

RECORD OF DISCUSSIONS ABOUT GENETIC/GENOMIC SAMPLE STORAGE AND ANALYSIS

Person agreeing to genetic/genomic testing:
Name _____
Address _____
Address _____
Address _____
Dob/CHI _____

Sample from:
(Name, dob, relationship – e.g. self, child, etc) _____

Nature of sample: _____

Family implications

1. The results of my test *may* have implications for other members of my family. I acknowledge that my results may sometimes be used to inform the appropriate health care of others. This could be done in discussion with me, or in such a way that I am not personally identified in this process.

Uncertainty

2. The results of my test *may* reveal genetic variation whose significance is not yet known. Deciding whether such variation is significant may require sharing of information about me including (inter)national comparisons with variation in others. I acknowledge that interpretation of my results may change over time as such evidence is gathered.

Unexpected information

3. The results of my test *may* reveal a chance of a disease in the future, and nothing to do with why I am having this test. These may be found by chance, whilst focussing on the reason for my test, and I may then need further tests to understand their significance. If these additional findings are to be looked for, I will be given more information about this.

DNA storage

4. Normal laboratory practice is to store the DNA extracted from my sample even after the current testing is complete. My sample might be used as a 'quality control' for other testing, for example, that of family members.

Data storage

5. Data from my genetic test will be stored to allow for possible future interpretations.

Health records

6. Results from my genetic test and my test report will be part of my Patient Health Record.

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

I agree to genetic/genomic investigations for* _____

Patient/Parent Signature _____ **date** _____

Discussion undertaken by (clinician's name and signature): _____

*insert eg. to investigate the cause of my child's developmental delay/ family history of cancer/ heart disease etc

Blood samples: DNA tests and Array CGH: 2–10ml in EDTA tubes. Translocation/FISH tests: 2-10ml in Lithium Heparin.