



Grant Agreement Number: 101047131

## NEUROSENSE Patient Advisory Board Charter

1<sup>st</sup> February 2023

Version 1.0



**Funded by the  
European Union**

## Executive summary

NEUROSENSE Project aims to have the patient perspective **embedded from the conceptualization of the SUDEP Predictive Medical Device (SMD) prototype so that the projected device adequately addresses the needs of the epilepsy community.** The NEUROSENSE Patient Advisory Boards (PAB) will be implemented as a patient-centricity initiative, to provide added value by identifying patient priorities, bringing the patient perspective on living with the condition and the impact of different treatments into clinical research, and using their extensive networks to ensure patient involvement at different levels of the NEUROSENSE Project. The NEUROSENSE PAB will support NEUROSENSE Consortium to be at the forefront of the patient-centricity reality.

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## 1. NEUROSENSE Patient Advisory Board

Patients must be at the heart of healthcare, from prevention and awareness, through research and development, regulatory and health technology assessment processes, to service design and outcomes measurement. Working with patients throughout the process delivers better outcomes for patients, for healthcare systems and for society as a whole.

In the past, industry, academia, healthcare professionals, regulators, and patient organisations have largely worked in silos. In practice, many decisions about patients' care, medical research, health information and service design were taken without meaningful patient involvement. This led to inefficiencies and low value in process and outcomes.

But this is starting to change. In recent years, many companies have developed new ways to incorporate Patient insights and to collaborate with Patients and patient organisations in a transparent and ethical way.<sup>2</sup>

As patient-centricity is at the core of the NEUROSENSE Project, its bold ambition is to have PWE perspective embedded in the conceptualization of the SMD so that the projected SMD reflects the real needs of the epilepsy community. The presence of PWE, their caregivers, and their families has been pivotal since the development of the NEUROSENSE proposal, in which the objective of the NEUROSENSE project was refined by the PWE visions. This joint effort is now being further materialized through the establishment of the NEUROSENSE Patient Advisory Board (PAB) which will support the NEUROSENSE Consortium to establish users' requirements that, alongside the technical requirements, will shape the design of the SMD prototype. Not only the PAB will advise NEUROSENSE during the lifespan of the project, but their insights will be open to the epilepsy community, pharmaceutical, and medical device industry. It is the NEUROSENSE Consortium's expectation that the patient-centric approach will become a model to foster patient-centric healthcare beyond epilepsy so that the pharmaceutical and medical device industries become increasingly more open to including patient perspectives.

### 1.1 Purpose

The purpose of the NEUROSENSE PAB is to create an environment where PWE, families, clinicians, and the NEUROSENSE Consortium can work together as partners to co-design the

[2. Working Together With Patients Principles For Remunerating Patients, Patient Organisation Representatives & Caregivers For Work Undertaken With The Pharmaceutical Industry](#)

SMD Prototype and improve NEUROSENSE overall strategy in best addressing the needs of PWE, caregivers, and families. NEUROSENSE PAB provides a formal mechanism for integrating the voices of the PWE and caregivers into the design of the NEUROSENSE research and development processes, by sharing their unique and invaluable perspective on epilepsy and SUDEP, associating unmet medical needs and their experiences with the products currently approved or in development with the goal of better serving the epilepsy community.

The NEUROSENSE PAB is set up to contribute to NEUROSENSE Project priority-setting by enabling ongoing full, frank and open discussions and information sharing between the NEUROSENSE Consortium representatives and PWE, their caregivers and families during the NEUROSENSE Project lifespan. This will be achieved through NEUROSENSE PAB representation on the annual NEUROSENSE Summits.

## 1.2 Mission

- The NEUROSENSE PAB shall be an active member in the NEUROSENSE Project by being represented in the Annual Meetings (NEUROSENSE Summit).
- The NEUROSENSE PAB will be an active participant in the decision-making process in the design and development of the SMD prototype.
- The NEUROSENSE PAB shall be an active member in organizing the Design-thinking workshops during the NEUROSENSE Project lifespan.
- The NEUROSENSE PAB will serve as an avenue for hearing to what the patient needs are, as well as allowing for an exchange of ideas and input on NEUROSENSE activities.
- The NEUROSENSE PAB will promote partnerships between NEUROSENSE and PWE.
- The NEUROSENSE Consortium will engage PWE in short and long-term quality improvement initiatives in partnership with researchers and clinicians.

NEUROSENSE PAB can offer:

- Insights on NEUROSENSE strengths and the identification of areas where changes may be needed.
- Feedback on practices and policies that PWE and families find meaningful and useful in helping them be active partners in their care.

- Timely feedback and a fuller picture of the care experience than standard patient and family satisfaction surveys provide.

### 1.3 Who makes up the NEUROSENSE Patient Advisory Board?

The NEUROSENSE PAB is a group of PWE, caregivers and PWE organisation representatives who have an interest in finding new therapeutic solutions to epilepsy and SUDEP. The NEUROSENSE PAB will have one facilitator who not only has experience moderating panel discussions but is also familiar with the clinic setting. This facilitator should be an active participant in the discussions and be able to make participants feel more at ease, lend credibility and trust to the panel discussion, and understand collective patient experience in managing a given disease condition.

### 1.4 Independence and conflict of interest

The NEUROSENSE PAB shall exercise its activities as an independent entity. The NEUROSENSE PAB does not have any relationship of agency, employment, or joint ventures with the NEUROSENSE Consortium. All the information shared between the NEUROSENSE Consortium and the NEUROSENSE PAB is public, to safeguard the NEUROSENSE Consortium Exploitation Strategy while allowing PWE associations to keep their mission, not withholding any information that could potentially benefit PWE, caregivers, and families.

## 2. Implementation of the NEUROSENSE PAB

### 2.1 Method to establish the network & Recruitment Tools

NEUROSENSE PWE network was initially created during the grant preparation stage, through NEUROSENSE members established networks. During the NEUROSENSE Project start-up phase, the NEUROSENSE PWE network was expanded through direct contact with PWE associations. For this purpose, a tailored presentation and NEUROSENSE Brochure were created to ensure consistency in the communication with the epilepsy community. The recruitment of members of the NEUROSENSE PAB will be further enhanced through the creation of an Advocacy section on the NEUROSENSE [website](#) and also in social media.

NEUROSENSE Consortium members may also invite their own patients to join the NEUROSENSE PAB.

## 2.2 Patient Advisor: Roles and Responsibilities

NEUROSENSE PAB members may be involved in the following activities:

- Joining a Steering Committee to provide input into all aspects from a patient or carer perspective.
- Commenting on NEUROSENSE goals to ensure they are relevant to patients and caregivers.
- Providing input on aspects of living with epilepsy that are important to PWE and caregivers, to inform guideline recommendations and future research studies.
- Offering advice on the best way to hear the views of PWE and caregivers and include them in the NEUROSENSE project.
- Taking part in and helping develop surveys and focus groups to provide the PWE and carer perspectives.
- Helping disseminate the NEUROSENSE project findings through their networks to PWE, professionals, and the public in general.
- Develop PWE-facing information materials, such as surveys, focus-groups materials, publications, lay guidelines, and factsheets.

## 2.3 PAB Summit Meetings

### 2.3.1 When, where and how will meetings take place?

NEUROSENSE PAB meetings are set to be held annually in 2023, 2024 and 2025, either face to face in an easily accessible European city or by tele/video conference. The NEUROSENSE Project Manager will send the invitation to all NEUROSENSE PAB Meetings. The meeting schedule will be set out and agreed within the NEUROSENSE PAB. If face-to-face attendance at a meeting is difficult due to health or accessibility issues, every effort will be made to allow NEUROSENSE PAB representatives to join remotely.

NEUROSENSE PAB Members are encouraged to exchange email addresses so they can share ideas and experiences between meetings. Other methods of online communication can also be used.

NEUROSENSE PAB minutes, along with any relevant documents, will be sent to the PAB representatives after the meeting. Representatives will be asked to provide feedback to other NEUROSENSE PAB members about the PAB meetings. The NEUROSENSE Project Manager will produce the minutes of all PAB meetings and share them with the NEUROSENSE PAB.

### **2.3.2 Who attends the meetings?**

The number of patient representatives who attend NEUROSENSE PAB meetings will vary depending on the budget and plans for patient input agreed upon in the Grant Agreement. Members can nominate themselves to attend or can be nominated by other PAB members.

### **2.3.3 What is expected from attendees?**

NEUROSENSE PAB members attending PAB meetings are expected to contribute the patient perspective to the discussions, give a balance of views and support each other. They will also be asked to collect input and provide feedback to the NEUROSENSE Consortium and the rest of the PAB before and after each meeting, so that their experiences can be used to inform the project.

## **3. Conclusion**

The foreseen establishment of the NEUROSENSE PAB is a concrete strategy forged to incorporate the PWE, families and caregivers' insights into the SMD prototype since its conceptualization until a mature stage at the end of the project. The results obtained in this scope are expected to set the standards for patient involvement in the research and development pipelines of the medical device industry.