Case study
Guiding and Co-Researching Youth-Centred Indicators of Health

SUMMARY

- Wellbeing Health & Youth Centre of Research Excellence in Adolescent Health (WH&Y CRE) Commissioners worked with staff from the Australian Institute of Health and Welfare (AIHW) in a full-day workshop and online to guide the selection of indicators of youth health. The indicators were used to create the AIHW report: Australia's Youth 2021
- These consultations led to the identification of new indicators not previously used in past AIHW youth health reports.
- As a result the AIHW invited Commissioners to author short evidence reviews on priority topics for young people: climate change, discrimination and the wellbeing and health of LGBTIQ+ young people

What was the aim?

For young people to directly inform the AIHW work program and indicators of youth health associated with the development of policy, programs and services.

How did it happen?

In 2020, the AIHW approached the WH&Y CRE to invite 2 young people to join the AIHW Child and Youth Information Advisory Group. The purpose of the Group was to help the AIHW shape the work program associated with youth information and reporting and advise as the Australia's Youth (2021) report was prepared and finalised. This Advisory Group was chaired by Professor George Patton, Director of the Centre for Adolescent Health and its members included other eminent academics and senior members of the Australian Public Service and associated agencies.

To maximise the experience of young people and the opportunity for the AIHW to hear from a broader range of young people, the WH&Y CRE proposed the AIHW engage the WH&Y CRE:

- To explore the wellbeing and health priorities of young people in Australia.
- Review and advise on the proposed set of indicators that form the basis of the evidence review and reporting in the AIHW reports.

What were the research project questions?

- What are the key issues that positively impact youth health?
- What are the key issues that negatively impact youth health?
- Are there any topics missing from the list of identified topics that impact youth health?
- What are your 3 highest youth health priorities
- What are your 3 lowest youth health priorities
- Are there any youth health priorities you would remove?
- What are the 3 youth health topics that we must have in the report?

Why engage young people in this project?

The AIHW wanted to include 'youth voice'. From a WH&Y CRE perspective, this was an excellent opportunity to provide a broader youth-centred review of the existing indicators and to ensure the indicator set used in the Australia's Youth 2021 report captured young people's perspectives on what matters for youth health and wellbeing.

When and how did young people participate in this project?

Phase	Approach or methods used	Young people's role/s
Ideation	WH&Y Commission was consulted on preferred model for participation	Advisors
Planning	N/A	
Ethics	Already approved	
Data collection	In-person workshop and commensurate online activities	Participants
Analysis	Review and recommendations for final set of indicators of youth health	Advisors: WH&Y Commissioners reviewed the findings and recommendations. Co-researchers: WH&Y Commissioners reviewed existing data and literature on key youth health topics.
Reporting	Review and recommendations	Co-authors: WH&Y Commissioners wrote brief evidence summaries that explained the importance of three key topics for youth health and wellbeing.
Dissemination		The WH&Y CRE and Commissioners contributed to the dissemination of the report through existing networks and media activity.
Impact/ evaluation	Online interview questions	Not involved

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YOUNG & RESILIENT RESEARCH CENTRE

What model of engaging with young people was chosen and why?

While the AIHW initially wanted to appoint just two young people as advisors to an adult advisory group, the WH&Y Commission model supported a youth-cented and participatory approach. Specifically:

- AIHW staff engaged with an existing group of young people (the WH&Y Commission)
- The process invited AIHW to try an engaged approach designed to work directly with diverse young people and to channel their insights directly into decision-making and co-creation of the indicators and content for the report
- The methods used were participatory and designed to explore young people's health priorities as well as their ideas, questions and concerns regarding youth health data and reporting
- Young people were empowered to review evidence and write topic summaries to highlight the importance of data gaps and key issues for youth health.

What actions were taken to meet ethical considerations relating to involving young people?

Mutual trust and accountability:

- Trust and accountability were built by challenging power imbalances implicit in inserting young people into adult-centric and hierarchical, representative processes (such as Advisory Groups) by adopting an alternative, participatory process.
- Working directly with the full WH&Y Commission. This demonstrated a commitment to working with the preferences and priorities of young people.
- The WH&Y Commission contribution was publicly acknowledged and some report sections were authored by Commissioners.

Equity and responsiveness:

- AIHW staff worked directly with WH&Y CRE Commissioners and Researchers to create a process, methods and outputs that centred young people's preferences and views.
- AIHW staff reported back to the WH&Y Commission on how their views were shared and considered in decision making.

- Staff communicated with young people in a timely way and explained delays. They were accommodating and supportive when young people required extended timelines for delivery.

Diversity and inclusion:
- Engaging with the Commission, in the location where most young people lived and at a time that suited them (a Saturday and online) enabled a greater number and diversity of young people to take part and be heard.
- The AIHW created a new category of the report to allow young people to analyse and express the significance of particular data gaps and topics for youth health.

What were some of the practical steps taken to prepare to work together, connect with young people, and reflect on each activity/step in the process?

Prepare:
- Agree on the purpose and aims of the project *with* young people who are likely to be involved.
- Prepare summary slides that tell young people about the aims, purpose and context of the AIHW and their Young Australians report.

- Brief the WH&Y Commissioners and provide them with background information (E.g. Past report; simplified explanation of theoretical frameworks such as the Social Determinants of Health).
- Provide information on who will be in the 'room'.

Connect:
- Create collaborative activities that encourage young people to work together.
- Adopt the modalities, location and timing that best suits young people
- Spend time to build rapport.
- Provide a key point-person where there are additional activities (E.g. To support young people and provide feedback on writing).
- Reimburse young people for their time.
- Explain the approach to editing and consult so that young people's meaning is not lost.

Reflect:
- Summarise insights and guidance from the workshop and online consultations.
- Invite and provide feedback on the experience.
- Acknowledge and celebrate young people's contributions in public fora.
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What were the outcomes of this project?

For the first time, young people were involved in guiding the work of the AIHW. The WH&Y Commission directly informed the indicators of youth health used to create the AIHW report. This report also included key topic summaries authored by 6 Commissioners based on their views – something the AIHW has never done before.

What was the impact of involving young people in this research?

Young people felt heard and could see how their contributions made a direct difference:

"... the inputs that we provide, I can definitely see has been translated into different results and output driven processes. For instance, the Australian Institute of Health and Welfare, it's such a massive government body and a report for young people and for us to write an article for them as WH&Y commissioners, I think that was the recent testament that I was just like oh wait, what I'm doing actually does matter." - WH&Y Commissioner

Engaging young people in the process of defining the indicators and writing content for the report has directly influenced the way the AIHW approaches preparing their policy-influencing reports:

"...Through our work with the WH&Y team, the views and experience of some young people were able to inform our thinking on the Australia's Youth publication. We would definitely consider working with the WH&Y team again to support youth input into future AIHW products" - Sally Mills, Head of Children and Families Unit, Community Services Group, Australian Institute of Health and Welfare

Key questions for researchers to reflect on if planning a similar project:

- Do we know what the topic or problem looks like from young people's perspectives?
- What process or methods would feel welcoming and meaningful to young people?
- What could we do differently to centre or showcase young people's views?
- How do we recognise young people for their contributions?

Tips/learnings from this project:

- Set expectations – including if there is uncertainty about what the process or final product should look like.
- Provide capacity-building and training where possible, such as critical thinking and writing skills.
- Meet regularly to discuss roles & responsibilities. Encourage young people to ask questions throughout the process to ensure they feel supported and that they are on the right track.
- Provide more generous timelines than might be usual.
- Give examples, tips and starter points for searching for credible, peer-reviewed pieces of evidence to support their arguments.
- Explain editing processes and discuss changes in order to maintain the integrity of the message and voice of the author.
- Provide a lot of reassurance to young people who are engaged in the project and give them specific feedback on how they can improve their work.