Advancing efforts to reduce inequity in cancer care

Overview

The *Alliance to Advance Patient-Centered Cancer Care* (the Alliance) is a response to the stark inequities in cancer care throughout the United States. This five-year, national effort set out to improve timely access to high-quality, patient-centered care for people living with cancer from underserved communities in Arizona, Georgia, Maryland, Massachusetts, Illinois, and Ohio.

The Alliance succeeded in reducing disparities in access to care, increasing timeliness of treatment, and improving patients' satisfaction with their care for a broad range of cancer patients: those from rural areas and low-income communities, racial and ethnic minorities, people with serious mental illness and the LGBTQ population.[1]

Led by the University of Michigan School of Nursing, this collective of six health care organizations from Boston to Tucson helped transform how people living with cancer receive care – improving their quality of life and advancing health equity.

Cancer disparities

Cancer is the second leading cause of death in America after heart disease.[2] The delivery of cancer care in the U.S. is fragmented, which has created barriers and delays to care, worsening patients' stress, quality of life and survival outcomes. Certain populations, including those living in areas with persistent poverty and racial, ethnic and gender minorities, face disparities in reliable access to quality cancer treatment and suffer greater cancer mortality rates in comparison to the rest of the population.[3]

Cancer in the U.S. 2022 facts & figures[2]

- 2nd most common cause of deaths in the U.S.
- 1.9 million new cancer diagnoses in 2022
- $246 billion – Expected cost of cancer-related direct medical care in the U.S. by 2030

Program design

In 2017, the Merck Foundation launched the *Alliance to Advance Patient-Centered Cancer Care*, a five-year, $15 million multi-site initiative to promote equitable access to high-quality cancer care in the U.S. The Alliance's six program grantees implemented a range of strategies to address inequities in cancer care and improve the quality of life for people living with cancer in underserved communities across the country.

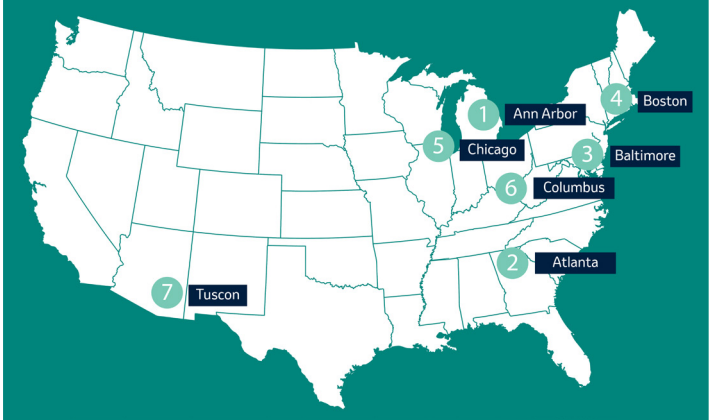
These six organizations focused on confronting barriers cancer patients face within and outside of the health system by:

1. **Improving coordination** across the continuum of cancer care from diagnosis through treatment and survivorship

2. **Enhancing communication** between patients and providers

3. **Offering psychosocial and other supportive care** that helps patients and their families cope with emotional and financial stresses during treatment.

The University of Michigan School of Nursing served as the Alliance's National Program Office, facilitating collaboration among the sites, providing technical assistance and disseminating program outcomes and best practices. The Alliance demonstrated the importance of partnering with other cancer centers to exchange interdisciplinary ideas and approaches that can inform, enhance and improve the effectiveness of future patient navigation interventions.[4]



Program partners

- **University of Michigan School of Nursing – National Program Office**, *Ann Arbor, MI*
- **Georgia Cancer Center for Excellence at Grady Health System**, *Atlanta, GA*
- **The Johns Hopkins University School of Medicine**, *Baltimore, MD*
- **Massachusetts General Hospital Cancer Center**, *Boston, MA*
- **Northwestern University Feinberg School of Medicine**, *Chicago, IL*
- **The Ohio State University Comprehensive Cancer Center**, *Columbus, OH*
- **University of Arizona Cancer Center**, *Tucson, AZ*

Transforming cancer care delivery

Program partners transformed how they delivered cancer care in underserved communities by addressing the social factors that influence health and linking patients to resources to meet their basic needs. Each of the six partners initiated significant changes within their organizations to develop a more integrated model of care that is contributing to improved health and quality of life for thousands of cancer patients across the country.

Alliance reach:

> 6,000
Cancer patients enrolled in Alliance programs

> 450
Health workers trained in cancer care coordination, communications, and supportive care

MERCK Foundation

As a collective, Alliance partners achieved the following outcomes:

Reduced disparities in access to care by:

- **Promoting a deeper understanding across their organizations** about inequities and barriers to care for vulnerable populations that result from the social drivers of health
- **Creating partnerships with local social service organizations** that offered affordable transportation to appointments, food delivery and financial support for uninsured patients

Increased timeliness of treatment by:

- **Establishing structured processes**, including patient screening and assessment workflows, checklists and team debriefs, which strengthened the exchange of information across care team members and with patients' primary care doctors throughout all stages of treatment
- **Implementing various technologies** that automated referrals and appointment reminders for patients; captured navigation, care transition and survivorship-related data in EPIC medical records; and offered patients a free, user-friendly electronic solution to report symptoms to their care teams between appointments via their smartphones

Improved patient satisfaction in care by:

- **Adding new team member roles** to provide patients with personalized support, including navigators, case managers and diet and exercise coaches
- **Embedding patient and family advisory councils** into organizational structures and acting on their feedback
- **Training care teams** to enhance communications and case management skills

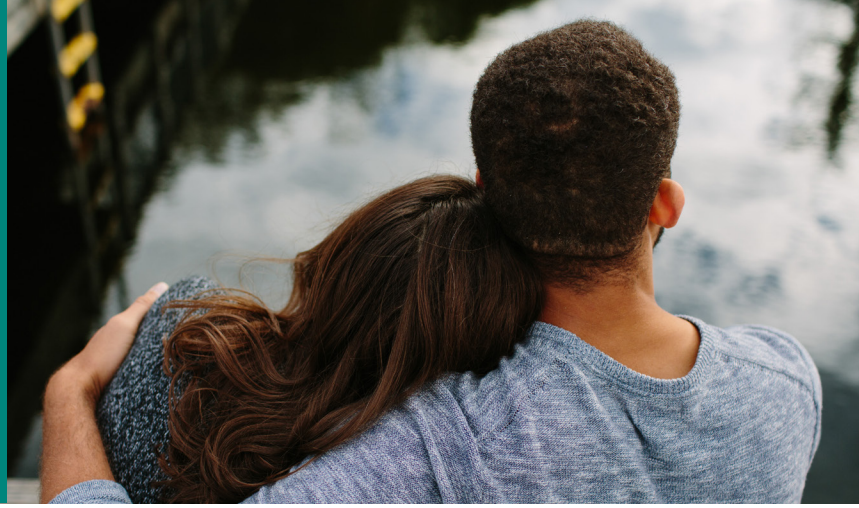
Merck Foundation's ongoing commitment to advance equitable cancer care

The *Alliance for Patient-Centered Cancer Care* united health care providers, community leaders and companies to improve the quality of cancer care and reduce disparities for underserved communities across the country.

The Alliance's success in transforming the delivery of cancer care is leading to sustained impact, long past the five-year grant period. The Ohio State University has recently enhanced its longstanding partnership with a service provider to provide smartphones for quality improvement and research studies aimed at reducing disparities in patient participation. Grady Health System has permanently embedded nurse navigators into the Cancer Center and in community initiatives. At University of Arizona, the College of Medicine has integrated implicit bias training for all medical students into its curriculum, reflecting a significant systems-level commitment to address inequities in cancer care by focusing on physicians. To learn more about the Alliance for Patient Centered Cancer Care, visit: www.cancercarealliance.org.

Building on the Merck Foundation's legacy of investing in community-focused programs that advance health equity, the Merck Foundation launched the *Alliance for Equity in Cancer Care* in 2022. This five-year national, multi-site initiative is focused on improving access to high-quality, culturally responsive cancer care for patients from underserved communities. To learn more about the Alliance for Equity in Cancer Care, visit: www.equityincancercare.org.

Partner profiles: Innovative solutions to address patients' needs



Scaling up patient navigation at a safety net hospital: **Georgia Cancer Center for Excellence at Grady Health System**

Need
Low-income communities and individuals from racial/ethnic minorities in Atlanta experience disparities in access to care that can lead to late diagnoses and delays entering cancer treatment.

Approach
Grady added six nurse navigators who work with clinical teams to identify and address bottlenecks in care. This cadre guided the development of a digital navigation dashboard to better track patients and coordinate care. The new tool helps navigators ensure that patients receive clear, timely and regular information and guidance on treatment plans, are supported to arrange appointments and diagnostic tests and have access to resources such as nutrition and exercise coaching. Navigators also referred patients to local social services, including safe transport and food delivery – which were particularly critical for patients throughout the COVID-19 pandemic.

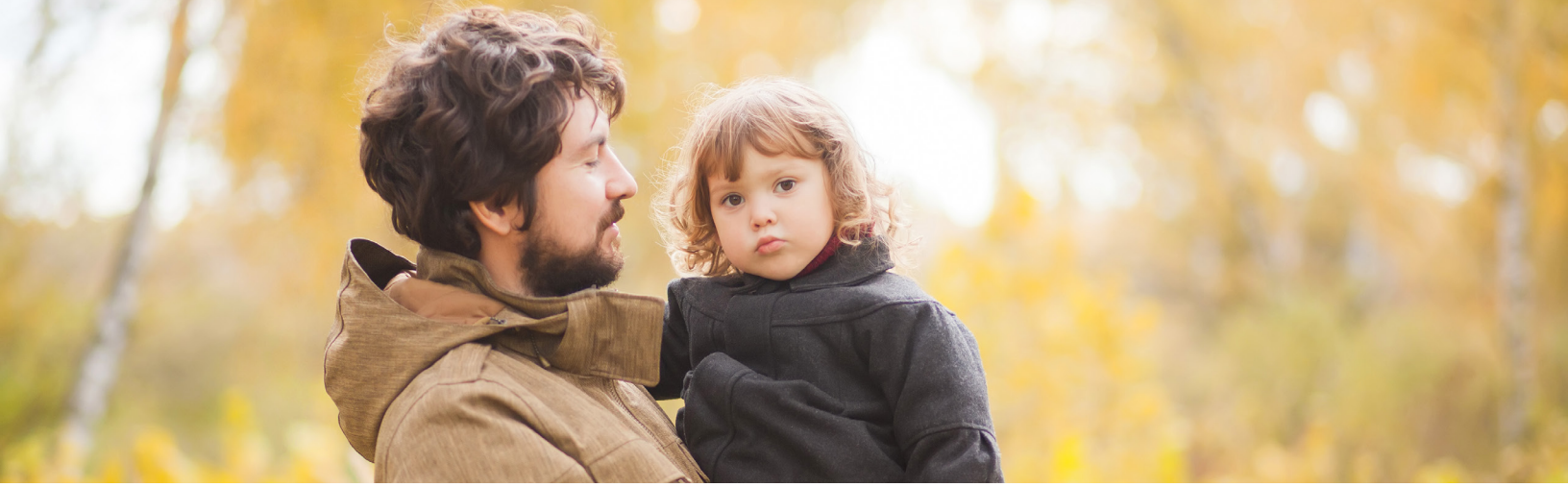
Impact
Significant improvements in timely care:
Treatment delays and missed appointments at the Center have dropped considerably since the program began in 2016. Grady reported:

- 93% of patients needing a same-day intervention now receive it
- 52% reduction in average time from breast cancer diagnosis to treatment
- 80% reduction in average time from gynecological cancer diagnosis to treatment
- 33% reduction in the rate of missed appointments

Grady received the global non-profit Planetree International Care's highest mark of achievement – *Gold Certification for Excellence in Person-Centered Care* – for creating an organizational culture that engages patients, families, staff and the community to improve health.

"When we started this journey, we knew it would have an impact, but I don't think any of us anticipated how far-reaching the changes would be – not only on patient care, but employee engagement…We have also reduced the time from diagnosis to treatment. The navigators, dieticians and exercise coaches have all been a huge piece of bringing those numbers down significantly."

– Grady Health System



Equipping primary care doctors to support cancer survivors: **The Johns Hopkins University School of Medicine**

"The hope was that by increasing knowledge among general internists, the coordination of care would improve between oncology and primary care providers because now the patients no longer had to rely solely on their oncologist for questions and management."

– Johns Hopkins University School of Medicine

Need

More people are surviving cancer than ever before in the United States.[5] However, primary care doctors may not have the latest guidance and tools to manage the long-term effects of cancer treatment on their patients.

Approach

The Johns Hopkins University developed an automated survivorship planning tool for primary care physicians. The tool creates transition care plans by pulling data from patients' medical records and generating care recommendations for patients in remission from lung and breast cancers, based on approved treatment guidelines.[6]

Impact

New standard of care:

- Johns Hopkins reported that the survivorship tool saved providers' time, made the transition from cancer care to primary care more seamless, and helped to empower patients by providing them with the information they need to understand and control their own care.
- The tool has become the default survivorship tool within EPIC, used by physicians across the university's extensive network, and is now available for replication by other health systems across the country.

Improving timely care for cancer patients with serious mental illness: **Massachusetts General Hospital Cancer Center**

Need

Individuals with serious mental illness (SMI) experience a 30% higher fatality rate from cancer, in part because they are less likely to receive timely, quality care.[7]

Approach

Massachusetts General Hospital (MGH) Cancer Center collaborated with North Suffolk Mental Health Association – one of the largest providers of mental health services in Massachusetts – to improve timely cancer detection and care for people with SMI. The Cancer Center developed a population-based registry of SMI patients so that local community cancer providers could quickly identify those who are more likely to experience disruptions in care.

The Center also led education programs designed to help mental health clinicians, frontline residential and recovery staff support SMI cancer patients to fully understand the risks of untreated cancer and crafted solutions with the medical team to keep patients from falling out of care. In addition to collaborating with Suffolk Mental Health Association, the Center also hired and trained multilingual patient navigators to guide immigrants and refugees, another underserved population, during cancer treatment.

Impact

New model of care to improve adherence to treatment:

- Innovation in improving cancer care for people with SMI, immigrants and refugees
  - Developed insights into the importance of continued education of health care workers about care, survivorship and navigation needs for patients with SMI
  - Expanded collaboration between psychology and psych-oncology both at the Cancer Center and the broader MGH system
  - Increased patient engagement and completion of treatment visits among immigrants and refugees

- The Patient Centered Outcomes Research Institute, a leading research funder, awarded MGH its prestigious **engagement award** in recognition of the hospital's work with marginalized cancer patients with serious mental illness. The award will fund continued research, including development of a digital engagement toolkit to support SMI patients living in congregate settings, from early detection throughout the stages of cancer treatment.

"Disparities are profound, intersectional and exist due to multilevel factors that include what insurance you have, challenges with trust and resource-related barriers…They also include the challenge of a complex condition, such as a co-morbid mental illness or addiction. All those factors contribute to disparities in cancer outcomes."

– Massachusetts General Hospital

Enhancing cancer care for the LGBTQ Community:
Northwestern University Feinberg School of Medicine

Need

The LGBTQ population faces unique barriers when entering the health care system and often does not receive integrated health care. Challenges in communication and coordination between primary care and oncology providers can result in disparities in cancer treatment.

Approach

Northwestern implemented its 4R (the right information, care, patient and time) cancer navigation and patient self-management tool to improve communication among primary care doctors and oncologists at Howard Brown Health (HBH), oncologists at referral centers and patients and their families.[8] Howard Brown is a Chicago-based Federally Qualified Health Center whose mission is to eliminate disparities in health care experienced by the LGBTQ community.

Northwestern surveyed a sample of HBH patients, caregivers, providers and members of community organizations to better understand the needs of LGBTQ patients. They then integrated the survey findings into the 4R model to ensure LGBTQ patients are informed about and receive the supportive, health maintenance and social care services offered by Howard Brown that could benefit the patients during their cancer treatment. The 4R tools also ensure that patients feel welcomed and safe in clinical settings and have access to psychosocial and other services based on their needs and preferences.

Impact

Integrated specific needs of the LGBTQ community into cancer navigation tool:

- The 4R Oncology model is engaging LGBTQ patients as members of care teams and bridging gaps in communication between clinical teams.
- Northwestern is using the findings from its work with HBH to refine and scale the 4R model and develop a broad protocol to provide coordinated, integrated, equity-centered and complete care to LGBTQ communities that can be replicated at the national level.

"If you want to address disparities across underserved populations, you need to personalize care given the needs and preferences of each patient. That is what 4R aspires to deliver."

– Northwestern University Feinberg School of Medicine

Leveraging mobile technology to improve access to care:
The Ohio State University Comprehensive Cancer Center

Need
Ohio has higher mortality rates than the national average for breast, colorectal, endometrial and ovarian cancers.[9] The disparity is often due to delays in treatment, caused in part by difficulties accessing care. This has long been a challenge for patients from low-income and rural communities in the Central and Appalachian regions of the state.

Approach
Through a partnership with Verizon Wireless, The Ohio State University (OSU) provided free smart phones and monthly phone service to a select group of cancer patients unable to afford service during treatment. All patients were provided access to the monthly symptom monitoring program, which enabled the symptoms and health care needs of all patients undergoing treatment to be monitored and reported to their clinical care teams between appointments. Patients' responses were also used to cue lay patient navigators to address patients' personal needs, such as transportation, paying for gasoline or housing concerns. This monitoring provided more timely responses and referrals as patients' needs evolved throughout the course of treatment.

Impact
Improved communication between patients and providers:

- OSU reported that two-thirds of participants with breast cancer and more than three-quarters of patients with endometrial and ovarian cancer said the program helped them communicate with their care team better and more quickly.
- Participants reported that the technology was extremely valuable in receiving health care remotely, and was especially important throughout the COVID-19 pandemic.
- OSU plans to expand the program to patients with other cancers and is exploring the use of symptom monitoring apps to integrate symptoms directly into patients' electronic health records.

> *"[The smartphone program] allowed the patients to connect with the team and discuss symptoms that they may be experiencing that either weren't addressed in clinic or had developed in the interim – between visits – that were key. I think this is important because during a clinic visit, you're so focused on the cancer, the disease, the treatment… you have limited time."*
>
> – The Ohio State University

Training the next generation of oncologists in culturally sensitive care:
University of Arizona Cancer Center

"[Implicit bias training] has become sustainable in a way that I never imagined. They are now requiring implicit bias training of pretty much everybody in the College of Medicine, from the first-year medical students all the way through the faculty."

– University of Arizona Cancer Center

Need
Language and cultural barriers can lead to delays in testing and treatment that affect health outcomes for cancer patients from Latino communities in southern Arizona.

Approach
University of Arizona developed new curricula and training plans to help its medical students recognize and reduce implicit bias when providing care to patients. The curriculum was developed as part of a larger initiative that included community-focused navigation and psychosocial support for patients and caregivers. The university then conducted observed structured clinical examinations to assess the impact of the training as well as the teaching of communication techniques to build rapport and trust with patients. The College of Medicine reported that more than 100 medical students participated in the pilot training.

Impact
Integrated implicit bias training throughout the medical school:

- The College of Medicine now requires implicit bias training for all medical students, staff and faculty, based on the success of the pilot.
- The focus on implicit bias and racism in medicine has expanded across the College and the hematology and oncology departments are integrating these trainings into their core curriculum.

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