HHS Public Access

Overview of Patient-Facing Systems in Patient-Reported Outcomes Collection: Focus and Design in Cancer Care

Roxanne E. Jensen[1,2], **Scott P. Gummerson**[2], and **Arlene E. Chung**[3,4,5]

[1]Department of Oncology, Georgetown University, Washington DC

[2]Cancer Prevention and Control Program, Lombardi Comprehensive Cancer Center Washington, DC

[3]University of North Carolina at Chapel Hill School of Medicine

[4]Lineberger Comprehensive Cancer Center Outcomes Research Program

[5]Carolina Health Informatics Program

Patient-facing systems are designed to provide a wide range of computer or internet-based services that support patient interactions with the healthcare system.[1] Examples of these systems include: patient portals,[2] mobile applications,[3] and online peer support communities.[4] A key element across all patient-facing systems is that each is able to promote and facilitate patient engagement with the healthcare system and their providers.

Electronic patient-reported outcomes (PRO) systems offer a patient-facing platform to capture and quantify patients' self-reported symptom severity. Patients answer questions about symptoms and their severity such as their fatigue and pain which can generate summary scores. Electronic PRO assessment in clinical care is associated with improvements in symptom identification[5-8] and doctor-patient communication.[9,10] Studies evaluating electronic PRO systems suggest a high level of patient interest and satisfaction with reporting symptoms,[11] and patients are more likely to complete a PRO assessment if it is clear that the scores will be used to inform their care.[12]

The number patient-facing systems that capture PROs in clinical cancer care settings has grown quickly over the past 5 years, providing an increasing number of options for integrating PROs into cancer clinical care.[13,14] This growth has been supported by web-based PRO data entry, decreasing data collection and hardware costs,[15] research demonstrating an association between PRO collection and improved patient outcomes,[16] interest in large-scale PRO surveillance to improve quality and outcomes,[17] and pragmatic research efforts using clinical data sources.[18]

For many years, the primary focus of most electronic PRO systems used in clinical oncology has been to provide clinicians symptom information at the point-of-care. Therefore, systems vary in the amount of access patients are given to their own PRO data. In a recent review, very few systems provided patients access to symptom alerts (29%) while only 63% provided patients access to their PRO scores.[19] While recent studies have examined both clinician and patient preferences in PRO score reporting,[20] there are only a couple of examples of patient-facing PRO reports designed specifically for cancer patients.[21,22] The

limited amount of patient-focused information available in electronic PRO systems is currently a missed opportunity to further engage patients in this process and in their care. As PRO collection increasingly embraces new data collection methods such as smartphones tailored to collect data capture outside of a care visit,[23,24] there are new opportunities to develop and promote a number of patient-oriented reporting functionalities. Mobile phone-based collection may offer more convenience and better usability in terms of the format and layout of questionnaires. By incorporating knowledge from data visualization, data representation, graphics design, and health infographics, PRO reports could provide tailored PRO data, incorporate patient preferences for format and presentation of the data,[25] provide low health literacy and numeracy options when necessary,[26] while encouraging patient engagement and self-care actions.[27]

Most systems are designed to collect PROs during the clinical encounter to inform a patient's visit. Case studies have shown that building in extra time (20-30 minutes) to collect PROs in the waiting room can be integrated with minimal workflow disruption when staff is provided training to address technical issues (e.g. iPad use, password retrieval, etc.).[15] As a result, in-clinic assessment has been shown to have high patient response rates,[28,29] but requires dedicated staff and hardware to enable collection.

Web-based (often pre-visit) PRO assessments offer data collection outside of the clinical encounter, lower costs due to decreasing staff burden needed to administer PROs and no hardware costs incurred by the clinic. This also provides an opportunity to longitudinally monitor symptoms regardless of the timing of office visits. However, features offering off-site ("at-home") web-based assessments report low rates of patient participation.[19] Furthermore, patients who are non-white or have less than a college degree are significantly less likely to complete web-based PRO assessments.[30] This may be due to a variety of factors such as lack of access (Internet, computers, tablets, smartphones, etc.), and literacy and numeracy issues that can be barriers to completion. Additionally, little is known about current design and accuracy barriers in off-site assessment among groups likely to require proxy reporting, such as those experiencing severe symptom burden or cognitive impairment.

As patient portals tethered to electronic health records such as Epic MyChart, offer more web-based PRO questionnaires as part of their foundation systems, alternate workflows for PRO capture (in-clinic vs. at-home collection), and displays of PRO data, more information is needed about the full range of staffing needs to integrate PROs into clinical care, workflow issues, cost, and patient compliance. It is likely that trade-offs that exist between off-site vs. in-clinic data collection. Moving the PRO data collection outside of the encounter has a number of benefits as it can provide efficiencies and can satisfy billing requirements for the review of systems.[31]

Electronic PRO systems were first designed to collect and report PROs for clinician use to inform the patient visit. As PRO data becomes increasingly captured by patient portals and mobile technologies between clinical encounters longitudinally, new opportunities exist, such as evaluating health care system-level quality of care and enabling comparative-effectiveness research. However, the full range of electronic PRO implementation challenges

must be better understood to support long-term sustainability and usefulness of electronic PRO data. As the adoption of mobile data capture and user-centered symptom reports improves, there is a unique opportunity for electronic PRO systems to fully embrace mobile health and patient-focused reporting as tools for patient use to foster engagement and participation, supporting patient care and improving health outcomes.

References

1. Ahern DK, Woods SS, Lightowler MC, Finley SW, Houston TK. Promise of and potential for patient-facing technologies to enable meaningful use. Am J Prev Med. 2011; 40(5 Suppl 2):S162–172. [PubMed: 21521591]

2. Irizarry T, DeVito Dabbs A, Curran CR. Patient Portals and Patient Engagement: A State of the Science Review. Journal of medical Internet research. 2015; 17(6):e148. [PubMed: 26104044]

3. Singh K, Drouin K, Newmark LP, et al. Developing a Framework for Evaluating the Patient Engagement, Quality, and Safety of Mobile Health Applications. Issue Brief (Commonw Fund). 2016; 5:1–11. [PubMed: 26934758]

4. Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. Journal of medical Internet research. 2008; 10(3):e15. [PubMed: 18504244]

5. Basch E, Jia X, Heller G, et al. Adverse symptom event reporting by patients vs clinicians: relationships with clinical outcomes. Journal of the National Cancer Institute. 2009; 101(23):1624–1632. [PubMed: 19920223]

6. Hilarius DL, Kloeg PH, Gundy CM, Aaronson NK. Use of health-related quality-of-life assessments in daily clinical oncology nursing practice: a community hospital-based intervention study. Cancer. 2008; 113(3):628–637. [PubMed: 18543317]

7. McLachlan SA, Allenby A, Matthews J, et al. Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2001; 19(21):4117–4125. [PubMed: 11689579]

8. Miller JJ, Frost MH, Rummans TA, et al. Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. J Psychosoc Oncol. 2007; 25(4):105–119. [PubMed: 18032268]

9. 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. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2004; 22(4):714–724. [PubMed: 14966096]

10. 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. European journal of cancer. 2010; 46(13):2381–2388. [PubMed: 20570138]

11. Wintner LM, Giesinger JM, Zabernigg A, et al. Evaluation of electronic patient-reported outcome assessment with cancer patients in the hospital and at home. BMC Med Inform Decis Mak. 2015; 15:110. [PubMed: 26699708]

12. Snyder CF, Herman JM, White SM, et al. When using patient-reported outcomes in clinical practice, the measure matters: a randomized controlled trial. Journal of oncology practice / American Society of Clinical Oncology. 2014; 10(5):e299–306.

13. Jensen R, Snyder C, Abernethy A, et al. A Review of Electronic Patient-Reported Outcomes Systems used in Cancer Clinical Care. Journal of Oncology Practice. 2013 In Press.

14. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. BMC Health Serv Res. 2013; 13:211.doi: 10.1186/1472-6963-13-211.:211-213 [PubMed: 23758898]

15. 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. Medical care. 2015; 53(2):153–159. [PubMed: 25588135]

16. Basch E, Deal AM, Kris MG, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2016; 34(6):557–565. [PubMed: 26644527]

17. Smith TG, Castro KM, Troeschel AN, et al. The rationale for patient-reported outcomes surveillance in cancer and a reproducible method for achieving it. Cancer. 2016; 122(3):344–351. [PubMed: 26619031]

18. Wu AW, Kharrazi H, Boulware LE, Snyder CF. Measure once, cut twice--adding patient-reported outcome measures to the electronic health record for comparative effectiveness research. Journal of clinical epidemiology. 2013; 66(8 Suppl):S12–20. [PubMed: 23849145]

19. Jensen RE, Snyder CF, Abernethy AP, et al. Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care. Journal of Oncology Practice. 2014; 10(4):e215–e222. [PubMed: 24301843]

20. Brundage M, Feldman-Stewart D, Leis A, et al. Communicating quality of life information to cancer patients: a study of six presentation formats. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2005; 23(28):6949–6956. [PubMed: 16192583]

21. Hartzler AL, Izard JP, Dalkin BL, Mikles SP, Gore JL. Design and feasibility of integrating personalized PRO dashboards into prostate cancer care. J Am Med Inform Assoc. 2016; 23(1):38–47. [PubMed: 26260247]

22. Vickers AJ, Savage CJ, Shouery M, Eastham JA, Scardino PT, Basch EM. Validation study of a web-based assessment of functional recovery after radical prostatectomy. Health and quality of life outcomes. 2010; 8:82. [PubMed: 20687938]

23. Falchook AD, Tracton G, Stravers L, et al. Use of mobile device technology to collect patient-reported symptoms during radiotherapy for head and neck cancer: A prospective feasibility study. Journal of Clinical Oncology. 2015; 33(15)

24. Torous J, Staples P, Shanahan M, et al. Utilizing a Personal Smartphone Custom App to Assess the Patient Health Questionnaire-9 (PHQ-9) Depressive Symptoms in Patients With Major Depressive Disorder. JMIR Ment Health. 2015; 2(1):e8. [PubMed: 26543914]

25. Bantug ET, Coles T, Smith KC, et al. Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words? Patient Educ Couns. 2016; 99(4):483–490. [PubMed: 26603445]

26. Arcia A, Suero-Tejeda N, Bales ME, et al. Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. J Am Med Inform Assoc. 2016; 23(1):174–183. [PubMed: 26174865]

27. Ricciardi L, Mostashari F, Murphy J, Daniel JG, Siminerio EP. A national action plan to support consumer engagement via e-health. Health Aff (Millwood). 2013; 32(2):376–384. [PubMed: 23381531]

28. Smith SK, Rowe K, Abernethy AP. Use of an electronic patient-reported outcome measurement system to improve distress management in oncology. Palliat Support Care. 2014; 12(1):69–73. [PubMed: 24128592]

29. Chiang AC, Buia Amport S, Corjulo D, Harvey KL, McCorkle R. Incorporating patient-reported outcomes to improve emotional distress screening and assessment in an ambulatory oncology clinic. Journal of oncology practice / American Society of Clinical Oncology. 2015; 11(3):219–222.

30. Judson TJ, Bennett AV, Rogak LJ, et al. Feasibility of Long-Term Patient Self-Reporting of Toxicities From Home via the Internet During Routine Chemotherapy. Journal of Clinical Oncology. 2013; 31(20):2580–2585. [PubMed: 23733753]

31. Chung AE, Basch EM. Incorporating the patient's voice into electronic health records through patient-reported outcomes as the "review of systems". J Am Med Inform Assoc. 2015; 22(4):914–916. [PubMed: 25614143]