

**Record of Discussion about
TESTING AND STORAGE OF GENETIC MATERIAL
Targeted confirmatory germline testing for
specific rare disease variants**

I have discussed genetic testing with my healthcare professional and I understand that:

1. The results of my test may be important for my family. They could be shared with my family through a discussion with me, or in a way in which I am not personally identified.
2. I understand that this test is looking just for the specific genetic variant(s) and / or genetic condition previously identified in my family. This test does not look for other genetic variants which can be associated with inherited genetic conditions.
3. My DNA sample will be stored after testing is complete. My DNA might be used in genetic tests for my family or other people.
4. My genetic data will be stored to allow for future investigations.
5. Whether or not genetic tests need to be declared for insurance purposes depends on the type of genetic test being undertaken. Insurance companies may ask for results of a “diagnostic” genetic test to confirm why a person has developed a genetic condition. They currently may not ask for results of a “predictive” genetic test which looks at the chance of an unaffected person developing a genetic condition in the future. I should seek specialized advice if I am concerned about insurance implications of a genetic test.
Further information about genetics tests and insurance is available at: <https://www.abi.org.uk/data-and-resources/tools-and-resources/genetics/>
6. The results of my test will be part of my patient health record.
7. My anonymised DNA sample (meaning my personal identity cannot be linked to the sample) may be used in ethically-approved research projects, for quality control and for the development of new tests, in order to help improve our understanding of genetic conditions.

Note of other specific issues discussed (*e.g. referral to particular research programmes*):

I agree to genetic/genomic investigations*	DATE _____
----- Patient/parent signature -----	Discussion undertaken by: (clinician’s name and signature) -----

Affix sticky label or fill in details

Patient name: _____ Date of birth: _____

Patient address: _____

Genetics ref. _____

1 COPY for notes, 1 COPY for patient to retain

**insert details here, e.g. variant/gene being tested*

More information regarding genomic testing and how my data is protected can be found at www.nhs.uk/conditions/genetics.

Note: this is adapted from CP, RCPATH and BSGM (2019) *Consent and confidentiality in genomic medicine: Guidance on the use of genetic and genomic information in the clinic*, Report of the Joint Committee on Genomics in Medicine, 3rd edition, p.36.