



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

Please initial box:

| 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. Lagree 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. | |





| my entire DNA sequence, ma | ay be placed | y studying my sample, including in an electronic archive with no |
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| archive will only be access | sible to rese data to ens | I identifier. I understand that this earchers who apply to use my ure the results are only used to ding. |
| Name of participant | Date | Signature |
| Name of person taking consent (If different from researcher) | Date | Signature |
| Researcher | Date | Signature |
| | | Staff to complete |
| | | NHS Number |
| 40) | | Pedigree/Family number: |