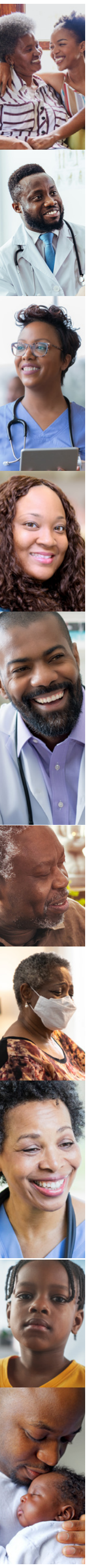

Advancing Equity for Black Patients with Serious Illness

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Advancing Equity for Black Patients with Serious Illness

To health equity champions working to improve care quality for people with serious illness:

Thank you, from the whole team at the Center to Advance Palliative Care (CAPC), for your actions to reduce disparities and provide equitable care. CAPC is deeply committed to health equity, and our promise to you is that we will continue to identify best practices, provide practical guidance on how to achieve more equitable care, and offer opportunities to connect with other equity champions. Why is this so important to us?

Palliative care is based on one essential principle—that every human life has value and meaning. We aim to learn the unique hopes and fears of each person in front of us and to do all we can to be present, provide support, and relieve suffering for our fellow humans.

Our country's shared history of racism and racial inequality has resulted in inequities that are apparent not just in journal articles, but in the stories and experiences of suffering of countless Black patients and families.

To address racial inequalities is to live our values as a palliative care community. No team, organization, or community can do this work alone. It will take action from all of us to achieve equitable care. The CAPC team hopes this guide provides inspiration, information, and tools to support your health equity work.

We applaud your efforts and hope to hear from you about what you're doing to improve equity in your community!

Brynn Bowman, MPA, *Chief Executive Officer*
Center to Advance Palliative Care

CHAPTER ONE

Using the Guide: Why, Who, and How

Black people in the United States experience disproportionate suffering when diagnosed with a serious illness—like cancer, heart failure, and dementia—compared to their white counterparts. Black patients often are not believed about their pain, or their pain is undertreated; they experience low-quality communication from their care teams; and Black family caregivers bear a high degree of emotional and financial burden. Racial and ethnic health inequities in America have an annual estimated economic burden of $451 billion, with most of the economic burden being attributable to the poor health of the Black population. Improving the quality of care and caregiver support for Black people living with a serious illness is an opportunity to reduce suffering and improve quality of life for patients and families.

In this guide, CAPC takes a practical approach to addressing health disparities in the care of Black patients with serious illness. We draw from research, examples of health equity initiatives from across the country, and the wisdom of health equity leaders to provide guidance to health equity change agents who want to take action.

By reading the guide you will learn:

- **How to engage Black patients, caregivers, and other community voices in the design of your health equity initiative**
- **Common focus areas for health equity quality improvement projects focused on Black patients and families, including case examples from across the country**
- **How to assess needs in your own organization and community**
- **How to design and seek funding for your health equity intervention**
- **Guiding principles for health equity work shared by experts**

Why Focus on Black Patients with Serious Illness?

In 2021, CAPC's Project Equity workgroup conducted a comprehensive literature review to understand what is known about disparities in health care experiences and quality of life specifically for Black people living with serious illness, and their families. Key findings from this literature review include:

- → Black patients living with serious illness receive poorer quality pain management from their health care providers, including less pain assessment and less pain treatment.
- → Black patients with serious illness report poor-quality clinician-patient relationships and communication.
- → Compared to other racial groups, Black patients living with serious illness tend to use more high-acuity care and have more care transitions at the end of life.
- → Black Americans frequently incur higher medical costs during serious illness and provide more unpaid family caregiving than other families.
- → Compared to white patients living with serious illness, Black patients are less likely to have advance care planning (ACP) discussions or documents.
- → Mistrust of the U.S. health care system may influence the decision-making of Black patients with serious illness and their loved ones.

As health equity champions, we have the opportunity—and the imperative—to consider our roles in addressing inequities for the Black patients with serious illness that we serve in our own programs, organizations, and communities. Each of us can make a difference.

Who Should Use the Guide?

This guide is written for palliative care leaders who aim to provide more equitable care for Black patients and families in their communities, as well as non-palliative care health equity champions focused on Black patients with serious illness. The guide draws on examples of health equity interventions from all care settings and types of health care organizations.

As health equity champions, we have the opportunity—and the imperative—to consider our roles in addressing inequities for the Black patients with serious illness that we serve in our own programs, organizations, and communities. Each of us can make a difference.

Key Terms Related to Health Equity

Throughout the guide CAPC references the following key terms, which are important for all health equity champions to understand. Below we provide definitions from the AMA and CDC.

Health Equity	The state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires ongoing societal efforts to: > Address historical and contemporary injustices > Overcome economic, social, and other obstacles to health and health care > Eliminate preventable health disparities
Health Inequity	Differences in health outcomes that are systematic, avoidable, unnecessary, unfair, and unjust.
Racism	A system of structuring opportunity and assigning value based on phenotype ("race"), that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources. Racism can operate at different levels: structural, institutional, interpersonal, and internalized.
Social Determinants of Health	The underlying community-wide social, economic, and physical conditions in which people are born, grow, live, work, and age. They affect a wide range of health, functioning, and quality-of-life outcomes and risks. These determinants and their unequal distribution according to social position result in differences in health status between population groups that are avoidable and unfair.

Getting Started

If you have not had the opportunity to learn about the historical drivers of current-day inequities for Black Americans, we recommend reading the supplement to this guide before you continue to Chapter 2. The supplement, *Historical, Structural, and Social Drivers of Health Care Inequities*, contains important information and context for health equity champions, including:

- A timeline of historical events that shape the experiences of Black Americans today, starting with the transatlantic slave trade, through major cultural trends and legislative milestones, to contemporary health care outcomes
- A history of medical malpractice and abuse that contributes to present-day disparities and mistrust of the health system
- Examples of current health disparities for Black patients with serious illness
- A public health framework for understanding the factors that shape equitable or inequitable care, from the interpersonal to the societal levels
- An exploration of social determinants of health, including adverse childhood events

The concepts in this supplemental resource are foundational for the design of a health equity initiative. Discussing these concepts as a team will help to ensure that all the people involved with the design and implementation of your initiative have a shared baseline understanding.

CHAPTER TWO

Patient Engagement: Health Equity’s North Star

“**Nothing about us without us**,” a mantra first used in health care among disability rights activists in the 1990s, has since been adopted by many patient advocacy groups.

If you are inspired to engage in health equity work, the first and foundational step to designing a health equity intervention is to seek out and listen to the voices of the patients you aim to serve. Patient and community buy-in are not “nice to have”. They are essential for progress in equity work, especially for populations that have historically been silenced or oppressed.

Engaging patients in the planning process of your health equity initiative will help you to:

- **Understand what drives negative and positive experiences for the people you want to serve**
- **Understand your patients’ historical relationships to your organization or service**
- **Clarify the goals of your health equity intervention**
- **Get feedback on effective, sustainable strategies to achieve your goal of providing equitable care**

While published studies about the experiences of Black patients can and do guide us, the reality is that a) available research is not comprehensive, and b) it was likely not done in your community, with your patients. Remember that the Black community is incredibly diverse. Every individual, organization, and community has unique characteristics and needs. If you are planning a health equity intervention, there is no one-size-fits-all approach. Engaging patients early and often in the design of a health equity intervention will help you tailor your efforts to meet the expressed needs of the community you serve.

An Example: In 2021 CAPC conducted a literature review to characterize the experiences of Black patients with serious illness. While the papers we found pointed to disparities (e.g., in the quality of clinician communication and pain management) that are prevalent and very important for clinicians to be aware of, very little had been published on how the social determinants of health affected Black patients. When we next conducted focus groups with patients and caregivers, the key theme they raised was financial toxicity—that the costs associated with being seriously ill were a burden for families.

What can we take from this discrepancy between what has been studied, and what was most important to the particular Black patients and families that participated in our focus group? We can’t know what is most important to our patients without asking them.

We can’t know what is most important to our patients without asking them.

What kinds of information might you learn when you engage patients? In a focus group of Black patients conducted by CAPC staff, participants reported experiences such as:

- **Not being believed when they reported pain.** One interviewee recounted how her doctor repeatedly dismissed her concerns about pain while she was suffering from neuropathy during cancer treatment. ***"Any medication I could limit I would. I didn't want to pop another pill. Pain management was so frustrating because pain is something they cannot see, but because I look ok and push through, it doesn't mean I'm not in pain."***
- **Not feeling listened to.** Another focus group participant with multiple myeloma that caused bruising shared, ***"I went to the hospital because I wasn't feeling well. They saw bruises on me and thought I was a domestic violence victim and that I was protecting someone. I kept telling them I had not been abused and asked them to run tests. The doctor got upset and tried to pressure me into saying I was being abused."***
- **Changing their behaviors in the hopes of getting better care.** Focus group participants described dressing up to go to the doctor or suppressing frustration for fear of being perceived as aggressive. ***"I was told, 'You don't look sick.' But why should I have to prove to you that I have all of these issues from my cancer diagnosis? How does one look sick? A lot of us don't want to speak up because we fear that we will be treated worse."***
- **Facing barriers to care.** Participants recalled not having time, transportation, or money to get medications prescribed by their doctors, or encountering local pharmacies that don't carry medications that are commonly prescribed to patients with serious illness.

These examples highlight that you need to understand what your patients are experiencing, and what is happening in your community, so your health equity work is responding to the real problems and opportunities that matter to the people you serve.

How to Engage Patient, Caregiver, and Community Voices

Before you proceed in the design of your health equity intervention, reflect on the following questions:

Am I addressing a need that my patients or the community have genuinely expressed, or am I designing a solution based on what I think is right?

How will I actively seek feedback and guidance from my patients or from the community I am serving?

Am I willing to adapt my ideas to reflect what I learn from patients?

Health equity work takes humility, which means listening to voices that aren't always heard, and co-designing solutions with the experts on the needs of the Black patients in your community: patients themselves. There are many approaches for involving patients and caregivers in the design of equitable care models, but the goal is always to emphasize collaboration, empowerment, and the inclusion of diverse perspectives. For example:

Find out whether your organization already has a PFAC that can be a partner in your health equity work.

- **Patient and Family Advisory Councils (PFACs):** PFACs are organized groups of patients, family members, and caregivers who collaborate with health care institutions to provide input and feedback on policies, programs, and quality improvement initiatives. These councils help ensure that the patient and family perspective is integrated into decision-making processes within health care organizations.
- **Community Partnerships:** Building relationships with community leaders and organizations enables you to learn about community dynamics that affect Black patients, and to engage patients through a trusted community entity. The Centers for Disease Control & Prevention (CDC) provides practical guidance on community engagement. Potential partners for community engagement in the design of your initiative include Federally Qualified Health Centers (FQHCs), faith groups, or other entities that work with and are trusted by the Black patients in your area. The most important principle for engaging community-based organizations as partners is to be humble, respectful, and take care to align with their work and their priorities.
- **Community-Based Participatory Research (CBPR):** CBPR is a collaborative research approach that involves partnerships between researchers and communities. In health care, it can involve patients, caregivers, and community members in all phases of research, from defining a problem to testing a solution. CBPR has been used in palliative care to design culturally responsive services for specific patient populations, and is an effective strategy for engaging patients in the design of a formal care redesign project.

CHAPTER THREE

Promising Models: A National Scan for Health Equity Initiatives Focused on Black Patients with Serious Illness

The Social Ecological Model: What Contributes to Lower-Quality Serious Illness Care for Black Patients?

The Social Ecological Model (SEM) is an established model in public health used to understand health outcomes—in this case, disparities among Black patients with serious illness.

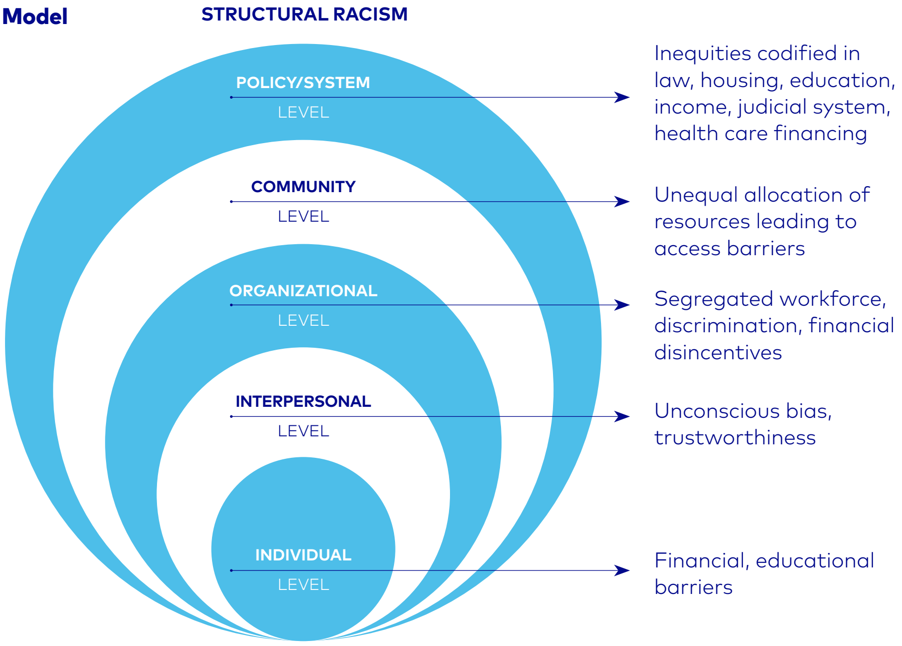
In a 2022 CAPC webinar, Dr. Kimberly Johnson, Professor of Medicine and Director of the Duke Center for Research to Advance Healthcare Equity, provided a comprehensive analysis of the SEM as it pertains to the experiences of Black patients within the health care system. Dr. Johnson utilized the SEM to illustrate how various factors at each level contribute to lower quality serious illness care for Black patients, underscoring the pervasive impact of structural racism. She emphasized that racism operates across all levels of the health care system—individual, interpersonal, organizational, community, and policy/system—often intersecting and overlapping to create significant disadvantages in achieving optimal health and well-being.

Examples shared in the webinar for each level of the SEM in the context of health care include:

- **Individual:** Black patients and families may have financial or educational barriers or may mistrust the health system based on personal or family history.
- **Interpersonal:** Interactions between patients and health care providers may be influenced by unconscious bias or discrimination, adversely affecting health outcomes for Black patients.
- **Organizational:** The "segregated workforce" refers to the underrepresentation of Black health care providers in the U.S. In her webinar, Dr. Johnson shared research indicating that a racially concordant health care workforce can improve outcomes for Black patients.
- **Community:** Unequal allocation of resources leads to disadvantages for Black communities. In the context of serious illness, this may mean lack of access to specialty palliative care within predominantly Black neighborhoods.
- **Policy/System:** Structural racism, embedded in health care policy, results in inequitable access to high-quality care.

Why does this matter? By understanding how each level interacts, we can create a more inclusive and equitable health care system that provides Black patients with equal opportunity to achieve optimal health and well-being.

Social-Ecological Model



In 2021, CAPC conducted a national call for information about health equity interventions focused on improving quality of life for Black patients with serious illness, and their families. A total of 144 initiatives were submitted, spanning a wide variety of organization types, geographies, and care quality improvement goals. In this chapter we describe the most common types of health equity interventions that were identified and offer several case studies that illustrate the powerful impact of this work for Black patients and families.

As you read about the types of health equity interventions being implemented across the country, pay attention to the goals of each intervention, and which level (or levels) of the SEM they seek to influence.

Common Focus Areas for Health Equity Interventions

The majority of the 144 health equity interventions submitted to CAPC fell into one of several common categories. This chapter contains descriptions of these intervention categories, along with detailed case studies of the work that several organizations are doing to improve care quality for Black patients with serious illness. While by no means comprehensive, we hope this spotlight on the work already being done across the country will inspire ideas about health equity initiatives that could make a meaningful impact in your own institution and community.

Data Collection and Patient Identification

As with any quality improvement or care redesign initiative, health equity interventions require an understanding of which patients you are focusing on for quality improvement, and the problem you aim to address. Several projects from CAPC's environmental scan began with a review of patient data to analyze health care access and utilization by racial group. Where the data showed differences between health care received by Black patients and other racial groups (e.g., whether patients received palliative care, hospice, or high-quality symptom management) equity champions could begin to look deeper at the cause of the disparities (which level of the SEM and which factors influence equitable care). Once an equity initiative is implemented, these data can be used as the baseline against which progress is measured.

For example, the palliative care team at Hackensack University Medical Center in New Jersey reviewed the records of patients with Sickle Cell Disease (SCD) and discovered inconsistencies. Some patients were treated by the pain service, while others were seen by the palliative care team, where they received more comprehensive and customized services to improve quality of life. The team used these data to successfully make the case for a standardized palliative care referral for all patients with SCD.

Improving Knowledge and Use of Palliative Care and Hospice

Do Black patients in your community know what palliative care and hospice are, and do they have equitable access to services? Many of the health equity interventions submitted to CAPC focused on answering these questions, using a variety of community engagement strategies to reach Black families in their areas:

- → After identifying low utilization of palliative care and hospice in one predominantly Black zip code, a community-based health care organization in Kentucky convened an advisory committee of community representatives to explore barriers to accessing care.
- → A California health system developed and tested a brochure featuring the stories of Black hospice patients in their community to raise awareness of the benefits of hospice for patients and families.

Palliative care, hospice, and other teams across the country are using a variety of creative approaches to raise awareness about their services, including hosting education workshops in partnership with trusted community organizations, providing training to primary care teams that serve predominantly Black populations, and building patient information resources featuring voices from the community they aim to serve. These ground-up strategies aim to influence a patient's likelihood to ask for, or accept, supportive services, and are focused on the Individual Level of the SEM. In other instances, health equity champions work to establish standardized triggers for palliative care referrals, to ensure that Black patients have equitable access, and that individual clinician bias does not influence whether a patient is offered palliative care. These interventions target the Organizational Level of the SEM.

Staff Education and Workforce Diversity

The second level of the SEM is the Interprofessional Level. This is the level at which an individual clinician's attitudes, beliefs, and biases can impact their patient interactions and care decisions. Many of the interventions submitted through CAPC's environmental scan focused on this domain, whether the intervention aimed to impact clinician behaviors through education, or to improve the diversity of clinical teams to be more concordant with their patient populations.

- The pediatric palliative care team at Seattle Children's Hospital harnesses the power of storytelling to educate their clinical staff, starting daily rounds with an "equity story." Their monthly interdisciplinary team meeting includes a longer discussion (usually with a case study) about equity and access issues that their patients may experience.
- Hospice of the Chesapeake in Maryland reallocated resources to recruit Black clinicians to its supportive care and hospice teams, improving racial concordance and building rapport among Black patients in its community.
- The University of Alabama at Birmingham developed African American Communities Speak, a skills-based training program to build empathy, shed light on biases, and guide behavior change among clinicians.
- Several respondents provide cultural competency training for their teams to bridge gaps in understanding and improve patient-clinician relationships.
- The Chrysalis Initiative, in addition to providing direct education and coaching for Black women with breast cancer, offers training for oncology clinicians on the unique needs of patients who are vulnerable to disparities. Chrysalis also offers services to health systems, including apps to assist with disease education and patient empowerment, and health equity assessments.

Faith-Based Initiatives

Research suggests that Black Americans are more likely to identify as religious, and attend church at higher rates than the overall population. Health equity efforts that recognize and address Black patients' spiritual needs, or that seek to engage patients and families through faith groups, can be powerful strategies for promoting better health outcomes for Black patients. As trusted and influential institutions, Black churches and their leaders have a long history of providing resources, education, and support to their communities, making faith communities a natural community partner for health equity work. Faith-based initiatives focus on the Community Level of the SEM.

Some health equity interventions reported to CAPC include:

- **Health Ministry Programs:** Partnering with Black churches and religious organizations to engage faith community members with information about palliative care and advance care planning. For example, the Louisville Community Model of Care Project is working to address care disparities through a partnership among local faith leaders, national advocacy organizations, and payers.
- **Spiritual Care:** Incorporating spiritual support services across health care settings to address the spiritual needs of Black patients and their families.

Community Health Worker and Care Navigator Models

The American Public Health Association (APHA) defines a Community Health Worker (CHW) as "a frontline public health worker who is a trusted member of and/or has a close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health care providers and the community to facilitate access to services and improve the quality and cultural competence of service delivery." With their connection to the community, CHWs can help bridge the divide between the medical system (or insurance providers) and marginalized communities.

Several of the health equity interventions submitted to CAPC employed CHWs or patient navigation services to liaise between Black patients and their health care teams or community services, and to be a trusted voice providing patients with practical information and resources. One initiative, Project Cornerstone, led by the University of Alabama at Birmingham, pairs lay navigators with the caregivers of Black cancer patients, to deliver telephone coaching sessions on stress management and caregiving skills.

Caregiver Needs

A large and ever-growing evidence base suggests that being a caregiver—while often a cherished role—can have negative psychological, social, and even physical consequences for caregivers. We also know that the availability and well-being of caregivers, located at the Interpersonal Level of the SEM, has an impact on the well-being of patients themselves. Among the health equity interventions reported to CAPC, the following strategies were used to support caregivers of Black patients with serious illness:

- **Needs Assessment:** The DC Coalition to Support Caregivers hosted listening sessions for caregivers in Ward 7 of the District to gain insights on their needs and concerns.
- **Caregiver Support Services:** One organization provides listening and empathy training geared toward the needs of Black caregivers who are considering end-of-life care decisions. The training includes the use of documentaries showing circumstances under which decisions must be made by a health care proxy and information to support shared decision-making.
- **Respite Care:** Providing respite care services to give Black caregivers a temporary break from their caregiving responsibilities.

Addressing the Social Determinants of Health

A 2017 literature review found that social isolation, concerns about burdening others, and a lack of financial resources were prevalent among Black patients living with serious illness. To address these and other social issues, the team at Ascension Health implemented a systematic social determinants of health screening and resource referral process.

Note that while social determinants of health (SDOH) have been recognized as a critical contributor to health and well-being (as seen in the Policy/Systems Level of the SEM), there are still widespread gaps in access to, or payment for, resources that would address SDOH. Patients enrolled in Medicare Advantage plans may have access to non-traditional benefits that address social needs (such as transportation or meal delivery). Some health equity champions are able to secure philanthropic support to address patients' social needs, either by working with their organization's development office or by partnering with local foundations.

Hospice of the Chesapeake: Reallocation of Organizational Resources to Improve Access to Palliative Care for Black Patients in Maryland

Overview

Hospice of the Chesapeake recognized that Black communities within its service region were underrepresented on its palliative care service. In response, it reallocated resources and staffing to provide culturally responsive care for Black patients, delivered by Black clinicians. Since January 2017, its Hospice and Supportive Care service line has remained committed to increasing access to care for Black people living with serious illness. This commitment also included an increase in staffing, particularly advanced practice nurses and social workers, to better meet the needs of this traditionally underserved population.

Impact and Outcomes

As a result of their changes, Hospice of the Chesapeake saw a significant increase in palliative care patients who identify as Black or African American. Through intentional and strategic outreach efforts, it has also enhanced relationships and partnerships with trusted community leaders and organizations, in order to provide education and raise awareness. These relationships have resulted in an improved understanding of both palliative care and end-of-life care within these communities. One method of accountability for Hospice of the Chesapeake's efforts is the distribution of care quality surveys to patients, which track whether patients feel their concerns are heard and addressed. Team members present results from these surveys to a monthly internal Quality Group for recommendations on program improvements. Hospice of the Chesapeake has also been able to demonstrate impact on hospital readmissions for its palliative care patients.

Feasibility

Hospice of the Chesapeake was able to implement this initiative due to several key factors:

- Prioritization: Organizational leadership stands behind the mission to address disparities in access to its services (as demonstrated by providing internal funding), paired with external philanthropy
- Continuous analysis of demographic and additional data to assess the best tailoring of its services within various communities
- Prioritized recruitment and retention of Black staff that reflect the Black community it serves
- The implementation of a new Electronic Health Record (EHR) system, which provided a patient portal for ambulatory palliative care services within two campuses. *(Note: Hospice of the Chesapeake secured philanthropic funding to implement the new EHR)*

> To build bridges in its communities, Hospice of the Chesapeake created a team of ambassadors tasked with building key community relationships.

Scalability

The supportive care service's staffing model is designed to use staffing resources efficiently. It relies upon advanced practice provider (APP) leadership, with nursing, social work, and coordinators rounding out teams.

During the pandemic, the supportive care program incorporated telehealth into their palliative care services to increase access and efficiency.

To build bridges in its communities, Hospice of the Chesapeake created a team of ambassadors tasked with building key community relationships.

Sustainability

Hospice of the Chesapeake aims to develop financial partnerships with payers and health systems to care for high-need patients in the communities they serve. Strategies that have been key to their effectiveness, and to delivering on metrics important to financial partners, include the recruitment and retention of a diverse team, as well as targeted outreach and relationship-building with key community leaders/organizations, including various faith-based institutions.

Key Advice

- Put yourself in your patients' shoes. Be intentional about assessing community/patient demographics and needs, and tailor your services accordingly.
- Do not simply replicate staffing models for all locations. Staffing and services should reflect the communities you serve.

Case Examples: Health Equity in Action

AC Care Alliance: An Advanced Illness Care Program Utilizing a 'Five Cornerstone' Approach in California

Overview

Research confirms that there are numerous benefits to utilizing care navigators in health care interventions, especially for Black people diagnosed with a serious illness. The AC Care Alliance created the Advanced Illness Care Program (AICP) to address the unique needs of this population, addressing serious illness care disparities in communities of color and advancing equity. The program builds on the confidence and trust that Black churches have gained in communities of color that may be distrustful of the health care system. Developed in 2013 with input from pastors, congregants, health systems, community groups, and national organizations, the AICP addresses the advanced illness care needs of diverse community members in alignment with their spiritual and religious values and preferences. In this model, care navigators are members of the communities they serve, trained in community outreach and holistic advanced illness care wraparound support. Acknowledging that a serious illness diagnosis affects the totality of a person, the AICP model uses a Five Cornerstone approach, which includes:

- **Spiritual needs**
- **Health needs**
- **Planning for advance care**
- **Social needs**
- **Caregiving needs**

Care navigators build trusting relationships with program participants who have advanced illnesses, and their caregivers. Through a series of meetings and phone calls over approximately six months, the care navigator helps participants meet their advanced illness care needs by providing trusted resources and referrals, as well as tools and training to promote participant empowerment and specific coping skills (e.g., communicating effectively with their primary care providers). Care navigators help participants improve their skills for accessing appropriate care, both within the health care system and from social/non-medical services in the community.

Impact and Outcomes

Per evaluation work led by the UC Davis Betty Irene Moore School of Nursing, implementation of the AICP led to:

- 1,400 people served since 2016
- 3.5 average referrals to social service providers by care navigators per participant
- 53% of visits had caregiver needs addressed
- 55% of participants completed an advance directive (compared to 15% national average)
- Trained care navigator workforce reporting high satisfaction in training and work

See full details of the program's impact.

Partnerships, particularly those between health care organizations and the faith community, are essential to the success of the program.

Feasibility

Two prerequisites for this program model are ensuring engagement with the community and building trusting, bidirectional organizational partnerships:

- Those who plan to implement a similar model must be committed to providing community support, engaging with community-based organizations, and deeply understanding both the gaps and assets of the target community.
- Trust between faith-based organizations, community members, academic institutions and the health systems must exist for any such program to operate. Partnerships, particularly those between health care organizations and the faith community, are essential to the success of the program.

Several respected faith leaders were part of the planning, implementation, and evaluation phases of the model. Health systems were also engaged to ensure that the medical/health component of the model is comprehensive.

Scalability

The AC Care Alliance has worked with multiple funders to design and test the AICP model, with a lens toward scalability. The Alliance has been developing technical assistance and other resources (e.g., their care navigator curriculum and training program) to bring additional partners into its local network. IT/data expertise, access, and integration is also essential to support care coordination and ensure compliance with HIPAA and other requirements. To date, the program has successfully expanded to counties in northern California, and leadership is working to scale and expand the model to reach more Black people and Latino communities nationally.

Sustainability

The AICP model has been largely funded through philanthropic support but is beginning to develop experience in identifying and connecting with local payers.

Key Advice

- Meaningful, trusting collaboration, particularly centering the voices and expertise of others, is the crux of this model. If developed from the faith community, strong pastoral and congregational leadership is essential.
- Community leaders, health partners, faith leaders, and academia should all be deeply committed and passionate about collaboration for the greater good.
- Telling stories is powerful. By using both storytelling and "story listening" care navigators can build trusting relationships, learn participants' concerns, and tailor the AICP to meet their needs.

Case Examples: Health Equity in Action

University of California
San Francisco

Dedicated staff time for data collection and review is critical to the sustainability of this initiative.

University of California, San Francisco (UCSF): Data Collection to Increase Palliative Care Clinic Visits by Black and Latino Patients in California

Overview

Data collection is a powerful tool in helping programs gain a better understanding of whether they are reaching patient populations equitably. When the UCSF outpatient palliative care team began reviewing its data with a more intentional equity lens, it discovered that Black and Latino patients were less likely to make initial and follow-up appointments compared to white patients. To address this, the team conducted 18 listening/qualitative interview sessions with Black and Latino patients and/or their caregivers to better understand the 'why' behind the disparities within their community. The team used the programmatic and qualitative data to create quality improvement projects, including incorporating intentional care team behaviors and actions to improve inclusivity and trust with these communities.

Impact and Outcomes

After conducting the series of listening sessions, the team learned that the palliative care team's makeup of interdisciplinary team members who demonstrated interest in, and respect for, patients' and care partners' backgrounds engendered trust. The team is also able to evaluate impact, including ongoing monitoring of the percentage of referrals and follow-up visits broken out by racial and linguistic backgrounds; and they will continue to collect qualitative data on patient satisfaction.

Feasibility

The UCSF palliative care team collaborated with the organization's IT team to create a dashboard to track and monitor this essential data over time. The data review component of this initiative is relatively straightforward to implement, although focus groups require additional time and resources. Palliative care programs should regularly examine their data to understand the population they are serving, and programs that have IT support may be able to create a similar dashboard. Other valuable internal partners in this work may include researchers, statisticians, and health equity experts.

Sustainability

Dedicated staff time for data collection and review is critical to the sustainability of this initiative. Additional funding and staff time will likely be required to conduct listening sessions, and staff may need training to do this work.

Key Advice

- Use data to analyze the current state of the program's patient reach. For qualitative information, consider adapting a script like USCF utilized to learn from patients and caregivers.
- Implementation always takes longer than expected. Build in additional time.
- Be a good collaborator. Regularly engage your colleagues who have a stake in the work, and ask for honest feedback.

Policy Tailwinds for Health Equity Work

Racial inequities are well-documented across U.S. health care and were made even more visible during the COVID-19 pandemic. Policy efforts to address disparities and build toward more equitable health care have accelerated in recent years. In its strategic plan, the Centers for Medicare & Medicaid Services (CMS) articulates how each CMS Center and office is building health equity into its core work to improve the experiences and outcomes of historically marginalized patients across Medicare and Medicaid programs. Though just a start, these efforts signal a shift in the health policy landscape toward greater prioritization of health equity.

Guiding an Improved Dementia Experience (GUIDE) Model

In 2023, CMS announced the voluntary nationwide *Guiding an Improved Dementia Experience (GUIDE)* Model, which aims to support people living with dementia and their unpaid caregivers. The GUIDE Model launched in July 2024 with 390 participating sites and will run for eight years.

Model Overview

People living with dementia often have multiple chronic conditions and receive fragmented care, leading to high rates of hospitalization and emergency department visits. The GUIDE Model offers a standardized approach to care, caregiver training, education, and support services, with the goal of allowing people living with dementia to remain safely in their homes for longer.

GUIDE focuses on dementia care management and seeks to improve the quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable individuals with dementia to remain in their homes and communities. It achieves these goals through a comprehensive package of care coordination, caregiver education and support, and respite services.

Alignment with Health Equity

Per the CDC, 14% of Black individuals in the U.S. aged 65+ live with Alzheimer’s disease, compared with 10% of white Americans in the same age group. This disparity is likely underestimated due to the prevalence of misdiagnosis among Black people. Projections indicate a fourfold increase in Alzheimer's cases among Black Americans by the year 2060, highlighting the urgency of addressing and rectifying the existing health care disparities.

The GUIDE Model aims to improve health equity by:

→ Requiring social needs screening and referrals

→ Providing financial and technical support to develop new dementia care programs in underserved areas

→ Requiring annual reporting on progress toward health equity objectives

→ Analyzing national data to identify disparities

→ Providing higher payments (an “equity adjustment”) for underserved beneficiaries

Medicare Payment for Lay Navigators

CMS's 2024 Medicare Physician Fee Schedule includes groundbreaking measures such as reimbursement for patient navigation services. These changes underscore a commitment to improving health care access and equity, with the aim of making these essential services widely available to those who can benefit.

Dr. Karen E. Knudsen, CEO of the American Cancer Society and American Cancer Society Cancer Action Network (ACS CAN), commended this development, emphasizing its importance in achieving the President's Cancer Moonshot goals of cancer health equity.

Putting It All Together

The more than 144 initiatives submitted to CAPC from across the country—all aiming to achieve more equitable care for Black patients with serious illness—tell us that change is possible. Health care teams and organizations of all types and sizes are taking action to ensure that Black patients receive the care that every patient deserves when they are diagnosed with a serious illness, and inspiring others to do the same.

In Chapter 4, you will find the practical guidance you need to translate these ideas into action within your health care organization.

CHAPTER FOUR

Getting Started: Planning Your Health Equity Initiative

Having learned about health disparities for Black patients with serious illness, and the many efforts underway across the country to address those disparities, you may be wondering: **How do I take action in my organization, and with my patients? Where do I start?**

Whether you're starting small or planning a major initiative, the key principles are the same: keep your patients at the center of the process, listen to what they tell you is important, and find partners who share your goals. While an enormous amount of creative work is being done across the country to improve equitable care for Black patients, remember that health equity interventions do not have to be new or flashy. They can be as straightforward (though not simple!) as expanding your operations to an underserved zip code or changing an existing organizational policy to make it more equitable.

Whatever your goal, CAPC recommends taking a structured approach to health equity work, just as you would when considering a new care program or service expansion. Any equity initiative will be more successful if you include the appropriate partners in your planning process at the onset, develop a clearly articulated goal, have a plan for measuring progress, and map out the resources you will need to implement the initiative. In this chapter we outline the core processes for designing your health equity intervention:

- **Needs assessment**
- **Intervention design and partnership development**
- **Business and operational planning**
- **Making the case for funding or support**
- **Data collection and evaluation**

Identifying the Need and Understanding Opportunities

The first step in designing a health equity intervention is conducting a needs assessment. The needs assessment is a process of systematically collecting and analyzing both internal and external information to determine:

- → The service or quality gap you aim to address
- → The priorities of your patients, your partners, and your leadership
- → Your readiness to proceed with the design and implementation of a health equity intervention.

Through the needs assessment process, you will gain a better understanding of your opportunities to provide more equitable care and the resources you may be able to tap into.

A needs assessment is a systematic process for identifying the gaps ("needs") between current conditions and desired conditions. An essential first step in your planning process, the needs assessment helps you clarify problems, build relationships with key partners, and identify appropriate solutions.

What Am I Looking For?

The needs assessment can help you identify and characterize:

- → **Barriers to receiving care:** While some disparities occur at the point of care delivery, there are communities that struggle to access care at all due to barriers such as lack of insurance coverage, language services, location, income, or immigration status.
- → **Health services or outcome disparities:** Do Black patients served by your organization receive the same services (e.g., documented goals of care/advance care planning, palliative care referrals, symptom management) and have similar outcomes to other patient populations (e.g., ED visits, patient or caregiver satisfaction, hospice utilization)?
- → **Patient population congruence:** Does your program's patient population match the demographics of the community?
- → **Staffing congruence:** Do the demographics of your clinicians align with the demographics of the patients you serve?

You may discover a number of disparities throughout the course of your needs assessment. Some will require top-down (e.g., federal or state policy) solutions, while others may be influenced by your team or your organization's work. Some will require long-term strategies (such as staff diversity), while others may be implemented more quickly and directly (e.g., standardized palliative care referrals for all patients with Sickle Cell Disease). As you design your health equity intervention, you will need to evaluate what is feasible and what will have a meaningful impact on your patients.

What Information Do I Need?

We recommend collecting three types of information during the needs assessment: quantitative data, qualitative data, and information about your partners' and leaders' priorities.

Quantitative Information: The measurable data that tells you who you're serving, how you're serving them, and how well (quality).

- → Recall the UCSF outpatient palliative care team's [project]() to analyze their patient visit data by race. This allowed the team to establish a baseline for measuring progress and explore the reasons why Black patients referred to their service were less likely than white patients to schedule initial and follow-up visits.

- → Depending on your access to data and data analytics, reviewing a sample of patient charts to examine service delivery or documentation is another option for gaining a better understanding of the care your Black patients are receiving.
- → CAPC provides an in-depth community assessment tool for palliative care programs to help collect and draw insights from publicly available data about demographics, social determinants, and other factors influencing patients in your locality.
  - Many health care organizations regularly conduct community needs assessments to understand the factors driving health outcomes in their area, and opportunities for improvement (see an example from Seattle-area hospitals). If you are part of a large organization, check to see whether this information already exists.

If you are part of a large organization, check to see if a community assessment has already been done.

Example: After reviewing internal data, you notice there are significant racial disparities in palliative care utilization for Black patients who were referred to your consult service. The data showed that although 10% of Black patients were referred to your inpatient palliative care program, only 2% completed follow up visits. With this data in hand, you have identified an opportunity for improvement. You are ready to move on to the next step: examining the reasons why Black patients who received a referral were less likely to enroll into your palliative care program.

Qualitative Information: Descriptive (not measurable) data helps you understand your patients' experiences and the factors that contribute to their quality of life or the quality of their health care interactions. While quantitative information tells the extent to which something is happening, qualitative information can better help you understand why it is happening.

- → Recall Chapter 2, "Patient Engagement." Your patients are the experts of their own lived experiences. If your data points to disparities in access or care delivery to Black patients, the next step is to engage patients themselves to learn more about why and how these disparities exist.
- → Methods to engage patients in your needs assessment include:
  - Working with your organization to identify existing mechanisms to learn from patients (e.g., patient and family advisory committees or patient ambassador programs)
  - Partnering with trusted community entities to hold a listening session about patients' health and health care experiences
- → Themes that may emerge from qualitative data include:
  - Interpersonal interactions with clinicians (e.g., whether Black patients feel respected and listened to)
  - Social determinants that compound suffering or make it difficult to access care, such as pharmacy deserts or inability to pay co-pays
  - Mismatches between how program resources are allocated and what is most important to patients and families

Priorities of Your Leaders and Partners: Factors that will influence the success of your health equity initiative, including the current strategic priorities of your organization, and the needs and pain points of potential collaborators.

You will need the support or approval of specific decision-makers and collaborators to launch your health equity initiative. Think about who these people or groups are, get to know what matters to them, and whether your work can help solve their problems. These people or groups may include:

- Patients and families
- Executive, financial, operational, or clinical leaders in your organization
- Community organizations, including health or social service providers, faith leaders, Area Agencies on Aging, and others

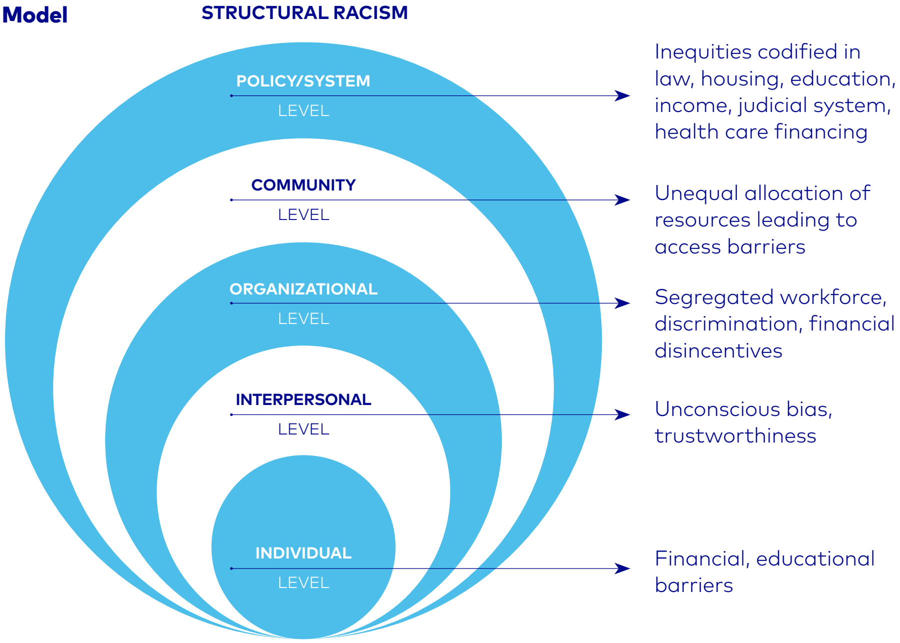
Keep in mind, the most sustainable way to practice health equity is to align your work with organizational or team goals. This might mean helping your organization achieve its targets on a particular quality measure or addressing a need identified by a community partner that serves Black patients.

Intervention Design and Partnership Development

You've collected data, learned from patients and caregivers about their experiences, and had meetings with leadership about their strategic priorities. Now what?

Let's return once again to the SEM.

Social-Ecological Model



In your needs assessment, you may have identified disparities that sit within one or more of the levels of the SEM. While every level of the SEM has an impact on patient experiences, the center circles—Individual, Interpersonal, Organizational—are those you are most likely to be able to influence. Consider the examples in the following table.

Problem	SEM Level	Potential Intervention
Black patients decline palliative care consults at higher rates.	Individual	Collaborate with a trusted community organization that serves Black patients to disseminate information about palliative care and dispel misperceptions about what palliative care is and is not.
Black patients are referred less often than white patients for palliative care consults.	Interpersonal and Organizational	While this problem may stem from interpersonal factors (individual clinicians' decisions whether or not to refer their patients), a solution at the organizational level (standardized triggers for palliative care referrals) may be the most effective strategy to remedy a disparity in palliative care access.
Black patients report that they cannot fill prescriptions for pain medications, because the neighborhood pharmacy doesn't carry them.	Community	Black patients are more likely than white patients to live in pharmacy deserts, or near pharmacies that do not carry opioids or other medications commonly prescribed to patients with serious illness. While it's unlikely you can directly influence your patients' pharmacy access, you can implement workflows to double-check that your patient's pharmacy carries the medication you plan to prescribe or help connect your patient with medication delivery services.

As you consider which problem you aim to solve, and how you will solve it, look for the overlap between what will make a meaningful impact for patients, what is feasible for you to implement, and what will help you get buy-in from your organizational leadership and potential external partners. As one example of how to organize and prioritize opportunities to advance equitable care, the Tacoma-Pierce County Health Department uses a Health Equity Planning Assessment Tool.

Partnership Development

Most health equity initiatives require, or significantly benefit from, partnerships. As you drill down into the design of your health equity intervention, think specifically about resource requirements, workflows, and measurement strategies. Consider the potential partners and goals listed in the following table.

Goal	Potential Partners
Obtain and analyze quantitative data	> Your organization's IT and/or data analytics team > Your organization's Office of Diversity or Equity (may have access to data, have already analyzed organizational data, or be able to help you draw insights from your program's data)
Reach Black patients in your neighborhood/community with information	> Trusted community organizations, including community centers or local libraries, faith communities/churches
Address social determinants of health affecting your patients	> Community service providers, including Area Agencies on Aging, transportation or meal delivery services, friendly visitor programs > Local philanthropies > Community or town/city government
Improve access or coordination of health care services	> Clinical leaders from in or outside of your organization (e.g., potential referrers or clinical collaborators, CHW programs, hospice or home health agencies)
Increase diversity of the care team	> Local teaching institutions and diversity pipeline programs Historically Black Colleges and Universities (HBCUs) or clinical education institutions

A core principle for establishing partnerships is to focus on mission alignment. If you have identified a potential partner that you believe could help your health equity initiative achieve meaningful results, ask yourself:

Do their goals align with mine?

Do my services meet an expressed need of theirs?

Chances are, your potential partner is juggling many priorities and working with limited resources, just like you are. Approach any new relationships with humility and respect, and be able to articulate how a potential collaboration is mission-aligned for both partners. When you engage a potential partner, seek their feedback on the design of your project or intervention. Be explicit about what you're asking (e.g., duration, roles and responsibilities, hoped-for outcomes).

For a deep dive on how to operationalize partnerships with external entities, see CAPC's Health Equity toolkit.

Business Planning

Once you've identified what you want to do to improve equitable care for Black patients, and who your partners are, it's time to plan. The process of writing a business plan will help you think through the details of the design of your health equity initiative and will be invaluable if you eventually seek philanthropic support for your work.

After defining your goal, ask yourself the "**why, who, what, when, where, how, and how much**," of your equity initiative.

WHY
Why do you expect your planned health equity initiative will have meaningful impact? Is the initiative aligned with your team and your organization's values? Why is now the right time to start?

WHO
Who is responsible for the various aspects of your planned initiative? This includes service delivery, but also communication, data collection and reporting, and other key roles.

WHAT
What services or processes are involved? How and where will you document them? Will you need materials (e.g., informational brochures or office supplies)?

WHEN
Consider both the milestones of your project plan, and the timing or availability of specific services or touchpoints (e.g., community meetings).

WHERE
Will you need physical space to conduct patient visits or team trainings?

HOW
What resources (financial and non-financial) do you need for your health equity initiative? What expertise is needed for your team?

HOW MUCH
Think about scale as it relates to resource requirements and projected impact. This could mean frequency, volume, geographic area, etc.

Writing your plan will help you organize for action, whether you plan to start on a smaller scale or design a large-scale initiative. If your initiative requires additional support, the plan will form the basis of a formal proposal you can take to your leadership, partners, or philanthropists.

For Example: For a project to build cultural competency training with your team, your plan will include the specific curriculum you will use, how and when you will train staff (Lunch-and-learn sessions? A standing agenda item on the interdisciplinary team meeting?), and how you will collect feedback from staff about the training.

For a more resource-intensive initiative to implement a palliative care trigger to ensure equitable access for Black patients, your plan will include budget implications (e.g., clinical FTE), IT resource requests, referral pathways, and other core design elements.

For comprehensive business planning tools, including sample plans, visit CAPC's website.

Note: 2024 Medicare billing updates offer a reimbursement mechanism for services that align with some health equity initiatives, and that were not previously covered by Medicare. These include:

- Performing a social determinants of health risk assessment
- Community health integration services (including payment for community health workers)
- Navigation services
- Time spent educating caregivers

CAPC provides detailed guidance on how to bill for each of these services (who can bill, how to code for services, and billing requirements) in our billing toolkit.

Making the Case for Funding or Support

Securing buy-in from leadership or funders for your health equity proposal is a critical step in the process. It's not uncommon for health equity efforts to be met with initial resistance or indifference, so it's critical to approach this phase with careful strategy and a compelling proposal. Whether your audience is your CEO or a local foundation, the following guidance will help you put together a compelling case for supporting your health equity initiative.

1. Begin by clearly defining the specific health inequity issue you aim to tackle, underlining its significance in terms of human impact and societal consequences. Make a strong case for the intervention by articulating why current solutions fall short in addressing the problem effectively.
2. Present a well-thought-out solution that is both evidence-based and logically sound. Describe how your intervention will operate, who it will benefit, how it directly addresses the identified issue, and the reasons you believe it will be effective. Ensure your plan is feasible by detailing the required resources, including personnel, technology, and financial support, while also outlining strategies for overcoming potential obstacles.
3. Emphasize the expected measurable impact of your intervention. Employ both quantitative and qualitative data to illustrate how the project will advance health equity within the targeted population. Include specific metrics and benchmarks to help potential funders gauge the intervention's effectiveness. When possible, construct a persuasive cost-benefit analysis to showcase the economic advantages of supporting your initiative, highlighting potential long-term cost savings or enhanced economic productivity.

4. Demonstrate your readiness to engage in partnerships and collaborations, which can strengthen the success and sustainability of your intervention. Develop a comprehensive risk mitigation strategy to anticipate and address potential challenges. Create a clear timeline with specific milestones, allowing funders to track your project's progress over time. Present a detailed budget, transparently illustrating how the funds will be allocated to various aspects of the intervention.
5. Lastly, convey the urgency and significance of your health equity intervention in a compelling call to action, underscoring the importance of timely funding support in making a meaningful impact. Remember to tailor your approach to align with the priorities of each potential funder and maintain open communication to foster trust and secure their support.

Condense this information into a 1-2 page document structured in a SMART format, allowing the reader to grasp the basics of the project, including:

- Current disparity
- Research grounding your project
- Short summary of project
- Length of project
- Cost of project
- Projected impact
- Sustainability

SMART FORMAT
Specific
Measurable
Achievable
Relevant
Time-Bound

Delivering Your Pitch

- **Request a meeting:** Rather than merely emailing a document, seek a virtual or in-person meeting with your leadership or potential funders. This creates a more engaging and personalized presentation and reduces the risk of confusion or misinterpretation.
- **Harness the power of storytelling:** Narrate the historical context and current situation in a compelling manner. Storytelling adds depth to your proposal, helping leaders better grasp the significance of the issue. Provide a relatable example, even if fictional, of an individual affected by the disparity. Humanize the issue with a name and a story. If possible, share a real-life case (with appropriate legal approvals) to emphasize the relevance and importance of your proposal.
- **Align with organizational goals:** Demonstrate how your initiative aligns with the values and the strategic objectives of your listener. Clarify how it will contribute to equity and quality.

Securing Philanthropy

You may need philanthropic support to get your initiative off the ground, or to fund a pilot period that allows you to measure results. While philanthropic support can fluctuate—foundations or donors won't fund your work forever—honing your skills at developing relationships with funders is an important leadership skill, and grants or donations can kick-start your project. CAPC has compiled practical resources to help you approach funders and write funding proposals:

- → Strategies for Funding Serious Illness Initiatives: Advice from Foundation Officers: A video conversation with program officers from local and national foundations, and a successful grantee focused on health equity, describing what makes for a strong proposal and a trusting foundation-grantee relationship
- → Letter of Inquiry Template Language: A sample funding proposal for a foundation, outlining key components for a strong proposal

Philanthropy can be critical to launching your health equity initiative, but keep long-term sustainability in mind. Use early results from your intervention to revisit conversations with organizational leadership about their support for your work. To maximize the sustainability and impact of your efforts, we strongly recommend the integration of health equity endeavors into your organization's operational budget. Additionally, we advise integrating health equity responsibilities into the existing job functions of your staff. This approach aligns with the overarching strategy of incorporating health equity into your organization's strategic goals and operations. It ensures that staff comprehends the rationale behind infusing health equity principles into their daily tasks, fostering a deeper commitment to these crucial objectives.

Sustainability Planning

From day one, take the long view on your health equity initiative. Consider our previous examples:

- → For the palliative care team embarking on team training in providing unbiased, anti-racist, culturally competent care to Black patients: How will the training be rolled out to new hires over time? How will learning activities be reinforced over time to ensure lasting clinical culture change?
- → For the medical group implementing palliative care triggers to ensure equitable access to services: What resources will the team need in order to meet demand if the practice grows? What middle- and long-term outcomes must leadership see to support added palliative care staffing?
- → For the philanthropically supported expansion of services in a majority Black zip code: What evidence of impact does your funder need to see to renew their support? What other funding sources are available—through your organization, through state grant programs, or through other philanthropies—that will ensure that your services sustain?

We've all seen examples of "flash in the pan" health equity initiatives that generate enthusiasm and mobilize resources in the short term, only to fizzle over time, leaving affected patients or partners feeling used or abandoned. **Planning forward for sustainability, including realistic assessment of the resources you'll need and your expected outcomes, will help to ensure that your important work continues.**

Data Collection and Evaluation

Guiding Principles

Measurement and evaluation tell the story of your health equity initiative: what it does, whom it serves, and its impact on outcomes important to Black patients and families, your team, leadership, collaborators, and funders. Consider the following goals for measurement and evaluation:

→ **Demonstrating value to leadership and funders:** Show the impact of your equity initiative on measures that leaders and funders care about to provide a rationale for increased program support. Leadership and funders are also interested in indicators of quality, reliability, and accountability for current resources. They will want to know:

- Is the program utilizing current resources effectively?
- What is the initiative's impact on overall organizational success, whether that is your health care organization, or the foundation supporting you?
- Is the initiative being run strategically, and in alignment with organizational priorities?

→ **Measuring process:** What (and how much) have you done throughout the course of your initiative? This could include, for example, the number of targeted patients seen, number of clinicians trained, or proportion of patients with documented pain management plans.

→ **Measuring quality and progress toward goals:** A fundamental design element for your health equity initiative is to select measures of success. How will you know that you are moving the needle toward equitable care? Remember that outcomes that matter to you may not be the most important outcomes to the Black patients and families you serve. As you engage patients throughout the design of your initiative, check your assumptions about what success looks like to them.

Remember that outcomes that matter to you may not be the most important outcomes to the Black patients and families you serve.

→ **Building trust:** If you're working with partners to implement your health equity initiative, regular reporting of agreed-upon measures will help to strengthen relationships, focus on shared goals and priorities, and identify problems.

CHAPTER FIVE

Overcoming Adversity

Meaningful and Challenging Work

Through health equity work, we live our values of providing highest-quality, equitable care for all patients with serious illness. But equity work is challenging. You will likely encounter barriers, whether structural or personal, that can impede your path to success. These challenges may include policy hurdles, limited funding and resources, compassion fatigue, political resistance, gaps in education and awareness, and even resistance to change from within the health care sector.

The objective of this chapter is to equip you with knowledge and inspiration to help you navigate the hurdles that will cross your path. Recognizing that every health system and health equity project is unique, bear in mind that your primary compass should be what is best for your patients and your team. Consider this information as generalized guidance to help you effectively navigate the meaningful and challenging field of health equity.

What I Wish I'd Known: Lessons Learned from Health Equity Experts

CAPC gratefully acknowledges the strategic guidance of the knowledgeable, experienced, and passionate advisory committee that steered the creation of this Guide. We asked the committee and other health equity leaders for their wisdom and advice to the equity champions reading this guide.

1.

"Recognize the complexity of health disparities."

As we've seen by analyzing the SEM, health disparities result from the complex interplay of multiple factors. No singular approach will "solve" health inequities for the community you're serving.

Recognizing this complexity and incorporating that recognition into the design of your intervention is key. A multifaceted approach to health disparities that tackles both social determinants of health and individual factors such as beliefs and attitudes of health care staff and patients is more likely to yield lasting results.

2.

“Take the time to think through your data collection objectives and strategy.”

Comprehensive data collection to measure disparities and track progress is key. Without it, you will be challenged to demonstrate impact to your leaders, collaborators, and funders. This could become a serious problem, preventing you from renewed funding and community buy-in. Many health equity leaders wish they had had a better understanding of data collection and analysis techniques at the outset. Their advice is to be sure to establish meaningful metrics and a data collection plan before you launch your initiative.

3.

“Engage your leadership and partners earlier and often.”

Effective health equity work often requires collaboration with, and buy-in from, various parties, including community organizations, health care providers, government agencies, or researchers. Health equity leaders urge equity champions to give these relationships the time and attention they require, including clear communication, alignment of strategic priorities, and cultivating trust.

One of our experts cautioned health equity champions to avoid a “checkbox” approach to collecting community input. Be sure to elicit a wide range of input to represent more accurately the diversity of the community, rather than gaining feedback from only one or two individuals.

4.

“Set a realistic timeline.”

Health equity often involves challenging and changing longstanding policies, practices, and norms. Health equity champions may feel pressure to create business proposals tied to immediate changes seen in six months or a year, but systemic change is a slow and iterative process. Consider the quote by the Rev. Jennifer Bailey: “Relationships move at the speed of trust, and change happens at the speed of relationships.” To set yourself up for success, our advisory panel recommends setting a longer timeline for your intervention, understanding that you’ll need to establish relationships and build trust with patients, partners, and leadership before you see impact.

If your organization requires you to set immediate goals, consider which short-term goals (including process measures) will feed into your long-term vision. For example, if your long-term goal is to increase the proportion of patients from a particular community that are seen by palliative care, consider this example of a short-term goal: “Host (x) number of palliative care education conversations with community members in Q1.” This short-term goal works toward building connection and trust, which will ultimately get you to your goal of increasing palliative care consults.

5.

“Don’t underestimate the staff time you’ll need for your equity initiative.”

While assembling your ideal dream team may not always be feasible, it’s crucial to adopt a realistic perspective on the staffing requirements necessary to maintain the work effectively. When you build your business plan, make sure you do the work to assemble detailed projections of the time and work required to achieve your goals, including data collection, communication and partnership-building, maintaining funder relationships, and other responsibilities that fall outside of clinical care delivery. If you find yourself short on staff time, consider adjusting the scope of your project to match your available resources. If possible, distribute the responsibilities of your equity intervention across multiple members of your team. This approach helps build team engagement while building a buffer if a team member is absent or particularly stretched.

6.

"Seek long-term funding."

Health equity initiatives frequently rely on short-term grants or one-off organizational commitments. Whenever possible, and to whatever degree, try to integrate this work into your ongoing operational budget. This demonstrates a sustained dedication to health equity and also safeguards against ups and downs in your funding sources. Adopting a "one and done" mentality in health equity work can adversely affect communities that have already suffered harm, because it inadequately addresses the intricate and persistent barriers they encounter. One-off health equity projects run the risk of being perceived as a mere public relations tactic for organizations aiming to enhance their reputation, further eroding trust between marginalized communities and the health care system.

Ask your philanthropic funders: "What outcomes would demonstrate to you and your Board that our initiative merits continued support?"

Ask yourself and your leadership: "What outcomes are of strategic importance for my organization, and how can my health equity initiative affect those outcomes?"

7.

"Prioritize self-care for yourself and your team."

Many of CAPC's health equity advisers shared that their work is often deeply personal and emotionally demanding, a sentiment that was particularly emphasized by those who come from marginalized communities themselves. While the connection to their community and the passion to catalyze change motivate many health professionals to pursue health equity work, this commitment can also lead to re-traumatization. Our experts stressed the importance of prioritizing self-care and developing coping mechanisms to mitigate burnout, both for themselves and their teams. This includes creating an atmosphere where team members feel comfortable sharing concerns about being overburdened or facing challenges.

One free, public resource is CAPC's Virtual Office Hours series, Achieving Health Equity and Reducing Implicit Bias in Palliative Care. These small-group discussion sessions are hosted by a rotating group of health equity and palliative care leaders and provide a space for health equity champions to share their work, ask for advice, and be in community with like-minded champions.

8.

"Expect some opposition."

The road to health equity is often challenging, and many of our advisory members and health equity interviewees stressed the importance of preparing for opposition. With a challenging political landscape, resource constraints, competing priorities, and other barriers, they underscored the importance of resilience and perseverance in the face of obstacles and setbacks for new health equity leaders.

9.

"Utilize the power of storytelling whenever you can."

Sharing the lived experiences of those affected by health disparities can be a powerful tool for advocacy and raising awareness. The power of storytelling cannot be understated. By successfully illustrating the impact inequities have on the people in your community, you invite your audience to be a part of your initiative to improve equitable care delivery for Black patients and families.

Finding Community

Health equity work is daunting, rewarding, and mission critical. For all of these reasons, it is best done in community. The following groups and venues are opportunities to connect with like-minded health equity champions; learn from experts and peers; commiserate about challenges; and stoke your passion for equitable care for Black patients and families.

- → Achieving Health Equity and Reducing Implicit Bias in Palliative Care Virtual Office Hour: discussion groups on equitable care delivery, Diversity, Equity, and Inclusion (DEI) best practices, and other health equity topics (free and public)
- → Breaking Point: Debriefing to Address the Challenges of Our Work: facilitated discussion sessions for health professionals to share common reactions to demanding work, and coping strategies to reduce the impact of stressors (free and public)
- → Health Equity toolkit: a CAPC resource filled with practical tools and information to advance equitable care for patients with serious illness
- → Guides and toolkits from the National Hospice and Palliative Care Organization on inclusion and access for hospice services, including an outreach guide for African American patients and families
- → The National Coalition for Hospice and Palliative Care's Equity and Inclusion Workgroup: a standing group of equity champions representing all palliative care and hospice organizations, which provides resource recommendations and works collaboratively across the Coalition's advocacy and education initiatives
- → DEI Resources from the American Academy of Hospice and Palliative Medicine: a collection of resources, education, and position statements focused on equitable palliative and hospice care delivery
- → The National Caucus and Center on Black Aging, Inc: educating and advocating on behalf of elder minorities and providing direct resources to patients and families to navigate health, housing, and employment challenges
- → The American Hospital Association's Institute for Diversity and Health Equity: disseminating evidence-informed practices, resources, and innovations that lead to sustainable transformation in health care

Additional Resources

The following resources provide additional information about the topics referenced in this guide:

- → How History Has Shaped Racial and Ethnic Health Disparities: A Timeline of Policies and Events, an interactive education resource from the Kaiser Family Foundation
- → *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, a National Book Critics Circle Award-winning book by Harriet A. Washington
- → *Just Medicine: A Cure for Racial Inequality in American Health Care*, a book by Dayna Bowen Matthew
- → A 'Forgotten History' Of How The U.S. Government Segregated America, a written summary of an episode of NPR's Fresh Air radio show
- → The U.S. Public Health Service Untreated Syphilis Study at Tuskegee, an online exhibit from the Centers for Disease Control and Prevention (CDC)

CAPC aims to support you as a health equity champion in every way that we can. We encourage you to let us know what resources, tools, or peer support will help you in your work, and we applaud your efforts to make health care more equitable for Black patients with serious illness, and their families and caregivers.

Together, we can make a difference.

The Center to Advance Palliative Care (CAPC), established in 1999, is a national organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively redesign care systems that meet this need. CAPC is funded through organizational membership and the generous support of foundations and private philanthropy. It is part of the Icahn School of Medicine at Mount Sinai, in New York City.

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