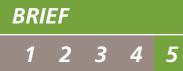


## **Breaking the Barriers to Specialty Care** Practical Ideas to Improve Health Equity and Reduce Cost



# Call to Action for a System-wide Focus on Equity



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

n 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



#### **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** 



#### Figure 2. Health Equity Solutions for Specialty Care

Increasing Specialty Care Availability	Health Equity Solutions	Health System Value Proposition
	<ul> <li>Coordinated specialist networks</li> <li>Telemedicine/ telementoring</li> <li>Development of primary care capacity</li> </ul>	<ul> <li>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.</li> <li>One provider network that formalized specialty care for uninsured patients reduced emergency room costs for its most expensive patients by 41%.</li> <li>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.</li> </ul>
Ensuring	Health Equity Solutions	Health System Value Proposition
High-Quality Care	<ul> <li>Incorporating culturally competent practices</li> <li>Efforts to address implicit bias among health care workers</li> <li>Harnessing quality improvement to include equity</li> </ul>	<ul> <li>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.</li> <li>Instituting shared decision-making for specialty care led one provider to in 2009 to a 38% reduction in unnecessary procedures.</li> <li>Data shows that patients with greater levels of engagement and higher levels of trust in providers experience better outcomes and higher patient satisfaction.</li> <li>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.</li> </ul>
Helping Patients Engage in Care	Health Equity Solutions	Health System Value Proposition
	<ul><li>Community outreach</li><li>Patient navigation</li><li>Patient support services</li></ul>	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.
		<ul> <li>Early diagnosis in HIV can save up to 50% of cumulative care costs.</li> <li>Diagnosing someone with lung cancer at Stage I vs. Stage IV can save up to 30% of first-year treatment costs.</li> <li>Patient navigation can yield up to 20% higher diagnostic resolution and engagement in treatment among disengaged patient groups.</li> </ul>



## 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.

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 "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."

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.<sup>1</sup> 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.

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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.<sup>2</sup> Against a backdrop of broader trends toward patient centered care,<sup>3</sup> patient and community voice is perhaps most important in specialty areas where patients face complex diseases and significant socio-economic barriers to good outcomes.

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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

<sup>44</sup> 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.<sup>77</sup>

> —Karen Burns White, Dana-Farber/Harvard Cancer Center

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.

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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.

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 \*\* 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

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).



## 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 valuebased 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.<sup>?</sup>



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.<sup>4</sup>
- 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.<sup>5</sup> 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).<sup>6</sup> 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.<sup>7</sup> As a result of these changes, the state

<sup>44</sup> 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.<sup>77</sup>



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.<sup>8</sup>

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.<sup>9</sup>

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.

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#### 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.

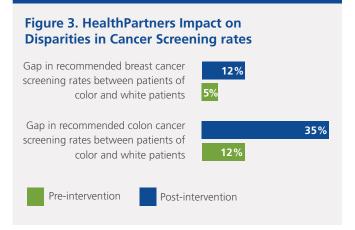


## **Private Payers**

Private payers, who insure and control reimbursement decisions for more than 55% of the U.S. population,<sup>10</sup> 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.<sup>11</sup>
- 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



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).<sup>12</sup>

 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.<sup>13</sup>

### 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

B oth 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.<sup>14</sup>

### 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**

E qually 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

D isease-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.<sup>15</sup>
- 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.<sup>16</sup> 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



Care Collaborations & Patient Su

#### 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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