national collaborative study of lysosomal storage disorders

ADDITIONAL CONSENT FORM FOR PARTICIPANTS 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 to participate in the National Collaborative Study of Lysosomal Storage Disorders. We are aware that your clinician has changed your treatment regimen due to a current world shortage of your treatment drug, and we would like to know more about how this is affecting you 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 you might attend prior to your next annual review.

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

Please initial box

1. I confirm that I have previously consented to participate in the NCS-LSD Study.	[ ]
2. 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 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 hospital visits.	[ ]
4. I agree to take part in this research.	[ ]

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature

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