



# Case study

## Case Study: Youth-led Advocacy for Respectful and Inclusive Health Research

### SUMMARY

- WH&Y Commissioners identified the need for greater awareness, understanding and respectful inclusion of young people who identify as gender and sexuality diverse within health research, policy and service design
- Working with WH&Y CRE staff, WH&Y Commissioners led a project to improve better understanding and research for improved health services for young people who are gender and sexuality diverse through better data collection and respect for lived experience.
- Young people and senior researchers met weekly for three months to plan a showcase of the experiences, knowledge and skills for engaging with LGBTQIA+ young people in research.

- The collaboration created a resource and hold a discussion forum to coincide with PRIDE Month, an international day to promote civil rights and justice for LGBTQIA+ people.

### What was the aim?

To promote researchers' understanding of gender and sexuality diversity and engagement with young LGBTQIA+ people, and researchers with lived experience, from the inception of research to the dissemination of research findings.

### How did it happen?

The WH&Y Commission Pride Project was a sub-project of the WH&Y Commission led by nine young people in collaboration with



two researchers, four support staff and two adult experts. The sub-project evolved from a series of WH&Y Commissioner workshops in 2019-2022 where young people identified key issues that they would like to see addressed in adolescent health research.

Among these was the need to provide accessible and supportive services for LGBTQIA+ young people. Key to this is the need for researchers to better understand the complex identities of young people who identify as LGBTQIA+, and how these shape their experiences of navigating the health system.

To build better awareness and understanding, a WH&Y Commissioner provided training on gender and sexuality diversity. In 2022, two young people and WH&Y researchers (identifying as LGBTQ+ or allies) discussed how to extend the content and learnings from the WH&Y Commission-led training session to encourage more young advocates and researchers to consider how their research can contribute to a better understanding and improved services for young people who identify as LGBTQIA+.

### **What were the research questions?**

- How can health research better capture the health and service needs and preferences of young people who identify as LGBTQIA+?
- How should health researchers, policy makers and professionals engage with the data and lived experiences of young people who identify as LGBTQIA+ to improve research and services?

### **Why engage young people in this project?**

Health research routinely excludes and misrepresents young people who identify as gender and sexuality diverse resulting in compounding and deepening health and social inequity.

Young people from LGBTQIA+ communities are experts in their lived experience. Involving them in the research process from inception through to dissemination will improve the accuracy and impact of research and will help ensure that the questions, methods and strategies used are inclusive and respectful. Young people want their experiences validated regardless of the labels with which they identify.





### **What model of youth engagement was chosen and why?**

This project was youth-led. The need to address the specific health needs and barriers to services that young people who identify as LGBTQIA+ was identified as a priority area by the WH&Y Commission along with the need to raise awareness and understanding of respectful practice. Commissioners were significantly supported by senior researchers and adult advocates who brought best evidence and practice in research inclusive of diverse gender, sexuality and sex characteristics as well as event planning and management.

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

The project contributed to improved engagement of research community with the topic as well as new collaborations between the WH&Y Commission and advocates.

The resources produced have helped shape the practices of organisations and professionals: *“I printed the resources and gave a presentation at to the leadership of my local health district. Some staff now display their pronouns and the presentation has gotten the attention of health and research executives in the district”* - Betty Nguyen, researcher team member.

For the young people involved they learnt how to run a large-scale online event, acquired time management, public speaking skills and more confidence in themselves to express what issues are most meaningful and important to them. They were also able to shape research and dissemination processes by thinking with LGBTQ+ groups in their own communities as well as peak bodies and media units like ABC Queer.



### When and how did young people participate in this project?

Phase	Approach or methods used	Young people's role/s
<b>Ideation</b>	Youth-led	Leaders Senior researchers guided young people to identify the aims and strategy
<b>Planning</b>	Collaborative	Senior researchers supported young people to prepare the event and resources
<b>Data collection</b>	Lived experience and expert informed	Leaders
<b>Analysis</b>	Co-Creation	Co-Creators: Commissioners and young advocates with lived experience contributed key ideas and messages alongside senior researchers and advocates. Messages were collaboratively created
<b>Reporting</b>	Co-Creation	Co-Authors: Commissioners wrote content alongside senior researchers and advocates
<b>Dissemination</b>	Leaders and Collaborators	Commissioners led the webinar and creation of messages for website and social media
<b>Impact/evaluation</b>	Participatory	Commissioners took part as participants in workshops and online activities to reflect on the experience, benefits and outcomes.





### **What actions were taken around the following ethical considerations relating to involving young people?**

#### Mutual trust and accountability:

- The project was youth-led. Commissioners were supported by a dedicated staff member to identify the aims, process and outputs.
- Commissioners were responsible for administration and delivery of the project with support from senior researchers.
- Senior researchers and Commissioners worked together to learn, share and engage with each other through common interests and understanding of young LGBTQ+ lived experiences.

#### Equity and responsiveness:

- Researchers communicated with young people in a timely way and offered additional support when timelines became tight.
- Commissioners were identified as leaders of the initiative and were reimbursed for their time paid for their time.
- Commissioners learnt a range of soft skills.

#### Diversity and inclusion:

- Partnerships and representation with people with lived experience across all aspects of LGBTQIA+ identity was sought.
- The project fostered intergenerational dialogue between young people, senior researchers and advocates.

### **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.
- Create and share a project brief with clear purpose, roles and timelines.

#### Connect:

- Weekly meetings.
- Provide a key point-person to guide and support delivery of key activities.
- Use shared documents to co-create questions, key messages and call-to-action.
- Identify gaps in lived experience and invite representatives to join the group or event.



- Develop a duty of care guide and provide support for young people to keep themselves safe.
- Reimburse young people for their time.

#### Reflect:

- Conduct one-on-one debriefs after the event.
- Invite and provide feedback on the experience.
- Acknowledge and celebrate young people's contributions.

#### What were the outcomes of this project?

WH&Y Commissioners, young advocates and researchers collaborated to create an online webinar during Pride Week 2022 which received more than 150 registrations. A resource informed by best evidence and live practice has been viewed more than 200 times. This resource guides researchers and others in how to engage meaningfully with young people who identify as gender and sexuality diverse and to best collect health data. A partnership with ABC Queer resulted in social media dissemination of the resource, reaching more than 30,000 followers and their wider networks.

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

- How can you create space for them to lead a research-practice initiative?
- What process or methods would feel welcoming and meaningful to young people and ensure they're supported to learn the new skills required?
- What could we do differently with your research and advocacy resources that will help amplify young people's perspectives?
- How could you 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 a safe space for young people to consider their own positionality and to allow them to contribute without having to speak out publicly.
- Keep a focus on timelines and tasks to ensure that all milestones are met and people feel confident in what they're doing.
- 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.