

Identifying Patient-Centered Outcomes for Digital Care for Chronic Conditions

Final Engagement Report

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Table of Contents

Executive Summary	3
Background.....	6
Objectives	7
Methods	7
Summary of formative engagement: January-August 2023	9
Patient and Community Perspectives	9
Health care perspectives	11
Research Perspectives.....	12
Virtual multi-stakeholder roundtable convenings on patient-centered digital care	15
Roundtable 1 summary: What is patient-centered digital care?	15
Roundtable 2 summary: Application of patient-centered outcomes	18
Recommendations and Toolkit.....	22
Measuring patient-centered outcomes for digital chronic disease care	22
Roadmap for measure implementation.....	28
Conclusions.....	30
References.....	31
Appendices	35
Appendix A: Formative engagement contributors.....	35
Appendix B: Patient surveys and results	36
Appendix C: Pre-meeting materials for virtual convenings.....	43

Executive Summary

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.

Background

Digital technologies are increasingly ubiquitous in our daily lives. For people with chronic health care needs, digital tools such as telehealth (phone/video visits), MyChart, remote monitoring, wearables/apps, and algorithm-based decision support are increasingly relevant. The COVID-19 pandemic created unprecedented demand and availability of digital tools in health care, which helped to maintain health care access during a challenging time. Health care systems continue to utilize technology to optimize care delivery, and thus digital health care is likely to reach an ever-larger population of patients.^{1-3,8}

While studies have established the efficacy of digital tools for managing chronic conditions,⁹⁻¹⁸ uncertainty remains the effect of digital tools on patient-centered outcomes. This is in part due to ambiguity about the meaning of patient-centered outcomes and methods for routine measurement.¹⁹⁻²¹ In the past, researchers have commonly used validated scales for assessing patient experiences of treatment burden, shared decision-making, and satisfaction with care. However, to fully understand the impact of digital tools on patients' experiences, we must identify the meaning of patient-centered outcomes in this novel, technology-centered health care environment.²²

The promise of digital tools for improving outcomes also is complicated by the potential problems created for those who experience economic, geographic, language and cultural barriers to care. While digital tools can help to overcome transportation, geography, and accessibility barriers for some, they may create new barriers for those without access to technology, digital literacy, or certain health needs. These ongoing concerns about equity represent a risk for digital strategies to worsen existing disparities in care for vulnerable populations.²³⁻²⁸

What is patient-centered digital care?

Patient-centered care places the patient, rather than the care team, at the "center" of their care. This means protecting patients' access to choices, creating partnership with their care team and shared decision-making, and honoring consent. It also means considering patients' lived experiences and creating strategies that work in people's complex lives.

In this project, **digital care** refers to any way in which technology or devices are involved in care for chronic conditions. This could include telehealth (phone/video), MyChart or other patient portals, remote monitors for specific conditions, wearables/apps that provide useful health information (like FitBit or Apple Watch), or algorithms in the electronic health record (EHR) that guide patient-provider decision making.

Objectives

This project aimed to lay the groundwork for future measurement of patient-centered outcomes related to digital and virtual tools for chronic disease care and management.

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

Methods

Setting and Partners

This project was conducted at HealthPartners Institute, in partnership with the HealthPartners Institute's Community Advisory Council for Research and Evaluation ("Community Advisory Council").²⁹ HealthPartners Institute is a research organization associated with HealthPartners, a large integrated health system in Minnesota and surrounding states. The Community Advisory Council comprises 11 individuals with diverse lived experiences and connections to communities affected by HealthPartners care, insurance coverage, and research.

Formative engagement

Between January and August 2023, we used a snowball method to seek perspectives on patient-centered digital care from multiple stakeholders inside and outside HealthPartners through virtual discussion groups, meetings, and non-representative surveys. Contributors included patients with chronic conditions, caregivers, and community partners; health system stakeholders including front-line health care workers (community health workers and interpreters) and leaders in digital product design, measurement, and care delivery; and researchers from both the HealthPartners Institute and the State of Minnesota's Department of Health. This period helped to identify important salient themes to form the basis of the virtual multi-stakeholder roundtable convenings.

Virtual multi-stakeholder roundtable convenings

In September and October 2023, we convened a sub-set of those we engaged with as well as additionally identified stakeholders in two multi-stakeholder roundtables. We used the World Café method³⁰ to explore the meaning of patient-centered digital care and the best application of patient-centered outcome measurement. In total, 49 individuals attended the first roundtable and 42 attended the second. Attendees were evenly distributed between patients, caregivers, and community members, health system staff, and researchers. Attendees documented their perspectives in a series of collaborative Google Jamboards, and the discussions were recorded on video and transcribed.

Analysis and conclusions

The project team used an ethnographic approach to understand the key issues raised in this project. Project co-leads synthesized quantitative and qualitative information from the many meetings and conversations of the formative engagement stage into an easily digestible summary, which led to the selection of the virtual convening topics in partnership with Community Advisory Council members. After the convenings, three team members carefully reviewed all meeting transcripts and Jamboard content and summarized lessons learned in a short brief. Participants of the convenings were given an opportunity to comment on the summaries to ensure findings were true to participant perspectives to help refine conclusions and make them as actionable as possible for health systems and health systems researchers. The team sought feedback from patient, community, health care, and research partners throughout this process until a level of thematic saturation was reached. That process underlies the conclusions.

Ongoing engagement

The Community Advisory Council was central to this project's engagement strategy. The council helped to identify the most important community concerns to explore as a starting place. A workgroup of council members helped to create and recruit for several community discussion groups and plan and facilitate the virtual convenings. The council's community co-chair, Dr. Apolinário-Wilcoxon, facilitated the convenings and was an important voice in connecting the topic to the priorities and interests of diverse communities. Research and health system partners were also engaged in planning the convenings, but to a lesser degree. It was important to ensure these groups would find the convening to be valuable for their work. Throughout the process, people we engaged with through the convenings were given the opportunity to comment on summaries and the conclusions included in the Executive Summary and Toolkit.

Summary of formative engagement: January-August 2023

Between January-August 2023, we connected with a wide variety of people to understand perspectives on patient-centered digital care, including **patients and community groups, health system colleagues, and researchers**. Contributors are listed in Appendix A.

Formative engagement was conducted using a snowball technique. We began with recommendations from our Community Advisory Council, research partners, and clinical partners. We continued to pursue discussions and identify patient perspectives until we reached a sense of thematic saturation in what we had learned, where perspectives consistently identified recurrent themes and nuances within themes.

By conducting this early engagement, we aimed to identify core issues in patient-centered digital care that would provide a framework for our multi-stakeholder virtual convenings in the fall. A summary of these findings was distributed to attendees of the virtual convenings to help all participants appreciate others' perspectives on patient-centered digital care.

Patient and Community Perspectives

We engaged with **patients and community groups** to learn how digital care is used to manage chronic conditions such as diabetes, heart conditions, and Parkinson's disease. We also spoke with groups about how digital care can resolve – or sometimes create – inequities, especially around physical and intellectual disability, larger body size, race, gender, limited English proficiency, and rurality. We reviewed several existing unpublished sources of survey data from HealthPartners and the Minnesota Department of Health regarding digital tools for chronic care. We were also able to field a short survey about digital tools and virtual care to a large panel of HealthPartners' members and patients. Our Community Advisory Council helped to ensure we identified diverse perspectives for these conversations, particularly from people subject to inequity in health care.

What we asked patients and community groups:

- What digital tools have you used in your health care?
- What are the pros and cons of digital care tools?
- What outcomes matter the most to you in your health care?
- What does patient-centered care mean to you?

Participants

During this phase, we spoke with 51 people across 9 discussion groups, including chronic disease patients, patient advocates, patient researchers, community health advocates, and community health workers. We also conducted a survey of 239 non-representative respondents from the HealthPartners MyVoice opinion panel and a survey of 30 Parkinson's disease patients and caregivers. We did not systematically collect demographic data (age, race/ethnicity, or gender) across our discussions, but we targeted diverse perspectives across many dimensions of diversity as identified in partnership with our Community Advisory Council (see Appendix A).

Most patients and community members we spoke with had chronic conditions, but not all. Chronic conditions that were disclosed across groups included: diabetes, hypertension, cardiovascular disease, chronic kidney disease, autoimmune disorders, sleep apnea, depression/anxiety, Parkinson’s disease, and others. Those who did not have chronic conditions informed us about digital equity issues that affect their communities, such as patients with intellectual and physical disabilities, transgender people, and those in larger bodies.

Patients reported using a variety of digital tools in their care, including: MyChart (patient portal), telehealth (phone and/or video), remote monitors (e.g., glucose, blood pressure), at-home diagnostic tools (e.g., for a sleep study), and wearables/apps (e.g., FitBit or Apple Watch).

Preliminary themes from patient and community groups

All patient and community groups advised on ways digital care intersects with both chronic care and health inequities. Below is a highly synthesized summary of themes we heard through our discussions and surveys. Detailed notes and summaries of survey data are included in the Appendices.

Theme 1: Patients value effective, patient-centered care. Overall, participants expressed that they value choices in their health care, the quality and appropriateness of their care, their relationships with care team, and positive health outcomes. These values were raised consistently as we discussed both the pros and cons of using digital tools in health care. Opinions about digital tools were largely expressed with these values in mind.

Theme 2: Digital care has many potential benefits (“pros”). The following observations were cited as ways that digital care can help patients:

- Telehealth can reduce unnecessary in-person visits
- MyChart aides in access to health information and ease of communication with care team
- Device data can help patients learn about their conditions and improve management
- Digital care is convenient for some
- Some technologies are easy to use
- More communication can improve relationship with care team
- Phone/video can reduce perceived bias or safety problems some patients face in-person
- Phone/video can support patients in communicating clearly with care team
- Potential for lower time and money costs

Theme 3: Digital care has many potential challenges (“cons”). The following observations were cited as ways that digital care can create problems, concerns, or barriers for patients:

- Telehealth is not always appropriate for certain conditions
- Risk of misdiagnosis without physical exam
- Too much or unexplained information/data can promote anxiety and worry
- Data accuracy, privacy, and security – digital information follows patients everywhere
- For some, digital interaction reduces personal connection with care team
- Risk of redundant visits (increased cost and inconvenience)

- Tech, language, and other barriers can exclude or even jeopardize care for some
- Cost barriers for using remote devices
- Some patients need support setting up and navigating starting digital tools to receive the benefits as other patients

Theme 4: Accessibility is a multi-faceted issue. Digital care can resolve transportation and accessibility barriers for some people, but worsen them for others. Some patients also prefer or require in-person care *despite* access barriers for reasons of quality of care or social connection. Technology access, language barriers, cost, and transportation/physical accessibility are major equity issues that put some people at risk of being excluded by digital strategies.

Theme 5: Support for patient learning and use of digital tools. Most patients identified the importance of health system support to allow patients to learn and benefit from digital care tools of their choosing. That support should focus on helping patients learn how to get started with digital tools and how to trouble-shoot problems with the ongoing use of technology. A clear point of contact or resource for help is beneficial for all patients.

Health care perspectives

We engaged with colleagues within the **integrated health system** to learn how healthcare providers and leaders are thinking about digital tools for chronic care, what priorities guide implementing digital strategies, and how the system is navigating barriers and supporting patients with new digital tools.

What we asked within the health system:

- What are current priorities for digital care?
- What are known barriers for patients?
- How are patient-reported outcomes being measured?

Participants

Within **HealthPartners**, we engaged 9 colleagues in various clinical and digital initiative areas as well as 12 medical interpreters from a diverse communities.

Preliminary themes from health system colleagues

Digital tools have become rapidly and deeply embedded in health care, especially since the COVID-19 pandemic. While digitizing care is a high priority, HealthPartners is committed to its stated vision: *“Health as it could be, affordability as it must be, through relationships built on trust.”*

Theme 1: Digitization is an ongoing priority across the health system. The ways the health system is digitizing and automating care include promoting and supporting telehealth (video visits), improving online scheduling processes, increasing capacity to integrate remote devices with the electronic health record (EHR), encouraging use of wearables (such as FitBits), and modernizing patient education to be digital-friendly and include technological support.

Theme 2: Community Health Needs Assessments (CHNAs) identified consistent concerns about digital equity and access. The CHNAs conducted in 2021 for the system’s 8 regional hospitals each reflect systematically collected community health concerns and are accompanied by an implementation plan for years 2022-2024. All CHNAs identified the same top ranked health priorities: amplifying mental health resources; access to health/social determinants of health; access to care, nutrition and physical activity; and reducing substance use. In all regions, transportation barriers, financial struggles, and technology access were described as important equity issues – especially in rural areas where broadband access is highly variable. Technology was also noted as a promising tool to address substance use, mental health needs, and social isolation. While technology-related goals in the implementation plans centered on mental health support, the equity issues described in telehealth demonstrate a need to focus on equity.

Theme 3: Limited English proficiency (LEP) patients need support with digital tools. Interpreters across the organization, representing languages from across the globe, expressed concern about the impact of telehealth and other digitization efforts on LEP patients. The current use of MyChart and video visits is especially challenging because of the need for both language support and help navigating new technologies that are presented primarily in English. Interpreters identified a need for LEP patients to receive more support from the care system for two reasons: so they do not “fall through the cracks” and miss necessary follow-up care, and so they can benefit equally from digital tools. These concerns were affirmed by reports from Community Health Workers (CHWs) about the need to support patients as they learn to use digital tools before they can access the benefits.

Theme 4: Patient-reported outcomes (PRO) measurement is of increasing interest in clinical areas. There is a relatively new effort to collect systematic patient-reported outcomes in certain clinical areas, which is made possible through research partnerships. There is a long road to implementing PRO measurement in individual clinical areas because the information is highly specialized. The health system is exploring how to integrate PRO measurement with the EHR to make the information relevant and useful for care. While there are not current plans to implement PRO measurement in chronic specialty care or primary care, this is one promising area for the future.

Research Perspectives

We engaged with **researchers** to learn how digital care is being investigated, what kinds of patient-centered data researchers have collected, and what concerns researchers have about patient-centeredness of digital interventions.

Participants

During this phase, we spoke with 9 researchers from HealthPartners Institute who have led studies that include digital interventions for chronic conditions. Study topics included remote blood pressure monitoring with phone-based pharmacist support, continuous glucose monitors, clinical decision support tools integrated into the electronic health record (EHR), and collection of patient-reported outcomes (PROs) for clinical use. We also spoke with researchers at the Minnesota Department of Health and Human Services (MDHHS) who are conducting research on telehealth and equity issues in order to advise the state on important policy decisions.³¹

What we asked researchers:

- What feedback have you heard about patient-centered digital care?
- What have you learned in your research about patient-centeredness?
- What data exist that we can learn from?

Preliminary themes from researchers

Research studies that include digital health strategies are increasingly common in chronic care research. Many studies assess some aspects of patient experience and patient-reported outcomes through surveys. **Identifying measures that are truly patient-centered means finding measures that reflect patients' priorities and concerns.** By recommending their inclusion in future research, we can better understand how digital strategies affect patient-centeredness.

Theme 1: Existing studies have shown many patient-centered benefits of digital tools. Data from a remote blood pressure monitoring study showed increased patient satisfaction overall with the use of remote monitoring.³² Clinical decision support studies have demonstrated increased communication between patients and their care teams.³³ And preliminary findings from the state-wide telehealth study reflects that broad access to telehealth has increased overall access to care in Minnesota.³⁴ These findings from specific local projects reflect a larger literature that suggests many ways patients benefit from using digital tools.

Theme 2: Patient-centered outcomes may vary by condition. In the diabetes world, the concept of *diabetes distress* provides a framework for understanding the quality of life impact of diabetes care and management. Researchers who have engaged with patients to identify patient-centered outcomes for research studies remarked that in addition to other types of outcomes, patients may still highly value biomedical measures of their condition (labs, vital signs, or test results) – though they may have preferences for looking at them in terms of control or improvement, and interest in “numbers” may be different across conditions, depending on the meaning to patients. Similarly, patient concerns may naturally vary by condition as a function of complexity, what is involved with treatment and care, and how the condition affects daily life.

Theme 3: There are several common research measures that could be adapted to assess patient-centeredness of digital care. These include measures of treatment burden (e.g., the diabetes-specific concept of *diabetes distress*), quality of care, patient satisfaction, shared decision-making, and cost of care. These are commonly utilized in surveys. To determine what measures are patient-centered for a particular condition or group of patients, researchers suggest engaging patients in identifying high priority patient-centered outcomes.

Theme 4: There may not be one patient-centered measure that meets all patients' needs. In one study that collected patient-reported outcomes to improve outcomes for orthopedic injuries, researchers found patients identified highly individualized outcomes for their care, suggesting that patient-centered outcomes may vary.³⁵

Theme 5: Impacts of telehealth on health care quality and equity are important research priorities.

The preliminary report to the Minnesota legislature from the State Telehealth study, published in June 2023, was unable to draw conclusions about the effects of telehealth on health care quality or equity issues. The study recommends further data collection to understand what types of care telehealth is best for and the relationship between technology access and health care access across socioeconomic and cultural groups.³⁴

Virtual multi-stakeholder roundtable convenings on patient-centered digital care

Roundtable 1 summary: What is patient-centered digital care?

Participants

Our first virtual Patient-Centered Digital Care Roundtable was on September 19, 2023 and brought together 49 people: 13 researchers from HealthPartners Institute, the State of Minnesota, and academia; 15 staff involved in digital care across HealthPartners' health plan and care delivery system; 15 diverse chronic disease patients and community partners; and 6 members of the HealthPartners Institute's Community Advisory Council for Research and Evaluation. Invitees were identified from formative engagement efforts, with additional invitations extended via snowball recruitment to balance groups.

Methods

Pre-meeting preparation

Prior to the meeting, invitees received a packet via US mail to orient attendees to the goals of the convenings and summarize what was learned in the formative engagement period. The packet included a meeting agenda, instructions for joining the virtual meeting, an abstract from a systematic review of PCORI-funded telehealth studies, a summary of what we learned in our formative engagement, and a pre-meeting activity to promote creative thinking (see Appendix D).

Objectives

The objectives of this first meeting were to:

1. Build a shared understanding of patient, community, health system, and research perspectives on patient-centered digital care
2. Identify a preliminary list of key patient-centered outcomes

Agenda

We crafted our agenda based on the World Café method^{5,30} for eliciting diverse perspectives:

1. Welcome to participants
2. Introduction and background: what is patient-centered digital care?
3. World Café: exploring patient-centered digital care in breakout rooms
4. Harvest/discussion through large-group reflection

World Café

The World Café method is designed to elicit focused conversations by having small groups answer open-ended questions over a series of "rounds." It is an important feature of World Café that participants mix and re-form groups for each round, meaning no two groups are the same. We used three guiding questions and randomly assigned 4-5 participants to each breakout room. Each group

included a room host from the Community Advisory Council or project team. Participants shared their ideas and typed them on a Jamboard for each round of questions.

World Café prompts to explore patient-centered digital care:

- Round 1: What past experiences have you had with digital health care? What worked and what did not work? What could change?
- Round 2: What would you like digital health care to be? What should health care providers think about in order to make digital health care useful and accessible to all?
- Round 3: What results matter most when using digital tools in health care? How do you want to feel after those encounters?

Synthesis of information

After the meeting, the project team reviewed the Jamboard statements and transcripts from the meeting to summarize the key take-aways using qualitative content analysis. The below summary was shared with all meeting attendees with an invitation to give feedback to ensure the summary is true to what was expressed.

Summary of learnings

The pandemic spurred major development of virtual and telehealth care, especially for mental health but also for primary and other specialty care. Participants reported experience with telehealth, other virtual care, MyChart, remote monitoring devices (such as home BP cuffs, continuous glucose monitors, or at-home sleep study), and wearables (including FitBit and Apple Watch).

Overall, participants discussed many ways that digital care has been helpful. However, most observed flaws or described some negative experience with digital health care that affected their overall health care experience.

People want digital care to be efficient, technologically comfortable, and personalized with tech preferences and information that, once put into the system, are incorporated and referenced in their care.

There was considerable discussion about the importance of encouraging and respecting patients' choice across mode of care, accessibility, convenience, quality of care, care team relationships, along with the health literacy benefits of having access to one's own medical information through digital tools.

Patient choice: in-person vs. virtual care

The choice of whether to engage in telehealth, virtual care or in-person care is personal and dependent on many factors that may be different from person to person or day to day. There is no "one size fits

all” solution, and participants stressed the desire for in-person care to remain just as available and accessible as telehealth and other virtual options. Many people found virtual visits particularly helpful for targeted requests, refills, and focused low-acuity interactions, while in-person care may be more appropriate for complex visits, things that require physical examinations, or more serious concerns. Other factors that may influence patient preference include accessibility, convenience, tech access and literacy, and relational considerations. Some also expressed concern about where digital information goes and who has access to it.

Accessibility

Accessibility was a major theme in the discussions. Most people have experienced technological difficulties establishing or maintaining a connectivity for telehealth. But certain patients have particular accessibility needs relating to tech literacy, English proficiency, and/or ownership/obtainability of devices and internet. Digital tools could be used to improve overall health care access for those groups, particularly if they were designed to address accessibility issues, but they are not currently.

Simpler and more uniform and integrated platforms would be helpful. Current platforms pose difficulty because they are not intuitive to navigate. In addition to improving universal function of digital tools, leveraging digital platforms to help communicate about patients’ accommodations across care teams would ease that burden for patients. Digital care may be particularly useful in rural areas, where providers and specialists are less available, given viable broadband or cellular access.

Participants expressed substantial desire for a coach or navigator to assist patients who face access barriers in establishing and navigating digital tools. Some also suggested creating community-based telehealth access points (for example, computers in dedicated spaces at public libraries).

Convenience

Many said that MyChart makes it convenient to make appointments, accomplish pre-visit tasks, view lab results, and communicate with their care team. Similarly, virtual care and telehealth can save time on travel and paperwork which translates to less time away from daily tasks; people with disabilities also benefit from minimizing these costs. However, gaps exist, and this is not a universal experience.

Quality of care

People want accurate diagnoses and timely, appropriate care. Some stories were shared about misdiagnosis via telehealth resulting in serious outcomes. (It was suggested that AI could help with this by being able to quickly scan the entirety of a person’s medical record and include all relevant information when making a diagnosis.) After any visit, patients want to feel that something has been accomplished and a plan is in place. Follow-up information in MyChart about recommended care and appointments is an area for improvement.

Telehealth and virtual care may promote continuity when people move, though they may also have to change digital mediums. It can be difficult to ensure continuity of care through digital strategies for those with accessibility barriers, which puts some patients at risk.

Care team relationship

There is a need to develop clinician etiquette and how to convey care and compassion (“bedside manner”) through virtual means. Some participants said that it is more difficult to establish and build relationships with new clinicians virtually. It is also difficult to include caregivers in telehealth and other digital health tools, such as being in the meeting for virtual care or getting proxy access to MyChart.

In a telehealth visit, the clinician and patient may need to be more aware of time and more straightforward in their discussion of symptoms, assessments, and treatment plans. Most people do not want to feel rushed, and many people are not able to reflect upon and quickly present their health concerns over digital mediums in contrast to in-person. However, some said they communicate more effectively virtually.

Health literacy

A benefit of digital tools is the opportunity to promote health literacy. Those with remote or wearable devices seem to have found them helpful for understanding and responding to their conditions. Many discussed the benefit of reading lab results and doctor’s notes in MyChart, which helps them research their condition and feel empowered. However, summaries and interpretations are often necessary for comprehension and to avoid alarm in the face of what can be a large amount of uncontextualized medical information.

Roundtable 2 summary: Application of patient-centered outcomes

Participants

Our second Patient-Centered Digital Care Roundtable brought together 42 people: 10 researchers from HealthPartners Institute, the State of Minnesota, and academia; 11 staff from across HealthPartners’ health plan and care delivery system; 16 diverse chronic disease patients and community partners; and 5 members of the HealthPartners Institute’s Community Advisory Council for Research and Evaluation.

Methods

Pre-meeting preparation

Prior to the meeting, attendees received meeting minutes and a summary of the first meeting. Participants were invited to review the themes from the first meeting to continue the conversation.

Objectives

The objectives of this second meeting were to:

1. Affirm or refine the list of recommended outcomes identified in the first meeting
2. Identify opportunities for measurement in health care and research
3. Craft a narrative about this topic that will resonate with patients, healthcare providers and leaders, and researchers

Agenda

We crafted our agenda on the World Café method^{5,30} for eliciting diverse perspectives:

1. Welcome to participants

2. Follow-up from the first roundtable: review of themes from the meeting summary
3. World Café: exploring outcome measurement in breakout rooms
4. Harvest/discussion through large group reflection

World Café

We used three guiding questions for our World Café. For each question, we divided participants into new groups of 4-5 people not previously in a group together so that each was explored with a new group of perspectives. Each group included a room host from the Community Advisory Council or project team. Participants shared their ideas and recorded them to a Jamboard for each round of questions.

World Café prompts to explore application of patient-centered outcomes:

- Round 1: As a patient, how would you like to be asked questions about how your care is going for you? What opportunities do we have to collect this information in routine health care?
- Round 2: How can we study the barriers and benefits in digital care so we can improve care?
- Round 3: How would you tell the story of what patient-centered digital care means?

Synthesis

After the meeting, the project team reviewed the Jamboard statements and transcripts from the meeting and summarized the key take-aways using qualitative content analysis. The below summary was shared with meeting attendees with an invitation to share feedback to ensure the summary reflects what was expressed.

Summary of learnings

Digital tools can make some visits easier and can promote overall patient-centeredness of care, but we know that there are barriers to using digital care and that digital tools also can create barriers to quality of care for some people. Investigating the patient-centeredness of digital tools is important for both future health care design and patient-centered health care research. Participants in our convenings emphasized patient-reported outcomes be used to improve individual patients' health care experience rather than only generally or globally for the system and offered suggestions about how to collect patient-reported data. We also heard what patient-centered digital care means to a broad group of stakeholders, which informs recommendations for outcome measurement.

Patient-centered data collection

Participants said they appreciated being asked about how their care is going for them, which affirms that someone is paying attention. However, an overarching theme in the discussions was that when people answer questions about their care, they want to know where and how responses will be used –

whether for general process improvement or to improve their experience. Many people prefer answering questions that will improve their personal care. Communicating clearly about the purpose of data collection is important and may improve responsiveness.

Participants were accustomed to answering surveys about their encounter, care, and providers after visits. Some prefer being asked questions directly by their care team during visits, but many described discomfort with answering direct questions in real time and would prefer to answer questions in writing in before or after an encounter, if at all. Texting, MyChart, and some digital monitoring devices offer additional opportunities for data collection and make it possible for people to communicate more continuously with their care team. For those tools to work, there needs to be a prior relationship established so that there is a sense of trust, caring, and shared goals. Many endorsed a preference against providing feedback via phone conversation. Participants expressed a preference for specific questions, even simple or singular ones, centered on personal goals that reflect prior knowledge about the patient. Participants generally endorsed a preference against generic, repetitive, or scaled questions (like a 1-5 rating).

Patients should be asked how they would like to answer questions about their care. It is likely that multiple modes are needed to collect patient-reported and patient-centered outcomes. Whatever questions are asked, it is important they are timely, like a pop-up at the end of a virtual visit or an AI chat form. There are many visual and design elements that could be used to make questions more effective. Questions about care should be simple and convey humanity and connection. Most importantly, the health care system needs link patient-reported data back into the electronic health record and after-visit summaries so the information can be applied to future individual care.

Future research opportunities on patient-centered digital care

It is generally challenging to study barriers to care, digital or otherwise, because barriers may prevent people from interacting with healthcare and research altogether. We know that technology, income, language, and disabilities may impede digital care, and we also know that digital care holds potential to help overcome or avoid challenges to in-person care. Participants also expressed how digital care can create new hurdles to quality of care, such as limiting involvement of family, friends, PCAs, or other caregivers in patients' health care.

Participants underlined that there are already extensive data available both in the electronic health record and in existing research studies that could inform questions about barriers to care and how digital care tools impact patient outcomes.

Specific recommendations or opportunities for future research included:

- Using surveys sparingly and framing survey questions at a granular level about a specific visit or encounter, rather than generally
- Ensuring focus groups have broad representation from patients and community members to elicit general concerns
- Conducting usability testing for website and digital tools to identify gaps around specific tools

- Focus health care and research questions on ways to overcome barriers to patient-centered care (for example, involving nurses, community health workers, and/or interpreters to teach patients to use digital tools)
- Compiling existing research and other EHR-based data to answer patient-centered research questions now, without the need for additional data collection.

The “story” of patient-centered digital health care

Providing opportunities for patients to tell their stories can give them a sense of hope. Stories can convey what someone is going through, how they approach things, how they’ve overcome a challenge, and what their results are. They can help health care systems understand successes and failures in delivering patient-centered care. Patient-centered care means that patients are at the center of their own care, and in the digital care space that means their preferences and desired outcomes drive the type of care that they receive, and it is delivered equitably.

At their best, digital tools can optimize care by facilitating monitoring, direct encounters, and two-way communication between patients and care teams. However, there are diverse definitions of accessibility and patient-centeredness. Patients should receive the same quality of care whether they use digital or not. It is imperative that individuals have choices about how and when to engage with digital or in-person care. Care teams and system also must support patients in making well informed decisions and by following patient preferences.

Recommendations and Toolkit

Measuring patient-centered outcomes for digital chronic disease care

A focus on patient-centered outcome measurement of digital tools is to some extent a focus on tools' use as a medium for healthcare delivery. Patients are highly interested in the ability of digital tools to improve their condition, relevant measures of their health status, and their understanding of their health and condition. However, patients are also interested in measuring how digital tools can help people access health care as well as barriers to using digital tools.

We recommend the following outcomes be measured in health care and future research that applies digital strategies to manage chronic conditions. These outcomes may not apply to every condition, study population, or individual patient. However, they emerged as strong themes in this engagement effort and may help to assess the patient-centeredness of digital strategies in chronic disease care:

- Accessibility (ease of access to care you need, when and how you need it, and related barriers)
- Quality of care (appropriate and timely care, diagnosis, and treatment)
- Convenience (or burden)
- Cost (time, money, and trade-offs)
- Quality of relationships with care team (impact of remote communication on relationships)
- Perceptions of bias (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

We recommend evaluating these outcomes with special attention to equity among these subgroups of patients: LEP, those less comfortable with technology, rural, and intellectually or physically disabled.

The following section summarizes the concerns and desires expressed by patients and participants throughout this project as they relate to each recommended outcome and provides examples of how future CER studies can apply these measures to assess patient-centeredness of digital interventions for chronic disease.

Accessibility

Problems	Opportunities	CER applications
<p>Poorly implemented digital strategies can create new accessibility barriers.</p> <p>Disabled patients, patients with limited English proficiency, those with low tech literacy or access to technology, and rural patients are especially at risk of experiencing accessibility barriers when technology is not designed to accommodate their needs and/or is presented as the only option. This can create a risk of compounding health care disparities experienced by these groups of patients.</p>	<p>Digital strategies should improve the overall accessibility of health care. Digital care strategies should <u>not</u> become the only option care.</p> <p>Patients should be able to choose their preferred mode of care and individual accessibility needs should be accommodated.</p> <p>Ideally, digital systems should also store information about individual accessibility needs so they can be known and applied in future care.</p>	<p>Studies should measure self-reported accessibility of interventions. Literature suggests this should include³⁶:</p> <ul style="list-style-type: none"> - Non-discrimination - Physical accessibility - Economic accessibility (affordability) - Information accessibility <p>Interventions should be designed for accessibility. A targeted universalism framework and participatory design may support more accessible intervention design.³⁷</p> <p>Consider how adaptive trial designs could support accessibility of interventions and reduce the potential for inadvertent harm. Adaptive trial designs can help to identify populations most likely to benefit from a treatment while avoiding exposing patients to less-effective interventions.³⁸</p>

Quality of care

Problems	Opportunities	CER applications
Telehealth is not appropriate for every condition or health concern. Some patients have experienced misdiagnosis and/or delayed care using telehealth with real and negative consequences.	<p>Digital care strategies should provide <u>at least</u> equal quality of care to comparable in-person visits. Patients expect timely and appropriate appointments, clinical examinations, diagnosis, and treatment regardless of mode.</p> <p>Ideally, digital strategies such as remote monitoring also should facilitate high-quality care by generating relevant and useful clinical data.</p>	<p>Studies should compare patient-reported quality of care measures,^{39,40} like those in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician and Group survey.⁴¹</p> <p>Additional measures could include:</p> <ul style="list-style-type: none"> - Self-reported misdiagnoses - Self-reported treatment delays - Self-reported use of device-generated data

Convenience or burden

Problems	Opportunities	CER applications
Digital care is meant to improve convenience. However, some people may not want to use a digital strategy for care, or digital strategies may create inadvertent redundancy, confusion, or other barriers that reduce convenience.	Digital care should make health care more convenient and decrease the overall burden of managing a chronic condition.	<p>Studies should measure the overall treatment burden^{32,42,43} of interventions to directly compare the relative burden or ease of care.</p> <p>The Treatment Burden Questionnaire (TBQ)^{44,45} can be used as originally written or adapted to a specific condition or intervention mode.</p>

Cost

Problems	Opportunities	CER applications
<p>Time: Digital strategies may save time compared to attending in-person visits. But they may also increase time spent on care if additional in-person care is needed to address the same issues.</p> <p>Out-of-pocket costs: Some remote devices cost less than analog methods overall (such as continuous glucose monitors vs. fingerstick monitors), but insurance coverage and out-of-pocket costs may create barriers to equity when it comes to use of remote devices.</p>	<p>Time: Saving time is desirable, but not if it jeopardizes the overall quality of care or other parts of the health care experience.</p> <p>Out-of-pocket costs: Costs of engaging in digital strategies like remote monitoring should be affordable and equitable to patients.</p> <p>Out-of-pocket costs should not incentivize digital care over health care, or vice versa, at the expense of appropriate treatment</p>	<p>Studies should consider the self-reported time impact of interventions as a patient-centered cost measure.</p> <p>This could include self-reported time away from work or other priorities, time spent engaging in health care, or perceptions of how care affects time in other areas of life.</p> <p>Studies may also consider directly comparing the out-of-pocket costs for patients associated with interventions.</p>

Quality of relationship with care team

Problems	Opportunities	CER applications
<p>Some patients feel telehealth and other remote strategies may harm their relationship with their care team, which they value highly.</p>	<p>Many patients desire trusting, personal relationships with their care teams. Others consider their relationships to be situational. Overall, patients would like to engage in a mode of care that fosters their preferred care team relationships.</p>	<p>Studies should measure the impact of interventions on self-reported quality of relationships with care teams.</p> <p>There are many established questionnaires to select from, depending on appropriateness to the study.⁴⁶</p>

Perceptions or experiences of bias

Problems	Opportunities	CER applications
<p>Some patients are especially subject to biased treatment in health care, including people of color, LGBTQ+ patients, and people in larger bodies.</p> <p>Telehealth may provide some protection from these biases by reducing the number of staff encountered during a visit (i.e., reception, nurses, lab, etc.), and by focusing the conversation.</p>	<p>Patients want to leave encounters feeling heard and not judged. Digital care may promote this experience for some.</p> <p>It is important that strategies to reduce biases in health care do not jeopardize quality of care. For instance, patients subject to biases should not have to rely on telehealth if it is not appropriate for their condition or care needs.</p>	<p>Studies may consider measuring self-reported perceptions or experiences of health care bias in interventions.⁴⁷</p> <p>Studies may consider measuring experiences of racial discrimination or unfair treatment,⁴⁸ measures of weight bias,⁴⁹ and patient perceptions of stigma related to disability, mental health, sexuality and gender.^{50,51}</p>

Health and eHealth literacy

Problems	Opportunities	CER applications
<p>Chronic conditions can be challenging to manage and can cause distress.</p> <p>Not everyone is comfortable using digital tools to improve their health and they may require support.</p>	<p>Many patients want to feel empowered by their health care experiences.</p> <p>Strategies that build health literacy are highly desirable to many. Remote devices and internet portals for information can promote learning about one's condition and build effective self-management skills through lifestyle strategies and/or medications. But patients need to know how to use the tools.</p>	<p>Studies may consider measuring self-reported changes in health literacy or understanding of one's condition in interventions as a mediator of outcome improvement using classic health literacy measures.⁵²</p> <p>Researchers may also consider including measures of eHealth or digital health literacy.^{53,54}</p>

Shared decision-making

Problems	Opportunities	CER applications
Patients want to choose their mode of treatment. However, it may be difficult for patients to discern the most appropriate course of action alone. Support is needed to make informed choices for one’s circumstances.	Care teams should partner with patients to help them make the most informed choices about the role of digital strategies in their care based on their condition, circumstances, health goals, and personal preferences.	Studies should measure self-reported occurrence of shared decision making ⁵⁵ , specifically as it applies to making choices about whether to use telehealth, remote monitoring, or other digital strategies in the course of care.

Disease outcomes

Problems	Opportunities	CER applications
Numbers alone, like lab values or vital measurements, do not always resonate with patients. However, most still desire positive outcomes for their condition so they can continue living life.	Digital care strategies should help patients achieve their desired outcomes for their condition. That could mean improvement, control of one’s condition, symptom management, or maintenance.	Studies should continue to measure biomedical outcomes of chronic conditions. It is valuable to identify patient-reported biomedical outcomes when designing a study through consultation with patients affected by the condition. ⁵⁶

Equity measures

Problems	Opportunities	CER applications
Patients at risk of being marginalized in health care are at risk of further marginalization with the introduction of technologies due in part to the digital divide. This may include patients with low tech literacy or limited access to technology, those with limited English proficiency, disabled patients, and those in rural settings.	Digital strategies should promote patient-centeredness of care, and not worsen disparities in health care. Special attention should be provided to patients who need support navigating technology, or they should be directed to high quality in-person care.	Studies should evaluate the impact of digital interventions on outcomes for patient subgroups who may be at risk of worsening outcomes and/or measure the ability for interventions to close equity gaps. ⁵⁷⁻⁵⁹

Roadmap for measure implementation

How to measure

Methods for measuring patient-centered outcomes for digital tools are already commonly in place, such as systematically collected pre- and post-visit questionnaires, text-message visit check-in and post-visit ratings, and secure messaging through patient portals. Each of these means could be leveraged to measure patient-centered outcomes to provide better individual care, promote care improvement across a health system, and answer important research questions.

Patient data collection

Patients are interested in being asked about their care and experiences with digital tools, but only if that information is used to improve their personal care. Patient-centered data collection includes minimizing the burden of providing feedback and honoring, tracking, and adhering to patient preferences about how digital tools are involved in their care, how an individual prefers to be contacted and asked for information, and what outcomes patients want their care teams to prioritize.

Bringing patients and health systems together

We brought patients and agents from health care systems together to discuss digital tools and measure their patient-centeredness. Participants in our convenings said they appreciated working though digital care and patient-centered outcomes together. Many suggested that such deliberate collaboration could be a model in the development of digital care tools and related outcome measures. To ensure that digital efforts remain patient-centered, it is important that health care systems place patients rather than systems at the center of their efforts.

Working with funders and reimbursement

Opportunities for research funding and parameters around reimbursement drive change in healthcare measurement. The Centers for Medicare Services is currently supporting pilot measures around patient-centered outcomes for common orthopedic surgeries. Given the limited avenues for support, it is important that each avenue that arises in the development of digital tools and patient-centered outcomes be capitalized upon to optimally orient their use.

Connecting efforts across health systems

Many different branches of health care are working on digital tools. Health insurers and health systems that provide care develop and maintain interactive web-based technologies for seeking, scheduling, facilitating, and following up on episodes of care. Those systems are also key to the integration of remote-monitoring tools. Given this diversity of activities, many agents and teams work on digital tools across healthcare systems, often in divided and uncoordinated ways.

The design process: embracing targeted universalism

The design of digital products in healthcare, as throughout the software and technology sector, is often aimed toward the production of a **minimum viable product** — a product that works to a minimum standard, which can be modified in the future through user testing to accommodate the diverse needs of patients. Federal accessibility standards provided through the Americans with Disabilities Act (ADA)

provides minimum requirements for accessibility. In contrast, a user-centered design approach based on **targeted universalism** would support the development of digital tools that enable patients to universally engage with them beneficially from the start.^{7,60} Targeted universalism seeks the development of a wide range of implementation strategies, tailored to promote the desired outcome for all populations, given diverse barriers. The goal of this strategy is to build a product that will work universally by targeting the design to those with the greatest impediments to use.

Conclusions

Since the onset of COVID-19, healthcare has experienced an unprecedented, rapid uptake of technology to facilitate many aspects of health care and management. While digital tools have the potential to improve the overall patient-centeredness of health care by helping to navigate and overcome barriers and bring health care into patients' daily lives, critical questions remain about the impact of telehealth and other technological tools on broad outcomes like utilization and access – particularly with respect to equity across socioeconomic and demographic subgroups.^{61,62}

Because of the prolific nature of digital tools in the diagnosis, treatment, and management of chronic conditions, it is imperative to consider and systematically investigate the ways technology influences patients' experience of their care.

Many of the patient-centered outcomes identified in this project represent true outcomes, including the overall quality and experience of care. Others represent process measures, or ways that digital tools may mediate the relationship between care for a condition and the outcome. Both are important to consider when investigating the comparative utility, experience, and effectiveness of different interventions for chronic conditions.

We propose that future CER studies involving a digital component in their interventions should aim to articulate and assess relevant patient-centered outcomes. Because the use of technology varies widely across conditions and interventions, researchers should partner with patients with chronic conditions, particularly from priority communities, to identify the most critical patient-centered outcomes and the most imperative equity issues to assess for a given situation. To the degree possible, CER researchers should engage patient and health system partners to support the design and implementation of equitable, patient-centered digital interventions and to garner useful evidence to support this goal.

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Appendices

Appendix A: Formative engagement contributors

Patients and Community groups	Topics/perspectives
11 HealthPartners Institute Community Advisory Council for Research and Evaluation members	Identifying communities most impacted by digital inequities
2 GlucoCare study patient investigators (PCORI-funded study on continuous glucose monitoring)	Diabetes care, continuous glucose monitors (CGM)
3 Hyperlink study patient advisors (PCORI-funded study on remote blood pressure monitoring)	Heart disease, remote BP monitoring, cardiovascular care
5 Special Olympics Health Input Council members	Disability and chronic disease
10 Twin Cities Fat Community Facebook group members	Weight-based health care stigma
8 Hue-MAN Partnership members	African American health, diabetes
4 Trans and non-binary community members	Trans health, chronic care disability
4 Amery Hospital Patient/Family Advisory Council members	Rural health care
5 Community Health Workers, Minnesota CHW Alliance	Economic, language barriers
30 Parkinson's disease patients and caregivers (survey)	Parkinson's care
239 MyVoice patient/member opinion panel members (survey)	Digital chronic disease care experiences, general
Health care colleagues	Topics/perspectives
2 Patient education leaders	Digital education, modernization
2 Diabetes education leaders	Diabetes and CGM education
1 Parkinson's care leader	Parkinson's disease, telehealth
1 Community engagement leader	Community Health Needs Assessments (CHNAs) from 8 regional hospitals
12 interpreters, representing >10 languages including ASL	Language barriers and inequities
2 Patient Reported Outcomes Measurement (PROMs) Steering Committee leaders	Technical and operational priorities around PRO measurement
1 "Virtual first" health plan initiative staff	Access to primary care
Researchers	Topics/perspectives
5 International Diabetes Center researchers	Diabetes, CGM
4 HealthPartners Institute researchers	Cardiovascular health, hypertension, clinical decision support, patient-reported outcomes
2 State Telehealth Study, MN Department of Health (MDH) and MN Department of Human Services (MN DHS)	Telehealth outcomes and equity research

Appendix B: Patient surveys and results

Identifying Patient-Centered Outcomes for Chronic Disease Management using Digital Healthcare Interventions: Patient engagement survey

Purpose: This is a qualitative, non-representative opinion survey designed to help elicit patient experiences with digital chronic disease care in order to identify key patient-centered outcomes.

Respondents: We will use this survey to gather input from a wide variety of respondent groups, including but not limited to MyVoice panelists and patient groups with specific chronic illnesses.

Mode: The survey will be conducted via MyVoice (for MyVoice panelists) and via Microsoft Forms for other groups.

Recruitment: We will work with organizational and community partners to identify respondents and share this survey. Respondents will be from a convenience sample and thus may not be representative of the range of patient perspectives. Note: we will need to figure out how to control access to the survey and incentive and cap the number of responses available. (Make new iteration for each respondent group).

Questions:

1. Do you have a **chronic health condition**? *This includes any health condition for which you need ongoing care (for example: diabetes, high blood pressure, heart or lung disease, neurologic condition, etc.).* (screener question) [Mark one]

<input type="checkbox"/>	Yes (proceed to question 2)
<input type="checkbox"/>	No (do not proceed) – <i>Thank you for your interest! Right now, we are looking for feedback from people with chronic conditions.</i>

2. Which digital care tools have you used in your care for your **chronic health condition**? [Mark all, 'None of the above' is exclusive]

<input type="checkbox"/>	Telehealth (phone or video visits)
<input type="checkbox"/>	Remote monitoring (using or wearing a device that sends health information to your care team) ○ Please specify: _____
<input type="checkbox"/>	Other (please specify): _____
<input type="checkbox"/>	None of the above - <i>Thank you for your time! Right now, we are looking for feedback from people who have used digital care tools.</i>

3. Rate your agreement with the following statements regarding why you like using **digital care tools** for your **chronic health condition**? – what are the “pros”? [Mark one for each]

	Strongly disagree				Strongly agree
	1	2	3	4	5
Helps me better understand my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduces unnecessary in-person office visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Convenience of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ease of using technology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Better control of my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Better relationship with my care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to get accurate information about my health to my care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential for lower costs (like fewer co-pays)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Something we missed? What are the other reasons you like using **digital care tools** for your **chronic health condition**? [Optional]

5. Rate your agreement with the following statements regarding hesitations you might have about using **digital care tools** for your **chronic health condition**? – what are the “cons”? [Mark one for each]

	Strongly disagree				Strongly agree
	1	2	3	4	5
Not appropriate for my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Could possibly worsen my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Too much information that makes me worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concern about accuracy of information provided to my health care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Less personal connection with my care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not having enough time with my provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Losing in-person interactions and hands-on exams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Privacy and security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems with using technology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing or vision accessibility of digital tools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language accessibility of digital tools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential higher costs (like co-pays for additional visits or costs of devices)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Did we miss something? Share any other hesitations you have about using **digital care tools** for your **chronic health condition**. [Optional]

7. How interested are you in each of the following outcomes related to using **digital care tools** for your **chronic health condition**? [Mark one for each]

	Not at all interested				Extremely interested
	1	2	3	4	5
Reducing costs of my care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reducing the time I spend on my care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Simplifying the things I need to do for my care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reducing the stress I experience related to my care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improving communication with my care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improving the overall quality of my care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improving my overall quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Something we missed? Share any other outcomes you're interested in related to using **digital care tools** for your **chronic health condition**. [Optional]

9. If you had to select one outcome from the list below that you are most interested in related to using **digital care tools** for your **chronic health condition**, which would you choose? [Mark one]

<input type="checkbox"/>	Reducing costs of my care
<input type="checkbox"/>	Reducing the time I spend on my care
<input type="checkbox"/>	Simplifying the things I need to do for my care
<input type="checkbox"/>	Reducing the stress I experience related to my care
<input type="checkbox"/>	Improving communication with my care team
<input type="checkbox"/>	Improving the overall quality of my care
<input type="checkbox"/>	Improving my overall quality of life
<input type="checkbox"/>	None of the above

10. Is there anything else you'd like to share about your experience using **digital care tools** for your **chronic health condition**? [Optional]

Results: MyVoice Opinion Panel

Respondents: This qualitative survey was sent in July 2023 to the entire myVoice panel (2,652 panelists) seeking those with chronic health conditions. N=239 (9%) of panelists completed the survey and indicated they use digital tools for a chronic condition. Respondents were 73% female, 93% white, and an average of 60-64 years old.

Digital tools reported by respondents included:

- Telehealth (phone or video visits)
- Remote monitors (heart monitor, blood pressure monitor, glucose monitor, insulin pump, pacemaker, CPAP machine, spirometer, or fitness app/tracker)
- Other (emails, apps, MyChart, Zoom calls)

Digital care “pros”

Respondents rated the following reasons to like using digital tools for chronic conditions (responses = agree or strongly agree)

- 78% Convenience
- 73% Ease of using technology
- 71% Reduce in-person office visits
- 63% Ability to get accurate information about my health to my care team
- 57% Better control of my condition
- 53% Potential for lower costs (like fewer copays)
- 48% Better relationship with my care team
- 45% Helps me better understand my condition

Other reasons provided included quick responses and immediate feedback, time savings, focuses time with provider, longer periods of monitoring, real-time feedback on health, and lowered anxiety with remote monitoring.

Digital care “cons”

Respondents rated the following reasons to hesitate using digital tools for chronic conditions (responses = agree or strongly agree)

- 39% Losing in-person interactions and hands-on exams
- 31% Less personal connection with my care team
- 21% Not having enough time with my provider
- 17% Not appropriate for my condition
- 17% Potential higher costs (like co-pays for additional visits or costs of devices)
- 15% Problems with using technology
- 12% Concern about accuracy of information provided to my health care team
- <10%: all others

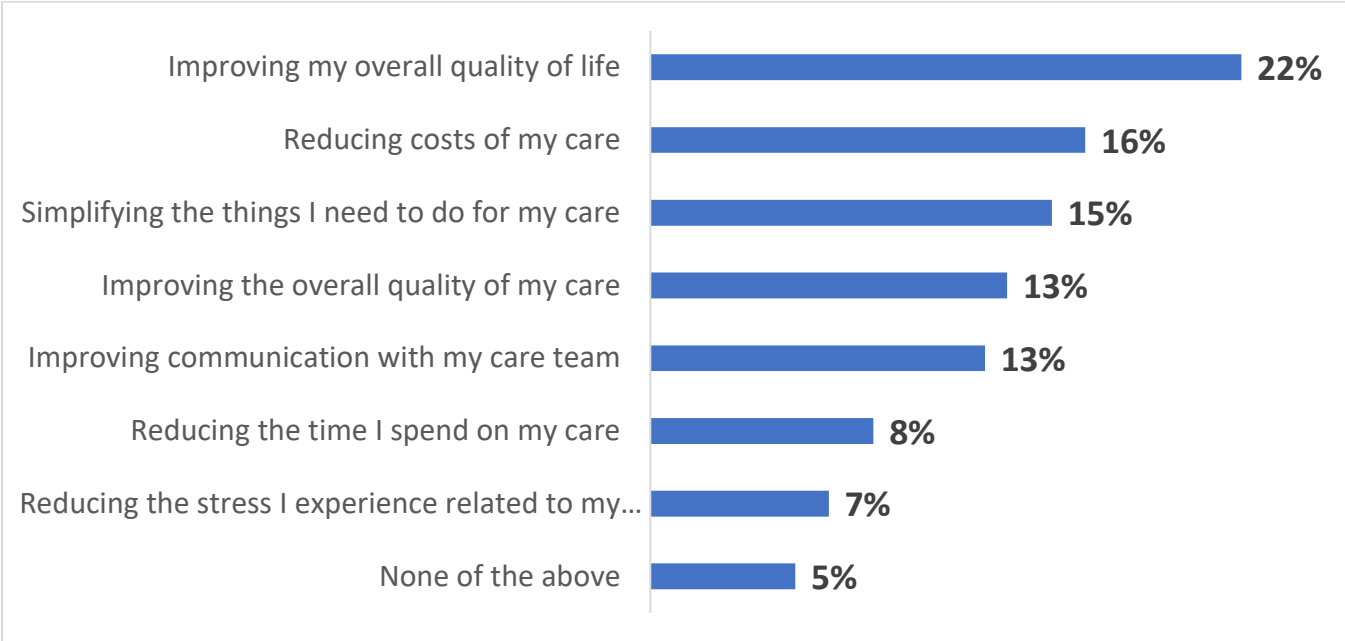
Other reasons for hesitation provided including technology difficulties, preference for in-person visits and hands-on exams, no cost savings over in-person, and need for redundant, in-person care.

Outcomes of interest

Respondents rated the following outcomes as important when considering using digital tools for chronic health conditions (responses = agree or strongly agree)

- 91% Improving my overall quality of life
- 86% Improving the overall quality of my care
- 83% Improving communication with my care team
- 80% Simplifying the things I need to do for my care
- 79% Reducing costs of my care
- 74% Reducing the stress I experience related to my care
- 69% Reducing the time I spend on my care

When asked to select one most important outcome, respondents most often selected quality of life, cost, and simplifying care.



In open-ended comments, some panelists stressed the importance of using in-person visits to manage their health conditions.

Results: Parkinson's disease patients and caregivers

Respondents: This qualitative survey was sent in August 2023 to a network of Parkinson's disease patients and caregivers through the Struther's Parkinson's Center at Park Nicollet in Saint Louis Park, MN. The questions were answered anonymously through an online poll. N=30 respondents completed the survey (26 Parkinson's patients and 4 caregivers). We did not collect further demographic data from this group.

Digital tools reported by respondents included:

- Telehealth (phone or video visits)
- Emails with provider
- Remote monitors

Digital care "pros"

Respondents rated the following reasons to like using digital tools for chronic conditions (responses = agree or strongly agree)

- 70% Convenience
- 67% Reduce in-person office visits
- 53% Ability to get accurate information about my health to my care team
- 50% Better control of my condition
- 50% Potential for lower costs (like fewer copays)
- 43% Ease of using technology
- 33% Helps me better understand my condition
- 30% Better relationship with my care team

Other reasons provided included time and cost savings, transferring information, avoiding unnecessary COVID exposure, mobility access, lowered stress and complication.

Digital care "cons"

Respondents rated the following reasons to hesitate using digital tools for chronic conditions (responses = agree or strongly agree)

- 70% Less personal connection with my care team
- 67% Losing in-person interactions and hands-on exams
- 46% Not having enough time with my provider
- 26% Problems with using technology
- 20% Potential higher costs (like co-pays for additional visits or costs of devices)
- 20% Privacy and security
- 17% Not appropriate for my condition
- <13% all others

Other reasons for hesitation provided included redundancy with in-person care, problems with missing symptoms, and insufficiency for all of the things needed to care for Parkinson’s disease.

Outcomes of interest

Respondents rated the following outcomes as important when considering using digital tools for chronic health conditions (responses = agree or strongly agree)

- 73% Improving the overall quality of my care
- 70% Improving my overall quality of life
- 70% Improving communication with my care team
- 63% Simplifying the things I need to do for my care
- 60% Reducing costs of my care
- 56% Reducing the time I spend on my care
- 53% Reducing the stress I experience related to my care

When asked to select one most important outcome, respondents most often selected quality of life, cost, and simplifying care.



In open-ended comments, respondents stressed the importance of using in-person visits to manage their condition.

Appendix C: Pre-meeting materials for virtual convenings

September 13th, 2023

Welcome to the upcoming roundtable series on Patient-Centered Digital Care for Chronic Conditions on September 19th and October 3rd. We are so grateful for your participation in these important conversations.

These roundtables will bring together patients, community members, health care professionals, and researchers to explore what patient-centered care looks like in a digital era and what outcomes we should measure to assess patient-centeredness of digital health care.

Enclosed are some background materials to tell you about what we are doing and what we have learned about this topic so far. We invite you to review these ahead of our first meeting. They include:

- A meeting agenda and instructions for participating
- A brief summary of our engagement on this topic to date
- A summary of an article from PCORI on patient-centered telehealth
- A simple creative exercise that will help you explore your own experiences in health care prior to our gathering
- A pen and notepad that you can use before, during, or after our meetings to keep your own notes on patient-centered digital care.

If you have any questions about the roundtables, please contact Anna Bergdall at anna.r.bergdall@healthpartners.com.

We are really looking forward to this unique gathering!

Your partners,

Bjorn Westgard, MD MA | Research Investigator, Co-Chair, HealthPartners Institute Community Advisory Council for Research and Evaluation

Antonia Apolinário-Wilcoxon, EdD | Co-Chair, HealthPartners Institute Community Advisory Council for Research and Evaluation

Anna Bergdall, MPH | Principal Research Project Manager

Natalie Brewster | Research Project Coordinator

Our mission is to improve health and well-being in partnership with our members, patients and community.

Identifying Patient-Centered Outcomes for Digital Care for Chronic Conditions: Virtual Roundtable Series

Please join the meetings **by computer** using the Microsoft Teams link sent to your email. You do not need to install the Teams app to join.

If you have any problems joining the meeting, contact: [email redacted]

Roundtable 1

September 19th, 5-6:30pm

Topic: What is patient-centered digital care? Understanding the patient experience

Roundtable 2

October 3rd, 5-6:30pm

Topic: How can we assess patient-centeredness of digital care in health care and research?



We will be holding a **World Café** – come prepared to share your personal experiences and opinions and learn from each other!

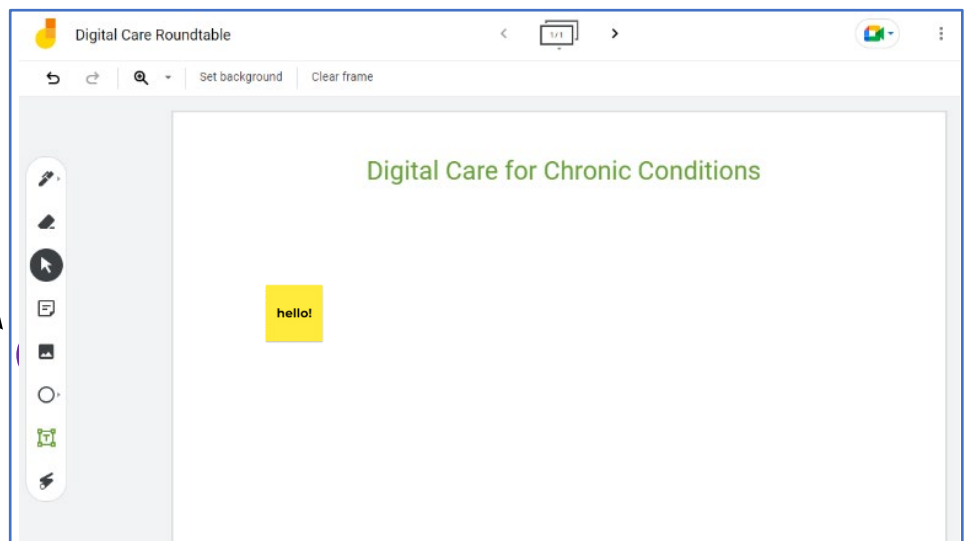
Jamboard instructions

We'll share a link in the meeting chat to the Jamboard

Click here to create a post-it

And it will appear on the board! (like the yellow example)

Sign out of your Google account if you want to remain anonymous



Identifying Patient-Centered Outcomes for Digital Care for Chronic Conditions:

Patient-Centered Digital Care Engagement Report

Contents

Background and Objectives	46
Formative engagement, January-August 2023	47
Contributors, January-August 2023	48
Preliminary Themes: Patient and Community Perspectives	49
Preliminary Themes: Research and Health Care Perspectives	50



Image (above): an older person with light skin is tapping on a cell phone next to a window. They are wearing a circular object on their right arm, which is a continuous glucose monitor (CGM). CGMs are currently being studied at the International Diabetes Center.

Image (right): a black & white handout describes how to take your blood pressure (BP) at home. It includes a picture of a darker skinned person sitting in a doctor’s office demonstrating proper form: right arm resting on a table, back supported, and feet flat on the ground. Around their arm is a BP cuff. This was used in a study at HealthPartners of remote BP monitoring with phone-based care.

How to Take Your Blood Pressure at Home

Before you start

- Avoid exercise, caffeine and tobacco for 30 minutes.
- Remove tight-fitting or bulky clothing from your upper arm.

Setting up (see picture)

1. Sit in a chair with your back supported.
2. Uncross your legs and keep your feet flat on the floor.
3. Wrap the blood pressure cuff around your upper arm according to equipment instructions. Make sure the cuff is snug enough to stay in place, but loose enough at the bottom that you can insert 2 fingers stacked on top of each other between your arm and the cuff. Place your arm on a table, desk or other solid surface so the cuff is at the level of your upper chest or heart.
4. Rest quietly for 5 minutes without talking. You may read or watch TV.

Taking your blood pressure

1. Press "start" or "go" on your blood pressure monitor. Keep your arm on the table, desk or other solid surface so the cuff is at the level of your upper chest or heart.
2. Keep your arm relaxed and do not move around or talk.
3. When the monitor has finished running the check, the cuff will deflate and the monitor will show you your numbers.
4. If you are keeping a log, record your numbers along with the date and time.
5. Keep the cuff on your arm and wait 1 minute in the same position.
6. Repeat the measurement 1 more time staying in the proper body position.

5

This project is funded by the Patient-Centered Outcomes Research Institute (PCORI), a non-profit, non-governmental organization that funds patient-centered health research and engagement projects across the US. Learn more about PCORI engagement awards at www.pcori.org

Background and Objectives

This one-year project funded by the Patient-Centered Outcomes Research Institute (PCORI) aims to lay the groundwork for future measurement of patient-centered outcomes related to digital and virtual tools for chronic disease care and management.

We are bringing together multiple perspectives to identify the following:

1. Patient-centered outcomes that should be measured to assess patient-centeredness of digital care strategies (e.g., access, experience, satisfaction, lifestyle/functioning, cost, and treatment burden).
2. Different methods for measuring these outcomes, including by hand, via the electronic health record (EHR), or other digital-based methods.
3. A potential roadmap for using these measures in health care and future research.

What is digital care?

For this project, digital care refers to any way in which technology or devices are involved in care for chronic conditions. This could include telehealth (phone/video), MyChart, remote monitors for specific conditions, or wearables/apps that provide useful health information.

What is patient-centered care?

This model of care places the patient, rather than the care team, at the “center” of their care. This means protecting patients’ access to choices, creating partnership with their care team and shared decision-making, and honoring consent. It also means considering patients’ lived experiences and creating strategies that work in people’s complex lives.

What we’ve been up to

So far, we have conducted focus groups, interviews, and brief surveys to engage with patients, community members from diverse backgrounds, researchers, and key individuals in the HealthPartners system. This has helped us understand some perspectives on this topic. We are sharing a summary of that information with you here to help prepare for our roundtables.

Where are we going?

- **You are invited to attend the Patient-Centered Digital Care Roundtables on September 19th and October 3rd.** Here, we will explore these concepts deeper together.
- We will summarize what we learn in the roundtables, and you will have an opportunity to comment on this summary.
- We will then create a toolkit with recommendations and a story-based video that communicate our conclusions and the importance of patient-centered outcome measurement for digital care. We hope that researchers and other health care organizations will use our recommendations in the future.

Formative engagement, January-August 2023

Between January-August 2023, we connected with a wide variety of people to understand various perspectives on patient-centered digital care, including **patients and community groups, researchers, and HealthPartners colleagues**. A full list of contributors is on the next page.

We engaged with **patients and community groups** to learn how digital care is used to manage chronic conditions like diabetes, heart conditions, and Parkinson's disease. We also spoke with groups about how digital care can resolve – or sometimes create – inequities, especially around physical and intellectual disability, larger body size, race, gender, low-English proficiency, and rurality. We were also able to field a short survey about digital tools and virtual care to a large panel of HealthPartners' members and patients. Our Community Advisory Council helped to ensure we identified the right people for these conversations.

What we asked patients and community groups:

- What digital tools have you used in your health care?
- What are the pros and cons of digital care tools?
- What outcomes matter the most to you in your health care?
- What does patient-centered care mean to you?

We engaged with **researchers** focused on diabetes and continuous glucose monitors, remote blood pressure monitoring, and clinical decision support tools integrated in the electronic health record. We also spoke with researchers at the Minnesota Department of Health (MDH) who are conducting research about telehealth and equity issues in order to advise the state on important policy decisions.

What we asked researchers:

- What feedback have you heard about patient-centered digital care?
- What have you learned in your research about patient-centeredness?
- What data are out there that we can learn from?

Within **HealthPartners**, we engaged colleagues in patient education, diabetes education, interpreter services, patient-reported outcome measurement, community engagement, and virtual initiatives in the health plan.

What we asked within HealthPartners:

- What are current priorities around digital care?
- What are known barriers for patients?
- How are patient-reported outcomes being measured?

Contributors, January-August 2023

Here are the specific groups/people we spoke with and a brief summary of their areas of special knowledge or lived experience.

Patients and Community groups	
GlucoCare (continuous glucose monitor) study patient investigators	Diabetes, continuous glucose monitors (CGM)
Hyperlink study patient advisors	Heart disease, remote monitoring
Special Olympics Health Input Council members	Disability and chronic disease
Twin Cities Fat Community Facebook group members	Weight-based health care stigma
Hue-MAN Partnership members	African American health, diabetes
Trans and non-binary community members	Trans health, chronic care disability
Community Health Workers, MN CHW Alliance members	Economic and language barriers
Amery Hospital Patient/Family Advisory Council members	Rural health care
Parkinson's disease patients and caregivers (survey)	Parkinson's care
MyVoice (HealthPartners patient/member survey panel)	Chronic disease care in general
HealthPartners Institute Community Advisory Council for Research and Evaluation members	Identifying communities most impacted by digital inequities

Researchers	
International Diabetes Center researchers	Diabetes, CGM
HealthPartners Institute researchers	Cardiovascular health, hypertension, cost, and patient-reported outcomes
Center for Chronic Care Innovation researchers	Clinical decision support for chronic conditions, cancer, and others
State Telehealth Study, MN Department of Health	Telehealth outcomes and equity

HealthPartners colleagues	
Patient education, leads	Digital education, modernization
Diabetes education, lead	Diabetes, CGM
Community engagement, lead	Community Health Needs Assessments (CHNAs)
Interpreter services (including ASL), lead and staff	Language barriers and inequities
Patient Reported Outcomes Measurement (PROMs) Steering Committee, operational leaders	Technical and operational priorities around PRO measurement
"Virtual first" health plan initiative, staff	Access to primary care

Preliminary Themes: Patient and Community Perspectives

Most patients we spoke with had chronic conditions, but not all. Those who did not were engaging to inform us about digital equity issues. **Still, all patient and community groups advised on ways digital care intersects with both chronic care and health inequities.** Here are some themes we heard through our discussions and surveys.

Patients reported using

MyChart
Telehealth (phone, video)
Remote monitors (e.g., glucose, blood pressure)
At-home diagnostic tools
Wearables and apps

Chronic conditions

Diabetes, Hypertension,
Cardiovascular disease, Chronic kidney disease, Autoimmune disorders, Sleep apnea, Depression/anxiety, Parkinson's disease, Other conditions

Patients strongly value

Choices in their health care
Quality and appropriateness of care
Relationships with care team
Positive health outcomes

Digital care “pros”

- Telehealth can reduce unnecessary in-person visits
- MyChart aides in transparency and ease of communication with care team
- Device data can help you learn about your condition and improve management
- Digital care is convenient for some
- Some technologies are very easy to use
- More communication can improve relationship with care team
- Phone/video can reduce some stigmas or safety problems patients face in-person
- Phone/video can support patients in communicating clearly with care team
- Potential lower costs

Digital care “cons”

- Telehealth is not always appropriate for certain conditions
- Risk of misdiagnosis without physical exam
- Too much information/data can promote anxiety and worry
- Concerns about data accuracy, privacy, and security – digital information follows patients everywhere
- For some, digital reduces personal connection with care team
- Risk of redundant visits (increase cost and inconvenience)
- Tech, language, and other barriers can exclude or even jeopardize care for some
- Cost barriers for using remote devices

Two sides of digital tools and health care access:

Digital care can resolve transportation and accessibility barriers for some, but worsen them for others. Some patients also prefer or require in-person care *despite* access barriers for reasons of quality of care or social connection. Technology access, language barriers, cost, and transportation/physical accessibility are major equity issues that put some people at risk of being left behind by digital strategies.

Preliminary Themes: Research Perspectives

Research studies that use digital health strategies are not uncommon. Many do assess some aspects of patient experience and patient-reported outcomes through surveys. **Identifying measures that are truly patient-centered means finding measures that reflect patients' priorities and concerns.** By recommending their inclusion in future research, we can better understand how digital strategies affect patient-centeredness.

Digital care studies at HealthPartners included:

Hyperlink: Home BP monitoring and telehealth (PI Margolis)
GlucoCare: continuous glucose monitoring (PI Bergenstal)
"Wizards": clinical decision support studies for various chronic conditions (PI O'Connor)

The State Telehealth Study

is a legislatively mandated study to understand effect of telehealth on patient outcomes & equity (MN Dept of Health and Human Services)

Existing studies have shown:

- Increased patient satisfaction with the use of digital tools
- Overall increased access to care in MN
- Increased communication between patients and care team (clinical decision support tools)

Common research measures

that could potentially be adapted to assess patient-centeredness of digital care include:

Diabetes distress or other treatment burdens, quality of care, patient satisfaction, shared decision-making, and cost of care

Preliminary Themes: Health Care Perspectives

Digital tools have become rapidly and deeply embedded in health care, especially since the COVID-19 pandemic. While digitizing is a high priority, **HealthPartners is committed to its vision:** *"Health as it could be, affordability as it must be, through relationships"*

HealthPartners digitization initiatives:

Telehealth
Online scheduling
Device integration
Wearables
Patient education
modernization

Interpreters have identified limited ability to help patients who don't speak English navigate digital tools

Community Health Needs Assessments (CHNAs) identified consistent concerns about equity & access

Patient Reported Outcomes Measurement

is a systematic effort to collect patients' self reported outcomes in some clinical areas. By integrating patient reports with the electronic health record, that information can be used in care.

Early Patient-Centered Outcomes Research Experience With the Use of Telehealth to Address Disparities: Scoping Review

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Abstract (Summary)

Background: Health systems and providers across America are increasingly employing telehealth technologies to better serve medically underserved low-income, minority, and rural populations at the highest risk for health disparities. The Patient-Centered Outcomes Research Institute (PCORI) has invested US \$386 million in comparative effectiveness research in telehealth, greatly expanding the body of research, yet less is known about the key early lessons garnered regarding the best practices in using telehealth to address disparities.

Objective: This paper describes preliminary lessons from the body of research using study findings and case studies drawn from PCORI seminal patient-centered outcomes research (PCOR) initiatives. The primary purpose was to identify common barriers and facilitators to implementing telehealth technologies in populations at risk for disparities.

Methods: A systematic scoping review of telehealth studies addressing disparities was performed. It was guided by the Arksey and O'Malley Scoping Review Framework and focused on PCORI's active portfolio of telehealth studies and key PCOR identified by study investigators. We drew on this broad literature using illustrative examples from early PCOR experience and published literature to assess barriers and facilitators to implementing telehealth in populations at risk for disparities, using the active implementation framework to extract data. Major themes regarding how telehealth interventions can overcome barriers to telehealth adoption and implementation were identified through this review using an iterative Delphi process to achieve consensus among the PCORI investigators participating in the study.

Results: PCORI has funded 89 comparative effectiveness studies in telehealth, of which 41 assessed the use of telehealth to improve outcomes for populations at risk for health disparities. These 41 studies employed various overlapping modalities including mobile devices (29/41, 71%), web-based interventions (30/41, 73%), real-time videoconferencing (15/41, 37%), remote patient monitoring (8/41, 20%), and store-and-forward (ie, asynchronous electronic transmission) interventions (4/41, 10%). The studies targeted one or more of PCORI's priority populations, including racial and ethnic minorities (31/41, 41%), people living in rural areas, and those with low income/low socioeconomic status, low health literacy, or disabilities. Major themes identified across these studies included the importance of patient-centered design, cultural tailoring of telehealth solutions, delivering telehealth through trusted intermediaries, partnering with payers to expand telehealth reimbursement, and ensuring confidential sharing of private information.

Conclusions: Early PCOR evidence suggests that the most effective health system- and provider-level telehealth implementation solutions to address disparities employ patient-centered and culturally tailored telehealth solutions whose development is actively guided by the patients themselves to meet the needs of specific communities and populations. Further, this evidence shows that the best practices in telehealth implementation include delivery of telehealth through trusted intermediaries, close partnership with payers to facilitate reimbursement and sustainability, and safeguards to ensure patient-guided confidential sharing of personal health information.

Pre-meeting exercise: My Digital Health Care Story

Ahead of our meeting, use this space to tell your personal digital health care story. How has technology influenced your care? You can explore this however you'd like (writing, drawing, etc). We won't ask you for this – it's just a warm-up!

