



Breaking the Barriers to Specialty Care

Practical Ideas to Improve Health Equity and Reduce Cost

BRIEF

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Helping Patients Engage in Specialty Care



REIMAGINING SOCIAL CHANGE



Bristol-Myers Squibb Foundation

About this series of briefs

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

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

About Bristol-Myers Squibb Foundation

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

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

Learn more at www.bms.com/foundation.

About FSG

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

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

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

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About this brief

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

About specialty care

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

Relevant patient groups and disease areas

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

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

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

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

These “social determinants of health” as documented by the CDC¹ and WHO,² among others, are massive drivers of health inequity in the United States across disease areas. Yet, in the context of specialty care, their impact is particularly stark. Patients requiring specialty care for conditions such as cancer or cardio-vascular disease engage in care more frequently and in more complex situations than others. For these patients, constraints related to health literacy, available time, transportation, finances, and other challenges are exacerbated and can impede a patient’s ability to engage in the care that they need. These factors create disparities along the care continuum, from initial screening and diagnosis to care, ongoing treatment, and post-treatment follow-up and monitoring. The most acute contributors to health disparities in specialty care include the following.

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

“We recognized that in [the city of] Lyndhurst, the average life expectancy was 86 years. If you drove 10 minutes away to Hough [neighborhood], the life expectancy was 10 years shorter. That drove huge conversations. We started to realize that there is not a comparable ability to access and benefit from care between our communities.”

—SARAH HACKENBRACHT,
FORMER EXECUTIVE DIRECTOR,
CUYAHOGA HEALTH ACCESS PARTNERSHIP*

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



- **The ability to navigate the health care and insurance system** is also more difficult for low-income patients who must balance care with the basic priorities in their lives while navigating a more complex medical system than affluent patients. Low-income patients often depend on patient assistance or charity care programs provided by pharmaceutical manufacturers, health care providing institutions, or nonprofit organizations, adding layers of complicated rules, application processes, deadlines, and requirements to access treatment or insurance coverage. Together, these can result in gaps and delays in critical treatment.^{5,6} These difficulties are compounded when patients do not speak or read English proficiently, and are even more challenging for patients with multiple medical needs requiring attention from multiple specialists. Specialists are affected as well; many struggle with a high “no-show” rate as a result of patient challenges, which drives health care costs higher because of un-utilized capacity, and can deteriorate providers’ attitudes toward low-income patients.
- **Lack of disease awareness and stigma** associated with certain diseases result in patients delaying screening and diagnosis. Lung cancer, for example, is heavily stigmatized with patient blame and a sense of hopelessness because of its association with smoking and its low survival rate relative to other cancers. This stigma has been shown to delay care initiation among patients who suspect they may be experiencing symptoms of the disease.⁷ Most people with lung cancer are diagnosed at Stages III or IV,⁸ when the 5-year survival rate is below 25%.⁹ Disease awareness can also be correlated with demographic factors such as language, race, and ethnicity, signaling a need for more targeted disease education. For example, Spanish-speaking Hispanics are far less likely to know all the stroke symptoms (18%) than English-speaking Hispanics (31%), non-Hispanic blacks (41%), and non-Hispanic whites (50%).¹⁰
- **Financial burden** associated with managing a serious disease is a key contributor to patient stress and a driver of patient disengagement from care. A recent survey by the Cancer Support Community found that 37% of cancer patients are seriously concerned about bankruptcy,¹¹ a valid fear given that **cancer patients are up to 2.5 times more likely to file for bankruptcy than non-cancer patients.**¹² Financial stress can have a direct effect on patient outcomes as well: a 2013 study found that **20% of cancer patients took less than the prescribed amount of medication in an attempt to “stretch” their prescriptions, and 24% avoided filling prescriptions altogether for financial reasons.**¹³ Further, since employers are not required to provide paid sick leave, hourly wage earners also face income insecurity when managing illnesses that require specialty care. Patients who work in seasonal, domestic or informal work are particularly vulnerable to consequences of taking time off, which can discourage them from seeking necessary treatment.

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

—GISELLE CARLOTTA-McDONALD,
YALE-NEW HAVEN HOSPITAL PROJECT ACCESS



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

“One of the issues that people call us about most frequently is medical debt or help accessing benefits. We’ve heard that people have used their rent to cover their medications, or vice versa. That puts people in an impossible position—to choose between keeping their homes or keeping their health.”

—ALAN BALCH,
PATIENT ADVOCATE FOUNDATION

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

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





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

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

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



Emerging Solutions

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

Figure 2. Three Emerging Solutions for Increasing Specialty Care Availability



Community Outreach

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

[Read more below](#)



Patient Navigation

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

[Read more on page 11](#)



Patient Support Services

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

[Read more on page 13](#)

Community Outreach to Engage Patients



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



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

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

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

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

—MEGHAN DAVIES,
WHITMAN-WALKER HEALTH



Cedars-Sinai Barber-Based Blood Pressure Program



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

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

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

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

Culturally relevant outreach increased control of hypertension by 20%



Patient Navigation



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

“For people that are challenged economically and in other social ways, and have chronic and extreme illnesses, the starting point is a trusted source that helps them coordinate and break down some of the impediments and barriers to care.”

—DEBORAH C. ENOS,
FORMER CEO, NEIGHBORHOOD HEALTH PLAN

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

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



Case Example

National Cancer Institute Patient Navigation Research Program



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

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



Patient Support Services



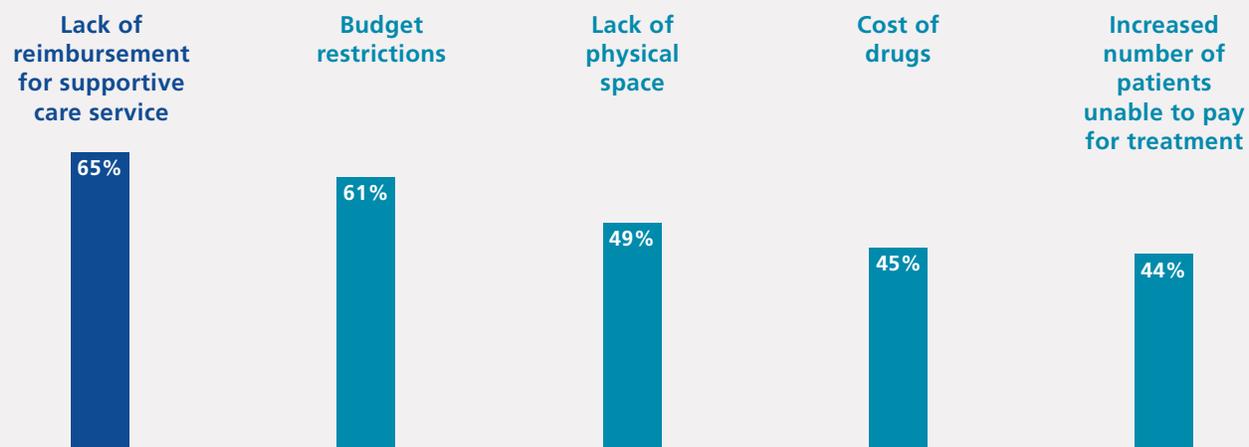
For some patients, navigation is important, but not sufficient. Particularly for low-income patients, who struggle to meet their basic needs, effectively managing complex care is impossible without additional support. In response, a number of patient and community-based organizations provide ancillary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

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

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

—LINDA HOUSE,
CANCER SUPPORT COMMUNITY

Figure 3. Biggest Challenges Facing Community Cancer Programs Today





Professional counseling, education, financial assistance, and health insurance literacy education are provided by numerous organizations. For cancer, some organizations have national reach, such as CancerCare, Cancer Support Community, and the American Cancer Society. These national initiatives complement many more informal and local efforts. Similarly, for rare diseases such as Duchenne muscular dystrophy, patient advocacy groups such as Parent Project Muscular Dystrophy provide a community and personalized counseling to families affected by these diseases.

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

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

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



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



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

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

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

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



Wrapping Things Up: Taking Action

The Value of Investing In Equity

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

> How patients benefit

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

> How providers and provider institutions benefit

These solutions can improve efficiency and patient satisfaction. As noted, community outreach efforts can increase early diagnosis and patient engagement, which has implications for emergency room use. Patient navigation reduces “no-show” rates and reduces the amount of time that providers and their staff spend connecting patients to supportive services, even as these services have significant effects on patient wellbeing and satisfaction. With capitation-based payment models, in which health care providing organizations are increasingly accountable for cost, outcomes, and patient experience, addressing these factors will be a critical step in achieving quality care—and in turn, reimbursement. In fact, beginning in 2012, Medicare began withholding 1% of reimbursements from hospital systems that did not meet satisfaction thresholds; that figure will increase to 2% in 2017.⁵⁰ Even for health care systems that do not move to capitation based models, addressing disparities and better meeting the needs of underserved patient groups helps to fulfill the quality goals that are central to many health care systems.

Scaling and Adopting Delivery Innovations Can Be Difficult

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

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

Bringing community health workers into the mainstream of U.S. health care

2015 Discussion Paper, Institute of Medicine⁴⁸



> How payers benefit

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

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

What's Needed to Scale These Solutions?

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

“We’re hoping to see more reimbursement for care coordination in the future. Everyone recognizes the benefits of care coordination services for patients, but there is insufficient funding to support it. This is a health systems delivery issue affecting many health care providers. We are optimistic there will be a Medicaid-based reimbursement for care coordination that doesn’t segment patients by insurance type or provider. For now, we must rely more heavily on grant funding.”

—KATE FOX NAGEL, DRPH, MPH,
CARE ALLIANCE HEALTH CENTER, CLEVELAND, OHIO



Community Outreach

State of Adoption

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

Opportunities for Further Implementation and Scale

Where to start

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

Success factors

- Close partnerships between providers and community organizations that enable efficient outreach to target populations in culturally appropriate ways in places where they already congregate.
- Strong pathways for referral to diagnosis and treatment for patients who receive abnormal screening results.
- Funders who support evaluation and data collection to assess health and cost impact, to “make the case” for additional investment.
- Leveraging opportunities for reimbursement, such as [CMS’s Preventative Services program](#), which allows state Medicaid programs to reimburse for preventative programs implemented by non-medical personnel.

Examples include

- NCI National Outreach Network
- Cedars-Sinai Heart Institute Barber Shop Outreach Project
- Washington AIDS Partnership Mobile Access Initiative



Patient Navigation

State of Adoption

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

Opportunities for Further Implementation and Scale

Where to start

- Navigation services can be structured in a number of ways: they can be offered directly by health care systems or offered by separate non-profit organizations, and they can be staffed by a range of professionals from lay navigators to professional nurse navigators. All of these models are effective, but the navigation approach should be tailored to the needs of the patient population.
- Navigation is particularly effective when the demographics of patient navigators reflect the demographics of the patient population and when navigators have a deep understanding of local community and social dynamics.
- The [Harold P. Freeman Patient Navigation Institute](#) has a range of resources on patient navigation and runs regular training programs for patient navigators.

Success factors

- Close engagement with senior health care system leadership to ensure a shared understanding of the value of navigation, a commitment to fund navigation services, and a plan to integrate navigation with core care delivery. As health care systems increasingly operate under value-based models there will be greater opportunity to directly integrate navigation into care provision.
- Capacity to collect data and conduct evaluations of the health and cost effects of navigation and engage public and private state health plans (e.g., Medicaid MCOs) to reimburse for navigation services.

Examples include

- Los Angeles County Department of Health Services
- Ralph Lauren Center for Cancer Care
- Project Access (Nationwide)



Patient Support Services

State of Adoption

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

Opportunities for Further Implementation and Scale

Where to start

- Potential implementers should prioritize psychosocial support services for disease areas associated with the highest burdens of anxiety and depression, such as cancer, though over time services can be broadened to serve other disease areas as well.
- Financial support models provided by national organizations are largely based on charitable giving, limiting their potential for replication. However, at the local level there is an opportunity to engage local funders such as community and conversion foundations to provide prescription drug support for low- and middle-income patients with serious diseases as part of broader strategies for addressing health disparities.

Success factors

- Data showing the significant clinical and quality of life effects of anxiety associated with managing serious diseases, and evidence on patient retention, engagement, and outcomes associated with implementation of psychosocial supports.
- Seamless integration into the care environment and greater accessibility (via phone or web) of patient information and psychosocial support.
- For diseases that affect smaller populations, successful engagement of the patient community to foster peer-to-peer support.
- Reimbursement of psychosocial services delivered in the care environment via bundled payments (e.g., for cancer care) or through state Medicaid waivers.
- Supportive employment policies that allow for patients to fully engage in care.

Examples include

- CancerCare
- Cancer Support Community
- Patient Advocate Foundation



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Figure 1

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

Figure 3

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Breaking the Barriers to Specialty Care

Practical Ideas to Improve Health Equity and Reduce Cost

Helping Patients Engage in Specialty Care

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