

# The Ethics of Suicide Research

## The Views of Ethics Committee Members

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**Abstract.** *Background.* Good quality, ethically sound research is needed in order to better understand, appropriately respond to, and reduce the incidence of suicide. There is, however, a lack of clarity around the nature of ethical problems associated with suicide research and how to resolve them. This is a formidable challenge for ethics committee members in approving and monitoring research. *Aims.* To describe the views that members of health research ethics committee hold regarding ethical problems and ethical practice in research involving people who are, or who have, been suicidal. *Methods.* Ethics committee members were invited to complete an online survey addressing the risks, benefits, and ethical problems associated with suicide research. Findings were aggregated into themes using an inductive form of content analysis. *Results.* Concerns of ethics committees centered on accessing the population, potential harm to participants or the researcher, researcher competency, maintaining confidentiality, providing support to participants, and responding sensitively to the needs of family. *Conclusions.* Ethical research involving suicidal people requires both procedures to protect participants, and consideration of ethics as an ongoing negotiated process. The findings of this research provide a snapshot of views held by a number of ethics committee members.

**Keywords:** suicide, research, ethics, research ethics, ethical review

## Introduction

Suicide is a pressing social concern with huge personal costs. However, there appears to be a reluctance in research to engage directly with people who may be suicidal, in part because of the formidable ethical problems that are raised (Goldsmith, Pellmar, Kleinman, & Bunney, 2002). Researchers and ethics review boards are challenged to articulate and satisfactorily address the ethical problems associated with research involving suicidal people.

Morgan (2007, p. 37–41) provided a rare published glimpse into the deliberations of a university ethics committee relating to a proposal that involved attempting to recruit young suicidal men to talk about their experiences. A number of concerns were unable to be resolved, including the liability of the researcher and the organization should a respondent die by suicide, and the extent of the duty of confidentiality should a person be deemed at imminent risk of suicide and not under the care of a health professional. Further discussion by the committee revolved around the perceived high likelihood of conflicting advice and requirements of different committees. This reflects the subjective nature of the review process, which is greatly influenced by the biases and moral positions of members. As Smith, Edwards, Robinson, and Dworkin (2004) assert, committees do not have access to a single moral truth and there are few comprehensive guidelines to which either researchers or review boards might appeal.

The United States National Institute of Mental Health (NIMH) published guidelines on issues to consider in intervention research with people at high risk for suicidal behaviors in order to encourage research (Pearson, Stanley, King, & Fisher, 2001). The NIMH noted that few studies have had sufficient power to determine the efficacy of interventions and persons at high risk for suicide are often excluded from treatment trials of individuals with mental disorders. Particular emphasis was placed on the need for clear risk assessment, treatment and referral protocols, protocols for the management of suicide attempts, researcher competency and training, and obtaining informed consent. Given that both ethics committees and researchers will vary in their moral positions in relation to suicide (Mishara & Weisstub, 2005), and the extent to which they may tolerate risk, it would be valuable to have normative guidelines on generally acceptable research practices. This survey aimed to describe the main problems associated with suicide research as perceived by ethics committee members.

## Methodology

Members of Human Research Ethics Committees were invited to complete a brief anonymous online survey. In Part Two of the study, reported elsewhere (Lakeman and Fitz-

Table 1. Characteristics of the ethics committee respondents

Country of committee	N	%	Affiliation of committee	N	%	Role on committee	N	%
Australia	9	7%	Government	6	5%	Chair Person	25	20%
Canada	26	21%	Health Service	82	66%	Ethicist	6	5%
UK	77	62%	Independent	3	2%	Health practitioner	34	27%
New Zealand	7	6%	Unclear	2	2%	Lay member	34	27%
Ireland	6	5%	University	32	26%	Researcher	14	11%
						Other	12	10%

gerald, in press), experienced researchers in the area of suicide were invited to complete a slightly modified survey. Human Research Ethics Committees were identified in the United Kingdom, Ireland, Australia, Canada, and New Zealand via web-based lists. These countries were chosen because they have similar health research ethics governance structures and traditions. A total of 513 e-mail invitations were sent to the listed contact person for the ethics committees (secretary, administrator, or chairperson). Approximately 40 were returned undelivered. E-mail replies were received from some people asking that the protocol be submitted to their committee before members would consider responding (such requests were declined). Some also stated that their committee did not deal with research concerning "mental health issues" or that any such research would be referred to another institutional committee (approximately 30). The survey portal page (on the internet) reiterated information about the project and contact details as well as a link to request a copy of a preliminary report.

The surveys were brief, collected basic demographic information, and asked several open ended questions:

- "Please outline the main risks and benefits of research involving people who may be suicidal."
- "What are the main ethical problems that you have encountered or might envisage with research involving people who may be suicidal?"
- "What advice have you/would you provide to researchers who plan to work with suicidal people to address ethical problems?"

The web forms were submitted directly to a Microsoft Access database and then imported into the software package QSR NVivo 7 for thematic content analysis. Demographic and closed questions were aggregated and summarized with descriptive statistics and a line-by-line analysis of open ended questions was undertaken. An essentialist/realist position was assumed with the aim being to generate an accurate, uncomplicated, and parsimonious representation of responses (Braun & Clarke, 2006). An inductive process of category formulation was followed (Mayring, 2000). Each line was assigned one or more categories and these were progressively aggregated into themes as more data were considered. At each point in which a new category or theme was added, the existing coding was reviewed. When all data were categorized the entire data set was reviewed

and categories reduced to encompassing themes where possible. The entire data set was reviewed by an independent expert in qualitative analysis.

## Results

A total of 125 ethics committee surveys were completed and submitted anonymously via the web form (Table 1). Respondents' length of time on the ethics committee varied from 2 months to 25 years ( $\bar{x} = 5.4$ ,  $SD = 4.6$ ); Respondents estimated that their committees considered between 10 to 480 protocols per year ( $\bar{x} = 113$ ,  $SD = 92.5$ ). (Twenty-two subjects did not respond to this question but completed the rest of the survey). Seventy-nine respondents (63%) reported reviewing 1 to 5 protocols each year involving suicidal people, 15 respondents stated they reviewed 6 to 10, and 10 respondents reported that their committee reviewed over 10 protocols per year involving suicidal people. Protocols involving suicidal people represented 4.5% of the total number of protocols considered by committees.

## Benefits of Undertaking Research

All respondents identified one or more potential benefits of undertaking research involving suicidal people. Most identified benefits for health professionals, the suicidal person, and society at large. For example:

"In general, research involving people who might be suicidal could help scientists/clinicians to form a better understanding of suicide, its antecedents, and what people want to achieve by attempting/committing suicide; and in the case of service providers how to effectively reduce risk through design of service, models of service delivery and treatments; improving general public awareness and understanding of suicide; and lastly but by no means least, in helping family and friends to reduce risk/seek assistance at an earlier stage."

Increased understanding was explicitly mentioned by over half of the respondents. This included increasing understanding generally and in relation to specific populations (e.g., understanding why young people or men in rural areas die by suicide). Understanding was considered by many to be a means to improving recognition, screening, and

treatment of illness and ultimately prevention of suicide. Six respondents mentioned that research could improve public knowledge of suicide and promote a higher public profile for the problem. Prevention of suicide was discussed by 25 respondents and improving care and treatment by 30 respondents. Some responses strongly alluded to beliefs about suicide as a psychiatric problem. More usually people talked about improving treatment and care generally, improving treatment of depression, or targeting treatment more effectively.

At least half of the respondents mentioned that being involved in research could be beneficial to participants directly. Some pointed out that people identified as suicidal via the research would be assessed and referred for treatment or would gain self-understanding and seek counseling or other help. Twenty-four respondents described different ways that the process of research could be directly therapeutic: by providing the opportunity for participants to exercise altruism (a sense of contributing to the greater good and helping others), by conveying hope (the researcher demonstrating caring and concern), by gaining personal insight (into own psychology and situation), by gaining a sense of universality (that they are not alone and others suffer similarly), and by being listened to (having the opportunity to talk and be heard).

### Ethical Problems Associated with Research Involving Suicidal People in Research

Most respondents alluded to what appeared to be hypothetical cases. Five respondents pointed out that ethics committees have a tendency to be paternalistic. For example:

*"[Researchers] need to make it clear to [the] Ethics Committee that one cannot make someone suicidal by allowing them to talk. In my experience, my fellow members of the Committee can be too cautious and protective of these subjects, who may often be very keen and willing to talk to a researcher."*

These respondents pointed out that conservatism and paternalism were also obstacles to undertaking research with other populations such as people diagnosed with mental illness and children. One respondent, an ethicist with many years of experience, stated *"these people need treatment first and foremost, not study."*

### Justification for Research

Twenty-seven respondents (22%) raised questions about justification for the research pointing out the difficulty of weighing benefits against risks, for example, *"Being sure that the potential benefit from the research is great enough to warrant intrusion on a vulnerable population"*. Research involving "placebo", waitlist, or minimal-care arms in intervention research posed particular problems given the potential risk that the person might complete suicide. As some

people noted, suicide is a rare event and it is difficult to demonstrate or guarantee benefits, just as it may be difficult to predict harm. Some raised questions about whether or not research has, or would, actually lead to better services.

### Access to the Population

Twenty-one respondents (17%) explicitly discussed problems and difficulties accessing the population. A number of questions were posed (although answers were not proffered). For example:

- *"Who holds information on suicidal people and should that information be accessed for research purposes?"*
- *"Could recruitment via services damage relationships between service users and providers?"*
- *"How can people be recruited in a sensitive manner?"*

Several people (4%) pointed out the difficulties associated with advancing knowledge if some groups are excluded (e.g., people not involved with mental health services) and pointed out that people who are suicidal are often excluded from research.

### Potential for Harm to Participants

This was the most dominant theme with almost all respondents acknowledging the potential for research to be harmful in some way. Eighty respondents (65%) suggested that suicidality might be exacerbated or "reinforced" by bringing attention to suicidal thoughts and feelings, revisiting or bringing up distressing material, inadvertently confirming the insolubility of problems, normalizing and advertising methods of suicide, and raising hope for assistance but not being able to provide any. Not having access to the right kind of supports to assist participants was mentioned by many people as being potentially problematic. For example:

*"... asking about suicidality isn't a risk in and of itself, but doing so through a research project increases the onus on the researcher to be able to source/provide an appropriate suicide risk assessment, safety plan, and treatment as necessary."*

Some people (~5%) suggested that delaying treatment or varying care as usual (in the case of intervention research) could be potentially harmful. Respondents pointed out that this was a vulnerable population and could readily be coerced or manipulated into participating in research or treatment. Further kinds of potential for harm cited were side effects from experimental drugs, the potential stigma of been labeled mentally ill, and the intrusion that research might entail.

### Potential for Harm to the Researcher

Approximately 25% of respondents cited some kind of potential harm to the researcher, most commonly distress, guilt, or liability if a participant attempted or completed suicide subsequent to research involvement. Insufficient training, supervision, support, or debriefing of the researcher were considered ethically problematic and potentially harmful to the researcher.

### Participant Competency and Consent

Close to half (~47%) of all respondents proposed that determining the competency of suicidal people to consent to involvement in research and the consent process itself are ethically problematic. Respondents varied in their estimations of the likelihood that capacity would be a problem. Some pointed out that being suicidal might be considered an indicator of incompetence while others pointed out that severe depression, and psychosis, could impact on people's comprehension. One person (< 1%) stated that suicidal people ". . . will not value their health and safety to the degree necessary to make sound judgment on the risks of the research." Two people (< 2%) suggested that suicidal people might not provide truthful responses, thereby, undermining the integrity of the research.

### Researcher Competency

Fourteen people (11%) suggested that the researcher might handle situations inappropriately. They might, for example, be over-intrusive, insensitive, or something that they do or say might cause distress, dissuade a person from seeking help, or encourage suicidal behavior. The use of interview tools and questionnaires without suitable training or supervision was deemed problematic. A similar number of people ( $n = 15$ , 12%) also considered that the researcher should have clinical qualifications or at least experience in working with suicidal people.

### Responsibilities of the Researcher to Participants

Over half (57%) of the respondents alluded to the researcher having responsibilities or a "duty of care" to the participant to provide or facilitate access to help. Some (< 10%) suggested that the role of researcher and care provider could blur and that this was a problem. Others (< 5%) suggested that it is necessary for the researcher to directly provide treatment or facilitate assertive follow-up even suggesting it may be unethical to obtain information from suicidal people without offering care or treatment. Respecting privacy and offering help or reporting suicidal ideation poses particular dilemmas.

Twenty-five respondents (20%) suggested that not hav-

ing the resources to provide help to people is a serious ethical problem particularly in terms of raising people's expectations that help will be provided. Concern was raised about uncovering problems that could not adequately be dealt with by the researcher or mainstream services. In relation to trials of interventions a potential problem is the withdrawal of helpful interventions when the trial is over. Some suggested (< 10%) that simply providing information about support services might not be enough as "a very depressed person may not have the energy to follow through [with seeking help]." Some emphasized the importance of the professional competency and virtues of the researcher to assess risk and respond sensitively and appropriately to individuals.

### Maintaining Confidentiality

One quarter of respondents (< 30) mentioned maintaining confidentiality as a problem. Anonymous questionnaires pose a problem in facilitating help for people. In contrast, focus groups may lead to disclosure to other group members who might become distressed. Undertaking research in rural or small communities poses difficulties in terms of confidentiality within the community and potentially identifying (and stigmatizing) the community in publication of findings.

### Dealing with Families

Only 14 comments (11%) related to problems associated with families. However, some of these were examples (e.g., a parent was reported to have complained about a questionnaire on suicidal thinking distributed in schools. Another family member objected to being contacted after their relative had completed suicide). One respondent stated "family members are not informed by health care professionals when a member of the family is considered to be a suicidal risk".

### Advice to Researchers

Some respondents (< 10%) stated that researchers should anticipate the concerns of ethics committees and address risks and vulnerabilities in as comprehensive and careful a manner possible. Several respondents (< 10%) noted that ethics committees may have little knowledge of the population and would likely err on the side of caution and conservatism. Researchers should provide details of how the population will be accessed, the procedures to ensure informed consent, and honestly outline the potential risks and how these will be attenuated.

## Attitudes and Attributes of the Researcher

Twenty-five respondents (20%) stated that researchers need to be experienced in working with suicidal people. Respondents recommended that researchers avail themselves of supervision for debriefing and problem-solving. Given the risks entailed, frequent reporting and monitoring were advocated. Many (some 25% discussed the need for debriefing of the researcher) recognized the potential psychological toll of working with vulnerable people and the need to unload or process people's disclosures and emotions that arise in a safe manner.

Respondents suggested the researcher should be self-aware, careful, respectful, culturally safe, sensitive to ethical problems that might arise, and knowledgeable regarding legal requirements to report and intervene.

## Consult and Involve

Respondents made the following suggestions about consultation: Before submitting a proposal researchers should discuss their plans with a representative of the ethics committee and avail themselves of those guidance notes that may be available. The researcher should consult with other experienced researchers, clinicians, and service providers involved with suicidal people. Potential participants or people that had previously been suicidal should be involved in the design of the research and in particular assist in the formulation of questions (support groups or service-user groups were recommended as potentially helpful); focus groups with potential participants and other experts was recommended as another way to involve others. There was an assumption by many that potential participants would be under some kind of psychiatric care. For example, "Before starting, discuss fully, over at least 12 months, with treating psychologists, psychiatrists, mental health nursing staff, and case managers." Some suggested that permission should be sought from a person's carer, such as their general practitioner or psychiatrist. However, this was also noted by some to be an ethically problematic and paternalistic course of action.

## Recruitment and Sampling

Respondents (~25%) commented about carefully defining a target group, and having a sound rationale for sampling procedures. There were assumptions that samples would be drawn from clinical populations and it was recommended that care providers be involved in the recruitment process. Only a few raised concerns about the potential for coercion inherent in the clinician-patient (< 5%) relationship. Some people (< 3%) suggested that recruiting those that were seriously ill should be avoided, while others suggested that the homeless and ethnic minorities might not access mainstream health services and might be under-represented in research. Some (< 5%) suggested that a range of recruit-

ment methods should be used, with the principle being that members of the target group should have the opportunity to consider at length whether or not they wish to be involved.

## Consent Procedures

Respondents (~20%) considered that researchers should describe how capacity to consent would be assessed and should describe the mental state of potential participants. As for general research, information about what will be required, possible risks (particularly in terms of distress), and the right to cease involvement should be provided to participants in plain language along with information about supports available. People should know the circumstances under which information might be shared with others and the potential consequences of this sharing. Some suggested that consent should be revisited frequently throughout the research project.

## Acknowledge and Address Vulnerability and Risk

Respondents suggested that suicidal people are likely to be vulnerable and this vulnerability needs to be acknowledged and responded to with sensitive handling of the research relationship and that care needs to be taken with approaching, interacting with respondents, and ending relationships beyond usual care or usual researcher-participant relationships. Researchers should have explicit protocols for assessing risk, or a deteriorating mental state and have a "contingency plan" to respond to risks including suicide. These should include statements regarding when confidentiality may be breached and to whom concerns will be reported.

## Ensure Help is Available

Respondents varied in their opinions regarding the extent to which researchers ought to actively intervene to provide help. They considered that, as a minimum, researchers ought to provide contact information regarding helping agencies. These agencies should have been previously briefed, consented to involvement, and have the capacity to respond quickly and competently to requests for assistance. Researchers should make themselves available for debriefing, to discuss any issues or problems that arise (for themselves as well as participants). A minority suggested a stronger, more assertive response, e.g., having psychiatrists and social workers on the research team, counseling the individual about options other than suicide, or undertaking a formal risk assessment. Others cautioned not to blur the roles between researcher and therapist. One person stated, "Whatever moral beliefs the researcher has about suicide should be suspended and it must be respected that the suicidal person has the right to take their own life if

they so wish.” Some (< 3%) suggested that a comprehensive support package ought to be available and accessible 24 h a day but some also raised questions about the responsibilities of the researcher if problems with service responsiveness or capacity were identified.

### Methodological Advice

Some (< 10%) respondents explicitly emphasized the importance of selecting the appropriate methodology to address the research question. Some recommendations made were highly specific to particular types of research. For example: People should not complete questionnaires on their own, individual interviews might be preferred over focus groups because they are more predictable (less likely to cause distress), comments to be published should be checked with participants to ensure that analysis captures their intent and meanings, placebos in drug trials are problematic (some stated that a placebo should never be used instead of an antidepressant). Some suggested having suicidal people “self-select” via the internet might be useful while others suggested that talking to clinicians (with the person’s consent) might be a fruitful way of obtaining information.

### Limitations

We used a convenience sample (~30% response rate) and did not attempt to ascertain whether the views of respondents were representative of all ethics committee members. Survey themes represent the dominant issues and equally demonstrate the different points of views held by some parties, some of which appear to be in conflict with each other. Ethics committees typically reach collective decisions and need to resolve differences of opinion. It is unclear how the opinions expressed by individual respondents might relate to the outcomes of the collective deliberations of ethics committees examining specific cases. Often the opinions expressed in this survey lacked elaboration and the survey did not allow responses to be explored in greater depth.

The responses of ethics committee members tended to be couched in plain language rather than in the language of philosophical ethics so it is difficult to tease out the ethical from other pragmatic problems or issues. Implicit in most responses were concerns about safety, that the research process does not contribute to further distressing the individual, and that the individual does not go on to harm his or herself.

### Conclusions

The results from this survey add to knowledge about ethical and pragmatic issues that arise within research involving

*Table 2.* Ethics committee members recommendations for ethical research involving people who are suicidal

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- Consult with the ethics committee, experienced researchers, support agencies, and potential participants
  - Provide a sound justification for undertaking the research, sampling and recruitment procedures, and the methodology/methods chosen.
  - Ensure support is available to participants. Liaise with support services and ensure they have the skills and capacity to respond if needed. Provide potential participants with details of support agencies and how to access them.
  - Establish procedures to assess suicide risk and to respond to people who may be an imminent suicide risk. Ensure that potential participants are aware of these procedures.
  - Provide full information to participants about the consequences of their participation and the boundaries of confidentiality. Provide time for people to consider information provided and revisit consent frequently.
  - Ensure the research is supervised, carried out by people who are experienced and competent in dealing with people in distress, and that both researcher and participants have opportunities for debriefing.
  - Acknowledge the vulnerability of participants and respond with care.
- 

suicidal people, and the issues that both researchers and ethics committees hold as important. The findings (summarized by way of the recommendations in Table 2) are reassuringly congruent with extant guidelines relating to research ethics (Ministry of Health, 2006; NHMRC, 2007; NHS, 2001; NIH, 1979; Irish Council for Bioethics, 2004; Tri-Council, 1998) and the limited literature specifically relating to research involving suicidal people (Fisher, Pearson, Kim, & Reynolds, 2002; Pearson et al., 2001). They represent opinions (albeit informed) rather than consensus on the issues that are important for researchers and ethics committees to consider. Further research might consider building a consensus on the most important principles to consider.

The recommendations for ethical research synthesized from the findings of this survey (see Table 2) are necessarily general and might apply to almost any research project in which research engages with potentially suicidal people. Researchers and ethics committees must also ensure that research reflects good practice in the use of specific research methodology, design, and methods. Working with suicidal people does pose some particular dilemmas with some designs. For example, the use of placebo, minimal, or no treatment control groups in intervention research involving people who are suicidal has been recognized as ethically problematic (Fisher et al., 2002). However, providing increased monitoring, surveillance, or “enhanced” ordinary care might paradoxically reduce the demonstrable effect sizes of interventions. Anonymous survey research might be considered ethically problematic if respondents’ suicidality is explored but no tangible help is accessible to respondents where need is identified.

Differences of opinion on central issues such as the extent to which researchers ought to intervene to prevent suicide reflect different moral positions regarding people's right to suicide, different beliefs about the meaning of suicidal behavior, pragmatic concerns about liability, and different views on what counts as good research. Resolution of these issues in the context of developing, approving, monitoring, and undertaking research is a practical and, to some extent, a social endeavor that requires accommodation of different positions.

Ethically sound research involving suicidal people requires scrupulous procedures relating to informed consent, assessment of risk, and access to competent support and assistance for the researcher and participants. As a human endeavor it requires the researcher to consult, liaise, and negotiate with key stakeholders. Researchers must manifest respect for participants by demonstrating sensitivity to their vulnerability and responding accordingly. Ethical research with people who may be suicidal is not greatly different to good research generally. It encompasses both the development of sound procedures and a consideration of ethics as an ongoing negotiated process.

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