Assent for recording information in the SMA REACH UK Database in association with Neuromuscular Clinical Network & for the additional assessments

Patient Details (or pre-printed label) Responsible health professional …………………………….

Hospital Number ………………………………. Job title ……………………………………..

Patient’s Surname ………………………………

Patient’s first names ……………………………

Date of birth ……………………………………

**NHS number** …………………………………… Patient’s other requirements ………………………………

(E.g. other language)

**Please tick Yes or No if you agree/disagree with the following statements**

**Mandatory to participate in SMA-REACH**

I agree that clinical information about me will be collected and saved in the SMA REACH UK Database

I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by employees from Regulatory Authorities or from <insert site> (and other academic institutions), for monitoring and auditing purposes. Also where it is relevant to myself taking part in this research going forward, these employees will have access to relevant sections to my medical notes. Furthermore, I understand that previous data about me (from the SMARTNET database) will be collected and saved in the SMA REACH UK Database. I give permission for these individuals to have access to my records

**Optional assessments**

I agree to be videotaped during the physiotherapy assessments



I agree to let my doctor (GP) know that I am taking part in this study



I agree to be involved in a group meeting to talk about my assessments



I agree to be contacted for an interview to talk about SMA and management and if agreed to participate, I agree to be recorded for analysis purposes.

 I agree that clinical and physiotherapy information about me (with my personal details removed), will be collected and saved in the SMA REACH UK database. I understand that this information will be shared with an international database with Biogen and other parties (pharmaceuticals/academic institutions/any government bodies as required) with my personal details removed. I agree that clinical information about me (with my personal details removed) can also be used for clinical audits, research, evaluation and health service planning as required.

**P.T.O**

 In addition, Pseudonymised personal data about me will be collected and saved in the SMA REACH UK database if enrolled onto the nusinersen (SPINRAZA®) Managed Access Agreement (MAA). This will be shared with NHS England, NICE, University of Strathclyde and Biogen.



I agree to be contacted by phone for short interviews/surveys on SMA (only at GOSH)

**If you don’t want to take part in this study, do not write your name.**

If you **do** want to take part, you can write your name below

Your name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_ Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_

**Practitioner Section:**

I have given the parent/guardian the information sheet entitled: **Recording information on the management of my Spinal Muscular Atrophy in the UK – SMA REACH UK Database in association with Neuromuscular Clinical Network.**

I have explained to the above patient the purpose of collecting and recording clinical information in the database.

……………………………………………. ……………………………………………

Signature Date

……………………………………………. ……………………………………………

NAME (BLOCK CAPITALS) Job title