



PARTICIPANT CONSENT FORM Generation of Induced Pluripotent Stem (iPS) Cells and Rare Diseases – Skin Biopsy - V1.1 03/02/15

Please initial box:

Flease Illitial DOX.	
1. I confirm that I have read and understand the information leaflet dated _/_/_ (version_) for the 'Generation of Induced Pluripotent Stem (IPS) Cells and Rare Diseases' study, and have had the opportunity to consider the information, ask questions and had them answered satisfactorily.	
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 any of my medical notes may be looked at by responsible individuals from my Clinical Care team, the NIHRBR-RD team or regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records.	
4. I agree to take part in the above study and, specifically, agree to undertake the procedure described as 'skin biopsy' on the Participant Information Leaflet in order to donate a sample of my skin for the purposes of this research project.	
5. I consent to give a blood sample	
6. I consent to give a saliva and/or urine/hair sample for the study if required.	
7. I understand that my identity will remain confidential to the doctors and nurses in my Clinical Care team and to authorised members of the NIHRBR-RD team. No data will be released with participant identification attached.	
8. I agree that the samples I have donated, the iPS cells and the information gathered about me can be stored and shared with other researchers in the UK and overseas for future research studies.	
9. I understand that this research will include the participation of commercial companies and that I will not benefit financially if this research leads to new treatment or medical tests.	



National Institute for Health Research

10. I agree that the information produced by studying my sample, including my entire DNA sequence, may be placed in an electronic archive with no connection to my name or other personal identifier. I understand that this archive will only be accessible to researchers who apply to use my samples and/or anonymised data to ensure the results are only used to advance scientific and medical understanding.			
Name of participant	Date	Signature	
Name of person taking consent (If different from researcher)	Date	Signature	
Researcher	Date	Signature	
		Staff to complete	
		NHS Number	
		Pedigree/Family number:	