

## AMPLIFYING THE PATIENT VOICE

*How patient-reported outcomes (PRO) data can help increase patient satisfaction, quality of life, and even survival when incorporated into clinical care*

Rigorously and systematically incorporating the patient’s perspective can significantly improve medical care. The proper use of patient-reported outcomes (PROs) in medical specialties from oncology to orthopedics has demonstrated benefits ranging from better patient satisfaction to improved quality of life, more effective control of pain and symptoms, and even increased survival.

By having patients complete validated questionnaires that ask about symptoms, medication side effects, ability to function, and overall well-being, then using that data to inform those patients’ own treatment, many different types of clinicians, practices, and health systems are able to provide more patient-centered care. The use of PROs may even improve health equity because of better clinician-patient communication.

“As medicine strives to partner more closely with patients, PROs are a powerful means for patients to convey how they feel, function, and live their lives,” says **Claire Snyder, PhD, Professor of Medicine, Oncology, and Health Policy & Management at the Johns Hopkins Schools of Medicine and Public Health, and Principal Investigator of The PROTEUS Consortium.** “We owe it to our patients to ensure that their perspectives count when it comes to their medical care, and PROs are an effective tool to amplify the patient voice.”

**EXPERT COMMENTATORS  
AVAILABLE FOR INTERVIEW**

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In the case of cancer, for example, studies have shown that clinicians frequently miss or underestimate patients’ symptoms during treatment, which can result in delayed or missed treatment and preventable emergency room visits, hospitalizations, and suffering. We can help close that gap by collecting and using PRO data as part of the care pathway.

“Shared decision-making is one of the hallmarks of high-quality cancer care, and this is another situation in which PRO data is invaluable,” says **Michael Brundage, MD, MSc, Professor of**

**Oncology and Public Health Sciences at Queen’s University and Co-Principal Investigator of the PROTEUS Consortium.** “When we get patients’ own reports of their experiences and priorities, it helps make optimal use of visit time, which supports better quality of life in a number of ways.”

## **PRO IMPLEMENTATION IS GROWING BUT CAN BE CHALLENGING**

PROs have been used as endpoints in clinical trials for decades, and their use in clinical practice is now expanding rapidly. Payers such as the Centers for Medicare and Medicaid Services are rewarding the collection of PROs, which is likely to drive continued widespread adoption. For example, the Center for Medicare and Medicaid Innovation’s [Enhancing Oncology Model](#) will [require](#) implementation of PROs in the electronic health records of all participating practices. PRO data will soon be [tied](#) to Medicare payment and quality ratings for total hip and total knee arthroplasty surgeries.

Implementing PROs effectively in clinical practice is not easy, however, and numerous barriers in the collection, analysis, interpretation, and integration of this data must be overcome in order to secure the benefits.

The PROTEUS Consortium (“PROTEUS”) provides a free, curated set of core PRO resources and custom tools at its [website](#). These include [The PROTEUS Guide to Implementing Patient-Reported Outcomes in Clinical Practice: A Synthesis of Resources](#), which offers step-by-step guidance to help health systems establish or optimize a PRO system that will work for them.

“There is no single ‘right’ way to implement PROs,” says **Norah Crossnohere, PhD, Assistant Professor at The Ohio State University College of Medicine’s Division of General Internal Medicine, PROTEUS Senior Project Scientist, and first author of the Guide.** “What’s critical is that a clinic or health system defines its goals for PROs first, then uses that information to adopt one or more approaches to design and implementation.”

In addition to sharing PRO tools and resources, PROTEUS also convened the PROMs Equity Project, which proposed solutions for overcoming barriers to PRO use in underserved communities, and the PROTEUS Learning Health Network, which helps oncology practices in the U.S. share experiences about the use of PROs.

## **ABOUT THE PROTEUS CONSORTIUM**

The PROTEUS Consortium provides curated resources, original tools, and other support to help optimize the use of PROs in clinical trials and clinical practice and, ultimately, to inform better, more patient-centered care. The Consortium is a distinguished international body that includes leading PRO researchers and representatives from more than 50 key patient, clinician, research, health system, industry, government, policy, and regulatory groups. Learn more at <https://theproteusconsortium.org>.

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