

## Patients Expert Group (PEG)

### Meeting Report 21 February 2025

#### 1. Participants' Motivations

- **Personal Experiences as Drivers:**

Several participants shared that their involvement in the project is rooted in personal experiences with rare diseases. They emphasized the emotional and physical challenges of frequent hospital visits, early trauma, and the difficulties of managing a condition from childhood. One participant mentioned having dealt with the disease since early childhood, which reinforced the desire to improve paediatric care and support others facing similar challenges.

- **Commitment to Improving Care:**

Motivations were linked to a deep commitment to effect positive change in healthcare. Participants expressed that their engagement was not only personal but also aimed at ensuring that future patients receive more empathetic and effective care.

#### 2. Medical Care Experiences

- **Challenges in Diagnosis and Treatment:**

Participants discussed difficulties in obtaining timely and accurate diagnoses. One account detailed how early symptoms were dismissed as psychological or attributed to growing pains, leading to prolonged periods of unmanaged pain and uncertainty.

- **Feeling Unheard and Misunderstood:**

Several members described experiences where their concerns were minimized by healthcare professionals. This led to frustration, stress, and a growing mistrust in the medical system, especially when false reassurances were given regarding treatment outcomes.

- **False Promises and Treatment Disappointments:**

There was a consensus that doctors sometimes offered overly optimistic expectations about new treatments. When these treatments failed to deliver the promised improvements, it resulted in feelings of disappointment and betrayal.

#### 3. Confidentiality and Communication Protocols

- **Strict Confidentiality:**

The importance of maintaining confidentiality was strongly emphasized. All discussions are to remain within the group to protect personal information and encourage honest sharing.

- **Preferred Communication Channels:**

Feedback from the group indicated a strong preference for direct communication methods (e.g., WhatsApp, Slack) over traditional email. These platforms are seen as more immediate and conducive to open dialogue.

#### **4. Feedback and Participation Guidelines**

- **Structured Feedback Summaries:**

It was agreed that a concise feedback summary would be circulated after each session. This summary will capture key points and allow participants to review, correct, or add to the record as needed.

- **Respect for Personal Information:**

Guidelines were reiterated to encourage sharing of experiences without disclosing highly personal or sensitive details, ensuring that the safe and confidential nature of the group is maintained.

#### **5. Experiences with Disease Management and Research**

- **Misdiagnosis and Ongoing Health Challenges:**

One participant recounted a long struggle with misdiagnosis—initially being told that growing pains were responsible—until a later, correct diagnosis of arthritis was made. Despite treatment, the persistence of pain remains a significant issue.

- **Emotional Impact of Medical Interactions:**

Discussions highlighted how inadequate communication and the failure to address both physical and mental health aspects have negatively affected patient trust. There is a clear need for healthcare professionals to validate the subjective experiences of patients.

- **Self-Initiated Research:**

Participants described extensive efforts to research their conditions using various sources (including internet resources, books, and clinical trial data). These self-guided investigations are used to better understand treatment options and the overall evolution of their diseases.

#### **6. Non-Pharmacological Approaches**

- **Exploration of Alternative Therapies:**

There was significant discussion around the use of non-drug treatments such as physiotherapy, Pilates, and other complementary therapies.

- **Monitoring Treatment Effectiveness:**

One participant highlighted the importance of tracking the response to various interventions (for example, through maintaining a diary), which aids in evaluating what is effective in managing symptoms and overall quality of life.

## 7. Future Meeting Topics

### • **Everyday Life Experiences:**

Participants expressed interest in discussing how their conditions affect daily interactions and community engagement, including managing the challenges of communicating about a rare disease to those who are unfamiliar with it.

### • **Enhancing Patient-Doctor Communication:**

There is a strong call for exploring strategies to ensure that the patient's voice is heard in clinical settings. Future discussions may focus on how to empower patients to share their experiences and how healthcare professionals can integrate these insights into treatment plans.

### • **Clinical Trial Feedback:**

Another topic for future meetings is the process of clinical trials and how patient feedback on new treatments can be systematically captured and integrated into decision-making.

## Follow-Up Actions

### • **Feedback Summary Distribution:**

A short summary of each session will be sent out promptly to allow participants to verify and refine the record of discussions.

### • **Updated Questionnaire:**

The questionnaire link will be updated with additional questions based on the session's feedback and shared with the group to capture further insights.

### • **Planning Future Discussions:**

The next meeting will include a focused discussion on daily life experiences and communication strategies regarding the management of rare diseases.

### • **Establishing a Dedicated Communication Group:**

A WhatsApp group will be set up to facilitate the exchange of ideas and suggestions between sessions.

These minutes now offer a more comprehensive and detailed record of the meeting discussions while ensuring all personal identifiers remain anonymous.