

# Provider Perspectives on the Feasibility and Utility of Routine Patient-Reported Outcomes Assessment in Heart Failure: A Qualitative Analysis

Peter Wohlfahrt, MD, PhD; Susan L. Zickmund, PhD; Stacey Slager, MS; Larry A. Allen, MD; Jose Nativi Nicolau, MD; Abdallah G. Kfoury, MD; G. Michael Felker, MD, MHS; Jorge Conte, MD; Kelsey Flint, MD, MSCS; Adam D. DeVore, MD, MHS; Craig H. Selzman, MD; Rachel Hess, MD, MS; John A. Spertus, MD, MPH; Josef Stehlik, MD, MPH

**Background**—Patient-reported outcomes (PROs) objectively measure health-related quality of life and provide prognostic information. Advances in technology now allow for rapid, patient-friendly PRO assessment and scoring, yet the adoption of PROs in clinic has been slow. We conducted a multicenter qualitative study of diverse providers to describe the barriers and facilitators of routine PRO use in heart failure clinics.

**Methods and Results**—Sixty heart failure providers from 5 institutions participated in 8 focus groups to explore provider perspectives on the use of heart failure-specific and generic PROs in clinical practice. A qualitative editing approach was used to analyze the data, whereby a coding dictionary was iteratively developed and applied using the qualitative software program Atlas.ti. Three main themes, supporting and impeding PRO use, emerged: (1) data collection; (2) presentation and interpretation; and (3) utility and value. For each construct, we identified perspectives that highlighted both barriers and facilitators. Providers identified burden, survey fatigue, and language/health literacy barriers as potentially impeding data collection. Optimal workflow, PRO frequency and length, use of PRO translations, and assistance of a patient's proxy were suggested as facilitators. Focus group discussions provided insight on how to display PROs to support its interpretability and sharing. Furthermore, the need to educate providers on the utility and value PROs over and above current clinical approaches emerged.

**Conclusions**—Overcoming the barriers and supporting facilitators of PRO adoption could potentially lead to more successful adoption of PROs in heart failure clinics. (*J Am Heart Assoc.* 2020;9:e013047. DOI: 10.1161/JAHA.119.013047.)

**Key Words:** patient reported outcome • qualitative research • quality of life

Patient-centeredness is 1 of the 6 pillars of high-quality care articulated by the Institute of Medicine's *Crossing the Quality Chasm*.<sup>1</sup> A foundation for becoming a more patient-centered healthcare system is to accurately and validly

capture patients' experiences with their diseases. This has led to an increased emphasis on the use of patient-reported outcomes (PROs), as both end points in clinical trials and as tools in routine clinical practice. A recent scientific statement by the American Heart Association underscored the need to routinely use PROs in clinical care.<sup>2</sup> However, despite the availability of numerous disease-specific and generic PROs, their adoption in clinical practice has been slow.

Heart failure (HF) is a disease state for which PROs may be particularly valuable.

First and foremost, patients care about both the quantity and the quality of their lives.<sup>3</sup> Given patients' concerns with their health status (their symptoms, function and quality of life [QoL]), improving health status outcomes in patients with HF is one of the main goals of care.<sup>4</sup> This is particularly important for HF therapies that improve symptoms, but do not prolong survival (eg, diuretics). Second, there are valid, reliable, sensitive, and short PRO instruments, such as the 12-item version of the Kansas City Cardiomyopathy Questionnaire (KCCQ-12), that quantify the impact of HF on patients'

From the University of Utah School of Medicine, Salt Lake City, UT (P.W., S.L.Z., S.S., J.N.N., J.C., C.H.S., R.H.); University of Colorado Anschutz Medical Campus, Aurora, CO (L.A.A., K.F.); Intermountain Medical Center, Murray, UT (A.G.K.); Division of Cardiology, Duke University Medical Center, Durham, NC (M.F., A.D.D.); Rocky Mountain Regional VA Medical Center, Aurora, CO (K.F.); Luke's Mid America Heart Institute, Kansas City, MO (J.A.S.).

Accompanying Data S1, Table S1, and Figures S1, S2 are available at <https://www.ahajournals.org/doi/suppl/10.1161/JAHA.119.013047>

**Correspondence to:** Josef Stehlik, MD, MPH, University of Utah Health, Division of Cardiovascular Medicine, 50N Medical Dr., 4A100 SOM, Salt Lake City, UT 84132. E-mail: [josef.stehlik@hsc.utah.edu](mailto:josef.stehlik@hsc.utah.edu)

Received April 28, 2019; accepted September 27, 2019.

© 2020 The Authors. Published on behalf of the American Heart Association, Inc., by Wiley. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

## Clinical Perspective

### What Is New?

- Using a multicenter qualitative study of diverse HF providers, we described the barriers and facilitators of routine patient-reported outcome (PRO) use in heart failure clinics.
- Three main themes, supporting and impeding PRO use, emerged: (1) data collection; (2) presentation and interpretation; and (3) utility and value.
- Based on identified barriers we created recommendations for PRO implementation in HF clinics.

### What Are the Clinical Implications?

- Our work resulted in a set of recommendations that provide guidance for a successful adoption of routine PRO use in HF clinics.

symptoms, function, and QoL.<sup>5</sup> Third, beyond quantifying patients' health status, the KCCQ is strongly associated with subsequent clinical outcomes, such as survival and hospitalization.<sup>6–8</sup> Thus, PROs can not only provide clinicians with an assessment of patients' health status, but they can also provide a continuous, updatable assessment of their clinical risk. In this context, PROs are currently being considered by multiple healthcare payers as performance measures and routinely collecting PROs in clinical care can meet this metric without causing additional documentation efforts.<sup>9</sup>

Yet, despite the apparent advantages of routine use of PROs, their introduction into clinical care has been limited. Qualitative research aspects of PRO implementation have been described in oncology and palliative care,<sup>10–14</sup> but not for HF clinics.<sup>15</sup> Because HF providers have different training and treatment strategies, a better understanding of the barriers and facilitators of PRO implementation in HF care is needed. To address this gap in knowledge, we conducted a multicenter qualitative study to solicit provider-perceived barriers and facilitators towards PROs. Our objective was to evaluate provider perspectives and experiences on the use of PROs in HF as a foundation for developing recommendations for implementing PROs in HF care.

## Methods

We conducted focus groups that included providers at HF programs at the University of Utah Health in Salt Lake City, UT, Intermountain Medical Center in Murray, UT, University of Colorado Hospital in Denver, CO, Duke University Medical Center in Durham, NC and Saint Luke's Mid America Heart Institute in Kansas City, MO. Two of the sites (University of

Utah, Intermountain Medical Center) had recently implemented PRO use into clinical care, and the remaining sites were at different stages of planning for PRO use in clinical care. Knowledge about PROs was not formally assessed as part of the interview process. We used qualitative research methods, which excel in their ability to capture nuanced perspectives of participants that would otherwise be difficult to measure.

In the design of the study we took thematic saturation into account. As thematic saturation can be achieved in 3 to 5 focus groups, especially if the participants represent a homogenous population (such as cardiovascular providers in our case),<sup>16</sup> we determined that a total number of 8 focus groups was likely to achieve thematic saturation.

## Recruitment

We solicited attending physicians, advance practice providers, nurses, study coordinators, physician trainees and office administrative personnel (Table 1) from 5 HF programs at various stages of PRO implementation. While all programs had experience with PRO use, some have used it only as part of research protocols, while others have used PROs as part of clinical care. The decision to include programs at different stages of implementation was driven by the fact that providers' experience and perceived barriers may differ by implementation stage. However, we did not test formal differences in providers perspectives by implementation stage.

We reached out to all members of the HF team asking them to consider participation in the focus groups. Participants were required to be care providers or be engaged in the oversight, coordination, or organization of healthcare delivery in HF program in the ambulatory care settings. Administrative personnel (eg, medical assistants) were included because of their experience with PRO collection from research studies. In addition, in all focus groups, at least 2 attending physicians and one advance practice provider or nurse were required to be included because these are the providers who would be

**Table 1.** Focus Group Participant Profile

	n=60
Attending physician, n (%)	25 (41.7%)
Advanced practice provider (nurse practitioner, physician assistant), n (%)	12 (20.0%)
Nurse, n (%)	12 (20.0%)
Study coordinator, n (%)	6 (10.0%)
Physician trainee, n (%)	4 (6.7%)
Office administrative assistant, n (%)	1 (1.7%)

reviewing results of the PRO assessments in routine clinical care. Participation in the focus groups was not associated with any financial incentives. The study conduct was approved by institutional review boards at all the institutions and participants provided a verbal assent to participate in the focus group.

### Focus Group Discussion Guide

Drawing on the literature,<sup>17,18</sup> and including sample outputs from 3 PROs, the content experts created an initial draft focus group script. Major domain selection was based on content expert input, and the focus group guide and the respective handout included themes and PRO illustrations deemed important to explore. The qualitative research expert refined the initial draft of the semi-structured guide for clarity and fluency, and this advanced draft was further revised by expert consensus. As a final step, the interview guide was read aloud during a meeting of the investigators to ensure clarity and the flow of the questions. Final modifications were done based on this step.

At the start of the focus groups an assent document was read aloud to the participants by the moderator. This document explained that the focus groups were being done to examine the use of PRO results by clinicians, before and after training in PRO interpretation, and that the focus group would also explore how sharing and discussing PRO scores with patients influence their understanding of disease, treatment goals and treatment preferences.

The discussion guide had 3 domains: (1) perception on utility and use of PROs, (2) KCCQ value for clinical practice in HF clinics and KCCQ results presentation, and (3) Patient-Reported Outcome Information System (PROMIS) value for clinical use and PROMIS results presentation. Open-ended questions from the guide were used to lead the discussion along these 3 overall topics. Handouts were used along the discussion that included printout of key information about the PRO measures and examples of different graphical ways in which PRO results could be presented to clinicians and to patients.

All study moderators used an identical focus group guide at each site. The semi-structured interview guide for focus groups is provided in Data S1.

### Data collection

The 2 focus groups conducted at the University of Utah and the 1 at Intermountain Medical Center were conducted by the qualitative methodologist (SZ). That moderator trained experienced qualitative researchers to serve as moderators at the other 3 sites to ensure the consistency of data collection. Note takers were present at all focus group discussions and the conversations were recorded for transcription. On average, the focus groups took 1 hour each.

## PRO Tools Discussed

### KCCQ-12

The KCCQ-12 is a disease-specific tool used to quantify the health status (symptoms, function, and quality of life) of patients with congestive heart failure. It is valid, reliable, sensitive to clinical change, and prognostic of both clinical events and costs.<sup>5</sup> KCCQ-12 domains include physical limitation, symptom frequency, quality of life, and social limitations and has been translated to 96 languages. The KCCQ score range from 0 to 100, with high score representing better HF-related QoL.

### Patient-Reported Outcome Information System

PROMIS is a publicly available system of person-centered measures that evaluates and monitors physical, mental, and social health. Measures were developed for children and adults and have been translated into >40 languages. The PROMIS bank has 70 domains, of which physical function, fatigue, depression, and satisfaction with social roles were selected by the University of Utah as relevant to HF and discussed in the focus groups. PROMIS uses computerized adaptive testing, which increases the precision of assessment, while decreasing respondent burden. The PROMIS score ranges from 0 to 100 with higher scores indicating a higher level of the symptom measured, eg, more fatigue and more physical function.

### Visual Analog Scale

The state of health visual analog scale, (a component of the EuroQoL 5 Dimensions [EQ-5D]), is a generic QoL instrument that records the respondent's self-rated perception of health status.<sup>19,20</sup> The visual analog scale score ranges from 0 to 100 with the score 0 labeled "Worst imaginable health state" and the score 100 labeled "Best imaginable health state." The patient is instructed to simply 'mark an X on the scale to indicate how their health is on the day of the assessment. This information can be used as a quantitative measure of health outcome as judged by the individual respondent.

### Data Analysis

All audio files were transcribed verbatim for analysis. We used the "Editing" approach to coding that was developed specifically for open-ended data collection in the context of medical research.<sup>21</sup> The Editing approach had 5 phases, including describing the data, organizing them, connecting them through a coding process, corroborating the coding process, and finally representing the codes in a final analysis. All qualitative coding was captured and managed using the

qualitative software program Atlas.ti (Scientific Software, Berlin Germany). One senior qualitative analyst (SS) coded all focus groups in consultation with the qualitative methodologist (SZ). The frameworks, and implementation science were unrelated to the coding process. Instead, coding was guided by qualitative science in general and the editing approach more specifically. After the codebook was iteratively developed, it was refined by expert consensus from the larger team. The research team also identified preliminary themes while reviewing the transcripts and used an iterative consensus process to continue to refine themes as data analysis continued. The senior coder and the qualitative expert discussed codes as needed and worked with the larger team to pinpoint emerging topics deemed important in the literature. Thematic saturation was achieved within the first 6 sessions and an additional 2 sessions identified no new themes, confirming the attainment of thematic saturation.

## Results

Provider attitude towards using the HF-specific KCCQ survey and the generic PROMIS and the visual analog scale surveys were evaluated. A total of 60 multi-disciplinary providers took part in 8 focus groups across 5 institutions.

Through the focus groups, 3 main concepts, supporting and impeding the use of PROs, emerged; (1) data collection; (2) presentation and interpretation; and (3) utility and value. For each of these areas, there were perspectives that highlighted the barriers, and the facilitators/potential benefits to using PROs instruments in routine clinical care. Salient quotations are provided in Table S1. The barriers and facilitators of each of these concepts are described below and summarized in Table 2. Based on identified barriers and utilizing suggested facilitators we provide recommendations about how to best address these issues (Table 2).

### PRO Data Collection

Two main barriers influencing data collection were identified. These include burden and language/health literacy barriers. In general, the following were seen as facilitators: electronic PRO data capture, PRO completion before the clinic visit, immediate scoring and availability for the provider, optimal PRO frequency and length, the use of available PRO translations, and using proxies when the patient was unable to complete the PRO.

## Barriers

### Burden

Forty-one providers raised the issue of burden on the patient and clinic. This was expressed by one participant as: “We already ask a lot of our patients, many of them have driven for

long distances, had to pay for parking. The idea of additional time, energy, burden on patients is an important piece of that.”

Another identified issue associated with patient burden is survey fatigue.

Providers raised concerns that patients might get annoyed when they are asked the same questions at many of their appointments. Moreover, the providers expressed that patients might be concerned if the PROs were not addressed in the clinic visit, implying a concern that patients might feel that they had wasted their time completing the PROs if the clinicians did not actually use them during the clinic visit. The issue of survey fatigue and its consequences on collected data was noted by one focus group participant: “I feel like you can also give a patient fatigue asking them this many questions every single time they come to clinic.”

### Language and health literacy/cognitive barriers

Providers expressed concerns about language barriers and health literacy. One physician noted: “For some patients who struggle with literacy or have language barriers, it’s a very daunting thing to do.” It was also expressed that patients may lack the physical or mental capacity to complete PROs. If a proxy was filling out the questionnaire, they may not answer the questions in the same way the patient would.

This was noted by one provider: “There is very often disconnect between the patient’s view and the spouse’s view of how they are doing.”

## Facilitators

### PROs in routine clinical care

Most providers (n=42; 70%) thought that PROs collection should become part of the routine clinical care as a health status measure. To limit the ever-increasing number of information inputs into clinical workflow, some suggested replacing unstructured questioning on functional status during medical history taking with PROs. One provider noted: “Fundamentally, it seems that PRO would need to replace something the clinicians are currently doing, eg, asking questions about functional status, rather than add an additional task. Otherwise it is hard to see how this gets much attraction.”

### Optimal workflow

To decrease the burden on patients and providers, providers thought that careful attention should be given to optimizing workflow and finding the most convenient time to have patients complete their PRO assessments. Several suggested that assessing PROs before the encounter with a provider, ideally through online data submission, would maximize efficiency. Additionally, real-time scoring of PROs using a computer program would be important decrease providers’ time burden.

**Table 2.** Recommendation for PROs Implementation in HF Clinics Based on Identified Barriers

Barrier	Recommendation
<b>Data collection</b>	
Burden	Secure administrative and financial support
	Achieve full engagement of the providers and patients
	Optimize workflow:
	Replace unstructured questioning on functional status with PROs
	Assess PROs before the clinic visit, ideally through online data submission
	Use real-time scoring of PROs with electronic health record integration with presentation in an interpretable format
	PROs frequency: HF-specific PROs with every encounter, comprehensive PRO panel at 3- to 6-mo interval
Language and health literacy/cognitive barriers	Use available PRO instrument translations
	Patient proxy or a nurse may be assisting in completing the PROs
<b>Results presentation</b>	
	Present PROs trends with time on the $x$ -axis and the PRO score on the $y$ -axis, ideally with clear labels along the $y$ -axis facilitating interpretation of the scores (eg, by New York Heart Association class; symptoms frequency—daily, weekly, monthly, no; health status—very poor, poor, fair, good, excellent)
Ambiguous meaning of scales	Educate providers on PRO interpretation
Summary score vs domain score	Provide summary score with the option to review domain scores
<b>PRO utility and clinical value</b>	
Clinical judgment supersedes PRO	Educate providers on PRO nature, utility, and additional value over standard history taking
Actionable PRO data	Educate providers on PRO thresholds for action
	Research demonstrating improved care and outcomes with the use of PROs is needed
PROs selection	Both HF-specific and generic PROs should be implemented in HF clinics, balanced with careful attention to patient response burden and interpretability
	Prevent repeating the same or similar questions when combining multiple PROs
Intended audience for PROs	Approach all providers that participate in care of HF patients

As mentioned by several providers, selecting optimal survey frequency can positively rectify survey fatigue. One physician noted: “PRO needs to balance getting more objective information from the patient on each visit or every other visit or every third visit, but not having the point where the data are inaccurate because the patient is getting frustrated.” Suggested frequency of PRO evaluation ranged from every visit to once every 3 to 6 months. Others considered it important to evaluate PROs when there is a clinical status change, or after changing treatment, to assess the effect of the intervention. This would determine discrepancies between patient clinical status as assessed by the provider and patient-reported health-related quality of life.

### *Proxy may be filling out survey*

To overcome the language and health literacy barriers providers advocated for the ability to complete assessments in the patient’s native language and with the help of a patient

proxy or a nurse, if the patient is not capable to fill the PROs by himself (eg, illiterate patient had forgotten glasses).

### **Data Presentation and Interpretation**

A critical concept raised by providers was how best to present the data to support its interpretation and sharing with the patient and other providers. Ambiguous meanings of scales and uncertainty in PRO score presentation were the main barriers influencing this concept. Providers desired presentations that would be easy to understand and readily interpretable. Furthermore, most providers considered trends more important than individual scores.

### **Barriers**

#### *Ambiguous meaning of scales*

Twenty-two providers reported confusion caused by ambiguity of scales in PRO evaluation. KCCQ12 and visual analog scale



scores were more intuitive, ranging from 0 to 100 with higher scores indicating better functioning. The PROMIS scales were less intuitive to providers, using a population mean of 50, and normalizing each standard deviation to a score of 10, with higher scores indicating a higher level of the symptom measured. As such, a higher score can be better for one item, but worse for another item. This confusion about different scales and their interpretation was described by one provider as: “They’re not equal in what you’re assessing. So, you would want a higher score for satisfaction, but you don’t want a higher score for depression.”

### **Summary score versus domain score**

Forty-six providers expressed uncertainty about which PRO scores should be presented. While most providers preferred summary scores to limit information overload, others considered domain-specific presentations useful in selected cases to tease out the major contributors to patients’ overall health status. One provider suggested: “It might be valuable to look in a patient that maybe has a more complicated symptom burden of every single question in graphical format to tease out where their symptom burden is lying.” Furthermore, some thought that domain-specific presentation may identify comorbidities that require a different therapeutic strategy.

## **Facilitators**

### **Visual PRO depiction**

The focus groups provided insights related to presentation of PRO data. Most providers considered trends more important than the absolute scores and want to be able to see PRO trends over time. One physician noted: “I would say that the numbers in isolation are not very helpful, so any graphical display has to have, be relative to, how they did in the past.” Two graphical versions of PRO presentation were discussed—Figures S1 and S2. Providers preferred result presentation in a format familiar to them, such as a graph with a time on the x-axis and the PRO score with its interpretation on the y-axis (shown in Figure S2).

### **Integration with electronic health record**

Providers considered PRO integration within the electronic health record to be an important step to improve data presentation and sharing. One participant noted: “It would be nice to have PRO automatically recorded in a letter, and also what their score was in the past, so the next person, it may not be you, had a discrete value being recorded in the note.”

### **Sharing PRO data with patients**

Some participants highlighted graphical presentation of PROs as an important tool with which to share the information with

patients. This was expressed by one participant: “The picture’s worth a thousand words. Sometimes I don’t know how much a patient gets from the office visit. If they see this, I think it is worth a lot to them. It is graphically saying how they are doing.” The issue of data sharing and reviewing with the patient was also mentioned by another participant as: “For a lot of our patients it’s going to be a challenge to understand this if they just get something in the mail or in their portal. If we have somebody to explain it to them and that would get them more engaged and help them to understand what it is and why we’re tracking it.”

### **Educate providers on PRO**

To prevent ambiguity in PRO interpretation, providers considered it important that each of them be educated on how to interpret findings in the same way. The importance of education was raised by one provider as follows: “The score goes from 50 to 60. What does that mean and how does it impact how I change my therapy? There has to be a lot of education of just how sensitive the scale is and what it means. And what influences it because it’s a conglomerate of different aspects of quality of life, so what changes the score?”

## **PRO Utility and Clinical Value**

Generally, providers requested that new information considered for incorporation into the clinical workflow be accurate, actionable, useful, and impactful. The concepts of the perceived utility and value to clinicians over and above their current approaches emerged. In general, the lack of familiarity with the PROs raised concerns by clinicians about their value to care. However, most providers expressed positive attitudes toward using PROs in clinical practice and named several benefits of this approach. Specific concepts and quotes related to this theme are provided below.

## **Barriers**

### **Clinical judgment supersedes PRO**

Several providers expressed negative attitudes toward using PROs. They were concerned about the incremental value of using PROs over and above what they currently do in routine clinical practice. A physician stated: “I’d have to wait to see how much that would really improve what I normally do.” They argued that if a provider knows a patient well, they may not need to use PRO data. Another provider noted: “I can ask a few questions in about 1 minute or 2 and have a good sense of how the patient is doing.” Others questioned whether there is any additional value of PROs to clinical judgment and whether PROs have prognostic value. Some considered PROs more of a research tool, rather than a test useful for patient care.

### Actionable PRO data

Another issue was how to make PROs actionable and impactful. Providers questioned the thresholds for action and specific appropriate action to be considered at different thresholds. Conversely, several acknowledged that in some cases, they may not be able to take any action that would help improve patient's quality of life based on PRO results not directly related to HF. For example, one provider noted: "We do all the best things we can do for heart failure, but we can't fix their social circumstances. I bet it would be a high probability finding they have a spouse at home who is sick, and they also have to take care of them and their kid doesn't have a job. . ."

### HF-specific and generic PROs

Another issue was the uncertainty whether both HF specific and generic instruments should be incorporated into HF clinic patient care and workflow. This ambiguity was expressed by one provider: "If they are getting to the same point and you are assessing the same thing, why use 2 tools?" In regard to clinical utility in HF clinics, most providers considered HF-specific PROs more useful than general quality of life tools. One provider noted: "I prefer disease specific PROs, because we are cardiologists, and that's what we are here to impact." On the other hand, some expressed concerns that HF-specific PROs may not include all aspects of QoL that are important to the patient.

### Intended audience for PROs

Providers also questioned who the intended audience was for PROs. Some thought that PROs should be preferentially used by primary care physicians, while they did not see any additional value for an HF specialist. This was expressed by one provider: "If the physician does a good job of asking these questions, they'll get to these answers on their own and that's what most HF specialists will do. It seems to me that these questionnaires would be most useful in the primary care setting, where they don't remember to ask these questions."

## Facilitators

### Disconnect between provider and patient perspective

Most providers had a positive attitude toward using PROs and suggested that PROs may be added as one of the vital signs physicians should be paying attention to, such as blood pressure. They highlighted several benefits of PRO use. One of the most often mentioned benefits was the ability of PROs to address disconnect between the provider and the patient. For example, one provider noted: "PRO is most useful when there is a big disconnect with my perception of how the patient is doing and the patient's perception." Similarly, the utility of

PROs was highlighted for situations where there is a discrepancy between the clinical assessment of disease severity and the unstructured patient report obtained by the provider.

### Patient engagement

There was a perception that PROs can make patients feel that they are better communicating their health status to their providers. Moreover, some felt that by using the PROs, it might be possible to better engage the patient in the decision-making and therapeutic process. The use of PROs may also help patients to see their health more objectively and subsequently encourage them to consider changing therapies to improve their health status. One provider noted: "Some patients we ask to come every 2 weeks to the office. And if we can use PROs to show them why we are asking them, then they may feel justified in coming every so often and paying their copays." From a therapeutic viewpoint, PROs can help providers see features of QoL that have benefited from previous changes in therapy and help refine additional changes in treatment to further optimize patients' health status.

Another aspect important to the participants was the belief that PRO assessment can capture the impact of comorbidities and delineate common symptoms from different morbidities, eg, fatigue caused by HF versus fatigue caused by depression. This can lead to treatment decisions that focus on symptoms resulting from comorbidities.

### Standardized assessment

During the focus group discussion, the concept of standardized assessment emerged. Providers highlighted the difference between a highly variable and subjective method of unstructured questioning that is currently used during history taking to obtain patient's health status with PRO assessments that uses a validated set of questions with standardized scoring on each and every assessment. Thus, PRO use can decrease confusion across the healthcare system surrounding patients' symptoms and function. Furthermore, it can also help maintain continuity of care when patients have interchanging providers or in communication among different practitioners, particularly when different providers may assess and report patients' symptoms and QoL differently.

## Discussion

As we strive to make healthcare delivery more patient-centered, and as organizations like the International Consortium for Health Outcomes Measurement advocate for the routine use of PROs,<sup>22</sup> we conducted a multicenter, qualitative study to elicit providers' perspectives on the barriers and

facilitators of routine PRO use in clinical care of HF. Our study found that 70% of providers think that PROs should become routine in HF clinics and identified important provider perspectives on implementation of PROs into clinical practice. The main themes identified by the provider focus groups were PRO data collection; PRO result presentation and interpretation; and the utility and value of PROs. For each domain, some providers identified barriers, while others found facilitators to help support routine PRO use. We believe these insights can be helpful for HF programs seeking to implement PROs in routine care. By acknowledging identified barriers and proactively developing strategies to overcome them, HF programs can plan initial steps with sensitivity to providers' perspectives.

The logistics of PRO data collection were of great interest to the clinicians.

Routine PRO data collection can only be successful if a workflow is established such that the additional burden on patients and providers is limited. To achieve that, it is necessary to secure the administrative and financial support to implement the technology needed for PRO assessment and real-time scoring. Our group previously reported our experience with time-efficient electronic PRO capture in an HF clinic. The PROs are immediately scored and integrated in the patient's electronic health record, with an average PRO assessment time of 7 minutes for the collection of the KCCQ-12 and PROMIS- physical function, fatigue, depression, and satisfaction with social roles and activities domains.<sup>15</sup> Even more importantly, achieving full engagement of the providers and patients in this process is paramount to realize the potential value of PROs in routine clinical care.

Specific barriers (eg, language barrier or poor health literacy) will have to be addressed, depending on the individual practice. As several PROs now have validated translations (PROMIS >40, KCCQ 96 languages), implementation of a multi-language option for the PRO electronic data collection may overcome the language barrier and improve communication with the patient. Availability of multiple translations should be an important aspect in PRO selection.

In some instances, the patient may not be capable of filling out the questionnaire alone. Most PRO instruments were designed to support interview administration; therefore, having a medical technician or a healthcare proxy read and help the patient to complete the survey might overcome this challenge. However, programs should avoid relying on data from proxies who complete the PROs, as this may decrease the PROs validity.

Which specific PROs should be used in HF clinics and at what frequency is important consideration? While there are well-described advantages of disease-specific versus generic PROs with regards to sensitivity to clinical change, these become particularly important in specialty clinics where the

treatments are often focused on a specific disease. In the setting of heart failure, explicitly understanding the severity of patients' heart failure symptoms and how they impact their function and quality of life is critical so that more aggressive HF treatments can be offered to those who are not doing well and their response to therapy can be explicitly quantified. Nevertheless, HF patients often have additional comorbidities (eg, depression, arthritis) and generic PROs can also capture the burden to these comorbidities. This may also help set expectations for patients on which domains of their health-related QoL are they likely to improve with a change in treatment. Furthermore, generic PROs allow comparison with the general US population and other populations within a health system. When combining several PROs, attention should be paid to prevent repeating the same or similar questions, to prevent survey fatigue.

The optimal frequency of PRO assessment in the clinic needs further study. One practical approach may be to use a succinct disease-specific tool with every encounter and complete a more comprehensive PRO panel at a longer interval (eg, a minimal interval of 3 or 6 months), as is currently being done at the University of Utah. Such tailored use of PROs would not only increase providers' familiarity with PROs but is also needed if they are to be used as a 'vital sign' for systematically quantifying patients' symptoms, function, and quality of life.

Result presentation is another important aspect that can enhance interpretability of PRO scores for both providers and patients. The focus group findings suggested that providers are more comfortable with results being presented as a graph with a time on the *x*-axis and the PRO score on the *y*-axis. Providing a clinically intuitive interpretation of scores on the *y*-axis, such as in Figure S2C or S2D, can support providers in better interpreting scores, thus overcoming a potential barrier to the use of these tools. Several previous studies addressed the presentation of PROs in clinical practice.<sup>23</sup> Similar to our observation, cancer patients and oncology clinicians rated simple line graphs highest for ease-of-understanding and usefulness for presenting individual patient data, as compared with tabulated scores, heat maps of normal scores, or bubble plots.<sup>24</sup> In the line graphs, both groups preferred thresholds to be depicted on the graphs to indicate normal versus concerning scores.<sup>25,26</sup> To decrease ambiguity of scales, cancer patients and clinicians suggested higher = better or to add descriptive labels to the *y*-axis (eg, none, mild, moderate, severe) to address directional inconsistency of scales.<sup>26</sup>

In the past, PROs in the field of HF have been predominantly used in clinical investigations of new therapies. As such, the exposure of clinicians to PRO results has mostly been in the format of a composite score for patient cohorts, rather than individual scores for unique patients. Several of the concerns by providers about the utility of the tools reflects



a limited understanding of PROs. To better address such concerns, detailed education about the nature, utility, and additional value over standard history taking, and the interpretability of PROs, seems essential to overcoming these concerns. This should directly address the issues, raised by the focus groups, about utility and value of PROs. The validity of PROs (such as the KCCQ-12), including their reliability, reproducibility, and prognostic importance, are well established.<sup>6–8</sup> The utility of using PROs specifically in patients with chronic HF has also undergone careful examination.<sup>27</sup> This suggests that dissemination of information on PRO utility and further structured education of providers is needed to promote their understanding of PROs and to enhance providers' interest in adopting them in their clinics. Additional research that would provide clinicians with structured guidance on how to respond to specific score thresholds and how to confirm that a specific action has resulted in the desired QoL outcome is also needed.

Others have explored PRO implementation in the clinical settings of other medical conditions. Similar to our findings, burden has been previously identified as a barrier. Specifically, the complexity of establishing routine PRO data collection,<sup>11</sup> the logistics of PRO collection and processing,<sup>10</sup> and identification of additional resources, including staff that can address issues newly detected by PROs.<sup>12,14</sup> Our work builds upon these studies by presenting recommendations specific to the practical use of PROs in HF clinics, exploring the preferred graphical presentations of the results and discussing use of summary versus individual domain scores for the KCCQ-12 instrument.

Our study has several limitations. An important limitation is the absence of patients' perspective on PRO implementation, which may differ from the providers' perspective. We are currently conducting a qualitative study with patients to explore their perspectives related to PRO use. We anticipate the results of this investigation will complement the findings described in this paper. Another limitation includes the self-selection of providers participating in the focus groups for which no financial incentive was offered. It is not possible to know whether those with particularly positive or negative attitudes about the use of PROs chose to participate. However, our final sample of providers was large and diverse and from multiple institutions, which likely minimizes this bias. Despite having attained saturation in our study, we cannot exclude the possibility that other potential barriers and facilitators exist. Furthermore, most providers participating in the focus groups had some previous experience with PRO use, either from clinical studies or routine clinical work. While we believe the profile of the focus group participants was diverse, perceived barriers and facilitators may differ in subjects with no previous knowledge or exposure to PROs. We included institutions at various stages of PRO implementation, which

provided broader perspectives of the participants, however, we did not formally test differences in focus group results by PRO implementation stage at the respective institutions.

In summary, this study provides important insights into providers' perceptions of PRO use in routine clinical care. As the assessment of PROs is being considered as a performance measure by multiple healthcare payers, it is important to consider how these tools might be integrated into clinical workflow so that the provision of such performance measures is a byproduct of care, rather than an additional unfunded mandate. Our findings have identified some barriers to routine PRO use in clinical practice; proactively addressing these future implementations may be more successful. In particular, emphasizing provider education, smooth data collection and scoring, interpretable presentations, and the selection of relevant and actionable PROs available in multiple languages are important. Future implementation studies will be needed to address practical applicability of our recommendations. Ultimately, explicit testing of the impact of routine PRO use on the care and outcomes of patients with HF can provide an important motivation for their adoption in clinical care.

## Sources of Funding

This work was funded by the American Heart Association through a Strategically Focused Heart Failure Research Networks award 16SFRN31890003 (PI: Stehlik J).

## Disclosures

Dr Spertus discloses that he owns the copyright to the Kansas City Cardiomyopathy Questionnaire (KCCQ). The remaining authors have no disclosures to report.

## References

1. Institute of Medicine Committee on Quality of Health Care in A. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
2. Rumsfeld JS, Alexander KP, Goff DC, Graham MM, Ho PM, Masoudi FA, Moser DK, Roger VL, Slaughter MS, Smolderen KG, Spertus JA, Sullivan MD, Treat-Jacobson D, Zerwic JJ. Cardiovascular health: the importance of measuring patient-reported health status. a scientific statement From the American Heart Association. *Circulation*. 2013;127:2233–2249.
3. Lewis EF, Johnson PA, Johnson W, Collins C, Griffin L, Stevenson LW. Preferences for quality of life or survival expressed by patients with heart failure. *J Heart Lung Transplant*. 2001;20:1016–1024.
4. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Drazner MH, Fonarow GC, Geraci SA, Horwich T, Januzzi JL, Johnson MR, Kasper EK, Levy WC, Masoudi FA, McBride PE, McMurray JJ, Mitchell JE, Peterson PN, Riegel B, Sam F, Stevenson LW, Tang WH, Tsai EJ, Wilkoff BL. 2013 ACCF/AHA guideline for the management of heart failure: executive summary: a report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. *Circulation*. 2013;128:1810–1852.
5. Spertus JA, Jones PG. Development and validation of a short version of the Kansas City cardiomyopathy questionnaire. *Circ Cardiovasc Qual Outcomes*. 2015;8:469–476.
6. Heidenreich PA, Spertus JA, Jones PG, Weintraub WS, Rumsfeld JS, Rathore SS, Peterson ED, Masoudi FA, Krumholz HM, Havranek EP, Conard MW, Williams

- RE. Health status identifies heart failure outpatients at risk for hospitalization or death. *J Am Coll Cardiol*. 2006;47:752–756.
7. Kosiborod M, Soto GE, Jones PG, Krumholz HM, Weintraub WS, Deedwania P, Spertus JA. Identifying heart failure patients at high risk for near-term cardiovascular events with serial health status assessments. *Circulation*. 2007;115:1975–1981.
  8. Pokharel Y, Khariton Y, Tang Y, Nassif ME, Chan PS, Arnold SV, Jones PG, Spertus JA. Association of serial Kansas City cardiomyopathy questionnaire assessments with death and hospitalization in patients with heart failure with preserved and reduced ejection fraction: a secondary analysis of 2 randomized clinical trials. *JAMA Cardiol*. 2017;2:1315–1321.
  9. Brogan AP, DeMuro C, Barrett AM, D'Alessio D, Bal V, Hogue SL. Payer perspectives on patient-reported outcomes in health care decision making: oncology examples. *J Manag Care Spec Pharm*. 2017;23:125–134.
  10. Philpot LM, Barnes SA, Brown RM, Austin JA, James CS, Stanford RH, Ebbert JO. Barriers and benefits to the use of patient-reported outcome measures in routine clinical care: a qualitative study. *Am J Med Qual*. 2018;33:359–364.
  11. Van Der Wees PJ, Nijhuis-Van Der Sanden MW, Ayanian JZ, Black N, Westert GP, Schneider EC. Integrating the use of patient-reported outcomes for both clinical practice and performance measurement: views of experts from 3 countries. *Milbank Q*. 2014;92:754–775.
  12. Schepers SA, Haverman L, Zadeh S, Grootenhuis MA, Wiener L. Healthcare professionals' preferences and perceived barriers for routine assessment of patient-reported outcomes in pediatric oncology practice: moving toward international processes of change. *Pediatr Blood Cancer*. 2016;63:2181–2188.
  13. Monroe AK, Jabour SM, Pena S, Keruly JC, Moore RD, Chander G, Riekert KA. A qualitative study examining the benefits and challenges of incorporating patient-reported outcome substance use and mental health questionnaires into clinical practice to improve outcomes on the HIV care continuum. *BMC Health Serv Res*. 2018;18:419.
  14. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. *J Patient Rep Outcomes*. 2018;2:46.
  15. Stehlik J, Rodriguez-Correa C, Spertus JA, Biber J, Nativi-Nicolau J, Zickmund S, Steinberg BA, Peritz DC, Walker A, Hess J, Drakos SG, Kfoury AG, Fang JC, Selzman CH, Hess R. Implementation of real-time assessment of patient-reported outcomes in a heart failure clinic: a feasibility study. *J Card Fail*. 2017;23:813–816.
  16. Namey E, Guest G, McKenna K, Chen M. Evaluating bang for the buck: a cost-effectiveness comparison between individual interviews and focus groups based on thematic saturation levels. *Am J Eval*. 2016;37:425–440.
  17. Ra K. *Developing Questions for Focus Groups*. Thousand Oaks, CA: SAGE; 1998.
  18. Krueger RACM. *Focus groups, a practical guide for applied research*, 4. ed. Thousand Oaks, CA: Sage Publications; 2009.
  19. *Health Policy*. EuroQol—a new facility for the measurement of health-related quality of life. 1990;16:199–208.
  20. Shmueli A. Subjective health status and health values in the general population. *Med Decis Making*. 1999;19:122–127.
  21. Crabtree B, Miller W. *Doing Qualitative Research*. Thousand Oaks, CA: SAGE; 1999.
  22. (ICHOM) ICFHOM. White Paper: A Gap Analysis Between The International Consortium For Health Outcomes Measurement Heart Failure Standard Set And A Global Selection Of Real-World Data Sources. 2017.
  23. Bantug ET, Coles T, Smith KC, Snyder CF, Rouette J, Brundage MD. Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: what makes a pro picture worth a thousand words? *Patient Educ Couns*. 2016;99:483–490.
  24. Brundage MD, Smith KC, Little EA, Bantug ET, Snyder CF. Communicating patient-reported outcome scores using graphic formats: results from a mixed-methods evaluation. *Qual Life Res*. 2015;24:2457–2472.
  25. Snyder CF, Smith KC, Bantug ET, Tolbert EE, Blackford AL, Brundage MD. What do these scores mean? Presenting patient-reported outcomes data to patients and clinicians to improve interpretability. *Cancer*. 2017;123:1848–1859.
  26. Smith KC, Brundage MD, Tolbert E, Little EA, Bantug ET, Snyder CF. Engaging stakeholders to improve presentation of patient-reported outcomes data in clinical practice. *Support Care Cancer*. 2016;24:4149–4157.
  27. Psootka MA, von Maltzahn R, Anatchkova M, Agodoa I, Chau D, Malik FI, Patrick DL, Spertus JA, Wiklund I, Teerlink JR. Patient-reported outcomes in chronic heart failure. *Appl Regul Approv*. 2016;4:791–804.

# **Supplemental Material**

## Data S1.

### Semi Structured Interview Guide for Focus Groups with Clinicians.

#### 1. PERCEPTIONS

As you may know, Medicare is developing performance measures with which to assess the quality of care that will require providers to collect patient-reported quality of life questionnaires, sometimes called patient reported outcomes or PROs, on all of their patients each year.

We would like to start inquiring about your perceptions for collecting PROs

##### **What are your opinions about the utility of assessing PROs in routine clinical care?**

- What are the barriers to assess quality of life in clinical practice?
- How frequently should the surveys be applied?

##### ***How would you envision using the results in clinical practice?***

- As a means of sharing with patients/caregivers how the patients are doing/progressing?
- As a means of refining prognosis?
- As a means for escalating/de-escalating treatment?

#### 2. KANSAS CITY CARDIOMYOPATHY QUESTIONNAIRE (KCCQ-12)

The final selection of measures/tools for the purpose of performance metrics has not yet been made. One of the proposed methods is KCCQ because of its brevity, and because it is a disease specific questionnaire for patients with heart failure.

We are hoping to convert the results of the KCCQ into something that is clinically useful so that you will WANT to collect and use it on each and every patient. This will transform the reporting of the KCCQ required by Medicare to something that will be useful in care and for which providing the data to CMS is merely a byproduct of what you are already doing.

In order to do that, we want the scores, which range from 0-100, to be clinically interpretable and useful.

##### **We would like to review the KCCQ with you and share a few potential outputs for you to consider.**

As you can see, the KCCQ is a 12-item questionnaire that takes 2-5 minutes to complete. It is divided into sections that ask about different aspects of how heart failure affects patients' health:

- Question 1 has 3 items that ask about physical limitations due to heart failure (Note: Point to Question 1)
- Questions 2-5 ask about the frequency of symptoms (Note: Point to Questions 2-5)
- Questions 6 and 7 ask about patients' perceptions of how heart failure impacts their quality of life (Note: Point to Questions 6 and 7)
- Question 8 asks about social limitations patients experience due to heart failure (Note: Point to Question 8)
- In addition, there is a summary score that summarizes all of these domains.



We are now going to ask you some questions about what information from the KCCQ would be most valuable to you from a clinical perspective.

- What would be most valuable to you from these scores, the overall summary score or the scores for each domain (limitations in physical activity, frequency of symptoms, quality of life, social limitations)?
  - How can we make the graphical outputs more meaningful to your practice?
  - What is the number of scores that should be displayed (e.g. just today, today and last visit, today and last 3 visits, all the scores that the patient has ever done)?
  - How important are axis labels to you? Is it sufficient to have the scores, or would it be important to add information to the labeling of the axis (e.g. how KCCQ score relates to frequency of symptoms, NYHA class, prognosis)?
  - Do you prefer the bar charts, or is the line graph more intuitive?

### **3. PATIENT-REPORTED OUTCOMES MEASUREMENT INFORMATION SYSTEM (PROMIS)**

Another proposed PRO tool to be used is PROMIS, a set of person-centered measures that evaluates and monitors physical, mental, and social health. It was developed and validated by NIH to be used with the general population and with individuals living with chronic conditions. PROMIS uses computer adaptive testing, which allows for accurate assessment with only a few questions selected from a large pool of questions.

The four domains proposed for assessment by PROMIS in our heart failure clinic are physical function, fatigue, depression and satisfaction with social roles and activities.

How do you think the results for the four discrete domains help you understand the patient's quality of life.

**We would like to share a few potential outputs for you to consider. Please let us know what would be most useful and valuable to you in your clinic.**

- **Handouts will be used to present different outputs**

- How can we make the graphical outputs more meaningful to your practice?
- PROMIS shows information that is distinctive from KCCQ12, but there is also overlap in the QoL aspects it measures. Do you think there are graphical outputs that would be best suited for PROMIS result display? Or, do you feel the graphical output should be fairly uniform regardless of what tool is being used?

There will be a fair amount of scores that can be presented to you based on the PROs collected in the HF clinic. Is it helpful to have the information on both the KCCQ and PROMIS results, or would you prefer to be presented with just a subset of this information?

**Table S1. Representative comments from qualitative interviews.**

Theme	Representative Provider comments	
PRO data collection	Barriers	<p data-bbox="940 386 1688 410">...the idea of additional time, energy, burden on patients...</p> <p data-bbox="940 456 1787 613">“If it's adding on to your clinic visit, when they start asking a lot of questions, then it's potentially going to add time to a visit, which is already crunched.”</p> <p data-bbox="940 659 1814 751">"I feel like you can also give a patient fatigue asking them this many questions every single time they come to clinic"</p> <p data-bbox="940 797 1696 821">"People might just answer just to get done with the survey"</p> <p data-bbox="940 867 1860 1024">“We’re doing so many of these different things over time that it could actually lead patients, like saying I really don’t even want to go see that Doctor, I can’t imagine having to fill out this form again”</p> <p data-bbox="940 1062 1598 1086"><b>Language and health literacy/cognitive barriers</b></p> <p data-bbox="940 1131 1854 1224">"...patients come from different backgrounds, in terms of ability to read, different language"</p> <p data-bbox="940 1269 1854 1362">"I think that how you get these answers would be a resource challenge because there are a lot of literacy issues."</p>

"Sometimes I think it's easier to just ask them when you access them because if they don't understand the questions you know right away and you phrase it in a different way"

"there is very often disconnect between the patient's view and the spouse's view of how they are doing"

"...but certainly, health literacy is an issue there. And there are patients that I work with for sure that you'd need a person to do this in person with cause they're not going to be able to do that on their own."

**Facilitators PROs in routine clinical care**

"let's collect it before the patient comes into the room, make it a vital sign"

**Optimal workflow**

"I would envision every couple months it would be reasonable to have that potential assessment"

"...or if you make a major change in therapy"

"heart failure patients on average are seen sort of somewhere between three and four times a year, on average, which so that's probably about the right frequency"

"they could get a pre-clinic survey and fill it out so they are not stressed when they come to clinic"

**Proxy may be filling out survey**

"somebody would have to sit down with the patient and read questions and fill it out"

"I think these are available in Spanish pretty readily but there's a lot of other languages"

**Data presentation and interpretation    Barriers**

**Ambiguous meaning of scales**

"They're not equal in what you're assessing. So you would want a higher score for satisfaction but you don't want a higher score for depression."

"you would want a higher score for satisfaction but you don't want a higher score for depression"

"You're rarely going to find someone three standard deviations above and below, even two. If you narrow it from 30 to 70, it's easier to interpret. Now, it just looks like I'm average."

**Summary score vs. domain score**

"but when I look at the vital signs I probably only want to see the overall summary score"



"It might be valuable to look in a patient that has a more complicated symptom burden of every single question in graphical format to tease out where their symptom burden is lying"

"the summary score obviously is a lot easier to look at than trying to look at each individual domain"

"it's probably important that they include a global metric of quality of life, not just heart failure"

"It's a great example of how you have two tools and they go the exact opposite direction, and it's a mess."

**Facilitators Visual PRO depiction**

"I would say that the numbers in isolation are not very helpful so I think any graphical display has to have, be relative to how they did in the past"

"You need something that you just look at quickly"

"trends are probably more important than actual numbers"

**Integration with electronic health record**

"It would be nice to have PRO automatically recorded in a letter, and also what their score was in the past, so the next person, it may not be you, had a discreet value being recorded in the note"

### **Sharing PRO data with patients**

"For a lot of our patients it's going to be a challenge to understand this if they just get something in the mail or in their portal. If we have somebody to explain it to them and that would get them more engaged and help them to understand what it is and why we're tracking it"

"The picture's worth a thousand words. Sometimes I don't know how much a patient gets from the office visit. If they see this, I think it is worth a lot to them. It is graphically saying how they are doing"

### **Educate providers on PRO**

"I would have to become a lot more familiar with a couple of the instruments before I could ever incorporate that in to my practice"

"The score goes from fifty to sixty. What does that mean and how does it impact how I change my therapy? There's has to be a lot of education of just how sensitive the scale is and what it means. And what influences it because it's a conglomerate of different aspects of quality of life, so what changes the score"

## **PRO utility and value**

### **Barriers**

#### **Clinical judgement supersedes PRO**

"without the score you most of the time actually know what's going on"

here"

"I'd have to wait to see how much that would really improve what I normally do"

"it will be interesting to learn how useful it is"

"it could be added workload for both provider and patient without any clear incremental value for that individual case"

"If it is utility, then I think pursue it, but if all we want to know is the PRO, those don't matter, but if you think that's helpful information keep it up."

#### **Actionable PRO data**

"I know what to do with the serum sodium goes from 136 to 134, but if it were to change in a quality of life instrument, I would be at a loss to know whether it should be acted upon or it's irrelevant."

"you're adding those tests and you need to figure out what you do with them"

"It's sort of hard to know what to do with the data "

#### **HF specific and generic PROs**

"Would you want both of these surveys, would you want one of them, if one, which one would you want?"

"If they are getting to the same point and you are assessing the same thing, why use two tools?"

**Intended audience for PROs**

"It seems to me that these questionnaires would be most useful in the primary care setting, where they don't remember to ask these questions"

**Evidence of QoL improvement**

"I'm not totally sure that as a patient that I would see it as value added"

**Facilitators Disconnect between provider and patient perspective**

"I would see that this is most useful is to correct when there is a big disconnect with my perception of how the patient is doing and the patient's perception"

"There often is disconnect between the patient's perception and sort of more objective things and this balances perception."

"it bridges the disconnect that may be present between your perception as the provider of how the patient is doing and what the patient feels"

"So, I like the idea that it would be something instead of relying on my memory of, how they were doing the last time"

"you could have people whose physical activity scores are stable but



their quality of life score is going down and you might think that they actually had depression more than worsening heart failure”

**Patients engagement**

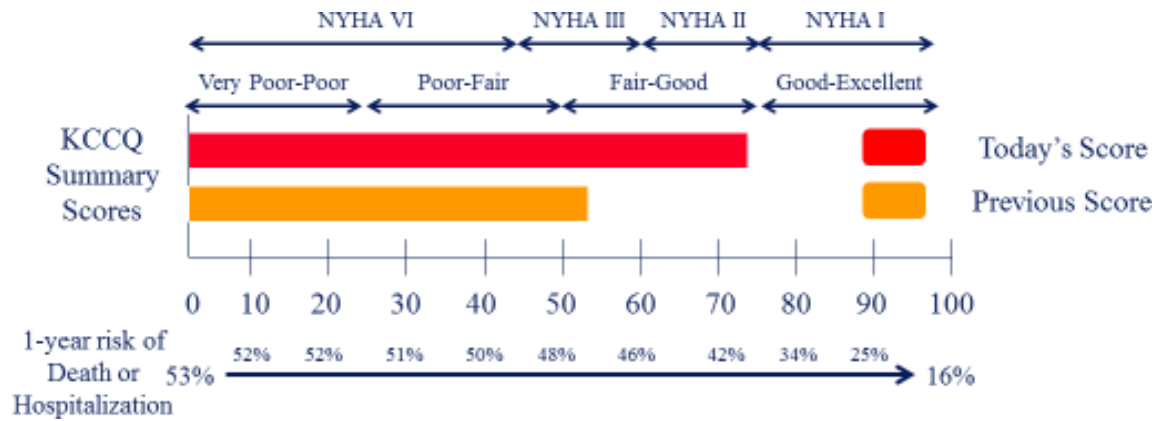
“a PRO tool can be one-way patients can connect with their provider to build a relationship on trust”

**Standardized assessment**

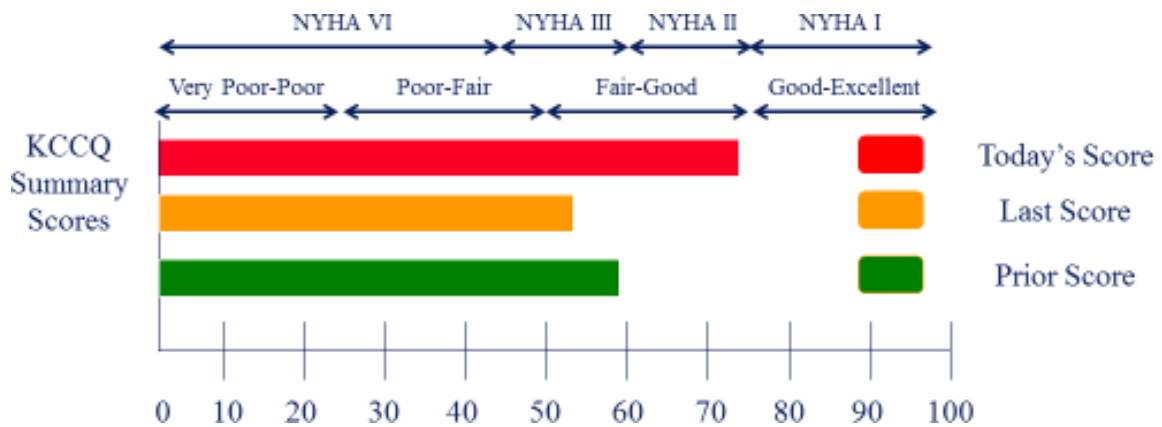
"there are potential advantages of using a more standardized PRO measure in contrast to kind of our more ad hoc asking questions"

**Figure S1. Different graphical presentations of KCCQ scores discussed in focus groups.**

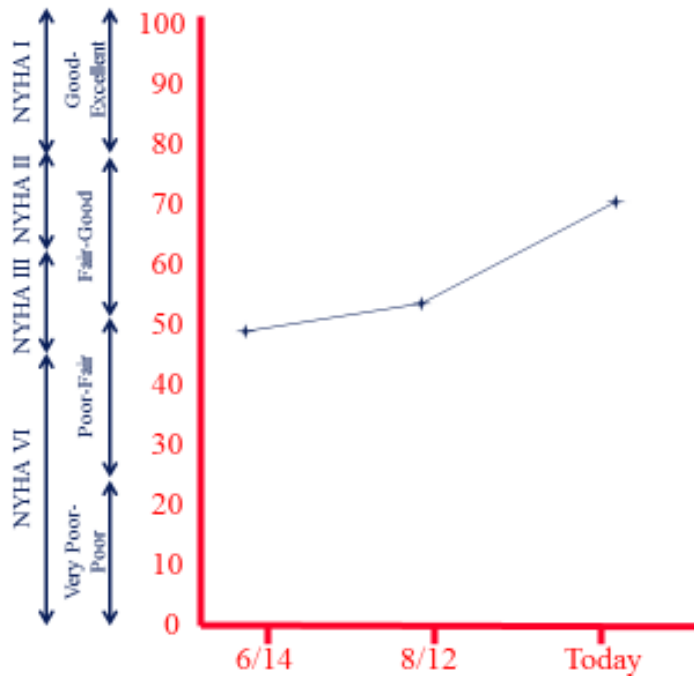
**A. Presentation 1.**



**B. Presentation 2.**



C. Presentation 3.



D. Presentation 4.

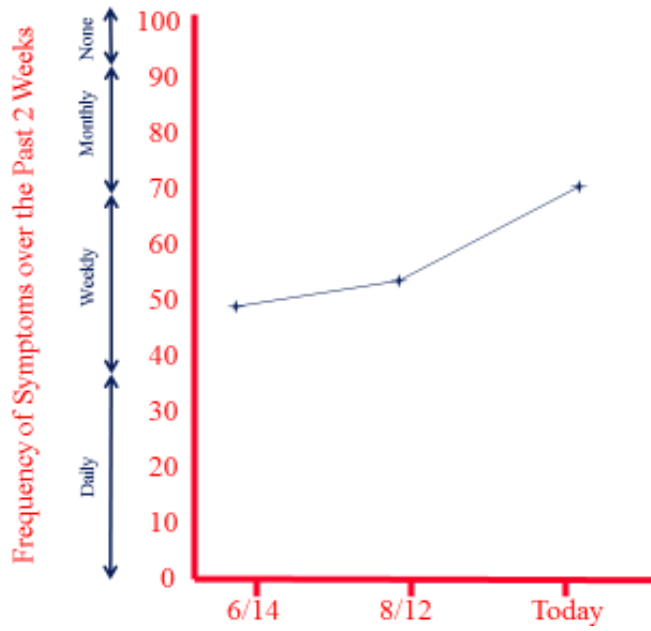
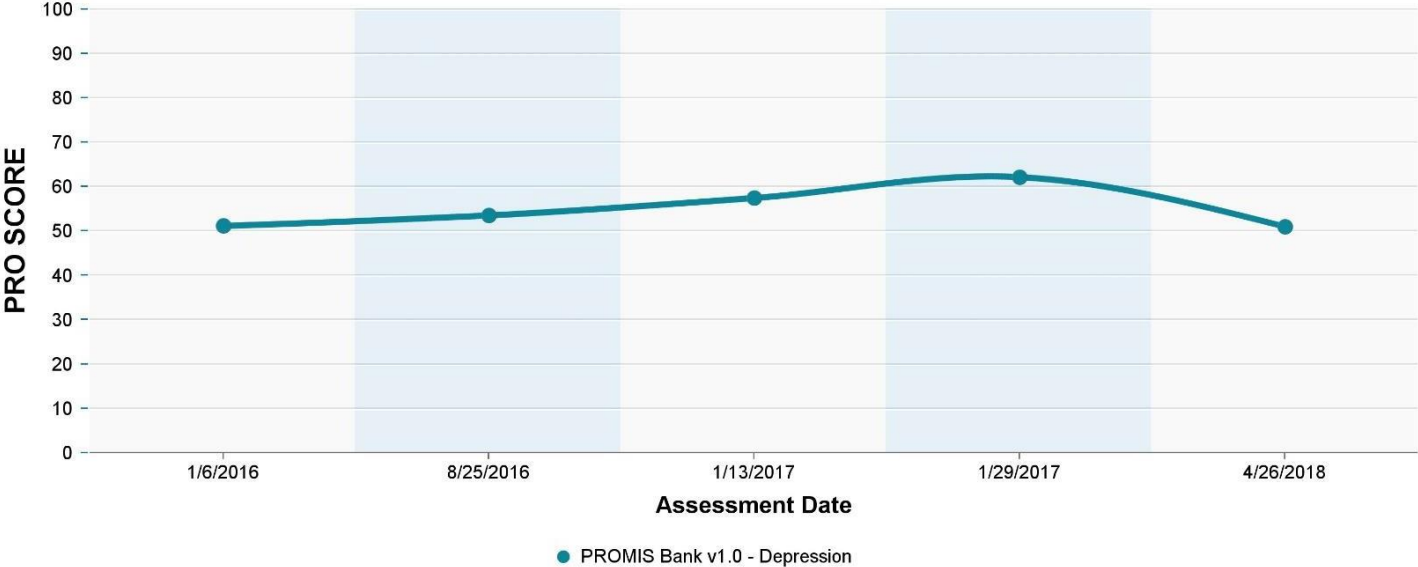
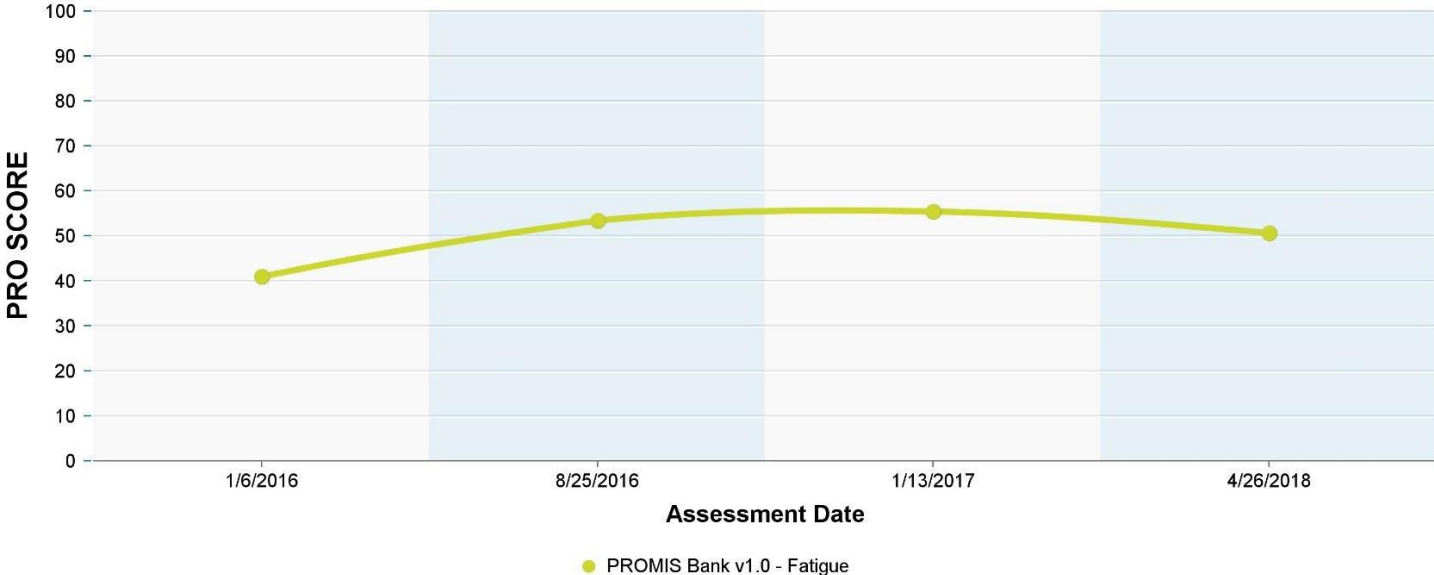


Figure S2. Presentation of PROMIS scores.

A. PROMIS - depression



B. PROMIS - fatigue





### C. PROMIS – physical function



### D. PROMIS- satisfaction

