

National Ethics Application Form

Version 1.1

PROPOSAL TITLE: Enabling inter-agency data sharing to support the spatial analysis of social vulnerability in a transforming region

FOR SUBMISSION TO: The University of Newcastle Human Research Ethics Committee (EC00144)

PROPOSAL STATUS: Complete

COMPLETION DATE: 20/10/2008

APPLICANT: Prof Pauline McGuirk

INSTITUTION: The University of Newcastle

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The University of Newcastle
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Business Hours	(02) 49215097
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PROPOSAL DESCRIPTION:

The purpose of the Project is to develop fine-scaled indicators of social vulnerability to assist NSW Government agencies to monitor emerging social conditions across the Hunter region and to appraise rapidly the differential needs of geographical districts and shifts through time in the key dimensions of social vulnerability. Working with a range of human services agencies in the Hunter Region brought together in the NSW state government's Regional Coordination Management Group (Hunter Region) and represented by the Dept of Premier and Cabinet (Hunter), the Project had devised a detailed memorandum of agreement (MoA) specifying the conditions under which selected agency data will be released to researchers at the Centre of Urban and Regional Studies (UoN) and the Urban Research Centre (UWS), aggregated such that it is permanently deidentified, and subsequently analysed. The project will then mesh standard socio-demographic data (e.g. Census and Socio-Economic Indicators For Areas), with participating

agency data and assembled non-agency data sets (eg produced data-sets on service locations) to develop information (composite indicators, sets of maps, images, graphs and charts) which will enhance collective planning and service prioritisation by the RCMG and other NSW government agencies. The project's framework will enable these indicators to be updated with relative ease and so enable time-series information to be developed to inform agency decision-making.

POINTS TO REMEMBER:

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- You can copy and paste text out of a PDF document in Adobe Acrobat by using the 'Tools> basic> text select' button.

1. TITLE AND SUMMARY OF PROJECT

1.1. Title

1.1.1 What is the formal title of this research proposal?

Enabling inter-agency data sharing to support the spatial analysis of social vulnerability in a transforming region

1.1.2 What is the short title / acronym of this research proposal (if applicable)?

Spatial Data Analysis Project (SDAP)

1.2. Description of the project in plain language

1.2.1 Give a concise and simple description (not more than 400 words), in plain language, of the aims of this project, the proposal research design and the methods to be used to achieve those aims.

The purpose of the Project is to develop fine-scaled indicators of social vulnerability to assist NSW Government agencies to monitor emerging social conditions across the Hunter region and to appraise rapidly the differential needs of geographical districts and shifts through time in the key dimensions of social vulnerability. Working with a range of human services agencies in the Hunter Region brought together in the NSW state government's Regional Coordination Management Group (Hunter Region) and represented by the Dept of Premier and Cabinet (Hunter), the Project had devised a detailed memorandum of agreement (MoA) specifying the conditions under which selected agency data will be released to researchers at the Centre of Urban and Regional Studies (UoN) and the Urban Research Centre (UWS), aggregated such that it is permanently deidentified, and subsequently analysed. The project will then mesh standard socio-demographic data (e.g. Census and Socio-Economic Indicators For Areas), with participating agency data and assembled non-agency data sets (eg produced data-sets on service locations) to develop information (composite indicators, sets of maps, images, graphs and charts) which will enhance collective planning and service prioritisation by the RCMG and other NSW government agencies. The project's framework will enable these indicators to be updated with relative ease and so enable time-series information to be developed to inform agency decision-making.

1.3. Type of Research

1.3.1 Tick as many of the following 'types of research' as apply to this project. Your answers will assist HRECs in considering your proposal. A tick in some of these boxes will generate additional questions relevant to your proposal (mainly because the National Statement requires additional ethical matters to be considered), which will appear in Section 4 of NEAF.

This project involves:

- Qualitative research
- Research on workplace practices or possibly impacting on workplace relationships
- Research conducted overseas involving participants [NS 1.21](#)
- Research involving deception of participants, concealment or covert observation [NS 17](#)
- Epidemiological research [NS 14](#)
- Administration of a drug for research but is not clinical research
- Clinical research (excluding those under the CTN/CTX schemes) [NS 12](#)
- Clinical trial under CTN/CTX scheme [NS 12](#)
- Research involving ionising radiation [NS 10](#)
- Research involving the use of embryos and/or gametes
- Genetic testing/research [NS 16](#)
- Research involving the collection and / or use of human samples [NS 15](#)
- Research involving assisted reproductive technologies (ART) [NS 11](#)
- None of the above

1.4. Research participants

1.4.1 The National Statement requires additional information to be provided to an HREC where research participants are certain or likely to include any of the categories of people listed in this question. HRECs need to know whether you intend to include or to exclude any of these categories. Answer this question by

- (a) selecting any of those categories that are targeted or likely to be included as participants in this research project,
- (b) selecting any other of these categories that will be excluded from participation, and
- (c) selecting any other of these categories who may be adversely affected by this research..

Where you select a category for inclusion, you will be required to answer additional questions later in the form.

1.4.1 Where any of the following participant populations may be involved, the National Statement requires additional information to be provided to the HREC. Tick as many of the following 'types of research participants' as apply to this project. If none apply please indicate this below. A tick in some of these boxes will require you to answer additional questions later in the form.

The participants who may be involved in this research are:

	a) Intended or targeted	b) Probable coincidental recruitment	c) Design specifically excludes	d) Research has potential to adversely affect this population
People whose primary language is other than English (LOTE) NS 2.26	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Children and/or young people (ie. < 18 years) NS 4	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
People with an intellectual or mental impairment NS 5	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
People highly dependent on medical care NS 6	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
People in existing dependent or unequal relationships with any member of the research team, the researcher(s), and/or the person undertaking the recruitment/consent process (eg. student/teacher; employee/employer; warden/prisoner; officer, enlisted soldier; patient/doctor) NS 7	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
People who belong to a collectivity NS 8	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Aboriginal and/or Torres Strait Islander peoples NS 9	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

1.5. Research techniques

1.5.1 The research techniques to be used in this project include (You must tick at least one. Tick as many as apply):

- Observation of non-identified people in public places
- Covert observation of identifiable people in non-public places
- Interviews - telephone
- Interviews - face to face
- Documentary/records analysis
- Focus groups
- Data linkage
- Physical activities / exercises / tests
- Taping - audio / video
- Biomedical / clinical interventions, tests, samples
- Use of complementary or alternative medicine, or a natural therapy
- Photos
- Use of gene therapy
- Survey instrument / questionnaire / diary
- Use of a medical device
- Internet / web based research
- Computer based tests
- Other techniques

Describe other techniques.

Quantitative analysis of non-identifiable aggregated socio-spatial data to produce indicators of social vulnerability.

Spatial analysis and graphical representation of socio-spatial data using geographical information systems

(GIS).

2. RESEARCHERS

2.0. Applicant

Provide the following information for the person making this application to the HREC.

2.0.1. Name and contact details

2.0.1.1 Title	Prof
2.0.1.2 First Name	Pauline
2.0.1.3 Surname	McGuirk
2.0.1.4 Mailing Address 1	Centre for Urban and Regional Studies (CURS)
2.0.1.5 Mailing Address 2	School of Environmental and Life Sciences
2.0.1.6 Mailing Address 3	The University of Newcastle
2.0.1.7 Mailing Address 4	University Drive
2.0.1.8 Suburb/Town	Callaghan
2.0.1.9 State	NSW
2.0.1.10 Postcode	2308
2.0.1.12 Organisation Name	The University of Newcastle
2.0.1.13 Faculty/department/school or centre name as appropriate (optional)	School of Environmental and Life Sciences
2.0.1.14 Position in organisation	Professor, Director of CURS
2.0.1.15 Business Hours Phone Number	(02) 49215097
2.0.1.19 Fax Number	(02) 49215877
2.0.1.20 Email Address	pauline.mcguirk@newcastle.edu.au

2.1. Principal researcher(s)

2.1.0 How many principal researchers are there? 2

2.1.1. Principal researcher 1

2.1.1. Name and contact details

2.1.1.1 Title	Prof
2.1.1.2 First Name	Pauline
2.1.1.3 Surname	McGuirk
2.1.1.4 Mailing Address 1	Centre for Urban and Regional Studies
2.1.1.5 Mailing Address 2	School of Environmental and Life Sciences
2.1.1.6 Mailing Address 3	The University of Newcastle
2.1.1.7 Mailing Address 4	University Drive
2.1.1.8 Suburb/Town	Callaghan
2.1.1.9 State	NSW
2.1.1.10 Postcode	2308
2.1.1.12 Organisation name	The University of Newcastle
2.1.1.13 Faculty/department/school or centre name as appropriate (optional)	School of Environmental and Life Sciences
2.1.1.14 Position in organisation	Professor, Director of CURS
2.1.1.15 Business Hours Phone Number	(02) 49215097
2.1.1.19 Fax Number	(02) 49215877
2.1.1.20 Email Address	pauline.mcguirk@newcastle.edu.au

2.1.2. Describe the qualifications, expertise and experience of the principal

researcher relevant to this project.

2.1.2.1 Qualifications

1992: PhD Geography, Dublin University, Ireland
1987: Diploma in Education, Dublin University, Ireland
1986: BA (Hons) Geography/History, Dublin University, Ireland

2.1.2.2 Expertise

McGuirk has a distinguished international reputation in the field of urban political geography with strong expertise relevant to this project including in (i) theoretical understanding of state institutional settings and governance capacity (ii) applications of socio-spatial data analysis using GIS (iii) critical interpretation and analysis of the social geography of regional change and its GIS representation and (iv) creating protocols and processes to facilitate interagency collaboration.

2.1.2.3 Experience

McGuirk's experience is informed by over 15 years of university research. She is also the Director of the Centre for Urban and Regional Studies (CURS), University of Newcastle, the key site where this research will be undertaken.

She has extensive experience in the management of major research projects and, specifically, of collaborative research with state government agencies in the Hunter, derived from previous ARC Linkage projects. This includes a prior ARC Linkage with the Dept of Premier and Cabinet (Hunter), the partners on current grant funding this research. McGuirk has a track record of working successfully with state agencies in integrated inter-agency settings. She has a thorough knowledge of the social geography of the Hunter and its communities. Finally, she has a history of experience in handling sensitive socio-spatial data and its related representation in graphical formats.

2.1.2.4 Name the site(s) for which this principal researcher is responsible.

Centre for Urban and Regional Studies, The University of Newcastle

2.1.3 Describe the role of the principal researcher in this project.

McGuirk will be the overall project director, taking responsibility for collaborative involvement and quality assurance. Along with Prof O'Neill (principal researcher at the UWS site) and Dr Mee (CI 3), she will be responsible for the project's conceptual development. McGuirk will also lead the process of investigating and devising the project's protocols, MoA with participating agencies, and theorising the institutional practices that embed data production and data sharing. She will take prime responsibility for liaison with the project reference committee involving representative from RCMG and all participating agencies. As project director, she will oversee the preparation of project publications.

2.1.4 Is the principal researcher a student? No

2.1.1. Principal researcher 2

2.1.1. Name and contact details

2.1.1.1 Title	Prof
2.1.1.2 First Name	Phillip
2.1.1.3 Surname	O'Neill
2.1.1.4 Mailing Address 1	Urban Research Centre
2.1.1.5 Mailing Address 2	University of Western Sydney
2.1.1.6 Mailing Address 3	Level 6, 34 Charles St
2.1.1.8 Suburb/Town	Parramatta
2.1.1.9 State	NSW

2.1.1.10 Postcode	2150
2.1.1.12 Organisation name	University of Western Sydney
2.1.1.13 Faculty/department/school or centre name as appropriate (optional)	Urban Research Centre
2.1.1.14 Position in organisation	Director of Urban Research Centre
2.1.1.15 Business Hours Phone Number	(02) 8833 5988
2.1.1.19 Fax Number	(02) 9891 5899
2.1.1.20 Email Address	p.oneill@uws.edu.au

2.1.2. Describe the qualifications, expertise and experience of the principal researcher relevant to this project.

2.1.2.1 Qualifications 1995: PhD (Economic Geography), Macquarie University
1975: BA (Hons 1) Dip Ed, Geography/Economics, Macquarie University

2.1.2.2 Expertise O'Neill has made a number of significant contributions that are relevant to this project involving integration of understandings and experiences from a range of discipline and research backgrounds. O'Neill has extensive expertise in core areas relevant to this research including in (i) state and institutions theory (ii) applied work on spatial indicators, especially for two recent ARC Linkage Projects, involving the use of novel data in the compilation of integrated indicators (iii) critical applications of GIS analysis and representation of socio-spatial data (iv) quantitative analysis of socio-spatial data.

2.1.2.3 Experience O'Neill has extensive experience based on nearly 20 years of research. He is Professor and Director of the Urban Research Centre, University of Western Sydney. He has wide-ranging experience in managing major collaborative research projects, and of working with state government agencies in inter-agency contexts. He has worked extensively in the past with the ARC Linkage partners on this project (NSW Dept of Premier and Cabinet, Hunter) as well as with an array of the agencies to be involved in the supply of data to this project. Finally O'Neill has in-depth knowledge of the economic and social geography of the Hunter and its communities accrued through nearly 20 years of Hunter-focussed research.

2.1.2.4 Name the site(s) for which this principal researcher is responsible.

Urban Research Centre, University of Western Sydney

2.1.3 Describe the role of the principal researcher in this project.

Prof O'Neill's primary role will be to lead the project's data analysis, drawing on his extensive expertise in socio-economic and socio-demographic change and its spatial analysis. In combination with statistician Dr King (CI4), he will be involved in resolving data, scalar and methodological issues and in devising and testing indicator development. He will also play a key role in the project's conceptual development, particularly around institutional practices, and will advise on the development of the project's protocols.

2.1.4 Is the principal researcher a student? No

2.2. Associate researcher(s)

2.2.1 How many known associate researchers are there? (You will be asked to give contact details for these associate researchers at question 2.2.1.1) 3

2.2.2 Do you intend to employ other associate researchers? No

2.2.1.0. Associate Researchers 1

2.2.1.1. Name and contact details

2.2.1.1.1 Title	Dr
2.2.1.1.2 First Name	Kathy
2.2.1.1.3 Surname	Mee
2.2.1.1.4 Mailing Address 1	Centre for Urban and Regional Studies
2.2.1.1.5 Mailing Address 2	School of Environmental and Life Sciences
2.2.1.1.6 Mailing Address 3	The University of Newcastle
2.2.1.1.7 Mailing Address 4	University Drive
2.2.1.1.8 Suburb/Town	Callaghan
2.2.1.1.9 State	NSW
2.2.1.1.10 Postcode	2308
2.2.1.1.12 Organisation name	The University of Newcastle
2.2.1.1.13 Faculty/department/school or centre name as appropriate (optional)	School of Environmental and Life Sciences
2.2.1.1.14 Position in organisation	Lecturer
2.2.1.1.15 Business Hours Phone Number	(02) 49216451
2.2.1.1.19 Fax Number	(02) 49215877
2.2.1.1.20 Email Address	kathy.mee@newcastle.edu.au

2.2.1.2. Describe the qualifications, expertise and experience of the associate researcher relevant to this project.

2.2.1.2.1 Qualifications	2000 PhD Geography, University of Sydney 1989 B Ec Hons, University of Sydney
2.2.1.2.2 Expertise	Mee is a social and cultural geographer with a background of previous work in applied socio-spatial analysis. She has expertise in critical analysis of the geography of regional social change and its representation. This, in particular, is underpinned by her work exploring the impacts of representation on vulnerable communities. She also has expertise in the critical application of GIS analysis of socio-spatial data.
2.2.1.2.3 Experience	Mee has been a lecturer and researcher at the University of Newcastle since 1995. She has extensive experience of research in major projects, including a long history of involvement with McGuirk and O'Neill on ARC Linkage projects with NSW Dept of Premier and Cabinet (Hunter) as well as with other Hunter human service agencies, especially the Dept of Housing. In addition she is currently leading a socio-spatial data analysis project with the NSW Dept of Premier and Cabinet (Central Coast). Mee's experience of dealing with sensitive data and the sensitivities around data representation for disadvantaged localities is particularly valuable to this project.

2.2.1.3 Description of the role of the associate researcher in this project.

Mee will participate directly in the project's conceptual development and contribute to the design and development of the protocols. She will also deploy her experience of socio-spatial analysis in the preparation of materials for agency dissemination and will contribute heavily to the development of critical awareness about the epistemologies of GIS representations. Mee will also co-supervise the APAI PhD student attached to the project (to be subject to a separate application for ethics approval).

2.2.1.3.1 Name the site at which the associate researcher has responsibility.

Centre for Urban and Regional Studies (UoN)

2.2.1.4 Is the researcher a student? No

2.2.1.0. Associate Researchers 2

2.2.1.1. Name and contact details

2.2.1.1.1 Title	Dr
2.2.1.1.2 First Name	Robert
2.2.1.1.3 Surname	King
2.2.1.1.4 Mailing Address 1	School of Mathematics and Physical Sciences
2.2.1.1.5 Mailing Address 2	The University of Newcastle
2.2.1.1.6 Mailing Address 3	University Drive
2.2.1.1.8 Suburb/Town	Callaghan
2.2.1.1.9 State	NSW
2.2.1.1.10 Postcode	2308
2.2.1.1.12 Organisation name	The University of Newcastle
2.2.1.1.13 Faculty/department/school or centre name as appropriate (optional)	School of Mathematics and Physical Sciences
2.2.1.1.14 Position in organisation	Lecturer
2.2.1.1.15 Business Hours Phone Number	(02) 49215548
2.2.1.1.19 Fax Number	(02) 49216898
2.2.1.1.20 Email Address	robert.king@newcastle.edu.au

2.2.1.2. Describe the qualifications, expertise and experience of the associate researcher relevant to this project.

2.2.1.2.1 Qualifications	1999 PhD Statistics, Queensland University of Technology 1990 BSc Hons (Statistics) The University of Queensland
2.2.1.2.2 Expertise	King has 12 years of research and lecturing experience and brings advanced statistical expertise to the project particularly in Bayesian statistics, a branch of statistics particularly useful to resolving scalar issues with the integration of data sets available at different scales (e.g. collectors district vs LGA). King's expertise lies in the field of applied statistics, most especially in the identification of patterns of related variables. His skills are therefore core to the application of quantitative techniques in this project to identify key variables for incorporation as components of new fine-grained social indicators.
2.2.1.2.3 Experience	King's experience in applied statistics is particularly relevant to the project, as is his experience of developing statistical tools to encourage ease of implementation for practitioners. In addition, King has previous experience of working with the Australian Bureau of Statistics, and thus brings important insights to the project about the potential and limitations of the array of data available publicly to the project through the ABS.

2.2.1.3 Description of the role of the associate researcher in this project.

With CI O'Neill, King will be responsible for the development of statistical techniques to enable data integration and analysis towards the production of composite indicators. He will lead the team's investigations of the properties of potential indicators.

2.2.1.3.1 Name the site at which the associate researcher has responsibility.

Centre for Urban and Regional Studies, University of Newcastle

2.2.1.4 Is the researcher a student? No

2.2.1.0. Associate Researchers 3

2.2.1.1. Name and contact details

2.2.1.1.1 Title	Dr
2.2.1.1.2 First Name	Lesley
2.2.1.1.3 Surname	Instone
2.2.1.1.4 Mailing Address 1	Centre for Urban and Regional Studies
2.2.1.1.5 Mailing Address 2	School of Environmental and Life Sciences
2.2.1.1.6 Mailing Address 3	University of Newcastle
2.2.1.1.7 Mailing Address 4	University Drive
2.2.1.1.8 Suburb/Town	Callaghan
2.2.1.1.9 State	NSW
2.2.1.1.10 Postcode	2308
2.2.1.1.12 Organisation name	University of Newcastle
2.2.1.1.13 Faculty/department/school or centre name as appropriate (optional)	School of Environmental and Life Sciences
2.2.1.1.14 Position in organisation	Lecturer
2.2.1.1.15 Business Hours Phone Number	(02) 49216637
2.2.1.1.19 Fax Number	(02) 49215877
2.2.1.1.20 Email Address	lesley.instone@newcastle.edu.au

2.2.1.2. Describe the qualifications, expertise and experience of the associate researcher relevant to this project.

2.2.1.2.1 Qualifications	2002 PhD Geography Monash University 1985 Master of Environmental Science, Monash University 1975 BA (Geography) Macquarie University
2.2.1.2.2 Expertise	The particular expertise that Instone (an ECR) brings to this project includes high level applied and theoretical expertise in socio-technology relationships and in the communicative spaces of digital multimedia technologies. Her research and practice in this area has focussed on how these technologies both represent and shape particular knowledge practices about places and people.
2.2.1.2.3 Experience	Instone has six years experience as a lecturer at Monash University and the University of Newcastle. She has additionally worked as an Academic Consultant and Educational Designer at Charles Darwin University (2003-2006). Moreover she has worked in community development with vulnerable communities and had involvement with projects developing community involvement related to society-technology interactions. Her experience will make valuable contributions to the project in devising appropriate formats for the representation and delivery of project outputs to the RCMG and participating agencies.

2.2.1.3 Description of the role of the associate researcher in this project.

Instone will participate in project development and advise on appropriate formats for the representation and delivery of project outputs. She will be the primary supervisor of the PhD scholar (APAI) on the project (along with CI Meel), to be subject of a separate application for ethics approval.

2.2.1.3.1 Name the site at which the associate researcher has responsibility.

Centre for Urban and Regional Studies, University of Newcastle

2.2.1.4 Is the researcher a student? No

2.3. Other personnel relevant to the research project

2.3.1 How many known other people will play a specified role in the conduct of this research project? 2

2.3.1.1 Describe the role, and expertise where relevant (e.g. counsellor), of these other personnel.

Two research assistants will be attached to the project. The first RA brings research, organisational and project management experience and will be involved in the protocols development side of the project: the organisation and coordination of joint activities and meetings between the research centres and government agency representatives; coordination of staff; literature searches; preparation of reports and other communications.

The second RA has extensive GIS experience with a particular focus on socio-spatial data analysis and GIS representation, including Census and agency data. This RA will work closely with the Department of Premier and Cabinet (Regional Coordination Management Group - Hunter Region) and participating government agencies in auditing, collecting, and deidentifying agency data to non-identifiable formats, and then processing and representing the project data.

2.3.2 Is it intended that other people, not yet known, will play a specified role in the conduct of this research project? Yes

2.4. Certification of researchers

2.4.1 Are there any relevant certification, accreditation or credentialing requirements relevant to the conduct of this research? No

2.5. Training of researchers

2.5.1 Do the researchers or others involved in any aspect of this research project require any additional training in order to undertake this research? No

3. PROJECT

3.1. Duration and location

3.1.1 In how many Australian sites, or site types, will the research be conducted?

Provide the following information for each site or site type (Australian and overseas, if applicable) at which the research is to be conducted

3.1.3. Site / Site Type 1

3.1.3.1 Site / Site Type Name

Centre for Urban and Regional Studies (CURS), The University of Newcastle

3.1.3.2 Site / Site Type Location

The Centre for Urban and Regional Studies (CURS) is located at the University of Newcastle. CURS will act as the primary custodian of the data received from participating government agencies and will ensure secure deidentification and aggregation of agency data to permanently de-identified (i.e. non-identifiable) formats. CURS will be the primary site where the integration, statistical analysis and GIS representation of agency and other publicly available data sets will occur.

3.1.3. Site / Site Type 2

3.1.3.1 Site / Site Type Name

Urban Research Centre (URC), University of Western Sydney

3.1.3.2 Site / Site Type Location

The Urban Research Centre (URC) is located at the University of Western Sydney Parramatta campus. URC will be a secondary research site. No identified data will be located at this site. It will be involved only in the integration, statistical analysis and GIS representation of permanently de-identified aggregated agency and other publicly available data sets.

3.1.4. Provide the start and finish dates for the whole of the study including data analysis

3.1.4.1 Anticipated start date 01/01/2008

3.1.4.2 Anticipated finish date 31/12/2011

3.1.5 Are there any time-critical aspects of the research project of which an HREC should be aware? Yes

3.1.5.1.1 Describe the time-critical aspects.

The Australian Research Council Linkage Project funding ceases mid year 2010.

3.2. Research plan

3.2.1 Describe the theoretical, empirical and/or conceptual basis, and background evidence, for the research proposal, eg. previous studies, anecdotal evidence, review of literature, prior observation, laboratory or animal studies. [NS 1.13](#)

This project's theoretical and empirical basis arises from three key areas. First, it directly addresses problems around the conception and measurement of social vulnerability and exclusion. These terms have become embedded in policy and political rhetoric, yet there is little clarity on the relation between causal factors, spatial distribution and indicators (Saunders et al. 2006). In addressing vulnerability, the project will confront restrictions on the availability of appropriate data that have plagued attempts to construct reliable and timely indicators (Levitas 1999). To achieve this we will develop GIS-based statistical techniques that address short-comings in existing approaches to the spatial analysis of vulnerability (e.g. use of problematic indicators and scales of analysis) (Adams 2001). Much recent Australian work aims to address the widely accepted components of exclusion (e.g. Burchardt et al 2002). Yet this work is confined to using a limited range of Census variables as somewhat crude proxies or it involves construction of multi-variate indicators involving a level of statistical complexity that renders them unusable by policy makers and practitioners (e.g. Daly et al 2006), or involves the use of Statistical Local Area (or LGA) as the dominant spatial unit of analysis despite recognition that this unit is too coarse to enable fine-grained spatial patterns to be identified (Baum et al 2006). This project aims to produce enriched indicators of vulnerability by meshing standard socio-demographic data packages (e.g. Census and Socio-Economic Indicators For Areas), with

agency data and assembled non-agency data sets (e.g. produced data-sets on service locations), and developing composite indicators based on Bayesian hierarchical models that account for various data forms.

Second, this project devises a set of protocols to systematically identify and reconcile the legal, ethical and IT security issues that have limited the possibilities for inter-agency data-sharing, as a precursor to the development of improved indicators. Technological advances in GIS capability have produced possibilities for public sector data sharing to provide decision-support systems, improve agency responsiveness, resource efficiency, and policy evaluation (Haque 2003). While these aspects of whole-of-government working are widely accepted as superior, attempts at enactment invariably fail due to the inability to resolve regulatory constraints (Kelman et al 2002). In particular, technological capacity brings to the surface deep concerns amongst academic, policy, and community interests about data collection, ownership and access, storage, retrieval and dissemination (Christen 2006). Yet, surprisingly, the question of how to resolve these concerns is invariably avoided. The potential benefits can only be realised if analysts, government agencies and the public trust how confidential data are handled (LHA & MacLeod 2005). The challenge this project takes up, then, is to address concerns and meet legitimate expectations about data protection while enabling data sharing to deliver tangible benefits. This requires systematic development of a set of transferable procedures and protocols to provide a framework for the secure, controlled and confidential sharing of data between agencies.

Third, this project devises procedures to address recognised institutional constraints that have impeded inter-agency data sharing. Despite a now considerable history of joined-up working, international experience demonstrates that agencies continue to operate largely with their own information (Higgs et al 2003). Matters of process and practice impede data-sharing initiatives (Drake et al 2004). Being acutely aware of agency practices and norms, and bringing to bear our history of research partnerships with these agencies, this project will provide a systematic framework to guide agencies towards management and resolution of impediments to data sharing.

3.2.2 State the aims of the research and the research question and/or hypotheses, where appropriate.

This project has three aims: first, construction of reproducible procedures and protocols to address legal, ethical and IT-security regulatory requirements so as to enable government agency data to be incorporated into socio-spatial analyses of social vulnerability and exclusion; second, the development of robust spatial methodologies for analysing multiple data-sets to produce enriched indicators of social vulnerability; third, design of procedures and protocols to overcome institutional and legal constraints to more comprehensive government agency data sharing to underpin whole-of-government responses to social vulnerability.

3.2.3 Describe how the research design and the methods to be used will enable the research aims to be achieved.

The research design has 4 stages. Stages 1 and 2 have been substantially achieved.

Stage 1: Detailed review of international literatures on social vulnerability and exclusion, quantitative indicators, data sources and processing techniques to inform selection and testing of data and variables for inclusion.

Stage 2: Development and verification of model protocols and procedures. These have involved a comprehensive review and assessment of organisational frameworks for existing data-sharing and data-integration initiatives internationally to inform the development of protocols and institutional arrangements to facilitate agency data-release, analysis and dissemination of results. These arrangements have been developed in close consultation with NSW Privacy Commissioner, NSW Crown Solicitor, University Solicitors of UoN and UWS, and the RCMG, represented by the Dept of Premier and Cabinet. This process involved establishing (i) the relevant legal framework relevant to data sources (ii) protocols for data procurement (iii) protocols to govern protected data transfer, (iv) an data security framework to govern on-going data storage, delimited access and retrieval (v) a framework governing ownership of project data outputs and the publication of research outcomes. The protocols are encapsulated in a Memorandum of Agreement (MOA) to be signed by CURS, URC, the RCMG and each participating agency (Appendix A). The MoA outlines overall project objectives, detailed procedures governing data collection, de-identification and aggregation to permanently de-identified (i.e. non-identifiable) formats, data analysis, and dissemination of data outputs, as well as the responsibilities of participating agencies and the research team. The MOA incorporates an overarching research agreement signed by the research partners (UoN, UWS and RCMG) setting out the conditions of confidentiality under which the research will be undertaken and the conditions under which research outcomes from the project may be published.

Stage 3: Spatial analysis and indicator development. The team will compile a range of data available to the project ie publicly available data (e.g. Census, SEIFA, Journey-to-Work data, Household Travel Survey Data, Australian Tax Office data); non-agency data (e.g. location of public services and institutions) and agency

data. Once participating agencies have signed the MoA, the data in their custodianship that align with the aims and technical criteria of the project will be identified through a Reference Committee made up of the researchers, representatives of the RCMG and representatives of each participating agency. In line with the conditions of the MoA, all selected agency data will be de-identified and aggregated to non-identifiable formats, and all identified data will be destroyed such that no data can subsequently be re-identified. Copies of aggregated data sets of each agency's data will be returned to the contributing agency only, for its own use, storage or destruction.

The second task is to undertake a critical assessment of data variables for inclusion in the development of a portfolio of indicators. Using quantitative techniques, the team will select and test candidate variables, consider their discriminatory power, and accept, reject or adjust their contribution to composite indicators. Data outputs from this stage of the project will include data tables of indicators, maps at collectors district and LGA scales, graphs and charts, plus appropriate analytical text. These materials will be delivered to the RCMG, for dissemination as appropriate to participating agencies.

Stage 4: Finalisation of an integrated socio-spatial data analysis process to enable collaboration between NSW Department of Premier and Cabinet NSW, CURS (UoN) and URC (UWS) intended to inform the policymaking and forward planning activities of RCMG agencies.

3.3. Research significance

3.3.1 What is the value of answering the research question and conducting the project? [NS 1.13](#) [NS 1.14](#) [NS 1.15](#)

The significance and value of the research project is in three areas. First, it will produce more incisive and geographically sensitive indicators of social vulnerability, marking major advances in the understanding and assessment of social vulnerability and exclusion. By improving state agencies' identification and redress of emergent social vulnerability, this research will generate major social benefits, enabling the development of research-based policy and program devices to better align human service delivery with community needs. The research therefore answers a key question for social policy makers by improving understanding of how social vulnerability and exclusion can be conceptualised, their variability assessed, their geography understood and their impacts addressed.

Second, regulatory and organisational constraints to inter-agency data sharing will be overcome by designing, trialling and fine-tuning a suite of data-sharing protocols and procedures. This will enable more efficient and effective public sector information management, create a secure and controlled environment for more joined-up use of confidential public agency data, contribute to savings in resource use, and enable enhanced interdisciplinary analysis and policy research.

Third, the project is built around an on-going process of engagement, knowledge and skills transfer with government agency staff. It will result in significant broadening of agency capability for conducting and interpreting socio-spatial analysis, skills in critical GIS and policy research capacity. It offers substantial assistance to governments in making more efficient and effective policy and planning decisions.

3.4. Peer review

3.4.1 Has the research proposal, including design, methodology and evaluation undergone, or will it undergo, a peer review process? Yes

3.4.1.1.1 Provide details of the review and the outcome. A copy of the letter / notification, where available, should be attached to this application.

The research proposal, its design and methodology and the suitability of the research team to the proposed research tasks, have undergone a peer review process as part of the successful application for the Australian Research Council Linkage Grant which is funding the research (Attachment E).

The following questions sets (Q 3.5 - 3.11) relate to the collection, use and disclosure of information for research purposes. In answering these questions please ensure that you address all issues relevant to the type of project and type of participants that will be involved in your research project. Refer for guidance to relevant chapters of the National Statement, NEAF Guidance and other NHMRC guidelines as appropriate.

3.5. Source and description of information about participants

3.5.1 Indicate the source of the information about participants which will be used in this research project.

- Information will be collected directly from the participant.
- Information will be collected from another person about the participant

Information will be collected by accessing a record or an information database held by an organisation other than your organisation.

Information will be used which you or your organisation collected previously for a purpose other than this research project.

3.5.1.3.0. Indicate the number of databases, from which you will be collecting information, held by any of these categories of agencies.

3.5.1.3.1. Indicate from which of the following you will be collecting information and indicate how many databases at each source.

3.5.1.3.1.1 A Commonwealth government department or agency 0

3.5.1.3.1.2 A state/territory authority 1

3.5.1.3.1.3 A private sector organisation 0

3.5.1.3.1.0. Organisation Database 1

3.5.1.3.1.1.1 Name of organisation

Indicative example: Hunter New England Health (see cover letter)

3.5.1.3.1.1.2 Name/description of the database eg. student academic results database, perinatal statistics collection

Indicative example: Hospital Emergency Departments Triage Records (see cover letter)

3.5.1.3.1.1.3 Describe the information which will be collected List all data items eg. date of birth, postcode, gender, highest education level achieved.

Indicative example:

Health ID number, episode date, patient address, suburb and post code for each of:

(i) Child injuries

(ii) Diabetes

(iii) Heart

(iv) Teen mothers

(v) Low birth weight

3.5.1.3.1.1.4 The information collected by the research team about participants will be in the following form(s). Tick more than one box if applicable.

Identified

Potentially identifiable

De-identified

3.5.1.3.1.1.4.1.1 Give reasons why it is necessary to collect information in identified or potentially identifiable (coded) form.

Given the complexity of integrating data from various source (agencies, Census, ATO etc), in a variety of formats and at a variety of scales, a key challenge of this project will be to maintain comparability, quality and reliability, consistency and robustness across the data sets. This is critical to the project's success. The task of permanently de-identifying agency data by geo-coding (applying spatial co-ordinates) and aggregating to collection district level therefore must be done in a manner that maintains these data qualities and produces consistency of format across the aggregated, permanently de-identified data sets ultimately to be used to develop the indicators. These require careful handling by staff with access to specialised software, appropriate expertise, and require a considerable commitment of time. Neither the software, expertise nor time is available within the participating agencies. Thus data will be supplied to the researchers in identified formats (along with full descriptive meta-data e.g. name of file; description; validation or edits applied; information on whether standardisation has occurred; level of precision of the field; and confidentiality provisions of the Act(s) under which data were collected). As detailed in the MOA (and approved by the NSW Privacy Commission and NSW Crown Solicitor), data will be encrypted for transfer to CURS where it will be immediately and permanently de-identified and aggregated, under secure conditions, in a prescribed, consistent and comprehensive manner. The identifiable data and all records of them will then be permanently destroyed under controlled conditions, rendering re-identification impossible. Only the non-identifiable data will be further used as part of the research project. This will be done by experienced data analysts at CURS and URC who have signed appropriate confidentiality undertakings (see MOA ie Attachment A). These procedures will ensure the usability of the data and maximize its potential.

3.5.1.3.1.1.5 Will consent be sought from participants (or for participants from persons with legal authority) for the collection and use of information about them? No

3.5.1.3.1.1.5.1.1 Give reasons why consent will not be sought for the collection and/or use of this information.

Consent to use information is not requested from individuals to whom agency data refers as (i) there is an adequate plan, approved by the NSW Privacy Commissioner and NSW Crown Solicitor, to protect data confidentiality; (ii) there is sufficient protection of the privacy of individuals achieved by the secure and permanent de-identification of all data and its aggregation prior to use in the project; (iii) gaining individual consent is impracticable and unnecessary; (iv) the research carries minimal risk and has acknowledged potential for substantial public benefit.

To summarise, all individual unit record data provided by the agencies will be encrypted for transfer to CURS from the agencies, then promptly geo-coded and aggregated such that it is permanently de-identified, under conditions of confidentiality approved by the NSW Privacy Commission and NSW Crown Solicitor as part of a prescribed MOA between the researchers, RCMG, and each participating agency. All identified data will be destroyed, with no possibility of data re-identification. No identified data or individual unit record data will be, or could be, further used as part of this project.

3.5.1.6. State/territory privacy related legislation or regulation - Does it apply to this project?

You have indicated in question set 3.5 that you are collecting and/or using personal information from a state/territory public sector agency without obtaining consent from participants or their legal representatives. If this is not correct please reconsider your answers at question set 3.5. If this is correct, state/territory law may affect the conduct and the review of your project.

It is your responsibility to ensure that the proposal complies with all relevant legislation and that you provide the HREC with relevant information to assess such compliance. NS 18.1 The additional information may be provided as an attachment which must provide the HREC to whom you are submitting your proposal with all the information it will need to fulfil the tasks that it has under State and Territory legislation.

The following references and websites may be assistance:

ACT NT NSW TAS

Queensland
Department of Justice and Attorney-General - Privacy

Queensland Health - Privacy

Victoria
Office of the Victorian Privacy Commissioner

Office of the Health Services Commissioner

3.5.1.6.1 Does this application include an attachment relevant to state/territory privacy legislation. Yes

3.6. Use of information about participants

3.6.1 Describe how information collected about participants will be used in this project.

In accordance with the MOA governing the project, selected identified unit record data collected by participating agencies will be encrypted and transferred to CURS under secure conditions. Data will be deidentified, geocoded and aggregated to collector district level by CURS analysts who have signed agreements to abide by the prescribed protocols and procedures as well a confidentiality agreements. All identifiable data will then be promptly and permanently destroyed under secure conditions at CURS, rendering any reidentification of the data impossible. Only permanently de-identified (ie non-identifiable) aggregated data will be further used as part of the research. This de-identified aggregated data will be combined with other data sources [e.g. Census data, SEIFA, Journey-to-Work, Household Travel Survey, Australian Taxation Office data, produced data sets on the service locations] in producing information including composite indicators, sets of maps, images, graphs and charts which will enhance collective planning and service prioritisation by government agencies in addressing regional social vulnerability.

With the agreement of relevant agencies as specified in the MOA (Attachment 1, MOA section 5q), the research team may further use permanently de-identified aggregated data produced by the project in

reports to government agencies and as part of academic publications and papers.

3.6.2 Will any of the information used by the research team be in identified or potentially identifiable (coded) form? Yes

3.6.2.1.1 Give reasons why it is necessary to use information in identified or potentially identifiable (coded) form.

Identified data are used only in the project's initial phase. For reasons detailed in section 3.5.1.3.1.4.1.1, it is necessary for data to be collected initially in identified form. However these data will be immediately de-identified, geocoded and aggregated to collection district level, with no further possibility for re-identification. The identified data will then be permanently destroyed. No further use will be made of identified data and only permanently de-identified (ie non-identifiable) aggregated data will be used for the remainder of the research project.

3.6.2.1.2 Indicate whichever of the following applies to this project:

- Information collected for, used in, or generated by, this project will not be used for any other purpose.
- Information collected for, used in, or generated by, this project will/may be used for another purpose by the researcher for which ethical approval will be sought.
- Information collected for, used in, or generated by, this project is intended to be used for establishing a database/data collection/register for future use by the researcher for which ethical approval will be sought.
- Information collected for, used in, or generated by, this project will/may be made available to a third party for a subsequent use for which ethical approval will be sought.

3.6.4 List ALL research personnel and others who, for the purposes of this research, will have authority to use or have access to the information and describe the nature of the use or access. Examples of others are: student supervisors, research monitors, pharmaceutical company monitors .

All five investigators named as CIs on the ARC Linkage grant funding this project (McGuirk, O'Neill, Mee, King and Instone) will have authority to use de-identified information: (i) in developing the methodological and theoretical frameworks for enabling inter-agency data sharing; (ii) in developing enhanced social indicators and the related production of descriptive and analytical text; and (iii) in producing academic publications and presentations in line with the process determined in the Research Partnership Agreement governing the project (Attachment 1, MOA see Appendix D).

Both RAs will have access to information. RA 1 will be dealing with project information as part of her role in project management, processual and conceptual development, meetings between the research centres and government agency representatives and the preparation of reports. The second RA will have direct access to the data as part of their central role in auditing, collecting, de-identifying and processing data.

All personnel who have access to information will be signatories to the conditions of the MoA agreed upon by the research centres and participating agencies and to the conditions of the Research Partnership Agreement. These conditions include confidentiality undertakings approved by the NSW Privacy Commission, NSW Crown Solicitor and by the legal officers of the UoN and the UWS.

There is the potential that a research student may become involved in the project and could have access to the de-identified information at a future date. Any such student would be bound by the confidentiality commitments and prescribed conditions for handling data spelled out in the MOA. Any such student would further sign a deed, devised by the UoN University Solicitor in consultation with the researchers, which deals with assignment of intellectual property, confidentiality undertakings, and the treatment of project materials generated by the student.

3.7. Storage of information about participants during and after completion of the project

3.7.1 In what formats will the information be stored during the research project? (eg. paper copy, computer file on floppy disk or CD, audio tape, videotape, film)

Computer files on CD and hard disk drives
Paper copies

3.7.2 Specify the measures to be taken to ensure the security of information from misuse, loss, or unauthorised access while stored during the research project? (eg. will identifiers be removed and at what stage? Will the information be physically stored in a locked cabinet?)

(1) Identified data

Encrypted identified data will be supplied by participating agencies to Authorised Data Recipients at the Centre for Urban and Regional Studies(UoN). On receipt of the CDs, two originals of a confidentiality form will be signed by data deliverers and recipients, one to be stored by CURS and one sent to the RCMG (see Attachment 1, MOA Appendix A). This form also commits the signatories to observing the prescribed conditions of the MOA. Encrypted identified data will be held temporarily on CD under secure conditions (locked filing cabinets) in CURS offices until the commencement of processing, which will take place on computers that are off-line throughout the process. Log-on to the computer and to the files containing the identified data will both be password protected. No-one other than a Registered Analyst, identified in the project's MoA, will be granted access to the identified data (see Attachment 1, MOA Appendix C). Analysts will sign confidentiality undertakings prior to commencing any work on the data (see Attachment 1, MOA Appendix B). These confidentiality undertakings also commit the signatories to observing the prescribed conditions of the MOA. Data will then be de-identified, geo-coded and aggregated on password protected computers at CURS. The original identified data will then be destroyed and written confirmation of its destruction will be provided by CURS to the relevant Agencies.

(2) De-identified data

De-identified, aggregated data will be maintained, stored and processed under secure conditions in CURS and the Urban Research Centre (at UWS). De-identified aggregated data may only be transferred to URC under secure conditions (in person), in accordance with conditions specified in the MOA. It will not be posted or emailed. De-identified data will be stored as password protected computer files on password protected computers at CURS and URC, accessible only to registered analysts who will sign confidentiality undertakings prior to commencing any work on the data (see Attachment 1, MOA Appendix B). Any paper copies of information will be kept in locked filing cabinets in CURS or URC, and will be stored as computer files on CD and hard disk drive of off-line computer.

Any de-identified data on CDs will be encrypted and stored under secure conditions (locked filing cabinet) at CURS/ URC.

3.7.3 In what formats will the information be stored after project completion? (eg. paper copy, computer file on floppy disk or CD, audio tape, videotape, film)

After project completion, all information will be in de-identified and aggregated forms and will be stored as computer files on CD and hard disk drive of off-line computer.

Any de-identified data on CDs will be encrypted and stored under secure conditions (locked filing cabinet) at CURS/ URC.

3.7.4 Specify the measures to be taken to ensure the security of information from misuse, loss, or unauthorised access while stored after project completion (eg. will identifiers be removed and at what stage? Will the information be physically stored in a locked cabinet?)

Data will be stored as password protected computer files on password protected computers, accessible only to registered Centre for Urban and Regional Studies (UoN) and Urban Research Centre (UWS) data analysts identified on the project's MoA. Any de-identified data on CDs will be encrypted and stored under secure conditions (locked filing cabinet) at CURS/ URC.

3.7.5 The information which will be stored at the completion of this project is of the following type(s). Tick more than one box if applicable.

- Identified
- Potentially identifiable (coded)
- De-identified

3.7.6 For how long will the information be stored after the completion of the project and why has this period been chosen?

Permanently de-identified aggregated project data will be retained by CURS and URC (under prescribed conditions) as part of collaboration with the RCMG (Hunter Region) represented by the NSW Dept of Premier and Cabinet (Hunter). This collaboration enables a time-series analysis using social indicators and will be sustained until such point that the MOAs governing the project expire. At this point de-identified aggregated project data will be destroyed unless the source agency approves its being retained for further specific research projects.

Information generated by the project (e.g. produced composite indicators, maps, graphs) will be retained by the CIs and by the RCMG.

3.7.7 What arrangements are in place with regard to the storage of the information collected for, used in, or generated by this project in the event that the principal researcher ceases to be engaged at the current organisation?

Should CI McGuirk leave the University of Newcastle, carriage of the project and responsibility for storage of project data (all in de-identified and aggregated formats) and information generated by the project will be taken over by CI Mee.

Should CI O'Neill leave the University of Western Sydney, carriage of the project will revert to the University of Newcastle.

3.8. Ownership of the information collected during the research project and resulting from the research project

3.8.1 Who owns the information collected for the research project?

The identifiable data to be used in the project is owned by the supplying agency, regardless of its use in the project (Attachment 1, MOA Appendix D, Research Partnership Agreement, clause 4.4).

3.8.2 Who is understood to own the information resulting from the research, eg. the final report or published form of the results?

Information produced by the project is owned by the University of Newcastle and the RCMG of the Dept of Premier and Cabinet, NSW (Attachment 1, MOA Appendix D, Research Partnership Agreement, clause 5.2)

3.8.3 Does the owner of the information or any other party have any right to impose limitations or conditions on the publication of the results of this project? Yes

3.8.3.1.1 Specify any limitations on publication.

Limitations on publications arising from the project are set out in a signed Research Partnership Agreement between University of Newcastle (CURS), University of Western Sydney (URC) and the RCMG of the Dept of Premier and Cabinet, NSW (Attachment 1, MOA Appendix D, Research Partnership Agreement, clause 6). The agreement states that material prepared for publication must be provided to the other party for approval at least 30 days prior to the publication or submission to a third party for publication. If the other party requests that the material not be published, then it must be amended or delayed for a period not exceeding 90 days having regard for their concerns.

3.9. Disposal of the information

3.9.1 Will the information collected for, used in, or generated by this project be disposed of at some stage? Yes

3.9.1.1.1 At what stage will the information be disposed?

Permanently de-identified aggregated data will be retained by CURS and URC (under secure conditions) as part of ongoing research collaboration with the RCMG (Hunter Region) represented by the NSW Dept of Premier and Cabinet (Hunter). This collaboration enables a time series of analysis using social indicators and will be sustained until such point that the MOAs governing the project expire. At this point de-identified aggregated data will be destroyed unless the source agency approves its being retained for further specific research project(s).

Information generated by the project (e.g. produced composite indicators, maps, graphs) and related descriptive and analytical text will be retained indefinitely by the CURS and URC and by the RCMG as records and databases.

3.9.1.1.2 How will information, in all forms, be disposed?

All paper copies, computer files or CDs will be shredded, deleted or permanently destroyed.

3.10. Reporting individual results to participants and others

3.10.1 Is it intended that results of the research that relate to a specific participant be reported to that participant? No [NS 1.18](#)

3.10.1.2.1 Explain/justify why results will not be reported to participants.

All results of the research will use non-identifiable aggregated information which cannot be directly linked or

reported to individuals.

3.10.2 Is the research likely to produce information of personal significance to individual participants? No

3.10.3 Will individual participant's results be recorded with their personal records? [NS 1.20](#) No

3.10.4 Is it intended that results that relate to a specific participant be reported to anyone other than that participant? No

3.10.5 Is the research likely to reveal a significant risk to the health or well being of persons other than the participant, eg family members, colleagues No

3.11. Dissemination of Final Results

3.11.1 How is it intended to disseminate the results of the research? eg report, publication, thesis

The results of the research will be disseminated via reports to the RCMG which will include composite indicators, maps, graphs and charts, and descriptive and analytical text. Dissemination of results will also be undertaken through academic journals, papers and reports which will attempt to: theorise the institutional practices that embed data production and sharing; resolve data, scalar and methodological issues of data sharing and indicator development; analyse and present patterns and processes of social vulnerability and exclusion in the Hunter as a case study of a region under socio-demographic stress; and develop critical awareness about the epistemologies of GIS representations of communities and social vulnerability.

3.11.2 Will the confidentiality of participants and their data be protected in the dissemination of research results? [NS 1.9](#) Yes

3.11.2.1.1 Explain how confidentiality of participants and their data will be protected in the dissemination of research results

All disseminated research results will use permanently de-identifiable aggregated data that cannot be linked in any way to individuals.

3.11.3 Is there a risk that the dissemination of results could cause harm of any kind to individual participants - whether their physical, psychological, spiritual, emotional, social or financial well-being, or to their employability or professional relationships - or to their communities? Yes

3.11.3.1.1 Describe the risk and explain how it will be managed.

The dissemination of results will not cause harm to individuals. The risk with the use of de-identified aggregated data and social indicators however is that some localities and, by inference, some communities may be identified as vulnerable or socially excluded. This research explicitly addresses this risk through two key aspects of the research process. First, the CIs have extensive experience of recognising the potential impacts associated with the publication of GIS representations which single out localities and identify them as disadvantaged, posing risk to the dignity and well being of their communities. All CIs have a history of critically reflexive and ethically-informed use of GIS analysis. They are adept at making careful decisions about the forms of data and scales of representation that will be deployed and that can be publicly disseminated in ways that take account of and avoid negatively identifying communities such that they may be placed at risk of stigmatisation or other psycho-social harm. Second, the research process ensures that the participating government agencies can be represented on the project Reference Committee and are all engaged in the research with ongoing opportunities to have input on the data involved, the manners in which it is represented and the audiences to which it can be disseminated. This will ensure that the research results are disseminated in ways that minimise the risk of harm to communities.

3.12. Benefits/Risks

In answering the following questions (Q 3.12.0 - 3.12.8) please ensure that you address all issues relevant to the type of participants that will be involved in your research project. Refer for guidance to relevant chapters of the National Statement and other NHMRC guidelines as appropriate.

3.12.0 Does the research involve a practice or intervention which is an alternative to a standard practice or intervention? No

3.12.1 What expected benefits (if any) will this research have for other members of the population to which the participants belong?

This research is expected to benefit local communities in the Hunter Region by better representing their social needs and assets to government agencies working in the region. This can help redirect government resources where they are needed and support existing social practices that will benefit these communities.

3.12.2 What expected benefits (if any) will this research have for the wider community?

The wider benefits of this research will arise from the establishment of procedures and protocols to promote and facilitate government data sharing more generally which will help to better target the social needs and assets of the wider community.

3.12.3 What expected benefits (if any) will this research have for participants? [NS 1.6](#)

Beyond the general community benefits outlined above, individuals will not directly benefit from the research as they cannot be explicitly linked to the research in any way.

3.12.4 Are there any risks to participants as a result of participation in this research project? No

3.12.5 Explain how the risks/burdens of participation are balanced by the any benefits of the research.

Individuals will not experience significant direct risks or burdens, as only permanently de-identified aggregated data will be used in the project. Processes described previously are in place to minimise the risk of any harm to communities. Information or representations with risk of causing harm to communities (e.g. through stigmatisation) will not be publicly disseminated. The information about communities that the project will generate will significantly enhance the capacity of individual agencies to target local human service provision through improved data and analysis capabilities. More significantly, the project will create marked improvements in agencies' collective strategic planning, decision-making and prioritisation capacities. These have the potential to yield substantial improvements in the approach to human service provision, its targeting, the timeliness of its delivery and its effectiveness in addressing the resource and support needs of vulnerable communities.

3.12.6 Is it possible that the research will involve the disclosure of unlawful conduct, or concealment of a crime, by individuals or definable groups? No

3.12.7 Explain how the dignity and wellbeing of participants takes precedence over the expected benefits to knowledge.

One of the core aspects of the project is to maintain critical reflexivity on the impacts of identifying, representing and mapping social vulnerability, among the researchers and among the practitioner community, so as to ensure that communities' dignity and well-being are respected over and above the benefits to knowledge. The researchers see benefits in measures of vulnerability but also recognise the need to avoid their uncritical use, in particular due to the ways in which indicators, maps etc can impact on the perception of communities both publicly and amongst policy communities. Information produced by the project (indicators, maps, graphs, data sets, descriptive and analytical texts) will consciously be framed and analysed with this recognition in mind. Information will be presented to participating agencies in the first instance through workshops in which the politics of representation are directly addressed. Indeed these workshops will operate as two-way conduits whereby practitioners provide feedback, based on local knowledge and understanding of communities, to the researchers about sensitivities around specific communities. Informed and site-sensitive decisions will be made about the formats and scales at which information will be presented. In addition, the Research Agreement Partnership and MoA (Attachment 1, Appendix D, Research Partnership Agreement, clause 6,) governing the project ensures that a process is in place whereby the RCMG must give its approval on any materials to be published as part of the project. These processes ensure that a system is in place which ensures that the dignity and well being of communities about whom information is being generated takes precedence over the expected benefits to knowledge.

3.12.8 Are there any other risks involved in this research? eg. to the research team, the organisation, others No

3.12.9 Is it anticipated that the research will lead No

to commercial benefit for the investigator(s) and or the research sponsor(s)?

3.13. Monitoring

3.13.1 What mechanisms do the researchers intend to implement to monitor the conduct and progress of the research project?

A central feature of the project is ongoing monitoring and documentation of the process involved in the development of the MOA and its subsequent enactment which frames the collection and analysis of project data and the development of the social indicators and other related data representations. The project CIs have regular meetings on the research process. In addition, quarterly meetings of the research team and the project Reference Committee will monitor the project's conduct and progress. The formation and definition of the role of Reference Committee--involving representation from all participating agencies, the RCMG and the project team--in guiding the research project is written into the project's MOA. Detailed records of the research process, with supporting documentation, are also being maintained as a means of ensuring the entire research team is informed of each stage of the research process. This provides a mechanism for the early identification and redress of any emergent problem.

5. PARTICIPANTS

5.1. Participant description

5.1.1 How many participant groups are involved in this research project? 1

5.1.2 Expected total number of participants in this project at all sites
N/A See Cover Letter

5.1.3. Group 1

5.1.3.1 Group name for participants in this group
N/A See Cover Letter

5.1.3.2 Expected number of participants in this group
N/A

5.1.3.3 Age range
N/A

5.1.3.4 Other relevant characteristics of this participant group
N/A

5.1.3.5 Why are these characteristics relevant to the aims of the project?
N/A

5.1.4. Your response to questions at Section '1.4 - Research Participants' indicates that the following participant groups are excluded from your research. If this is not correct please return to section 1.4 to amend your answer.

People whose primary language is other than English (LOTE)\

Children and/or young people (ie. <18 years)

People with an intellectual or mental impairment

People in existing dependent or unequal relationships with any member of the research team, the researcher(s), and/or the person undertaking the recruitment/consent process (eg. student/teacher; employee/employer; warden/prisoner; officer, enlisted soldier; patient/doctor)

People who belong to a collectivity

Aboriginal and/or Torres Strait Islander peoples

5.1.4.1 Explain why this group(s) of people is specifically excluded from the research project.
N/A
See Cover Letter

5.2. Participant experience

5.2.1 Provide a concise detailed description, in not more than 200 words, in terms which are easily understood by the lay reader, of what the participants will experience.
N/A

5.3. Relationship of researchers to participants

5.3.1 Specify the nature of any relationship, existing or possible, between the research team or an organisation involved in the research and the potential participants.
N/A

5.3.2 Describe what steps, if any, will be taken to ensure that the relationship does not impair participants' free and voluntary consent and participation in the project.
N/A

5.3.3 Describe what steps, if any, will be taken to ensure that decisions about participation in the research do not impair any existing or foreseeable future relationship between participants and researcher or organisations.
N/A

5.4. Recruitment

5.4.1 What processes will be used to identify potential participants?

N/A

See Cover Letter

5.4.3 Describe how initial contact will be made with potential participants.

N/A

5.4.2 Is it proposed to 'screen' or assess the suitability of the potential participants for the study? No

5.4.4 Is an advertisement, e-mail, website, letter or telephone call proposed as the form of initial contact with potential participants? No

5.4.5 If it became known that a person was recruited to, participated in, or was excluded from the research, would that knowledge expose the person to any disadvantage or risk? No

5.4.6 Will the research involve the intentional recruitment of any groups whose welfare, rights, beliefs, perceptions, customs or cultural heritage requires specific regard ? [NS 1.2](#) No

5.5. Consent process

5.5.1 Will consent for participation in this research be sought from all participants? No

5.5.1.1.1 Explain why consent will not be sought from all participants.

N/A

See section 3.5.1.3.1.1.5.1.1

7. RESOURCES

7.1. Project Funding / Support

7.1.1. Indicate how the project will be funded? Indicate whether funding is confirmed or sought and whether there will be a budget shortfall.

7.1.1.1. External competitive grant

7.1.1.1.1 Confirmed or Sought? Confirmed

7.1.1.1.2 % of project 100

7.1.1.2. Internal competitive grant

7.1.1.2.1 Confirmed or Sought? Not Sought

7.1.1.3. Sponsor

7.1.1.3.1 Confirmed or Sought? Not Sought

7.1.1.4. By researcher's department / organisation

7.1.1.4.1 Confirmed or Sought? Not Sought

7.1.1.5. Other

7.1.1.5.1 Confirmed or Sought? Not Sought

7.1.1.6. Shortfall

7.1.1.6.1 Confirmed or Sought? Not Sought

7.1.1.1.0. External competitive grant

7.1.1.1.1 Name of granting body / name of grant

Australian Research Council Linkage Project Grant with the Department of Premier and Cabinet (Regional Coordination Management Group - Hunter Region) as the Linkage partner.

7.1.1.1.2 Research title on grant

Enabling inter-agency data sharing to support the spatial analysis of social vulnerability in a transforming region

7.1.1.1.3 Grant number assigned by granting body (if known)

LP 0776385

7.1.1.1.4 Indicate the extent to which the scope of the grant and the scope of this HREC application are aligned.

The scope of the grant is entirely aligned with this HREC application.

7.1.2 Will the project be supported in other ways Yes eg. in-kind support/equipment by an external party eg. sponsor

7.1.2.1.1 Describe the support and indicate the provider.

In-kind support is being provided by the Dept of Premier and Cabinet, particularly through the role of the RCMG coordinator who is the front line liaison with the participating agencies. The coordinator will facilitate agency collaboration on the project and chair the Reference Committee. The coordinator will additionally be responsible for providing consultative advice on indicator selection and availability, contextualised social planning expertise, input on priority service needs, and assistance with negotiation with government agencies on data release.

7.2. Duality of Interest

7.2.1 Describe any commercialisation or intellectual property implications of the funding/support arrangement.

There are no commercialisation implications of this research. The Intellectual Property implications are fully

addressed and covered by the Research Partnership Agreement between The University of Newcastle, the University of Western Sydney and the Department of Premier and Cabinet NSW (Hunter Region Coordination Management Group) (see Attachment 1, Appendix D, Research Partnership Agreement).

7.2.2 Does the funding/support provider(s) have a financial interest in the outcome of the research? [NS 2.21](#) No

7.2.3 Does any member of the research team have any affiliation with the provider(s) of funding/support, or a financial interest in the outcome of the research? [NS 2.21](#) No

7.2.4 Does any other individual or organisation have an interest in the outcome of this research [NS 2.21](#) No

8. APPROVALS

8.1. Ethical review

Some HRECs may require researchers to provide information additional to that contained in a NEAF proposal. For this reason, it is prudent to check whether the HRECs to whom you propose to submit this proposal require additional information.

8.1.1 To how many Australian HRECs (representing site organisations or the researcher s organisation) is it intended that this research proposal be submitted? 1

A list of NHMRC registered Human Research Ethics Committees (HRECs), along with their institutional affiliations and contact details is available on the NHMRC website at the following web address; <http://www.nhmrc.gov.au/ethics/human/hreecs/information.htm#a4>.

8.1.1.1. HREC 1

8.1.1.1.1 Name of HREC The University of Newcastle Human Research Ethics Committee (EC00144)

8.1.1.1.1.1. Provide the start and finish dates for the research for which this HREC is providing ethical review.

8.1.1.1.1.1.1 Anticipated start date or date range 01/01/2008

8.1.1.1.1.1.2 Anticipated finish date or date range 31/12/2011

8.1.1.1.1.2 For how many sites at which the research is to be conducted will this HREC provide ethical review? 2

8.1.1.1.1.2.1. Site 1

8.1.1.1.1.2.1.1 Name of site Centre for Urban and Regional Studies (CURS), The University of Newcastle

8.1.1.1.1.2.2 Which of the researchers involved in this project will conduct the research at this site?

Principal Researcher(s)
Prof Pauline McGuirk

Associate Researcher(s)

Dr Kathy Mee

Dr Robert King

Dr Lesley Instone

8.1.1.1.1.2.1. Site 2

8.1.1.1.1.2.1.1 Name of site Urban Research Centre (URC), University of Western Sydney

8.1.1.1.1.2.2 Which of the researchers involved in this project will conduct the research at this site?

Principal Researcher(s)
Prof Phillip O'Neill

Associate Researcher(s)

8.1.2 Have you previously submitted an application, whether in NEAF or otherwise, for ethical review of this research project to any other HRECs? No

9. DECLARATIONS AND SIGNATURES

9.1 Project Title

Enabling inter-agency data sharing to support the spatial analysis of social vulnerability in a transforming region

9.2 Human Research Ethics Committee to which this application is made

The University of Newcastle Human Research Ethics Committee (EC00144)

9.3 Signatures and undertakings

Applicant / Principal Researchers (including students where permitted)

I/we certify that:

- All information is truthful and as complete as possible.
- I/we have had access to and read the National Statement on Ethical Conduct in Research Involving Humans.
- the research will be conducted in accordance with the National Statement.
- the research will be conducted in accordance with the ethical and research arrangements of the organisations involved.
- I/we have consulted any relevant legislation and regulations, and the research will be conducted in accordance with these.
- I/we will immediately report to the HREC anything which might warrant review of the ethical approval of the proposal (NS 2.37), including:
 - serious or unexpected adverse effects on participants;
 - proposed changes in the protocol; and
 - unforeseen events that might affect continued ethical acceptability of the project.
- I/we will inform the HREC, giving reasons, if the research project is discontinued before the expected date of completion (NS 2.38);
- I/we will not continue the research if ethical approval is withdrawn and will comply with any special conditions required by the HREC (NS. 2.45);
- I/we will adhere to the conditions of approval stipulated by the HREC and will cooperate with HREC monitoring requirements. At a minimum annual progress reports and a final report will be provided to the HREC.

Applicant / Chief Researcher(s) / Principal Researcher(s)

Prof Pauline McGuirk
The University of Newcastle

_____ / ____ / ____
Signature Date

Prof Pauline McGuirk
The University of Newcastle

_____ / ____ / ____
Signature Date

Prof Phillip O'Neill
University of Western Sydney

_____ / ____ / ____
Signature Date

Associate Researchers

Dr Kathy Mee
The University of Newcastle

_____ / ____ / ____
Signature Date

Dr Robert King
The University of Newcastle

_____ / ____ / ____
Signature Date

Dr Lesley Instone
University of Newcastle

_____ / ____ / ____
Signature Date

Heads of departments/schools/research organisation

I/we certify that:

- I/we are familiar with this project and endorse its undertaking;
- the resources required to undertake this project are available;
- the researchers have the skill and expertise to undertake this project appropriately or will undergo appropriate training as specified in this application.

Title First name

Surname

Position

Organisation name

____/____/____
Date

Signature

10. ATTACHMENTS

10.1 List of Attachments

Core Attachments	Attachments which may be required/appropriate.
Recruitment/invitation	Copy of advertisement, letter of invitation etc
Participant Information	Copy or script for participant Copy or script for parent, legal guardian or person responsible as appropriate
Consent Form	Copy for participant For parent, legal guardian or person responsible as appropriate For, optional components of the project eg. genetic sub study
Peer review	Copy of peer review report or grant submission outcome
HREC approvals	Copy of outcome of other HREC reviews

Attachments specific to project or participant group	Attachments which may be required/appropriate.
People whose primary language is other than English (LOTE)	English translation of participant information/consent forms
Children and/or young people (ie. < 18 years)	Information/consent form for parent, legal guardian or person responsible
People with an intellectual or mental impairment	Information/consent form for legal guardian or person responsible
People highly dependent on medical care	Information/consent form for legal guardian or person responsible
People who belong to a collectivity	Evidence of support / permission of leaders of collectivity
Aboriginal and/or Torres Strait Islander peoples	Evidence of support / permission of elders and/or other appropriate bodies

10.2 Participant information elements

Core Elements

Provision of information to participants about the following topics should be considered for all research projects.

Core Elements	Issues to consider in participant information
About the project	Full title and / or short title of the project Plain language description of the project Purpose / aim of the project and research methods as appropriate Demands, risks, inconveniences, discomforts of participation in the project Outcomes and benefits of the project Project start, finish, duration
About the investigators / organisation	Researchers conducting the project (including whether student researchers are involved) Organisations which are involved / responsible Organisations which have given approvals Relationship between researchers and participants and organisations
Participant description	How and why participants are chosen How participants are recruited How many participants are to be recruited
Participant experience	What will happen to the participant, what will they have to do, what will they experience? Benefits to individual, community, and contribution to knowledge Risks to individual, community Consequences of participation
Participant options	Alternatives to participation Whether participation may be for part of project or only for whole of project Whether any of the following will be provided: counselling, post research follow-up, or post research access to services, equipment or goods
Participants rights and responsibilities	That participation is voluntary That participants can withdraw, how to withdraw and what consequences may follow Expectations on participants, consequences of non-compliance with the protocol How to seek more information How to raise a concern or make a complaint
Handling of information	How information will be accessed, collected, used, stored, and to whom data will be disclosed Can participants withdraw their information, how, when Confidentiality of information Ownership of information Subsequent use of information Storage and disposal of information
Unlawful conduct	Whether researcher has any obligations to report unlawful conduct of participant
Financial issues	How the project is funded Declaration of any duality of interests Compensation entitlements Costs to participants Payments, reimbursements to participants Commercial application of results

Core Elements	Issues to consider in participant information
Results	What will participants be told, when and by whom Will individual results be provided What are the consequences of being told or not being told the results of research How will results be reported / published Ownership of intellectual property and commercial benefits
Cessation	Circumstances under which the participation of an individual might cease Circumstances under which the project might be terminated

Research Specific Elements

Provision of information to participants about the following topics should be considered as may be relevant to the research project.

Specific to project or participant group	Additional issues to consider in participant information
People who belong to a collectivity	describe consultation process to date and involvement of leaders whether status of being in collectivity will be recorded
Aboriginal and/or Torres Strait Islander peoples	describe consultation process to date and involvement of leaders whether ATSI status will be recorded