



Genomic Imaging in Neonatal Encephalopathy (GENIE STUDY)

CONSENT FORM

Baby's name _____ Date of birth

Mother's name _____ Date of birth

Father's name _____ Date of birth

	Initials
1. I have been fully informed of what the study involves for my child who is named above. I have read the study information sheet (version 1.1, 16/09/17) and have had the opportunity to ask questions about the project. I have received satisfactory answers to all my questions.	
2. I agree to allow a sample of my child's blood to be used for genetic analysis for the above research study.	
3. I understand that the genetic analysis may be performed in appropriate laboratories in the UK, Europe or USA.	
4. I give permission for my child's medical and electronic health records to be looked at and analysed in strict confidence by responsible individuals from the research team or the NHS Trust.	
5. I agree that you may use my baby's MR data and neurodevelopmental outcome assessment data for linking with the genetic information	
6. I understand that participation in this project is voluntary and that I am free to withdraw my child from the study at any time, without giving a reason and without affecting his/her medical care or legal rights.	
7. I understand that I will not receive specific results or feedback about my child's clinical information or blood sample.	
8. I agree for my child's information and the blood sample he/she has donated for this study to be stored on a long-term basis at Imperial College London for use in future ethically approved research. The data (including identifiable data) and any remaining samples may be stored securely at Imperial College London, and the local hospital for 10 years following the completion of the study.	
9. I agree for my child's genetic information to be linked to his/ her electronic health record in the National Neonatal Research Database.	
10. I agree that you may contact my GP to inform about my baby's participation in this study or request clinical information from them or from my local hospital.	
11. a) I agree for information on my child's future health status to be collected and analysed in strict confidence by responsible researchers conducting this study. This includes information held in electronic medical records and other relevant registers. b) I understand that identifiable information including my child's NHS number will be used to trace future data.	
12. I agree to be contacted for future related ethically approved studies and understand that I am free to decline if I do not wish to participate.	

