



 **Drygen**

The National Centre of Excellence
in Youth Mental Health

Co-designing with young people

The fundamentals

.....



Introduction

Young people have expert knowledge of their own lives. Their participation in all aspects of youth mental health is vital to ensure that care provided is accessible, appropriate and effective.¹ Meaningful participation involves young people being partners in the decisions that affect them, whether that be in their direct care, service design, quality improvement or evaluation.²

In Australia, there is an expectation that Primary Health Networks (PHNs) engage their communities in the co-design of regional health care services, including mental health services for young people.³ Whilst many organisations see the value of partnering with young people and young people are often enthusiastic to be involved, ensuring meaningful participation can be challenging.

Acknowledgements

Orygen, the National Centre of Excellence in Youth Mental Health would like to thank the members of our Youth Advisory Council and PHN Advisory Group for their vital contributions in producing this guide.

About this document

This guide aims to assist PHNs and youth mental health services co-designing with young people by addressing some of the fundamental issues. This guide will cover:

- What is co-design and how does it differ from other forms of participation?
- What are the opportunities to co-design?
- What do young people say about being involved in co-design?
- How can young people be supported to be active participants?
- Where can useful resources be accessed?

Key takeaways

- There is no one right way to co-design but core features include:
 - Equal value given to expertise by lived experience and expertise by profession or education
 - Sharing of decision-making power
 - A design-led process
 - Use of design methods to support active participation
- Not all participation is co-design. If decision-making power is not shared equally, it is a consultation and not a co-design process.
- Co-design principles and methods can be applied throughout the whole commissioning cycle.
- Orygen's principles of youth participation can help organisations to think through how they can support young people to be active participants in co-design.

What is co-design?

In simple terms, co-design is a process which involves people in the decisions that will have an impact on them.

Co-design is not a new idea. It is rooted in the principles of participatory design, which emerged in 1970s Scandinavia.⁴ Underpinning the approach are the fundamental beliefs that (a) everyone should have the right to participate in the decisions that impact on their life and (b) everyone has valuable knowledge to contribute to a design process.⁵

Whilst differences between co-design and participatory design are debated in the design field,⁶ these differences remain largely insignificant in the context of healthcare design. Both approaches share essential features and the terms are used interchangeably. It is common to come across the term participatory design in the academic literature, but co-design is the more frequently used term in the healthcare sector.

There is no single right way of doing co-design, but it is worthwhile to consider its core features:

1. Equal value given to expertise by lived experience and expertise by profession or education

In youth mental health, co-design may involve people working in the mental health system (e.g. service funders, service providers, service designers and researchers), young people and families who have lived experience of using youth mental health services, and other members of the community.

Incorporating multiple perspectives into the design process helps to develop a more comprehensive understanding of a situation, opening up more ideas and opportunities than any one party could develop alone. In co-design, lived experience and local knowledge have equal value to professional* expertise and scientific evidence. It is not who holds the knowledge that is important, but the knowledge itself that really matters.⁷

2. Sharing of decision-making power

In co-design, the participation of service users goes beyond providing information to professionals who then make decisions on their behalf.⁸ Young people and families with lived experience may be asked to share their stories, but they should also be given the opportunity to actively participate in the design process. Their role may include helping to shape the desired outcomes, generating and testing ideas, and helping to decide how these ideas can shape the design and delivery of services.⁹

By treating young people as equal partners, they are acknowledged for their knowledge and skills, and the value they can add to the development of new services and solutions.¹

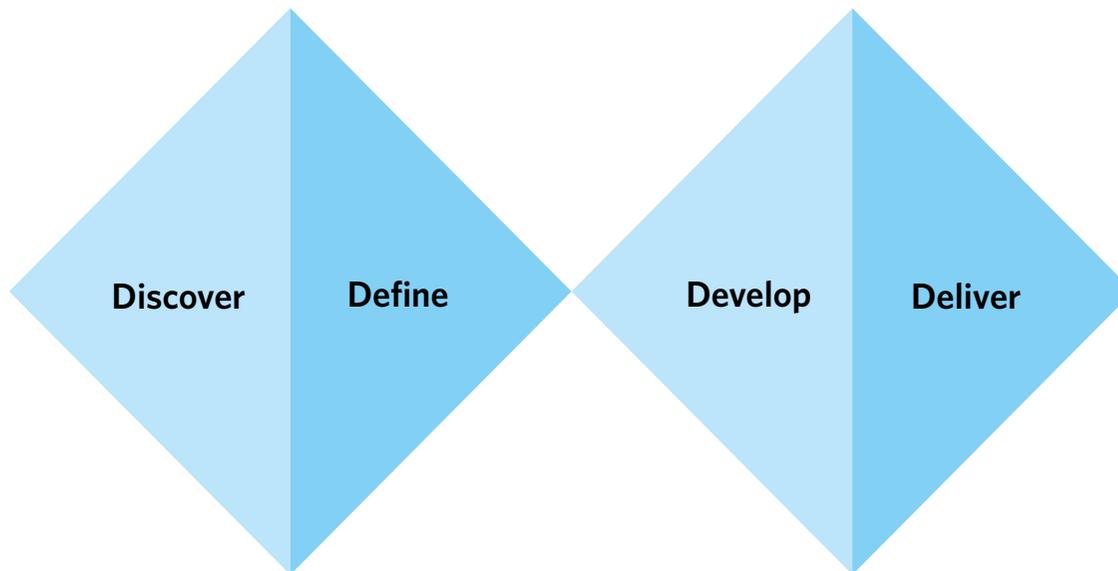
*The term 'professional' is used throughout this document to refer to people working in the mental health system. We acknowledge that in reality, young people with lived experience of mental ill-health may also have professional expertise, and professionals may also have lived experience of mental ill-health.

3. A design-led process

In healthcare, descriptions of co-design tend to focus on the collaboration of people with lived experience and people working in healthcare. Co-design makes use of principles and methods from the field of design (i.e. is design-led), which is often underemphasised⁸

Co-design involves more than a one-off event or workshop, as it is a process consisting of multiple phases. Whilst there are a variety of design processes, they tend to share common features, which have been summarised up the UK Design Council's 'Double Diamond' process.⁸

Figure 1: The Double Diamond Design Process



The Double Diamond process comprises of four distinct phases: discover, define, develop, and deliver.¹⁰ The process maps how initial insights about needs and problems (discovery) are turned into a new service or solution (delivery). The diamonds illustrates how design processes involve stages where broad thinking and ideas are encouraged (divergence), and stages where ideas are purposely narrowed down (convergence).⁸

4. Use of design methods to support active participation

Whilst people with lived experience may be highly motivated to be involved in the design process, they need to be able to communicate their experiences, perspectives and expectations to actively participate.¹¹ To facilitate this, methods from design can be used alongside more typical research methods, such as interviews, surveys and focus groups.

Using design methods can help to create mutual learning, generate collaborative ideas and enable sharing of decisions.¹² These methods are often visual and practical in nature, with examples including: journey mapping, storyboarding, context mapping, brainstorming, user personas, games, paper prototyping and scenarios.^{10,11,13} Links to further information on design methods can be found in Useful resources on [page 13](#).

NOTE: Consideration should also be given to supporting the active participation of professionals. Whilst professionals may be experts in their field, they may not be able to fully engage in the design process because of a lack of familiarity with the design process and uncertainty about their role in it.

Case study

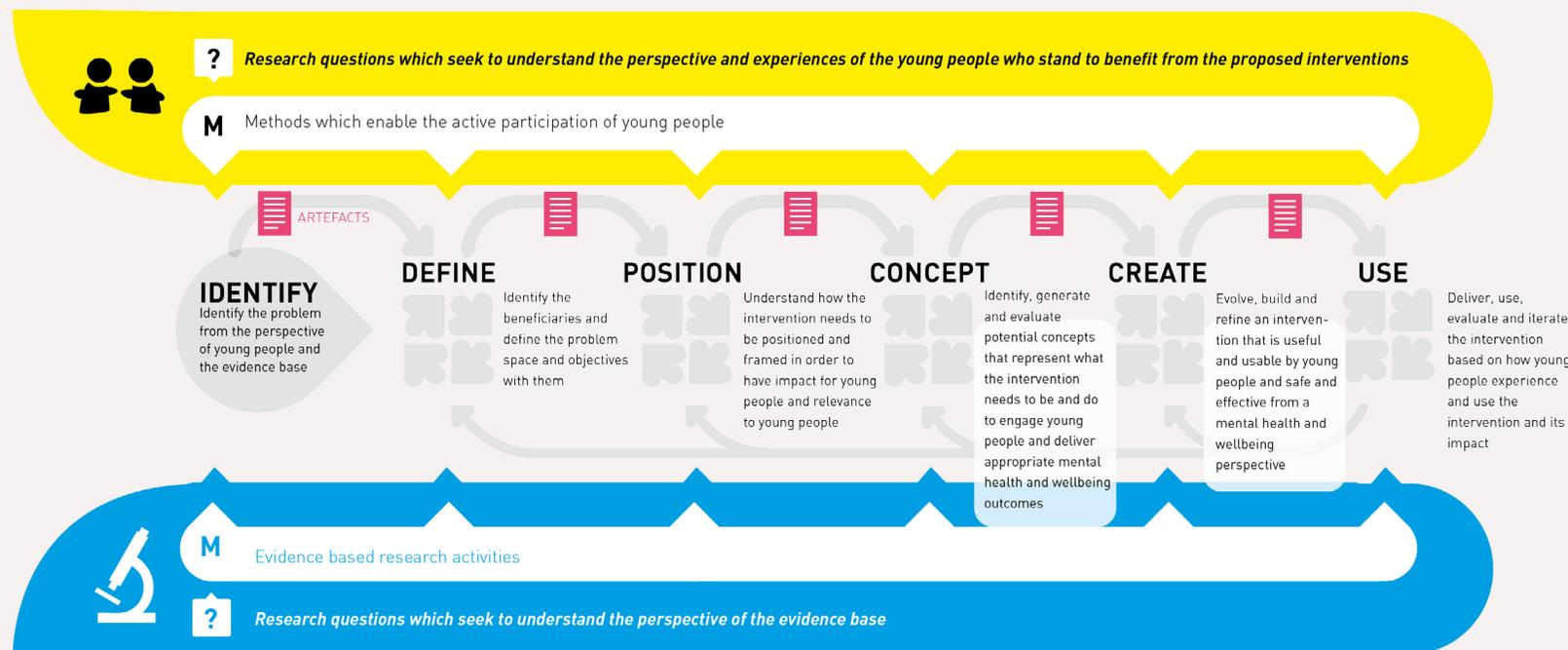
Co-designing an online youth mental health intervention¹²

Young and Well CRC developed a framework which details how youth mental health interventions can be designed using ongoing input from young people and other stakeholders in conjunction with the available evidence base. Their process consists of five phases: identify, define, position, concept, create and use. Each phase consists of a cycle of collecting insights from young people and the evidence base,

generating and evaluating ideas, and making proposals which inform the next phase of the process. Depending on the context and the questions that are being asked, different methods and tools are used in each phase. For example, in the define phase, online surveys and discovery workshops may be used alongside literature reviews and epidemiological data analysis.

The framework has been used to redesign ReachOut.com's mental health services for young people and, more recently, to design a virtual world for young people experiencing psychosis.^{12,14}

Figure 2: Components of the Young and Well CRC framework¹². Reproduced with permission from Dr Penny Hagen.



Not all participation is co-design

Confusion about the definition of co-design means that the term is often mistakenly used to describe any type of participation activity. Whilst we have tried to bring clarity to the term by describing some of co-design's core features, it is also useful to think about where co-design sits in relation to other participation activities. The New Economics Foundation's alternative ladder of participation broadly categorises participation activities as 'doing to', 'doing for', or 'doing with', based on the level of consumer involvement required.¹⁴

- 'Doing to' activities, such as informing, educating and coercing, require the least amount of consumer involvement.
- 'Doing for' activities require more involvement from people who use services and include activities such as consulting and engaging. People are generally asked for their opinions and to share their experiences but have little to no involvement in decision-making.

- 'Doing with' activities represent the highest levels of participation, where decision-making power is shared between professionals and people who use services. Activities include co-designing and co-producing (where people who use services are also involved in service delivery).

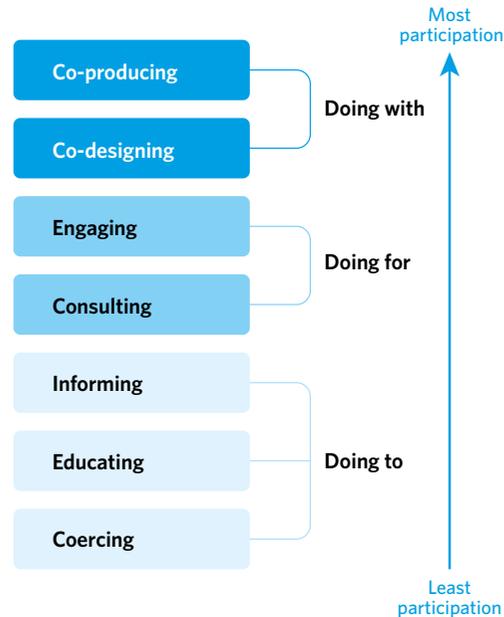
Is it OK to consult rather than co-design?

As we should always be trying to maximise the participation of young people in the decisions that affect them, co-design should be the default method that we use to develop youth mental healthcare.

However, co-design does require an investment in time and resources, and there will be times where it may not be feasible. In reality, most organisations will need to use a mix of co-design and consultation depending on the context.

Consultation is a perfectly valid form of participation, but if you do decide to consult, make sure that (a) you are able to justify why you are not co-designing and (b) everyone involved is clear that what you are engaged in is consultation rather than co-design.

Figure 3: An alternative Ladder of Participation¹⁴



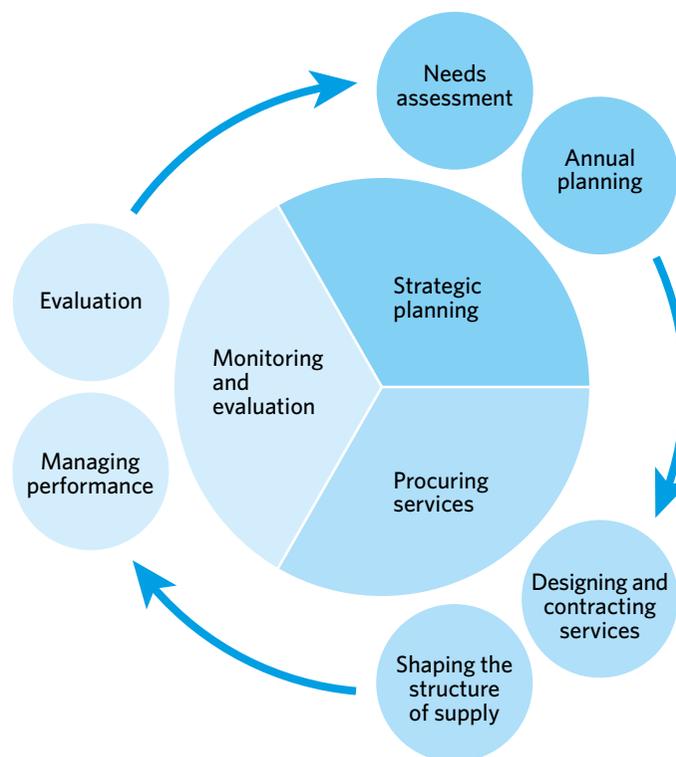
Opportunities to co-design

Whilst most of us probably associate co-design with developing new services or interventions, there are opportunities to work with young people and apply the principles and methods of co-design throughout the whole commissioning cycle.

Figure 4: PHN Commissioning Framework¹⁵

Young people can

- Assist in identifying what should be monitored and measured.
- Inform continuous improvement in service delivery by helping to review data (e.g. service feedback forms) and identify ways that services can be improved upon.
- Contribute to evaluation during its design (e.g. setting of priority questions), interpreting data, making recommendations and helping to communicate the findings in an accessible way. (See 'Program evaluation: Laying the Right Foundations' in Useful resources on [page 13](#)).



Young people can

- Provide perspectives on their health care needs during a needs assessment.
- Help to develop priorities and population outcomes during annual planning.

Young people can

- Shape design goals during the design of services and strategies.
- Generate, test and refine ideas.
- Design service specifications.
- Review tender applications.
- Sit on interview panels.
- Develop service outcomes and Key Performance Indicators (KPIs).

Case study

Co-design from a young person's perspective

Emily recalls her experience of being involved in the co-design of mental health courses for her local community.

What was the situation?

I was involved in co-designing courses for a local mental health agency, which aimed to educate and empower people to take charge of their recovery and wellbeing.

The co-design teams consisted of workers in the mental health/drug and alcohol field and people with a lived experience (of mental ill-health or drug and alcohol difficulties). We were given documents to show us the process and the majority of us had received training on how to co-design courses. Those who hadn't received training had a one on one meeting with the program co-ordinator prior to joining a co-design team to discuss what co-design is, the principles and the way it works. The groups

had no facilitator, so it was up to us to delegate and ensure we were all working in line with the co-design principles.

What made the co-design process worthwhile?

To me, having people with a variety of life experiences, cultures and beliefs is what made this project worthwhile. It helped myself and the other co-design team members gain a further understanding of the different ways that people perceive things and why.

It also made for a course that was more relevant and appropriate to a broader range of people. Attendees of the courses said how much easier they found it to relate to our courses because they were created by people who had similar experiences.

“Myself and the other members who had [co-design] experience/training were able to spot and address things like power imbalances and ensure everyone's expertise were taken into account.”

What do you think worked well?

Many people believe involving people with a range of experiences can make the group more difficult as they're more likely to have differing views. However, this can happen no matter who's involved since it's the nature of co-design.

I believe having people who have experience and knowledge of co-design involved in the project made it run so much smoother. Myself and the other members who had experience/training were able to spot and address things like power imbalances and ensure everyone's expertise/opinions were taken into account.

When I was involved in a large co-design team we were broken into smaller groups to brainstorm and workshop ideas. This ensured that everyone had an opportunity to have an input. Breaking into smaller groups and feeding back was also more time effective and gave us a chance to explore multiple ideas in depth.

What could have been improved on?

At times I found the workload quite unfair as the workers only set aside time to attend meetings from their work schedule, meaning that the majority of the follow up/paperwork and writing up an agenda/minutes fell to me. Otherwise it wouldn't be done as they didn't allocate enough time during their work hours to do it.

Something my group struggled with is the balance between having time for in-depth discussions, trying to incorporating everyone's opinions and expertise, and completing the project on time. We would often get off-track or spend too much time on a part of the project, neglecting other parts. It would have been helpful to have an overview of an expected timeline so that everyone in the room knows when it's time to make a decision and move on.

Another barrier and reason that we struggled to finish on time is because some people had differing views to the approach we should take, so it would have been useful to have more time than expected to complete the project so there's extra time to work together to come to a mutual agreement in case of differing views.

Supporting young people to actively participate in co-design

Young people's active participation in shaping the direction of the co-design process is key to its success. The best outcomes will be achieved if organisations provide support to young people, as described below (and informed by Orygen's youth participation principles¹⁵).

Principle	What can organisations do?
Have clear expectations	<ul style="list-style-type: none">• Have a clear purpose and scope for your co-design process. What are the key questions/problems you want to address? How much time and money is available for design and implementation?• Communicate what can and cannot be changed from the outset to ensure unrealistic expectations are not created.• Make sure young people are aware of the expectations being set of them.
Be flexible	<ul style="list-style-type: none">• Offer young people opportunities to participate that require varying levels of commitment. There are opportunities for young people to be involved in co-design throughout the commissioning cycle. (See Opportunities to co-design on page 7).• Consider using a mix of face-to-face and online methods (e.g. co-design workshops, focus groups, online surveys and webchats).• Ensure that activity times and locations are accessible to young people (e.g. not during school or office hours, near public transport).• In more remote areas, online methods may be helpful but also consider travelling to where the young people are rather than expecting them to travel to you.• Be willing to change your approach based on learning from the design process.

Principle	What can organisations do?
Involve more than one young person	<ul style="list-style-type: none"> No one young person or group of young people can ever represent all young people's views, but it is important to make your co-design process as inclusive as possible. Involve multiple young people, as it may not be feasible for a single person to be involved throughout the entire process. Use a variety of recruitment strategies. Youth Advisory Groups (YAGs) or reference groups can be helpful but also consider strategies like social media or approaching other organisations who can help you reach other young people.
Value experience and skills	<ul style="list-style-type: none"> Include young people with diverse experiences and backgrounds, e.g. people with lived experience of mental ill-health, experience of supporting others with mental ill-health, Aboriginal and Torres Strait Islander young people, culturally and linguistically diverse backgrounds, LGBTIQ+, experience of juvenile justice or those disengaged from school or work. Identify which experiences and backgrounds are not represented. Consider reaching out to other organisations who may be able to help. Recognise individual skills and interests of the young people involved and try to draw on and build on them. Young people's involvement should go beyond sharing their experiences, they should also have the opportunity generate and test ideas.
Ensure there is mutual benefit	<ul style="list-style-type: none"> Co-design provides a great opportunity for professionals and young people to learn from each other. Before co-design begins, consider what skills and knowledge young people may require to meaningfully participate and what opportunities you can provide to develop them e.g. how to review tenders or facilitation skills. Provide value, give the young people an opportunity to make a difference and learn something about themselves.
Reimburse appropriately	<ul style="list-style-type: none"> Pay all young people for their time; their participation is not cost-neutral. Have a reimbursement/payment policy and process for payment. Consider how payments may affect Centrelink or other payments they may be receiving, e.g. scholarships or other bursaries.
Support involvement	<ul style="list-style-type: none"> Ask young people what they need to be able to attend and consider what practical support you can offer. Different young people will require different supports and considerations (e.g. transport, accessibility needs, parental permission, provision of childcare, observing cultural norms, English literacy). Avoid the use of jargon and keep language as accessible as possible. Use creative and engaging methods from design in addition to more typical research methods. (See Useful resources on page 13). Ensure that staff are available to answer questions and provide support during activities.

Principle	What can organisations do?
Provide adequate resource	<ul style="list-style-type: none"> ▪ Effective co-design requires an investment of time and money, plan ahead for the involvement of young people. ▪ Ensure that young people are provided with accessible materials. ▪ Provide young people with the information and skills to contribute and participate. ▪ If you are not sure whether you have the skills to co-design, consider partnering with an organisation with experience in co-design youth partnerships.
Give and receive feedback	<ul style="list-style-type: none"> ▪ Ensure that you communicate to young people what was achieved as a result of their involvement. ▪ Ask young people about their co-design experience. Did they feel valued? What could be improved?
Avoid tokenism	<ul style="list-style-type: none"> ▪ Promote a safe and supportive culture that celebrates young people being genuine partners in decision-making. Professionals have to be prepared to trust the decisions of young people and young people have to be able to trust the advice of professionals. ▪ Do not ask young people to provide input when it is too late to make meaningful changes. ▪ If you are only consulting with young people, do not call it co-design.



Useful resources

Auckland Co-design Lab

<https://www.aucklandco-lab.nz/resources>

Co-designing for mental health: creative methods to engage young people experiencing psychosis – Nakarada-Cordic et al.

<https://doi.org/10.1080/24735132.2017.1386954>

Community Engagement Toolkit – Collective Impact Forum

<https://www.collectiveimpactforum.org/sites/default/files/Community%20Engagement%20Toolkit.pdf>

Considering Consulting? A guide to meaningful consultation with young people from refugee and migrant backgrounds – Centre for Multicultural Youth

<https://www.cmy.net.au/sites/default/files/publication-documents/Considering%20Consulting%20good%20practice%20guide%202009.pdf>

Design Methods for Services – UK Design Council

<https://www.designcouncil.org.uk/sites/default/files/asset/document/Design%20methods%20for%20developing%20services.pdf>

Enabling participation: a companion document to the Young and Well Cooperative Research Centre Innovative Methodologies Guide to Participatory Design – Hagen et al.

http://www.smallfire.co.nz/wp-content/uploads/2016/09/Hagen_Young_and_Well_CRC_Enabling_PD_Guide.pdf

The Field Guide to Human-Centered Design – IDEO

<http://www.designkit.org/resources>

Participatory Design of evidence-based online youth mental health promotion, prevention, early intervention and treatment. – Hagen et al.
https://www.westernsydney.edu.au/__data/assets/pdf_file/0005/476330/Young_and_Well_CRC_IM_PD_Guide.pdf

Program evaluation: laying the right foundations – Orygen The National Centre of Excellence in Youth Mental Health
[https://www.orygen.org.au/Education-Training/Resources-Training/Resources/Free/Toolkits/Program-evaluation/Orygen_evaluation_toolkit.aspx?ext=.](https://www.orygen.org.au/Education-Training/Resources-Training/Resources/Free/Toolkits/Program-evaluation/Orygen_evaluation_toolkit.aspx?ext=)

Service Design Tools – Density Design Lab
<http://www.servicedesigntools.org/>

References

1. Blanchard M, Fava N. Co-designing New Solutions to Support Young People's Mental Health and Wellbeing. In: White MA, Slemper GR, Murray AS (eds). *Future Directions in Well-Being*. Springer International Publishing: Cham, 2017, pp 197–201.
2. Palmer VJ, Weavell W, Callander R, Piper D, Richard L, Maher L et al. The Participatory Zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Medical Humanities* 2018; : medhum-2017-011398.
3. Australian Government Department of Health. PHN Primary Mental Health Care Flexible Funding Pool Implementation Guidance: Consumer and Carer Engagement and Participation. Australian Government Department of Health, 2016 [http://www.health.gov.au/internet/main/publishing.nsf/Content/2126B045A8DA90FDCA257F6500018260/\\$File/8PHN%20Guidance%20-%20Consumer%20and%20Carer%20Engagement%20and%20Participation.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2126B045A8DA90FDCA257F6500018260/$File/8PHN%20Guidance%20-%20Consumer%20and%20Carer%20Engagement%20and%20Participation.pdf) (accessed 27 Feb2019).
4. Sanders EB -N. Perspectives on Participation in Design. In: Mareis C, Held M, Joost G (eds). *Wer gestaltet die Gestaltung?* transcript Verlag: Bielefeld, 2013 doi:10.14361/transcript.9783839420386.65.
5. The Co-Design Initiative. Co-design: Shared perspectives on authentic co-design. The Co-Design Initiative, 2016 <https://auspwn.files.wordpress.com/2016/05/codesign-shared-perspectives-report-vf1-5-040616.pdf> (accessed 2 Jan2019).
6. Sanders EB-N, Stappers PJ. Co-creation and the new landscapes of design. *CoDesign* 2008; 4: 5–18.
7. Durose C, Richardson L. *Designing public policy for co-production: Theory, practice and change*. 1st ed. Bristol University Press, 2015 doi:10.2307/j.ctt1t896qg.
8. Blomkamp E. The Promise of Co-Design for Public Policy. *Australian Journal of Public Administration* 2018; 77: 729–743.
9. Burkett I. *An Introduction to Co-Design*. Knode: Sydney, 2012.
10. Design Council. *Design methods for developing services*. Design Council: London, 2015 <https://www.designcouncil.org.uk/sites/default/files/asset/document/Design%20methods%20for%20developing%20services.pdf> (accessed 24 Mar2019).
11. Hagen P, Rowland N. *Enabling Codesign*. Johnny Holland. 2011. <http://johnnyholland.org/2011/11/enabling-codesign/> (accessed 2 Jan2019).
12. Hagen P, Collin P, Metcalf A, Rahilly K, Swainston N. *Participatory Design of evidence-based online youth mental health promotion, prevention, early intervention and treatment*. Young and Well Cooperative Research Centre: Melbourne, 2012.
13. Design Council. *Design for Public Good*. Design Council: London, 2013 <https://www.designcouncil.org.uk/sites/default/files/asset/document/Design%20for%20Public%20Good.pdf> (accessed 13 Mar2019).
14. Slay J, Stephens L. Co-production in mental health: A literature review. new economics foundation, 2013 https://b.3cdn.net/nefoundation/ca0975b7cd88125c3e_ywm6bp3l1.pdf (accessed 3 Jan2019).
15. Orygen The National Centre of Excellence in Youth Mental Health. *How to partner with young people*. Orygen The National Centre of Excellence in Youth Mental Health: Melbourne, 2016 https://www.orygen.org.au/About/News-And-Events/Orygen-launches-Toolkit-at-Youth-Partnerships/11171_SnDYouthPartnershipToolkit.aspx?ext= (accessed 24 Mar2019).

Disclaimer This information is not medical advice. It is generic and does not take into account your personal circumstances, physical wellbeing, mental status or mental requirements. Do not use this information to treat or diagnose your own or another person's medical condition and never ignore medical advice or delay seeking it because of something in this information. Any medical questions should be referred to a qualified healthcare professional. If in doubt, please always seek medical advice.