**Lynch Syndrome genetic testing consent form**

Record of discussion regarding genetic testing and/or storage of genetic material

(including tumour tissue/normal tissue/blood/saliva/DNA)

|  |  |
| --- | --- |
| Requesting DNA analysis for the condition(s):  ***Lynch Syndrome***  The intended purpose is:  ***Diagnostic genetic testing*** | Patient Name: ……………………………………….  Date of Birth: …………………………………………  NHS no. (If known): …………………………………  Hospital no.: ………………………………………….  Address: ……………………………………………... …………………………………………………………………………………………………………………… |

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

*Clinical implications*

* The test will be specific only for the condition named above and will not detect other genetic/health conditions.
* Genetic testing may be performed on my blood sample or saliva, as well as tissue (cancerous and non-cancerous).
* The results of my test may confirm I have a genetic condition and will need ongoing clinical management (e.g. colonoscopic surveillance, surgery, medication etc).
* The test may not be able to identify a genetic diagnosis, or may not provide clear answer (please see next section).

*Uncertainty*

* The results of my test may be uncertain and the relevance to my health may not yet be fully understood. To understand the clinical relevance of this result, my data may be kept under active clinical review.
* I acknowledge that interpretation of my results may change over time and I will be informed of any updates which have clinical implications.

*Family implications*

* The results of my test may have implications for other members of my family. I acknowledge that my results may be shared with other genetic centres to inform the appropriate healthcare of others.

*DNA and data storage*

* 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 from my test will be stored so it can be looked at again in the future if necessary.

*Health records*

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

*Referrals*

* Depending on the result, referral to clinical genetics may be necessary

Other specific issues discussed:

………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………

*Next of kin*

* If, for any reason, I am unable to receive the results of my test, I would like the results to be given to:

Name: ……………………………………………………… Tel no.: ………………………………...…

Patient signature: ……………………………………………………………. Date: ……..............

Or guardian/signature of parent if under 16: ………………………………………………….

I confirm the issues above have been discussed.

Counsellor signature: ………………………………. Name: ……………………………………..

\*If an interpreter has been used, please confirm you have interpreted this information to the patient and to the best of your knowledge, they have understood the discussions and contents of this form.

Interpreter signature: ……………………………….. Name: ……………………………………..

Patient signature: ………………………………………………………………………………………. Date: …………………

Or signature of parent/guardian if under 16: ………………………………………………………..... Date: ………………..

I confirm the issues above have been discussed.

Counsellor name: ……………………………..…………………………Signature: …………………………………………...

Patient signature: ………………………………………………………………………………………. Date: …………………

Or signature of parent/guardian if under 16: ………………………………………………………..... Date: ………………..

I confirm the issues above have been discussed.

Counsellor name: ……………………………..…………………………Signature: …………………………………………...

NB: One copy for patient and one copy retained for departmental records.

Patient signature: ………………………………………………………………………………………. Date: …………………

Or signature of parent/guardian if under 16: ………………………………………………………..... Date: ………………..

I confirm the issues above have been discussed.

Counsellor name: ……………………………..…………………………Signature: …………………………………………...

Patient signature: ………………………………………………………………………………………. Date: …………………

Or signature of parent/guardian if under 16: ………………………………………………………..... Date: ………………..

I confirm the issues above have been discussed.

Counsellor name: ……………………………..…………………………Signature: …………………………………………...