

Report SIG 'Patient Autonomy' meeting

November 16-17 2017, Milan - Italy

Twenty six health professionals and researchers (neurologists, psychologists, nurses, health scientists and methodologists) from five European countries participated in the 2017 SIG interim meeting, which was entitled 'The expert MS Patient: moving along the illness trajectory'. Overarching projects regarding MS patient empowering and shared decision-making were discussed, from the early phase of decisions regarding disease modifying treatments [1,2] and MRI understanding, to the needs of patient transitioning to secondary progressive MS [3], and patient and carer involvement in guideline production on MS palliative care. The meeting structure was new, as current projects held in this topic were discussed during the first day of the meeting, and in the second day new ideas and embryonic projects were shared. Carla Finocchiaro, Grant Officer at Fondazione IRCCS Istituto Neurologico C. Besta, participated to the meeting and supported participants in navigating pertinent calls. The final aim was to foster collaborative projects in the field of MS patient autonomy, involving professionals and researchers that are not currently part of our SIG. The close collaboration with the SIG Psychology is now well established (Jana Pöttgen, chair of the SIG Psychology participated and joined meetings proved successful and will be repeated), and such collaboration and networking can be also proposed with other groups.

References

1. Heesen C, et al. What should a person with relapsing-remitting multiple sclerosis know? - Focus group and survey data of a risk knowledge questionnaire (RIKNO 2.0). *Mult Scler Relat Disord*. 2017;18:186-195
2. Rahn AC, et al. Nurse-led immunotreatment DEcision Coaching In people with Multiple Sclerosis (DECIMS) - Feasibility testing, pilot randomised controlled trial and mixed methods process evaluation. *Int J Nurs Stud*. 2017. pii: S0020-7489(17)30189-X
3. Giovannetti AM, et al. Managing the transition (ManTra): a resource for persons with secondary progressive multiple sclerosis and their health professionals: protocol for a mixed-methods study in Italy. *BMJ Open*. 2017 Aug 23;7(8):e017254