



The Future of Patient Registries

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Patient (or disease) registries can play a crucial role in providing a real-world picture of a disease or medical condition. Though there's no agreed upon definition or set of standards for organizing patient health data into a registry, it is typically defined as *a data set of standardized information about a population of patients that all share a disease or condition.*

Traditionally, patient registries have been established and maintained by researchers. An academic institution or a collection of institutions will often create a registry to further a specific research agenda or leverage it for other purposes, including:

- to recruit patients for clinical trials;
- to learn more about a particular disease or condition in the population;
- to develop therapeutics;
- to learn about population behavior patterns and their association with disease progression; or
- to improve and monitor the quality of health care specific to a disease or condition.

Registries often collect data over a long period of time to build a database that can answer immediate and long-term questions related to a specific population. The expectations of

registries and the way they work for patients and researchers is changing with technology, and the future of patient registries will look much different than it does today.

Patients are leveraging registries to help build communities and to drive the need for more research. The availability of real-world data in registries has the potential to improve quality of life, update treatment guidelines, inform drug coverage policies, enhance patient safety, and foster the availability of new treatments. The use of these registries is accelerating, and patients are primary beneficiaries of this growing trend.

Access to Registries: Competition vs. Collaboration

There are several challenges with patient registries today, the largest of which relates to access. It's difficult to generate a large and representative sample, as most registries are made of a minority of well-informed patients that are already connected to some level of advocacy around their disease or condition¹.

This is further complicated in cases where multiple registries exist for the same disease or condition. When multiple registries exist, patients are often faced with a competitive environment in selecting which registry to join; this means that data sets for a

¹ Frydman G. Patient-driven research: Rich opportunities and real risks. *Journal of Participatory Medicine*. 2009;1(1):e12.

given disease are often fragmented across multiple registries. For researchers, this means that patient data often exists in silos and can be difficult to access. As options around patient registry technology continue to expand, these problems will continue to grow.

Another challenge is the lack of standardization of data collection in patient registries. This has led to concerns around informed consent and the patients understanding of the subsequent potential use of their data. This lack of standardization will be an important issue for regulators, patient groups and all stakeholders to tackle, especially as many registries consider joining a larger network of registries across other jurisdictions. While further collaboration on patient registries would be seen as positive for research, it has been slow due to the lack of data collection standardization.

While technology can help patients and researchers build stronger registries, it's important to find the right technology to support patients in the collection of real-world data.

The importance of Patient Registries for Rare Diseases

It's estimated that 350 million people worldwide are affected by a rare disease. Patient registries and the collection of real-world data have greatly helped rare disease research, as these patient populations are typically small and geographically dispersed. Registries have also been able to consolidate rare disease patient data across jurisdictions,

giving researchers valuable real-world data, and putting patients at the centre of the push for advancing rare disease research. There are several benefits to applying registries to rare diseases, specifically:

- As a tool for learning more about the progression and treatment of a rare disease(s) with real-world evidence;
- To allow patients to connect with a community of peers, where we can measure treatment progress and trends;
- To build an international community of physicians who can work together to develop recommendations on standard of care for specific rare diseases.
- To analyse data related to treatment outcomes in order to facilitate the creation of therapeutic targets for patients with rare diseases;
- To create a channel to educate and inform patients with updates related to their disease or condition (e.g., providing latest guidance to patients)

There are significant opportunities in developing and operationalizing patient registries and those built for rare diseases have additional benefits, such as patient identification, engagement, and recruitment for clinical trials.

Creating a successful registry for rare diseases will mean leveraging these opportunities through multiple approaches that implement innovative solutions, and evolving resources that allow researchers to connect with

patients in new ways. We've already seen the benefits of searchable data banks, and the future is full of potential for advancing rare disease research with digitized, accessible patient registries. As more ways to collect and analyze real-world data emerges, rare diseases can expect to be at the forefront in supporting this work.

How can Sciteline Help?

Sciteline provides technology solutions for clinical research including an innovative, purpose-built patient registry platform. We're partnering with patient groups and health organizations to leverage technology that put patients first by developing consolidated, accessible, and secure patient registries to support advanced understanding of the most challenging diseases or conditions patients face today.

Connect with us to learn more at www.sciteline.com

About Sciteline

Sciteline combines creative thinking, robust research and cross industry leadership experience to develop decentralized clinical trial solutions to help solve some of Canada's most challenging issues facing clinical research. Our mission is to accelerate the generation of new knowledge by enabling researchers to achieve their best work while connecting them with a diverse population of clinical trial participants. We believe that by reducing the patient burden and changing the status quo, we can lower the cost of delivering new treatments and medical devices to patients.

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