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Tenets for implementing electronic patient-reported outcomes (ePROs) for remote symptom monitoring during cancer treatment

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Abstract

Background: Symptoms are common in patients receiving systemic treatment for metastatic cancer. Monitoring patients with electronic patient-reported outcomes (ePROs) detects severe and worsening symptoms early, enabling care teams to intervene and prevent downstream complications, thereby improving outcomes. The Centers for Medicare & Medicaid Services will require PRO monitoring in the upcoming Enhancing Oncology Model and many practices will likely attempt to implement PROs in patient care for the first time.

Methods: To assist practices with the design and implementation of ePRO remote symptom monitoring programs, tenets were drawn from prior ePRO program experiences and research.

Results: Successful implementation requires a quality improvement approach to change management with attention to software functionality, measured outcomes, personnel deployment, leadership and culture, workflow, equity, and patient engagement. Specific approaches in each of these areas can optimize program participation and effectiveness. Continuous program monitoring to identify and address barriers is essential to success. Initial challenges with personnel acceptance and patient participation are common, and can be overcome by employing these tenets.

Conclusion: Remote symptom monitoring with ePROs is a key component of quality cancer care and population health management that requires organizational commitment and a deliberate approach by practices using established tenets to assure successful implementation.

INTRODUCTION

The Centers for Medicare & Medicaid Services (CMS) recently released a request for applications from oncology practices to their new payment model, the Enhancing Oncology Model (EOM).[1] EOM is a 5-year voluntary program, focused on patients receiving systemic

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treatment for a number of cancers, that is scheduled to commence on July 1, 2023. In addition to requirements being carried over from CMS' prior Oncology Care Model, EOM will require practices to implement the use of electronic patient-reported outcomes (ePROs) for remote symptom monitoring, as foundations for navigation and population health management.

Remote symptom monitoring can be paper-based, digital as in the form of ePROs, or a hybrid approach. Most practices will adopt some system of digital capture in ePROs. Implementation of ePROs across a practice generally involves a software system through which patients can self-report symptoms on a regular basis via an electronic survey using a computer, smart device, or automated telephone system.[2] Severe or worsening symptoms trigger alert notifications to the care team (generally to a nurse and/or navigator), enabling the team to react and manage concerning symptoms in near real time. Reports of longitudinal symptom trajectories can be viewed by the nurse and/or oncologist at clinic visits to guide discussions and care.

A growing body of evidence demonstrates that ePRO remote symptom monitoring during systemic treatment for advanced and metastatic cancers, if linked to navigation programs that employ evidence-based interventions, can result in improvements in symptom control, quality of life, reduced hospitalizations, patient satisfaction, and possibly lengthened overall survival.[3,4,5,6,7,8] Yet the implementation of remote symptom symptom monitoring is a considerable operational lift for practices, which is the impetus for this paper. There is limited published evidence on optimal methods for implementing PROs in oncology practice, although several guidance documents,[9,10,11] and examples of prior implementations,[12,13,14] are available. From these experiences, a number of tenets have emerged that practices can employ when implementing a PRO system. Initial change management with healthcare personnel acceptance and patient participation are common and can be achieved by employing these tenets. As many practices seek to newly incorporate ePROs in routine patient care, socialization of successful tenets for implementation are useful to help practices achieve their goals.

TENETS

Table 1 summarizes the tenets for implementing ePRO remote symptom monitoring during cancer treatment, which are described in detail in the below sections.

Tenets for PRO software functions:

Currently available commercial and academic ePRO software platforms vary in their level of integration into electronic medical record (EMR) systems, and in their extent of custom configurability. ePRO software can be part of an EMR system and therefore have full integration with data visualization, messaging, and patient portal functions of that EMR. Alternatively, it can be third-party software that is interfaced with the EMR, yielding some or all of the functions of integration. Finally, it can be third-party and free-standing from the EMR, i.e., not interfaced and therefore requiring users to login to a separate system for access. At the current time, in general, free-standing ePRO software systems tend to be more highly configurable and patient-friendly (i.e., easier to access and navigate), whereas

integration with the EMR provides greater ease of use for clinicians and administrators. Therefore, if selecting a free-standing system, then more implementation work and staff engagement will be necessary to ensure success as personnel will need to go outside of the EMR for their PRO work. Conversely, if selecting an EMR integrated system, more implementation work will be needed to engage patients and assure they are able to access the patient interface as easily as possible. Optimizing onboarding for patients and clinical staff, ease of use, clear process workflow, dashboard visualization, and alert management are key components to optimal software use.

It is recommended that practices not try to develop their own ePRO software at this time. There are multiple high quality commercial ePRO software systems that bring experience in the field with usability and implementation. Many home-grown systems fail in implementation and ultimately incur equal or greater expense than working with an existing vendor or system.

PRO software must include three interfaces, a patient interface, clinician interface, and administrative interface:

a. *Patient interface*. A key tenet for the patient interface is ease of access and usability. Patient adherence rates substantially fall if their interface requires logging into an EMR portal or re-entering a password each time they login. It is essential that the patient interface be simple to use across populations. For screen visualization, words should be large enough to view with adequate space between buttons. Clear and simple instructions should be included with attention to accommodating different literacy levels. Design elements should be included to ensure a user-friendly experience.[15] In terms of functionality, the patient interface should include an electronic ePRO survey for patients to complete, for example via computer, smart device, or automated telephone system. For remote (home) ePRO monitoring programs, there should be capability to send electronic prompts to participating patients at prespecified intervals reminding them to complete surveys, via email, text message, EMR portal message, or automated telephone call. Ideally, electronic prompts should include links directly to the survey with passwordless (or one-time password) passthrough to enable easy access. The ability to deliver ePRO surveys in different languages should be included. If possible, an automated telephone system should be available, given that in the US, about one-third of patients will prefer to use an automated telephone system.[16] The patient interface should be able to convey alert notifications to specified clinical team member(s) for severe or worsening symptoms, for example via a shared inbasket, email, or other messaging system. Additional features to consider include: indicating for patients what symptom score thresholds are considered concerning and will trigger an alert notification to the care team or might warrant the patient calling the office or seeking care; enabling patients to see their own current and past self-reported symptoms; and providing self-management symptom advice. A statement can be included that the ePRO system cannot be relied upon as the sole form of communication with the practice about health concerns.

b. *Clinician/navigator interface*. As noted below, the front-line personnel who most commonly receive alert notifications and address reported symptoms are nurses and/or navigators. For these individuals, the interface should enable receipt of alert notifications in real time, and ideally will include a functionality for clinicians to record their actions in response to notifications. Notifications should be received via email, EMR, or secure messaging, ideally with a link to the patient full ePRO report, patient contact information, and/or the medical record; or with a unique identifier to enable looking up the patient in the EMR. Reports showing ePRO data in tabular and/or graphical format should be visualizable for individual patients for all members of the care team (e.g. nurse, physician, pharmacist). For EMR-integrated ePRO software, there should be an ability to import PRO data into notes and messaging. Physicians (oncologists) less commonly are designated/assigned to receive alert notifications in US practices, although this is more common in other contexts such as Europe. In the US, oncologists most commonly receive the alert notification information via discussions with the nurses/navigators who field the alerts, or view longitudinal reports of symptom trajectories at visits that have been printed or visualized electronically. For EMR-integrated ePRO platforms, the ability to import PRO information into medical chart documentation is a desirable function.

c. *Administrative interface*. The administrative interface should enable individual patients to be registered and unregistered into the ePRO monitoring program, with assignment of specific survey(s), timing of prompts (reminders) to patients to complete surveys, and specification of where alert notifications should be sent (e.g., to a shared inbasket, email address, etc). For EMR-integrated ePRO software, a rules-based approach to automatically enroll patients meeting specific criteria can be used (e.g., all patients with a given cancer type, therapy, provider, or clinic). The administrative interface should enable tracking of patient enrollment and compliance with PRO self-reporting at the individual patient level, at the level of the responsible clinical team member, and at the aggregate level (i.e., as a dashboard) to generate compliance reports. In addition, the interface should allow for reporting time to alert closure to ensure response times are consistent with institutional goals for responding to patient concerns.

For optimal implementation, ideally a single software solution will be employed within a practice or health system to address all ePRO needs, even if across disease types or contexts, and/or administering a variety of different surveys across populations.

Tenets for PRO Survey Selection:

ePRO software administers surveys to patients which contain PRO items (i.e., questions) that represent underlying “outcomes” of interest (e.g., particular symptoms). For a program including patients receiving systemic cancer therapy across disease types, a set of common and cross-cutting outcomes[17] is often selected, for example pain, nausea, vomiting, constipation, diarrhea, dyspnea, as well as potential questions about insomnia, depression, oral intake (eating/drinking), anxiety, and physical function/performance status. Using

established survey questions to clinicians such as the PRO-CTCAE can optimize clinician interpretation, as the understanding of symptom severity architecture is familiar to them.

There has been controversy regarding inclusion of fatigue, as interventions are limited and fatigue is highly prevalent limiting actionability despite frequent alert notification triggers. Nonetheless, fatigue is important to patients. Some PRO programs monitor physical function/performance status rather than subjective fatigue.

Additional outcomes may be added depending on the population of interest, or for tailoring to specific populations (e.g., based on cancer type or therapy). In general, outcomes should be selected that are meaningful to patients and are clinically actionable. Outcomes may be selected that are associated with preventable hospitalizations when caught early through monitoring.[18] There is increasing interest to supplement remote symptom monitoring with other ePRO based screening assessments such as for financial toxicity[19] and baseline social determinants of health (i.e., health-related social needs such as food, transportation, or housing security).

Ideally, software will also include a free-text (open ended) option for patients to add in unsolicited problems they are experiencing to convey to the team. This may not be feasible in automated telephone systems unless natural language processing is incorporated. Optionally, there can be items asking patients if they feel the reported problem(s) can wait until the next appointment, and whether the problem(s) are already being addressed by a clinician. Such qualifying questions can provide context about relative urgency for the care team when receiving alert notifications.

There are multiple sources of items for capturing symptoms in PRO monitoring programs. Multiple published programs have used items from the following sources: the National Cancer Institute's PRO-CTCAE,[20] PROMIS,[21] the Edmonton Symptom Assessment Survey (ESAS),[22] MDASI,[23] and EORTC QOL item library[24]. These are all well-established and tested sources of items. That said, many of these tools were initially developed for clinical research rather than for guiding routine clinical care, suggesting the need for future research to evaluate these tools in clinical care or to modify/develop new tools with clinical care specifically in mind. For common outcomes, practices are discouraged from developing their own items, although creating items may be necessary for less common outcomes or questions about demographics. Items that have been used in PRO programs to assess physical functioning or frailty include patient-reported Eastern Cooperative Oncology Group (ECOG) criteria,[25] the Geriatric Assessment,[26] or PROMIS global items.

For ePRO programs that include fairly frequent survey administration such as weekly, surveys should be brief, for example no more than 10–15 items. This length will enable most patients to complete the survey in under 3 minutes, thereby not representing a substantial burden. A one-time baseline survey can be longer, for example up to 30 items to collect information about demographics or social determinants. For example, the EOM will require that practices report on several social determinants of health, which can be captured during a longer baseline assessment.

Tenets for setting and frequency of PRO monitoring:

Patients can be asked to complete PRO surveys remotely from home between visits, at clinic visits, or both. Remote symptom monitoring allows for a regular schedule of reporting and addressing emergent problems between visits, while in-clinic monitoring gives practices more control over reminding patients to report, and tablet computers or kiosks can be provided to patients for self-reporting. Most current ePRO programs use remote monitoring.

In populations of patients receiving systemic cancer therapy (e.g., cytotoxic chemotherapy, targeted therapy, immunotherapy), weekly survey completion has become a standard frequency of survey administration. In interviews of patients and clinicians across US practices, weekly was widely viewed as an ideal frequency.[13] Less frequent monitoring is appropriate during hormonal monotherapy (e.g., adjuvant breast cancer hormonal therapy or prostate cancer hormonal therapy), or in patients receiving maintenance therapies, or during post-treatment surveillance. Conversely, more frequent monitoring is appropriate during radiation therapy and for monitoring patients following cancer surgery. Many ePRO software systems also include the ability for patients to self-report on-demand any time they wish to report an emergent problem, which may provide access to symptom reporting when patients need it most.

Duration of ePRO monitoring can be variable as cancer treatment can be variable. For cancer patients initiating a new medical therapeutic intervention, planned duration of monitoring for six months to one year after initiation of therapy may be a reasonable time frame to detect symptoms that can be controlled related to disease and treatment, with an option for patients to continue participation after that.[3]

Tenets for population selection:

Most studies of ePRO monitoring in oncology have been among patients receiving systemic therapy for metastatic disease. Benefits are most established in this population. Some benefits have also been seen during adjuvant cancer therapy,[27] radiation therapy,[28] and post-operatively,[29,30,31] although these areas are less well established.

Tenets for alert notifications:

Alert notifications should be triggered to the care team for any symptom reaching a concerning absolute level threshold of severity, or with a meaningful worsening. As an example approach used in some ePRO studies,[3,4,8] an absolute level threshold for triggering notifications has been set for any time a symptom is reported as “severe” or “frequent” (or reported at or above a numerical score of 6 on a 0–10 numerical rating scale), with a threshold for worsening been set at a 2-point increase on a 0–4 numerical or verbal rating scale (or a 3-point increase on a 0–10 scale). There have been other studies setting the threshold for alerts to “moderate” (for example, if there are not accompanying alerts for worsening, or in the postoperative setting where catching problems early is particularly desirable). Some implementations have only included absolute thresholds for notifications and not worsening, which is not ideal, as many of the most clinically meaningful notifications are related to worsening of symptoms.

Notifications are common in populations receiving systemic cancer therapy, especially for patients with metastatic disease. Up to one-third of surveys will trigger a notification, of which about half of those are generally considered clinically actionable by the care team. Strategies to reduce the number of triggered notifications are under investigation currently, including asking patients if the problem can wait until the next appointment, enabling clinicians to selectively turn off or pause notifications for specific patients (e.g., pausing diarrhea alerts for a patient with known short bowel syndrome), and uses of machine learning or artificial intelligence to determine which problems are likely to lead to downstream complications thereby warranting immediate action.

The number of notifications will depend on the selected thresholds, which can be adjusted if leaders of a program feel that is appropriate for a given population. Thresholds may be adjusted for specific symptoms, for example, higher thresholds may be appropriate for fatigue during chemotherapy, or for pain in postoperative settings, due to high baseline prevalence.

Tenets for staffing (clinical and non-clinical):

One of the most important and too often overlooked elements for the success of a ePRO program is staff deployment, roles and responsibilities, and engagement. Clinic staff or lay health workers (e.g. medical assistants, care coordinators, lay navigators) are needed to invite patients to participate in the program, register them into the software, train them to use the system, and be available for technical or logistical assistance.

Clinical personnel, most commonly nurses and/or nurse navigators must be designated and trained to receive and respond to alert notifications. The person(s) assigned to receive these notifications will vary by practice or clinic depending on the existing approach to fielding patient voicemails or portal messages and symptom management, which should be mirrored in the ePRO program. Because up to one-third of notifications will trigger an alert notification, time may need to be carved out and protected for fielding notifications, and not just be piled on top of existing work. Where appropriate, these nurses could operate remotely and service greater than one clinical area in a hub-and-spoke model to support clinical staffing. Nurses in ePRO programs have stated that they value the program, but need protected time for reviewing and addressing notificaitons.[13] Planning for staffing allocations to answer, triage, and manage increased messaging volumes is a key to success and sustainability.

Increasing staffing or adjustment of roles to support ePROs may be a challenge for some practices. The aforementioned workflow suggestions, such as creating thresholds for responding to symptom reports or asking patients whether these symptoms can be addressed at a scheduled clinic visits, may mitigate some of these staffing issues. Telephone and operator systems may also require augmentation in staffing and function to accommodate a higher volume of communication between the patients and the practice. Other digital healthcare investments within a practice (e.g., an updated patient portal, omnichannel communication, or artificial intelligence enabled triage enhancement) may assist practices in managing increased staffing requirements to efficiently manage patient symptoms.

Engagement of staff by providing information on the value of ePRO monitoring for quality of care and patient centeredness may increase staff enthusiasm to participate. Prior research demonstrates that once providers participate in PRO programs, most recognize the value of symptom monitoring for care quality and efficiency.[13]

Tenets for engaging patients:

ePRO software systems cannot just be "turned on" with an expectations that patients will participate without knowing about the value to them and their provider. It is essential that it be conveyed to the patient that their doctor and nurse want them to participate, and that PRO monitoring is a standard part of how care is delivered. Communicating how the ePRO reports fit into their care experience (e.g., can lead to more active/earlier symptom management) and goes beyond a "checkbox" that needs to be completed is crucial. Not conveying this message will negatively impact patient participation and adherence. Ideally, patients who do not report when expected will be contacted by a staff member to inquire reasons for non-adherence and offer assistance. Similarly, implementation must assure that the clinical team is viewing and responding to ePRO information, so that patients will directly experience how the ePROs are integrated into care processes. Prior research demonstrates that once patients participate in PRO programs, most feel that value has been added to their care.[13]

Attention to equity:

There is risk that a digital divide can translate into disparities in care. For example, population subgroups without experience or access to some technologies such as broadband or smart devices, limited data plans, or different styles of communication, may not reap the full benefits of an ePRO monitoring program if attention is not given to engagement and technology. As noted above, offering patients a menu of interface options will increase participation, for example by web, smart device, or automated telephone system, with options for prompts by email, text, or automated phone call. This enables a program to meet people where they are. Similarly, all patients should be approached and invited to participate in the ePRO monitoring program by staff, regardless of whether staff suspect they have lesser technical avidity or may be difficult to train or engage, and regardless of age, race, ethnicity, education, or level of frailty. Some individuals may need additional support from a member of the care team, such as a navigator or coordinator. Populations with limited prior computer experience have been found to engage highly successfully with PRO software, and in fact to yield greater benefits from PROs than their more technically avid counterparts, likely because of baseline communication barriers the software can transcend.[32]

Tenets for practice commitment, culture, continuous assessment, sustainability:

Although the concept of administering electronic symptom surveys is simple, implementation is not. Like any care enhancement, implementation requires changes in workflow, information flow, deployment, and culture. Commitment from practice leadership is necessary, with messaging across staff and clinicians that program success and is a priority for successful change management. Unit leaders such as nurse and physician champions should be enlisted to map processes and orient involved personnel, and remain engaged with frequent updates and communication. Engagement of leaders and

champions may be enhanced by providing information to them on the clinical benefits of ePRO monitoring. Implementation should be handled as a quality improvement project with ongoing systematic assessment, identifying process improvement opportunities and participation levels by patients as well as personnel, barriers, and acceptance. Program assessment may employ tools from implementation science frameworks.

Specific metrics to continuously collect include:

- The proportion of eligible patients who are approached and invited to participate. All or most eligible patients should be approached.
- The proportion of invited patients who agree to participate. A target of 70–80% is reasonable in a general oncology context.
- The proportion of participating patients who complete a survey at least once. A target of 90% is reasonable in a general oncology context.
- The proportion of participating patients at each specified time point (e.g., weekly) who complete an expected survey. A target of 65–80% adherence is reasonable in a general oncology context.
- Prevalence of each symptom across the population.
- Nurse/navigator time to alert closure and responses to alert notifications (e.g., called/counseled patient; prescribed supportive medication; made new appointment; referred to urgent care/ER; no action necessary [symptom already addressed; can wait for next visit]). There should be a documented response for all notifications, even if no action was necessary.

The program should be monitored continuously over time. It is important to recognize that initial challenges with personnel acceptance (resistance to the idea of ePRO monitoring, dissatisfaction due to altered work) and a slow start to patient participation/adherence are common, and can be overcome through deep dives into barriers or staff dissatisfiers to improve to optimize engagement, attention to the above tenets, and persistent messaging on the importance of program goals to improve quality and the patient experience.

Practices should be deliberate in care redesign around how they manage the heightened awareness of symptoms across their patients that results for a PRO program, because better monitoring reveals problems previously unaddressed that now must be addressed. This may include development of support groups and patient and family learning resources; increasing the pool or use of navigators, social workers, clinical pharmacists, counselors, and/or palliative care providers; deploying adjunct digital tools for symptom management advice to patients and nurses; and enhanced coordination with home health services and/or primary care providers. Together, these approaches represent a deliberate approach to care management and coordination that improve quality of care and the patient experience.

CONCLUSIONS

Proactive remote symptom monitoring with patient-reported outcomes is an evidence-based care enhancement that improves outcomes, quality, patient experience, and efficiency of

population health management in oncology practice during systemic treatment. Successful implementation requires a quality improvement approach with attention to software functionality, measured outcomes, personnel deployment, leadership and culture, workflow, equity, and patient engagement. Continuous program monitoring to identify and address barriers is essential to success. Initial challenges with personnel acceptance and patient participation are common, and can be overcome by employing tenets based in prior implementation efforts.

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CONTEXT SUMMARY:

Key Objective:

Symptom monitoring with electronic patient-reported outcomes (ePROs) detects problems early, enabling care teams to intervene and prevent downstream complications, thereby improving outcomes.

Knowledge Generated:

To assist practices with implementing ePRO programs, tenets were developed based on prior research and publications. These tenets include using a quality improvement approach to change management with attention to software functionality, measured outcomes, personnel deployment, leadership and culture, workflow, equity, and patient engagement.

Relevance:

Specific approaches in each of these areas can optimize program participation and effectiveness. Continuous program monitoring to identify and address barriers is essential to success. Initial challenges with personnel acceptance and patient participation are common, and can be overcome by employing these tenets.

Table 1.

Tenets for implementing electronic patient-reported outcomes (ePROs) for remote symptom monitoring during cancer treatment

Area	Tenets
Software function	- Patient interface: Prioritize ease of access and usability. - Clinician/navigator interface: Assure smooth integration with existing clinical workflow and information systems. - Administrative interface: Enable patient registration, program tracking, and auditing.
PRO Survey Selection	- Include a set of common/cross-cutting outcomes. - Use established sources for PRO survey items. - If frequent survey administration (e.g., weekly), surveys should be brief.
Alert notifications	- Alert notifications should trigger for symptoms reaching a threshold of severity or meaningful worsening. - Include ability to review clearing of alert notifications.
Staffing (clinical and non-clinical)	- Designate staff to educate and enroll patients in the ePRO program provide technical assistance. - Designate clinical personnel to respond to alert notifications and reports.
Engaging patients	- Convey to patients that clinical teams want them to participate and that ePRO monitoring is a standard of care. - Contact patients who are non-adherent to offer assistance.
Equity	- Approach all eligible patients to participate. - Provide additional support to patients with lesser technical ability.
Practice commitment, assessment, sustainability	- Engage practice leadership to message that program success is a priority. - Designate nurse and physician champions. - Implement the ePRO program using a quality improvement approach.