

**AUSTRALIAN
LONGITUDINAL STUDY OF
WOMEN'S HEALTH**

*Report 1 for the Commonwealth
Department of Human Services and Health*

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

June, 1995

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On 10th April 1995 Dr Carmen Lawrence, the Federal Minister for Health, announced that the University of Newcastle in collaboration with the University of Queensland was to be awarded the contract to conduct the Australian Longitudinal Study of Women's Health.

The contract between the Commonwealth Department of Human Services and Health and the University of Newcastle was signed on 13th June 1995, and the contract between the University of Newcastle and the University of Queensland was signed on 27th June 1995.

The contract with the Commonwealth requires that the University of Newcastle provides one report (Report 1) within 14 days of signing the contract, another (Report 2) by the end of June 1995 and subsequent reports every 6 months with the final one due in June 1998.

The content of Report 1 is to include:

- a) Costings for the establishment of
 - administrative procedures, office space and equipment for the conduct of the study;
 - project staff to undertake the study.
- b) A report on the ethical and privacy issues concerning the recruitment of the study sample.
- c) A report outlining the reasons for choosing special cohorts of particular groups of Aboriginal and Torres Strait Islander women and women of non-English speaking backgrounds.

This report is presented in two parts, from the University of Newcastle (part A) and the University of Queensland (part B), together with Appendices containing material related to the staffing and the recruitment of participants.

REPORT 1

UNIVERSITY OF NEWCASTLE AND QUEENSLAND

JUNE 1995

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PART A: UNIVERSITY OF NEWCASTLE

1. ADMINISTRATIVE PROCEDURES

The University has set up administrative and accounting procedures for the Australian Longitudinal Study of Women's Health (ALSWH) under the auspices of the Office for Research - pending the establishment of the Centre or Institute for Women's Health Research.

The research team has been meeting at least weekly and electronic mail is being used to circulate minutes as well as draft materials that are being developed for the pilot study. The research teams at Newcastle and Queensland are in regular contact by telephone and are exchanging minutes of meetings. On June 27 an all day face to face meeting of representatives from both teams was held in Newcastle.

2. OFFICE SPACE

The University of Newcastle has allocated two offices and a large open area (currently a computer laboratory) to ALSWH. They are located in the Mathematics Building close to the offices of Professors Dobson and Bryson. They are in good condition, have air conditioning and all except one of the small rooms are carpeted. The areas are as follows

Room	Area
Room V202	83.8 square metres
Room V203	7.8 square metres
Room V203A	7.8 square metres
Total Area	99.4 square metres

Arrangements have been made for removal of existing furniture and equipment from V202 (the other rooms are already empty), installation of telephone and computer lines, and for borrowing furniture. At this stage costs are not available but are unlikely to exceed a few thousand dollars.

3. EQUIPMENT

No equipment or furnishings have yet been ordered. Our plans are to purchase immediately 6 relatively powerful PCs and a laser printer. These will be linked to one of the University's Novell networks to facilitate access to software and communications. Later a powerful workstation will be purchased for maintenance of the data base and statistical analysis. (The choice of this machine will take account of the special security and confidentiality requirements of ALSWH).

4. PROJECT STAFF

The University advertised the following positions: Project Manager, Data Manager, Secretary, Research Assistants (advertisements and other material are in Appendix 1).

The table below summarises the outcomes to date

Position	Number of applicants	Number interviewed	Appointment
Project Manager	7	3	Interview completed
Data Manager	11	4	Offer accepted
Secretary	55	6	Offer accepted
Research Assistants	61	8	4 positions offered, 3 accepted so far

The selection procedures were conducted with due regard to EEO principles.

The people who have accepted positions already (in alphabetical order) are as follows:

Adamson, Lyn - Appointed part-time research assistant for 6 months. Years of experience in questionnaire development, interviewing and project management with the Hunter Centre for Health Advancement in the Faculty of Medicine and Health Sciences at the University of Newcastle.

Arnold, Beverly - background in nursing, BA (Sociology) and currently undertaking the research component of M.Med Sci (Health Promotion). Appointed part-time research assistant for 6 months. Years of experience as a research assistant in the Hunter Centre for Health Advancement.

Ball, Jean - B.Math, Dip Med Stat. Appointed full-time data manager for 3¹/₂ years. 5 years experience in computing, data base management and statistics in the Hunter Health Statistics Unit. Extensive experience with large data sets (eg hospital separations and mortality).

Bissett, Phoebe - BA (Psychology) - Appointed full-time secretary for 3¹/₂ years. Secretarial and administrative experience at the University of Sydney.

Ellem, Joy - BA Hons (Psychology). Appointed full-time research assistant for 6 months. Recent graduate with particular interest in research in women's health.

Also Anne Harvey has been providing secretarial support for 2 days per week.

In addition offers have been made for the following positions

Project Manager - research academic position full-time for 3¹/₂ years.

Research Assistant - full-time for 6 months.

The estimated salary costs for the remainder of 1995 are \$101,690 which includes on-costs and, where applicable, superannuation.

The annual salary costs (with on-costs and superannuation) for the Project Manager, Data Manager and Secretary (at 1995 rates) will be \$156,156.

5. PLANS FOR THE PILOT STUDY

Arrangements are underway to conduct a pilot study during the second half of 1995.

It is planned to pilot all aspects of the baseline survey including the media campaign to enhance recruitment, sample selection, contact with participants, logging responses, follow-up procedures, content and format of questionnaires, quality assurance methods and data summary.

The pilot study will have the following characteristics:

- a) Conducted in the Illawarra and Central West Statistical Divisions of NSW (covering both urban and rural areas and using local media to encourage high participation rates).
- b) 1000 women in each of the 3 age cohorts - 18-22, 45-49 and 70-74 years - will be selected (so that the actual numbers of subjects will be fewer than this).
- c) The sampling probability for women in remote areas will be higher than the probability for urban women.
- d) Women will be randomly selected from the records of the Health Insurance Commission (HIC) using a sampling procedure specified by the research team.
- e) HIC will post the initial survey items to all selected women. The mailing will include information about the study and women will be requested to provide signed consent for follow-up and data linkage.
- f) Women will be offered the option of a telephone interview in their chosen language and a toll free phone number with 24-hour answering service will also be provided.
- g) There will be two follow-up mailings to non-respondents.

During the pilot study various alternative recruitments strategies will be tested. Full details of the pilot study will be provided in Report 2.

Quotations of conducting various aspects of the survey have been obtained from: AGB McNair, Reark Research, and Roy Morgan Research Centre. We are also investigating the possibilities for data entry by scanning survey forms using equipment at the University of Newcastle and conducting the computer-assisted telephone interviews through a local company, the Hunter Valley Research Foundation. Further discussions with all these groups (and others) will be needed as details of the pilot study are finalised.

6. NEGOTIATIONS WITH THE HEALTH INSURANCE COMMISSION

HIC will be involved in three main ways:

- a) Selection and recruitment of the study sample.
- b) Provision of unit record data on consenting women (for record linkage).
- c) Provision of anonymous aggregate data on non- participants.
- d) Update of participant data base for subsequent surveys.

HIC will work with the study team to pilot the procedures for sample selection recruitment.

These roles have been negotiated with HIC and their commitment to the project is assured (see Appendix 2).

Costing for HIC involvement is being prepared.

For the main survey, HIC will select random samples of women. The sample will be sufficient to recruit 20,000 participants in each age group. The number of women to be sampled will depend on the expected response rate (determined from the pilot study).

The sample will be stratified according to the system for classification of Rural, Remote, and Metropolitan Areas developed by the Department of Primary Industries and Energy, and used by the Department of Human Services and Health. The sampling rate will be higher in rural and remote areas.

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

- a) a letter from the Commonwealth HIC explaining their involvement.
- b) letter from the study team (signed by the Director).
- c) a pamphlet containing information about the study.
- d) an identification numbered consent form and identification numbered questionnaire to be completed and returned to the study team.
- e) a reply paid envelope.

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).

For women who consent to record linkage, HIC will provide unit record data with the participant's study identification number on all claims for two years prior to the baseline survey, and for two years prior to the second survey.

Anonymous group data will be provided for women in the sample who do not consent to participate in the study. These data will include: age, postcode of residence, claims for two years prior to the baseline survey (number of consultations, procedures, pathology services), and claims for two years prior to the second survey.

For women who consent to participation in the survey, but not to record linkage, anonymous group data will be provided on claims for two years prior to the baseline survey (number of consultations, procedures, pathology services), and claims for two years prior to the second survey.

Letters relating to the role of the HIC and draft information materials to be sent to the women selected for the study are in Appendix 3.

7. ETHICAL AND PRIVACY ISSUES CONCERNING RECRUITMENT OF THE STUDY SAMPLE

The recruitment of study participants and the collection, collation, storage and analysis of data will be conducted in accordance with the Information Privacy Principles (Privacy Act, 1988), NHMRC Guidelines for Protection of Privacy in the Conduct of Medical Research (NHMRC 1991), Section 135 A of the National Health Act (1953), Section 130 of the Health Insurance Commission Act (1973) and International Ethical Guidelines for Biomedical Research Involving Human Subjects (CIOMS, 1993). The study will also be reviewed by the University of Newcastle Human Research Ethics Committee and will not proceed without the written approval of the committee.

The ethical issues to be considered at each phase of the study are discussed below.

7.1 Recruitment of study participants

A stratified random sample of women in each age group will be obtained from HIC lists. There is an ethical imperative to protect the privacy of those individuals who appear on the HIC lists, by not disclosing their names or addresses to the researchers without their prior permission. To adhere to this principle, HIC will send letters drafted by the study team (examples attached) to all women in the sample, informing them of the study and seeking their participation. Consenting women will send an identification numbered reply to the research team. In this way, the research team will only have access to the names and addresses of women who have provided their explicit, written and informed consent to be included in the study; non-participants will remain anonymous to the researchers.

7.2 Solicitation of personal information

Women will be asked to provide written informed consent to receive the questionnaire and to record linkage (see below). To help women make an informed decision regarding their participation, the following information will be provided:

- a) Women are invited to join the Australian Longitudinal Study of Women's Health.
- b) The purposes of the study are to:
 - Identify those factors that assist and those that reduce good health in women;
 - Clarify the interaction between women and the health system, in particular the experiences of women in obtaining health care and their attempts to have their continuing needs met by the health system.

The study will be a guide and basis for determining future policy in the area of women's health services.

- c) That the women were randomly selected from the HIC (Medicare) lists; that the sample is designed to provide a cross-section of Australian women in three age groups; and there is no particular reason why any individual woman was selected.
- d) Information from all women in the sample is valuable in identifying the needs, experiences and outcomes for all Australian women.
- e) Participation is voluntary, and failure to participate will in no way affect Medicare benefits or any aspects of medical care.
- f) Participation will involve receiving an initial postal questionnaire that can be completed in private. Questions will cover: physical health, life events over the previous twelve months, contact with the health system, social circumstances, exercise and eating habits, emotional health. The initial questionnaire will take approximately one hour to complete.
- g) That further questionnaires will be sent throughout the study period. Completion and return of each questionnaire are voluntary.
- h) Participants are free to withdraw from the study any time.
- i) All information provided by the women will be confidential, accessible only to members of the study team, and no individual data will be reported to the government or other agencies. Data will only be reported in anonymous, aggregated form.
- j) Individually identified information will be destroyed at the end of the study period.

- k) A telephone information line is provided for women who wish to contact the study team with any questions.
- l) A telephone number and contact for the University of Newcastle Ethics Committee will be provided for women who wish to discuss any concerns about the questionnaire.
- m) A telephone interview is available for women who have difficulties completing the questionnaire.
- n) During the study, women will be informed of the study progress and results:
 - in a regular newsletter;
 - through national print and electronic media.

To ensure true informed consent, the information letter and all other survey materials will be pre-piloted with small samples of women to assess comprehension and acceptability.

7.3 Participant tracing

- a) The initial questionnaire will include consent to re-contact the women in two years.
- b) To maintain the cohort over time, women will be asked to provide the names and addresses of people who could be contacted in the event that they themselves change address and lose contact with the study team.
- c) HIC records will also be used for tracing women who have changed their address. Separate consent for the use of the records in this way will be obtained.
- d) Other cohort maintenance procedures of, tracing through electoral rolls, electronic phone directories, the National Death Index, post office, local councils and so on, will also be applied.

7.4 Use of routinely collected data

7.4.1 *Principles underlying the use of routinely collected data*

It is legally and ethically possible to access HIC records where individuals give free and informed consent to release that record to a researcher (McCallum et al., 1993). Provision for disclosure of individual records for the purposes of research has been allowed within Section 95 of the Privacy Act (1988). Consequently, a Commonwealth agency may disclose identifiable records for medical research purposes without infringing the Privacy Act (NHMRC, 1991). This waiver is also in accordance with the International Ethical Guidelines for Biomedical Research Involving Human Subjects (CIOMS, 1993) which states:

"Epidemiological studies that require the examination of documents, such as medical records...may be conducted without the consent of the individuals concerned, as long as their right to confidentiality is assured by the study methods."

The Guidelines for Protection of Privacy in the Conduct of Medical Research require that the research be considered by an Institutional Ethics Committee (IEC), to decide whether public interest in the research outweighs the public interest in the protection of privacy.

Further, Section 135A of the National Health Act provides for the disclosure of information held by HIC were the patient consents in writing to the disclosure of the information (Paragraph 8ai).

7.4.2 Procedure for obtaining access to data routinely collected by HIC

In accordance with the provisions of the Privacy Act (1988) and NHMRC Guidelines (NHMRC 1991), access to data which are routinely collected by HIC will depend on the approval of the University of Newcastle Ethics Committee, the Health Insurance Commission, and the Privacy Commissioner. Under the NHMRC Guidelines, approval of the research requires that the public interest in conducting the research outweighs to a "substantial degree" the public interest in privacy. The duties of confidentiality and informed consent must also be applied.

7.4.3 Obtaining informed consent to record linkage

Women selected for inclusion in the study will be asked to provide separate and explicit consent to HIC record linkage. Previous research (McCallum et al 1993) demonstrates that several processes are fundamental to gaining consent to record linkage:

- demonstration of potential public benefit;
- assurance of confidentiality;
- use of the records for research rather than administrative purposes;
- use of the records for high profile research performed by Universities;

HIC also requires that individuals are informed:

- which records will be accessed and the information they contain;
- for which years;
- the use to be made of the records (unidentified records in aggregate analyses for scientific publication only);
- the intent to publish anonymous, aggregate information.

7.4.4 Provision of information on HIC records

Each woman in the HIC sample will be given a unique study identification number. This study number will be used for record linkage, avoiding the need for Medicare numbers to be revealed to the researchers.

HIC data from consenting women will be provided to the study team as individual records,

identified by the study identification number.

Aggregate data for the group of women who do not consent to individual participation in the study will also be provided to the researchers. At baseline, these data allow comparison between consenting and non-consenting women to assess the representativeness of the study sample in terms of their use of health services charged to HIC. In the longer term, the data will allow services provided to participating and non-participating women and those lost to follow-up to be monitored and compared.

7.5 Participant care

It is acknowledged that certain items in the questionnaire may raise distressing issues for some women and that these women may require counselling or other support. While it is not the intent of this study to provide counselling or other intervention for women, the survey materials sent to participants will include a directory of existing community information and support services for those women who require help.

7.6 Renewal of consent

Consent to participate in the study will not be in perpetuity. Consent to the survey and to record linkage will be renegotiated for each main survey (ie at baseline, at 2 years, and so on).

8. COMMUNICATION STRATEGIES

Discussions have taken place with Kate Tully of CommuniKate and a quotation has been obtained for itemised work for the first 6 months of the study. This includes development of study materials and media contacts.

Selecting a 'catchy' name and designing an appropriate logo is vital for the image of the project - to promote recognition of the study, recruitment and retention of participants. Because of the importance of this component an advertising agency, Peach Productions, is

being contracted to develop these in consultation with the project team.

9. REFERENCES

Commonwealth of Australia. Privacy Act (1988). Section 95 Medical Research Guidelines.

Council for International Organisations of Medical Sciences (CIOMS). *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, ISBN 92 90360569. Geneva, 1993.

Health Insurance Commission Act (1973). Canberra: Australian Government Publishing Service, 1994. Catalogue: 94 0357 4.

McCallum, J., Lonergan, J., Raymond, C. *The NCEPH Record Linkage Pilot Study: A preliminary examination of individual Health Insurance Commission records with linked data sets. Record Linkage Pilot Study. Working Paper 1.* ISSN 1321-2834 ISBN 07315 1889 2. Canberra: National Centre for Epidemiology and Population Health, 1993.

National Health Act (1953). Canberra: Australian Government Publishing Service, 1993. Catalogue: 93 6484 4.

National Health and Medical Research Council Guidelines for Protection of Privacy in the Conduct of Medical Research (1991).

PART B: UNIVERSITY OF QUEENSLAND

REASONS FOR CHOOSING SPECIAL COHORTS OF PARTICULAR GROUPS OF ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN AND WOMEN FROM NON-ENGLISH-SPEAKING BACKGROUNDS

1. INTRODUCTION

The document entitled "Tender for the Australian longitudinal study on women's health prepared by the University of Newcastle in collaboration with the University of Queensland", dated December 1994, proposed that the University of Newcastle carry out a 20-30 year cohort study of 60,000 Australian women, in age-groups 18-22 years, 45-49 years, and 70-74 years. In parallel with this study, the University of Queensland would carry out a cohort study of 2,400 women within the 18-22 years and 45-49 years age groups. Within this study, 8 separate cohorts (termed "Special Cohorts"), each of size 300 would be selected from Aboriginal and Torres Strait Islander women and from women from non-English-speaking backgrounds. As in the main study, the Special Cohorts Study would address the five themes of time use, weight, exercise and health, violence against women, life stage and key events, and use of satisfaction with health services. However it was acknowledged that there may be differences between the two cohort studies in the specific issues examined and the methods used to deal with them. The Special Cohorts Study was seen as a stand-alone study in its own right , but which nevertheless afforded unique opportunities to compare findings with the main cohort study.

2. COHORTS TO BE SELECTED

It is herein proposed that the following groups (each of size 300) comprise the Special Cohort Study.

Aboriginal and Torres Strait Islander Urban		18-22 years age group
Aboriginal and Torres Strait Islander Urban		45-49 years age group
Aboriginal and Torres Strait Islander Urban		60-69 years age group
Aboriginal and Torres Strait Islander Non-urban		18-22 years age group
Aboriginal and Torres Strait Islander Non-urban		45-49 years age group
Aboriginal and Torres Strait Islander Non-urban		60-69 years age group
Filipina	QLD	18-22 years age group
Filipina	QLD	45-49 years age group

2.1 Justification for selection of these cohorts

2.1.1 *Aboriginal and Torres Strait Islanders*

While the life expectancy of Aboriginal women has improved slightly in the last 20 years, the main component of this gain has been improved infant mortality; life expectancy beyond childhood remains unchanged and Aboriginal women experience mortality rates 3-4 times those of their non-Aboriginal Australian counterparts. Racism and disenfranchisement have led to poverty, poor literacy, low self respect, mobility, and consequent extremely poor health conditions. While there have been improvements related to morbidity and mortality due to infectious diseases, non-communicable diseases, such as cardiovascular disease and diabetes, are becoming increasingly important. Domestic violence has been highlighted as a particular problem for Aboriginal and Torres Strait Islander women, with links to unemployment, alcohol, low self-esteem and the lack of ability to escape a violent environment. Many culturally-specific issues are likely to influence the decision among Aboriginal and Torres Strait Islander women to seek medical treatment and the choice of provider or service. These include the provider's gender, language patterns, and family connections, fears related to particular health beliefs and paradigms, financial factors, and expectations of and confidence

in treatment provided by health services.

As stated in the original proposal, a suitably-sized cohort of 70-74 year-old Aboriginal and Torres Strait Islander women could not be obtained. The life expectancy at birth of Aboriginal and Torres Strait Islander women is 65 years compared to 80 years for all Australian women (ATSIC, 1994), and the 70-74 year age group number not much more than 100 in Queensland communities, based on 1984-1990 figures (Hogg and Thomson, 1992). However, it is now proposed to add a cohort of 60-69 year-old Aboriginal and Torres Strait Islander women. This is partly in acknowledgment of ageing as a significant health issue particularly in developing countries as life expectancy increases, and partly due to the need to consider the role of elders in Aboriginal and Torres Strait Islander communities,. It has been argued that concern is with ageing rather than with a particular age (WHO, 1995) and cut-off points for age should be have biological, social and cultural meaning within a particular society (Bonita, 1995) . In addition such a cohort will provide a baseline for evaluating changes in health status of the elderly over the course of the study as the 45-49 year cohort ages into the 60-69 age group. Additionally, it is believed that this inclusion will also increase the acceptability of the study to the Aboriginal community.

2.1.2 *Filipina*

Filipinas comprise the second-largest South-East Asian group in Australia (after Vietnamese women). The younger age-group will include both first and second generation Filipinas. Specific foci of the research involving these groups will relate to marriage arrangements, migration, developing relationships in a new country, experience of discrimination and prejudice, and economic and social change. It has also been noted that Filipino women who marry Australian men, particularly through agencies, experience special problems with violence. Their vulnerability is compounded by lack of awareness of welfare agencies, isolation from their own community and general lack of social supports. Many women of non-English-speaking backgrounds are unaware of health services in general and have additional access problems related to language problems and prejudices. This has resulted in lower use of health screening programs as well as curative services.

The document referred to above had proposed the selection of cohorts of women from the former Yugoslav Republics. Due to budgetary constraints, the inclusion of an additional cohort of ATSI women necessitates the restriction of the study of women from non-English speaking backgrounds to one migrant group.

3. REFERENCES

ATSIC. *Indigenous Australia Today - A statistical focus by ATSIC regions*. Canberra: Commonwealth of Australia (1994).

Bonita, R. *Women, aging and health - a draft issues and policy paper prepared for the WHO Global Commission on Women's Health* (1995).

Hogg, R., & Thomson, N. *Fertility and mortality of Aborigines living in Queensland Aboriginal communities 1972-1990*. AIHW ATSI Health Series, No 8 AGPS, Canberra, (1992).

World Health Organization. *Women's experiences of aging in the Western Pacific Region: a diversity of challenges and opportunities*. Women's Health Series, volume 2. WHO Regional Office for the Western Pacific, Manila, (1995).

APPENDIX 1

Advertisements and position descriptions

APPENDIX 2

Correspondence from the Health Insurance Commission

APPENDIX 3

Letters and draft information materials to be sent to the women

Letter from HIC/Department

date

Name

Address

Salutation,

You are invited to become part of a very important project for Australian Women. This project will provide key information for planning and delivering services for women.

The study is being conducted by the University of Newcastle. The University will process your survey forms and provide anonymous summary results to the Department. These results will be used by the Government to plan better health services for women. No personal information about you will be given to the Government or to anyone else. The University will treat your reply as strictly confidential.

Your name has been randomly selected from all women Medicare card holders in your age group. We have not released your name to the University, but hope you will become part of this vital initiative by returning the enclosed forms to the researchers at the University of Newcastle.

Yours sincerely,

Marion Powall
Commonwealth Department
of Human Services and Health

Jackie Wood
Health Insurance Commission

Information letter sent to respondents

date

addressee

.....

.....

.....

Salutation,

(Project name) is a very important project for Australian women. The project is designed to make sure that women's life-long experiences of health, sickness and health care are understood, so that the government can plan health services which meet women's needs.

You have been selected at random from all women who have Medicare cards in your age group, to be a part of this project. Your experiences and views are extremely important in the planning of health services for women, and we hope you will be willing to share them with us.

Being a part of the project will involve filling in a number of survey forms (like the one attached) over the next 20 years. These surveys will help us to see how women's health changes over the years. Some women may also be asked to complete other surveys about particular issues. We will keep you up to date with the findings and developments of the study through a regular newsletter

I hope you will become a part of this important project for all Australian women.

Yours sincerely,

Prof. Annette J Dobson

Director

Australian Longitudinal Study of Women's Health

Why is the (study name) so important?

(Study name) is important because governments make decisions about health services using information they receive from the community. Often studies involve men only and the results are assumed to be true for women as well. This is not good enough. To make sure that health services meet **women's** needs, we must learn about **women's** health problems and **women's** views about health services.

Why does the study need to run for twenty years?

The study will explore the changes in women's lives, the choices they make and the effects on their long term health and well being. The study will also find out which services are of greatest benefit to women and which could be improved.

How was my name selected and why are my views important?

All women's views are important. However, we cannot ask all Australian women to be part of this study. Your name was selected at random from a list of all women in your age group who are Medicare Card Holders.

What does being part of the study mean for me?

You will be asked to:

- Sign the attached consent form.
- Fill in the enclosed survey form.
- Fill in further survey forms in ____, ____, and ____ months time.
Fill in further survey forms in 2 years, then every 3 to 5 years for twenty years.
- Allow access to routinely collected information about services paid by Medicare, (eg. the number of visits you make to a general practitioner).

In return you will have an opportunity to shape services for Australian women. You will also receive regular reports on the survey results so you can see how your contribution is working for better services.

What sort of questions will I be asked?

We will ask questions about all sorts of health issues. Some of these will include:

- Physical health - past and present health problems.
- Major events in the last 12 months which could affect health - for example, childbirth, moving house, illness, menopause, caring roles etc.
- Contact with hospitals, doctors and other health care - and whether you are happy with the service you received.
- Social health - how you balance your work at home, in the workforce, caring for children or the sick/elderly. We will also ask about

support from family and friends.

- Exercise and eating habits - plus your past, present and ideal weight.
- Emotional health - including your experiences of violence, depression, anxiety, stress and your general well being.

That's a lot of questions! How long will the survey take to complete?

It will probably take an hour altogether. But you can do it in 15 minute "bits" whenever you have the time.

What information will be available from Medicare?

If you agree, Medicare can provide us with information on the number of times you visited a doctor, or received health care which was paid for by Medicare. This will save you a lot of time answering questions about visits to doctors, tests and some operations. Medicare can only tell us that you went to see a doctor. We will not know which doctor or what the doctor said or did. Also, they will only tell us that you had a test or operation, not the result.

Will Medicare see my survey answers?

No. Medicare will not see any information about you, except that you are willing for us to see your Medicare record.

Will my Medicare benefits be affected?

No. Whether you take part in the study or not, you will still be entitled to the same benefits.

Will the information I give be kept confidential?

Absolutely. There will be no names on any of the survey forms - just a number which is known only to you and the research team. All the information we collect will be reported in an "anonymous" form. No-one else need even know you are a part of the project, unless you choose to tell them.

What if I want to fill in the survey form but I don't want to allow access to my Medicare record?

Your answers to the survey will still be valuable. However, we will ask you to fill in regular surveys about your use of health services. These surveys are important to solving women's health problems.

Who is conducting this project?

The Researchers are based at the University of Newcastle in NSW and the University of Queensland. The Institute of Women's Health Research at the University of Newcastle is the central base for the project and the researchers can be contacted there at any time. (Telephone: (049)).

I would like to be a part of the project, but cannot fill in the form?

[English]

You can choose to answer the questions by telephone, in English or in another language. Please indicate on the consent form that you would like to do this.

[Italian]

You can choose to answer the questions by telephone, in English or in another language. Please indicate on the consent form that you would like to do this.

[Spanish]

You can choose to answer the questions by telephone, in English or in another language. Please indicate on the consent form that you would like to do this.

[Vietnamese]

You can choose to answer the questions by telephone, in English or in another language. Please indicate on the consent form that you would like to do this.

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to track

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over a number of years.

