Genomics Education Programme

NHS
Health Education England

National Genomic Research Library: Top tips for discussing genomic research with patients

Introduction

The National Genomic Research Library (NGRL) was developed based on the experience delivering the 100,000 Genomes Project in the NHS.

Members of the Genomics England Participant Panel, made up of patients and family members with rare disease and cancer who took part in the 100,000 Genomes Project, support the view that while a therapy or cure may not be immediately available for a patient's condition, by participating in the NGRL the chances of finding one are increased. It can help lay the foundation for personalised medicine for patients, their families and for wider society.

We asked members of the panel for their feedback as individuals who have been offered genomic testing that involves associated research. Below are some key points that they suggested healthcare professionals could consider when discussing the NGRL with their patients.

Top tips to consider

Convey the collective value of genomic data

It is important to explain the rationale for obtaining data from many individuals. With more data available for researchers, there is potential for more to be learned about cancer and rare diseases. This also increases the chances of identifying effective treatments and diagnostic or prevention strategies.

With genomics, clinical care and research are inextricably linked

Our understanding of the consequences of genomic variants depends on the continued interaction between clinical testing and health information, as well as research evidence. If research is discussed as an afterthought, or as a distinctly separate discussion to the clinical test, it may not be considered as important by the healthcare professional or the patient. Healthcare professionals should therefore be transparent about the overlap between research and clinical genomic testing with regards to interpreting genomic data to inform accurate results.

Data access: who and how?

Ensuring the security of data, responsible sharing with trustworthy parties, and its use for the improvement of healthcare are key messages for individuals taking part in genomic research. Some individuals may have concerns about whether anyone can profit from their data, and if data could be accessed by law enforcement, border control agencies, insurers or employers. These concerns could be alleviated by explaining the strict terms of the NGRL.

Being transparent with the patient is vital, including noting that access could be granted to commercial companies undertaking health-related research. Individuals may also find it helpful to know that the committees overseeing data access include a patient and public voice.

The possibilities – and limitations – of genomic research

Patients may wish to know about the types of information ascertained from research that could be fed back to them, especially anything that could have an impact on their or their family members' health. It is therefore important to explain when and how this would take place, as well as the limitations – for example, not all genomic conditions will be deliberately looked for in research participant data.

Consider barriers to testing and research

There are a number of factors that can influence each individual's perspectives and decisions about genomic testing and research. This may include one's cultural and religious background, language, family dynamics, personal values and prior experiences. For example, a greater mistrust in research, or worries about stigmatisation within the family unit or community may be more prevalent in some cultures. It is important for healthcare professionals to appreciate, explore and address these concerns. This may include using interpreter services in appointments or for written information.

It may just not be the right time

Sometimes, individuals may not wish to engage with research because they are focusing on the immediate circumstances of their health or feel overwhelmed by information they are receiving at that time. As a clinician, you may also feel that there are other clinical issues to address where it would not be appropriate to have an informed discussion about the NGRL. It is important to acknowledge this and note that the decision to take part in the NGRL can be made at another time and revisited with the patient in the future.