

# Australian Mental Health Consumer and Carer Perspectives on Ethics in Adult Mental Health Research

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## Abstract

Barriers to research arise when national ethical guidelines governing the inclusion of consumers in mental health research are implemented at the local level. Equivalent guidelines for research involving carers are not available. A social science investigation of Australian mental health consumer and carer perspectives on research ethics procedures was conducted in two interlinked stages: (a) a discussion forum with consumers, carers, and lived-experience researchers and (b) in-depth interviews with consumers and carers. Data collection and analysis drew strongly on methodological features of grounded theory. Privacy, confidentiality, and stigmatizing ethics procedures were key issues for consumer and carer participants. Recommendations for research practice include the following: considering the impact of information sharing on participants' relationships and adopting individual-focused approaches to managing research risks.

## Keywords

carer involvement, consumer involvement, mental health, research ethics, caregiver, service user

The perspectives of people with lived experience of mental health issues, either personally (consumers) or as a supporting family member or friend (carers), are an essential part of progressive mental health research (Gillard et al., 2010; Moule & Davies, 2016). Including these perspectives ensures research is relevant to consumer and carer-identified areas, and governed and conducted according to their needs (Boote et al., 2014). National research ethics guidelines, in Australia and elsewhere, provide specific guidance for conducting research involving consumers, but barriers can arise when guidelines are operationalized at the local level (DuBois et al., 2012; Iltis et al., 2013). Research involving carers is not specifically addressed by national research ethics guidelines, and few practice guidelines are available to assist researchers in applying general ethical principles and guidelines to this context.

Australia, the United States, and Canada have similar procedural approaches to the ethical review of human research (Guillemin & Gillam, 2004). A national set of principles and guidelines are applied to all forms of research with human participants and are enacted by local review boards or committees, usually situated within a university (Guillemin & Gillam, 2004). However, poor implementation of these guidelines can prevent research from being conducted with populations labeled “vulnerable,” excluding these populations from the potential benefits of health research. National guidelines in these countries define the

characteristics that render a group of people vulnerable to harm during research participation. All three sets of guidelines include reduced capacity or autonomy to freely consent to research participation as a key criterion for vulnerability (a common focus of vulnerability concerns in developed countries; Levine et al., 2004) and indicate that mental or intellectual disability may reduce a participant's capacity to provide informed consent (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014; “Federal Policy for the Protection of Human Subjects, 45 C.F.R. § 46,” 2009; National Health and Medical Research Council [NHMRC], Australian Research Council, & Australian Vice-Chancellor's Committee, 2007/2015).

The Australian National Statement on Ethical Conduct in Human Research (NHMRC et al., 2007/2015) specifically states that having a *mental illness* may limit an individual's

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freedom or capacity to make an autonomous decision to participate in research, and may increase their susceptibility to certain kinds of harm, distress, and discomfort. The National Statement also states that the application of guidelines requires judgment, deliberation, and consideration of context (NHMRC et al., 2007/2015), but in research environments averse to risk, issues may arise. Research projects involving mental health consumers may automatically require full ethical review, even when the research is low risk and would receive an expedited review or exemption from review if conducted with the general population (DuBois et al., 2012). This can unnecessarily delay mental health research and result in the unjust exclusion of certain populations from the potential benefits of research (Iltis et al., 2013). Incorporating the perspectives of people with lived experience of mental illness, as a consumer or carer, can inform improved ethics processes when working with this population (DuBois, Bante, & Hadley, 2011; DuBois et al., 2012; Iltis et al., 2013).

The current study was a social science exploration of consumer and carer perspectives on mental health research ethics procedures, with the goal of developing recommendations for research practice.

## Research Design

The study comprised two stages, drawing strongly on the methodological features of grounded theory (Charmaz, 2006) to develop a broad and deep understanding of the issues: (a) a relatively unstructured forum with mental health consumers and carers to explore their ideas on ethics and mental health research, which was analyzed to create an initial thematic framework and (b) individual in-depth interviews with consumers and carers to elaborate on the issues raised at the forum and provide further conceptual depth. Theoretical sampling was employed during interview recruitment to explore identified concepts and seek out potentially contradictory information. The interview data were used to test and modify the thematic framework.

## Ethics Approval

The ethical aspects of the project were approved by The Australian National University Human Research Ethics Committee (protocol number 2015/247). All participants were required to read an information sheet and give written consent before participating. Interview participants were offered a 20 AUD voucher for their time.

## Consumer and Carer Forum

### Material and Methods

To investigate consumer and carer views on mental health research ethics procedures, a half-day forum was held in

June 2015. Fourteen members of the Australian Capital Territory (ACT) community who identified as people with lived experience of mental illness, either as a consumer ( $n = 5$ ) or as a carer ( $n = 9$ ), were recruited through local mental health consumer and carer organizations and the register of people interested in the work of ACACIA: The ACT Consumer and Carer Mental Health Research Unit. Due to the specialized nature of the forum topic, five participants (including one author, M.B.) were also lived experience researchers (i.e., researchers with personal experience as a mental health consumer and/or carer) who could bridge the consumer/carer and research perspectives and facilitate discussions (Griffiths, Jorm, & Christensen, 2004). Lived experience researchers use both their academic training and their personal experience of mental illness to inform their research practice. The views of lived experience researchers may differ from those of consumers and carers without formal research training (Griffiths et al., 2004), thus it was of interest to collect the perspectives of both groups.

The event protocol and materials were developed in collaboration with the ACACIA Consumer and Carer Advisory Group, who provided valuable input on the structure, organization, and focus of the forum. Advertising materials used the headline “Whose story is it?” and prompt questions included the following: “Can consumers and carers participate in research if the other declines? How can carers of people who disagree with their diagnosis participate in research? Can consumers and carers participate without the knowledge of the other?”

The forum was facilitated by a professional mental health advocate and trainer, who self-identified as a consumer, and had significant previous experience facilitating events with a mental health focus. Participants were briefed regarding respectful communication and protocols for safety and self-care. Discussions were initially separated into consumer-only and carer-only groups. After this, consumers and carers were brought together for a combined discussion of the issues.

Forum recordings were transcribed verbatim, and initial analyses were conducted on de-identified transcripts by researchers who did not participate in the forum event to reduce the opportunity for bias. The coding framework was developed by one author (B.A.J.). This framework was subsequently refined by a second author (O.F.) and reviewed by the other authors, including the author present at the forum, to produce the final themes and associated quotes.

## Results

The semistructured approach produced in-depth discussion of a range of topics in the consumer-only and combined groups. However, in the carer-only group the discussion was focused on a small number of themes, resulting in an

underrepresentation of the carer-only perspective across some issues. Initially, 20 subthemes were identified and these were then organized into five major themes. This article presents a detailed discussion of three themes focused on practical considerations for mental health research: *privacy and confidentiality*, *mechanics of conducting research*, and *stigma*. Two other themes relating specifically to the consumer-carer relationship are discussed in a separate paper (Morse et al., submitted manuscript, 2018).

**Privacy and confidentiality.** An issue that proved to be contentious between consumer and carer perspectives related to *privacy and confidentiality*. Consumers emphasized that privacy was an important consideration for the conduct of ethical research, especially in qualitative research where personal stories could be recognized by third parties even when information was de-identified. A lack of agreed boundaries around the information that could be shared could leave both consumers and carers feeling uncomfortable about the research. While most participants were concerned with possible privacy breaches by carers about consumers, some recognized that the breach could go the other way.

If a third party were to suddenly have that information and be able to say OK. . . I know who that person is that does become a problem because it's no longer between me and the person who's directly involved. (Consumer 5)

However, carers felt that they were able to share stories in a respectful and considerate manner without violating consumers' privacy.

I've never met a carer who wants to divulge really personal information about their consumer in a way that it will go out in public. (Carer 1)

**Mechanics of conducting research.** Across all groups, participants discussed the *mechanics of conducting research* to understand issues including informed consent, and the role and operation of Human Research Ethics Committees (HRECs). Comprehensive informed consent processes were considered to be crucial, particularly in relation to respectful story sharing. Participants also felt that HRECs should take a greater role in educating participants about proactive communication within their relationships.

Where can we plug that hole by providing information for people to say, "Here's some suggestions on the way you can manage this?" . . . There may be a problem in the relationship if there's a difference of opinion about participating. . . . From an ethics perspective, they need to ask that question. (Consumer 3)

The carer group had limited discussion on research mechanics, but generally supported researchers providing greater information and education, while expressing some doubt about the extent to which consumer-carer relationships are the concern of the HREC. This was also raised in the combined session, by a consumer participant who felt that it may not be appropriate for an HREC to interfere with or comment on consumer-carer relationships within a family.

**Stigma.** Stigmatizing attitudes toward mental illness were thought to contribute to the separate treatment of research involving people with mental health issues within Australian ethics guidelines. Participants did not approve of the categorization of people with mental illness alongside those with intellectual disability in these guidelines, and disputed the default classification of mental health research at the highest level of risk for ethical review.

It does seem in most other cases as long as you give the people enough information then [the HREC] are OK with it. There seems to be this weird exception here . . . that somehow the minute you have a mental illness you don't have agency. (Consumer 2)

Some people might argue that that's positive discrimination, to safeguard someone that's vulnerable—where I say no, it's just discrimination, it's creating a stereotype and stigmatising a particular person based on a certain clinical list of symptoms. (Consumer 1)

However, there was acknowledgment that for research involving people who may be acutely unwell or currently hospitalized, a greater degree of scrutiny and care is justified. Nevertheless, overall it was felt that ethics procedures were affected by stigma and negative assumptions about mental illness, and that HRECs should do more to respect the agency and capabilities of people with mental health issues.

People with mental illness can make their own decisions . . . even someone extremely unwell can still have a pretty good idea of what they want in their life. . . . In reality, they're quite functional people. (Consumer 1)

## Consumer and Carer Interviews

### Material and Methods

The topic guide for the interviews was developed based on findings from the forum, with the aim of building on the initial results. The interviews sought to develop a deep understanding of the *mechanics of conducting research*

theme and of consumer and carer concepts of risk and vulnerability. These concepts had emerged during the forum discussions but were not explored in depth. In addition, the interviews aimed to develop a detailed understanding of carer perspectives across the identified themes and to explore whether contrasting consumer and carer views of *privacy and confidentiality* had been amplified by in-group identification at the forum. To this end, interview questions were deliberately neutrally worded and participants were asked to consider hypothetical scenarios to encourage them to think reflectively and consider multiple perspectives. As for the forum protocol, the interview protocol (see the supplementary file) was developed with input from the Consumer and Carer Advisory Group.

Ten participants (nine female, one male) were recruited for the interviews from the ACT and surrounding region. Five identified as consumers, four as carers, and one as both a consumer and a carer. Five participants (three carers, two consumers) were initially recruited using the methods described for the forum. Theoretical sampling was then employed to develop a deeper understanding of several concepts. Carers who had provided occasional support for a friend or family member were interviewed to explore their views on *privacy and confidentiality*. Carer participants at the forum and in the early interviews had provided high levels of support for a family member, while in contrast most consumer participants received occasional social support from family and friends. This mismatch in experience may have driven some of the contrasting views at the forum. Consumers who participated in the forum and interviews were quite well at the time; however, many participants had previously experienced periods of significant disability and were able to provide considered discussion about their changing needs at different levels of wellness. Young adult consumers and carers with little or no advocacy or representation experience were interviewed to explore their concepts of the *mechanics of conducting research*, vulnerability, and risk. Many previous participants had been engaged in mental health advocacy or education, and it was of interest to explore whether this affected their views on storytelling and research practice. A consumer researcher was also recruited to explore the influence of their role and professional expertise on these concepts.

Interviews were conducted in-person by one of two authors (A.R.M. and O.F.) and audio-recorded with participants' consent. At the beginning of each interview, participants were given a description of the aim of the research project, the purpose of the interview and a definition of the term "carer," as not everyone identifies with this term. After each interview, interviewers recorded written reflective notes about the nature and key content of the discussion. Audio-recordings were transcribed verbatim with identifying information removed, and subsequent analyses were performed on the transcripts and interviewer reflective notes.

Primary interview analysis was conducted by one author (A.R.M.), in consultation with the research team. Data were managed using QSR International's NVivo 11 Software. An initial coding framework was developed using the themes and subthemes from the forum analysis and key concepts identified from interviewers' reflective notes. As the interview data were coded, the applicability of the framework was tested and themes were modified to accommodate new information. Memos were utilized to facilitate and record the process of developing the final thematic framework. Throughout this process, A.R.M. regularly discussed the coding framework and thematic development with other members of the research team to test assumptions and clarify themes.

## Results

The themes developed from the forum data were maintained in the interview analysis; however, their content was modified or expanded to account for the new information gathered through the interviews. In contrast to the forum, the carer perspective received equal representation across themes in the interviews, and consumer and carer perspectives on the key issues within each theme were similar. In addition to the themes from the forum analysis, two additional themes were developed from the interview data: *vulnerability and risk* and *benefits, values, and motivations*.

*Privacy and confidentiality.* This area was one of the most contentious in the forum, but was less polarized in the one-on-one interviews. Similar to the forum, the concepts of privacy and confidentiality were closely related to storytelling and story ownership in the interviews, but participants were less focused on the consequences of information sharing and more reflective on roles and responsibilities. Protecting the privacy or anonymity of individuals was highlighted as the primary way to safely tell personal stories that involve other people. Responsibility for protecting privacy and confidentiality lay both with the storyteller and the researcher. When telling a personal story, participants felt the storyteller should avoid disclosing identifying, personal, or sensitive information about other people. This was particularly important if the story involved a consumer or if nondisclosure had been requested by a consumer. Carers were aware of the challenges of communicating effectively and safely in storytelling contexts. They described being conscious of generalizing and depersonalizing details when talking about their own experiences, and considering how a "story is going to land from a consumer perspective" (Carer 2).

In the context of research focused on carers, researchers were expected to design and ask appropriate questions that targeted the carer experience, and to sensitively write-up material for publication. A smaller number of participants

felt the research context itself protected confidentiality because data are de-identified and information is typically published about groups, not individuals.

Yeah, and I think it [research] can be more anonymous too. I don't know that I'd want to identify myself in a study. . . . I'm not comfortable with people knowing widely that I've been through this. (Consumer 5)

**Mechanics of conducting research.** As was the case in the forum, participants discussed the roles and responsibilities of researchers and participants. Discussion in the interviews went beyond the HREC responsibilities discussed at the forum, with a focus on the role of the researcher. When conducting research with carers, researcher responsibilities centered on protecting confidentiality. This included designing appropriate questions, selecting and analyzing relevant data, and producing respectful publications. Carers expected researchers to have an understanding of mental health issues and to reflect on their practices, allowing them to work sensitively and appropriately with participants.

Well I would hope that the person doing the research did have a good understanding of mental health before they started. I think you'd have to be aware of the person's illness and where they're at, and whether they're high-functioning . . . (Carer 1)

A small number of participants also discussed their own role and responsibilities in the research process, beyond those discussed under *privacy and confidentiality*. Participants indicated that they were responsible for deciding if and how they would participate in a study, whether they were well enough to participate, and whether any of their personal relationships were relevant to these decisions.

**Stigma.** While forum participants discussed stigma in response to prompts from facilitators, nine out of 10 interview participants talked about mental health stigma without being prompted to do so, highlighting the salience and impact of stigmatizing attitudes for both consumers and carers. Some consumer participants shared their personal experiences of stigma in day-to-day settings and, in one case, a research setting. Similar to the forum discussions, some interview participants felt that identifying people with a mental illness as a high-risk category for ethical review and treating them differently was condescending and stigmatizing. In contrast, other participants supported including people with mental illness in a high-risk category to ensure safe, accountable and high quality research was conducted with people who were potentially vulnerable to psychological harm (e.g., distress) or exploitation.

And so I don't think they should be treated any differently to someone who is also not mentally ill. . . . I wouldn't like to be involved in research and [have] someone say, "Hey, like you can't do this 'cause you can't give informed consent because you have experience with a mental health issue." Um like, sure I can. (Consumer 4)

I strongly support that. Strongly support that. Because I think, too, and for me part of that is that people deserve to be protected, to be able to tell their story and get it out, to be able to influence policy and services and our understanding of mental illnesses. But I think in doing that and in having lived experience that you need to acknowledge that it can be a very tough journey. It can be a very tough life. (Carer 3)

**Vulnerability and risk.** The concepts of *vulnerability and risk* in research emerged at the forum as part of the stigma-related ethics discussions. The interviews explored these concepts to develop an understanding of consumer and carer perceptions of risk in research settings and how risks could be effectively managed. In general, participants did not believe experiencing a mental illness increased the risk of encountering psychological harm by participating in research. However, certain situations, such as participating in research during acute or severe periods of illness, were acknowledged as higher risk. One participant also highlighted power imbalances between professionals and consumers as an important vulnerability to consider when working with consumers. Overall, participants agreed that vulnerability to harm should be judged based on a person's "functionality and capacity and not a diagnosis" (Carer 1).

Several participants suggested that it was important to adopt a trauma-informed perspective when conducting research because any participant could have an undisclosed history of trauma or mental health issues. This was recommended for all research investigating potentially sensitive topics, not just research with participants who identified as consumers.

So I think maybe it's not so much about singling out mental health consumers, I think it's about a trauma informed approach to the topic of research. So acknowledging that there are certain types of research that don't involve mental health consumers that could very well, if handled wrong, they could actually traumatise a person who has no history of mental illness but has a history related to that research. (Consumer 2)

To facilitate research participation for particularly vulnerable people, consumers and carers suggested researchers should consider and cater for the comfort of participants. Ideally, research would be conducted in an environment that is "more like a normal conversation than like a board interview" (Consumer/Carer) and is accessible to participants with limited capacity to travel. Several participants

suggested that offering people the option to bring a support person with them would be beneficial. A small number of consumers and carers further suggested that researchers could discuss specific needs and boundaries with participants to identify individual sensitivities, such as topics or activities the participant would prefer to avoid. Emphasis was placed on participant autonomy and choice; supportive measures should be responsive to participants' needs, not imposed as blanket measures.

... unless of course someone like couldn't deal with particular situations or scenarios. I feel like that sort of stuff should be addressed at the start, like if you walked in and were like do you have any issues with anything being said or done and like most people would just go "No, all good." (Consumer/Carer)

**Benefits, values, and motivations.** This theme was unique to the interviews: Many interview participants talked about the importance of conducting mental health research and its role in improving services and outcomes. Research also had personal benefits and, in general, participants felt that participating in research was a positive experience. Sharing stories of personal experiences was described as a valuable and empowering way to increase understanding about mental health and to improve services. Some participants also discussed the importance of not excluding certain groups from research, including consumers who may be unwell.

... like even when I have been mentally ill I guess, and been involved in research, I've always found it quite positive, and quite empowering to be able to talk about my own experiences. (Consumer 4)

Some consumers thought it would be positive for their carers (family members) to have more opportunities to share their experiences in personally beneficial ways. Consumers felt these family members had had difficult experiences but few opportunities to talk about them.

I think it's hard for her in a different way but it's just as hard for her as it has been for me because she cares about me and things haven't always gone the way that they should. ... Yeah so I think it'd actually be really good for her. (Consumer 5)

Participants were motivated to participate in research by these potential real-world benefits. Other motivations for participation centered on how well the values and goals of a research team or institution aligned with participants' personal values and goals. Participants were more likely to participate in research relevant to their personal circumstances or interests and carried out by a trusted and ethical institution. Participants were less likely to participate in research

if the results were likely to be published in a negative or derogatory light.

The more that I think that it's actually like going to make a difference the more time I'd be happy to put into it. (Consumer 5)

And if it was political, if it was any [pause] say an organisation like in the area of mental health where I didn't agree with their philosophies or it was a religious organisation I didn't agree with, that would be a huge factor for me in determining whether or not I would actually participate in the research. So it is more about why they want to do it and what they're trying to achieve out of it. (Consumer 2)

## Discussion

The present study explored consumer and carer perspectives on mental health research ethics. The five themes discussed—*privacy and confidentiality*; *mechanics of conducting research*; *stigma*; *vulnerability and risk*; and *benefits, values, and motivations*—demonstrate the value and the risks in mental health research broadly, including research involving carers. Participants suggested there are potential risks to privacy and to relationships, which are particular to conducting research with carers and consumer-carer dyads. Based on these results, researchers and HRECs are charged with facilitating the safe and confidential telling of shared stories, educating participants about the potential privacy and relationship risks of research participation, and providing resources to facilitate conversations about information-sharing boundaries. Risks need to be managed respectfully, particularly as consumer participants find current Australian guidelines for consumer research stigmatizing and condescending.

### Addressing Risks With Respect

The findings of this study provide suggestions for managing risk respectfully when conducting mental health research with adults. In Australia, people with a mental illness are classified as a "vulnerable" population who may require additional protections when participating in research (NHMRC et al., 2007/2015). When operationalized at the level of local HRECs, this classification can result in research with mental health consumer automatically requiring full ethical review, even when the topic and protocol of the project would usually receive an expedited review. The automatic scrutiny of research involving consumer participants is not unique to the Australian context (DuBois et al., 2012; Iltis et al., 2013) and was perceived as stigmatizing or condescending by participants. While participants acknowledged that certain consumers under certain circumstance required special protection, they felt that most people with a mental illness were capable of consenting to research participation

and were not more vulnerable to risk of psychological harm than the general population. Thus, a nuanced approach to the ethical review of research involving consumers may be required, one that does not assume participant risk level based on a mental illness diagnosis. These criticisms align with the views of consumers, researchers, and other stakeholders from the United States (DuBois et al., 2012), and with academic criticisms of the concept of vulnerability in research (Levine et al., 2004; Luna, 2009). Labeling an entire group of people as “vulnerable” stereotypes the individuals within the group and fails to acknowledge individual differences in the necessity and level of supports required to allow a person to participate safely in research (Levine et al., 2004).

Individual-focused approaches, including offering optional safeguards (e.g., bringing a support person to an interview) and discussing participant needs prior to data collection, were suggested by consumers and carers as acceptable ways to manage risk. Findings also indicate that a trauma-informed approach to research design may provide a respectful and effective way to manage risk, recognizing that any participant may have a history of trauma relevant to a research topic and may therefore be at higher risk of experiencing psychological harm. The findings of this study reflect a “layered” concept of vulnerability, in contrast to the “label” concept of vulnerability currently implemented (Luna, 2009; Luna & Vanderpoel, 2013). Consumers felt that they were not vulnerable by definition, but acknowledged that certain circumstances or contexts could render a person vulnerable (Luna, 2009). For example, participants felt that periods of severe illness or hospitalization could render a person more vulnerable to harm. To improve the design and implementation of procedural ethics processes for conducting research with consumers and carers, it is recommended that researchers and HRECs consider the individual needs of participants within the context and setting of a research project, allowing for flexibility and participant choice in the application of safeguards.

This position aligns with the Australian National Statement, which specifies that the application of ethical guidelines “always requires, from each individual, deliberation on the values and principles, exercise of judgement, and an appreciation of context” (NHMRC et al., 2007/2015). It also aligns with the Helsinki Declaration, which states “All vulnerable groups and individuals should receive specifically considered protection” (World Medical Association, 2013, p. 2192, emphasis added). Thus, it is possible for HRECs and researchers to implement ethical procedures that are respectful and acceptable for consumers. Consumers and carers in the present study were aware of the importance of participant diversity to our understanding of mental health, and believed research participation can confer direct benefits to the individual by providing a positive and empowering experience for consumers and carers, even in times of illness. It is unjust to exclude

populations labeled as “vulnerable” from the potential benefits of mental health research (Iltis et al., 2013).

### **Limitations and Future Directions**

The suggestions for research practice drawn from our findings have not been previously implemented. Therefore, it may be beneficial to test the efficacy and acceptability of these measures before broad implementation. New research practices should be developed in consultation with the best available evidence (including community consultation) and implemented within the parameters of relevant ethical guidelines (DuBois et al., 2012). The authors intend to use the findings of this project as a starting point for broader consultation with consumers, carers, researchers, and other relevant stakeholders in Australia, and the subsequent co-creation of guidelines for mental health research practice.

The conclusions that can be drawn from the findings of the present study are limited by the small number of mostly female participants recruited from a restricted geographical area (the ACT and surrounding region). Compared with national averages, participants from this geographical region are likely to have relatively high education levels, good health, and high socioeconomic status (Anstey et al., 2012). While human research practices are based on the same founding ethical principles internationally, some of the research experiences of participants may be specific to the Australian context. These factors limit the generalizability of results, and further research or stakeholder consultation may be required before implementing the proposed suggestions for research practice in different contexts.

### **Conclusion**

Conducting research involving mental health consumers and carers raises ethical issues related to privacy, confidentiality, and respectful risk management. When conducting research with carers, or focused on consumer–carer relationships, it may be necessary to facilitate the negotiation of information-sharing boundaries within relationships and the safe and confidential telling of shared stories. Current Australian ethics procedures are perceived as stigmatizing by consumers and carers and may unjustly exclude certain populations from the benefits of mental health research. When implementing ethical safeguards, it is important to maintain participant autonomy and ensure measures are respectful and acceptable to, and tailored to the needs of the affected community.

### **Best Practices**

The key learning for practice from our findings is the importance of implementing ethical safeguards and risk management strategies with respect for participants. Our findings

indicate that Australian mental health consumers and carers find group-based definitions of vulnerability to harm or coercion stigmatizing. Future research should aim to support the development of more nuanced approaches to the ethical review of mental health research that do not automatically assume risk on the basis of diagnosis. Our findings suggest that individual-focused approaches to risk management, such as offering optional safeguards and discussing participant needs prior to data collection, are likely to be more acceptable ways to manage risk when working with consumer and carer participants. As far as possible within the parameters of relevant ethical guidelines, we recommend that researchers and HREC members begin to develop mechanisms that would allow them to consider the range of variation in participant needs in the context of a research project and allow for flexibility and participant choice in the application of safeguards.

## Research Agenda

The findings of this study suggest there is a need to improve procedural ethics processes in Australia to address the stigmatizing treatment of people with lived experience of mental health issues. Work is needed to develop or co-create new risk identification and management strategies in consultation or partnership with consumers, carers, and other relevant stakeholders. Newly implemented guidelines and research practices should be formally evaluated to assess their acceptability, effectiveness and impact, and to support continued improvement. It is also of interest to determine whether similar procedural ethics issues are encountered in mental health research conducted in countries or regions whose approach to the ethical regulation of human research differs from the model used in Australia, Canada, and the United States (Canadian Institutes of Health Research et al., 2014; “Federal Policy for the Protection of Human Subjects, 45 C.F.R. § 46,” 2009; NHMRC et al., 2007/2015). Different procedural ethics issues may also arise in complex situations, such as those encountered in low-income countries or emergency settings (Chimento, Rahman, Frith, Snider, & Tol, 2017). Lessons learned from such comparisons may facilitate the development of improved mental health research and procedural ethics practices.

## Educational Implications

Our findings indicate that Australian consumers and carers believe that stigmatizing attitudes toward mental illness contribute to the special conditions for research involving people with mental health issues within Australian ethics guidelines (NHMRC et al., 2007/2015). Carers also expected researchers to have an understanding of mental health issues to enable them to work sensitively and appropriately with participants. This suggests it is important for

mental health researchers and HREC members to have good mental health literacy. Future research could explore levels of mental health literacy among mental health researchers and HREC members, determine whether this impacts their ethical decision-making, and work to develop psychoeducational interventions to fill-in any identified deficits in knowledge.

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## Supplemental Material

Supplemental material for this article is available online.

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**Bethany A. Jones** is an early career researcher in population health. Her research interests include consumer- and carer-focused research, gender issues in mental health, mental illness prevention, and e-mental health. She contributed to the study conception and design, and conducted the initial analysis of forum data.

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