



Enabling Participation

// A companion document to the Young and Well Cooperative Research Centre Innovative Methodologies Guide *Participatory Design of Evidence-Based Online Youth Mental Health Promotion, Intervention and Treatment*

YOUNGANDWELL
Cooperative Research Centre



An Australian Government Initiative



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This is a companion document to the Young and Well CRC Innovative Methodologies Guide: *Participatory Design of Evidence-Based Online Youth Mental Health Promotion, Intervention and Treatment*. It includes additional practical resources for creating a safe and inclusive space for participation, and potential strategies for recruiting young people in the design process as participants and co-designers.

This guide follows the linear steps of involving young people in a project, ensuring that an organisation is prepared for participation, is thinking through ethical considerations, is recruiting effectively, and is providing an inclusive space.

A participatory design approach is important to develop outcomes that are meaningful and relevant to young people so that our interventions have a greater impact. In order to provide interventions that respond to the diverse needs of young people across Australia it is vital to provide an inclusive and respectful environment where young people feel safe and supported to explore new ideas and express themselves freely.

This companion document has drawn on expertise from participatory design practitioners and scholars, as well as Young and Well CRC Partners including Berry Street, Hitnet, the Centre for Multicultural Youth, Ladder and Orygen, The National Centre for Excellence in Youth Mental Health. These organisations have a wealth of expertise working with groups of young people to design and develop interventions. We endeavour to learn through their experiences working with difference and diversity in order to promote engaged and inclusive practice.

ORGANISATIONAL CULTURE AND PROCEDURES

Organisational Culture

Before young people are engaged, an organisation must ensure that the culture is ready for youth participation. Without the appropriate culture, participation risks being under-resourced, underappreciated, or tokenistic. A change of culture can reduce common barriers to participation, such as staff that underestimate the ability or capacity of young people.

Recommendations

- Consciously celebrate the contributions and successes of young people, both publicly and within the organisation. This ensures that the potential of young people is acknowledged and appreciated throughout an organisation.
- Ensure that every staff member appreciates that young people can be involved in all processes, and that they understand what is meant by meaningful involvement. This may be achieved by including young people in the recruitment of all employees and training staff in meaningful youth participation as part of the organisation's induction process.
- Understand that young people are irreplaceable partners that provide incomparable insight. They have the ability to meaningfully direct all areas of an organisation, including the vision, mission, values and agenda. Without their direction, an organisation cannot meet the needs of young people.

Organisational Procedures

Procedures must be considered to fully enable the participation of young people. Youth participation requires both planning and procedures to create a safe space for meaningful engagement. Without appropriate planning, the organisation may not be supporting or enabling young people.

Recommendations

- Manage stigma by promoting positive mental health messaging and encouraging respect between members of the group. It is important that people feel comfortable to be open, but have also considered the boundaries in terms of what they are willing and prepared to share.
- Ensure young people (or their guardians, if they are under the age of 18) have provided informed consent about confidentiality and usage of content or images.
- Certain groups and communities may work in different time frames and it may be important to plan additional time into a project.
- Train staff on as crisis response policies, and cultural or diversity training. Staff members should also seek external qualifications, such as Youth Mental Health First Aid or Applied Suicide Intervention Skills Training (ASIST) where appropriate.
- Confidentiality and disclosure policies should be provided to outline the rights and responsibilities of staff and participants. It's important to highlight how this relates to confidentiality and disclosure, and how that relates to your organisation's duty of care or your responsibilities when ordered by a court of law.

Personal care plans are a useful tool for participants and staff to think about what keeps them mentally healthy and identify support networks they can access if they become distressed during their period of engagement.

- Create a risk management plan that outlines potential concerns, strategies to mitigate them and clear processes to follow in the event they occur. For example, one risk may be that a young person becomes distressed during their involvement. A strategy that may mitigate this risk would be to ask young people to fill in a personal wellness or self-care plan, which allows the young person to list barriers to participation, preferred methods to improve their wellbeing, and information about how best to enable participation. In the event that a young person began to feel distressed, they may wish to take some time to themselves in a designated 'chill out' space. If a staff member was concerned about their wellbeing, they should have a clear escalation policy to ensure the young person receives the appropriate care. When identifying risks, it's important to consider the effect on all stakeholders including participants, staff, volunteers and external support networks (parents/guardians, friends or family).
- Pathways to care should be made clear and available throughout the project regardless of whether your interactions occur face-to-face or online. If engaging with young people online, clear access to support services needs to be available at all times. The types of resources available will depend upon your risk assessment of the planned activities and prior experiences of participants. After engaging young people, provide them with information about what they can do and who they can contact should they start to feel upset or concerned.
- Support staff should be made available to young people, and clinical support may be appropriate. Staff should also have the opportunity for clinical supervision throughout the project.
- Contextual situations may also affect they way you work with young people. There should be an acknowledgment of the greater risk for those living in small communities to disclose information or to be seen accessing a particular service. Privacy must also be considered when exploring online communities and platforms to utilise.

To create a supportive and safe space, it is important to have:

- Regular breaks and a chill out space, but avoid long periods of isolation
- Individual participant wellness plans and knowledge of best person to contact
- Clinical backup staff on call
- A range of engagement methods
- Easy to understand language
- Warm up exercises and appropriately placed breaks can provide opportunities to reflect and observe behaviour so as to respond or alter activities as needed.

A planning checklist:

- Does the organisation or project have a culture that enables youth participation?
- Is the organisation resourced to enable young people responsibly?
- Does the facilitator or moderator have the skills required for working with diverse groups of young people who may be experiencing mental health difficulties?
- Do you have strategies in place for dealing with stigma amongst participants, or supporting participants who are particularly vulnerable?
- Are there supports and plans in place should young people choose to disclose during the session? For example, support staff for young people to talk to, or to be on call to provide clinical back up?
- Are appropriately trained support staff available for the specific needs identified by your participants?
- Do you have emergency contact numbers for all participants?

Case Study: Hitnet

Hitnet create culturally targeted, rich learning media in co-creation with marginalised communities. We use a process that holistically engages with entire communities rather than individuals. This requires that we have an existing connection with individuals and community groups, as well as an understanding of local community cultural protocols. By working with communities to explore the issues facing them, we allow communities to set the parameters and address it in a way that will work for them. Every group is unique, and we need to be flexible and supportive in their work. Each project is co-located with a rural and remote mental health team and there is always a mental health expert on staff. We also recruit two role models from the local community who are passionate about building the capacity of young people. It's important for the whole team to model positive behaviours, have fun but also take the job seriously.

Young people are involved in the concept through to final production, which includes things such as scripting, music production, casting and acting. Bringing new technologies and something a bit different into their lives provides us with an enticing way to tap into many undiscovered talents like singing, acting or physical movement. These are often young people who may have lower levels of education, live in a socially chaotic environment, or have experienced severe trauma. We are able to harness their talents to produce interactive and engaging content that showcases the importance of everyone's contribution. Once the project is complete, we go back to the community for a celebration and each person receives a copy of the DVD. Celebrating their work is one of the most important aspects of the program.

Case Study: High Res

With the Department of Veterans' Affairs, the Young and Well Cooperative Research Centre used participatory design to create an online resilience resource for serving and ex-serving members of the Australian Defence Force. A reference group was consulted to guide the development of a website that resonates with members of the Australian Defence Force. When provided with a safe space, reference group meetings can be a place for the reference group to provide open and honest feedback and direction to a project. The information received from the reference group formed recommendations that ensured the website contained the voice of veterans and provided actionable information. High Res is informed by evidence, but the uptake and impact is greater through the participatory design process.

Case Study: Centre for Multicultural Youth

The Centre for Multicultural Youth are an organisation that support young people from migrant and refugee backgrounds in Australia. When working with young people, we are careful to consult with cultural partners to identify potential barriers and always use accessible language in our communications. This can also be an important opportunity for networking and finding more young people to participate. We provide multiple ways for people to apply rather than relying too heavily upon written forms. This also provides an opportunity for us to ensure they understand the program and what their involvement will require. Sometimes they also ask us to talk with their families to reassure them about who we are and to let them know that we always keep information confidential unless there is a direct risk of harm.

We try to bring diverse groups together to provide as many perspectives from the broader community, but it's important to keep in mind that each person is an individual and can only speak from their own experience. In order for people to feel more comfortable, the first activity is always writing a group agreement that outlines some rules and boundaries. To maintain their engagement, they also need to have an interest in the project and should be developing their own skills. Even with the best intentions, there are many things that can impact on young people's ability to remain involved; they may have experienced trauma in their lives, be at risk of becoming homeless or have other personal and family commitments. We understand that young people have many competing priorities and their wellbeing is our primary consideration.

ETHICAL CONSIDERATIONS

The National Statement on Ethical Conduct in Human Research section 4.2 outlines particular ethical considerations relevant to working with children and young people. Though the guidelines are intended for researchers, they are a useful resource to inform the way that young people should be involved in any co-design process, emphasising respect for their consent, privacy, and integrity, and ensuring that their best interests are kept in mind.

Consent

Where young people are engaged as part of a co-design process, consideration must be given to whether or not they are able to provide informed consent. As a general rule, consent must be requested from a parent or guardian of a young person if they are under 18, though exceptions may be permitted for projects that are deemed to be 'low-risk' and where the young person is considered to be of sufficient maturity to provide their own consent.

As part of the consent process, it is important that the nature and purpose of the participation is clearly explained to the young person, in simple and comprehensible terms. This should be especially remembered when engaging young people from different backgrounds and who may be receiving the information in a language other than their first. It is also important to consider the developmental stage of each child involved and their maturity with regard to the area under investigation.

Privacy and confidentiality

When engaging children and young people in participatory design, it is important to consider how their information will be used, who will have access to their information, and whether they will be able to be identified by the information they provide. Consideration should also be given as to the method by which young people should be invited to participate. For example, and with sensitivity to the nature of the participation, young people's confidentiality may be limited when their participation involves taking part as a member of a group as opposed to alone. Wherever possible, steps should be taken to ensure that the privacy of young people is respected and that their right to confidentiality is maintained throughout the participation process.

Online participation

The digital world provides a new context for participation, enabling young people to participate in different ways, from remote locations, and with greater anonymity. When engaging young people online, it is important to remain conscious of providing informed consent (for them and their parents if necessary), and of taking steps to ensure their identity and information are protected. This may extend to consideration of how digital data are stored, where records are kept, and ensuring that processes are in place with regard to digital security.

Working with schools

When considering engaging young people in participation through their schools, a number of additional ethical concerns may need to be addressed, in addition to the key issues already noted. Firstly, approval to invite young people to participate will need to be first granted by the school principal, and perhaps even a higher board of governance. Some schools may have 'standing parental consent', whereby parents consent for their children to participate in any research that is approved by the school, but this should be checked for each school that is approached for involvement. In any case, students and their parents should be advised of their right to withdraw their consent or their capacity to choose not to participate in a given project.

Where young people are invited en masse, as is often the case through a school-based approach, students should be advised that their decision to participate will not affect their studies, or their relationship with their teachers or the school. Care should also be taken to ensure that no young person feels obliged to participate because the process is endorsed by their school, or because their classmates may participate.

Incentives

The use of incentives to encourage young people's participation should be thoroughly considered. As a general rule, incentives should only be used if they are proportionate to the time involved, and do not pressure participants to consent or take any risks. Sometimes, it might be worth considering offering a reward as a 'thank you' after participation once their involvement is complete. This strategy shows appreciation for a young person's time and contribution, but would not coerce them into participation.

Example incentives are:

- Codesign Workshops \$20/hr
- Bullying Campaign (Contribution via Facebook) \$100 prize to most popular
- Stealth Campaign (Young people upload images of themselves with ReachOut.com promotion material) \$5,000 cash prize

Providing incentives or reimbursements should not be confused with hiring young people as research or project assistants. Reimbursement should be considered, particularly when young people need to travel. Young people on casual employment contracts may be participating in your research, and their unavailability may be causing a loss of income.

Recommendations

- Ensure that your organisation is familiar with the National Statement on Ethical Conduct in Human Research (<https://www.nhmrc.gov.au/book/chapter-4-2-children-and-young-people>)
- Consider how young people's information will be used and who may be able to access their information

- Respect each young person's right to privacy and confidentiality throughout the participation process
- Take care to ensure that each young person is treated with respect and sensitivity, and with consideration of their education, cultural, and familial background
- Ensure that young people do not feel coerced to participate and will not experience any adverse effects if they choose not to participate
- Consider whether your opportunity should have an incentive or reimbursement

Young people aged under 18 are required to provide written consent from a parent or guardian to participate in a workshop. Where they have been granted independent status by a state court, they should provide consent from a carer that is over 18. It is important to ensure that the young person, parent or guardian has provided informed consent for the young person. Further resources on working with young children can be found in the Resources section.

RECRUITMENT

As the outcomes of the participatory process should reflect the views of the young people who are involved in the research and design processes, ensuring effective recruitment of a target audience can be critical. Recruitment strategies will differ depending on the project and how connected you already are with the young people you wish to work with. Selected recruitment strategies and their benefits and drawbacks are outlined below.

Recruitment agencies

Private companies with existing connections to groups of people from which to recruit.

Pros

- Can provide very specific and highly representative demographic sample.
- Able to designate specific requirements around diversity of the group.

Cons

- More expensive than other methods.
- Different agencies will have different/better connections with young people so a known agency is best.

Existing online communities

Many communities already exist on social networks, forums and other websites, drawn together through shared interests or commonalities.

Pros

- Leverage existing connections between young people.
- Can target your recruitment to communities with an interest in your topic.

Cons

- May be seen as uninvited or intrusive advertising.

Partner organisations and networks

Utilising partner organisations or networks can allow you to recruit from groups of young people that are already engaged in similar work.

Pros

- Can tap into demographics of people you don't have an existing relationship with.
- Useful to recruit young people from rural or remote areas, or diverse backgrounds.

Cons

- Places responsibility on partner organisations, who may have limited resources.
- No ability to influence how connected they remain with young people.
- Can result in the same people participating across multiple projects, this could limit the breadth of your engagement.

Snowball sampling

Asking young people you have a connection with to invite their friends to join the project. Asking young people to recruit their friends can be a successful strategy, particularly as young people often have extensive online social networks.

Pros

- Make use of young people's extensive social networks.
- New participants will feel comfortable with people they already know in the group.
- Provides an additional level of engagement for the young person that is recruiting.

Cons

- May limit the diversity of people involved in your project.

Live recruiting

Pop-Ups or targeted advertising can be used to recruit young people directly from a website or social network.

Pros

- Connecting with young people who may not previously have engaged in this type of work.

Cons

- The impersonal nature of the advertising can result in a low response rate.

Schools and alternative education settings

Building relationships with schools and other educational institutions can provide a strong network from which to recruit.

Pros

- Opportunity to work with younger children and groups of young people.
- Ability to connect with entire cohorts.

Cons

- Negotiating access can be quite a time consuming process.
- Projects may need to be structured around the requirements of the institution.

Drop in spaces

Connecting with local youth centres and other drop in community spaces can provide important access to young people that may not usually be involved.

Personas that describe the background and characteristics of the kinds of young people you are hoping to work with can help focus and direct recruitment activities. Recruiters, for example, can use these as a guide in addition to demographics.

Pros

- Can provide important access to groups of people with diverse life experiences, such as young people who are homeless.

Cons

- Informal recruitment can impact negatively on the level of investment and interest participants have in the project or activity.
- Participants may still be experiencing hardship or trauma which must be taken into consideration.

Building networks and capabilities

In addition to the one-off strategies named above, it may also be important to develop an ongoing network of engaged young people, which fosters a long term relationship that can be called on for various engagement opportunities. Consider asking whether participants of one-off sessions would be happy to be contacted again in the future.

Diversity

In most cases, when you engage with a group of young people it is not intended that they represent the entire population of young people. Rather, it aims to allow for diverse and different perspectives to be heard to improve the outcomes for your project.

Consideration is required to ensure the inclusive representation of a broad range of young people, such as young people with disabilities. The time required for recruitment of certain user groups will take longer than others, but it is essential to capture these voices. Specific community organisations may be able to assist with recruitment, and Universities and TAFEs have disability support units. It may also be important to invest in processes and relationships over time that help to build the capacity to engage diverse groups of young people at the right time when required.

Recommendations

- Use a recruitment strategy that suits the project or organisation.
- Develop your own network of engaged young people if you have a large number of opportunities over a long time period. This could be achieved using a newsletter or social media group.
- Recruit a diverse group to ensure that you are directed by the diverse experiences of young people.

If your participants are from geographically and culturally diverse areas, ensure that the contracted cultural assistants are appropriate. Australia is made up of over 500 independent Aboriginal and Torres Strait Islander nations and people that have migrated from all over the world. Assistants should be engaged from the earliest stages of possible planning to ensure appropriate strategies of engagement are utilised.

PROVIDING AN INCLUSIVE SPACE

There are a number of things we can do to ensure that activities are inclusive, and that a diversity of young people are supported and enabled to participate. Only by working with difference and diversity can we ensure that interventions are appropriately informed by those who our programs seek to engage.

It is important to consider the specific needs of the young people you intend to work with during the earliest possible stages of project planning. Inclusive practices can have budget implications, and you must plan early to allocate sufficient resources. This may influence the methods you choose to use, the number of young people you work with, the location of events or the way you engage with them. This must always be weighed up against the benefits that broader participation will have for the outcomes of the project.

Accessibility

Prior to an activity, check whether any of your participants have support or assistance requirements, such as wheelchair access, a support person or carer, lip reading services, Braille versions of text, screen readers, interpreters, cultural assistants or support for non-native English speakers. As each individual has different needs, check with each young person as to the kind of support that will enable them to fully participate in the program.

Different methods can be more or less suitable for different groups of young people. For example, projective methods can be more accessible than text-based methods, particularly for those with low literacy or ESL (which may include young people who use AUSLAN as their first language). These are methods that use external stimuli, such as photographs or other media, to draw ideas and feedback from participants.

Physical disabilities may impact on young peoples participation in many ways. It is important to ensure that:

- Physical spaces and facilities are accessible for their abilities
- Sufficient breaks are scheduled
- Activities are presented in accessible formats and everyone can participate in the interactive components.
- Support staff or interpreters will be available if required.
- Facilitators are aware of each person's requirements, and have the appropriate training or experience.

Ensure materials prepared for people with disability are in a format that meets the access needs of each person. Keep in mind that two people with the same disability may have different needs, so it is useful to inquire with individuals prior to preparing workshop materials. Online and remote methods should be reviewed to ensure compliance with W3C accessibility guidelines and to determine whether alternative text versions will be required. Appropriate online methods might also be used to enable remote participation from geographically diverse participants. However, young people from rural areas often also face limitations to mobile reception and internet access. Is it possible to fly young people in from rural communities to attend face-to-face sessions, or fly researchers to those young people? Perhaps modified methods can enable you to engage rural young people in a manner that is more cost effective. For example, this can be achieved by conducting interviews with friendship groups instead of focus groups, as done for ReachOut.com and outlined in the primary [Innovative Methodologies Guide](#).

Being accessible requires thinking through the varied aspects of a young person's life to assess what might be a barrier to their participation. Ask participants with a disability if they have a preferred mode of communication. More informal methods may be required for young people who have had significant contact with government agencies and are fearful of monitoring or surveillance. This may mean no recording of any kind, including asking participants to sign consent forms.

Requirements can be varied, and need to be considered thoroughly. For example, people may require an accessible environment for their guide dog. This may also require considerations about allergies to dogs within the group, or training people to not interact with a dog in service without permission of the owner.

Language and culture

In order to involve young people in the design and development of projects, it is important to observe cultural norms from their communities. For example, with some groups, you may need to consult with elders first before approaching young people.

Inclusive language

Use inclusive language in workshops, on forms, and in any information young people receive. This may include:

- Use of gender neutral language.
- if it is necessary to enquire about gender, provide gender options that are not binary. Ideally, use a text field instead of specifying options.
- All content should be accessible to young people, which may require using simple and accessible language based on the people you are working with.
- Not using terms that categorise people based on their disability (such as disabled person), instead use terms such as people or person with a disability. For further advice on accessible language see [dontdismyability.com.au](#).

Flexibility

Effective youth participation allows young people a variety of opportunities to engage. As young people may have fluctuating availability with life, study, volunteer work or paid employment, opportunities should be flexible so that young people can incorporate it into their life. These opportunities may be flexible in time or effort, and can adjust as the availability of the young person changes.

Session planning checklist

- Does the facilitator or moderator have experience working with people from your target demographic?
- Are there physical barriers that may prevent participation in any of the activities or make participation in any of the activities difficult for those with intellectual or physical disabilities?
- Is it necessary to allow additional time for certain activities, for example extra reading time for young people for whom English is a second language?
- Are physical spaces accessible for young people with limited-mobility, including the bathrooms and other facilities?
- Has the group developed their own set of rules and boundaries?

Communication with participants

It is important to maintain communication with participants and keep them informed as to what is happening in the project.

The results of the project should be provided as feedback to the group. For example, if the group created a video, it's important that they have somewhere to access and watch it.

When ensuring access for participants who use wheelchairs, it is important to know what type of chair your participants are using - Australian guidelines only require accessibility for manual sized chairs, and large electric chairs can be wider and higher.

The website [Designing with People](#) has a range of evidence-based personas that can be used to assist in planning inclusive activities.

ADDITIONAL RESOURCES

// SAFE

- Develop a [Self Care Plan](#) – ReachOut Australia (<http://au.professionals.reachout.com/developing-a-self-care-plan>)

// INCLUSIVE

- [100 ideas to help engage Hard To Reach people](#) – Capire Consulting Group (<http://www.mengage.org.au/Work-Effectively/Engaging-Men-In-Health/100-Ideas-To-Engage-Hard-To-Reach-Populations>)
- [Engaging Culturally and Linguistically Diverse Communities: A guide for the Western Australian Public Sector](#) – Office for Multicultural Interests (http://www.omi.wa.gov.au/publications/omi_engaging.cfm)
- [W3C Guidelines](#) – WC3 (<http://www.w3.org/>)
- [Accessible Content Writing Starter Kit](#) – AccessIQ (<http://www.accessiq.org/create/content/accessible-content-writing-starter-kit>)
- Resources to improve the [accessibility of your next conference](#) – Geek Feminism (<http://geekfeminism.wikia.com/wiki/Accessibility>)
- [Training](#) to improve staff and organisational understanding on topics such as diverse sexuality, sex and gender, and inclusive terminology – Freedom Centre (<http://www.freedom.org.au/>)

// ENGAGE

- [YLab Diagnostic](#) support organisations to reflect on how they engage young people and make improvements – Foundation for Young Australians (<http://ylab.global/diagnostic/>)
- A thorough toolkit for effective [youth engagement](#) – YACVic (<http://yerp.yacvic.org.au/>)
- Orygen have created a [toolkit](#) that focuses on when and how to partner with young people - Orygen, The National Centre of Excellence in Youth Mental Health (https://orygen.org.au/About/News-And-Events/Orygen-launches-Toolkit-at-Youth-Partnerships/11171_SnDYouthPartnershipToolkit.aspx)
- [Case studies](#) and a wide range of resources for youth participation – NSW Advocate for Children and Young People (<http://www.acyp.nsw.gov.au/participation-resources>)
- A range of [model policies](#) to work respectfully with young people, including a code of ethics – Youth Action (http://www.youthaction.org.au/model_policies)