

Report SIG 'Patient Autonomy' in-between meeting

November 23 - 24 2018, Berg - Germany



Picture 1: From back/left: Christoph Heesen (DE), Sascha Köpke (DE), Insa Schiffmann (DE), Carolin Festner (DE), Anna Barabasch (DE), Ambra M Giovannetti (IT), Alessandra Solari (IT), David Wilkie (UK), Anne Rahn (DE), Emma Nicholas (UK), Richard Nicholas (UK), Ingo Kleiter (DE), Andrea Giordano (IT)



Picture 2: David Wilkie presents his project to the SIG

Participants:

Anna Barabasch, Universitätsklinikum Hamburg-Eppendorf, Hamburg – DE

Sascha Köpke, Universität zu Lübeck, Lübeck - DE

Andrea Giordano, Fondazione IRCCS Istituto Neurologico “C. Besta”, Milan - IT

Ambra M Giovannetti, Fondazione IRCCS Istituto Neurologico “C. Besta”, Milan - IT

Christoph Heesen, Universitätsklinikum Hamburg-Eppendorf, Hamburg - DE

Richard Nicholas, Imperial College, London - UK

Emma Nicholas, Royal Trinity Hospice, London - UK

Birgit Basedow-Rajwich, Marianne-Strauß-Klinik, Berg - DE

Ingo Kleiter, Marianne-Strauß-Klinik, Berg - DE

Carolin Festner, University Medical Center, Hamburg - DE

Anne Rahn, Universitätsklinikum Hamburg-Eppendorf, Hamburg - DE

Insa Schiffmann, Universitätsklinikum Hamburg-Eppendorf, Hamburg - DE

Alessandra Solari, Fondazione IRCCS Istituto Neurologico “C. Besta”, Milan - IT

David Wilkie, Imperial College, London - UK

Summary

Fourteen health professionals and researchers (neurologists, psychologists, nurses, health scientists, and a pharmacist) from 3 European countries participated in the 2018 SIG interim meeting, which was entitled *‘The autonomous MS patient - Defining evidence gaps and setting an agenda for new collaborations’*.

We used this meeting to define where we stand at the moment regarding “patient autonomy in MS” and to find ideas where to go next. Therefore, updates on existing projects guided by the MRC framework to locate the evaluation status of different projects were given and fruitful discussions of those projects provided further guidance. An overview on information provision and rehabilitation programmes for people with primary progressive (PPMS) was also presented in order to define research gaps.

Ingo Kleiter showed us and gave a presentation of, the Marianne-Strauß-Klinik (<https://www.ms-klinik.de/>), which is a specialised clinic for PwMS. Birgit Basedow-Rajwich, also from the Marianne Strauß-Klinik, who is a palliative care (PC) specialist provided information on the PC services at the clinic. As a couple of members are involved in the production of an EAN guideline on PC for people with severe MS (lead by A. Solari) and Emma Nicholas, who is a PC nurse, presented her Master thesis project on this topic, PC for PwMS was discussed in much detail. It was reflected what makes PC special in MS and that it is therefore necessary to develop tailored interventions for PwMS.

Further, David Wilkie showed us a 2 min-movie to motivate PwMS to think about immunotherapy, which led to a discussion on video-based engagement strategies for PwMS, feedback on the movie as well as possible next steps to be considered in this field.

First results of ManTra ('Managing the transition to secondary progressive MS'), a project led by A. Solari (participating countries: Italy and Germany), which aims to develop and test a user-led resource for newly diagnosed people with SPMS, were provided and a discussion on the online survey results and candidate resources followed.

Finally, we discussed three project ideas in more detail: 1) Motherhood choice in MS, 2) Information needs of people with PPMS as well as intervention development, and 3) Advance care planning in severe MS. In the next few months, we will develop the three project ideas and present them to the whole SIG 'Patient Autonomy' group during the next Annual RIMS Conference, in order to choose one/two SIG project(s) to work on. The possibility to apply for the RIMS RiGra grant was also discussed.

In summary, we had a very informative meeting with in depths discussions leading to potentially new collaborations between countries and we identified three topics as ideal areas for future SIG "Patient Autonomy" projects.