AN INTERVIEW WITH
DR. KEVIN WEINFURT

Chair, NIH Collaboratory Patient-Reported Outcomes Core

Co-Principal Investigator, NIH Collaboratory Coordinating Center

Interviewed by Karen Staman, MS, Coordinating Center Staff Writer

On November 8, 2017, we sat down with Kevin Weinfurt and asked him to reflect on the first 5 years of the Patient-Reported Outcomes (PRO) Core as well as on the challenges ahead.

How would you describe the first 5 years of the PRO Core?

We worked to support the subset of projects that collected PROs, including the Trauma Survivors Outcomes and Support (TSOS) Trial and the Collaborative Care for Chronic Pain in Primary Care (PPACT). The larger focus of the Core involved national initiatives to improve inclusion of PROs in the electronic health record (EHR). For example, we convened a policy meeting in Washington, DC, to discuss barriers and opportunities for getting PROs into the EHR, and that along with some other initiatives gave rise to a Patient-Centered Outcomes Research Institute (PCORI) project, which was led by our Hopkins colleagues Claire Snyder and Albert Wu, that resulted in a Users' Guide for Integrating Patient-Reported Outcomes in Electronic Health Records.

What accomplishments of your Core are you most proud of?

I'm proud that the Core has been a part of national efforts that are helping increase interest in collection of PROs among a broader array of people. Embedded pragmatic clinical trials (ePCTs) hold the promise of providing real-world evidence, but for certain conditions, the variables that are in the EHR are not the outcomes that matter to all stakeholders. The value of PCTs could be greatly increased by integrating these patient-centered outcomes into the EHR. To this end, the PRO Core is continuing participation in these national policy initiatives to incentivize collection of PROs in the EHR and encourage the use of interoperable PRO measures across health systems to facilitate research.

The Core has also created a great set of resources in the Living Textbook of Pragmatic Clinical Trials, including a chapter on Choosing and Specifying Endpoints and Outcomes and a resource chapter on Patient-Reported Outcomes. These chapters provide clear information that bolsters the broader goal of getting more people engaged and supportive of PROs.

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What work is important to tackle going forward?

One of the roles the Collaboratory could play in the coming years is to identify the value proposition of PROs. Because there are costs associated with collecting PROs, we need to determine when PROS are essential, supporting, or not at all informative for the clinical questions. This gets at the value proposition: When are they of value and to whom?

"For different kinds of clinical research questions, we need to identify if PROs are

- Necessary to answer a research question

- Not necessary, but would provide useful, supporting, or clarifying information

- Not at all informative"

— Weinfurt

For example, for an intervention designed to treat chronic obstructive pulmonary disease, acute exacerbations will be recorded in the EHR. However, important secondary outcomes include effects on day-to-day functioning, social activities, and fatigue, and not all of these outcomes are routinely collected. If the Core can demonstrate the value proposition of PROs to different stakeholders, then there is more incentive to include them in the EHRs. Ideally, the

outcomes that matter to decision makers—including PROs—will be routinely collected as part of the patient's interaction with the health system.

The Core is also anticipating being able to support PROs in the next series of Demonstration Projects.

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