Future Forum:
COVID-19, genetics research and medical data

Exploring young people’s views with the Wellcome Centre for Human Genetics
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The partners

Wellcome Centre for Human Genetics

In the first decades of the 21st century, researchers are beginning to understand, in detail, how our genetic inheritance makes us who we are. At the Wellcome Centre for Human Genetics, our aim is to extend that understanding to gain a clearer insight into mechanisms of health and disease. Looking across all three billion letters of the human genetic code, the Centre aims to pinpoint variant spellings and discover how they increase or decrease an individual’s risk of falling ill.

With more than 400 active researchers and around 70 employed in administrative and support roles, the Centre is an international leader in genetics, genomics, and structural biology. They collaborate with research teams across the world on a number of large-scale studies in these areas.

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British Science Association

The British Science Association is a charity that wants to see science at the heart of culture and society. Through our work in education, public engagement, and collaboration with other sectors, we inspire people to get involved in all areas of science — whether it be natural, social, technological, or otherwise. We have established major campaigns and initiatives across the UK, including British Science Week, the British Science Festival, and the CREST Awards. We bring together thought leaders, opinion formers and professionals from across industry and society, including business, politics, sport, and the arts. Society’s biggest issues cannot be solved by science alone. By unlocking the potential of a more diverse group of people, we increase our ability to tackle some of the world’s most intractable challenges and shape our future for the better.

www.britishscienceassociation.org

Fusion

Fusion is an engagement and communications agency, specialising in producing impactful events and programmes. Our approach is always participant-driven, designing effective ways to engage people in the content, combined with inventive facilitation techniques. Working with the British Science Association for the second time, this has been an enjoyable and meaningful opportunity to start to engage young people in science topics that matter to them.

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Key findings

Young people believe genetics and medical data research will impact their futures.
While they are hopeful that the impact of these areas will be positive, they expressed concerns about the impact of future pandemics and climate change.

Young people want to be involved in discussions about the ethical impact of COVID-19, genetics, and medical data.
Young people feel researchers and academic institutions do not do enough to share their research. They expressed a preference to access information on websites but are open to engage in conversations about these topics via workshops and face-to-face discussions.

Young people are more personally engaged with scientific research where they can see a clear, everyday connection.
Emphasising the impact or importance of a research topic to young people’s lives makes the topic more relatable and engaging for them.

COVID-19
Young people hold the Government authorities as most responsible for managing the pandemic response but are largely dissatisfied with the way the current UK Government has handled COVID-19. Most believe that a key tactic in handling the virus is to learn from other countries and leaders. Female leaders such as the First Minister of Scotland, Nicola Sturgeon, and the Prime Minister of New Zealand, Jacinda Ardern, were praised. Young people want to hear more from scientists and the NHS about the pandemic.

Genetics research
Though not all young people are familiar with genetics research, they actively debate it once topics have been introduced, such as gene therapy and genetic testing for diseases.
In general, they do not trust research institutions and companies to use genetic research ethically. This stems from the perceived lack of transparency and openness of their work.
When considering what genetics research and usage is ethical, they acknowledge that there is no ‘right’ answer and that each situation may require its own ethical considerations.

Medical data
As with genetics research, young people feel they do not know how academic institutions and companies use medical data. They do not trust such organisations to use medical data ethically.
Young people are comfortable sharing medical data if there is a clear benefit for society. Most are comfortable with the NHS using medical data for research and with private companies using this information when there is a clear public benefit.
Introduction

The British Science Association (BSA) believes that young people should be consulted on, and invited to give, their views about research and its impact on society and their generation. Despite this, research conducted by the BSA in 2017 indicated that young people do not feel that they are able to have their say on issues affecting their future.

Future Forum 2020 was funded by the Wellcome Centre for Human Genetics, an international leader in genetics, genomics, and structural biology, investigating the genetic mechanisms of health and disease. The Forum aims to start a conversation between young people and researchers about genetic research – current and future – and its potential social impact. The workshops focused on three main areas:

- COVID-19
- Genetics research
- Medical data processing

To understand the views of young people, the BSA commissioned a survey of 1,000 14-to-18 year olds across the UK; the results of this survey informed our Future Forum 2020 workshops.

In 2019, Future Forum ran four half-day workshops in Glasgow, Gateshead, Bury St Edmunds and London on the four Industrial Strategy Grand Challenges. For 2020, Future Forum ran two online workshops due to COVID-19 restrictions. This strategy provided the opportunity to bring together young people from across the country in a way that was not previously possible.

On 27 October and 3 November 2020, a group of 14 young people from across the UK took part in Future Forum 2020. The demographic of this group, who ranged from ages 14 to 18, largely reflected the diversity of the UK. Of the 14 participants, four came from Mixed and/or Black and Asian minority ethnic communities. There was an even split of young people who identified as male and female, and three participants identified as having disabilities or special education needs. All participants came from a mix of rural, urban, and suburban localities.

The first workshop introduced the three topics and our expert speakers from the Wellcome Centre for Human Genetics to the young people. It included moments for learning and interactive activities to start the participants’ conversation and opinion-sharing. The second workshop reflected on the first workshop before looking towards the future: what the young people’s future research priorities are and how these could potentially impact them.

Participants engaged in this topic through interactive activities and view-capture technology. They were recruited by a recruitment agency and paid an incentive to attend these sessions.

Expert contributors from the Wellcome Centre for Human Genetics

Melanie Dunstan
Melanie studies immunology as a post-doctoral researcher. Her current work focuses on the T cells of children with autoimmune diseases. She is based at the Kennedy Institute of Rheumatology (NDORMS) and Nuffield Department of Clinical Medicine.

Magda Marečková
Magda is a DPhil candidate identifying the cells of the endometrium for her research on endometriosis, a debilitating but common disease that affects 10% of people with a uterus. She is based at the Nuffield Department of Women’s and Reproductive Health.

Adam Keen
Adam is a postdoctoral researcher working on the effects of mechanical forces, like blood flow, on the cardiovascular system. His research has implications for the development of new treatments for numerous cardiovascular diseases. He is based at the Radcliffe Department of Medicine.

For more information on the Future Forum programme and youth voice work at the BSA, please get in touch with the BSA team at info@britishscienceassociation.org

I want a future where young people are more involved in research.

Workshop participant
Introduction

COVID-19 is a viral disease which has spread rapidly around the world. By the beginning of March 2020, the World Health Organisation had characterised it as a pandemic. At the time of writing, the virus has claimed over a million lives and has infected as many as 40 million people around the world. Businesses, health services and political systems have been severely impacted by the virus. This global pandemic has demanded that individuals, organisations, and states adapt to unprecedented societal changes.

Like many research institutions, the Wellcome Centre for Human Genetics has pivoted to COVID-related research. The virus has impacted almost every aspect of young people’s lives and has highlighted the complex role of science in their daily activities. A whole host of possibilities, both daunting and exciting, have been imagined for a post-COVID future.
Survey insights

An overwhelming 80% of young people polled in the UK say COVID-19 affected their lives six months ago, and continues to do so now, but just over half (55%) believe they know something about COVID-19.

Young people hold the Government (40%) as the most responsible entity for handling the COVID-19 health crisis, followed by scientists (18%), the NHS (14%), and individuals (11%). Over half of young people think the virus will have a significant impact on society for one or two years.

This was reflected in the issues young people think will affect them in the future; seven out of ten believe future pandemics (69%) and climate change (71%) will have an impact. In comparison, fewer thought gene editing in plants and animals (47%) or genetic disease (54%) would have an impact on them in the future.

Workshop report

The national survey highlighted that COVID-19 remains a significant issue for young people. Following a discussion about the origins of COVID-19 and how it has spread, presented by the Wellcome Centre for Human Genetics’ researcher Adam Keen, participants were invited to give their opinions on how the virus has been handled by the UK Government and scientific community. This prepared them for the second workshop, where they reflected on learnings from the current handling of COVID-19 to open a dialogue on how to better prepare for future global pandemics.

Dissatisfaction at UK Government COVID-19 regulations

In the first workshop, held before the second lockdown in England, participants had the chance to “be” Prime Minister and decide on a course of action in the face of a third spike. The activity received a lively response and it encouraged participants to think about the past, present and potential future impact of COVID-19. While people agreed on the policy of wearing masks, this activity revealed a unanimous dissatisfaction with the UK Government’s general handling of the pandemic. Policies suggested by participants either directly or indirectly opposed actual Government actions, such as providing guidance over legal restrictions.

“More rules, less advice.”

Workshop participant

Learning from other countries

Participants were asked how we could better prepare for another global pandemic, and what society has learned from COVID-19. Some participants suggested learning from other countries and pointed to the success of countries led by female leaders such as the Chancellor of Germany, Angela Merkel, First Minister of Scotland, Nicola Sturgeon and Prime Minister of New Zealand, Jacinda Ardern.

Communicating COVID-19

During the workshop, participants were asked who they wanted to hear from about COVID-19. The most popular answer was the NHS (79%), followed by scientists (71%) and finally, the Government (64%). In late October 2020 – before the announcements about successful vaccines – the participants did not want to hear from pharmaceutical companies (7%) but 29% did want to hear from people on social media platforms like TikTok, Twitter and YouTube.

When asked whether scientific researchers have done enough to share information about COVID-19 and the pandemic response with young people, 64% of participants were unsure and 36% felt that researchers had not done enough.

There is a desire from young people to be involved in the conversation about COVID-19 and its impact on society. When asked how they would like to be involved in conversations, most participants preferred face-to-face discussions and workshops like Future Forum (57%), followed by speaking with MPs or other policy makers (43%).

Key takeaways

- Workshop participants reached a consensus that, while the Government should be responsible for handling the pandemic, they would like to hear more from the NHS and scientists.
- Participants want to be involved in conversations about COVID-19, but they feel not enough is being done by the scientific community to reach them and other young people with information about COVID-19.
- To engage in conversations about COVID-19 and its impact, participants prefer face-to-face discussions (57%), followed by speaking directly with MPs or other policy makers (43%).
Introduction
The Wellcome Centre for Human Genetics is at the forefront of genetics research, where recent advancements indicate positive impacts for the public. Genetics researchers are learning how to treat and even prevent debilitating genetic diseases by identifying risk factors and developing gene therapies. Current research has shown promising results for far-reaching and common diseases, such as asthma, heart disease and cancers. With the implications of this affecting their future, young people provided their opinions on the genetics research of today and what the future of such research could, or should, be.

Survey insights
Young people are aware of common genetics topics: the study of genes to prevent and treat diseases, genetic testing to diagnose diseases, gene therapy, population genetics and gene editing in plants and animals.

Respondents were asked how familiar they are with these research areas and around one in two had heard a little or a fair amount about each (ranging from 51-59%). The results were similar across age and gender.

Young people were asked about their perception on the impact that these areas of genetics will have on their future. A large majority (60-70%) of young people were hopeful overall. Concerns were quite low among young people, across gender and age, and hardly varied between topics. Respondents had a positive outlook on the impact of genetics research.
Workshop report
Participants were less familiar with genetics concepts and research areas before the workshops, but once the topics were introduced by expert contributor Mel Dustan, the young people were highly engaged in the conversation. Genetics-related scenarios which posed ethical dilemmas prompted group discussion. For instance, students discussed whether parents should have the right to genetically edit their unborn child to:

- Prevent a deadly disease (e.g. Huntington’s disease)
- Prevent a disability (e.g. blindness)
- Influence other traits (e.g. athletic ability)

Ethical dilemmas
While Future Forum aimed to capture participants’ views, these workshops showed that their opinions developed as they considered these complex topics and gained more information.

In one activity, participants considered the ethics of gene editing. They discussed whether a parent should have a child knowing that they could have a non-life-threatening genetic disease leading to blindness. Some questioned whether blindness leads to a poorer quality of life, while others thought gene editing was ethically acceptable if it improved someone’s quality of life. In the dilemmas which considered ‘improving’ the genetics of an individual, rather than preventing life-threatening or debilitating genetic diseases, the young people questioned whether parents were entitled to alter their child’s genes.

Participants were understanding of a range of arguments and recognised that there is no single ‘right’ answer – 62% of participants said they believe young people should be consulted on the ethical rules of genetics research.

"I think [genetics research] should be used [for] life-threatening diseases, because you can still live a good life if you are blind."
Workshop participant

Communicating genetics research
When asked how they would prefer to access information on current research, almost seven out of ten (69%) participants prefer to access information about the genetics research universities/academic institutions are doing through news and media.

Most prefer to be involved in a consultation of the ethical rules of genetics research via face-to-face discussions and workshops like Future Forum (46%). The second most popular option was speaking with researchers (23%), followed by surveys (15%).

The future of genetics research
During the second workshop, participants were presented with five current projects from the Centre. They were tasked with allocating funding to each of them. Young people clearly prioritised projects that had direct human relevance. Participants gave more funding to projects that treated diseases than those that investigated structural biology.

This graphic shows how the participants divided the funding:

- Developing oral insulin to prevent type 1 diabetes in infants: £27 million
- Developing treatments for an inflammatory heart condition that affects young people: £23 million
- Protecting foetal blood supply in the placenta: £11 million
- Sequencing the RNA of gut cells: £9 million
- Histone research and epigenetics: £6 million

Key takeaways
- Young people are interested in learning about and participating in conversations about genetics research. Once engaged, they had strong opinions on the ethics of the research and the implications of treatments that use it.
- Seven out of ten (69%) participants are unsure whether they trust research institutions and companies to use genetics research data ethically. The ethics of individual agency and choice featured in participants’ debates on what genetics research and work is acceptable.
- Young people believe they should be consulted on the ethical regulations of genetics research with a preference for face-to-face discussions and workshops like Future Forum (46%).
- When engaging in conversation about future genetics research priorities, participants support funding for research that impacts people directly, such as type 1 diabetes treatments.
Medical data processing

Introduction

Data and genetics are inherently entwined. As data has become a ubiquitous currency for industry and economic growth, the use and harvesting of medical data has become an important societal conversation.

The future of processing medical data can pose a number of hopeful possibilities:

- Current drugs and vaccinations can be analysed to see whether they are safe and effective;
- The relationship between disease and lifestyle can be better understood;
- Population data can uncover hereditary causes of diseases;
- The long-term effects of medical treatment can be tracked.

In a year overwhelmed by COVID-19, discussing the consequences of collecting such data has never been more relevant. Young people gave their insights into how medical data should be used.
Survey insights

Most young people are not aware of how medical data gets used. More than six out of ten (61%) feel they don’t know much or anything, and the results do not differ by gender or age.

When asked how important sharing and using medical data is to the future of medicine and the health of the population, 80% of young people, across age, gender, and ethnicity, think it is important. However, one in four respondents (24%) say they are pretty worried or deeply worried about security breaches or data exploitation.

Young people trust the NHS to process their medical data the most (70%). There was a significant drop in the trust of universities/academic institutions (31%), the Government (23%) and pharmaceutical companies (18%).

Data for a good cause

It was generally believed, amongst the group of young people, that using medical data was acceptable if there was a clear benefit to the public by both the NHS and private companies.

Engagement with young people

All participants thought young people should be consulted by the research community on the ethics of how medical data is used. Most preferred face-to-face discussions and workshops like Future Forum (85%), followed by speaking with researchers (54%) and surveys (45%).

If the intentions are good, and it’s helping people, then [medical data] should be used.

Workshop participant

Workshop report

Medical data was introduced through the lens of genetics research by expert contributor Magda Marečková. Similar to the conversations on genetics overall, ethics quickly became a key concern. However, the young people were more aligned in their opinions of how medical data should be used.

Distrust towards institutions

Concerns over medical data exploitation seen in the survey were reflected in the workshop. In total, 77% of participants were either unsure or did not trust research institutions and companies with their medical data. Participants associated private companies with using data for profit, rather than for the good of society.

While all participants prefer to access information about medical data on NHS/Government websites, 92% still think the Government is not open enough about how this data can be used. This distrust may be exacerbated by COVID-19 as the Government was frequently criticised in both workshops.

Key takeaways

- Young people do not trust the transparency of the Government’s regulations on how medical data is used (92%). That is reflected in 77% of participants expressing that they do not trust private companies or research institutions with their data.
- When there is a clear benefit for society, young people believe it is acceptable for private companies and research institutions to use medical data.
- Young people believe they should be consulted on the ethics of how medical data is used with a preference for face-to-face discussions and workshops like Future Forum (85%).
Recommendations

Future Forum is an opportunity to share research with young people, but also reflect on what young people think, what they most enjoy discussing, and understand the research and topics they would like to engage with in the future.

Through this process, the BSA has highlighted the following recommendations for future engagement projects on genetics research and tangential areas, such as medical data and COVID-19.

Connect with real-life implications
Participants were most engaged when discussing genetics in the context of everyday examples. Emphasising this connection may improve young people’s interest and participation with research.

Let young people lead engagement
In the first workshop, topics were introduced and participants were encouraged to grapple with complex ideas. In our second workshop, participants discussed the ethical challenges around genetics and medical data amongst themselves. The young people were keen to participate and, in fact, had much to say about these issues.

Encourage young people’s opinions
Young people want to be involved in current research and shaping future priorities. Ethical implications were of particular interest in the workshops.

Use active participation
The participants clearly preferred workshops that involved active participation to engage with research. While this was a group who were recruited, which may mean they have an existing interest in research, the national survey suggests this is a popular option for many. Those who responded preferred to engage via ‘surveys’ (37%), followed next by the two methods used in Future Forum: ‘speaking with researchers’ (25%) and ‘face-to-face discussions with other young people’ (24%).

Recontextualise engagement
In both the survey and workshop, schools were among the least popular places of engagement - they are embedded with (often negative) preconceived notions of science. Bringing engagement outside of school provides new opportunities for young people with low science capital or who do not identify with science.
Expert contributor reflections

Adam Keen

“Future Forum 2020 was a great experience to discuss current science with young adults. It was refreshing and encouraging to see and hear the enthusiasm for scientific discussion from this group and highlights the need to make findings from recent research available and accessible to those studying for their GCSEs and A-levels. It was interesting to hear their frustration at the lack of accessibility to scientific research and the desire for greater information, which would surely nurture their interest. The workshops were fun despite needing to be virtual due to COVID, however, I expect that future ‘in-person’ events would be even better.”

Melanie Dunstan

“Waiting in the online lobby, I felt rather uncomfortable. I can remember being a teenager, and how critical and dismissive teenagers can be. This, along with a bit of imposter syndrome was making me feel rather jittery and anxious. I’m happy to say that these feelings evaporated very quickly once the event had started. The teenagers were friendly, genuinely interested and readily participated in open and frank discussions. Views which did not necessarily reflect their own were cheerfully tolerated (this is often not the case with professional scientists!). I really enjoyed the event and left with a renewed enthusiasm and optimism for science.”

Magda Marečková

“This was the first time I took part in an event of such format, be it the Future Forum workshops or a workshop held virtually. I was really impressed by how smoothly it went, and the way young people engaged in the workshops. Having the facilitator and the whole BSA team running the workshops was very helpful. It meant we scientists could focus on what we wanted to talk about with the young people. It was great to see a diverse group of young people engage with science, share their opinions and ask interesting questions.”