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[Event Review: A public dialogue on genomic medicine](#)

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The NHS is built around a social contract - an understanding that patients, the public, clinicians and government each have a part to play in saving lives and improving health. Where within this contract does the emerging practice of genomic medicine sit?

This question was addressed in the report '[A public dialogue on genomic medicine: time for a new social contract?](#)', commissioned by Genomics England and led by Ipsos MORI. The report detailed the findings of a public dialogue, involving 97 members of the public and 30 experts in cities across England and Scotland. At the launch of the report, at the Science Gallery London, members of the NHS, Genomics England, policymakers, patients and members of the public came to hear and discuss its findings.

The public opinion on genomic medicine was generally favourable, the report found, with a belief that it will change and add to the existing social contract. There was also seen to be a need for more 'genomic literacy' among research and clinical staff, and for assurance that research benefits will be translated to care as quickly as possible. But despite the enthusiasm for genomic medicine, a number of 'red lines' that should be crossed emerged throughout the dialogue.

Vivienne Parry, head of engagement at Genomics England, introduced the report. She described how developing the genomic industry would transform research, clinical health and the NHS. She highlighted the importance of dialogue engagement as part of Genomics England's work, and welcomed the report's in-depth research. Parry was then joined by Michael Parker, professor of bioethics at the University of Oxford, and co-author of a chapter on the social contract in the Chief Medical Officer's 2016 annual report, 'Generation Genome'.

Parry and Professor Parker began by discussing the public's lack of familiarity with the term 'social contract'. Professor Parker described the basis of social contracts as a reasonable set of expectations of what good practice looks like and what limits should be set. Although some aspects of social contracts are written, such as consent forms, other are implicit. As medicine evolves, this concept must be reconsidered and sustained with constant public involvement, he said.

Next, Parry was joined by Rebecca Middleton, vice-chair of the Genomics England National Participant Panel, representing patients and participants of the 100,000 Genomes Project. Middleton discussed the importance of having a group to help transparent communication with the public, build up trust and allow patients to be involved in the design of their care, ensuring that patient voices are heard and understood. Next, Simon Burall, programme director of Sciencewise, run by UK Research and Innovation, then spoke

on the benefits of public dialogue and its format. The crucial aspect was to ensure that the chosen participants are able to come to informed conclusions through extensive deliberation with expert scientists and policymakers, Burall said.

Sarah Castell, head of futures at Ipsos MORI, and Graham Bukowski, associate director at Ipsos MORI, then presented some of the central findings of the report. The project used real examples to lead the discussion using imaginary families and recent news stories as case studies, said Castell. It was considered vital to 'bring to life' how genomics might work in the future. Castell highlighted the fact that very few people know exactly what data companies have on us, or what it is used for, but that the participants trusted sharing their data with the NHS. One of the core findings was that the most important pillars of the social contract were seen to be reciprocity, altruism and solidarity.

But this trust should not be taken lightly. Points of concern that emerged in the discussion included concerns about how data might be used outside of the NHS, such as by insurers, as well as the rise of surveillance capitalism and genomic information being used in marketing.

Bukowski discussed the reservations that dialogue participants had about who their data was being shared with, which purpose it was being shared for, and whether there were strong safeguards in place. Although many dialogue participants showed a limited understanding of genomics, when they learned more about it, they had high expectations and an enthusiastic outlook on the future of genomic medicine.

Bukowski highlighted the importance of having some expectation management to ensure that the public did not lose trust in the idea of genomics. The advice of the report was that the core set of principles of the social contract that came out of the dialogue – altruism, reciprocity, and solidarity – should be enshrined in the NHS constitution.

Professor Dame Sally Davies, the Chief Medical Officer for England, was then invited to discuss the report. She said she was pleased by the strong positive outlook that the patients and participants had for genomic medicine. Professor Dame Sue Hill, Chief Scientific Officer for NHS England, also welcomed the report, adding that encouraging sharing of data would have positive impacts in NHS genomic medicine. Professor Hill added that contractually all laboratories and centres in the NHS genomics programme must have local awareness with high levels of patient involvement.

The floor was then opened for questions, and there was a particular interest in how misuse of data could be controlled with legal regulation. Professor Davies was concerned by the public's reliance on legislation, discussing the lack of flexibility it allows as research progresses, and pointed out that it could add to unnecessary NHS bureaucracy.

Sandy Starr of the Progress Educational Trust, which publishes BioNews, questioned the failure to distinguish between some of the technologies and ethical issues discussed in the public dialogue, including the public's concerns about genome editing in relation to genomic medicine. A stronger effort must be made to be clear and consistent, he said, so as not to perpetuate misapprehensions.

Overall, the report launch was an insightful and interesting event demonstrating the importance of public engagement and public dialogue in the future of genomic medicine. The event revealed the interest and support genomic medicine received from the public dialogue group, but only once it had been adequately explained. This demonstrates the need for more public outreach on the benefits of personalised medicine to ensure it receives maximum support.

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