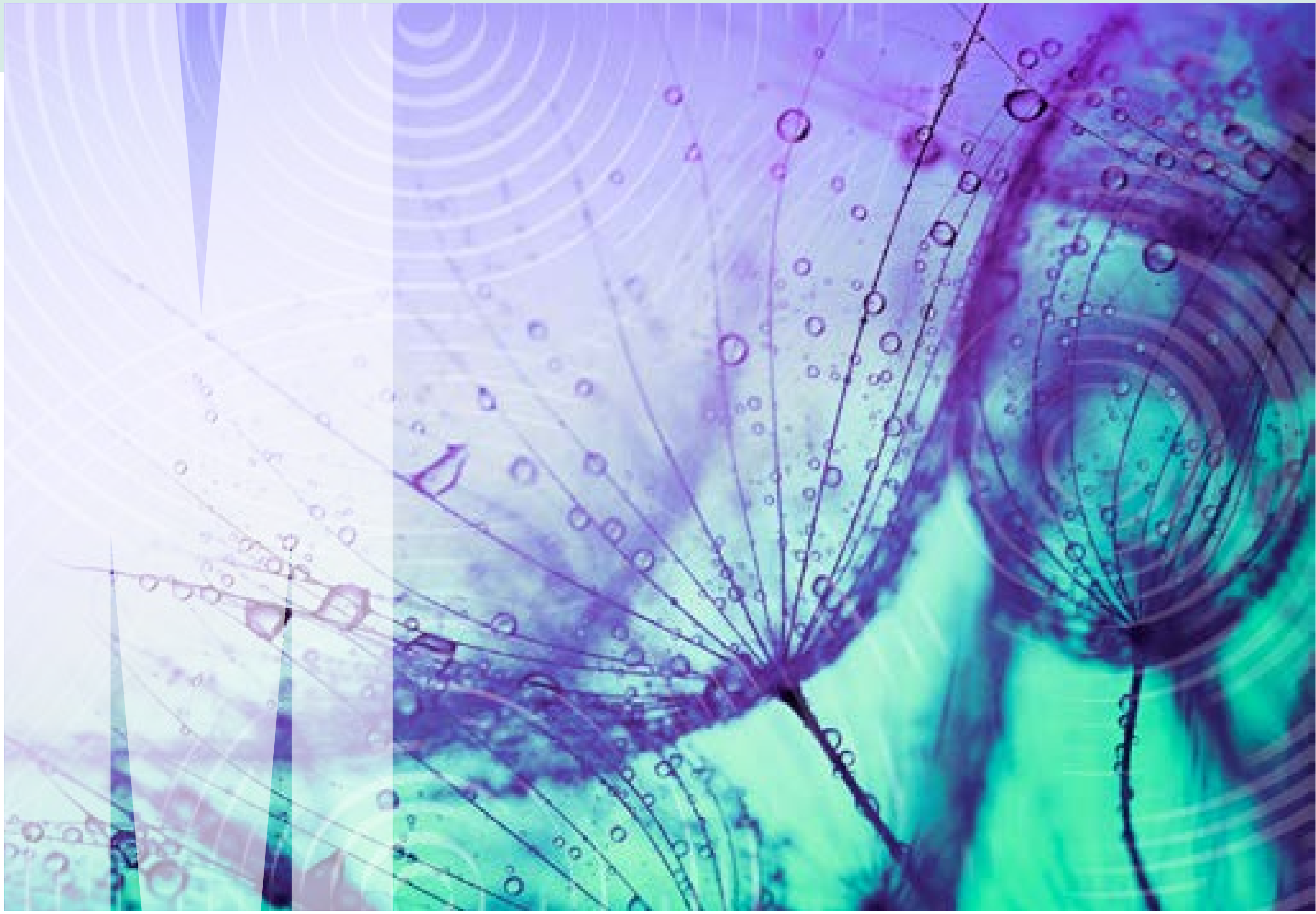
MONASH
University

COMMUNITY & LIVED EXPERIENCE PARTICIPATION AND ENGAGEMENT TOOLKIT



A toolkit providing guiding principles and practical tools for CLE participation in research and education projects.

TURNER
INSTITUTE FOR
BRAIN AND
MENTAL HEALTH

INTRODUCTION

The landscape of brain and mental health research is currently undergoing a transformative change, with funding bodies, ethics committees, health services, and government agencies increasingly requiring evidence of meaningful public participation in the research process.

This toolkit draws on two established frameworks to guide that engagement. The **IAP2 Spectrum of Public Participation** provides a structured approach to planning engagement, from informing through to empowering, helping researchers identify the appropriate level of participation for their project. The **4L Framework**, developed by Professor Eoin Killackey at Orygen, recognises the valuable contributions of: lived experience (personal experience of having mental illness), loved experience (the experience of caring for someone with mental illness), laboured experience (the experience of working with people with mental illness such as a clinician or researcher), and learned experience (the experience of studying mental illness).

Together, these frameworks provide practical guidance for researchers and educators to meet participation requirements and integrate diverse perspectives into research design and practice.

PART 1: IAP2 SPECTRUM OF PUBLIC PARTICIPATION FRAMEWORK

THE INTERNATIONAL ASSOCIATION FOR PUBLIC PARTICIPATION (IAP2)

The International Association for Public Participation (IAP2) is a global community committed to advancing the practice of public participation. The work of the Association is underpinned by seven core principles:

1. Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.
2. Public participation includes the promise that the public's contribution will influence the decision.
3. Public participation promotes sustainable decisions by recognising and communicating the needs and interests of all participants, including decision makers.
4. Public participation seeks out and facilitates the involvement of those potentially affected by or interested in a decision.
5. Public participation seeks input from participants in designing how they participate.
6. Public participation provides participants with the information they need to participate in a meaningful way.
7. Public participation communicates to participants how their input affected the decision.

IAP2 FRAMEWORK

In 1999, the IAP2 developed a tool to facilitate a shared understanding around what is meant by public participation and engagement. This tool is known as the IAP2 Spectrum of Public Participation Framework (henceforth referred to as the IAP2 Framework).

About iap2

Founded in 1990 by a group of dedicated P2 practitioners, the International Association for Public Participation (IAP2) has grown into an international organisation of more than 15,000 professionals in 26 countries working to advance the practice of P2. IAP2 members benefit from research, training and networking opportunities with IAP2 peers.

IAP2's mission is to provide public participation practioners around the world with the tools, skills, networking and training opportunities to advance and extend the practice of public participation.

Training Today's Practitioners for Tomorrow's Challenges

IAP2 works with international licensed trainers. To find one in your area, visit www.iap2.org.

Become a Member

IAP2 is composed of regional and national affiliates including Australasia, Canada, Indonesia, Latin America, Southern Africa and the United States. To become a member, contact your local affiliate. If you reside outside the geographic areas served by an IAP2 affiliate, you are eligible the IAP2 region of your choice. To become a member, contact your local affiliate or iap2hq@iap2.org.

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IAP2 | Public Participation Pillars

iap2

Public Participation Pillars

Internationally Recognized Princ
for Making Better Decisions Toget

3 Pillars for Effective Public Participation

As an international leader in public participation (P2), IAP2 developed three pillars for effective P2 processes. Developed with broad international input, these pillars cross national, cultural and religious boundaries, and they form the foundation of P2 processes that reflect the interests and concerns of all stakeholders.

IAP2 Spectrum of Public Participation | IAP2 Core Values | IAP2 Code of Ethics

IAP2 Spectrum of Public Participation

IAP2 developed The Spectrum of Public Participation to help groups define the public's role in any public engagement process. The Spectrum is quickly becoming an international standard.

INCREASING IMPACT ON THE DECISION

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

IAP2 Core Values

IAP2 Core Values define the expectations and participation process. P2 processes based on the Core Values have proved to be the most successful and respected.

1 Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.

2 Public participation includes the promise that the public's contribution will influence the decision.

3 Public participation promotes sustainable decisions by recognizing and communicating the needs and interests of all participants, including decision makers.

4 Public participation seeks out and facilitates the involvement of those potentially affected by or interested in a decision.

5 Public participation seeks input from participants in designing how they participate.

6 Public participation provides participants with the information they need to participate in a meaningful way.

7 Public participation communicates to participants how their input affected the decision.

IAP2 Code of Ethics

IAP2 Code of Ethics is a set of principles that guides the actions of P2 practitioners and enhances the integrity of the P2 process.

Purpose: We support public participation as a process to make better decisions that incorporate the interests and concerns of all affected stakeholders and meet the needs of the decision making body.

Role of Practitioner: We will enhance the public's participation in the decision making process and assist decision makers in being responsive to the public's concerns and suggestions.

Trust: We will undertake and encourage actions that build trust and credibility for the process among all the participants.

Defining the Public's Role: We will carefully consider and accurately portray the public's role in the decision making process.

Openness: We will encourage the disclosure of all information relevant to the public's understanding and evaluation of a decision.

Access to the Process: We will ensure that stakeholders have fair and equal access to the public participation process and the opportunity to influence decisions.

Respect for Communities: We will avoid strategies that risk polarizing community interests or that appear to "divide and conquer."

Advocacy: We will advocate for the public participation process and will not advocate for interest, party, or project outcome.

Commitments: We ensure that all commitments made to the public, including those by the decision maker, are made in good faith.

Support of the Practice: We will mentor new practitioners in the field and educate decision makers and the public about the value and use of public participation.

IAP2 | Public Participation Pillars www.iap2.org

IAP2 SPECTRUM OF PUBLIC PARTICIPATION INCREASING IMPACT ON THE DECISION

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure their concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision, including developing alternatives and identifying the preferred solution.	To place final decision-making in the hands of the public.
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IMPLEMENTING THE IAP2 FRAMEWORK FOR COMMUNITY & LIVED EXPERIENCE PARTICIPATION AND ENGAGEMENT

WHAT THIS LOOKS LIKE	• One-way communication. • People receive information but don't provide input. • Examples: websites; fact sheets; newsletters; public notices.	• Two-way communication, but decision-makers retain control. • People share their views, opinions, or preferences. • Examples: surveys; public comment periods; focus groups; public meetings.	• Ongoing, active participation throughout the process. • Public participants may have roles like facilitating or committee membership. • Public is involved from problem identification through to evaluation. • Examples: Deliberative design; design workshops; consensus building methods.	• Equal partnership between decision-makers and public. • Shared control and authority. • Joint problem-solving and solution development. • Examples: peer/co-researchers in the research team; co-design workshops; lived experience advisory groups.	• Public has control over the final decision. • Decision-makers commit to accepting and implementing the public's choice. • Examples: supporting community partners to design and lead projects; capacity building (PhD/postdoc opportunities for researchers with lived experience); projects led by researchers with lived experience.

CONSIDERATIONS

THE LEVELS ARE NOT A HIERARCHY

It is important to note that the five levels are not a hierarchy wherein one level (e.g., empowerment) is inherently better than another level (e.g., inform). The appropriate level of public participation depends on factors such as:

- the specific goals of the project
- available time and resources
- how much the decision affects people
- the capacity of participants.

POWER SHARING ACROSS THE LEVELS

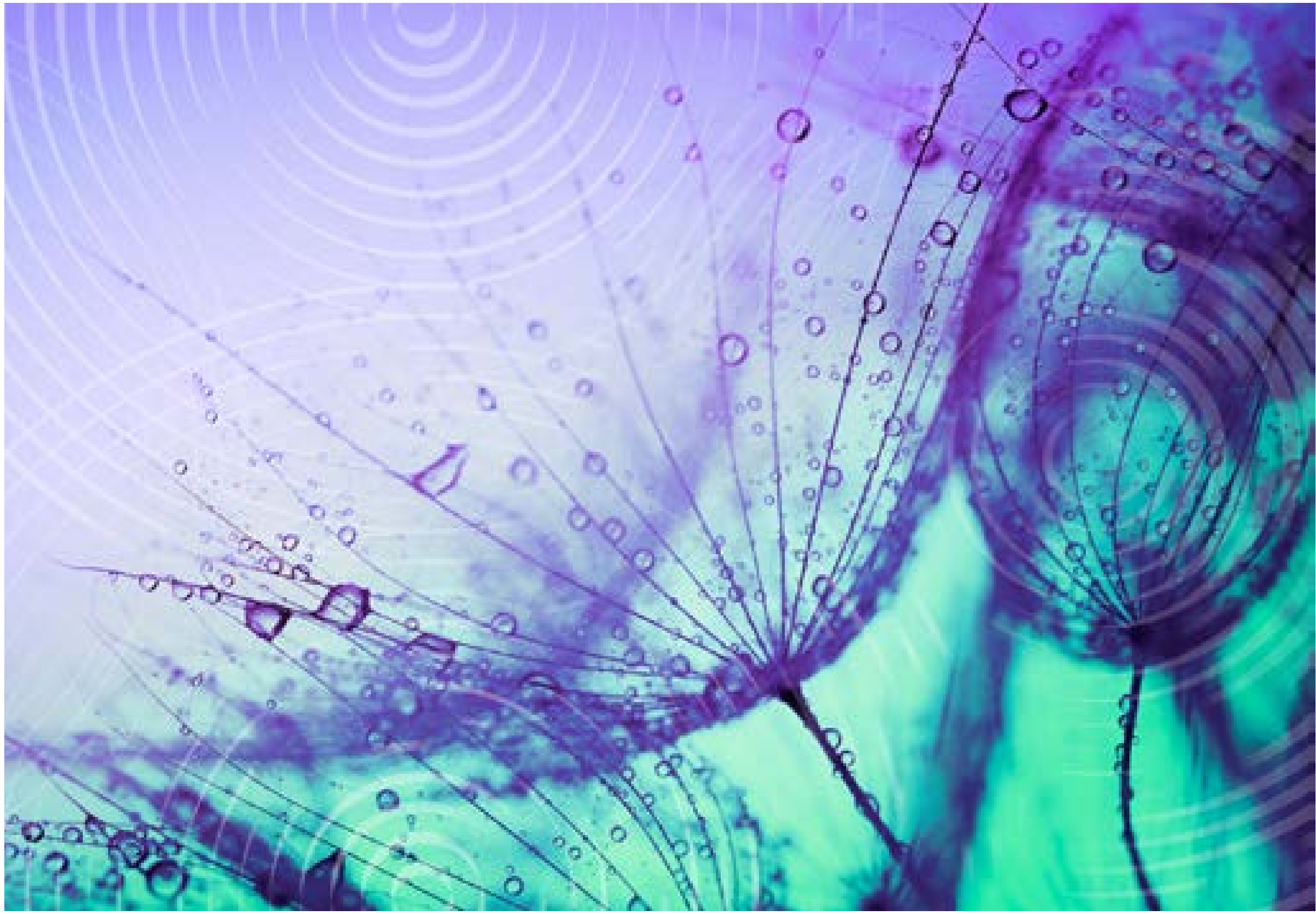
While no level is inherently better than another, it is important to recognise that what does change, as we move from left to right across the levels, is the amount of impact that public participants have on the decision/outcome. At the Inform level, public participants have no impact on the outcome while at the Empower level, the public participants make the final decision.

THE IMPORTANCE OF IDENTIFYING THE RIGHT LEVEL

- Each level makes a different promise about how much influence people will have.
- Breaking these promises (e.g., asking for input but ignoring it) damages trust.
- People may feel frustrated if they expect one level of influence but receive another.
- Clear communication about which level you're using prevents mismatched expectations.

COMMON PITFALLS

- “Consultation theatre”: Asking for feedback but having already made the decision.
- Overwhelm: Demanding extensive participation time without tangible results.
- Exclusion: Not providing support for people who need accommodations to participate.
- Power imbalance: Leaders maintaining control while claiming to “collaborate”.



PART 2: ORYGEN'S 4L FRAMEWORK

The 4L Framework (Killackey, 2023) was developed in the context of youth mental health research. However, as noted by Killackey, the framework is applicable to mental health research more broadly and across other areas of participatory research, including disability and other conditions or circumstances affecting wellbeing. The core principle of the framework is that there are four types of experience; **lived**, **loved**, **laboured** and **learned** experience, which are equal and should be included throughout the research process. People who have had these different types of experiences each bring different and valuable perspectives to a project.

THE 4LS

01

LIVED EXPERIENCE

Definition:
Personal experience of having mental illness.

What this means:

- You have directly experienced mental ill-health yourself.
- You understand what symptoms, recovery and challenges feel like from the inside.
- You know what it's like to navigate the mental health system as a patient/client/consumer.

Why this matters:
People with lived experience know things that cannot be learned from textbooks or research studies. They understand the subjective reality of mental illness.

02

LOVED EXPERIENCE

Definition:
The experience of mental illness through the role of being a carer, family member, friend or colleague of someone with a mental illness.

What this means:

- You are a family member, partner, friend, or supporter of someone with mental illness.
- You have witnessed the impact of mental illness on someone you care about.
- You may have navigated the mental health system as a support person.
- You understand the emotional, practical, and social aspects of supporting someone with a mental illness.

Why this matters:
People with loved experience have unique insights from a relational perspective. They bring the perspective of having engaged with services and systems in terms of advocating for their loved one.

03

LABOURED EXPERIENCE

Definition:
The experience of working with people with mental illness.

What this means:

- You work as a clinician, therapist, psychiatrist, nurse, social worker, peer worker, or in another professional role.
- You have practical, hands-on experience delivering services or treatments.
- You acknowledge what interventions work in practice, not just in theory.
- You may see patterns across many people over time.

Why this matters:
People with laboured experience know what is realistic and feasible in real-world settings. They understand system barriers and opportunities from a professional perspective.

04

LEARNED EXPERIENCE

Definition:
The experience of studying mental illness.

What this means:

- You are a researcher, academic, or student studying mental health.
- You have access to and knowledge of theoretical and empirical research literature.
- You understand how to conduct and critically evaluate research.
- You can synthesize information across studies and contexts.

Why this matters:
People with learned experience contribute systematic knowledge, rigorous methods, and evidence-based understanding. They can identify patterns across populations and evaluate what works.

KEY POINTS ABOUT THE 4LS

MULTIPLE EXPERIENCES ARE COMMON

Many people have more than one type of experience. For example:

- A psychiatrist who has a mental health condition (Laboured + Lived).
- A researcher who is also a parent of someone with mental illness (Learned + Loved).
- A peer support worker who has studied psychology (Lived + Laboured + Learned).

> The framework acknowledges that people often have more than one type of experience. However, usually an individual has a primary type of experience as the lens through which they contribute to a conversation or collaboration. As an example, I have loved, laboured, and learned experience of mental illness. However, in a project or a grant meeting or when translating research into policy, I am primarily there because of my learned experience. Therefore, my presence does not satisfy a requirement for the presence of loved or laboured experience. For loved or laboured experience to be represented, someone who is there primarily because of their loved or laboured experience is required. *(Killackey, 2023, p. 917)*

NO HIERARCHY

A core tenet of the 4L Framework is that there is no hierarchy amongst the four types of experience. That is, they are all of equal value, with each being a unique and necessary perspective.

PRACTICAL APPLICATION

When including people in research:

- be explicit about which types of experience you are seeking
- recognise that people often bring multiple perspectives
- don't assume that only people with lived experience can contribute meaningfully
- create roles and processes that respect all types of experience.

WHY THE 4L FRAMEWORK MATTERS

REDUCES TOKENISM

- Traditionally, "consumer participation" has often meant finding someone with lived experience to add to a team. Such participation is often tokenistic in that the person is effectively being used to tick a box without their contribution being genuinely valued.

CREATES CLEARER LANGUAGE

- Reduces ambiguity about what "lived experience" means.
- Makes it easier to identify and explain what type of contribution you are seeking.
- Helps people understand how their specific experience is valuable.

PREVENTS POWER IMBALANCES

- By explicitly stating that the four types of experience are of equal value, the framework prevents situations where researchers or clinicians implicitly position their knowledge as being somehow more legitimate than that of people with lived or loved experience.
- The framework also prevents the opposite problem: romanticising lived experience as being the only "authentic" knowledge.

POTENTIAL TENSIONS THE FRAMEWORK ADDRESSES

- The 4L Framework normalises the idea that people often have more than one type of experience. This can help a researcher with lived experience decide whether or not to disclose their lived experience.
- Due to the growing emphasis on lived experience, clinicians can sometimes feel that their perspective is dismissed as "not lived experience". However, within the 4L Framework, laboured experience is explicitly valued.
- Similarly, family members can sometimes feel invisible in discussions about "lived experience". However, within the 4L Framework, loved experience is recognized as distinct and valuable.

HOW THE TWO FRAMEWORKS RELATE

While these frameworks were developed for different contexts (public participation vs. mental health research), they share common principles:

1. Power and influence: Both acknowledge that different levels or types of participation involve different degrees of influence and control.
2. Explicit promises (setting expectations): Both emphasize being clear and honest about what role people will have, to prevent disappointment or broken trust.
3. Context matters: Both recognise that the "right" approach depends on the specific situation, goals, and constraints.
4. Inclusion: Both aim to make participation more inclusive by providing clear frameworks for how different people can contribute.

PUTTING THESE FRAMEWORKS INTO PRACTICE

For IAP2:

- Decide which level is appropriate BEFORE you start engaging people.
- Be explicitly clear about which level you're using.
- Match your language to the level (don't use "collaborate" language if you're only consulting).
- Provide the resources and support needed for the level of participation you're requesting.
- Follow through on the promise you make at each level.

For 4Ls:

- When seeking participation, specify which type(s) of experience you're looking for.
- Create distinct roles or opportunities that make use of different types of experience.
- Avoid assuming that one type of experience is more valuable than others.

Sources

International Association for Public Participation (IAP2): www.iap2.org

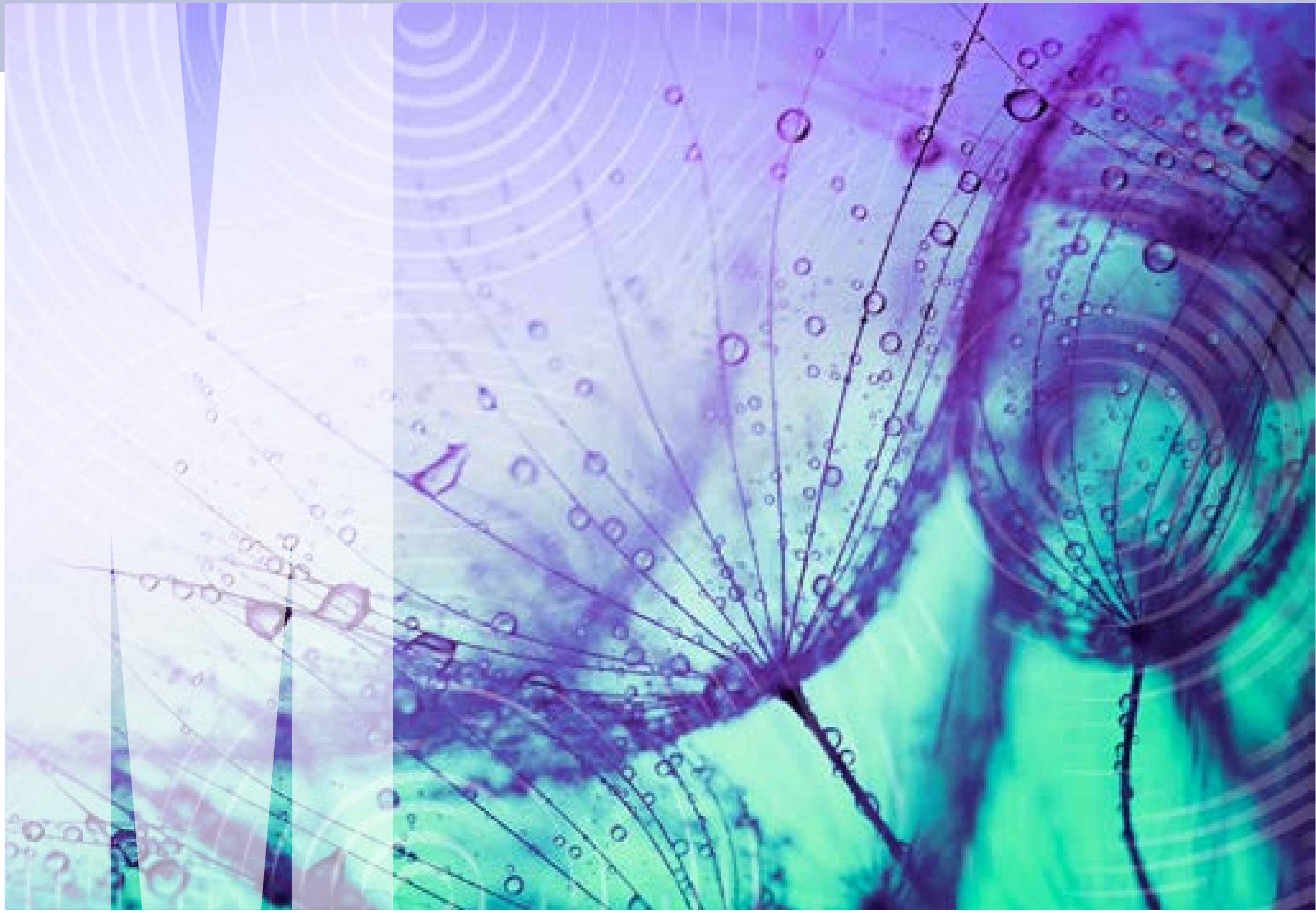
Killackey, E. (2023). The 4 Ls of experience: lived, loved, laboured, and learned: The Lancet Psychiatry

Orygen: www.orygen.org.au

GUIDING PRINCIPLES

The following principles underpin the practical guidance in this toolkit and reflect the values that distinguish genuine from tokenistic engagement. They should inform every stage of the engagement process, from initial planning through to evaluation and follow up.

1. Be honest about the level of participation you are offering.
2. Match your promises to what you can realistically deliver.
3. Invest in accessibility and inclusion from the start.
4. Recognise and share power.
5. Pay people appropriately for their time and effort.
6. Build relationships, don't just extract information.
7. Follow through on commitments.
8. Learn from mistakes for continuous improvement.



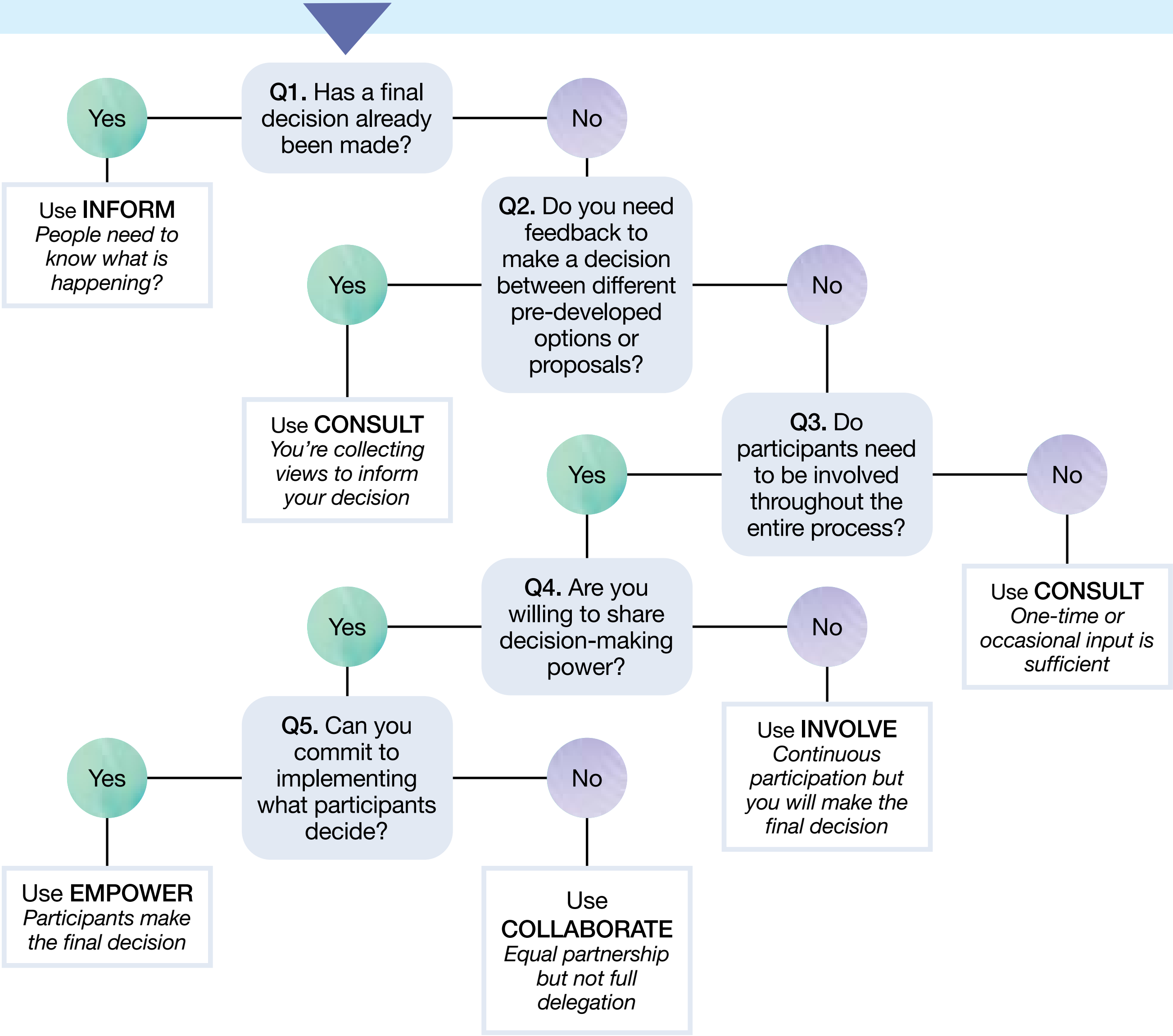
1. PRACTICAL
APPLICATION TOOLS

1.1 DECISION PATHWAY

Use this decision pathway to determine which level of the IAP2 Spectrum is appropriate for your project or specific engagement activity.

Important considerations:

- The engagement process is not linear; the level of participation (along the spectrum) will ebb and flow depending on the stage of the project.
- Your available time and resources, including budget constraints, may limit which level is feasible.
- Legal or institutional requirements may restrict decision-making authority.
- Participant capacity and interest should match the level of involvement.
- Be honest about limitations - false promises damage trust.



Note: If your answer changes to any question depending on the stage in your project, run through the pathway for each engagement activity separately.

1.2 ENGAGEMENT PRACTICE

Before beginning your engagement process, use this guide to navigate your participation approach.

CLARITY AND HONESTY

☐ I can clearly articulate why we need public participation for this project.
☐ I understand the difference between the five levels of the IAP2 Spectrum.
☐ I know which IAP2 level is appropriate for this project.
☐ I am prepared to be honest about what participants can and cannot influence.
☐ I will not ask for input on decisions that are already made.

RESOURCES AND SUPPORT

☐ I have sufficient time allocated for this engagement (a rushed process damages trust).
☐ I have a budget for participant remuneration, accessibility support, and other costs.
☐ I have administrative support for coordination and communication with participants.
☐ I have approval from my institution/supervisor for this approach.
☐ I know who to contact if I encounter problems or need advice.

INCLUSION AND ACCESSIBILITY

☐ I have considered who might be excluded by my proposed methods.
☐ I can provide materials in accessible formats.
☐ I can accommodate different communication needs.
☐ I have a plan for supporting people who need additional support.
☐ I understand that accessibility is not one-size-fits-all.
☐ I appreciate the importance of correct terminology and language use.

POWER AND RELATIONSHIPS

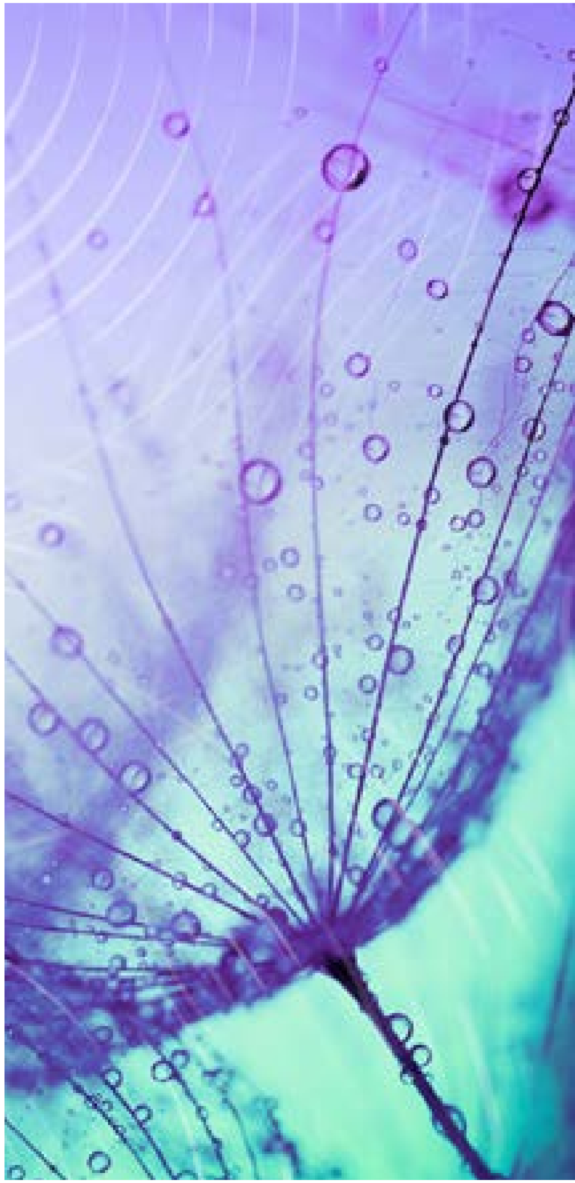
☐ I recognise that I hold institutional power as a researcher or educator.
☐ I am willing and able to share control and decision-making.
☐ I am comfortable with participants challenging my assumptions.
☐ I will not treat participants as data sources or informants.
☐ I am prepared to build relationships with participants, not just extract information from them.

EXPERIENCE AND EXPERTISE

☐ I can identify which types of experience (Lived, Loved, Laboured, Learned) are relevant.
☐ I recognise that people often have multiple types of experience.
☐ I do not assume that any one type of experience is more valuable than another.
☐ I understand that experiential knowledge is as valuable as academic knowledge.

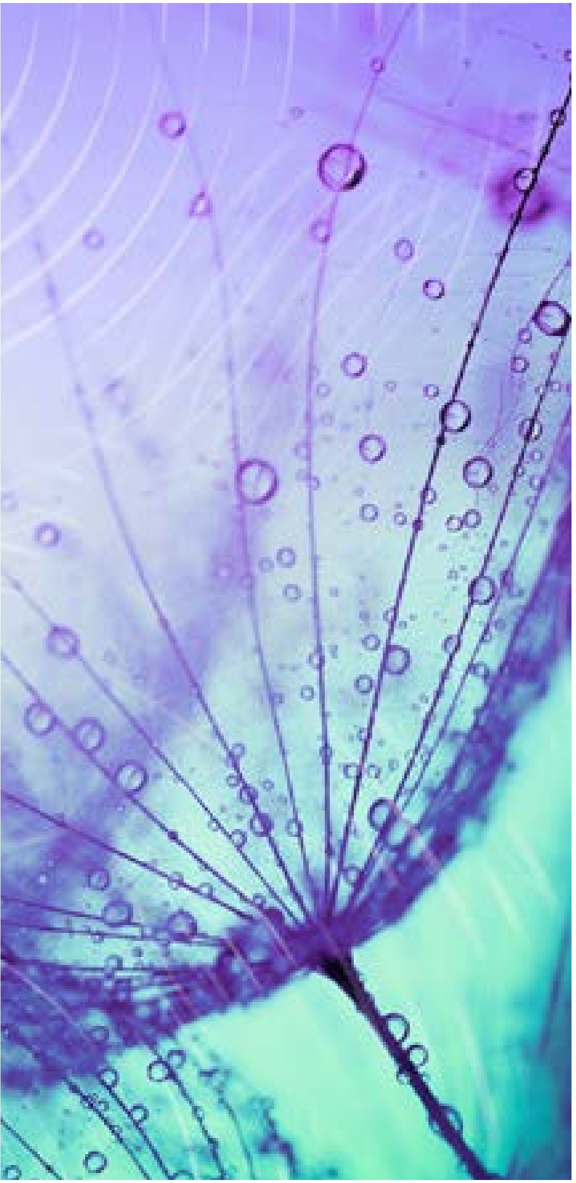
FOLLOW-THROUGH AND ACCOUNTABILITY

☐ I have a plan for how participant input will actually influence the research.
☐ I will report back to participants about what happened with their contributions.
☐ I am prepared to explain decisions that go against participant preferences.
☐ I have a process for repair, addressing complaints or concerns.
☐ I will acknowledge participants' contributions in research outputs.



1.3 SIGNS OF PROBLEMATIC PRACTICE

The following signs indicate your engagement may be tokenistic, exploitative, or ineffective.



CONSULTATION THEATRE

Pretending to listen but decisions have already been made

- Asking for input despite having already decided what is going to happen.
- Needing approval or funding and participation is a box ticking exercise.
- Wanting to be viewed as being consultative but not genuinely wanting input.
- Only talking to people who you believe will agree with your predetermined approach.
- Calling it collaboration or co-design when you mean consultation.

TOKENISM

Using people as props without valuing their contribution

- Only having one person with lived experience on the team to 'represent' everyone with lived experience.
- Asking people to share their stories or contribute in other ways but not compensating them appropriately.
- Only involving people with lived or loved experience for the 'experiential' parts, (e.g., sharing personal stories, reviewing content for tone and/or language, providing quotes) rather than across all aspects of the project.
- Dismissing suggestions that challenge your research design.

EXPLOITATION

Taking without giving back

- Asking people to do substantial work without payment.
- Not reporting data/findings back to participants.
- Not acknowledging participants in publications or presentations.
- Treating the engagement as extractive rather than reciprocal.

POWER IMBALANCE

Maintaining control while claiming partnership

- Calling it collaboration but you make all the final decisions.
- Setting all the meeting times, agendas, and discussion topics.
- Using academic jargon that excludes people without research training.
- Expecting people to fit into your existing processes without adaptation.
- Treating participant knowledge as less valid than research literature.

OVERWHELM

Demanding too much without support

- Expecting people to attend frequent, long meetings without appropriate remuneration.
- Providing dense documents without summaries or accessible versions.
- Not providing emotional or practical support for challenging discussions.
- Rushing the process because of your own deadlines, meetings are too short.
- Assuming everyone has the same level of capacity for participation.

EXCLUSION

Creating barriers to participation

- Meetings are only during business hours, thereby excluding employed people.
- The location is inaccessible for people with mobility issues.
- Not providing transport assistance or reimbursement.
- Only recruiting from services you already have connections with.
- Not accommodating different communication styles or needs.

EXTRACTION

Not 'closing the loop'

- Benefiting from lived experience contribution to a project without feeding back to the lived experience community about the findings of the study.
- Members of the community who contribute their knowledge to research want to know what the findings were, how their input was used, and if it led to change. Without this, the lived experience community can be left feeling undervalued, which erodes trust.

1.4 LEVELS OF PARTICIPATION

Clearly communicate what level of participation you're offering and what participants can expect.

INFORM

INFORM LEVEL

What we're providing:

- Information about the project and decisions.
- Explanation of how decisions were made.
- Contact details if you have questions.

What we're NOT asking for:

- Your input on the decisions (the decisions have already been made).
- Your ongoing participation in the project.

CASE STUDY

When developing a new unit for psychology students on suicide prevention and support, Dr Kylie King and Dr Kim Johnston sought input from practitioners, researchers, and people with lived experience related to suicide.

After developing and delivering the unit, the academic team wanted to share the initiative and student feedback to the broader lived experience of suicide community. They implemented several one-way communication strategies including:

- an accessible plain language summary report with infographics, highlighting key learnings.
- a meeting with the Lived Experience Advisory Group of the community organisation that was involved with the project.
- presenting about the unit at a lived experience of suicide summit, attended by people with lived experience and people in the sector.

The goal was to ensure transparency and knowledge dissemination rather than to gather input or collaborate.

View Project

CONSULT

CONSULT LEVEL

What we're asking for:

- Your opinions, preferences, and concerns about mental health supports, treatments, navigating the health system.
- Feedback on pre-developed options or proposals.

What will happen with your input:

- We will review and consider all feedback received
- Your input will inform but not determine the final decisions
- We will explain how feedback influenced our decisions

CASE STUDY

Dr Emma Morton led a project with the CREST.BD network (University of British Columbia, Canada) that aimed to develop understanding of the perspectives of potential end-users in order to inform the design of a prototype app to support mental health and wellbeing for people living with bipolar disorder (PolarUs).

Data collection: A large-scale, international, web-based survey was selected as a foundational step for the PolarUs app development project, in order to gauge the preferences and needs of a geographically and demographically diverse range of respondents. Participants were surveyed about their use of smartphones and mental health apps, preferences for various app features, privacy concerns, and digital health literacy. Participants could also leave free-text comments about desired or unwanted app features and content.

Intervention development: Survey findings were utilised to identify candidate features/content for in-depth consideration from the research team, app developers, and project lived experience advisory group.

Degree of participation: Although this specific data collection activity occurred at the level of consultation, it also showcases the possibility of moving across levels of participation over the course of a larger project. Findings from this survey were used to inform subsequent research activities occurring at the level of collaboration: the project advisory group were consulted to help clarify contradictory or ambivalent findings, and findings were used as prompts for the project advisory group across the app development process. At the inform level, survey findings were shared with the community in a plain language blog post that also described engagement with the project advisory groups to integrate these findings in the app development process.

View Project

INVOLVE

INVOLVE LEVEL

What we're asking for:

- Ongoing participation throughout the project [duration].
- Input on research design, methods, and interpretation.
- Participation in meetings/workshops [approximate frequency].

What you can expect:

- Your concerns and perspectives will be directly reflected in the project.
- We will provide feedback on how your input influenced decisions.
- You will have regular opportunities to raise issues or concerns.

An example of this engagement is a Consumer Advisory Group or Lived Experience Panel, that works alongside the research team across the life of the project. They can provide input into the research design, intervention development, and recruitment, and may facilitate or support broader dissemination of the research findings.

CASE STUDY

A research project led by A/Prof Melinda Jackson and funded by Dementia Australia aimed to develop a sleep intervention tailored for people living with dementia and their care partners in the community. The research team engaged two Community Advisors who were integral to the project and involved throughout the project lifecycle.

Their input influenced methodology, facilitation style, and intervention content, for example:

Design Phase: Advisors helped develop and review the discussion guide, recruitment materials, consent forms, and explanatory statements. Dementia Australia's Consumer Engagement Officer also reviewed materials.

Data Collection: Advisors attended focus groups and interviews, asked questions, shared personal experiences, and helped create a comfortable environment for participants.

Intervention Development: Advisors collaborated with researchers to design the Dementia, Sleep and Wellbeing intervention, including: Session structure (frequency, duration); Content (CBT-I, mindfulness, light therapy, fatigue management); Delivery format (group vs. individual, online vs. in-person). Feedback from participants shaped the toolkit approach and adaptability across dementia stages.

Redesign Phase: Advisors contributed to refining the intervention after initial feedback.

They were listed as co-authors on the subsequent manuscripts (e.g., Brown et al 2024), reflecting substantive involvement beyond token consultation.

View Project

COLLABORATE

COLLABORATE LEVEL

What this partnership means:

- Shared control and authority over research decisions
- Joint problem-solving and solution development
- Equal voice in discussions and decision-making
- Lived experience co-production of project outcomes/deliverables

Your role will include:

- Co-developing research questions and methods
- Participating in data analysis and interpretation
- Contributing to publications and presentations

CASE STUDY

A research team led by Dr Beth Johnson sought to understand Autistic people's, families', and professionals' perspectives on autism genetics research—a topic with significant ethical concerns and historical mistrust within the Autistic community due to lack of meaningful involvement in research decisions. The research team established a partnership with Autistic people from the outset, working together to shape how the study would be conducted.

Co-design of Research Approach: Autistic advisors partnered with researchers to design the study methodology, determine appropriate ways to gather community input (interviews, focus groups, and surveys), and shape interview questions and discussion topics to ensure they addressed community priorities.

Shared Decision-Making: Autistic partners had input into who should be included as participants (Autistic people, families, professionals), and ethical considerations for conducting sensitive discussions about genetics research. Research processes were adjusted based on feedback from Autistic collaborators throughout the project.

Joint Analysis and Interpretation: The analysis process incorporated perspectives from both researchers and Autistic community members to identify themes. Findings were interpreted through both academic and lived experience lenses, ensuring community concerns were authentically represented.

This represents genuine partnership where Autistic people were not just consulted but actively involved in decision-making throughout the research process.

View Project

EMPOWER

EMPOWER LEVEL

What this means:

- The research team will provide support but not direction.
- We will implement what you decide.
- You have control over final decisions.

Support we will provide:

- Information and resources to support informed decision-making.
- Facilitation of the decision-making process.
- Implementation of decisions.

CASE STUDY

A project led by Dr Kate Gould aimed to provide practical insights into maximally authentic design processes, emphasising the leadership roles of individuals with acquired brain injury (ABI) in program initiation, planning, delivery, and reporting.

Leadership by Lived Experience: Individuals with ABI were central leaders, not just participants. They initiated, planned, conducted, and reported the project.

Setting Up the Co-Design Team: A collaborative team of 11 people, including those with ABI and self-advocacy representatives, formed to co-design a peer-led relationship workshop model.

Peer-Led Workshops: The team delivered three workshops led by individuals with ABI, covering relationships post-brain injury—from conception to facilitation.

Training and Support: The study provided training and support to people with ABI to empower their facilitation role and leadership in workshops.

Evaluation of Involvement: Researchers conducted 18 interviews with participants and ABI-facilitators, identifying themes such as: The leadership identity of people with ABI; The transformative impact of lived experience; The benefits of co-delivery in fostering authenticity and empowerment.

View Project

2. IMPLEMENTATION GUIDANCE IAP2 LEVELS

This section provides step-by-step guidance for implementing each level of the IAP2 spectrum, including resource requirements, timelines, and common pitfalls.

2.1 INFORM: PROVIDING INSIGHTS & INFORMATION

GOAL: Provide balanced, objective information to help people understand decisions.

STEP-BY-STEP PROCESS

STEP 01

Identify who needs to be informed

Who will be affected by these decisions?

Who has a right to know what's happening?

Who might have questions or concerns?

STEP 02

Prepare clear, accessible information

What decisions have been made?

Why were these decisions made?

What will happen next?

Who can people contact if they have questions?

STEP 03

Choose appropriate communication channels

Email, website, newsletter, fact sheet, public notice.

Consider multiple formats for accessibility.

Ensure language is clear and jargon-free.

STEP 04

Distribute information

Send through appropriate channels.

Make information easily findable and accessible.

Provide contact details for follow-up questions.

STEP 05

Respond to questions

Monitor for questions or requests for clarification.

Provide timely, helpful responses.

Update information if needed.

STEP 06

Evaluate

Collect feedback to assess communication effectiveness.

Evaluate reach and engagement across channels.

Analyse uptake metrics to measure accessibility.

RESOURCE REQUIREMENTS

Time: Low to medium (hours to days depending on complexity).

Budget: Low (primarily staff time for writing, distribution and responding to questions).

Staffing: One person for small projects, small team for large projects.

Skills needed: Clear writing, plain language communication. Depending on the engagement activities, other skills might include knowledge of social media algorithms, graphic design, video/podcast production.

COMMON PITFALLS

- Using complex jargon or technical language.
- Providing incomplete information that raises more questions.
- Not providing clear contact details for follow-up.
- Assuming everyone has internet access (provide multiple formats).
- Not considering accessibility needs.
- Calling it 'consultation' when it's actually just information-sharing.

INFORM

2.2 CONSULT: SEEKING FEEDBACK

GOAL: Obtain feedback on analysis, alternatives, or decisions.

STEP-BY-STEP PROCESS

STEP 01

Define what you're consulting on

What specific feedback do you need?

What options or alternatives are you considering?

What can actually be influenced by feedback?

STEP 02

Identify who to consult

Who will be affected by these decisions?

Who has relevant experience or expertise?

Are you reaching diverse perspectives?

STEP 03

Choose consultation methods

Surveys (online or paper).

Focus groups or listening sessions.

Public meetings or forums.

One-on-one interviews.

Written submissions.

STEP 04

Prepare materials

Background information.

Clear questions or discussion prompts.

Explanation of how feedback will be used.

Timeline for providing feedback.

STEP 05

Conduct consultation

Provide multiple ways to give feedback.

Allow sufficient time for thoughtful responses.

Be available to answer clarifying questions.

Thank people for their participation.

STEP 06

Analyse feedback

Review all feedback received.

Identify themes and patterns.

Consider both majority and minority views.

Note areas of consensus and disagreement.

STEP 07

Make decisions

Consider feedback alongside other factors.

Document how feedback influenced decisions.

Prepare to explain decisions that go against feedback.

STEP 08

Report back

Explain what you heard in the feedback.

Describe how feedback influenced decisions.

Acknowledge contributions.

COMMON PITFALLS

- Asking for feedback despite having already made decisions (consultation theatre).
- Not providing enough context for informed feedback.
- Making it difficult to participate (complex surveys, inconvenient times).
- Ignoring feedback that doesn't align with your preferences.
- Not reporting back to participants about how feedback was used.
- Rushing the process so people can't provide thoughtful feedback.

RESOURCE REQUIREMENTS

Time: Moderate (weeks to months depending on scope).

Budget: Moderate (venue hire, materials, remuneration, analysis).

Staffing: Small team (2-3 people for coordination, facilitation, analysis).

Skills needed: Survey design, facilitation, qualitative analysis.

CONSULT

2.3 INVOLVE: CONTINUOUS PARTICIPATION

GOAL: Work with participants throughout the process to ensure their input is reflected.

STEP-BY-STEP PROCESS

STEP 01

Plan the engagement process

What is the scope and duration of the project?

What roles will participants have?

How frequently will you meet/communicate?

What decisions will participants help shape?

Have the safety and accessibility of participation been actively considered?

STEP 02

Recruit participants

Clearly communicate the time commitment and expectations.

Reflect the diversity of the relevant community across intersecting identities and experiences.

Provide information about remuneration and support.

Allow time for people to consider and ask questions.

STEP 03

Establish ways of working

Co-create agreed practices and expectations

Agree on communication methods and frequency.

Clarify roles and decision-making processes.

Establish how conflicts will be addressed.

STEP 04

Work together throughout the project

Hold regular meetings or workshops.

Share information in accessible formats.

Provide opportunities for input at each stage.

Be responsive to participant concerns.

Adapt the process based on feedback.

STEP 05

Demonstrate influence

Show participants how their input is shaping decisions.

Explain reasoning when you can't implement suggestions.

Be transparent about constraints and limitations.

Acknowledge and credit contributions.

STEP 06

Provide ongoing support

Maintain regular touchpoints at agreed times/dates.

Address access or participation barriers as they arise.

Provide appropriate support for challenging discussions.

Respect people's time and energy limits.

STEP 07

Evaluate and close

Reflect on what worked and what didn't, and invite feedback.

Thank participants for their contributions.

Share final outcomes and how input was used.

Discuss opportunities for continued involvement if relevant.

RESOURCE REQUIREMENTS

Time: Substantial (months, running parallel to project timeline).

Budget: Moderate to high (remuneration, venue, materials, support).

Staffing: Dedicated coordinator plus facilitators/support.

Skills needed: Relationship building, facilitation, project management, conflict resolution, impact and evaluation expertise.

COMMON PITFALLS

- Underestimating the time commitment required.
- Not providing adequate remuneration for substantial involvement.
- Treating participants as consultants rather than active team members.
- Only involving people for 'lived experience' components.
- Not adapting to participant feedback about the process.
- Allowing participation to become burdensome or overwhelming.
- Failing to show how input actually influenced the work.

INVOLVE

GOAL: Partner equally with participants, sharing control and decision-making.

STEP-BY-STEP PROCESS

STEP 01

Co-create the partnership

Don't arrive with a fixed plan - design together from the start.

Discuss what equal partnership means in practice.

Identify shared goals and potential tensions.

Agree on how power will be shared.

STEP 02

Build the partnership

Invest time in relationship building.

Create safe space for honest discussion.

Address power imbalances explicitly.

Consider what capacity building may need to be provided to partners early in the engagement to enable people to feel empowered to join the process (e.g., training in research processes/methods).

Establish trust through consistent follow-through.

STEP 03

Share decision-making

Make decisions together, not unilaterally.

Use consensus-building approaches where possible.

Ensure everyone has an equal voice in discussions.

Address disagreements respectfully and transparently.

STEP 04

Distribute work equitably

Negotiate roles based on skills, interests, and capacity.

Don't assume researchers should do all the 'technical' work.

Provide training and support to build skills.

Recognise and compensate all contributions appropriately.

STEP 05

Navigate challenges together

Address problems and conflicts as they arise.

Be willing to change course based on partner input.

Support each other through difficult parts of the process.

Celebrate successes together.

STEP 06

Share credit and ownership

Co-author publications and presentations.

Share intellectual property as appropriate.

Present work together when possible.

Acknowledge the contributions of all participants publicly.

RESOURCE REQUIREMENTS

Time: Substantial (significant ongoing commitment from all participants).

Budget: High (meaningful remuneration, capacity building, shared resources).

Staffing: All participants need adequate support.

Skills needed: Co-design/co-creation, negotiation, conflict resolution, understanding of power dynamics, facilitation, project management, evaluation and impact expertise.

COMMON PITFALLS

- Claiming collaboration while maintaining researcher control.
- Not providing adequate remuneration for partnership roles.
- Expecting participants to fit into existing institutional structures.
- Treating disagreement as a problem rather than valuable tension.
- Rushing the relationship-building phase.
- Not addressing power imbalances explicitly.
- Taking sole credit for shared work.
- Giving up when collaboration gets difficult.

COLLABORATE

2.5 EMPOWER: DELEGATED DECISION-MAKING

GOAL: Place final decision-making authority in the hands of participants.

STEP-BY-STEP PROCESS

STEP 01

Define scope of delegated authority

What specific decisions will participants make?

What are the boundaries or constraints?

What resources are available to support implementation?

How will the institution genuinely honour these decisions?

STEP 02

Secure institutional commitment

Obtain written agreement that decisions will be implemented.

Clarify what happens if decisions conflict with institutional policies.

Ensure adequate resources for implementation.

Establish accountability mechanisms.

STEP 03

Support informed decision-making

Provide all relevant information in accessible formats.

Offer opportunities to ask questions and seek clarification.

Present pros and cons of different options.

Don’t steer participants toward particular outcomes.

STEP 04

Facilitate the decision-making process

Create space for deliberation and discussion.

Support participants to make decisions that work for them.

Provide facilitation but not direction.

Respect the timeframe participants need.

STEP 05

Implement decisions

Follow through on commitments.

Keep participants informed of implementation progress.

Address obstacles or barriers that arise.

Acknowledge the authority of participants publicly.

Important note: This level requires institutional willingness and readiness to delegate authority and may not be possible for certain types of research decisions.

RESOURCE REQUIREMENTS

Time: Variable depending on scope.

Budget: High (remuneration, support, implementation resources.)

Staffing: Support team for facilitation and implementation.

Skills needed: Co-design/co-creation, facilitation, negotiation, conflict resolution, power sharing, project governance and strategic project management, evaluation and impact expertise.

COMMON PITFALLS

- Calling it empowerment but retaining veto power.
- Not securing genuine institutional commitment.
- Providing biased information that steers decisions.
- Setting unrealistic constraints that limit real choice.
- Not following through on implementation.
- Using this approach when institutional context won’t support it.

EMPOWER

3. ACCESSIBILITY & INCLUSION PRACTICES

Accessibility and inclusion must be actively planned for. This section provides practical guidance for making your engagement accessible to diverse participants.

3.1 COMMUNICATION ACCESSIBILITY

WRITTEN MATERIALS

- Use plain language (avoid jargon and complex terminology).
- Provide materials in advance.
- Offer multiple formats: print, large print, electronic, audio.
- Use clear formatting with adequate white space.
- Include visual elements to support understanding.
- Provide summaries or key points.

VERBAL COMMUNICATION

- Speak clearly and at moderate pace.
- Face participants when speaking (important for lip reading).
- Use microphones in larger spaces.
- Repeat or rephrase if asked.
- Allow time for processing and response.
- Avoid talking over people.

SUPPORT SERVICES

- Auslan interpreters (book in advance).
- Captioning for video content.
- Translators for non-English speakers.
- Note-takers or meeting minutes.
- Visual facilitators or graphic recording.

ONLINE/VIRTUAL ACCESSIBILITY

- Ensure platform is screen-reader compatible.
- Provide captions for video meetings.
- Share materials in accessible digital formats.
- Test technology in advance.
- Have tech support available.
- Offer alternative participation methods (phone, video, written).
- Explicitly acknowledge that people can choose how they engage in online meetings (e.g., have video off, use chat feature to contribute).
- Live documentation of contributor ideas to facilitate memory, organisation and attention.


Photo by LinkedIn Sales Solutions on Unspalsh

3.2 CULTURAL SAFETY & RESPONSIVENESS

Cultural safety means creating environments where people from diverse backgrounds feel safe, respected, and able to participate authentically.

INDIGENOUS PEOPLES AND COUNTRY

- Acknowledge Traditional Owners and pay respects.
- Understand sovereignty and right to self-determination.
- Seek guidance from First Nations advisors or community members.
- Be aware of colonial history and ongoing impacts.
- Respect First Nations knowledge systems and ways of knowing.
- Allow time and space for cultural protocols.

CULTURALLY & LINGUISTICALLY DIVERSE COMMUNITIES

- Provide interpreters and translated materials when needed.
- Be aware that some concepts don't translate directly.
- Understand that participation styles vary across cultures.
- Respect different communication norms and practices.
- Be mindful of migration experiences and trauma.
- Don't assume familiarity with Australian systems (e.g., Centrelink, NDIS, PHNs).

LGBTIQA+ COMMUNITIES

- Use inclusive language and avoid assumptions.
- Use correct pronouns.
- Be aware of discrimination and minority stress experiences.
- Create explicitly safe and affirming spaces.

GENERAL PRACTICES

- Ask people about their needs rather than assuming.
- Be open to feedback about cultural insensitivity.
- Address discrimination or exclusion immediately.
- Recognise your own cultural biases and assumptions.
- Invest in cultural safety training for your team.
- Build authentic relationships with communities.
- Understand intersectionality (people have multiple identities).

Image from Mindframe online image collection

3.3 POWER-SHARING PRACTICES

Researchers hold institutional power. Genuine engagement requires consciously sharing or redistributing that power.

RECOGNISE POWER DYNAMICS

- You shape research design, methods, funding, timelines.
- You have institutional credentials and authority.
- You decide whose knowledge is ‘valid’ or ‘rigorous’.
- You have more control over how findings are interpreted, published and disseminated.
- You often gain professional benefits from the research (publications, career advancement).

SHARE DECISION MAKING

- Co-create research questions rather than arriving with fixed questions.
- Give participants real influence over methods and approach.
- Involve participants in research design, not just data collection.
- Share authority over interpretation and analysis.
- Negotiate roles and expectations rather than imposing them.

SHARE RESOURCES

- Budget for power-sharing activities from the start.
- Pay participants meaningfully and appropriately (not just token reimbursement).
- Share research funding where appropriate.
- Provide capacity building and skill development.
- Share access to institutional resources and networks.

SHARE KNOWLEDGE & CREDIT

- Co-author publications and presentations.
- Present findings together when possible.
- Acknowledge all contributions publicly.
- Share plain language summaries alongside academic outputs.
- Report findings back to participants and communities.

Image from Adobe Stock by Studio Nova

CHALLENGE INSTITUTIONAL NORMS

- Question whose knowledge is privileged in academic settings.
- Advocate for changes to ethics processes that exclude lived experience.
- Push back on institutional timelines that don’t allow for relationship-building.
- Challenge academic gatekeeping of publications and presentations.
- Model different ways of doing research.

3.4 SUPPORTING DIFFERENT PARTICIPATING CAPACITIES

People have different capacities for participation based on their circumstances, energy, health, and other commitments. A one-size-fits-all approach excludes people.

FLEXIBLE PARTICIPATION OPTIONS

- Offer multiple ways to participate (in-person, online/digital, written or verbal).
- Allow for synchronous or asynchronous formats so people can review, consider and respond in their own time.
- Allow people to choose their level of involvement.
- Allow people to step back at any time when needed, without penalty.
- Provide different time commitments (some people can't do intensive work).
- Don't penalise people who miss sessions due to health or circumstances.

PRACTICAL SUPPORTS

- Flexible scheduling (work around people's commitments).
- Breaks during long sessions.
- Food and refreshments provided.
- Quiet spaces for overwhelm or distress.
- Support people welcome - make sure this is discussed early and ground rules set for the involvement of supports (e.g., can they participate in the discussion themselves if they have relevant experiences; invited to provide feedback in an alternative way).
- Childcare provision or reimbursement.

EMOTIONAL & PSYCHOLOGICAL SUPPORT

- Acknowledge that engagement can be difficult or activating.
- Provide warnings about potentially distressing content.
- Have support resources available (e.g., co-facilitators, resources) and maintain touchpoints to offer support.
- Respect people's boundaries and limits.
- Don't pressure people to share beyond their comfort level.

TIME & ENERGY CONSIDERATIONS

- Don't schedule overly lengthy sessions (2-hour blocks maximum, with breaks).
- Allow time between sessions for recovery and reflection.
- Be realistic about what you're asking for (don't underestimate burden).
- Compensate appropriately for the energy and effort required.
- Recognise that participation is labour, not volunteerism.


Image from Mindframe online image collection

WHEN PARTICIPATION ISN'T POSSIBLE

- Sometimes people want to be involved but may not be able to participate on the day.
- Don't guilt or pressure people who need to step back.
- Keep the door open for future involvement if circumstances change.
- Recognise that saying no is valid and important.
- Find alternative ways to include perspectives (e.g., brief consultations).

3.5 PHYSICAL ACCESSIBILITY

It's important to consider how people will get to your venue, how they will navigate their way around it, and how well their physical needs will be met.

VENUE SELECTION

- Wheelchair accessible entrance and facilities.
- Accessible parking nearby.
- Clear signage and wayfinding.
- Accessible bathroom facilities.
- Hearing loop or assistive listening system.
- Good lighting; ideally natural lighting where possible.
- Quiet space available for breaks.
- Temperature control.

TRANSPORT SUPPORT

- Provide detailed transport information including accessible routes.
- Offer transport reimbursement or assistance.
- Consider providing transport if venue is difficult to reach.
- Allow participants to bring support people.
- Offer virtual participation options when appropriate.

MEETING SETUP

- Arrange seating in accessible configurations (avoid cramped spaces).
- Ask about lighting and seating preferences once in the space.
- Provide different seating options (chairs with/without arms).
- Ensure tables are wheelchair accessible.
- Leave clear pathways for movement.
- Position materials within easy reach.
- If providing catering, consider options for people with disability (e.g., small bite-sized food), dietary restrictions and cultural/religious considerations.

Image from Adobe Stock by Kasto

FURTHER READING

This toolkit provides a foundational framework for initiating meaningful public participation and engagement. The following additional resources may also be useful to support you in your continued development and practice in participatory research.

AHRA Health Research Hub homepage
https://healthresearchhub.com

AHRA Researchers getting started page
https://healthresearchhub.com/health-and-medical-research/getting-started

Australian branch of the International Association for Public Participation
https://engagementinstitute.org.au

Australian Eating Disorders Research and Translation Centre Resource Hub
https://hub.eatingdisordersresearch.org.au/lived-experience-coproduction-checklist

Black Dog Institute
https://www.blackdoginstitute.org.au/wp-content/uploads/2020/04/anu-lived-experience-framework.pdf

Centre for Cultural Diversity in Ageing (Webinar Series and Practice Guides)
https://www.culturaldiversity.com.au/

Health Translation Queensland – CCI Resources
https://healthtranslationqld.org.au/resources/consumer-and-community-involvement

International Association for Public Participation
https://www.iap2.org

Monash Centre for Health Research and Implementation (MCHRI)
https://www.monash.edu/medicine/mchri/training/courses/consumer-and-community-involvement

Monash Partners – CCI Education Modules
https://monashpartners.org.au/education-training-and-events/cci

National Mental Health Commission
https://www.mentalhealthcommission.gov.au/lived-experience/consumer-and-carers/consumer-and-carer-engagement-%281%29

NSW Co-design
https://aci.health.nsw.gov.au/projects/co-design

NSW Health Agency for Clinical Innovation
https://aci.health.nsw.gov.au/projects/co-design/working-together

Roses in the Ocean – Lived Experience Resources
https://rosesintheocean.com.au/lived-experience-of-suicide-informed-and-inclusive-culture-change-suite-of-resources

WA Gov - Research Education Program
https://www.cahs.health.wa.gov.au/Research/For-researchers/Research-Education-Program

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