community mental health drug and alcohol
RESEARCH NETWORK
CMHDARN

ASK THE EXPERTS:

A CMHDARN Best Practice Guide to Enabling Consumer and Carer Leadership in Research and Evaluation

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mhcc
mental health coordinating council

NADA
network of alcohol and other drugs agencies

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of New South Wales

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We intend to keep this resource current. Please tell us about new tools and resources as you find them. To make suggestions for the improvement of this guide, please contact:

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About This Guide

This guide is intended to provide community organisations with a short and accessible 'how to' guide to involving consumers, peer workers and carers in each and every stage of research and evaluation, including co-production and research leadership. We have called it *Ask the Experts*, because people with lived experience of mental health, or alcohol or other drugs issues, are experts by experience and are therefore the go-to people for all your research needs.

An earlier draft of this Guide was prepared by Carla Cowles from Human Capital Alliance (International) Pty Ltd (HCA) for CMHDARN in December, 2014. Carla consulted widely and made every effort to ensure that the evidence on which her report relied was obtained from proper sources.

The current revised version was prepared by the CMHDARN Project Coordinator, in late 2015, in consultation with the CMHDARN Steering Committee and Project Reference Group. It remains a work in progress and your suggestions for its improvement are extremely welcome.

CMHDARN wishes to thank CMHDARN members and stakeholders from the mental health and alcohol and other drugs sectors who participated in consultations or contributed to the guide in any way.

About CMHDARN

The Community Mental Health Drug and Alcohol Research Network (CMHDARN) is a partnership project between the Mental Health Coordinating Council (MHCC), the Network of Alcohol and other Drugs Agencies (NADA) and the Mental Health Commission of NSW.

CMHDARN was established in 2010 to broaden the involvement of the community mental health and alcohol and other drugs sectors in practice-based research and to promote the value of research and the use of research evidence in practice. Its overall aim is to improve the quality of service delivery and correspondingly, the outcomes for consumers of community managed services.

CMHDARN aims to facilitate the development of a culture of research by providing opportunities and a context for the exchange of ideas, the sharing of resources, support and collaboration among community organisations and between community organisations and research bodies, including universities and research institutes.

In order to build the research capacity of the sectors, the Network shares information via its website, workshops, forums, reflective practice webinars/webcasts, E-communications and other activities.

For further information about;
CMHDARN, go to www.cmhdaresearchnetwork.com.au
NADA, go to http://nada.org.au
MHCC, go to http://mhcc.org.au/
The Mental Health Commission of NSW, go to http://nswmentalhealthcommission.com.au

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Terminology

Community Organisations

This guide uses the term community organisations to refer to organisations within the mental health and alcohol and other drugs sectors.

Consumer / client / psych survivor/ service user

In this guide, the term 'consumer' is used to refer to a person with a lived personal experience of mental health, and/or alcohol and other drug issues. The use of the term in the mental health context has its origins in the civil rights movements of the 1960s and 70s. Survivors in numerous contexts sought to find a counter-narrative of empowerment and resistance to negate negative experiences of 'treatment' and choicelessness within systems that served to perpetuate the system rather than make it human. The use of the term 'consumer' today remains as contentious as it ever was. Many people within the mental health sector would advocate for the use of 'survivor' or 'psychiatric survivor' instead.

There also remain significant differences in language usage within and between the mental health (MH) and alcohol and other drugs (AOD) sectors. Broadly, in the alcohol and other drugs sector, the term 'client' is still far more commonly used. These differences in usage are based on dissimilar sector histories, policy environments and service models.

The deliberate use of the term 'consumer' throughout this guide is intended to draw into question the use of medical and clinical language, and to redirect the conversation towards recovery oriented and trauma informed languages, reflecting hope, optimism and focusing on strengths.

The meanings that each person gives to their own experience of mental health or alcohol or other drug issues are entirely individual. No two 'consumers' are in any way the same. Active engagement and leadership in research and evaluation means that consumers and/or carers as insiders to the processes of knowledge creation have a better chance of having more say and control over their lives.

Peer

In this guide, the term 'peer' is used to describe other consumers who experience mental health and/or alcohol and other drug issues. It includes people employed as peer workers.

Carer

In this guide, the term 'carer' is used to describe the people who care for, or support people who experience mental health and/or alcohol or other drug issues. A carer may be a friend, peer, spouse, sibling, grandparent, child, neighbour or other supporter. Carers/ supporters come from a diverse range of backgrounds, experiences and circumstances. They may be young or old. The individual experiences, needs and interests of carers are similarly dissimilar from one another.

Acronyms

AOD   Alcohol and Other Drugs

CMHDARN   Community Mental Health Drug and Alcohol Research Network

CMO/s   Community Managed Organisation/s

DA   Drug & Alcohol

HREC   Human Research Ethics Committee

MH   Mental Health

MHC NSW   Mental Health Commission of NSW

MHCC   Mental Health Coordinating Council

MHDA   Mental Health/Drug & Alcohol

NADA   Network of Alcohol and other Drugs Agencies

NGO/s   Non-Government Organisation/s

Introduction

This guide is intended to empower you to work with consumers and/or carers as active instigators, developers, leaders and experts by experience, whose expertise can benefit each and every stage of research and evaluation.

'Best practice' is taken to mean ideas and practices that are current, relevant, useful and the best of their kind. We need to move away from unnecessarily limited and outmoded depictions of consumers and carers as passive participants or research 'subjects.' A broad understanding of best practice was derived from consultation feedback, a literature review and other resources discussed in this guide.

A number of key themes emerged during the consultations undertaken to develop this guide. These addressed the need:

- for consumers, peers and carers to be more involved in every stage of research and evaluation
- for organisations to increase and build the capacity of consumer, peer and carer involvement and leadership in research and evaluation
- for resources, strategies and activities to support consumer, peer and carer leadership in research and evaluation
- to support consumer, peer led research and co-production research.

This guide is available as a stand-alone guide as well as downloadable resource. Both versions of the guide are intended to provide community organisations with clear and accessible advice about how to go about actively involving consumers, peers and carers in each and every stage of research and evaluation, including research co-production and leading research.

The guide is organised into short, easily digestible parts. It begins with a brief introduction, then offers a range of ideas and resources for organisations, consumers, peer workers and service workers who are thinking about involving consumers and/or carers in research and evaluation. The guide is also intended to orient and guide readers who are ready to increase or grow consumer, peer and carer involvement in research and evaluation.

Prepared in consultation with diverse key stakeholders in the mental health and alcohol and other drugs sectors, including people with lived experience of mental health and/or drug and alcohol issues, as well as carers, this guide also contains a brief review of existing resources, tools and models of consumer involvement. Additional resources and tools are available at the end of the guide.

We aim to keep this resource as up to date as possible. It is your job to help us. Please share any new tools and resources with us and we will include them here. Email the CMHDARN project coordinator or submit your suggestion via the CMHDARN website.

Getting started – where are you?

Some organisations and their people are already well on the way to building consumer/peer and/or carer involvement into all that they do. Others are only just starting to think about it. To cater to a range of starting points, this guide is structured to provide direction and practical strategies. Importantly, it aims to be relevant regardless of organisational capacity, so that all organisations will have somewhere to begin or continue to grow consumer and/or carer involvement and leadership in research and evaluation.

This guide is useful for **organisations**, **peer and service workers** that are:
- thinking about the importance of consumer, peer and carer leadership in research and/or evaluation,
- ready to start increasing consumer, peer and carer leadership in research and/or evaluation, or
- looking to develop or expand consumer, peer and carer leadership in research and/or evaluation.

The guide is also intended for **consumers, peer workers and/or carers** who are thinking about getting involved in research or evaluation, have been invited by an organisation to become involved, or may be considering undertaking their own independent or co-production research. It aims to provide some ideas about what best practice might mean for consumers, peers and carers, and what they might expect along the way.

While this guide has been designed to be a generic resource intended to support organisations and their people, we are aware that there is enormous diversity between and within the sectors and that each and every consumer and carer will approach research and evaluation very differently.

Across the mental health and alcohol and other drugs sectors, there are large variations in how, when, or why consumers and carers engage with services. Some consumers access services on a short-term basis, or access a service or program for a discrete amount of time, perhaps even just once. Other consumers access services for longer periods of time, or have multiple instances of engagement. The variations in patterns of engagement are reflective of individual needs, choices and circumstances and the types of support services available.

There are also differences in patterns of engagement between consumers and carers within and across the mental health and alcohol and other drugs sectors. Influenced by their caring responsibilities, carers tend to be less engaged with services and their engagement is greater in some areas of the mental health and alcohol and other drugs sectors than others. These differences are discussed here because when it comes to consumer and carer leadership in research and evaluation, one size doesn't and can't possibly fit all.

The table on the next page provides a simple outline of some of the many modes of involvement available to consumers and carers in research and evaluation, including leadership roles.

A range of modes of involvement are available to consumers and carers in research and evaluation:

Participation	Engagement	Involvement	Leadership
Where consumers and carers take part in a research or evaluation activity.	Where information and knowledge about research or evaluation is provided and shared with consumers and carers.	Where consumers and carers are actively involved in research and evaluation projects.	Where every stage of research or evaluation is conceived, led and conducted by consumers and/or carers as independent researchers.
An example of participation: • people recruited to a clinical trial and/or other research study as a 'subject' (e.g. they are required to complete a questionnaire, participate in an interview or focus group).	Examples of engagement include: • a forum, seminar, or conference, open to the public with debates and discussions on services, research and evaluation • open day at a service where people are invited to find out about the services and other activities • awareness raising via newsletters, websites, newspapers and social media • sharing findings of a study or evaluation activity with participants, colleagues or members of the public	Examples of involvement include: • joint grant holders or co-applicants on a research project • identifying research priorities • members of a project advisory or steering group/committee • developing research or evaluation methodology, information sheets and/or other research materials • undertaking interviews, conducting focus groups, etc. • carrying out the research • assisting with or carrying out data analysis, report writing and publication	Examples of leadership include: • sole grant holders/sourcing their own funding arrangements for a research project • determining support and resources (e.g. mentoring, office space, computer, etc.) • identifying research priorities • establishing project advisory or reference groups • developing research methodology, information sheets and/or other research materials and tools • conducting research including undertaking interviews and focus groups, administering surveys. data analysis, report writing and publication

Adapted from INVOLVE UK[1]:

Passive ➡ Active

[1] INVOLVE, *Briefing notes for researchers: public involvement in NHS, public health and social care research*, NHS National Institute for Health Research, 2012. (Accessed online at http://www.invo.org.uk/resource-centre/resource-for-researchers/ 20 November 2014).

Thinking about consumer and carer leadership in research and evaluation

Why involve consumers and carers in research and evaluation?

This is the single most important question that any organisation, consumer or carer can ask before deciding to engage in research and evaluation. Meaningful collaboration with consumers, peers and carers takes planning, commitment and a genuine willingness to share leadership responsibilities. Unplanned or thoughtless attempts to increase consumer, peer and carer involvement will at best appear tokenistic and at worst, will simply fail.

Consumers, peers and carers should be involved in research and evaluation because:

- consumers, peers and/or carers are expert knowledge holders
- ethically it makes sense to listen to and involve consumers and their named representatives in all the decisions that affect their lives – 'nothing about us without us' is a key message and understanding
- research or evaluation quality will be enhanced by input from and leadership by participants with lived experience
- many consumers bring not only their lived experience to research, but also professional expertise
- consumers and carers may benefit from research participation, personally and/or professionally
- consumers, peers and carers understand the practical realities of how services operate and can ask real world research questions to guide service improvement and innovation.

Consumer and carer participation is now an integral component of health and medical research generally, and this trend is quickly gaining momentum across the community sector. Consumer and community participation is a requirement of quality improvement and accreditation processes in Australia.[2] In other countries, such as in the UK, consumer and community participation is required by law across health services.[3]

Information and links to some useful models that aim to increase consumer and carer participation in Australia and internationally are listed on the next page.

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[2] Department of Public Health, Flinders University and the South Australian Community Health Research Unit, *Improving Health Services Through Consumer Participation: A Resource Guide for Organisations.* Commonwealth of Australia, 2000.(Accessed online 11 Dec 2014 at http://www.healthissuescentre.org.au/documents/items/2008/08/226533-upload-00001.pdf
[3] NHS Choices, 'Get involved in the NHS' webpage. Accessed 10 Dec 2014 at http://www.nhs.uk/nhsengland/thenhs/about/pages/getinvolved.aspx

Consumer and carer participation/involvement models and organisations

The following models and organisations use diverse strategies that range from ensuring that consumers and carers are always consulted, to those that facilitate consumer, peer/carer led or controlled research and evaluation. Each aims to increase the range of consumer and/or carer voices in research.

AUSTRALIA

ACT Consumer and Carer Research Unit (ACACIA)
The ACACIA Unit, within the National Institute for Mental Health Research at Australian National University, was formed to involve consumers and carers. The Unit employs research staff with a lived experience of mental health issues and involves and engages consumers and carers from the community.

Consumer Research and Evaluation Unit (CREU)
The CREU sits within the Victorian Mental Illness Awareness Council, a consumer created and led organisation. CREU is staffed by personnel with experience and skills in research and evaluation techniques, and their work is largely underpinned by lived experience. CREU advocates for research that is initiated, designed, controlled and conducted by consumers and for new methods and approaches developed from a consumer perspective.

Consumer Led Research Network
The Consumer Led Research Network is a newly established independent body, currently hosted by the Mental Health Commission of NSW. The Network was established to facilitate collaborative partnerships between consumer researchers and build capacity for consumer led and co-production research. The Network held its first public forum in Sydney, 4 November 2015, supported by CMHDARN and the Commission. The forum was called *Enabling Consumer Led and Co-Production Research in a World That's Not Used To It*, and it opened an important conversation in this space.

OTHER CONTEXTS

INVOLVE
INVOLVE is a government funded advisory group in the UK that aims to support active public involvement in the National Health Service (NHS, public health and social care research). It provides resources and information in the field of public involvement in research.

McPin Foundation
The McPin Foundation in the UK aims to build and direct research on mental health that is informed by consumers and involves consumers as peer researchers in peer led or collaborative research.

Scottish Drugs Forum
The Scottish Drugs Forum aims to increase consumer or user involvement in service planning and delivery. It does this by delivering training to consumers and services, and commissioning peer led research on drugs issues.

User involvement in research: A Route Map
The Route Map is a guide to help health organisations and research bodies. It funds consumers and community research.

Benefits of consumer and carer leadership

Involving consumers, peers and carers makes great sense and aligns with recovery oriented and person centred practices. It is important to understand and promote the potential benefits for consumers, peers, carers, workers, organisations, and the community more broadly.

Community organisations need to have a clear understanding of why they want to involve consumers and/or carers in research. Consumers and carers also need to know and understand what the purpose of their involvement will be and whether participating will directly or indirectly benefit them. It may be that there is little direct benefit. For this reason, it is very important to be clear and up front about the purpose and impact, so that consumers and carers can make **an informed choice** in relation to choosing to become involved, or not.

> *"It is important that any research investigates concepts such as 'value', 'evidence' and 'effective' from a consumer standpoint. It needs to ask: valuable to whom, and why?"*
>
> *(Roper, 2003)[4]*

> *"…the opportunity to 'speak' was synonymous with having their 'humanness' recognised and acknowledged; it represented a person's basic (human) right."*
>
> *(Rance & Treloar, 2014)[5]*

A growing body of evidence around consumer, peer and carer leadership in research and evaluation shows that research and evaluation activities can be improved through consumer and/or carer involvement. For some consumers and carers, the process of research itself is also part of, and instrumental to, processes of recovery. This is most often the case when the consumer researcher's own life experiences inform the research while also providing an opportunity for personal and/or professional growth and resilience building.[6]

Consumers and carers benefit from being recognised and valued as experts. Professional and personal empowerment can also help to ameliorate the power imbalance between the researcher and research participant.[7] Consumer and carer participation can challenge who holds power and can even help to level the playing field between consumers and staff in CMOs. This is beneficial to the community organisation, as well as consumers and carers.[8]

The quality of research and evaluation can also be enhanced by consumer and carer involvement. Engagement is frequently increased by the more flexible approach that researchers with a lived experience might take.[5] Consumers and carers, as well as service providers, may also be less guarded or reluctant to disclose information to researchers with a lived experience. Higher response

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[4] Cath Roper, 'Consumer Participation in Mental Health: We Want It!,' *Health Issues*, no. 74, 2003, pp. 19-22. Accessed online 10 Dec 2014.

[5] J. Rance & C. Treloar, "We Are People Too": Consumer Participation and the Potential Transformation of Therapeutic Relations Within Drug Treatment, *International Journal of Drug Policy*, 2014, http://dx.doi.org/10.1016/j.drugpo.2014.05.002

[6] Bradley Foxlewin, *What is Happening at the Seclusion Review that Makes a Difference? – a Consumer-led Research Study*, 2012.

[7] L. Buckley, *et al.*, 'Are We Recovery Oriented? An Australian Encounter of Learning from People with Lived Experience,' in L. Goodson & J. Phillimore (eds.), *Community Research for Participation: from Theory to Method*, The Policy Press, 2012, pp. 185- 199.

[8] J Rance & C. Treloar "We Are People Too": Consumer Participation and the Potential Transformation of Therapeutic Relations Within Drug Treatment,' *International Journal of Drug Policy*, 2014. http://dx.doi.org/10.1016/j.drugpo.2014.05.002

rates can be achieved when research and evaluation priorities are set or informed by consumers and carers who are able to prioritise research that is relevant and important to them.

The National Health and Medical Research Council has published *A Model Framework for Consumer and Community Participation in Health and Medical Research.*[9] This document highlights how consumers and carers can add value and help strengthen research processes by:

- making sure that proposed methods are consumer and/or carer friendly and that the research does not impose undue burdens on any participants
- rejecting research practices that are insensitive or inappropriate
- helping write information sheets to ensure that style and content is useful to consumers or carers
- suggesting alternative methods to increase consumer and/or carer involvement and leadership
- ensuring that research questions are asked in ways that provide answers relevant to consumers and/or carers
- approaching peers – consumers are members of a peer community and have credibility within it. Particularly where research is sensitive in nature, or a community may be wary of outsiders, peer researchers are key to research success.

Principles of consumer and carer involvement and leadership

Organisations need to consider the values and principles that underpin consumer and/or carer involvement and leadership in research and evaluation.

The National Health & Medical Research Council (NHMRC) supports consumer and broader community participation in health and medical research. NHMRC's *Statement of Participation*, 2002 states:[10]

> *"Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research […] will improve the health of humankind."*

Promoting Consumer Participation in Mental Health Research: A National Workshop[11] provides a useful set of guiding principles:[12]

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[9] NHMRC, *A Model Framework for Consumer and Community Participation in Research.* Commonwealth of Australia, 2005.

[10] NHMRC, *Statement on Consumer Participation on Health and Medical Research*, Commonwealth of Australia, 2002. (see also *Revised Statement on Consumer and Community Participation in Research*, Consultation version, August 2014).

[11] KM Griffiths, H. Christensen, L. Barney, A. Jenkins, C. Kelly, C. & K. Pullen, *Promoting Consumer Participation in Mental Health Research: A National Workshop.* Centre for Mental Health Research, Australian National University: Canberra, 2004, pp. 9-12.

[12] The principles have been edited and modified to be more relevant to the MH and AOD sectors and to include carers.

Aim:
To improve, expand and strengthen the current MHDA knowledge base through increased consumer and carer participation in research and evaluation activities.

Principles:

1. The meaningful and person-led involvement of consumers and carers at all stages of research and evaluation activities including its conception, design, implementation, evaluation and dissemination, will add value to the research or evaluation.
2. The level of consumer and carer involvement required would vary from project to project, dependent upon the extent to which the research and findings will impact people accessing services.
3. Research partnerships involving consumers and carers should be adaptable and based on understanding, respect, and shared commitment.
4. Each partnership will be sensitive to its research or evaluation purposes and the expertise and experiences of the people involved and the environment in which it functions.
5. The roles and responsibilities of consumers, carers, workers or researchers will be clearly defined and agreed between those involved in the research or evaluation and may evolve over time and the course of the project.
6. To fulfil their roles and responsibilities, consumers, carers, workers or researchers may need support and/or training to understand relevant aspects of research, ethics and each other's perspectives.
7. Budgets would appropriately include the cost of consumer and carer involvement in research or evaluation activities. This may include as a member of an advisory committee/reference group, attending meetings, reviewing documents or being part of a research or evaluation team/project, or as principal researcher.
8. Resources should be provided to evaluate the research processes and contributions of consumer and carer participants in order to foster continuing improvement of the implementation and benefits of consumer and carer involvement.
9. Consumer, carer, worker or researcher involvement will be acknowledged appropriately in research or evaluation reports.
10. The results of research and evaluation activities will be:
    i) Made available to research and evaluation participants in an appropriate and sensitive way; and
    ii) Disseminated to relevant communities in a balanced and accessible manner
11. Organisations and research groups will have a policy on consumer and carer participation in research.

What are the key issues we need to think about?

Commitment – organisations and consumers need to make a commitment to enabling consumer and/or carer involvement and leadership in research and evaluation. This means that all levels of the organisation need to endorse, promote and implement consumer and/or carer involvement. This will ensure that consumer/carer involvement is sustainable and becomes part of the fabric of the organisation.

Increasing consumer, peer and/or carer involvement and leadership can be achieved by:

- developing policies
- developing a research and evaluation framework
- proactively identifying opportunities for consumers and carers to lead and be involved in all stages of research and evaluation, including leadership
- allocating funds for consumer and carer remuneration and/or reimbursement
- providing support and training to consumers and/or carers to develop their skills
- supporting and encouraging consumers and/or carers to undertake their own independent or co-production research.

Time – meaningful engagement takes time. A commitment to involving consumers and carers from the very beginning of a research or evaluation activity requires good time management and planning.

It takes time to:

- consult with consumers and carers to determine research priorities that are consumer led and person centred
- recruit consumers and carers
- support and train consumers and carers in research skills
- manage unexpected events or circumstances, for example, consumers and carers who may be experiencing challenging life events
- change the culture of the community organisation to enable meaningful consumer and carer participation
- undertake research ethically (see CMHDARN *Best Practice Guide to Ethics in Research/ NHMRC Guidelines*).

Resources – a commitment to consumer and carer involvement means committing resources and allocating time to consult with consumers and carers about:

- research and evaluation priorities – what consumers and/or carers think should be researched? What is important? What is relevant?
- funding to provide remuneration and/or reimbursement to consumers and carers
- peer supervision, mentoring support and/or other supervision.

What are some of the barriers to consumer, peer and carer involvement?

Increasing consumer, peer and carer involvement in research and evaluation elevates and places greater value on the lived experience of consumers and carers and the expertise that they bring. For community organisations, large or small, this means changing practices. Changing practices can pose challenges and create barriers, and these need to be acknowledged and explored.

Consumer, peer and carer barriers

Barriers to involvement are individual and are experienced differently. However, the consumers and carers consulted in preparing this guide said that the most common barriers that they encountered included:

- stigma, discrimination and unequal access to power
- lack of support/mentoring – not enough support/mentoring is provided to consumers, peers and carers to develop the skills that would enable them to participate meaningfully and sustainably. For example, consumers and carers on reference groups require sufficient time to review relevant documents in order to participate and respond with confidence
- lack of remuneration/reimbursement of the costs associated with participation
- lack of time to engage fully and meaningfully
- prejudice – some people simply don't understand and don't try to understand consumer researchers
- tokenism – consumer and carer involvement is often sought, but not taken seriously
- exclusion through language and culture – the use of jargon, exclusive rather than inclusive language and research practices, as well as the failure to provide information in accessible ways13
- gatekeepers – some people just doesn't want to share power, and this is as true in research and evaluation as it is anywhere
- limited self-perception – many consumers and carers say that they lack the confidence or self-esteem to engage in research because they have been denied the right to exercise power or control over their lives in so many life domains
- life events/challenge – consumers and carers may experience negative life events, periods of being unwell, or other challenges that impede participation. Caring responsibilities and lack of support remain constant barriers for carers
- limitation by others – sometimes carers (with the best of intentions) see the risk of potential overstimulation as a reason to limit consumer participation

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13 Peter Beresford, Beyond the Usual Suspects – Towards Inclusive User Involvement. *Shaping Our Lives*, London, 2013.

Organisational barriers

Organisational barriers to increasing consumer, peer and carer involvement are often related to infrastructure and resources, but are also associated with organisational culture and attitudes.

The consumers and carers consulted in the making of this guide said that organisational barriers typically included:

- lack of time and resources – few organisations have dedicated staff, let alone departments for research and evaluation. The infrastructure or support to include consumers, peers and carers is frequently non-existent. For staff not in dedicated research or evaluation roles, time is a significant barrier.
- policies and procedures – organisations lack clear policies and procedures to guide consumer, peer and carer involvement. They are often unsure of where, or how to start.
- funding – consumer, peer and carer participation is generally not included or allocated for within program/service budgets and this poses significant difficulty for organisations.

Negative staff attitudes also limit consumer and carer involvement in research and evaluation. Power imbalances between service providers and consumers play a role in this. Staff may resist sharing power and information with consumers. They may also be unwilling to include consumers and carers in decision-making.[14]

The section Getting ready to increase consumer, peer and carer involvement provides information and tools to help overcome many of these barriers and to guide your organisation moving forward.

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[14] J. Bryant, M. Saxton, A. Madden, N. Bath, S. Robinson, 'Consumers' and Providers' Perspectives About Consumer Participation in Drug Treatment Services: is There Support to do More? What are the Obstacles?' *Drug and Alcohol Review*, 27, 2008, pp.138 – 144.

Getting ready to increase consumer, peer and carer involvement in research and evaluation

This section is useful to organisations that are **ready to start,** or are looking to **expand** the ways consumers and carers become involved in research and evaluation. It is also useful for organisations that are still **thinking** about how to increase participation, because it can help with understanding and planning the processes involved.

Nine key areas have been outlined and described here to guide your organisation towards **meaningfully** and **sustainably** involving consumers and/or carers. Each key area includes practical tools and additional resources to support the process. This section of the guide is based on the *User involvement in research: A route map*[15] and has been customised for the MH and AOD sectors.

1. **Assessing your organisation – getting set for success**
2. **Planning for consumer, peer and/or carer involvement**
3. **Evaluating consumer, peer and/or carer involvement**
4. **Getting buy-in**
5. **Developing policies and procedures**
6. **Recruiting and retaining consumer, peer and carer participants**
7. **Training and skills development for consumers, peers and carers**
8. **Supporting consumers, peers and carers**
9. **Ethics & practicalities**

While these key areas are described in a linear way, there is no single direction for your organisation to take. Ideally, your resources and framework would already be in place, but in the 'real world' organisations do what they can, when they can, working with what they have.

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[15] This site was developed by Kristina Staley and Bec Hanley of TwoCan Associates, with support from the AMRC.

1. Assessing your organisation – getting set for success

Assess or take stock of what is, or is not, happening in your organisation. This could form part of routine quality improvement or management systems already in place, or it may be something to be developed.

Use this checklist to:

- assess what your organisation has done in relation to consumer, peer and/or carer involvement in research and/or evaluation
- assess how much your organisation has achieved and where improvements can be made
- benchmark progress

The checklist can be used on a regular basis (3 or 6 monthly), or you might like to download the checklist and add further strategies that you think would be useful.

Remember: Set your organisation up for success. Acknowledge achievements, areas for improvement and set achievable and realistic goals within realistic timeframes.

Tip: This checklist is best completed by a team that includes consumers and/or carers. It will help to promote and increase awareness and share responsibility for increasing participation.

Checklist: Organisational commitment to consumer, peer and carer involvement in research and evaluation

CHECKLIST: Organisational Commitment to Consumer, Peer and Carer Participation in Research and Evaluation				
Strategy	Completely in place	Somewhat in place	Not at all in place	Action Plan
A research and/or evaluation strategy that includes consumers, peers and carers has been developed				
Practical, planning and ethics guidelines have been developed				
Consumer, peer and/or carer involvement/ leadership in research and evaluation is supported and endorsed by the executive and senior levels of the organisation				

Staff have been consulted and provided with information about the importance and benefits of consumer, peer and/or carer involvement				
There is a written policy and procedure for consumer, peer and/or carer involvement/ leadership				
Consumers, peers and/or carers are invited or recruited to be involved in/ lead research and evaluation				
Training and education is provided to consumers, peers and/or carers				
Consumers, peers and/or carers are provided with research supervision or mentoring in ways that are satisfactory to them				
Funding has been allocated to pay consumers, peers and/or carers for their involvement				
Results of research and evaluation are disseminated to consumers, peers and/or carers and all staff				
Consumer, peer and/or carer involvement is evaluated for effectiveness and the results shared				

If your organisation is interested in **assessing consumer involvement throughout your whole organisation** click here to use the 'Consumer Participation Workplace Audit' developed by NADA
http://www.nada.org.au/media/62306/nada_consumer_participation_workplace_audit_tool_sept14.pdf

2. Planning for consumer, peer and/or carer involvement

- Develop a strategy that considers:
    - o why your organisations wants to involve consumers, peers and/or carers
    - o who to approach to get involved
    - o where and when to involve consumers, peers and/or carers
    - o how best to do it
    - o what resources are needed – staff and funding
    - o what your organisation hopes to achieve
    - o what your organisation needs to do to get started
    - o how you will measure the impact of consumer, peer and carer involvement through evaluation (see Evaluate consumer and carer involvement).

- Develop a research strategy with/ led by consumers, peers and/or carers
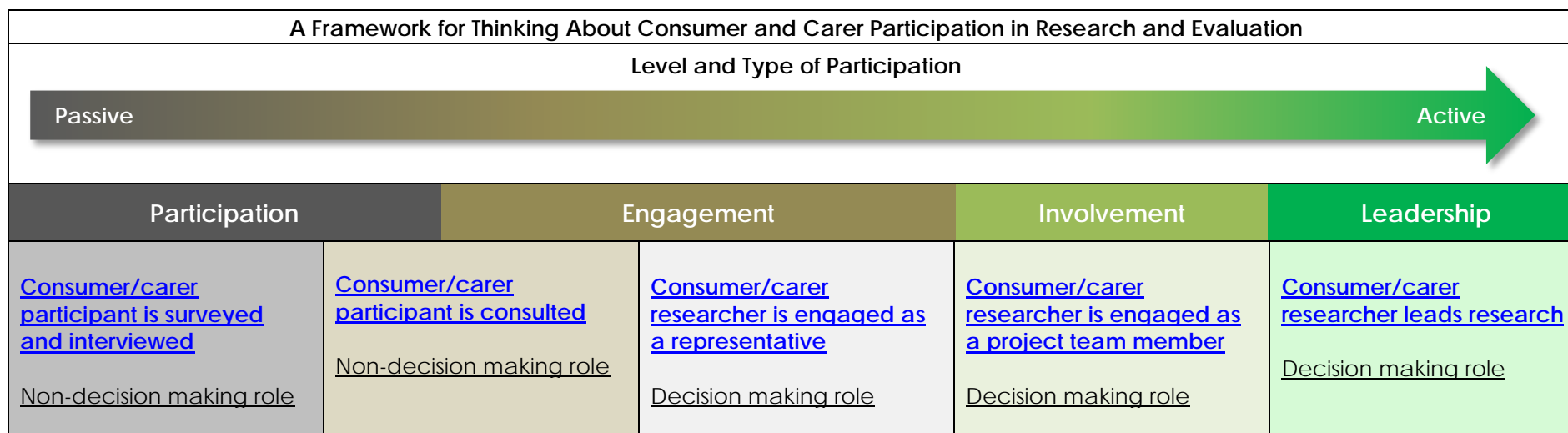
Appendix 2: Strategy for Consumer, Peer and Carer Involvement in Research and Evaluation

Creating a framework for thinking about consumer, peer and carer involvement in research and evaluation

When developing a strategy for consumer, peer and/or carer involvement, your organisation will need to think about where and when to involve them. The introduction to this guide described four levels of inclusion: Participation, Engagement, Involvement and Leadership.

This framework describes some specific ways that your organisation can involve consumers, peers and/or carers, ranging from participation to leadership. This framework was developed in consultation with consumers, peers and carers and shaped by existing resources such as *Consumer Participation Resource Kit for Housing and Homelessness Assistance Services.*[16]

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[16] HomeGround Services and Rural Housing Network Ltd., *Consumer Participation Resource Kit for Housing and Homelessness Assistance Services*, 2008. Accessed online at http://www.homeground.org.au/assets/cpkit_full.pdf 11December 2014.

A Framework for Thinking About Consumer and Carer Participation in Research and Evaluation				
Level and Type of Participation				
Passive → Active				
Participation	Engagement		Involvement	Leadership
Consumer/carer participant is surveyed and interviewed Non-decision making role	**Consumer/carer participant is consulted** Non-decision making role	**Consumer/carer researcher is engaged as a representative** Decision making role	**Consumer/carer researcher is engaged as a project team member** Decision making role	**Consumer/carer researcher leads research** Decision making role

For more ideas and information about where and how to **increase consumer involvement throughout your whole organisation** click here for a comprehensive 'Strategy Selector Table' developed by HomeGround Services and Rural Housing Network Ltd in Victoria. The table lists 47 different types of strategies according to 10 categories, with a consumer participation level rating. http://www.homeground.org.au/assets/cpkit_full.pdf

CONSUMER/CARER PARTICIPANT IS SURVEYED AND INTERVIEWED

<u>Non-decision making role</u>

Consumers and carers participate in a research or evaluation by completing a survey, being interviewed or participating in a focus group.

Their role might involve:
• engaging in complaints and feedback processes
• evaluating services or programs
• evaluating quality improvement processes
• being recruited to participate in an external research group

Checklist	
Ethics and risk assessment has been addressed in the project plan. <u>or</u> If an external research body or organisation is leading or partnering, ethics approval has been sought and obtained.	❑
Consent has been obtained – consumers and carers have been provided with accessible written information about the purpose and goals of the research or evaluation. This information explains: • how they will participate, for example via survey or interview • who will collect information • how the information will be used • how and where the information will be stored • how the findings will be shared with participants and the wider community • that participation is voluntary and can end at any time • how confidentiality will be protected.	❑
Signed consent has been obtained – signed consent has been sought, especially where consumers, peers/carers are interviewed or surveyed and when the information collected will be published. Note: Signed consent may not always be necessary, for example, for data collected in short surveys to be used by an individual service.	❑
Remuneration or reimbursement has been offered and budgeted for. This may cover: • refreshments • transport costs • cash or gift vouchers (iTunes, movies, large retail companies)	❑

Research results have been shared with participants. This can be via: • follow-up phone calls • social media such as Facebook or Twitter • noticeboards • meetings • informal meetings such as a morning tea • face-to-face • a discussion that explains the findings from peer-reviewed publication	❑
Data is stored securely – all information collected is safely stored or deleted when no longer required.	❑

Sector Examples

1: Residential drug and alcohol treatment facility for women

Using a grant from an external funding body, this organisation conducted an evaluation of their service by seeking input from the residents of the service.

The service partnered with a university (and continues in this partnership) to provide staff with mentoring and support in research and evaluation. Ethics approval was obtained through the university's ethics committee.

Information sheets and flyers were developed for residents about the project. Information meetings were also held, during which service staff left the room. An independent researcher explained the project.

Interviews with residents were conducted by an independent researcher. Candid responses were obtained because residents felt safe about speaking openly and honestly.

All residents who participated were given a $20 Woolworths gift voucher as a sign of respect and appreciation.

The project brought about a cultural shift. The voice of residents was accorded greater value by the service. Interviews highlighted that Dialectical Behaviour Therapy (DBT) was viewed favourably, which provided evidence for the introduction of a six week DBT based rehabilitation program. Interviews also led to other changes being implemented, such as a buddy system being put in place for new admissions.

2: Support and advocacy service for carers

This organisation aims to contribute to the development of evidence based practice in relation to carers. It maintains a database of carers interested in participating in research conducted by external research groups. The database assists research groups recruit relevant and appropriate carer participants. Visit http://www.carersnsw.org.au/research/community for more information.

3: Psychosocial support service, caffeine use study

A study was conducted to look at the role of caffeine in the lives of consumers. The study was initiated in response to an earlier project that indicated that caffeine use may be problematic for some people, including people living with schizophrenia.

The main purpose of the study was to improve the ways staff supported consumers to improve health and wellbeing by recognising the potential harms associated with excessive caffeine consumption.

A total of 58 consumers agreed to complete a survey about their caffeine use and general health. Twenty consumers also agreed to be interviewed to find out more about how caffeine fits into their lives (why they drink it, whether it has negative consequences etc.).

The study provided important information:
- 95% of participants drank caffeinated drinks because they liked the taste, while 50% drank caffeinated drinks to help them calm down
- instant coffee was the most popular caffeinated drink, 17% of people drank 2-3 mugs per day, 17% of people 4-6 mugs per day
- 37% of participants put two or more teaspoons of coffee in each drink
- 22% of participants were taking five or more prescription medications per day (including medications for physical health conditions)
- analysis of the data suggests that the more teaspoons of coffee people have in each drink, the greater the number of medications they take
- 50% of participants had been diagnosed with a physical health condition
- most participants (77%) had not been told about the effect of caffeine on their medications.

The information obtained was used to develop targeted health promotion strategies to minimise the potential negative health consequences which may arise from high levels of caffeine use.

Tools and Resources

Ethics and Risk Assessment Guidelines
Appendix 3: Internal Research Approval Checklist
Appendix 5: Participant Information Sheet for Research
Appendix 6: Participant Information Flyer for Research
Australian Privacy Principles Information Sheet
Survey Development Toolkit
CMHDARN *Best Practice Guide to Ethics in Research and Evaluation*

CONSUMER/CARER PARTICIPANT IS CONSULTED

Non-decision making role

Consumers, peers and carers are periodically provided with information or invited to attend a meeting or a forum to comment on:

- publications and resources
- setting research and evaluation priorities
- designing a research and/or evaluation methodology
- developing surveys or questions for research and evaluation.

Checklist	
Ethics and risk assessment – has been considered in the project plan.	❏
Invitation to contribute – an advertisement inviting consumers, peers/ carers to attend an event, or their contribution sought by providing the following: • description of the project (who and what) • timeframe and location of the event • offer of remuneration/reimbursement • outline of skills and contributions required • contact person and details • a guarantee and plan for confidentiality (if applicable). The invitation is widely promoted and advertised via noticeboards, meetings with consumers and carers, newsletters, websites and intranet. _Note: it is recommended that at least two consumers, peers or carers are selected or invited. This is a good way of ensuring that there will be peer support._	❏
Running the event or meeting – consumers, peers/ carers will be made comfortable and welcome by providing: • a location that is easily accessible via public transport • a bright and airy room • accessible amenities • refreshments and water • adequate breaks.	❏
Signed consent – has been sought from consumers, peers and/or carers. Note: Signed consent may not always be necessary, e.g. short surveys relevant to an individual service.	❏
Remuneration or payment – consumers, peers and carers have been remunerated for their contribution and <u>this is budgeted for</u>. This may include: • sitting fees • refreshments • transport costs • cash or gift vouchers (iTunes, movies, large retail stores).	❏
Support has been planned for and made available to assist consumers, peers and/or carers to contribute. This may include providing : • emotional support – for when consumers, peers and/or carers become distressed • practical support – supporting consumers, peers and carers to prepare for meetings or forums by providing plain language documents with sufficient time to review • information about how results will be communicated.	❏

Sector Examples

4: MHCC, Physical Health Research Project
In partnership with Sydney University, MHCC coordinated a research project looking at how the physical health needs of people with mental health issues were being addressed within the sector. Consumer and carer consultation was central to the project. The Physical Health Reference Group, convened by MHCC, included consumer, carer and worker representatives, who assisted with:

- planning – including remuneration for research participants, organising where and how interviews would take place etc.
- developing questions for the interview schedules
- interpreting and analysing the data
- framing the direction of the final project report.

Participants provided a wealth of knowledge and insight about how consumers feel about physical health, how their needs can be addressed, what is, or isn't useful, as well as what is, or isn't currently available in terms of support. With this information, together with findings from a literature review, a set of best practice principles and six key recommendations were developed to support and guide CMOs to improve physical health practices and provide support to consumers.

A summary of the project can be found on the MHCC website:
http://mhcc.org.au/media/43314/ph-project-flyer-final.pdf
A copy of the full report can be downloaded at:
http://mhcc.org.au/media/41452/ph-research-project-report-final-170314.pdf

Tools and Resources

Ethics and Risk Assessment Guidelines
Appendix 6: Participant Information Flyer for Research
Consumer Orientation Checklist
Australian Privacy Principles Information Sheet
Consumer Involvement Self-assessment
NHMRC National Statement on Ethical Conduct in Human Research March 2014)
Ethical Issues in Research into Alcohol and Other Drugs: An Issues Paper Exploring the Need for a Guidance Framework
Keeping Research on Track: a Guide for Aboriginal and Torres Strait Islander Peoples About Health Research Ethics

CONSUMERS/CARERS ARE REPRESENTED

Decision making role

Consumers and carers are included in decision making and have a formal role on a working group or advisory committee. They may be included to co-produce, review and/or contribute to:

- publications and resources
- setting research and evaluation priorities
- designing research and evaluation methodology
- developing surveys or questions for research and evaluation
- reviewing and editing funding applications.

Checklist	
Ethics and risk assessment – have been considered and addressed in the project plan.	❑
Communication – consumer, peer or carer representatives have been recruited via staff, through emails, team meetings, newsletters and noticeboards.	❑
Recruitment advertisement – an advertisement or invitation for the position is developed with the following information included: • title and description of the role and responsibilities • timeframe and location • remuneration offered • specific skills needed/selection criteria • on-the-job support offered • how to apply • contact person and details • supporting documents. The position is widely promoted and advertised via noticeboards, meetings with consumers and carers, newsletters, websites and intranet. _Note: it is recommended that at least two positions are made available as a way of facilitating peer support for the successful candidates._ _The rigour of the recruitment process is at the discretion of the organisation. However, information and expectations need to be clear._	❑
Remuneration or reimbursement – consumers, peers and carers have been remunerated for their role in the research and evaluation and this is budgeted for. Some examples include: • refreshments • transport, accommodation and any other out-of-pocket costs • sitting fees, or time to review and comment on documents. _Note: some consumers, peers and carers may choose not to be paid for their role. Alternatively, gift vouchers may be offered._	❑

Support – Support is planned for and made available to consumers, peers and carers to assist them in their role and responsibilities.
 	
This may include:
• emotional support - offering or providing access to mentoring, facilitating peer support. This will be especially necessary if consumers and/or carers;
    o become discomforted/distressed by the issues raised by the project
    o feel overwhelmed in their new role, or experience periods of being unwell
 	
• practical support – support to carry out their role, such as assistance with travel arrangements, out-of-pocket expenses, meeting procedures, etc.
	❑

Sector Examples

5: Psychosocial support service, development of a Recovery Action Framework
Consumers assisted with the development of a Recovery Action Framework by joining a working group.

A call for expressions of interest was placed on the organisation's intranet (poster and announcement). Posters were displayed at all service sites, and staff discussed the project during member/house meetings, group sessions, one-to-one sessions, etc.

Consumers were assisted and supported:
- with their application (if needed) and by providing access to a scanner and computer to submit the application
- with booking travel and accommodation (centrally, at Head Office). This meant that participants didn't have to worry about how to get to meetings, where they would stay, or how much it would cost
- providing IT facilities, e.g. a fixed-line telephone to participate in teleconferencing and a computer with internet access, to enable communication via email and online research
- copying in email communication to a support person of choice, to ensure that participants did not miss out on any information
- accompanying the participant to head office/ train station/airport if needed. In one instance, a staff member attended a meeting with the participant in person
- providing taxi vouchers to enable the person to get from the airport/train station to head office. In one instance, the person was collected from the airport by a staff member
- paying for all meals and related expenses, so that it did not cost the participant anything to be involved.

6: MHDA advocacy, care and support organisation
This organisation received a small grant to support the development of a research proposal to look at cocaine use among consumers accessing the service. The organisation ensured that consumer engagement was part of the research process and that there was a consumer reference group to support and guide the project.

Consumers were invited to participate in focus groups. Participants were asked to comment/give feedback on the context, frequency and reasons for their cocaine use, in addition to their perceptions on what they considered problematic cocaine use to be.

The consumer reference group emerged from these focus groups and were invited to give feedback/comment on research methodology, effective recruitment strategies and output/dissemination of findings from the research. The final research proposal had the endorsement of the consumer reference group.

The organisation determined that peer-based focus groups were an effective way of developing closer and better links with consumers, compared with online surveys and qualitative interviews.

The consumers who participated in the focus group and consumer reference group felt that:
- the proposed research would be beneficial to consumers
- the opportunity to engage in a discussion around cocaine use was mutually beneficial. Consumers learnt about harm reduction strategies through hearing personal stories from peers.

Tools and Resources

Interview Questions for Consumer Representatives
Appendix 8: Consumer Project Assistant Position Description
Consumer Orientation Checklist
Consumer Involvement Self-assessment

CONSUMER/CARER RESEARCHER IS ENGAGED AS A PROJECT TEAM MEMBER

Decision making role/ Co-production

Consumers and carers are volunteers or employed as part of a research or evaluation project team, to carry out the research or evaluation tasks. They may be involved in:

- designing the research and evaluation methodology
- developing surveys or questions for research and evaluation
- implementing the research or evaluation plan
- conducting interviews
- analysing the information obtained
- writing a project report or making a presentation.

Checklist	
Ethics and risk assessment – have been considered and addressed in the project plan.	❑
Communication – call for consumer, peer/carer participation has been announced to staff via emails, team meetings, newsletter and noticeboards, and has been communicated to consumers and/or carers.	❑
Recruitment advertisement – for the position has been developed with the following information included: • title and description of the role and associated responsibilities • timeframe and location • remuneration offered • specific skills required and selection criteria • on-the-job support • how to apply • contact person and details • supporting documents. The position is widely promoted and advertised on noticeboards, meetings with consumers and carers, newsletters, websites and intranet. *Note: it is recommended that at least two positions are made available as a way of providing peer support for the successful candidates.* *Clear and upfront information should always be provided to set clear expectations, regardless of whether participation is paid or voluntary.*	❑
Remuneration or reimbursement– Consumers and carers have been remunerated for voluntary or paid participation and this is budgeted for within the research or evaluation project. At a minimum, voluntary positions should be reimbursed for all out-of-pocket costs (travel, food and accommodation expenses) and vouchers have been offered in recognition of contribution. Consumers and carers employed by the organisation should be paid according to the relevant award and skill level required.	❑

Support – Support is planned for and made available to consumers and carers to assist them in their role and responsibilities. This may include providing:
• emotional support – offering or providing access to mentoring, facilitating peer support, especially when
     o consumers, peers/ carers become upset by the issues raised by the project
     o consumers, peers/carers feel overwhelmed by their new role, or experience periods of being unwell
• practical support – to carry out the day-to-day requirements of the role, such as making travel arrangements, reimbursing out-of-pocket expenses, providing orientation with the workplace etc.
• research support and supervision – training in research practices and supervision, to help with setting research boundaries, project management etc., in ways that are satisfying to them.
	❑

Sector Examples

7: Disability employment and training service
With the assistance of a small grant, the organisation conducted the Managing Personal Information Project and employed a Consumer Project Assistant. People accessing the service were encouraged to apply. Visit https://youtu.be/M38uMYCIK4c to view a clip about the project.

8: Advocacy and support service for people who use drugs
A user-led service provides information to people who use drugs, develops resources and runs a number of education and skill development programs, all of which are developed and delivered by people who use, or have a history of using drugs. The service aims to increase user self-determination and participation and to decrease stigma and marginalisation. The organisation also works closely with university research groups to help inform research methodologies and ethics protocols around research involving participants who use drugs.

9: Psychosocial support service, evaluation of a support model for consumers
Working together with a university, the organisation undertook a study of a support model for consumers to measure effectiveness, to investigate whether it was being used as intended and to use the information gathered to improve and modify the program where needed. Consumer researchers were employed to undertake the study which involved surveying and interviewing staff and consumers about specific elements of the program and related resources and tools.

Tools and Resources

Ethics and Risk Assessment
Appendix 3: Communication Strategy
Appendix 7: Recruitment Advertisement for Consumer Project Assistant
Interview questions
Appendix 8: Consumer Project Assistant Position Description
Training guide for Consumers and Carers to Engage in Research

CONSUMER/CARER RESEARCHER LEADS RESEARCH
Decision making role Consumers and carers conduct their own independent research or evaluation, with or without the support of an organisation or research group/partner. The research is entirely conceived, led, conducted and analysed by consumers and/or carers as sole grant holders sourcing their own funding and implementing their own support and resources.

Checklist	
Funding – Funding for the research project has been sought and secured, e.g. from a university research group, government or CMO/NGO to cover expenses such as: • paying principal and co-researchers • physical resources – office space, computer, etc. • printing and admin • travel costs • payment/ remuneration/ vouchers for participants as required.	❏
Partnerships and support – Partnerships and support have been considered, sought and secured for the project. This may include: • partnership with a research group, CMO/NGO or other relevant agencies • creation of a reference group comprised of peers, to obtain support to plan and carry out the project • a mentor who can support and assist in professional development	❏
Self-care support and strategies – Self-care management throughout the project has been considered and support plans and strategies secured. This may include: • mentoring • emotional support during periods of being unwell • coping with stressful events during the project • staying in contact with friends and/or family who can provide support • peer support by consumer/carer researchers	❏
Ethics and risk assessment – risks have been examined and addressed in the project plan. or If an external research body or organisation is partnering in the research, ethics approval has been sought and provided.	❏

Informed consent – Consumers, peers, carers and other participants, e.g. service providers, are given written information about the purpose of the research or evaluation. Information includes: • how they will participate. e.g. by completing a survey or interview • who will collect the information • how the information will be used • where the information will be stored • how the findings will be shared • a statement that participation is voluntary and that opting out at any time is ok • a guarantee and plan for confidentiality • in area supports are identified. Information is widely disseminated in an accessible form, such as via noticeboards, newsletters, meetings, etc.	❑
Signed consent – has been sought from potential participants to participate in interviews, surveys etc. and when any information collected will be used in publications or reporting. Note: Signed consent may not always be necessary e.g. for short surveys relevant to an individual service.	❑
Remuneration or reimbursement – participants are remunerated for their participation in research and evaluation activities and this is budgeted for within the research or evaluation project. Some examples include: • refreshments • transport costs • cash or gift vouchers (iTunes, movies) for participation in an interview or survey.	❑
Support for participants – is planned for all participants to: • complete surveys, e.g. assistance with reading and writing, phone or computer access, transport to a site • debrief and talk about any distress or questions that may arise from completing a survey or interview.	❑
Dissemination of results – The results of the research or evaluation project are shared with participants. This can be via: • follow-up phone calls • social media, such as Facebook or Twitter • noticeboards • meetings • informal meetings, such as a morning tea • face-to-face.	❑
Storage of data – Once the results are analysed, ensure that information collected via surveys and interviews is safely stored electronically, or where possible delete results if no longer required (this is often a requirement of ethics approval with research partners).	❑

Sector Examples

Consumer Researcher – *What is Happening at the Seclusion and Restraint Review that Makes a Difference: a Consumer Led Research Study*

The research project, *What is Happening at the Seclusion and Restraint Review That Makes a Difference? A Consumer Led Research Study* (SRRM), was undertaken by independent consumer researcher, Bradley Foxlewin.

The aim of the research was twofold:
1. to track two years of the SRRM at the Canberra Hospital that led to a huge reduction in the use of seclusion and restraint between 2009 and 2012; and,
2. to reiterate the importance of including consumer voices in implementing systems change.

The research took the epistemological standpoint that change is enabled within social and relational domains. The methodology reflected the collaborative and relational aspect of the SRRM whilst maintaining consumer voices and experiences at the centre. Stories and anecdotes from consumers and clinicians were collected to gain an understanding of the changes at the SRRM. A Consumer Reference Group (ACT Mental Health Consumer Network) was also consulted to guide the proposal and methodology, help seek ethics approval, and help produce the final document. This ensured consumer perspectives were included at all stages of the research.

The study included quantitative data, as well as literature reviews on both seclusion reduction and review processes and consumer led research. The study brought seclusion and the ideas that underpin practices of seclusion, to the fore. These ideas had informed the changing culture, personal and professional identities and practices at the SRRM and the Canberra Hospital.

The research project was a significant and highly symbolic undertaking. Taking on the role of the independent consumer researcher brought its own set of challenges. In addition to the research process itself, the primary researcher, Bradley needed to manage his own mental health self-care, and fluctuating stress levels.

Being an independent researcher meant that Bradley had to keep his own supports in place, while also ensuring that ethics processes protected and supported research participants.

Bradley found the research project was key to his path towards recovery and resilience. The study was warmly received by the mental health community and won a TheMHS award in 2014.

Tools and Resources

The Ethics of Survivor Research – Comprehensive guidelines for consumers to conduct their own research.
Ethics and Risk Assessment Guidelines
Appendix 4: Internal Research Approval Checklist
Appendix 5: Participant Information Sheet for Research
Appendix 6: Participant Information Flyer for Research
Australian Privacy Principles Information sheet
Download "What is Happening at the Seclusion Review that Makes a Difference? – a Consumer-led Research Study" by Bradley Foxlewin
CMHDARN *Best Practice Guide to Ethics in Research and Evaluation,* coming soon

3. Evaluating consumer, peer and carer involvement

If consumer and/or carer involvement in research and evaluation is important to your organisation, then it is a good idea to evaluate its impact and usefulness and understand the difference(s) it has made.

Evaluating consumer, peer and carer involvement in your research and evaluation activities can help to:

- identify what works (or not)
- identify if and/or how consumer/carer involvement makes a difference
- generate evidence of the value of involvement to convince others – to help you 'prove that it works'
- celebrate success – recognise achievements
- share learning
- improve planning of future projects
- provide another mechanism for involving consumers and/or carers.

Ideally, evaluation happens from the very beginning of a project, so it is a good idea to include an evaluation plan as part of your overall strategy for consumer and carer participation (see 'Planning for consumer, peer and/or carer involvement').

Your evaluation strategy may be different for each research or evaluation project that your organisation undertakes, but should always include:

- broad evaluation questions – what do you need to evaluate?
- monitoring questions – what do you want to know?
- indicators – how will you know?
- data sources – how will the information be collected?
- responsibility – who will collect the data?
- timeframe – when will the data be collected?
- budget & resources.

Appendix 2: Evaluation strategy for consumer/carer participation in research and evaluation activities

Example: Neami Research and Evaluation Framework 2014

'Participation: finding out what makes the difference' Doel et al (2007) Social Care Institute for Excellence

4. Getting buy-in

Winning support from all levels of the organisations is key to *meaningful* and *sustainable* consumer, peer and carer involvement in research and evaluation.

Making sure that you have 'buy-in' is especially important if consumers, peers and carers of the service are recruited as paid employees of the organisation.

The success and growth of consumer, peer and carer leadership in research also needs 'buy-in' from organisations and the MH and AOD sectors more broadly. Leadership in independent discovery research needs to be nurtured and supported.

Staff may not be as supportive as they should be because they:

- may not see or understand the value of consumer and carer participation
- may think that it will increase their workload
- may believe that consumer and carer participation will result in inferior results and/or research quality.

You can build a case for the value of consumer, peer and carer involvement by:

- getting senior level staff to endorse and support involvement – they need to be seen and heard to be endorsing consumer, peer and carer participation
- supporting staff by:
  - providing clear information about goals and aims
  - speaking at team meetings, or discussing the purpose and benefits to the organisation of consumer and carer participation
  - talking about the process and discussing any concerns
  - discussing consumer, peer and/or carer participation as part of induction or orientation to the service/organisation
  - allowing staff plenty time to understand the purpose and benefits
- providing regular updates about the project and celebrating successes
- inviting consumer, peer and carer researchers to speak at staff meetings about their role and the project.

Appendix 3: Communication Strategy

5. Developing policies and procedures

It is important to develop or adopt policies and procedures to support consumer, peer and carer involvement in research and evaluation.

Policies should be developed in consultation with consumers, peers and/or carers.

This will help to:

- clarify the roles and responsibilities of all stakeholders – for example, explain what you expect from participants and what they can expect from the organisation. This includes guiding and supporting staff who may need to begin to work in a new way
- ensure consistency in practice across the organisation
- manage challenging situations.

It is a good idea to look at other areas of the organisation where consumers, peers and/carers are involved to ensure there is a consistency of approach. For example, if you want to follow best practice and ensure that service users are quickly reimbursed for their expenses, you may need to work with your finance department to find out how this can best be achieved.

Advocacy for Consumer, Peer and Carer Involvement in Research and Evaluation
Limited funding is a significant impediment to many organisations. Funding often does not allocate money for consumer, peer and carer involvement and organisations are forced to find resources elsewhere. Organisations and peak bodies need to continue to advocate for consumer, peer/carer involvement to be included within program funding. Organisations need to say that consumer, peer/carer participation is a project requirement and that it will be measured.

At the same time, have a clear policy in place to help guide and assist your organisation to include consumers, peers and carers whenever and wherever feasible.

Participation Policy
MHCC Participation Policy from the 'MHCC Organisation Builder (MOB) - Policy Resource'
http://mob.mhcc.org.au/media/2217/participation-policy-2012-12-14.pdf

Example policy in: M. Clarke & R. Brindle, Straight from the Source: *A Practical Guide to Consumer Participation in the Victorian Alcohol and Other Drug Sector.* Association of Participating Service Users (APSU): Victoria, Australia, 2010.

6. Recruiting and retaining consumer, peer and carer participants

For consumer, peer and carer participation to be genuine and sustainable, organisations need to be inclusive and collaborative. That means making the commitment to putting in place processes and infrastructure that will enable engagement on an ongoing basis.

Increasing consumer, peer and carer participation in research and evaluation is difficult. It is about building trust and rapport with people who have been excluded from meaningful research engagement and denied individual agency and the right to self-determination. Therefore, organisations need to show and communicate the message that consumer, peer and carer participation is highly valued and is part of core service delivery and associated activity.

Being clear about the **purpose** and **benefits** of research or evaluation, and being aware of consumer, peer and carer **expectations**, is likely to make participation more enticing and relevant.

"User involvement is most likely to attract a wide response if it takes account of why people want to get involved. Most people want to get involved to bring about positive change. Involvement that doesn't offer this prospect is unlikely to have a wide appeal. It isn't enough to hear what people say. It has to be listened to and acted upon."

(Beresford, 2013, pp. 9)[17]

The following suggestions come from the stakeholders we consulted in preparing this guide:

- provide a clear description of the role, responsibilities and skills required
- explain what support and training will be provided
- ask consumers, peers and carers how they want to be involved
- provide a clear description of how consumers and carers can be involved in setting research and evaluation priorities, including
  - participating in workshops/forums
  - completing surveys
  - holding their own meeting to generate ideas
  - contributing to a comments or suggestions box
  - joining an advisory committee or working group
  - identifying research priorities and refining research questions
  - designing methodologies
  - leading research
  - developing questionnaires

Retaining and supporting consumers and carers to want to stay involved is no different from supporting other employees in your organisation. Sustainable consumer, peer and carer involvement in research and evaluation is more likely when an organisation provides: [18]

- appropriate and timely training
- opportunities for developing trust and respect
- a supportive infrastructure that considers stressors
- carefully planned processes
- a supportive workplace culture.

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[17] Peter Beresford, *Beyond the Usual Suspects – Towards Inclusive User Involvement. Shaping Our Lives*: London, 2013.
[18] R. Callander, *et al.*, 'Consumers and Carers as Partners in Mental Health Research: Reflections on the Experience of Two Project Teams in Victoria, Australia,' *International Journal of Mental Health Nursing*, vol. 20, 2011, pp. 263-273.

Remuneration and reimbursement

Some form of remuneration or reimbursement should be budgeted for and offered to consumers, peers and carers involved in research. Remunerating or reimbursing consumers, peers and/or carers is one way of demonstrating that their contribution is highly valued and their expertise respected.[19]

Some people have ill-founded concerns about paying consumer and carer participants. Researchers may fear that remuneration is coercive (that they are buying informed consent). Researchers sometimes also fear that cash payments may be used to purchase drugs or alcohol. Many consumers resent this judgement on their lives and reject this logic. Research shows that it is safe and reasonable to remunerate research participants, regardless of who they are.

Consumers, peers and carers who are members of a working group or advisory committee should be reimbursed for travel and expenses at the very least, or even more appropriately, be paid a sitting fee for their contribution. Consumers, peers and/ or carers employed as part of a research or evaluation project should be paid according to the relevant award for the role.

Sometimes consumers do not want to be remunerated for their time and expertise. It is up to the consumer to decide, although it is important to consult with them as to their reasons. Learned helplessness and low self-esteem are not reasons to refuse remuneration.

Appendix 6: Recruitment Advertisement for Consumer Project Assistant

Tool: Consumer Orientation Checklist

Tool: Consumer Involvement Self-assessment

Bennets, W. (2009). *Real lives, real jobs: Developing Good Practice Guidelines for a Sustainable Consumer Workforce in the Mental Health Sector Through Participatory Research*, Victoria.

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[19] W. Bennets, *Real Lives, Real Jobs: Developing Good Practice Guidelines for a Sustainable Consumer Workforce in the Mental Health Sector Through Participatory Research*, Victoria, 2009.

7. Training and skills development for consumers, peers and carers

Training is essential to sustaining consumer, peer and carer involvement in research. Knowledge of, and experience with research processes will vary greatly from person to person. Providing participants with a spectrum of opportunities to develop and enhance skills, ranging from attending project meetings to leading research projects, is extremely important. As with all professional development and training, these opportunities should be available for the life of the research project, not as a one-off event. Access to formal or informal supervision, or the opportunity to assess and debrief with a team leader or peer participant, should also always be possible.

Some useful considerations in relation to training:[20]

- timing – adapt it to the needs of participants
- address the wider context of the project and research
- be flexible, adapt to individual needs, strengths and levels of research experience
- context – provide training in comfortable physical surroundings, with refreshments and regular breaks
- introduce aspects of support and supervision, risks and safety measures relevant throughout the project
- support – tell participants how they will be supported.

Organisations looking to provide training for consumers, peers and carers involved in research and evaluation can access and download the freely available 'Demystifying Research' training guide which includes 10 modules.

'Demystifying Research' Training Module

Outline of the Health Issues 3 Day Consumer Leadership Course

Outline of the Health Issues Graduate Certificate in Consumer Engagement Course

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[20] A. Faulkner, *The Ethics of Survivor Research: Guidelines for the Ethical Conduct of Research Carried out by Mental Health Service Users and Survivors*, Bristol, 2004.

8. Supporting consumers, peers and carers

Consumers, peers and carers involved in research may require the following kinds of support:[21]

Practical support – making it as easy as possible to be involved. This can mean providing:

- upfront payment of out-of-pocket expenses – many consumers and carers rely on pensions and benefits, so having to pay for small extras can put pressure on already tight budgets
- orientation in the workplace.

Emotional support – consumers, peers and carers may experience distress, or may go through periods of being unwell. Emotional support might include:

- providing access to, or facilitating mentoring (some consumers, peers and carers may already have a mentor in their life)
- enabling peer support networks to emerge
- facilitating debriefing opportunities with peers.

Research related support – providing consumers, peers and carers with training and supervision relevant to their level of involvement in the research, and their skills and experience. Supervision can take place on an ongoing basis, or as needed in a particular phase of a project.

Tip: Be flexible and adaptive to people's needs and circumstances – this may mean that timeframes are extended

9. Ethics & practicalities

All research or evaluation with human participants will involve negotiating a range of ethical and practical considerations. Research projects vary, and so does the extent of participant engagement. Some participants may engage with a service on a short-term, or one-off basis, whereas others may access a service on multiple occasions or on a long-term basis. These variations are dependent not only on individual needs and circumstances, but also on the types of support provided by the service. Specific considerations are described in the next section.

The following resources also provide useful and practical references to guide your organisation.

Australian Injecting & Illicit Drug Users League (AIVL), (2002). *National statement on ethical issues for research involving injecting/illicit drug users.* Canberra, ACT.

The Research Ethics Guidebook: a Resource for Social Scientists

CMHDARN *Best Practice Guide to Ethics in Research and Evaluation* coming soon

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[21] A. Faulkner, *The Ethics of Survivor Research: Guidelines for the Ethical Conduct of Research Carried out by Mental Health Service Users and Survivors*, Bristol, 2004.

Seeking ethics approval

Your project may require formal ethics approval. If your organisation is partnering with a university research group, or if the research is conducted within a government department, ethics approval will probably be required. Many universities and other organisations already have their own Human Research Ethics Committees (HRECs). All HRECs must be registered with the [National Health and Medical Research Council (NHMRC)](#).

The NHMRC website provides further information about when ethics approval may be required and how to register a HREC.

Information about how to decide whether you need to apply for ethics approval will be available in the CMHDARN *Best Practice Guide to Ethics in Research and Evaluation* soon.

[The Research Ethics Guidebook: A Resource for Social Scientists](#)

Assessing and managing risk

Assessing risk is about ensuring that all issues have been considered and planned for. Managing risk is about responding to challenges as they arise. Proactive planning, rather than waiting for issues to arise, is essential not only for organisations, but also for consumers, peers and carers, particularly those taking on independent research. Self-care and managing mental health, along with other practical considerations, should all form part of initial research planning.

Assessing risk is about looking at potential harms, risks and benefits. Some risks and harms to consider in research and evaluation include:

- risks or harms to consumers, peers and/or carers participating in a survey, interview, or advisory committee, etc.
- risks or harms to researchers, including consumer, peer and carer researchers.

Consumers, peers, carers and/or service providers may be upset by a particular research or evaluation activity. A clear response plan should be in place that describes how an organisation will deal with such situations. This plan should be communicated when the project is first promoted and advertised. Participants need to understand that their participation is voluntary and they can stop at any time. Very mild distress is not always a harm, and even though a consumer/ peer/carer/service provider may be experiencing distress, they may still wish to contribute.

Involving consumers, peers and carers in the development of surveys and interview design is also a useful way to limit risks/ potential harms and increase the benefits for participants. Consumers, peers and carers can provide:

- better ways to frame questions
- advice on whether a question is relevant or not
- suggestions about other methods of obtaining information
- advice on safe and desirable locations and times for interviews or surveys to be administered.

Appendix 4: Research Approval Checklist

The Research Ethics Guidebook: a Resource for Social Scientists

Providing information

When involving consumers, peers and carers, it is important to provide clear information about:

- the purpose of the research
- whether participants may be required to discuss or reflect on personal and/or personally confronting issues
- what support will be provided if participants have questions or concerns before, during and after participating
- how the information will be collected, e.g. interview, survey, focus group
- how the information will be used
- who is funding the research
- if the information being collected will be available to government agencies, such as the police. For consumers or peers being asked about illegal drug use, this can be very important
- who will be collecting the data. This can be a particularly complex issue for peer researchers. It is essential to determine how much distance is needed between researcher and participant to reduce the risk of coercion, and to establish and maintain clear boundaries for the researcher and participant. Participants in research and evaluation should always feel comfortable providing open and honest responses
- how the information will be stored and the results shared
- the voluntary nature of participation and the right to withdraw at any time
- how they will be remunerated.

Appendix 6: Participant Information Flyer for Consumer Participation in Research

Appendix 5: Participant Information Sheet for Consumer Participation in Research

Dealing with power imbalances

Power is not distributed evenly among people. It is important to implement strategies to shift the balance of power.

Power imbalances exist between organisations and consumers, between researchers and research participants as well as between consumers and carers. In most cases, consumers are in a vulnerable position and have less agency and say than is their right.

Many MH and AOD services are residential services. Researchers and services need to be mindful that consumers are not always free to leave the service. If participation in research might increase vulnerability, then consumers should not be made to feel coerced or under pressure to participate in any research activity.

Organisations can act to address power imbalances by:
- providing clear and timely information – allowing plenty of time for participants to think about and ask questions
- involving consumers at the start of research and evaluation processes – setting research priorities, designing surveys etc.
- maintaining independence – where possible, researchers should be independent of the organisation conducting the research, so that consumers and carers/others feel safe to respond honestly. This is particularly important when participants are providing feedback about the service they access.
- keeping participants involved throughout the research process, to the extent that they choose to remain involved
- involving participants in research analysis/interpreting results
- sharing the results of research
- supporting consumer and/or carer led research.

Power differences also exist between consumers and carers. While carers often play a very significant role in empowering consumers, consumers may be uniquely limited by stigma, discrimination and legal constraint.

There are also power imbalances between peers with dissimilar lived experiences and symptoms. Perceived differences can be diminished through training sessions, or by ensuring that peer support is available to enable people to feel more confident about the contribution they can make.

Recruitment

It can be difficult to engage and recruit consumers, peers and carers. For this reason, organisations may find that they need to approach the same consumers and carer representatives frequently.

One way to deal with the ongoing challenge of recruitment is to maintain a database and invite consumers, peers and carers to register their interest as future participants who can be contacted as required. Peer support and the opportunity to engage in research can help overcome power inequities.

Confidentiality

Consumers, peers, carers and others need to be given a guarantee that any information they provide will be treated in confidence. This needs to be explicitly stated in information sheets and notices.

When consumers, peers, carers and others wish to be identified in order to show ownership/agency in their research, this should be open to negotiation.

All research participants need to be trained to maintain confidentiality. Training and supervision should address this issue.

Boundaries and disclosure

There are many advantages to involving consumers, peers and/or carers as researchers, and these have been discussed throughout this guide. Disclosing a lived experience can be a useful way to gain the trust of other participants. Disclosure can help overcome some of the power imbalances in interactions between researchers and participants.

However, it is also important to maintain safe emotional boundaries. Organisations need to have a clear approach and/or guidelines in place to support consumer, peer and carer researchers to decide when and how much they want to disclose. Ongoing supervision should support reflection on how to maintain appropriate boundaries.

Consumers, peers and carers who are thinking about participating in research should ask:

- how relevant is my lived experience to the research project?
- do I feel comfortable disclosing my experience in this situation/ with these people?
- what will happen if I choose to disclose?

Carers who participate in research often have to make a decision about how much to disclose about the person they care for. This poses a range of ethical as well as practical questions. If carers are unable to physically leave the person they care for without support, completing interviews over the phone can be a practical solution. However, disclosing information about the person they care for when that person is present in the home can be difficult. Carers should only be asked and should disclose only what is absolutely relevant to the research. In some instances, completing a written survey can be a more appropriate method of obtaining information.

Disseminating the results

Communicating and disseminating the results and the impact of research or evaluation is a simple, effective and important way of showing that consumers, peers and carers are highly valued and respected as experts in research. It makes good sense to share information first with the people who contributed to the research, and who may be affected by the results.

Some research may require participants to verify the accuracy and appropriateness of the findings before publication. However, not all organisations will be able to follow-up with consumers, peers and carers in this way. For example, many drug and alcohol services provide residential programs for a discrete period of time and consumers then move on from the service.

Organisations can overcome this barrier by:

- conducting follow-up phone calls
- emailing reports or publications
- social media, for example, via the messaging service on Facebook
- holding information sessions
- placing notices on websites and noticeboards
- asking other organisations, particularly consumer-led organisations, to place notices on community noticeboards and websites.

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Other useful websites

Health Issues Centre
Victorian organisation that supports consumer participation for health care improvements. The website is a great source of information and resources on consumer and carer participation.
http://healthissuescentre.org.au/

Consumer Health Forum (CHF)
CHF is the peak organisation providing leadership in representing the interests of Australian healthcare consumers. The website provides a variety of resources and useful information.
https://www.chf.org.au/

Other useful publications

'How to develop a strategy', compiled by Kristina Staley and Bec Hanley
http://www.twocanassociates.co.uk/perch/resources/files/Usercarer%20strategy%20252.pdf

'Voices on Choices', Teresa Hinton Anglicare
http://www.nada.org.au/media/25189/voices_on_choices_anglicare.pdf

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Appendices

Appendix 1 - Template: Strategy for Consumer, Peer and Carer Involvement in Research and Evaluation

This template is intended to help your organisation develop a broad strategy for consumer, peer and/or carer involvement in research and evaluation.

How to use this template:

The following template can be downloaded as is, or customised to the needs of your organisation.

It is recommended that this template be completed:

- in consultation with/by consumers, carers and staff, including key senior managers within the organisation
- during a planning meeting for a research and/or evaluation strategy, and also at team meetings (this will help to promote and raise awareness and to share responsibility for increasing participation)
- alongside **Appendix 2:** Evaluation Strategy for Consumer, Peer and Carer Participation in Research and Evaluation

in order to establish an organisational culture that supports consumer and carer participation in research and evaluation, a summarised version of the completed strategy should be shared and distributed to consumers/carers and staff, preferably by senior management. This version should inform, raise awareness and provide clear guidance on how this will take place. See also **Appendix 3:** Communication Strategy

Research/evaluation topic or project activity	Objectives	Who will be involved?	How will consumers/carers be involved? E.g. as survey participants, committee members, researcher, etc.	Timeframe of project	Budget and resources required	Evaluation plan: how will the impact/usefulness of consumer participation be measured?

Appendix 2 - Template: Evaluation Strategy for Consumer, Peer and Carer Involvement in Research and Evaluation

This template is here to help your organisation develop a strategy to evaluate and understand the impact and usefulness of consumer, peer and carer involvement in a specific research or evaluation activity.

How to use this template:

The following template can be downloaded as is, or customised to the needs of organisation.

It is recommended that this template be completed:

- ideally, at the commencement of each new research and evaluation activity
- In consultation with and by the consumers/carers and staff
- during a planning meeting for the activity
- alongside **Appendix 2:** Evaluation Strategy for Consumer, Peer and Carer Participation in Research and Evaluation

The completed evaluation strategy should be referred to and reviewed on completion of the evaluation.

Broad Evaluation Questions	What do we want to know?	How do we know?	Data Source/Methods	Responsibility	Timeframe	Budget & resources
Example: To what extent did consumers and carers gain a greater awareness of the service after the research project?	• How many consumer and carers were aware of the service? • To what extent were consumers and carers involved in the project? • How was the service promoted? • do consumers and carers have a better understanding about the service?	• Percentage of consumers/ carers aware of service pre & post project • Extent of participation, engagement and/or involvement • Communication methods used pre and post project • number of consumers and carers who have accessed the service before and after the research project	Survey Review of project plan Review of service plan Survey Survey Service records	Consumer and carer researcher, Research coordinator, Program coordinator	March 2015 – Post project	• printing costs • staff time • consumer and carer researcher remuneration • remuneration for survey participants

Adapted from the *Evaluation Toolbox* website developed by Victorian Department of Environment and Primary Industries, accessed online 9 December 2014 at http://evaluationtoolbox.net.au/

Appendix 3 - Template: Communication Strategy

The purpose of this template is to help your organisation develop a strategy and/or plan for communicating and disseminating information about an activity related to consumer, peer and carer involvement in research and evaluation.

How to use this template:

The following template can be downloaded as is, or customised to the needs of your organisation.

It is recommended that this template be completed:

- in consultation with and by the consumers, peers/carers and staff involved with the particular activity or project and other key stakeholders, e.g. the research team
- during a planning meeting for the activity.

The completed communication strategy should then be referred to, to guide the communication process and then be evaluated on completion of the activity.

The strategy should also be shared with managers and team leaders to support the communication process. This template can also be used alongside **Appendix 2:** Evaluation Strategy for Consumer, Peer and Carer Participation in Research and Evaluation

---

Author: Date:

Aim of Strategy: *To promote and increase awareness of ......*

Project Title:

Description:

Who needs to know?			
Staff	❏	Consumers/consumer researchers	❏
Senior Managers	❏	Carers/ carer researchers	❏
Team Manager	❏	Volunteers	❏
	❏		❏
	❏		❏

Objective	Why	Who	How	When
Promote and increase awareness of the project	Ensure stakeholders understand the purpose of the project	Staff, Team Managers, Senior Managers	Project Information Sheet - via email, service noticeboards, Intranet, Staff meetings, Newsletters, Email from CEO	e.g. March 2015
		Consumers, peers and carers	Project Information sheet on service noticeboard, Newsletters, Meetings	
		Volunteers	Project Information sheet on service noticeboard, Newsletters, Meetings	
		External services/organisations	Interagency meetings, email, newsletters	
Promote project surveys	Ensure all staff complete the survey	Team Managers	Email, Staff Meetings, Face-to-face conversations	
		Staff	Email, Staff meetings, Face-to-face conversations	
	Ensure all consumers and carers complete the survey	Consumers, peers and carers	Email, Meetings, Face-to-face conversations	

Neami National Research Approval Checklist[22]

Contact information and brief project summary

Title of Research Project

Name of researcher(s)

Contact details (Phone/email)

Name of sponsoring institution

Principal Contact (email)

Has the project received approval from a Human Research Ethics Committee? ❏ Yes ❏ No

If yes please provide a copy of the Ethics Approval letter

If no provide details as to when ethics approval is expected

Name of associated Neami program/service

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[22] Provided by Neami National and also available for download from http://www.neaminational.org.au/our-approach/research-and-evaluation

Ask the Experts: *A CMHDARN Best Practice Guide to Enabling Consumer and Carer Leadership in Research and Evaluation*

50

Why has Neami been approached to participate in this research project?

```



```

Is funding from Neami required for this research? ❑ Yes ❑ No

If so, give details:

```



```

If the research is part of a degree requirement, please indicate type and year of degree:

```



```

Anticipated commencement and conclusion:

```



```

When do you need approval for this research?

```



```

Key Contact at Neami (must be at Manager level or above)

```



```

Summary description of the research project (please attach further documentation if required)

```



```

Specific project details

1. What are the credentials and competencies of those involved to conduct the proposed research?

2. What is the purpose of the research, and how will this benefit consumers and/or staff of Neami's services?

3. Are there any ethical issues relevant to the project? Please attach any relevant documentation. E.g. process for gaining informed consent, proposed questionnaires, screening tools, etc.

4. Has the Neami program or service site that will be associated with the research been consulted and given its approval?

5. Have you reviewed the National Health and Medical Research Council (NHMRC) Statement on Consumer and Community Participation in Research? If so, please describe how consumers have been involved in the design of the study and their ongoing role in the study? If not please describe why.

6. How will consumers be involved in the research? E.g. Critical reference group, Co-researchers, participants

7. How will Neami staff be involved in the research? i.e. advertising study and recruiting participants, as participants of the research itself?

8. In total how many study participants do you anticipate being involved? i.e. both Neami staff if they are involved and consumers as study participants

```

```

9. How do you plan to disseminate the results of the research, including to consumers?

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```

10. Are there any issues regarding *participants'* safety and/or wellbeing that might be associated with this research project? What steps have you taken to address these issues?

```

```

11. Are there any issues regarding *researchers'* safety and/or wellbeing that might be associated with this research project? What steps have you taken to address these issues?

```

```

12. Do you anticipate any conflicts of interest arising in relation to this project? If so, how do you intend to address them?

```

```

13. Do you anticipate any other ethical issues arising in relation to this research project? If so, how do you intend to address them?

```

```

(Continued over)

Signatories

<div style="border:1px solid black; height:80px;"></div>

Researcher

<div style="border:1px solid black; height:80px;"></div>

Date

<div style="border:1px solid black; height:80px;"></div>

Please forward the checklist together with any other relevant supporting information, including research instruments to be used and Certificate of Ethics Approval to Adam Zimmermann, Research Coordinator, adam.zimmermann@neami.org.au or fax to (03) 9458 3321.

Internal use only

Manager ……………………………………………………………………….

Date…………………………………………………………………

State/Regional Manager……………………………………………….   Date……………..……

Recommended by Manager Service Development   Yes / No

…………………………………………………………………………

Approved by Research Committee

Date…………………...

Appendix 5 - Example: Participant Information Sheet for Consumer Participation in Research

ABN 15 211 513 464

DR NICOLA HANCOCK
Discipline of Occupational Therapy
Faculty of Health Sciences

Room 120
Building J, C42
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 2 93519379
Email: nicola.hancock@sydney.edu.au

How do Community Managed Organisations in NSW Assist People Living with Mental Illness to address their Physical Health Needs?

CONSUMERS
PARTICIPANT INFORMATION STATEMENT

(1)   What is the study about?
You are invited to participate in a study to help us learn more about current physical health programs being run by mental health Community Managed Organisations in NSW. We would like to understand more about what you enjoy and find helpful about the program you are attending and also if you have any ideas about what might make the program better

(2)   Who is carrying out the study?
The study is being conducted by Dr Nicola Hancock from the University of Sydney in partnership with the Mental Health Coordinating Council (MHCC). MHCC is the Peak Body that represents mental health Community Managed Organisations across NSW.

(3)   What does the study involve?
If you agree to be involved in this study we will ask you to:

- Complete an interview with one of our research team to help us understand what you do with the program. We also would like to know what you think is good about the program and what you think might improve it.

Your interview will be audio-recorded to ensure we capture all of the information you provide. Once the recording has been typed up, the recording will be deleted.

(4)   Where will the interviews take place and how long will they take?
If you choose to join the study you will be asked to complete an interview that will take about 30-45 minutes.

Interviews will be arranged at a time and place that are convenient for you. They may be conducted by telephone if this is the more convenient method for you.

(5)   Are there any risks to participating?
There are no risks associated with participating in this study.

Enhancing the Physical Health of people living with Mental Illness   Page 1 of 2
Date

(6)   Can I withdraw from the study?
Participating in this study is completely voluntary. You are not under any obligation to consent. If you do agree to be involved, you can still withdraw at any time without it affecting your relationship with The University of Sydney, MHCC or the staff from your physical health program. You may stop the interview at any time if you do not wish to continue.

(7)   Will anyone else know the results?
Only the researchers will have access to the information you give us at the interview. Reports of this study will be submitted for publication and provided to your mental health service, but these will report group data only and individual consumers and programs will not be identifiable.

(8)   Will the study benefit me?
The study may benefit you indirectly as a result of final recommendations made for improving physical health programs run by CMOs in NSW. However, we cannot guarantee that you will get any benefits from being involved in the study.

(9)   Can I tell other people about the study?
Yes

(10)   What if I require further information about the study or my involvement in it?
If you would like to know more at any stage, please feel free to contact the researcher Nicola Hancock at The University of Sydney via phone ((02) 93519379) or email nicola.hancock@sydney.edu.au.

(11)   What if I have a complaint or any concerns?
Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (phone); +61 2 8627 8177 (fax) or ro.humanethics@sydney.edu.au (email).

This information sheet is for you to keep

Enhancing the Physical Health of people living with Mental Illness   Page 2 of 2
Date

Appendix 6 - Example: Participant Information Flyer for Consumer Participation in Research

CONSUMER PARTICIPATION NEEDED

**Physical Health Programs
for people living with mental illness**

What works for you and what doesn't?

The Mental Health Coordinating Council and the University of Sydney are conducting a study to learn more about NSW community based physical health programs or activities that are being run for people living with mental health conditions.

We want your views about programs and activities aimed at improving the physical health of consumers.

What works, what could be different or better, what isn't available?

Are you willing to be interviewed by one of our researchers?
- The interview can be by telephone or face-to-face depending on what suits you and it will take about 30 - 45minutes.
- We will give you a $20 Movie voucher or an ITunes voucher as a small thank you for sharing your time and expertise.

If you interested in being involved:
Please contact Carla Cowles, Project Consultant on 0404 899 231 or email: carla@mhcc.org.au

We look forward to hearing from you.

This research project is being conducted by:

THE UNIVERSITY OF SYDNEY

mhcc
mental health coordinating council

Appendix 7 - Example: Recruitment Advertisement for Consumer Project Assistant

Please note: The following example advertisement has been provided by a CMO consulted for the development of this guide but de-identified for privacy concerns.

Consumer Project Assistant x 2
Hunter Region
Casual – an average of 10 hours per week for 12 months
(hours will vary according to project needs)

Clients of the service are encouraged to apply
Provides real potential for developing research skills

Our service is a leading not for profit organisation in the disability / employment services sector. We offer flexible fringe benefit packages with generous opportunities for training & career progression.

The successful applicants will be providing support to a research project for 12 months. The role will involve assisting with the preparation of & attendance at training sessions, team meetings and the development of surveys and questionnaires. Working with the Research team the successful applicants will also be assisting project clients to complete the Depression Anxiety Stress Scale (DASS) self-assessment, conducting consumer interview with participants and conducting a monthly review of job placements.

The successful applicants will receive training provided by the Research team on all key position responsibilities.

Essential requirements:

- Sound written & verbal communication skills, along with the confidence to interact with a wide variety of people. Some computer literacy is required.
- Due to the funding arrangements for this project, this position requires the successful applicants to have:
- personal experience of mental illness and/or
- drug & alcohol problems and;
- personal experience as a client within the Australian Government Employment Services System.(e.g. a client of this service)

At this service our core values are RESPECT, INTEGRITY, EXCELLENCE, COLLABORATION & RESILIENCE. Our employees live & breathe these values in their every day. Our people demonstrate a strong commitment to our vision of courageously promoting the value, potential & inclusion of all people in the life of their community.

A position description can be found on our website. To apply, please forward your resume by email or for more information please contact the Research Coordinator.

Applications close at 5pm on Friday 7th September 2012.

Appendix 8 - Example: Consumer Project Assistant Position Description

Please note: The following position description has been developed using an existing example provided by a CMO consulted for the development of this guide, but modified and de-identified for privacy concerns.

POSITION DESCRIPTION

Position Title: Consumer Project Assistant
Program: Research Project
Report to: Research Coordinator
Direct reports: Nil
Location: Sydney
Classification: Administrative Assistant

Position purpose:

This position seeks to engage consumers of the services with inclusive, recovery-oriented research, embedded within practice, and to ensure the research project benefits from the valuable experiential understanding The Consumer Project Assistant has of Mental Health/Drug & Alcohol problems.

Working relationships:

Internal:	External:
• Regional Manager • Business Manager • Team Leader • Research Team • Staff participating in the project • Staff on site	• Consumer of the service participating in the project

Key position responsibilities:

- Assist the Research Coordinator to prepare and attend research project training sessions.
- Assist the Research Coordinator to prepare and attend project team meetings.
- Assist project client participants to complete the Depression Anxiety Stress Scale (DASS) self-assessment on two occasions.
- Assist the Research Coordinator to develop questions for client participant interviews.
- Assist the Research Coordinator to develop questions for employee surveys.
- Conduct monthly review of site replacements.
- Conduct consumer interviews with project client participants.
- Complete all administration and tasks within timeframes set by the Research Team.
- Collaboratively contribute to the analysis of research data.
- Contribute to the reflexive project evaluation report and methodological journal article.
- Positively promote the organisation at all times.
- Apply ethical principles to carry out all duties and responsibilities.
- Other duties as agreed upon by the Research Team or as directed by the Research Coordinator.

Person Specification

Qualifications/educational profile:

- Records of school achievement or equivalent

Skills/attributes:

- Able to travel independently
- Sound written and verbal communication skills
- Confident to interact with a variety of people
- Ability to work within the organisation's core values and contribute to the organisation's goals/vision
- Ability to work under and adhere to the organisation's policies and procedures
- Ability to work proactively and productively as part of a team
- Ability to be flexible and undertake *ad hoc* duties.

Knowledge:

- Current knowledge or capacity to learn the areas below:
  - Computer literacy (e.g. Microsoft Office)
  - Relevant legislative provisions (e.g. Privacy Act & National Privacy Principles & Anti-Discrimination Act)
- Personal experience of mental illness and/or drug and alcohol problems
- Personal experience as a client within the Australian Government Employment Services System

Language:

Be prepared and willing to speak your native language with clients who have a preference to speak that language.

Agreement:

I have read and understand the above position description and agree to undertake the duties as outlined.

Employee Name: _____

Signature: _____ Date: _____

For and on behalf of the organisation:

Signature: _____ Date: _____