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**YOUR GENOME, YOUR RESEARCH AGENDA**

30th September 2016 -

Public Engagement (<https://connectingscience.wellcomegenomecampus.org/what-we-do/public-engagement/>),

Society and Ethics Research (<https://connectingscience.wellcomegenomecampus.org/what-we-do/society-and-ethics-research/>)

## YOUR GENOME, YOUR RESEARCH AGENDA

Listening to patient experiences of sequencing

**IT'S VERY EASY FOR US TO ASSUME WE KNOW WHAT THE QUESTIONS PATIENTS HAVE WHEN THEY SIGN UP FOR A GENOMICS STUDY. BUT WHAT ARE THEIR CONCERNS? WHAT DO THEY WANT TO KNOW... OR NOT KNOW?**

At the end of September Connecting Science co-led an exciting event to listen to patient representatives and find out the answers to these questions. The workshop is part of [Genomics England Clinical Interpretation Partnership \(https://www.genomicsengland.co.uk/about-gecip/\)](https://www.genomicsengland.co.uk/about-gecip/) involving social scientists from across the UK.

Patient advocates and social science researchers came together at the Wellcome Trust in London to share their experiences of sequencing (before, during and after testing). The event gave researchers the opportunity to listen to the experiences of participants and find out what they felt would be important to them if they were involved in the [100,000 Genomes Project \(https://www.genomicsengland.co.uk/the-100000-genomes-project/\)](https://www.genomicsengland.co.uk/the-100000-genomes-project/), and, together, participants and researchers were able to identify new research questions to address the psychological, social and ethical issues of [genome sequencing \(http://www.yourgenome.org/stories/what-is-dna-sequencing\)](http://www.yourgenome.org/stories/what-is-dna-sequencing).

The event was co-organised by Anna Middleton, head of Connecting Science's Society and Ethics Research group, and other social science researchers from across the UK, and the workshop was facilitated by members of Connecting Science's Public Engagement team, who encouraged discussion and debate amongst the participants and researchers.

The event was structured enough to enable focused discussion but flexible enough to enable new issues to emerge, all the time being driven by the participants themselves, and included an Open Space session where the participants decided the questions they wanted to focus on. A 'graffiti wall' was to capture participant feedback and the research questions they wanted explored further, which was then developed into a 3m-wide graphic by illustrator Sandra Howgate, summarising the day's discussions.

The social scientists listened carefully to what was important to the participants and what they thought should be the priorities for future social research and from this gathered a collection of research questions that they felt social science should study over the next couple of years.

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Wellcome Genome Campus, Hinxton, Cambridgeshire, CB10 1RQ, UK

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