Prion Surveillance in Primary Immunodeficiency Patients
CONSENT FORM
Version 8.0 (25/02/2016)

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Name of immunology centre:……

Name of patient:……**Participant ID:**……

		Please initial box
1.	I confirm that I have read and understand the information on the sheet dated 25/02/2016, version 7.0 for the above study and have had the opportunity to consider the information and ask questions.	☐
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3.	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the Sponsor or the NHS organisation, where it is relevant to my taking part in this research, for quality assurance purposes. I give permission for these individuals to have access to my records.	☐
4.	I understand that my personal details, PID diagnosis and details of immunoglobulin treatment will be held by the research team in a study database.	☐
5.	I consent for my records to be searched for details of any blood transfusions, blood components and products received, including the location, date, amount and batch numbers received, and past surgical procedures. I understand that this is to help identify spare tissues for testing and to undertake future risk assessments	☐
6.	I agree to give a blood sample from which genetic material (DNA) will be extracted and used for codon-129 typing to help classify my prion protein type.	☐
7.	I agree to give a blood sample once every two years which will be stored for future testing for prion infection, when an appropriate test becomes available. I understand the samples may be stored beyond the end of the study until testing has been completed.	☐
8.	I agree to the testing of spare tissue samples taken as part of my routine treatment and care, for evidence of prion infection.	☐
9.	I agree to post-mortem examination and removal of tissue samples for prion testing. I understand this may involve the keeping of small tissue samples as blocks and slides to be kept as part of the medical record. I confirm that I have discussed my wishes for post-mortem with my next of kin.	☐

10. I agree to annual telephone follow-up by the study research team, to discuss the study, feedback new information and address any concerns I may have. ☐

11. I agree to my General Practitioner being informed of my participation in this study. ☐

12. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

Please provide copies as follows:

1x original	Principal Investigator site file;
1x copy	Participant's medical records;
1x copy	Participant;
1x copy	NCJDRSU study file