

Case Study: Genomic Medicine

Genomic medicine uses knowledge about a person's genetic information to guide and improve their healthcare. As scientific understanding of the human genome develops, more effective treatments will become available, particularly for some cancers and for rare diseases. However, genomic medicine also raises challenges regarding the use and ownership of an individual's genomic data. From July 2018 to May 2019, Genomics England, with support from Sciencewise, ran a public dialogue to explore public views on how genomic medicine should be mainstreamed into the NHS.

1. Background

After the success of the 100,000 Genomes Project, which has significantly enhanced understanding of the human genome, NHS England is establishing infrastructure to mainstream genomic medicine across the NHS. In 2016 the Chief Medical Officer for England's 2016 Annual Report, 'Generation Genome' sought to explore the potential of genomics within the health and social care system¹. The report discussed how the use of genomics in the NHS might require a re-thinking of the implicit 'social contract' which underpins the NHS Constitution. It also highlighted what would be required for genomic medicine to be ethically and socially acceptable to the UK population. This informed the public dialogue that Genomics England commissioned, to explore public attitudes towards the use of genomic medicine in the NHS.



Figure SEQ Figure * ARABIC 1 Image from Dialogue Report

The dialogue brought together 97 members of the public and thirty experts in a series of reconvened workshops in Coventry, Edinburgh, Leeds and London, to discuss their views on the use of genomic medicine in the NHS. During the dialogue workshops participants explored their aspirations and concerns for genomic medicine; set out their red lines for the use of their data; and explored the nature of a 'social contract' between the public and the NHS. The dialogue was informed by guidance from an Oversight Group made up of key stakeholders who helped design the workshops and develop materials used during them.

A key output of these discussions was that participants felt that the relationship between the NHS and the public is based on the core principles of 'reciprocity, altruism and solidarity'.² Participants did not think that these three elements underpinning the public's relationship with the NHS would necessarily change as a result of a genomic medicine service. Instead, they would intersect in new ways, leading to new expectations of all actors involved in the system. Overall participants were enthusiastic about the potential benefits of genomic medicine, on the condition that clear boundaries and rules are in place to mitigate the acknowledged risks. These include the possibility of unequal access increasing health inequalities and the misuse of data by third parties.

¹ <https://www.gov.uk/government/publications/chief-medical-officer-annual-report-2016-generation-genome>

² Ipsos MORI. 2019. A public dialogue on genomic medicine: time for a new social contract? Available from: <https://www.genomicsengland.co.uk/public-dialogue-report-published/>

2. Impact

This dialogue has come at a key stage in the policy development process and has given valuable insight into public perceptions of genomic medicine and aspirations for, and concerns over its introduction in the NHS. The three core values identified - reciprocity, altruism and solidarity - provide a framework that enables the public to benefit from the use of genomic medicine whilst mitigating any risks. To raise awareness of the dialogue and maximise its impacts, policy briefings on emerging findings were provided to key stakeholders, including the 100,000 Genomes Project participants' panel, the Association of British Insurers (ABI) and the Genomics England senior leadership team. The evaluation report cites a number of future potential impacts.



Figure 1 Image from dialogue report.

For example, when the NHS Constitution comes up for review it could enshrine the new tripartite understanding of the implied social contract. Additionally, the findings of this dialogue will feed into related genomics policy strands involving commercial stakeholders, such as the National Genomics Healthcare Strategy 2019, led by Baroness Blackwood, and the Science and Technology Committee Inquiry into Commercial Genomic Testing.

The dialogue sponsors hope that the findings will be taken forward by the Genomic Leadership Group in Scotland, and that they will help to encourage public dialogue approaches within the EU initiative to access one million human genomes by 2022. The extent of these anticipated impacts led the evaluation report to conclude "A number of evaluation interviewees told us that the final report would be a major contribution to the literature in the field and that it is set to become a key reference point for future public dialogue on this topic, helping to broaden discussion about the key issues and how to tackle them."³

The dialogue was praised by both the Chief Medical Officer and Chief Scientific Officer and "is expected to directly influence the roll out of genomic medicine in the NHS in terms of expectations of clinicians, researchers and genetic counsellors and feed into Genomics England's advice to government."⁴

Dame Sally Davies, the CMO, said: "I am delighted to see the publication of this important and timely report" and that the potential benefits of genomic medicine "are only fully achievable and sustainable in the context of well-founded public trust and confidence." This indicates a highly useful Sciencewise supported public dialogue which can continue to have policy impact going forward

3. Key statistics

Commissioning Body	Genomics England
Duration of Process	July 2018 to May 2019
Number of Participants	97 public and 30 specialist participants in Coventry, Edinburgh, Leeds and London
Financial cost of project	£174,000
Dialogue Contractor	Ipsos MORI
Evaluation Contractor	Ursus Consulting Ltd.

³ Ursus Consulting Ltd. 2019. Evaluation of a public dialogue on Genomic Medicine: Time for a new social contract? Pg13.

⁴ Ursus Consulting Ltd. 2019. Evaluation of a public dialogue on Genomic Medicine: Time for a new social contract? Pg6.