The role of young people in Wellcome’s new strategy
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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Discussion
These findings are based on two inputs

<table>
<thead>
<tr>
<th>Rapid Evidence Review</th>
<th>Stakeholder consultations</th>
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<td><strong>Aim:</strong> 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</td>
<td><strong>Aim:</strong> To gather feedback on Rapid Evidence Review findings and get stakeholders' views on how Wellcome can strengthen young people's involvement in health research</td>
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<td><strong>Scope:</strong> This review comprised a database of 187 peer-reviewed articles published since 2005.</td>
<td><strong>Scope:</strong> 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</td>
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Discussion
Young people can be involved in a variety of roles in research (1/2)

1. Identify research questions that are more aligned to young people's experiences and needs
2. Select research tools/approaches that will be more acceptable to young research subjects
3. Recruit young research subjects
4. Lead data collection so that data reflect their own perceptions on what is important to be captured
5. Interpret language used by other young people in qualitative data analysis for adults
6. Present research findings in formal settings
7. Share and translate findings through existing networks to their peers and their wider communities
Young people can be involved in a variety of roles in research (2/2)

**Research stage**
- Agenda setting
- Research design
- Data collection
- Data analysis
- Dissemination

**Roles young people can play**

1. Identify research questions that are more aligned to young people’s experiences and needs
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**Example 1:** Young people living with HIV were invited to participate in an international HIV/AIDS conference. The perspectives they shared during the conference led directly to the reshaping of a global research agenda.

**Example 2:** Young people in the US conducted research into health disparities in unintended teen pregnancy rates in the country. The quality of the research carried out was improved by their involvement in focus group design, data collection and analysis, and the dissemination of findings.

**Example 3:** Young people in South Africa participated in science and media workshops and developed films about their community’s experiences of TB. They increased the dissemination and translation of knowledge about TB and contributed to reducing the stigma around the disease.
Our five-dimension framework describes young people’s involvement in health research

Who: These aspects of the framework describe who is conducting research: their identity and their geographical context.

How: These aspects of the framework describe what these people do, and the level of responsibility they have in making decisions.

What: This aspect of the framework describes the topic young people are researching (within Wellcome’s three areas of interest).

- **Geography**: Country of research (and low/middle/high income).
- **Inclusiveness**: The gender, ethnicity, or socioeconomic status of young people involved.
- **Depth of involvement**: The degree to which young people’s views influence research outcomes.
- **The universe of young people’s involvement in health research**.
- **Stage of research**: Agenda-setting, funding, research design, data collection, analysis, or dissemination.
- **Health Challenge Area**: Infectious disease, mental health, or climate change.
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)

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

- 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
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Benefits to the research project
- Increased relevance of the research agenda
- Research design that drives higher engagement among young people
- Increased recruitment of research participants
- Higher ethical standards
- Better data collection due to increased trust and rapport with their peers
- More insightful data analysis by translating meaning to adult researchers
- Wider and more effective research dissemination and/or translation

Benefits to the community
- Higher community engagement
- Prompting community action

Benefits to young people
- Feel empowered and increased self-efficacy
- Gain research and wider career skills
- Improved academic or career outcomes
- Increased motivation to pursue a health-related career or continue academic study
- Increased knowledge of health issues
- Improved health outcomes
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
What action is recommended to improve how young people are involved in health research?
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

**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*