

Issue Spotting: Promising Practices in Effective and Equitable Patient Engagement Via Technology

Summary

The historic COVID-19 pandemic ushered in a new era of the digital age. Technology became even more important in our daily lives – turning into a requirement for meeting our basic needs and communications. The sudden, forced acceleration in digital interactions was particularly significant in health care – where it became a literal lifeline: Virtual visits became the only option for receiving many forms of care. The pandemic crystallized the urgent need to identify and implement available learnings about how to best use technology to partner with people and communities in the pursuit of better health.

While many of the examples found derived from engaging patients and family caregivers in virtual visits with health care providers, the lessons learned can also inform patient and community engagement in health care research, policy, and practice. The following promising practices have been gleaned from the emerging patient-centered outcomes research evidence base, and informant interviews with experts and advisers on patient-centered care and technology.

At the same time, it is important to note that the current evidence base fails to adequately or consistently encompass the experiences of Black, Indigineous, and other People of Color communities, people with limited English proficiency, LGBTQ individuals, people with disabilities, and other people marginalized by structures of disadvantage.

This paper distills key lessons on how to leverage technology to engage patients and families in their health and health care. Our goal is to continue progress in the direction of authentic and meaningful involvement to ensure that virtual patient and consumer engagement advances health and health equity.



JULY 2021 1

Engaging Patients and Families in Ways That Engender Trust, Build Relationships, and Advance Health Equity

The available evidence is compelling: Meaningful engagement of patients, family caregivers, and communities is essential for advancing high-quality, person-centered health care. People and communities are the experts on their needs and the barriers they face to meet them. They must be included in developing health care research, delivery, and governance in order to achieve better health for all.

While the value of engaging patients in their care is well known, health care providers and other stakeholders struggle to effectively and consistently engage people in meaningful ways. As the nation continues its shift toward digital tools and technologies, it is critical to identify best practices for patient and family engagement in online or virtual settings. These digital encounters offer the potential to continue with, or even augment, engagement practices, but also run the risk of further marginalizing communities who face barriers to access and use of specific technologies. This is particularly true for people and communities made vulnerable by systems of oppression, including communities of color and rural communities, where inadequate infrastructure or financial barriers have resulted in lower levels of access to broadband internet or internet-enabled devices.

Patient-centered outcomes research (PCOR) is providing much-needed evidence of the quantitative and qualitative impact of digital health care, as well as promising strategies and approaches for building trusted partnerships. However, the current evidence base fails to adequately or consistently encompass the

experiences of Black, Indigineous, and other People of Color (BIPOC) communities, people with limited English proficiency, LGBTQ individuals, and other people marginalized by disadvantage.

First, historic and ongoing barriers have limited these communities' participation in medical and health systems research. Even when they have been included, the collection of important demographic data and the analysis of results by those cohorts has been inconsistent, if not entirely lacking. This continues to be the case in the field of patient engagement, so health care stakeholders have been making assumptions that what works to engage white, heterosexual, native Englishspeaking populations will work equally for all communities. This will undoubtedly exacerbate harm and deepen long-standing racial, ethnic, and other inequities. Therefore, even as we examine and derive learnings from the evidence that is available, we also underscore the need for more research, data, and analysis on BIPOC and other communities who face structures of disadvantage.

This bulletin offers lessons associated with effective digital engagement of patients and families in ways that engender trust, build relationships, improve experiences, and advance health equity. While our emphasis is on engaging patients and families in clinical care – based on available evidence and common-use cases – we have also included recommendations regarding patient engagement in broader health-

promotion activities, such as research and governance. In summary, we have identified five promising practices for effective virtual patient engagement:

- 1. Intentionally and explicitly design for equity to meet the needs of those people and communities most disadvantaged and harmed by current approaches to health care.
- **2.** Maximize options for access and communication by offering a variety of modalities to connect with and engage patients and their families.
- 3. Use technology to build trust and meaningful relationships and augment

- interactions with patients and their families.
- **4. Provide user-friendly technology and support** for people on how to get the most out of a virtual interaction.
- **5.** Promote and protect privacy and confidentiality, including documentation and information-sharing practices.

In addition to the above practices, we have identified lessons specifically related to engaging patients and families in managing their own health and care during telehealth visits. Such lessons include the importance of clearly communicating what to expect from a digital encounter, such as anticipated costs (if applicable).

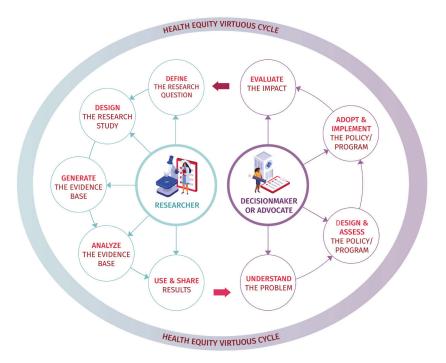
A WORD ON OUR METHODOLOGY

Our process for distilling recommendations for virtual patient and family engagement included a review of available evidence as well as conversations with advisers and stakeholders with expertise in engagement and digital health. The first step was a review of nearly 700 completed studies funded by the Patient-Centered Outcomes Research Institute (PCORI) to identify research projects that used some kind of digital technology to engage patients or families in care, communication, or knowledge transfer. An initial scan identified a dozen potentially relevant studies, focused on a range of medical conditions and patient populations (e.g., birthing people,* parents, teens, Medicaid beneficiaries), and used one or more of the following engagement strategies: virtual visits, interactive education platforms, or technical assistance and support. More careful review of the research reports and other materials narrowed the list to four promising studies.

We then engaged the project Advisory Council – a multi-stakeholder group of 12 patients, caregivers, consumer advocates, health care providers, and other thought leaders with diverse backgrounds and perspectives. Members brought subject matter

^{*}We recognize and respect that pregnant, birthing, postpartum, and parenting people have a range of gender identities, and do not always identify as "women" or "mothers." In recognition of the diversity of identities, we prioritize the use of non-gendered language.

CHOOSING HEALTH EQUITY: DECISION POINTS IN RESEARCH AND POLICY



expertise on health equity, patient- and family-centered care, mental health, and digital health – among other areas. Members helped to develop the study selection criteria, and ultimately recommended four studies as the most compelling, relevant, and well-positioned for inclusion. Those studies are summarized on pages 7-10.

We analyzed the selected studies, focusing on the results, demographic characteristics of the participants, elements of patient and family engagement, equity considerations, and potential applications and limitations. During this process, we used the questions and recommendations from the National Partnership's Choosing Health Equity guides and resources. These tools are designed to help health care stakeholders make decisions that advance health equity in research, policy, and practice. They pose concrete questions to consider and provide recommendations and resources for individuals to apply. Our goal is to support stakeholders in building and sustaining a Health Equity Virtuous Cycle, which generates and applies evidence that eliminates inequities and improves health for everyone. Because this bulletin analyzes available research, we examined health equity decision points specific to researchers, including: research question development, study design, evidence generation, analysis, and use of results. Finally, Advisory Council members and other digital health and patient engagement experts provided input on recommendations, and helped to apply an equity lens to the selected studies.

The Evolution of Patient, Family, and Community Engagement in Health Care

Over the past decade, significant strides have been made to more purposefully and effectively engage patients and caregivers in health care activities. There is a continuum of engagement, moving from consultation through involvement and ultimately toward partnership.† Effective patient and family engagement must also be culturally congruent, respectful, supportive, and confidence-building to effectively and equitably engage people from different backgrounds, cultures, languages, etc.



In **clinical care delivery**, patient and family engagement promotes two-way communication and information sharing, as well as shared decisionmaking and care planning – all oriented around people's priorities, needs, and goals. There is a range of specific functions and capabilities that facilitate engagement in health care delivery, such as joint goal setting, electronic two-way communication, capture and use of patient-generated outcomes and other data, and connections to community-based services and supports. Early data indicate that patient and family engagement can result in improved knowledge, confidence, and skills – among other positive indicators.



In **health research**, a community-based participatory research framework seeks to engage affected populations to understand the issues, strengths, and solutions from their perspective – arguably resulting in a stronger study. Following the study's completion, engaging patients and caregivers helps to understand and communicate study results from the community's perspective.



In health care programs and policies, partnerships with people and communities are likewise critical to effective and sustainable policy solutions. Health care decisionmakers can engage with communities in a number of ways, ranging from discrete, consultative interactions (e.g., opinion polls and focus groups) to long-term, well-resourced, continuous relationships that characterize community partnerships. Effective engagement in governance or programmatic settings requires robust processes for onboarding and supporting individual advisers serving on governing boards, quality improvement task forces, or other advisory bodies.

[†] Kristin L. Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, et al. "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies, Health Affairs, February 2013, https://doi.org/10.1377/hlthaff.2012.1133

Technology Is Becoming Central to Effective Patient Engagement

Technology is and will continue to be foundational to health and health care. Designed and implemented effectively, digital technologies have the potential to transform patient and family engagement in clinical encounters for the better, by improving experience, increasing participation in decisionmaking, and enhancing satisfaction with the care patients receive.

However, there are also significant risks of digital interactions reinforcing barriers to communication and meaningful partnerships between patients and their families and health care providers – barriers that fall disproportionately on people of color, lowincome people, and people with disabilities. Significant gaps remain in people's ability to access digital devices and broadband internet - otherwise known as the digital divide. BIPOC, low-income, and rural communities have been affected by "digital redlining," which has left approximately 42 million people without access to broadband at any price.* Even where it is available, nearly 75 million people do not subscribe to broadband because it is too expensive.† While typically used to refer to the availability or affordability of digital equipment or broadband internet access, the digital divide also encompasses their qualitative experience – such as the ease of using technology, or the ability to find and share necessary information.

The patient-centered outcomes research that informed these lessons are summarized on pages 7-10. All PCORI-funded studies



examined the use of digital technology to engage patients and families in care, communication, or knowledge transfer. While these studies focused on engaging patients and families in clinical health care activities, the fundamental recommendations are the same, regardless of the specific setting.

^{*} John Busby, Julia Tanberk, et al. "FCC Reports Broadband Unavailable to 21.3 Million Americans, BroadbandNow Study Indicates 42 Million Do Not Have Access," BroadbandNow Research, February 3, 2020, https://broadbandnow.com/research/fcc-underestimates-unserved-by-50-percent

[†] Monica Anderson. "Mobile Technology and Home Broadband 2019," Pew Research Center, June 13, 2019, https://www.pewresearch.org/internet/2019/06/13/mobile-technology-and-home-broadband-2019; Shelley McKinley. "Microsoft Airband: An Annual Update on Connecting Rural America," Microsoft on the Issues, March 5, 2020, https://blogs.microsoft.com/on-the-issues/2020/03/05/update-connecting-rural-america

Comparing Online Care with In-Person Care for Patients with Psoriasis

STUDY OVERVIEW

Compared the effectiveness of virtual and in-person treatment for psoriasis. The intervention group communicated with a dermatologist over the phone and asynchronously via a website. Patients were asked to take pictures of their skin using a camera on a mobile device to share with a dermatologist. The control group attended face-to-face appointments with a dermatologist.

RESULTS

- Online and in-person visits resulted in similar improvements in patients' psoriasis, quality of life, symptoms of depression, and reported quality of care.
- Patients who received online care reported spending less time traveling to and from doctor's offices and in waiting rooms.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Researchers convened an Advisory Council of 18 patient partners with psoriasis. Helped plan the study and plan the online platform.

Engagement in Care: Dermatologists answered follow-up questions from patients and providers online or by phone.

They reported quality of care similar to that of in-person care.

AVAILABLE DEMOGRAPHIC INFORMATION*

Race: Gender: Women: 50% Pacific Islander: 2% Men: 50%

Asian: 6%

American Indian/Alaska **Average age:** 49

Native: 2%

White: 63% Study results stratified

Other: 24% by demographic characteristics:

not available

Ethnicity:

Hispanic/Latino: 34%

APPLICATION

- Allows for patients and primary care providers to access dermatologists directly and asynchronously, which could benefit rural communities and/or areas that lack access to specialists.
- With high-quality images and a complete medical history, dermatologists' online patients can have the same clinical and quality-of-life outcomes as those seen in person.

- Patients needed: internet access, a digital camera or cellphone with a camera, and a primary care doctor.
- To adapt the online model, care facilities need to account for its cost and improve the technological interface.
- For some patients, impressions toward the online platform shifted based on the severity of their symptoms.

^{*}We are using the labels that the researchers use to maintain fidelity to the data. As such, there is significant variation in the demographic characteristics included for each study, and the language used to describe the study participants.

<u>Comparing Online and In-Person Family Therapy for Teens</u> <u>with Traumatic Brain Injury (TBI) and Their Parents</u>

STUDY OVERVIEW

Compared the effectiveness of therapist-guided virtual therapy and/or self-guided virtual therapy to in-person therapy for teens with TBI and their families.

Patients in the therapist-led virtual group received online materials and partook in therapist-guided appointments via video calls. Patients in the self-guided group received access to online materials, but did not meet with a therapist. The control group attended face-to-face appointments with a therapist and received printed materials.

RESULTS

• All three health care delivery methods were equally effective. For teens, there was no variation in behavior, ability to get things done, quality of life, TBI symptoms, and depression. For parents, there was no difference in depression or ability to deal with stress.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Parent and adolescent advisory boards provided input from the study's inception and throughout implementation.

Stakeholders provided input to refine materials that families received and selected outcome measures.

Engagement in Care: Family problem-solving therapy (the type of therapy provided in this study) engages the entire family to address issues with effective communication and problem-solving.

AVAILABLE DEMOGRAPHIC INFORMATION

Race/ethnicity

Teens:

African American: 11%

Hispanic: 4%

More than one race: 5% Native American: <1% Native Hawaiian/ Pacific

Islander: <1% White: 83%

Gender:

Male: 64% Female: 36%

Average age during

treatment: 16

Parents:

Mother is primary caregiver: 85% Education

College degree: 28%
Information about
parents' race/ethnicity
and age was not

provided.

Study results stratified

by demographic characteristics:

not available

APPLICATION

- Access to TBI specialists is limited, and the efficacy
 of self-guided online family problem-solving therapy
 could allow more people to have access to care.
- Potential for the creation of an online training (e.g., webinars) to teach more therapists how to implement this approach.
- Online intervention may be applicable for family therapy settings beyond TBI.

- Limited racial and ethnic diversity among study participants.
- Families who did not speak English at home were excluded.
- Therapists require training to help convert their inperson practices to an online platform.
- Patients needed access to computers and internet connection.
- Technology glitches interfered with the quality of participants' experiences in both online groups, which may have dampened treatment effects.

<u>Does a Video Chat Referral Process Help Families with Children Who Have</u> <u>Medicaid to Initiate Mental Health Care?</u>

STUDY OVERVIEW

Developed a video chat referral process to help families with children who have Medicaid get mental health care. Participants in the intervention group were shown informational videos and video-chatted with eligibility screeners in a provider's office. Members of the control group did not watch a video, and spoke with screeners on the telephone.

RESULTS

- Compared to the control group, children in the intervention group were three times more likely to finish screening mental health care. Parents in the intervention group were more likely to say their doctors kept families informed and involved, and expressed more satisfaction with the referral process and overall care.
- There were no differences in reported quality of life related to health.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Used a community-partnered design process to create intervention.

Parents helped the research team determine the relevance of the research question, study design, processes, and outcomes measured.

Engagement in Care: Secondary measures included family-centeredness of care.

AVAILABLE DEMOGRAPHIC INFORMATION

Race/ethnicity
Among children:

Black, non-Latino 2%

Latino: 87%

White, non-Latino: 7%

Other, non-Latino: 4%

Average age: 8.6 years old

Gender:

Male: 62%

Among parents:

Race/ethnicity
Non-Hispanic African

American: 2%

Latino: 87%

Non-Hispanic white: 7%

Gender

Women: 96%

Study results stratified

by demographic characteristics: **not available**

APPLICATION

- Video chat referral process could be applicable to counties/states that use a similar multi-step referral process for Medicaid-insured children.
- Participants were not required to have access to video chat technology.
- Videoconferencing was available in English and Spanish.

- Could reach more patients if additional languages were offered.
- Focused on increased access, but did not address whether video chat referral was associated with improved clinical outcomes.

Can an Online Program Help Women with a History of Preeclampsia **Reduce Their Risk of Heart Disease?**

STUDY OVERVIEW

Examined the effect of an interactive online education program in reducing the risk of cardiovascular disease among women with a history of preeclampsia. The intervention group was offered interactive online lessons, personalized lifestyle coaching, an online community forum, and an online toolbox of resources (i.e., meal plans and exercise videos). The control group had access to a static website with educational information about preeclampsia and heart disease.

RESULTS

- Intervention was effective in improving participants' understanding of their future risk of cardiovascular disease and their feelings of self-efficacy to reduce that risk (e.g., increased confidence in ability to change eating habits and greater feelings of control over risk of heart disease).
- The groups didn't differ in how well they followed the recommended eating plan or confidence in their exercise habits, blood pressure, or weight loss.
- There were no differences in reported quality of life related to health.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Patient advocates who previously had preeclampsia worked with the team during the study.

An advisory council convened multiple times.

Engagement in Care: Intervention included interactive education modules, personalized coaching from a dietician trained in patient-centered counseling, and access to an online community forum.

AVAILABLE DEMOGRAPHIC INFORMATION

Race/ethnicity:

Non-Hispanic African

American: 3%

Hispanic/Latina: 9%

Non-Hispanic Asian: 2%

Non-Hispanic white: 82%

Non-Hispanic mulit-race: 2% Study results stratified

Gender:

Women: 100%

Average age: 31

Education:

71% of participants held

a college degree

by demographic characteristics:

not available

APPLICATION

- Program available in English and Spanish.
- Women identified their relationship with their lifestyle coach and its associated accountability, the community camaraderie, and the patient-centered approach as stand-out benefits of the program.

- Patients needed access to the internet via computer or mobile device.
- Researchers noted that the intervention is relatively costly.
- Research participants were more highly educated and of higher socioeconomic status than the average U.S. population.
- Nine months might not be enough time to see changes in weight or blood pressure.

Recommendations for Improving Patient and Family Engagement via Digital Platforms

In an increasingly virtual world, technology offers more opportunities for connecting, communicating, and collaborating with people and communities. Here, we distill recommendations for engaging patients, families, and advocates in health research, policy, and governance activities broadly. While the evidence base is still emerging and largely focused on clinical applications, we can confidently point health care stakeholders in the direction of promising practices for virtual engagement – and caution against methods and approaches that exacerbate inequities and detract from authentic, meaningful engagement with patients, families, and communities. Nevertheless, PCORI studies and the experiences of experts in the field converge on several promising practices.

1. INTENTIONALLY AND EXPLICITLY DESIGN FOR EQUITY

Engagement policies and practices should take an "equity first" approach. This means that all practices and policies must be designed, implemented, and evaluated with the needs and priorities of the communities made vulnerable by systemic oppression at the center. Focusing on building systems and practices so they work for those who are consistently marginalized, rather than those who are consistently included, will produce systems and practices that can meet everyone's needs.

HOW TO DO IT

 Design digital experiences to meet the specific needs of people with limited digital literacy, limited English proficiency, and disabilities. For example, use pictures, translate information into non-English languages, and comply with accessibility standards that enable people to enlarge the text size or utilize text-to-voice translation.



In "Comparing Online and In-Person Family Therapy for Teens with Traumatic Brain Injury and Their Parents," a parent of a child with a traumatic brain injury helped to identify and reduce usability issues with the therapy website (e.g., reducing written content, replacing photos with illustrations).

2. MAXIMIZE OPTIONS FOR ACCESS AND COMMUNICATION

Offering a single mode of communication (e.g., video chat) may cause individuals and communities who are more comfortable with a different technology (e.g., audio-only calls) to be left behind. This is especially important given the persistence of the digital divide.

HOW TO DO IT

 Offer a range of digital modalities to care for patients and families with diverse preferences, familiarity, and access to technology and broadband internet connections (e.g., text message, phone calls, video visits, pre-visit photos).

In "Comparing Online Care with In-Person Care for Patients with Psoriasis," patients or primary care providers submitted digital photos of the patient's skin via a secure web-based platform. A dermatologist then provided treatment recommendations and patient education materials online to the provider and directly to the patient. Dermatologists were available to answer follow-up questions from patients online or by phone.

 Explore options to provide virtual technological connections to provide virtual/technological connections at an onsite location, or loan people smartphones or tablets on a temporary basis.



In "Does a Video Chat Referral Process Help Families with Children Who Have Medicaid to Initiate Mental Health Care?" Telehealth eligibility screening visits took place in the referring providers' offices. One day a week, clinical staff helped parents connect by videoconference with the screening department at the community mental health center.

• Invite and encourage patients and families to communicate and share information outside of traditional working hours – for example, sending comments, questions, and information via patient portal or email. This may be more convenient for hourly workers, or be a time when patients can be supported by a caregiver.

4. USE TECHNOLOGY TO EXTEND AND ENHANCE BUILDING TRUST AND MEANINGFUL RELATIONSHIPS

Meaningful engagement is built on a foundation of trust, respect, transparent communication, and the shared pursuit of agreed-upon health goals and priorities. Virtual engagement strategies must similarly identify and leverage opportunities to use technology in ways that build trust and foster relationships.

HOW TO DO IT

Use technology to enhance communication and augment interactions
with patients and families. Technology should never be used to replace or
substitute for high-quality, in-person relationships.



In "Can an Online Program Help Women with a History of Preeclampsia Reduce Their Risk of Heart Disease?" women described their relationship with their lifestyle coach and its associated accountability, the community camaraderie, and the patient-centered approach as stand-out benefits of the program.



In "Comparing Online Care with In-Person Care for Patients with Psoriasis," a patient shared their how their feelings about the online platform shifted based on the severity of their symptoms: "If I felt overwhelmed by the disease and in need of reassurance and a pep talk, then the platform made me mad because [it] is not set up for that [type of communication].... However, when the disease subsided, then I thought, no problem; this is great. I can just check in. It had to do with an emotional component of a relationship with the doctor that wasn't there."

4. PROVIDE USER-FRIENDLY TECHNOLOGY AND SUPPORT

When engaging patients and families remotely, create and plan for a positive user experience tailored to their specific technology equipment, digital literacy levels, and preferences, so participants can focus on communication and feedback rather than troubleshooting the technology platform.

HOW TO DO IT

- Consider factors such as the number of clicks and passwords needed, the types of authentication and set-up protocols required, backup processes for day-of technology issues, and other factors that will impact the overall experience.
- Send connection and login instructions in advance of the virtual encounter. This will allow patients and families to test systems and troubleshoot. Instructions could include: how to download and install the necessary platform (e.g., Zoom), suggestions to familiarize themselves with equipment such as a webcam, and reminders to charge their device.
- Achieving high-quality virtual engagement requires more than great technology – it requires real-time technical support and assistance for people using it. Make available trained staff capable of answering questions and providing technical assistance in the moment.



In "Does a Video Chat Referral Process Help Families with Children Who Have Medicaid to Initiate Mental Health Care?" the medical assistant showed parents a five-minute video introduction to the referred community mental health center following a primary care visit. If the parent did not have time to watch the video, they received a text message link to watch the video at a later time. It was a direct link that does not require a password or app.

5. PROMOTE AND PROTECT PRIVACY AND CONFIDENTIALITY

Clarity around how sensitive health information will be protected and shared can facilitate trust between patients and their providers.

HOW TO DO IT

 Set and clearly communicate expectations around how information will be used, documented, and shared with others, as well as the mechanisms by which information will be kept secure (e.g., encrypted data, password protections).



TELEHEALTH SPOTLIGHT: ENGAGING PATIENTS & FAMILIES IN VIRTUAL VISITS

In the context of clinical care, telehealth encompasses many uses of digital health technologies, including real-time video or audio patient-provider interactions; communications between patients and providers by email, text message, an app, or an online portal; and remote patient monitoring and the direct transmission of a person's clinical information from a distance to a provider.

While the health care system was already moving toward greater use of telehealth, the COVID-19 pandemic and necessary social distancing requirements unleashed a tidal wave of new telehealth usage. In March 2020, fewer than 20 percent of people in the United States had experienced a telehealth appointment. By March 2021, more than 61 percent had undergone a telehealth visit.*

Early evidence shows how telehealth can expand access to clinical care, information, and support – especially for those who encounter specific barriers

^{*} Sykes. "How Americans Feel About Telehealth: One Year Later," accessed June 8, 2021, https://www.sykes.com/resources/reports/how-americans-feel-about-telehealth-now/

related to systemic racism or economic inequality. Ongoing research will help determine the kinds of health care conditions and patients for whom virtual type of care is most valuable. In the interim, health care providers can build upon the above strategies with some additional lessons specifically related to engaging patients and families in managing their own health and care.

USE CLEAR COMMUNICATION AND SET REASONABLE EXPECTATIONS:

Proactively address the similarities and differences between a digital encounter and an in-person encounter.

HOW TO DO IT:

Provide clear guideposts for patients such as "frequently asked questions."
 These could include: Who am I going to be meeting with? How long is the visit? What technology or platform am I going to use? What information do I need to gather in advance (e.g., medications, blood pressure reading, list of questions for the provider)?

ENABLE AND SUPPORT COMMUNICATIONS FOR PEOPLE IN LANGUAGES OTHER THAN ENGLISH:

People with limited English proficiency have a right to linguistically responsive care (e.g., having an interpreter present at appointments, receiving instructions and information in their native language). These rights apply regardless of the modality used to connect to care. Moreover, just as in an in-person setting, it is not appropriate to rely on family members or friends as a substitute.

HOW TO DO IT:

- Inquire about the patient's and families' language, communication and technology preferences, and capabilities in advance of an encounter.
- Implement technology that enables communication to support the interpreter's participation, in addition to health care providers and patients.
- Care team members should make a plan so that patients and families

understand how to initiate follow-up communication in their preferred language once the virtual visit ends, and offer digital literacy resources (e.g., Zoom download and visit instructions) in a variety of languages.

ENGAGE PATIENTS IN NEW WAYS:

Virtual visits provide new opportunities to learn from patients and families. The ability of a provider to see inside someone's home during a virtual visit creates new opportunities for coaching and technical assistance.

HOW TO DO IT:

- Providers can instruct patients to conduct a self-exam (e.g., palpate areas, tug on ear).
- Patients can show providers prescriptions in their medicine cabinet, or food in their fridge, or demonstrate how they complete medical tasks at home (e.g., using nebulizer, mixing formula).

INCLUDE FAMILIES AND CAREGIVERS IN NEW WAYS:

Virtual visits create opportunities for the family members and other caregivers who are part of the patient's care team to join and participate – even from a distance.

HOW TO DO IT:

- During a virtual visit, caregivers who are on site with the patient can
 participate and assist with aspects such as dealing with the technology,
 or holding the camera to allow the provider an unobstructed view of the
 patient.
- Provide technology that allows multidirectional communications so that caregivers and family members who are not on site can engage in the conversation and be invited to share observations or concerns about the patients' health.

AVOID SURPRISE BILLS:

Unanticipated medical bills can have profound economic consequences and impede patient-provider trust. Patients and families may have varied expectations for whether and to what extent care will be covered in virtual settings.

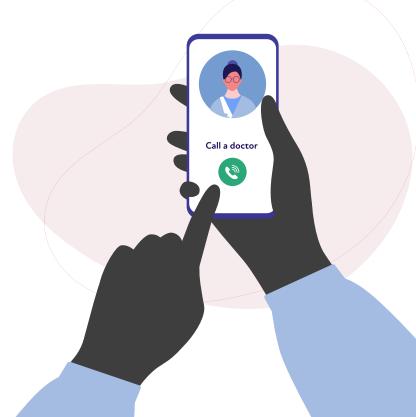
HOW TO DO IT:

• Care team members must be clear with patients and families about anticipated costs, including whether care is covered by insurance, and expected cost sharing in advance of the visit.

Conclusion

Meaningful engagement of patients, family caregivers, and communities is essential for advancing high-quality, person-centered health care. The emerging patient-centered outcomes research evidence base reveals actions stakeholders can take now to leverage technology to engage patients and families in remote settings. As the nation continues its shift toward digital tools and technologies, it is critical to build upon these promising practices to advance health equity, engender trust, build relationships, and improve experiences. However, while digital encounters offer new opportunities to advance engagement, they also run the risk of further marginalizing communities who face barriers to access and use of specific

technologies. Therefore there is an urgent need for more research, data, and analysis on BIPOC and other communities who face structures of disadvantage.





About the Authors

This resource was authored by

- Erin Mackay, Managing Director for Health Justice
- Dani Gillespie, Health Justice Policy Associate
- Sinsi Hernández-Cancio, Vice President for Health Justice

The following people also contributed:

- Caroline Le, Health Justice Intern
- Jorge Morales, Independent Editor
- Nichole Edralin, Designer

About the National Partnership

The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to achieving equity for all women. We work to create the conditions that will improve the lives of women and their families by focusing on achieving workplace and economic equity, and advancing health justice by ensuring access to high-quality, affordable, and equitable care, especially for reproductive and maternal health. We are committed to combatting white supremacy and promoting racial equity. We understand that this requires us to abandon race-neutral approaches and center the intersectional experiences of women of color to achieve our mission.

This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (14238-NPWF)

1875 Connecticut Ave. NW, Suite 650 Washington, DC 20009 nationalpartnership.org