

## BACKGROUND ON CLINICAL REGISTRIES AND PATIENT ENGAGEMENT

### The Importance of Registries for Medical Specialty Societies

Specialty society clinical data registries (CDRs) have been gathering and analyzing clinical data in a variety of specialty areas for more than 40 years. Initially, registry data population started with manual chart abstraction, and while this method is still used, our health information technology data infrastructure has evolved, allowing interoperability and automatic abstraction from electronic health records (EHRs), patient data portals, payment systems, and public health systems. CDRs continue to play an important role in the health care system by monitoring and informing the quality of medical care and generating new clinical knowledge that can lead to improved patient care and outcomes.

Clinical registries have been a major investment for specialty societies in evidence generation, discovery and quality improvement:

- ▶ Aggregate investment of approximately \$500 million over five years;
- ▶ Hundreds of peer-reviewed scientific papers have been developed using the registry data;
- ▶ Registries contributed to informing clinical and health policy;
- ▶ Registries generated new knowledge and best practices; and
- ▶ Registries served as a major component of society value propositions for members.

Societies continue to use registries for a variety of quality initiatives, including benchmarking, drill-down reports, quality improvement training, collaborative quality projects, and quality improvement toolkits. From annual CMSS registry surveys, we can track the degree of engagement with patients and use of PROs. While there are significant opportunities for improvement, many registries have begun to incorporate the patient voice and PROs into their registries:

- ▶ 36% of the registries reported having engaged patients or patient groups.
- ▶ 24% of the registries reported having incorporated patient-reported outcomes into registry data.

Understanding the incorporation of the patient voice in registry design, development, and use is of growing importance in an era in which the health care system is striving for patient-centeredness and increasing value through initiatives such as CMS' Meaningful Measures.

#### **What is a Clinical Registry?**

A clinical data registry records information about the health status of patients and the health care they receive over varying periods of time. Clinical data registries typically focus on patients who share a common reason for needing health care. They allow health care professionals and others to see what treatments are available, and how patients with different characteristics respond to various treatments. This information can be used to inform patients and their health care professionals as they decide the best course of treatment and to improve care for patients in the future. Information from registries may also be used to compare the performance of healthcare providers with regard to their outcomes and resource use.<sup>iii</sup>

Specialty society registries present evolving value propositions for physicians, societies, the profession, and populations through the following:

- ▶ Improving quality of care
- ▶ Quality reporting under MACRA (MIPS)
- ▶ Generating new science/evidence
- ▶ Informing health policy decisions
- ▶ Enhancing society value to members
- ▶ Interfacing analytics from EHRs and other data sources:
  - Imaging systems
  - Patient-reported outcome tools
  - Genetics data sets
  - Claims management

In addition, 45% of the specialty society registries indicated conducting research or analytics with registry data to assess quality of care and provider performance, which drives momentum for understanding the patient perspective.

As the use of registries expands and the health care system's focus on meaningful measures and patient-centric care evolves, the impetus for broad stakeholder input, including that from patients and families, is also growing. Patients, families, and caregivers are now playing an essential role in helping to identify and prioritize aspects of care that are important to them.

## Why a new generation of clinical registries?

*Societies are well positioned to create new value for registry data by partnering with patients*

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| <ul style="list-style-type: none"><li>• <b>Old Generation Characteristics</b></li><li>• Registries designed and developed by clinicians</li><li>• Prioritized culture of performance improvement in practice</li><li>• Measurement tools aligned to meet provider needs and objectives</li><li>• Major outputs centered on<ul style="list-style-type: none"><li>• Monitoring quality of care</li><li>• Generating new clinical knowledge</li></ul></li></ul> | <ul style="list-style-type: none"><li>• <b>New Generation Characteristics</b></li><li>• Registries designed and developed in partnership with patients</li><li>• Prioritize patient role in culture of performance improvement</li><li>• Measurement tools aligned to meet what matters to patients</li><li>• Major outputs centered on<ul style="list-style-type: none"><li>- Monitoring quality with patient input</li><li>- Generating novel patient experience knowledge</li></ul></li></ul> |
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Adapted from: Empowering patient partnerships in clinical registries  
...of the people, by the people, for the people: CMSS Summit: The Future of Clinical Registries | May 10, 2018  
Sally Okun | VP Policy & Ethics | [PatientsLikeMe](#)

With the health system's growing emphasis on patient-centric care and the acknowledgment that the patient voice (and that of the family and caregiver) is essential to achieving better outcomes, patient engagement in specialty society quality activities, particularly registries, is essential.

## The Importance of Patient Engagement

Before providing a summary of best practices, tools, and resources that can support registry initiatives to integrate the patient voice into activities, it's imperative to understand concepts in patient-centeredness and patient engagement.

**Patients are living longer with chronic conditions due to [advances in medicine], and their role in health care is shifting from that of a passive recipient of medical care to an active participant in clinical decision-making.**

**—21<sup>st</sup> Century Patient Registries (Agency for Healthcare Research and Quality)<sup>iv</sup>**

Active, meaningful patient engagement provides a connection between the health care provider and the patient, which is needed to identify what is most important to patients in both the process and outcomes of care. This connection can align care goals and promote mutual understanding. While patient input into the clinical process is essential to drive improvements in quality and to ensure alignment of goals, there is also a need for information to come back to the patient in a feedback loop. Patients want to know how their input into the system ultimately impacts them. They want to know how their experience and care trajectory is similar to or different from that of others.

A comprehensive patient engagement strategy requires an atmosphere of active, sustainable, and bidirectional collaboration that encompasses providers, patients, families, and caregivers to understand and meet the diverse health needs of the population of interest. There is a spectrum of opportunities to engage patients in the medical process, from gathering input through surveys and focus groups to patient advisory meetings, inclusion on governing committees and boards, or giving patients leadership roles to ensure capture of the patient's voice.

## How Are Specialty Societies Currently Engaging Patients and Families?

Nearly half of the specialty societies that responded to the 2019 CMSS Registry Survey reported the engagement of patients in their registry initiatives. A variety of mechanisms are employed by specialty societies to garner input from patients, family, and caregivers, including:

- ▶ Focus groups
- ▶ Seats on advisory committees
- ▶ Guideline and measure development panel membership
- ▶ Meetings with patient groups
- ▶ Registry public advisory boards

While these are examples of active patient engagement by societies, they are not specific to registry development and use. However, societies have indicated interest in understanding how to both start engaging patients (for those that haven't yet) and strengthen and broaden areas of opportunity to include the patient voice, including in registry initiatives. Following are examples of how specialty societies and clinically focused registries are starting to include the patient voice in registry and research initiatives:

### **American Urological Association**

At the 2019 CMSS Registry Summit held in Chicago in May 2019, the American Urological Association (AUA) described the development and implementation of the AQUA Quality Registry and indicated that

the overarching goal for adding patient-reported outcomes to the registry is to: “Gather information, from the patient’s perspective, on the impact of a medical condition/treatment on functional status, symptom management, and quality of life.” The AUA indicated that the uses of data are intended to include:

- ▶ Patient and provider monitoring of health care outcomes over time
- ▶ Determining comparative effectiveness of treatments
- ▶ Informing shared decision-making discussions
- ▶ Benchmarking the performance of health care providers

### **American Academy of Orthopaedic Surgeons**

The American Academy of Orthopaedic Surgeons Registry Program’s mission is to improve orthopaedic care through the collection, analysis, and reporting of actionable data. By collecting and reporting data, the American Joint Replacement Registry (AJRR) provides actionable information to guide physician and patient decision-making to improve care.<sup>v</sup> Recognizing the importance of public participation in the AJRR, the governing board recommended convening a formal Public Advisory Board for the registry. The mission of the Public Advisory Board is to enhance the value of the AJRR by ensuring a public voice in the registry’s data collection, reporting, and utilization activities. The Public Advisory Board consists of 12 members who are representatives of patient/consumer groups, people with joint replacements, or other important public stakeholders. The board is an important component of engaging relevant stakeholders, including patients and families, in contributing to the efforts of the registry.

The AJRR Public Advisory Board objectives include:

- ▶ Bring the voice of people with joint replacements, their caregivers, and key stakeholders to the oversight of the AJRR and ensure that the AJRR addresses concerns of individuals with or considering joint replacements and the general public
- ▶ Provide guidance to the AJRR Board of Directors and staff on issues such as:
  - Adequacy, quality, and accessibility of data
  - Information security
  - Research activities using data from the AJRR
  - Policy issues
  - Communication to the public and interested stakeholder groups including:
    - Information about AJRR and joint replacements for consumers
    - Public reports from AJRR

Many specialty societies with registries are on the path toward incorporating the voice of the patient by integrating patients in a continuous learning cycle, which will be of interest to others in the registry space. A growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs.<sup>vi</sup> As a result, many public and private health care organizations are employing strategies to better engage patients, such as educating patients about their conditions and involving them more fully in making decisions about their care.