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

BRIEF

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Striving for Equity in Specialty Care

FSG 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.

Learn more about FSG at **www.fsg.org**.

Foreword

Lauren A. Smith, MD, MPH
Managing Director, FSG

Over the past year, FSG has partnered with the Bristol-Myers Squibb Foundation to explore a tremendously significant yet often overlooked problem in today's healthcare landscape: the challenge of eliminating systemic health disparities for patients with serious diseases that require specialty care. These disparities are pervasive and persistent, with disturbing differences in diagnosis, quality of treatment, and ultimately, mortality.

Nearly half of all deaths in the United States are caused by heart disease and cancer,[1] both of which require specialty care. Patterns in how those diseases are treated undoubtedly affect life expectancy overall in the United States. As recent studies have shown, the gap in average lifespan between the rich and the poor in the United States has grown over time: for those born in 1950, the top 10% of income earners now live 13 years longer than the bottom 10% of earners—a gap that is twice as large as it was for those born 30 years earlier and one that equates to 15% of the average lifespan in this country.[2]

Our approach to health care contributes to these disparities. While the healthcare sector in the United States has developed remarkable advances in medical treatment, the structure of our delivery system consistently limits access to these same advances. Too many low-income people with life-threatening illnesses struggle to find a specialist who will see them, and too many rural patients are forced to travel great distances to access specialty care. For those who can access medical care, high out-of-pocket costs, from co-pays to prescription medication, put needed care out of reach for many. In addition, specialty fields have historically treated illness as a singular problem, failing to recognize fully the powerful impact that social determinants of health can have on a patient's ability to seek care and adhere to recommended treatments. Focusing system resources so intently on treatment and cure leaves fewer resources for other contributing factors and elements of care. And lastly, the health care delivery system has not consistently supported health care providers to assess how their own implicit biases and unconscious attitudes toward patients with different backgrounds or experiences might be compounding the challenges that patients experience.

Together, these dynamics have resulted in substantial disparities in health outcomes for those experiencing serious diseases, along dimensions of race and ethnicity, gender and sexual orientation, English proficiency, geography, and socio-economic status. The five-year survival rate for lung cancer, for example, is 20% lower for black patients than for white patients.[3] People with lower socio-economic status have a 50% greater risk of developing heart disease than those with higher incomes and more education,[4] and studies suggest that even for people with similar income levels, those who live in lower-income neighborhoods fare worse than their peers and are less able to adhere to treatment recommendations.[5] The same pattern holds for HIV—despite accounting for only 12% of the U.S. population, black men and women account for 45% of new HIV diagnoses but are less likely to be retained in treatment.[6] These and other disparities have persisted or even worsened despite the impressive advances in medical care that have been made in a country with one of the most advanced and well-resourced health systems in the world.

The picture, however, is not entirely bleak. A major benefit of the Patient Protection and Affordable Care Act (ACA) is the growing focus on healthcare quality and outcomes, and a greater understanding of the link between eliminating disparities and controlling health systems costs and improving quality. As a result, there is tremendous innovation across the healthcare system—not just to develop the next "blockbuster" drug, but also to create new models of care to improve outcomes and reduce costs, new methods of data collection and analysis to identify and address disparities, and new partnership models to better reach and support populations that experience the deepest inequity.

This represents a real moment of opportunity to turn these sparks of innovation into sustainable models that are seamlessly integrated into health care. However, all of this optimism will amount to nothing and disparities will persist or even worsen if we don't work together to support and scale these solutions. Payers, healthcare providers and provider organizations, community organizations, policy-makers at the federal and state levels, and others—everyone has a role to play.

Many of us who are healthcare providers, caregivers, and community supporters can recall the patients and families who are the real people whose suffering is obscured by statistics. And theirs are the stories that motivate us to harness the innovative solutions highlighted here to make meaningful progress toward equitable health for all. Our aim in this series of issue briefs is to raise up what is working to meet this aspiration, show how these solutions provide a return on investment, and bring often disparate pieces together to create a comprehensive common agenda for the field. With understanding, commitment, and collaboration, we can eliminate health disparities for those challenged with the most life-threatening diseases over the next decade.

1   U.S. Department of Health and Human Services, National Center for Health Statistics (2016). *Health, United States, 2015*. Available at: http://www.cdc.gov/nchs/data/hus/hus15.pdf#019

2   Tavernise, S. (2016). Disparity in Life Spans of the Rich and the Poor Is Growing. *New York Times*. Available at: http://www.nytimes.com/2016/02/13/health/disparity-in-life-spans-of-the-rich-and-the-poor-is-growing.html

3   National Cancer Institute, National Institutes of Health (2012). NCI SEER Cancer Statistics Reviews. Available at: http://seer.cancer.gov/csr/1975_2013/

4   Bikdeli B, Wayda B, Bao H, et al. (2014). Place of residence and outcomes of patients with heart failure: analysis from the telemonitoring to improve heart failure outcomes trial. *Circulation: Cardiovascular Quality & Outcomes*.

5   Dasgupta S, Oster AM, Li J, Hall HI. (2016). Disparities in Consistent Retention in HIV Care — 11 States and the District of Columbia, 2011–2013. *CDC Morbidity and Mortality Weekly Report*.

The challenge of health equity in specialty care

There is a growing imperative to address health disparities in the United States. This emerging focus is the result of a convergence of several factors: the passage of the Patient Protection and Affordable Care Act (ACA) in the policy arena, an ever-growing focus on quality improvement that is driving delivery and payment reform across the health care sector, and a broad national dialogue that is challenging the persistence of inequities across racial and ethnic categories, as well as socio-economic status.

To date, research and action to reduce health disparities have been focused almost entirely on prevention and primary care, both critical levers in improving population health outcomes. But with the confluence of these powerful factors and the realities of an aging population that increasingly needs complex care, it is clear that improving health equity must include a focus on specialty care as well.

Indeed, disease and conditions requiring specialty care create the deepest disparities. Today's specialty care landscape is full of incredible medical advancements—new immunotherapies are reducing mortality for some cancers by up to 32%,[1] new devices and surgical practices are driving improvements in cardio-vascular health to prevent heart disease and stroke, and anti-retroviral therapies (ART) continue to have tremendous impact, enabling HIV patients to live long and healthy lives instead of facing what was once considered a "death sentence."

These advances, however, are not unequivocally and uniformly benefitting the populations that need them. The same innovations in treatment and practice that help extend the lives of some patients directly drive widening disparities between those who have access to these new innovations and those that do not. This pattern is evident in the data, which shows a widening gap between the lifespans of rich and poor Americans. Between 1920 and 1950, the gap in life expectancy between the top and bottom 10% of earners more than doubled from 6 to 14 years for men and 4.7 to 13 years for women.[2] In this reality, the full promise of transformational medical advances is not being realized.
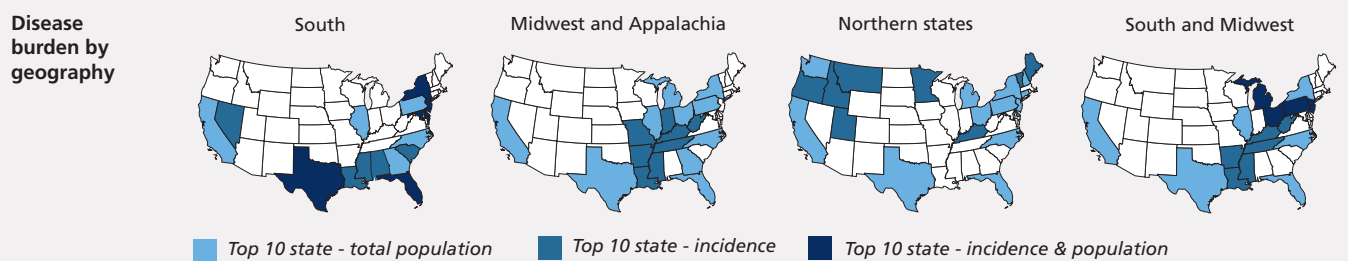
How is "specialty care" defined?

Specialty care encompasses healthcare services dedicated to a specific branch of medicine or, in other words, all healthcare services not considered primary care. Typically, patients are referred to a specialist by a primary care provider for disease-specific care that requires expert support. Specialty care encompasses many common and serious disease areas, including cardiology, dermatology, oncology, rheumatology, immunology, psychiatry, and many others. For many patients, accessing and staying engaged in specialty care is significantly more challenging than in primary care given the need to engage with multiple providers and pursue complex and often long-term courses of treatment.

The data and case studies included in this paper will focus primarily on four disease areas: lung cancer, skin cancer, cardio-vascular disease (CVD), and HIV/AIDS *(additional detail in Figure 1 on the following page)*. Together, they represent the breadth of health conditions handled by specialists and illustrate the diverse challenges and opportunities to deliver equity in specialty care.

Figure 1. Overview of Focus Disease Areas

	HIV/AIDS	Lung Cancer	Skin Cancer	Cardovascular Disease and Stroke
Impact	• 50,000 new cases per year • 1 million living with HIV and/or AIDS	• 220,000 new cases per year • Nearly 160,000 deaths per year	• 3.5 million new cases per year • 73,000 of which are melanoma	• 787,000 deaths per year
Trends	• Rates of new infections have remained constant for over 10 years • Treatment advances have significantly reduced AIDS-related morbidity and mortality • Only 36% of HIV-positive Americans are in care	• Incidence and mortality from lung cancer are declining, but lung cancer remains the leading cause of cancer deaths in America • The average 5-year survival rate from lung cancer is only 17%	• In some parts of the country, incidence of melanoma has increased 15% over the past 15 years • Incidence of melanoma has increased for both men and women	• Cardiovascular disease is the leading cause of death in America • The most common types of cardiovascular disease include coronary heart disease, heart failure and stroke • 49% of Americans have at least one of the three major heart disease risk factors—high blood pressure, high LDL cholesterol, or smoking
Disease burden by geography	South	Midwest and Appalachia	Northern states	South and Midwest

Top 10 state - total population   *Top 10 state - incidence*   *Top 10 state - incidence & population*
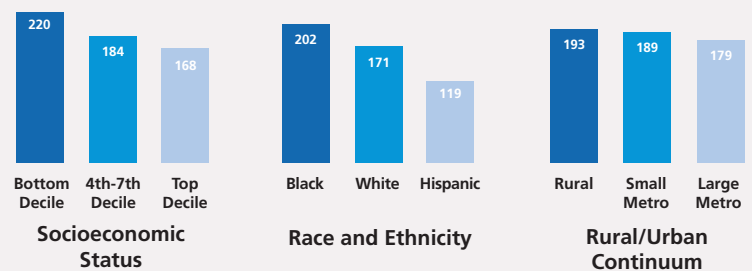
Socio-economic status, race and geography remain strong determinants of health outcomes, even for acute medical conditions. There is robust evidence that low-income patients, rural patients, and patients belonging to racial or ethnic minority groups are more likely to die from cancer and other diseases than their wealthier, urban, and white peers *(see Figure 2)*. Studies suggest that **the elimination of racial disparities in cancer mortality alone would result in roughly 250,000 fewer cancer deaths and nearly 4 million fewer years of life lost per year**.[3]

These disparities in health outcomes result from a complex set of factors, worsened by broader trends of race, poverty, and the policy environment in the United States. Together, these create an accumulation of disparities across the care continuum for low-income, minority, and rural patients who must not only manage serious conditions more frequently, but also must do so without access to the full suite of resources and

Figure 2. Disparities in Cancer Outcomes by Population Group

Age adjusted all cause cancer mortality, per 100,000 population

Socioeconomic Status			Race and Ethnicity			Rural/Urban Continuum		
220	184	168	202	171	119	193	189	179
Bottom Decile	4th-7th Decile	Top Decile	Black	White	Hispanic	Rural	Small Metro	Large Metro

support necessary for recovery. If these disparities are left unaddressed, each new advance in medical technology will help extend the lives of a select few, but will also result in a growing number of preventable and premature deaths for many others.
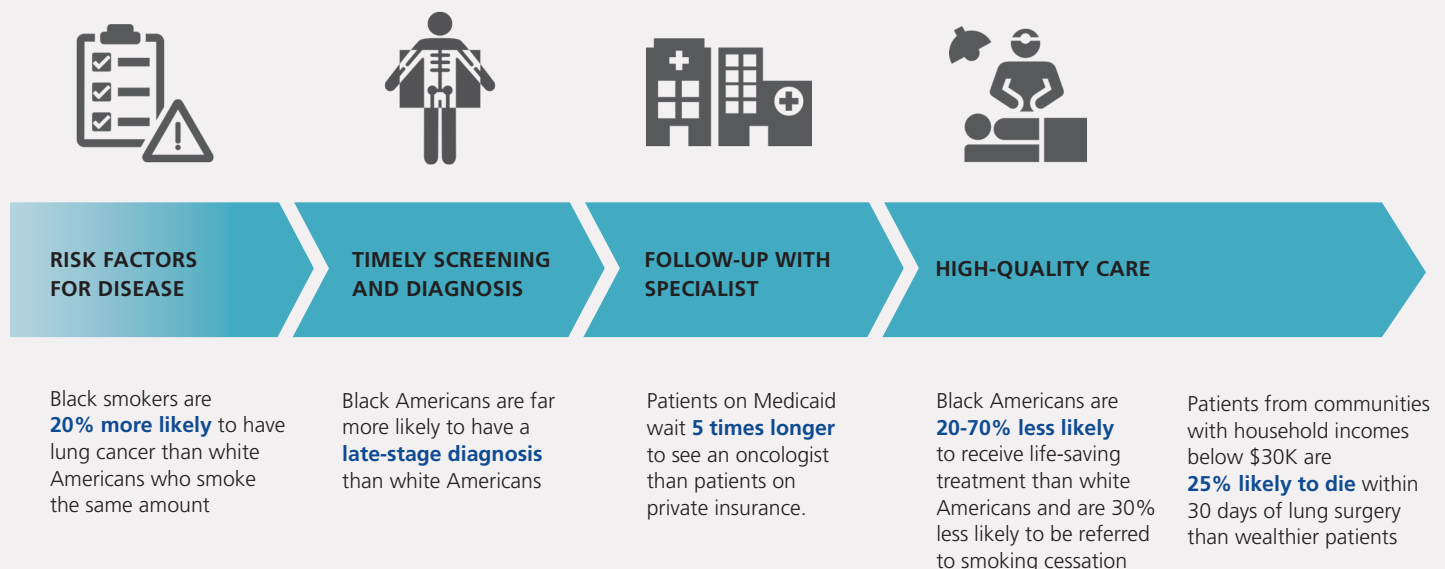
The battle against lung cancer casts these disparities in sharp relief. Lung cancer is one of the leading causes of death in the United States and the leading cause of cancer deaths, resulting in nearly 160,000 deaths in 2015—*more than 400 deaths every day*. Not only is it one of the most common cancers, it is also among the deadliest. Even when they are diagnosed at the earliest stages, lung cancer patients have only a 50% chance of five-year survival. If diagnosed in Stage III, five-year survival rates plummet to 14%. They are just 1% for those diagnosed in Stage IV *(see Figure 4 on the next page).* [4]

For a disease this pernicious, new immunotherapies can truly save lives, but only if the populations that currently experience the worst outcomes have access to them. For example, the five-year survival rate for lung cancer is 20% lower for black men than white men.[5] Reducing such drastic differences will require far more than traditional pharmaceutical company patient assistance programs or even the expansion of insurance coverage under the Patient Protection and Affordable Care Act (ACA). Addressing this need and eliminating these disparities will require new models of engaging and supporting patients across the care continuum, from initial risk factors for disease, to screening and diagnosis, through to follow-up care and treatment *(see Figure 3)*.

> *"Of all the forms of inequality, injustice in health care is the most shocking and inhumane."*
>
> —Martin Luther King, Jr. (1966)

Figure 3. Disparities in Lung Cancer Throughout the Patient Pathway

| RISK FACTORS FOR DISEASE | TIMELY SCREENING AND DIAGNOSIS | FOLLOW-UP WITH SPECIALIST | HIGH-QUALITY CARE | |

Black smokers are **20% more likely** to have lung cancer than white Americans who smoke the same amount

Black Americans are far more likely to have a **late-stage diagnosis** than white Americans

Patients on Medicaid wait **5 times longer** to see an oncologist than patients on private insurance.

Black Americans are **20-70% less likely** to receive life-saving treatment than white Americans and are 30% less likely to be referred to smoking cessation

Patients from communities with household incomes below $30K are **25% likely to die** within 30 days of lung surgery than wealthier patients
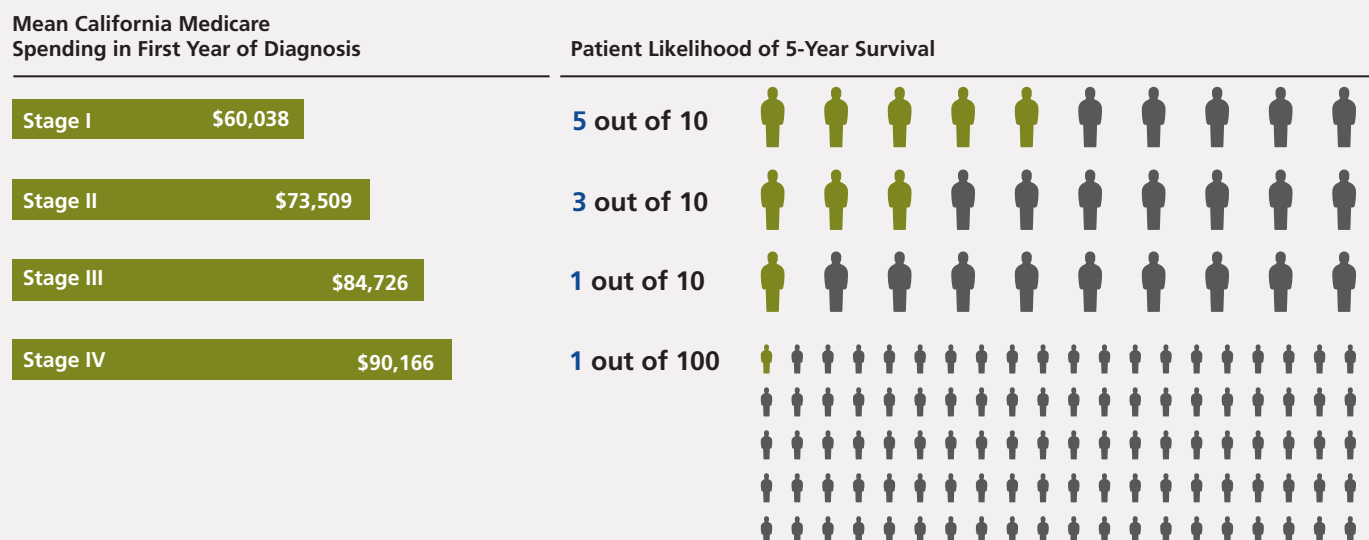
An opportune moment for sector-wide action

With mounting evidence of these disparities, there is a growing conversation around health equity. Health equity is "achieved when everyone, regardless of race, neighborhood, or financial status, has the opportunity for health—physical, mental, economic, and social well-being."[6] Spurred by the 2002 landmark report from the Institute of Medicine (IOM), "*Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,*" the sector is increasingly recognizing the importance of health equity to drive improvements in health outcomes for patients. The 2011 U.S. Department of Health and Human Services *Action Plan to Reduce Racial and Ethnic Disparities: A Nation Free of Disparities in Health and Health Care* illustrates this growing focus.

> "*It is time to refocus, reinforce, and repeat the message that health disparities exist and that health equity benefits everyone.*"
>
> —Kathleen G. Sebelius,
> Former Secretary,
> U.S. Health & Human Services

Implementation of the ACA in 2014 inaugurated the next stage in this conversation. With a goal of universal health insurance coverage, the ACA lays the groundwork to realize affordable, accessible, high-quality health care for all. Payers and providers are also increasingly recognizing the need to address equity in specialty care head-on. For example, the Dana Farber Cancer Institute in Boston has established a Cancer Care Equity Program (CCEP). Private insurer UnitedHealth Group created the Health Equity Services department in 2010

Figure 4. The Health Outcome and Financial Costs of Late Diagnosis in Lung Cancer

Mean California Medicare Spending in First Year of Diagnosis

Stage I	$60,038
Stage II	$73,509
Stage III	$84,726
Stage IV	$90,166

Patient Likelihood of 5-Year Survival

- 5 out of 10
- 3 out of 10
- 1 out of 10
- 1 out of 100

to consult with business units to support the development and implementation of solutions to drive improved health equity among their members. In addition, professional associations like the American Society of Clinical Oncology (ASCO) and the American Association for Cancer Research (AACR) have introduced specific initiatives focused on disparities, including the Health Disparity Committee at ASCO and the annual AACR Conference on the Science of Cancer Health Disparities in Racial and Ethnic Minorities and the Medically Underserved.

For the health system, addressing these disparities is not only a moral but also a financial imperative. **Researchers estimate that eliminating racial disparities across all cancers would save $2.3 billion in direct care costs, and $500 million in productivity costs.**[7] Studies have also shown that late diagnosis of cancer is directly related to these costs of treatment. In lung cancer, for example, early diagnosis and treatment saves an average of 30% of treatment costs in the first year and up to 50% of costs over a seven-year period *(see Figure 4)*.[8] In this case, the cost of treatment and patient likelihood of survival are also closely linked.

Despite its importance for patients, payers, providers, and policy makers, improving specialty care provision for low-income, rural, and minority patients has historically been addressed through the efforts of individual organizations, piecing together grant funding from public and private sources. Today's health care landscape, however, provides a strong enabling environment to tackle disparities along the care continuum comprehensively and sustainably. Five current trends make this an opportune moment to develop sustainable, scalable solutions for equity in specialty care.

1 **Expanded insurance coverage under the Patient Protection and Affordable Care Act (ACA)**. The ACA has driven the greatest gains in health insurance coverage in decades, enabling more people to seek affordable care and health care providers to better serve more people.[9] Since the passage of the ACA, more than 20 million people have gained insurance coverage through Medicaid expansion, procuring individual plans on state or federal exchanges, or as young adults newly able to remain on their parents' plans until age 26.[10] These changes have reduced the uninsured rate from 20.3% in 2013 to 11.9% by the end of 2015,[11] bringing millions of low-income patients, many of whom had previously relied on charity care, into the formal health care system. This makes equity more important for specialty care providers in two ways: it increases the patient load, particularly of low-income patients, that specialists will need to manage, and it enables payers and providers to move beyond "charity care" programs to develop sustainable solutions to improving equitable care and outcomes for previously underserved populations.[12, 13]

"With the advent of accountable care and other new models, if we're well organized, we can do more to mitigate disparities because we are looking at whether patients have a well-functioning system of care as opposed to specific pieces of the care they need."

—MEDICAL DIRECTOR, MAJOR PRIVATE HEALTH INSURANCE COMPANY

2 **Movement toward value-based payment models.** Recognizing that health outcomes and health costs can be closely intertwined, insurance providers are increasingly experimenting with new payment models that link reimbursement to improved quality of care and health outcomes rather than the volume of services provided.[14] The ACA itself is accelerating this shift by supporting uptake of models such as capitation, episode-based payment, and accountable care—which reimburse providers on the basis of the number of people treated, the number and type of medical episodes treated, and health care quality, respectively.[15] This renewed focus on results necessitates attention to health equity and to improving health outcomes for those who have historically been left behind. Enabling payers and providers to invest in solutions to drive patient outcomes that have historically fallen outside of fee-for-service payments, these new models show potential to create the necessary financing structures to address health disparities in specialty care.

> "We've become much more strategic about building community partnerships. We don't just show up—we engage our partners, and their partners. We sit down and share our knowledge and engage in a dialogue of how to move forward. And I've seen our grassroots efforts have significant impact and added value."
>
> —KAREN BURNS WHITE
> DANA-FARBER/HARVARD CANCER CENTER

3 **Investment in new care delivery models.** Payment reform has also accelerated innovation around health care delivery. The Centers for Medicare & Medicaid Services (CMS) are supporting several large programs to fund experimentation with new payment and delivery models that could improve health outcomes while reducing costs. These include the Health Care Innovation Awards[16] and the State Innovation Models program,[17] which have disbursed almost $2 billion since 2012.[18] In addition, a growing number of patients are being served through integrated delivery networks, which bring together hospitals, primary care providers, clinics and health insurance providers. Together, these shifts have enabled innovations like patient-centered medical homes, which have been shown to reduce health disparities.[19]

4 **Greater collaboration between communities and the health care system.** This increased focus on health outcomes is pushing payers and providers to look outside of their own doors toward the social determinants of health. For example, recognizing housing insecurity as a key source of stress and as a contributor to health disparities for low-income patients, CMS announced in 2015 that Medicaid funding could be used to support housing services for chronically homeless individuals.[20] CMS is broadening this work through the "Accountable Health Communities Model" initiative. Established in January 2016, the initiative is a five-year, $157 million program to test how helping patients access community-based social services related to their health needs will improve quality and affordability in Medicaid and Medicare.[21] With these initiatives, CMS is picking-up a growing practice of providers to

establish community-clinic collaborations to better meet the needs of their patients, while leveraging the core competencies of each partner organization. A 2013 Robert Wood Johnson Foundation survey of health and community development practitioners highlighted numerous examples of community-clinic collaborations to address issues including physical activity, access to health care, and access to healthy food.[22] These collaborations are essential to removing barriers and ensuring that everyone can benefit from specialty care.

⑤ **A national conversation on equity.** These changes are taking place within the context of a broad, national conversation on racial, economic, and gender equity in the United States. This context is an essential factor in efforts to address health disparities. It serves to raise awareness and understanding of health disparities, highlight the need for solutions, and heighten the sense of urgency for action. Over the past year, the national conversation has manifested in the health care field with the emergence of groups like White Coats for Black Lives, a student-led initiative whose mission is "to counteract systemic and interpersonal racism and its effects on the practice of medicine and the health of our patients." Associations for medical professionals are also increasingly integrating equity as a primary focus of their work, illustrated by Equity of Care, an organization established by the Association of Academic Medical Centers, the American Hospital Association, and others, as 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 staff's cultural competence capabilities; and (3) increasing diversity in governance and leadership. To date, nearly 1,000 hospitals have signed the "#123 For Equity" pledge.

> "*New people coming into the health system with insurance are less likely to speak English, less likely to have a college education, and more likely to be part of a minority group. So we all need to think about it—are we really prepared to take care of these populations? Health organizations are starting to understand that and it's driving growing activity to address health disparities. And requirements from CMS to track and report data and desire to control costs are all contributing to the momentum.*"
>
> —Aswita Tan-McGrory,
> The Disparities Solutions Center at
> Massachusetts General Hospital

These five trends will enable greater adoption of solutions for health equity—but much of what needs to change is yet to come. The current health care landscape presents both significant remaining disparities and emerging solutions to address them. These solutions are summarized in the next section, and explored in more detail in the other briefs in this series.

Emerging health equity solutions in specialty care

A number of solutions are emerging to improve equity in specialty care. These efforts originate from various points in the specialty care system—some initiated by provider institutions, some led by community organizations or local governments, and others introduced by public or private payers. Despite these varied origins, the most successful efforts consistently integrate and leverage the core competencies of multiple actors in the health system to effectively support and engage patients and develop sustainable financing mechanisms that enable programs to last beyond an initial pilot phase.

Together, these solutions address the diverse factors that drive health disparities both within and outside of the health care system. In order to create true health equity—across socio-economic status, race, ethnicity, and geography—all of these factors will need to be addressed. These solutions fall into three categories *(see Figure 5)*.

The sections below provide additional detail on each area, highlighting the current equity challenge and emerging solutions. The other briefs in this series provide a deeper look at each area, including case studies of effective initiatives, evidence of impact on health outcomes and health systems costs, and recommendations for broader adoption of these solutions.

Figure 5. What is Needed to Improve Equity in Specialty Care

Increasing Specialty Care Availability to better enable access to specialty care for rural and low-income populations.

For more analysis, examples, and solutions, see Brief 2: Increasing Specialty Care Availability

Ensuring High-Quality Care to better meet the needs of low-income and minority patients engaged in specialty care.

For more analysis, examples, and solutions, see Brief 3: Ensuring High Quality Specialty Care

Helping Patients Engage in Care by addressing the social factors that impede patients' ability to promote and protect their own health, engage in care, and adhere to treatment.

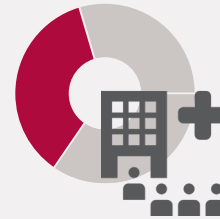For more analysis, examples and solutions, see Brief 4: Helping Patients Engage in Specialty Care

Increasing Specialty Care Availability

One of the largest drivers of inequity in specialty care is access. Specialist availability is limited, particularly for low-income and rural patients. Many specialists are unwilling to see uninsured patients and are even reluctant to see patients on Medicaid. This stems both from inadequate reimbursement—a 2012 study found that Medicaid reimbursed 66 cents for every dollar reimbursed by Medicare—and from the additional administrative burden posed by caring for low-income patients, who often require more eligibility paperwork and are more likely to miss appointments.[23, 24] As a result of limited specialist availability, patients requiring specialty care face significant delays—a 2013 study by the Ralph Lauren Cancer Center of stage IV lung cancer patients showed that **patients with commercial insurance wait an average of 10 days to see an oncologist, while Medicaid patients typically wait up to 53 days for the same appointment.**[25] This disparity is even more problematic when considering that the average life expectancy for untreated stage IV lung cancer patients is just 90 days.[26]

Snapshot: Increasing Specialty Care Availability

Target Patient Populations
- Low-income patients
- Rural patients

Relevant Drivers of Inequity in Specialty Care
- Provider refusal of uninsured or Medicaid patients
- Limited availability of specialists in rural areas
- Complex or ad hoc referral processes between primary and specialty care, especially for uninsured patients

Health Equity Solutions
- Telemedicine and telementoring
- Development of primary care capacity to provide appropriate specialty care
- Coordinated specialist networks that streamline charity care

For patients in rural areas, the access problem is different. Rural areas are home to 20% of the U.S. population but few specialists—for example, just 3% of medical oncologists practice in rural areas. These circumstances force rural patients to travel significant distances to see specialist providers in urban centers, which is particularly challenging for those undergoing daily or weekly treatments for cancer and other diseases (e.g., for chemotherapy, radiation, or dialysis). According to the Community Transportation Association (CTA), approximately 3.6 million Americans miss or delay medical care because of transportation reasons.[27] Numerous studies have shown that this holds even for critical cancer treatments, including a 2012 study of colorectal cancer patients in Virginia in which 19% of cancer patients surveyed struggled with transportation to treatment. While every state Medicaid program offers some form of reimbursement, subsidy, or service for non-emergency medical transportation, many states require a formal request and prior approval, often a minimum of 72 hours in advance.[28]

"*One of the great frustrations articulated by every health center clinician is that when their patients need care that goes beyond their skills, such as specialty care, they struggle greatly to find someone who will accept their patients – even those with some kind of marketplace coverage or Medicaid.*"

—DAN HAWKINS,
NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Emerging Solutions: Increasing Specialty Care Availability

Recognizing that the status quo is insufficient, the sector is increasingly looking at solutions that will enable greater access to specialty care among low-income and rural populations. Community organizations like the Project Access partnerships in communities across the country, are establishing **coordinated networks** of specialists across health care providers in a local area to improve access to care for the un- or under-insured and to streamline provision of care for providers. In addition, initiatives like Project ECHO are increasingly leveraging new technologies that allow specialists and super-specialists to use **telemedicine** to teach and support **community-based and primary care physicians** to provide some specialist services. These solutions leverage existing health infrastructure and technology to enable "task shifting" between different cadres of health care workers to provide greater specialty care access to hard-to-reach populations.

Learn more about these solutions in Brief 2: Increasing Specialty Care Availability.

Ensuring High-Quality Specialty Care

Increasing the availability of specialty care services is just one part of the solution. Ensuring high-quality care is equally important to delivering health outcomes and reducing health disparities. Health care in the United States, especially specialty care, is often delivered through a two-tiered system. Those who can afford it get treatment at high-quality academic specialty medical centers, like the National Cancer Institute-designated Comprehensive Center Centers or the Cleveland or Mayo Clinics. For those who cannot afford this level of care, however, there is a different system of safety-net facilities and free clinics. These differences result in real disparities in health outcomes—a 2013 study comparing results for colorectal cancer patients across a public safety-net hospital and a private comprehensive cancer center found that **three-year overall survival and relapse-free survival rates were significantly higher for patients at the private cancer center than for those who received care at the safety-net facility.** The study also found that patients at the safety-net facility were less likely to complete full courses of chemotherapy and were more likely to experience delays and service defects.[29]

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
- Quality improvement approaches to target disparities

These differences extend to the broader care environment, which is not welcoming or comfortable for many low-income patients. Safety-net health care facilities in New York City, for example, often have armed guards in waiting rooms, glass partitions, and overwhelmed front office staff, all of which send implicit messages to patients that they are neither trusted nor welcome.[30] For patients who do not speak fluent English, the health care environment is even more challenging.

Unfortunately, providers themselves often compound these challenges. Research increasingly suggests that implicit or unconscious biases can influence providers' perceptions of low-income or minority patients. These biases affect their manner with patients as well as their decision-making. A recent study of a hospital in Pennsylvania found that health care workers, including physicians and nurses, use fewer supportive social cues such as standing next to a patient's bedside or holding a patient's hand with their black patients relative

to their white patients.[31] In some cases, these biases influence the courses of treatment that doctors recommend. For example, a large study of Medicare patients from 1991 to 2002 showed provider bias, alongside patient attitudes, as a significant contributor to disparities between patients of different races. In the study, **black early-stage, non-small-cell lung cancer patients were 37% less likely to receive surgery and 42% less likely to receive chemotherapy than their white peers.** For late-stage cancer, this rose to a 57% disparity in treatment received.[32]

For patients, these factors culminate in feelings of disempowerment and dissatisfaction with their care that eventually affect their retention in care and health outcomes. Multiple studies have demonstrated strong links between patient trust and health outcomes from specialty care: for example, **a 2012 study of 175 patients at urban HIV clinics found that patients with trust in their physicians were more likely to adhere to ARV regimens**.[33] Similar results have been found across diseases—a recent 2014 study of black women also cited health care worker bias as a factor in delayed cervical cancer screening and disparities in follow-up and treatment between black and white patients.[34]

> "*At many of the hospitals in impoverished neighborhoods, not going in for screenings or follow-up care is a very sane decision. They can be dirty and crowded, you might be met with security guards or hospital police, and you are likely to wait for hours. Who among us would go back? We essentially have a two-tiered health care system—and we need to recognize that.*"
>
> —Gina Villani, MD,
> Ralph Lauren Center for Cancer Care

Emerging Solutions: Ensuring High-Quality Specialty Care

To improve the quality of treatment that low-income and minority patients receive, there is growing understanding and practice amongst payers and providers, such as Kaiser Permanente in California and HealthPartners in Minnesota of *culturally-competent care* for patients. Leading organizations are also *harnessing the tools of quality improvement* to identify disparities and innovate to address them. In addition, a diverse set of actors, including medical schools such as University of California, San Francisco (UCSF), patient advocacy organizations, and health care providers are exploring different methods of addressing and mitigating the effects of *implicit bias* among health care workers, including building the diversity of their own staff and leadership.

Learn more about these solutions in Brief 3: Ensuring High-Quality Specialty Care.

Helping Patients Engage in Specialty Care

These improvements to specialty care availability and quality are essential—but insufficient. In order to truly address disparities, specialty care providers and other actors in the system must support patients to engage in care. This will require the health system to look beyond its traditional boundaries, towards what are now understood to be the "social determinants of health."

The most commonly recognized challenge for low-income patients in specialty care is the cost of specialty care treatment and medicines. The introduction of even small co-pays (or "cost sharing" under Medicare) for screenings can reduce uptake—one study showed that rates of mammography screening decreased by 12.3% in low-income populations after the introduction of a co-pay, more than three times the impact in higher income populations.[35] This same dynamic holds for drug coverage as well. The new generation of Hepatitis C drugs, for example, is highly effective in curing the disease—but prices for the drugs are so high that few state Medicaid plans provide full coverage for them. In thirty-four states, patients are denied access to the cure until they show signs of existing liver damage.[36]

Snapshot: Helping Patients Engage in Specialty Care

Target Patient Populations

- Low-income patients
- Minority patients

Relevant Drivers of Inequity in Specialty Care

- Disease awareness and health literacy
- Environmental factors (e.g., housing, food security, childcare)
- Stigma and/or distrust of the healthcare system
- Financial burden of disease
- Psychological burden of disease

Health Equity Solutions

- Community outreach to engage patients
- Patient navigation
- Patient support services

The barriers facing specialty care patients are not solely financial. For some, inflexible work hours, lack of childcare, and transportation challenges can make it difficult for patients to seek and stay engaged in care. For others, socio-economic factors can impede their ability to adhere to treatment recommendations. Patients with cardio-vascular disease, for example, are recommended a "heart healthy diet," comprised primarily of fresh fruits and vegetables, whole grains, and lean proteins like fish. Yet patients who live in low-income neighborhoods often lack easy access to high-quality grocery stores, relying instead on local convenience stores and bodegas for food. Patients who live in these areas, known as "food deserts," are at higher-risk for contracting heart disease and are less likely to adhere to a physician's dietary restrictions. Research has shown that adherence to dietary recommendations is directly related to proximity to grocery stores for low-income populations.[37] As a result, studies show that heart failure patients living in low-income neighborhoods are 10% more likely to be readmitted to the hospital than those living in wealthier neighborhoods.

Social attitudes and stigma can also play a role. Evidence, for example, suggests that people are reluctant to seek HIV testing in health care settings, often listing a different service as the primary reason for attending a health care appointment.[38] For some with cancer, a sense of "fatalism" directs patients to opt-out of treatments with life-saving potential. A related concern is patients' attitudes towards the health care system. In particular, African Americans have a well-documented distrust for the health care system and medical research, rooted in the history of events such as the Tuskegee Syphilis Experiment, research conducted from 1932 – 1972 by the U.S. Public Health Service (PHS) and Centers for Disease Control (CDC) that studied but knowingly denied curative treatment to 600 African American sharecroppers with syphilis, including failure to inform the patients of their diagnosis, in order to observe the progression of the disease. The participants were provided free health care and meals in exchange for their uninformed participation, and were often lied to about the nature of diagnostic tests and other activities. Current perceptions of differences in care quality due to race perpetuate this distrust.[39]

> *It has been said that the most important factor in understanding someone's health status is their ZIP code. Your circumstances impact your overall health and your ability to access adequate health care.*
>
> —DEBORAH C. ENOS,
> FORMER CEO, NEIGHBORHOOD HEALTH PLAN

In addition, for specialty care patients, navigating the care continuum is an immensely difficult challenge. A patient with lung cancer, for example, undergoes multiple tests in the diagnosis phase followed by months of treatment that can include radiation, chemotherapy and surgery. These patients are required to navigate an assortment of health insurance, charity care and pharmaceutical company patient assistance programs to cover the costs of the tests and treatments. While more low-income patients have health insurance coverage under the ACA, this is driving a growing need for patients to have health insurance literacy. Surveys of the newly insured population suggest that many patients are on plans with narrow networks and that patients have confusion about which doctors are in their new networks. This has led to continued difficulty for patients and additional administrative burden for specialists through the referral process.[40, 41] Language and cultural barriers between patients and providers can exacerbate this problem.

Given these challenges, the results are not surprising: **of the 1.2 million people in the US living with HIV, 65% are diagnosed but not in consistent care**.[42] Studies of cancer patients show similar patterns, with the evidence suggesting that low-income and minority patients have lower cancer screening rates and experience longer lags between diagnosis and follow-up across cancer types—factors that are directly responsible for disparities in morbidity and mortality outcomes.[43]

Emerging Solutions: Helping Patients Engage in Specialty Care

Seeking to improve health equity and control costs, specialty providers like Cedars-Sinai Heart Institute and the Dana Farber Cancer Center, are increasingly conducting **community outreach to engage patients**, through community health workers or mobile units, to reach patients who would not otherwise engage with the health care system and introducing **patient navigation** to support patient retention in care. Simultaneously, community and patient support organizations, like Cancer*Care* and Cancer Support Community, are aligning with the health care system to support patients with patient **support services** such as psychosocial counseling, transportation and housing. Insurance providers, such as UnitedHealth Group, are also recognizing the value of these activities and starting to identify them as reimbursable expenses in support of patient outcomes.

Learn more about these solutions in Brief 4: Helping Patients Engage in Specialty Care.

This series of five briefs explores these solutions and others, to highlight what is working to deliver improved health access and outcomes, identify opportunities to make these solutions a core part of the health care system, and inform evolving federal and state policy dialogues. Addressing these issues will require coordinated activity across communities and all levels of the health care system (read more about the need for institutional and sector action in **Brief 5: Call to Action for a System-wide Focus on Equity**). Our hope is that this comprehensive portrait of current dynamics and opportunities for improvement will provide a common agenda for the progress that we so desperately need.

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

Striving for Equity in Specialty Care

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Breaking the Barriers to Specialty Care

Practical Ideas to Improve Health Equity and Reduce Cost

BRIEF

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Increasing Specialty Care Availability

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.

Learn more about FSG at **www.fsg.org**.

About this brief

This brief illustrates how the health system can effectively increase timely access to high-quality specialty care services for low-income and rural populations by investing in three types of solutions: developing primary care capacity to deliver specialty care for select conditions, using telemedicine and telementoring to expand access to locally-based specialty care, and coordinating specialty care referral systems for underserved groups.
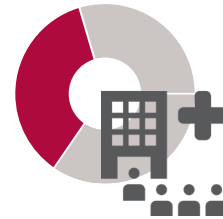
About specialty care

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: Increasing Specialty Care Availability

Target Patient Populations

- Low-income patients
- Rural patients

Relevant Drivers of Inequity in Specialty Care

- Provider refusal of uninsured or Medicaid patients
- Limited availability of specialists in rural areas
- Complex or ad hoc referral processes between primary and specialty care

Health Equity Solutions

- Telemedicine services
- Development of primary care capacity to provide appropriate specialty care
- Coordinated specialist networks that streamline charity care

Relevant patient groups and disease areas

This brief will dedicate specific attention to the following groups and issues.

- **Uninsured and low-income patients** who face the challenge of limited availability and selection of providers due to low Medicaid reimbursement or lack of insurance, out-of-pocket costs, transportation costs and time costs.
- **Rural patients** who are particularly affected by a shortage of local specialists and are often required to travel long distances to seek care.

The Equity Challenge: Unequal Access to Specialty Care

Accessing specialty care is inherently more difficult than accessing primary care. Although there are more specialists than primary care physicians in the United States, there are far fewer specialty care doctors for each type of specialty than primary care; this fact in turn limits the number of patients that can be seen.[1] This results in access challenges for low-income and rural patients, who regularly face delays and other hardships that contribute directly to disparities in health outcomes.

> " *My Medicaid patients sometimes have to wait six months for a consult with a specialist. And six months matter when you're talking about cancer.* "
>
> —Nurse Practitioner, Community Health Center, Alabama

In particular, the limited availability of specialists drives health disparities in three ways.

- *Inaccessible or delayed care due to insurance status:* Specialist practices often cap the number of Medicaid patients they are willing to see. In large part, this is due to differences in reimbursement rates between Medicaid and more well-resourced plans like Medicare or private insurance. A 2012 survey of reimbursement rates found that Medicaid reimburses 66 cents for each $1 reimbursed by Medicare.[2] As a result of such differences, fewer than 50% of all medical practices in America accept Medicaid patients, and that rate is far lower for specialist practices.[3,4] **For example, studies suggest that only 27% of dermatology practices currently accept Medicaid patients**.[5] Even when they can see a specialist, Medicaid patients face delays. For example, Medicaid patients on average wait a full month more than Medicare patients to see a dermatologist, even for skin cancer consultations.[6] Examples from California show that Medicaid patients can wait as long as a year and a half to see a cardiologist.[7] Patients without insurance wait even longer.[8]

- *Transportation time and cost:* The supply of specialty care is not only inadequate, but it is also highly concentrated in urban areas. Estimates suggest, for example, that **97% of medical oncologists in the United States practice in urban areas**.[9] For the 20% of the U.S. population that lives in rural areas, this creates a significant challenge. Rural patients often need to travel hundreds of miles for care, a task that is particularly difficult when repeat visits are necessary to complete a course of treatment (e.g., for chemotherapy, radiation, or dialysis). According to the Community Transportation Association (CTA), approximately 3.6 million Americans miss or delay medical care for transportation reasons every year. This is borne out in health outcomes data: research shows that **rural cancer patients, regardless of income or insurance coverage, experience higher mortality rates than their urban peers** with access as one contributing factor. Although every state Medicaid program offers some form of reimbursement, subsidy, or service for non-emergency medical transportation, half require a formal request and prior approval, often a minimum of 72 hours in advance.[10]
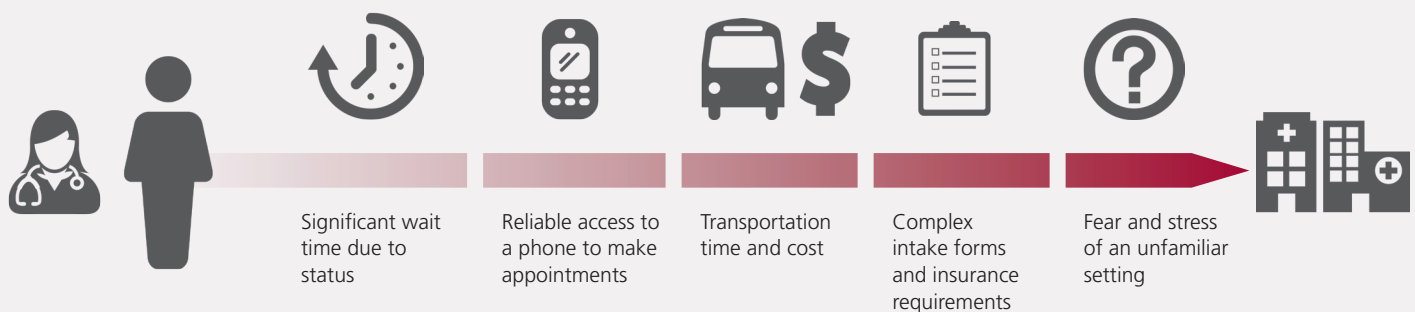
- ***Disparity in care environment and quality:*** In this context of poor access to specialty care, low-income and rural patients are too often forced to settle for lower-quality care. Lacking the resources to travel to the highest-ranked specialty care centers or the insurance coverage and resources to access the best specialists, low-income and rural patients often seek care at charity care clinics attached to specialty institutions, safety-net facilities, or hospitals that lack extensive experience with their specific conditions and latest treatment guidelines and standards of care. In practice, this can include conducting a lower volume of specific surgeries per year, slower adoption of updated diagnostic and management protocols, and lower capacity for early recognition, prevention, and management of complications. These differences have direct and significant impacts on health outcomes. For example, a 2015 study by the California Healthcare Foundation found that patients who have cancer surgery at "low-volume" hospitals—hospitals that do not specialize or conduct significant numbers of a certain surgery—experience higher post-surgery mortality rates, higher rates of post-surgery complications, and longer hospital stays.[11] Similar trends were found in comparisons between public safety-net hospitals and private comprehensive cancer centers—a 2013 study of colorectal cancer patients in New York found that **three-year overall survival and relapse-free survival rates were significantly higher for patients at the private cancer center and that patients at the safety-net facility were less likely to complete full courses of chemotherapy and were more likely to experience delays and service defects**.[12]

> "*One of the most common requests for assistance that we get is for transportation. Nearly 15% of our requests are for transportation, and almost all of those callers are low-income cancer patients who are traveling over 60 miles to receive specialty care. Nearly half of our rural patients travel over 100 miles for care—that's a huge challenge.*"
>
> —ERIN SINGLETON,
> PATIENT ADVOCATE FOUNDATION

Figure 1. Barriers along the Patient Pathway in the Traditional Referral Model

Even with a referral from a primary care provider (PCP), uninsured, underinsured, and Medicaid patients may be unable to find specialists willing or able to see them. Those able to be seen by a specialist face additional challenges:

Significant wait time due to status

Reliable access to a phone to make appointments

Transportation time and cost

Complex intake forms and insurance requirements

Fear and stress of an unfamiliar setting

These barriers not only drive poor health outcomes, but they also have implications for health systems costs. Without timely access to specialty care, many Medicaid and uninsured patients seek care in the emergency department (ED). In a 2015 survey of ED doctors, **75% of respondents noted that ED visits have risen because patients cannot otherwise get the specialty care they need**.[13] The ED is seen as more convenient (34% of ED visits are during regular doctors' office hours);[14] further, it is sometimes seen as a "back door" to specialty care for the uninsured, because patients can access care within days rather than months.[15, 16, 17] Studies and anecdotal evidence show that some specialists are more likely to see Medicaid patients when they are referred from the ED, and patients are aware of this. In some instances, patients who wait for months to see specialists are able to meet with one just four days after going to the emergency room.[18] Although convenient for patients, care provided in an ED is much more expensive than care provided in other settings, and the practice often perpetuates patient disengagement from more consistent and comprehensive primary and specialty care. Cumulatively, this has an enormous impact on the health system, as evidenced by a 2010 study, which found that over half of emergency room visits are avoidable and that ED overuse nationally costs more than $38 billion in unnecessary healthcare spending.[19]

The example of specialty care for deep vein thrombosis, a condition that results in blood clots, illustrates this dual effect of poor outcomes and high costs. Research suggests that uninsured patients admitted to the hospital for deep vein thrombosis averaged a length of stay of 5.5 days, where insured patients averaged 3.7 days. Rates of return to the emergency department were 26.1% for uninsured patients compared to 11.3% for insured patients. This resulted in a significantly **higher average cost of care for uninsured patients than for insured patients—$12,297 versus $7,758.**[20]

In the worst-case scenario, some patients will never reach a specialist. Evidence from the Voices for Detroit Initiative, a network that coordinates care for the un- and under-insured population of Detroit (*see profile on page 14 for additional detail*), suggests that this is not uncommon—36% of the program's first-time enrollees were found to have pre-existing, untreated chronic conditions. Without the care provided through the program, these patients would have remained undiagnosed and untreated.[21] Poor access to care is a clear driver of both disparities in health outcomes for low-income and rural patients and health care system costs—as such, it should be a top priority for reform.

Emerging Solutions

The health sector is increasingly recognizing this dual challenge of poor outcomes and high costs—and working to address it. New innovations to improve access to specialty care focus on the lack of specialists in rural areas, the need to increase access to specialists for low-income and uninsured patients in urban areas, and efforts to reduce administrative and financial costs for hospitals and patients alike. These solutions fall into three categories.

Figure 2. Three Emerging Solutions for Increasing Specialty Care Availability

PCP Provision of Specialty Care

Building the capacity of primary care physicians (PCPs) to deliver some specialty care not only increases access, but also enables patients to access care from trusted providers in their communities

Read more below

Telemedicine

Leveraging technology to enable physicians to treat patients remotely or from their PCP location helps reduce the travel, cost, and inconvenience burden on patients to see a specialist, especially in rural areas

Read more on page 11

Coordinated Specialist Networks

Creating a central coordinator to streamline access to specialists for un- or under-insured patients increases access to care for patients and improves efficiency and reduces administrative burden for providers

Read more on page 14

Primary Care Physician Provision of Specialty Care

Primary care providers are a highly valuable channel to reach a broad range of patients: they are often located in a patient's community, have trusted, long-term relationships with their patients, and have a comprehensive understanding not only of their patients' health status, but their social and economic status as well.

The health sector increasingly recognizes the potential of primary care physicians (PCPs) to deliver select specialty care services. Indeed, building the capacity of PCPs to deliver care for complex, chronic diseases, such as HIV and some cancers, is a new way to expand the reach of limited specialty care services to serve more patients. Delivering this care through PCPs has been found to drastically reduce delays and improve

access, reduce the travel and administrative burden on patients, and enable patients to receive specialist care in a comfortable and trusted environment—all while maintaining the same level of care quality that patients would have received from a medical specialist. Recent recommendations from the U.S. Department of Health on making the "medical neighborhood" more effective and efficient for patients focuses heavily on expanded roles for PCPs (along with the support of improved navigation for patients and better coordination across providers).[22] For specialty care providers, this type of "task-shifting" can greatly increase their own efficiency, enabling them to support many more patients through a network of PCPs or other allied health professional such as nurse practitioners.

> "*Project ECHO is a multiplier for the amazing work that hospitals and doctors already do and are mandated to do—it is a scaling tool in and of itself. And while our doctors do Project ECHO to have greater impact, not to make more money, it does have a cost-saving element.*"
>
> —ERIKA HARDING,
> PROJECT ECHO

Though there are several models for building the capacity of PCPs and other health professionals to deliver specialty care, most successful programs are grounded in a training curriculum on relevant treatments or procedures,[23] along with ongoing support and mentorship from specialists. These specialists help participating PCPs manage particularly complex cases through regular weekly or bi-weekly video conference calls between or among providers or teams of providers.[24] Some organizations supplement this training with on-site "champion PCPs" who focus on a particular disease or condition's treatment through additional research and training, provide support to their institution's PCPs, and consult on difficult cases.

These programs have long-existed in local pockets. For example, Project CICERO at Montefiore Medical Center in the Bronx, New York has used this practice to deliver HIV care to 1,000 patients in their community (see Case Example on the next page). This approach is now receiving renewed attention and interest through the emergence of Project ECHO—short for Extension for Community Healthcare Outcomes—which leverages videoconferencing technology to build collaborative care partnerships between specialist teams at academic medical centers and other centers of excellence and PCPs who provide care in rural and underserved communities. The Project ECHO platform operates through 39 "hubs," which provide specialty care training and support for PCPs in 30 disease areas across 22 states. This model enables patients to access high-quality care more quickly and more easily, and also allows for smooth transitions to specialty care facilities when needed. While these projects continue to be funded largely by grants, there are signals that this could change: Medicaid managed care plans in the state of New Mexico, where Project ECHO is based, recently agreed to reimburse for the ECHO Care model on a fee-for-service basis in addition to the grant support that the state Medicaid agency already provides to support the Project ECHO hub at the University of New Mexico.[25]

Case Example

Project CICERO: Expansion of HIV Care through PCPs

Montefiore
Inspired Medicine

Recognizing the challenges that many HIV/AIDS patients experience in seeking care from specialists, particularly as the number of HIV/AIDS specialists has decreased over the past several years, Project CICERO at Montefiore Medical Center in the Bronx, New York, provides patients with the opportunity to receive HIV treatment from their PCPs (in a patient-centered medical home model). Treatment provision by PCPs is not only more convenient for patients; it also mitigates stigma, one of the most common barriers to HIV testing and treatment adherence. Treatment by PCP enables HIV patients to be "anonymous" by avoiding HIV-specific clinics.

Established in the late 1980s, Project CICERO is made possible by leveraging a small cadre of HIV specialists at Montefiore, who support 100 primary care providers working in 10 community health centers throughout the Bronx to manage and treat more than 1,100 patients with HIV. These community-based physicians receive special training and ongoing support as needed from the specialists at Montefiore, as well as automatic reminders from the system about their HIV patients. Through the program, PCPs are supported by the program's director, a medical director, an administrator, an HIV specialist pharmacist, a psychologist, a psychiatrist, a retention specialist, and 2 patient navigators. Drug and treatment costs are covered by Medicaid and insurance, and ancillary support services for the program are funded by the Ryan White HIV/AIDS Program and other government grants. Patients come to the program through a network of partnerships that Montefiore has established in the community, including partnerships with drug outreach, jail transition, homeless shelters, and community HIV/AIDS service organizations.

Project CICERO has created an environment of PCP empowerment and a community of practice within its participating clinics. This is achieved through several key components:

- Each clinic has a "specialty champion" PCP who acts as the HIV-specific medical director for that clinic, stays up-to-date on the latest advances in HIV treatment, and supports other PCPs to provide HIV care.
- Participating PCPs and specialists meet via videoconferencing to discuss challenging cases on a regular basis.
- PCPs are encouraged to reach out to specialists with questions, but they are required to consult with a specialist when changing a patient's protocol. This policy makes collaboration an expectation and ensures that quality of care is maintained.

The program has achieved 87% viral suppression, compared with a city-wide average of 73%, and comparable treatment outcomes to those in hospital-based specialty centers, all while reducing delays in treatment initiation for low-income patients with HIV. Evidence suggests that it has been a good investment as well: few CICERO patients use the emergency room to access HIV care or other health needs, reducing capacity and cost strains on the city's healthcare system.

"The average wait time from learning you are HIV positive to being engaged by your treating doctor is about 6 seconds—because it's the same person."

—Paul Meissner, Project CICERO, Montefiore Medical Center, Bronx, NY

Program Director Paul Meissner notes, "Montefiore is developing a Medicaid Health Homes program for patients with high needs that result in high costs. I expected a lot of our Project CICERO patients to be on that list—but they're not. The fact that our patients don't meet that high need/high cost threshold means that we're doing something right." The program has been so successful that it will be replicated to treat patients with Hepatitis C.

Achieved 87% viral suppression in HIV patients

Telemedicine

Telemedicine provides the opportunity for patients to consult with specialists remotely via video technology, either by appointment or on call from emergency rooms. Telemedicine can be used in a range of different applications, including enabling more efficient reading of medical imaging, allowing providers to monitor patient's vitals and wellbeing while they are at home, and enabling direct patient-provider consultation and services in a range of specialties.

Telemedicine is a particularly helpful solution to improve access to specialty care for rural patients. The Indian Health Service, for example, has made Health Information Technology (HIT) and telemedicine a cornerstone of its efforts to reduce health disparities for the reservation-based Native American population. The IHS has established collaborations between tribes and academic medical centers to create a system for both "real-time" interactions between patients and remote providers and asynchronous services (also known as "store and forward" telemedicine), where doctors consult on patient cases outside of an immediate patient consultation (e.g., consulting on a scan or test). For example, the IHS's tele-ophthalmology program enables patients on rural reservations to easily have their retinal images remotely analyzed by ophthalmologists. As a result of this service, screening rates for diabetic retinopathy increased from 50% to 75% and treatment rates increased from 19.6 to 29.5 per 1,000 patients between 1999 and 2003.[26] Telemedicine is also increasingly used for dermatology. Kaiser Permanente has one of the largest tele-dermatology programs, run in both urban and rural settings. The majority of users are in fact primary care physicians, who can send a photo of a questionable skin problem to a dermatologist via email and receive a quick response that they can then pass on to their patients. This model allows specialists to spend more of their time with patients who require more intensive, in-person assistance and reduces travel, wait time, and costs for patients.[27]

In order to further scale the use of telemedicine, more consistent practice guidelines and policy and reimbursement frameworks will need to be established. The Patient Protection and Affordable Care Act (ACA) expanded many provisions for telemedicine for Medicaid and Medicare.[28] Policies currently vary widely by state, but more consistent reimbursement frameworks and policies to enable use of telemedicine across state lines will be needed for telemedicine to flourish.[29] Several states are leading the charge—Maryland, for example, requires that private insurers reimburse for medically necessary use of telemedicine and has established a state-level task force dedicated to shaping telemedicine policy. Seven states currently receive an "A" rating from the American Telemedicine Association (ATA) for policies that support telemedicine, and the American

> "*Transportation is a big barrier. I work on a Navajo reservation and the reservation is huge, some roads are unpaved. Patients have to travel long distances to come see us and they often don't have money for gas or the roads are bad in the winter. I had one HIV patient who was enthusiastic about getting care but had no phone and no car. Once [a funder] covered those expenses, suddenly, he did great in care and now has an undetectable viral load. Addressing those challenges is critical.*"
>
> —PRIMARY CARE PHYSICIAN, ARIZONA

Medical Association has also recently issued guiding principles of the use of telemedicine.[30] However, advocates note that Medicare reimbursement is lagging, as it only reimburses for telemedicine consultations conducted in health care facilities and does not allow for patients to have telemedicine consultations at home.

Improving Access to Palliative Care: Balancing Access and Quality

Palliative care is a core component of treatment for many serious illnesses, including cancer, cardiac disease, and other chronic conditions such as organ failure. Palliative care is often provided simultaneously with curative care, but focuses on alleviating pain and distress, helping to coordinate care, and supporting patient care decision-making. The practice is supported by a strong evidence base of outcomes and cost efficiency—studies have found palliative care consultation to be associated with significant reductions in the overall cost of care.

There is a strong movement to expand access to palliative care through a variety of channels, including hospitals, nursing homes and assisted living facilities, in-home care services and telemedicine. These new initiatives are leveraging a broad range of health care workers, from physicians to nurse practitioners.

As this tremendous expansion occurs, however, access continues to vary greatly by state and by providers and payers. And there is a growing focus on ensuring that quality standards remain consistent as expansion occurs through alternative channels.

Organizations like the Center to Advance Palliative Care (CAPC) are leading this effort. CAPC advocates with public and private payers and policymakers to ensure equal access to palliative care for those in need, provides support to provider organizations to integrate palliative care into their services, and works with other palliative care organizations to establish consistent definitions and standards of practice for palliative care across states.

Case Example

Center for Connected Health Policy: Specialty Care Safety Net Initiative

The Specialty Care Safety Net Initiative was launched in 2010 by the Center for Connected Health Policy with support from the California Health Care Foundation. The three-year pilot program aimed to expand the state's safety net to include specialty care, with a focus on the use of telemedicine. This effort was particularly relevant in California, where some patients were travelling as much as 600 miles to see a specialist. Over three years, the program connected five University of California medical centers with patients at 43 safety-net facilities around the state. Through this system, 2,301 consultations were provided to patients in the areas of dermatology, endocrinology, hepatology, neurology, orthopedics, and psychiatry. Lasting relationships were built between CHCs and academic hospitals, allowing hospital employees to feel as though they were contributing to healthcare to those who would otherwise be unable to access it, and CHC patients received care that would have taken months or been impossible to reach due to distance.

Despite enthusiasm expressed by participating providers about the success of the pilot and the progress that was made toward fostering acceptance of telemedicine within participating clinics, payment and reimbursement are the biggest barriers to continuing the established partnerships. In its concluding report, the Center for Connected Health Policy outlined potential options for covering the costs of providing telemedicine-based specialty services at safety net clinics, including purchasing a portion of a specialist's time from an academic medical center (rather than paying on a fee-for-service basis), partnering with other community health centers to hire a central cadre of specialists that could consult with patients at all of the participating providers via telemedicine, and advocating for greater reimbursement of telemedicine services.[31]

Three-year pilot provided 2,300 telemedicine consultations

Coordinated Specialist Networks to Streamline Charity Care

Specialists have traditionally seen uninsured patients on an ad hoc basis. Even to get these appointments is a struggle—primary care providers are often required to rely on personal relationships and favors rather than an established system. These informal referral networks are vulnerable to uncertainty in terms of specialist availability, inconsistent communication, unclear policies and protocols, and mixed patient follow through.

Some community health centers and hospitals, however, are establishing more formal partnerships. These collaborations operate under unified policies and systems, share electronic medical records, and often provide patient navigation services to more efficiently and effectively manage specialty care for uninsured patients.

These networks can form either directly between provider organizations or can be facilitated by an intermediary organization that coordinates donated care across a number of local providers. Project Access for example, which is independently administered in a number of metropolitan areas, coordinates donated care between specialists and safety net providers in its communities. The organization works with specialist providers to understand and coordinate their availability, and works with patients to minimize missed appointments and ensure that patients are well-prepared for their visits. To do so, Project Access provides a number of additional services to its patients such as transportation, information about providers, and counselling. This service is generally funded through grants from government agencies and local providers, who realize cost savings and efficiencies from these initiatives. The history of the Cuyahoga Health Access Partnership (*see Case Example on the next page*) illustrates how local actors can come together to establish and maintain these collaborations.

> "*We have a deep knowledge of the local underserved population and we're neutral among all of the different local providers. These are unique assets that can be leveraged for a lot of different purposes to help improve access and efficiency in the local health care system.*"
>
> —SALLIE NEILLIE,
> PROJECT ACCESS NORTHWEST

The Voices of Detroit Initiative (VODI), a collaboration between several Detroit-based health systems and local FQHCs, provides strong evidence of the opportunity these networks offer for cost savings. Similar to CHAP, VODI works to strengthen the continuum of care in the safety-net through shared polices and referral protocols for primary and specialty care in Detroit. Over a five-year period, the program produced cost savings of $23 million for the local health care system, including $8.2 million in revenue enhancements from helping patients enroll in insurance and $13.3 million in cost savings associated with reduced ED utilization.[32] Despite the value these efforts bring to patients and the healthcare community, similar organizations elsewhere have had to cease operations due to a lack of consistent funding.

Case Example

The Cuyahoga Health Access Partnership: Streamlining Referral Networks for the Uninsured

Cuyahoga Health Access Partnership (CHAP) is an organization in the Cleveland area that coordinates donated specialty care among community health centers, free clinics, and hospitals, including the Cleveland Clinic. At the core of the program is CHAP's "Access Plan," which confirms a patient's eligibility for donated services at participating provider institutions. Uninsured patients are screened for eligibility and entered into the system by their PCP, at which point they receive a "network card" that allows them access to free or discounted care within the network. All participating hospitals are connected to the same eligibility system, making it much easier for uninsured patients to receive the same care as commercially insured patients.

The streamlining of administrative paperwork and processing has major advantages for participating hospitals, as well as for patients. Prior to CHAP, an uninsured patient would be required to receive financial counseling and screening at each hospital separately. Each site required different documentation and had different standards to determine eligibility for charity care. Because CHAP centralizes the application, patients can be processed at a single location with eligibility that applies to the entire system. This not only makes things easier for the patient, but it also reduces the administrative burden for hospitals. Moreover, CHAP complements this system by supporting patients with navigation services. This ease of use increases the patient's retention in care, and decreases his/her likelihood of resorting to emergency treatment.

Building such a collaborative system required vision, cooperation and financial support on the part of hospitals and MCOs, as well as strong support from local officials. CHAP was conceived in 2008 at the county level, when a local report shone a light on Cuyahoga County's high uninsured rate and attendant health disparities. The report noted that the populations of two neighboring towns, which were situated just a few miles from one another, had life expectancies that differed by a full decade. County and city officials met with hospital administrators and federally qualified health centers (FQHCs) to determine the best way to ensure equitable health for all county residents,[33] and that meeting eventually led to the creation of CHAP. Today, CHAP's operational expenses are covered by grants from participating hospitals, managed care organizations, state initiatives, and other sources.

Wrapping Things Up: Taking Action

The Value of Investing In Equity

These three solutions—building the specialty care capacity of primary care providers, leveraging telemedicine and telementoring, and establishing coordinated local networks—are showing tremendous promise to both address health disparities for low-income and rural patients and strengthen systems of care.

> How patients benefit

Access to timely specialty care can be the difference between life and death. These models and initiatives not only enable improved access to specialty care services, but also deliver an improved health care experience. Patients treated via telemedicine, for example, have been found to have reduced travel time and cost—an assessment of a telehealth program at the University of Arkansas found that **94% of patients that used the services would have travelled more than 70 miles for medical care, 84% would have missed a day of work, and 74% would have spent $75 to $150 for additional expenses**.[34] Studies suggest that impact is achieved without reducing the quality of care provided. Several studies of telemedicine have found that patient satisfaction is more than 98% when telemedicine from home was utilized instead of hospital-based treatment and have shown telemedicine to result in comparable health outcomes to hospital-based care.[35] Patients who receive specialty care from their PCPs also experience comparable quality, as the outcomes of Project CICERO demonstrate. Similar trends hold for the other solutions discussed in this brief, each of which increases patients' access to specialty care services.

> How providers and provider institutions benefit

- Telemedicine, particularly when employed by a hospital in a capitated setting, has been consistently shown to provide cost savings, in some cases up to 19% of health care delivery costs. For example, one study on remote monitoring of elderly patients with conditions requiring specialty care found the use of telemedicine provided "comparable or better outcomes compared with similar inpatients and [with] higher satisfaction levels," and reduced re-admissions and emergency room visits for high utilization patients."[36, 37]

- PCPs who receive training to provide specialty services, especially in rural areas, feel there is an opportunity to grow professionally that wouldn't otherwise be afforded to them. By staying connected to specialists for support, they have access to the latest advances in their field, and it may even help retain physicians where they are located and enhance their job satisfaction.[38, 39] The model also helps provider institutions use their resources effectively, employing "task shifting" to ensure that each cadre of health care workers is operating at the highest levels of their capabilities. Project CICERO provides a strong example, leveraging just a handful of specialists to effectively reach thousands of patients.

- Effective implementation of formally coordinated networks for the uninsured also results in cost savings for health providers. In North Carolina, the Carolina Health Net program calculated that "20% of patients [accounted] for 86% of costs." By streamlining these patients' care in the system and utilizing a medical home model as a "home base" for those also under specialty care, emergency room visits by the targeted cohort "declined by 47% and [emergency room] charges decreased by 41%."[40] Similarly, the VODI initiative in Detroit delivered **$23M in cost savings for local health systems** by helping patients get access to insurance and by reducing ED usage and readmission rates.

> How payers benefit

By investing in services and technology that improve patients' ability to access specialty care, payers can also benefit from reduced use and cost of hospital-based services. The Veterans Health Administration, for example, has instituted telemedicine as a core component of its care model to coordinate the care of veteran patients with chronic conditions. Ongoing analysis of a cohort of 17,025 telehealth users found a **25% reduction in numbers of bed days of care, a 19% reduction in numbers of hospital admissions, and a mean satisfaction score rating of 86% for patients enrolled in the program**.[41] Recognizing the opportunity for similar savings, insurers Aetna, Wellpoint, UnitedHealth Group, and Blue Cross Blue Shield are all developing partnerships to provide telehealth services to members. In 2015, for example, UnitedHealth began offering one million of its self-funded members the ability to connect with medical services via smartphone, tablet, or computer and the program is set to expand to 20 million fully-insured members in 2016.[42, 43] These programs are currently focused on primary care, but they will set the stage for future consideration of specialty care services.

What's Needed to Scale These Solutions?

While it can be daunting for one doctor or one hospital to improve the system alone, these models demonstrate the mutual value that can be created when safety net providers, PCPs, and specialists work together to increase the availability of specialty services. Institutions interested in supporting or implementing these approaches can learn from the best practices of existing implementers, outlined in the tables below.

For additional recommendations on what's needed to scale these solutions, please see **Brief 5: A Call to Action for a System-wide Focus on Equity.**

PCP Capacity Building

State of Adoption	In-person PCP training and support has been used in isolated instances around the country for various specialties, but the advent of virtual training and support models heralds the promise of further scale.

Opportunities for Further Implementation and Scale

Where to start

- For institutions interested in building PCP **capacity, selection of disease areas** should be driven by the local burden of disease and relevant disparities, as well as considerations about the complexity of managing a given disease relative to provider capacity.
- Potential adopters should **consider the relative trade-offs of in-person vs. virtual models.** In-person support may offer greater personalization and a clearer channel for referring complex cases, though it may not be feasible in rural or low-resource areas.

Success factors

- **Data capture on clinical outcomes and cost effectiveness** as a platform for greater advocacy for reimbursement coverage.
- **Ample support for the specialists who are providing PCP training** (e.g., through communities of practice that foster the development and sharing of best practices).
- **Ongoing engagement and mentorship** between specialists and PCPs beyond a one-off training.

Examples include

- Project ECHO
- Project Cicero, Montefiore Medical Center

Telemedicine

State of Adoption	Telemedicine is gaining prominence in the broader U.S. healthcare marketplace, but adoption among safety net institutions remains low and systems are ad hoc.

Opportunities for Further Implementation and Scale

Where to start

- **Detailed pre-implementation assessment and planning** is a crucial first step; often providers are attracted by the technology but do not fully assess whether it is the right solution for their context or do not fully develop staffing and workflow plans, leading to underutilized implementations.

- **Healthcare systems can partner with safety net providers** to identify high-need disease areas in which telemedicine might offer greater efficiency in care and to make remote specialty services available.

Success factors

- **Policy advocacy to increase the standardization of telemedicine regulations** (e.g., to enable more cross-state care, lower barriers to entry).

- **Full engagement of primary care staff during telemedicine implementation** to reduce potential resentment of the technology and to collaboratively develop workflows.

- **Consortiums of safety net providers** can pool resources to secure needed specialist capacity that can be shared virtually and reduce cost.

Examples include

- Indian Health Service

- Center for Connected Health Policy

- Kaiser Permanente

- Veterans Health Administration

Formal Network Coordination

State of Adoption	Partnerships have been implemented in various forms around the country, but remain opportunistic and ad hoc.

Opportunities for Further Implementation and Scale

Where to start

- **Local data on disparities** presented in a compelling way can initiate political momentum and interest in seeking systemic solutions to specialty care access challenges.

- Depending on the local context, **various models for network coordination can be effective**. In places where there are strong pre-existing relationships between medical centers and safety net providers, coordination can be achieved simply through developing shared referral protocols. In many cases, however, a dedicated organization is needed to help coordinate available donated services.

Success factors

- **Ancillary supports** that go beyond matching patients with needed donated services by providing services such as transportation assistance, translation services, or patient education.

- **Data on outcomes and cost effectiveness** to increase the level of healthcare system commitment to organizations providing coordinating services.

Examples include

- Cuyahoga Health Access Partnership (CHAP)

- Voices of Detroit Initiative (VODI)

- Project Access

- Carolina Health Net

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

Increasing Specialty Care Availability

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Breaking the Barriers to Specialty Care

Practical Ideas to Improve Health Equity and Reduce Cost

BRIEF

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Ensuring High-Quality Specialty Care

FSG — 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.

Learn more about FSG at **www.fsg.org**.

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*).[1] 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.**[2] At a time when one in five Americans does not speak English at home,[3] 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

Percent of patients who believe they would receive better health care if they were of a different race and/or ethnicity

Asian American	11%
African American	15%
Latino	13%
White	1%
All	5%
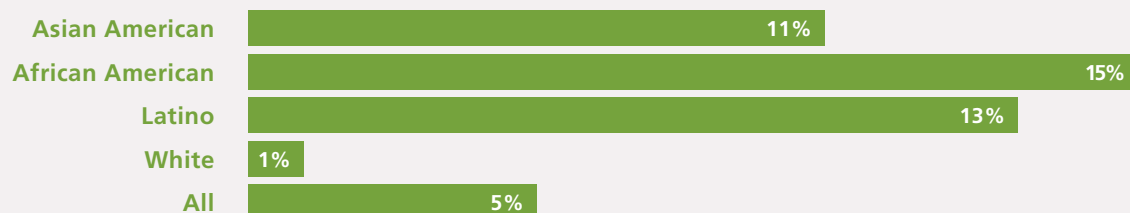
Beyond language, providers often fail to understand and accommodate the diverse values, beliefs, and interpersonal styles of patients that are different from their own.[4] Surveys suggest that only 48% of Asian American and 47% of African American patients believe that their health care provider understands their background and values.[5] 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**.[6] 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.[7] 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**.[8]

- ***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.[9] 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.[10] 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).[11, 12] On average, health care workers are also more likely to believe that black patients will not adhere to treatment recommendations than their white peers.[13]

  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*).[14] 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.[15]

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.
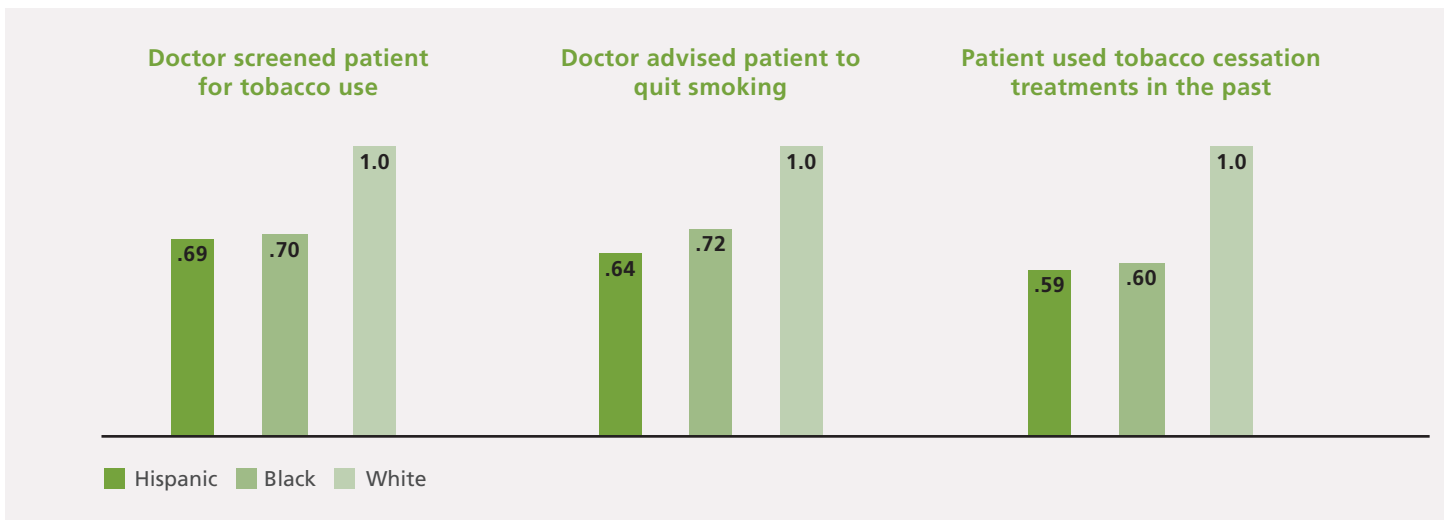
Patient-provider trust has a tangible effect on patient retention in care and patient adherence to treatment recommendations. A 2012 study examining the association between patient trust and antiretroviral (ARV) adherence among 175 patients at urban HIV clinics found that **high trust in a physician was strongly associated with increased odds of ARV adherence**.[16] 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**.[17] 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.[18]

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

Doctor screened patient for tobacco use
- Hispanic: .69
- Black: .70
- White: 1.0

Doctor advised patient to quit smoking
- Hispanic: .64
- Black: .72
- White: 1.0

Patient used tobacco cessation treatments in the past
- Hispanic: .59
- Black: .60
- White: 1.0

■ Hispanic ■ Black ■ White

Emerging Solutions

Leading 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
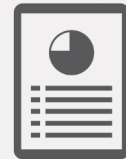
Harnessing Quality Improvement to include equity

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.[19] 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.[20]

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").[21]

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.[22]

While these approaches require investment, they also yield returns: use of trained medical interpreters 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%.[25] 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**.[26] 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.[27] 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.[28] 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.[29]

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.[30] Additionally, California law requires that payers provide interpretation and translation services to patients with limited English proficiency.[31] 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.[32] 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.

Case Example

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.[23]

93% of staff surveyed said the program improved communication with patients and their families[24]

Case Example

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.

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).[33,34]

"*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

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%**.[35]

> "*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 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).[36] 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.

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.

Case Example

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

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

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' 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.[38]

> "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

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 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.

Figure 4. MGH Health Equity Tracking and Reporting Tools
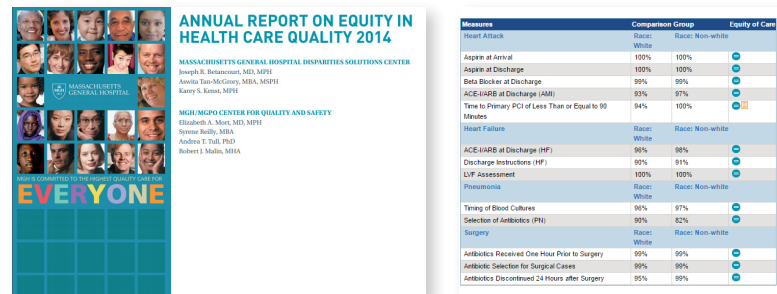
MGH's example illustrates a number of significant internal capabilities that have helped the institution make tremendous progress towards health equity for diseases such as cardiovascular disease, diabetes, prostate and colorectal cancer, and breast cancer. With significant support from its leadership 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.[39]

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.[40]

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.[41]

- **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.[42]

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).[43] 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.[44] 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[45] and diagnosing lung cancer at Stage I vs. Stage IV can save up to 30% of first-year treatment costs.[46] 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.[47] 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/the-evidence-base-for-cultural-and-linguistic-competency-in-health-care

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

Success factors

- Leadership and support from key decision-makers 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

Collins, K., Hughes, D., Doty, M., Ives, B., Edwards, J., & Tenney, K. (2002). Diverse Communities, Common Concerns: *Assessing Health Care Quality for Minority Americans*. The Commonwealth Fund. Retrieved from http://www.commonwealthfund.org/usr_doc/collins_diversecommun_523.pdf.

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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Breaking the Barriers to Specialty Care

Practical Ideas to Improve Health Equity and Reduce Cost

BRIEF

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Helping Patients Engage in Specialty Care

FSG — 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 illustrates how the health care system can effectively reduce disparities in health outcomes by engaging in community outreach, integrating patient navigation into care provision, and providing the additional support patients need to improve their engagement with, retention of, and outcomes from specialty care.

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: Helping Patients Engage in Specialty Care

Target Patient Populations

- Low-income patients
- Minority patients

Relevant Drivers of Inequity in Specialty Care

- Disease awareness and health literacy
- Environmental factors (e.g., housing, food security, childcare)
- Stigma and/or distrust of the healthcare system
- Financial burden of disease
- Psychological burden of disease

Health Equity Solutions

- Community outreach to engage patients
- Patient navigation
- Patient support services

Relevant patient groups and disease areas

Broader implementation of these solutions would improve health outcomes for several patient groups, in particular:

- **Low-income & minority patients**, who are most likely to receive late diagnoses for serious diseases and have the greatest difficulty accessing and staying engaged in care because of socio-economic and community factors, distance from providers, limited provider hours, and/or language barriers for those with low English proficiency.
- **Patients with stigmatized diseases**, including lung cancer and HIV/AIDS, who face self and societal shame that present barriers to early diagnosis and treatment.
- **Patients with serious and complex diseases** that place a significant psychological and financial burden on them, including cancer, cardiovascular disease, and stroke.

The Equity Challenge: Complexity, Cost and Distress for Patients in Need of Specialty Care

For millions of Americans, factors such as income, education, housing situation, access to transportation, neighborhood, family structure, social network, and familiarity with the health care system play a tremendous role in their well-being.

These "social determinants of health" as documented by the CDC[1] and WHO,[2] among others, are massive drivers of health inequity in the United States across disease areas. Yet, in the context of specialty care, their impact is particularly stark. Patients requiring specialty care for conditions such as cancer or cardio-vascular disease engage in care more frequently and in more complex situations than others. For these patients, constraints related to health literacy, available time, transportation, finances, and other challenges are exacerbated and can impede a patient's ability to engage in the care that they need. These factors create disparities along the care continuum, from initial screening and diagnosis to care, ongoing treatment, and post-treatment follow-up and monitoring. The most acute contributors to health disparities in specialty care include the following.

> " *We recognized that in [the city of] Lyndhurst, the average life expectancy was 86 years. If you drove 10 minutes away to Hough [neighborhood], the life expectancy was 10 years shorter. That drove huge conversations. We started to realize that there is not a comparable ability to access and benefit from care between our communities.* "
>
> —Sarah Hackenbracht,
> Former Executive Director,
> Cuyahoga Health Access Partnership*

- *Social and community context* can pose challenges for low-income patients' ability to receive and engage in high-quality specialty care. The challenges include lack of transportation and reliable communication tools, family and inflexible work obligations, and environmental and community factors such as public safety, air pollution, and/or access to healthy foods. These factors increase patients' risk for certain diseases and can impede patients' ability to adhere to a doctor's recommendations (for example, to exercise more or eat healthier foods) and remain in care. For example, a 2012 study in New York City found that patients who relied on public transportation were twice as likely to miss doctor's appointments as patients who were able to drive to their appointments.[3] A recent study by the Fred Hutchinson Cancer Research Center suggests that these barriers also apply to clinical trials. The study found that low-income cancer patients were 32% less likely to participate in trials, citing difficulties in transportation, childcare, and taking time away from work.[4] Though these challenges are also barriers to engagement with primary care, the intensity of disease and involvement with the health care system associated with specialty care makes them all the more challenging for patients with serious diseases.

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* Cuyahoga Health Access Partnership, a navigator and care coordination nonprofit in the Cleveland area. See Brief 3 for a full case study.

- **The ability to navigate the health care and insurance system** is also more difficult for low-income patients who must balance care with the basic priorities in their lives while navigating a more complex medical system than affluent patients. Low-income patients often depend on patient assistance or charity care programs provided by pharmaceutical manufacturers, health care providing institutions, or nonprofit organizations, adding layers of complicated rules, application processes, deadlines, and requirements to access treatment or insurance coverage. Together, these can result in gaps and delays in critical treatment.[5,6] These difficulties are compounded when patients do not speak or read English proficiently, and are even more challenging for patients with multiple medical needs requiring attention from multiple specialists. Specialists are affected as well; many struggle with a high "no-show" rate as a result of patient challenges, which drives health care costs higher because of un-utilized capacity, and can deteriorate providers' attitudes toward low-income patients.

"Cancer patients are overwhelmed with appointments. Typically, they know that they need to be at the hospital at 5 AM. But they have no idea who they are seeing or what the appointment is for. And they have all sorts of other needs—food pantries, legal assistance. A navigator is there to explain—what's happening on that day, who the patient is meeting with, and help them follow-up and get connected to other services. One of our patients called a navigator to ask where he could get a mattress because he was sleeping on the floor. That type of support is critical."

—Giselle Carlotta-McDonald, Yale-New Haven Hospital Project Access

- **Lack of disease awareness and stigma** associated with certain diseases result in patients delaying screening and diagnosis. Lung cancer, for example, is heavily stigmatized with patient blame and a sense of hopelessness because of its association with smoking and its low survival rate relative to other cancers. This stigma has been shown to delay care initiation among patients who suspect they may be experiencing symptoms of the disease.[7] Most people with lung cancer are diagnosed at Stages III or IV,[8] when the 5-year survival rate is below 25%.[9] Disease awareness can also be correlated with demographic factors such as language, race, and ethnicity, signaling a need for more targeted disease education. For example, Spanish-speaking Hispanics are far less likely to know all the stroke symptoms (18%) than English-speaking Hispanics (31%), non-Hispanic blacks (41%), and non-Hispanic whites (50%).[10]

- **Financial burden** associated with managing a serious disease is a key contributor to patient stress and a driver of patient disengagement from care. A recent survey by the Cancer Support Community found that 37% of cancer patients are seriously concerned about bankruptcy,[11] a valid fear given that **cancer patients are up to 2.5 times more likely to file for bankruptcy than non-cancer patients**.[12] Financial stress can have a direct effect on patient outcomes as well: a 2013 study found that **20% of cancer patients took less than the prescribed amount of medication in an attempt to "stretch" their prescriptions, and 24% avoided filling prescriptions altogether for financial reasons**.[13] Further, since employers are not required to provide paid sick leave, hourly wage earners also face income insecurity when managing illnesses that require specialty care. Patients who work in seasonal, domestic or informal work are particularly vulnerable to consequences of taking time off, which can discourage them from seeking necessary treatment.

- **Psychological burden** associated with managing a serious diagnosis can also drive patient disengagement from care. A high proportion of specialty care patients struggle with affective disorders (including mood disorders). One study found that among the general patient population, 13–17% of all patients had an affective disorder, but this prevalence rises to 20–25% for those with a chronic disease such as rheumatoid arthritis or diabetes and is highest among patients with cancer (30%).[14] Beyond affecting patient quality of life, this distress can also affect clinical outcomes; some studies have demonstrated that cancer patients affected by depression and cancer-related distress have lower survival rates as a result of poor adherence to treatment and depression's direct neuro-immune effects.[15]

> "*One of the issues that people call us about most frequently is medical debt or help accessing benefits. We've heard that people have used their rent to cover their medications, or vice versa. That puts people in an impossible position—to choose between keeping their homes or keeping their health.*"
>
> —ALAN BALCH,
> PATIENT ADVOCATE FOUNDATION

- **Public distrust of the health system** is not uncommon in many American communities, in particular those of ethnic minorities, immigrants, and undocumented workers. Distrust includes feeling like information is not being shared forthrightly, that personal health information is not kept confidential, and that a patient's voice is not being fully listened to or that providers are not adequately empathizing with their suffering or taking it seriously.[16] For example, one 2009 study of distrust in the health care system found that **almost half of women agreed they had "sometimes been deceived or misled by health-care organizations**," and 39% of African American women agreed that "health-care organizations don't always keep your information totally private."[17] Though this distrust also prevents patients from engaging in primary care, it affects all aspects of a patient's engagement in specialty care, from participating in screening and diagnosis to fully sharing personal information with health care providers, to adhering and treatment protocols.

Figure 1. Mean California Medicare Spending in First Year of Diagnosis for Lung Cancer Patients

Stage I	$60,038
Stage II	$73,509
Stage III	$84,726
Stage IV	$90,166

Low-income and minority patients in particular are acutely affected by pronounced barriers to access and engagement across the specialty care continuum. Data shows that patients of lower socio-economic status have delayed HIV treatment initiation after diagnosis and experience higher morbidity and mortality rates from the disease relative to more affluent patients.[18] Another study of the National Cancer Institute's cancer registry found that black patients were diagnosed at more advanced cancer stages than white patients in the vast majority of cancer types tumor sites studied.[19] Additionally, the challenge of staying engaged in specialty care is more pronounced because the complexity of managing a serious disease such as cancer adds stress and new demands on already limited time and resources. These challenges can have significant negative effects on patient outcomes, in turn reinforcing disparities in specialty care.

These challenges not only impact patient health, but also drive health system costs. One study found that HIV patients diagnosed at advanced stages had a cumulative cost of care for their first year of treatment of $37,104 vs. $9,829 for patients diagnosed at an earlier stage in the disease. This higher cost of care persisted over the full course of treatment, totaling $135,827 vs. $86,721 by the 7th year, a 56% difference.[20] Similarly, a recent study by the California Healthcare Foundation on Medicare spending for cancer care in the state found that late diagnosis was associated with higher cost of care (*see Figure 1*).[21]

Improving early diagnosis and retaining patients in care is critical—both for the health of the patient and to contain health care system costs. Yet doing so requires payers and health care providing institutions to look outside the traditional boundaries of the health care system to broader social, economic, and community factors to meet patients where they are with new forms of supportive services that are integrated with clinical care. This type of external engagement is an increasingly important facet of today's health care landscape.

Emerging Solutions

Three well-established approaches have emerged to help patients engage in specialty care: (1) community outreach, (2) patient navigation, and (3) patient support services. Though each of these models has been implemented in various forms in health care systems across the country, they have yet to be widely and consistently adopted and integrated with formal health care delivery.

Figure 2. Three Emerging Solutions for Increasing Specialty Care Availability

Community Outreach

Community outreach initiatives reach high-risk patients in their communities to build awareness, provide easier access to screening, and offer direct referrals to care

Read more below

Patient Navigation

Patient navigators help patients coordinate and manage their medical care, connecting patients to additional services, and acting as a trusted advisor

Read more on page 11

Patient Support Services

Ancillary support services provide a range of support including patient education, psychological support, and financial assistance

Read more on page 13

Community Outreach to Engage Patients

Community outreach programs seek to engage populations at high risk for serious disease "in place" where they live and work, in order to increase their awareness and provide pathways for diagnosis and treatment. These programs are often led by a local health care provider or jointly by a community organization in partnership with a provider. While this approach is not feasible or cost effective in every circumstance, it has been proven effective in instances where there are pronounced disparities in a particular disease and an efficient, culturally appropriate, and trusted mechanism for reaching underserved patients.

A unique example of how these programs can engage a high-risk population in-place is Moffitt Cancer Center's "Mole Patrol" program, which provides free skin cancer screening and referral to local providers at outdoor sporting events and public beaches in Florida and Puerto Rico. By focusing on reaching people in situations in which they were likely to experience significant sun exposure, the program efficiently **screened 5,169 people between 2007 and 2010—21% of whom were identified as likely to have non-melanoma skin cancer** and referred for further follow up.[22]

Community outreach is a well-established public health strategy that has seen broad adoption in a range of disease areas. In HIV, for example, the CDC consistently supports local and state health departments to implement comprehensive prevention, outreach, diagnosis, and social services programs for high-risk groups with low voluntary usage of HIV testing, such as intravenous drug users and men of color who have sex with men.[23] One of the CDC's pilots, the Advancing HIV Prevention program, worked with community organizations in seven major U.S. cities to support rapid mobile testing and counseling units that operated out of vans or portable tents and would travel to community locations where high-risk populations were likely to congregate, such as parks or bars, special events such as health fairs or gay pride festivals, and social service organizations such as drug treatment facilities or homeless shelters. Between 2003 and 2006, this program succeeded in testing 24,172 high risk individuals, 30% of whom had never been tested for HIV before and 267 of whom were newly diagnosed with HIV through the program, demonstrating the value of reaching into the community to engage new people.[24]

Similarly, in cancer, the National Cancer Institute supports the National Outreach Network, which works with cancer centers across the country to assess local cancer disparities and develop a program for targeted education, prevention, and early detection.[25] However, despite the success and prevalence of such community outreach programs, they remain largely supported by government and philanthropic grants. Persisting disparities in disease awareness, diagnosis, and treatment highlight the need for more consistent adoption and financial support from health care payers and provider organizations.[26, 27]

> *"We need to get into the community to reach people where they are. We need to see how they live and bring health care to them. Without that, it is difficult to know how people who are not coming in to our site are treating their HIV, whether they are virally suppressed—and that has implications not just for patient health, but also for emergency room visits and other system costs."*
>
> —MEGHAN DAVIES,
> WHITMAN-WALKER HEALTH

Case Example

Cedars-Sinai Barber-Based Blood Pressure Program

African American men in the United States have strikingly high rates of hypertension—some estimate a rate of up to 40%. Yet the majority of these men—up to 70%—do not have the condition under control, and African American men are among the demographic groups least likely to seek preventative care from their physicians. Recognizing that the solution to this challenge lay outside its own doors, the Cedars-Sinai Heart Institute looked to earlier HIV/AIDS programs developed by the CDC, which trained community members to serve as peer educators among populations at high risk for HIV. Seeking to adapt that program for African American men at risk of hypertension and heart disease, the Cedars Sinai team identified barbershops as a comfortable, community-based gathering point for many adult men not engaged with the healthcare system.

To deliver the program, the team trained participating barbers on the basics of hypertension and taught them to use and interpret the results of a blood pressure machine. Following this training, the barbers offer screenings to their patrons and record the blood pressure reading on a card. For patrons with abnormal blood pressure readings, the barbers offer educational materials, stressing the need to see a doctor and can even offer referrals for people without a primary care physician. For patrons who deny the problem, the barbers are trained to gently recommend that they continue to have their blood pressure checked when they come in for haircuts. The barbers are complemented by a team of program coordinators and overseeing physicians to ensure that referrals flow smoothly and that barbers are supported in case questions or high-needs cases arise. All of these activities are reinforced by a system of incentives: barbers receive $3 for each blood pressure they record, $10 for each call they make for referral assistance, and $50 for each confirmed doctor visit resulting from a referral. In turn, patients who visit a doctor are given a voucher for a free haircut.

The barbershop-based screening and referral model has been implemented in Dallas, Chicago, and Los Angeles. These programs have consistently shown good results. In Dallas, a study showed that barbershops that provided educational materials increased the proportion of patients undergoing treatment for hypertension by 6%, while it increased 11% in the barbershops providing testing and referral support in addition to education. Additionally, systolic blood pressure under control increased by 20%. Extrapolating these findings, the Dallas program concluded that if every African American barbershop in the country implemented this program, it would prevent 800 heart attacks, 550 strokes, and 900 deaths in the first year alone, saving $100M in healthcare expenditures and yielding an ROI of 40%.

While these figures are hypothetical, they speak to the profound untapped potential that can be achieved by smartly conducting outreach to underserved communities. Based on the success of the current program, Cedars-Sinai was recently awarded an $8.5M grant from the National Institutes of Health to expand the model.[28]

Culturally relevant outreach increased control of hypertension by 20%

Patient Navigation

A patient navigator works closely with a patient and his or her medical team as a dedicated advocate who is committed to assisting in managing patient needs. This can take place in a hospital or clinic setting, but some community health workers (CHWs) serve as navigators who reach patients in their own homes, connecting them to a health care system they would otherwise not have access to. Patient navigators demonstrate the most value for patients who require chronic specialty care, such as those with HIV, cancer, rheumatoid arthritis, or heart disease, who must balance management of a serious condition over time with a range of other medical and non-medical issues, such as transportation, childcare, nutrition, and psychiatric support. Navigator programs are based on a care management model that includes four components: (1) identification of cases requiring additional support, (2) identification of individual or institutional barriers that affect a patient, (3) development of an individualized plan to address the barriers, and (4) systematic follow-up through the completion of treatment.[29] Specific services can include initial counseling and advice, appointment booking and reminders, arranging for transportation, and home visits.

> "For people that are challenged economically and in other social ways, and have chronic and extreme illnesses, the starting point is a trusted source that helps them coordinate and break down some of the impediments and barriers to care."
>
> —DEBORAH C. ENOS,
> FORMER CEO, NEIGHBORHOOD HEALTH PLAN

Patient navigation was established in 1990, when Dr. Harold Freeman initiated a navigators program for black breast cancer patients at the Harlem Hospital Center in New York City. The initial pilot program **dramatically increased rates of early diagnosis and resulted in huge gains in 5-year survival rates, from 39% to 70% of patients**,[30] proving the incredible potential for navigation to reduce health disparities. In 2005, the federal government began to further study the impact that patient navigators have on cancer outcomes through the Patient Navigator Act and National Cancer Institute's Patient Navigator Research Program. Today, there is consistent evidence to suggest that patient navigation, whether conducted by community health workers, lay people, or nurse navigators, improves health outcomes for low-income, minority, and non-English speaking patients that experience the worst disparities. For example, studies have shown that patient navigation for Korean-American women resulted in a 32% increase in rates of breast cancer screening,[31] doubled rates of colorectal cancer screening in low-income patients,[32] resulted in fewer treatment disruptions for American Indian patients undergoing curative radiation therapy for cancer,[33] and reduced stress and improved patient satisfaction.[34]

Spurred by this evidence, ACA provisions included funding for patient navigation programs for patients with cancer and other chronic diseases, and added a requirement that all grant-funded programs have formally qualified patient navigators.[35] Building on this mandate, Colorado and several other states began funding patient navigator training seminars and websites to create standards and allow for patient navigators to interact with and learn from each other.[36] Patient navigation is also increasingly covered by health insurance providers like UnitedHealth Group, which recently included navigation in a pilot program to test bundled payments for cancer patients.[37] Though navigation is gaining prominence, further development, standardization, and research on the cost and health outcomes of navigator programs will be needed for it to reach further scale and sustainability.

Case Example

National Cancer Institute Patient Navigation Research Program

NIH

In one of the largest studies of patient navigation studies to date, the National Institutes of Health (NIH) National Cancer Institute's (NCI) Patient Navigation Research Program studied the effects of navigation on time to treatment and diagnostic resolution for traditionally underserved patients with breast, cervical, colorectal, or prostate screening abnormalities at nine cancer centers across the country. Between 2007 and 2010, the program studied time to outcomes for 10,521 patients, 73% of whom were minorities, 40% of whom were publicly insured (Medicare or Medicaid), and 31% of whom were uninsured all together. For patients who received navigation, support began at the time of an abnormal screening and continued through treatment or diagnostic resolution, with services including face-to-face and phone counseling to resolve community barriers to care (e.g., lack of transportation), arranging appointments, providing reminders, coordinating care among providers, arranging interpreters, and linking patients with community based supports. The study results demonstrate the benefits of these services; depending on the center, patients receiving navigation support had up to 20% higher rates of timely diagnostic resolution and higher rates of treatment initiation within the year. This was particularly true in cases where patients were typically otherwise lost to follow up.[38]

Patient navigation increased diagnostic resolution of cancer by up to 20%

Patient Support Services

For some patients, navigation is important, but not sufficient. Particularly for low-income patients, who struggle to meet their basic needs, effectively managing complex care is impossible without additional support. In response, a number of patient and community-based organizations provide ancillary support —services not routinely offered by the health care system that address the psychological and socioeconomic effects of serious diseases. For specialty care patients, this can include psycho-emotional support, financial support, educational resources, or tangible supports like transportation and food.

By alleviating some of these non-treatment stresses, patients and their families are able to be more engaged participants in their care. Studies of breast cancer patients found that patients who received support had significantly less anxiety and reported fewer side effects associated with their treatment than patients who had not received additional support.[39] This effect was particularly pronounced among African American breast cancer patients, who had a lower level of care participation than white women prior to receiving support, but higher levels of participation after the intervention.[40] Another study showed that the survival of breast cancer patients who attended support group once a week was 1.5 years longer than those who did not.

"*Today, intervention for psychosocial issues for cancer patients is tough. Reimbursement for a [facility-based] support group is $5 per patient—that doesn't even cover the cost of setting up the billing system. Distress screening is part of the Commission on Cancer standards now, which is great. It's a standard of care for cancer, but it's been an unfunded mandate.*"

—LINDA HOUSE,
CANCER SUPPORT COMMUNITY

Figure 3. Biggest Challenges Facing Community Cancer Programs Today

Lack of reimbursement for supportive care service	Budget restrictions	Lack of physical space	Cost of drugs	Increased number of patients unable to pay for treatment
65%	61%	49%	45%	44%
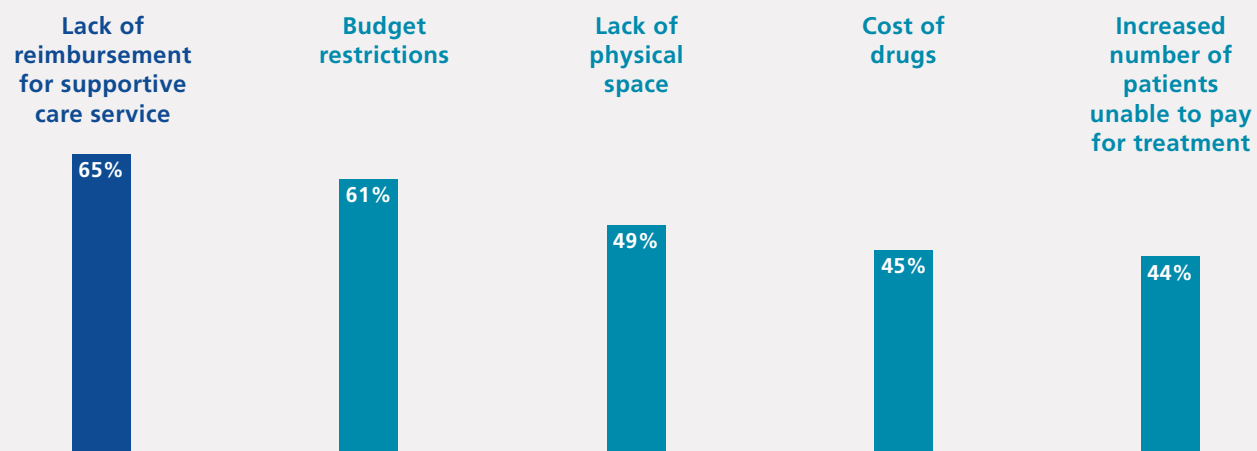
Professional counseling, education, financial assistance, and health insurance literacy education are provided by numerous organizations. For cancer, some organizations have national reach, such as CancerCare, Cancer Support Community, and the American Cancer Society. These national initiatives complement many more informal and local efforts. Similarly, for rare diseases such as Duchenne muscular dystrophy, patient advocacy groups such as Parent Project Muscular Dystrophy provide a community and personalized counseling to families affected by these diseases.

Legal issues can also create immense financial and life stresses for patients, and specific solutions have been developed to address those challenges. The National Center for Medical-Legal Partnership (MLP), for example, has replicated a model across the country where lawyers are embedded in health systems, working with doctors to identify and serve patients with legal issues that affect their health. According to MLP, one in six people has a civil legal issue that affects his or her health; at one center in Nebraska, the MLP recovered almost $1 million in payment for past or current services for oncology patients alone.[41] They focus on a variety of unmet health and basic needs, from unsanitary and unsafe housing conditions for children with leukemia to ensuring that nutrition needs are met for food insecure patients. Through this initiative, patients, lawyers, and doctors collaborate to support patients and address barriers to equitable health outcomes.[42]

These types of resources are crucial for helping patients in all specialty disease areas to navigate and cope with their diseases. In many cases, while these models have been tested extensively over the past several decades, they are not often formally integrated with the health care system, have limited specific focus on the most underserved patients, and are sub-scale relative to the persistent challenges they seek to address. And these services are rarely reimbursed by payers—in fact, a 2015 survey of community cancer centers found that lack of reimbursement for supportive care services was the most significant challenge facing providers today (*see Figure 3*).

One promising opportunity to increase the sustainability and adoption of supportive services for patients is the growing prominence of bundled payments, under which insurers reimburse health care providing institutions with a set amount per patient per month for a specific disease. This funding is more flexible than previous "fee-for-service" arrangements, and can be used to cover additional support. For example, many are advocating for the inclusion of behavioral health among the services eligible for bundled payment coverage.[43] In addition, Medicaid is growing increasingly flexible in the use of its funds to provide support for patients, including case management. In Minnesota, CMS approved a pilot program to provide resources for housing for patients who are chronically homeless.[44] Although CMS is working across the country to pilot new payment models,[45] and some states such as Massachusetts have implemented policies enabling broader adoption of bundled payment schemes, implementation is still infrequent; the Catalyst for Payment Reform Scorecard estimates that as of 2014, only 0.1% of all health care payments were bundled and only 10% of outpatient specialist payments were a part of a value oriented model.[46]

Case Example

Cancer Support Community: Psychosocial distress screening and follow-up support reduces depression and anxiety in cancer patients

The Cancer Support Community (CSC) provides evidence-based support, education, and healthy lifestyle programs through a network of 170 locations across the United States, an online community and a telephone Helpline.

One of Cancer Support Communities' approaches is a distress screening program, CancerSupportSource, which allows the group to assess patients' level of psychosocial distress and provide appropriate support needs, if needed, as a way to intervene before the patient progresses to a state of having a clinical diagnosis of anxiety or depression as a result of the cancer diagnosis. Patients participating in CancerSupportSource demonstrated a 10% overall reduction in distress and a 25% reduction of reports of being very seriously distressed.

In 2014, Cancer Support Community provided in-person services to 85,000 individuals, the majority of which involved high-touch on-going support over time, manifesting as approximately 400,000 visits. To expand its reach and delivery of these free services, the Cancer Support Community now has formal contracts with a number of hospitals and works closely with healthcare providers to incorporate and even co-locate its programs so they are available in the same facility where patients receive medical care. CSC also conducts research and quality improvement projects to refine and optimize their offerings.[47]

Distress screening and follow-up services reduced cancer-related distress by 25%

Wrapping Things Up: Taking Action

The Value of Investing In Equity

When successfully implemented, community outreach, patient navigation, and patient supportive services have shown tremendous value to all actors within the health care system. Greater intention, investment, and collaboration mean that payers, providers, and patients will realize the benefits of improved health equity.

> How patients benefit

In addition to the significant impact of these programs on health outcomes, community outreach, navigation, and support services provide a very real qualitative benefit to patients. Addressing non-treatment related challenges significantly improves not only their health outcomes and overall wellbeing, but also their experience with the health care system. Early detection, counselling, education, and financial support all help patients manage their disease with less stress and greater satisfaction with the system than they might otherwise experience.[49]

> How providers and provider institutions benefit

These solutions can improve efficiency and patient satisfaction. As noted, community outreach efforts can increase early diagnosis and patient engagement, which has implications for emergency room use. Patient navigation reduces "no-show" rates and reduces the amount of time that providers and their staff spend connecting patients to supportive services, even as these services have significant effects on patient wellbeing and satisfaction. With capitation-based payment models, in which health care providing organizations are increasingly accountable for cost, outcomes, and patient experience, addressing these factors will be a critical step in achieving quality care—and in turn, reimbursement. In fact, beginning in 2012, Medicare began withholding 1% of reimbursements from hospital systems that did not meet satisfaction thresholds; that figure will increase to 2% in 2017.[50] Even for health care systems that do not move to capitation based models, addressing disparities and better meeting the needs of underserved patient groups helps to fulfill the quality goals that are central to many health care systems.

Scaling and Adopting Delivery Innovations Can Be Difficult

"[With community health workers], [w]e have an innovation that is showing tremendous gains in improving health, especially among vulnerable populations…. [E]xamples keep emerging from around the country about its effectiveness in improving health outcomes and reducing emergency room visits and hospitalizations.

If these were the results of a clinical trial for a drug, we would likely see pressure for fast tracking through the FDA; if it were a medical device or a new technology, there would be intense jockeying from a range of start-ups to bring it to market. Instead, despite the promise this innovation has shown for years—and recognition from the Institute of Medicine, the Affordable Care Act, and the Department of Labor—it still has not been widely replicated or brought into the mainstream of U.S. health care delivery…"

Bringing community health workers into the mainstream of U.S. health care
2015 Discussion Paper, Institute of Medicine[48]

> How payers benefit

Addressing community and psychosocial barriers to equitable specialty care outcomes can result in lower per-patient cost of care, derived from the clinical benefits of earlier diagnosis and better patient engagement and retention. For example, **early diagnosis in HIV can save up to 50% of cumulative care costs**,[51] and diagnosing lung cancer at Stage I vs. Stage IV can save up to 30% of first year treatment costs.[52]

Although these three approaches are increasingly common, particularly in primary care, their adoption and incorporation into the formal health care system is inconsistent. At the same time, these approaches are not one-size-fits-all solutions to patient engagement challenges, and so they may not be applicable in every health care context. Though the specific opportunities for scaling these different approaches varies by the approach itself and the potential context for implementation, it is clear that payers, providers, policy makers, and community organizations must work together to take the necessary next steps, as detailed below.

What's Needed to Scale These Solutions?

Despite the success of organizations implementing these approaches, millions of patients are still failing to access or stay engaged in care because of reasons related to their socioeconomic and community context. And while these approaches represent a promising place for many health care systems and community organizations to start to help patients overcome these challenges, ultimately this implementation must be part of a more systemic approach to addressing disparities in specialty care to be fully effective. For additional information on what's needed to scale these solutions and catalyze this systemic approach, please see **Brief 5: Call to Action for a System-wide Focus on Equity in Specialty Care**.

> "*We're hoping to see more reimbursement for care coordination in the future. Everyone recognizes the benefits of care coordination services for patients, but there is insufficient funding to support it. This is a health systems delivery issue affecting many health care providers. We are optimistic there will be a Medicaid-based reimbursement for care coordination that doesn't segment patients by insurance type or provider. For now, we must rely more heavily on grant funding.*"
>
> —Kate Fox Nagel, DrPH, MPH,
> Care Alliance Health Center, Cleveland, Ohio

Community Outreach

State of Adoption	Community outreach efforts have been successfully implemented in several disease areas and contexts.

Opportunities for Further Implementation and Scale

Where to start

- Organizations interested in starting a community outreach program should begin by using local health needs and demographic data to identify the right target population, and networking with existing community organizations to better understand the population and co-create an approach to effective engagement.

Success factors

- Close partnerships between providers and community organizations that enable efficient outreach to target populations in culturally appropriate ways in places where they already congregate.

- Strong pathways for referral to diagnosis and treatment for patients who receive abnormal screening results.

- Funders who support evaluation and data collection to assess health and cost impact, to "make the case" for additional investment.

- Leveraging opportunities for reimbursement, such as CMS's Preventative Services program, which allows state Medicaid programs to reimburse for preventative programs implemented by non-medical personnel.

Examples include

- NCI National Outreach Network

- Cedars-Sinai Heart Institute Barber Shop Outreach Project

- Washington AIDS Partnership Mobile Access Initiative

Patient Navigation

State of Adoption	Patient navigation has been employed in various ways across many disease areas. Models vary widely in terms of how support is offered and the types of services available.

Opportunities for Further Implementation and Scale

Where to start

- Navigation services can be structured in a number of ways: they can be offered directly by health care systems or offered by separate non-profit organizations, and they can be staffed by a range of professionals from lay navigators to professional nurse navigators. All of these models are effective, but the navigation approach should be tailored to the needs of the patient population.

- Navigation is particularly effective when the demographics of patient navigators reflect the demographics of the patient population and when navigators have a deep understanding of local community and social dynamics.

- The Harold P. Freeman Patient Navigation Institute has a range of resources on patient navigation and runs regular training programs for patient navigators.

Success factors

- Close engagement with senior health care system leadership to ensure a shared understanding of the value of navigation, a commitment to fund navigation services, and a plan to integrate navigation with core care delivery. As health care systems increasingly operate under value-based models there will be greater opportunity to directly integrate navigation into care provision.

- Capacity to collect data and conduct evaluations of the health and cost effects of navigation and engage public and private state health plans (e.g., Medicaid MCOs) to reimburse for navigation services.

Examples include

- Los Angeles County Department of Health Services

- Ralph Lauren Center for Cancer Care

- Project Access (Nationwide)

Patient Support Services

State of Adoption	Counseling and financial assistance are provided by some national disease organizations, and as part of some health care systems, but systemic adoption remains limited.

Opportunities for Further Implementation and Scale

Where to start

- Potential implementers should prioritize psychosocial support services for disease areas associated with the highest burdens of anxiety and depression, such as cancer, though over time services can be broadened to serve other disease areas as well.

- Financial support models provided by national organizations are largely based on charitable giving, limiting their potential for replication. However, at the local level there is an opportunity to engage local funders such as community and conversion foundations to provide prescription drug support for low- and middle-income patients with serious diseases as part of broader strategies for addressing health disparities.

Success factors

- Data showing the significant clinical and quality of life effects of anxiety associated with managing serious diseases, and evidence on patient retention, engagement, and outcomes associated with implementation of psychosocial supports.

- Seamless integration into the care environment and greater accessibility (via phone or web) of patient information and psychosocial support.

- For diseases that affect smaller populations, successful engagement of the patient community to foster peer-to- peer support.

- Reimbursement of psychosocial services delivered in the care environment via bundled payments (e.g., for cancer care) or through state Medicaid waivers.

- Supportive employment policies that allow for patients to fully engage in care.

Examples include

- CancerCare
- Cancer Support Community
- Patient Advocate Foundation

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Figure 1

Adapted from California Healthcare Foundation (2015). *Cancer Care Spending in California: What Medicare Data Say*.

Figure 3

Association of Community Cancer Centers (2015). 2015 *Trends in Cancer Programs*. Retrieved from https://www.accc-cancer.org/surveys/pdf/Trends-in-Cancer-Programs-2015.pdf

For their invaluable contribution to our research, we would like to thank:

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

Helping Patients Engage in Specialty Care

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FSG REIMAGINING SOCIAL CHANGE

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Breaking the Barriers to Specialty Care

Practical Ideas to Improve Health Equity and Reduce Cost

BRIEF

1 2 3 4 **5**

Call to Action for a System-wide Focus on Equity

FSG — 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.

Learn more about FSG at **www.fsg.org**.

The Value of Investing in Equity

In order to eliminate disparities in specialty care, health system actors will need to wholly embrace a focus on equity, both within their individual institutions and in partnership with others. Every aspect of the patient experience is critical to achieving the best possible health outcome—from initial patient engagement to screening and diagnosis to the intimate relationship between a doctor and patient—and every health system actor has a role in addressing those inequities.

This series has highlighted key insights and effective models for providing equitable specialty care to vulnerable and medically underserved patients (*see Figure 1 below*). Investments in these solutions will not only drive improved health outcomes for patients but will also improve processes and more efficiently utilize health care resources.

While there is growing evidence that these solutions are effective, supportive institutional leadership and the right enabling environment remain essential to adopting these solutions sustainably and at scale. This brief will highlight the key factors that consistently enable successful adoption of health equity solutions and the resulting implications for key actors in the health system.

Figure 1. Overview of Other Briefs in This Series
Detail on following page

Increasing Specialty Care Availability
to better enable access to specialty care for rural and low-income populations.

For more analysis, examples, and solutions, see **Brief 2: Increasing Specialty Care Availability**

Ensuring High-Quality Care
to better meet the needs of low-income and minority patients engaged in specialty care.

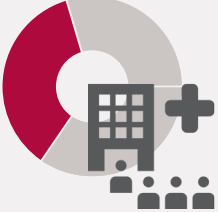For more analysis, examples, and solutions, see **Brief 3: Ensuring High Quality Specialty Care**

Helping Patients Engage in Care
by addressing the social factors that impede patients' ability to promote and protect their own health, engage in care, and adhere to treatment.

For more analysis, examples and solutions, see **Brief 4: Helping Patients Engage in Specialty Care**

EQUITABLE HEALTH OUTCOMES

Increasing Specialty Care Availability

Ensuring High-Quality Care

Helping Patients Engage in Care

Figure 2. Health Equity Solutions for Specialty Care

Increasing Specialty Care Availability

Health Equity Solutions

- Coordinated specialist networks
- Telemedicine/ telementoring
- Development of primary care capacity

Health System Value Proposition

Availability of specialty care is a critical barrier for patients, including practices denying Medicaid and uninsured patients, long wait times, and long distances to travel. Innovative solutions allow patients to receive consistent care by overcoming these barriers, keeping patients out of expensive and unproductive visits to the emergency room.

- One provider network that formalized specialty care for uninsured patients reduced emergency room costs for its most expensive patients by 41%.
- Analysis of a cohort of telemedicine patients showed a 25% reduction in numbers of bed days of care, and a 19% reduction in numbers of hospital admissions.

Ensuring High-Quality Care

Health Equity Solutions

- Incorporating culturally competent practices
- Efforts to address implicit bias among health care workers
- Harnessing quality improvement to include equity

Health System Value Proposition

The quality of care that patients receive can be hindered by cultural barriers, low health literacy, and unconscious biases among providers. Emerging solutions that address these interpersonal challenges are demonstrating value and improving outcomes.

- Instituting shared decision-making for specialty care led one provider to in 2009 to a 38% reduction in unnecessary procedures.
- Data shows that patients with greater levels of engagement and higher levels of trust in providers experience better outcomes and higher patient satisfaction.
- Implicit bias training for nurses allowed for a 55% decrease in the discrepancy between the amount of pain medication recommended for white and black patients.

Helping Patients Engage in Care

Health Equity Solutions

- Community outreach
- Patient navigation
- Patient support services

Health System Value Proposition

Investment in services that would fall outside of traditional "treatment" have tangible impacts on patient outcomes, wellbeing and cost of care—at the individual and population levels.

- Early diagnosis in HIV can save up to 50% of cumulative care costs.
- Diagnosing someone with lung cancer at Stage I vs. Stage IV can save up to 30% of first-year treatment costs.
- Patient navigation can yield up to 20% higher diagnostic resolution and engagement in treatment among disengaged patient groups.

What Works to Achieve Equity in Specialty Care

Five factors emerge consistently as enablers of success and scale for efforts to improve health equity in specialty care. Together, these factors form a **common agenda for the field**. And while each factor is important individually, they are mutually reinforcing and significantly more powerful when brought together.

1 **Effective use of data to identify disparities and track effectiveness and impact is an essential component of initiatives to improve equity in specialty care**. This practice is a core part of traditional quality improvement efforts, but it has not been rigorously applied to health equity. Better leveraging data can yield significant impact on disparities. At the outset, disaggregating care quality and health outcome data by race, socio-economic status, and income enables analysts to recognize disparities. For example, Kaiser Permanente's disaggregation of patient satisfaction scores by race enabled the provider to recognize and act upon poor patient experiences for minority patients (see **Brief 3: Ensuring High-Quality Specialty Care**) and the proactive use of patient data enabled UnitedHealth Group to better reach and engage patients who were lagging in colorectal cancer screening (see **Brief 4: Helping Patients Engage in Specialty Care**). The Centers for Medicare and Medicaid Service (CMS) have included these very measures for decision-making and evaluation at the provider level in their Equity Plan for Improving Quality in Medicare.[1] The adoption of sector-wide quality measures, such as The Healthcare Effectiveness Data and Information Set (HEDIS) scores, as well as others, will only increase the sector's ability to identify and track disparities across communities, states, and the nation. This data is a critical foundation to fully harnessing the tools of quality improvement to create and implement solutions for health equity.

"First, we look at the data, to identify where disparities exist—by age, race, geography, gender, etc. Then we start discussions about specific action steps, partnerships and programs to mitigate those disparities. It's not a question of whether disparities exist—it's about the magnitude and the opportunity, and prioritizing among them."

—U. Michael Currie,
UnitedHealth Group

2 **Taking a community-based approach is necessary to fully address health disparities, even for specialty care**. For example, the patient navigator programs profiled in **Brief 4: Helping Patients Engage in Specialty Care** have found that the most effective navigators are those who are members of and/or understand the community they serve. This principle applies across the spectrum of health care workers, and efforts are underway to increase the diversity of

"We found that community health workers helped us reach patients who were failing in the traditional model, that we reduced hospital admissions from this population by 60 to 70% in 2 years. And that data was important—but it wasn't enough. You need a culture shift, you need political will, and you need enlightened leadership with a long-term perspective."

—Heidi Behforouz, MD,
Founder and former Executive Director, Project PACT
(Prevention and Access to Care and Treatment)

the provider and medical researcher workforce, such as the National Cancer Institute's Diversity Training Branch that seeks to increase the number of cancer researchers from diverse populations. Community orientation is also important in program design and management, as evidenced by the increasing use of geospatial "hot-spotting," which maps disease information against patient addresses in the aggregate to find particularly underserved neighborhoods, and the open source development process of the National HIV/AIDS Strategy.[2]   Against a backdrop of broader trends toward patient centered care,[3] patient and community voice is perhaps most important in specialty areas where patients face complex diseases and significant socio-economic barriers to good outcomes.

3 **Efforts to address health equity require leadership with a systems orientation and an equity mindset**. When institutional leaders view equity as a core value and a mark of the excellence and high quality of their health care institution—on par with their cutting edge research and care—dedicated resources are more likely to flow to the implementation of solutions like those highlighted in these briefs. With executive leadership support in place, health organizations must look outside their own doors to understand how they fit into a larger picture of institutional and socio-economic influences that affect patients. They need to expand their understanding of their own roles and their definition of "quality" care to account for these external factors. They need to foster collaboration with others to develop effective solutions to address the breakdowns that exist in care for certain patients—from establishing new models of referrals between primary and specialty care to building new community outreach efforts. Throughout all of this work, payers and providers will need to embrace a learning mindset, trying new things and learning from pilot projects. This systems orientation is essential to enabling investments in solutions like those profiled in **Brief 4: Helping Patients Engage in Care**, such as patient navigation or the Medical-Legal Partnership, which support patients on issues beyond the health care system, or strengthening collaboration between a hospital system and a community health system. Leaders with a systems orientation not only see that these investments are ethical, but also recognize the connections between these investments and their ability to run an efficient and effective health system.

> "*The data showed that we needed to do better on cancer disparities. We've been good at creating coalitions to look at this, so that we're not all operating in a vacuum. It's a nice indicator that there are so many invested parties that want to see this improvement made. When you have what once could be seen as competing institutions coming together and really trying to solve the issue, and thinking beyond the organizations themselves to focus on the individuals who are impacted—it makes a huge difference.*"
>
> —KAREN BURNS WHITE,
> DANA-FARBER/HARVARD CANCER CENTER

4 **An enabling policy environment is essential to help programs that reduce disparities in specialty care to thrive and to encourage and incentivize participation from system actors at all levels**. For instance, most of the programs working on disparities exist in states with expanded Medicaid, and many of the most successful programs are focused on HIV/AIDS with support from the federally-funded Ryan White program. In addition to funding, relevant supporting policies also include regulations that change the way in which care is provided and funded. These include, for example, regulations that allow for tele-health reimbursement and licensure or require providers to use translation services. Shifts to value-based care and incentives to more broadly address population health and improve the quality of health delivery have proven essential to introducing sustainable health equity solutions. As discussed in **Brief 2: Increasing Specialty Care Availability**, comparisons of efforts to deliver health equity across different states illustrate that policy context can be either a crucial enabler or hindrance to equitable specialty care.

5 **While every organization must take action to address health disparities, no one provider, payer, policy maker, or patient can change the system in isolation**. Collaboration is already fundamental to how the health care system works; within the confines of a hospital room or surgery theatre, the dynamic between provider, patient, payer, policy, and research is at play. This same dynamic drives the ways entire populations or communities benefit or fail to benefit from specialty care. And in order to make collaboration effective, partners need to make investments in collaborative infrastructure. With more structured collaboration, health system actors are better able to connect with one another and track and support patients, while returning better outcomes and efficiencies for each individual organization and improved outcomes for the patients they serve. Technology is playing an increasingly important role in enabling improved collaboration in the health sector. Many local health partnerships, for example, are investing in shared electronic medical records systems, which allow community organizations like Project Access to provide patient navigation services to specialty care patients while closely coordinating with local care providers and payers. On a national level, Project ECHO and other virtual training and collaborative care programs are working to increase the availability of high-quality specialty care delivery by creating long-term, structured partnerships between providers (see **Brief 2: Increasing Specialty Care Availability** for more detail).

> "*The persistence of health disparities can be seen as a quality improvement (QI) problem—there is unwanted variation in outcomes. Creating solutions requires collecting data to identify problems and then doing something about those problems. The QI field has focused on all sorts of other things—efficiency, safety, timeliness. But we need to do more on equity.*"
>
> —KEDAR MATE, MD,
> INSTITUTE FOR HEALTHCARE IMPROVEMENT

How Key Actors Can Bolster Equity Efforts

To date, progress towards improving equity in specialty care has been driven by specific organizations or individuals with the foresight, motivation and persistence to create change. But broader attention and collaborative action are needed to reduce disparities at a national scale. As evidenced by the factors for success identified in the previous section, there is a complex ecosystem of actors that play a role in increasing—or reducing—health disparities, and coordinated action across this landscape is needed for progress to occur. Each organization, including community organizations, funders, health care providers and payers, and policy makers, has a role to play.

The following section identifies these roles and highlights leading examples of health system actors that are striving to create sustainable, scalable models to realize the vision of health equity.

Federal and State Health Care Policy

Policy makers create the legal frameworks and incentives that can enable or hinder greater equity in specialty care health outcomes at the national, state, and local levels. Medicaid and other safety net policies and their implementation across states play a fundamental role in improving specialty care access for patients by providing resources, creating incentives, and establishing regulatory frameworks to encourage solutions. Beyond the safety net, payment reforms, coverage determinations, health plan specialist access requirements, tele-health regulations, and a range of other disease- or issue-specific policies can help or hinder the ability of specific programs or organizations to provide specialty care to underserved populations.

Some examples of policy supports for health equity in specialty care include:

- **Value-Based Care:** At the national level, one of the greatest policy influences on specialty care access is the ACA's emphasis on value-based care, which in turn is increasing the health care system's focus on health outcomes at the individual and population

> "*Things are shifting on the payment side in a really good way. In states like California, Oregon, and New York, we're seeing legislation for FQHCs that shifts from volume- to value-based payments. That creates much more flexibility for innovation. A lot of things that people couldn't do because they couldn't pay for them are now feasible. And we're seeing reductions in the cost of care, especially with managing complex patients—for example, even leveraging something as inexpensive as text messaging.*"
>
> —Veenu Aulakh,
> Center for Care Innovations

levels. As providers and payers see more incentives to deliver these results, better meeting the needs of underserved patients becomes a priority. This creates an enabling environment for a range of programs that seek to reduce inequities in specialty care.

- **Medicaid coverage determinations:** As the largest health insurance provider for low-income Americans, Medicaid coverage is a critical lever to ensuring sustainable funding for many of the solutions described in this series. With the ACA, Medicaid has become more flexible. For example, in 2014, Medicaid opened the door for states to use Medicaid funding to better support patients living in chronic homelessness, providing coverage for services like case management, health care navigation, and skill building around activities of daily living—supports that are critical to helping patients successfully remain in housing and services that nonprofit service providers would otherwise need to cover with grant funding.[4]

- **Incentives for New Models of Care Delivery:** The Center for Medicaid and Medicare Innovation (CMMI) provides incentives for payers and providers to pilot new models of care delivery with the potential to reduce specialty care disparities. One example, the Oncology Care Model, is studying the health impact and cost implications of providing a payment of $160 per patient per month for care coordination of patients undergoing chemotherapy.[5] The new Accountable Health Communities Model is supporting pilot projects for providers to screen patients for health-related social needs and connect them to community-based services—a frequently informal practice common at FQHCs and community primary care clinics that has great potential for impact and efficiency if integrated more systematically into all medical care delivery. In this way, CMMI is exploring new models of delivery that can address challenges in specialty care, with a direct channel for scaled implementation through Medicare and Medicaid rulemaking and policy.

Delivery innovation is also needed at the state level. The CMMI State Innovation Models (SIM) Initiative provides support to individual states to reform payment and delivery to improve quality and reduce costs for Medicaid, Medicare, and the Children's Health Insurance Program (CHIP).[6] States are given tremendous flexibility under this program and are piloting many different approaches to reforming delivery. For example, Oregon has structured its Medicaid health plans into 16 "coordinated care organizations" (CCOs) to centralize care in Patient Centered Medical Homes (PCMHs), which provide co-location of primary and specialty services, integration of physical and behavioral health services, and community representation on health plan boards.[7] As a result of these changes, the state

> "*Every part of the health care system is so stretched that nothing happens until it is required. Recently, CMS had to actually pass a requirement that hospital staff need to communicate with a patient's caregivers upon discharge. That seems like common sense—but it doesn't happen until it's a rule. For palliative care, we have a strong evidence base in terms of delivering health outcomes and lower costs. There's no reason not to do it. But it needs to come from Medicaid and Medicare policy, accreditation, changes to the 5-star quality ratings program. That's how you raise all boats.*"
>
> —DIANE MEIER, MD
> CENTER FOR ADVANCEMENT OF PALLIATIVE CARE

is seeing significant returns: the average cost of specialty services has declined from $13.57 to $12.53 per patient per month between 2011 and 2014, and emergency department utilization has declined from 700 to 550 per 1,000 patients.[8]

• **Regulation:** In addition to incentives and support for innovation, health care regulations and requirements also play a role in driving equity. One such example is the "network adequacy" guidance for the private managed care organizations (MCOs) that administer Medicaid benefits in thirty nine states. Under federal law, states are required to set standards for access to care that MCOs must meet. These standards include the maximum distance to primary and specialty providers that a patient would have to travel, the maximum wait time before patients are seen, or number of patients per provider. MCOs that cannot meet these standards must allow patients to see out-of-network providers at no additional cost. When implemented, these standards ensure that Medicaid patients have consistent and timely access to specialty services, but in practice, standards vary widely and most compliance testing is very weak.[9]

In May 2016, CMS built on these standards and issued a sweeping set of new rules for MCOs. The rules include a number of changes in service of improved access and quality of care for Medicaid beneficiaries, including: flexibility for states to provide incentives for quality improvement and sharing of patient information with other providers, requirements for states to establish plans for value-based payment models for hospitals and doctors, and encouragement for states to establish quality rating systems. While many key provisions remain under state authority (e.g., time and distance requirements), these rules have the potential for significant impact on health disparities along socio-economic lines.

> FEDERAL AND STATE HEALTHCARE POLICY: WHAT'S NEEDED

Federal and state policies are essential to achieving scale with any equity solutions. At the federal level, investment in demonstration projects and dissemination of learnings through the Center for Medicare and Medicaid Services and the Agency for Healthcare Research and Quality remain critical. Greater focus on specialty care within programs like the State Innovation Models would drive significant movement to address disparities for conditions like cancer and cardiovascular disease. At the state level, improved understanding of the impact of supporting regulations and policies on health outcomes and health systems costs and improved information sharing between states would help make the case for broader adoption of effective practices.
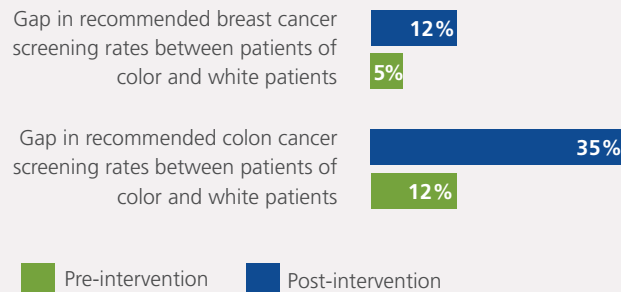
Private Payers

Private payers, who insure and control reimbursement decisions for more than 55% of the U.S. population,[10] are undertaking internal and external efforts to improve health equity and reduce disparities. With the Affordable Care Act and the movement toward value-based care, payers now have increased incentives to improve the quality of care that patients receive and to reduce health care costs. Taken together, these forces have spurred innovation for health equity, and their continued efforts will be critical to improving health equity for all.

Some current institutional efforts by payers include:

- **UnitedHealth Group's Health Equity Service Program**: Recognizing the need to spur internal innovation around health equity, UnitedHealth established the Health Equity Service Program in 2010. The program supports various business units throughout the company to identify opportunities and develop programs to improve equity, including the development of culturally relevant communications and targeted member outreach campaigns. The goal of its health equity efforts is to better understand their members' unique needs, identify gaps, and target new solutions.[11]

- **HealthPartners "Partners for Better Health Goals"** Initiative: HealthPartners, an integrated health care organization based in Minnesota that serves 1.5 million members, has also taken an equity approach to improving outcomes for its members. HealthPartners developed a comprehensive system to collect data on its members, including: primary language, need for an interpreter, race, and country of origin, alongside clinical information. This data is then used to identify key disparities

Figure 3. HealthPartners Impact on Disparities in Cancer Screening rates

Gap in recommended breast cancer screening rates between patients of color and white patients: 12% / 5%

Gap in recommended colon cancer screening rates between patients of color and white patients: 35% / 12%

Pre-intervention | Post-intervention

and develop targeted interventions in priority areas such as patient satisfaction, diabetes care, and mammography and colorectal cancer screenings. To reduce disparities in recommended cancer screening rates, for example, HealthPartners conducted targeted outreach to African American and Native American patients and their providers, began offering same day mammograms, and followed up with patients who were overdue for a screening. These measures resulted in drastic reductions in disparities between white patients and patients of color (see Figure 3).[12]

- **National Health Plan Collaborative**: Under the direction of America's Health Insurance Plans (AHIP), 26 private insurers that are focused on reducing racial and ethnic disparities have established a learning collaborative. The collaborative's goals include: collecting data to inform disparity reduction efforts,

enhancing language services, supporting investments in disparity reduction by making the business case for addressing disparities, and improving the dissemination of disparity-related information. Most recently, the collaborative published the "*Toolkit to Reduce Racial & Ethnic Disparities in Health Care*," which consists of resources, lessons, best practices, and case studies designed to encourage other health plans to address disparities to help foster stronger and larger collaborative efforts.[13]

> ### PAYERS: WHAT'S NEEDED

Private payers can further **leverage their access to tremendous volumes of patient data to better serve their members**. Payers can examine member data to identify breaks along the continuum of care and develop innovative solutions to help members overcome barriers. Additionally, through collaboration with providers, payers can spur innovations and pilot new delivery models that reduce costs while improving specialty outcomes for underserved patients. Experience with these solutions also provides an opportunity for payers to **be thought leaders and advocates on the issues that underserved patients face**, which will be increasingly relevant with the expansion of insurance coverage under the ACA and the increasing participation of private managed care organizations in Medicaid programs.

Health Care Providers and Provider Institutions

Both primary care and specialty health care providers play important roles in increasing the adoption of patient-centered approaches and coordinating infrastructure that enables collaboration. Leading specialty care providers are increasingly adopting patient-centered approaches, and safety-net provider institutions are working to develop solutions to meet the specialty needs of their patients. At the institutional level, many provider organizations are creating internal structures to focus on equity in processes such as staff recruitment and retention, quality improvement, and leadership in addition to care delivery and patient engagement.

Some current efforts by providers that illustrate this focus on equity in specialty care include:

- **Dana-Farber/Harvard Cancer Center (DF/HCC) Initiative for Eliminate Cancer Disparities (IECD)**: DF/HCC created the IECD in order to centralize and coordinate efforts related to addressing cancer disparities across all seven of its member institutions. In particular, the IECD supports community outreach activities, conducts research on disparities, supports faculty diversity, promotes greater minority patient participation in clinical trials, and conducts education and awareness building on the effects of race and culture on medical decision making and patient care.

- **Kaiser Permanente**: As a leading integrated delivery network (IDN), Kaiser Permanente provides a model for how other IDNs can enable innovation for health equity throughout the organization. Kaiser has established strong data systems to identify disparities in health outcomes or in care quality (e.g., in patient satisfaction scores) and allow space for innovation to address these disparities with specific program development in the care setting, and has invested in building knowledge and skillsets for culturally-competent care through broader programs, such as the Health Care Interpreter Certificate Program.

- **National Cancer Institute's Community Network Program Centers (CNPC)**: A CNP Center is a NIH community partnership headquartered at an academic institution or community-based organization that works closely with the local community to identify its cancer disparity problems and cancer prevention and control needs. CNPCs help local communities craft patient-centered approaches to reducing disparities by providing training, leadership, capacity, and tools to serve the needs of a community's in-need populations. CNPCs span the country focusing on various population sub-groups, from Washington State's focus on American Indian populations to South Carolina's focus on the African American population.[14]

> **HEALTH CARE PROVIDERS AND PROVIDER INSTITUTIONS PAYERS: WHAT'S NEEDED**
>
> Provider institutions can take the lead in developing **centralized internal structures to address inequities in specialty care**. To develop these capabilities, providers can pull on existing assets such as quality improvement expertise, which can be leveraged to identify and act on disparities. Building these structures and processes will enable providers to better collect the data needed to understand and identify disparities, support innovation to address disparities, and improve providers' ability to develop the community partnerships necessary to fully address the social determinants of health. Collectively, this will better position providers to create sustainable equity solutions to improve patient outcomes and patient satisfaction.

Professional Associations

Equally important are the professional associations that serve health care providers, including specialist organizations like the American Society of Clinical Oncology (ASCO), broader professional organizations like the American Medical Association (AMA), and associations for provider organizations like the Association of Community Cancer Centers (ACCC) or the Association of Academic Health Centers (AAHC). Minority medical associations have also long advocated for improved prevention and treatment of health issues that affect minorities, including the Association of Black Cardiologists (ABC), the National Medical Association (NMA), and the National Hispanic Medical Association (NHMA), among others. Through conferences, continuing education programs, and development of guidelines and standards, these professional bodies can play a key role in promoting an equity approach and supporting members to implement equity solutions. The AAMC, for example, recently launched the Health Equity Research Virtual Site Visit, highlighting effective provider-led initiatives to reduce health disparities. ASCO has established a Health Disparities Committee, which aims to increase awareness of health disparities among its members, support efforts to improve workforce diversity in the field of clinical oncology, and support research on cancer disparities.

> **PROFESSIONAL ASSOCIATIONS: WHAT'S NEEDED**
>
> Professional associations for specialists and specialty care provider organizations can **contribute by formally establishing a focus on health equity**. With the implementation of the ACA, the broader national conversation on equity, and changes in health care delivery and payment, promoting health equity is a growing priority for both health provider organizations and individuals. Professional associations can help members navigate these changes, as they do regularly on others, and help meet the needs of all patients.

Patient Advocacy Groups

Disease-specific patient advocacy organizations like the American Cancer Society, The Promise Foundation, and AIDS United play an important role in building awareness and providing support for current and former patients and their families. Today, groups focused on HIV tend to have a strong focus on health disparities and inequities—in large part due to the epidemiology, history, and social vulnerability and exclusion of many people living with the disease. In particular, HIV/AIDS organizations focus on community outreach and patient engagement, advocate for comprehensive approaches that take into account the social determinants of health, and work to enable greater collaboration. Patient advocacy organizations for other disease areas, however, do not yet share this strong focus on health equity.

> ### PATIENT ADVOCACY GROUPS: WHAT'S NEEDED
> Advocacy organizations for patients requiring specialty care have a significant opportunity to increase their impact by **more closely engaging and understanding the needs of underserved populations** and orienting their advocacy, education, and patient support efforts to better serve all in need, and lifting those patients' voices.

Private Foundations

Private foundations can play an important role in facilitating greater action on health equity among payers, providers, and policy makers. Private foundations play three primary roles: sparking and incubating innovative solutions or enabling system-wide collaborative initiatives to address disparities in specialty care and supporting research and advocacy efforts to catalyze greater field-wide action on health equity.

- A leader on the issue of specialty care is the **California Health Care Foundation (CHCF)**. The Foundation's Specialty Care Initiative supported more than 20 coalitions of actors to develop community-specific strategies to address the barriers to specialty care for underserved populations from 2007 to 2012. The coalitions were funded to develop comprehensive solutions that included issues like streamlining the referral process between primary and specialty care, expanding the availability of specialty care providers, increasing primary care provider capacity and scope of practice, and improving care coordination.[15]

- The **Robert Wood Johnson Foundation (RWJF)** is expanding its efforts to mitigate health disparities by tackling not only access to quality health care, but also addressing upstream social determinants of health. For example, the Culture of Health program supports community collaboratives that include a broad range of traditional and non-traditional partners to assess the health status of an entire community and work together to create the conditions for optimal health and well-being for all.

- The **Center for Care Innovations (CCI)** is another example of what private funders can do to better enable uptake of health equity solutions among providers. Supported by the Blue Cross Blue Shield of California Foundation and The Nicholson Foundation, among others, the CCI funds pilot projects and

research to identify and spread best practices in care among safety net providers. The CCI also engages health care leadership through trainings on topics such as employee engagement and human-centered design to further embed health equity in the structure and core functions of provider organizations.

- **The Commonwealth Fund** provides a good example of the research approach. In 2013, the Foundation published a seminal report, "Improving Access to Specialty Care for Medicaid Patients: Policy Issues and Options," which raised awareness of the challenges faced by low-income populations seeking specialty care.[16] It highlighted models that increased access to care in three ways, similar to those highlighted here: 1) increasing availability through telemedicine, 2) expanding the role of PCPs to provide more specialized care, and 3) improving coordination of patients' care.

- In early 2016, the **Aetna Foundation** partnered with **Grantmakers in Health** to publish a feature in the Stanford Social Innovation Review on "Innovations in Health Equity."

- Finally, the funder of this series of briefs, the **Bristol-Myers Squibb Foundation**, has launched the *Specialty Care for Vulnerable Populations* initiative. The goal of this national initiative is to catalyze sustainable improvement and expansion of specialty care service delivery by safety net providers to achieve more optimal and equitable outcomes for the people they serve who are living with cancers, HIV/AIDS, and cardiovascular disease. Beyond grant making, the initiative is undertaking extensive outreach to the specialty care sector to deepen the understanding and increasing the awareness of health and health care inequities and collaboratively finding solutions. The Foundation is also providing grantees with technical assistance for policy advancement and advocacy, as well as payer and health system engagement, in order to optimize the sustainability and scaling of effective models of care *(see Figure 4 below)*.

Figure 4. Bristol-Myers Squibb Foundation Specialty Care for Vulnerable Populations Initiative

Bristol-Myers Squibb Foundation
Specialty Care for Vulnerable Populations
Care Collaborations & Patient Support
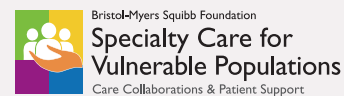
Grant making and partnership development will focus on two areas:

1. **Health systems strengthening** to complete systems of care and expand specialty care delivery capacity through safety net primary care and community-based provider collaborations with local and remote specialists.
2. **Patient education, engagement, and community supportive services** to optimize specialty care utilization and self-care.

Key indicators of success:

- Improved and expanded safety net provider **capacity** to deliver specialty care
- Improved and expanded **patient engagement** and **social support services**
- Improved **access** to recommended specialty services among Medicaid and medically underserved patients
- Improved patient **retention** in and **utilization** of specialty care services
- Improved **health outcomes** and **quality of life**
- **Sustained** capacity, care collaborations, supportive services, and connected systems of care

> **PRIVATE FOUNDATIONS: WHAT'S NEEDED**

There is a need for more foundations to work on issues of equity in specialty care to create the critical mass of thought leadership, advocacy, and resources needed to help catalyze transformative change. Foundations are uniquely positioned to partner with providers, payers, and other players to take risks in testing new innovations, sharing data to encourage the system to meet the needs of all patients.

Looking Forward

The organizations and initiatives highlighted here represent some of the most innovative and promising attempts to address the deep and persistent inequities that exist in specialty care. Their efforts have averted preventable deaths, improved health outcomes, enhanced quality of life, and improved quality of care and the patient experience for thousands of vulnerable and medically underserved people. While they serve as compelling proof that health equity initiatives benefit patients, health care providers, payers, and communities, no further progress will be made without system-wide action. In order to address the deficiencies in our current system, these solutions must be scaled and replicated for deeper impact and embedded within care delivery and payment.

Any health actor can initiate these efforts—payer, providers, and community organizations can all play a leading role. But each actor needs to engage other partners within the health system. Achieving health equity will require cross-sector collaboration at the national and local levels, visionary leadership combined with technical expertise, community organizations working with specialists, and the ability to innovate within a complex system. The development of once-in-a-generation medical advances in specialty care alongside implementation of the Affordable Care Act, create an opportune moment to strive toward this vision of creating an equitable system of specialty care that ensures equal access to high quality care and equal health outcomes for all patients who experience serious, complex illnesses, irrespective of their race, ethnicity, socio-economic status, or ZIP code.

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Figure 2

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Figure 3

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

Call to Action for a System-wide Focus on Equity

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