

The Role of Patient-Centered Outcomes Research in Improving Evidence and Advancing Health Equity

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The Center on Health Equity Action for System Transformation is the only national entity exclusively dedicated to the development and advancement of patient-centered health system transformation policies designed to reduce racial, ethnic, and geographic inequities. We focus on advancing equity while improving outcomes, increasing value, and lowering costs. We catalyze and coordinate action to develop and implement health equity-focused health care delivery and payment policies. We achieve impact by partnering with and supporting community leaders, health equity experts, and other stakeholders at national, state, and local levels.



The Evidence for Equity Initiative focuses on synthesizing, translating, and disseminating evidence to help community leaders and decision-makers in developing and implementing effective health equity policies and programs, particularly Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER).

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The ongoing effort to transform health care in the United States is an important opportunity to address racial, ethnic, and other health inequities directly and deliberately. A central pillar in delivery system and payment reform is the principle of promoting evidence-based care: Incentivize treatments with strong evidence of success and appropriate value, and disincentivize those that are not supported by a strong evidence base. The accuracy and completeness of available clinical and health systems research results have direct implications for the quality and safety of the care that we receive. Increasingly, this research informs not only clinical practice but also provider payment and even insurance benefit design.

To ensure these transformation efforts not only result in high-value and high-quality care but also help reduce health inequities, decision makers need a reliable, representative, and transparent evidence base to guide their decisions about allocation of resources and the design of health care delivery and payment systems.

Unfortunately, the Institute of Medicine notes that most treatments provided in this country are not well-supported by evidence.¹ First, historically, most medical research has studied the average efficacy and safety of individual medications, medical devices, and treatments.² However, relatively few studies have compared the effectiveness of different options.

The evidence available to inform both clinical practice and payment reform is incomplete and often biased, and it rarely measures outcomes that are most important to patients and their families.

Second, most clinical and health systems research is based on the experiences of unrepresentative groups of subjects.³ Women, children, and communities of color have been significantly underrepresented in medical research.⁴ Third, even when the subject pool is more diverse, researchers may not disaggregate results by demographics in a way that would allow for more comprehensive analyses. Instead, findings tend to be generalized across all populations, which may not always be appropriate and may fail to identify some important variations. Without detailed information about the treatments and interventions that are effective for specific communities that experience disproportionate burdens of particular conditions, narrowing these inequities will be difficult. Finally, clinical and health systems research primarily focuses on outcomes defined by researchers and clinicians, which may not necessarily include the kinds of outcomes that patients would find most useful in helping them make decisions about their health care.⁵

In summary, the evidence available to inform both clinical practice and payment reform is incomplete and often biased, and it rarely measures outcomes that are most important to patients and their families. Moreover, insufficient useful evidence is a problem across the entire health system—not only as it relates to communities of color.

Diversity in Research

Generating a richer, more complete evidence base that allows for race- and ethnicity-specific subgroup analyses is essential to achieving equitable care.

Patient-centered outcomes research (PCOR) is intended to produce information on the results that matter most to patients and their families and to shape clinical research around those questions. As discussed below, PCOR has an important role in improving the evidence available to develop treatments, modes of delivering care, and targeted strategies to reduce inequities, and in helping patients, their families, and providers to make better decisions. This paper describes the limitations of traditional approaches to clinical and delivery systems research, the advances that led to increased federal support for comparative effectiveness research (CER) and PCOR, and the implications of these research approaches for health equity and for medical science more broadly.

Exclusion of Communities of Color in Research Contributes to Many Health Inequities

Including diverse research subjects in medical and health system research—particularly people of color—has long been a challenge in this country. This lack of diversity has created a troubling mismatch between the available evidence and its applicability to particular communities. The participation of sufficient numbers of diverse subjects in research enables analysis of whether specific treatments are generally effective for everyone, or if there are significant differences in outcomes depending on subjects' race, ethnicity,

and other defining factors. Generating a richer, more complete evidence base that allows for race- and ethnicity-specific subgroup analyses is essential to achieving equitable care.⁶

Improving the evidence base is increasingly important because of the role of evidence in informing clinical practice guidelines. Guidelines are recommendations developed by organizations, such as medical associations, to inform clinicians' and patients' decision-making about appropriate treatments and interventions for specific clinical circumstances, based on systematic reviews and synthesis of existing evidence. However, the impact of guidelines extends beyond the medical decisions made by patients and their providers. Insurers use them to decide what services to cover, and policymakers use them to determine which health programs to fund and health policies to implement. Guidelines are considered an important mechanism to help improve and standardize the quality of care provided, decrease inappropriate variations in care, and reduce provision of treatments that do not improve health outcomes and might even harm patients.⁷

However, despite the growing importance of evidence-based clinical practice guidelines in improving our health care system and people's health, communities of color remain severely underrepresented in research as both participants and investigators.

Blacks and Latinos, for example, have constituted only 6 percent of all participants in federally funded studies but account for almost one-third of the total U.S. population.⁸ Further, less than 5 percent of federally funded lung disease research has focused on communities of color in the last 20 years despite higher prevalence of lung-related diseases and mortality among Blacks.⁹ Underrepresentation of people of color also plagues cancer research.¹⁰ Racial and ethnic minority populations have the highest burden of cancer prevalence but are the primary target of less than 2 percent of the National Cancer Institute's clinical trials.¹¹

Many factors influence the significant underrepresentation of people of color in medical research, including the fact that, historically, communities of color have been subject to grossly unethical research practices.¹² The resulting mistrust of medical research and the broader health care system has lowered participation in research. The lack of diversity among researchers also plays a role. Black, Latino, and other minority researchers are more likely to examine health issues among communities of color. However, white investigators are twice as likely as their Black peers to receive National Institutes of Health (NIH) research grants, even when controlling for education, training, and experience. Inadequate researcher training on designing and implementing studies in minority communities, and an absence of incentives to recruit and retain minority participants, compound the lack of diversity among researchers. The time and resources needed for subjects to travel to and spend time at research sites also present barriers.¹³

Underrepresentation in Research Leads to Health Inequities

The exclusion of communities of color in research is one factor that has fueled health inequities for decades. For reasons that are insufficiently understood, communities of color experience disproportionate rates of cancer deaths. For example, compared to Whites, American Indians and Alaska Natives are 48 percent more likely to die from stomach cancer and almost two-thirds more likely to die from liver cancer.¹⁴ Latinas are more likely to die from cervical cancer¹⁵ than white women, and Black men are twice as likely to die from prostate cancer than their white counterparts. Breast cancer mortality rates have decreased in the past several years but have remained disproportionately high among Black women, even though they are slightly less likely to develop breast cancer than white women.¹⁶ One factor in this higher mortality rate is that no effective treatment is available for the aggressive breast cancer subtypes most prevalent among Black women, while targeted and effective treatments are available for the subtypes most commonly found among white women.¹⁷ Furthermore, in cancer research, the paucity of people from these communities in clinical trials denies them an equitable opportunity to benefit from participation in potentially more effective cancer interventions and, ultimately, diminishes their chances of survival.¹⁸

Inequities in cancer-related mortality rates are only one example of the need to close the clinical research gap. Other instances of ineffective drug therapies undermining the well-being of communities of color include:

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- » Puerto Ricans and Blacks are more likely than Whites to have asthma,¹⁹ but albuterol, the first-line treatment for asthma attacks, is less effective for these populations.²⁰ Unsurprisingly, both groups are more likely to end up in emergency departments because of acute asthma attacks,²¹ and more likely to die from this condition.²²
 - » Native Hawaiians and Pacific Islanders are three times as likely as Whites to be diagnosed with coronary heart disease.²³ However, three-quarters of Pacific Islanders have a genetic trait that makes them react adversely to clopidogrel (brand name Plavix), a blood thinner commonly used to prevent strokes and heart attacks. As a result, that medication actually increases their risk of the very condition it is formulated to prevent.²⁴
 - » Warfarin is the most commonly used anticoagulant medication in the country. However, 86 percent of people of Asian descent are hypersensitive to the drug, putting them at risk for excessive bleeding at higher therapeutic doses.²⁵
- The impact of the clinical research gap on the health of racial and ethnic minority communities is well known. Multiple initiatives across federal agencies, including the NIH, the Federal Drug Administration (FDA), and the Centers for Medicare and Medicaid Services, have been deployed to help address this issue.²⁶ In addition, Congress has enacted legislation designed to increase the representation of communities of color and other marginalized groups in clinical research.²⁷ However, while these efforts are encouraging, they have not yet resulted in achieving an evidence base that reflects our population.

Researching Adverse Childhood Experiences in American Indian Communities: The Importance of Community Partnership

Childhood trauma can affect healthy brain development and physical, social, mental, emotional, and behavioral health and well-being.²⁸ Adverse childhood experiences (ACEs) can have a significant impact on one's health as an adult and are linked to elevated risk for poor health behaviors, chronic health conditions, and premature death.²⁹ Moreover, there is a clear dose effect—the more ACEs an individual experiences, the higher the risk.

ACEs affect all communities, but children of color are more likely to be subjected to multiple ACEs. One in three Black children experiences two or more ACEs, compared to one in five white non-Hispanic children, and Latino children are 25 percent more likely to experience one or more ACEs than non-Hispanic white children.³⁰ Therefore, effective health equity strategies must include efforts to prevent ACEs in the first place, identify children at higher risk, and develop and implement interventions to mitigate their impact and ensure children are healthy and stay as healthy as possible throughout their lives.

Health inequities are pervasive among American Indian and Alaska Natives (AI/AN). Therefore, researching the prevalence and impact of ACEs on AI/AN children is an important potential basis for developing strategies to reduce these

inequities. Furthermore, existing data shows that AI/AN children are more likely to experience certain adverse experiences, such as poverty, than white children.³¹ However, conducting research in AI/AN communities requires sensitivity to an ugly history of outside researchers' prioritizing their own community's norms over respect for AI/AN traditions or sovereignty.³² Outside researchers have failed to maintain collaboration, transparency, and respect in their conduct and methods.³³ For example, researchers working with members of the Havasupai in Arizona misused blood samples from participants to conduct research on topics that the tribe considers taboo. Another study published its results on venereal diseases among a Native American community in a local newspaper without properly masking its identity, stigmatizing the group.

When researchers working in South Dakota sought to examine the prevalence of disparities in alcohol and drug use and mental health conditions in rural areas and reservations, they took a different approach—community-based participatory research.³⁴ Researchers obtained permission from seven of the nine tribes in South Dakota before starting to collect data, and they did not collect data from tribes that did not provide permission. The team was co-led by an investigator who is a member of

a South Dakota tribe and who had experience conducting research with AI communities. Further, research assistants from within reservation communities were hired to help collect data. The team also shared the study's findings with the leadership of participating tribes. The data collected resulted in the South Dakota Health Survey, which is noteworthy for oversampling AI communities previously underrepresented in state data, thereby ensuring their inclusion in the evidence base.³⁵

The same research group used the South Dakota Health Survey to evaluate ACEs among AI communities in the state. They found that 20 percent of adults had experienced six or more ACEs, compared to 4 percent of non-AI adults. Further, the study found that AI adults were more than twice as likely to have post-traumatic stress disorder and be current smokers, and 86 percent more likely to have depression, than non-AI adults.³⁶

This team's methods address understandable community hesitations and illustrate what research and researchers should consider when undertaking studies in communities of color, and especially among those with experiences of trauma, whether historical or contemporary.

The Role of CER and PCOR in Generating Better Evidence for Equity

Given that the nation is in the midst of health system transformation and that we are less than one generation away from becoming a “majority minority” country,³⁷ addressing disparities in clinical and health systems research must be a top priority. The overall quality and efficiency of the health care system depends on whether it can evolve into one that eliminates health inequities and can provide excellent care for everyone, regardless of income, background, or identities. In recent years, there has been an increasing focus on two approaches to medical research intended to help patients, providers, payers, and policymakers make more informed decisions that align more effectively with patients’ priorities: CER and PCOR.

CER and Health Equity

The purpose of CER is to assist patients, clinicians, purchasers, and policymakers to make more evidence-based decisions that support better health care quality and improved individual and population outcomes. The ubiquitous traditional model of clinical research is to compare a given treatment modality to a placebo or other control. CER goes several steps further by directly comparing the benefits and harms of two or more alternative methods to prevent, diagnose, treat, or monitor a clinical condition or to improve the delivery of care at both the individual and population levels.³⁸ CER also has the potential to directly address the concerns discussed above regarding representation and disaggregation of evidence for communities of color. CER includes a strong focus on analyzing what alternatives work best, for whom, and under what circumstances—including for subgroups that may have been overlooked in prior research. In addition, CER focuses on testing alternatives in real-world, community settings, not just in laboratories.³⁹ In this

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way, CER is intended to be considerably more useful than traditional clinical studies in developing clinical practice guidelines, best practices, and policies, including those that account for diverse populations and allow for targeted interventions that directly address health inequities.

CER involves de-emphasizing some elements of traditional clinical research. Although randomized controlled trials (RCTs) are considered the gold standard of clinical research, they have some significant shortcomings that can reduce the applicability of their results. RCTs are usually conducted in academic settings that may not be as accessible to diverse communities, contributing to the absence of subpopulations not typically represented in or recruited for research.⁴⁰ In addition, RCTs generally have highly exclusionary criteria⁴¹ that disqualify potential participants, such as those who have comorbid conditions. Such exclusions limit the pool of subjects, as well as the general applicability of results in the real world, given that one in four Americans has more than one chronic condition.⁴² Further, RCTs generally seek to identify aggregated outcomes

for hypothesis testing.⁴³ As described earlier, these aggregated findings are too often based on essentially homogeneous subjects. However, even if the subjects are diverse, an aggregated study cannot provide the specific data needed to ensure that we surface the best treatments for particular groups.

Another clinical approach to building the evidence base is observational research that uses administrative claims databases. Claims-based research has significant limitations in its ability to provide reliable data that is generalizable and relevant for diverse populations.⁴⁴ Whether and how race and ethnicity data are collected in payer data is uneven, and often incomplete. Even when race and ethnicity data are available, they are often collected, analyzed, and reported in aggregated groups that mask clinically important differences among subgroups of larger categories such as Asian Americans and Latinos. Some groups are often missing altogether; these include Pacific Islanders, Native Hawaiians, American Indians, and Alaska Natives. The absence of subgroups in data used in these types of studies means researchers cannot examine important racial and ethnic variations, making the data less relevant and useful.⁴⁵ For example, only by separating the data on Puerto

Ricans from those of other Latino populations in the U.S. was it possible to identify serious inequities in asthma prevalence, outcomes, mortality, and albuterol response. Looking at Latino data overall obscured these critical inequities.

CER helps to address many of these limitations. It is conducted in a variety of clinical settings, including in community-based settings, and typically uses diverse populations and subgroups to achieve results that may be generalizable to the overall population, and often have a special focus on groups frequently absent from clinical trials, such as communities of color.⁴⁶ Moreover, because CER is often conducted in more accessible community settings, in addition to promoting a more diverse subject pool it better reflects real-world conditions. CER is explicit and intentional about studying subgroups and not generating “one size fits all” results. CER studies are often designed to tease out variations in response by people with specific characteristics, making it possible to tailor recommendations to particular groups and circumstances. As a result, CER can be useful in generating the more robust and representative evidence base needed to advance equity.⁴⁷

Subgroups in Data

Even when race and ethnicity data are available, they are often collected, analyzed, and reported in aggregated groups that mask clinically important differences among subgroups of larger categories.

PCOR: Going Further

PCOR aims to prioritize the research questions that will be most useful to patients in guiding their decisions about their and their families' health care: Of the available options, which is best for us?

CER received a significant boost with the passage of the American Recovery and Reinvestment Act of 2009, which allocated \$1.1 billion to CER.⁴⁸ A variety of research institutions and government agencies have supported CER, including the NIH, the Agency for Healthcare Research and Quality (AHRQ), the Department of Veterans Affairs, and the Office of the Secretary of Health and Human Services.⁴⁹

PCOR and Health Equity

PCOR adds another dimension to CER, focusing on results that patients prioritize. Traditionally, medical research has examined the questions that clinicians and researchers deemed important, which were not necessarily those that mattered to patients and their families.⁵⁰ In assessing outcomes for a particular medication, clinicians might focus on biomedical outcomes, such as blood test results, while patients might focus more on quality of life measures such as side effects, pain management, or the ability to engage in activities that are important to them. To illustrate, studies researching Alzheimer's disease often focus on objectively measurable changes in cognitive function. While this is important to science, patients and their caregivers may care more about what treatment is most likely to preserve the patient's autonomy and extend

his or her ability to participate in activities of daily life.⁵¹ Similarly, the parents of an asthmatic child may prioritize whether a medication helped the child sleep through the night and go to school the next day as much as, or more than, specific changes in pulmonary function. That said, PCOR should not be confused with patient satisfaction research, which focuses on the patient-provider relationship, communication, and the patient's overall assessment of how well they were treated.

PCOR aims to prioritize the research questions that will be most useful to patients in guiding their decisions about their and their families' health care: Of the available options, which is best for us?⁵² Therefore, in addition to comparing at least two treatment options, PCOR focuses on finding the answers that matter most to patients by meaningfully engaging them and their caregivers in research from beginning to end. PCOR recognizes that patients should be more than just research end-points and should be engaged not only in their health care but also in the planning, implementation, analysis, and dissemination of health care research.⁵³

An important benefit of engaging patients and caregivers in the planning aspects of research is that they will be more likely to flag research issues most important and relevant to them⁵⁴ and may

come up with novel ideas that might not occur to bench researchers. These patient contributions can generate new discoveries. Even before the advent of PCOR as a conceptual frame, history provides some compelling examples of patient contributions to clinical research design:

- » It was the mother of a patient with vaginal cancer who first suggested that her own use of the synthetic estrogen diethylstilbestrol (DES) during pregnancy may have been linked to her daughter's cancer.⁵⁵ This was later confirmed, leading to the FDA withdrawing its approval for use of the drug during pregnancy.
- » The mother of a child suffering from a developmental condition due to an additional chromosome (Edward's Syndrome or Trisomy 18) first suggested that low levels of an alpha fetoprotein (AFP) may be a prenatal indicator for this chromosomal anomaly.⁵⁶ Today, AFP testing is routinely offered to pregnant women as a screening option.

PCOR's emphasis on patient engagement and use of real-world populations and settings is an important opportunity to advance health equity by broadening the evidence base and making it more transparent, relevant, and actionable. PCOR opens the door to significantly more diverse research subjects that generate priorities and questions that are directly responsive to the needs of different communities that may hold particular values and experience a variety of challenges. Expanding the evidence base so it is more representative will help produce more effective and generalizable therapies, interventions, and strategies that work for more people.

Another way PCOR has the potential to advance health equity is that meaningfully engaged patients may help improve the quality, relevance and impact of research by challenging and countering researchers' assumptions. Engaging diverse patient populations is particularly necessary considering the relatively small number of researchers of color. In addition to promoting the inclusion of more diverse populations, patient involvement can serve as a check on researcher biases that otherwise might go undetected and that might lead to inaccurate research results.

Interest in and funding for CER and PCOR has increased over the last several years. Federal research organizations in particular have increased support and implementation of patient-centered approaches. For example, AHRQ has involved patients in nominating and prioritizing topics for systematic reviews and selecting research questions and primary outcomes.⁵⁷ The NIH has collaborated with public interest organizations, including rare disease organizations, to guide research priorities for several years.⁵⁸ Similarly, to help prioritize their research agenda, the FDA launched its Patient-Focused Drug Development Initiative in 2013, aimed at gathering patient perspectives on the severity of and available treatment options for 24 conditions.⁵⁹

The Patient-Centered Outcomes Research Institute and Its Potential to Advance Health Equity

The Patient-Centered Outcomes Research Institute (PCORI) is an important component of the growing role of PCOR in the federal health care research enterprise. PCORI has played a critical role in advancing and supporting PCOR, including research focused on addressing disparities. Created by Congress as an independent nonprofit in 2010 through the Affordable Care Act, PCORI was directed to:

“[A]ssist patients, clinicians, purchasers, and policymakers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis that *considers variations in patient subpopulations*, and the dissemination of research findings...”⁶⁰ (Emphasis added.)

Given this charge, PCORI studies must include patient perspectives and rely on them to help determine which health care options work best for which patients given their values, preferences, goals, and other relevant characteristics.⁶¹

PCORI’s Approach to Research

According to PCORI’s description of its work, in addition to comparing the effectiveness of at least two interventions, PCORI research projects must also:

- » Focus on the research topics, questions, and outcomes that are most important to patients and those who care for them.
- » Be guided by priorities developed through close partnerships with a range of health care stakeholders—including patients, caregivers, scientists, clinicians, health systems, and insurers.
- » Include patients not only as subjects, but also as partners who help determine what to study and how.⁶²

FOR EXAMPLE

To test or not to test?

Daily home blood glucose monitoring has long been recommended for people with diabetes, including those with non-insulin–dependent type 2 diabetes.⁶³ However, evidence of benefit to those who do not use insulin was unclear, and pricking oneself daily to test glucose levels can be painful, inconvenient, and costly. Research specifically on the value of this level of monitoring on this population was lacking. PCORI funded a study to determine whether non-insulin–dependent people with diabetes who tested daily achieved better control of their glucose levels than those who did not.⁶⁴ The study found almost no difference between the two groups after one year.

Research projects must explore patient-centered topics and must show they have potential outcomes that would influence practice and improve decision-making and health.

PCORI promotes the inclusion of patient perspectives in research by encouraging partnerships among researchers and patients during the research funding application process and throughout research planning and implementation.⁶⁵ Research projects must explore patient-centered topics and must show they have potential outcomes that would influence practice and improve decision-making and health.⁶⁶ Additionally, PCORI solicits questions from patients and caregivers on what matters most to them and then involves them in prioritizing these questions to guide research funding.⁶⁷ PCORI also appoints and convenes multi-stakeholder advisory panels that include patients, caregivers, clinicians, researchers, policymakers, and others to help develop and prioritize research questions, assess which are ripe for evidence synthesis or new research, and review findings. From 2013 to 2017, this included the Addressing Disparities Advisory Committee, which was later merged with the Advisory Panel on Improving Health Systems to create the current Advisory Panel on Healthcare Delivery and Disparities Research.⁶⁸

PCORI has awarded \$2.1 billion for more than 600 PCOR studies and other projects.⁶⁹ A substantial number of these awards have focused on addressing health

disparities or on specific racial and ethnic minority populations. As of August 2018, PCORI's Addressing Disparities program had provided \$252 million to fund 81 studies designed to provide people at risk for disparities the data that they, their caregivers, and providers need to improve their health.⁷⁰ Projects include:

» **Helping Latino parents better manage their children's mental health care: a tailored educational program versus a support group.**

Latino children with mental illness are half as likely to receive mental health care as their non-Hispanic white peers. Latino parents have reported that they have a hard time getting appropriate care. Researchers developed an education program to help Latino parents and caregivers develop parent activation skills to secure mental health care for their children, and compared the program to participating in a parental support group. The education program included helping parents to build confidence and advocate for their children's health care needs and to identify when and where to get help for their children. Results showed that the education program was more effective than the parental support groups.⁷¹

» **What is the best way to ask patients about sexual orientation and gender identity in the emergency room: filling out a form or talking to a nurse?** Hospitals typically do not ask about a patient’s sexual orientation or gender identity, information that can be relevant to improving the quality of care. Researchers tested two methods to collect this information: having a nurse ask the patient and having the patient fill out a form. Results showed that patients were more comfortable filling out a form than speaking with a nurse.⁷²

» **Increasing hepatitis B and C screening among Asian-Americans with mobile apps: Is a hepatitis-specific app more effective than a general health app?** Asian-Americans are at higher risk for contracting hepatitis B and C and three times more likely to get liver cancer than their white peers. Researchers compared two technology-based approaches aimed at increasing screening. One group of Asian-American patients received a general mobile health app, and a second group received a more specific hepatitis health app that taught them about the virus and prepared them to ask a provider about screening. Patients using the hepatitis app were more likely to report talking to their provider about the virus and to get tested.⁷³

In addition to research funded directly through the Addressing Disparities portfolio, other PCORI programs have funded research to address racial, ethnic, and other health inequities. For example, the Improving Health Systems program (later part of the Healthcare Disparities and Delivery Research program) separately funded 44 additional projects that address inequities, for a total of 125 projects.⁷⁴

Conclusion

As we seek to transform our health care system so it is more efficient, affordable, and equitable, patients, caregivers, clinicians, payers, and policymakers need reliable, relevant evidence to inform their decisions. Yet there are enormous gaps in the current evidence base, and we do not know whether much of the evidence we have holds true for racial and ethnic minorities and other groups that experience health inequities and are underrepresented in medical and health systems research. Ensuring a representative and transparent evidence base is a foundational priority for advancing health equity.

CER and PCOR provide important windows of opportunity to remedy evidence deficiencies. These approaches are intended to incorporate the experiences and priorities of diverse populations. PCOR has the potential to make a significant difference in generating improved evidence to support health equity by informing the development of tailored treatments, interventions, guidelines, and policies.

KEY TERMS

Comparative effectiveness research (CER): Compares the benefits and harms of two or more existing health care options to determine which works best for which patients.⁷⁵

Community-based participatory research: Generally undertakes a collaborative approach that equitably involves community members of interventions as partners in the research process.⁷⁶

Patient-centered outcomes research (PCOR): Compares two or more existing health care options to determine which works best for which patients, and under which circumstances, based on the needs, preferences, and outcomes most important to patients and those who care for them.⁷⁷

Randomized controlled trials (RCTs): Studies in which the participants are divided randomly into separate groups that compare different treatments or other interventions. Dividing participants by chance means the groups will be similar and makes it possible to compare the effects of the treatment or intervention fairly, and average the results. At the time of the trial, it is not known which treatment is most effective.⁷⁸

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