The Revised Hammersmith Scale for Spinal Muscular Atrophy: Moving towards meaningful measurement, content validity from a patient/carer perspective

D. Ramsey, M. Scoot, F. Muntoni
Dubowitz Neuromuscular Centre, UCL & Great Ormond Street Hospital, London, UK

BACKGROUND:

- Functional outcome measures are frequently designed by professionals to assess body structures, functions and reflect real life activities. User involvement in the development of outcome measures is an essential part of scale construction.
- Identification of the Minimally Clinically Important Difference (MCID) of an outcome measure is often difficult to quantify but much sought after. It is therefore important to clarify that what is measured is meaningful to patients, and in the case of children also their parents and carers.
- The Revised Hammersmith Scale for SMA (RHS) was designed by physiotherapists and clinicians to assess physical abilities of people with type 2 and 3 SMA.
- SMA REACH UK undertook a patient involvement exercise to identify whether each item on the RHS relates to real life activities and what meaning people with SMA/families of those with SMA give to it.

AIM:

To investigate content validity of the RHS from a patient/carer perspective in patients with type 2 and 3 SMA.

METHODS:

- Participants: SMA REACH UK registered patients & parents/carers
- Focus groups (March & September 2015):
  - Each item of RHS presented by SMA REACH UK Physiotherapist
  - Focussed discussion on real life activities & post-its/workbooks
  - Rate 3 most important items to them
  - Questioned on meaningful change related to their last RHS assessment.
- Participants: n = 19 (SMA 2 = 6 families, SMA 3 = 3 families), 4 children (SMA 2A = 1, SMA 3A = 3)
- Content Validity: Qualitative data obtained for all 36 items on patient/carer meaning and real life activities, figures 1 & 2.
- Meaningful Measurement: 7 case studies relating to meaningful changes related to RHS score, example case study below.

RESULTS:

Figure 1: Overview of patient/carer perceptions of the RHS - what the RHS means and real life activities

Figure 2: Example of qualitative content validity data from a patient/parent perspective for items on the RHS

CONCLUSION:

- Meaningful change is more than a description of how many points are scored on a scale.
- This study has anchored a clinically reported scale to ‘real life’ activities and given meaning from an SMA patient/patient perspective, this is a valuable step towards identifying the minimally clinically important difference of the RHS.
- These results are also of relevance the original Hammersmith Functional Motor Scale Expanded.