

PiCC

PULSE

February 2026

Newsletter



Welcome!

Meet our Chair, Jenny Royle

News from our partner





Welcome to PiCC Pulse

February reminds us why we exist. Patient involvement is not simply about inviting people into the room. It is about removing the barriers that prevent them from being there in the first place.

This month, we share a powerful story that illustrates how structural rules — not attitudes, not willingness — can unintentionally silence patient voices. Because meaningful involvement requires more than good intentions. It requires systems designed to enable participation.

Across Europe and beyond, there is growing recognition that patient partnership must move from symbolic engagement to structural integration. That means governance. Fair compensation. Accessible pathways. Policy alignment. This is where PiCC United stands. We are not only advocating for patient involvement — we are working to build the frameworks that make it possible.

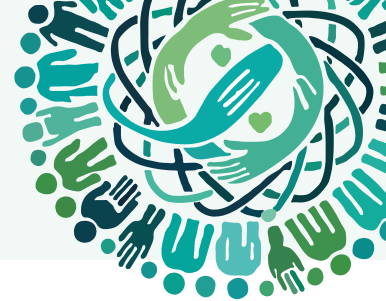
Warm regards,
Team PiCC United

Introducing Jenny Royle

Time to meet our fifth board member, Jenny. She brings calm leadership, thoughtful reflection and razor-sharp strategic insight to every room she walks into. But don't be fooled — Jenny's journey into patient involvement began, as she puts it herself, as "a very happy coincidence."

By day, Jenny serves as Head of the Programme Management Office at MediPaCe, where she works at the intersection of strategy, structure and delivery.





Introducing Jenny Royle

I'm so excited about PiCC United – it feels like the community we've needed for decades. I have worked in the pharmaceutical, NHS, Charity, and research industries and am now Chief Executive Officer for MediPaCe, values-first patient involvement and research company, as well as Chair for PiCC United, the global community we've all built together.

For years I've seen how powerful it is when patients, families, and professionals sit at the same table, share stories honestly, and co-create better care and research together.

It never gets old: seeing the spark of an idea form when people really hear what's important versus what's actually happening, then helping them to turn that spark into something practical that can improve care.



It's what drives me every day and shapes what I value most in the workplace: listening deeply, being transparent, sharing power, and always remembering there's a person and a family behind every idea, innovation, study and service improvement. Patient involvement is a wonderful thing, however, it's frustrating that the way involvement is delivered prevents so many from taking part. **We need to hear from you!**

There are rules for every good reason: Everyone must be treated fairly, respected, feel safe, and the information gathered must be used wherever possible. But just because it was set up one way, does that mean that it's the only way we can meet these rules? Especially when so many aren't being represented?

I will never forget the day when I met Lisbeth. We are so different in so many ways, but our values are the same, our excitement, and our drive to find the solution is almost overwhelming.

Fun facts about me:

- I prefer being outside to being indoors
- I love a good book
- I do woodcraft in my spare time (or at least try to)



When combined with John's calming influence (and delightful giggle) and the other board members' contributions, PiCC United has grown from initial concept into the community that links others, sharing best practice, and providing an alternative involvement approach.

We still stick by those original rules, but have changed the 'how' to make sure that anyone can find a warm, welcoming way to get involved that fits around them and provides the support they need to go from knowing nothing about involvement to confidently contributing research, policy, and practice.

That's the heart of PiCC United for me: Community, courage, and collaboration, all focused on making healthcare and research kinder, fairer, and more human. I couldn't be prouder to be on this journey with you.



For me, PiCC United is about changing the 'how' of patient involvement. It's not enough to invite patients to the table — we must create space where their lived experience is recognised as expertise, where power is shared responsibly, and where everyone feels safe, respected, and truly heard.

By Jenny Royle



PiCC News Update



We are part of a groundbreaking European collaboration

Project COMFORT

We are proud to be part of the four-year, cross-sectoral IHI initiative Project COMFORT, in which researchers, patient organisations, companies and healthcare professionals are working together to make blood tests more comfortable and accessible.

Project COMFORT aims to develop and test patient-centred micro-blood sampling – i.e. small blood samples that patients can take themselves, e.g. at home – and to organise the necessary infrastructure and logistics to make this a standard part of healthcare services and clinical studies. This can reduce the need for hospital visits, make sampling less invasive and thus significantly improve the patient experience and access to health data.

You can participate in the project by answering the questionnaire about experiences and attitudes – it only takes a moment and helps to ensure that the patient perspective is included throughout the process [participate here](#).

In many EU collaborations such as this, we often find that patient organisations and NGOs do not get their involvement publicly recognised, even though our contribution is crucial to ensuring that new solutions actually benefit the people they are designed for.

This is a shame – but also a very real part of everyday life for many civil society organisations involved in large international projects.



PiCC News Update

From Advocate for Patient inclusion in Research, EUPATI Fellow



Overcoming Structural Obstacles to Patient Involvement in Research

When Policy Silences the Patient Voice

Patient involvement in research is often described as essential. But what happens when structural rules prevent patients from participating?

In this powerful reflection, Robert Joyce, Advocate for Patient Inclusion in Research and EUPATI Fellow, shares his lived experience of being prevented from speaking at a conference due to restrictions linked to disability payments in Ireland.

What began as a personal barrier became a national policy issue — exposing a contradiction between health policy promoting PPI and social protection rules restricting it.

After sustained advocacy, collaboration with key stakeholders, and engagement at parliamentary level, the rules were amended in 2025. Today, recipients of Invalidity Pension in Ireland can take part in Patient and Public Involvement (PPI) activities — a change that protects inclusion instead of limiting it.

But this is not just an Irish issue.

Across many countries, structural barriers continue to silence patient voices — particularly those dependent on social welfare systems.

If we believe in meaningful patient partnership, we must ensure inclusion is not conditional on financial independence.

 Read the full article on our website [here](#)

PiCC United Update

Join Our Upcoming Partner Webinar Workshops

At PiCC United, we believe meaningful patient involvement is built through dialogue, collaboration, and shared learning.

We invite you to participate in our upcoming Partner Webinar Workshops — interactive sessions designed to bring patients, caregivers, researchers, industry professionals, and policy stakeholders together.



By joining, you will:

- Gain Perspective

Engage in forward-looking discussions on patient partnership and evolving engagement practices.

- Connect Across Sectors

Meet professionals and advocates working across the healthcare and research ecosystem.

- Contribute to the Future

Help shape the direction of meaningful and sustainable patient involvement.

These are not **passive webinars**.

They are **strategic conversations**.

Register here: [PiCC United Partner Workshop Webinar](#)

Never stop collaborating

Sometimes the best ideas and strongest connections are born over a cup of coffee ☕. Because sometimes, the simplest conversations make the biggest difference.



PiCC News Update

Our First Annual Report Is Here
– A Year of Building Together



We are proud to share something very special with you.

PiCC United's very first Annual Report is now published – and it marks a year of meaningful steps, strong partnerships, and growing patient voices across healthcare.

This first year has been about more than activity. It has been about building foundations. Lowering the barrier to patient involvement.

Creating practical structures.

Opening doors for collaboration across research, policy, and health systems. From new partnerships and advisory roles to project development and community building, this report reflects what is possible when patients are not just included – but meaningfully involved.

We are incredibly proud of what has been achieved in our very first year of involvement. And even more excited about what comes next.

[Read the report here](#)

Annual Report



Mission

- Make patient involvement and engagement easier
- Increase Diversity of Voices and Perspectives
- Provide support and education needed for more people to get involved with confidence
- Work for Better Ways to Involve Patients

Searching for PiCC Lounge...

Find the PiCC Lounge Podcast on your normal podcast provider and sign up, follow and get the latest episodes delivered right into your ears!



Tell us what you think...

Since we launched PiCC United we have consistently been reflecting, rebuilding and developing our approach, to provide a better service to you, the community.

However to help us develop further we would love to have your input.

If you haven't already given your feedback, please add your thoughts by completing our short survey: [PiCC United Pulse check](#).

Your input will really help us!

Explore the PiCC United YouTube Channel



Would you like to dive deeper into patient involvement, partnership, and best practices across healthcare and research?

On our PiCC United YouTube channel, you will find recordings from our Partner Workshops, expert talks, strategic conversations, and practical insights from patients, professionals, and collaborators across Europe.

Our channel is designed to:

- Make knowledge accessible and transparent
- Amplify diverse patient voices
- Document best practices in patient engagement

Whether you represent research, industry, public health, policy — or you are a patient or carer — our videos offer valuable perspectives you can return to anytime. Visit and subscribe to our [YouTube channel](#). Let's continue the conversation — beyond the webinar.





PiCC[®]
UNITED

Trust, inclusion, and action

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



PiCC United

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