



WELLBEING HEALTH & YOUTH (WH&Y) COMMISSION

2021 Youth health, research
and policy priorities and
concerns

August 2021

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Wellbeing Health & Youth (WH&Y) NHMRC Centre of Research Excellence

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The Wellbeing Health & Youth (WH&Y) NHMRC Centre of Research Excellence in Adolescent Health is an Australia-wide network of interdisciplinary researchers working 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 our research, please visit www.why.org.au

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EXECUTIVE SUMMARY

The Wellbeing Health & Youth NHMRC Centre of Research Excellence in Adolescent Health (WH&Y CRE) convenes the WH&Y Commission: made up of diverse young people, aged 14-23, who consult with, co-design, co-research and advise researchers, policy-makers, advocacy organisations and services on youth health and wellbeing.

In 2021, the Commission took part in a series of workshops to identify priority youth health concerns and to propose ways for these concerns to be addressed by research, policy and services. Our aim is to inform and achieve more accessible and sustained support for young people's health and wellbeing – now needed more than ever as we experience the COVID-19 pandemic and in the long-term.

The workshops illuminated the health and wellbeing concerns of diverse young people living in Greater Western Sydney. Their views are informed by their lived experiences, their study, training and work experience in health-related areas and their personal, peer and community struggles during the COVID-19 pandemic. The Commissioners' priorities highlight the urgent need to address short and long-term health and wellbeing concerns of young people - with young people. Commissioners identified the following as

Health priorities:

1. COVID-19
2. Mental health and eating disorders
3. Sexual health
4. Health ethics in a digital society
5. Environments and products
6. Youth-centred health information and education

Research and policy priorities:

1. Understanding the impact of social determinants of health for young people
2. Address negative and deficit discourses of youth health in policy and professional practice
3. Acknowledge intersectionality and support diversity in health information and professions
4. Ensure access to health services and health information for all young people
5. Advance youth participation in adolescent health research, policy and practice

Principles for addressing youth concerns:

1. Holistic approaches to wellbeing and health
2. Authentic and respectful communication with young people
3. Supporting and growing young people's autonomy and agency
4. Working respectfully with diversity and promoting inclusiveness
5. Integrative and innovative approaches to health and wellbeing
6. Promote responsiveness, accountability, credibility and transparency

Strategies to address youth health concerns:

1. Create youth partnerships with peer groups, networks, and youth representatives
2. Support intergenerational collaboration and dialogue
3. Focus on excluded or under-served groups
4. Support youth-led solutions that are co-designed and driven by interdisciplinary teams

These workshops highlight a pressing issue that cannot be ignored - the current health information and services for young people are not effectively working for all. Young people call for greater engagement between youth and the policy-makers and researchers who influence their health and wellbeing.

“Let’s bridge the divide between adults and adolescents and make the discussions about healthcare less daunting”.

– WH&Y Commission

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INTRODUCTION

The Wellbeing Health and Youth NHMRC Centre of Research Excellence in Adolescent Health (WH&Y CRE) is an Australia-wide network of interdisciplinary researchers committed to championing good health in the Teenage Decade. WH&Y works alongside clinicians, administrators, policy-makers, families and young people to transform how teenage healthcare is researched and designed so that all young people can experience the best possible wellbeing and health.

Key to our work is establishing collaborative partnerships with young people and ensuring meaningful youth engagement and capacity building towards making healthcare work better for young people. To promote youth participation and achieve meaningful and ongoing collaboration, we have co-created with young people a WH&Y Commission. In 2021, the Commissioners are 27 young people (aged 14-23) from the Greater Sydney Region. Commissioners receive training in research methods, ethics and communication. Many are representatives of other community and youth-serving organisations and so together they are the foundation of a powerful network for change.

Commissioners are involved in WH&Y research from the very start, helping to set research agendas and co-create ethical and meaningful ways for teenagers and young people to be involved in research and its translation at national, state and territory, and local levels. The WH&Y Commissioners come from diverse cultural and socio-economic backgrounds and have a wide range of capacities and experiences including migration and seeking asylum, diverse sexual orientation and gender identity and living with disability or chronic illness. All share a commitment to improving the health and wellbeing of young people in a digital society.

Health in the teenage decade of life is crucial to the short - and long - term benefits to individuals, communities and society. Yet young people are not prioritised in the health system and are rarely consulted on the kinds of information, support and services that can help them attain and maintain health as they grow from a child into an adult. Consequently, young people are seriously disadvantaged within the health system and many leave adolescence in poorer health than when they entered it (AIHW, 2021; Robards et al., 2019). The effects of intersectionality – the way different aspects of a person’s identity and social forces (such as gender, sexuality, class or ethnicity or culture) create compounding or overlapping forms of discrimination and inequality – means that many young people are at a ‘double’ disadvantage when it comes to health.

The COVID-19 pandemic has exacerbated many of these issues for young people. Those aged 12-29 years are disproportionately affected by the COVID-19 pandemic in direct and indirect ways such as through interrupted education, limited work opportunities or unemployment and declining mental health (AIHW, 2021). They have had the highest rates of COVID-19 cases nation-wide, including in NSW during the Delta outbreak (AIHW, 2021a; Department of Health, 2021; NSW Health, 2021). At the same time, many young people have been speaking to their communities to understand their experiences whilst advocating for and supporting their needs (Vijayan, n.d.).

If health policy, services and research were co-developed with young people, government responses and communications could be empowering and positively influence community behaviours. This report outlines the 2021 Commissioners’ health and research priorities. These priorities reflect Commissioners’ lived experiences and aspirations, and the communities that they represent.

METHOD

Underpinned by WH&Y's Engagement Framework, youth participatory methods and co-design were used to explore: youth health issues; the research and policy responses needed to address these issues; and, the role young people can play in youth health research and policy.

Between March - July 2021, we conducted four 2–4-hour workshops in Liverpool (1), Parramatta (2) and online (1). Twenty-six young commissioners aged 14-23 and 9 researchers took part (see Appendix A). The purpose of these workshops was to explore young people's health and research priorities and to understand what factors impact upon young people's experiences of health and wellbeing in a digital society. The following questions framed the initial activities and discussions:

1. What are youth health priorities from your point of view?
2. What do we need to research and why?
3. What are the big issues for youth health you want the Commission to help address?
4. What are effective ways to work with young people in health research & advocacy?

Following the identification of these priorities, the following questions were used to stimulate deeper discussions around the research priorities the Commission identified:

1. Why should this be a research priority/area?
2. What are 1-3 research questions for this topic?
3. What research approaches/methods would be appropriate?

FINDINGS

Young people have a range of concerns relating to adolescent and youth health. They highlight that these issues are interrelated, are exacerbated by the pandemic and are all equally important to address.

WHAT ARE THE COMMISSIONERS' HEALTH PRIORITIES?

COVID-19

The pandemic, and government responses to minimise viral spread as well as access to vaccines and general healthcare are of ongoing concern. The Commissioners highlight the need for new quantitative and qualitative data on the impacts of COVID-19 on young people and their communities.

The Commissioners want acknowledgement of the pandemic's effects on all aspects of youth health and the social determinants of health including, but not limited to, the impact that COVID 19 has on their education, work (and work prospects), relationships and networks. But, more importantly, young people want greater financial, emotional and moral support in order to be resilient during these trying times - not only for themselves, but also for their families and communities.

**"[we] want to understand the state of youth in the Covid-19 context - how has the pandemic impacted their mental health and to what extent?"
- *WH&Y Commission***

Commissioners also call on policy-makers and researchers to collaborate with young people in decision making and intervention design, so that young people's health is maximised throughout the pandemic. For example, by working with young people to create messages related to public health directives, vaccination and mental health. Young people are also members of diverse cultural and interest-based communities and can be assets to governments and others in minimising the impacts of COVID-19 in the short and long-term.

Mental health and eating disorders

The Commissioners highlight the need to prioritise mental health promotion, early intervention, initiatives to promote help seeking and resourcing to provide treatment for young people with mental health needs.

**"Individuals from diverse communities are suffering in silence, especially where mental health and eating disorders still remain taboo and stigmatised".
- *Jahin***

This is particularly important for suicide prevention because the Commissioners are concerned that young people are not aware of the services and strategies that they can utilise to get help.

Commissioners call for holistic approaches that better unite mental health and physical health care throughout young people's health care journeys whether that is in the community or in treatment settings)

The Commissioners are also concerned about the role of influencers on social media and its impact on young people's expectations of body image, eating habits and food.

The Commissioners want a greater focus on the impact of eating disorders on young people in multicultural communities to ensure eating disorders are better understood and not stigmatised in these communities.

Sexual health

Sexual health education, particularly in schools, is ineffective and does not comprehensively reflect young people's lived experiences. Young people want reliable information and guidance that is respectful, empowering, and co-designed with youth.

More and better educative resources are required so that young people learn about the realities of sex and topics such as teen pregnancy and LGBTQIA sexual health.

The Commissioners want sex-positive, culturally sensitive, and queer appropriate educational materials that consider other factors that influence their decision to have sex (for example, feelings, peer-pressure, culture, religion) and practical solutions to address rape culture and social media's expectations of sex.

Health and ethics in a digital society

Commissioners identify that digital technologies - including emerging technologies such as artificial intelligence and machine learning - are integral to their everyday lives. They highlight that youth-engaged research and education is needed to support young people's understanding of the relationship between technology and health, and how that can be used to empower and protect young people from risks.

The Commissioners want digital technologies used to enhance how young people receive and access credible and accountable health information and healthcare in ways that respect their identities, practices and rights.

Improving digital health governance is also important to ensure that health information is being collected and used in a confidential and consensual manner.



Environments and products

The Commissioners want research and policy to prioritise ensuring the environments and products that are available to young people benefit health and wellbeing in the present and future.

Environmentally sustainable and youth-friendly spaces are important to enhancing young people's health and wellbeing. The Commissioners want some spaces to be separate from adult spaces and all built environments must be accessible, safe, and appropriate for all young people. Natural and built environments and infrastructures for exercise are especially important because these directly impact on young people's physical and mental health.

Commissioners are concerned about the lack of regulation allowing poor quality foods (specifically fast food) and harmful products (such as vapes) to be marketed directly or indirectly to young people, especially those in low-income communities. They want to see research and policy prioritise access to healthy, affordable food and to be better protected from harmful products.

Youth-centered health information and education

The Commissioners value transparent and accountable health information and healthcare. They want to use this information to inform their decision making whilst retaining their sense of agency and autonomy.

The Commissioners believe that health information is often presented from an adult's perspective or is not engaging for young people. More fun and engaging health resources should be co-designed with young people, for young people. The Commissioners want to create and translate these resources into a product that young people can relate to and understand.



WHAT ARE THE COMMISSIONERS' RESEARCH POLICY PRIORITIES?

Policy, research and services should increasingly prioritise the social determinants of health for young people

The Commissioners want policy-makers, health professionals and researchers to consider and acknowledge the social, political, cultural and economic factors that contribute to all aspects of young people's health and wellbeing. This must account for the impacts of COVID-19 as well as climate change and other crises.

The Commissioners are particularly concerned about how economic stability, education, healthcare, safe housing and employment impact young people's health and access to health information and services. They want more information for young people about how these factors interact at the micro, meso and macro levels (Swanson et al, 2003). They also want more information about how social determinants impact young people's autonomy within social systems to support young people to overcome these barriers to health services, health information, and health and wellbeing generally.

**“Focusing on the social determinants of health improves our quality of life and helps decrease the [health] disparities between people”.
- John, Jenon, Anhaar & Jahin**

The Commissioners call for health professionals, researchers, and policy-makers to look at the social determinants of health and take a whole-of-community approach to health and wellbeing to make an impact on young people's health and wellbeing as well as to reduce health disparities and improve health equity.

This will help empower young people to take charge of their health and wellbeing.

Promote positive, strength-based discourses of youth in policy and professional practice

Young people are often defined by labels (eg. child or adolescent), and negative language that constructs them as risk-takers, as irresponsible and generally 'a problem' for society. Public discourse frequently allocates blame toward young people. Moreover, the Commissioners are acutely aware that young people's concerns and opinions are often disregarded and labelled as "misinformed" or "misguided" and experience a disconnect or lack of empathy from health professionals and researchers.

Young people feel acknowledged and respected when health professionals and researchers use language that specifically and inclusively reflects their needs, values, interests and life experiences.

The Commissioners want adults to stop using negative and generalised terms or medical categorisations to identify young people's needs when describing them and their health. These terms delimit young people's capacities and create assumptions about them. For example, the Commissioners prefer the term 'young people' to 'adolescent' because they find it less medicalising and because it largely encompasses the age range of adolescence (10 - 19) (WHO (n.d.)).

Moreover, the term young people is seen as more inclusive and helps with conversations about wellbeing and health with their communities. It shifts the discourse from young people as a 'problem' for public health to understanding how young people are discriminated against and face barriers to good health behaviours and choices. By authentically communicating the value of young people's opinions and experiences, the Commissioners believe that an equitable health future can be created for all young people.

The Commissioners are determined to address stigma – of youth and help-seeking - to bridge the power imbalances that exist between young people and adults in health research and policymaking.

"We want to see a more inclusive way of speaking to young people, especially clinicians when one has to share personal details".
- Grace and Lisa

Support diversity in the health professions and acknowledge intersectionality in health information and service delivery:

Young people experience judgement and stigmatisation in regard to mental and sexual health, sexuality and ethnicity when they present to health services or professionals.

Commissioners call for greater cultural sensitivity and diversity amongst health professionals, health services and health information to reflect the complexities of young people's lived experiences. They highlight the positive impact of having clinicians who are from similar backgrounds who are empathetic and can relate to diverse young people's experiences.

The Commissioners want all young people to be represented in the narratives about young people's health and wellbeing. In particular, they want to see greater representation of young people from culturally and linguistically diverse backgrounds (CALD), refugee and immigrant backgrounds, low socioeconomic backgrounds, LGBTQIA+, Aboriginal or Torres Strait Islander backgrounds, those who have experiences with unstable housing or homelessness, those who have a disability, or are from rural, regional or remote areas.

Better training, youth-friendly health information and awareness of cultural diversity and backgrounds amongst health professionals and organisations are needed so that healthcare and health information are effectively tailored to address young people's needs and intersectionality.

The Commissioners want opportunities for their peer and community networks to be included in conversations about health and wellbeing and their healthcare in order to build greater cross-cultural and intergenerational trust in the health services young people access.

"It is evident that young people experience disadvantage or inadequate access to essential health services due to their intersecting identities. Therefore, it is vital that we use an intersectional lens to examine the processes, policies and structures that result in inadequate health services for disadvantaged young people".
- Bethlehem and Rose

Ensure access to health services and health information for all young people

Young people need health information and health services that are accessible regardless of their culture, race, age, gender, or upbringing. Accessibility of health services and health information is the starting point for young people's experiences of healthcare and their willingness to seek help for their health and wellbeing over their lifetime.

The Commissioners call for more accessible resources and services that:

- Are in the languages - and vernacular - that young people speak. This means young people advise on 'youthful language' that young people use to describe their health and wellbeing and identify language that is unclear, unhelpful or offensive.
- Help young people who face stigma or taboo in their families, communities or culture to access support on topics such as mental and sexual health.
- Overcome barriers to healthcare for young people with experiences of homelessness or unstable housing and who may not have a phone, Medicare card or proof of identity.

"Accessibility sets the tone/path of our health journey".
- Dominique R, Jean, Deborah, Ali, Bayan

Advancing youth voice in adolescent research, policy and practice:

The Commissioners want dedicated spaces for young people to share their experiences and opinions about their health and wellbeing. This is important because youth policies, research and services are created by adults and not young people.

The Commissioners believe that by understanding young people's perspectives on health and wellbeing, health professionals, researchers and policy-makers can create health services, information and policies that accurately align with young people's needs and interests.

The Commissioners want more young people to be a part of the research process. Often, research is conducted without young people's input which results in findings that do not reflect their current hardships. The quantitative data that are produced by research fall short of representing young people's voices.

By understanding and responding to young people's perspectives, the Commissioners believe that healthcare will become less daunting for young people. Commissioners call for improvements to health services and policies through education and conversations about topics that are taboo or complex (e.g., sexual health).

"Often research fails to engage youth in the process, so it falls short of reflecting the true concerns and opinions of youth".

- Jane



THE WH&Y COMMISSIONERS' GUIDE TO ADDRESSING YOUTH HEALTH CONCERNS

The WH&Y Commissioners have developed a series of guiding principles and values that will enable policy-makers, health professionals and health researchers to practically address young people's concerns. Each principle is equally important in addressing young people's concerns.

Principles for addressing youth concerns

The Commissioners recommend the following principles:

- Holistic approaches to wellbeing and health based on young people's needs and values to achieve health equity
- Authentic communication with young people
- Supporting and growing young people's autonomy and agency
- Diversity and inclusiveness
- Integrative and innovative approaches to health and wellbeing
- Advocacy, responsiveness, accountability, credibility and transparency

"Just as we have specific sectors for health, we should give the same focus and attention for young people's health and decision-making. Why? Because equal access to healthcare and information is the fundamental basis of respect and equity".

- Lisa

How to address youth health concerns:

- Create youth partnerships with peer groups, networks and youth representatives.
- Implement intergenerational collaboration and create dialogues between young people. The Commissioners want to see more researchers, schools, health professionals, services and government organisations working with young people. Young people want to partner with adults and other youth representatives to achieve change on these health priorities.
- The Commissioners want young people who identify as migrants or refugees, Aboriginal or Torres Strait Islander and gender or sexuality diverse (and their organisations) to be more involved in shaping health and wellbeing agendas.
- Generate youth-led solutions that are co-designed and supported by interdisciplinary teams. Young people are experts in identifying and articulating their lived experiences within their communities. Adults, including researchers and policy-makers from all sectors, should work collaboratively with young people at all times.



RECOMMENDATIONS

The following recommendations draw on the collective lived experience and expertise of young people who are Commissioners in the Wellbeing Health and Youth Commission.

1

.....

Work in partnership with young people
The Commissioners want the NSW and Commonwealth governments to work directly with young people to develop, co-design and assess youth health policies and their implementation in practice. Co-design should be embedded in youth health policy development. All stakeholders can engage meaningfully and build trust with young people, their peers and communities and develop innovative solutions for a better health system and to achieve positive health outcomes.

2

.....

Utilise young people’s networks and the online platforms they use
Communications to and about young people must be developed with young people. The Commissioners are calling for organisations and the government to include young people’s peer networks, community leaders and online platforms in creating and disseminating health information.

3

.....

Involve young people in enhancing cultural awareness resources for health professionals
The Commissioners recommend that young people should be given the opportunity to co-design, co-create and consult on cultural awareness resources and training for health professionals that acknowledges their culture and intersectionality.

4

.....

Invest in young people’s capacity and skill building
The Commissioners want young people to learn and be equipped with the health literacy and research skills to navigate the health system and provide feedback on policies, practices, and the health services they access. Skill building and training should be accessible to all young people who are interested.

5

Create a shared language and understanding between young people and health professionals

The Commissioners recommend conducting research on young people's experiences of health professionals' language and attitudes to give insights into how researchers and health professionals can create a shared language and understanding of young people's health and wellbeing.

6

Invest in promotion, prevention and early intervention

The Commissioners recommend **more** investment in strategies to promote health and prevent illness in adolescence. Also, early invention programs and initiatives that young people identify as effective should be boosted to assist young people to seek help early with regards to their health and wellbeing, in particular, mental health.

7

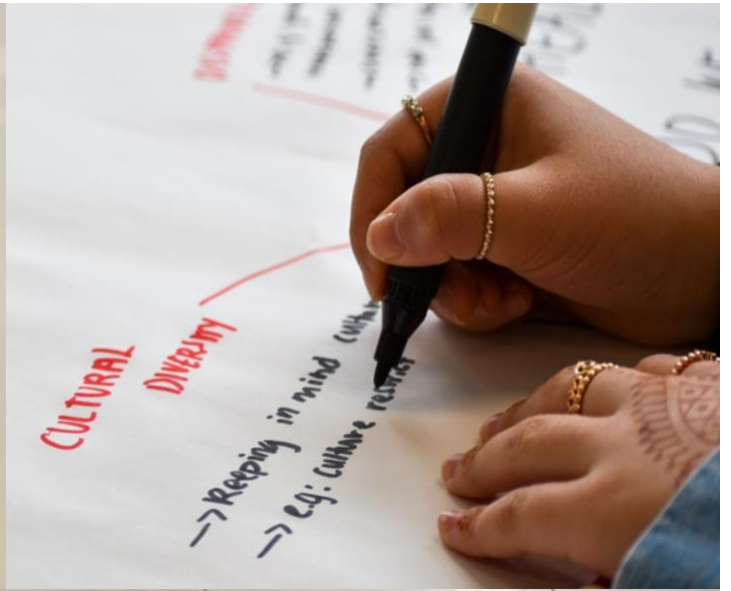
Centralise and streamline information that allows young people to navigate to the right health service

The Commissioners want a mechanism for young people to access health care information and/or get a referral for acute medical and allied healthcare services in the one spot.

8

More research and education on the social determinants of health

The Commissioners want health professionals, researchers, and policy-makers to utilise a whole-of-community approach to look at the social determinants of health and wellbeing. This approach makes an impact on young people's health and wellbeing as well as reduces health disparities and improves health equity, including in rural & regional communities. The Commissioners recommend that the social determinants of health be embedded into health and wellbeing curriculums in schools.



APPENDIX A

WH&Y Commission Workshop Participants

	March	May	June	July
Number of Participants	7	17	17	15
Age	<ul style="list-style-type: none"> 14-17 years: 1 18-23 years: 6 	<ul style="list-style-type: none"> 14-17 years: 6 18-23 years: 11 	<ul style="list-style-type: none"> 14-17 years: 6 18-23 years: 11 	<ul style="list-style-type: none"> 14-17 years: 4 18-23 years: 11
Gender	Male: 2 Female: 5 Non-Binary: 0 Different term: 0	Male: 8 Female: 9 Non-Binary: 0 Different term: 0	Male: 4 Female: 13 Non-Binary: 0 Different term: 0	Male: 5 Female: 10 Non-Binary: 0 Different term: 0



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