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

BRIEF

1 2 3 4 5

Striving for Equity in Specialty Care

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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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.
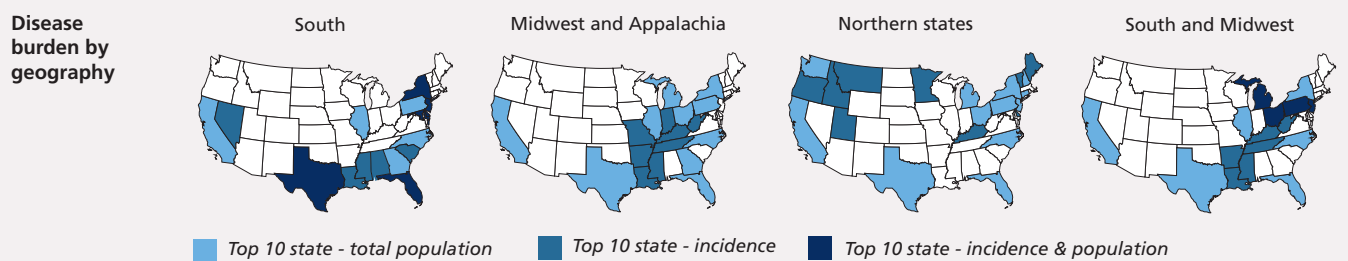
How is "specialty care" defined?

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*
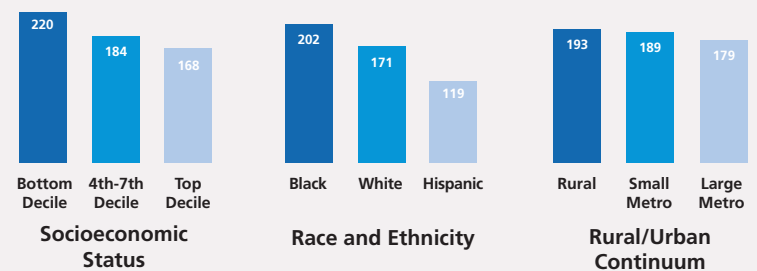
Socio-economic status, race and geography remain strong determinants of health outcomes, even for acute medical conditions. There is robust evidence that low-income patients, rural patients, and patients belonging to racial or ethnic minority groups are more likely to die from cancer and other diseases 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		
Bottom Decile	4th-7th Decile	Top Decile
220	184	168

Race and Ethnicity		
Black	White	Hispanic
202	171	119

Rural/Urban Continuum		
Rural	Small Metro	Large Metro
193	189	179

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.
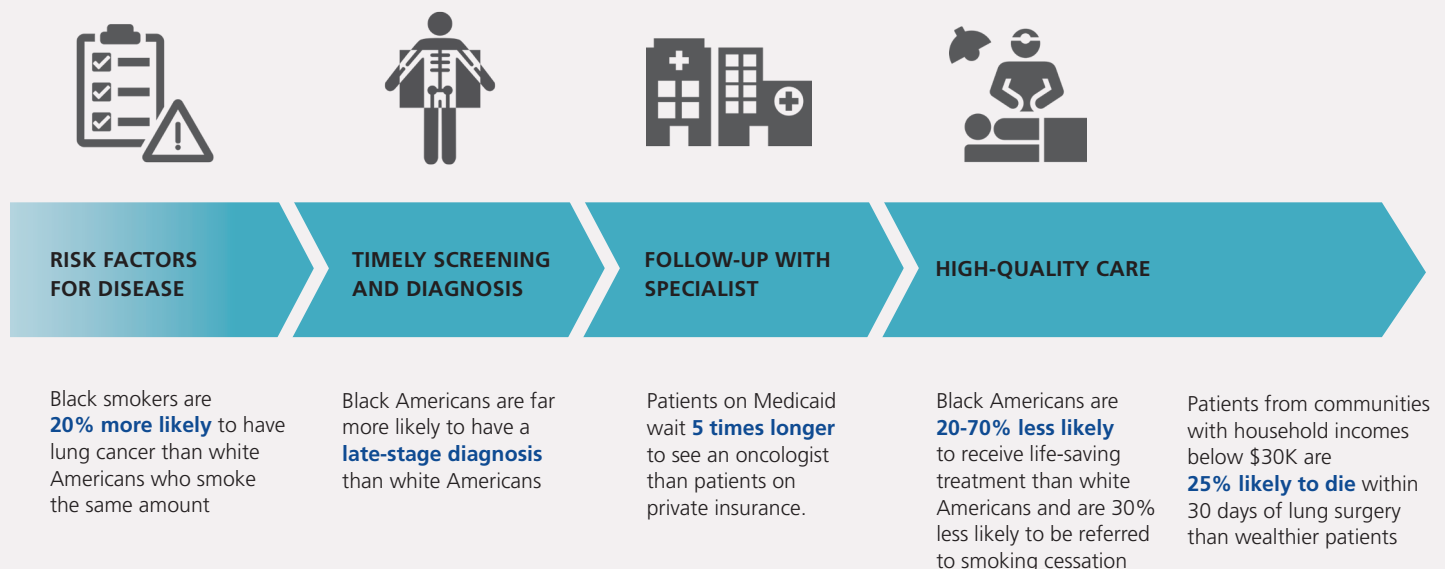
The battle against lung cancer casts these disparities in sharp relief. Lung cancer is one of the leading causes of death in the United States and the leading cause of cancer deaths, resulting in nearly 160,000 deaths in 2015—*more than 400 deaths every day*. Not only is it one of the most common cancers, 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
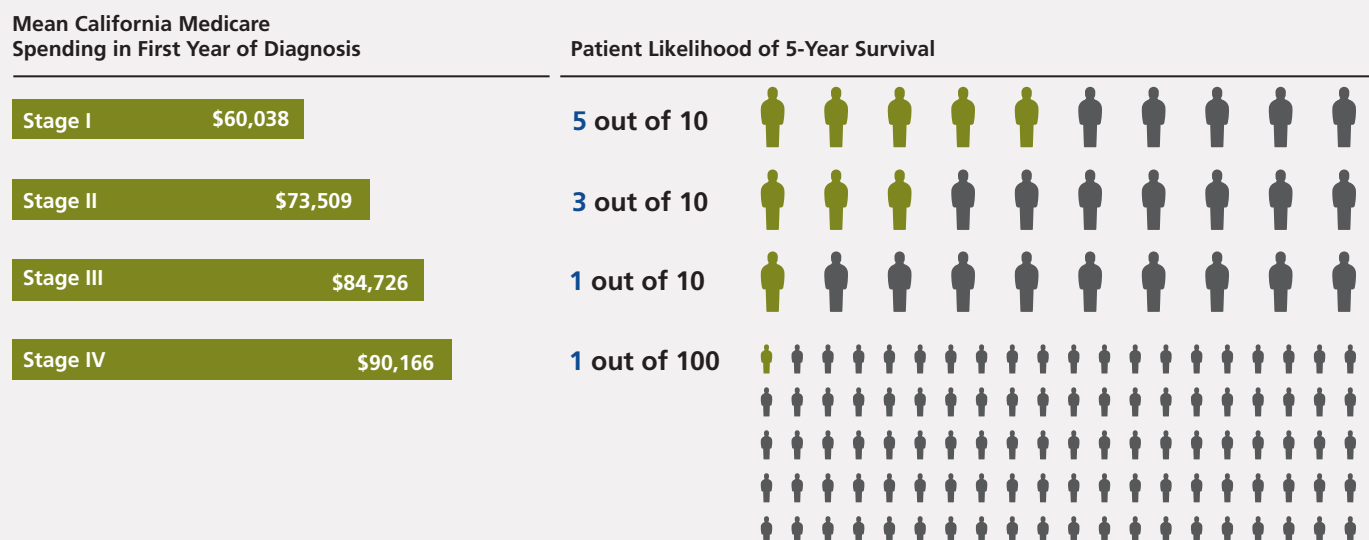
An opportune moment for sector-wide action

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	Spending
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.

> *"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

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]

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.

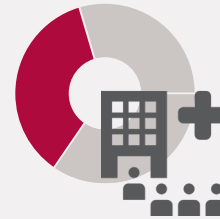For more analysis, examples and solutions, see Brief 4: Helping Patients Engage in Specialty Care

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
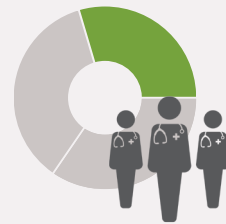
Target Patient Populations

- 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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Practical Ideas to Improve Health Equity and Reduce Cost

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