The National Mental Health Commission's

Consumer and carer engagement: a practical guide

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Introduction

This guide is intended to provide a clear framework and set of principles for best practice in consumer and carer engagement and participation. It is hoped that this guide will be read and used by mental health consumers and carers and by people working within the mental health system at all levels.

As a good practice guide, it also aims to give practical advice on how to act on principles and associated values. For this reason, each principle is outlined at a high level, and illustrated with an 'applied' example. Since examples cannot address every possible scenario, it is the intention that each reader adapts and applies the principles to their unique circumstances.

This guide is the result of the extensive work done for the Commission's 2017 *Engage and Participate in Mental Health* project. It attempts to capture the core values and principles expressed by participants in the project who shared what engagement and participation mean to them.

The creation of this guide is an example of co-production in practice. Mental health consumers and carers contributed their views on engagement and participation in a series of activities designed to engage a wide range of people. Lived experience researchers and consultants participated in running the project in partnership with a Lived Experience Steering Group. A lived experience researcher wrote the guide, and incorporated feedback from a final round of consultation with the sector.

A note on language

Throughout this guide, we have used terms including engagement, participation, lived experience, co-design, and co-production. Not all of these have commonly agreed definitions, and not all readers will identify with the use of labels in the same way as they are presented here. For clarity, we propose the following definitions.

Carers are people, often family members, who provide, or have provided in the past, ongoing personal care, support, advocacy and/or assistance to a person with mental illness.

Co-design is a process of identifying and creating an entirely new plan, initiative or service, that is successful, sustainable and cost-effective, and reflects the needs, expectations and requirements of all those who participated in, and will be affected by the plan, initiative or service.[1] Co-design processes should include people who are directly affected by an issue, but can also include other stakeholders and the general community.

Consumers are people who identify as having a living or lived experience of mental illness, irrespective of whether they have a formal diagnosis, have accessed services and/or received treatment. This includes people who describe themselves as a 'peer', 'survivor' and 'expert by experience'.

Co-production is a process of implementing, delivering and evaluating supports, systems and services, where consumers, carers and professionals work in an equal and reciprocal relationship, with shared power and responsibilities, to achieve positive change and improved outcomes.[2]

Engagement refers to methods and actions taken by organisations to involve the public, consumers and carers generally but also allows for decision-making and co-design and co-production processes to be undertaken.

Mental health is a state of wellbeing in which the individual realises their own abilities and potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to their community.

Mental illness refers to a wide spectrum of diagnosable conditions that affects a person feels, thinks, behaves, and interacts with other people. Mental illness can vary in both severity and duration. In this report 'mental illness' is used in place of 'mental health problem', 'mental health disorder', 'mental ill-health', 'mental health issue' and 'mental health disease'.

Participation in this document refers to the practice of involving people directly, as equal partners, and with safety and equity.

Recovery is personal and means different things to different people. Personal recovery is defined within the National Framework for Recovery-Oriented Mental Health Services as 'being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues'.[3]

Why engagement and participation matters

Engagement and participation are not merely ideals for interactions between consumers and carers and those who work within the mental health system. They are essential approaches that honour human rights and represent genuine partnerships to deliver the best outcomes at individual, service, organisation and system level. The World Health Organization has recognised that the empowerment of mental health consumers and carers 'leads to tangible biological, psychological and societal benefits'.[4]

Mental health consumers and carers hold vital knowledge about what is needed from the system, both for individual care and at broader levels. Engagement of consumers and carers in recovery focussed services can lead to healing of historical traumatisation within services and promote cultural change.

Full and meaningful participation by mental health consumers and carers can support more effective and efficient services, delivering benefits for clinicians, policy makers and funders, as well as for consumers and carers. Engaging with people who are most directly affected by mental health services, policies and programs is essential to understanding whether these different components of the system are achieving their aims and opportunities for continuous improvement.

Engagement and participation is also vital to ensuring the safety and dignity of mental health consumers and carers and achieving a person-centred approach to care. It supports consumers and carers to exercise choice and control, and influence the decisions that affect their lives. Engagement and participation can also foster emotional wellbeing and self-confidence, and can be a powerful way to break down stigma and prevent discrimination against people living with mental illness.

The right to actively participate in decisions about care and the mental health system is embedded in policy.[5] However, doing engagement because a policy says 'we have to' doesn't capture its true spirit or encourage buy-in from people in professional or managerial roles. Effective engagement and participation is about shared control and decision-making within a partnership, where all parties are committed to that sharing. It is therefore important that all parties understand and genuinely value the role of engagement and participation in effective mental health service delivery and policy design.

It was clear from the voices of participants in the *Engage and Participate in Mental Health* project that we need to move away from a culture of 'doing to' to one of 'working with' consumers and carers. As described throughout this guide, there are many ways in which people can participate, and great value that can result from these activities.

Perhaps the most value is achieved when there is a shift within the system to a genuinely person-centred, recovery focussed model. When this occurs people receive the care and support they need to lead contributing lives.

Overview of this guide

This guide sets out a step-by-step process for planning, delivering and evaluating engagement and participation activities.

Step 1 focuses on **identifying ways to engage**. It provides an overview of the different levels of engagement and the types of activities that fall within each level. It also offers guidance on matching these activities to particular tasks, to ensure that engagement opportunities are realistic in the circumstances and relevant to the task.

Step 2 outlines a series of **best practice principles** that should inform the planning and delivery of engagement and participation activities at all levels. The principles outlined in this guide include the following:

- Consumer and carer engagement and participation should be seen as *routine practice*, with organisations moving towards greater involvement of consumers and carers wherever possible and appropriate
- The *skills and knowledge* required for effective engagement should be *recognised* as an important form of expertise, and consumers and carers should be supported to *develop* this expertise
- *Leaders* within both organisations and the lived experience community should work to create an *inclusive organisational culture* that strongly supports consumer and carer engagement
- Specific *resources* (time, money and people) should be dedicated to consumer and carer engagement activities
- Organisations should work to create a *safe environment* for engagement and participation in which everyone receives the support they need for an activity
- Organisations should regularly *evaluate* engagement and participation activities, and use the results of evaluations to *improve* future activities.

Step 3 provides detailed guidance on **planning** engagement and participation activities. It describes a range of different activities that can be used to facilitate consumer and carer engagement in the design, governance, delivery and evaluation of services, programs and policies; and explains how these activities can work in practice and at various levels.

Step 4 sets out some basic guidance on **evaluating** participation and engagement activities, and using the results of these evaluations to **improve** future activities.

This step-by-step process aims to provide a clear framework for planning, delivering and evaluating consumer and carer engagement and participation activities. However, it is not intended to be exhaustive or prescriptive. Readers are encouraged to adapt and build on the ideas set out in this guide, using best practice principles to explore different ways of promoting engagement and participation.

Step 1: Identify ways to engage

A new way of working

Historically, people living with mental illness and those who support them had little (if any) say in the decisions that affected them. While things have improved over time, consumer and carer engagement and participation is still a new area for many organisations. Engaging effectively with consumers and carers requires a new way of working that recognises the value of lived experience perspectives and acknowledges consumers and carers as equal partners.

Meaningful engagement and participation is not possible unless organisations create environments in which people feel confident that they have the right, responsibility and organisational support to be involved in decision-making and that their views and perspectives will be respected and implemented. Effective engagement requires acceptance, kindness, understanding and compassion, things which cannot always be neatly captured in a policy or framework. It is about building the organisational culture and fostering the mindset needed to support authentic and meaningful dialogue and collaboration.

Creating the right environment is a key aspect of organisational readiness for consumer and carer engagement and participation, and therefore should be addressed at the outset. However, it is also an ongoing process that organisations and consumers and carers can work on together, as engagement and participation shifts from being a new way of working to being part of routine practice.

Spectrum of engagement and participation

A second factor to consider is the level of engagement and participation that can realistically be offered in the context of specific activities. The different approaches can be viewed as a spectrum from 'no engagement' through to 'citizen led' engagement. Figure 1 below illustrates this spectrum, outlining the increase in decision making and control for consumers and carers at each stage. The spectrum was developed for the Western Australia Mental Health Commission's *Working Together: Mental Health and Other Drug Engagement Framework 2018-2025*.[6]

When deciding where on the spectrum an opportunity falls, it is important to match the level of engagement and participation to the task. Include the nature of the opportunity, the organisation's capacity and experience in engagement, and whether the time commitment involved is proportionate to the scale of the task.

Higher on the spectrum is not necessarily better if it is not appropriate for the task or if those involved aren't equipped to manage that level of participation. At the same time, it is generally good practice to aim for the highest level of engagement and participation that is possible in the circumstances. There will always be constraints, but try to think about ways you could overcome them rather than simply offering fewer or lower-level opportunities for engagement. There may be a need to explore different ways of doing things (such as arranging activities at a different time or place) or look beyond existing networks so that you can find the right people for the role.

As an organisation, it is important to be honest and upfront about the level of engagement that is being offered to consumers and carers. Clear communication and use of commonly understood language are integral to meeting the expectations of all involved. For example, it is important to understand what is and isn't 'co-production' and ensure that only genuine instances of co-production are labelled as such and offered under this label. The extent to which control and authority can be shared depends on the particular process and relevant activities that are being undertaken.

Figure 1. Engagement spectrum[7]

An important part of measuring progress along the spectrum within a community or organisation is looking at the current versus best practice. As with all types of evaluation and quality improvement, this work is not an end goal but an ongoing process. The remainder of this guide will help to unpack the things you need to think about for evaluation and ways you can approach this process even before activities commence.

Knowing where to start can be a challenge. It can be especially difficult for consumers or carers who may have experienced exclusion or who do not know where opportunities are, how to create them or why they would want to engage at all. Overcoming these obstacles is one of the biggest challenges faced by organisations wanting to improve their engagement and provide participation opportunities for consumers and carers.

A useful starting point is to think about engagement and participation as a range of different activities that can suit different purposes. There is no 'right' activity for everyone; it will vary depending on who is seeking to participate. At the individual level people participate and want to be engaged as part of their right to make decisions about their own care and recovery. At the service, organisation or system level people seek engagement opportunities to participate in making a difference for consumers and carers and contribute to a more inclusive community.

The below matrix is a tool to help organisations, consumers and carers identify opportunities to engage and participate. The matrix represents the national mental health system as a whole. The columns guide likely starting points for different stakeholders while the rows refer to different processes. For example, policy makers may look to the system-level column for activities to engage consumers and carers in the policy-making process. However, the entire matrix also applies *within* organisations, so in this case these policy makers should also consider activities from other sections of the matrix, such as co-evaluation.

Matrix of engagement and participation activities[8]

	A. Individual	B. Service or program	C. Organisation	D. Policy or system
1. Design	Shared decision-making in treatment and care planning	Co-design of services and programs	Steering committee, advisory groups, representatives in working groups	Co-design of policies and strategies
2. Governance		Reference groups Steering committees	Representatives on committees consumer/carer-led committees, equal representation in decision-making bodies	
3. Delivery	Self-help programs and tools	Peer workers Peer-led programs	Consumer-led and carer -led training for staff	Regular reviews of policy and its implementation by consumer and carer representatives
4. Evaluation	Experience surveys	Consumer and carer feedback Co-evaluation	Interviews with consumer and carer representatives Regular audit of engagement activities	

BEST PRACTICE APPLIED

Start by identifying the level at which you wish to enhance engagement and look at the column relating to this level. In each column, activities are given for four key processes. Take note of these activities and use them to direct your reading in Step 3 of this guide, which provides more detail and examples of the activities in the matrix. This list of examples is in no way exhaustive and is not meant to limit the range of opportunities to engage and participate. We encourage organisations, consumers and carers to be creative about how they approach these aims, and adapt principles and examples to their circumstances.

The Commission also has a resource database (available at http://mentalhealthcommission.gov.au/our-work/consumer-and-carer-engagement-project.aspx) which provides details of a broad range of frameworks and tools to help get started.

BEST PRACTICE APPLIED

There are a range of factors to consider when deciding which level of engagement and participation is best suited to the task at hand. For organisations, things you might like to consider include:

– the degree to which your task is open to change. If you are limited by how much you can alter things in response to input, look at the middle levels of the spectrum

– the existing levels of experience of people in your organisation have working in partnership with consumers and carers. Consider what other training, skill development or exposure to lived experience principles and work may be necessary to develop these skills, so that genuine co-design and co-production activities may be undertaken.

– the amount of time you have to deliver the task. A common observation by consumers and carers is that they are not given sufficient time to properly consider and contribute, reducing possible co-design to a truncated consultation.

– guidance from consumers and carers on the level of engagement and participation they consider necessary for your task. Seek advice from established leaders and consumer and carer-led organisations, as well as people in your local community and those who use your services.

For consumers and carers, think about the types of engagement and participation that suit your circumstances, skills and capacity. If you can't find opportunities that are suitable for you, reach out to organisations to discuss ways they could make their opportunities more accessible or support you to engage at the level you wish. If you think an organisation should be aiming for a higher level of engagement and participation, take the opportunity to provide advice on how they could achieve this.

Step 2: Consider best practice principles

Six key best practice principles for engagement and participation were identified in the course of developing this Guide.

a) Conceptualising Participation and Engagement as routine practice (framing your approach)
b) Skills and knowledge are recognised and developed (capacity building)
c) Leadership culture
d) Dedicated resourcing
e) Respect, safety and support
f) Evaluation and quality improvement

Each of these is explored in further detail in the following pages.

a) Conceptualising Participation and Engagement as routine practice

The core of best practice in engagement and participation is framing – or perhaps reframing – your approach. This includes seeing participation and engagement as routine practice, and moving towards greater involvement of consumers and carers wherever possible and appropriate. A common description of this shift is the difference between 'doing to' and 'working with'. This involves a necessary change in the balance of power between organisations and mental health consumers and carers; acknowledging that historic power imbalances have, and continue to exist in the provision of mental health services and that active attention is critical to achieving equality.

Co-design and co-production are terms now commonly used in policy and organisations. However, applying a label is not enough. At the heart of these terms is a redistribution of control and decision-making authority. Genuine sharing of planning and delivery of policies, services, research and programs is only possible with a shift in frame.

It is essential to consider practical challenges and barriers when planning engagement and participation activities. Some issues are unlikely to be entirely overcome as not everyone wants to engage and participate in the same way. However, there are also some easily addressed or avoided practical challenges. Looking for these issues and working to minimise or remove them can increase diversity in the pool of consumers and carers who are able to engage.

A list of factors that commonly present challenges for successful engagement and participation are below.

Organisational culture: Beliefs and attitudes about consumers and carers, and the perceived value of their engagement and participation, can undermine or enable engagement and participation. If consumers and carers encounter negative attitudes, stereotypes, an 'us-an-them' mentality or tokenism, it will not be possible to achieve respectful dialogue or build genuine partnerships. On the other hand, an organisational culture that respects consumers and carers as equal partners, is free from stigma and discrimination and takes lived experience perspectives seriously, creates an enabling environment for effective engagement and participation.

Language: This is one of the most powerful ways that people are excluded. Language differences can be due to cultural background (e.g. non-English speaking), education or literacy levels. Take care to avoid the use of jargon, acronyms or language that place labels on consumers (e.g. schizophrenics).

Timing: The timing for engagement and participation activities should meet people's needs around the rest of their commitments. For organisations, it may seem best to schedule things in business hours when staff normally work, or providing longer periods of time for people to prepare for or engage in an activity. However, this often does not allow consumers and carers who also work to contribute. Some consumers and carers may therefore prefer out-of-hours opportunities, but this requires flexibility and in some cases a willingness to work overtime from staff.

Access: Ease of access also plays a large and varied role in who participates. People who have a disability may need extra support, such as access to a hearing loop for the hearing impaired. Distance or location may be challenging

for people who don't have their own transport. Using plain English is important. Translating into other languages or formats may be required for people from diverse cultural and linguistic backgrounds. Online activities require reliable internet access and a moderate level of tech savvy. By offering alternatives and options where possible, accessibly can be increased rather than narrowed.

Expectations: Shared expectations are crucial to a good experience. Often we assume that everyone expects the same from engagement and participation but this may not be the case. Both the process and the outcomes need a shared understanding for success. The group should also consider that success must be bound to the project's current political, structural, economic and organisational cultural contexts. Examples of areas that are important to discuss early include clearly identifying the reason for engaging, where decision-making lies, the extent to which a document or process can be changed in response to feedback, and how much time and input is expected.

Diversity: A common criticism of engagement and participation is that it does not represent a wide enough range of experience of mental health issues and mental illness. It can be tempting to focus on engaging with people who you already know, whose views are similar to your own or with whom you find it easy to 'get along'. However, part of the point of engagement and participation is to hear from people who can offer alternative perspectives, challenge assumptions and approach tasks from different angles. Engaging with people who have a diversity of views and experiences is an important part of addressing problems comprehensively.

BEST PRACTICE APPLIED

Start by critically reflecting on how you frame engagement and participation. This applies whether you are an organisation seeking to co-create knowledge or services, or a consumer or carer seeking to participate. Look for areas where a power imbalance shows (e.g. language). Commit to addressing these issues by working with all involved. Reflect on who might be included or excluded by engagement and participation activities. If you are an organisation seeking to engage with consumers and carers, plan who you would like to engage with and think about how you can create a supportive environment that will enable their participation. . If you are a consumer or carer who needs some support to participate, don't be afraid to ask. Pay attention to the language you use and find ways to speak the same language when together. Document and agree on expectations.

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b) Skills and knowledge are recognised and developed

Good communication, creative thinking, problem-solving, the ability to adapt to people's needs and a commitment to change are among the skills needed for successful engagement and participation. Everyone, including staff and mental health consumers and carers engaged to contribute, should feel welcome and at ease to share their expertise. However, the skills it takes to navigate these processes may not come naturally to everyone, and in some cases, may need to be fostered. For success, everyone involved in the process needs to be inclusive and committed to recognising and developing skills and knowledge. It is not enough to just give people a seat at the table.

Organisations can create an environment that is receptive to expertise and supportive of people with the right skills to engage and participate. Look for people – both on staff and externally – who have some skills for good engagement and leadership and ask them what they need to gain others. Some skills for engagement (such as leadership and advocacy) are often cast as something that people naturally do or do not have the skills to do. Rather than a black and white approach, the need to up-skill people for leadership roles should be seen as a development opportunity that can be offered.

At the same time, consumers and carers should not have to develop 'special' skills in order to have a say in decisions that affect them. People should not be excluded from *all* opportunities to engage and participate on the basis that they do not yet have the skills needed for a higher-level advocacy or leadership role. Try to provide a variety of opportunities for engagement and participation, so that consumers and carers can choose to engage in ways that suit their skills and knowledge.

It is also important to remember that the right skills and knowledge are needed by everyone involved. Organisations should consider whether their staff team has the skills and knowledge needed to engage effectively with consumers and carers. Good engagement requires people who are good communicators, empathetic, solution focussed and organised. Some staff may already have some these skills and attributes; others may not and could benefit from training. Providing all staff the opportunity to improve and expand their engagement skills as part of their professional development benefits the individual and the organisation.

For mental health consumers and carers, communication and engagement skills can bring confidence in your own expertise and what it contributes to the conversation. Doing so improves your chances of being heard and triggering action as a result. Look for activities where you have at least some of the skills needed, and also identify skills you would like to develop to strengthen your capacity for participation as a leader and a contributor. Ask for support from staff and organisation, for opportunities to develop these skills through professional development and training.

BEST PRACTICE APPLIED

For both organisations and consumers and carers, the skills needed for an inclusive and committed process might not all be present in the people involved in engagement. Identify the skills required and the skill sets of everyone involved in an activity before getting started to understand possible gaps and opportunities for mentoring and education. Choose activities that allow people to use and extend existing skills, and don't assume that certain types of knowledge (e.g. scientific and clinical facts) are limited to only one type of person (e.g. practitioners). Provide, or ask for, supports where skills or knowledge might be limited.

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c) Leadership culture

A key enabler of successful engagement and participation is leadership. To create an inclusive organisational culture, this needs to come from all people and at all levels of a system but particularly from those at the top. This includes leaders from within the lived experience community and from the highest levels of organisations – board chairs, CEOs, senior clinicians, senior policy makers and research leads.

Strong leaders must work together to champion engagement and participation for mental health consumers and carers. They identify opportunities, support activities and monitor the processes and outcomes. Responsibility for carrying out engagement and participation activities should be shared across your organisation, but it is the leaders who are accountable for setting the culture and modelling best practice.

Developing future leaders is central to strong ongoing direction in engagement and participation. This means adopting staff development practices that encourage collaboration with consumers and carers as part of standard practice. These development activities are themselves a chance to build participation into your organisation, e.g. with education and training delivered by consumers and carers.

Staff members who are not (yet) in leadership positions can also demonstrate leadership by helping to build an organisational culture that supports consumer and carer engagement and participation. This may include, for example, requesting professional development opportunities that focus on consumer and carer engagement; incorporating consumer and carer engagement and participation activities into workplans; discussing the importance of lived experience perspectives with colleagues; and speaking out against negative attitudes in the workplace.

Mental health consumer and carer leaders also have a key role to play to develop an inclusive culture. This may include actively advocating for consumer and carer participation in organisations or at governance levels where it is not yet established. This may include encouraging organisations to hire people with lived experience as part of their leadership teams. You can also co-deliver staff development activities and leadership training for future organisational leaders. This helps to build cultural change and capacity for successful future collaboration.

Existing leaders usually have both the reputation and relationships needed to engage with organisation leaders for change. However, in order to maintain momentum, it's also important for leaders to identify and mentor consumer and carer leaders of the future. Particularly in times of strong reform, demand for consumer and carer

input can far exceed the capacity of current leaders. Look out for mental health consumers and carers who might be interested in getting involved and help them out such as with advice and sharing opportunities.

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BEST PRACTICE APPLIED

If you are an organisation, make a point of looking for leaders throughout your organisation and your community. Actively seek out those with the skills or desire to develop a strong culture of engagement and participation. Equip your leaders with frameworks and tools to monitor progress and continually improve practice. If you're a consumer or carer leader, be a champion for new chances to contribute and to mentor upcoming leaders and those seeking to engage with mental health consumers and carers.

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d) Dedicated Resourcing

One of the biggest hazards for engagement and participation is a lack of resourcing. This includes time, money and people. Ideally, planning the engagement and participation should itself be a joint activity, with consumers and carers engaged early in processes to support a genuine process of co-design.

Genuine co-production is generally more time-consuming than top down decision-making and requires careful strategic planning including human resource management. There also needs to be enough time for everyone to think about and discuss issues. Participation often becomes tokenistic when timeline pressures take priority over time to consider questions and issues deeply. Planning activities well in advance – such as through developing a formal annual engagement strategy – can help to avoid this pitfall.

Likewise, proper engagement and participation needs funding. Including a dedicated budget in annual engagement strategies can help to ensure that adequate funding is available. At a minimum, mental health consumers and carers should not be out-of-pocket when participating. Covering costs such as travel, printing and carer support allows a wider range of people to participate, increasing diversity of views, knowledge and skills. It should also be standard practice to pay those who do not receive a salary to take part in your activity. However, payment should be agreed on an individual basis as it may be considered income for tax and social security purposes.

Finally, proper resourcing means enough people for the job. It's not fair to expect too few people from an organisation or too few consumers or carers to work well together. Best practice includes getting multiple views on what engagement and participation will take, ahead of getting started. If possible, build in back up or proxy team members to help with rapport and keep momentum should anyone need a break for any reason.

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BEST PRACTICE APPLIED

Invest in engagement and participation. Make sure that the timelines for activities are agreed between all groups involved. Don't start engagement and participation activities that don't have enough time for genuine commitment. Recognise that participation comes with costs and ensure these are fairly covered. Jointly plan for enough people to achieve your goals. If you are facing an activity where these resourcing principles can't be met, don't give up, consider revising the goals. Consider a paid participation policy to ensure expectations around reimbursement are clear from the outset. The Commission has a Paid Participation Policy[9] which may be a useful guide.

Organisations should also consider openly and publicly celebrating outcomes and achievements. Celebrating achievements and giving recognition to all participants, especially volunteers, can advance a culture of continual improvement.

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e) Respect, safety and support

Safety is an essential part of successful engagement and participation for all of those involved. It is about creating an environment in which everyone feels comfortable and receives the support they need to engage and participate effectively. People express safety as a culture of openness, respect, equality and comfort for sharing stories.

A good place for organisations to start is to create a mentally healthy workplace. Strategies such as better work design and culture, building resilience and supporting awareness of mental health will facilitate a positive engagement and participation environment.[10]

Applying the other best practice principles will help to create a safe environment for engagement and participation. A respectful and supportive environment can be enabled by well-framed activities, good skills and leadership, resourcing and critical reflection on processes and outcomes.

Safe engagement and participation ensures that everyone, not just mental health consumers and carers, has the support they need for an activity. Practical safety supports may include:

- co-developed ground rules about safe and acceptable disclosure
- formal documents to support the engagement and participation process, such as Terms of Reference that clearly state roles and responsibilities
- designated physical space for people to take a break if needed
- available methods of extra support should this be requested (e.g., peer or professional debriefing, Employee Assistance Programs)

It is important to remember that safety is about the environment in which the activities occur and the issues under focus. It is not about targeting specific individuals, or creating processes that apply only to mental health consumers and carers. The supports needed may differ, but in some cases consumers and carers may have greater coping skills due to their previous experience. Talking about safety and what everyone needs as a safety response is part of building a strong culture of respect.

Safety is also about more than just 'risk management'. A risk management approach tends to frame safety issues in a negative way (as potential problems or dangers) and can lead to certain individuals or groups being singled out as 'risky'. This can have a stigmatising effect, which can in turn undermine safety. Creating a safe environment should instead be proactive, focussing on respect, inclusiveness and support for everyone, recognising that we all need support to feel safe.

BEST PRACTICE APPLIED

Safety is essential for everyone involved. You should precede all activities with deliberate study of the environment of engagement and participation. Your examination should focus on the issues, not the people involved. Discuss and agree on safety responses with everyone before getting started to foster respect and equality.

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f) Evaluation and quality improvement

An important part of best practice is evaluating the process and outcomes and using the results of the evaluation for quality improvement. We often miss this step, and this could be for several reasons:

- Not thinking about it at all
- Thinking it's too hard to do
- Fearing what it might show
- Not knowing how to use the results.

People frequently observe that there is a lack of information on engagement and participation outcomes. This is a missed learning opportunity. It can be difficult to look inwards and assess what worked and what didn't but this is important for gathering evidence for improvement. However, we can't share our successes or learn from our mistakes if we don't study them. More information and practical strategies for evaluation are outlined in Step 4 of this guide.

BEST PRACTICE APPLIED

Evaluation is itself an opportunity for engagement and participation. Not only can mental health consumers and carers participate in evaluating programs and services, they can and should participate in evaluating engagement and participation. This includes evaluation design and methods, collecting and interpreting feedback and planning what to do with it.

Step 3: Plan your activities

This section outlines activities that map to the matrix of engagement and participation at Step 1.

Once you have decided where on the matrix to start you can use this section to plan your activities. The descriptions below are short guides to the nature of each activity and how it might work at various levels. Activities that are similar across levels are combined. References to further resources and real-world examples are included to help your thinking.

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BEST PRACTICE APPLIED

Referring to the activities you noted in Step 1, use the description below of each to help plan your engagement. Keep in mind that this list should not be viewed as an exclusive, exhaustive menu. The activities described give ideas on how engagement and participation might work but that doesn't mean the activities would not work for other purposes or that the listed ones are the only choices. As organisations, consumers and carers practice working with each other across the whole matrix, novel ways of adapting activities will emerge.

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1. Design

	A. Individual	B. Service or program	C. Organisation	D. Policy or system
1. Design	1A. Shared decision-making in treatment and care planning	1B. Co-design of services and programs	1C. Advisory group, representatives in working groups	1D. Co-design of policies and strategies

1A & 2A. Shared decision-making

The majority of the *Engage and Participate in Mental Health* project focussed on activities beyond the individual level. However, people with experience of mental health issues and mental illness want and have a right to actively participate in their own care. This includes looking for information and self-help outside services. It also includes working together with service providers to plan care.

There are a number of tools available to support shared-decision making within services.[11] Existing tools within clinical practice such as mental health care plans are also an excellent way of promoting shared control over care and recovery if developed together. As for all engagement and participation activities, proper sharing of care means empowering people with personal lived experience of mental illness and, where this is welcomed by the consumer, their families or carers too.

If you are a consumer, you should advocate for your preferred way of looking after your own health along with the advice of health professionals.[12] Families and carers can also help with choices and support. If you are a clinician, listen to and respect the choices of consumers to promote ownership of recovery.

1C. Advisory groups and working groups

An advisory group provides strategic expertise, usually to the whole organisation or broad section.[13] As the name suggests, advisory groups are for advice and are not usually decision-making bodies. Likewise, working groups are set up to progress certain tasks. By their nature, these groups can be more 'top down' than other activities as they often involve an organisation seeking input on ideas that are at least partly formed. However, power can still be shared with an advisory group.

Advisory and working groups can and usually should involve people from different parts of the sector. A mix of consumers, carers, policy and clinical expertise can help to identify and creatively solve problems in design and beyond. Key elements of best practice for advisory groups include clear, agreed Terms of Reference and a defined role for the group in organisation processes. Regular, informal feedback on how the group is working along with formal evaluation is helpful.

Consumers and carers can offer unique insight into design and planning for programs, services, research and policy. This sets all processes up for better relevance and further participation.

When organisations seek out consumers and carers to sit on working or advisory groups, they should commit to acting on the advice received through the group wherever possible, and explain any cases where advice was not followed. Organisations should also avoid the temptation to engage too late. This is why advisory and working groups have been placed within the design stage of the matrix.

If you are a consumer or carer participating in an advisory or working group, make sure you are familiar with the purpose of the group and the Terms of Reference. Don't be afraid to question processes that are unclear or suggest improvements. Have confidence in the expertise that you have been selected to provide. Engage in respectful, robust debate with people from other areas of the sector to ensure that consumer and carer views are equally heard.

1B & 1D. Co-design of services, programs research and policy
Co-design is not a single activity. It's an approach that can draw on any number of other engagement and participation activities. Along with co-production, co-design is about a true shift to a human rights and citizenship approach. Co-design equally values and blends professional, consumer and carer expertise. Done with skill, it allows everyone with knowledge about what works and what doesn't to share their ideas for change.[14] Critical reflection and action on the best practice principles described earlier will move you further along the 'co' path.

Co-design and co-production are now requirements in many areas. The Fifth National Mental Health and Suicide Prevention Plan[15] describes consumers and carers as 'critical partners' and commits to being inclusive in service design, planning etc. Health and medical research has the Statement on Consumer and Community Involvement in Health and Medical Research.[16] However, policy directives do not produce change by themselves and may increase tokenism. The following example illustrates the democratic principles of co-design in practice.

NSW Lived Experience Framework

Background:
The *Lived Experience Framework* (Framework) was co-designed by the Mental Health Commission of NSW and people with lived experience of mental health issues and caring, families and kinship groups, as well as stakeholders from the mental health and social service systems.

The Framework acts as a guide on how people with lived experience of mental health issues and caring, families and kinship groups can work with service providers as equal partners.

Best practice principles implemented:
Conceptualising participation and recognition of skills and knowledge
The NSW Mental Health Commission implemented these actions by supporting the development of this Framework through a *two-staged co-design approach* from start to finish. Recognition of the expertise, leadership and value for the input of people with lived experience was at the core of the framework development project.

Stage one included:
- a *Consumer-led Lived Experience Project:* the Consumer Lived Experience Project Steering Group was established in 2016 to develop a priority project that they thought would make the greatest positive impact. As part of this project the group arranged a consumer feedback survey as well as events in the three locations in which consumers participated in and led group discussions exploring how consumers can take a stronger role in shaping all aspects of mental wellbeing. Efforts were made to represent a range of experiences and participants were encouraged and supported to step into positions of leadership such as group facilitators.
- a *Carer-led Lived Experience Project: t*he Carer led Lived Experience Project Steering Group was established in 2017 to highlight the ways that mental health carers and families can shape reform. As part of this project the group arranged a carer feedback survey and one day event where where families and carers came together to share and learn how they could make their voices heard and from which the *My Carer Pathway* videos and paper were developed.

Stage two involved:
- Establishing an *Advisory Group*, including three members of each of the previous projects' steering groups as well as additional stakeholders. The purpose of the Advisory Group was to design processes and inform a co-design workshop.
- A *co-design workshop* brought together members of the previous projects' steering groups and stakeholders from a mix of mental health services, peak bodies, government and non-government health, education/vocation, justice, disability and social service providers and policy makers. Over the course of the two day event, attendees participated in sessions on co-design methodology, looked at past attempts at embedding lived experience, and determined what the lived experience framework should look like and what it will take for it to be adopted.

Dedicated resourcing
- All of the Advisory and Steering Groups were provided with paid participation and reasonable transport costs.
- Throughout the various stages of the project, financial support was offered to people from rural and regional areas to attend
- Food was provided at engagement events
- The Commission also used a designer and printer with lived experience to produce the Lived Experience Framework publication.

2. Governance

	A. Individual	B. Service or program	C. Organisation	D. Policy or system
2. Governance	2A. Shared decision-making in treatment and care planning	2B. Reference groups Steering committees	2C & 2D. Representatives on committees Consumer/carer-led committees, equal representation in decision-making bodies	

Across all levels of the system and any type of organisation, engagement and participation in governance is about equal representation in decision-making. Participation in governance processes systematically embeds consumer and carer expertise within organisations.[17] Documents which clearly articulate principles and approaches to governance, such as Terms of Reference, should themselves be co-produced with representatives of all groups to whom they will apply (consumers, carers, clinicians etc).

2A. Shared decision making (see above at 1A)

2B. Reference groups and steering committees
Reference groups are like advisory groups in form, but they tend to have a narrower focus.[18] Where advisory groups are often at the organisational level and operate across a number of projects or services, reference groups are usually restricted to a single service or program within an organisation or a specific research project. Like advisory groups, reference groups are a way of bringing people from various groups together to discuss the program or project, provide advice and report to the groups they represent.

Steering committees represent a higher level of engagement and participation. The key difference between a steering committee and a reference group is decision-making capacity.[19] As the name suggests, steering committees direct programs, services and research projects and have substantial or even full control of decisions.

When setting up or joining a reference group or steering committee, you need to discuss and agree on who should be a member and what the group can and can't do for the program, service or project. If there are things that are not negotiable, from a consumer, carer or organisation perspective, these should be stated up front. Make sure you include where the group or committee fits in your organisational chart. If you are setting up a steering committee, take care that the delegated decision-making control fits with overall organisational policy and is feasible.

2C & 2D. Committee representation and consumer/carer-led committees
Systemic advocacy through committee representation is probably the most familiar form of engagement and participation in mental health. Done well, the inclusion of consumer and carer representatives on existing committees across an organisation or system builds participation into existing governance. This can be easier than trying to define the position of an entirely separate group such as a reference or advisory group.

However, committee representation is also the space in which many consumers and carers have experienced tokenism and exclusion.[20] It's not enough to just add a consumer or carer member to an existing committee of other health system members. It can be very hard to break into committees that have been established a long while or include high level staff. Problems such as established power differences and jargon tend to be more common in these settings.

There are some things that organisations can do to overcome some of the common difficulties experienced by consumers and carers being placed on existing committees. Consider creating more than one consumer position and one carer position on committees, particularly those at high levels of governance. Talk to the consumer and carer organisations who you ask for representatives about what you should do to include them. Use the practical challenges outlined in the best practice principles as a guide to the issues you need to think about. Make time to work on the other principles in Step 2 to increase your chance of success.

If you are a consumer or carer representative, seek out the formal training and support offered by consumer and carer organisations. At meetings, make sure you provide a lived experience view where possible. If you are not happy with how you are being included, first talk to the committee chair. If this doesn't work or is not an option, talk with the

representative co-ordinator at your consumer or carer organisation, or the person nominated by the organisation in cases where you are recruited directly.

One way in which control can be shifted to consumers and carers is through consumer-led and carer-led committees and boards. These may be traditional health service, system or research committees with a consumer or carer chair, or they may be entirely consumer and/or carer committees with decision-making authority. As a chair or member of such a group, it is important to remember that power relations still apply. These committees should still follow all the principles of best practice already described.

West Australian Exposure draft Compulsory Treatment (Alcohol and Other Drugs) Bill 2016

The West Australian Government's Exposure Draft Compulsory Treatment (Alcohol and Other Drugs) Bill 2016 (Exposure Draft Bill) was developed for the purpose of providing for the compulsory treatment, stabilisation and support of persons with a severe substance use disorder and provide for the protection of those persons when they are made subject to interventions under the Act.

In the development of the Exposure Draft Bill and associated summary model of service, the West Australian Mental Health Commission (WAMHC) used a range of strategies to ensure close and regular engagement with a Community Advisory Group. Practices outlined below demonstrate the ways in which this process aligned with best practice principles outlined in this guide:

Conceptualising participation
- A broad expression of interest was circulated
- The Advisory Group was Co-chaired by a family member supporting a person with a lived experience of mental health, alcohol and other drug issues.
- The Lived Experience Co-chair was also a member of the Project Steering Committee, which was recognised to have equal influence with the Advisory Group in relation to the development of the draft legislation.
- The Advisory Group consisted of people with a diverse range of experiences and perspectives, including regional, Aboriginal, youth, sexuality, gender and bodily diverse orientation and people from culturally and linguistically diverse backgrounds.
- Members were included from the beginning of the process.
- The WAMHC was clear with the Advisory Group about the extent of their influence on the draft legislation.

Recognition of skills and knowledge
- The selection panel for the Advisory Committee included a person with a lived experience of mental health, alcohol and other drug issues.
- Members were provided with information and issues for discussion in advance of meetings.
- WAMHC demonstrated and communicated how and where Advisory Group recommendations had been reflected in the draft legislation. Where final outcomes were not the same as Advisory Group recommendations, these were transparently outlined and explained to the Advisory Group.

Dedicated resourcing
- Opportunities were provided for regionally based members to attend face-to face meetings in Perth.
- Members were remunerated in line with WHMHC's Consumer, Family, Carer and Community Paid Partnership Policy.

Safety and support
- Meetings were held at a location with easy access to public transport.
- Members were provided with access to free counselling via the organisation's employee assistance scheme, if required.
- Respectful discussion and debate was encouraged and actively facilitated during meetings.

Content adapted from : Government of Western Australia, Mental Health Commission 2018
https://www.mhc.wa.gov.au/media/2531/170877-menheac-toolkit-web.pdf

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3. Delivery

	A. Individual	B. Service or program	C. Organisation	D. Policy or system
3. Delivery	3A. Self-help programs and tools	3B. Peer workers Peer-led programs	3C. Consumer-led and carer-led training for staff	3D. Regular reviews of policy and its implementation by consumer and carer representatives

3A. Self-help

At the individual level, self-help tools and programs engage people to participate in their own health care. Although this may not seem to fit with most of the engagement and participation described in this guide, it's a very important element of 'working with' in service delivery. Similar to shared decision-making, seeking information and using tools to manage your own care gives you knowledge and choice. In turn, these give you control in your own recovery.

Tools and programs to manage care may range from shared electronic health records, through information leaflets to online e-mental health treatment programs.[21] Websites such as Head to Health[22] are a good place to start.

3B. Peer workers and peer-led programs

Mental health peer workers openly identify as mental health consumers or carers and their experience as consumers or carers is an essential requirement of the role. They use their experiences to connect with others with lived experience to role model recovery. There has been rapid growth in peer work roles and peer-led programs in recent decades, including the development of a formal qualification, the Certificate IV in Mental Health Peer Work.[23] The scope of peer work ranges from acute and community-based services provision across both public and private settings to policy advice and research involvement.[24] Peer work is more than just peer support, although this forms part of a peer work role.

Just as for other forms of engagement and participation, the success of peer work positions depends on leadership, safety, skills, resourcing and attention to practical barriers.[25] The peer workforce brings a unique aspect to the system but this is at risk without the right supports. If your organisation wants to create peer work positions, take care to create position descriptions that clearly describe the role (including whether it is a consumer or carer role) and that match peer work competencies rather than clinical roles. Take the time to talk to existing staff about their understanding of peer work before you start. Try to create a safe space that lets a peer worker establish their niche. Avoid passing off unwanted clinical or administrative tasks to the peer worker.

If you are a peer worker entering a new service, take the opportunity to keep the peer workforce moving forward. Look carefully at position descriptions and role statements. These are often standard templates across organisations that nobody thinks to change for a new role. If there are tasks or other elements of the role or workplace that are not consistent with peer work, talk with the service. Find ways to promote peer leadership, such as suggesting new programs for your role to deliver. Look for ways to make the service a safe, skilled and recovery-oriented place for consumers, carers and other staff.

Perinatal mental health peer led project

As a result of a needs assessment and strategic planning processes for the commissioning of low intensity psychological services, Brisbane North PHN identified significant gaps for services which support new parents transitioning to parenthood.

As part of the tender process to fill this gap, Peach Tree Perinatal Wellness (Peach Tree) was identified as an organisation delivering promising, evidence informed, peer-led practice that had potential to be further developed through the use of the PHN's low-intensity lead site activities.

Peach Tree is a 100% Peer-led organisation, meaning all staff and volunteers have their own personal experiences of perinatal mental illness, each with unique stories of hope and recovery. Their goal is to work in partnership with perinatally-focused professionals and health practitioners to provide compassionate support and services to parents and families within the community.

The result of this process has been the procurement of Peach Tree's Sunshine Parenting Program (SPP) which provides a perinatal low intensity support service for new mothers (with infants aged 0-12 months) who are at risk of, or currently experiencing perinatal mental illness symptoms.

Brisbane North PHN also funded an independent evaluation of the program by Queensland University of Technology to build the evidence base for effective low intensity peer led services to support perinatal health. The evaluation is focused on training for peer workers and the program's impact on participants, partners and peer workers. Interim results have provided insight into the needs of new parents during this time and also into the peer worker framework required to support compassionate and meaningful program delivery. Final results are due to be published in August 2019.

To date, participants have experienced clinically significant improvements in postnatal depression and distress as well as decreases in feelings of social isolation and improvements in postnatal bonding experiences with their baby. Peach Tree has also been funded by Queensland Health to deliver the SPP in the Brisbane South.

The activities and practices below demonstrate some of the ways this process has aligned with the best practice principles outlined in this guide:

Conceptualising participation as routine practice, recognition and development of skills and knowledge and leadership culture
- Consultations were undertaken with the sector, consumers and carers prior to gap analysis and tender process. The consultations process was informed by the PHN's designated Lived Experience Engagement Coordinator (LEEC).
- Online survey conducted as part of the gap analysis and promoted to consumers and carers through PHN and LEEC networks. Survey results informed the tender documents developed by the PHN.
- Recognition of lived experience expertise in commissioning of services through funding of peer-led organisation
- The SPP reference group includes a number of both peer and perinatal health professionals and is facilitated by a member with lived experience.
- The reference group supported the implementation of the SPP and provided ongoing support for program planning, implementation and evaluation
- SPP delivered by peer workers who were trained and supported by a lived experience workplace wellbeing framework

Dedicated resourcing, evaluation and quality improvements
- Independent program evaluation funded by commissioning body.
- Dedicated resources allocated towards continuing professional development and supervision of the lived experience workforce to improve quality of service delivery.

3C. Consumer-led and carer-led staff training

The involvement of consumers and carers in staff training is another area of recent growth. University courses for health professionals such as nurses, psychologists and doctors are more often including lectures by consumers and carers.[26] Skills-based courses such as Mental Health First Aid[27] and Applied Suicide Intervention and Skills Training[28] are frequently delivered by consumers and carers. In the research sector, lived experience researchers are mentoring other researchers on effective engagement and participation.[29]

Organisations have several options for including this activity in their engagement and participation efforts. Search for education and training that includes a lived experience component and seek graduates from these courses to fill positions. Also search for internal training that could be led or co-led by a mental health consumer or carer. Think about whether mentoring could form part of existing or new peer-identified role in your organisation.

If you are a consumer or carer and want to contribute to staff training, you may have to actively pursue chances. Contact university course convenors in areas such as nursing and psychology to offer a lived experience lecture. Look for champions of lived experience expertise within education and research institutions. Think about training for delivering short courses such as Mental Health First Aid.

3D. Policy and implementation reviews by consumer and carer representatives (see 4B & 4D, below)

4. Evaluation

	A. Individual	B. Service or program	C. Organisation	D. Policy or system
4. Evaluation	4A. Experience surveys	4B. Consumer and carer feedback Co-evaluation	4C. Interviews with consumer and carer representatives Regular audit of engagement activities	4D. Regular reviews of policy and its implementation by consumer and carer representatives

4A. Experience and satisfaction surveys

Experience surveys are most commonly used within services as a way to collect feedback about people's experience of health care. In many cases, questions are tied to specific service quality indicators and form part of quality improvement processes.[30] This is a simple yet powerful way of engaging people in your service evaluation.

To be most effective, your choice of survey matters. Surveys that were developed in partnership with consumers and carers are more likely to cover the areas of most concern from the service user rather than provider view.[31] A defined link between the questions and quality indicators, and commitment to use of survey results can mean consumer and carer participation in quality improvement.

These surveys are only useful if used properly. If you are an organisation using one of these surveys, simply doing the survey is not enough. Surveys that lead to no change in services are tokenistic and can lead to frustration in staff and consumers. Spend the time to choose a survey that is a good fit for your service and that is widely used (see box). Devote resources to running the survey and linking the results with quality processes. Commit to action on areas of concern.

If you are a consumer or carer who is asked to complete an experience survey, treat it as your chance to improve

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'Your Experience of Service' (YES) survey

The Your Experience of Service (YES) survey is designed to gather information about the experiences of care received by people accessing public mental health services.

It was developed and tested with people with lived experience in the Consumer Experiences of Care Project. Consumers were involved throughout the process of literature review, development, trial, evaluation and refinement of the survey. This helped to ensure that the questions focus on areas of concern for people with lived experience.

The YES survey has 35 questions in four types:

Experience questions
Outcome questions
Open-ended questions
Demographics

People answer on a frequency scale (Never-Always) or a performance scale (Poor-Excellent) with questions covering major areas of experience such as shared decision-making, access to appropriate care and respect. Outcome questions focus on recovery.

The survey is being rolled out across Australian mental health services, with a version developed for use in Community Managed Organisations. Further information and licensing information is available at https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/national-mental-health-committees/mental-health-information-strategy-standing-committee/your-experience-of-service-survey-instrument

4B & 4D. Consumer and carer feedback, review and co-evaluation

Involving consumers and carers in the evaluation and review of policies, services, programs and research (methods and outcomes) brings new perspectives. Mental health consumers and carers have unique expertise to offer on what works and what doesn't. They often also have creative suggestions for how to act on findings to improve future efforts. Co-evaluation processes can help improve response rates and the quality of information gathered, which ultimately can feed into a more useful end-product.

If you are an organisation carrying out an evaluation or review, talk to consumers and carers about how they can help with the process.[32] Use the best practice principles described earlier to plan the review with active participation. Engaging with consumer and carer perspectives should be part of your evaluation evidence. However, active participation of consumers and carers in the process of collecting, analysing, writing up and acting on findings gives true voice and purpose. There are many lived experience-led research and consultancy groups that can offer mentoring and assistance in this area. More detail on evaluation is in the next section.

If you are a consumer or carer, seek out chances for co-evaluation. You may know a consulting firm or research group who works on mental health projects. Talk to these groups about your interest and ask to hear about projects you can help with. Find out how services use experience surveys and get involved in the process. Look for chances to review policies, such as input through consumer and carer organisations who are often invited to comment. Be confident in the expertise you have to offer and seek out any extra skills you feel you need to work with others in the process.

4C. Interviews and audit of engagement and participation activities

Auditing engagement and participation activities is a final area to involve mental health consumers and carers. Your audits must look across the organisation/system at where engagement and participation occurs and the level of participation. Use the matrix and level of engagement spectrum in Part 2 as a guide. The audit is a chance to gather feedback on what worked and what didn't for engagement and participation. A useful place to start is with interviews of consumers and carers who have participated in these activities. Act on the feedback as you plan further activities.

For consumers and carers, getting involved or leading an audit of engagement and participation is a powerful way to get a high level view of how the system is 'working with' you. It may also open doors to further participation opportunities. Taking stock of where activities are occurring and getting feedback on how well they are working allows direct input to the growth of a co-created system.

4D. Reviews of policy and its implementation by consumer and carer representatives (see 4B, above)

Step 4: Evaluate and improve upon your engagement approach

It can be tempting to think of evidence only in terms of numbers from an audit, e.g. the number of activities conducted and the number of consumers and carers involved. However, numbers can't tell us *why* people had a good or poor experience. It is also difficult for people to give different views or creative feedback if restricted to rating scales.

Open-ended feedback is often dismissed as 'anecdotal.' For effective evaluation, this needs to shift to an understanding of the value of experiential knowledge. Simple open-ended questions can provide rich information on how things went from the perspective of those involved. The process of pulling this information together, looking at common themes and deciding what to do with it makes it far more than an anecdote.

Evaluating engagement and participation does not have to be complex or involve specialists. A good starting point is this set of five basic questions.[33]

Five evaluation questions

1.	**What was the best part about participating in [activity]?**
2.	**Was there anything that you didn't like about participating in [activity]?**
3.	**Were your expectations of participation met?**
4.	**What do you suggest could improve [activity]?**
5.	**Do you have any other comments or suggestions?**

People's responses to these questions are mostly direct and fairly easy to interpret. Comments usually cover many aspects of activities (e.g., comments on food and timing are common) but all can inform planning for your next activity. Using the best practice principles outlined in Step 2 as a guide, look for key things people are saying about their participation. Did they feel safe? Did they feel heard? Do they describe language, practical or technical barriers?

Evaluating engagement and participation is not just from the perspective of consumers and carers. It's also important to evaluate the experiences of staff and volunteers in your organisation. The same five questions can be used with all groups. Comparing responses may help to see where things really worked and where things went wrong. For example, what does each group say about their expectations? Are there mismatches? What might you do to help everyone feel respected and positive?

There is no point in doing an evaluation if you don't intend to act on what it shows. People will quickly disengage if there is no clear action from the feedback they provide. It is also important to ensure that people who participated in the activity receive specific information about how their input has contributed to change (this is sometimes called a 'feedback loop').

There are a number of practical steps organisations, consumers and carers can take to facilitate action:
- As part of evaluation planning, look for how the findings can be used.
- Discuss how input will be used and be open about any limits.
- Create a register of key evaluation outcomes.
- Keep a record of changes to processes made as a result of evaluation.
- Follow up with people who participated in the activity to provide information about outcomes over time.
- Make records available to people within your organisation and people who fifth to show a culture of improvement.
- Consider publishing a report on your engagement and participation processes and outcomes (e.g. on your website) to add to our knowledge.

The following headings provide a simple framework for reporting on the outcomes of engagement and participation activities:

- What we asked of you
- What we heard for you
- What we will do as a result
- When we plan to do it
- How we will keep you informed/ involved

Conclusion

Engaging with people is an essential part of delivering the best outcomes at individual, service, organisation and system levels. The knowledge that consumers and carers have about what is needed is an important resource in shifting the mental health system to a genuinely person-centred, recovery focussed model.

Having now been through the steps of this guide you should have a plan for enhancing engagement. You have identified the level the engagement is operating at, and from this decided on one or more key activities. You have also clearly identified where on the spectrum of engagement your approach is located. You have taken into account the best practice principles and know how to apply them. You have thought through how the key activities you have identified will work in practice. And you have planned for evaluation of your engagement.

In providing provide a clear framework and set of principles for best practice in consumer and carer engagement and participation, hopefully this guide has been useful in informing your decision about how to proceed with the essential task of engaging with mental health consumers and carers.

References

[1] National Mental Health Consumer and Carer Forum. Advocacy Brief. Co-design and Co-production; 2017.

[2] Slay, J., Robinson, B. (2011). In this together: Building knowledge about co-production. London: New Economics Foundation; cited in National Mental Health Consumer and Carer Forum. Advocacy Brief. Co-design and Co-production; 2017.

[3] Commonwealth of Australia, A national framework for recovery-oriented mental health services: Guide for practitioners and providers (2013).

[4] World Health Organization Regional Office for Europe. User empowerment in mental health: A statement by the WHO regional office for Europe. Copenhagen: World Health Organisation; 2010. http://www.euro.who.int/__data/assets/pdf_file/0020/113834/E93430.pdf

[5] Commonwealth of Australia. The Fifth National Mental Health and Suicide Prevention Plan. In: Department of Health, editor. Canberra: Commonwealth of Australia; 2017; United Nations. Fact Sheet No 2 (Rev 1): The International Declaration of Human Rights. Geneva: United Nations, ; 1996 [29/10/18]; Available from: https://www.ohchr.org/documents/publications/factsheet2rev.1en.pdf; United Nations. Convention on the Rights of Persons with Disabilities. Geneva: United Nations; 2006.

[6] https://www.mhc.wa.gov.au/media/2532/170876-menheac-engagement-framework-web.pdf

[7] Ibid

[8] Adapted from Suomi A, Freeman B, Banfield M. Framework for the engagement of people with a lived experience in program implementation and research: Review and report prepared for the LifeSpan suicide prevention project. Canberra: Australian National University; 2017. https://www.blackdoginstitute.org.au/docs/default-source/lifespan/anu-lived-experience-framework.pdf

[9] http://www.mentalhealthcommission.gov.au/media/198375/Paid%20Participation%20Policy%20-%20signed%20-%2022%20June%202017(2).PDF

[10] http://www.mentalhealthcommission.gov.au/media/116414/Developing%20a%20mentally%20healthy%20workplace_Final%20November%202014.docx

[11] Dahlqvist Jonsson P, Schon UK, Rosenberg D, Sandlund M, Svedberg P. Service users' experiences of participation in decision making in mental health services. Journal of Psychiatric and Mental Health Nursing. 2015;22(9):688-97; Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical encounters. Patient education and counseling. 2013;93(1):102-7; Elwyn G, Hutchings H, Edwards A, Rapport F, Wensing MJP, Cheung WY, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. Health Expectations. 2005;8(1):34-42.

[12] Shepherd HL, Barratt A, Trevena LJ, McGeechan K, Carey K, Epstein RM, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. Patient education and counseling. 2011 Sep;84(3):379-85.

[13] McKenzie A, Haines H. Consumer and community participation fact sheet series. Second ed. Perth: University of Western Australia School of Population Health and Telethon Kids Institute; 2014.

[14] Larkin M, Boden ZVR, Newton E. On the brink of genuinely collaborative care: Experience-based co-design in mental health. Qualitative Health Research. 2015;25(11):1463-76.

[15] Commonwealth of Australia. The Fifth National Mental Health and Suicide Prevention Plan. In: Department of Health, editor. Canberra: Commonwealth of Australia; 2017.

[16] National Health and Medical Research Council and Consumers' Health Forum of Australia. Statement on Consumer and Community Involvement in Health and Medical Research. Canberra: Commonwealth of Australia; 2016.

[17] Litva A, Canvin K, Shepherd M, Jacoby A, Gabbay M. Lay perceptions of the desired role and type of user involvement in clinical governance. Health Expectations: An International Journal of Public Participation in Health Care & Health Policy. 2009;12(1):81-91.

[18] McKenzie A, Haines H. Consumer and community participation fact sheet series. Second ed. Perth: University of Western Australia School of Population Health and Telethon Kids Institute; 2014.

[19] Ibid.

[20] MacDonald D, Barnes M, Crawford M, Omeni E, Wilson A, Rose D. Service user governors in mental health foundation trusts: accountability or business as usual? Health expectations : an international journal of public participation in health care and health policy. 2015 Dec;18(6):2892-902.

[21] Druss BG, Ji X, Glick G, von Esenwein SA. Randomized trial of an electronic personal health record for patients with serious mental illnesses. The American Journal of Psychiatry. 2014;171(3):360-8; Marchinko S, Clarke D. The Wellness Planner: empowerment, quality of life, and continuity of care in mental illness. Archives of psychiatric nursing. 2011 Aug;25(4):284-93; Meyer D. Online self-help: Developing a student-focused website for depression. Counselling & Psychotherapy Research. 2007;7(3):151-6.

[22] https://headtohealth.gov.au

[23] See http://mentalhealthcommission.gov.au/our-work/mental-health-peer-work-development-and-promotion.aspx

[24] Meagher J, Stratford A, Jackson F, Jayakody E, Fong T, editors. Peer work in Australia: A new future for mental health. Sydney: Flourish Australia and Mind Australia; 2018.

[25] Ibid

[26] Morgan A, Jones D. Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: a literature review. Medical teacher. 2009 Feb;31(2):82-95; Simons L, Tee S, Lathlean J, Burgess A, Herbert L, Gibson C. A socially inclusive approach to user participation in higher education. Journal of Advanced Nursing. 2007;58(3):246-55.

[27] https://mhfa.com.au

[28] http://www.livingworks.com.au/programs/asist

[29] Banfield M, Randall R, O'Brien M, Hope S, Gulliver A, Forbes O, et al. Lived experience researchers partnering with consumers and carers to improve mental health research: Reflections from an Australian initiative. International journal of mental health nursing. 2018 Aug;27(4):1219-29.

[30] Gardner K, Parkinson A, Banfield M, Sargent GM, Desborough J, Hehir KK. Usability of patient experience surveys in Australian primary health care: a scoping review. Australian journal of primary health. 2016;22(2):93-9.

[31] Victorian Department of Health. Your Experience of Service survey instrument. Melbourne: Victorian Department of Health 2013; Victorian Department of Health. National mental health consumers experiences of care project: Final report. Melbourne: Victorian Department of Health 2013.

[32] Perreault M, Renaud J, Bourassa F, Beauchesne L, Mpiana A, Bernier S, et al. Implementation of a panel of service users for the evaluation of mental health outpatient services. Evaluation & the health professions. 2010 Dec;33(4):480-96; Oades LG, Law J, Marshall SL. Development of a consumer constructed scale to evaluate mental health service provision. Journal of Evaluation in Clinical Practice. 2011;17(6):1102-7.

[33] McKenzie A, Hanley B. Consumer and community participation in health and medical research: A practical guide for health and medical research organisations. Perth: University of Western Australia and Telethon Institute for Child Health Research; 2007.