Wellbeing Health & Youth Engagement Framework

Values, questions and guiding practices for ethical engagement with young people in health research and translation

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WELLBEING
HEALTH &
YOUTH

NHMRC Centre of
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in Adolescent Health

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A Framework for Youth Engagement in Adolescent Health

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The Wellbeing Health & Youth NHMRC Centre of Research Excellence in Adolescent Health (WH&Y CRE) unites young people, families, researchers, health practitioners and policy makers in research and advocacy to improve health services and health outcomes for adolescents in digital society. The WH&Y CRE will conduct research with young people that is ethical, relevant and productive, and that addresses both the emergent possibilities of, and the challenges to, research and health service delivery in digital society. This approach ranges from increasing young people's involvement in health research design and participation to enabling the best possible translation of research into policies and services that truly work for young people. This Framework establishes WH&Y's commitment to engagement with young people in order to improve research in and about health services for adolescents in digital society.

This novel endeavour is not without challenges. The right to health and wellbeing is embedded in the United Nations Convention on the Rights of the Child (UN, 1989) and is one of the Sustainable Development Goals endorsed by governments around the world (UN, 2016). Enacting these principles requires a clear and demonstrable commitment to young people's participation in health research and translation. While participation is one of eight standards for quality healthcare services for adolescents listed by the World Health Organisation (2015), young people are not routinely involved in health research. Participation, when it occurs, may be limited or tokenistic in nature and insufficiently inclusive.

Despite significant improvements, more needs to be done to improve the capacity of established researchers and research support services to be more receptive and responsive to the views and needs that young people express. Moreover, as digital technologies evolve and become more embedded in health systems, services and everyday life, new ethical issues associated with digital data, machine learning and automation must also be understood and addressed. The distinction between online and offline has dissolved and we must now approach 'the digital' as a setting for social life – and for our ongoing work with young people. The Australian Digital Health Agency (2018) recognises the need not only for leadership and innovation, but also collaboration, so as to enhance digital health capability across healthcare and infrastructure.

We have co-produced the Wellbeing Health & Youth (WH&Y) Engagement Framework with young people and other experts in our growing community of practice. The Framework is just a beginning and is a 'living document' that will be reviewed and refined over the course of the Wellbeing Health & Youth initiative. However, we believe that the key to achieving true change in adolescent health research and its translation into benefits, now and for future generations, requires a new form of partnership with young people. We present this Engagement Framework as an open invitation to join with us to navigate the complexities of research and its translation into improved health services. Keeping young people at the centre of our endeavours is key to transforming adolescent health in the digital age. ■

Foreword: Why We Need an Ethics of Engagement

By Betty Nguyen

Young people can experience many issues when it comes to health - especially in digital society. We are often faced with stereotypical assumptions about young people and don't always understand or use the language that adults use to describe health. We are concerned with when, where and why our personal information is being collected, shared, accessed, stored and used. How public and private organisations are collecting and benefiting from young people's data needs to be better understood. We are also concerned with the management of visible and invisible aspects of health, and how we can be supported when making decisions that affect our health. We are also faced with multiple barriers that can prevent us from accessing healthcare and shaping the quality of care that we receive. We are not always aware of the health services and resources that are available. Like many young people, we are not part of the research translation processes and we wonder if the current approaches to education and training for healthcare professionals will change youth health outcomes for the better or worse.

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We want to play a real role in adolescent health research because its impact will be long lasting – for us and for future generations. Older adults can empower us by creating opportunities for co-design in health research and supporting us to be influential ambassadors. If we get the right information and make the right changes, long-term rewards will be created for young people and broader society. Engaging with a diverse range of young people in adolescent health is essential – meaning we should be included more in the design, consultation and research processes of adolescent health. Engaging with us will encourage our interest and likelihood of participation in this research that is often detached from our everyday lives. We are hopeful the WH&Y CRE will make a difference because:

– We value feeling empowered and in control of our sense of holistic self (both invisible and visible aspects of health). We value a range of experts and older adults listening to us and working with us, not just for us. We want to have a say about what is researched and better still, co-design it. We also think that research should be communicated well so it can benefit everyone.

– We value access to information, knowledge and solutions by connecting with others. Accessibility creates a sense of belonging and community for all people that can improve health.

– We value the genuine inclusion of young people that allows us to make decisions and achieve power and influence. ■

With Gerard-Lachlan Abadines, Gillian-Audrey Abadines, Maria Domina Augustine, Tairongo Crombie, Eliseus Feng, Hsu-Hung Tim Huang, Hannah Lai, Lilly Lyons, Kendall Marshall, Diya Mehta, and Veronica Sheanoda.

Introducing the Wellbeing Health & Youth Engagement Framework

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.
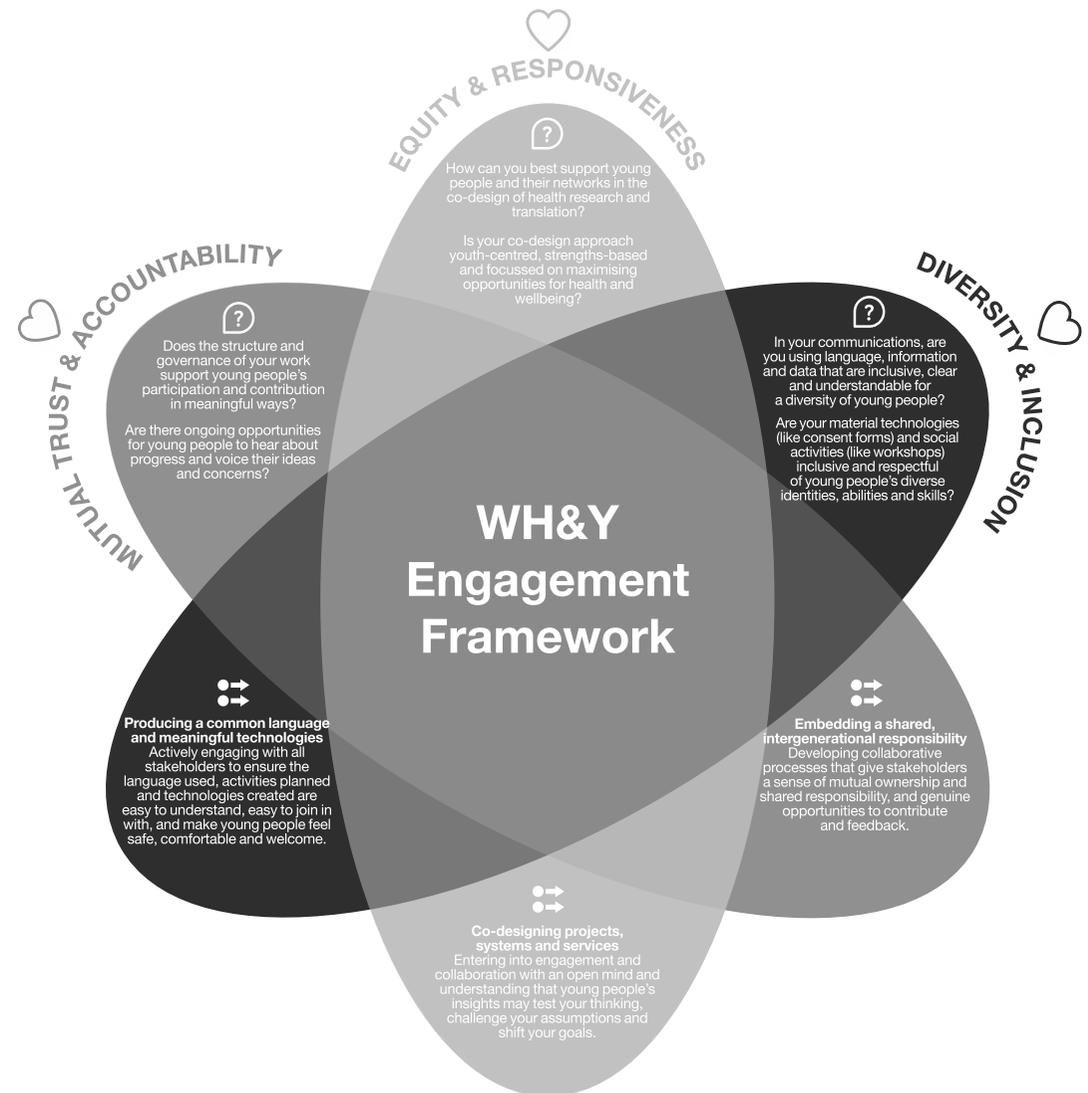
Think: Values prompt reflection and thought about how organisations aspire to engage with young people (both now and in the future)

Explore: Questions spark discussion to identify existing engagement with young people alongside gaps where there might be room for improvement

Apply: Ethical practices demonstrate an organisation's ongoing commitment to the proposed values – by integrating new ideas, and adapting to the diverse needs and changing circumstances of young people

WH&Y Engagement Framework

EQUITY & RESPONSIVENESS

How can you best support young people and their networks in the co-design of health research and translation?

Is your co-design approach youth-centred, strengths-based and focussed on maximising opportunities for health and wellbeing?

DIVERSITY & INCLUSION

In your communications, are you using language, information and data that are inclusive, clear and understandable for a diversity of young people?

Are your material technologies (like consent forms) and social activities (like workshops) inclusive and respectful of young people's diverse identities, abilities and skills?

Embedding a shared, intergenerational responsibility
Developing collaborative processes that give stakeholders a sense of mutual ownership and shared responsibility, and genuine opportunities to contribute and feedback.

MUTUAL TRUST & ACCOUNTABILITY

Does the structure and governance of your work support young people's participation and contribution in meaningful ways?

Are there ongoing opportunities for young people to hear about progress and voice their ideas and concerns?

Producing a common language and meaningful technologies
Actively engaging with all stakeholders to ensure the language used, activities planned and technologies created are easy to understand, easy to join in with, and make young people feel safe, comfortable and welcome.

Co-designing projects, systems and services
Entering into engagement and collaboration with an open mind and understanding that young people's insights may test your thinking, challenge your assumptions and shift your goals.

Mutual Trust and Accountability

♡ What this means

The value of 'mutual trust' in adolescent health recognises the multiple stakeholders (for example, peers, members of their support networks, researchers and representatives from a range of sectors) and activities that inform young people's trust in health professionals, services and resources. This links to the value of 'accountability' that reflects structures and feedback that support young people's engagement across health research, policy and practice. These values can be explored and demonstrated by stakeholders embedding a shared, intergenerational responsibility for how projects, systems and services are generated and maintained.

⟮?⟯ Key questions

– What are the core values that reflect an ethics of engagement for adolescent health in digital society?

– What are the practical questions that can help explore these values?

– What are the ethical practices that demonstrate our particular approach across health research and translation?

⇉ Evidence of ethical practice

Embedding a shared, intergenerational responsibility across projects, systems and services can foster mutual trust and accountability by recognising the range of stakeholders and activities that contribute to young people's health and wellbeing.

Diversity and Inclusion

♡ What this means

The value of 'diversity' in adolescent health respects a range of young people's experiences and views (for example, across age, gender, ability, sexual identity, location, economic, educational and health status). This relates to the value of 'inclusion' that seeks to expand choices, opportunities and tools for young people's participation in health research, policy and practice. These values can be explored and demonstrated by stakeholders producing a common language and meaningful technologies, so that communications and resources are relevant to young people's everyday lives.

⌗ Key questions

– Are the language, information and data being used in your research/policy/practice communications inclusive, clear and understandable for a diversity of young people?

– Are the associated material technologies (for example, consent forms, apps, electronic health records) and social activities (for example, workshops, events) inclusive and respectful of young people's diversity and needs?

⮂ Evidence of ethical practice

Producing a common language and meaningful technologies across projects, systems and services can foster diversity and social inclusion by respecting the complexity of young people's lives and needs.

Equity and Responsiveness

♡ What this means

The value of 'equity' in adolescent health is about respecting the current needs and future potential of young people so as to reduce unfair differences in health outcomes. This corresponds to the value of 'responsiveness', which recognises the responsibility of adults and institutions to act in relation to the different experiences and perspectives of young people throughout design, implementation and evaluation processes. These values can be explored and demonstrated by stakeholders co-designing projects, systems and services that are youth-centred, strengths-based and focussed on reducing health inequities.

ⓘ Key questions

– How can young people and their support networks in your research/policy/practice best be supported in the co-design of health research and translation?

– Is the co-design approach youth-centred, strengths-based and focussed on maximising opportunities for health and wellbeing?

⇶ Evidence of ethical practice

Co-designing projects, systems and services can foster equity and responsiveness by ensuring that research, policy and practice genuinely relate to young people's hopes, experiences and differences.

Work With Us

We aim for this framework to inspire dialogue and decision-making for you (and your organisation) to support and advance ethical engagement with young people. Our team welcomes opportunities to work with organisations and groups to undertake adolescent health research, youth health advocacy and to further the use and impact of this Engagement Framework. Please get in touch to discuss.

Connect with us

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Collaborate with us

Organisations across community and government sectors

Are you a local, state or national organisation working with young people and interested in collaborating with WH&Y? Email info@why.org.au

Young people from urban, regional and remote areas

Are you a young person who would like to be involved in transforming health research with young people in digital society? Find out more about our Adolescent Health Research Commission! Email info@why.org.au

Technologists, entrepreneurs, and philanthropic foundations

Are you a technology company, social entrepreneur, or philanthropic foundation keen to advance research and co-design health products, systems and services with young people and a range of interdisciplinary researchers?
Contact Teresa Swist at t.swist@westernsydney.edu.au

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