words to actions

practical ways to work together

NSW Regional Health Partners

Many frameworks have principles. Words are good, actions are better.

We share practical actions that researchers and others can take to co-design and co-deliver research.

The actions link to our key principles (page 3) and focus on relational ways of working.

How to use this document

You could:

- Identify where you are in the research cycle and find the page for that phase. As a team, talk about what you're doing and what you could be doing. Set responsibilities.
- Set commitments for co-designing and co-delivering research. Revisit your commitments. See our tool, "**how are we going?**".
- Identify changes needed to processes or standard ways of working.
- Identify a past project to evaluate against the actions.

In this document you'll find:

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Design by Lucy Klippan, **Good Point Design**

(figure 1 - five principles to work as a team)

key principles to work as a team

As researchers, consumers and co-design facilitators we identified five principles (figure 1) that build on NSW Health's **All of Us Guide** [1] and other resources [page 9] to help researchers, consumers, carers and health workers co-design and co-deliver research.

A note on the key principles

We acknowledge many knowledge and value systems, especially those of Aboriginal and Torres Strait Islander peoples. We recommend the key principles as a guide for research co-design and co-delivery, not as a rigid set of rules or as a replacement for communities' own language, world views, values or protocols.

read more on the key principles here:
doingresearchtogether.com.au/key-principles/

phase: before you start

am I / are we:

working from shared values / commitments?

staying open to different priorities and changing how we work? e.g. hearing our idea isn't valued by people with lived experience?

seeing consumers and carers as colleagues and partners, not only as participants? [2]

taking time to build relationships before making decisions?

have one-to-one conversations before and outside meetings

Understand consumers', carers' and researchers' perspectives, strengths and access needs.

check if co-design is possible and if you're the right person to lead the co-planning

Consider timelines and budget, rules and constraints, power differences and your relationship to the communities you want to work with.

be open to different priorities, or a lack of community interest

People with lived experience might not share your priorities and have other suggestions. Are you open to hearing them? Are you clear what can and can't be co-decided?

budget for lived experience roles at every level of the project

From senior leadership to research delivery, think about on-going and ad hoc roles (e.g. artsts, advocates) and support costs.

work with multiple consumers and carers (not one person)

One person can't represent all perspectives. So, work with many consumers and carers to plan your approach and set priorities.

slow down to build relationships, awareness and trust

Take time to understand individual and community histories, skills and struggles.

what will you do?

What matters to the consumers and carers you're working with?

What's worked well for participation before?

Talk about what you'll do as a team to foster a collaborative process

phase: decide what to research

am I / are we:

setting priorities together?

seeing consumers and carers as colleagues and partners, not only as participants? [2]

showing consumers, carers, communities and others how we're incorporating their feedback?

be honest about what can and can't be co-decided

e.g. funding rules, pre-existing focus areas, regulations, mandated protocols such as ethics. Identify areas for shared decision-making.

name the principles, values or mindsets you'll work from

Principles, values and mindsets [3] guide actions and can help everyone get back on track if the work isn't following what the team agreed to – *e.g. you might agree to take a non-pathologising approach, to practice curiosity, or commit to on-going learning about how best to work together.*

reframe existing priorities and research terms in ways community understand

If your funding has set priorities, find accessible language that consumers understand and connect with – *e.g. service transformation could be 'making services better'.*

ask about community priorities outcomes that matter to each group

Researchers, funders and communities might have different priorities and desired outcomes – explore if multiple outcomes can be met.

be flexible with meeting times, places, format and offer choice

Don't expect decisions to be made in one meeting. Give people options to take part and be flexible with changes.

what will you do?

What matters to the consumers and carers you're working with?
What's worked before in this phase?

Set commitments.

phase: decide how to research

am I / are we:

understanding decision-making as a process not a single event or meeting?

seeing consumers and carers as colleagues and partners, not only as participants? [3]

noticing where culturally-specific or community-specific approaches and protocols are needed?

creating inclusive activities?

use interactive tools to co-decide methods and approaches

see method card example

Communities often don't have access to information about methods and can't be active partners in decision-making without choices. So, you might add methods to cards to select which ones to use.

talk about roles and support structures

Make a map of potential roles. Be open to new roles, talk about building-in support for the team and research participants. Revisit budget for lived experience roles.

see example of role map in **"talking about roles"**

make it easier for consumers and carers to join the team

Simplify processes to bring consumers and carers onto the team. Be honest about the responsibilities of different roles (e.g. of a Chief Investigator versus an Associate Investigator, steering group member etc.) including ethical and legal obligations.

co-decide how to make decisions and address disagreements

Aim for equal representation of consumers and researchers. Take time to listen to and acknowledge different perspectives. Acknowledge power imbalances.

see consensus decision-making example

consider inclusive and creative research methods

Some methods may better engage people who are often left out of research – *e.g. arts-based approaches, yarning, peer-led interviews, workshops and other activties.*

what will you do?

What matters to the consumers and carers you're working with?
What's worked before in this phase?

Set commitments.

phase: when doing research

am I / are we:

taking time to understand other's skills, identities and struggles?

checking in with each other, including to pre-brief and debrief outside meetings and activities?

noticing where to link people up for support, career progression and skill-sharing?

adjusting our approach as we learn?

finding people to address gaps we've noticed?

check in, notice who isn't speaking up or has left the project

When we're busy we stop talking to each other. Keep checking how it's going. Repair damaged relationships. Keep asking: *Is lived experience in the room?*[4].

learn more in **"how are we going?"**

co-create and update a respectful language guide

Agree how you'll talk about people's health, experiences, identities and bodies. Use the guide to make decisions about recruitment and research materials, communications and, later, language in publications.

communicate decisions and address disagreements, revisit values and principles

When people with lived experience aren't involved in decisions clearly explain what was decided and how. After disagreements try to repair relationships.

be flexible with meeting times, places, format and offer choices

Don't expect decisions to be made in one meeting. Give people options for how they can contribute, which can change.

co-analyse the data and name the findings together

Value different perspectives. Explore co-analysis methods – *e.g. Hemming et al* [5]

what will you do?

What matters to the consumers and carers you're working with?
What's worked before in this phase?

Set commitments.

phase: let people know the results

am I / are we:

using strengths-based language?

being sensitive about deficit-based and stigmatising language?

continuing the 'co' into dissemination and evaluation?

co-deciding who we're trying to reach and what might engage them best? (writing articles, events, videos, something else)

co-plan communications, key messages, events and advocacy

Stay curious about each other's skills and ideas. Agree on key messages to inform communications and advocacy. Agree what won't be shared.

talk next steps

Discuss what's next (e.g. running events, more research, implementation, making changes). Have honest conversations about what team members can and want to do.

make time to celebrate

Celebrate. Reflect on what worked in the process and what to do differently next time. Notice new skills and insights. It's normal to be tired.

be flexible with lived experience co-presenters

It can be hard for people with lived experience to attend conferences and other events. So, you might pre-record someone's talk if they can't be there due to health, caregiving or other reasons, or, if they feel more comfortable that way.

be flexible with feedback on plans and publications

As well as using track changes, provide other ways to give feedback, e.g. a meeting to talk it through, making a voice note or something else. Think about access needs.

work with advocates, artists and campaigners from the community you've researched

make everyone who contributed a named author subtitle

Check if and how they'd like to be named.

what will you do?

What matters to the consumers and carers you're working with?
What's worked before in this phase?

Set commitments.

references and further reading

[1] New South Wales Government, Ministry of Health. (2023). All of Us: Six ways of working. Retrieved from **https://www.health.nsw.gov.au/patients/experience/all-of-us/Pages/six-ways-of-working.aspx**

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[3] McKercher, KA. (n.d.). Six mindsets for co-design. Retrieved from: **https://www.beyondstickynotes.com/mindsets-for-codesign** also in McKercher, KA. (2020). Beyond Sticky Notes. Doing co-design for Real: Mindsets, Methods, and Movements, 1st edn.

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[5] Hemming, L., Pratt, D., Bhatti, P., Shaw, J., & Haddock, G. (2021). Involving an individual with lived-experience in a co-analysis of qualitative data. Health Expectations, 24(3), 766-775. **https://onlinelibrary.wiley.com/doi/pdf/10.1111/hex.13188**

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