

# PiCC PULSE

March 2026

Newsletter



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# Welcome to PiCC Pulse

March is a time of momentum. At PiCC United, it's where ideas begin to take shape and collaborations turn into action — sometimes visibly, sometimes more quietly, but always with intention.

Over the past months, we've continued to engage across projects, networks, and dialogues in Europe and beyond. What connects them all is a shared understanding: meaningful patient involvement requires trust, structure, and transparency — not just good intentions.

As we move forward, we focus on strengthening what we build — supporting those new to patient involvement, while working with partners to create real and lasting impact. Because progress is not just about doing more, but about doing it better — together.

## Introducing Lisbeth Snede



Hi, I'm Lisbeth – I work at the intersection of patient advocacy, leadership, and health system development. But more than that, I spend my time building something I deeply believe in: spaces where people feel they belong, and where their experiences actually matter.

Over the years, I've learned that patient involvement is not just about being invited into the room.

It's about being heard, understood, and able to influence what happens next. That is what I work to create – structures that make involvement real, meaningful, and sustainable.

I love opening doors  
Into conversations that were previously closed  
Into communities where people feel seen  
Into spaces where patients and professionals meet as equals

# My perspective

But even more than that, I love building bridges.

Between systems and people.

Between lived experiences and decision-making.

Between those who want to contribute – and those who are ready to listen.

My perspective comes from more than three decades of lived experience as both a patient and a relative, combined with years of working across organisations, partnerships, and governance. I serve on several boards and advisory settings, where I contribute to shaping direction, strengthening collaboration, and ensuring that patient perspectives are meaningfully embedded.

I am someone who naturally sees connections, moves quickly, and builds momentum – but I have also learned the importance of slowing down when it matters. Because real impact doesn't come from speed alone, but from clarity, trust, and structures that can hold over time.

I joined PiCC United to help build an inclusive, globally connected platform for meaningful patient involvement – one that doesn't just talk about patients, but partners with them. My ambition is to equip patients and carers with the tools, knowledge and confidence they need to shape the future of healthcare side by side with professionals.



# Personal experience

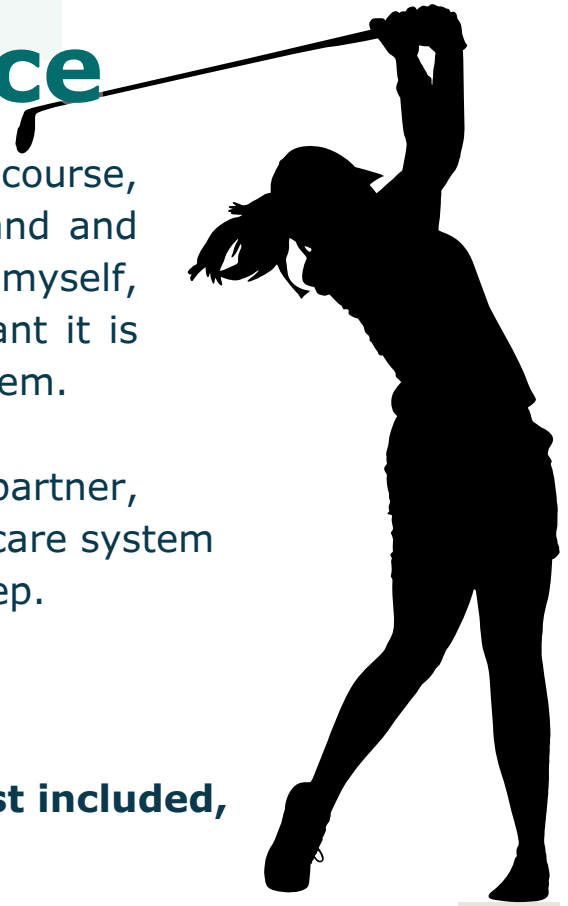
When I'm not working, I'm often on the golf course, enjoying nature or spending time with my husband and two adult children. I live with several diagnoses myself, so I know from personal experience how important it is to be understood and heard in the healthcare system.

Whether you are a patient, carer, professional or partner, there is a place for you in building a better healthcare system – and PiCC United is here to help you take that step.

At the core of everything I do is a simple belief:

**Healthcare improves when people are not just included, but truly part of shaping what comes next.**

Kind regards,  
Lisbeth



# Space for everyone

**PiCC United is a space for everyone who wants to make a difference.**

Whether you are a patient, advocate, carer, healthcare professional, or working within pharma — your perspective matters here. We believe that real change starts with real voices. Your ideas, your experiences, your thoughts — they all have the power to shape better healthcare. There is no “right way” to share. Whether it’s a story, an idea, a question, or a perspective — we will help you find the platform that fits you.

Because your voice deserves to be heard.  
Reach out to us: [hello@piccunited.org](mailto:hello@piccunited.org)



# News Update

## Building a better evidence base

### Patient experiences are also evidence – but are they taken seriously?



Miles Sibley, Director,  
the Patient Experience Library

In healthcare, almost everything is based on evidence-based medicine. Clinical guidelines, education, and decisions are based on research and data.

But when it comes to patient experiences, the system lags behind. In this article, Miles Sibley from the Patient Experience Library explains why patient experiences are still not treated as real evidence – even though thousands of studies based on patients' lived experiences are published every year.

Essentially, the article points out that:

- There is a wealth of knowledge about patient experiences – but it is not used systematically
- Patient experiences are often regarded as subjective stories rather than evidence
- Healthcare systems lack the structures, competencies, and tools to translate patient knowledge into practice
- This creates an imbalance where healthcare is only partially evidence-based

The Patient Experience Library works to ensure that patient experiences are taken as seriously as clinical research – and to create the structures that are lacking so that patient knowledge actually leads to better decisions and better treatment.

You can read the entire article on our website, where Miles delves into why patient experiences are crucial for a safer, fairer, and more humane healthcare system.



[Read the whole article \*\*here\*\*](#)

# News Update

## From our Partners

### Reinventing Healthcare Through Authentic Partnership

At PiCC United, we are inspired by initiatives like the PFAnetwork, where patients, caregivers, and communities come together to shape healthcare through authentic partnership.

Their work highlights an important truth: lived experience is not an add-on — it is expertise.



By creating spaces for Patient and Family Partners to grow, co-design, and lead alongside professionals, PFAnetwork is helping move healthcare from consultation to true collaboration.

Their approach also emphasises the importance of building readiness on both sides — because meaningful partnership requires capacity, trust, and shared understanding.

As new areas such as AI emerge, their focus on equipping patients to engage early and confidently ensures that innovation remains inclusive.

It's a powerful reminder that when partnerships are real, healthcare becomes more responsive, equitable, and human.

Read the full articles [here](#)





# News Update

Now our website is 100% Free



At PiCC United, we believe knowledge should be accessible to everyone. That's why we've updated our structure — and everything on our website is now **free**.

**No barriers. No login required.**

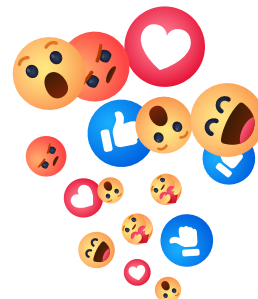
Just open access to knowledge, resources, and community. Because getting involved in patient engagement should be easy — for everyone.

## Practical support

The Global Patient Voices Project, led by pRxTrialPort, shares real stories from people across the rare disease community, making sure lived experience is not just acknowledged, but truly heard. By bringing these voices together, the project helps create deeper understanding, stronger connection, and more human-centered research.

Access the project here: [The Global Patient Voices Project](#)

## Follow us on Social Media



# News Update

## From our Partners



The Mended Hearts, Inc.

### Strengthening Patient Communities Across Europe

The article highlights the growing need to better support patients and carers following diagnosis—particularly in cardiovascular conditions—where many individuals leave the healthcare system feeling uncertain and unsupported. At the first Partner Workshop of the year, Andreea Gheorghe, Director of International Affairs at Mended Hearts Europe, shared valuable insights into building structured patient advocacy and peer support models across Europe. Her contribution emphasized the importance of creating sustainable frameworks that enable patients to support one another while strengthening advocacy efforts at both national and European levels.

Across Europe, initiatives are emerging to address these gaps by bringing together patients, caregivers, and healthcare professionals in structured dialogues and roundtables. These interactions create a space for shared experiences, mutual understanding, and co-creation of solutions that reflect real patient needs.

A key focus is on strengthening patient communities by:

- improving communication between patients and healthcare teams
- ensuring patients feel supported beyond the clinical setting
- creating networks where lived experience becomes a resource for others

The article emphasizes that patient communities are not just support systems—they are essential contributors to improving healthcare systems. By connecting patients across countries and contexts, these initiatives help build more resilient, informed, and empowered communities.

Ultimately, the work demonstrates how collaboration and structured engagement can transform the patient journey—from isolation and uncertainty to connection, understanding, and active participation in care.

Read the full article [here](#) or see the full presentation on [YouTube](#)





# Get Involved

## With PiCC United

PiCC United is more than a network — it is a space for action, collaboration, and real impact. Whether you are a patient, partner, or organisation, there are clear ways to engage and contribute.

**By engaging with PiCC United, you gain access to knowledge, networks, and opportunities to actively shape healthcare.**

### Join the Community



Connect with others, share your experiences, and become part of a growing international movement shaping the future of healthcare.

### Be in our sponsor ad board



Partner with PiCC United to co-create impactful patient engagement initiatives — while gaining access to real-world patient insights, networks, and perspectives across healthcare and research.

### Contribute Your Experience



Your lived experience is valuable. Share insights, participate in projects, and help shape better, more inclusive healthcare systems.

### Explore Our Platform



Access open resources, tools, and knowledge — no barriers, no login required, just open access for everyone.

### **For organisations and partners**

PiCC United offers structured collaboration models, access to patient expertise, and support in designing meaningful engagement initiatives — built on real partnership, not token involvement.

Contact us: [hello@piccunited.org](mailto:hello@piccunited.org)





**PiCC**<sup>®</sup>  
UNITED

## **Trust, inclusion, and action**

We make it easier for people to engage, share their voices, and help shape better, more inclusive healthcare.

[Explore our platform](#)



**PiCC United**

Email: [Hello@piccunited.org](mailto:Hello@piccunited.org)