

# The Genomics Conversation – An Overview

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# AN INTRODUCTION TO THE GENOMICS CONVERSATION

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Genomics England was set up to deliver the 100,000 Genomes Project. The four main aims of this flagship whole genome sequencing project are:

- to create an ethical and transparent programme based on consent;
- to bring benefit to patients and set up a genomic medicine service for the NHS;
- enable new scientific discovery and medical insights;
- to kick start the development of a UK genomics industry.

Genomics is a new medical science and has a number of potential ethical implications. Earning and retaining the trust of patients, project participants and the wider public is essential to effective delivery of the Project's aims. This was acknowledged in the 'Strategy for UK Life Sciences' (2012)<sup>1</sup> which preceded the 100,000 Genomes Project:

*"...we will implement a public communication and engagement plan which addresses the aspirations and concerns of the public. We will begin a dialogue with patients and partners to establish the correct approach within the NHS to capitalise on the creation of a health care system able to generate and use large amounts of genetic data to improve the health of patients."*

The purpose of the Genomics Conversation 2016 was to begin a dialogue with the general public and relevant stakeholders to raise awareness of issues relevant to the 100,000 Genomes Project. We also wanted to better understand potential barriers to embedding genomics into mainstream healthcare today.

The aim is to use the findings from the conversation to inform further engagement and communications work by Genomics England and its partners. In addition, insight from the conversation will feed into a broader discussion within wider communities and organisations involved in engagement work on genomics that go beyond Genomics England and the life of the 100,000 Genomes Project.

The Genomics Conversation activities are separate to, but ran in parallel with the development of the UK Chief Medical Officer's Annual Report on Genomics, due for publication in 2017.

## What is the Genomics Conversation?

With the help and support of a number of different organisations the Genomics Conversation used a broad mix of communications activities, which included debates, presentations, media outreach, social media engagement, websites and video content. Its main aims were to:

- stimulate the debate about genomic medicine;
- engage as many relevant audiences as possible, as efficiently as possible;
- discover the issues that are meaningful to different audiences;

- measure outcomes to feed into future communications.

The purpose and scope of the conversation has been guided by the following principles:

- **Timing:** genomics is a relatively new science and predicting all future potential benefits and issues is not possible. For this reason the conversation has not been designed to be a time-limited, standalone programme: rather it is the start of an ongoing engagement which will evolve and change over time. Consequently, this document is an overview of where the conversation is today, rather than an evaluation of a completed project.
- **Current understanding:** ‘genetics’ is a term that is now widely understood – for example, it has been included in the GCSE curriculum since the 1980s. By contrast, ‘genomics’ was only included in the curriculum for the first time in 2015. For meaningful dialogue to take place, we first need to understand where the public are in terms of familiarity with the concepts, terminology and language of genomics. In a Wellcome Trust Monitor survey<sup>2</sup> in May 2013, only 12 per cent of the public said they had a good understanding of what a genome is. As part of the conversation, we undertook to explore this in more detail through the ‘Socialising the Genome’ Project and build on it throughout the Genomics Conversation.
- **Feedback:** a key principle of the conversation has been to ensure that insights and learning are continually fed into new engagement activities to make sure they continue to be relevant.

## Audiences and partners

The Genomics Conversation set out to reach:

- patients, their families and the wider public; and
- more specialist audiences such as **parliamentarians** and **healthcare professionals**, who have responsibility for creating the environment in which genomic medicine can flourish.

This phase of the Genomics Conversation did not include other significant stakeholders, such as academia and industry, who are engaged through separate mechanisms and so were not specifically targeted.

At the start of the conversation, the cancer arm of the 100,000 Genomes Project had not reached a comparable scale to rare disease. Because of this we did not commission work relating to cancer.

Partnership is critical. No single organisation can deliver the dynamic, practical and long term programme of engagement that is required alone. The conversation has built on Genomics England’s existing engagement strategy of mobilising and acting as a catalyst for other partners working in genomics engagement.

To achieve this, Genomics England has, wherever possible, harnessed the resources, expertise and existing networks of partner organisations in this initial phase of the conversation. The Genomics Conversation was delivered largely through existing science and health networks, whilst additional activities and research was designed to engage with more specific audiences.

Genomics England has worked in partnership with:

- Genetic Alliance UK (GAUK).
- National Institute of Health Research (NIHR)
- NHS England
- The All Party Parliamentary Group on Personalised Medicine (APPGPM).
- The British Science Association (BSA).
- The Department of Health.
- The Medical Research Council (MRC).
- The PHG Foundation.
- The Science Museum.
- The Wellcome Trust Sanger Institute.
- The Wellcome Trust.
- Verge Magazine (an online publication for students).

## THE WIDER GENOMICS DEBATE

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Before detailing the various elements of the Genomics Conversation it is important to acknowledge that it is just one of many initiatives aimed at progressing the genomics debate. Genomics England has also been involved in a number of reports and discussions relevant to, but not part of, the Genomics Conversation. These complementary initiatives, running in parallel to or preceding the conversation, have helped to inform activity to date. Key examples include:

- Socialising the Genome project.
- The Wellcome Trust workshop on engaging the public in genomics, and their report on public trust in commercial access to data.
- The Caldicott Report 2016.

### Socialising the Genome

A particular concern from the outset has been that language itself presents a barrier to engagement. How can there be a meaningful 'conversation' about genomics unless there is widespread understanding of the concepts – using words in everyday use rather than scientific terms?

To explore this, Genomics England, together with the Wellcome Trust and the Wellcome Trust Sanger Institute funded the award-winning 'Socialising the Genome' initiative.\*

Socialising the Genome has explored the public's level of awareness of the concepts and language of genomics. The research was led by Dr Anna Middleton, genetic counsellor and social scientist at the Wellcome Trust Sanger Institute. Julian Borra (Global Creative Strategist, and founder of Thin Air Factory and ex Saatchi and Saatchi Group Creative Director) led on the creation of the concepts and animations using industry expertise to see if techniques from advertising campaigns would have more resonance with new audiences.

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\* The animations have been selected as finalists for the Raw Science Film Festival 2016 and The L.A. Awareness Festival 2016.

Socialising the Genome began with a series of focus groups with members of the public that explored what people already understood about DNA and genomics – and how they were talking about it.

The insights gained were given a creative makeover using skills employed in the advertising industry. Six short animated films were produced and published online. Members of the public were invited to view the films and give feedback on whether the animations helped in making DNA, genes and genomics a more ‘social’ concept – i.e. something that everyday people could relate to and which helped them start conversations with others.



Still from the #mygnome animation. Image courtesy of Genetube.org

To date, the Socialising the Genome Project has worked to widen general understanding and discussions around genomic medicine by engaging with the media, academic and clinical groups and online audiences.

Socialising the Genome, by running ahead of and alongside the Genomics Conversation, helps to Genomics England to gain a better understanding of what people understand about genomics and the ways in which they like and want to be communicated with about it.

As an example of this learning, analysis of each of the six videos on the Genetube website<sup>3</sup> has shown that #mygnome is the most successful film.

It’s quirky and light hearted approach to the complexities of genomics has resonated with audiences.

Reaction to the films is largely positive amongst the public and healthcare audience segments. A small proportion of academics had more mixed views:

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*“It is informative and helpful initiative. I like the concept and approach.” (Public respondent – UK)*

*“This is excellent. I am a co-lead of a GMC in Southampton. We will try and publicise.” (Healthcare respondent – UK)*

*“It would be really important to share this videos with all the people around the world.” (Public respondent – Argentina)*

*“The images used on this website do not give any information about the genome.” (Clinical scientist)*

*“I am a retired Professor of Biosciences, the shuffling of the pack takes place long before sex, not after it! They call it meiosis and random assortment and segregation. The very corner stone of genetics!” (Retired academic)*

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### Key learning

The public have a better understanding of genomics than they realise, whilst not necessarily being familiar with the terms and language used in genomics.

There is sometimes a mismatch between the language used by patients and the public on one hand, and health professionals and academics on the other. However both the public and professionals were supportive of the term 'glitch' when describing genetic variants.

## The Wellcome Trust workshop

The Wellcome Trust has held a workshop for a wide range of partners involved in engaging the public with genomics, and examined what genomics engagement should look like in the medium to long term. The workshop identified specific gaps in engagement activity. These included:

- the lack of a commonly understood language to describe the science;
- a need for further engagement looking at the ethical and social issues around the use, privacy and implications of personal data;
- the need for engagement tackling controversial topics such as the ethics and acceptability of genome editing of the human germ line; and
- the need for more creative forms of engagement that can reach a larger and more diverse public with genomics.

The Wellcome Trust also published their report on public trust in commercial access to data<sup>4</sup>. This found that:

- the majority of people are in favour, provided there is a clear public benefit and appropriate safeguards are in place;
- many are unaware of how patient data is already used within in the NHS, academic researchers, charities and commercial organisations;
- a small minority of people object to their data being used under any circumstances; and
- there was a suggestion that public confidence in the system would be strengthened if insurance and marketing uses of patient data were not allowed.

## Review of Data Security, Consent and Opt-Outs (The Caldicott Report 2016)

Dame Fiona Caldicott published her much anticipated review on data in June 2016.<sup>5</sup> A public consultation took place during the summer of 2016.

An **Independent Taskforce on Data**<sup>6</sup> has also been established to build on the work of the Caldicott Review, helping to develop a framework for clear and transparent discussions with the public, patients and healthcare professionals about how data can be used to improve health. It will develop innovative approaches and tools to encourage more effective dialogue and communication.

Issues about data and attitudes to data sharing have a far wider application than genomics alone. It is important that future engagement recognises this. Issues that concern the public about genomics can and do overlap with more general worries about the use and sharing of data.



## GENOMICS CONVERSATION – PUBLIC, PATIENTS AND THEIR FAMILIES

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Working closely with its network of partners, Genomics England began the Genomics Conversation with a wide range of events across England, Wales and Scotland. The main delivery partner for public conversations has been the British Science Association (BSA).

Before beginning the debate events, the BSA undertook a 'social environment' literature review which examined research on public attitudes to data sharing and genomic data. The report also explored some of the wider issues surrounding this topic, which was used to inform the subsequent regional debates and focus groups. The main findings from the desk research were:

- Many people are eager to share their data if there is a benefit to society but are less eager when profit-making companies are involved. Research by companies who profit from the sharing of genomic data is only considered acceptable if it brings about a wider social benefit.
- The type of institution handling genomic data is very important. Public institutions and academic institutions are the most trusted, followed by charities. Pharmaceutical companies and insurance companies are significantly less trusted.
- The public has concerns about privacy and confidentiality. The public is generally happy with the sharing of aggregated data but there is some concern that this could lead to discrimination on a societal level.
- There is significant debate about the best way for people to consent to take part in genomic research.
- Members of the public show a great deal of interest in finding out about their genomic data. However, they want this to be done in a context where they have access to an expert or professional, such as a genetic counsellor.

### British Science Association Future Debates

#### Purpose

The British Science Association (BSA) runs an annual series of Future Debate events, which aim to engage the public in science's role in their lives, their local economy, and the UK's future. The BSA uses its own UK network and the resources of partner organisations to ensure that these conversations reflect the thoughts and opinions of whole of the UK. Working with Genomics England, the topic focus in the summer of 2016 was genome data privacy.



**BSA 2016 Future Debates across the UK**

### Approach

The genomics-focused Future Debates included 23 events across all regions of England as well as events in Scotland and Wales. In total, 775 people attended the BSA’s Future Debates.

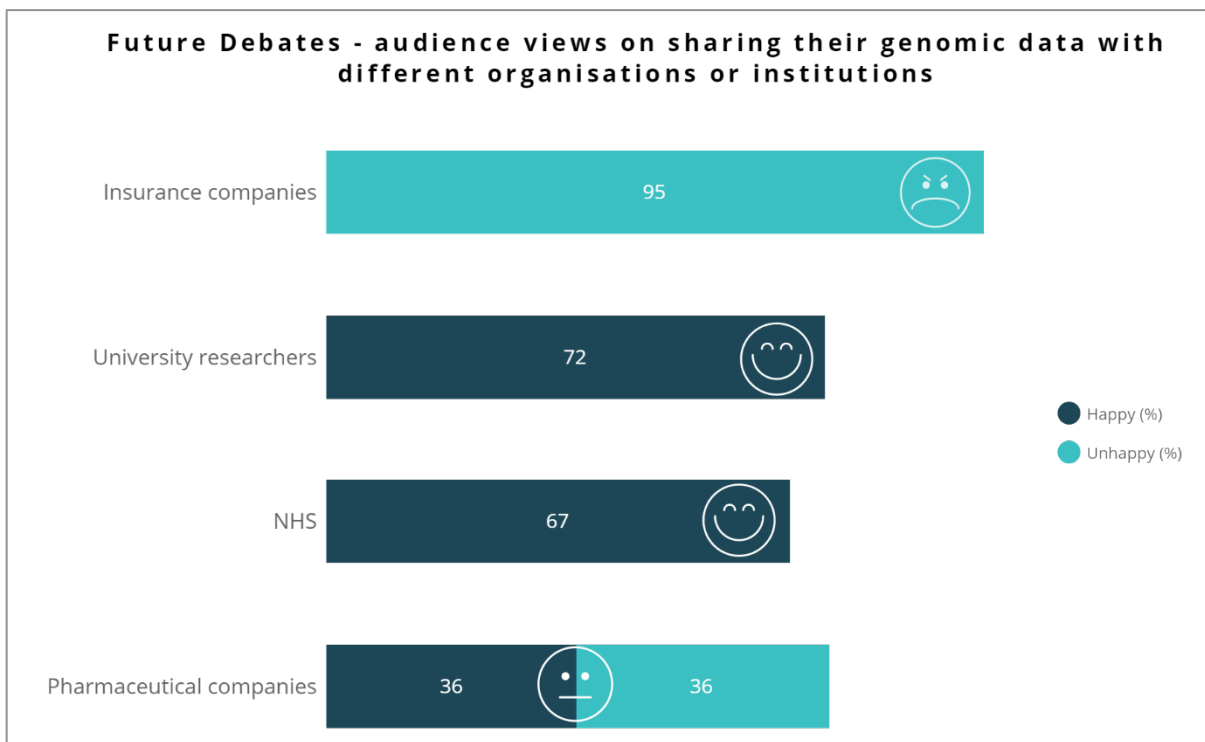
The debates followed a similar format: opening with a short animated film on genome data privacy, before moving to a panel discussion between experts and audience members. Audience members were encouraged to submit questions before the debate. A final ‘flagship’ debate was held at the Wellcome Collection in central London on 20 September 2016 – under the heading of ‘Who owns your genome?’ Speakers included: Professor Sir Mark Walport, Government Chief Scientific Adviser and Head of Government Science and

Engineering Profession; and Dr Anna Middleton, Head of Society and Ethics Research, Wellcome Genome Campus, Cambridge.

Topics raised included:

- Should everyone have their genomes sequenced at birth?
- Who should have access to genome data and how much anonymity is appropriate?
- Will genomic information affect insurance, education, healthcare and other services?

Participant use of social media platforms such as Twitter was also encouraged – helping to share the debate beyond those able to attend in person.



Following the debates, audience members were asked to rate their willingness to share their genomic data with four different types of organisation or institution – universities, the NHS, pharmaceutical companies, and insurance companies. Responses showed a range of views on data privacy and data use:

- Over 95% of respondents reported they would be **unhappy** to share genomic data with insurance companies.
- Close to three quarters (72%) would be **happy** to share data with university researchers.
- Over two thirds (66.9%) would be **happy** to share data with the NHS.
- The picture with pharmaceutical companies was more mixed, with virtually equal numbers stating they would be **happy** (36.1%) or **unhappy** (36.4%) to share their data.



**Katherine Mathieson**  
@Kath\_Math

 Follow

Great audience qu: if genetic data can save or improve lives, should there be a moral obligation to share one's genome data?  
[#futuredebates](#)

### Key learning

This data is in line with other work showing a willingness to share data by about 70%. There are two notable areas of concern:

- There was a mixed view about use by pharmaceutical companies. It differed markedly from the views of patients/participants which are much more positive.
- Access to genomic data by insurers is a red line.

## British Science Association Deliberative Dialogue

### Purpose

Whilst the Future Debates series was an effective way of engaging the public, we recognised that audiences were self-selecting and therefore likely to skew attendees towards those who have an existing interest in science and/or genomics.

As a means of accessing the views of a more general audience, Genomics England commissioned the BSA to hold an additional dialogue, which invited members of the public without a pre-existing interest in the topic. Attendees were selected by a market research company. Whilst participants were all recruited from the Greater London area, they were carefully selected to reflect the diversity of the UK population.

### Approach

Twenty six people attended the one-day event, which aimed to:

- educate participants about genetic data and help them to feel empowered to engage in meaningful conversations about the topic;
- enable and encourage interaction between members of the public and experts;
- identify and explore the issues that are important and/or controversial in the view of participants;
- understand what factors inform and underpin the views and attitudes of participants;
- record and summarise the outputs of the dialogue event in a way that enables to inform the work of Genomics England.

## Outcome

Responses generally mirrored those in the Future Debates series.

What was perceived as the positive power of genomic medicine was clearly expressed:

- “You can get so much information from a blood test! It’s really valuable.”
- “In the future you’ll be able to repair body parts – we’ll need genomes for that!”
- “More knowledge is power. Why would we turn away?”
- “It could completely change our relationship with medical problems.”

So too, however, was what was perceived as the negative power of genomic medicine, particularly in relation to the participation of private insurance and pharmaceutical companies:

- “The health equivalent of a credit rating.”
- “It’s like having a barcode on yourself.”
- “There’s a profit motive and I’m not interested in that.”
- “The issue boils down to drawing a line between what is and isn’t acceptable to do with the information, and who will have the ‘decision power to draw that line.’”

Some participants insisted on full transparency: with the need to clarify which companies would have access to the data; what partnership agreements were in place; how the project was funded; and what its research aims were. The crux of the dilemma was summarised by one participant, who stated: “It feels like it is all wobbling plates – like privacy against health.”

### Key learning

Participants seemed torn between a desire for effective applications of genomic medicine and a belief that individuals’ interests – their privacy – would eventually be sacrificed.

The risk of data breaches was perceived to be a fact of life to be faced with resignation, rather than an outrage – although some felt genomic data merited its own data legislation.

Participants repeatedly touched on the moral and ethical dimensions of genomic medicine, mostly concentrating on issues of fairness.

What participants ‘know’ about genomics may come from film, TV and sci-fi literature. This may be the reason why participants consistently overestimate current understanding of the genome.

## Patients and project participants

### Purpose

Genomics England clearly also needs to understand the views of patients and their families. To gain these opinions, it has worked with the [Genetic Alliance](#) – a UK umbrella organisation which brings together over 180 charities to help patients and their families face the issues associated with genetic conditions.

### Approach

Genomics England commissioned the Genetic Alliance to conduct two surveys to record the views of patients and their families. Surveys were sent out for four weeks in July and August 2016 to patients (with genetic, rare and undiagnosed conditions, and those with cancer) and to those who care for them.

Recipients were identified, and surveys distributed, through the Genetic Alliance's UK-wide network, including email lists and social media. 172 people responded to the first survey and 103 to the second.

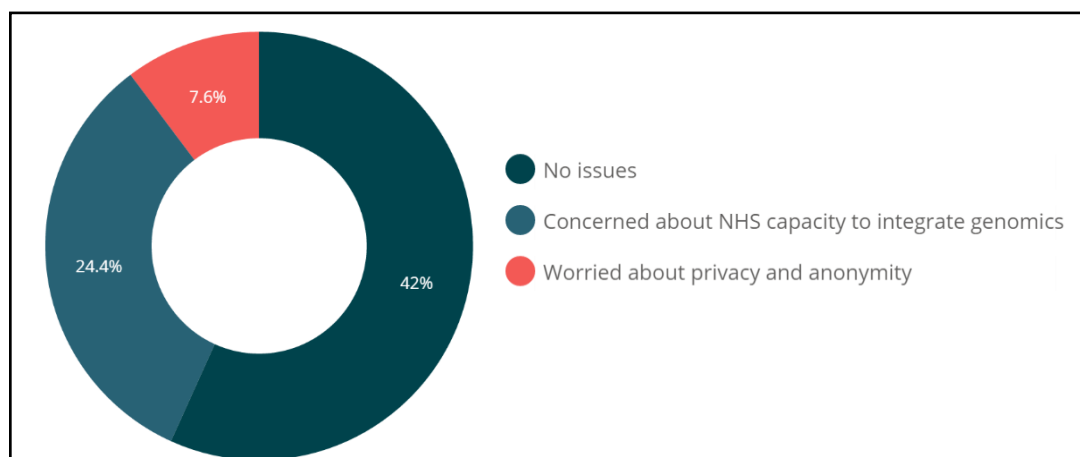
The surveys covered a range of issues relevant to genomic medicine, including:

- patient and family expectations and concerns;
- data sharing;
- regulatory frameworks;
- data use by commercial organisations;
- consent.

### Outcome

Once again, data sharing and privacy emerged as a major theme from the surveys.

The NHS is largely trusted with data – asked about potential issues over the integration of genomic medicine in the service: 42% saw none; 24.4% were concerned about NHS capacity to integrate genomics; and just 7.6% expressed worries over privacy and anonymity.



Whilst more mixed, the survey suggests that patients and their carers do have confidence in pharma to treat their data appropriately: 59% of respondents report they agree or strongly agree that they trust these companies to use their data only for the research projects they had consented to (17.9% disagree or strongly disagree).

Comments, however, still show unease about commercial involvement:

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*“Pharmaceutical companies have profit as their main aim. Unless, like the Human Genome Project data was freely available to all, I would object to my data being shared with a single pharmaceutical company”*

*“They are a money making machine. It is not in their interests to find cures for diseases or better, cheaper products with fewer side effects. I wouldn’t trust the study results they published....”*

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#### **Key Learning**

The results of these surveys show that people with rare diseases are generally very positive about sharing genetic data for research – more so than amongst members of the ‘general public’, i.e. those not affected by a rare disease or condition.

The surveys also show that there are clear areas – such as data sharing with commercial organisations and its regulation and the involvement of the insurance industry – where there are concerns that need to be addressed if patients and their carers are to fully embrace the science.

## GENOMICS CONVERSATION – PARLIAMENTARIANS

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### Purpose

Parliamentarians have a key role to play in shaping the regulatory and policy environment for the speedy adoption of genomic medicine in the NHS – and consequently are an important partner in the Genomics Conversation. They have the ability to help raise awareness of the potential health benefits of genomic medicine with their constituents, and their understanding can help to ensure that genomics remains high on the government agenda.

### Approach

On 6 July 2016 Genomics England in association with the [PHG Foundation](#) – a health policy think tank – held an event with the All Party Parliamentary Group on Personalised Medicine (APPGPM) in the Palace of Westminster. The aims of the APPGPM include:

- raising awareness of genomic medicine;
- deepening understanding of its benefits to patients and the public;
- explaining the potential of genomic medicine to transform the NHS;
- giving an overview of the economic opportunities that the UK's lead in genomic medicine offers; and
- to determine the issues relating to genomic medicine that are relevant to parliamentarians.


The event was well attended by health-focused parliamentarians from both the House of Commons and the House of Lords. Speakers at the event included representatives from organisations such as Cancer Research UK, Macmillan Cancer Support and the Wellcome Trust Sanger Institute – as well as participants from the Department for Business Innovation and Skills and Pharmaceutical Companies.

Parliamentarian attendees demonstrated a good existing understand of genomic medicine, which prompted an in-depth Q & A session on often highly specific issues. These included:


- Genomics England's relationship with other UK healthcare bodies such as NICE.
- The approach to data privacy and security.
- NHS capacity, particularly in relation to the number of pathologists needed to deliver genomic medicine in the NHS.
- Access to the 100,000 Genomes Project around the country – ensuring that patients with the greatest need could benefit from genomic medicine. This included discussions on referral processes, awareness raising and managing patient expectation.
- Partnership with industry and efforts to export genomics internationally.
- The apparent disparity between the number of biopsies taken and those entered into the UK Biobank.


- The potential to expand the remit from those with rare diseases and cancer to other healthcare priorities such as mental health.




 **NHSA**  
@The\_NHSA

Discussing @GenomicsEngland at @personmedAPPG HoL today with @sangerinstitute @bmj\_latest @PHGFoundation #genomics #datasaveslives

 3 MONTHS AGO

 **PersonMed APPG**  
@personmedAPPG

100,000 Genomes Project offers hope to all participating families - for themselves, and for others in the future #personalisedmedicine

 3 MONTHS AGO

### Key Learning

The engagement with parliamentarians and other key stakeholders revealed that:

- there is strong support amongst parliamentarians for the project and its aims;
- parliamentarians are keen to do what they can to ensure that regulation and oversight is 'joined up' and the relevant organisations with responsibility for this are talking to each other;
- they share the same concerns about data sharing and privacy as the public;
- they are keen to ensure the NHS takes the right steps to ensure an equitable and efficient genomics service can be integrated into its work;
- they are also keen to hear how the project can be rolled out to other conditions and areas of healthcare such as mental health.



# GENOMICS CONVERSATION – HEALTHCARE PROFESSIONALS

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## Purpose

Genomics demands that academic research fuses with practical application, so healthcare professional of all levels and disciplines need to understand how they can translate discovery into patient benefit. This demands that they fully appreciate the potential of genomic medicine and are empowered to share these insights with the populations they serve.

## Approach

In partnership with Genomics England, the PHG Foundation held a *Conversation with Clinicians* event in July 2016, bringing together leaders from Genomics England and NHS England with senior clinicians who have an interest or leadership role for genetic medicine within their specialty. Also joining the discussion were practitioners with more generalist interests within a specialty, and others with an interest in professional development including within the Royal College of General Practitioners (RCGP) and Health Education England (HEE).

## Outcome

This resulted in a detailed and specialised debate which included discussions on the opportunities open to the NHS and the actions needed to realise them. These included:

- Diagnostic and therapeutic areas.
- Near patient care and responsiveness.
- Improved patient care and outcomes.
- Reduced costs.
- Repurposing drugs.
- Applications of a multiplex technology.
- Complexity.
- Clinical applicability of genomic testing.
- Commissioning.
- Evidence of benefit.
- Budgetary issues.
- Changes to care pathways.
- Professional education and training.
- Capacity and capability of services.
- Regulatory and ethical issues.
- Public education and hype.

### Key Learning

It comes as no surprise that this group of clinicians clearly saw huge potential opportunities for the healthcare system that genomics could provide, including:

- The possibility of pre-emptive clinical testing that could, for example, inform drug choice. This, therefore, could lead to more effective prescribing and improving outcomes in areas such as dementia, asthma, depression and other common chronic conditions.
- The ability of whole genome sequencing to be used for a number of situations including predicting drug response, and the likelihood of adult onset acute or chronic conditions which could facilitate measures to mitigate the risks.

For the successful implementation of genomic medicine there are also a number of barriers that need to be removed. These include:

- Unravelling the complexity of delivering genomic medicine, which includes: understanding its clinical applicability; making arguments for cost-effectiveness with bodies such as NICE; moving and consolidating commissioning budgets; and education and training, both of the NHS workforce and the public more generally.
- The turnaround time for providing whole genome analysis, particularly in areas such as infectious disease, where timely information is important

## EXTENDING THE PUBLIC DEBATE TO OLDER AND YOUNGER AUDIENCES

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Genomics England is engaging with specific demographic segments, such as older people (over 65) and young people (18-25).

### University of the Third Age

In October Genomics England took part in a discussion event in Ormskirk in Lancashire hosted by the [University of the Third Age](#), a body which provides educational talks and visits for retired and semi-retired people. U3A audiences tend to be highly educated.

#### Key learning

Whilst it is the case that no one over the age of 65 was taught about DNA at school (it was over 15 years from the discovery of its structure in 1953 that it began to appear in school text books), these audiences tend to be fascinated by genomics and can see its potential.

Older people are a potential untapped education resource, having the time and interest to give talks to other groups like them. Their efforts could be harnessed to help spread the word by engaging them and equipping them with the knowledge and resources to do so.

### Verge Magazine

[Verge](#) is the UK's largest online student magazine. As part of the conversation, Genomics England worked with Verge to engage young people (18-25 year olds) with some of the issues around genomics. A series of articles were published online<sup>7</sup> (with a monthly reach of 800,000 hits and circulation to their 93,000 twitter followers), along with a debate about whether we are living in a 'DNAge'. Other activities included collecting vox pops from students in London and Manchester and a roundtable discussion with five students on genomics.

Through a series of vox pops we asked young people if they would be willing to donate their DNA for research. All were quick to agree, with the reservation that their anonymity was maintained i.e. once they had taken part, they would not want to be associated to the data even if findings would directly benefit them.

They also raised common questions around who would be funding the study, and aims and objectives of the research.

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*"..I suppose you can get tests yourself separate from the study if you want, so I think I would definitely want it to be secure and anonymous." **Liam***

*"If it would help someone, or help someone's life, if someone needs something that I have I'd be happy to help." **Maureen***

*"What kind of medical research is the DNA for, who is founding it, and what are the final objectives? I think I will say I am willing to donate my DNA as long as I know the objectives."  
**Carmen***

*"As long as I fully understand how you're going to use it and how safe the data is, that's probably my only problem." **Kay***

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### **Key learning**

For a generation who are more likely than any other to post intimate details of their lives online and on social media, it is perhaps surprising that many of the concerns about privacy of data and anonymity are still front of mind for young people.

Some of the students we spoke to had a public health background and so were interested in the wider health research agenda and how genomics had the potential for population-level benefits.

During the roundtable discussion, some students were insistent that 'third parties' such as the police, employers and other non-health or research related organisations, should not be allowed to access their genomic data. Others felt less strongly, and raised the point that you have to do health checks in some professions anyway, so why would genomic data be any different? A key theme was that although everyone could see the value of donating their DNA for research, they would want transparency about who would be given access to the data, and for what purposes. Students also said that a monetary reward or other reason to engage with genomics would not make them more willing to take part, highlighting the altruistic nature of this demographic.

## CONCLUSIONS AND PRIORITIES

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The first year of the Genomics Conversation has enabled Genomics England to gain a more accurate understanding of its core audiences – not least:

- current levels of genomic understanding;
- the issues that most concern them; and
- the communications approaches and channels that resonate most effectively.

This learning will be used to better inform ongoing communications and engagement.

Engagement with core groups has identified clear themes and issues arising from the 100,000 Genomes Project in particular, and with the use of genomics in healthcare more generally.

### Understanding of genomics

Understanding of what genomics can achieve tends to be based on what is ‘known’ from popular culture and, in general, vastly over estimates what is actually known or possible.

Whilst the terms may not be understood, however, the public know more than they first think and quickly grasp both ethical implications and potential benefits. There are some barriers around the use of scientific language to describe complex issues and more could be done to make future conversations with the public more accessible.

More work needs to be done with healthcare professionals and researchers to ensure that they are using the right language to engage with the public on genomics.

### Data

**Access.** The most compelling and consistent issue is about the use of individual data, and in particular who has access to it.

The use and abuse of personal data emerges as an issue for both members of the public and patients and project participants. It seems from the conversation that whereas patients are less concerned about appropriate access to their personal health information – possibly because the potential benefits are more immediately apparent – both groups share concerns about inappropriate access and use.

Whilst there is a clear majority of people who are happy for their data to be shared appropriately and used for wider societal benefit, there is considerable unease about non-NHS access to personal health data. This was relevant for pharmaceutical companies – but it is notable that all audiences saw access by insurers as unacceptable.

**Security and confidentiality.** Unease about data is perhaps understandable in the wider context of its use and sharing – given recent high profile instances of data loss. Examples include online hacking and government security breaches. This context has helped to create a mood of distrust. Taken

together, all these combine with and conflates public unease over commercial involvement in the NHS and perceptions of 'privatisation'.

Despite this, it should be noted that audiences are pragmatic about data security with an assumption that those in charge of it are doing their best to keep it safe, but that there will always be security breaches.

**Other data issues.** In line with the work undertaken by the Wellcome Trust, the distinction between individual level data and aggregate data was not universally appreciated by audiences – nor is the use of data in the NHS widely understood.

## Industry

The public's view on the role of industry is perhaps inevitably caught up in broader societal issues. These include the current debates about globalisation and an antipathy to 'big business.'

Health is widely thought to be 'beyond price' – particularly in the UK where the NHS delivers healthcare free at the point of delivery. It is not surprising, therefore, that the profit motive of businesses involved in accessing data is regarded with suspicion and even hostility.

Knowledge of industry's role in developing new drugs and treatments and how they work with public institutions and the NHS is not widely understood. More needs to be done to explain their role. The fact that doing so will not change opinion overnight should not be a reason to avoid explanation.

A consistent strand throughout the conversation has been the observation that personalised medicines will be unaffordable by the NHS because of the very high prices that people think drug companies will charge. This is of particular relevance for rare disease participants where patient numbers are low. This was reflected in the survey of rare disease patients by the Genetic Alliance. Whilst over half of respondents said that they trusted pharmaceutical companies with their data, those that didn't raised the topic of profit and commercial gain.

"I am concerned that pharmaceutical companies might be concerned with profit above responsibility to patients and researchers." There is considerable hostility to the use of genomic data by insurance companies. This is a consistent red line that was apparent with all the audiences. Use by marketing companies is also very strongly opposed.

It's clear that communications need to address these concerns more effectively.

### Industry engagement with the 100,000 Genomes Project

- Private companies are working in partnership with Genomics England to provide the tools needed to deliver efficient and cost effective routine genomics medicine. This includes cooperation through a pre-competitive consortium (GENE) involving 5,000 genomes.
- The bio-informatics and analytics industries are working to deliver interpretation tools and services needed to translate academic research into effective treatments.
- Software companies are developing the highly complex informatics systems needed to deliver on consent, data models, protocols, education and communications.

This level of cooperation is critical if genomic medicine is to integrate into day-to-day, frontline NHS care.

## Insurance

It is clear that access by the insurance industry in the assessment of personal risk is a widespread and serious concern amongst all audiences. Whilst the Association of British Insurers' Moratorium<sup>8</sup> is in place until 2019, unsurprisingly many questioned what would happen after this time.

Genomics England will work to raise awareness of the details of insurance industry participation: participation, including: the comprehensive consent form which makes clear that access to the data is strictly regulated; that the explicit refusal of access to insurers for individual level risk assessment. Genomics England will continue to work alongside and support the government's policy work in this area.

## Cancer

Now that the cancer programme is recruiting at scale we'd like to focus some of our engagement activity around the cancer community in the coming year and understanding their views and concerns.

Cancer participants differ significantly from rare disease participants. In many cases they have just received a diagnosis and may have little or no knowledge about their condition or genomics. In addition, at this point, there is little likelihood of them benefiting personally from sequencing because of the long turnaround time for results.

Genomics England needs to know whether cancer patients are more enthusiastic about data sharing – as with rare disease patients – or whether they have views more similar to those of the healthy public. Cancer patients' views on additional findings also need to be identified – with the assumption that they will differ from those with rare disease. Genomics England plans to undertake survey work in partnership with cancer charities to explore this.

Further engagement work in this area may include: a series of TED style online talks for use in social media; and formats similar to Radio 4's 'Inside the Ethics' series on the ethical dilemmas that are specific to cancer.

It is worth noting that some of the cancer patients recruited to the project are people who will have thought of themselves as healthy until very recently. This speaks to engagement with the general public, rather than with specific cancer groups, especially on a local level by GMC PPI groups, through local media.

Cancer is also primarily a disease of older people and we know that this group is very unlikely to have any understanding of genomics from their formal education. Consequently, older people are seen as a target group. Genomics England is looking at further collaboration with organisations such as the U3A, which has 1,000 groups made up of nearly 500,000 people across the UK.

Genomics England is also looking, with Health Education England, to engage specific healthcare professional groups, including by building on the engagement work with medical students wishing to specialise in genomic medicine who have already been involved with Genomics England on the project.

### **Equipping the public to talk about genomics**

There is more work to be done to ensure the public feels equipped to discuss genomic developments. There may be situations where the ways in which the public chooses to talk about genomics may not align with those in academia or the healthcare professions – and Genomics England needs to work to bridge this divide.



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