

# **Experiences of an Unsuccessful Ethical Application Process Involving Research on a Sensitive Topic**

## **Suicide in Older People in Rural Areas**

**Rural Research Capacity Building Program**

**Research Project Final Report**

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**GREATER SOUTHERN  
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**Title of Proposed Research Project:**

Looking Beyond the Demographics: Identifying Factors Contributing to Suicide in the over 65's in a Rural Region: A Thematic Analysis of Coroners Files 1999 – 2005

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**Glossary:**

IRCST	- NSW Institute of Rural Clinical Services and Teaching
RRCBP	- Rural Research Capacity Building Program
GSAHS	- Greater Southern Area Health Service
CSU	- Charles Sturt University
NSW ESPN	- NSW Elderly Suicide Prevention Network
WHO	- World Health Organisation
ABS	- Australian Bureau of Statistics
NHMRC	- National Health & Medical Research Council
NOK	- Next of Kin
SPA	- Suicide Prevention Australia
GP	- General Practitioner
AUSEINET	- Australian Network for Promotion, Prevention and Early Intervention for Mental Health

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## 1. Executive Summary

### **Introduction:**

In 2006 the NSW Institute of Rural Clinical Services and Teaching (IRCST) within NSW Health initiated and commenced an innovative program, the Rural Research Capacity Building Program (RRCBP), to provide opportunities for rural clinicians to increase their research skills and be supported in the process.

As a member of the 2006 RRCBP the author undertook the development of a work related research project relating to suicide prevention in older people. The rationale for undertaking any research in health care is based on the concept of Evidence Based Practice. The importance of having up to date evidence to support clinical practice is well documented. It is also important to have local rural evidence to support rural practice. Localising suicide data and investigating the rural contextual issues that impact on particular communities and groups of people is important in the development of any intervention, prevention or promotion strategy.

Suicide across the lifespan has been identified and recognised as a major public health issue by the World Health Organisation (WHO) (in O'Connell et al 2004) and is a tragedy no matter which age group is affected. Rates of suicide are also reported as being higher in rural than metropolitan areas (Hirsch 2006). While suicide is an issue across the lifespan it has been proposed that the ageing of the population will see an increase in suicide numbers and rates for older people.

### **Research Plan:**

A comprehensive literature review on suicide in older people and in rural areas revealed several gaps in the information available regarding contextual data on suicide in older people from a rural region. Few studies, if any, had been completed in rural areas about older people and suicide. The evidence available on suicide in rural areas was predominantly relating to farmers and younger people.

From consultation with the GSAHS Population Health Unit it was determined that approximately 50 people over 65 years of age had died by suicide in the rural region covered by the health service from 1999 to 2005. A research proposal was then developed which aimed at undertaking a thematic analysis of Coroners files for those 50 people to illuminate possible contextual information that could inform the development of mental health promotion, prevention and intervention strategies.

The anticipated outcomes of the research were considered to include:

- the development of local evidence base data to inform and improve rural clinical practice with older people at risk and with mental health issues;
- strengthening the capacity and capability of health and community services staff to identify and respond to older people at risk of depression and suicide;
- informing the development of aged mental health promotion, prevention and education programs in the health service;
- having local evidence will make it more meaningful to the communities which the health service works with and bring it home that suicide in older people is a local issue and reinforce that prevention is everyone's business.

- Adding to the literature and improve knowledge on suicide in older people in rural areas
- Highlight other questions that need to be answered or further areas of research that need to be undertaken in this area

**General:**

It could be argued that there is sufficient information in the public arena already on suicide in older people generally and for rural communities without having to undertake additional research that may cause discomfort to the relatives of the deceased. However, there is still a need to have local and up to date evidence to support and inform the work that is being done and for future development of effective programs and strategies. It is also important to have research based in rural areas taking into account the rural environment as conditions and contextual circumstances are often very different to those in metropolitan areas where the majority of research has been undertaken.

Due to the sensitive nature of the topic and Ethics Committee concerns regarding the adequate supervision of a novice researcher with this type of research, the project also became the basis of a Masters Dissertation with two experienced supervisors appointed.

A number of challenges were faced by the author in attempting to gain Ethics approval for the research proposal. Overall the Ethics application process took 12 to 18 months with the research proposal being submitted to the local Ethics Committee three times and with several changes made to the proposal as a result. Ultimately, the Ethics Committee chose not to approve the project.

Alternative strategies were investigated in order to forward the research at a future point in time, and a further limited literature review was carried out regarding the ethics process and issues pertaining to confidentiality in rural research, consent and privacy, and the public interest.

While it was recognised that the topic of suicide may be a sensitive issue to some in the community, it was surprising how the topic and the need to gain consent were issues perceived very differently by the various stakeholders involved. All parties appeared to be advocating on behalf of the subjects and their families but from different perspectives, though legally it was the Ethics Committee's view that prevailed.

With any sensitive research, particularly in rural areas, it is imperative that confidentiality and privacy be preserved as much as possible. De-identification of cases alone is often not sufficient in rural areas to mask the individuals/community involved. This can often leave rural researchers in a dilemma as to how to ethically undertake research and disseminate their findings.

**Results:**

While the research was not able to be undertaken, there have still been some outcomes from the project that can be described.

We know that

- older people in rural areas do take their own lives,

- the majority of older people taking their own lives in the GSAHS are male, which is consistent with state and national suicide trends
- there is a definite gap in the literature and evidence regarding contextual information dealing with suicide of older people in rural areas.
- a general list of risk factors for suicide in both older people and rural communities have been ascertained from the literature
- the main risk factor for suicide in older people is depression (from urban studies).

The literature also implied that a consequence of the ageing of the population could see increased suicide numbers and rates in older people, and this has implications for rural communities which are ageing. The review also highlighted the need for more evidence based practice in rural areas as well as providing a basis for further work required in the area.

While the author found the ethics process quite frustrating and inconsistent at times, the Ethics Committee feedback was also a positive as it constantly challenged the reasoning behind the choice of particular methodologies and provided suggestions about alternative ways of obtaining the information that may not previously have been considered.

Based upon the author's critical analysis of their ethics application process the following are some of the learnings and suggestions that have resulted from this.

1. Become familiar with Ethics application guidelines and what they mean and use them in your application. The NHMRC guidelines are a useful tool to consult in this.
2. Learn the language or jargon of the Ethics process and quote it back to them. Sometimes the meaning of words is interpreted differently by the Ethics Committee to what you had intended. By using the Ethics language then misunderstandings regarding concepts and methodology is minimised.
3. The importance of mentors and supervisors for their advice, assistance and guidance along the way is invaluable, not only for navigating the process but also for ensuring that you are trying to answer your research topic in an ethical way. This is especially important for novice researchers when undertaking research on sensitive topics. Also use the Ethics Committee themselves and/or their Executive Officer for their advice and to clarify issues you are not sure about.
4. Effective time management is essential when endeavouring to combine a busy work and clinical role with added research responsibilities
5. Explain everything and with little jargon. The Keep It Simple principle certainly applies. Don't assume that members of the Ethics Committee know what you are talking about or have a background in your area of expertise, or that they understand the importance of the research topic to your field. They often don't.

6. While trying to explain everything adequately it is still important to be as concise as possible in writing the application. Ethics Committee members usually have several applications to consider and little time to do so before the next meeting. The easier it is for committee members to read and comprehend the application the better.
7. The Ethics process certainly assists one to forward plan with the proposed research project. It is important and necessary to think about and consider what it is that you want out of the proposed research, how you are going to achieve this, expected outcomes, what tools and research methods will be utilised, consent issues, and how to maintain confidentiality and privacy of subjects. The Ethics application form and process certainly requires one to have considered these issues and be able to articulate them.
8. Be familiar with conditions regarding confidentiality, consent, and privacy, particularly with sensitive topics, and ensure that your reasoning for the research being in the public interest is tight and outweighs the need for privacy.
9. Having a sound strategy for the securing of information and data both during and at completion of the project is important, as is being able to elaborate on this within the ethics application form.
10. It is important to not be too focussed on doing the research in a particular way. Keeping an open mind is valuable as there may be other ways of obtaining the information that you hadn't considered. Often Ethics Committees provide valuable feedback regarding your research proposal with suggestions and requests for modifications before they approve it.

On the other hand if the research methodology chosen for the project is what you consider the best option for your needs after considering various alternatives then clearly outlining and justifying the methods chosen is vital.

The importance of having a good research design, methodology and process in place is vital to both being able to effectively answer one's research topic question but also for carrying out the research in an ethical way. An integral part of the preparation of the research proposal is deciding on the theoretical framework and methodologies that the research project is being built upon. This is where the author found their involvement in the RRCBP and the education and knowledge imparted being invaluable, as was the assistance provided by the CSU research supervisors.

### **Conclusion**

Due to the research project on suicide in older people in rural areas not gaining approval from the local Ethics Committee, this project ultimately evolved into two separate investigations. The first being an exploration of the literature surrounding suicide in older people in rural areas, and the second an examination of ethics concepts and processes.

While the suicide literature review did establish that there is a growing amount of information regarding suicide in older people generally, this research was predominantly

based on urban cohorts. The rural suicide literature dealt mainly with farmers and young people with little, if any, reference to older people over 65 years of age. What the review did highlight, though, was the need for more evidence based practice in rural areas as well as providing a basis for further work required in the area.

As Davis et al (2008) contend, "Comparative studies on retirement, health promotion, community participation, health seeking behaviour, health services are needed to better understand the complexities of the ageing experience across different types of rural communities and support healthy ageing". Including mental health issues and suicide in these studies is vital to having an overall picture of the context and environment of older people in rural areas. Having this information will aid the development of a range of health promotion and intervention programs focusing on the needs of older people in different regions and assist to enhance their overall health and wellbeing, and their increased resilience.

Both the review of the ethics literature and the experience of going through an unsuccessful ethics application process has greatly increased the author's understanding and knowledge of the process and issues involved. As a novice researcher this was an invaluable experience and with hindsight the lessons learned will certainly assist with any future research projects they are involved in, and it is also hoped that this reflection and the insights gained will aid other novice researchers in their research journeys.

## 2. Introduction

In 2006 the NSW Institute of Rural Clinical Services and Teaching (IRCST) within NSW Health initiated and commenced an innovative program, the Rural Research Capacity Building Program (RRCBP), to provide opportunities for rural clinicians to increase their research skills and be supported in the process.

A requirement of the RRCBP is that participants develop and undertake a work related research project. The research proposal developed by the author, and which also became the basis for a Masters Dissertation with Charles Sturt University (CSU), related to suicide in older people in a rural region.

Suicide across the lifespan has been identified and recognised as a major public health issue by the World Health Organisation (WHO) (in O'Connell et al 2004) and is a tragedy no matter which age group is affected. Rates of suicide are also reported as being higher in rural than metropolitan areas (Hirsch 2006). It has also been identified and well documented by the WHO (as quoted in O'Connell et al 2004) that there are high suicide rates in older people in Australia and other Western countries (Burdekin 1993 p511; Cattell et al 1995 p451; Conwell et al 2002; Draper 2003; Livermore et al 2005; NSW Health 2006).

The establishment of the NSW Elderly Suicide Prevention Network (ESPN) in 1998 also reflected concerns regarding older people and efforts to ensure a better state wide approach to suicide prevention in older people (Livermore et al 2005).

In reviewing the literature dealing with suicide in both older people and rural communities, it was found that while a number of risk factors had been documented for both areas, there had been a limited focus on suicide prevention and management in older people (WHO in O'Connell 2004; De Leo 2002; Conwell 2002). This is particularly so in the various studies that have discussed the issues and linkages between rurality and suicide, and which occur predominantly in the domain of farmers and younger people. On investigation the number of suicide deaths for older people within the health service region for the proposed study time span of 1999 to 2005 was 50 people.

The rationale for undertaking any research in health care is based on the concept of Evidence Based Practice. The importance of having up to date evidence to support clinical practice is well documented. As much of the research on suicide in older people is based in urban environments and therefore has limited relevance to rural communities (Hirsch 2006), it is important to have local rural evidence to support rural practice. Localising suicide data and investigating the rural contextual issues that impact on particular communities and groups of people is important in the development of any intervention, prevention or promotion strategy.

A number of challenges within the Ethics process were encountered by the author. While the review of the literature revealed a number of gaps pertaining to the topic, particularly for rural areas, the sensitive nature of the subject coupled with issues of small populations and confidentiality, consent, privacy, and being a novice researcher, to name a few, ultimately resulted in the local Ethics Committee not approving the project. However, the process did encourage the further investigation of possible

alternative strategies as a way to forward the research, as well as improving the understanding of the ethics process itself.

This report will discuss the RRCBP, the research topic, the ethics process, as well as some of the issues and challenges faced in the hope that this critical analysis of one novice researchers experience will assist other rural novice researchers along their journeys.

### 3. Background

#### RRCBP

The RRCBP aims to enhance the development of a research culture within both rural clinicians and rural health services. It is an annual program where up to 30 rural clinicians across NSW are provided an opportunity and supported to undertake a work related research project. Support is provided via mentoring, basic education on research theory and skills, access to the expertise and knowledge of experienced researchers, and the provision of finances to the area health service to support clinicians to undertake their research one day per week over a two year period.

The NSW IRCST commenced the RRCBP in 2006 with funding from NSW Health. The author was part of the inaugural intake of the program in 2006 and was employed at that time by Greater Southern Area Health Service (GSAHS), one of the four rural area health services in NSW.

#### Research Topic Rationale

Suicide is a rare event and accounts for approximately 1.6% of all deaths in Australia, with its impact and consequences, however, being felt acutely by the family and friends of those left behind (Australian Bureau of Statistics 2004).

Development of the actual research project topic –

*"Looking Beyond the Demographics: Identifying Factors Contributing To Suicide in the over 65's in a Rural Region: A Thematic Analysis of Coroners Files 1999 - 2005"*

grew out of the work role of the author whose position related specifically to suicide and depression prevention and mental health promotion in older people for the rural health service in which they were employed. Also, ongoing involvement with the NSW ESPN highlighted for the author the imbalance of information available regarding suicide in older people in rural areas compared to metropolitan areas. There was a need to have local rural evidence to base the important prevention programs and practice on, as much of the prevention work developed and implemented in GSAHS, NSW and Australia was based on studies undertaken in metropolitan areas of Australia, and from overseas.

#### Project Aim and Plan

As there had been little data available regarding the particular issues or factors for older people in rural areas that could contribute to their decision to take their own life, the aim of the research project was to look beyond the basic demographics to develop a rich contextual picture to complement and give life to the statistics and the stories of those people who have died who make up these figures.

It was planned to audit Coroners files for those people over 65 years who had died from suicide within the region covered by the rural area health service. Undertaking a thematic analysis of the information contained in the Coroners files could help to illuminate the particular rural issues involved and the practical aspects of prevention for this group of people to be better understood. In this way the information could be utilised to improve knowledge, understanding, and practice in order to ultimately assist in preventing other at risk older people of dying unnecessarily.

Other data collection methodologies were considered in the development of the research proposal. However, auditing of coroners files was felt to be the most appropriate strategy to utilise, particularly, as these files were considered the first step in gaining data thus providing a baseline of information that could be built upon. As well, it is a proven method that has been utilised in many previous suicide research studies.

It was anticipated that the outcomes of the research would also include:

- the development of local evidence base data to inform and improve rural clinical practice with older people at risk and with mental health issues;
- strengthening the capacity and capability of health and community services staff to identify and respond to older people at risk of depression and suicide;
- informing the development of aged mental health promotion, prevention and education programs in the health service;
- having local evidence will make it more meaningful to the communities which the health service works with and bring it home that suicide in older people is a local issue and reinforce that prevention is everyone's business.
- Adding to the literature and improve knowledge on suicide in older people in rural areas
- Highlight other questions that need to be answered or further areas of research that need to be undertaken in this area

### Literature Review

A comprehensive literature review was carried out on the subject of suicide in older people and rural suicide to determine what information was known regarding suicide in older people in rural areas so as to both not duplicate research that had already been undertaken, and to elucidate what gaps existed. It was found that gaps certainly existed regarding the availability of contextual information to do with suicide in older people in rural areas. The studies in Australia that had been reported on were mainly carried out in urban environments. Few studies, if any, had been completed in rural areas about older people and suicide. The evidence available on suicide in rural areas was predominantly relating to farmers and younger people. While there is also a growing amount of literature focusing on older people in rural areas and the ageing process, little mention is made of mental health and suicide in these articles.

Later a further review of the literature was performed regarding issues raised within the context of the Ethics process such as confidentiality in rural research, consent and privacy, novice researchers and sensitive topics.

A brief summary of the literature reviews are below.

#### *Suicide - Elderly and Rural*

While the overall rates of suicide in NSW and Australia have decreased slightly (ABS 2007) as has the rate for older people over 75, the rates are still considered to be high. While the actual numbers of older people taking their own lives in the past have been small compared to other age groups due to smaller population size, this trend is theorized to increase with the ageing of the population. Beautrais and Draper in separate papers in 2003 have both indicated that with the ageing of the population the numbers and rates of suicide in older people can be expected to increase.

O'Connell et al (2004) have also pointed out that "Although the prevalence for completed suicides in elderly people does not at first suggest a major public health problem, completed suicides are likely to represent only the tip of the iceberg for psychological, physical, and social health problems in older people". It has also been shown that "older people have a higher risk of completed suicide and higher lethality due to intent to die and frailty", and that "suicide in the elderly is more planned and less impulsive than younger people" (De Leo 2002). This is demonstrated in attempt to death ratios. Younger people are reported to have a ratio of between 200:1 and 300:1 while the ratio for older people is 4:1 (Johnston 1996; Conwell 2002; O'Connell 2004; NSW Health 2006). This means that the window for detecting risk in older people is very small.

A universal finding in the literature is the strong association between depression and suicide in older people with up to 90% of older people who have died by suicide having had a depression (Draper 1994, 1998, 2003; Cattell et al 1995; Johnston et al 1996; Duffy et al 1997; Chiu et al 2001; De Leo 2002; Turvey et al 2002; Conwell et al 2002; Beautrais 2003; O'Connell et al 2004; Livermore et al 2005; Harwood et al 2006; NSW Health 2006). Improving the identification, treatment and management of depression in older people was seen as one of the most effective suicide prevention strategies to date (Burdekin 1993; Cattell et al 1995; Chiu et al 2001; De Leo 2002; Beautrais 2003; Draper 2003; Livermore et al 2005).

Apart from depression, being male and over 75 years of age were the predominant risk factors referred to in the various studies (Draper 1994, 2003; Johnston et al 1996; Duffy et al 1997; Chiu et al 2001; De Leo 2002; Beautrais 2003; O'Connell et al 2004; Livermore et al 2005; NSW Health 2006). The documented psychosocial stressors that have a major influence on the development of suicidal behaviour in older people include grief and loss issues particularly the loss of a spouse; social isolation; poor relationships and lack of family/community/social support; change in circumstances; alcohol and substance abuse; financial issues such as reduced income post retirement; feelings of hopelessness and helplessness; and a previous suicide attempt (Johnston et al 1996; De Leo 2002; Draper 1994, 2003; Turvey et al 2004; Livermore et al 2005; NSW Health 2006).

The literature informs us that suicide rates are higher in rural compared to metropolitan areas (Page et al 2002; Caldwell et al 2004; Taylor et al 2006; Hirsch et al 2006), and that age and male gender are the most consistent factors across studies of rural suicide (Hirsch et al 2006; Taylor et al 2005). However, these studies have mainly focused on farmers and younger people. As Thacore et al (2000) also contend – "Data [on suicide] at the regional level are not available, yet these very data are crucial in formulating intervention strategies".

The rural suicide literature was found to be misleading at times as most studies deal with issues of suicide that related mainly to the farming community. However, as Taylor et al (2005 p288) pointed out not all rural residents live on farms, and rural communities are heterogeneous in nature (Judd et al 2006; Levin et al 2005). Also, these articles have further limitations, recognised by Hirsch (2006), as what constitutes urban and rural is often defined differently between many of the studies.

While geographic isolation and remoteness have been cited by many authors as a contributing factor to suicide in rural areas (Hirsch 2006; Levin 2005; Taylor 2005; NSW Health 2006), Judd (2006) contends that psychosocial factors were more important determinants than remoteness on its own. Rural life, culture and attitudes have also been discussed as contextual issues that could contribute to increased suicide risk (Taylor 2005; Judd 2006; Judd et al 2006; Hirsch 2006).

Of particular note in several studies has been the role of economic factors in suicide in rural areas. Economic downturn and eroding of rural infrastructure (Hirsch 2006 p192), changing agricultural policy (Judd et al 2006), restructuring of the rural economy (Page et al 2002) have all been described as having a significant impact on farming communities. Turvey et al (2002) found that financial loss or a change in financial status rather than low income or poverty per se was the main risk factor, after controlling for depression, for suicidal ideation in a rural community.

The general links between rurality and suicide are apparent from the literature, but little evidence was available regarding the context and factors contributing to suicide for older people in rural areas. General risk factors for suicide in both the elderly and rural communities were well documented in the literature. While many of the risk factors may have been similar between the two groups, it was difficult to determine linkages between the two areas of suicide research due to a lack of empirical evidence.

#### *Ethics - Confidentiality in Rural Research, Consent and Privacy, In the Public Interest*

To better understand the rationale behind the decisions of the local Ethics Committee regarding issues with the proposed research project a further limited review of the literature was undertaken dealing with the particular topics of confidentiality, consent and privacy, the public interest, and a general overview of the ethical process. This review also assisted the author with increasing their knowledge and comprehension of the ethics process itself. While a limited review of the ethics literature was carried out as part of the groundwork for preparation of the initial ethics application this further review was done in relation to specific issues raised during the ethics process.

The starting point in the literature was the National Health and Medical Research Council (NHMRC) ethics and privacy guidelines, as well as the NSW Health privacy, research and release of data policies. These documents combined with several articles from the literature provided a good overview of ethics processes and the main issues they are dealing with, as well as presenting a rationale for many of the guidelines that exist. Privacy NSW – Statutory Guidelines on Research (2004 p14) remind us that “an overriding obligation....is at all times to respect the dignity and privacy of the individual”. It is evident from the literature as well that the ethics application process and forms have been tightened up considerably in recent times in response to many of these issues.

The literature certainly explained well the need to protect vulnerable groups from harmful research, the importance of informed consent, and the need to maintain confidentiality and privacy particularly for research participants (Alston & Bowles, 2003; Bell, 2005; Leedy & Ormrod, 2005; Parsons & Oates, 2004; Portney & Watkins, 2000b). However, it did not seem to cover these issues well in regards to paper based research and when substitute consent is required due to the ‘participants’ being deceased. In

similar suicide research to that which was proposed by the author it appeared that this substitute consent was provided by the Coroner. No mention was made of seeking consent from families unless there was an intention to undertake a psychological autopsy and interview family and key informants.

A slightly different perspective was put forward regarding consent by the Office of the Privacy Commissioner in a presentation to the 2007 National Research Ethics Conference regarding the interaction between the Privacy Act and research. It was noted that special provisions for health and medical research do exist "Where consent is 'impracticable' and "handling [of the information] is in accordance with relevant guidelines, then the Privacy Act permits personal information to be used and disclosed for health or medical related research without consent".

It was evident, also, from the literature that there was considerable discussion and differences of opinion regarding what constitutes informed consent, and how this should be obtained. There also appeared to be some dissatisfaction with the increasing complexity and bureaucratisation of the research ethics application process, while others applauded the increased stringency of this process as a necessary step. Davison et al (2006) in their discussion of negotiating the ethical review process infer that there has long been arguments by researchers and ethicists regarding the purpose of current ethics review practices, the inadequacies of [ethics] protocols for qualitative and collaborative research, and the contentiousness of standards for informed consent.

Suicide is a sensitive topic and Gibson (1996) defines sensitive research as that 'which potentially poses a substantial threat to those who are or have been involved'. Further, Gibson (1996) states that what is sensitive to one group may not be to others. Also, that obtaining ethical approval for proposed research in a sensitive area may be a significant problem with them twice as likely to be rejected.

The NHMRC Guidelines regarding the use and disclosure of health information are based on the premise that they can only be approved if it is satisfied that the public interest in the use of the information outweighs the public interest in maintaining privacy. Defining "Public Interest" is not well done in the official guidelines, though they have set out a process for ethics committees to follow to determine the public interest. It seems to be a subjective call of the ethics committee involved. The National Statement on Ethical Conduct in Human Research (2007 p14) also highlights that the risks and benefits of research and participants consent must always be considered, and that the likely benefit of the research must justify any risks or harm or discomfort to participants or others. What is interesting though is that the National Statement does imply that assessment of risk inevitably involves the exercise of judgement (p15).

From a rural perspective Fraser et al (2006) contend that "Research focusing on rural issues, including health, is important, as the population and health needs of this group of people are often different from those of their urban counterparts". However, it was also pointed out by Fraser (2006) that "Ethically, research projects in small communities may not be publishable if the population is identifiable" and that "often de-identification [of subjects/communities] is inadequate and the people concerned can be identified by a small amount of demographic information". Which means according to Fraser (2006)

that "Health researchers need to consider the potential benefits and risks of [their research] and publishing their findings".

### Theoretical Framework

"Qualitative researchers are interested in studying people's perceptions, views, intentions and logic of thinking using those people's words. Quantitative researchers are concerned with testing hypotheses and establishing cause-effect relationships which can be analysed using statistical procedures" (Axford et al 2004).

While the author's personal interest and preference is for the interpretive and descriptive approaches to research encompassed in the qualitative paradigm an increased understanding and appreciation of how research and theory are related and the different theoretical approaches has been one of the main benefits from involvement with and participation in the RRCBP.

Identifying the theoretical framework behind the research being undertaken and understanding why they are important had previously been a struggle for the author. While being aware on one level that their own values could influence the development of the research question and assumptions made about possible outcomes, the author had not consciously thought that this translated into a theoretical framework. However, the importance and integral nature of the researchers own values in influencing both the research question and how it is investigated is confirmed in the literature (Alston & Bowles, 2003; Horsfall et al., 2007).

Also, it has been pointed out in the literature that the philosophy of the professional discipline one belongs to can influence how a subject matter is perceived or conceptualised (Portney & Watkins, 2000a). Thus the author's philosophical background and perceptions are influenced by being a health worker with a social welfare background based in aged mental health, and who would tend to work on the premise found in the literature that "social research is more about critical awareness, careful thinking and the ability to view situations from new perspectives than about numbers" (Alston & Bowles, 2003), and that it is about improving our practice for the benefit of clients (Alston & Bowles, 2003; Bell, 2005; Horsfall et al., 2007; Minichiello et al., 2004; Sim & Wright, 2000).

Primarily the research project was to be qualitative in nature with the methodology that was to be utilised incorporating a mixed method approach that is mainly descriptive in nature but with features of exploratory and explanatory research. This continuum and mixed method approach is certainly supported in the literature (Alston & Bowles, 2003; Axford et al., 2004; Portney & Watkins, 2000a).

Based in grounded theory, the proposed methodological approach to interpreting the data from the Coroner's files was to be a thematic analysis of the contents thus summarising and making sense of the emerging issues and themes. According to Grbich (2007 p9) thematic analysis occurs when all the data are in and it is the process of segmentation, categorization and relinking of aspects of the data base prior to its final interpretation.

Interpretive approaches to research can provide a much richer picture of the context and experiences of people, as well as help to understand the phenomenon being studied (Alston and Bowles, 2003, Berg, 1995, Heading, 2006, Leedy and Ormrod, 2005, Grbich, 1999, Sarantakos, 2005) than of quantitative methods alone. This can be demonstrated from the studies in the field of suicide prevention. While the quantitative statistics gained about suicide rates do give us good information regarding the numbers involved, trends, the methods used, the age range, and gender of those who have died by suicide they do not inform us about the context behind the person's suicide or the factors contributing to their death.

Qualitative research methods such as documentary analysis of coroner's files, psychological autopsies which include interviews with key informants, case studies, prospective studies, and clinical follow up studies can and do help us to fill the gaps and understand the context behind the statistics, give a voice to the experiences of the people involved, and have enabled the determination of risk factors which assist with the development of suicide prevention strategies.

## 4. Methods

As previously stated the research project was to be qualitative in nature with the methodology that was to be utilised incorporating a mixed method approach that is mainly descriptive in nature but with features of exploratory and explanatory research.

While the research project did not proceed, the following are the range of methods that were initially utilised to gain the information required for developing the research proposal, and those intended to be employed in the actual implementation of the research plan. With subsequent feedback from the Ethics Committee several of the intended methodologies were modified or changed as a result.

### *Literature Reviews*

Initially a literature review was undertaken regarding the subject matter of suicide in the elderly and in rural communities. In searching for appropriate literature the author has utilised books, government policy documents, and articles already in their possession, referred to relevant suicide related websites i.e. Auseinet, NSW Health, SPA and also followed up bibliographic references from sourced articles.

An electronic search using CIAP, Google, GSAHS Library, CSU Library, and Joanna Briggs Institute was undertaken. The data bases utilised included Psych Info, Journals @ Ovid, Cochrane Collaboration. Search terms used included suicide; elderly; rural; suicide and elderly; rural suicide; suicide prevention; aged; preventing late life suicide; rural mental health; risk factors; depression; discrimination; ageism; stigma; evidence based practice.

Information and resources provided via the RRCBP and CSU were utilised to learn more about research methods, theory and practice to assist in determining what theoretical basis the author was using for the research as well as the different methodological approaches and processes that could be employed, in particular, the theoretical basis behind thematic analysis. Invaluable support and assistance was provided by both the RRCBP and CSU regarding ethics and ethical processes.

The later literature review regarding the ethics process was electronic in nature and encompassed search terms such as consent and privacy; sensitive research; rural research; novice researchers; ethics; ethical processes; ethics committees; coroners; confidentiality in rural research; research ethics. A more detailed exploration of the research methodology and designs utilised in published suicide research articles was also undertaken to determine if alternative strategies could be utilised and on the issue of consent with the auditing of coroners files.

### *Selection Criteria*

The Selection Criteria established for the research subjects were

- people over 65 years of age
- who were living within the region covered by the area health service and
- that the Coroner had determined had died by suicide between the years 1999 and 2005.

Initially, it had been intended to focus on only one particular area of the health service region. However, given the possible confidentiality and identification issues the research was extended to include the whole of the GSAHS which is a much larger geographical region. By doing this it also provided a larger sample size.

### *Data Collection and Analysis*

Auditing of Coroners files for these people was proposed as the chief method of data collection. Reasons for selecting this method for the proposed research included:

- potentially all the information regarding the person who had died by suicide was in the one place;
- with the limited time frame and resources available to undertake the research it was the most manageable for one person to undertake;
- it was also the least intrusive method with no interviews with family members or other key people involved;
- with approximately 50 coroners cases it was considered a good sample number and manageable within the research project time frame by one person
- the sample was also felt to be the least biased in regards to selection criteria as it included all official suicide deaths for those over 65 years in the region.
- the audit was also seen as being the first step in a research process. It would gain the basic information, determine possible gaps in the information, and through the thematic analysis highlight other potential questions or issues for follow up research.

While other research methodologies were considered they were seen more as follow up strategies after the base line information was gained rather than a starting point. Their focus would be different and could fill in the gaps or provide possible answers to questions raised from the initial research. These potential alternative strategies included:

- advertising for and interviewing the families of those who had died;
- interviewing or undertaking focus groups with older people from rural areas regarding their perceptions of suicide;
- interviewing or focus groups with health and community workers re their perceptions of suicide in older people;
- interviewing or surveying GPs;
- auditing of mental health service files;
- interviewing aged mental health workers and their clients.

An essential part of the research process and method incorporated consultation with key stakeholders. This included the NSW State Coroner and Wagga Wagga local Coroner; the GSAHS Population Health Unit; the GSAHS Ethics Committee Executive Officer; Mentors; RRCBP; GSAHS Mental Health Service Management; the NSW ESPN, and CSU Masters Supervisors. This consultation process revolved around data collection, access and consent issues as well as bureaucratic procedures to be undertaken.

Once the primary data had been collected it was intended to review it and undertake a thematic analysis of the contents thus illuminating common themes and issues. Information found in Coroner's files usually, but not always, encompasses the following:

- Police form and report
- Capturing of Demographics
  - Age
  - Nationality
  - Pension
  - Marital state
  - Where live
- Nature of the scene
- Interviews that Police have done with
  - Next of Kin / Family
  - GPs
  - Key witnesses
- Family statements re circumstances leading up to the suicide
- Photos
- Suicide Notes
- Comprehensive timeline of events
- Results of the autopsy and toxicology
- Reasonable idea of the health and physical condition of the person
- Coroner's determination

As not all the information was likely to be available in all the coroners files it was intended to focus mainly on the family and GP statements; the demographics particularly where the person lived; the police report; and reports on the physical and mental health of the person.

It is in the context and detail of their stories found in the Coroner's files that particular risk factors and rural issues might be illuminated, for example -

social isolation	ie -	live on a farm, family moved to city for work
financial issues	ie -	drought impacting on the farm, problems with family business, no cash flow, banks foreclosing on loans, reduced income post retirement
depression	ie -	lack of access to services and support, illness not recognised, feels a burden on family
grief and loss	ie -	loss of farm, moving to town, shooting of stock, loss of spouse, loss of driver's licence, no one to pass the farm on to, can't do what used to on the farm
method	ie -	access to guns, pesticides

#### *Information Security*

Securing the information during and at the finalisation of the research project was also an expressed concern of the ethics process. This was partly due to the researcher needing to physically visit several local Coroner's offices in the region where the relevant coroners files were kept, as well as ensuring the confidentiality and privacy of the subjects. After liaising with colleagues, supervisors, the Ethics Committee Executive Officer, and other researchers regarding their experiences, a strategy was proposed. This included:

- developing individual client data collection sheets for each coroner's case
- keeping these in a transportable and lockable document case during the data collection phase

- Coding the individual sheets so only the researcher would be able to trace the identity and geographical location of the deceased
- Development of an excel suicide data collection report template to include the overall coded data for each of the 50 suicide cases being investigated and to enable some comparison of this basic data
- No identifying information regarding the families of the deceased was to be recorded
- If there is less than five of a specific detail that is intended to be reported on then this information is either not used or described as a whole population rather than individually
- During and at the conclusion of the project it was intended to file any paper based information in a locked filing cabinet
- Any computer based information would be on GSAHS's password accessible system and only accessible by the principal researcher.
- One back up copy only of the information would have been stored on either a master CD/DVD/USB stick
- At the end of the project and if the principal researcher left the organisation all the files would have been transferred to the GSAHS Aged Care Evaluation Unit for secure storage.

#### *Consent*

As the research would have involved predominantly a paper based audit and utilised the files of deceased people whose death was investigated in a public forum by the Coroner, consent for use of the files for research purposes was seen by the author as coming from the State Coroner. This view was supported by the literature. However, the Ethics Committee viewed it differently, and required that the Next of Kin (NOK) be contacted to provide formal consent. As such draft NOK Research Project Information and Consent Forms were developed. These are attached.

#### *Dissemination of Results*

Following the completion of the research it was intended to publicise the findings. Initially, a report would have been written and submitted to the GSAHS, RRCBP, and CSU for their information, as well as a copy being sent to the NSW ESPN. The relevant findings would also have been incorporated into and informed the development of suicide prevention and mental health promotion programs for the area health service. Having an article published in a relevant journal and presenting the findings at appropriate conferences and/or forums would have assisted in a wider dissemination of the information gained from the research.

#### *Ethics Application Forms*

Completing the ethics application forms for a research project is a requirement and as much part of the research methodology as is the actual data collection. It is important to familiarise oneself with the forms and the processes involved as well as the language used. Using NH&MRC guidelines, supervisors, mentors, and the executive officer of the local ethics committee to assist with this is essential. How one answers the questions and the language used will have a bearing on how the proposed research is accepted and interpreted by the Ethics Committee.

## 5. Results

Given the non approval of the research proposal by the Ethics Committee, the project plan could not be put in place or formal research undertaken. As such few new findings can be reported on.

Even though alternative strategies were investigated and some possibilities identified to assist with the project moving forward in a different direction, ultimately time availability was a key factor in this not happening. With the RRCBP time frame of two years coming to an end coupled with the author being due to take extended leave this did not leave much room for movement. Where had the time gone? With a time allocation of one day per week to work on the research, the development of the research proposal including the literature review took approximately six to eight months, and as stated previously the ethics application process took 12 to 18 months.

Despite the above and the research not being undertaken, there have still been some outcomes from the project that can be described that resulted from the initial investigations in regards to developing the research proposal and subsequent literature reviews.

### ***Suicide:***

What do we know about Suicide in Older People in Rural Areas?

- Firstly, we do know that older people in rural areas do commit suicide.

From the basic statistics available from the ABS, NSW Health, and the GSAHS Population Health Unit we know that there were 50 people over the age of 65 years who had died by suicide within the region covered by the health service from 1999 to 2005. The total number of deaths by suicide in the GSAHS for all age groups during this period was approximately 357 people. Thus, those aged over 65 years formed 14% of all suicide deaths in the GSAHS for this time period. However, more detailed data was not available until Ethics approval was gained in order to protect the privacy of the individuals.

What we also don't know is just as important, that is the rural context in which these deaths occurred. The several Australian studies that have investigated suicide in older people have been based on urban populations. Several research studies from overseas Western countries have found high rates of suicide in older people in rural areas (Hirsch 2006).

When comparing NSW metropolitan with rural area health services the numbers for GSAHS are certainly lower. From statistics available on the total number of suicide deaths for people over 65 years for all NSW rural area health services for the years 2002, 2003 and 2004 respectively we can ascertain that 32, 26 and 21 people died. Whereas the numbers for the metropolitan area health services for the same years were 58, 60 and 76 people. This variance can only partly be explained by the differences in population size. Determining rates is difficult with small populations and can be misleading.

De Leo (2002) suggests that suicidal behaviour in the elderly is often under reported and that many deaths given open or accidental death verdicts by Coroners have upon further investigation of the circumstances surrounding the death indicated possible suicide (Harwood 2006).

Also, it has been proposed in the literature that due to the ageing of the population the suicide numbers and rates for older people will increase (Beautrais 2003; Draper 2003). This could have dramatic consequences for some rural areas where many regions have older populations due to younger members leaving for better education and work opportunities, and have consequently fewer services in place, and in areas where migration of retirees occurs such as to coastal or river towns.

- Secondly, the majority of the older people taking their own life in the GSAHS were male.

The GSAHS statistics did indicate that by far the majority of older people taking their own life in the project time period were male. This trend is in line with NSW, Australian and overseas suicide statistics and research findings. The literature states that apart from depression, being male and over 75 years of age were the predominant risk factors for suicide in older people (Draper 1994, 2003; Johnston et al 1996; Duffy et al 1997; Chiu et al 2001; De Leo 2002; Beautrais 2003; O'Connell et al 2004; Livermore et al 2005; NSW Health 2006).

As reported in the NSW Health Service Plan for Specialist Mental Health Services for Older People (2006 p10), the suicide rate among older men in Australia has generally been high when compared to other age groups. For NSW in 2001 the suicide rate for older people was 13.2 per 100,000, with the rate for older men being 22.8 per 100,000 and 6.3 per 100,000 for older women (ABS in NSW Health 2006). The Service Plan further quotes 2001/02 ABS data which showed that suicide rates for men over 70 years were 21.6 per 100,000 compared to 29.3 for men aged 30-49 years. But the rate in oldest age groups, those over 85, were higher at 32.7 per 100,000 (NSW Health 2006). To put this in context the overall suicide rate for across the lifespan in 2001 was approximately 12 per 100,000.

The literature also informs us that males are less likely to talk to others about their health and well being, and have low help seeking behaviour, thus putting them at greater risk.

- Thirdly, there is a definite gap in the literature and evidence available directly relating to suicide in older people in rural areas

The majority of studies on rural suicide in Australia have generally focused on younger people and farmers. Several studies, as demonstrated by Hirsch (2006) in his review of the literature on rural suicide, showed that the US, Canada, Asia, the UK, and Greece recognised that there was an increased suicide risk for older people in rural areas. Australian literature, generally, has not recognised this increased risk in older people. While Draper (2003) did indicate that there were higher rates in rural areas for younger and older people he did not reference where this data came from.

Whilst it has also been reported by Caldwell (2004), Hirsch (2006) and Judd (2006, 2006) that rural suicide rates are highest in young men and lowest in men over 60, it is recognised that these rates are still much higher than the overall suicide rate. Both Hirsch (2006) and Judd (2006 p190) also indicate that both younger and older rural people are 30-50% more likely to suicide than their urban counterparts. Judd (2006 p193) further states that the elderly are one of several sub groups that have a higher risk of suicide and require further investigation.

Age and male gender are the most consistent factors associated with suicide across the various papers on rural suicide (Hirsch 2006; Taylor et al 2005). The oft quoted statistic of "One male farmer dies from suicide every 4 days" (Page et al 2002) is based on suicide data for the period 1988 to 1997 for the ABS occupational classifications of farm managers and agricultural labourers. These occupational classifications are no longer available which makes comparison of more recent statistics difficult.

- Fourthly, a general list of risk factors for suicide in both older people and rural communities has been ascertained from the literature.

A risk factor is a factor which predicts a higher likelihood of an event occurring. The process that brings someone to the point of taking their own life is complex and involves a range of factors and issues.

The literature in Australia and Overseas does describe many risk factors for suicide in both older people and rural communities. Many of these risk factors may be similar for the two groups. At present, though, it is difficult to determine linkages between the two areas of suicide research due to the apparent lack of Australian empirical evidence regarding suicide in older people in rural areas.

**Table 1: General Suicide Risk Factors**

<b>Classic Risk Factors for People over 65:</b>	<b>Rural Risk Factors:</b>
• Male over 75 years	• Males
• Depression	• Farmers
• Social Isolation	• Social and economic changes ie drought, population decline
• Grief & Loss	• Financial and business related problems
• Loss of Spouse	• Health Service availability and accessibility
• Lack of family / community support	• Rural culture / place
• Chronic Illness / Disease / Pain	• Community attitudes to mental illness
• Change in health status	• Low help seeking behaviour
• Previous Suicide Attempt	• Access to means ie firearms, pesticides
• Rigid Personalities / coping styles	• Isolation and loneliness
• Financial issues	• Mental illness
• Change in circumstances / relationships	• Physical illness
• Ageist Attitudes	• Stress
• Feeling Hopeless / Helpless	• Stigma
• Alcohol & substance abuse	• Hopelessness / helplessness
• Retirement	• Relationship breakdown
• Less likelihood of contacting services to seek help	• Alcohol and substance abuse
	• Lack of social support

Source: Compiled from various articles contained in the Suicide in Older People/Rural Suicide Literature Review

- Fifthly, the most common mental health problem associated with suicide in older people is depression

While the literature informs us that emotional wellbeing generally increases with age, this is not so for an older person who experiences major health problems, disabilities or social disadvantage (NSW Health 2003).

We know, from the literature, that depression has been the main risk factor identified for suicide in older people with up to 90% of older people who have died by suicide having had a depression which has either been unrecognised, undiagnosed or not treated appropriately. Detection and early response to depression is seen in the literature as one of the most effective ways to prevent suicide in older people.

However, other prevention strategies are also considered important, as O'Connell et al (2004) point out, "Although treatment of depression is vital in combating suicide in elderly people, preventive measures at an individual and population level are also essential".

The importance of social supports and community connectedness for older people to their overall health and well being including their mental health has also been highlighted in a number of articles as a crucial element in suicide prevention strategies. As has the improvement of physical and emotional health, exercise, and modification of lifestyle to the promotion of successful ageing (Beautrais 2003; Draper 2003; O'Connell et al 2004; NSW Health 2006).

As previously stated these suicide studies in Australia have focussed on urban cohorts and included little information regarding the experiences of rural older people. Without Ethics approval more in depth local data was not accessible, and as such the mental health status of those older people who had died by suicide not able to be determined.

### *The Ethics Process*

From both the experience and frustration of going through an unsuccessful ethics application process and from the literature the author has learnt a great deal. Hindsight is a wonderful tool and allows for reflection, insight and learning to occur. However, while the author did consider some of the expressed concerns and requirements of the Ethics Committee as being overly stringent and inconsistent at times, the advice and suggested directions provided by them were also very useful.

Despite the concerns of the Ethics Committee, the author came to the conclusion following the critical reflection of the ethics review process that the methodology chosen for the research project i.e. reviewing Coroners files, was the most appropriate one for the project. However, in the writing of this report it became evident that the reasoning provided in the Ethics application by the author for utilising this methodology was not sufficient. Nor had the author adequately allayed the Ethics Committee's concerns regarding the balance of public interest over right to privacy.

With hindsight and experience, the author would have written the ethics application somewhat differently if preparing it now. However, while this may have improved the chances of the research project being approved it would not have guaranteed this.

## 6. Discussion

As the research project was not able to proceed, there is only limited new information that can be reported on and discussed regarding suicide in older people in a rural area. However, from the author's experience of being a novice researcher and going through an unsuccessful ethics application process there have been a number of insights that can be shared.

The question does need to be asked though, with the extent of literature available regarding suicide in older people generally and the growing amount of information about rural suicide, would doing this research on suicide in older people in rural areas have achieved what it set out to do and could the findings have been utilised effectively in suicide prevention programs? Other queries raised were - would the research have added to the literature or made a difference, would it have filled a gap, and would have the right to privacy outweighed the public interest in the results? These are all very valid concerns.

It could be argued that there is sufficient information in the public arena already on suicide in older people and for rural communities without having to undertake additional research that may cause discomfort to the relatives of the deceased. It is possible that with this information you should be able to make linkages and educated guesses as to what the situations are and how to adapt prevention, promotion, and treatment strategies to rural conditions. While in some respects this is already occurring there is still a need to have local and up to date evidence to support and inform the work that is being done and for future development of effective programs and strategies. It is also important to have research based in rural areas taking into account the rural environment as conditions and contextual circumstances are often very different to those in metropolitan areas where the majority of research has been undertaken. Thacore et al (2000) support this view when they contend that regional level data on suicide is not readily available and is necessary for the formulation of intervention strategies at the local level.

From the literature review it was determined that a gap certainly did exist in regards to contextual information available regarding suicide in older people in rural areas within the Australian environment. As stated earlier, Hirsch (2006) had indicated that several Western countries had indeed recognised the increased risk of suicide for older people in their rural areas. Providing data from an Australian rural context would have added to the literature and partly filled the gap.

The process that brings someone to the point of taking their own life involves a range of factors and issues, is never one thing, and is usually the last straw in a continuum of events that triggers the act. However, there are opportunities across the continuum of care and the spectrum of mental health promotion for suicide prevention interventions to occur. It is also important to establish that suicide is a phenomenon which affects all strata of society and age groups.

However, for older people the statistics demonstrate that suicide has been an issue for this group of people generally since suicide data has been recorded. While the numbers have been low compared to other age groups the rates have been high.

Nonetheless, reiterating what O'Connell (2004) has stated that "Although the prevalence for completed suicide in elderly people does not at first suggest a major public health problem, completed suicides are likely to represent only the tip of the iceberg for psychological, physical, and social health problems in older people." It has also been proposed in the literature that the ageing of the population will see an increase in suicide numbers and rates for older people. With the projected peak in the ageing of the population being the year 2050 where 25% of the population is expected to be over 65 years, now is the time that we need to put in place programs that assist older people to build resilience and strengthen their mental health and well being.

This is particularly important for rural communities, as Davis et al (2008) in their review of healthy ageing in rural Australia had also indicated that 36% of the Australian rural population were older people over the age of 65 years. They also point out that "in the next 20 years while most of the growth in the proportion of older people will be concentrated in metropolitan areas, rural Australia is growing older at a faster rate - 2.93% per annum - than the total rural population - 1.31% (Davis et al 2008). This has implications for rural communities with high elderly populations or for areas which have popular retirement living appeal such as on the coast and on inland rivers.

While it was recognised that the topic of suicide may be a sensitive issue to some in the community, it was surprising how the topic and the need to gain consent were issues perceived very differently by the various stakeholders involved. All parties, though, appeared to be advocating on behalf of the subjects and their families but from different perspectives.

The position taken by the author was that while the topic was a sensitive one the project was going to utilise information contained in the coronial files about deceased people whose deaths had been publicly investigated by the Coroner. Therefore, the Coroner could provide consent. The information gained was to be used to inform the development of effective suicide prevention strategies and assisting to prevent other older people from dying unnecessarily and was therefore in the public interest. So, as long as the information was handled sensitively, and the reporting of any recognisable data minimised particularly in regards to both identity and geographical location then the risk of causing distress or harm to the Next of Kin (NOK) was considered minimal.

From the Coroner's perspective, both that of the State and Local Coroner, they were supportive of the research provided ethics approval was gained first, and had considered that consent to use information in coronial files could be provided by their office. The Coroner also felt that having to gain consent from the NOK for the use of their relative's coronial files could re-traumatise some family members who had not come to terms with how their loved one had died. Administratively, the Coroner stated it would also have been very difficult determining who the actual NOK was from their records.

The Ethics Committee took the view that the NOK needed to be informed about the research and given the opportunity to provide consent or otherwise for use of their relative's information. Expressed concerns of the Ethics Committee included that the families may not want the researcher to know they were related to the deceased, or that the family may be able to recognise their relative from the report or presentations

resulting from the research and be possibly put at risk of harm due to this and ask why they were not consulted. Legally, it was the Ethics Committee view which prevailed stating that it was not evident from the application that the public interest in the research outweighed the risk to privacy of the Next of Kin.

With any sensitive research, particularly in rural areas, it is imperative that confidentiality and privacy be preserved as much as possible. De identification of cases alone is often not sufficient in rural areas to mask the individuals/community involved. This leaves rural researchers in a dilemma. How to still undertake valuable rural research in order to gain local evidence to base one's practice on and to disseminate the findings without breaching the confidentiality and privacy of those involved. Reiterating what Fraser et al (2006) have contended that rural health researchers need to consider the potential benefits and risks of their research and the publishing of their findings before doing so. As such these issues need to be seriously considered right from the start when designing one's research project, methodology, and dissemination of possible findings. The Ethics Committee is also very sensitive to this issue as well and will require more stringent safeguards be included in the research design as a result.

In working with the Ethics Committee to overcome these issues with this project some of the strategies the author intended to utilise, apart from the de-identification of cases and their geographical locations, included only reporting on the overall emerging themes rather than specific cases and widening the geographical selection area from one part of the health service region to encompass the whole of the region. The author also intended to adhere to suicide research confidentiality protocols of not reporting on results if less than five participants were found to have had or reported on a particular study factor.

In the Ethics Committee role as adjudicators on proposed research projects, research methodologies, and ensuring the adequate protection of privacy or minimizing the risk of harm to research subjects, they considered that security of information with this project needed to be tighter than normal given the project was being undertaken by a novice researcher. Further, that as a novice researcher was undertaking research of this sensitivity there needed to be an appropriate level of supervision. The Ethics Committee initially suggested two courses of action in this regard. The first one was to link in with an existing and experienced researcher in the field and incorporate the proposed project in with their research. The other course suggested was to liaise with and develop a partnership with a university to ensure adequate supervision.

The author chose to enrol in a Masters of Gerontology course at CSU with this research project forming the basis of the Masters dissertation. Two experienced research supervisors from CSU were appointed and met with the author on a regular basis. However, in the end the Ethics Committee still felt more supervision was required and suggested the first course of action recommended would have been the most effective.

The importance of having a good research design, methodology and process in place is vital to both being able to effectively answer your research topic question but also for carrying out the research in an ethical way. An integral part of the preparation of the research proposal is deciding on the theoretical framework and methodologies that the research project is being built upon. This is where the author found their involvement

in the RRCBP and the education and knowledge imparted being invaluable, as was the assistance provided by the CSU research supervisors.

While the author found the ethics process quite frustrating and inconsistent at times, the Ethics Committee feedback was also a positive as it constantly challenged the reasoning behind the choice of particular methodologies and provided suggestions about alternative ways of obtaining the information that one may have not previously considered. Indeed, sometimes as the author found, the intended methodology chosen is not always accepted by the Ethics Committee as the most ethical way of obtaining the information required, and so alternative ways of answering the research topic need to be found.

Based upon the author's critical analysis of their ethics application process the following are some of the learnings and suggestions that have resulted from this.

1. Become familiar with Ethics application guidelines and what they mean and use them in your application. The NHMRC guidelines are a useful tool to consult in this. This is an important part of the process so take the time to do this before starting to complete the ethics application forms, as it will certainly save time in the long run and also assist with completing of the forms appropriately.
2. Learn the language of the Ethics process and quote it back to them. Sometimes the meaning of words is interpreted differently by the Ethics Committee to what you had intended. For example, the word links or linkages. The Ethics Committee construed this to mean the linking of different data bases that had identifying information, but this was a completely different interpretation to what the author had intended. By using the Ethics language then misunderstandings regarding concepts and methodology is minimised.

The importance of language is also highlighted by Bell (2005) when she indicates that one of the problems about research is the use of terminology and jargon that may be 'incomprehensible' to other people. So familiarise yourself with the jargon of the ethics application process.

3. The importance of mentors and supervisors for their advice, assistance and guidance along the way is invaluable, not only for navigating the process but also for ensuring that you are trying to answer your research topic in an ethical way. This is especially important for novice researchers when undertaking research on sensitive topics. Also, use the Ethics Committee themselves and/or their Executive Officer for their advice and to clarify issues you are not sure about. The Ethics Committee also like to see that adequate supervision has been put in place. Having mentors and supervisors with experience in research and in the field of your research topic is always helpful. Having people with expertise in the area of statistics that you can call upon for assistance in analysing data is also useful.
4. Effective time management is essential when endeavouring to combine a busy work role with added research responsibilities. As the author found out the time

However, for busy clinicians undertaking research, even when supported by a program such as the RRCBP, it can be difficult to do when faced with the demands of their core business, coupled with the sometimes frustrating, bureaucratic, and time consuming procedures of the ethics process.

5. Explain everything and with little jargon. The Keep It Simple principle certainly applies. Don't assume that members of the Ethics Committee know what you are talking about or have a background in your area of expertise, or that they understand the importance of the research topic to your field. They often don't. It can be similar to having a job interview with colleagues; you still need to explain everything as if they don't know. Perhaps, ask for a face to face meeting with the Ethics Committee to explain the rationale of your project if you don't feel that they have adequately taken into account or understood the written submission.
6. While trying to explain everything adequately it is still important to be as concise as possible in writing the application. Ethics Committee members usually have several applications to consider and little time to do so before the next meeting. The easier it is for committee members to read and comprehend the application the better.
7. The Ethics process certainly assists one to forward plan with the proposed research project. It is important and necessary to think about and consider what it is that you want out of the proposed research, how you are going to achieve this, expected outcomes, what tools and research methods will be utilised, consent issues, and how to maintain confidentiality and privacy of subjects. The Ethics application form and process certainly requires one to have considered these issues and be able to articulate them.

For first time researchers this can be a daunting exercise when, as the author found, what was in mind was predominantly getting their research question and proposal in hand, rather than the outcomes.

8. Be familiar with conditions regarding confidentiality, consent, and privacy, particularly with sensitive topics, and ensure that your reasoning for the research being in the public interest is tight and outweighs the need for privacy.
9. Having a sound strategy for the securing of information and data both during and at completion of the project is important, as is being able to elaborate on this within the ethics application form.
10. It is important to not be too focussed on doing the research in a particular way. Keeping an open mind is valuable as there may be other ways of obtaining the information that you hadn't considered. Often Ethics Committees provide valuable feedback regarding your research proposal with suggestions and requests for modifications before they approve it

On the other hand if the research methodology chosen for the project is what you consider the best option for your needs after considering various alternatives then clearly outlining and justifying the methods chosen is vital.

## 7. Conclusions

Being part of the RRCBP offered the author an opportunity to expand their knowledge and understanding of research theory and practice, and to undertake a work related research project in an area that was of particular interest to them in their work role. This research would have provided some much needed local evidence to support and enhance the suicide prevention programs for older people being implemented in the area health service.

Due to the research project on suicide in older people in rural areas not gaining approval from the local Ethics Committee, this project ultimately evolved into two separate investigations. The first being an exploration of the literature surrounding suicide in older people in rural areas, and the second an examination of ethics concepts and processes.

### **Suicide**

Suicide is a sensitive issue in the community particularly for those who are left behind and constantly asking why their loved one died in such a way. While suicide affects all strata of society and age groups suicide prevention programs have generally and historically been focused more on younger age groups than those over 65 years of age. This imbalance is slowly being rectified for both older people and other at risk groups such as those living in rural areas. However, more needs to be done particularly in relation to contextual information regarding older people in rural areas who have taken their own lives.

Despite the planned research project not going ahead, from the initial investigations in the development of the research proposal and the subsequent literature review there were some outcomes which could be reported on that have implications for rural health services in regards to working with older people at risk of depression and suicide.

We know that

- older people in rural areas do take their own lives,
- the majority are male,
- the main risk factor is depression (from urban studies),
- there is a definite gap in the literature and evidence regarding contextual information dealing with suicide of older people in rural areas.

The literature also implied that a consequence of the ageing of the population could see increased suicide numbers and rates in older people, and the subsequent implications this has for rural communities which are ageing.

While the literature review did establish that there is a growing amount of information regarding suicide in older people generally, this research was predominantly based on urban cohorts. The rural suicide literature dealt mainly with farmers and young people with little, if any, reference to older people over 65 years of age. What the review did highlight was the need for more evidence based practice in rural areas as well as providing a basis for further work required in the area.

As Davis et al (2008) contend, "Comparative studies on retirement, health promotion, community participation, health seeking behaviour, health services are needed to better understand the complexities of the ageing experience across different types of rural communities and support healthy ageing". Including mental health issues and suicide in these studies is vital to having an overall picture of the context and environment of older people in rural areas. Having this information will aid the development of a range of health promotion and intervention programs focusing on the needs of older people in different regions and assist to enhance their overall health and wellbeing, and their increased resilience.

### **Ethics**

Both the review of the ethics literature and the experience of going through an unsuccessful ethics application process has greatly increased the author's understanding and knowledge of the process and issues involved. As a novice researcher this was an invaluable experience and with hindsight the lessons learned will certainly assist with any future research projects they are involved in, and it is also hoped that this critical reflection will aid other novice researchers in their research journeys.

For rural health researchers, particularly novice researchers, it is vital to have

- a good overview of the ethics application process before you start,
- an understanding of ethical issues such as consent, privacy & confidentiality, the public interest, sensitive topics and how they impact on the proposed research project and the dissemination of its results,
- a sound theoretical framework, research design, methodologies and processes in place,
- the support and assistance of mentors and supervisors for guidance along the way, as well as using the Ethics Committee themselves for advice when needed,
- an enquiring mind and the desire to improve their practice by gaining local evidence,
- support from your managers to undertake the research as it is often not seen as part of core business

For rural clinicians to be better able to undertake research on issues related to their work and rural communities in order to improve their practice for the benefit of clients then increased support is required for them to do so. When work loads are high and time is short, research is often not seen as part of core business. The sometimes frustrating, bureaucratic, and time consuming ethics application process can be a hurdle for some that is difficult to jump. However, it can also be seen as a challenging and learning experience.

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## **9. Appendices**

- I. Proposed Data Collection Sheets
- II. Proposed Consent Forms for Next of Kin
- III. Proposed Research Information Forms for Next of Kin

## Suicide in the Elderly - Data Collection Sheet





## **Research Project: Exploring Suicide in the Over 65s in a Rural Region**

### **Information Statement for Next of Kin**

Thank you for taking the time to read this, and we know that suicide is a very sensitive issue particularly for those family members left behind and wondering why. This research is being undertaken so we can improve our understanding of the issues and circumstances surrounding the death by suicide of older people in rural areas, particularly in the region covered by the Greater Southern Area Health Service. Ultimately, it is about being more able to support older people who are stressed and about saving lives so other families, like yours, don't go through the trauma of losing someone through suicide.

Older people have one of the highest rates of suicide in NSW and Australia. However, little information is available regarding issues and circumstances in rural areas that might influence an older person's decision to end their life prematurely. The information gained from this study will increase both the health service and community's ability to recognise and support older people at risk, and to better promote mental health and well being.

Greater Southern Area Health Service (GSAHS), Charles Sturt University (CSU), and the NSW Institute of Rural Clinical Services and Teaching (NSW IRCST) are supporting new researcher Margaret Dalmau in undertaking this project. We hope to look beyond the basic statistics of age, sex, year of death and method supplied by the Australian Bureau of Statistics. To do this we need to look through the Coroner's files from 1999 to 2005 for those people over 65 years of age who the Coroner has identified as dying by suicide and who lived in the region covered by the GSAHS. No files will be removed from its secure location during this research.

Coroner's files usually contain information collected during the investigation of a person's death and could include the following:

- Police form and report
- Demographics i.e. age, nationality, pension, marital status, place of residence, previous employment, previous attempt, physical condition
- Nature of the scene
- Police interviews with relevant family members, friends, GPs, key witnesses
- Photos
- Suicide notes
- Comprehensive time line of events
- Results of the autopsy and toxicology screens
- Reasonable idea of the health and physical condition of the person
- Coroner's determination

All information at the time of collecting it will be coded so no-one other than the principal researcher will know who is involved in this research. Putting all the information together from the several files examined will assist us to get a clearer picture of the issues and possible circumstances surrounding these untimely deaths.

While we will be talking with the NSW State Coroner regarding permission to access individual Coroner's files, we understand that having someone looking into your relative's file may be distressing to you. We feel it is important to give you the opportunity, as Next of Kin, to indicate your support or otherwise for the involvement of your deceased relative's files in this research. We would appreciate your support in this important research. If you would

prefer that your family members file not be included please fill in the attached form and return it by 30 April, 2008 to the principal researcher.

All the information gathered during this research project will be securely stored and only available to the research team. The final report of the research may be presented at conferences or published in journals. However, when any information gathered from the project is presented, rest assured, it will be impossible to identify your relative or anyone else who has been involved. We would also acknowledge the important and courageous support of the families who gave their permission for their relative's files to be included in this research in order to help prevent others going through what they have.

If you have any questions about the research project please contact Margaret Dalmau on 02 6932 3020. If you have any questions about the ethical aspects of the research component of this project, please contact the Executive Officer, GSAHS Ethics Committee, P.O. Box 3095, Albury NSW 2640, phone 02 6021 4799 or fax 02 6021 4899. If this subject raises any personal issues for you then please contact Lifeline on 13 11 44 for support.

Margaret Dalmau  
Principal Investigator.

This research project is being supervised by Drs Mason & Osburn  
at Charles Sturt University in Wagga Wagga.

Contact: School of Humanities and Social Sciences  
Ph 02 6933 2249 Fax 02 6933 2792



**Research Project:  
Exploring Suicide in the Over 65s in a Rural Region**

**NEXT OF KIN CONSENT FORM**

I .....

as Next of Kin of .....

1. Agree to the release of my relative's Coronial file for inclusion in this research project. I understand that this information will only be made available in full to the research team.

I acknowledge that I have read and understood the Information Statement provided.

I understand that all information gathered in the research process will be treated with all the confidentiality and sensitivity required by ethical research standards. I understand that this page will be removed from the information concerning my relative so that they cannot be linked to them.

I also agree that the research data gathered from the project may be published, provided that neither my deceased relative nor any other participant in the project can be individually identified.

2. Do Not Agree

Signed .....

Witness .....

Print Name .....

Print Name .....

Date .....

Date .....

**COPY FOR NEXT OF KIN**



**Research Project:  
Exploring Suicide in the Over 65s in a Rural Region**

**NEXT OF KIN CONSENT FORM**

I .....

as Next of Kin of .....

1. Agree to the release of my relative's Coronial file for inclusion in this research project. I understand that this information will only be made available in full to the research team.

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I also agree that the research data gathered from the project may be published, provided that neither my deceased relative nor any other participant in the project can be individually identified.

2. Do Not Agree

Signed .....

Witness .....

Print Name .....

Print Name .....

Date .....

Date .....

**COPY FOR PRINCIPAL RESEARCHER**  
Please return to P.O. Box 842, Wagga Wagga 2650 by 30 April, 2008



**GREATER SOUTHERN  
AREA HEALTH SERVICE**  
**NSW HEALTH**

Dear

Re: Research Project – Exploring Suicide in over 65s in a Rural Region

A research project is being developed that is endeavouring to look at the circumstances surrounding the suicide deaths of people over 65 years from 1999 to 2005 and living in the region covered by the Greater Southern Area Health Service. The aims of the research are to improve our understanding of the issues and circumstances surrounding the death by suicide of older people in rural areas, as well as being more able to support older people who are stressed, and about saving lives so other families, like yours, don't go through the trauma of losing someone through suicide.

The reason why we are writing to you is that you are the next of kin for an older person who the Coroner has identified died by suicide in the years this research is investigating. As it is intended to gain the necessary information for this research from the Coroner's files, we felt it important to give you the opportunity to support or deny access to your relative's coronial file for this project.

Attached are an information sheet which will explain the research in more detail plus a consent form for you to sign indicating your support or otherwise of your relative's inclusion in this project. Please be assured that at the end of this project your relative will not be able to be identified.

We would appreciate your support with this important project so that we can try to develop strategies to save lives in future and to help avoid the trauma that families such as yours go through when you lose a loved one to death prematurely.

If you require any further information regarding this research project please contact the principal researcher, Margaret Dalmau, on 02 6932 3020.

Yours sincerely

Margaret Dalmau  
Principal Researcher