Consent 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)

**Medical Diagnosis: …………………………………………………**

**Mandatory to participate in SMA-REACH**

**Please *initial* each statement**

I agree that clinical information about me will be collected and

saved in the SMA REACHUK 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 Great Ormond Street Hospital/ Institute of Child Health (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 part of the physical assessments.



(if you refuse, you may still take part in the study).



I agree that my GP will be informed that I am taking part in this study



I agree to be involved in a patient/parent/researcher focus group

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 the fully anonymised clinical and physiotherapy information about me, collected and saved in the SMA REACH UK database, will be shared with an international database and that this information can be accessed by Biogen and third parties (pharmaceuticals/academic institutes/any government bodies as required) in a strictly anoymised form. I agree that anonymised clinical information about me 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)



……………………………………………

Signature (patient) Date…………………………………………….

**Practitioner Section:**

I have given the patient 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