

PReS JDM working party - Summary document- January 2020

Who are we?

The core members of the Working Group Steering Committee were elected in June 2019 as follows:

- Chair: Liza McCann (UK)
- Secretary: Meredyth Wilkinson (UK)
- Past Chair: Helga Sanner (Norway)
- Representative for basic science: Judith Wienke (Netherlands)
- Representative for clinical care / clinical science: Charris Papadopoulou (UK)
- Representative for education/training: Raquel Campanilho-Marques (Portugal)
- Representative for EMERGE: Raquel Campanilho-Marques (Portugal)

Since that time, we have co-opted the following members:

- Allied Health Professional Representatives: Sara Röstlund (Sweden) and Mette Nørgaard (Denmark)
- Parent representative: Joanne Swan (Scotland)
- Patient representatives: Alannah Murray (Ireland) – has needed to step down; **another patient representative is needed.**

Aims & progress:

- Our aim is to frame our work in line with the PReS pillars – clinical & research, basic science and education / training.
- At the last PReS meeting, a brainstorm with the group defined some items that could be achieved, as follows:
 - Angelo Ravelli presented the JDM multidimensional assessment report - JDMAR. It was suggested to merge available tools as much as possible to facilitate harmonization of the registries.
 - It was suggested that we could have a platform with all the ongoing and/or futures projects that centers are working on, allowing multi-centric collaborations so all the centers potentially interested could contribute with patients/samples.
 - We were informed that there will be a plenary session (at PRES congress) where WP members can present their ongoing projects for a wider audience.
 - A possible education project was suggested: to apply JDMAR to a group of physicians with less experience in JDM (once licensing issues resolved).
 - Parent teaching was suggested.
 - There was recognition of the need to improve transition processes.

What is important to us?

We think that part of our role within the PReS Working Group is to help standardise care, facilitate multi-centre research projects and enhance educational opportunities.

What have we done so far?

We have:

1. Created a survey to define opinion / use in practice of the SHARE consensus guidelines, sent to all members of the JDM working group and EMERGE.
2. Brought together experts in PROMs to start to explore how we can potentially use available tools such as the PROMIS questionnaires in practice – work in progress.
3. Developed a research proposal on sleep in JDM – work in progress.
4. Clarified the role of shared databases – creating a document on Euromyositis and data sharing. This will be added to PReS website.
5. Informed members of the EMERGE group of training opportunities / fellowships.
6. Presented a PReS update at the IMACs meeting – promoting shared working and collaboration.

How to contact us:

Please contact us with suggestions / comments / feedback:

E-mail the JDM working group secretary (Meredyth Wilkinson) or Chair (Liza McCann): meredyth.wilkinson.14@ucl.ac.uk / liza.mccann@alderhey.nhs.uk