

Introduction to the Special Issue on Inclusive Engagement in Cancer Research and Practice

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We invite readers to explore the works included in this special issue not only for their academic insights but as inspiration for what is possible when research, practice, and community experience converge. Inclusive engagement is not an accessory to cancer research and care — it is central to achieving just, equitable, and transformative outcomes. practice, and community experience converge. Inclusive engagement is not an accessory to cancer research and care — it is central to achieving just, equitable, and transformative outcomes.

The burden of cancer across the United States, as well as globally, continues to shift in ways that challenge our healthcare, research, and community systems. In 2025, the American Cancer Society projected 2,041,910 new cancer cases and 618,120 cancer deaths nationwide—an average of 1,700 lives lost from their communities each day (American Cancer Society, 2025)., Disparities in incidence, survival, and access remain persistent and troubling despite remarkable advances in treatment. Younger adults are experiencing increased rates of colorectal cancer, while Black and Native American patients continue to face survival outcomes two to three times worse than their White counterparts for several major cancer types (American Cancer Society, 2025). Rural communities also shoulder a disproportionate burden, experiencing higher incidence and mortality, especially in regions where

access barriers—like long travel distances, fewer specialists, limited broadband, unstable housing, and gaps in insurance coverage— combine with long-standing inequities to increase risk and delay care (Semprini et al., 2024).

These realities underscore the importance of partnerships that span health systems, research institutions, and communities. It is from this context that the ENGAGE! Special Issue, “Inclusive Engagement in Cancer Research and Practice,” emerges. Developed in collaboration with the Indiana University Simon Comprehensive Cancer Center (IUSCCC) Office of Inclusive Excellence, this issue reflects a shared commitment to uplifting the evidence, practices, and community wisdom needed to advance equitable cancer prevention, care, and survivorship.

Symposium Roots and Evolving Vision

This special issue grows directly from the “Cancer Burden Across Indiana Symposium” series, which has quickly become a signature statewide convening point connecting biological findings at the molecular level, clinical care, and community engagement. From its inception, the symposium was designed not only as a forum for research dissemination but as a tool for community empowerment—a space to inform

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communities about how to participate fully in the cancer continuum and a mechanism for surfacing best practices for reducing cancer risk and improving survival.

The 2024 Inaugural Symposium. Held under the title “Cancer Health Disparities Symposium”, the inaugural event set the foundation for a new model of statewide engagement. Keynote speaker Ruemu Birhiray, MD, delivered a compelling address on “Strategies for Confronting Our Common Responsibility of Equitable Cancer Care: Driving Diversity in Cancer Clinical Research,” calling participants to reshape systems that have long excluded minoritized populations. The program highlighted differences in tumors that may be linked to inherited traits by race and ancestry, and stakeholder-engaged interventions to improve access to curative therapy among Black and low socioeconomic status patients. Breakout sessions explored research that looks at cancer patterns across groups of people and communities (population science); everyday factors that affect that stratify health outcomes, such as housing, transportation, food, income, education, and insurance (social determinants of health/SDOH); and programs meant to equitably improve access in care delivery (equity-focused interventions). As described in the 2024 Research Newsletter summary, the event “captured the breadth of cancer disparity-focused research on campus from basic science studies to clinical applications,” while charting a course for sustained collaboration (Indiana University Simon Comprehensive Cancer Center, 2024).

The 2025 Cancer Burden Across Indiana Symposium. Building on that momentum, the

symposium held in July 2025 expanded its scope, drawing more than 100 participants—including faculty, clinicians, trainees, community leaders, and industry partners—to explore the theme “Connecting Molecular Mechanisms to Treatment, Care, and Community.” Keynote speaker Tuya Pal, MD, delivered a timely and deeply relevant address on “Inherited Factors in Breast Cancer: Care and Outcomes Across Populations,” underscoring how genetics, inequities in access, and population-specific risk shape clinical outcomes. Sessions addressed differences in tumors linked to inherited traits as a tumor feature that can guide treatment (molecular biomarkers); perspectives as to how culture, beliefs, family roles, trust, and lived experience shape cancer care; survivor experiences; rural health equity; and the connective tissue of community engagement. A closing reflection captured the spirit of the symposium, describing it as a space where “bench, bedside, and community interface to address Indiana’s cancer burden” (https://cancer.iu.edu/about/news/stories/2025-07-31-cancer_burden_across_indiana.html).



The central purpose of the symposium series is to create a shared space where community members gain the knowledge, language, and partnerships needed to recognize risk, navigate care, and advocate for equitable outcomes across the cancer continuum. These symposia have not only elevated current research but have also helped the community understand where they can act and how they can shape the system that serves them. While the series is hosted locally, its core aim is broadly applicable: to strengthen trust, improve access, and accelerate equitable outcomes by building partnerships that treat community members as co-creators of solutions.

Symposium Roots and Evolving Vision

This special issue continues that spirit of collaboration by bringing together articles grounded in prevention, access, advocacy, and equity. Because the call was issued broadly, the contributions extend the work to span diverse regions, care settings, and community contexts while remaining firmly anchored in the lessons, values, and practices of community-engaged cancer research. Importantly, each article offers something that community members can take away—knowledge to act on, questions to ask, and pathways to engage.

Theme 1: Strengthening Prevention, Screening, and Early Detection Through Community-Engaged Approaches. This theme highlights how community-engaged strategies can help individuals recognize cancer risk earlier and navigate the screening process with confidence. “Understanding Help-Seeking Behavior in Oncology Through Community Engagement” provides insight into how misinterpreted symptoms, fear, and communication

gaps delay care, and offers community members strategies for preparing questions and advocating for their needs. “Partnering with Native Communities to Reduce Tobacco-Related Cancer Risk” demonstrates how culturally grounded, community-led approaches support commercial tobacco cessation while honoring Native traditions. “Colorectal Cancer Risk Assessment: A Community-Engaged Tool for Screening Equity” shows how a simple community-informed risk assessment helps people determine screening eligibility and overcome insurance or stigma barriers. Lung health contributions reinforce these lessons: “From Eligibility to Results” demystifies lung cancer screening and encourages early detection through clear, accessible information, while “Increasing Lung Cancer Screening Through Opportunistic Referrals” teaches readers that screening opportunities may arise during other healthcare encounters and empowers them to proactively ask about eligibility. Collectively, these articles reinforce that prevention and early detection begin with knowledge, culturally relevant tools, and active community advocacy.

Theme 2: Expanding Equitable Access to Treatment, Precision Medicine, and Clinical Research Participation. Articles in this theme explore how community members can navigate treatment decisions and advocate for equitable access to emerging therapies and clinical research. “Enhancing Clinical Decision-Making in Cancer Treatment Through DRIVE Scores” introduces a practical tool that helps community members evaluate whether cancer treatments were tested in populations similar to their own, strengthening informed decision-making and trust in care. “Lung Cancer Outcome Improvement Through Genotype-Specific Care”

explains how biological testing to match treatment to the tumor’s genetic features (precision medicine) shapes personalized lung cancer treatment and empowers patients—especially those facing insurance or geographic barriers—to ask about comprehensive testing options that may change their prognosis. “Digital Equity in Clinical Trials: Lessons from an E-Consenting Pilot” reveals how digital platforms can reduce travel burdens and support thorough consent review, while also acknowledging the digital literacy support needed to ensure equity rather than deepen disparities. Together, these articles help community members understand the value of inclusive science, recognize gaps in access, and engage more confidently with treatment and research options that can improve outcomes.

Theme 3: Lived Experience, Advocacy, and Community-Rooted Leadership Across the Cancer Continuum. The final theme centers on how lived experience and advocacy shape cancer care, policy, and survivorship. “Addressing Healthcare Utilization Inequities in LGBT Cancer Survivorship” gives community members practical insight into how discrimination, stress, and financial strain affect care, while offering strategies to recognize inequities, seek affirming support, and navigate survivorship more safely. “The Evolving Landscape of Sexual Orientation and Gender Identity (SOGI) Data Collection” helps readers understand why SOGI data improves care and how to make informed disclosure decisions in shifting policy environments with privacy and safety concerns. “Fighting for the Few: Advancing Research in Rare Childhood Cancers” demonstrates how families, researchers, and advocates drive progress for rare diseases, showing readers how community advocacy influences research agendas, funding, and

legislative action that directly benefit children and families. Together, these contributions underscore that meaningful change in cancer care relies on community leadership, shared stories, and cross-sector collaboration grounded in equity and compassion.



Looking Forward

Our intent is that this special issue serves not only as a scholarly resource but also as a call to action. By amplifying the voices and insights of symposium contributors and national partners, we demonstrate how institutions, health systems, policymakers, and communities can work together to co-create solutions that reduce cancer disparities across populations. The Cancer Burden Symposium series will continue in 2026, expanding opportunities for new collaborations, community leadership, and innovative approaches to cancer equity. This special issue stands as both a marker of collective progress and an invitation for continued engagement.



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