

# Introduction to Youth Engagement in Health Research

# 01

GUIDEBOOK  
SECTION

Youth Engagement  
in Health Research



## Content overview

### Guidebook Introduction

- How to use this Guidebook and resources
- Why does youth engagement matter in health research?
- The need for improved engagement with young people in health research
- Approaches to involving young people

### Practicing Youth Engagement in Health Research and Translation

- Implementing the WH&Y Engagement Framework in your research
- Implementation model

### Steps for Getting Started

- Toolkits and guides

### Definitions

**WELLBEING  
HEALTH &  
YOUTH** NHMRC Centre of  
Research Excellence  
in Adolescent Health

**YR** **YOUNG &  
RESILIENT  
RESEARCH  
CENTRE**

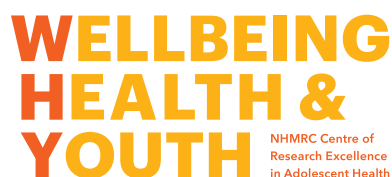
# Acknowledgements

This Guidebook was prepared by Maia Giordano, Betty Nguyen, Mia Cox and Professor Philippa Collin in collaboration with the Wellbeing, Health & Youth Commission (WH&Y Commission). The WH&Y Commission is made up of young people aged 14 – 25 from around Australia. WH&Y Commissioners work with researchers to define and collaboratively deliver research proposals and projects, to advocate and translate young people’s perspectives and research findings for better health policy and everyday healthcare.

The Guidebook and accompanying resources were developed from our iterative and participatory research with young people, researchers and policy and advocacy partners in the Wellbeing, Health and Youth Centre of Research Excellence. The Guidebook was informed by a desktop review, 18 in-depth interviews with young people and researchers and drawing on guidelines for youth participation and engagement. The Guidebook also includes materials and resources based on content developed by the following WH&Y Commissioners: Bethlehem Mekonnen, Rose Mekonnen, Gerard-Lachlan Abadines, Grace McGowan and Emily Morrison.

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## Wellbeing Health & Youth NHMRC Centre of Research Excellence in Adolescent Health

Wellbeing Health & Youth (WH&Y) NHMRC Centre of Research Excellence in Adolescent Health is an Australia-wide network of interdisciplinary researchers. Alongside clinicians, administrators, policy-makers, families and young people to transform how youth healthcare is researched and designed so that all young people have the opportunity to experience the best possible wellbeing and health. For more information about their research, please visit: [www.why.org.au](http://www.why.org.au)



## Young and Resilient Research Centre

The Young and Resilient Research Centre, at Western Sydney University, is an Australian-based, international research centre that unites young people with researchers, practitioners, innovators and policy makers to explore the role of technology in children’s and young people’s lives and how it can be used to improve individual and community resilience across generations. For more information, go to: <https://westernsydney.edu.au/young-and-resilient>

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## Acknowledgement of Country

With respect for Aboriginal cultural protocol and out of recognition that its campuses occupy their traditional lands, Western Sydney University acknowledges the Darug, Eora, Dharawal (also referred to as Tharawal) and Wiradjuri peoples and thanks them for their support of its work in their lands (Greater Western Sydney and beyond).

# Guidebook Introduction



Youth is a unique stage of life – with major significance for social, psychological and physical health of individuals and communities right across the life course. Yet, young people are neglected in health research and, consequently, health policies, services and systems regularly fail them. But, if we reconfigure health research as a partnership to be undertaken with young people, we can deliver the research needed to make health systems and services that work for them now and into the future.

According to the World Health Organisation, the Lancet Commission on Adolescent Health<sup>1</sup> and many other experts, youth participation should be a pillar of research and translation to address inequity and maximise health for young people. Yet only 1% of health research involves young people as advisors and even less is participatory. Mostly research is done ‘on’ young people or their data.

If we genuinely want to create health systems, services and brilliant professional practice for youth health, then we need to engage with young people as partners in research and translation.

Since 2018, the Wellbeing Health and Youth Centre for Research Excellence, with the Young and Resilient Research Centre, has brought together young people and researchers to develop a platform and methods for meaningful and ongoing engagement with young people in youth health research<sup>3</sup>.

This Guidebook: Youth Engagement in Health Research shares our findings and offers a practical implementation framework, to support researchers to advance youth participation in health research and translation. This Guidebook turns recent research and practice into simplified steps to follow and reflect on, regardless of your level of experience or stage of your research project.

## How to use this Guidebook and accompanying resources

This Guidebook provides a best practice framework as well as tools and resources co-created with young people to help us all do better together across all stages of the research process. Here you will find the foundational information you need to start – or scale - your engagement with young people, using practical tools, methods and case studies.



### Find out more

- [What is the WH&Y Commission?](#)
- [WH&Y: 6 things we can all learn about youth engagement](#)
- [Guiding, sustaining and growing the public involvement of young people in an adolescent health research community of practice](#)



## Why does youth engagement matter in health research?

Young people are experts in their own lives and experiences and have a right to good health and to participate in decisions that influence their health.

The Convention on the Rights of the Child (United Nations General Assembly, 1989) and Charter of Human Rights enshrine young people's right to participation and influencing the kind of society, systems and services that realise their other rights. Adults, institutions, governments and other duty-bearers are responsible for working together with young people to ensure full access and experience of these rights. Evidence shows that respectful and meaningful youth participation is an essential part of building strong and supportive societies<sup>4</sup>.

In health research contexts, there is growing evidence that health research on issues which affect young people is better when young people have been engaged across the research phases.

The [Wellcome Inquiry](#) into involving young people in health research found engaging young people resulted in the following benefits to research<sup>5</sup>:

- Increased relevance of the research agenda
- Research design that drives higher engagement among young people
- Increased recruitment of research participants
- Higher ethical standards
- Better data collection due to increased trust and rapport with their peers
- More insightful data analysis by translating meaning to adult researchers
- Wider and more effective research dissemination and/or translation

Research that is intergenerational and multi-stakeholder produces better outcomes. Research and policymaking can benefit from intergenerational and multi-stakeholder engagement and dialogue which overlays the expertise and knowledge of each group as well as being underpinned by a robust process. Better research can translate into better advocacy, policies, services and professional practice which ultimately lead to better health outcomes for young people and their communities.

### Different stakeholders can bring different knowledge

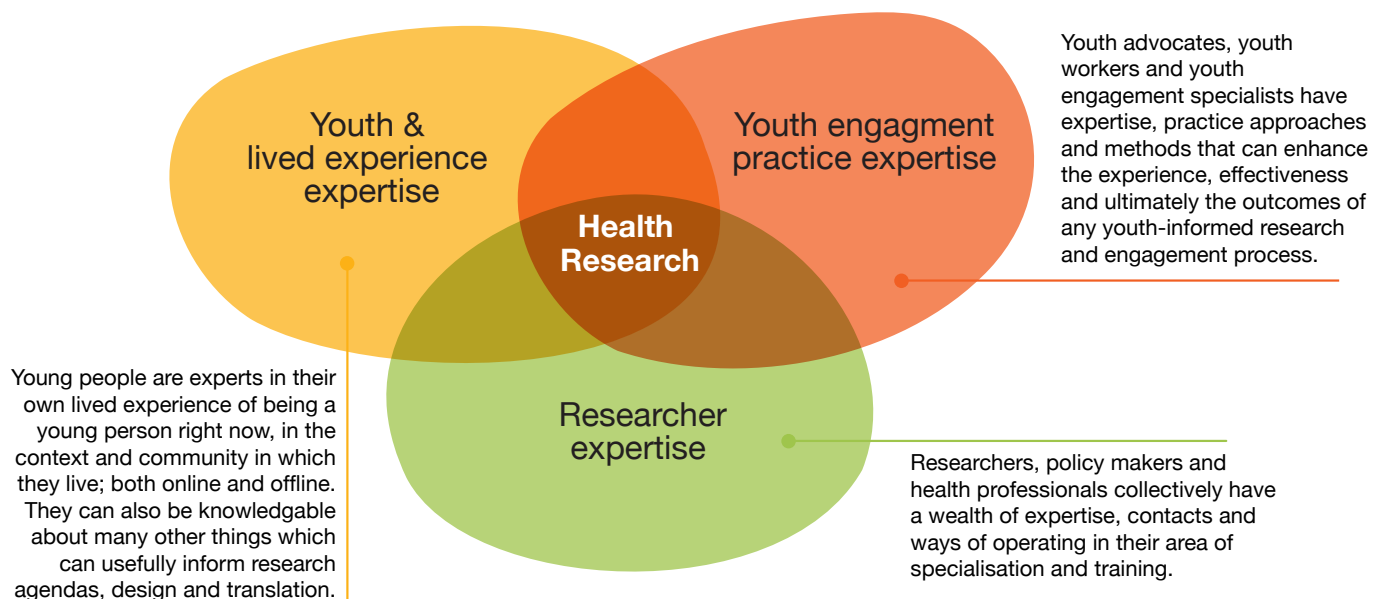


Figure 1. The different knowledge stakeholders bring to health research



## The need for improved engagement with young people in health research

Despite these benefits to health research, there is still much room for improvement when it comes to involving young people.<sup>6</sup> According to the Wellcome inquiry, some current gaps include:<sup>7</sup>

- Young people are more likely to be involved in research on mental health than research on infectious diseases or the health implications of global heating/ climate change.
- Most published research does not report on the background of the young people who have been involved, so it is difficult to conclude how inclusive it has been.
- Young people are most frequently involved in research design and data collection, and less frequently involved in agenda-setting and dissemination/ translation of findings.
- Young people tend to have some control over decision-making in health research, but typically less than adults.
- The majority of research involved the most privileged young people and excludes those who are disadvantaged<sup>8</sup>

As researchers we are often locked into routines or ways of doing research by the expectations of our field or discipline, institutions, research funding bodies and ethics committees that govern research. This means we often miss opportunities to think about how things could be done differently – creating new approaches and roles that engage with the capabilities and knowledge young people have.

While it's important to consider how young people can – and do – participate in research, it is essential to consider how research practices, teams and other bodies operate and what attitudes, processes and practices need to change to meaningfully engage with young people in research.



# Approaches to youth involvement in research

Young people can be involved in research in many different ways, depending on the values and approach of the research. How young people are positioned, and the methodology of the research, also depends on the attitudes of the senior researchers involved<sup>9</sup>. Young people can be consultants, co-researchers and leaders of research as well as participants (Figure 1.)

Different methodologies position young people involved as informants, advisers and co-creators of research, data and analysis/interpretation. For example, in Participatory Action Research young people are often included in identifying problems, generating data, analysing and interpreting the data, designing, testing and evaluating a response to the problems they identified.

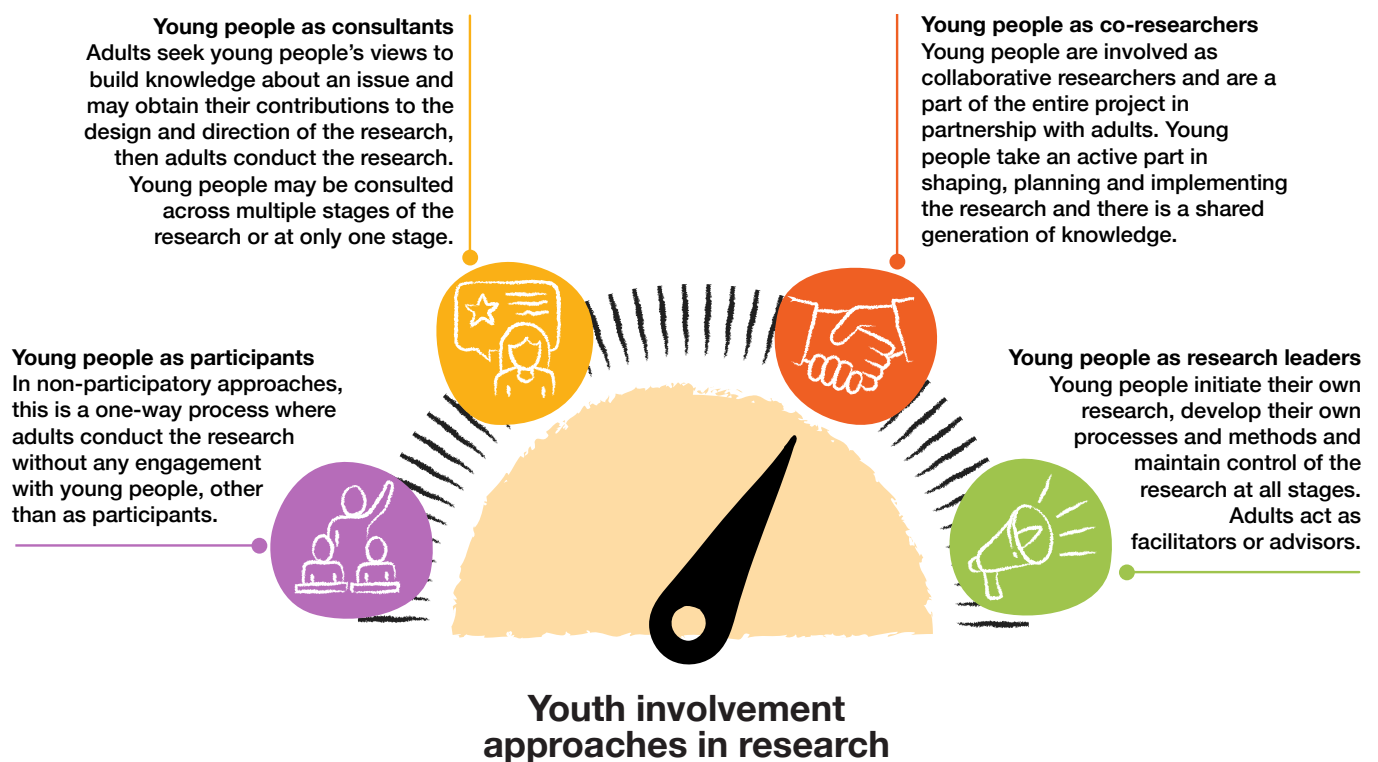


Figure 2. Youth involvement approaches in research, Youth Co-research Toolkit, Centre for Resilient and Inclusive Societies (CRIS Consortium) 2022, page 5



# Practicing Youth Engagement in Health Research & Translation

We have co-produced the Wellbeing Health & Youth (WH&Y) Engagement Framework with young people and other experts in our growing community of practice. Rather than provide principles that direct how researchers, projects, organisations or governments should achieve engagement with young people, the WH&Y Engagement Framework presents a set of values and practical questions that we hope will prompt responses and decision making that promote ethical practices of engagement with young people.

At every phase or activity in your research, it is vital to continually check in with yourself, your organisation and young people to ensure that you are considering how this set of values apply:

- Mutual trust & accountability
- Equity & responsiveness
- Diversity & inclusion

## Find out more

- [WH&Y Engagement Framework](#)

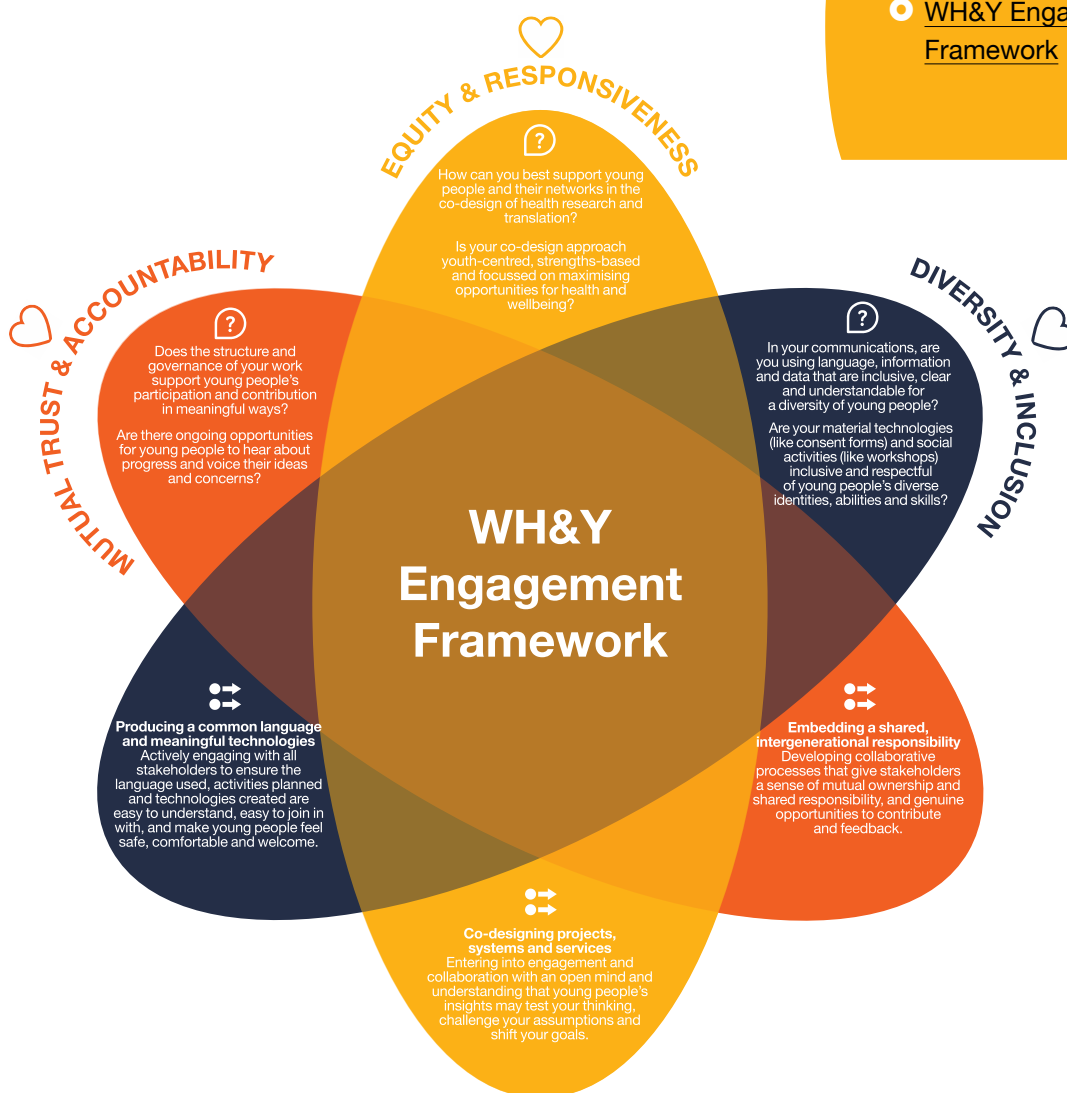


Figure 3. WH&Y Engagement Framework, NHMRC Centre of Research Excellence in Adolescent Health, page 7

# Implementing the WH&Y Engagement Framework in your research

Each research project is unique but we offer a simple implementation framework that can be scaled up or down to adapt to the needs of researchers, young people and the research project itself.

Implementing good youth engagement practice in health research requires continual preparation, listening to young people, co-production of knowledge, feedback loops and reflective practice.

Whatever your starting point for engaging young people in your research, there are some important things you need to identify in order to plan, implement and evaluate your engagement:

1. The stage of research young people are involved in
2. The level of involvement young people have (anticipated and actual)
3. How your research is going to be inclusive of young people from diverse backgrounds
4. Where young people involved are based
5. The health topics young people will be focusing on<sup>10</sup>

Our experience tells us that even if you have already commenced on your research process without involving young people from the start, it is better to try and involve young people later than not at all.

In this Guidebook you will find a three-step implementation model which you can apply across any and all stages of your research process.

This model applies:

- By activity (eg. Young people involved on a panel to disseminate the research findings)
- By research phase (eg. Young people involved in data collection for research)
- By whole research project/cycle (eg. Young people involved in co-designing the research end to end over a year)

Within this Guidebook, we have linked practical resources and tools which can assist you in applying this framework to your research activities, phase or project.

We have also included some key questions for you to reflect on against each of the core values in the WH&Y Framework under each topic in this Guidebook.

## Implementation Model

Before you interact with young people, there are key considerations you need to take into account to prepare yourself, your team and young people to ensure meaningful and fit for purpose engagement.



When you are actively engaging with young people, there are key considerations to ensure how you are engaging is accessible, safe, inclusive and delivers positive outcomes to both the health research project and young people.

After you engage with young people, there are key considerations and steps to be taken to reflect on the engagement process, outcomes, feedback loops, and next steps.



# Steps for Getting Started

Here are some simple tools to help you as you get started, and some important reflection questions to ask yourself around your own positionality (your status and power).

We strongly recommend you take some time to undertake background reading and review of other toolkits and resources relating to quality engagement with young people in health research.

To help you reflect critically on your own positionality and practice at all stages of the research process, you may want to keep a self-reflection journal. You can also use this simple checklist to help you think through some key steps as you get started on your youth engagement journey. This applies no matter what stage of the research project you are starting your engagement journey at.

## Further resources

- [Checklist: Getting Started](#)

## Toolkits and guides

[Youth Co-Research Toolkit, CRIS Consortium, 2022](#)

[A Guide to Establishing a Children and Young People's Advisory Group, ACYP 2021](#)

[YERP: Youth engagement toolkit, Youth Affairs Council Victoria, 2013](#)

[Youth Partnership Toolkit, Orygen, 2020](#)

[Your Go to Guide to Attending and Surviving a Conference, Orygen](#)

[Ethical Research Involving Children, Child Ethics](#)

[Enabling Participation Guide, Hagen et. Al, 2016, Young and Well CRC](#)

[Participatory Design of evidence-based online youth mental health promotion, prevention, early intervention and treatment, Hagen et al., 2012, Young and Well CRC](#)

[Wayipunga \('supporting young people' - Aboriginal and Torres Strait Islander youth participation framework\), Koorie Youth Council VIC](#)



# Definitions



## Young people

The term young people commonly relates to those 12 to 25 years and is the preferred term for this age group. While young people are often defined as 'not' children or 'adults' their activities, responsibilities and life experience may overlap with these groups. In policy and law, the distinctions are often very unclear.

'Youth' is a not categorical phase that can be identified by biological markers. It is a social category that is culturally and contextually specific.

It is important, then, to think about all young people, first and foremost, as experts in their own lived experience and youth cultures. They will have evolving capacities and engagement preferences and may have sophisticated knowledge of particular topics or issues within or outside of their own experience.



Each project varies so it is always advisable to provide your own definition in terms of age range and any other requirements as part of your project recruitment.

## Youth participation

Youth participation is when young people are involved in decision-making processes. The concept is related to ideas of citizenship, personal development, and broader involvement in society.

As a practice, youth participation takes place when young people are involved in determining the activities, organisations, governments and policies, community processes and decisions about issues that directly affect them. This can include individual care or learning plans, programs and services, public policy and wider community-based projects. Participation is where young people have a say, have their contributions heard and considered and contribute directly to decisions that shape society.

Youth participation is also about young people having the opportunity to contribute ideas and feedback, to have their views considered or to be involved directly in agenda-setting and decision making. This challenges top-down flows of information and control and can help address power imbalances between young people and adults.

## Youth engagement

Youth engagement relates to youth participation, but particularly focusses on systems and approaches that support mutual exchange of expertise and ideas to benefit the people involved and the research project.

When adults and adult-led organizations meaningfully engage with young people, innovation in partnerships becomes possible. Engagement with young people should aim to maximize young people's agency within existing social and political structures; transform adult and institutional perceptions of young people; and generate new research and policy processes and organizational forms.<sup>12</sup>

Engagement with young people is underpinned by a commitment to challenging assumptions and rethinking dominant ideas of young people. It also means turning the lens on how adults, institutions and systems need to change to enable youth participation in different settings.



In practice this means a mutual exchange and sharing of both skills, ideas and expertise between young people and researchers.

Further information on definitions of youth participation & engagement can be found on the [Youth Affairs Council of Victoria's website](#).



## Partnership

Working in partnership with young people can occur in a range of different ways but must consider some key concepts to build successful researcher-young people partnerships. Key concepts to address include power dynamics, acknowledging diversity of expertise, capacity strengthening, roles and remuneration. Partnerships are based on mutual benefit and respect. They require parties to have shared goals, values and commitments.

## Co-...

Co-creation, co-design and co-production are all underpinned by a doing with approach where power imbalances are addressed. This means that adult ways of working, welcoming, engaging and listening seek to set a tone and context where young people can access, engage, and meaningfully shape the research they are involved in. Co-produced research generates:

- an exploratory social space that challenges conventional framings of key concepts, actors and knowledge
- experimental and generative processes
- new communities, interactions, practices, and different modes of knowledge and value production<sup>13</sup>

## Co-research

In co-research, young people are trained to work as collaborative partners on projects with more experienced researchers. Young people are fully included and embedded into the project team, beyond the roles of advisors, co-designers or informants. They are involved across all stages of the research cycle, from conceptualising the aims, designing the approach, data collection, analysis, reporting, dissemination and evaluation.

The co-research model is grounded in the following principles<sup>16</sup>:

- Shared decision-making
- Shared understanding
- Respecting and valuing the knowledge that is brought from all perspectives
- Reciprocity, mutual benefit and learning
- Prioritising relationships and trust
- Capacity strengthening

The overall goal of co-research with young people has been described as creating spaces and opportunities for mutually beneficial partnerships where youth are empowered and their individual capacities and experiences are supported. Young people's roles and involvement in different stages of the research often change over the course of a project. Flexibility and adaptability is key to managing these changes.



Keep in mind that 'co-etc' can also create 'co-nfusion' and 'co-nflict' and that it is always important to reflect on how things are going, from the perspective of different collaborators.

## Research-Practice Partnership:

A research-practice partnership is "... an activity where researchers and practitioners work together, with different roles, to use research both to solve practical problems and to contribute to science".<sup>14</sup> Research-practice partnerships aim to guide participation, sustain collaboration and grow public involvement of young people in health research and translation and is the approach developed for the Wellbeing, Health and Youth Centre of Research Excellence in Adolescent Health (WH&Y).<sup>15</sup>



# Wellbeing Health & Youth Commission: Our youth engagement methodology

At WH&Y, we work alongside clinicians, administrators, policy-makers, families and young people to transform how teenage healthcare is researched and designed so that all young people have the opportunity to experience the best possible wellbeing and health in adolescence.

Made up of young people aged between 14 and 25, the WH&Y Commission represents the interests and perspectives of young people and plays an important role in defining and collaboratively delivering research, designing trials, assessing the value of projects and thinking through how new findings can be translated into health policy and everyday healthcare.

The WH&Y Commission uses a Living Lab<sup>11</sup> methodology which is a place-based open innovation process that brings together a broad range of stakeholders in ongoing cycles of research, design, development, testing, evaluation and delivery to implement effective responses to complex social and cultural phenomena.

This iterative process requires four core areas to be in place:

- 1. Robust, flexible process**
- 2. Right team approach and skills**
- 3. Shared understanding and tools**
- 4. Clear and ongoing communication**

This process has enabled WH&Y to co-develop and produce:

- 1. An engagement framework to guide youth participation in health research**
- 2. A partnership model to sustain youth and adult stakeholder collaboration**
- 3. The growth of public involvement of young people with a range of projects and partners**

## Footnotes

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- <sup>7</sup> *Ibid*
- <sup>8</sup> Zeinali, Z., Bulc, B., Lal, A., van Daalen, K. R., Campbell-Lendru, D., Ezzine, T., Whitmee, S. (2020). A roadmap for intergenerational leadership in planetary health. *The Lancet Planetary Health*, 4(8), e306-e308. doi:10.1016/S2542- 5196(20)30171-6
- <sup>9</sup> Pincham, Hannah L et al., (2020), Successful youth participation in health research depends on the attitudes of adults, *The Lancet Child & Adolescent Health*, Volume 4, Issue 12, 857 - 859
- <sup>10</sup> Das, S., Daxenberger, L., Dieudonne, L., Eustace, J., Hanard, A., Krishnamurthi, A., Mishra, P., Njavika, S., Quigley, P., Vergou, A., and Wilson, O. (2020). *An inquiry into involving young people in health research - Executive summary*. London: Wellcome, p 5
- <sup>11</sup> Collin, P., Notley, T. & Third, A. (2018) Cultivating (Digital) Capacities: A role for Social Living Labs?' in Dezuani, Foth, Mallan, Hughes (eds) *Digital Participation through Social Living Labs*, Chandos pp. 19 – 36.
- <sup>12</sup> Collin, P. Lala, G. & Fieldgrass, L. (2018) 'Participation, empowerment and democracy: Engaging with young people's views' in Pam Alldred, Fin Cullen, Kathy Edwards and Dana Fusco, (eds) *The SAGE Handbook of Youth Work Practice*, Sage: 183 – 196
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