

***RECORD OF DISCUSSIONS regarding testing and/or storage of genetic material***

I have discussed genomic/genetic testing with my health professional and I understand that:

*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 healthcare 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. This may be found by chance, while focusing on the reason for my test, and I may then need further tests to understand what this means for me. 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 test will be stored to allow for possible future interpretations.

*Health records*

6. Results from my test and my test report will be part of my patient health record.

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

---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

|  |  |
| --- | --- |
| **I agree to genetic/genomic investigations:****\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** | **DATE: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_** |
| **Patient/parent signature:****\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** | **Discussion undertaken by: (clinician name/signature)****\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |

***Affix sticky label or fill in details***

Patient Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date of Birth \_\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ CHI: \_\_\_\_\_\_

Patient Address:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Genetics ref \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ 1 COPY for notes, 1 COPY for patient to retain