



**NATIONAL  
QUALITY FORUM**

Driving measurable health  
improvements together

# **Patient-Reported Outcomes: Approaches and Challenges in Selection and Data Collection— An Environmental Scan**

**FINAL REPORT**

**DECEMBER 18, 2019**

This report is funded by the Department of Health and Human Services under contract HHSM-500-2017-00060I, Task Order 75FCMC19F0003.

# CONTENTS

---

<b>EXECUTIVE SUMMARY</b>	<b>2</b>
<b>BACKGROUND AND CONTEXT</b>	<b>2</b>
<b>GOALS, OBJECTIVES, AND APPROACH FOR THE ENVIRONMENTAL SCAN</b>	<b>4</b>
<b>SCAN RESULTS AND ANALYSIS</b>	<b>5</b>
<b>NEXT STEPS</b>	<b>14</b>
<b>APPENDIX A: Technical Expert Panel Members and NQF Staff</b>	<b>16</b>
<b>APPENDIX B: Environmental Scan Methodology</b>	<b>18</b>
<b>APPENDIX C: PROMs Relevant to Burns, Trauma, Joint Replacement, and Heart Failure</b>	<b>20</b>
<b>APPENDIX D: PRO-PMs Relevant for Burns, Trauma, Joint Replacement, and Heart Failure</b>	<b>39</b>

## EXECUTIVE SUMMARY

Although patient-reported outcomes (PROs) are increasingly used for various healthcare-related activities, their use has many inherent challenges.

In the summer of 2019, HHS contracted with the National Quality Forum (NQF) to convene a multistakeholder **Technical Expert Panel** (TEP) to identify best practices to address challenges in selecting and collecting patient-reported outcome (PRO) data. The TEP will make recommendations to (a) address challenges in PRO selection and data collection, (b) ensure PRO data quality, and (c) apply the recommendations on PRO selection and implementation to use cases related to burns/trauma, heart failure, and joint replacement. Application of the recommendations to the selected use cases will allow the TEP to pilot test

them for both acute and chronic conditions that often necessitate provision of care across settings and providers.

This report describes the methodology and findings from an environmental scan NQF conducted to identify the approaches and challenges in selecting both PROs and PROMs, as well as the challenges in collecting PRO data. The report also describes PROMs that NQF has identified as relevant for burns/trauma, heart failure, and joint replacement. These PROMs will be considered as the TEP applies its best practice recommendations to the above use cases.

## BACKGROUND AND CONTEXT

Patient-reported outcomes (PROs) are increasingly used for various healthcare-related activities including care provision, performance measurement, and clinical, health services, and comparative effectiveness research.<sup>1,2</sup> They may be particularly valuable in improving the quality of care that is provided to patients and families, because PROs allow those actually receiving care to provide information on issues of import to them (e.g., symptoms, functional status, side effects, engagement in decision making, goals of care, etc.).<sup>3,4,5,6,7,8</sup>

In 2012, the Department of Health and Human Services (HHS) provided funding to the

National Quality Forum (NQF) to convene a multistakeholder Expert Panel to lay the groundwork for future PRO-PM development, testing, endorsement, and implementation. As part of this work, the Panel defined and differentiated patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient-reported outcome-based performance measures (PRO-PMs), as shown in Table 1. The Panel also provided guidance for selecting PROMs for use in performance measurement and articulated a pathway to move from PROs to NQF-endorsed PRO-PMs.

TABLE 1. DISTINCTIONS AMONG PROS, PROMS, AND PRO-PMS

Concept	Definition	Example
<b>PRO</b> (patient-reported outcome)	Any report of the status of a patient’s (or person’s) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else. <sup>9</sup>	Symptom: depression
<b>PROM</b> (patient-reported outcome measure)	Various tools (e.g., instruments, scales, single-item measures) used to assess the PRO concept as perceived by the patient, obtained by directly asking the patient to self-report	PHQ-9 <sup>®</sup> , a standardized tool to assess depression
<b>PRO-PM</b> (PRO-based performance measure)	A performance measure that is based on PROM data aggregated for an accountable healthcare entity	Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF 0711)

As noted in the 2013 final report<sup>10</sup> for that project, the word “patient” includes all persons, including patients, families, caregivers, and consumers more broadly, and is intended to cover all persons receiving support services, such as individuals with disabilities. As noted in a previous report of the Measure Applications Partnership,<sup>11</sup> a single term cannot apply to all individuals in all situations, and individuals may self-identify as a person, client, or patient at a single point in time.

In addition, the 2013 report identifies the following four key domains of patient-reported health information:

- Health-related quality of life (including functional status);
- Symptoms and symptom burden (e.g., pain, fatigue);
- Experience with care; and
- Health behaviors (e.g., smoking, diet, exercise).

These domains reflect the major categories of outcomes for which individuals receiving healthcare and support services may be the best

or only source of information. Although patient reports of experience with care and health behaviors typically are not classified as patient-reported outcomes, many of the challenges associated with the selection and implementation of PRO data described in this environmental scan report apply across all four of these domains.

The desire to use PROs in healthcare accompanies recognition of many challenges inherent in their use. For example, healthcare providers may be interested in using PRO data to guide the provision of care. Yet, there is currently a lack of standardization in how PRO data are used to drive improvements in care. For example, healthcare providers and others may need guidance in how to select PROs and PROMs for monitoring and managing patient care or conducting other downstream activities such as performance measurement. Challenges pertaining to the implementation of PROMs center on achieving buy-in from various stakeholders given the realities of the data collection burden (e.g., workflow concerns of clinicians and their staff; time and privacy issues for patients, if/how to

incorporate data into EHRs, etc.) and ensuring that the data are of high quality and the results are interpretable and actionable. However, the collection of high-quality PRO data depends, in part, on the source of data (e.g., self-report vs. proxy), the mode of PROM administration (e.g., self- vs. interviewer-administered), and the method of PROM administration (e.g., paper and pencil, telephone-assisted, electronic capture via tablets, etc.).<sup>2</sup> Other considerations influence the quality of PRO data as well, such as patient motivation in providing data, confounding due to medical or social factors of the patient, the extent of missing data, and overall response rates.

In the summer of 2019, HHS contracted with the National Quality Forum (NQF) to convene a multistakeholder **Technical Expert Panel** (TEP) to identify recommendations to address challenges in selecting and collecting PRO data. More specifically, the TEP will make recommendations to (a) address challenges in PRO selection and data collection, (b) ensure PRO data quality, and (c) apply the recommendations on PRO selection and implementation to use cases related to burns/trauma, heart failure, and joint replacement.

Application of the recommendations to the selected use cases will allow the TEP to pilot test them for both acute and chronic conditions that often necessitate provision of care across settings and providers.

To provide background for the TEP's deliberations, NQF conducted an environmental scan to identify literature relevant to the work. The scan also identified instruments (i.e., PROMs) used to gather PRO data for the aforementioned conditions. While not a focus of this work, NQF also identified PRO-PMs relevant to these use case conditions to serve as reference, if needed. Although the scan was intended to inform the TEP's deliberations, the TEP itself provided substantial input on the scan, including feedback on initial findings, provision of relevant literature, websites, and PROMs, and identification of additional challenges. This report describes both the scan methodology as well as the findings from the scan. A draft of the report was released for public comment in October 2019. NQF modified the report in response to the comments received, as well as in response to suggestions from the TEP.

## GOALS, OBJECTIVES, AND APPROACH FOR THE ENVIRONMENTAL SCAN

The environmental scan had an overarching goal to identify current practices in selecting PROs and collecting PRO data and to identify PROMs and PRO-PMs relevant to use cases considered in the project.

The objectives of the scan were to:

- Identify current approaches to PRO/PROM selection and implementation
- Identify challenges associated with the selection and implementation of PROs

- Document how the various approaches to selection and implementation affect the quality of PRO data
- Identify PROs and PROMs relevant to burns/trauma, heart failure, and joint replacement
- Identify performance measures and measure concepts relevant to burns/trauma, heart failure, and joint replacement

To characterize approaches and challenges associated with selecting and implementing PROs and PROMs, NQF staff consulted both peer-reviewed and grey literature. NQF staff identified

peer-reviewed literature via systematic queries of PubMed and Google Scholar, as well as a university library database. NQF identified grey literature and other published literature through internet searches of relevant organizations, including the Patient-Centered Outcomes Research Institute (PCORI), the International Society for Quality of Life Research (ISOQOL), and the U.S. Food and Drug Administration (FDA). NQF identified additional resources via backwards reference searching of pertinent articles or reports. In addition, TEP members identified additional articles, reports, and websites for review.

To identify relevant PROMs and PRO-PMs, NQF staff used measure inventories including the Patient-Reported Outcomes Measurement Information System (PROMIS), the International Consortium for Health Outcomes Measurement (ICHOM), PsycTESTS, NQF's Quality Positioning

System (NQF's repository of endorsed measures), and CMS's Measures Inventory Tool. NQF augmented these results using feedback from the TEP. Additional detail regarding the conduct of the scan is included in [Appendix B](#).

The body of literature relevant to PRO and PROM selection and to PROM implementation is vast, and a full review and synthesis of available literature is beyond the scope of this current project. Therefore, to the extent possible, for this scan, NQF staff focused primarily on articles and reports that have summarized information relevant to the work of the TEP, including the 2015 *PROs in Performance Measurement*<sup>2</sup> report by Cella and colleagues. Interested readers should consult these sources for primary references from the broader literature, as well as for more detailed discussions of the findings presented below.

## SCAN RESULTS AND ANALYSIS

This portion of the environmental scan report is divided into three sections. The first section catalogues the various approaches and challenges of PRO/PROM selection and PROM implementation that were identified in the scan, as well as associated effects of these approaches/challenges on the quality of PRO data. The second section summarizes the PROMs identified through the scan that pertain to the use cases of interest for the project (i.e., burns/trauma, heart failure, joint replacement). The third section summarizes the PRO-PMs identified through the scan that pertain to burns/trauma, heart failure, and joint replacement.

### Approaches and Challenges in PRO/PROM Selection and Implementation

As noted above, the objectives of this scan were to identify current approaches to, and

challenges with PRO/PROM selection and PROM implementation, as well as to document ways in which the various approaches to selection and implementation affect the quality of PRO data. Although discussed separately below, the approaches and challenges of PRO and PROM selection are related. Similarly, there is considerable overlap in approaches and challenges of PROM selection versus implementation.

---

#### Approaches to PRO Selection

---

As indicated in the above definitions, PROs reflect the concepts (e.g., fatigue) that are reported on by patients, whereas PROMs are the instruments used to elicit information from patients about those concepts. Importantly, the TEP agreed that the selection of PROs for various use cases is distinct from the selection of PROMs. Therefore, the findings regarding approaches and challenges related to the selection of PROs are presented

separately from those related to the selection of PROMs.

While some literature identified in the scan specifically addresses approaches to the selection of PROs, the majority focuses more on the selection of PROMs. Nevertheless, the following approaches for selecting PROs were identified:

- **Asking patients what outcomes are most important to them**

The PCORI Methodology Standards<sup>12</sup> specifically recommend inviting input from “the population of interest,” which includes those affected by the condition of interest as well as, if appropriate, their surrogates and/or caregivers. This approach, which is also included in FDA guidance<sup>9</sup> regarding PROs, is included in the concept of “meaningfulness” that is a guiding principle for the selection of PROMs (see below).

- **Expert opinion of clinicians or other researchers**

PROs may be selected, or at least heavily influenced, by expert clinicians or researchers. While eliciting patient input is becoming more common, Tractenberg and colleagues<sup>13</sup> assert that expert opinion is often the “starting point” in the selection process (e.g., through position papers or consensus guidelines, or through preparation of interview or focus group materials that are used when inviting patient input). These authors have shown that conceptualizations or definitions of PROs differ when input is obtained from patients prior to obtaining information from clinicians or other stakeholders, rather than the reverse.

- **Goals for collecting PRO data**

Selection of PROs based on the goals of use is particularly relevant for selecting PROs in clinical practice. Examples of clinical goals of use include screening (typically a one-time PRO assessment), monitoring progress over time (which requires multiple PRO assessments), or aggregating patient-level data for the purposes of quality improvement or accountability.

---

## Challenges in PRO Selection

Conflicts in perceived importance by patients (or their caregivers) as compared to clinicians remain the key challenge in PRO selection. Studies have shown that outcomes considered most important by patients may not match those considered most important by clinicians who are managing their care. For example, clinicians may want to focus on PROs that guide or inform medical treatment, while patients may be interested in clinician input on outcomes that are less proximal to treatment decisions (e.g., quality-of-life issues). Similarly, a surgeon may be interested in screening for clinical depression because it can be a predictor of surgical outcomes. However, patients may not be aware of this relationship, and therefore may not believe that results of a depression screening to be useful information for their surgeon. A related issue, verbalized by the TEP, is the lack of PROMs that focus on PROs considered most important by patients.

---

## Approaches to PROM Selection

As part of the aforementioned foundational work on PROs conducted by NQF, the 2012 Panel conceptualized five guiding principles for selecting PROMs in the context of performance measurement. They also are applicable to other uses of PROs, including monitoring and managing patient care. These principles, which are discussed in more detail below, include:

- Psychometric soundness
- Person-centeredness
- Meaningfulness
- Amenability to change
- Implementability

### Psychometric Soundness

This principle of psychometric soundness incorporates eight long-held consensus-based criteria for selecting PROMs, as follows:

- The conceptual model and the measurement model. The conceptual model lays out the concept(s) included in the PROM and the target population; the measurement model explains how the concept(s) relate to each other and the items in the instrument.
- Reliability, including estimates of internal consistency for multi-item scales and estimates of stability over time.
- Validity, including demonstration of content validity, construct and/or criterion validity, and responsiveness (i.e., ability to detect change over time or in response to an intervention)
- How scores are interpreted, including how to interpret high and low scores, the mean and standard deviation of scores in the reference population, and information on minimally important differences in scores between groups or across time that are meaningful both to clinicians and to patients.
- Burden, including time and effort to fill out the PROM for respondents and those implementing the PROM.
- Information regarding the burden associated with, and comparability of, alternative modes and methods of administration.
- Information regarding how to evaluate equivalence in scores when fielded to respondents with different cultures and languages.
- Key considerations regarding how the PROM can be integrated into electronic health records (EHRs).

These criteria derive from the work of entities such as the FDA, the Medical Outcomes Trust, the consensus-based standards for the selection of health measurement instruments (COSMIN), the International Society of Quality of Life (ISOQOL), and the PROMIS network, among others. Each of the above criteria reflects characteristics of PROMs that should be considered when selecting PROMs

for use in research, quality improvement, and healthcare performance measurement. Adequate documentation should be available to explain the extent to which a particular PROM meets each criterion. When selecting PROMs, users should compare and contrast the performance of candidate PROMs across these eight criteria. Note that when articulating the guiding principle of scientific soundness, the 2012 NQF Panel emphasized the critical nature of the criteria regarding reliability and validity. Recently, Francis and colleagues (2016)<sup>14</sup> have proposed use of a checklist that includes many of the above criteria, as a way to identify strengths and weaknesses of potential PROMs. However, these researchers acknowledge that the relative importance of the items included on the checklist may vary substantially, depending on how the PROM will be used.

#### Person-Centeredness

An overarching theme of the Panel discussions, the guiding principle of person-centeredness reflects the extent to which a PROM can help facilitate the co-creation of a person-centered health system by patients, their healthcare providers, and other entities. Aspects of this principle include the ability to foster shared decision making (with the caveat that not all patients want to engage in shared decision making) and assessment of decision quality. A key point is that person-centeredness vis-à-vis PROM implementation entails the bi-directional flow of information, such that patients as well as clinicians can benefit from the PRO data.

#### Meaningfulness

The guiding principle of meaningfulness reflects the relevance and importance of particular PROs, as perceived by patients, families, and caregivers, as well as by clinicians. The 2012 NQF Panel articulated three aspects of meaningfulness:

- Conceptual meaningfulness. This can be demonstrated by asking patients, families, caregivers, etc., what matters most to them.

- Contextual meaningfulness. This aspect reflects how patients and clinicians use the information derived from a PROM.
- Consequential meaningfulness. Relevant to PRO-PMs, and how information from a PRO-PM is used in quality improvement or accountability applications such as public reporting or payment programs.

### Amenability to Change

This guiding principle reflects the desire for the outcome(s) measured by the PROM to be responsive to healthcare interventions. It includes the idea that healthcare professionals should be able to influence the PRO(s) included in selected PROMs (i.e., the PROM results should be actionable). Notably, not all of the 2012 expert panelists agreed with this selection principle for PROs that are being considered for purposes of accountability or performance measurement. They suggested that some PROs may be particularly important to patients, or otherwise worthy of measurement, even if a clinician cannot directly influence the PRO (e.g., by exposing variations in care that could be ameliorated through other types of interventions).

### Implementability

This guiding principle highlights the need, when selecting PROMs, to consider the myriad practical factors and potential barriers that can hinder implementation, particularly those related to collecting data and reporting results. While the 2012 NQF Panel discussed many implementation challenges, the following issues were specifically called out in the report:

- Addressing respondent literacy (primarily language literacy, which is needed to read and understand items on a PROM) and health literacy (the ability to obtain, process, and understand health information needed to make appropriate health decisions);
- Addressing cultural competency of clinicians and other service providers;

- Dealing with patient selection bias (e.g., lack of participation due to lack of a telephone) and the resultant unintended consequences;
- Covering the costs incurred when using PROMs (e.g., initial cost and maintenance of data collection hardware such as tablets, licensing fees for the PROM and the software used to administer them, etc.); and
- Adapting PROMs to computer-based platforms or other formats.

In their discussions, TEP members for the current work also highlighted PROM length as a critical aspect of implementability. See Tables 2 and 3, below, for methodological options to address these barriers, as well as potential effects of these barriers on PRO data quality.

---

## Approaches to PROM Implementation

---

Various methodological approaches for implementing PROMs have both strengths and weaknesses that can affect the choice of a PROM for a particular use case (depending on whether a particular option is available or feasible). These approaches also can affect the quality of the PRO data that are collected. Table 2, adapted from Cella et al. (2015)<sup>2</sup> and augmented with information from other resources listed in the references, lists several key methodological options, along with selected potential effects on PRO data quality. Each of these options will have other advantages and disadvantages that should also be considered when selecting PROMs, beyond their effects on data quality. For example, a self-administered questionnaire may have more item nonresponse than an interviewer-administered questionnaire; however, self-administration may be less expensive. Moreover, each of these options will generate a variety of additional challenges that must be considered, particularly in their potential effects on data quality. For example, if data are collected outside of a clinic setting, issues related to lack of availability of, or comfort with technology, could bias results.

TABLE 2. METHODOLOGICAL OPTIONS FOR PRO DATA COLLECTION AND EFFECTS ON DATA QUALITY

Methodological options	Potential negative effects on data quality
<b>Self-report versus proxy report</b>	<p>Self-report: validity can be negatively impacted if used with respondents with limited/low literacy or medical/functional/cognitive deficits (e.g., due to overall or item nonresponse, or through misunderstanding of PROM items)</p> <p>Proxy: responses may not adequately reflect those of the patient, although use of proxy responses may be particularly helpful for those with significant disability; use of a proxy can also provide complementary information</p>
<b>Self-administration versus interviewer administration</b>	<p>Self-administered: there is potential for item nonresponse and misunderstanding of questions (which negatively impacts the validity of responses)</p> <p>Interviewer-administered: Potential for response bias (e.g., social desirability, tendency to agree with questions, etc.); however, there is less likelihood of missing data</p>
<b>Paper-and-pencil versus electronic</b>	<p>Paper-and-pencil: potential for data entry errors</p> <p>Electronic: potential for higher overall or item nonresponse due to discomfort with medium, which negatively impacts the validity of responses; minimizes data entry errors</p>
<b>Clinic setting versus home setting versus other settings</b>	<p>Clinic setting: potential for higher overall or item nonresponse due to interruptions, lack of privacy, or discomfort with medium</p> <p>Home setting: potential for lower overall response rates</p> <p>Other settings: potential for lower overall response rates (e.g., due to functional/cognitive deficits) and negative impacts on validity due to cognitive limitations</p>
<b>Scoring based on classical versus modern test theory (i.e., respondents answer all items versus answering fewer or different items, which is enabled through use of computer adapted testing)</b>	<p>Classical test theory: Item nonresponse, which can negatively impact validity</p>

While the first four approaches listed in Table 2 are relatively straightforward, the two scoring approaches (i.e., classical versus modern) require more explanation. When using the classical test theory approach to measurement, respondents must answer all items in a particular PROM (or, alternatively, values from any missing responses must be imputed). The modern test theory approach to measurement refers specifically to item response theory (IRT). IRT is a family of mathematical models that assumes that responses on a set of items are related to an unmeasured “trait” (e.g., function) and this trait can be estimated using different items from the set.<sup>2,15</sup> Items in a set have varying levels of

difficulty, and redundant items can be removed from the set. Use of IRT allows data collection via computerized adaptive testing (CAT). With CAT, the items (including their number and order) that are selected from a particular set are tailored to a particular individual.<sup>2</sup> Use of items tailored to individual respondents allows more precise measurement of a particular trait. Thus, use of IRT and CAT allows better measurement using fewer questions.

Note, again, that the above methodological approaches to implementation likely will impact which PROMs are selected for a particular use case. For example, if resources are not available

for electronic implementation, then decision makers may select from available PROMs that can be completed via paper and pencil (although that decision itself may have resource implications if subsequent electronic data entry is desired).

### Challenges in PROM Implementation

Table 3, also adapted from Cella et al. (2015),<sup>2</sup> lists seven overarching challenges in the collection of PRO data, along with some of the key effects of the challenges on PRO data quality.

**TABLE 3. CHALLENGES IN PRO DATA COLLECTION AND EFFECTS ON DATA QUALITY**

Challenge	Effects on PRO data quality
Administration of PROMs in vulnerable populations. Various types of vulnerability exist, including sociodemographic (e.g., age, race, ethnicity, income, education, insurance coverage, place of residence, etc.) and medical/functional/cognitive status.	Vulnerable populations often face barriers to submitting PRO data, and therefore their information may be unintentionally excluded (e.g., they may be unable to read, understand, or respond to traditional paper-and-pencil instruments, those available in English only, those accessible via patient portal, etc.). This can affect overall or item response rates, as well as validity of individual or aggregated data.
Limited literacy levels, including both language literacy and health literacy	Limitations in literacy can negatively affect overall or item response rates. For example, those with limited literacy may be less likely to provide data through patient portals. Responses may not be valid if the respondent cannot read or understand self-administered or orally administered questionnaires.
Differences in language and culture	There may be directional bias in how members of different racial, ethnic, linguistic, or other groups answer PROM questions. This may limit ability to pool data from different groups and/or compare results across different groups.
Functional limitations/disabilities, such as difficulties in vision, hearing, motor and cognitive skills	Respondents from vulnerable populations may not be included in data collection efforts. Aggregated responses (e.g., for use in performance measurement) may not be valid unless provision is made to address these limitations (e.g., use multiple modes or methods of data collection, use proxy respondents, etc.). However, use of alternative modes or methods may increase measurement error.
Response shift, which is a change in how a respondent reports on a particular concept over time, due to changes in internal standards of measurement, internal definitions of the concept, or in personal values vis-à-vis the construct	Response shift decreases ability of clinicians and researchers to interpret results. Additionally, it impacts validity of longitudinal data and thus poses challenges in identifying trends.

In general, the above list of challenges applies regardless of the use case for a particular PROM. However, many other issues and challenges exist when implementing PROMs in the context of clinical care planning and management. Some of the overarching challenges in PROM implementation for this context include the following:

- Data collection burden
- Difficulties incorporating into the clinician workflow
- Difficulties incorporating the data into electronic medical records
- Lack of clear interpretation of scores, both to patients and clinicians
- Achieving stakeholder buy-in

These challenges also extend to use in healthcare performance measurement and associated quality improvement/accountability applications, and they also may exist in research applications. It is important to note that, although listed separately, many of these challenges intertwine (e.g., clinician buy-in may be compromised if clinic workflow is disrupted). Key issues related to these overarching challenges are briefly described below. For additional context on these challenges, consult the recently published “Methods Toolkit” (a collection of 14 articles published as a supplement to *Medical Care*) that provides methods and examples for interpreting and acting on PRO scores.<sup>5</sup>

### Data Collection Burden

The burden of data collection challenges both the person providing the data and the clinician using the data.<sup>14</sup> Perhaps most importantly, patients perceive PROMs as burdensome if they do not see the content as important or meaningful (e.g., to their treatment or well-being). Burden from the perspective of the patient includes the time it takes to complete the instrument (lengthy instruments typically are viewed as more burdensome than shorter instruments). Patient burden may also be related to other factors associated with the instrument (e.g., literacy or functional limitations that make it difficult to complete). Patients also view PROMs as burdensome if the PROM includes questions that patients perceive as intrusive. Patients also are burdened if they are being asked to respond to many different PROMs or to the same PROM many times, or if the PROM seems redundant to other components of the clinical workflow. Finally, patients believe PRO data collection is burdensome if they do not receive value from the score obtained from the PROM (e.g., if they are not given the data or are given data that they do not understand or find helpful).

Burden from the perspective of clinicians often relates to perceived extra work (by themselves or their staff) in administering PROMs and reviewing/interpreting results, as well as when PRO data

collection impacts their workflow. Burden for clinicians also can accrue if PRO data are stored in such a way that interactions with additional electronic systems (e.g., with different browsers, passwords, etc.) are required.<sup>6</sup>

### Workflow Challenges

Workflow considerations include when, where, and how the PRO data collection will occur (e.g., home vs. clinic; how to schedule data collection within the context of the clinical interaction; and how PRO data are delivered to clinicians in a way that facilitates review and use).<sup>16</sup> Workflow considerations also include when and how scores are presented to and interpreted by clinicians, and when and how they are presented to and discussed with patients. Specific workflow challenges include PRO data collection activities that actually delay or disrupt care delivery, require additional interventions (e.g., a follow-up telephone call or e-mail), take too much time, or otherwise distract clinicians from more immediate clinical issues. Some of these challenges can be ameliorated if PRO data collection is integrated into EHRs. Yet such integration has its own set of challenges, as discussed below.

### Integration into EHRs

Pulling from the recently published *User's Guide to Integrating Patient-Reported Outcomes in Electronic Health Records*,<sup>17,18</sup> challenges related to integration of PROMs in EHRs can be categorized in terms of planning, selection, and engagement. Some of the key considerations identified within each of these categories are listed below; note that each consideration has its own set of advantages and disadvantages.

#### Planning

- Determining the extent of integration. Options range from full integration, where PRO data are collected and reported entirely within the EHR system, to minimal integration, where data are manually entered or scanned.
- Governance. Systems of governance can be distributed (i.e., left to individual clinicians

or departments, centralized (i.e., have organizational oversight), or a hybrid of the two. Other issues related to governance include who—besides core clinicians, IT personnel, and practice managers—should be involved. Options include using existing governance bodies, adding patient representatives or advocates, or expanding to an even larger group of stakeholders beyond patients.

- Ethical and legal issues. This includes decisions about the types of consent or disclosure needed for integrating PRO data into the EHR and decisions about types of consent needed to share/use PRO data. There are also issues related to provider obligations to act on data revealed through PRO data collection (e.g., suicidal ideation) and potential for liability.
- Pooling data from multiple EHRs. This includes decisions related to the type of software architecture used (i.e., centralized versus distributed data warehouse) and the data model, shared terminology, and metadata used/collected when sharing data.

### *Selection*

In the context of integration into EHRs, the issues around selection pertain to how EHRs can help support the implementation of PROMs. Some key issues include:

- Deciding which patients should be included in data collection efforts, and if/how EHRs can support identification of these patients
- Deciding on which PROs should be measured and which PROMs will be used, and if/how EHRs can be used to tailor the “fielding” of PROMs to patient subgroups

### *Engagement*

- Administration of PROMs. This topic includes the frequency and timing of PRO data collection, if/how much the EHR should serve as the “coordinator” for administering PROMs, whether quality or error checks should be built in, whether data from various modes of

administration (e.g., in-office, smartphones) should be combined, what types of metadata should be collected, and how the EHR monitors and/or reports response rates.

- Issues related to how data will be displayed and accessed. This includes questions of the target audience (e.g., the clinician, the patient, or others), the presentation format (e.g., numbers vs. charts or graphs), the types of scores presented (e.g., trends over time, cross-sectional results, or change scores), the aggregation level (individual patient scores versus scores aggregated across specific patient groups), and complexity of display (e.g., simple versus drill-down features).
- Subsequent actions after PRO data collection. This involves questions of whether clinicians should be required to review/accept the data, if/how providers should receive alerts about newly collected data, which providers should receive those alerts, and whether PRO data should be used to drive clinical decision support. Regarding the latter, there are trade-offs between use of PRO data and potential for alert fatigue.
- Training and engagement for both patients and providers. Regarding patients, this involves questions of who/what should inform the patient of the PRO data collection request, how the value of PRO data collection is conveyed to patients, and how to incentivize patients to provide PRO data. Regarding providers, this involves how to motivate use of PROs and the types of training needed to interpret scores and use the results.

Other issues and challenges<sup>19</sup> related to integration of EHRs include:

- Ability of the EHR system to accurately score the PROM (e.g., by appropriately handling missing data)
- Ability of the EHR system to combine PRO data with other data stored in EHRs

- Ability to pool or share data from different EHR systems across settings or institutions

Note that many of the above issues and challenges apply even if PROMs are implemented outside of EHRs.

### Issues with Interpretability of Scores

For effective use of PRO data in care planning and management, understandable results must be provided to clinicians in a timely manner. In this instance, understandable includes knowing how the results reflect clinical meaning. Scores also should be interpretable by patients. This includes having access to the score itself (or to changes in scores), as well as the meaning of the score (e.g., higher is better), and the clinical import of the score (e.g., high level of disability).<sup>16</sup> Challenges for clinicians include having access to both the meaning of the scores and their clinical import, having reference scores available for comparison (if deemed appropriate or useful), knowing how scores have changed over time, and having the ability to format results in a useful way (e.g., graphical and/or tabular). Training of clinicians and their staff may be needed to ensure they understand the meanings of PROM scores and can respond appropriately. The extent to which PROM scores are interpretable directly relates to the concepts of person-centeredness and meaningfulness that were discussed earlier.

### Stakeholder Buy-In

Any or all of the above challenges can affect the overarching challenge of stakeholder buy-in. But stakeholder buy-in also includes what can be considered “attitudinal” challenges, in the parlance of Valderas, et al.<sup>20</sup> For example, clinicians may not accept PROs for use in clinical work if they believe that the PROs reveal issues that cause unwarranted concern, issues that the clinician cannot control or influence, or that otherwise interfere with patient-clinician communication. Another attitudinal challenge identified by the TEP is that clinicians often have long-held patterns of

providing care that may need to change if PROMs are implemented. Other concerns center on the validity of PROMs and perceived lack of evidence linking use of PRO data to improvements in patient care and patient outcomes.<sup>21</sup>

Other challenges that can be seen as impacting stakeholder buy-in include lack of a business case to collect PRO data or other issues related to costs or lack of reimbursement,<sup>22, 23</sup> heterogeneous patient populations (e.g., in primary care), which makes it difficult to select which PROMs should be implemented, and a recognized need for training of clinicians on how to use PRO data for care management and to promote shared decision making.<sup>24</sup>

From the patient perspective, buy-in may diminish if patients do not consider the PRO to be important or relevant to their treatment or well-being,<sup>23</sup> if they believe the data may be used in a threatening way (e.g., outside of direct clinical care), if they believe the results are not being used to further their care, or if they do not actually get to see the results.

## PROMs Relevant to Burns, Trauma, Joint Replacement, and Heart Failure

NQF staff identified a total of 69 PROMs relevant to burns, trauma, joint replacement, and heart failure (see **Appendix C** and Table 4). PROMs related to burns made up a substantial proportion of the identified instruments. Staff also identified 38 additional PROMs that could be relevant for patients with these conditions. As noted earlier, the TEP will apply its recommendations for PRO selection and implementation to these use case conditions. As shown in Table 4, many of the identified PROMs include more than one PRO domain.

TABLE 4. NUMBER OF PROMS IDENTIFIED IN THE SCAN, ACCORDING TO CONDITION AND PRO DOMAIN

	Domains Included in PROM				Total (n=107)
	HRQoL/ Functional Status	Symptoms/ Symptom Burden	Experience with Care	Health Behaviors	
<b>Burns</b>	34	4	0	4	<b>37</b>
<b>Trauma</b>	4	10	1	3	<b>11</b>
<b>Heart Failure</b>	2	4	2	0	<b>6</b>
<b>Joint Replacement</b>	11	12	3	2	<b>15</b>
<b>Other</b>	24	6	14	1	<b>38</b>

### PRO-PMs Relevant to Burns, Trauma, Joint Replacement, and Heart Failure

NQF staff identified a total of 16 PRO-PMs relevant to joint replacement, as well as 11 other PRO-PMs

that could be relevant for patients with the conditions selected for the use case exercise (see [Appendix D](#)). We did not identify any PRO-PMs related to burns, trauma, or heart failure. Of the 16 PRO-PMs relevant to joint replacement, 10 are endorsed by NQF.

## NEXT STEPS

The TEP will use the results of the environmental scan to spur discussion and identification of consensus recommendations for addressing challenges in PRO selection and data collection and ensuring PRO data quality. The TEP also will use the results of the scan when applying these recommendations to use cases related to burns/trauma, heart failure, and joint replacement.

## REFERENCES

- 1 Basch E. New frontiers in patient-reported outcomes: adverse event reporting, comparative effectiveness, and quality assessment. *Annu Rev Med.* 2014;65:307-317.
- 2 Cella D, Hahn EA, Jensen SE, et al. *Patient-Reported Outcomes in Performance Measurement.* Research Triangle Park, NC: RTI Press; 2015.
- 3 Lavalley DC, Chenok KE, Love RM, et al. Incorporating patient-reported outcomes into health care to engage patients and enhance care. *Health Aff (Project Hope).* 2016;35(4):575-582.
- 4 Greenhalgh J, Dalkin S, Gooding K, et al. *Functionality and Feedback: A Realist Synthesis of the Collation, Interpretation and Utilisation of Patient-Reported Outcome Measures Data to Improve Patient Care.* Southampton (UK): NIHR Journals Library; 2017.
- 5 Snyder C, Brundage M, Rivera YM, et al. A PRO-cision Medicine Methods Toolkit to Address the Challenges of Personalizing Cancer Care Using Patient-Reported Outcomes: Introduction to the Supplement. *Med Care.* 2019;57 Suppl 5 Suppl 1:S1-S7.
- 6 van Egdom LSE, Oemrawsingh A, Verweij LM, et al. Implementing Patient-Reported Outcome Measures in Clinical Breast Cancer Care: A Systematic Review. *Value Health.* 2019;22(10):1197-1226.
- 7 Basch E, Deal AM, Kris MG, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol.* 2016;34(6):557-565.
- 8 Baumhauer JF. Patient-Reported Outcomes — Are They Living Up to Their Potential? *N Engl J Med.* 2017;377(1):6-9.
- 9 U.S. Department of Health and Human Services, Food and Drug Administration. Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Chains. December 2009.
- 10 National Quality Forum (NQF). *Patient Reported Outcomes (PROs) in Performance Measurement.* Washington, DC: NQF; 2013. <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=72537>.
- 11 National Quality Forum (NQF). *Finding Common Ground for Healthcare Priorities: Families of Measures for Assessing Affordability, Population Health, and Person- and Family-Centered Care.* Washington, DC: NQF; 2014. <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=77001>. Last accessed November 2019.
- 12 Patient-Centered Outcomes Research Institute (PCORI) Methodology Committee. *The PCORI Methodology Report.* Washington, DC: PCORI; 2019.
- 13 Tractenberg RE, Garver A, Ljungberg IH, et al. Maintaining primacy of the patient perspective in the development of patient-centered patient reported outcomes. *PLoS ONE.* 2017;12(3):1-20.
- 14 Francis DO, McPheeters ML, Noud M, et al. Checklist to operationalize measurement characteristics of patient-reported outcome measures. *Syst Rev.* 2016;5(1):129-129.
- 15 HealthMeasures. Item Response Theory (IRT). <http://www.healthmeasures.net/resource-center/measurement-science/item-response-theory>. Last accessed October 2019.
- 16 Snyder CF, Aaronson NK, Choucair AK, et al. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Qual Life Res.* 2012;21(8):1305-1314.
- 17 Synder C, Wu A. *Users' Guide to Integrating Patient-Reported Outcomes in Electronic Health Records.* Baltimore, MD: Johns Hopkins University; 2017. <https://www.pcori.org/document/users-guide-integrating-patient-reported-outcomes-electronic-health-records>. Last accessed September 2019.
- 18 Gensheimer SG, Wu AW, Snyder CF, et al. Oh, the places we'll go: patient-reported outcomes and electronic health records. *Patient.* 2018;11(6):591-598.
- 19 Wu AW, Kharrazi H, Boulware LE, et al. Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research. *J Clin Epidemiol.* 2013;66(8):S12-S20.
- 20 Valderas J, Kotzeva A, Espallargues M, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res.* 2008;17(2):179.
- 21 Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *Journal of Evaluation in Clinical Practice.* 1999;5(4):401-416.
- 22 Basch E. Patient-reported outcomes — harnessing patients' voices to improve clinical care. *N Engl J Med.* 2017;376(2):105-108.
- 23 Lohr KN, Zebrack BJ. Using patient-reported outcomes in clinical practice: challenges and opportunities. *Qual Life Res.* 2009;18(1):99-107.
- 24 Hsiao C-J, Dymek C, Kim B, et al. Advancing the use of patient-reported outcomes in practice: understanding challenges, opportunities, and the potential of health information technology. *Qual Life Res.* 2019;28(6):1575-1583.

## APPENDIX A: Technical Expert Panel Members and NQF Staff

### TECHNICAL EXPERT PANEL

---

#### **Christine Norton (Co-chair)**

Minnesota Community Measurement  
Minneapolis, Minnesota

#### **Albert Wu, MD, MPH (Co-chair)**

Professor, Johns Hopkins Bloomberg School of Public Health  
Baltimore, Maryland

#### **Amy Acton**

Executive Director, Phoenix Society for Burn Survivors  
Grand Rapids, Michigan

#### **Jay L. Alberts, MD**

Vice Chair of Innovations, Neurological Institute,  
Cleveland Clinic  
Cleveland, Ohio

#### **David Baker, MD, MPH, FACP**

Executive Vice President, Healthcare Quality Evaluation, The Joint Commission  
Oakbrook Terrace, Illinois

#### **Rosie Bartel**

Patient Family Advisor  
Long Beach, California

#### **Rachel Brodie**

Director, Pacific Business Group on Health  
San Francisco, California

#### **Patrick Dolan, MD**

Pediatric Emergency Department Physician, Champion for Quality, University of Chicago, Comer Children's Hospital  
Chicago, Illinois

#### **Kathleen Fear, PhD, MSI**

Data Scientist, University of Rochester Medical Center  
Rochester, New York

#### **Patricia Franklin, MD, MBA, MPH**

Professor, Northwestern University, Feinberg School of Medicine  
Chicago, Illinois

#### **Janel Hanmer, MD, PhD**

Medical Director, University of Pittsburgh Medical Center  
Pittsburgh, Pennsylvania

#### **Stephen Hoy**

Chief Operating Officer, Patient and Family Centered Care Partners, Inc.  
Long Beach, California

#### **Roxanne Jensen, PhD**

Program Director, Outcomes Research Branch, National Cancer Institute  
Bethesda, Maryland

#### **Diana Jolles, PhD, CNM**

Midwife, El Rio Community Health Center  
Tucson, Arizona

#### **Carolyn Kerrigan, MD, MHCDS**

Professor of Surgery, Active Emerita, Dartmouth-Hitchcock Medical Center  
Lebanon, New Hampshire

#### **David Levine, MD, MPH**

Group Senior Vice President of Advanced Analytics and Product Strategy, Vizient  
Chicago, Illinois

#### **Cari Levy, MD, PhD, CMD**

Professor of Medicine, Denver VA Medical Center  
Denver, Colorado

#### **Jana Malinowski**

Cerner Corporation  
Kansas City, Missouri

#### **Donald Patrick, PhD, MSPH**

Professor, University of Washington  
Seattle, Washington

#### **Marla Robinson, MSc, OTR/L, BCPR, BT-C, FAOTA**

Assistant Director, Inpatient Therapy, University of Chicago Medical Center  
Chicago, Illinois

#### **Margaret Samuels-Kalow, MD, MPhil, MSHP**

Assistant Director of Emergency Medicine, Massachusetts General Hospital  
Boston, Massachusetts

#### **Jeffrey Schneider, MD**

Medical Director, Spaulding Rehabilitation Hospital  
Charleston, Massachusetts

#### **Paul Shekelle, MD, PhD, MPH**

Director, Southern California Evidence-Based Practice Center, RAND Corporation  
Santa Monica, California

#### **Leif Solberg, MD**

Senior Advisor and Senior Investigator, HealthPartners  
Minneapolis, Minnesota

#### **John Spertus, MD, MPH**

Professor, University of Missouri, Kansas City  
Kansas City, Missouri

NATIONAL QUALITY FORUM STAFF

---

**Elisa Munthali, MPH**

Senior Vice President, Quality Measurement

**Karen Johnson, MS**

Senior Director

**Andrew Lyzenga, MPP**

Senior Director

**Suzanne Theberge, MPH**

Senior Project Manager

**Roara Michael, MHA**

Project Manager

**Hannah Bui, MPH**

Project Analyst

## APPENDIX B: Environmental Scan Methodology

The overarching goal of the environmental scan was to identify current practices in selecting PROs and collecting PRO data and to identify PROMs and PRO-PMs relevant to use cases considered in the project. The specific objectives were to:

- Identify current approaches to PRO/PROM selection and implementation
- Identify challenges associated with the selection and implementation of PROs
- Document how the various approaches to selection and implementation affect the quality of PRO data
- Identify PROs and PROMs relevant to burns/trauma, heart failure, and joint replacement
- Identify performance measures and measure concepts relevant to burns/trauma, heart failure, and joint replacement

Several research questions helped guide the scan. These included:

- How can one identify which PROs would be most valuable for care planning?

- How do clinicians (or other stakeholders) accurately interpret PRO data? More specifically, how can one determine whether a PROM is sensitive enough to detect clinically meaningful changes, and how can one determine whether changes in PRO scores reflect clinically meaningful change?
- How can one obtain stakeholder buy-in for PRO data collection?
- How can users incorporate PRO data collection into clinician workflow?
- How can respondent burden be measured and addressed?
- How can implementers increase response rates and maintain high response rates over time?

To characterize approaches and challenges associated with selecting and implementing PROs and PROMs, NQF relied on PubMed, Google Scholar, and a university library database to identify an initial set of peer-reviewed articles. NQF searched these databases using combinations and variations of the example search terms shown in Table B1.

**TABLE B1. LITERATURE SEARCH PARAMETERS**

Included	Excluded
<ul style="list-style-type: none"> <li>• Published on or after January 1, 2005 AND</li> <li>• Contains the strings: “patient-reported outcomes” AND (“care planning” OR “clinical practice” OR “selection” OR “clinical decision making”) AND (“challenges” OR “barriers”)</li> <li>• Contains the strings: “patient-reported outcomes” AND (“care planning” OR “clinical practice” OR “selection” OR “clinical decision making”) AND (“best practices” OR “solutions”)</li> <li>• Contains the strings: “patient-reported outcomes” AND (“meaningful” OR “minimal important differences” OR “clinical significance”) AND (“challenges” OR “barriers”)</li> <li>• Contains the strings: “patient-reported outcomes” AND (“meaningful” OR “minimal important differences” OR “clinical significance”) AND (“best practices” OR “solutions”)</li> <li>• Contains the string “patient-reported outcomes” OR “patient-centered” OR “patient experience” AND (burden OR buy-in OR workflow OR nonresponse)</li> <li>• The above terms, along with the terms “burns” OR “trauma” OR “joint replacement” OR “heart failure”</li> <li>• Relevant MeSH terms: Patient Reported Outcome Measures; Patient Care Management; Patient Health Questionnaire; Self Report; Arthroplasty, replacement; Burn; Wounds and injuries; Heart Failure</li> </ul>	<ul style="list-style-type: none"> <li>• For the initial literature searches, we excluded articles published before 2005. However, some legacy articles that describe attributes of PROMs included in the scan that were published prior to 2005 and are included.</li> <li>• Not available in English</li> </ul>

NQF identified grey literature and other published literature through internet searches of relevant organizations/efforts. These included:

- Patient-Centered Outcomes Research Institute (PCORI): <https://www.pcori.org/>
- Patient-Reported Outcomes Measurement Group: <https://phi.uhce.ox.ac.uk/about.php>
- HealthMeasures: <http://www.healthmeasures.net/index.php>
- International Society for Quality of Life Research (ISOQOL): <https://www.isoqol.org/>

NQF identified additional resources via backwards reference searching of pertinent articles or reports. In addition, TEP members identified additional articles, reports, and websites.

To identify relevant PROMs (i.e., those applicable to burns, trauma, heart failure, and joint replacement), NQF staff searched the Patient-Reported Outcomes Measurement Information

System (PROMIS) tools, tools from the International Consortium for Health Outcomes Measurement (ICHOM), and those identified as Qualified Clinical Outcome Assessments by the FDA. Staff also identified instruments and associated literature via the PsycTESTS database accessed via a university library.

To identify relevant PRO-PMs (i.e., those applicable to burns, trauma, heart failure, and joint replacement), NQF staff queried NQF’s Quality Positioning System (NQF’s repository of endorsed measures), CMS’s Measures Inventory Tool, and CMS’s QPP Resource Library.

The senior director for the project identified the search terms and parameters used for the scan. Three staff members shared responsibility for conducting the searches for published articles, grey literature, PROMs, and PRO-PMs. However, the senior director selected resources ultimately cited in this scan.

## APPENDIX C: PROMs Relevant to Burns, Trauma, Joint Replacement, and Heart Failure

### Burns

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Adult Burn Outcome Questionnaire (ABOQ)<sup>1</sup></b>	The ABOQ was derived from the YABOQ.	Individuals age 18 years and older	14	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>American Burn Association/ Shriners Hospitals for Children Burn Outcomes Questionnaires<sup>2</sup></b>	The burn outcomes scale assess function in patients with burns. Deltroy et al., 2000.	Children 5-18 years old	38	HRQoL/ Functional Status
<b>American Burn Association/ Shriners Hospitals for Children Burn Outcomes Questionnaires for Children age 11 – 18 years old<sup>2</sup></b>	The burn outcomes scale assess function in patients with burns. Deltroy et al., 2000.	Children age 11-18 years old	Not specified	HRQoL/ Functional Status
<b>American Burn Association/ Shriners Hospitals for Children Burn Outcomes Questionnaires for Infants and Children<sup>2</sup></b>	The burn outcomes scale assess function in patients with burns. Deltroy et al., 2000.	Infants and children younger than 5 years old	55	HRQoL/ Functional Status
<b>Beck Depression Inventory II<sup>5</sup></b>	The BDI-II is a self-report inventory measuring the severity of depression in adolescents and adults. Beck et al., 1996.	Not specified	21	HRQoL/ Functional Status
<b>Birleson Depression Scale<sup>4</sup></b>	The Birleson Depression Scale is a depression self-rating scale for children. Birleson, 1981.	Youth age 8-14 years old	18	HRQoL/ Functional Status
<b>Body Esteem Scale for Adolescents and Adults<sup>5</sup></b>	The Body Esteem Scale is a self-evaluation of one's body and appearance. Mendelson et al., 2001.	Persons age 12 years or older	23	HRQoL/ Functional Status

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Brisbane Burn Scar Impact Profile (BBSIP)<sup>6</sup></b>	The BBSIP was developed as a patient-report measure of health-related quality of life. The measure consists of 66 items across the following dimensions: overall impact of burn scars, itch, pain, and other sensations, impact of sensations (including itch, pain, discomfort, and other sensations), work and daily activities, relationships and social interaction, appearance, emotional reactions, and physical symptoms. Tyack et al., 2013.	Adults 18 years and older	66	HRQoL/ Functional Status
<b>Burns Anxiety Inventory (Burns AI)<sup>7</sup></b>	The Burns AI is a self-report scale that measures anxious feelings, anxious thoughts, and somatic symptoms of anxiety. Burns, 1989.	Adults 18 years and older	33	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Burn Specific Pain Anxiety Scale<sup>8</sup></b>	The 9-item Burn Specific Pain Anxiety Scale measures anxiety related to painful procedures in burn patients. Echavarría-Guanilo et al., 2011.	Not specified	9	HRQoL/ Functional Status
<b>Children's Attitude Towards Their Illness Scale<sup>9</sup></b>	A measure of illness attitudes within pediatric chronic illness. Informs recommendations for its use. Austin and Huberty, 1993.	Youth age 8-12 years old	13	HRQoL/ Functional Status Health Behavior
<b>Coping with Burns Questionnaire (CBQ)<sup>10</sup></b>	The CBQ was developed to assess coping following burn injury. Willbrand et al., 2001.	Adults 18 years and older	33	Symptoms/ Symptom Burden
<b>Death Anxiety Questionnaire<sup>11</sup></b>	The Death Anxiety Questionnaire measures individual differences in and perceptions of death anxiety. Conte et al., 1982.	Not specified	17	HRQoL/ Functional Status
<b>Fear-Avoidance Beliefs Questionnaire (FABQ)<sup>12</sup></b>	The FABQ focuses specifically on how a patient's fear-avoidance beliefs about physical activity and work may affect and contribute to their pain and resulting disability.	Adults 18 years and older	96	HRQoL/ Functional Status
<b>Harter's Self-Perception Profile for Adolescents<sup>13</sup></b>	A self-report magnitude estimation scale that measures a school-age child's sense of general self-worth and self-competence in the domain of academic skills. There is no overall self-perception score. Harter, 1988.	Adolescents age 13-18 years old	45	HRQoL/ Functional Status

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Harter's Social Support Scale for Children</b> <sup>13</sup>	Designed to assess and understand the social support or approval from four sources including parents, teachers, close friends, and classmates. Harter, 1985.	Youth age 8-18 years old	24	HRQoL/ Functional Status
<b>The Impact of Events Scale</b> <sup>14</sup>	The Impact of Events Scale is a short set of questions that can measure the amount of distress one associates with a specific event. Horowitz et al., 1979.	Not specified	22	HRQoL/ Functional Status
<b>Junior Eysenck Personality Questionnaire</b> <sup>15</sup>	The JEPQ measures personality traits, usually called temperament, in four scales. Eysenck and Eysenck, 1973.	Not specified	81	HRQoL/ Functional Status
<b>Life Impact Burn Recovery Evaluation Profile (LIBRE)</b> <sup>16</sup>	The LIBRE is a computerized adaptive test developed for a U.S.-based study examining the impact burn injuries have on social participation. Kazis et al., 2017.	Not specified	126	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Multidimensional Anxiety Scale for Children</b> <sup>17</sup>	A comprehensive multirater assessment of anxiety dimensions in children and adolescents. It distinguishes between important anxiety symptoms and dimensions that broadband measures do not capture. March, 1997.	Youth age 8-19 years old	39	HRQoL/ Functional Status
<b>Pediatric Quality of Life Inventory</b> <sup>18</sup>	A brief measure of health-related QoL in children and young people. The measure can be completed by the parents (the Proxy Report) as well as children and young people (the Self-Report). Varni et al., 1999.	Not specified	23	HRQoL/ Functional Status
<b>Perceived Stigmatization Questionnaire (PSQ)</b> <sup>19</sup>	The PSQ is used to assess the perception of stigmatizing behavior among burn survivors. The questionnaire categorizes three types of stigmatizing behaviors: absence of friendly behavior, confused and staring behavior, and hostile behavior.	Not specified	21	HRQoL/ Functional Status
<b>Piers-Harris Self-Concept Scale v2</b> <sup>20</sup>	This scale provides an overall view of an individual's self-perception and helps identify children, adolescents, and teenagers who may require further testing and possible treatment. Piers et al., 2002.	Not specified	60	HRQoL/ Functional Status Health Behavior

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Psychosocial Adjustment to Burn Questionnaire (PABQ)</b> <sup>21</sup>	The Psychosocial Adjustment to Burn Questionnaire assesses emotional and behavioral symptoms specific to children who have suffered a burn injury that required medical attention. Pelley et al., 2013.	Children age 0-5	35	HRQoL/ Functional Status
<b>Resiliency Scales for Children and Adolescents</b> <sup>22</sup>	The RSCA are three scales for assessing the relative strength of three aspect of personal resiliency as a profile in children and adolescents. Prince-Embury, 2007.	Youth age 9 - 18 years old	64	HRQoL/ Functional Status
<b>The Revised Children's Manifest Anxiety Scale</b> <sup>23</sup>	This is a brief, simple yes-or-no response format, an elementary reading level, and content-based item clusters help to pinpoint children's problems and to focus intervention. Reynolds et al., 1981.	Not specified	49	Health Behavior
<b>Rosenberg Self-Esteem Scale (RSES)</b> <sup>24</sup>	A self-esteem measure used in social-science research, using a scale of 0-30. Rosenberg, 1979.	Patients 13 years and older	10	HRQoL/ Functional Status
<b>Satisfaction with Appearance Scale (SWAP)</b> <sup>25</sup>	The SWAP assesses both the subjective appraisal and social-behavioral components of body image among burn survivors. Lawrence et al., 1998.	Not specified	14	HRQoL/ Functional Status
<b>Self-Perception Profile for Children</b> <sup>26</sup>	A self-report estimation scale that measures a child's sense of self-worth and self-competence in the domain of academic skills. Harter, 1995.	Children ages 8-15 years old Adolescents ages 13-18 years old	36	HRQoL/ Functional Status
<b>Short form of the Manifest Anxiety Scale</b> <sup>27</sup>	A measure of manifest or general anxiety. Bendig, 1956.	Not specified	20	HRQoL/ Functional Status
<b>Social Skills Rating System</b> <sup>28</sup>	The Social Skills Rating System allows you to obtain a more complete picture of social behaviors from teachers, parents, and even students themselves. Gresham and Elliot, 1990.	Pre-school, elementary, and secondary students	34	HRQoL/ Functional Status
<b>Social Worries Questionnaire</b> <sup>29</sup>	A brief parent-report measure of social anxiety on children 8-17 years old. Spence, 1995.	Children age 8-17 years	13	HRQoL/ Functional Status

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Strengths and Difficulties Questionnaire<sup>30</sup></b>	The Strengths and Difficulties Questionnaire (SDQ) is a brief behavioral screening questionnaire about 3- to 16-year-olds. It exists in several versions to meet the needs of researchers, clinicians and educationalists. Goodman et al., 2001.	Adolescents age 3-16 years old	25	HRQoL/ Functional Status
<b>Young Adult Burn Outcome Questionnaire (YABOQ)<sup>31</sup></b>	The YABOQ is used as a burn-specific metric to understand health needs and outcomes of burn patients.	Individuals age 19-30 years old	Not specified	HRQoL/ Functional Status
<b>Youth Experience Survey 2.0<sup>32</sup></b>	Surveys high-school aged adolescents about their developmental experiences in an extracurricular activity or community-based program. Hansen and Larson, 2005.	High-school aged adolescents	66	HRQoL/ Functional Status
<b>Youth Quality of Life Instruments<sup>33</sup></b>	This instrument measures QoL in youth with and without chronic conditions and disabilities. Topolski et al., 2002.	Youth ages 12-18 years old	41	HRQoL/ Functional Status
<b>Youth Self Report<sup>34</sup></b>	Assesses behavioral competency and behavioral problems. Parallels the Child Behavior Checklist. Achenbach and Rescoria, 2001.	Youth ages 11-17 years old	112	Health Behavior

## Heart Failure

Title	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>9-Item European Heart Failure Self-Care (EHFScB-9)<sup>35</sup></b>	The 9-item European Heart Failure Self-Care Behavior Scale (EHFScB-9) is a revision of the 12-item European Heart Failure Self-care Behaviour Scale (EHFScBS; Jaarsma et al., 2003), a brief, reliable, and valid measure of effective self-management for chronic heart failure. Jaarsma et al., 2009	Adults age 18 years and older	9	Experience with Care
<b>Chronic Heart Failure Questionnaire<sup>36</sup></b>	Designed to assess longitudinal change over time of patients with chronic heart disease or heart failure.	Adults, age not specified	20	Symptoms/ Symptom Burden

Title	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Chronic Heart Failure Assessment Tool (CHAT)</b> <sup>37</sup>	A patient-centered measure comprising important dimensions of health-related quality of life (HRQL) as identified by patients with chronic heart failure (CHF) Dunderdale, Karen et al., 2008	Adults, age not specified	30	HRQoL/ Functional Status
<b>Kansas City Cardiomyopathy Questionnaire (KCCQ)</b> <sup>38</sup>	An instrument that measures patient-reported symptoms, function and quality of life for patients with heart failure.	Patients with symptomatic heart failure	23	HRQoL/ Functional Status Experience with Care Symptoms/ Symptom Burden
<b>KCCQ-12</b> <sup>39</sup>	A self-administered health status tool for patients with heart failure. This is the short version of the KCCQ and includes domains of symptom frequency, physical limitation, social functioning, and quality of life.	Patients with symptomatic heart failure	12	Symptoms/ Symptom Burden
<b>Minnesota Living with Heart Failure Questionnaire (MLHFQ)</b> <sup>40</sup>	The MLHFQ is a reliable and valid patient-oriented measure of the adverse effects of heart failure on a patient's life.	Adults 18 years and older with heart failure	21	Symptoms/ Symptom Burden

## Joint Replacement

Title	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Experience of Hip Arthroplasty Questionnaire</b> <sup>41</sup>	The purpose is to assess patients' evaluation of care and recovery after hip arthroplasty. Salmon, Peter, 2013.	Adults, age not specified	5	Symptoms/ Symptom Burden
<b>Forgotten Joint Score</b> <sup>42</sup>	Designed to measure the ability of the patient to "forget" about their problematic joint after treatment. Behrend, et al., 2012	Adults, age not specified	12	Health behaviors

Title	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Hip disability and Osteoarthritis Outcome Score (HOOS)</b> <sup>43</sup>	HOOS was developed as an instrument to assess the patients' opinion about their hip and associated problems. It is intended to be used for hip disability with or without osteoarthritis. It is meant to be used over both short and long-time intervals to assess changes from week to week induced by treatment or over years due to the primary injury or posttraumatic osteoarthritis. Lyman, 2003	Not specified	40	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>HOOS-12</b> <sup>44</sup>	HOOS-12 is a measure derived from the original HOOS. Roos, et al., 2003.	Not specified	12	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>HOOS-JR</b> <sup>45</sup>	The HOOS-JR is a joint replacement short form derived from the HOOS.	Adults age 18 years and older	7	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Injustice Experiences Questionnaire—Revised</b> <sup>46</sup>	Measures individuals' appraisals of their illness in terms of the severity and irreparability of losses, unfairness, and blame. Yakabov et al., 2014	Adults, age not specified	12	HRQoL/ Functional status Symptoms and symptom burden Experience with Care
<b>Knee Injury and Osteoarthritis Outcome Score (KOOS)</b> <sup>47</sup>	A knee-specific instrument developed to assess the patients' opinion about their knee and associated problems. It evaluates both short-term and long-term consequences of knee injury. Roos, et al., 1990	Patients 13 - 79 years old	42	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>KOOS-12</b> <sup>47</sup>	KOOS-12 is a measure derived from the original KOOS. It contains 4 KOOS Pain items, 4 KOOS Function items, and 4 KOOS QoL items.	Not specified	12	HRQoL/ Functional Status Symptoms/ Symptom Burden

Title	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>KOOS-Child</b> <sup>47</sup>	KOOS-Child was developed as an instrument to assess the patient's opinion about their knee and associated problems.	Adolescents 7 – 16 years old	39	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>KOOS-JR</b> <sup>47</sup>	The KOOS-JR is a joint replacement short form derived from the KOOS.	Adults age 18 years and older	6	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Oxford Hip Score (OHS)</b> <sup>48</sup>	A joint-specific, patient-reported outcome measure tool designed to assess function and pain, and disability in patients undergoing total hip replacement (THR). Judge, et al., 1996.	Not specified	12	HRQoL/ Functional Status
<b>Oxford Knee Score (OKS)</b> <sup>49</sup>	Specifically designed and developed to assess function and pain after total knee replacement surgery. Judge et al, 1996.	Adults, age not specified	12	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Stanford Health Assessment Questionnaire</b> <sup>50</sup>	Self-administered and used to assess clinical status, evaluate effectiveness in clinical and observational trials, and to define health outcomes. J. Dawson et al., 1980	Adults and children, age not specified	20	Symptoms/ Symptom Burden Experience with Care Health Behaviors
<b>Surgical Patient Education Interview</b> <sup>51</sup>	Explores patients' experiences from an education program ahead of orthopedic surgery. Conradsen et al., 2016	Adults, age not specified	46	Experience with Care
<b>Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)</b> <sup>52</sup>	A widely used proprietary set of standardized questionnaires used by health professionals to evaluate the condition of patients with osteoarthritis of the knee and hip, including pain, stiffness, and physical functioning of the joints.	Adults	24	HRQoL/ Functional Status Symptoms and Symptom Burden

## Trauma

Title	Description	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Adverse Childhood Experiences Scale<sup>53</sup></b>	The Adverse Childhood Experiences Scale measures adverse childhood experiences related to death, trauma, and abuse. Skarupski et al., 2016	Adults 18 years and older	21	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Acute Stress Disorder Scale<sup>54</sup></b>	The purpose of the Acute Stress Disorder Scale is to index acute stress disorder and predict posttraumatic stress disorder. The ASDS is a 19-item inventory that is based on Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV, American Psychiatric Association, 1994) criteria. Bryant et al., 2000	Adults age 18 and older	19	Symptoms/ Symptom Burden
<b>Anaphylactic Shock Symptoms and Exposure Measure<sup>55</sup></b>	The purpose of the Anaphylactic Shock Symptoms and Exposure Measure is to assess trauma exposure characteristics of those with anaphylactic shock experience. Chung et al., 2011	Adults 18 years and older	19	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Child Stress Disorders Checklist<sup>56</sup></b>	The CSDC was developed to measure acute stress disorder and posttraumatic stress disorder symptoms in children. Saxe et al., 2003	Adolescents age 2-18 years old	36	Symptoms/ Symptom Burden
<b>The Child Stress Disorders Checklist-Short Form<sup>56</sup></b>	The Child Stress Disorders Checklist--Short Form is a shortened form of the Child Stress Disorders Checklist and is a user-friendly scale that measures traumatic stress responses in injured children. Enlow et al., 2010	Children age 6-18 years old	4	Symptoms/ Symptom Burden
<b>Child Trauma Screening Questionnaire (CTSQ)<sup>57</sup></b>	This assesses risk of developing posttraumatic stress in children, particularly following accidental injury.	Childhood (birth-12 years) School age (6-12 years) Adolescence (13-17 years) Adults (18 years and older)	10	Symptoms/ Symptom Burden

Title	Description	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Children’s Post-Traumatic Cognitions Inventory—Short Form (CPTCI-S)</b> <sup>58</sup>	The purpose of the Children’s Post-Traumatic Cognitions Inventory—Short Form is to measure maladaptive cognitions in children and young people following exposure to trauma McKinnon et al., 2016	Childhood (birth-12 years) School age (6-12 years) Adolescence (13-17 years)	10	Symptoms/ Symptom Burden Health Behaviors
<b>Coping Self-Efficacy Scale-7 (CSE-7)</b> <sup>59</sup>	The CSE-7 is a shortened version of the 20-item CSE Scale that was composed using only those items that were applicable to all types of potentially traumatic events. Enlow et al., 2010	Not specified	27	HRQoL/ Functional Status Experience with Care
<b>Danieli Inventory of Multigenerational Legacies of Trauma: Part I: Posttrauma Adaptational Styles</b> <sup>60</sup>	The Danieli Inventory of Multigenerational Legacies of Trauma: Part I: Posttrauma Adaptational Styles is used to measure Holocaust survivors’ children’s perceptions of their parents’ post trauma adaptational styles. Danieli et al., 2015	Adults 18 years and older	60	Symptoms/ Symptom Burden Health Behaviors
<b>Danieli Inventory of Multigenerational Legacies of Trauma, Part II: Reparative Adaptational Impacts</b> <sup>60</sup>	The purpose of the Danieli Inventory of Multigenerational Legacies of Trauma, Part II: Reparative Adaptational Impacts is to comprehensively assess the range of psychological and social impacts experienced by adult offspring of Holocaust survivors. Danieli et al., 2015	Adults 18 years and older	36	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>Description of Event Questionnaire (DEQ)</b> <sup>61</sup>	The purpose of the Description of Event Questionnaire is to assess traumatic work-related situations typically experienced by first responders. Regambal et al., 2015	Not specified	14	Symptoms/ Symptom Burden Health Behaviors

## Other Potentially Relevant Instruments

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Assessment of Quality of Life-8D (AQoL-8D)</b> <sup>62</sup>	AQoL instruments measure health-related Quality of Life. The four instruments differ in sensitivity and length in different domains of health.	Not specified	35	HRQoL/ Functional Status
<b>Assessment of Quality of Life-7D (AQoL-7D)</b> <sup>62</sup>	AQoL instruments measure health-related Quality of Life. The four instruments differ in sensitivity and length in different domains of health.	Not specified	26	HRQoL/ Functional Status
<b>Assessment of Quality of Life-6D (AQoL-6D)</b> <sup>62</sup>	AQoL instruments measure health-related Quality of Life. The four instruments differ in sensitivity and length in different domains of health.	Not specified	20	HRQoL/ Functional Status
<b>Assessment of Quality of Life-4D (AQoL-4D)</b> <sup>62</sup>	AQoL instruments measure health-related Quality of Life. The four instruments differ in sensitivity and length in different domains of health.	Not specified	12	HRQoL/ Functional Status
<b>Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey 5.0</b> <sup>63</sup>	A survey that asks health plan enrollees to report about their care and health plan experiences as well as the quality of care received from physicians.	Adults 18 years and older, or parents/guardians of children aged 0-17 years old	39	Experience
<b>CAHPS Child Hospital (HCAHPS)</b> <sup>64</sup>	The HCAHPS assesses the experience of pediatric patients and their parents or guardians with inpatient care.	Individuals 17 years or younger	62	Experience
<b>CAHPS Home- and Community-Based Service Measures (HCBS CAHPS)</b> <sup>65</sup>	The HCBS CAHPS is designed to assess the experiences of adult Medicaid beneficiaries who receive long-term services and support from State HCBS programs.	Adults 18 years and older, enrolled in Medicaid	102	Experience
<b>CAHPS Home Healthcare Survey</b> <sup>66</sup>	A survey that asks patients who receive home healthcare services about their experience	Not specified	34	Experience
<b>CAHPS Hospice Survey</b> <sup>67</sup>	The survey is intended to measure the experiences of hospice patients and their primary caregivers.	Not specified	47	Experience
<b>CAHPS Item Set for Addressing Health Literacy</b> <sup>68</sup>	The CAHPS Item Set for Addressing Health Literacy consists of supplemental items designed for use with the CAHPS Clinician & Group Surveys to address the following: communication with providers, disease self-management, communication about medicines, communication about tests, communication about forms.	Not specified	31	Experience

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>CAHPS Nursing Home Survey: Discharged Resident Instrument</b> <sup>69</sup>	The CAHPS Nursing Home Survey: Discharged Resident Instrument is a survey used to gather information on the experience of short stay (5 to 100 days) residents recently discharged from nursing homes.	Not specified	50	Experience
<b>CAHPS Nursing Home Survey: Family Member Instrument</b> <sup>69</sup>	This survey asks respondents to report on their own experiences (not the resident's) with the nursing home and their perceptions of the quality of care provided to a family member living in a nursing home.	Not specified	51	Experience
<b>CAHPS Nursing Home Survey: Long Stay Resident Instrument</b> <sup>69</sup>	This survey gathers information on the experience of long stay (greater than 100 days) residents currently in nursing homes.	Not specified	45	Experience
<b>Consumer Assessment of Healthcare Providers and Systems (CAHPS)<sup>®</sup> Surgical Care Survey Version 2.0 (SCAHPS)</b> <sup>70</sup>	The SCAHPS asks patients to report on surgical care, surgeons, surgical staff, and anesthesiologists.	Not specified	47	Experience
<b>Clinician/Group CAHPS Cultural Competence Item Set</b> <sup>71</sup>	The CAHPS Cultural Competence Item Set consists of supplemental items designed for use with the CAHPS Clinician & Group Surveys.	Not specified	34	Experience
<b>Experience of Care and Health Outcomes (ECHO) Survey</b> <sup>72</sup>	A survey that asks health plan enrollees about their experiences with behavioral healthcare and services.	Adults 18 years and older	53	Experience
<b>EuroQol-5D (EQ-5D)</b> <sup>73</sup>	A standardized measure of health status developed to provide a generic measure of health for clinical and economic appraisal.	Not specified	15	HRQoL/ Functional Status Symptoms/ Symptom Burden Experience
<b>Health Utilities Index (HUI)</b> <sup>74</sup>	A family of generic health profiles and preference-based systems for the purpose of measuring health status, reporting health-related quality of life, and producing utility scores.	Individuals age 5 years and older	15 (self-administered) 40 (interviewer administered)	HRQoL/ Functional Status

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>National Core Indicators Adult Family Survey (NCI-AFS)</b> <sup>75</sup>	A quality of life survey for individuals with intellectual and developmental disabilities and their families about the services they get and how they feel about them.	Not specified	79	HRQoL/ Functional Status
<b>National Core Indicators Family/Guardian Survey (NCI-FGS)</b> <sup>76</sup>	A quality of life survey for the families of individuals with intellectual and developmental disabilities.	Not specified	67	HRQoL/ Functional Status
<b>National Core Indicators - Aging and Disabilities (NCI-AD)</b> <sup>77</sup>	A quality of life survey for older adults and adults with physical disabilities. It measures community participation, choice and decision making, relationships, satisfaction, service and care coordination, etc.	Adults 18 years and older	111	HRQoL/ Functional Status
<b>Nottingham Health Profiles</b> <sup>78</sup>	A general patient-reported outcome measure which seeks to measure subjective health status.	Not specified	45	HRQoL/ Functional Status
<b>Patient Activation Measure</b> <sup>79</sup>	A measure that assesses an individual's knowledge, skill, and confidence for managing one's health and healthcare.	Adults age 18 years or older	10 or 13	Health behavior
<b>Pediatric Quality of Life (PedsQoL) Inventory 4.0</b> <sup>80</sup>	The PedsQL is a modular instrument or measuring health-related quality of life in children and adolescents.	Children and adolescents age 2-18	23	HRQoL/ Functional Status
<b>Personal Outcome Measures</b> <sup>81</sup>	Personal Outcome Measures are used to understand the presence, importance, and achievement of outcomes, involving choice, health, safety, social capital, relationships, rights, goals, dreams, employment, and more.	Not specified	21	HRQoL/ Functional Status
<b>PHQ-9</b> <sup>82</sup>	The PHQ-9 is used for screening, diagnosing, monitoring, and measuring the severity of depression.	Not specified	9	HRQoL/ Functional Status Symptoms
<b>PHQ-2</b> <sup>83</sup>	The PHQ-2 inquires about the frequency of depressed mood and anhedonia over the past two weeks. It includes the first two items of the PHQ-9.	Not specified	2	Symptoms/ Symptom Burden
<b>PROMIS Depression</b> <sup>84</sup>	The PROMIS Depression assesses self-reported negative mood, views of self, and social cognition, as well as decreased positive affect and engagement.	Not specified	20	Symptoms/ Symptom Burden

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>PROMIS Global-10</b> <sup>85</sup>	A generic health-related quality of life survey that measures symptoms, functioning, and healthcare-related quality of life for a wide variety of chronic diseases and conditions.	Not specified	10	HRQoL/ Functional Status
<b>PROMIS-29</b> <sup>86</sup>	A generic health-related quality of life survey that assesses each of the 7 PROMIS domains (physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles and activities, pain interference, pain intensity) with four questions each.	Not specified	29	HRQoL/ Functional Status
<b>PROMIS Physical Function (PF) Item Bank</b> <sup>87</sup>	A generic physical function item bank that can be used across diseases and different levels of ability. It contains four domains: instrumental activities of daily living (IADL), mobility or lower extremity function, back and neck (central) function, and upper extremity function.	Not specified	165 items that can be used in a variety of short forms of varying lengths and via computerized adaptive tests (CATs)	HRQoL/ Functional Status Symptoms/ Symptom Burden
<b>PROMIS Self-Efficacy Item Bank</b> <sup>88</sup>	The PROMIS Self-Efficacy item bank assesses self-reported current level of confidence in managing chronic conditions, including confidence in managing daily activities, managing emotions, managing medication and treatments, managing social interactions, and managing symptoms.	Adults age 18 years and older	147 items that are used in a variety of short forms of varying lengths and via computerized adaptive tests (CATs)	HRQoL/ Functional Status Self-Efficacy
<b>Quality of Well-Being Scale (QWBS)</b> <sup>89</sup>	A general health quality of life questionnaire which measures overall status and well-being over the previous three days in four areas: physical activities, social activities, mobility, and symptom/problem complexes.	Adults age 18 years and older	71	HRQoL/ Functional Status
<b>SF-6D</b> <sup>90</sup>	The SF-6D focuses on seven of the eight health domains covered by the SF-36: physical functioning, role participation, social functioning, bodily pain, mental health, and vitality.	Not specified	11	HRQoL/ Functional Status
<b>SF-12</b> <sup>91</sup>	A patient-reported survey of patient health. Ostendorf et al.	Not specified	12	HRQoL/ Functional Status
<b>SF-36</b> <sup>92</sup>	SF-36 is a patient-reported survey of patient health. RAND Corporation	Not specified	36	HRQoL/ Functional Status

PROM Name	Description, Author, Year	Target Demographic/Care Setting	Number of items (questions)	PRO Domain
<b>Sickness Impact Profile (SIP)</b> <sup>93</sup>	A behavioral-based measure of health status. It assesses quality of life and level of dysfunction that results from disability or illness.	Not specified	68	HRQoL/ Functional Status
<b>Symptoms of Major Depressive Disorder Scale (SMDDS)</b> <sup>94</sup>	The SMDDS is a PROM developed to capture the core symptoms of major depressive disorder that matter most to patients.	Adults age 18 years and older	16	Symptoms/ Symptom Burden
<b>Veterans RAND 12 (VR-12)</b> <sup>95</sup>	VR-12 is a patient-reported global health measure that is used to assess a patient's overall perspective of their health. RAND Corporation	Not specified	12	HRQoL/ Functional Status
<b>Young Adult Health Care Survey (YACHS)</b> <sup>96</sup>	A survey of adolescents that assesses how well the healthcare system provides adolescents with recommended preventive care.	Adolescents 14-18 years	56	HRQoL/ Functional Status Experience

## REFERENCES

- 1 Chen L, Lee AF, Shapiro GD, et al. The Development and Validity of the Adult Burn Outcome Questionnaire. *J Burn Care Res.* 2018; 39(5):771-779.
- 2 Daltroy L, Liang M, Phillips C, et al. American Burn Association/Shriners Hospitals for Children burn outcomes questionnaire: construction and psychometric properties. *J Burn Care Rehabil.* 2000; 21(1):29-39.
- 3 Psychiatry & Behavioral Health Learning Network. <https://www.psychcongress.com/saundras-corner/scales-screenersdepression/beck-depression-inventory-ii-bdi-ii>. Last accessed December 2019.
- 4 Ivarsson T, Lidberg A, Gillberg C. The Birleson Depression Self-Rating Scale (DSRS). Clinical evaluation in an adolescent inpatient population. *J Affect Disord.* 1994; 32(2):115-25.
- 5 Mendelson BK, Mendelson MJ, White DR. Body-Esteem Scale for Adolescents and Adults. *J Pers Assess.* 2001;76(1):90-106.
- 6 Tyack Z, Kimble R, McPhail S, et al. Psychometric properties of the Brisbane Burn Scar Impact Profile in adults with burn scars. *PLoS ONE.* 2017;12(9):e0184452.
- 7 Scribd website. <https://www.scribd.com/document/399672604/Burns-Anxiety-Inventory>. Accessed December 2019.
- 8 Taal LA, Faber AW. The burn specific pain anxiety scale: introduction of a reliable and valid measure. *Burns.* 1997;23(2):147-50.
- 9 Austin J, Huberty T. Development of the Child Attitude Toward Illness Scale. *J Pediatr Psychol.* 1993;18(4):467-480.
- 10 Willebrand M, Kildal M, Ekselius L, et al. Development of the coping with burns questionnaire. *Pers Individ Dif.* 2001;30(6):1059-1072.
- 11 Conte HR, Weiner MB, Plutchik R. Measuring death anxiety: conceptual, psychometric, and factor-analytic aspects. *J Pers Soc Psychol.* 1982; 43:775-785.
- 12 Shirley Ryan Ability Lab. <https://www.sralab.org/rehabilitation-measures/fear-avoidance-beliefs-questionnaire>. Last accessed December 2019.
- 13 Wichstrøm L. Harter's Self-Perception Profile for Adolescents: reliability, validity, and evaluation of the question format. *J Pers Assess.* 1995; 65(1): 100-116.
- 14 McCabe D. The Impact of Event Scale - Revised (IES-R). Try This: Best Practices in Nursing Care to Older Adults. 2019;(19).
- 15 Educational & Industrial Testing Service website. <https://www.edits.net/products/jepq/>. Last accessed December 2019.
- 16 Kazis LE, Marino M, Ni P, et al. Development of the life impact burn recovery evaluation (LIBRE) profile: assessing burn survivors' social participation. *Qual Life Res.* 2017; 26(10):2851-2866.
- 17 Pearson. Multidimensional Anxiety Scale for Children website. <https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Personality-%26-Biopsychosocial/Multidimensional-Anxiety-Scale-for-Children-%7C-Second-Edition/p/100000735.html>. Last accessed December 2019.
- 18 Child Outcomes Research Consortium website. <https://www.corc.uk.net/outcome-experience-measures/paediatric-quality-of-life/>. Last accessed December 2019.
- 19 Freitas NO, Forero CG, Caltran MP, et al. Validation of the Perceived Stigmatization Questionnaire for Brazilian adult burn patients. *PLoS One.* 2018;13(1):e0190747.
- 20 WPS website. <https://www.wpspublish.com/piers-harris-2-piers-harris-childrens-self-concept-scale-second-edition>. Last accessed December 2019.
- 21 Pelley TJ, Brown KJ, Odar CC, et al. The development and preliminary validation of the Psychosocial Adjustment to Burn Questionnaire. *Clinical Practice in Pediatric Psychology.* 2013;1(2):171-183.
- 22 Pearson. Resiliency Scales for Children & Adolescents: A Profile of Personal Strengths website. <https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Resiliency-Scales-for-Children-%26-Adolescents%3A-A-Profile-of-Personal-Strengths/p/100000655.html>. Last accessed December 2019.
- 23 WPS website. <https://www.wpspublish.com/rcmas-2-revised-childrens-manifest-anxiety-scale-second-edition>. Last accessed December 2019.
- 24 Rosenberg M. Society and the adolescent self-image. Princeton University Press. 1965. <https://www.docdroid.net/Vt9xpBg/society-and-the-adolescent-self-image-morris-rosenberg-1965.pdf>. Last accessed December 2019.
- 25 Caltran MP, Freitas NO, Dantas RA, et al. Satisfaction with Appearance Scale-SWAP: Adaptation and validation for Brazilian burn victims. *Burns.* 2016;42(6):1331-9.
- 26 National Longitudinal Surveys website. <https://www.nlsinfo.org/content/cohorts/nlsy79-children/topical-guide/assessments/what-i-am-likeself-perception-profile>. Last accessed December 2019.
- 27 Bendig, AW. The development of a short form of the Manifest Anxiety Scale. *J Consult Psychol.* 1956; 20(5), 384.

- 28 Pearson. Social Skills Rating System website. <https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Social-Skills-Rating-System/p/100000115.html>. Last accessed December 2019.
- 29 Stuijtzand S, Dodd H. Young children have social worries too: validation of a brief parent report measure of social worries in children aged 4–8 years. *J Anxiety Disord.* 2016; 50:87-93.
- 30 SDQ website. <https://www.sdqinfo.com/>. Last accessed December 2019.
- 31 Ryan CM, Lee AF, Kazis LE, et al. Is real-time feedback of burn-specific patient-reported outcome measures in clinical settings practical and useful? a pilot study implementing the Young Adult Burn Outcome Questionnaire. *J Burn Care Res.* 2016;37(1):64-74.
- 32 University of Illinois, Urbana-Champaign. Youth Development website. <http://youthdev.illinois.edu/wp-content/uploads/2013/11/YES-2.0-Instrument.pdf>. Last accessed December 2019.
- 33 University of Washington. Seattle Quality of Life Group website. <http://depts.washington.edu/seaqol/YQOL>. Last accessed December 2019.
- 34 The National Child Traumatic Stress Network. <https://www.nctsn.org/measures/youth-self-report-11-18>. Last accessed December 2019.
- 35 Jaarsma T, Arestedt KE, Martensson J, et al. The European Heart Failure Self-care Behaviour scale revised into a nine-item scale (EHFScB-9): a reliable and valid international instrument. *Eur J Heart Fail.* 2009;11(1):99-105.
- 36 American Thoracic Society website. <https://www.thoracic.org/members/assemblies/assemblies/srn/questionnaires/chfq.php>. Last accessed December 2019.
- 37 Dunderdale K, Thompson DR, Beer SF, et al. Development and validation of a patient-centered health-related quality-of-life measure: the chronic heart failure assessment tool. *J Cardiovasc Nurs.* 2008;23(4):364-70.
- 38 Green CP, Porter CB, Bresnahan DR, et al. Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. *J Am Coll Cardiol.* 2000;35(5):1245-55.
- 39 Spertus JA, Jones PG. Development and validation of a short version of the Kansas City Cardiomyopathy Questionnaire. *Circ Cardiovasc Qual Outcomes.* 2015;8:469-476.
- 40 Bilbao A, Escobar A, Garcia-Perez L, et al. The Minnesota living with heart failure questionnaire: comparison of different factor structures. *Health Qual Life Outcomes.* 2016;14:23.
- 41 Salmon P, Hunt GR, Murthy BVS, et al. Patient evaluation of early discharge after hip arthroplasty: development of a measure and comparison of three centres with differing durations of stay. *Clin Rehabil.* 2013;27(9):854-863.
- 42 Larsson A, Rolfson O, Karrholm J. Evaluation of Forgotten Joint Score in total hip arthroplasty with Oxford Hip Score as reference standard. *Acta Orthopaedica.* 2018;90(3):253-257.
- 43 Nilsson AK, Lohmander LS, Klassbo M, et al. Hip disability and osteoarthritis outcome score (HOOS) – validity and responsiveness in total hip replacement. *BMC Musculoskeletal Disord.* 2003;4(10).
- 44 Gandek B, Roos EM, Franklin PD, et al. A 12-item short form of the Hip disability and Osteoarthritis Outcome Score (HOOS-12): tests of reliability, validity and responsiveness. *Osteoarthritis Cartilage.* 2019; 27(5):754-761.
- 45 Hospital for Special Surgery. HSS website. <https://www.hss.edu/hoos-jr-koos-jr-outcomes-surveys.asp>. Last accessed December 2019.
- 46 eProvide website. <https://eprovide.mapi-trust.org/instruments/injustice-experience-questionnaire>. Last accessed December 2019.
- 47 Knee injury and Osteoarthritis Outcomes Survey website. <http://www.koos.nu/index.html>. Last accessed December 2019.
- 48 Oxford University Innovation. Health Outcomes website. <https://innovation.ox.ac.uk/outcome-measures/oxford-hip-score-ohs/>. Last accessed December 2019.
- 49 Oxford University Innovation. Health Outcomes website. <https://innovation.ox.ac.uk/outcome-measures/oxford-knee-score-oks/>. Last accessed December 2019.
- 50 Bruce B, Fries JF. The Stanford Health Assessment Questionnaire: dimensions and practical applications. *Health Qual Life Outcomes.* 2003;1:20.
- 51 Conradsen S, Gjerset MM, Kvangarsnes M. Patients' experiences from an education programme ahead of orthopaedic surgery – a qualitative study. *J Clin Nurs.* 2016;25(19-20):2798-806.
- 52 Shirley Ryan Ability Lab. Western Ontario and McMaster Universities Osteoarthritis Index website. <https://www.sralab.org/rehabilitation-measures/womac-osteoarthritis-index-reliability-validity-and-responsiveness-patients>. Last accessed December 2019.
- 53 National Council of Juvenile and Family Court Judges website. <https://www.ncjfcj.org/sites/default/files/Finding%20Your%20ACE%20Score.pdf>. Last accessed December 2019.
- 54 Bryant RA, Moulds ML, Guthrie RM. Acute stress disorder: a self-report measure of acute stress disorder. *Psychol Assess.* 2000;12(1):61-68.
- 55 Chung MC, Walsh A, Dennis I. Trauma exposure characteristics, past traumatic life events, coping strategies, posttraumatic stress disorder, and psychiatric comorbidity among people with anaphylactic shock experience. *Compr Psychiatry.* 2011;52(4):394-404.

- 56** National Child Traumatic Stress Network. Child Stress Disorders Checklist. <https://www.nctsn.org/measures/child-stress-disorders-checklist>. Last accessed December 2019.
- 57** National Child Traumatic Stress Network. Child Trauma Screening Questionnaire. <https://www.nctsn.org/measures/child-trauma-screening-questionnaire>. Last accessed December 2019.
- 58** McKinnon A, Smith P, Bryant R, et al. An update on the clinical utility of the Children's Post-Traumatic Cognitions Inventory. *J Trauma Stress*. 2016;29(3):253-258.
- 59** Lambert JE, Benight CC, Harrison E, et al. The firefighter coping self-efficacy scale: measure development and validation. *Anxiety Stress Coping*. 2012;25(1):79-91.
- 60** Danieli Y, Norris FH, Lindert J. The Danieli Inventory of Multigenerational Legacies of Trauma, Part II: Reparative Adaptational Impacts. *Am J Orthopsychiatry*. 2015;85(3):229-237.
- 61** Kubany ES, Kaplan AS, Leisen MB, et al. Validation of a brief measure of posttraumatic stress disorder: The Distressing Event Questionnaire (DEQ). *Psych Assess*. 2000;12(2):197-209.
- 62** Assessment of Quality of Life website. <http://aqol.com.au/>. Last accessed December 2019.
- 63** Agency for Healthcare Research and Quality (AHRQ). CAHPS Health Plan Survey website. <https://www.ahrq.gov/cahps/surveys-guidance/hp/index.html>. Last accessed December 2019.
- 64** AHRQ. CAHPS Child Hospital Survey website. [https://www.ahrq.gov/cahps/surveys-guidance/hospital/about/child\\_hp\\_survey.html](https://www.ahrq.gov/cahps/surveys-guidance/hospital/about/child_hp_survey.html). Last accessed December 2019.
- 65** AHRQ. CAHPS Home and Community-Based Services Survey website. <https://www.ahrq.gov/cahps/surveys-guidance/hcbs/index.html>. Last accessed December 2019.
- 66** AHRQ. CAHPS Home Health Care Survey website. <https://www.ahrq.gov/cahps/surveys-guidance/home/index.html>. Last accessed December 2019.
- 67** Centers for Medicare and Medicaid Services. CAHPS Hospice Survey website. <https://hospicecahpsurvey.org/>. Last accessed December 2019.
- 68** AHRQ. About the CAHPS Item Set for *Addressing Health Literacy*. Rockville, MD: AHRQ; 2012. <https://cahpsdatabase.ahrq.gov/files/CGGuidance/About%20the%20Item%20set%20for%20Addressing%20Health%20Literacy.pdf>. Last accessed December 2019.
- 69** AHRQ. CAHPS Nursing Home Surveys website. <https://www.ahrq.gov/cahps/surveys-guidance/nh/index.html>. Last accessed December 2019.
- 70** American College of Surgeons. S-CAHPS website. <https://www.facs.org/advocacy/quality/cahps>. Last accessed December 2019.
- 71** AHRQ. CAHPS Health Literacy Item Sets website. <https://www.ahrq.gov/cahps/surveys-guidance/item-sets/literacy/index.html>. Last accessed December 2019.
- 72** AHRQ. CAHPS Mental Health Care Surveys website. <https://www.ahrq.gov/cahps/surveys-guidance/echo/index.html>. Last accessed December 2019.
- 73** EuroQol website. <https://euroqol.org/>. Last accessed December 2019.
- 74** Horseman J, Furlong W, Feeny D, et al. The Health Utilities Index (HUI): concepts, measurement properties and applications. *Health Qual Life Outcomes*. 2003; 54(1):1-3.
- 75** National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). *What We Learned from the National Core Indicators (NCI) Adult Family Survey*. [Ohio]. 2013. [https://www.nationalcoreindicators.org/upload/core-indicators/OH\\_AFS\\_User\\_Friendly\\_12-13\\_FINAL\\_Report.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/OH_AFS_User_Friendly_12-13_FINAL_Report.pdf).
- 76** National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). *What We Learned from the National Core Indicators (NCI) Family/Guardian Survey*. [Michigan]. 2016. [https://www.nationalcoreindicators.org/upload/core-indicators/Michigan\\_Report\\_FGS\\_2015-16.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/Michigan_Report_FGS_2015-16.pdf).
- 77** Advancing States, Human Services Research Institute (HSRI). National Core Indicators Aging and Disabilities website. <https://nci-ad.org/>. Last accessed December 2019.
- 78** Nottingham Health Profile. <http://reseauconceptuel.umontreal.ca/rid%3D1J1WXGYDK-CPP19Z-IZQY/>. Last accessed December 2019.
- 79** Insignia Health. Patient Activation Measure website. <https://www.insigniahealth.com/products/pam-survey>. Last accessed December 2019.
- 80** Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001;39(8):800-812.
- 81** The Council on Quality and Leadership. Personal Outcome Measures website. <https://c-q-l.org/the-cql-difference/personal-outcome-measures>. Last accessed December 2019.
- 82** Center for Quality Assessment and Improvement in Mental Health. *The Patient Health Questionnaire (PHQ-9) – Overview*. [http://www.cqaimh.org/pdf/tool\\_phq9.pdf](http://www.cqaimh.org/pdf/tool_phq9.pdf). Last accessed December 2019.

- 83** Center for Quality Assessment and Improvement in Mental Health. *The Patient Health Questionnaire (PHQ-2) – Overview*. [http://www.cqaimh.org/pdf/tool\\_phq2.pdf](http://www.cqaimh.org/pdf/tool_phq2.pdf). Last accessed December 2019.
- 84** HealthMeasures. A brief guide to the PROMIS® Depression instruments website. [http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS\\_Depression\\_Scoring\\_Manual.pdf](http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Depression_Scoring_Manual.pdf). Last accessed December 2019.
- 85** HealthMeasures. A brief guide to the PROMIS® Global Health instruments website. [http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS\\_Global\\_Scoring\\_Manual.pdf](http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Global_Scoring_Manual.pdf). Last accessed December 2019.
- 86** New South Wales Agency for Clinical Innovation. PROMIS-29 Survey. [https://www.aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0003/402087/Overview-of-the-PROMIS-29\\_EH-140817.pdf](https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0003/402087/Overview-of-the-PROMIS-29_EH-140817.pdf). Last accessed December 2019.
- 87** Rose M, Bjorner JB, Gandek B, et al. The PROMIS Physical Function Item Bank was calibrated to a standardized metric and shown to improve measurement efficiency. *J Clin Epidemiol*. 2014;67(5):516-526.
- 88** HealthMeasures. A brief guide to PROMIS® Self-Efficacy Instruments website. [http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS\\_Self\\_Efficacy\\_Managing\\_Chronic\\_Conditions\\_Scoring\\_Manual.pdf](http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Self_Efficacy_Managing_Chronic_Conditions_Scoring_Manual.pdf). Last accessed December 2019.
- 89** Shirley Ryan Ability Lab. Quality of Well Being and Self-Administered instrument website. <https://www.sralab.org/rehabilitation-measures/quality-well-being-and-self-administered-version>. Last accessed December 2019.
- 90** Optum. SF-6D instrument. <https://www.optum.com/content/dam/optum/resources/Manual%20Excerpts/SF-6D.pdf>. Last accessed November 2019.
- 91** RAND. 12-Item Short Form Survey website. [https://www.rand.org/health-care/surveys\\_tools/mos/12-item-short-form.html](https://www.rand.org/health-care/surveys_tools/mos/12-item-short-form.html). Last accessed December 2019.
- 92** RAND. 36-Item Short Form Survey Instrument website. [https://www.rand.org/health-care/surveys\\_tools/mos/36-item-short-form/survey-instrument.html](https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form/survey-instrument.html). Last accessed December 2019.
- 93** Shirley Ryan Ability Lab. Sickness Impact Profile instrument website. <https://www.sralab.org/rehabilitation-measures/sickness-impact-profile>. Last accessed December 2019.
- 94** U.S. Food and Drug Administration (FDA). DDT COA #000008: Symptoms of Major Depressive Disorder Scale (SMDDS) website. <https://www.fda.gov/drugs/drug-development-tool-qualification-programs/ddt-coa-000008-symptoms-major-depressive-disorder-scale-smdds>. Last accessed December 2019.
- 95** Code Technology. Veterans RAND 12 Item Health Survey (VR-12) global health measure website. <https://www.codetechnology.com/vr-12-general-health-pro-tool/>. Last accessed December 2019.
- 96** The Child & Adolescent Measurement Initiative. Young Adult Health Care Survey. <https://www.cahmi.org/projects/yahcs/>. Last accessed December 2019.

## APPENDIX D: PRO-PMs Relevant for Burns, Trauma, Joint Replacement, and Heart Failure

### Burns

No PRO-PMs relevant to burns were identified.

### Heart Failure

No PRO-PMs relevant to burns were identified.

### Joint Replacement

Measure Title	Description	Service Setting	Level of Analysis	NQF #	NQF-Endorsed?	PRO Domain
<b>Functional Status Change for Patients with Knee Impairments</b>	A self-report measure of change in functional status for patients 14 year+ with knee impairments. The change in functional status assessed using FOTO's (knee) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level to assess quality.	Outpatient Services Post-Acute Care Hospital Outpatient	Clinician: Group/Practice  Clinician: Individual Facility	0422	Endorsed	HRQoL/ Functional Status
<b>Functional Status Change for Patients with Hip Impairments</b>	A self-report measure of change in functional status for patients 14 years+ with hip impairments. The change in functional status assessed using FOTO's (hip) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level to assess quality.	Outpatient Services Post-Acute Care Hospital Outpatient	Clinician: Group/Practice  Clinician: Individual Facility	0423	Endorsed	HRQoL/ Functional Status
<b>Functional Status Change for Patients with Foot and Ankle Impairments</b>	A self-report measure of change in functional status for patients 14 years+ with foot and ankle impairments. The change in functional status assessed using FOTO's (foot and ankle) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level to assess quality.	Outpatient Services Post-Acute Care Hospital Outpatient	Clinician: Group/Practice  Clinician: Individual Facility	0424	Endorsed	HRQoL/ Functional Status

Measure Title	Description	Service Setting	Level of Analysis	NQF #	NQF-Endorsed?	PRO Domain
<b>Functional Status Change for Patients with Low Back Impairments</b>	This is a patient-reported outcome performance measure (PRO-PM) consisting of an item response theory-based patient-reported outcome measure (PROM) of risk-adjusted change in functional status (FS) for patients aged 14 years and older with low back impairments. The change in FS is assessed using the Low Back FS PROM. The measure is adjusted to patient characteristics known to be associated with FS outcomes (risk adjusted) and used as a performance measure at the patient, individual clinician, and clinic levels to assess quality. Scores are reported on a 0 to 100 continuous scale with higher scores indicating better FS. The Low Back FS PROM maps to the Mobility and Self-care constructs within the Activities and Participation domain of the International Classification of Functioning, Disability and Health.	Home Care Other Outpatient Services Post-Acute Care	Clinician: Group/Practice  Clinician: Individual Facility	0425	Endorsed	HRQoL/ Functional Status
<b>Functional Status Change for Patients with Shoulder impairments</b>	A self-report outcome measure of change in functional status for patients 14 years+ with shoulder impairments. The change in functional status assess using FOTO's (shoulder) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level to assess quality.	Home Care Other Outpatient Services Post-Acute Care	Clinician: Group/Practice  Clinician: Individual Facility	0426	Endorsed	HRQoL/ Functional Status Experience with Care
<b>Functional Status Change for Patients with Elbow, Wrist and Hand Impairments</b>	A self-report outcome measure of functional status for patients 14 years+ with elbow, wrist, hand impairments. The change in functional status assessed using FOTO (elbow, wrist and hand) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level to assess quality.	Other Outpatient Services Post-Acute Care	Facility  Clinician: Group/Practice  Clinician: Individual	0427	Endorsed	HRQoL/ Functional status Experience with Care

Measure Title	Description	Service Setting	Level of Analysis	NQF #	NQF-Endorsed?	PRO Domain
<b>Functional Status Change for Patients with General Orthopedic Impairments</b>	A self-report outcome measure of functional status for patients 14 years+ with general orthopedic impairments. The change in functional status assessed using FOTO (general orthopedic) PROM is adjusted to patient characteristics known to be associated with functional status outcomes (risk adjusted) and used as a performance measure at the patient level, at the individual clinician, and at the clinic level by to assess quality.	Other Outpatient Services Post-Acute Care	Facility Clinician: Group/Practice Clinician: Individual	0428	Endorsed	HRQoL/ Functional Status Experience with Care
<b>Average Change in Functional Status Following Total Knee Replacement Surgery</b>	For patients age 18 and older undergoing total knee replacement surgery, the average change from pre-operative functional status to one year (nine to fifteen months) post-operative functional status using the Oxford Knee Score (OKS) patient reported outcome tool.	Outpatient Services	Clinician: Group/Practice	2653	Endorsed	HRQoL/ Functional Status
<b>Informed, Patient Centered (IPC) Hip and Knee Replacement Surgery</b>	Informed, Patient Centered (IPC) Hip and Knee Replacement Surgery	Outpatient Services	Clinician: Group/Practice	2958	Endorsed	HRQoL/ Functional Status
<b>Shared Decision-Making Process</b>	This measure assesses the extent to which healthcare providers actually involve patients in a decision-making process when there is more than one reasonable option. This proposal is to focus on patients who have undergone any one of 7 common, important surgical procedures: total replacement of the knee or hip, lower back surgery for spinal stenosis of herniated disc, radical prostatectomy for prostate cancer, mastectomy for early stage breast cancer or percutaneous coronary intervention (PCI) for stable angina. Patients answer four questions (scored 0 to 4) about their interactions with providers about the decision to have the procedure, and the measure of the extent to which a provider or provider group is practicing shared decision making for a particular procedure is the average score from their responding patients who had the procedure.	Outpatient Services	Clinician: Group/Practice	2962	Endorsed	Experience with Care

Measure Title	Description	Service Setting	Level of Analysis	NQF #	NQF-Endorsed?	PRO Domain
<b>CollaboRATE Shared Decision-Making Score</b>	CollaboRATE is a patient-reported measure of shared decision making which contains three brief questions that patients, their parents, or their representatives complete following a clinical encounter. The CollaboRATE measure provides a performance score representing the percentage of adults 18 and older who experience a high level of shared decision making. The measure was developed to be generic and designed so that it could apply to all clinical encounters, irrespective of the condition or the patient group. The measure asks the patient to evaluate the 'effort made' to inform, to listen to issues that matter to the patient, and to include those issues in choosing 'next steps'. The items were co-developed with patients using cognitive interview methods.	Inpatient/Hospital Outpatient Services	Clinician: Group/Practice	3227	Endorsed	Experience with Care
<b>Average Change in Functional Status Following Total Hip Replacement Surgery</b>	For patients age 18 and older undergoing total hip replacement surgery, the average change from pre-operative functional status/quality of life to one year (nine to fifteen months) post-operative functional status/quality of life using the PROMIS Global-10 and/or HOOS-PS (Short Form) patient reported outcome tool.	Outpatient Services: Clinician Office/Clinic	Clinician: Group/Practice		Not Endorsed	HRQoL/ Functional Status
<b>Care Goal Achievement Following Total Hip Arthroplasty (THA) and/or Total Knee Arthroplasty (TKA)</b>	The measure is derived from patient responses to a new instrument that will be developed related to care goal achievement following total hip arthroplasty (THA) and/or total knee arthroplasty (TKA). The new tool will assess the patient's main goal(s) (e.g., expectations) before the surgery (e.g., specific to functional status, pain, ability to work) and its achievement at X time after the surgery (e.g., 3, 6 and 12 months). We will define and develop an achievement score to assess if (or the level to which) the patient's goals/expectations were addressed. The target population is adult patients (age 18 and older) who had a THA and/or TKA. The numerator, denominator and the exclusions criteria need to be defined, developed and vetted with stakeholders.	Outpatient Services: Clinician Office/Clinic	Clinician: Group/Practice		Not Endorsed	HRQoL/ Functional Status Experience with Care

Measure Title	Description	Service Setting	Level of Analysis	NQF #	NQF-Endorsed?	PRO Domain
<b>Functional Status Improvement for Patients Who Received a Total Hip Replacement</b>	Average change in functional status assessment (FSA) score for patients age 18 and older who received an elective primary total hip arthroplasty and completed an FSA within 90 days before their surgery and in the 270 to 365 days after their surgery.	Not available	Not available		Not Endorsed	HRQoL/ Functional Status
<b>Functional Status Improvement for Patients Who Received a Total Knee Replacement</b>	Average change in functional status assessment (FSA) score for patients age 18 and older who received an elective primary total knee arthroplasty and completed an FSA within 90 days before their surgery and in the 270 to 365 days after their surgery.	Not available	Not available		Not Endorsed	HRQoL/ Functional Status
<b>Functional Status Outcomes for Patients Receiving Primary Total Hip Replacements</b>	Average change in functional status assessment score for 19 years and older with primary total hip arthroplasty (THA) in the 180-270 days after surgery compared to their initial score within 90 days prior to surgery.	Not available	Not available		Not Endorsed	HRQoL/ Functional Status
<b>Functional Status Outcomes for Patients Receiving Primary Total Knee Replacements</b>	Average change in functional status assessment score for 19 years and older with primary total knee arthroplasty (TKA) in the 180-270 days after surgery compared to their initial score within 90 days prior to surgery.	Not available	Not available		Not Endorsed	HRQoL/ Functional Status

## Trauma

No PRO-PMs relevant to trauma were identified.

## Other Potentially Relevant PRO-PMs

NQF #	Measure Title
0209	Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment
0228	3-Item Care Transition Measure (CTM-3)
0676	Percent of Residents Who Self-Report Moderate to Severe Pain (Short Stay)
0677	Percent of Residents Who Self-Report Moderate to Severe Pain (Long Stay)
0711	Depression Remission at Six Months
1884	Depression Response at Six Months- Progress Towards Remission
1885	Depression Response at Twelve Months - Progress Towards Remission
2483	Gains in Patient Activation (PAM) Scores at 12 Months
2789	Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care
3227	CollaboRATE Shared Decision Making Score
0710e	Depression Remission at Twelve Months

**NATIONAL QUALITY FORUM  
1099 14TH STREET NW, SUITE 500  
WASHINGTON, DC 20005**

**<http://www.qualityforum.org>**