



SMA REACH UK

SMAReach and iSMAC NND user guide

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National Neuromuscular Database (NND)

SMA REACH

Spinal Muscular Atrophy

National Neuromuscular Database

DMD SMA

Start typing to search. Records: 121

Number	Created	Sponsor	Party Number	Consent
SN0456	12/07/2019 15:22	GOSH	[REDACTED]	✗
SN0455	12/07/2019 15:20	GOSH	[REDACTED]	✗
SN0445	09/05/2019 14:23	GOSH	[REDACTED]	✗
SN0431	10/04/2019 11:13	GOSH	[REDACTED]	✗
SN0424	07/03/2019 17:05	GOSH	[REDACTED]	✗

Summary
Timeline
Documents

Patient

()

Diagnosis

Unspecified

Clinic

GOSH

Assessments

Key Medical

Medical ()

Physio ()

Side Effects

Submitter:

- Scannable SMA REACH Key Medical
- Scannable SMA REACH Follow-up medical
- Scannable FUP SMA
- Scannable KM SMA
- Scannable FUM SMA
- Scannable SMA REACH Key Medical for patient
- Scannable SMA REACH Follow-up Medical for patient
- Scannable KM SMA for patient
- Scannable FUM SMA for patient
- Scannable FUP SMA for patient
- Manage Consent
- Manage Primary Centre
- Manage Current Centres
- Manage Cohort Membership
- SMA Summary Sheet Report
- Change Patient Phase
- iSMAC baseline report
- iSMAC Laboratory Measures Form
- iSMAC Physiotherapy form
- iSMAC Visit Form
- SMA REACH Physiotherapy form
- FUM SMA
- KM SMA

Database details

- DMD tab is for Northstar patients, SMA tab for SMA-REACH patients
- Patients can be filtered according to their ID number i.e Northstar or Smartnet number, Sponsor (primary site), party number (NHS number).
- **Summary tab** provides a list of completed documentation, and selected information
- **Timeline tab** provides a timeline of documentation completed (can view/modify past assessments)
- **Documents tab** allows users to download any completed documentation, including scanned forms

To enter a new patient

- Ensure that the patient has been appropriately consented to the new version 1.5 SMA-REACH as per study requirements.
- Create patient to add this patient to the database and a SMARTNET ID number is automatically generated. You will need the patient's NHS number. The number must be entered correctly as the database does not automatically check the number.
- Ensure the patient is marked as consented (green tick) on the database by clicking on the 'manage consent' field.
- For any general queries (IP whitelisting, technical issues), please contact 'nnd.support@certus-tech.com' where queries will be dealt with by either the SMA-REACH data managers or NORTHSTAR Horeja Njai (h.njai@ucl.ac.uk) .

SMA-REACH sites - which forms to complete?

iSMAC medical/lab measures/visit forms are different from SMAREACH key and follow-up medical forms

- First visit: Complete
 - SMA-REACH key medical (KM) form
 - SMA-REACH Follow-up medical (FUM)
 - SMA-REACH PT form.
- All subsequent visits: Complete
 - SMA-REACH Follow-up medical (FUM)
 - SMA-REACH PT form
 - SMA key events form-record deaths, other significant events as required

Complete either scannable versions for later transcription or posting to Certus or non-scannable for online completion

BIOGEN ISMAC sites - which forms to complete?

Only ISMAC sites can access ISMAC forms (aka 7 UK sites)

- First visit (visit 1): Complete
 - ISMAC baseline form
 - ISMAC Lab measures
 - SMA-REACH PT form
- All subsequent visits: Complete
 - ISMAC visit form
 - ISMAC Lab measures
 - SMA-REACH PT form .
 - SMA key events form-record deaths, other significant events as required
- Complete lab measures form as required.

Reminder: if *any patient is on a clinical trial please mark yes and **do not** complete any further sections on the datasets.*

Please note these forms are currently online only. They can be saved and modified as required.

PT Assessments in order of priority

ALL SITES COLLECT – WHO / VIGNOS/ ARM FUNCTION ENTRY ITEM
SUMMARY FUNCTION

Non-sitters - Younger
CHOP-INTEND
HINE

Non-sitters - Older
RULM
EK2 – UK mainly

Sitters - Younger
RHS / HFMSE
RULM
HINE

Sitters - Older
RULM
EK2 – UK mainly
RHS / HFMSE

Walkers – all ages
RHS / HFMSE
6MWT
RULM

For **Global Biogen ISMAC CRF's**, we are aiming for all other scales listed to be performed if space is available

For **Other national SMA-REACH sites** we are aiming for at least one additional assessment from each of the other boxes

Video assessments and assessments not completed:

Where a Video Assessment is done, please complete the:
WHO motor milestones

(see remote working SOP and video <https://vimeo.com/415169890>)

Where a specific assessment was not completed, please provide reasons by using codes on the SMA Reach forms.

*For older children and adults, ability to sit independently, stand and walk are main focus

ALL PATIENTS – WHO* / VIGNOS/ ARM FUNCTION ENTRY ITEM
SUMMARY FUNCTION

6MWT (W)

Valid from 30 months but can start earlier
1. RHS. 2. HFMSE (S + W)

Minimum start age 2.5 years
RULM (loss of arm function predominant)

1. CHOP-INTEND 2. HINE (NS)

7 years min
EK2 (not a W)



What assessment should I prioritise especially for MAA?

One that will pick up change

Patient has room to move on scale

E.g.

Being doing CHOP-INTEND
Getting stronger in supported sitting
Start RHS as might do item 21 and 22 and soon score on item 1

Older weak non-sitter,
Could have been a type 3 or 2
Scores virtually nothing on RHS
Use RULM

Stronger Type 2 scores a point on WHO walk item for first time (5 balanced steps)
At next visit consider 6MWT

Key Points SMA Reach and ISMAC forms

Visit ID on ISMAC forms-*not applicable*, please enter a generic number e.g. **00** as this data is not submitted to Biogen.

Enter data **only once** if you are involved in both projects.

Enter date, time, evaluator fields **only once**

It has been agreed, that if there is not available information to be entered, “-9” should be entered instead. This includes the fields: Growth, Spirometry values, Chest infections and Scoliosis values (E.g. Cobb Angle)

Always check on the clinical letters for this information.

ISMAC forms- FYI DOB, NHS number and other identifiable information are removed from the report submitted to Biogen therefore completely anonymising the data.



www.physiotherapy.newcastle-muscle.org



Welcome

Welcome to our JWMDRC Physiotherapy Portal

You will find the most up to date version of several clinical outcome assessments which we have either:

- Been involved in the development of, and / or
- Been involved in creation of the manuals associated with the measures

The SMA tab contains slide decks which have been approved for use in the UK by Biogen UK. You will need to check with your local Biogen office if their use has been approved in your country.

You are logged in!

Hello Anna,

You are now logged in with the following username

Anna.Mayhew.

[Logout](#)



Request access
via the website

Spot a
mistake? New
user needs
adding?

Contact our data managers-

Matthew Madden
m.madden@ucl.ac.uk

Elzo Cavalcante
e.cavalcante@ucl.ac.uk

Have a
question
about
functional
assessments?
Need
training?

Contact Anna

Anna.mayhew1@nhs.net