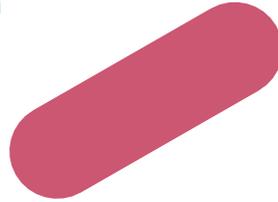




PPI IGNITE
NETWORK

IMPACT CASE STUDY



SYNERG-IE: Transforming Sjögren's Care Together

Who was involved?

- One lead site
- One patient advocacy organization
- One patient representative researcher
- Ten PPI contributors

Summary

The SYNERG-IE programme, funded by the Health Research Board, emerged from a RCSI-Sjögren's Ireland collaboration, one of many meaningful partnerships developed across the PPI Ignite Network in recent years. The programme aims to address needs identified by the Sjögren's community, by improving awareness and education on Sjögren's, and by impacting policy and practice. The research questions and research plans were co-created with the research team during grant writing. The voice of lived experience is influencing all aspects of the research, including the data collection tools and processes and stakeholder communication, with the patient voice helping to share research findings for broader impact.

Our work

A previous collaboration between a scientific researcher at RCSI and people living with Sjögren's disease motivated the latter to establish a patient advocacy group, Sjögren's Ireland, and to get involved in and advocate for further research into the condition.

SYNERG-IE is a five-year multidisciplinary research programme aimed at improving education, policy, and practice for Sjögren's disease – a misunderstood autoimmune disease often with debilitating symptoms. PPI is deeply embedded within the SYNERG-IE programme and all levels in the governance structures.

Early planning and grant development:

Collaboration with Sjögren's Ireland began in the early planning stages, with PPI contributors co-authoring the grant application and participating in the funding panel interview.

Governance: Sjögren's Ireland plays a critical role in our governance structures, including the executive, steering and PPI committees. This ensures that patient perspectives are considered throughout all decision-making processes.



Members of SYNERG-IE marking world Sjögren's Day (23 July) 2024

Patient research integration: A patient researcher with Sjögren's, employed 0.4FTE, is a key team member bringing personal experience to the research and, coordinating the work of the PPI committee, and enhancing patient-focused content across SYNERG-IE's digital platforms. Her insights are invaluable in shaping the direction and execution of our research activities.

PPI Committee: To involve a diverse range of patient perspectives in our research, we established a panel of 10 people through [an open call recruitment process](#).

Right across our work, we adopt fatigue-friendly practices, such as time-limited meetings and providing hybrid options for attending meetings.

We track the influence of PPI contributions using an impact log to enhance transparency and accountability.

Our impact

Research programme designed to meet patient needs

By involving Sjögren's Ireland in setting SYNERG-IE's direction, we ensured our goals directly addressed the specific needs of those living with Sjögren's disease. A patient representative researcher, pivotal to our team, along with Sjögren's Ireland and the PPI panel, continues to refine our approach to research and knowledge dissemination. This enhances the relevance of our work and boosts trust and engagement within the Sjögren's community.

Building a committed patient community

One of our notable successes was the organization of a hybrid knowledge exchange event that attracted over 120 stakeholders,



“We believe that incorporating the patient perspective into this vital research will lead to much needed changes in the diagnostic and care landscape for Sjögren’s patients nationally and globally.”

Deirdre Collins, Sjögren’s Ireland co-founder

including patients, carers, researchers, and healthcare professionals. This event bridged the gap between scientific research and community insights. Feedback highlighted the impact on community building, with attendees appreciating the opportunity to meet others affected by Sjögren’s disease, to network, and to feel part of a community.

Refinement of research tools

Input from our PPI panel has impacted our data collection processes. Modifications to the design of our patient survey, like adding section introductions and defining terms such as ‘flare-ups’, has made our survey more accessible and user-friendly. The patient researcher has played a central role in co-designing and co-facilitating photovoice workshops, ensuring these activities are tailored to patients’ needs and relevant to their experiences.

Inclusivity in meetings

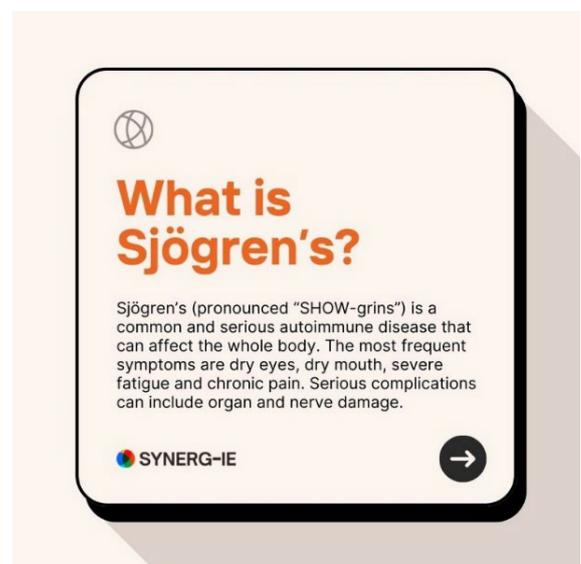
We’ve adopted ‘fatigue-friendly’ practices in our PPI meetings to ensure inclusivity for participants with Sjögren’s disease. These include keeping meetings short, providing rest-breaks, offering virtual options, and ensuring physical accommodations at in-person meetings. These adaptations have been crucial in maintaining continuous engagement and input from all panel members, which is essential for the integrity and relevance of our research.

Impact of a patient researcher

The inclusion of the patient representative

researcher has been critical, bringing a valuable perspective to the centre of our work and ensuring the patient perspective is considered in all our activities.

In conclusion, the SYNERG-IE programme demonstrates the substantial impact of a meaningful partnership on the research, enhancing the care and understanding of Sjögren’s disease. Our aim is that having our research guided by the direct input of those affected will lead to tangible improvements in education, policy, and practice, and set a benchmark for future patient-involved research programmes.



IMPACT CASE STUDY

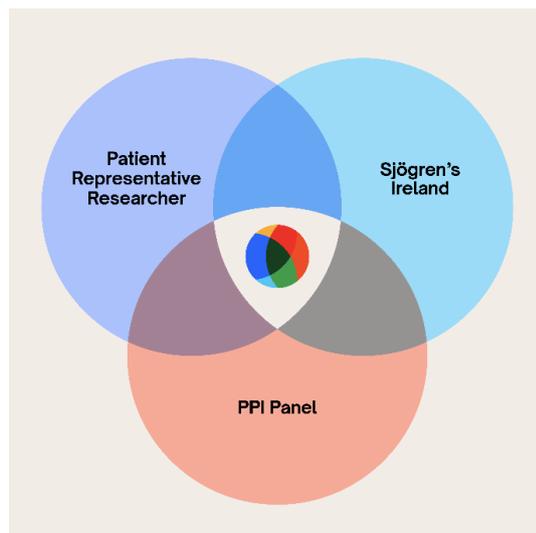


“First time since diagnosis (8 years ago!) that I felt seen and heard. I found myself nodding along to what all the speakers had to say and the voice of the patient was clear throughout.”

Patient attendee, Knowledge Exchange Event, November 2024

“My role is to draw on my lived experience of Sjögren’s to help the team better understand the needs of patients. It is exciting to join a project that has PPI embedded throughout, and in which the patients who are experts by experience are valued as partners.”

Gráinne Tynan, SYNERG-IE patient representative researcher



PPI input into SYNERG-IE



This work is funded by the Health Research Board and Taighde Éireann – Research Ireland, with co-funding from the seven Universities at the centre of the PPI Ignite Network