

Patient Engagement Professionals Industry Community

Draft Charter



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Table of Contents

Who is a Patient Engagement Industry Professional?	4
Vision	4
Mission	4
Goals	5
Appendix	6

This draft document¹ will remain open for input to ensure we capture all Patient Engagement Industry Professionals' (PEPs) input and feedback as our group continues to evolve. Please feel free to make comments and/or introduce changes to the tracking tool.

¹ This document has been co-developed based on the results of a co-created survey (launched during July 2024) and with input from a designated task force of 12 PE Industry Professionals.

Who is a Patient Engagement Industry Professional?

For the purpose of this Community, "a Patient Engagement Industry Professional is a person² working or having worked in or for³ a life sciences for-profit organization⁴ whose role⁵ includes ensuring that relation-based⁶ patient perspectives are incorporated into the organization's decision-making processes, policies, and practices along the medicine and/or product lifecycle"

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.

Vision

Enabling a world where patients are key partners in shaping sustainable care and driving innovation in healthcare research and development, where their perspectives are integral to decision-making processes.

Mission

Our mission is to foster better-performing⁷ life sciences for-profit organizations³ by co-designing life sciences health strategies and products for patients WITH patients. To achieve this, we believe these organizations must develop strong patient engagement (PE) capability and capacity.

PEPs is the first global community by and for PE industry professionals across all different levels of experience and specialty. Through collective engagement, the **PEPs international community strives to enable and empower its members to drive meaningful change within their organizations and across the life sciences industry.**

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

- A. Defining the current and future practice of PE within the life sciences industry
- B. Being a global community for PE industry professionals

² Membership is individual and nominative.

³ As an employee, or as a for-profit service provider (full-time, part-time) who has relevant experience in the industry last ten years.

⁴ Especially pharmaceutical companies, biotechnology firms, and medical technology companies; often referred to as "industry".

⁵ As a leader and/or practitioner.

⁶ As opposed to (only) ad-hoc questioning, survey or AI.

⁷ Including, but not restricted to, shareholder return.

- C. Leveraging collective thought leadership to train the next generation of PE leaders by sharing learnings, best practices, and innovative solutions, fostering better patient-centred strategies and improved health outcomes.
- D. Speaking as a unified voice of the PE profession

Goals

Goal 1	Goal 2	Goal 3
Shape PE Professional Guidances	Demonstrate the value of PE	Develop a Community and its Network
Develop and enhance ethical and professional standards and career development frameworks for PEPs, ensuring they embody core principles and skills essential for high-quality PE activities that elevate the impact of PE.	Demonstrate PE's value and function by educating internal stakeholders and making a case for its recognition in improving patient outcomes. This includes emphasizing the importance of individual health empowerment as a central goal of PE, supported by patient engagement strategies, measurement and clear guidance.	Creating a structured platform for all PE industry professionals to learn, share, and collaborate, thereby driving the field forward with collective expertise and innovation while engaging externally to disseminate PE value.

Annexe with membership and funding model available [here](#).

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 or for Life Sciences for-profit Organizations: A critical aspect of the discussions was the recognition that patient engagement industry professionals include both individuals employed directly within life sciences for-profit organizations and those working externally as consultants. "Consultants often drive the patient engagement agenda in organizations without internal capacity," making it essential to include external experts who actively influence or undertake PE activities.
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: "AI-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.