



national collaborative
study of lysosomal
storage disorders

CONSENT FORM FOR PARENTS/ CARERS

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 my child's participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my or my child's medical care or other legal rights being affected.
3. I understand that sections of any of my child's medical notes may be looked at by responsible individuals from the NCS-LSD Team, for the purpose of extracting material for incorporation in the proposed database, or from regulatory authorities. I give permission for these individuals to have access to my child's records.
4. I understand that my child will be asked to complete some age- appropriate quality of life questionnaires at his/her annual review.
5. I understand that I will be asked to complete some questionnaires about my child and two further questionnaires related to service use and family impact.
6. I give permission for my child's GP to be informed of their participation in this study
7. I agree for my child to take part in this research.

Name of Child _____

Name of Parent

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

3 copies: 1 for parent; 1 for researcher; 1 to be kept with hospital notes