

PATIENT CENTRICITY IN ACTION

DIRECTION study patient & caregiver advisory board

The Ipsen team held an advisory board and workshop with adults living with spasticity and caregivers, to gain insights on the DIRECTION study design, patient materials, and challenges.



NEUROSCIENCE



Rationale

There is limited feedback from people living with spasticity regarding the clinical trial process and how materials could be made more accessible. The team were interested in learning how study participants could be better supported, how study materials could be adapted to make them easier to understand, and what existing challenges, associated with participation, exist.



Co-creation

The team sought input from advisors to discuss their experiences of living with spasticity, their needs and expectations from participation in the DIRECTION study, as well as potential challenges specific to the study and solutions to address them.



Project description

The discussion focused on several key areas relevant to the patient/caregiver experience:

- The story of their spasticity, how it emerged, how it affects their daily life, and challenges they face.
- The study general outline in plain language, and their feelings around the challenges or advantages of participation.
- Their feedback on study materials for participants, such as sample informed consent forms (ICFs) and study cards.
- Logistical challenges around transportation, scheduling, or how easy or difficult it may be to participate in such a study.



Impact/results

The workshop lead to some key insights to improve the experience of people living with spasticity during clinical trials, including:

- Providing a very plain language summary, at the top of the ICF, of what to expect during the study.
- Logistical support, such as organizing transport and scheduling appointments.
- Encouraging clear communication between HCPs and study participants.



Learnings and next steps

- Ipsen will consider how these insights can be integrated into the study process and how interim study progress updates can be shared with participants to keep them informed.
- Ipsen will share how the information gathered at this patient advisory board has been used with the participants.

“ We want patients and caregivers to know that they are at the heart of our study design. These advisors provided insights that only someone living with spasticity can, and it is so important that we continue holding workshops like this to truly listen to patient needs and take action. ”

Dr James Otto, DIRECTION Lead, Ipsen

ALL-ALL-003665

Date of preparation: November 2021



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