



All of Us

An introduction to our guide
to engaging consumers, carers
and communities across NSW Health

Made by many and for many

NSW Ministry of Health - Experience Team

NSW Health



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SHPN (MoH) 230271

ISBN 978-1-76023-500-0 (print), 978-1-76023-501-7 (online)

Published May 2023

Acknowledgements

We acknowledge people of the many traditional countries and language groups of New South Wales. We acknowledge the wisdom of Elders past and present.

We recognise and value consumers, carers, supporters and loved ones. Lived and living experience is powerful [1].

Thank you to Jenni Smith, Garth Hungerford, Tara Lee, Ged May, Alicia Wood, Ali Cook, Sam Dart, Heather Moses, Megan Alston, Jacqueline Karim and other Design Crew¹ members. To our Advisory Group and the 160+ consumers, carers and staff who gave their views on our first draft. KA McKercher (Beyond Sticky Notes®) and Sue Muller (Better Together Collective) led the process to make this guide. Design by Lucy Klippan (Good Point Design).

1. Made up of consumers, carers, community members and staff.

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All of Us is more than a document.

All of Us has a website with tools and tips:
www.health.nsw.gov.au/patients/experience/all-of-us

Learn how All of Us was made:

www.health.nsw.gov.au/patients/experience/all-of-us/Pages/making-all-of-us.aspx

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Who the Guide is for

All of Us is for:

- NSW Health staff engaging consumers, carers and communities in projects, research, events and committees – or NSW Health staff hiring external facilitators and organisations who do training on consumer, carer and community engagement
- anyone else leading engagement for NSW Health agencies
- consumers, carers and communities. We hope you can use [Six ways of working](#) and five tools to:
 - know what to expect
 - work with health staff to plan projects, events and committees
 - reflect on how you're engaged and what to do better.

Six ways of working

The [Six ways of working](#) are for any engagement. In this document we introduce these ways of working and give examples of how to use them across engagement phases (pages 13-17).

On our website, you'll find tips, videos and tools for each way of working. We include:

- what we mean
- what consumers, carers, staff and communities should expect
- what facilitators and meeting Chairs can do
- what's not okay.

What's in the Guide

All of Us is a high-level guide to respectful consumer, carer and community engagement across NSW Health.

It doesn't replace consumer or community engagement frameworks from local health districts or NSW Health agencies.

The Guide doesn't include:

- how to engage specific cultural groups or identities or in specific parts of health – for example, mental health, justice health, LGBTQI+ health
- why health services should engage with consumers or the benefits (this information has been available for many years)
- how to deliver services
- how staff should interact with consumers and carers in clinical care
- how to do co-design or co-production.

Five tools

Consumers, carers, staff and independent facilitators created five tools to put the [Six ways of working](#) into action.

1. **Plan questions**
2. **Essentials checklist**
3. **Method cards**
4. **Explore access and inclusion questions**
5. **Explore safety activity**



Why we made it

In 2021, a few hundred staff, consumers and carers were involved in working groups. The groups were about the enablers of human experience [2] in the Elevating the Human Experience (ETHE) Guide to Action. In the groups, a high-level guide for consumer, carer and community engagement was a priority.

This Guide is the result.

What it helps with

Respectful engagement

Talking with consumers and carers, we heard about good experiences and not-so-good experiences of engagement activities across NSW Health. Good experiences used the [Six ways of working](#). Not-so-good experiences didn't.

Here we (the NSW Ministry of Health Experience Team) explain the impact we want to have with this Guide. We use a simple Theory of Change (Figure 1). A Theory of Change is a tool to explain the impact we want to have and how we think we'll get there.

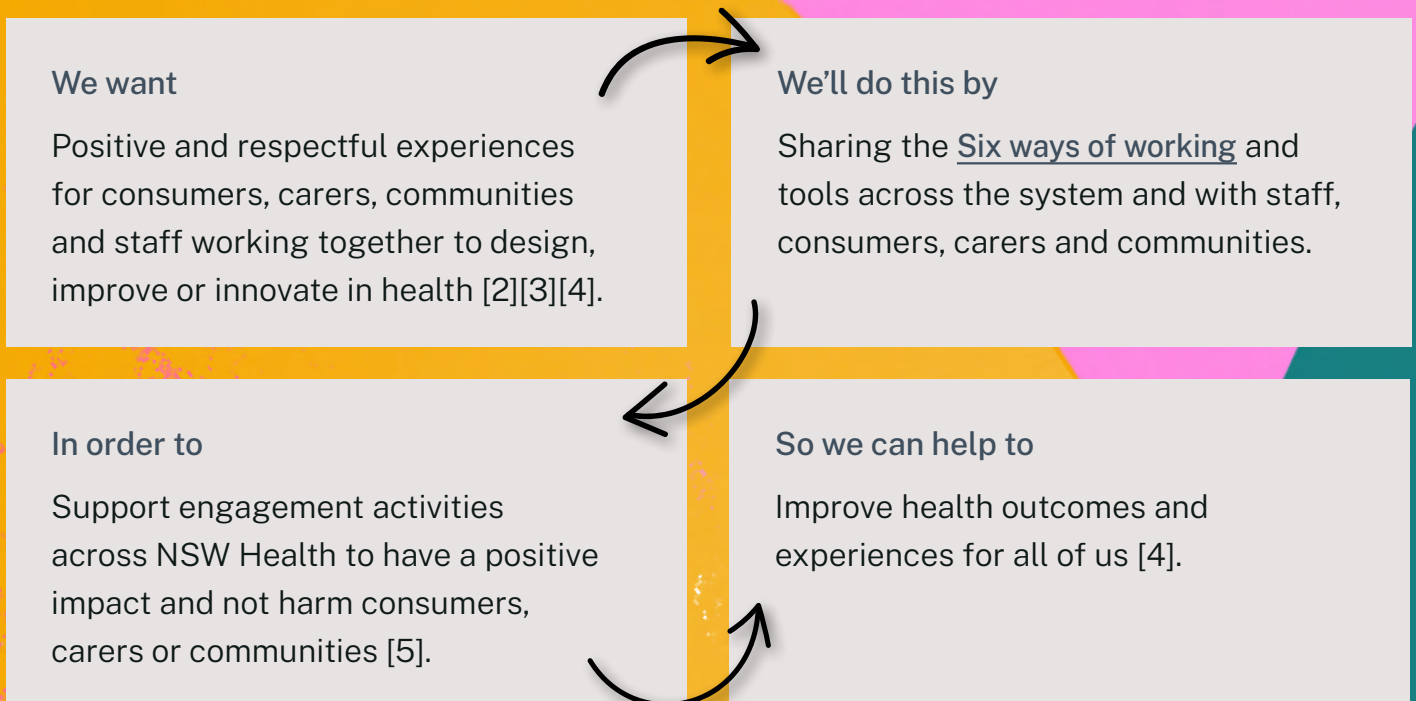


Figure 1: Theory of Change

Key Terms

Here are some words we use in 2023. If you're reading this in the future, language may have changed.

Consumers: People who use, have used, or are potential users of health services. Some consumers have formal roles (such as Consumer Representatives) – others don't want to. All perspectives are valuable. No one can represent all consumers.

Carer: A person who provides care and support to a family member, friend or as part of a kinship system. Consumers and carers are different people with different perspectives.

Communities: Groups of people who share things such as culture, language, religion, beliefs, location, sexuality or gender. We use 'communities' because there is no one 'community'.

Engagement: Consumers, carers or communities taking part in the planning, design, delivery, measurement and evaluation of systems and services [3] [4]. There are different levels of engagement [6].

Engagement activity: Specific ways that consumers, carers and communities take part. Here are a few examples: co-design, service design, research, hospital redevelopments. Read about more activities on pages 7 and 8.

Engagement process: The parts or 'phases' that happen across a project. We use four phases: **Plan, Invite and support, Do and decide, Review and learn.**

Facilitator: A person leading activities and making sure the [Six ways of working](#) happen. Facilitators can be NSW Health staff, contractors, consumers, carers or community members.

Lived or living experience: The knowledge you get when you have lived or are living through something. For example, a person with lived experience of mental illness brings their understanding and knowledge from their direct experience [7].

Marginalised: A person or life experience (such as being homeless or leaving foster care) that has been or is excluded from support, community and services.

Power: Someone's ability to do something – for example, set an agenda or decide what engagement happens. Power is getting to decide who gets listened to.

Safety: Safety can be physical, emotional, legal and cultural. No one should be harmed by their experience of engagement. [Learn what we mean.](#)

Tool: A tool helps you do something – for example, have a conversation, create a safety plan or plan a project with consumers, carers and communities.

Activities the Guide applies to

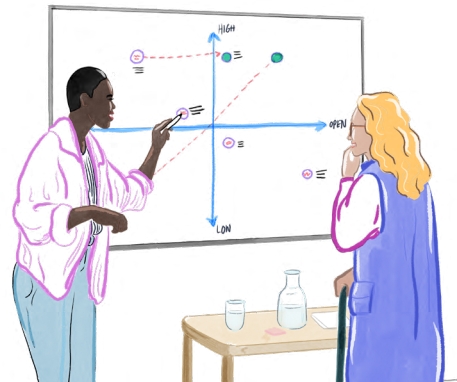
All of Us applies to all consumer, carer and community engagement activities led by or on behalf of NSW Health, local health districts and other health agencies.



research



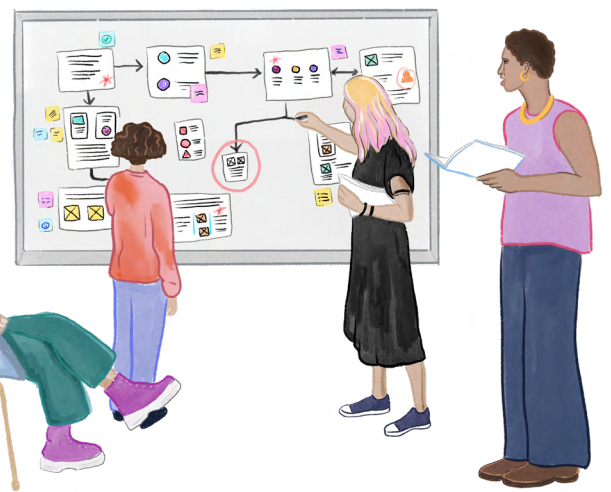
co-design and co-production



policy, strategy and reform

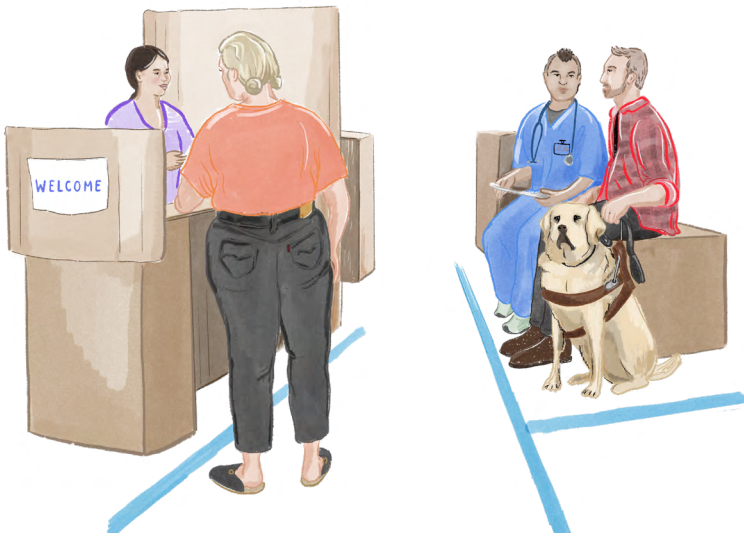


measurement and evaluation



quality and safety

Continues on next page...



facility redevelopment



continuous improvement



service design and clinical redesign



committees and working groups



governance and leadership

What the Guide connects with

All of Us connects with and supports:

- [Elevating the Human Experience - Our guide to Action](#)
- [The Australian Commission on Safety and Quality in Health Care - Partnering with Consumers Standard](#)
- [The NSW Health Future Health Strategy](#)
- [NSW Regional Health Strategic Plan for 2022-2032](#)
- [The NSW LGBTIQ+ Health Strategy](#)
- Trauma-informed practice (specifically - safety, choice, trustworthiness and collaboration) [8].

This guide *doesn't* focus on engaging patients in their own care. So it doesn't connect with frameworks for clinical communication or service delivery.



Six ways of working

For respectful consumer, carer and community engagement.

1. **Create and maintain safety**
2. **Ensure accessibility and welcome**
3. **Offer recognition**
4. **Use power in partnership**
5. **Be honest and keep people informed**
6. **Increase diversity and inclusion**

The Six ways of working are non-negotiable for all levels of participation. From consultation to co-design and everything in between [6].

We call these ways Core Ingredients. When the ingredients are missing, or there's not enough of them, we leave people out. Then, we miss out on their insights and ideas. In your context, communities may ask for more of some ingredients (such as more safety). And, they'll bring their own ingredients. [Watch Jess Smith talk about the ingredients of good engagement with Aboriginal communities.](#)

On the [website](#), you'll find:

- what each ingredient means
- videos with consumers, carers and staff
- tips and tools for facilitators [9] and meeting Chairs.

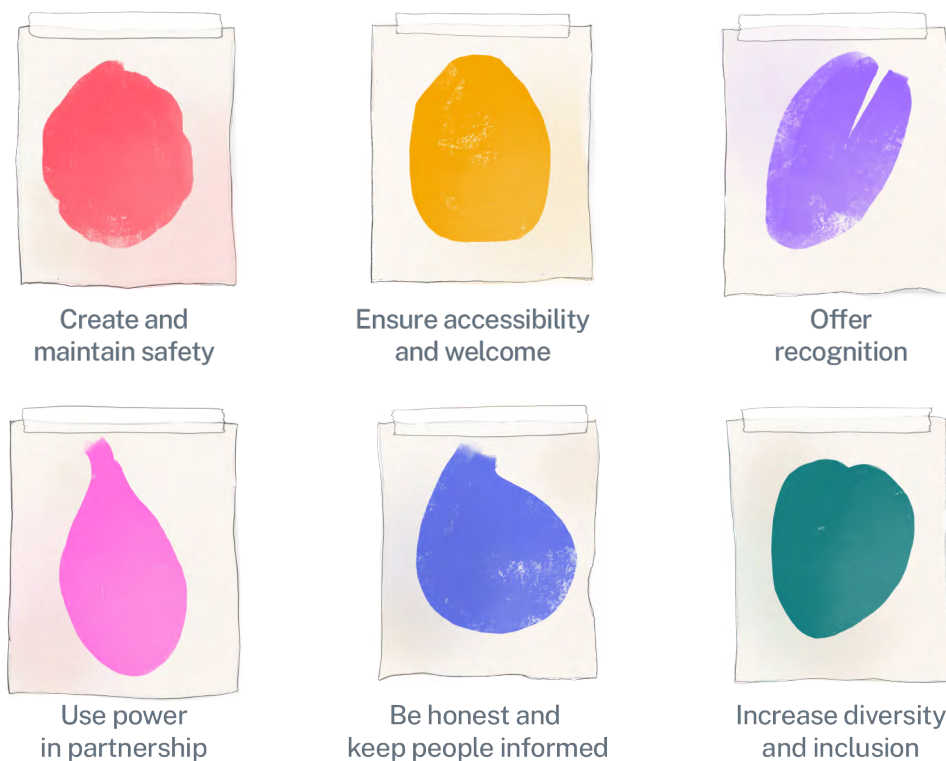



Figure 2: Core Ingredients for respectful consumer, carer and community engagement.

Click on each  Core Ingredient to read more

Core ingredients for all consumer, carer and community engagement at a glance

Find tips and videos at:
[www.health.nsw.gov.au/patients/
experience/all-of-us/Pages/six-
ways-of-working.aspx](http://www.health.nsw.gov.au/patients/experience/all-of-us/Pages/six-ways-of-working.aspx)



Create and maintain safety

We create physical, emotional, legal and cultural safety. We know just saying 'this is a safe space' isn't enough. We make sure everyone knows what to expect and what isn't ok. We make changes when there's not enough safety.



Ensure accessibility and welcome

We make everyone welcome. We're hospitable and caring in physical and virtual spaces. We communicate in ways we all understand. We remove barriers to consumers, carers and communities taking part.



Offer recognition

We value lived experience for time. We're curious about what recognition means to the people we're engaging. We do financial and non-financial recognition. Our payment processes are accessible, prompt and fair.



Use power in partnership

We make sure decisions that impact consumers, carers and communities are informed them. We acknowledge historic and current power differences between organisations and communities. We partner in the planning, design, delivery, measurement and evaluation of care.



Be honest and keep people informed

We say what can be changed and how decisions will be made. We share progress so we can all improve our health system. We show consumers, carers and communities how their contributions make a difference.



Increase diversity and inclusion

We don't expect one conversation or person to represent a community. We reflect the diversity of our communities in conversations, groups and committees. We use different ways to engage different people. We listen to communities on how to engage them best.

How to use the Six ways of working and tools

As commissioners and contract managers

If you're hiring external facilitators or an organisation who does training on consumer, carer and community engagement:

- link to the [Six ways of working](#)
- ask the contractor(s) to show specific examples of how they'll use the [Six ways of working](#)
- listen to the people engaged about their experience.

As staff and facilitators

Work with consumers, carers and communities to:

- Use the **Plan questions** and **Method cards** to plan a project, group or event.
- Use the [Six ways of working](#) to identify strengths and things to improve.



Here are some questions you can ask:

- What practices from the [Six ways of working](#) do we use?
- What do the ways of working mean to local consumers, carers and communities? For example, safety. If you're talking about safety, you could use the **Explore safety activity**.
- How confident are facilitators in using the ways of working? [9]

- Do staff facilitating engagement have any learning needs? For example, additional support with trauma-informed facilitation [8], working with power differences.
- Should staff facilitate the engagement(s)?

Use the **Essentials checklist** to:



- plan a project, meeting or event
- check what you might be missing
- assess safety and accessibility
- help staff know what to do.

Use the **Explore access and inclusion questions** so consumers, carers and communities can take part.



As consumers, carers and communities

We hope you'll find the [Six ways of working](#) and tools helpful to:

- know what to expect
- work with health staff to plan inclusive and safe projects and committees
- reflect on how you're engaged and what could be better.

Showing the ways of working across phases

To give you a head start on using the Six ways of working we show you some actions you can take.

We do this across four common phases of engagement (Figure 3).

- Phase 1: Plan
- Phase 2: Invite and support
- Phase 3: Do and decide
- Phase 4: Review and learn

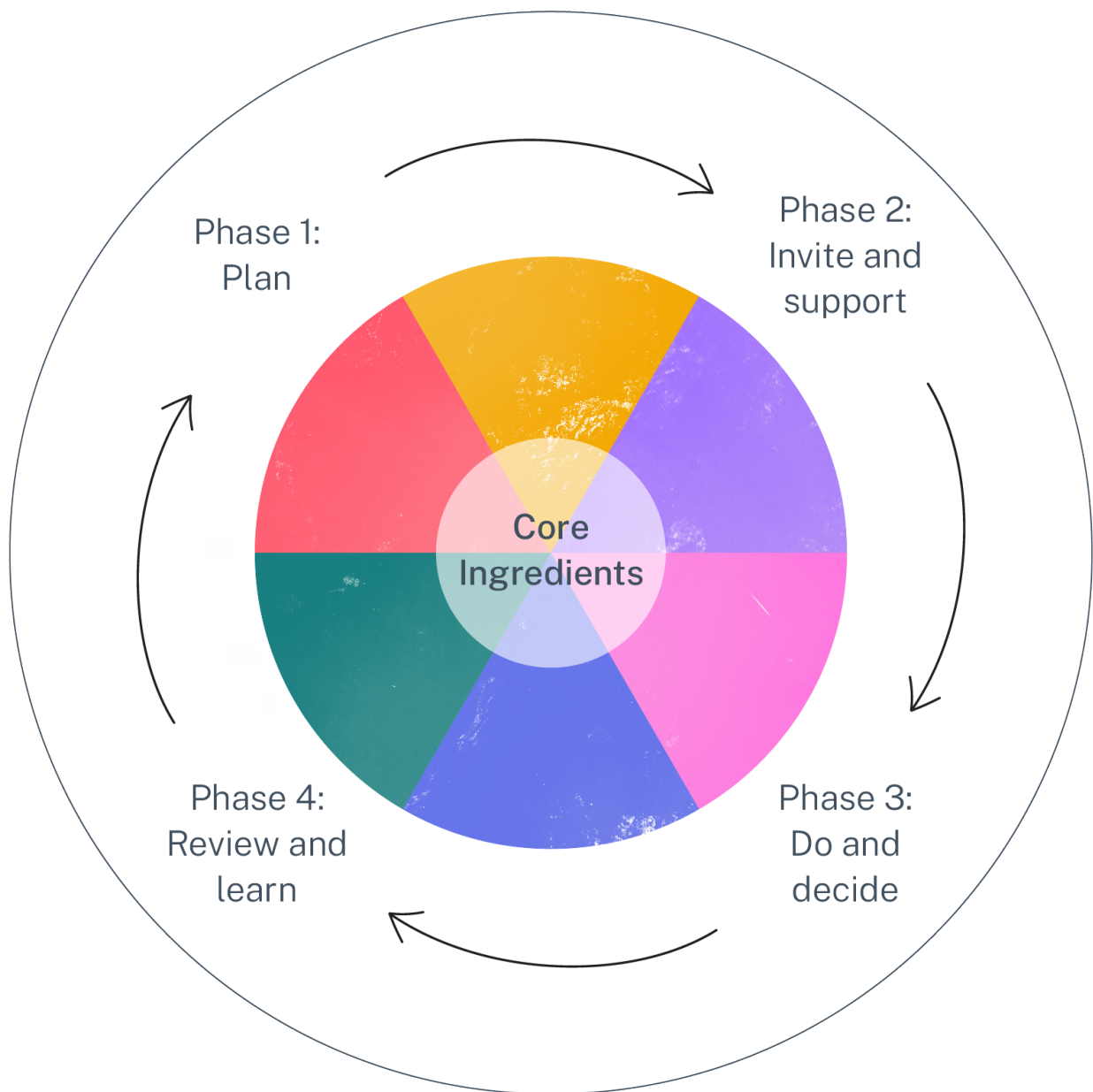


Figure 3: Four common phases of engagement

Phase One: Plan

Build relationships and decide how to do things together.

To make decisions about engagement, here are six things to think about.

1. What's the purpose?
2. What's the budget?
3. What's the pace?
4. Who needs a say?
5. Who are your partners?
6. What methods to use?



Here you can find a tool to help:

<https://www.health.nsw.gov.au/patients/experience/all-of-us/Documents/plan-questions.pdf>

Using the [Six ways of working](#):

- Identify what can and can't be influenced by consumers, carers and communities. Communicate honestly.
- Making planning decisions with consumers, carers and community members.

- Be clear about the diversity you need and expect. No one should be expected to represent their entire community.
- Talk with consumers, carers and communities about what recognition means to them. Offer choices.
- Build payment (for those who want it) into your project budget.
- Ask people what they need to be included. Don't assume. Do your homework about what different people might need. Let consumers, carers and communities know how you're planning for access and inclusion.
- Plan for **safety** (yours, too).
- Pick accessible venues where consumers, carers and communities are comfortable.
- Add another way of communicating that isn't only writing – images, a rough video or something else.

Tools for facilitators:



- Plan questions
- Essentials checklist
- Method cards
- Explore access and inclusion questions

Get tips and watch videos:

www.health.nsw.gov.au/patients/experience/all-of-us/Pages/tools.aspx

or via this QR CODE:



Phase Two: Invite and support people to stay included

Be welcoming and warm.

Using the Six ways of working:

- Let consumers, carers and communities know:
 - what you're asking them to do and why
 - the time commitment and options for how they'll be recognised for their help
 - the rules that will limit ideas and solutions (such as law and regulation, branding, money, staffing)
 - what decisions have been made
 - what support they can access.
- Know if you're consulting, co-designing or something else [6]. If it's co-design, involve consumers, carers and communities in making things and making decisions (where possible). **Don't say it's co-design if it's not.**
- Ask people what they need to be included. Don't assume. And, do your own homework about what different people might need. Here's an example of how to plan for access and inclusion.
- Warmly connect with consumers one-to-one before activities. This will help you understand what they need and give you time to make it happen.
- Know that people who haven't felt safe may not be able to explain safety or trust that needs will be met.
- Share welcome information (you might call this *onboarding*). Try to use a few different ways (for example, pictures, a chat, a rough video).
- Give permission for everyone to look after themselves. This could mean leaving the room, fidgeting, turning cameras off or having a support person or pet.
- Make agreements on what is okay.

Tools for facilitators:



- Essentials checklist
- Explore access and inclusion questions
- Explore safety activity

Get tips and watch videos:

www.health.nsw.gov.au/patients/experience/all-of-us/Pages/tools.aspx

or via this QR CODE:



Phase Three: Do and decide

Make decisions together.

Using the Six ways of working:

- Be open to slowing down or changing your approach. It's okay to make changes so the engagement is valuable for everyone involved. And so everyone has time to make good decisions.
- Ask for feedback from consumers, carers and communities on how the work is being done.
- Give choices about how people contribute. Think about different ways that will suit different people – using drawing, writing, having someone else contribute on your behalf, post-it notes (digital and physical), messaging, speaking, yarning, polls or something else.
- Repair safety or accessibility when it's missing. Apologise when you get things wrong.
- Think about hospitality in physical and virtual spaces. That might include warm hellos and goodbyes, a nourishing meal, a cup of tea, checking-in afterwards or something else.
- Give regular updates on the work. Don't assume what consumers, carers and communities want to know. Share the good and bad bits in different ways (such as pictures, rough videos).
- Acknowledge the input of people with lived experience in the work. And acknowledge their input when you talk about the work in meetings, reports and presentations. Provide ways for people to share the work they're involved in [10].



Tools for facilitators:



- **Essentials checklist**
- **Method cards**
- **Explore access and inclusion questions**

Get tips and watch videos:

www.health.nsw.gov.au/patients/experience/all-of-us/Pages/tools.aspx

or via this QR CODE:



Phase Four: Review and learn

Review the experience of the people involved and the impact of what you made together.

While we describe reviewing here, we hope you'll listen and learn throughout engagement activities. Not just at the end.

Using the Six ways of working:

- Plan how you'll end projects or work phases. Recognise people's contributions.
 - Celebrate (if that's appropriate). Or make time for grief and disappointment if the work didn't turn out as you'd hoped.
 - Look for ways to co-present with consumers, carers and communities. And for ongoing involvement in other things – service design, delivery, leadership and evaluation.
 - Make sure consumers, carers and communities help to review the engagement efforts. What worked from their perspective? What didn't work?
- Consider how and where you'll share the outputs of the work. If things didn't go well, consider sharing a 'fail report' [11] or something similar of the parts that didn't work so we can all learn.
 - Notice who didn't or couldn't show up after the first meeting or session. Who left and didn't come back? What can you learn?
 - Identify barriers that stopped people from participating. Or that meant they couldn't be themselves. Identify how to improve next time.
 - For co-design projects, review if you met your goal for higher participation [6].
 - Know that while you might think you did co-design, the people involved might not.



Our current tools don't focus on measurement or evaluation.

We're curious ... what did you use from this guide? Which of the Six ways of working made a difference? Let us know: MOH-PatientExperience@health.nsw.gov.au

Other enablers of respectful engagement

What else makes respectful consumer, carer and community engagement happen?

Here are a few things:

- **having strong leadership and support from local or agency leaders and executives**
- having leadership and participation of consumers, carers and communities at all levels
- partnering in the co-design and implementation of models of care [4]
- taking and making time to build relationships, partnerships and trust
- using cultural practices and protocols for engagement [11]
- using the Elevating the Human Experience enablers [2]
- making health-literate print, audiovisual, website and social media content [4][11]
- offering ways for everyone to learn new skills and share the skills they have
- bringing together research, empirical and experiential evidence [11]
- having clear processes and procedures for involving consumers, carers and communities with room for flexibility
- on-going feedback on the quality and impact of engagement.

Thank you for reading.

You've come to the end of the introduction.

Visit our website to find tips and videos:

www.health.nsw.gov.au/patients/experience/all-of-us



References

On our website, you'll find many more references connected to the **Six ways of working**.

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