White Paper

Making Patient Advances Together, Faster

A practical guide to life science partnerships for patient organizations

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Introduction

The relationship between patient organizations and life science companies continues to evolve, revealing new opportunities for collaborations that set and meet mutual goals. Several factors have led to this increase in teamwork, whereby each party provides unique avenues of contribution to accelerate treatment innovations and support patients. For patient organizations and life science companies to each gain value from a partnership, there are some key considerations to ensure long-term success.

This paper explores trends that have shifted the relationship between patient organizations and life science companies, how to tailor partnership formats based on mutual needs, and some of the key considerations for working symbiotically when visions and definitions of success may differ. The information outlined aims to assist patient organizations' ability to establish strong life science partnerships to achieve their goal of advancing patient and research initiatives, rather than topics related to access, policy coverage, and regulations.

Trends driving increased collaboration with life science companies

What used to be straightforward, transactional relationships are now transforming into more complex and ultimately more collaborative and rewarding partnerships. A few larger trends have driven this transformation:

Need for diversified non-profit funding to sustain mission initiatives

Pandemic and now post-pandemic influences, economic strains and changing philanthropic donation incentives, oversaturation of non-profit and social impact options, and changes in giving trends to philanthropy overall place patient organizations in a position with a need to diversify funding away from traditional individual gifts and major donations, and peer-to-peer fundraising. In its place, organizations are moving towards more strategic partnerships that tap into stakeholder groups with mutual goals, requiring strategic alignment and a higher level of collaboration and involvement. In many cases, a natural fit is looking to identify companies with a vested interest in a disease or disorder community, such as companies with an asset in their development pipeline or a commercially available therapy that serves a patient community. A natural win-win to this is the ability to infuse patient-centricity and priorities into the therapeutics development process.

Shift of development focus towards rare diseases and precision medicine

Life sciences' focus on rare diseases and precision medicine research in the past 10 years has increased the engagement with on patient organizations, many of whom are dedicated to rare diseases and niche populations. This life sciences focus has nicely coincided with the impact of the internet and social media in fostering the increase and ease of connection for affected patients and families in virtual community building. The value that patient organizations provide is meeting and perhaps even exceeding the corresponding investments from life sciences in the rare disease and precision medicine space — these two sides have never had as much to offer each other as they do now.

Patient ownership of data leading to a more active role in research processes

The 21st Century Cures Act gives patients in the United States ownership of their data and control over its use. In addition to a growing use of patient-centric technology that collects valuable health data, such as wearable devices, there is a large and holistic repository of patient information controlled and owned by the patient. For patient organizations with patient health data initiatives, this shift brings an increased responsibility to engage with and educate their patient communities about research participation and data sharing and the ability to initiate strong partnerships with life science companies to accelerate treatment options.

Evolving regulatory standards and growing acceptance of real-world data

While randomized control trials are still considered the gold standard for clinical research, there are practical and ethical limitations that are leading to the exploration of how real-world data (RWD) can support product development. In the U.S., this shift has been supported by regulatory bodies with the release of draft guidances by the Food and Drug Administration (FDA) that provide considerations for how to use RWD and real-world evidence (RWE) in regulatory decision-making for drugs and biologics.

With the increased support from the FDA, life science companies are increasingly looking to partner with patient organizations due to their trusted role as data stewards for their patient communities and existing relationships with patients, allowing access to novel data sources and avoiding conducting duplicative efforts for data collection, minimizing the burden on patients.

Increased need for long-term RWD collection to accelerate regulatory approval

Due to the high demand and limited alternatives for rare disease treatments, there has been an uptick in accelerated approval for certain drugs. To gain accelerated approval, regulators have stricter requirements for post-approval monitoring and RWD studies. For rare disease patient organizations that are able to consistently collect data from patients through their lifetime, there will be a growing demand for their registry data by life science companies to support post-approval monitoring. However, there will also be pressure on the data collection programs to meet the standards that the life science companies value – standards around data completeness, data cleanliness and data timeliness.

Increased need for long-term follow-up driven by next-generation biotherapeutics

Next-generation therapeutics, such as cell, gene, and RNA therapies, are incredibly promising for precision and personalized medicine. To ensure these therapies are safe and efficacious, life science companies are being given 10–15-year safety commitments on each patient. With over 800 therapies currently in the pipeline, patient organizations that are able to engage with patients long-term are in a prime position to support life science partners by supporting and enabling data collection efforts.

Prioritization of diversity, equity, and inclusion (DE&I) in clinical research

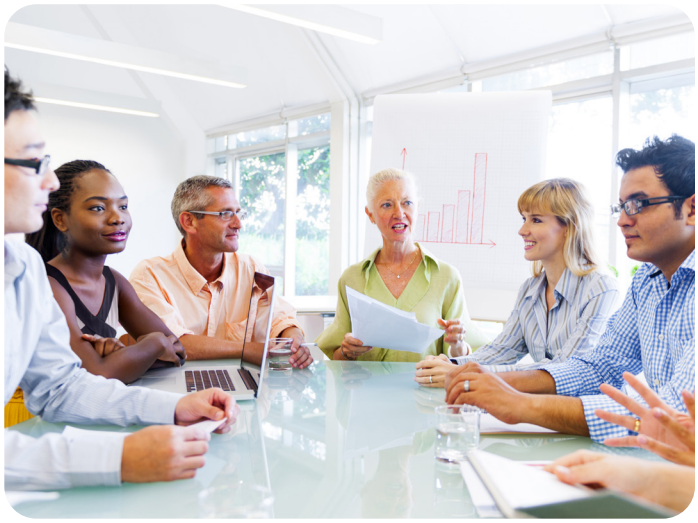
An outcome of the stringent requirements and heavy logistical burden for participation in traditional Randomized Clinical Trials (RCT), is the underrepresentation of diverse patient populations in the research system, leading to continued disparity in health outcomes. In April 2022, the Food and Drug Administration (FDA) released a draft guidance with recommendations on how sponsors can ensure accurate representation of racial and ethnic populations starting from the study design phase. This means that industry stakeholders, including life science companies, are looking to other strategies (e.g., patient advocacy and community organizations) as a way to have boots on the ground with a community they have limited access. Another area of focus is partnerships with organizations with patient health data initiatives that provide them with data that accurately represents the diverse patient communities of interest. Patient organizations can act as critical liaisons between life science partners and patients by providing the necessary resources and support that are needed to overcome historical barriers to research participation. This includes providing education, tools, and guidance to help patients advocate for themselves, synthesizing data collection to reduce duplicated efforts, and identifying the factors, such as geography, finances and trust, that have impeded participation in on-site trials.

These trends have culminated in a paradigm shift in patient organization and life science partnerships, with patient organizations increasingly taking on the role of trusted relationship holder and data steward for their disease and disorder communities, becoming proactively involved with research to ensure that the patient voice is central to ongoing research and treatment development. However, to foster a successful relationship with life science companies, there are several factors such as partnership format and practical barriers that patient organizations should consider. We list some items for examination below.

Evolving relationship between life science and patient organizations

Historically, patient organizations may have looked to life sciences for philanthropic donations to support various research grants and patient programs. Today, patient organizations are looking to proactively drive research agendas and build out their capabilities, services and infrastructure in ways that are mission-aligned and address key care gaps within their communities while also being responsive to life science development needs. This more significant role allows patient organizations to overcome historically siloed efforts and drive the whole field forward to advance research and eventually improve patient care.

In addition to supporting initiatives and assets with broad stakeholder impact, patient organizations also have an increased focus on ensuring the financial sustainability of their business assets and programs. Many organizations saw a drop in donation-based funding during the pandemic, which highlighted the vulnerabilities inherent in relying on philanthropy to fund mission-centric activities. Today, more patient organizations are building up their internal capabilities both to elevate the patient voice in research and to support revenue-generating activities that can fund mission-critical activities.



Pros and cons of different partnership structures

When it comes to the structure and format of partnerships, there is no one-size-fits-all paradigm. Partnership structures will vary based on the strengths and priorities of each organization, as well as the overall goals of the partnership, which may include supporting patient-centric research initiatives (e.g., a data registry, research grants, clinical trials), patient education and support services, advancing treatments, supporting diversity, equity, and inclusion goals in research or patient care, and supporting sustainable funding for mission-driven activities.

Despite these necessary variations, we have seen a few categories of approaches that may be a helpful starting point as you consider how best to structure a formal partnership to support your organizational mission. The section below outlines a few joint partnership formats and their general pros and cons.

Partnering with life science companies on an opportunity-by-opportunity basis (short-term partnership)

Patient organizations can take a straightforward approach to steering their partnerships with life science companies by pursuing specific initiatives that can help accelerate the development of new treatments and improve patient outcomes. Patient organizations can build out a set of offerings that are both mission-aligned and of interest to potential life science collaborators, allowing patient organizations to set appropriate guardrails and test out scoped partnerships around specific opportunities of interest.

Examples of offerings that patient organizations can build out include providing patient voice to study design or understanding key unmet needs through market research, improve disease understanding, providing expert inputs into protocol design and feasibility, supporting focused trial recruitment to get more patients access to relevant studies, and/or validating product efficacy through the analysis of registry data assets for market access negotiations. Patient organizations may also seek support on their own internal initiatives, such as patient education programs, disease awareness campaigns, and/or testing programs.

PROS: A short-term partnership can have lower barriers to entry, fewer terms that need to be agreed upon, and provide ways of working that are more familiar to both parties.

CONS: A short-term partnership can mean less innovation and a lower potential for long-term impact.

Collaborating on a research project or other initiative (medium-term partnership)

Beyond a short-term relationship, patient organizations and life science companies can form more collaborative partnerships by structuring them around common research projects or initiatives of interest, such as characterizing the natural history of disease, mapping patient journeys, addressing gaps in care or creating more patient-friendly study designs. The goal is to identify mutual objectives, such as increasing trial accrual for therapeutic advancements, by finding the intersection between patient and business needs. Patient organizations play a crucial role in driving these partnerships through awareness and educational programs, while in disease areas with available drugs, commercial teams often collaborate with patient advocacy organizations on treatment awareness initiatives.

PROS: Drive research forward on questions of interest to both parties, which can evolve into a longer-term partnership if of interest. This will allow organizations to address a larger scale of unmet needs without extending beyond their current capabilities.

CONS: Requires more commitment from each party, need to find areas of alignment that are suitable for joint research or other partnership, and may need to be careful of avoiding undue influence from one single partner.

Collaborative investments to create programs, services, and/or infrastructure with long-term value to multiple stakeholders (long-term partnership)

Often to truly address complex unmet needs in patient communities, a large-scale program is needed. These programs require significant investment, multi-stakeholder involvement, significant expertise, and capacity to enable, which often are not readily available for smaller organizations. Patient organizations can seek collaborations with life sciences where interests align to overcome these hurdles. Initiatives can include implementing large scale screening programs to help overcome underdiagnosis, developing a clinical trial network to accelerate therapeutic development, or developing a new disease registry to help improve disease understanding.

For example, patient organizations seeking to stand up a registry to improve disease understanding and drive a clinical trial and/or the development of new treatments might seek seed funding from multiple life science partners. While the registry would ultimately be run and hosted by the patient organization, life science partners would get a seat at the table to drive registry design and rights to access the registry data for a set period for mutually agreed on research and development use cases. In addition to the financial benefits of partnerships that both life science and patient advocacy organizations can realize, there are mission-oriented benefits from standing up assets that serve multiple stakeholders, such as accelerate research, fill data gaps, and generate new insights. This creates sustainable streams of revenue that will support those essential assets and other patient-facing services well into the future.

PROS: This partnership approach has a high potential for long-term impact. It can support the research and development of new patient therapies for multiple stakeholders.

CONS: This partnership approach requires a longer-term commitment and more resources (e.g., time, people, and potentially money); working with multiple partners can create challenges balancing input and interests.

Key considerations for partnerships between patient and life science organizations

Principles of a successful partnership from the perspective of a patient organization

The relationship is relational and not transactional

It's important to establish a mutually beneficial relationship that is based on supporting one another's aligned goals. An ideal relationship would be one where the life science company understands and supports your mission and activities (not only engaging transactionally on a project), while you are able to show a return on investment (ROI) for the partnership through the impact of your time, insights, and energy invested in their work.

There is a strong champion for your organization within the life science company

Life science companies can be hard to navigate. Finding a champion within the company who shares your vision and passion and who can help you navigate and make connections internally is vital. The company should be actively engaged in the partnership and should come to you for insight into lived experiences, commentary on trial design, and more.

You are able to clearly articulate your organization's value

Your value is your community and your voices. Focusing on where your unique value lies and looking for ways to bring that value forward within the life science company will ensure you are invited, included, and supported in areas where you and your community can make the most impact.

Be transparent, open, and direct about your goals

If there are goals your group has identified, share those with the life science company so they understand what is important to you and to your community. Additionally, be receptive of their goals.

Engage in bi-directional communication

There should be an open flow of communication between your organization and your life science partner, including, but not limited to, regularly set check-ins to discuss the relationship, progress, and patient needs.

Know the worth of your data

If you have a data set, understanding its worth can be challenging. Think about the uniqueness of your data elements, the longitudinality of the data set (the longer you have for any given patient, the better), and the quality of your processes that support that data collection. These are the levers that impact the value of the data and its suitability for most research.

Principles of a successful partnership from the perspective of a life science company

PATIENT ORGANIZATIONS CAN PROVIDE MUTUAL BENEFITS THAT HELP REACH LIFE SCIENCE BUSINESS GOALS

Convening power

- Patient organizations have access to valuable insights on patient and caregiver lived experiences, connections to the provider community, and institutional and regulatory relationships.

Collaboration with patient and provider communities

- As the champion for patients, organizations can share patient insights, journey, and experience with a disease.
- Patient organizations can improve research participation and help life science companies drive treatment advances by providing education and services to patients and caregivers.
- Patient organizations existing relationships with healthcare providers and key opinion leaders will ensure life science companies get insight into their preferences and priorities for research and patient care to foster better outcomes.

Addressing information gaps to achieve mutual goals

- Patient organizations will help drive mutually beneficial initiatives by filling information gaps that life science companies face.
- The depth of patient information a patient organization can provide will help life science companies address the shared goal of increasing the representation of diverse patient populations in research and patient care.

LIFE SCIENCE COMPANIES HAVE SPECIFIC PRIORITIES WHEN AGREEING TO PARTNER WITH A PATIENT ORGANIZATION. HERE'S SOME GUIDANCE ON HOW PATIENT ORGANIZATIONS CAN ESTABLISH THEMSELVES AS A STRONG PARTNER:

- Measuring impact and success of initiatives and reporting this back to the partner
- If the patient organization has existing data — life science organizations will evaluate patient organization data to ensure it has high quality, good access processes, consent models in place for their use cases, the ability to link (if it is important to them) and provides agreed-upon pricing models.
- If the patient organization is building out new data asset(s), life science companies will consider all of the above, plus:
  - » Organizational capacity devoted to registry planning efforts.
  - » That there is a realistic registry roadmap (even if in progress).
  - » Provides a clear opportunity for a win-win scenario in the collaboration — including the willingness to adapt the registry design and data collection to meet life science partner needs, with the understanding that this effort is to enable the development of new therapies for patients.
  - » Demonstrates the ability to meet future life science needs; through planning a dynamic registry that can evolve over time alongside the latest thinking.

LIFE SCIENCE COMPANIES CAN WORK WITH YOUR PATIENT ORGANIZATION AT ANY STAGE OF BUILDING OUT A DATASET AND/OR REGISTRY:

- If the patient organization is more mature, life science companies will value the immediate availability of data, but you may need to collaborate on making it fit for their purpose.
- If the patient organization is in the process of planning a new registry or enhancing an existing registry, life science partners can assist in accelerating your momentum and will see value in early investment to help guide the design in a way that will fit their long-term needs.

Where to start

Navigating a life science company, especially a larger more established organization, can be quite daunting. There are many different divisions, roles, people, goals, and priorities to familiarize yourself with, and it might sometimes seem nearly impossible to break through to establish a meaningful relationship and influence decisions. It can also be difficult identifying the right person or people within an organization to become an internal champion for your community and organization and who can also help you best navigate internally.

Typically, the best place to start would be through developing a relationship with the patient advocacy role (e.g., Chief Patient Officer or VP, Senior Director, Director, or Manager of Patient Advocacy). Within larger companies, the roles are divided by condition or disease area. These individuals are normally tasked with managing the overall portfolio of patient organization relationships, the overall budget for partnerships, and know how best to navigate the company relationship (i.e., rules of the road) with patients and patient organizations.

While it might be compelling to want to have relationships with the big, household life science company names, it's important to take a step back and understand the motivators and drivers affecting how and why life science companies prioritize their external partnerships.

Motivators for a life science company (includes device and testing) to be a partnership fit

- Has a pipeline with an active trial or trials in the space or commercially approved therapy (or test or device) for condition/disease area (more interest when not a generic drug and still under patent).
- Has an approved indication for a targeted therapy targeting similar gene mutation or biomarker expressed in disease area (mechanism of action looking to expand to additional indications).
- Has clear gaps at the organization within a condition/disease area such as:
  - » Need to drive clinical trial awareness and recruitment or testing awareness and education.
  - » Looking to drive approved therapy awareness.
  - » Looking to learn and understand the state of the disease, patient insights, and natural history where there is unmet need.
  - » Need for patient engagement and insights for patient access, coverage, and value discussions.

Another influencing factor that impacts patient advocacy partnerships is the all-too-common "what happens" when there is a trial failure or development programs are cut or de-prioritized. These are all dynamic factors that change the ability for life science companies to financially support and partner with patient organizations. Not only is it disappointing for the disease or disorder community and the potential for progress, it also makes the relationships ever-changing and complicated to depend on for long-standing partnerships.

Who's who

While the patient advocacy role at a life science company is traditionally the first line into the organization, it's also helpful to understand the other potential avenues for effective and successful relationships. Each area has a unique lens for looking at what a successful partnership entails. In a smaller or emerging biotech organization, there may not be the same kind of organization depth and an individual might wear multiple hats. Of course, the ultimate goal would be to have executive level engagement, although it's important to lean on your strongest relationships to develop the foundation.

The following is a list of roles you might engage with. This list is not exhaustive, but rather illustrative.

- **Patient Advocacy (which could live in multiple different areas such as Commercial, Medical Affairs, Marketing, Corporate Affairs and Policy, etc.)**
  - » They are the translator and traditionally navigate the overall day-to-day relationship with patient organizations and prioritize which organizations to focus on.
  - » Traditionally navigate the overall relationship and day-to-day relationship with patient organizations and prioritize which organizations to focus on.
  - » Oversee and navigate the corporate giving and traditional grants mechanisms.
- **Medical Affairs**
  - » This would be the team where you'd partner on RWE-generation, patient data programs or initiatives, patient insights, and healthcare provider/KOL engagement. They traditionally oversee one asset.
  - » Their interests are in label expansion, supporting market access, provider adoption, guidelines development, etc.
- **Clinical Development**
  - » This team is focused on drug pipeline, prioritizing investments, and runs clinical trials.
  - » Their interests are trial awareness, recruitment, basic understanding of the disease, and patient voice.
  - » If the patient organization is looking to partner with a life science company on a sponsored trial, this is the team you'd want to communicate with.
- **Market Access**
  - » This team is focused on developing a compelling value story for a novel therapy to support market access and pricing negotiations.
  - » Their interest would be patient voice and involvement with payors/policymakers/regulators. Additionally, they'd be interested in patient organizations' leadership on behalf of the patient community.
- **Commercial**
  - » These are the sales team structures nationally, although normally broken out and divided locally, looking to develop Health Care Provider (HCP) engagement and therapy awareness.
  - » The company's patient advocacy role would broker and manage this engagement with the commercial team, although the commercial team is a great way to build engagement within the community and engage staff locally as volunteers.
- **Marketing**
  - » This team would be where you might co-develop disease/disorder awareness campaigns.
  - » The marketing teams would be interested in market understanding and patient insights and stories.
  - » The patient advocacy role would broker and manage this engagement.
- **Executive Suite**
  - » This team is responsible for the entire corporate strategy and has a remit that encompasses the company's entire portfolio of assets.
  - » The likelihood to have executive level engagement increases when a specific disease or therapeutic area is a corporate priority, there is an approved therapy on the market for the company, or there is a personal connection to the disease or disorder.

One size does not fit all when it comes to the makeup or dynamics of the relationship between your organization and a life science company. Each relationship you have will be different from company to company, along with what good looks like, based on a number of variables. Once you are aware of varying avenues for partnership, you can begin to strengthen the overall relationship.

Mutually beneficial partnerships in action

A session held during IQVIA's Patient Advocacy Summit in November 2022 brought together members of patient organizations and life science companies to discuss how to approach developing and maintaining mutually beneficial partnerships that enable making patient advances together, faster.

The goal of examining practical barriers to collaboration and mitigation considerations was to educate and inform others through personal experience about areas to prepare and consider when investing in collaborations. While both patient organizations and life science companies have identified areas of mission alignment and the advantages of establishing closer partnerships, the specifics of what those partnerships look like vary widely. Below are some key considerations to establish successful partnerships with life science companies that were discussed during the session, such as alignment on messaging, ways to increase patient engagement, and breaking down information siloes.

Bringing stakeholders together

Getting stakeholders to align around common goals is critical for success, especially when multiple partners exist. This includes breaking down information siloes to identify common areas of interest when establishing the partnership. This can help reduce the burden for patients and families who have historically had to duplicate their efforts when providing health information to multiple stakeholders.

Understanding differences in process among sponsors

Life science companies may have different processes for collaborating with patient organizations and different protocols for compliance. Companies may also differ in how they want to contribute to a project. Furthermore, most companies prefer having other sponsors involved to reduce risk and the perception of bias or influence. Some companies focus on donations, others on sponsorships. It is important that patient organizations are proactive and ask direct questions about these issues before developing an application for a sponsorship or a donation, as a misunderstanding of the process may lead to delays in mission critical activities. Creating a profile and checklist specific to each company may be a helpful tool for patient organizations to better understand their unique processes.

Creating a common language

The first of these considerations for building and maintaining a good relationship between a patient organization and a life science company requires an investment in communication. The teams will need to address potential differences in language, variations in processes among sponsors, and decide together on metrics to ensure alignment around measurements of success. Taking this time up front to align on language, explain processes, and decide on mutual goals with life science partners allows for the correct building blocks to realize the ultimate vision of driving science forward.

Having a common language is often a challenge for collaborations between patient organizations and life science companies. While the goals of collaboration are often shared, specific terms may have different meanings. Some examples were shared during the session: The term "advocacy" is typically used by patient organizations for public policy engagements, whereas industry tends to view advocacy as the entire engagement with patients. "Therapeutic areas" are commonly used by industry, while patient organizations talk about disease areas. While not mentioned during the session, "patient engagement" is typically used by life sciences to mean patient engagement around a clinical trial, whereas patient organizations often use a broader definition covering any engagement with patients (e.g., patient experience).

It is essential to be cognizant of differences in language, including the use of acronyms, when aiming to foster good collaborations. This is particularly challenging in global partnerships where team members on both sides need to be clear and explicit, using words and understanding cultural differences. Alignment on cultural considerations is especially critical to ensure the inclusion and engagement of historically under-represented patient communities.

Co-creating an opportunity

When mutual goals are identified, patient organizations and life science partners can align their initiatives to drive medical advances more effectively or improve patients' access to care. An illustrative instance of a successful collaboration involves addressing burden placed on patients with chronic diseases and the healthcare system due to the lack of services provided upon discharge from the hospital while simultaneously providing partner benefits through their respective strengths. This particular project unfolded between a small biotech company and a patient organization that boasted an established patient community, both sharing a common objective of enhancing transitional care for chronic illness patients after hospital discharge. Working together, the partners devised an education and support program that materialized thanks to the patient organization's existing relationships and the industry partner's pilot funding, which enabled its implementation.

Addressing turnover

One of the biggest challenges in collaboration is consistency with staff, as there are often changes on both sides. When a key point of contact leaves, progress on existing initiatives may be impeded by the need to establish new relationships within the partnering organization; and once the new point of contact is established, they may have different priorities that could impact the level of engagement or buy-in from patients and stakeholders. Another impact of turnover may be the arrival of a new compliance officer in a life sciences company who may impact project approval process and requirements through a change in compliance protocols. Keeping an open conversation going (about potential staff changes, for example), conducting regular check-ins, developing role-based processes, and building authentic relationships is important to address such challenges.

Engaging patients in the work

Bringing patients into the work will become imperative for patient organizations to achieve successful initiatives and will support cohesive alignment with life science partners. For example, organizations can host a listening session with patients to ensure their voice is woven into initiatives early in the process. Additionally, the creation of a patient survey driven by a patient group can help a life sciences company zero in on the symptoms that patients experience with the disease and their impact on quality of life.

Learning from failures

Another way of co-creating opportunities is by addressing the challenges of patient advocacy and life science joint efforts. Instead of the instinctive approach to only share successes, collaboration should focus on learning from failures to generate the most holistic insights. Some common examples of failures include providing information resources on research participation that are too complex for patients to understand and not dedicating enough time to listening to patients and caregivers to learn about their expectations and unique burdens. Projects should address areas that did not work in the past and utilize co-creation to help generate better outcomes.

Improving progress

The ability to monitor and measure the outcomes of collaborations is very important to industry sponsors, and most times it is a requirement for the support. Therefore, patient organizations should take the time to think through what their own measure of success will be before conducting outreach for support. It is not enough to look at traffic on an organization's website. Evidence of meaningful impact is important; for example, whether an education campaign motivates patients to go for a screening or see a doctor. The impact is also very important to patients. Determining and sharing metrics for the measurement of success are important prerequisites for driving the value of collaborations between patient organizations. Illustrating impact and reporting metrics help validate whether ROI is delivered to mutual satisfaction for both sides in a partnership.

Conclusion

Moving forward together

Life science companies and patient organizations share the mutual goal of prioritizing and accelerating meaningful therapeutic advances. Finding ways to partner with life science companies that have different processes and stakeholder priorities can be complex. Still, there are various ways to tailor the approach that will benefit both parties, including filling gaps that patient organizations and life science companies face on their own. Patient organizations can provide immense value to life science companies due to their earned trust with their disease and disorder communities. This includes their ability to share lived experience perspectives, and provide access to data on rare diseases, diverse and representative patient populations, and a rich repository of patient-reported treatment outcomes and insights. Conversely, patient organizations can benefit from resources life science companies can provide, including financial sustainability and resources to strengthen their mission initiatives, ensuring patient voices are front and center in the drug development and approval process.

More than ever before, patient organizations are in a prime position to be an integral stakeholder and influencer in the healthcare innovation process, and partnering with life science organizations can be a mutually beneficial step toward the goal of innovation.

HOW IQVIA SUPPORTS PATIENT ORGANIZATIONS

Our goal in working with patient organizations is to empower these organizations to accelerate advancements to improve patient outcomes and quality of life. Through comprehensive, tailored advisory support, technology and data solutions, and long-term strategies, we enable our customers to achieve their organizational health data and treatment outcome goals.

Advancing health is about navigating complexity to achieve extraordinary results. Our success stems from decades of clinical research and data expertise. Regardless of where you are in your organization's evolution, we can help you design, deliver, and drive sustainable research, data, and patient initiatives that support and accelerate your mission.

Whether your focus is on driving awareness and therapeutic prioritization for a disease or condition, unearthing deeper understanding of a disease to spark innovation, or empowering improved patient outcomes and discoveries, we can help. IQVIA provides the right connections, intelligence, infrastructure, and resources to advance the state of patient care in your community. We enable innovative organizations to deliver what matters most to patients through initiatives such as patient-focused drug development, patient support services, trial awareness and education, research and patient data initiatives and technologies, and nonprofit-sponsored clinical research and trials.

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Prior to joining IQVIA, she spent over six years leading industry relations and engagement for an oncology patient advocacy organization. While there, Alex worked closely on their Scientific & Medical Initiatives, raised funds to drive progress, and represented the patient voice for industry-hosted initiatives. She has spent over a decade in philanthropic leadership roles and is immediate past chair of her local hospital's cancer institute board. Alex received a BA in Psychology from Southern Methodist University. She is currently based in the Los Angeles area.

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