drinkers drank at harmful levels (Watson et al, 1988). It is important to note that abstinence from alcohol consumption is higher in some Aboriginal communities than in the general community. Furthermore a number of communities in the Northern Territory have recently introduced partial or complete prohibition.

It is generally conceded that drug alcohol consumption among indigenous people is a direct result of the disempowering effects of colonisation. This does not imply that problems associated with alcohol use are intractable but that Aboriginal and Torres Strait Islander drug and alcohol services need to treat drug and alcohol problems in an appropriate context.

10.2.10 *Mental Health*

There is a paucity of data on mental health among Aboriginal women. Although the 1987 Royal commission into Aboriginal deaths in custody drew attention to suicide and suicide attempts among indigenous people the focus was predominantly on men.

Brice (1992) highlighted issues of class, poverty and powerlessness rather than culture or colour in a study of suicide attempts among female sole parents. Both non-Aboriginal and Aboriginal female sole parents were more likely to attempt suicide if they had a history of drug and alcohol problems, had experienced violence, were isolated (lack of telephone or car) and were subject to a high level of interaction with the police.

10.2.11 *Caring for the aged and dying*

Accounts of the care provided for elderly women in the Aboriginal and Torres Strait Islander communities are highly polarised. In some accounts elderly aboriginal women

are portrayed as disadvantaged members of Aboriginal society, unable to gather food by traditional means and expected to forfeit most, if not all, cash income to their children (Bolger, 1991; Jones & White, 1994). This depiction of elderly Aboriginal women is illustrated in Bolger (1991, pp29):

"Tomorrow men will finish their money. They'll wait till next week for pension, for granny and old mother. \$200 pension-they just take the whole lot just leave \$20 for old man old woman. Some old people cry: 'where will I find tucker, you won't kill kangaroo for me your brain is full of beer.' If old people go out bush for bush tucker, they [young men] bring them back for pension, say give me whole lot."

In other accounts elderly Aboriginal women are depicted as loved, respected and cared for members of the Aboriginal community.

"When our mother, father, auntie, uncle or any of relatives get sick we first of all organise shelter for her.

Then all children, grandchildren and other relatives come together and care for just as she cared for them when they were little kids. " (Laklak Yunupinga and Dhuwarrwarr Yunupingu in Reid, Yunupingu & Yunupingu, 1978, pp25).

This polarity, in part, reflects the different agendas of researchers. Bolger's (1991) report on violence towards Aboriginal women would not be expected to include data on positive aspects of the relationship between elderly women and their children similarly Reid et al' (1978) article on palliative care would not be expected to include data on violence towards elderly women. Compartmentalising different types of interactions without reference to the social context in which they occur may lead to inaccurate or distorted perceptions about the relationship between elderly Aboriginal women, their family and their community.

Elderly women's interactions with their community may depend on the extent to which traditional culture is intact. Reid et al (1978) suggest that there are traditional beliefs and customs which ensure that the elderly are cared for in Aboriginal communities while in western society much of the responsibility for caring for the elderly has shifted from the family to the state. Individuals who do not fulfil their obligations for caring for the elderly can expect severe social censure and even be held responsible for their death. This may also affect the acceptability of palliative care in hospitals because it does not allow people to be surrounded by their kin.

The status of elderly Aboriginal women has traditionally been associated with their possession of assets, such as knowledge of sacred beliefs and the whereabouts of various food resources, and their strong position in social networks built up throughout their lives (Reid et al, 1978). The value placed on these assets is likely to be highly dependent on social structure and belief systems. This is reflected in sex differences in the relationship between elderly women and their children.

Bolger's (1991) research suggests that while elderly women may distribute a high proportion of any wealth they possess to their sons their daughters are expected to care for them.

'My mother-her sons, not daughters, just sons, always take her money. So she comes to her daughters for a feed, but its hard, I have a big family to feed with food only for kids but I have to give to my mother' (Anonymous, Bolger, 1991, pp29)

It is important to note that these obligations are not one way. Mothers, grandmothers and aunts are expected to take some of the responsibility for child care when parents are unable to (Reid et al, 1978). Sex differences in relationships with elderly women may reflect a greater degree of reciprocity between women.

10.3 OVERVIEW

The health information on Aboriginal and Torres Strait Islander women tends to have predominantly addressed mortality and maternal and child health. Data on morbidity is generally restricted either to self report data or hospital separations. Although this is useful for identifying differences between Aboriginal and Torres Strait Islander populations and other Australian women no information is available on why these differences occur. Studies of specific health problems (eg. diabetes) have generally been relatively small scale and have not linked morbidity to health care utilisation. Consequently, little is known about reasons for heterogeneity in health and health outcomes among different Aboriginal and Torres Strait Islander communities. Lack of information about what works in what type of community is likely to hinder the ability of Aboriginal and Torres Strait Islander people to develop appropriate models of health care.

11. BACKGROUND PAPER ON THE HEALTH OF FILIPINA AND FORMER YUGOSLAVIAN WOMEN

11.1 FILIPINO WOMEN

Filipinas comprise the second largest Asian immigrant group in Australia. Data from the Department of Immigration showed a 52 per cent increase in the Filipino population in Australia between 30 June 1986 and 30 June 1988 (Hagan, 1989).

There are striking differences in the social circumstances of Filipino women, compared to their Vietnamese counterparts. The countries of birth of the majority of partners of Filipino women in Australia (93 per cent), are born in Australia, New Zealand, Britain or other European countries. In contrast, only four per cent of the partners of the Vietnamese women were non-Asian born. The distinction between the two groups is paralleled by their differing routes of entry. After the Vietnamese war, many were accepted as refugees and as family groups. Filipino women most often entered Australia as newly married brides to Caucasian men (Howell, 1989). This is an important characteristic, for unlike Vietnamese women, who tend to live together in the same geographical area, often with family support, Filipino women are spread across the country and do not have access to similar support networks.

The literature available on Filipino women deals almost exclusively with the "Filipino bride" phenomena, the role of the Filipino wife in a cross cultural marriage, and the

social circumstance surrounding such marriages (Australian Foreign Affairs and Trade, 1990; Tan and Davidson, 1994; Brown, 1993; King, 1992; Pendlebury, 1990; Watkins, 1982; Ungson, 1982; Rodell, 1982; Cooke, 1986; Chauh *et al*, 1987; Kaminskas & Smith, 1990). Filipino women married to Australian men are known to have special needs caused by isolation, loneliness, marital stress, and underemployment or unemployment (Kaminskas & Smith, 1990) However the literature on the health needs of Filipino women is virtually non-existent. There has been no literature identified which has investigated Filipino health values, beliefs, practices and behaviour, disease aetiology, prevention, treatment, and traditional theories on achieving and maintaining good health. Such baseline data is crucial for appropriate and effectively designed health education and health promotion programs, and the provision of health care services. This information does not exist for Filipino immigrants in Australia.

Specific areas where information is required are: the use and acceptability of existing health services to Filipino women; barriers to the use of these services; family planning; health problems in the areas of pregnancy, antenatal care, birth outcomes, and postnatal care; infant feeding, child health and child rearing; health values, practices and beliefs; dietary patterns; morbidity and planning.

Only two studies have been identified that attempt to look at the obstetric profile (Chan *et al*, 1988) and intrapartum differences of Filipino women, compared to Australian women (Howell, 1989). Both of these studies showed that Filipino primiparas were found to have a worse outcome in all parameters of labour than Australian or Vietnamese women. They experienced increases in total duration of labour, duration of the second stage, oxytocin augmentation, instrumental delivery rate, and caesarean section rate (particularly caesarean section performed in the second stage of labour) (Howell, 1989; Chan *et al*, 1988). Both of these studies recommended further research into these differences.

Currently two other studies are being undertaken by the Centre for the Study of Mothers' and Children's Health, La Trobe University, which include Filipino women. These are:

1. Perinatal outcomes for women born in the Philippines.
2. Mothers in a new country: interviews with Vietnamese, Filipino, and Turkish women about maternity care and motherhood.

While both of these studies will provide useful and much needed information they are limited to the Victoria region and will not provide an overall picture of Filipino women in Australia.

As stated previously, Filipinos are now the second largest ethnic population in Australia but there is a disturbing lack of research into their health status, or specific health needs. Such information is not only useful but essential to the Australian health service providers to understand and appreciate the health values, beliefs, and behaviours of the Filipino population and to provide appropriate and effective health education, health promotion, and the provision of health care services.

The information that is available on Vietnamese women cannot be applied to Filipino or other Asian groups, as their cultures and social characteristics effecting health are distinctly different, which reinforces the need to study Filipino women as a separate Asian group.

11.2. FORMER YUGOSLAVIAN WOMEN

Relatively large scale migration from Yugoslavia took place in the 1960s. However recent political unrest has lead to a new wave of immigration from the former Yugoslavia. It is likely that these groups despite similar cultural backgrounds would have very different experiences of immigration and health problems.

Immigrants from Yugoslavia in the 60s were largely men, recruited with their families, to work in heavy industry. A major health concern among them was the high levels of alcohol consumed, resulting in different forms of cancer being detected. High levels of rectal cancer were also detected, attributed to a large increase in beer consumption following migration. Additionally, high rates of stomach cancer may reflect the high consumption of spirits (McMichael, 1985:157). Conversely men and women from former Yugoslavia have a significantly lower risk of suffering form respiratory diseases compared to Australians (Dollis et al, 1993:39).

Young (1991) notes that former Yugoslavians are highly reliant on unemployment benefits in Australian, and are disadvantaged in income levels, education and formal qualifications, with women being effected more severely than men by these factors. With the recent immigration of refugees, these problems have increased. Since the outbreak of the civil war in the former Yugoslavia in 1992, there has been a steady flow of migrants to Australia. Former Yugoslavian refugees form one of the largest groups in Australia who lack fluency in English. Groups from non-English speaking backgrounds tend to suffer greater socioeconomic disadvantage than English speaking migrants and this is particularly true for those migrants from former Yugoslavia.

A high majority of these refugees have experienced torture and other forms of emotional and physical deprivation, and as a result, they are far more vulnerable to emotional and physical strain than most other migrants. Many have lost family members, other loved ones and their previous life. Abalo and Zaia (1991) state that the most pressing problem for migrants who have experienced torture, caused by forms of organised violence, is the resulting severe physical and psychological disturbances, which can become chronic in later life if not treated with specialised medical care. Reid and Strong (1988) document that psychological disturbances commonly associated with torture in adults include guilt, severe anxiety, suicidal feelings, sexual dysfunction, panic, impaired memory and sleep disturbances. Randall and Lutz (1991) (see also Dollis et al. 1993) list the common physical consequences of torture as cardiovascular disease, nutritional, genital, respiratory, urological, gastrointestinal, neurological, musculoskeletal, hearing, skin, dental and pharmacologic disorders, psychosomatic complaints, and drug and alcohol abuse.

A study of how immigrant Serbs, Croats and Bosnians coexist in Australia has been undertaken by Hill (1993) and attitudes of migrants in Australia by Kiernan (1983). Differences in health and disease profiles among migrants (McMichael, 1985; and

Podgorelec, 1990) provides limited information about former Yugoslavian women's health. Cultural perceptions of disability (Scibilia & Sharples, 1991) and Yugoslav family life in Australia (Tisay, 1985) have also been documented. The mental health of the Yugoslav community in Australia has been studied by Mestrovic (1988), indicating the mental health of injured workers requires attention.

Overall, there is very little data on the health of women from the former Yugoslavia in Australia. Women from the former Yugoslavia are often reluctant to provide information to government agencies or health services because of negative experiences in Yugoslavia (personal communication Selvickam, 1995). This suggests that unless specifically researched and addressed the health needs of these women are likely to go unmet.

12. REFERENCES

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