**Improving Cancer Care Through the Patient Experience: How to Use Patient-Reported Outcomes in Clinical Practice**

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**OVERVIEW**

**Poorly controlled symptoms are common and debilitating during cancer treatment and can affect functional status and quality of life, health care resource utilization, treatment adherence, and cancer survivorship. Historically, the patient expe- rience, including symptoms during treatment, has not been tracked or documented in the patient health record. Measure- ment of patient-reported outcomes (PROs), including symptoms, is an essential component to cancer care focused on the illness impact to the patient and family. PROs can be useful at the individual level for monitoring and promoting symptom care both in the clinic and remotely and at the population level for aggregating population data for use in research and quality improvement initiatives. Implementation of PROs in cancer clinical care requires a carefully thought out process to overcome challenges related to integrating PROs into existing electronic health records and clinical work flow. Issues with implementing PRO collection may include making decisions about measurement tools, modes of delivery, frequency of measurement, and interpretation that are guided by a clarification of the purpose for collecting PROs. We focus on three aspects of PRO use: (1) improving care for individual patients, (2) analyzing aggregated data to improve care and outcomes overall, and (3) considerations in implementing PRO collection.**

ontinuing advances in cancer treatment and target- ed therapies have improved cancer survival and out- comes. However, cancer and its treatment are accompa- nied by distressing symptoms and serious toxicities that affect functioning and quality of life.1 Patients arrive in the therapeutic setting with varying levels of symptoms. Once cancer treatment begins, another profile of symptoms com- mences as toxicities and treatment-related complications develop. Symptom burden is negatively correlated with a patient’s quality of life, and distressing symptoms can persist long after treatment.2,3 Dealing with the demands of treatment and the accompanying symptoms, toxicities, and worries dominates the patient and family experience. Standard symptom care includes providing patients with a variety of prescriptions for symptom treatment and written educational materials on symptom management at the be- ginning of treatment and instructions to call the oncology clinic if symptoms are not well controlled. Despite this, there is evidence that patients rarely call and that symptom burden remains considerable.4 When symptoms are poorly controlled, they can result in emergency department visits, unplanned hospitalizations, delays in treatment, and lack of adherence and persistence with an effective treatment course.5-8 Symptoms commonly linger after initial treatment

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is complete. Survivors requiring prolonged maintenance therapy after initial treatment, such as hormonal therapy, often discontinue their medication due to symptoms, even though it has clearly been shown to prolong disease free survival.9,10

Improving cancer outcomes requires a focus not only on the tumor but also the illness experience and its impact on patients and their families. With an increasing emphasis on value-based care rather than fee-for-service, the patient’s perspective on what brings value is central to improving outcomes.11 Measurement of outcomes, including the pa- tient experience, is also an essential component to system- atically monitor and improve care. Historically the patient experience, including symptom presence and severity, has not been systematically tracked or consistently document- ed in the electronic health record (EHR) in contrast to other data elements, such as laboratory values or tumor mark- ers. Adding patient-reported outcomes (PROs) and data to routine clinical care requires substantial planning, logistics, and adjustment in care delivery practices. Technology now permits electronic capture of patient-reported symptoms, functioning, and quality of life, but adoption into routine care is slow. In a recent perspective, Basch12 identified three challenges limiting adoption: lack of integration of PRO data

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into EHR systems, lack of reimbursement for implementa- tion and monitoring PROs, and lack of effective processes for integration into the clinical care work flow.

Despite current barriers that dampen adoption, a growing number of cancer care organizations are implementing elec- tronic PRO measurement, sharing their experiences, and improving care and outcomes on the basis of the data.12 As the benefits of systematic PRO collection and integration in clinical care become more widely known, the tipping point for adoption will rapidly occur. PROs have several import- ant uses. They can be used during the clinical encounter to intensify symptom care and improve quality of life, and they can be used to remotely monitor patients and inter- vene in between clinic visits. In addition, they can be ag- gregated into population-level data and used to guide qual- ity improvement initiatives. Through analysis of large PRO data sets, they can also be used to provide patients with information and decision aids in choosing among treatment options or understanding the likely patient experience and recovery course of a particular treatment approach. In this article we summarize our session at the 2017 ASCO Annual Meeting on the use of PROs in clinical practice. We focus on three aspects of PRO use: (1) improving care for individual patients, (2) analyzing aggregated data to improve care and outcomes overall, and (3) considerations in implementing PRO collection.

# USING PROS AT THE POINT OF CARE FOR INDIVIDUAL PATIENTS

Many cancer clinicians and researchers are aware of the importance of measuring both the tumor response as well as the individual’s experienced response. Analytic reports have emphasized the relationships between quality of life and survival outcomes. Today’s rapid expansion of genomic profiling adds another dimension to what has been termed personalized or precision medicine. Cancer care that at- tends to genetic risk, tumor profiles, and biologic respons- es, yet omits systematic assessment and treatment of the patient’s personal experience, is incomplete. Too often, the

**KEY POINTS**

* **Measurement of PROs is an essential component of cancer care.**
* **PROs are useful at the individual level for monitoring and promoting symptom care both in the clinic and remotely.**
* **PROs are useful at the population level for aggregating population data for use in research and quality improvement initiatives.**
* **Issues with implementing PRO collection may include making decisions about measurement tools, modes of delivery, frequency of measurement, and interpretation that are guided by a clarification of the purpose for collecting PROs.**
* **Clinician champions are essential to accelerate the adoption of PROs in clinical practice.**

care system priorities of logistics and cost take precedence, and patient-centered care remains a frequently espoused ideal without meaningful implementation and evaluation. The first step in addressing the priority concerns of a pa- tient treated for cancer is to assess those priorities. Since the 1960s, cancer clinicians and researchers have used var- ious approaches to patient-reported information and data as the subjective component of a comprehensive assess- ment. Although there is a universal understanding that the patient’s self-appraisal does not always match the clinician’s appraisal, we still grapple with how to reconcile differing perspectives. The path to a reliable and valid patient-reported symptom or quality-of-life instrument is neither simple nor rapid. Contemporary understanding of usability, literacy, and cultural sensitivity issues demands instrument and pro- gram testing in diverse settings and populations.

Patient-provider communication is required for ade- quate symptom management. Clinicians obtain infor- mation about patients using several methods, including physical examination, imaging, clinical chemistry, and di- rect questioning of the patient to obtain history and symp- toms. There is considerable evidence that patients and physicians do not communicate well with respect to this last category of patient-reported data. In a study from the Memorial Sloan Kettering Cancer Center, 467 patients with breast, lung, genitourinary, or gynecologic cancer completed symptom questionnaires at a total of 4,034 clinic visits. Their reports were compared with those recorded by doc- tors and nurses treating those patients at the same visits as a part of standard institutional documentation. Clini- cians dramatically underestimated symptom incidence. For instance, at 1 year, appetite loss was reported by about a third of patients but was documented in the case notes of fewer than one in 20.13

This study is complemented by an extensive literature. Xiao et al14 conducted a systematic review that included no fewer than 36 papers comparing physician- and patient- reported symptoms in cancer and documented consistent evidence that clinicians “underestimate the incidence, severity, or distress of symptoms experienced by cancer patients.” Thus to be accurate, the patient experience, including symp- toms, needs to be reported by the patient and clearly docu- mented and tracked in the patient’s health record.

Thoroughly discussing symptoms and quality-of-life is- sues in the face-to-face clinic visit can promote partnership between clinicians and patients,15 validate the patient’s ex- periences, enhance communication and satisfaction16 and reduce symptom distress.17 However, our current health system is characterized by limited face-to-face patient- clinician contacts. Time constraints within the context of an exam visit and patients’ hesitancy to verbally report certain symptoms18 can result in missed or undercommunicated symptoms and quality-of-life issues of important clinical sig- nificance.19 PRO assessment prior to the actual face-to-face en- counter and summarized data and graphs displaying trends over time greatly improve the likelihood that symptoms can be addressed efficiently during the visit.

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Various strategies to enhance patient-clinician communi- cation have been studied. Trials in the United States, Can- ada, Australia, and northern Europe have shown symptom and quality-of-life clinical screening with or without sup- portive intervention to be feasible and clinically beneficial with regard to communication and, most important, patient outcomes. Table 1 provides a summary of some of these trials. The methods of delivery vary widely, and only a minority conducted usability and feasibility testing. Several large trial20-23 interventions included a substantial component of personal contact by study nurses or coordinators, minimizing the practicality of such interventions outside of the research setting. Yet we see evidence that clinicians can readily use PRO summaries in practice,24,25 and such use results in significantly enhanced communication and improved pa- tient experience.23,26 Questions remain, however, on the cost-effectiveness of programs in which patients monitor symptoms and quality of life, and feedback is given to clini- cians who may or may not intervene appropriately.27

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There is copious evidence from high-quality randomized trials that beyond being valid and feasible, integrating elec- tronic patient-reported data in clinical care improves both care processes and care outcomes. Berry et al17,26 conducted two randomized trials in a total of 1,512 ambulatory pa- tients starting active cancer therapy at two comprehensive cancer centers in Seattle and Boston. All patients completed online symptom questionnaires but, in the first trial, were randomly assigned to have a graphical summary of symp- toms and quality-of-life concerns reported or not reported to the clinical team. The probability that a symptom was dis- cussed during a consultation differed between groups only if the patient reported the symptom as problematic on the electronic questionnaire (p = .03), providing clear evidence that reporting of electronically gathered patient-reported data to doctors did influence the subsequent consultation. Of particular interest, there was no difference in consultation time. In other words, patient-reported data appear to im- prove the quality of the consultation without increasing the duration of the consultation.26 The intervention in the sec- ond randomized trial added a patient-facing intervention to the graphical clinician summary: self-monitoring between visits and communication coaching and self-management instructions tailored to each problematic symptom. Again, the intervention enhanced patient provider communication,34 and the intervention patients reported significantly less symptom distress and depression than the control group patients.17

Cleeland et al38 examined the effects of electronic pa- tient-reported outcomes on postoperative outcomes. One hundred patients undergoing thoracotomy for lung cancer or lung metastasis, 60% of whom were aged over 60, re- ceived automatic telephone calls and completed interactive voice response system symptom reports twice weekly for 4 weeks. Using a similar approach to that of Berry et al,26 patients were then randomized to have their reports forwarded to clinical staff members or not. Patients in the experimen- tal arm had a far greater reduction in severe symptoms

over time than controls. This was particularly apparent for the pain endpoint, with 60 severe pain events in controls compared with only 20 in patients on the intervention arm. There were also statistically significant differences between groups in symptom interference and patient satisfaction.38

The largest trial, which was recently reported by Basch et al,23 involved 766 participants undergoing chemotherapy for advanced solid tumors. Participants were randomized to electronic symptom reporting on tablets in clinic and via email from home or to routine symptom monitoring from clinicians. Health-related quality of life was measured for all patients at 6 months. In the usual care control group, 53% of patients experienced worsening of quality of life during the trial, 18% improved, and 29% were unchanged. In contrast, only 38% of patients in the intervention group had poorer quality of life at 6 months, with 34% improving and 28% unchanged (p < .001 for difference between groups). Given the high morbidity in this population, these quality-of-life differences translated to a statistically significant difference is emergency department visits. Survival was also higher in the electronic symptom reporting group, with 75.1% 1-year survival compared with 68.6% in controls. If a drug were found that could reduce mortality while improving quality of life and decreasing urgent care visits, we would consider such a drug to be standard of care.

Patient-reported data can identify patients at risk for missed chemotherapy, adverse events, and even shortened survival. For example, nonadherence to oral chemotherapy or hormonal agents has been related to severity of cancer symptoms and side effects36,39 as well as demographic vari- ables such as gender,34,40 marital status,36,40,41 and working status.31 PRO tracking systems can monitor side effects and facilitate adherence and resolution of unpleasant side effects. PRO use can also decrease inappropriate health care utilization. Symptom and quality-of-life monitoring and in- terventions have been shown to reduce unplanned hospital admissions and emergency department visits.23,42,43 Finally, PRO monitoring that results in improved symptom and qual- ity-of-life outcomes may contribute to extending survival, as there is emerging evidence that depression and anxiety44,45 and fatigue46 are significant independent predic- tors of survival.

# USING PROS FOR CLINICAL DECISION MAKING THROUGH USE OF PRO DATABASES

The adoption of systematic PRO use in clinical practice al- lows PRO data to be aggregated and used for clinical deci- sion support and quality improvement initiatives, or what has been termed data integration. The theory behind data integration is that if a patient is asked a question once elec- tronically, the response can be reused for multiple different purposes: clinical care, research, and quality assurance. The Division of Urology at the Memorial Sloan Kettering Can- cer Center has played a leading role in piloting the concept of data integration. Urology patients complete electronic questionnaires about recovery of erectile and urinary func- tion after radical prostatectomy at home via an email link

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## TABLE 1. Selected Cancer Symptom and Quality-of-Life Assessment and Intervention Studies With Multisymptom PRO Outcome Evaluation in Patients With Cancer at the Point of Service During Active Curative or Palliative Treatment, 2004 to 2016

**First Author, Year;**

**Country Sample Design; Intervention PROs**

**Usability Testing**

**Feasibility testing**

**Satisfaction or Acceptability Measure**

**Significantly Enhanced Communication Outcomes**

**Significantly Improved Outcomes on Specific PROs**

Velikova, 2004,28

201029; U.K.

N = 286; mixed dx, 73% wom-

en, 83% meta- static in cancer specialty clinic

RCT; in clinic PR using touch- screen PCs with graphed results to MD

EORTC QLQ-C30); HADS; FACT-G; MCQ

Yes Yes Yes Communication subscale of MCQ at 3 months

General, emotional, physical and functional well-being of FACT-G; over time 3+ months

Boyes, 200630; Australia

Rosenbloom, 200721; U.S.

Carlson, 201031; Canada

N = 80; mixed dx, 60% women, stage NR, in cancer special- ty clinic

N = 213; breast, colorectal, lung; 67%

women; 56% stage IV

N = 1,134; lung and breast cancer, 73%

women; 19% stage IV in can- cer specialty clinic

RCT; in clinic PR using touch- screen PCs with graphed results to MD

RCT; in clinic PR on paper, research RN interview plus info passed to clinic RN

RCT; in clinic PR using touch- screen PCs, screening with triage; graphed results

to MD

Physical symptoms; HADS; SCNS

FACT-G; FLIC; brief POMS-17;MOS- PSQ III

DT;

PSSCAN

No No Yes Not tested Better physical symptoms at

second clinic/study visit

No No No Not tested None

No Yes No Not tested In breast cancer, lower DT scores

at 3 months

Hilarius, 200832; Netherlands

N = 219; mixed dx, 70%

women, 32% receiving pal- liative therapy in community hospital clinic

Pre-post; PR in clinic on touchscreen PC with graphed results to RN

PRO survey regarding wheth- er particular issue discussed; SF-36; FACT-BCS; FACT-C; FACT-L

No No Yes More topics discussed at fourth clinic/study visit

None

Ruland, 201033; Norway

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[mer-Schalk](https://www-ncbi-nlm-nih-gov.offcampus.lib.washington.edu/pubmed/?term=Klinkhammer-Schalke%20M%5BAuthor%5D&%23x0026%3Bcauthor=true&&x0026%3Bcauthor_uid=22315052)e, 201220; Germany

N = 145; lym- phoma and leukemia, 38% women in can- cer specialty units and clinics

N = 200; breast cancer; 100% women; mixed stages in community hospitals

RCT; PR on tablet PC in

clinic or hospital unit with printed summary to MDs and RNs

RCT; PR in hospital just be- fore discharge; referral to experts for issues related to physical, psychosocial, pain and nutrition/fitness issues

19 cancer symptom categories

EORTC QlQ C-30 &

Breast-25

Yes Yes Yes No Less discomfort, better eating/ drinking, sleep/rest and sexu- ality up to 1 year

No Yes No Not tested Better Global QOL and emotional

function at 6 months; physical and emotional function at 9 months; arm symptoms at 12 months

Continued

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## TABLE 1. Selected Cancer Symptom and Quality-of-Life Assessment and Intervention Studies With Multisymptom PRO Outcome Evaluation in Patients With Cancer at the Point of Service During Active Curative or Palliative Treatment, 2004 to 2016 (Cont'd)

**First Author, Year;**

**Country Sample Design; Intervention PROs**

**Usability Testing**

**Feasibility testing**

**Satisfaction or Acceptability Measure**

**Significantly Enhanced Communication Outcomes**

**Significantly Improved Outcomes on Specific PROs**

Berry, 2014,17,34

2015,35 201536; U.S.

N = 752; mixed dx, 48%

women, 28% stage IV

in cancer spe- cialty clinic

RCT; in clinic PR using home access or touchscreen PCs with graphed results to clinicians, plus electronic communication coaching and tailored self-care instruction

SDS; EORTC QLQ C-30; EO-

RTC-CIPN-20; PHQ-9; PINS;

PROMIS pain interfere; skin changes

Yes Yes Yes Number of patient to provider statements for problematic symp- toms and QOL

Lower symptom distress on SDS and lower depression on PHQ- 9 at end of treatment

Basch, 201623; U.S. N = 766; mixed

dx, 58% wom- en, advanced solid tumors in cancer spe- cialty clinic

RCT; in clinic PR touchscreen PCs + home access with graphed results to RN+MD and auto-alerts to nurses who provided telephone support

EuroQol EQ-5D No Yes Yes Not tested Better QOL on

EuroQol EQ-5D

Steel, 201622; U.S. N = 261; liver, gall-

bladder can- cers, primary and metastatic; 27% women,

100% advanced in cancer spe- cialty clinic

RCT; in clinic PR via interview

+ home access or with face—face care coordina- tion in clinic + telephone support

CES-D; BPI;

FACT-G; FACT-Fa-

tigue; FACT-Ane- mia; FACT-Hep

No No No Not tested Depression on CES-D and QOL on

FACT-G at 6 months

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Watson, 201637; N = 1,274; mixed | Pre-post; paper PRO results | ESAS; CPC; FACT-G | No | Yes | No | Not tested | Fewer severe symptoms on ESAS |
| Canada dx; gender % | given to RN or radiation |  |  |  |  |  | and fewer problems on CPC |
| NR; stage NR; | therapist for discussion |  |  |  |  |  | reported in 10 month post |

population

based, provin- cial specialty clinics

with patient; referrals

made as needed

period

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Abbreviations: PRO, patient-reported outcomes; dx, diagnosis; RCT, randomized controlled trial; PR, patient report; PC, personal computer; MD, medical doctor; NR, not reported; RN, nurse.

or in the clinic on tablets. The data are presented to sur- geons at follow-up visits in the form of a report. This allows surgeons to focus the consultation on relevant aspects of patients’ recovery. Take, for instance, a patient who has re- covered urinary but not erectile function. Instead of starting the consultation with a list of general questions (e.g., “Are you using pads?”, “Do you have to rush to the bathroom?”, “Are you able to get an erection?”), the surgeon is able to say, “Your urinary function seems reasonable but you seem to be having erectile dysfunction. Do you want to talk about that?”

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The use of electronically reported patient data in predic- tion modeling aids in clinical decision making. In a report provided to urologists at Memorial Sloan Kettering Cancer Center following patients after radical prostatectomy, there are several prediction models that inform clinical decision making. First, in Fig. 1A, actual patient recovery is plotted against expected recovery for the individual patient. For instance, the patient is an older man with only moderate erectile function at baseline. The graph shows that his ex- pected erectile function was estimated using linear regres- sion, predicting postoperative function using patients' age and erectile function before surgery. Second, we can make predictions about future progress based on a patient's prog- ress to date. The patient, for instance could be told even at 6 months that he was unlikely to recover erectile function and that a referral to sexual medicine might be appropriate. As another example, Fig. 1B shows the life expectancy cal- culation based on data electronically reported by a patient with prostate cancer about his comorbidity and general health status. Patients and providers are given the probability that a man will die of other causes within 10 and 15 years and then the probability that he will die of prostate cancer, taking into account the risk for other-cause mortality.47 This life expectancy information aids in deciding whether active treatment of the patient is warranted or whether the pa- tient’s disease is better followed through an active surveil-

lance program.

Additionally, there is increasing use of PROs for develop- ing quality improvement initiatives focused on clinical care of symptoms and improvement of patient quality of life. PROs provide unique information about the patient’s per- spective on what brings value.11 Measurement of outcomes, from the perspective of the patient, is an essential compo- nent to systematically monitoring the care provided in any institution or care setting. PROs may be useful for studying patients’ experiences with care, for assessing hospital care quality, and for developing standing methods for monitoring symptomatic adverse effects to medications.48-50 Troeschel et al51 described the use of PROs to develop symptom man- agement quality improvement reports, demonstrating feasi- bility and acceptability. At a clinical care level, PROs provide valuable information about clinician symptom management effectiveness and value from the patient perspective.51,52 Importantly, PRO databases provide an efficient method for collecting and tracking patient-based data related to care effectiveness, care outcomes, and care satisfaction.

# CONSIDERATIONS IN IMPLEMENTING SYSTEMATIC PRO MEASUREMENT

Successful implementation of PRO measurement and rou- tine use in clinical practices or to track outcomes requires a number of choices and a carefully thought through process. The International Society for Quality of Life Research offers a very helpful guide for planning PRO implementation.53 To begin the process, practices should clarify the purpose for collecting PROs. For example, is it to improve individual pa- tient care or to track outcomes using pooled data for qual- ity improvement? Design decisions will vary on the basis of the primary purpose. Subsequent choices, such as ques- tionnaire selection, frequency of delivery, and immediacy of scoring, depend on a clear understanding of purposes. If both patient-level and population-level data are desired, some compromise in selection will be needed. Assessment of resources that will be needed for PRO implementation and availability of technology and technical support for pa- tient and for staff and clinician users is also an important early consideration.54

Choosing the questionnaire(s) to use should be based on the domains to be measured, which may include symp- toms, functional performance, and/or quality of life. Patient burden must be balanced with the completeness of mea- surement. Another consideration is whether to use generic measures that can be compared with population norms and used across cancers throughout the continuum of care. Generic measures are often used if the primary purpose is to track outcomes. If, however, the primary purpose is to im- prove care at the individual patient level, using disease- or treatment-specific measures is recommended because they better capture the pertinent symptoms the patient is expe- riencing. Knowing the expected symptoms in a particular patient population and treatment scenario also influences questionnaire choice. Patients become annoyed when they complete lengthy symptom questionnaires and yet key symptoms they find bothersome are not assessed.

Symptom assessment questionnaires can be a series of single-item measures of individual symptoms or multiple items for each symptom. Single items are concise, address patient burden, and allow the greatest number of symptoms to be addressed, whereas multiple items for each symptom may be more precise and valid but reduces the number of symptoms that can be assessed because of burden. Some multi-item scales, such as the PROMIS measures, come in computerized adaptive testing formats that allow rapid as- sessment with fewer questions per assessment than the static version. Choosing particular questionnaires should match the focus of the desired assessment such as symptom presence, severity, frequency, or burden.

Although studies have found that patient acceptability of PRO measurement is generally high, especially if they see the data being used to address their needs, questionnaire selection needs to address health literacy, readability, avail- ability in various languages, and the quality of visual display or format.55 Patients need an explanation of the purpose of collecting PROs, especially if frequent assessments are

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# FIGURE 1. Electronic Patient-Reported Data Can Be Used Immediately by Clinicians to Aid in Medical Decision Making

(A) Expected versus observed erectile and urinary function after radical prostatectomy for an individual patient. Expected recovery is estimated using data collected from other patients with similar characteristics (e.g., similar age and baseline function). (B) Probability of death of prostate cancer and other causes using data reported by the patient regarding general health status.

planned. PRO measurement can increase patients’ satisfac- tion and engagement in their care if the patients understand the purpose.56

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An important consideration in implementation design is the mode of delivery. Technology advances make electronic delivery feasible, but there is cost associated with deploying tablets or installing computer kiosks or other devices to col- lect PROs in clinic settings. To be useful at the point of care, PRO data should be immediately available and integrated into the EHR, because it is the single source of all other pa- tient data. EHR vendors have been slow to facilitate PRO in- tegration, although patient portals have evolved to include some PRO questionnaires that can be pushed to patients for completion prior to clinic visits.53

Frequency of measurement is another decision point. When tracking outcomes and change over time is the pri- mary purpose, periodic measurement is appropriate. Con- sideration should be given whether assessments should be based on calendar dates, such as quarterly, or timed to phases in care transition or some combination. However, when the primary purpose is improving the individual pa- tient experience, more frequent assessment is needed. Commonly, measurement is paired with a clinic visit and can be completed at home prior to the appointment or at check- in for the visit. Collection in the clinic involves consideration of work flow and participation of front-end staff members in facilitating collection. Adoption of PRO measurement can be hampered by clinicians’ concern that it will be disruptive to work flow. Attention to integration is critical.

If improving individual patient care is the objective, mon- itoring between clinic visits may also be considered. This overcomes several key issues in symptom management, namely, that patients may not initiate calls to clinicians about poorly controlled symptoms, and symptoms normally peak at various times during the interim period between visits and are therefore missed if measurement is only timed with a scheduled visit. Although feasible, remote monitoring does add burden to clinicians in monitoring and responding to intensify care. Severity thresholds can be set to automati- cally alert clinicians of poorly controlled symptoms, thereby decreasing the burden of reviewing all PRO data reported. This, combined with automated self-care coaching based on the symptom severity reported, can significantly im- prove symptom outcomes.4 Mooney et al4 recently reported on a clinical trial of automated home monitoring of PROs in which patients receiving chemotherapy reported daily symptom presence and severity for 11 symptoms. The in- tervention group immediately received automated self-care coaching based on the specific symptom pattern reported, and automated alerts were sent to a nurse practitioner who used a guideline-based decision support system to call pa- tients and adjust care for poorly controlled symptoms. The intervention group had significantly less symptom severity across all symptoms (p < .001), with a symptom reduction burden of nearly 43% compared with usual care. Examining days when participants reported one or more severe or one or more moderate symptoms, intervention participants had

67% fewer severe days and 39% fewer moderate days com- pared with the usual care group (p < .001 for both). As tele- health approaches become more widespread, remote PRO monitoring may extend care beyond the walls of the health systems to patients and families at home.

Scoring and interpretation of PROs also requires sub- stantial planning when used for individual patient care.57 Immediacy of the data and scoring is imperative. Integra- tion in the EHR is ideal. Protocols must be designed to clar- ify who will receive the reports, what are clinically action- able thresholds, who will be responsible for follow-up, and whether any automatic referrals are generated. The design of reports is also important. Use will improve if interpreta- tion is easy and concisely addresses and displays the data. For example, will only numeric scores be presented, or can they be accompanied by simple visual graphs to clearly spot out-of-norm values and trends over time? Other consider- ations include whether a copy of the data will be provided to the patient as a part of the care planning and to engage the patient in self-care. A final consideration is whether guideline-based decision support recommendations should be provided to clinicians so that they can efficiently take the next steps to improve care for poorly controlled symptoms and quality-of-life concerns.58 Measurement of PROs alone with not improve patient outcomes unless clinicians act on the data.59

Clinical champions are essential to create enthusiasm and accelerate the adoption process. Involvement of clinicians and staff members in thinking through the many deci- sions and designing and adapting processes to fit with work flow and clinic characteristics is exceedingly important. Greater value will be gained beyond the individual patient level, by involving clinicians in examining aggregated data and gen- erating quality improvement initiatives as needed. Ongoing clinical analysis of the real-world patient experience of cancer and its treatment through PROs is an important component for a rapid learning system to improve cancer care.60

# CONCLUSION

There is considerable evidence that patient-reported data are poorly documented by clinicians. Collection of patient-reported data using electronic tools has been shown to be accurate and feasible in both the clinical and research settings and has been demonstrated, in randomized trials, to improve both quality of life and mortality endpoints. An added benefit of collecting patient-reported data is the doc- umentation of the patient perspective on care endpoints, which then can be used to direct quality improvement initia- tives. Collection of PROs is now feasible and generally well accepted by patients. It is consistent with a patient-centered philosophy and a value-based care framework. Systematic PRO collection, integration in the EHR, and use of the data to improve care now provide both a broader and richer approach to evaluating cancer outcomes. Implementation requires the commitment of resources, thoughtful planning and monitoring, and clinical champions who see the value and are willing to work through the process of adoption.

**References**

1. Esther Kim JE, Dodd MJ, Aouizerat BE, et al. A review of the prevalence and impact of multiple symptoms in oncology patients. *J Pain Symptom Manage*. 2009;37:715-736.

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1. Deshields TL, Potter P, Olsen S, et al. The persistence of symptom burden: symptom experience and quality of life of cancer patients across one year. *Support Care Cancer*. 2014;22:1089-1096.
2. Deshields TL, Potter P, Olsen S, et al. Documenting the symptom experience of cancer patients. *J Support Oncol*. 2011;9:216-223.
3. Mooney KH, Beck SL, Wong B, et al. Automated home monitoring and management of patient-reported symptoms during chemotherapy: results of the symptom care at home RCT. *Cancer Med*. 2017;6:537- 546.
4. Barbera L, Atzema C, Sutradhar R, et al. Do patient-reported symptoms predict emergency department visits in cancer patients? A population- based analysis. *Ann Emerg Med*. 2013;61:427-437.e5.
5. Eliasson L, Clifford S, Barber N, et al. Exploring chronic myeloid leukemia patients’ reasons for not adhering to the oral anticancer drug imatinib as prescribed. *Leuk Res*. 2011;35:626-630.
6. Land SR, Walcott FL, Liu Q, et al. Symptoms and QOL as predictors of chemoprevention adherence in NRG Oncology/NSABP Trial P-1. *J Natl Cancer Inst*. 2016;108:djv365.
7. Spoelstra SL, Given CW, Sikorskii A, et al. Treatment with oral anticancer agents: symptom severity and attribution, and interference with comorbidity management. *Oncol Nurs Forum*. 2015;42:80-88.
8. van Herk-Sukel MP, van de Poll-Franse LV, Voogd AC, et al. Half of breast cancer patients discontinue tamoxifen and any endocrine treatment before the end of the recommended treatment period of 5 years: a population-based analysis. *Breast Cancer Res Treat*. 2010;122:843- 851.
9. Simon R, Latreille J, Matte C, et al. Adherence to adjuvant endocrine therapy in estrogen receptor-positive breast cancer patients with regular follow-up. *Can J Surg*. 2014;57:26-32.
10. Porter ME. What is value in health care? *N Engl J Med*. 2010;363:2477- 2481.
11. Basch E. Patient-reported outcomes—harnessing patients’ voices to improve clinical care. *N Engl J Med*. 2017;376:105-108.
12. Basch E, Jia X, Heller G, et al. Adverse symptom event reporting by patients vs clinicians: relationships with clinical outcomes. *J Natl Cancer Inst*. 2009;101:1624-1632.
13. Xiao C, Polomano R, Bruner DW. Comparison between patient- reported and clinician-observed symptoms in oncology. *Cancer Nurs*. 2013;36:E1-E16.
14. Underhill ML, Sheldon LK, Halpenny B, et al. Communication about symptoms and quality of life issues in patients with cancer: provider perceptions. *J Cancer Educ*. 2014;29:753-761.
15. Takeuchi EE, Keding A, Awad N, et al. Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *J Clin Oncol*. 2011;29:2910-2917.
16. Berry DL, Hong F, Halpenny B, et al. Electronic self-report assessment for cancer and self-care support: results of a multicenter randomized trial. *J Clin Oncol*. 2014;32:199-205.
17. Jenssen BP, Mitra N, Shah A, et al. Using digital technology to engage and communicate with patients: a survey of patient attitudes. *J Gen Intern Med*. 2016;31:85-92.
18. Kai J, Beavan J, Faull C. Challenges of mediated communication, disclosure and patient autonomy in cross-cultural cancer care. *Br J Cancer*. 2011;105:918-924.
19. Klinkhammer-Schalke M, Koller M, Steinger B, et al; Regensburg QoL Study Group. Direct improvement of quality of life using a tailored quality of life diagnosis and therapy pathway: randomised trial in 200 women with breast cancer. *Br J Cancer*. 2012;106: 826-838.
20. Rosenbloom SK, Victorson DE, Hahn EA, et al. Assessment is not enough: a randomized controlled trial of the effects of HRQL assessment on quality of life and satisfaction in oncology clinical practice. *Psychooncology*. 2007;16:1069-1079.
21. Steel JL, Geller DA, Kim KH, et al. Web-based collaborative care intervention to manage cancer-related symptoms in the palliative care setting. *Cancer*. 2016;122:1270-1282.
22. Basch E, Deal AM, Kris MG, et al. Symptom monitoring with patient- reported outcomes during routine cancer treatment: a randomized controlled trial. *J Clin Oncol*. 2016;34:557-565.
23. Mullen KH, Berry DL, Zierler BK. Computerized symptom and quality- of-life assessment for patients with cancer part II: acceptability and usability. *Oncol Nurs Forum*. 2004;31:E84-E89.
24. Basch E, Wood WA, Schrag D, et al. Feasibility and clinical impact of sharing patient-reported symptom toxicities and performance status with clinical investigators during a phase 2 cancer treatment trial. *Clin Trials*. 2016;13:331-337.
25. Berry DL, Blumenstein BA, Halpenny B, et al. Enhancing patient- provider communication with the electronic self-report assessment for cancer: a randomized trial. *J Clin Oncol*. 2011;29:1029-1035.
26. Kroenke K, Cheville AL. Symptom improvement requires more than screening and feedback. *J Clin Oncol*. 2016;34:3351-3352.
27. Velikova G, Booth L, Smith AB, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*. 2004;22:714-724.
28. Velikova G, Keding A, Harley C, et al. Patients report improvements in continuity of care when quality of life assessments are used routinely in oncology practice: secondary outcomes of a randomised controlled trial. *Eur J Cancer*. 2010;46:2381-2388.
29. Boyes A, Newell S, Girgis A, et al. Does routine assessment and real- time feedback improve cancer patients’ psychosocial well-being? *Eur J Cancer Care (Engl)*. 2006;15:163-171.
30. Carlson LE, Groff SL, Maciejewski O, et al. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol*. 2010;28:4884-4891.
31. Hilarius DL, Kloeg PH, Gundy CM, et al. Use of health-related quality- of-life assessments in daily clinical oncology nursing practice: a community hospital-based intervention study. *Cancer*. 2008;113:628- 637.
32. Ruland CM, Holte HH, Røislien J, et al. Effects of a computer-supported interactive tailored patient assessment tool on patient care, symptom distress, and patients’ need for symptom management support: a randomized clinical trial. *J Am Med Inform Assoc*. 2010;17:403-410.
33. Berry DL, Hong F, Halpenny B, et al. The electronic self report assessment and intervention for cancer: promoting patient verbal reporting of symptom and quality of life issues in a randomized controlled trial. *BMC Cancer*. 2014;14:513.
34. Berry DL, Blonquist TM, Patel RA, et al. Exposure to a patient-centered, Web-based intervention for managing cancer symptom and quality of life issues: impact on symptom distress. *J Med Internet Res*. 2015;17:e136.

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1. Berry DL, Blonquist TM, Hong F, et al. Self-reported adherence to oral cancer therapy: relationships with symptom distress, depression, and personal characteristics. *Patient Prefer Adherence*. 2015;9:1587-1592.
2. Watson L, Groff S, Tamagawa R, et al. Evaluating the impact of provincial implementation of screening for distress on quality of life, symptom reports, and psychosocial well-being in patients with cancer. *J Natl Compr Canc Netw*. 2016;14:164-172.
3. Cleeland CS, Wang XS, Shi Q, et al. Automated symptom alerts reduce postoperative symptom severity after cancer surgery: a randomized controlled clinical trial. *J Clin Oncol*. 2011;29:994-1000.
4. Lebovits AH, Strain JJ, Schleifer SJ, et al. Patient noncompliance with self-administered chemotherapy. *Cancer*. 1990;65:17-22.
5. Noens L, van Lierde MA, De Bock R, et al. Prevalence, determinants, and outcomes of nonadherence to imatinib therapy in patients with chronic myeloid leukemia: the ADAGIO study. *Blood*. 2009;113:5401-5411.
6. Hershman DL, Kushi LH, Shao T, et al. Early discontinuation and nonadherence to adjuvant hormonal therapy in a cohort of 8,769 early-stage breast cancer patients. *J Clin Oncol*. 2010;28:4120-4128.
7. Berry DL, Hong F, Blonquist T, et al. Self report assessment and support for cancer symptoms: Impact on hospital admissions and emergency department visits. *J Clin Oncol*. 2013;31 (suppl, abstr e20552).
8. Barbera L, Sutradhar R, Howell D, et al. Does routine symptom screening with ESAS decrease ED visits in breast cancer patients undergoing adjuvant chemotherapy? *Support Care Cancer*. 2015;23:3025-3032.
9. Vodermaier A, Lucas S, Linden W, et al. Anxiety after diagnosis predicts lung-cancer specific and overall survival in patients with stage III non-small cell lung cancer. A population-based cohort study. *J Pain Symptom Manage*. Epub 2017 Jan 4.
10. Antoni MH, Jacobs JM, Bouchard LC, et al Post-surgical depressive symptoms and long-term survival in non-metastatic breast cancer patients at 11-year follow-up. *Gen Hosp Psychiatry*. 2017;44:16-21.
11. Hsu T, Speers CH, Kennecke HF, et al. The utility of abbreviated patient- reported outcomes for predicting survival in early stage colorectal cancer. *Cancer*. Epub 2017 Jan 12.
12. Kent M, Vickers AJ. A systematic literature review of life expectancy prediction tools for patients with localized prostate cancer. *J Urol*. 2015;193:1938-1942.
13. Johnson ML, Rodriguez HP, Solorio MR. Case-mix adjustment and the comparison of community health center performance on patient experience measures. *Health Serv Res*. 2010;45:670-690.
14. O’Malley AJ, Zaslavsky AM, Elliott MN, et al. Case-mix adjustment of the CAHPS Hospital Survey. *Health Serv Res*. 2005;40(6p2): 2162-2181.
15. Kluetz PG, Chingos DT, Basch EM, et al. Patient-reported outcomes in cancer clinical trials: measuring symptomatic adverse events with the National Cancer Institute’s Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE). *Am Soc Clin Oncol Educ Book*. 2016;35:67-73.
16. Troeschel A, Smith T, Castro K, et al. The development and acceptability of symptom management quality improvement reports based on patient-reported data: an overview of methods used in PROSSES. *Qual Life Res*. 2016;25:2833-2843.
17. Tribett EL, Tun S, Winget M, et al. From PRO screening to improved wellness: A nurse-led intervention. *J Clin Oncol*. 2015;33 (suppl, abstr 72).
18. Aaronson N, Elliott T, Greenhalgh J, et al (eds). *User’s Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice Version 2*. Milwaukee: International Society for Quality of Life Research; 2015.
19. Rose M, Bezjak A. Logistics of collecting patient-reported outcomes (PROs) in clinical practice: an overview and practical examples. *Qual Life Res*. 2009;18:125-136.
20. Howell D, Molloy S, Wilkinson K, et al. Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Ann Oncol*. 2015;26:1846-1858.
21. Kotronoulas G, Kearney N, Maguire R, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol*. 2014;32:1480-1501.
22. Jensen RE, Rothrock NE, DeWitt EM, et al. The role of technical advances in the adoption and integration of patient-reported outcomes in clinical care. *Med Care*. 2015;53:153-159.
23. Hughes EF, Wu AW, Carducci MA, et al. What can I do? Recommendations for responding to issues identified by patient- reported outcomes assessments used in clinical practice. *J Support Oncol*. 2012;10:143-148.
24. Mooney KH, Beck SL, Friedman RH, et al. Automated monitoring of symptoms during ambulatory chemotherapy and oncology providers’ use of the information: a randomized controlled clinical trial. *Support Care Cancer*. 2014;22:2343-2350.
25. Abernethy AP, Etheredge LM, Ganz PA, et al Rapid-learning system for cancer care. *J Clin Oncol*. 2010;28:4268-4274.