

Returning genomic results: A competency framework

Introduction

This competency framework outlines the core competencies required to communicate germline genomic test results in the NHS. The GEP has developed this framework in collaboration with healthcare professionals from across the health service, as well as input from patient communities.

Importantly, the individual competencies in this framework should be interpreted by healthcare professionals considering their individual 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 intended 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. Recognises scope of practice and seeks further assistance where relevant

- Knows how to contact their local Genomics Laboratory Hub, clinical genetics service, and additional clinical services where relevant.
- Recognises one's professional responsibilities and boundaries, and when to refer to relevant specialists for further support, including:
 - cases that would benefit from specialist genetics involvement, such as genetic counselling to aid patients in understanding or adapting to their result;
 - Genomic Laboratory Hub colleagues for updating a patient's phenotype, requesting re-analysis of data, or follow-up studies (such as segregation or functional assays); and
 - other clinical services for clinical patient management.
- Collaborates with other specialists by requesting and/or attending multidisciplinary review meetings as appropriate.
- Knows how to access educational resources to support continuing professional development.



2. Plans for the provision of the genomic result in the context of the patient's current clinical pathway

- Assesses information that would have been conveyed to the patient prior to the genomic test (such as information about the condition, test, genetics and inheritance).
- Understands the outcomes of any multi-disciplinary discussion(s) that may have taken place to inform the patient's genomic result.
- Obtains any new information learned about the patient's phenotype and/or family history that may inform the results conversation.*
- Plans for an appropriate mechanism, environment and amount of time to convey the genomic result (such as via letter, telephone, face to face, joint consultation with other relevant specialists).



3. Applies knowledge to understand the genomic result and its implications

- Assesses the suitability of the genomic result in relation to the patient's clinical situation.*
- Understands the outcome of variant classification as outlined on the laboratory report, including that the interpretation of a result can change.*
- Understands the implications of the result for clinical care, including referring to relevant management guidelines.*
- Initiates next steps that may be needed to clarify a genomic result where relevant, including those outlined in the laboratory report.*

See page 2 for competencies 4-6 >

The competencies cont.



4. Communicates the genomic result and its implications in relation to the patient's clinical symptoms and/or family history

- Understands general genomic concepts in order to facilitate the results conversation.
- Explains the result in context of the reason for testing (such as for diagnosis, carrier or predictive status).
- Describes the confirmed or suspected inheritance pattern (with numerical figures where relevant), including risks to other family members.
- Outlines any implications for current or future clinical management (or lack thereof), including potential advantages and/or disadvantages of different options.*
- Conveys the scope and limitations of the genomic result, including potential additional or alternative explanations.*
- Emphasises the uncertainties that exist with regard to genomic results as this applies to current and future management.
- Describes the wider familial impact of a result, including clinical management and genetic testing implications.*
- Outlines any reproductive options that may or may not be available based on the result.*
- Understands the implications of genomic testing for insurance, including the UK Code on Genetic Testing and Insurance.



5. Identifies and explains next steps related to the genomic result

- Outlines any further genomic testing and/or clinical investigations that may be considered based on the genomic result, including conveying when no further tests are anticipated at the present time.*
- Recognises the potential for research initiatives that may be relevant to the patient based on the genomic result.
- Identifies relevant patient resources and support groups.
- Provides a copy of the result to the patient and/or family in writing (eg by letter or copy of genomic report).
- Acts on national and local clinical guidelines and facilitates onward referrals to other specialists as required. Depending on area of specialty, onward referrals may be regarding:
 - clinical management and treatment;
 - discussion about familial implications, including genomic testing in adults and children; and
 - discussion of reproductive options.
- Communicates a clear plan for follow-up, including the time frame (specific or open-ended), mechanism (such as telephone or face to face), and appropriate contact information for any queries.
- Describes the potential for future changes based on the result (such as to treatment options, variant classification or new information identified through research) and where the patient may be re-contacted, while appropriately managing expectations.*
- Conveys the importance of the patient and family notifying of any changes in their medical or family history, as this may have an impact on their genomic result or future care.
- Documents clinical contact about the genomic result appropriately, including:
 - recording the patient's diagnosis and result appropriately in relevant patient record systems;
 - recording patient diagnosis in registries with appropriate consent and where available; and
 - communicating to relevant professionals involved in the wider care of the patient.



6. Applies core clinical skills to support the patient and family in adapting to the genomic result

- Addresses the different types of uncertainty raised by a genomic result.
- Considers the factors that may influence an individual's response and adaptation to a genomic result*, 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.
- Recognises where further support is needed with regard to the patient and family members' reaction, expectations, concerns and coping in light of the genomic result.*
- Explores communication of the result within the family, including supporting the patient to share information and addressing any barriers to communication.*
- Employs effective communication skills to support families with the immediate and longer-term psychosocial impact of a genomic result for the individual and family, including a 'normal' result.*