Patient Engagement Professionals Industry Society

Draft Charter



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This document has been co-developed based on the results of a co-created survey, with input from a designated task force of 12 PE Industry Professionals and further refined by PEPS members. This draft document will remain open for input to ensure we capture all Patient Engagement Industry Professionals (PEPs) input and feedback as the group continues to evolve.



What is PEPS - Patient Engagement Professionals Industry Society¹?

PEPs is the first global community made by and for Patient Engagement (PE) professionals working in the for-profit life-science industry — specifically pharmaceutical, biotechnology, or medical technology (Medtech) companies involved in the development and commercialization of medicines, therapies, or devices.

Representing a diversity of roles, experiences, and backgrounds, the PEPS industry society strives to enable and empower its members to drive meaningful change within their organizations and across the life sciences for-profit industry.

This is a non-competitive, non-promotional space designed to foster open dialogue, learning, and personal and professional growth. Marketing approaches and competitive discussions are not permitted, ensuring a safe and supportive environment for all members.

Mission

Our mission is to unite patient engagement professionals in the life sciences industry, amplify their collective voice, and foster a culture of co-design—shaping health strategies and products with patients, not just for them. Through this, we aim to drive systemic change and deliver better outcomes across the for-profit life sciences ecosystem.

Vision

A future where patient engagement is woven into the fabric of the life sciences industry, and driven by empowered professionals as a united global biopharma community for delivering groundbreaking, patient-centered innovations.

¹ The use of such a term is not intended to create any legal entity or concept



Who is a Patient Engagement Industry Professional?

For the purpose of this society, "a Patient Engagement Industry Professional" <u>is a person</u>² working or having worked in a Sponsor company within the past 10 years, <u>defined as a for-profit pharmaceutical</u>, <u>biotechnology</u>, or <u>medical technology</u> (<u>Medtech</u>) <u>firm that develops and commercializes medicines</u>, <u>therapies</u>, or <u>devices</u>, <u>whose responsibilities</u>³ include ensuring that <u>relation-based</u>⁴ patient perspectives are meaningfully integrated into the organization's decision-making processes, policies, and practices along the medicine and/or product lifecycle⁵

This includes professionals in dedicated PE roles, as well as those in adjacent functions (e.g., clinical development, RWE, communications, policy, market access, regulatory, or innovation) who actively contribute to patient engagement efforts.

Individuals with experience only with Service Providers—defined as companies or individuals that offer contracted services, expertise, or technology to sponsor companies but are not themselves responsible for the development or commercialization of medicines, therapies, or devices (e.g., Contract Research Organizations, Agencies and Consultancies, Tech and Data Vendors, Independent Consultants, etc.)—are not eligible for membership.

Goals and Strategic Objectives

PEPs shape the future of the PE function, teams, and individual PE professionals globally by:

- Providing a platform for unified positioning and communication
- Demonstrating the value of PE for the life science sector
- Defining the current and future practice of PE within the life sciences industry
- Leveraging collective thought leadership to train the next generation of PE leaders
- Being a global community for PE industry professionals

² Membership is individual and nominative.

³ As a leader and/or practitioner.

⁴ As opposed to (only) ad-hoc questioning, survey or Al.

⁵ Exceptions may be made at the discretion of the governance body, allowing individuals outside of these criteria to participate in meetings relevant to their expertise or role.



Strategic Objectives

Demonstrate the value of Patient Engagement	Shape PE Professional Guidances	Develop a Community and its Network
Build a case for the recognition of PE in improving patient outcomes and educate internal and external stakeholders by emphasizing the importance of individual health empowerment as a central goal of PE.	Develop and enhance ethical and professional standards and career development frameworks for PEPs, ensuring they embody core principles and skills essential for high-quality PEessential for high-quality PE activities.	Creating a structured platform for all PE industry professionals to learn, share, and collaborate, thereby driving the field forward with collective expertise and innovation.

Governance and Operations

As PEPS is a newly formed professional society, a lean and adaptable governance structure is key. The goal is to establish essential operational frameworks without becoming overly bureaucratic, allowing for growth while ensuring accountability and smooth functioning from day one.

Initially, a small <u>Steering Committee</u> was established as a working board. With the <u>Secretariat</u>'s support, these individuals are hands-on in getting the society off the ground and representing the society's core interests. In addition, <u>Working Groups/Task Forces</u> have been created dedicated to specific relevant topics.

In the future, as the society grows, <u>additional Governing Bodies</u>, including a compliance/audit element, will be formally established, and responsibilities will be transferred.



Current Governance and Operations Model (August 2025)

Steering Committee		
WHO	MEETS	RESPONSIBILITIES
Founding Members: Bronwyn Lewis, Rebecca Vermeulen, Roslyn Schneider	Ad hoc	 Operational decisions until a general assembly and a board of directors are established Strategic development Task Forces/Working groups supervision

Charter-dedicated Task Force		
WHO	MEETS	RESPONSIBILITIES
Volunteer Members	Ad hoc	Mission, vision, objectives, and guiding principlesCharter drafting

Working Groups

Publication on the value of the PE Function Working Group		
WHO	MEETS	RESPONSIBILITIES
Volunteer Members	Ad hoc	Publication Strategy, review and output



Building a PE Industry Competency Framework Working Group		
WHO	MEETS	RESPONSIBILITIES
Volunteer Members	Ad hoc	 Review of existing frameworks, job descriptions, and skill gap analysis Develop the competency domains

Community & Network for cross-industry collaboration Working Group		
WHO	MEETS	RESPONSIBILITIES
Volunteer Members	Ad hoc	Build the community and the network

Secretariat		
WHO	MEETS	RESPONSIBILITIES
The Synergist	Weekly	 Administrative host Website & comms Membership management Task Forces/Working Group coordination Meeting logistics Financial oversight and fundraising



Appendix

Rationale Behind the Definition of a Patient Engagement Industry Professional

This definition of a Patient Engagement Industry Professional was developed to determine who can be part of the PEPs Industry Community (PEPs), as reflected in the charter.

Below, we elaborate on the key considerations discussed during the development of this definition in the task force conversations:

1. Defining Participation: Working in a Sponsor company

A key outcome of foundational discussions was the recognition that patient engagement industry professionals are those employed within for-profit Sponsor companies—defined as pharmaceutical, biotechnology, or medical technology (Medtech) companies that develop and commercialize medicines, therapies, or devices.

These individuals may hold dedicated patient engagement roles or work in adjacent functions that contribute to embedding patient perspectives across the product lifecycle.

While many external experts and service providers support patient engagement efforts in the ecosystem, PEPS membership is limited to those working or having worked within the past 10 years in eligible Sponsor companies to ensure a shared experience base and focused peer-to-peer exchange.

2. Leadership and Practitioner Roles

During the task force discussions, it was noted that patient engagement industry professionals take on varying roles within an organization, ranging from strategic leadership to hands-on implementation.

"Leaders set the vision and create the framework for embedding patient engagement," (...) "while practitioners work to ensure those frameworks are put into action on the ground."

Including both "leaders and/or practitioners" in the definition reflects this distinction and ensures that individuals at all levels of influence are part of the PEPs Industry community.



3. Relation-Based Engagement

The discussion highlighted the importance of focusing on relation-based engagement as a core principle: "Al-driven surveys and ad hoc digital tools can't replace the depth of understanding that comes from ongoing, trust-based relationships with patients."

The task force agreed that effective patient engagement must be grounded in these relationships. This relational approach is central to the PEP's roles, as it ensures that patient perspectives are not only heard but deeply understood and acted upon.

4. Incorporating Patient Perspectives into Decision-Making

One of the most significant outcomes of the task force discussions was the agreement that PEPs are those who play a crucial role in ensuring patient perspectives are embedded in decision-making processes: "The goal is not just to gather patient insights, but to make sure those insights influence the organization's key decisions, from policies to practices."

This point underscores the impact PEPs role have in shaping how life sciences organizations operate, ensuring that patient engagement is not just a checkbox but a fundamental part of their decision-making processes.