

An abstract background consisting of numerous thin, glowing lines that radiate from a central point, creating a funnel-like shape. The lines transition in color from blue and purple at the top to yellow and orange at the bottom, set against a dark blue background.

BioPharma leaders: Are you  
prepared for the next patient  
engagement (r)evolution?



A decade ago, patient engagement was principally undertaken by biotech companies operating within the orphan disease arena, where the “voice of the patient” carried significant weight when advocating for developing treatments for underserved patient classes and accessing high-cost emerging therapies. But today, it’s an increasingly critical aspect of how pharmaceutical companies determine growth areas, drive and deliver innovation, and ultimately increase access to new medicines.



That said, ownership varies significantly across organizations, sitting anywhere from communications, public/government affairs, commercial/marketing, R&D, medical affairs and, on some occasions, even at the C-suite table.

To understand how biopharma leaders view their evolving mandates and the role patient engagement plays therein, Russell Reynolds Associates analyzed a range of patient engagement and advocacy functions and interviewed fifteen leaders across large-cap biopharma organizations,

orphan drug pharma companies, and patient organizations. Through this, we learned how biopharma leaders derive insights, create value and meaningful treatment options for patients, and how they interact with the external stakeholder community, ultimately driving business growth.

Regardless of the organizational structure they adopt, biopharma leaders looking to create an impactful patient engagement in their organizations need to consider the following:

#### 01. Enterprise-wide scope and early engagement

While many companies instinctively speak to patient-centricity as part of their *raison d'être*, in reality, placing the patient at an organization's core can often require a deep cultural and operational shift across all departments, from the earliest phases of R&D, where the patients' engagement is increasingly happening, to the commercialization. Identifying supporting organizational layouts will be vital.

#### 02. Top-down sponsorship and leadership alignment

Direct support from senior management – including the CEO – is essential. Initiatives must align with leadership's vision to secure the necessary resources and influence.

#### 03. Balance of external and internal focus

Patient engagement leaders must work to shift internal attitudes while maintaining their traditional external stakeholder focus, always placing the patient at the core of the value chain.

#### 04. High-EQ and versatile corporate influence

Successful patient engagement leaders are both innately empathetic listeners and agile, mission-driven corporate champions capable of influencing all stakeholders with tailored and authentic narratives, rich communication, and a willingness to take risks.

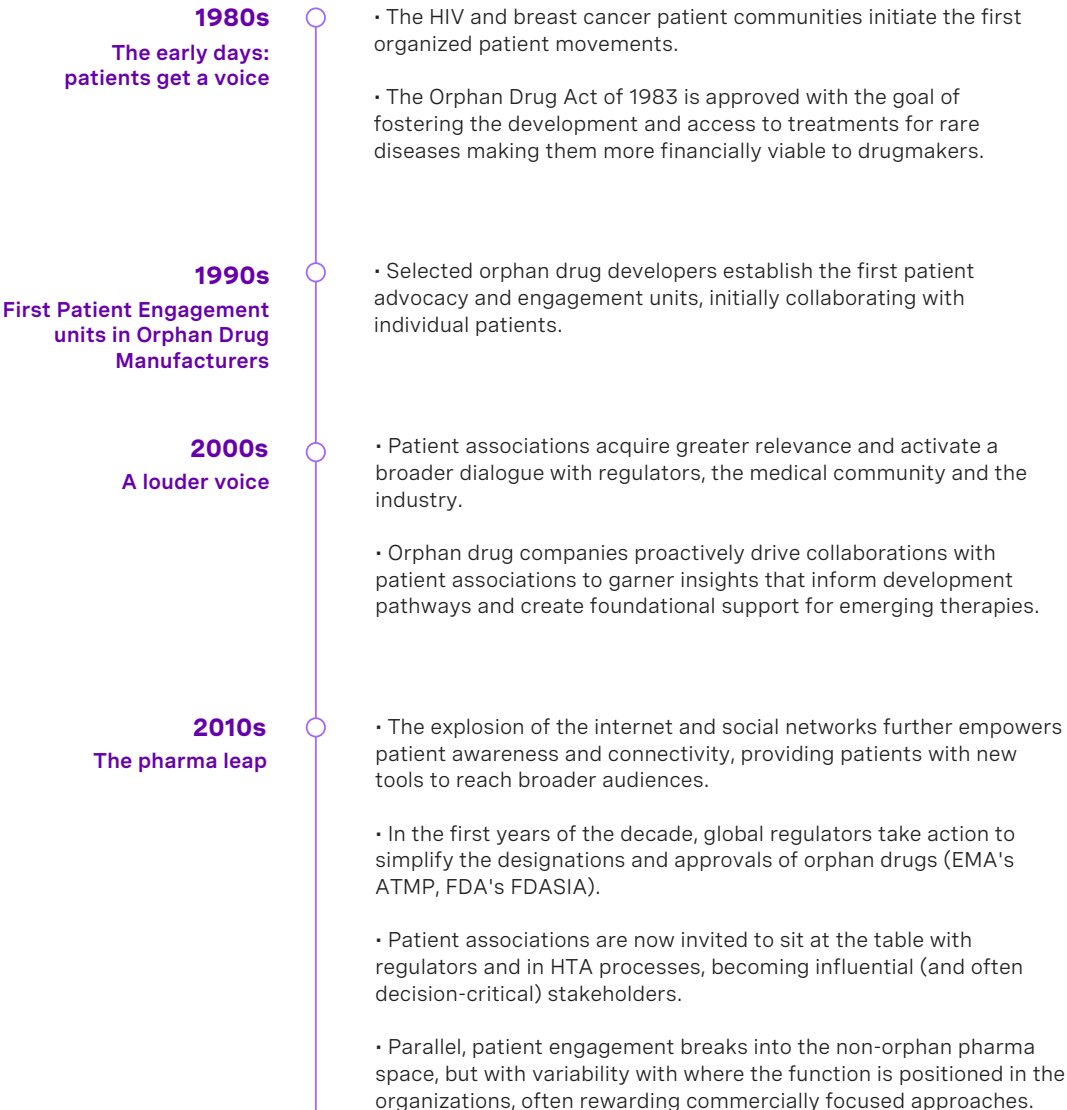
#### 05. Accountability and Impact Measurement

Patient engagement leaders will be increasingly asked to creatively use composite data sources and new technologies to demonstrate their function's ROI and transversal impact on the broader organization.

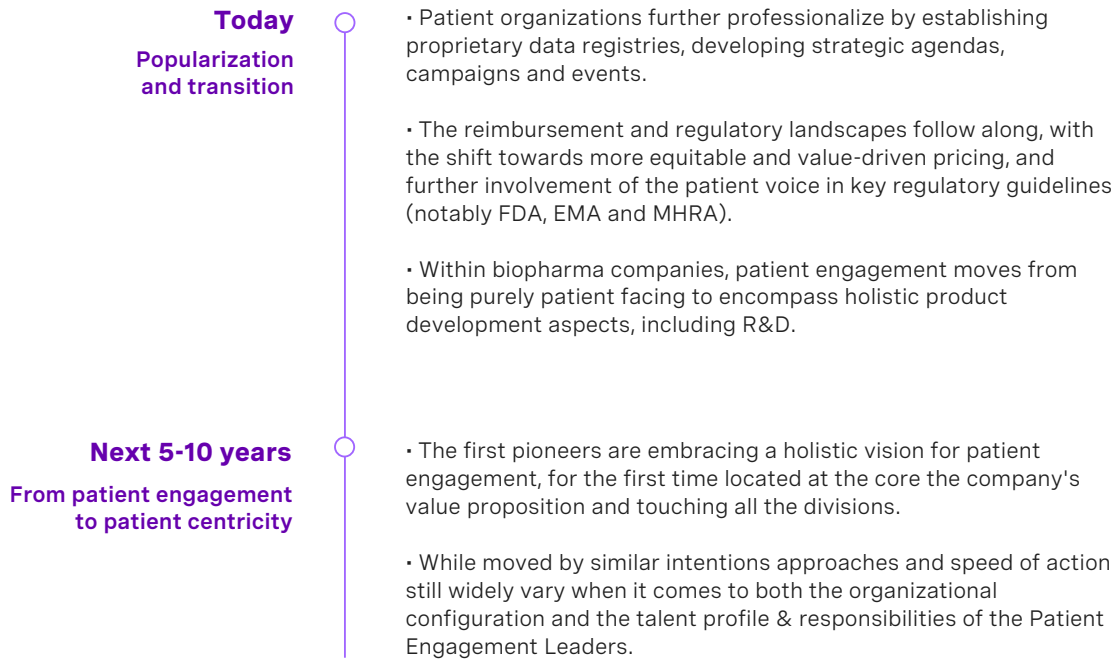
# Over the last forty years, the biopharma industry has responded to shifting external contexts with new strategic approaches

As patient engagement has expanded and progressed over the years, so has its ownership within biopharma organizations. With the patient evermore centered in the drug lifecycle development process, companies will need to evolve their structures as well.

**Figure 1: A timeline of patient engagement's evolution within biopharma**



**Figure 1: A timeline of patient engagement's evolution within biopharma**



More recently, the patient engagement function in pharma sits in medical affairs or R&D, acknowledging the impact of involving patients early in the drug lifecycle on endpoints, trial outcome, reputation and top line growth. Companies that are now mastering patient engagement have successfully built leaner, more effective pipelines and therapies designed around patients' needs, while simultaneously improving their credibility among the patient and medical communities.



"Large pharma companies working in multiple therapeutic areas are still grappling with how to do patient engagement at scale. Most tend to focus on only one part of the lifecycle—be it development, commercial, or early research. They are not yet consistently and systematically engaging patients across the entire value chain."

**Marc Boutin**

Global Head of Patient Engagement, Novartis



"In the last 15 years, an unprecedented number of medicines and diagnostic tests have come to the market, transforming patients into real healthcare consumers, and eventually into partners to product makers. The importance of patient voice has grown alongside, and is now involved extremely early in the R&D process, influencing the prioritization of programs."

**Naziah Lasi-Tejani**

Global Patient Partnership Group Leader, Hematology/Oncology, Roche



"A mix of external and internal forces drove change in the patient engagement function. Regulators are increasingly involving patients in HTA processes and pharma companies want to work with them to understand their needs and develop better solutions."

**Eva Bretschneider**

Head of Patient Partnerships & Stakeholder Engagement, Bayer



As both external and internal forces demand new value paradigms, the industry is now readying itself for an additional pivot, placing patients at the core of their value proposition and involving them, in different modalities, across all the stages of the drug lifecycle. Drug makers will be asked to evolve and rethink how they design, develop and commercialize their products. The shift will require a radical cultural and strategic realignment.

While these are still the early days of the patient centricity era, we already see innovators and trendsetters setting themselves apart from companies with more reactive strategic responses.



"It started as a philanthropic initiative, but biopharmaceutical industries now understand how important it is for patients to be educated and well-versed on the innovation that's coming on to the market—so this helps them be their own advocates for that innovation, which makes their voice more and more important."

**Lisa Lacasse**

President, American Cancer Society,  
Cancer Action Network



"Developing patient engagement in healthcare companies yields tangible benefits: it fosters enhanced patient outcomes and a refined pipeline, boosts engagement for long-term competitiveness and more sustainable R&D, and provides a distinct edge in the market. Lastly, and perhaps most crucially, it embodies a commitment to prioritizing patient welfare. As such, building an integrated patient engagement platform is mission-critical in biopharma"

**Vanina Laurent-Ledru**

Director General, Foundation S-  
The Sanofi Collective



"First, we need agreement across the healthcare system stakeholders on the terms 'patient engagement' and 'patient advocacy.' We still see stakeholders defining these terms differently—one may focus on clinical development engagement, while another may see the role as collaboration with the patient community across the complete drug development lifecycle, from clinical trials through disease awareness and access. Many times, a company has a singular focus on what they want this function/name to mean versus what is important to the patient community and broader system."

**Amber Spierer**

Strategic Engagement Director,  
TransCelebrate BioPharma (ex-EQRx,  
Novartis)

# Where to position patient engagement in biopharma organizations

As patient engagement has expanded and progressed over the years, with patients increasingly centered in the drug lifecycle, so has its ownership and reporting structure within organizations.

To help biopharma leaders determine the right model for their organization, we asked our patient engagement experts to assess the most common structures. We then

asked leaders from patient and scientific organizations which of these configurations they preferred to interact with. From these conversations, we developed the following three models, all with differing strategic purposes and structural requirements. We then identified key traits of future layouts for leaders to leverage as they embrace patient centricity.



"Patient engagement used to focus on lobbying and commercial activities. Now it's moving earlier into the drug's life cycle, into R&D and clinical operations. It's become more data-driven, with regulators extensively incorporating patient-reported data in their drug review processes. This is creating a new paradigm in the way pharma companies interact with patients and their organizations."



**Emma Sutcliffe**  
VP, Global Patient Officer, Ipsen



"The placement of patient engagement within an organization is less about its formal location and more about the expertise and dedication of the team involved. While an ideal scenario might involve chief patient advocacy officer or CEO oversight for greater emphasis, practicalities often dictate its integration under R&D or corporate affairs. I recommend steering clear of commercial pressures."



**Tim Hunt**  
Chief Executive Officer, Alliance for Regenerative Medicine



"The effectiveness of patient engagement lies not in its organizational position, but in the empowerment and leadership support it receives. The optimal structure may well be an autonomous unit, led by a chief patient officer, with the necessary processes and governance to operationalize the necessary work."



**Wendy Erlen**  
VP, Global Head Patient Experience and Advocacy, Alexion AstraZeneca



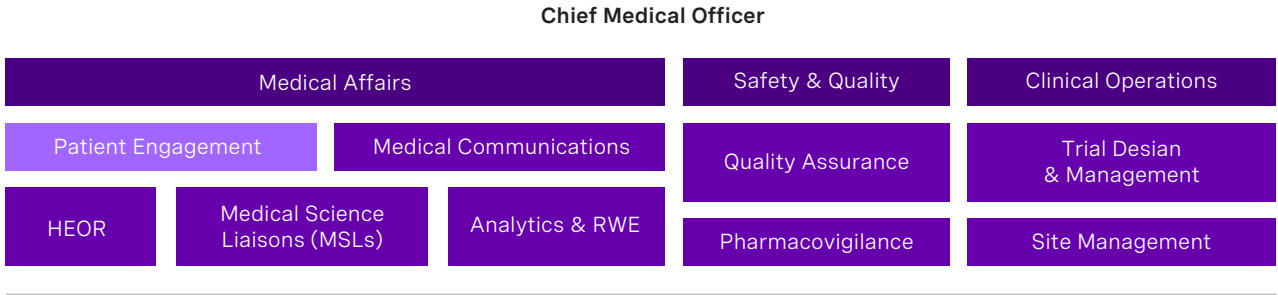
"Housing patient engagement in product development is what enables us to have biggest impact. Being part of the global medical affairs organization allows to focus on both the earliest phases, from discovery to development, and the later ones, around commercialization and access, making sure that our solutions are more tailored to the patients' needs."



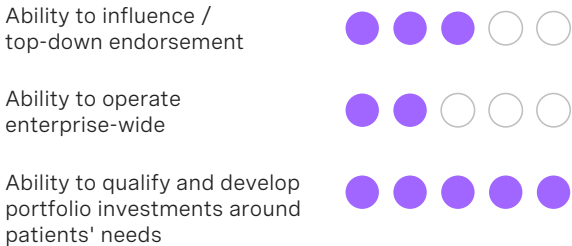
**Rebecca Vermeulen**  
VP, Global Patient Networks, Product Development Medical Affairs, Roche

# 01. In Medical Affairs: At the core of portfolio investments

**Figure 2: Most common position of the patient engagement function when housed within biopharma medical affairs**



**Internal impact**



**External impact**



Source: RRA analysis, patient engagement functions in biopharma companies, 2024

## Benefits

Presently, the patient engagement function is increasingly found in the Medical Affairs division. This approach seems to work best for CEOs and CMOs who want to improve the quality of their asset pipeline, mitigate portfolio risks, and embrace patients as active partners in co-developing solutions that are clinically effective, fulfill unmet needs, and deliver high uptake and increased satisfaction.

By involving patients in early pipeline decisions, this configuration builds trust and better relationships between patients, companies, and the broader medical community. It also helps biopharma organizations create successful sponsorship campaigns and events, while enabling better access to anecdotal stories, patient reported outcomes and experiences, as well as clinical RWE. Finally, linking patient engagement to portfolio development, as well as internal and external data sets, typically allows for stronger financial and qualitative cases, enabling organizations to reach new patient groups.

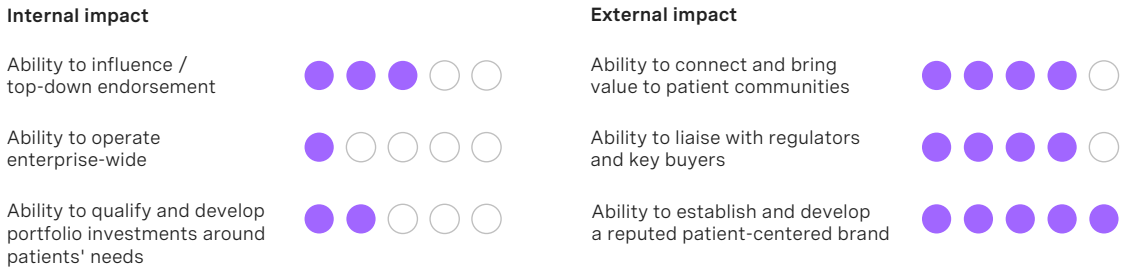
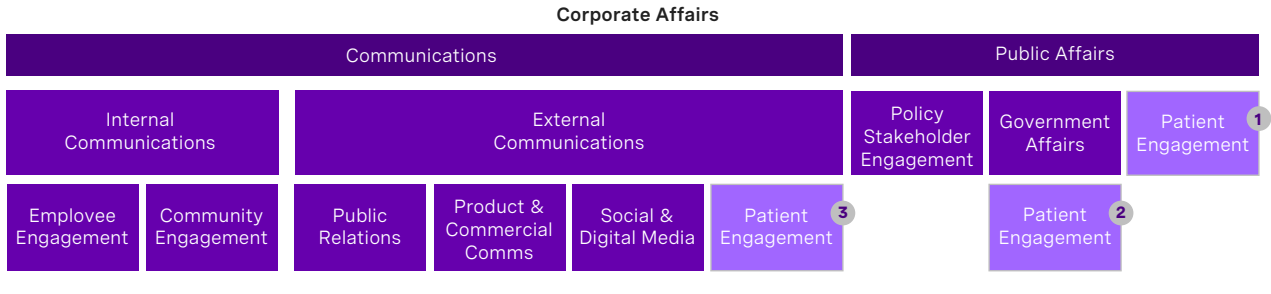
## Potential limitations

However, patient engagement leaders working in Medical Affairs report that they often struggle to break out beyond the scientific and medical silos and integrate across functions. They may need to develop secondary processes or pathways to work with regulatory, access, policy, and commercial teams to ensure the patient perspective is integrated into all aspects of the drug lifecycles. While demonstrating that the short-term impact of patient engagement initiatives are crucial to secure budget and endorsement, this model is more likely to deliver benefits in the long term.



## 02. In public affairs or external communications: The external voice

**Figure 3: Most common positions of the patient engagement function when housed within biopharma corporate affairs**



Source: RRA analysis, patient engagement functions in biopharma companies, 2024

### Benefits

Housing patient engagement within Public Affairs / External Communications allows boards and executive teams to enhance their organization’s reputation, melding it into a broader narrative of corporate responsibility and addressing enterprise culture, social purpose, and sustainability in a proactive, responsible, and impactful way. This model effectively engages with external groups and builds a stronger brand for the company.

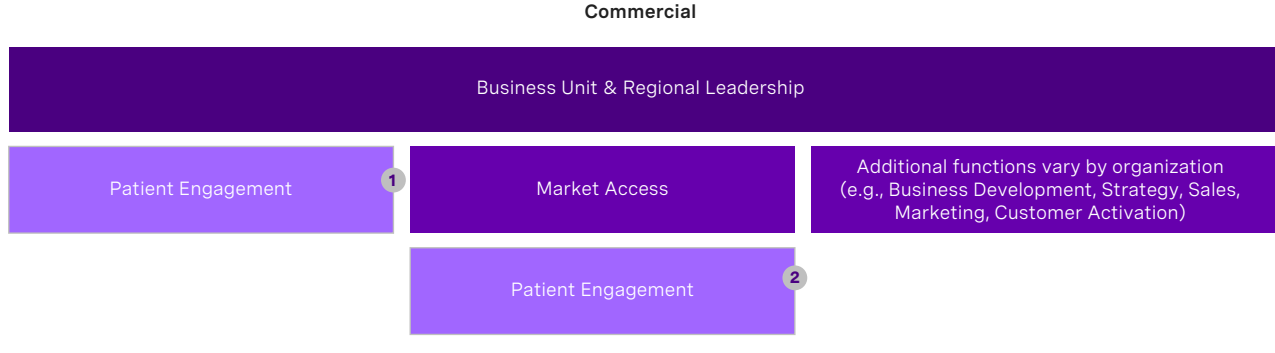
This approach also empowers patient engagement leaders to better answer strategic imperatives from internal stakeholders – typically, CEOs looking to manage the external stakeholder engagement agenda; general counsels who seek the opportunity to shape regulatory outcomes and mitigate reputational risks; CHROs who are concerned with employee engagement; and chief medical officers who need a consistent and resonant messaging, especially for patients.

### Potential limitations

Given this predominant external focus, this model is limited when it comes to involving patients in the R&D phases, product labelling, and broader development. While supported at connecting and vocalizing stages, patient leaders adopting this configuration may struggle to drive a broader and deeper impact in terms of tangible outcomes for patients, especially in the long term.

### 03. In commercial: The marketer and alliance maker

**Figure 4: Most common positions of the patient engagement function when housed within biopharma commercial functions**



Internal impact		External impact	
Ability to influence / top-down endorsement	● ● ● ● ○	Ability to connect and bring value to patient communities	● ● ○ ○ ○
Ability to operate enterprise-wide	● ● ○ ○ ○	Ability to liaise with regulators and key buyers	● ● ● ● ○
Ability to qualify and develop portfolio investments around patients' needs	● ○ ○ ○ ○	Ability to establish and develop a reputed patient-centered brand	● ○ ○ ○ ○

Source: RRA analysis, patient engagement functions in biopharma companies, 2024

### Benefits

This structure was especially prevalent in the 2010s among pharma boards and CEOs seeking to establish a link between patients and commercial teams. In most instances, patient engagement falls under global P&L leaders or market access teams. This go-to-market approach is centered around the end-users, ensuring that products and their benefits gain exposure among the relevant patient and medical communities. It can also facilitate drug uptake by reducing potential barriers to adoption and syncing reimbursement rates with payers' willingness to pay.

This configuration allows patient engagement leaders to address CFOs and commercial leaders who want to develop their global market access and pricing / reimbursement strategies. It also allows for greater regional patient support and gives commercial executives better and more direct ways to influence stakeholder outreach. Additionally, it contributes to make the company's delivery and service models more patient focused, empowering patient

engagement leaders to craft key processes, tools, programs, and content to support patients and their caregivers, ultimately fostering uptake and access.

### Potential limitations

While effective at growing product awareness and empowering global commercial teams, this approach is less versatile when engaging with scientific communities to gain and grow access among patients. Lacking proximity with the internal scientific teams, this layout is less suitable for endorsing patients' perspectives in the drug discovery and development phases, including processes such as drug labelling, which frequently relies on product user input.

Additionally, while supportive when it comes to establishing relationships with key buyers, this structure does not facilitate engagement with regulatory bodies such as the FDA and EMA.

# The future patient engagement function

Biopharma organizations have unique stories, portfolios, and divisional layouts. While there is no one position that satisfies the strategic needs of every organization, the experts we interviewed agree that the following requirements will reshape the patient engagement function in the years to come:

- **Proximity to the CEO:** Organizations that excel at engaging patients tend to have their patient engagement leader reporting into a member of the executive committee, with clear buy-in from CEO. Sustained and genuine endorsement from the company's leadership is crucial for a meaningful change within and without the organization.
- **Connectivity and ubiquitous presence in the organization:** Regardless of where the function is placed, it is crucial that it is connected to all the key departments (commercial, R&D, corporate affairs) through a network of direct reports. This is especially crucial in companies where market access, P&L and R&D teams may operate in a more siloed way, particularly in early development phases. It also serves CEOs and boards who want to bring different departments (including commercial, research, corporate affairs, finance) together around a unified mission.
- **Structured platform for external engagement:** Patient engagement leaders need to develop a system where different external stakeholder groups can cooperate to achieve the best patient care, while also aligning with the CMO and public affairs' external communications plans. Critical patient organizations should be involved early in the drug development process and engaged throughout, with long-term engagement plans after launch.
- **Access to key datasets:** Patient engagement have the complex task of building business cases and narratives that support the proliferation and continuation of patient-

centered initiatives among different stakeholders. Thanks to technological advancements, we have recently witness a sophistication in the way Patient Reported Outcomes (PROs) and Experience (PREs) metrics are collected by patient associations or other parties, opening new possibilities to patient engagement departments. Internally, leaders need a creative mix of qualitative and data-driven tools—such as dashboards or innovative KPIs—to demonstrate the impact of the patient voice along the value chain. CHROs are key allies when it comes to reinforcing and divulgating internally the importance of patient engagement.



"It's the patient (and their family) who's the real expert on their disease, a Patient Engagement Leader unlocks that knowledge and integrates those perspectives into company decisions. And only leaders with a genuine passion for patients' lived experiences can do that."



**Jayne Gershkowitz**  
Chief Patient Advocate,  
Amicus Therapeutics

# The changing skillset of the patient engagement leader

As the patient engagement function continues to evolve, biopharma organizations need modern leaders who can demonstrate empathy and genuine care when interacting with patient groups and representatives to build reciprocal trust. Some will move into the function having worked in other roles in industry, but companies are increasingly looking to patient advocacy organizations as talent pools.

In fact, over the last two decades, leaders from non-profit organizations have begun making the move to large biopharmaceutical entities in a much more observable and sustained way. Our research shows that, as of October 2023, **30% of patient engagement leaders in large-pharma and 40% in orphan drug development organizations previously worked in non-profit associations or patient advocacy organizations.**

That said, leaders in patient engagement must also display a good understanding of corporate frameworks and have both scientific and business mindsets. They are expected to internalize external patient inputs at multiple phases of the drug development, approval, and commercialization journey, while synthesizing these insights into pipeline decisions and external alliances that drive growth.

Statistically, biopharma companies have recently preferred profiles with acquired commercial experience in marketing, market access and, less frequently, as P&L holders. Other qualities of successful leaders are excellent communication and negotiation skills, minimizing frictions and aligning the interests of various stakeholder groups.

This combination of highly diverse skillsets is not easily found. Within the industry, we observe many organizations in rare diseases that look at the Big Pharma world to source their talent, typically preferring navigated profiles with previous experience in the function.

As job descriptions and leadership profiles are rapidly changing in parallel with the fast evolution of the organizational function, defining new future-proofed skill sets for patient engagement is critical to the growth of this function.



“We have been researching and understanding the broader patient experience environment to ensure we don't only increase patient voice in the clinical trial setting, but seek to continuously hear and respond to all aspects of patients' lives in the way we develop medicines, co-create support services for patients and support patient communities and organizations.”



**Sandra Silvestri**  
Chief Medical Officer, Ipsen

**Figure 5: Skillset of the next-generation patient engagement leader**



Source: RRA analysis, patient engagement functions in biopharma companies, 2024

# A critical historical moment

Patient Engagement is a relatively new function in the complex organizational mosaic of pharmaceutical companies. After rapidly evolving in an erratic way through the impulses of internal and external forces, its profile and purpose is now stabilizing both from a structural and talent point of view, entering a more mature phase.

This will however require most companies to rethink their patient engagement models and compare their internal talent pool with emerging external standards to make the right appointment. If they are successful, we believe that these organizations will be able to build a competitive advantage and create long-term value for their patients and shareholders.



"Now that engaging with patients is an obligation for drug developers, there is the risk that hiring a patient officer just becomes ticking a box. But if you hire someone to lead patient engagement, use the opportunity to the fullest and do not limit his/ her role to check the community's pulse, but instead setup a process to co-create solutions with the patients."



**Yolande Adiibi**

Patient Support Operations  
Director Hematology,  
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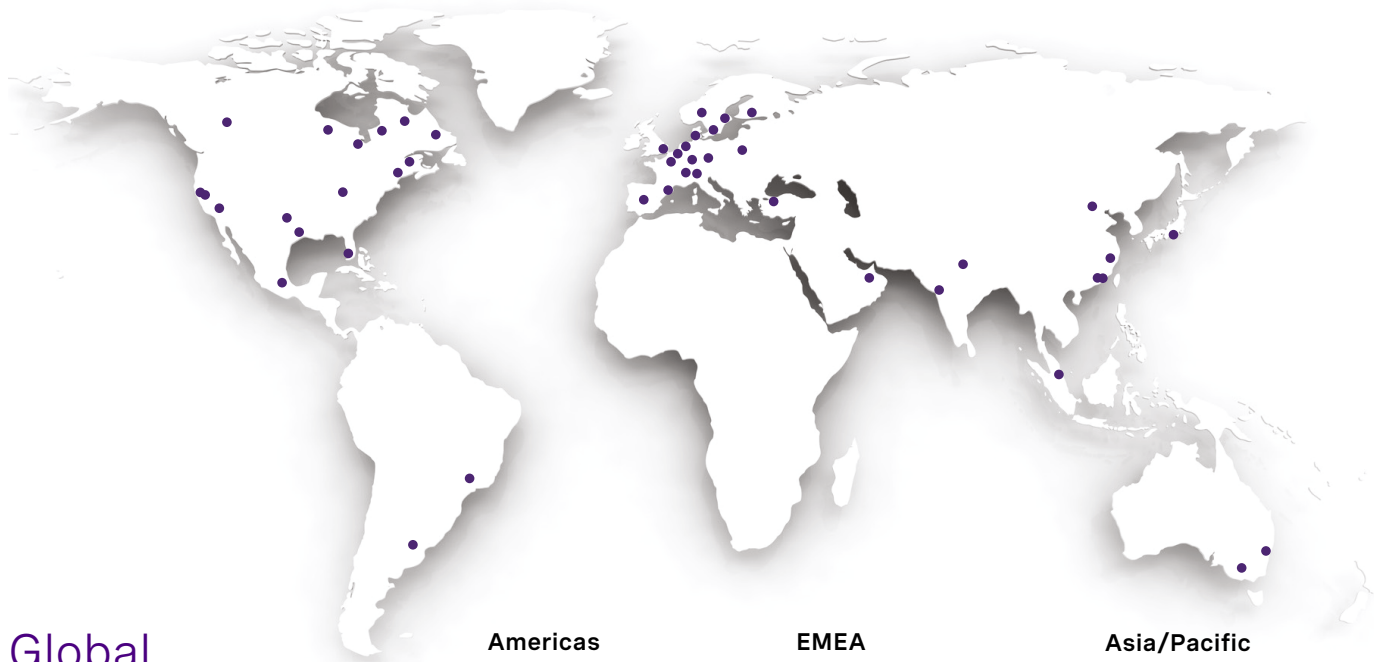
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# About Russell Reynolds Associates

Russell Reynolds Associates is a global leadership advisory firm. Our 600+ consultants in 47 offices work with public, private, and nonprofit organizations across all industries and regions. We help our clients build teams of transformational leaders who can meet today's challenges and anticipate the digital, economic, sustainability, and political trends that are reshaping the global business environment. From helping boards with their structure, culture, and effectiveness to identifying, assessing and defining the best leadership for organizations, our teams bring their decades of expertise to help clients address their most complex leadership issues. We exist to improve the way the world is led

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