

The Impact of Home Care Nurse Staffing, Work Environment & Collaboration on Patient Outcomes

APPLIED HEALTH RESEARCH QUESTION (AHRQ):

- *How are Patient Reported Outcome Measures implemented?*
- *What Patient Reported Outcome Measures exist for home-based nursing care?*
- *How do Patient Reported Outcome Measures fit with other organizational performance measures?*

Findings:

- ✓ Patient reported outcome measures (PROMs) are standardized, validated self-reported questionnaires or instruments that measure patient perceptions on aspects of their own health at a single point in time without interpretation by a clinician [Canadian Institute for Health Information (CIHI), 2015; Ousey & Cook, 2011]
- ✓ PROMs are not nationally mandated or standardized in Canada, therefore utilization varies across jurisdictions
- ✓ Common constructs measured by PROMs include; a) general health status b) health-related quality of life, c) functional status, d) well-being, e) symptoms and symptom burden, and f) health behaviours (Cella et al., 2015; Meadows, 2011)
- ✓ PROMs have been found to be particularly important in elective surgeries and chronic disease management – where the prevailing goal is enhancing patients' quality of life (CIHI, 2015)
- ✓ When selecting a PROM, it is imperative that clinicians/researchers consider: a) reliability, b) validity, c) interpretability of scores, d) burden, e) alternative modes and methods of administration, f) cultural and language adaptations, and g) electronic health records (Cella et al., 2015)
- ✓ With respect to generic tools, the SF-family of instruments (i.e, a group of instruments measuring patient health from the patient's perspective) and the EQ-5D (i.e.,EuroQual – five dimensions – measures five dimensions of health related quality of life from the patients perspective) have been identified as the most suitable tools for use in Canada (CIHI, 2015)

- ✓ PROMs expand the criteria for how organizations evaluate care by including outcome measures from the patient's perspective to obtain a broader understanding of the impact of care (American Joint Replacement Registry, 2016)

The emerging interest in patient-focused integrated health care delivery systems provides organizations with an opportunity to incorporate new categories of outcome measures that assess the impact of patient care on patient outcomes (Cella et al., 2015). Historically, patient outcomes have focused on clinical measurements (e.g., laboratory values) in response to treatment or intervention effectiveness. Clinical outcome values such as hemoglobin A1C for patients living with diabetes or peak flow rates for patients living with obstructive lung disease fail to capture the patient's perspective and the impact of the disease on his/her quality of life. As such, patient involvement in assessing the process and outcome of care has evolved from simply seeking satisfaction with care, to the integration of patient reported outcome measures (PROMs or PROs) in the evaluation of health care services (Black, 2013; Meadows, 2011).

Broadly defined, PROMs are standardized, validated self-reported questionnaires or instruments that measure patients' perceptions of aspects of their own health at a single point in time without interpretation by a clinician [Canadian Institute for Health Information (CIHI), 2015; Ousey & Cook, 2011]. In contrast to the United Kingdom (UK), Sweden and parts of the United States (US), PROMs are not nationally mandated or standardized in Canada. As such, utilization of PROMs to measure patient outcomes varies across jurisdictions. However, over the next several years, PROMs have the potential to be incorporated into Canadian health system performance measurement (CIHI, 2015). To better understand how PROMs can impact home-based nursing care it is necessary to explore the current literature, discuss criteria for selecting appropriate PROM instruments, highlight challenges as well as organizational structures/processes required for PROM implementation success, and finally examine how PROMs fit with other organizational performance measures.

The search strategy used to answer these AHRQs can be found in [Appendix A](#).

Literature Review

Types of PROMs

It is estimated that more than 700 instruments exist measuring various health-related domains (CIHI, 2015). Common constructs measured by PROMs include but are not limited to; a) general health status, b) health-related quality of life (HRQoL), c) functional status, d) well-being, e) symptoms and symptom burden, and f) health behaviours (Cella et al., 2015; Meadows, 2011). PROMs can be further subdivided into generic

(e.g. self-care or mobility) or condition specific (e.g. diabetes) measures (Black, 2013). Research suggests that condition-specific PROMs are likely to be of greater clinical relevance and are more sensitive in detecting clinically significant changes from treatment interventions when compared to generic measures (Cella et al., 2015; CIHI, 2015; & Meadows, 2011). However, generic PROMs are efficacious when target populations are comprised of generally healthy individuals or those living with multiple chronic conditions (Cella et al., 2015).

Benefits of PROMs

PROMs are considered to be the gold standard outcome measures of patients' subjective experiences (Antunes, Harding, & Higginson, 2013). Despite their absence in routine clinical practice in Canada, PROMs have been used extensively in research, national audits of health care systems, and registries for joint replacement (Dawson et al., 2010; McGrail, Bryan, & Davis, 2012). PROMs have been found to be particularly important in evaluating the outcomes of elective surgeries and chronic disease management programs – where the prevailing goal is to enhance patients' quality of life (CIHI, 2015). For example, in the UK, the Oxford Hip Score (Dawson et al., 1996) is used to help clinicians decide if and when to operate on patients requiring hip replacement (Black, 2013). The extensive use of PROMs in research has highlighted the potential for expanding the use of these measures in clinical practice. In addition to evaluating the outcomes of care, PROMs could be used as screening and diagnostic tools to identify patient preferences, to help patients and clinicians make informed decisions, to monitor treatment responses or the progress of care, to improve the quality of health care service delivery, to improve patient-provider communication, and to track the performance of health care organizations (e.g. benchmarking) (Antunes et al., 2013; Cella et al., 2015; Greenhalgh, 2009; Marshall, Haywood, & Fitzpatrick, 2006; & Nelson et al., 2015). Perhaps most importantly, PROMs have the potential to aid in monitoring patients' health status. In a systematic review of the literature conducted by Greenhalgh and Meadows (1999), PROM utilization improved the detection of psychological and functional problems.

Barriers of PROMs

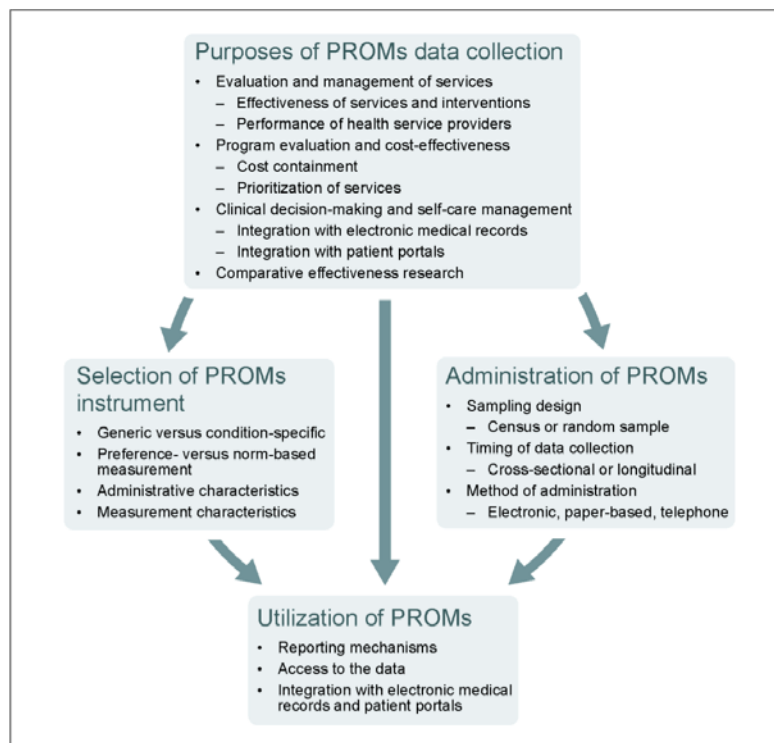
Many barriers exist to the effective utilization of PROM instruments in clinical practice. Barriers include lack of human resources, time, and money needed to collect, analyze, and evaluate the data (Greenhalgh & Meadows, 1999). In addition, there is a lack of consensus among clinicians around which assessments are most relevant and how PROM scores and changes in these scores can be meaningfully interpreted (Antunes et al., 2013; Greenhalgh & Meadows, 1999). To date, limited high-quality evidence exists suggesting that PROMs result in improved health outcomes. In several systematic reviews, a general lack of clarity around the intended application of PROMs in clinical practice has been identified (Devlin et al., 2010; Greenhalgh & Meadows,

1999; Marshall et al., 2006; Valderas et al., 2008). Moreover, Gilbody, House, and Sheldon (2002) demonstrated that HRQoL score feedback failed to make a significant difference to the process or outcomes of patient care. However, researchers do highlight that the methods in which PROMs are implemented in clinical practice may influence their effect on patient health outcomes (Howell & Liu, 2012).

Frameworks for Implementing PROMs Initiatives

A framework of evidence-based practice is essential to the successful implementation of a PROMs initiative (Greenhalgh & Meadows, 1999). In addition to the framework designed by CIHI (2015) which is presented below in Figure 1, many frameworks have emerged within the literature to support PROMs implementation (Antunes et al., 2013; Greenhalgh et al., 2005). The framework developed by CIHI highlights four key areas for consideration when implementing a PROMs initiative including: (1) the purpose of PROMs data collection, (2) PROMs instrument selection, (3) how the PROMs will be administered, and (4) how PROMs data will be utilized. Selection of a PROMs instrument, administration of PROMs, and utilization of PROMs data should be aligned with the purpose of data collection (e.g. establishing effectiveness of a clinical intervention) (CIHI, 2015). In addition, PROMs initiatives should have a plan for data linkage with relevant databases or registries (CIHI, 2015).

Figure 1. Framework to Guide Decisions About PROMs Initiatives



(From “PROMs Background Document” by Canadian Institute for Health Information, 2015, Copyright 2015 by CIHI)

Implementing PROMs

Factors that have been identified as essential to successful PROMs implementation include the following:

- ✓ Clinical leadership is essential to the successful implementation of any PROMs initiative (McGrail et al., 2012; Antunes et al., 2013)
- ✓ *Shared* accountability model (McGrail et al., 2012) with top-down leadership, clearly designated roles and accountabilities, and bottom-up clinician engagement to identifying and solve PROMs implementation challenges (Howell & Liu, 2012)
- ✓ Clear description of how the implementation of a PROMs initiative will lead to expected outcomes (Greenhalgh, 2009)
- ✓ Systematic process and formalized methods to build a core framework for PROMs data collection
- ✓ Implementation strategies that are guided by theory, allowing barriers to be identified and solved more effectively (Greenhalgh & Meadows, 1999)
- ✓ Clear links between PROMs data and clinical guidelines / care pathways (Greenhalgh & Meadows, 1999; Howell & Liu, 2012)
- ✓ Access to technological infrastructure that ensures direct data entry, analysis, and interpretability for clinicians, patients, and provincial performance reporting (Howell & Liu, 2012)
- ✓ Local coordination and patient engagement initiatives aimed at encouraging patients to complete PROMs (Howell & Liu, 2012)
- ✓ Payment incentives for institutions or providers to collect and utilize PROMs to improve care quality (McGrail et al., 2012)

Methods for Selecting and Administering PROMs

Selecting the appropriate PROM is the most critical aspect of implementing a PROMs initiative (Meadows, 2011). To select the most appropriate PROM, the researcher or clinician should have a clear understanding of the disease (e.g., heart failure) or patient population (e.g., home care patients) as well as the outcomes relevant to the disease process (e.g., physical limitations, symptom burden etc.) or patient population (e.g., quality of life) being evaluated (Cella et al. 2015; Meadows, 2011)

In addition, clinicians should consider collaborating with researchers when implementing PROMs initiatives. Together, the following criteria should be considered in order to select the most appropriate PROM tool as outlined by CIHI (2015) and Cella et al. (2015).

Effectiveness:

1. **Instrument Reliability.** Researchers and clinicians should understand how consistently the instrument measures the construct of interest.
 - a) *Internal consistency* is the extent to which all items in an instrument measure the construct of interest. Internal Consistency is usually examined using Cronbach's alpha score. Reliability estimates should be at least 0.7 for group level scores and at least 0.9 for individual level scores.
2. **Instrument Validity.** Researchers and clinicians should understand how effectively the instrument measures what it is supposed to measure in the population of interest (Higgins & Green, 2011).
 - a) *Content Validity* – The extent to which an instrument comprehensively measures what it is suppose to measure in the context of a specific population and setting. Content validity is determined by consulting the literature, representatives of the population under study, and content experts.
 - b) *Construct Validity* – The extent to which relationships between items, domains, and concepts reflect theoretical understanding of the concept of interest and demonstrate that logical relationships exist with patient characteristics and other measures.
 - c) *Criterion-related Validity* - The extent to which PROM scores are related to other measures of the same outcome.
 - d) *Responsiveness* – The ability of the instrument to detect change over time or change in response to an intervention or program.

Meaningfulness:

3. **Interpretability of Scores.** The instrument should support and assist users in the interpretation of scores. For example, providing information related to what high and low scores represent as well as guidance on what are considered meaningful changes in scores over time. This is a critical aspect of PROMs utilization in clinical practice.

In a study conducted by Flynn et al. (2009), researchers identified that a 5-point difference in the Kansas City Cardiomyopathy Questionnaire (KCCQ) and a 3-point difference in the Visual Analog Scale (VAS) were considered to be clinically meaningful when compared to clinical measures for patients living with heart failure.

Appropriateness & Feasibility:

4. **Burden.** Instruments should indicate the time required to complete the questionnaire, effort and other demands of both the participant and administrator. Investigating whether or not a short-form version is available may be particularly helpful for busy clinic or research settings.
5. **Alternative Modes and Methods of Administration.** Information should be available regarding the comparability across multiple methods (e.g. telephone, touchscreen-based, etc.) and modes of administration (e.g. self-administration or interviewer administration). Specific to the home-based environment and the aging population, clinicians should consider instruments that are designed for administration in any health care setting and that take into consideration individuals' cognitive and/or functional limitations. For example, for those with advanced cognitive impairment, proxy respondents (e.g. primary caregivers) should be considered to complement and/or substitute patient responses. Additionally, when completing PROMs in the home setting, clinicians must ensure; a) PROM technology is accessible (e.g. internet), b) a plan is in place to address critical or acute problems identified through PROM responses/scoring (e.g. worsening heart failure symptoms), and c) health information privacy and secure data collection/storage is outlined.
6. **Cultural and Language Adaptations.** Documentation should address methods to mitigate or addresses cultural differences as well as linguistic equivalence.
7. **Electronic Health Records.** The instrument should describe key consideration for incorporation into electronic health records to achieve real-time measurement, reporting, and subsequent analytic capabilities to maximize efficiency and efficacy.

PROMs Instruments

With respect to generic tools, the SF-family of instruments (i.e, a group of instruments measuring patient health from the patient's perspective) and the EQ-5D (i.e.,EuroQual – five dimensions – an instrument that measures five dimensions of health related quality of life from the patients perspective) have been identified as the most suitable tools for

use in Canada (CIHI, 2015). To note, the majority of Canadian projects utilized both generic and condition-specific instruments together, a recommendation suggested by CIHI (2015) and Cella et al. (2015).

A summary of generic PROMs examined by Bryan et al. (2013) and CIHI (2015) can be found in [Appendix B](#). For the purpose of identifying condition-specific PROMs for home care settings, this AHRQ focuses on chronic disease management measures as opposed to PROMs related to elective surgeries. A summary of condition-specific instruments can be found in [Appendix C](#).

How do PROMs Fit with other Organizational Performance Measures?

Howell and Liu (2012) highlight that “payment for quality performance is closer than we think” (p. 46). As such, many organizations in the healthcare sector are increasingly interested in moving towards use of PROMs for clinical accountability and quality improvement applications (Cella et al., 2015). PROMs expand the criteria for how organizations evaluate care by including outcome measures from the patient’s perspectives to obtain a broader understanding of the impact of care (American Joint Replacement Registry, 2016). They serve a complementary role to other organizational quality improvement initiatives such as national accreditation, performance indicators, and benchmarking (e.g. wait times for hip replacement surgery). Therefore, as the health sector and health care organizations strive to incorporate quality measurement, PROMs should be an important consideration in the overall conceptual framework.

Conclusion

Patient reported outcome measures (PROMs) are standardized, validated self-report questionnaires or instruments that measure patient perceptions of their own health at a single point in time without interpretation by a clinician (CIHI, 2015; Ousey & Cook, 2011). Despite Canada’s lack of a national mandate to incorporate PROMs, a great deal of research is being conducted on the utilization of PROMs in clinical practice. This document summarizes the types of PROMs (generic or disease-specific), the benefits and barriers to PROMs utilization, frameworks for incorporating PROMs, and key considerations for PROM selection including a) reliability, b) validity, c) interpretability of scores, d) burden, e) alternative modes and methods of administration, f) cultural and language adaptations, and g) electronic health records (Cella et al., 2015). Finally, healthcare organizations are encouraged to incorporate PROMs into existing measures of organizational performance for clinical accountability and quality improvement applications.

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Appendix A

Search Strategy

To identify relevant literature pertaining to the research question, CINAHL and MEDLINE databases were utilized. Search terms included *patient reported outcome measures*, OR *patient-reported outcomes* OR *PROMs*, OR *PROs*. The search was limited to English language articles published from 2000 onwards. Articles were included if a) health care outcomes were examined in relation to PROM utilization, b) they examined PROMs utilization, implementation or evaluation, c) reflected the needs of home care organizations and/or populations. Titles were reviewed for relevance and articles were excluded based on inclusion criteria. Subsequently, grey literature was searched including the Canadian Institute for Health Information (CIHI). Reference lists of the selected articles were hand-searched and additional relevant articles were included for full review. A total of 42 articles were synthesized for this report.

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Appendix B

Generic PROM Instruments

Generic Instruments				
	<i>Domains</i>	<i>Validity/Reliability</i>	<i>Effectiveness/ Appropriateness</i>	<i>Canadian Projects</i>
SF-36/SF-12 (Ware & Sherbourne, 1992; Ware, Kosinski, & Keller, 1996).	Vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, mental health	+++	-SF-36- 10 minutes to complete -SF-12- 2 minutes to complete -Grade 7 reading level required -Multiple translations: +++ -Modes of Administration: paper based, telephone, online, interactive voice response (IVR) -Methods of Administration: self, interviewer -Track record of widespread implementation: +++	-Alberta province-wide use of PROMs -Alberta Hip/ Knee Replacement -Winnipeg Hip /Knee Replacement -National Spinal Cord Injury Registry -Canadian Multicentre Osteoporosis Study
Health Utility Index 3 (HUI3) <i>Feeny et al., 2002</i>	Sensation, mobility, emotion, cognition, self-care, pain	+/-	-8-10 minutes to complete -Grade 7 reading level required -Multiple translations: ++ -Modes of Administration: paper based, telephone -Track record of widespread implementation: ++	-Alberta Heart & Lung Transplant -Statistics Canada (Canadian Community Health Survey)
EuroQoL-5D (EQ-5D) <i>Dolan, 1997</i>	Mobility, usual activities, self-care, pain, anxiety/ depression	+/-	-2 minutes to complete -Grade 11 reading level required -Multiple translations: +++ -Modes of Administration: paper based, telephone, online, IVR -Methods of Administration: self, interviewer -Track record of widespread implementation: +++	-Alberta's Caring for Diabetes Project -British Columbia elective surgery (VALHUE project) -British Columbia knee arthroplasty (PEAK project) -Ontario Cancer Care Ontario (Symptoms and Toxicity)
PROMIS Global Health Instrument: National Institute of Health (NIH) <i>(Reeve et al., 2007)</i>	Anxiety, anger, depression, fatigue, pain behavior, pain interference, satisfaction with social activities and roles	++	-2 minutes to complete -Grade 7 reading level required -Multiple translations: + -Modes of Administration: paper based, telephone, online -Methods of Administration: self -Track record of widespread implementation: +	<p style="text-align: right;"><i>Legend:</i> +++ strong evidence ++ moderate evidence + limited evidence +/- conflicting evidence</p>

Appendix C

Condition-Specific PROM Instruments

Condition-Specific Instruments				
	Domains	Validity/ Reliability	Effectiveness/ Appropriateness	Projects
Diabetes (<i>El Achhab et al., 2008</i>)				
Audit of Diabetes-Dependent Quality of Life (ADDQoL) (<i>Bradley et al., 1999</i>)	Impact of diabetes (future, travel, employment, sex life, social life, etc.)	$\alpha = 0.84 - 0.90$	-19-items -More than 20 translations -Validated in NIDDM and IDDM populations	-Clinic and community-based education settings
Diabetes 39 (D-39) (<i>Boyer & Earp, 1997</i>)	Energy and mobility, diabetes control, anxiety and worry, social/peer burden, sexual functioning	$\alpha = 0.81 - 0.93$	-39-items -More than 2 translations -Validated in NIDDM and IDDM populations	-Adult outpatient clinics and community settings
Heart Failure (<i>Garin et al., 2009; Thompson et al., 2015</i>)				
Kansas City Cardiomyopathy Questionnaire (KCCQ) (<i>Green et al., 2000</i>)	Physical limitation, symptoms, quality of life, social limitation, self-efficacy, KCCQ functional status, KCCQ clinical summary	$\alpha = 0.62 - 0.91$	-23-items -Self-administered -MID- 4-5 points	-Has been validated as primary/secondary outcome in many clinical trials
Minnesota Living with Heart Failure Questionnaire (MLHF-Q) (<i>Rector, Francis & Cohn, 1987</i>)	Physical, emotional	$\alpha = 0.91 - 0.95$	-21-items -Self-administered	-Has been validated as a primary outcome in many clinical trials

Condition-Specific Instruments				
	Domains	Validity/ Reliability	Appropriateness/ Effectiveness	Projects
Chronic Obstructive Pulmonary Disease (COPD) (<i>Weldam et al., 2013</i>)				
St. George's Respiratory Questionnaire (SGRQ) (<i>Jones, Quirk, & Baveystock, 1991</i>)	Symptoms, activity, impact	Validity +++ Reliability +++	-10 minutes to complete -76-items -MID – 4%	-Toronto and Hamilton Pulmonary Rehabilitation Program (Puhan et al., 2004) -Ottawa Hospital Emergency Department (Aaron et al., 2002)
Chronic Respiratory Disease Questionnaire (CRQ) (<i>Gyatt et al., 1987</i>)	Dyspnea, fatigue, emotional function, mastery	Validity +++ Reliability ++	-10 minutes to complete -20-items -MID – 0.5 -Methods of Administration: self, interviewer -Widespread utilization	-Canadian Thoracic Society Clinical Practice Guidelines -Toronto and Hamilton Pulmonary Rehabilitation Program (Puhan et al., 2004)
Arthritis (<i>Thorborg et al., 2010</i>)				
Western Ontario and McMaster Universities Arthritis Index (WOMAC) (<i>Bellamy, 1982</i>)	Pain, stiffness, physical function, total index score	$\alpha = 0.86 - 0.98$	-24-items -12 minutes to complete -Administration modes: telephone, touchscreen based platforms -Available in over 65 languages	-Most widely used instrument in arthritis research -Over 1500 studies examining changes following treatments including pharmacotherapy, arthroplasty, exercise, physical therapy and acupuncture
Hip Disability and Osteoarthritis Outcome Score (HOOS 2.0) (<i>Nilsdotter et al., 2003</i>)	Pain, symptoms, ADL, sport/ recreation, quality of life	Not reported	-10 minutes to complete -40-items -18 different languages -Self-administered	-Used in several studies in patients with or without hip replacement -Adaptation of the WOMAC