

Editorial

Using a Patient-Centered Approach: Research Done Differently

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Editorial

Nursing has been described as both an art and a science. In order to continue to advance nursing science and practice, it is up to us as nurse scientists, clinicians and scholars to advance nursing in the scientific realms in addition to the translation of evidence into practice. To generate new knowledge, this means securing funding to develop and formulate meaningful questions in which answers are sought. Common venues for funding of research and grants may include individual nursing associations or other entities such as National Institute of Nursing Research (NINR) or the National Institutes of Health (NIH). Many researchers are familiar with both of these entities as possible funding sources; however, there are others that exist. In fact, one organization in particular is changing the way research in healthcare is being conducted.

'P' what?

PCORI or Patient Centered Outcomes Research Institute was authorized in 2010 by Congress as an independent, not for profit, non-governmental organization as part of the Patient Protection and Affordable Care Act (ACA). Its key objective is to determine which of the many healthcare options available to patients and those who care for them work best in particular circumstances. This is achieved through PCORI's mission which "is help people make informed healthcare decisions and improve healthcare delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader healthcare community" [1].

PCORI values research that has attributes which include the usefulness of research, transparency, patient-centeredness and inclusiveness through the use of evidence. There are five priority funding areas in which to submit an application for consideration of funding. These five areas include:

- Assessment of Prevention, Diagnosis, and Treatment Options
- Improving Healthcare Systems
- Communication and Dissemination Research
- Addressing Disparities
- Accelerating Patient-Centered Outcomes Research and Methodological Research

PCORI is unique in that the patient-centeredness and patient engagement factors are paramount from inception and formulation of the research question, throughout the entire research process, and to the analysis and dissemination of results. Patients, patient representatives and caregivers alike must be instrumental through each phase of the research process. The application should consider such questions such as "What outcomes are most important and meaningful to the patient or patient partners?" Patient partners may include the patient, family, caregiver and others. The research plan should demonstrate active engagement among scientists, clinicians, stakeholders, patients and patient partners [1].

Nurses, clinicians, researchers and other healthcare providers must change the way they engage patients and stakeholders in research. Asking and soliciting input can lead to meaningful questions and potentially significant findings if this route is chosen. For instance, a particular rating on a depression scale may not be meaningful to patients, yet how many days from work that are lost due to depression can be very important and meaningful.

Medical terminology or medical jargon is not particularly meaningful to patients and stakeholders. According to Tai-Seale, Greer Sullivan, Cheney, Thomas and Frosch [2], engaging patients can provide a useful perspective not only for the research question (s) asked, but also of the terminology used. The authors found during the PCORI application process of engagement patients, that the term "mental illness" denoted a negative image in the minds of patients; whereby mental wellness was viewed more positively by patients [2].

The process

Funding cycles and deadlines are posted on the PCORI website. A Letter of Intent (LOI) is typically the first step in the process. Once an application has been submitted, it is reviewed initially on line by a team of reviewers. This team includes the following individuals:

- 2 scientific reviewers
- 1 Patient Stakeholder reviewer
- 1 Clinician Stakeholder reviewer

Applications are reviewed on 5 distinct criteria:

- Impact of the Condition on the Health of Individuals and Populations
- Potential for the Study to Improve Health Care and Outcomes
- Technical Merit
- Patient-Centeredness
- Patient Engagement

After a rigorous online review process, those applications receiving the lowest scores (a lower score is better) progresses to

the next step to the Merit Review. The Merit Review is an in person 1-2 day in which the team of reviewers comes together and formally reviews and discusses applications. The goal of the Merit Review is to identify those applications with the strongest potential to improve patient outcomes (and answer those questions that are most relevant and meaningful to patients). If funded, the application is referred to as a contract- not a grant. Use of the term contract and not grant again distinguishes PCORI from other funding agencies. Ultimately final funding decisions are made by the PCORI Board of Governors.

Keys to success

Those applications that are funded typically have key elements such as a clearly defined target population with well defined comparators (as well as a strong rationale for the comparators), take place in a real world setting, and have meaningful outcomes to the patient. Having preliminary evidence of the potential for successful recruitment and strategies used in the past for recruitment as well as identifying potential barriers and a plan to overcome them are all important. Demonstrating the likelihood of the research to improve current clinical practice along with actively engaging patients and stakeholders throughout the research process is imperative. Likewise delineating the open communication, involvement and active engagement of patients, patient representatives, clinicians and other stakeholders along each step of the way is paramount.

At conferences and meetings, some colleagues have been overheard saying that it's "too hard" to get PCORI funding or that it is too much "effort" to get patients involved in the research process. Researchers may have a different perspective or framework in how research should be conducted versus that of the lay community. However, times are changing at a rapid pace in both healthcare and research. PCORI prides itself on "research done differently". Engaging patients and the patient perspective in not only healthcare research is here to stay. Concepts of open communication, collaboration,

patient-centered and active engagement are now fundamental, critical components in innovative research application submitted to PCORI. Only through a collaborative and harmonious synergy of working with patients, patient representatives, clinicians and other vested stakeholders can we hope to advance the science as well as to answer those questions most important to patients.

Resources

To learn more about PCORI, go to: www.pcori.org, for more information on how to become more involved, please consider any of the following:

- Subscribe to the PCORI newsletter
- Suggest a PCORI question
- Become a Merit Reviewer
- Participate in PCORI events and activities
- PCORI Conference: November 15-17, 2017 in Washington, DC
- Attend a PCORI teleconference / webinar
- Attend a free, in person meeting offered by PCORI
- Join an advisory panel
- Become a PCORI Ambassador

References

1. Patient Centered Outcomes Research Institute.
2. Tai-Seale M, Sullivan G, Cheney A, Thomas K, Frosch D. The Language of Engagement: "Aha! Moments from Engaging Patients and Community Partners in Two Pilot Projects of the Patient-Centered Outcomes Research Institute". *The Permanente Journal*. 2016; 20.