

Identifying Patient-Centered Outcomes for Digital Care for Chronic Conditions

Executive Summary

PCORI Award EASC-26626

Background and Objectives

Digital technologies are increasingly ubiquitous in daily lives. For people with chronic health care needs, digital tools like telehealth (phone/video visits), MyChart, remote monitoring, wearables/apps, and algorithm-based decision support are increasingly relevant.¹⁻³ While digital tools hold great promise for improving convenience and quality of care for some patients, there are ongoing concerns about equity with regard to digital accessibility, quality of care, and the potential for inadvertently worsening existing disparities in care.

By eliciting multi-stakeholder engagement to understand how digital tools affect patients with chronic conditions and their care experiences, we intend to lay the groundwork for future measurement of patient-centered outcomes in both healthcare and research. We specifically aimed to identify a list of patient-centered outcomes that should be measured when using digital strategies, methods for outcome measurement, and a roadmap for implementing measures in health care systems and future comparative effectiveness research (CER) studies.

Methods

This one-year project was funded by the Patient-Centered Outcomes Research Institute (PCORI) and was conducted at HealthPartners Institute, in partnership with HealthPartners Institute's Community Advisory Council for Research and Evaluation. HealthPartners Institute is a nonprofit research organization associated with HealthPartners, a member-governed nonprofit integrated health system in Minnesota and surrounding states with 1.8 million insured members and 1.2 million patients.

Between January and August 2023, we used a snowball method to learn perspectives on patient-centered digital care from multiple stakeholders inside and outside our organization through virtual discussion groups, meetings, and non-representative surveys. Contributors included patients with chronic conditions, caregivers, and diverse community partners; health system stakeholders including front-line healthcare workers (community health workers and interpreters); leaders in digital product design, measurement, and care delivery; and researchers from HealthPartners Institute and the Minnesota Department of Health.

In September and October 2023, we convened a sub-set of those we had met, as well as additionally identified stakeholders, in two multi-stakeholder roundtables. We used the World Café method^{4,5} to explore the meaning of patient-centered digital care and the best application of patient-centered outcome measurement. Forty-nine individuals attended the first roundtable, and 42 attended the second. Attendees were evenly distributed among patients, caregivers, community members, health system staff, and researchers. Attendees documented their perspectives in a series of collaborative Google Jamboards⁶, and discussions were

recorded on video and transcribed. The Jamboard content and transcripts were reviewed by three team members and summarized. Participants of the convenings were given an opportunity to comment on the summaries to ensure findings were true to participant perspectives.

Summary of learnings

Participants discussed many ways that digital care has been helpful. However, most also observed flaws or described a negative experience with digital tools that affected their overall health care experience. People want digital care to be efficient, accessible, easy to use, and personalized. They also expressed a wish for better leveraging of digital systems to document and communicate patient preferences and information, including about accessibility needs. Discussions emphasized the importance of protecting patients' choice in mode of care, accessibility, convenience, quality of care, care team relationships, and the health literacy benefits of having access to one's own medical information. Specific groups of patients were identified as at-risk for possible worsening outcomes using digital strategies, including those with limited English proficiency (LEP), low digital and technology literacy, intellectual and physical disabilities, and certain medical needs. It was recommended that all patients, but particularly these groups, have teaching and tech support available to help them learn and benefit from the digital care tools they would like to use.

Participants identified fatigue with health system surveys and expressed a desire for questions to be personalized to them and their conditions and have a direct correlation to their care. Mode preference for data collection varies, but many participants preferred to use digital modes to answer questions before or after a visit instead of providing direct feedback to their care team during a visit. Participants repeated that digital systems should track the status of patient-centered outcomes over time so the information can be used in ongoing care and research. Participants were enthusiastic to identify barriers to digital care and ways in which digital care may present barriers to overall care quality. In addition to self-report, participants recommended using the extensive data already available in the electronic health record or existing studies to understand more about how digital tools affect barriers to care or otherwise impact patient outcomes.

Recommendations

We recommend that the following outcomes be measured in health care and in future research that employs and examines digital care strategies for chronic conditions to assess the patient-centeredness of those strategies:

- Accessibility (ease of access to needed care, when and how it is needed, and related barriers)
- Quality of care (appropriate and timely care, diagnosis, and treatment)
- Convenience (or burden)
- Cost (time, money, trade-offs)
- Quality of relationships with care team (effect of remote communication)
- Perceptions or experiences of bias in care (being treated differently virtually vs. in-person)

- Health literacy (understanding of one’s condition)
- Shared decision-making (specifically for telehealth or remote vs. in-person options)
- Disease outcomes (maintaining, improving, or worsening health)

We also recommend evaluating outcomes with special attention to groups of patients who tend to encounter a higher number of barriers when accessing health care: those with limited English proficiency (LEP), those less comfortable with technology or with limited access to technology, rural, and intellectually or physically disabled.

We recommend that future CER investigate the patient-centeredness of digital care strategies, emphasizing early engagement with patient partners to identify the most important patient-centered outcomes for the condition(s) and intervention(s) of interest. We also recommend researchers partner with health systems to produce and collect patient-reported data, for example through systematic documentation in the electronic health record (EHR), so that research measurement can also be used to improve direct patient care.

We recommend that digital interventions be designed intentionally in partnership with diverse patient stakeholders and employ a Targeted Universalist⁷ approach to design in order to ensure that digital interventions can be used by all people who prefer to use them.

Conclusions

Digital tools present opportunities and challenges for the care of chronic conditions and should be designed and leveraged to make health care more patient-centered. Despite the promises of advancing technology, assumptions should not be made about how patients are affected by digital health care strategies. Measuring patient-centered outcomes can improve health and health care outcomes by ensuring patients are able to receive and participate in their health care appropriately, using the suitable strategies for their situation, with the sufficient support in place. Due to the prevalence of technology across health care, the fundamental equity issues surrounding digital care, and the inexorable pervasiveness of technologies like artificial intelligence (AI), future CER that includes digital care interventions should consider including the measures and approaches recommended by this project.

References

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