

Activity 3, EPICLUSTER workshop: Accelerating Patient Involvement in European Epilepsy Research

Background and context for event: Over the last decade Patient Involvement has become a central feature of healthcare, with growing evidence of its positive impact on clinical research, and increasing adoption by health authorities, regulators and industry. Patient involvement in basic and preclinical research remains limited, including in the epilepsy field. To unveil these opportunities and to set the stage for multi-stakeholder collaboration, in October 2021, [EPICLUSTER](#) organized the first workshop in Europe on patient involvement in epilepsy research. The workshop began with an overview of definitions, principles, and trends in the field. This was followed by a practical session on how to start PI addressed to researchers new to the field. Then, the event went on with a roundtable highlighting opportunities and a number of PPI-enabling initiatives. Finally, the last session presented several case histories to assess the readiness of the epilepsy field with regard to research partnerships between patients and the scientific community.

Patient involvement and health research in Europe

Current best practice on patient involvement

The workshop was opened by **Jim Elliot** (NHS, Health Research Authority) who provided an overview on the definitions and current best practices on patient involvement. To offer some insights into the underlying principles of PPI that might apply to preclinical research, Elliot shared guidelines developed in the United Kingdom to help PPI practices in clinical research. This included involving the right people, to involve enough people, to involve them enough and finally to describe how the involvement has helped the research.

Patient involvement in research: Co-production and why it is essential now.

The second speaker, **Erik Van der Eycken** shared the experience of [Global Alliance of Mental Illness Advocacy Networks-Europe](#) (GAMIAN-Europe), an umbrella organization of National Patient Organizations in Mental Health. He focused on the opportunities arising from patient involvement throughout the project and how GAMIAN-Europe has lead a broad range of activities aimed at collecting and integrating the patient perspectives in research. To follow, **Joke Jaarsma, President of the [European Federation of Neurological Associations \(EFNA\)](#)**, emphasized the numerous challenges that prevent the realization of meaningful patient engagement, and provided a cross-section of the landscape facing patients with neurological diseases. The session ended with **Tsveta Schyns-Liharska** who shared her journey as a parent and driver of engaged patient communities for a rare genetic disease.

Session 2: Patient involvement: A beginner's guide

Getting patient involvement started – practical advice.

Dr. Heather Mortiboys (Sheffield Institute for Translational Neuroscience) shared practical information and insights into how to implement patient involvement for basic researchers. Working in the field of

Parkinson's disease, she explained how she trains early career basic researchers on the value of PPI. This includes how to start, relationship and building the knowledge base and maintaining engagement.

Moderated panel discussion

Experts from various PPI-related organizations and initiatives (Maria Duterte, Executive Director, European Patients' Academy - EUPATI; Richard M Ballerand, EUPATI training fellow; Nicholas Brooke, executive director, Patient Focused Medicine Development – PFMD - and founder of The Synergist; Valentina Strammiello, Head of Programmes, European Patients Forum - EPF) shared their perspectives in a panel discussion moderated by Donna Walsh, executive director EFNA. This included key learnings on:

1. How patient involvement in research is gaining momentum and is expected to increasingly transform the biomedical research landscape.
2. Lack of readiness and need for researchers' training
3. Treating patients as equal partners and reward their time investment and contribution.
4. How to identify the right people
5. How to incentivize researchers to embrace patient involvement

Session 3: Patient involvement in epilepsy research

The workshop ended with a spotlight on some case histories of patient involvement in epilepsy research. Four testimonies provided practical insights into what people with epilepsy and their organizations can contribute to research, and the reasons why patient involvement can be a game-changer for the epilepsy research. These were by **Isabella Brambilla**, mother of a boy with Dravet syndrome and active epilepsy advocate. She shared her experience of organizing multi-stakeholder meetings, raising funds and supporting research projects, and participating in the creation of a patient registry. EUPATI fellow **Bojana Miroslavljevic**, the founder of a patient organization for families with children affected by rare diseases in Serbia, further emphasized that people with epilepsy and their carers have not only their lived experience with the disease to contribute but are also increasingly equipping themselves with knowledge and skills to better understand and participate in research projects. **Simon R.W. Lees** brought the audience into the realm of digital health technologies and shared his experience as a patient advisor for the RADAR-CNS project (Remote Assessment of Disease And Relapse - Central Nervous System). Finally, the Patient Value Strategy at UCB was presented by **Alexandra Moutet** (Global Head of Patient Engagement at UCB). The initiative's goal is to build a cycle in the R&D process where everything starts from the patients and, ultimately, returns to the patient.