

Steps to Delivering a Genetic Test Result

'Getting it right first time, every time'



DELIVER THE GENETIC TEST RESULT (IDEALLY FACE TO FACE)

- Suggest the patient/carer brings a support person when they receive the news
- Take time to understand the test result in the context of the clinical facts
- Seek advice from the laboratory or geneticists if clarity is required
- Check-in if further information is best delivered in the appointment or at a follow-up
- The result can be life-changing, handle the result with compassion and empathy.



LISTEN: ASSESS THE INDIVIDUAL'S UNDERSTANDING OF SITUATION

- Don't withhold information, even if it is difficult information
- Tailor information based on understanding
- Check understanding throughout



KEEP THE LANGUAGE SIMPLE AND SENSITIVE

- Avoid complex scientific terminology or acronyms
- Consider individual circumstances when choosing your words
- Consider broken relations or bereavement
- Avoid negative terminology and focus on positivity



ALLOW TIME

- For emotions/reactions
- To digest information
- To ask questions



CONSIDER THE IMPACT

- For themselves
- For family members and future generations



SUMMARISE

- Information covered in the appointment
- Clarify next-steps in management of the condition and further referrals
- Offer follow-up options and time scales



SIGNPOST

- Who can they ask questions? and how can they contact them?
- Support groups including printed leaflets, papers or website information
- Consider further referrals to clinical genetics or specialist clinics
- Consider a follow-up appointment
- Clinical trials if appropriate

How to use this document

This document is a part of the 'Return of Germline genetic test results' education training package developed by North Thames Genomic Medicine Service.

This package is intended for healthcare professionals (HCP) who have been/will be involved in communicating germline genetic/genomic test results. It is aimed at HCP currently working in the NHS and is intended as a cross-professional guide for best practice. The programme is in line with the Health Education England Genomics Education Programme (HEE GEP) competency framework for communicating germline genomic results.

This document is a stepwise guide of key points to remember when delivering a genetic test result to a patient/carer and ideally used in conjunction with the training module. The intention of this document is to highlight that receiving a result is potentially a life changing moment for the patient and the family. Therefore healthcare professionals should always deliver the results like it is the first time one has ever given one, taking the 'First time, every time' approach.

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References

- Parents perspective on rare disease document: <https://www.m4rd.org/videos/do-you-hear-me-a-parents-perspective-on-rare-disease/>
- Good Diagnosis document: <https://www.genomicsengland.co.uk/patients-participants/participant-panel>; <https://geneticalliance.org.uk/gauk-news/news/good-diagnosis/>
- Genomic education programme: <https://www.genomicseducation.hee.nhs.uk/competency-frameworks/communicating-germline-genomic-results-a-competency-framework/>