



100,000 Genomes Project Participant Feedback Report



The project team are continuously working to improve the experience of patients participating in the 100,000 Genomes Project. We asked over 150 Cancer and Rare Diseases participants over the last three months to complete a patient participation survey. The survey was broken down into three parts asking about their experience before, during and after they had been recruited to the project. The responses have been collated to assess critical points in patient recruitment and understand each aspect of the experience from a participant perspective. We would like to thank our participants for sharing their experiences!

Prior to the consent conversation

The survey included a number of questions on how patients came across the project. The majority of respondents (91%) were introduced to the project by a consultant/nurse or by the project team. Overall, most respondents (77%) had not participated in any type of research project before. Only 16% of respondents had seen our digital screens and banners in the hospital or posters in the waiting room publicising the project. The main reasons for participating in the project, as illustrated in the below chart, were to help others and help doctors better understand and treat their condition.

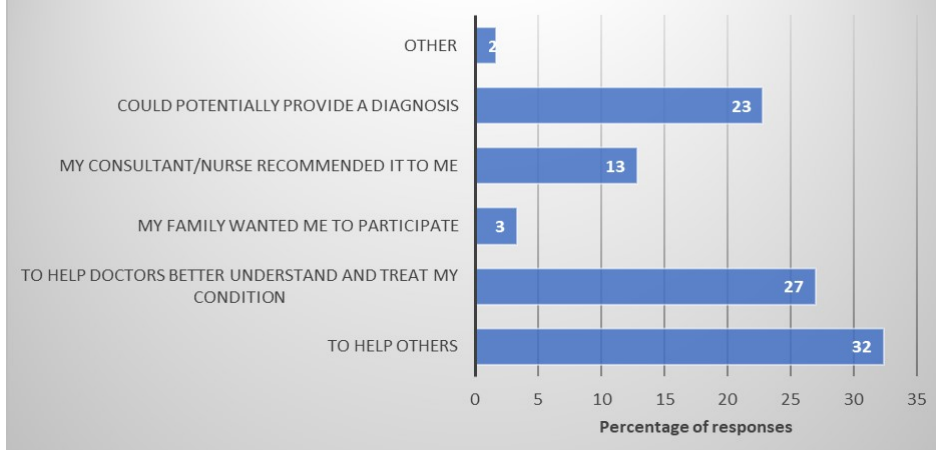
Who responded?

- 162 questionnaires returned (85% Rare Diseases and 15% Cancer participants)
- 57% Female, 43% Male
- 82% White/White British
- 68% aged between 25 to 54

"This could help with my other medical problems"

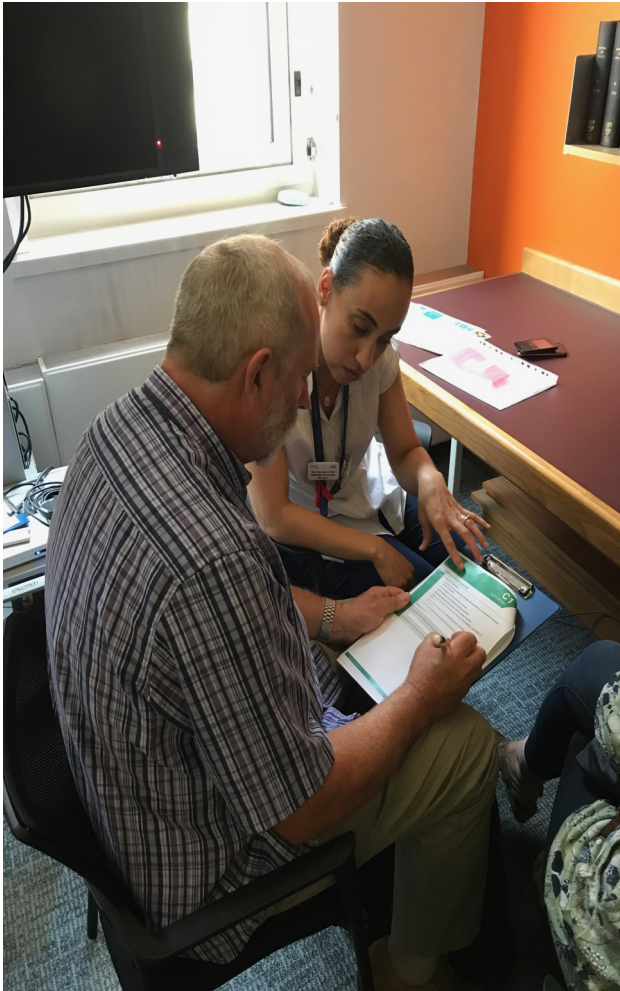
"I participated to increase medical understanding of rare diseases"

Main reasons for participating in project





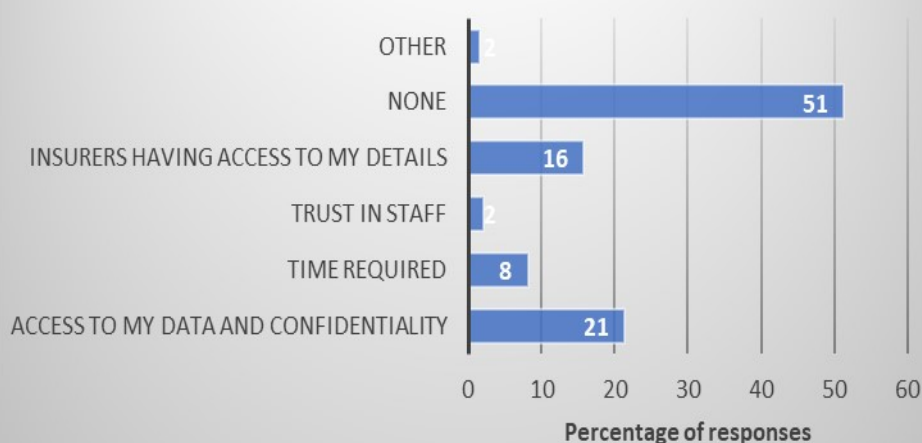
Consent conversation



The next section of the survey examined the quality of the consent conversation focusing on the team of consenters and written resources available. The results were overwhelmingly positive with 98% of respondents stating that they strongly agreed or agreed that all their queries were answered by the consenters and they were happy with the verbal explanation of the project. 96% stated they strongly agreed or agreed that the consenters were sensitive to their needs. The recent changes to the written resources have proven effective with 93% of respondents stating they strongly agreed or agreed that the patient information sheet was easy to understand and 96% stating they strongly agreed or agreed that the consent form was easy to understand.

Agreement over how easy it was to contact the project team was lower with 72% stating they strongly agreed or agreed that the project team were easy to contact. Although 51% stated they had no concerns about participating in the project prior to the consent conversation, a significant amount of respondents voiced concerns about access to their data and confidentiality.

Main concerns about participating in project



“My main concern was the impact on our child”

“I had to think a long time about additional findings”

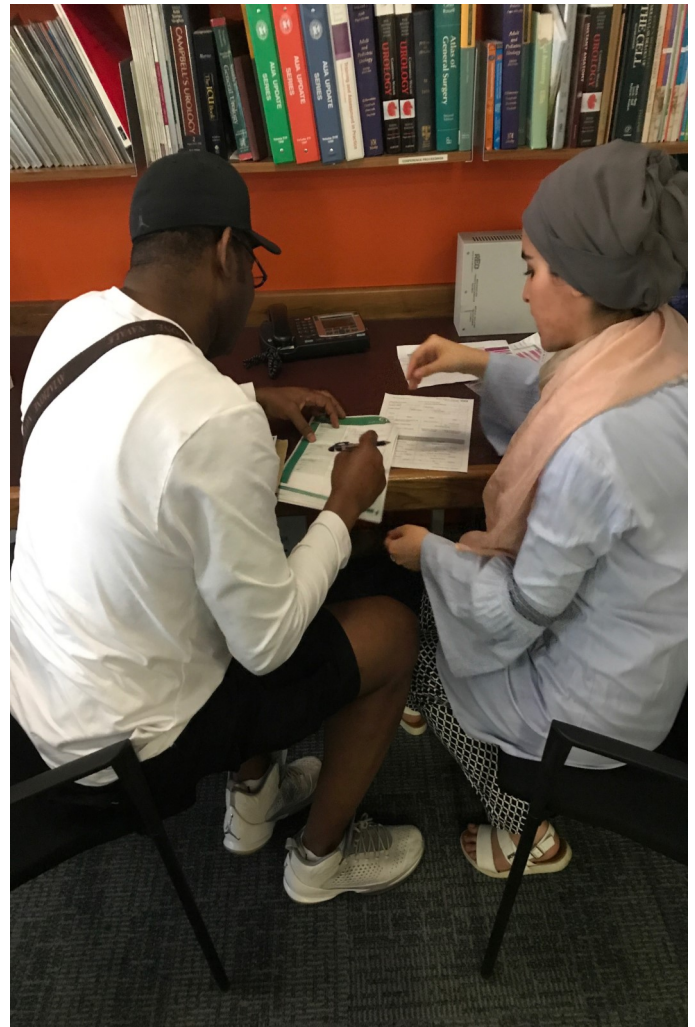


Cancer pathways

An additional section was added to the questionnaire specifically for Cancer participants. We are aware that each cancer pathway varies and make every effort to tailor recruitment accordingly. Cancer pathways are usually time sensitive and sufficient time is needed for patients to fully understand their diagnosis. We wanted to explore this further and asked participants for suggestions on the most convenient time to introduce the project.

The majority of respondents stated they were consented during pre-assessment for surgery or during an outpatient appointment. 92% felt this was an optimum time to be approached for recruitment.

One participant stated that consenting on the day of surgery can be stressful if plans change on the day. Most participants stated that the doctors and research team fully explained the project and they felt they had adequate time to think about participating in the project.



"It was good timing as I was waiting for my surgery"

"At this stage, I had already decided on my surgery options so could more easily take part in the project"





Next steps

Thank you to all our participants who took the time to answer our survey, which will help shape the service we deliver. There have already been some great suggestions that we can explore further to improve and develop our service. Reassuringly, 95% of Rare Diseases and 96% of Cancer respondents rated their overall experience of the project as excellent or good. Further suggestions and comments from the survey are outlined below.

Key areas that we aim to work on include improving our access to the service and ensuring that participants receive a timely response from the project team. Public awareness of the project both internally and externally can certainly be improved. We have recently obtained 'Ask me about the 100,000 Genomes Project' badges which have been distributed to multi-disciplinary members of staff across the Trust. This has created informal opportunities for patients to ask staff about the project, usually in the lift on their way to an appointment!

We are planning to consolidate the feedback we have received and discuss this in more detail in patient focus groups.

If you would like to get in touch with the team, please contact us on genetics100k@gstt.nhs.uk or cancer100k@gstt.nhs.uk.

