



# PiCC United

Annual Report

2025



# The initiative

PiCC United was established with a clear purpose: to make patient involvement more accessible, meaningful and sustainable across healthcare systems.

The initiative arose from the realisation that patients were often invited to participate too late in the process – or without any real influence. There was a lack of a structured approach where patients were not merely consulted, but actively contributed as partners.

PiCC United was therefore created as a platform that lowers the barrier to participation whilst enhancing the quality of patient involvement through knowledge, networks and practical tools.

Today, PiCC United is working towards becoming a key player in the development of future patient partnerships, where patients, healthcare professionals, researchers and industry collaborate to create better solutions – with a focus on implementation, ethics and real value for patients.



PiCC United is an initiative of MediPaCe Ltd., registered in England and Wales under Company Registration Number 10943570. MediPaCe Ltd. Suomen Sivuliike (Finland Branch) is registered with the Finnish Trade Register under Registration Number 3403110-4. Registered address: PL 15, 00811 Helsinki, Finland.

PiCC United is currently in the process of establishing itself as an independent NGO (Spring 2026)



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# Our Mission



## PiCC United

Where diversity, partnership and collaboration make patient involvement better



## 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



## Aligns: UN Sustainable Development Goals



# 2025 Highlights

A year of building foundations – enabling future growth and impact



Developed and agreed a strategy



Led on 3 patient projects



Wrote and published a White Paper on the mental health considerations within clinical trials



Established a board of Directors



Over **7,5 thousand** Euros have been paid to the patient community



Launched a community newsletter, social media comms and podcast

# Patient-centered project



**Led 3 patient-centered projects across research, advisory and system-level collaboration:**

**Published a white paper on mental health in clinical trials**

→ Developed and published a white paper highlighting recommendations to improve patient support and experience.

**Hypertension Patient Leadership Council (PLC) (industry-sponsored)**

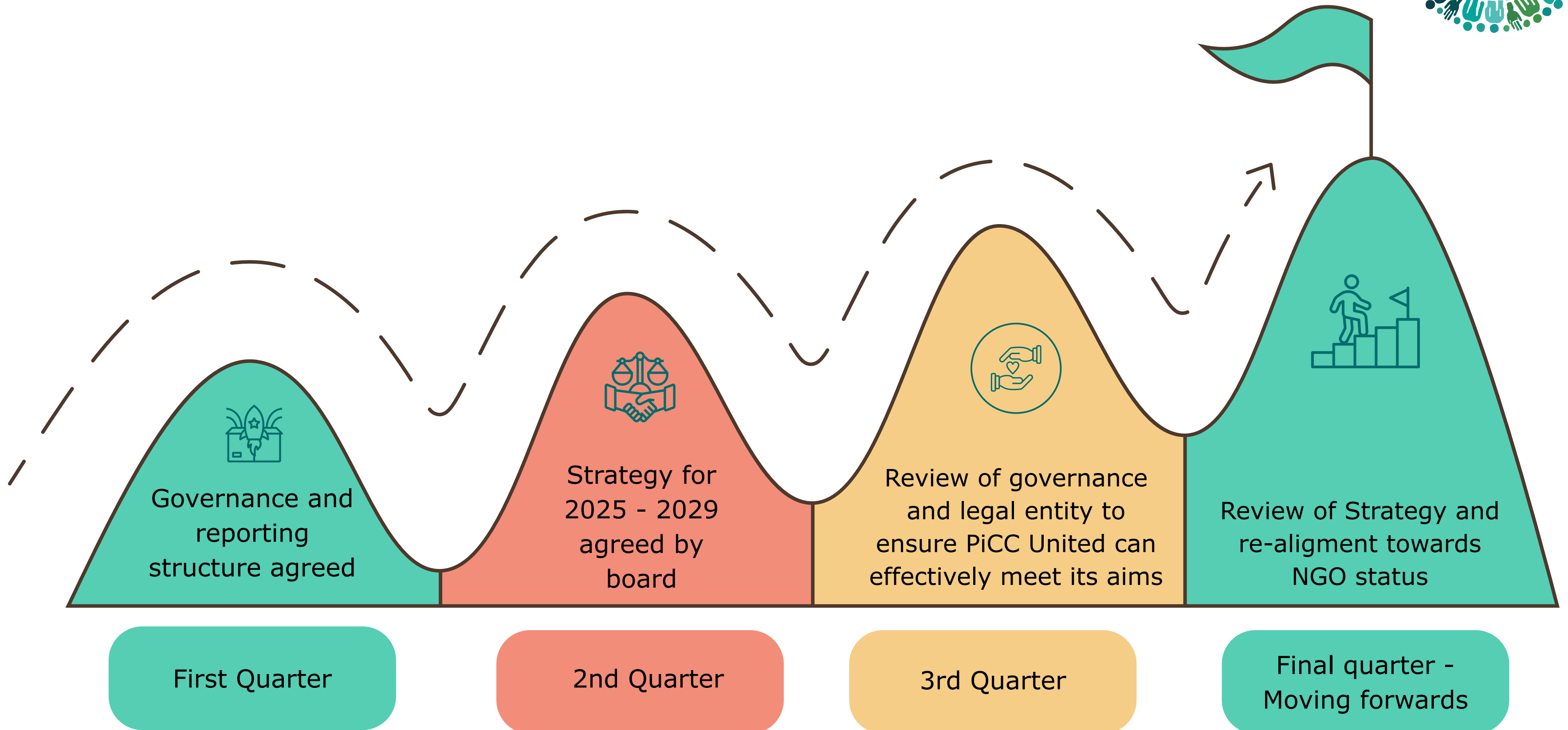
→ Established a patient-led advisory structure to inform strategy, engagement and real-world perspectives.

**International quality of care and patient safety collaboration**

→ Contributed to strengthening the visibility and integration of patient perspectives within healthcare systems.

ProjecAcross clinical research, advisory leadership and international collaboration  
– bridging research, industry and policy to strengthen patient engagement.

# 2025 Organisational Milestones



# Patient Highlights



Total number of patients involved



Over 20 directly involved and more than 50 engaged\*

Where have patients come from



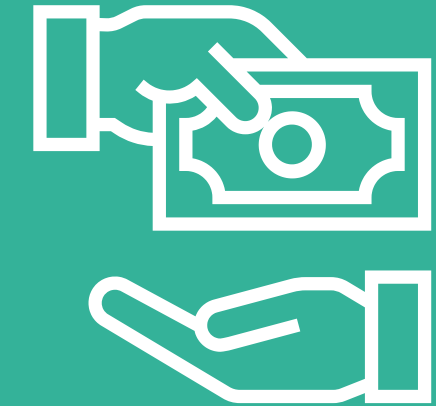
United Kingdom  
United States of America  
Across Europe

Focus of projects



Hypertension  
Mental Health  
Clinical Trials  
Blood Sampling

Total reimbursement made



Over **7,5 thousand** Euros + fees

- \*'Involved' - having deeper engagement and influence within specific projects and sharing their experience on our podcast series. 'Engaged'- to include low level engagement within projects, attendance at webinars and meetings etc.

# How PiCC United Contributes



PiCC United contributes patient expertise across European and international initiatives — ensuring continuity, quality, and ethical consistency in patient involvement beyond single projects or one-off consultations.



## Embedded in key patient and system-level networks

PiCC United actively contributes to national and international networks focused on shared decision-making, patient leadership, and meaningful public involvement across healthcare systems, research, and policy development.

- Examples (not exhaustive):**
- ICHOM**
  - National Centre for Shared Decision Making (DK)**
  - Shared Commitment to Public Involvement (SDM)**
  - Patient Leadership & Patient Leadership communities**
  - Moving Mountains**
  - Further cross-border collaborations**

## Why this matters

Being present across multiple projects, committees, and networks allows PiCC United to carry learning, patient priorities, and ethical standards from one initiative to another — strengthening trust, consistency, and quality in patient involvement.



# Partners & Collaborations



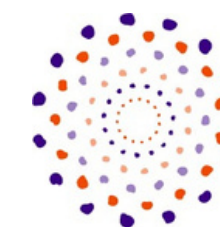
More  
than 35  
Knowledge Partners



Launched partner  
collaboration  
workshops  
meetings



The Mended Hearts, Inc.



**PsorAsia**  
IFPA Region Asia



**World  
Patients  
Alliance**



International Alliance of  
Patients' Organizations  
A global voice for patients

**EUACT**



**ICHOM**

Together with our partners, PiCC United now has a network reach of more than 350.000 patients, cares and stakeholders globally

# Representation and Awareness



More than  
**12 EU**  
Conferences  
attended

It is important to continue to represent patients and raise awareness within discussion's furthering patient engagement

Patient Engagement and Centricity in:

- Mental Health
- Research
- Outcomes
- Strategy and Partnerships
- and more



2025 Global Forum Programme

Clinical Innovation Summit

EPF Congress

ICHOM

PEOF 2025

4th National Meeting on Clinical Research and Biomedical Sciences

LSX Nordic Congress

Patient and Researcher:  
Together for Better Research

Patient Centricity Congress

Remote Patient Monitoring  
Conference

Theme day on shared  
decision-making

WHO/Europe and the French  
Ministry of Health and Access to  
Care

# What we have learned this year



## Lessons Learned = Insights from 2025

Early involvement is critical  
→ Late engagement limits real impact

Partnerships drive meaningful change  
→ Collaboration outperforms one-way communication

Implementation is the biggest gap  
→ Many initiatives exist, but few are embedded in practice

Patients bring insight, not just experience  
→ They contribute to better decisions and outcomes

Trust is built through continuous dialogue  
→ Not one-off engagement

## Next Steps = Strategic priorities for 2026

Strengthen early-stage patient involvement  
→ Integrate patients from project design phase

Scale strategic partnerships  
→ Expand knowledge partner network globally

Focus on implementation tools  
→ Develop practical frameworks and resources

Advance PiCC AI and digital solutions  
→ Support accessible, scalable patient engagement

Position PiCC United as a knowledge partner  
→ Across research, policy and healthcare system

Moving from awareness to action – enabling real patient partnership in practice



# Thank You for your support this year

If you want to get involved or find out more:



[www.piccunited.org](http://www.piccunited.org)



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