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Dennis J. Baumgardner

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FROM THE EDITOR

Defining Patient-Oriented Research for the Average Person (and Potential Research Partner)

Dennis J. Baumgardner, MD | Editor-in-Chief

Department of Family Medicine, Aurora UW Medical Group, Aurora Health Care, Milwaukee, WI

In the lead article of this issue of *Journal of Patient-Centered Research and Reviews (JPCRR)*, we find Kaur and Pluye describing their analytical development of an operational definition of patient-oriented research (POR) using a modified e-Delphi technique.[1] The purpose of their study was to adapt a definition of POR that would be adequate and appropriate "to filter and retrieve POR-related publications from bibliographic databases in a reliable manner."

As editor of a medical journal dedicated to improving patient-centered care outcomes as well as the institutional official for a research subject protection program, I fully recognize the importance of their purpose. The authors' resultant definition, which aptly suits its intended use, lays out two conditions that should be met for research to qualify as patient-oriented:

- *Condition 1:* Patients (including relatives, family caregivers, and the public) are involved as research partners with multidisciplinary or transdisciplinary research team members (including decision/policy-makers, patients, and clinicians) along a continuum, (from being consulted to being engaged) in addressing patient priorities or planning/conducting research (eg, formulation of the question; data collection/analysis; interpretation, diffusion, dissemination, or application of results), or both addressing patient priorities and planning/conducting research.
- *Condition 2:* Studies are aimed to (a) address outcomes deemed important by patients; (b) have a direct impact on at least one of the following targets: patient health and experiences, health professionals' practice, or health care services and policies; or (c) achieve both objectives C2(a) and C2(b).

Such parameters will help researchers identify published works that truly report patient-oriented study outcomes. However, in the words of one anonymous reviewer, "This lengthy definition can fit the need for a standardized search of the literature, but [as a general definition of POR] would be difficult to explain to another person in a regular conversation." Since the very concept of engaging patients in the research process involves working with those generally unfamiliar with scientific terminology, how might we describe POR to the average "person on the street" in more readily understandable language?

As Kaur and Pluye accurately point out, currently there is not a single agreed-upon POR definition worldwide.[1] The U.S. National Institutes of Health continues to define POR as "research conducted with human subjects (or on material of human origin, such as tissues, specimens, and cognitive phenomena) that requires direct interactions with human subjects."[2] In Canada, POR is "a continuum of research that engages patients as partners (and) focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare

Correspondence: Dennis J. Baumgardner, MD, Aurora Sinai Medical Center, 1020 N. 12th Street, #4180, Milwaukee, WI 53233 (dennis.baumgardner@aurora.org)

systems and practices."[3] In the United Kingdom, POR is described as "an active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research … for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research."[4]

Each of these statements is a bit of a mouthful. Some authors have truncated the concept of POR to simply "research that focuses on an intact person or patient as the unit of observation."[5] But perhaps this language is too broad and nondescript.

In introducing their topic, Kaur and Pluye condensed the Canadian definition of POR to "a continuum of research that engages patients as partners."[1] This certainly is an appealingly succinct definition, but lacks the examples of "engagement" that the U.K. definition notes.[4] Two articles previously published in *JPCRR* and two recent workshop synopses highlight the advantages, challenges, complexities, and nuances regarding patient engagement in research and the inability to measure its effectiveness.[6-9] As Hahn et al emphasized, patient engagement in research must be genuine, productive, and void of "tokenism."[9]

And to just what does "continuum" refer? Of course, those of us embedded in the edifices know that traditionally it refers to bench-to-bedside translational research. Peter Stacpoole, however, criticized this concept as being a "fundamentally misleading and harmful paradigm for describing patient-oriented [research]."[10] Contrasting the reality of the iterative, nonlinear, multidimensional process that leads to meaningful discoveries in medicine with the "linear and unidirectional" concept of bench-to-bedside research, Stacpoole emphasized the interdependence of laboratory and patient-oriented research along with the utility of astute bedside hypotheses.[10] The Canadian Institutes of Health Research also acknowledges the complex, dynamic, and iterative nature of translational research.[11] Yanos and Ziedonis further emphasized the importance of trained clinician-researchers to bridge the gap between the research and practice communities.[12]

At the turn of this century, Shaywitz et al outlined 5 principles of POR.[13] Principles 3 and 4 were technical in nature, and the final principle called for a "discrete academic discipline." But the first 2 principles — "the patient is the focus" and "the patient and physician are equal partners and share responsibility"[13] — remain intriguing as building blocks for a person-on-the-street definition of POR. Serendipitously, they faintly echo Abraham Lincoln's famous description of democracy, "of the people by the people for the people."[14] While I do not envision patients sharing equally in my preparation of microbiologic growth media or performing half of the statistical planning and analysis of a pragmatic clinical trial, I do believe there is value in communicating these fundamental tenets of patient focus and involvement. Many POR experts agree that patient involvement must be meaningful and may include helping set research agendas, input regarding project design and feasibility, feedback on and dissemination of the implications of research results, and sometimes actual involvement in carrying out the project.[4,6,8,9,15]

Freely admitting that I am not myself a POR expert, I wonder if the following could function as a reasonable definition of POR for the average person on the street: *research intended to benefit individual patients and that meaningfully partners with patients to plan, conduct, or interpret the study*.

Want to weigh in?
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