Consent Form for Exome Sequencing

Patient		
Surname	Given Name(s)	
Address		
	Postcode	
Date of Birth	Telephone	

Parent or Guardian		
Surname	Given Name(s)	
Address		
	Postcode	
Date of Birth	Telephone	

To be completed by the Health Professional

I, ______________________________________ have informed this patient/parent/guardian regarding results and limitations of exome sequencing. We have discussed the consequences and procedures involved in testing and the storage of patient data.

To be completed by the Patient/ Guardian

1. I wish that DNA from **me/ my child / person under my legal guardianship** will be stored and tested by exome sequencing for the following condition and type of analysis:

Condition :____

Type of analysis:

☐ Only genes known to cause the condition (gene panel)

☐ Genes known to cause the condition followed by exome wide analysis

2. I understand that only genes known to cause the condition in question will be analyzed initially. The test results will be discussed with me on completion of the analysis. If this initial testing does not identify a cause, and I have opt for further exome analysis, all genes will then be analyzed (exome wide analysis, in specific cases analysis of *de novo* variants). In this case I will also be informed if findings relevant to the condition in question are identified by exome sequencing.

3. If I have opt for further/complete exome analysis I understand that there is a small chance that unsolicited findings not related to the specific condition in question may be identified.

I understand that any unsolicited findings will be assessed by an independent expert committee. Only if the mutation identified is considered to have a significant impact on my healty/ the health of my child, the committee in consultation with my doctor, may inform me of these unsolicited findings.

4. I understand that the knowledge of genetic conditions is likely to improve in the future. I can ask my doctor if further information becomes available about the exome sequencing results relating to the genetic condition in my family.

5. I understand that the information from the exome sequencing will be stored at the Department of Human Genetics, UMC St. Radboud and that it may be shared with researchers in other departments after it is de-identified.

6. I understand that I have the ability to withdraw my consent at any time without influencing **my management /the management of my child/my ward.**

7. I have had the opportunity to ask additional questions I and am satisfied with the explanations.

____ ________________________

Signature of Patient/Guardian Print name of Patient

________________________ ____________

Signature of Health Professional Date