Government of **Western Australia**
Department of **Health**

Working with Consumers and Carers Toolkit

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Overarching guidance

Context, key ideas and information on how to use the toolkit

Overview

The toolkit provides 4 stages to follow for any initiative. Each provides step-by-step guidance on how to use them, and tools and templates for working with consumers and carers in the state.

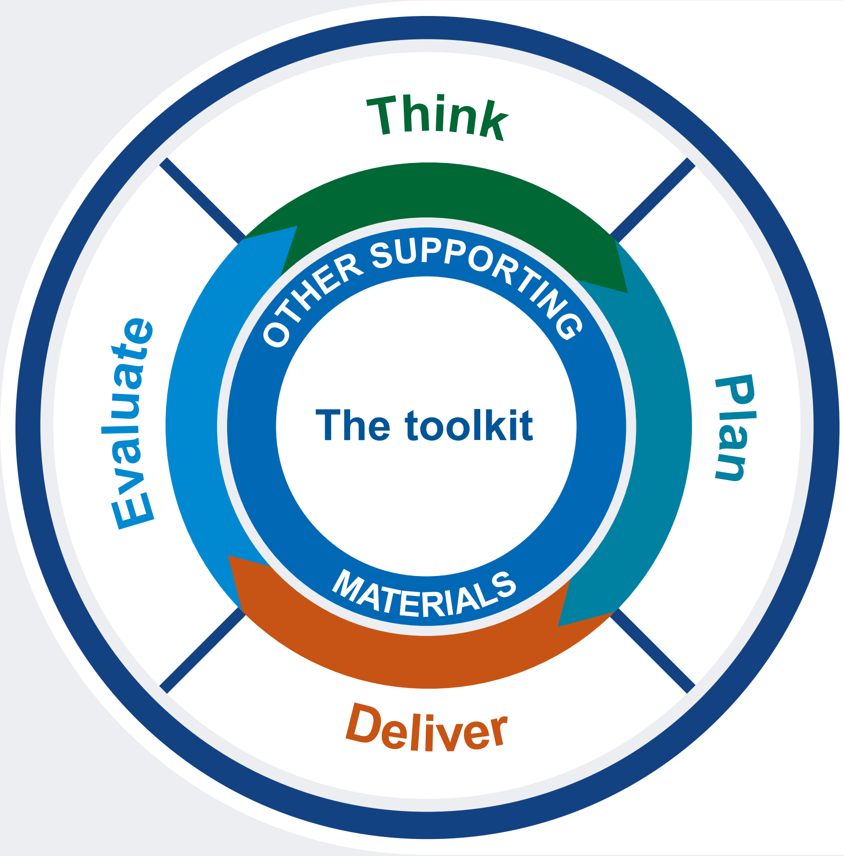
Stage 1: Think
Key enablers and considerations for effective engagement

Stage 2: Plan
Practical planning advice and templates

Stage 3: Deliver
Tools and templates to undertake and sustain engagement

Stage 4: Evaluate
Steps and considerations for understanding what works, and improving

Other supporting materials
A wide range of existing tools and reference guides



How to use the toolkit

The toolkit is designed to provide step-by-step guidance through the 4 stages of the consumer and carer engagement process.

- Use the checklists for each stage to ensure each steps is considered.
- Skip to the parts you need – working through end-to-end will help at first, but won't be appropriate every time.
- Scale for the size of the engagement – smaller engagements may only need quick, high-level thoughts, whereas larger ones will likely benefit from more detailed planning.
- Test your thinking with others – try not to work in isolation, but communicate regularly with your team and your stakeholders, and check in with your line manager or the Health Networks Team if you are unsure.
- Be flexible – working with consumers and carers is often a dynamic process. The toolkit provides structure, but cannot cover every scenario. Use common sense and your professional perspective to inform a nuanced approach.
- Use the supporting materials to access or get inspiration from other relevant resources, and keep aware of events that will help build your capabilities.

Links

Orange link graphics indicate a link to other parts of the toolkit or external documents.

Action boxes on each page indicate an important action to consider for each element.

Get in touch

For further assistance or queries, contact the Health Networks team:

Phone: 9222 0200

Email: HealthPolicy@health.wa.gov.au

About the toolkit

This toolkit describes how health staff can work with consumers and carers to meaningfully achieve important outcomes in the WA health system.

The toolkit was developed primarily for the Department of Health (the department), to support consistent and intentional engagement with consumers in the development of systemwide strategies, policies and plans. It may also serve as a valuable resource for any health organisation in WA.

There are different forms that working with consumers and carers can take.
This toolkit will help you determine the appropriate form and how best to enact it.

Link to 1.4

Key features of working with consumers and carers

- working together over a defined period to achieve an agreed objective
- mutual understanding of the value of each other's contributions
- respect and trust between stakeholders
- power imbalances being recognised and taken into account
- acknowledgement of different contexts
- a concerted effort to recognise the needs and safety of consumers and carers
- accessible, equitable and inclusive processes.

Link to toolkit high level summary

Principles for working with consumers and carers

The toolkit is based upon 6 guiding principles for working with consumers and carers, which are fundamental to achieving genuine and meaningful engagement.

① Accessible and inclusive

Understand power imbalances and clearly delineate roles so that all stakeholders have the means to fully participate, fostering equality and equal balance in contribution.

② Respectful and safe

Create trust by respecting, understanding and valuing the unique expertise, experiences, perspectives and needs of all consumers and carers.

③ Authentic

Form relationships that are real, genuine, flexible and compassionate, empowering all parties to bring their true selves to the initiative and to be realistic about their roles.

④ Clear communication and transparency

Establish initial and ongoing two-way communication, to ensure that information is clear and openly shared between all people.

⑤ Purposeful

Engage with clear intent based on a mutually agreed purpose, vision, goals and outcomes.

⑥ Committed and accountable

Confirm the interest and commitment of all stakeholders – including key internal approvers, as well as consumers and carers – at the outset of the initiative. All stakeholders have both expectations and responsibilities to ensure the work progresses as it should.

Continually monitor alignment to these principles throughout the initiative.

The benefits of working with consumers and carers

Consumer and carer engagement has become an increasingly important and central component of health care over the last 20 years. It has a range of benefits for both consumers and carers, and health care systems – as well as the community at large.

Ensure you have a full understanding of the benefits of working with consumers and carers in the context of your initiative. These might include:

- Opportunities to leverage the unique skills and expertise each person brings – their insights, experiences and perspective – to inform a richer understanding to the initiative.
- Health, human and community systems that better address critical challenges across agencies, sectors and jurisdictions.
- More responsive health services, informing efforts to improve patient experience, safety and quality.
- Greater responsiveness in system performance – which has a critical role in safe and high quality care.
- Improved overall population health through greater insights into the social and cultural determinants that are impacting communities.
- More effective system planning and reform that is informed by and reflects the needs and aspirations of consumers and carers.

Ensure you have a full understanding of the benefits of working with consumers and carers in the context of your initiative.

Benefits synthesised from Australian Commission on Safety and Quality in Health Care. Partnering with Consumers Standard. 2023; Safer Care Victoria. Partnering in healthcare: A framework for better care and outcomes. 2019; The Kings Fund. Understanding integration: How to listen to and learn from people and communities. 2021; Government of Western Australia Department of Communities. Communities Partnership Framework. 2021

Why working with consumers and carers matters

For most staff, meaningfully working with consumers and carers is not fully integrated in work patterns and may introduce added complexities to an initiative. However, regular and meaningful consumer and carer input keeps the health system focused and in touch with the people it fundamentally exists to serve.

Consumers and carers

- have a unique perspective that is fundamentally different to that of health staff
- find treatment and recovery more straightforward without the added stress of 'fighting' the system
- are most impacted if the health system makes mistakes
- find it easier to trust and follow the advice of health staff who are listening, understanding and genuinely considering their point of view
- are highly invested in the health system and want to contribute to making it even better.

Health staff

- who hear regularly from consumer and carer voices are more grounded and motivated
- make better decisions when helped by consumers and carers who better understand the health system
- can more easily improve safety and quality when they fully understand the real-world impact of their services
- may struggle for influence in political forums where consumers and carers can have powerful voice
- can ensure initiatives are fit for purpose with genuine consumer and carer input.

Use these points to motivate and advocate for meaningful engagement across all your initiatives.

Key terminology

Term	Definition
CALD	An initialism referring to culturally and linguistically diverse.
Carer	A person who provides unpaid and ongoing care, support and assistance to a consumer – including formal carers, families, friends and others who provide support. The toolkit uses 'consumers and carers' as standard terminology.
Co-design	One of the toolkit's 5 levels of engagement, to actively involve consumers and carers from the start of an initiative so they are involved in design and decision-making opportunities.
Community	A group of people who share something in common. It may be location, interests, culture, language, beliefs, values or traditions. Communities often identify and form around issues. These issues may magnify the similarities or differences of community members. The term is also used to refer to 'the community' in the context of healthcare – meaning broader society beyond the specific healthcare interactions in question.
Consult	One of the toolkit's 5 levels of engagement, to gain information and feedback from consumers to inform internal decision making.
Consumer	A current, previous or future user of health services. The toolkit uses 'consumers and carers' as standard terminology.
Engagement spectrum	Sets out a continuum of engaging with consumers and carers to guide the progress of an initiative.
Health staff	Any person working in the health system i.e. clinician, researcher, health educator, etc.
Inform	One of the toolkit's 5 levels of engagement, to educate or provide timely information to consumers in one-way communication.
Initiative	Any program, project or activity undertaken by a health agency that requires engagement with consumers.

Term	Definition
Involve	One of the toolkit's 5 levels of engagement, to provide input that influences specific parts and decision points of an initiative.
Lived experience	The personal knowledge someone has about the world gained through a specific life experience, rather than through representations constructed by other people.
LGBTQIA+	An inclusive initialism referring to lesbian, gay, bisexual, transgender, queer, intersex and asexual, with the '+' including all other identities e.g. pansexual, genderqueer, non-binary, questioning etc.
Participation	Direct engagement or involvement in an initiative.
Partnership	To work very closely with consumers, empowering them to help make decisions alongside those leading an initiative. This term is explicitly stated and commonly used in the SHR, and is indicated by the 'partner' level of the consumer engagement spectrum.
Principles of working with consumers and carers	A set of 6 fundamental 'ways of working' which can be used to guide working with consumers and carers.
Stakeholder	A person or group involved in the health care system and affected by changes to that system.
System manager	The role of the department – responsible for the overall management and strategic direction of the WA health system, ensuring the delivery of high quality, safe and timely health services.
WACHS	WA Country Health Service
Working with consumers and carers	When an organisation engages in informed dialogue with consumers and carers to gather insights that will inform an initiative such as planning, policy, research, service design, service delivery and service improvement.

Terminology will change and evolve over time, to ensure the toolkit remains contemporary and reflects good practice.

Case study 1

The ministerial taskforce into the future of public infant, child and adolescent mental health services in WA (2021).

Key features

- lived experience members on the taskforce
- three expert advisory groups, including a lived experience group with 35 carers and consumers
- open application process for membership
- consultations across WA with many other consumers and carers
- the lived experience group individually and collectively endorsed the taskforce recommendations.

Situation

The independent Ministerial Taskforce into Public Mental Health Services for Infants, Children and Adolescents aged 0 to 18 years in WA (the taskforce) was created in response to the tragic death of 13-year old Kate Savage in 2020.

The taskforce was charged with investigating the pressures and demands on the state's mental health system and reporting on how to ensure children receive the treatment and care they need, when they need it.

The role of consumers and carers

The 10 person taskforce included a consumer and carer member who had equal decision making powers.

A lived experience expert advisory group (EAG) had 35 members who were selected from an open recruitment process that received over 70 applications. The EAG was co-chaired by the 2 lived experience members of the taskforce. It worked alongside a clinician and interagency EAG.

The independent chair (Robyn Kruk AO) told each EAG from the outset that the taskforce would only put forward recommendations endorsed by the EAGs. All 3 unanimously endorsed the recommendations.

In addition the taskforce actively consulted children, young people, families, clinicians, support providers and other key stakeholders to inform the design of the future ICA mental health system. More than 100 carers and consumers participated in these consultations, including dedicated focus groups with Aboriginal consumers and carers, CALD consumers and carers, and regional consumers and carers.

Outcomes

The recommendations from the taskforce were presented to the Minister in late 2021, tabled at Cabinet early in 2022 and endorsed by Government in April 2022. Government committed to implementing all of the recommendations.

The co-chairs of the lived experience EAG received feedback from many of their members that the involvement of consumers in the taskforce should be a model for consumer and carer engagement going forward. Of particular note was the positive feedback on the efforts made to ensure the psychological safety of all consumer and carer participants throughout.

What was done well?

- Consumer and carer members of the taskforce with equal decision making powers.
- Broad consultation with various consumer and carer groups including Aboriginal, CALD and rural and remote communities.
- Deliberate efforts to promote a psychologically safe engagement environment for all participants.

Notable challenges

- Ensuring the psychological safety of young people and parents having to work alongside clinicians who had treated them (or their loved ones) during childhood.

Case study 2

The 'culturally and linguistically diverse (CaLD) cancer information needs for consumers and carers' project.

Key features

- Community organisations with existing connections with CaLD communities were awarded grants via an open process to carry out consultations.
- Organisations received support and were briefed on ways to keep consumers safe during consultations.
- 175 CaLD consumers and carers across metropolitan and regional WA were consulted.
- Flexible approaches were used to consult consumers and they were paid for their time.
- The consultations helped build understanding the cancer information needs of consumers and carers.
- The findings were used to support the development of resources and other initiatives.

Situation

In 2021, the department commissioned a desktop review and consumer survey to assess the cancer information needs for Western Australians. The review found that there were limited cancer resources for CaLD people and that CaLD communities were significantly underrepresented in the survey. The review recommended investigating alternative engagement strategies to identify cancer information needs for CaLD people across the cancer journey.

Additionally, CaLD communities in WA may face more barriers to accessing and understanding cancer information compared to non-CaLD Australians, including language barriers and cultural differences. As a result of these barriers, the network undertook the project to better understand the cancer information needs for CaLD consumers and carers affected by cancer.

The role of consumers and carers

From May to July 2022, the network conducted an open and competitive expression of interest process to identify key stakeholders to lead consultation with CaLD consumer and carers across metropolitan and regional WA. The network awarded 5 grants to community organisations to consult with CaLD consumers and carers.

Organisations were supported by the network and briefed on ways to keep consumers and carers safe during consultation. This included confidentiality measures and providing access to support services.

The organisations were encouraged to use a range of recruitment and consultation approaches best suited for their communities. This included utilising existing networks and connections. The timeframe for consultation was August to October 2022.

Overall, 175 CaLD consumers and carers were consulted through 53 interviews, 16 focus groups and 2 written responses. Having flexible consultation methods allowed consumers to participate in a way that suited them best. Consumers were also remunerated for their time as per the department's policy.

Outcomes

The 5 organisations captured 4 key themes relating to cancer information that were important and helpful to CaLD communities on their cancer journey – how cancer information is accessed, how information is delivered, the types of information that are important to CaLD communities and the role and influence of culture in addressing information needs.

These findings were communicated back to the organisations and consumers via a debriefing session. They were to inform the development of resources for CaLD consumers and carers.

Lessons learnt

- Amongst CaLD communities, word of mouth was a more effective recruitment strategy than social media and flyers.
- Established relationships and trust were essential to recruitment. Where existing relationships did not exist, additional time and resources were required.
- Consumer involvement was effectively supported by offering flexibility in consultation methods (one-on-one interview, group discussions, or written survey), modality (face-to-face, teleconference, telephone) and scheduling.
- Providing project information and discussion questions upfront and examples during discussions helped participants answer the questions during consultation.
- Emphasising to participants that they will help other CaLD people encouraged them to be more involved in the sessions.
- Discussions on sensitive health topics such as cancer can prompt distress amongst participants and so it is important that participants are able to access social support and resources throughout the consultation process.

Case study 3

Hospital stay guidelines.

Key features

A series of engagement activities were undertaken from October 2022 to February 2023 where WA Health sought to listen and understand stakeholder views, needs and expectations for implementing the guidelines. The stakeholder groups aligned with the 3 foci of the guidelines:

- people with disability, family, friends and carers
- disability service providers
- hospital staff.

Establishing genuine partnerships with a shared goal of improving health outcomes has been a journey with some significant insights to recognising and addressing challenges and future implications. The unique needs and perspectives of the audiences drove critical differences in the presentation of the material.

Situation

The Western Australia Disability Health Network (DHN) developed the hospital stay guideline for hospitals and disability service organisations in 2016 and outlined a best practice approach for disability service organisations and hospitals when managing the hospital experience of individuals with disability.

Due to changes in the provision of healthcare for people with disability, the DHN revised and updated the 2016 guideline through a co-design process with key stakeholders. The updated Hospital Stay Guidelines (guidelines) were launched in November 2022 and aim to inform people with disability and their support networks, disability service providers and hospital staff of their respective roles and responsibilities throughout a person's stay in hospital in WA. The goal of the guidelines is to improve the hospital experience for people with disability and empowering people to have more say in their healthcare.

The role of consumers and carers

From the outset the DHN partnered with people with lived experience, Developmental Disability WA, Carers WA and hospital staff to co-design the revision of the guidelines.

The DHN engaged an external consultant with lived experience and knowledge of the disability and community services sector to lead the discussion and stakeholder engagement.

The guideline was co-written by people with disability and their supports, disability organisations, lead agencies and health staff. Stakeholders were contacted to identify their preferred method of engagement, with options including:

- Survey – provided in accessible format compatible for screen readers, written in plain English and accompanied by a plain English video with closed captions.
- Alternative options to engage such as phone calls, video calls, 1:1 engagements and facilitated small workshops were available to people with lived experience.

Future implications – to plan the future implementation of the guidelines, 120 people across the disability and health sectors were consulted including people with lived experience (n=34), Disability Service Organisations (n=42), WA hospital staff, clinicians, HSP NDIS lead, allied health, nursing, cognitive care leads (n=44).

Outcomes

Each of the group responses were themed according to identified barriers along with implementation recommendations for the guidelines. These recommendations will be presented to Health Networks for consideration.

Insights

- co-design challenges health as 'the expert' and the outcome may not be a usual health product
- power imbalances exist and need to be recognised and addressed
- language is important, so partnering with consumers is critical
- universal access results in improvements for all.

How the toolkit was developed

Strategic context

The toolkit is part of a response to Recommendation 4 of the Sustainable Health Review (SHR).

The SHR was published in April 2019 outlining 8 enduring strategies and 30 recommendations with the aim to prioritise the delivery of patient-centred, high quality and financially sustainable healthcare across WA.

Recommendation 4 is to 'commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes.'

The toolkit is intended to be a practical and accessible collection of tools and resources that can be used predominantly by health staff in the department, and potentially by other health system stakeholders. It provides opportunities for flexibility and adaptation over time, reflecting the rapidly evolving nature of the area. It will also assist internal and external stakeholders in determining, designing, delivering and/or participating in engagement activities with consumers and carers across the health and social care systems.

Development

The construction of the toolkit was overseen by the SHR4 Steering Group. The steering group commissioned a review into good practice related to consumer and community partnerships in WA and other jurisdictions – some of these insights were included in the toolkit.

A working group was established to guide the development and implementation of the toolkit. The working group met 4 times to shape, inform and test the contents of the toolkit. The group comprised of 22 members:

- **2** co-chairs: Department of Health lead and Health Consumers' Council lead
- **9** lived experience representatives
- **5** Health Service Provider representatives
- **4** Department of Health representatives
- **1** Western Australia Council of Social Service (WACOSS) representative
- **1** Aboriginal Health Council of Western Australia (AHCWA) representative.

The steering group provided feedback on the toolkit materials throughout its development.

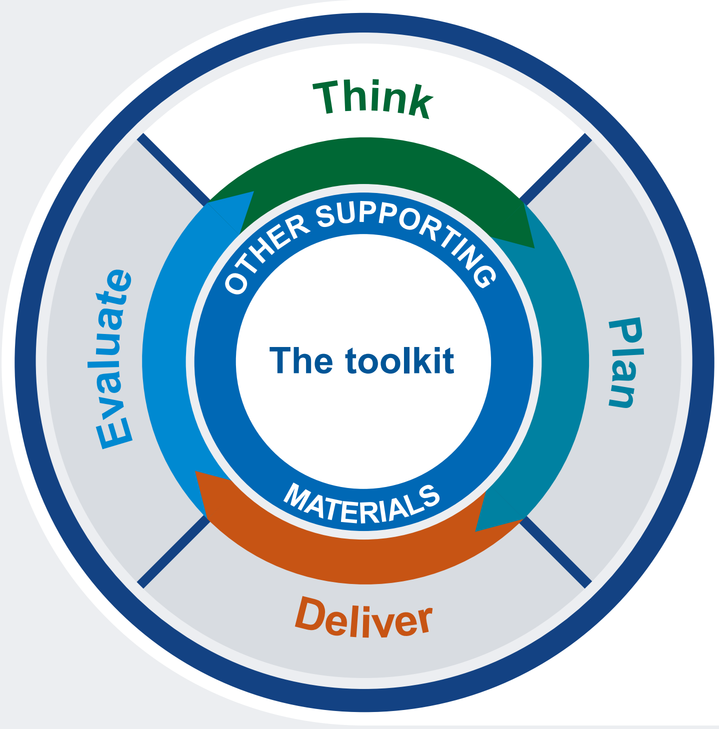
1. Think

1

Checklist

Key enablers to effectively working with consumers and carers

	Tick
1.1 Recognise unconscious bias	☐
1.2 Define your objectives and outcomes	☐
1.3 Consider your budget and resourcing	☐
1.4 Choose the appropriate form of engagement	☐
1.5 Think about the voices you may need	☐
1.6 Think about responsibilities	☐
1.7 Think about privacy and information management	☐



As a baseline, make sure you've considered everything – and vary the level of detail and documentation as suits the scale and context of the proposed initiative.

1.1 Recognise unconscious bias

As you begin to think about planning and delivering an initiative, it is important to understand your own 'lens' – the view you automatically bring to any situation.

Unconscious bias is the preconceptions, attitudes, stereotypes, privilege or other assumptions that individuals may hold without being aware of them.

This is particularly important to account for in a health setting, because it can lead to judgements, decisions and other actions that have significant effects on consumers and carers. For example, placing more weight on voices who have similar characteristics to you (e.g. gender, nationality, sexual orientation), and therefore tacitly discriminating against those who are more different.

Recognition

Everyone has unconscious bias to some degree – but by reflecting and calling it out, it is much easier to correct for. The benefits of doing this include:

- better 'gap analysis' of voices in your initiative, to inform who may need to be engaged
- better decisions based on information that reflects the actual experience of consumers and carers, rather than assumptions
- broadening of knowledge and skills through learning and listening to new perspectives
- improved inclusion of and relationships with consumers and carers through more active listening.

Avoidance

To help recognise and overcome your own unconscious bias, you can make efforts to:

- listen to the stories of others and tell your own story
- avoid stereotypes and over-generalisations
- self-reflect regularly about your perspective and where you could have unconscious bias
- embrace and communicate the importance of inclusive spaces to foster productive discussions and self-reflection
- have a peer review your work early on to provide any feedback.

Link to 3.2

1.2 Define your objectives and outcomes

For your initiative to succeed, it is essential that everyone clearly understand the outcomes it seeks to achieve. Having a clear purpose help you focus on what matters most, communicate clearly, and maximise the impact of the work you do.

Overarching priorities

Think first about the broader context of your initiative – what it intends to achieve and the value it will create. Wider priorities to consider might include:

- the department's current strategy and system priorities (all initiatives need this connection at some level)
- the specific strategies and work priorities of your area
- the high-level priorities your prospective consumers and carers might have – what, fundamentally, they are likely to care about and want to achieve.

Check to see what other consultations may have already taken place, and test any assumptions with consumers and carers.

Objectives

The specific things you seek to achieve – for example:

- capture high quality consumer and carer input on the design and implementation of a systemwide strategy
- distribute clear health information to a target community.

Outcomes

Why you are working together – the specific (usually lasting) changes you seek to bring about, by achieving your objectives – for example:

- The toolkit is based upon a clear understanding of consumers and carers' needs, cultures and preferences.
- The implementation of clinical policy X takes consumer and carer requirements into account.

Key steps

1. capture your initiative's proposed outcomes
2. capture what objectives might help achieve them
3. test your thinking with colleagues, then consumers and carers, and adjust based on feedback
4. consider how you will measure and evaluate your progress.

Link to 4

1.3 Consider your budget and resourcing

Take into account the feasibility of your initiative, especially the potential costs. The scope of your available resources and budget will determine what type of engagement can be implemented in your given timeframes.

Paid participation

Pay for consumers' time is outlined by department policy, and may include transport reimbursements.

Technology

Costs of setting up, adopting, running and onboarding people with various technology (e.g. collaboration software, videoconferencing).

Training

For staff and consumers and carers to build key capabilities and confidence – including bringing people up to speed on skills assumed as standard for the department workforce.

Recruitment

Link to 2.4

Time and costs associated with attracting relevant consumers and carers for your initiative.

Communications

Link to 3.4

Time and costs to create accessible materials for consumers and carers, such as interpreters, translators and alternative formats.

External experts

Costs for the right expertise (e.g. facilitation, engagement design) to achieve specific outcomes.

Governance

Salaries and on-costs associated with staff overseeing and managing the engagement.

Evaluation

Link to 4

Time to properly listen, reflect and make changes in approach to ensure genuine and authentic input.

1.4 Choose the appropriate form of engagement

Each initiative will have a different form of engagement, and may incorporate different aspects along the continuum simultaneously. You will need to choose what form is most appropriate to achieve the outcomes and objectives you have defined, within the constraints of your available budget and resources.

The spectrum on the following page outlines 5 forms of engagement to carefully consider. No one form is necessarily better or worse than the other – but in general, the higher levels of consumer and carer involvement will yield greater insight, as well as greater levels of expectations that need to be managed.

Key steps

1. Consider which level may be appropriate for your context, your consumers and carers, your objectives, and your budget constraints.
2. Consider whether different levels of engagement may be appropriate for different stages or components of your initiative.
3. Consider the specific methods of engagement you will use for each level.

Link to 2.5

The consumer and carer engagement spectrum is informed by a range of similar concepts in other toolkits:

- MHC Framework
- WACOSS Toolkit
- Department of Communities Partnership Framework 2021

The consumer and carer engagement spectrum

Increasing consumer and carer involvement

Increasing potential resources required

Inform

Consumers and carers receive information from us, but do not have an opportunity to provide input into your decisions.

You might want to provide them with clear and timely information that is relevant to them and their circumstances.

Consult

Consumers and carers are asked to provide structured feedback to help you form ideas, make decisions and refine designs.

You might want to listen, validate and learn from their experiences, and consider their feedback in your decisions.

Involve

Consumers and carers are involved throughout parts of an initiative so their perspective is understood and input is reflected in the decisions made.

You might want to use their feedback and advice to influence specific parts or decision-points of your initiative.

Co-design

Consumers and carers are actively involved in the co-design of your initiative from the start, often with some form of shared decision-making.

You might want to ensure that their voice influences every aspect of the initiative.

Partner

Consumers and carers have elevated (at times equal) decision-making power, are closely involved in initiatives from start to finish, and act as partners.

You might want to empower them carers to make decisions and take action alongside those leading the initiative.

Doing to… Doing for… Doing with… Doing by…

1.5 Think about the voices you may need

The consumers, carers and health staff you engage will have a significant impact on the design of your initiative. It is important to work with a diverse range of voices.

Consumer and carer voices

	What they can bring	What they might need
Person with lived experience	Personal, individual experiences and an authentic sense of the impact services have	Safe space to share and be vulnerable, trauma-informed approaches to engagement, support from a lived experience facilitator, engagements to be held at a convenient time, follow up on wellbeing after engagements
Carers, families and other supports	Personal, individual experiences and a unique perspective of supporting consumers	Safe space to share and be vulnerable, trauma-informed approaches to engagement, engagements to be held at a convenient time, follow up on wellbeing after engagements
Health consumer advocate	Insights into a broader representation of consumer voice and greater familiarity with health terminology and process	Clear information on the subsets of consumers your initiative needs to capture, up-front clarity on scope and objectives
Community representative	Perspective on consumer experience within a local area and/or community network	Opportunity to show people their area, allowance for travel, for you to come to them Consumer and carer voices

Link to 3.4

Health staff voices

	What they can bring	What they might need
Project or program team	Clear and cohesive coordination, in depth understanding of the initiative, interface with departmental governance	Clear authorising environment, administrative support
Project or program sponsor	Strong endorsement of the initiative, decision-making authority, good relationships with key stakeholders, ability to resolve conflicts	High-level briefing that gets to key issues quickly, capable team, clear authorising environment
Clinician	Insight on specific clinical contexts and best practice, pragmatic lens on implementation considerations	Lots of notice for engagements to fit their roster, flexible communications options (e.g. phone calls)
Researcher	Evidence base and analysis for key ideas, understanding and connections with wider institutional perspectives and other jurisdictions	Opportunity to take ideas away and review, guidance on appropriate level of detail for all audiences, information regarding briefings and consent forms
Health educator	Expertise in facilitation and capability building, subject-matter knowledge in laypersons' terms	Engagement formats that maximise use of their skills

1.6 Think about responsibilities

To conduct effective engagement, participants should understand their roles and responsibilities, and the other potential roles involved. It is important to communicate responsibilities early on, during recruitment, so that all parties have clear expectations from the outset.

Link to 2.4

Responsibilities

How to get the most out of engagement

- listen to others' views, be respectful and provide considered feedback
- be open to feedback and prepared to accept other's perspective
- bring concepts to life with real experience
- avoid using jargon
- recognise that clinical evidence and real life experience can often contradict each other.

Health staff responsibilities

- communicate clearly with up-to-date process information
- manage administration and secretarial functions of the engagement
- provide subject-matter expertise and professional perspective
- liaise with other services
- frame and solicit input from all parties on current projects and programs.

Consumer and carer responsibilities

- identify and communicate the needs and perspectives of the cohort they represent (which could just be themselves)
- convey information to others in their cohort
- engage with and listen to the views of other consumers and carers, and report back
- provide input on the design and implementation of initiatives
- bring ideas to life with personal experiences.

Think about the responsibilities different people may have – discuss this with them and then clearly communicate this to others.

1.7 Privacy and information management

Government agencies are required by law to ensure privacy and good information management for any health information that may be disclosed during engagement.

Health information

Personal information relating to health, a disability, wishes in regard to future healthcare, health services provided – or any other personal information collected in providing a health service.

Privacy

An individual's right or expectation that their information will be maintained security and in confidence.

Disclosure

When a person causes information to appear or be seen, makes it known or otherwise reveals it.

Information management

Ensuring information is dealt with appropriately throughout its life cycle, including collection, storage, access, disclosure, use and disposal.

A wide range of policies support good information management and privacy practices, as well as legislation including:

- *Health Services Act 2016 (WA)*
- *State Records Act 2000 (WA)*
- *Mental Health Act 2014 (WA)*
- *Health (Miscellaneous Provisions) Act 1911 (WA)*
- *Health (Offences and Penalties) Regulations 2016 (WA)*
- *Privacy Act 1988 (Cth)*

When thinking about how you engage consumers and carers, pay attention to the information you collect, and what you do with it.

Privacy and information management tips

Working with consumers and carers requires additional care to ensure not just that your privacy and information management is sound, but that consumers and carers understand and trust in your process.

Limit collection

Design your engagements so you only collect personal information you think is important for your outcomes. Collecting more than you will use only increases the processes you may need to follow. Standard information that is not collected includes individuals' names (except for consent forms), images of participants, date of birth and address.

Anonymise and aggregate

Consider how you might collect information in an anonymised way that is not able to be linked to any individuals, and how you might aggregate insights to make information even more difficult to link to individuals (e.g. anonymous survey, followed by analysis and insights across all respondents).

Be transparent

Tell people what you're planning to collect from them, what you intend to use it for, and if and how they can request the information be destroyed if they wish. Consider briefing consumers in a group so they are all aware and can ask questions. Allow consumers and carers to access the information you have collected, upon request.

Obtain informed consent

Ensure consumers and carers genuinely understand what you have outlined (in a language that they understand), and ask them to formally consent to their information being used in this way. Make sure to document their informed consent in written form.

Use appropriate systems and storage

Only use devices and storage solutions provided by the department – never store personal information on personal devices. Follow broader department guidelines on handling and storage of information.

Maintain confidence

Don't discuss information shared by a person directly (e.g. in a one-to-one conversation or email), even with colleagues, unless they have given you informed consent (see above).

Report breaches

If you think information has intentionally or unintentionally been shared where it shouldn't, notify your manager and ensure the department's information security team is aware.

Monitor third parties

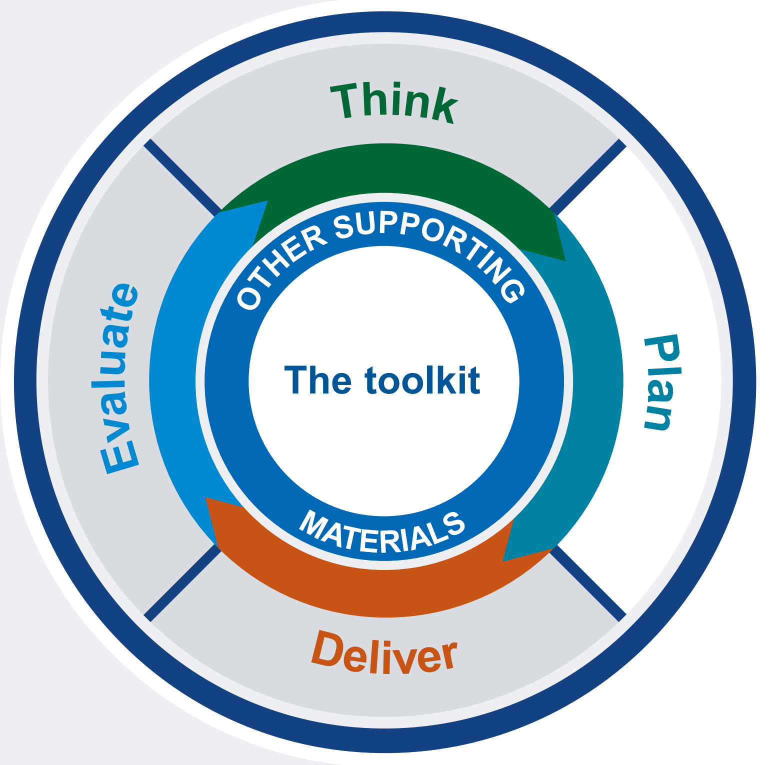
If there are third-party contractors or services involved in your engagement, make sure expectations are clear about how information is managed. Check at regular intervals to confirm this is happening.

2. Plan

Checklist

Tangible steps and standardised templates to translate intention into action

		Tick
2.1	**Timeframes and critical milestones**	☐
2.2	**Key early contacts**	☐
2.3	**Consumer and carer engagement plan template**	☐
2.4	**Recruitment and onboarding**	☐
2.5	**Methods of engagement**	☐



As a baseline, make sure you've considered everything – and vary the level of detail and documentation as suits the scale and context of the proposed initiative

2.1 Timeframes and critical milestones

Set your initiative up for success by building the planning process around your timeframes and milestones.

Communication (ongoing)

- Do you have the buy-in of your managers and other senior stakeholders?
- What are the 'key messages' you can use to explain your initiative to a broad audience?

Recruitment

- When do you need to start contacting potential consumers? This is most often very early in the initiative.
- How long will it take you to find the right consumers (including working through others' networks)?

Onboarding

- When will you need to communicate key information to your consumers, and what will they want to know?
- When will this commence?

Delivery

- When do you want to commence delivering the initiative?
- What is the delivery timeline?
- Is the delivery on track to achieve its objectives and outcomes?

Evaluation

- How much time is available at the end of the initiative for evaluation?
- When have you scheduled your evaluation activities? Are they compatible with the timeline of consumers?

Monitoring

- When will you collect feedback during each stage?
- How will you incorporate feedback into the execution of the next stage?

2.2 Key early contacts

Many organisations have experience, expertise, and well-established networks across a wide range of groups – they are good starting points to check in with for work in and around the WA health system. Identify and touch base with relevant contacts early for insights and updates.

As a first step, quickly check in with your manager, other teams in your area and budget holders to identify what support is available through existing contracts and networks.

Approaching individual community organisations may not be representative of all community groups – you may require third party organisations to reach people of interest.

Potential questions for contacts

- What other work is already planned or underway in the space you're looking at?
- Who might be the best people or organisations to contact?
- What local context do you need to know about for the type of organisation you are contacting?
- What channels might be best for getting in touch with the right people?
- What methods of engagement might make your initiative more attractive and meaningful?
- What data might be available to help us refine who we target?

Identify and touch base with relevant contacts early for insights and updates.

Service providers and government entities

- Mental Health Commission
- Mental Health Advocacy Service
- Western Australian Country Health Service (WACHS) and associated District Health Advisory Councils
- WA Primary Health Alliance (WAPHA)
- Child and Adolescent Health Service (CAHS)
- East Metropolitan Health Service (EMHS)
- North Metropolitan Health Service (NMHS)
- South Metropolitan Health Service (SMHS)
- Office of Multicultural Interests
- Department of Communities

Consumer and carer advocacy groups

- Health Consumers' Council
- Carers WA
- WA Peer Supporters' Network
- Consumers of Mental Health Western Australia
- Mental Health Matters 2
- People With disabilities Western Australia (PWdWA)
- Developmental Disability WA
- Western Australian Association for Mental Health
- Alcohol and Other Drug Consumer and Community Coalition
- Living Proud
- Youth Affairs Council of Western Australia
- Council on the Ageing (COTA) Western Australia
- Men's Health WA
- Centre for Women's Safety and Wellbeing

Community organisations

- TransFolk of WA
- Connect Groups
- HepatitisWA
- Helping Minds
- Mental Health Law Centre
- Rise Network
- Womens Health & Family Services
- Multicultural Futures
- Little Dreamers Australia
- Young Carers Network
- Ishar Multicultural Women's Health Services Inc
- Multicultural Services Centre
- Multicultural Communities Council of WA
- Diabetes WA
- Organisation of African Communities

Professional and member organisations

- Western Australian Council of Social Service
- Ethnic Communities Council of Western Australia
- Aboriginal Health Council of Western Australia (AHCWA)

Policy and research organisations

- Cancer Council WA
- Western Australian Network of Alcohol and other Drug Agencies
- Heart Foundation

2.3 Consumer and carer engagement plan

Make a plan to outline and describe the responsibilities, timeframes, and level of participation for your initiative.

This will be a living documents that changes during your engagement, and also aid in reporting back to other organisations. Ideally, it will be adapted in consultation with people who have insight into the needs of the target audience.

Adapted from the ACI Co-Design Toolkit.

As a first step, quickly check in with your manager, other teams in your area and budget holders to identify what support is available through existing contracts and networks.

Approaching individual community organisations may not be representative of all community groups – you may require third party organisations to reach people of interest.

Focus areas	Key questions
Engaged stakeholders	• What type of consumers and carers will you need to get the best representation? • How many of them are needed and feasible to engage? Link to 1.5
Activities	• What are the ideal activities you can conduct to meet the objectives of this engagement? • What level of engagement do you want from consumers and carers? • What is the best method of participation for them?
Responsibilities to stakeholders	• What is your commitment to the consumers and carers you are engaging in terms of how you will engage them and use the insights they provide? • How will you ensure you can meet this? • What level of influence will consumers and carers have in the final decision?

Focus areas	Key questions
Timeframes	• What is the timeframe of your activities? • How much time do you want from consumers and carers across the whole initiative?
Consumer support	• How will you support individuals? • Have you asked consumers and carers how you can best support them? • Have you explained what you will do with their information? Link to 3.2 Link to 3.4
Budget	• What are your likely expenses (including the cost of paid participation)? • Do you have focus groups or workshops you will have to cater? • Will there be out of pocket expenses such as travel or parking? • What expenses are required to make engagement more accessible?
Resourcing	• Who can lead this initiative? • Which team members can support this initiative? • Are external skilled facilitators needed to support the initiative? • What technology, dedicated facilities, or print resources do you have available? Link to 1.3
Risk mitigation	• What are your key risks? • How can you mitigate them? • Do you have a mitigation strategy?
Evaluation	• How will you collect feedback from consumers and carers? • How do you know if your initiative and engagement have been successful? • How often will you conduct evaluation activities? Link to 4

2.4 Recruitment and onboarding

An ideal recruitment process is transparent, inclusive, fair and clearly communicates the roles and benefits of being part of your initiative. Initiatives are only as strong as the people and organisations in them – so recruiting the right consumers and carers is critical.

This involves identifying, attracting and working with the right consumers and carers in ways that are meaningful to them.

Key steps

1. Assign a consumer or carer contact from your team – this person will provide the consumers with content and context knowledge, lead the onboarding process and run any debrief sessions.
2. Identify the skills you are looking for from consumers, including their experiences and qualifications. You may develop a consumer role statement outlining their roles and responsibilities.
3. Identify the specific voices or individuals you need that match the required skillset.
4. Conduct your recruitment – note your budget and any constraints that may have on your recruitment, onboarding and engagement of consumers and carers.

Link to 1.5

Link to 1.3

Questions to consider

- What experience and insights does the consumer or carer bring that are relevant?
- Which groups might need to be represented?
- What are the potential barriers to recruiting the right consumers and carers, such as language or accessibility?
- How will you ensure the consumer or carer is safe if involved in the initiative?
- Are there political consequences of including one group or organisation over another?

Common methods of recruitment

It is important to ensure that a range of people know about the opportunity to participate, as some methods can unintentionally exclude certain cohorts.

The methods of recruitment should suit the consumers and carers you are trying to recruit, as well as your team.

Common methods of recruitment

	Advantages	Consideration
Traditional, online and social media platforms	• wide reach • low cost (if a subscriber base exists) • can respond to feedback in real time • potential to track engagement.	• assume the consumer or carer has an internet connection • some consumers or carers may be hard to reach • requires active maintenance for full impact.
Physical methods e.g. flyers and posters	• can be more visually engaging • reach cohorts who are less likely to use online and social media platforms.	• higher associated costs – printing, time to design and distribute • distribution and promotion strategies are important – some consumers and carers may not be aware of the initiative.
Expression of interest	• more equity of opportunity • gives you more control in selecting your consumers and carers to ensure a diverse group.	• requires an expression of interest to be created • time consuming to look through large numbers • may be difficult for individuals with lower literacy levels.
Existing networks or groups	• time efficient • utilises internal expertise • likely to engage consumers who are already interested in participating.	• the same consumers may be recruited for different initiatives (which may be good or bad thing).
Self-nomination and referral	• opt-in likely attracts consumers who are very interested in the initiative.	• prioritise consumers if receiving large numbers of nominations or referrals • consumers and carers need willingness to nominate.

This step is critical to ensure that individuals have the necessary resources, support, and understanding to fulfill their role. It sets participants up for success throughout your initiative.

A standard method is to organise a briefing session before you start (particularly for larger scale engagements such as workshops). This gives you the opportunity to:

- provide information on the initiative's context and objectives
- ask the consumer if they have any requirements or preferences for how they are engaged
- inform the consumer how they can opt out of any discussions or engagements if required
- discuss paid participation and any key responsibilities of the consumer.

To run an effective briefing session, think about the:

- **mode** – running an online briefing session may save time, but it may be easier to build rapport face to face.
- **size** – consumers may like the opportunity to meet other consumers in a group setting, whilst others may find this overwhelming and prefer to meet individually.
- **available resources** – ensure that you have adequate time and facilities to brief your consumers.
- **consistency** – ensure messages are consistent across different formats and presentations.

Considerations

- What insights and networks do the different groups of consumers and carers have?
- What opportunities can you create for our staff to learn about the experiences and knowledge of the individuals?
- What specific insights does the initiative require?
- Is there a gap in insights or networks the initiative requires and what some of the consumers and carers currently have?
- What ways will the consumers and carers want to participate in the initiative?
- What supports can you provide to people so that they can fully participate?

Think through how you will bring individuals on board – and don't be afraid to ask them too.

2.5 Methods of engagement

It is important to design, shape and adapt engagement approaches to best suit the consumer. 'Closing the loop' will also help build trust.

Seek to understand how your consumers and carers want to engage to build their trust and ultimately achieve better outcomes.

Link to 4.4

	Advantages	Consideration
One-on-one interviews	• One-on-one • useful to gather targeted and in-depth information • easier to see nuanced nonverbal communication • builds relationships • language can be easily altered • most suitable when using an English as a second language interpreter • timing and location can be flexible.	• time-consuming to interview and synthesise response, particularly for large numbers • tailor language and communication style to each consumer • communication channels suit the consumer (in-person or virtual) • send questions and background information beforehand.
Focus groups (2 to 10 people)	• builds relationships between stakeholders • can focus discussions on issues specific to each group • consumers and carers may feel safer in a small group • location can be somewhat flexible.	• timing may be difficult to accommodate • if in-person, logistics are inclusive (location, access requirements) • send questions and background information beforehand.

	Advantages	Consideration
Workshops (10 or more people)	- builds relationships between all stakeholders - can share and hear the ideas of many others - ability to establish consensus among stakeholders - more efficient use of time for health staff.	- allow time to coordinate availability - logistics are inclusive (location, access requirements) - language is easy for all to understand - number of people can be overwhelming - trauma histories are considered in who is included - more detailed pre-reading to be sent prior.
Surveys	- relatively inexpensive - useful to gather quantifiable information - allows anonymity - can accommodate a large number of people.	- literacy and language may be an issue - can seem impersonal - appropriate promotion and circulation approaches to overcome low response rates - requires time to synthesise the responses.
Membership on project management	- ongoing participation provides a longer-term consumer and carer perspective - increased accountability.	- requires organisational commitment to allow meaningful participation - logistics are inclusive (location, access requirements) - send questions and background information beforehand - consider allowing proxies or other support mechanisms
Integrated governance	- consumer and carer voice prominent in decision-making - other consumers and carers have a direct point of contact and support - ensures accountability.	- the initiative is suited to consumers and carers having decision-making power - appropriate balance of health staff and consumers as part of the governance structure.

	Advantages	Consideration
Blended teams	• receive regular consumer input • can help build relationships with consumers and carers over time.	• requires ongoing support and commitment • understand each party's preferred ways of working to be effective • appropriate balance of health staff and consumers in the team.
Crowdsourcing	• efficiently upload and update information • low cost and time commitment • potential for broad input from individuals • empowers active participation.	• risk of information being incorrect or irrelevant • copyright concerns • users may not trust the information.
Recruitment	• deep integration of consumer perspective within decision-making • low barrier to engagement and input • strong ability to build relationships and provide nuanced, innovative perspectives.	• slow to implement, with significant administrative overhead • biases towards individuals who also have professional skillsets • risk of tokenism without adequate thought in role design • risk of consumer and carer perspective shifting, or alienation from non-employee consumers and carers.

Link to 3.5

Considerations

Cultural safety

Consumers and carers may not feel as comfortable with some forms of engagement depending on their cultural context – be sure to test with them before engaging.

Regional and remote

Regional stakeholders can engage in-person, but where this is not possible, offer appropriate digital formats and consider connectivity issues.

Digital literacy

Not all stakeholders will be comfortable and confident on digital platforms – other mechanisms may be required, or training and support.

Link to 3.4

Seek to understand how your consumers and carers want to engage to build their trust and ultimately achieve better outcomes.

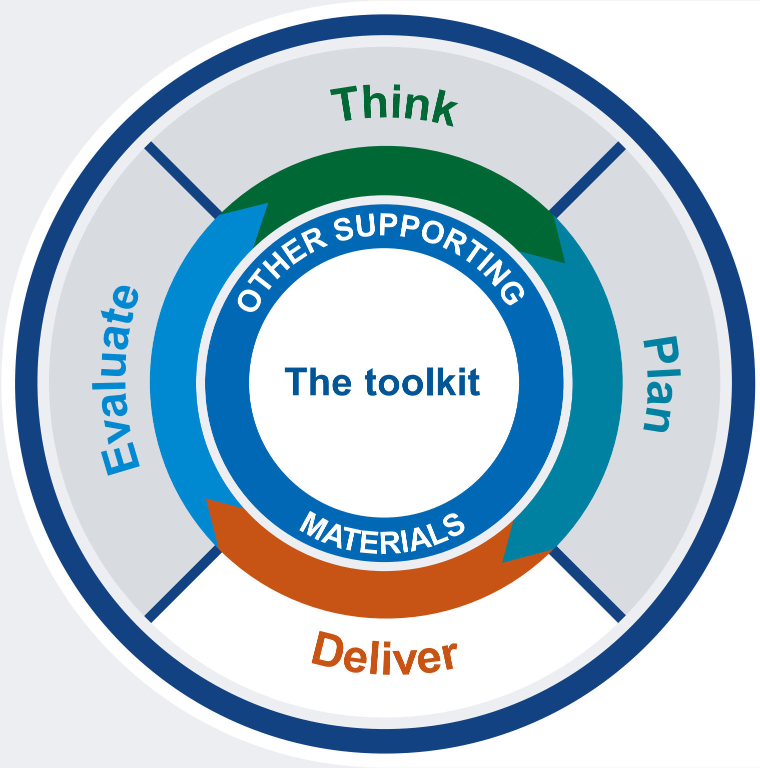
3

3. Deliver

Checklist

Build and maintain effective engagements with consumers and carers

	Tick
3.1 Paid participation	☐
3.2 Consumer and carer needs	☐
3.3 Consumer and carer expectations and obligations	☐
3.4 Cohort-specific guidance	☐
3.5 Facilitation guide	☐



As a baseline, make sure you've considered everything – and vary the level of detail and documentation as suits the scale and context of the proposed initiative.

3.1 Paid participation

Paid participation recognises the valuable, specialised and expert contribution made by people who have a lived experience, their families, carers and support people. It is one of the cornerstones of working with consumers and carers, and was emphasised as such in the SHR.

The department's Paid Participation Policy sets out how much it will pay, when and for what.

Supporting materials

① Ensure transparency

Ensure paid participation is transparent and clearly outlined to consumers and carers before they enter into the initiative, so they can make an informed decision about participating.

② Recognise all work

Recognise work required before and after the engagement activity, e.g. pre-reading, briefing, providing feedback and other participation activities as required. This is to be in line with the minimum and maximum payment time in any one day, and accounts for out of pocket expenses.

③ Consider the role

Consider the participation role required by each consumer and carer, which impacts the hourly rate.

④ Consider total participation

Consider the total participation required across your initiative for each consumer, and that this fits within the constraints of the budget. This is important when taken alongside other costs, including venue hire, catering and transport.

⑤ Be discreet

Be mindful of discussing payment with the consumer or carer in front of others, as it can often be viewed as a private matter.

⑥ Allow choice

Encourage consumers and carers to take the payment if hesitant, but it Is up to the individual's discretion. Provide hard copies of electronic documents if that is preferred.

3.2 Consumer and carer needs

Consider effective ways of engaging a variety of consumers and carers who may have different lived experiences. Always try to ensure that your initiative is safe and inclusive to the needs of all consumers and carers.

Creating safe and productive spaces will help you achieve better outcomes.

Link to 3.4

Tips for working with all consumers and carers

① Don't make assumptions

It is easy to assume that spaces and information are accessible, however do not make assumptions and remain flexible to changing engagement approaches with consumers and carers by asking what they need.

② Use easily understood language

Consider your language, clarity of information and methods of communication used to ensure that they are accessible.

③ Distribute pre-reading

Typically send out at least one week in advance of the meeting and provide adequate background. Offer the opportunity for documents to be made in alternative formats, such as Plain English or Easy Read.

④ Ensure a safer space

Consider who else is in the room and whether this might cause re-traumatisation (e.g. a clinician who has treated a consumer). Look to provide supports as needed (e.g. peer support counsellors) and flag sensitive content matter in advance.

⑤ Be flexible

Decide if meeting times, engagement methods and reading materials suit the needs of consumers through asking them. Allow time for consumers and carers to process information and provide responses.

Tips for working with all consumers and carers (continued)

6 Provide adequate resources

Have adequate resources available for remuneration, appropriate venues, capacity building, transport, interpreters, catering and childcare. Ensure you choose the right facilitators (look externally if necessary).

7 Respect time

Plan productive sessions that best allow consumers and carers to contribute. Remember to thank consumers and carers for providing their time to the initiative.

8 Observe the room

Ensure that people with lived experience are not feeling distress due to the behaviour of others.

9 Respect confidentiality and privacy

Develop and discuss rules around protecting confidentiality and identity. Anonymity may be important, especially in smaller communities.

10 Seek feedback

Ask for ongoing feedback, acknowledge contributions, provide a summary of outcomes in an understandable format and give consumers and carers avenues to provide additional feedback.

Link to 4.1

Create safe and productive spaces with consumers and carers to achieve better outcomes.
Remember that carers have separate needs to consumers – check in with carers on their own wellbeing.

Trauma

Trauma is an emotional response to an overwhelming, distressing event (or series of events) that can have lasting effects on an individual's mental, emotional and physical wellbeing.

If you think your engagement is likely to involve people with lived experience of trauma, seek out further guidance and consider specific training on trauma-informed care and facilitation technique, for you and your team.

When engaging with consumers and carers more often or not you are asking them to draw upon their lived experience, which creates a real risk of re-traumatising them. It is therefore of utmost importance that you are aware of and keep an eye out for signs of a trauma response in stakeholders, and initiate practical steps to respond to this.

Watch for signs and cues of hypo arousal:

- rapid breathing
- irritability
- being easily startled
- lack of focus
- apparent panic
- expressing excessive guilt or shame.

Watch for signs and cues of hyper arousal:

- becoming distant
- eyes glazing over
- slowed responses
- reduced movement or frozen limbs and hands.

Adapted from the Caraniche at Work

Support with trauma-informed practice:

Validate

Empathise with the person, without rushing to resolve their distress

Support safety

Emphasise they are in a safe place, and they are in control

Change focus

Use grounding exercises to shift their focus away from the trauma

Release energy

Divert resources from brain to body

Decrease stimulus

Turn down the lights, move them away from people, turn off devices

Grounding exercises:

- 'box breathing' to count of 4
- tense and release muscles from face to feet
- call out things you can see, feel, hear, smell and taste in the room
- plant feet and focus on just the room.

3.3 Consumer and carer expectations and obligations

It is valuable for consumers and carers to participate in initiatives as they can help create real, positive changes to the health system and allow the rights of consumers and carers to be identified, defended and upheld.

To include their voice in initiatives, it is important for consumers and carers to be clear about the scope of their role so they can contribute honestly and effectively.

Adapted from Health Consumers' Council WA

Consumers and carers will expect to:

- have their value and role in the initiative made clear (why should they participate – clarity is key)
- be heard, listened to respectfully and understood by other members
- see where their input has made a difference – or why it may not have, if this is the case
- be provided information that is easy to understand and free from jargon
- receive all relevant and necessary information, guidance and agendas for meetings, with enough time to read and understand them, and to enable consultation with other consumers, carers and relevant groups if required
- be entitled to disagree with other individuals and to have this disagreement taken into account
- be able to talk to others about the engagement, its deliberations and processes, within the constraints of confidentiality
- feel safe.

Remember to always ask consumers and carers what they think when designing how you will work with them.

Consumers and carers have a responsibility to:

- keep any sensitive information confidential and confirm what may be shared with others
- share the information with others (e.g. consumer advocates, consumer groups, friends and family) where this is part of their role
- treat others with respect and to be treated with respect.

Consumers and carers' obligations are to

- attend and participate in your specified meetings regularly
- participate effectively and constructively
- undertake any duties required of them e.g. reading pre-reading material
- stay informed of community concerns and developments in the area of health they represent.

Consumers and carers also have the right to be paid for many roles:

- Payment depends on the specific role the consumer or carer is playing in the governance activity.
- If the participant has been invited to actively participate, they will be eligible to receive payment.
- It is the responsibility of the project lead to set up the payments at the start of the initiative.

Many health consumers and carers will be dealing with the impacts of health conditions and other life matters. This may mean that they are unable to participate as they would wish, sometimes at short notice.

Other supporting materials

Remember to always ask consumers and carers what they think when designing how you will work with them.

3.4 Cohort-specific guidance

These general tips are not exhaustive, and requirements can differ between people who have the same lived experience.

Tips for working with specific groups of consumers and carers with lived experience

Aboriginal people

- Demonstrate cultural respect by:
    - asking and holding meetings in culturally safe locations and venues
    - ensuring facilitators have completed Aboriginal Cultural training
    - using an Aboriginal co-facilitator.
- Provide information in suitable and culturally appropriate ways such as using plain English and audio visual and pictorial aides.
- Consult with community leaders and Elders prior to and during community engagement to ensure appropriate local protocols are adhered to.
- Include a Welcome to Country delivered by a recognised Elder of the community on whose traditional land the meeting is held.
- Include an Acknowledgement of Country delivered by an Aboriginal or non-Aboriginal person respectfully acknowledging the Traditional Custodians of the land on which the meeting is held.

Culturally and linguistically diverse communities

- Respect community protocols, beliefs and practices.
- Use an appropriate co-facilitator
- Hold engagement activities in culturally appropriate venues, at convenient times and in ways that are comfortable for that community.
- Consult with community leaders prior to and during engagement to ensure appropriate local protocols are adhered to.
- Apply multilingual communication strategies to help people understand the content and express their views, including different language formats, Plain English, audio visual and pictorial aides, Easy Read and face to face interpreters.

Other supporting materials

Tips for working with specific groups of consumers and carers with lived experience

People living with mental health issues

- Support the needs of participants who may want to be accompanied by a friend, family member or peer support worker for support, and in environments where the participant feels most comfortable.
- Offer different engagement approaches which can empower participants to meaningfully participate. The best approach can be gathered through asking the consumer.
- Provide sensory tools when meeting to help improve focus, reduce restlessness and manage anxiety.
- Use tools to support self-regulation e.g. water, snacks, fidgets, paper and pencils, quiet space, colouring etc.

People with a disability

- Consider the individual first and ask them what their preferences might be regarding communication styles.
- Provide information that is accessible such as plain text versions, Braille, audio, jargon free, pictures, plain English, Easy Read and face to face interpreters.
- Provide accessible spaces that are appropriate for consumers, such as including the provision of wheelchairs, guide dogs and support persons.

LGBTQIA+ community

- Ask for and use people's preferred names – name can be an important aspect of identity, particularly for trans people.
- Ask for and use appropriate pronouns (e.g. they/them, he/him, she/her).
- Don't assume people's gender or sexual orientation based on appearance alone.
- Create a supportive environment with flags or posters, overt messages of support in framing materials.

Remember that you can always ask consumers and carers the best way to engage with them.

Tips for working with specific groups of consumers and carers with lived experience

People from rural and remote areas

- WACHS has established consumer and community advisory groups that can support identifying the right consumers and carers to engage with.
- Consumers and carers outside of the main regional centres are very used to utilising virtual technologies, but it is good practice to give them the option to attend in-person or virtually.
- The 7 main regions across country WA are very different in terms of demographics, local service provision and local challenges. Don't assume that there is a 'one size fits all' approach to working with consumers and carers in these areas.

Families and carers

- Ensure informed consent so that families and carers are well informed about their contribution.
- Deliver information that is easy to understand for those who don't directly receive care.
- Remember to ask families and carers about their perspective independently of the person they may be supporting.

Young people

- Use language that is jargon free.
- Conduct less formal meetings, with regular breaks.
- Ensure good practice through attaining informed consent to participate, and obtaining a Working with Children Check.
- Be mindful that young people may be more hesitant to speak in larger engagements – ask for their opinions and consider individual activities that do not require them to actively speak out.
- Meet them where they are' – young people may prefer emails or messages over text, and in-person engagements may be difficult to attend.
- Use tools to support self-regulation e.g. water, snacks, fidgets, paper and pencils, quiet space, colouring etc.

3.5 Facilitation guide

Facilitators have an important role in creating productive and inclusive conditions for all engagements. Effective facilitation fosters genuine relationships with individuals – and is not a tick box exercise.

Facilitation can create safe and effective spaces for consumers and carers, so it is important to invest in developing the facilitation skills of internal staff, and engage an expert facilitator where required.

Effective facilitation involves:

- helping people to participate and harnessing the diverse and equally valuable insights from each person
- creating and fostering safe spaces where people can contribute openly
- planning sessions to get desired outcome
- keeping all participants focused
- identifying and managing issues and conflicts.

Good facilitation is:

- **collaborative** – focus on problem-solving, and maintaining involvement and buy-in
- **interactive** – typically involves activities, including discussions where each person can actively contribute
- **guiding and leading**, not lecturing (it’s about their ideas, not yours)
- **group-based** – allowing people to hear other people’s contributions and collectively build ideas and solutions facilitation involves.

Principles for effective facilitation:

- ensure objectives and expectations are clear
- keep the space safe and inclusive
- listen actively
- honour time
- be flexible
- reflect and evaluate
- close the loop.

Link to 4.4

Common methods of facilitation

Have a broad idea of what your session could include before designing it. Consider what you are trying to get out of the session – from here, identify the types of facilitation required.

There may well be a mix of all types of facilitation throughout a session. It is important to recognise the types that will be required and ensure you have suitable facilitators.

Types of facilitation can include:

1 Guide

The facilitator directs participants in a session, such as presenting an activity and informing people of how to comply with its rules.

2 Connector

The facilitator invites discussion from participants, connecting comments and drawing out key insights.

3 Subject matter expert

The facilitator has strong subject matter knowledge of the content, and uses this to challenge the ideas of participants and push for higher value insights.

Identify the types of facilitation required for your session and use suitable facilitators.

Icebreakers

Warming up your participants, making them feel energised and ready to participate will set you up for success.

Icebreaker examples:

Something in common

Each participant pairs up with another and tries try to find something that they both have in common. Each pair then shares this with the room.

Birthday line up

Participants line up in order depending on when their birthday lies in the year (day and month).

Storytelling circle

Participants sit in a circle and share a brief personal story related to their experiences with healthcare or similar topics. The facilitator can provide a prompt to guide the storytelling, e.g. 'share a positive healthcare experience.'

Choose an animal

Participants share which animal they most identify with. Images of different animals can be presented to participants as a prompt.

Start your session with a suitable icebreaker to create energy in the room.

Activities

In planning your session, consider the activities you will use to keep participants productive and engaged.

Good practice principles for session activities include:

- Questions are straightforward and clear
- Templates directly reflect the questions you are asking
- During group activities, move around the room and answer participant questions throughout
- Participants write down their thoughts rather than just verbalising
- One idea per sticky note
- A maximum of 8 people per table for group or breakout activities
- Return to plenary to summarise and hear whole-of-group views
- Consider sticky dots as voting tools, with a set number of dots per person to demonstrate prioritisation
- When gaining a whole of group or confidential view, consider using an online polling site

Planning a session

When facilitating a session, an agenda and facilitation guide can keep you on track throughout the session. Appropriately planning the session will set you up to generate the output you require whilst keeping all involved stakeholders satisfied with the engagement process.

Key tips:

Ensure accessible logistics promote consumer and carer safety and ease of use for people of all abilities.

Be aware of your influence – your identity may impact the session dynamics, i.e. your gender, culture, age and attire, or simply your place 'as facilitator.'

Brief all facilitators of what their roles will be on the day.

Don't cram too much into the agenda – where relevant, allow time for people to settle into the session, as well as time for staff to be available after the session if the topics have raised any issues that need to be talked through.

Minimise presentations or any time that has people sitting back passively.

Prepare participants – share pre-reading material and the agenda with participants in advance.

Know your audience – for sensitive topics, ensure facilitators have experience or knowledge of who is being engaged and any potential issues that could arise.

Identify a small number of key objectives and be clear on what outputs are needed.

Allow a mix of different activities – individual thinking time, group discussion and plenary discussion time.

Understand who is in the room – the relationships, dynamics and power differentials at play, and organise accordingly to support active participation.

Delivering a session

Once you have planned, you can focus on delivering the session to consumers and carers. Whilst planning sets you up for success, be flexible to the participants in the room when facilitating.

Key tips:

Arrive early to set up the room and test all technology.

Conduct a meaningful Welcome to or Acknowledgement of Country.

Be considered in your language and body language i.e. use Plain English, display good posture and open body language.

Get people moving – give regular short breaks (e.g. stretch or toilet breaks).

Remember that participants do not know your facilitation agenda in detail – if things deviate from the plan, go with the flow rather than overcorrecting.

Engage participants on arrival.

Clearly introduce the facilitation team, objectives, agenda and any ground rules for the session.

Actively listen to stay in tune to the group dynamics and individual needs, e.g. drawing out the participation of quieter participants and managing loud voices.

Adapt your agenda if overrunning – better to cut out content than to rush content.

End the session by thanking people for their time and contributions, summarise what you've heard and indicate how you will close the loop.

Virtual facilitation

Online facilitation has become more common due to remote working and its ability to engage harder to reach cohorts.

When done well, it can greatly enhance reach and impact by removing or reducing some barriers to participation that stakeholders may face, such as distance, availability, access and others. However, it also presents challenges and risks that need to be prepared for.

Practical tips:

- Test your calls – try to quickly test your platform with someone outside of your organisation to understand the joining experience for stakeholders and accommodate for it.
- Be considerate of timing – ensure you choose a session time that is accessible to all of your stakeholders' time zones. Scheduled breaks can help keep longer sessions productive.
- Acknowledge Country everywhere – when conducting an Acknowledgement of Country, recognise that the participants are likely to be located in many different indigenous lands and nations, and adjust your acknowledgement accordingly.
- Trim your agenda – you will typically get through less in a virtual setting than in-person. Be targeted, so you don't have to rush, and everyone gets time to be heard.
- Provide engaging pre-reading – stimulating pre-reading material can help stakeholders buy-in to a virtual session and stay better engaged. It can also provide guidance on how to gain access to the meeting, and if they need a camera and a quiet space.
- Use virtual breakout rooms – most conferencing software supports breakouts, which help bring small-group activities to a virtual setting.
- Keep an eye on the chat and raised hands – ensure you know how to see any comments or raised hands, and acknowledge these appropriately during the session.

Make sure to test and update for compliance with your ICT environment.

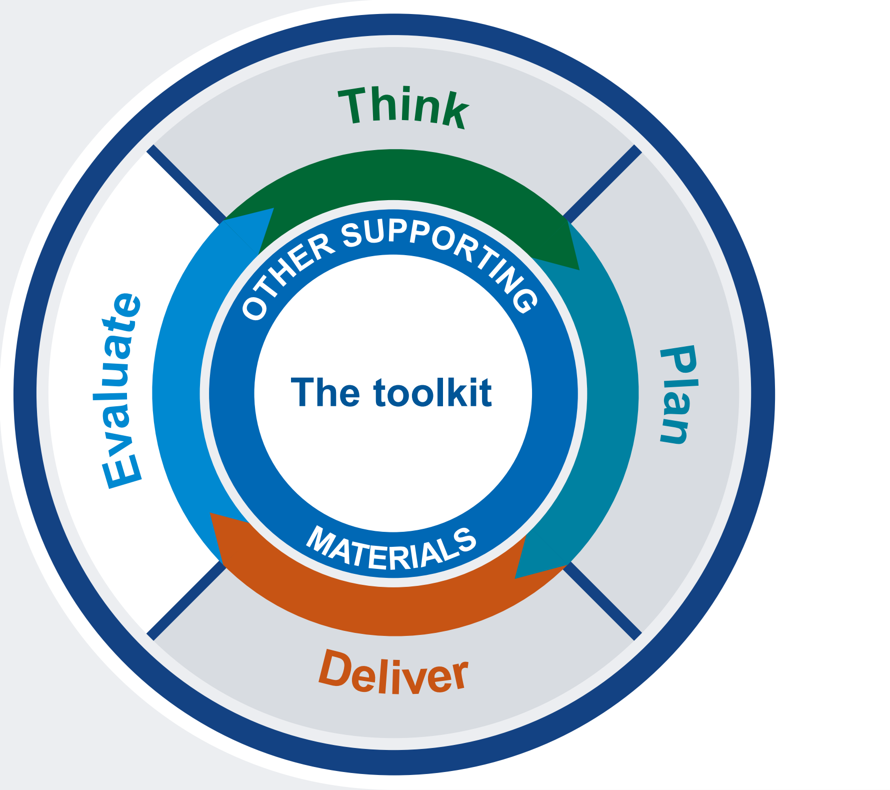
Options	Uses
Microsoft Teams	Chat, videoconferences, collaboration channels, file sharing, virtual whiteboarding.
Zoom	Videoconferences, desktop sharing, webinars.
Kahoot!	Game-style quizzes, polls and discussions.
Slido	Participant quizzes, polls, word-clouds and feedback. Miro Interactive whiteboarding for virtual and hybrid sessions.
Mentimeter	Interactive presentations with questions, polls, quizzes.

4. Evaluate

Checklist

Build and maintain effective engagements with consumers and carers

	Tick
4.1 Evaluation and its benefits	☐
4.2 Types of evaluation	☐
4.3 Seeking feedback	☐
4.4 ‘Closing the loop’	☐
4.5 Evaluation resources	☐



As a baseline, make sure you’ve considered everything - and vary the level of detail and documentation as suits the scale and context of the proposed initiative.

4.1 Evaluation and its benefits

Continuous improvement is achieved through the development of a quality evidence-base to support fair and transparent decision-making.

The information gathered can provide critical insights that enable more productive and rich engagement opportunities with consumers and carers in the future that enable positive outcomes in the health system.

Evaluation is the regular and routine process of collecting, analysing and reviewing information on the results and outcomes of an initiative – or in this case, the outcomes of engaging with consumers and carers.

This information is then used to determine how well you have done in achieving your desired outcomes, and:

- understand what could be done differently or how to improve future practice
- recognise if public resources have been used effectively
- build transparency and accountability through sharing your outcomes

Link to 1.2

Think about evaluation from the very beginning, and throughout the engagement process.

4.2 Types of evaluation

When you start to plan and conduct your evaluation, consider its purpose and what you are trying to measure. Deciding what you are trying to evaluate will guide the type of questions you will answer.

There are many different accepted types of evaluation – in this context, there are 2 types of evaluation that will be most relevant to use, outlined below. Ideally you will use both types of evaluation when working with consumers and carers.

1 Process evaluation

Focuses on the actual engagement process itself, rather than the outcomes. Some questions to consider include:

- What was the participants' level of satisfaction with the project?
- How did you ensure your engagement was inclusive?
- Were participants aware of how their contributions would be used?
- What practical changes would you make to your engagement approach if you were to do it again?

2 Impact evaluation

Focuses on creating meaningful changes for consumers and carers as a result of the work. Some questions to consider include:

- Were the objectives and outcomes achieved?
- Were the engagement strategies effective to gather the required information?
- How valuable were the insights and outputs in contributing to the final outcomes?
- Are the consumers and carers bought into the outcomes?

Decide what you are trying to evaluate to guide the type of questions you will answer.

4.3 Seeking feedback

Gathering and sharing consumer and carer feedback helps all stakeholders understand what is or isn't working, how things might be improved, and how to get the most out of their efforts supporting the initiative.

Seeking feedback effectively means finding useful ways to seek it, and the right ways to frame and share it, so it does not feel threatening or combative – but also gets to the point. Ask consumers and carers how they would like their feedback collected, and keep it simple.

How do I collect feedback?

To identify how you will frame and solicit consumer and carer feedback, consider these key questions:

- How often do you want to collect feedback?
- What channels are consumers and carers most familiar with? Does feedback need to be collected in different formats (e.g. Citizen Space, Microsoft Forms, hardcopy surveys, emails, phone calls)?
- What accessibility and other requirements do consumers and carers have (e.g. translation or interpreter requirements)?

Key tips

To effectively collect consumer and carer feedback, create feedback mechanisms that consumers are likely to respond to, and that will be useful for staff once collected.
Tips for soliciting feedback include:

- be concise
- use a format that is accessible i.e. non-digital or digital, with access to translation or an interpreter – this can include offering multiple formats
- use simple language in Plain English
- be easy to use for staff, where data can be compared across multiple periods
- tailor to what people in the community care about and want to be involved (ask them!)
- allow people the opportunity to provide feedback anonymously
- allow and emphasise open lines of communication for feedback from the outset
- capture notes throughout your meetings and other engagements
- ensure that feedback is captured throughout the process, and not just at the very end
- view constructive feedback as an opportunity to grow and improve rather than an insult – it is often the most valuable form of feedback to receive.

4.4 Closing the loop

'Closing the loop' means informing consumers and carers of the impact that their involvement has had, demonstrating that their time and contribution is valued and ultimately builds trust. This in turn encourages them to participate in future initiatives.

Closing the loop can actually happen throughout the process – not just at the end. The diagram below represents 3 important steps for you to close the loop with consumers and carers.

1 We asked

- Remind participants about the initiative, its intended outcomes and why it is important.
- Ensure they understand the importance of their contribution to the initiative.

▶

2 You said

- Provide participants with an overview of what people have said so far and the information that has been captured. This could be a summary document highlighting key themes, or verbal feedback given to a group.
- Updates can be provided periodically throughout an initiative, not just at the end.

▶

2 We did

- Outline what happened with the participants' contributions, including what it was used for and why it was or was not used. Where possible, share this information publicly, e.g. online, to build further trust.
- As there may be months or years between the end of the initiative and any outcomes, regular updates are important. This could include a formal thank you and acknowledgement of members for large initiatives.
- Remember to 'circle back' internally to ensure the solution addresses participant feedback.

Key considerations

- How much detail will you include in your communications?
- Have you asked participants how they want to be informed, and given them options to easily opt out if they wish to?
- How often will you communicate with participants on the outcomes of their contributions?
- What communication channels will be used to close the loop?

Other supporting materials

4.5 Evaluation resources

Evaluating any initiative will help you understand the strength of the engagement process, as well as the initiative itself. Although the scope of the evaluation will depend on the size and nature of the initiative, it is important that you plan for the evaluation early and review the engagement regularly.

Additionally, consumers could be involved in the design of your evaluation from the outset of the initiative (if time and resources permit and it is appropriate).

Key considerations

Before beginning an evaluation, it is important to consider the context in which it will be conducted:

- Are the intended methods secure and accessible for culturally and linguistically diverse people? If not, what adjustments need to be made?
- Is the format suitable to collect the information needed? Will other methods e.g. enabling latent input be required?
- What is the next step following the evaluation? Consider how you will close the loop.

Existing evaluation resources

- Public and Patient Engagement Evaluation Tool (PPEET) – McMaster University, Canada
  - A series of 3 questionnaires to evaluate public and patient engagement. The Project Questionnaire is most relevant, and the tool requires free sign up to download.
- Evaluation of Consumer Involvement – Cancer Australia
  - A resource from the Consumer Involvement Toolkit highlighting key evaluation questions and methods that can be used when engaging consumers, carers and the community.
- Research and Evaluation Framework Implementation Guide – Department of Health, WA
  - A detailed guide for planning and evaluating the outcomes for health promotion programs.

Other supporting materials

Leverage the strength of existing guidance and templates, including from other organisations, and supplement your understanding of working with consumers and carers.

Other tools and resources

Working with consumers and carers is not a new concept and there is a lot of good practice guidance from other organisations that can support you.

Frameworks and toolkits

- Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2015 and accompanying Toolkit – **WA Mental Health Commission**
    - Provides step-by-step guidance on planning, developing, actioning and reviewing engagement strategies and practices.
- South Australia's Better Together Handbook – **Government of South Australia**
    - Outlines key principles for effective engagement.
- Stakeholder Engagement Toolkit – **Department of Health and Human Services, Victoria**
    - Provides a step-by-step guide to developing and implementing successful engagements with stakeholders, including templates to use.
- Co-Design Toolkit – **WACOSS**
    - Provides a range of practical tools to engage funders, community service organisations and the users of community services in the co-design of programs and services.
- Communities Partnership Framework – **Department of Communities, WA**
    - Provides guidance to all of their staff in their relationships with stakeholders across all sectors.
- Health Engagement Network – **Health Consumers' Council**
    - A community of practice for those involved in consumer and carer engagement across the health system in WA. The online platform links to existing frameworks on consumer and carer engagement in the health sector in WA.

Cohort specific guidance

- Connect with me co-design guide and toolkit – **People with Disabilities WA**

  Provides guidance on how to co-design with people with disability on all aspects of policy, services, and facilities intended for use by people with disability.

- Seven threads prompt book – **Australian Centre for Social Innovation**

  Helps non-Aboriginal and Torres Strait Islander organisations engage with First Nations people.

- Tips for engaging culturally and linguistically diverse communities – **Office of Multicultural Interests, WA**

  A guide to help service providers engage with CaLD groups and individuals who differ according to religion, race, language and ethnicity (except those whose ancestry is Anglo Saxon, Anglo Celtic, Aboriginal or Torres Strait islander).

Relevant policies and procedures

The following links provide important guidance about the Department of Health's internal policies and procedures to adhere to.

Paid Participation Policy guidance

- Consumer, carer and community paid participation in engagement activities policy
- Consumer, carer and community paid participation in engagement activities guideline
- Schedule of consumer, carer and community payment for participation (by participant tier and engagement activity).

Aboriginal Health Impact Statement and Declaration Policy

- Outlines requirements to declare and demonstrate that the interests of, potential impacts on, and opportunities for, Aboriginal people are considered and appropriately embedded within policy development processes.

Information security and privacy policies

- Information Access, Use and Disclosure Policy
- Information Security Policy
- Information Storage Policy
- Information Retention and Disposal Policy.

Upcoming engagement activities

If consumers wish to participate in relevant consumer and carer engagement activities, the links below provide information on upcoming engagement activities that could be of relevance to them.

Citizen Space – Department of Health

A hub for people to participate in online consultations in the areas of public health and clinical services, planning for frameworks, policy and guidelines.

Citizen Space

Stakeholder Connect – Mental Health Commission

Allows subscribers to receive email newsletters and tailored communication on opportunities to contribute to the work of the Mental Health Commission and the broader sector, and information on key sector reform projects that are both upcoming and underway.

Stakeholder Connect

Training advice

Though it is helpful to follow this toolkit's advice to build capability in working with consumers and carers, engaging in other training opportunities is valuable to support this capability building process. The following links below provide practical and interactive training and development opportunities.

HCC's Upcoming Events and Training Opportunities

Offers different workshops to support the development of health service staff and consumer representative, such as improving your understanding of cultural diversity and providing networking opportunities for consumers.

Link to Workshops

This document can be made available in alternative formats.

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