

OVERVIEW AND PURPOSE

Patient and family engagement is increasingly acknowledged as a key component of a comprehensive strategy to achieve a high-quality, affordable health system. Health care providers are collecting massive amounts of data in electronic health records, patient registries, and other data sources for multiple purposes, including quality reporting, value-based purchasing, outcomes-based contracting, accreditation, and patient safety. While these real-world data can help us learn what works best, for which people, and under which circumstances, what is often missing from these data is the patient voice, which is needed to inform shared decision-making by patients and clinicians to ensure that care is aligned with patients' goals, values, and preferences.

A top priority for CMSS is to drive quality through value and quality assessment, including clinical registries, innovative care delivery models, and achieving equity in health care. In 2016, the organization released the *CMSS Primer for the Development and Maturation of Specialty Society Clinical Data Registries*.ⁱ The registry primer was developed to serve as background and as a resource guide for those who are new to the area and for organizations interested in remaining current on new and emerging issues. Since 2016, the U.S. health care system has been continuously evolving, with advances in medicine and treatment, movement toward value-based payment, and a much stronger emphasis on patient-centered care.

In 2017, the Centers for Medicare & Medicaid Services (CMS) launched the Meaningful Measures initiative, which identifies the highest priorities for quality measurement and improvement. At the core of Meaningful Measures is the intent to focus health care quality efforts on what is really important to patients, families, and caregivers, including making informed decisions about their care, aligning care with the patient's goals and preferences, and improving quality of life and patient outcomes.ⁱⁱ CMS' focus on meaningful measures and empowering patients and providers requires input and the ongoing involvement of health care stakeholders. Perhaps the most important stakeholders are patients, families, and caregivers. To ensure and promote patient-centricity, stimulating, motivating, and catalyzing patient engagement in the process of care is essential in our evolving health system.

This *Engaging Patients in Clinical Registries* primer is intended to provide background on key principles of effective patient engagement, identify opportunities for increased patient engagement in specialty society quality initiatives, and provide tools and resources for specialty societies and other organizations interested in advancing patient-centric approaches to improving quality.