NATIONAL
QUALITY FORUM

Measuring What Matters to Patients:

Innovations in Integrating the Patient Experience into Development of Meaningful Performance Measures

AUGUST 28, 2017

This project was supported by PatientsLikeMe®,
with funding from the Robert Wood Johnson Foundation.

CONTENTS

EXECUTIVE SUMMARY

To make a meaningful shift to patient-centeredness, quality measurement needs to focus on patient priorities. This can only be accomplished through broad engagement of patients during measure development and implementation.

The Robert Wood Johnson Foundation (RWJF) funded PatientsLikeMe® in partnership with the National Quality Forum (NQF) to evaluate the novel approach of using online patient-reported data to inform the development and refinement of patient-reported outcome performance measures (PRO-PMs). This work builds upon NQF's previous PRO-PM research and PatientsLikeMe's online patient community-based platform research.

The findings of this work confirm that patient-reported outcomes are integral in developing meaningful quality measures and suggest that in aggregate, patient-reported outcomes can offer several solutions to current measurement challenges:

- **Improving data quality**—Real-time collection of patient-report data through virtual community-based platforms can minimize recall bias and improve the quality of symptom-related data.
- **Representing patient experience**—Aggregate feedback from heterogeneous communities of patients can generate a rich and broad spectrum of data, which, in turn, provides a more realistic representation of the collective patient experience.
- **Identifying patient concerns**—Collective data on the patient experience illuminate the prioritization of certain symptoms, limitations, goals, and attitudes that may not be apparent when patients are queried through traditional research approaches.
- **Prioritizing symptoms—**Commonalities of symptoms across diagnoses provide opportunities and new approaches to symptom assessment that focus on what is important to patients from a health-related, quality-of-life perspective.

The innovative work outlined in this paper demonstrates the remarkable power of online patient communities to insert the collective experience of patients into measurement. Online patient communities have the potential to serve as virtual "town squares" where measure developers and other stakeholders can access the patient experience not otherwise available. This new approach will help advance the nation toward more patient-centered care that meets the needs of individual patients and the population as a whole.

INTRODUCTION

The use of performance measures for public reporting and quality improvement has improved healthcare to a degree over the past two decades. Clinical measures developed to meet the needs of clinicians and payers are abundant. However, the patient's "voice" is often silent or barely audible within existing measures. To achieve and sustain a high-performing healthcare system, measurement must catalyze progress towards care that is not only safe and effective, but also patient-centered. Moreover, as pay-for-performance programs continue to gain ground in the public and private sectors, it has never been more important to develop measures that assess healthcare quality in a way that matters to patients.

Existing models of patient engagement have demonstrated some success in measure development. However, innovative approaches are needed to capture the range of perspectives among patients with specific health conditions or within specific healthcare settings. To that end, the Robert Wood Johnson Foundation (RWJF) commissioned this paper as part of work to test an innovative approach to engaging patients in measure development using patient-reported outcome measures (PROMs). This paper provides a high-level background on patient-reported outcome-based performance measurement and patient engagement in measure development. This paper also summarizes grant-funded work by **PatientsLikeMe®**, in partnership with the National Quality Forum (NQF) Measure Incubator™, using PatientsLikeMe's online patient community-based platform to gather patient experience and feedback for use in measure development. The results of this work provide a pathway to amplifying the patient's voice in quality measurement, ensuring that measures used in quality improvement and accountability programs reflect those outcomes that are most meaningful to patients.

BACKGROUND

The National Quality Forum defines patient-reported outcomes (PROs) as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else." PROs are typically captured using validated instruments or questionnaires called patient-reported outcome measures (PROM). In other words, PROMs measure what patients are able to do and how they feel by asking questions.

PROMs offer patients an opportunity to reflect on outcomes important to them on an individual and population level. PROMs assist patients not only in identifying individual preferences in care, but also in providing valuable outcome information to drive more meaningful performance improvement and accountability in a high-quality, affordable health system. PROMs have an extensive history as clinical research tools. FDA has long supported their use in clinical trials, with over 15 percent of new drugs from 2011 to 2015 including PRO labeling.[1] Incorporating PROMs in the clinical setting offers a greater opportunity to engage patients as stewards in their health and healthcare. Furthermore, the routine collection of PROMs at clinically relevant inflection points can enhance shared decision making and promote more patient-centered healthcare. After engaging in shared decision making, patients tend to experience better outcomes[2,3,4] and choose less costly, more effective interventions.[5] PROMs also provide critically necessary information for clinicians that frequently has been absent to date. However, guidance and real-world examples are still needed for the emerging use of PROMs in clinical practice and measurement.

NQF Framework for Translating PROs into Performance Measures

In 2013, NQF published *Patient Reported Outcomes in Performance Measurement.* The report outlines a framework to translate PROs into NQF-endorsed patient-reported outcome performance measures (PRO-PMs)[6,7] that may be used in public reporting and reimbursement programs (Figure 1). The report also highlights methodological and data challenges in the development and use of PRO-PMs, including data collection and aggregation to assess organization and provider-level performance and accountability.

This seminal work, together with broad recognition of critical gaps in PRO-PMs, has established patient-reported outcomes as a high priority of the **NQF Measure Incubator™**. The NQF Measure Incubator™ is an innovative effort that facilitates efficient measure development and testing, while addressing important aspects of care for which quality measures are underdeveloped or nonexistent. Over half of the Measure Incubator's current projects focus on PRO-PMs. Multistakeholder project teams are using NQF's PRO to PRO-PM framework to explore agile approaches to incubate and test PRO-PMs more efficiently and to engage patients throughout the measure development process. More information about the Measure Incubator and the current projects is available on the NQF Measure Incubator **projects webpage**.

FIGURE 1. NQF FRAMEWORK: PRO TO NQF-ENDORSED PRO-PM

PRO →	PROM →	PRO-PM
patient-reported outcomes	*instrument, tool, single-item measure*	*PRO-based performance measure*
information on the patient, told by the patient, without interpretation	way to collect information told by the patient without interpretation	way to aggregate the information that has been shared and collected into a reliable, valid measure of performance
EXAMPLE: Patients with Clinical Depression		
Symptom: depression	**Patient Health Questionnaire (PHQ-9©), a standardized tool to assess depression**	**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)**

Engaging Patients in Measure Development

Consumers are the ultimate stakeholders in quality measurement, offering viewpoints inherently distinct from other stakeholders.[8] Patients can offer a unique perspective in identifying and prioritizing measurement gaps by sharing their experiences with specific conditions and treatments.[9] Thus, policymakers and quality experts advocate for quality measures that broadly encompass patient perspectives, values, and priorities. Several organizations have issued practical guidance for engaging patients throughout measure development and implementation:

- The Centers for Medicare & Medicaid Services (CMS) outlined within its Measures Management System Blueprint best practices for working with patient partners, engaging focus and work groups, and managing patient/family technical expert panels.[10]
- In its 2017 report, *Principles for Making Health Care Measurement Patient-Centered*, American Institutes for Research (AIR) outlined five principles for patient-centered quality measurement, including patient-driven and co-created measurement.[11]
- Substantial patient participation is a cornerstone of all Patient-Centered Outcomes Research Institute (PCORI)-funded research. In addition, PCORI has issued guidelines for patient-centered measure development, automated data collection, and performance improvement.

Both the public and private sectors have worked to engage patients in measure development and reporting and to incorporate their feedback on meaningful outcomes of interest. Such real-world input has guided the development of PROs, PROMs, and PRO-PMs focused on health-related quality of life, functional status, symptom burden, and health behaviors. For example:

- The National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS) is a resource of highly reliable, precise measures of patient-reported health status across physical, mental, and social well-being. Patients were directly involved in developing and validating the PROMIS measures, which are used in clinical trials and translational research.[12]
- PCORI-funded research to develop PROMs and PRO-PMs for various conditions and healthcare settings has incorporated substantial patient and caregiver input in the development and validation of these outcomes.[13]
- The pharmaceutical industry is beginning to incorporate patient input to develop PROMs to better assess the impact of new pharmaceuticals.[14]
- The International Consortium for Health Outcomes Measures (ICHOM) has developed over 20 outcome standard sets for varying conditions, with patient representatives involved throughout standard set development. PROs are featured prominently within these standard sets.[15]

Challenges of Current Models for Patient Engagement

Current models for patient input include engaging individual patients or small groups of patients through technical advisory panels, structured or unstructured interviews, or formal testing of instruments. These efforts are often met with significant challenges—in particular, the variability and subjectivity of patient experience and perception—limiting the substance and diversity of the resulting patient input. Without sufficient patient representation, it is impossible to know whether patient feedback is idiosyncratic or representative of the target population. In addition, the individual patient voice may be somewhat overwhelmed by the views of clinicians, providers, and others. Ideally, larger population segments could consult in this process to ensure that the outcomes are both meaningful and comprehensive for the population of interest.

Policymakers, healthcare providers, and measure developers continue to test new approaches to involve patients, families, and consumers in quality measurement. Despite these advances, there remain barriers to effective and sustained stakeholder engagement throughout the quality measurement lifecycle. A recent report by RAND Corporation—*Engaging Consumers in the Quality Measurement Enterprise*—identified six barriers to consumer engagement throughout the quality measurement lifecycle. These barriers largely related to delayed or insufficient patient representation during the measure development process and inadequate education on measure development.[16] Thus, opportunities remain to identify effective ways to integrate the patient's experience, values, and priorities in quality measurement.

A New Model for Patient Engagement

The proliferation of patient participation in social networks via online platforms creates an opportunity for greater patient engagement in quality improvement. Online patient communities have led to new mechanisms to identify patient priorities in measure development. These forums can provide information and disease education, along with opportunities for patients and caregivers to interact with each other. For example, the Association of Cancer Online Resources links to over 140 online communities for cancer patients and caregivers,[17] and the National Organization for Rare Disorders provides information on over 1,800 patient organizations related to rare diseases, many of which include online patient portals.[18]

With over 500,000 members (representing over 2,700 conditions and 43 million data points), PatientsLikeMe is the most widely used web-based patient community today. It is an online research platform where patients share structured data on health conditions, treatments, symptoms, and comorbidities via personal profiles. All patients are asked to report on five cross-cutting or core symptoms—fatigue, pain, insomnia, depressed mood, and anxious mood—along with other symptoms specific to their health conditions. Membership at PatientsLikeMe is free, and members join the network with the explicit understanding that any data provided will be shared anonymously but openly for research purposes. Patients also participate in online forums, where additional perspectives may be collected and analyzed through qualitative data analysis and natural language processing. Periodically, PatientsLikeMe members are invited to participate in research surveys. PatientsLikeMe's research mission is to conduct participatory research with its members, creating opportunities to understand their perspectives regarding their health conditions, treatment experiences, and healthcare delivery. Social network and community resources like PatientsLikeMe can provide a valuable bridge from the community to healthcare quality and improvement.

OBJECTIVE

To explore and evaluate a novel approach to inform the development and refinement of PRO-PMs using patient-reported data, PatientsLikeMe in partnership with NQF, sought to identify, prioritize, and contextualize health-related quality-of-life and functional status outcomes for Chronic Obstructive Pulmonary Disease (COPD),[19] Multiple Sclerosis (MS),[20] and Rheumatoid Arthritis (RA)[21] and to establish a foundation for developing patient-centered performance measures using aggregated qualitative and quantitative data generated from online communities like PatientsLikeMe.

METHODS

Three measure development projects in the NQF Measure Incubator™ served as the research testbed for this effort, and were used to examine how aggregated qualitative and quantitative patient-reported experience data might inform:

- Identification of outcomes that are meaningful to the target population and are amenable to change;
- Selection of PROMs that best capture these outcomes;
- Refinement of measures to match patient priorities;
- Examination of the impact of generic and specific measures to address multiple conditions; and
- Development of meaningful performance measures.

Aggregated patient-reported data were summarized in Patient Experience Reports prepared by PatientsLikeMe, and were shared and reviewed in detail by each Measure Incubator project team. Report content and methodology are described below.

Patient Experience Report Components

For each of the three conditions (COPD, MS, and RA), PatientsLikeMe collected and analyzed qualitative and quantitative platform data. In addition, the RA and COPD projects elicited targeted feedback in the form of a survey from the PatientsLikeMe community on existing PROMs. PatientsLikeMe collected the results to develop condition-specific Patient Experience Reports. Each report described the patient community (gender, age, race, ethnicity, diagnosis status, education level and insurance), analyzed multiple data sources from the PatientsLikeMe platform, and provided associated recommendations.

Member self-reports on the PatientsLikeMe platform included their responses to five core symptoms (pain, fatigue, insomnia, depressed mood, and anxious mood) that are presented in a Likert format (none, mild, moderate, severe) across all conditions. These core symptoms are derived from physical and mental health symptoms identified in the **Patient-Reported Outcomes Measurement System (PROMIS) domain framework** of health-related quality-of-life.

Patient Profile Data Analysis

The analysis used structured data collected via the PatientsLikeMe platform to support retrospective, exploratory analyses of patient-contributed data within patient communities. Analyses yielded information about community characteristics (e.g., demographics, age of disease onset), symptom severity, health-related quality of life, comorbidities, medications, and nondrug treatments. Results were based on those patients who chose to report a specific data element, as all data donation on the PatientsLikeMe platform is voluntary.

Survey Data Analysis

To gain patient perspectives and input on PROMs under consideration in the COPD and RA performance measures, PatientsLikeMe conducted surveys to determine how the PROMs match patient priorities and address important gaps. The surveys aimed to help measure developers better understand which PROM items reflected content that is important to patients and what additional content patients define as relevant. Patients were presented with individual PROM items and asked to rate the importance of each item's content using a five-point Likert-type rating scale. Patients were also asked to assess overall content coverage of the PROM and provide additional feedback about items not covered that they considered important to discuss with their provider.

Free Text Data Analysis

PatientsLikeMe forums capture discussions of patient health experiences, including posts of patient-reported outcomes. Directed content analysis was used to identify themes relating to patient-reported topics, including symptoms and health outcomes.[22] Irrelevant posts (e.g., social chatter and moderator posts) were excluded. The relevant forum posts were qualitatively analyzed to create a better understanding of patient discussions of outcomes and symptoms.

Introduction into Measure Incubator Project Cycles

The Patient Experience Reports were then introduced at different times to the Measure Incubator projects.

- **COPD project:** the project team received the report after the measure had been specified and posted for public comment;
- **MS project:** the project team received the report after a strategy session meeting which brought together an expert panel to develop prioritized measure concepts—but prior to formal measure development;
- **RA project:** the project team received the report prior to a strategy session meeting which allowed for expert panel consideration and aided in measure concept prioritization.

Multistakeholder expert panels participating in the MS and RA strategy sessions referred to the reports to explore measure outcomes such as health-related quality of life, symptom management, and functional status. The panels considered how the distinctions in the individual conditions (e.g., different treatments, newly diagnosed) informed outcome measurement. The Patient Experience Reports provided a broad range of experiences accounting for variation in different symptoms and symptom burden across disease stages and progression. For all of the projects, the qualitative analysis of the condition-specific discussion forums provided valuable context for the panel's deliberations.

RESULTS

Patient Experience Reports for COPD, MS, and RA provided valuable feedback to the Measure Incubator projects for the development of both measure concepts and measures. The reports also provided input on assessing the usefulness of specific PROMs and identifying what is missing from the patient perspective in quality of care that, if included, could provide a more comprehensive assessment directly connected to patient priorities. Highlights from each condition-specific report are included below.

Chronic Obstructive Pulmonary Disease (COPD) Patient Experience Report[a]

PatientsLikeMe produced the first Patient Experience Report in September 2016, in response to a call for public comment on a COPD-focused measure already under development by Minnesota Community Measurement (MNCM).[23] In producing this report, PatientsLikeMe leveraged information from its platform population of 2,545 patients with COPD. Key findings are summarized below.

Patient Profile Data Analysis – Approximately 75 percent of PatientsLikeMe's COPD patient community reported *moderate to severe* fatigue in their most recent symptom report, with nearly 70 percent reporting *moderate* to *severe* pain. Fatigue and pain were reported as *moderate* to *severe* more frequently than respiratory symptoms, including dyspnea, cough, and wheezing. More than half of patients reported *moderate* to *severe* insomnia, and over 45 percent reported *moderate* to *severe* anxious mood.

Survey Data Analysis – Prior to this project, MNCM had selected two PROMs—the *Clinical COPD Questionnaire* (CCQ)[24] and the *COPD Assessment Test* (CAT)[25]—to determine the health status of patients with COPD. PatientsLikeMe members who matched the measure's target population[26] were invited to provide feedback on the two PROMs. Specifically, patients were asked to evaluate the importance of individual PROM items in discussions with their healthcare provider. Twenty-four PatientsLikeMe members, representing each stage of COPD, responded. Half of the participants reported having five or more comorbid conditions, including asthma, diabetes type 2, pneumonia, hypertension, multiple sclerosis, and generalized anxiety disorder.

Most CCQ and CAT items were rated as *very important* ("4" on a 5-point Likert scale) in patient/ provider discussions regarding the impact of COPD on health status. However, there was variability in ratings across patients. For example, 70 percent of CCQ items were rated as *not important* ("1" on a 5-point Likert scale) or *a little important* ("2" on a 5-point Likert scale). Future research with a larger sample size might have the power to determine if the stage of COPD or other clinical or demographic characteristics may account for these differences.

After reviewing all CCQ and CAT items, patients were asked to identify additional outcomes and topics they would like their doctors to discuss with them. Content analysis of this open-text data revealed the following themes:

Symptom characteristics (frequency, seasonal patterns, daily patterns, triggers, chest pain, and shortness of breath during or after eating);

Lifestyle issues (sleep and weight gain/loss);

Treatment issues (understanding when medications are effective, transporting oxygen, and compliance with and usefulness of breathing techniques); and

Fears of becoming breathless, which can interfere with desired activities.

---

[a] Results are based on those patients who chose to report a specific data element, as all data donation on the PatientsLikeMe platform is voluntary. Access to the full report is at https://www.patientslikeme.com/.

Free Text Data Analysis – All posts written within the PatientsLikeMe Lung and Respiratory forum were queried for references to "COPD." Patients discussed symptomatic outcomes that were consistent with proposed measure specifications (e.g., coughing, excessive phlegm, and dyspnea). In addition, patient forums reflected discussions of concerns that were noted as gaps in the CCQ and CAT survey instruments. Identification and management of COPD symptom triggers were mentioned frequently. For instance, patients referred to fear associated with symptom exacerbation and subsequent irreversible lung damage due, in part, to not recognizing and/or managing their potential triggers. Patients also discussed coping strategies, alternative therapies, and challenges with interacting with the medical community.

Multiple Sclerosis (MS) Patient Experience Report[a]

The Patient Experience Report for MS was created after NQF Measure Incubator held a strategy session, where an expert panel identified and prioritized measure concepts. The report included analyses of patient profile and free text data, gathered from PatientsLikeMe's MS population (51,699 patients at the time the report was generated). Below are major themes from the report.

Patient Profile Data Analysis – PatientsLikeMe's large MS community allowed for PatientsLikeMe to characterize differences among three MS subtypes: **relapsing-remitting MS** (RRMS), **primary progressive MS** (PPMS), and **secondary progressive MS** (SPMS). Patients with progressive subtypes of MS (PPMS and SPMS) reported higher prevalence of *moderate* to *severe* symptoms for PatientsLikeMe core symptoms (i.e., fatigue, pain, insomnia, and depressed and anxious mood) and MS-specific symptoms. Patients with progressive forms of MS also appeared more likely to have potentially risky experiences of choking on foods and liquids. Likewise, they reported increased numbness, tremor, and photophobia. Patients with PPMS were found to have relatively elevated chances of experiencing *moderate* to *severe* problems with all MS relapsing items and higher levels of PatientsLikeMe core symptoms, such as fatigue, pain, insomnia, and mood, relative to patients with RRMS. Furthermore, patients with SPMS reported significantly elevated levels of spasticity, sexual dysfunction, bladder problems, and bowel problems. These differences suggest that it might be appropriate to consider quality of care as arrayed against the patient's specific MS subtype, rather than applying a one-size-fits-all approach.

Platform data showed the prevalence of *moderate to severe* ratings of symptoms among the PatientsLikeMe MS community. Of PatientsLikeMe's core symptoms, fatigue was most frequently rated as *moderate* to *severe*. Among MS-specific symptoms that PatientsLikeMe tracks (i.e., stiffness/spasticity, excessive daytime sleepiness, brain fog, bladder problems, mood swings, sexual dysfunction, emotional lability and bowel problems), stiffness/spasticity had the highest rate of *moderate* to *severe* ratings.

Free Text Data Analysis – Patients referred to a loss of intimacy with their partners due to a loss of sex drive and the inability to share a bed. Patients also mentioned that weather exacerbated some of their symptoms, further decreasing their mobility. Worry and depression were attributed to rapid functional or neurological changes experienced frequently and without notice. Typically, these changes were discovered during imaging tests (i.e., magnetic resonance imaging, or MRI) and doctor visits, creating apprehension surrounding such appointments.

Patients also noted the side effects of many MS medications. The most frequent discussion focused on modes and tricks for a painless

---

[a] Results are based on those patients who chose to report a specific data element, as all data donation on the PatientsLikeMe platform is voluntary. Access to the full report is at https://www.patientslikeme.com/.

injection experience. Patients mentioned the injection's low temperature as the principal cause for intolerability. To minimize this pain, patients reported removing their injectable medication from the refrigerator up to a week before use. Outside of discussions regarding symptom burden, patients also shared concerns that their children might be diagnosed with MS. Patients discussed alternative therapies, desire for support and understanding, and challenges when interacting with the medical community as well.

Rheumatoid Arthritis (RA) Patient Experience Report[a]

The RA Patient Experience Report was created before the NQF Measure Incubator strategy session and circulated as pre-read material to inform prioritization of measure concepts. Major findings are summarized below.

Patient Profile Data Analysis – Analysis of PatientsLikeMe's RA community database of nearly 10,000 patients indicated that most patients with RA experience *moderate* to *severe* joint pain. Patients also reported high levels of fatigue and insomnia. Nearly 90 percent of patients reported that their health has limited their scope of possible activities *some, most,* or *all of the time*. Physical health and emotional health interfered with social activities, as reported by 74 percent and 58 percent of patients, respectively. In addition, 67 percent of patients reported that their illness or treatment interfered with their sex life *some, most,* or *all of the time*.

Survey Data Analysis – The Routine Assessment of Patient Index Data (RAPID3),[27] a PROM routinely used for rheumatic diseases, was selected to elicit patient priorities when discussing their RA with their healthcare provider. RAPID3 is recommended as a clinical care tool due to its sensitivity to change, its discriminatory power, and its feasibility in the clinical setting.[28] Patients with RA were asked to evaluate the importance of individual RAPID3 questions in tracking their disease severity, along with the overall relevance and coverage of the tool. The survey was completed by 109 members of the PatientsLikeMe RA community who, on average, had been diagnosed with RA for 12 years (SD=11.6). Over half of respondents described their RA as "somewhat" under control. Comorbid diagnoses of fibromyalgia, osteoarthritis, hypothyroidism, and asthma were also reported.

Most patients indicated that individual RAPID3 items—and the overall PROM—were *very important* to discuss with their healthcare providers. However, patients identified several gaps that would be important in discussing the impact of RA with their providers:

- Difficulty completing daily activities due to limited mobility;
- Impairment in role functioning (occupational/homemaker/caregiver activities);
- Impact on social/recreational activities;
- RA-specific symptoms and other health-related concerns;
- Emotional well-being; and
- Treatment-related concerns.

Respondents noted the importance of understanding their symptoms within the context of triggers and environmental factors, similar to comments in the COPD Patient Experience Report. Patients also provided item-specific feedback on the RAPID3, most frequently on the pain item. Patients described challenges in quantifying pain, including subjectivity in pain-rating scales, and fluctuations in pain in a given week. Patients also requested more specific pain questions (e.g., for different types of pain) and questions to capture the impact of pain on psychological health.

Finally, patients provided feedback on how to best collect and use the PROM data. Suggestions

---

[a] Results are based on those patients who chose to report a specific data element, as all data donation on the PatientsLikeMe platform is voluntary. Access to the full report is at https://www.patientslikeme.com/.

included having options to write in free text for items not covered, using responses to inform treatment and care, administering the PROM in a conversation format (e.g., semi-structured interview) with healthcare providers, and having questions that more effectively target impaired functioning for patients with all levels of RA. For example, one patient indicated that the RAPID3 did not accurately capture his mild impairment due to RA (i.e., the questionnaire was more appropriate for patients with more moderate or severe impairments).

Free Text Data Analysis – Qualitative analyses of forum posts uncovered important outcomes related to living with and managing RA, which were not captured through other sources. Patients most frequently mentioned joint pain, decreased mobility, fatigue, depression, inflammation, anxiety, and chronic pain. Sleep disturbance, worry, fear, and loss of independence due to RA were mentioned less frequently. The unpredictable nature of RA symptom flares causes anxiety and depression for some patients. Others reported that providers did not listen and did not understand the emotional burdens of RA, such as anxiety and depression. Patients also expressed concerns regarding the impact of weather on their symptoms, worry that their children may be diagnosed with RA, and challenges when interacting with the medical community.

Common Symptoms Across Reports

Measures that focus on common symptoms may be more valuable than ones that focus on specific diagnoses because they allow comparisons in the patient experience across conditions. PatientsLikeMe prompts for five core symptoms—fatigue, pain, insomnia, depressed mood, and anxious mood—in a consistent manner across a vast array of conditions. This demonstrates that these problematic symptoms are shared, despite the varied nature of the specific conditions. This finding is particularly prominent for a symptom like fatigue, which has at least moderate severity across conditions as different as MS, COPD, and RA. Determining a suitable subset of common symptoms to measure is not an easy task, but these five general symptoms may provide a reasonable starting point to define health-related quality of life via a single patient-reported measure.

TABLE 1. KEY SYMPTOMS AND POTENTIAL MEASURE CONCEPTS FROM COPD, MS, AND RA PATIENT EXPERIENCE REPORTS*

Key Outputs	COPD Topics	MS Topics	RA Topics
PRO (patient profile data analysis)	• Fatigue • Pain • Shortness of breath (dyspnea) • Insomnia • Anxious mood • Cough • Phlegm • Wheezing	• Activity level • Pain • Medication side effects • Fatigue • Healthy diet • Incontinence • Loss of intimacy	• Joint pain • Chronic pain • Fatigue • Decreased mobility • Depression • Inflammation • Anxiety
PRO (free text analysis)	**Symptom characteristics**: frequency, seasonal patterns, daily patterns, triggers, check pain, shortness of breath during or after eating **Lifestyle issues**: sleep, weight gain/loss **Treatment issues**: understanding when medications are effective, transporting oxygen, compliance with and usefulness of breathing techniques **Breathlessness fears:** impact on engaging in activities	**Symptom characteristics:** activity levels, loss of sex drive, incontinence, sleep disturbance, loss of mobility, feeling "pins and needles," pain and fatigue **Lifestyle issues**: loss of intimacy with partners **Treatment issues:** side effects and variety of MS medications, modes and tricks for a painless injection experience **Worry/concern** that their children might be diagnosed with MS	**Symptom characteristics:** decreased mobility, rash, sleep disturbance, burning eyes **Lifestyle issues:** loss of independence, staying active, job loss, isolation **Financial burden** concerns because of frequent visits to providers and daily medication use
PRO-PM Measure Concepts	• Measures assessing symptoms of depression across all stages of COPD patients • Measures for the identification and management of COPD triggers • Measures assessing positive management techniques (managing diet, exercise, and weight as techniques to alleviate COPD) • Measures assessing common limitations for activity experienced by COPD patients (difficulty due to dyspnea, mobility (e.g., with oxygen tanks), and triggers (e.g., allergens, weather)	• Measures to assess acknowledgment/discussion of HRQoL symptoms with clinicians • Measures that assess key symptoms based on form and stage of MS	• Measures that assess the diagnosis process and treatment effectiveness (time to diagnosis, prognosis, and treatment effectiveness at reducing flares) • Measures that assess treatment decision making from the patient perspective • Measures to assess disease progression over time

* The population size supporting the key outputs in this table vary depending on the number of patient reports available when the analysis was done. Results are based on those patients who chose to report a specific data element, as all data donation on the PatientsLikeMe platform is voluntary. For more specific information, readers should refer to the original reports.

EXPERT PANEL REACTIONS TO PATIENT EXPERIENCE REPORTS

After reviewing the Patient Experience Reports, expert panel members were asked for feedback on the importance, relevance, and comprehensiveness of the information for the development of PRO-PMs and other patient-centered measures. Members agreed that the reports represented a rich data source illustrating patient experiences and priorities for measure development and as well as a valuable synthesis of patient priorities that is all too often absent from PRO-PM development.

Patient Perspective

Expert panel patient representatives found that the Patient Experience Reports offered unique evidence-based support to the panel discussions, and significantly magnified the patient voice. Patient panelists offered practical ideas and suggestions about the application, use, and value of PRO-PMs and expressed willingness to participate in data collection (particularly when the results would inform healthcare decisions).

Patients also recommended real-world approaches for the successful use or implementation of PROMs in the clinical setting. Many of the patient panel members observed that the language in PROMs used to describe common symptoms such as fatigue, depression, and insomnia was not reflective or consistent with the lived experience of individuals with their conditions. In one case, a survey respondent re-wrote a PROM in patient-centered language, providing a tangible example of how the tool could extend its value for patients and enhance their experience with care. Many patients suggested the use of computer-adapted tools and other technologies to ease the data collection burden and improve response rates.

Several patient panelists notably observed that the quality and experience of care transcend office visits. A patient on the MS expert panel suggested that the patient and provider relationship could be greatly enhanced with the addition of PRO data collection over time to track symptoms and functions as they related to treatment. The same panelist went on to suggest a measure concept focused on patient and provider communication leveraging regular PRO capture, with the goal of moving care to a patient-centered model that includes what is most meaningful to the patient, be it valuable symptom or other experience information similar to what was captured in the Patient Experience Reports.

Nonpatient Reactions

Several themes emerged during interviews with measure developers, clinicians, and other healthcare professionals that served on one or more project expert panels. The themes revealed strengths and weaknesses of using these types of reports to inform the measure development process as described below.

Accuracy of Patient Input

Longitudinal data collection, including retrospective recall of symptom data, can be prone to recall bias. As many databases collect data retrospectively, additional consideration needs to be given to the limitations of recalled information and appropriate ways to incorporate it into analysis. In this sense, real-time—or at least timely—collection of PRO data through virtual community-based platforms such as PatientsLikeMe may minimize recall bias. Such platforms can also serve as a richer source of qualitative data from the shared patient commentary. As one person noted, “The qualitative nature of histories and concerns provides rich feedback to measure developers.”

Generalizability of Patient Input

Consulting larger population segments through online patient communities, such as PatientsLikeMe, helps ensure that PROs are both meaningful and comprehensive for the population of interest. This model offers more realistic representation of the collective patient experience with a specific condition and associated healthcare. It also provides a framework for engaging patients in a feedback loop that yields richer information than involving a single patient in the measure development process. This approach directly addresses challenges in the current model of ascertaining one or a handful of individual perspectives and captures greater diversity in patient perspectives.

One concern, however, is that the sample from online platforms may be biased toward individuals who are more symptomatic, more motivated to report symptoms, or do not have technological barriers to participation. In addition, another consideration is the strength of community engagement and how that is represented in the aggregate experience. Engaged communities are likely to have richer and broader results than smaller or less engaged ones. Specific attention is needed to ensure that the perspectives of vulnerable populations (e.g., the frail elderly; persons of low socioeconomic status; or persons with disabilities or literacy challenges) are heard so that the collective patient experience is as representative as possible. Capturing diverse patient perspectives may be accomplished through the use of multiple modalities for patient data input which may also ensure language is understandable and culturally sensitive. For measure development, performance results require stratification to better understand and address the concerns of populations that have different outcomes.

Balancing Cross-Cutting and Condition-Specific Symptoms

All patients on the PatientsLikeMe platform, regardless of the health conditions they report, are prompted to evaluate the severity of five core symptoms: pain, fatigue, insomnia, depressed mood, and anxious mood. An analysis of the Patient Experience Reports validated these symptoms as common and problematic across all three conditions. This finding is particularly prominent for a symptom like fatigue, which has at least *moderate* severity across conditions as diverse as COPD, MS, and RA. For some condition-specific communities, including COPD, MS, and RA, these five core symptoms are augmented with additional disease-specific symptoms. Patient expectations for improvement, stability, or decrement in these core symptoms may vary by condition. Assessments of these core symptoms, however, are extremely beneficial in the measurement development process and can serve as a reasonable starting point to define health-related quality of life via a single PRO-PM, particularly as these symptoms are common among validated PROMs.

While many symptoms are common across diagnoses, current tools may not suffice in assessing all of the symptoms that are important to patients. For example, the RA project demonstrated that the RAPID3 did not fully capture symptoms related to fatigue, impacts on sex-life, and challenges with functioning (including cooking, feeding self, hygiene, chores, and occupational, social, and recreational functioning). Patient participants also suggested that the responses to the RAPID3 could be linked to referrals and education materials, demonstrating how patient input can provide insights on how PRO tools can be more meaningful to the patients who use them.[29]

CONCLUSIONS AND RECOMMENDATIONS

To make a meaningful shift to patient-centeredness, quality measurement needs to focus on patient priorities. This can only be accomplished through broad engagement of patients during measure development and implementation. This innovative work demonstrates the remarkable power of online patient communities to insert the collective experience of patients into measurement.

Many stakeholders recognize PROs as the "missing piece" in improving the quality of care and in capturing the patient's voice in quality measurement. Routine collection of PRO data—and presentation of that information to patients in a form and manner that informs their decision making—can empower patients by encouraging them to learn from the comparative experiences of others. Likewise, patients can make informed healthcare decisions according to the outcomes that are most important to them as individuals. For providers, aggregated data can illuminate the prioritization of symptoms, limitations, goals, and attitudes that may not be apparent when patients are queried through traditional research approaches or during routine clinical encounters. Armed with this information, providers can shift care plans towards managing symptoms that are more important to a patient's health-related quality of life and establish realistic expectations based on the patient's preferences, goals, and health status.

Existing models of patient engagement are insufficient to ensure that the broad spectrum of patient values, preferences, and needs are reflected in quality measurement. Thus, new models are needed to gather patient input in the measure development process. A potential approach—evaluated within the context of PRO-PM development—is leveraging community-based platforms to capture the range of perspectives among patients in specific care settings or with specific health conditions. These platforms can be used to engage patients in the measure development process in several ways, including:

- Posting measure concepts for comment;
- Using the platform for patient advocacy efforts;
- Feeding information collected back to providers at the point of care;
- Documenting common symptoms that are not captured in the literature; and
- Determining patient priorities.

Stakeholders for these three projects (COPD, MS, and RA) agreed that information about the collective patient experience, gathered via the PatientsLikeMe platform and summarized in the Patient Experience Reports, benefitted the measure development and prioritization process. Examining these reports helped to detect language used more commonly by patients, so that PROMs can be worded in ways that are more relevant for patients. Stakeholders also noted the value of this information in pre- and post-testing of a measure to determine if the most important content was captured.

Current methodologies may not leverage real-time data collection, gather experiences from large patient groups, delve into patient concerns, or identify the symptoms that matter most to patients. These findings suggest that data gathered from online patient communities can help address several PRO-PM measure development challenges:

- **Improving data quality**—Real-time collection of PRO data through virtual community-based platforms can minimize recall bias and improve the quality of symptom-related data.

- **Representing patient experience**—Aggregate feedback from heterogeneous communities of patients can generate a rich and broad spectrum of data, which, in turn, provides a more realistic representation of the collective patient experience.
- **Identifying patient concerns**—Collective data on the patient experience illuminate the prioritization of certain symptoms, limitations, goals, and attitudes that may not be apparent when patients are queried through traditional research approaches.
- **Prioritizing symptoms**—Commonalities of symptoms across diagnoses provide opportunities and new approaches to symptom assessment that focus on what is important to patients from a health-related quality-of-life perspective.

This innovative approach demonstrates that the collective patient voice and experience from online patient communities holds enormous promise for the development of meaningful measures. Online patient communities have the potential to serve as virtual "town squares" where measure developers and other stakeholders can access the patient experience not otherwise available. Most importantly, the new approach will help advance the nation toward more patient-centered care that meets the needs of individual patients and the population as a whole.

ENDNOTES

1 Gnanasakthy A, Mordin M, Evans E, et al. A review of patient-reported outcome labeling in the United States (2011-2015). *Value Health*. 2017;20(3):420-429.

2 Remmers C, Hibbard J, Mosen DM, et al. Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *J Ambul Care Manage*. 2009;32(4):320-327.

3 Shay LA , Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Making.* 2015;35(1):114-131.

4 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.

5 Weinstein JN, Clay K, Morgan TS. Informed patient choice: patient-centered valuing of surgical risks and benefits. *Health Aff (Millwood)*. 2007;26(30):726-730.

6 National Quality Forum (NQF). *Patient-Reported Outcomes (PROs) in Performance Measurement*. Washington, DC: NQF; 2013. Available at http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx. Last accessed August 2017.

7 Cella D, Hahn EA, Jensen SE, et al. *Patient-Reported Outcomes in Performance Measurement.* Research Triangle Park, NC: RTI Press; 2015. Available at http://dx.doi.org/10.3768/rtipress.2015.bk.0014.1509. Last accessed August 2017.

8 Concannon TW, Friedberg MW, Hwang A, Wiitala K. *Engaging Consumers in the Quality Measurement Enterprise.* Santa Monica, CA: RAND Corporation; 2017. Available at http://www.rand.org/pubs/research_reports/RR1760.html. Last accessed August 2017.

9 The National Patient-Centered Clinical Research Network. Engagement in research website. http://www.pcornet.org/about-pcornet/engagement-in-research/. Last accessed August 2017.

10 Centers for Medicare & Medicaid Services (CMS). *Blueprint for the CMS Measures Management System Version 13.0*. Rockville, MD: CMS; 2017. Available at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Blueprint-130.pdf. Last accessed August 2017.

11 American Institutes for Research (AIR). *Principles for Making Health Care Measurement Patient-Centered*. Washington, DC: AIR; 2017. Available at http://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf. Last accessed August 2017.

12 National Institutes of Health (NIH). PROMIS® Instrument Development and Validation Scientific Standards Version 2.0 (revised May 2013). 2013. Available at http://www.healthmeasures.net/images/PROMIS/PROMISStandards_Vers2.0_Final.pdf. Last accessed August 2017.

13 Patient-Centered Outcomes Research Institute (PCORI). Research & Results website. . Available at http://www.pcori.org/research-results-home. Last accessed August 2017.

14 Wicks P, Sepassi M, Sharma G, Delogne MC. Partnering with patients to rapidly develop a quality-of-life measure in Mycosis fungoides/Sézary syndrome type cutaneous T-cell lymphoma. *Am J Manag Care*. 2016. Available at http://www.ajmc.com/journals/evidence-based-oncology/2016/june-2016/partnering-with-patients-to-rapidly-develop-a-quality-of-life-qol-measure-in-mycosis-fungoidesszary-syndrome-type-cutaneous-t-cell-lymphoma. Last accessed August 2017.

15 International Consortium for Health Outcomes Measurement (ICHOM). Our standard sets website. Available at http://www.ichom.org/medical-conditions/. Last accessed August 2017.

16 Concannon TW, Friedberg MW, Hwang A, Wiitala K. *Engaging Consumers in the Quality Measurement Enterprise.* Santa Monica, CA: RAND Corporation; 2017. Available at http://www.rand.org/pubs/research_reports/RR1760.html. Last accessed August 2017.

17 Association of Cancer Online Resources (ACOR). ACOR website. http://www.acor.org. Last accessed August 2017.

18 National Organization for Rare Disorders. Find a patient organization website. https://rarediseases.org/for-patients-and-families/connect-others/find-patient-organization/. Last accessed August 2017.

19 A chronic obstructive pulmonary disease (COPD) PRO-PM is in development by Minnesota Community Measurement. The Measure Incubator™ received funding from GlaxoSmithKline to support this project.

20 A multiple sclerosis (MS) PRO-PM is in development. The Measure Incubator™ received funding from Biogen.

21 Outcome measures will be developed for rheumatoid arthritis (RA), including a measure focused on treat-to-target approaches and a PRO-PM, made possible with support from Bristol-Myers Squibb.

22 Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.

23 MN Community Measurement (MNCM). MNCM public comment welcomed for COPD measures website. https://mncm.org/public-comment-welcomed-for-copd-measure. Last accessed August 2017.

24 van der Molen T, Willemse BW, Schokker S, et al. Development, validity and responsiveness of the Clinical COPD Questionnaire. *Health Qual Life Outcomes*. 2003;1:13.

25 Jones P, Harding G, Wiklund I, et al. Improving the process and outcome of care in COPD: development of a standardised assessment tool. *Prim Care Respir J.* 2009;18(3):208-215.

26 MN Community Measurement (MNCM). *Controlling the Impact of COPD on Health Status Measure Specifications*; 2017. Available at http://mncm.org/wp-content/uploads/2016/08/COPD-PRO-PM-Specifications-for-Public-Comment.pdf. Last accessed August 2017.

27 Pincus T, Yazici Y, Bergman MJ. RAPID3, an index to assess and monitor patients with rheumatoid arthritis, without formal joint counts: similar results to DAS28 and CDAI in clinical trials and clinical care. *Rheum Dis Clin North Am.* 2009;35(4):773-778.

28 Anderson J, Caplan L, Yazdany J, et al. Rheumatoid arthritis disease activity measures: American College of Rheumatology recommendations for use in clinical practice. *Arthritis Care Res (Hoboken).* 2012;64(5):640-647.

29 Okun S, Goodwin K. Building a learning health community: by the people, for the people. *Learning Health Systems*. 2017. Available at http://onlinelibrary.wiley.com/doi/10.1002/lrh2.10028/full. Last accessed August 2017.

APPENDIX A:
Authors and Acknowledgements

Authors

Helen Burstin, MD, MPH
Chief Scientific Officer
National Quality Forum

Kyle Cobb, MS
Senior Director
National Quality Forum

Katherine McQueston, MPH
Project Manager
National Quality Forum

Lyn Paget, MPH
Consultant
PatientsLikeMe

David Cella, PhD
Professor and Chair
Department of Medical Social Sciences
Northwestern University Feinberg School of Medicine

Stacey McCaffrey, PhD
Research Scientist, Consultant
PatientsLikeMe

Stephanie Eaneff, MSP
Data Scientist
PatientsLikeMe

Emil Chiauzzi, PhD
Research Director
PatientsLikeMe

Acknowledgements

The authors thank the following for their support and helpful comments on the content of this paper:

Alejandra Herr, MPH
Managing Director Quality Innovation
National Quality Forum

Sofia Kosmetatos, MJ
Director Media Relations and Online Communications
National Quality Forum

Lisa Gale Suter, MD
Assistant Professor and Associate Director
Yale School of Medicine and Yale/CORE

Sally Okun, RN, MMHS
VP Advocacy, Policy & Patient Safety
PatientsLikeMe

David Blaser, PharmD
Director Health Informatics
PatientsLikeMe

Timothy Vaughan, PhD
Principle Scientist
PatientsLikeMe

Caroline W. Chan, BA
Senior Program Manager
PatientsLikeMe

NATIONAL QUALITY FORUM
1030 15TH STREET, NW, SUITE 800
WASHINGTON, DC 20005

www.qualityforum.org

ISBN 978-1-68248-061-8