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WEAVERS



Shift



HOW CAN **YOUNG PEOPLE** IN THE UK PLAY A BIGGER ROLE IN HEALTH AND SCIENCE RESEARCH?

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EXECUTIVE SUMMARY

WHY
involve
young
people in
research?

Young people deserve to have a say in the big issues that are shaping our world. With a particular focus on the Wellcome Trust's three global health challenges (mental health, climate and health and infectious diseases), this report explores the role young people can play in health and science research and outlines recommendations for researchers looking to involve young people in their work.

Our team of six young Co-Lead researchers aged 18-24 working alongside a team from Shift and Beatfrees have been funded by the Wellcome Trust. We have used our own valuable insights and lived experience to design a research project by and for young people. Over three months we spoke directly with 87 young people aged 13-24 and reached a further 116 through an immersive survey. We surfaced 8 key themes which we outline below.

1. LACK OF REPRESENTATION

Representation is an important issue to young people who view the scientific community as distanced from their interests and experiences. This lack of connection can discourage underrepresented people from pursuing jobs within research, perpetuating the lack of diversity in the field.

2. HISTORICAL MISTRUST

A longstanding mistrust towards scientists and researchers underpinned some of the conversations we had with young people, especially within the Black and the LGBTQ+ community, resulting from past and present mistreatments of these communities in medical research young people seemed to also distrust research where the sources of funding were unclear or were likely to lead to bias.

3. GENERATIONAL GAP

Most young people we spoke to felt a stark generational gap, generally seeing the older generation as less interested in change, and themselves as more creative and adaptive. Many felt their experiences of and opinions on pressing issues were dismissed by older people leaving them feeling misunderstood as a generation.

4. INVOLVING YOUNG PEOPLE FROM THE START

Young people are aware of how their involvement is sometimes used as a box-ticking exercise and are sceptical of this type of inclusion. Their knowledge, skills, experience and fresh perspective should be valued and meaningfully brought into research.

5. RECRUITMENT

Young people seem eager to be involved with research, both as participants and researchers, but there are too few opportunities, and these tend to be hard to access without an existing link to research communities or the confidence to engage with researchers and/or academic spaces.

6. INCLUSIVE WAYS TO TAKE PART

Accessibility should be built in from the start of every project and needs to go beyond considering only people's physical accessibility needs. This means considering methods of engagement, language and additional support people may need to take part.

7. COMMUNICATION

Young people found scientific research inaccessible and elitist and found it hard to assess what information could be trusted. Many suggested researchers using social media to communicate in more engaging and direct ways but were aware of the potential risks.

8. RESEARCH NEEDS TO LEAD TO IMPACT

Young people want to see change and many feel research should have a greater influence on government policy, though most felt unclear about how research can lead to impact.

HOW
to do it
well?

Reflections from the Co-Leads are available in video here:



<https://vimeo.com/578379746>
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<https://vimeo.com/579784327>

3 CHALLENGE AREAS

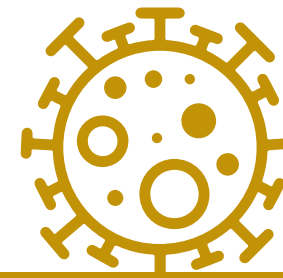


These eight themes were echoed across all three of Wellcome's challenge areas, and each challenge area demonstrated a different level of personal engagement with the topic. Mental Health was a challenge that felt personal to the majority of young people we spoke with, many citing their own experiences or supporting family and friends. The landscape of Infectious Disease has been dramatically changed by COVID-19, and young people spoke of the impact on them, their communities, while Climate and Health was something most young people saw as removed from their own day to day and impacting those who lived further afield.

MENTAL HEALTH

The young people we spoke with were keen to be involved in mental health research and spoke of a strong desire to have their voices heard. Many referenced a generational gap and a disconnect with older people that could be bridged with a role for young people in shaping mental health research. While they could see current research improving an understanding of symptoms, it was felt more focus should be placed on prevention and causation.

Whatever their level of involvement, feeling safe and supported while contributing to research was a key theme. That might look like offering a variety of ways for young people to share their thoughts and/or providing access to mental health support to research participants. Social media was a focus of many of our conversations for its benefits as well as the challenges it creates—much of those conversations centred around having a trustworthy source of mental health information available online. Further research into more effective ways to disseminate robust mental health information via social media and offering communication training opportunities to researchers are just some of the ways this could be improved.

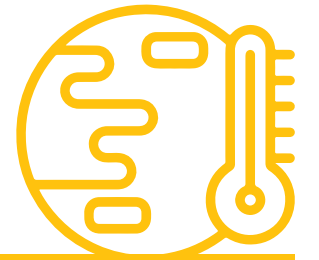


INFECTIOUS DISEASES

COVID-19 took centre stage in our discussions about infectious disease research. Young people spoke of the increased visibility of health and science researchers whom they considered more objective than politicians and noted their current influence over policy as a moment to leverage and exert greater influence at a national level. However, infectious disease research was the challenge area most closely linked to our historical mistrust theme and the underfunding of diseases that impacted minorities or those in low-income countries was highlighted again and again. Offering marginalised groups the opportunity to shape infectious disease research and transparency on who was funding it were just some of the next steps young people identified.

This challenge area also tied in closely to a perceived lack of representation. It left some young people feeling that the needs of their communities were not being met or understood and negative experiences of the healthcare system appeared to impact their perceptions of the science and research community. Visible diversity within the field and prioritising diversity in participants were identified as a way forward.

When asked about the type of research they would like to see, much of the focus was on pandemic preparedness and its impact on young people. This moved beyond the physical impacts of infectious disease and encouraged a more holistic study of its social impact on wellbeing, mental health and future options and outcomes for young people.



CLIMATE AND HEALTH

The impact of climate change on people's health was seen as disconnected from the day-to-day experiences of young people living in the UK. Instead, the focus of these discussions turned to climate action and climate change. Overall the sentiment was that space should be made in research for people directly affected by climate and health and their needs met, particularly those in low-income countries.

The lack of urgency in climate action that many young people saw happening in business and politics was interpreted as a generational disconnect and exclusionary. They highlighted the failure to recognise holders of knowledge and expertise that fall outside of accepted scientific context and a need to be more open to indigenous perspectives and practices in conversations around climate.

This is a generation of young people who are ready and already working towards action on climate change, who are jaded by bad news but can see a path forward by combining their creativity with the expertise of Climate and Health researchers. This challenge area was the one that most clearly aligned to our 'research needs to lead to impact' theme, and the emphasis for further exploration was on facilitating government action on climate change through clear and convincing communication of research, advocating for those most at risk and influencing change at a policy level.

WHAT RESEARCHERS CAN DO...

Here is a summary of what we think researchers and research institutions can do differently to make sure young people can take part in health and science research meaningfully.

OVER THE COURSE OF A PROJECT...



INVOLVE YOUNG PEOPLE FROM THE START

- 4.1** Collaborate with young people from the earliest stages of the research process.
- 4.2** Design roles where young people are able to utilise their skills & knowledge.
- 4.3** Provide relevant training so that the young people involved can take a full and active role in the research.

RECRUIT DIVERSE PARTICIPANTS

- 5.1** Recruiting participants from marginalised groups can be facilitated by hiring researchers and/or consultants from the groups you are trying to engage.
- 5.2** Work with schools to recruit young people but don't stop there.
- 5.3** Consider language carefully, as it can play a huge role in attracting people or putting them off.
- 5.4** Use social media, but show you are trustworthy. used carefully, as language can play a huge role in attracting people or putting them off.
- 5.5** Compensate people for their time.

GENERALLY...

ADDRESS LACK OF REPRESENTATION

- 1.1** Prioritise the voices of young people from underrepresented backgrounds.
- 1.2** If you are in a position to recruit staff, value diversity.

ADDRESS HISTORICAL MISTRUST OF THE SCIENCE COMMUNITY

- 2.1** Offer full transparency about who is funding the research and what their aims and affiliations are.
- 2.2** Enable marginalised people to shape the focus of the research they participate in.

2.3 Outline how your research will benefit the group being researched.

2.4 When research institutions acknowledge the past and any mistreatment of certain groups, they are taking the first step towards repairing relations and moving forward.



COMMUNICATE FINDINGS IN WAYS THAT WILL RESONATE WITH YOUNG PEOPLE

- 7.1** Use simpler language and communicate on accessible platforms.
- 7.2** Researchers may benefit from taking part in communication training opportunities within their institution, or from working with scientific communication specialists.
- 7.3** Work with sensitivity readers with lived experience from a range of backgrounds.

ADDRESS YOUNG PEOPLE'S DESIRE FOR RESEARCH TO LEAD TO IMPACT

- 8.1** Communicate the solutions and actions that arise from research.
- 8.2** Where realistic, ensure that budgets factor in time, money and staff so that researchers have the ability and resources to advocate for policy change.
- 8.3** Institutions may consider having placement opportunities for researchers to work within government departments.

ABOUT

Shift

Shift uses design thinking to tackle social problems. They take a collective, collaborative approach, working with a range of organisations to help maximise impact.

shiftdesign.org



Beatfrees is an engagement and insight agency with a growing community of young creatives. Beatfrees work with brands, government and funders who see value in sharing power with young people.

beatfrees.com



Wellcome is a global charitable foundation. We want everyone to benefit from science's potential to improve health and save lives.

wellcome.org

We would like to thank all of the participants in this research for sharing their experiences, ideas and hopes for the future with us so openly and honestly. Our thanks to the team at Wellcome who supported this work - particularly Carla Ross and Juan Sebastian Dennis-Beron who championed this project and brought great insight and feedback to all that we did. We would also like to thank the team at UNICEF C4D for their input, the team at Body & Soul who supported our participants and to the researchers and scientists who shared their experiences and expertise with the team and fed back on our work along the way.

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INTRODUCTION

Young people nowadays are seen as a generation that are increasingly socially aware. From Xiuhtezcatl Martinez, who filed the first lawsuit against the U.S. government for failing to act on climate change, to Greta Thunberg, we are seeing young people wanting to incite change and build a better future. More recently we saw Simone Biles withdraw from the Tokyo Olympic games to prioritise her mental health, showcasing the importance of mental wellbeing. This report looks at the role young people can play in health and science research. It is based on insights from primary research with young people in the UK (aged 13-24), and will outline recommendations for researchers looking to involve young people in their work.

CONTEXT

Health and science researchers use science to address health issues that affect both individuals and communities from both a UK and international context. In this project, we focus on three pressing challenges: mental health, climate and health, and infectious disease. Young people, who make up 40% of the global population, tend to be disproportionately impacted by these issues. Therefore, it seems key to involve them in solving these challenges (Das, 2020). The scientific community is starting to acknowledge that young people have something valuable to offer, both as participants and as part of the research team. However, historically, where projects are designed for young people as participants, their contribution has been on a surface level but there is a growing desire for deeper, more collaborative, involvement (Wilson, 2020).

This report is part of Future Weavers, a global participatory research project coordinated by Wellcome and UNICEF that aims to engage young people in shaping solutions to global challenges as partners in research, decision making and action. The UK portion of this research was funded and coordinated by Wellcome with support from researchers at SHIFT and BeatFreeks. This research is framed around three global health challenges that Wellcome are championing: Mental Health; Infectious Disease; Climate and Health.

See also
P62 for
reflections
on the
process

A PARTICIPATORY PROCESS

Reflections from Shift / Beatfreeks

To ensure that the questions asked during fieldwork were aligned to the priorities of young people and that the methods used to collect their perspectives were relevant to their lives, the research was designed and conducted by a team of 6 young Co-Leads aged 18-24. While a team of professional researchers supported and facilitated the process the whole way through, the ambition was for the Co-Leads to have as much decision making power and agency as practically possible.

The Co-Leads were recruited from nearly 200 applicants from all over the UK. They were selected for their interest in making health and science research more inclusive, with the aim to reflect a diverse range of life experiences, socio-economic backgrounds, geography, education levels and perspectives. The Co-Leads were paid for their time and their roles were tailored to their skills and interests, to ensure meaningful involvement. The team met every 2 weeks to plan the project, review key decisions, and get trained up in research methods where necessary. The Co-Leads defined the research questions and designed the methods based on what they felt would resonate most with their age group. They also conducted the fieldwork, with the view that it would be more comfortable for participants to speak openly to peers rather than to adult researchers. Finally, they took ownership of the analysis of the data, and wrote this report, which outlines the insights they consider a priority.



METHODS

As Co-Leads, we have each provided our own valuable insight and lived experience of health and science research, and of the three challenge areas. Researchers from Shift and Beatfreeks facilitated and guided us through the project but took a backseat in the decision making process to allow us to steer the direction of the research. We received five days of research skills training before the project began as well as ongoing development training throughout. This included skills like interviewing, workshop facilitation, report writing and analysis. This was a vital aspect of our involvement within the project, equipping us with the necessary skills and knowledge to lead this project meaningfully

To delve deeper into these topics, we began by developing two research questions: 'How can the experience of young people who are involved in research be the best it can be?' and 'How can health and science research as a professional field become more inclusive of young people and under-represented groups?'

To recruit young people we used opportunity sampling and a combination of social media advertising, reaching out to Beatfreeks' network of young people and direct communication with groups with links to marginalized communities, as well as our own personal networks when necessary. Our criteria for inclusion was more weighted towards groups who tend to be less represented in health and science research, based on disability, gender and race. We had to iterate our communication to reach a good balance of participants. In total, 223 young

people from England, Northern Ireland, Wales and Scotland signed up to take part. Participants were compensated for their time and insights in the form of financial payment. This ranged from £10 for light touch contributions to £80 to complete a toolkit and an interview.

As a team we designed a range of research methods we felt would be inclusive and allow people to take part in a way that suited them. This included semi-structured interviews with 36 participants and group discussions with a total of 52 participants. These were carried out by two Co-Lead Researchers with technological support from a researcher from Shift. Of these participants, 57 also chose to complete toolkits where they were asked to share their thoughts on Mental Health, Climate and Health, and Infectious Disease in a range of creative mediums. Finally, we sent out a narrative-based survey that asked young people to imagine how they would design a research project in order to reach other young people for the purpose of tackling an impending climate crisis. This was completed by 116 young people.

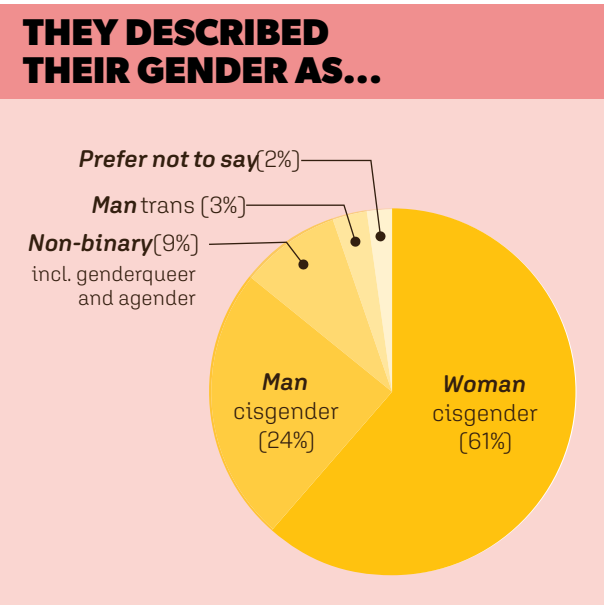
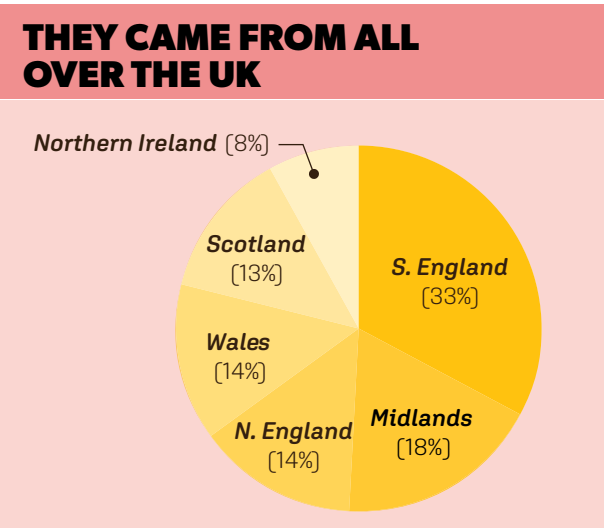
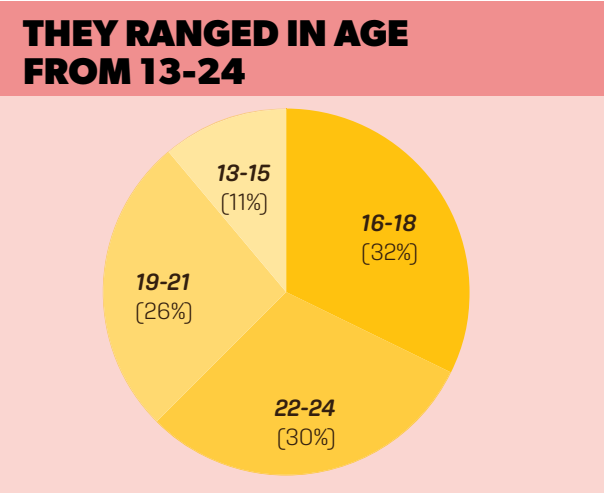
We also brought together 14 researchers working on the three challenge areas to test how our insights resonated with their reality. A full list of the researchers who participated is included in the Appendix.

From our analysis of the data that was collected, 8 key themes emerged, which we have outlined in this report. The first half of the report focuses on why young people feel underrepresented in research, and the latter half explores ways this could be addressed, based on the perspectives we heard from the young people who participated in our research.

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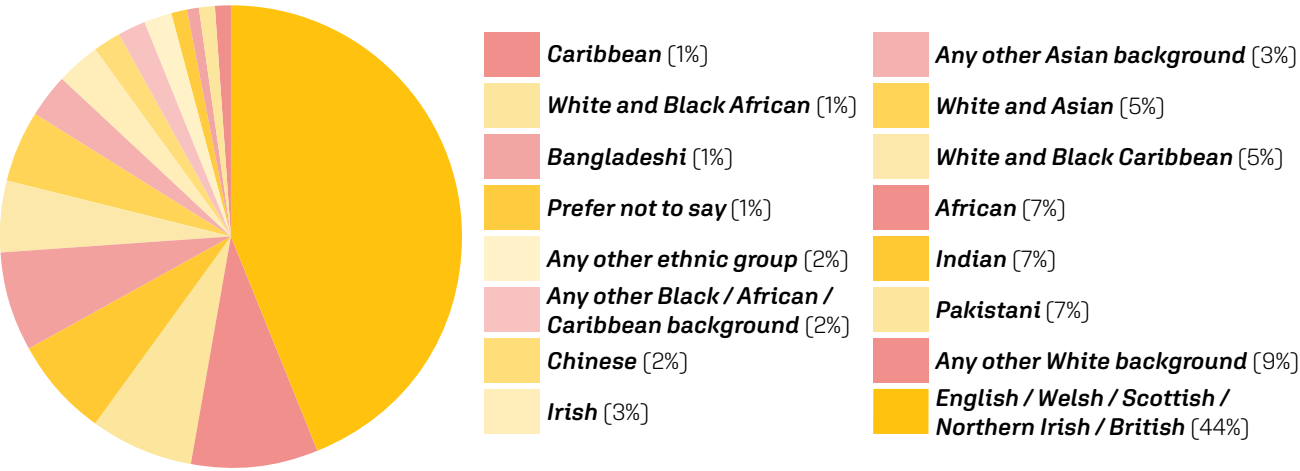
WE SPOKE TO 87 YOUNG PEOPLE

This is how they described themselves:



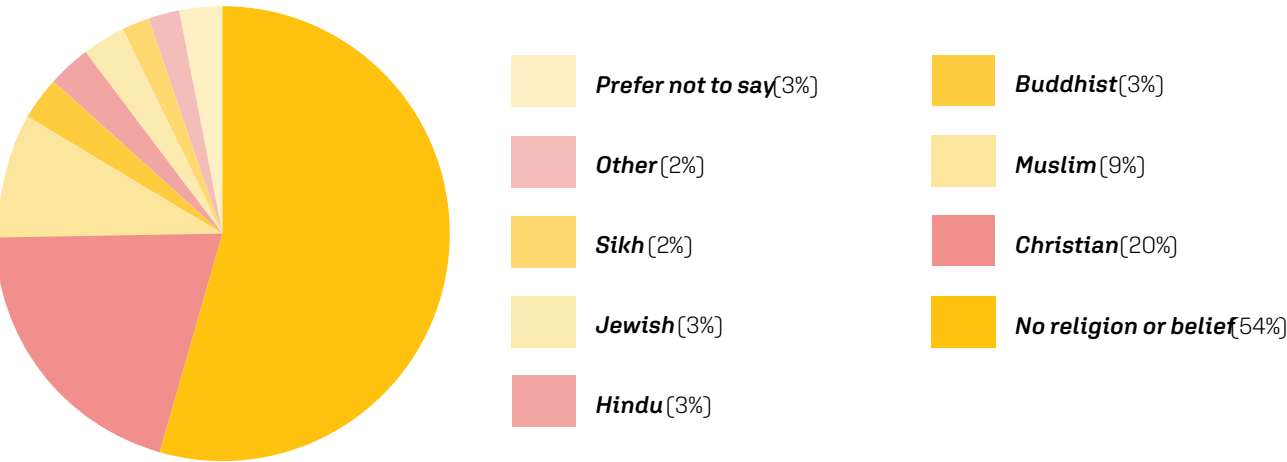
THEY DESCRIBED THEIR ETHNICITY IN A MULTITUDE OF WAYS...

Young people who described themselves as ethnically white totalled 55%, below the UK average of 86%.



SOME WERE RELIGIOUS BUT MANY WERE NOT

The young Muslim people we spoke with made up 9% of the people we spoke with, almost double the UK total of 4.8%.



10% Had immigrated to the UK and a further 26% had at least one parent who had immigrated.

36% Grew up in a household where neither parent had been to University.

24% Spoke more than one language at home.

WHY
involve
young
people in
research?

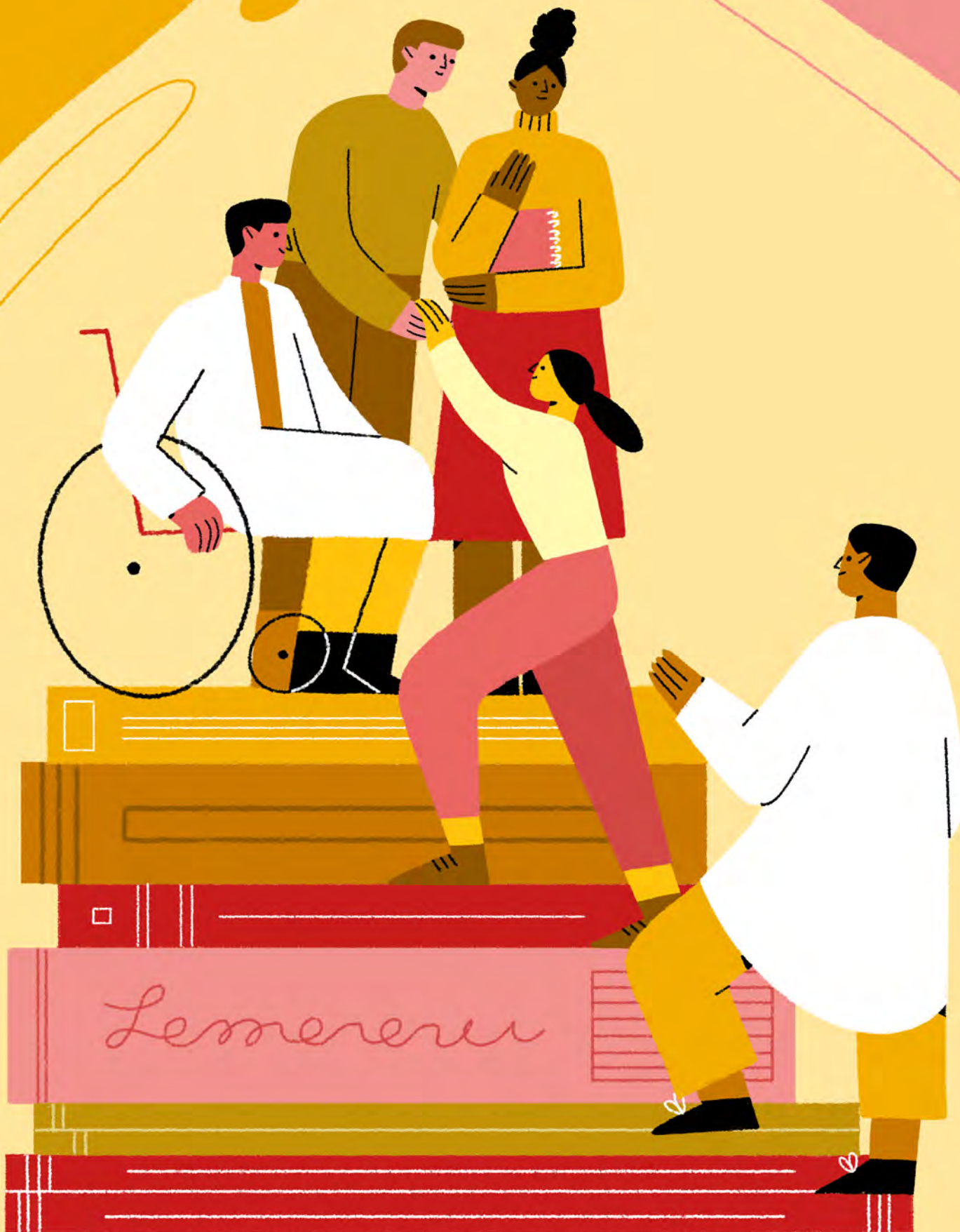
1. LACK OF REPRESENTATION

Throughout our research, we have consistently heard that representation is an incredibly important issue to young people. Those from underrepresented groups (e.g. ethnic minorities, LGBTQ+, low income, and disabled people) in particular felt that health and science research – or the way it was communicated to them – often ignored their needs.

“

There should be equal research into the presentation of mental health conditions in males, females, non-binary, and individuals of all other genders. There is also a great need to diversify the research field beyond white, middle-class, western European citizens. Mental health illnesses can present in vastly different ways amongst different people and, in order to provide the best support for all people, mental health research needs to be representative of all people.”

Emily*, 17, Wales



What we heard from YOUNG PEOPLE

The vast majority of young people interviewed (72%) spoke of the scientific community as distanced from their own interests and experiences. This is partially due to the perception of research (in medical, academic and other contexts) being dominated by straight, cis, White, older men. This can feel alienating, especially to those from marginalised backgrounds. Shannon* [22, Northern England] talked about her experience of looking through academic papers to find information about her own mental health issues: ***“I think a lot of academic articles are usually written by older white guys, which obviously, I don’t really relate to.”***

While researchers from marginalised groups do exist, they are not always as visible. This lack of connection can discourage young people from marginalised groups from pursuing careers and participating in research, which perpetuates a lack of diversity in the field and in research. Shifting the demographics of those involved in research will ensure that the data collected is more representative of the needs of a whole population, including those from marginalised groups. If the sector does not change, research risks leaving whole groups behind, furthering their existing marginalisation by not investigating their needs.

While it can be challenging to reach certain groups, especially when there is long-standing mistrust involved, it is important to directly communicate with them so that the health and science community can focus on the needs of everyone. Additionally, it's important to note that this issue of feeling unrepresented extends beyond the scientific community, with young people referencing similar demographic trends (whiteness, cisness, being older) among those in political power and, in turn, in which policies are implemented. Emma* [23, Wales] said ***“I think you see that lots of older, bushy-haired white men in politics are actually the same people in science [...] I think it needs to be diverse because honestly we’re putting in place white women and white men from upper class backgrounds and it can’t be that. It has to be people from all across society.”***

72%
**OF INTERVIEWEES VIEWED
THE SCIENTIFIC COMMUNITY
AS DISTANCED FROM THEIR
INTERESTS AND EXPERIENCES.**

How this relates to Wellcome’s CHALLENGE AREAS

<div>INFECTIOUS DISEASES</div> <div></div>	<p>Lack of representation in healthcare leads to some feeling like the needs of their community are not being met or understood. There are greater risks of Covid-19 to those from lower-income backgrounds who have been forced to work in high-risk environments – such as retail, social care, and plant and machine operatives (Gov.uk, 2021a). Negative experiences of healthcare seem to impact the way that the health and science research community is perceived, as people tend to conflate the two. For example, in response to a question about whether she felt represented in science, Careese [18, Midlands] talked both about being aware that research on sickle cell disease (an illness that predominantly affects Black people) is underfunded as well as about seeing people she knew having poorer experiences of medical care, which she attributed to them being Black: <i>“My friend’s mom was pregnant recently and when she was at the hospital they’d treat her like a guinea pig. They weren’t sure how [different treatments] would affect her because she had this [condition].”</i></p>
<div>MENTAL HEALTH</div> <div></div>	<p>Similarly, there was concern that medical professionals often have rigid ideas about who experiences a particular mental health condition, and frustration that some conditions may be overlooked if the patient's identity doesn't match those who professionals generally expect to display certain symptoms. People from different backgrounds will have different experiences of the same condition – from risk factors to symptoms and viable treatment options. For example, Black people are disproportionately likely to be detained under the 1983 Mental Health Act and are more likely to have been sent for treatment by a judge or a police officer than by a GP (Omonira-Cyekanmi, 2014). Ensuring representation in research will help to make sure these sorts of health inequalities and inequities of treatment are prioritised, understood and actioned. Stephanie* [23, Southern England] shared her struggle trying to get a therapist she could trust and relate to, saying: <i>“It’s definitely impossible to find a Black therapist. [...] I guess it goes back to underrepresentation in terms of access and how it affects relatability.”</i> It's essential that a variety of needs are visible within mental health research and direct involvement from people with lived experience seems to be the best way to ensure that happens.</p>
<div>CLIMATE AND HEALTH</div> <div></div>	<p>While the UK is beginning to see more of the obvious effects of climate change through increasing temperatures and flash flooding, there is still a disconnect for many of the young people we interviewed. Beyond a few references to asthma and air pollution, and to climate anxiety, most struggled to see how climate change might impact their health. <i>“I have this family friend and, you know, she suffered from insomnia because of worrying about the climate crisis, and this massively impacted her mental health.”</i> (Samantha*, 18, Wales). Those who felt closer to climate and health tended to have a personal connection to a low income country affected by the detrimental effects of climate change and were disproportionately from immigrant backgrounds. For example, Janistar [20, Northern England] said: <i>“So climate change is quite an important issue for me specifically because I come from Thailand, and obviously in a lot of Western countries you don’t see the impact that climate change has on that specific country. But, obviously, in developing and third world countries, the impact of climate change is a lot more visible.”</i> This indicates a need for space to be made within climate and health research for people from lower income countries and people living in the worst-affected (usually lower income) areas of the UK (Gov.uk, 2018). This will help ensure the needs of those most affected by climate change are being met, and ensures that any proposed solutions are relevant and accessible.</p>

What we heard from RESEARCHERS

It's interesting to see how issues of representation affect researchers who don't fit the demographic young people generally assume researchers to be. One researcher, Pranav Shah, who works at the Wellcome Trust Centre for Human Genetics, University of Oxford, saw research as a relatively diverse field: *"I have lived and worked in Scotland, Germany, United States and now England, and I have never felt like an outsider. In all these places, I have been fortunate to have worked with, [been] mentored by and made friends with diverse individuals representing different parts of the world and different identities. However, I also recognise that [this] has been a privilege that perhaps has not been afforded to other colleagues in the field."*

Myles-Jay Linton, who is a psychologist and mental health researcher at the University of Bristol, spoke about his experience as a Black researcher. *"I've joined Zoom calls for research things where I've been assumed to be a participant rather than a researcher, or presumed to be a student rather than a lecturer."* He emphasised the need to celebrate people based on merit and knowledge, rather than on who is historically in specific roles. Rachel Burns, Research Fellow at the Institute of Health Informatics, University College London, said that her PhD cohort was diverse, but that in higher seniority levels, there was less diversity and that this needed to be looked into, to understand why people from some groups were elevated whilst others weren't. Dr. Esther Odekunle, Antibody Engineer in the pharmaceutical industry, also noted that while diversity programmes were a sign of progress, some failed to take into account intersectionality, with some prioritising gender equality but paying less attention to race and ethnicity, for example.

Finally, Araceli Camargo, a neuroscientist who is part of Centric Lab, an organisation focused on how our environment impacts our health, highlighted how academia devalues certain kinds of knowledge and therefore limits who can access scientific spaces. Centric Lab aims to remedy that in part through the diversity of their team, which impacts directly on their research priorities.

66

"Every single one of our scientists is from a marginalised background, whether it's LGBTQ+ or indigenous as myself, or Black, and they tell us: 'This is what's happening with my people, can we direct some work in that direction?'"

Araceli Camargo
[Centric Lab]

"When I hire people, I also try to understand what people's stories are. I think sometimes the most successful scientists are the ones who have had to overcome challenges."

Anna Blakney
[University of British Columbia]

What can RESEARCHERS DO?

1.1

PRIORITISE THE VOICES OF YOUNG PEOPLE FROM UNDERREPRESENTED BACKGROUNDS. Researchers and institutions should consider going beyond proportional representation and instead actively seek out the participation of more people from these groups. While some people might deem proportional representation the most 'fair' or 'impartial', this avoids their perspectives being overshadowed by the majority group. This will help to change the impression of research being unrepresentative of the experiences of many people to gather relevant data.

1.2

IF YOU ARE IN A POSITION TO RECRUIT STAFF, VALUE DIVERSITY, whether that is through connecting to existing diversity programmes or hiring people directly. This will help to ensure your research feels close to people's reality, but also enrich it through different perspectives.

66

"I haven't taken part in any scientific research before and I didn't get an opportunity to either, so I wouldn't say that i'm represented. I know that the government does post like results of different research and they're just like yeah this works for like 12 to 17 year olds, but I personally haven't taken part in any research and I don't know anyone who has."

Daria* [16, Southern England]



WHY
involve
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2. HISTORICAL MISTRUST

A longstanding mistrust towards scientists and researchers seemed to underpin some of the conversations we had with young people, in particular those that come from groups historically excluded based on disability, gender, class and race. There was an overwhelming feeling that research traditionally let them down in both its methods, focus and applications.

“

“I heard about this American project - I can’t remember the specific disease - but they gave it to some Black people in order to experiment. So when I talk about trust issues, I’d say there can be a lot of mistrust between certain groups and certain races because of the history of healthcare research.” Ethan* [17, Midlands].



What we heard from **YOUNG PEOPLE**

For example, some participants spoke of pharmaceutical and clinical trials and the mistreatment of Black communities within research, with some referring to the Tuskegee experiment. *“I heard about this American project - I can’t remember the specific disease - but they gave it to some Black people in order to experiment. So when I talk about trust issues, I’d say there can be a lot of mistrust between certain groups and certain races because of the history of healthcare research.”* [Ethan*, 17, Midlands]. Similarly, those from the LGBTQ+ community mentioned the mishandling of the AIDS epidemic - including political silence and inaction, and failure by pharmaceutical companies to communicate information about drug development [Vulliam, 1999] - as something which carries a damaging legacy for both researchers and policymakers. This prevents representation of these individuals as both participants and research staff. It is also important to note that on top of these historical abuses, people from marginalised communities are still experiencing [or seeing others from their community experiencing] mistreatment and abuse in the present day. For example, Black birthing parents in the UK are four times more likely to die in pregnancy or childbirth than their white counterparts [MBRRACE, 2020], trans people are still struggling to access healthcare [Bachmann, 2018] and seeing research being done that does not seek to serve their interests at all or even seeks to “disprove” their identities [Barasch, A. 2018], and the autistic community is voicing concerns about the fact that significant funding was recently awarded to researchers whose research has contributed to negative preconceptions about autism for a genetic study which they fear will not serve the interests of autistic people [O’Dell, 2021].

Young people seemed to also distrust research where the sources of funding and affiliations to certain groups were unclear, out of concern about their intentions and the risk of bias. In addition, they perceive white, educated and non-marginalised people are more likely to receive funding. Indeed, a report from the Wellcome Trust found that funding success rates for Black, Asian and Minority Ethnic applicants are persistently lower than for White applicants (8% compared with 14%) [Wellcome, 2021]. This affects what is being researched. For example, some participants felt that infectious diseases had been underfunded in comparison to other diseases because of who they tend to impact. *“When I think infectious disease I think underfunded [...] I guess they’re mainly linked with poverty so if you are very rich and you do research, you’re not going to be funding research in something that doesn’t affect you [...] while viral infectious diseases mainly affect people in poverty.”* Emma (23, Wales). It is important that there is transparency with regards to who is funding research, and how funding decisions are made.

There is still a lot of work to be done in addressing this mistrust, and it must be handled very sensitively so as to avoid furthering the damage. If trust can begin to be repaired, people from marginalised groups will feel more able to see research as a tool to gather valuable data about their experiences and improve their care experiences and health outcomes.

How this relates to Wellcome’s **CHALLENGE AREAS**

<div>INFECTIOUS DISEASES</div> <div></div>	<p>In terms of our three challenge areas, historical mistrust seemed most prevalent in relation to infectious diseases. More recently, this can be evidenced with the COVID-19 vaccine hesitancy among Black or Black British people being 21% in comparison to 4% of White adults [Gov.uk, 2021b]. This is particularly concerning as it has been shown that Black people are four times more likely to die from contracting COVID-19.</p>
<div>MENTAL HEALTH</div> <div></div>	<p>Additionally, this mistrust towards health professionals more broadly can have detrimental effects on marginalised people’s ability to seek support for mental illness. It is especially important that marginalised people feel able to access mental health treatment as they are statistically more likely to suffer from mental health conditions and experience trauma. LGBTQ+ people are twice as likely to report symptoms of poor mental health and are 50% more likely to suffer from depression and anxiety disorders than heterosexual adults [LGBT Health, 2018].</p>

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“It took so long to develop any kind of defence against HIV because it was gay men, they didn’t want to acknowledge or anything like that. I think there needs to be more openness about who it’s affecting and how you can be empathetic and sympathetic to them.”

Tiger-Mai (18, Southern England)

What we heard from RESEARCHERS

Araceli Camargo (Centric Lab) was particularly passionate about working with marginalised communities and shared that *“Centric Lab has built up long standing relationships with a variety of communities by working with and being guided by members of those communities.”* So now marginalised communities will come to them asking for research to be done, rather than the other way around. *“That means that the community directly instructs us what we’re going to research. So for example when we did work with Southall¹, they already knew that air pollution was affecting your health. They just needed the data part of it, and the analysis part of it which is what we came in to do.”*

A conversation between three researchers working on infectious diseases highlighted how transparency in research can help to rebuild trust in communities which would help to overcome issues such as vaccine hesitancy.

Dr. Esther Odekunle (pharmaceutical industry) also spoke about how scientific research communication needs to highlight the scientists and researchers involved. This would, in her opinion, help people trust the research being carried out so the research doesn’t feel like it is being carried about by nameless, faceless people.

“What would be good to know and understand is why they made the decisions they made. It is easy to ascribe a political agenda to a decision in the absence of a clear scientific explanation. The ball is now in the Government’s court to come clean on the decisions it made during the pandemic to prevent the erosion of trust in the health system.”

Pranav Shah (University of Oxford)

What can RESEARCHERS DO?

2.1

OFFER FULL TRANSPARENCY ABOUT WHO IS FUNDING THE RESEARCH AND WHAT THEIR AIMS AND AFFILIATIONS ARE. This will help to build trust with people who are unsure of researchers’ intentions. The mention of certain funders might further distrust, but if information about who is funding research is kept buried, suspicion is likely to remain.

2.2

ENABLE MARGINALISED PEOPLE TO SHAPE THE FOCUS OF THE RESEARCH THEY PARTICIPATE IN. Allow them to prioritise what knowledge they want to be gathered about their community, and decide what kinds of research questions would be useful and relevant. If they are able to direct the scope of the research in service of their needs, people might begin to see how their participation can lead to valuable insight for their communities. This helps ensure they feel that their inclusion is meaningful, as opposed to being performative.

2.3

OUTLINE HOW YOUR RESEARCH WILL BENEFIT THE GROUP BEING RESEARCHED. In addition to long term benefits that may come as a result of the research outcomes, participants should see immediate benefits such as adequate financial compensation (sufficient to allow people to take time off work if needed, so as not to exclude low-income participants who cannot miss work for something unpaid), the chance to develop skills, and potential for further opportunities arising from their involvement. This makes it clear the needs of the participants are being prioritised and helps to ensure they feel like valued peers as opposed to subjects of curiosity.

2.4

WHEN RESEARCH INSTITUTIONS ACKNOWLEDGE THE PAST AND ANY MISTREATMENT OF CERTAIN GROUPS, they are taking the first step towards repairing relations and moving forward. By taking responsibility and apologising for harm caused, they are showing a recognition of past harms. This can then be learned from to ensure history does not repeat itself. This may be perceived as a performative action, so it is important that it is followed by material change, ensuring that research provides measurably positive outcomes for marginalised groups.

1. A premoniantly South Asian neighbourhood in West London

WHY
involve
young
people in
research?

3. **GENERATIONAL GAP**

Most of the young people we spoke to felt that there is a stark generational gap in views related to wider societal topics as well as attitudes and behaviours. The older generation were seen as more stoic and less interested in change, whereas the younger generation view themselves as more creative and adaptive. Participants also shared that they viewed the younger generation as more likely to embrace change, diversity and inclusivity.

“Without a doubt there is expertise and experience that young people have that [researchers] in those programs, projects or firms don’t have. But [...] you are kind of letting people down in a way, by not sharing some of the things that you know [as a researcher].”

Kate Martin [Wellcome Trust]

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“When you’re younger, you’re expected to just stand by and let things happen, especially when you can’t vote yet.”

Samantha* [18, Wales]

What we heard from YOUNG PEOPLE

Many young people voiced concern that research did not reflect them as a group, or their needs. Daria* [16, Southern England] for example said: **“All of the research is conducted by adults and they may think that we either don’t have opinions or we don’t know about science yet, or we don’t really care about what’s happening in the scientific world which is not true [...] I feel like they just don’t count us as being capable of providing value for whatever they’re trying to find out.”** Young people can bring creative thinking and different perspectives to research, and sometimes a new way of doing or seeing things can lead to exciting developments. Natasha* [23, Southern England] summarised this well: **“I think young people see the world in a completely different way, they’re a little more optimistic, they’re a lot more creative. They aren’t as restricted by ideas of failure, or self doubt, or whatever. So they can be a bit more out of the box thinkers.”**




Many of the young people felt dismissed by older people about their opinions on climate change and mental health topics, which will heavily affect them in the future. This left them feeling alone and misunderstood as a generation. That feeling was perpetuated by the negative spotlight placed on influential young people within the mainstream media; for example, Greta Thunberg, who is only 18 years old, has received hate and backlash for her efforts against climate change [Nevett, 2019]. **“People undermine what she’s saying because she is a teenager, and people don’t take it seriously, which is quite harmful. And a lot of people make what she’s saying into a joke because she’s young. It’s very, very harmful.”** Sienna* [14, Wales]

What we heard from RESEARCHERS

This was supported by the researchers we spoke with who expressed that current policy was too short sighted. Clare Heaviside, NERC Independent Research Fellow and Associate Professor at the UCL Institute for Environmental Design and Engineering mentioned: **“The biggest obstacle I would say is always the short-term thinking of people in charge of a government, whereas climate change is a long-term problem which requires a long-term solution.”** In this respect, the issue seems to not just reflect a generational difference, but a disconnect between research and policy or even a difference of perspective amongst different researchers. This point was also reflected by Myles-Jay Linton (University of Bristol): **“I wonder whether it is also important for us to recognise that in and amongst healthcare practitioners and academics there isn’t just one generation there, there are lots of different views and lots of different perspectives on how mental health works and how mental health research should be done.”**

Some researchers mentioned adapting their research methods to address this gap. For example, Anna Lawrence-Jones, Patient and Public Involvement and Engagement Lead at the Institute of Global Health Innovation, Imperial College, said that they tried to get younger people to facilitate workshops, as they feel people would be more comfortable expressing opinions to people closer to them in age, rather than senior professors. Kate Martin, Lived Experience and Public Engagement Lead at the Wellcome Trust also spoke about how having young people involved in the day-to-day running of a project helped overcome this generational gap because young people see and understand mental health differently to other generations. She also highlighted the importance of support and training so that young people can contribute the best they can, and know how to navigate the challenges that might arise during research.

How this relates to Wellcome’s CHALLENGE AREAS

<div>INFECTIOUS DISEASES</div> <div></div>	<p>With regards to infectious diseases, there was a feeling that the younger generation has been abandoned and overlooked throughout the COVID-19 pandemic, especially when considering the government’s responses to it. The disruption to schooling was a source of upset for a large number of young people, especially when it came to peer socialisation. Nicole* [17, Northern Ireland] said “I definitely think that teenagers [had it] one of the worst. Obviously not for risk from COVID or anything, but disruption to their normal life.” Many participants held the belief that the older generation didn’t really care about the impact of the pandemic on young people or how the restrictions would affect them, with several participants expressing a feeling of being kept in the dark. For example, Archie* [14, Northern England] said “I feel like if they’d informed us and told us what was going on before everything happened, we could have been more prepared for it and known what was going to happen at any time, but they just kind of sprung on us and it wasn’t really fair.”</p>
<div>MENTAL HEALTH</div> <div></div>	<p>Generational differences were highlighted most commonly when discussing mental health. In this respect, older generations were perceived to view young people as ‘weak’ due to their more open and transparent attitudes towards mental health. For example, Sienna* [14, Wales] said: “My mum is saying how my generation is too soft on social media.” On the other hand, young people generally described older generations as preferring to ignore mental health conditions, pushing forward rather than talking about their feelings. There was a general consensus that mental health was a bigger priority for young people and were more willing to discuss their mental health than older age groups. Research by Bupa conducted in 2019 has found that 84% of 18-34 year olds with a mental health condition tell at least one person about their symptoms. 43% tell a partner and 50% tell a friend, compared to 33% and 28% respectively for over 55s [Bupa, 2019].</p> <p>Sienna* share their belief that this will result in a shift towards a greater prioritisation of mental health research: “As the younger generations grow up there probably will be more people in assigned fields and more people doing research on things like that.”</p>
<div>CLIMATE AND HEALTH</div> <div></div>	<p>Climate change and its mounting effects were also frequently mentioned. There was a sense of frustration from young people who are struggling to see a sustainable future based on the measures currently in place. There was a feeling that older generations are not taking these issues seriously and that they display a lack of urgency to act. Many participants felt that their generation has been unfairly burdened with the task of combating climate change in the face of prior generations’ failures to do so. One example of this is Archie* [14, Northern England] who said “There’s not really been a change in years, and I feel like kids and children are grasping on to that. So they’re the ones willing to change everything.”</p>

4. INVOLVING YOUNG PEOPLE FROM THE START

Young people are aware of how their involvement is sometimes used as a box-ticking exercise and are sceptical of this kind of inclusion. They expressed a greater interest in being part of research where the role they are filling has been carefully considered and designed for them.

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“I think youth-led, participatory research is key to youth inclusion. If young people are involved meaningfully from the start, instead of bolted on or not treated like human beings with valuable contributions to the conversation, then the process is going to be a better representation of what young people actually think. I think adult-led youth research can also sometimes be unethical in that sense because it forces the adults’ perspectives on the young people - even in the activities they create, or questions they ask.”

Phoebe [19, Midlands]

What we heard from YOUNG PEOPLE

Young people should feel that their knowledge, skills and experiences are being utilised and valued in the role they are taking on from the earliest stages. While researchers might be most familiar with working alongside fellow academics, it is also important to recognise that not everyone has had access to academic opportunities and academic prowess is not the only way for people to offer valuable contributions. Designing roles with this in mind allows for greater representation and variety of perspectives. Young people want researchers to recognise that they can play a part by using their voices and experiences to help others.

Allowing young people to play roles in shaping the research at every step of the way helps ensure research stays relevant, accessible and their strengths are utilised rather than their involvement being performative. *“I was part of the patient representative group at [a children’s hospital] and one of the things we were asked to do was look at research and provide feedback on the design. [...] You know, researchers found that very helpful and, in the end, it saved them time and money.”* Jonathan* [24, Southern England].

Ashleigh [21, Wales] - spoke about her involvement in ALPHA: a group of young people who advise researchers at Cardiff University through feedback and discussion on materials and research design: *“They came back and showed us what they changed. So you know just before the interview, or questionnaires, then they would come back again and be like “this was the first question, this is what we’re sending out - what do you think?” and that was cool. It was great to be able to see what we changed, what the results of the research were [...] I like to think that we made the research more valuable to them as well.”*

How this relates to Wellcome’s CHALLENGE AREAS

<div>INFECTIOUS DISEASES</div> <div></div>	<p>Some people might struggle to imagine how young people could be useful within infectious disease research, but they have a unique experience that differs from older generations, which means they have unique needs to be considered. For example, young people were particularly keen to see research into the impacts of missed schooling during the pandemic and how this might affect their mental health, future prospects, and general quality of life. By failing to research the unique impacts felt by young people, a whole range of experiences and problems go unaddressed, further driving home how young people have felt left behind with regards to the pandemic. There is an opportunity to ensure the needs of young people, especially from underrepresented groups, are taken into account in preparation for future pandemics to avoid disproportionately negative impacts on them.</p>
<div>MENTAL HEALTH</div> <div></div>	<p>Lauren* [18, Northern Ireland] said: <i>“I feel such a disconnect when I think about talking to older people about mental health.”</i> If that disconnect is felt during the research, young people might not feel comfortable or simply feel that what is being asked is irrelevant to them, discouraging full participation. When young people shape the research, this disconnect can be overcome because it’s more similar to the peer-to-peer engagement in which young people are most used to discussing mental health.</p>
<div>CLIMATE AND HEALTH</div> <div></div>	<p>Research being done now on the impact of climate change on health and the suggestions and changes that may result from it will shape the future for young people. It’s important to ensure that this research involves young people to make those changes relevant and doable and positive for that generation. This was echoed by Clare Heaviside [UCL]: <i>“When we look at adapting to climate change [...] that has to involve young people because they are the people who are going to be around for a long time, and our houses and our infrastructure and our travel and transport has to all tie in with where young people now will be in the future.”</i> Clare went on to refer to the Well-being of Future Generations Act, which requires public bodies in Wales to think about the long-term impact of their decisions, as a positive example of policy-making with a long-term view. By combining the expertise of older generations and the creative thinking of young people, there are new approaches to this massive challenge to be found.</p>

What we heard from RESEARCHERS

The researchers we spoke to understand the value of having young people in their research. However, most are cautious of their involvement, citing primarily shortages of both funding and time as well as difficulties in gaining ethical approval if working with young people. Researchers are also aware that young people's involvement should be meaningful and ensure *“that the people who do get the opportunities are supported meaningfully contribute so it's not tokenistic and everyone is listened to on an equal basis.”* Anna Lawrence Jones [Imperial College London]

Some researchers, however, feel that involving young people is not relevant in their field or that they don't have the skills to work with young people. Others feel that with relevant support both financially and in terms of training, they would be keen to involve young people in their research. When researchers take the time to engage with young people, it can help both parties develop new skills and help to ensure that research is relevant to the generations who will grow up in a world influenced by research underway right now.

Kate Martin [Wellcome Trust] said that they are making sure that the work she funds genuinely involves young people with lived experiences through young people leading and co-designing projects themselves. Lucy Biddle, Lecturer in Medical Sociology at the University of Bristol, and Anna Lawrence Jones [Imperial College London] also mentioned taking similar co-productive approaches. Myles-Jay Linton [University of Bristol] also mentioned that it is about changing the culture in academia about who people see as being able to contribute and cited this very project as a useful example proving that young people can make a valuable contribution to academia. Araceli Camargo [Centric Lab] also echoed this view about broadening who is seen as being able to contribute to science and emphasising that anyone can make a meaningful contribution if given the tools and opportunity, not simply the kinds of people we traditionally view as scientists and researchers.

“It's not that we are engaging communities or that we're patronising them; they are hired directly as another pair of scientific eyes.”

Araceli Camargo
[Centric Lab]

What can RESEARCHERS DO?

4.1

COLLABORATE WITH YOUNG PEOPLE FROM THE EARLIEST STAGES OF THE RESEARCH PROCESS. This will avoid putting work into designing a research plan that might not be relevant or engaging for young people. There is the issue of ethical approval to address, but it is better to do this in the early stages of the research design rather than retroactively.

4.2

DESIGN ROLES WHERE YOUNG PEOPLE ARE ABLE TO UTILISE THEIR SKILLS & KNOWLEDGE. This will make them feel more empowered and valued as part of the team, especially if they feel they are being treated as equal to everyone else involved. It can be hard to anticipate exactly what role will suit someone best. Still by allowing for flexibility and being open to discussion, young people can work alongside researchers to design roles that allow them to bring their best work to the table.

4.3

PROVIDE RELEVANT TRAINING so that the young people involved can develop the skills and confidence they need to take a full and active role in the research, in addition to sharing their own lived experience.

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“Unless you give a young person the tools to be able to match you on some level in that power dynamic, you're never going to erase it.”

Phoebe, [19, Midlands]

5. RECRUITMENT

HOW
to involve
young
people in
research?

Addressing issues of underrepresentation begins with inclusive recruitment that actively seeks to engage people from all kinds of backgrounds. Something we heard from young people was how interested they are in getting involved with research, but that they have no idea how to find opportunities and ways into the sector. It seems to be the case that there are simply too few opportunities, and that where these are available, they are hard to access.

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100%
**(57) OF THE YOUNG PEOPLE WHO
COMPLETED OUR TOOLKITS SAID
THEY WERE MORE LIKELY TO TAKE
PART IN RESEARCH AFTER THEIR
EXPERIENCE WITH THIS PROJECT.**

What we heard from **YOUNG PEOPLE**

Only 8 of the 38 people we interviewed directly had participated in research before; most of these young people were recruited because they had lived experience that was specifically relevant to the context of the research. Outside of this kind of recruitment, we found that students attending private schools and universities tend to have greater exposure to a variety of opportunities. This was illustrated during an interview with Daria* [16, Southern England], who attended a private international school and shared how their school composed a weekly email of exciting opportunities. She had found this research project through one of the aforementioned emails and found financial support (a university scholarship). Some non-privately educated participants also reported finding the prospect of engaging with researchers and academic spaces daunting and prevented them from engaging with research further.

Paying participants fairly for their time and insight was seen as key by young people. If payment is not offered for participation, it runs the risk that those from lower-income backgrounds (who are disproportionately belonging to marginalised groups) are less likely to get involved. This is because they often have to dedicate their time to paid roles, ensuring they are earning enough money to meet essential living expenses. In our survey, we asked young people what messages they would prioritise on recruitment materials and the incentive was deemed the second most important message out of 5 choices. The first was the opportunity to make an impact on a pressing issue.

Although it can be challenging and time consuming, by recruiting young people from a diverse range of backgrounds, research benefits from a range of expertise and lived experiences, harnessing the open-mindedness and new perspectives young people have to offer.

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“I’d jump at the chance to be involved in more research, but I think as someone from a lower-income background, I just don’t see myself within that space. It seems too complicated and too high-level for me to get my foot in the door.”

Phoebe, [19, Midlands]

How this relates to Wellcome’s **CHALLENGE AREAS**

INFECTIOUS DISEASES



Many young people also voiced a desire to see research into the effects of the pandemic (particularly with regards to missed schooling) on their long-term wellbeing outcomes and a willingness to be recruited for this kind of research.

MENTAL HEALTH



A large number of young people are especially keen to be involved with research into mental health, as it is something many of them have encountered struggles with - whether personally or through supporting loved ones with mental health conditions. There is a strong desire to have their voices heard and to have a chance to share their lived experiences in service to better understanding of - and treatment for - mental illness.

What we heard from **RESEARCHERS**

The researchers we spoke to reported that trying to engage with schools can be a complicated and lengthy process, but by sharing how their engagement could benefit the students’ futures (including skills and opportunities), they have managed to increase school and parental engagement. Additionally, public engagement departments at universities can aid in reaching out to schools and building connections with young people there. Anna Lawrence-Jones (Imperial College London) spoke of how she uses social media to build connections with young groups: ***“In terms of communicating and research we try and do things in different ways, so we have an Imperial podcast, we obviously have social media as well, though I think we use Twitter a lot more than Instagram.”***

It seems that researchers are aware of the value social media has, and some are using it to recruit young people. However, in more recent times, some of the researchers we spoke to have found recruitment more challenging, potentially due to fatigue from individuals spending so many hours online during prolonged lockdowns. It also seems

that some may still be wary of the impersonal nature of online recruiting. Lucy Biddle (University of Bristol) spoke of her experience, saying:

“I wonder if it’s just you know people are getting a bit fatigued who’ve been approached that way as well making recruitment more difficult, recently. And I do worry as well that it feels a bit more impersonal, whilst before we would be sending out invitation letters and so on. So it could still have that sort of connotation of using people a little bit.”

When it comes to recruiting young people as staff, rather than as research participants, Rachel Burns (UCL) spoke about how she frequently gets asked for work experience, and although she’d like to offer it, she feels uncomfortable about not being in a position to cover payment or even expenses for students’ time. Anna Blakney, Assistant Professor of Biomedical Engineering at the University of British Columbia raises the point that even if she had the budget to cover paying high school students to work with her, she feels like it wouldn’t be ***“the best financial decision to pay a high school student to work in your lab”*** and use of her discretionary funds. Therefore she feels that more centralised ways of involving young people in research, such as scholarships or summer programmes, are best.

What can RESEARCHERS DO?

5.1

RECRUITING PARTICIPANTS FROM MARGINALISED GROUPS CAN BE FACILITATED BY HIRING RESEARCHERS AND/OR CONSULTANTS FROM THE GROUPS YOU ARE TRYING TO ENGAGE. People are much more likely to trust someone who shares their experiences to ensure the research is respectful and relevant to their experiences. For example, Lewis* [21, Northern England] talked about how they were more inclined to apply for this research because one of the Co-Leads sharing the recruitment link is trans himself, saying *“so the person that tweeted it was transgender [...] and they asked for more gender diverse people to try and join. But if it was a study about trans people or by somebody who wasn’t trans and from the phrasing of it put me off, I wouldn’t want to join that when I wouldn’t feel safe going into that private conversation with somebody in the same way.”*

5.2

WORK WITH SCHOOLS TO RECRUIT YOUNG PEOPLE BECAUSE IT ALLOWS RESEARCHERS TO REACH LOTS OF YOUNG PEOPLE AT ONCE, BUT DON’T STOP THERE. The young people who do not attend school often belong to some of the most underrepresented groups, so consider reaching out to youth groups and other non-academic environments when recruiting, giving everyone equitable access to the projects which may reflect them. Our survey respondents also highlighted partnering with groups working on the issue being researched [28%] and using influencers and ads on social media platforms like Instagram to reach more people [70%] as effective ways to reach people. If active recruitment of these groups is overlooked, data cannot properly reflect them as we do not have insight into their needs.

5.3

WHEN POSTING ADS TO RECRUIT, CONSIDER THE LANGUAGE USED CAREFULLY, AS IT CAN PLAY A HUGE ROLE IN ATTRACTING PEOPLE OR PUTTING THEM OFF. Language that is not inclusive or is overly academic can dissuade groups who are already likely to be underrepresented from applying. Test your recruitment materials with young people to make sure your wording isn’t a barrier to participation.

5.4

USE SOCIAL MEDIA BUT SHOW YOU ARE TRUSTWORTHY. Young people are generally aware of the risks involved in social media advertisements e.g. scams, and may be sceptical of online research opportunities. Despite this, social media seems to be an effective way of reaching a wide variety of young people and advertising research projects. Potential participants begin to trust the legitimacy of the projects if you emphasise that trustworthy organisations are backing the project.



“I think reaching out to schools is the wrong way to do it. I think reaching out to youth clubs is the better way to do it because those are the people who are not attending school, who are bouncing around the foster system [...]. When I was attending youth club, there was a far greater mix of people from different backgrounds there than there was in school. [...] In school, they already have a baseline education rate, whereas the people who were showing up to youth club were sometimes the people who have been homeschooled, or the people who aren’t attending school.”

Ashleigh [21, Wales]

6. **INCLUSIVE WAYS TO TAKE PART**

When looking to involve a diverse group of participants in research projects, it's essential to not only have a plan for how to make your recruitment process inclusive, but also to make sure the research design itself can be applied to a range of participants. Accessibility needs to be considered at every step of the process and must go much deeper than just considering physical needs. This means considering non-visible conditions and implementing participant support procedures such as: hiring interpreters so D/deaf people can participate, making sure any venues are step-free, having a quiet space for people to rest and avoid overstimulation, and considering the use of font, colours, and visuals when creating materials to ensure they are understandable for people with dyslexia, to name a few.



What we heard from YOUNG PEOPLE


Accessibility should also be considered by creating a range of avenues for data collection. This could mean offering a variety of ways to participate, for example, through speaking, writing or making something visual; designing a mix of interviews, surveys, toolkits. Moreover, researchers should consider offering the opportunity to participate online (including with camera off or over typed messaging, rather than only video calling) as well as in person. In our survey, respondents were asked to select three research methods that would help them to learn from a diverse group of young people. Group workshops came out on top, with 56% selecting that method, followed by creative exercises (45%), surveys (44%) and remote video interviews (41%). One respondent elaborated on this by saying: ***“Different facets always need to be taken into consideration. Not everyone will be able to make a speech, join a workshop or make it to in-person events, so a wide range of different research techniques should be a prerequisite in any and all research projects in order to reach and get opinions from a wide range of people.”*** By having a range of options, the research better accommodates disabled people and those with other responsibilities to balance such as education, work or caring/parental responsibilities. For example, Joshua (18, Midlands) felt positively about research led by Beatfreaks he had previously taken part in, saying it was ***“not intrusive in your life.”***

When looking at the actual materials used, language is another important consideration. This means both considering how incorrect or outdated terminology can alienate marginalised groups who see that as a sign their experiences have not been considered and ensuring the language used is accessible to those with less academic exposure. Additionally, 50% of survey respondents emphasised the importance of offering anonymity to participants, so people feel able to participate without censoring themselves for fear of people they know coming across something they shared. ***“The more remote and anonymous it is, the more likely young people are to participate.”*** [Survey respondent]

In summary, for research to be inclusive, it is essential to respect the fact that people’s minds and bodies work in different ways. By working with those differences instead of against them, people will be able to bring their whole selves when they participate, allowing the data to be as complete as possible.


How this relates to Wellcome’s CHALLENGE AREAS

MENTAL
HEALTH



When it comes to involving young people in mental health research, it is essential that special consideration is given to ensuring that they feel supported and safe throughout the process. This might mean offering a variety of ways to share their thoughts, rather than expecting everyone to feel comfortable in an interview-style environment, and/or providing access to trained mental health specialists to support them through anything that might come up emotionally during - and after - the research.

CLIMATE
AND HEALTH



When we look at Climate and Health, a small number of young people mentioned exclusionary ideas about who are and aren’t perceived as holders of knowledge, and the failure to recognise different kinds of expertise when it falls outside of accepted scientific contexts. ***“We need more focus on Indigenous perspectives and frameworks on how to care for our environment. We need to centre Indigenous voices and practices in conversations about climate health.”*** Amy (22, Wales). This point was emphasised by Araceli Camargo, who pointed out that Indigenous knowledge about how to take care of the earth or people’s knowledge about how pollution affects their bodies are also sciences even when they exist outside of academia. When researching the impacts of climate change on health, it’s vital to tailor research approaches to reflect that.

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“When considering the question about how to make spaces feel safer for young people to feel comfortable sharing their views [...]here could be two options presented, either a meeting online or in person. For some, the online meeting might be more comfortable and less daunting. It might also be a more flexible option for full-time students (which most young people are). The in-person meeting might be more suitable for young people who prefer to be in direct contact with someone. However, there might be some young people who don't want to meet face to face with a researcher and don't feel comfortable expressing their views at home or don't have internet access.”

[Survey respondent]

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What we heard from RESEARCHERS

Araceli Camargo (Centric Lab) emphasised the need to tailor questions to the audience, especially if it is an area they might not be used to discussing: *“For example, if you ask somebody living in Peckham, if they are experiencing climate change, they might associate climate change with a hurricane or a huge climactic event and they might say no, but if you ask them specifically “Well actually, how do you deal with the heat?” you might get different answers.”*

It's important for participants to know that their insights are equally valuable to that of researchers, especially in relation to marginalised communities where lived experience is key.

Myles-Jay Linton (University of Bristol) also spoke about being aware of the burden that a project may place on people and about the importance of ensuring that the work done is of reciprocal benefit and that researchers are not simply acting as extractors. Kate Martin (Wellcome Trust) mentioned that when working with people with lived experiences as researchers, it is important not to treat them as another research participant and that they are there to offer guidance on the research process, not just to share their personal experience.

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“I think that’s part of getting rid of this knowledge supremacy that somehow we know better, we don’t, we really don’t. I learned this every single time I work with communities that I really don’t know. What I do know is my own skill which is data analysis, and perhaps the neuroscience biological side. [...] We all know that working with science is always better to work with in a multi-disciplinary way because it’s impossible for everybody, for all of us to have all our blind spots covered, and that’s where the community is so invaluable.”

Araceli Camargo (Centric Lab)

What can RESEARCHERS DO?

6.1

OFFER AS MANY WAYS FOR PEOPLE TO PARTICIPATE AS POSSIBLE AND RECOGNISE THAT PEOPLE’S BRAINS WORK IN DIFFERENT WAYS AND FAVOUR DIFFERENT FORMS OF COMMUNICATION.

This might mean utilising a mixture of written, spoken and visual communication. Where possible, offer ways to participate online as well as in person, as online participation is often more flexible and accessible. Without consideration of individual circumstances and requirements, researchers risk alienating marginalised groups and losing their valuable insights. Furthermore, utilising a variety of mediums can gather insights from more creative channels.

6.2

HIRE DISABLED PEOPLE AS ACCESSIBILITY CONSULTANTS SO THEY CAN PROVIDE FEEDBACK ON THE BARRIERS TO PARTICIPATION.

It's essential to hire a consultant who is well-versed in a range of disabilities (physical and otherwise) or ideally hire a range of consultants with different types of lived experience of disability (e.g. neurodivergent people, mobility aid users, D/deaf people, chronically ill people, people with experience of mental illness).



HOW
to involve
young
people in
research?

7. COMMUNICATION

Across all ages, participants found scientific research inaccessible due to how it is communicated. Young people indicated that several factors prevented them from seeking out research, including perceived elitism, barriers to understanding scientific research, education level, and access to publications and journals. They mentioned that the scientific jargon and language used can make research difficult to comprehend. This, alongside the length of articles, made them less likely to engage with scientific content.

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“You’d have no clue what it was saying if you hadn’t done the science degree, which I think is an issue that shouldn’t have been missed because the press obviously looks at the papers and takes the headlines from it and often misinterprets it.”

Emma* [23, Wales]

What we heard from YOUNG PEOPLE

A majority of participants mentioned that they would like to see an increase in researchers using social media as a tool for communicating scientific research. Most young people get their information on social media through infographics on Instagram, posts on Twitter or videos on Tiktok and Youtube. Social media - when used correctly - can present research in a more engaging and comprehensible manner. 78% of survey respondents suggested social media as the best way to reach young people. A few participants had also indicated that older professionals trying to use memes or internet language can feel condescending or inauthentic. Young people would rather be communicated with like equals and see a depth of information being shared.

When viewing social media as a communication tool for researchers, most participants were aware of the need to verify sources. There were some concerns among young people about whether social media is a trustworthy source of information. A small number of young people didn't use social media at all, citing negative experiences (particularly with regards to its impact on mental health). In contrast, others indicated they are less likely to trust information presented on social media. *"I don't really trust the research I see from social media [...] because some of the time there might be biased information, especially with fake news on social media"* (Oliver*, 19, Southern England). Platforms such as the NHS website and BBC were largely seen as trustworthy and used commonly by young people. The accessibility, reliability and reputation of these organisations was cited as the primary reasons for their popularity.




"As much as you think that you know everything when you're that young, or even up to 17 or 18, you're probably woefully under-educated in comparison with even somebody with a college degree or somebody with more specific experience. I felt like just by being on Twitter I was so knowledgeable about all these things, and then a lot of these things that I thought I knew were conspiracy theories or fringe things."

[Michael*, 24, Northern Ireland]

78%

OF SURVEY
RESPONDENTS
SUGGESTED SOCIAL
MEDIA AS THE BEST
WAY TO REACH
YOUNG PEOPLE.

How this relates to Wellcome's CHALLENGE AREAS

<div>INFECTIOUS DISEASES</div> <div></div>	<p>When looking at infectious disease, there is a desire for researchers to communicate their work on solutions more. Young people felt worn down by the stress and anxiety brought on by constant bad news surrounding the pandemic. They would like to see scientists having a more significant role in communicating how to tackle problems directly impacting the public. Some have also pointed out how the pandemic has changed scientists' relationship with the public in a positive way. <i>"Because of how open the government had to be with the statistics and the information and the science, I feel like people learnt a lot from it. And that kind of relationship with the public, I thought that was very beneficial, really eye-opening to see what people did to actually keep people healthy and keep people safe."</i> (Samantha*, 18, Wales)</p>
<div>MENTAL HEALTH</div> <div></div>	<p>In terms of mental health, engagement on social media seemed to have both negative and positive effects on young people. This is partly due to the false information which is spread online alongside the high expectations social media generates and gives people the perception of a vastly unachievable body image or lifestyle. In light of this, young people would like to access information on social media but would prefer this to be backed by credible organisations. Currently, communication around mental health tends to focus on negative mental health and conditions over positive mental health, with a minority of participants mentioning positive mental health in interviews and workshops. <i>"There's also more negativity, especially on social media because, I mean, I'll look at positives[but] there's gonna be more people who discuss that negative side. I think social media is a big part of that."</i> (Amelia*, 16, Scotland)</p> <p>However, many young people mentioned a desire for greater access to research about holistic methods of promoting wellbeing.</p>
<div>CLIMATE AND HEALTH</div> <div></div>	<p>With regards to climate change, young people especially felt that solutions were not appropriately reported in a way that emphasises the severity and need for immediate action. Some participants wanted to hear practical advice as to what young people could do to lessen their contribution to climate change. However, many also emphasised the importance of communicating to those in power, highlighting that the biggest contributors to climate change are large corporations and that individual changes have little power in comparison.</p>

What we heard from RESEARCHERS

Most of the researchers we spoke to saw the need for more effective communication of their findings. However, there was a debate about whether that was the role of researchers, or whether there should be more scientific communication roles dedicated to doing that. Infectious disease researcher Pranav Shah (University of Oxford) discussed how scientists do not always have the appropriate training or will to communicate their work. Diana Feliciano from the School of Biological Sciences, University of Aberdeen, mentioned how few researchers seem to know how to utilise social media to disseminate information. Researchers also feel that there is not enough funding or time built into their research projects to support and facilitate communication of their work.

Dr. Esther Odekunle (pharmaceutical industry) is active on social media and recognises the need for scientists to communicate their work directly. *“I think there’s really a push and a drive now to effectively communicate science. [...] We can, and should, have committed science communicators who do the work. But [...] sometimes the public wants to get information from someone that they see as directly, or somehow involved in that work.”* She also talked about how social media can grow trust in scientists by making them more approachable.

Anna Blakney (University of British Columbia), talked to us about how she was encouraged by Team Halo, a group of scientists and healthcare professionals volunteering to address COVID-19 vaccine concerns and misinformation, to start a Tik Tok channel in October 2020, to share her team’s journey of developing an RNA COVID-19 vaccine. Her channel now has around 233,000 followers, and she continues to use it to bust myths about vaccines through short and engaging

videos. *“Something I realised from being on Tik Tok is that there’s actually really a thirst for it, people are really interested in science [...]. I think most typically it’s just too dry or too boring in the way that it’s often communicated and so I think if you can make it fun, but still informative as well, it’s a really great way to get the point across. I think you can do that for any type of science.”*

However, she mentioned that she doesn’t think academics value communication through social media as they don’t realise how many people they can reach. She also did reflect on the potential barriers that might prevent other scientists from communicating their research through social media: *“You know, scientists are really busy [...]. Believe me, I still feel like I’m just wasting time when I make Tik Tok videos. It’s hard to feel like that’s actually your job. So I think that’s one of the main barriers.”*

“My most popular content hasn’t actually been something that’s traditionally science communication, but it’s really where I’ve been able to show the person behind the science, and that’s what people have gravitated towards.”

Dr. Esther Odekunle
[pharmaceutical industry]

What can RESEARCHERS DO?

7.1

USE SIMPLER LANGUAGE AND COMMUNICATE ON ACCESSIBLE PLATFORMS.

Where more complex communication is needed for dissemination to other scientists, consider creating a second form of communication aimed at the general public and/or young people specifically, using language suitable for lay audiences and engaging imagery. *“I think [when it comes to] how you’re going to implement the findings and how you’re going to communicate, you should get young people in then, because I think a lot of the time, you could have a document then for people who have scientific understanding and then a document in layman’s [sic] terms with like ‘this is what we did’ in a very child friendly way. And I think they would be surprised by how many adults would pick that document over the sciency one.”* [Ashleigh, 21, Wales].

7.2

RESEARCHERS MAY BENEFIT FROM TAKING PART IN COMMUNICATION TRAINING OPPORTUNITIES WITHIN THEIR INSTITUTION OR FROM WORKING WITH SCIENTIFIC COMMUNICATION SPECIALISTS.

This will ensure that researchers feel confident about sharing their research on social media and with the public more generally so that their findings have a wider reach. It may also help to prevent research findings from being wrongly interpreted.

7.3

WORK WITH SENSITIVITY READERS WITH LIVED EXPERIENCE FROM A RANGE OF BACKGROUNDS

to ensure that the language used in any communications or written materials is relevant, inoffensive, and not alienating any marginalised groups. This will ensure researchers better understand language connotations and how to best communicate with marginalised groups.

HOW
to involve
young
people in
research?

8. RESEARCH NEEDS TO LEAD TO IMPACT

During our interviews, young people shared that they felt that research wasn't making an impact and frequently resulted in performative rather than meaningful action. In their view, impact typically meant policy change.

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“It would be giving some sort of interview or even filling out a questionnaire and then publishing some sort of results or making some sort of change, based on what I and other people in the research said. So if they ask about how the NHS can be improved, and then they post the results somewhere and the government takes some sort of action based on the research that was conducted.”

[Daria*, 16, Southern England]

Illustrations by Emilia Schettino

What we heard from YOUNG PEOPLE

Young people felt that seeing the impact of their involvement was one of the most important things when making their participation in research feel valuable. They seemed to become disengaged with research if they felt like it was research ‘for the sake of it’. A closer working relationship with the government was cited as a way of improving the gap between research and policy change, although there was a recognition that the government must play a substantial role in creating this.

There was also a lack of understanding from many young people about how policy change is brought about and a lack of differentiation between research findings and policy action. *“I feel like there’s a gap between science research and then there are policies made that are based on it, but we don’t hear about how that happens.”* [Nur*, 23, Scotland]

A few young people did speak about the challenge of academics and researchers who will not be comfortable with this side of the work, as they went into academia for different reasons. Others were aware that researchers might be restricted by bureaucracy, lack of time and lack of skills to effectively advocate and lobby their research for policy change.


To address this, young people would like to see scientists using their knowledge and voice to play an active role in advocacy and lobbying in order to both represent the needs of underrepresented groups and challenge policymakers.

“*I feel like the government has the scientists[...] just as part of a performance so they can say ‘look we have scientists and they are doing the sciency science things’, but then they get up and they ignore it.”*

[Ashleigh, 21, Wales]


How this relates to Wellcome’s CHALLENGE AREAS

INFECTIOUS DISEASES




Many young people spoke positively about the increased visibility of infectious diseases and the status and responsibility that scientists have had during the COVID-19 pandemic. They have had a significant influence on government policy, and many mentioned individuals who have become well respected and trustworthy individuals, such as Chris Whitty. Young people also had more trust when scientists were influencing decisions, as they are considered more objective than politicians, who are perceived to be motivated by ideology rather than facts and data. *“The government has repeatedly picked and chosen which information to believe and which information to act upon based on what it already wants to do instead of going to the scientists and asking for guidance. They’re there, they have an idea, and they go to scientists looking for confirmation, and if they can’t get it, they ignore it.”* Conall [17, Southern England]. Young people would like health and science researchers to capitalise on the increased role that scientists have had and continue to exert greater influence on government policy in the future.

MENTAL HEALTH



Despite current research improving the understanding of symptoms of mental health issues, young people felt like research was not focusing enough on prevention and causation. *“To my mind, there’s nothing being done about the causes. There’s no preventative work being done saying: ‘Hey, these are the things that could stop you from getting to this really bad point!’ There’s just this kind of plastered over approach afterwards when you’re already in a mess.”* [Taylor*, 22, Midlands]

CLIMATE AND HEALTH



In relation to climate and health, young people were concerned about research achieving impact too slowly. They believed there was a clear difference in timeline, with young people wanting to see immediate impact while older generations did not have the same urgency. Young people also believed that research funding should prioritise urgent problems rather than hypothetical ideas. For example, Tanvi* [19, Southern England] perceived funding research into exploratory research like space exploration as potentially wasteful. *“Researchers looking for solutions may actually be contributing to climate change through their methods of experimentation. Right now a lot of researchers are focusing on space exploration. That’s incredibly polluting and resource-intensive. Is it the right time to be focusing on space?”*

What we heard from RESEARCHERS

Researchers highlighted that academics viewed impact in terms of articles, citations, views and shares known as an ‘impact factor.’ Anna Lawrence-Jones (Imperial College London) commented on this saying: *“From a funder perspective, you have to publish as many papers as possible and therefore you get recognised as a really senior researcher and will win more funding.”* Insecure contracts also often mean that their professional worth is judged on their output. This prevents academics from pursuing policy change.

However, there has been a push in the field to ensure that impact on people’s lives starts being accounted for. *“There’s the REF - that’s the research excellence framework which is a method to assess the quality of research in UK universities. The assessment used to be based mainly on research outputs, but now it includes case studies of real-world impact. So, if you can show that your research has had an impact on policy or something like that, then it gets counted.”* Clare Heaviside (UCL).

Some researchers felt that better transparency would help people understand why they have little time to advocate for policy change. In addition, they pointed out that when carrying out research in an emerging field, data has to be established before policy change can occur to avoid bad policies being made.

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“Transparency in the process may help to explain why there is less advocacy or why there is less impact. For example, if you knew the timeline and the budget constraints or that the fact that something hasn’t achieved impact is a political decision rather than a scientific one.”

Rachel Burns (UCL)

What can RESEARCHERS DO?

8.1

COMMUNICATE THE SOLUTIONS AND FURTHER ACTIONS THAT ARISE FROM RESEARCH. When research leads to policy changes or actions being taken, communicate this with the public so they can see how research gets translated into solutions. However, this could create an expectation that research must always lead to solutions, so it is important to also communicate the process that transforms research results into real-world solutions. By seeing more clearly how research impacts their lives, the public is more likely to want to engage more deeply with it, whether as participants or becoming researchers themselves.

8.2

WHERE REALISTIC, ENSURE THAT BUDGETS FACTOR IN TIME, MONEY AND STAFF so that researchers have the ability and resources to advocate for policy change through communication and lobbying rather than simply wishing for it.

8.3

INSTITUTIONS MAY CONSIDER HAVING PLACEMENT OPPORTUNITIES FOR PHD STUDENTS OR RESEARCHERS, WHERE THEY CAN WORK WITHIN GOVERNMENT DEPARTMENTS. This allows them to better understand how policy is developed, how to implement research findings, and how scientists can play a role in strengthening the relationship between the different themselves and policy-makers. Without this type of action, it is challenging for students and researchers to gain first-hand experience in policy development, meaning it remains more challenging to influence this, and action remains harder to achieve.

FURTHER RESEARCH

This research brought us lots of useful data about what matters to young people, how research can meet their needs better, and what barriers get in the way of researchers involving them meaningfully. This is an exciting and promising foundation that can be used to design more specific research studies and deepen some of the knowledge we have gathered here. Further research that could build on our findings could include:

- **A review into the approaches people have used in an attempt to diversify the demographics within research** (both for participants and research teams), with a view to analysing what has worked well, what hasn't, and if there were any risks to any of the approaches.
- **Delving deeper into the specifics of what marginalised groups would like to see happening in health and science fields in order to help build trust.** This could be through focus groups, interviews or other direct means of communication. Where there are examples of institutions trying to address the historical mistrust from marginalised groups towards health and science, it would also be helpful to analyse the outcomes, both positive and negative.

- **Greater analysis of the differing priorities and views of younger generations, in contrast to older generations.** We frequently heard a feeling of disconnect between the two; there was a perception that older generations simply do not understand young people. It is important to bridge that gap to provide a foundation for co-production and other synchronous ways of working together.
- **Research into the benefits of involving young people across a variety of health and science fields where this has happened and any barriers that may be experienced so that these can be accounted for.** It is important that researchers can see and understand how involving young people can improve the quality of their research and the resulting data and conclusions. This evidence might also be helpful in encouraging universities and other institutions to value the involvement of young people when it comes to what they look for in grant proposals (especially since many researchers cited lack of funding as a barrier to involving young people).
- **Exploration of alternative tools for recruiting young people who do not use social media or attend education.** This could also look at methods of trying to find effective ways of recruiting people from the most marginalised backgrounds. Often the young people who are not in school or not on social media will be from particularly marginalised backgrounds (e.g. travellers, foster children, children from low income households who don't have access to a phone and/or internet connection) and their experiences often go unheard in research (and everywhere else) because they cannot be reached within commonly accessed communications.

- **Seeking a greater understanding of the impacts of language and how language can attract and dissuade various groups from engaging.** Many participants talked about the power of language, both in regards to overly-academic language and language surrounding marginalised groups, but it would be helpful to get more information on the specifics within those two subheadings. Particularly of interest is how to strike the balance of not losing any information or coming off as patronising whilst also making sure language is accessible and understandable for those without a university education. Here, it may be helpful to employ psychologists or linguistic experts to better understand the power of language and its underpinnings. It is also important to get information directly from marginalised groups about the appropriate language to use when recruiting them, whilst also recognising that this is constantly shifting, and so this has to be an ongoing collaboration: it cannot simply be answered through one research paper.
- **Delving deeper into the most effective ways to utilise social media to disseminate health and science information.** Many of the researchers we spoke to felt they didn't know enough about how to use social media effectively for science communication and didn't feel they had the support or resources to do so, with some expressing that they weren't sure how helpful it would be. It's important for researchers and scientists to be shown what a powerful tool social media can be and how to utilise it most effectively. This may include testing different training interventions to see if they are helpful and which is most effective.
- **Further investigation into how communicating the impacts of research shifts how people engage with and perceive research.** The desire to see research having real-life impacts was something we heard from a significant number of the young people we spoke to. Additionally, it is useful to know what degree of communication is needed, how much of an impact the research needs to have to feel impactful and if there are certain kinds of impact that carry more or less weight.

When it comes to the 3 main challenge areas (mental health, climate and health, and infectious diseases), young people themselves said they would really like to see more research into:



The impacts of COVID-19 on young people specifically, with a particular focus on the disruption to education and the effects of prolonged social isolation. Young people wanted research into the impacts of this on their wellbeing and mental health (both current and future) and how it might affect their future options and outcomes.



Exploring treatment options for mental health conditions (particularly for depression, anxiety and eating disorders due to their prevalence) and looking for new approaches which aren't centred around medication. Several young people expressed frustration with how much focus was placed on defining disorders rather than treating illnesses and improving quality of life in a holistic way. Many felt the current approaches simply are not working for the majority of people, and there is a real need to be pushing for new, innovative approaches to treatment.



The impacts of the biggest companies on climate change, and what governments could be doing to counter that. Something we heard frequently was the frustration with pressure on individuals to address climate change whilst the biggest polluters are large companies who seem to be under no pressure to change and value profit over welfare. Many young people expressed a desire for pressure to be put onto these companies, with most referring to the government as the best people to do that. Thus, there is a desire for research that can be used to encourage and facilitate government involvement in curbing the impact these large companies are having on our planet and advocating for those most at risk.

NEXT STEPS

Following the end of the research, this completed report will be shared with researchers and policy makers throughout Wellcome and UNICEF and available through the Future Weavers site. This will also be made publicly available to be shared on the Wellcome Trust website where appropriate and with interested parties. The international work organised by UNICEF is ongoing at the time of writing this report. The insights from this report and others from around the world will be brought together under the Future Weavers banner to paint a global picture of the role young people can play in health and science research.

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APPENDIX 1

REFLECTIONS

In designing this qualitative study it was important that we [the project team at Wellcome, Shift and Beatfrecks] were giving voice and agency to the young people this work is representing. A rigorous recruitment process brought together our 6 young co-leads, a group of 18-24 year olds based across the UK. Each person on the team brought with them a set of experiences and objectives that have shaped our work together.

Our full team of researchers and co-leads began working together in April 2021 and from the outset worked as a team to ensure this research was asking the right questions. This approach has added a lot of depth to our work. During the research phase participants spoke of feeling at ease as they were speaking with peers and at the analysis phase we were surfacing and highlighting the insights that were important to our co-leads. It is important to note how central the experiences and identities of our team are in this work, as with any qualitative study a different team with the same set of questions may have surfaced a different set of insights.

We are including our team reflections below as we believe there is a lot to learn from the approach we took to the project and the journey we have been on as a team. Not everything was easy or straightforward and we want to share some of those moments as well.

CO-LEAD PROFILES

ELLIS

I'm a 23 year old disabled trans man and I've lived in Devon since I was 10 but I'm moving to Brighton in just a couple of weeks! I have spent the last month travelling around parts of England and Wales with my partner and filming a series of interviews with people about their hopes and dreams for a better world. I enjoy journaling, making art, cooking (especially with, and for, other people) and learning new things. But most of all I just enjoy people - talking to them, sharing ideas, having fun together, growing alongside each other. This meant I really enjoyed this project as it was a chance to work alongside other people my age and learn about them and from them, and it was also a chance to engage with a significant number of young people and hear lots of their ideas and stories, which was very exciting to me. I signed up for this project because I'm passionate about building a better future for everyone and I wanted to bring a disabled and trans perspective to the work, to ensure that these experiences that are often overlooked were considered and valued in this project.

MAX

I am studying Public Policy (MSc) with a focus on health policy, as I had been volunteering for the Buchanan Institute, a student-led think tank based in Edinburgh before the project started. Some of my hobbies include reading and writing about current affairs and long-distance running. I am originally from Bury, in Greater Manchester and have been based in Edinburgh for the last five years, for my undergraduate degree in geography and my master's. I signed up for the project as the ability to work with the Wellcome Trust would be extremely valuable, especially considering the role that they have played as clear and effective communicators of science throughout the Covid-19 pandemic. I also liked how the project was specially aimed at young people as so often young people are overlooked in decision making due to their lower political priority, through either not being old enough to vote, their demographic being smaller than older generations or being disillusioned with politics.

ZUHUR

I am based in London and I'm a final year soon to graduate student at King's College London studying International Development. I've always wanted to know how to implement change and real positive impacts. I signed up to be a Co-Lead as inclusivity is a topic that's really important for me and I have previously led and taken part in inclusivity and widening participation projects for young people. I really liked how relevant the themes that the project covered are as they have direct impacts on many people's lives. This really stood out to me as something I wanted to be part of. Conducting research and working with researchers has been an amazing experience especially because of the influence over decisions the Co-Leads and I have had. Overall I have learnt a lot through this role and look forward to taking part in more impactful research projects in the future.

AMBER

I'm a 22 year old Psychology student, originally from Nottinghamshire, currently going into my final year at the University of Leeds following a year on placement at Bradford Institute for Health Research. Since beginning university I have had an interest in research so when I saw this project, I thought it would be a great opportunity to get involved with a project that we could lead and shape ourselves. This project also had a clear focus on diversity and inclusion, particularly for groups who are historically unheard, which is something I am passionate about. As someone who is from an underrepresented group (working class, estranged), I know how frustrating it can be, particularly within the education system; research like this where we speak directly with young people is really exciting and important.

CO-LEAD REFLECTIONS

ERIN

I grew up in Australia but moved to Ireland when I was in my mid teens. I now live in Bristol on my little 20ft narrowboat Aethelswith, so when I'm not working I spend most of my free time working on her! Being an identical twin and a participant of health research from a young age, I felt I could bring a unique perspective to the team. I'm also passionate about bringing in young people from backgrounds that wouldn't necessarily have the opportunity to be involved in research and the project seemed to work towards that. Having started this project in my final year of my Civil Engineering degree, it gave me an interesting perspective to approach my own research. Now working for an engineering firm and toward my nursing qualifications, I will take what I've learnt from the discussions here into my future career.

SHAKIRA

I'm really interested in psychology -which I'll be studying at university this year - hence why I was drawn to the mental health aspect of the project. I also enjoy art and being creative so working on the visual aspect of this report was incredibly rewarding. I'm Nigerian-Welsh, born and raised in Swansea where I currently live. I hope to have a career researching social issues so the idea of interviewing young people from a range of backgrounds seemed like an exciting challenge. I liked how relevant the challenge areas were to the lives of young people today and felt like it was a project I could see making a genuine impact. Additionally the emphasis on including underrepresented voices within the team strongly appealed to me. As a young person with multiple underrepresented identities I felt like my voice would be heard and my perspectives would be taken into account.

Here we reflect on our contributions to the project, challenges and how we resolved them, alongside some insights on the overall project and what we have learnt from the data collected and about ourselves.

These reflections are also available in video. Click on the links below.



1. INVOLVEMENT IN THE PROJECT

During the planning of the research project, all the Co-Leads were involved in designing and implementing the different methodologies used to gather the data used in this report. This included the group workshops on each of the three topics, the individual interviews and the toolkits. We had all hosted these interviews and workshops collecting notes for the mid-way synthesis.

Max: All Co-Leads were involved in designing the methodology of how the research project would be carried out. Then myself and another Co-Lead researcher worked on the interview questions about the various topics.

Ellis: We looked at research methods, decided what we thought was best, then we looked at what questions we were going to use in the interviews, we designed how we were going to do group discussions. And then we were the ones running those group discussions. We were the ones leading those interviews, the ones taking the notes, the ones putting those notes together, and now we have collated all of that information and put that into this report. We have been part of every single step of the way.

Shakira: As a young Co-Lead on this research project, I've had the opportunity to be involved in each level of the decision process including the planning, the actual conducting of the interviews, and also the synthesis.

Zuhur: My role was leading the design of the group workshops. This included working out how to group the participants according to their age, background and interests in three topics. Alongside the team, I created the questions and activities for the group workshops. Alongside this, I also helped with formulating the questions for the individual interviews. Currently, I am also involved with the designing of a lo-fi game, where young people will be able to design their ideal process of how inclusion in health and science research looks to them.

Amber: So as Co-Leads we've worked on the project from beginning to end in all aspects, for example, designing the research questions, carrying out interviews and writing the final report. One of our key roles was to ensure the project was designed with young people in mind from our lived experience, based on what they might need or want to see.

2. HOW OUR PERSONAL EXPERIENCES SHAPED THE PROJECT

The Co-Lead Researchers come from a diverse range of backgrounds and we felt that it was important for this to be reflected throughout our research project. This included ensuring a diverse range of participants were recruited, alongside ensuring interview, workshops and toolkits were accessible and appropriate. Throughout the project we aimed to work as inclusively as possible, being mindful of those from a diverse background whether they've attended university, and being inclusive to all identities, disabilities and ethnicities. We are all young people ourselves, this gave us a greater insight to how participants at times felt allowing us to achieve richer discussions.

Ellis: *I've been really grateful to be a part of this research and have the chance to bring a different perspective to it, to be a young person in this field, figuring out how best to reach young people and also to be a trans and a disabled person, saying, hey, this is why you aren't reaching people like me, this is why trans people aren't participating in your research, this is why you aren't getting to disabled people because your research methods are really inaccessible. So I've been able to bring a different perspective to that project.*

And that means that we're reaching different kinds of people, and we're speaking to them in their language so they feel able to give us the best and most honest selves and give us the best information to work with. I think that's so valuable. But honesty and that trust that is built by being like, hey, I'm like you. I get it. I'm not some 40 year old White man that cannot relate to anything you're saying.

Max: *So I think being a fellow young person in this research has really helped. As I feel like it removes some of the formality that might have occurred if they're being interviewed by someone a lot older, I feel like because we can relate to a lot of the experiences that they're talking about, it really aids our questioning.*

Amber: *I think as a young person, we were able to co produce the projects with consideration of what we'd like to have seen if we were on the other side. As a group of Co-Leads we're from a range of backgrounds, so we're able to get a really diverse range of views at all stages which was really valuable. For me personally, I'm also from a working class background, meaning I had my own insights into the challenges that presents, with relation to things like money and time. I also have experience of chronic illness and caring responsibilities, so I think I was hyper aware of how these groups are simultaneously quite often left out and in need of greater support.*

Shakira: *I think being young people involved in research has really impacted how the research itself was conducted. Because we were kind of innately aware of what issues affect young people and what young people want to see prioritised. And because of that, we added additional questions on how underrepresented groups access research for example.*

Zuhur: *Being a Black Muslim woman throughout the project, I wanted to ensure that questions were inclusive. Alongside that I also avoided making any premature conclusions. I wanted to ensure that underrepresented groups can be represented in the best way possible, and feel as included as possible. My personal experience with mental health meant that I ensured asking questions in an appropriate and sensitive way. When asking participants for further detail, it was really*

important to me that I could be as emotionally sensitive as possible. I felt that my experience with COVID as a young person made sure that I could relate with young people more and have a greater understanding of what it really is like to study from home, and be a young person, and navigate our way throughout the pandemic.

Erin: *I learnt that I found a surprising amount of confidence during the interviews. Initially I was very anxious and nervous about doing them but there was lots of support and guidance from the rest of the team. I'm also still very proud of the young people we've interviewed, they've answered with maturity and sincerity. Reading through transcripts for the data, many were very articulate and I hope that this research can disprove some misconceptions arounds young people's opinions.*

3. LARGEST CHALLENGES WE FACED

The recruitment of young participants from diverse backgrounds was the largest challenge that most of us Co-Leads had indicated. Diversity in participants was important for the team. However this was challenging due to many young people not having participated in research beforehand. This contributed towards a mistrust in the project leading to greater unlikeliness to sign up. As mentioned by Ellis, the team also had limitations on recruiting those not in higher education as 5/6th of the team are attending or plan on attending university.

Zuhur: *A challenge that I came across during this research project was recruiting people from a diverse range of backgrounds. Research projects are not something that everyone is familiar with nor trusts and is typically a space dominated by those who attended higher education or are from more privileged backgrounds. Therefore, because of this unfamiliarity, it was more difficult to gather participants from underrepresented groups*

Erin: *I found working together, around our own different time schedules, personal workloads and working preferences difficult.*

Max: *One challenge that we've come across retrospectively is in recruitment, and some young people have said that they're almost distrustful of the advertisement on Facebook as the remuneration for the project almost seem too good to be true. And young people almost aren't used to getting paid that well for their time. Alongside other problems, like on Facebook, there can be lots of fake ads or different scams going around and people might have lumped this advertisement into that sort of group.*

Shakira: I think a lot of issues sort of arise when trying to involve young people in research, especially those of disadvantaged groups. Because rarely ever, do you see young people involved directly in the research process. We're usually participants. And even then, there are a lot of young people who aren't given the opportunity to be involved in research. I've seen from my interviews, a lot of people want to be involved in research and will ask about more research opportunities, but they're just never ever presented to young people.

Amber: Although our aim was to be considerate and inclusive, as six people we can only represent a percentage of the needs of the groups we belong to. It would be great if this research could be replicated with people from a range of other groups included at each stage. I'd also echo what Ellis said in terms of us trying not to buy into the issues we're trying to solve. One of the things that came up a lot in interviews was the way in which science is communicated and how this can be confusing. At university, you're taught to write in a certain sort of way which probably follows this theme so this was something I had to try and unlearn to make my writing more accessible and engaging.

Ellis: I think the challenge that I've been very aware of throughout the whole project has been that even as we're looking to solve these issues, we are replicating the very same issues of underrepresentation in our own team and in our own research. And it's a real reminder of how difficult these things can be to tackle and how overlooked a lot of things are. For example, we're specifically looking to target people that haven't been to uni and aren't going to uni. And yet, in our team of six, I am the only person that meets that criteria.

4. MITIGATING THE CHALLENGES

The team had also indicated potential solutions to mitigate these challenges.

Zuhur: I also believe that it's important to empower young people that are leading projects and are part of research projects, ensuring that the young person feels confident in their abilities. I think that will strengthen the results of the overall project. This will mean not having a sense of hierarchy and that they truly feel like they have agency over the project, which I think that the team here at Future Weavers has done a great job at.

Max: In terms of the advertisement, I think a way to remove the mistrust from this is just to ensure that the advertisement looks professional, to sort of stand out from the other ads that may be scams on Facebook. As well as just to be clear that this is being funded by the Wellcome Trust and hopefully, by focusing on that that's a name which I think most people will have heard of throughout the pandemic and know that they can trust and therefore they can trust this project.

Shakira: I think one aspect of our research project that would be really well integrated into other research projects is using the young Co-Leads on the project to actually recruit the young people that are participants in the research. I say this because of access. I think young people are a lot more likely to trust people that are in their circles. And so for me, recruiting participants from Wales was quite easy.

Ellis: I think the most important thing in addressing these challenges is just a willingness to keep being creative, to keep experimenting, to keep learning and trying different things and trying new ways to reach people. Being willing to go out of the accepted norm of what we do in research, looking for new solutions to these problems, and also paying people. If you can't reach a specific group, if they're not coming to your research, you've got to be willing to pay someone who is a part of that group to tell you how to reach those people...People trust people that are part of that community that share their experiences, who can speak their language. So if you get them involved, they will involve their communities. And that is how you reach those people.

ADVICE FOR YOUNG PEOPLE PARTICIPATING OR CONDUCTING RESEARCH

Zuhur: Don't be afraid to suggest new ideas and challenge existing ones! I think it's really important to contribute as much as you can and not doubt your abilities no matter your experiences.

Amber: I think it's really important that young people feel comfortable within the research community. Coming from a background where this sort of participation isn't common, I feel imposter syndrome all the time. I'd say just go for it and get involved if you want to. Your opinion is just as important as that of anyone else and if you don't know something, don't be afraid to ask questions. Researchers spend their whole careers on these subjects and a lot of the time they'll be more than happy to go over something with you!

Shakira: When presented with research opportunities, share them with any interested peers in whichever way you're able. Young people were generally seen to be more trusting of research opportunities that their peers suggested/supported.

Max: My advice would be to be as honest and open as possible during the process and not to try to answer in a way that you think the researcher wants.

Ellis: Don't be afraid of being "too much"! Bring all your experiences and don't feel like you have to downplay any part of yourself or your thoughts. If you have constructive criticism, share it! If you want to talk more about something, ask for space to do that! Sharing yourself and your thoughts is a gift and should be celebrated.

SHIFT & BEATFREEKS REFLECTIONS

SETTING UP A PROJECT WITH YOUNG PEOPLE

Running of the project

It was great to have one person overseeing the various strands and keeping everything moving in the right direction, as at times the project was time intensive. When running a similar project, it's important to consider timelines and the workload level of individuals working on the project .

Timeframe

Make sure that you understand your project's timeframe. Working with young people is no different to working with adult participants, in the sense that managing different schedules will always be difficult. In hindsight we would have spent longer on design tasks and asked for more time than allocated to be able to analyse all the rich data we collected. We concluded the project in five months, with two months lead-up and recruitment.

Consent

Consent procedures need to be clear regarding the targeted age group and agreed upfront with the funder, ideally before a project is commissioned. It quickly became clear that Wellcome had very set consent and data protection guidelines that we needed to adhere to, but this was not clear from the start and caused significant delay in getting the recruitment process signed off. For future projects it would be good to have a really clear conversation up front on this and set expectations based on the data that partners are permitted to collect under their data protection rules.

Collecting Consent

Consent can take a lot of time to chase, especially when parental or guardian consent is needed. Establishing a clear form and system to follow-up and collect consent is crucial. Making sure that there is a verification process for parents or guardians is key, as young people can sometimes attempt to impersonate them. We used a phone call to verify, however, this was a problem at times especially with people whose parents did not speak English. Make sure your process is inclusive depending on your target audience.

RECRUITING YOUNG PEOPLE

Recruitment

The recruitment was a lot of work but worked out really well in the end! I think going into their next project it's important to have an understanding of how difficult recruitment is and that especially when you're working with large numbers, it's always going to be difficult to get a perfect sample (equal gender splits, age splits etc.). It's always something to strive for but I think it's important to aim for 'good enough', rather than perfect.

Representation

Make sure that there are robust recruitment criteria, especially if you are considering working with a team of young people. Make sure to have clear priorities of what is the most important mix of young people for the project – is it lived experience, age, background, ethnicity or something else? Also, be flexible. We ended up recruiting six Co-Leads instead of five as we felt representation was really important to cover.

Be clear and fair

Be very clear with the expectations you have from young people. Young people are as busy as all of us, make sure to reimburse them for their time. If they are only taking part in a specific research method like an interview, vouchers would be a good way to reimburse young people for their time, however if their involvement is more substantial you might have to think about monetary payments.

WORKING WITH YOUNG PEOPLE AS CO-LEADS

Fairness and Compensation

If you want to develop a co-design process where you work with young people over time, make sure that you are able to provide a bursary to cover their time. Young people might not have the experience of working with an organisation, completing invoices, and claiming money to pay tax. It is your responsibility to support them. Make sure to close the loop and not set up them to fail in future.

Role of the researcher

When devising a co-research project with young people, your role will change from being the active researcher to being as much a facilitator. Make sure that the team has all the skills necessary and is able to let go of some of the responsibilities by delegating those to young people in supportive ways.

Trust

You need to trust that the young people you have selected to work with you will complete their tasks. Do not patronise or handhold when there is no need to do so. Maintaining a transparent and respectful attitude will pay off.

Accessibility

Make sure to allow the young people the opportunity to take part in the project. If they need extra support such as scheduling, data, travel expenses it is best to provide for those before you engage the young people.

Training up

Do not underestimate the amount of time that will be required to build a new team and to impart the key skills needed for the young people to work on the project. Some young people might have all the skills you need but more often than not they are involved because of their lived experience, therefore they might need upskilling in areas such as writing, analysis, interviewing. Make sure to provide those skills,

otherwise the project will suffer. Also make sure to create a culture where they feel comfortable to ask for help when they are overwhelmed with the task at hand.

Professionalism

A lot of young people might not have had to work in a professional environment so the etiquette that researchers take for granted will not be part of their routine. Make sure to understand this and to have patience – they are not being unprofessional by not replying to the email, this isn't their full-time job. Make sure to always have clear communication channels, set clear expectations and stay patient.

Communication

There is no over-communication when working with a person who might not be experienced in a professional environment. Make sure you contact young people you work with when necessary and make sure to always confirm any decisions and actions. Be very concise and clear, do not expect that young people will have the professional context to understand what is expected of them. Clear channels of communication helped us to be on top of the work the Co-Leads achieved.

Feedback

You might be working with young people who do not have the confidence to bring ideas up or challenge the process in a group environment, always allow several channels, ideally an anonymous one too to hear back from the young people.

BODY & SOUL REFLECTIONS

We were aware that the research might bring up some sensitive topics for the participants (especially around mental health). We also wanted to acknowledge the challenging circumstances we were doing this research in, and the impact this might have on people's mental health. Therefore, we offered the 88 participants who took part in interviews and workshops a free counselling session provided independently by the charity Body & Soul.

Hettie Chadwick Dickinson,
from Body & Soul, says:

"7 young people came forward for 1-1 support with us, these sessions lasted 45 mins, however, 10 reached out but either did not arrange a session or joined.

The themes that came up in sessions were many of the YP becoming aware of their mental health and how it has been impacting them. And with this awareness, there seemed to be a frustration in not acknowledging sooner or not perhaps being more attuned with their emotional selves, giving priority to other parts of themselves. The pandemic and the fallout from this were beginning to come into consciousness and there was the feeling of trying/needing to make sense of the past 2 years.

The loss was a common theme, loss of people, the mass loss experienced in the pandemic brought up some individual's feelings of personal losses for them. There were themes of loss of connection and loss of identity more so related to the inactivity experienced in the last year. Not knowing what to do next...

Feelings I had from the sessions, was how little mental health support there is for young people, many of them were not aware of where to access support or what it may look like. This appeared to bring up feelings of anxiety for some of them, many of them felt successful in other parts of life but struggled with mental health and this wasn't something they shared with many people or with no one.

I felt sessions gave the young people an insight into what mental health support may look like, demystify, and prejudices or ideas of support. I felt the young people really valued having a space to offload and also valued this being with a person who was unknown to them."

APPENDIX 2 RESEARCHERS WHO TOOK PART

We hosted 3 workshops to dig deeper into our findings with health and science researchers.



INFECTIOUS DISEASES

- Dr. Esther Odekunle, Antibody Engineer in the pharmaceutical industry
- Rachel Burns, Research Fellow at the Institute of Health Informatics, University College London
- Pranav Shah, who works at the Wellcome Trust Centre for Human Genetics, University of Oxford
- Anna Blakney, Assistant Professor of Biomedical Engineering at the University of British Columbia



MENTAL HEALTH

- Myles-Jay Linton, who is a psychologist and mental health researcher at the University of Bristol
- Anna Lawrence-Jones, Patient and Public Involvement and Engagement Lead at the Institute of Global Health Innovation, Imperial
- Kate Martin, Lived Experience and Public Engagement Lead at the Wellcome Trust
- Inês Pote, Research Advisor, Wellcome Trust
- Lucy Biddle, Lecturer in Medical Sociology at the University of Bristol



CLIMATE AND HEALTH

- Clare Heaviside, NERC Independent Research Fellow and Associate Professor at the UCL Institute for Environmental Design and Engineering
- Diana Feliciano from the School of Biological Sciences, University of Aberdeen
- Shakoar Hajat, Associate Professor in Epidemiology and Medical Statistics, London School of Hygiene and tropical Medicine
- Araceli Camargo, Neuroscientist, Centric Lab

