

GENOMIC DATA AND THE NHS: VIEWS OF RARE DISEASE PATIENTS AND CARERS

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Background

Introducing whole genome sequencing (WGS) into mainstream NHS care raises important questions for patients and carers and it is vital that, as potential beneficiaries, their views are sought to help guide healthcare policy. The new Genomic Medicine Service (GMS) will initially offer WGS to patients with rare and undiagnosed conditions, and certain cancers, and in 2019 this will be extended to all seriously ill children.

Aim

Genetic Alliance UK conducted a survey, commissioned by and in collaboration with Genomics England, to capture the views, expectations and potential concerns of patients and carers as the NHS prepares to deliver the GMS.

Method

Genetic Alliance UK developed an online survey, building on previous qualitative data about the opinions of rare disease patients and carers about WGS, and with input from Genomics England.¹ The survey was piloted using think-aloud and remote feedback. A link to the survey was sent directly to: patient group members of Genetic Alliance UK; supporters of the Rare Disease UK campaign; and families of children with an undiagnosed genetic condition who are members of SWAN UK (syndromes without a name). The link was also shared more widely through social media. Patients and carers of individuals with rare or undiagnosed genetic conditions were invited to take part. The survey was live for 27 days in October 2018 and received a total of 597 responses.

Conclusions

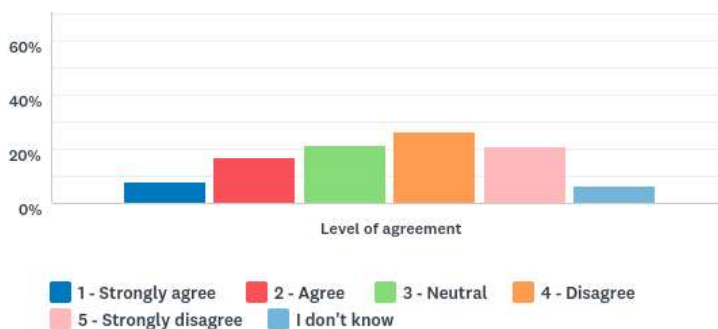
Consistent with the emerging picture of patient and public attitudes to access to health data, our respondents see the value in using WGS data for medical research, but this comes with caveats.² There must be an expected public benefit, and individuals may wish to have the power to choose whether and by whom their genomic data is accessed (with fewer respondents being supportive of access by commercial organisations than by the public sector). Data misuse and security are identified as potential concerns. An effective public discourse, and a consistently applied communication process within the NHS to carefully manage expectations, will help address these issues.

Patient satisfaction with WGS through the NHS is also likely to be influenced by the post-diagnostic service they receive, which in turn will be affected by resource constraints and the effectiveness of specialised services. While the Genomic Medicine Service promises a cutting-edge approach to diagnosis, whether it ultimately delivers on its promise will depend on factors other than pure progress in genomic technology.

Key findings

- The most commonly hoped-for benefits of WGS through the NHS were: improvement of the individual's care or treatment; contributing to research into their condition; and obtaining a diagnosis.
- Knowledge of how different organisations use health data collected during NHS care is limited amongst patients and carers. Although they are willing for healthcare professionals and researchers in the NHS to have access, a quarter of respondents 'might decline' WGS because of concerns about wider access to data.

Chart 1: Would patients and carers decline WGS if different organisations would be able to access their data? (% respondents)



- Patients and carers recognise the value in using WGS data for research and the vast majority support it. However they feel it is important that there is choice about whether their data is used in this way.
- Patients and carers overwhelmingly believe that, if different organisations will have access to their WGS data, this should be with the clear expectation that there will be a public benefit.