

References

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Appendix A

The University of New England

THE HUMAN RESEARCH ETHICS COMMITTEE

Non-Invasive Procedures FORM A

Proposed Research Project

1. Title of Project:
Aged and Disabled Needs Household Survey

2. Aims of Project:
This is part of a wider consultancy in aged care that I also intend using as part of both my academic position and for my Masters research degree. The study is looking at aged care needs, training and employment in NorthWest/New England. The particular aspect of the consultancy/study which is the subject of this application is a householders' survey to assess levels of aged/ disability, retirement planning intentions, service utilisation and attitudes about aged/disability service provision.

3. Person responsible
Name: Dr. Jeanne Madison
Position: Program Director, Health Management
Department: School of Health
UNE Extension: 3652/67655398

4. Associates (including Honours and Postgraduate students):
David Briggs
Master of Health Management (Honours) student
'Hakea' RMB 850A
Tamworth NSW 2340

5. Technicians associated with the experiment:
Nil

6. (a) Funding: Is this application the subject of a grant proposal?
NO
(b) If YES, *state* name of organisation:
(c) Has this protocol been funded?
YES
7. Proposed date of commencement:
January 2000
8. Duration and estimated finishing date:
March 2000
9. Approximate intended number of participants:
38,000
10. Source of participants:
LGAs of Tamworth, Parry, Nundle, Walcha, Manilla, Barraba, Gunnedah
and Quirindi
11. Briefly describe the research methods to be used (eg., interviews, focus
groups, etc.).
Interviews with Local Government and aged care providers and household
survey distributed with electricity rate notices by courtesy of NorthPower.
12. Please describe any risks or serious burdens which this research might pose
for your participants and how this will be rectified (e.g. intrusion upon
privacy, embarrassment, emotional upset).
Participation/completion voluntary with no identification of participants.
13. (a) Does this research involve subject matter of a particularly sensitive
nature? (e.g issues deemed particularly sensitive by the cultural
community of which the participants are members; participants'
knowledge of, or participation in, illegal issues; etc.)
NO
(b) If YES, provide details.
14. (a) Does this work involve considerable interaction with Indigenous
Australians?
NO

- (b) If Yes:
 - (i) What steps have been taken to ensure that community support has been obtained? (Note: Proof must be attached to the application.)
 - (ii) How will community members will be involved in oversight of the project?
 - (iii) What training is associated with this research project for the Indigenous participants?

- 15 If the research involves interviews with participants, briefly explain what mechanisms will be in place to respond to foreseeable eventualities such as: a revelation of illegal activity by or involving the participant; disclosure of institutional mismanagement; a participant becoming distraught because of the subject matter of the interview, etc. (e.g. Are interviewers trained for this project? Will interviewers have names and contact numbers of appropriate referral services? Is it appropriate for some arrangements to be made to respond to disclosure of harm or illegal activity involving participants? What steps have been taken to ensure that community support has been obtained?)

No interviews involved with survey other than Local Government officials and aged care providers.

16. (a) Will your participants receive any financial reward or other compensation for their time and inconvenience?

NO

17. What steps will you take to obtain the agreement of your participants to take part in the research? Please attach a copy of the Plain Language Statement/Consent Form.

Household survey was accompanied by press release and community service television commercial.

- 18 (a) Does this research involve any impediments to obtaining the full understanding, free agreement of participants to take part in the project? (e.g. will some or all participants be young children or people of limited competence to consent?)

YES

- (b) If so, give details of how you will negotiate an agreement for the participation of these persons through a family member, carer, legal guardian or other person.

While the survey is about the aged and disabled it can be completed by any member of the household and the completion is entirely voluntary.

19. (a) Are potential participants in this research in dependent relationships which may limit their belief that they are free to refuse participation?
YES
- (b) If YES, give details of the steps you will take to preserve their right to refuse participation
As above, participation entirely voluntary and researcher not aware of dependent relationships.
20. (a) Does the project require the withholding of relevant information about the aims and conduct of the research?
NO
- (b) If YES, explain why.
21. (a) Does this research require that participants be deceived about a relevant aspect of the aims or nature of the research or their participation?
NO
- (b) If YES, explain why deception is required and how the interests of the participants will be protected, including what they will be told about the research and their participation.
22. (a) Will participants be informed that they are free at any time to discontinue participation?
NO
- (b) If YES, give details. If NO, explain why.
Only requires a once only decision to complete survey tool, with no personal identification.
23. Who will have access to the information you collect?
The completed survey tool will contain no personal identifiers. The information will only be presented in aggregated data form for publication.
24. Confidentiality of records:
(a) How will the confidentiality of records be maintained during the study?
There are no personal identifiers in the survey tool and the researcher will retain completed surveys.

- (b) Given that the *UNE Code of Conduct for Research* requires that research data records are preserved for at least five years after the study is completed, how will the confidentiality of the records be protected during the period of their preservation?

Retained by researcher

25. Ethical issues:

Please indicate which, if any, of the following ethical issues are involved

- (a) Will participants be photographed by camera or video?

NO

- (b) Will participants be tape recorded?

NO

- (c) Does the research involve any stimuli, tasks, investigations or procedures which may be experienced by the subjects as stressful, noxious, aversive or unpleasant?

NO

- (d) In this study are there any procedures known (or thought) to be beneficial or harmful to one group of participants (EXPERIMENTAL) being withheld from another group of participants (CONTROL)?

NO

- (e) Are any of the subjects minors? (i.e. under the age of 18 years)

NO

26. If your research involves children (i.e. under the age of 18 years), or persons with a mental or intellectual disability, what special steps have you taken to comply with the HREC Policy on Research Involving Children and Persons with a Mental or Intellectual Disability?

N/A

- (a) Accreditation from an appropriate organisation?

NO

If YES, please attach documentation

- (b) Police Clearance Check

NO

- (c) Other measures

NO

27. (a) Are there any other ethical issues raised by this research?
NO
28. (a) Is anything in the conduct of the research project likely to be subject to legal constraint?
NO
29. How will the results of your research be presented?
Thesis and consultancy report
30. Conformation to accepted guidelines for research involving humans. Please indicate whether the protocol conforms to either
(a) NH&MRC *Statement on Human Experimentation* and its Supplementary Notes, (1992) as appropriate, or
YES
31. If this protocol involves working with Indigenous Australians, which additional guidelines have been used?
N/A
32. Signatures of responsible investigator and associates:
I certify
- (i) that I have read the UNE HREC Guidelines and the Summary of the NH&MRC Statement on Human Experimentation and its Supplementary Notes (1992);
 - (ii) that the proposed experiment will conform to these guidelines; and
 - (iii) that I will notify the Committee of anything that might affect ethical acceptance of this protocol such as adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events.

Person responsible: J. Madison

Associates: D Briggs

Head of School: V. Minichiello

Date: January 2000

Additional Declaration by Head of School:

I have read this application and the accompanying Plain Language Statement(s)/Consent Form(s) and am satisfied that the applicant(s) have fulfilled the UNE Human Research Ethics Committee's requirements, specifically those imposed by the HREC Policy on Research Involving Children or Persons with a Mental or Intellectual Disability if relevant to this application

Head of School: V. Minichiello

Date: January 2000

Appendix B

The University of New England Human Research Ethics Committee

PLAIN LANGUAGE STATEMENT

1. Title of Project:

‘Aged and Disabled Needs Household Survey’

2. Aims of Project:

The aims of the project are to assess the views of both the older ‘fifty plus’ population of selected local government areas in the New England region about issues of ageing and aged care services in the context of current national and international research and public policy, and consult with aged care industry providers in this context with a view to developing new and appropriate models of care.

3. Person responsible:

Name: Dr. Jeanne Madison
Position: Program Director, Health Management
Department: School of Health
UNE Extension: 3667

4. Associate: David Briggs

Master of Health Management (Honours) student
Student Number: 099092612
‘Hakea’ RMB 850A
Tamworth NSW 2340
02 67 655398
dsbriggs@northnet.com.au

5. Methodology:

Phase One: Literature review
Phase Two: Development of draft household survey tool,
conduct of local government, aged care industry
focus surveys, validation of survey tool.

- Phase Three: Development of database. Conduct of household survey, data input and analysis utilising SPSS 10.1 statistical package.
- Phase Four: Comparison of results with the New South Wales Older People's Health Survey 1999.
- Phase Five: Reflective consideration of the literature and the analysed data. Testing of findings at aged care industry forums. Further literature review.
- Phase Six: Development of models of care concepts and research outcomes.
6. Your Involvement: Your participation in the project is sought by completion of the questionnaire if delivered to your home and its return to the address indicated. There are no identifying details to link you personally to the completed questionnaire.
- If you are an aged care industry or local government representative your participation in an interview designed to seek your views about the aged care industry will be sought. There will be no personal identification of participants in the research, but your input will be presented as summarised industry views. You will not be disadvantaged in any way by refusing to participate and/or subsequently withdrawing from the project, and the information supplied in relation to the project will be kept strictly confidential.

7. University Requirements:

It is a University requirement that before electing to participate in this study, the project has been explained and is understood by you and that an opportunity has been given for you to ask questions. Any additional questions concerning the project entitled 'Aged and Disabled Needs Household Survey', can be directed to Dr Jeanne Madison (Supervisor) of the UNE Department, School of Health on 02 67733667. In addition, should you have any complaints concerning the manner in which this research is conducted, please contact the University's Ethics Committee at the following address:

The Secretary
 Human Research Ethics Committee
 Research Services
 University of New England
 Armidale NSW 2351
 Telephone: 02 67732352; Facsimile: 02 67733543

Thank you for your co-operation in this important study

Appendix C

Plain Language Statement/Consent Form

My name is David Briggs. I am a part time lecturer at the School of Health, University of New England and a Health Management consultant. I am also currently enrolled in the degree of Master of Health Management (Hons). The research component of this degree is the subject of our proposed interview and deals with the delivery of aged care services in rural communities. The results of this research will also form part of a consultancy I am undertaking for the Area Consultative Committee who are looking to identify the future needs of aged care in the region.

I would like to invite you to participate in this research study and would be very grateful if you choose to do so.

If you agree to participate in the study I would like to ask you a series of questions that include information about aged care facilities services in your community, demand for those services, potential for various models of aged care delivery and about attitudes and retirement intentions.

The interview would last approximately 60 minutes and the results will be completely confidential. While I will need to take handwritten notes of the interview, the information you provide will not be identified in any subsequent summary or report.

If, during the interview, you wish to continue at another time or discontinue the interview completely you are free to do so even though you previously agreed to be interviewed.

Please note, that you are free to withdraw this consent at any time during the study for any reason. If this happens, any information which has already been collected from you will be destroyed if you so wish.

Any questions concerning this study on future aged care needs in rural communities can be directed to Dr Jeanne Madison, Senior Lecturer, School of Health, University of New England, Armidale, New South Wales, 2351, telephone (02) 67733667

Should you have complaints concerning the manner in which this research is conducted, please contact the Research Ethics Officer at the following address:

Research Services
University of New England
Armidale NSW 2351
Telephone 6773449 or Facsimile 6773543

Consent to Participate in the Research

‘Future Aged Care Needs in Rural Communities’

I have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

.....
Signature of participant or
authorised representative

.....
Date

.....
Signature of investigator

.....
Date

Appendix D

Aged Care & Disability Aged Care — Household Survey

Please take a few minutes to complete and return this survey — the information is vital for our community planning. This survey is being conducted on behalf of the New England North West Area Consultative Committee and is supported by Challenge Disability Services and your local government. The committee acknowledges the tremendous support from NorthPower in ensuring this document is broadly distributed and returned. These groups understand that aged care is an important service in our community and we would appreciate your assistance in this matter by having one person from the household complete this survey. **Note that some questions are directly related to a person with a disability.** When complete, please forward to Aged Care Survey, Reply Paid Permit No.15, PO Box 487, Tamworth, 2340 — no postage stamp is required. If you have any concerns, contact David Briggs on 6765 5398 or Bruce McLean on 6767 1033. **PERSONAL DETAILS ARE NOT REQUIRED.**

Thank you for helping us plan Aged Care needs for your community.

Peter Botfield, Chairman

1. Household details

Number of people in house _____

Please insert numbers in following age groups

	Male	Female
0-20	<input type="checkbox"/>	<input type="checkbox"/>
20-40	<input type="checkbox"/>	<input type="checkbox"/>
40-50	<input type="checkbox"/>	<input type="checkbox"/>
50-60	<input type="checkbox"/>	<input type="checkbox"/>
60-70	<input type="checkbox"/>	<input type="checkbox"/>
70-80	<input type="checkbox"/>	<input type="checkbox"/>
80 +	<input type="checkbox"/>	<input type="checkbox"/>

2. Your main source of income

- Self employed
- Employee (work for someone else)
- Pensioner
- Self funded retiree

If you receive a pension what type is it?

- Disability Support pension
- Aged pension
- Unemployment benefit
- Other (please specify) _____

3. Household income

- Under \$20,000
- \$20,000-\$50,000
- \$50,000 & above

4. Housing

- Own your own home
- Owner occupied
- Rented

5. Is there a member of your household who has a disability?

- Yes No
- | | Male | Female | Age |
|--------------|--------------------------|--------------------------|-------|
| Intellectual | <input type="checkbox"/> | <input type="checkbox"/> | _____ |
| Physical | <input type="checkbox"/> | <input type="checkbox"/> | _____ |
| Other | <input type="checkbox"/> | <input type="checkbox"/> | _____ |

Extent of disability

	Male	Female	Age
Mild	<input type="checkbox"/>	<input type="checkbox"/>	_____
Medium	<input type="checkbox"/>	<input type="checkbox"/>	_____
High	<input type="checkbox"/>	<input type="checkbox"/>	_____

6. Who provides care to the aged/disabled members of your household?

- Cares for him/herself
- Family
- Neighbour
- Friend
- Community health
- Home care
- Hospital
- Home & Community Care (HACC)
- Dept Community Services (DOCS)
- Challenge Disability Services
- Other (please specify) _____

7. Services used by aged/disabled members of household and frequency of use

	Daily	Weekly	Monthly
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meals on wheels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported Employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cleaning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home maint./Mowing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other services (please detail) _____			

8. Who do you pay for the above services?

- Free of charge
Private contractor/firm
Hospital/health service
Home care
Voluntary organisation

Other (please specify: _____)

9. On average how much in total would you spend on these services each week?

\$ _____

10. Planning for retirement

Have you retired?

Yes No

If not, how long before you intend to retire?

- 1-5 years
6-10 years
11-15 years
16-20 years

11. At what age do you plan to retire?

- Less than 55
55-60
60-65
65-70
70 +

12. Where do you plan to retire?

- Locally
Small rural community
Regional centre
Outside New England region

13. Do you intend to or have you retired into:

- Your own home
Rented premises
Unit/townhouse
Retirement complex

14. If you had a choice of the following in your town would you utilise them?

- Self-care units
Hostel
Nursing home
Own home with community services
Group home

Other (please specify) _____

15. If the services in question 14 were available locally would you:

- Become an investor
Invest to occupy
Purchase
Rent/lease
Contribute (please specify how):

16. Please tick those agencies who you think should provide aged care.

- Local hospital
Community health
State government
Commonwealth government
Local government
Private aged care provider
Not-for-profit provider
Churches
Organisations such as:
Challenge
Salvation Army
St Vincent de Paul
Red Cross
Other (please specify) _____

17. Of all these groups who do you think should be most responsible for aged care services and facilities in your community?

18. In which local government area do you live?

19. What is your postcode? _____

20. As part of your business or employment, do you provide services to the aged and disabled in your community?

Yes No

Nature of goods/services you provide:

Employed Self-employed

On average, please estimate the percentage of your income derived from providing goods/services to the aged/disabled.

Thank you for completing this survey!