The Leeds Teaching Hospitals NHS
NHS Trust

PENNA Award 2025

“Patient Voices at the Heart of Cystic Fibrosis Care: Creating a Patient-Led Focus Group to Improve Patient Experience”

Leeds Centre for Cystic Fibrosis · Leeds Teaching Hospitals NHS Trust

Leeds Centre for Cystic Fibrosis

Crash Course in Cystic Fibrosis

- Biggest genetic condition in UK (1 in 25 carry CF gene)
- Life-limiting, lifelong care needs
- Median life expectancy ~42 (improving with new treatments)
- Leeds = 3rd largest UK CF unit (430 patients)
- Pre-2003: strong patient community
- Post-2003: segregation → **patient voice + friendships lost**

Why the Group Started

- COVID showed value of connecting online
- Physio → virtual exercise classes
- Nurses → online quizzes
- Patients said: “We need better communication”
- **Created regular Teams meetings with shared agendas**

Improving Patient Experience

- Patients now **have their say**
- Ward updates shared directly with community
- Honest feedback → what works & what needs fixing
- Shifted comms: Twitter → Instagram
- Co-produced **patient newsletter**

Practical Changes (Patient-Led)

New **comfy rainbow chairs** (charity + patient choice)

Mood lights → support sleep, reduce anxiety, enhance palliative care

Fundraising for new TVs → future “movie nights”

Wider Impact

- Research support (e.g., oral health survey 30% response)
- Patients highlight diet issues → kept favourite snacks

- Patients shaping future agenda (e.g., PIP benefits session)

- Building stronger **community + patient experience**

What We've Learned

•Don't assume — ask what matters
• Co-production builds trust
• **Improves patient experience & outcomes**

Closing Quote

We feel valued — staff listen carefully, even when feedback is hard to hear.