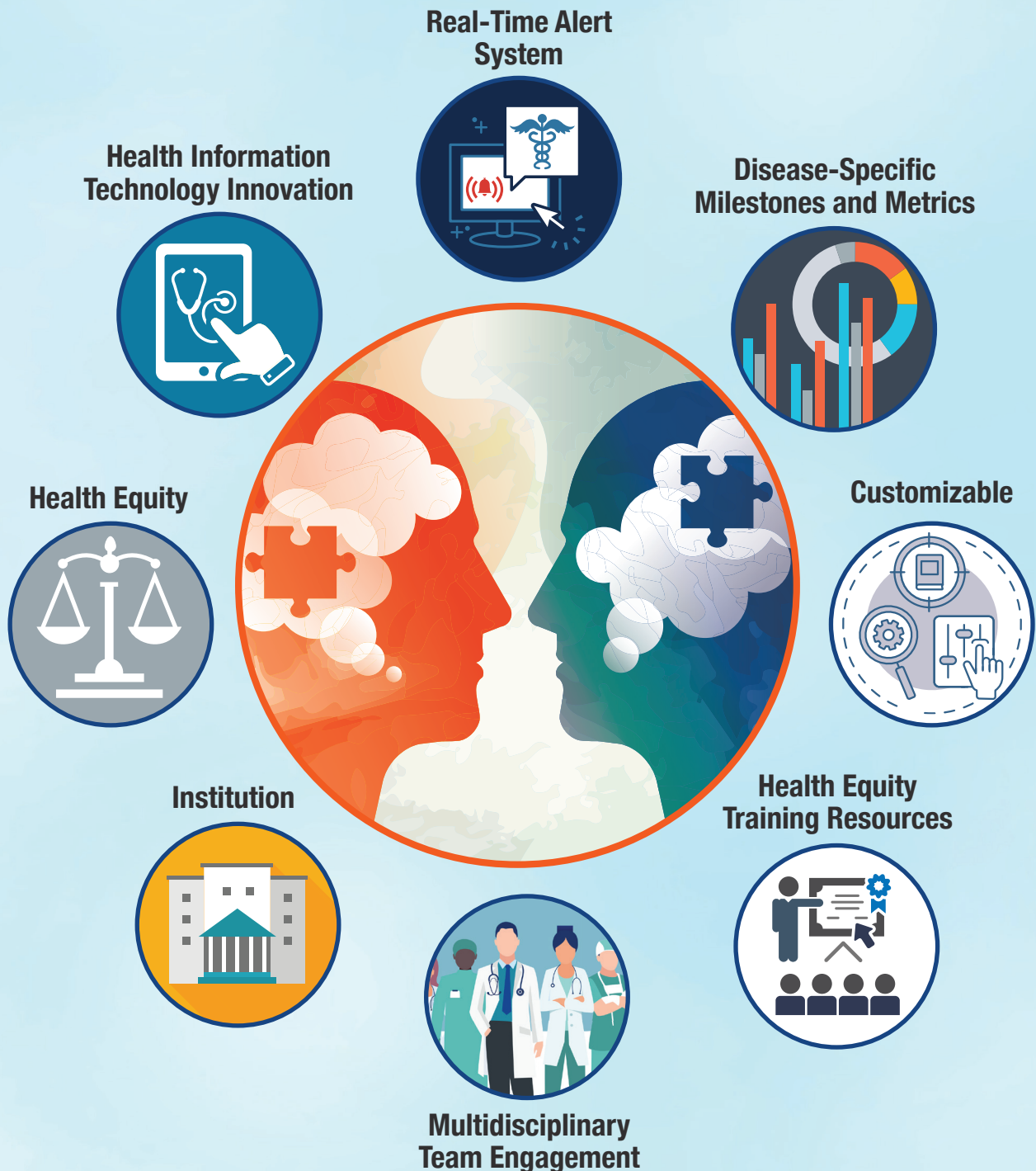


Reducing Racial Disparities in Cancer Care

Using the ACCURE Trial as a Model Learning Guide



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Reducing Racial Disparities in Cancer Care Using the ACCURE Trial as a Model Learning Guide

Learning Guide Overview

Mission	To transform the continuum of cancer care for better patient outcomes
Vision	Increase overall health equity in cancer care
	Assist institutions to achieve the results seen in the ACCURE trial
	Provide practical implementation steps applicable to a range of different systems
Objectives	Describe how health information technology innovation can create a real-time alert system within electronic health records
	Discuss race-specific data related to treatment completion rates
	Identify key interdisciplinary team members needed to positively impact change in clinical practice settings
	Review available health equity training resources
Strategy	Utilize a “how-to” learning guide to support multidisciplinary team engagement in addressing barriers to care and racial disparities

Introduction

Access to and utilization of the healthcare system among racial and ethnic minority groups remains largely inferior to that of white patients.¹ According to the 2019 National Healthcare Quality and Disparities Report, black, Native American, and Alaskan Native populations received worse care than white patients for nearly 40% of the more than 250 quality measures assessed in the study.² Hispanic patients received worse care than white patients for more than one-third of the quality measures.²

Racial disparities related to cancer treatment and survival have been documented for a number of different cancer types.^{3,6}

- Evidence has shown that patients of color are less likely to receive optimal cancer care relative to white patients, even after controlling for socioeconomic factors.^{3,7-11}

The root causes of racial disparities in cancer care are complex, including implicit bias, poor communication and potential language barriers in care delivery, lack of representation in the oncology community, mistrust of the healthcare system, and social determinants of health.^{3,11}

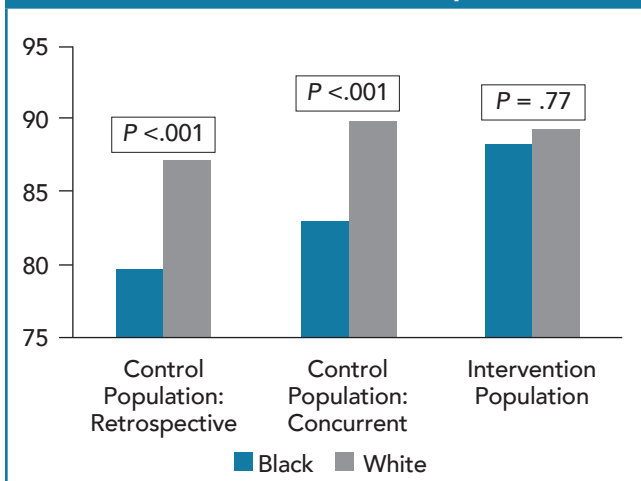
Deficiencies in the US healthcare system were clearly demonstrated by the COVID-19 pandemic. Racial and ethnic minority communities experienced disproportionately high infection and death rates from COVID-19, and existing inequities in care for unrelated health conditions, including cancer, were exacerbated.¹² A number of national organizations, such as the National Minority Quality Forum’s Diverse Cancer Communities Working Group, Academy of Oncology Nurse & Patient Navigators, and the National Comprehensive

Cancer Network (NCCN), have championed patient navigation as an essential tool for reducing disparities across the cancer care continuum and of particular importance as the country moves on from the pandemic.¹¹⁻¹³

Lung cancer is the leading cause of cancer death in the United States.^{14,15} Surgical resection for early-stage non-small-cell lung cancer (NSCLC) is a reliable treatment option that often provides the best chance to cure the disease.¹⁶ However, without surgery or other anticancer treatment, patients have a median survival of <1 year.¹⁷ Surgical rates are lower for black patients compared with white patients, especially among black patients with multiple comorbidities and no regular source of healthcare.^{18,22} A recent study found that the counties in the United States with the lowest levels of surgery were those with a high proportion of non-Hispanic black patients, high poverty, lack of insurance, low surgeon-to-population ratio, and rural population.²³ Even after improved access to care, black patients are less likely to have surgery recommended, and are more likely to refuse surgery.²⁴ Among those who do undergo a surgical procedure, there is evidence that black patients are less likely to have their lymph nodes resected overall and when stratified by stage.²² Due to the lower rates of surgical intervention, the treatment disparity leads to worsened survival outcomes for black patients with NSCLC.^{19,20}

Breast cancer is the second most common cause of cancer death in women after lung cancer.^{14,25} Early termination of chemotherapy for breast cancer is associated with black race and has been shown to result in poorer survival.²⁶ According to

Figure 1. Completion Rates (%) in the ACCURE Trial Control and Intervention Groups³⁰



the most recent data from the American Cancer Society, although breast cancer incidence rates are highest among non-Hispanic white women, non-Hispanic black women have the highest breast cancer death rates.¹⁴ A 2018 report from the South Carolina Central Cancer Registry found that breast cancer mortality rates were 43.5% higher in black women compared with white women.²⁷ Even among insured women, studies have found that white patients are diagnosed at earlier stages and have lower mortality rates relative to black patients.²⁸ Similarly, in a study of underinsured patients, black women had higher breast cancer-specific mortality rates compared with non-Hispanic white women; however, this increased risk was reduced and no longer statistically significant after adjustment for clinical and sociodemographic factors.²⁹

In an effort to address the racial disparities in lung and breast cancer treatment, the 2019 ACCURE (Accountability for Cancer Care through Undoing Racism and Equity) trial (National Cancer Institute [NCI] Grant# 1R01CA150980-01A1) used a multifaceted, system-based intervention to improve treatment completion for both black and white patients and reduce racial disparities.³⁰ The intervention included a real-time alert system that was developed using automated uploads of data from electronic health records (EHRs) coupled with race-specific completion of cancer treatment information that was sent to clinical teams.³⁰ Nurse navigators were also given access to the alert system and played a critical role in the success of the intervention.³⁰ Control populations in the ACCURE trial consisted of retrospective data from early-stage lung and breast cancer patients seen between January 2007 and December 2012 as well as from non-study patients seen concurrently with patients receiving the intervention, between 2014 and 2015.³⁰ **Figure 1** shows the significant racial disparity in treatment completion rates among the control populations and the elimination of this disparity resulting from the ACCURE intervention.³⁰

Sam Cykert: “We have these great digital systems across medicine now, and we don’t harness the data in real time when that data can really drive care and make things like disparities and clinical inertia transparent. But if humans are not responsible for the systems they build then nothing happens. That’s where navigation and communication comes in.”

Matt Manning: “The time is right for organizations to address health inequities.”

Additionally, the ACCURE intervention improved survival overall and reduced racial disparities in survival for both lung and breast cancer.³¹ The 5-year observed survival for white and black breast cancer patients increased from 91% and 89% ($P = \text{NS}$) in the control group, respectively, to 94% for both races in those who received the intervention.³¹ In lung cancer patients, the 5-year observed survival increased from 43% and 37% ($P = \text{NS}$) in the control group to 56% and 54% in the intervention group, among white and black patients, respectively.³¹ These results further demonstrate the impact of the ACCURE intervention on reducing racial disparities and improving care for all patients.³¹

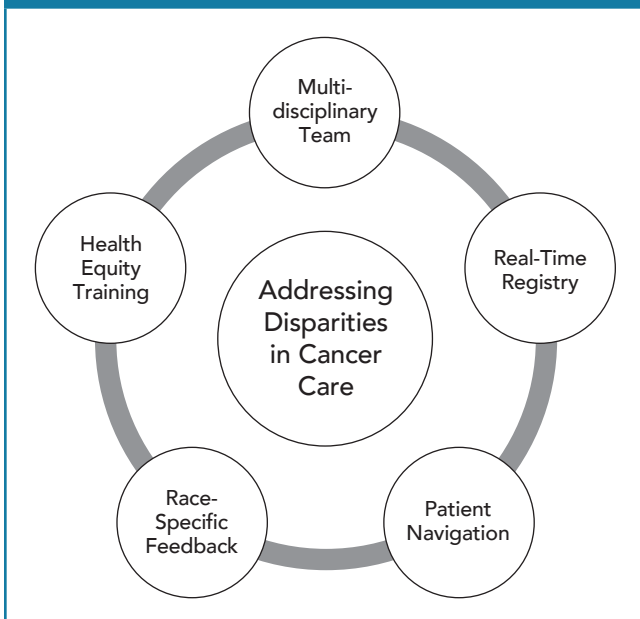
As part of the solution to address racial disparities in cancer care, healthcare professionals may benefit from actionable guidance on how to combat inequities in their own institutions through the use of real-time data. The following learning guide provides concrete steps and resources for the implementation of one approach to reducing racial disparities in treatment completion. Modeled on the successful intervention used in the ACCURE trial, these recommendations are intentionally customizable to meet the specific needs of any institution. **Figure 2** depicts the essential factors of this approach and detailed information is provided in the following sections.

1. Gather a Multidisciplinary Team

Essential to the success of the ACCURE trial intervention was the involvement of a multidisciplinary team, including clinicians, information technology specialists, institutional committees and administrators, and community representatives. Active community outreach is needed for optimal development of a successful intervention. The Elevating Cancer Equity panel discussion from the 2021 NCCN Annual Conference highlighted the importance of gathering input from the community, creating marketing and educational materials with linguistically and culturally appropriate messaging, and developing more formal partnerships with community-based practices and organizations that can assist with conducting community health needs assessments and subsequent action plans.¹¹

Within the clinical care setting, a systematic approach to change management, as outlined in this learning guide, may help to engage the multidisciplinary team in discussions about combating racial disparities. **Table 1** provides a list of suggested

Figure 2. Critical Components of the ACCURE Trial Intervention



team members for involvement in discussions and implementation of new practices aimed at improving health equity in cancer care.³²

Completion of an initial gap analysis is recommended to more fully understand the needs of a specific institution, program, department, and community served. The knowledge gathered from the key stakeholders allows for the most appropriate action to be taken to bridge gaps and provides a baseline for assessing progress of the desired outcomes.^{33,34}

For more guidance on how to conduct a gap analysis, please see:

- Utilizing a Gap Analysis to Strengthen the Strategy of Navigation Programs: www.jonsonline.com/component/mams/?view=article&artid=2722:utilizing-a-gap-analysis-to-strengthen-the-strategy-of-navigation-programs&Itemid=0
- Gap Analysis Facilitator’s Guide: www.ahrq.gov/patient-safety/capacity/candor/modules/facguide3.html

Using the list of suggested team members in Table 1 as a guide, each institution must develop a map of people with whom to:

1. Discuss the intervention and gather information
2. Approve the project
3. Be directly involved in implementation of the intervention
4. Keep informed or bring in as needed.

Emily Gentry: “...one of our first steps was to build a relationship with the community that we were partnering with. It’s helpful to have someone from that grassroots perspective along to share their voice.”

A recent roundtable discussion with representatives from NCI-designated cancer centers focused on the impact of placing community outreach and engagement in the NCI Cancer Center Support Grant guidelines. There was clear and overwhelming consensus among participants regarding the need to enhance diversity and reduce racial inequities in cancer research, care, and survival, along with enthusiastic support for funding and budget incentives to broaden the efforts of community outreach and engagement teams at cancer centers and enhance relationships with communities served.^{11,35}

2. Develop a Real-Time Registry

Tracking data in real time to monitor patient progress from suspicious finding to cancer diagnosis to treatment was a major pillar of the ACCURE trial intervention. Important milestones were identified to encourage timeliness of care. When a milestone was missed, an alert warning was generated in the real-time registry within the EHR. This portion of the intervention relied heavily on information technology (IT) professionals to develop data tracking programs and alert system notifications. However, prior to involvement of IT professionals, preparation is needed to reach a consensus among key stakeholders regarding the specific milestones and metrics to be built into the EHR alert system.

How to Identify Milestones

In addition to following NCCN Guidelines and referring to the Elevating Cancer Equity recommendations, information must be gathered from key stakeholders within each institution and surrounding community.^{11,36} Tumor boards are often well-attended meetings and have a multidisciplinary list of participants, making it a good place to begin discussions about tumor-specific timelines and milestones. Cancer committee meetings offer another venue for milestone discussions. Community input is critical as well. Literature searches can be performed to ascertain milestones for cancer types that do not have clearly defined timelines.

Tips for Creating Milestones:

Vikas Mehta: “At our institution, the way that we’ve tried to tackle establishing milestones is understanding how the different cancer teams work—splitting them up into subsites (breast, colorectal, lung, etc) and utilizing their tumor boards as a nice place to sit down and meet with them to understand the process map from suspicion through the end of treatment and survivorship, how that looks regarding the ideal and realistic number of days things should take place within our system.”

Table 1. Suggested Team Members for Success

Clinical	Information Technology (IT)	Healthcare Institution	Community
<ul style="list-style-type: none"> • Medical Oncologists • Radiation Oncologists • Surgical Oncologists • Physician Champions • Oncology Advanced Practice Providers (Nurse Practitioner, Physician Assistant, Clinical Nurse Specialist) • Oncology Pharmacists • Oncology Nurses • Nurse and Patient Navigators • Pathologists • Home Health Nurses • Anesthesiologists • Occupational Therapists • Physical Therapists • Registered Dietitians/Nutritionists • Pain Specialists • Genetic Counselors • Social Workers/Case Management • Hospice Care Specialists/Palliative Care Specialists 	<ul style="list-style-type: none"> • IT: Leadership (CIO, CMIO) • IT: Data Building and Mapping • IT: “Boots on the Ground” Support • IT: Analytics • Pharmacy Informatics • Nurse Informatics • Physician Informatics 	<ul style="list-style-type: none"> • Administrators • Cancer Committee Chair • Tumor Registrar • Staff Training and Education Department • Patient Engagement Team • Chaplain • Quality or Performance Improvement Team • Community Outreach and Engagement Specialists • Discharge Coordinator • Human Resources Department • Diversity and Inclusion Leaders 	<ul style="list-style-type: none"> • Community Advisory Board • Faith-Based Organizations • Cultural Centers • Sororities • “Buddy”/Peer/Volunteer Navigation from Survivors • Patient Advocacy Organizations

CIO indicates chief information officer; CMIO, chief medical information officer.

Sam Cykert: *“It is important to have stakeholder meetings, especially with the patient care community to see what they think is reasonable, but you also have to push the envelope a bit, especially now that we have data that shows that delayed care leads to worse outcomes.”*

Beth Smith: *“We met with our surgeons and our medical oncologists and our radiation oncologists and talked with them about benchmarks; we wanted to incorporate what they felt were appropriate times.”*

Vikas Mehta: *“Engaging everyone, the physicians and other practitioners, is very helpful and shows the importance of cancer type because these warnings are not generic.”*

Dana Herndon: *“With the utilization of national guidelines and other recommendations, the cancer care team can identify checkpoints and milestones that are critical to achieve for patients.”*

An important consideration is that the evidence on the optimal time-to-treatment for certain cancer types is only just emerging, emphasizing the need to effectively collaborate and consult with experts and do what is reasonable at the institu-

tion. Benefits and drawbacks exist for creating milestones that occur over too short or too long a time frame.

Vikas Mehta: *“The time frame really needs to be tailored to the cancer site and the overall aggressiveness of the tumor. The data support that with more aggressive tumors, like lung or pancreatic cancer, getting patients treated in an expedited manner significantly improves the survival outcomes. However, when you have more indolent tumors, like most prostate cancers, shorter time frames may have no impact, or actually be detrimental, to patient outcomes. The optimal times and alerts then need to be customized to the cancer sites and should be based on the best available evidence.”*

Examples of Milestones

1. ACCURE Trial Milestones

Milestones are built to correspond to a specific cancer type and stage. Examples of milestones from the ACCURE trial, involving early-stage lung and breast cancers, are shown in Table 2.³⁰

2. Missed Appointments and Treatment Delays

Tracking missed appointments in real time and sending alert reminders to navigators can improve patient outcomes and

Table 2. Unmet Milestones Used to Trigger Warnings in the Real-Time Registry in the ACCURE Trial

Lung Cancer
No clinical appointment, diagnostic test, or treatment scheduled within 30 days of the index visit
No surgery or radiation scheduled within 90 days of the index visit
No surgery performed by day 130 from the index visit
Breast Cancer
No clinical appointment, diagnostic test, or treatment scheduled within 30 days of the index visit
No breast cancer surgery completed within 30 days of the initial visit
No chemotherapy or radiation appointments scheduled within 21 days of breast cancer surgery
No chemotherapy treatments actually received within 90 days of breast cancer surgery
No radiation treatments actually received within 90 days of breast cancer surgery

continuity of care. Apart from the clinical ramifications of missed appointments for the patient, they also represent a significant loss of revenue for healthcare institutions and contribute to suboptimal use of resources.^{37,38} Patient navigator programs have been shown to decrease the rates of missed appointments. One study evaluating a patient navigator program at a tertiary care referral colposcopy center found that missed appointment rates declined from 49.7% to 29.5% after implementation of the navigation program.³⁹ Another study involving 5 clinics within a large academic cancer center used a predictive model to target only those patients most likely to miss a scheduled appointment, and found that patient navigation significantly decreased the rate of missed appointments from 17.5% to 10.2% in this targeted population.³⁸

Barriers to care represent important obstacles to overcome to reach optimal outcomes. A study of 2600 breast screening participants found that approximately 75% had ≥1 documented barriers to care, with more than one-third having ≥3 barriers, and the presence of barriers was associated with less-timely resolution compared with not having barriers.³⁹ Tracking treatment delays is critical for keeping patients engaged in care. Alert reminders indicating delays alert navigators that potential barriers to care may need to be addressed.

Beth Smith: *“The [real-time registry] gives us the ability to have and meet benchmarks and to be notified when we’re not meeting those benchmarks. Our ultimate goal is to be able to use the tool to help us make sure that all of our patients receive the same standard of care.”*

IT Involvement

Following the identification of variables to be tracked and milestones to be built into the alert system, IT specialists are needed to develop, support, and analyze data within the programs. Building a real-time registry and warning system derived from automated uploads of data from EHRs requires IT professionals to first establish automated data feeds (devoid of identifiers) that are uploaded on a consistent basis (ie, nightly). This allows for patients to be identified and followed from cancer

diagnosis through treatment, with warnings alerting the clinical team when milestones are not met. It has been shown that EHR systems with clinical decision support (ie, ordering preventive, clinical, and treatment services) can greatly improve process outcomes, particularly when guided by the “Five Rights” of clinical decision support.^{41,42} These “Five Rights” can serve as a framework when planning clinical decision support interventions within a healthcare institution to optimize the impact of the tool.⁴² The Centers for Medicare & Medicaid Services recommend this framework as a best-practice approach to health IT-enabled quality improvement.⁴³

The “Five Rights” of clinical decision support:

- The right information
- To the right people
- Through the right channel
- In the right intervention format
- At the right time in workflow

More information about the “Five Rights” can be found in the following resources:

- Jerome Osheroﬀ, MD (editor). *Improving Medication Use and Outcome with Clinical Decision Support: A Step-by-Step Guide*. 2009
- Jerome Osheroﬀ, MD, et al. *Improving Outcomes with Clinical Decision Support: An Implementer’s Guide*, second edition. 2012
- Clinical Decision Support Collaborative for Performance Improvement. The Clinical Decision Support 5 Rights. <https://sites.google.com/site/cdsforpiimperativespublic/cds>

It is important to consider how patients are initially entered into the registry. In the most straightforward situation, a pathologist enters a cancer diagnosis into a patient’s record following a positive tissue biopsy, and that positive diagnosis is captured by the automated nightly data upload and the patient

is entered into the registry. It can be more challenging to capture a potential cancer diagnosis when pathology is not involved (ie, no tissue diagnosis). In such instances, a “high-probability trigger” may be used to identify and enter patients into the registry prior to pathology. This high-probability trigger would be cancer-type specific, prioritizing suspicion of aggressive cancer types and flagging patients needing timely follow-up. One method for achieving this is to develop “reportable terminology” in software for radiological images. Creating a multi-pronged algorithm to keep probable patients in the tracking system prior to a tissue diagnosis is an example of a technological innovation that enhances patient engagement and has the potential to improve clinical outcomes.

Sam Cykert: *“Entering patients into the system is crucial. Most times you need this to happen before tissue diagnosis—patients who are in denial or who have an incidental finding can disappear before the diagnostic workup. One way of doing this would be to have suspicious radiology findings coded consistently as possible cancers; another way would be to have clinicians use specific diagnostic codes (either real or dummy) for patients that have worrisome symptoms or findings.”*

Jonathan Molina: *“One of the keys is how do you first enter a patient into the real-time registry because sometimes a patient doesn’t have a tissue diagnosis at the first visit, and so the pathologist isn’t going to get them in there. If you have a patient with a 2.5-centimeter nodule that is spiculated on their CT but they don’t have a tissue diagnosis so you wait to enter them into the registry, then that patient could disappear before they get a diagnosis, especially if it’s a patient who’s in denial.”*

Sam Cykert: *“If it’s somebody with a low-grade prostate cancer, you can wait a while. But with aggressive cancers, if you’re suspicious, they have to be followed up because we found in previous research that particularly black patients who don’t have a regular source of care will disappear.”*

Jonathan Molina: *“We used reportable terminology (that we gave to the software) to flag any cases from radiology that say a certain type of phrase or type of cancer for us to review.”*

Analytics professionals are also needed to create automated features that provide information about trends and patterns in the data. These patterns could potentially be used to develop a predictive model through identification of a “high risk for sub-optimal care” patient profile using factors such as zip code, distance from treatment center, age, race, and other social determinants of health.⁴⁴ In addition, analytic tools could be utilized to measure the effect of this model. For example, a *Current Procedural Terminology* code could be created for navigation,

enabling data from claims databases to be coupled to registry data to study patients who utilized navigation. Another potential analytic project could be to track interest in this learning guide by quantifying the number of downloads and following up with a survey to see how it was received and implemented. There is a need for project managers to monitor, maintain, and improve these initiatives over time.

3. Patient-Centered Navigation

Sam Cykert: *“The other really, really important element was navigation. The navigators were not only accountable, they were responsible for enhanced communication and really engaged, and re-engaged, [patients] when there were problems with comprehension or continuation of care. [Navigators] followed the patient all the way through the system. It wasn’t just a radiation navigator or a chemotherapy navigator. It was folks following all the way through and that relationship really enhanced the ability to keep folks in through care completion.”*

A critical component of the ACCURE intervention was the involvement of nurse navigators. They proactively initiated 2 face-to-face meetings with patients within the first month of diagnosis, then scheduled monthly progress assessments, often carried out over the telephone.³⁰ Reminders for these visits were sent by the real-time registry system until the visit was documented by the navigator.³⁰ Patients had the same navigator from diagnosis through treatment, allowing for trust and familiarity to develop over time.³⁰ When milestones were missed, the real-time registry system generated a warning that was shared with the navigator, who then either interacted directly with the patient to address the issue or advocated on the patient’s behalf with the clinical team to progress toward the next milestone in a timely manner.³⁰ By providing accountability, communication, education, and ingenuity, navigators have been shown to offer highly effective patient-centered solutions and enable timely continuity of care even when barriers arise.^{39,45-48}

Vikas Mehta: *“Navigators are not just making appointments for people, not just helping them get their imaging done, or helping them see the social worker. By helping them get their treatment done in a timely and appropriate manner, they’re saving the patient’s life.”*

Successful navigators have a passion for their job and understand that their efforts to keep patients engaged in care can improve clinical outcomes. Navigators are often tasked with thinking outside the box to overcome challenging barriers to care. **Table 3** provides educational resources for initiating and enhancing nurse navigation programs, nurse navigation tools, and specialized information for navigators working in the field of oncology.

Table 3. Educational References for Patient Navigation

Resource Title	Where to Find Online
Patient Navigation in Cancer Care 2.0	www.patientnavigation.com
Team-Based Oncology Care: The Pivotal Role of Oncology Navigation	https://navigationroundtable.org/resource/team-based-oncology-care-the-pivotal-role-of-oncology-navigation
Establishing Effective Patient Navigation Programs in Oncology: Proceedings of a Workshop	www.ncbi.nlm.nih.gov/books/NBK500558
Provider Education on Patient Navigation	https://aonnonline.org/education/navigation-tools
Educating the Health Care Team on the Roles and Responsibilities of Navigators and Support Staff	
AONN+ 2020 Navigation Metrics Toolkit	
Patient Navigation Evaluation Toolkit	https://patientnavigatortraining.org/resources/downloadable-resources
Cancer Patient Navigator Toolkit	http://keepitsacred.itcmi.org/wp-content/uploads/sites/5/2017/12/Cancer_Patient_Navigation_Toolkit.pdf
Equipping the Novice Oncology Nurse Navigator: An ONS Collaboration with AONN+	www.ons.org/courses/equipping-novice-oncology-nurse-navigator-ons-collaboration-aonn
Making the Case for Nurse Navigators	www.accc-cancer.org/docs/Documents/oncology-issues/articles/SO11/so11-making-the-case-for-nurse-navigators
Evaluating the Cost-Effectiveness of Cancer Patient Navigation Programs: Conceptual and Practical Issues	www.ncbi.nlm.nih.gov/pmc/articles/PMC2790004/
The Efficacy and Cost-Effectiveness of Patient Navigation Programs Across the Cancer Continuum: A Systematic Review	https://acsjournals.onlinelibrary.wiley.com/doi/pdf/10.1002/cncr.32147
Maximizing the Value of Patient Navigation: Lessons for Optimizing Program Performance	www.advisory.com/Topics/Oncology/2011/03/Maximizing-the-Value-of-Patient-Navigation
Becoming a Breast Cancer Nurse Navigator	www.amazon.com/Becoming-Breast-Navigator-Shockney-2009-12-21/dp/B01FIXSM9Y
Using a Nurse Navigation Pathway in the Timely Care of Oncology Patients	www.jons-online.com/issues/2014/june-2014-vol-5-no-3/1272-using-a-nurse-navigation-pathway-in-the-timely-care-of-oncology-patients
Development of an Actionable Framework to Address Cancer Care Disparities in Medically Underserved Populations in the United States: Expert Roundtable Recommendations	https://ascopubs.org/doi/full/10.1200/OP.20.00630

Dana Herndon: *“Navigators are not only an asset to the care team with expediting patient care but can also connect to the patient in meaningful ways. This connection can lead to identification of barriers to care that could otherwise be missed. An example is a patient with high anxiety. We can connect these individuals to support resources like art therapy and talk to providers about possible medications.”*

Barriers within the institution and throughout the health-care system, such as implicit bias, must be identified and addressed to successfully reduce racial disparities. Racial equity training can help, and resources are provided in the next section.

Matt Manning: *“[Navigators] specially trained in racial equity—there’s a lot to that in terms of meeting with patients, [understanding] where they are, and what they are going through.”*

Utilizing Technology to Optimize Navigation

Technology can be both helpful and efficient for navigators.⁴⁹ A portal for navigators can be built into the system that provides workflow tracking and care coordination guidelines based on cancer type and stage. The ACCURE trial developed an “umbrella” portal for navigators that could be modeled in any EHR system at any institution. A customized “survivorship care plan” can also automatically generate following a patient’s

last treatment visit for navigators to review and share per institutional guidelines. In addition, as healthcare in the United States progresses toward value-based payment models and subsequent shifts in reimbursement structures,⁵⁰ navigation may be an ideal “win-win” for the organization and patients within these payment structures.⁵¹⁻⁵³

4. Provide Race-Specific Feedback Information to Clinical Teams

Objective data collected by the real-time registry can be used to address potential racial disparities regarding patient progress through the continuum of cancer care. Clinical teams can be provided with race-specific data and analytics to understand the issues at their own institution and to develop customized solutions to meet their needs.

Of note, entering race and ethnicity information into the EHR can be challenging. Most institutions, in accordance with federal data collection efforts, offer 5 race categories for patients: Black or African American, White, Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander.^{54,55} Often only 1 race can be selected, despite the fact that many people identify as multiracial.⁵⁶ If an “other” option is selected for a multiracial individual, it is uncommon and/or not possible to enter multiple races manually. Gathering and analyzing ethnicity information can present additional difficulties; for example, patients of differing races can identify as ethnically Hispanic.

Matt Manning: *“You really need to have accurate data on race in order to really track disparities and, unfortunately, a lot of health systems don’t track race very well.”*

Staff training is critically important to entering accurate racial data. Registrars and intake specialists should ask a patient directly about their race and not make an assumption based on the patient’s visual appearance. Unfortunately, inaccurately entered racial information is carried forward from encounter to encounter in the EHR, and rarely, if ever, corrected. One study found that up to 33% of 81 patients saw themselves differently from the way they were racially categorized in a clinical database.⁵⁷ Initiatives to improve data collection on race and ethnicity, along with ongoing training on how to collect these appropriately, is foundational to addressing disparities.

Clara Lambert: *“We weren’t trained or told of the relevance of [racial] information. If we knew that this was important data that was going to be used for studies, I think that might help us get accurate information.”*

Racial data collected by healthcare institutions serve as an invaluable source for understanding disparities in healthcare. It is important to note that studies of racial disparities control for other social determinants of health, such as income, education,

insurance, comorbidities, and age, in order to isolate the effect of race. While it is imperative that race and ethnicity information is collected accurately, other demographic data are necessary as well to understand the full picture of health inequities.

Resources for accurately entering and assessing race and ethnicity data:

Agency for Healthcare Research and Quality. Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. www.ahrq.gov/research/findings/final-reports/iomracereport/index.html

National Research Council (US) Panel on DHHS Collection of Race and Ethnic Data. Eliminating Health Disparities: Measurement and Data Needs. www.ncbi.nlm.nih.gov/books/NBK215751

Sam Cykert: *“Every one of these cancer studies that have shown racial disparities in treatment are controlled for income and education, and just like in medical systems, black women who are PhDs are more likely to lose their baby than poor white women, the same thing holds true for cancer.”*

In the ACCURE study, the intervention teams followed the People’s Institute for Survival and Beyond Undoing Racism™ framework as a conceptual model for medical care.^{30,58} This model aims to communicate that “effective community, systems and institutional change happens when those who serve as agents of transformation understand the foundations of race and racism and how they continually function as a barrier to community self-determination, self-sufficiency, and interdependency.”⁵⁸ Race-specific feedback was provided to clinical teams on a quarterly basis, allowing for quality improvement efforts to be tested and altered as needed to provide better care for all.³⁰ The time frame for providing race-specific feedback to clinical teams is a modifiable variable, able to be customized to best meet the needs of an individual institution.

Sam Cykert: *“We made sure that on a quarterly basis, the cancer care teams received clinical reports that were specific so that there was a direct comparison of how black patients were doing compared to how white patients were doing.”*

Transparency and Accountability to the Community

Creation and distribution of a community report or a grassroots community board appointed to get updates on progress regarding racial- and/or ethnic-specific care under the new intervention is an important component of this approach. Community engagement coupled with shared goals and open discussions has the potential to build trust and customize the details of the intervention to best meet the needs of the population served by the institution.

5. Offer Routine Health Equity Training

Successfully addressing racial disparities within an institution requires that employees understand the scope and significance of the health inequities issue. Staff training initiatives should be offered on a regular basis using established definitions, topics, programs, and guidance resources. These training sessions should be customized to the identified needs of the communities served by the institution.

Emily Gentry: *“Whatever community you’re working in, you need to be aware of what [issues] are there in the community.”*

Suggested definitions for basic health equity terminology⁵⁸⁻⁶⁰:

- **Disparity:** Differences in status or outcomes between groups of people
- **Inequity:** Disparities that are a result of systemic, preventable, avoidable, and unjust social and economic policies and practices that create barriers to opportunity
- **Implicit bias:** Any unconscious or unacknowledged preferences that can affect a person’s outlook or behaviors, and in particular, an unconscious favoritism toward or prejudice against people of a certain race, gender, or group that influences one’s own actions or perceptions

Suggested topics to discuss:

- Social determinants of health⁶¹:
 - Healthcare access and quality, education access and quality, social and community context, economic stability, neighborhood and built environment
- Healthcare system focus:
 - Implicit bias, gatekeeping, institutional racism, poor communication, literacy, denial, mistrust, comorbidity bias, negative perceptions of poor postsurgical functioning

Suggested training programs and guidance documents:

- People’s Institute for Survival and Beyond (PISAB) – Undoing Racism® Workshop: <https://pisab.org/undoing-racism-community-organizing-workshop>
- Racial Equity Institute – Groundwater Institute Presentation and Phase 1 Workshops: www.racialequityinstitute.com
- Intercultural Cancer Council publications – focus on encouraging diversity in clinical cancer research: www.interculturalcancercouncil.org/icc-publications
- The ConNECT Framework – a model for advancing behavioral medicine science and practice to foster health equity: www.ncbi.nlm.nih.gov/pmc/articles/PMC5296246

Sam Cykert: *“We often use an organization called the Racial Equity Institute and they do what they call a groundwater training, which is a 3-hour presentation that provides an introduction to how and why institutional racism exists. They also do a 2-day phase 1 training that really digs into the history and projects it into the present regarding how these systems were*

built. That 2-day training can change your life. It’s very uncomfortable, but it really reveals the underpinning of how racism in institutions was created.”

It can be challenging, especially for clinicians, to find time to attend workshops. It could be beneficial for leadership and/or staff education team members to learn from longer, in-depth programs and then create shorter videos or presentations for training sessions offered to all employees of the institution. The content could be tailored to address barriers and concerns specific to the institution and community served. Rather than focusing only on imparting knowledge, these training sessions could include role-playing or other forms of behavior demonstrations to identify problems more clearly and offer actionable solutions.

Beth Smith: *“One of the challenges that we had with these training sessions was selecting a time that was best because we wanted physicians to come. Times that were good for staff were not great for physicians and we wanted staff to be there. So, if staff are taking care of patients, it was hard to find a good time. Having something like a ‘TED talk’ that doesn’t take a lot of time to review and having it available is a good idea.”*

Linda Fleisher: *“I think it’s both the knowledge and demonstration of the behaviors and ways of coping with some of the issues that I think would be important.”*

Summary

This learning guide provides actionable steps that institutions can take to acknowledge and address racial disparities in cancer care. Modeled after the ACCURE trial, the approach discussed has been shown to improve care for all patients.^{30,62}

- Utilizing digital data in real time to enhance transparency and monitor patient progress from cancer diagnosis through treatment is a practical and efficient use of resources
- Timely, objective, race-specific feedback provided to clinical teams can drive sustainable transformation within cancer facilities, with solutions catered to the specific needs of the community served and the institution
- Navigators provide coordination and accountability to ensure that milestones are met, and barriers are resolved
- Health equity training of healthcare employees is recommended to provide a broader background and perspective on the topic in general and to demonstrate helpful behaviors and practices for employees to adopt at their own institution.

As this learning guide describes, the key is to build a system capable of signaling missed appointments on the patient side or clinical inertia on the medical side, in addition to identifying barriers and linking users to workflows created to find solutions. The result translates to optimized care for all patients and a marked reduction in disparities.

A working group consisting of multistakeholder cancer care

experts recently published a framework for addressing disparities in cancer care among underserved populations in the United States, and in concurrence with this learning guide, the convened experts identified community engagement, patient navigation, and healthcare system changes as the critical issues to focus on to provide equitable cancer care.¹² As in this learning guide, the framework highlighted the role of navigators, and the importance of tracking patients through transitions of care, using data and IT solutions to monitor metrics throughout the cancer care continuum, and watching for cancer-related distress and social determinants of health among patients.¹²

Sam Cykert: “It’s the transparency of real-time digital data with the accountability of good communicating, real human beings who happen to be navigators.”

Tracking patient progress digitally is an effective strategy for improving outcomes. The Commission on Cancer (CoC) National Cancer Database released the Rapid Cancer Reporting System on September 28, 2020, for use in all CoC-accredited programs as a Quality Indicator Tool.⁶³ Insurance companies are gradually switching to pay-for-performance or value-based reimbursement models.⁶⁴ The suggestions outlined in this learning guide align with these trends but also focus on intentional interventions aimed at reducing racial disparities.

Matt Manning: “[It’s] a lot of work to address the status quo and say, ‘That’s really not good enough, we need to do better.’”

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