

Opportunities to Improve Care and Promote Health Equity for Black People with Serious Illness

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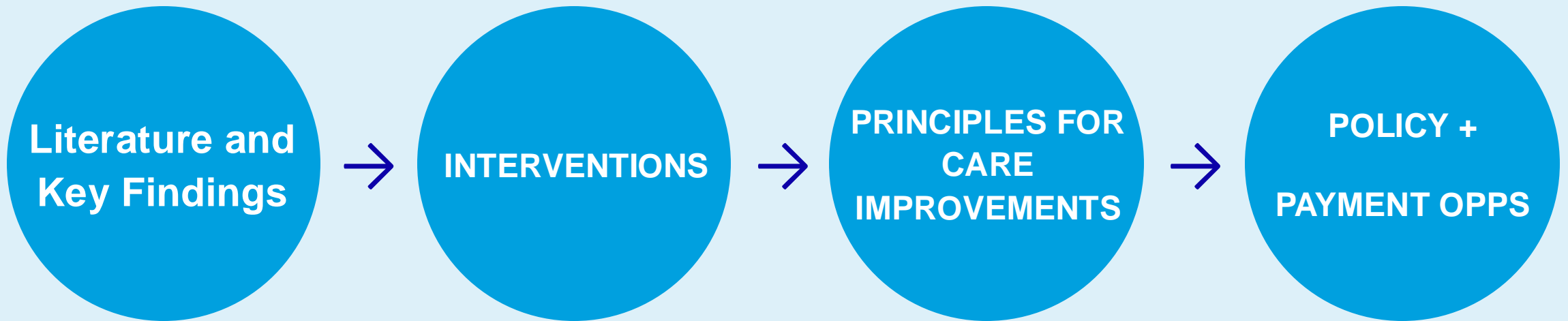
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Today's Agenda





Key Findings

- Black patients living with serious illness receive **poorer quality pain management** from their health care providers.
 - Other symptom management provided to Black patients living with serious illness is worse than that for White patients.
- Black patients with serious illness report poor-quality clinician-patient **relationships and communication**.
- Black patients are less likely to have **advance care planning (ACP) discussions** or documents, compared to White patients.
- Health care organizations providing care for people living with serious illness have identified cultural competency training and workforce diversity as areas in need of improvement.

NOTE: There are mixed findings on whether racial disparities exist in the utilization of palliative care.

- Scoping review of the literature to categorize studies on care for Black patients living with serious illness and their family.
- January 2011 – June 2021
- 160 articles out of 433 articles screened
- 12% of 433: Intervention
- Most common topics focused on documenting disparities in access to services and life-sustaining treatment rather than investigating the root causes of disparities.
- Further research should examine the root causes of disparate care experiences.

The Experience of Black Patients With Serious Illness in the United States: A Scoping Review

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Research Questions:

- 1. What interventions have been tested to improve access to high-quality care for Black people living with serious illness?**
- 2. What is known about the barriers and facilitators of their implementation?**

Some interventions have focused on improving knowledge and perceptions of palliative care.

- Healthcare organizations have used both written material and educational sessions to improve understanding and perceptions of palliative care.
 - Some of which incorporated the education of church leaders and the use of lay navigators to reach Black community members.
- Others have designed culturally based palliative care consultations that can be provided in the community using telehealth technology.
- Tested interventions have resulted in improved performance on a survey of knowledge of the purpose of palliative care services.

Organizations have also looked inward to improve the cultural competence and diversity of their own workforces.

- Interventions include cultural competency training, anti-racism education sessions, and creating culturally concordant conversation guides.
- One study described a quality improvement project to test the feasibility of adding a racism-screening question to their palliative care consult note.
- Some organizations are also building towards a more diverse workforce to better align with their patient population.
- For interventions in this area, some organizations were still in the implementation process and, therefore, we await shareable outcome measures in the future.

Community Health Worker supports:

Training and provision of lay health workers or peer navigators have been tested to improve the quality of life for Black patients living with serious illness.

- Navigators specific to a disease category, like cancer, have been used to support Black patients with unique needs or stressors, such as spiritual concerns.
- One study found that the intervention lowered costs and ED utilization for both Black and White patients.
- A study currently underway is testing an intervention that recruits and trains the wives and widows of Black clergy to serve as peer supports to cancer patients.
- An East Coast nonprofit organization supports Black women with breast cancer as patient advocates to ensure they receive equitable access to services.

Facilitators: Factors that aid in implementation efforts

- Community-based participatory research and the use of Community Advisory Groups (CAG) helped maintain participation over long periods of time.
- Clinician advocacy: Referring clinician endorsement and encouragement is vital to patient acceptance of interventions.
- Influence of faith communities: Investigators noted the importance of endorsement by not only pastors, but other church leaders as well (e.g., deacons) if church-based interventions are to succeed.



CAPC's Guide for Advancing Equity for Black Patients with Serious Illness (coming soon!)

Guide will provide information on:

- 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

Thank you to members of the external Strategic Advisory Committee that steered the development of this guide

Patient Engagement: Health Equity's North Star

→ “Nothing About Us Without Us”

→ How to Engage Patient, Caregiver, and Community

Voices



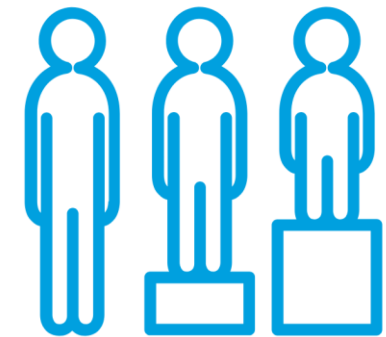
Promising Models: A National Scan for Health Equity Initiatives Focused on Black Patients with Serious Illness

- The Social Ecological Model: What Contributes to Lower- Quality Serious Illness Care for Black Patients?
- Common Focus Areas for Health Equity Interventions
- Case Examples: Health Equity in Action
- Policy Tailwinds for Health Equity Work



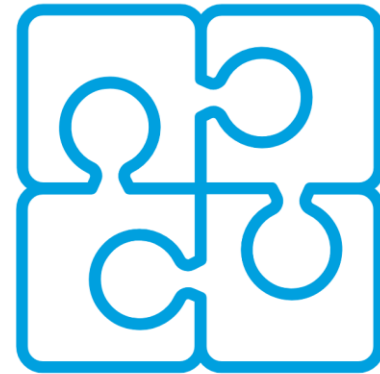
Getting Started: Planning Your Health Equity Initiative

- Identifying The Need and Understanding Opportunities
- Intervention Design and Partnership Development
- Business Planning
- Making the Case for Funding or Support
- Data Collection and Evaluation



Overcoming Adversity

- Meaningful and Challenging Work
- What I Wish I'd Known: Lessons Learned from Health Equity Experts
- Finding Community



Supplement

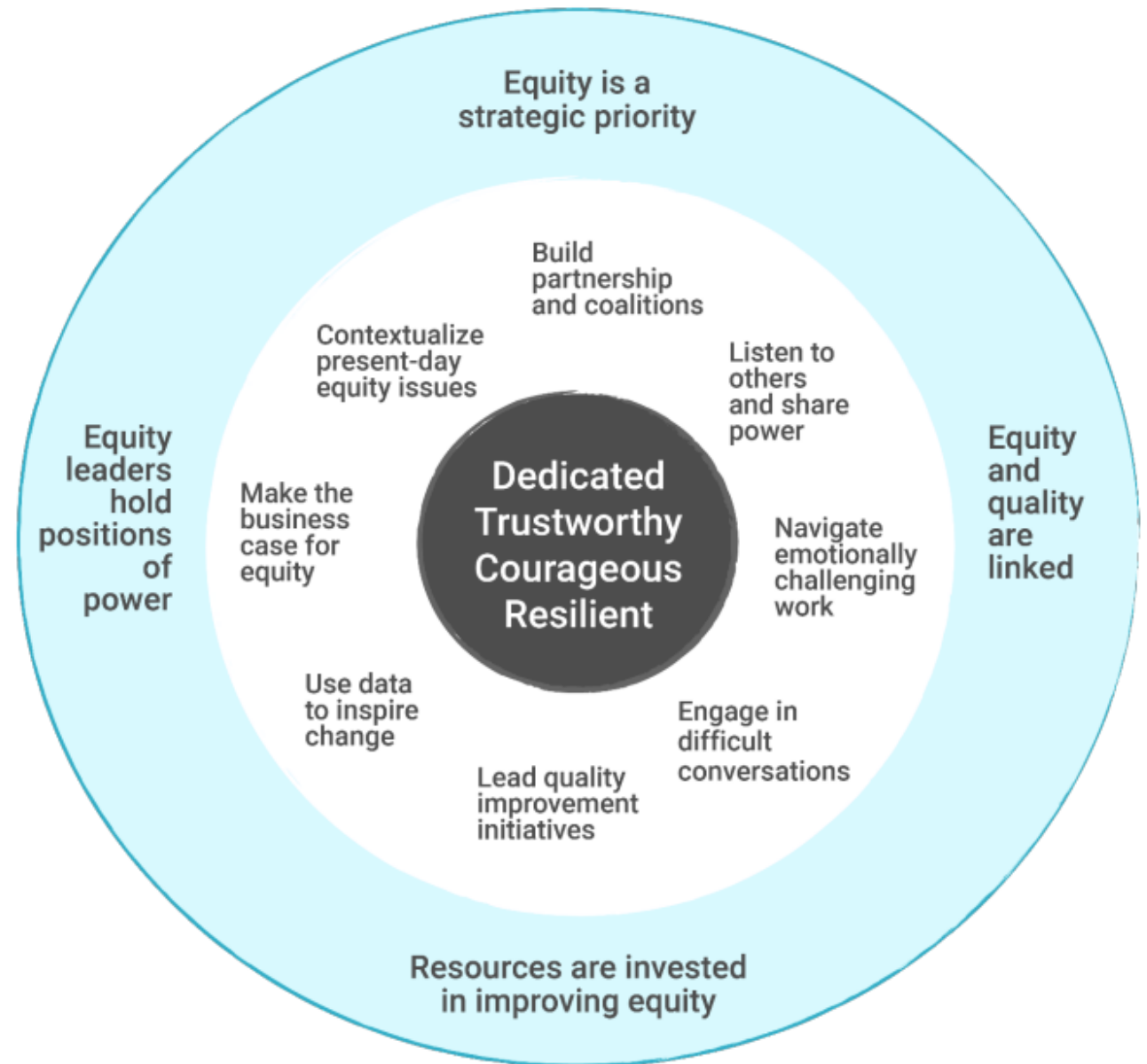
Historical, Structural, and Social Drivers of Health Care Inequities:

- How History shapes the present: Including a timeline with a brief sample of historical events and policies that enshrined and enforced racism in the U.S.
- Present-Day Health Disparities Among Black Americans

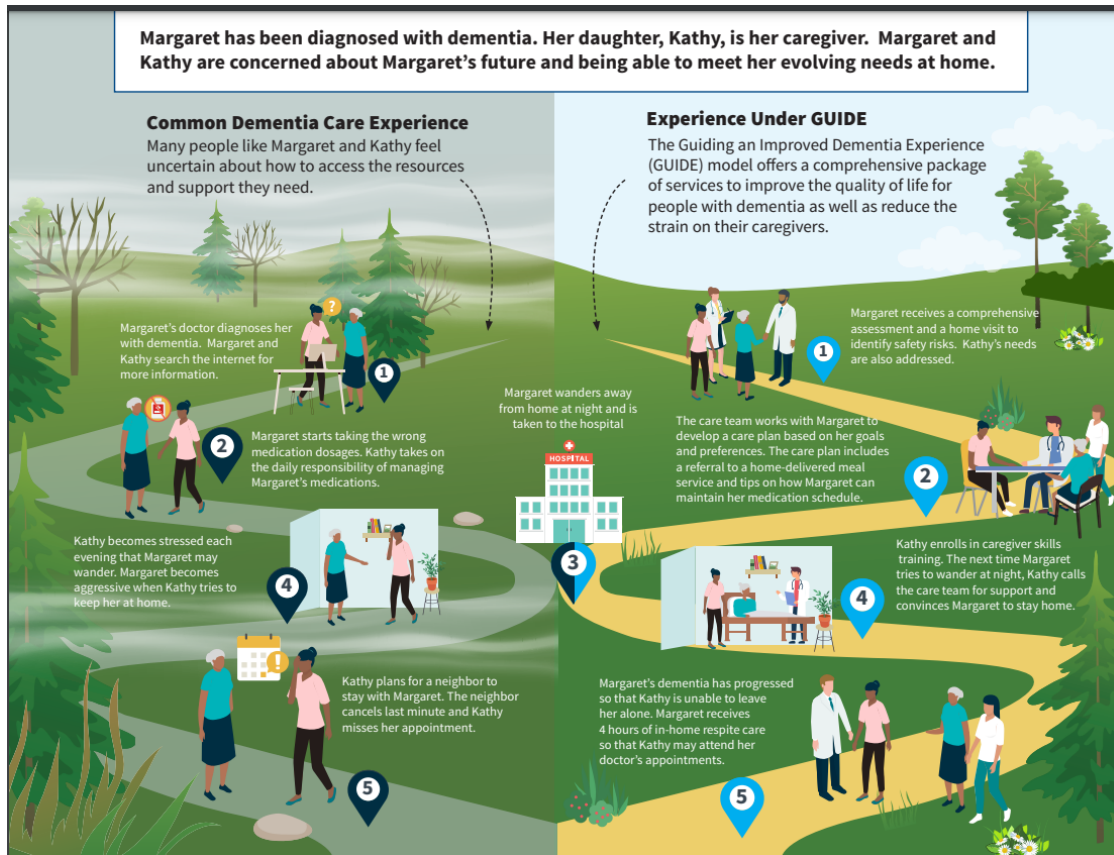


Health Equity Leadership Framework

Figure 1. IHI Health Equity Leadership Framework

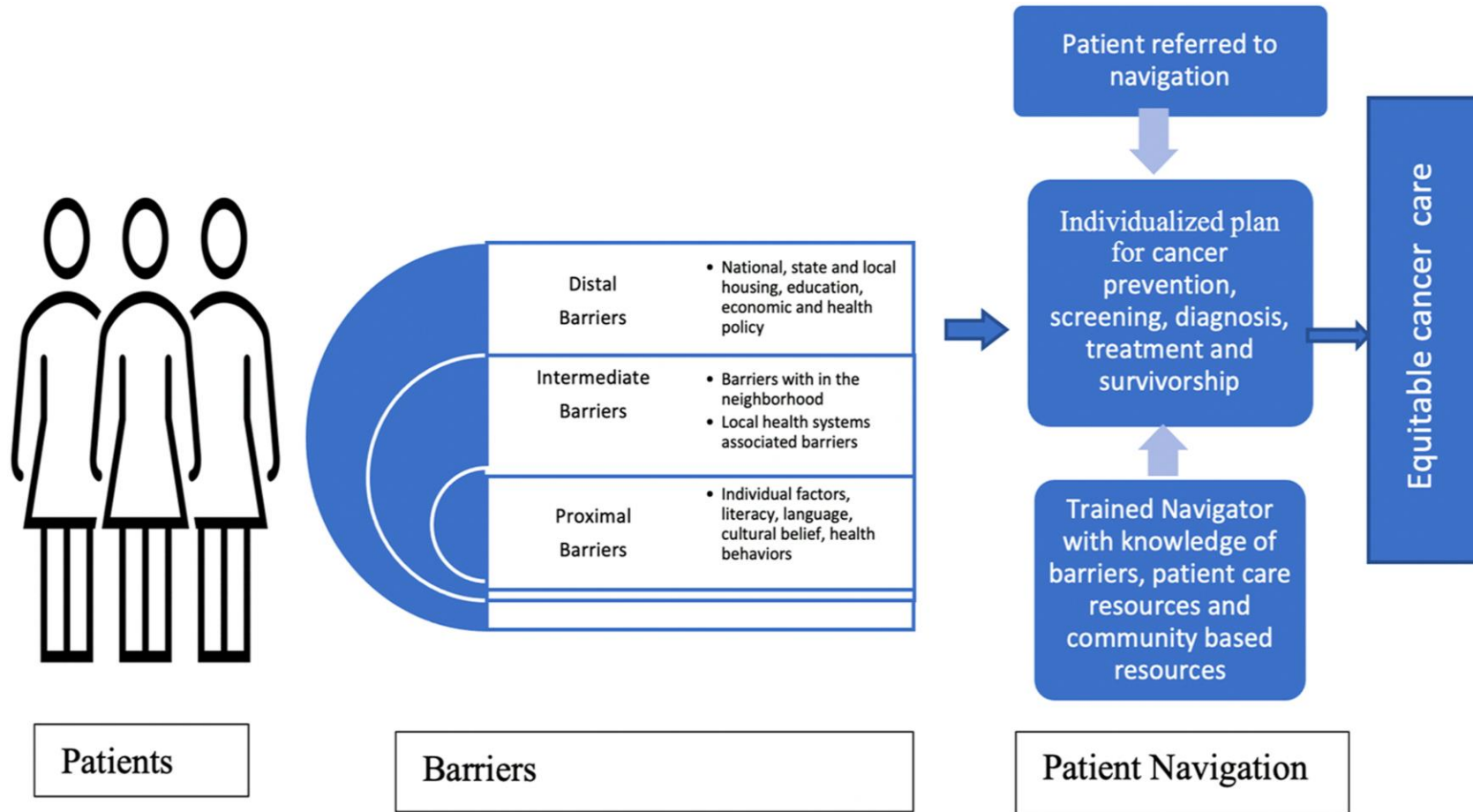


Guiding an Improved Dementia Experience (GUIDE) Model



- Sets a standard approach to care,
 - Including 24/7 access to a support line, as well as caregiver training, education, and support services.
- Incorporates policies to enhance [health equity](#) by ensuring that underserved communities have equal access to the model intervention.

Coding and Reimbursement for Principal Illness Navigation (PIN) services



Expanding to Other Patient Populations

HEALTH EQUITY

The Invisible Millions: Caring for Latino Patients and Families during COVID-19

Updated January 8, 2021 | By Stacie Sinclair, MPP; Brittany Chambers, MPH, MCHES; and Carine Davila, MD

[f](#) [X](#) [in](#) [✉](#)

How the pandemic has impacted Latinos living with serious illnesses – and the important role palliative care teams play in providing culturally humble care.



HEALTH EQUITY

How to Support AIAN/Native American Populations during COVID-19

Updated November 23, 2020 | By Brittany Chambers, MPH, MCHES and Stacie Sinclair, MPP

[f](#) [X](#) [in](#) [✉](#)

A discussion around the impact of COVID-19 on American Indian and Alaska Native (AIAN)/Native American populations, and how palliative care teams can help address health care inequities.



Image by Molly Ferguson for STAT News

HEALTH EQUITY

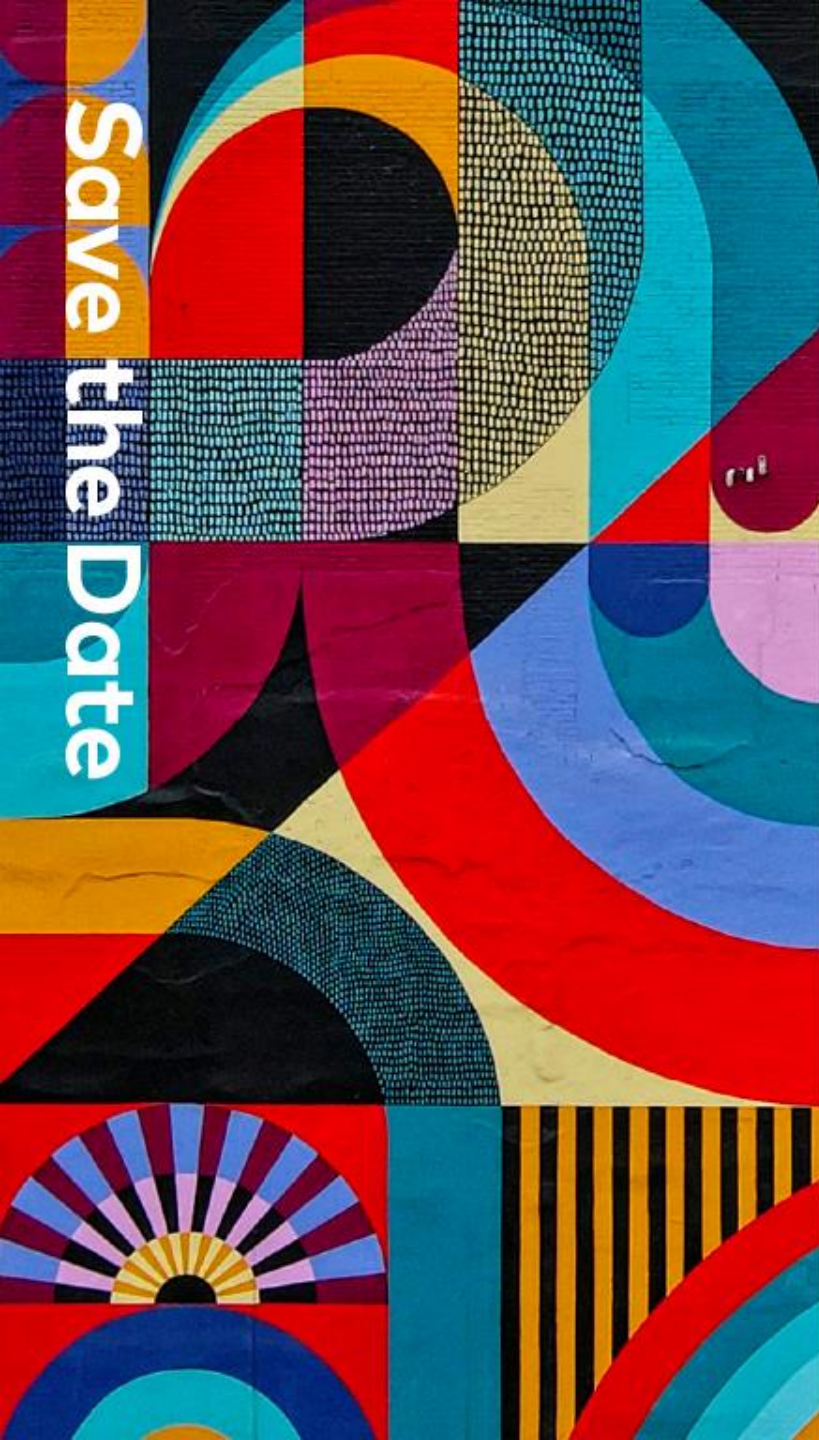
Fostering a Safe Space for Our LGBTQ+ Patients and Staff

Updated July 19, 2022 | By Noelle Marie Javier, MD

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A palliative care physician discusses some of the unique needs and experiences of LGBTQ+ patients, and how clinicians can improve care for these populations.





Save the Date

Center to Advance Palliative Care

National Seminar 2025



September 15-17, 2025 • Philadelphia, PA
capc.org/seminar

CAPC Resources

- Monthly Virtual Office Hours: [Achieving Health Equity and Reducing Implicit Bias in Palliative Care](#)
 - (9/25 AT 10:30AM) *(OPEN TO ALL)*
- [Health Equity in Palliative Care Toolkit](#)
 - [Diversity, Equity, Inclusion, and Belonging \(DEIB\) Principles for Palliative Care Leaders](#)
- **NEW!** CAPC Circles: Health Equity *(For CAPC Members only)*