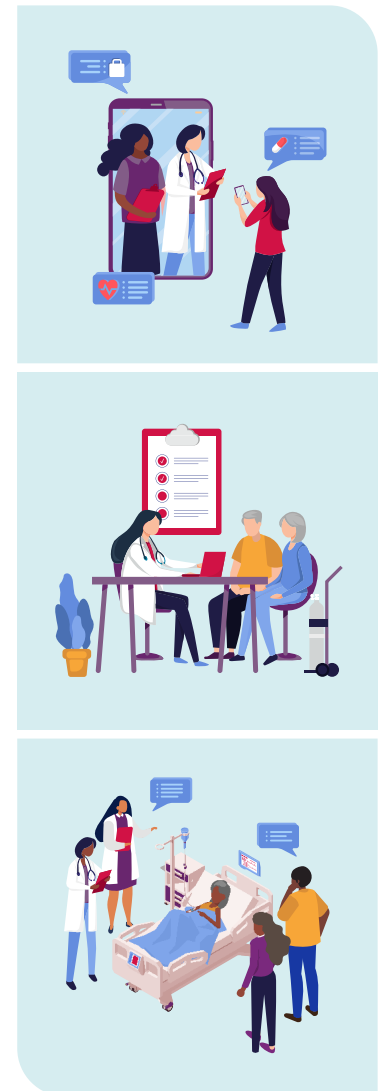# Patient & Family Engagement:
Improving Health and Advancing Equity

Executive Summary

Patient-centered outcomes research (PCOR) is providing much-needed evidence of the quantitative and qualitative impact of patient and family engagement (PFE) in health care. Despite the well-documented importance of centering patients and their experiences in health care delivery, the actual experiences of many people are far from this kind of transformation, especially for women and people of color. People routinely report feeling disrespected, dismissed, or discriminated against during their encounters with the health care system. These experiences of discrimination and disrespect translate to significant inequities in health care treatment and outcomes. The COVID-19 public health crisis underscores the urgency of gleaning learnings from the emerging evidence base and providing the framework and tools to put this evidence into practice to advance health equity, prioritize patient-centered care, and improve patient experience.

Evidence now shows why PFE is not only the right thing to do, it is necessary to improve care quality and optimize health outcomes. Recent studies funded by the Patient Centered Outcomes Research Institute (PCORI) provide new evidence of the multifaceted impact of PFE – such as better patient-reported outcomes and identification of more patient safety errors and adverse events. In sum, a system centered on patients and families performs better across several factors – including quality, safety, and patient experience.

However, while the emerging evidence is compelling, it fails to fully capture the experiences of people of color or other communities marginalized by structures of disadvantage. Health care researchers, decisionmakers, and advocates must understand how to effectively engage people of all races, ethnicities, primary languages, income levels, sexual orientations, gender identities, and abilities. They must also recognize that cultural values can vary greatly, to ensure that they are providing equitable, quality care to everyone.

This review of available evidence regarding the value of PFE indicates there is much to gain from transforming health care – and very little, if anything, to lose. There remain critical gaps in the evidence as to exactly how and to whom those benefits accrue – for example, based on race, ethnicity, and varying levels of health literacy – to ensure that we're getting a truly transformed and person-centered health system. This is a rich area for continued research, analysis, and application to ensure that the people and communities most likely to experience inequities, mistreatment, and discrimination can partner meaningfully and effectively in the pursuit of better health and better care.

To achieve this, we recommend the following:

Researchers and those who fund research should:

- **Require partnerships with diverse community leaders and organizations to ensure research prioritizes the needs and preferences of patients and families.** Researchers must build authentic, long-term community partnerships based on mutual respect and trust to effectively identify and prioritize outcomes that people care about, over clinical outcomes.

- **Plan for and resource sufficient diversity in research participants to enable results to be disaggregated by race and ethnicity, including relevant subgroups.** Study design should proactively identify and address the numerous barriers to research participation, including the institutional racism that drives well-founded mistrust in the medical establishment and fear of discrimination and mistreatment.
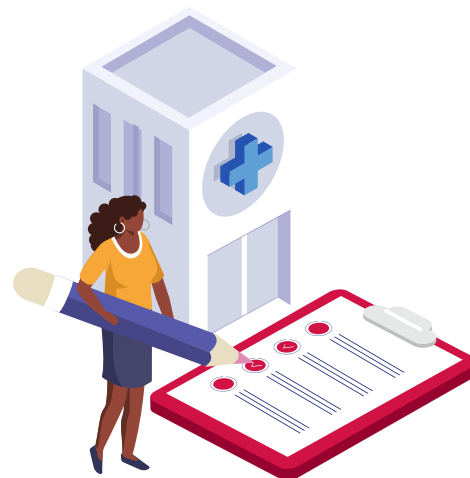
- **Analyze the gaps.** To be truly patient-centered, research must include a robust analysis of quantitative and qualitative heterogeneity of treatment effects by race, ethnicity, gender, and other relevant subgroups. It is the only way to determine groups who may benefit the most, as well as those who may be harmed.

- **Focus on trust.** We need to refine and use measures of trust and dignity in medical research, as well as in health care delivery. Research could examine whether outcomes such as quality of communication, satisfaction with care, and question-asking are effective proxies for trust. Additionally, research should examine strategies to address distrust among certain populations, including Black, Indigenous, and other people of color (BIPOC) communities.

- **Examine impact of decision aids and other shared decision-making strategies to reduce implicit bias in providers.** Implicit bias has a demonstrable effect on health care outcomes. Future research on decision aids (and other shared decision-making strategies) should examine the impact of these tools to reduce implicit biases on treatment decisions or recommendations.

- **Incorporate reporting on caregivers.** Caregivers play a crucial role in the health and health care of their loved ones. Researchers must prioritize collecting data on caregiver-reported outcomes and experiences.

- **Study the longitudinal impact of efforts to engage patients and families.** Researchers should explore ways to capture longitudinal data to better understand the long-term effect and returns on investment of PFE strategies on the health and well-being of study participants.

Health care providers and decisionmakers should:

- **Take into consideration the demographics of research study participants when designing health care policies and programs.** Not all policies or programs will work equally for all people: Individuals and communities experiencing structural racism and other inequities often face barriers to specific resources, programs, and policy solutions, even as their risk for poor health is greater. Unless providers and decisionmakers are clear as to whom evidence applies, they might design and implement programs that widen inequities.

- **Make publicly available the shared decision-making, goal setting, and other engagement tools that are used in PCORI-funded studies.** To truly advance person-centered care, publicly funded research should make tools developed and used as part of the study available online, along with complete study results. This enhances the effectiveness and speed at which important PFE strategies can be applied to improve health care delivery.

- **Strengthen provider training in skills necessary for PFE.** Engaging in shared decision-making, active listening, joint goal setting, and motivational interviewing are critical skills for meaningful PFE but have not been consistently prioritized in medical education. Similarly, providers need to understand how to communicate with and engage patients from different cultures and backgrounds to advance health outcomes and equity.

- **Improve diversity in hiring.** There is an urgent shortage of providers of color, providers who come from historically marginalized communities, and providers trained in culturally congruent care. Promoting greater diversity in the health care workforce (including race, ethnicity, physical ability, and other factors) as well as multidisciplinary care teams is crucial to meet the needs of individuals and to produce more equitable health outcomes.

- **Maximize options for access and communication by offering a variety of modalities to connect with and engage patients and their families.** Health care providers should offer a range of communication modalities to care for patients and families with diverse preferences, familiarity, and access to technology and broadband internet connections.

- **Consider varying levels of patient literacy and numeracy when implementing PFE interventions.** The effectiveness of shared decision-making or disease management tools depends on patients' ability to understand and apply health information, including numerical concepts (e.g., decision aids based on risk score). Providers should understand and respond to these factors when communicating risk and other relevant information to patients and families.

- **Select and use algorithms in ways that prioritize health equity.** As algorithms are increasingly used in health care delivery (e.g., to identify patients at potential risk), health care leaders should be mindful of whether and how these technical rules inadvertently perpetuate biases. Predictive algorithms derived from biased training data sets will not perform equally well for all groups – and may exacerbate inequities.

- **Foster a learning environment for continuous improvement.** Health care providers will face numerous challenges in adopting alternative approaches to care delivery, such as time limitations, difficulty achieving staff or leadership buy-in, and cultural resistance. Health care leaders should encourage and champion an environment for continuous learning and growth.

Promoting greater diversity in the health care workforce (including race, ethnicity, physical ability, and other factors) as well as multidisciplinary care teams is crucial to meet the needs of individuals and to produce more equitable health outcomes.

Introduction

Patient-centered outcomes research (PCOR) is providing much-needed evidence of the quantitative and qualitative impact of patient and family engagement (PFE) in health care. PCOR also reveals promising strategies and approaches for building trust between patients and their families on one side, and health care providers on the other. This issue brief synthesizes findings from PCOR research, and distills important lessons on how to effectively engage patients and families in ways that engender trust, build relationships, improve outcomes and experiences, and advance health equity.

As the COVID-19 pandemic continues to ravage the United States, PFE is more valuable – and more challenging – than ever. Many health care services are still being delivered via "virtual visits." Quarantine and social distancing can leave patients alone and isolated right when they feel vulnerable and in need of social support and are least able to advocate for themselves. Family members struggle to take care of loved ones from a distance.

This public health crisis underscores the urgency of gleaning learnings from the emerging evidence base and providing the framework and tools to put this evidence into practice to advance health equity, prioritize patient-centered care, and improve patient experience.

We Are Missing the Mark on Centering Patients in Health Care, Especially for Women and People of Color

The importance of centering patients and their experiences in health care delivery is well established. Yet health care in this country still struggles to achieve this consistently, and large swaths of our population report egregious failures in this regard. Transforming health care delivery to a coordinated system of care that emphasizes meaningful partnerships between patients and providers is critical to advance health equity, improve health outcomes and patient experience, and lower the cost of care.

Ideally, person-centered care would include:

- shared, informed decision-making between patients and providers;
- the development and tracking of personalized care plans tailored to people's needs, values, and preferences;
- education and coaching for managing health and care;
- the use of digital health tools to access information, communicate, and coordinate with care team members; and
- timely connections to community-based support services.

Unfortunately, the actual experiences of many people are far from this standard. People routinely report feeling disrespected, dismissed, or discriminated against during their encounters with the health care system. Women in particular often report not being listened to,[1] feeling ignored or overlooked, or having their pain not taken seriously by health care providers[2] – especially when it comes to sexual and reproductive health. Likewise, many childbearing people[*] have reported being ignored, having their concerns dismissed, being denied choices in care, and otherwise being disempowered and mistreated during pregnancy, childbirth, and the post-partum period.[3] Women of color are even more likely to feel ignored or mistreated, with clear negative effects. For example, higher rates of maternal mortality and morbidity are often anecdotally linked to Black women's concerns and pain not being taken seriously.

The medical establishment's long history and ongoing practice of mistreating and discriminating against people of color in this country is well documented. Racial and ethnic inequities in health care access, quality, and outcomes are entrenched. People of color routinely experience discrimination in health care settings.[4] Roughly one-third of Black Americans (32 percent) and at least one in five Native Americans (23 percent) and Latinos (20 percent) say they have experienced racial discrimination at doctors' offices or health clinics. And many of those avoided seeking medical care for themselves or a member of their family to protect themselves from experiencing racism.

[*] We recognize and respect that pregnant, birthing, postpartum, and parenting people have a range of gendered identities, and do not always identify as "women" or "mothers." In recognition of the diversity of identities, this report gives preference to gender-neutral terms such as "people," and "birthing persons." In references to studies, we use the typically-gendered language of the authors.

These experiences of discrimination translate to significant inequities in health care treatment and outcomes. Overall, Black Americans are consistently undertreated for pain, relative to white patients, due to the racist perception that Black people feel less pain.[5] Black women experiencing pelvic pain are significantly less likely than white women to be diagnosed for endometriosis – and instead misdiagnos ed as having pelvic inflammatory disease.[6] Compared to white non-Hispanic women, Black women are more than three times as likely – and Native women are more than twice as likely – to experience pregnancy-related deaths.

These negative experiences are rooted in the entrenched structural racism and paternalism that is endemic to the health care system. They exact stratospheric human and financial costs in the form of medical errors and increased morbidity and mortality. The lack of meaningful patient engagement and culturally congruent care results in care plans and treatment recommendations that are not concordant with people's priorities, ignore their available resources, and which patients and families cannot implement. In other words, what is perceived by health care providers as non-compliance may be the result of them not fully understanding patients' needs or goals, or not being responsive to what is realistic, effective, and prioritized by the patient (or family caregiver).

In short, the health care system too often administers care to patients and not *with* patients. While there have been some notable improvements in person-centered care, patients are typically involved as an afterthought, as opposed to being deliberately and meaningfully engaged in the design, implementation, and evaluation of care delivery.

Evidence now shows why PFE is not only the right thing to do, it's necessary to improve care quality and optimize health outcomes. Recent findings from PCORI-funded studies provide new evidence of the multifaceted impact of PFE – including better patient-reported outcomes and identification of more patient safety errors and adverse events. In sum, a system centered on patients and families performs better across several factors – including quality, safety, and patient experience.

While the emerging evidence is compelling, it fails to fully capture the experiences of people of color or other communities marginalized by structures of disadvantage. Health care researchers, decisionmakers, and advocates must understand how to effectively engage people of all races, ethnicities, primary languages, income levels, sexual orientations, gender identities, and abilities. They must also recognize that cultural values can vary greatly, to ensure that they are providing equitable, quality care to *everyone*.

Health Equity: Gaps in Evidence

Further research is necessary to understand how to effectively engage patients and families. However, the current evidence base fails to adequately or consistently encompass the experiences of Black, Indigenous, and other people of color (BIPOC) communities; people with limited English proficiency; lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals; people with disabilities; and other people marginalized by disadvantage. As a result, we don't have enough data on how to engage these groups, which makes it more difficult to engage them effectively and to meaningfully improve health outcomes.

First, historic and ongoing barriers have limited these communities' voluntary and ethical participation in medical and health systems research. The United States' abhorrent history of inhumane medical experimentation, eugenics, continuing racism, and discriminatory health practices has produced justified mistrust of the medical and research establishments among communities of color. For example, the practice of gynecology and obstetrics was built on abusive experimentation on enslaved Black women – including developing cesarean and other surgical procedures without anesthesia. Over a century later, the medical establishment used Henrietta Lacks's cervical cancer cells to help understand disease and develop treatments, without her or her family's knowledge, nor recognition, until 2010. Women[7] and LGBTQ populations[8] continue to be significantly underrepresented in clinical trials and medical research, which helps perpetuate health inequities.

Second, even when these cohorts have been included, the collection of important demographic data and the analysis of results has been inconsistent, if not entirely lacking. This continues to be the case in the field of patient engagement. In the absence of granular demographic data, health care stakeholders have been making assumptions that what works to engage white, heterosexual, native English-speaking 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, LGBTQ, and other communities who face structures of disadvantage.

HEALTH EQUITY
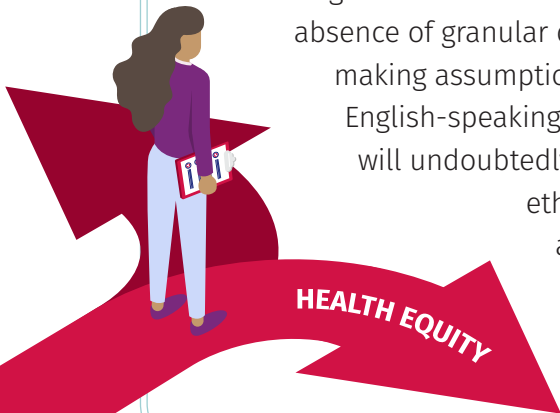
Our Process

Our process for distilling recommendations for patient and family engagement (PFE) included a review and analysis of the available evidence, and conversations with advisers and stakeh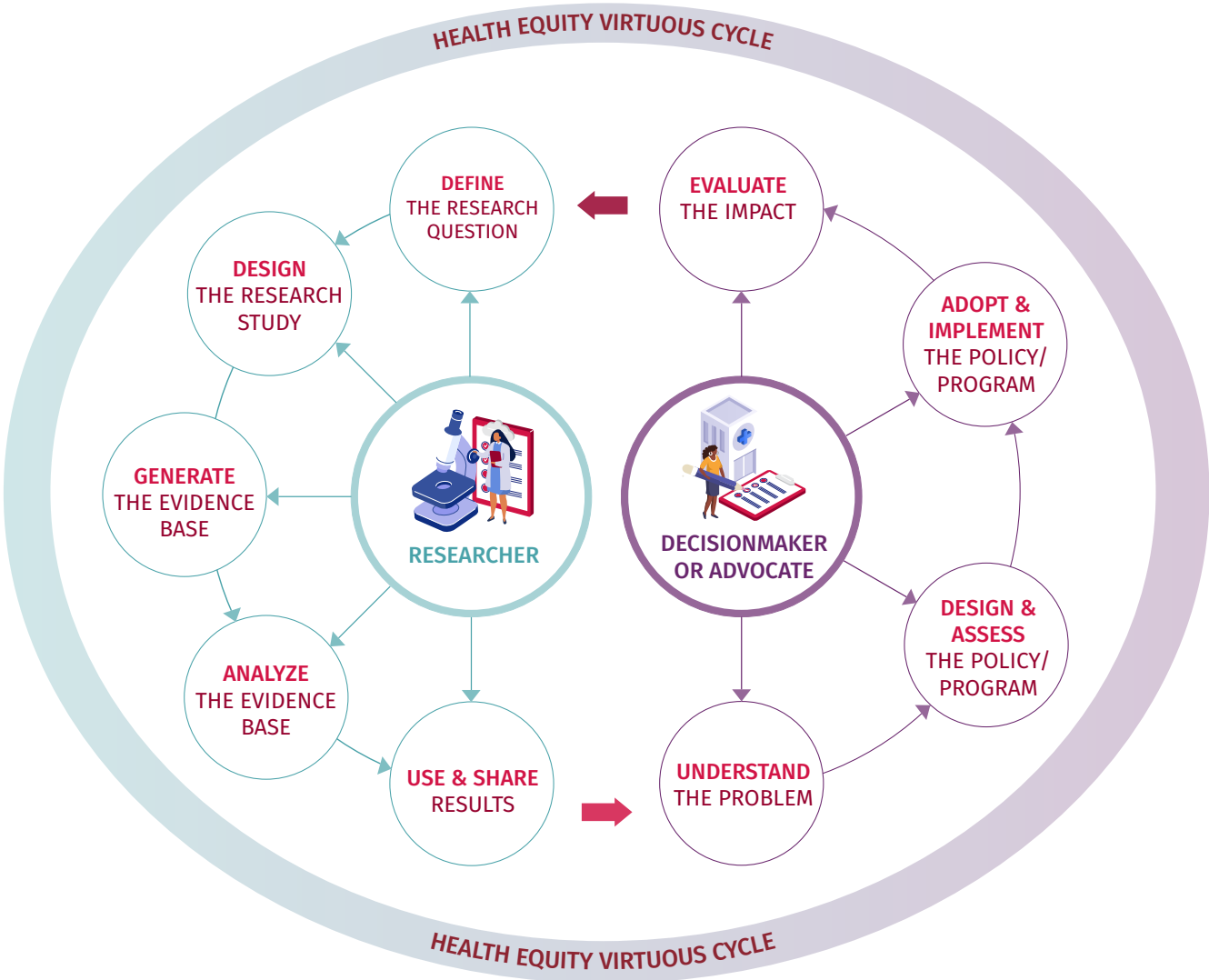olders with expertise in engagement and digital health. The first step was a review of nearly 700 PCORI-funded studies to identify research projects that effectively engaged patients and families. An initial scan identified approximately 35 potentially relevant studies focused on a range of medical conditions and patient populations. More careful review of the research reports and other materials narrowed down the list to 13 promising studies.

We then engaged the project's 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 contributed subject matter expertise and lived experience 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 13 studies as the most compelling, relevant, and well-positioned for inclusion. Those studies are summarized on pages 27-39.

We analyzed the selected studies, focusing on the results, demographic characteristics of the participants, elements of PFE, equity considerations, and potential applications and limitations. During this process, we used the questions and recommendations from the National Partnership's Choosing Health Equity[9] 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. Our goal is to support stakeholders in building and sustaining a Health Equity Virtuous Cycle (see page 10), which generates and applies evidence that eliminates inequities and improves health for everyone.

Because this paper 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.

CHOOSING HEALTH EQUITY:
DECISION POINTS IN RESEARCH AND POLICY

HEALTH EQUITY VIRTUOUS CYCLE

DEFINE
THE RESEARCH
QUESTION

EVALUATE
THE IMPACT

DESIGN
THE RESEARCH
STUDY

ADOPT &
IMPLEMENT
THE POLICY/
PROGRAM

GENERATE
THE EVIDENCE
BASE

RESEARCHER

DECISIONMAKER
OR ADVOCATE

DESIGN &
ASSESS
THE POLICY/
PROGRAM

ANALYZE
THE EVIDENCE
BASE

USE & SHARE
RESULTS

UNDERSTAND
THE PROBLEM

HEALTH EQUITY VIRTUOUS CYCLE

Studies Examining PFE Strategies

1. Testing a Decision Aid for Patients with Low-Risk Chest Pain in the Emergency Room: The Chest Pain Choice Trial[10]

2. Does a Decision Aid Help Patients Learn About Their Treatment Options for Advanced Heart Failure?[11]

3. Training Staff at Doctors' Offices to Use Shared Decision-Making with Patients Choosing Asthma Treatments[12]

4. Using Question Prompt Lists During Pediatric Asthma Visits to Increase Adolescent Involvement[13]

5. Does a Patient- and Family-Centered Hospital Communications Program Reduce Medical Errors?[14]

6. Do Video House Calls with a Specialist Help Get Care to People with Parkinson's Disease?[15]

7. Designing and Testing a Visit Planner to Help Patients Address Their Top Concerns During Health Care Visits[16]

8. Using a Decision Aid in the Emergency Room to Help Parents of Children with Head Trauma Understand Options for Diagnosing Brain Injury[17]

9. Improving Communication by Preparing Patients and Doctors for a Conversation about Care Goals for Serious Illness[18]

10. Comparing Online Care with In-Person Care for Patients with Psoriasis[19]

11. Does a Video Chat Referral Process Help Families with Children Who Have Medicaid to Initiate Mental Health Care?[20]

12. Comparing Online and In-Person Family Therapy for Teens with Traumatic Brain Injury (TBI) and Their Parents[21]

13. Can an Online Program Help Women with a History of Preeclampsia Reduce Their Risk of Heart Disease?[22]

Tapping PCORI's Evidence Base to Advance PFE

The available evidence from completed PCORI studies 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, design, and delivery in order to achieve better health.

Over the past decade, significant strides have been made to more purposefully and effectively engage patients and caregivers in health care. There is a continuum of engagement, moving from consultation through **involvement** and, ideally, toward **partnership**.[23] Effective PFE must also be culturally congruent, respectful, supportive, and confidence-building to effectively and equitably engage people from different backgrounds, cultures, languages, and other life experiences that may affect their interactions with the health care system.

In clinical care delivery, PFE promotes two-way communication and information sharing, as well as shared decision-making 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:

- tools to improve patient-provider communication, goal setting, and shared care planning;
- patient educational programs;
- digital health tools (including the capture and use of patient-reported outcomes and other patient-generated data via mobile health and electronic health records); and
- connections to community-based services and supports.[24]

Given PCORI's mandate to fund research focused on patient-centered outcomes, the portfolio of PCORI-funded research provides a collection of studies that could add important learnings to the existing evidence base on effective PFE. At the same time, we recognize that even these studies may fail to capture the full impact of PFE because of persistent medical and research biases that focus on a narrow set of clinical outcomes. Experience and outcome measures that more directly align with patient, family, and community priorities are still underemphasized in study design, implementation, and analysis. To identify what can be learned from the PCORI portfolio regarding PFE, we developed a methodology that combined an analysis of the entire portfolio with key input from a panel of advisors, which eventually narrowed down the pool to 13 studies. (See "Our Process" sidebar for more details.)

Project staff analyzed these studies in depth, distilling benefits, key themes, outstanding questions, and future research needs related to PFE. The selected studies focused on a range of medical conditions and patient populations (e.g., birthing people, parents, teens, Medicaid beneficiaries, people with a serious illness) and used one or more of the following engagement strategies: decision aids, pre-visit tools and resources (e.g., agendas and question prompts), family-centered communication, and digital health tools. Studies explored different levels and types of engagement, based on available resources and context.

Topline Individual Study Findings

All 13 studies found important benefits of PFE, such as improvements in patient knowledge and quality of communication. Most demonstrated either some improvement or no difference in a variety of outcomes, such as quality of life and trust in providers. In no instance were patient experiences or outcomes made worse. At the same time, few studies demonstrated improvements in the purely clinical outcomes that were measured.

The Evidence Shows a Range of Significant Benefits of PFE

There were noteworthy improvements in patient knowledge, confidence, quality of communication with providers, engagement in decision-making, and patient safety.

1. Effective Shared Decision-Making.

Engaging patients and families in shared decision-making provides opportunities to make decisions that reflect patients' values and preferences and will work with their life circumstances. Decision aids are tools for preference-sensitive treatments such as diagnosing injury and medical device implantation. In all three decision

aid studies, patients[25] and families[26] experienced less decisional conflict† and increased engagement in the decision-making process. In the decision aid study where parents in the emergency room[27] needed to decide whether to do a CT scan to determine whether their child had a traumatic brain injury, the use of the aid increased parents' feelings of involvement in the decision-making process and did not result in any cases where a brain injury was missed and a child's health was put at risk.

Moreover, use of shared decision-making can help patients feel more involved and increase their sense of ownership over care decisions. In a study where patients with serious illnesses[28] filled out a form about their care goals before a visit, patients reported they were more likely to receive care in line with their goals (known as "goal concordance"). Another study comparing different levels of physician training[29] in shared decision-making found that the patients of doctors who had more training reported greater participation in treatment decisions – indicating that the amount and type of training makes a difference.

† Decisional conflict is defined as, "a state of uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret or challenge to personal life values for oneself or for someone else" (Annie LeBlanc, David A. Kenny, Annette M. O'Connor, and France Légaré. "Decisional Conflict in Patients and Their Physicians: A Dyadic Approach to Shared Decision Making," *Medical Decision Making*, January-February 2009, DOI: 10.1177/0272989X08327067).

In "[Using a Decision Aid in the Emergency Room to Help Parents of Children with Head Trauma Understand Options for Diagnosing Brain Injury](#)," *some parents of children in the emergency room for head trauma were given a decision aid to help parents talk with doctors about whether their child should get a CT scan in the hospital or engage in home monitoring. Parents who used a decision aid were more likely to participate in the decision-making process, felt less conflict, and were happier about their decisions than parents who did not use the aid.*

2. Improved Patient Education. Patient education materials and other efforts to enhance health literacy and knowledge can help patients and families be more active partners in their care plans. In addition to providing a template for patients and providers to collaboratively make decisions, decision aids are also helpful for improving patient knowledge and education. In the three selected studies that incorporate decision aids, patients and families reported greater knowledge about available treatment options. Likewise, parents of children with head trauma who used a decision aid thought the information discussed with doctors was clearer.[30] However, the chest pain decision aid study found that the knowledge benefits did not accrue equally between white people and people of color, with twice as many white people reporting increased knowledge.[31] In another study that examined the effect of an interactive

online education program to reduce the risk of cardiovascular disease among women with a history of preeclampsia, participants reported an increased understanding of their future risk of cardiovascular disease and 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).[32]

3. Improved Communication with Clinicians and Staff. Effective two-way communication is foundational to cultivate relationships and trust and to improve experiences. Patient engagement tools such as visit planners and question prompts can help improve communication, proactively identify patient concerns, and mitigate medical risk factors. For example, introducing a question prompt list[33] helped adolescents ask more questions, a visit planner[34] made patients more likely to share their top concerns at the beginning of a doctor visit, and patients who filled out a form about care goals for serious illness reported better communication and were more likely to talk with their doctors about goals for care.[35]

4. Improvements in Patient Safety. Meaningful PFE is also essential to prevent harm and reduce risk and errors to patients receiving health care. A study on family-centered rounds examined whether helping doctors and nurses communicate with families during rounds would reduce hospital medical errors and adverse events.[36] The impressive results included a nearly 50 percent decrease in adverse medical events, as well as improvements in patient experience and quality of communication.

> *In "*[Does a Patient- and Family-Centered Hospital Communications Program Reduce Medical Errors?](#)*" researchers found that preventable errors decreased by 37 percent, overall adverse medical events diminished 47 percent, and patient safety improved without significant increase in rounds duration, or a decrease in teaching activity.*

Some Evidence Showed Either No Difference or Improved Results

While much of the research showed compelling improvements in outcomes, there were some areas where improvements were not consistent, but outcomes were not worse either.

1. Trust in Providers. When it came to patients' trust in their providers, results were mixed between equal and better. In one decision aid study on patients with head trauma, parents who used the decision aid reported greater trust in their doctors.[37] In contrast, in the decision aid study on heart failure, there was no overall reported effect on physician trust, although patients with low self-reported health literacy did report increased physician trust.[38]

2. Quality of Life. Some patients reported greater quality of life compared to patients who received standard care, while others reported no significant difference. For example, patients who used a decision aid

to choose a course of treatment for their heart disease reported greater satisfaction with life and better quality of life.[39] In contrast, adolescents given a question prompt[40] to increase their involvement in asthma management, and patients who had virtual house calls[41] with disease specialists, reported no significant difference in their quality of life.

Overall, the impact of digital health interventions on quality of life appears to be the same as in-person interventions. Patients who received either in-person or virtual care for their psoriasis reported similar improvements in their quality of life, as well as reported quality of care.[42] There was also no difference in quality of life between families who received online family therapy for teens with a traumatic brain injury and those who received in-person therapy.[43] Likewise, there were no differences in reported quality of life among women who received interactive online coaching to manage risk factors for heart disease, versus women who received static information.[44]

3. Reducing Unneeded and Inappropriate Care. The ability to reduce medically inappropriate or unnecessary care – while maintaining high quality and patient safety – is a promising potential outcome of PFE, and is reflected in some of the research. When presented with decision aids to assess treatment options, patients and families in the chest pain study were less likely to be admitted for observation and

less likely to seek further testing.[45] In the childhood head trauma decision aid study, parents were equally likely to obtain a head CT for their child in the emergency room, but were less likely to bring their child in for further evaluation after discharge (e.g., outpatient imaging and blood testing).[46] In no cases did the integration of PFE intervention increase the number of tests performed. At most, decision aids resulted in similar uses of tests, while also providing benefits such as increased trust and reduced decisional conflict.

The Evidence Reveals Limited Change/Improvement in Clinical Outcomes

Despite documented improvements in patient knowledge, confidence, and experience (as described above), few studies reported a significant change in the priority clinical outcomes identified by study researchers other than the aforementioned reduction in medical errors and adverse events. The two studies that examined the effect of PFE on asthma management did not demonstrate significant improvement in asthma symptoms[47] or control[48] (e.g., ER visits, hospitalizations, oral steroid prescriptions, taking medication as prescribed). Similarly, a study that measured the effect of a visit planner did not find that the planner (or subsequent communication) affected how often patients took medications as directed or closed identified care gaps (e.g., completed needed tests and treatments).[49]

Decision aids were shown to add just two minutes of clinicians' time in the child head trauma study and one minute in the chest pain study.

Cross-Cutting Learnings

In addition to the results specific to particular studies, a holistic analysis of this collection of studies suggests some important conclusions regarding the value of PFE.

The Evidence Indicates That PFE Works Effectively in a Multitude of Settings, Despite Preconceived Barriers

It is possible to implement successful PFE strategies while adding minimal time/burden to providers. Decision aids, which are not traditionally used in high-pressure settings like emergency rooms, were shown to add just two minutes of clinicians' time in the child head trauma[50] study and one minute in the chest pain study.[51] In the I-PASS study,[52] efforts among doctors and nurses to more effectively communicate with families did not increase time spent on rounds, even as it increased patient safety, experience, and quality of care.

The Evidence Underscores That Digital Technologies Are Increasingly Being Used to Engage with Patients and Families

Designed and implemented effectively, digital technologies can improve PFE in clinical encounters by improving experience, increasing participation in decision-making and enhancing satisfaction with the care patients receive. In the study examining video calls for patients with Parkinson's disease, patients preferred virtual visits over in-person visits.[53]

Several studies found that offering a range of digital modalities for patients to connect with their health care providers (e.g., text messages, phone calls, video visits, pre-visit photos) enhanced communication and built strong relationships with care team members. For example, in a study that examined the effect of a video chat referral process to help families with children who have Medicaid get mental health care, parents were more likely to say their doctors kept families informed and involved them in their care.[54] Moreover, patients who used digital health interventions for Parkinson's disease[55] or psoriasis[56] spent less time traveling to and from the doctor's offices and sitting in waiting rooms, and more time talking with specialists during their visits. Likewise, women with a history of preeclampsia who used an online program described their relationship with their lifestyle coach and its associated accountability, the community camaraderie, and the patient-centered approach as standout benefits of the program.[57]

However, patient perceptions of the value of digital health interventions may differ depending on their unique needs during a course of treatment or disease progression.

Additionally, patients can often complete digital interventions such as informational videos while waiting to see a health care

provider,[58] or even outside of clinical settings.[59] Some digital health tools used independently by patients and families demonstrated important benefits: A study that compared in-person and online family therapy for teens with a traumatic brain injury found that families who exclusively used online materials on their own had similar outcomes in terms of behavior, depression, and quality of life as those who met with a therapist in person or those who met with a therapist online.[60]

In "Comparing Online Care with In-Person Care for Patients with Psoriasis," a patient shared 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."
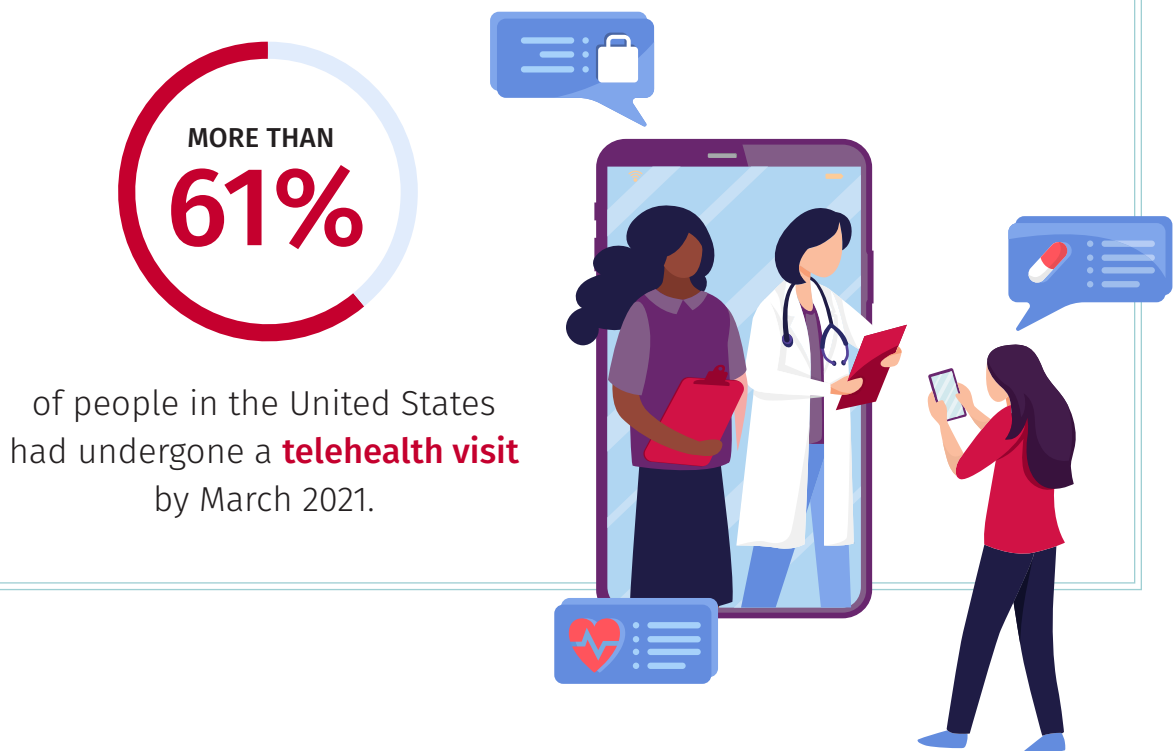
People and communities are the experts on what their needs are and the barriers they face. Therefore, research that reflects priorities defined by affected communities is most likely to have a positive real-world impact.

Virtual Patient Engagement

Technology has become even more important for human interaction during the COVID-19 pandemic, given the need for social distancing. Health care is no exception. By March 2021, more than 61 percent of people in the United States had undergone a telehealth visit, up from less than 20 percent in March 2020.[61]

The increased adoption of digital health care visits and other forms of distance health care offers the potential to continue with, or even augment, engagement practices, but also runs the risk of further marginalizing communities who face barriers to access and use of specific technologies. This is particularly true for communities made vulnerable by systems of oppression, including people of color and rural communities, where inadequate infrastructure or financial barriers have led to lower levels of access to broadband internet or internet-enabled devices.

The National Partnership's bulletin "Issue Spotting: Promising Practices in Effective and Equitable Patient Engagement Via Technology" distills key lessons on how to leverage technology to engage patients and families in their health and health care.[62]

MORE THAN

61%

of people in the United States had undergone a **telehealth visit** by March 2021.

There Are Significant Limitations and Outstanding Questions in the Existing Evidence

The lack of diversity in medical research persists – with studies consistently underrepresenting Black and Hispanic[‡] populations[63] and overwhelmingly focusing on white populations of European descent.[64] This produces an evidence base that is not representative of the U.S. population, and precludes the ability to effectively improve health and health care for all populations – especially racial, ethnic, and other minorities.[65] Insight about whether and how people and communities who are especially vulnerable to racism and other systems of oppression benefit from PFE interventions is especially important.

- **Race and Ethnicity:** In a majority of the available studies on PFE strategies, more than 60 percent of participants are white – including nine out of the 13 studies featured in this issue brief. One study did not include demographic information on race or ethnicity at all, and another categorized people into only two racial and ethnic categories: white and nonwhite.

  Given the documented health inequities between white and Black, Indigenous, and other people of color (BIPOC) communities, assumptions that strategies proven to effectively engage white patients will work equally for patients of racial and ethnic minorities (or other underrepresented groups) are likely to exacerbate harm and deepen inequities.

  Even when data is disaggregated by race, the level of analysis is still not enough to make meaningful assessments about the effect of various PFE interventions on health equity. The chest pain decision aid study notes that the aid increased knowledge to a greater degree in whites compared to nonwhites, but does not explore

the reason for this inequity.[66] The same study collects baseline racial demographic information (e.g., white, Black, Asian, Hispanic), but its data analysis only differentiates between white and nonwhite.

In addition, studies rarely reported data on the race and ethnicity of health care providers. This information is crucial, as emerging research underscores the importance of provider-patient racial concordance. For example, a recent study found that Black newborns are more likely to survive when cared for by Black physicians.[67]

- **Language:** Approximately 22 percent of people in the United States speak a language other than English at home, and about 8 percent report speaking English less than "very well."[68] Yet health care providers rarely relay information in languages other than English. Seven out of the 13 studies included in this issue brief (i.e., more than half) used only English. In six of the studies, providers used Spanish as well as English, and in one study, providers used four languages in addition to English.[69]

‡ To be more inclusive of diverse identities, the National Partnership uses "Latinx" to describe people who trace their roots to Latin America, except where the research uses "Latino/a" and "Hispanic," to ensure fidelity to the data.

- **Sexual Orientation and Gender Identity:** No study collected or reported information on participants' sexual orientation, and all approached gender as a binary concept (male or female). Patients' sexual orientation and gender identity have clinical relevance and are vital for improving health outcomes and advancing health equity. For example, transgender individuals have increased risk for depression, suicide, and HIV. And they rarely receive preventive screenings appropriate to their gender assigned at birth, such as Pap tests, mammograms, and prostate exams. We also know that roughly one in six LGBTQ people (16 percent) report being discriminated against at doctors' offices or health clinics because of their sexual orientation or gender identity.[70]

Study Outcomes May Not Be Those Prioritized by Patients

While many studies did not find statistical improvements related to clinical outcomes (e.g., disease control or medication adherence), these may not have been representative of patient priorities (e.g., feeling more hopeful or able to care for oneself, reduced anxiety). Additionally, measuring a narrow indicator related to lack of illness or illness progression is not the same as measuring comprehensive patient health or well-being. People and communities are the experts on what their needs are and the barriers they face. Therefore, research that reflects priorities defined by affected communities – rather than the perceptions, priorities, and internal biases of research teams or institutions – is most likely to have a positive real-world impact.

The Long-Term Effects of Interventions Remain Unclear

In examining study results, it is important to note the studies' limited timeframes. Many of the studies lasted between three and six months, and no study took longer than one year. This makes it difficult to estimate the long-term effects of PFE interventions. The long-term effects of behaviors and outcomes, such as asking more questions during visits,[71] receiving care more in line with their goals,[72] and feeling less conflict or uncertainty about a care decision,[73] may play out over the course of patients' lives. In other words, it may be too early to tell whether and how these skills will affect health care experiences and outcomes.

Ongoing Need to Focus on Caregiver Needs

Caregivers provide a vital perspective on care, and were engaged in the development of many studies featured in this issue brief. Yet the reported results rarely include caregiver-reported outcomes and experiences. Of the 13 studies in this issue brief, only three measure caregiver burden, whereas physician burden is measured in a majority of studies. In one study, caregivers provided information on medication problems in teens with asthma.[74] Another study measured the burden on caregivers for people with Parkinson's disease.[75]

Lack of Focus on Culturally Congruent Care as a Component of PFE

Cultural congruence is a foundational component of high-quality care, because conscious or unconscious bias, stereotyping, and lack of cultural awareness and sensitivity can result in misdiagnosis, improper treatment, and mutual mistrust between providers and patients. Patient engagement efforts that focus on improving shared decision-making and communication (among other strategies) may be particularly affected by cultural congruence – or lack thereof. The lack of explicit focus on culturally responsive patient engagement limits generalizability of study results to BIPOC communities, non-English speaking populations, and LGBTQ individuals – as well as people living at the intersection of these structures of disadvantage.

Cultural congruence is a foundational component of high-quality care, because conscious or unconscious bias, stereotyping, and lack of cultural awareness and sensitivity can result in misdiagnosis, improper treatment, and mutual mistrust between providers and patients.

RECOMMENDATIONS

Recommendations for Researchers

As PCORI, academic institutions, and government agencies continue to fund research related to PFE, we offer the following recommendations for researchers to address existing gaps and augment the evidence base.

1. **Require partnerships with diverse community leaders and organizations to ensure research prioritizes the needs and preferences of patients and families.** We should prioritize outcomes that people care about, over the largely clinical outcomes typically prioritized by researchers. To expedite progress toward this goal, researchers must build authentic, long-term community partnerships based on mutual respect and trust. This will create channels for timely information sharing on the changing needs and experiences of the people and communities that researchers aim to serve.

2. **Plan for and resource sufficient diversity in research participants to enable results to be disaggregated by race and ethnicity, including relevant subgroups.** While we have made progress toward the diversification of research participants, much more is needed – particularly among communities of color – to ensure that all communities equitably accrue the benefits of research and medical advancements. Study design should proactively identify and address the numerous barriers to research participation, including the institutional racism that drives well-founded mistrust in the medical establishment and fear of discrimination and mistreatment. Investing in community partnerships will help design processes and structures to effectively address these barriers, build trust, and reach people and communities traditionally excluded.

3. **Analyze the gaps.** Collecting disaggregated data is merely the first step in ensuring that research advances health equity. To be truly patient-centered, research must include a robust analysis of quantitative and qualitative heterogeneity of treatment effects by race, ethnicity, gender, and other relevant subgroups. It is the only way to determine groups who may benefit the most, as well as those who may be harmed.

4. **Focus on trust.** We need to refine and use measures of trust and dignity in medical research, as well as in health care delivery. Few studies explicitly measure trust as an outcome, but we know that earning and sustaining trust is a critical component of high-quality care. Research could examine whether outcomes such as quality of communication, satisfaction with care, and question-asking are effective proxies for trust. Additionally, research should examine strategies to address distrust among certain populations, including BIPOC communities. For example, research could study whether reducing decisional conflict builds more trust with patients and families.

5. **Examine impact of decision aids and other shared decision-making strategies to reduce implicit bias in providers.** Implicit bias has a demonstrable effect on health care outcomes. Future research on decision aids (and other shared decision-making strategies) should examine the impact of these tools to reduce implicit biases on treatment decisions or recommendations.

6. **Incorporate reporting on caregivers.** Caregivers play a crucial role in the health and health care of their loved ones. Therefore, researchers must prioritize collecting data on caregiver-reported outcomes and experiences.

7. **Study the longitudinal impact of efforts to engage patients and families.** Given the common duration of research studies, it is often difficult – or impossible – to understand the effect of PFE strategies on the long-term health and well-being of study participants. Researchers should explore ways to capture longitudinal data to better understand the long-term effect and returns on investment.

Recommendations for Health Care Providers and Decisionmakers

As we strive to create a learning health system that continuously generates and uses new evidence for the benefit of care delivery, we offer the following recommendations for decisionmakers to improve examination and implementation of emerging research:
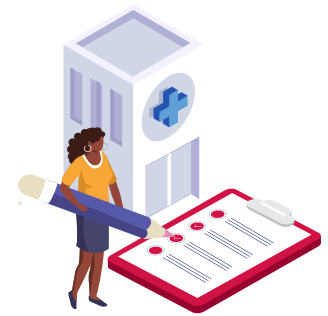
1. **Researchers must be transparent about the demographics of their study participants so that providers and policymakers can take them into consideration when designing health care policies and programs.** Not all policies or programs will work equally for all people: Individuals and communities experiencing structural racism and other inequities often face barriers to specific resources, programs, and policy solutions, even as their risk for poor health is greater. Unless providers and decisionmakers are clear as to whom evidence applies, they might design and implement programs that widen inequities.

2. **Make publicly available the shared decision-making, goal setting, and other engagement tools that are used in PCORI-funded studies.** Many patient engagement tools are proprietary or have licensing fees associated with their use. To truly advance person-centered care, publicly funded research should make tools developed and used as part of the study available online, along with complete study results. This enhances the effectiveness and speed at which important PFE strategies can be applied to improved health care delivery.

3. **Strengthen provider training in skills necessary for PFE.** Engaging in shared decision-making, active listening, joint goal setting, and motivational interviewing are critical skills for meaningful PFE but have not been consistently prioritized in medical education. These are skills that require specific training and practice in order to be effective. Similarly, providers need to understand how to communicate with and engage patients from different cultures and backgrounds to advance health outcomes and equity.

4. **Improve diversity in hiring.** There is an urgent shortage of providers of color, providers who come from historically marginalized communities, and providers trained in culturally congruent care. Promoting greater diversity in the health care workforce (including race, ethnicity, physical ability, and other factors) as well as multidisciplinary care teams is crucial to meet the needs of individuals and to produce more equitable health outcomes.

5. **Maximize options for access and communication by offering a variety of modalities to connect with and engage patients and their families.** Not all patients want to communicate in the same way, and the same patients may need different communication methods at different points in their life or disease progression. Health care providers should offer a range of communication modalities to care for patients and families with diverse preferences, familiarity, and access to technology and broadband internet connections.

6. **Consider varying levels of patient literacy and numeracy when implementing PFE interventions.** The effectiveness of shared decision-making or disease management tools depends on patients' ability to understand and apply health information, including numerical concepts (e.g., decision aids based on risk score). Providers should understand and respond to these factors when communicating risk and other relevant information to patients and families.

7. **Select and use algorithms in ways that prioritize health equity.** As algorithms are increasingly used in health care delivery (e.g., to identify patients at potential risk), health care leaders should be mindful of whether and how these technical rules inadvertently perpetuate biases. Predictive algorithms derived from biased training data sets will not perform equally well for all groups – and may exacerbate inequities.

8. **Foster a learning environment for continuous improvement.** Health care providers will face numerous challenges in adopting alternative approaches to care delivery, such as time limitations, difficulty achieving staff or leadership buy-in, and cultural resistance. In some cases, providers may think they are already providing person-centered care that engages patients and families. Health care leaders should encourage and champion an environment for continuous learning and growth.

CONCLUSION

This review of available evidence regarding the value of PFE indicates there is much to gain from transforming health care – and very little, if anything, to lose. There remain critical gaps in the evidence as to exactly how and to whom those benefits accrue – for example, based on race, ethnicity, and varying levels of health literacy – to ensure that we're getting a truly transformed and person-centered health system. This is a rich area for continued research to ensure that the people and communities most likely to experience inequities, mistreatment, and discrimination can partner meaningfully and effectively in the pursuit of better health and better care.

The findings we do have should be implemented right now to improve health, health care, and health equity. There is no reason to wait.

Testing a Decision Aid for Patients with Low-Risk Chest Pain in the Emergency Room: The Chest Pain Choice Trial

OVERVIEW

Decision aid (DA) gave patients information on their personal risk of having a heart attack to help patients and ER doctors decide whether patients would stay in the hospital for observation and tests or go home and wait for an outpatient appointment to discuss additional tests.

RESULTS

- Patients in the intervention group were less likely to decide (with clinician) to be admitted for observation and/or testing, were less likely to have cardiac stress testing within 30 days of their initial visit, and experienced shorter ER stays (90 mins).

- Patients in intervention group reported increased knowledge, increased engagement in the decision-making process, and decreased decisional conflict.

- DA increased knowledge to a greater degree in white participants than in nonwhite participants.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Patients, caregivers, and advocates were involved in the study and intervention design, monitoring study conduct, data interpretation, manuscript review, and approval of the final manuscript for publication.

Engagement in Care: DA was used to increase patient and caregiver involvement in shared, risk-informed decision-making.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
American Indian/Alaska Native: 0.9%
Asian: 1.3%
Black or African American: 34.4 %
Native Hawaiian or other Pacific Islander: 0.4%
White/Caucasian: 58.1%
Other: 4.9%

Gender:
Female: 60%

Average age: 50

Study results stratified by demographic characteristics: **limited data available**

APPLICATION/USE CASE

- Explored risk-informed decision-making in the emergency setting (rather than a chronic condition management).

- Intervention resulted in a one-minute increase in the length of clinician/patient discussion.

- 63% of clinicians would recommend using intervention, and 63% would use it for other decisions.

LIMITATIONS

- Cost is often a factor in patient's decisions about care and is not addressed in the DA.

- Need for further studies on how to ensure that patient preferences guide decision-making in ED encounters.

- Varying patient numeracy levels affect ability to communicate risk in a DA that uses numbers.

Does a Decision Aid Help Patients Learn About Their Treatment Options for Advanced Heart Failure?

OVERVIEW

Left ventricular assist device (LVAD) treatment can help patients with advanced heart failure live longer and improve symptoms, but it has risks such as stroke and infection. The research team created a DA to see whether such an intervention helped patients learn if LVAD treatment was right for them.

RESULTS

- Intervention group reported increased shared decision-making, greater LVAD knowledge, and significantly greater satisfaction with life one month after the intervention.

- Overall increase in quality of life for both groups (self-report measure from 1 to 100).

- No significant difference in rates of acceptance vs. declination of LVAD treatment.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Patient and caregivers served as research partners and as study participants at all stages.

In-depth interviews with 45 patients and caregivers to create patient-centered study procedures and outcome measures.

Engagement in Care: Intervention was designed to increase patients' knowledge, decrease decisional conflict, increase accurate risk perceptions, and increase treatment match between values and choice.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
Black or African American: 28%
Asian/non-Vietnamese: 2%
White: 67%
Prefer not to answer: 2%
Multiple: 1%

Gender:
Female: 23%
Male: 77%

Average age: 50

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- Use of the DA helped speed clinical flow by standardizing patient education at early stages of a patient's candidacy and reducing information variability.

- Demonstrates ability to engage in meaningful shared decision-making for decisions patients must make quickly while in the hospital.

- Checklist and implementation training video are available to support widespread implementation with fidelity in practice.

LIMITATIONS

- Clinics need to train hospital staff and plan for long-term use of the DA.

- Requires buy-in from senior LVAD cardiologists and cardio-surgeons at each site.

Training Staff at Doctors' Offices to Use Shared Decision-Making with Patients Choosing Asthma Treatments

OVERVIEW

Created and enrolled doctors in two training programs for use of shared decision-making (SDM) with asthma patients:

· 12 one-hour-long training sessions over 12 weeks; or

· One-time hour-long training session.

Compared two training groups to assess whether patients felt more involved in decisions about their care, as well as compared to a group with no training.

RESULTS

- Patients who visited practices with facilitator-led trainings reported greater participation in treatment decisions compared to those who went to lunch-and-learn groups.

- Both groups experienced an increase in participation overall.

- No significant difference in asthma exacerbation (compared Medicaid data on ER visits, hospitalizations, and oral steroid prescriptions).

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Patients and family caregivers involved in study planning, identification of outcomes, toolkit input, data analysis, dissemination strategy, and policy development.

Engagement in Care: Intervention designed to assess whether amount and style of provider training makes a difference in effectively engaging patients in asthma management decisions.

Patient engagement was evaluated by the following question, "Who made the decision in your meeting with the care team about what your asthma treatment would be?"

DEMOGRAPHIC DATA AVAILABILITY

Facilitator-led practices:
African American: 46.5%
Caucasian: 48.3%
Hispanic: 6.6%

Lunch-and-learn practices:
African American: 56.2%
Caucasian: 36.7%
Hispanic: 8.7%

Control practices:
African American: 59.4%
Caucasian: 32.2%
Hispanic: 11.0%

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- Facilitator-led approach allows each practice to tailor the intervention to its own needs.

- Researchers adapted major components of the SDM tool into a tablet-based tool.

- Materials available online including SDM toolkit (available in Spanish) and implementation guide.

LIMITATIONS

- Potential for uptake, although there are time and capacity constraints at small physician practices.

- Key barriers to implementation:
  - Staff buy-in;
  - Time involved in determining logistics of trainings sessions and provider training; and/or
  - Existence (or lack) of a strong learning climate and a desire to improve current practice.

Using Question Prompt Lists During Pediatric Asthma Visits to Increase Adolescent Involvement

OVERVIEW

The research team studied whether giving youth ages 11–17 a question prompt list and an educational video about asthma management in the pre-visit time helped get them more involved in clinic visits and better manage their asthma.

RESULTS

- Intervention significantly increased number of questions asked per youth and provider education about medication, triggers, and environmental control during visit.

- Youth were more satisfied with their visit and more likely to rate their providers as using a participatory decision-making style.

- Decreased number of caregiver-reported medication problems, but did not significantly affect medication adherence.

- Asthma control, asthma management self-efficacy, and quality of life did not improve significantly.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Teen patients and their families helped create educational videos and questions used in appointments for asthma patients.

Engagement in Care: Focus on self-efficacy managing asthma and teen satisfaction.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
African American: 37%
Hispanic: 13%
Native American: 11%
White: 36%

Gender:
Male: 57%

Average age: 13

Range: 11–17 years old

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- The question prompt list and video intervention are easy to implement, inexpensive, and take minimal time to complete.

- Video in English and Spanish is on a YouTube channel.

- Generalizable for pediatricians and asthma specialists.

LIMITATIONS

- Limited in geographic generalizability because it was conducted in rural and suburban areas, and not in urban and other parts of the United States.

- Requires tablet for patients to watch video before appointment.

Does a Patient- and Family-Centered Hospital Communications Program Reduce Medical Errors?

OVERVIEW

Examine whether providing an intervention to increase communication between physicians, nurses, and families to increase involvement of families in decision-making reduces hospital medical errors and adverse events within hospital pediatric units.

RESULTS

- Preventable adverse events decreased 37.9% and overall adverse events (harms to patients due to medical care) decreased 45.6%.

- Rate of overall medical errors (harmful and nonharmful) did not change.

- Improvements in safety, experience, and quality of communication on rounds without significant increase in rounds duration, or a decrease in teaching activity.

- Increase in frequency of family-centered rounds and families' experience score.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Families and health literacy experts were engaged in concept, design, and execution of study.

Family advisory council included parents with backgrounds in patient engagement and patient safety.

Engagement in Care: Focused on creating family-centered rounds where patients and parents were encouraged to provide input and were later provided a writeup of the rounds.

DEMOGRAPHIC DATA AVAILABILITY

Patients

Race/ethnicity:
Non-white: 50%

Gender:
Female: 50%

Average age: 7

Parents

Race/ethnicity:
Non-white: 53%

Gender:
Female: 81%

Average age: 36

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- Lack of additional time spent on rounds may address concerns about administrative burden.

- Study tools and results may be applicable for patients who are not able to communicate or advocate for themselves (e.g. ICU patients, geriatric patients).

- Significant results challenge assumptions about true patient-centered care, as five study sites already practiced family centered rounds-prior to intervention, though practices and levels of experience differed.

LIMITATIONS

- Many resources are required to implement intervention, including buy-in from key individuals (e.g., parent champion, hospital director), communication training for staff residents and faculty, and integration into morning rounds.

- Implementation and side effects of this profound culture shift should be explored.

Do Video House Calls with a Specialist Help Get Care to People with Parkinson's Disease?

OVERVIEW

Examine if video house calls with specialists were convenient, improved quality of life, and reduced travel time for Medicare beneficiaries with Parkinson's disease. The team also wanted to learn if video house calls improved quality of care and reduced burden on caregivers.

RESULTS

- 98% of patients completed at least one virtual house call; 84% did all four.

- Patients preferred virtual visits over in-person visits; most reported being satisfied or very satisfied with the virtual care.

- Patients who used video house calls spent less time traveling and more time talking with specialists during visits.

- After 12 months, no differences in quality of life or quality of care.

- No significant change in caregiver burden.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Researchers engaged with the National Parkinson Foundation, patient advisory board, and steering committee (which included one patient).

Engagement in Care: Engaged with patients via virtual house calls to deliver specialty care in effort to improve patient's quality of life and quality of care.

Prioritized enrollment of patients not currently seeing a neurologist or from an underserved region.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
Hispanic/Latino: 2%
Non-Hispanic
White: 94%
Other: 2%
Unknown: 3

Gender:
Female: 47%

Average age: 66

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- Beneficial for patients in rural communities and other areas lacking in access to specialists.

- Video house calls relevant and a value-add for other health conditions and follow-up appointments.

- Illustrates that quality of virtual care is comparable to in-person care. Virtual care may be preferable to patients because of comfort and convenience.

LIMITATIONS

- Clinicians must be licensed to provide care in patient's state.

- Patients must have a private, Internet-enabled device and manage periodic changes in software and operating system.

- Sites must have software and infrastructure to conduct virtual appointments, as well as staff to provide technical assistance to implementation sites and patients.

Designing and Testing a Visit Planner to Help Patients Address Their Top Concerns During Health Care Visits

OVERVIEW

The research team created a visit planner to help new patients and patients with more than one long-term health problem prepare for their visits. The tablet-based planner helped patients identify their top concerns before their visits and understand the care plan after their visits.

RESULTS

- Patients receiving the visit planner were more likely to report they prepared questions for their doctors and told their doctors their top concerns at the start of their visits.

- The two groups didn't differ in how often patients were satisfied with care, were offered treatment choices, were asked about their ideas and goals for care, took medicine as directed, or attended follow-up visits.

- After six months, no differences in closure of care gaps (e.g., needed tests and treatments).

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Extremely robust stakeholder engagement (patients and providers) in development of visit planner.

Convened a stakeholder advisory group that had a core membership of five people with chronic conditions.

Engaged stakeholders at each stage of project until thematic saturation occurred (e.g., no new suggestions) and as consensus formed.

Engagement in Care: Planner supports patient-centered decision-making as it supports patients to identify top concerns and effectively communicate their priorities with providers.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
African American: 28%
Hispanic: 22%
Asian: 7%
White: 38%

Gender:
Female: 65%

Average age: 61

Languages:
Spanish as primary language: 16%

Study results stratified by demographic characteristics: **not available**

APPLICATION/USE CASE

- Potential first step to address patient concerns in limited appointment time window.

- Researchers hope to convert tablet-based application to a nationally available website, facilitating a wider reach.

- Visit planner available in English and Spanish, so intervention can be implemented in Spanish-speaking communities.

LIMITATIONS

- Requires purchase and maintenance of tablets.

- The existing integrated care delivery approach of the study site may have moderated the clinical outcomes (results may have been enhanced in less-integrated care settings).

- Corresponding training and education for clinicians to respond to visit planners likely necessary.

Using a Decision Aid in the Emergency Room to Help Parents of Children with Head Trauma Understand Options for Diagnosing Brain Injury

OVERVIEW

When a child has head trauma, parents in the ER need to decide – with their doctor – how to check if the child has a traumatic brain injury (TBI). The research team created a decision aid (DA) to help doctors talk with parents of children with medium risk about whether their children should get computed tomography (CT) scans or have home monitoring.

RESULTS

- Parents that used the aid knew more about ways of checking for a TBI and risks, felt less conflict about the decision, and had more trust in their doctors.

- Additionally, those using the aid thought information discussed with doctors was clearer, were happier with their decisions, and participated more in the decision-making process.

- No difference in happiness with the information discussed, the number of children who got CT scans, or the number of other visits to the hospital or ER.

- No cases of TBI were missed in the group using the decision aid.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: The decision aid was refined based on the input of a parent and an emergency department patient advisory council, among others.

Decision aid was tested and feedback was collected from parents and clinicians.

Engagement in Care: Decision aid gave parents a voice in evaluating their child's head trauma and engaging in shared decision-making to check for TBI (either imaging at the hospital or observation at home).

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
Black: 12%
White: 74%
Other: 16%

Gender:
Male: 59%

Average age: 7

Study results stratified by demographic characteristics: **limited data available**

APPLICATION/USE CASE

- Use of the tool requires only two additional minutes of clinicians' time.

- Clinicians were educated via video demonstration and FAQ document. Study coordinators provided refreshers of DA to clinicians as needed during the trial.

- Demonstrates effectiveness in emergency room settings.

- DA is available online, as are shared decision-making implementation toolkits, including prepared presentations and testimonials from patients and clinicians.

LIMITATIONS

- Decision aid was not used among children with either low or high risk of TBI, so its impact with these groups is unclear.

- Ability to provide training on the use of a decision aid may affect results in other settings.

- Effects of the decision aid may be different for racial, ethnic, and other subgroups – given the large number of white participants and the finding of a lower likelihood of imaging in parents with low health literacy.

Improving Communication by Preparing Patients and Doctors for a Conversation about Care Goals for Serious Illness

OVERVIEW

Patients with serious illnesses filled out a form about their goals for care and how they would like to discuss those goals. In one group, patients, doctors, and families saw information from the form before a visit. The other group didn't see the results. Tested whether filling out a communication tool alone is as effective as sharing the tool with family and provider before routine clinic visit.

RESULTS

- Patients in the group who saw the results of the form were more likely to talk with their doctors about goals for care. They reported better communication with their doctors and were more likely to report receiving care in line with their goals (as long as those goals did not change later in the study).

- Symptoms of depression or anxiety and rates of referrals did not differ between the two groups.

PATIENT AND FAMILY ENGAGEMENT

Engagement in Study: Patients with serious illnesses, family members, and community members served on the community advisory board that provided input on study materials and design.

Engagement in Care: Intervention designed to promote discussions between providers and the patients about his or her goals of care, based on the patient's self-reported preferences for communication.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
Black: 12%
Hispanic: 1%
Asian: 3%
White: 79%
Other/mixed race: 6%

Gender:
Male: 52%

Average age: 74

Study results stratified by demographic characteristics: **not available**

APPLICATION/USE CASE

- Final research report includes information on necessary resources for health systems interested in replicating the intervention, including communication form and video on how to use the form.

- Holds promise for health care systems seeking to increase goals-of-care communication for all patients.

- The majority of patients indicated they want to have these kinds of conversations with their physicians, signifying the value of tools that promote discussion about goals of care.

- Clinicians in study provided all types of care: family physicians, physician specialists, nurse practitioners, and physician assistants.

LIMITATIONS

- Requires process to identify patients eligible for goals-of-care conversation and set up infrastructure to track patent responses.

- Requires the ability to collect and integrate patient information into the electronic health record.

- Clinicians and patients may have varying levels of interest, comfort, or capability talking about goals of care.

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

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.

DEMOGRAPHIC DATA AVAILABILITY*

Race:
Black: 3%
Pacific Islander: 2%
Asian: 6%
American Indian/Alaska Native: 2%
White: 63%
Other: 24%

Ethnicity:
Hispanic/Latino: 34%

Gender:
Women: 50%
Men: 50%

Average age: 49

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- 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.

LIMITATIONS

- 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.

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

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.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity
Among children:
Black, non-Latino 2%
Latino: 87%
White, non-Latino: 7%
Other, non-Latino: 4%

Among parents:
Race/ethnicity
Non-Hispanic African American: 2%
Latino: 87%
Non-Hispanic white: 7%

Average age:
8.6 years old

Gender:
Male: 62%

Gender:
Women: 96%

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- 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.

LIMITATIONS

- 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.

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

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

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.

DEMOGRAPHIC DATA AVAILABILITY

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/USE CASE

- 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.

LIMITATIONS

- 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 in-person 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.

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

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.

DEMOGRAPHIC DATA AVAILABILITY

Race/ethnicity:
Non-Hispanic African American: 3%
Hispanic/Latina: 9%
Non-Hispanic Asian: 2%
Non-Hispanic white: 82%
Non-Hispanic mulit-race: 2%

Gender:
Women: 100%

Average age: 31

Education:
71% of participants held a college degree

Study results stratified by demographic characteristics:
not available

APPLICATION/USE CASE

- 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.

LIMITATIONS

- 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

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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.