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Stakeholder consultation on involving young people in health research



2020

Dalberg

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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.

Executive summary

Background

The Wellcome Education and Learning team has commissioned a stakeholder consultation on the involvement of young people (aged 10-24) in health research³. This is part of a larger research project that also includes a rapid evidence review (RER), exploring the role, benefits and potential of young people's involvement in research in Wellcome's defined health "challenge areas" of mental health, infectious disease, and the direct health impacts of climate change⁴.

The stakeholder consultations took place in September and October 2020 and were conducted in three stages:

- 1. consultations with young people (aged 10-24) and adults of influence within their ecosystems applying the Human-Centred Design (HCD) approach and using virtual individual interviews and focus groups;**
- 2. consultations with adult experts using virtual individual interviews;**
- 3. consultations with additional adult experts through an online survey. In total 146 stakeholders across six continents were consulted.**

These consultations were used to test the findings of the RER, to fill in knowledge gaps in the academic literature and to further explore solutions to strengthen young people's involvement in health research.

Findings

Stakeholders largely agreed with findings from the RER and were able to provide more nuance and detail in areas where less knowledge is captured in academic papers.

Landscape of young people's involvement in health research today

Stakeholders reported that young people's involvement in health research is increasing over time, but that this growth should be accelerated.

Consultations with stakeholders explored how young people's involvement can be understood using a five-dimensional framework developed as part of the RER. The dimensions were health topics, stage of research, level of involvement, inclusiveness and geography. In more detail:

Health topics: Young people are involved in mental health research more than in research focused on infectious diseases or the direct health impacts of climate change. Young people stated they find the topic of mental health relevant to their everyday experiences, which might explain why they gravitate towards getting involved in research on this topic more than others. Researchers in other fields can look to their peers in mental health for examples on how to involve young people effectively.

Stage of research: Stakeholders agree with academic literature that demonstrates that young people are most frequently involved in research design and data collection. However, they also reported that young people's involvement in agenda-setting and research dissemination is higher than suggested by the RER (see more below). Guidelines on how to involve young people in health research effectively should ensure additional emphasis is placed on earlier and later stages of the research cycle, which tend to be overlooked in academic articles.

³ For the purposes of this review, 'involvement' is the term used to describe 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.

⁴ The term 'health topic' is used interchangeably with the term 'health challenge' in this report.

Level of involvement: When they are involved, young people say they tend to feel heard but would like more agency and control over critical decisions within research. This can be addressed by increasing young people's voice in agenda-setting and improving team cultures (see below for more information on these issues).

Inclusiveness: Experts reported that they found it hard to recruit young people from disadvantaged and marginalised groups but did provide some examples of successfully involving them in health research.

Geography: The RER showed less evidence of young people's involvement in health research in low- and middle-income countries (LMICs) as compared to high-income countries (HIC), and the stakeholder consultations aligned with this finding. Under-reporting of research may explain some but not all of the gap. To address this issue, and also the barriers of involving young people from diverse backgrounds, researchers could partner with organisations that are established in LMICs and have strong relationships with disadvantaged and/or marginalised groups (e.g. local NGOs working with young people from low-income backgrounds). Best practices need to be tailored to these specific settings and monitoring and evaluation needs to be stronger and more consistent. The analysis of the stakeholder views led to the development of different profiles of young people and their influences in their ecosystems in LMICs. The three profiles of young people were Confident Practitioners, Experimental Investigators, Inexperienced Enthusiasts and the three profiles of their key older adult influencers were Sceptical Gatekeepers, Community Catalysers and Experts.

When focusing specifically on how young people are involved in **agenda-setting**, stakeholders were somewhat divided. Most were confident that young people can and should be involved in agenda-setting and funding decisions. However, a minority were more cautious. They said that although they were supportive, they were less confident that some influential actors in the global health research ecosystem would be willing to involve young people in this context.

The motivations of young people and benefits of involving young people in health research

Young people are most **motivated to get involved** in health research to help others and to further their academic and career prospects. For young people from low-income backgrounds, research opportunities must address their need to earn an income now and in the future. As such, there is a need to mainstream appropriate compensation practices.

Stakeholders agreed with the RER's findings that the involvement of young people in health research can benefit research, young people involved and their local communities.

Benefits to research: The most commonly reported benefit by stakeholders was that young people understand their peers and local contexts in a way that adults cannot. In addition, young people are often trusted by their peers and communities, allowing them to do work that adults cannot.

Benefits to young people involved: Young people learn new skills and gain confidence from research. Involvement in health research gives young people a vocabulary to articulate their feelings and talk about their health challenges more openly.

Benefits to communities: Several examples were shared of young people's involvement that led to action that helped their communities. Young people also said they were able to share knowledge from their involvement in research to inform their families' decisions about health, and that involvement in research into stigmatised health topics can help them become better community advocates, educating people beyond just their families.

Stakeholders were asked to indicate themes and research questions that could benefit from **young people's involvement**.

They were largely divided. Some viewed it as important to involve young people in all health research questions that affect them, because their perspectives and lived experience as young people are important. Others viewed young people's involvement as particularly important on certain issues which they were most interested in or which affected them the most. These included topics such as mental health, sexual and reproductive health, technology, food and nutrition, and climate change.

Where more support is needed

The stakeholder consultation identified several major challenges that must be addressed to scale up young people's involvement in health research.

- There are too few opportunities for young people to get involved in research.
- Although young people are enthusiastic about health research, it can sometimes be difficult to keep them engaged with research projects over a sustained period. Stakeholders also acknowledged the challenge of working around young people's more rigid schedules.
- There is a lack of training and guidance materials on how to involve young people effectively. Stakeholders also expressed an interest in having access to wider networks, so that they can learn from peers operating in different contexts.
- Several experts singled out weak monitoring and evaluation as a critical blind spot across young people's involvement.
- An underlying driver of these challenges is a lack of support from funding organisations within the health research ecosystem.
- Team cultures hinder the effective involvement of young people in health research, due to biases among adult researchers.
- Stakeholders reported involving young people from diverse backgrounds as a challenge. 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 get involved. And young people with disabilities or chronic conditions are less likely to get involved in health research because researchers fail to accommodate their needs.

When looking at **challenges that are more likely to exist in LMICs**, several additional factors were cited by stakeholders. They said young people can be harder to access in these contexts, that cultural norms can make them less likely to take part, and that trust-building can be a bigger challenge. Stakeholders also said that systemic inequities in funding and capacity-building make it difficult to involve young people in health research in LMICs.

Recommendations for Wellcome

A series of recommendations for Wellcome have been developed, and potential partner organisations to consider have been identified by the stakeholders. These are based on the opportunities and challenges that have been indicated through the RER and the stakeholder consultation and in summary are:

- 1. develop a new standard among funders on how young people's involvement in health research should be supported;**
- 2. develop best practices on how to involve young people successfully;**
- 3. connect and formalise existing networks focused on involving young people in health research;**
- 4. strengthen and standardise M&E practices;**
- 5. support the generation and dissemination of evidence to fill gaps and garner more support across the research community.**

Experts surveyed were most strongly in favour of connecting and formalising networks (#3), followed by establishing dedicated funding for young people's involvement (#1).

Recommendations were also developed for Wellcome to actively support the **involvement of young people in health research in LMICs**. Much of these focus on which stakeholders to bring into the conversation: LMIC-based

experts; large health funders focused on LMICs; NGOs and local religious and political bodies with strong community networks; young leaders and influencers. Engaging groups will be essential when scaling up young people's involvement effectively. Moreover, best practices need to be adapted to these settings. Similar recommendations apply to how to ensure **research that involves young people is inclusive**. NGOs can help reach young people from disadvantaged or marginalized backgrounds. Guidelines must also be tailored to working with these groups.

Particular attention was paid to how Wellcome can create **conducive working cultures** in teams for young people to work effectively. Developing and institutionalising training materials which identify and help address bias against young people and promote a sustainable and enjoyable research culture for all would help contribute towards this aim.

When looking at **how Wellcome might involve young people in internal agenda-setting and funding decisions**, recommendations focused on finding engaging methods to listen to and involve young people in various activities of a funder. For example, involving young people in the assessment of funding applications, establishing a youth advisory council, and using town halls for senior leadership to speak with young people directly.

Glossary

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

Civil Society Working Groups are a means for engagement and a platform for diverse groups of civil society to voice their concerns, share ideas and experiences, and dialogue with an organisation on a wide range of issues topics (adapted from World Bank, 2017).

Community Advisory Board (CAB) “is a type of advisory board consisting of representatives of the general public who meet with representatives of an institution to relay information between the two groups” (Oxford University Clinical Research Unit, 2020).

Community-Based Participatory Research (CBPR) is an approach to research that values the role of community members as equitable partners and acknowledges the importance of building partnerships with the people that ultimately are targeted by research efforts (Israel et al., 1998).

Human-Centred Design (HCD) “is the process of integrating human perspectives in all steps of the problem-solving process. The process aims to better understand an issue from the human perspective and focuses on how it looks and feels to users and stakeholders within their environment and context. This understanding informs the iterative development of concepts designed to address a problem” (Design for Health, 2020, p. 20).

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 (adapted from INVOLVE, 2012).

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.

Monitoring and Evaluation (M&E) is used to “assess the performance of projects, institutions and programmes” and “to improve current and future management of outputs, outcomes and impact” (ASCEND International, 2020).

Participatory Action Research (PAR) seeks to bring about change by involving both researchers and participants in an iterative approach to research. “The reflective process is directly linked to action, influenced by understanding of history, culture, and local context and embedded in social relationships The process of PAR should be empowering and lead to people having increased control over their lives” (Baum et al., 2006, p.854).

Participatory Health Research (PHR) is an approach in which those people whose life or work is the subject of the research influence the research process from deciding the topic of the research to the dissemination of the findings. PHR seeks to describe and explain health problems and their causes, and to bring social change for the benefit of people’s health (adapted from International Collaboration for Participatory Health Research, 2013). PHR is emerging as an umbrella international term for research into health or health care issues (Abma et al., 2017). The term is often used interchangeably with the terms community-based participatory research or participatory action research.

Rapid Evidence Reviews allow for a “structured and rigorous search, as well as a quality assessment of the uncovered evidence, but are not as extensive and exhaustive as a systematic review. They often provide a brief summary of the evidence discovered, so that informed, evidence-based, conclusions can be drawn” (Manchester Metropolitan University Library, 2020).

Tokenistic involvement in research is when it limits young people’s expression of views or when it allows young people to be heard but fail to give their views due weight (United Nations, 2009, paragraph 132)

Translation of knowledge in health research is a “dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of people” (Canadian Institutes of Health Research, 2020).

Young Person’s Advisory Group (YPAG) is a method of implementing co-production with young people in health research through advisory groups that provide a forum for young people to collaborate with and support researchers. “Some YPAGs play a more consultative role (for example, improving the quality of information sheets), whereas others take on a more active, collaborative role in shaping the research. For example, they may collaborate with researchers in setting priorities for research, developing tools, writing, etc.” (Pavarini et al., 2019, p.744). The term is often used interchangeably with the terms Youth Advisory Board and Youth Advisory Council.

List of Acronyms

APHRC:	African Population and Health Research Centre
BERA:	British Educational Research Association
CAB:	Community Advisory Board
CBO:	Community-Based Organisation
CBPR:	Community-Based Participatory Research
GDPR:	General Data Protection Regulation
HCD:	Human-Centred Design
HICs:	High-Income Countries
IFMSA:	International Federation of Medical Students Association
LMICs:	Low- and Middle-Income Countries
M&E:	Monitoring and Evaluation
NCB:	National Children's Bureau
NCD:	Non-Communicable Diseases
NGO:	Non-Governmental Organisation
PAR:	Participatory Action Research
PHR:	Participatory Health Research
RER:	Rapid Evidence Review
SES:	Socio Economic Status
SRHR:	Sexual and Reproductive Health Rights
TB:	Tuberculosis
WHO:	World Health Organization
YPAG:	Young Person's Advisory Group

Introduction

Project context

Wellcome is an independent global charitable foundation that supports science to solve the urgent health challenges facing everyone. Wellcome supports discovery research into life, health and wellbeing and is taking on three worldwide health challenges: mental health, global heating⁵ and infectious diseases. It is a politically and financially independent foundation.

Wellcome is interested in exploring the potential role young people can play in its newly launched strategy. In particular, the Education and Learning team at Wellcome has commissioned research to investigate the potential of young people's involvement in health research, with a particular focus on the challenge areas of mental health, infectious disease, and the direct health impacts of climate change. The geographic scope of this work extends to the UK and low- and middle-income countries (LMICs). The research was carried out with the support of Dalberg, a global mission-driven advisory firm focusing on social impact.

For the purposes of this research, 'involvement' means research that is done 'with' or 'by' young people, as opposed to 'for', 'about', or 'on' them (adapted from NHS Health Research Authority, 2020). Young people can contribute to research through 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. Moreover, this review has adopted the World Health Organization (2011) definition of 'young people' which covers the age range 10-24 years. We acknowledge that the terms young people, youth, adolescents etc. may be used interchangeably or defined differently.

The research included two phases.

- 1. A rapid evidence review (RER) of academic research published in peer-reviewed international journals from 2005-2020, focusing on young people's involvement in health research. The RER identified strengths, weaknesses and gaps in the literature and developed a framework for young people's involvement in health research.**
- 2. A stakeholder consultation on how young people can be most effectively involved in health research and how Wellcome can best support them. This report concentrates on the health topics mentioned above, while applying a wider scope when relevant to capture insights that might be transferable to different contexts.**

The RER has been published separately. This report presents the findings of the stakeholder consultation.

The key questions that that guided the stakeholder consultation are:

- 1. To what extent do stakeholder's views and related experiences align with the findings of the rapid evidence review?**
- 2. What can Wellcome do to enable young people to be meaningfully involved in health research?**
 - How can young people be involved in agenda-setting and funding decisions at Wellcome across its three challenge areas?
 - What are the key themes and research questions on health and the three challenge areas that could benefit from young people's involvement and are relevant to young people?
 - What new insight/evidence is needed to increase and improve young people's involvement in health research in general and in the health challenge areas in particular?
 - What barriers exist in LMICs that prevent young people from being involved in health research? How can these be addressed?

⁵ 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.

- e. How can Wellcome ensure that a diverse range of young people (in terms of gender, socioeconomic status, ethnicity, and ability) are involved in health research?
- f. How can Wellcome ensure a research culture where young people involved in health research feel they are treated ethically and with respect, they are supported to make their contribution and are acknowledged for their contribution?
- g. Who would be the key agents/stakeholders to be engaged in the implementation of the future work?
- h. What can Wellcome do to work with partners to catalyse young people's involvement in health research?

To address these questions, this report is laid out to discuss sequentially the methodology, findings, and recommendations. Each chapter starts with a summary providing an overview of the content of that chapter. Chapter 1, the methodology, discusses how the consultations were conducted. Chapter 2 discusses how the stakeholders that were consulted involved young people or were involved themselves with health research where young people played a role, and how this varies across different topics, geographies, and demographics. This chapter also provides answers related to the first research question. Chapter 3 discusses the benefits of involving young people in health research, including benefits for the research project, their communities, and for themselves. In doing so, it also addresses the key themes and research questions where young people provide the most benefit. Chapter 4 discusses where stakeholders feel more support is needed to overcome the barriers to involving young people in health research. Chapter 5 presents recommendations for how Wellcome can provide support to increase and improve young people's involvement in health research. In the Annex, the reader can also find additional information related to the methodology and the stakeholders who were consulted.

1. Methodology

The stakeholder consultations took place in September and October 2020. The consultations were conducted in three stages:

1. consultations with young people (aged 10-24) and adults of influence within their ecosystems applying the Human-Centred Design (HCD) approach and using virtual individual interviews and focus groups;
2. consultations with adult experts using virtual individual interviews; and
3. consultation with additional adult experts through an online survey. All interviews and focus group discussions for the consultations were run online due to the geographically dispersed nature of participants and the travel restrictions related to the ongoing COVID-19 pandemic.

Below, there is a description of the HCD approach and methods including a presentation of the background of the different stakeholder groups and how they were identified. During the identification and selection of participants emphasis was given to ensure stakeholders from LMICs were represented. All stakeholders participating in the consultations with young people were from LMICs (India, Indonesia, Kenya, Senegal, South Africa, Vietnam), 28% of the adult experts interviewed were from LMICs, and more than half of the expert survey respondents were from LMICs.

Table 1:
Number of stakeholders from each country

Country where the stakeholders are based/working in	Number of young people and adults of influence interviewed	Number of adult experts interviewed	Number of adult experts responded to the survey	Total
Bangladesh			1	1
India	11	1	11	23
Indonesia	10			10
Philippines		1		1
Thailand			1	1
Vietnam	6		3	9
Australia		2	2	4
Kenya	7	2	9	18
Malawi			1	1
Rwanda			1	1
Senegal	8		1	9
South Africa	13	5	5	23
Zimbabwe			1	1
Switzerland		2		2
UK		7	18	25
Argentina		1		1
USA		7	5	12
Canada		1		1
Stated various countries			3	3
Total	55	29	62	146

ETHICAL CONSIDERATIONS

The commissioning of this research required adherence to existing ethical guidance including the BERA (2018) Ethical Guidelines for Educational Research, DFID's (2019) Ethical guidance for research, evaluation and monitoring activities and The Nuffield Council on Bioethics (2020) Research in Health Emergencies: ethical issues. These were adhered for all the individuals who participated in the consultation. In addition, the research complied fully with GDPR and Wellcome's Data Protection and safeguarding standards.

Throughout this report, the names of the participants have been changed to ensure their anonymity. The positions and institutions of the experts interviewed are included in an anonymised list in Annex 3.

In relation to the young people in particular, the research team identified potential risks associated with the safeguarding of the young people and took additional steps to mitigate them. These potential risks included emotional harm due to a breach of privacy, a lack of full consent, exposure to distressing materials, and a lack of sensitivity and support demonstrated by the research team members. The mitigating actions that were taken included collecting and recording consent in advance of participation, providing a clear explanation to young people of the purpose of this research, and making participants aware that they may end their participation at any stage of the session for any reason. The full project team, including members of Wellcome, could review research materials for sensitivity. Informed consent was sought from all young people and their guardians (for participants under the age of 18).

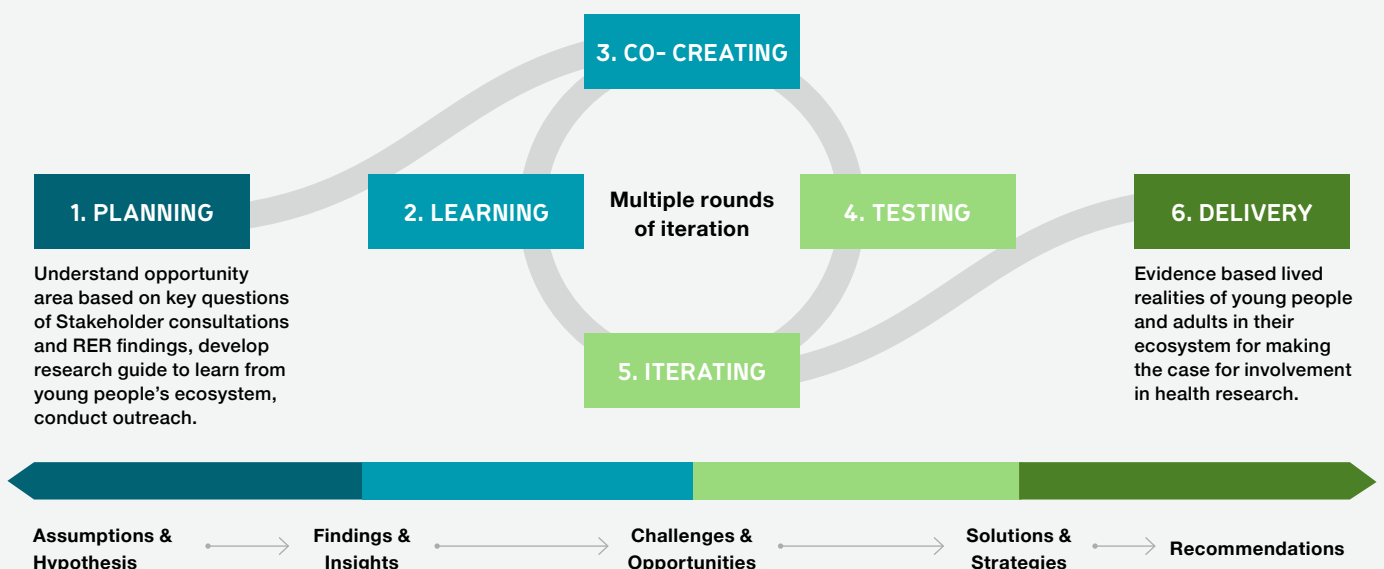
The three stages of the consultation including the approaches and methods used, are outlined in detail below.

1.1. HCD consultations with young people and adults of influence from their ecosystems

APPROACH

HCD is an interdisciplinary research, design, and creative facilitation methodology that engages stakeholders across an ecosystem. The HCD process is flexible and built to produce evidence-based strategies and policies, as well as robust user-tested products, services, and programmes. The HCD research approach, enables researchers to gain deep empathy for users, to question core assumptions, and inspire new solutions. The goal is to uncover insights through in-context observations of users, and learning from what they say, think, feel and do. Dalberg's approach to HCD is outlined in the graphic below.

Figure 1:
HCD methodology followed during the project



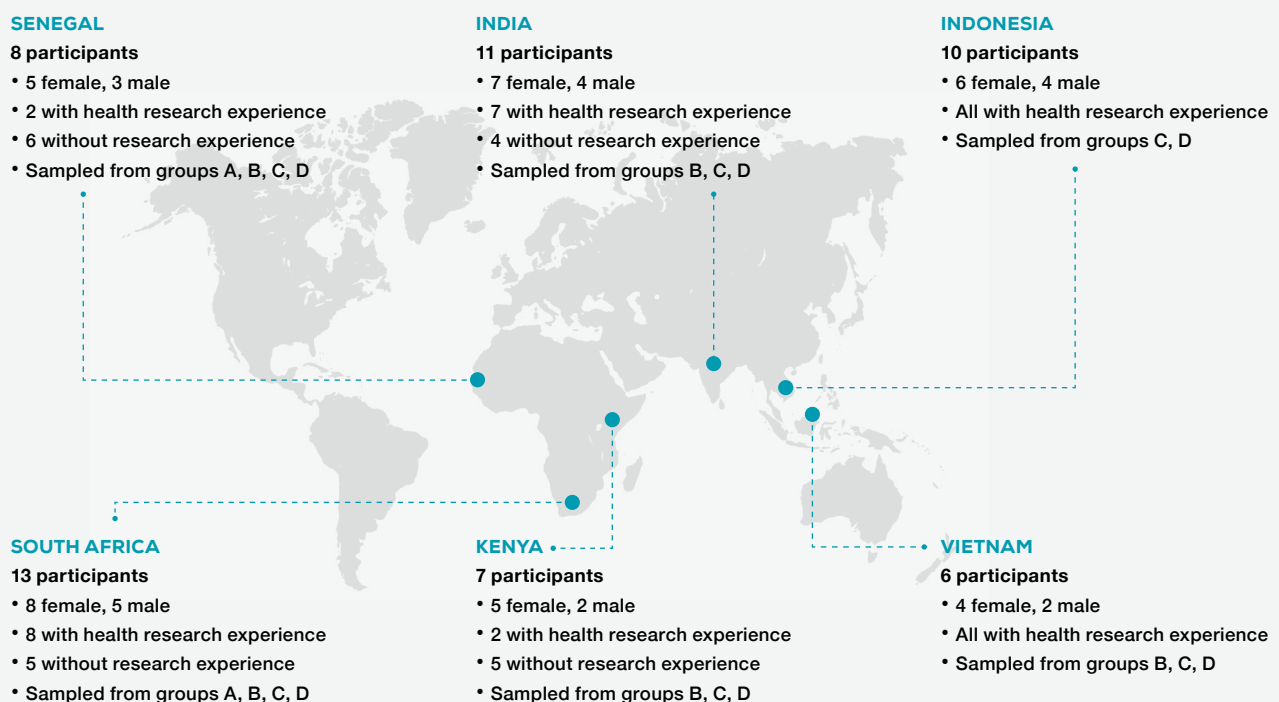
The HCD methodology was applied in 31 sessions (12 focus group discussions and 19 individual interviews) with a total of 55 participants (40 young people and 15 adults of influence from young people’s ecosystems). The sessions lasted between 1 to 1.5 hours. These adults of influence consisted of health workers, youth leaders, community leaders, researchers that work with young people and parents. Participants were identified through a series of methods including direct outreach from Dalberg and Wellcome networks as well as outreach through Community Based Organizations (CBOs) and local health and research organizations. Out of all the participants identified, only one participant declined to show up for a focus group discussion.

SAMPLING

Six LMIC countries across Asia and Africa (Senegal, South Africa, Kenya, India, Vietnam and Indonesia) were selected with the aim to achieve as diverse a mix as possible across income level, religio-cultural context (e.g. including both majority Hindu, Muslim and Christian countries), language (particularly in Africa, ensuring representation from anglophone and francophone countries) and country size (see figure 2). To ensure the diversity of the sample of young people who participated in the HCD stage, inclusion criteria were developed for the selection process, around gender (targeting a mix of male and female), location (targeting young people from rural, urban and peri-urban areas), range of education levels, range of experiences with research (from no experience to leading health research) and age (young people within the ages of 10-24 years). Due to the wide age range of the young people and varied experiences between young people and adults in their ecosystem, participants were divided into age sub-groups that informed the types of questions that were asked in the sessions and also to ensure participants were feeling comfortable. These groupings took into consideration maturity, independent thinking, comprehension and experience with research. The age subgroups are outlined below:

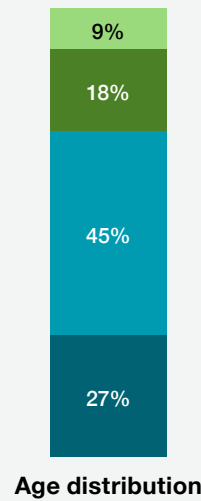
- **Group A:** Early adolescence- age 10-14 (has strong parental oversight and influence).
- **Group B:** Middle adolescence- age 15-17 (growing into independence, beginning to form opinions).
- **Group C:** Young adults- age 18-24 (fairly independent, confident and likely to have opinions).
- **Group D:** Influential adults- Health workers, youth leaders, community leaders, adult researchers, parents, etc.

Figure 2:
Socio-demographics of young people and adults of influence from their ecosystems



Sample key for group

- A: Early adolescence: Age 10-14**
Has strong parental oversight and influence
- B: Middle adolescence: Age 15-17**
Growing in to independence, beginning to think abstractly
- C: Young adults: Age 18-24**
Fairly independent, confident and likely have opinions
- D: Influential adults: Age 25+**
Health workers, youth leaders, community leaders, adult researchers, parents



22

Experience with health research

33

No experience with health research

REMOTE INTERVIEWS AND FOCUS GROUPS

Interviews and focus groups were scheduled based on participant availability and access to digital communication tools. In order to conduct remote research during the COVID-19 pandemic, different digital platforms, such as Zoom, Skype and WhatsApp, were used for the interviews and group discussions, depending on participant familiarity and access. All sessions were led by members of the Dalberg team and had at least two team members present. Translators were commissioned for sessions where participants did not speak English or preferred to use another language. In line with the HCD approach, participants were encouraged to drive the beginning of the conversations by talking about themselves and their experiences, allowing them to get to a natural level of comfort with the conversation. This approach minimised the risk of low levels of interpersonal rapport, which is easier to achieve during face-to-face interactions. Younger participants were allowed to have parents or chaperones that they trusted in the sessions, if they so wished, although it was recognised that this could bias some of their responses.

REIMBURSEMENTS

All participants were reimbursed a total amount of US \$15 each as compensation for their time used to engage in the 1 or 1.5- hour sessions. Donations of US \$200 were also made to the CBOs that provided access to some of the young people that participated in the consultation.

1.2. Expert Interviews

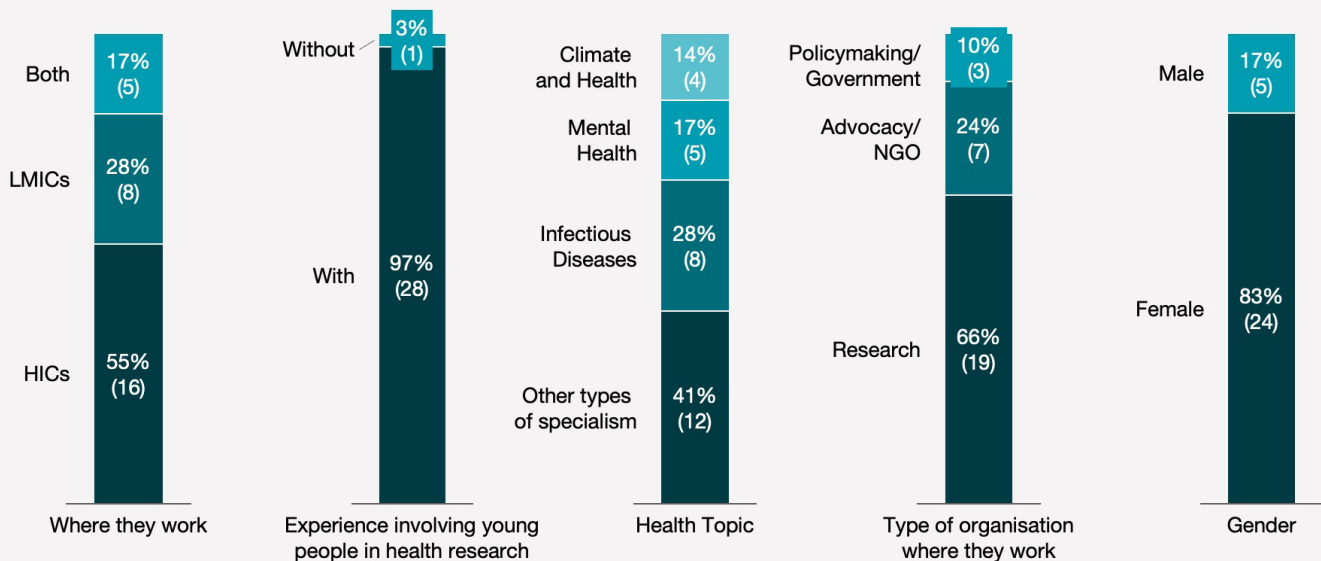
29 experts were interviewed who had experience relating to health research involving young people. The experts were selected in three ways:

1. **researchers who had written papers included in the RER;**
2. **experts who were known to Dalberg or Wellcome;**
3. **experts who were identified through online searches.**

52 individuals were contacted in total. Five declined and 18 did not respond. Interviews were conducted online, lasted 45-60 minutes and were led by 1-2 members of the Dalberg research team. Interviews followed a semi-structured

approach and used questions designed to answer the key research questions of the stakeholder consultation (see Introduction). All interviews were conducted individually, with the exception of one interview which involved two researchers together who had worked very closely. The positions and institutions of interviewees is available in Annex 3, and Figure 3 provides an overview of the interviewees' background. The interviewees' position in their organisations varied from being a member of the governing board, executive director, head of research department and professor to being a postdoctoral researcher, technical officer, senior advisor and manager.

Figure 3:
Background of adult experts interviewed



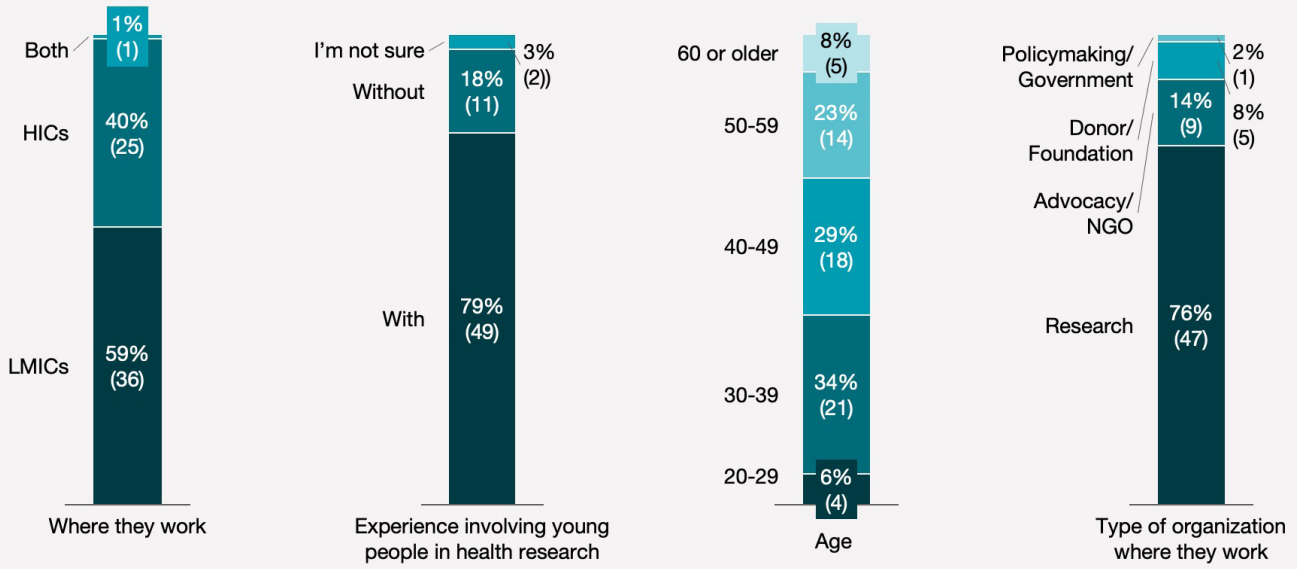
1.3. Online survey of adult expert stakeholders

The consultation also included a survey of adult experts who had experience relating to health research involving young people, although not all of them had direct experience working with young people. The survey was disseminated to 155 adult experts and received 62 responses. Apart from age, detailed sociodemographic characteristics of the respondents were not collected to protect their anonymity. The recipients of the survey were identified in four ways:

1. **individuals in the global health research ecosystem with relevant experience who were known to Dalberg and Wellcome;**
2. **individuals mentioned by interviewees in the expert interviews;**
3. **individuals identified through online searches; and**
4. **individuals who had contributed to research included in the RER.**

The survey was conducted online and in the English language. A full list of survey questions is available in Annex 4 of this report. Figure 4 gives an overview of the respondents' background. It should be also noted that the experts varied in terms of their seniority in their organisations from being the Vice president or director of the organisation, professor, and head of department, to being a research fellow, PhD student, manager, coordinator, and officer.

Figure 4:
Background of adult expert survey respondents



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

CHAPTER SUMMARY

Consultations with stakeholders explored how young people's involvement can be understood in terms of five dimensions: (1) Health topics (2) Stage of research (3) Level of involvement (4) Inclusiveness (5) Geography. On each of these dimensions, consultations revealed how the landscape of young people's involvement in health research looks today.

- 1. Health topics:** Young people are involved in mental health research more than in research focused on the other health topics.
- 2. Stage of research:** Stakeholders agree with academic literature that finds that young people are most frequently involved in research design and data collection. However, they also said that young people's involvement in agenda-setting and research dissemination is higher than suggested by the RER.
- 3. Level of involvement:** When they are involved, young people say they tend to feel heard but would like more agency and control over critical decisions within research.
- 4. Inclusiveness:** Experts reported that they found it hard to recruit young people from disadvantaged groups but had several examples of successfully involving them in health research.
- 5. Geography:** The RER showed less evidence of young people's involvement in health research in LMICs, and insights from stakeholder consultations suggest this is accurate.

This landscape represents opportunities and challenges. Health researchers looking to involve young people can look to their peers in mental health for examples of how to do this effectively. When developing guidelines on how to involve young people, existing academic literature can act as a good starting point, but special attention needs to be paid to areas that are overlooked in this literature: early and late stages of the research cycle; involvement in LMICs and involvement of young people from disadvantaged groups. And to address young people's lack of agency in some research, there are ways to improve team cultures and create space for young people to play a role in agenda-setting, both of which would help them have their voices heard.

Experts interviewed agree with findings from the academic literature, which indicate that the frequency of young people being involved in health research is increasing over time. There was a consensus among experts that the body of evidence is growing, which aligns with the findings from the RER. More than half of academic articles published about involving young people in health research between 2005 and 2020 have appeared in the past five years.

Across all health challenge areas, young people are more likely to be involved in research on health issues which have a greater impact on young people or related to social stigma. Young people are more likely to be involved in research of health issues which affect them because they can influence how researchers discuss or approach health topics to make them more relevant. An expert in the health effects of climate change explained

“Young people are involved in mental health research because a lot of young people develop mental health conditions in adolescence. But the climate change and health aspect does not yet have a specific ‘patient’ and has not yet identified young people as more at-risk of climate health issues than other people.”

Additionally, young people are effective at reducing stigma around health problems as they tend to be more open to reducing social injustices and are therefore consulted for research on diseases with high stigma. For example, young people are involved more in HIV research than research on other, less stigmatised, infectious diseases.

2.1. Young people's involvement across each health topic

2.1.1. Mental health

Young people are involved in mental health research more than in research focused on the other health topics.

Interviewees' views aligned with RER findings that many more articles focused on young people's involvement in mental health research than in infectious diseases or the health effects of climate change. Experts felt that this was 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.

Young people said they find the topic of mental health relevant to their everyday experiences, which might explain why they gravitate towards getting involved in research on this health topic more than others. Young people are deeply aware of the mental health challenges they and their peers face, even when they lack the vocabulary and outlets to talk openly about it. Personal experiences with mental health drive young people's interest in research on this topic. Young people are then able to deploy the vocabulary, tools and mechanisms that they learn during research to normalise conversation on otherwise taboo topics within their immediate ecosystem. James⁶, a 15-year-old secondary school student in Kenya, shared the following about young people's daily life experiences

“Most of us at this age are trying to cope with mood swings. Some people are very emotional, so you have to be careful when you are speaking to them. Others are easily triggered, can become angry, especially during sports, or when a teacher is favouring a certain pupil”.

Mina, a 21-year-old college student from Mumbai, India, decided to work on the topic of stress as a research fellow with a CBO.

“I have to manage my studies, my family, this youth fellowship. This was creating so much pressure. There are many like me who also have to earn money as their families are not financially stable. We ... [research fellows] realised that this is a common experience for many people like us. These were the things that made us select this topic... [stress and mental health].”

In the field of mental health, stakeholders said they had mostly seen young people's involvement in research design, data collection, and dissemination. This is similar to the RER's findings, although the academic literature reported less on young people's involvement in dissemination activities than interviews with young people and adult experts revealed. Interviewees also reported some examples of bringing in young people to the agenda-setting stage. For example, a mental health researcher explained that she had brought in young people from the beginning of the research when they had very few plans for what they would research, and the young people helped shape the research. However, young people's involvement at this stage was stressed as unusual, and experts agreed that it happens less frequently than involvement at other stages, for two reasons. Firstly, because young people need a certain level of knowledge to do agenda-setting, which is rare among most young people and requires significant training. Secondly, because when researchers are deciding their research agenda, they typically don't have funding yet, so there is no guarantee that their work will go ahead (see section 2.2 for more on young people's role in agenda-setting).

2.1.2. Infectious diseases

A significant proportion of infectious diseases research is clinical, which has historically involved fewer non-technical individuals (including young people). Laboratory-based research often involves individuals working with biohazardous agents including infectious particles. This research requires lengthy training to be conducted safely and is widely perceived by experts as a less appropriate context in which to involve young people. It is also perceived as a less accessible discipline for young people, in comparison to other health topics, because of the technical nature of skills required and the length of time needed to learn them. Clinical research is often more fast-paced than qualitative research, so clinical researchers often find it harder to invest the time in involving young people.

6 All the names of the consultation participants have been changed to ensure anonymity.

Young people’s involvement in infectious diseases research tends to be in a non-clinical setting and in multiple stages of research. Researchers provided several examples of how this occurred in their own work, where young people were involved in leading data collection or advocacy so that approaches were better tailored to other young people or their surrounding communities. For example, one adult researcher described how young people designed the questions and led the data analysis for a focus group in East Africa. The focus group discussed the themes emerging from a trial investigating the link between payments to women and HIV prevalence. The researcher running the HIV research programme explained

“They [young women] grouped things together into different themes, and organised and sorted the risks and barriers for HIV prevention. Young people were the researchers, they designed the questions and analysed the data through community-based participatory research (CBPR)⁷.”

Young people’s involvement in infectious diseases research often focuses on sexual and reproductive health as it helps increase community knowledge and reduce stigma. When asked where young people’s involvement could make the greatest impact, experts surveyed frequently pointed to sexual and reproductive health. Multiple experts interviewed told us how they had involved young people in research on sexual and reproductive health to help navigate the challenges of working on highly stigmatized health issues and the misinformation that can come with that.

2.1.3. Health implications of climate change

The health impact of climate change is a nascent field of research, which explains why young people are less likely to be involved in it. Experts reported that there was very little activity in this topic of research, aligning closely with the RER findings. This is particularly true in LMICs. People who did work in climate and health were not specialists in this area, but more public health experts who occasionally touched on this topic. While it is uncommon, experts were strongly in favour of young people being involved in this field of research. An expert from a climate and health advocacy group argued

“Young people have an enormous role to play in the climate change-health research nexus. They are the generation that will most suffer from the impact of climate change. They bring ‘useful impatience’ and energy and do have the skills to contribute.”

Young people who were interviewed as part of validating the consultation findings also highlighted that the link between health and climate change is not a topic widely discussed as part of the environmental advocacy activities. It was also suggested the need to raise awareness about the effect of climate change on health by disseminating accessible information through digital channels so that young people can be involved in this area.

Interviews identified a small number of examples of young people’s involvement in research projects regarding the health effects of climate change. The WHO Climate Change and Health Civil Society Working Group involves young people from the International Federation of Medical Students Associations (IFMSA) in their current research project. The project is a review of evidence relating to the health effects of climate change. Interviewees reported that the students are appreciated because they are eager and more motivated to work on this topic than adults. However, the young people did not influence the research questions on this study and are only screening papers for the review.

Young people are more commonly involved in advocacy related to the health effects of climate change, and their voices are recognised as being particularly powerful here. Experts emphasised the importance young people could play in advocacy and activism roles related to the health effects of climate change and noted that this is where they were most frequently involved. In the climate and health advocacy space, experts recognised young people as skilled, effective, and using their voices as powerful advocacy tools. An expert in climate change and health explained

⁷ For a definition of CPBR see glossary

“[Young people] are a part of the climate change generation. They are organised and competent. They bring a useful impatience and energy of youth that you don’t get elsewhere. They’re willing to [call out] political leaders [and tell them] ‘this issue needs to be addressed’.”

Another expert in climate change and health stated

“[Young people] bring a tremendous amount of sincerity and authenticity to these conversations... they are never doubted or suspected.”

2.2. Young people’s involvement across different stages of research

Young people are most likely to be involved in research design and data collection. The RER found that young people are most commonly brought into the middle stages of research cycles - research design and data collection. Stakeholders confirmed this and provided several examples of this from their own work. One researcher working on infectious diseases in an LMIC spoke about how young people took part in focus group discussions to develop a play about tuberculosis transmission in a community. The young people were involved in designing the intervention (i.e. the research design phase) by informing the main themes and the script for the play. Some experts also spoke about young people’s involvement in data collection. For example, a policymaker at an international organisation who has conducted research, talked about how young researchers were better at collecting data because young research subjects were more comfortable talking with people their own age. Aisha, a 24-year-old youth leader and mental health documentary filmmaker from Dakar Senegal, shared what she believes is limiting young people to data collection roles may signal

“I think that when involving young people in research it’s important to view them as co-researchers instead of a means to an end. By doing this, you would be confirming that our contributions are valuable.”

It should be also noted that other young people who took part in the consultation suggested that field work was the most interesting part of their involvement in comparison to attending meetings organised by adults that were about information dissemination. They explained that they enjoyed collecting data in the field as it made them feel they ‘participate’ more actively.

Consultations also reported examples of young people being successfully involved in dissemination of findings. This is a stage of research that was found to be less commonly reported in the RER. A policymaker at an international organisation, explained the powerful dissemination capabilities of young social media influencers she had met at a youth forum event. The young influencers’ posts on social media, discussing sexual and reproductive health issues reached tens or hundreds of thousands of people. This compares to typical campaigns at the interviewee’s organisation that are seen as successful if they reached only 5,000 people.

When asked specifically about young people’s potential involvement in agenda-setting, some experts advocated strongly in favour. Experts across countries and specialisms voiced their support of young people’s involvement at the agenda-setting stage, arguing that it allows young people to be more meaningfully involved in research by influencing the direction and purpose of research, not just how it is implemented. Almost nine out of ten experts surveyed agreed to some extent that young people should be involved in agenda-setting (see figure 5). Stakeholders emphasised the benefits brought to the research project by having young people involved from an early stage. For example, young people bring a better understanding of the existing efforts in their communities to address issues related to the topic being researched. Some of the experts surveyed added that young people should be also designing their involvement in agenda-setting; and should know what will be required of them and what to expect in return. An expert highlighted the need for securing sufficient funding

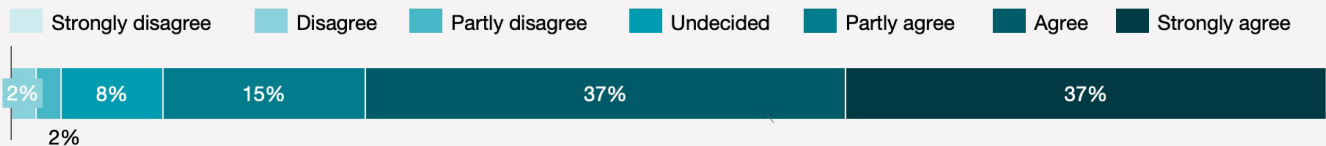
“Involve young people in planning, design, and implementation. Most research fails to adequately budget for meaningful understanding of what’s happening on the ground.”

Another expert argued

“Talk to young people about how they might want to be involved (in agenda-setting), what the mutual benefit would be, what the mechanisms for engagement should look like and how the organisation will know when it’s ‘not working’ for the young people.”

Figure 5:

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



Young people can play an active role guiding the strategy/agenda-setting of health research institutions and funders, including funding decisions

Other experts, while positive about the potential impact of involving young people in agenda-setting and funding stages, had concerns about the feasibility of doing so. Some experts were concerned about the ability of organisations to adapt to allowing young people to have a say in high-level decisions. Other expert interviewees pointed to the restrictive requirements from funders as an explanation for the lack of young people in the agenda-setting stage. Funders for biomedical research are typically more prescriptive about the uses of their funds, as this type of research is extremely expensive. An adult researcher explained

“[Agenda-setting] is quite a high-level stage and it is not open to community involvement at all. I think leadership would love the idea of a youth community advisory board on paper, but in practicality they would not let youth have much of a say in research funding.”

Stakeholders are generally aligned that young people should be involved across all different research stages.

The majority of experts agreed that young people should be involved at each stage of research, to gain the range of benefits of young people’s inputs, and to make their input equal to that of adult researchers. However, one academic did also say that whilst young people’s involvement should be considered at each stage of research, it should not be assumed as appropriate on every occasion. The academic highlighted

“The appropriate level of involvement must be assessed through rigorous methodological processes and depends on the question researchers are trying to answer.”

A policymaker suggested

“[It should be about] co-creation [and a] partnership of equals. Young people should be part of the whole process and allowed to choose which stage they want to be involved in. They should be able to assert themselves in the whole spectrum of an initiative (policy-making, community activism, etc.).”

In-depth interviews with young people revealed that achieving positive outcomes for the community (for example, developing better ways to talk about mental health) is a key motivator for being involved in research. They see value in deep involvement, across various stages of research, as opposed to being compartmentalised in stages like data collection. Agung, a 24-year-old user-experience and mental health researcher from Banten, Indonesia, expressed her desire to translate research findings into interventions that the community needs

“I really want young people like me to be involved in more than just doing research for ... [the sake of] making a journal. I want to be involved in events or activities based on research findings, that help the communities we are doing research in, because I think I can contribute more that way. Most issues on the mental health of young people need urgent attention. Instead of making research a process of gathering information and publishing journals, we can make it an activity or intervention that ... [actually] helps the communities that the information comes from.”

Cherise, a 23-year-old in South Africa who was involved in data collection for the local government’s COVID-19 response research, expressed her dissatisfaction with not being involved in the data analysis

“I took the data so I have to see if they verified the information correctly. What if the information I took was misjudged or was not put in the right view? I know it is the government and they do not make everything public, but the analysis should be at least knowledgeable to me. They could even just send me the final product to see if it was evaluated correctly. You use the local people, so let the local people see what was done!”

2.3. Young people’s level of involvement and influence in health research

Young people stated that they would like more agency and influence over decision-making. Among young interviewees, those who do not have formal training in research said that they are usually involved in phases like data collection, which require less creative contribution and more physical work. This makes their experience with research unstimulating and extractive. Young people feel involved when their understanding of the community’s context shapes research questions. They are also keen on being part of the process when research findings give rise to outcomes that directly impact the community. However, adult researchers tend to set meeting agendas and organise activities that use academic format. As a result, young people feel uninspired, not welcomed and not motivated to contribute. Cherise, a 23-year-old COVID-19 response researcher and youth leader from South Africa, believes she was left out of the analysis phase because she lacks what she describes as professional skills. In more detail she explained

“When [adult] researchers come together and evaluate, the local people [like herself] who did the research should be a part of those meetings. Isn’t it better to get a first-word opinion than a second opinion from someone who heard about it? I do basic health research. But when it comes to analysing, I do not have the full amount of knowledge to drive the statistical part. All I have is the knowledge of the community.”

Marie, a 21-year-old researcher and Community Advisory Board (CAB) member for a tuberculosis (TB) research group in the Western Cape, South Africa shared her frustration on the approach adult researchers took to involve young people

“Those meetings are so long, they [adult researchers] should do a PowerPoint, keep it short and nice, pictures, something we can touch and see. If you give us a lot of files and papers to read, we won’t do it. Always make young people feel valid. Ask us questions and let us know that there is nothing like a ‘dumb’ question.”

Stakeholders views align with RER findings that young people tend to have some influence in decision-making, but less than adults. Evidence from the RER shows that young people are typically less involved as true collaborators with decision-making power and influence. Instead, they are mostly listened to and consulted by adults, who take young people’s opinions into account in decisions, but continue to control the direction of work and are not held accountable for factoring in young people’s views.

2.4. The diversity of groups of young people involved in health research

Experts reported that they found it hard to recruit young people that face disadvantages and/or are marginalised but had several examples of successfully involving them in health research. Several researchers explained that they found it challenging to identify participants from marginalised and/or disadvantaged groups. They

often work with gatekeepers in the charity sector to recruit them, as these organisations already have a network with disadvantaged young people and are trusted by them. However, once recruited, the young people often contributed very successfully. A research coordinator in an LMIC spoke about how she had successfully included marginalised young people in research projects for years, and those projects had made tangible changes to the community's environment, such as increased lighting and better road transport (see section 3.2.2 for more information). Another expert who coordinated YPAGs stated that she works with young people with health conditions and that these young people successfully advocated for change within their communities.

Although the young people who were consulted were from diverse backgrounds, this was not representative of their experience of their peers' involvement in health research. The consultation deliberately identified and selected young people from disadvantaged and/or marginalised communities, who reported that diversity amongst their peers is not always so strong. With regards to gender, young female researchers who had actively led different stages in health research, reported that women are typically under-represented in research because of community and cultural attitudes to their involvement. The burden of reconciling social and cultural norms that come in conflict with research efforts are also left with the young women and their families. Young people from the LGBTQI+ community are also less likely to be involved in health research, due to adverse social or legal contexts.

However, the consultation revealed ways that safe spaces for their involvement can be created through role models, channels of outreach that make these opportunities more inviting as well as mechanisms that help navigate conflicts that arise from norms that don't recognise their sexuality. It has been also indicated that young people from a poorer socio-economic status are less likely to be involved in research unless they were specifically targeted, due to a lack of opportunities promoted within under-privileged communities. With regards to disability, the consultation found that few young people with a disability are being involved in research, because of issues to do with access and social stigma. More information on the diversity of the background of the young people involved in health research, and the challenges and barriers which they face, is available in section 4.4.

2.5. The involvement of young people in health research in LMICs

The RER showed less evidence of young people's involvement in health research in LMICs, and the stakeholder consultations align with this finding. Only 15% of papers in the RER were based on studies in LMICs. While many experts were unable to say outright whether there was more involvement of young people in HICs or LMICs, one or two felt that this was less of a priority in LMICs. Additionally, the consultation showed more institutional support for research involving young people in HICs and many more researchers conducting this work than in LMICs.

Under-reporting of research may explain some of the gap between HICs and LMICs. Experts agreed under-reporting is probably a greater challenge in resource-constrained environments, accounting for some of this gap. Part of the under-reporting is simply a dissemination gap: research from LMICs is not as widely disseminated as in HICs because networks are smaller and not as well funded. The use of different terms to describe young people's involvement in health research also contributes to under-reporting, explained a researcher. Many young people, CBOs' professionals and other adults who influence young people's lives, have highlighted that young people are typically involved in enumerator roles during the data collection phases of research, and it is likely that these types of contributions are not acknowledged in research reporting. That said, under-reporting and reporting using different terms cannot explain all of the gap in involvement in LMICs, and it is likely that constrained resources also make it more difficult to involve young people at all. A researcher shared

“Health research with adolescents is already so rare [in LMICs]; youth engagement with research is another step we have not reached yet. There is still a lot to be learnt.”

See more about the role of resource constraints in LMICs in section 4.

The role that young people play in health research is closely tied to their motivations and influences in their immediate ecosystem. In the absence of extensive literature (from LMICs) on the roles of young people and outcomes

of their involvement in health research, the stakeholder consultation has produced evidence to create profiles of young people. These profiles are built based on the behaviours, motivations, aspirations and lived realities of the young people that were consulted across the six LMIC countries. These profiles are meant to provide an understanding of the young people in LMICs and some of their key influencers in their ecosystems.

Three main profiles of young people being involved in research have been constructed: confident practitioners, experimental investigators, inexperienced enthusiasts (see table 2). The experimental investigators and confident practitioners' profiles represent those who are already involved in health research. For the experimental investigators, their research involvement is based on their knowledge of their community, rather than any formal training. Confident practitioners have been formally trained in research. Inexperienced enthusiasts are young people without health research experience who are aware about research, but their involvement is untapped due to various barriers (presented in section 4 of the report).

Table 2:
Overview of profiles of young people involved in health research in LMICs

	Confident practitioners	Experimental investigators	Inexperienced enthusiasts
Who are they	Young people who have been formally trained in research and get deeply involved in it through research organisations, fellowships, academic institutions	Young people who do not have any formal research training but have a wealth of contextual knowledge, because of which they have been involved in research efforts	Young people who may have been one-off research participants (as subjects of the research) but have not been actively involved in any of the stages of the research. They are curious and motivated to learn more and get involved if they had the opportunity
What are their influences	Family, peers, professors, academic communities, local NGOs, religious institutions	Family, peers, local NGOs, academic institutions, religious institutions	Family, peers, academic institutions, religious institutions
What kind of roles do they typically play in health research	Involved in research design, data collection, data analysis and dissemination of research findings.	Involved with tasks that do not require a great degree of technical skills or training: data collection, recruiting people in the community, advice on relevance or appropriateness of questions.	They have been exposed to research in their communities, and may have been participants, but have not been involved more deeply.
What are their motivations for getting involved in health research	Careers that connect to their community as well as provide financial stability, desire to change their communities for the better	Academic training, more significant participation in the research process, desire to grab learning opportunities, commitment to their community	To have their voice represented in research and feel like their opinions are valued

The young people's level of involvement in research is influenced by their immediate ecosystem. Therefore, in addition to the three profiles of young people, three profiles of people who act as key influencers and shapers of young people's research experiences have been also constructed. These are:

- **Sceptical gatekeepers:** Community members whose permission is needed for young people to be involved in research
- **Community catalysers:** Members of the community who encourage young people to get involved in research, make research relevant, train them, and convince their gatekeepers. They are typically members of NGOs and may or may not be researchers themselves.
- **Experts:** Adult researchers working in academic or other research institutions, who are involving, or could potentially involve, young people in their research.

The six full profile descriptions can be found in Annex 2.

3. The motivations of young people and benefits of involving young people in health research

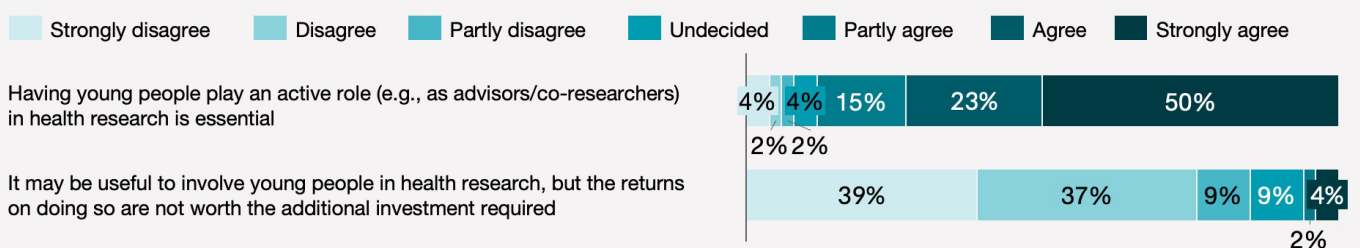
CHAPTER SUMMARY

Consultations reported that young people want to be involved in research to help others and further their own academic or career prospects. Stakeholders agreed with the RER’s findings that involvement in health research can benefit research, young people involved and their communities. The benefit to research most commonly reported by stakeholders was that young people understand their peers and local contexts in a way that adults cannot. In addition, young people are often trusted by their peers and communities, allowing them to do work that adults cannot. Young people themselves also benefit. Through involvement, they learn new skills and gain confidence. Examples of young people’s involvement that led to action which helped and informed their communities were also pointed out. As such, there is a strong case for scaling up young people’s involvement in research. It should be recognized, however, that some of these benefits are better evidenced than others.

Stakeholders were also divided on whether it was more important to involve young people in all health research which (directly or indirectly) affected them, or whether young people’s involvement should be channelled into specific health research questions. Examples of these more specific research questions related to issues which affected young people more, such as sexual and reproductive health and mental health, and issues which young people are more invested in, such as climate change and technology. Food and nutrition were also cited by a number of experts. Moreover, some stakeholders may be less aware of some evidence of benefits. As such, more work is needed to continue filling gaps in knowledge and ensuring that evidence that already exists is disseminated widely.

Stakeholder consultations largely aligned with findings from the review of academic literature on the benefits of involving young people in health research. The RER reported benefits of involving young people with respect to how they influence the quality of research, the personal and professional development of the young people involved, and the impact on their local communities. The stakeholder consultations aligned with these findings and provided more detail on: (1) young people’s motivations to be involved; (2) benefits in LMICs, which tend to be under-reported in academic literature; (3) the research questions/themes where young people can make the greatest impact. Most experts indicated it is essential to involve young people in health research. 88% of experts surveyed partly to strongly agreed that having young people play an active role in health research is essential. Only 6% of experts surveyed responded that the returns on involving young people in health research were not worth the additional investment required (see Figure 6).

Figure 6:
Percentage of experts surveyed, by level of agreement with the statements on the importance and usefulness of involving young people in health research



3.1. Young people's motivations to be involved in health research

Young people tend to be motivated mostly by a desire to help others. Experts and young people agreed with this finding, often reporting that the desire to help others was the one of the most powerful factors in young people's involvement. One expert interviewee running a network of YPAGs comprising primarily young people diagnosed with health conditions, reported that the overwhelming majority of young people participated in the YPAGs to help other children with health problems. Interviews with young people confirmed this motivation. Research topics that fulfil young people's desire to be change makers in their communities, motivates them to get involved. Mohan, a 21-year-old young research fellow from Mumbai, India, working on infectious disease research in his community shared the following about why he got involved in research

"I was already working on community-level initiatives like getting old clothes from people to make blankets for the homeless. In my slum, there are issues with waterborne diseases especially during rainfall, so I've been involved in these sorts of things for a while. I imagined a social service career and wanted to become a civil servant, so I have been interested in social initiatives for a long time now."

Young people are also motivated by the better academic and career opportunities that may arise as a result of skills and experiences gained from health research. Young people acknowledged that research exposes them to people, places and experiences that they would usually not have access to. Young people believe that this type of exposure has the ability to propel them into future career opportunities. Sujal, a 20-year-old young mental health researcher from Mumbai, India talked about the skills and qualifications she gained through research

"I got a diploma certificate at the end of my research fellowship, I learnt how to design surveys, conduct analysis, these are highly valuable skills for career prospects."

Faith, a 23-year-old college student from Nairobi, Kenya, worked on a research and leadership development programme after her graduation. She shared the following about how she intentionally opted for a research opportunity to prepare herself for the job market

"I decided to get into that training programme because I felt like I wasn't ready for the job market. During my college, I did not get any hands-on experience. After joining this programme, I was getting to work with different organisations and getting exposure to the real world."

Professionals from research institutions and CBOs also reported that they often frame research opportunities to young people in a way that appeals to their career aspirations, as they recognise this to be a key motivator. Nguyen, a professor in public health in a university in Vietnam explained

"We have a research centre in our school. We encourage students to volunteer for short-term research engagements and tell them that if we like their work, we will offer them to be research assistants at the centre. Many students have become colleagues like that."

For young people from low-income backgrounds, research opportunities must address their need to earn an income now and in the future. Experts spoke about the importance of compensating young people, particularly those from disadvantaged groups, because they need to be able to afford to spend time doing research. Other experts suggested that payment was important for all young people, not just those who were facing disadvantages. The distinction between vouchers and payment was also discussed. Vouchers are sometimes given to young people in lieu of payment, but most experts felt this was not acceptable as it did not solve the need for some young people to earn money to support themselves or their families. In-depth interviews with young people from low-income backgrounds shed more light on this issue, showing that while compensation might not be their top-ranked motivator, it is the most immediate constraint they face. Some interviewees explained that they are expected to contribute financially at home once they reach high school. Alimatou, a 22-year-old college student from Dakar, Senegal talked about the financial pressures that many young people in her country face

“One thing that is common across young people in Senegal is that everyone feels the stress and pressure to contribute towards family.”

Moreover, Sanjay, a research coordinator from Mumbai, India, who is involved in health research projects as a survey enumerator, also shared the following example about how research presented him with an opportunity to earn and support his family

“I only knew the world where I went from home to school and school to home. In the kind of slum communities [informal settlements] we live in, we don’t have many opportunities. I was in the tenth grade, there were few opportunities and I needed to support my family. The work I do with ... [the research CBO] allowed me to earn money while also meeting new people from outside the community.”

3.2. The benefits of young people’s involvement in health research

3.2.1. Benefits to the research process and outcomes

The most commonly reported benefit by stakeholders was that young people understand their peers and local contexts in a way that adults cannot. Experts agreed that young people brought a greater understanding of their peers, their preferences for language, modes of communication, and methods of engagement. This understanding allowed researchers to identify more creative ways to include young people, such as through different recruitment methods and new approaches to dissemination. This can have a positive effect on the research outcomes. A researcher shared

“Those outputs of research projects [which involve young people] generally better meet the perspectives of young people around the nature of the problem, they are more engaging and efficacious.”

Young people are also often more trusted by their local communities. Interviews with young people revealed that trust levels between local communities and “outsider” researchers can be low, especially when the community perceived past experiences with researchers as extractive. Young people are considered less likely to have political agendas or hold traditional belief systems that discriminate against people based on factors such as caste, religion or ethnicity, deeming them to be neutral parties that take the role of “trust negotiators” between researchers and communities. This creates an opportunity for young people to act as useful allies for researchers trying to build trust within communities. Marie, a 21-year-old student who works on a CAB for a TB research group in the Western Cape, South Africa explained

“As CAB members, we are the link between the community and the research organisation. We are the messenger. As CAB members, we come up with solutions from the community side to better circumstances for people.”

This unique understanding and position of trust allows young people to add value at each stage of the research cycle, including the recruitment of their peers. Experts mentioned several examples where they had formed a small group of young people to be involved in research which then recruited other young people. A stand-out example was from a YPAG in a HIC. The coordinators of the YPAG had supported a small group who worked together for a year but wanted to increase the diversity of the group in the future. They discussed some ideas with the YPAG, who suggested targeting adverts on social media to more disadvantaged areas of the country. This action successfully resulted in a more diverse group of YPAG members the following year. Interviews with young people reinforced this view. Young people reported that they rely closely on their peer networks to self-educate and share information or opportunities for research involvement. These networks are safe spaces that young people control without the power dynamics that exist in the presence of adults. As such, young people are able to reach and recruit a wider set of young people from the networks they are part of and can access more diverse groups that traditional sampling may not have access to.

Young people can also improve research design and data collection. A researcher in a HIC explained how her team involved young people in a study on well-being. They worked with young people as co-researchers to develop a survey which would be broadcasted on a TV show targeting young people. The young people were able to work semi-

independently after some training, and over 33,000 children and young people ultimately participated in the TV-based surveys, in a rare example of involving young people in health research at scale. Moreover, interviews with young people showed that consulting them on language, culture, and local knowledge helps researchers build better rapport in communities as well as elicit better responses to research questions. Anastasia, a 21-year-old student and CAB member for a TB research group in the Western Cape, South Africa said the following when asked about how she and her peers engage other young people in schools about TB research

“We go and we talk in our way, maybe talk slang and talk to them in a comfortable way.”

Marie, also 21-years-old and a fellow CAB member from the same research group added

“We get a script, but we do our best to give it in our lingo.”

Young people are also equipped to handle sensitive or taboo topics like mental health as they have the local knowledge and know of the unspoken rules that communities use to deal with these topics. Sensitive or taboo subjects tend to be related to local cultural beliefs, norms or practices that would be less obvious or even completely hidden from researchers or outsiders in general. Young people hold this local knowledge and can be key informants to research when they are involved in an advisory capacity to contextualize or design research approaches for fit or appropriateness. Sanjay, a research coordinator from Mumbai, India, explains how he probed on a line of questioning, anchoring on what would have otherwise seemed to be a mundane activity to understand a participants’ mental health experience

“If I asked a direct question about [people’s levels of] stress or tension, they would not open up or people will expect me to have a solution ...[for them]. In the survey, we added the question ‘In the last seven days, have you woken up to fetch water?’ This lady would answer that she did not wake up and fetch water because there was some tension and stress, and then we would ask further about ...[why] that ...[was].”

Experts and young people also pointed out how young people’s involvement can strengthen dissemination.

Young people can be powerful voices for dissemination. For example, two infectious disease experts explained an instance from an LMIC where young people performed in a play about the spread of TB and the effects it can have on people’s lives. Because young people were performing to their peers in their local language, it was more engaging than if the play came from adults or professional performers. Young people confirmed this view. They reported that they can communicate research outcomes, especially when the outcomes are relevant to communities and other young people, in ways that increase the potential for research outputs to turn into tangible outcomes in people’s lives. Mohan, a 21-year-old young researcher from India shared how infectious disease-related research by young people in his community led to advocating for community toilets through dissemination efforts

“We... [a group of young research fellows] completed the research and one thing we did was launch a petition on Change.org and also uploaded videos about the slum situation on social media, tagging the municipal corporation on Twitter. Two days ago, we had a response on Twitter from the municipal corporation.”

3.2.2. Benefits to young people and their communities

Young people learn new skills and gain confidence from research. Experts interviewed provided examples of how young people develop new skills, knowledge, confidence, and networks from involvement in research. One professor explained how students who had been part of a research club at university, gained confidence and, over time, inspired other, less confident students to get involved in research. Another expert reported seeing adult researchers gaining new skills and confidence, too. Furthermore, expert interviewees highlighted that young people developed specific health knowledge about the topics they were researching, which was useful in addressing stigma and misinformation. Young people who were interviewed also confirmed that involving them as partners in research increases their confidence and willingness to contribute to future research. They also reflected on how research experiences advance their ability to think critically about research questions and other topics in general. Huong is a researcher who also trains young people

in the LGBTQI+ community to conduct research in Hanoi, Vietnam. He shared an experience about how presenting the results of his first research project boosted his confidence as a contributor in research

“There were times during the research I wanted to quit. I think I would have given up, but with the support of the team, I didn’t. It took me nine months. One year later, I got the opportunity to present the findings in Hong Kong, so it felt fruitful for me in the end.”

Amrita, a 26-year-old field research coordinator from Mumbai, was involved in a community research programme that uses tools such as storytelling to tackle sensitive subjects like sexual abuse. She shared her reflections on her time in the programme

“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?].”

Involvement in mental health research gives young people a vocabulary to articulate their feelings and talk about their mental health challenges more openly. It also gives them the capacity to reflect on and change how they talk about other people’s mental health problems. Young people stated that they are able to combine their first-hand experiences with their newfound understanding of mental health to normalise conversations on otherwise taboo topics within their ecosystems. Aisha is a 24-year-old journalism graduate who is producing a documentary on mental health in Senegal. She conducted interviews with mental health experts, policymakers and other young people as part of her film research process. She stated the following about her learning on language and mental health

“‘A crazy person never heals’ is a phrase we use in Senegal. In hindsight, I realise that every time I would say ‘you’re crazy’ to people, my cousins, whose mother passed away due to complications with schizophrenia, always seemed uncomfortable with the word, and they probably associated it with their mom, and I realised that language matters and I have to be careful.”

Local communities benefit from young people’s involvement in health research. Experts gave examples of young people making their neighbourhoods safer. In one case, young women in a middle-income country mapped instances of sexual harassment across their city, which revealed that harassment correlated to poor lighting. They met their municipal representative who arranged for more lighting to be put in place. The same expert pointed out how data collected through young people’s research resulted in the building of a railway bridge so that their community could reach the local hospital with fewer delays.

Young people also reported that they were able to share knowledge from involvement to inform their families’ decisions about health. Young people highlighted that what they learned from being involved in research on topics like mental health and infectious diseases helped them cope with similar challenges in their lives, such as stress about making career choices and advising family members on infectious diseases-related symptoms. Nabil, a young researcher who now trains other young people from an informal settlement in India to get involved in health research, explained the way that research equips young people with new knowledge

“Young people who stay for a longer period of time in research efforts realise that they get to learn new things that first are useful for their life. You get to know about your own health. For example, 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.”

3.3. Key themes and research questions on health issues that could benefit from young people's involvement

Young people tend to be most interested in working on health research that directly affects them or their communities. In interviews, researchers with experience working with young people from low-income communities stated it was important to have them involved with issues that were directly relevant to their communities. An adult researcher working in a marginalised community in a middle-income country shared

“Our community has a lot of more pressing things to think about than climate change. They are more worried about if they will get TB, HIV, or COVID-19. There is more and more depression and suicide amongst their peers. There is a lot of anxiety among young people and they talk about it more, which is maybe why they get more involved in mental health. It depends where the community is based but they worry about infectious diseases far more than climate change.”

Sanjay, a research coordinator from Mumbai, India explained the way that he uses community issues that people care about to get young people involved in research

“To be a researcher, you should be from the community and you should care about the problems in the community. I go to other communities like mine [as every community has their own problems] and I would talk to young people hanging out and ask them about life and what is going on. Depending on the type of problems that come up, I would take that to the office, and we would figure out how to engage those young people [in research].”

This point was further reinforced by the expert survey results and young people who also shared that they anchor their motivation on research topics that can lead to improved community outcomes. Survey respondents asserted that young people's lived experience was important in health research, even if that experience was simply a young person's perspective, rather than experience as a young person with a specific health condition.

Interviews with young people shed more light on how research topics that are specific and relevant to young people's lives are more appealing to them. They reported that topics they can associate with allow them to quickly relate, engage and own parts of the process. Anchoring the research on young people's life experiences (i.e. sexual health, school related stress, or bullying) enables them to talk more confidently about research. Mina is a 21-year old mathematics student and research fellow working on a mental health project in Mumbai, India. She explained what led her to select mental health as a research topic

“I didn't know why I was going through this stressful season. I have to manage my studies, my family, this youth fellowship, and it was creating pressure on me. ...It is very stressful. These were the things that made me select this topic ... [mental health].”

Mina explained further how her team had to delegate the topic to their specific areas of interest

“We did unstructured searching initially, would go to google, type mental health, and there would be a bunch of research it would throw up, and would go to another link and another throughout the week. On Sundays, we would talk about our doubts and questions and findings. We then realised there were different categories ... [of mental health] and based on our interests, we delegated further research on different types of stress One person did stress and romantic relationships, one did stress and money”

Expert survey respondents noted how young people's motivation is tied to their interests. In doing so, they flagged the topics which they saw young people as interested in, including climate change, technology, and mental health. All of these are discussed in further detail in the following paragraphs.

Some experts suggested that young people's involvement in research was most valuable regarding stigmatised health topics and incorporating technology. Interviews with experts confirmed that young people were better, in

comparison to older adults, at discussing topics related to inclusion, justice, misinformation, and overcoming stigma when involved in health research. For example, one expert told us that young researchers in India were more able to discuss stigmatised and sensitive topics with adults because as young people they were not seen as manipulative or judgemental, which adults could be. This makes young people ideal participants in discussions related to sensitive topics like mental health and sexual and reproductive health rights. Experts also reported that young people were creative and insightful about bringing in aspects of technology to participatory health research. For example, young people informed the design of a game intended to improve mental health, and they were knowledgeable about how to use social media to influence discussions related to health. Expert survey respondents agreed with this, confirming that young people's ease and familiarity with technology, as well as high usage rates, made them particularly relevant to researching technology and health. Suggested research questions included technology as a health supportive tool, leveraging technology for mental health, technology's impact on mental health, and technology's impact on our behaviours, including to better understand how health messages are transmitted.

Other experts surveyed were also supportive of young people's involvement in health research related to climate change or food and nutrition. For example, they wanted to involve young people in research questions related to the impact of exposure to environmental risks in early life, and young people's concerns about the future of the environment. In terms of food and nutrition, several survey respondents wanted young people to be involved in research that helps promote their dietary and exercise habits or research into obesity and diabetes.

Furthermore, young people who experience and advocate for better outcomes on topics around LGBTI+ health, mental health, suicide or sexual violence are naturally driven to conduct research on these topics as a way to understand these issues better. Young people working in advocacy and activism acknowledged that research has the ability to give them the tools and mindsets that they need to advance their knowledge and practices for better outcomes in their respective fields. Aisha is a 24-year-old journalism student, mental health youth leader and documentary maker from Dakar, Senegal. She shared that, for her, taking a qualitative research approach catalyses her work in mental health advocacy and helps her better understand and communicate the topic

“Mental health might not always be visible, but it is just as important as physical health. I thought addressing this in a visual way would make it more accessible. I realised a written output wouldn't be the best...We came across a lot of topics that were very loaded, and I came to realise that it would be easier to process it in a visual than written [format]. I also wanted to reach a broader audience. In Senegal not everyone is literate. I can cover more languages in a documentary, so people hearing others speaking in Wolof and talking about this in Wolof would be more effective.”

Thanh, is a 16 year old student and founder of an autism advocacy and support CBO based in Hanoi, Vietnam. She suggested that research can advance their activism work

“I consider our organization an advocacy and support organization, we don't focus on research. We do need research for better insights, to be sure of what we are doing. We will stay like this as a support system that is substantiated by research.”

However, other experts were reluctant to prioritise young people's involvement in some topics over others when asked where young people could make the greatest impact. Some researchers disagreed with the idea that young people might be better at contributing to research on one health topic and this stance was also articulated in some of the expert survey responses. An academic researcher stated

“There is not one particular research question or set of research questions which it is important to get young peoples' views on, and instead young people can have an impact on any area of research.”

4. Where stakeholders think support is most needed

CHAPTER SUMMARY

Stakeholders reported challenges that align closely with what was revealed by the RER. There are few opportunities for young people to get involved in research. Young people can be harder to access and sustain engagement from. More guidance is needed on how to involve young people effectively, how to improve monitoring and evaluation (M&E) and how to build wider networks to share best practices. Working cultures in research teams are often not conducive to young people working effectively. In LMICs, these challenges can be amplified by cultural norms and greater resource constraints. 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 get involved. And young people with disabilities or chronic conditions are less likely to get involved in health research because researchers fail to accommodate their needs.

While the previous chapter showed the benefits of involving young people in health research, this chapter demonstrates critical challenges that must be addressed if the involvement of young people is to be mainstreamed in health research. In the next chapter (chapter 5), recommendations are presented as solutions to these challenges.

4.1. Challenges reported by stakeholders

There are too few opportunities for young people to get involved in research. Young people interviewed reported that they were interested in getting involved in research when opportunities are available and accessible to them. This applies to both young people with and without experience in health research.

Although young people are enthusiastic about health research, it can sometimes be difficult to keep them involved in research projects over a sustained period. Several experts described experiences of struggling to maintain young people's involvement when tasks become mundane, or when the impact of their efforts is slow or difficult to observe. This barrier can be exacerbated if young people feel under-valued by the adult experts running the research, which can happen if the adult experts are sceptical of the validity of young people's views and experiences in contributing to research. This perception from adults can limit the role of young people in research to mundane tasks like passive data collection or other activities that may not value their experiences and opinions. As such, a vicious cycle can appear where young people's skills are under-estimated, young people do not feel valued, they then withdraw from active participation, and this then reinforces their adult team-mates' biases. Sandra, a 20-year-old student and CAB member for a TB research programme from the Western Cape in South Africa explained how she hopes to be involved in more active activities in the field

"They only come to us during meeting times. If they could involve us more in the field work, that would be awesome. When they ...[go out and] have to tell people about TB, ...[tell them about] vaccines, something ... [about how] they ...[can] go to the hospital ...[for] the screenings, I don't know ...[exactly] what they do because they don't take us...[with them]."

Marie, a 21-year-old student and also a CAB member for the same TB research programme in South Africa also expressed her desire to have a more impactful role in the research

“Even collecting mucus to do those developments of the tests. Personally, I would do field work even if I don’t have the qualifications and background. I would do that if they taught us, taking patients to clinics and stuff like that, we could do ...[that].”

CBOs and researchers acknowledged the challenge of working around young people’s more rigid schedules.

Young people in LMICs have competing priorities including school/college related responsibilities, household chores, and side jobs, which make it difficult for them to commit extended time periods to research. CBOs and other research organisations end up investing more time in refreshing or retraining efforts to onboard and retain young people. This increases the likelihood that research organisations limit young people’s involvement to short-term and low-stake roles, such as data collection, that require minimal training. Conversely, young people seek research opportunities that are regular and stable enough to improve their career prospects and contribute to improving the quality of their lives and that of their families. Pooja, is a research coordinator from Mumbai, India. She works with a CBO that involves young people in health research. She shared her experience with the challenge around young people’s competing priorities and commitments

“We have to adjust time based on their school or college schedule...That makes the pace of getting work done slower. It is very hard to keep adjusting. Due to the gap between projects and irregularity of their engagements, [young people] forget training, so they have to be refreshed...We provide them with refreshments as well as compensation for participating in training.”

Experts cited few examples of training or support materials adult researchers, funders, and young people can turn to (see table 3).

The RER identified several gaps in established best practices, including identifying appropriate methodologies for involving young people, seeking consent from young people, and identifying appropriate remuneration for young people. Stakeholder consultations confirmed that there was a lack of supporting materials in these areas. Two-thirds of experts surveyed agreed or strongly agreed that more training and guidance documents are needed. Most of the experts consulted, who had developed significant experience involving young people over time, said that they had relied on on-the-job learning to develop the skills needed to effectively involve young people in health research. This on-the-job learning had often come from colleagues who were more senior to them at the time. These experienced researchers noted a lack of resources tailored to training adults. Some of these experts with extensive experience were able to cite a few examples of training materials which had been helpful to them in addition to their on-the-job learning. However the documents they cited were typically complimentary to the hands-on experience they were getting, and provided high-level training (e.g. focused on principles rather than actionable tips and tricks) or overly narrow guidance (e.g. mental health in Australia) which would not be applicable to others doing this work without more senior colleagues to learn from. Furthermore, only one of the materials mentioned was tailored towards introducing young people to being involved in research. Finally, expert interviewees also highlighted that training would be useful for funders, to help them understand how to monitor this work, drive accountability, and what research outcomes to expect. An academic expert explained the need for training young people

“Young people often don’t get involved because they feel like they do not have the right skills, even though such skills would be easy to learn if they had the right resources.”

Kevin, a 22-year-old graphic design student from Badung, Indonesia conducted research on “the black plague” [a highly infectious disease in Indonesia] for a public awareness design campaign. He highlighted the need for researchers to applied targeted and appropriate modes of communication for young people

“Nobody wants to read research articles, and it is important for researchers to simplify their content and connect to the public in new ways.”

Table 3:

List of guidance documents on young people’s involvement in health research, shared by stakeholders during consultations

Name	Description
Embedding young people’s participation in health services , (Brady, 2020a)	Book that provides a framework to involve young people in health research, with in-depth case studies and practice examples featuring the voices and experiences of young people
A guide to actively involving young people in research: For researchers, research commissioners, and managers , (Kirby, 2004)	Guide co-developed with young people that describes the benefits and challenges of involving young people in research, and how to best involve them
Report on Involving Children and Young People in Research , (Sonpal et al., 2019)	Report mapping YPAGs in the UK, and presenting the results of a survey on the barriers and enablers to involving young people in research
Involving children and young people as advisors in research: top tips and essential key issues for researchers , (INVOLVE, 2019)	Guide co-developed with young people on the key issues and top tips for involving them in health research
Reward and recognition for children and young people involved in research – things to consider , (INVOLVE, 2016)	Guide on specific issues to think about when planning research involvement that includes young people
iCAN curriculum , (iCAN, 2020) ⁸	Curriculum being developed for young people to provide them with the skills to advise on health research projects
Young People in Research: How to involve us , (PEAR, 2010)	Guidance for researchers from the PEAR young people’s public health group
Rhetoric to reality: challenges and opportunities for embedding young people’s involvement in health research , (Brady, 2020b)	Chapter 42 of “The Routledge Handbook of Service User Involvement in Human Services Research and Educations” which focuses on service user involvement in education and research in different regions and with different client groups
Involving young people with lived experience of adverse childhood experience in a systematic review , (Brady & Lester, 2018)	Blog post with tips on how to involve young people with adverse childhood experience in a health research project
Exploring co-production in a virtual world – what we’re learning , (Brady, 2020c)	Pros and cons of involving young people in health research virtually (due to COVID-19)
Meaningful youth engagement: sharing power, advancing progress, driving change , (Women Deliver, 2019)	Guide on how to practice meaningful youth engagement, and the benefits of it
Factsheet on the participation process , (Council for Disabled Children, 2020a)	Factsheet on the steps of the participation process to consider when working with young people with a disability
Factsheet on involving children and young people in formal meetings , (Council for Disabled Children, 2020b)	Factsheet on the steps that should be taken to ensure that young people with a disability feel comfortable and confident in formal meetings, and that their input is valued and respected

8 Resource still being developed

Experts expressed an interest in having access to wider networks, so that they can learn from peers operating in different contexts. Adult health researchers said they lack channels to consult other researchers doing work involving young people, particularly those in other geographies. They also think networks would be helpful when trying to connect young people and adult researchers who are interested in collaborating. Some adult researchers said they would benefit from some top-down direction on how to spread knowledge on participatory approaches involving young people using these networks. An academic researcher explained

“We don’t have pathways to collaborations or networking, we need ways of connecting with youth programmes and institutions involving young people in the design of youth-centred programmes.”

Although some networks do exist, interviewees said they are either too small to effectively distribute knowledge or lack the funding to operate effectively. One adult researcher cited reduced funding for INVOLVE⁹ in the UK as an example, which has prevented the group from playing the convening role it had previously.

Several experts singled out weak M&E as a critical blind spot across health research projects that involve young people. Inconsistent use of terminology to describe young people’s involvement contributes to the difficulty communicating about this work, as does the lack of a standardised M&E methodology for the sector. The lack of M&E also makes it difficult for adult researchers to learn from each other or build an evidence base to support best practices. An academic researcher suggested

“There is still no agreement on the process of evaluation of research with youth involvement.”

The lack of effective M&E means that evidence that could persuade more funders to invest in young people’s involvement in health research does not exist. This is a particularly exacerbated issue in LMICs since, in resource-constrained settings, M&E risks being the first thing to be deprioritised. Experts said funders need to be clearer on what evidence they expect from grantees regarding young people’s involvement. Indicatively, a policymaker shared

“Lots of funders don’t know how to do M&E on youth involvement - this prevents us from developing a solid evidence base about the outcomes of youth involvement.”

Moreover, an expert surveyed argued

“... anecdotally we know [involving young people in health research] is valuable, and morally we know it’s the right thing to do but we lack hard evidence to persuade others of the value. It would be particularly helpful to have some long-term financial impact (cost-benefit analyses, cost efficiencies etc.) to convince those whose primary language is money.”

An underlying driver of these challenges is a lack of support from funding organisations within the health research ecosystem. Some experts reported that funding constraints aggravate each of the challenges listed above. Adult researchers across HICs and LMICS agreed on and emphasised this point. Other experts added more nuance to this and felt that although major donors are generally positive towards the idea of involving young people, this positivity did not translate into funding because funders did not understand how to effectively support young people’s involvement. One of the biggest direct consequences of under-funding can be the superficial involvement of young people in research, as the adults running the research lack the necessary time and resources required to build trust with young researchers. An expert surveyed explained

“[Funding young people’s] involvement takes time and resources - this is not necessarily readily available and drives the tokenistic tick box approach with the researcher wanting someone to agree with what they are doing. One of the issues I have often found is that everyone wants Patient and Public Involvement (PPI) but nobody pays for it, you can write it into the grant, but really good PPI should have taken place long before the grant is submitted.”

⁹ INVOLVE is part of, and funded by, the UK National Institute of Health Research. It is dedicated to Patient and Public Involvement (PPI) in public health and social care research. It is one of the few government-funded programmes of its kind in the world.

4.2. Themes on new insights and evidence needed to strengthen young people's involvement in health research

Stakeholders identified the lack of best practices as one of the key challenges when involving young people in health research. In line with this finding, stakeholders have suggested through their responses in the survey, what new evidence and insight is needed to strengthen young people's involvement in health research. The responses fall into the broad themes of diversity and inclusion, effective methods for involving young people, motivations and perceptions of young people, ethics, and impact.

Moreover, some stakeholders pointed out particular methodologies that should be used to produce this evidence including case study, participatory action research, and ethnographic research. Some stakeholders also highlighted the importance for not only generating but also disseminating widely this evidence using appropriate formats e.g. a toolkit that presents in an accessible way what works, an online course, through infographics. The table below (figure 7) provides illustrative examples of the stakeholders' responses. These could be used to articulate research questions and inspire further research in the field.

Figure 7:

Themes of new insights and evidence on involving young people in health research

Diversity and inclusion

- What diversity looks like when you get youth involved and how to do it meaningfully
- Create more evidence along the regional, linguistic, age, (adolescent, young adults, so on) class variations.
- Involving vulnerable adolescents in research
- How to engage you people from diverse backgrounds in environmental health research
- Reach out to people who have already worked with underserved communities/young people

Effective methods for involving young people

- Research on the ways that the youth have been engaged by different organizations in different parts of the world
- More creative approaches to research that engage young people
- How to harness long-term engagement
- Studies that test different involvement methods
- More research on the best ways to involve young people in health research e.g. ways to create interest in young people in research
- Evidence in meaningful engagement of young people in setting health and research priorities, e.g. with funders and national and international policy forums.
- Using IT technology to involve young people

Motivations and perceptions of young people

- Research on understanding young people's motivations
- How young people want to be engaged within health research.
- Youth perceptions of health
- How young people perceive risk factors that will affect their livelihoods
- Evidence on what is important to young people and how the evidence can be used by them, what health areas are the most burning issues to them, segmented evidence according to young age and background

Ethics and compensation

- Ethics for involvement of young people-dos and don'ts to prevent their exploitation
- What responsible consultation entails
- Research on how to conduct ethical research in minority communities
- How to cost for youth engagement in your project/organisation's budget
- How to fairly compensate their involvement

Research into the impact

- Research into the impact of youth engagement activities on the youth themselves, e.g. cognitive ability, solidarity and group efficacy and leadership capacity.
- Evidence of the impact their involvement had

In the sections that follow, three areas are called out for special attention, in line with Wellcome's strategic priorities.

4.3. The extent to which research culture enables young people to be part of a research team and be appropriately acknowledged for their contribution

Young people may need further support to gain the confidence to sign up for opportunities and to operate effectively within research teams. Experts and young people interviewed described the challenge of young people wanting to be involved in research but lacking the self-belief needed to do so. In LMICs, research is a concept that young people associate with professional specialisation, deep scientific knowledge, academia, or years of work experience; characteristics that they feel they lack. Young people in LMICs shared their perception of research as an 'elitist' pursuit, one not intended for "young and inexperienced" people like themselves who may also lack academic skills. When research is framed specific to something that they experience and can talk about (i.e. sexual health, school-related stress, or bullying) and more so when it is broken down into stages (i.e. planning, action, analysis, conclusion), young people tend to gain some confidence when speaking about it. This allows them to be more than passive participants and become drivers of the research. A policymaker argued

"Young people want a seat at the table, they are ready to get involved in research but often do not know how to make a case for themselves and still lack confidence."

Faith, a 15-year-old high school student from Nairobi, Kenya shared her perspective from experiencing research in practice

"Research is perceived to be a specialised and rigid practice that is accessible by an educated few. For communities, research is never contextualised or explained, making it hard to engage".

Experts voiced a concern about the over-investment in a few exceptional young people, which can lead to one-off opportunities for a few, rather than sustained investment in young people as a whole. Some experts were concerned that some short-term programmes to involve young people in health research had led to international organisations 'touring' one or two exceptionally talented young people around international conferences and at UN meetings. This approach does not lead to systemic opportunities for representation of young people, just a string of one-off opportunities and pressure for someone with the responsibility to "be the voice of youth" globally on a certain topic. When asked about best practices to involve young people in agenda-setting, three experts surveyed also highlighted the importance of involving a broad diversity of young people, rather than a few talented ones.

Some young people say their opinions are discounted by adult researchers because of biases against young people's knowledge. Young people working with formally trained adult researchers find that technical knowledge is prioritised over local, contextual knowledge. In LMICs, this leads to the perception that the knowledge held by western or western-educated researchers is most valuable. Young people find it hard to challenge these power dynamics and said they often do not feel valued during research. This holds them back from contributing fully. Adult experts acknowledged the role of power dynamics in preventing young researchers in universities from being involved as extensively as they could be in research. The hierarchical nature of traditional university research is biased towards academics with decades of experience (who are older) and fails to account for the value of the opinions and experience of young researchers. Experts recounted how this can sometimes go as far as supervisors trying to claim their students' work as their own, stifling them and preventing even well-qualified young researchers from voicing their ideas. 81% of

experts surveyed partly to strongly agreed that young people involved in health research projects often face working cultures or team dynamics that make it difficult to have their voice heard (see figure 7 below). Younger experts (under 40 years old) all agreed that culture can be a challenge for young people, while only 68% of experts over 40 years old agreed. An adult researcher shared

“There is a feeling that you need years of experience, grants, and PhDs to have an opinion worth hearing. It is a hierarchical, intimidating environment.”

Huong, a transgender researcher from Indonesia, recounted his first experience of conducting research as a young person.

“One of the things that changed my perspective, moving from a community member to a researcher is the power dynamics. When I participated in the training, I was so shy and was so nervous. The professors who were researchers were so confident and they did not have conversations with us to listen to us. I had to express my fear and say that I had limited understanding to conduct the research...We have to change the power dynamics.”

Figure 8:
Percentage of experts surveyed, by level of agreement with the statement “working cultures on research projects can make it difficult for young people to have their voices heard”



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

Young people prefer to work in welcoming and non-intimidating settings and experts pointed out how researchers need to adopt more engaging and creative ways when involving them in health research. Two adult experts who were interviewed explained how the university setting in which they had to hold the meetings with young people could be intimidating. Instead, they wanted the budget to host in a more welcoming space, such as a museum or a young people’s club, where young people might have felt more comfortable and creative. Several experts cited the COVID-19 pandemic as a surprisingly positive force to increase accessibility of meetings by hosting them online. This made it easier for young people to join, and they prefer it because they do not need to travel. One academic researcher pointed to the pandemic as a force for change to involve young people in health research, and be more inclusive, given that meetings were remote. Experts surveyed agreed. When asked about how to best involve young people in agenda-setting, several experts recommended making it easy and fun for young people to be involved. Young people consulted also highlighted the need for researchers to employ more engaging methods in order to enable and encourage young people to contribute to research. An expert surveyed suggested

“Plan around the way children and young people like to work, and not the way you are accustomed to working; make it fun; be creative - there won’t be a tick list for what you want to do, you need to be imaginative and shape existing tools and resources as well as develop new ones”

4.4. Challenges when trying to involve a diverse group of young people

Young people can be marginalised because of various factors. In this section, we focus on young people who are disadvantaged because of their socio-economic status, their gender, their ethnicity or a disability or chronic condition.

4.4.1. Socio-economic status

Young people from low-income communities may:

1. **have less free time;**
2. **be forced to navigate parents or community leaders who are less familiar with the benefits that their involvement in research will lead to; and**
3. **encounter research materials or approaches that are less suited to their capabilities.**

Some experts said that in low-income settings, it may be more important for research teams to demonstrate in advance that young people's involvement will benefit them and their communities. Adult researchers from LMICs reported that communities in informal settlements are less likely to have experience working with formal research institutions. This indicates the need to dedicate activities and resources to build trust. One way to build trust, according to experts, is to demonstrate the immediate and direct value of research projects to the community, which requires additional time and effort.

Young people involved in research, especially those from low-income and marginalised communities, suggested they can be vulnerable to threats from local leaders. Young people explained that when the research they are involved in exposes the lack of basic rights or amenities in a community, or rallies support from their communities, local leaders may feel challenged or threatened. This can put young people at risk of backlash by those in authority. Nabil, a research trainer living in an informal settlement in Mumbai, India, shared his experience of receiving threats from local leaders that supported the water mafia in their community

“When our [young] researchers were doing research on access to water, the water mafia stopped giving water to their homes...They did not get water for 15 days. The water mafia is afraid that their business will stop if people start getting to know about the high prices they are having to pay. So, they approached the political leaders in our area to scare us indirectly”

Research often is not as adaptable to the needs and capabilities of young people from low-income backgrounds. Young people from low-income backgrounds, stated that formal research processes and protocols, such as signing consent forms, can be unfamiliar and intimidating. While these protocols are set up for safety and protection, they can be daunting, as many young people from low-income backgrounds are not accustomed to such formalities, and they can often be enough to turn young people away from engaging with research entirely. Experts interviewed agreed that research processes needed to be adapted in order to work with young people from low-income backgrounds, and that they are likely to need more training to be able to participate meaningfully. Aisha, a 24-year-old youth leader from Dakar, Senegal, recalled how one of the participants of a focus group discussion dropped out at the last minute

“[The participant] said that the fear came from not knowing the organisation, not seeing or meeting them in person. Having to sign the papers [consent form] added another level of fear. She said that signing papers hints to something being very serious and that it's not always clear what they are allowing companies to do with their information.”

4.4.2. Gender and sexual minorities

In some geographies, cultural norms on gender roles and an associated threat of violence make it harder for women and girls to get involved in health research. Cultural norms also mean that boys and men will be less likely to get involved on some health topics (e.g. mental health).

Cultural expectations regarding gender roles can make it harder for women and girls to get involved in research, particularly in LMICs. Women and girls who were consulted said that when they are involved in research, their families and communities worried about the risk of sexual harassment and violence, or the inappropriateness of girls venturing outside their homes for something other than school. The burden of reconciling social and cultural norms that come in conflict with research efforts are also left with the young women and their families. These restrictions placed on women and girls are exacerbated by norms that give more freedom and opportunities to men and boys. A researcher in an HIC agreed, saying that women do face gendered barriers to accessing health research, especially in communities where men hold the power. Sadiya, a 20-year-old research fellow from Mumbai, India, shared the norms that made it hard for girls like her to be involved in research

“I have always had a dream of doing UPSC [a civil service exam in India] ...but [my parents] always say that the world is not a safe place and that we [women] should chase our dreams from where we are [by staying at home]. Most people do not want their girls to go out due to this fear [of their safety].”

16-year-old Safiya, a high school student from Mumbai, India, shared how she experiences this differential treatment in her community.

“Parents give a lot of freedom to boys during childhood...while at the same time locking girls up. Parents see the boys as [a sign of] family honour so this is why they are given so much freedom”.

Tasnim is an 18-year-old student and “changemaker” in a local community programme on issues of menstrual hygiene and gender-based violence, for young women and girls in Mumbai, India. Tasnim talked about the norms that she has to work against whenever she leaves her house to participate in the research programme.

“Before, when I would step out, the neighbours would talk about me to my mother and I would feel very shy to talk to them. They would ask her why she was letting me out and question the use of letting a girl go out like that. Gradually, I started talking to them and telling them what I would learn and how it would help me, and I would not avoid them anymore and they would also understand me.”

Women and girls’ involvement in research in LMICs can equip them to challenge restrictive norms but can also expose them to an increased risk of backlash when they speak out. When young women and girls are involved in research, they can gain the information, tools, role models and confidence they need to challenge social norms, however they still face the threat of backlash for speaking out and challenging these norms. Experts agreed and pointed to the additional threat of violence that girls and women face in LMICs, especially if research processes or findings are considered disruptive to power brokers within communities and families. Safiya, a 16-year-old high school student from Mumbai, shared her experience of being involved in a research programme that advocates for the rights of girls in informal settlements.

“We were taught [by the CBO facilitator] not to stay quiet when we were spoken to or touched inappropriately... This was difficult [initially] as we are not used to [speaking out]. Over time...I started gaining confidence and feeling like I could do this. It was not only that they were teaching me about it, but whoever was teaching me about it would behave in a confident way within the community and that gave me courage to do the same.”

Arya, an 18-year-old research fellow shared her early experiences of being involved in research in her community that made her feel discouraged in pursuing such opportunities

“I did not want my community to shame me [for participating in the research programme]. Most communities, when they see girls talking to boys [which we have to do during research], will start calling them names and shame them by saying that they have boyfriends around.”

On some health topics, men and boys face additional barriers of their own. The social pressure on men and boys to project an image of ‘strength’ may affect their involvement in research on more sensitive topics. For instance, a topic like mental health can mean going against the norm that boys and men should avoid showing or talking about their emotions. A researcher working in mental health in an HIC witnessed this first-hand as she shared that significantly more girls were involved in her YPAG than boys. Lerato, a health worker who supports young people explained the pressures that affect men and boys’ willingness to get involved in research that requires expressing emotions

“Indoctrination by family says that a man is supposed to be strong, not show emotions, and provide for his family. It is mainly tradition that has a certain image of a man.”

Young people from the LGBTQI+ community are less likely to be involved in health research, however safe spaces for involvement can be created through role models from within the community. Young people, CBOs professionals and other experts consulted pointed out that social and/or legal landscapes can be a deterrent to involving young people from the LGBTQI+ community in research. They fear being ‘outed’ in the absence of safe ways to involve, and mechanisms that can support managing tensions that arise when cultural norms on sexuality come in conflict with research efforts. However, it is important to note that there are examples of young people being involved successfully when there are role models from within the community with a track record of successful involvement in research. Dian, a 21-year-old clinical psychology master’s student from West Java, Indonesia has been conducting her research on the mental health of sexual minorities. She shared her experience of working with the LGBTQI+ community during research

“Here... [in Indonesia], we don’t discuss sexuality and gender. I am a Muslim, and my being pro-LGBT is important ... [for this work].”

Huong, a transgender researcher and activist from Vietnam, has been working in mental health research for a few years. He now runs a community-based organisation that trains young people [members of the LGBTQI+ community and their allies] on ways to conduct research on mental health in the community. While discussing the journey in research that led him to start this organisation, Huong recalled the open call and recruitment process of his first project

“I remember this was the first time I read that they wanted to recruit a transgender assistant and that they would be a part of the whole process to assist the university with the data analysis. I saw it as an opportunity to support the community. As the first trans person from my country ... [to do this type of research], I was very proud of that.”

4.4.3. Disability and chronic conditions

Young people with disabilities or chronic conditions are less likely to get involved in health research because researchers fail to accommodate their needs.

Experts said that researchers sometimes fail to accommodate the reduced mobility of young people with a disability or a chronic condition. Many young people with a disability find it difficult to physically access semi-public spaces including university buildings, and the hassle of travel is amplified for them. As a result, these young people often struggle to travel to research meetings or carry out research activities that require them to travel to different places, explained a researcher in a HIC.

Experts shared that young people with disability or a chronic condition often lack free time and face mental health issues. Many undergo regular, long-term treatment, which leaves them with less time or energy to participate in health research. This increases the difficulties of scheduling time for them to participate in health research, and increases other barriers, such as creating a safe space for research to take place.

Chronic conditions can also lead to other challenges for young people, which further reduces the likelihood they will be involved in research opportunities. Young people with chronic conditions may lack access to appropriate technology, not have a permanent home, or avoid public spaces such as schools or clinics for fear of being marginalised or criminalised. One expert interviewed explained that she had faced some of these challenges while working with young people who experience substance abuse. As a result, health researchers and community organisations have to invest time in designing targeted strategies to communicate research opportunities to these young people.

4.5. Challenges in involving young people in health research in LMICs

As mentioned in section 2, the RER showed less evidence of young people's involvement in health research in LMICs. Evidence gathered during stakeholder consultations confirms this finding. There was greater institutional support for research involving young people in HICs, and more experts in young people's involvement conduct their studies in HICs. However, most experts were not able to state with confidence whether there was more evidence in LMICs versus HICs on this topic.

Fewer young people in LMICs enrol in university, where many research opportunities exist. Many young people in HICs access research opportunities as students in their universities, for example by acting as a research assistant on a professor's project. In LMICs, financial and cultural constraints make higher education inaccessible for most young people, as explained by an advocacy expert and former young researcher in an LMIC. Consequently, young people in LMICs tend to rely more on CBOs in their communities to access research opportunities.

Communities can be governed by several levels of gatekeeping that can make it difficult for researchers to access young people. Informal gatekeepers in communities, for example, 'Mama kijijis' (village mothers) in Kenya or 'Sarpanch' (village leaders) in India, are motivated by direct benefits such as monetary gains, power and reputation for their role in research. While they offer researchers security and can provide quick access to young people because of their familiarity with the community, they also transfer their selection biases, which can in turn, bias research sampling. Linda, a 16-year-old secondary student from Nairobi, Kenya shared her perspective on how gatekeepers impose their selection biases

"This community can be corrupt. When people come and use a middle community. Like "mama kijiji" to get respondents - they want to get paid and take a cut on what originally belongs to the community. For example, they will pick Nancy, not me, because we had a disagreement, or I am not talking as much. You should come to us directly and not use middlemen."

To overcome this issue, NGOs and CBOs professionals and researchers have had to find innovative means to reach young people directly in order to involve them in research, like attending existing gatherings where young people come together (festivals, community meetings, schools and after school tuition classes). Moreover, expert researchers in LMICs reported that they instead entered communities without affiliations with local informal gatekeepers and developed relationships and trust directly with the parents of young people.

Conversely, in HICs, some experts reported that working with volunteer organisations and NGOs (seen as forms of gatekeepers) was the best way to reach disadvantaged groups. One researcher that recruited for a YPAG for young people with drug and alcohol problems, explained more about their work with gatekeepers.

"The most efficient way to connect with marginalised young people is to connect with the volunteer sector. It's about finding the gatekeepers and the trusted people in the community. We found organisations working with vulnerable young people, they brought them to meetings and supported them".

Young people in LMICs said that the approach to education in some LMICs prepares them less well to work on research. In some interviews with young people in LMICs, it was reported that traditional teaching approaches demotivated young people from adopting inquisitive research mindsets or did not encourage debate or divergent

views. One adult researcher with experience working with young people in LMICs explained that their involvement in the ideation stages of research requires them to exercise curiosity, take risks, feel safe to fail and challenge perceptions, which may not be in line with their formal education principles. She explained that young people in her country are often at a disadvantage compared to young people from the US. They are naturally hesitant to get involved in research whereas many young people from the US have been socialized to believe they can do anything. Young people interviewed confirmed facing such a barrier. Aida, a 20-year-old college student from Dakar, Senegal, shared an experience where her curiosity and initiative were discouraged in the classroom

“The professor said I would never be able to finish [the chemistry experiment] on time and asked me to leave the lab. I stayed back anyways because I was excited by the idea of trying to do the experiment on my own. The next day he told me that I did it all wrong without even seeing it. He did that because I did not obey him.”

Training young people while conducting research in LMICs results in a culmination of challenges around language, time, and varied education levels that adult researchers are not set up to navigate. Although not impossible, it is difficult for academic or technically trained researchers to give on-the-go, in-depth practical and theoretical training to young researchers, given barriers such as limited and sporadic research durations, access to training software or tools and the varying education levels of young people (including numeracy and literacy). For young people, it can feel uninviting when the training and facilitation style is full of jargon and does not take into account their language preferences. CBOs professionals emphasised the importance of using ‘youth-friendly’ language in research materials and training in order to engage young people and sustain their interest. Bonang, a youth leader and researcher in South Africa who coordinates with research organisations to involve young people in health research highlighted

“The facilitation style of the trainer is important in creating a safe space for [research] training...Young people are intimidated by language/knowledge/terminology, hence use language they can relate to.”

Huong, a transgender activist and researcher from Hanoi, Vietnam recalled their challenging first experience of research training

“The training curriculum was difficult to read and understand as a person who didn’t have the background. It was overwhelming.”

Some researchers said cultural norms in LMICs leave less room for young people’s voices to be heard in research. Experts and young people reported that some communities in LMICs can be perceived to value young people’s opinions less than in HICs. Young people are considered as lacking the agency, knowledge and credibility to get involved in research, explained two adult experts who were interviewed. These cultural norms are internalised by both researchers and young people. They lead researchers to undervalue young people’s involvement; and steer young people to think they do not have enough expertise to participate in health research, shared a researcher in a LMIC. Other interviews with stakeholders in LMICs indicated that the role and contribution of young people in research, especially those who are not formally trained, is often undervalued by communities and families. Joseph, a lab technician working in a maternal health clinic doing outreach initiatives with young people in Nairobi, Kenya explained particular community perceptions

“A traditional African belief is that young people are not old enough to give valuable input, their minds are too young. We are always told that the days of the young people are tomorrow. Not today.”

Young people and CBOs professionals in LMICs stated that cultural norms may make parents more cautious about their children’s involvement. They said parents fear that if their children get involved in research, they might be unsafe, fall into bad company, or get “spoiled” if they learn about taboo topics, such as sexual health and mental health. This makes it less likely for parents to give consent for their children to get involved in research. Karabo, a health worker from Pretoria, South Africa, who trains young people in her community on health awareness programmes explained

“Some parents are very strict so kids can’t talk to them...The parents don’t feel comfortable if their kids learn about periods, HIV, etc... They have questions like why are you teaching my kids all these things.”

Furthermore, Bokamoso, a 15-year-old high school student from Cape Town, South Africa, argued that

“Parents and grandparents need to be more open-minded about what young people can do and should not just force what they think is right.”

Young people in LMICs also believe that funding restrictions prevent them from having the influence over research direction and outcomes that they would like. Interviews with young people involved in research revealed that funding timelines and resources leave them with little agency to steer their research in the directions that emerge during research and are critical to outcomes. Setting up health research requires time, effort and resources on young people’s behalf in order to build trust and establish relationships before conducting research. Working on timelines driven by funding does not account for these efforts. Young people feel that they do not have the bargaining power they need to engage funders for flexibility needed for good research. Dian is a 22-year-old master’s student of clinical psychology from Jakarta, Indonesia, who conducts research on mental health with sexual minorities through a CBO. She shared her inability to negotiate flexibility with funders.

“I have funding from university to conduct research, but it is limited to the end of year. It makes me feel forced to conduct research at a fast pace. Whenever I find a new direction in the middle of the process, when I report that, I can’t go in that direction, but that direction is very interesting. It is sad but, what can you do? It is their money.”

Echoing similar sentiments, Thanh, a 16-year-old high student from Hanoi, Vietnam who works with a youth-run CBO pointed out the pressure to produce results within a timeline that is set by funders.

“I would say [to funders], please be patient. Often, they expect immediate results, but in this field, it is hard if you are impatient. Education is much more than putting in USD and getting immediate results.”

Trust can act as a significant barrier to working with young people in LMICs. It takes time and effort for adult researchers to build trust with communities in LMICs and to overcome the cultural barriers hindering young people’s involvement in health research. Experts shared that researchers, especially those from HICs, often come into communities to conduct their research project without having built trust with the community, and without a strong understanding of the local context. This approach does not work for participatory health research, especially when it involves young people. Experts explained that researchers need to be trusted by the community in order for adults to give their consent or approval and for young people to have the confidence to get involved. An advocacy expert explained

“Often, researchers do not invest sufficient time in building networks with LMIC ecosystems. But due to cultural norms, it is even more important to invest in network-building.”

For researchers from LMICs, systemic inequities in funding and capacity-building make it difficult to involve young people in health research. Experts and young people who were interviewed agreed that there are systemic inequities in how funding is allocated. According to a researcher in a HIC, most of the funding is still allocated to health researchers based in HICs who do research in LMICs and get the credit for it, even when they have partnered with researchers based locally. It is therefore difficult for researchers in LMICs to find the resources, and to have the agency, to involve young people in their research. Eventually, this limits the research opportunities young people in LMICs have access to. Constrained funding also leads to a lack of capacity-building for researchers from LMICs who would like to involve young people in health research. They cannot easily access support and best practices and might shy away from involving young people in their work as a result. For instance, even though there is an international network for participatory health research, researchers from LMICs often do not have the funding to access the network’s conferences.

5. How Wellcome can support the scale-up of young people's involvement

CHAPTER SUMMARY

A series of recommendations for Wellcome have been developed and potential partner organisations to consider have been identified by the stakeholders. These are based on the opportunities and challenges that have been indicated through the RER, and the stakeholder consultation and in summary are:

- 1. Develop a new standard among funders on how young people's involvement in health research should be supported.**
- 2. Develop best practices on how to involve young people successfully.**
- 3. Connect and formalise existing networks focused on involving young people in health research.**
- 4. Strengthen and standardise M&E practices.**
- 5. Support the generation and dissemination of evidence to fill gaps and garner more support across the research community.**

Recommendations were also developed for Wellcome to actively support the involvement of young people in health research in LMICs. Much of these focus on which stakeholders to bring into the conversation: LMIC-based experts; large health funders focused on LMICs; NGOs and local religious and political bodies with strong community networks; young leaders and influencers. Engaging these groups will be essential when scaling up young people's involvement effectively. Moreover, best practices need to be adapted to these settings. Similar recommendations apply to how to ensure that research that involves young people is inclusive. NGOs can help reach young people from disadvantaged or marginalized backgrounds. Guidelines must also be tailored to working with these groups.

Particular attention was paid to how Wellcome can create conducive working cultures in teams for young people to work effectively. Developing and institutionalising training materials which identify and help correct bias against young people and promote a sustainable and enjoyable research culture for all would help contribute towards this aim.

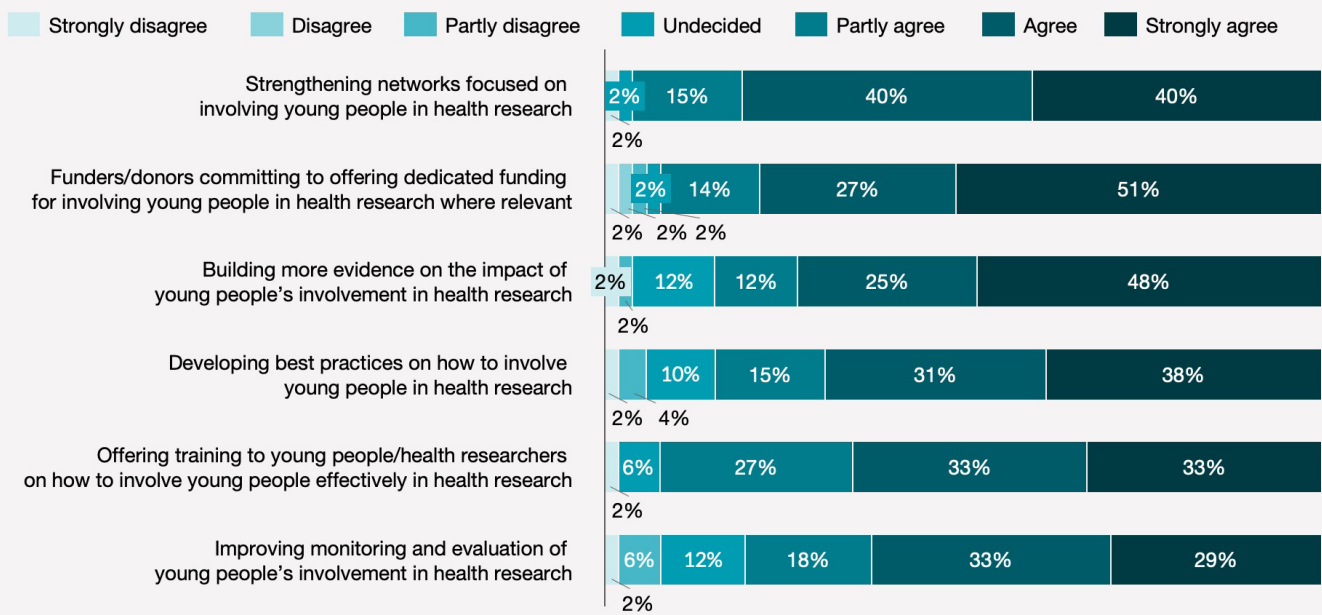
When looking at how Wellcome might involve young people in internal agenda-setting and funding decisions, recommendations focused on finding engaging methods to listen to and involve young people in various activities of a funder. For example, involving young people in the assessment of funding applications, establishing a youth advisory council, and using town halls for senior leadership to speak with young people directly.

5.1. Recommendations on how to strengthen the involvement of young people in health research

A series of recommendations for Wellcome and potential partner organisations to consider, have been developed. These are based on the opportunities and challenges that have been identified through the RER and the stakeholder consultation. In the sections that follow, a number of solutions are presented, describing the challenges they address and the steps Wellcome could take to implement them. Special attention is called out for how these recommendations apply to specific contexts and/or groups that Wellcome has prioritised (e.g. research in LMICs, or young people from diverse backgrounds).

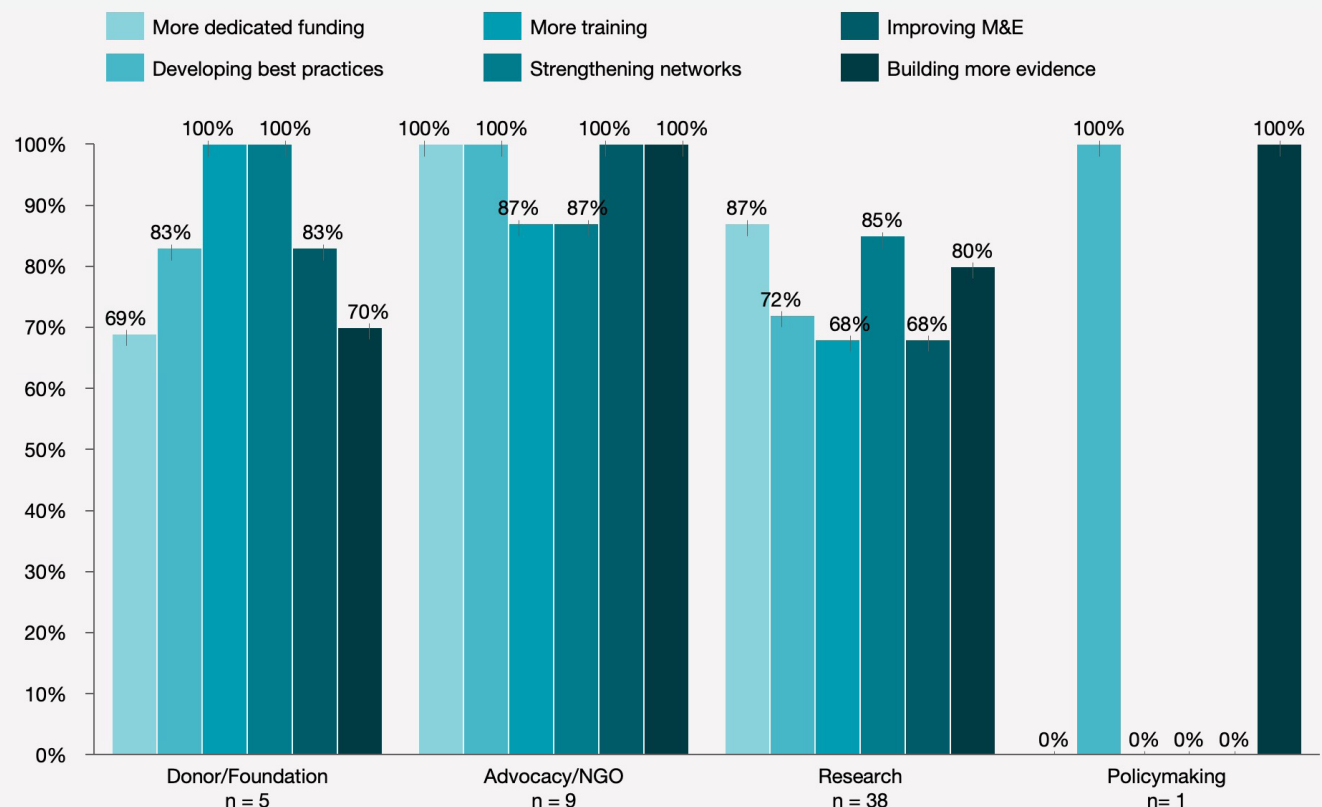
Experts surveyed were asked to provide their views on how useful each of the recommendations might be (see figure 8 below). More than 80% of experts surveyed partly to strongly agreed with each of the recommendations listed in this section. The experts agreed most strongly with the importance of strengthening networks focused on involving young people in health research (see recommendation 5.1.3) and funders committing to offering dedicated funding for involving young people in health research (see recommendation 5.1.1).

Figure 9:
Percentage of experts surveyed, by level of support for each recommendation



Stakeholders views on which recommendations are most needed vary by their type of organisation (see figure 9). Funding was cited as a top priority by all groups excluding a policymaker and, most importantly, donors and foundations, who in fact rank it last. Donors and foundations instead indicated that it is most critical to strengthen networks and offer more training.

Figure 10:
Surveyed experts' views on recommended solutions for strengthening and scaling up young people's involvement in health research, by type of organisation (% who agree/strongly agree)



RECOMMENDATIONS

5.1.1. Develop a new standard among funders on how young people's involvement in health research should be supported

WHY IS THIS NEEDED?

Many adults and young people involved in health research who were consulted highlighted the lack of funding as a critical bottleneck. Notably, this was the second-highest ranked recommendation among surveyed experts. 78% agreed/strongly agreed that it would help effectively scale up young people's involvement in health research.

Moreover, stakeholders reported that researchers tend to under-estimate the time and resources required to involve young people in health research effectively. For example, too little is invested in adapting research methods to ensure that young people feel empowered to share their opinions and challenge the direction of decision-making. Experts also said that there is a need for more funding, beyond the budgets set for specific research projects. This dedicated funding would, for example, allow young people to play a role in deciding which projects get funded and what their objectives should be. There is an opportunity then for Wellcome to identify what amount of funding is needed in health research to involve young people effectively, how to deploy that funding and how to ensure it is being used effectively.

WHAT COULD WELLCOME DO?

Short-Term Actions

Assemble a group of health researchers with expertise in involving young people across varied contexts to understand funding needs. There are several factors that are likely to influence the level of funding required on a research project or programme. These factors include but are not limited to: where the research takes place (e.g. LMIC or HIC), the health topic being researched (e.g. infectious diseases or mental health), the research setting (e.g. schools or clinical labs), the role that young people are playing in the research (e.g. leading data collection or disseminating research within their communities). Specific attention must be paid to the mechanisms that can be used to incentivise and enable young people's involvement (e.g. one-off payments for work carried out; long-term scholarships; financing of research facilities appropriate for young people). A range of experts on involving young people in health research in different contexts could advise on the extent to which these factors influence funding requirements, and how indicators and metrics can be used to estimate funding needs at the outset of projects.

Pilot a focused set of projects to test these recommended funding approaches. Once the factors and corresponding indicators mentioned above have been proposed, Wellcome could prioritize a varied set of projects to fund. Once these projects have been implemented, there would then be an opportunity to evaluate the extent to which methods used to forecast funding requirements are fit-for-purpose. As mentioned in later recommendations, this piloting will also be a chance to test how to monitor and evaluate projects.

Medium- To Long-Term Actions

Develop guidance for the global health research ecosystem on how young people's involvement could be funded. Lessons taken from the piloting phase could then be translated into a formal and public set of guidelines on funding that donors, policymakers, universities, private companies and other researchers could use to set budgets and monitor outcomes on projects involving young people. This guidance could be incorporated into a wider set of best practices to be mainstreamed by Wellcome.

Allocate funding that allows young people to exert influence on agenda-setting. Section 5.5 provides recommendations on how Wellcome could create spaces for young people to influence decisions on what research gets funded.

5.1.2. Develop best practices on how to involve young people successfully

WHY IS THIS NEEDED?

This was the fourth highest ranked recommendation among surveyed experts. 69% agree/strongly agree that it would help effectively scale up young people's involvement in health research. Moreover, adult experts could not point to a comprehensive, universally relevant and mainstreamed set of guidelines on how to successfully involve young people in health research. In particular, they reported that there is no guidance on how to:

- 1. Understand the role young people could play in health research.** Researchers lack guidance on understanding what roles young people can play and which of those would best fit their research. Indicatively, an adult researcher who was interviewed in an LMIC context said that he was part of several committees which decided policies on child health, and he and his group were open to involving young people. However, in that context, they did not know what role young people could play or how they could contribute.
- 2. Involve diverse groups of young people in specific health research topics and in particular settings.** Less is known about how to involve young people from disadvantaged and/or marginalised groups (e.g. low-income or disabled), and how to involve young people in some health research topics (e.g. health implications of climate change) or contexts (e.g. in LMICs).
- 3. Compare and contrast different methodologies and methods of involving young people in research.** Experienced adult researchers had often developed expertise in involving young people applying one particular approach - such as a YPAG. However, they did not have expertise in involving young people through other approaches, and they cited a lack of guidance for how to select the most appropriate ones for involving young people.
- 4. Seek consent from young people or navigate country-specific ethics norms and rules.** One of the biggest barriers to researchers is the lack of guidance on how to approach ethical involvement of young people in unfamiliar legal environments. Different countries have different laws on whose permission must be sought, what child protection safeguards must be in place, and how young people can be remunerated for their work. All adult researchers consulted expressed their willingness to conduct research as ethically as possible but were put off conducting research in new settings because of the difficulty of understanding other countries guidelines and laws.

WHAT COULD WELLCOME DO?

Short-Term Actions

Synthesise existing best practices into one publicly accessible document. Wellcome could collaborate with experts in the field to gather documentation on best practices regarding young people's involvement. Wellcome could work with these experts to synthesise key recommendations from this library into guidance documents that relate to different aspects of young people's involvement in health research, such as how to establish research projects with young people (choosing a methodology, obtaining funding, ethical considerations), how to conduct research with young people (practical recommendations for location, scheduling, transport, and remuneration), and how to evaluate research with young people. Moreover, there is a pressing need for better ways to identify and celebrate projects and institutions who are exemplars of best practice.

Medium- To Long-Term Actions

Fill gaps in best practices by consulting with adult experts in young people's involvement in health research and young people with experience in health research. Wellcome could consult with adult experts and young people with experience in health research from countries across the world, to develop a comprehensive and globally relevant set of guidelines which cover all aspects of establishing a health research project that involves young people. This guide could potentially be modular, with different sections of guidance for working with different age groups, in different health topics, or in different country settings. Within this work, there is an opportunity to ensure that ways of working are adjusted based on creative and engaging methods that appeal to young people and sustain their engagement over time.

Test these recommendations in different settings with local experts. Wellcome could work with experts (adults and young people) in different local settings, working on different health topics, to test these synthesised recommendations. After a period of trial and feedback, Wellcome could iterate on these best practices to develop guidance which suits researchers in different environments, with different goals.

Actively involve young people in the development and dissemination of best practices. Young people could be involved in co-producing the best practice guidance and could be empowered to develop research dissemination plans which complement more “traditional” dissemination activities like publishing the documents in a journal and presenting them at conferences. Additionally, involving young people in the dissemination of research findings of best practice back to the communities that they come from, can also enable collaborative thinking between researchers, young people and communities.

Keep the guidance documents up to date by adapting recommendations over time based on emerging evidence of what works well or less well in practice. After developing guidance materials and disseminating them, Wellcome would need to ensure that these are being updated when new evidence becomes available.

Develop training resources and other capacity-building initiatives for adult researchers and young people that can help standardise these best practices in local research ecosystems. 66% of experts surveyed agree/strongly agree that offering training to adult researchers and young people would help effectively scale up young people’s involvement. Moreover, information from guidance documents could also be disseminated through training resources, workshops, and interactive exercises. These could be adapted to in-person and online channels. These training resources should ideally be developed with young people to ensure they meet their needs. They should be accessible to young people, simplifying the language and learning techniques by incorporating mediums such as audio, visuals or video. Further ways to consider for promoting best practice are via establishing a network of centres of excellence or funding a prize for exemplar individuals and institutions.

5.1.3. Connect and formalise existing networks focused on involving young people in health research

WHY IS THIS NEEDED?

Adult experts reported several networks and working groups connecting them together to share experiences and learnings, but these networks are typically small-scale. These networks are typically based on a specialism within young people’s involvement in health research, such as involving young people through YPAGs, or involving young people in a school setting. Adult researchers really appreciated these networks as opportunities to share information and connect with others. However, they recognised the limitations of these networks in terms of scale, focus, and funding. They identified some features they would appreciate that existing networks lack:

- 1. opportunities for less experienced young and adult researchers to connect with more experienced adult researchers who will act as mentors to support their learning;**
- 2. connections to NGOs and CBOs that are trusted by young people and their local communities;**
- 3. channels for adult experts to connect with peers in different regions and countries;**
- 4. connections between adults and young people (as well as between young people) so that young people are better able to access opportunities that exist.**

Experts consulted highlighted the need for a sector coordinator to create a platform for knowledge to be shared. Some experts also recommended Wellcome organised a regular conference, which previously existed in this space but is no longer held. Connecting and formalising existing networks was the highest ranked recommendation among surveyed experts. 80% agreed/strongly agreed that it would help effectively scale up young people’s involvement in health research.

WHAT COULD WELLCOME DO?

Short-Term Actions

Conduct a survey in existing networks to understand the additional support needed from a larger, more formal network and to identify opportunities for capacity building or capacity matching. Wellcome could use a survey to understand the priorities for network members and identify potential crossover where existing separate networks have complementary capabilities.

Support existing networks in this space to connect and collaborate. Wellcome could establish regular information-sharing events for different researchers and representatives of existing networks to collaborate. Helping these groups communicate beyond these events could support more partnerships and collaborations to occur organically.

Compile a directory of youth and health-focused NGOs and CBOs to help connect researchers with organisations in their local communities, especially in LMICs. NGOs and CBOs have experience and expertise in trust building in LMICs and could help introduce researchers to their local communities to enable through partnerships, to involve young people in health research.

Medium- To Long-Term Actions

Formalise existing networks into a coordinated global platform for young people's involvement in health research. Wellcome could identify key roles and responsibilities for the new network, such as developing learning materials and establishing partnerships. Network members would include adult researchers, professionals from NGOs and CBOs, school staff, and young people who want to be involved in health research, such as members of the IFMSA. Wellcome could then build out activities, including task forces for different health topics and design programmes to meet the additional support requested by network users (such as a mentoring programme).

5.1.4. Strengthen and standardise Monitoring and Evaluation practices

WHY IS THIS NEEDED?

Many experts interviewed raised weak M&E as a key concern. Stakeholders pointed out this gap needs to be addressed for three reasons:

- 1. There is no standardised evaluation methodology for assessing the impact of involving young people in health research, or standard use of terminology to describe young people's involvement. This makes it difficult for adult researchers to access information on activity that is happening.**
- 2. Some funders want more quantitative evidence of impact on project outcomes, rather than the data generated by existing qualitative approaches.**
- 3. Young people involved in research can sometimes misconstrue the purpose of M&E, seeing it as an evaluation of their own performance, and therefore avoiding or under-investing in the task.**

However, it should be noted that improving M&E was the lowest ranked recommendation among surveyed experts when compared to other recommendations. Specifically, 62% of the respondents agree/strongly agree that improving M&E would help effectively scale up young people's involvement in health research.

WHAT COULD WELLCOME DO?

Short-Term Actions

Invest in building a library of existing M&E guidelines and tools to inform this process. As with best practices in general, Wellcome could compile, assess and synthesise existing guidance on M&E practices.

Pilot different evaluation approaches. When funding pilot projects (see recommendation 5.1.1), Wellcome could also experiment with different approaches and tools to evaluating the projects, informed by the aforementioned library of existing M&E guidance. For example, quantitative and qualitative metrics could be tracked against the predetermined outputs and outcomes and/or the perspectives of stakeholders involved could be collected (e.g. through structured and open-ended feedback from young people and the local community members).

Partner with leading health funders to understand the quality of evidence required for them to further scale up their support for young people's involvement in health research. Wellcome could work with other funders in this space, such as Fondation Botnar or the Ford Foundation, who may be supportive of young people's involvement in health research, to understand the types of metrics and outcomes they expect to see when investing in this research. Wellcome could also use a partnership as a way to open up dialogue in how to scale up young people's involvement in health research more generally.

Medium- To Long-Term Actions

Integrate robust M&E practices into a comprehensive document and develop a plan to make these practices mainstream. After piloting and testing ideas and working across the sector to understand common metrics which should be captured and existing barriers to more comprehensive evaluation, Wellcome could develop these findings into a 'How To' document on M&E for health research involving young people. 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. These findings could be incorporated into the "best practices" document suggested in 5.1.2. Wellcome could then plan a series of dissemination activities to ensure this document becomes widely known, well-understood, and the 'gold standard' document for M&E guidance for involving young people in health research. This dissemination plan could include producing evaluation templates and checklists, running training sessions, organising launch events and producing videos. The 'How To' document on M&E could be circulated through the existing networks to amplify the reach of the new guidance.

5.1.5. Support the generation and dissemination of evidence to fill gaps and garner more support across the research community

WHY IS THIS NEEDED?

Evidence suggests that young people's involvement in health research is growing, and the RER and stakeholder consultations have yielded compelling examples of the impact it can make on research quality and the development of young people and their surrounding communities. However, as mentioned earlier in this chapter, significant gaps in evidence persist. Certain health topics (e.g. the health implications of 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. The expert survey respondents ranked the support for generating and disseminating evidence as the third highest recommendation. 73% agreed/strongly agreed that it would help effectively scale up young people's involvement in health research.

WHAT COULD WELLCOME DO?

Short-Term Actions

Prioritise under-reported areas in pilot projects. Wellcome could fund research projects which pro-actively involve young people in its three health challenge areas, particularly in LMICs. This would give Wellcome an opportunity to pilot new funding and M&E approaches and support the systematic measurement and reporting of evidence of impact.

Advocate for involving young people in health research with funders and researchers. Wellcome could champion young people's role and involvement in research with researchers and funders focused on its three health challenge areas. The role of a funder as a key champion is crucial, to encourage other funders to invest in research that involves young people and also incentivise research and research institutions accordingly. Funding can drive behaviour hence it is important for funders to promote the value of involving young people as researchers as much as trying to lift the barriers that prevent this.

Medium- To Long-Term Actions

Establish a norm to involve young people in all relevant health research funded by Wellcome across each of the three health challenge areas. Wellcome's research funding could stipulate that additional budget will be provided to involve young people wherever grantees can demonstrate the purpose, need and appropriate approach for involving them and use these examples to demonstrate to other grantees how young people can be meaningfully involved in different research topics and on different themes. Wellcome could also develop this norm by inviting researchers and funders from each health challenge area to participate in a formalised network on young people's involvement (see recommendation 5.1.3).

5.2. How Wellcome can support the involvement of young people in LMICs

Support LMIC-based experts in involving young people. The majority of health experts whose work involves young people are based in HICs. Targeted funding is needed to redress this imbalance and build stronger expertise in LMICs. These specialists can then be leveraged to advise their wider national and regional ecosystems of health research.

Prioritise advocacy with large health funders in LMICs. In LMICs, initiatives to involve young people in health research are more reliant on foundation support than in HICs. These funders tend to prioritise urgent, more fundamental health interventions because they are typically less comprehensively addressed than in HICs. This means that in LMICs, foundations are seeking a higher burden of proof for the impact of involving young people in health research than in HIC settings.

Prioritise NGOs, CBOs in LMICs as central members of new networks Wellcome develops. NGOs and CBOs in LMICs have strong links to communities, particularly those that are less likely to be involved in research. They are often trusted in local communities and have strong track records of creating research opportunities for young people without formal academic training. Therefore, these organisations should be integral to any network-building activities and given a direct link to other experts in involving young people in health research.

Prioritise young leaders and influencers based in LMICs. When Wellcome works with organisations and youth groups based in LMICs, it could specifically identify influential young leaders to work with to promote messages about involving young people in health research. Examples of young leaders could be those with large social media followings, or those who are well-known for their activism. Wellcome could develop partnerships with these young people to raise the profile of this area of work.

Align with local political and religious bodies to create a conducive environment for young people's involvement in research. Research towards better health outcomes can overlap with the work local leaders are pursuing, and when aligned, these authorities can amplify research efforts involving young people. However, young people and

CBO professionals felt resistance from leaders who feared that young people-driven research and advocacy would draw attention to the shortcomings in their communities. This resistance manifested as threats or disruptions to basic services. It is important to consider these safety and risk factors and, where possible, align with local leaders before the research begins.

Create best practices specific to LMIC contexts. Researchers with deep expertise in involving young people in LMICs feel that existing guidelines need to be better tailored to local contexts in terms of language, legal frameworks, and cultural norms. For example, best practices could act as a resource for adult researchers and young people to navigate the conflict that involvement in research can provoke when it challenges cultural norms or engage in topics that are sensitive. This resource would help to build trust with community gatekeepers, assure parents about the participation of their children, and provide a safe space for young people to learn.

5.3. How Wellcome can support the involvement of diverse groups of young people

When developing funding estimates, allow for additional funding to reach and involve disadvantaged and/or marginalised young people. During the development of investment portfolios that will support research involving young people it is important to understand, estimate, and factor in the level of resources required to involve young people from disadvantaged backgrounds. Stakeholders most commonly reported trust-building as the key barrier to engaging low-income and other marginalised groups in health research. The additional efforts to develop trust with young people take more time, and require more support, and training (for example, regarding safeguarding).

Work through NGOs and CBOs to contact disadvantaged groups of young people. Experts and young people recognised that their strongest links to disadvantaged groups had been created through local NGOs and CBOs who have well established relationships with their communities. This highlights the importance of making CBOs/NGOs central players within any network-building Wellcome supports.

Develop best practices specific to working with disadvantaged groups. The primary barrier that deters disadvantaged and/or marginalised young people from being involved in research is the need to cover their expenses of participation, or to outweigh the opportunity cost of other income-earning activities which conflict with the research. Young people from disadvantaged backgrounds would also benefit from best practices informing adult researchers how to avoid unintended consequences of involvement in research, such as dropping out of school to focus full-time on income-generating health research. Best practices can guide researchers on the issues around remuneration, such as the appropriate amount to compensate young people, the appropriate form of payment (e.g. vouchers, money, gifts), and the best methods of paying them (e.g. cash, bank transfer). The answers to these may differ by country and by age group.

5.4. How Wellcome can influence a research culture that is conducive to the involvement of young people

According to experts and young people, health research teams that involve young people can reinforce cultures that make it harder for them to have their voices heard. This can stem from three issues: (1) A bias toward technical knowledge over experiential knowledge of local contexts or emerging issues; (2) Risk aversion among research funders causing grants to be allocated disproportionately to the most experienced or senior researchers; (3) Geographic or income biases, particularly in some LMICs where it can be culturally less acceptable to challenge the hierarchy which favours wealthy, Western, educated researchers. When opting to use peer networks to access young people, it is important for researchers to take a collaborative or youth-led approach in order to maintain young people's sense of control and agency and to avoid rupturing the open and safe dynamics that exist within these networks.

Support healthy team dynamics by institutionalising anti-bias training and checks internally. Wellcome could implement checks for unconscious biases against young people in funding allocation decisions at Wellcome. This

could be led by an advisory group such as the one described in section 5.5. An example of an anti-bias check could be involving representatives for young people in funding decision meetings to flag language which is dismissive of young people. Wellcome could also implement unconscious bias training throughout the organisation to foster an environment supportive of young people's involvement.

Integrate bias screening and correction tactics into best practice documents. Wellcome could allocate time early in projects for research teams to build rapport and establish communication and decision-making norms between adults and young people, particularly when disadvantaged groups are involved or when research teams comprise different nationalities and cultures. Best practices could also outline the available training materials on how to identify and correct for biases that may disrupt teams. In countries with a limited history of young people challenging the "authority" of adults in civic life, best practices could recommend that the adult researchers running the project engage religious or political authorities to openly support young people's involvement in research and in civic life more broadly.

Develop training materials which advise on working with young people in a way which is sustainable and enjoyable for them. Training materials could focus on developing a healthy environment for young people, such as through the anti-bias checks and training mentioned above. Training materials could emphasise maintaining young people's attention throughout a research project, including during stages which young people typically see as more mundane or routine, and working with them through methods and mediums relevant to them, such as through using technology and social media.

5.5. How Wellcome can involve young people in internal agenda-setting and funding decisions

Experiment with different methods of involving young people. There is an opportunity to explore and pilot mechanisms for involving young people in senior levels of decision-making to understand how one or a combination of options best fit Wellcome's needs. Different examples have been proposed by experts, including:

- 1. Regularly involve young people the assessment of funding applications.** Involving young people at the funding stage enables them to provide input on which proposals might have the most appropriate mechanisms of a project involving young people in the research. This role could be structured in a number of ways. For example, a young person might be an equal member of the review panel assessing the research proposals or might be responsible for scoring different proposals on their "youth-friendliness."
- 2. Establish an internal Youth Advisory Council (YAC).** An internal advisory council made up of young people could collaborate on decision-making with senior leadership at regular intervals. For example, they could develop new ideas for ways to involve young people throughout the organisation. This YAC would not necessarily need to be specific to Wellcome, but instead could be made up of invitees who sit on different YPAGs across the country and internationally, who already have some understanding of research and some experience in this type of role.
- 3. Hold online or in-person town halls for senior leadership to speak directly to young people.** These town halls would be an opportunity for Wellcome to quickly understand the perspectives and ideas of large groups of diverse young people, and where its existing strategies, policies, and practices are not aligned with young people's interests.

5.6. Stakeholders that Wellcome can partner with to catalyse young people's involvement in health research

Experts in involving young people in health research

Wellcome could partner with experts in involving young people in health research to:

1. **synthesise best practices;**
2. **create additional guidelines and training materials;**
3. **disseminate those materials;**
4. **identify the varying funding needs of their research projects.**

Experts in involving young people in health research are best placed to identify what guidelines already exist and help Wellcome determine how to fill any gaps.

People¹⁰ and organisations to consider:

- Researcher with expertise in malaria, who works with young women at KEMRI-Wellcome.
- Expert in child and youth-participatory research, working for the Centre for Children and Young People at Southern Cross University, Australia.
- Members of the IMFSA, Association of medical students who carry out research, notably on the health effects of climate change. They supported the WHO with a climate and health literature review and helped funders with the dissemination of research findings.
- Researcher working for the Population Dynamics and Reproductive Health Unit at the African Population and Health Research Center (APHRC)¹¹. The researcher has been involved in several youth-focused projects including the Global Early Adolescent Study which involved young researchers.
- Researcher in South Africa, working on the understanding of TB within a youth-based community engagement initiative run by Eh!Woza.
- Researcher, member of the IMFSA, who is a strong advocate for climate and health and is part of the Civil Society Working Group for the WHO Non-Communicable Diseases (NCD) team, which is regarded as one of the most advanced at involving young people in health research.
- Researcher who has worked with young people in health research in North and Latin America, and has authored a book on community-based participatory research for health.
- Wellbeing Health and Youth Centre of Research Excellence: Interdisciplinary team of researchers working with young people on adolescent health. Have created a commission of young people to ensure that they are involved from the very start, setting research agendas and co-creating ethical and meaningful ways for young people to be involved in research and translation at national, state and territory, and local levels.

CBOs, NGOs (local, national, international) and other community representatives

Wellcome could partner with CBOs, NGOs and community representatives to access diverse groups of young people and foster the trust necessary for community representatives and parents to consent to the involvement of these groups of young people in health research. CBOs and NGOs have often built strong ties with young people with diverse backgrounds in their communities, and with other important community representatives such as political and religious leaders. Wellcome could partner with them to get access to diverse groups of young people and gain the trust of communities. Youth-led CBOs working on activism and advocacy in LMICs reported that research can boost their ability to validate findings or create strategies for growth. These CBOs often hold rich data that they are unable to report or test. Young people and CBOs emphasised the need for partnership networks that would allow young people in CBOs to build capacity or engage with skilled researchers, for better health and climate outcomes in their research and advocacy.

¹⁰ The names of the individuals who were identified by the stakeholders are not included because of GDPR.

¹¹ Research institution and think tank, generating evidence to improve the health and well-being of African people.

Organisations to consider:

- Apnalaya NGO: Empowers the urban poor to get access to basic healthcare in India. Their health programme intervenes in the area of maternal, child, and adolescent sexual and reproductive health.
- Campaign for Tobacco Free Kids: Have set up a Youth Engagement Alliance, which cultivates and advances effective strategies for youth engagement and advocacy in tobacco control by providing support, networking, training and resources for those working with young people.
- Centre for Catalyzing Change: The centre empowers adolescent girls in India to advocate for their rights, including sexual health and reproductive rights.
- Child In Need Institute: It has partnered with local communities in India to strengthen the capacity of deprived children to improve their health.
- citiesRISE: Global platform mobilising young people to be leaders in the field of mental health; they support youth-led programming, amplify young people's advocacy, and engage young people's networks.
- Co.think Indonesia: the organisation involves young people in health research across mental health, climate change and infectious diseases to influence national policies
- Eat Foundation: Have a track record of involving young people in their initiatives. For instance, the CO-CREATE initiative aims to reduce obesity among adolescents, by working directly with adolescents to create obesity-preventive policies and promote action among relevant stakeholders.
- HCD Exchange: Aims to elevate young people's agency and transform sexual and reproductive health outcomes for adolescents, with a focus on low-resource settings in Sub-Saharan Africa and South Asia. Advocates for young people's participation in program design and implementation.
- Ikamva Youth: Recruitment partner of Eh!Woza in South Africa, which provides after-school programmes to vulnerable young people. It was an active partner during the HCD process.
- It's OK to Talk: Provides a safe space for young people, especially for the LGBTQI+ community in Vietnam to share their experiences with mental health.
- National Children's Bureau: Have set up their own YPAG and involve young people in their governance, research and policy work, and ask for their advice on their projects and programs. Have programs relating to disabled children and mental health.
- NCD Child: Global multi-stakeholder coalition focused on NCDs in young people. Supports the inclusion of youth and family voices in global and country planning for NCDs. They are partners with the Centre for Global Child Health which conducts collaborative research with young people.
- Orygen: Mental health organisation in Australia which created helpful guidance on co-designing with young people
- Pukar: Independent research collective in India working with young "barefoot researchers" in informal settlements and involving them in health research.
- UNICEF: Focused on saving children's lives, defending their rights, and helping them fulfil their potential. Have experience running initiatives involving young people in health research, including the Global Early Adolescent Study.
- Youth Initiatives Kenya: Involve young people and their communities in health initiatives to transform the lives of young people affected by HIV/AIDS in Kenya. Offer leadership and capacity-building training for young people.

Funders

Wellcome could partner with funders to:

- 1. understand how to involve young people in its work;**
- 2. pilot new approaches and develop best practices to fund the involvement of young people;**
- 3. understand the quality of evidence required for funders to scale-up their support.**

Some funders already involve young people internally, such as Fondation Botnar, which launched a global youth council in 2019 to provide a platform for young people to shape the agenda around digital innovation for universal health coverage. Wellcome could learn from their experience in order to set up their own Youth Advisory Council. Wellcome could also work with other funders to pilot new funding approaches that they will have co-developed with experts in involving young people in health research. Based on these pilots, it could co-develop best practices for how to fund initiatives which empower young people to exert influence on health research and involve them beyond a single project.

Wellcome could also work with funders to understand what kind of evidence it needs to scale-up its support. Wellcome and other funders could aim to fill the gaps in M&E flagged by experts and bring more funders on board.

Organisations to consider:

- **Fondation Botnar:** Focused on the health and wellbeing of young people in growing urban environments. Established a global youth council in 2019 to provide a platform for young people to shape the agenda around digital innovation for universal health coverage.
- **Foundation for Young Australians:** Co-designs programs for young people, with young people in collaboration with educational institutions, government, corporate and philanthropic partners. Are skilled at monitoring and reporting on the impact of young people's involvement.
- **Ford Foundation:** Focused on reducing poverty and injustice, and advancing human achievement; and has experience funding health research involving young people
- **Bill & Melinda Gates Foundation:** Works to help all people lead healthy, productive lives and has a focus on reducing inequity and empowering young people. Their Youth Investment, Engagement, and Leadership Development (YIELD) programme advocates for young people's participation in youth sexual and reproductive health and rights (SRHR) initiatives.
- **Government of Denmark:** Cited by an interviewee as an example of a government with foreign aid agencies that value young people's participation and should be included in a network on young people's involvement in health research
- **Government of Norway:** As above
- **William T Grant Foundation:** Supports research to improve the lives of young people, and has experience funding health research involving young people
- **The McPin foundation:** Focused on putting the lived experience of people affected by mental health problems at the heart of research methods and the research agenda. Have their own YPAG, as well as a wider Young People's Network, that advise on mental health research.
- **The Myer Foundation:** Provides grants for a just, creative, enlightened, caring and sustainable Australia; and has experience funding health research involving young people.
- **Azim Premji Philanthropic Initiative:** Focused on reducing vulnerabilities, inequalities in India; and has experience funding health research involving young people.
- **South Africa Medical Research Council:** Focused on improving the health of the South African population through research, development and technology transfer. Has experience funding health research involving young people.
- **Rockefeller Foundation:** Focused on improving access to electricity, food, healthcare, and economic opportunity.
- **TATA Trusts:** Focused on building sustainable communities and empowering the most vulnerable in India. Has experience funding health research involving young people.
- **Vic Health:** Focused on promoting good health and well-being in Victoria and are a prominent funder of participatory health research. Committed to work with young people to undertake research, co-design health promotion activities, and evaluate their effectiveness.

Existing networks

Wellcome could partner with existing networks to:

- 1. help them connect and collaborate and support their growth;**
- 2. circulate best practices;**
- 3. develop and coordinate a formal, global platform for young people's involvement in health research.**

Some existing networks already promote the involvement of young people in health research, such as INVOLVE's Generation R or the International Collaboration for Participatory Health Research. However, experts mentioned that they often work in silos and lack funding to be formalised and expand. In the short-term, Wellcome could help them connect and collaborate, and support their growth. These networks could then help disseminate the consolidated and improved guidelines that will have been developed by Wellcome and its partners. The experts interviewed suggested that Wellcome could also act as a sector coordinator and, in the long term, develop a formal, global platform for young people's involvement in health research where best practices would be regularly shared and updated. This platform could include health researchers, young people, NGOs and CBOs professionals, community representatives, advocacy

experts, funders, policymakers, and any other key experts in health research. Wellcome could partner with networks of young people to develop it, in order to ensure this platform also responds to their needs.

Networks to consider:

- Emerging Voices for Global Health: Training programme aimed to support young health researchers and practitioners, particularly from LMICs.
- Generation R: Alliance of YPAGs based around the UK, which meet regularly to discuss how to make health research work better for young people.
- iCAN: Consortium of YPAGs providing a voice for children and families in medicine, research, and innovation; mostly focusing on HICs.
- International Collaboration for Participatory Health Research: Youth-led PHR is one of their focus areas and several experts interviewed were part of this network. Aims to establish PHR as an integrated part of research strategies to meet the needs of disadvantaged communities by addressing issues of health inequality.
- Multi-Regional Clinical Trials Center (MRCT): Engages diverse stakeholders, including young people, to define emerging issues in global clinical trials.
- Global Health Mentorships Program: Online mentorship programme between students and young professionals, and experienced global health professionals.

Key experts and influencers in health research

Wellcome could partner with key, widely acknowledged experts in health research to:

- 1. understand what evidence they would need to scale-up their support;**
- 2. share new guidelines and evidence on the impact of involving young people in health research;**
- 3. provide guidance on how to reduce harmful power dynamics within research teams.**

Stakeholders interviewed shared the view that key experts, influencers in health research, such as research institutions and universities professionals, are often sceptical of the value of young people's involvement in health research. A researcher in an LMIC explained that she encountered pushback from her university when involving young people in her work. Wellcome could partner with key experts to better understand what evidence they would need to support young people's involvement. Wellcome could share the relevant guidelines and evidence to address their concerns. Once convinced of the value of young people's involvement, key experts could exert influence on other researchers to work with young people, by tweaking rewards or promotion systems to encourage young people's involvement. They could also help address harmful power dynamics which systematically put young people at a disadvantage. Several researchers interviewed shared the concern that young people's voices are often dismissed in research, that their creativity is stifled, and that recognition for research findings almost always goes to the most senior member of the team. Wellcome could provide key experts with guidance on how to foster supportive research cultures.

People¹² and organisations to consider:

- Africa Mental Health Foundation: Conduct mental health research and dissemination and advocates for the rights of persons with psychosocial disabilities to influence policy.
- African Population and Health Research Center (APHRC): Research institution and think tank, generating evidence to improve the health and well-being of African people. Consider themselves to be ahead of most other research organisations in the region on the issue of involving young people.
- Expert member of the climate change and health team at the WHO .
- Experts who work on Adolescent Sexual and Reproductive Health at the WHO.
- European Research Council: One of the most prominent stakeholders in Europe's research ecosystem. Might be sceptical of the value of young people's involvement.
- London School of Hygiene & Tropical Medicine (LSHTM) - DEPTH Initiative: Conduct research on the implications and effects of community involvement and dialogue in promoting health.

12 The names of the individuals who were identified by the stakeholders are not included because of GDPR.

- UK Health Alliance on Climate Change: One of the most prominent players in the field of health and climate change in the UK. Brings together doctors, nurses and other health professionals to advocate for responses to climate change that protect public health.
- UK Research and Innovation: One of the most prominent stakeholders in the UK's research ecosystem. Works with universities, research organisations, businesses, charities, and government to create the best possible environment for research and innovation to flourish.
- Expert member of the Lancet Countdown, which tracks the connections between public health and climate change.

Additional list of organisations recommended by stakeholders surveyed:

The Pivot Collective, Interfer, Young Scientists for Africa, PRB, RHSC, PopCouncil, E2A, India Praxis, Centre for Social and Behavioral Change at Ashoka University, Pravah, Africa Academy of Science, Gallamanor, Young Scientist Kenya, Pwani University, the iBali network, GOSH, RCPCH, AHRI, AFIDEP, TMG Think Tank, HIV Free Generation, I Choose Life, Sangath, India Quicksand, CSBC, UNAIDS, Global Fund, Youngminds, Mind, Youthfocus, International AIDS Society, Y+ Global, Soul City, Treatment Action Campaign, Newham County Council.

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Annex 1: HCD approach

Driven by key research questions (see Introduction), the HCD methodology was applied during the stakeholder consultation (see Methodology). Informed by the RER on the extent of young people’s involvement in research, the young and adult participants across six LMIC countries were divided into sub-groups. These sub-groups informed the types of questions asked during research, taking into consideration maturity, independent thinking, comprehension and experience with research (see table 4).

Table 4:
Key learning themes across groups of young people and influential adults in LMICs

Group	Characteristics	Learning themes
Group A	Early adolescents <ul style="list-style-type: none"> Age 10-14 Have strong parental oversight and influence 	<ol style="list-style-type: none"> Perceptions of YP (All groups) What is the importance of engaging YP in health research? Lived experiences (Group A, B, C, D) What are the experiences of YP in their roles, at different phases during re-search. Across mental health, climate change (global heating), and infectious diseases? Journeys of involving YP in research (All groups) How they become aware, onboard and get involved in health research? Tools & mechanisms (All groups) How are research mechanisms for health research chosen and deployed? Barriers and drivers (All groups) What drives or inhibits YP involvement in health research? Research ecosystem (Group C, D) Is the current research ecosystem setup able to redistribute power and resources in service of engaging YP?
Group B	Middle adolescents <ul style="list-style-type: none"> Age 15-17 Growing into independence outside of parental influence 	
Group C	Young adults <ul style="list-style-type: none"> Age 18-24 Fairly independent, confident and likely have opinions 	
Group D	Influential adults <ul style="list-style-type: none"> Health workers, youth leaders, community leaders, adult researcher, parents Are advocates/ skeptics/ gatekeepers to opportunities for health research with YP, likely have valuable experience and insights based on their experiences that we can learn from 	

1. Setting the research agenda

The following research agenda (across the key areas of mental health, infectious diseases and the health implications of climate change) informed the development of research guides for interviewing young people and influential adults in their ecosystem:

i) Perceptions of YP

Target subgroup- [All groups]

Why is it important to involve young people in health research?

- What are young people's mindsets on research?
- What do young people think about their involvement in health research?
- How does young people's involvement in research affect research outcomes?

ii) Lived experiences

Target subgroup- [C, D]

What are the experiences of young people in their roles during research across mental health, climate change, and infectious diseases?

- What roles are young people in LMIC typically playing in health research?
- What do young people and researchers in LMICs think about (1) benefits, (2) challenges, (3) best practices of involvement in research? How does this vary by gender, SES status, and other factors?
- What additional support do young people need in these settings?

iii) Journeys (understanding how they become aware, onboard and engage in health research)

Target subgroup- [All groups]

At what stage of research are YP engaged? How does that define their agency in the process?

- How do young people discover opportunities in health research?
- What questions do young people have before signing up for research opportunities?
- How do young people decide to commit time towards health research efforts?
- What are the drivers and/or benefits of involving in health research according to YP?
- Why are more YP not participating in such opportunities?

iv) Tools & mechanisms

Target subgroup- [All groups]

How are research mechanisms chosen and deployed?

- What type of training, support, and mentoring do young people receive for conducting research?
- What tools do they use to conduct research? How do they decide on what tools to use? Who decides what methods to use (for example, interview, survey, etc)?
- What challenges do young people face in using the tools for health research?

v) Barriers and drivers

Target subgroup- [All groups]

What drives or inhibits YP involvement in health research?

- What challenges do young people face in engaging with health research?
- To what extent are young people aware of research and opportunities to get involved?
- Are there stages of research that are more difficult to engage? Why?
- Who are the gatekeepers/cheerleaders in the young people ecosystem that inhibit/catalyse their engagement in research? What are their concerns/motivations?

vi) Research ecosystem

Target subgroup- [C, D]

Is the current research ecosystem setup able to redistribute power and resources in service of engaging YP?

- What evidence of impact is required by researchers so that they invest meaningfully in involving young people in health research?
- What opportunities exist for young people to contribute to health research today?
- How available/accessible/appropriate are best practices/guidelines that exist today? What can be improved about them?
- What are the biggest drivers of cost/complexity for involving young people in research?
- What will it take to involve young people in driving (not just participating) research?
- What type of research is deemed appealing for youth participation?

2. Research preparation: Toolkit development (see figure 11) and HCD research methods

The research agenda was expanded to develop the lines of enquiry for young people and their influencers in the form of a research guide. In-depth interviews (up to 60-minute conversations with participants recruited based on predefined criteria) and group discussions (60-90 minute interactive sessions to understand a range of opinions, group dynamics and collective decision making, from a representative set of participants) were used as key mechanisms to conduct research remotely. HCD research tools like journey mapping, ecosystem mapping, and child-friendly tools (e.g. digital whiteboarding) were used to uncover lived realities, needs, behaviours and aspirations.

A user-led approach was implemented, which means that throughout the interviews, we anchored on the young people’s lived realities, knowledge and their definitions of research to guide the discussions. The interviews were the space that was used to practice divergent thinking, in order to get as broad a spectrum of perspectives and learnings as possible.

Figure 11: A snapshot of the questions and activity worksheets from the research toolkit

5. ECOSYSTEM MAPPING

Questions from phase 2:

Who would be the key agents/stakeholders to be engaged in the implementation of the future work?

What can Wellcome do to work with partners to catalyse young people’s involvement in research?

Group: C [18-24 years], D [Influential adults]

Activity: Ecosystem mapping

3. Completion of HCD research and synthesis of findings

Exploration of different sub-groups of young researchers, uncovering the diverse experiences of young people engaging in health research across academically trained and untrained profiles, with different education levels and socio-economic backgrounds. Through these long form-interviews and focus groups, the study was able to identify motivations and barriers that impact young researchers and how these characteristics may vary across sub-groups, which can support programmatic targeting.

Uncovering of additional insights by engaging youth influencers, including parents, teachers, community members, CBOs and health workers who engage youth in health research (over the age of 24), many of whom also had first-hand experience conducting research as youth. These influencers were able to provide additional system wide insights into funding in the young people's research ecosystem, research planning, and incentives and barriers that impact young researchers.

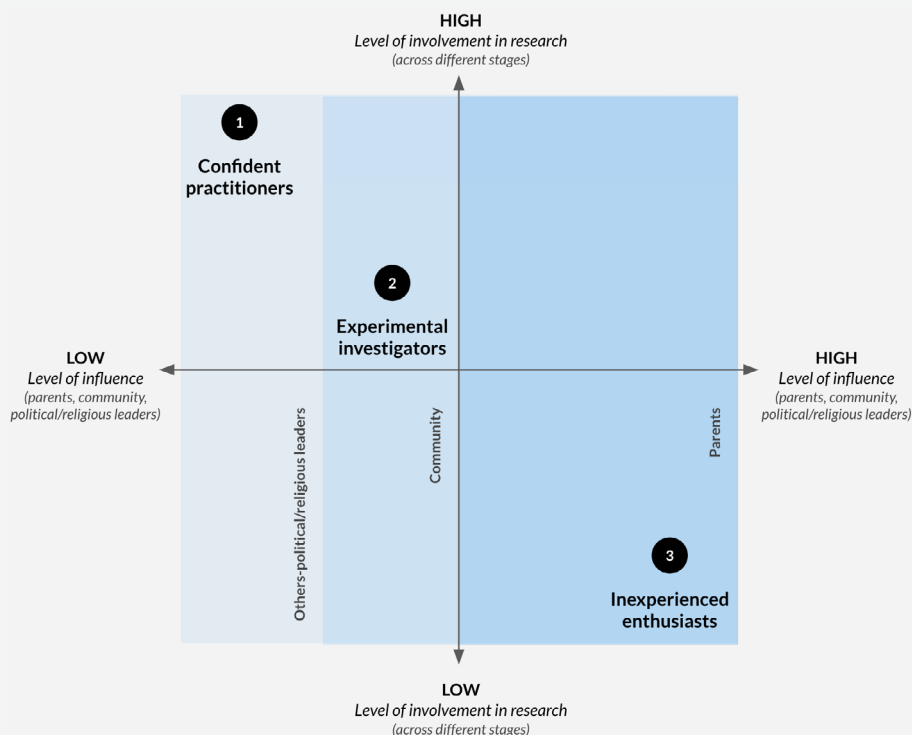
Identification of existing practices by uncovering what people do through real-life anecdotes. These existing practices can shed light on specific opportunities and barriers in involving young people in research and provide a foundation for future involvement of young people or programme design that seeks to leverage existing structures.

Construction of young people and influencer profiles, in the absence of extensive literature (from LMIC) on the roles and outcomes of young people in health research. Representative profiles from stakeholder consultations have been created. These profiles are built based on the behaviours, motivations, aspirations and lived realities of the people we met, across six countries. These profiles are meant to provide an understanding of the young people in LMIC and some of their key influencers in their ecosystems.

The immediate influencers (see section 2.5) thus directly affect the research ecosystem around young people.

4. Classification of young people from LMICs based on level of influence from immediate community

Figure 12:
Classification of young people from LMICs



The classification of young people based on their geography, urban/rural area, gender, income levels, among others, provides the necessary diversity for HCD research. As the HCD research progressed, two parameters were found to cut across the initial demographic variables: level of involvement across various stages of research and level of influence from the ecosystem they live in. These two parameters affect the overall experiences of young people in research. These parameters are defined as:

Level of involvement in research (across different stages): Young people's circumstances that define the extent of their involvement in research across agenda setting, research design, data collection, data analysis, implementation/dissemination.

Level of influence (parents, community, others-political/religious leaders): Young people's agency and support environment that defines their likelihood of taking on research opportunities, when available. Treating these two parameters as axes on a two-by-two matrix, resulted in creating a contextually relevant and actionable framework for understanding the profiles of young people who were interviewed across the 6 countries.

Annexe 2: Young people and influencer profiles

Profile 1: Confident practitioners



Khushal

BACKGROUND

Khushal is a 19-year-old university student, working towards a BSc in physics. He lives in Mumbai, India, in an informal settlement. Khushal is constantly confronted by the disparities of the city—he lives adjacent to high-end development, yet in his community, the toilet blocks have not been fixed for years, and a single toilet serves over a hundred people. Along with his university studies, Khushal also has a part-time content writing job, which he took on to support his family financially, as he's the oldest child. In addition, Khushal is working on a survey on young people and stress, as part of a fellowship with a research organization. He juggles many responsibilities but makes time to write poetry and maintain a blog with his friends.

Age	19
Gender	Male
Education	College student pursuing BSc in physics
Experience with research	Experience working with a research organisation on survey design, data collection and data analysis
Typical ways in which they get involved in research	<ul style="list-style-type: none">• Fellowships with research organisations• Academic institutions
Major motivations for participating in research	<ul style="list-style-type: none">• Desire to contribute to and improve the community• Hard research skills, a certification and practical experience that ties to future career aspirations
Barriers to participating in research	<ul style="list-style-type: none">• Busy schedules and multiple responsibilities (academic, family, jobs)• Insufficient pay or compensation• Power dynamics and biases against them because of age, education level, SES (Socio-Economic Status), gender

RESEARCH JOURNEY

Ayanda was recruited for the research position by an agency that reached out to her through the youth organisation she works with. She says they chose her because of her familiarity and engagement with the community, as both a resident and a youth worker. Ayanda was curious about research, and about the effects of the pandemic on her community, given her interest in youth and employment, so she took up the offer. Her parents worried about her safety but ultimately left the decision to her.

In her research role, Ayanda interviews community members and takes photos. She is given the interview questions by the agency, and they range from mask usage to awareness on government grants. Ayanda sends the photos and responses to the agency, where they analyse the data, and the findings are then sent to the local government. Ayanda is not involved with the data analysis and does not even get to see the end product of the research, as it is confidential. She feels disappointed by her disconnect from the final research product. While she says she does not have the knowledge or skills to participate in statistical analysis, she wishes that would not impact the power she has in research decisions. Ayanda has a love for learning and is eager to continue in the world of research and play a bigger role in it. In underserved communities like hers, research opportunities are limited, but she hopes that she will be able to get more training someday, and that the youth organisation will continue to open avenues to research.

RESEARCH MOTIVATIONS

“People who continue [doing research] realise that they get to learn new things that first are useful for your life. You get to know about your own health. For example, 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”

RESEARCH INVOLVEMENT

“I do basic health research. But when it comes to analysing, I do not have the full amount of training. All I have is the knowledge of the community. I think having professional skills and educational knowledge helps and that is why they do not reach out for these kinds of things.”

“The reason behind engaging youth like me is that most youth need opportunity. It is possible that adults already have jobs and won't be available. Even in my case, ... I was doing it over the weekends and over the weekdays I was still in school. I have worked in maternal health, immunisation, and TB.”

RESEARCH ASPIRATIONS

“One of the things that changed my perspective moving from a community member to a researcher is the power dynamics. Back in 2016 when I participated in the training, I was so shy and was so nervous. The professors who were researchers were so confident and they did not have conversations with us to listen to us. [...] We have to change the power dynamics. In 2018 and 19 when I was able to start another research I shared my experience in order to inspire other researchers to learn through another process.”

Profile 2: Experimental investigators



Ayanda

BACKGROUND

23-year-old Ayanda is an intern with a youth organization and a part-time engineering student in Atlantis, in the Western Cape province of South Africa. She took on her role as a youth worker to help her family financially, but she had been involved with the organization as a tutor in the past and loves working with young people and helping them reach their full potential. Ayanda feels like the experience, and joy she gets from her involvement with the youth organisation far exceeds what she gets from her engineering studies. Since the COVID-19 pandemic, Ayanda has also been conducting research for the local government on how the pandemic has affected communities.

Age	23
Gender	Female
Education	Part-time college student
Experience with research	Experience working at the local government to collect qualitative data in her community
Typical ways in which they get involved in research	Research agencies, governments or CBOs looking for local support from within the community they are researching
Major motivations for participating in research	<ul style="list-style-type: none"> • Curiosity to understand the research process, with limited opportunities to do so • Chance to learn more about personally relevant and interesting topics • Familiarity with the community being researched
Barriers to participating in research	<ul style="list-style-type: none"> • Lack of formal training • Alienating research jargon • Not being seen as valuable contributors to the research agenda or outputs, beyond menial tasks • Support or permission from family members, particularly for women • Power dynamics and biases against them because of age, education level, SES, gender • Insufficient pay or compensation

RESEARCH JOURNEY

Khushal has always been motivated to change his community and has been actively involved with initiatives to make life better for his fellow community members, such as collecting second-hand clothes for the homeless. Although he is studying physics, he aspires for a career in social service, e.g., as an administrative service officer. Khushal sees research as another way to improve his community, and this is what drives his involvement. He is particularly interested in researching topics, such as mental health, that impact young people like himself. Khushal's expenses are compensated by the research organisation he works with, but they do not pay him beyond that. Though his family worries that his research role keeps him away from his university studies and from other opportunities to earn money, Khushal believes that the skills he is building through his research involvement—like survey design and data analysis, and the certificate he will earn at the end of the fellowship—will improve his future career prospects. He chooses to invest time into his community, and his research work aligns closely with both his passion for social service and his future career goals, in a way that his college classes or other paid jobs do not.

RESEARCH MOTIVATIONS

“Research is technical, we should admit. It can also be learned if someone has passion. Everyone can be a researcher if they want to, as young as they can be. I started my journey in high school, I did not learn anything about research. But I was curious about something, and that was the starting point.”

RESEARCH INVOLVEMENT

“We got training on survey analysis, using Microsoft Excel. We exported results in CSV file, and sliced data to see the gender, caste, age, effects of stress.”

RESEARCH ASPIRATIONS

“We completed the research and one thing we did was launch a petition on Change.org and also uploaded videos about the slum situation on social media, tagging the municipal corporation. [...] We usually don't have a mandate to take the projects forward, not even after data collection - we don't have to disseminate. [...] But we are all from the community, so most are motivated to take things forward.”

Profile 3: Inexperienced enthusiasts



Mercy

BACKGROUND

Mercy is a 16-year-old secondary school student living in a densely populated informal settlement in Nairobi, Kenya. She has a passion for Geography and Christian and Religious Education (CRE). Outside of school, she likes to play football with her friends and spend time with her younger siblings. She has a close group of friends who she confides in, and also has a close relationship with her mother. Mercy cares deeply about climate change, having seen the way it has impacted the water supply in her community, and hopes to one day work towards fixing the issue.

Age	16
Gender	Female
Education	Secondary school student
Experience with research	No experience conducting research; has one-off experience as a research participant for a local NGO
Typical ways in which they get involved in research	<ul style="list-style-type: none"> • Recruited for research projects by local NGOs • Asked to participate in surveys • School projects
Major motivations for participating in research	<ul style="list-style-type: none"> • Desire to contribute to the community • Desire to have their voice and perspective heard • To work on personally relevant and interesting topics, such as sexual and reproductive health, gender-based violence, and entrepreneurship
Barriers to participating in research	<ul style="list-style-type: none"> • Perception that they are too young and inexperienced to be involved in research • Lack of relatable role models in research • Lack of training • Undervaluing of young people's voices and contribution by researchers or research organisations

RESEARCH JOURNEY

To Mercy, research is about finding the answer to a problem. She sees research as a way to get to know what is going on in a community, or with a specific person, and understand how to find a solution for that community or person. Mercy has never conducted research herself, but she has been a participant in an NGO's research project. The organisation was distributing free sanitary pads in her community, and asked Mercy questions on how she uses sanitary products, as well as other broader questions on her life. She said that most of the young women in her community felt uncomfortable answering the questions around menstrual health, but because it's a topic she talks about at home, Mercy did not mind responding. Mercy says that the people who come to do research sometimes do not explain what the research they are conducting is about and wishes they would build more trust with young people like herself. She notes that in her area, those most "vulnerable" such as the old and the sick seem to be most often selected to do research.

RESEARCH MOTIVATIONS

"People who are asked questions are 18-35. People feel like they have an opinion. 36-59 are left out who are at home taking care. And then 60+. What about 10-18? No, we are completely left out. They say we don't have anything to add. But we do have something to add."

RESEARCH INVOLVEMENT

"The only young people who do research are college students. Or the school gives you a project and you have to go out and ask a few people."

RESEARCH ASPIRATIONS

"They should make [research] a bit more fun so that those people who can't understand when they are taught very technically [can still get involved]."

"Most people in marginalized places get water in small quantities, so the best way is these organizations involving people who are going through it, and hardest hit by climate change could and should be involved as contributors in these research organisations."

Profile 4: Sceptical gatekeepers



Safina

BACKGROUND

Safina is a doting grandmother, an expert tailor, and a respected community elder. She lives with her son, his wife, and their three children, in a low-income neighbourhood in Mumbai, India. The houses in the community are closely packed, and all the residents know each other. Safina's two grandsons are in primary school, and her granddaughter, Ameera, is in her first year of college. Safina is closely involved with key decisions about the family's food, finances, and the children's lives.

Role in influencing young people in research	<ul style="list-style-type: none">• Give researchers or organisations permission to reach young people and enable their participation in research• Shape the social norms that define young people's participation
Motivations for involving young people in research	<ul style="list-style-type: none">• Financial stability• Good career opportunities
Barriers to involving young people in research	<ul style="list-style-type: none">• Worry that research takes away from young people's ability to study, complete household duties, or get a better paying job.• Concerns about young people learning about "taboo" topics• Lack of trust in 'outsider' organisations and researchers• Social norms that limit young women's participation in activities outside the home

ROLE IN YOUNG PEOPLE'S RESEARCH JOURNEYS

To Mercy, research is about finding the answer to a problem. She sees research as a way to get to know what is going on in a community, or with a specific person, and understand how to find a solution for that community or person. Mercy has never conducted research herself, but she has been a participant in an NGO's research project. The organisation was distributing free sanitary pads in her community, and asked Mercy questions on how she uses sanitary products, as well as other broader questions on her life. She said that most of the young women in her community felt uncomfortable answering the questions around menstrual health, but because it's a topic she talks about at home, Mercy did not mind responding. Mercy says that the people who come to do research sometimes do not explain what the research they are conducting is about and wishes they would build more trust with young people like herself. She notes that in her area, those most "vulnerable" such as the old and the sick seem to be most often selected to do research.

HOW THEY INFLUENCE YOUNG PEOPLE'S INVOLVEMENT IN RESEARCH

"Some parents are very strict so kids can't talk to them. Some parents understand, some don't. They have questions like why you are teaching my kids all these things. We come from different backgrounds. The parents don't feel comfortable if their kids learn about periods, HIV, etc."

"Maybe us as adults should be supportive and we can bash them or force them to go back to school when school is not for everybody. It is high time we embrace different talents in the youth and support them."

"Adults need to have a forum where we have youth and adults where youth can tell us about the freedoms that they want and the limitations and responsibility that comes with those freedoms. We cannot be so rigid in the way that we were brought up. You have to understand your child and be supportive."

Profile 5: Community catalysers



Agung

BACKGROUND

31-year-old Agung lives in Jakarta, Indonesia. He is a youth mobiliser and trainer for an organisation that builds young people's involvement and capacity in health research and loves his work. Agung's own research journey started when he was a teenager. He is not a formally trained researcher, but started volunteering with a local health institute and gradually got more and more involved. This experience had a hugely positive impact on his life, and he chose to work with the youth organisation so that other young people could have similar research experiences.

Role in influencing young people in research	<ul style="list-style-type: none">• Build the community's trust in research• Convince family and community members to let young people participate• Motivate, inspire and train young people to take on research opportunities
Motivations for involving young people in research	<ul style="list-style-type: none">• Value that young people and local communities add when they shape research outcomes• Benefit of research to young people's lives and futures
Barriers to involving young people in research	<ul style="list-style-type: none">• Inability to make research relatable and relevant to young people• Insufficient training or support materials they can use to involve young people effectively• Social norms that limit young women's participation in activities outside the home• Young people's rigid schedules, and the cost of research trainings

ROLE IN YOUNG PEOPLE'S RESEARCH JOURNEYS

When Agung was just starting off as a researcher, he observed a power dynamic in the research institute based on age and education. He wanted to make sure not to replicate that in this organisation. He strives to make it a safe, welcoming and fun space, so that young people feel motivated to get involved in research and stay involved long-term. When Agung trains young people on research, he makes it approachable and relatable. Agung knows how to talk to young people in a way that makes them feel comfortable and heard, using familiar language and references. For a lot of the young people in the youth organisation, he is their go-to confidant.

In addition to building young people's trust, a big part of Agung's job is building the trust of their family members. Without their buy-in, it is hard to get young people to participate at all. Agung meets with parents to allay their concerns about their children participating, clear up misconceptions about research, and tells them about the value of research, by sharing his own story. When Agung talks to the parents of young women who are particularly concerned about their daughter's participation, his female colleagues in the organisation accompany him, as they are able to build trust more easily in such scenarios.

HOW THEY INFLUENCE YOUNG PEOPLE'S INVOLVEMENT IN RESEARCH

"For youngsters, when we say we are doing research, they imagine it takes a lot of time and a lot of skills, which is why they never want to do the research. We are trying to change the definition of research by introducing it to the community through different community meetings. We use the meetings to get people to understand the premise of the research [...] This way youngsters get acquainted with the research. This is used because the communities know more about themselves."

"Parents of young people are worried that their children will fall in bad company if they go out. We invite parents of young people to the [research] training to reassure them. We schedule training at a time that works for them. We used examples of success from previous projects to encourage others to participate in research. When parents see other young people in the community doing research, speaking with confidence and earning a living, they call us and ask us to consider training their children to do research."

"There is a gender dynamic also, so for example, if I talk to girls, their parents would not send them to work with us. We work on building trust. We understand that people need money, but they need to also want to help their community. It shows how people trust us that more of our barefoot researchers are girls than boys."

Profile 6: Experts



Professor Naledi

BACKGROUND

Professor Naledi is a public health researcher and lecturer at a university in Cape Town. For the past 15 years, she has worked extensively on HIV/AIDs, stigma and harm reduction in South Africa. She is particularly interested in the role of young people’s participation in HIV risk reduction, with an emphasis on at-risk and marginalised youth. She has been trying to actively involve young people in the research she does, by consulting with them in the research design phase.

<p>Role in influencing young people in research</p>	<ul style="list-style-type: none"> • Set research agendas • Build the community’s trust in research • Convince family and community members to let young people participate
<p>Motivations for involving young people in research</p>	<ul style="list-style-type: none"> • Enable the creation of research material that is relevant and engaging to young people • Better research outcomes, specifically on topics that focuses on young people, or that need communities’ trust (for example mental health, HIV)
<p>Barriers to involving young people in research</p>	<ul style="list-style-type: none"> • Insufficient funding and buy-in from institutions to support young people’s engagement • Inadequate training or support materials to effectively engage young people in health research • Lack of global networks to connect with researchers or organisations involving young people in research • Difficulty demonstrating the relevance and benefits of their research to convince parents and communities to let young people participate • Difficulty convincing funders and donors of the value of young people’s involvement in research

ROLE IN YOUNG PEOPLE'S RESEARCH JOURNEYS

Professor Naledi created a youth advisory group to inform the design of her research on HIV risk reduction. She strongly believes that young people understand their peers and local contexts in a way that she, and her fellow researchers, do not. While she and her team were designing the survey instrument, she held monthly group discussions with 12 young people in her advisory group, to shape the survey. She connected with the young people through local youth organisations that she has collaborated with in the past. Some of the young people were tentative about contributing to the group discussions, having never been involved with something like this before, and some young people's motivation withered over the months, but she was confident that what she learnt from the consultations made the survey more relevant, engaging and effective. She was particularly impressed by how the topic of stigma reduction organically emerged from the conversations with young people.

Once the survey was administered, Professor Naledi had another group discussion to show the young people how their voices manifested in the research design, but because of funding constraints, that was her last consultation. While she wants to continue engaging with young people as the research advances, she is restricted by the priorities of funders and institutions, which have not given their buy-in.

HOW THEY INFLUENCE YOUNG PEOPLE'S INVOLVEMENT IN RESEARCH

"We try to put processes in place for systemic youth involvement, but many young people report that in clinic meetings they don't feel confident enough to speak up. Some young people with more experience is more confident, but for most, I am not sure we make enough opportunities to build leadership skills".

"In one of our first projects, we recorded the conversation around surveys and printed the best quotes on posters alongside the data from the survey so that the youth could see if their recommendations were accurately reflected in the survey. Have this tangible reminder of the things they said and show them how important it was."

"If they [young people] have capacity and they have been able to talk about something sensitively, then we should have the faith that they have the power to bring value everywhere. I think YPs should be involved in everything that will happen in their lives."

Annex 3: Expert interviewees

Table 5 - List of expert interviewees, anonymised

#	Where they work	Job category level	Institution / Description
1	Kenya	Head of Department	KEMRI-Wellcome Trust
2	South Africa	Postdoctoral Researcher	University of Cape Town
3	Argentina	Board Member	Incubator for young researchers in Global Health
4	UK	Research Assistant	Oxford University
5	UK	Senior Research Fellow	UCL
6	Sub-Saharan Africa	Director of Department	Health research centre
7	South Africa	Member	African Union
8	Australia	Director	Youth-focused research centre
9	UK/Kenya	Researcher	KEMRI-Wellcome Trust Research Programme
10	Australia	Programme Director	University of Melbourne
11	Global / Kenya	Technical Officer	WHO
12	USA	PhD Candidate	Harvard T.H. Chan School of Public Health
13	South Africa	Director	Network of paediatric AIDS-focused clinics
14	South Africa	Senior Lecturer	University of Cape Town
15	Canada	Programmatic Lead	Professional association
16	USA	Senior Research Associate	University of Cincinnati
17	Global	Director	Network for climate and health organisations
18	USA	Director	Youth-focused network of patient advisory groups
19	USA	Professor	University of California, Berkeley
20	India	Director	Non-profit involving young people in health research
21	UK	Postdoctoral Researcher	Oxford University
22	USA	Professor	Gillings School of Global and Public Health
23	UK	Community engagement manager	University of Liverpool
24	Global	Senior Advisor	WHO
25	USA	Professor	Morgan State University
26	UK	Professor	Oxford University
27	South Africa	Clinical Manager	Vaccine-focused non-profit organisation
28	USA	Department Director	Cornell University
29	UK/Netherlands	PhD candidate	University of Cambridge

Annex 4: Expert Survey Questions

1. What country do you work in?
2. What is the primary function of your/your organisation's work?
3. What is your job title?
4. Which category below describes your age:
 - a. 20-29
 - b. 30-39
 - c. 40-49
 - d. 50-59
 - e. 60 or older
5. Have you ever supported or worked directly on health research that has involved young people (10-24 years old)? By "involved" we mean tasks like (1) deciding the research questions to be asked (2) designing research (e.g., choosing whether to run a survey or a set of interviews) (3) collecting data (e.g., leading a set of interviews; asking people to fill out a questionnaire) (4) analysing data (5) sharing research findings. This does NOT include if you have filled out surveys/questionnaires/been interviewed etc.
6. To what extent would you agree or disagree with the following statements? (Likert scale: Strongly agree to strongly disagree)
 - a. "Having young people play an active role (e.g., as advisors/co-researchers) in health research is essential"
 - b. "It may be useful to involve young people in research, but the returns on doing so are not worth the additional investment required"
7. To what extent would you agree or disagree with the following statement? (Likert scale: Strongly agree to strongly disagree)
 - a. "Young people can play an active role guiding the strategy/agenda-setting of health research institutions and funders, including funding decisions"
8. If you agreed with the above statement, what recommendations would you give to organisations trying to actively involve young people in their strategy/agenda-setting? (optional)
9. If you know of any guidance supporting organisations (e.g. funders, research institutions) to involve young people in their strategy/agenda setting please reference it here (optional)
10. What health research questions/themes do you think young people's involvement could be most useful on, if any? (e.g. sexual and reproductive health; technology's impact on mental health) (optional)
11. If you think 'building more evidence' would be useful, what type of evidence do you think would be most useful? (E.g. more research on how to engage young people from diverse backgrounds in health research etc.) (optional)
12. If you have supported or worked directly on health research involving young people, to what extent do you agree with the following statement? (Likert scale: Strongly agree to strongly disagree)
 - a. "Young people involved in health research projects often face working cultures or team dynamics that make it difficult to have their voice heard"
13. If you think working cultures or team dynamics are a problem, do you have recommendations how it can be solved (e.g., training adult researchers, creating team norms at the beginning of research initiatives that involve young people)? (optional)
14. To what extent do you think the following initiatives would help effectively scale up how young people are involved in health research? (Likert scale: Strongly agree to strongly disagree)
 - a. Funders/donors committing to offering dedicated funding for involving young people in health research where relevant
 - b. Developing best practices on how to involve young people in health research
 - c. Offering training to young people/health researchers on how to involve young people effectively in health research
 - d. Strengthening networks of focused on involving young people in health research
 - e. Improving monitoring and evaluation of young people's involvement in health research
 - f. Building more evidence on the impact of young people's involvement in health research
15. In a few words, please explain why you scored some initiatives higher/lower. (optional)
16. Would you recommend any other initiatives/activities that are missing from the list above, for improving and increasing young people's involvement in health research? (optional)
17. Could you recommend specific organisations/individuals that could be engaged in the initiatives you scored highly for scaling up young people's involvement in health research (question 14)?

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