Title: Getting ready for real-world use of electronic patient-reported outcomes (ePROs) for patients with cancer: A National Comprehensive Cancer Network (NCCN®) ePRO Workgroup paper

Running title: Perspectives on ePROs in the real-world

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The use of electronic patient reported outcomes (ePROs) has increased dramatically in recent years across healthcare systems and specialties, including oncology. Thus, an ePRO Workgroup was formed under the auspices of the NCCN EHR Oncology Advisory Group aimed at clarifying the scope and potential value of ePROs with respect to clinical practice for the general oncology audience. The Workgroup members represent physician informaticists at leading academic centers involved with developing and implementing ePRO programs for people with cancer. The members are also practicing clinicians who will have to consider ePRO data in the context of caring for patients. With this unique dual perspective, the Workgroup explored several questions regarding ePRO definition, potential value, and roll-out readiness. The Workgroup arrived at an iterative process for successful ePRO programs consisting of "10 Guiding Principles." We believe these Guiding Principles can serve as a starting point for healthcare systems entering this exciting but daunting time of ePRO integration in the real-world care of people with cancer. We recognize our Guiding Principles will find ePRO programs at varying states of maturity. These Principles can serve cancer centers that might be contemplating ePRO implementation for the first time, as well as centers who have already embarked on collection but are seeking to refine their approach. Thus, these Principles can and should be approached in iterative stages across the ePRO program lifecycle. Finally, these Guiding Principles also serve to inform payors, EHR vendors, and other stakeholders making decisions that ultimately influence ePRO program inception and development.

What is an ePRO?

In this era of increasing technology use and patient-centeredness, we see many aspects of a patient's cancer journey being captured electronically. A question that naturally arises is, "What do we even mean by an ePRO?" as the term ePRO is applied to a variety of data.

According to CMS, PROs are measurements based on a report coming directly from a patient, without any other individual amending or interpreting this response, such as a clinician documenting symptoms by re-structuring information reported by a patient to "fit" medical thinking.(1) The National Quality Forum defines a patient reported outcome (PRO) as "any report of the status of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."(2) PRO measures are instruments or questionnaires used to report PRO data.(3) Notably, these definitions do not account for caregivers who may be providing information, especially in the case of children, older adults, or those at end-of-life. PROs have traditionally been captured via high-touch methods such as calling a patient and entering a free-text note or reviewing and transcribing paper surveys. However, low-touch, high-tech solutions such as automated electronic portal-based methods are increasingly common.(4) Thus, somewhat axiomatically, ePROs refers to the electronic capture of PRO data, including data collected via patient portals, email, text, or interactive voice response (IVR).(5)

The term Patient Generated Health Data (PGHD) can be used as an umbrella term to include all health-related data created or recorded by patients to inform their self-care and understanding of their own health.(6) For instance, many healthcare systems permit patients to input information about medications, allergies, and medical history into patient portals. This example of PGHD is distinct from PROs because other sources of verification exist and data is both historic and subjected to re-interpretation by clinicians. PGHD may also include patient-reported experience and satisfaction data used to improve the process of care delivery, such as cleanliness of a clinic or the parking situation.(7)

The distinction of PROs as a subset of PGHD is not always apparent to patients and clinicians. Confusion can occur when PGHD is being provided by patients with the expectation that data will be acted upon to improve an outcome. Consider the PGHD category of remotely connected "hard" data that is passively collected from devices to assist with monitoring patients. Body weights can now be automatically imported from electronic scales, filed as structured data into a patient's portal, and ultimately be integrated into the patient's electronic health record (EHR)for clinical review. Patients engage in remote monitoring with the expectation that clinicians will act on the data (e.g., a heart failure clinic monitoring for efficacy of diuresis). Social determinants of health (SDoH) are another PGHD category collected from patients. SDoH may include employment type which might be reported without expectation of intervention. This contrasts with SDoH questions about food insecurity, where both patients and clinicians would likely believe that such data should generate action. **Figure 1** highlights the intersection of ePROs with other types of electronically captured PGHD.

We consider ePROs to be actionable data created electronically by a patient or caregiver to identify and address factors that may impact patients during their cancer journey. This definition carries the expectation that ePRO data will trigger a response, if necessary, to address a concern. ePRO data must be ingested in a method that enables the data to be automatically encoded in a structured, discrete format without further manipulation. Although ePRO data does not necessarily need to be acquired or stored in the EHR, the data must be available as part of a patient's designated record set and must be presented to clinicians in the EHR at the point-of-care so that it can be acted upon when necessary.

What is the potential value of ePROs in cancer care?

Cancer care is a chief driver of healthcare spending in the United States and costs are expected to rise.(8) The Agency for Healthcare Research and Quality (AHRQ) estimates that in 2019 US direct medical cost for cancer was $140.7 billion.(9) In addition, hospitalizations pose a significant burden to people with cancer as a large component of out-of-pocket spending.(10) Acute hospitalizations are especially costly, accounting for almost half of all Medicare expenditures among people with advanced cancer.(11) One recent study of 29.5 million cancer-related emergency room visits showed that visits among people with cancer were significantly more likely to result in inpatient admissions (59.7%) compared to non–cancer-related visits (16.3%) ($p<0.001$).(12) However, studies have suggested that a substantial number of cancer-related acute hospital encounters may be preventable with earlier intervention.(13, 14) By addressing symptoms before they necessitate more costly interventions, such as an acute hospital encounter, oncology clinicians can contribute substantially to reducing total cancer care expenditures.

ePRO implementation in oncology is a promising strategy for early and accurate identification of people with cancer who are at-risk for acute hospital encounters. The "traditional" approach of provider-assessed reporting of adverse events is associated with substantial under-detection of symptom burden(15) and results in "reactive" approaches in which symptoms are noted and acted on at a planned clinical contact (e.g., follow-up oncology visit) or when the severity of symptoms reaches a threshold driving patients to seek care. These "traditional" approaches are time-sensitive and often insufficiently reliable in preventing potentially avoidable acute hospital encounters. Proactive approaches using remote symptom monitoring facilitated by ePROs have demonstrated clinical benefits including improved communication, reduced acute hospital encounters, and improved overall survival.(1, 16, 17, 18,

19) Therefore, there is reason for optimism with respect to the routine use of ePROs in clinical care. While optimistic, it should be acknowledged that barriers to ePRO implementation may be encountered in patient, clinical, and informatics workflows. We have seen that promising outcomes in clinical trials can sometimes be dampened following the transition to real-world settings.(20) Realizing exciting outcomes from ePRO integration into routine clinical oncology care will require overcoming technical, resource, and time constraints that exist across all oncology care settings. The oncology workforce is stretched(21), therefore, we will need to supplement traditional high-touch approaches with innovative ways of collecting, reviewing, and acting on ePROs data.

How do we get ready for real world rollouts of ePROs in Oncology?

ePROs, designed to improve the quality of cancer care and impact outcomes, have demonstrated promise in clinical trials.(1, 16, 17) This promising evidence has driven the incorporation of ePROs in value-based payment models (**Figure 2**). Building on the lessons learned from the Oncology Care Model (OCM),(22, 23) the Centers for Medicare and Medicaid Services (CMS) announced the Enhancing Oncology Model (EOM)(24) June, 2022. Among the EOM requirements is the use of ePRO measures that capture information related to the following domains: symptoms and/or toxicity, functioning, behavioral health, and health-related social needs. Additionally, the American Society of Clinical Oncology (ASCO) and Community Oncology Alliance developed the Oncology Medical Home (OMH) certification program which encourages the use of PROs.(25) While optimistic about the benefits of ePROs, these programs acknowledge the technical, resource, and workflow challenges of ePRO implementation and call for incremental implementation of ePROs.

Further supporting the acceleration of ePROs in routine oncology care, the National Cancer Institute (NCI) developed a funding opportunity (26) associated with the Beau Biden Cancer Moonshot Initiative known as the *Improving the Management of symPtoms during And following Cancer Treatment (IMPACT)* consortium (27, 28, 29, 30, 31). This consortium includes three individual research centers that are deploying integrated electronic systems to monitor and manage cancer symptoms in diverse practice settings (**Figure 2**). The IMPACT consortium clinical trials should further inform the integration of ePROs into routine clinical care, but how we translate these trial findings into the "real-world" and build infrastructure to implement meaningful ePRO programs outside of clinical trials remains a question. As we consider this broadening implementation, it is important to remember what we are trying to accomplish with ePROs. In other words, *"What are the potential applications? What might be the practical clinical impacts, positive and/or negative?"* With these questions in mind, we developed 10 Guiding Principles for the development of a robust ePRO program.

Ten Guiding Principles for ePRO Programs: Define-Collect-Act-Monitor, Repeat!

As noted, the NCCN ePRO Workgroup members represent physician informaticists, involved with developing and implementing ePRO programs, who are also practicing oncology clinicians. Members referenced the Plan-Do-Study-Act model(32) to frame the activities around actionable PGHD as iteratively addressing a defined problem (Define→) by following the steps of "Collect → Act → Monitor." Informatics and governance input are necessary across all 10 Guiding Principles (**Figure 3**) to maintain engagement of patients, clinicians, and healthcare systems.

The Workgroup generated concepts for potential Principles via initial brainstorming and literature review. Iterative discussions amongst the Workgroup served to collate individual

concepts into ten broad categories. Iterative discussions refined and assigned Principles to either an individual step (e.g., Collect) or broadly across the process (e.g. governance).

Principle 1-Define the Problem.

ePROs that are personal, timely and relevant to a defined problem serve as the foundation of collection. Such problems are defined by the need to improve outcomes for people with cancer and would typically be set by governance that involves clinicians, patients and system representatives.

Principle 2-Selection of ePRO Measures.

Diagnosis-based ePRO instruments targeting the most relevant areas for assessment versus general quality of life measures is one important consideration. The use of "validated" versus "customized" measures developed by the clinical team will depend on the defined problem. **Figure 2** references the ePRO measures collected as part of recent IMPACT clinical trials in people with cancer, but systems may also wish to consider other measures for a variety of reasons. For example, when assessing acute surgical patients after discharge, validated PRO measures for acute and chronic toxicity related to treatment have been adapted to monitor symptoms relevant to acute surgical patients. (18, 33)

Principle 3-Delivering ePROs to Patients.

From an informatics perspective, systems need to consider how to deliver ePROs. This includes consideration of delivery method technology (e.g., text, email, mobile health [mHealth] app, interactive voice response [IVR]), how the delivery method facilitates or impedes EHR integration, and the security of the method (mHealth apps that are separate from the patient

portal may be more "convenient" but mHealth vendors may be subject to different privacy considerations).(34)

Principle 4-Timing of Delivery to Patients.

In addition to delivery method, systems must consider timing of delivery. One of the fundamental benefits of ePROs are that they allow patients to respond outside of clinical visits. Moreover, ePROs can be delivered at relevant times during care, in contrast to routine visit intervals. This requires that clinical and informatics teams consider which episodes of cancer care would benefit from ePROs and which clinical triggers will be used to ensure timely delivery. From a cancer perspective, it makes more sense to deliver ePROs at timepoints relative to events such as a cancer diagnosis (e.g., ePROs are received by all patients one month after diagnosis) rather than cross-sectionally (e.g., ePROs are received every six months, regardless of time from diagnosis). However, data regarding cancer diagnosis and end of treatment are frequently not present as structured data within EHRs to trigger survey distribution.(35, 36, 37) By contrast, discharge after surgery or initiation of radiation or chemotherapy are typically structured data that could trigger administration of ePROs.

Principle 5-Who Receives ePROs?

Systems must consider which populations should routinely receive ePROs and establish governance managing this. For instance, should all patients with cancer receive ePROs or only those with cancer treated curatively? What is the role of ePROs during end-of-life care in helping patients manage symptoms outside of the hospital? These are important questions for which there is not a sufficient evidence base. From an informatics perspective, the data to define specific sub-populations may not be present as structured data to trigger nuanced ePRO distribution. For example, systems often do not have structured data about stage and intent of

therapy.(37) This may drive healthcare systems to consider inappropriately broad populations or rely on manual referral by clinicians for ePRO capture.

Healthcare systems must also consider the role of the patient proxy. For pediatric patients or those approaching the end-of-life, is it the patient from whom the data should be collected or should a caregiver be empowered? Approaches to align ePROs across a healthcare system should also be considered. This will require governance to apply ePROs in a patient-centered way so that ePROs are coordinated to ensure that patients are not inundated and redundancy of questions is minimized.

Principle 6-Address and Mitigate Disparities.

This principle needs to be considered throughout the process. Governance and informatics teams need to actively address and minimize potential sources of disparities in terms of response. For example, disparities can emerge related to language (e.g., is the ePRO available in multiple languages?) and digital literacy (e.g., does the patient have access to a device to answer ePROs, broadband access to make answering the ePROs quick, and/or comfort with the relevant technology to answer the ePROs?). If ePROs will be used to trigger access to care, non-responders will be at risk for missing out and potentially not receive the standard of care per new proposed CMS requirements. Non-responders may include those overwhelmed by chronic illnesses or lacking resources to take on any additional responsibilities. Unfortunately, these non-responders may also stand to benefit the most from the additional resources enabled by responding to ePROs. Gathering ePROs through an omnichannel framework (text or email or patient portal or IVR) will likely increase patient responsiveness and better address digital health equity divides.

Principle 7-Who is Responsible For Action?

Responsibility for taking "action" in response to ePROs must also be regarded as a key consideration for clinician engagement. Some remote symptom monitoring programs have developed centralized teams, siloed from the treating clinical team, to manage patient responses.(29, 38) Others have the treating clinical team responsible for monitoring and acting on patient responses,(18) although this presents challenges when busy clinicians are not provided adequate time to react to ePRO responses arriving outside of clinical visits.(39) Multidisciplinary care adds complexity in that it often involves many treating clinicians, such as a radiation oncologist, medical oncologist, and surgical oncologist with unique symptom burden domains, all of whom may at least want or need to know about the concern.(40) Defining who will respond to which ePRO amongst these providers is necessary to prevent symptoms from going unaddressed or over addressed, and should be managed proactively as ePROs are decided upon by system governance. For example, should medical or radiation oncology respond regarding mucositis in a patient undergoing concurrent chemoradiation therapy for head and neck cancer? Action on this symptom necessitates both medical and radiation oncology team awareness that there is a symptom requiring response. Clear signaling that action is being taken, and by whom, prevents duplicative responses that waste time, or even worse, deliver contradictory instructions to the patient.

The main difference between ePROs and patient phone calls is that we need to proactively automate where ePROs will land for review. Recognizing nonphysician clinicians as potential ePRO responders (e.g., nurses, advanced practice providers, medical assistants) should be considered given distinct clinical workflows, goals and preferences.(40, 41) Some ePRO programs will empower the patient by prompting them to call the office when symptom

thresholds are reached. However, requiring patients to act could have the potential to be perceived as "burdening" by the patient.

Principle 8-Minimize Burden and Maximize Action.

Patient and clinician engagement and sustained participation with respect to ePROs is driven by minimizing burden and maximizing action in response to ePRO completion. (42, 43) Thus, the success of an ePRO program depends on how patients and clinicians engage with the program and if they perceive it as beneficial. Patients are most likely to engage with ePROs when it is easy to respond,(34) such as a direct hyperlink delivered via text message versus needing to log in to a patient portal in response to an email. Experience suggests that patients are compelled to continue their engagement with patient satisfaction surveys when they perceive the completed surveys as triggering an action.(44) Similarly with respect to ePROs, engagement is more likely to be maintained if completing an ePRO measure triggers action such as when a complaint of nausea triggers the cancer team to contact the patient to address the nausea.(45)

Maximizing clinical action requires seamless integration into clinical care. Clinical actions typically hinge on EHR integration. (41) Reviewing and acting on ePRO responses needs to fit within existing clinical workflows.(43) Therefore, ePRO adopters are looking for EHR solutions that place ePROs in "high-traffic" clinical workflows. Patient portals, EHR in-baskets, clinical flowsheets, and office notes are places that are highly used and familiar to clinical teams, representing ideal locations for ePRO integration. Siloed ePRO navigators that require clinicians to visit a separate platform or adding areas for review and action on top of already complex EHRs represent barriers for ePRO action in clinical care.(43)

Principle 9-Measure and Monitor Outcomes.

Monitoring outcomes at the patient, clinician, and healthcare system levels aids in maintaining and improving an ePRO program. An ePRO program should include continuous improvement cycles of assessing and adjusting with input from clinical teams, patients/advocates, health informaticists and system administrators. Defining relevant outcomes is the first step. For patient outcomes, the goals of an ePRO program should be defined. For example, some programs may be designed to benefit current patients through remote symptom monitoring while others are designed to benefit future patients by evaluating comparative effectiveness of treatment.(46) Outcomes measured in research efforts of remote symptom monitoring include acute care visits, readmissions, symptoms, heath related quality of life, calls to the healthcare team, patient satisfaction, increased physician/patient communication, increased patient engagement and activation, and overall survival.(1, 16, 18, 29, 47) Patient burden should also be monitored including time spent answering ePROs, number of ePROs to complete, and adoption rates. Careful attention should be paid to non-responders which may uncover inherent disparities. Early involvement by governance bodies during the institutional development phase can play a role in limiting ePRO redundancy that treating oncology clinical teams may not be positioned to monitor such as cardiology or orthopedic ePROs. Through consistent monitoring of surveys, timing, and patient populations, ePRO programs can be refined to assure programs are value added to patients, clinicians, and healthcare systems.

In addition to patient outcomes, monitoring should be undertaken at the clinician and system-levels. Potential clinician outcomes include how clinicians perceive value from ePROs, time spent recognizing ePROs, time spent acting on ePROs, and time spent monitoring actions taken to address ePROs. Potential system outcomes may include intra- and inter-institutional monitoring of resources used in building and acting on ePROs, overall ePRO response rates, cost

of maintenance and new available technology leading to digital and organizational solutions which are needed to guide and improve future design.

Finally, the development of ePRO-based clinical decision support tools can help achieve standardized and efficient responses in addition to improved clinical documentation, workflows and implementation.(48) Similar to clinician-reported treatment toxicity grading(49), clinical decision support tools provide standardized guidance to clinicians about care that a typical patient should receive based on evidence-based practices. Proponents support automated approaches to inserting standardized interventions to ePRO responses into EHRs(43), with ongoing trials using Smart Phrases™ to help clinicians add ePRO symptom scores to documentation.(47)

Principle 10-Maintain Engagement.

Governance teams are well poised to evaluate engagement and disseminate lessons learned (outcomes) to ensure opportunities for improvement and synergy are developed. Clinical informaticists, whether nurses, physicians or pharmacists, should be engaged early and often to ensure that programs follow principles of maintaining engagement by minimizing burden and maximizing action, and maximize the integration of information technology builds with clinical workflows.

Final Take-Aways

We want to emphasize that oncology is not the only specialty contemplating the real-world roll out of ePROs, nor is it the only specialty facing these challenges. Best practices for ePRO selection, implementation, and evaluation need to be shared across all specialties. Increasing data to support the value of ePROs within the cancer population is likely coming soon

from the IMPACT trials (**Figure 2**) and other efforts. Further experience will come as payers such as CMS call for ePROs integration in value-based payment models. The temptation will be for cancer centers and healthcare systems to "go-live" with ePROs given the perceived low resources required to obtain ePRO measures. However, strategies that 1) fail to define the key problems we are trying to address and/or 2) fail to sufficiently consider appropriate workflows for responding to ePROs before collecting them, are unlikely to effect change, risk increasing clinician burnout and may jeopardize patient care. The only thing worse than not asking patients about their symptoms may be asking but failing to act on what they report.

Prior work by the NCCN EHR Oncology Advisory Group revealed that governance models are widely variable in oncology when it comes to PGHD.(50) Thus, as healthcare systems contemplate deploying ePROs, best practices are needed as well as in-depth discussions and data collection regarding the impact of implementations. There is need to create more real-world evidence on ePRO adoption and the value derived at various parts of a person's cancer journey. Finally, efforts to benchmark ePROs across various institutions are needed to yield valuable insights and support continuous quality improvement efforts.

Figure Legends:

- Figure 1: *Electronically Capturable Patient-Generated Health Data by Type, Potential Frequency of Collection and Expectation for Clinical Action*
- Figure 2: *Care Initiatives and Trials Informing Real-World Oncology ePROs*
- Figure 3: *Ten Guiding Principles for Oncology ePRO Programs Organized as a Define-Collect-Act-Monitor Iterative Cycle*

References:

1. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. J Clin Oncol. 2016;34(6):557-65.
2. The National Quality Forum. [Available from: https://www.qualityforum.org/Patient-Reported_Outcomes.aspx.
3. Weldring T, Smith SM. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Serv Insights. 2013;6:61-8.
4. Stabile C, Temple LK, Ancker JS, Basch E, Carter J, Miranda M, et al. Ambulatory cancer care electronic symptom self-reporting (ACCESS) for surgical patients: a randomised controlled trial protocol. BMJ Open. 2019;9(9):e030863.
5. Austin E, LeRouge C, Hartzler AL, Chung AE, Segal C, Lavallee DC. Opportunities and challenges to advance the use of electronic patient-reported outcomes in clinical care: a report from AMIA workshop proceedings. JAMIA Open. 2019;2(4):407-10.
6. Cohen DJ, Keller SR, Hayes GR, Dorr DA, Ash JS, Sittig DF. Integrating Patient-Generated Health Data Into Clinical Care Settings or Clinical Decision-Making: Lessons Learned From Project HealthDesign. JMIR Hum Factors. 2016;3(2):e26.
7. S H. Distinguishing Patient Experience, Patient-Reported Outcomes, and PGHD. [Available from: (https://patientengagementhit.com/features/distinguishing-patient-experience-patient-reported-outcomes-and-pghd).
8. Mariotto AB, Enewold L, Zhao J, Zeruto CA, Yabroff KR. Medical Care Costs Associated with Cancer Survivorship in the United States. Cancer Epidemiol Biomarkers Prev. 2020;29(7):1304-12.
9. Economic Impact of Cancer [Available from: https://www.cancer.org/treatment/finding-and-paying-for-treatment/managing-costs/economic-impact-of-cancer.html.
10. Iragorri N, de Oliveira C, Fitzgerald N, Essue B. The Out-of-Pocket Cost Burden of Cancer Care-A Systematic Literature Review. Curr Oncol. 2021;28(2):1216-48.
11. Whitney RL, Bell JF, Tancredi DJ, Romano PS, Bold RJ, Wun T, et al. Unplanned Hospitalization Among Individuals With Cancer in the Year After Diagnosis. J Oncol Pract. 2019;15(1):e20-e9.
12. Rivera DR, Gallicchio L, Brown J, Liu B, Kyriacou DN, Shelburne N. Trends in Adult Cancer-Related Emergency Department Utilization: An Analysis of Data From the Nationwide Emergency Department Sample. JAMA Oncol. 2017;3(10):e172450.
13. Lipitz-Snyderman A, Pfister D, Classen D, Atoria CL, Killen A, Epstein AS, et al. Preventable and mitigable adverse events in cancer care: Measuring risk and harm across the continuum. Cancer. 2017;123(23):4728-36.
14. Panattoni L, Fedorenko C, Greenwood-Hickman MA, Kreizenbeck K, Walker JR, Martins R, et al. Characterizing Potentially Preventable Cancer- and Chronic Disease-Related Emergency Department Use in the Year After Treatment Initiation: A Regional Study. J Oncol Pract. 2018;14(3):e176-e85.
15. Fromme EK, Eilers KM, Mori M, Hsieh YC, Beer TM. How accurate is clinician reporting of chemotherapy adverse effects? A comparison with patient-reported symptoms from the Quality-of-Life Questionnaire C30. J Clin Oncol. 2004;22(17):3485-90.
16. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA. 2017;318(2):197-8.
17. Denis F, Basch E, Septans AL, Bennouna J, Urban T, Dueck AC, et al. Two-Year Survival Comparing Web-Based Symptom Monitoring vs Routine Surveillance Following Treatment for Lung Cancer. JAMA. 2019;321(3):306-7.

18. Simon BA, Assel MJ, Tin AL, Desai P, Stabile C, Baron RH, et al. Association Between Electronic Patient Symptom Reporting With Alerts and Potentially Avoidable Urgent Care Visits After Ambulatory Cancer Surgery. JAMA Surg. 2021;156(8):740-6.
19. Basch E, Stover AM, Schrag D, Chung A, Jansen J, Henson S, et al. Clinical Utility and User Perceptions of a Digital System for Electronic Patient-Reported Symptom Monitoring During Routine Cancer Care: Findings From the PRO-TECT Trial. JCO Clin Cancer Inform. 2020;4:947-57.
20. Takvorian SU, Anderson RT, Gabriel PE, Poznyak D, Lee S, Simon S, et al. Real-World Adherence to Patient-Reported Outcome Monitoring as a Cancer Care Quality Metric. JCO Oncol Pract. 2022;18(9):e1454-e65.
21. Copur MS. Burnout in Oncology. Oncology (Williston Park). 2019;33(11).
22. Center for Medicare and Medicaid Services: Oncology Care Model [Available from: https://innovation.cms.gov/innovation-models/oncology-care.
23. Chong A, Witherspoon E, Honig B, Ela E, Cavanagh H, Strawbridge L. Reflections on the Oncology Care Model and Looking Ahead to the Enhancing Oncology Model. JCO Oncol Pract. 2022;18(10):685-90.
24. Center for Medicare and Medicaid Services: Enhancing Oncology Care Model [Available from: https://innovation.cms.gov/innovation-models/enhancing-oncology-model#:~:text=The%20Enhancing%20Oncology%20Model%20(EOM,Medicare%20fee%2Dfor%2Dservice.
25. Woofter K, Kennedy EB, Adelson K, Bowman R, Brodie R, Dickson N, et al. Oncology Medical Home: ASCO and COA Standards. JCO Oncol Pract. 2021;17(8):475-92.
26. Optimizing the Management and Outcomes for Cancer Survivors Transitioning to Follow-up Care (R01 Clinical Trial Required. NCI.
27. Improving the Management of symPtoms during And following Cancer Treatment (IMPACT) [Available from: https://healthcaredelivery.cancer.gov/impact/.
28. Hassett MJ, Wong S, Osarogiagbon RU, Bian J, Dizon DS, Jenkins HH, et al. Implementation of patient-reported outcomes for symptom management in oncology practice through the SIMPRO research consortium: a protocol for a pragmatic type II hybrid effectiveness-implementation multi-center cluster-randomized stepped wedge trial. Trials. 2022;23(1):506.
29. Finney Rutten LJ, Ruddy KJ, Chlan LL, Griffin JM, Herrin J, Leppin AL, et al. Pragmatic cluster randomized trial to evaluate effectiveness and implementation of enhanced EHR-facilitated cancer symptom control (E2C2). Trials. 2020;21(1):480.
30. Wintheiser GA, Ruddy KJ, Herrin J, Rahman PA, Pachman DR, Leppin AL, et al. Receptivity to a Nurse-Led Symptom Management Intervention Among Highly Symptomatic Patients With Cancer. J Natl Cancer Inst. 2022;114(3):458-66.
31. Lancki N, Bass M. NU IMPACT Study:Recruiting and Consenting through the EDW in REDCap 2021 [Available from: https://www.feinberg.northwestern.edu/sites/firstdailylife/docs/bass_presentation_slides.pdf.
32. Langley GJ, Moen RD, Nolan KM, Nolan TW, Norman CL, Provost LP. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance. 2nd edition ed: Jossey-Bass; 2009.
33. Avery KNL, Richards HS, Portal A, Reed T, Harding R, Carter R, et al. Developing a real-time electronic symptom monitoring system for patients after discharge following cancer-related surgery. BMC Cancer. 2019;19(1):463.
34. Vo V, Auroy L, Sarradon-Eck A. Patients' Perceptions of mHealth Apps: Meta-Ethnographic Review of Qualitative Studies. JMIR Mhealth Uhealth. 2019;7(7):e13817.
35. Luoh RP, Tevaarwerk AJ, Chandereng T, Smith EM, Carroll CB, Emamekhoo H, et al. Patterns and predictors of cancer-specific patient health portal usage among patients with cancer: results from the UWCCC Survivorship Program. Cancer Med. 2021;10(20):7373-82.

36. Tevaarwerk AJ, Hocking WG, Zeal JL, Gribble M, Seaborne L, Buhr KA, et al. Accuracy and Thoroughness of Treatment Summaries Provided as Part of Survivorship Care Plans Prepared by Two Cancer Centers. J Oncol Pract. 2017;13(5):e486-e95.
37. Tevaarwerk AJ, Klemp JR, van Londen GJ, Hesse BW, Sesto ME. Moving beyond static survivorship care plans: A systems engineering approach to population health management for cancer survivors. Cancer. 2018;124(22):4292-300.
38. Daly B, Kuperman G, Zervoudakis A, Baldwin Medsker A, Roy A, Ro AS, et al. InSight Care Pilot Program: Redefining Seeing a Patient. JCO Oncol Pract. 2020;16(10):e1050-e9.
39. Haun JN, Alman AC, Melillo C, Standifer M, McMahon-Grenz J, Shin M, et al. Using Electronic Data Collection Platforms to Assess Complementary and Integrative Health Patient-Reported Outcomes: Feasibility Project. JMIR Med Inform. 2020;8(6):e15609.
40. Sandhu S, King Z, Wong M, Bissell S, Sperling J, Gray M, et al. Implementation of Electronic Patient-Reported Outcomes in Routine Cancer Care at an Academic Center: Identifying Opportunities and Challenges. JCO Oncol Pract. 2020;16(11):e1255-e63.
41. Zhang R, Burgess ER, Reddy MC, Rothrock NE, Bhatt S, Rasmussen LV, et al. Provider perspectives on the integration of patient-reported outcomes in an electronic health record. JAMIA Open. 2019;2(1):73-80.
42. Nadine Jackson McCleary RKS, Ravindra Uppaluri, Sarah Whittaker, Jessica Cleveland, Brittany Black, Sunyi Zhang, Michael J. Hassett, Laura A. Goguen. Implementation of electronic patient-reported outcomes in head and neck oncology at a comprehensive cancer center. 2022.
43. Harle CA, Listhaus A, Covarrubias CM, Schmidt SO, Mackey S, Carek PJ, et al. Overcoming barriers to implementing patient-reported outcomes in an electronic health record: a case report. J Am Med Inform Assoc. 2016;23(1):74-9.
44. Baker GR, Fancott C, Judd M, O'Connor P. Expanding patient engagement in quality improvement and health system redesign: Three Canadian case studies. Healthc Manage Forum. 2016;29(5):176-82.
45. Kathi Mooney P. A randomized control trial to determine necessary intervention elements to achieve optimal symptom outcomes for a remote symptom management system.: ASCO Poster; Abstract ID 370886; ASCO poster from 2022.
46. Ivatury SJ, Hazard-Jenkins HW, Brooks GA, McCleary NJ, Wong SL, Schrag D. Translation of Patient-Reported Outcomes in Oncology Clinical Trials to Everyday Practice. Ann Surg Oncol. 2020;27(1):65-72.
47. Hassett MJ, Cronin C, Tsou TC, Wedge J, Bian J, Dizon DS, et al. eSyM: An Electronic Health Record-Integrated Patient-Reported Outcomes-Based Cancer Symptom Management Program Used by Six Diverse Health Systems. JCO Clin Cancer Inform. 2022;6:e2100137.
48. Stover AM, Tompkins Stricker C, Hammelef K, Henson S, Carr P, Jansen J, et al. Using Stakeholder Engagement to Overcome Barriers to Implementing Patient-reported Outcomes (PROs) in Cancer Care Delivery: Approaches From 3 Prospective Studies. Med Care. 2019;57 Suppl 5 Suppl 1:S92-S9.
49. Institute NC. Common Terminology Criteria for Adverse Events (CTCAE) v.5.
50. Stetson PD, McCleary NJ, Osterman T, Ramchandran K, Tevaarwerk A, Wong T, et al. Adoption of Patient-Generated Health Data in Oncology: A Report From the NCCN EHR Oncology Advisory Group. J Natl Compr Canc Netw. 2022:1-6.