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ABSTRACT

Patient Reported Outcomes Measures (PROMs) have been used since the 1960's, with some of the earliest in the field of mental illness. Today, there is a large and increasing number of PROMs across virtually all medical specialties.

PROMs continue to be used principally for research purposes. However, there is growing recognition of their potential to assist in clinical decision making, value-based medicine and sustained patient engagement. PROMs can thus be a useful vehicle for addressing some of the larger challenges in modern healthcare.

However, the design and use of PROMs present serious challenges for the busy clinician. These include selecting or designing the PROMs most relevant to a specific practice, execution, cost, personal health information protection, patient enrollment and continuing engagement, data verification and audit trail, adequate data to generate statistically significant correlations.

Fortunately, modern tools now allow clinical groups of any size to generate clinical and financial value from PROMs.

PROMS: THE THEORY AND THE REALITY

Capturing longitudinal outcomes data is essential to evidence-based medicine. Thus, standardizing PROMs constructs¹ and scoring systems for all categories of clinical interventions and patient cohorts is a worthy goal. Many medical societies, for example, develop PROMs in the context of their registries. Other

¹ The term “construct” refers to what PROMs are trying to measure, the concept that defines the PROM such as pain, physical function, or depressive mood. Constructs are the postulated attributes of the person that investigators hope to capture with the PROM. See *Cochrane*, below.

organizations publish free and licensed PROMs. Other groups analyze the strengths and weaknesses of various PROMs.²

On the one hand, there typically exist multiple PROMs for any pathology. On the other hand, the busy clinician will find it daunting to select PROMs which drive clinical and other value in his particular context. Moreover, PROMs for the same condition can be in part contradictory, duplicative, incomplete and/or confusing.³ Well intentioned attempts at standardization of PROMs have been unavailing.⁴

PROMS AS TOOLS IN THE CLINICAL SETTING

PROMs can play an important role in two major trends in modern healthcare – value-based medicine and clinical decision-making.

Value-Based Medicine

As [stated](#) in the New England Journal of Medicine:

Value-based healthcare is a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes. Under value-based care agreements, providers are rewarded for helping patients improve their health, reduce the effects and incidence of chronic disease, and live healthier lives in an evidence-based way.

This approach is found in accountable care organizations, narrow networks, and many other clinical intervention revenue models. Capturing and analyzing

² For more information, see [Cochrane](#), [PROMIS](#), [COSMIN](#), [COMET](#), [ICHOM](#).

³ See [Patient-Reported Outcomes Measures \(PROMs\): A Review of Generic and Condition-Specific Measures and a Discussion of Trends and Issues](#), Churruccia et al.

⁴ See [Challenges to Global Standardization of Outcome Measures](#), Liao et al.

outcomes in a systematic, longitudinal manner are essential elements of value-based medicine.

However, efforts to derive useful correlations for value-based medicine from EMRs, claims databases, patient registries, and other traditional data sources have been disappointing.⁵ These sources often reflect only partial data, poor clinical context, challenges in verifiability, and other weaknesses. Of particular note, there is usually a paucity of outcomes data, and wide variation and discrepancies in what little exists.⁶

Meeting these challenges with respect to PROMs begins at the clinic. The treating clinician must select/design the proper PROM construct for each patient cohort. For example, what exactly is the PROM intended to measure – pain, function, quality of life etc. – in the context of a particular class of clinical intervention? Only then, will the outcomes data truly support value-based medicine.

Clinical Decision Making

Medical science is advancing ever more quickly. Clinicians must learn to deal with concepts not even mentioned during medical school, as well as new equipment, medications, and diagnostic tests. Modern communications channels offer practitioners and their patients good and bad information on any topic – both good and bad.⁷

⁵ See for example [Challenges and Opportunities of Big Data in Health Care: A Systematic Review](#), Kruse et al.

⁶ See [A Scoping Review of Core Outcome Sets](#), Maregaglia et al.

⁷ In this brave new world, ChatGPT can be expected to play a major role in clinical decision-making in the coming years. See for example [Using AI-Generated Suggestions From ChatGPT To Optimize Clinical Decision Support](#), Liu et al..

Despite these oceans of information, or perhaps because of them, the informed judgment of the experienced clinician remains central to accurate diagnoses and safe, efficacious treatment protocols.

PROMS AS THE FOUNDATION OF PATIENT-ENGAGEMENT

An attractive website, efficient front office, well-lit reception area, testimonials and five-star reviews are only the beginning of patient engagement in the 21st century.

Yes, patients are consumers; but they are first and foremost patients. They have a patient story, one or more specific conditions, outcomes objectives, perhaps disappointments with past treatments. Patients have often already researched their conditions and options. They want to be heard, and to be a part of their recovery. Moreover, listening to patients from the initial consult and then throughout their treatment journey can be critical to successful outcomes.⁸

PROMs can represent an excellent tool for intermediating the respective “languages” of the patient and the clinician. Properly designed and executed, they make clear to the patient that her doctor is genuinely interested in the success of the long-term outcomes they both are seeking.

REMOVING THE BURDEN; GENERATING THE VALUE

As indicated, PROMs have significant potential clinical, patient engagement and financial value. For them to be a realistic part of the active clinician’s armamentarium, however, they must have several key characteristics:

- Impose minimal burden on the clinician, her staff, and patients.

⁸ See [How Doctors Think](#), Groopman.

- Conform in their constructs to the indications, treatment protocols and other aspects of the clinician's everyday practice.
- Comply with patient data privacy and security laws.
- Real-time mapping of outcomes against a variety of clinician-selected treatment factors.
- Generate statistically and clinically significant correlations.
- Allow easy collaboration within peers within and across institutional and national boundaries.

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