# AUSTRALIAN LONGITUDINAL STUDY OF WOMEN'S HEALTH

*Report 2 for the Commonwealth Department of Human Services and Health*

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

**June, 1995**

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The contract between the Commonwealth Department of Human Services and Health and the University of Newcastle requires that Report 2, due on 28th June, 1995, shall include:

a) A protocol for the pilot study including:
   - details of the sampling frame and sample selection procedure;
   - the process for gaining consent to participation and a copy of the consent letter;
   - draft questionnaires;
   - follow-up procedures for non-respondents to the consent letter and the questionnaire;
   - Computer Assisted Telephone Interview (CATI) procedures for women who indicate a preference for telephone interview;
   - quality assurance procedures;
   - planned data analyses.

b) Detailed study plans for the special cohorts (for approval by the Commonwealth) including:
   - reasons for choosing the particular groups of women and preferred options;
   - arrangements for consultation with these groups of women;
   - recruitment procedures.

c) A progress report on ethics approvals.

d) A preliminary communications strategy.

e) A report on the appointment of project staff, development of management structures, and establishment of facilities for the conduct of the study.

This report is in two parts: A - from the University of Newcastle, and B - from the University of Queensland.

# REPORT 2

## UNIVERSITY OF NEWCASTLE AND QUEENSLAND

## JUNE 1995

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# PART A: UNIVERSITY OF NEWCASTLE

## 1. PROJECT STAFF

In addition to the appointments for the positions of Data Manager, Secretary and Research Assistants, a recommendation has now been made to the University administration for the appointment of a Project Manager (a person with substantial research and management experience in women's health.

## 2. FOCUS ON QUALITY

To ensure that the study is conducted very well, it is important to create a culture of striving for excellence among the study team. Aspects of this focus on quality include:

- effective communication within the team and outside (regular worthwhile meetings; quick dissemination of information and materials; careful listening; and clear written and spoken communication);
- creation of a participative, co-operative and creative workplace;
- clear lines of authority and responsibility;
- focus on "customers", ie. the women who participate in the study, as well as key stakeholders (DHSH, women's groups, the media, the University, etc);
- encouragement of staff and students to continuously improve the study and to develop their own skills further;
- pride in the work done and sharing of credit for achievements.

To achieve these objectives, appropriate management structures and processes are needed.

Now that the key staff are appointed, work can begin on these issues, with particular attention to good communication with the Queensland team and with the wider community through the National Steering Committee and other means.

## 3. ETHICS APPROVALS

The University of Newcastle Human Research Ethics Committee has granted approval in principle for the conduct of the study. The protocol for the pilot study, questionnaire and pre-tested information and consent materials will be submitted for specific approval for the pilot study in July 1995.

## 4. PILOT STUDY FOR MAIN COHORT

Prior to the main study, a pilot study will be conducted during August - October 1995. The pilot study is designed to provide information for refining the survey procedures and instruments to be used in the main study. The aim is to pilot all stages of the sampling, recruitment and survey process. The pilot study will be conducted in two NSW Statistical Divisions: Illawarra and Central West. Restricting the pilot study to these two geographically discrete areas allows for pilot testing of the community awareness campaign as well as other procedures to encourage participation by the selected women.

The aims of the pilot study are:

a) To pilot the sampling and recruitment procedures including the community awareness campaign;
b) To estimate the response rate for the main survey;
c) To pilot the survey instruments: questionnaire and computer assisted telephone interview (CATI);
d) To pilot procedures for linkage to HIC records;
e) To pilot analyses for the main study.

## 4.1 Sampling and recruitment procedures

To ensure that study participants are representative of Australian women in the selected age groups, it is necessary: a) to select a random sample with sufficient women from all areas of Australia, including rural and remote areas; b) to achieve high response rates to initial recruitment. A major aim of the pilot study is to identify and test the sampling and recruitment procedures, and to identify those procedures with the potential to achieve the greatest response rates.

### 4.1.2 *Sampling Frame and Sample Selection*

The Health Insurance Commission (HIC) data base will be used as the sampling frame. **HIC has wide coverage of the Australian population including groups who are under-represented on the electoral roll, such as migrants and younger women. The database is updated automatically each time a claim is lodged, providing one of the most accurate population lists in Australia.**

For the pilot study, HIC will select random samples of 1000 women in each age group from all women who are resident in two NSW Statistical Divisions: Illawarra and Central West. The numbers of women in each age group for each statistical division are provided in Table 1.

**Table 1**

**Estimate Resident Female Population of Statistical Local Areas in Illawarra, Central West Statistical Divisions, 30 June 1993**

| Statistical Division | Statistical Local Areas | Age | | |
|---|---|---|---|---|
| | | **20-24*** | **45-49** | **70-74** |
| **Illawarra** | **Shellharbour** | 1,842 | 1,469 | 606 |
| | **Wollongong** | 7,733 | 5,644 | 3,395 |
| | **Kiama** | 445 | 558 | 444 |
| | **Shoalhaven** | 1,838 | 1,999 | 1,764 |
| | **Wingecarribee** | 1,076 | 1,224 | 670 |
| **Central West** | **Bathurst** | 1,387 | 802 | 396 |
| | **Orange** | 1,316 | 1,027 | 598 |
| | **Greater Lithgow** | 720 | 604 | 385 |
| | **Blayney** | 192 | 179 | 100 |
| | **Cabbone** | 250 | 409 | 220 |
| | **Evans** | 141 | 192 | 66 |
| | **Oberon** | 144 | 149 | 62 |
| | **Rylstone** | 111 | 132 | 86 |
| | **Bland** | 168 | 177 | 119 |
| | **Cowra** | 330 | 402 | 236 |
| | **Forbes** | 330 | 329 | 216 |
| | **Parkes** | 392 | 404 | 270 |
| | **Weddin** | 94 | 135 | 86 |
| | **Lachlan** | 184 | 234 | 115 |

Source: Australian Bureau of Statistics. Estimated Resident Population by Age and Sex in Statistical Local Areas. New South Wales. 30 June 1993. Catalogue No. 3209.1

* Estimates are available by conventionally defined five-year age groups so only the age group 20-24 is used here as an approximation for the age group 18-22 years to be used for ALSWH.

The sample will be stratified to allow for greater representation of women from rural and remote areas in the study sample than would be achieved through simple random sampling. Such stratification is necessary to ensure sufficient numbers of women from rural and remote areas to allow for sub-group analysis on this criterion. The sample will be stratified according to the

Rural, Remote and Metropolitan Area system of classification developed by the Departments of Primary Industries and Energy, and Human Services and Health. Postcodes included in the Statistical Division will be identified and grouped by Statistical Local Area using the Australian Bureau of Statistics' Postcode/Statistical Local Area Concordance. Postcodes will then be sorted into Statistical Local Areas classified as "Other Metropolitan Centres" , "Large Rural Centres", "Small Rural Centres" "Other Rural Areas" and "Other Remote Areas" (see Table 2).

**Table 2**

**Rural and Remote Area Classification of Statistical Local Areas in Illawarra and Central West Statistical Divisions**

| **Statistical Division** | **Other Metropolitan Centres** | **Large Rural** | **Small Rural** | **Other Rural Areas** | **Other Remote Areas** |
|---|---|---|---|---|---|
| **Illawarra** | Shellharbour<br>Wollongong<br>Kiama | Shoalhaven | | Wingecarribee | |
| **Central West** | Orange | | Bathurst<br>Lithgow | Blayney<br>Cabbone<br>Evans<br>Oberon<br>Rylstone<br>Bland<br>Cowra<br>Forbes<br>Parkes<br>Weddin | Lachlan |
| **Estimated Female Population Age group:** | | | | | |
| **20-24** | 10,020 (53.6%) | 3,154 (16.9%) | 2,107 (11.3%) | 3,228 (17.3%) | 184 (1.0%) |
| **45-49** | 7,671 (47.7%) | 3,026 (18.8%) | 1,406 (8.75%) | 3,733 (23.2%) | 234 (1.5%) |
| **70-74** | 4,445 | 2,362 | 781 | 2,125 | 115 (1.2%) |

| | | | | | |
|---|---|---|---|---|---|
| | (45.2%) | (24.0%) | (7.95%) | (21.6%) | |

For the pilot study the sample will be selected so that 40% of each age group (ie. 400 women) will be from the "Metropolitan" areas, 30% from "Large or Small Rural Areas", and 30% from "Other Rural" or "Remote Areas". This represents oversampling, by a factor of about 1.5 from the "Other Rural and Remote Areas" and slight undersampling from "Metropolitan" areas.

### 4.2 Strategies to obtain a high response rate to initial recruitment

To ensure a representative sample is obtained for the main cohort study, a high response rate to the initial recruitment is essential. Strategies found to be associated with high response rates in previous mail surveys will be incorporated in the recruitment strategy. These strategies include:

a) A study name and logo to create a study identity.

b) Publicity to precede the initial recruitment contact with women.

c) Personally addressed invitations to participate.

d) Message framing to emphasise the significance of the study and the importance of participation by all selected women, and to reduce anxiety regarding confidentiality of responses and access to Medicare data.

e) Material incentives for participants.

f) Reminders for non-responders.

g) Optional telephone interview for those who have difficulties completing the questionnaire in English, or who for any other reason would prefer a telephone interview.

In addition to these aspects, the pilot study will assess the relative merits of a single, long questionnaire against a two-stage data collection process - a short questionnaire at the time of gaining consent followed by a longer questionnaire.

Procedures for the development and pilot testing of the recruitment strategy are summarised in Table 3 and described below.

**Table 3**

**Development of Recruitment Strategies**

| **Developmental or Pilot Phase** | **Recruitment Strategy** |
|---|---|
| Focus groups | Message framing |
| Intercept surveys | Name and logo<br>Message framing |
| Randomised controlled trial of recruitment procedures | |
| Procedures to be used for all women | Name and logo<br>Publicity<br>Message framing<br>Personally addressed invitation<br>Reminders for non-responders |
| Procedures to be randomly allocated | Material incentives<br>Questionnaire length<br>Timing of offer of telephone interview |

### 4.2.1 *Name and Logo*

Peach Advertising has been commissioned to develop a name and logo for the study. Intercept surveys will be used to gauge women's views about the impact and appropriateness of suggested names and logos. Responses to these interviews will be used to decide the name and logo with the greatest potential to attract women to the study.

The name and logo will be important for creating a study identity. This study identity will allow women to easily link the questionnaire to the supporting publicity. It is also possible that women will make the decision to complete the questionnaire solely on the basis of the study title (Frey, 1991).

The name and logo will also be used on the questionnaire cover. Questionnaire cover design has been shown to be an important factor in encouraging participation in surveys (Frey, 1991) and is important for attracting women's attention and promoting their interest in completing the questionnaire. An attractive and memorable cover will also make the questionnaire easier to recall and retrieve in response to reminder notices (Nederhof, 1988). In one study (Nederhof, 1988), it was found that a largely black contrastive cover yielded an 11% higher response rate than a low contrast (white) version.

### 4.2.2 *Publicity*

Publicity will provide an opportunity to raise the profile of the study, highlighting its importance for Australian women. The publicity will also introduce the women to members of the study team, so the women feel they are relating to people rather than a faceless organisation. Such publicity and public identity conveys a sense of personal involvement on the part of the researchers, and has been shown empirically to produce higher response rates (Rucker, Hughes, Thompson, et al., 1984).

The publicity will be designed and co-ordinated by CommuniKate, and will include articles in local newspapers and local radio interviews. This media exposure will partially simulate the strategies to be employed in the main study which will include national newspaper, magazine and television coverage.

### 4.2.3 *Personally addressed invitations*

Personally addressed invitations to participate are likely to increase the personal relevance of the study for the study participants. It may also cause respondents to feel they are receiving individual, personal consideration and attention (Worthen and Valcarce, 1985). Previous research shows that individually addressed letters, personalised salutations, hand signed signatures, and handwritten post-scripts increase response rates (Worthen and Valcarce 1985). Dillman and Frey (1974) found that personalizing the cover letter resulted in an approximate gain of 9% over less personalized approaches.

### 4.2.4 *Message Framing*

In recruiting the women it will be important to communicate several points:

- the purpose and importance of the study;
- how the women were selected;
- what participation will involve;
- what HIC record linkage involves;
- participants' and non-participants' rights;
- assurances of confidentiality;
- contacts and phone numbers for women who wish to contact the study team, HIC, or the University of Newcastle Ethics Officer.

It is important that these complex messages are read and understood by the women. Women must also perceive that the messages are believable and personally relevant. To meet these needs for message framing, information material will be pre-tested through intercept surveys with a number of women.

A critical aspect of message framing will be communication of the scope and limitations of the HIC record linkage. Before the pilot study, focus groups will be conducted to identify the likely acceptability of this component of the study, and to identify women's concerns and ways to address them.

### 4.2.5 *Material incentives*

Previous research demonstrates that material incentives can increase response rates significantly (Heberlein and Baumgartner, 1978). Gitelson, Kerstetter and Guadagnolo (1993) found that the overall response rate for those receiving an incentive of a raffle was 67.3%; the response rate for those not receiving an incentive was 58%. There is a clear trend for the response rate to increase with the monetary value of the incentive (James and Bolstein, 1990).

A number of potential incentives will be explored through preliminary qualitative research with women (focus groups and intercept surveys). Potential incentives include prize draws, diaries and calendars which include survey dates and change of address forms, pens with the study logo etc.

The impact of the incentive scheme on response rates will be assessed in a randomised controlled trial conducted as part of the pilot survey (see below).

### 4.2.6 *Reminders for non-responders*

Follow-up reminders to non-respondents have been found to increase the overall response rates of mail surveys (Graetz 1985). Dillman (1978) suggests three reminders: a postcard reminder sent one week after the initial mailing; a second reminder including a replacement survey sent two weeks after the postcard reminder; and the final mailing with a replacement survey sent 6-7 weeks after the initial mailing of the questionnaire.

A modified version of the Dillman protocol will be trialed in the pilot survey. A postcard reminder will be sent to all women who have not replied within two weeks of the initial invitation. This time frame allows for replies to be returned and logged by the study team. A second reminder including a replacement survey will be sent one month after the initial invitation. The necessity and likely cost-effectiveness of a third reminder will be assessed from the response to the first three approaches.

### 4.2.7 *Opportunity for telephone interview*

**Some participants in the sample may not be able to fill in a written questionnaire due to illiteracy, poor eyesight, physical disability and so on, so the offer of a telephone interview will be made. The timing of whether to give this option with the initial mailing or on the second follow-up reminder will be tested.**

### 4.2.8 *Questionnaire length*

It is hypothesised that the response rate will be inversely related to the length of the questionnaire. However, the findings of previous research into the effects of questionnaire length are conflicting. A number of studies have demonstrated no effect (Fox, Crash and Kim, 1988; Linsky, 1975; Scott, 1961). Other studies have demonstrated minor but statistically significant reductions in response rates with longer questionnaires (Dillman 1991; Heberlein and Baumgartner, 1978).

It is, therefore, unclear whether better response rates will be achieved through sending a single comprehensive questionnaire, or sending two shorter questionnaires. The advantages of the former approach is that women will only be approached once, and the process is simpler and less expensive. The second approach presents the women with more achievable tasks, and allows telephone follow-up of women who do not return the second questionnaire. A personalized contact of this sort is estimated to improve response by as much as 25% (Heberlein and Baumgartner, 1978). For these reasons, it will be necessary to test the impact of questionnaire length and the number of approaches in a randomised controlled trial of recruitment.

## 4.3 Randomised Controlled Trial of Recruitment Procedures

In each age group, women will be randomly allocated to various recruitment strategies using a factorial design (see Table 4).

This will allow the differential response rate to each strategy to be assessed, so the most effective recruitment strategy can be used in the main survey.

**Table 4**

**Recruitment Strategies**

| | **Questionnaire** | **Material incentives** | **Offer of telephone interveiw** |
|---|---|---|---|
| **Strategy 1** | Single Long | Yes | First approach |
| **Strategy 2** | Single Long | Yes | Third approach |
| **Strategy 3** | Single Long | No | First approach |
| **Strategy 4** | Single Long | No | Third approach |
| **Strategy 5** | Two Stage | Yes | First approach |
| **Strategy 6** | Two Stage | Yes | Third approach |
| **Strategy 7** | Two Stage | No | First approach |
| **Strategy 8** | Two Stage | No | Third approach |

## 4.4 Procedures for gaining consent to participation

HIC will post initial survey items to women in the study group. These survey items will include:

- a letter from the Department and HIC explaining the involvement of HIC in the study;
- a letter from the study team (signed by the Director);
- an identification numbered consent form (see Appendix 1) and identification numbered questionnaire to be completed and returned to the study team;
- a reply paid envelope.

Women will be invited to consent separately to participation in the survey and to authorise release of their HIC records to the study team. Women who consent to the survey will return the completed questionnaire and consent form (with or without completing the consent to release of HIC records) to the study team at the University of Newcastle.

Replies will be logged by the study team (or sub-contractors). Names, addresses and study numbers of participants will be forwarded to HIC.

HIC will send a reminder card to women in the sample who do not reply within two weeks of the initial invitation.

HIC will send a second set of survey items to women who do not reply within one month of the initial invitation (two weeks after the first reminder).

### 4.5 Survey Instruments

The draft questionnaire for the study has been developed. It addresses questions on the main themes of the study as well as a wide range of social, psychological, environmental, economic and health indicators. At this stage we have chosen to include rather than exclude items and issues. The questions will be further refined by the research team and through extensive local pre-testing before undertaking the pilot study in August 1995. This draft will be used as the basis for developing separate questionnaires for each of the three age cohorts as well as the special cohorts. A copy of the draft questionnaire is in Appendix 2.

The questionnaire has 8 sections.

Section One: Demographics Questions in this section ask about age, marital status, employment, education, ethnicity, living situation, etc. Questions are drawn from a variety of sources such as the Australian Living Standards Survey and the National Health Survey.

Section Two: Medical history This asks about major medical conditions, medical problems experienced over the past 12 months, medication use, and about health related behaviours such as smoking, alcohol use, screening behaviours, contraceptive use, etc. Questions are largely drawn from the National Health Survey.

Section Three: Use of and satisfaction with health care services This asks about the types of health care services used recently and satisfaction with these. Some questions are drawn from the National Health Survey, but many are modelled on those that tap uniquely women's health issues.

Section Four: Life events The Norbeck Life Events Questionnaire is used as the basis of this section, asking whether a range of life events have been experienced over the past twelve months. Participants are also asked what are the three most important life events and what sort of impact these 3 events had. This instrument was selected because it was specifically designed for women. It has previously been used in the study of Mothers and Babies by the Melbourne group.

Section Five: Time use and aspirations This section asks questions about paid and unpaid work, how women divide their time between different types of work and how well this fits with their aspirations. It is a refinement of previous time-use questions with a specific focus on the patterns of women's time-use. It also assesses the extent to which current time-use patterns match the aspirations women have.

Section Six: Quality of life and psychological and social aspects of health Quality of life is measured by the SF-12. This is a short form of the SF-36 which is being used in the ABS National Health Survey. The SF-12 has been found to yield reliable and valid scores for physical and mental health comparable with the full SF-36 scale. Psychological well-being is measured by the 10 item Mental Health Screening Scales which has been well validated by Ron Kessler from the Institute for Social Research/Survey Research Center at the University of Michigan and used in the US National Health Interview Survey.

Social Support is measured by the MOS Social Support Survey. This is a 20 item scale developed for the US Medical Outcomes Study (MOS) and taps a range of social support dimensions with good face validity for Australian samples.

Section Seven: Weight This section is about eating and exercise, and concerns about weight,

shape and dieting. The EDE-Q has been selected as the best available screening instrument for eating disorders. This will allow definition of an at-risk group which will be followed up in a substudy. Exercise items are modified from the National Heart Foundation (NHF) survey and other Australian studies. Self-reported weight and height will allow Body Mass Index (BMI) to be calculated.

Section Eight: Violence, including sexual abuse. These items come from previous Australian, New Zealand and American studies on violence. For the older cohort only, the Hwalek-Sengstock Elder Abuse Screening Test, a 15 item scale, is used to measure neglect, financial abuse, physical abuse and emotional abuse.

## 4.6 Quality Assurance Procedures.

Creating a culture among the study team of performing high quality work is the first step to quality assurance (see section 2 of this Report).

### 4.6.1 *Documentation*

Detailed written documentation will be developed for as many aspects of the pilot study as possible, eg. sample selection, printing of individual identification number and names and addresses on survey materials, logging-in of returned survey forms, data entry, and telephone interviews. The purpose is to clarify all details and to ensure that future researchers using the data understand exactly how they were obtained.

### 4.6.2 *"Special Intelligence Group"*

A small group of 30-50 friends and relatives of the study team, scattered throughout Australia, will be added to the sample selected by HIC. Their written consent will be obtained beforehand so HIC can add them to the sample. This "special intelligence group" will enable us to check that mail is sent out correctly and arrives on time, and logging and follow up procedures are correctly used.

### 4.6.3 *Contact with a sample of participants*

For every 30th signed consent form received, the study team will contact the women by telephone and ask her opinions and suggestions about the study and the survey materials. Half of these women who have completed the survey form will be randomly selected and asked to repeat the survey over the phone to check any problems of understanding and to obtain reliability data.

### 4.6.4 *Data entry*

Data entry will be performed at least weekly as the survey forms are returned and basic tabulations will be performed on the weekly data to detect problems quickly. Detailed range and logic checks will be developed for the data and these will be performed on the weekly batches. Twenty percent (20%) of all survey forms (randomly selected) will be sent back for data entry, mixed with newly in-coming forms. Data from the forms entered twice will be compared to assess the accuracy rate of data entry.

### 4.6.5 *Subcontractors*

The more the work is subcontracted to other organisations (eg. companies performing surveys, mailing, data entry or telephone interviewing), the greater the potential problems of ensuring high quality work. Detailed negotiations will be undertaken with subcontractors to develop mechanisms for monitoring quality.

## 4.7 Data Analysis for the Pilot Study.

The most important results from the pilot study will be the response rates and representativeness of the sample. Response rates will be calculated by age group and geographic area to obtain information required to estimate the relative sampling rates for urban, rural and remote areas needed for the baseline survey, and the total sample size which should be selected in order to recruit 20,000 women in each age group. The number requesting a telephone interview will also be important for planning and budgeting for the baseline survey. Detailed comparisons of

response rates and other results will be undertaken for the trials of alternative recruitment strategies (see section 4.3 of this Report).

Representativeness of the sample will be assessed by tabulating the socio-demographic characteristics of respondents and comparing them with census and other data from the Australian Bureau of Statistics for the same geographic areas. Where individual questions or groups of questions have been used in other recent Australian studies, the response distribution in other studies and the ALSWH pilot study will be compared. To assess the performance of every item in the questionnaire, the distributions of responses will be tabulated by age group (and possibly by geographic area) and presented in a data book. One purpose will be to identify poor items (eg. those with little variability in responses or with high proportions of missing values). Another will be to compare responses among age groups (for these items used in more than one age group) and geographic areas in order to detect anomalies.

### 4.8 Linkage to HIC data

The pilot study will also be used to develop procedures to obtain HIC data on respondents and non-respondents. HIC has agreed to provide unit record data with the participant's study identification number for all women who consent to record linkage. The records will cover all claims for 2 years prior to the pilot study. For those women who consent to participation but not linkage with HIC data, anonymous group data will be provided. Similarly, anonymous group data will be provided for women who did not participate in the pilot study. For women selected for the pilot study the main purpose of the HIC data will be to compare use of health services between full participants, participants not consenting to linkage and non-participants. We will also compare patterns of use between the three age groups and between geographic areas to determine useful ways of summarising the diverse data on consultations, procedures and pathology service.

## 5. COMMUNICATION STRATEGY

The aims of the communication strategy are:

a) To obtain a high consent rate for participation in both the pilot and the main study.

b) To maintain the cohorts recruited into the study for the duration of the entire study.

c) To communicate the findings of the study to all interested stakeholders.

The communication strategy will be designed in collaboration with CommuniKate. Key components of the planned strategy are presented in Table 5.

## Table 5

### Components of the Communication Strategy

| Strategy | Time Frame | Indicator |
|---|---|---|
| Work with Peach Advertising to develop a graphic image for the study (ie development a name and logo which will be used on all communications from the study team). This will aid recognition, and promote an identity for the study. | July | Name and logo developed. Letterhead and business cards designed. |
| Work with CommuniKate Ltd to develop and distribute publicity about the study to all major women's magazines, national newspapers and radio stations, and selected TV stations. This will ensure that women who receive a letter inviting them to participate will already know something about the study, and will be keen to participate. | July - December 1995 | Number of media articles promoting the study. |
| Explore the possibility of using high profile women to promote the study. | August 1995 | Discussions held with suitable candidates. |
| Develop the recruitment letter and consent form. The letter will emphasise the importance of the study so that women are encouraged to participate. The letter will be pre-tested before the pilot study and then pilot tested before the main study. | July - August 1995 | Letter and consent form developed. |
| Ensure that survey forms are "reader friendly" by checking the reading age of materials and use of lay terminology. Careful design and wording will promote ease of reading (in conjunction with CommuniKate). | July - August 1995 | Survey form checked. |
| Develop materials which will help the study team to keep in touch with the study participants. (eg cards to track participants who move, newsletter to inform stakeholders of the progress of the study). | October 1995 | Draft materials developed. |
| Disseminate pilot study results to all stakeholders through use of newsletter, and communication through magazines, radio and television. | Early 1996 | Pilot results disseminated. |

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# PART B: UNIVERSITY OF QUEENSLAND

## 1. STUDY PLANS FOR THE SPECIAL COHORTS

### 1.1. Introduction

The Special Cohort Study comprises the following cohorts

| | | |
|---|---|---|
| Aboriginal and Torres Strait Islander | Urban | Young age group |
| Aboriginal and Torres Strait Islander | Urban | Middle age group |
| Aboriginal and Torres Strait Islander | Urban | Elderly age group |
| Aboriginal and Torres Strait Islander | Non-urban | Young age group |
| Aboriginal and Torres Strait Islander | Non-urban | Middle age group |
| Aboriginal and Torres Strait Islander | Non-urban | Elderly age group |
| Filipina | QLD | Young age group |
| Filipina | QLD | Middle age group |

Preliminary consultation with a group representative of women working in Aboriginal and Torres Strait Islander health in most regions within Queensland, has indicated major dissatisfaction with and lack of appropriateness of the set age-groups. In consequence, age-groups will be finalised after consultation with reference groups. It is emphasised that those finally chosen will reflect the aims of the overall project in identifying life stages relevant to the health of women.

### 1.2 Reasons for choices of these particular groups of women

This has been documented in the "Report Outlining the Reasons for Choosing Special Cohorts of Particular Groups of Aboriginal and Torres Strait Islander Women", dated May 1995 and submitted to the University of Newcastle.

## 1.3 Arrangements for consultation with these groups of women

A preliminary meeting (20th June 1995) has been held with a group of about twelve Aboriginal and Torres Strait Islander women (see Introduction) with a view to commencing the construction of an Aboriginal and Torres Strait Islander reference group. As soon as funds are available, it is planned to appoint an Aboriginal or Torres Strait Islander Liaison Officer to work with the Research Officer, also to be appointed as soon as possible. The role of the Aboriginal or Torres Strait Islander Liaison Officer will be to identify a Queensland wide reference group, to develop mechanisms for consulting with them, to identify issues for their discussion, and to establish an ongoing process for consultation over the next three years.

### 1.3.1 *Torres Strait Islander Reference Group (27th June 1995)*

A meeting has been held with the chairperson of the Ethnic Health Advisory Committee to the Queensland Minister of Health; she is also the former president of the Filipino Community Coordination Council. This meeting has identified the major Filipino community groups within Queensland, and the geographic location of their membership. Background data on the Filipino community women has been received from the Council and the process of establishing a reference group is now underway, in conjunction with the current President of the Filipino Community Coordination Council.

## 1.4 Recruitment procedures

The original submission proposed the use of targeted snowball sampling for the Special Cohorts Study, starting with the membership of existing community-based groups. This process was criticised by some (but not all) reviewers who felt that generalisability was threatened. While generalisability is not such a major issue in longitudinal studies (since one is concerned with changes within individuals over time), efforts will now be made to develop a sampling strategy which is population-based. The method outlined below is based on discussions with Mr Tony Barnes (a statistician within the Aboriginal health section of the Australian Bureau of Statistics and Dr Martin Bell (a consultant statistician with particular expertise in sampling issues in relation to Census data).

As the first step in devising an appropriate sampling frame, 1991 census data is currently being examined to identify those Statistical Local Areas (SLA) which contain high numbers of women in the ethnic groups and age groups of interest. Within selected SLAs, Census Collection Districts (CCD) will similarly be identified. A population-based sampling frame can then be constructed by selecting whole CCDs randomly. This procedure may be modified with consultation with the reference groups for the participating populations. For instance, it may be necessary to choose clusters of CCDs to correspond to Aboriginal and Torres Strait Islander communities. Permission will be sought from the appropriate Aboriginal and Torres Strait Islander leaders to carry out the study in their community. The aim of the sampling procedure will be to produce a sample of women in a manner which is feasible and acceptable, but which compromises generalisability as little as possible.

Within selected communities, after appropriate consolation with them and having obtained permission at the community level, participants will be recruited by household survey which will use CCD maps, as published by the Australian Bureau of Statistics. The household survey will aim to obtain full enumeration of all eligible women within selected CCDs. The scope and purpose of the survey will be explained to potential participants and informed consent will be sought from them to become involved in the study.

## 1.5 Summary of work in progress

1. Identification and specification of sampling frame.
2. Preliminary consultation with community groups and other representatives.
3. Collection, cataloguing and review of relevant resource material, with two background papers currently in preparation to review relevant issues in each of the Aboriginal and Torres Strait Islander and Filipina populations.

## 2. A PROGRESS REPORT ON ETHICS APPROVALS OF THE SPECIAL COHORTS

Final approval for the study will be sought from the University of Queensland and will follow procedures set out by NHMRC, including those which apply to studies involving Aboriginal and Torres Strait Islander populations. Approvals can not be applied for until a more detailed protocol has been developed. In particular, the NHMRC guidelines make clear that researchers must, in preparing a submission for Aboriginal and Torres Strait Islander health research, have had appropriate consultation with and sought permission from Aboriginal and Torres Strait Islander communities. This process is foreshadowed in section 1 of this report "STUDY PLANS FOR THE SPECIAL COHORTS", and is expected to be completed by the end of 1995.

Ethical approval must also be obtained, as an Australian Centre for International and Tropical Health and Nutrition requirement for all Aboriginal and Torres Strait Islander health research, from the Board of Studies of the Indigenous Primary Health Care Unit. This will proceed in parallel with the process at institutional level.

## 3. APPOINTMENT OF PROJECT STAFF, DEVELOPMENT OF MANAGEMENT STRUCTURES, AND ESTABLISHMENT OF FACILITIES FOR THE CONDUCT OF THE STUDY

### 3.1 Appointment of project staff

A part-time secretary has been made available for secretarial support to the research team and to minute meetings.

A joint advertisement for the following positions is being drafted and will be placed as soon as the institutional process allows after the sub-contracts is signed. The University of Queensland requires an authoritative statement of the existence and availability of funds before approval to advertise is given.

The positions to be advertised will be:

- Full-time Research Officer to manage the project;
- An Aboriginal and Torres Strait Islander Liaison Officer;
- Part-time Research Assistant for statistical technical assistance;
- PhD Scholarship.

## 3.2 Development of management structures

A Steering Committee has been set up and has met twice. Its membership will include all investigators, with relevant additional members to represent the participating populations and the required areas of expertise. The Steering Committee is to meet al least monthly and will be minuted. Its terms of reference will be to provide overall supervision of the research, to ensure consultation with study populations, to provide an overview of dissemination of study findings, to facilitate collaboration with the University of Newcastle, to monitor the budget, and to ensure that the Special Cohorts Study submits deliverables as required under the contracts in a timely fashion.

A Working Group has been established and has met twice. Its membership will include the two Principal Investigators, project staff, and associates involved in active research components. Members of the reference groups will be invited from time to time as appropriate. It will meet weekly and will be minuted. The terms of reference of the Working Group will be to monitor work in progress and to report to the Steering Committee.

Mechanisms for collaboration with the University of Newcastle have been developed. These include regular teleconferences, e-mail exchange of minutes of meetings, face-face interviews to be held 2-3 times per year via ACITHN and PHA conference meetings and special meetings. The first of the latter is planned for June 27, 1995 in Newcastle.

A cost centre has been established at the University of Queensland for receiving and accounting for income.

## 3.3 Establishment of facilities for the conduct of the study

Office space has been allocated within the Indigenous Primary Health Care Unit located within the Edith Cavell Building on the site of the Royal Brisbane Hospital until the end of 1995 when the project will be re-located to the extended Public Health Building on the Herston campus of the University of Queensland. At both sites staff have Internet access for communication and data exchange with the University of Newcastle.

Decisions regarding the purchase of necessary computing equipment have been made. Orders will proceed when funds are available.

# APPENDIX 1

***Identification numbered consent form***

**ID NUMBER**

**CONSENT TO PARTICIPATE IN (STUDY NAME)**

I ..... have read and understood the information sheet which explains (Study name). I understand that participating in the study will involve filling in a number of survey forms. The study team may contact people nominated by me if I change my address during the study.

I also understand that participation in the study is voluntary and that I can withdraw from the study at any time.

Signed ..... Date .....

**CONSENT TO ACCESS TO MEDICARE RECORDS**

I have read and understood the information sheet which explains the request for access to my Medicare data. Before signing this document, I have been given the opportunity to ask any questions about the study and the use of Medicare records. I understand that I can withdraw my consent at any time. I agree that the results of the study may be published provided my name is not used and that I cannot be identified in any way.

I ....., agree to authorise the release of information to the Institute of Women's Health Studies at The University of Newcastle concerning services for which Medicare has been paid.

Signed ..... Date .....

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If you have any complaints about this study, and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Ethics Officer, Ms Sue O'Connor on 049 216 333.

***If you speak english but are unable to or do not wish to complete a written survey***

| | Yes | No |
|---|---|---|
| **Would you be willing to answer questions over the telephone? It would take 20-30 minute** | **1** | **2** |

**What are the best times to contact you? .....**

***If you do not speak english***

| | Yes | No |
|---|---|---|
| **Would you be willing to take part in the study with any of the following help?** | | |
| **A written questionnaire in your main language** | **1** | **2** |
| **A telephone interview in your main language** | **1** | **2** |

**What is your main language?**

| | |
|---|---|
| **Italian** | **1** |
| **Greek** | **2** |
| **Chinese languages** | **3** |
| **Arabic including Lebanese** | **4** |
| **German** | **5** |
| **Vietnamese** | **6** |
| **Spanish** | **7** |
| **Croatian** | **8** |
| **Other (*please specify)*** _____ | **9** |

**What are the best times to contact you?**
**.....**

**What is your current HOME phone number? .....**

**What is your current WORK phone number (if you have one)? .....**

**If your name or address printed on the front of this form are not correct, please write your current name or address here?**

**NAME:**
**.....**

**Address:**
**.....**

**.....**

## HELP US TO KEEP IN TOUCH WITH YOU

**Many people will move house several times over the next few years. In order to help us keep in touch with you, would you please:**

**Let us know if you change address or phone number over the next 2 years by completing the yellow reply-paid card.**

**Write down the name, address and phone number of two (2) people close to you that you are certain you will stay in touch with for many years to come. These could be a parent, or relative who is unlikely to move from their present address and who is likely to know where you are if you move. Please write down two (2) people who live at different addresses. This will help us to keep in touch with you if you move over the next few years.**

**First Contact Person**

**NAME:** .....

**Address:** .....

.....

.....

**Phone number (home)** .....

**Phone Number (work)** .....

**Second Contact Person**

**NAME:** .....

**Address:** .....

.....

.....

**Phone number (home)** .....

**Phone Number (work)** .....

**Please give the enclosed green cards to these two (2) people to let them know that you have**

**given their name and phone number so we can keep in touch if you move. You should check that they are happy to do this.**

# APPENDIX 2

***Draft questionnaire***