

# Person-centered implementation of patient-reported outcome measures (PROMS) in complex care programs

**Rebecca Sax,** Senior Program Manager for Field Building & Resources, Camden Coalition of Healthcare Providers

Mark Humowiecki, Senior Director & General Counsel, Camden Coalition of Healthcare Providers

August 2021





**The National Center** for Complex Health & Social Needs An initiative of the Camden Coalition

## Person-centered implementation of patient-reported outcome measures (PROMS) in complex care programs

In 2020, the **National Center for Complex Health and Social Needs** partnered with the **Kaiser Permanente Institute for Health Policy** and **Care Management Institute** to examine the factors that support or hinder the implementation of patient-reported outcome measures (PROMs) in complex care programs. This brief outlines what stakeholders — including clinicians, evaluators, consumer experts, and program administrators — can do to support person-centered measurement in their programs. Case studies provide additional resources for teams looking to implement PROMs and other person-centered measurement strategies.

### Introduction

The field of **complex care** has long wrestled with the best way to demonstrate the success of programs tailored for individuals with complex health and social needs. While reducing healthcare costs and hospital utilization have frequently been the primary metrics of success, complex care programs also seek to improve health and well-being, the experience of care, and health equity. The field's over-reliance on cost and utilization, and lack of more holistic measures, mean that we risk ignoring many of the benefits experienced by those receiving care.

The *Blueprint for Complex Care*, a strategic plan for the field developed by the Camden Coalition's National Center for Complex Health and Social Needs (National Center), the Center for Health Care Strategies (CHCS), and the Institute for Healthcare Improvement (IHI), calls out the need for additional measures to use for quality improvement efforts, accountability mechanisms such as value-based-purchasing, and program evaluations related to the delivery of complex care. As a first step toward fulfilling the *Blueprint's* recommendation to align on quality measures for complex care programs, the National Center commissioned IHI to perform a landscape report of complex care measures, culminating in "Measuring complexity: Moving towards standardized quality measures for the field of complex care."

Patient-reported outcome measures (PROMs) are a promising way to assess individuals' health and well-being in a manner that upholds the person-centered principle of complex care. Through PROMs, individuals assess their own health status using a structured tool that can be either self-administered or completed in an interview. However, simply including PROMs in a complex care measurement strategy is not enough to uphold person-centered values. While PROMs are patient-reported by definition, they must be thoughtfully implemented using **person-centered principles**. This ensures that the outcomes measured are meaningful for patients and that using the tool leads to improvements in care delivery that support health and well-being on both the individual and population level.

The goals of this project were to better understand and start to address the measurement challenges

facing complex care programs. Through input from the field, we found that while some complex care programs are using PROMs, data collection can be burdensome and, once collected, the data are not used to the fullest extent. This brief will expand on these issues and propose the following recommendations:

- Develop a measurement strategy that centers patients' goals and priorities;
- Embrace the roles that all stakeholders bring to measurement development; and
- Streamline workflows as needed to reduce measurement burden.

These recommendations were informed by providers, evaluators, and patients through an expert advisory committee, a community survey on the use of PROMs (view survey responses in Appendix B), multi-stakeholder key informant interviews (view interview responses in Appendix C), and an expert convening. While this project focused primarily on the use of PROMs, many of the recommendations are applicable to complex care measurement as a whole. We hope that clinicians, evaluators, consumer experts, and program administrators find this brief useful in developing and refining person-centered measurement strategies for their complex care programs.

# Patient-reported outcome measures (PROMs): A promising tool for evaluating complex care

#### Case study: Using PROMs in complex care

Advancing Integrated Models (AIM), led by the Center for Health Care Strategies (CHCS), is a national multi-site demonstration, with eight pilot sites working to integrate innovative, person-centered approaches for individuals with complex health and social needs.

The AIM Measures Library was created in partnership with Joslyn Levy & Associates and an expert advisory committee to support pilot sites in their evaluation efforts and help advance complex care measurement more generally. The library provides a set of patient- and staff-reported measures that pilot sites can draw from to better understand the implementation and impact of their work.

The AIM Measures Library, as well as the process of creating it, is now available to the field in **this brief** from CHCS.

The **National Quality Forum** defines PROMs as "various tools (e.g., instruments, scales, single-item measures) that enable researchers, administrators, or others to assess patientreported health status for physical, mental, and social well-being." PROMs capture individuals' perspectives on their own health and wellbeing, and can be narrow or broad in what aspects of health they measure.

PROMs have been gaining prominence in healthcare quality improvement for more than a decade since National Quality Forum received funding from the federal Department of Health and Human Services in 2012 to identify patientreported outcomes to endorse for performance measurement and accountability. More recently, **Purchaser Business Group on Health** is leading an initiative to support the implementation of patient-reported outcomes in healthcare organizations through scaling,

stakeholder engagement, and integration in Medicare payment reform programs.

PROMs are particularly promising for complex care programs because these programs often serve heterogeneous populations with multiple chronic conditions that are exacerbated by some combination of behavioral health, cognitive, functional, and social needs. By capturing the individual's overall sense of health, PROMs that assess overall well-being are relevant to the entire population served even if their underlying conditions vary significantly. For this reason, complex care programs may be more interested in general well-being PROMs (e.g., What Matters Index, Healthy Days, and PROMIS), rather than disease-specific PROMs (e.g., Functional Living Index-Cancer for chemotherapy or Kidney Disease Quality of Life for end-stage renal disease). A list of PROMs that may be applicable to complex care programs can be found in Appendix A.

PROMs can both reflect and promote the value of person-centered care that is at the foundation of complex care. By seeking an individual's self-assessment of health and treating it as important and valid data, PROMs integrate patient autonomy and voice into the evaluation of complex care programs. This data collection also has clinical value: PROMs can inform care teams of a person's sense of well-being, which can be used to identify changes in health status and to adapt care plans accordingly.

PROMs, however, are not a panacea. While PROMs may be a way to engage patients in their own care, we heard from multiple experts that just because a measure is patient-reported, it is not necessarily patient-centered. Participants in the field survey, interviews, and convening consistently emphasized the need for purposeful implementation to fulfill the potential of PROMs. They noted that PROMs require planning, design, and execution to ensure stakeholder buy-in, data integrity, efficient workflows, and maximum impact from the data collected.

The following recommendations summarize the ways that programs can integrate person-centered principles to support the successful implementation of PROMs in complex care programs.

## Themes & recommendations

#### Measurement strategy and selection

Throughout the project, experts noted that measurement is a process and that any new measure should be selected and implemented as part of an overall measurement strategy. A measurement strategy goes beyond individual measures, evaluating "whether a [program] has met its goals by using a set of measures with expected outcomes."<sup>1</sup>

Interviewees acknowledged that the process of measure selection and implementation often falls short of this standard. Measures are often imposed by external parties (e.g., payers, government agencies) and are implemented without adequate time for planning. In addition, providers and patients already experience significant measurement burden due to multiple quality initiatives and funding requirements. This can result in duplicative measurement tools, excessively long workflows, and a disconnect between measurement results and improvements to clinical practice. Developing an overall measurement strategy

<sup>1</sup> Agency for Healthcare Research and Quality. Designing and Implementing Medicaid Disease and Care Management Programs. 2008. https://www.ahrq.gov/patient-safety/settings/long-term-care/resource/hcbs/medicaidmgmt/mm7.html.

ensures that programs are able to communicate program impact, support quality improvement efforts, and enhance patient care.

#### **Recommendations:**

- Identify program goals: A measurement strategy should be anchored in the overall goals of the program. These goals should be co-developed in partnership with community members and/or individuals with lived experience. If program goals are developed without this partnership, these critical stakeholders can still be brought into the process to ensure that the overall measurement strategy is driven by patient priorities.
- **Identify existing measures:** Since program measures may have been introduced via different pathways (e.g., funding requirements or other organizational priorities), it is useful to catalog all measures currently in use.
- Map existing measures to program goals: Once the measures have been identified, assess how the current measures align with the program goals. This process can highlight if there are any redundancies or gaps in your existing measures and if it is necessary to add or streamline measurement tools.

Fill gaps using person-centered
 principles: If new measures are needed
 to evaluate program goals, use person centered principles to identify outcomes and
 tools that are meaningful for patients. Consider
 using PROMs as a way to hear directly from
 patients about their own health. PROMs
 identified as particularly relevant for complex
 care programs through project literature review
 and conversations with patients and providers
 are included in Appendix A.

#### Stakeholder engagement

Patients, providers, and evaluators alike have perspectives and expertise that can improve the process of measure selection and implementation. Effective engagement not only improves relationships and trust among these stakeholders but also improves uptake of measurement efforts. If providers do not perceive the measure as valuable or actionable for clinical care, they may deprioritize data collection when faced with urgent crises, or ignore data and rely solely on their personal experience with the patient. If patients, particularly those who have experienced trauma or have reason to distrust the healthcare system, do

## Case study: Patient-centered measurement principles

The American Institutes for Research developed the **Principles for Making Health Care Measurement Patient-Centered** to highlight how to partner with patients in a meaningful way to decide what to measure, how to measure it, and how to report and use the results of measurement. AIR launched small-scale pilots to demonstrate how to implement the principles in real-world settings, offering a vision of measurement that is patient-driven, holistic, transparent, comprehensible, timely, and co-created with patients.

One of the pilot sites, National Coalition for Cancer Survivorship (NCCS), formed a project team of cancer survivors and advocates that developed a <u>set of measure concepts</u> to assess individuals' functional status following cancer diagnosis. This measure set includes patient-reported outcomes and accompanying process measures for routine assessment of functional status during and after treatment, and timely follow-up actions in response to assessments. not understand the value of the questions they are being asked, they may not respond truthfully or may decline to respond at all.

#### **Recommendations:**

- Embrace the roles individuals bring to the table. It is not necessary for patients and providers to have formal expertise in research and evaluation to participate in the measurement selection process. The goal of the process is not necessarily to train participants on technical aspects of measurement but rather to incorporate their perspectives on what is important to measure and how to best collect it. Establish norms that account for disparities in power and privilege. These may include inviting patients to give feedback in group discussions before clinical providers or using holistic definitions of health and well-being that include questions about issues like food security and housing.
- **Be flexible about process.** Participants who contribute their expertise beyond any professional duties are often forced to balance other time commitments. This may include patients or clinicians that choose to participate in the development of a measurement process in addition to their existing responsibilities. Opportunities to contribute throughout the process and multiple ways to provide feedback (e.g., synchronous discussion or asynchronous written feedback) make it more likely that these stakeholders will not have to choose between project participation and other responsibilities.
- Be transparent with language and data. Like many areas of healthcare, measurement can seem impenetrable due to its technical language. Jargon can be alienating, so use plain language and define concepts or acronyms preemptively. In addition, put data from the measurement tool in context when reporting back to stakeholders and make it easily available. This allows for patients and partners to clarify how this data will be used and why. It is also an opportunity to discuss ways that previous or current data use and interpretation may have led to harm or mistrust.

#### Logistical considerations

Over the course of the project, providers, patients, and evaluators alike highlighted the challenges of implementing PROMs and other measurement tools in practice. Health information technology and clinical workflows are not optimized to facilitate data collection and measurement in general. If PROMs are not integrated into an organization's electronic health record (EHR) or other core systems, it is difficult for providers to fully incorporate the data into care planning or to track patient progress longitudinally. This is especially true for tools like PROMs that require the active engagement of patients.

#### **Recommendations**:

- Streamline clinical workflows that include measurement. PROMs are often added to existing workflows, leading to long and burdensome processes for both providers and patients. A robust measurement strategy and stakeholder engagement process can help build a workflow that integrates data collection within the clinical process while meeting the needs of patients, clinicians, and researchers. For example, one consumer surveyed said she would prefer to complete the tool prior to a doctor's visit so the provider could incorporate her feedback into the appointment.
- **Optimize EHRs to support PROMs.** EHR integration is key to make the most of PROMs data. Integration not only supports data-sharing within a care team, but also allows non-clinical staff, e.g., evaluators, to use the data to assess program impact. An Indian Health Services clinic incorporated

the Patient Activation Measure into its EHR, enabling the care manager to extract data for program quality improvement. It is also helpful to ensure numeric scoring for PROMs for easier data entry and analysis.

Tailor language for patient population. PROMs data cannot be meaningful if the language or concepts are unclear to the participating patient. Also, be mindful of challenges facing the patient population. Individuals with complex needs may have limited health or English literacy, individual and/or historical trauma connected with healthcare institutions, and a long history of chronic illness. It may be useful to have other provider team members, e.g., community health workers or promotores, administer the tools and explain why the questions are being asked and how the information will be used.

## Next steps

For complex care programs looking to supplement cost and utilization as indicators of success, PROMs are an appealing approach to measurement. However, findings from this project suggest that PROMs are still underutilized in complex care, especially PROMs that are implemented as part of a comprehensive measurement strategy. More research and experimentation are necessary to better understand the opportunities for PROMs to inform care delivery, quality improvement, and even payment and accountability. We hope that this report gives complex care programs tools to develop new approaches to measurement. It is critical that the field continue to innovate, engage stakeholders

Case study: Using patient- and staffreported measures to assess the impact of complex care models

#### Led by Health Leads, the **<u>Collaborative</u>** to Advance Social Health Integration

(CASHI) was a learning collaborative comprised of 21 nationally distributed primary care teams committed to integrating social health interventions into primary care. One aspect of the project was to test the use of PROMs, specifically the Health Confidence Index, as one way to further integrate these interventions. Teams reported monthly on a number of measures, including patient-reported health confidence.

Some CASHI teams said that the PROM facilitated better conversations between care teams and patients. However, changes in levels of health confidence and in access to essential resources were not strongly associated with the use of this tool. Teams expressed the need to have choices when using PROMs, including which versions to use and when to administer them. Some chose to modify the wording, rating scales, and/or sequencing of the PROMs based on feedback from their patient leadership. They also found that different outcome measures should be used for different populations, such as adult and pediatric populations.

In general, Health Leads noted that implementing PROMs can be challenging and requires careful workflow design and adequate resourcing.

including patients and providers, and share resources with each other as we work to improve the health and well-being of individuals with complex needs.

## Acknowledgements

This work would not have been possible without the support and dedication of Kaiser Permanente, specifically **Rebecca Hambright** and **Krysten Joyce** of the Institute for Health Policy, and **Michelle Wong** and **Mariana Sáenz** of the Care Management Institute.

We are also grateful for the guidance provided by our expert advisory committee members and other key advisors:

- Heidi Bossley, Healthcare Quality Consultant
- Wendolyn Gozansky, National Permanente Quality Lead for Complex Needs, Vice President and Chief Quality Officer, Kaiser Permanente Colorado
- Danielle Hodges, Program Manager, Data & Quality Improvement, Camden Coalition of Healthcare Providers
- Clemens Hong, Director of Whole Person Care-Los Angeles, Medical Director of Community Health Improvement, Los Angeles County-WPC
- Stephen Hoy, Chief Operating Officer, PFCC Partners
- Eric Schneider, Senior Vice President for Policy & Research, Adjunct Professor of Health Policy and Management, Commonwealth Fund, Harvard T. H. Chan School of Public Health
- Ellen Schultz, Former Senior Researcher, American Institutes for Research
- **Janice Tufte**, PCORI Ambassador, National Consumer Scholar, Patient-Centered Outcomes Research Institute, National Center for Complex Health and Social Needs
- Therese Wetterman, Former Director, Programs and Learning, Health Leads

## Appendix A

Holistic patient-reported outcome measures for complex care programs

Measure title	Description
Short-Form 36 (SF-36)	The SF-36 includes eight domains: physical functioning (PF), role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health.
Short-Form 6D (SF- 6D or Six Dimensions)	The SF-6D, which is derived from the 36-item Short Form Health Survey (SF-36).
EuroQol-5D (EQ-5D)	The EQ-5D includes a five attribute health-status classification system: mobility, self- care, usual activity, pain/discomfort, and anxiety/depression, with three levels per attribute: no problem, some problem, or extreme problem.
Health Utilities Index Mark 3 (HUI3)	The HUI3 system includes eight attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain and discomfort, with five or six levels per attribute, from severely impaired ("so unhappy that life is not worthwhile") to no problem or normal ("happy and interested in life").
Quality of Well-Being Scale (QWB)	The original version of the Quality of Well Being Scale (QWB) included three attri- butes (mobility, physical activity, and social activity) and a problem/symptom com- plex. The more recent QWB-SA (self-administered) retains the same structure but includes fewer levels within each attribute and fewer problems/symptoms.
Healthy Days	The core Healthy Days measures assess a person's perceived sense of well-being through four questions on: 1) self-related health, 2) number of recent days when physical health was not good, 3) number of recent days with mental health was not good, and 4) number of recent activity limitation days because of poor physical or mental health. Healthy Days is an index of the overall number of days during the previous 30 days when the respondent felt that either his or her physical and mental health was good.
Health Confidence Index	Multi-item measure: I have trouble doing all of my regular leisure activities with oth- ers, I have trouble doing all of the family activities that I want to do, I have trouble doing all of my usual work (include work at home), I have trouble doing all of the activities with friends that I want to do. Response scale: Never, rarely, sometimes, often, always.
Patient Health Ques- tionnaire (PHQ-9)	The Patient Health Questionnaire (PHQ) is a self-administered version of the PRIME- MD diagnostic instrument for common mental disorders. The PHQ-9 is the depres- sion module, which scores each of the nine DSM-IV criteria as "0" (not at all) to "3" (nearly every day).
Functional Assessment of Chronic Illness Therapy—Fatigue scale	The FACIT-Fatigue is a 13-item patient-reported outcome instrument (PRO) that was designed to assess fatigue-related symptoms and impacts on daily functioning.
Patient Activation Measure (PAM)	The Patient Activation Measure (PAM) is a 100-point, quantifiable scale determining patient engagement in healthcare.

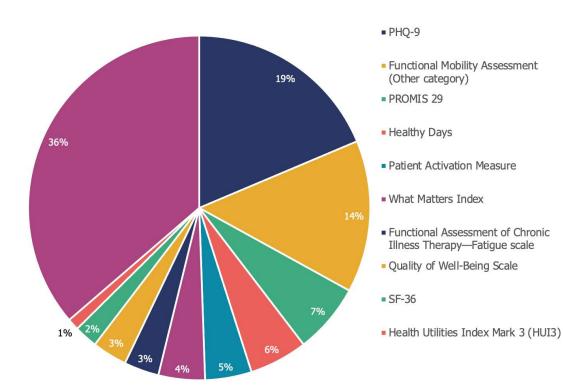
## Appendix B

Results from the field survey on the use of PROMs in complex care programs.

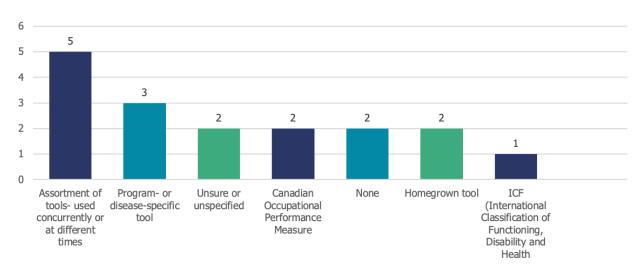
#### By the numbers:

- Open from August 27 September 14, 2020
- 78 respondents
- Not all questions were required; totals may not add up to 78
- 23 were willing to participate in follow-up interviews
- Over 15 states represented
- Patients vs. providers:
  - Providers: 68%
  - Patients: 32%

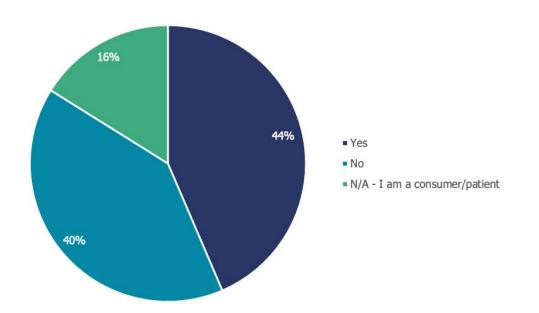
# What is the primary PROM that you use in your complex care programs as a provider and/or as a consumer?



#### **Other PROMs reported**



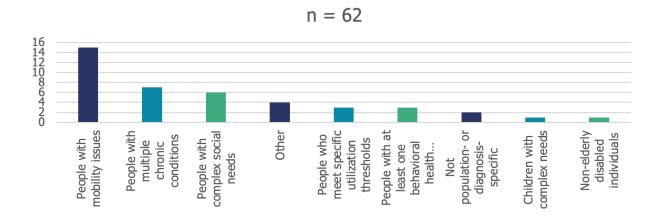
#### Were you responsible for selecting this measure?



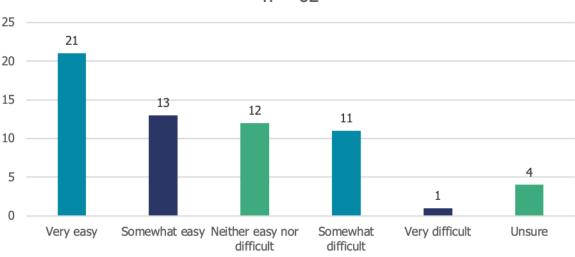
#### Why did you select this particular measure as a PROM?

- Tool measures functioning that is relevant to
  specific patient population (e.g. how wheelchair
  use impacts quality of life)
- Tool assists with program or patient evaluation (e.g. captures relevant data)
- Tool is mandated by funder or project
- Tool is validated and/or standardized
- Staff preferred this tool to others
- Cost considerations

#### Specific populations that complete the PROM



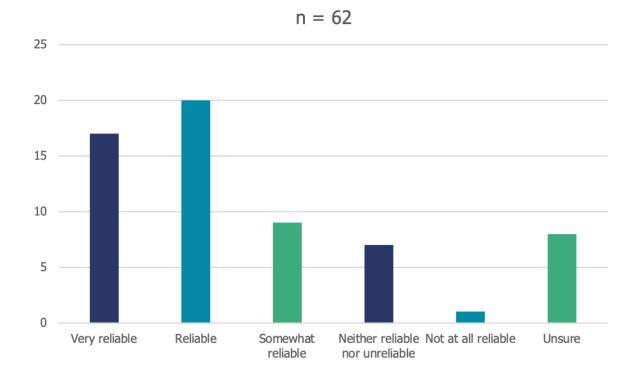
## How would you rate the ease of use of this measure? I.e., Are the questions burdensome to ask, answer, or analyze?



n = 62

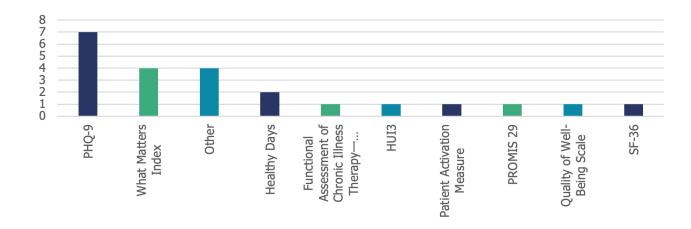
#### Factors that impact ease of use:

- · Ability of patients to provide meaningful answers
- Adaptable for different patients
- Complicated questions or wording
- Connection to treatment or care planning
- Format of answers for future scoring/analysis
- Meaningful for patient
- Meaningful for provider
- Sensitivity of topic (e.g., mental health)
- Time given to administer tool during appointment
- Time it takes for patient to complete tool



How would you rate the reliability of this measure? I.e., From your experience, is the score consistent with the well-being of the respondent?

#### **PROMs identified by consumers & caregivers**



Other measures used:

- Care Coordination for Health Promotion and Activities in Parkinson's Disease
- Direct questions as caregiver role that cover ADLs, pain, and mobility
- National Core Indicators; Consumer Assessment of Healthcare Providers and Systems HCBS Experience of Care; Personal Outcome Measures

## Appendix C

Summary of key informant interviews, selected from field survey responses and content experts.

#### Rationale

Interviewees chose to use PROMs because they provide helpful context for patient behaviors and what they need to improve their own outcomes. They also provide unique outcome measures to show effectiveness, adapt the intervention, and make the case for funding and other infrastructure.

The field survey and interviews showed that tools were generally selected because they seemed most appropriate for the setting and patient population. Also mentioned: clinical validation, accessible language for the patient or translator, and that the tool was part of funding requirements. An interviewee said that the PAM was trialed and discontinued due to licensing costs and the lack of staff buy-in because they were used to a less formal assessment.

The consumer interviewed doesn't currently have a provider that uses PROMs but received the What Matters Index questionnaire from a colleague looking for feedback. However, she appreciated that the tool identified issues besides her utilization.

# "What matters to me is very different than what matters to healthcare providers, it's my whole world."

#### Workflow & data access

Most interviewees administered the tool in person at the beginning of an appointment or enrollment. There is limited integration into EHRs, so most providers filled out the tool on paper, which created more work to incorporate into the patient's record or population health management system. The Humana interview uses robocalls to administer Healthy Days to specific markets but has a limited response rate.

Almost all interviewees administered the tool at intake to get a baseline of patient priorities. Sometimes it was re-administered at a specific point in care (e.g., after receiving mobility aid) or at regular intervals throughout the program. Humana administers Healthy Days monthly with no connection to clinic visits or member utilization. Data access for other clinical staff members, e.g., evaluation/QI purposes, depends on EHR and the population health management system used at the organization.

The consumer is not currently provided the What Matters Index but serves on an EPIC patient advisory committee so she knows how EHRs could support PROMs and provider education and by extension, how her providers could and are not using the EHR to her benefit. The most important factor would be to give the tool in advance to inform the visit. Current assessments are based on healthy patients so future tools should reflect how complex the issues are. It is also important to respond to data from using PROMS. For example, she is regularly given mental health assessment but there is not any follow-up based on her answers.

#### Use and application of data

Every provider interviewed used the data to inform the patient care plan. The data was used for program QI in organizations that shared results with evaluation staff, though that did not extend to overall evaluation efforts or payment/reimbursement. One interviewee suggested using data to justify costs to insurers or marketing to patients. Humana uses Healthy Days as a leading indicator because it is predictive of negative outcomes and is working on a manuscript comparing Healthy Days data to costs.

Interviewees generally did not connect PROMs to other analyses because of team capacity and bandwidth. Numeric data is more likely to be analyzed because it requires less staff time to code. Humana used Healthy Days as a short-term measure in conjunction with mid-term and longer-term measures (quality measures and utilization, respectively).

The consumer said she would ideally complete the assessment before an appointment to inform the visit. Currently, she will come to an appointment with her own goals and research but the provider has already made a clinical decision based just on the information in her records.

Lessons from the PROMs depended on the tool:

- **PAM:** Patients had limited literacy, leading the IHS clinic to develop a low-literacy version with support from Insignia. They attempted to validate the new version but the community is sensitive to evaluations/research.
- **EUROQOL:** Case managers and health coaches learned about what makes people feel like they have good health (Interviewee didn't have that information on hand).
- **Healthy Days:** Humana identified a correlation between unhealthy days and social isolation; individuals who indicated social isolation had 2x the higher rate of unhealthy days. A provider identified that the patients were "really, really, really" sick. As a result, the tool didn't feel like a strengths-based approach since it asked patients to identify all the ways they didn't feel healthy, especially because they were asked while admitted to the hospital.
- **FMA:** The tool has identified that people either love their mobility aid and specific pain points in quality of life, particularly comfort in the chair or difficulty transferring from the chair to other surfaces.

#### Impact of PROMs on care delivery

Interviewees identified three non-exclusive populations who found the respective PROMs particularly difficult. Non-native English speakers required interpreter services to complete the tools because of language and cultural barriers. Older populations who have lived with chronic conditions found it difficult to compare their current health to a hypothetical time when they were healthier. Tools also didn't seem to capture the experiences of patients with diverse backgrounds and individual or historical histories of trauma.

The survey also highlighted the factors that impact perceived reliability of the tool. In general, the results seemed to align with the providers' experience although this depends on the staff buy-in and the patient's understanding and circumstance (e.g. mood, existing relationship with provider).

There was mixed feedback on how the tool impacts relationships. Patients may appreciate a program that prioritizes their feedback, even if they do not understand the questions or how to answer. However, this isn't the primary way that trust is established. Tools that are not customized to the particular patient population have the potential to degrade the patient relationship because the provider could seem tone-deaf or out of touch with the patient's issues.

The major barriers identified were low patient literacy, lack of EHR integration, and difficulty incorporating into the workflow. Providers cannot track results of patients longitudinally or fully incorporate into care planning without full EHR integration. The assessment workflow is challenging because care teams might already feel that they know the patient's goals, be reluctant to administer tools that don't have good resources to offer as a result, or because care managers are so often working through crises so the tool is less of a priority. Respondents to the field survey also noted that the provider and the patient have limited time, so overly long and complicated tools are challenging.

Interviewees also noted that the tool should be holistic — both in how health and well-being is defined and the other tools used to assess impact which should include patient experience and outcome metrics.

#### Improving the impact of PROMs

- Measures need to be able to show progress over time and feel meaningful to the provider and patient.
- There needs to be EHR integration and easy scoring in order to really use the data, e.g. track the results over time.
- Measures need to account for the true complexity and historical trauma of populations.
- Measures should be as simple as possible for the maximum impact and be useful for patients, care teams, and evaluation purposes.
- Important elements to consider: a broad definition of health and self-efficacy

#### **Other notes**

Interviewees were skeptical about a tool that can work for multiple patient populations and programs, especially considering how unstandardized complex care programs are currently.

Social connection and isolation came up as a key topic in multiple conversations. Humana has identified the connection between increased social isolation and low Healthy Days scores. A provider noted that successful patients were those who had at least one strong social connection.



camdenhealth.org P 856-365-9510 F 856-365-9520



#### The National Center for Complex Health & Social Needs

An initiative of the Camden Coalition

nationalcomplex.care P 856-365-9510 ext #2013

# About the Camden Coalition of Healthcare Providers

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of **complex care** by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our communitybased programs deliver better care to the most vulnerable individuals in **Camden** and **regionally**. The National Center for Complex Health and Social Needs (National Center), an initiative of the Camden Coalition, connects complex care practitioners with each other and supports the field with tools and resources that move complex care forward. The National Center's founding sponsors are the Atlantic Philanthropies, the Robert Wood

Johnson Foundation, and AARP.