wellcome

# A rapid evidence review of young people's involvement in health research

2020

Dalberg

# Acknowledgements

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# Foreword

Wellcome is embarking on an ambitious new global strategy to tackle urgent health challenges with a focus on mental health, infectious diseases, and the health impacts of global heating[1]. Young people[2] 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 commissioned a rapid evidence review (RER) of research on the involvement of young people (aged 10-24) in health research.[3] This is part of a larger research project that also includes a stakeholder consultation phase, exploring the role, benefits, and potential of young people's involvement in research in Wellcome's defined health "challenge areas" of mental health, infectious diseases, and the direct health impacts of global heating/climate change.

The core questions that this RER seeks to address are:

1. **What are the different approaches to involving young people in health research?**
2. **What are the benefits and challenges of involving young people in health research?**
3. **What are the skills and capabilities young people need and what additional support do they require for effective involvement in health research?**
4. **How do adults working with young people need to be supported to effectively involve young people in health research?**

This review is built on a database of 187 peer-reviewed articles published since 2005. It is important to note that much of young people's involvement in health research is likely not captured by academic literature. This review, therefore, has been complemented with a consultation of stakeholders to verify that its findings align with ground-level realities.

## Key findings

### Landscape of young people's involvement in health research today

The academic literature on young people's involvement in health research is still emerging - over half the articles that appeared in the review's search were written since 2015.

Existing frameworks for young people's involvement do not fully capture the issues this study aimed to explore. Hence, a new framework was developed that was informed by an evaluation of existing frameworks and considerations of how these can be adapted to Wellcome's context. The framework's dimensions are:

1. **the stage of research in which young people are involved;**
2. **the level of involvement they have;**
3. **inclusiveness[4] of the research in terms of the background of young people involved;**
4. **the geographies in which they are based;**
5. **the health topics they focus on.**

The review found that young people's involvement, or at least the documenting of it in academic literature, is uneven across these five dimensions. In particular:

- Stage of research: young people are most frequently involved in research design and data collection, rather than agenda-setting and dissemination/translation[5] of findings.

3 For the purposes of this review, 'involvement' in research means research that is done 'with' or 'by' young people, not 'to', 'about' or 'for' them (NHS Health Research Authority, 2017).

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

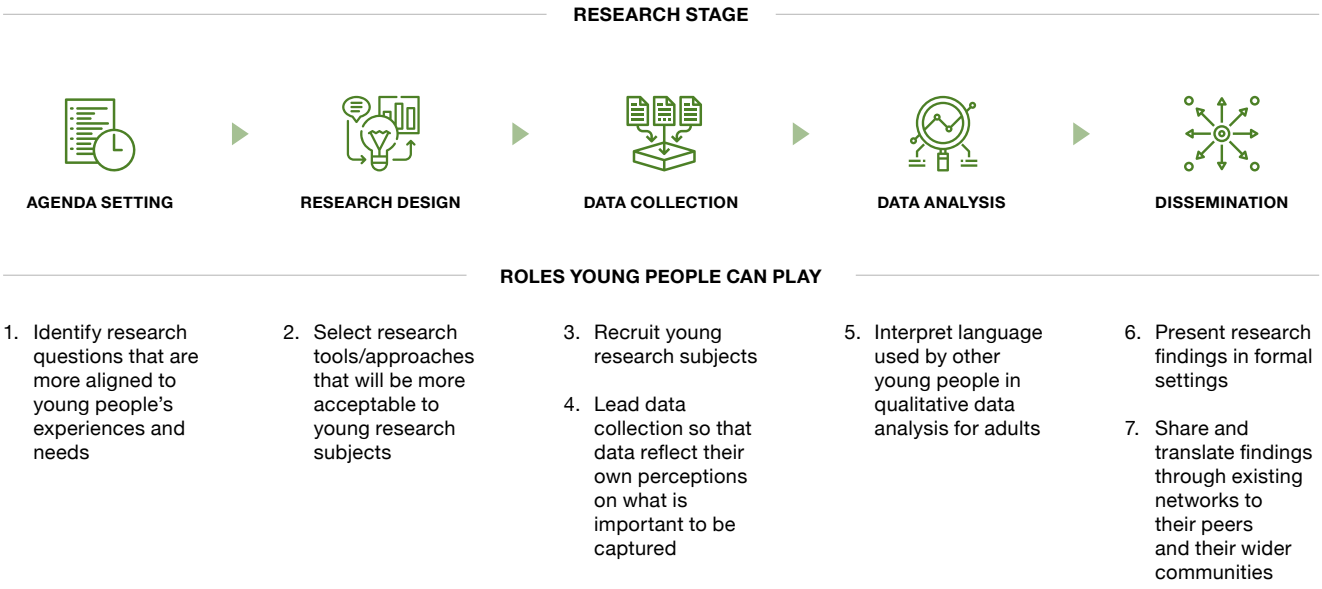
5 Translation of knowledge is a "dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge" (Canadian Institutes of Health Research, 2020).

- **Level of involvement:** young people tend to have some control over decision-making, but typically less than adults.[6]
- **Inclusiveness:** gender, ethnicity, socio-economic status or disability status of young people involved are often not reported.
- **Geography:** research carried out in high-income countries makes up the vast majority of what is reported in articles.
- **Health topics:** young people are more likely to be involved in health research related to mental health, rather than infectious diseases or the health implications of global heating/climate change.

One important point to note is that, according to experts in youth engagement, the monitoring and evaluation of young people's involvement remains inconsistent, as does the terminology used to describe it. As such, the likelihood is some activity that takes place today goes unreported.

## Benefits of involving young people in health research

The RER has identified several roles that young people can play in research.




These roles can occur at different stages of the research cycle – young people can be involved in agenda-setting, research design, research funding decisions, data collection, data analysis, and research dissemination or translation of findings. The literature shows that they add value at each of these stages. Young people's involvement also results in research being conducted with higher ethical standards.

Importantly, there is evidence in peer-reviewed literature of the benefits of involving young people in health research. Young people can better identify research questions and methods that fit young people's needs and experiences because they understand their peers' needs, preferences, and capabilities. They also are more trusted and have better access to networks, allowing them to recruit young research participants, lead data collection and disseminate research findings in ways that adults cannot.

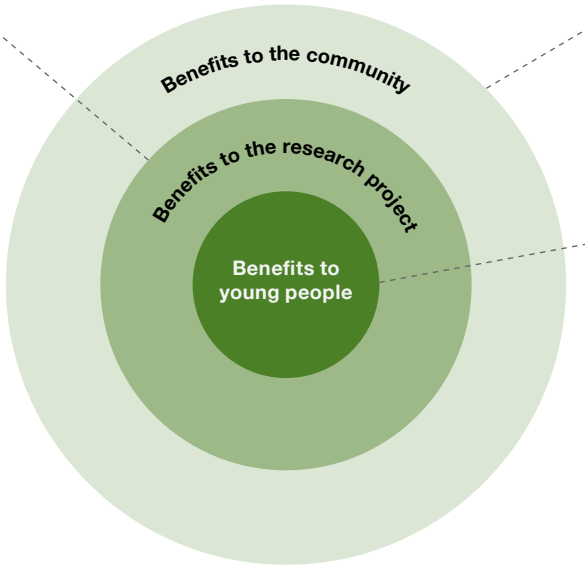
Apart from benefiting the research itself, evidence shows that young people's involvement in health research can also benefit the community e.g. by increasing community awareness of particular problems and in some cases influencing communities to take action to respond to particular health challenges.

6 It is important to note that this review was designed to focus on evidence that described non-tokenistic involvement of young people in health research.

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

**Benefits to the research project**

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




**Benefits to the community**

- Higher community engagement
- Prompting community action

**Benefits to the young people**

- Feel empowered and increased self-efficacy
- Gain research and wider career skills
- Improved academic or career outcomes
- Increased motivation to pursue a health-related career or continue academic study
- Increased knowledge of health issues
- Improved health outcomes

## Challenges in involving young people in health research

The evidence of the impact of involving young people in health research is overwhelmingly positive. While challenges are reported less commonly than benefits, they are significant. They speak to the opportunity that Wellcome and other stakeholders in the health research ecosystem have to support the scale-up of young people's involvement in health research.

Literature has documented five areas of challenges that go with effectively involving young people in health research.

1. **Attitudes and awareness:** Some researchers lack an awareness of evidence that demonstrates the potential benefits of involving young people. Moreover, a limited number of papers found that young people themselves may not see health research as an attractive activity.
2. **Ethics protocols:** Some adult researchers are discouraged by the complexity of or lack of clarity on protocols they need to follow to receive ethical approval for working with legal minors.
3. **Skills:** Both adults and young researchers need training to effectively collaborate and materials/tools need to be adapted to match young people's capabilities.
4. **Ways of working together:** Researchers can find it a challenge to adapt ways of working to young people's needs, capabilities and less flexible schedules and identify and maintain a network of young people they can work with over a sustained period of time.
5. **Funding:** Although it was not widely reported in literature, some papers conclude that a lack of funding aggravates these challenges.

## Best practices when involving young people in health research

Experts have developed guidelines on how to effectively involve young people in health research, some of which have been documented in the peer-reviewed papers. While this is a welcome development, literature shows that these guidelines are limited in scope, in terms of the contexts in which apply and the issues that they cover. Also, importantly, the guidance has yet to be mainstreamed into research ecosystems.

Existing literature is generally aligned on emerging best practices related to five aspects of involving young people in health research:

1. **Consent** – researchers should collect written consent from young people and consult their parents when minors are involved;
2. **Evaluating risks and comparing against potential benefits** – risks to young people should be minimised but also weighed against potential benefits;
3. **Communication** – communication must suit young people's needs, build trust, and sustain their involvement;
4. **Trust and balancing power** – establishing trust and a sense of equality between adults and young researchers can enhance research success;
5. **Logistics** – the spaces and times in which young people are involved should be convenient and welcoming.

When looking at gaps in best practices, this review has revealed a number of areas that need to be addressed most critically:

1. Experts have yet to develop guidelines on the scenarios in which to use different approaches to involving young people in research (e.g. when is it more appropriate to use a Young Person's Advisory Group rather than Youth-led Participatory Action Research?);
2. How young researchers should be compensated for their contribution remains an open question;
3. There is also a gap in guidance around how best to train adult researchers and young people.

## Recommendations for Wellcome and other agenda-setters in health research

Although knowledge gaps persist, insights from this review have been able to identify five action areas that could help scale up young people's involvement. These are in response to the challenges and opportunities reported above, particularly: insufficient funding; a lack of alignment on best practices, including monitoring and evaluation; a desire to promote learning between different members of the health research ecosystem; and gaps in evidence/understanding.

1. **Develop best practices on how to involve young people effectively.** There is a scarcity of guidance for researchers. There are gaps in knowledge that need to be filled e.g. by guidance on when it is appropriate to use different approaches to involvement, and there is a need for the guidance to be made accessible and standardised.
2. **Mainstream best practices by supporting training for researchers, young people, and other stakeholders.** Once best practices are developed it is important that they are mainstreamed across different groups. This could be done by training tailored to different stakeholders.
3. **Build new or expand existing networks of researchers and other organisations focused on involving young people in health research.** Such networks can mainstream best practices, share lessons learned, and broker relationships between stakeholders looking to collaborate (including researchers and young people).
4. **Strengthen and standardise the monitoring and evaluation of young people's involvement in research.** By consistently tracking how young people are involved and the outcomes of that involvement, lessons learned during research will be accessible to others. Moreover, it will help build a stronger evidence base to garner more support.
5. **Support the generation and dissemination of evidence to fill gaps in current peer-reviewed literature to garner more support across the research community.** The review indicated areas where more research is needed such as involving young people in infectious diseases and the health implications of climate change, involving young people in health research in LMICs, and involving young people in agenda-setting. Moreover, more effort is needed to advocate for young people's involvement by disseminating compelling evidence widely.
6. **Ringfence funding to involve young people in research including both one-off project involvement and more long term, sustainable types of involvement.** Funders in the global health research ecosystem can lead by example by ensuring adequate support is made available to cover the additional cost of involving young people effectively.

These recommendations were verified and developed further in stakeholder consultations that have been carried out following this review (Das et al., 2020).

# Glossary

**Assent** is the term for a minor's willingness to participate, even where not legally required. This differs from consent. Consent is a legally defined decision given by someone who is competent, informed and can therefore provide consent themselves. This does not apply to minors, who, by definition, are not legally considered adults (NHS, Health Research Authority, 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).

**External Advisory Group (EAG)** is a body made up of topic experts which provides non-binding independent advice on research being carried out by an organisation.

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

**Institutional Review Board** refers to an "administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution with which it is affiliated" (Oregon State University, 2020).

**Involvement** in research means "research that is done 'with' or 'by'" young people, "not 'to', 'about' or 'for' them" adapted from (NHS Health Research Authority, 2020b). 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.

**Patients and Public Involvement (PPI)** in research "is defined as an active partnership between the public and researchers in the research process, rather than the use of people as 'participants' of research" (INVOLVE, 2016a).

**Peer researcher** is a person with lived experience of the issues being studied who takes part in directing and conducting the research (Lushey & Munro, 2015).

**Photovoice** is a participatory method that asks participants to take photos in their local communities and personal lives that are used to visualise issues and serve as the basis for discussions. The visuals are seen as a facilitation tool to enhance spoken communication and are found to be more effective when presenting issues to communities or policy makers. A variation called Participatory Video uses video instead of photographs as the main medium (adapted from Valdez et al., 2019).

**Rapid Evidence Reviews (RERs)** 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).

**Snowballing** refers to "using the reference list of a paper or the citations to the paper to identify additional papers" (Wohlin, 2014, p. 1). Snowballing is also the process that involves asking advice on "relevant publications in a particular field or topic from key experts" (Overseas Development Institute, 2013, p. 10).

**Systematic review** refers to "a review of a clearly formulated question that uses systematic and reproducible methods to identify, select, and critically appraise all relevant research, and to collect and analyse data from the studies that are included in the review" (Curtin University Library, 2020).

**Translation of knowledge** is a “dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge” (Canadian Institutes of Health Research, 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 (adapted from United Nations, 2009, para. 132).

**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 (e.g. improving the quality of information sheets), and others take on a more active, collaborative role in shaping the research (e.g. collaborating with researchers to set priorities for research, develop tools, or co-author papers)” (Pavarini et al., 2019, p. 744). The term is often used interchangeably with the terms **Youth Advisory Board** and **Youth Advisory Council.**

**Youth-led Participatory Action Research (YPAR)** is an “approach to scientific inquiry and social change grounded in principles of equity that engages young people in identifying problems relevant to their own lives, conducting research to understand the problems, and advocating for changes based on research evidence” (Ozer, 2016, p.189).

# List of Acronyms

**CBPR:** Community-Based Participatory Research

**EAG:** External Advisory Group

**HICs:** High-Income Countries

**IRB:** Institutional Review Board

**LMICs:** Low- and Middle-Income Countries

**NCB:** National Children's Bureau

**NGO:** Non-Governmental Organisation

**NHS:** UK's National Health Service

**NIHR:** National Institute of Health Research

**PEAR:** Public health, Education, Awareness, Research – a young people's public health group

**PPI:** Patient and Public Involvement

**RER:** Rapid Evidence Review

**USAID:** United States Agency for International Development

**WHO:** World Health Organization

**YPAG:** Young Person's Advisory Group

**YPAR:** Youth-Led Participatory Action Research

# Introduction

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, infectious diseases, and the health implications of global heating[7]. It is a politically and financially independent foundation.

Wellcome is interested in exploring the role young people (aged 10-24 years old) could play in its newly launched strategy. 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 diseases, and the direct health impacts of global heating. 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.

As part of this effort, a rapid evidence review (RER) was conducted which focused on peer-reviewed academic literature on young people's involvement in health research published since 2005. The RER identified strengths, weaknesses, and gaps in the literature and developed a framework for youth involvement in health research. It has concentrated on the three aforementioned health challenges, while applying a wider scope when relevant, to capture insights from articles that might be transferable to different contexts.

The RER is complemented by a stakeholder consultation on how young people can be most effectively involved in health research and how Wellcome can best support them. The stakeholder consultation also tested the extent to which findings from the RER align with stakeholders' perspectives.

For the purposes of this review, '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, 2020b). 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 (WHO) (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 in the literature.

The research questions that this RER sought to address are:

- What are the different approaches to involving young people in health research (highlighting any research related to mental health, infectious diseases, and the direct health impacts of climate change)?
  - What were the types of health research projects they were involved in?
  - What were the strengths and weaknesses of these approaches?
  - Under what conditions were the approaches most effective?
  - How equitable were these approaches in including young people from a diverse range of backgrounds?
- What are the challenges and benefits of involving young people in health research?
- What are the skills and capabilities young people need and what additional support do they need (preparation) for effective involvement in health research?
- How do adults working with young people need to be supported to involve effectively young people in health research?

The remainder of this report is divided into six chapters. Chapter one describes the methodology followed during the rapid evidence review whilst chapter two discusses the landscape of young people's involvement in health research today. Chapter three presents the benefits of involving young people and chapter four explains the challenges associated with involving young people. Chapter five documents the best practices that have emerged, and where critical gaps exist. The final chapter concludes with a discussion of recommended next steps.

7 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.

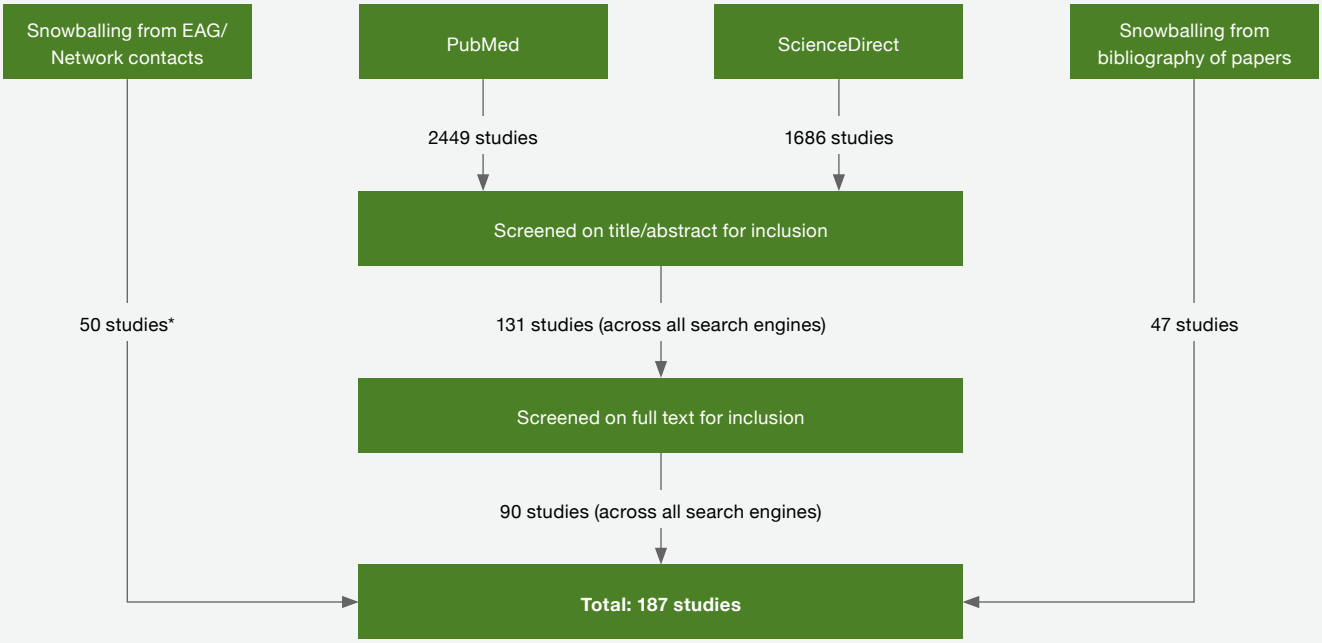
# 1. Methodology

The review took place between July and September 2020. Papers were identified using three distinct methods:

1. **A keyword search;**
2. **Using the bibliography of a paper to identify additional papers; and**
3. **Recommendations from an External Advisory Group[8] (EAG) and Wellcome staff.**

These three sources of articles, once screened for relevance and quality, **generated 187 papers that were analysed systematically** (see figure 1). The scope of the review includes peer-reviewed academic research articles published since 2005 in English. This scope was chosen to prioritise rigorous primary and secondary research relevant to current contexts. Grey literature (e.g. newspaper articles, reports, government policy documents, etc.) is mostly excluded from this review, except for some exceptional cases where it was included to address gaps in academic literature.

**Figure 1:**
**Schematic of included papers**




* The 50 studies used from the EAG and network contacts met screening criteria for relevance and quality

## 1.1. Keyword search

The keyword search consisted of running a series of combinations of keywords in two databases of academic journals: PubMed and Science Direct. Searches were filtered to include only academic articles published in English since 2005.

As described later in this report, one of the challenges of studying the involvement of young people in health research is the wide range of terminology that is used to describe the activity, for example, participatory research, action research, involvement, co-researchers, consultation, and advisory boards. In some cases, these terms are also used to describe instances where young people are not actively involved in research, but are instead research subjects (e.g. responding to a questionnaire). Both issues influenced the study's approach to this keyword search. It was designed to strike a balance between covering a wide range of terms while also dealing with the inevitable large number of irrelevant returns that would appear.

8 The External Advisory Group (EAG) is a body made up of topic experts which provides non-binding independent advice on research being carried out by an organisation.

A shortlist of 67 terms was considered, related to the people (e.g. young people, children, adolescent), action (e.g. involvement, participation, contribution) and topic (e.g. health research, Community-Based Participatory Research[9] (CBPR), Patient and Public Involvement[10] (PPI)). After a rapid test of people/action/topic combinations of search terms, 12 terms were identified as generating a high proportion of relevant search results. The team then conducted exhaustive searches of all possible combinations of these 12 terms.

To broaden the search and include the 55 remaining search terms, the team then split them into whether they related to people, action, or topic. Then the team identified the combination among the initial 12 search terms that yielded the most relevant returns (this combination was "youth" AND "engagement" AND "health research"). Into this combination, each of the remaining 55 search terms was substituted by either people, action, or research topic components, while leaving two dimensions constant. For example, for the term "SARS", which fell into the list of 55 terms, and was then classified as a research topic, the team conducted the search "youth" AND "engagement" AND "SARS". As an example for substituting the people component, the team conducted the search "kids" AND "engagement" AND "health research". As an example for substituting the action component, the team conducted the search "youth" AND "consultation" AND "health research".

To address the high number of irrelevant returns that these keyword search combinations generated, results were screened until ten consecutive search outcomes were judged to be irrelevant. This judgement was based on screening the title and abstract. In total, the team screened 4,264 articles in this way, of which 131 were considered relevant. Articles were considered relevant when they described the involvement of young people in health research or any aspect of this involvement deemed relevant to the review. Articles were excluded when they were describing tokenistic involvement of young people or provided insufficient description of the nature of youth involvement.[11]

The next step for relevance screening was to read each article in full. The remaining articles were then screened for quality based on whether author views were based on clear evidence and whether the methodology used by study was adequately described. This screening reduced the article count to 90.

## 1.2. Snowballing[12]

### 1.2.1. Using the bibliography of relevant articles to identify additional articles

Articles that appeared in the keyword search that met the relevance and quality criteria were also screened so that the articles referenced in them could be considered for review. This provided access to additional papers, which were also screened for relevance and quality. This process yielded an additional 47 articles.

### 1.2.2. Recommendations from an EAG and Wellcome staff

An EAG was convened during this study to bring together a small group of experts in the field of young people's involvement in research, some of which were young people.[13] The group's role was to direct the research team to articles that did not appear in the keyword search or during initial snowballing from the bibliography of relevant papers. Furthermore, Wellcome staff members provided additional papers for consideration. Both sets were reviewed using a full read to test for relevance and quality criteria. This process yielded another 50 articles.

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9 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).

10 Patient and Public Involvement (PPI) in research "is defined as an active partnership between the public and researchers in the research process, rather than the use of people as 'participants' of research" (INVOLVE, 2016a).

11 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 (adapted from United Nations, 2009, para. 132).

12 Snowballing refers to "using the reference list of a paper or the citations to the paper to identify additional papers" (Wohlin, 2014, p. 1). Snowballing is also the process that involves asking advice on "relevant publications in a particular field or topic from key experts" (Hagen-Zanker,& Mallett, 2013, p. 10).

13 The members of the EAG are listed in the Annex.

# 2. Current landscape of young people's involvement in health research

### Chapter summary

This chapter provides a framework to describe young people's involvement in health research. This is informed by an evaluation of existing frameworks and considerations on how these can be adapted to Wellcome's context. The framework comprises five dimensions:

- Stage of research: the stage(s) of research in which young people are involved;
- Level of involvement: the degree to which young people have control/influence over key decision-making in research;
- Health topic: the subject that young people's research is investigating, focusing particularly on the three health areas prioritised by Wellcome's strategy – mental health; infectious diseases; the health implications of global heating/climate change;
- Geography: the country/region in which the research occurs;
- Inclusiveness: the extent to which a diverse range of young people are involved, including young people who face disadvantage .

This review revealed insights across each of these dimensions:

- Stage of research: young people are most frequently involved in the design or data collection stages of research;
- Level of involvement: young people tend to have some control over decision-making, but typically less than adults;
- Health topic: articles describing young people's involvement in mental health outnumbered those in infectious diseases or the health implications of climate change almost three to one;
- Geography: the vast majority of articles are based on research carried out in high-income countries (HICs);
- Inclusiveness: most articles do not report on the gender, ethnicity, socio-economic status, or disability status of young people involved.

## 2.1. Developing a framework to describe young people's involvement in health research

**Different frameworks have attempted to describe young people's participation in decision-making, but none consider the impact of a young person's background.** Since at least the 1960s, researchers have considered how to conceptualise public involvement in decision-making processes. The earliest framework, Arnstein's 1969 'ladder of citizen participation', is a landmark conceptualisation of public participation, but does not focus on research or young people specifically (see figure 12 in the Annex). It places 'citizen control' at the top of the ladder, as the ultimate goal in involving the public (Arnstein, 1969), therefore, it does not value the strengths of a researcher and a citizen collaborating together. However, this model brought clarity to the use of the term 'participation', a feature maintained by Hart (1992) when he adopted Arnstein's model and created the 'ladder' of young people's participation. As Hart's model is an adult-centred framework which has been adapted for application to young people, it risks overlooking the perspectives and real-life experiences of young people. It assumes, as Wong et al. (2010) point out, that the highest participation type is the most desirable. Nevertheless, Hart did later clarify that he did not intend to "imply that forms of participation occur in sequence", while noting that "not all forms of participation are equal" (Arunkumar et al., 2018, p. 4).

Treseder's model (Treseder, 1997) also adapts Arnstein's 'ladder' to apply it to young people's involvement in research, but does not present a hierarchy of researcher-young people involvement: each type of collaboration is presented as different non-hierarchical 'degrees' of collaboration (see figure 14 in the Annex). Wong et al. (2010) and Arunkumar et al. (2018) both build on these models with more conceptually complex analogies. Arunkumar et al. (2018) propose a 'rope ladder' adaptation to Arnstein's model, which recognises the dynamic approaches to working with young people (see figure 16 in the Annex). Wong et al. (2010) offer a 'pyramid' structure (see figure 15 in the Annex) to present young people and adults sharing control at its highest point.

**Figure 2:**
**Summary of frameworks of young people's involvement**

| Model | Description | Strengths | Drawbacks |
|---|---|---|---|
| **Arnstein (1969)** | Ladder model of public participation, which places 'citizen control' at the top of the ladder | • Brings clarity to 'participation'<br>• Critiques tokenistic involvement | • No young people/ research focus<br>• Does not value the strengths of a researcher and citizen collaborating |
| **Hart (1992)** | Stepwise model of young people's participation, places young people and adult sharing decision-making at top | • Recognises the benefits of adult-young people power-sharing | • Adapted adult model, inflexible<br>• Fails to consider social status |
| **Treseder (1997)** | Non-hierarchical 'degrees' of participation | • Considers full breadth of participation models between adults and young people | • Lacks stance on value of different types of young people/adult participation<br>• Conceptually over-simplified |
| **Shier (2001)** | Sequential model building on Hart's, clarifies distinctions / activities at each stage | • Specific to young people<br>• Widely used<br>• Conceptual simplicity | • Fails to consider social status |
| **Wong (2010)** | Pyramid model of participation, places pluralistic power-sharing at pinnacle | • Builds on participation focused on young people<br>• Recognises value in power-sharing | • Greater conceptual complexity<br>• Fails to consider social status |
| **Arunkumar (2018)** | Rope model which accounts for flexibility in young people's participation | • Accounts for influence of social status to some extent<br>• Recognises dynamic approach to young people's involvement | • Over-stretches the 'rope ladder' analogy<br>• Conceptual complexity |

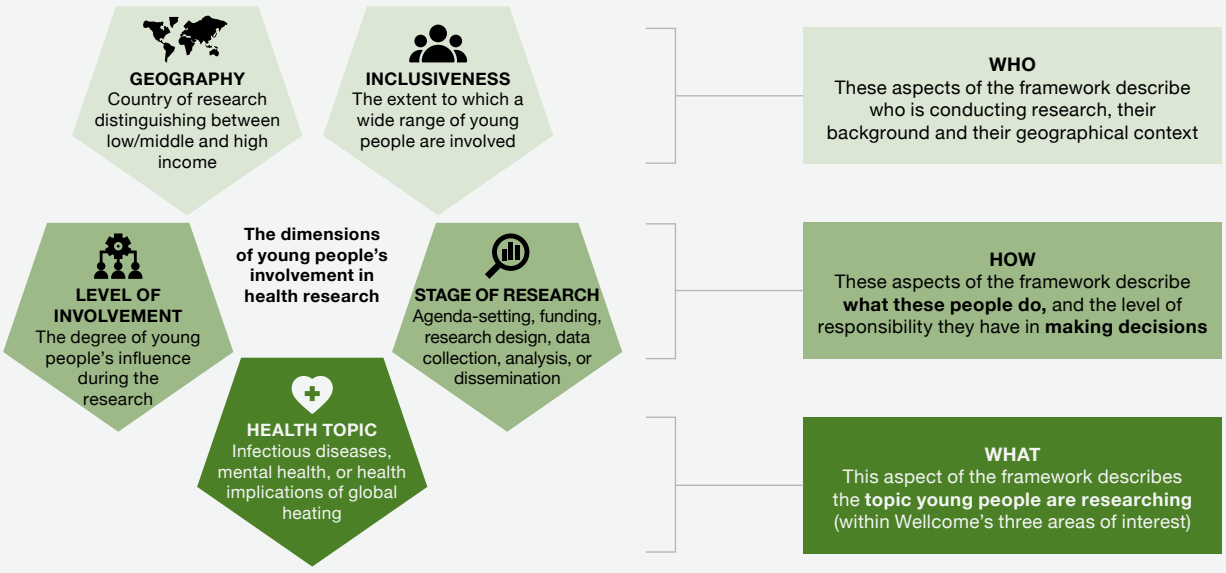
**This study proposes a framework that adds more emphasis on who is involved and in what health research activities and has five dimensions i.e. stage in research process, level of involvement, health topic, geography, and inclusiveness (see figure 4).** None of the frameworks reviewed consider how a young person's background (gender, socioeconomic status, ethnicity, ability) affects the balance of power, or how this power manifests in real responsibilities or tasks. Several experts in participatory research discuss the need to better document the background of people involved (Brady & Preston, 2017). As this model is intended to be globally relevant, this gap becomes more problematic, and therefore a distinct dimension on inclusiveness is suggested. The proposed framework also considers which research activities involve young people, as some authors (Mawn et al., 2016; Oliveras et al., 2018) assert that

young people's involvement is more meaningful when young people are involved earlier in the research lifecycle. Moreover, Shier's model (see figure 3) has been adopted to analyse a young person's level of involvement, which builds on Hart's model, and provides examples of how a young person's level of control might manifest in different activities. Critics argue that Shier's typology has an underlying adult bias given that the questions in it are designed for adult responses (Wong et al., 2010), and as seen in figure 2 it has other drawbacks. However, due to its relative conceptual simplicity, widespread use amongst researchers in this field, and the clarity of separation between levels of participation, it is regarded as the best basis for this dimension. We have attempted to mitigate its shortcomings (i.e. its lack of consideration for how social status affects an individual's involvement) by using it in the context of a five-dimensional framework (see figure 4).

**Figure 3:**
**Shier's 'Pathways to participation' model (Shier, 2001)**

| | | |
|---|---|---|
| LEVEL 1 | **Young people are listened to** | If a young person decided to express their view, they would be listened to, but no organised efforts are made to request young people's views |
| LEVEL 2 | **Young people are supported in expressing their views** | Adults must create supportive physical and psychological environments where young people feel respected and confident to express themselves |
| LEVEL 3 | **Young people's views are taken into account** | Adults must consider the opinions of young people in decision making, although decisions do not necessarily have to be made in accordance with a young person's wishes |
| LEVEL 4 | **Young people are involved in decision-making processes** | Rather than just being consulted, young people are actively making decisions with adults, for example with seats on a committee with adults |
| LEVEL 5 | **Young people share power and responsibility for decision-making** | Young people make decisions alongside adults, but are not (out of practice) or cannot (due to policy) be out-voted or vetoed by adult voices |

**Figure 4:**
**Framework for young people's involvement in health research**



| Dimensions | Description |
|---|---|
| **Stage in research process** | Young people are involved in different activities at each stage of the research process. These include agenda-setting, funding, research design, data collection, data analysis, research dissemination and knowledge translation, and cross-cutting activities.[14] |
| **Level of involvement** | This dimension relates to the level of power a young person has in the research process. For this dimension, we adopt Shier's Pathways to Participation model which separates 'depth' of participation along five levels (see figure 3 for the levels, and the activities in which this would emerge) (Shier, 2001). By actively aiming for a higher level in Shier's framework, adult researchers would naturally evolve the way they worked with young people, either through seeking their input using surveys (Level 3), consulting them in advisory groups led by young people (Level 4), or placing them on research committees and seeking their input as equals in decision-making (Level 5). |
| **Health topic** | Health topic relates to the focus of research with regards to the three health challenge areas that Wellcome has prioritised: mental health, infectious diseases, and the health implications of climate change. |
| **Geography** | Geography references the country or region where research is carried out. |
| **Inclusiveness** | This dimension relates to the extent to which a wide range of young people have opportunities to be involved in and influence research, including young people who face disadvantage and may feel they do not often have these opportunities – sometimes referred to as marginalised or seldom-heard (INVOLVE, 2012). This dimension looked at the documented aspects of an individual's background including gender, ethnicity, disability, and socio-economic status. These aspects can affect an individual's power and status within a research context, particularly when individuals face disadvantage and/or are from marginalised groups. |

## 2.2. Strengths and weaknesses of the evidence based on the framework on young people's involvement in health research

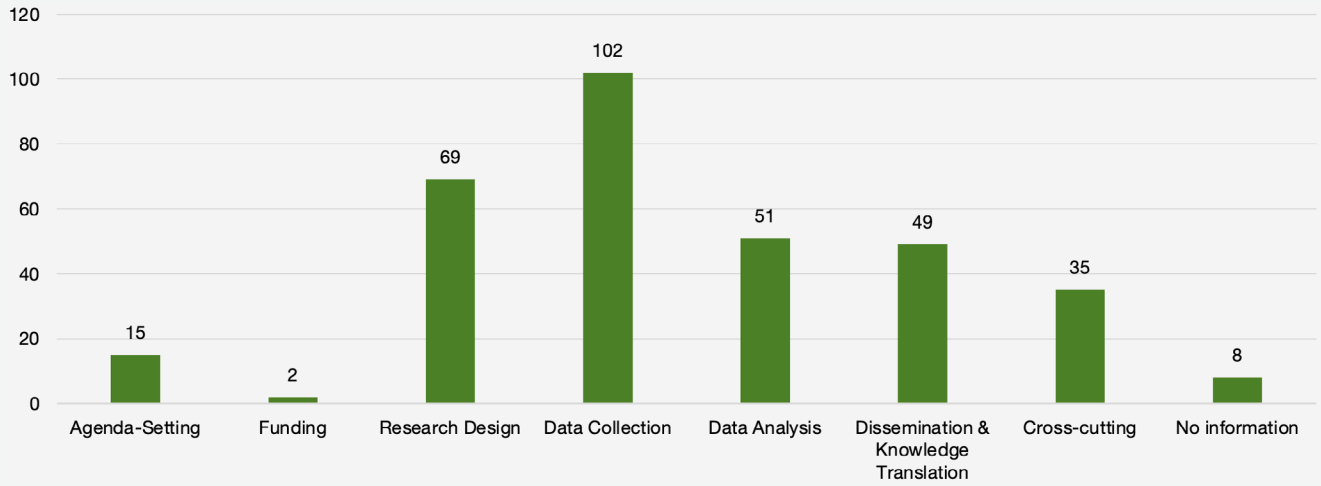
The framework on young people's involvement in health research provided a lens to look at the published evidence in this field and identify strengths and weaknesses across the five identified dimensions.

### 2.2.1 Stage of research

**Young people are most often involved in research design and data collection (see figure 5).** Literature reports that they may prefer to be involved at some stages rather than others. For example, school children in a CBPR project studying bullying preferred to be involved at the data collection phase rather than the research planning phase (Gibson et al., 2015). When young people are involved earlier in the research process, they have more influence over the direction of the research rather than just how it is conducted. Therefore, young people can see that their contribution has a more profound impact on research outcomes (Kulbok et al., 2015; Nygren et al., 2017). However, it is not necessary for young people to be involved at every stage for them to feel they have meaningfully influenced the research (Cepanec et al., 2013).

14. Agenda-setting includes deciding on research topics. Funding includes assisting in decisions related to grant funding proposals. Research design relates to data collection methodology and recruitment methodology. Data collection and data analysis relates to young people implementing the research methodology. Dissemination and translation relate to sharing the research findings with various stakeholders e.g. by providing a summary of results to the study sites, presenting at conferences, writing papers, producing videos and infographics, and publishing these through social media etc.

**Figure 5:**
**Number of articles reviewed, by stage of research.**




**Only 15 articles reviewed involved young people at the agenda-setting stage (i.e. defining broad priorities or directions of research).** This review found low participation of young people at the earliest stages of research, potentially because involving young people this early on requires researchers to plan their involvement in advance, before they have funding to secure it. It also means consistently investing in young people outside the project context, and significantly investing in researcher training. In the fewer instances where young people are involved in setting the research agenda, they attend meetings with experts and adult researchers and comment on the topics of the research which are important and relevant to them (Denison et al., 2017; Lincoln et al., 2015). While many papers do not report explicitly on young people being involved in agenda-setting, two papers examine the issue and conclude it might be more common. First, in a study of 84 researchers who stated they involved young people in their research, almost a quarter said they involved young people at the agenda-setting stage (Hawke et al., 2020). Secondly, a non-systematic review of CBPR involving young people identified 56 papers partnering with young people to conduct research, 77% of which involved young people in the "identification of needs, priorities, and goals of research" (Jacquez et al., 2013, p. 179).

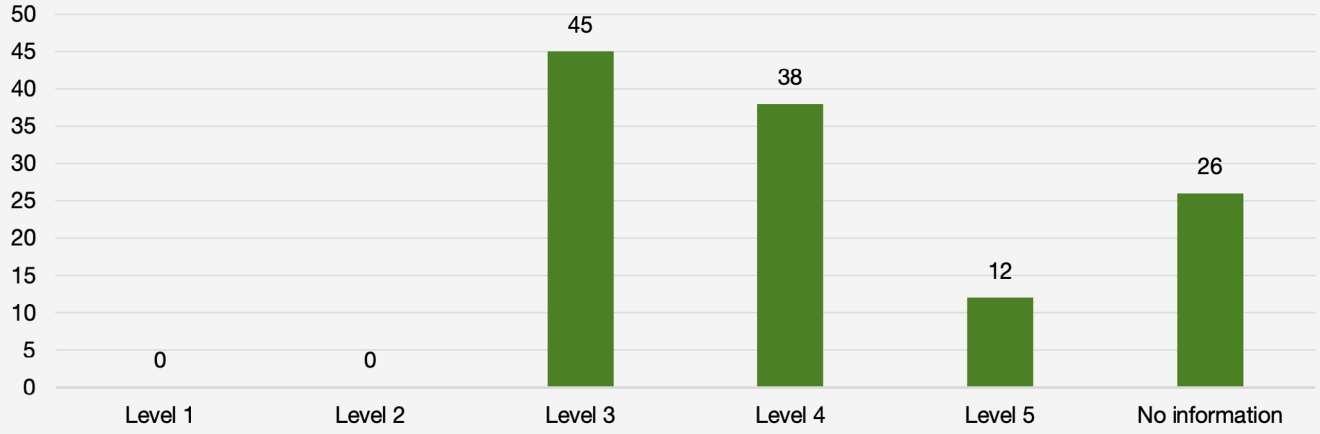
**Young people are often involved at multiple stages of research.** Nearly two-thirds of relevant papers (63%) involved young people in at least two stages of research, and 31% involved young people in at least three stages. Eight papers did not give enough information to discern the stage of research.

### 2.2.2. Level of involvement

**Most papers reviewed describe cases where young people's views were taken into account and/or influenced decisions, but they have had less decision-making power than adults.** In 69% of articles, young people's views were taken into account (Level Three in Shier's model) or young people participated in decision-making (Level Four). This would include activities such as conducting youth surveys, running youth advisory councils, or running Young Person's Advisory Groups[15] (YPAGs), and inviting young people to join agenda-setting meetings (although not in large enough numbers to out-vote adults). Only 10% of articles described young people making decisions alongside adults (Level Five). An example of this could be where young people are invited to sit on a committee with adults, to make decisions about research, and the adults cannot overrule the young people due to the committee's governance rules. Level Five can only be achieved when adults plan to involve young people early in the planning stages of research (McCartan et al., 2012). Importantly, the review did not identify papers that present examples of the lower levels of involvement (Levels One and Two), due to the design of this RER. The keyword search was designed specifically to gather papers where young people's involvement was not tokenistic. In reality, we suspect that tokenistic involvement may be much more prevalent.

15 A Young Person's Advisory Group (YPAG) is an increasingly common method of implementing co-production with young people in health research through advisory groups that include patients, research participants and members of the public. 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).

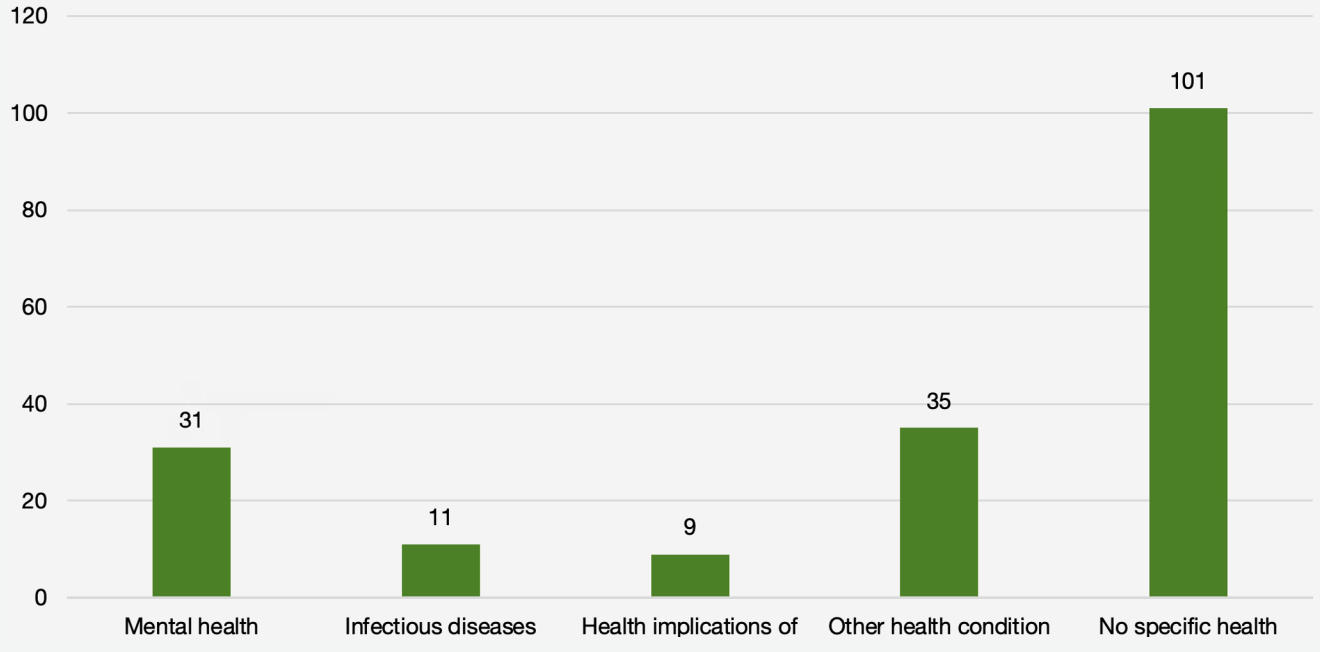
**Figure 6:**
**Number of articles reviewed by level of young people's involvement, based on Shier's (2001) Pathways to Participation model**




### 2.2.3. Health topic

**Most articles on young people's involvement focus on health research in general, rather than a specific health topic. Of those that do, mental health is the most frequently studied topic (see figure 7).** Mental health research includes studies of substance use and psychosocial needs of patients of other health conditions. It also includes different mental health intervention approaches, such as community-based interventions. 31 papers are focused on mental health, whilst fewer papers are focused on infectious diseases (which includes HIV, TB, and other diseases) and the health effects of climate change. The 136 papers researching other health issues examined a broad range of topics, including diabetes, obesity, cancer, disability, and palliative care, or were papers not concerning a specific health condition.[16] Some papers' focus was not specific to a particular health condition. These, for example, concern cross-cutting issues ranging from involving young people in education research to guidance on developing YPAGs. This research was included as it often covers relevant frameworks or best practices for involving young people.

**Figure 7:**
**Number of papers reviewed by health topics.**




16 For example, some articles discuss ethical implications of involving young people in any form of health research.

### 2.2.4. Geography

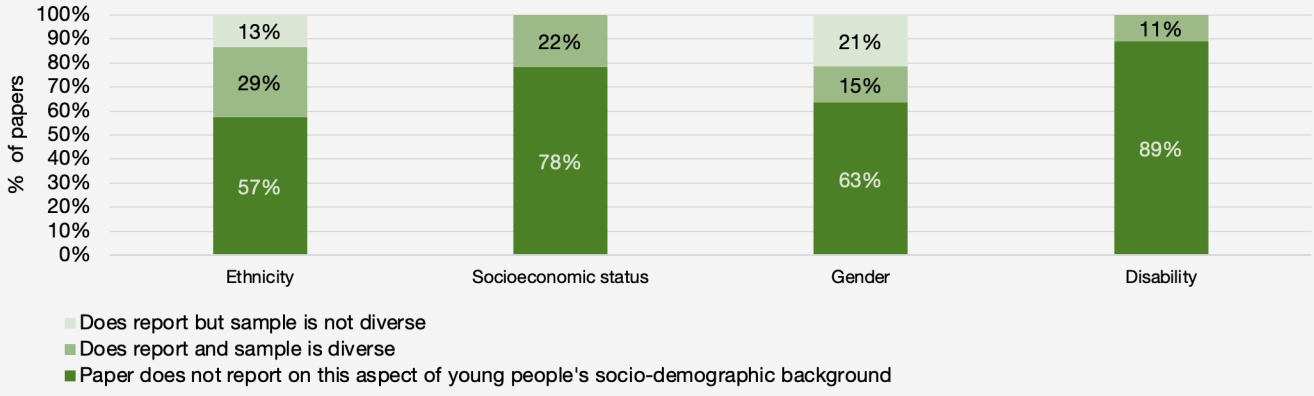
**140 papers reported on country focus, of which only 21 were in LMICs (15%).** The most reported LMICs are South Africa, Kenya, Brazil, and India, while the most reported high-income countries (HICs) are the US, the UK, and Canada. It should be noted that 42% of the world's population is under 25 and the majority of these young people are in LMICs (Khokhar, 2017). However, nearly 90% of all research about adolescents comes from HICs (Blum & Boyden, 2018). This means that most research focuses disproportionately on the most privileged young people (i.e. those in HICs), and misses out on the experiences of young people in LMICs (Zeinali et al., 2020). This RER confirms this statement.

**Evidence regarding the setting of research that involves young people is limited, but it does suggest that it mostly takes place in schools, universities, and community settings.** A systematic review of 41 papers on young people's involvement in health research found that participatory research is most likely to be used in school systems (Larsson et al., 2018). This finding was echoed in other literature (Anyon et al., 2018; Vaughn et al., 2013). Ozer et al. (2010) explain that there are benefits to working in schools, such as their responsiveness to students' rights and needs. However, some evidence highlights the difficulties of involving young people in research in a school setting, including a restrictive top-down environment preventing young people's ability to work independently, or the implications of a teacher as a 'gate keeper' (in addition to parents) who can be particularly strict (Huang et al., 2016; Larsson et al., 2018; Massey et al., 2013).

### 2.2.5. Inclusiveness

**The majority of articles do not report the background of young people involved, which makes it difficult to draw conclusions on the inclusiveness of the research.** Papers tend to not report the socio-demographic status of young people involved in health research, including gender, socioeconomic status, ethnicity, and disability. However, this varies significantly by different aspects of socio-demographic status. For example, ethnicity was most widely reported on (43% of all papers), whereas disability was the least reported (11%) (see figure 8). It is also important to note how diverse samples are when socio-demographic information is reported. For example, all papers that reported on the socioeconomic or disability status of their samples of young people had diverse samples. That is, a significant proportion of the sample were from low-income groups or identified as having a disability. However, this is not the case for papers that reported the gender and/or ethnicity of their samples. The analysis also found that a paper which reported on one aspect of socio-demographic status was more likely to report on another aspect, with 35% of papers reporting on more than one aspect.

**Figure 8:**
**The extent to which papers report the socio-demographic characteristics of samples of young people involved (n = 127)[17]**




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

# 3. Benefits of involving young people in health research

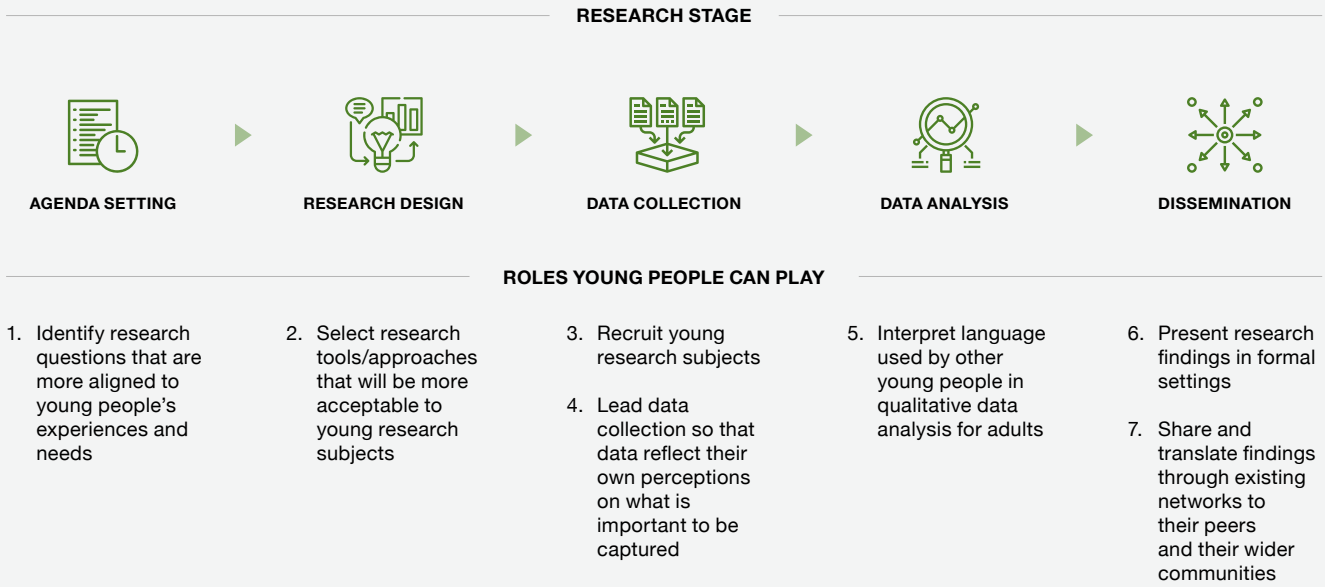
## Chapter summary

Young people can play a wide range of roles across each stage of the research cycle. Experts largely agree that young people have the right to play a more significant role in research, especially where the impact of that research will affect them. Beyond the rights-based argument, an increasing number of studies examine the impact of involving young people in research, with the overwhelming majority reporting positive effects. Young people's unique perspectives, lived experiences, and ability to effectively disseminate information within their communities all improve the quality of research projects. Young people gain research skills, they feel empowered and their involvement has a ripple effect, improving their local community. However, evidence in this field is still emerging and there is a need to continue investigation into how young people's involvement affects outcomes.

**Researchers widely recognise the value of listening to young people's lived experience.** Adult researchers are aware that young people's lived experience is the reason they can help access deeper insights when working with young research participants. This "contemporary experience" is culture-specific and age-specific (Bradbury-Jones & Taylor, 2015, p. 166; Marco-Crespo et al., 2018; O'Brien, 2019). But beyond lived experience, young people have a wide range of capabilities to bring to research, related to their contextual knowledge of their local environment and their access to local networks.

**This review has demonstrated that young people can play a wide range of roles across each stage of the research cycle.** While most studies have focused on young people's involvement in health research design or data collection (see section 2), the literature also includes compelling examples of young people effectively contributing to agenda-setting or research dissemination and translation. Figure 9 lays out the roles that young people can play at each stage of the research cycle and the distinct skills and knowledge that allow them to do so.

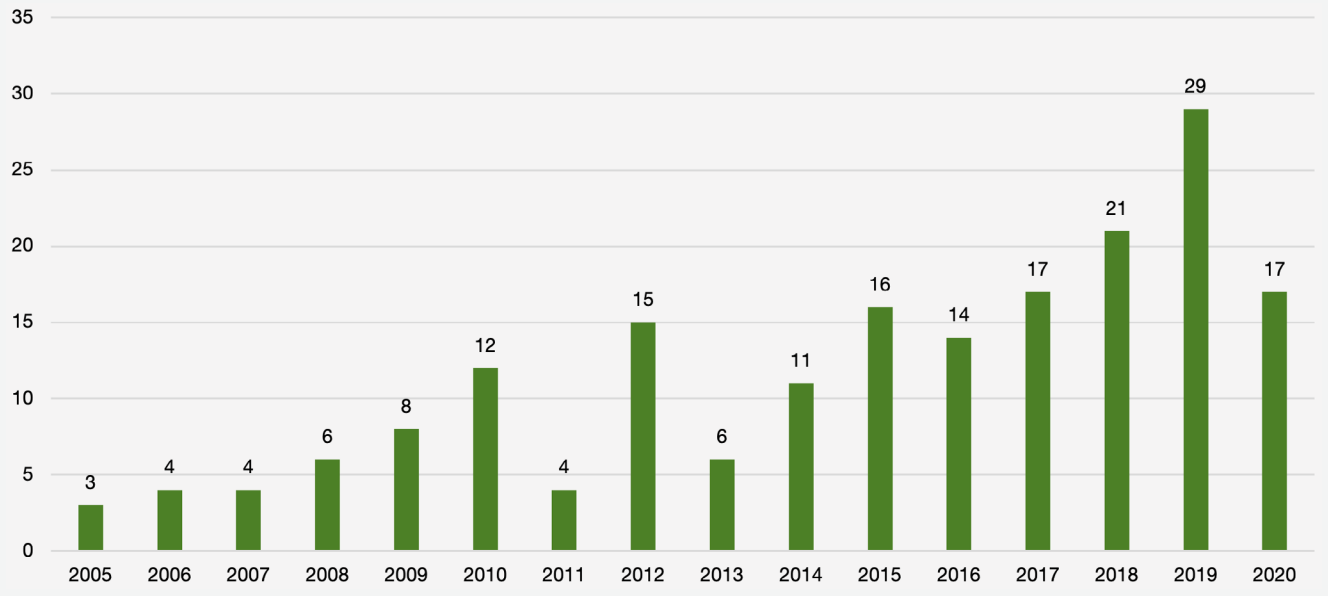
**Figure 9:**
**The roles young people can play at different stages of research**



**The review identified seven case studies that exemplify the range of roles young people play across research stages and different health topics that Wellcome focuses on.** These case studies demonstrate the varied and detailed ways young people can contribute to research, in a range of settings and through different mechanisms. Two of these are featured in this chapter, alongside a discussion of other examples of evidence of the benefits that young people's involvement can lead to when carrying out certain roles. The remaining case studies can be found in Annex 1.

**The health research community is increasingly involving young people in health research. As it does so, the case for involving young people is becoming more and more compelling.** Of the 187 papers analysed for this RER, 52% were written in-between 2016-2020 (see figure 10). A systematic review of young people's involvement in health research has also noted increasing volumes of literature on this topic (Anyon et al., 2018). This mirrors trends seen in involvement of the broader population in health research. For example, the European Medicines Agency (EMA) notes that patient and consumer involvement in activities has increased more than 5.5 times between 2008 and 2017 (Tsang et al., 2019). In the UK, the National Institute of Health Research (NIHR) is making public involvement in health research, particularly with young people, a central feature in funding applications (NIHR, 2015). However, while the frequency of young people's involvement is increasing, the depth of this involvement is varied, ranging from tokenistic to full power-sharing (Clarke, 2015; Oliveras et al., 2018; Pavarini et al., 2019).

**Figure 10:**
**Number of articles reviewed, by year published**




**There is wide consensus among researchers that young people should be involved in health research.** According to the UN Convention on the Rights of the Child (UN Commission on Human Rights, 1989), children and young people have a right to be involved in decisions that affect their health, which includes health research. This argument is strengthened by the fact that 42% of the world's population is under 25 years old (Khokhar, 2017). Leading voices on the ethics of science strongly advocate for involving young people in health research on human rights grounds (e.g. the Council of International Organizations in Medical Sciences, the European Medicines Agency, and the Nuffield Council on Bioethics) (Marsh et al., 2019; Modi, 2020; Preston et al., 2019). Increasingly, the research community is accepting and expecting young people's involvement in health research (Schelven et al., 2020). The Council of International Organizations in Medical Sciences guidelines state "children and adolescents must be included in health-related research unless a good scientific reason justifies their exclusion" (Council for International Organizations of Medical Sciences, 2016, p. 65).

**In addition to this rights-based argument, evidence from the literature shows how involving young people may benefit research outcomes, the young people themselves, and their communities.** Accordingly, to best present

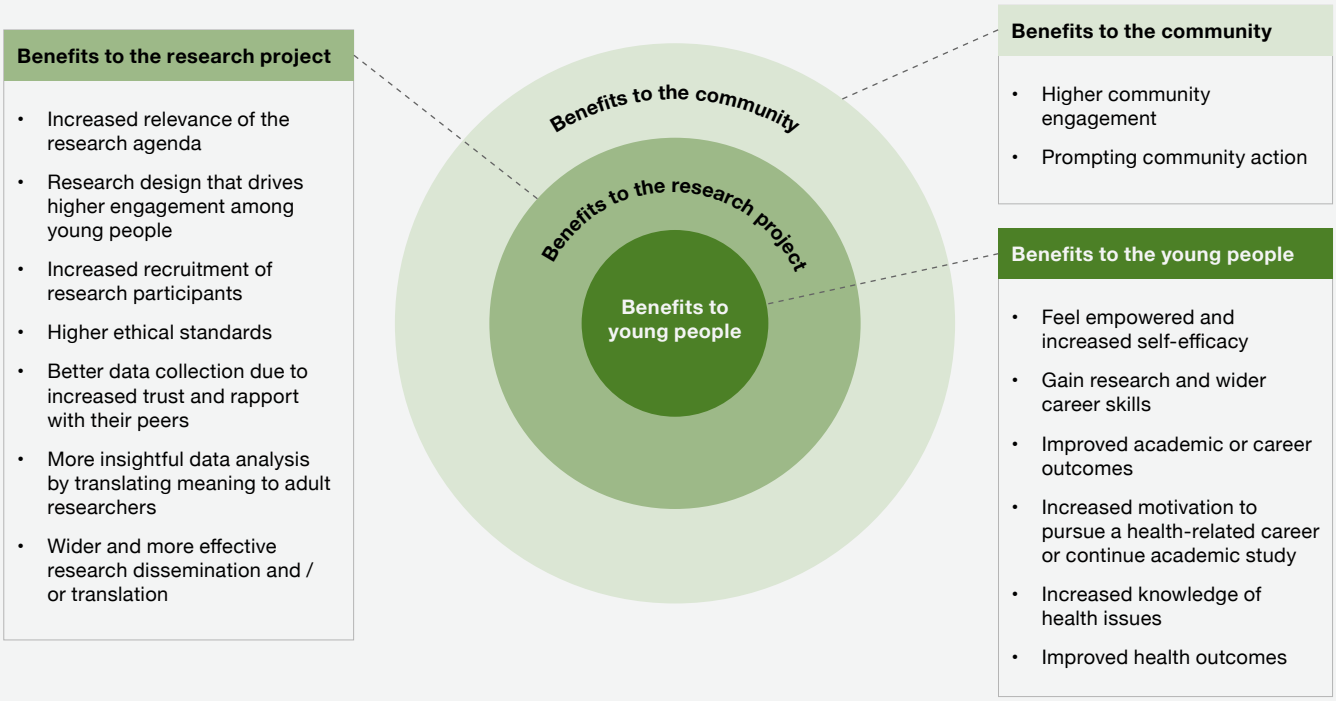
this evidence, we have separated it into benefits to (1) the research project, (2) the young researcher and (3) the wider community (see figure 11).

- **Benefits to the research project** describe how the research process is improved by involving young people. This may include, among others, a greater focus on questions important to young people, improved phrasing of questions, recruitment of more participants from groups of young people that face disadvantage, and use of research methods that are more relevant to young people. These changes would increase the likelihood that research outcomes (i.e. knowledge creation) are high-quality.
- **Benefits to the young researcher** describe the advantages gained by the individual young person by being involved in health research. This may include development of skills related to research, improved career prospects, experiencing a sense of empowerment and/or civic engagement, improved knowledge of health problems, and even improved health outcomes.
- **Benefits to the wider community** describe how the society around a research project might benefit when young people are involved. This may include a more civically engaged population, better data on local health issues, increased trust in science, and higher community awareness of relevant health issues.

**Almost all articles reported the positive impact of involving young people, but there is reason to believe that a lot of involvement that takes place goes unreported.** This is for several reasons:

1. While young people are being involved in more studies, the overall number of studies they have been involved in to-date is still relatively low.
2. Non-academics involved in participatory research may be less motivated to invest time in writing up their experiences for academic journals, which would contribute to the collective learning and evidence base on this topic (Cook et al., 2017; Davies et al., 2020).
3. Short time scales for research funding mean that the likely longer-term impact of this work will occur beyond the life-cycle of project implementation and reflection, thus they go uncaptured (Cook et al., 2017).
4. It is difficult for researchers to capture the impact of involving young people as the field of measuring research impact itself is still evolving, and tools and methods to measure impact are still under debate and development (Cruz Rivera et al., 2017).
5. The terminology and reporting standards for this field of research are still emerging, which means that some research is mis-labelled. For example, some research is labelled as 'participatory' when it is not. Some papers do not clearly outline how young people contributed or how they arrived at their conclusions. This reduces the quality of data that does exist (Bales et al., 2018; Jacquez et al., 2013).

**Figure 11:**
**Overview of evidence by type of benefit**



## 3.1. Benefits to the research project

Young people can play a variety of roles in health research and add value in each stage. The evidence that young people add value at the research design and data collection stages is particularly compelling. Overall, many papers suggest that their advantage comes from their understanding of their peers' needs and capabilities, and because they are more trusted by and connected with their communities.

### 3.1.1. Increased relevance of agenda-setting

**Young people's involvement at the agenda-setting stage increases the relevance of the research to their peer's experiences and priorities.** Giving young people the opportunity to shape the agenda-setting stage allows them to use their unique understanding of other young people's needs to influence research priorities. This can take the form of altering the entire research project. For example, Pavarini et al. (2019) ran a YPAG focused on mental health. Her team shifted the focus of their research from the ethics of predicting poor mental health based on genetic testing to the ethics of predicting poor mental health based on digital footprints. The team shifted focus because the YPAG "deemed [it] more relevant to their daily lives" (page 749). In other examples, young people's impact on research questions can be more subtle, bringing a new light to their experiences, whilst retaining the same overall focus of the research (see case study 1 for an example of this).

### Case study 1
### Young people's experiences inform the research agenda for HIV research at an international conference - Denison et al. (2017)

**WHO?**
Four young people (ages 18-24) living with HIV from Botswana, South Africa, and Zambia. They were identified through consortium partners of the United States Agency for International Development (USAID) project "Supporting Operational AIDS Research (SOAR)", and through experts participating at an international HIV/AIDS conference.

**WHERE?**
An international HIV/AIDS conference hosted by USAID in Washington D.C., with 50 participating experts, aimed at developing an implementation science research agenda to improve HIV outcomes in young people (implementation science is the "application and integration of research evidence in to practice and policy" Glasgow et al., 2013, p.26).

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**
4 out of 5 – Young people are involved in decision-making processes, and their experiences inform the decision, although they are not responsible for the outcome.

**WHAT HAPPENED?**
The young attendees started the meeting by sharing their own stories of HIV with the researchers, funders, and policymakers: how they learnt about their HIV positive status, navigated care, coped with stigma, and managed school. This was followed by a more open discussion with the experts present. Throughout the meeting, the adolescents maintained the focus of the discussion issues relevant to young people living with HIV.

**WHAT WAS THE IMPACT?**
The young people influenced the adult researchers' decision-making, to the extent of changing the implementation science research agenda developed during the conference. The adult experts then voted on all implementation science research agenda questions which had been generated through discussion at the conference, and those which were directly informed by the young people's input were voted as the top two questions. The questions examined the effects and costs of stigma-reduction interventions in HIV testing, counselling, and care. Finally, the young people's presence reminded the experts that public health terminology can have different meanings to younger audiences and that researchers need to communicate in a manner accessible to young people.

### 3.1.2. Research design that drives deeper engagement from young people

**Young people can propose data collection methods that are more engaging for their peers.** There is particularly compelling evidence that young people suggest effective methods of collecting data from their peers. These include using young people as peer data collectors to make young research participants feel more relaxed. For example, one study describes how young people suggested using "peer-led interviews… where participants take turns asking each other pre-defined questions from flashcards, which resembles a conversation between peers". These were considered highly engaging by the young participants (Pavarini et al., 2019, p. 749). Elsewhere, young people used photovoice[18] as a data collection method, which can be more effective at yielding high-quality data from other young people (Jardine & James, 2012; Valdez et al., 2019). Finally, there are many examples of young people's ability to make data collection tools, such as questionnaires, interview guides, and leaflets more relevant and suitable to young people by adjusting the wording or format (Bird et al., 2013; Brett et al., 2014; Dang et al., 2019; Dennehy et al., 2019; Horsfield et al., 2014; Maticka-Tyndale & Barnett, 2010; McLaughlin, 2005; O'Brien & Moules, 2010; Powers & Tiffany, 2006; Sangalang et al., 2015).

**Recruitment of young participants to health research is easier when it is designed and led by young people.** Studies show that involving young people in health research improves recruitment and retention of participants (Gaillard et al., 2018; Kulbok et al., 2015; Tsang et al., 2019) and results in more effective recruitment messages which better resonate with target participants (Comfort et al., 2018; Vaughn et al., 2013). Other articles point to more specific ways that young people improve recruitment, such as by securing higher survey response rates from young participants than adults do (Bradbury-Jones & Taylor, 2015; Kim et al., 2019; Yanar et al., 2016) and by more effective use of online platforms (including social media) for research recruitment (Parsons et al., 2018; Pavarini et al., 2019). Less comprehensive evidence points to young people's effectiveness at reaching marginalised populations (Powers & Tiffany, 2006), and developing trust and instilling confidence in young participants (Maticka-Tyndale & Barnett, 2010; Powers & Tiffany, 2006).

**Research that involves young people has also been found to achieve higher ethical standards.** While the evidence for this is less conclusive than other benefits, it hints at an under-recognised advantage of working with young people. For example, a paper describing three large-scale studies involving 517 adolescent sex-workers in China in CBPR found that the participatory approach led to higher ethical standards and increased validity and relevance of the research (Zhang et al., 2019). Similar findings have been found in other studies (Gaillard et al., 2018; Hawke et al., 2020; Mawn et al., 2016).

### 3.1.3. Better data collection and analysis

**Young researchers are more trusted by and have better rapport with their peers. This allows them to collect higher quality and more credible data.** Some authors describe participants as more relaxed, open, and candid than they would be with adult researchers (Bird et al., 2013; Jardine & James, 2012), or as having an improved rapport with participants (Kelly et al., 2018). Two papers directly identify this improvement in data quality as a result of increased trust between researcher and subject (Delman, 2012; Maticka-Tyndale & Barnett, 2010).

**Young people bring new skills and attributes to data analysis by virtue of being young, which adults cannot contribute.** These include an understanding of their peers' ways of expressing themselves, and an understanding of young people's contemporary mindsets and attitudes. Young people use this understanding to better interpret their peers' responses to research questions and translate these responses for adult researchers. For example, one paper describes how young people's understanding of the patterns and use of their peers' language is the most useful factor in 'translating' meaning for adult researchers (Delman, 2012). Another example from Chappell et al. (2014, p. 393) found that young co-researchers were able to "glean insights that may not necessarily have been available to the adult researcher". They give the examples of how young co-researchers showed that young research participants with disabilities had developed their own "secret language around issues of love, sex, and relationships", and that "this oppositional language is only understood by other youth".

18 Photovoice is a participatory method that asks participants to take photos in their local communities and personal lives that are used to visualise issues and serve as the basis for discussions. The visuals are seen as a facilitation tool to enhance spoken communication and are found to be more effective when presenting issues to communities or policy makers. A variation called Participatory Video uses video instead of photographs as the main medium (adapted from Valdez et al., 2019).

### 3.1.4. Wider research dissemination and/or research translation

**Young people can play a unique role in sharing research findings with policymakers and other researchers.** Young people's involvement in dissemination with policymakers and academics can be similar to the adults' role, including co-authoring manuscripts and presenting at public health conferences (Hunskaar et al., 2009; Noone et al., 2016). When young people present in this manner, it can be more memorable, as audiences rarely see young people presenting their research and sharing their own experiences to a general audience (Bradbury-Jones & Taylor, 2015; Findholt et al., 2011; Gaillard et al., 2018).

**Young people can also be involved in disseminating information within their own communities.** There is compelling evidence that when disseminating information within their own communities e.g. family and friends, young people's ideas and access to networks provides them with a unique advantage (Marco-Crespo et al., 2018; Young, 2018). For example, a CBPR project with young Native American people suggests that dissemination activities, like helping community elders and demonstrating pride of local communities, caused improved dissemination (Ford et al., 2012). Some evidence suggests that the reason why young people are more effective at information dissemination is because the audience perceives the research as more trustworthy when young people were involved in creating findings (Mitchell et al., 2017; Nguyen et al., 2019; O'Brien & Moules, 2012). Young co-researchers can also improve the appeal of dissemination materials to other young people, making it more relatable (Bird et al., 2013; McLaughlin, 2005).

## 3.2. Benefits to the young researcher

A large body of evidence consistently suggests that young researchers acquire research and transferable skills through involvement in research, increase their understanding of health issues, and that research makes them feel more empowered (see case study 2). Other evidence, less frequently published, suggests that this increased knowledge and empowerment translates into improved career/academic outcomes or improved health outcomes.

**Involvement in health research helps young people to learn more about health issues.** Evidence from young people's involvement in research consistently suggests that they develop increased awareness relating to their research topic. For example, a systematic review (Valdez et al., 2020) of youth participatory action research[19] (YPAR) for substance use prevention, highlighted that in 13 out of 15 articles reviewed, young people's knowledge increased as a result of involvement. A long list of other papers reviewed had similar conclusions (Abma et al., 2020; Aceves-Martins et al., 2019; Kulbok et al., 2015; Lane et al., 2019; Madrigal et al., 2016; Oliveira et al., 2014; Robbins et al., 2008). For example, following a photovoice project aiming to raise awareness of obesity, student researchers reported an increase in awareness of the factors which influence child obesity and food choices (Findholt et al., 2011).

**Increased health knowledge can lead to better health outcomes for young people.** Research in this area is still emerging, but existing evidence supports the link, in some cases, between improved health outcomes and increased knowledge about specific health issues. For example, an evaluation of different approaches to HIV prevention found that peer-led education was associated with reductions in methamphetamine use and increases in condom use over 12 months among a sample of young people (Sherman et al., 2009). Another paper found that young people involved in researching substance use had decreased use of alcohol and marijuana (Valdez et al., 2020). The review did find one example of a less direct link between participation in health research and health outcomes. A literature review of young people's involvement in different types of health research found that it can help young people develop emotional skills and understand that their views matter, which can positively affect their health outcomes (Aceves-Martins et al., 2019).

19 Youth-led Participatory Action Research (YPAR) is an "approach to scientific inquiry and social change grounded in principles of equity that engages young people in identifying problems relevant to their own lives, conducting research to understand the problems, and advocating for changes based on research evidence" (Ozer, 2016, p.189).

**Young people feel more empowered when involved in health research.** Research in this area is relatively comprehensive, with multiple primary research interventions demonstrating this effect. For example, a YPAR evaluation of a children's health and activity programme identified children's empowerment as a core outcome, as the children found satisfaction in seeing the results of their participation (Anselma et al., 2020). A review of expert opinions and articles related to patient involvement in paediatric drug development also found that having their voices heard instilled a sense of empowerment in young people (Tsang et al., 2019). Young people's involvement in YPARs and other forms of health research have led to greater self-reported empowerment and self-efficacy, potentially linked to the realisation of young people that they are important and are capable of creating impact (Atkins et al., 2016; Bailey et al., 2015; Bird et al., 2013; Brickle & Evans-Agnew, 2017; Fletcher & Mullett, 2016; Garcia et al., 2014; Haynes & Tanner, 2015; Lindquist-Grantz & Abraczinskas, 2020; Sheridan et al., 2020; Soleimanpour et al., 2008; Suleiman et al., 2006; Taylor et al., 2018; Trott, 2019). Furthermore, many young people have expressed a desire to be involved in health research after experiencing it once (Bulc et al., 2019; Kembhavi & Wirz, 2009; Lawler & Patel, 2012; Oliveira et al., 2014; Torronen, 2014; Trott, 2019; Woodgate et al., 2018).

**Involvement in health research provides young people with new academic and career skills.** Many papers support the link between involvement in health research and developing new skills. For example, a systematic review of YPAR found that 75% of the 63 articles included in the review highlighted that participation increased young people's sense of agency and leadership skills (Anyon et al., 2018).[20] Another systematic review of young people's involvement in substance abuse research came to a similar conclusion, reporting that young people gain skills in qualitative data collection and analysis and in video development (Valdez et al., 2020). Many other papers point to young people developing transferrable skills such as presentation, teamwork, leadership, problem-solving, and communications skills (Baukus, 2019; Csiernik et al., 2018; Dang et al., 2019; de Jong et al., 2018; Fowler et al., 2014; Garinger et al., 2016; Jardine & James, 2012; Marco-Crespo et al., 2018; Massey et al., 2013; McAndrew et al., 2012; Noone et al., 2016; Ozer, 2016; Pavarini et al., 2019; Sales et al., 2019; Soleimanpour et al., 2008; Valdez et al., 2020). Some papers highlighted gains in research-specific skills, including qualitative data management and analysis, planning projects, developing data collection instruments, and using different methodologies (Bailey et al., 2015; Brosnan et al., 2005; Cepanec et al., 2013; Dehaven et al., 2011; Lindquist-Grantz & Abraczinskas, 2020; Powers & Tiffany, 2006; Russell et al., 2007; Suleiman et al., 2006).

**Involvement in research increased some young people's motivation to pursue a health-related career or continue academic study.** While existing evidence in this area is less frequent, it does suggest that there is an under-explored link between involvement in research and future career and study choices. For example, a study of five nursing students involved in a summer programme of research indicated that their involvement made them 'more likely' or 'somewhat more likely' to pursue graduate studies at some point in the future (Cepanec et al., 2013). We also found an example of young people eventually finding employment at the centre they originally conducted research with (Gishawn et al., 2010) and an example of an individual who had changed their study plans to become a researcher (James et al., 2013, p. 2218).

**In other cases, involvement in research and the skills gained resulted in improved academic or career outcomes.** Although this link has not been widely researched yet, the existing evidence suggests that involvement in research significantly impacts young people's career and academic choices. For example, a review of undergraduates in a research programme found that of 79 participants, 92% later entered a career or further studies related to the health profession (Stewart et al., 2020). This link is also supported by a systematic review of 63 papers investigating the impact of youth involvement in YPAR, where 56% reported that individuals experienced outcomes associated with academia or their careers (although the review did not give further detail on what these outcomes were) (Anyon et al., 2018). Finally, Sheridan et al. (2020, p. 54) acknowledge the potential impact on career and academic attainment from research involvement: "New opportunities may be available, for example, the ability to meet new people, meet researchers working in a relevant area, and the opportunity for travel. For all age groups, these experiences may also be of use for academic, career and personal development".

20 These articles and others are based on self-reported observations on changes in skills etc.

## Case study 2

### Young people with disabilities lead focus groups and interpret language used by their peers in qualitative data analysis - Chappell et al. (2014)

**WHO?**

Three young co-researchers with a physical disability. Two participants were female, aged 17 and 20, and one was male, aged 15. The young co-researchers were selected from different geographical locations and based on their interpersonal skills. Two of the co-researchers had completed at least four years of secondary education, while the third co-researcher had left school at nine years old.

**WHERE?**

KwaZulu-Natal, South Africa. The province is characterised by high HIV prevalence (24.7%).

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**

3 out of 5 - Young people were involved in research design and data collection during focus groups conducted with their peers and in some aspects of the data analysis. No mention of their involvement in agenda-setting or dissemination or translation was noted.

**WHAT HAPPENED?**

The three co-researchers with a disability were trained by the lead-researcher for a study on youth sexuality in the African context, particularly in settings with high HIV-positive population rates. The young researchers followed a one-week training on confidentiality, research design, skills, and ethics. Following the training, the young people were responsible for carrying out focus group discussion and individual interviews with other youth with disabilities. Meetings were held between co-researchers and the lead researcher to discuss their experiences and conduct data analysis. Youth identified emerging themes and discussed their views on focus group outcomes.

**WHAT WAS THE IMPACT?**

The impact evaluation of young people's involvement in the research process was based on a qualitative assessment of the lead-researcher's observations and feedback discussions with young participants. The young researchers learned about health and sexuality and felt empowered in their communities and improved their communication skills. They also developed a better approach to their relationship with adults, especially in research contexts.

## 3.3. Benefits to the wider community

Strong evidence suggests that young researchers can become more civically engaged after being involved in research, experiencing a desire to positively influence their communities and societies. Involvement in research can also draw a community's attention to a health issue, which can translate to community action.

**Young researchers' involvement can make them more civically engaged (see case study 3).** Robust evidence supports the link between young people's involvement in health research and involvement in their communities. For example, in a study of YPAR the author observed that young people experienced a "motivation to influence schools or communities in constructive ways" (Ozer, 2016, p. 197). The connection between involvement and civic engagement has been widely studied and documented in other examples (Bruno et al., 2014; Garnett et al., 2019; Jardine & James, 2012; Lane et al., 2019; Martinez et al., 2012; Noone et al., 2016; Umoren et al., 2015).

**Young people's research can also raise their communities' awareness on a health issue, which sometimes translates into community action.** Several papers reported that young people's involvement in health research led to increased community awareness of a particular health problem (Davies et al., 2019; Dennis et al., 2009; Findholt et al., 2011; Masuku et al., 2018; Young, 2018). Whether young people's involvement can, in addition to leaving them better informed, mobilise communities to act is less widely evidenced. Two studies – one describing research into the health

of homeless people in New York and another on climate change and disaster risk reduction in the Philippines - provide such evidence (Haynes & Tanner, 2015; Powers & Tiffany, 2006). One report in a systematic review observed an increase in community-level self-efficacy as a result of young people's involvement in health research, and two others noted the community researched as having the direct benefit of more data with which to guide local policy decisions. The review does not note whether these links were examined in other papers (Valdez et al., 2020).

## Case study 3

## Young people from a health policy advocacy organisation present research findings to their community - Noone et al. (2016)

**WHO?**

High school and college Latino students age 14-24. They were part of a coalition of community members focused on health policy advocacy to address health disparities in unintended teen pregnancy rates. Two high school students and two college students participated in a first-year pilot of the CBPR involving academics and other community members.

**WHERE?**

Jackson County, Oregon, USA. The county is home to a large Latino community, where pregnancy rates of Latina teenagers are double those of non-Hispanic rates.

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**

4 out of 5 – Young people were included in designing the questions and format of a focus group interview, as well as collecting data through a photovoice project. They were also involved in data analysis by discussing feedback and interpreting responses from focus group participants with adult members of the coalition. Finally, young people actively participated in disseminating research outcomes.

**WHAT HAPPENED?**

The coalition of community members recruited young researchers for a community assessment and diagnosis from local high schools and colleges. Young researchers were involved in designing and asking questions in a focus group of Latino parents to understand their perspectives on teen pregnancy in the community. They then collected and analysed responses with mentorship support from coalition researchers. In the second phase, young people participated in a photovoice exercise and collected photographs from peer participants outside of the research programme. Following these data collection phases, a cast was recruited to write a script and deliver an interactive theatre intervention in Spanish to facilitate parent-adolescent communication about sexuality and pregnancy. Finally, young researchers were involved in analysing the feedback on activities and disseminating the findings. Dissemination activities included a presentation of photovoice results to an audience of 400 people and interviews for academic and community newsletters.

**WHAT WAS THE IMPACT?**

Young people's involvement in the research project increased the quality, integrity and validity of the research process and outcomes. They contributed to the design of the community assessments and the design of the theatre study and improved data collection and interpretation. Through participatory research, the community's capacity for research increased. The project brought further community benefits, including greater community self-efficacy and engagement. The young people involved in the study felt more committed to and capable of raising awareness and overcoming issues related to teen pregnancy within the Hispanic community. In terms of benefits to the young researchers, young people reported an increased sense of engagement in their community as a result of an enhanced understanding of community issues directly related to them. Personal benefits were also reported, including an increased ability to speak in public and communicate with their parents. Some young people noted that their involvement had provided focus on career development, by increasing their networking and research skills.

## IN FOCUS: Evidence from LMICs

**Few studies based in LMICs examine how young people's involvement in research affects project outcomes. Those that do report positive effect.** Two articles already mentioned in this report are based in or involve young people from LMICs. Case study 1 described how young people from LMICs effectively shaped a research agenda (Denison et al., 2017). Young et al (2018) describes young people's involvement in data collection and analysis in South Africa, where they created documentary films on tuberculosis in high-prevalence communities. The authors found that their involvement led to a "nuanced and richer description of the social determinants of the disease... as well as of the impact that TB has on the area's population" (Young et al, 2018, p. 6).

**Young researchers in LMICs report they benefit from their experience in similar ways to their counterparts in HICs.** This link is well-supported by evidence from LMICs. Young people experienced the same sense of empowerment and increased confidence (Chappell et al., 2014; Zhang et al., 2019), reported feeling "important, smart, and even proud" (Denison et al., 2017, p. 199), and feeling more confident in expressing their views (Marco-Crespo et al., 2018). Evidence also suggests that they experience improved academic and career skills and outcomes (Bales et al., 2018; Mostafa et al., 2006) and a greater awareness of different health concerns (Bales et al., 2018; Marco-Crespo et al., 2018).

**In LMICs, communities benefit when young people are involved in health research.** A few papers from studies in LMICs reported that children and young people use their experiences from research to serve their communities. For example, young people involved in climate change projects helped their families, schools, and communities to adapt to risks of climate change, by identifying risks, developing risk reduction programmes, or educating peers in schools and communities (Lawler & Patel, 2012). Medical students who conducted research in LMICs as part of their studies were more likely to return home to work in primary care positions, which disproportionately benefit their communities (Bruno et al., 2014). Involvement in research also generates more locally-focused data to solve localised problems, such as epidemiological data (better surveillance of health issues) or environmental data (tracking seasonal changes in the climate) (Bales et al., 2018; Lawler & Patel, 2012).

## IN FOCUS: Evidence from each of Wellcome's health challenge areas

**Most studies identified by this evidence review do not focus on a specific health topic. Of those that do, mental health is by far the most commonly studied.** Of the 187 papers included in the review, 51 focus specifically on the three health topics. Within these, 31 are mental health, 11 are infectious diseases, and another nine studies are climate change. 75% of these, focused directly on health topics, include evidence of the impact of including young people in research.[21]

### 1. Mental health

**Young people's involvement in mental health research benefits the projects.** Several mental health focused papers discuss young people's importance in improving some aspect of the research process. For example, young people have altered research objectives to make the research agenda more relevant (Garinger et al., 2016; Gishawn et al., 2010; Pavarini et al., 2019), improved data collection methods to generate richer and more reliable data (Delman, 2012; Kelly et al., 2018), implemented more effective recruitment strategies (Pavarini et al., 2019), increased the quality of data analysis (Delman, 2012), improved presentation of the results , and contributed new ideas and perspectives throughout the research process (de Jong et al., 2018). Delman (2012) reflects on working on five participatory research projects over a ten-year period with young adults with psychiatric disabilities. In his reflections of his experiences, he argues that young people's involvement in the research process increases the validity of data collected, because young people can more easily gain the trust of other young people and their understanding of young people's language leads to improved data analysis.

21 Recognising the dearth of academic literature on young people's involvement in research into the health implications of climate change, this RER included some articles that discuss young people's involvement in research into climate change more generally.

**Young people themselves also benefit when involved in mental health research.** They develop transferable skills such as leadership and decision-making (Csiernik et al., 2018; de Jong et al., 2018; Lindquist-Grantz & Abraczinskas, 2020) and research-specific skills like developing research methods (Pavarini et al., 2019; Valdez et al., 2020). Young people also joined networks that would improve their chances of learning more skills in the future (McAndrew et al., 2012; Valdez et al., 2020). Being involved in mental health research increased their awareness of causes and symptoms of poor mental health (de Jong et al., 2018; Valdez et al., 2020). There is some evidence that young people experienced academic and career benefits, although less so than in the research focused on other health topics. One study offered student participants opportunities to conduct research which was tailored to their studies, thereby contributing towards theses or other academic work (de Jong et al., 2018). Another CBPR programme went on to hire the young researchers who originally worked with them (Gishawn et al., 2010).

**Stigma and the risk of emotional distress may be greater barriers for young researchers in mental health than other challenge areas.** As in the wider literature, some adult researchers in mental health are concerned about the quality of the data collected by students (de Jong et al., 2018) and discuss the importance of training young researchers in maintaining the quality of the work (Penner et al., 2017). Two areas where mental health has additional barriers to involving young people is in ethics and stigma. The ethics of either exposing young people to distressing information regarding mental health topics, or asking people with lived experience of mental health issues to recount their experiences, is more immediate and problematic for mental health than other health areas (Bell, 2015). Additionally, young people can worry about the stigma potentially associated with involvement in a mental health research project. Similarly, a study which looked specifically at psychiatric disability asserted that the "double stigma of having a psychiatric disability and being young" acted as a barrier to active involvement in research (Delman, 2012, p. 232).

### 2. Infectious diseases

**This RER identified fewer articles focused on young people's involvement in research into infectious diseases.** Just 11 articles were identified compared to 31 mental health articles. However, experts consulted during the production of this review believe considerable work is being done in this space, suggesting the findings here may be under reporting activity.

**Young people demonstrate the ability to impact each stage of the research cycle for infectious disease-related research, although evidence is sparser than for mental health.** One article shows that young people have successfully influenced agenda-setting for research into HIV (Denison et al., 2017). When involved in research design or data collection, young people's ability to build trust and understand their peers' capabilities and communication improves research quality. Young people acting as 'peer educators' have been critical to increasing trust in research for HIV and suggesting more appropriate research methods, and therefore reaching target participants better (Maticka-Tyndale & Barnett, 2010). Another example studies the impact of young people's involvement evaluating a Chagas disease programme in Ecuador (Marco-Crespo et al., 2018). Authors found that young people's unique knowledge increased the quality of research, as they can contribute ideas and perspectives which would not occur to adults. In research dissemination and knowledge translation, young people have also played an important role. Their involvement in a TB research programme that asked young participants to produce film documentaries has helped raise TB awareness more widely (Young, 2018).

**Young people also gain important skills in research related to infectious diseases.** Young people involved in the Chagas prevention programme in Ecuador developed their critical and reflexive thinking skills (Marco-Crespo et al., 2018). The same study and one other report that young people gained confidence as a result of engaging with adults and public speaking (Denison et al., 2017). Other studies report that young people increase their advocacy skills and civic engagement (Young, 2018) and improve their health awareness (Massey et al., 2013; Masuku et al., 2018; Sherman et al., 2009).

**Barriers to involving young people in infectious disease research are similar to other areas.** Many barriers described in infectious disease papers are not necessarily specific to infectious disease research. For example, young people overall are harder to retain as engaged researchers, partly due to competing interests (Maticka-Tyndale & Barnett, 2010; Oliveras et al., 2018); they require different safe-guarding requirements and adult coordinators must adhere to complex ethical guidelines which vary by location (Zhang et al., 2019); and adult researchers must invest time

into adapting approaches and materials to be youth-friendly (Denison et al., 2017; Marco-Crespo et al., 2018). Young people researching infectious diseases do need appropriate training about the disease in question, but young people researching any topic will need training specific to that topic (Marco-Crespo et al., 2018; Maticka-Tyndale & Barnett, 2010; Young, 2018).

### 3. Climate change

**Evidence on young people's involvement in research into the health implications of climate change was more limited than other areas.** Just nine articles about involving young people in climate change research were identified in the evidence review. This reflects the nascency of the field of research. As such, we also reference some academic articles that look at how young people have been involved in research on climate change more generally, rather than its health implications.

**A small number of papers describe how research on climate change improves when young people are involved, although this evidence is limited and fewer papers have a direct link to health.** Researchers considering climate change and disaster risk reduction (and its impact on health) in Brazil found that young people's knowledge was relevant in improving responses to disasters and other climate issues (Trajber et al., 2019). The evidence review did not come across other studies with a distinct focus on health implications of climate change. However, other studies described how young people have been involved in research on climate change in general, providing further indirect evidence of potential benefits. For example, Peek et al. concluded that young people were 'collaborators' who could provide guidance to adult researchers in a climate change context (Peek et al., 2016). In the Philippines, Haynes & Tanner, (2015), involved young people in a photovoice project to document citizen responses to climate change. The young people decided to use local dialects in their film-making, so the film felt more relevant for local communities and decision makers.

**Involvement in climate change research benefits young people and their communities, although few papers investigate the link.** Young people who have been involved in climate change research reported an increase in levels of confidence, self-efficacy, and knowledge about the environmental issues which surround them (Haynes & Tanner, 2015; Trott, 2019). Their involvement in climate change research can also lead to better outcomes for their communities, for example by motivating communities to develop and contribute to climate change adaptation plans (Haynes & Tanner, 2015; Lawler & Patel, 2012). However, only a subset of the papers focused on climate change and health considered this link.

# 4. Challenges in involving young people in health research

## Chapter summary

Literature has observed five areas of challenges that go with effectively involving young people in health research:

1. **Attitudes and awareness:** Researchers can lack awareness of evidence on the benefits of involving young people, and a small number of papers suggest young people may not perceive opportunities to get involved in research as desirable;
2. **Ethics protocols:** There is compelling evidence that adult researchers are discouraged by the protocols they need to follow to receive ethical approval for working with legal minors;
3. **Skills:** Many papers suggest that both adults and young researchers need training to effectively collaborate, and materials/tools need to be adapted to match young people's capabilities;
4. **Ways of working together:** Researchers can find it a challenge to adapt ways of working to young people's needs, capabilities, and less flexible schedules, and identify and maintain a network of young people they can work with over a sustained period of time;
5. **Funding:** A small number of papers report that many of these challenges may be aggravated by a lack of funding. While challenges are not as commonly reported as benefits, they are significant and speak to the opportunity that Wellcome and others have to support the scale-up of young people's involvement in health research.

## 4.1. Shaping attitudes and raising awareness

**Some researchers lack an awareness of evidence that demonstrates the potential benefits of involving young people.** Whilst the evidence in this topic is strong, it is not widespread. The review found that the concept of valuing young people's expertise, and viewing them as experts within their own experience, is still emerging and has not yet been fully appreciated across the research spectrum (Kendal et al., 2017). Some researchers lack information on what it means to involve young people in research, or of the potential benefits of involving the public in their research, or they assume that young people lack the skills necessary to meaningfully contribute to research (Bird et al., 2013; Gamble et al., 2015; Lundy et al., 2011). Wadman et al. (2019, p. 8) conducted research with adult mental health researchers regarding their attitudes to involving young people. They felt that their research was often "not held in the same esteem as other research activities".

**Some articles found that young people themselves may not see health research as an attractive activity, although evidence is limited.** Some evidence suggests there are negative perceptions of health research amongst young people. For example, young people can see health research as boring, complex, or slow-moving (Csiernik et al., 2018; Gouda et al., 2018). Sometimes negative connotations stem from a lack of awareness of how research works in practice (Marco-Crespo et al., 2018). Certain stages within the research process are also seen as less interesting: the data analysis stage has been associated with being time-consuming and mundane (Mawn et al., 2016).

## 4.2. Navigating ethical approval processes

**Some researchers are discouraged by the burden of ethics approval processes that must go with collaborating with young people.** Researchers must grapple with a different set of ethical questions that apply to legal minors, and this barrier is well-evidenced in the literature, suggesting it is significant in deterring researchers from conducting this work. Researchers can face a range of complications when looking to navigate the ethical challenges of working with minors. These include: how to recruit young people to be involved in health research (Kirk, 2007); how to overcome challenges caused by unequal power dynamics (Coad & Evans, 2008; Huang et al., 2016; Ozer et al., 2013; Wickenden &

Kembhavi-Tam, 2014); how to ensure child safeguarding practices protect young people without restricting their agency (Bird et al., 2013; Clavering & McLaughlin, 2010; Taylor et al., 2018); the ethics of paying children for their involvement in research (Huang et al., 2016); and how to provide the right amount of mentoring and guidance throughout the process without restricting their freedom of choice (Gishawn et al., 2010). The age at which parental consent becomes unnecessary, and only the consent/assent[22] of the young person is required, has yet to be agreed upon by experts, and has not been clearly defined in national laws (Huang et al., 2016). These ethical questions have led to researchers deliberately excluding minors from projects (Denison et al., 2017).

## 4.3. Upskilling

**To work effectively with young people, adult researchers themselves need access to more and better training.** Working with young people requires specific skills and knowledge which adults need to develop (Franklin & Sloper, 2005), although currently there is little material to support this training. Evidence for this barrier is hinted at in many papers, such as by suggesting difficulties in recruiting young people or working with young people, and a few papers address this gap directly. For example, a study of 84 researchers familiar with involving young people in research found that 37 did not know how to prepare young people to be involved (Hawke et al., 2020). Regarding training, Mitchell et al. (2019) describe how training for adults is yet to be widely adopted, and although some trainings have been assembled, they have not yet been standardised and mainstreamed. Therefore, the process for researchers can be difficult to navigate.

**Young people also need training in how to contribute to research effectively.** The requirement for young people to be trained in order to meaningfully engage in research is widely reported in the literature (Bradbury-Jones & Taylor, 2015; Coad & Evans, 2008; McCartan et al., 2012). Mawn et al. (2015, p. 6) describe how researchers can underestimate the planning and resourcing required to work effectively with young people, and how, when studies are "inadequately planned and resourced, in terms of funding, training and time, [the studies] are likely to result in tokenistic and methodologically poor research". Researchers also recognise the need to properly train young researchers to maintain quality of the research (de Jong et al., 2018; Penner et al., 2017). For example, one study (de Jong et al., 2018, p.512) reflecting on nursing student researchers noted that the "limitations of our study were mainly located in the interview skills of the students and their experiences with and capabilities of analysing qualitative data". The research team for this study provided training on qualitative data collection methods for their young research participants. However, the training and support required is expensive, and requires support from grant making organisations (McCartan et al., 2012).

## 4.4. Adapting to new ways of working

**In addition to training, researchers can find it a challenge to adapt ways of working to young people's needs and capabilities.** Involving young people is more than a tick-box exercise and a wide range of papers emphasised the importance of investing time and careful planning into adapting ways of working to facilitate the best input from young researchers. For example, adult researchers must hold pre-meetings to familiarise young contributors with topics or concepts (Denison et al., 2017), mentor them to guide them through the research process (de Jong et al., 2018), adapt meeting plans for different concentration periods and activity preferences (Frank, 2006; Franklin & Sloper, 2005; Holland et al., 2010; Mathews et al., 2010), or adapt communication styles and meeting materials to be more suitable for young people (Nygren et al., 2017; Peek et al., 2016). Alternatively, where young people are struggling to contribute and learn, the researchers may need to re-imagine their role to match their skills (Pavarini et al., 2019). All of these activities require time and effort.

22 Assent is the term for a minor's willingness to participate, even where not legally required. This differs from consent. Consent is a legally defined decision given by someone who is competent, informed and can therefore provide consent themselves. This does not apply to minors, who, by definition, are not legally considered adults (NHS Health Research Authority, 2017).

**Researchers need to work around young people's schedules which tend to be less flexible, as the extent to which young people are motivated to seek out and invest time in research opportunities is crucial.** Many papers discuss the importance of time constraints as a barrier to young people's involvement (Gishawn et al., 2010; Oliveira et al., 2014; Suleiman et al., 2006; Taylor et al., 2018). Young people are limited in their scheduling freedom due to school, part time work, and social activities. School timetables restrict young people's flexibility during term time (Gaillard et al., 2018). Young people value their extra-curricular and social activities, which can be an additional scheduling barrier (Parsons et al., 2018). Researchers should respect the complexity and competing interests in young people's lives, and do what they can to schedule meetings around this (Mawn et al., 2016; Mawn et al., 2015).

**Identifying and maintaining a network of young people that researchers can work with over a sustained period can be a challenge.** A small number of papers suggest that researchers have difficulty sustaining involvement and trust with young people over time. Sustaining involvement is important to prevent turnover of the group of young researchers (Peek et al., 2016; Redman et al., 2017). There are also challenges in identifying appropriate young people to involve: assembling a representative group of young people who are close to the research topic of interest but distanced enough to be able to contribute to reflective analysis is a significant challenge in involving them (Hawke et al., 2020; McCartan et al., 2012). There are examples of successfully attracting and involving young people over a longer period, but it requires long-term funding and significant effort from the adult researchers (Pavarini et al., 2019).

## 4.5. Attracting funding

**Although it was not widely reported in literature, some papers conclude that a lack of funding aggravates these challenges.** Some papers investigating the problems faced by researchers consider the importance of funding and find it to be a significant barrier. For example, almost half of adult researchers with experience working with young people reported that a lack of institutional funding was a barrier (Hawke et al., 2020). Other literature echoes this lack of institutional support. Indicatively, Wadman et al. (2019) surveyed mental health researchers to understand their attitudes towards involving young people. Whilst the mental health researchers were aware of the benefits of involving young people, they experienced difficulty expressing the true value of young people's involvement in grant applications, often finding that their research was "not taken seriously" (ibid, p. 8), and therefore they were unable to obtain the financial support required to train and mentor young people to be involved. There are other examples of research that has not involved young people further because of limited funding (James et al., 2013). Sustainable funding was also mentioned as an issue. Mawn et al. (2015) describe difficulty in securing long-term funding for their YPAG, Youth Speak. There is a lack of specific funding aimed at sustained PPI for a long period of time.

# 5. Best practices and relevant guidance when involving young people in health research

## Chapter summary

Experts have developed guidelines on how to effectively involve young people in health research, some of which has been documented in peer-reviewed papers. While this is a welcome development, literature shows that these guidelines are limited in scope in terms of the contexts in which they can be used and the issues that they cover. Also, importantly, the guidance has yet to been mainstreamed into research ecosystems. Existing literature is generally aligned on emerging best practices related to five aspects of involving young people in health research:

1. **Consent;**
2. **Evaluating risks and comparing against potential benefits;**
3. **Communication;**
4. **Trust and balancing power;**
5. **Logistics.**

When looking at gaps in best practices, this review has revealed a number of areas that need to be addressed most critically:

1. **Experts have yet to develop guidelines on the scenarios in which to use different approaches to involving young people in research (e.g. when is it more appropriate to use a YPAG rather than YPAR?);**
2. **How young researchers should be compensated for their contribution remains an open question;**
3. **There is also a gap in guidance around how best to train adult researchers and young people.**

## 5.1. Emerging best practices when involving young people in health research

**Existing literature is generally aligned on emerging best practices when involving young people in research.** These concern five areas: seeking consent; evaluating risks against potential benefits; communication; trust and balancing power; and logistics.

**Experts tend to agree on most but not all aspects of seeking consent from young people involved in research.** In the UK, most researchers recommend obtaining written consent from young people participating in research, even though it is not legally required (Mitchell et al., 2019). Researchers generally agree that parental consent should be obtained for younger groups, in addition to 'assent' from young people themselves (Embleton et al., 2015; Gibbs et al., 2018; Huang et al., 2016; Modi, 2020). The age at which parents' consent should be required alongside that of young people is a more contentious point. Official guidance is limited, so researchers typically decide for themselves. The most frequent suggestion was that parental consent should be sought when the child is under 16, and children older than around six years should be asked for assent (Huang et al., 2016; Mitchell et al., 2019; Oliveras et al., 2018).

**Involvement in research can expose young people to risks. This should be minimised, but also needs to be weighed against potential benefits to young people.** Research can put a young person at risk of psychological or emotional harm (Huang et al., 2016; Mawn et al., 2016). Often young people are invited to be research participants because they have lived experience of a health condition or disability. Asking them to recall their experiences with that condition can risk asking them to recall upsetting memories that can cause psychological distress (Oliveras et al., 2018). Researchers note the potential to cause harm through mis-management of data and the importance of protecting the anonymity of individuals (Huang et al., 2016; Oliveras et al., 2018). Peer-reviewed literature is broadly aligned on the need for researchers to minimise the potential risks while preserving access to opportunities to young people. The opportunities must be activities that young people see as beneficial, such as learning new skills, conference presentation opportunities, or co-authoring papers (Huang et al., 2016; Mitchell et al., 2019).

**Evidence indicates that effective work with young researchers relies on communication that is tailored to their capabilities.** Researchers recognise the importance of adjusting communication to suit young people's needs, build trust, and retain their involvement (Huang et al., 2016; Kulbok et al., 2015; Liabo & Roberts, 2019). This includes the language used, methods of communicating, and listening to how young people prefer to speak about a topic (Hawke et al., 2018; Modi, 2020). For example, young people might prefer not to use terms like "palliative care", and instead suggest "life-limiting" conditions, or "conditions which may or may not get better" (Mitchell et al., 2019, p. 5). Another example of good communication recognised the role of encouragement and recognition in motivating young people. Suleiman et al. (2006) reflected on conducting seven projects which involve young people in school settings. They described one example where praise from a city health official was enough to motivate young people who "could barely be convinced to show up for a meeting a week prior" to working on the project for another school year and meeting about it over the summer (ibid, p. 137). Researchers also recognise the importance of using appropriate communication channels (e.g. email, social media) to interact with young people (Noone et al., 2016; Preston et al., 2019).

**Trust-building and balanced power-sharing between adults and young people can be key ingredients of success.** Various papers offer a range of practical tips for interacting with young people to build trust and reduce power imbalances such as asking for feedback and acting on it, not being patronising, being transparent, and being open to new ideas (Hawke et al., 2018; Mitchell et al., 2019; Nguyen et al., 2019). Some examples of recommendations to reduce power imbalances include paying attention to the skills and benefits researchers can offer young people, as much as the benefits those young people can offer to the researchers. Another example is to give young people opportunities to choose some of the parameters of their work, including research location and time (Huang et al., 2016; Peek et al., 2016).

**Several authors focus on logistics. Meeting spaces should be welcoming, and locations and times should be convenient.** All papers reviewed that made recommendations on how to involve young people agreed that young people should be invited to join meetings at times and in locations which suit them (Mawn et al., 2016; Noone et al., 2016; Preston et al., 2019). Other papers focus on how meeting spaces and materials can be adapted to young people of various ages (e.g. through holding games and ice-breakers, setting chairs in a communal arrangement, and adults dropping the titles before their names) (Avery, 2019; Hawke et al., 2018; Oliveras et al., 2018; Preston et al., 2019).

**Many authors demonstrate the value of adopting particular research methodologies and methods to best fit young people's capabilities. Photovoice is one of the most common examples of this.** Through photovoice, young people photograph their experiences related to research themes, and add a narrative explaining their choice of photographs (Kembhavi & Wirz, 2009; Pavlopoulou & Dimitriou, 2020; Valdez et al., 2019). One primary study involving 64 6th-8th grade students (approximately aged 11-14) explained that the photovoice research method was selected "because it is interactive, works well in a group format, and involves art and movement, which was thought to appeal to youth who have competing activity choices" (Lindquist-Grantz & Abraczinskas, 2020, p. 3). A common method of involving young people in research design is through YPAGs, which are defined earlier in this report and in the glossary.

## Comparing YPAR and YPAGs

Several papers within the RER focus on research that employs either YPAR or YPAGs. **Youth-led Participatory Action Research (YPAR)** is an approach to research that engages young people in identifying problems relevant to their own lives, conducting research to understand the problems, and advocating for changes based on research (Ozer, 2016). A **Young Persons' Advisory Group (YPAG)** is a specific research method to co-produce research with young people through an advisory group, which can include young people as patients, research participants, and members of the public (Pavarini et al., 2019).

YPAR trains young researchers to understand and analyse their environment, then plans interventions to solve community problems, often through engagement with community members and leaders (Valdez et al., 2019). It is an effective method because it directly seeks to identify barriers to more cohesive societal relations and empowers young people to act on their findings, to overcome barriers and improve their local community through dialogue and action (Lindquist-Grantz & Abraczinskas, 2020; Ozer, 2016).

YPAGs are a method of co-producing health research with young people, where around 15-20 young people, often with lived experience of a health condition, meet regularly with a YPAG leader (Preston & Moneypenny, 2014). The leader is normally a researcher with experience working with young people, and they liaise with outside groups who conduct research, such as pharmaceutical companies (Pavarini et al., 2019; Preston & Moneypenny, 2014). These outside groups want to understand young people to inform their research. YPAG is an effective research method because it specifically empowers young people with lived experience to advise and collaborate directly with these outside groups and it is a convenient way to work with young people (Pavarini et al., 2019; Powell, 2019).

## 5.2. Gaps in best practices

**Guidance in best practices is limited in a variety of ways.** Some is sector-specific, such as Hawke et al. (2018) which focuses on mental health. Some is limited to a particular research method like Chan et al. (2020), which focuses on YPAGs, and other guidance only covers one challenge in working with children, such as Huang et al. (2016), which only considers ethical barriers. The literature mostly considers one form of guidance, such as either how to practically run a research project involving young people (e.g. where to host research meetings, how to make meetings youth-friendly) or ethical considerations. The evidence review did not find literature that attempts to address the entire range of decisions facing health researchers trying to involve young people in research (e.g. the most appropriate methods, in what circumstances it is appropriate, etc.).

**Experts have yet to develop guidelines on the scenarios in which to use different approaches to involving young people in research.** For example, Chan et al. (2020) developed a YPAG start up tool, but the tool does not include a decision-making process to decide whether a YPAG is the appropriate method for involving young people (ENRICH Network, 2020). Similarly, Lindquist-Grantz & Abraczinskas (2020) provide recommendations for how to optimally work with young people in YPAR, but do not provide any framework for assessing whether YPAR is the most suitable approach.

**How young researchers should be compensated for their contribution remains an open question.** Literature shows agreement on the need to incentivise students using snacks and food at meetings to motivate young people to attend. However, there is less consensus on remuneration for young people. Modi (2020) describes how parents feel that remuneration could pose a danger, and how young people can be split on the issue. Tisdall (2012) makes the point that within the UK, it is very difficult to offer paid compensation for participation in research to any person under 14 due to European regulation and UK legislation, so at times it can be difficult legally to pay young people. However, most papers argue that remuneration acts as an incentive, and, importantly, shows young people that their input is valued (Embleton et al., 2015; Hawke et al., 2018; Kulbok et al., 2015; Mawn et al., 2016; Nguyen et al., 2019). Remuneration should be fair based on the amount of time and effort young people have contributed, and conform with cultural norms (Pavarini et al., 2019). While guidance on this topic in the UK exists from INVOLVE (2016b), it leaves the question open as to how young people should be rewarded and recognised in different countries and different cultural contexts.

**There is also a gap in guidance around how best to train adult researchers and young people.** As noted in the previous chapter, several papers reference the importance of and demand for training adult and young researchers (Bird et al., 2013; Hawke et al., 2020; Mitchell et al., 2019; Wadman et al., 2019). Despite this, the evidence review found limited guidance related to approaches or considerations for training adults and young people. Some examples exist of adults training young people for specific skills, but these did not extrapolate to generalisable principles for training. One training resource identified was in Darnay et al. (2019), although training guidance within this document is limited to half a page of suggestions for training resources. Other training material identified was the NIHR's 'Good Clinical Practice' training (National Institute for Health Research, 2020). This, however, is more focused on protecting the rights and wellbeing of study subjects, rather than how best to involve young people in health research.

## 5.3. Institutional guidelines in grey literature

**Institutional guidance for involving young people in health research is limited and has not been adopted into mainstream practice. In addition, the existing institutional guidance is context-specific and limited in the range of topics covered.** The shortage of mainstreamed guidance in involving young people in health research is widely recognised. It is worth noting that guidance for involving adults in health research has been mainstreamed. Examples include: "A Researcher's Guide to Patient and Public Involvement" (Turk et al., 2017), and "Patient and public involvement in health and social care research: A handbook for researchers" (NIHR, 2014).

**Of the institutional guidance that does exist, just two publications appeared in this review that could be considered broadly comprehensive, and both have some limitations.** The first is a guidebook on how to approach and develop a meaningful youth engagement programme: the Innovate Youth Engagement Guidebook for Researchers (Darnay et al., 2019). Although this is the closest resource to being a comprehensive sector guide, it is not peer-reviewed and was developed to inform mental health research. It does not address in detail ethical issues, instead recommending that researchers work with their relevant Institutional Review Board[23] (IRB) (Darnay et al., 2019). The second is from INVOLVE: 'A Guide to Actively Involving Young People in Research' (Kirby, 2004).[24] INVOLVE's guidance (ibid) explains the benefits of involving young people in health research and when and how to do so, although it does not contain a discussion of how to approach the ethical issues of involving young people.

**Other documents in the grey literature offer 'tips and tricks' to researchers, which may be helpful but fall short of a comprehensive guide on the full set of decisions that go with involving young people.** These include INVOLVE's 'Involving children and young people in research: top tips and essential key issues for researchers' (INVOLVE, 2019) and the National Children's Bureau (NCB) guide 'Young people in research: how to involve us', developed by young people as part of the Public health, Education, Awareness, Research (PEAR) project (PEAR, 2010). The NCB guide offers practical recommendations including how to involve young people, how not to involve them, and some challenges and mitigations.

23 Institutional Review Board refers to an "administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution with which it is affiliated" (Oregon State University, 2020).

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

# 6. Conclusions and recommendations

This review has shown that the body of academic literature on the involvement of young people in health research is growing rapidly. As this growth continues, researchers will be able to judge with more confidence how young people's abilities can be best harnessed in health research and the specific actions that are required to make this possible.

Although knowledge gaps persist, insights from this review have been able to identify six action areas that could help scale up young people's involvement. These are in response to the challenges and opportunities reported above, particularly: insufficient funding; a lack of alignment on best practices, including monitoring and evaluation; a desire to promote learning between different members of the health research ecosystem; and gaps in evidence/understanding.

These recommendations have been verified and developed further in stakeholder consultations that have been carried out following this review.

## 6.1. Develop best practices on how to involve young people effectively

The last chapter of this review highlighted the scarcity of guidance for researchers on how to involve young people effectively. There are two issues that require solutions: first, for some aspects of working with young researchers, there are gaps in knowledge that simply need to be filled (e.g. guidance on how to choose between different approaches of involving young people). Second, for other aspects, experts are broadly aligned on what works best, but these recommendations need to be codified into actionable, easily implementable processes for researchers. They then need to also be made accessible and standardised across research communities, while leaving room for them to be tailored to different contexts (e.g. gaining consent or assent or compensating young people for their time).

## 6.2. Mainstream best practices by supporting training for researchers and young people and other stakeholders

Once best practices are aligned upon, the priority then will be to ensure that this information is mainstreamed across different groups. This could be done by, for example, standalone training tailored to different groups (e.g. health researchers interested to work with young people, young people involved in health research, non-governmental organisations (NGOs) working closely with young people in health research in LMICs; donors looking to scale-up involvement of young people in the health research they fund). It could also be embedded within existing training curriculums (e.g. medical students' university modules).

## 6.3. Build new or expand existing networks of researchers and other organisations focused on involving young people in health research

As an emerging field, a large amount of knowledge on the landscape of young people's involvement in health research will not be contained in peer-reviewed academic literature and publicly accessible information. Instead, this knowledge is held by researchers and others who are working with young people, including young people themselves. A formal network can allow experts in youth involvement to build on each other's learnings in real time. It can also help researchers who are less experienced in youth involvement to collaborate with experts. This forum could also be a way for research leaders to align on (and negotiate) different perspectives on ways of working that could then become standardised across the community. The evidence review also revealed that researchers and young people can find it difficult to identify or get in contact with each other. This network, by also involving young people or people who work with them closely (e.g. NGOs), could address this challenge.

## 6.4. Strengthen and standardise the monitoring and evaluation of young people's involvement in research

This review has shown that one of the root causes of the lack of evidence of impact is that the research community has yet to standardise the language and processes used to measure the impact of young people's involvement in health research. This creates an information block that prevents researchers from building on each other's work and systematically tracking young researchers' achievements. For example, little is known about the degree to which young people who may face disadvantage and/or are marginalised are involved in research, because articles tend to not record the socio-demographic backgrounds. This challenge can be addressed by establishing more rigorous and consistent monitoring and evaluation practices around youth involvement in the research, among funders, governing bodies in research ecosystems and researchers themselves.

## 6.5. Support the generation and dissemination of evidence to fill gaps in current peer-reviewed literature to garner more support across the research community

This evidence review has noted several areas where academic literature is relatively scarce on how and why young people should be involved in research. Literature describing their involvement on research related to infectious diseases, and particularly the implications of climate change on health, is much less common than mental health. Less is reported on how young people are involved in agenda-setting than other stages of research, and most articles focus on HICs. Very few papers demonstrate that the young people involved are from diverse backgrounds, including young people that face disadvantage and/or are marginalised. These gaps likely contribute to some actors not yet being convinced that involving young people is worth the time and resources required. Funders, research institutions, and individual researchers may want to see specific evidence (e.g. research conducted in the contexts in which they operate) that has yet to be generated, or they may simply be unaware of evidence that already exists. Funders and advocates can address this by supporting new research or better disseminating existing relevant research findings.

## 6.6. Ringfence funding to involve young people in research including both one-off project involvement and more long term, sustainable types of involvement

Some academic papers report that resources – time and money – are a key challenge for researchers looking to involve young people in research effectively. As a new norm, dedicated budget should be set aside by funders when supporting research projects that are relevant to young people. If young people are to have a meaningful voice in research agenda-setting, resources and effort must be allocated to involving them outside of project contexts and over a longer period of time. Young people can be involved in reviewing research proposals, or even at higher levels of strategy-making at research organisations, but this can only happen if sustainable resourcing is made available, and senior leadership in organisations are supportive.

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# Annex 1 – Case studies describing roles young people can play in health research

## Case Study 4

### A young persons' advisory group shows scientists from Pfizer how to increase the youth friendliness of research design - Powell (2019) and (Hoff, 2019)

**WHO?**

10-15 members of the Alder Hey Children's Hospital YPAG, aged 8-19

**WHERE?**

Alder Hey Children's Hospital, Liverpool, UK

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**

3 out of 5 – Young people's views are taken into account, but they are not involved in making decisions alongside adults, nor are they responsible for the outcomes of these decisions.

**WHAT HAPPENED?**

NIHR is a National Health Service (NHS)-affiliated body which supports clinical research in the UK. It developed a new Patient Engagement in Clinical Research service to bring together patients and life science companies early in the trial development process to make commercial clinical trials more patient friendly. NIHR piloted this new service through a collaboration with the pharmaceutical company Pfizer, which wanted to conduct a study trialling a treatment for eczema in children. The NIHR facilitated two meetings between the YPAG and Pfizer's scientists. The clinician who wrote the protocol met with the YPAG and their parents/carers separately, as did another representative from Pfizer who works on recruiting people for clinical trials.

**WHAT WAS THE IMPACT?**

The scientists were impressed with how advanced some of the YPAG members' questions were.

*"Some of the questions were very scientifically technical, for example around how the drug might alter your immune system and what effects that might have on the body. The young people were not afraid to say what they felt and were very clear about what they wanted to see included in the informed consent and assent document"*
– Pfizer representative leading work on the trial

Because of the consultation, the researchers adapted the study design and the information given to patients before the trial. The scientists expect that the adaptations to the study will increase the recruitment and retention of patients for the clinical trial itself, and it benefits their future clinical trials which seek to involve patients.

*"It enabled us to work through the many legal and compliance challenges and develop documentation that we can use time and time again for patient engagement activities, regardless of the study, patient group, or therapeutic area"*
– Pfizer representative leading work on the trial

As a result of the successful consultation on the Pfizer trial, the NIHR is now working with other companies to trial this model of patient involvement further. Additionally, young people recognised the value of their perspectives and felt it was important to involve young people when they are impacted by the research. They wanted to be involved at the earliest possible stage to ensure their involvement was non-tokenistic.

## Case study 5

### High school students who are members of health and science clubs successfully recruit underrepresented community members for a health survey on obesity and diabetes - Branch & Chester (2009) and Bardwell et al. (2009)

**WHO?**

210 high school students who were part of a network of 18 health and science clubs in rural West Virginia. The clubs' members are typically poorer members and minorities in their communities.

**WHERE?**

Appalachian communities in rural West Virginia. West Virginia has the second-highest obesity rate and the highest number of diabetes-related deaths in the US.

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**

3 out of 5 – Young people were involved in study design and data collection in their local communities, and in high-level statistical analysis. Their work was facilitated by science club teachers.

**WHAT HAPPENED?**

23 student members of the health and science clubs designed a CBPR study protocol to gather information on obesity levels in West Virginia. To recruit participants for the study, a total of 210 student members conducted the survey with their families and friends. The 210 students were trained in ethical conduct and how to approach family members and peers appropriately to gather consent in oral and written form. They were allowed to recruit only people who could expect to influence each other's behaviour: siblings in their own generation, parents, uncles, aunts, and grandparents. Consenting individuals were then individually approached to confidentially provide their body-mass index score and respond to a confidential health care questionnaire.

**WHAT WAS THE IMPACT?**

In total, the 210 student members recruited 989 research subjects, who were mostly from geographically dispersed, disadvantaged, and underrepresented communities. This model demonstrates that adolescent members of student clubs represent a successful model of identifying and recruiting members of local families for participatory research. Additionally, the respondents could potentially be a basis for future active intervention beyond data collection for sustained obesity management and prevention.

## Case Study 6

### Young people lead a research activity to identify new risk factors for substance abuse in US/Mexico - Valdez et al. (2019)

**WHO?**

A youth health coalition of 23 adolescents aged 14-18, composed of 12 females and 11 males. 20 participants identified as from Hispanic and/or Mexican origin. The research participants worked with one adult lead researcher.

**WHERE?**

A rural border community of less than 25,000 people in the southwestern U.S. The targeted community included members living in the Mexican cross-border city at the time of the study.

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**

3 out of 5 – Young people were involved in data collection, analysis, and dissemination, and translation of research outcomes through community-level advocacy and local policy-change efforts. The research question and the design of the methodology, however, were developed by the lead-researcher.

**WHAT HAPPENED?**

The purpose of the research was to use YPAR methods and photovoice to identify young people's perceptions of the factors influencing substance use among adolescents living in their community. Young people as researchers were equipped with a digital camera and attended twelve training sessions to improve their data collection and analysis skills. They were asked to capture and select photographs that reflected their own perception of the factors driving youth substance use in the community and build a storytelling narrative to explain their selection. Finally, young researchers disseminated their findings through community-based advocacy events and presented research outcomes at a conference.

**WHAT WAS THE IMPACT?**

The use of YPAR and photovoice-based methods showed an increased sense of responsibility among young people from the community, as well as a feeling of empowerment from having their voices heard. It also enabled the research team to identify new risk factors unique to border regions. These included the normalisation of drug trafficking and of substance use as well as cross-border access to substances. Young people's involvement in the research also demonstrated participants' awareness of the nature of drug trafficking and the presence of cartels in their community, which they identified as a factor influencing substance use among adolescents. Protective solutions were also identified in research outcomes, including the positive influence of strong community support networks that reduced risks of substance use, and the importance of youth-friendly spaces.

## Case study 7

**Young people work with the Eh!Woza initiative in South Africa to learn about tuberculosis (TB) and make community-focused documentaries of the patient experience – Young (2018) and Masuku et al. (2018)**

**WHO?**

56 young people aged 14-20 have taken part in the programme between 2014-2017. Each year, 12-15 learners were recruited via an application process through a local NGO based in Khayelitsha called IkamvaYouth, which aims to empower young people through education.

**WHERE?**

Khayelitsha, a township outside Cape Town, South Africa with a high prevalence of tuberculosis.

**LEVEL OF INVOLVEMENT (BASED ON SHIER'S, 2001 MODEL)?**

4 out of 5 – Young people are involved in decision-making processes, but they are not responsible for making the decisions, or for the outcome of the decisions

**WHAT HAPPENED?**

Eh!Woza began as a one-off project (in 2014), but has since developed into an ongoing, annual programme. It is jointly run by the University of Cape Town's Institute of Disease and Molecular Medicine, a local visual artist, and IkamvaYouth, an NGO. The programme involves young people in biomedical TB research and provides space, guidance and equipment for participants to produce documentaries about personal experiences of TB. Young people learn about TB, clinical trials, and TB research through six science workshops. They then complete a two-week film production programme. The young people throughout the film production period spend time in Khayelitsha, interviewing local township residents. Different topics are highlighted in their films, such as the story of an employed single HIV-positive mother with drug-resistant TB, or the story of ex-mineworkers who have silicosis (from mine dust), TB, asthma, and are fighting the mine company to receive pension pay.

**WHAT WAS THE IMPACT?**

An external evaluation of the project and an anthropological study have gathered evidence of the impact of the Eh!Woza programme. Preliminary findings suggest that young people's involvement in Eh!Woza increases the dissemination and translation of knowledge about TB. Young people have become more comfortable having conversations about TB with their families and have found opportunities to talk openly about issues related to TB which were considered taboo. Further work is required to determine whether the conversations young people are having in their community change perceptions of TB.

# Annex 2 – Overview of frameworks used to describe young people's involvement in health research

**Figure 12:**
**Arnstein's (1969) ladder model of involvement in decision-making separated different levels of power into 'rungs' but did not consider how these levels of power manifest in activities, or how this power is influenced by aspects of a person's background (e.g. socioeconomic, ethnic, abilities etc.).**

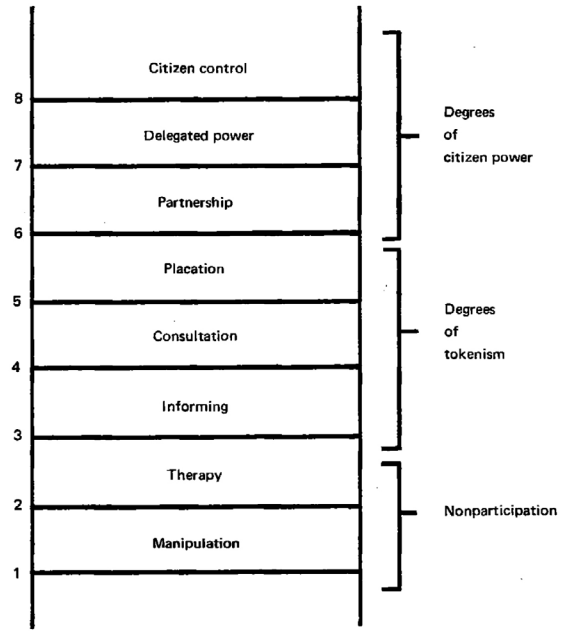



**Figure 13:**
**Hart's (1992) model of youth participation places shared decisions at its peak**

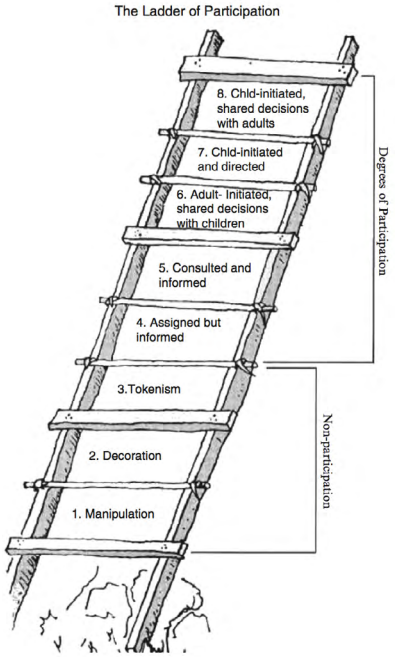


**Figure 14:**

**Treseder's (1997) non-linear model of participation does not reflect the value that certain youth–adult participation arrangements can lend to the empowerment and positive development of youth**

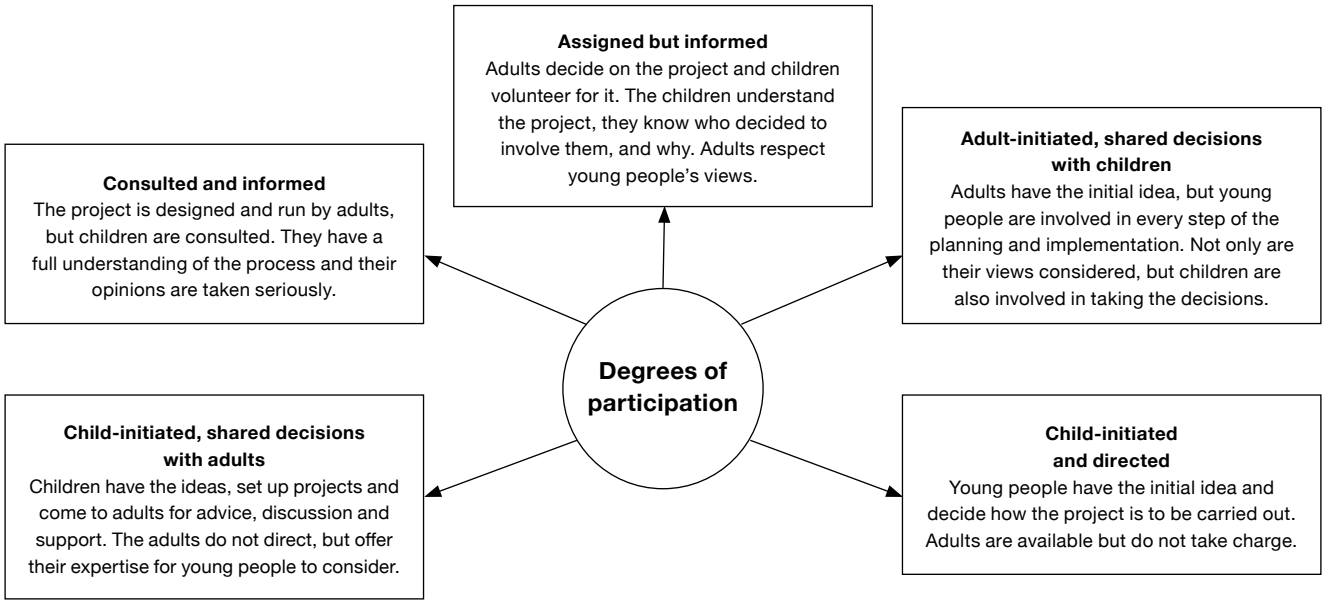



**Figure 15:**

**Wong's (2010) TYPE Pyramid places a pluralistic power-sharing between adults as its ideal, in opposition to other models which have typically shown the highest level of youth control at their highest points**

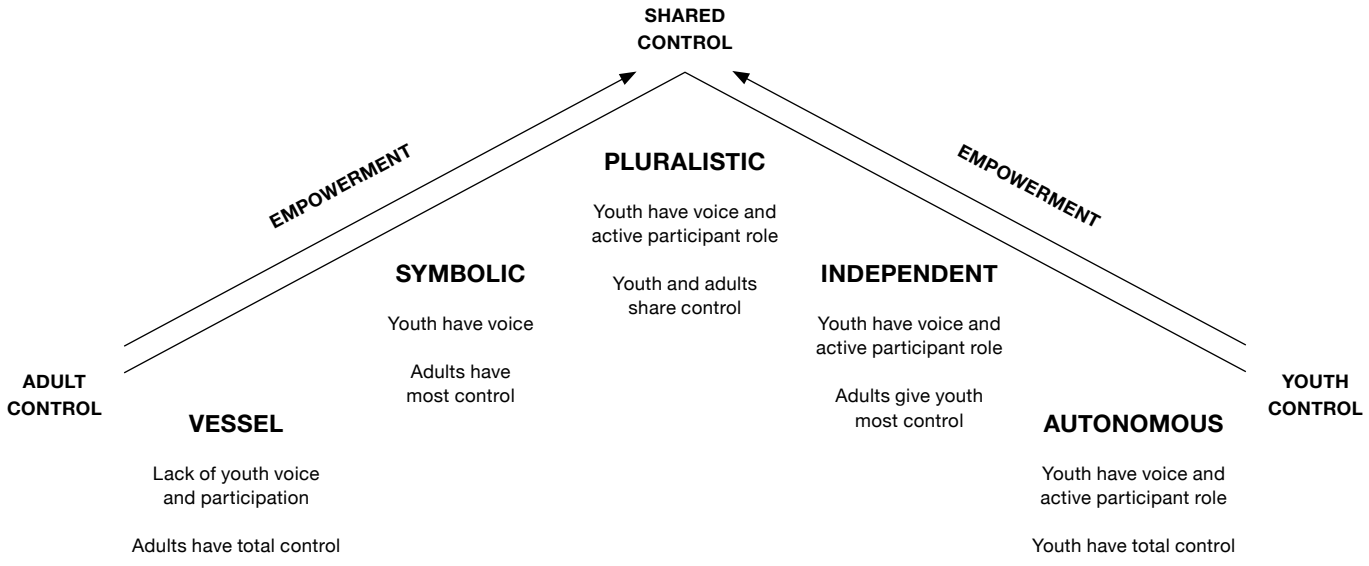
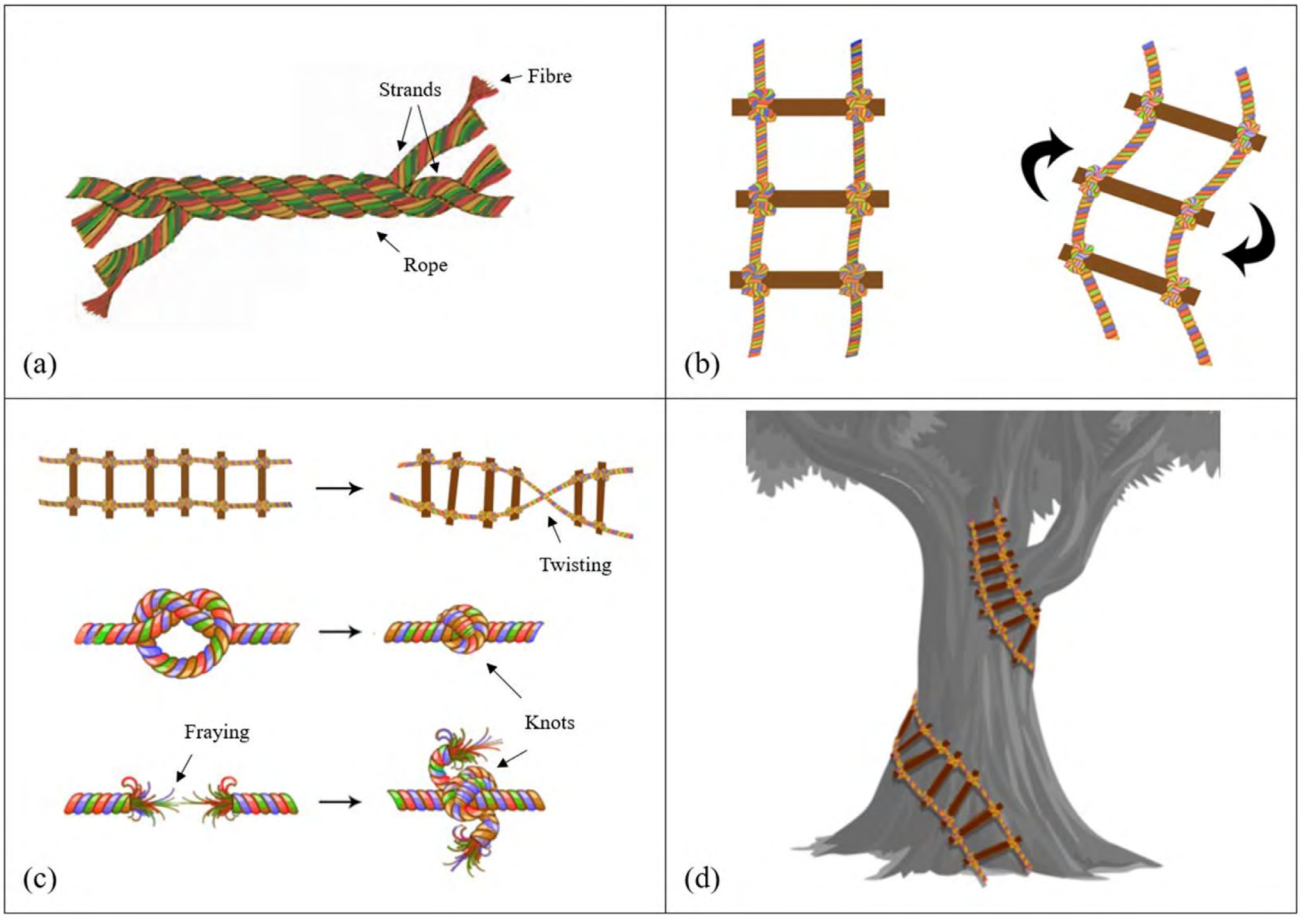


**Figure 16:**

**Arunkumar's (2018) rope ladder model of youth development allows for flexibility**



# Annex 3 – External Advisory Group (EAG)

The following members of the EAG provided guidance on the emerging findings of this research to steer the direction of the inquiry.

| Name and expertise | Designation and institution |
|---|---|
| **Dr. Alun Davies**<br>Participatory research specialist | Schools Engagement Lead, KEMRI-Wellcome Trust Research Programme, Kenya |
| **Lian Zeitz**<br>Mental health specialist | Director of Youth Engagement and Advocacy, citiesRISE, USA |
| **Dr. Renzo Guinto**<br>Climate and health specialist | Chief Planetary Doctor, PH Lab and Inaugural Director, Planetary and Global Health Program, St. Luke's Medical Center College of Medicine, Philippines |
| **Alaa Dafallah**<br>Medical student | Student representative, University of Khartoum, Sudan |
| **Sukhnidh Kaur**<br>Youth behaviour change and social media expert | Psychology student, St Xavier's University, India |
| **Jennifer Preston**<br>Youth involvement specialist | Senior Patient and Public Involvement Lead, University of Liverpool, UK |
| **Dr. Maryam Shahmanesh**<br>Infectious disease specialist | Faculty Member, Africa Health Research Institute, South Africa. Associate Professor Clinical Epidemiology, UCL Institute for Global Health, UK |

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