

# The Participation Ladder

## A consumer/survivor lens



**People want to have a say about the things that affect their lives.**

The bigger the impact, the more say we want.

And if a service or system has the power to take away our human rights, if it can hurt us—then we should be the people whose voices matter most.

**Moving up the ladder is a way to address social injustice and inequity.**

The higher you move up the participation ladder, the more say we get to have about our own lives.



Power imbalances are very real and quickly felt, for people who've experienced others having complete control over their lives. Addressing power imbalances will be your biggest and most challenging task in any participatory work.

**It's good to move up the ladder—but it's even more important to be honest.**

We'd rather know that you can only do engagement, and then do some good quality engagement, than be part of tokenistic co-design.

Being upfront about the limits of your participation process is one way to recognise power, avoid tokenism, and build trust.

# Participation Ladder



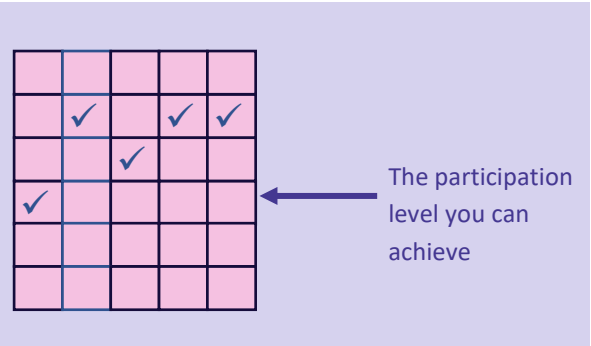
Type of participation	What happens at each level	Implications & views	Power
Consumer owned	Consumers: <ul style="list-style-type: none"><li>Define the problem or need</li><li>Design &amp; provide the solution, delivery &amp; evaluation.</li></ul> Govt/sector support this with funding. Work is within consumer-run enterprises.	<b>People doing it themselves.</b> <i>Enabling, empowering.</i>  Government trusts that people are best placed to lead and own the development and delivery of what they need - if resources are provided.	<i>People have power over the services they need and use</i>  <i>Consumers have expertise that govt doesn't – and this expertise matters most.</i>
Consumer-led	Consumers lead the process, with others, to: <ul style="list-style-type: none"><li>Define the problem or need</li><li>Design &amp; provide the solution, delivery &amp; evaluation.</li></ul> Govt/sector support this with a range of resources. Work is within existing services & systems.		
Co-Production	Govt/sector works in partnership with service users <sup>1</sup> to: <ul style="list-style-type: none"><li><b>Co-plan</b> &amp; define the problem or need and</li><li><b>Co-design</b> the solution, <b>co-deliver</b> the service &amp; <b>co-evaluate</b> it</li></ul> Consumers form a majority of committee and project group memberships. Govt/sector ensure they privilege, hear, value, debate & act upon consumer views. Decisions are not made unless the majority of consumers agree. Power imbalances are proactively redressed.  Consumers are part of delivering and evaluating the solution.	<b>Doing <u>with</u> people.</b> <i>Collaborative partnering.</i>  Government shares power and potential equally with the people who will receive the service.  Recognition that each party has something valuable to bring to the process.  Decision making is shared, as is design & delivery to some degree – or even completely.	<i>Govt &amp; sector shares the power with the people who use services.</i>  <i>The expertise of consumers is just as critical as other expertise.</i>
Co-Design	Govt/sector works in partnership with service users <sup>1</sup> to <b>plan, design, deliver or evaluate</b> the problem and solution.  For whichever part of the process that is co-developed, consumers form a majority of committee /project group memberships. Consumer views are privileged, heard, valued, discussed and acted upon. Power imbalances are proactively redressed.  Consumers may or may not part of delivering the end result.		
Engage	Govt/sector involve consumers in thinking through some, many or all aspects of decisions. This is most commonly seen by having a minority of team members as consumers (good practice should be a <i>minimum</i> of 2).  Consumers are a minority, often with less power and resources than others, and just one of many stakeholders.	<b>Doing <u>for</u> people.</b> <i>Participants without power.</i>  Government takes account of consumer perspectives & opinions in some way.  They create limited opportunities for people to 'have their say' or get involved – but government (or the sector) makes the final decisions.	
Consult	Govt/sector ask consumers what they think, and this becomes one of many considerations.  This is most commonly done by holding dedicated consultation sessions or surveys with consumers.		<i>Govt and sector hold the power and value their own expertise most of all.</i>
Inform	Govt/sector tell consumers about their decisions.  They may provide an opportunity for feedback. What is done with feedback varies.	<b>Doing <u>to</u> people.</b> <i>Passive recipients.</i>  Consumers are not part of policy, service design or delivery. Govt/sector makes the decisions based on their own expertise.	
Educate	Govt/sector teach consumers about what they've decided so people know why it is good for them.		
Coerce	Govt/sector expect consumers to accept the changes made on their behalf.		
Exclude	Consumers are unable to access services or systems or decision making.	<b><u>Excluding</u> people.</b> <i>No involvement in any way.</i>	

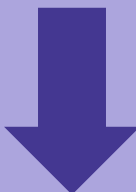
<sup>1</sup> **Service users (consumers and carers):** It is a common misconception that consumers and carers should have equal 'representation' on committees and projects. In practice, if co-production or co-design is about services for mental health consumers, then consumers should form a majority of working group memberships. This is intended to redress power imbalances, and to put the people who have lived-expertise of the issue, and will use the service, at the heart of the work. This is also about addressing power imbalances, and striving to create equity and promote self-determination. Carers/family would in most cases still be included as critical stakeholders, with the role of addressing carer needs. Carers should have more than one representative in order to redress the power imbalances. If the end service is for carers, then carers are the service users and they should be in the majority, while consumers would be a smaller group of stakeholders.

# What level of participation can your project achieve?

Use this checklist to assess the participation options for your project.

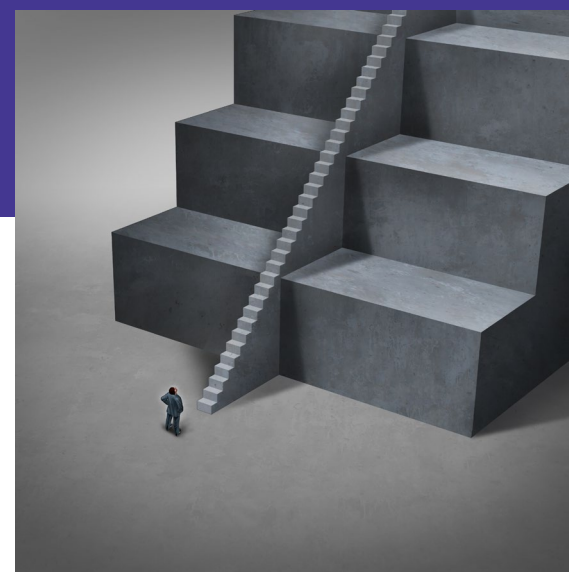
**Instructions:** Work through one column at a time, and work from the top down. Identify the highest level you can reach in each column and tick that option. The lowest row with ticks is the level of participation that your project can achieve.



Participation level 	How many consumers are involved & how?	Who decides the project scope, defines the problem & sets the outcomes?	Who will deliver the project?	Scope of engagement	Process	Decision making during the project	Budget	Timing
		Who decides the problem being addressed? Who decides on the project scope and outcomes?		What is the limit of engagement?	How will processes redress power imbalances?	How will decisions be made during project work?	Do you have budget to pay for consumer participation?	How much time do you have to allow for consumer participation?
Consumer owned	<input type="checkbox"/> All consumers + deep involvement	<input type="checkbox"/> Consumers will initiate the project and make all decisions. We provide the funding.	<input type="checkbox"/> Consumers	<input type="checkbox"/> Consumer enterprises are accountable for all aspects of project planning & design	<input type="checkbox"/> The process is outside of us and inside consumer enterprises.	<input type="checkbox"/> Consumers will make all the decisions (which may include inviting non-consumers to be part of the process).	<input type="checkbox"/> We have budget to fund these initiatives.	<input type="checkbox"/> Consumers told us the timelines they needed
Consumer led	<input type="checkbox"/> High majority of consumers + deep involvement	<input type="checkbox"/> Consumers lead decision making and have the final say.		<input type="checkbox"/> Consumers lead project planning, design.	<input type="checkbox"/> Consumers lead the process.	<input type="checkbox"/> Consumers will define how decisions are made during the project.	<input type="checkbox"/> Consumers manage the project budget.	<input type="checkbox"/> We have time to allow for consumers to lead the project. We understand the process may be different and take longer.
Co-production	<input type="checkbox"/> Majority of consumers (or at least 50%) + deep involvement	<input type="checkbox"/> We'll work with consumers to make these decisions together, with consumer views being prioritised.	<input type="checkbox"/> Consumers will be employed to be part of delivering the project	<input type="checkbox"/> Consumers share equally in project planning & design. Nothing starts until consumers have joined.	<input type="checkbox"/> Consumers form a majority of working group or committee memberships. <input type="checkbox"/> Consumers have an equitable status and resources to others. <input type="checkbox"/> Proactive steps are taken to redress power imbalances & seek equity	<input type="checkbox"/> Open & critical discussions are had about differing views. <input type="checkbox"/> Decisions are not made until the majority of consumers agree	<input type="checkbox"/> We have budget to pay all involved consumers for their time and relevant expenses, and pay is commensurate with expertise.	<input type="checkbox"/> We have time to allow for in depth, challenging & innovative work with consumers.
Co-design				<input type="checkbox"/> Planning is already done. <input type="checkbox"/> Consumers are partners in project design.				
Engagement		<input type="checkbox"/> Low number of consumers + deep involvement	<input type="checkbox"/> These decisions are set & cannot change.	<input type="checkbox"/> Consumers may or may not be part of delivering the project	<input type="checkbox"/> Consumers will be one of many inputs to design. Consumer views will be sought but necessarily incorporated.	<input type="checkbox"/> Consumers will be one of the groups represented in project work.	<input type="checkbox"/> Consumers will have a say in decisions.	<input type="checkbox"/> There is only enough budget to pay a small number of consumers for their participation.
Consultation	<input type="checkbox"/> High number of consumers + shallow involvement	<input type="checkbox"/> We will ask consumers what they want and need, and how we should go about the project – but this will be outside of the project work itself.			<input type="checkbox"/> Consumers are not part of decision-making. But we will take what consumers want into account when we make decisions.	<input type="checkbox"/> There is no budget to pay consumers for participation.	<input type="checkbox"/> Timelines are tight and cannot be changed.	
Informing	<input type="checkbox"/> High number of consumers + no involvement	<input type="checkbox"/> We will tell consumers what we've planned & designed.			<input type="checkbox"/> We will seek consumer feedback after the project.			
Educating	It is not recommended to operate in these levels for any work that affects consumers.							
Coercing								
Excluding								



## Good practice regardless of participation level



**1. RELEVANCE.** Think about what the project or committee is about—and what kinds of lived experience are relevant.

- For example, if your project is about seclusion on inpatient units, seek consumer participants who collectively bring:
  - lived experience of seclusion, and
  - expertise in consumer perspective and consumer literature about seclusion

Some participants may have only one of these areas of experience. A good quality project will ensure that the collective mix of consumer members covers both sets of expertise.

Remember that lived experience work may involve people drawing on their personal stories, but it is far more than that—it includes critical thinking, expert knowledge of historical and debated consumer views and positions, and expert knowledge of the relevant context and its issues.

**2. RELEVANCE AND CONSUMERS & CARERS.** If your project is related to services experienced by consumers, then consumers *must* be involved. Importantly:

- Consumers and carers are *never* interchangeable.
- Consumers are there to speak about consumer needs, and carers are there to speak about carer needs. Do not invite carers to speak on behalf of consumers or vice versa.
- Don't refer to consumers as 'stakeholders'—they are the key players, the people everyone else 'has a stake in'.
- It is not necessary, and usually inappropriate, to try and have equal numbers of consumers and carers. Equality is not an issue here – **equity** is. That means privileging the most disadvantaged voices.
- Carers should be involved when the issue or service has an impact on carers/family which needs to be understood.
- Not every issue that affects consumers will also impact carers, and vice versa.
- If the project is about services received by carers, then the roles are reversed.

**3. CONFLICTS OF INTEREST.** Be aware of subjects and issues where there are particular conflicts of interest, or high degrees of sensitivity between consumers and carers, and what this means for your project. For example:

- Trauma informed practice may involve consumers speaking about child abuse or family violence. These topics can be difficult for consumers to discuss openly and safely if carer/family advocates attend.
- Consumers and carers have some particular, longstanding conflicts. In many topics, like compulsory treatment, this puts consumers and carers in direct conflict. For example, consumers tend to advocate for human rights as the top priority: choice, liberty, equality, freedom from abuse. Whereas carers have tended to advocate for safety as the top priority: Access to beds, CTOs, access to private medical records.

**4. PAY FAIRLY.** Remunerate people appropriately for their time and level of skill and expertise. Too often, organisations remunerate all consumers at the same rate. This would be inappropriate in any other field. It's important to recognise that some consumer workers also bring along many years of expertise and qualifications.

**5. TIME.** Allow reasonable time to source people, and time for preliminary reading, and to form views and responses.

**6. DIVERSITY.** Seek a diversity of consumer experiences and views, in particular aim to include:

- **Both current and past service users.** Current consumers can speak with recency about what helped, but may not yet know what will make the biggest difference to their recovery. Past consumers can speak with hindsight, and from a place of recovery, about what helped and why.
- **Demographic, cultural and identity diversity**
- **Diverse experiences, including the challenging ones** – People with positive/helpful experiences and negative/harmful experiences—of both treatment and of care
- **People with expertise in consumer perspective** – the consumer/survivor body of knowledge. There is a thriving and growing body of literature by people with lived experience. Historically this was mostly in the grey literature but is increasingly appearing now in peer-reviewed journals
- **People with relevant knowledge** of key consumer issues, debates, barriers and research, as well as knowledge of the sector and relevant technical skills and expertise.

**7. POWER.** Think about power and seek to redress it. Ask a consumer expert to brief you on power dynamics in your particular setting, and collaboratively explore ways to level the playing field.

- Having more consumers is often a practical strategy. Avoid inviting just one consumer into a space predominated by other disciplines, particularly if those disciplines are ones which have power over consumers in services.
- Other strategies include: setting aside time on the agenda to discuss and identify power, providing a separate space for consumers to discuss issues outside of the main group, and identifying language issues. A useful strategy may also be to intentionally identify areas where there are conflicting views, past harms, and emotional impacts. The group can then plan how to approach these topics with sensitivity and equity – rather than avoid difficult topics, or be taken by surprise.

**8. INFORMED.** Provide all relevant background information, for people to make informed choices about whether to participate, and about their contributions.

**9. ACCESSIBILITY.** Ask whether people have access to email for reading material. Ensure meeting facilities have disability access. Provide interpreters if required.

**10. DISTRESS.** Be aware if content may be triggering and let people know by flagging the topics in advance. Offer paid reflective time with a consumer supervisor. Avoid discriminatory, paternalist approaches such as requiring project participants to create safety plans or having mental health assessments. Consumers expect some reasonable adjustment, but not discrimination. The views and choices of participants should be the deciding factor.

**11. CLOSE THE LOOP.** Do not invite consumer participants unless you are also able to provide feedback on what happened to their contributions, and why (particularly if advice is not taken)