

# Empowered by Data: Strengthening Patient Organisations for Health Equity

*Patient organisations are uniquely positioned to harness the power of data to identify disparities and drive targeted interventions, paving the way towards fair health outcomes.*

**JAMES BUCKLEY**, Patient Advocacy Specialist  
**SERGIO DIAZ**, Associate Director Patient Advocacy

At IQVIA's recent 2024 Health Equity Summit, a diverse group of patients, charities, healthcare professionals, industry representatives, and researchers came together to co-create solutions for health equity.

A key highlight of the summit was a workshop, co-hosted with the Association of Medical Research Charities, focused on the pivotal role patient organisations in driving health equity through effective data strategies. Below, we delve into the key insights and takeaways from these discussions.



## Data strategy takeaways for patient organisations



### Implement strategic data planning

Develop and implement data strategies with clear short, mid, and long-term objectives. This approach helps address immediate challenges and lays the groundwork for future-focused solutions. Continuously align these strategies with the organisation's mission and patient needs to maximise impact.



### Foster multi-stakeholder collaboration

Engage with diverse stakeholders, including patients, families, clinicians, industry, and other patient organisations, to design, refine, and implement robust data strategies. Prioritise transparent communication, ethical data use, and patient involvement to ensure the most efficient, impactful, and sustainable utilisation of data.



### Leverage data for advocacy

Patient organisations can play a crucial role by ensuring that data collection, management, analysis and sharing reflect patient needs and drive meaningful research. By leveraging these comprehensive data practices, organisations can advocate for and convene better data collections, inform policy decisions, and accelerate equitable access to treatments.

## Why are data strategies needed?

Data strategies refer to comprehensive plans that guide how data is collected, managed, utilised, and protected to achieve specific goals.

For patient organisations, data strategies are essential for several reasons:

### 1 Understand community needs

Comprehensive data collection allows deeper insights into specific conditions. This understanding underpins patient organisations' activities, enabling them to set strategic goals that align closely with the needs of the communities.

### 2 Enable data-driven advocacy

By utilising data on unmet needs and gaps in care, patient organisations can facilitate evidenced-based advocacy for better services and resources for their communities.

### 3 Accelerate research and development

Effective data strategies bridge the gap between laboratory discoveries and patient care, offering patients more opportunities to participate in clinical trials and benefit from innovative treatments .

### 4 Support evidence-based decision making

By providing robust 'real-world' data on the personal, familial, and societal impacts of conditions, patient organisations can strengthen healthcare decision making and aid the accessibility of new treatments.

**MADHU MADHUSUDHAN, Head of Charity and Patient Engagement at LifeArc**, highlighted:

*“Patient organisations play a vital role in shaping a patient-centric data ecosystem that fosters a culture of trust and transparency while also promoting use of the data for development of new medicines.”*

## What is the role of patient organisations in promoting health equity?

Patient organisations are integral to the healthcare ecosystem. These trusted groups, often led by those directly affected by specific health conditions, provide support, education, advocacy, and drive research initiatives.

As one of our workshop participants highlighted:

*“Patient organisations have the power to bring industry together, articulate the needs of the community, and act as a coherent voice to the health system”.*

A participant from a leading medical research charity explained:

*“Patient organisations are uniquely positioned to identify the unmet needs of patient communities, including those from underserved groups. They connect with members and the broader system to highlight gaps in data and care”.*

This united approach ensures that diverse patient voices are heard and represented, and research is both patient-centric and inclusive.



## What are the current challenges in data utilisation?

Despite their key role, patient organisations face a range of challenges that hold back their ability to effectively leverage data for health equity. Internally, these organisations often struggle with limited resources. Financial and human resource constraints make it difficult to invest in advanced data capabilities, and there is sometimes a lack of specialised knowledge to manage and interpret complex data effectively.

Externally, broader systemic issues further hinder progress:

- **Patients** are generally willing to share their data to support research but are concerned about privacy and data security.
- **Researchers** often face research delays due to insufficient access to timely and high-quality datasets.
- **Clinicians** require data linkage to improve patient care and facilitate the adoption of innovative treatments, but fragmented data systems often hinder this progress.
- **Companies** encounter challenges efficiently accessing patient-centric insights to implement in clinical trial design, recruitment, regulatory and market access processes.

To overcome these challenges, patient organisations need the appropriate tools, knowledge, and resources to improve data collection and utilisation.

It is equally important to foster confidence among patient organisations, empowering them to see themselves as 'conveners of research' for their communities, leading the way into data-driven advocacy and change.

**LIZ PERRAUDIN, Clinical Policy Manager**, from the **Association of Medical Research Charities**, shared:

*“There is huge appetite in patient organisations to fill gaps in NHS data collections. Linking patient-reported outcome measures to health data in registries can drive research into new interventions. Failing to unlock this data risks perpetuating health inequity and inadvertently harming those most in need.”*



## How can patient organisations develop an effective data strategy?

Creating an effective data strategy that aligns with immediate patient needs and long-term research goals involves several key steps:

- 1 Conduct community needs assessments**  
Begin by engaging a broad range of stakeholders through surveys, focus groups, and direct interviews. This includes patients, carers, families, clinicians, researchers, and industry experts. Gathering insights on patient demographics, care gaps, barriers to access, and specific needs ensures that the data the strategy is grounded in diverse, real-world data, leading to a more comprehensive approach to promoting health equity.

*“Consider how we can lift and shift data strategies across therapy areas by leveraging collective expertise.”*

- 2 Set clear goals**

Setting bold, time-bound, and actionable goals is core for any data strategy. This involves defining both short- and long-term objectives that align with the organisation’s mission and the community’s needs. One participant highlighted, “consider why we are collecting this data and for whom [...] create a shared understanding of what success looks like”. This involves making decisions about scientific questions, research goals, target populations, geographical coverage, and the necessary data types and sources. This clarity helps focus efforts and measure progress.

It is important to note that setting up a registry is not the only solution for every organisation. For many, the focus will be on how to effectively leverage existing data and encourage the healthcare system to improve data access and use for research purposes.

- 3 Establish a collaborative framework**  
Involving multiple stakeholders is essential. Collaboration with patients, healthcare providers, and researchers, ensures that diverse perspectives are considered. Partnerships with academic institutions, umbrella patient organisations, and industry experts opens the possibilities to expertise, training, and support. Regular contact and the formation of steering committees are important for maintaining momentum and ensuring the strategy remains impactful.

- 4 Ensure sustainability**  
Understanding that most patient organisations face financial restrictions, it is important to be open to innovative collaboration models to share financial risks and responsibilities. These challenges can be overcome by applying for grants, engaging in targeted fundraising activities, and partnering with industry stakeholders with similar data aspirations. Securing diverse funding sources and revenue streams can help continue data initiatives, ensure long-term impact, and financial sustainability. Developing a robust business case addressing costs, funding models, and services provided is recommended. Avoid aiming for a comprehensive registry overnight; instead, focus on building capacity.



## CASE STUDY: Prostate Cancer Research

### Overview

Prostate Cancer Research (PCR), with support from IQVIA, is launching an innovative prostate cancer data platform and registry called 'Prostate Progress'. This patient-centric platform integrates health-related data from multiple sources with patient-contributed information to accelerate prostate cancer research and improve evidence-based care.

**DAFYDD, a 61-year-old Prostate Cancer Patient Advocate**, highlighted the importance of data collection:

*"With the broad range of patient-contributed information, I'm certain this platform will become a very important resource in shaping treatments in the future."*

### Maintain patient trust and engagement

Given that health data is highly sensitive and personal, it is crucial to reassure patients that their data will be handled ethically and securely. This involves maintaining consistent transparency, education of communities on the societal benefits of data sharing and ensuring that research outcomes are communicated back to participants. One participant noted, "Patients must understand the purpose of data collection and how it benefits them directly and the broader community".

To support ethical and secure data management, the platform adheres to the '5 Safes' framework, which ensures that data is used safely by trusted people in secure settings, processes to prevent identification, and used in ways that produce safe

outputs. Moreover, the platform follows the 'FAIR principles', ensuring that data is Findable, Accessible, Interoperable, and Reusable. These principles improve data utility and trust, making the data more useful and reliable for research and patient care.

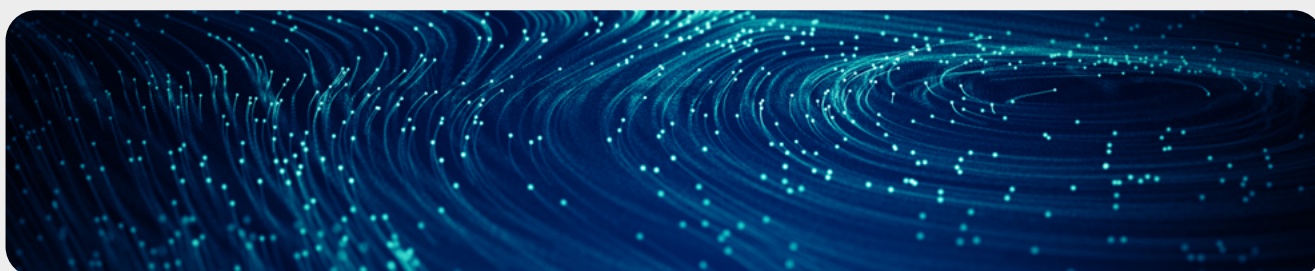
### Patient pledge of support

PCR ran a successful outreach campaign, collecting over 3,000 pledges of participation from patients with prostate cancer, underscoring strong community support before embarking on the platform development. By securing patient consent upfront, patient organisations can begin to break down barriers to data collection across health system siloes.

Empowering patients to control access to their data can build trust and ensure that data is used appropriately, fostering a more collaborative approach to data sharing. This approach improves data portability, ensuring that comprehensive patient information is available across different healthcare settings, thereby improving continuity of care and research quality.

### Integration with existing data infrastructure

Prostate Cancer Research's data initiative has been specially selected as the first flagship 'driver project' for the NHS Data R&D Programme, demonstrating the co-ordinated collective use of Secure Data Environments (SDEs) to drive cutting-edge research. These SDEs facilitate secure access to health data, ensuring robust data governance and privacy protection. By working within the framework of the NHS SDEs, this initiative can link diverse data sources. This integrated approach helps provide a comprehensive view of patient health trajectories and supports advanced research initiatives.



## Conclusion

Not every patient organisation may have the resources or infrastructure to develop a large-scale registry like Prostate Cancer Research. However, by implementing a successful and fit for purpose data strategy, organisations can significantly advance their research capabilities and improve the lives of their communities.

PCR's extensive stakeholder engagement with patients, clinicians, policymakers, researchers, and companies demonstrates the potential impact of a well-executed data strategy.

If you want to learn more, see the [Unlocking the Value of Prostate Cancer Data](#) report.



If you represent a patient organisation and would like more information on data strategies reach out to IQVIA's Patient Advocacy Centre of Excellence for further information and support email [PatientAdvocacy@iqvia.com](mailto:PatientAdvocacy@iqvia.com).



### **IQVIA'S COMMITMENT TO PATIENT ADVOCACY**

At **IQVIA's Patient Advocacy Centre of Excellence**, we understand the essential role that patient organisations play in shaping the future of healthcare. To this end, we build collaborative, mutually beneficial, relationships with the purpose of achieving positive impact on the patient communities we jointly serve.

We work with patient organisations around the world to bring patient voice into clinical research as early as possible, ensuring that our research reflects communities' needs and perspectives. With tailored support in data strategy and health equity, we aim to help organisations navigate their unique challenges and opportunities. Our approach is centred on active engagement, open communication, and leveraging advanced technology to provide meaningful support.

**Our mission aligns with yours:** to advance healthcare and ensure that patient voices are at the heart of every decision.

## Authors



### **JAMES BUCKLEY**

Patient Advocacy Specialist

James holds a master's degree in Global Public Health from Imperial, and has a background in Real-

World Evidence, Epidemiology, and Biostatistics. With experience leveraging large datasets and driving data-driven initiatives, he leads IQVIA's Health Equity Network, and is committed to developing inclusive strategies that address healthcare disparities.



### **SERGIO DIAZ**

Associate Director Patient Advocacy

Sergio holds a master's degree in Health Economics Policy and Management by the London School

of Economics and an postgraduate in International Health Technology Assessment. With 9-years of experience working with patient organisations, he focuses on improving care across therapeutic areas bridging the gap between patient organisations and the power of data.



### **CONTACT US**

[PatientAdvocacy@IQVIA.com](mailto:PatientAdvocacy@IQVIA.com)

X: [@IQVIA\\_UK](#)

LinkedIn: [IQVIA UK & Ireland](#)

[iqvia.com](http://iqvia.com)