

## Patient-Centered Outcomes for Population Health Research

American healthcare is in the midst of a *patient-centeredness* revolution. Patient-centeredness is one of the National Academy of Medicine's six aims for healthcare quality improvement,<sup>1</sup> and the term now infuses patient care, research, clinical organization and delivery, and policy.

On a personal note, my interest in the topic began with two coincidental encounters during my first months at Thomas Jefferson University. A woman I knew socially shared that she was undergoing breast cancer treatment and was dismayed that no one had broached the topic of sexual functioning with her. The second involved a senior physician with whom I spoke on the elevator frequently, who explained that his prostate cancer diagnosis and treatment had made his grandchildren afraid to sit on his lap. Both of these individuals were relating to me that the system had failed to ask them what was important to them as it related to potential outcomes of their care, and both encounters had a profound impact on me. If you have ever left a doctor's appointment feeling like you didn't say everything you might have, or ask all the questions you wanted to, then you might suspect that it is difficult for some patients to clearly say exactly what is important to them. This is true in both clinical and research settings. Yet the mandate for patient-centeredness demands that we do just that: ask, listen closely, and then process the information in order for it to be useful.

In the clinical realm, definitions of patient-centeredness vary, but they do commonly mention features like 'understanding the patient as a unique person'<sup>2</sup> and 'exploring the patient's experience of illness'.<sup>3</sup> The notion of patient-centeredness appears in discussions of *compassionate care*, *culturally appropriate care*, and *transformative care*. It is no wonder some

have gone so far as to describe it as the 'magic bullet' of healthcare.<sup>4</sup>

In the research world, patient-centeredness is most often operationalized through patient-centered outcomes research (PCOR), which has its roots in the collaboration between social sciences and medicine, and the call for measurement of so-called 'humanistic outcomes' in the 1960's. In this era, outcomes research was born, where the possibility was raised that outcomes could include patient experience and functioning, not just death and disease. However, research activities looking at outcomes such as quality of life or social functioning were a relatively remote pocket of research until the passage of the Affordable Care Act (ACA) when the term *patient-centeredness* was enshrined in law. The law repeatedly refers to patient-centeredness, patient satisfaction, patient experience of care, and patient engagement in its provisions.

The ACA mandated funding for comparative effectiveness research (CER), the purpose of which is "to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at both the individual and population levels."<sup>5</sup> One effect of this mandate was funding for the Patient-Centered Outcomes Research Institute (PCORI), a non-governmental body to administer CER research funding. (There is anecdotal evidence that the choice of the term 'patient-centered outcomes research institute' rather than 'comparative effectiveness research institute' was driven in part by fears in some sectors that 'comparative effectiveness' implied rationing of treatments).<sup>6</sup> Nonetheless, arguably the largest incursion of patient-centeredness into research was through the PCORI's call for the inclusion of 'patient-reported outcomes' (PROs) as endpoints in

research studies. PCORI codified this in their methodology standards to guide CER.

***Use patient-reported outcomes when patients or people at risk of a condition are the best source of information***  
(Standard PC-3)

***"Measure outcomes that people representing the population of interest notice and care about."*** (Standard RQ-6)

PROs are defined as "any outcomes (usually questionnaire or diary-based) reported directly from patients without interpretation by health care providers."<sup>7</sup> However, a reading of the history of the science of PROs reveals that their study is primarily an academic one, led by researchers and computer programmers<sup>8</sup> who are making assumptions about what is important to patients, usually in the absence of patient input. Given the importance PCORI places on authentic engagement of research participants in all phases of research, my colleagues and I wanted to ask the question: *What is the best way to engage patients to identify their own important treatment outcomes?* These could be personal outcomes for use in making treatment decisions or in a clinical encounter, but we also wanted to answer a more generalizable question about patient-important endpoints to include in clinical studies.

Focus groups and individual patient interviews are the two prime methods by which qualitative socio-medical researchers have directly elicited opinions from relevant patient stakeholders. However, for research purposes, individual interviews and focus groups are time- and labor-intensive. These methods also require some interpretation on the part of researchers as they code and

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analyze the qualitative results. Dr. Kristin Rising of Thomas Jefferson University's Department of Emergency Medicine had been conducting studies of this type, using interviews to elicit patients' own important outcomes for transitions of care<sup>9</sup> when we began collaborating on alternate methods of allowing patients to voice their own important outcomes. The method we are testing is called 'Group Concept Mapping.'

Concept Mapping uses group brainstorming to a narrow 'prompt', and then the organization of the brainstormed material into maps based on each participant's ideas about the relatedness of the brainstormed concepts.<sup>10</sup> It is inclusive of the ideas of all the participants in the group, and the results are driven entirely by the group without incursion of the researchers' ideas. I had already conducted a CM study to elicit patients' views on practice improvement in our primary care practice, as well as collaborated on a project with Dr. Lara Weinstein using

concept mapping to investigate barriers to mammography in women with serious mental illness.<sup>11</sup> On the basis of this initial work, I suspected that concept mapping might be a good approach for eliciting patients' self-identified important outcomes.<sup>11</sup> Our project was funded by PCORI in 2015 to directly compare the patient-important outcomes elicited by interviewing to those elicited through concept mapping. The study is called the VOICe project - Voicing Outcomes Important to Care. We are conducting the study in a population of patients with Diabetes Mellitus with the expectation that information about the methods will be generalizable to other patient populations.

Some have argued that there is a tension between 'population health' and 'patient-centeredness,'<sup>12</sup> namely that by focusing on individual patients we risk losing a population health focus. Our study intends to use individual patient voices to arrive at generalizable patient-important outcomes

for treatment decisions that can inform both research and patient care. No one argues that knowing everything we can about the populations we serve will be important, including the outcomes that are important to individual patients within the population. This knowledge will allow us to choose appropriate endpoints for clinical studies, as well as arm clinicians with information about the patient in the room with them. We hope to show that concept mapping provides an efficient way – and truly patient-centered way – to gather this information.

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