

How Patient and Public Involvement Shaped the Noetic Pain AI Platform

Background

We are creating *Noetic*, an AI tool that helps turn people's stories about chronic pain into clear information for healthcare staff. Standard pain forms often miss key details, and many people feel their pain is not understood or believed. Because of this, we involved patients and the public from the very start to make sure the tool is useful, fair, and easy to use.

What we did

- **Surveys:** Using an online form, we asked more than 60 people with a chronic widespread pain condition called fibromyalgia about their pain and how they use technology.
- **Interviews:** We spoke with people one-to-one so they could share their experiences in more detail.
- **Advisory panel:** In May 2025, we presented our early ideas to the [Brain Health Advisory Panel](#) and used their feedback to guide our design.
- **Healthcare staff input:** We also talked to clinicians, nurses, physiotherapists, and researchers to learn about what they find hard when assessing chronic pain.
- **Co-design group:** A small group of people with chronic pain meet with us every few months to test new designs and help shape the tool.

What difference did it make?

Patient and public involvement led to several key changes:

- **Feeling believed matters:** Most people told us they often feel they must prove their pain is real. This made us focus on ensuring better communication, not just on recording symptoms.
- **Diverse ways to use the tool:** Not everyone uses health apps in the same way. Because of this, we designed more than one option for using Noetic.
- **Fatigue included as a core symptom:** Many people said fatigue affects them as much as pain, so we made sure the AI tool includes it.
- **Cultural differences recognised:** People express pain differently across cultures and communities. This helped us plan multilingual and culturally aware features.
- **Supporting research:** Most people were happy to share their data safely for research. This strengthened our work on secure data-sharing.