Report SIG Patient Autonomy meeting 2023

SIG group	Patient Autonomy
Date of in-between meeting	10/10/2023
Venue (incl. city, country)	Online
Topic	Patient and Public Involvement and Engagement in Research

Report:
About 20 MS health professionals and researchers (e.g. neurologists, psychologists, nurses, physiotherapists) participated in the online meeting organized by our SIG Patient Autonomy. The meeting was held online on 10th October 2023.
The meeting was entitled *'Patient and Public Involvement (PPI) and Engagement in research'.* During this meeting, various stakeholders presented: clinicians, researchers and people with MS reported on the topic according to their perspectives and experiences. Then, there was a roundtable discussion involving all the stakeholders and participants.

After a short introduction by Andrea Giordano (SIG Co-Chair), during the first session, Rachele Paolucci (person with MS, working in the Italian MS Society and representative of the Italian MS Foundation) made a general overview of Multi-ACT and Alameda projects. These are two European-funded projects involving MS people in relevant executive and working groups, such as the Engagement Coordination Team and the Local Community Groups, which include people with MS and caregivers.
Then, Sinead Hynes reported on the status of ‘Patient involvement in the Cognitive Occupation-Based programme for people with MS (COB-MS) project’. The COB-MS trial involves 110 participants in a 2 arm – intervention and wait-list control trial. PPI was a key component of each study stage (i.e., design, management, analyzing & interpreting, dissemination, and implementation), and a PPI contributor is an embedded patient researcher. Interestingly, along with the trial results, PPI is also being evaluated using a checklist/evaluation tool based on PPI input and previous literature that focused on areas such as Policy and Practice, Participatory Culture and Collaboration, and Influencing Outcomes of PPI.
Then, Insa Schiffman made a short overview of PPI involvement in clinical practice guidelines. Based on two recent reviews, she showed that PPI has been recommended but poorly realized. There was no consensus/guideline on PPI in clinical guidelines development. If PPI occurs, most commonly, patients and advocates have been involved, recruited from patient groups, and primarily engaged in identifying the questions to be addressed in the clinical guidelines.
Finally, Helen Burchmore, EUPATI Fellow, reported on her personal experience in joining EUPATI initiative and its Patient Expert Training Program. EUPATI’s mission is ‘to provide accessible, innovative and inclusive education that empowers patients and patient representatives with the right knowledge, skills and competencies to engage effectively and partner with all other stakeholders in the medicines Research and Development process’.

The Patient Expert Training Programme is an expert-level training on medicines Research and Development: it is non-disease specific, using an online & face-to-face format. The duration is 12-14 months, with 250+ graduates. The programme aims to empower fellows to play leadership roles in patient organisations, advising pharmaceutical companies, advising a regulatory agency, and advising a reimbursement / HTA body.
After that, there was a discussion-rich roundtable involving the speakers and participants. Finally, there was a short update on NIPS and MoMS projects.

The meeting was fruitful and discussion-rich, and participants appreciated the possibility of attending such a meeting.

Future plans:
To continue the discussion on PPI within our SIG.

Next in-between meeting:
The next in-between meeting of the SIG Patient Autonomy will take place in Autumn 2024.

Participant list:

Sinéad Hynes
Alessandra Solari
Alex Maximilian Keller
Amanda Keller
Barbara v. Glasenapp
Daphne Kos
Giulia Di Domenico
Gianluca Florio
Heleen Beckernan
Helen Burchmore
Insa Schiffmann
Karin Riemann-Lorenz
Klara Novotna
Lina Dümmer
Nicole Krause
Rachele Paolucci
Susan Seddiq Zai
Christoph Heesen
Julia Peper