

The consent process: Researching participant understanding and recall

Wessex Patient Experience Survey – Initial Findings

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What have we achieved?

We're ensuring that members of the public – and future generations - can benefit from developments in genomic medicine in a responsible and inclusive way.

What problem does it solve?

With our patient survey we are exploring the practical, ethical, and social issues of taking part in the 100,000 Genomes Project. It is important that the 100,000 Genomes Project develops in an ethically sound way, to benefit patients and their families, whilst also protecting them from harm.

Why are we proud of this achievement?

We are the only NHS Genomic Medicine Centre (GMC) exploring participant experiences of the 100,000 Genomes Project. We have had **975³ surveys returned** so far; **67% from rare disease (RD) participants**, **31% from cancer participants**, and **2% unknown**. **44% of the RD cohort were patients with a RD**, **54% were parents of patients**, and **2% were other relatives**.

Initial Findings

Figure 1 shows participants' survey responses regarding their primary motivation for participating in the project. Free text answers illustrating motivations to take part can be found in Figure 2. Figure 3 includes quotes from in-depth interviews demonstrating views of the consent process.

Why is Wessex GMC doing so well in this area?

The health professionals that consent participants in our GMC make sure every patient gets the opportunity to express their views via the survey. We are also working closely with the Clinical Ethics and Law Southampton (CELS) unit, who have led this survey study. CELS is a multidisciplinary research group exploring ethical and legal issues in health care practice through research, innovative teaching, and public engagement.

What impact has this had on patient care?

Our research shows participants have positive experiences of the consent process and trust the health professional taking consent to act in their best interest. However, early findings also show that participants misremember, or do not remember, the details of that consent appointment. This suggests that - in genomic medicine – health professionals cannot rely on the consent process entirely for patient participation in research. We believe it is reasonable for shared decision-making to include trusting the health professional to act in the participants best interests.



News flash!

CELS have been awarded a public engagement grant to explore future parents' views on carrier screening. As the 100,000 Genome Project is offering couples carrier testing, these stakeholder views will help shape future service delivery.

Figure 1.
Number 1 motivation to take part

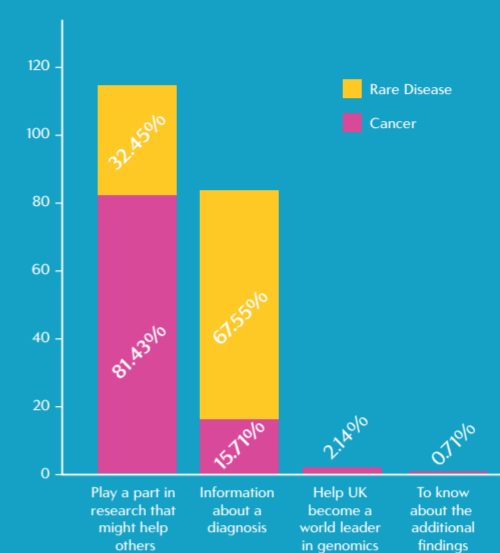


Figure 2.
Motivation - free text answers

"To find out more about my son's condition" (P01 – RD participant parent)

"Helping future patients with cancer" (P200 – cancer participant)

"To assist research for future generations" (P21 – RD participant)

Figure 3.
Views on the consent process –
Quotes from in-depth interviews

"I was really pleased to be asked to take part. I sat down with somebody who was really interested in me, and spent some time with me, and explained things to me. It was a positive part of the process. You don't get that so much with the rest of what you're going through." (P02 - cancer participant)

"I mean if I'm honest, I'd read it [PIS], I suppose I could have read it in more, it was all, I found it was quite clear to understand, and you know I mean the thing that leapt out at me was that I can stop this at any time, and I think that's all you need to know really, as far as I'm concerned." (P03 – RD participant)

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