

THE PATIENT'S PARAMOUNT PLACE: EMPHASIS ON EMPOWERMENT, ENGAGEMENT, EXPERIENCE

The third in a series of articles bridging the predictions from our [Emerging Trends](#) body of knowledge to current health care realities

CONSUMERISM is the thread that binds four trends integral to AMCP Foundation's landmark report [Top 10 Emerging Health Care Trends](#). Patient empowerment is a critical component for the success of health care consumerism, and it plays an important role in: Increasing Patient Cost Sharing, Migration to a Value-Oriented Marketplace, The Role of Technology in Patient Engagement, and Health Care Everywhere. Empowered patients may be more adherent to treatment, and they may contribute to an improved health care system. In this article, we update developments across these interrelated areas.

data) may result in the use of low-value care, and thus higher overall expenditures.

Patients are actively seeking this information, and thus empowerment. They want to be a part of the medical decision-making process. Indeed, [shared decision-making](#) is directly related to patient empowerment. One [study revealed](#) that hospitalized patients with chronic diseases want to be included in their health care discussions, such as nursing bedside handoff and medical rounds. Participants expressed frustration with failures in communication among their health care team during and after hospitalization (i.e., transitions of care) and with behaviors that interfered with the care team's communication with them. Patients also expressed interest in maintaining their own health histories and information, but they had to use several methods to keep track of their health status. For example, when receiving care from multiple providers, they found it more challenging to integrate the information received from several physicians' offices.

Another method for gaining information to build empowerment is through [participation in patient support groups](#). Patient engagement in support groups may be increasing because of easy [access through social networks](#). These peer-to-peer communities also contribute to health literacy and education, and may provide avenues for better access to care. In addition, the use of health care [decision aids](#) seems to result in more informed decisions, better health literacy, and greater participation in the decision-making process.

Personalized, mobile health (mHealth) applications can contribute significantly to information sharing. In addition to simply recording test results, mHealth apps may also be useful in improving patient use of electronic health records, and monitoring medication therapy adherence. As

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Empowering and Engaging Patients in Health Systems

A key finding of the research conducted in 2014 was that patient empowerment drives the search for health knowledge; it is a foundational requirement of health care consumerism. Therefore, information availability and exchange accelerate patient empowerment.

Information helps patients choose health plans, providers, participate in shared medical decision-making with their doctors, and understand how to adhere (and the need to adhere) with their medical therapy.

Patient empowerment must also be accompanied by the knowledge and data on which to make health care decisions. Consumerism without empowerment (through better knowledge and

reported by [Saint Luke's Health System](#), integration of its mHealth applications resulted in a 30 percent increase in patients accessing the EHR system.

With optimal patient engagement, we are better able to understand what clinical outcomes measures are most important to them (as opposed to what clinicians believe are most important). Patient input can also be valuable in determining what they perceive to be clinical improvement associated with an intervention or treatment. The Food and Drug Administration (FDA) held the first meeting of its [Patient Engagement Advisory Committee](#) in October 2017. The Committee comprises patients, caregivers, and those who represent the patients' needs. Its purpose is to broaden patient engagement in the clinical trial process (including trial design).

As basic as the need for patient empowerment and patient engagement seems, one critical area is still lacking. How do we measure these concepts? Assessing the role of [patient empowerment](#) and [engagement](#) is dependent on effective measures, which are still being developed.

The Move to Improve Patient Experience

The [Triple Aim](#) is a driving force behind many of the health reform initiatives of the past decade. Developed by the [Institute for Healthcare Improvement](#), one of the distinguishing characteristics of the Triple Aim is the inclusion of improving patient experience as a principal component (lowering cost of care and improving care quality being the other two).

Patient experience is defined by [six dimensions per the Institute of Medicine](#) (safe, effective, patient-centered, timely, efficient, and equitable). It covers nearly all aspects of direct provider–patient contact, from the patient's ease of parking his or her car at the health care facility, to the response time to nursing call button activation, to hospital food, to satisfaction with the actual treatment received. As the spotlight on patient experience grows in intensity, providers, plans, and suppliers have begun to address this trend in a number of ways.

One example is the evolution of a new high-level position in health organizations, the [Patient Experience Officer](#). Growing need for these positions is apparent in hospitals, health systems, and others. In the pharmaceutical industry, Sanofi and Merck have introduced [Chief Patient Officers](#); Sanofi's executive was hired from the Patient-Centered Outcomes Research Institute (PCORI).

Another example is through attempts to improve the patient's experience with a health plan's web portal, including the ease of communicating with doctors, scheduling appointments, and collecting laboratory results. Organizations have also begun to use [quality improvement processes](#) to improve patient experience.

Collecting information about patients' experiences can be an excellent method for identifying and understanding [problems in health care provision](#) or gaps in care. This may also be the case with patient journey mapping, which is assisted by collating the experiences of groups of patients with the same disease or disorder.

Patient-Reported Outcomes

For certain disease states, patient-reported outcomes are the principal measures of patient-specific therapeutic effect (e.g., depression, [pain](#), [migraine](#)). Patient-reported outcomes measures (PROMs) can include valuable information about symptoms and their severity, as well as the patient's functional ability.

Patient-reported outcomes (PROs) can help complete a clinical picture by supplementing clinician's observations and tests with information from the patient. For example, PROs are integral to [multiple sclerosis](#) care, describing levels of fatigue, cognitive deficits, and disability. Scales using [patient ratings](#) (e.g., Multiple Sclerosis Impact Scale–29) have been found to better correlate with prognosis than the traditional, physician-reported [Expanded Disability Status Scale](#) (EDSS).

Measureable clinical endpoints do not always capture what is most important to the patient. These [PROMs are the missing link](#). Turning patient observations into numerical scores through validated questionnaires can help translate the

severity of symptoms into recordable clinical information.

In 2012, the [National Quality Forum](#) released its report on the use of PROMs in performance measurement, and found that (1) they are not in widespread use in clinical practice and (2) the use of aggregated patient-reported outcomes data for the measurement of healthcare provider or payer performance is still not widely practiced.

Several reports nonetheless offer the hope that the PROM field is advancing. According to a September 2017 [report](#) from Partners HealthCare, the health system now “collects PROMs in 21 specialties and across 64 clinics in orthopedics, urology, psychiatry, and cardiac surgery. We have collected over 200,000 PROMs and are collecting at a rate accelerating quickly past 12,000 per month.” For example, the health system uses this information to evaluate which patients with back pain are the likeliest to benefit from lumbar surgery, or collect real-world evidence on the symptoms of incontinence or impotence in patients receiving different modes of prostate cancer treatment.

A 2017 [literature review](#) of studies in oncology care found that the use of PROMs improved patients’ awareness of symptoms, and patient–physician communication and discussion. Subsequently, this promotes shared decision making.



TAKEAWAYS FOR PLANS

- To improve the efficiency of the care dollars you invest, improve and track the education your patients receive
- Focus your communication with covered populations through their preferred modalities (e.g., E-mail, web portals, printed mailings, phone calls)
- Continue to consider patient health literacy in multiple aspects of benefits administration
- Health care coverage remains highly complex; patient empowerment and comprehension is critical to keeping nonmedical costs low



TAKEAWAYS FOR PHYSICIANS

- Shared decision-making promotes patient empowerment

- To improve the efficiency of care dollars, you should collaborate with plans and health systems to improve the education your patients receive
- Patient-reported outcomes are important and can provide a more complete clinical picture of a patient’s health status
- Health systems are focusing on patient experience as important measures of performance and value (and potentially for reimbursement purposes)

CHALLENGES IN THE USE OF PROs

AMCP convened a [Partnership Forum on challenges in improving quality, value, and outcomes with PROs](#) in October 2017. The gathering identified a number of obstacles limiting more widespread use:

- All patients are not the same, but representative patients and patients with a specific condition should help determine which the most meaningful outcomes to report or measure are.
- PROMs must be collected and monitored while minimizing bias and mitigating disparities (e.g., because of a patient subgroup’s inability to report).
- The role of caregivers and/or parents in reporting PROs should be considered.
- **Technological barriers:** To rapidly administer surveys, calculate scores, and trend results, the data need to be electronic. An electronic platform that works with the patient portal and the electronic health record system (e.g., via Wi-Fi–connected tablets) is optimal. Accuracy in real-time reporting is essential to provide information at the point of care.
- **Operational barriers:** The incorporation of PROMs requires time commitments from both patients and clinical team. Coordination of efforts in the use of technology and interpretation of the resultant outcomes measures is also needed to optimize use in reality. [AMCP will convene a follow-up partnership forum](#) in October 2018 to discuss how to arrive at a more ideal state for PROs.



TAKEAWAYS FOR PHARMACISTS

- You contribute greatly to patient empowerment when you help explain pharmaceutical prescriptions and answer general health questions, or by participating on clinical teams, collecting and analyzing PROMs from patients
- Do your best to clarify coverage and plan policies for members and patients, enabling them to better navigate their pharmacy and medical benefits



TAKEAWAYS FOR PATIENTS

- You are the key to a value-based health system; informed patients are able to make better health care choices
- Your reporting about your own symptoms, such as fatigue, pain, cognitive function, and depression, will be increasingly collected from your health care team to better inform your care plan
- You will be asked to take on an active role in your health care decision-making; share when information is helpful and is readily understood



TAKEAWAYS FOR INDUSTRY

- Patient-reported outcomes will grow in importance as part of clinical trial data design (and perhaps postmarketing studies) and therefore formulary and coverage policies and determinations
- Expect that patient advocacy groups and health providers will turn to industry for information on PROs that may not have been included in investigational studies or product labels
- Empowered, activated patients are probably more adherent patients

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The AMCP Foundation, founded in 1990 as a 501(c)3 nonprofit organization, is the research and education arm of the Academy of Managed Care Pharmacy (AMCP). The Foundation advances collective knowledge on major issues associated with the practice of pharmacy in managed health care, including its impact on patient outcomes.