

Platinum Session: Making Patient Engagement Truly Meaningful in Chronic and Complex Mental Health Conditions

Brain Innovation Days 2023 | Panel outcomes

Moderator:

- **Vanessa Pott**, Global TA Patient Engagement Lead, Boehringer Ingelheim

Panellists:

- **Péter Kéri**, President, GAMIAN-Europe
- **Alice Medalia**, Professor in the Department of Psychiatry, Columbia University Irving Medical Center
- **John Saunders**, Executive Director, European Federation of Associations of Families of People with Mental Illness (EUFAMI)

Introduction

In partnership with Boehringer Ingelheim, the Brain Innovation Days organised a panel discussion on how we can deepen the involvement of people living with mental health conditions in cross-disciplinary work. With expert speakers sharing clinical, lived experience and carer perspectives, this session explored ways to ensure our work is co-created with those who are most impacted by chronic and complex conditions like schizophrenia, discussing topics like: how can patient participation improve care pathways? How do we move beyond tokenism?

Meaningful patient engagement

Patient engagement plays a crucial role today. Meaningful patient engagement is a cornerstone of modern healthcare, emphasizing a collaborative and empowering relationship between healthcare providers and individuals seeking care. It goes beyond the traditional model of a passive recipient of medical advice, involving patients as active participants in their own health journey. This approach recognizes the unique perspectives, preferences, and values of each patient, fostering open communication and shared decision-making.

Péter Kéri shared his personal experience of being diagnosed with late-onset schizophrenia and highlighted the natural inclination of individuals, even with mental health conditions, to be involved in decision-making about their lives. In addition, he also expressed the importance of involving individuals who face significant challenges due to their conditions and suggested a future where those directly affected by illnesses play a more active role in discussions and decision-making.

Patient participation and co-creation

Working with people living chronic and complex mental health conditions shines a light on how patient participation and co-creation can improve care pathways and outcomes in mental health. Patient co-creating in mental health represents a transformative shift from traditional clinician-led approaches to collaborative models that actively involve individuals in the design and implementation of their mental health care.

Alice Medalia emphasized the significance of a learning healthcare system where patient feedback continually informs and updates mental health services. She discussed involving patients in research from the grant proposal stage, creating shared vocabulary, and framing discussions in a positive light.

Carer perspective

Family and friends can be converted into carers and advocates providing meaningful support to people with chronic and complex mental health conditions, and carers can ensure patients voices are heard and become more involved in driving progress.

John Saunders emphasized the shift from institutional care to community-based care and highlighted the trauma and challenges faced by families in providing care. He mentioned the stigma and shame associated with mental health issues, making it difficult for families to seek support. John also stressed the importance of involving family members in the recovery process and how they can contribute valuable information.

Conclusion

In the final part, the audience shared their reflections on mental health, expressing inspiration, hope, and the need for collaboration. The importance of bravery in discussing mental health openly and a call for a future where such discussions are considered natural were highlighted. The session ended with a reminder of the complexity of mental health issues and the need for collaborative efforts to address them comprehensively.