

**Decision Making or Legal Representative Consent to Participate Form**

**and**

**Decision Supporter Assent to Data Processing Form**

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| **Study title: Research Use of Diagnostic Genomic Testing Data for Epilepsy** |

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| I have read and understood the **Information Leaflet** about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction. | **Yes** | **No** |
| I understand that the person I am the legal representative for does not have to take part in this study and that I can opt them out at any time. I understand that no reason for opting out is required and I understand that opting out won’t affect their future medical care. | **Yes** | **No** |
| I am aware of the potential risks, benefits and alternatives of this research study. | **Yes** | **No** |
| I give my permission for researchers to be given access to the results of:  genetic testing recommended to the person I am representative for by their doctor  genomic testing recommended to the person I am representative for by their doctor  (Note: Genomic testing looks at all of your genes whereas genetic testing may only look at a very small number of genes. Your doctor will decide what option is most appropriate for you and recommend accordingly.) | **Yes**  **Yes** | **No**  **No** |
| I give permission for researchers to look at the medical records of the person I am legal representative for to get information. I have been assured that information about the person I am legal representative for will be kept private and confidential and that the researchers will not be given identifiable personal information. | **Yes** | **No** |
| I have been given a copy of the Information Leaflet and this completed consent and assent form for the records of the person I am legal representative for. | **Yes** | **No** |
| I give consent for the person I am legal representative for to take part in this research study having been fully informed of the risks, benefits and alternatives. | **Yes** | **No** |
| I give assent to have the data of the person I am legal representative for processed as part of this research study. | **Yes** | **No** |
| I consent to be contacted by an authorised person as part of this research study on behalf of the person I am legal representative for. | **Yes** | **No** |

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| **FUTURE CONTACT** |  |  |
| **OPTION 1:** I consent to be re-contacted by an authorised person about possible future epilepsy research **related** to the current study for which the person I am legal representative for may be eligible. | **Yes** | **No** |
| **OPTION 2:** I consent to be re-contacted by an authorised person about possible future epilepsy research **unrelated** to the current study for which the person I am legal representative for may be eligible. | **Yes** | **No** |

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| **STORAGE AND FUTURE USE OF INFORMATION** | | |
| **RETENTION OF RESEARCH MATERIAL IN THE FUTURE** | | |
| **Option 1:** On behalf of the person I am legal representative for I give permission for material/data to be stored for possible future epilepsy research **related** to the current study **only if consent is obtained** at the time of the future research but only if the research is approved by a Research Ethics Committee. | Yes | No |
| **Or**  **Option 2:** On behalf of the person I am legal representative for I give permission for material/data to be stored for possible future epilepsy research **related** to the current study **without further consent being required** but only if the research is approved by a Research Ethics Committee. |  |  |
| **Option 3:** On behalf of the person I am legal representative for I give permission for material/data to be stored for possible future epilepsy research **unrelated** to the current study **only if consent is obtained** at the time of the future research but only if the research is approved by a Research Ethics Committee. | Yes | No |
| **Or**  **Option 4:** On behalf of the person I am legal representative for I give permission for material/data to be stored for possible future epilepsy research **unrelated** to the current study **without further consent being required** at the time of the future research but only if the research is approved by a Research Ethics Committee. | Yes | No |
| **Option 5:** On behalf of the person I am legal representative for I agree that some future epilepsy research projects may be carried out by researchers working for **commercial/pharmaceutical companies.** | Yes | No |
| **Option 6:** On behalf of the person I am legal representative for I agree that some future epilepsy research projects may be carried out by researchers working for **commercial/pharmaceutical companies.** |  |  |

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Participant Name (Block Capitals) | Participant Signature | Date

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Legal Representative Name Legal Representative Signature Date

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Translator Name (Block Capitals) Translator Signature Date

**To be completed by the Principal Investigator or nominee.**

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

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----------------------------------------------------------------------------------------------------------------------------Name (Block Capitals) | Qualifications | Signature | Date

3 copies to be made: 1 for patient, 1 for PI and 1 for hospital records.