

Patient Organizations Gave \$22 Billion in Grants for Research, Patient Services, and Access to Care Over the Last 5 Years, Says IQVIA Institute for Human Data Science

10/5/2023

- There are more than 3,000 active patient organizations across the U.S., supporting patients through their health journeys and shaping research and care delivery
- Patient organizations are assuming an ever-expanding role, including developing patient registries to better understand diseases and funding scientific research to find cures
- The 21st Century Cures Act required changes that are expanding the role of patient organizations as partners for life sciences organizations to better understand the patient experience and incorporate patient views into drug development
- Nearly 700 deals with an estimated aggregate value of \$2.4 billion have been publicly announced between patient organizations and life sciences companies over the past 15 years
- Over the past 5 years, the aggregate revenue of patient organizations exceeded \$62.5 billion, with a third of that going toward grants and much of the rest to supporting community programs

RESEARCH TRIANGLE PARK, N.C.--(BUSINESS WIRE)-- Patient organizations play a vital role in the U.S. healthcare system, according to a new report from the IQVIA Institute for Human Data Science, *Supporting Patients through Research Collaboration: Interactions Between Patient Organizations and Life Sciences Companies*. Over the past five years, patient organizations have contributed \$22.2 billion in grants to support patient services, research, and access to care.

Nonprofit patient organizations have existed for more than 100 years and now number in excess of 3,000 in the United States. Following the passage of the 21st Century Cures Act in 2016, there was a seismic shift in the role and contributions that patient organizations make in collaboration with life sciences companies to develop novel therapeutics consistent with the recommendations of the U.S. Food and Drug Administration (FDA).

“In addition to funding research in collaboration with life sciences companies, a growing number of patient organizations are taking on more complex roles in the healthcare ecosystem, building on their original missions with the intent to advance research and address unmet needs in specific diseases,” says Murray Aitken, Executive Director, IQVIA Institute for Human Data Science. “Patient organizations are becoming the fulcrum for positive change in healthcare by building their own patient registries, inspiring novel trial designs and endpoints in clinical research, and promoting diversity and inclusion in clinical and population research.”

A few key highlights of the report include:

- Role and profile of patient organizations in the U.S.: More than 3,000 patient organizations are active across the country, with more than 1,000 created in the past decade. The disease and mission focus of patient organizations has shifted and expanded over time as well. Nearly 600 patient organizations, 18% of all, focus on rare diseases. In addition to advocating for patients’ interests and generating funding for scientific research to find cures, a new generation of patient organizations now support patients in complex and sophisticated ways that demonstrate the scientific and service-delivery expertise they have built. As an example, more than 150 registries are now run by patient organizations, of which 62% focus on rare diseases, positioning patient organizations as custodians of data for their communities.
- Areas of collaboration with life sciences companies: Constructive initiatives between patient organizations and life sciences companies have been created when the mission of the patient organization overlaps with a company’s area of focus and investment. These collaborations occur in particular areas, such as understanding disease and patient experience of disease, improving outcomes through the development and optimized use of medicines, and strengthening patient communities through education, advocacy and innovation. Such collaborations have evolved further, as the regulatory changes set in motion by the 21st Century Cures Act of 2016 are expanding the role for patient organizations as partners to life sciences companies who are looking to better incorporate patient views in drug development. Overall, patient organizations describe their engagement with life sciences companies as both fruitful and challenging.
- Deals with life sciences companies: Nearly 700 deals – commercial and non-commercial, including research grants – have been publicly announced between patient organizations and life sciences companies over the past 15 years, with an estimated aggregate deal value of \$2.4 billion. About 75% of the disclosed deals involve providing research funding, mostly to small and mid-sized life sciences companies and their academic

partners, as well as allowing the use of their intellectual property to accelerate discovery-stage and translational research. Many of the multi-stakeholder deals – collaborations involving multiple companies or organizations – focus on discovering and validating disease biomarkers. Nearly half of all deals between patient organizations and life sciences companies over the past decade have focused on neurology, where there are several large patient organizations – including The Michael J. Fox Foundation for Parkinson's Research, Muscular Dystrophy Association and Alzheimer's Drug Discovery Foundation – that have been particularly active in funding research.

- Involvement in clinical development: FDA guidance over the past several years on patient-focused drug development and real-world data has opened new opportunities for patient organizations to play a more significant and collaborative role with life sciences companies in the pursuit of new treatments and cures across all phases of clinical development, including trial design, recruitment, and regulatory submissions. Similar initiatives have been undertaken by the European Medicines Agency to ensure the systematic incorporation of the patient voice throughout drug development and associated evidence generation. An important area for inclusion of the patient voice is the use of patient reported outcome measures in clinical trials, which has increased over time with as many as 27% of Phase III oncology clinical trials including them in 2019. Furthermore, patient organizations increasingly work together with life sciences companies to create novel measures that better reflect disease symptoms and the improvements patients value in how they feel or function.
- Financial trends: Over the past five years, the aggregate revenue of patient organizations exceeded \$62.5 billion and the largest 20% of patient organizations accounted for 92% of this revenue. While overall revenue grew by 26% over the period, only the largest patient organizations have seen revenue growth on average since 2016, while numerous smaller patient organizations experienced a contraction in revenue. The impact of the COVID-19 pandemic was seen in 2020 – the most recent years for which financial information was available. Contributions – including grants received – represent a steady 80% of patient organization income, while more than a third of all spending is given as grants and about three quarters of other expenses support programs. Over the past five years, patient organizations have contributed \$22.2 billion in grants to support patient services, research and access to care, including nearly a third given to individuals by groups primarily focused on financial assistance.
- The future of patient organizations: Patient organizations will continue to play a vital role in supporting further research on behalf of their communities, which includes leveraging new technology trends that bring great promise to accelerate cures and other therapeutic advances. Shared post-market surveillance platforms may also hold particular promise for future collaborations between patient organizations and life sciences companies to build robust information on diseases and their treatments – especially for rare diseases that may currently have nothing in place. AI/ML and wearables are creating new opportunities to benefit patient

communities, offering to make trial participation and care easier for patients. A number of internal processes and external actions are essential to ensure successful collaborations between a patient organization and a life sciences company — whether they focus on community programs, research or data. Learning from success cases of other organizations can advance these collaborations for the benefit of all patients.

The full version of the report, including a detailed description of the methodology, is available at **www.IQVIAInstitute.org**. The study was produced independently as a public service, without industry or government funding.

About the IQVIA Institute for Human Data Science

The IQVIA Institute for Human Data Science contributes to the advancement of human health globally through timely research, insightful analysis and scientific expertise applied to granular non-identified patient-level data.

Fulfilling an essential need within healthcare, the Institute delivers objective, relevant insights and research that accelerate understanding and innovation critical to sound decision making and improved human outcomes. With access to IQVIA's institutional knowledge, advanced analytics, technology and unparalleled data, the Institute works in tandem with a broad set of healthcare stakeholders to drive a research agenda focused on Human Data Science, including government agencies, academic institutions, the life sciences industry, and payers. More information about the IQVIA Institute can be found at **www.IQVIAInstitute.org**.

About IQVIA

IQVIA (NYSE: IQV) is a leading global provider of advanced analytics, technology solutions, and clinical research services to the life sciences industry. IQVIA creates intelligent connections across all aspects of healthcare through its analytics, transformative technology, big data resources and extensive domain expertise. IQVIA Connected Intelligence™ delivers powerful insights with speed and agility — enabling customers to accelerate the clinical development and commercialization of innovative medical treatments that improve healthcare outcomes for patients. With approximately 87,000 employees, IQVIA conducts operations in more than 100 countries.

IQVIA is a global leader in protecting individual patient privacy. The company uses a wide variety of privacy-enhancing technologies and safeguards to protect individual privacy while generating and analyzing information on a scale that helps healthcare stakeholders identify disease patterns and correlate with the precise treatment path and therapy needed for better outcomes. IQVIA's insights and execution capabilities help biotech, medical device and pharmaceutical companies, medical researchers, government agencies, payers and other healthcare stakeholders tap into a deeper understanding of diseases, human behaviors, and scientific advances, in an effort to advance their path toward cures. To learn more, visit **www.iqvia.com**.

Nick Childs, IQVIA Investor Relations (**Nchilds@us.imshealth.com**)

+1.973.316.3828

Trent Brown, IQVIA Media Relations (**trent.brown@iqvia.com**)

+1.919.780.3221

Source: IQVIA