

Youth Lived Experience Co-Design Guide

Purpose

This document aims to provide guidance for co-design interactions with young people by outlining important points to consider and offering practical suggestions for each phase of co-design engagement. It demonstrates successful youth engagement by detailing how to work alongside young people to identify priorities, co-create solutions, and promote accessible, youth-friendly systems. Genuine commitment, curiosity and willingness to listen to young people are necessary to creating genuine meaningful interactions, and hence, underpin the suggestions provided.

Who is the guide for?

This guide supports Primary Health Networks (PHNs) to engage in co-design with young people. PHNs are service planners and commissioners, and as such youth engagement will likely involve, though is not limited to, advocacy and system design to improve community wellbeing. While designed for PHNs, much of the guide remains relevant to other organisations and services seeking guidance on co-design.

Led by lived and living experience

Inherent to framing living and lived experiences as a form of expertise is acknowledging the strength, resilience, and vulnerability it requires to share such experiences. The invaluable contributions of lived experience voices enable organisations to meet the needs of the people and communities they intend to serve.

We also acknowledge that lived experience expertise is not restricted to young people or service users, but that those working with young people in a professional capacity often carry their own lived experiences.

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Avoiding tokenism

To avoid tokenistic co-design, engagement must include a genuine commitment to collaboration and valuing the young people's experiences and insights as equally valuable to academic and clinical expertise. Youth engagement must begin at the start of a project and be maintained throughout every phase of co-design. Signs of tokenistic co-design include:

- meeting with young people but not taking onboard their suggestions
- having young people attend unnecessary meetings
- not supporting young people to share their insights
- having insufficient representation of young people in a group
- inadequate recognition and disclosure of young people's contributions

Disclaimer

Although the guide aims to provide key information and examples of youth engagement, the unique nature of co-design means the guide is not a one-size-fits-all. This document builds on the *Youth Lived Experience Framework* by providing practical information and more detailed, step-by-step guidance. It acknowledges that young people have diverse needs and perspectives, and emphasises the importance of creating supportive environments so that young people can contribute meaningfully throughout every stage.

Principles

For each phase of co-design, a relevant case study is provided to demonstrate the application of this guide in practice. The case studies are linked to the *Youth Lived Experience Framework* principles as indicated by the highlighted sections. Please use the key below to see the relevant principles.

Accountability

Integrity

Accessibility

Diversity

Transparency



Phases of Co-Design

Phase 0 Inception & Governance

Example: working with the PHN Youth Advisory Group to identify commissioning priorities

Phase 1 Promoting Co-Design

Example: advertising a co-design workshop, clearly stating what is involved, remuneration, accessibility and the value of lived experience

Phase 2 Pre-Co-Design

Example: an online form asking young people for preferred name/pronouns/contact method, a safe person as their emergency contact and any supports to help them participate

Phase 3 During Co-Design

Example: have a youth co-facilitator, explain what supports are available, have cold water, snacks, fidgets and a printed agenda on tables

Phase 4 After Co-Design

Example: develop a sustainability plan with young people, seek feedback via paper and online forms, and provide young people with actions for how their feedback will be used

Phase 5 Project Completion

Example: provide young people with an update about how their feedback influenced the project and a letter of thanks for their involvement

Phase 0: Inception and Governance

To allow for sustainability and genuine engagement, PHNs should clearly establish their objectives for engaging young people early within a project's timeline. In recognition that youth engagement is a mutually beneficial partnership, PHNs should endeavour to ask young people what they would like to gain from participation in co-design. Involving young people from the outset better enables youth voices to be integrated throughout processes and ensures that co-design is truly youth-led across each stage. This means involving young people when defining priorities, shaping goals and informing governance. Inviting young people to Steering Committees or Youth Advisory Committees can provide a dedicated space to champion youth voices.

Case Study

Accountability Integrity Accessibility Diversity Transparency

A PHN has identified that a youth mental health service model could be improved by listening to young people who are previous or current service users to hear their insights into improving accessibility to the service. The PHN would like to run a series of workshops over an extended period to gather these insights but are unsure of how to maintain youth engagement. They decide that alongside the workshops they would like to create an ongoing Youth Steering Committee for young people to help inform and guide ongoing youth engagement.

Phase 1: Promoting Co-design

It is important to explain what co-design is and how it works, particularly in reference to the project, when promoting it to young people. Doing so ensures young people understand their roles, responsibilities and expectations in the project, ultimately leading to open and active engagement. Framing young people's experiences as expertise equal in value to academic and clinical knowledge fosters trust, respect and equal status.

It is also important to be transparent around the capacity to provide remuneration or honorariums during recruitment. This recognises the value of lived experiences and acknowledges that young people are providing their time and expertise alongside, or at times at the expense of, other priorities.

During project promotion, technical jargon should be avoided or explained so project aims are clearly understood by young people. Diverse needs should be considered by

using easily legible fonts and colours and being screen-reader compatible. Appropriate language, which accounts for the nuances in language used by different communities, should be used. Strengths-based and non-stigmatising language should be used to engage young people in a culturally safe and empowering way. Stigmatising language such as clinical labels or terms (e.g. “schizophrenia”, “paranoia”) may carry negative connotations and can unintentionally ostracise some young people, impeding their ability to feel safe to engage.

Overall, explaining co-design, remunerating young people for their time, valuing lived experiences, and catering for accessibility needs when promoting projects, empowers young people to actively participate. For PHNs, it can be helpful to frame co-design as an opportunity for young people to shape service priorities, improve systems and advocate for youth-friendly care that meets their needs.

Case Study

Accountability Integrity Accessibility Diversity Transparency

A PHN is developing a new youth mental health service model and is committed to embedding young people's voices across planning, implementation and evaluation to drive genuine system improvement and advocacy. To recruit young people the PHN co-designs a youth friendly flyer with its existing Youth Advisory Committee, who recommend use of strengths-based language, and provide practical advice to remove potential engagement barriers such as using clear language and offering flexible contact options for accessibility.

The flyer reads in legible and accessible font, “Join our co-design project to improve mental health services! What does this mean? We want to work with you and support you to share your lived experience in a 3-day workshop series. The first workshop will include group discussions about current issues young people face when seeking mental health support. The second workshop will involve brainstorming different ways that young people can engage with services (eg. text, meeting in the park, video calls), and the third workshop will involve working with a service to implement a new way for them to reach young people, piloting your ideas and feedback. Your involvement won't end at the final workshop. Young people from this co-design group will be encouraged to join our Youth Advisory Committee to guide further implementation, monitor progress and outcomes, and influence PHN-wide planning and advocacy. Your voice will help shape ongoing decisions not limited to just this one project. If interested, please contact us in the way that best suits you via call (1234 567 891)/ SMS (1234 567 891)/ email (livedexperiencematters@gmail.com). You will be reimbursed \$___ per workshop for your time, food and refreshments will be provided. We look forward to hearing your ideas!”

Phase 2: Pre-Co-Design

Prior to the co-design project, PHNs should gather information about how to best support and empower the young people who have expressed interest during co-design. This includes gathering their preferred name, pronouns, preferred method of contact and accessibility requirements – all of this is vital in recognising that different young people engage and are most comfortable in different ways. To ensure active communication during the co-design process, PHNs communicate with young people via their preferred method of contact.

To support safety while respecting young people's privacy, PHNs should clarify that emergency contacts may be any trusted adult over 18, not necessarily a parent or guardian. PHNs should also ask young people what supports or accommodations would help them participate fully in co-design. Examples include more frequent breaks, access to quiet spaces, reminder messages, debriefs or check-in calls and flexible options to provide feedback. Establishing these early during the co-design process helps to diminish the risk of harm and ensures the co-design process is accessible, youth-friendly, and trauma informed.

Another way to support this is by advertising opportunities for young people to take on leadership or co-facilitator roles (e.g. delivering the lived experience acknowledgement, co-leading debriefs, or helping guide session agendas). These opportunities recognise lived experience as expertise, give young people agency, build confidence and model youth leadership for others. This recognises that young people's contributions extend beyond consultation to include authentic and meaningful involvement in shaping engagement.

By collecting this information prior to engagement, PHN processes and interactions can accurately reflect youth priorities, guide service commissioning, strengthen partnerships and create accessible, responsive mental health systems. This approach is grounded in trauma-informed practice that safeguards wellbeing and celebrates lived experience as a strength. It aligns with the *Youth Lived Experience Framework* and positions young people as advocates and partners in co-design, enabling genuine systemic change.

Case Study

Accountability Integrity Accessibility Diversity Transparency

A PHN sets up a short registration form for young people interested in their design project to complete. The form asks for their preferred full name, pronouns, email and emergency contact, with the explanation that an emergency contact can be a trusted adult over 18. The form also asks about accessibility needs and wellbeing

supports, giving examples of such (e.g. access to quiet spaces, regular breaks, need for regular check-ins) so that young people can feel supported, safe, valued and better engage in the co-design space. The form also lists an option for young people interested in leadership or additional advocacy roles, giving them agency to advocate for youth perspectives, influence system wide planning and guide service improvements.

Phase 3: During Co-Design

Key to successful co-design is the active engagement of young people. To promote this, PHNs should affirm that the lived experiences of young people are a form of valued expertise within co-design processes. Creating space for young people requires ensuring that processes are not purely catered to service providers or academics. Alongside processes that champion the voices of young people, involving a youth representative to support youth engagement can reduce the uncertainty of engaging with service providers. Additionally, PHNs must actively avoid creating or fostering “us vs them” attitudes between young people and academic or clinical staff. By highlighting that lived experience expertise is complementary to academic and clinical knowledge, it ultimately works to improve policy and practice.

Lived experiences, broadly speaking, are not devoid of distress and thus the sharing and involvement of lived experience voices involves listening to and navigating sensitive conversations. When engaging young people in co-design, to guarantee or enforce a safe space entirely devoid of distress or discomfort is misleading and underestimates the resilience and strength of young people. Instead “safe and brave spaces”, which recognise that the sharing of challenging or sensitive experiences may occur during co-design processes, involve minimising the risk of harm in co-design participation for young people. Whilst organisations must recognise the resilience and strength in young people’s stories of survivorship, they must mitigate the impacts of co-design participation and ensure that they are not re-traumatising. Young people, by expressing their interest in co-design, are showing willingness to share their lived experience expertise and an understanding of their personal capacity to do so. By denying the opportunity for young people to be included in co-design due to the assumption of over vulnerability and fragility we silence their voices.

To avoid tokenism, organisations must communicate to young people their genuine commitment to implement co-design practices. This involves clearly outlining how young people’s lived experience expertise will be incorporated within projects. Additionally, PHNs should endeavour to actively seek and provide multiple channels to receive ongoing feedback from young people about their experiences during co-design.

During co-design, PHNs must present information and facilitate activities in an engaging way. For some young people, particularly those who identify as neurodivergent, providing fidget aids can be helpful for regulation and concentration.

Case Study

Accountability Integrity Accessibility Diversity Transparency

During co-design, the session facilitator outlines the goals for the session, establishing how they intend to incorporate lived experience voices into their service plan and the value of lived experience expertise, and explains what supports are available, including directions to the quiet room. The session is also co-facilitated by a young person with lived experience who has been paid for their time co-facilitating. The tables have a printed agenda for the day that includes a QR code to provide anonymous feedback throughout the session, cold water, snacks and fidget aids. PHN staff actively involve young people by asking for their input into the conversation and having young people guide the session. To encourage sharing, most attendees are young people, with only a few PHN members present. The session facilitators also include options for young people to share their insights through written form via surveys, post it notes, and online collaborative boards, allowing for diverse methods of engagement.

Phase 4: After Co-Design

Important considerations when approaching or immediately upon the completion of a co-designed project include seeking feedback, communicating how such feedback will be implemented in the future, promoting future opportunities, developing evaluation tools with young people and creating opportunities for young people to participate in the evaluation process.

Feedback is an integral component of co-design. It is essential that young people have access to multiple channels for providing feedback and that these channels allow for optional and anonymous responses. Common feedback methods include debriefing sessions, youth-led reflection sessions, surveys, follow-up messages, and informal discussions. Ongoing evaluation and engagement, through the development of a sustainability plan, can ensure youth voices remain active beyond the project. A sustainability plan may include evaluation tools co-created with young people, forming a dedicated PHN advisory group position or a specific Youth Steering Committee to foster enduring partnerships and leadership development, and a list that participants can join if they want to be contacted for future co-design opportunities.

Feedback questions may ask young people about:

- The way they were engaged (e.g., online/in-person, the length of the sessions, etc.)
- How supported they felt throughout the co-design process
- How safe and supported they felt to share their insights during the session
- If they found the experience to be personally beneficial, and why
- Whether the service's commitment to co-design and genuine partnership was upheld
- The venue and its accessibility for face-to-face co-design

Providing young people with a list of actions or plans to implement their feedback helps ensure accountability and actionable change. If a project has multiple workshops or meetings, it can be helpful to send out a summary, including action items, with the option for young people to voice additional thoughts they did not share during the workshop.

Case Study

Accountability Integrity Accessibility Diversity Transparency

Shayaan attended a series of in-person co-design workshops to develop a new mental health service directorate. After each workshop, young people were sent a document that summarised their feedback from the session, decisions made, action items, including a timeline, and an update on the previous workshop's action items.

During the final workshop, the last 10 minutes of the agenda were dedicated to giving young people the chance to complete an anonymous feedback form (digitally via a QR code, or on paper). Within the next week, everyone received an email with a document summarising the young people's feedback, how it has influenced the development of the service directorate so far, and any final adjustments that will be made based on feedback from the final workshop. The email also included a link to the feedback form that was completed in the final workshop, in case anyone had further comments, and the option to be added to a list for future opportunities. Shayaan had extra feedback he wanted to share, but did not want to complete the feedback form a second time, so he emailed to organise a phone call to share his feedback and ask to be added to the future opportunities list.

Phase 5: After Project Completion

After a project is completed, young people should be provided an update about how their expertise and feedback influenced the project following the final workshop. For some projects, particularly those which are longer-term, providing young people with a certificate or letter can be one way to recognise their contributions and formally

thank them. Furthermore, ensuring that young people retain access to the products and outcomes they helped build ensures their efforts remain valued and avoids tokenistic engagement across all stages of the project, even after its completion. For example, this may include contacting young people with links to websites or services they help build, or access to research models and data they help inform.

Case Study

Accountability Integrity Accessibility Diversity Transparency

Darcy was part of an LGBTQIA+ working group that created a social media campaign advocating for and promoting queer-affirming health services in the PHN. After the edits from the last meeting were applied, Darcy was emailed a final version of the social media posts, a formal letter of thanks from the PHN, and informed of the expected launch date for the campaign. A month later, they received a text message letting them know that the campaign had been launched and the posts were published.

Frequently Asked Questions

Question (Q): How do we define the age bracket of “young people”?

Answer (A): Services, Primary Health Networks and Local Health Districts differ in their definitions of “child”, “young person” and “adolescent”. However, we recommend following the NSW Child and Youth Mental Health Services Competency Framework, which states that a ‘child’ includes infants (0-1 years), toddlers (1-2 years), pre-schoolers (3-4 years) and children (5-11 years inclusive) and a ‘young person’ includes adolescents (12-17 years inclusive) and youth (18-24 years inclusive). Engagement should ultimately involve people of the ages relevant to the project.

Q: What do we do if young people have not expressed interest in co-design?

A: If you are struggling to engage young people in co-design, this is usually due to the way that it is being promoted. Consider promoting co-design in other ways, evaluate the language being utilised, reinforce that people’s experiences are valued, remunerate young people for their time, and be explicit when explaining what the engagement will involve. You can also ask other young people who have participated in co-design to review your co-design process.

Examples to promote co-design include: using language that is easy to understand,

sets clear expectations and highlights that people's experiences are valued; having easy ways for young people to sign up or learn more (e.g. QR codes, hyperlinks, paper expression of interest forms); having different methods of advertising (e.g. asking the PHN Youth Advisory Board to promote it, social media posts and videos, brochures, having a website, videos, posters on university notification boards, flyers/posters at local youth centres or mental health services, reaching out to existing advisory boards and asking them to promote it).

Q: Should we engage parents/carers when working with young people?

A:

- Consent must be obtained from a “safe person” when engaging young people under the age of 16 years old. A “safe person” may not be a young person's legal guardian or biological parent; it could be anyone over the age of 18 who the young person feels safe speaking to. Young people should also be provided the option to invite a support person, when engaging in co-design.
- It can be helpful as well to ask young people the extent they would like their safe person to be engaged with the project, and establish procedures that can be followed when necessary prior to the workshop or activities (e.g. whether safe person should be contacted when young person is distressed).
- It is also important to recognise that existing relationships can also exist between one young person's “safe person” and other young people involved in a wider project, especially when engaged with small communities (e.g. local LGBTQIA+ or culturally and linguistically diverse communities). In these situations, it may be beneficial to discuss with young people, how support people should or should not be involved (e.g. should support people be included in the room, or should they be asked to wait elsewhere).
- *Please follow the relevant legislation for your state or territory.*

Q: How do I follow up with a young person who has expressed interest, but have been unable to contact?

A: Try contacting the young person via another method (eg. Messaging or emailing). We recommend messaging or emailing as the primary method of contact, unless the young person has specified otherwise, as this allows young people to engage on their own time and provides the details in a way young people can refer to when needed.

Establishing a primary contact for young people to engage with can also help. It can be difficult for young people to remain engaged if their engagement with a project is handled by a new person each time they reach out. Having a consistent contact or contacts can help to build trust, comfort, and make it easier for young people to remain in contact or keep the team updated if they know who to reach out to regardless of what is going on.

Q: What if a young person becomes distressed during a co-design session?

A:

- Supports to prevent distress may include having a dedicated quiet room/safe space, developing a group agreement around safe language at the start of engagement, having fidgets available and having a peer worker or clinician available onsite. Young people should be informed of these supports and their locations at the start of a session and ideally, prior to the day.
- Establishing clear, discrete methods where young people can ask for support or communicate distress can be helpful, especially in large group settings where it may be difficult to stop the activity or may cause further distress if attention is drawn. For example, establishing a series of hand signals young people can give when leaving a room to indicate they would like support or to show they are fine.
- If a staff member sees a young person walking out of the room during the session, we recommend sending the peer worker/clinician to check on them shortly after.
- If a young person becomes distressed during the session, we recommend that a peer worker or clinician engage with the young person and utilise their expertise to support the young person. Please only call the young person's nominated "safe person" if necessary and the peer worker/clinician is unable to adequately support the young person.
- If a young person needs to leave the session early, establishing a plan to follow up with them can help them feel supported, and ensure they are safe. This might include asking them if they want to be contacted by a peer worker/clinician, when they would like this to occur, and how so – as well as whether their "safe person" should be contacted.
- Whilst these supports are recommended, it is important to note that **young people participating in these processes do not inherently need additional support, and should be given the autonomy to engage and request supports as needed.**

Q: How do we balance different levels of engagement with young people to ensure they are being involved to the level they feel comfortable with?

A:

- Recognise that commitment and energy can vary between people and periods, and engagement can shift as a result. Young people may engage in various ways that suit their needs best and there is no one "correct" way to engage.
- In online meetings, allowing young people to self-manage their cameras and microphones ensures they have autonomy in their engagement. Some young people may like to have their cameras on whilst others may find this uncomfortable or that it requires more effort, thus detracting from their focus and engagement.

- Allow additional work and opportunities to be opt in and opt out. The availability of choice does not diminish the effort young people will put in, but rather allows them to self-manage and ensures they commit with genuine interest.

Q: If something goes wrong with the engagement or project, should we tell the young people we are engaging with?

A:

- Transparency and accountability are vital to ensuring engagement with young people is ethical and positive. These are relevant when outcomes are positive, and even more vital when they are not. Selecting certain information to share with or exclude from young people can often lead them to feel blindsided when decisions opposing their advice are made or the project is unable to continue.
- Within the restraints of confidentiality, young people should remain appropriately updated about the project's progress, decisions being made and the reasoning behind them. Where information cannot be readily shared with young people, they should be informed that certain information cannot be shared and why (eg. confidentiality). This can help young people feel valued and respected, while fostering a transparent dialogue and approach to the project.

Q: How should I select the young people I am engaging with for a project?

A:

- It is important to acknowledge that young people are not a uniform entity, and their experiences can be highly diverse. The young people being engaged with should reflect the goals and target audience of the project.
- When looking for young people to reflect diverse communities, it is important to recognise nuances between communities. Asking young people and their communities to engage and speak on issues that they may not have appropriate knowledge or lived experience on can be hugely detrimental. For example, if a project seeks to understand services for Indigenous Australians, engagement should focus specifically on Indigenous young peoples, not all young people who identify as people of colour.

For any questions or to contact the National Youth Reference Group, please email bmc.right-care@sydney.edu.au

This guide was created on the unceded lands of the Eora nation.

