

**Breaking the Barriers to Specialty Care** Practical Ideas to Improve Health Equity and Reduce Cost



Ensuring High-Quality Specialty Care



REIMAGINING SOCIAL CHANGE



Bristol-Myers Squibb Foundation

## About this series of briefs

This series aims to highlight the urgent need for the health care sector to make progress towards achieving equity in outcomes from diseases that require specialty care and to identify effective solutions for the payers, providers, policy makers, patient organizations, and community actors who will be critical to creating change.

The series was researched and written by FSG with the support and partnership of the Bristol-Myers Squibb Foundation. Findings were informed by an extensive review of clinical and field studies and more than 60 interviews with field experts, health care providers, and representatives from insurance companies. This work builds on the exceptional research in this field done by many others, referenced throughout this report. A full list of references and contributors can be found at the end of each brief. To access all the briefs in this series, please visit **www.fsg.org/publications/breaking-barriers-specialty-care**.

## About Bristol-Myers Squibb Foundation

The mission of the Bristol-Myers Squibb Foundation is to promote health equity and improve the health outcomes of populations disproportionately affected by serious diseases and conditions by strengthening community-based health care worker capacity, integrating medical care and community-based supportive services, and mobilizing communities in the fight against disease.

In 2015, the Bristol-Myers Squibb Foundation launched the Specialty Care for Vulnerable Populations Initiative, which aims to address inequities in access to and utilization of specialty care services in the United States. The goal of this national initiative is to catalyze sustainable improvement and expansion of specialty care service delivery to achieve more optimal and equitable outcomes for the people they serve who are living with cancer, cardio-vascular disease, or HIV/AIDS.

Learn more at www.bms.com/foundation.

## About FSG

FSG is a mission-driven consulting firm supporting leaders in creating large-scale, lasting social change. Through strategy, evaluation, and research, we help many types of actors—individually and collectively—make progress against the world's toughest problems.

FSG seeks to reimagine social change by identifying ways to maximize the impact of existing resources, amplifying the work of others to help advance knowledge and practice, and inspiring change agents around the world to achieve greater impact. With a deep commitment to health equity, FSG works with actors across sectors, including foundations, companies, governments, and nonprofits to accelerate and deepen population health improvements in the United States.

As part of its nonprofit mission, FSG also directly supports learning communities, such as the Collective Impact Forum, Shared Value Initiative, and 100,000 Opportunities Initiative, to provide the tools and relationships that change agents need to be successful.

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## About this brief

This brief focuses on the effect that a patient's experience in the health care environment has on their ability to access, engage, and benefit from specialty care and the steps that health care providers are taking to improve that experience, particularly for low-income and minority patients.

## About specialty care

Specialty care encompasses health care services dedicated to a specific branch of medicine—in other words, all health care services not considered primary care. Typically, patients are referred to a specialist by a primary care provider for disease-specific care that requires expert diagnosis and management. Specialty care encompasses many common and serious disease areas, including cardiology, oncology, rheumatology, immunology, psychiatry, and many others. Across disease areas, many patients face more challenges accessing and staying engaged in specialty care than in primary care.

### **Snapshot: Ensuring High-Qualty Specialty Care**



### **Target Patient Populations**

- Low-income patients
- Minority patients
- Low-English proficiency patients

#### **Relevant Drivers of Inequity in Specialty Care**

- Cultural and linguistic challenges
- Implicit biases among providers that result in sub-optimal treatment
  - recommendations and limited choice for patients
- Lack of patient empowerment and confidence with medical decision-making

#### **Health Equity Solutions**

- Culturally-competent care and language services
- Efforts to address implicit bias among health care workers
- Harnessing quality improvement approaches to target disparities

## Relevant patient groups and disease areas

Challenges associated with the patient experience present barriers to optimal outcomes in all specialty areas. This brief, however, will dedicate specific attention to the following groups.

- **Patients of an ethnic or racial minority group:** These patients are most likely to experience discrimination in their interactions with health care providers.
- Low-English proficiency patients: Patients who cannot communicate directly with their doctors face additional barriers to quality care, and doctors are challenged to build relationships and clearly understand patient needs.
- **Health care providers:** Both clinicians and provider institutions are the primary audiences to adopt the solutions highlighted in this brief.



## The Equity Challenge: Inconsistent Specialty Care Quality

Ensuring equitable availability of specialty care does not by itself solve the health equity challenge. Even for those engaged in care, a number of factors related to the health care environment and the doctor-patient relationship influence quality of care and health outcomes. This is particularly true for patients who belong to a racial or ethnic minority group, low-English proficiency (LEP) patients, and patients who hold cultural and religious beliefs that are different from those held by most health care providers. For these patients, the specialty care experience can be more intimidating, confusing, difficult to manage, or even hostile than for others—and this divergence has clear effects on health outcomes.

An indication of this unfortunate truth are patients' reflections on their own experiences: surveys have shown that African American, Latino, and Asian American patients are significantly more likely to feel that they would receive higher quality care if they were a different race or ethnicity than white non-Latino patients (*see Figure 1*).<sup>1</sup> Several factors are driving this perception:

Cultural and linguistic differences: For many patients, cultural and linguistic differences act as a barrier to quality care. Under civil rights and disabilities laws, recipients of public funds for health care (e.g., Medicaid and Medicare recipients, patients at federally funded facilities) are entitled to an interpreter in each medical appointment. The actual use of interpreters or multi-lingual materials, however, is limited. Payers generally do not reimburse for interpretation services. As a result, surveys suggest that only half of patients who need translation services have regular access to it during health appointments.<sup>2</sup> At a time when one in five Americans does not speak English at home,<sup>3</sup> insufficient investment in doctor-patient communication will increasingly contribute to poor health quality. Hospitals and specialty care centers in particular are less likely to provide signage, pamphlets and informational materials in languages other than English than are primary care facilities that cater to a higher proportion of non-native speakers.



### Figure 1. Racial and Ethnic Minorities are Less Satisfied with the Health Care They Receive



Beyond language, providers often fail to understand and accommodate the diverse values, beliefs, and interpersonal styles of patients that are different from their own.<sup>4</sup> Surveys suggest that only 48% of Asian American and 47% of African American patients believe that their health care provider understands their background and values.<sup>5</sup> In another survey, **19% of transgender people report being denied treatment for being non-gender conforming, and 28% respondents postponed treatment due to fear of discrimination**.<sup>6</sup> These experiences with providers can diminish patient trust in the health care system, lead to patients feeling disrespected by their health care provider, and hamper a patient's ability to make appropriate decisions about their medical care.<sup>7</sup> A 2007 study of Spanish-speaking female patients illustrated this impact: **patients with access to language-concordant information were twice as likely to be up-to-date on recommended breast, cervical and colorectal cancer screenings than those operating in their non-primary language.<sup>8</sup>** 

Implicit bias: A growing body of evidence points to a second challenge facing patients of a racial or ethnic minority in the health care system: implicit bias among health care providers. Implicit bias refers to unconscious attitudes, perceptions and stereotypes that individuals act on unintentionally, unlike conscious racism or bigotry.<sup>9</sup> While implicit bias can apply to many demographic characteristics, implicit bias toward racial and ethnic minority groups is the most pronounced, and a growing body of evidence suggests that implicit bias is a driving factor in creating health disparities.

Studies have shown, for example, that health care workers are more likely to underestimate levels of pain and prescribe less pain medication for black patients than white patients.<sup>10</sup> A 2015 study of hospital-based physicians in Pennsylvania found that physicians exhibited fewer positive, rapport-building nonverbal cues with their non-white patients, such as listening to a patient's story, remaining positive, or offering the patient a social touch (e.g., a hug or handshake).<sup>11, 12</sup> On average, health care workers are also more likely to believe that black patients will not adhere to treatment recommendations than their white peers.<sup>13</sup>

This bias has a direct impact on the quality of specialty care that minority patients receive. Studies have shown, for example, that black and Hispanic patients are far less likely to be counselled on smoking cessation than white patients (*see Figure 2*).<sup>14</sup> Another study looked at the rate of necessary invasive cardiac procedures for more than 10,000 cardiac patients and found differences in surgery across both race and gender: **relative to white men, white women were 72% as likely to receive the recommended surgery, black men 67%, and black women just 50%**. The study accounted for age, in-hospital mortality, health insurance, and hospital transfer rates, leading researchers to conclude that both race and sex affected doctors' recommendations for procedures.<sup>15</sup>

These factors are important drivers of health disparities in specialty care. By influencing treatment recommendations from providers, failing to facilitate effective communication between patients and providers, and eroding trust in the doctor-patient relationship, these factors create disparities in outcomes even for those patients who have equal access to care.



Patient-provider trust has a tangible effect on patient retention in care and patient adherence to treatment recommendations. A 2012 study examining the association between patient trust and antiretroviral (ARV) adherence among 175 patients at urban HIV clinics found that **high trust in a physician was strongly associated with increased odds of ARV adherence**.<sup>16</sup> A 2014 study of black women and cervical cancer screening found similar results, noting that **health care worker bias was a factor in delayed screening, and disparities in follow-up and treatment between black and white patients**.<sup>17</sup> These disparities remain consistent even when controlling for socio-economic factors and insurance status.

There is emerging evidence that these disparities persist in palliative care as well. Several studies document lower-quality palliative care for minority patients, and surveys suggest that black patients and their families are more likely to report absent or problematic physician communication, concerns with "being informed," and concerns with family support around palliative and end-of-life care than white patients and their families.<sup>18</sup>

Given mounting evidence of the importance of patient experience, trust, and the relationship between providers and patients, as well as the critical role these elements play in treatment experiences for diseases like cancer, stroke, and HIV/AIDS, among other diseases that require specialty care, the medical community must do more to address these challenges. Medical schools, provider organizations, and professional associations must invest in helping individual providers and health care institutions improve the quality, cultural competency, and equality of their care.



### Figure 2. Likelihood of Activities Related to Smoking Habits



## **Emerging Solutions**

eading health care providers are investing in three approaches to mitigating disparities in the quality of care that patients receive: (1) the development of culturally competent care practices; (2) efforts to mitigate implicit biases among health care workers; and (3) harnessing quality improvement methods to address equity. While various actors have started to explore these areas, initiatives have yet to be consistently adopted and integrated across the health system.

### Figure 3. Three Emerging Solutions for Increasing Specialty Care Availability



## Incorporating culturally competent practices

Training, awareness, and culturally appropriate materials allow for providers and patients to have the most complete treatment experience, leading to fewer medical errors and improved care.

**Read more below** 



## Mitigating implicit bias among health care workers

Understanding of and training around implicit bias is essential to mitigating proven differences in treatment based on aspects like race, gender, and age, and has critical implications across a variety of specialties.

Read more on page 11

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## Harnessing Quality Improvement to include equity

Existing quality improvement efforts can include equity considerations, including differences in outcomes, costs, safety and patient satisfaction across key demographics (age, race, gender, etc.).

Read more on page 13

## Incorporating culturally competent practices



Culturally competent care is defined as the ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of their patients.<sup>19</sup> For some, this reflects a basic need for language translation services; for others, recognizing religious practices and beliefs, sensitivity and respect for transgender patients, or a preference for

family-oriented decision-making may be important. Culturally competent care can also have the advantage of tapping in to health traditions and beliefs that support patient's healing.<sup>20</sup>



Health care providing institutions are integrating cultural competency in a number of ways. Some of the most effective programs include: providing trained and qualified medical interpreters (e.g., having an interpreter attend appointments alongside patients), using linguistically and culturally competent materials (e.g., prevention and disease pamphlets in multiple languages), and instituting cultural competency training for staff (e.g., training staff to "identify, understand, and respect the values and beliefs of others").<sup>21</sup>

While these approaches require investment, they also yield returns: use of trained medical interpreters

### **Cultural Humility**

Another approach to ensuring a fair and positive patient experience is cultural humility. While cultural competency focuses on knowledge, cultural humility emphasizes the attitude that doctors have toward their patients, especially in diverse cultural settings. Doctors are encouraged to consider the background, experiences, and expectations of their patients, expand their engagement with the broader community, and commit to the practice of ongoing learning, dialogue, and growth for this aspect of their practice.<sup>22</sup>

instead of informal, ad hoc interpreters (e.g., family members or non-medical, bilingual staff) reduces the likelihood of medically critical translation mistakes by anywhere between 30 and 900%.<sup>25</sup> A recent 2015 study of primary care visits with Spanish-speaking Latino patients at a public hospital clinic found an even bigger impact: **the incidence of clinically significant errors was reduced by 75% when a patient was provided with a medical interpreter**.<sup>26</sup> Medical errors are a serious concern—in the United States, estimates suggest that they account for 250,000 deaths annually and are the third largest cause of death behind heart disease and cancer.<sup>27</sup> In addition, litigation over medical errors can create massive financial considerations for health care providers.

Beyond language, evidence suggests that health care providers' ability to adapt to cultural needs and preferences improves health outcomes for patients and efficiency for health systems.<sup>28</sup> For example, a 1994 study found that African American teenagers who watched a culturally relevant video about HIV/AIDS were 18% more likely get an HIV test within two weeks than a group exposed to a culturally dissimilar video.<sup>29</sup>

Investment is growing in the use of translation and culturally competent practices. In 2001, the Office of Minority Health published the *National Standards for Culturally and Linguistically Appropriate Services in Health Care*, providing guidelines for broader adoption. Since then, five states, including California and New Jersey, have passed legislation requiring cultural competency training for at least part of the health care workforce.<sup>30</sup> Additionally, California law requires that payers provide interpretation and translation services to patients with limited English proficiency.<sup>31</sup> Pushing beyond standards and existing federal requirements, the ACA provides incentives for health plans and providers to utilize language services, community outreach, and cultural competency training to reduce disparities.<sup>32</sup> Some providers are making focused efforts to build cultural and language capabilities, which are highlighted in the Kaiser Permanente and L.A. Care Case Examples on the following pages.



## Kaiser Permanente's Northern California Language Access Program



One example of culturally competent care in practice can be found in Kaiser Permanente's 21 hospitals in Northern California. The Language Access team created a number of interpretation programs, including quick and easy access to video interpretation services in each hospital room. The video technology enables patients and providers to connect with a live remote interpreter for use across many different languages in seconds, from either the room's computer workstation or a dedicated iPad. Kaiser has found the program to be incredibly successful. After the initial pilot year, each of the hospitals began covering the costs for the service themselves, and usage of the technology has greatly increased over time. Surveys have shown that the service reduced stress, wait times, administrative burden, and improved communication between patients and staff, including doctors, nurses, social workers, and others. Video translation was selected over phone interpretation because of the added quality of interpreters' ability to see the patient and doctor, and vice versa. And because video translation is charged by the minute, it is more affordable and more convenient than in-person translators, which often require one- or two-hour minimums, and must be arranged in advance. Kaiser Permanente is expanding the program to other states in 2016 and 2017.<sup>23</sup>

93% of staff surveyed said the program improved communication with patients and their families<sup>24</sup>





# L.A. Care Health Plan's Support for Medical Interpreters

California is one of the most ethnically and linguistically diverse states in the country: more than 42% of residents speak a language other than English at home. This requires the health care system to be highly adept at responding to a wide range of patient communication needs, expectations, and perceptions.

L.A. Care, the largest public health plan in the United States, has developed extensive resources and patient education programs to ensure that its 2 million members receive culturally sensitive, high-quality care. L.A. Care provides interpreter services to its patients for free, in-line with state regulations, but they also go a step further. A central component of its efforts is patient education around these services and patients' rights to ensure that both providers and patients are aware of the opportunity to use professional interpretation services. While doctors can initiate interpretation services, the driving force behind L.A. Care's 1,500% increase in the use of interpreters over the past several years has been demand from patients.



"Providers need to use professional interpreters. Too often, we pull in a staff or family member, but they don't necessarily have the right skillset. That's the first step in addressing disparities because you can't treat someone if you can't communicate with them. But this goes beyond that—education and awareness, early on in medical school, for example, is key. Respect can go a long way in terms of patient trust, satisfaction, and adherence. It seems warm and fuzzy, but it has real implications for how patients behave."

> —NAI KASICK, L.A. CARE HEALTH PLAN

L.A. Care also provides an "I Speak" card that low-English proficiency (LEP) members can be given to providers to communicate the need for interpreter services and has developed a toolkit for health care providers to help them assess the cultural and linguistic competency of their staff (available here).<sup>33,34</sup>



## Mitigating implicit bias among health care workers

A growing number of U.S. medical schools, health care institutions, and professional associations have begun to incorporate trainings for health care professionals to recognize and mitigate their own implicit

biases. These trainings are designed to encourage health care workers to recognize their biases and develop tactics to combat them—and they have proven to be effective.

For example, in a 2010 study, nurses who were shown pictures of patients in pain recommended significantly more pain medication for white than black patients. Once the nurses were instructed to use an implicit bias training method to "imagine how the patient felt," however, the **discrepancy between recommended pain medication amounts for white and black patients decreased by 55%**.<sup>35</sup> "A lot of quality improvement work is about reducing unwanted variation. And inequities are just that—undesired, unwanted variation. Improvement tools have been used for generations to root out variation in products, services, and systems. We believe such tools could be applied to inequities in health outcomes – so long as quality improvers make a conscious choice to focus on those with the worst outcomes, not just the median."

> —Kedar Mate, MD Institute for Healthcare Improvement

The trainings incorporate the Implicit Association Test (IAT) as

a central component. The IAT is a free online test that measures the associations that people have between different concepts—for example, between people of different races, gender, or age and certain characteristics like "pleasantness." The trainings also share strategies for mitigating how these biases impact provider-patient interactions—to slow down and reflect for several moments before beginning a patient interaction, to be

See page 21 of this brief, What's Needed to Scale These Solutions?, for the link to the online Implicit Association Test (IAT), which is offered at no cost by Harvard's Implicit Project. aware of potential biases, and to recognize any assumptions one might be making that will influence the patient's experience. Other strategies include individuating (making a conscious effort to focus on specific information about an individual rather than information about their social category), and perspective-taking (making a conscious effort to envision another person's viewpoint).<sup>36</sup> Medical schools and professional associations, like University of California at San Francisco School of Medicine (*see Case Example on the next page*) are increasingly building training sessions like this into core medical training.



## University of California, San Francisco School of Medicine Implicit Bias Training

### UCSF

The UCSF School of Medicine is one of the roughly 40 medical schools that have included instruction on unconscious bias in their curriculum. A campus-wide initiative was developed after medical school leaders were asked to assess their own biases by completing the Implicit Association Test (IAT). As a result, they recognized the prevalence of these biases and the urgent need to address them in their schools. While the training was initially focused on first-year medical students, it has since been expanded to 2,500 people at UCSF including residents, fellows, staff, and students of the dentistry, pharmacy, and nursing schools.

The program takes a unique approach to teaching. On the topic of biases, traditional lecture-style

approaches tend to result in students either feeling bad about themselves or negatively about the person administering the training, neither of which leads to behavior change. In contrast, the UCSF training starts with an understanding that everyone holds some biases and that they cannot be eliminated. From this point, the training aims to help students recognize and mitigate their biases through use of the Implicit Association Test and sharing of techniques for mitigating the impact of biases on provider behavior. The UCSF School of Medicine uses a "case-based approach" to better illustrate biases in the health care setting and enable participants to practice skills for mitigating the impact of biases. Additionally UCSF is investing in a long-term evaluation for the program to assess the behavior of participants and its impact over time.37

\*\* Ten years ago, there were probably only 20 schools thinking about bias. But when the Association of American Medical Colleges (AAMC) started making this a priority a few years ago, that was instrumental in getting the attention of more schools. And as the evidence linking bias to treatment outcomes evolves, the skeptics are having a harder time saying that this isn't an issue. In the next 5 to 10 years, I hope that this will be a part of every school's curriculum."

> -Rene Salazar, MD, Former Professor, UCSF School of Medicine



# Harnessing the Power of Quality Improvement Approaches to Improve Equity

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Quality Improvement (QI) efforts have long been demonstrated to improve clinical care, patient safety, and hospital efficiency, among a number of other factors. For most providers, quality improvement is a typical component of care

delivery. These resources, however, have rarely tackled the issue of equity head-on. Most hospitals already invest resources into QI staff, tools, and best practices. QI efforts frequently collaborate across various departments, among other hospitals, and with payers and other key actors in the system. And QI already has well-established, time-tested tools to reduce "unwanted variation" in results—exactly what is needed to address health disparities. Leveraging these existing resources will allow providers to focus on equity within their existing feedback and improvement systems.

For example, Kaiser Permanente has started to engage the quality improvement teams at its hospitals and clinics to focus on equity. One measure that Kaiser has taken is to disaggregate existing patient satisfaction metrics by race, age, gender, and other demographic factors, to understand if and how patients'

"We consider three types of data: (1) core quality measures like HEDIS that we all already collect and report on, but can stratify by race and ethnicity and language; (2) disparities—sensitive measures that we know from the national research are likely to be areas of disparities such as asthma, which affects minorities more than white populations; and (3) data on other social determinants of health such as housing and food security, which is a new area for many that can be overwhelming to consider, but that is critical to understand."

> —Aswita Tan-McGrory The Disparities Solutions Center at Massachusetts General Hospital

experiences differ. On a quarterly basis, clinicians receive data from their patients' responses to the survey, including their overall score and scores disaggregated by these categories. This allows them to recognize and mitigate their own biases; the data are also factored into their formal evaluations and compensation. Institutionally, programs like this one can help improve care, service, and satisfaction, thereby increasing patient retention rates. Since introducing disaggregated patient satisfaction measures, Kaiser has seen narrowing gaps in patient satisfaction scores across patients of different race and ethnicity groups.<sup>38</sup>



## Massachusetts General Hospital's Annual Report on Equity in Health Care Quality



Massachusetts General Hospital (MGH) is one of the country's oldest and largest hospitals, currently ranked as the #1 hospital in the United States by *U.S. News & World Report*. In 2002, following the issuance of the Institute of Medicine report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, MGH leadership recognized the need to address disparities within their own institution. To do so, MGH established an internal Disparities Committee to identify and address disparities in health and health care amongst MGH's patients and to improve the diversity of MGH's staff.

MGH also developed a robust data collection and reporting system to build accountability for equity

into its work. In 2013, MGH began publishing an Annual Report on Equity and Healthcare Quality. In the report, MGH cited the key disparities it was working on to address and its progress towards key goals. MGH also made public a dashboard that includes progress towards metrics such as screening rates for breast, cervical, colorectal, and prostate

### Figure 4. MGH Health Equity Tracking and Reporting Tools

| ANNUAL REPORT ON EQUITY IN<br>HEALTH CARE QUALITY 2014  | Measures<br>Heart Attack  |
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| Measures   | Comparis       | on Group   | Equity of Care |
|--|----------------|------------|----------------|
| Heart Attack   | Race:<br>White | Race: Non- | white          |
| Aspirin at Arrival   | 100%           | 100%       | •              |
| Aspirin at Discharge                                       | 100%           | 100%       | •              |
| Beta Blocker at Discharge                                  | 99%            | 99%        | •              |
| ACE-I/ARB at Discharge (AMI)                               | 93%            | 97%        | •              |
| Time to Primary PCI of Less Than or Equal to 90<br>Minutes | 94%            | 100%       | •              |
| Heart Failure  | Race:<br>White | Race: Non- | white          |
| ACE-I/ARB at Discharge (HF)                                | 96%            | 98%        | •              |
| Discharge Instructions (HF)                                | 90%            | 91%        | •              |
| LVF Assessment   | 100%           | 100%       | •              |
| Pneumonia  | Race:<br>White | Race: Non- | white          |
| Timing of Blood Cultures                                   | 96%            | 97%        | •              |
| Selection of Antibiotics (PN)                              | 90%            | 82%        | •              |
| Surgery  | Race:<br>White | Race: Non- | white          |
| Antibiotics Received One Hour Prior to Surgery             | 99%            | 99%        | •              |
| Antibiotic Selection for Surgical Cases                    | 99%            | 99%        | •              |
| Antibiotics Discontinued 24 Hours after Surgery            | 95%            | 99%        | •              |

cancers and diabetes and heart disease testing disaggregated by race and ethnicity (*see Figure 4*). The dashboard highlights areas of equitable care in green and highlights disparities in care across race and ethnicity categories in red for further attention.

MGH's example illustrates a number of significant internal capabilities that have helped the institution make tremendous progress towards health equity for diseases such as cardiovascular disease, diabetes, prostate and colorectal cancer, and breast cancer. With significant support from its leadership team, MGH developed the capability to capture the right data and it established internal capacity to reflect on the data to identify disparities and develop strategies to address them. It also created internal and external monitoring and reporting mechanisms to build accountability for its own work.

MGH now houses the Disparities Solutions Center, which supports other health care providers to implement the processes and programs that MGH has found effective in mitigating health disparities.<sup>39</sup>



## Equity in Clinical Trials: Lack of Minority Representation



The same factors that create disparities in health care also create disparities in access to and participation in clinical trials. Lack of access to clinical trials can mean lack of access to treatment options for patients with advanced disease who have exhausted options within current standard of care.

Clinical trials are essential tools to understand what works in medicine and health care. To fully understand the epidemiology of a disease or

the effect of a drug, trials must include adequate proportions of diverse groups. In fact the National Institute of Health's (NIH) Revitalization Act sets criteria for the inclusion of women and racial and ethnic minorities in federally-funded clinical trials.

While 40% of Americans belong to a racial or ethnic minority, fewer than 5% of clinical trial participants are non-white. That proportion is even lower for trials for complex conditions, like cancer. Studies have shown that since 1993, fewer than 2% of the more than 10,000 cancer clinical trials funded by the NIH included enough minority participants to meet the NIH's own guidelines. Additionally, fewer than 2% of clinical cancer research studies focused on non-white ethnic or racial groups. Given that racial minority populations generally have higher burdens of cancer and higher rates of cancer mortality, the lack of research focused on this population is particularly problematic.<sup>40</sup>

## The barriers

A number of challenges lead to low participation rates of minority patients in clinical trials. These include:

- **Patients:** Minority patients, particularly black Americans, have a lower level of trust in the clinical trial system. This mistrust is informed by negative experiences with clinical trials, such as the now discredited Tuskegee Syphilis Study (see **Brief 1: Striving for Equity in Specialty Care**).
- **Providers:** Providers often fail to refer minority patients to clinical trials, either because the doctors and health care institutions who most often serve minority patients are not well-connected to clinical trials or because they make negative assumptions about minority patients' willingness or suitability for a trial.
- **Trial investigators:** Disproportionately fewer clinical trial investigators come from racial and ethnic minority groups.



## A multi-faceted solution

With barriers ranging from patient attitudes to the demographic composition of clinical trial researchers, increasing minority participation in clinical trials will require a system-wide approach:

- Setting guidelines: Recognizing the importance of representative participation, organizations that run clinical trials, such as the NIH and pharmaceutical companies, are increasingly setting guidelines for diversity in clinical trial participation as well as reaching out to patient advocacy and community groups to encourage participation. While these guidelines alone do not solve the problem, they are an important prompt for further action to identify, engage and support trial participants from underrepresented groups.
- Providing patient navigation and culturally sensitive educational materials: UC Davis's Comprehensive Cancer Center provides every Asian American cancer patient with culturally sensitive clinical trial educational materials and supports trial enrollees with a patient navigation.<sup>41</sup>
- Increasing the number of minorities interested in becoming cancer researchers: The National Cancer Institute's Center to Reduce Cancer Health Disparities (CRCHD) has established several programs to attract and support more individuals from under-represented groups to become cancer researchers. Based on a belief that a diverse workforce is essential for advancing cancer knowledge, and particularly knowledge of cancer disparities, the programs offer participants financial and mentorship support along the education pathway, from high school through college and medical school, and continue to support investigators with cancer research opportunities.
- Increasing the capacity of minority physicians to become clinical trial investigators: Academic centers, like Morehouse School of Medicine, connect with minority physicians (many in smaller community practices) to provide physicians with training on how to conduct clinical trials and better connect their patients to other trial opportunities. Interestingly, pharmaceutical companies are increasingly supporting these efforts. Eli Lilly, for example, has established several collaborations with cancer institutes to train physicians from minority groups to become clinical trial investigators.<sup>42</sup>



# Wrapping Things Up: Taking Action The Value of Investing In Equity

When successfully implemented, these approaches have shown tremendous value, not just for patients, but also for health care providers and public and private payers.

## How patients benefit

Implicit bias trainings and the strategies that physicians gain during these trainings help to reduce disparities in care and improve health outcomes for patients. Attention to implicit bias and culturally competent care increases patient trust, keeps patients more engaged in the medical system, and ensures that patients can receive care in a manner that aligns with and respects their preferences and beliefs.

## How providers and provider institutions benefit

Investments in culturally competent care and efforts to mitigate provider biases have several benefits. First, they improve the quality of care that patients receive, as described above, and increase patients' engagement in care. A 2004 study found that the **provision of interpreter services increased the use of health services**—patients with interpreters were more likely to be recommended preventative services (7.3% versus 2.7%) and made more than twice as many office visits on average than those who did not have access to interpretive services (1.74 versus .71).<sup>43</sup> Improved engagement of patients and more regular preventative care can have long-term cost-saving implications. Second, evidence suggests that **providing interpretive services and mitigating biases and disparities in care can reduce malpractice claims**. Implicit bias training has been shown to reduce underdiagnoses and misdiagnoses, some of the most common and costly causes of malpractice suits.<sup>44</sup> Using QI tools and processes will also allow provides to track cost savings related to equity-focused policy changes and investments.

## > How payers benefit

Culturally competent care, which includes qualified medical interpreters, not only increases patient trust in the health care system and decreases disparities in outcomes, but also likely leads to long-term cost savings. **Effective, high quality care improves early diagnosis, which has been shown to result in significant cost savings**—early diagnosis of HIV can save up to 50% of cumulative care costs<sup>45</sup> and diagnosing lung cancer at Stage I vs. Stage IV can save up to 30% of first-year treatment costs.<sup>46</sup> Strong evidence also links culturally competent care and improved patient-doctor relationships to reductions in medical mistakes, improved patient



engagement in care, improved adherence to treatment recommendations, and reduced emergency department use. **Molina Healthcare's TeleSalud initiative, for example, resulted in direct cost savings for the insurer**. By providing 24-hour live access to advice and interpretation in the patient's preferred language (English or Spanish), the insurer realized \$0.14–\$1.35 cost savings per patient per year, a total of \$750,000 in annual savings across their membership; the greatest savings came in areas with a significant Spanish-speaking population.<sup>47</sup> Payers can support hospitals and providers in their QI efforts to focus on equity and can analyse data that affects patient outcomes, repeat hospitalizations, and other costly elements that may be related to inequitable care.

## What's Needed to Scale These Solutions?

While there is a long history of advocacy for culturally competent care and efforts to address bias, health care actors are just starting to engage with these solutions. The American Hospital Association, among others, has created a call to action for health care providers to make progress on three pillars of equity: (1) the collection and use of race, ethnicity, and language preference data, (2) increasing the cultural competence capabilities of staff, and (3) increasing diversity in governance and leadership. To date, nearly 1,000 hospitals have signed the "#123 For Equity" pledge. However, adopting processes to address racial and other inequities is still inconsistent, limiting the potential of these solutions to benefit thousands of patients. In order to spur adoption, greater research is needed, both to better understand how to address these issues and to "make the case" that links these practices to health impact and cost savings for the health system.

Further detail on what is needed to scale these solutions is included below. For additional information on what's needed to scale these solutions, please see **Brief 5: Call to Action for a System-wide Focus on Equity**.





### **Culturally Competent Care**

### **State of Adoption**

Cultural competency has been a hallmark of primary health care facilities that serve a large proportion of minority or low-English-proficiency patients. It is less common in specialty care settings.

### **Opportunities for Further Implementation and Scale**

### Where to start

- Surveying patients and analyzing data on their patient experience, outcomes and perception of the environment is a helpful baseline to understand what areas of cultural competency are or are not addressed by providers, and what investments will provide the greatest return in patient care.
- Some helpful resources include:

The U.S. Health Resources and Services Administration (HRSA) includes additional background, workbooks, and examples related to race, age, and gender, among other factors.

### http://www.hrsa.gov/culturalcompetence/ index.html

The Commonwealth fund's The Evidence Base for Cultural and Linguistic Competency in Health Care provides helpful background (developed in collaboration with the National Center for Cultural Competence at Georgetown).

http://www.commonwealthfund.org/ publications/fund-reports/2006/oct/theevidence-base-for-cultural-and-linguisticcompetency-in-health-care

The National Center for Cultural Competence web site provides best practices, selfassessments, and other helpful resources for providers: http://nccc.georgetown.edu/ information/providers.html

### **Success factors**

- Leadership and support from key decisionmakers is critical to creating a learning and self-reflective environment, including investment of resources and time by providers and hospital staff.
- For hospitals, having a dedicated content expert for cultural competency helps embed these concepts and practices throughout different departments.
- Educating patients on their right to an interpreter through multi-lingual signs and information pamphlets helps patients demand services when doctors or other providers may not proactively provide them.
- Systematically incorporating feedback from patients on needs, priorities, and performance is important to remaining responsive to patient needs.
- State- and local-level policies that require culturally competent care are helpful forcing functions for investment.

### **Examples include**

- Kaiser Permanente
- L.A. Care
- Molina Healthcare



## Efforts to Mitigate Implicit Bias

### **State of Adoption**

Implicit bias training is now being implemented at more than 40 medical schools in the United States, with increasingly sophisticated approaches and curricula.

### **Opportunities for Further Implementation and Scale**

### Where to start

Because of the individual and self-reflective nature of understanding and addressing implicit bias, fully supportive and committed leadership is critical to institution-wide success in this approach. In health care settings, medical leadership and executive-level decision-makers should participate in implicit bias testing and awareness training, to begin to create the necessary learning environment at all levels.

USCF has a web site dedicated to resources and further information on implicit bias in medicine: https://diversity.ucsf.edu/resources/ unconscious-bias-resources

The Implicit Project at Harvard offers an IAT online for free: https://implicit.harvard.edu/ implicit/education.html

### **Success factors**

- Training and awareness are most beneficial early on in medical training (i.e., the first year of medical school)
- Systematically incorporating feedback from patients on needs, priorities, and performance is critical to effectively meeting patient needs.
- Encouraging open discussion among doctors and staff helps foster an environment of constructive problem-solving.

### Examples

### include

- UCSF School of Medicine
- Kaiser
  Permanente





### Harnessing Quality Improvement to Address Equity

### **State of Adoption**

Quality Improvement (QI) is a central part of safety, efficiency, and patient outcomes in today's health care system. Considering equity in quality—and vice versa—allows providers to leverage existing resources for all patients equally.

### **Opportunities for Further Implementation and Scale**

### Where to start

QI teams often lead data collection and analysis and improvement processes at provider institutions. The inclusion of equity measures in their work, including analyzing data by ethnicity, age, race, or language of preference, is an effective place to start. This analysis will enable providers to determine if, and to what extent, the hospital is equitably meeting the needs of all patients and to identify areas with the greatest disparities. These areas can include disparities in treatment recommendations, surgery outcomes, length of hospital stays, patient satisfaction and no-show rates, among many others. All of these can result from disparities in care quality. In addition, QI tools and methods can help payers and providers identify, test, and improve upon effective solutions to addressing disparities as they have been doing for many years.

The Disparities Solutions Center at MGH has a number of helpful resources, including "Improving Quality and Achieving Equity: A Guide for Hospital Leaders," a comprehensive resource to guide efforts to integrate quality improvement and equity efforts with case studies and tactical action steps for health systems leaders.

The national Agency for Healthcare Research and Quality also publishes an annual Healthcare Quality and Disparities Report.

### **Success factors**

- Leadership commitment to health equity enables providers to integrate equity considerations more deeply into QI efforts.
- Creating a disparities committee or task force to identify and track equity issues can be a good place to start.
- Identifying existing data sources (e.g., HEDIS scores) can help identify existing disparities without additional investment in QI or monitoring.
- Systematically incorporating feedback from patients on needs, priorities and performance to ensure that solutions are responsive to patient needs.
- Including demographic factors (e.g., ethnicity or first language) in analyses of doctors' performance and patient satisfaction to help highlight potential bias challenges.

### **Examples include**

- Kaiser Permanente
- Massachusetts
  General Hospital
- PartnersHealth



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#### Figure 1

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#### Figure 2

Adapted from American Cancer Society Cancer Action Network Cancer Disparites Chartbook.

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## **Breaking the Barriers to Specialty Care**

Practical Ideas to Improve Health Equity and Reduce Cost

## Ensuring High-Quality Specialty Care

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