

Enhancing the communication of genomic results: Understanding Patient and Clinician Perspectives

Eleanor Johnston¹, Leanna Goodwin¹, Zoulikha Zair¹, Gillian Nicholls¹, Matthew G Krebs^{1,2}, Emma Darlington¹, Fiona Thistlethwaite^{1,2}, Donna Graham^{1,2}, Louise Carter^{1,2}, Natalie Cook^{1,2}

¹Experimental Cancer Medicine Team, The Christie NHS Foundation Trust, Manchester, M20 4BX; ²The University of Manchester, Oxford Road, Manchester, M13 9PL

Background

- Patients participating in early phase cancer clinical trials (EPCCTs) often have access to genomic testing (GT).
- There is significant variation across institutions in how GT results are communicated to patients and healthcare providers (HCP).
- Best practice has not been defined, and there is limited evidence on patients' preferences.
- Sub-standard practices in feedback of these results can cause distress to patients, increased confusion about what the results mean, and there could be inequalities between patients depending on the level of information they receive or understand.

Aims

- The aim was to explore the views and needs of patients and their clinicians with regards to the communication of GT results.
- The long-term goal of this project is to develop a well-defined approach for feedback of GT results that can be incorporated into standard practice for other experimental cancer medicine centres (ECMCs) across the UK.

Methods

We utilised a mixed-methods approach to explore the feedback of GT results.

Clinician survey

- A questionnaire was developed and distributed to 60 EPCCT clinicians to understand processes when informing patients of GT results.
- Clinicians were also presented with seven statements related to barriers to feedback and asked to rate on a 5-point Likert scale.

Focus groups

- Opinions regarding patient/relatives/carer experiences with GT were examined through focus groups, using a range of audio-visual methods.
- Attendees reviewed a generic GT report and clinician feedback letter and provided feedback.

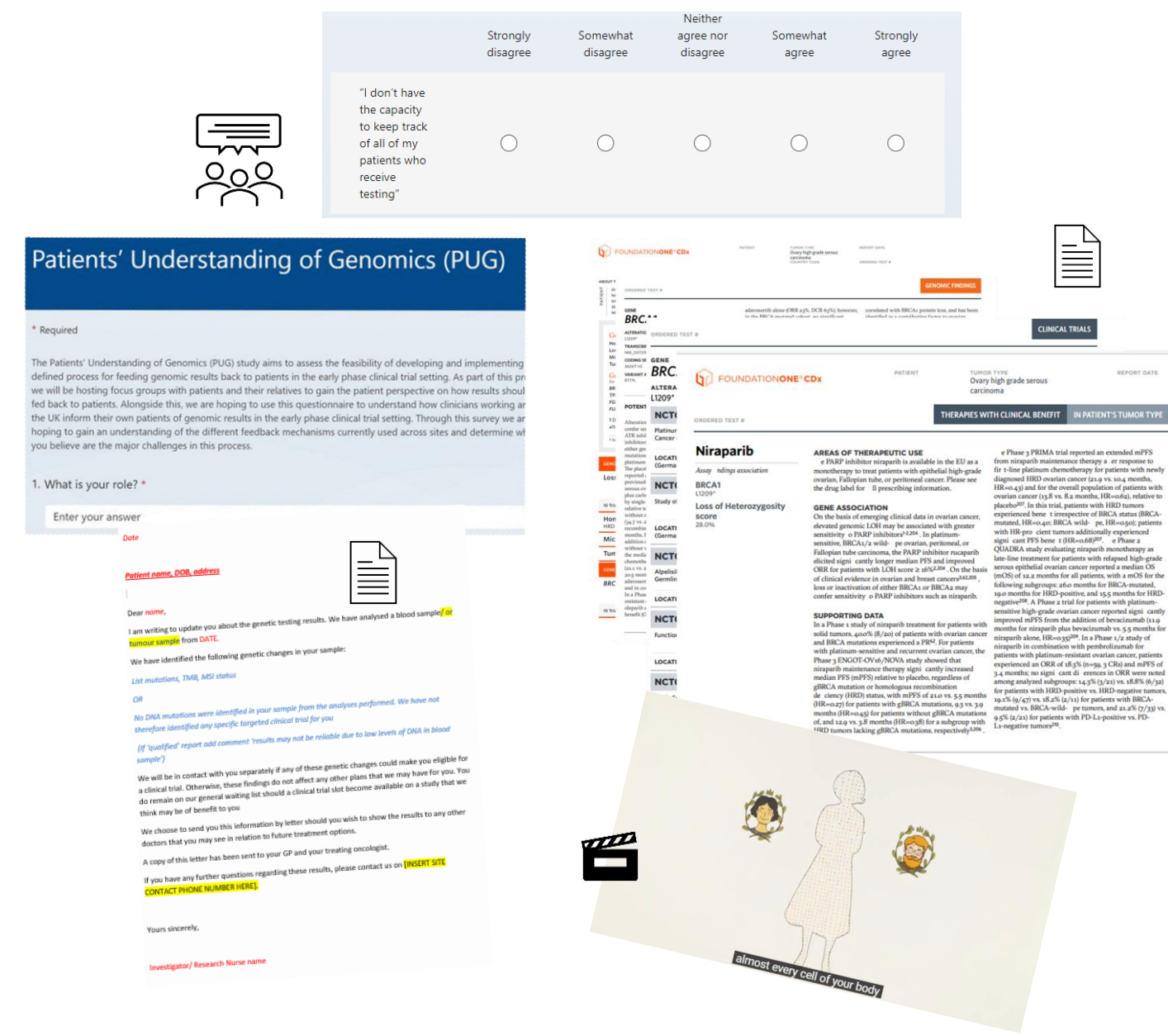


Figure 1 (above). Materials used as part of the clinician survey and focus groups.

Results

Clinician survey

Demographics of respondents
Data from 37 clinicians across 10 UK sites were collated, with a response rate of 62%.

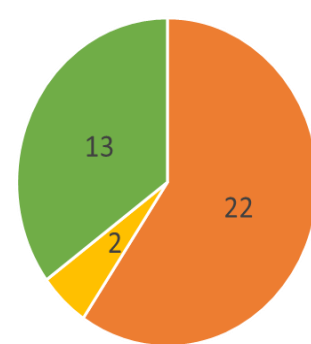
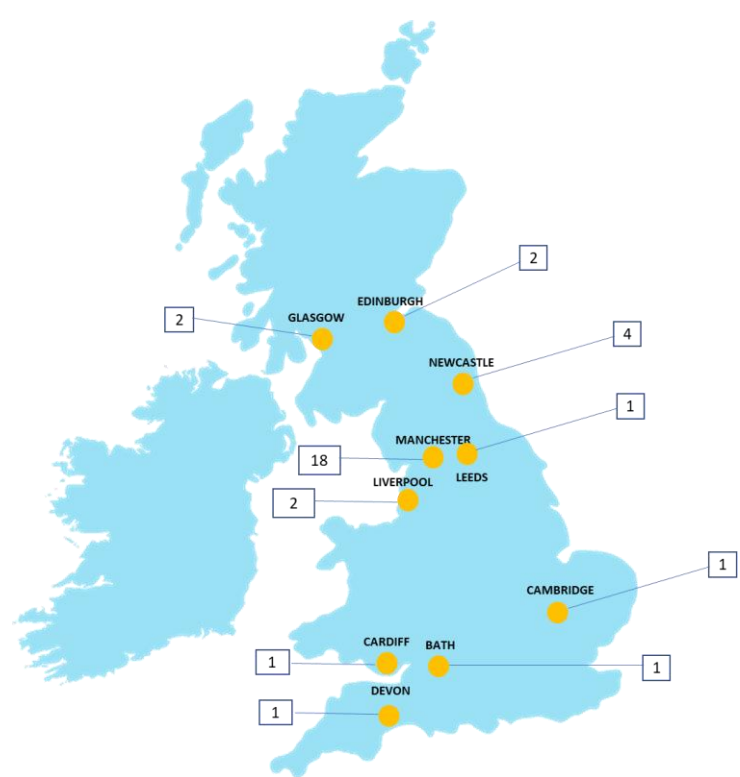


Figure 2 (above). Pie chart displaying the roles of respondents (left) and a summary of the number of responses per site (right).

Current practises for feeding back genomic results

92% ensured patients received feedback on their GT results.

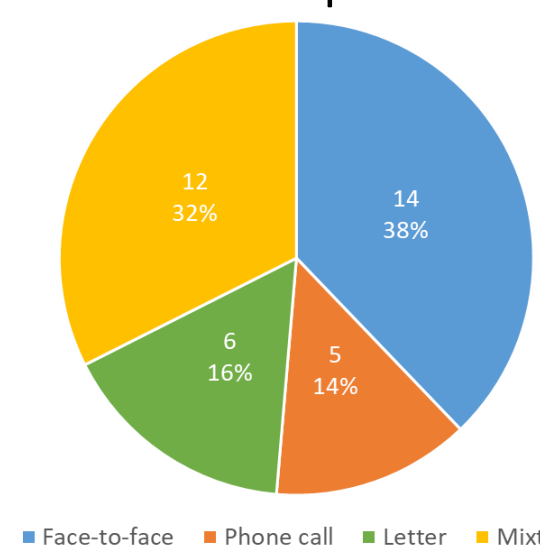


Figure 3 (above). Pie chart displaying the methods used by clinicians to feedback GT results.

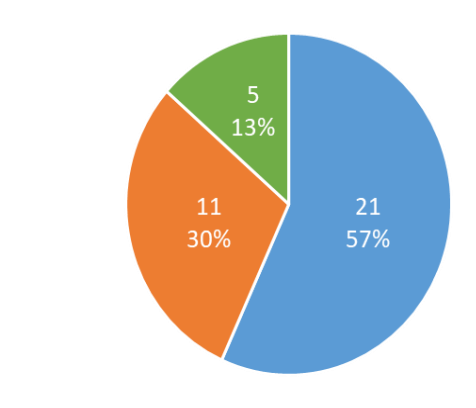


Figure 4 (above). Pie chart displaying the type and amount of information fed back by clinicians.

Some clinicians had received feedback from their patients about their return of GT results.



Figure 5 (right). Word cloud summarising the feedback received from patients.

Evaluating the barriers faced by clinicians in feeding back genomic results

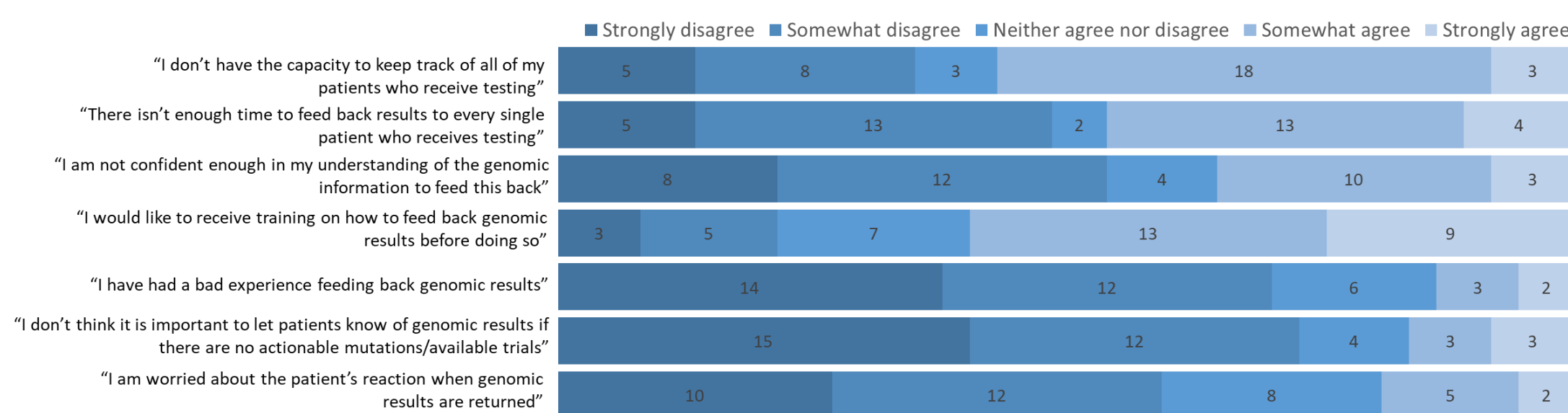


Figure 6 (left). Stacked bar chart displaying the responses to the seven statements within the clinician survey.

Some clinicians proposed suggestions for improving the process of feeding back genomic results to patients, summarised in Figure 7.

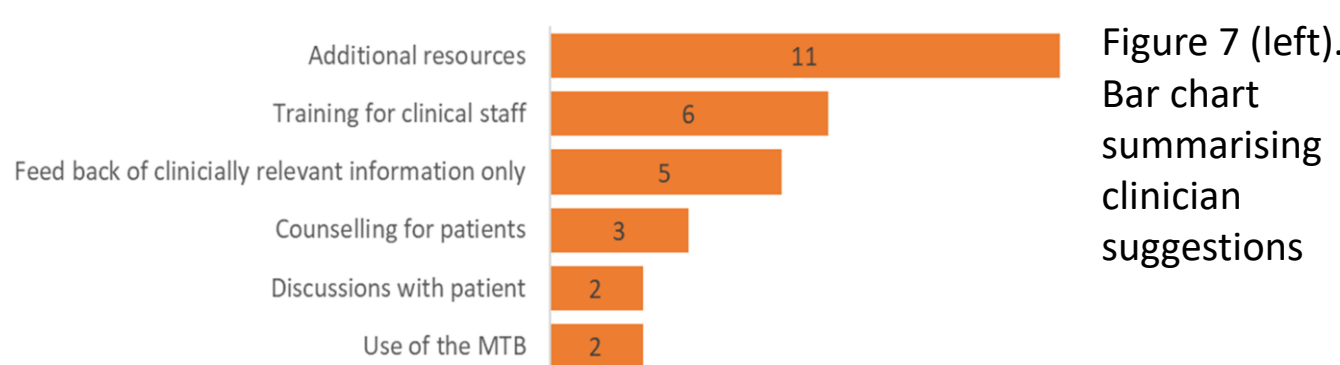


Figure 7 (left). Bar chart summarising clinician suggestions.

Focus groups

Demographics of participants

Seven focus groups involving 34 participants were held between April and August 2023. 24 participants were patients with a current/previous cancer diagnosis, seven were family members and three were carers.

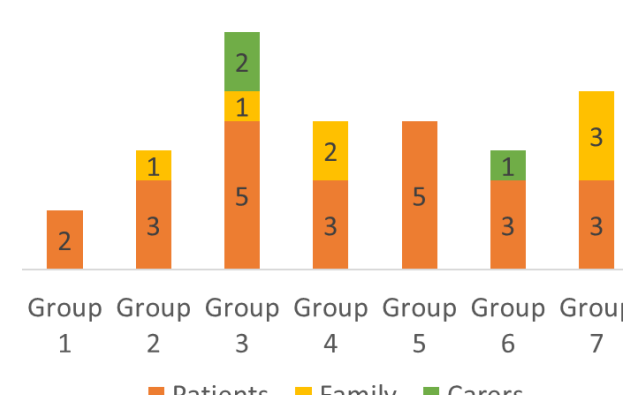


Figure 8 (above). Bar chart of the participants within each of the seven focus groups.

13 participants had an existing knowledge of genomics and/or genomic testing. This was through the internet, from their profession or due to having being tested for a specific gene (i.e. BRCA2).

Additional resources included a leaflet or information sheet explaining genomic results in lay terms and using videos or infographics.

A full thematic analysis of all of the focus group transcripts is ongoing but Figure 9 displays six themes that came up repeatedly across the groups



Figure 9 (above). Summary of the themes that came up across the seven focus groups.

Conclusion

- It is important to incorporate patient and clinician's preferences when developing feedback mechanisms for return of GT results.
- Increased educational opportunities covering interpretation of GT would be valued by healthcare professionals.
- The information provided to patients must be easily understandable to patients. Language used should be uncomplicated and scientific jargon should be avoided.
- A summary of the main genomic findings should be tailored to the patient based on their results and preference.
- There is a preference for face-to-face consultations when receiving GT results.
- Patients would like to be directed to regulated and reliable information about GT, recommended by their HCPs.

Next steps

- Complete thematic analysis of the focus group transcripts
- Continue to work towards developing a standardised approach for GT results feedback that can be used by EPCT centres across the UK.

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Corresponding author: Dr Natalie Cook; natalie.cook17@nhs.net
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