

PFMD.org
Made WITH Patients



10 Years of Transforming Patient Engagement

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Building on a decade of trust and carrying the work forward

By **Derick Mitchell**
Executive Director

As PFMD enters its second decade, we stand on foundations built together, by a community that turned Patient Engagement (PE) from an idea into infrastructure. The change has always been about the shared conviction that healthcare works best when it is built with patients, not for them.

For those of us who have been with PFMD from the beginning, this next chapter is about protecting the impact you've already built — preserving good practices, ensuring PE remains meaningful and impactful, and continuing to serve as a guiding light for the wider community.

And it's also about going further, faster. The frameworks, trust, and shared standards created over the past decade are now shaping how regulators, funders, and innovators work worldwide. Staying at the table ensures your leadership continues to guide the standards and policies that will define the next generation of healthcare.

For those not yet part of PFMD, this is your moment to step in.

The world is no longer debating whether patient engagement matters — that question is settled.

What matters now is how it is implemented, and who will lead in shaping its future.

By joining this community, you don't just follow the shift, you influence it. You bring your voice and perspective into the global framework being built.

Based on our collective experience reimagining PE, Patient Experience Data (PED), clinical trials, ESG and more, our community is ideally placed to shape the future. It is not too late to get on board, and in fact, now is the ideal time to do so.

The next decade of patient engagement will echo the defining moments of past generations. Just as the HIV/AIDS movement reshaped public health in the 1980s, online communities transformed access in the 1990s, and privacy debates defined the 2010s, the 2020s and 2030s will be remembered as the era when patient voices became fundamental to how we design, deliver, and sustain healthcare.

In an age shaped by Artificial Intelligence — and at a time when civil society itself is under pressure — nothing is more vital than embedding patient and public engagement into the core of our systems.



Foreword

By **Nicholas Brooke**
Executive Director (2016–2025)

Ten years ago, a group of people with a common goal sat down together to address a deep-rooted challenge in healthcare: the absence of patients in the decisions that shaped their care.

We believed then — as we do now — that healthcare must be built **with** patients, not **for** them. That conviction sparked a movement that has grown into a global community, powered by practical tools, shared standards and publications, and deep trust.

Back then, patient engagement (PE) was fragmented and inconsistent. There was no shared language, no agreed definition of what “good” looked like, and few ways to measure or replicate success. The barriers weren’t only technical — they were cultural, institutional, and systemic.

Through collective action, the PE community began to shape and gradually change that. Together, we co-created the tools and guidance needed to do patient engagement well. Together, we built a virtual and real-world network to map, connect, and support practitioners around the globe. Together, we grew from 10 founding members to 62, with thousands more contributing through working groups, public consultations, and real-world implementation.

This report is not just a record of PFMD’s progress — it is a story of shared achievement. It captures what the community has made possible: the shift from awareness to application, from siloed projects to embedded infrastructure, from passive consultation to active co-creation.

None of this would have been possible without you — the patient advocates (including people with lived experience, their loved ones and caregivers, and representatives of patient and advocacy organizations), researchers, regulators, investors, clinicians, and companies who have helped shape this ecosystem. PFMD’s role has been to convene, support, and accelerate your work; to set standards, build capacity, lay the foundations for a community, and help navigate the path ahead.

As we reflect on this decade of progress, we also recognize how much more there is to do. Patient engagement is now expected in many settings — but not yet embedded everywhere. The groundwork has been laid. What comes next depends on us and on how we continue to build it — together.

Thank you for being part of this movement.
Thank you for making it real.

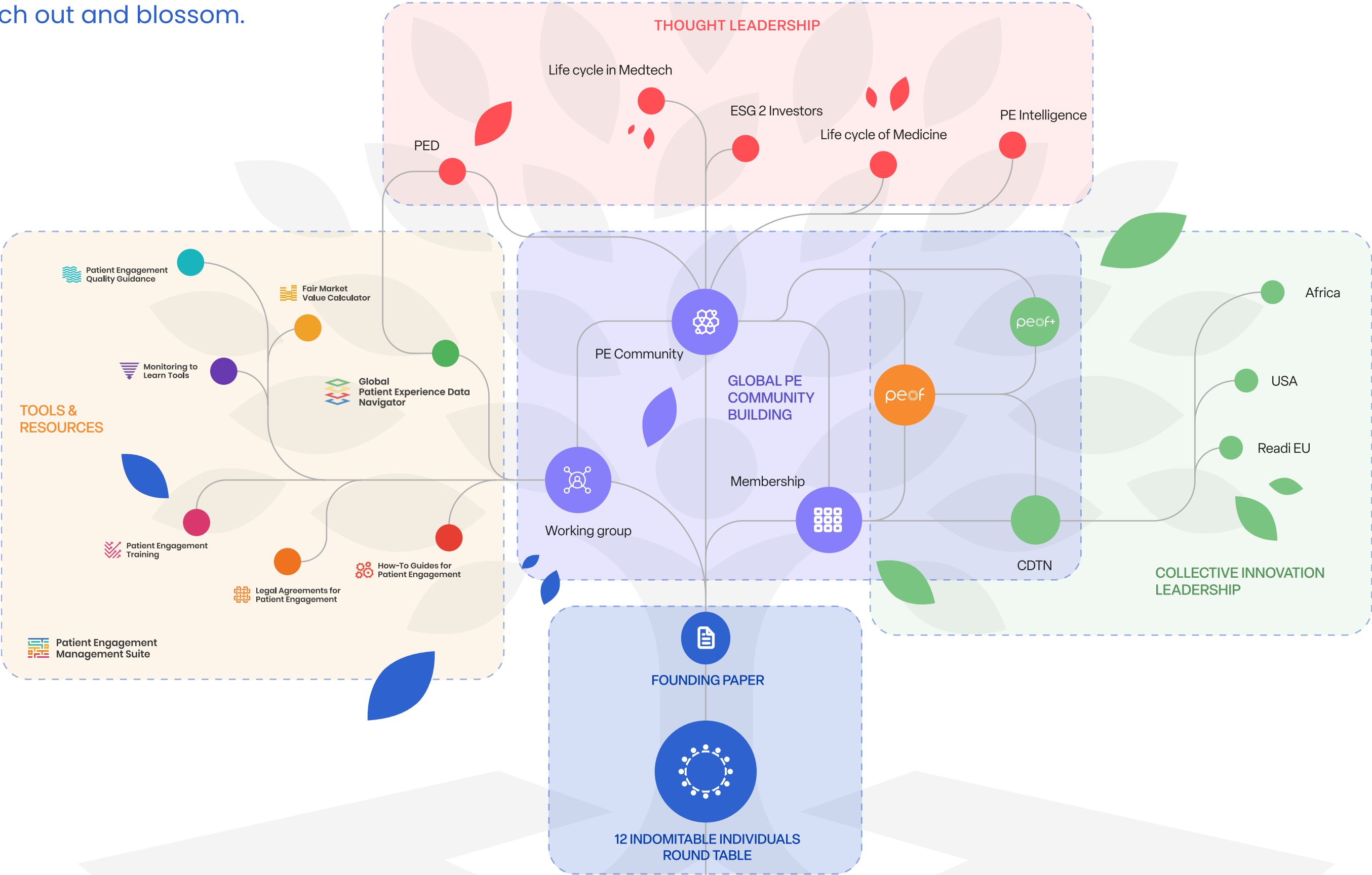


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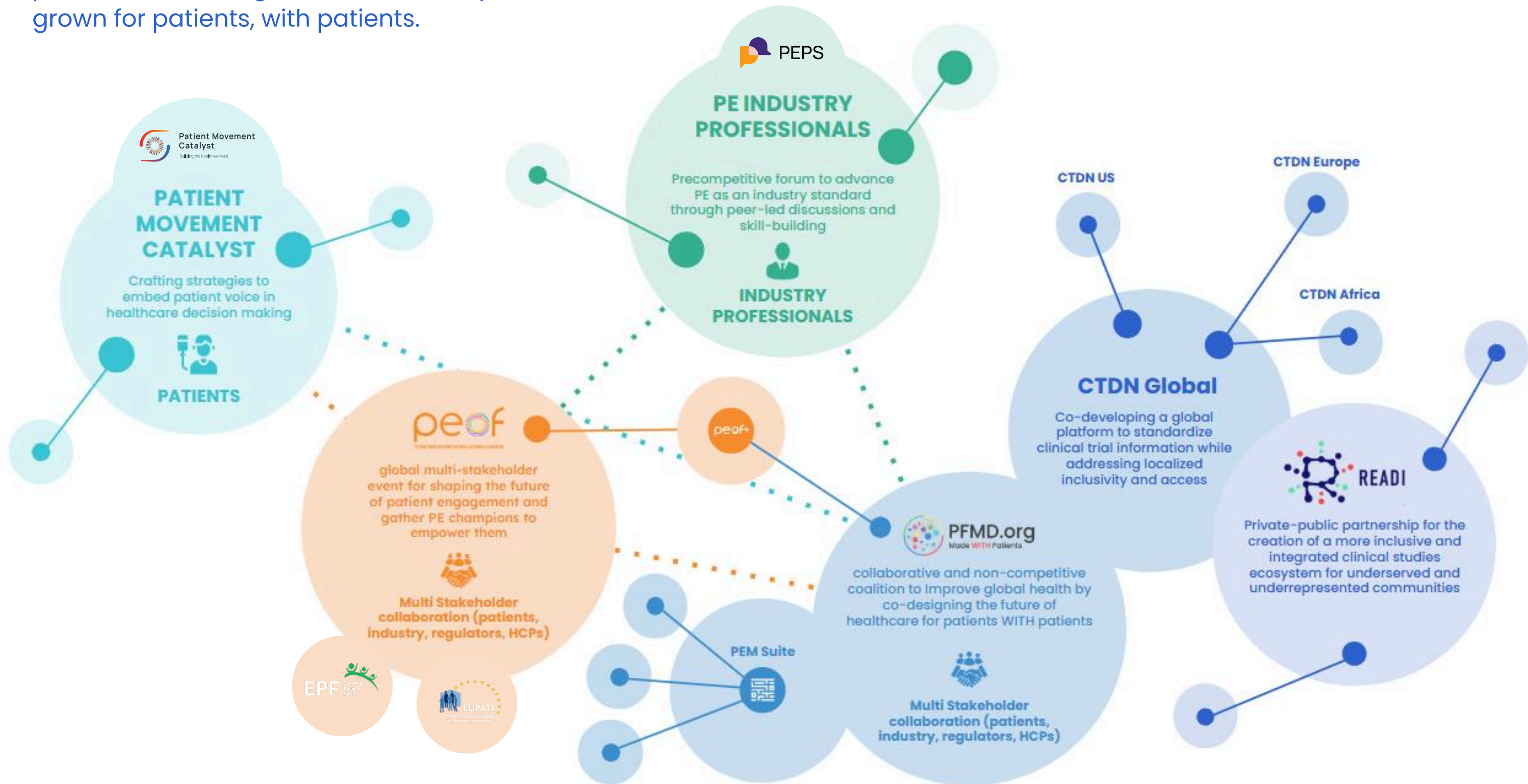
The Decade We Built Patient Engagement Together

After ten years, the PFMD tree – rooted in collaboration – continues to branch out and blossom.

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The PFMD tree is one tree in a **thriving forest**.
From policy and research to industry and
platforms for dialogue, this is an ecosystem
grown for patients, with patients.



How We Got Here

How We Got Here

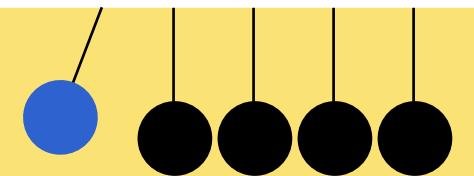
From pilots to policies: how shared tools, open access, and collaboration changed the system.

Systems are shifting:

- Regulators using co-created guidance to shape new standards.
- Companies adopting frameworks that change how engagement is structured.
- Investors embedding patient perspectives into ESG and risk decisions.
- Patient advocates leveraging shared tools to push for meaningful change.
- Health systems are adapting PE resources locally, proving they work anywhere.

PFMD continues to serve four key roles: standard setting, capability building, community building, and thought leadership. The collective impact is our shared achievement. It is proof that patient engagement, once optional, is now becoming standard practice across the ecosystem.

IMPACT



Ten years of work made these shifts possible. Each framework, training, and platform built under PFMD's umbrella was created with the community — open access, co-created, and scalable. The result: what began as scattered projects is now measurable infrastructure shaping decisions across regulation, policy, investment, and care.

The Journey So Far:

A movement in motion

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patients

2015–2019

Foundations

Together we built the first common language for patient engagement.

2020–2023

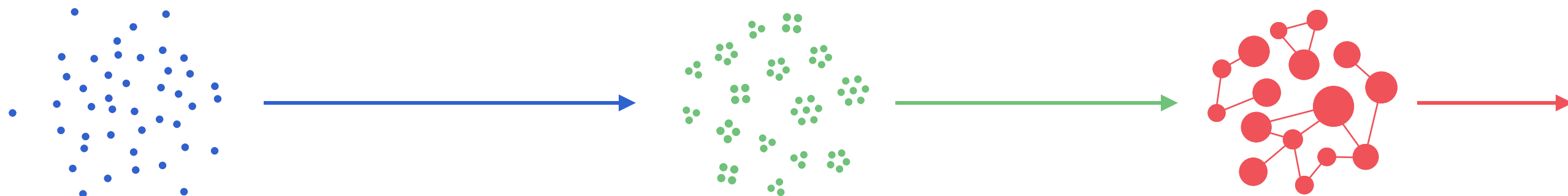
Infrastructure

The foundations turned into shared practice.

2024–2025

Systems

The shift is now structural



2015–2019 Building Foundations

What happened

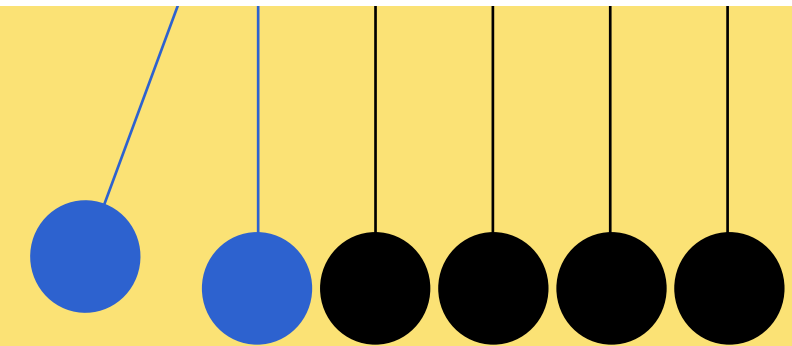
Patient engagement was still fragmented. Together, early adopters built the shared language, trust, and first practical tools to make engagement real.

Key moments

- Co-created the **PE Quality Guidance** (7 criteria that define what “good” looks like).
- Published the first **Book of Good Practices** to capture real-world examples.
- Launched **Synapse**, the first global mapping of PE people, organisations, and resources.
- Founded the **Patient Engagement Open Forum (PEOF)** — a safe and brave space for collaboration.
- Adapted core resources for MedTech companies and delivered the first conference session linking PE to ESG priorities

2020–2023

2024–2025



IMPACT

From belief to shared standards —
creating the roots of the PE
ecosystem.

2015–2019

2020–2023 Turning Practice into Infrastructure

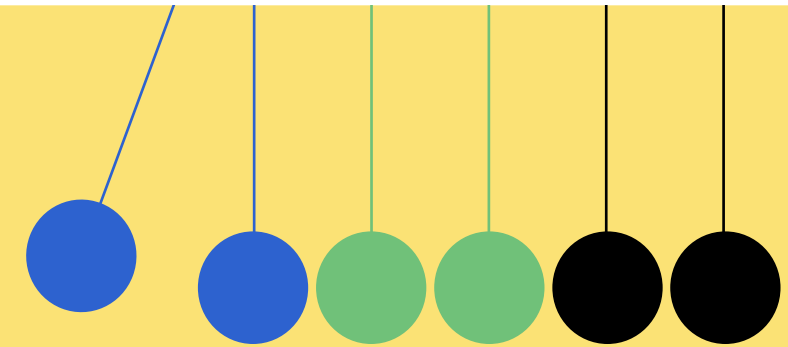
What happened

Once the language was built, the community scaled it. Companies, regulators, and advocates began embedding structured engagement into their systems and training their people.

Key moments

- Expanded to **63** member organisations; co-created the **Patient Engagement Management Suite** (How-to Guides, Metric Selector, Global Patient Experience Data Navigator).
- Rolled out the **PE Training Program**, reaching **38 000** learners and giving **500 000** employees access across **11** pharma companies, and co-created a dedicated MedTech adaptation in partnership with MedTech companies and patient organisations.
- Launched the **Made with Patients Awards** to celebrate and benchmark excellence.
- Adapted resources for MedTech and began linking PE to ESG and sustainability priorities.

2024–2025



IMPACT

From standards to systems —
turning tools into everyday
practice.

2015–2019

2020–2023

2024–2025 **Shaping Systems**

What happened

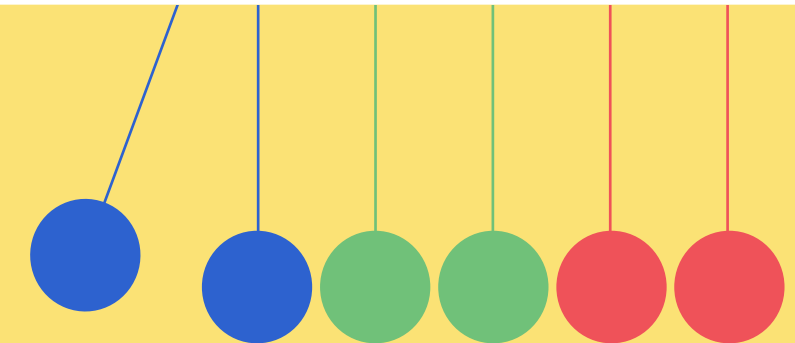
Patient engagement became structural. The same principles now guide policy, regulation, investment, and innovation. PFMD evolved from convenor to enabler of new, self-sustaining initiatives.

Key moments

- Regulators and payers citing **PE Guidance** and **PED Navigator** in reflection papers and guidelines.
- Investors incorporating patient perspectives into ESG criteria.
- Health systems across Asia and Europe adapting PE tools locally.
- Incubated the "initiation of new **engines of change**" including Clinical Trials Data Network (**CTDN**) and its contributions to **IHI-READI**, Patient Engagement Professionals Society (**PEPS**), Patient Movement Catalyst (**PMC**).



CTDN



IMPACT

From projects to policy — patient engagement as infrastructure for healthcare innovation.

10 Years of Collective Impact

Highlights

PEOPLE & REACH

9 200

individuals on Synapse

90 +

countries represented

1.2 M

people reached (2024)

LEARNING & CAPABILITY

38 000

learners trained

500 000

employees with access through
11 pharma companies

RECOGNITION

470

Made with Patients Award
nominations till date.





COLLABORATION SPACE

8

PEOF editions (2018–2025)

5 500

attendees

50 +

countries

RECOGNITION

470

Made with Patients Award nominations till date.

TOOLS & STANDARDS
PE MANAGEMENT SUITE

- Fair PE Planner
- PE Quality Guidance
- Metric Selector

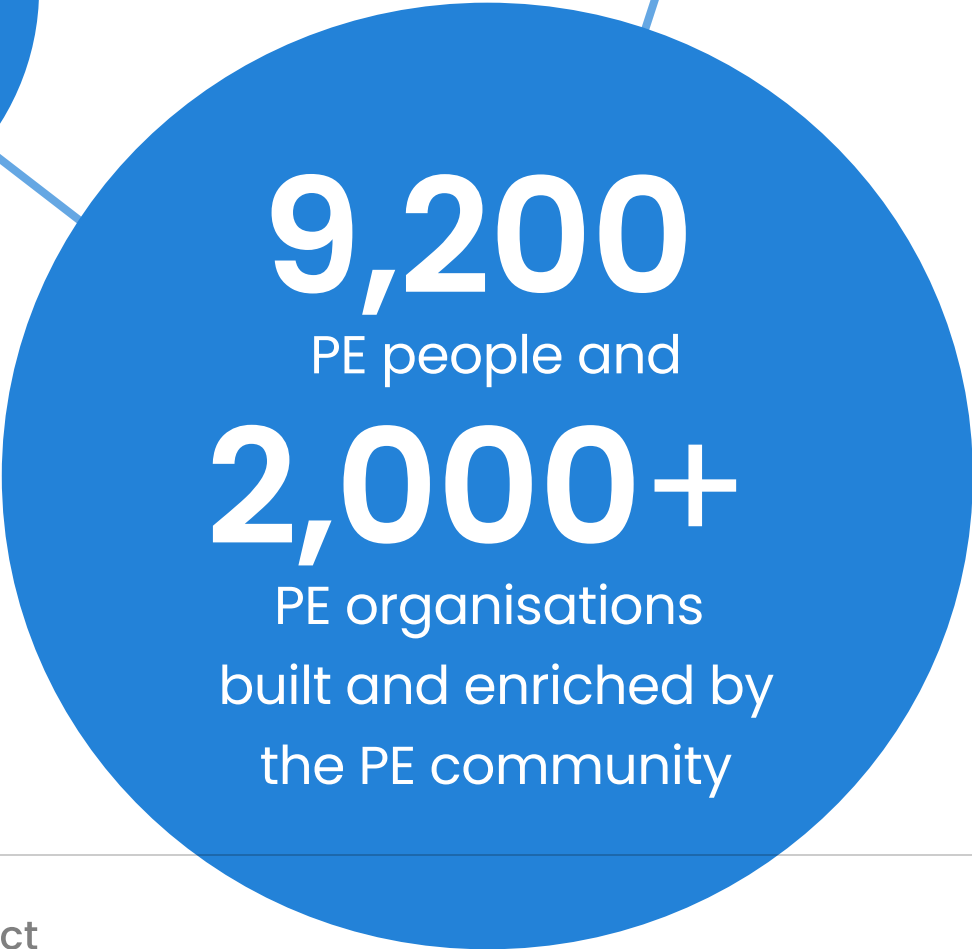
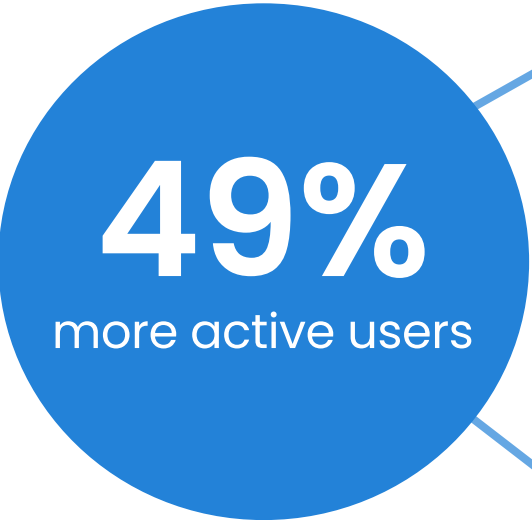
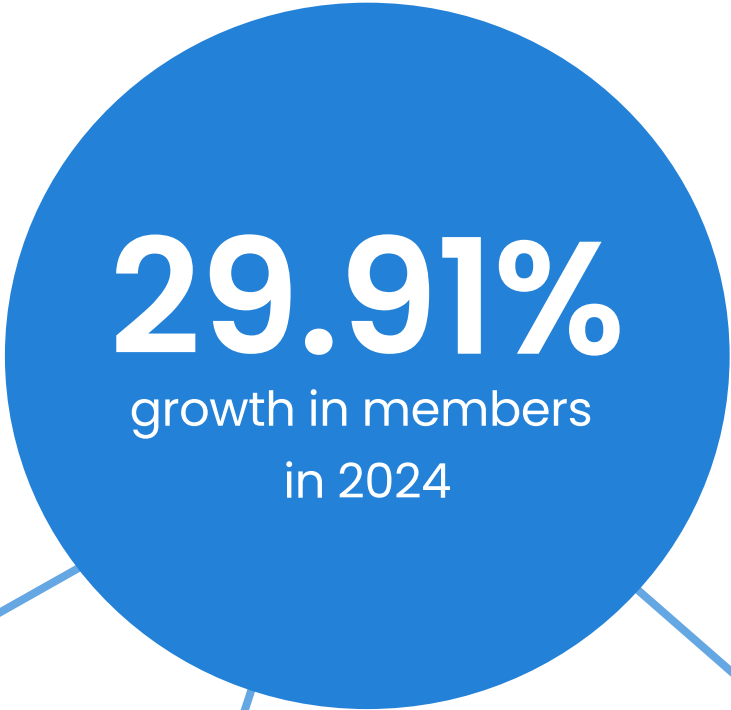
System Influence PFMD tools cited in EMA Reflection Paper, PMDA Japan, UK PIF Guidance; referenced in ESG and MedTech

EACH NUMBER REPRESENTS TRUST BUILT, SYSTEMS OPENED, AND PATIENTS SHAPING HOW HEALTHCARE WORKS. TOGETHER, THEY MARK A DECADE OF SHARED PROGRESS.

The PE Infrastructure



Synapse is the world’s largest patient-engagement network. It maps projects, training, tools, and experts so anyone can find collaborators, resources, or inspiration in minutes.

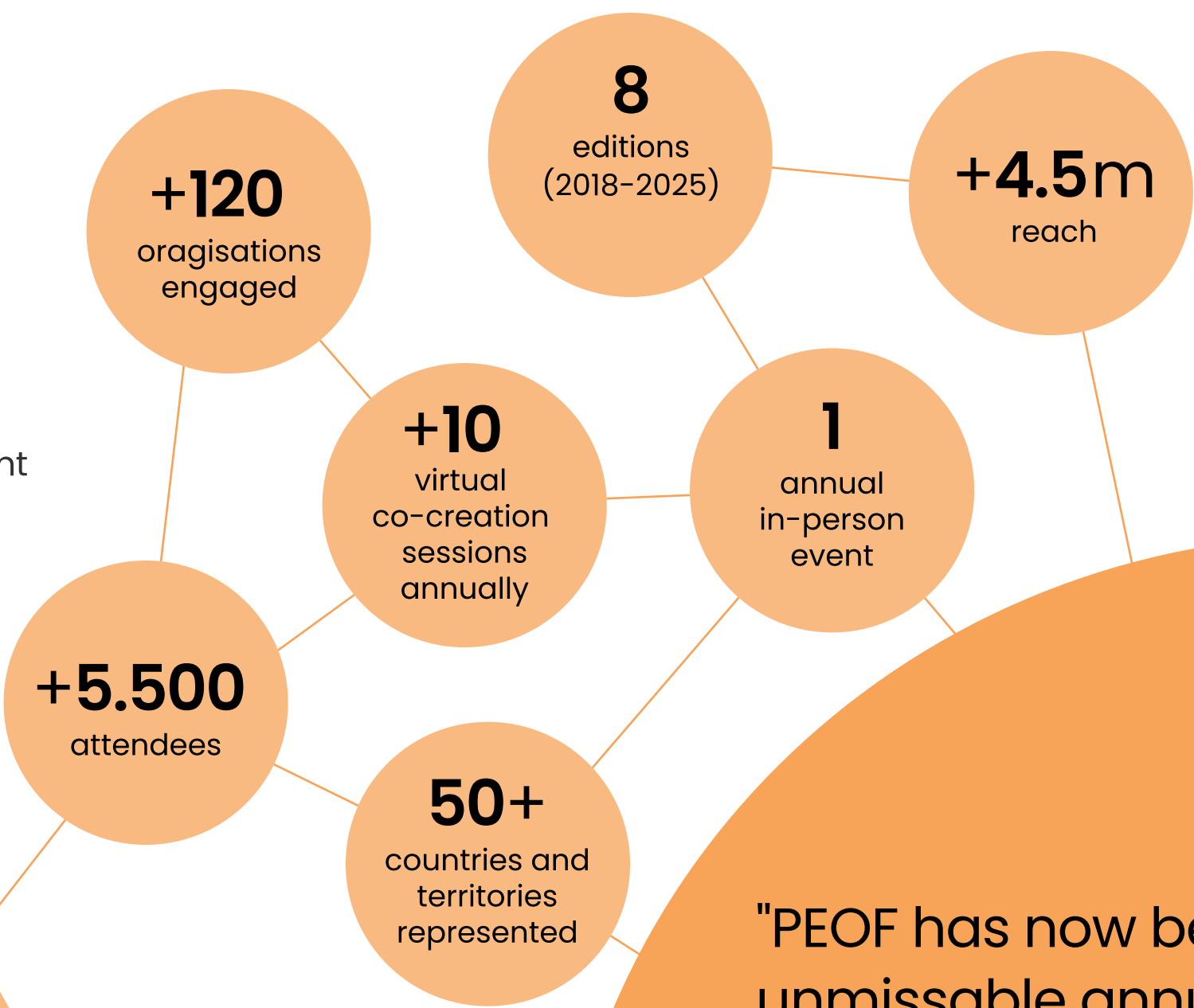
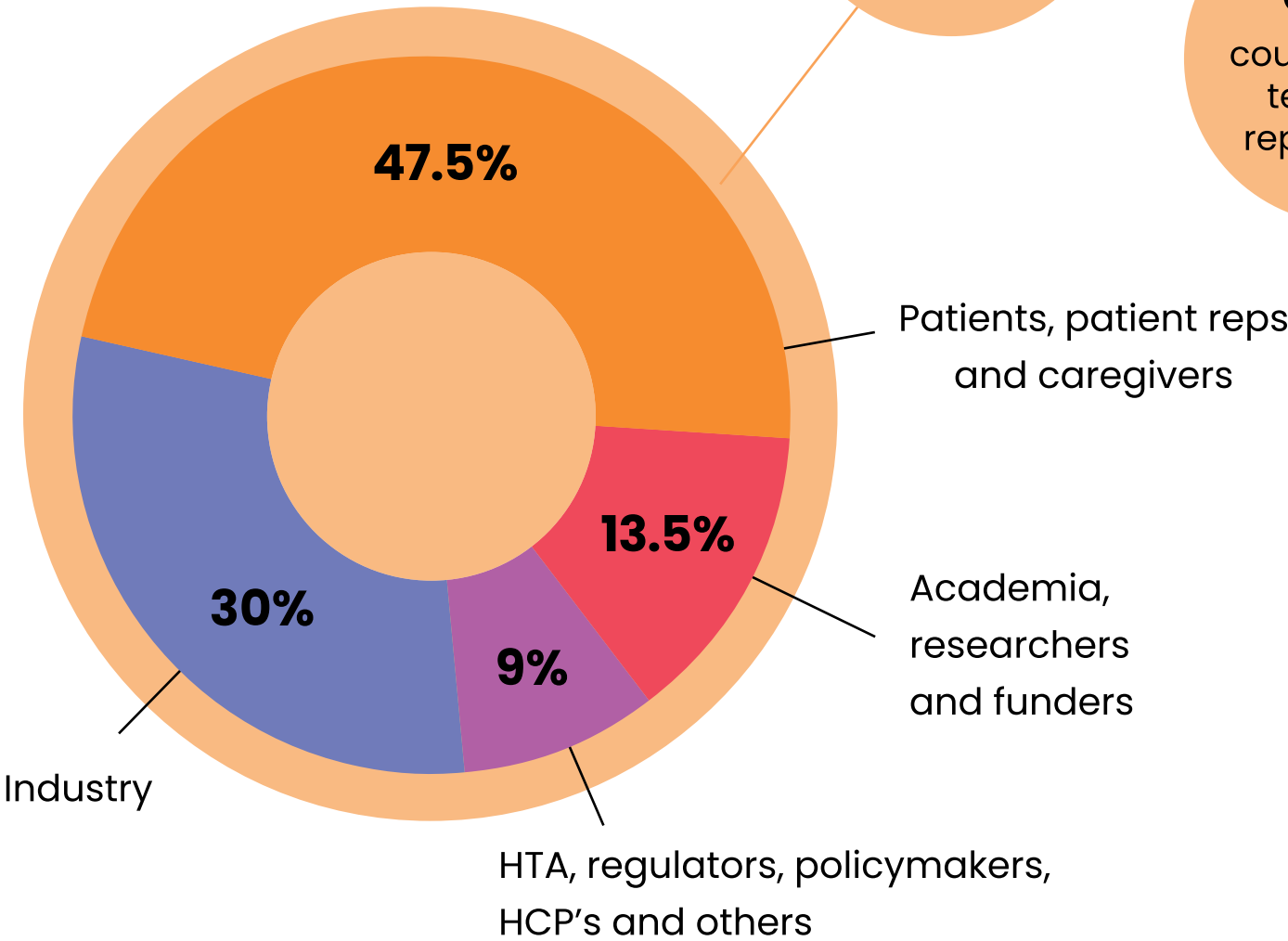


“Synapse is the largest PE network I know — full of valuable contacts, stakeholders, and resources. For anyone starting work with patient communities, it’s an indispensable resource.”

Oleks Gorbenko
Global Patient Affairs Director
Ipsen



The Patient Engagement Open Forum (PEOF) is the only multi-stakeholder event driving the future of PE. Through virtual sessions and an annual in-person forum, it offers a safe and brave space to co-create practical answers to shared challenges, throughout the year.



"PEOF has now become an unmissable annual event... more than just a forum, it's a collective movement, a space for learning, sharing, discovering new developments, and exchanging best practices."

Bahija Gouimi
AMAL, Morocco

Made with Patients Awards

Presented annually at PEOF, the Made with Patients Awards honor initiatives and individuals who put patient perspectives at the center of healthcare solutions

From a handful of pioneers to a global movement, every edition of the Awards has seen:

- More voices joining in
- Geographies expanding
- Quality and impact reaching new heights



Nominations

220
(2025)

110
(2024)

20
finalists

9
winners

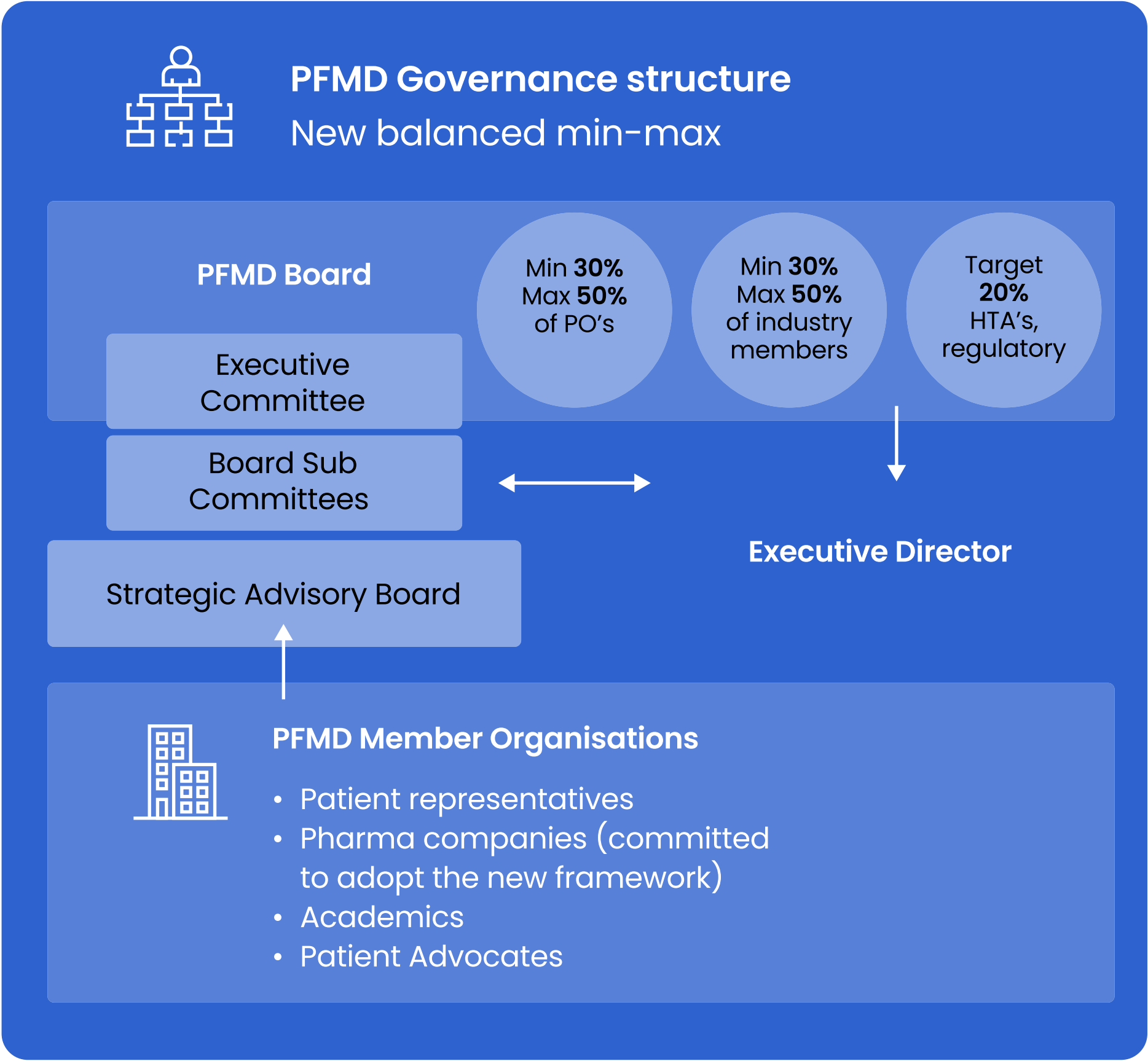
“I’m deeply grateful to PFMD and the PEOF community for this recognition. I’m just one part of the puzzle, it’s the collective effort that has brought us this far and will keep pushing patient partnership forward.”

Emma Doble
Patient and Public Strategy Editor, The BMJ and 2025 Jury Special Award Winner, Made with Patients Awards

Governance



PFMD’s governance mirrors the ecosystem it serves — bringing together patients, industry, academia, regulators, HTA bodies, and experts from health, digital, and device sectors to ensure balance, accountability, and collective direction.



The Work Continues

5-Year Shared Agenda

This is about shaping WITH patients what it will mean to be human in healthcare over the next 10–20 years. Whether you’ve been part of this journey since the beginning or are joining today, this is the moment to lean in. The next decade will be defined by those who choose to lead.

✓ **Strengthen standards** so that PE is embedded in policy, practice, and evidence generation.

✓ **Build capabilities** through training, shared intelligence, and peer learning across regions and sectors.

✓ **Drive local adoption** by enabling country-level leadership and sustainable implementation.

✓ **Integrate PE into evidence** by making patient experience data central to decision-making.

✓ **Co-create innovation** across MedTech and digital health pipelines from the very start.

✓ **Shape future value** by linking PE to sustainability and investment metrics that redefine what success in healthcare means.

Vision & Mission

We see a world where healthcare is continuously shaped, delivered, and improved WITH patients—where patients help drive innovation, better health outcomes, and more effective systems. PFMD’s mission is to create the conditions which are required for such systematic and meaningful patient engagement for better patient and societal health outcomes.

2030 Goals

1

Drive systematic, meaningful and impactful PE outcomes
By deepening PE integration

2

Extend the patient engagement community
Through targeted dissemination, adoption, and advocacy of PE best practices

3

Transform the healthcare ecosystem to actively supporting & enabling PE
By building the conditions for meaningful and impactful PE

Guiding Principles

- 1. **Integrate PE and PED for Impact:**
Leverage the connection between patient engagement and patient experience data to optimize involvement and enhance evidence-based practices.
- 2. **Generate and Share PE Intelligence:**
Build a self-learning community that articulates the value of PE to diverse stakeholders through continuous intelligence and insights.

- 3. **Foster a Representative Response:**
The health future we’re shaping is rooted in the needs and lived experiences of all patient communities.
- 4. **Harness Digital Transformation & AI:**
Apply innovative digital and AI solutions to develop meaningful, patient-focused outcomes.

Made possible by our members



ASSOCIATE MEMBERS:



The next decade will be defined by those who choose to lead — with patients, not without them.

made with
patients

Join the movement:

info@patientfocusedmedicine.org

patientfocusedmedicine.org – pe.synapseconnect.org

[Bluesky](#) – [LinkedIn](#)

