HRSA Ryan White HIV/AIDS Program
CENTER FOR QUALITY IMPROVEMENT & INNOVATION

'Valuing the Voices of Patients' - A Literature Review of Patient Reported Outcomes and Experience Measures

By Zainab C. Khan
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Patient Reported Outcome Measures (PROMs)

Patient Reported Outcome Measures (PROMs) are commonly defined as the measurement instruments utilized to assess patient reported outcomes (PROs), which are usually standardized, validated questionnaires that are completed by patients to ascertain perceptions of their "functional status, health-related quality of life, symptom and symptom burden, personal experience of care, and health related behaviors, such as anxiety and depression" (Kingsley, Patel, 2017) (Hodson et al., 2013). Other areas of focus include the patient's social wellbeing, cognitive functions, and role activities. Not only can the outcomes related to the patient's health, quality of life, and a patient's functional status be measured in absolute terms, but also allow for a more holistic "comprehensive assessment of the benefits and of the treatment under investigation" (Hodson et al., 2013). Popular PROM tools include patient-completed questionnaires, which patients use to score their perceived status against a statement with a pre-determined scale (Kingsley, Patel, 2017). PROMs are directly reported by the patients to gain their individualized insights rather than reported by a member of the health care team. While the importance of considering patient reported markers have been recognized, the health care field lags in routinely and fully assessing the impact of health care on individual patients using their perspectives and voices (Hodson et al., 2013).

Patient Reported Experience Measures (PREMs)

Patient Reported Experience Measures (PREMs) are defined as a "measure of a patient's perception of their personal experience of the health care they have received" (Hodson et al., 2013). PREMs focus and prioritize the aspects of care that matter most to the patient, facilitating a focus on patient-centered approach. PREM results are commonly used to improve services and provide a perspective "that moves away from the technological or economic model that is often employed in service design" (Hodson et al., 2013). Increasingly, patient experiences with health care have become multifaceted since the "disease-specific healthcare experience of a patient may involve different facets of care that reflect different aspects of a patient pathway or journey, for example, a hospitalization for

a severe exacerbation compared with a routine review in primary care" (Hodson et al., 2013). According to Hudson, PREMs have the potential to dramatically affect the interactions with the health care team by "altering the focus from what the clinician wishes to communicate to an interaction based upon what is important to the patient. In this context, a disease specific PREM is essential" (Hodson et al., 2013). While disease-specific PROMs exist and are tried and true, disease-specific PREMs are not widely available or utilized to gauge the quality of the patient's interactions with health care, which leads a larger emphasis being placed on generic measures in order to compensate. It is important to note that satisfaction is one component of PREMs and may not address the full spectrum of patient experiences.

In summary, PROMs measure the patients' views of their health status while PREMS measure the patients' perceptions of their experience receiving care (Kingsley, Patel, 2017). Other commonly used terms include ePROM (electronic patient reported outcome measure), and ePREM (electronic patient reported experience measure).

PROMs/PREMs Frameworks

Barriers to fully implement PROMs and PREMs in routine care exist and lead to a need for specific and tailored implementation strategies (Stover et al., 2020). A variety of implementation science frameworks exist to effectively integrate PROMs or PREMs implementation strategies. The following widely used implementation science frameworks and theories related to PROMs and PREMs include: Consolidated Framework for Implementation Research (CFIR), Theoretical Domains Framework (TDF), Integrated framework for Promoting Action on Research Implementation in Health Services (i-PARIHS), and Knowledge to Action (KTA), Normalization Process Theory (NPT) (Stover et al., 2020).

Implementation framework or theory	**Nilsen classification**	**Constructs influencing implementation**	**Case studies**
Implementation framework or theory Consolidated Framework for Implementation Research (CFIR) www.cfirquide.org	Nilsen classification Determinant framework: categorizes implementation barriers/enablers	Constructs influencing implementation Characteristics of intervention or practice (e.g., evidence, complexity, cost) Outer setting (e.g., patient needs, policies) Inner setting (e.g., organization/clinic	Case stud(ies) Ahmed et al.: implementing ePROMs in a pain network van Oers et al.: implementing ePROMs in multiple pediatric and adult health clinics Manalili and Santana: implementing ePREMs

		characteristics, culture, implementation climate) Characteristics of individuals (e.g., clinician knowledge, self-efficacy) Implementation process (e.g., engaging, evaluating)	for quality improvement in primary care
Theoretical Domains Framework (TDF)	Determinant framework: categorizes implementation barriers/enablers	Factors Influencing Clinician Behavior Change, e.g.: Knowledge, skills Professional role/identity Beliefs about capabilities Beliefs about consequences Reinforcement Intentions/goals Environmental context and resources Social influence Memory, attention, decision influences Behavioral regulation	Ahmed et al.: implementing ePROMs in a chronic pain network
Integrated framework for Promoting Action on Research Implementation in Health Services (i-PARIHS)	Determinant framework: categorizes implementation barriers/enablers	Successful implementation formula = Roberts et al. 1311: implementing paper and Fac?(I + R + Q electronic PROMs in a medical oncology Fac = facilitation outpatient department Person or organization assigned to do work of facilitation (implementation support) I = innovation Characteristics of innovation Degree of fit with existing practice and values Usability Relative advantage Trialability/observable results R = recipients Clinical experiences/perceptions Patient experiences, needs, preferences C = context Leadership support Culture, receptivity to change Evaluation capabilities	Roberts et al.: implementing paper and electronic PROMs in a medical oncology outpatient department
Knowledge to Action (KTA) Kt.canada.org	Process model: describes practical steps in translating	Knowledge creation phases: Knowledge inquiry Knowledge synthesis Create knowledge tools	Manalili and Santana: implementing ePREMs for quality improvement in primary care

	research to practice	Action phases: Determine the know/do gap Adapt knowledge to local context Assess barriers/facilitators to use Select, tailor, implement Monitor knowledge use Evaluate outcomes Sustain knowledge use	
Normalization Process Theory (NPT) normalizationprocess.com	Implementation theory: specifies causal mechanisms	Coherence/sense-making (what is the work?) Cognitive participation (who does the work?) Collective action (how do people work together to get the work done?) Reflexive monitoring (how are the effects of the work understood?)	Manalili and Santana: implementing ePREMs for quality improvement in primary care

PROMs and PREMs in HIV Care

The benefits of implementing PROMs and PREMs in HIV care and its demonstrated need are undeniable. PROM questionnaires for people with HIV include the assessment of the patient's outcomes related to physical problems, cognitive and psychological problems, social issues, welfare issues, and information needs (Hughson, 2020). Pain is also an essential area, especially around gastro-intestinal issues. Finance, immigration status, and stigma associated with race/ethnicity were also emphasized as well as areas around aging, long-term outcomes, co-morbidities, and treatment decisions.

PROMs implementation in HIV care is essential because it can improve patient-clinician communication, symptom recognition, treatment adherence, and clinical decision-making. People with HIV have long reported that the focus on viral suppression and adherence to treatment is already well reflected within clinical consultations, but there exists a lack of attention and opportunity to discuss needs beyond antiretroviral therapy-related concerns. Not only does the incorporation of PROMs improve outcomes on an individual level, but it can also ensure that services are delivered equitably and with a high quality of care that matches the needs of various populations (Bristowe et al., 2019). The results can drive service quality improvement in clinical settings and provide support

to patient assessment and care coordination. Care that is centralized to what matters to the individual and is respectful and responsive to their needs has the aptitude to improve care experiences and health outcomes.

To assess PREMs in an HIV clinical setting allows the patient to better express their needs and by addressing those needs the potential exists that the communication between the patient and the heath care team improves (Hughson, 2020). In a cross-national multicenter study by Bristowe, semi-structured qualitative interviews were conducted with adult people with HIV, HIV health care professionals, and government representatives. Some of the perceived benefits of utilizing PREMs in routine HIV care included "improved patient-centeredness, patient empowerment, fewer missed concerns, increased engagement with services, and informed planning of services" (Bristowe et al., 2019). Perceived potential challenges were the heterogeneity of people with HIV, literacy, and utility for individuals struggling to engage in care and stay retained in care.

Priorities, Problems, and Concerns for HIV Patients Highlighted in PROMs Domains of Need (Bristowe et al., 2019)

Physical problems and concerns	Pain and discomfort (headache, neuropathy, pins and needles, joint pain) GI symptoms (bloating, constipation, diarrhea, lack of appetite, nausea, vomiting, reflux, dry mouth) Body and/or weight changes Fatigue Frailty and mobility Skin reactions (sweating) Other (warts or herpes, and eye problems from early HIV treatments) Problems taking ART
Cognitive problems and concerns	Dizziness Memory problems Sleep disturbance Difficulty concentrating

Psychological wellbeing	Negative experiences (anxiety, worry or fear, depression or low mood, stigma and discrimination, concerns around disclosure, shame, self-stigma, guilt, anger, unresolved issues relating to diagnosis or means of contracting HIV, body image, lack of confidence, low self-esteem) Positive experiences (self-esteem, self-worth, confidence, acceptance regarding diagnosis, happiness, meaningfulness, motivation, resilience, and coping)
Welfare, lifestyle and safety problems and concerns	Welfare (financial, housing, immigration, safety at home and in relationships) Self-care (diet and lifestyle, recreational drug use, alcohol consumption, smoking)
Social wellbeing - ability to live their life as they would like to	Relationship status (sex, intimacy, initiating new relationships and concerns about having a child) Social support (family, friends and community, support groups, organizations, faith groups) Isolation or marginalization Independence Impact of HIV on social wellbeing (socializing, employment, education, travel)
Information needs	Knowledge that HIV is under control Knowledge about the future, prognosis and aging with HIV Knowledge about HIV and treatments

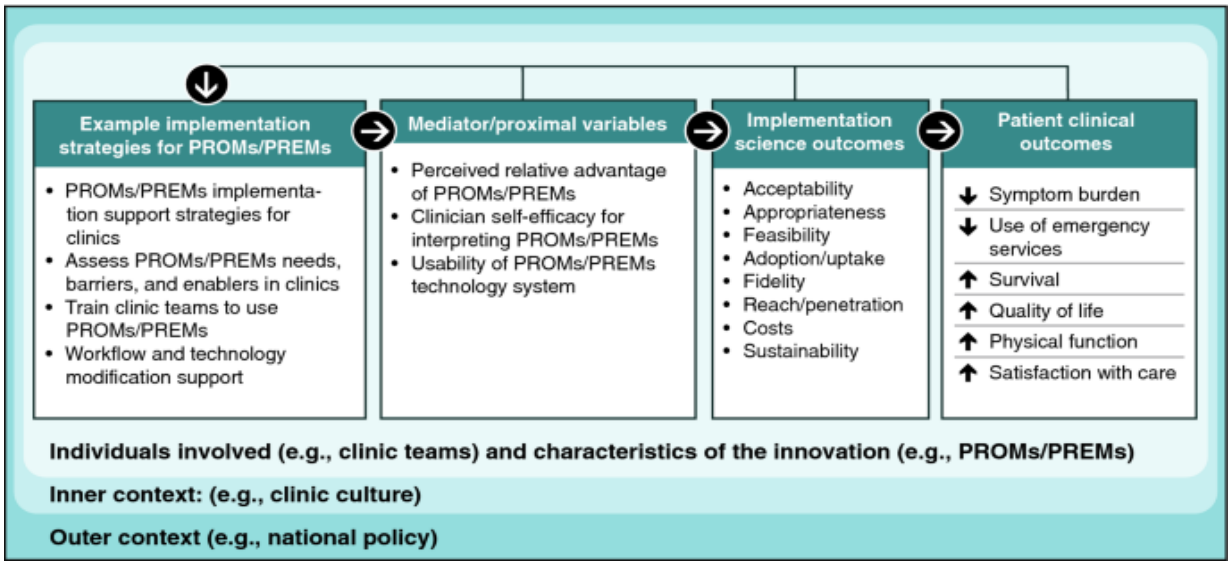
PROMs and PREMs in Implementation Science

In Stover's publication on using an implementation science approach to implement and evaluate PROMs initiatives in routine care settings, three PROMs case studies were shared: pain clinic in Canada, oncology clinics in Australia, and pediatric/adult clinics for chronic conditions in the Netherlands. Another case study by Stover uses PREMs implementation in Canadian primary care

clinics (Stover et al., 2020). In these cases, PROMs were utilized to monitor symptoms, psychosocial functioning, and health-related quality of life.

From these case studies, PROMs and PREMs were not integrated in the electronic health record systems and repeatedly identified as a key barrier (Stover et al., 2020). Some other common barriers were technology barriers with PROMs collection systems that were difficult to use, access, and separate login required from third-party systems. Also, stakeholder knowledge and perceptions were consistent barriers due to clinicians struggling to interpret PROMs responses and fostering discussions surrounding their responses with their patients.

Enablers across the four case studies varied greatly compared to the barriers and included "designing PROM/PREM technology systems to be easy for clinicians to use and enabling automatic access to PROM results for use at point-of-care. More unique enablers capitalized on local resources, such as peer champions, availability of a nurse scientist to provide long-term implementation support in an oncology clinic, and a research team working with a health system to create a pain PROM business plan and move resources (including money) to clinics" (Stover et al., 2020).



(Stover et al., 2020)

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