national collaborative study of lysosomal storage disorders

CONSENT FORM FOR CONSULTEES

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

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

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

Study Number: ☐

	Please initial box
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 understand that I will be asked to complete some quality of life questionnaires about the participant and two further questionnaires related to service use and family impact.	☐
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 Consultee; 1 for researcher; 1 to be kept with hospital notes