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Embedding a Recovery Orientation into Neuroscience Research: Involving People with a Lived Experience in Research Activity.

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Title

Embedding a Recovery Orientation into Neuroscience Research: Involving People with a Lived Experience in Research Activity.

Introduction

Traditionally, mental health consumer involvement in research activities has largely been as “subjects” (or, more correctly, participants) and their role has mostly been as the passive recipients of research activity. This participation has incorporated significant ethical protections; an area in which some consumer involvement has come to be expected – as university or hospital ethics committees usually include lay or community members. However, a critique of this very limited approach to consumer involvement is that it is fundamentally paternalistic – through defining consumer roles as participants (who no doubt need protection from unethical research processes) and recipients (those likely to benefit from research outputs). This approach does little to engage consumers in assisting to develop the rationale for research activity and more critically evaluating its potential value to those it is claiming to assist. Furthermore, adding the voice of one or two people, who are only able to influence research within the narrow frame of an ethics review, is not sufficient to meet contemporary expectations about the value of consumer participation (i).

It has now been over a decade since the National Health and Medical Research Council (NHMRC) in Australia published its statement on consumer and community participation in health and medical research. The NHMRC recommended that: “consumers should be given the opportunity to participate in decisions about what types of research should have priority; that they should be informed about the outcomes of the research they are involved in; and that researchers should involve the community in the research process by disseminating information about research” (ii).

While this may have been revolutionary at the time, further developments have suggested inviting consumers and carers into the centre of research activities and enabling their involvement at multiple stages and in multiple ways. This is well described by the work of TwoCan Associates (iii) in the UK and the McPin Foundation (iv) who have promulgated the benefits of consumer involvement in health research. The McPin Foundation (iv) and others argue that involving mental health service users more directly in research activity has the potential to transform mental health research, through improving the quality of research, the value of the findings, and the reduction of stigma.

Further, since some have argued that academic psychiatry has become less and less relevant, through an increasing focus on basic biological research that has yet to generate new treatments; this participation may also help to redress the balance in favour of a broader, more humanistic framework (v). A particular challenge for neuroscience research is how remote it may be from the community it serves. How does the scientist in the laboratory, undertaking specific and very technical research activity, identify benefit in community engagement and participation? We would argue that to do so enables numerous benefits, especially in establishing the direction and utility of the research. The scientist has an opportunity to benefit from an up-to-date perspective on the everyday problems faced by people with the condition or disease they are investigating. A contemporary connection with people living with mental ill health also enables more than just the sharing of information (vi). It has the potential to enable shared values and principles, such that scientists know what is meant by terms like “recovery”. It is notable, in this regard, that very early work on the cognitive neuroscience of delusional beliefs embraced recovery. Sacks, Carpenter and Strauss (vii) tracked improvements in consumers’ delusions in terms of changes in how they appraised the experience of being a participant in neuroscience research. In brief, during early engagement with experimental apparatus, the participants tended to incorporate the experience into their delusions. As their clinical status improved, so did their reality monitoring, passing through a phase of double awareness in which they endorsed delusional interpretations of the experiments, but nevertheless agreed to participate. Next, participants began to feel special and cared for and that they were helping and engaged. Finally, the tone became negative as the slow pace of research became evident, with participants becoming dismayed that data were not analysed rapidly enough and that the exercise had been a waste of time.

Embracing recovery in neuroscience research will involve an appreciation of how people with mental ill health view their own experience. Currently, neuroscience tends to define consumer experiences as problems to be fixed or as burdens to the community. The potential benefits to neuroscience research of embracing a recovery focus are clear. Gallagher (viii) described how we might use phenomenological analysis (appraising participant experiences) to “front load” research, guiding it toward more fruitful or relevant dimensions. This approach has recently been described with regards to auditory hallucinations (ix). Put simply, by listening to the people with the experiences, we turn our efforts to the parts of experience most salient to them and stand a better chance of delivering progress. Furthermore, by listening, rather than assuming, we gain new insights into the problems we devote our careers to. The double-awareness observation is one example of this. That delusions can be simultaneously endorsed and rejected has implications for models and theories that try to explain them. There are examples of theory and empirical research inspired by this observation (x, xi). Of course this point is relevant not just to neuroscience but to behavioural and clinical sciences also. In order for neuroscience and recovery to mutually enrich one another, a dialogue is necessary. Part of that dialogue involves defining recovery and incorporating that definition into the training of neuroscience researchers.

The Recovery Paradigm and mental health research

The concept of “recovery” has become a central influence on policy and practice in mental health service delivery around the globe. Its origins may be traced to increased empowerment of consumers supported by longitudinal research showing that many persons with serious mental health challenges experience significant improvements over time (xii). While there is the potential for contested views about what “recovery” means in this context, the authors draw on the work of Davidson (vi), Deegan (xiii), Anthony (xiv), Slade (xv) and others who describe recovery as a personal journey that emphasises hope, choice, empowerment and personal responsibility. People with lived experience lead contributing lives within and beyond the limits of impairments and this would include contribution to the neuroscience research enterprise. Consumers are recognised as experts through their lived experience and, as a result, their voice needs to be heard in relation to knowledge development as well as in relation to the use of this knowledge in their own care. Services that embrace a recovery orientation are committed to breaking down traditional power differentials and enabling a stronger focus on collaborative and person-centred care. This approach recognises that many people who have experienced serious mental ill health have also experienced stigma and social exclusion, as have many of their carers, thereby requiring every effort to be made to enable them to regain or maintain their citizenship in the community (xvi). In this way, recovery-oriented care is not about “doing to” or “for” the “other” – it is about consumer engagement, involvement, mentoring, guidance, and full participation. Hence its relevance is not only to policy, practice, and law – but also to mental health research activity.

In parallel, although carers do not experience recovery from mental ill health in the same way as consumers, they nonetheless indirectly experience some of the adverse impacts of living with mental health challenges through their close involvement with their loved one, and are therefore experts in their own right as well (xvii, xviii).

Recovery requires attention to process as much as to outcome. As suggested by Meehan et al. (xix):

The implication for service providers is that they should seek to leverage their services to promote the components of recovery highlighted by patients. This will require mental health staff to approach service provision with new thinking, refined skills, and more positive attitudes. Moving beyond a focus on psychopathology towards helping people foster self-efficacy and pursue their personal goals is seen as a key component of this transition (p: 178).

There is substantial potential for mental health research to contribute to this recovery agenda and this does not necessarily relate solely to research that focuses directly on personal recovery. A recovery orientation can be demonstrated through a readiness to work alongside those who have a lived experience and to value their contribution as transformative of the entire research enterprise.

Of relevance to research, efforts have been made to define the key ingredients for enabling consumer, family, and carer participation in mental health service evaluation and quality improvement. Oakley, Mailins, Riste, and Allan (xx) have identified seven fundamental components for ensuring consumer participation in health service evaluation and quality improvement. These include providing opportunities for consumer-driven activity, a cyclical process that ensures reporting back to services and consumers, and partnership.

An excellent model that encourages research to practice pathways has been developed by the University of St Louis in the U.S.A. It emphasises “Community Engaged Research” (xxi). The Centre for Community Engaged Research describes itself as a transformative initiative that aims to improve community engagement in research including; improving public trust, reducing the barriers for underrepresented populations in research, and improving the relevance, conduct and impact of research. This is particularly through bi-directional communication and education.

Staley (xxii) undertook an evaluation of service user involvement in studies adopted by the Mental Health Research Institute in the UK. The Institute supports more than 800 studies and trials in England, including neuroscience research. Staley (xxii) explains:

The term “involvement” in research is the term used to describe the active engagement of service users and carers in the design, delivery and dissemination of research – where service users and carers are partners in the research process and can influence what research is done and how it is done. This is the commonly accepted definition of involvement as described by INVOLVE (p: 8) (xxii).

Findings from Staley’s (xxii) review were that the most frequent way of involving consumers was as members of steering committees. In 20% of projects, consumers were involved as co-researchers, and in just under 20%, researchers were consulting consumers at the design phase and using a variety of approaches to engage consumers throughout projects. Consumers have contributed to the design of research questions but more often to practical strategies to improve recruitment and retention of participants.

Staley’s (xxii) review also provides a number of case studies that reflect how consumers could be involved in research, including steering committees and research management teams, and also as researchers and interviewers. There is an increasing expectation by funding bodies that consumers will be involved in the development of research proposals and research activity, including governance. The Victorian Mental Illness Research Fund (Australia) provides an example of a mental health-focused research fund that placed considerable emphasis on consumer and carer involvement as one of the criteria for assessing project proposals (xxiii).

Case Examples of the impact of improved engagement and participation

One of the most powerful examples of what can be achieved, in terms of consumer involvement in research, comes from the field of Human Immunodeficiency Virus (HIV). The Acquired Immunodeficiency Syndrome (AIDS) epidemic began to dominate medicine in the 1980s and it was characterised by two very powerful emotions, fear and stigma: fear because the cause was unclear, there was no effective treatment and mortality rates were high; and stigma because it mainly affected marginalised groups of people: gay men and drug users. People with AIDS started grassroots activism that became known as the People with AIDS (PWA) Self-Empowerment Movement and AIDS Coalition to Unleash Power (ACT-UP). A group of activists attended the 2nd National AIDS Forum and the National Lesbian and Gay Health Conference in Denver in 1983. Discussions at that forum led to what are now called The Denver Principles, probably a world first for consumer involvement in health care and research. The principles emphasise the importance of respect and taking a non-blaming approach (xxiv). The label “patient” is rejected because it implies passivity, helplessness and dependence upon the care of others. Instead: “(we are) People With AIDS”.

The Denver Principles and HIV activism resulted in people living with HIV being involved in the design of pharmaceutical trials. In 1988, following a series of demonstrations outside the headquarters of the U.S. Food and Drug Administration (FDA) in Maryland (xxv), the FDA responded and adopted the ACT-UP demands, which were:

- Shorten the drug approval process, as people were dying
- Stop carrying out placebo controlled trials, they are unethical and people are dying
- Include people from all affected populations such as women and Hispanics in clinical trials
- Medicare and private health insurers should pay for experimental therapies
- FDA must be supportive of community groups

Over the ensuing decade, the outlook for those living with HIV underwent a revolution with provision of a broad array of effective treatments. Mortality rates have plummeted and the HIV community is experiencing improved health and wellbeing.

What can be identified in this example is that community engagement and participation has extended beyond expectations that tend to focus very much on how the researchers will benefit, through, for example, increased fundraising and improved recruitment and more influential knowledge dissemination. Rather, the focus was not on what the community might do for the researchers but making the researchers much more accountable to the people living with the condition. “Living with” is most important here. Thus there is a shared interest in not only a “cure” and “prevention” but also a focus on recovery and living with, or living outside, the experience of mental ill health (vi). Research that focuses solely on cure holds little relevance for people who have no choice but to live their lives in the face of ongoing conditions for which we have yet to discover effective cures. Recognizing this fact, first with HIV and since with serious mental illnesses, broadens the research agenda significantly.

Another current relevant example is the Melbourne-based Australian Imaging, Biomarker & Lifestyle Flagship Study of Ageing (AIBL) (xxvi). This research seeks to discover which biomarkers, cognitive characteristics, and health and lifestyle factors determine subsequent development of symptomatic Alzheimer’s disease (AD). AIBL researchers have made considerable effort in valuing community engagement. They have reconsidered their use of language and use the term “volunteer” when referring to people who are contributing. The research volunteers, approximately 1,000 elderly people who have made a long term connection to the project by participating in physical and cognitive testing, are invited to annual social events where they have an opportunity to meet and hear from the lead researchers and interact with all the staff working on the project (including neuropsychologists, microbiologists and geriatricians), as well as share their experiences with each other. These events contribute to attempts to build an AIBL community, who are people working together to improve the understanding of AD and its prevention and treatment. The research team refer to having a moral and ethical obligation to follow up all the volunteers and have carefully developed ethics protocols that ensure participants are monitored and referred to their general practitioner or a specialist clinician if there are any unexpected abnormalities in their assessments (Joanne Robertson, 2014; personal communication). The research team also undertook research to further understand service utilisation and the experience of people involved in carer roles in the study (xxvii). As well as the general benefits for all staff and volunteers in building a community, AIBL has achieved very good retention, with 72% retention of the initial cohort of 1,112 as the project is nearing the end of the 5th round of assessments (72 month follow up). It is noteworthy that AIBL’s title is of a study of “ageing”, as opposed to a study of disease, with the implication being that ageing encompasses a broad range of influential variables and outcomes.

Current status of neuroscience research

In the discipline of psychiatry, research activity relates to understanding or treatment of illnesses that are variously called psychiatric disorders or mental health problems. Neuroscience research in the 21st century encompasses a broad church of research disciplines involved in studies of any aspect of the nervous system in health and disease. The disciplines include, but are not limited to the following: cognitive, computational, developmental, molecular and cellular, and social as well as neural engineering, neuroanatomy, neurochemistry and neuropharmacology, neuroimaging, neuroinformatics, neurolinguistics, neuropsychology, psychiatry, and psychology.

These neuroscience disciplines are highly technical in the language and experimental protocols that they employ, which can often make them difficult for members of the general community to understand. In addition, the brain and nervous system mechanisms that neuroscience researchers are attempting to understand can appear far removed from any apparent relevance to clinical practice and the needs of individuals with lived experiences and their family and carers. These issues may pose potential barriers to involving consumers and carers in neuroscience research activity. In order to embed consumers and carers in neuroscience research activity we need to acknowledge and address the following areas of potential difficulty:

1. Differing ideas about what “causes” psychiatric disorders
2. Differences in understanding of language used in neuroscience
3. Differences in perceptions of the value of the expertise of consumers and carers
4. Differences in priorities, areas of emphasis and experimental practices
5. The time taken from neuroscience laboratory research to practical improvements and improved quality of life resulting in challenges to demonstrating the practical applications of neuroscience research
6. Barriers to collaborative research due to funding limitations.

These challenges are addressed below, with proposals as to how they may be overcome.

The “causes” of psychiatric disorders

In order to develop a successful partnership that embraces consumer and carer participation in neuroscience research we need some agreement on the “causes” of psychiatric illnesses. At the end of the 19th century and beginning of the 20th century the prevalent view was that a disorder such as schizophrenia had biological causes. The early years of the 20th century saw the rise of psychoanalytic theory. This new model of understanding the mind had significant consequences for how psychiatric illness was viewed, as psychosocial disorders of the mind whose symptoms were presumed to have arisen as a result of ongoing intrapsychic conflicts and emotional problems in childhood.

Theories about the biological roots of psychiatric illnesses began to be resurrected in the 1950s, with the introduction of antipsychotic medications. This biomedical approach then achieved considerable status over the next few decades.

However, it appears that our current best understanding of mental ill health is that it incorporates a complex interaction of biological, psychological, and social/environmental factors. This complex understanding is by no means accepted by all, whether researchers or consumers, and differing (and partial) views of these complexities therefore lead to differing priorities for research.

As well as the complexity of causality there has recently been renewed interest in the role of trauma in severe mental illness. Many consumers have identified dealing with earlier experiences of emotional, physical, or sexual trauma as an important issue for them in their recovery, suggesting that, even if trauma is not a “cause” there is strong evidence to support dealing with the impact of trauma as being an important component of healing or recovery. Trauma is only one of a number of social factors such as migration, experiences of discrimination, chronic stress, and lack of social support that influence the development of mental ill health (xxviii). However, these social factors have been relatively neglected in research, perhaps in part because of the relative lack of consumer and carer involvement in research. Their increased involvement could assist with better integration of social, psychological, and biological perspectives (xxix).

Recommendation: For the neuroscience and recovery communities to commence a dialogue about factors that underlie, precipitate, perpetuate, or reduce mental health challenges.

Recommendation: For neuroscience researchers to endeavour to further understand the links between persons’ brains, their mental health, and their social environments.

Understanding the Language Used in Neuroscience and its Purpose

Even if we achieve general consensus on “causes”, partnering between researchers and consumers is complicated by the technical language of neuroscience research. There needs to be a common language to assist

in the translation of research findings into clinical practice. A general framework for doing this with treatment-related research is becoming established (xxx). Important to this is the training and education of neuroscientists (i) that emphasises the critical need to explain the research simply and to stress why they think that it would be important to carry out these experiments and what would be the hoped-for benefits. Such training could also include consumer involvement, as has been achieved in psychiatry training (xxx), and focus on establishing the relevance of people's experience to research questions and the value of research findings.

More broadly, the use of language, and especially professional terminology (or jargon), has been a point of contention between researchers and clinicians on the one hand and persons with a lived experience of mental ill health and their loved ones on the other. Recovery encourages a move away from the problem-saturated language that often accompanies clinical research. Despite undoubted goodwill, when there is an emphasis on reducing the "burden" of mental illness to the community as a fundamental purpose of the research endeavour, then there is a subsequent, although inadvertent, message that we can fix, rectify, or eliminate this "burden". When applying a personal recovery lens to this dialogue, the question is then raised about how someone with a diagnosis of schizophrenia, bipolar disorder, epilepsy, or Alzheimer's disease feels when what they are facing is constructed in this manner. So that while there may be much genuine concern being expressed towards those who are "afflicted," the language seems out of step with a new agenda that conveys the alternative messages of hope, empowerment, and citizenship.

The recovery movement has endorsed, as an alternative, the use of "person-first" language, which emphasizes the person's humanity first and foremost and accords the mental health condition secondary status (e.g., a "person with schizophrenia"). The language of recovery also emphasizes a focus on the individual's strengths rather than describing solely their perceived deficits.

A further change in language is that clinicians are moving from the concept of caring *for* patients to working collaboratively *with* individuals experiencing mental ill health. This is in line with the British Government's initiative on "The Expert Patient", which defines two experts in the relationship, one through training and one through experience (xxxii). Researchers could benefit from greater exposure to this concept.

Recommendation: The education of neuroscience researchers needs to include training in communication and use of respectful and non-pejorative language.

The value of the expertise of consumers and carers

Becoming an expert in neuroscience is a significant achievement that carries considerable status in the community. However, the current training does not necessarily include interaction with consumers or carers and needs to navigate and mediate the significant stigma experienced by consumers and carers (xxxiii). It has been suggested that:

...without a system designed to elicit, organize, and amplify the voice of the patient, the psychiatrist can easily miss information that would make the clinical decisions more informed and relevant (p:436) (xxxiv).

This advice drawn from the practice arena is equally relevant to neuroscience research. Closer collaboration with consumers and carers, as demonstrated in recovery oriented practice, enables consumer and carer perspectives to assist to set the agenda for research so that it is more likely to target and benefit the outcomes that are most highly valued.

Through dialogue, researchers could consider the challenges that people with mental ill health experience in their daily life; such as obtaining employment or organising finances, looking after their home or relationships. These insights could assist researchers in refocusing their research aims to, for example, understand the brain resources required and strategies for improving how consumers go about these daily activities, including environmental adaptations, as they are dependent on the individual's adequate cognitive, emotional and behavioural skills within a particular context. A good example is cognitive remediation. Cognitive skills may be impaired in the context of serious mental ill health and thereby significantly impact on the person's ability to maintain employment. Cognitive remediation techniques can be used to improve cognitive skills as well as to develop compensatory strategies and workplace adaptations (xxxv). Increasing application of such research is likely to result in positive outcomes for consumers, carers, and the community at large.

Recommendation: Neuroscience research careers should include exposure to recovery-oriented practice and its model of partnering with consumers and carers.

Differences in priorities, areas of emphasis, and experimental practices.

Research in the health domain has traditionally been hierarchical, with strong opinions about what constitutes "reliable evidence". This promotes a positivist, primarily objective, and inevitably distant stance for the "good"

researcher. However, as we discussed regarding the changes effected by AIDS activism, objectivity has substantial limitations. Improving the participation of consumers and carers will impact on research design because of the potential to make a shift from a purely “objective” stance to incorporate methods which embrace the “subjective” experience of people involved. There is now increasing respect for subjectivity obtained through qualitative research methods (xxxvi) and value seen in mixed method approaches that enable triangulation in research, potentially enriching and verifying findings through combining multiple methods of inquiry and validation (xxxvii). These methods offer greater opportunity for consumer involvement (i).

There is increasing interest in consumer and carer-led research, whereby the questions that are focused on are the ones consumers and carers themselves identify as their priorities and the methods of investigation include them. Davidson et al. (xxxviii) suggest that: *“These methods require a collaborative approach to involving people with experience of the phenomena of focus to participate as partners throughout all stages of a study”* (p. 101-102).

Recommendation: Neuroscience research training should embrace interaction with carers and consumers to understand their lived experience, shared research priorities, and preferred methodologies and use this to inform the research agenda.

The translation and knowledge dissemination of neuroscience research

A potential challenge in neuroscience is related to its remoteness from everyday clinical practice. It has even been argued that biological psychiatry has become disconnected from the essential humanity of psychiatric research (v). There is a pressing need for neuroscience researchers to understand more about the people involved who potentially may benefit from their research. Blue-sky research is a significant aspect of research activity whether it occurs within universities or industry. It is generally considered to be research in which the “real world” applications are not immediately apparent but can ultimately do great good for society. For example, in the 18th century Michael Faraday discovered that he could generate an electrical current in copper wire by exposing it to a moving magnetic field, a discovery whose application was not immediately apparent but now forms one of the primary methods for the generation of electricity in power stations across the world and has revolutionised our quality of life. More blue-sky research activity in neuroscience should be funded and designed to take into consideration how researchers can more effectively communicate the practical applications of their research as well as design studies that demonstrate these. Understanding more about the brain and its reaction to trauma is a case example of research that has been transformative in developing more sophisticated understanding and interventions in the area of early childhood development. Materials have been developed to make the findings of highly technical research accessible to parents and mental health professionals (xxxix). The AIBL study provides another example of these efforts (27). The point here is that there is potential for accessible knowledge translation activities even when current findings may be remote from the everyday if they can be shown to represent building blocks towards generating knowledge that is relevant to all stakeholders.

Recommendation: Neuroscience researchers consider how they can more effectively communicate the practical applications of their research.

Barriers to collaborative research due to funding limitations

Collaboration with consumers and carers at all stages of the research effort has the potential to counteract the uncertainty and reluctance many consumers experience towards participation in research, for example, by developing good processes for feedback of research findings (xl). Sensitive feedback can also foster hope and empowerment. However, collaboration requires time and effort as well as expertise, with resulting implications for research funding and infrastructure as well as organisational processes such as employment policies xl, i.

Recommendation: Research funding bodies and institutions should develop policies and procedures that support and reward meaningful consumer involvement.

Summary

In summary, we suggest the following initial guidance for how neuroscience can be enriched through increased community and consumer participation:

- Implementing existing standards needs to be monitored and developing guidance for future policy and action needs to be established, endorsed, and then followed. It is most likely that the broader institution or university within which neuroscience programs exist is likely to have some overall strategy already. The challenge will be to make that more locally applicable and there may be opportunities to establish a community advisory group who can assist in this process. Senior members of staff need to be fully engaged in this process to maximise success.

- Often what is plain language in a university or hospital environment does not match what is accessible to those outside. Guidance about how to improve the accessibility of documents and other forms of communication should be available and demonstrate literacy levels of those that might be required to understand the information. This type of activity can be very enlightening. Once again, getting advice from consumers and carers about how to use more accessible and inoffensive language may be required.
- There are opportunities for centres, schools, or particular projects to establish steering or advisory committees that may have roles that range from policy and procedure development to short-term specific consultation around individual tasks. We are not suggesting a tokenistic inclusion of consumers or carers onto established committees but rather creating new opportunities for meaningful involvement or changing committee structures such that the voices of consumers and carers can be more readily heard and respected.
- Participants (or volunteers) and potentially their carers and other supporters should be involved from the start of research and throughout the research activity (even though it may be less obvious to do so because, for bench science, participants are not always required or may not remain involved once they have provided scans or samples). It is suggested that this will improve the quality and ethics of research, the values of the outputs, and reduce stigma.
- Ensure that researchers consider and communicate to consumers how research impacts on people's recovery and their day-to-day life, even when the research is laboratory-based and seems remote.
- Involve consumers and carers in providing training and ongoing staff development activities for neuroscience researchers.
- Seek help and participation from knowledgeable consumers to decipher the language and the benefits of neuroscience research for other consumers, especially to support knowledge dissemination activities.

Conclusion

It is important for even the most rigorous, positivist scientist to consider the value and challenge of engaging community members, who are the potential beneficiaries of their research endeavour, in their research activity from beginning to end. This will be enabled by improved sensitivity and respect, for example through recognising the importance of having a shared language that moves away from a problem-saturated view of the "burden" of mental ill health to a shared language about hope and possibility. Such involvement should not be tokenistic or due solely to the requirement of funders. To achieve benefit from consumer and carer involvement, the value of having community/consumer and carer participation and engagement throughout the research process to support the research to practice – and indeed recovery – pathway needs to be considered, and investigated itself, so that attention is given to good processes as well as shared outcomes. There is increasing evidence that consumer engagement in research is to everyone's benefit: research leaders, the person in the laboratory or doing the fieldwork and data collection, service providers, and – most importantly – the quality and relevance of the research itself and the contributions it can make to health, wellbeing, and the quality of life of persons affected by these conditions.

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