

Very useful, but do carefully: Mental health researcher views on establishing a Mental Health Expert Consumer Researcher Group

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Abstract

Introduction

Contemporary mental health policy identifies consumers as active participants in all aspects of mental health services from design to evaluation. Consumer researchers should be actively involved in mental health research and contribute to quality service delivery.

Aim

To gain a snapshot of mental health researcher views on strategies for increasing research by or with consumers in mental health through the establishment of an Expert Consumer Researcher Group (ECRG).

Methods

Cross-sectional survey of 41 non-consumer mental health researchers from Australia or New Zealand.

Results

The introduction of an ECRG was considered an effective strategy for linking consumer and non-consumer researchers, and providing specialist advice on research design and methodology. The most suitable location for this group

was identified as within: consumer advocacy agencies (71%), universities (66%), or research funding bodies (66%). Participants rated their likelihood of seeking advice from the ECRG as high.

Discussion:

Research participants supported the value of an ECRG. They emphasised the importance of ensuring the group reflected a diversity of views and offered specialised expertise related to the specific topic. The ECRG could benefit both individual researchers and larger research organisations.

Implications for practice:

An ECRG could facilitate collaborations with consumer researchers and in turn enhance the quality of mental health research.

Keywords

Attitudes

Consumer

Expert Reference Group

Mental health

Partnerships

Research

Relevance statement

Consumer participation in all components of mental health services is now a clear policy directive in Australia and increasingly internationally. Quality mental health services require a strong research base, and as active participants consumers must be integral to the research agenda. An expert consumer reference group is a potential strategy to enhance access to and build capacity within consumer research. How receptive nurses and other health professional researchers would be to such an initiative is not known.

This research provides important information about attitudes to an expert consumer reference groups and further advances nursing leadership in this field.

Accessible summary

What is known on the subject

- Contemporary mental health policy stipulates consumer participation in all aspects of mental health services including service evaluation and other forms of mental health research
- Research is identified as underpinning quality mental health services and therefore consumers researchers could enhance the mental health sector by contributing to the quality, credibility and relevance of mental health research

What the paper adds to existing knowledge

- Non-consumer researchers generally supported the concept of a consumer expert reference group for researchers at the individual and institutional level
- A consumer expert reference group should reflect diversity and offer expertise relevant to the topic of research, and may represent one way to normalise partnerships with consumer researchers and realise the benefits they can bring to research

What are the implications for practice

- Quality mental health services are underpinned by robust research evidence. It is crucial that consumers are active participants in research activity
- The availability of a consumer expert reference group could facilitate collaborations between consumer and non-consumer researchers and contribute to a stronger consumer focus embedded in mental health research.

People with lived experience of 'mental illness' and mental health services (herein referred to as consumers) have considerable expertise to contribute to reforming mental health research agendas and designs to better meet their needs, values and purposes (Byrne, Stratford, & Davidson, 2018; Happell, Gordon, Bocking, et al., 2018b). Existing literature clearly illustrates a wide range of benefits of consumer involvement in research, including: ensuring research agendas address service gaps; diversifying perspectives on the meaning of qualitative data; identifying ethical concerns; facilitating recruitment of consumers in research; and leading theoretical and cross-disciplinary work (Ennis & Wykes, 2013; Michalak et al., 2016; Mjosund et al., 2017; Rose, Carr, & Beresford, 2018). Despite these benefits, presumptions that consumers can or will not be part of research teams are widespread (Happell, Gordon, et al., 2019; Vollm, Foster, Bates, & Huband, 2017).

It should be noted that the term 'consumer' is used throughout to describe people with lived experience of mental illness and services not only because it is consistent with the language most often used in Australian policy (Australian Commission on Safety and Quality in Health Care, 2017), but also because it represents a term chosen by an Australian consumer movement (Our Consumer Place, 2012). 'Consumer researcher' refers to researchers who have lived experience of mental illness and services who used that perspective in their research work (Happell, Gordon, et al., 2019). It has been argued that providing a consumer perspective when not

employed in such a capacity might serve to diminish or silence the expertise that consumers can bring to mental health services (Happell & Scholz, 2018), suggesting the importance of ensuring lived experience expertise be valued for the benefits it brings.

There has been some progress in research partnerships between consumer and non-consumer researchers, as seen in the growing success of the Service User Academia Symposium (2018). Resources to support partnerships between non-consumer and consumer researchers are increasing in some areas (e.g., data analysis procedures supporting collaborative research work; see Jennings, Slade, Bates, Munday, & Toney, 2018). However collaboration between consumer and non-consumer mental health researchers is still not common; whether it be 'slight' forms such as advice on research design or more meaningful forms such as co-production and consumer-led research (Gillard, Simons, Turner, Lucock, & Edwards, 2012; Roper, Grey, & Cadogan, 2018).

Co-production between consumer and non-consumer researchers is limited by several barriers, include stigma and lack of organisational supports (Boaz, Biri, & McKeivitt, 2016; Lawn, 2016; Patterson, Trite, & Weaver, 2014; Veseth, Binder, Borg, & Davidson, 2017). Even if non-consumer researchers are interested in collaborating with consumer researchers, research ecosystems in universities or health services are often not conducive to partnerships – with the onus on individual researchers or groups to challenge systemic barriers to collaboration (Scholz et al., 2019).

Acknowledgement of the impact of negative attitudes of health professionals to working collegially with consumers and the systemic barriers to collaboration led to the introduction of an academic position for mental health consumer in an Australian School of Nursing (Happell & Roper, 2002, 2009). This and subsequent positions demonstrated more positive attitudes of nursing students towards people diagnosed with mental illness and the

mental health field more broadly (Byrne, Platania-Phung, Happell, Harris, & Bradshaw, 2014; Happell, Pinikahana, & Roper, 2003; Happell, Platania-Phung, et al., 2019).

Since the establishment of these positions, research has found that non-consumer researchers find several benefits to collaborations with consumer researchers, including bringing perspectives to research that could not have come from someone without lived experience (Happell, Gordon, Bocking, et al., 2018a). The establishment of an expert consumer reference group (ECRG) could potentially influence similar outcomes. The ECRG would provide specialist advice from a consumer perspective to foster stronger research engagement and partnerships between consumer and non-consumer researchers, and address the stigma related barriers to their genuine involvement in mental health research. It also provides an excellent opportunity for nursing to again demonstrate leadership by facilitating, as allies, consumer researcher positions.

Objective

The objective of the current study is to explore one potential strategy to overcoming identified barriers to consumer involvement in mental health research. While we suggest that the specific details of exactly how such an ECRG might operate should be decided by consumer researcher group members and with other consumer stakeholders, the aim of the current study is to develop understandings of non-consumer researchers about accessing such a group, and the value it might bring.

Method

Setting

This study was conducted collaboratively by consumer and non-consumer researchers. It involved a cross-sectional survey of 41 non-consumer mental health researchers located in Australia or New Zealand to canvass views on strategies for increasing research by or with consumers in mental health areas; especially through the establishment of an ECRG.

Design

This research is cross-sectional and based on self-report survey data.

Participants and Procedure

Participants were mental health researchers from the disciplines of Social Work, Psychology, Psychiatry, Nursing or Occupational Therapy in Australia and New Zealand. Our recruitment strategy involved writing to the Heads of School or Department of the five disciplines at universities from Australia and New Zealand. In addition we contacted the professional organisations for each discipline in both countries: the Australian College of Mental Health Nurses, the Royal Australian and New Zealand College of Psychiatrists, the Australian Association of Social Workers; Occupational Therapy Australia; the Australian Psychological Society; the Australian College of Nurses; Te Ao Māramatanga New Zealand College of Mental Health Nurses; Aotearoa New Zealand Association of Social Workers; the New Zealand College of Clinical Psychologists; Occupational Therapy New Zealand; and the New Zealand Nurses Organisation. These organisations were invited to promote the study via their mailing lists and web pages. The members of these bodies were invited to participate in the survey, accessed via e-newsletter, announcements on the organisations' homepage, or individual mailout. The survey was also promoted via twitter and other social media platforms by the host organisations. Repeated releases of the advertisement were deployed to maximise the response rate. Data collection

occurred between September 2017 and March 2018. Forty-one completed questionnaires were returned.

Survey

No previous questionnaire designed to canvas views on an ECRG in mental health research was identified in existing literature or other internet searches. The survey, Consumers as Researchers in Mental Health, (CaRiMH) was therefore developed specifically for this project. An earlier qualitative study of mental health researchers on their views of consumer involvement in mental health research more broadly [authors anonymised for review process] informed the content of the survey. Consumer and non-consumer researchers designed the instrument collaboratively.

The self-report survey was delivered via the internet, through the Qualtrics platform. Survey questions included: demographic and health research background; perceived benefits and limitations of consumer research; workplace and research arrangements for consumer researchers at the participant's organisation; experiences of undertaking research in collaboration with consumer researchers; views about the effectiveness of avenues for increasing mental health consumer research; and intentions to partner with mental health consumer researchers. Participants were also provided with the opportunity to provide open-ended responses to each section of the survey.

Increasing prominence of consumer researchers

Participants were asked to rate the potential usefulness of 12 strategies for advancing mental health consumer research, on a scale from 'extremely useful' to 'not at all useful'. Example items included: 'Connect consumer research more with human rights organisations'; 'Build consensus on best

practice'; and 'Making mental health consumers central in mental health research policy'.

Expert Consumer Researcher Group

A working definition about a potential group was provided to participants within the section of the survey specifically focusing on the group, as follows:

It has been suggested that the establishment of an ECRG could benefit non-consumer mental health researchers. Such a group could aim to support non-consumer researchers who want to include consumers-as-researchers in all stages of research, but are unsure how to go about it. This group would comprise consumer researchers with lived experience and expertise in theory and practice based on that experience, as well as research skills and competencies. Further, members of the group would have experience in mental health research across the spectrum, including consumer-led research projects. While the ECRG would provide consultation and advice for any level of consumer participation in research, it would emphasise the importance of co-production.

The first section of this part of the survey sought comment on the potential value of such a group, where respondents considered 11 types of value, for instance: 'My organisation would find the availability of such a group useful'. Each was rated on a likert scale with responses ranging from 'strongly agree' to 'strongly disagree'. The second section asked more specifically about the likelihood of respondents accessing such a group for 12 functions or purposes – for instance, 'training on how to collaborate effectively with mental health consumers in research' and 'advice on research priorities'. An open comments box was provided below this section inviting views on additional services or functions. The third section provided

eight institutional positionings (e.g. within a government agency) to be rated on 'most value to both mental health researchers and communities'. The response options were: 'not of value', 'valuable' and 'not sure'. The fourth section related to perceived likelihood of contacting the group within the next three years, on a 5-point Likert scale ranging from 'extremely likely' to 'extremely unlikely'. The final section asked 'would you support major funding bodies requiring that each mental health grant application includes consumers as researchers?' on a 5 point Likert scale ranging from 'definitely yes' to 'definitely not'.

Ethics

This study was approved by the [ethics committee blinded for review]. The introductory material to the study described confidentiality arrangements – that no participant names or individual organisational affiliations would be recorded and raw data would only be viewed by the research group. Participants were advised their decision to be involved or otherwise was voluntary. Consent to participate was indicated by the return of the completed questionnaire.

Data analysis

The quantitative survey data was analysed in SPSS25 (IBM, 2017). There was a very low rate of missing numerical data: between zero and five per cent for most items. The raw distribution of each item response was analysed in terms of both frequencies and percentages.

The qualitative data from the survey utilised open comment responses which were analysed using a content analysis approach (Crowe, Inder, & Porter, 2015). Following this approach, the data were closely analysed independently by three members through coding and identifying categories

and then linking findings to existing knowledge. The researchers then met to discuss analysis. This sub-group's perspective on respondent comments were then circulated with the full team to discuss and verify interpretations.

Results

Participant demographics

Two thirds of respondents identified as female. Seventy-eight per cent were located in Australia (n=32) and 22% in NZ (n=9). In terms of age, 15% were between 31 and 40, 22% between 41 and 50, 51% between 51 and 60, and 12% over 61 years. Almost all (98%) undertook their research at a university, and 15% of such research was undertaken within a health service. A wide range of disciplines and areas of mental health research were included in the sample. The most represented disciplines were mental health nursing (51%), service user/consumer perspective (24%), psychology (17%), sociology (15%), occupational therapy (12%), psychiatry (10%), and counselling or psychotherapy (10%). Other areas included pharmacology, mental health law and exercise interventions. In terms of experience of working collaboratively with mental health consumers as colleagues, 71% had done so in mental health research, 56% in teaching, and 39% in clinical work.

Usefulness of strategies for more research by and with consumers

Table 1 presents perceived potential usefulness of a range of strategies for further establishing research by mental health consumers. Over a third of respondents rated half of the 12 strategies for advancing research by or with consumers avenues as "extremely useful". Of these, the strongest support was for the ECRG (44%), making mental health consumers central in mental health research policy (39%) and strongly prioritising consumer led or controlled research (37%).

[Table 1 about here]

Views about the Expert Consumer Researcher Group

While the main feature of questions on the ECRG were rating scales, thirteen respondents (31.7%) provided open comments on the Group and both are reported in conjunction below.

General viewpoints on the Expert Consumer Researcher Group

Table 2 shows levels of agreement with statements about a consumer expert research group. In general, there was agreement with statements on the benefits of such as group, and disagreement or neutrality expressed in response to statements of potential problems or limitations that the ECRG group may pose. Forty six percent of respondents strongly agreed that the group would make it easier to recruit a consumer with a background in research (46%), to gain advice on research at the planning stage (44%) and to provide an avenue for consumers who want to be involved in research activities (44%). About 85% agreed (somewhat or strongly) that their organisation would find the availability of such a group useful.

[Table 2 about here]

It was also suggested that the ECRG could be useful to postgraduate students and professionally isolated consumer researchers:

"I would like them to be available to higher degree by research students." (Participant[P]8; Nursing)

Another respondent made reference to the ECRG conducting outreach into academic settings, including engaging with students, rather than just being a body that could be approached:

"A proactive approach ...contacting universities, offering speaking and engagement with students" (P16; Education)

A single respondent suggested providing symbiotic support for mental health researchers:

"letters of support for research; in kind support (advertise through their newsletter etc)." (P4; Nursing and Sociology)

Other comments appeared to be cautionary statements or suggestions on governance arrangements for the ECRG. One respondent suggested boundaries would need to be set on the influence of group members:

"I personally think that these types of groups are not done well. They tend to be full of 'uber users' who are involved in everything and exclude everyday people who just want to be involved in research. They might be good for advice, but you wouldn't want research agendas being controlled in that way." (P31; Service design and policy)

In contrast, another respondent, based on their own positive experiences, was highly in favour of an Expert Consumer Researcher Group with some qualification, including: the need to be able to access specialist consumer/service user expertise by topic, as opposed to generic research expertise and (similar to the respondent quoted above) concern with over-influence of some members:

"I already have such a group. I strongly recommend it. The key is having people with relevant expertise - generic consumer representation is not sufficient. This is particularly important when researching specialist issues - gendered violence, Aboriginal communities, involuntary treatment. People without specific experience of these issues should not be expected to be representative of those who have. It is also vital to have a balance between carer and consumer perspectives, and to manage the group so that it is not dominated by a small number of participants." (P32; Mental health law)

A further respondent with experience with consumer groups made a point about specifics by locality:

"I think relationships with service users need to be local. A consumer expert group might have some value, but my experience is that local expertise is critical." (P39; Nursing)

Likelihood of accessing

Table 3 charts participants' reported likelihood of accessing a Consumer Expert Research Group. A very low proportion chose 'unlikely' (somewhat or extremely) across the purposes listed. Forty-four per cent self-reported as extremely likely to access the group for advice on designing a study; this was the highest proportion at the 'extremely likely' end. The next highest proportions were 39%, for both advice on research priorities, and for facilitating partnerships between consumer and non-consumer researchers.

[Table 3 about here]

Figure 1 indicates support for funding body requirements that consumers be included in grant applications. More than half (53.7%) definitely agreed that this should occur.

[Figure 1 about here]

Organisational Location

Table 4 shows the percentages of responses on how the ECRG should be positioned organisationally, for greatest impact. The highest percentages for institutional positioning that would be valuable were for within a consumer advocacy agency (71%), a research funding body (66%) and within a university (66%). Organisational contexts considered to be of lesser value were within a government agency (19%), a nation-wide internet-based group (19%), and in the commercial sector (51%)

[Table 4 about here]

One respondent commented on the availability of this type of group in certain parts of Australia:

“Many states have such groups already that we access for consumer input and advice...” (P2, Medicine)

Funding conditions in mental health research

When asked whether they would support major funding bodies requiring that each mental health grant application includes consumers as researchers, participants responded definitely yes (32%), probably yes (29%), might or might not (27%), probably not (5%) and definitely not (7%).

One respondent added that funding requirements are applied in a major state of Australia:

"[State health department] already states must have consumers involved in any grant submission and have such advisory councils and reference groups." (P2; Medicine)

Discussion

Non-consumer mental health researchers in this study have indicated support for the establishment of an ECRG, and are likely to access it if one became available. These views are broadly consistent with previous studies on the value of collectives of consumers in advancing mental health research agendas in ways that better serve the needs and preferences of their peers (Banfield et al., 2018; Happell, Scholz, et al., 2018; Rose, 2017; Wallcraft et al., 2011; Wallcraft, Schrank, & Amering, 2009). This study extends existing findings by elaborating on the potential value of the group in addressing known barriers to non-consumer researchers partnering with consumers; stigmatised attitudes and practices, lack of direct channels for advice and the small number of consumer academics currently available. While it is important to note that the size and capacity of this group would be limited at least initially, it presents a strategy to promote the availability of consumer expertise worthy of further exploration. The ECRG would provide a clear structure for research co-produced with or led by consumers and therefore assist in time to establish its legitimacy and credibility. Non-

consumer researchers interested in collaborative research partnerships with consumers would have a clear pathway to initiate discussions with potential partners. The expected increase in consumer research activity would likely to contribute over time to additional positions to address the limited number of consumer academics currently available. Establishing a formal group environment for consumer researchers will facilitate communication and collegiality within this cohort and further stimulate the exchange and development of expertise.

The percentage of respondents in favour of making mental health consumers central in mental health research policy needs to be contrasted with policy implemented in the UK (Rose, 2015), where consumer input is a requirement of research funding. The majority of respondents in this study indicated they would support major funding bodies having similar requirements for mental health grant applications (with 32% choosing 'definitely') in Australia and New Zealand. This position is perhaps reflective of what people have observed in the UK where there has been an increase in research with and by consumers following this type of policy lever (Kalathil & Jones, 2016) and the increase in indigenous health research in New Zealand and elsewhere following similar initiatives. It is interesting to note however, that approximately one third of participants were unsure or did not support this mandatory requirement. Similarly, there was less definitive support for other ways of mandating consumer involvement in mental health research. Given the overall positive attitudes towards consumer involvement in research and in the availability of an ECRG, this response may reflect concerns about availability. Consumer academics are limited in number and availability, and participants may believe a mandatory requirement for their involvement could create an expectation that cannot be met (Happell et al., 2015). The need for capacity building has been identified as crucial for the development of the consumer workforce more broadly (Bennetts, Pinches, Paluch, & Fossey, 2013; Byrne, Happell, & Reid-Searl, 2017).

Tokenistic responses to mandatory requirements are likely, as has certainly been the case in the UK (Staley, Kabir, & Szmukler, 2013), however, tokenism is arguably less likely to occur if a visible ECRG is available that non-consumer researchers can approach for support. It would be important that the purpose and process of the group is driven by consumer researchers, and ongoing effort be made to minimise tokenism and power imbalances. The value of such a resource is particularly pronounced for those situated in research institutions where consumer researchers are non-existent and/or marginalised.

What the study adds to the existing evidence

The current study provides insight into non-consumer researchers' perspectives about collaborating with consumer researchers through an ECRG. As this is an exploratory area, the findings of the current study contribute to understandings about the benefits of such a group, and how such a group might operate.

Two respondents indicated that locally or regionally (e.g. State) situated expert groups are available, yet there is clearly neither a national-level body or Trans-Tasman body that is dedicated to supporting non-consumer mental health researchers. Further, to the authors' knowledge there are no consumer-operated *expert* research groups, which value consumer researchers' own lived, and academic expertise, and view input into research decision-making as their central goal. One aim of the proposed ECRG would be to reduce the tokenism often present in existing hierarchies, in which one consumer is expected to represent the whole spectrum of consumer viewpoints (Scholz, Stewart, Bocking, & Happell, 2017), or where the value of lived experience of mental distress and related service use is not appreciated (Scholz, Bocking, & Happell, 2018).

Another strategy used to silence consumer perspectives and keep them away from the 'table' is to argue that certain types of consumers would not be appropriate for involvement (Happell, Gordon, Bocking, Ellis, Roper, Liggins, Scholz, et al., 2018). In the current study, one of the participants had suggested that consumers who are "involved in everything" would be suitable for "advice" but not for the development of "research agendas". Instead, they stated that "everyday people who just want to be involved in research" should not be excluded. Although facilitating "everyday people" to be involved in research is important, this appears to differ considerably from the way other participants conceptualised an ECRG. Expanding on with existing research about harnessing the value of diverse consumer perspectives (Scholz et al., 2018), other participants noted that an ECRG should include a range of experts so as not to rely on any one consumer being "expected to be representative of" a broad range of experiences.

Against a backdrop of stark shortages in organisational resources and support for mental health consumer researchers and their allies internationally (Byrne et al., 2018), this paper represents an innovative research-based approach to strategic thinking on further developing and progressing both consumer-led research and cross-disciplinary, consumer-centred mental health research agendas. Such approaches to improving mental health research infrastructure are currently rare. As part of this, a strength of the current research was providing a detailed description of the notion of an ECRG – itself the result of qualitative primary research [authors anonymised for review process] – and providing an opportunity for non-consumer mental health researchers to express their views in detail on potential benefits and problems of such a group. There is a long way to go in aligning mental health research with the degree of consumer participation mandated by policy and international human rights conventions (authors names left out for anonymous review). Therefore we strongly recommend other countries

consider gaining knowledge about non-consumer mental health researcher stances on the potential value of an ECRG. Further research encompassing more sites would aid decision-making on best approaches to progress more relevant interdisciplinary agendas and culturally relevant strategies to advance consumer academia.

Limitations

The small sample size for this survey study limit the confidence that can be attached to the quantitative data. We suspect that 'non-consumer mental health researchers' who have previously collaborated with consumers in either research, clinical work or teaching were over-represented among respondents and acknowledge the need to seek the views of those without such experience. Such data is particularly important as these investigators would be the prime focus for the ECRG.

A further limitation of the quantitative survey design of the study is that participants were largely limited to predetermined responses about collaboration with consumer researchers, and the establishment of the ECRG. Further research could explore non-consumer researchers' own thoughts and perspectives on such a group.

Conclusion

Mental health researchers surveyed supported the establishment of an Expert Consumer Researcher Group. Some respondents were concerned that such a collective be sensitive to diversity of views, to locality and to specialised expertise by mental health topic. The establishment of a highly effective and qualified Expert Consumer Researcher Group could be an important strategy in advancing mental health research in line with contemporary policy in Australia and New Zealand.

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Table 1. Potential usefulness of strategies for further establishing mental health consumer research

Strategy	Extremely useful	Very useful	Moderately useful	Slightly useful	Not at all useful
Making mental health consumers central in mental health research policy	39.0	46.3	9.8	2.4	2.4
Mental health researcher symposia workshops, seminars and conferences	34.1	31.7	24.4	9.8	0.0
National or Australian-New Zealand community of practice	22.0	39.0	22.0	9.8	4.9
Make mandatory to have mental health consumer input/consultation in planning of mental health research	24.4	26.8	19.5	17.1	12.2
Establish an expert consumer group to support non-consumer researchers who want to include consumers in all stages of research	43.9	31.7	17.1	7.3	0.0
Learn from establishment strategies in other countries/nations	31.7	41.5	19.5	7.3	0.0
Learn from successful initiatives by other minority groups	26.8	48.8	14.6	9.8	0.0
Connect consumer research more with human rights organisations	26.8	26.8	29.3	14.6	2.4
Highlight the position of consumer research in the consumer movement and	34.1	29.3	26.8	7.3	0.0

	Extremely useful	Very useful	Moderately useful	Slightly useful	Not at all useful
Strategy survivor movement*					
Locate more firmly consumer research as public involvement in research*	29.3	36.6	19.5	12.2	0.0
Build consensus on best practice	22.0	34.1	34.1	9.8	0.0
Strongly prioritise consumer led or controlled research	36.6	24.4	29.3	7.3	2.4

Table 2. Potential Value of a Consumer Expert Group

Statement	Strongly agree	Somewhat agree	Neither		
			agree nor disagree	Somewhat disagree	Strongly disagree
My organisation would find the availability of such a group useful	31.7	53.7	9.8	2.4	2.4
This would give a higher prominence of mental health consumer research in the wider research community	34.1	48.8	17.1		
Such a group would make it much easier to recruit a consumer with a background in research	46.3	39.0	14.6		

Statement	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Would be helpful for gaining advice on research at the planning stage*	43.9	36.6	9.8	7.3	0.0
Would be a good avenue for consumers who want to be involved in research (doing research)	43.9	43.9	12.2		
This group may not represent the interests and values of mental health consumers	7.3	29.3	31.7	19.5	12.2
My colleagues would be unreceptive to learning about this group	2.4	14.6	34.1	39.0	9.8
The group would present another challenge to deal with when trying to conduct my research	7.3	4.9	31.7	26.8	29.3
Access to consumer researchers is already available through other organisations, such as non-governmental organisations	7.3	19.5	29.3	31.7	12.2
Colleagues in my organisation would be unlikely to contact this group for support	4.9	22.0	36.6	29.3	7.3
This would make accessing consumers with research experience more complicated than it needs to be	12.2	19.5	46.3	22.0	
This group may not represent the interests and values of the mental health consumers my research focuses on	12.2	26.8	34.1	19.5	7.3

Table 3. If a Consumer Expert Group was available in Australian/New Zealand, to what extent would you be likely to access it for the following:

Statement	Extremely likely	Somewhat likely	Neither likely nor unlikely	Somewhat unlikely	Extremely unlikely
Gaining input for setting up a reference Group	31.7	43.9	17.1	7.3	0.0
Inviting one of its members to join a reference group of advisory panel	34.1	43.9	17.1	4.9	0.0
Advice on designing a research study that involves mental health consumers as research participants	43.9	36.6	17.1	2.4	0.0
Writing grant applications	34.1	36.6	17.1	9.8	2.4
Advice on action research/participatory research	22.0	41.5	26.8	2.4	7.3
Guidance on strengthening policy and research protocols at my organisation	29.3	43.9	22.0	2.4	2.4
Training in how to collaborate effectively with mental health consumers in research	34.1	39.0	19.5	4.9	2.4
Facilitating partnerships between consumer and non-consumer researchers	39.0	39.0	14.6	4.9	2.4
Advice on research ideas	34.1	39.0	17.1	7.3	2.4

Statement	Extremely likely	Somewhat likely	Neither likely nor unlikely	Somewhat unlikely	Extremely unlikely
Advice on research priorities	39.0	36.6	14.6	7.3	2.4
Engaging an appropriate person/people to consult at all stages of a research project	34.1	51.2	9.8	2.4	2.4
Engaging an appropriate person/people to co-produce a research project	36.6	43.9	12.2	4.9	2.4

Table 4. Institutional positioning for value

	Not of value	Valuable	Not sure
Within a university	9.8	65.9	24.4
Within a human rights organisation	4.9	51.2	43.9
Within a government agency	19.5	46.3	34.1

	Not of value	Valuable	Not sure
Within a consumer advocacy agency	2.4	70.7	26.8
As a non-governmental organisation	7.3	53.7	39.0
Within the commercial sector	51.2	14.6	34.1
Virtual/internet group that is nation-wide	19.5	43.9	36.6
Within a research funding body	12.2	65.9	22.0

Note: The full question was: In your view, if such a group was established, how could it be positioned institutionally to be of most value to both mental health researchers and communities?

Figure 1. Likelihood to support a requirement by funding bodies for consumers in research.

