Original Contribution

Qualitative Analysis of Practicing Oncologists' Attitudes and Experiences Regarding Collection of Patient-Reported Outcomes

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Abstract

Purpose: There is growing interest in incorporating routine collection of patient-reported outcomes (PROs) into cancer care. Practicing oncologists are a stakeholder group whose views are not well characterized.

Methods: We developed an interview guide after literature review and in-depth interviews with leaders in the field. We conducted 45-minute semistructured interviews with a diverse sample of medical oncologists identified through affiliation with the Quality Oncology Practice Initiative or a minority-based Community Clinical Oncology Program until thematic saturation. Multiple analysts independently reviewed and thematically coded verbatim transcripts.

Results: Seventeen interviews were conducted with oncologists from 15 states. Emergent themes included variable understanding and experience with PROs. There was enthusiasm for the potential of PROs to improve the efficiency and thoroughness of the patient encounter. Fundamental concerns included information overload, possibility of identifying problems without access to intervention, depersonalization of the physician-patient encounter, cost, and inefficiency. Barriers identified included the need for buy-in from other stakeholders in the practice, lack of appropriate referral resources, staffing needs, and technology concerns. Few identified patient compliance, data sharing/privacy, or medical liability as a major barrier to implementation.

Conclusion: Practicing oncologists had variable understanding of the details of PROs but, when introduced to the concept, recognized utility in improving the efficiency and thoroughness of the patient encounter if implemented properly. The time is right to begin pilot testing such measures with community oncologists so they can lend their expertise to national discussions on which measures to use and how best to use them.

Introduction

The concept of a health information technology–facilitated rapid-learning health care system is gaining national support,[1] and oncology presents a strong platform for the application of this paradigm.[2] A key component of the rapid learning system vision is bidirectional information exchange among patients and providers. The aims are to engage patients to provide information that can be used to inform shared decision making and timely clinical intervention and to improve the patient experience.[3] Patient-provided information includes physical symptoms, functional status, emotional well-being, and health-related quality of life. There is a growing focus on the systematic collection and use of patient-reported outcomes (PROs) in research and clinical settings, using validated instruments, such as standardized symptom assessment questionnaires administered before clinic visits[4,5]; PROs can thus directly contribute to the rapid-learning health care paradigm.[6,7] Various pragmatic approaches for clinical practice have been proposed.[8-13]

Research has shown that collection and use of PROs in oncology can identify issues most concerning to patients,[14] inform treatment decisions,[15] improve communication,[12,16-20] and improve patient outcomes.[19,20] However, no studies to date have sought to understand the attitudes and experiences of stakeholders based in community practices, the largest contingent of US medical oncologists.[21] In this study, we conducted semistructured interviews to investigate practicing oncologists' perceptions of PROs, with a focus on identifying the critical features to ensure acceptance of the collection of PROs within the context of routine oncology clinical practice.

Methods

Design

We developed an interview protocol after literature review of PROs and six exploratory interviews with leaders in the field (including American Society of Clinical Oncology executives, patient advocates, and researchers). The interview protocol (Appendix, online only) used both closed and open-ended questions related to a number of domains. Interviewers initially asked about general knowledge and prior experiences with collection of PROs, followed by a description of PROs to ensure uniform understanding (Appendix, online only). Interviewers asked about attitudes toward content and use of PRO instruments, how widespread initiatives to collect PROs would affect respondents' practices, perceptions of how patients and other practice stakeholders would react to PRO collection, and spe-

cific reaction to a sample PRO output (from the Edmonton Symptom Assessment System) as a springboard for eliciting specific domains and formats preferred by the respondents.[4]

Sample

Selected medical oncologists were identified through their participation in the Quality Oncology Practice Initiative (QOPI)[22] or their affiliation with a minority-based Community Clinical Oncology Program (MB-CCOP).[23] These programs include oncologists from a variety of practice types and locations and with diverse patient populations. For this study, leaders of 17 MB-CCOP practices and 639 physicians on the QOPI physician listserve received an e-mail invitation to complete an online questionnaire reporting practice characteristics and to participate in a telephone interview regarding the feasibility and use of PROs in oncology practice. We received responses from 23 practices.

Data Collection

An in-depth, semistructured telephone interview was planned with one oncologist from each responding practice. All interviews were scheduled for 45 minutes and conducted by one of four practicing oncologists, who also served as the primary data analysts. An initial training interview, involving the entire team, was conducted to improve consistency of interviewing style. The interviews were audio recorded and transcribed by an independent professional transcriptionist. Data analysis was conducted iteratively as the data were collected. After interviews with 17 medical oncologists from a diverse group of practices, the four data coders determined that the criterion of thematic saturation was met, and data collection was considered complete.

Data Analysis

Verbatim transcripts were analyzed using a thematic analysis approach, as described by Braun and Clarke.[24] All transcripts were independently reviewed and thematically coded by multiple analysts. Some potential codes were anticipated; others were generated de novo from the transcripts. After independent coding, the analysts discussed identified themes and quotations coded as exemplary of various themes in regular teleconferenced meetings. At that time, differences in interpretations were discussed and arbitrated; disagreements were resolved by consensus discussion. Cross-cutting themes and recurrent patterns were identified and examined for analytic connectedness. Thematic saturation was determined based on consensus of the coders that new thematic categories were no longer being added to the coding framework with additional interviews.

Results

Characteristics of Interview Respondents

Table 1 details the practice characteristics of the interview respondents. Most practices were located in the Northeast, located in urban communities, larger in size, and community based. There were no differences between the practices initially responding to our survey and those completing the interview.

Table 1. Baseline Characteristics of Responding Practices and Practices Selected for Interview

	Responding Practices (n = 23)		Interviewed Practices (n = 17)		
Characteristic	**No.**	**%**	**No.**	**%**	***P***
Practice location					
Northeast	9	39	8	47	.75
Southeast	3	13	2	12	.99
Midwest	5	22	3	18	.99
Southwest	2	9	2	12	.99
West	4	17	2	12	.69
Practice size, No. of physicians					
1	3	13	2	12	.99
2 to 5	5	22	4	24	.99
> 5	15	65	11	65	.99
Practice setting					
Urban	14	64	10	59	.99
Suburban	6	27	5	29	.99
Rural	2	9	1	6	.99
Unknown	1	4	1	6	.99
Affiliation					
Academic	7	30	5	29	.99
Private, with academic affiliation	7	30	4	24	.73
Private, independent	9	39	8	47	.75

Knowledge of PROs

Participants varied considerably in their ability to describe PROs. Four respondents demonstrated clear understanding and could describe the process of PRO collection and even, sometimes, specific instruments that might be used in detail. Four others had a basic understanding but could not go in depth, whereas the remaining nine interviewees were unable to describe PROs or did so inaccurately. For all respondents, we proceeded to define PROs to ensure consistent interpretations for the remainder of the interviews.

Value of PROs

Several participants described what they perceived as the added value of incorporating PROs, as we defined them, into their clinic flow. Many of these comments focused on improving the thoroughness and quality of the interaction with the patient.

"Something like this would clearly improve … the quality of care of our patients because I think a lot of times in our hectic and busy day, a lot of these things slip through the cracks."

Major benefits perceived by several participants included increased efficiency and better accuracy and communication with regard to identifying a patient's concerns before the visit.

"It would be getting the patient to think about what's going on with their body and their symptoms so that they can perhaps engage in a better discussion or dialogue with their doctor …

and help point the physician or nurse practitioner in the right direction in terms of concentrating their questioning or concerns in the areas that the patient has already pointed out."

Several respondents expressed additional potential for efficiency by facilitating referrals (eg, social work) and interventions, such as education by the nurse regarding specific issues (eg, antiemetic or bowel regimens).

Common Fundamental Concerns

Although many could see the benefits of adopting PROs in their clinics, many of these same respondents also had concerns about receiving excessive information.

"If somebody came in and filled out an entire review of systems, it would … be a little bit overwhelming in terms of trying to deal with all the symptoms that they may check off."

Others expressed concern about the limited ability to intervene in certain problems.

"There are some things that … we just don't have a very good way of treating, like tiredness or fatigue."

Many interviewees also expressed concerns about the effect of substituting a form in place of more detailed patient-physician communication.

"It does remove a human touch … our patients always comment that part of the experience here that they like is the human interaction. So I think there's a potential with that approach that you might lose that or at least diminish it."

Finally, there was concern about how this information would be used and if it could be used in ways that might penalize providers (eg, by divulging measures of patient satisfaction for provider assessment).

"If this is a tool that we will eventually make public in any fashion, you will have a lot of resistance … if you are sincere about improving care, you don't put it out in the public domain."

Practice Implementation Issues

A number of respondents were concerned about the cost of implementation and impact on clinic flow and efficiency, given the current climate of ballooning health system costs and shrinking margins for reimbursement.

"The number-one thing is that the burden to the practice in terms of implementing—whether that's financial, technical, or personnel—is not too onerous that it becomes problematic."

One oncologist suggested incorporating midlevel providers or nurses to review the forms. Most respondents felt that attention to efficiency was critical. Another emphasized careful consideration of workflow including identifying staff to educate the patient or help with data entry. In addition, several emphasized the importance of buy-in from other stakeholders (eg, nurses, medical assistants, front-desk staff, and patients).

One practice had already incorporated routine collection of PROs on paper. This did not significantly affect clinic flow, and the electronically scanned form was made available to referring providers. Another provider told of rejection of a pilot project using electronic tablets to capture PROs because of technology costs. Several respondents mentioned that PRO collection could ideally be coordinated with the use of electronic medical records in their practices, especially if patients could use tablets for automatic data transfer into medical records.

Regarding referral resources for patients identified with specific needs, some practices had social workers and nutritionists available on site, but others cited a lack of access to palliative care or pain specialists, financial counselors, or psychiatrists.

"Psychological issues in the community are very difficult to treat and it's hard to get a referral to a psychiatrist. In fact, a majority of psychiatrists in our area will not take a referral if I call for patient X; they won't accept the referral unless the patient X calls them directly."

Other Issues

Most respondents felt that there would be high acceptance and use of instruments to collect PROs by patients (several estimated > 85% compliance), especially if patients perceive the information they are entering as actionable and used to trigger interventions. Respondents noted that patients are routinely asked to fill out questionnaires for information at physicians' offices and cited examples from their own experiences as patients.

"[Patients] want to relate their symptoms in as much detail as they are permitted to relate. And so I think the acceptance would be high … they would perceive that as an improvement in the quality of care, that the team here is listening to the symptoms that they want to report."

Populations who might require additional assistance or education were identified: elderly, non–English-speaking, and semiliterate patients who may be less comfortable with electronic interfaces.

Not only did some respondents feel that patients would welcome the opportunity to participate more directly in their care, most felt that patients would be willing to share deidentified data with others for purposes of improving the quality of care and research. Few were concerned about liability associated with the collection of PRO data.

"If you constantly ignore important information then you are at risk from a liability standpoint and you shouldn't be ignoring it … the liability issue is not something I would be really particularly concerned about … the more information you get from patients and try to use to make them feel better or be better, you know, reduces your liability."

PRO Instrument Content

Participants provided positive comments regarding the content of the sample patient questionnaire report we presented (Fig 1), including simplicity and ease of use in prioritizing symptoms and the ability to track symptoms and effect of interventions over time. Some felt that common chemotherapy-induced symptoms such as neuropathy and constipation should be included. Others felt strongly that this would be an ideal way to screen for social and financial issues or to address functional status.

In general, respondents felt that it would be best to pilot test PRO collection using an instrument with a limited number of general symptoms. However, there was interest in the idea of

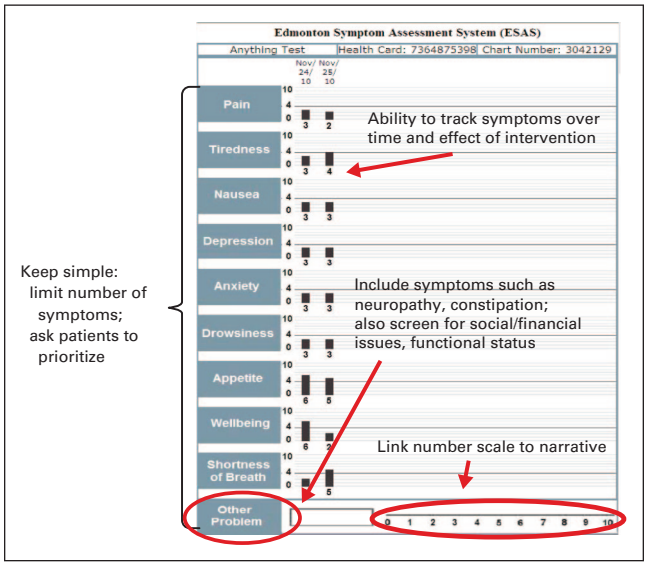

Figure 1. Copy of Edmonton Symptom Assessment System provided to oncologists during the interview. Four comments (shown in figure) were mentioned by a significant proportion of interviewees, including simplicity of the tool, ability to track symptoms over time, ability to personalize with the "others" option, and use of scale to measure symptom level. Edmonton Symptom Assessment System output from the Distress Assessment and Response Tool (permission for reproduction obtained from M. Li, personal communication; Bagha SM, Macedo A, Jacks LM, et al: Eur J Cancer Care (Engl) 22:60-69, 2013).

tailoring questions for specific patient populations in different phases of care (eg, active treatment *v* survivorship or palliative care). For example, patients with breast cancer undergoing adjuvant endocrine versus chemotherapy could be screened for a different constellation of treatment-related symptoms than survivors being monitored for post-treatment effects or symptoms of spread to metastatic sites (Fig 2).

Discussion

In recent years, considerable effort has been devoted toward developing valid and appropriate measures of PROs.[25,26] Numerous studies have successfully reported experiences with implementation of PRO collection in selected care (usually tertiary) and academic settings.[12,27-29] Although PRO instruments have been successfully integrated into routine community medical practice, little is known about the attitudes and experiences regarding PRO collection of oncologists in general practice, where the majority of US cancer care is delivered.[30-32] Some work has identified challenges to the collection of PROs in community practice, such as response burden and confidentiality concerns of patients, resource and time use by providers, and collection and management of costs of PRO data for health systems.[21] This study adds further to the understanding of the perspectives of practicing oncologists regarding incorporating PRO data collection into their daily practice. Our findings complement previous reports, which have also suggested that physicians and patients are generally positive about PRO collection and wanted questionnaires to address individual treatment- and disease-specific issues along with common symptoms and problems. Also important was the timing and frequency of these assessments to prevent questionnaire fatigue after initial enthusiasm about PRO collection.[33,34]

Our results showed that awareness of PROs among practicing oncologists was variable; however, when introduced to the concept, these oncologists saw utility in improving the efficiency and quality of the patient encounter. Similarly, a report on the PACE (Patient Assessment, Care and Education) system, an electronic patient symptom screening and reporting system for oncology, showed that providers from community oncology practices valued this tool. In particular, they valued its ability to identify, track, and document patients' most important symptoms.[35] Consistent with the themes from our interviews, use of the PACE system improved the ability of providers to identify under-reported symptoms, enhance communication with patients, and increase efficiency by highlighting patients' most bothersome symptoms.

The main concerns expressed by oncologists in our study centered on the cost and feasibility of implementing the technology, the potential flood of information that could overwhelm providers if not summarized and prioritized properly, the possibility of identifying problems for which no good interventions exist, use or misuse of this information by third parties, and the depersonalization of the physician-patient encounter. We specifically prompted our providers to discuss liability issues associated with PROs and received few concerns. In contrast, many felt that data collection might actually offer greater protection by minimizing overlooked symptoms.

As a whole, our interviewees felt that these questionnaires would be well received by their patients, that compliance would be high, and that sharing of information would not be a concern. This is consistent with a recent Livestrong report on electronic health information that surveyed 8,731 patients or people connected to patients with cancer, revealing a strong willingness to take a more active role in their care. Ninety-one percent of respondents were in favor of allowing patients to enter information about their symptoms (eg, pain or fatigue) or health for health care providers to review; 86% agreed that patients should be able to enter information about their emotional needs for providers to review. In addition, 88% of those surveyed agreed with using this information for research, as long as patient identifiers were removed.[36]

Our study has several strengths, including its analytic approach, which was strengthened by the participation of multiple interviewers and analysts who were diverse in their training, medical specialty, practice setting, sex, and race, allowing for investigator triangulation. Its primary limitation is its sample size and sacrifice of breadth for depth. However, in an attempt to ensure a wide range of perspectives, we attained a diverse sample and continued to accrue participants until meeting the criterion of thematic saturation. Both techniques are commonly used in qualitative research to minimize concerns about generalizability. Moreover, the study was carefully designed to conform to criteria that have been articulated as indicative of methodologically sound qualitative research,[37,38] and its sample size

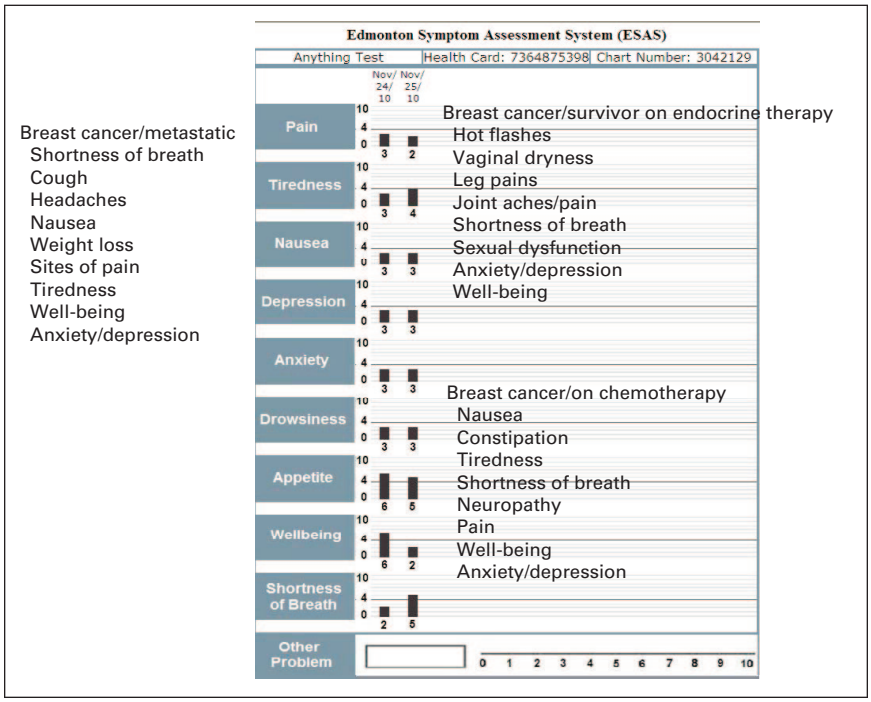

Figure 2. Example of the Edmonton Symptom Assessment System with suggestions for tailoring to patients with breast cancer at different stages of treatment. For example, a tool designed to collect data from patients with metastatic disease would focus on palliative measures, whereas a tool designed for patients undergoing treatment with endocrine therapy or chemotherapy would focus on treatment-related symptoms. Edmonton Symptom Assessment System output from the Distress Assessment and Response Tool (permission for reproduction obtained from M. Li, personal communication; Bagha SM, Macedo A, Jacks LM, et al: Eur J Cancer Care (Engl) 22:60-69, 2013).

is not surprising for a study with this design.[39] Other limitations include concerns about sample selection. We deliberately did not select individuals based on their level of expertise with PRO data collection; therefore, a large proportion of our respondents had little experience. Had more of our respondents actually experienced PRO collection, they might have raised additional concerns based on that experience. In addition, the majority of the practices selected had participated in QOPI, and most did not see sharing deidentified data as a major privacy or liability concern. Whether non-QOPI oncologists would have shared this or other sentiments is not known. Finally, there is the possibility of biased responses. For example, social desirability bias might have led our participants to overstate enthusiasm, especially because the interviewers themselves were oncologists.

In conclusion, this study of the attitudes of oncologists practicing in QOPI and MB-CCOP practices suggests providers may have enthusiasm for routine collection of PROs in oncology but also highlights that many may have limited experience or understanding. Future quantitative research is necessary to build on these findings to determine which providers are likely to be the least experienced and enthusiastic, for whom additional outreach or support may be necessary if PRO collection is to become a routine part of oncology practice.

Important benefits of routine PRO collection that were perceived by our participants included the potential to improve efficiency and quality of care, and most believed their patients would embrace PRO collection. However, several concerns identified merit consideration as policymakers prepare to encourage implementation of PRO collection in oncology practice. These include the need to ensure adequate resources for management and referrals for issues identified, consideration of impact on efficiency, and efforts to maintain the human touch of the physician-patient encounter. Specific suggestions of our participants regarding the optimal content and formatting of PRO instruments should also be considered. In addition, to ensure physician buy-in, care is necessary to ensure that PRO collection is not perceived as a mechanism for the constraint of professional autonomy but rather as an essential component of quality improvement. Moreover, oncologists must realize that future quality metrics will incorporate more patient-centered quality measures and that PROs will likely be critical to those measures. Taken together with the robust evidence collected by others, the findings of general enthusiasm and inexperience observed in this study suggest that the time is right to pursue additional research and begin pilot testing such measures in the oncology setting so that the oncology community can lend its expertise to ongoing national discussions.

Acknowledgment

R.J., A.C., B.N.P., and B.C.M. contributed equally to this work. Supported in part by the American Society of Clinical Oncology (ASCO) Leadership Development Program. The funding body played no role in the design or conduct of the study; collection, management, analysis, or interpretation of the data; or preparation, review, or approval of the manuscript. Presented in preliminary form at the ASCO Annual Meeting Board of Directors closed session, May 2012. The study was approved as exempt by the University of Michigan Institutional Review Board. We thank the oncologists who took the time to participate in this study. We

also thank Dana Sambuco, Kathy McLenithan, Michal Tibbits, and Anna Norsky for assistance with transcription and administration.

Authors' Disclosures of Potential Conflicts of Interest

Although all authors completed the disclosure declaration, the following author(s) and/or an author's immediate family member(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a "U" are those for which no compensation was received; those relationships marked with a "C" were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

Employment or Leadership Position: Reshma Jagsi, Eviti (C); Amy P. Abernethy, Advoset (C), Orange Leaf Associates (C) **Consultant or Advisory Role:** Amy P. Abernethy, Pfizer (C), Novartis (C) **Stock Ownership:** None **Honoraria:** None **Research Funding:** Amy P. Abernethy, Pfizer, Helsinn, Amgen, Kangalate, Alexion, Biovex, DARA BioSciences, Mi-Co **Expert Testimony:** None **Patents, Licenses, or Royalties:** None **Other Remuneration:** None

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DOI: 10.1200/JOP.2012.000823; published online ahead of print at jop.ascopubs.org on August 6, 2013.

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Appendix

Interview Guide

General

Have you ever heard of patient-reported outcomes (often called PROs)?

If yes or sort of:

- Tell me what the term PROs means from your perspective.
- Do you currently use PROs in your clinic? If so, tell me about your experience using them.
- (If what they say is not exactly what you expected, you can continue on to the "if no" bit below, if it seems useful to make sure you're both on the same page.)

If no:

- Patients can be asked to directly report their symptoms, experiences, and satisfaction with care. This is very similar to doing a full clinical review of systems with a patient to elicit symptoms and experience and determine if there is anything that you have missed. The innovation is that now some oncology clinics are asking patients to report the clinical review of systems systematically using PRO scales (like 0-10 rating scales or a specific survey instrument) at each clinic visit and/or between visits to track concerns over time. There are a number of ways of doing this, and there is growing interest in using technology to allow patients to report symptoms, experiences, and satisfaction electronically to augment the traditional patient-physician interview. This information can be elicited before a clinic visit and be given to providers in formats that can be used to affect the care individual patients receive. This information can also be used to evaluate the quality of care or in research. When I talk about PROs in the rest of this interview, this is what I'm talking about.
- What sorts of patient concerns do you think PRO systems should take into consideration? What are the main problems that you would like to see monitored and tracked over time?

If not enough coming from them, you can say:

- Do you see breast cancer cases? If not, what kinds of cancer do you usually see?
- Please think about a patient with breast cancer (or case they do see if they don't see breast cancer) you have seen as a new patient consultation in the last 1 to 2 weeks. What information would you like to have collected from that patient through a PRO instrument?
- How about a patient actively receiving chemotherapy?
- How about a follow-up visit with a survivor on hormonal therapy?

Content

- Consider your clinic. What tasks do you think that a patient reported outcomes tool should accomplish?
- Should the tool highlight just core symptoms frequently encountered in oncology?
- Does the tool need to be comprehensive enough to cover a full clinical review of systems on each visit?
- Should this kind of information be collected differently by visit type (eg, new patient visit, follow-up visit, chemotherapy visit)?
- Would you like to see specific tools developed for individual diseases and particular stages of that disease?
- Would you like to have a general tool that assesses patients' symptoms equally independently of the underlying disease?

Be careful not to be repetitive here; if they already told you this, move on.

- Do you need to know satisfaction with care?
- Do you need information on psychological distress and social/financial issues? If so, how detailed? If not, who is collecting this information for you now?
- Should the tool capture information on family history? What about cancer screening?
- What do you think about using a tool like this to document billing requirements of the standard review of systems?
- How do you want information presented?