‘It is always worth the extra effort’:
Organisational structures and barriers to collaboration with consumers in mental health research: perspectives of non-consumer researcher allies

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ABSTRACT

Consumer collaboration in mental health research has demonstrated significant benefits and reflects both contemporary research practice and policy goals for the expected genuine involvement of consumers in all aspects of mental health service delivery. Notable barriers have been identified as impeding consumer researcher positions that must be better understood and ultimately addressed. The aim of this research was to better understand these barriers from the perspectives of non-consumer researchers who have worked collegially with consumer researchers. We developed a self-report survey, Consumers as Researchers in Mental Health (CaRiMH) and administered it to non-consumer mental health researchers in Australia and New Zealand. Findings suggest a lack of organisational structures to support both consumer research and capacity building of consumer researchers. Most consumer researchers were employed casually with no set hours. Although consumer researchers were typically remunerated, inadequate funding and inflexibility of employment were highlighted as major barriers. There was variation in opinion about token involvement of consumer
researchers and some uncertainty about whether these roles, where they existed, were actively resisted. Despite the acknowledged barriers, participants were positive about collaborations with consumer researchers. Overall, findings suggest consumer research is unlikely to proliferate without greater attention to organisational structures. A systematic and strategic approach to advancing mental health consumer research is required, including extra-organisational policy factors.

KEYWORDS

Allies
Barriers
Consumer participation
Lived experience
Mental health
Organisational structures
Researchers

INTRODUCTION

As the prevalence of mental health conditions increases globally, the importance of mental health research intensifies (Winkler et al., 2017). This research has traditionally been primarily the domain of scientists and researchers from the mental health professions. The active involvement of people with lived experience of mental health service use (referred to in this paper as ‘consumers’) has not been embodied in the majority of mental health research (Wallcraft et al., 2009, Vollm et al., 2017, Banfield et al., 2018, Happell et al., 2018a). More recently, collaboration with consumers in mental health research has been increasing, however the extent and quality of consumer involvement in research is variable and tends to be ad hoc, without clear organisational structures to support and advance such

Benefits of consumer participation in research (Wallcraft et al., 2009, INVOLVE, 2012, Happell et al., 2018b) include increasing the relevance of such investigations from a consumer perspective (McAllister et al., 2012, Happell et al., 2018b), enhances successful participant recruitment (Ennis and Wykes, 2013) and provides unique and important insights into data analysis (Wallcraft et al., 2009, Gillard et al., 2012, Mjosund et al., 2017, Michalak et al., 2016, Happell et al., 2018b). For the past two decades, consumer participation in all aspects of services has increasingly become central to mental health policy (Health Services Executive, 2018, Mental Health Commission of Canada, 2016, Commonwealth of Australia, 2017, Mental Health Commission, 2012), and similar expectations are required for mental health research.

The failure of consumer collaborations in mental health research to proliferate has been attributed to major barriers such as stigma, tokenism and the lack of value attributed to knowledge developed from lived experience (Boaz et al., 2016, Ward et al., 2009, Veseth et al., 2017, Gee et al., 2016, Banfield et al., 2018, Domecq et al., 2014, Patterson et al., 2016, Scholz et al., 2018). Lack of funding to remunerate consumers (Scholz et al., 2019, Happell et al., 2019b, Staley, 2012) and the absence of a clear organisational structure to support consumer involvement in collaborations are also significant barriers (Scholz et al., 2019, Happell et al., 2018d, Happell et al., 2019b, Banfield et al., 2018).

Surveys (both closed and open-response formats), reflective accounts of joint research endeavours (Lawn, 2016, Staley et al., 2013), and articles describing insights and lessons from joint research projects (Fothergill et al., 2012, Case et al., 2014) identify stigmatised views about consumers’ capacity for research as a key barrier. This can result in tokenistic involvement, minimal
access to organisational facilities or lack of sustained financial support (Staley et al., 2013, Happell et al., 2018c). This literature is predominantly from the UK and Canada, where consumer research is well established in mental health and more widely in health policy and practice (e.g. Faulkner, 2017, Rose, 2017, Michalak et al., 2016). Despite support at a policy level in Australia and New Zealand, exploration of other mental health researcher views on consumer research, and the barriers to these collaborations, have to date only been reported through small qualitative studies (Happell et al., 2018b, Scholz et al., 2019, Happell et al., 2019b).

**Aims:**

Acknowledging the paucity of literature and the need to understand non-consumer researchers experiences and opinions in more detail, the aim of this study was to explore the opinions and experiences of non-consumer mental health researchers from Australia and New Zealand regarding working collaboratively with consumers in the conduct of research, with the view to enhance understanding of how such collaborations in research could be increased and developed. The term non-consumer was purposively chosen by the team to refer specifically to mental health researchers who do not identify as a consumer of mental health services.

This survey study was driven by the following research questions:

- Where do collaborations between non-consumer and consumer researchers originate?
- What is the nature of collaborations with consumer researchers?
- What are the characteristics of successful collaborations?
- What are the views of non-consumer researchers about organisational support and barriers?
- How frequently are organisational structures and specific policy that support consumer researchers identified?
• What is the basis for mental health consumers' employment and are they remunerated?
• What are non-consumer researchers planning to do over the next few years in the consumer researcher space?
• In what areas would increased consumer researcher engagement be desirable?

METHODS

Design

A cross-sectional approach utilising self-report survey data was adopted for this research. The research was undertaken through a collaboration between consumer and non-consumer researchers from Australia and New Zealand. The research team comprised an equal number of consumer and non-consumer members, a very important aspect in avoiding tokenism and facilitating genuine collaboration.

Participants and Recruitment

Mental health researchers from the disciplines of Social Work, Psychology, Psychiatry, Nursing and Occupational Therapy in Australia and New Zealand were targeted for participation in this research. Recruitment targeted all researchers from these fields with no specific requirement to have collaborated with consumers on research projects. Three strategies were employed for recruitment. Firstly, information about the study and how to participate was sent to Heads of School or Department of the five disciplines at universities in Australia and New Zealand. Secondly, information was sent to professional organisations representing the disciplines in both countries, with a request to distribute to members. Thirdly, the research was advertised through social media.

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Survey

A comprehensive review of the literature was unable to identify any surveys designed to elicit views on consumer collaboration in mental health research. The project team therefore developed a survey, Consumers as Researchers in Mental Health, (CaRiMH) for this research project. This was based on a qualitative study of mental health researchers’ perspectives, views and experiences of consumer involvement in mental health research (Reference withheld to facilitate anonymous review. Qualtrics was used to present and administer the survey.

The survey included demographic and research background questions. Table 1 presents survey questions and response options. To gain a general background on views on organisational commitment to mental health consumer researchers, participants were asked to rate three statements on a five-level scale. It was also asked whether their organisation had a written policy for conducting research with mental health consumers.

Participants who specified that their department had consumer academics and/or consumers as members of research teams were asked in what capacity are these consumers employed. Consumer academic was defined in the survey as ‘the community of researchers and scholars working from a service user mental health perspective in higher education and research.”

Insert Table 1 about here

Participants who indicated they had worked collaboratively with mental health consumers as colleagues were asked to consider one study where they had the most engagement with mental health consumers as researchers. This sub-group, were also asked if the consumers on the
nominated study had been remunerated. As outlined in Table 1, participants were also asked about characteristics of successful collaborative research with consumer researchers. Future aspirations were sought by asking: ‘What would you like to do in terms of consumer involvement in your own research over the next few years?’

Ethics

Ethics approval was granted by [ethics committee blinded for peer review]. The introductory material advised that participants’ names and individual organisational affiliations would not be published and that participation was voluntary. Submission of the completed questionnaire was taken as an indication of consent to participate.

Data analysis

Quantitative data were analysed in SPSS25 (IBM Corp, 2017). A very low rate of missing numerical data was observed: between zero and five per cent for most items. The raw distribution of each item response was analysed through frequencies and percentages.

Qualitative data derived from open comment responses were analysed using a content analysis approach (Crowe et al., 2015). To enhance the trustworthiness of data, independent analysis was undertaken by three members of the team. Each researcher coded the data and identified categories. On completion the researchers then met and discussed their individual analysis which was subsequently modified to achieve consensus. This analysis was then distributed to the full research team for further discussion and to verify interpretations.

RESULTS

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Participants

Fifty-five completed questionnaires were received. Table 2 provides an overview of the participant backgrounds. Most were employed at a university, followed by health services, government, and non-government organisation, with participants having the opportunity to indicate more than one type of organisation. Of the 36.4% currently working in a mental health service setting, 65% were from public services, 25% private, and 10% non-government. Thirty-four (72%) had worked collaboratively with mental health consumers as colleagues, 25 (54%) as colleagues in teaching, 19 (40%) as colleagues in clinical work, eight (17%) ‘a little’ as a colleague (e.g. sitting in on a meeting that included mental health consumers), and four (8%) had not worked at all with mental health consumers as colleagues. Several survey questions were only for sub-groups of the overall sample (e.g. those who indicated they had consumer academics in their department). Numbers responding to each question are shown in the headings for the figures below.

Insert Table 2 about here.

Commencement of research collaboration with consumers

Values of the participants was the most common reason given for the development of research collaborations with consumers. Only 6.4% of respondents identified formal requirements as accounting for collaborations. More information is presented in Figure 1.

Insert Figure 1 about here.

Capacity building

Responses to the statement, ‘my organisation invests in capacity-building in consumer research,’ demonstrate that structures for capacity building are
often absent. See Figure 2 for more detail. Some participants referred to specific strategies to build capacity, including peer group development:

‘All researchers are better if they are engaged continually in peer group professional development’

And education and training opportunities:

‘It should be mandatory and be funded automatically [consumer research] for all mental health research. Training and education opportunities need to be provided to consumers interested in being researchers too.’

Insert Figure 2 about here

**Employment of consumer researchers**

Figure 3 outlines the employment arrangements for consumer researchers within departments, divided by those departments with and without consumer academics. Casual employment was the most frequent, with only full-time consumer academics employed very rarely.

Insert Figure 3 about here.

The number of hours worked by consumer researchers appeared variable, and was frequently reported as ‘dependent on grants’, ‘varies depending on projects’. Very few respondents had consistent stable hours.

**Remuneration**

The majority of consumer researchers were remunerated (see Figure 4).
Organisational policy

Most participants’ employing organisations did not have a policy to support consumer collaborations in research (See Figure 5).

Barriers

Only 10.3% of respondents agreed or strongly agreed that their department is resistant to the inclusion of consumer mental health researchers (see Table 3 below. Around 38% percent disagreed that tokenism takes place when consumers are included as researchers, and around 21% agreed (Table 3).

Two participants provided additional comment on barriers:

‘…consumer researchers don’t really understand the context of academic work sometimes and will be easily discouraged by the types of hits full time academics are faced with every day. So these issues need to be negotiated and managed so people don’t feel discouraged by missing out on a grant, publication etc.’

And:

‘…the ethics approval process can be very difficult when you involve a consumer researcher – this is not because of them but because of stupid ethics committees which base decisions about capacity on stereotypes.’
Characteristics for successful collaborative research

The most important characteristics of mental health research vital to successful collaborative research with consumer researchers were considered to be openness to difference and openness to uncertainty. (See Figure 6 for more details).

Insert Figure 6 about here

Additional issues raised in free comments emphasised the importance of sufficient time flexibility:

‘flexibility in time – I have found it takes longer if conducted respectfully since there is more discussion and learning at each stage; which is the kind of point I have been learning….’

And the issue of flexibility more generally:

‘Flexibility, extra support. It takes a lot more time, especially when working with people who are being involuntarily treated – the service system puts up major barriers to their participation in research’.

Another respondent emphasised that successful collaborative research with consumers requires non-consumer researchers to have ‘self-awareness and skills to negotiate differences’ in perspectives.

Non-consumer researcher plans
There were thirty open comment responses to this section of the survey. Some highlighted the intention to continue or sustain collaborations with consumer researchers (e.g. ‘more of the same!’):

‘Continue to access based on qualifications and match to research’
‘Maintain my commitment to prioritising researchers with lived experience in grant applications’

Another theme was increasing the consumer participation-level in relation to research:

‘Progress toward fully co-produced and collaborative research’

And facilitated research learning for both consumers and non-consumers:

‘I would like to further develop my skills in supporting consumer researchers to develop questions, build a team around them, gain skills they may require, and undertake projects of their own design.’

‘I would like to engage a mental health consumer to undertake a PhD under my supervision. I would like to work collaboratively (‘moving away from the ‘consultation’ approach) with consumers as research partners and members of the actual research team (rather than external advisors).’

For some, a more strategic and planned approach to research funding was needed to achieve these shifts:

‘...be more planned around upcoming funding options so that we don’t revert back to putting together projects in a rushed way that means consumers have less involvement form the beginning. Try and make permanent roles of consumers with larger funding schemes.’
Establishing solid employment conditions and staff roles were considered vital to achieving greater and more pervasive levels of consumer participation:

‘To build greater capacity through an increase in paid positions for consumer researchers. It is very difficult to achieve co-production without paid positions; consumers must be paid for their time. Full and part-time ongoing positions with secure funding is essential.’

Many responses were reflected in the following statement:

‘There are barriers to doing it – mainly getting funding to pay them appropriately, and working with and around what is happening in everyone’s life – but it is always worth the extra effort.’

**Increased consumer research**

Participants were asked ‘where would you like to see more participation of consumers in research activities?’ Table 1 presents the frequency of responses to the set options, ordered from highest frequency to lowest.

**DISCUSSION**

The findings from this study suggest the absence of clear organisational structures to support collaboration between consumer and non-consumer researchers. The way consumer researcher positions were introduced initially suggests that collaborations were largely driven by the values and beliefs of individual researchers. This situation mirrors the experience for consumer academics and educators in professional and clinical education in mental health, where the initiative has generally been driven by mental health
academics with respect for and commitment to this approach (Arblaster et al., 2015, Happell et al., 2015c). As a result, involvement tends to be ad hoc and limited (McCann et al., 2009, Happell et al., 2015b, Scanlan et al., in press). Consequently, there are often absent or inadequate structures and supports to allow consumer researcher positions to develop and proliferate (Happell et al., 2019a, Happell et al., 2015a).

Advances made in including consumers as research collaborators will be limited without a broader organisational approach which recognises consumer researchers as legitimate and valuable members of research teams (INVOLVE, 2012, Gillard et al., 2012, Slay and Stephens, 2013, Happell et al., 2018d). This perspective was echoed by those involved in the present study observing that in most instances there was no clear process to guide their collaborations with consumers. Widespread organisational structures are needed to support consumer researchers and to build capacity are essential to the development of consumer researchers and their important contribution to mental health research. Structural adjustments are required to allow more flexibility within research environments more conducive to consumer involvement (Scholz et al., 2019). Organisationally these structures will assist in supporting genuine consumer involvement and avoiding tokenism (Minogue and Girdlestone, 2010). Specific examples include education and training and professional development; and peer group support.

This lack of organisational structure in relation to consumer involvement in academia has been described in both education and research (Scholz et al., 2019, Happell et al., 2018a, Gee et al., 2016). The lack of training for consumers to develop and enhance research skills is of particular concern (Gee et al., 2016, Happell et al., 2018a, Happell et al., 2019b, Staley et al., 2013), as is the lack of funding to employ consumer researchers (Lawn, 2016, Gee et al., 2016, Happell et al., 2018a, Happell et al., 2019b, Scholz et al., 2019, Staley, 2012).
At an individual level, the absence of mentorship, support, supervision and debriefing specifically tailored to people with lived experience of mental health conditions are significant barriers for both consumer academics and educators (Happell et al., 2015a, Meehan and Glover, 2007) and the consumer workforce more broadly (Bennetts et al., 2013, Byrne et al., 2019). While this literature does not specifically refer to consumer researchers, it is likely that these issues are entirely germane and should be considered priorities if consumer research is to be strengthened.

Most participants did not agree there was resistance to consumer researchers. This contrasts with several other reports that found consumer research is frequently not valued. This was attributed to the hierarchical approach to evaluation of scientific information using a ‘levels of evidence’ and predominantly quantitative model, rather than other kinds of research, particularly those based on lived experience (Happell et al., 2018a, Happell et al., 2018c, Happell et al., 2019b, Landry, 2017, Patterson et al., 2014). A possible explanation is survey participants were referring to their own, and their immediate co-researchers, attitudes and beliefs rather than in the sector more widely.

Responses to the question about tokenism revealed quite different experiences. Most participants provided a neutral response with slightly more agreeing than disagreeing that tokenism was evident. The neutral responses may reflect participants’ uncertainty about the views of colleagues more broadly, or about the definition or measurement of this concept. Tokenism has been identified as a major barrier to consumer engagement in research (Domecq et al., 2014, Happell et al., 2018a, Happell et al., 2019b, Rose et al., 2018). Consumer involvement can be seen as a box that needs to be ticked, rather than a meaningful exercise, so tokenistic involvement may be worse than none at all. (Staley et al., 2013, Happell et al., 2018c). The tokenistic treatment of consumers significantly impacts genuine collaborations in that it
compromises consumers’ opportunities to influence the research topic and contribute their expertise to the process and outcomes of the research (Happell et al., 2018d, Gee et al., 2016, Patterson et al., 2014).

Despite concerns about its frequency and impact, tokenism as a term is often not well understood (Happell et al., 2019b). Non-consumer researchers might interpret small contributions to one specific component of the research project as representing meaningful engagement. It has been suggested that many non-consumer researchers may define coproduction and collaboration in ways that do not meet expectations of those approaches to research (Happell et al., 2019b, Bromley et al., 2015, Las Vergnas and French, 2017). A much clearer understanding of principles of consumer collaboration and co-production are essential to promoting genuine collaborations and partnerships that enhance the potential benefits of consumer involvement in research (Roper et al., 2018).

Most participants reported that consumer researchers are paid for their contribution. Remuneration of consumers for their time and expertise is rapidly becoming an expectation, supported by a clear policy from the National Mental Health Commission (National Mental Health Commission, 2019). This policy was developed specifically for the Commission, however it is frequently used as a guide to other organisations. At the same time, participants described funding as a major barrier to employing consumer researchers. Inadequate funding can result in many projects not supporting meaningful consumer involvement or not including it at all.

Furthermore, most consumers were employed on a casual basis which impacts on job security and potentially deters consumers from pursuing research careers. Funding has been identified as a major barrier (Staley, 2012, Lawn, 2016, Scholz et al., 2019). Funding for consumer researchers is generally project-specific, which results in job-insecurity and limits the ability to develop ongoing partnerships with non-consumer researchers. There are
rare exceptions to this: in one qualitative study a non-consumer researcher described creative methods to quarantine funds from other sources to use them to employ consumer researchers when possible (Happell et al., 2018d).

Of the characteristics identified by participants as supporting successful research collaborations, the majority were attitudinal, including openness to difference and to uncertainty, as well as empathy and support for recovery approaches to mental health. This is congruent with identification of negative attitudes towards consumer researchers as a major barrier to successful collaborations (Boaz et al., 2016, Ward et al., 2009, Veseth et al., 2017, Gee et al., 2016, Scholz et al., 2018). Although participants suggested policy changes to mandate consumer involvement, unless negative attitudes are addressed the risk of tokenistic responses remains (Wallcraft et al., 2009, Patterson et al., 2014, Domecq et al., 2014).

Consumer-led education and training has demonstrated the potential to promote more positive attitudes among students of the health professions (Arblaster et al., 2015, Goossen and Austin, 2017, Gordon et al., 2014, Happell et al., 2014, Happell et al., 2015b, Happell et al., 2019c, Horgan et al., 2018, Mahboub and Milbourn, 2015, O’Donnell and Gormley, 2013, Ridley et al., 2017, Scammell et al., 2016, Schneebeli et al., 2010) and may contribute to reducing stigma against consumer involvement in research.

Flexibility in research environments was also identified as an important characteristic in both the survey and the open-ended comments. Research environments are generally governed by tight timelines. These timeframes frequently do not allow for adequate time for collaborations with consumer researchers to be established and developed (Happell et al., 2018a, Scholz et al., 2019, Honey et al., 2019). Many of the barriers these create are external to the organisation and therefore difficult to mitigate, nevertheless without increased flexibility meaningful consumer involvement in research will be seriously impacted.

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Despite the acknowledged barriers, participants saw opportunities for increased consumer involvement in research. This appears to reflect the findings of a small qualitative study where non-consumer researchers described themselves as ‘chipping away’ at the barriers (Happell et al., 2019b). Such research will need significant changes in organizational support, and this is likely to take some time to achieve, at least in a fully-developed form. In the interim, there appears an opportunity to extend the nascent concept of allyship to the consumer movement. Allies generally hold senior positions within organisations and do not identify as having lived experience. Allies use their privileged positions to support and promote consumer roles, including in research activities. Because of their positions they are well placed to manage resource allocation and facilitate opportunities for consumers (Happell and Scholz, 2018).

Allyship as a concept is not without controversy. There are concerns that allies may (intentionally or otherwise) co-opt consumer knowledge and direct activities (Juntanamalaga et al., 2019). Although such risks must be openly discussed, the concept appears worthy of further exploration. In the context of research collaborations between consumer and non-consumer researchers, allyship requires further exploration to harness its potential and ensure clear boundaries regarding expertise are identified and observed.

Limitations

The low participation rate in this research posed the major limitation of this project. The reasons for non-participation could reflect: a very small number of researchers with an interest in or engaging collaboratively with consumer researchers; the survey distribution methods missing members of the target population; or a lack of time or interest in completing the survey. In addition, it is possible there was more than one participant per organisation or
university department. As these were anonymous responses, we do not know how often this occurred.

CONCLUSIONS

Despite the acknowledged limitations, these findings suggest that while participants were generally supportive of collaborating with consumer researchers, they have encountered significant barriers in carrying out collaborative research. The findings presented in this paper provide important information about barriers encountered that may assist consumer/non-consumer research collaboration, and provide some direction for further research activities.

While commitment to the cause is essential and there is a clear need for allyship, the magnitude of organisational barriers makes it very difficult for one individual or small team to overcome them effectively. If policy goals for active collaboration are to be realised, there need to be clear organisational structures that provide a framework for employing consumers, providing appropriate remuneration and resources to support their roles, and supports for professional development as consumer researchers, with appropriate mentorship.

Table 1. Survey questions and response options.

<table>
<thead>
<tr>
<th>Survey question(s)</th>
<th>Response options</th>
</tr>
</thead>
<tbody>
<tr>
<td>My department is resistant to the inclusion of mental health researchers</td>
<td>Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree</td>
</tr>
<tr>
<td>When inclusion of consumers as researchers occurs, it is tokenistic</td>
<td></td>
</tr>
</tbody>
</table>

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My organisation invests in capacity-building in consumer research.

In what capacity are these consumers employed?  
- Full time,  
- Part time (at least half-time),  
- Part time (less than half-time),  
- Casual

Does your organisation have a written policy for conducting research with mental health consumers?  
- *No; Not sure; Yes, in getting input from mental health consumers on certain stages of the research; Yes, to consult mental health consumers early in the research; Yes, co-produced or collaborative research; Yes, consumer-led research; Yes, consumer involvement is mandatory in my organisation

In your view, what characteristics of mental health research are vital to successful collaborative research with consumer researchers?  
- *Championing policy,  
- Flexibility in working arrangements,  
- Training in participative research/co-produced research,  
- Openness to uncertainty,  
- Openness to difference,  
- Recovery paradigm,  
- Empathy, *Other

*More than one response category could be chosen, *Option to add ‘other’ responses.
Table 2. Demographic background of participants.

<table>
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<tr>
<th>Background</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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</tr>
<tr>
<td>Female</td>
<td>67.3%</td>
</tr>
<tr>
<td>Male</td>
<td>29.1%</td>
</tr>
<tr>
<td>Prefer not to respond</td>
<td>3.6%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>31-40</td>
<td>16.4%</td>
</tr>
<tr>
<td>41-50</td>
<td>25.5%</td>
</tr>
<tr>
<td>51-60</td>
<td>47.3%</td>
</tr>
<tr>
<td>61 and over</td>
<td>10.9%</td>
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<tr>
<td>Employment</td>
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<td>University</td>
<td>90.0%</td>
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<td>Health service</td>
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<td>Government</td>
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<td>NGO</td>
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<tr>
<td>Primary location research</td>
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<tr>
<td>workplace</td>
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<td>Metropolitan</td>
<td>73.0%</td>
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<tr>
<td>Regional</td>
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<td>Remote</td>
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Table 3.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SD</td>
</tr>
<tr>
<td>My department is resistant to the inclusion of mental health researchers</td>
<td>22.4</td>
</tr>
<tr>
<td>When inclusion of consumers as researchers occurs, it is tokenistic</td>
<td>15.5</td>
</tr>
</tbody>
</table>

Note: SD – Strongly Disagree, D – Disagree, N – Neutral, A – Agree, SA – Strongly Agree.

Table 4. Areas for potential inclusion or expansion of consumer researcher engagement in mental health research (frequencies in brackets).

- Co-collaborators with non-consumer researcher (35)
- Setting the agenda in mental health research programs (34)
- On research ethics committees (e.g. reviewing ethics applications) (33)
- Advise on how research findings are translated to improved health services and practice (33)
- Key member of advisory panels, reference groups, management group or study steering group (30)
- Consumer academic (30)
- Decision making on what research projects to get funding (29)
- Chief Investigator (28)
Contribute to review and monitoring of already funded research project (28)
Research Assistant (21)

NB participants were able to provide multiple responses

REFERENCES


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Figure 3. Employment types for mental health consumers and consumer academics (n=29).
Figure 5. Does your organisation have a written policy for conducting research with mental health consumers and if so in what form? (n=55)

- No
- Not sure
- Yes, getting input from MH consumers on certain stages of research
- Yes, to consult with MH consumers early in the research
- Yes, co-produced or collaborative research
- Yes, consumer-led involvement is mandatory in my organisation
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