



national collaborative study of lysosomal storage disorders

# ADDITIONAL CONSENT FORM FOR PARENTS/CARERS OF PATIENTS WHO ATTEND CLINIC FOR ADDITIONAL HOSPITAL VISITS

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 Principal Investigator: Please add in clinician

Study Number:

Thank you very much for your previous consent for your child to participate in the National Collaborative Study of Lysosomal Storage Disorders. We are aware that your child's clinician has changed their treatment regimen due to a current world shortage of their treatment drug, and we would like to know more about how this is affecting them and your family. We would therefore like you to complete a further set of Quality of Life and Service Use Questionnaires at this additional hospital visit, and any other visit your child might attend prior to their next annual review.

The questionnaires are exactly the same as those you previously completed at your child's annual review. We are asking for this additional consent, as previously we asked your permission to complete these questionnaires **only** at your child's annual review.

**Please initial box**

1. I confirm that I have previously consented for my child to participate in the NCS-LSD Study.
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 child's medical care or other legal rights being affected.
3. I understand that I will be asked to complete some questionnaires relating to quality of life and service use at each of my child's additional hospital visits.
4. I agree for my child to take part in this research.

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Name of Child \_\_\_\_\_

\_\_\_\_\_  
Name of Parent / carer                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent                      Date                      Signature