Genomics Education Programme

NHS
Health Education England

Facilitating genomic testing: A competency framework

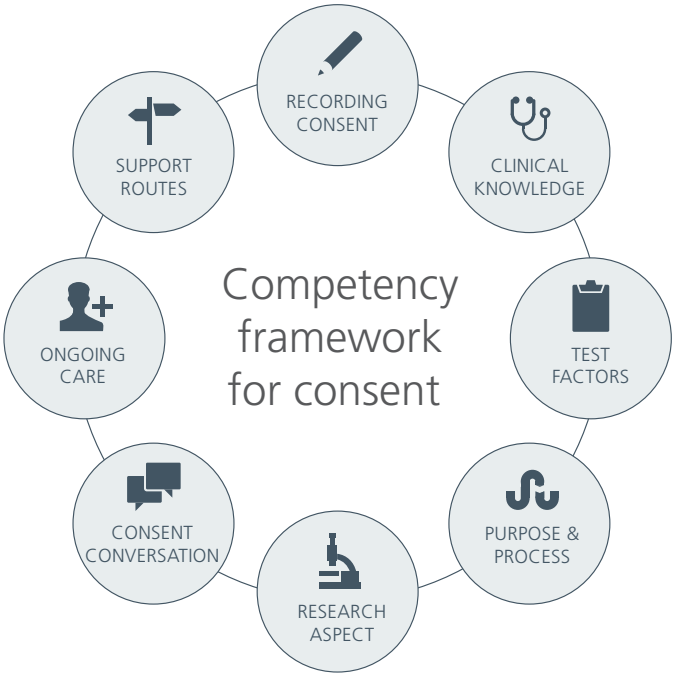
Introduction

This competency framework identifies the core competencies required to facilitate and consent patients for germline genomic tests. The Genomics Education Programme has developed this framework in collaboration with healthcare professionals from across the health service.

Importantly, the individual competencies in this framework should be interpreted in the context in which a healthcare professional is offering genomic testing, considering their scope of practice. Not all competencies, or parts of a competency, will be applicable for all healthcare professionals, or in all clinical situations or settings.

This framework has been designed to be a developmental tool to support individuals and organisations. It is not indented to be used as a grading or an assessment tool.

For more information about the framework, how it was developed, and how it can be used, please visit www.genomicseducation.hee.nhs.uk.



The competencies

1. **Ensures the process of recording consent for a genomic test follows national and local processes and governance arrangements, and is appropriate for the test being requested**
   - Demonstrates familiarity with the National Genomic Test Directory and adheres to this guidance when offering genomic testing, including the funding model, sample requirements and local requesting pathways.
   - Understands the national and local processes for changes to consent (i.e. at age 16 with capacity, for additional tests, when a patient changes their mind about having the test).
   - Demonstrates familiarity with principles of the Human Tissue Act 2004, Data Protection Act 2018 and/or General Data Protection Regulation 2018 as they apply to the use of DNA and genomic data.

2. **Demonstrates up-to-date knowledge of the conditions occurring within their specialist area for which genetic or genomic testing may be offered**
   - Understands general genetic concepts, the inheritance and mechanism of disease.
   - Is able to elicit a family history to assess the risk of one or more conditions.
   - Understands how conditions may present and the variability of clinical presentations.
   - Knows the likelihood of the patient's presenting condition having a genetic basis, versus other possible factors (i.e. behavioural, social, environmental) that may contribute.
   - Recognises the different implications of somatic versus germline analysis.

3. **Assesses where genomic testing is appropriate in the patient's clinical pathway**
   - Knows why a test may or may not be offered.
   - Considers ethnic and/or population-specific factors that may influence the type of test being offered.
   - Is aware of alternative tests to the genomic test being offered, if applicable.
   - Knows of possible future test options and choices, pending the results.
   - Recognises when it would be appropriate to offer genetic testing to children.

See page 2 for competencies 4-8 >

The competencies cont.

4. Conveys to patients the purpose and process of the clinical test being offered

- Explains the context of the test (diagnostic, predictive or carrier).
- Outlines the scope and limitations of the test based on the technology being used.
- Explains the possible results and the turn-around time and feedback process for any results.
- Describes the potential relevance of the test for that patient/family, including clinical actions that may or may not be taken.
- Explains possible unexpected results (incidental findings).
- Describes the potential uncertainty of genomic information, and the iterative nature of analysing results.
- Describes how samples and data may be used, stored and accessed.
- Outlines the familial implications of results and the importance of sharing results with relatives.
- Understands the Code on Genetic Testing and Insurance.

5. Explains and answers questions relating to the National Genomic Research Library* where applicable

- Outlines the potential benefits and risks of data and sample use, storage and sharing on personal, familial and societal levels.
- Describes how samples and data may be used, stored and accessed.
- Explains the process of partial or complete withdrawal of consent for research at any time.

* Based on research offer in the 100,000 Genomes Project, and initially only applicable to whole genome sequencing indications in the GMS.

6. Applies core clinical skills to the genomic test conversation

- Assesses capacity according to the Mental Capacity Act 2005 and other guidelines (such as Gillick competency).
- Establishes the patient's understanding and expectations of the genomic test being offered.
- Employs effective communication skills to support decision making and enable patients to make a choice without coercion or bias.
- Tailors provision of information based on the patient's cognitive ability, age and language.
- Engages with all individuals present in the discussion and incorporates the potentially different views of family members.
- Addresses the psychosocial impact of genomic testing and risk, taking into consideration the impact of disease on the individual and/or family.
- Considers the factors that may influence an individual's choice to consent, including additional physical and mental health history; cultural, religious, familial and personal values; and timing of the conversation with respect to the patient's care and/or other life events.
- Respects the patient's right to decline the genomic test, and is able to explain potential implications, limitations, and/or alternatives for the patient's care.

7. Recognises one's ongoing responsibilities to the patient and acts when appropriate

- Understands that duty of care may extend beyond the initial feedback of genomic findings.
- Is able to inform relevant professionals involved in managing the patient's care and initiate onward referrals to other specialists.
- Knows of patient resources, support groups, and eligibility criteria for research (where applicable).

8. Seeks further assistance, where relevant, based on scope of practice

- Knows how to contact their local genomics laboratory, Clinical Genetics service and multidisciplinary review meetings if relevant.
- Can recognise and understand one's professional responsibilities and boundaries, and when to refer to relevant specialists for further support or patient management.
- Knows how to access educational resources to support learning where relevant (such as Good Clinical Practice training and Genomics Education Programme courses).