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An inquiry into involving young people in health research

EXECUTIVE SUMMARY

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Dalberg



Acknowledgements

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Foreword

Wellcome is embarking on an ambitious new global strategy to tackle urgent health challenges with a focus on mental health, infectious disease, and the health impacts of global heating¹. Young people² are disproportionately impacted by these health challenges and will have to live with them longer. They will not only be key beneficiaries of Wellcome's new strategy but will also be key in helping Wellcome achieve the desired impact. Demographics alone highlight the central role young people will need to play if Wellcome is to achieve and sustain its goals:

- **there are 1.8 billion young people in the world today;**
- **40% of the global population is under 24 (for example, there are 600M people under 25 in India; 42% of the population of Nigeria is under 14);**
- **nearly 90% of the population aged 10-24 lives in developing countries.**

Young people are often considered the “next generation” whom we must prepare for citizenry and the workforce. However, these large numbers demonstrate that involving them in the here and now is critical to achieving Wellcome's strategic aims. They are often not invited to participate in research, but we believe it is crucial that we empower and support young people to take their rightful place in shaping health research. Wellcome is interested in better understanding how we can involve young people meaningfully in our work and what it entails to do that well.

In the last few decades, increased attention has been paid to involving the public in health research and taking their views, knowledge, and experiences into account. The “children's rights' agenda” ratified through the UN “Convention on the Rights of the Child” in 1990 has led to a growing acceptance of the need to include younger generations in any issues that affect them, including research. Involving young people in co-creating new knowledge in health research has been emphasised but is a nascent area of work. Concerns about their competence to be involved in research or worries that involving them could harm them lead to hesitation about involving young people in health research. As a result, health research often involves parents, caregivers, and other stakeholders instead of the young people themselves.

We commissioned this study, which involves a rapid evidence review and stakeholder consultation, to explore the role, benefits, and potential of young people's involvement in research in Wellcome's defined health challenge areas. We are interested in youth involvement all along the research chain—from influencing questions and research design to data collection and advocating for the issue.

The findings will inform Wellcome's approach to youth involvement as we embark on our ambitious new research agenda. It highlights the challenges that must be overcome and provides recommendations for how we can strengthen young people's involvement while showing how we can maintain an intentional lens on diversity and inclusion. Wellcome now has a significant opportunity to use these findings to develop a robust understanding and practice of youth involvement in health research, and to involve young people as stakeholders and activators of impact for our new strategy.

Dr Anita Krishnamurthi

Head of Education and Learning
Wellcome

1 Wellcome's (2020) strategy focuses on the effects of global heating on health but recognising that this is a nascent field and in order to be able to capture as many relevant insights as possible, this inquiry used also the term climate change. It should be highlighted that the terms are not considered as synonyms.

2 We use the WHO definition of 'young people' which covers the age range 10-24 years.

Key findings

This study, comprising a rapid evidence review and a stakeholder consultation, explored the role, benefits and potential of young people's involvement in health research, with a focus on mental health, infectious disease, and the health implications of global heating/climate change. Some key findings were as follows:

- The academic literature on young people's involvement in health research is still emerging, with an increasing number of articles being published in the last five years.
- The vast majority of published health research that involves young people occurs in high-income countries.
- Most published articles do not report on the background of the young people who have been involved, hence it is difficult to conclude to what extent the research has been inclusive.
- Young people are most frequently involved in research design and data collection, rather than agenda-setting and dissemination/translation of findings. However, young people's involvement in agenda-setting and research dissemination may be higher than what is reported in literature.
- Young people tend to have some control over decision-making in health research, but typically less than adults.
- Young people are more likely to be involved in mental health research in comparison to research on infectious diseases or the health implications of global heating/climate change.

Young people's involvement in health research benefits the research, the young people themselves, and their communities. Young people can better identify research questions and methods that fit young people's needs and experiences because they understand their peers' preferences and capabilities. Young people feel more empowered, have improved career/academic outcomes, and have increased understanding of health issues. Young people's involvement can increase community awareness of particular problems and, in some cases, influence communities to take action to address these. Although there is evidence of the benefits of involving young people in health research, there are also challenges to overcome.

- There are too few opportunities for young people to get involved in health research.
- Sustaining young people's commitment to research over time can be difficult.
- Researchers need to employ new ways of working with young people.
- There is a lack of training and guidelines on how young people can be involved in health research effectively.
- There is a lack of standardised language and methodologies for Monitoring and Evaluation (M&E) of research that involves young people.
- The working culture of teams and organisations is not always conducive to young people's needs and capabilities.
- In low- and middle- income countries challenges can be amplified by cultural norms, greater resource constraints and systemic inequities.
- Additional barriers exist when trying to involve young people from a diverse range of backgrounds, such as those from low-income backgrounds, girls and women, and young people with disabilities.
- There is a shortage of funding and support from some key stakeholders in the global health research ecosystem that aggravates these challenges.

The study resulted in a number of recommendations to address these challenges:

- 1. developing a new standard among funders on how young people's involvement in health research should be supported;**
- 2. developing and mainstreaming best practices;**
- 3. generating and disseminating more evidence;**
- 4. improving the M&E of health research;**
- 5. strengthening networks focused on involving young people in health research;**
- 6. involving young people in the funding organisations of health research.**

Introduction

As an independent, global charitable foundation dedicated to solving the urgent health challenges faced by everyone, Wellcome is interested in exploring the potential role young people (aged 10-24) can play in its new strategy, which is primarily focused on three health topics:

1. **Mental health**
2. **Infectious diseases**
3. **The health implications of global heating/climate change**

The Wellcome Education and Learning team commissioned this two-phase research project to better understand the involvement³ of young people in health research. It comprises a rapid evidence review (RER) of peer-reviewed academic literature, and a stakeholder consultation. The study aimed to explore the role, benefits, and potential of young people's involvement in health research in Wellcome's defined health "challenge areas" of mental health, infectious diseases, and the health implications of global heating/climate change. The geographic scope of this work extends to the UK and lower- and middle-income countries (LMICs). The research was carried out between July and November 2020 with the support of Dalberg, a global mission-driven advisory firm focusing on social impact.

The two objectives and key research questions that guided this study were:

Objective 1

To conduct a RER of current published credible international research in young people's involvement in health research, strengths, weaknesses, and gaps in the literature and develop a framework for young people's involvement in health research.

- What are the different approaches to involving young people in health research and how equitable are they in involving young people from diverse backgrounds?
- What are the challenges and benefits of involving young people in health research?
- What are the skills and capabilities young people need and what additional support do they need for effective involvement in health research?
- How do researchers need to be supported to effectively involve young people in health research?

Objective 2

To gather the views of a variety of stakeholders on how young people can be most effectively involved in health research and how Wellcome can best support them to contribute.

- To what extent do stakeholder's views and related experiences align with the findings of the RER?
- What can Wellcome do to enable young people to be meaningfully involved in health research?

³ Involvement in research means research that is done 'with' or 'by' young people, not 'to', 'about' or 'for' them (NHS Health Research Authority, 2020). It means that young people contribute to tasks like defining research agendas, designing research, collecting and analysing data, or disseminating and translating findings. In the literature, terms such as engagement or participation are often used interchangeably to the term involvement.

1. Methodology

The RER is built on a database of 187 peer-reviewed articles published since 2005. These articles were identified using three distinct methods:

1. a keyword search;
2. using bibliographies of relevant articles that appeared in the keyword search to identify additional papers;
3. recommendations from an External Advisory Group⁴ and Wellcome staff.

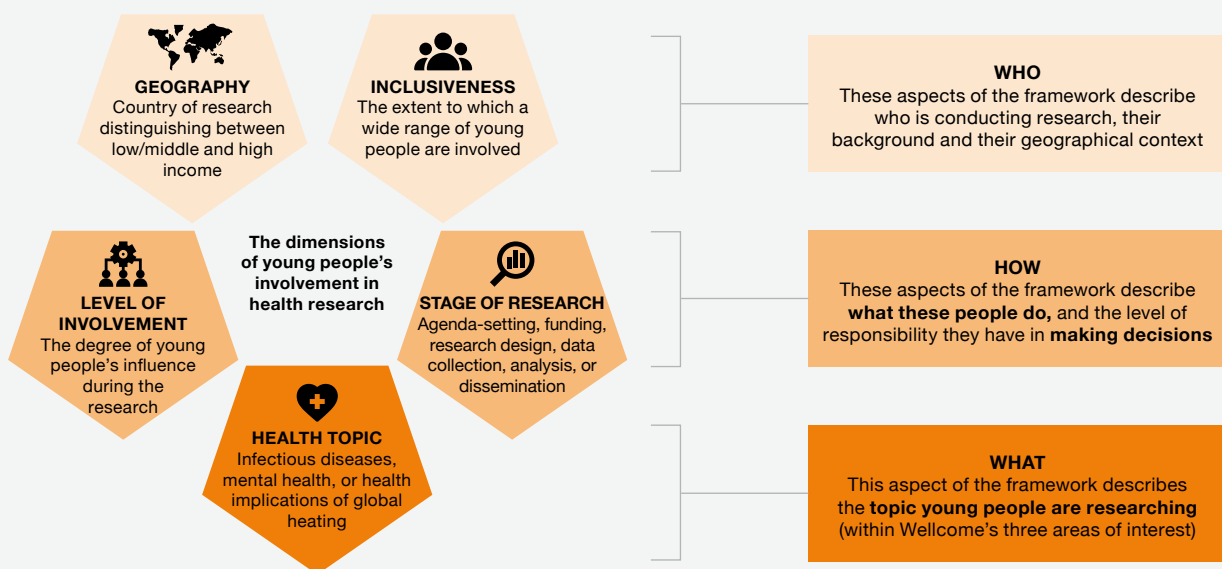
Following the RER, the stakeholder consultation engaged 146 stakeholders from 18 countries with a deep dive in India, Indonesia, Kenya, Senegal, South Africa, and Vietnam. The consultation took place online due to COVID 19 restrictions and comprised:

- individual interviews and focus groups with 55 young people and adults of influence within their ecosystems applying the Human-Centred Design (HCD) approach;
- individual interviews with 29 adult experts;
- survey of 62 additional adult experts;
- focus group of 10 young people to validate the findings at the end of the consultation phase.

2. The landscape of involvement of young people in health research today

The study developed a five-dimension framework (see figure 1) which provided a lens to look at and critically examine the current landscape of young people’s involvement in health research. This was developed based on the research questions, whilst also adopting Shier’s (2001) “Pathways to participation” model.

Figure 1:
Framework to describe young people’s involvement in health research



4 The Expert Advisory Group comprised seven members, who were a mix of adult researchers with extensive experience of involving young people in health research, and young people who have been involved in health research.

1. Geography:

The country/region in which the research occurs.

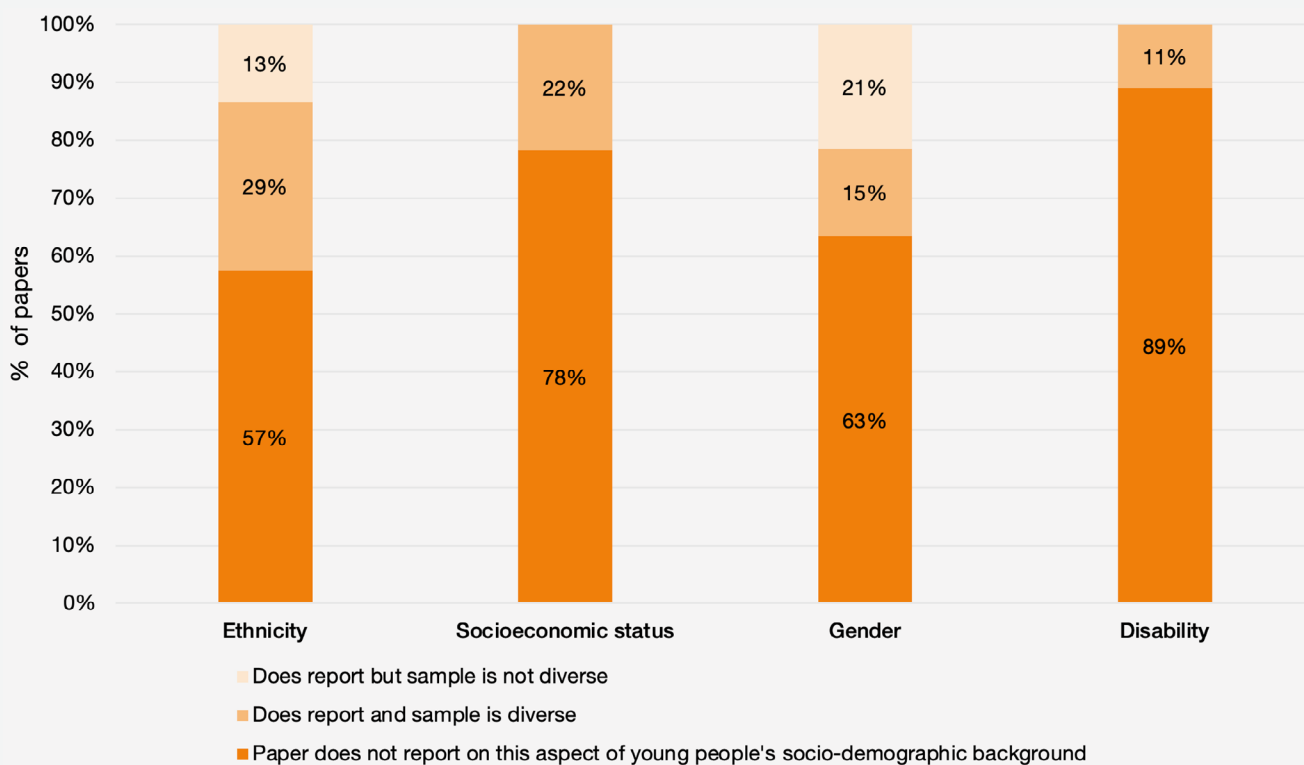
The vast majority of articles (85%) found in the RER are based on research carried out in high-income countries (HICs). Experts consulted agreed that this aligns with their experiences. Constrained funding in LMICs means researchers are less likely to have the time and budget required to effectively involve young people. Experts said that some of the gap in activity between HICs and LMICs may be explained by under-reporting, which is also a consequence of tighter budgets.

2. Inclusiveness:

The extent to which a wide range of young people have opportunities to be involved in and influence research, including young people who face disadvantage and may feel they do not often have these opportunities – sometimes referred to as marginalised or seldom-heard (INVOLVE 2012).

Most articles do not report key aspects of the background of participants: gender, socioeconomic status, ethnicity, and disability. Moreover, of the papers that do report on gender and ethnicity, a significant proportion do not report a diverse range of young people involved (see figure 2). Experts agree that the global health research ecosystem must work harder to ensure that diverse groups of young people are involved in research. For example, in some geographies, girls and women are less likely to be involved in research because of gender norms imposed by their own communities that limit their participation in activities outside the home.

Figure 2:
Socio-demographic characteristics of young people involved in health research, as recorded in academic literature (n=127)⁵



⁵ Note that the sample of n=127 is less than the total number of papers included in the RER, because some papers do not discuss a sample (e.g., guidelines on how to involve young people in health research).

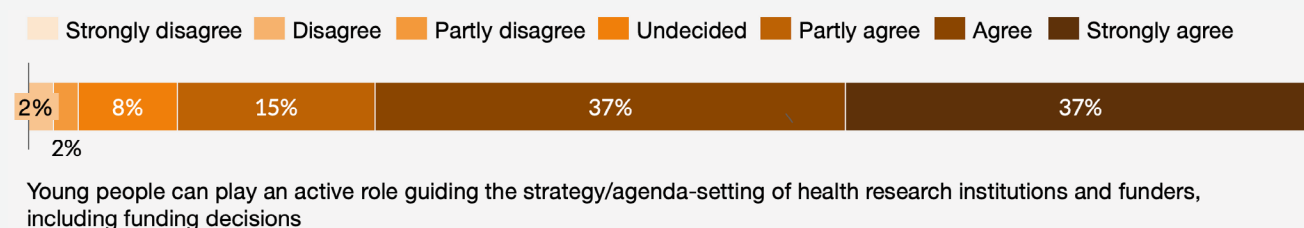
3. Stage of research:

The stage(s) of research in which young people are involved.

Academic literature and stakeholders consulted agreed that when young people are involved in research, it is most commonly in the middle of the research cycle: research design and data collection. However, stakeholders were supportive of young people being involved at all stages throughout the research cycle, for example agenda-setting and research dissemination, and provided many examples from their own experience of this working well. On agenda-setting, almost three-quarters of stakeholders surveyed agree that young people should be involved (see figure 3).

Figure 3:

Percentage of experts surveyed, by level of agreement with the statement “young people can play an active role in agenda-setting”⁶



4. Level of involvement:

The degree to which young people have control/influence over key decision-making in research.

Young people tend to have some control over decision-making, but typically less than adults. Most academic literature describes cases where young people’s views were taken into account and/or influenced decisions, but just 10% describe young people having as much influence as adults. Young people interviewed corroborated this analysis. While most of them said they had felt listened to when they were involved in health research, they also said they would like more agency and influence over decision-making.

5. Health topic:

The subject of the research that young people are involved in, focusing particularly on mental health, infectious diseases, and the health implications of global heating/climate change.

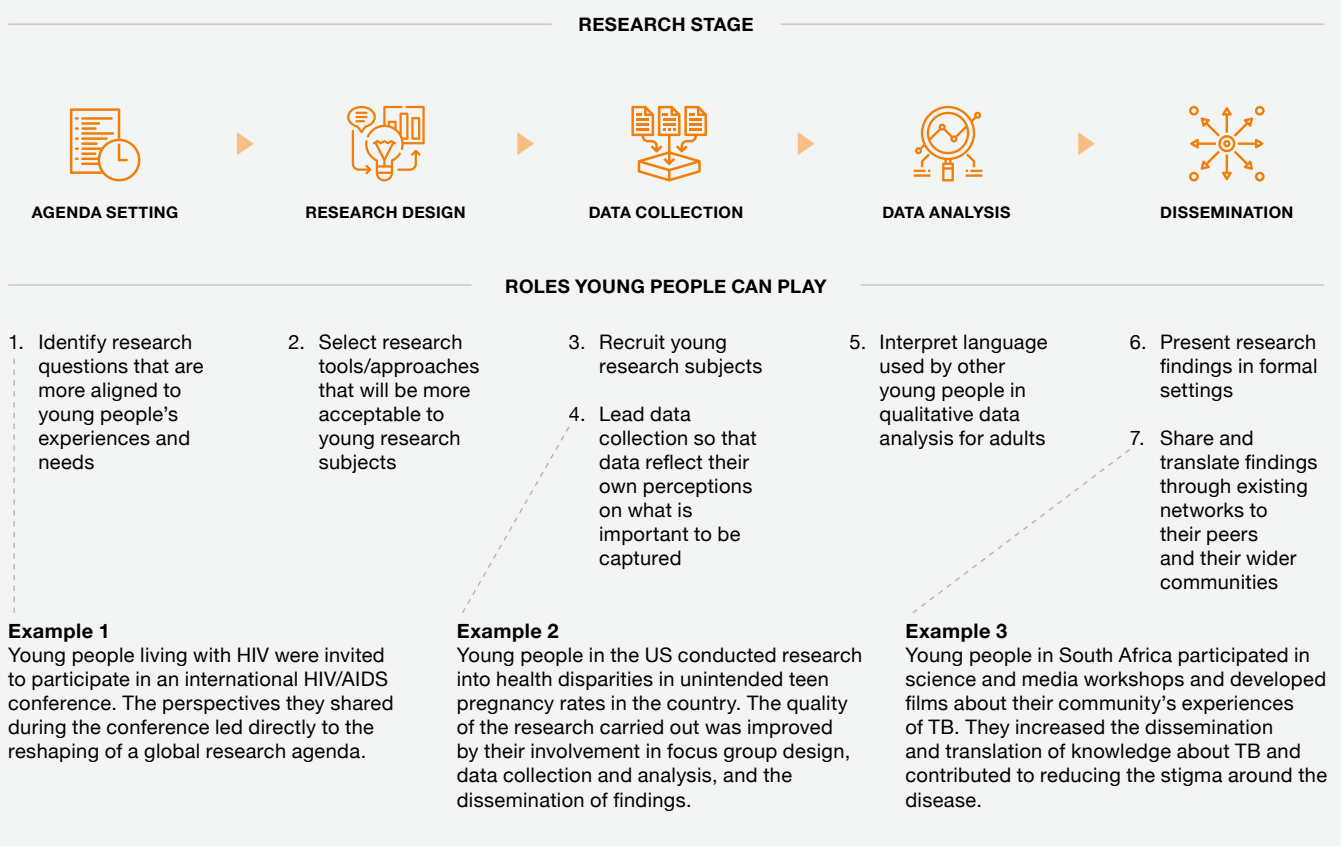
Young people are more likely to be involved in health research that focuses on mental health. The RER found three times as many articles related to mental health than those related to infectious diseases or the health implications of global heating/climate change. Stakeholders consulted explained that this is because mental health is a more participatory field of research and tends to more commonly address research questions that are focused on the patient’s experience or perceptions, making public involvement more of an imperative.

⁶ Agenda-setting is used to describe activities that set the direction and priorities of research, e.g. by identifying stakeholder needs, identifying themes/topics/issues, or identifying specific research questions to advance knowledge, then ranking these according to priority (adapted from Essink et al, 2020). Agenda-setting can take place at different levels: a single research project; a wider research programme; an institutional level (e.g. a research centre or a research funder); a national level; or an international level.

3. The roles young people play in health research and benefits of their involvement

The RER identified several roles that young people can play in research. These were further illustrated by the stakeholder consultations which provided additional examples of how this involvement looks in practice. These roles can occur at different stages of the research cycle: agenda-setting, research design, research funding decisions, data collection, data analysis, and research dissemination or translation of findings (see figure 4). The literature and stakeholders consulted showed that young people add value at each of the research stages. Young people’s involvement also results in research being conducted with higher ethical standards.

Figure 4:
Roles that young people can play in health research

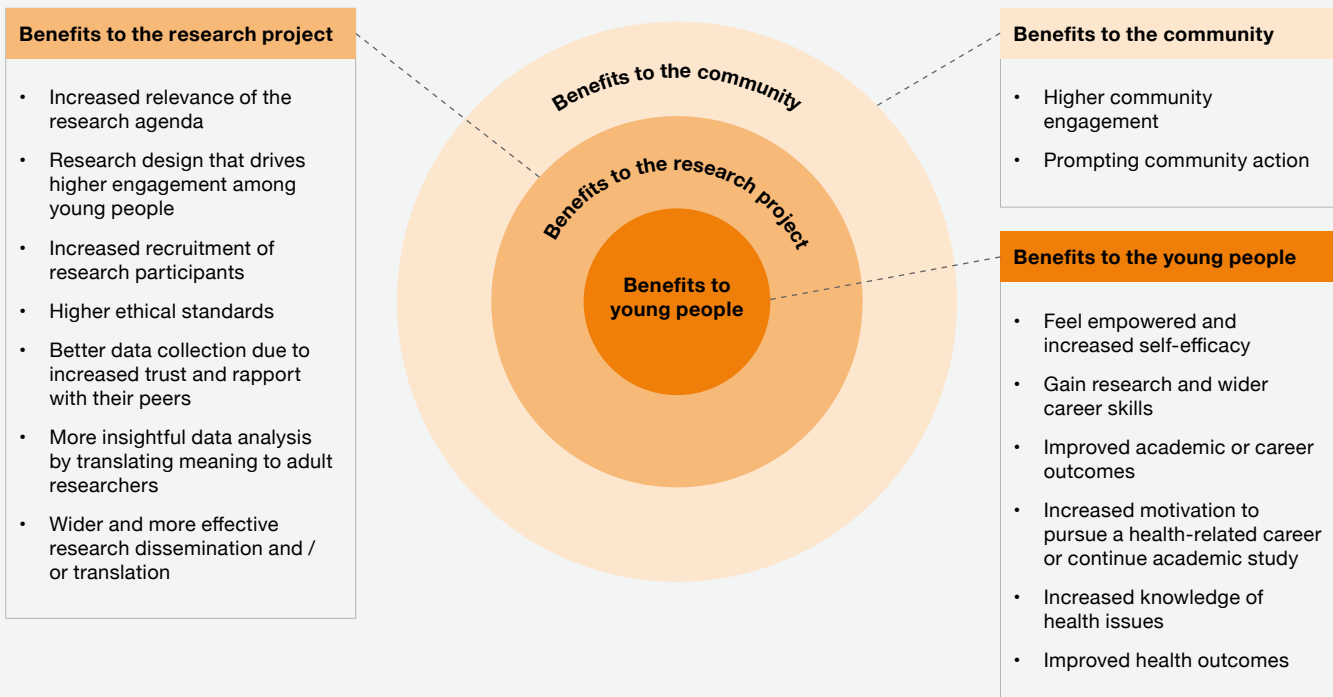


Importantly, the study showed (see figure 5) how young people’s involvement benefits the research itself. Young people can better identify research questions and methods that fit young people’s needs and experiences because they understand their peers’ needs, preferences, and capabilities. They are also more trusted and have better access to networks, allowing them to recruit young research participants, lead data collection, and disseminate research findings in ways that adults cannot.

Apart from the research itself, evidence shows that young people’s involvement in health research can also benefit their surrounding communities. For example, involvement can increase community awareness of particular problems and, in some cases, influence communities to take action to respond to particular health challenges.

Evidence also suggests that young researchers acquire research and transferable skills through involvement in research. They feel more empowered, have improved career/academic outcomes, and increase their understanding of health issues. In some cases, this might lead to improved health outcomes.

Figure 5:
Benefits of young people's involvement in health research



While the evidence is positive, a significant proportion of benefits probably go unreported. The terminology and reporting standards for this field of research are still emerging, which means that some research is mis-labelled and harder to find. Another challenge is that non-academics involved in participatory research may be less motivated to invest time in writing up their experiences for academic journals, which would contribute to the collective learning and evidence base on this topic.

Some stakeholders suggested topics where young people's involvement could be most useful, especially topics that are pertinent to them. Those most cited were stigmatised topics like mental health and sexual and reproductive health, but also other topics including climate change and health, physical health, food and nutrition, substance abuse, and disability or health solutions that involve technology. However, a significant proportion of stakeholders also said they felt the potential impact of involving young people is equal across all health topics that affect them.

4. Challenges to overcome when involving young people in health research

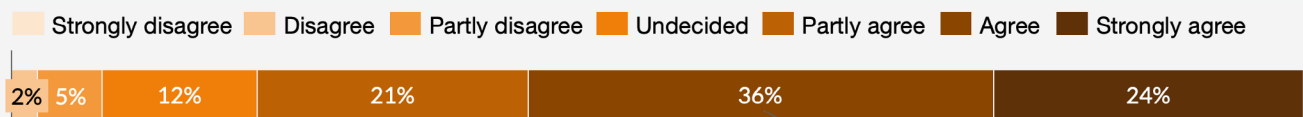
Although overwhelmingly positive about young people's involvement in health research, stakeholders and academic literature also pointed to challenges:

- **There are too few opportunities for young people to get involved in health research.**
- **It can be harder to access and sustain engagement from young people.**
- **Researchers need to employ new ways of working with young people, including working around the more rigid schedules of young people.**
- **There is a lack of training and guidelines on how young people can be involved in health research effectively .**
- **There is a lack of standardised language and methodologies for M&E of research that involves young people.**
- **An underlying driver of these challenges is a lack of support from funding organisations within the health research ecosystem.**

In addition to these challenges, working cultures in research teams are often not conducive to young people working effectively. Young people working with formally trained adult researchers find that technical knowledge is prioritised over local, contextual knowledge and power dynamics make them feel less confident to voice their opinions. Some say their opinions are discounted by adult researchers because of biases against young people’s knowledge. Most experts surveyed acknowledged that young people often face working cultures that make it difficult to have their voices heard (see figure 6).

Figure 6

Percentage of experts surveyed, by level of agreement with the statement “young people often face working cultures or team dynamics that make it difficult to have their voice heard”



Young people involved in health research projects often face working cultures or team dynamics that make it difficult to have their voice heard

In LMICs, challenges can be amplified by cultural norms, greater resource constraints and other barriers.

Fewer young people in LMICs enrol in university, where many research opportunities currently exist. The attitudes of parents and community leaders can be less supportive of young people’s involvement, particularly when trust in outside researchers is low. When research that involves young people in LMICs (especially those from disadvantaged and marginalised backgrounds) exposes social issues in a local community, researchers need to ensure that young people are not being put at risk of backlash by the local leaders. Stakeholders also reported that in some LMICs, cultural norms mean that young people have less of a say in decision-making more generally. Researchers in LMICs highlighted that systemic inequities in funding and capacity-building make it difficult to involve young people in health research.

Additional barriers also exist when trying to involve young people from a diverse range of backgrounds.

Young people from low-income backgrounds have less free time to get involved. Cultural norms on gender roles and an associated threat of violence in some geographies make it harder for women and girls to be involved. And young people with disabilities or chronic conditions are less likely to be involved in health research because their needs are not accommodated.

5. Recommendations for strengthening young people’s involvement

This analysis of academic literature and stakeholder consultations has resulted in identifying a set of recommendations to strengthen the involvement of young people in health research. These could be implemented by funders or other key leaders and influencers within the global health research ecosystem. Some of these are general whilst others are more targeted such as improving teams’ working cultures or creating scope for young people to be involved in agenda-setting at funding organisations such as Wellcome. Yet others focus on specific groups, for example, young people in LMICs or those from diverse backgrounds.

It should be highlighted that many of the recommendations may be considered as widely known solutions.

What this study offers is evidence of the opportunities and challenges that have been used to justify the choice of the particular recommendations, many of which have been suggested by stakeholders. The stakeholder consultation also offered insights on which recommendations should be prioritised. For example, the expert stakeholders from the survey

agreed more strongly with the recommendations on strengthening networks, building more evidence on the impact of young people's involvement in health research, and commitments from funders for dedicated funding to involve young people in health research.

The 10 overarching recommendations and more specific actions linked to these that could be applied across different contexts are:

- 1. Developing a new standard among funders on how young people's involvement in health research should be supported.** Effectively involving young people in health research requires additional time and resources. The first priority is to understand better the funding requirements of their involvement in different settings and different types and stages of research. This can be done by consulting experts and running pilots. Once best practices have been established, these must be mainstreamed by leading funders and health research institutions implementing them consistently.
- 2. Developing and promoting best practices on how to involve young people in health research effectively.** Key gaps in our understanding of best practices exist, including, for example, (i) how to identify the methodologies best suited to different contexts, (ii) how to compensate young people for their involvement, (iii) how to navigate around ethical requirements, (iv) how to make involvement in health research more appealing to young people, and (v) how to make involvement an interesting and engaging experience for young people. Moreover, there is a pressing need for better ways to identify and celebrate projects and institutions who are exemplars of best practice. The best practices that already exist need to be synthesised and made widely available. Gaps that remain could be filled via consultations with a diverse range of stakeholders (including young people themselves) and then adapted to local contexts. Any guidance documents and best practices need to be further tested and updated over time, and it is essential that young people are involved throughout the development and dissemination of best practices. Other ways to consider promoting best practices could include establishing a network of centres of excellence or funding a prize for exemplar individuals and institutions.
- 3. Offering training and other capacity building activities to young people and researchers on how they can work together most effectively in health research.** Once guidelines of best practice are developed, the next step will be to ensure that they are made accessible to relevant audiences and they are used in practice. The guidance, including examples of best practice, can be embedded into existing training curriculums (for example, within research skills training at university level) or can be used in standalone training programmes targeting health researchers or young people accordingly (for example, as part of the implementation of a health research project that involves young people).
- 4. Strengthening networks focused on involving young people in health research.** A number of these networks already exist but tend to operate on a small scale or are focused on specific contexts. Several key features were identified as key for strengthening existing network efforts, such as (i) opportunities for less experienced young and adult researchers to connect with more experienced adult researchers who will act as mentors to support their learning, (ii) connections to NGOs and CBOs that are trusted by young people and their local communities, (iii) channels for adult experts to connect with peers in different regions and countries, and (iv) connections between adults and young people so that young people can more easily access opportunities to be involved in health research.
- 5. Improving the M&E of young people's involvement in health research.** A lack of knowledge on how to conduct M&E effectively reduces the ability for researchers to learn from each other, prevents funders from driving accountability and limits the evidence base that demonstrates that young people's involvement delivers impact. This can be addressed by building a library of existing M&E guidelines and tools, piloting different evaluation approaches, and creating a 'how to' resource on M&E of the involvement of young people in health research. This should cover essential and ideal practices, adaptations for different activities, settings, and topics, and have examples for how to be as cost-effective as possible in M&E. This resource should be linked to the aforementioned best practice guidance and be disseminated widely. Leading health funders should be consulted during this process to understand the quality of evidence required for them to further scale up their support for involving young people in research. This insight should also inform the development of M&E resources.

- 6. Building and disseminating more evidence on the impact of young people's involvement in health research.** Significant gaps in evidence persist. Certain health topics (e.g. the health implications of global heating/climate change), experiences in LMICs, and experiences of young people from disadvantaged backgrounds are all less reported on. Separately, experts commented that some health research funders may want to see more robust evidence before scaling up their support further. These gaps may be addressed by prioritising under-reported areas in pilot projects. Furthermore, key champions are needed, such as leading health research funders who will advocate and encourage other funders to invest in research that involves young people and also incentivise researchers and research institutions accordingly. Funding can drive behaviour hence it is important for the funders to promote the value of involving young people as researchers as much as trying to lift the barriers that prevent this.
- 7. Providing support that is tailored to young people in LMICs.** It is important to support LMIC-based experts in involving young people. These specialists can then be leveraged to advise their wider national and regional ecosystems of health research. It is also important to prioritise advocacy with large health funders in LMICs as initiatives to involve young people in LMICs are more reliant on foundation support than in HICs. Furthermore, best practices must be tailored to LMIC contexts and any network-building in LMICs must ensure CBOs and NGOs with strong ties to local communities are central members, because they are more trusted than outside researchers. Influential young leaders could be identified to promote messages about involving young people in health research to their peers and any efforts should be aligned with local political and religious bodies to create a conducive environment for young people's involvement in research.
- 8. Strengthening the involvement of a diverse range of young people in health research.** When developing funding estimates for involving young people in health research, additional funding is needed to reach and involve disadvantaged and/or marginalised young people, for example, for developing trust with young people which requires time, financial resources and training. Creating partnerships with CBOs and NGOs who have well-established relationships with their communities is crucial for accessing young people from disadvantaged groups. Developing best practices specific to working with disadvantaged groups is also important, for example, on issues around remuneration or on how to avoid unintended consequences of involvement in research, such as dropping out of school to focus full-time on income-generating health research.
- 9. Building a working culture in health research that is conducive to the involvement of young people.** Young people could be involved in the decision-making process for allocating funding to health research that involves young people, for example, by flagging language which is dismissive of young people. Funding criteria and requirements should include allocating time early in projects for research teams to build rapport and establish communication and decision-making norms between adults and young people. To support healthy team dynamics, anti-bias training for researchers is important on how to identify and correct for biases that may disrupt teams. Integrating bias screening and correction tactics into best practice documents may also help. Developing best practices and training materials which advise on working with young people in a way which is sustainable and enjoyable for them is also crucial.
- 10. Involving young people in internal agenda-setting and funding decisions.** Young people are less involved in the agenda-setting stage of health research, which includes deciding the key themes, topics, and priorities of the health research. To some extent this gap can be addressed by involving young people in the funding organisations of health research. Funders and donors can make it a norm, where relevant, to consult young people in the assessment of funding proposals. A young person could be an equal member of the review panel assessing the research proposals or could be responsible for scoring different proposals on their 'youth-friendliness'. Forming an internal youth advisory council could allow young people to collaborate on decision-making with senior leadership at regular intervals. The council could also develop new ideas for ways to involve young people throughout the organisation. Holding online or in-person town halls can allow senior leadership to speak directly to and hear from large groups of young people, for example, their views on key research themes that should be prioritised in funding.

Concluding remarks

To be successful, the actions recommended by this study will need to be the work of a large collective of stakeholders committed to supporting the involvement of young people in health research. This will include academics, CBOs, NGOs and other community representatives, funders in health research and networks of experts that have been created to address this issue. There is good cause for optimism. More health research involving young people is being published today than five years ago, and an increasingly wide range of experts recognise the importance of this approach. We hope that the evidence generated by this study reinforces this momentum, while also underscoring the need for targeted investment and continued effort to overcome the challenges that go with involving young people effectively.

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