

The role of young people in Wellcome's new strategy

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LET'S TALK - WORKSHOP
14 JANUARY 2021

Agenda

Methodology

Findings

Roles young people play in health research

Benefits of young people's involvement

Challenges associated with young people's involvement

Recommendations to strengthen young people's involvement

Discussion

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These findings are based on two inputs

1

Rapid Evidence Review

Aim: To understand the landscape of evidence in peer-reviewed academic literature on how young people are involved in health research and the implications of that involvement

Scope: This review comprised a database of 187 peer-reviewed articles published since 2005.

2

Stakeholder consultations

Aim: To gather feedback on Rapid Evidence Review findings and get stakeholders' views on how Wellcome can strengthen young people's involvement in health research

Scope: Interviews, focus groups discussion and surveys with: (1) young people in LMICs (2) adults in their ecosystems (3) researchers, NGO representatives, policymakers, health research funders linked, some of which are experts in involving young people in health research



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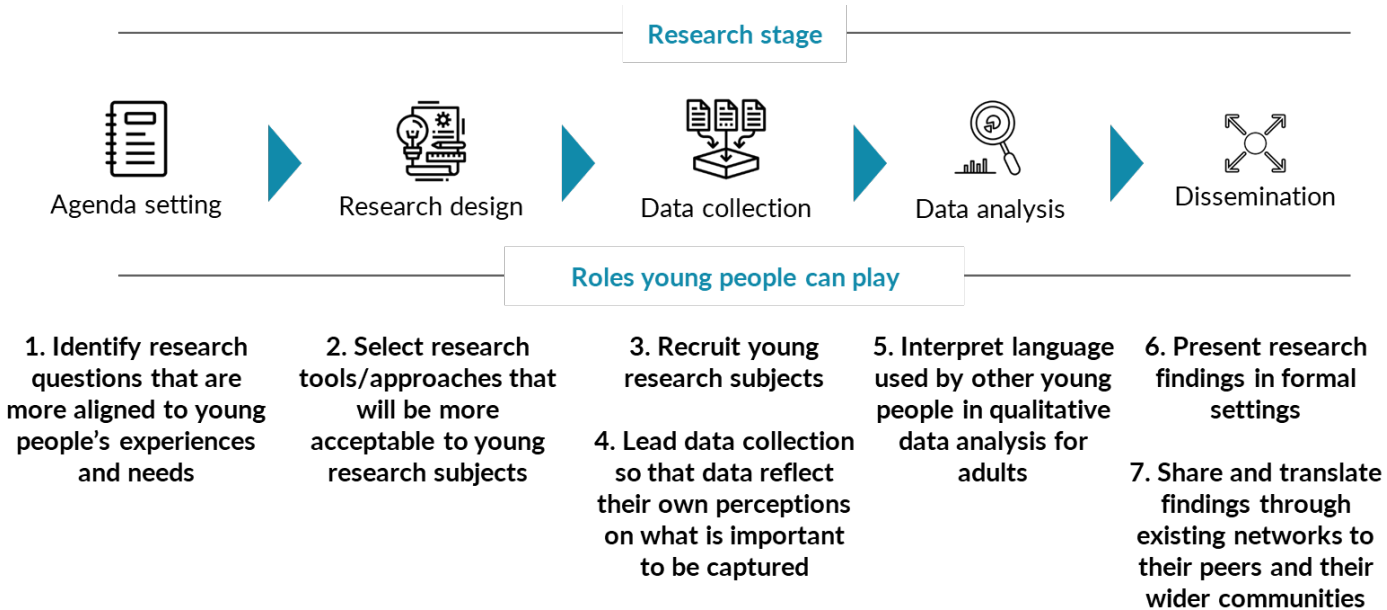
Benefits of young people's involvement

Challenges associated with young people's involvement

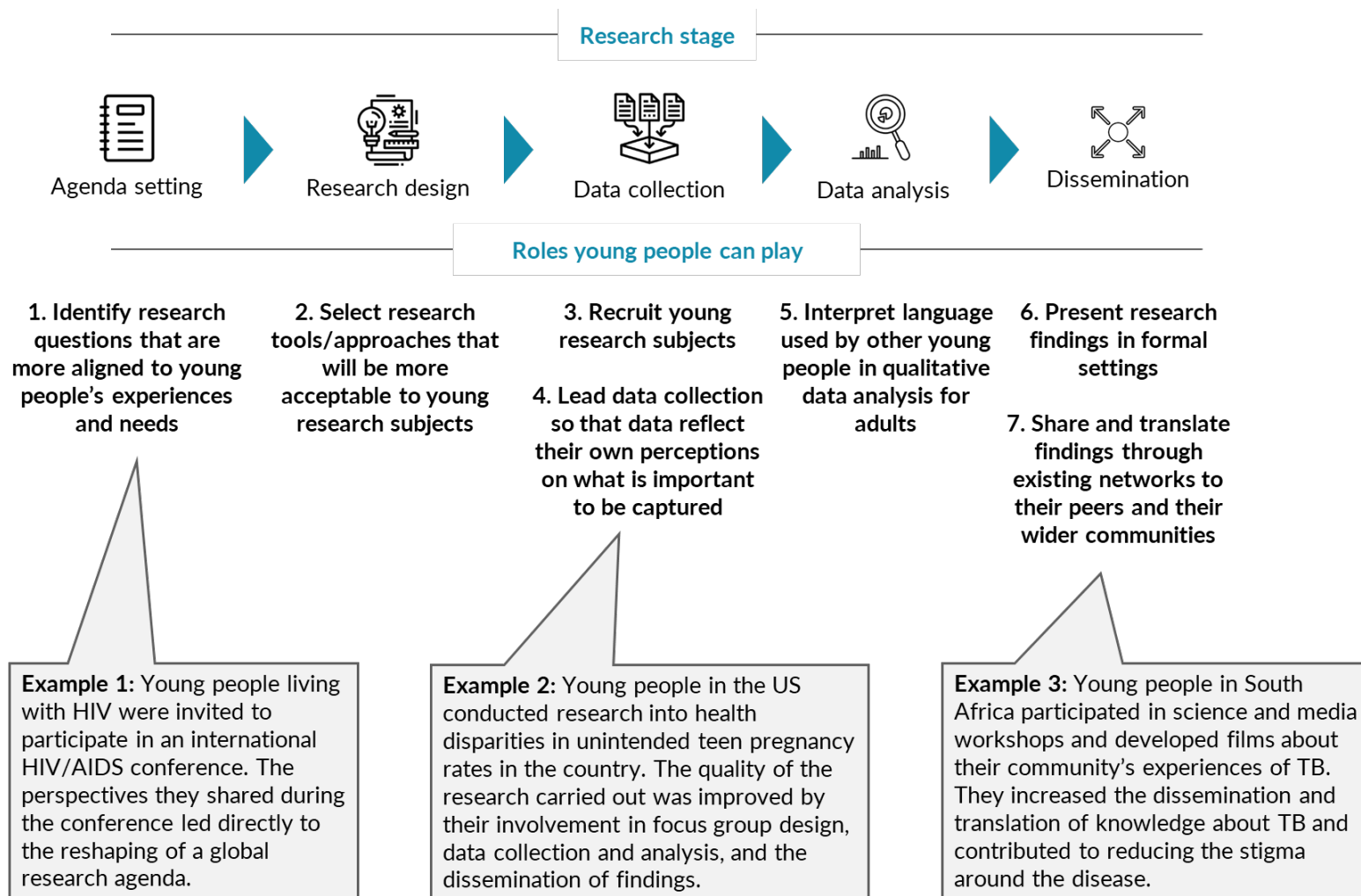
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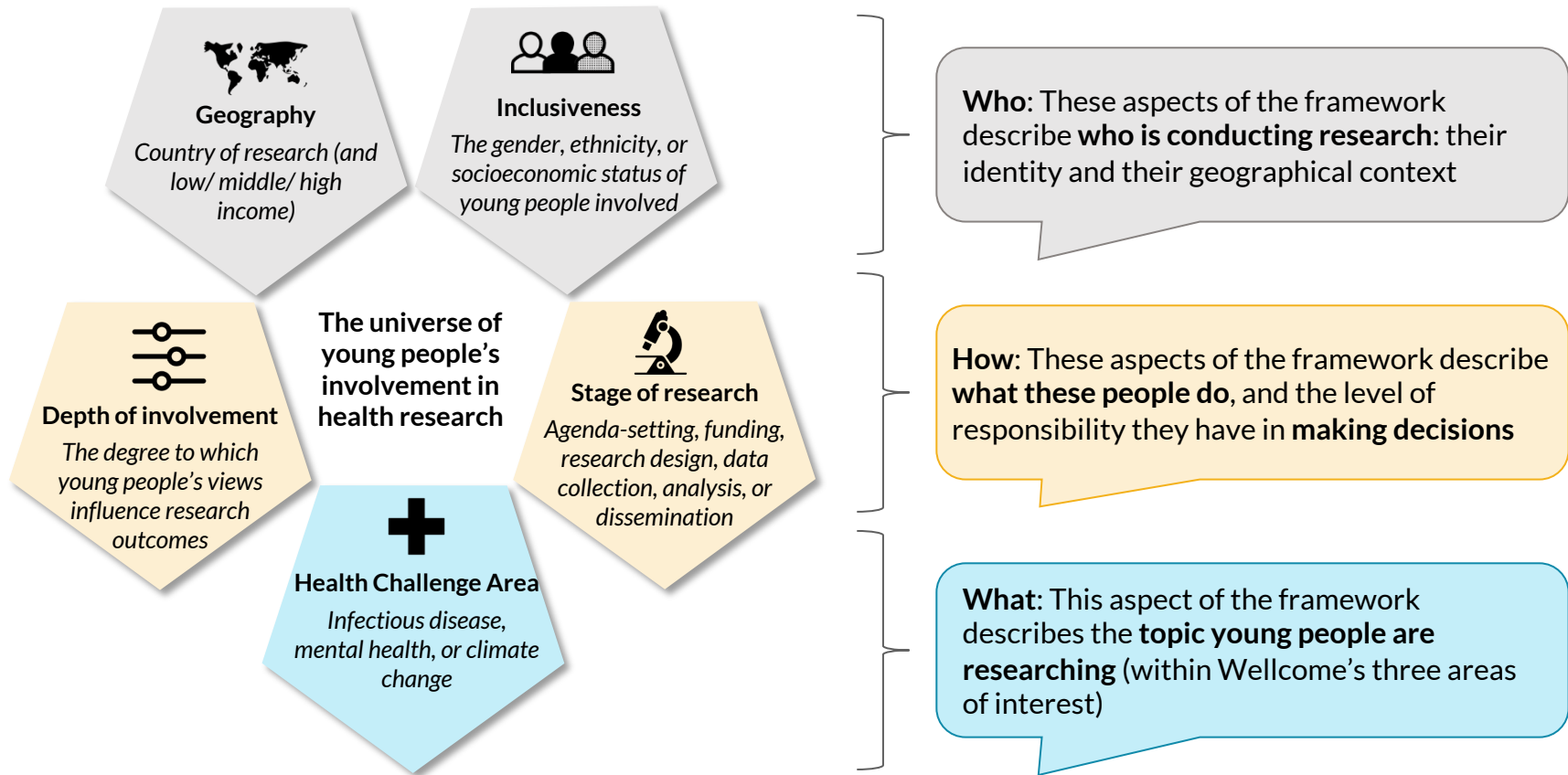
Young people can be involved in a variety of roles in research (1/2)



Young people can be involved in a variety of roles in research (2/2)



Our five-dimension framework describes young people's involvement in health research



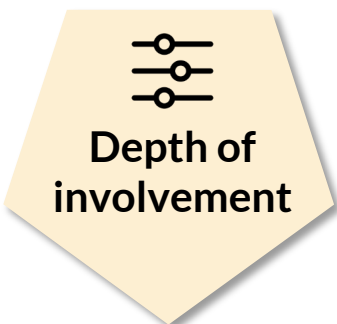
The evidence review reveals how involvement tends to look across each dimension of the framework (1/2)



- **More likely to be involved in mental health research than other health topics**



- **Most commonly involved in research design or data collection**



- **When involved, young people would like more influence on project outcomes and agency in decision-making**

The evidence review reveals how involvement tends to look across each dimension of the framework (2/2)



Geography

- Only **15% of academic papers reviewed** were based on studies in LMICs

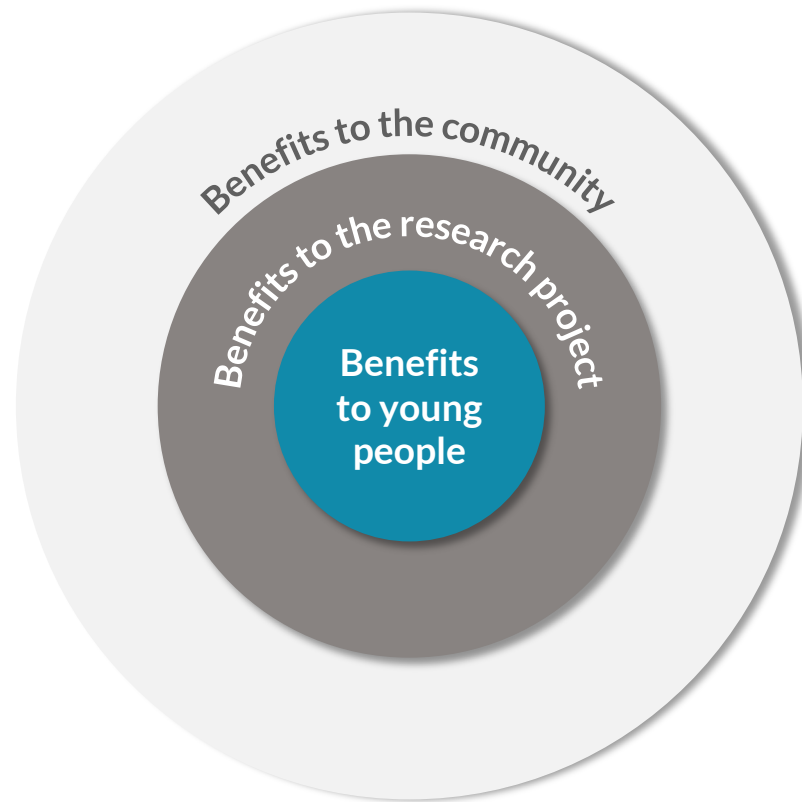


Inclusiveness

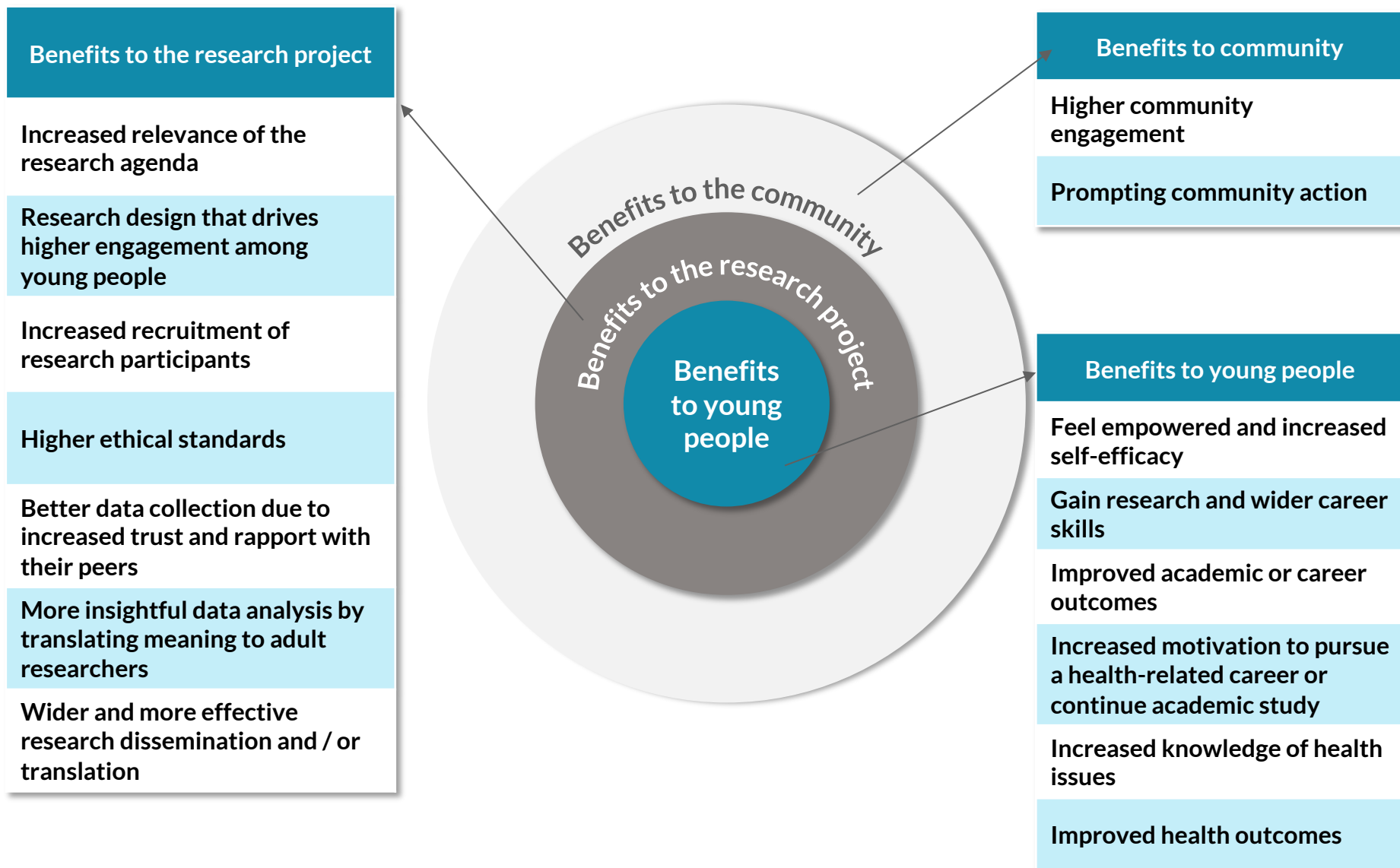
- Most research does not report on **key socio-demographic factors** of young people involved

What are the **benefits** of involving young people in health research?

Young people's involvement benefits research, young people and their communities



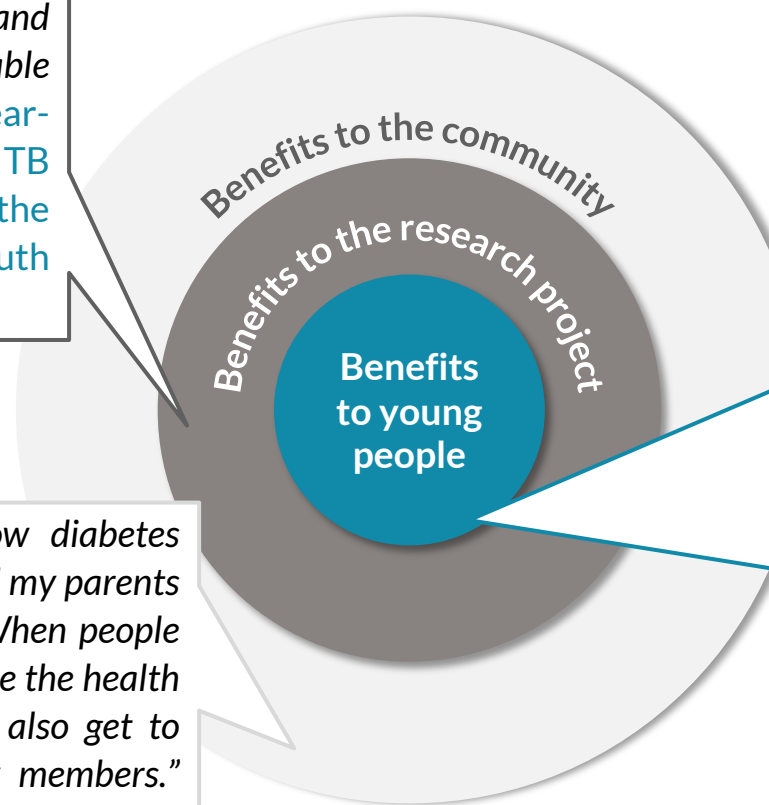
Young people's involvement benefits research, young people and their communities



Young people we interviewed provided a first-hand account of these benefits

"We go and we talk in our way, maybe talk slang and talk to them in a comfortable way." Anastasia, a 21-year-old student in a TB research group in the Western Cape, South Africa

When I learnt about how diabetes works, I first went and told my parents to stop eating oily food. When people learn about how to improve the health in their community, they also get to take care of their family members." Nabil, a young researcher who trains young people from an informal settlement in India in health research



"I feel like today's Amrita is so different from yesterday's Amrita...I feel like I have come so far...[as a person] When I think of boys, I feel like I have come so far and it would be so hard to find a boy who thinks like me [that I can be with?]. - Amrita, a 26-year-old field research coordinator from Mumbai, was involved in a community research

What are the **challenges** associated with involving young people in health research?

There are also challenges associated with involving young people in research (1/2)

1. There are **too few opportunities** for young people to get involved in health research
2. It can be **harder to access and sustain engagement** from young people over time
3. Researchers **need to employ new ways of working** with young people, including working around the more rigid schedules of young people

There are also challenges associated with involving young people in research (2/2)

4. There is a **lack of training and guidelines** on how young people can be involved in health research effectively
5. There is a **lack of standardised language and methodologies for M&E** of research that involves young people
6. An underlying driver of these challenges is a **lack of support from funding organisations** within the health research ecosystem

The 10 overarching recommendations to address these challenges and opportunities

Strengthening ways of working together

- Promote **best practices**
 - Offer **training** to young people and researchers
 - Build a **working culture** that is conducive to the involvement of young people
 - Strengthen **networks**
-

Supporting knowledge and advocacy

- Improve **M&E**
 - Build and disseminate **more impact evidence**
 - Develop a **new standard among funders** on how young people's involvement in health research should be supported
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Adapting to different contexts

- Provide support that is tailored to **young people in LMICs**
- Strengthen the involvement of a **diverse range of young people**
- Involve young people in **internal agenda-setting** and **funding decisions**