By working in partnership with participants, we aim to deliver a patient-centred recruitment process to the 100,000 Genomes Project. We recently gathered questionnaire responses from 162 participants regarding their experience of the 100,000 Genomes Project focusing on before, during and after they had been recruited to the project.

There were several emerging themes such as public awareness of the project, motivation to join the project and varying experiences of the consent process which we wanted to discuss in more depth. We invited participants to attend a focus group to gather anecdotal feedback to expand on the existing quantitative responses received, recognising that a tick box approach does not fully address participants' experiences.

The focus group took place in August, facilitated by Zoe Bright, a Patient Engagement officer based at the Trust. Professor Frances Flinter provided an update on the scope of the project prior to the focus group.

After the session took place, afternoon tea was served providing an opportunity for the participants to meet the project team. The project team was not present during the focus group to reduce response bias.

The findings detailed in this report are based on the experiences of the individuals who attended and should be considered and interpreted within this context.

Who attended?

5 RD participants, 6 Cancer participants, 2 family members/friend

91% White British

Age range from 16-74

* 2 attendees preferred not to answer demographic information
The focus group proceeded to explore emerging themes from the questionnaire responses and determine underlying drivers of opinion on key areas. Attendees were asked to write comments on their experience and their expectations of the project on our posters (pictured on the right) over the course of the afternoon.

None of the attendees had prior knowledge of the project before they were approached by a clinician/member of the project team. However, after being introduced to the project, some attendees recalled seeing posters displayed in the hospital and hearing about the project on the radio and news channels.

Attendees believed there was low general public awareness of the project. Suggestions to improve this included publicising the project in GP practices. It was thought that primary care physicians could be a valuable source of information. As plans to embed genomic medicine into routine patient pathways progresses, raising awareness and understanding of genomics is paramount in gaining public support.

Motivation for consenting to the project ranged from those wanting to support their family member to those having a general interest in helping the health service. Many were particularly interested in contributing to the lasting legacy of the project.

Concerns identified around the privacy of data collected as part of the project included pharmaceutical companies accessing data, personal information being freely available on the internet, travel and health insurance being affected and the NHS being under threat over recent cyber attacks. The biggest concern shared by all attendees centred around anonymity.

"I signed up straightaway. I have a background in science and am fascinated by clinical genetics. I was keen to give it a go. That's how progress is made".

"This could help me but also someone else".

"Felt reassured once information was given about anonymisation of data and personal details".

"Always will have concerns when it comes to research but I trust those running the project that they have the best interests".
During discussions, it was evident that the consent process experience differed significantly for Cancer and Rare Diseases participants. Rare Diseases participants felt they were given ample time to digest project information whilst Cancer patients felt more rushed. Recollection of events for Cancer patients was also blurred due to the many other decisions and questions they had with dealing with their diagnosis.

"It was all a whirlwind at the time. Between the diagnosis and pre-op, there was a limited window so I do understand but the information would have been good in advance."

"There were a million other things going on at the time. It was overwhelming. But having it all in one go was preferable."

The location of the consent conversation also differed with Rare Diseases patients being consented within Outpatient departments and Cancer participants consented in various locations from clinics to wards to pre-assessment or pre-surgery rooms. One individual stated that they had been asked to consent in a consultation room but then were given the explanation of the project in the waiting room which was suboptimal. Some Cancer participants felt that the project information was tagged onto the bottom of their pre-operation packs and stated it was not always clear who had referred them to the project. However, participants also understood that Cancer recruitment was time-sensitive and preferred the consent conversation to coincide with existing hospital consultations.
In addition to the focus group, we wanted to continue to build collaborative relationships with participants and invited attendees to become local Patient Ambassadors for the project. Participants will be asked to contribute to the planning of our upcoming patient engagement event and to join us on information stands at the hospital to promote awareness of the project. A number of attendees have signed up to become Patient Ambassadors in addition to the National Participant Panel.

The focus group elicited rich and varied responses from our participants which will be used to shape and influence the delivery of the project at Guy’s and St Thomas’ Trust and across the South London Genomic Medicine Centre. We would like to thank our participants for providing us with their invaluable time and open and honest feedback. Special thanks to Professor Frances Flinter, Zoe Bright and the project team for their contribution to the planning and delivery of the afternoon.

“Communication has been excellent to now. Continued communications regarding results would be excellent”.

“Initially a little confused about the focus group objective but was very happy to contribute to the understanding of our pathway of our participation”.

“Therapeutic - you’re not alone, you matter and can contribute”.

“A well organised day and nice to meet patients and NHS staff involved. Important process as results themselves may be a long time coming”.

“It was not too high-level for me as someone who does not understand genomics too well. Very useful”.

“This is an important part of the whole project and should continue. These are sensitive issues and the whole project should be supportive to the participants”.

“Self-selecting focus group based on people who are free. Demographics is not all encompassing. More local groups needed with different locations and times”.

“Highlights the importance of patient input and a bottom-up approach to information sharing”.

“It has the makings of a very supportive idea/group. Well done!”

Focus group attendees requested more regular support groups to meet other participants in different locations and at different times. Opportunities to attend seminars led by clinicians tailored to the public on the future direction of the project were also popular requests. From this feedback, plans are underway to organize a large patient engagement event at Guy’s Hospital in the new year for the public to find out more about Genomics and to hear from clinicians and participants from the project. Specific feedback on improving recruitment pathways as a result of the focus group have been implemented by the project team including ensuring the consent conversation takes place in an adequate and relaxed environment, timely information provision provided to participants to improve decision-making and clearly outlining the referral route to participants.

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