SMA Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Diagnosis	Choose the clinical diagnosis if known.
Classification	Choose the classification if known.
Currently able to walk	Is the individual able to walk with or without help (orthoses, assistive device or human assistance) inside or outdoors? Tick box if the individual is able to walk; leave blank if not able to walk.
Currently able to sit without support	Is the individual able to maintain a sitting position on a chair or wheelchair without using their upper limbs for support or leaning against the back of the chair? Tick box if individual is able to sit without support; leave blank if not able to sit without support.
Best function	Select the option that describes the patient's current best level of motor function. Walking refers to functional walking with or without help (orthoses or assistive device or human assistance), inside or outdoors. Sitting independently: able to maintain the sitting position on a chair or a wheelchair without support of upper limbs or leaning against the back of the chair.
Acquisition age	If walking or sitting specify age of acquisition in months.
Wheelchair use (over 3 years of age)	If the individual needs to use a wheelchair permanently (because they are not able to walk at all) or if they need to use a wheelchair intermittently (because they are still able to walk sometimes).
Wheelchair usage age	Age in years when the individual started using a wheelchair.
Scoliosis surgery	Indicate if the individual has had any type of surgical procedure for lateral curvature of the spine in the coronal plane with a Cobb angle of greater than 10 degrees.
Gastric/nasal tube	Does the patient require nutritional supplementation via nasogastric or nasojejunal tube or gastrostomy?
Non-invasive ventilation	Does the patient regularly use a non-invasive ventilation device? Mechanical ventilation with nasal or bucal mask. Part-time means usually at night.
Invasive ventilation	If the individual has a tracheostomy for ventilation. Also indicate if the ventilation is used usually at night (Part-time) OR during day time and at night.
FVC Score	The individual's last Forced Vital Capacity expressed as a % predicted for height (not in mL). This is a pulmonary function test performed with spirometry.
FVC date	The date of the last FVC test (DD-MM-YYYY).
Family Members Table	The details of family members with a history of SMA.

SMA Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Clinical Trials Table	The trial and drug details of any current and previous trials the individual has participated in.
Other registries	Other registries the individual is registered in.
Notes	Include any relevant details not covered in the previous sections here.
Genetic Module	
Gene	Enter the gene as appropriate.
Technique	Select the technique from the drop-down list.
Deletion of Exon 7 SMN1 gene	Select the appropriate classification from the drop-down list.
Exon 7 Sequencing	Select if Exon 7 has been sequenced.
DNA variation	If Exon 7 has been sequenced, enter the DNA variation as appropriate.