

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 1780 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 1812 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 1692 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 1060 1593 1084">Language and health literacy/cognitive barriers</p> <p data-bbox="940 1130 1850 1222">"...patients come from different backgrounds, in terms of ability to read, different language"</p> <p data-bbox="940 1268 1850 1360">"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

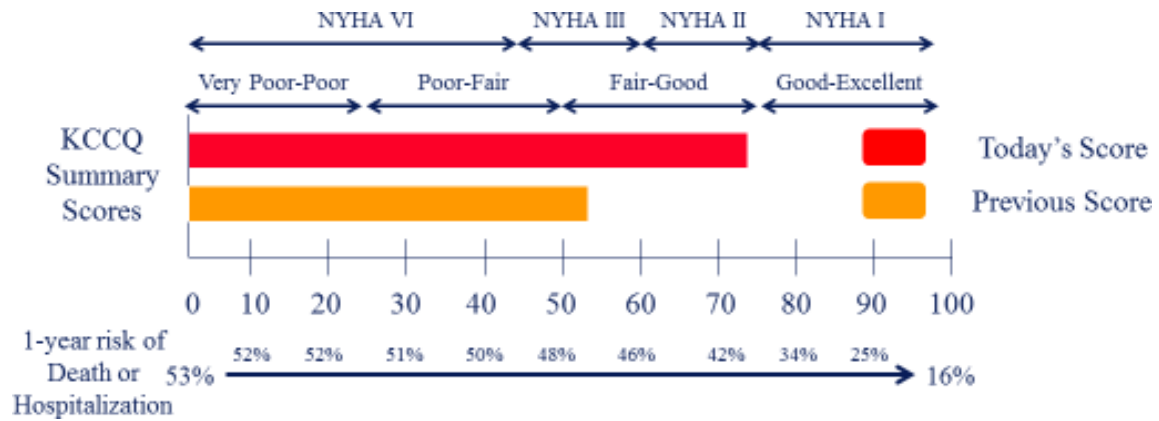
“a PRO tool can be one-way patients can connect with their provider to build a relationship on trust”

Standardized assessment

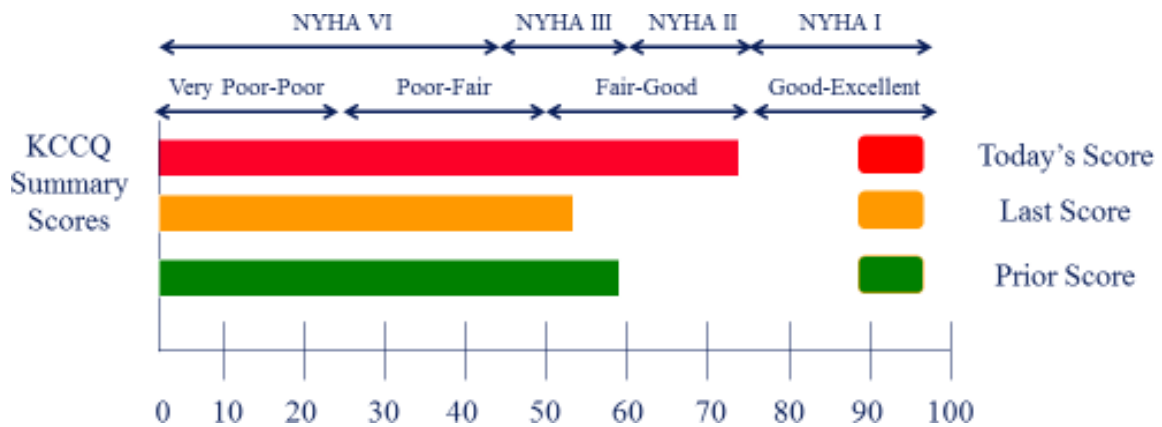
"there are potential advantages of using a more standardized PRO measure in contrast to kind of our more ad hoc asking questions"

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

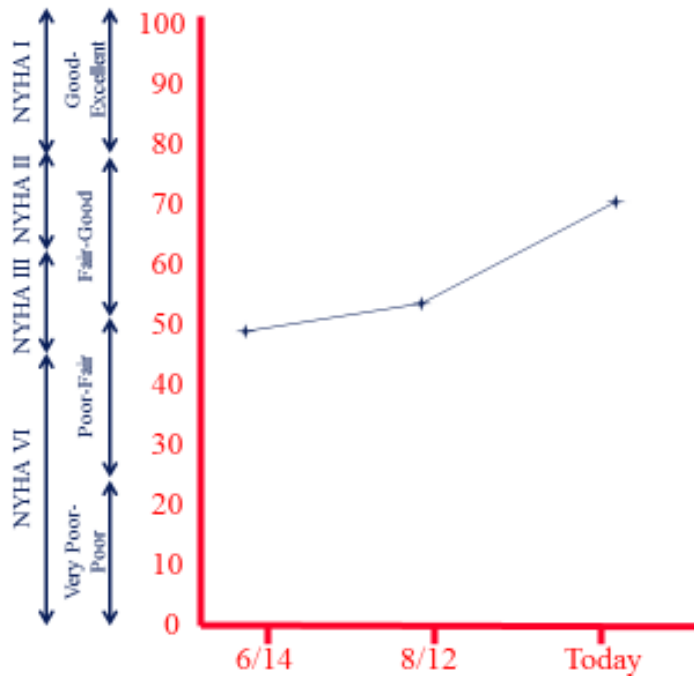
A. Presentation 1.



B. Presentation 2.



C. Presentation 3.



D. Presentation 4.

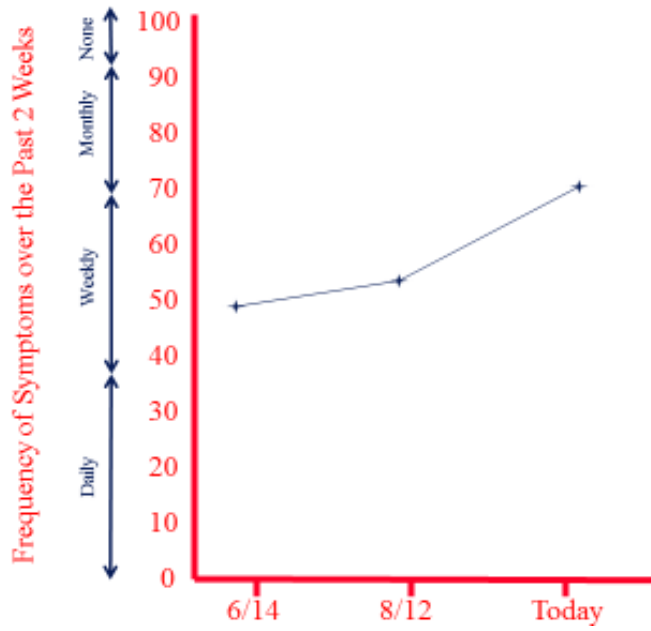
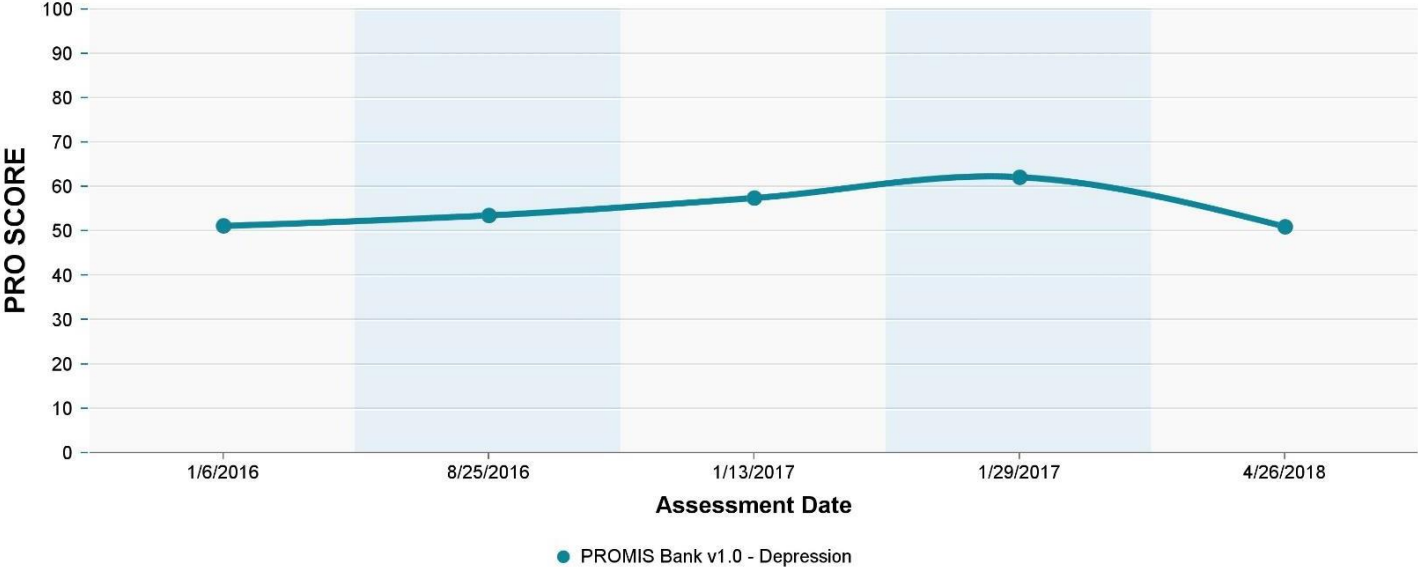
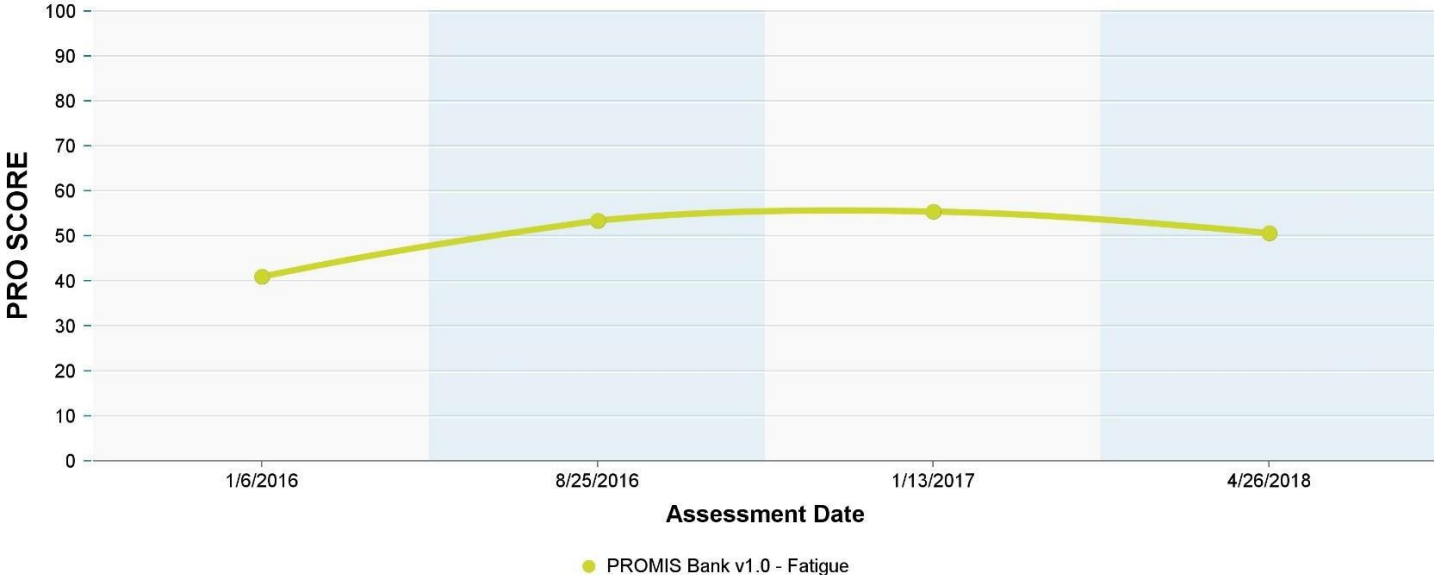


Figure S2. Presentation of PROMIS scores.

A. PROMIS - depression



B. PROMIS – fatigue



C. PROMIS – physical function



D. PROMIS- satisfaction

