

PiCC

PULSE

January 2026

Newsletter



Welcome!

Welcoming a **New Year**

News from our partner



PCSIG



Welcome to PiCC Pulse

January is here – a new year, new momentum at PiCC United.

A new year always brings reflection, renewed energy and fresh ambition – and at PiCC United, 2026 is already taking shape.

This month, we look ahead and share what's next for our community: new initiatives, upcoming collaborations, and continued efforts to strengthen meaningful, ethical patient involvement across borders. We're building on what we've learned, expanding our partnerships, and creating more spaces where patients, caregivers and professionals can engage as equal partners.

Warm regards,
Team PiCC United

Bridging knowledge, context and patient reality

This month, PiCC United has formally become involved in the work of the Patient Centric Preanalytics Special Interest Group (PCP SIG) under The Association for Laboratory Medicine (LabMed UK).

Through this collaboration, we contribute patient insight and perspective to the group's work on patient-centric sampling, with a particular focus on access, equity, and real-world patient experience in diagnostics and blood testing. This engagement aligns closely with PiCC United's broader work with our knowledge partners this month, where we continue to focus on genuine patient involvement – not as a theoretical concept, but as an active and practical element in the design and implementation of healthcare solutions.



Together

In parallel, we are continuing our work on Project COMFORT, which centres on the human experience of participating in clinical trials. The purpose of Project COMFORT is to explore how trial participation affects mental health, engagement, and personal values in patients' everyday lives, recognising that understanding lived experience is just as important as understanding clinical data.

Together, these efforts bring real-world challenges and patient perspectives into focus, supporting the development of clinical studies and healthcare solutions that are more empathetic, inclusive, and effective.



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The Association for Laboratory Medicine (LabMed UK) – one of the UK's leading professional membership organisations in clinical laboratory medicine and patient care. LabMed works to promote the highest standards in laboratory diagnostics, health science and education in clinical biochemistry, immunology and microbiology.

Their focus on patient safety and – in special seminars such as “Putting the patient at the heart of diagnostics” – emphasises how patient perspectives can and should be integrated into technical and clinical processes to improve experience and outcomes.

Pulse News

At PiCC United, we always strive to highlight the latest and most relevant topics in our PiCC Pulse news.

We closely follow developments in patient involvement, health, research and partnerships – and select topics that we believe are important right now. If you feel that a topic, angle or debate is missing, please do not hesitate to let us know – we would love to hear from you.



New Webinar series

In this PiCC Knowledge Partners session, we explore what meaningful patient partnership truly looks like in clinical research — moving beyond buzzwords and surface-level engagement to focus on real collaboration and impact.



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!

We are now on most platforms, including [Apple](#), [Spotify](#), [Amazon](#), [PlayerFM](#), and [Podchaser](#)!

If you have an idea for a topic or want to share your story with the community, [email us](#) or [follow this link](#).

Tune in to listen to Keith talk about his organisation PRXEngage and their aim to support, signpost and guide patients into feeling more confident about taking part in Clinical Trials. Keith also shares his view on the biggest opportunities for patient involvement in the years ahead



www.piccunited.org

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

This month's partner highlights the importance of putting the patient at the centre of clinical sampling — not the system.



Patient Centric Sampling

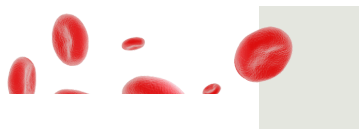
The collection of human biological samples (blood, plasma, urine, etc) is an important part of healthcare and clinical trials. These samples help us to know what is going on in our bodies. However, the current approach for blood collection using venepuncture is difficult for some people and can cause stress, discomfort and pain.

In addition, the samples must be collected by a qualified healthcare provider in a central facility. Furthermore, the collection of other biological samples like urine can be messy and embarrassing and nasal swabs can be painful. Unfortunately, the current approaches for the collection of these samples is not built around the main person who should be benefiting from the process – the patient. This can result in important samples not being collected and the process being inconvenient, stressful and time consuming.

Thankfully, there are now a number of technologies available that enable these samples to be collected in a manner that puts the needs of the person collecting the sample at the centre of the process.

These technologies include approaches for blood sample self collection (or collection by a carer) in the home, or a local pharmacy, using a finger stick, or a device placed on the upper arm. Urine samples can be collected with easy to use technologies that give a high quality sample without the mess associated with traditional container collection.

Not only are these approaches more convenient and comfortable for the person collecting the sample, they also give that person a greater degree of choice as to how they wish these important samples to be collected, with traditional collection in a clinical facility still being an option in most cases.



Patient Centric Sampling



Unfortunately, whilst these technologies have the approval of national regulatory bodies and are capable of being used for the high quality measurement of many factors associated with traditional sampling approaches, they are not yet widely implemented in healthcare systems.



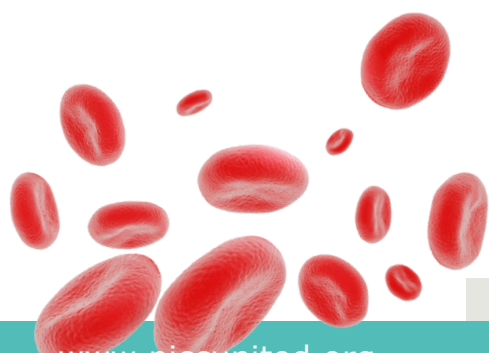
This can be because patients and healthcare providers are not aware of their existence. In addition, there are concerns that the devices are more costly than traditional tubes. However, this is not a fair comparison, as convenience and other factors are not taken into consideration.

The Patient Centric Sampling Interest Group (PCSIG) is a not for profit organisation, which was founded to help overcome this

lack of information and understanding of these patient centric technologies and to help with their more widespread adoption where they can bring benefits to patients, healthcare systems and clinical trials. It is important that the voice of the patient is central in these discussions, which is why we are so excited and honoured to be working with PiCC United, who bring a real world perspective to our discussions and decision making.



Bringing about these changes in how we collect samples is not easy. However, making sure that the patient voice is front and centre of these conversations will help to make sure that the new approaches that follow are fit for purpose, are an improvement on current ways of working and lead to improved outcomes for all.



You can read more about PCSIG on their website [here](#)

Buddy up



We “buddy up” with small patient organisations

Many small patient organisations and informal groups want to make a difference but lack the capacity to manage administration, governance, and compliance alongside their core mission.

PiCC United acts as a backbone organisation, allowing small associations to continue focusing on what truly matters – patient support, lived experience, and advocacy – while we provide the structure that makes involvement sustainable.

Through a “buddy-up” model, patient groups keep their independence and voice, while gaining practical and ethical support behind the scenes.

What PiCC United supports

Small organisations and informal patient groups can continue their core activities while PiCC United helps to:

- raise awareness of patient involvement and engagement
- provide members with a safe, realistic and accessible pathway into involvement
- handle the administrative, legal and ethical framework around involvement

This ensures that more patients can participate meaningfully – without small organisations burning out or carrying an unsustainable burden.

A patient-driven, peer-supported engagement environment

No new patient representative should stand alone.

Through PiCC United, patients and carers entering engagement gain access to:

- a safe and moderated community
- peer support from experienced patient representatives
- sparring, guidance and shared learning
- clear expectations, boundaries and ethical standards

This lowers barriers, builds confidence, and turns involvement into something that feels possible and safe – not overwhelming.



Buddy up



A lifeline for small and ultra-rare patient groups

Some patient communities are very small – sometimes just a Facebook group, a WhatsApp chat, or a network of parents and carers.

For these groups, PiCC United can act as a backbone and legal proxy, offering:

- administrative and organisational support
- a legal and governance framework when none exists
- guidance on ethics, transparency and collaboration
- support in dialogue with healthcare systems, researchers and industry

This allows even the smallest and most fragile patient voices to be heard in the development of healthcare, research and policy – without forcing them to become a full organisation overnight.



Why this matters

*Without a backbone model:
only the most resource-strong
patient groups survive
small and ultra-rare
conditions remain invisible
patient involvement becomes
unequal*

*With PiCC United as
backbone:
access to involvement
becomes fairer
diversity of voices increases
engagement becomes
sustainable and ethical*

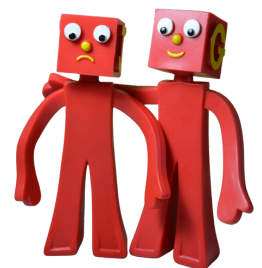
What this model protects

The backbone model is built on one clear principle:

PiCC United supports – it does not take ownership.

Patient groups always retain:

- their identity
- their priorities
- their messages
- their autonomy



PiCC United provides the structure so patient communities can grow, engage and be heard on their own terms.

“The backbone support can be temporary or long-term, depending on the needs and development of each patient community.”

PiCC News Update

Here we highlight the latest news from the PiCC Community, including new events, webinars, developments and improvements.

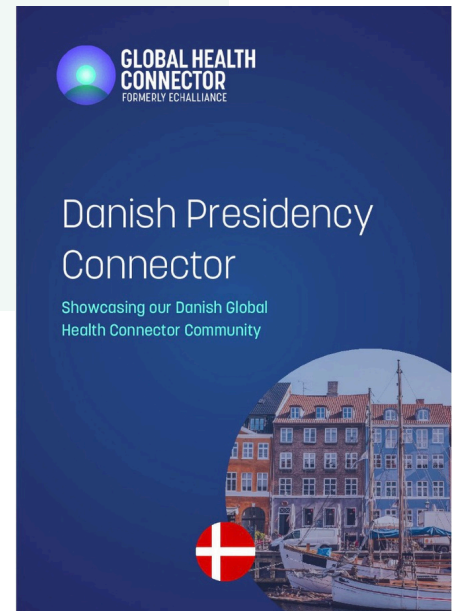
PiCC United is now featured in the Danish Presidency Connector, developed in collaboration with ECHAlliance.

A new platform to strengthen patient perspectives in global health collaboration.

This means that the voices and experiences of patients and carers are represented within a strong international community working to advance collaboration, connectivity and human-centred innovation in health.

The collaboration provides an important platform to bring lived experience into cross-border dialogue and action — ensuring that patient partnership is not just an aspiration, but a meaningful and embedded part of future health systems.

We look forward to contributing actively with insights, experience and patient perspectives as part of this growing global health community.



Do you have something to share?

We would love to help share your ideas, experiences or opinions. No matter how you like to share, we can find the perfect platform to help get your voice heard.

Talk to us: hello@piccunited.org or click here: [Tell us more](#)

PiCC United takes the next step



– becoming an independent NGO

During 2025, our capacity, network and collaborations have grown significantly. We have moved from individual collaborations towards long-term partnerships and strengthened our cooperation with international patient organisations and public structures.

At the beginning of 2026, this development takes its next natural step: PiCC United will be established as a fully independent non-profit organisation. This marks a new chapter for patient involvement.



While our organisational structure is changing, our purpose and values remain the same. We continue to work to:

- increase the diversity of patient and family voices that are heard
- make patient involvement more accessible and realistic in practice
- support and reassure people who have never been involved before
- ensure that patient and family perspectives become a natural part of research, system improvement and health policy

Becoming an NGO allows us to strengthen areas that many small patient associations and informal groups are calling for. This includes building a patient-driven, peer-supported engagement environment, and offering a legal proxy and engagement lifeline for small and ultra-rare patient communities.

As an independent non-profit NGO, PiCC United can enter into sponsorships and collaborations that are fully aligned with our mission and values. This enables us to better identify gaps, unmet needs and emerging challenges where patient involvement can be strengthened.

All collaborations are guided by clear ethical principles, transparency and well-defined boundaries.

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.



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!

PiCC Lounge Podcast

Tune in to listen to Keith as he shares insights into his organisation, PRXEngage, and their mission to support, signpost and guide patients toward feeling informed, confident and empowered to take part in clinical trials. In this episode, Keith also reflects on the biggest opportunities for patient involvement in the years ahead — including how trust, clear communication and practical support can make research more accessible and meaningful for patients.

🎧 Listen here: <https://picclounge.podbean.com/e/keith-x-from-prxengage/>



Good input for us?

PiCC United is here for everyone, whether you are a patient, advocate, carer, healthcare or Pharma professional or anyone with a role in this field.

Contact: hello@piccunited.org





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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