

## **CONSENT FORM FOR CONSULTEES**

Centre SAL/ MAN/ B'HAM/ CAM/ GOSH/ RF/ ICH

national collaborative study of lysosomal storage disorders **Title of Project:** A study to investigate the natural history, effectiveness and cost effectiveness of current and emerging treatment options for people with lysosomal storage disorders

Please initial box

Name of Chief Investigator: Professor Stuart Logan Name of Principle Investigator: Please add in clinician

Study Number:

- 1. I confirm that I have read and understand the information leaflet (dated xx/xx/xx) for the above study and have had the opportunity to ask questions.
- 2. I understand that participation in this study is voluntary and that the participant is free to withdraw at any time, without giving any reason, and without medical care or other legal rights being affected.
- 3. I understand that sections of the participant's medical notes may be looked at by responsible individuals either from the NCS-LSD Team for the purpose of extracting material for incorporation in the proposed database or from regulatory authorities and I give permission for these individuals to have access to the participant's records.
- 4. I agree to the participant's information being collected but do not wish to complete any additional questionnaires
- 5. I give permission for the participant's GP to be informed of their participation in this study
- 6. I agree for the participant to take part in this research.

| Name of Participant  |                         |                                      |
|--|-------------------------|--------------------------------------|
| Name of Consultee  | Date                    | Signature                            |
| Name of Person taking consent (if different from researcher) | Date                    | Signature                            |
| Researcher   | Date                    | Signature                            |
| 3 copies: 1 for Co   | nsultee; 1 for research | er; 1 to be kept with hospital notes |

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