Performance Measures Based on How Adults With Cancer Feel and Function: Stakeholder Recommendations and Feasibility Testing in Six Cancer Centers

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QUESTION ASKED: What symptoms would stakeholders (clinicians, patients, caregivers, administrators, and thought leaders) recommend testing for performance measures (PMs) on the basis of how patients feel and function, and is it feasible to collect patient-reported symptoms at home between visits for PMs?

SUMMARY ANSWER: Clinicians, patients, and other stakeholders agree that PMs based on how patients feel and function would be an important addition to quality measurement. This study also shows that patient-reported outcome (PRO)–based PMs can be feasibly captured at home during systemic therapy and are acceptable to patients.

WHAT WE DID: Interviews were conducted with 124 stakeholders to determine priority symptoms and risk adjustment variables for PRO-PMs and perceived acceptability. Stakeholders included patients and advocates, caregivers, clinicians, administrators, and thought leaders. Feasibility testing was conducted in six cancer centers. Patients completed PRO-PMs at home 5-15 days into a chemotherapy cycle. Feasibility was operationalized as ≥ 75% completed PRO-PMs and ≥ 75% patient acceptability.

WHAT WE FOUND: Stakeholder priority PRO-PMs for systemic therapy were GI symptoms (diarrhea, constipation, nausea, vomiting), depression/anxiety, pain, insomnia, fatigue, dyspnea, physical function, and neuropathy. Recommended risk adjusters included demographics, insurance type, cancer type, comorbidities, emetic risk, and difficulty paying bills. Clinicians, administrators, and thought leaders believed strongly that PRO-PMs should be part of an overall approach where PRO measures are used at the point of care to improve communication among clinicians and patients and then used as aggregated PRO-PMs at the clinic level. In feasibility testing, 653 patients enrolled (approximately 110 per site), and 607 (93%) completed PRO-PMs, indicating high feasibility for home collection. The majority of patients (470 of 607; 77%) completed PRO-PMs without a reminder call, and 137 (23%) of 607 completed them after a reminder call. Most patients (72%) completed PRO-PMs through web, 17% paper, or 2% interactive voice response (automated call that verbally asked patient questions). For acceptability, > 95% of patients found PRO-PM items to be easy to understand and complete.

BIAS, CONFOUNDING FACTORS, IMPLICATIONS: Additional PRO-PMs may need to be developed for systemic therapy, such as patients' preferences for symptom management and whether the care team is meeting those expectations. Clinicians at all sites mentioned that their patients are more at risk than other institutions, and thus, training on how risk adjustment variables were empirically chosen and their function may increase transparency. It is unknown whether recommended PRO-PMs for systemic therapy will generalize to other cancer treatment types (eg, radiation therapy), disease stages, or other health conditions. Future research should also consider adding payers as a stakeholder group. Our next analysis steps are to empirically determine an optimal set of symptoms and physical function domains and risk adjustment variables for PRO-PMs in systemic therapy. Single-item PRO-PMs and composites of items will be evaluated. A second wave of data collection is under way to determine the stability of aggregated scores for cancer centers and to increase sample size. Quantitative analyses of PRO-PMs and risk adjustment variables will be reported elsewhere.

ASSOCIATED CONTENT

Appendix

Author affiliations and disclosures are available with the complete article at ascopubs.org/journal/op.

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abstract

PURPOSE Patient-reported outcome measures (PROMs) that assess how patients feel and function have potential for evaluating quality of care. Stakeholder recommendations for PRO-based performance measures (PMs) were elicited, and feasibility testing was conducted at six cancer centers.

METHODS Interviews were conducted with 124 stakeholders to determine priority symptoms and risk adjustment variables for PRO-PMs and perceived acceptability. Stakeholders included patients and advocates, caregivers, clinicians, administrators, and thought leaders. Feasibility testing was conducted in six cancer centers. Patients completed PROMs at home 5-15 days into a chemotherapy cycle. Feasibility was operationalized as ≥ 75% completed PROMs and ≥ 75% patient acceptability.

RESULTS Stakeholder priority PRO-PMs for systemic therapy were GI symptoms (diarrhea, constipation, nausea, vomiting), depression/anxiety, pain, insomnia, fatigue, dyspnea, physical function, and neuropathy. Recommended risk adjusters included demographics, insurance type, cancer type, comorbidities, emetic risk, and difficulty paying bills. In feasibility testing, 653 patients enrolled (approximately 110 per site), and 607 (93%) completed PROMs, which indicated high feasibility for home collection. The majority of patients (470 of 607; 77%) completed PROMs without a reminder call, and 137 (23%) of 607 completed them after a reminder call. Most patients (72%) completed PROMs through web, 17% paper, or 2% interactive voice response (automated call that verbally asked patient questions). For acceptability, > 95% of patients found PROM items to be easy to understand and complete.

CONCLUSION Clinicians, patients, and other stakeholders agree that PMs that are based on how patients feel and function would be an important addition to quality measurement. This study also shows that PRO-PMs can be feasibly captured at home during systemic therapy and are acceptable to patients. PRO-PMs may add value to the portfolio of PMs as oncology transitions from fee-for-service payment models to performance-based care that emphasizes outcome measures.

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ASSOCIATED CONTENT

Appendix

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INTRODUCTION

Performance measures (PMs) are standardized measures of clinical performance in health care settings.[1,2] They are widely used in oncology care settings for benchmarking, quality improvement, and payment.[2-5] Conventional PMs assess outcomes such as emergency department visits and patient experiences of care (eg, satisfaction with care).[2-5] A notable gap is the patient perspective of symptom burden, quality of life, and physical function, which are measured with patient-reported outcome measures (PROMs).[6] PRO-based PMs[7-9] are in use in some medical specialties in the United States (eg, orthopedics),[10,11] but PRO-PMs for oncology are in a more nascent stage.

Organizations that prioritize or endorse quality measures, such as ASCO,[8] the Centers for Medicare & Medicaid Services (CMS),[12] the National Quality Forum,[2,13] and the National Committee for Quality Assurance,[14] have signaled their interest in using PRO-PMs in oncology. Systemic therapy, such as chemotherapy, is a natural starting point for developing PRO-PMs, given the high symptom burden[15,16] and national guidelines.[17,18] State and federal initiatives are under way to develop PRO-PMs for systemic therapy. For example, a state-based initiative (and collaborator on this study) called MN Community Measurement is testing PRO-PMs for nausea, pain, and constipation during chemotherapy and risk adjusters as part of its larger portfolio of PRO-PMs in

multiple health conditions.[19,20] Similarly, CMS is funding cooperative agreements to develop PRO-PMs for chemotherapy and palliative care in the areas of pain, fatigue, and quality of life.[21] These contracts are currently field testing items and adjustment variables.

As the United States moves toward alternative payment models that emphasize health outcomes, such as the proposed Oncology Care First Model,[22] PRO-PMs will become increasingly important for cancer centers to collect. It is unclear, however, what the most important symptoms and quality-of-life domains are to collect and which risk adjustment variables are most appropriate for PRO-PMs. In the current study, national stakeholder recommendations were elicited to prioritize PRO-PM domains for systemic therapy and risk adjustment variables. Feasibility and acceptability testing was then conducted at six cancer centers.

METHODS

Recruitment Sites (for Both Interviews and Feasibility Testing)

Six cancer centers in California, Connecticut, Florida, Minnesota, North Carolina, and Texas participated. Recruitment sites were chosen to represent different US regions, given variation in quality across the country,[2,5] and diverse demographic and clinical characteristics of patients with cancer. Three cancer centers were academic, and three were community. Institutional review board (IRB) approval was obtained at each cancer center. To protect the anonymity of cancer centers, they are identified by numbers.

Identification of Relevant Outcomes: Stakeholder Interviews and Literature Search

Stakeholder interviews were conducted to determine priority symptoms and risk adjustment variables for PRO-PMs. Stakeholders were ages ≥ 21 years and English speakers. Several recruitment methods were used for professional stakeholder groups. Site principal investigators sent e-mails to medical oncologists, nurses, administrators, and thought leaders at their cancer center. National thought leaders with expertise in PMs, PROMs, and/or cancer care delivery were also invited to participate.

Patients were purposively sampled from cancer centers, which is a qualitative research technique that involves strategic choices about which individuals to include in a study.[23] In qualitative research, the purpose is to maximize the variety of responses rather than establish generalizable samples like in quantitative research.[23] Our goal was to recruit at least 20% of the total patients who were ≥ 65 years of age, had an ethnic minority heritage, and/or had a high school education or less. Prior research has shown that at-risk groups may respond in different ways or may have more difficulty understanding health-related questionnaires[24,25] and are at greater risk for poor outcomes.[26] Caregiver inclusion criteria were adults with self-reported primary caregiving responsibilities for a chemotherapy patient receiving care at a recruitment site. Caregivers did not have to be linked to a patient participating in an interview. Patients and caregivers completed standardized items on age, sex, race/ethnicity, education, and cancer type.[27,28]

Interview guides were informed by a literature review[7-9,29-32] and tailored to each stakeholder group. Semistructured interview guides elicited recommendations for priority symptoms to test as PRO-PMs, risk adjustment variables, and optimal timing to administer PROMs at home during systemic therapy. We also asked stakeholders to describe what high-quality care meant to them and potential barriers and benefits to PRO-PMs. Interviews were conducted by phone and audio recorded. Consistent with gold standard methodology,[23,33] we continued interviewing until conceptual saturation was reached within each group (ie, no new ideas emerged). Interviews were transcribed verbatim.

Transcripts were independently coded in Atlas.ti (Scientific Software Development, Berlin, Germany) by three coding teams using a common codebook.[23,33] The codebook was developed on the basis of recommendations by the scientific advisory board (authors), literature search,[7-9,29-32] initial readings of transcripts by the coders and research team, and codes for emerging/new themes. Coders pilot tested the initial codebook by independently coding two transcripts from patient and professional interviews and comparing them to coding done by research team members (A.M.S. and J.J.). A few concept definitions were revised, and the enhanced version was applied to remaining transcripts. Coding discrepancies were reconciled by consensus. Research team members and the scientific advisory board (authors) reviewed summary reports to discuss and confirm themes, and this process led to a final set of symptom domains.

Feasibility Testing

Questionnaire items for PROMs were selected on the basis of psychometric properties, validity and reliability of evidence, applicability to systemic cancer care, and public availability without licensing fees. Through this process, questionnaire items were selected from the PRO version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE),[34,35] PROMIS,[36,37] and a version of the Eastern Cooperative Oncology Group PRO that assess physical function.[38] Patients completed standardized items on demographics, insurance type, difficulty paying bills, and computer use as potential risk adjustment variables, as tested in prior studies.[27,28] Patients also completed acceptability items that assessed comprehensibility and ease of use.[27,28] The total number of items ranged from 32 to 36, depending on skip patterns. Items were loaded into an electronic system securely housed at the University of North Carolina (UNC) at Chapel Hill, which enabled PROMs to be

completed by patients through web response or interactive voice response (IVR; automated call that verbally asked patient questions). A protocol was approved by the IRB of record at UNC and at each site.

Adults ages ≥ 21 years who were receiving systemic chemotherapy, immunotherapy, or targeted therapy (nonhormonal) for any type of cancer at the six recruitment sites were approached to participate and underwent informed consent. Participants needed to be able to write/speak English, Spanish, or Mandarin Chinese. Exclusions were inability to provide consent or ongoing participation in a clinical trial of an investigational drug. At enrollment, patients chose their preferred response mode (web response or IVR), and a brief tutorial was provided. Patients also selected their preferred language (English, Spanish, or Mandarin Chinese). The PROM was administered once, and participants were given a $20 gift card.

At enrollment, patients were educated that the PROM needed to be completed at home on days 5-15 of the treatment cycle. The 5-15-day time frame was chosen on the basis of interview recommendations and reviews that showed that symptoms are commonly experienced during this time frame.[16,39] For each participant, a treatment cycle was identified after which they would self-report on PROM questions. Patients were commonly recruited in infusion centers, and thus their current cycle was typically used. This cycle could be at the initiation of a new treatment regimen or during the course of an existing regimen and could be during any line of treatment.

Starting on day 5 after initiation of the cycle, participants received an automated electronic prompt (either e-mail or IVR) to complete the PROM questions. The e-mail prompt provided a web link to the questionnaire, while IVR was an automated call to the patient. For patients who preferred not to complete questions electronically, paper questionnaires were offered. Participants received a daily electronic prompt until day 9 of the cycle or until the questionnaire was completed. If patients did not complete the questionnaire by day 10 after treatment, they received a human reminder by telephone or in person at a clinic encounter to encourage them to check their email for the link or to offer to administer the questionnaires verbally by interview. The questionnaire was considered to be missed if not completed by day 15. Feasibility was operationalized as > 75% completed PROMs and > 75% patient acceptability.[32]

Chart abstraction was used to collect the following clinical risk adjustment variables: cancer type, comorbid conditions, insurance type, oral or intravenous chemotherapy, drug regimen and emetic risk, and whether chemotherapy was curative or palliative. Sites raised concerns that stage would be difficult to obtain, and thus, a variable for curative or palliative chemotherapy was collected from the electronic health record as a proxy.

PM specifications were generated for each symptom (Appendix Table A1, online only). For example, a pain item from PRO-CTCAE[34,35] is, "In the last 7 days, what was the severity of your pain at its worst (none, mild, moderate, severe, very severe)?" The corresponding PRO-PM specification for high-quality care was the proportion of adult patients in a participating cancer center receiving systemic cancer therapy whose pain severity rating was none or mild during days 5-15 of the cycle. Quantitative testing of these PRO-PMs will be reported elsewhere.

RESULTS

Interview Results

Members of each stakeholder group were included from participating cancer centers, advocate organizations, and national organizations. Clinicians (n = 11) were medical oncologists at recruitment sites. Administrators (n = 16) were medical directors, nursing leaders, and quality officers. Their educational backgrounds included seven MDs, five RNs (three also had PhDs), and four bachelor's- or master's-trained executives. Thought leaders (n = 15) included nine with PhDs, three MDs, two RNs, and one master's-trained scientist.

Our purposive sampling targets for patients met or exceeded 20% representation for older age, minority, and low education. Of the 56 patients interviewed, 48% were women, 34% were age ≥ 65 years, 23% were ethnic minority, and 20% had a high school education or less. Cancer types included genitourinary (32%), GI (27%), breast (21%), and lung (20%). Primary caregivers (n = 21) were 71% female, 24% age ≥ 65 years, 76% non-Hispanic white, and 14% with a high school education or less. Caregiver relationships were typically spouse/partner or an adult child.

Table 1 lists stakeholders' recommended key symptoms, including GI symptoms (nausea, vomiting, constipation, diarrhea), fatigue and sleep issues, depression/anxiety, pain, neuropathy, dyspnea, and physical function decrements. Stakeholders recommended the collection of PROMs 5-15 days after the start of a treatment cycle when some symptoms related to therapy, such as nausea, might peak. Twelve potential risk adjustment variables were also identified through interviews and a literature search.[2-4,7-9] Five were variables commonly used as risk adjusters: age, sex, race/ethnicity, insurance type, and cancer type. Seven additional risk adjustment variables were education, working, married/partnered, difficulty paying bills, palliative versus curative care, regimen and emetic risk, and comorbid conditions.

Interview themes indicated that PRO-PMs were perceived to be acceptable by stakeholder groups, with benefits and barriers noted (Appendix Table A2, online only). Clinicians, administrators, and thought leaders suggested a dual-purpose approach, where individual-level PROMs

TABLE 1. Priority Domains Stakeholders Recommended for PRO-PM Testing and Illustrative Quotes

Domain That Should Be Developed as a PRO-PM	Quote
Clinicians	
Toxicities	"All sorts of known burden from chemotherapy, so constipation, nausea, neuropathy, depression, hot flashes.…Neuropathy is one, for instance, that varies a lot from patient to patient and with regards to how we adjust the dose, so that's something that could be helpful because there's really no—it's very lackadaisical in terms of how we monitor that and adjust the doses."
Symptom control, emotional distress, financial burden	"Things on that list that would be most useful to us would be really neuropathy; gastrointestinal symptoms, particularly nausea and diarrhea; infectious symptoms; any skins reactions. I think [patients] often put fatigue, energy, appetite concerns higher on the list. Then I think, too, emotional distress or even financial distress of symptoms…we often but not 100% of the time we will capture."
Physical function, symptoms	"I think that symptoms and physical function are also related in part to treatment and the underlying disease. That means that time to diagnosis and type of treatment that's been given for that diagnosis are variable so may impact symptom and function, and those may vary geographically as well for a variety of reasons."
Patients' preferences for symptom management	"Then I think, from a symptom gathering standpoint…assessing patients' wants around symptom management and assessing whether we're actually meeting those.…I think just really assessing the information needs and desires of patients and whether we're meeting those."
Health care administrators	
Care experiences and satisfaction with care	"[I]f there was one piece of patient-reported data that I could get on every patient at every visit during the visit that would be the most useful to me in running the business, it would be their perception of their experience because not only are they gonna tell their friends and family and all that. Increasingly, we're getting paid based on how patients feel about their care, not necessarily what their care is, but how patients feel about it."
Communication, adherence to guideline-concordant care	"It has to do with the patient interaction and the communication. Are you listening to the patient? Are you communicating with them? Are you sure that they're understanding you? It has to do with the treatment decisions you're making. Which are they, NCCN or ASCO guidelines? Are they adherent to those? Do they take into consideration new data that's coming out? Are you fully up to date in terms of if you're their new agents, what the side effects are?"
Symptom control, physical function	"With me, I need aggregated information. How well are we doing managing our patients in oncology and looking at the various parameters? As I mentioned, how we're dealing with pain control? How we're dealing with returning patients to their function? How well do we manage their side effects from treatments? How quickly do we resolve those? Is there variation in care across care centers? If so, what are they? Then, that informs improvement opportunities. Are there positive outliers at the physician level? Are there positive outliers at the clinic level?"
Pain, emotional distress, physical function, care experiences, financial burden	"I think it's very important to understand the patient's perspective.…Pain, mental status. With things like depression.…I think understanding the support system that a patient has, what a patient is capable of doing, and how they're progressing, and I think to a great extent it's kind of…care plan oriented. What is your plan of care, and do you feel good about your plan of care? Is that something that you [patient] can afford? Is it something that your family and the patient can manage?"
Thought leaders	
Symptom control	"It's hard to come up with metrics that are more important to people than the way they express their health." "I think symptoms and functional status are the things that you would routinely monitor over time."
Physical function	"I think the critical question [for PRO-PMs] is asking people what is it that they wanna do that they're not able to do…they put up with a lot until they get to the point of not being able to do what they wanna do, and that's what drives people to seek care."
Process and outcome measures	"I guess to try to wrap that into a neater package, quality of symptom care, from my perspective, needs to include both processes of care and the actual outcomes of the symptoms themselves."

(continued on following page)

TABLE 1. Priority Domains Stakeholders Recommended for PRO-PM Testing and Illustrative Quotes (continued)

Domain That Should Be Developed as a PRO-PM	Quote
Patients	
Emotional distress, physical function, care experiences, communication	"I think responsiveness to how I present on the day is wanting: my emotional state, my physical state, things that I'm saying, how well they listen, yeah, I think that the quality of the advice that I get. If I'm given advice to try this medication or try it in this way, whether that works or not, part of it is attitude and just all of those soft skills of patient bedside manner."
Communication with care team	"Each doctor has certain nurses that are assigned to them that if you need to call to get any questions answered, you can, at least, have a person you can talk to. That, I find very helpful."
Care coordination	"During my first visit, I saw three different doctors, and they were all knowledgeable. They all knew what they were talkin' about. They were all on the same sheet of music."
Information provision that is understandable	"[Clinicians] are using evidence to make decisions, and not only that, but they give you lots of information it sounds like to be able to understand as much or as little as you want to about the treatment and about the different options for you it sounds."
Symptom control	"I think that would be useful, because, especially with the chemo, you wanna see that you're doing better…it [PRO-PMs] would give you the opportunity to see whether pain and nausea were being managed or controlled or coming down."
Comparing cancer centers on PRO-PMs may not be useful because insurance limits choices on where to seek care	"I have to say I probably wouldn't spend too much time looking at it [comparison of PRO-PM scores across practices] because I don't have a choice. My insurance said this was the only clinic I could go to. And it's the only one I can afford." "Yeah, if a cancer center in [another state] has great scores for managing their symptoms, well, most of us can't get there every 3 weeks for chemo…and it would be a lot of money."
Caregivers	
Communication and care experiences	"They seem to listen. They ask questions. They offer information, sometimes unsolicited. He had a scan as part of the diagnosis, and the oncologist went through, showed it to us, and explained what we were looking at. It was very helpful." "I was out of town and didn't go with him [patient]. I think that was part of the problem. There's a lot of information, a lot of new terms. It's easy to lose track. He ended up not asking a bunch of questions he should have asked, and this doctor was just not forthcoming and did not offer basic information. It was a bad deal all around. I feel it would have been better if I had been there. Whether he would have still changed doctors, maybe so, but yeah, I think it's important. It's important for me to go now."
Physical function, quality of life, nausea	"I think it's huge because it signifies a quality of their life and how they [patients] go about their day-to-day routines. And if they're very nauseated, I mean, you can't function, so…"

Abbreviations: NCCN, National Comprehensive Cancer Network; PRO-PM, patient-reported outcome–based performance measure.

are used at the point of care to improve communication among clinicians and patients during visits and then used as PRO-PMs at the clinic level. Clinicians noted that PRO-PMs could help practices to learn from the successes of colleagues and reveal when system-wide improvements are needed. For barriers, clinician themes were validity and relevance of PRO-PMs.

Administrators perceived that PRO-PMs may encourage natural competition to increase symptom control rates. They also believed that PRO-PMs could enhance their understanding of care costs and help to improve care. Perceived barriers included validity and reliability of PRO-PMs and risk adjustment variables, information overload, liability, potential for staff to dismiss PRO-PM data, and lack of funding for implementation and sustainability. Thought leaders discussed similar topics, with the addition of concerns about what a meaningful difference between practices would be for PRO-PMs.

Patients and caregivers discussed how understanding their symptom burden in relation to other patients would be very helpful to them. Patients and caregivers speculated about the possibility of choosing a treatment center on the basis of average symptom scores at cancer centers but also noted that their choices are limited because of insurance, geographic, and financial constraints.

Feasibility Results

Table 2 lists the demographic characteristics of the feasibility testing patient sample. The sample's demographic characteristics reflect typical systemic therapy patients.

Figure 1 shows that 793 patients were approached, 11 were ineligible, 129 refused, and 653 enrolled. Patients who chose not to participate had similar characteristics to participants on the basis of sex, race/ethnicity, and age (data not shown).

Nearly all enrolled patients (n = 607 of 653; 93%) completed the PRO-PM, which indicates high feasibility for collecting PROMs at home. Figure 1 shows that 470 (77%) of the 607 patients completed the PROM without a reminder call. An additional 137 (23%) completed the questionnaire after a human reminder call (15% web, and 8% completed questions during the reminder call). The majority of participants (439; 72%) completed PROMs through the web; the remainder responded on paper (105; 17%) or through in-person or phone interview (48; 8%) or IVR (11; 2%). Few patients selected Spanish (n = 27; 5%) or Mandarin Chinese (n = 3). Patient acceptability was very high, with 586 (96%) reporting that PROM items were easy/very easy to complete and 590 (97%) reporting that it was easy/very easy to understand.

DISCUSSION

This study adds to the literature by using stakeholder engagement to prioritize domains for PRO-PMs in systemic therapy. The study also shows that PROMs can be feasibly collected at home during a treatment cycle for the development of PRO-PMs.

TABLE 2. Demographic Characteristics for Feasibility Testing

	Sample, No. (%)							
Characteristic	**Total**	**Site 1**	**Site 2**	**Site 3**	**Site 4**	**Site 5**	**Site 6**	**χ^2 *P* for Site Differences**
No. of participants	607	105	97	107	93	105	100	
Sex								.7530
Female	307 (51)	51 (49)	49 (51)	61 (57)	43 (46)	53 (51)	50 (50)	
Age, years*								< .0001
< 65	376 (62)	81 (77)	45 (46)	71 (66)	37 (40)	72 (69)	70 (70)	
≥ 65	231 (38)	24 (23)	52 (54)	36 (34)	56 (60)	33 (31)	30 (30)	
Ethnicity*								< .0001
Hispanic	65 (11)	19 (18)	2 (2)	34 (32)	2 (2)	4 (4)	4 (4)	
Race*								< .0001
White	444 (73)	54 (52)	71 (75)	76 (72)	78 (84)	89 (85)	76 (76)	
Nonwhite	159 (26)	50 (48)	24 (25)	30 (28)	15 (16)	16 (15)	24 (24)	
Education*								< .0001
No college	267 (44)	44 (42)	22 (23)	69 (64)	45 (48)	46 (44)	41 (41)	
College	340 (56)	61 (58)	75 (77)	38 (36)	48 (52)	59 (56)	59 (59)	
Marital status*								< .0053
Married/partner	395 (65)	69 (66)	67 (69)	52 (49)	62 (67)	73 (70)	72 (72)	
Working*								< .0001
Full/part time	211 (35)	48 (46)	33 (34)	34 (32)	24 (26)	40 (38)	32 (32)	
Not working	194 (32)	27 (26)	17 (18)	41 (38)	32 (34)	30 (29)	47 (47)	
Retired	202 (33)	30 (29)	47 (48)	32 (30)	37 (40)	35 (33)	21 (21)	
Bill trouble*								< .0003
None/somewhat	539 (89)	93 (89)	95 (98)	86 (80)	77 (83)	93 (89)	95 (95)	
Trouble with bills	68 (11)	12 (11)	2 (2)	21 (20)	16 (17)	12 (11)	5 (5)	
Insurance*								< .0001
Private	318 (52)	71 (68)	51 (53)	50 (47)	37 (40)	63 (60)	46 (46)	
Medicare	186 (31)	26 (25)	38 (39)	23 (22)	34 (37)	25 (24)	40 (40)	
Medicaid	75 (12)	5 (5)	5 (5)	25 (24)	20 (22)	12 (11)	8 (8)	
Frequency of computer use*								< .0001
Infrequently	75 (12)	4 (4)	6 (6)	28 (26)	19 (20)	5 (5)	13 (13)	
Frequently	532 (88)	101 (96)	91 (94)	79 (74)	74 (80)	100 (95)	87 (87)	

*$P < .01$.

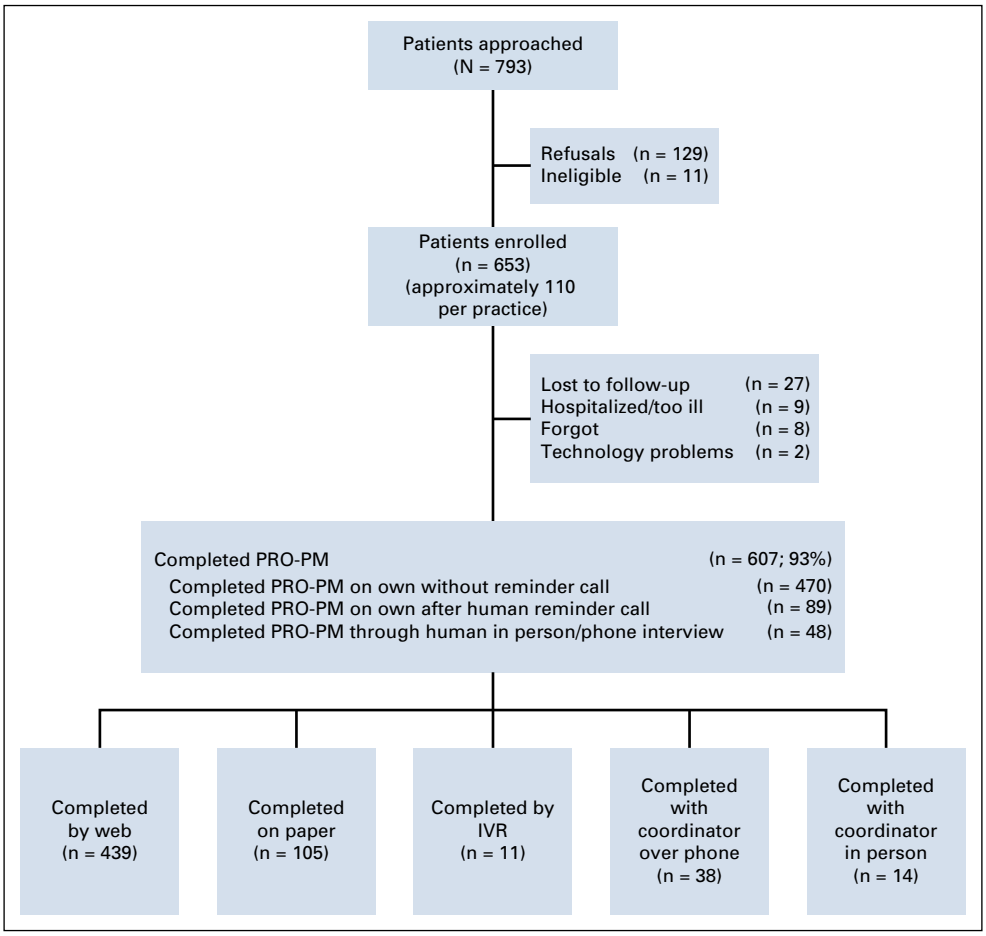

FIG 1. Flow diagram for feasibility testing. IVR, interactive voice response; PRO-PM, patient-reported outcome–based performance measure.

Stakeholder priority symptoms were pain, mental health, sleep, GI symptoms, numbness, dyspnea, and physical function, which mostly overlap with the National Cancer Institute's (NCI's) recommended symptoms to assess in clinical trials[40] and a growing literature on recommended symptom sets.[41,42] Physical function is not on NCI's list but was mentioned by stakeholder groups, albeit with some reservations. Stakeholders raised concerns that physical function may not be a fair performance metric because it may be influenced by factors beyond treatment.[43,44] Stakeholders also recommended continuing to collect patient experiences of the visit (eg, CAHPS Cancer Care[45]), which are already common in quality programs.[2-5]

Clinicians, administrators, and thought leaders believed strongly that PRO-PMs should be part of an overall approach where PROMs are used at the point of care to improve communication among clinicians and patients and then used as aggregated PRO-PMs at the clinic level. Clinicians wanted to be informed of PROMs at visits so that they can intervene, which may increase acceptability of PRO-PMs. Stakeholders noted benefits of PRO-PMs that were mostly consistent with their health care role. Clinicians and administrators described how PRO-PMs could help practices to learn what they are doing well and improvements needed for symptom control. Administrators believed that PRO-PMs may encourage natural competition and could enhance their understanding of care costs. Patients and caregivers believed that understanding symptom burden in relation to other patients would be very helpful. However, patients and caregivers speculated that they may not be able to choose a treatment center on the basis of PRO-PM rates because of insurance, geographic, and financial constraints.

Similar barriers were noted by clinicians, administrators, and thought leaders: validity and relevance of PRO-PMs. Clinicians at all sites mentioned that their patients are more at risk than at other institutions, and thus, training on how risk adjustment variables were empirically chosen and their function may increase transparency. Barriers unique to administrators were liability and lack of funding for implementing PROMs and PRO-PMs. Thought leaders stated that there may be few benchmarks for meaningful differences between practices.

We recommend engaging clinicians, administrators, thought leaders, patients, and caregivers to develop PRO-PMs to increase transparency of the process for professional groups and to include the patient voice. Future research should consider adding payers as a stakeholder group. It is

unknown whether recommended PRO-PMs for systemic therapy will generalize to other cancer treatment types (eg, radiation therapy), disease stages, or other health conditions. Additional PRO-PMs may need to be developed for systemic therapy, such as patients' preferences for symptom management and whether the care team met those expectations.

Compliance rates with PROM questions were high. Patients self-reported on their own 77% of the time, and an additional 23% completed the questions after a human reminder call. Future research is needed to determine whether these percentages generalize to routine care settings and the overall US cancer population. Although stakeholder interviews suggested that both web and IVR be available to patients for reporting PROMs, only a small proportion of patients ultimately used IVR, which suggests that web response with paper and human backup may be sufficient in this context. Potential benefits of IVR are that patients do not need Internet access or computer experience. Broadband access in the United States is highly variable,[46] and at-risk groups (eg, older, rural) are less likely to have Internet access.[47,48] In a large, pragmatic PROM intervention trial in community oncology practices, more than one third of chemotherapy patients chose IVR to complete their weekly PROM, and these patients represented at-risk groups.[28] Dependent on available resources and priorities, cancer centers may want to include an option to contact patients to recover otherwise missing data.

A small number of patients reported not receiving the e-mail prompt to self-report, typically because of the e-mail going to junk folders. There were mixed views about offering a paper option. Some participating sites requested a paper option, and one site opted not to offer paper because of the resources necessary to track and enter patient responses. For sites that offered a paper option, it was difficult to track whether and when PROMs were completed. There were also added expenses of self-addressed stamped envelopes, extra calls to patients, and data entry that may not be feasible for routine care. However, paper or IVR may be necessary to capture PROMs for at-risk groups, especially when considering low response rates for CAHPS questionnaires when used in routine care settings.[49]

Our next analysis steps are to empirically determine an optimal set of symptoms and physical function domains and risk adjustment variables for PRO-PMs in systemic therapy. Single-item PRO-PMs and composites of items will be evaluated. A second wave of data collection is under way to determine the stability of aggregated scores for cancer centers and to increase sample size. Quantitative analyses of PRO-PMs and risk adjustment variables will be reported elsewhere.

In conclusion, clinicians, patients, and other stakeholders agree that PMs that are based on how patients feel and function would be an important addition to quality measurement. This study also shows that PRO-PMs can be feasibly captured at home during systemic therapy and are acceptable to patients. PRO-PMs may add value to the portfolio of PMs as oncology transitions from fee-for-service payment models to performance-based care that emphasizes outcome measures.

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Performance Measures Based on How Adults With Cancer Feel and Function: Stakeholder Recommendations and Feasibility Testing in Six Cancer Centers

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APPENDIX

TABLE A1. PRO-PMs Tested in Feasibility Testing

Symptom Domain	Question	Response Options	Measure	PRO-PM Specification for High-Quality Care
Nausea	In the last 7 days, how often did you have nausea?	Never[a] Rarely[a] Occasionally Frequently Almost constantly	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose nausea frequency rating was never or rarely during days 5-15 of cycle
	In the last 7 days, what was the severity of your nausea at its worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose nausea severity rating was none or mild during days 5-15 of cycle
Vomiting	In the last 7 days, how often did you have vomiting?	Never[a] Rarely[a] Occasionally Frequently Almost constantly	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose vomiting frequency rating was never or rarely during days 5-15 of cycle
Constipation	In the last 7 days, what was the severity of your constipation at its worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose constipation severity rating was none or mild during days 5-15 of cycle
Diarrhea	In the last 7 days, how often did you have loose or watery stools (diarrhea)?	Never[a] Rarely[a] Occasionally Frequently Almost constantly	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose diarrhea frequency rating was never or rarely during days 5-15 of cycle
Dyspnea	In the last 7 days, how much did your shortness of breath interfere with your usual or daily activities?	Not at all[a] A little bit[a] Somewhat Quite a bit Very much	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose dyspnea interference rating was not at all or a little bit during days 5-15 of cycle
Neuropathy	In the last 7 days, how much did numbness or tingling in your hands or feet interfere with your usual daily activities?	Not at all[a] A little bit[a] Somewhat Quite a bit Very much	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose numbness interference rating was not at all or a little bit during days 5-15 of cycle
Pain	In the last 7 days, how often did you have pain?	Never[a] Rarely[a] Occasionally Frequently Almost constantly	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose pain frequency rating was never or rarely during days 5-15 of cycle

(continued on following page)

TABLE A1. PRO-PMs Tested in Feasibility Testing (continued)

Symptom Domain	Question	Response Options	Measure	PRO-PM Specification for High-Quality Care
	In the last 7 days, what was the severity of your pain at its worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose pain severity rating was none or mild during days 5-15 of cycle
	In the last 7 days, how intense was your pain on average?	Had no pain[a] Mild[a] Moderate Severe Very severe	PROMIS	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose pain severity rating was had no pain or mild during days 5-15 of cycle
	In the last 7 days, how much did pain interfere with your usual or daily activities?	Not at all[a] A little bit[a] Somewhat Quite a bit Very much	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose pain interference rating was not at all or a little bit during days 5-15 of cycle
Fatigue	In the last 7 days, what was the severity of your fatigue, tiredness, or lack of energy at its worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose fatigue severity rating was none or mild during days 5-15 of cycle
	In the last 7 days, how fatigued were you on average?	Not at all[a] A little bit[a] Somewhat Quite a bit Very much	PROMIS	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose fatigue severity rating was not at all or a little bit during days 5-15 of cycle
Insomnia	In the last 7 days, what was the severity of your insomnia (including difficulty falling asleep, staying asleep, or waking up early) at its worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose insomnia severity rating was none or mild during days 5-15 of cycle
	In the last 7 days, I had trouble sleeping.	Not at all[a] A little bit[a] Somewhat Quite a bit Very much	PROMIS	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose insomnia severity rating was not at all or a little bit during days 5-15 of cycle
Anxiety	In the last 7 days, what was the severity of your anxiety at its worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose anxiety severity rating was none or mild during days 5-15 of cycle
	In the past 7 days, my worries overwhelmed me.	Never[a] Rarely[a] Sometimes Often Always	PROMIS	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose anxiety frequency rating was never or rarely during days 5-15 of cycle

(continued on following page)

TABLE A1. PRO-PMs Tested in Feasibility Testing (continued)

Symptom Domain	Question	Response Options	Measure	PRO-PM Specification for High-Quality Care
Depression	In the last 7 days, what was the severity of your sad or unhappy feelings at their worst?	None[a] Mild[a] Moderate Severe Very severe	PRO-CTCAE	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose depression severity rating was none or mild during days 5-15 of cycle
	In the last 7 days, I felt depressed.	Never[a] Rarely[a] Sometimes Often Always	PROMIS	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose depression frequency rating was never or rarely during days 5-15 of cycle
Physical function	To what extent are you able to carry out your everyday physical activities, such as walking, climbing stairs, carrying groceries, or moving a chair?	Completely[a] Mostly[a] Moderately A little Not at all	PROMIS global health	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose physical function ability rating was completely or mostly during days 5-15 of cycle
	In the last 7 days, how would you generally rate your activity?[a]	(0) Normal with no limitations[a] (1) Not your normal self, but able to be up and about with fairly normal activities[a] (2) Not feeling up to most things, but in bed or chair less than half the day (3) Able to do little activity and spend most of the day in bed or chair (4) Pretty much bedridden, rarely out of bed	PG-SGA	Percentage of patients age ≥ 21 years with cancer receiving chemotherapy and/or biologic immunotherapy whose physical function ability rating was normal with no limitations (0) or not your normal self, but able to be up and about with fairly normal activities (1) during days 5-15 of cycle

Abbreviations: PG-SGA, Patient-Generated Subjective Global Assessment; PRO-CTCAE, Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events; PRO-PM, patient-reported outcome–based performance measure.

[a]Threshold for high-quality care.

TABLE A2. Stakeholder Perceptions of Benefits and Barriers for PRO-PMs

Subtheme	Quote
Clinicians	
Perceived benefits	
Learn from successes and mishaps of colleagues	"I think [PRO-PMs] really could help…whole practices, just to know what we're potentially missing…it can be hard to learn from the successes or mishaps of my colleagues cuz we just don't see that data about each other. We don't have…a clear sense of, are there any cultural or strategy differences about how we do this?"
System-wide intervention may be possible if symptom control is low	"I think there's benefit. I mean if somebody's way out of whack on how well they're treating pain or nausea or something then that clinic probably does need to do something from a system-wide intervention to fix it. It's not just the doc. It's not just the—it's that they don't have nurses educating the patients enough or they're not using the right, for example, pain medicines."
Perceived barriers	
Validity and relevance of PRO-PMs	"Very touchy for community practices…. If you're gonna be using something as a performance metric, what you really want from the provider population is a belief that, number one, it's valid, and number two, it's relevant to patient care. Physicians get really grumpy about being evaluated on metrics that they don't think are fair, right?"
Patient populations across practices too different to make useful performance comparisons	"If my patients are young and Hispanic and have trouble paying medication copays and don't speak English and another physician's patients are older, wealthier, all married to supportive partners, then it's very conceivable that one physician's patients may do better in terms of nausea control than another physician's patients. Again, for reasons that aren't really within the physician's control, necessarily. I don't necessarily think it's useful to attach that information to a physician because the variation by physician is gonna be driven by a lot of factors that you're not controlling for."
Some symptoms may not lend themselves well to PRO-PMs	"I think knowing somebody is fatigued, it's helpful [for clinical care]. From a reporting standpoint and finding reward for or punishment for how long either achieves or doesn't achieve metrics, those are more challenging outcomes. I think it depends a lot on the context."
Methods for aggregating data unclear	"I think that it is a little bit harder, though really not impossible, to think about how to translate individual symptom reports into something that reflects overall quality as a practice. I know that there's a lot of work going around that and had some major efforts from some large groups. I think that it's a little bit harder conceptually to see how that works, just because different patients' experiences are so different."
Health care administrators	
Perceived benefits	
Natural competition across practices if PRO-PMs tracked	"The community has embraced the value of transparency, and so what we have experienced, and what we hope to continue, is groups are looking at each other's rates, and people really don't want to be at the bottom."
Better understanding of care costs	"[A]ll the symptom management is going to be very important so that when we understand our cost of care, [whether] we're running high compared to others…[that] we understand why. All this data is important for us."
Practices learning from one another	"Having that information in aggregate from a quality improvement standpoint, to know are there [PROM] metrics that are slipping? Are there metrics that we could do better on? Are there other organizations that are managing the symptoms better that we could learn from? Yes, that would be helpful for us to know."

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TABLE A2. Stakeholder Perceptions of Benefits and Barriers for PRO-PMs (continued)

Subtheme	Quote
PRO-PM reporting could trigger quality improvement initiatives	"Let's say constipation turns out to be a big problem for a subset of patients, that would trigger looking into what type of education is given to these patients and maybe we would discover deficiencies in what our staff tells them with regards to that."
Perceived barriers	
Validity and reliability of PRO-PMs	"Can you really trust a number when so much goes into that number and so much goes into the physician and the nurse having a two-way discussion about symptoms? Can that be really reduced to a number, and is that number really reliable?"
Change over time is different for different patients	"Because it's so subjective but also the point, the change between each individual number, could be different for different patients, which [is] why I find the concept of measuring improvement a little bit problematic for that reason."
Validity and reliability of risk adjustment variables	"I'm concerned that there are so many variables in the patient population, the demographics, the cancer types themselves. At the same time, I don't like to let perfect be the enemy of good. It [PRO-PMs] probably would be of interest. In cancer, we're not even very good at coming up with standard treatment protocols that we can agree on because the evidence just is not that robust for a lot of these cancer subtypes. Getting to apples to apples would be the challenge there."
Unknown value, information overload, potential liability	"I think that the concern in most clinician's minds is that is there added information there that's going to be of value? Is this going to be too much information? Is there going to be liability in missing, or not capturing, or paying attention to information?"
Which questionnaires are used to assess PRO-PMs	"Regardless, in oncology, everyone has their favorite [questionnaire]. You'll get detractors who, even if you're using the most psychometrically sound instrument that exists, you'll still [have] people who say, 'Well, you're not using mine, and I like my organization's better than anything else.' All the standard performance measure pushback, I think, and then a little bit more maybe because it's a new and different area."
Potential for staff to dismiss PRO-PM quality data	"I'm skeptical that we're close to having clinicians, and the frontlines, pay attention to those things. They may be very likely to dismiss some of those [PRO-PM] reports…as well, my patients are sicker, and that's why my scores are lower. A common phenomenon."
Lack of funding for implementation and sustainability	"I don't think we'll be able to take on much more of that [PRO-PMs] without funding…it takes a lot to implement this going forward, year after year…I would be foolish to say it doesn't cost anything to do this."
Thought leaders	
Perceived benefits	
Organize health care around PRO-PMs	"Over time, I think people will naturally get over that [suspicion of a new quality metric] as they have with lots of other quality measures and start to organize their care around those metrics [PRO-PMs]."
Benchmarking and reinforcing best practices	"You can benchmark yourself as an individual provider as well as your clinic as a collective group against others that are similar to say, 'Hey, are we all doing a good job? If not, what can we do to improve?' Also too then, if we are doing a good job, it reinforces what we're doing."

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TABLE A2. Stakeholder Perceptions of Benefits and Barriers for PRO-PMs (continued)

Subtheme	Quote
Perceived barriers	
Unknown what a meaningful difference between practices is for PRO-PMs	"What's a meaningful difference between practices? 'Cause [you've] got grouped data, and let's say that you have a one-point difference. Because it's grouped data, there's lots of patients participating. That could be statistically significant, but is that a meaningful difference that should be considered a deficiency or relative advantage, for that matter? Maybe it is. Maybe it isn't, and how do you know that? There's lots of questions like this to imagine researching."
Patients	
Perceived benefits	
Possibility of choosing a treatment center on the basis of average symptom scores	"Yeah, [comparing symptom scores across practices] might be interesting, mainly because now my hospital group is like—was bought by a much larger one. I have a lot of options for an infusion center. So say I had to go to a different one because mine was full, like that might be useful to know that I'll have a really similar experience in terms of like, 'Oh, my symptoms won't get worse,' or, 'Oh, if I go to this one, my symptoms might be better.' That's a, I feel like, a recent, unique thing."
Understanding symptom burden in relation to average	"[Knowing other patients' average symptom scores would be useful] cuz I could compare myself to the average…score. If I'm a 5 and everybody else is a 2, I would wonder why my fatigue is more than everybody else."
Perceived barriers	
Unclear whether patients have choice in treatment centers even if PROM scores compared across centers, limited geographically	"Yeah, if a cancer center in [another state] has great scores for managing their symptoms, well, most of us can't get there every 3 weeks for chemo…and it would be a lot of money….Unless they can figure out what [other state] is doing and disseminate or spread that to other clinics. That's where it's useful in my mind." "[Comparison scores across practices would be useful]…as long as it would be data that people could use to compare which clinic I should go to based on the outcome of what their patients went through."
Caregivers	
Perceived benefits	
Understanding individual symptom burden in relation to the average	"I think [knowing average symptom scores from other patients would be] very important, you know, and I think that they [clinicians] need to know. Plus, they can reciprocate and tell her, either this is normal, or no, it's not normal, it's okay. And then, once you let the patient know that, to expect some of these symptoms, then they're more at ease, instead of them going, 'Oh my God, why is she feeling this now?'"
Perceived barriers	
Potentially second guessing where to seek treatment	"Well, I'm not sure if you were to say, 'Oh, here's your clinic, and here are the average scores at the other five clinics,' and they demonstrated which clinics they were. I'm a little uncertain about that because I would be worried that it would prompt some second guessing about the treatment decisions that we made when it might not really be a good indicator."
Comparing cancer centers on PRO-PMs may not be useful because of financial limitations	"If we were really well off financially, we could probably find the one [treatment center] that tracks the best [on PRO-PMs] and then have her treated there. But we're not."

Abbreviations: PROM, patient-reported outcome measure; PRO-PM, patient-reported outcome–based performance measure.