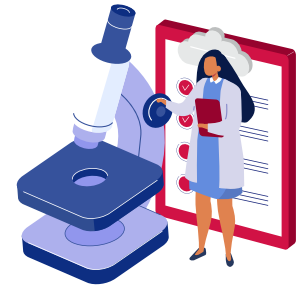


RECOMMENDATIONS

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.

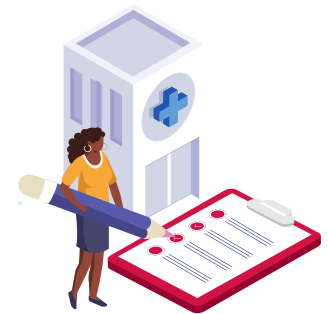


- 1. Require partnerships with diverse community leaders and organizations to ensure research prioritizes the needs and preferences of patients and families.** We should prioritize outcomes that people care about, over the largely clinical outcomes typically prioritized by researchers. To expedite progress 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.