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ENGAGE!

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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

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_accross_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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Reflection of Help-seeking Behavior in Oncology through Community Engagement

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Abstract

Cancer care is not only about the medical treatments people receive but also about the support that helps them through the journey. In this study, we surveyed twenty-five people (eight patients and 17 supporters) to learn more about the challenges they face when seeking help and the ways they cope during a cancer journey. Patients often talked about difficulties like misinterpreting symptoms or dealing with the impact of COVID-19, while supporters pointed to a need for more information and resources. Both groups highlighted the importance of access to treatment, patient-centered care, and steady emotional and social support. Patients were less comfortable than supporters in raising concerns with oncologists, showing the need for supporters to be the bridge to stronger communication and trust. Many participants described leaning on emotional coping strategies, while also wishing for clearer information and guidance to help them make decisions. These stories show common patterns in how people seek help, what makes them feel supported, and where there are gaps that can be addressed by their community of support. By listening to these voices and reflecting on their responses, we can work with the community to create resources and programs to increase successful outcomes during a cancer journey using community-participatory approaches.

Keywords: Help-seeking behavior, Coping strategies, Cancer care journey, Patient support systems, Patient-provider communication, Community-engaged Research

Introduction

According to the Indiana Cancer Consortium, two out of every five Hoosiers will experience cancer in their lifetime; as of 2019, Indiana's cancer mortality rate (adjusted for age) was 11.4% higher than the national average (Indiana Cancer Consortium, 2021). In 2017, the most reported cancers in Indiana included breast (31.4%), prostate (21.3%), and lung (males: 15.2%; females: 13.6%) (Indiana Cancer Consortium, 2021). Importantly, many factors shape an individual's response to symptoms that may be related to cancer. Childhood trauma, or adverse childhood experiences (ACEs), is associated with co-occurring anxiety and depression, which could influence help-seeking, adherence to treatment, quality of life, and coping (Coupe et al., 2024). Additionally, social needs (i.e., food security, access to healthcare, housing, transportation, etc.), also referred to as social determinants of health (SDH), can influence how a person responds to symptoms and health behavior (Andrejko & Katrichis, 2022). Thus, attending to the individual social, emotional, and mental needs of cancer patients is critical to improving the quality of care and outcomes for all Hoosiers.

Hoosiers from different racial and socioeconomic backgrounds have varying cancer-related beliefs based on ACEs, experiences of medical racism, and more. These beliefs about cancer can influence how individuals respond to symptoms that may be related to cancer. Research suggests that individual differences can shape whether barriers are service-related, emotion-related, or both (Moffat et al., 2016; Oshiro et al., 2022). Service-related barriers include physical barriers to accessing care, such as difficulty getting into an oncologist and a lack of health insurance. Emotion-related barriers, potentially resulting from ACEs or unresolved medical trauma, include fear of being a burden on healthcare staff and difficulty discussing symptoms with the medical team, among others. These emotional and social conditions can affect how easily someone gets care, how quickly they are diagnosed, how they make treatment decisions, how they cope, and their overall outcomes.

Effective patient-provider communication, both verbal and nonverbal, plays a crucial role in the quality of treatment and overall patient satisfaction. Research shows that physician bias based on race and ethnicity exists in cancer care. This bias can be unconscious or intentional and can affect how doctors communicate with and treat patients. Surveys of oncologists suggest that people may be treated differently within the healthcare system depending on their race or ethnicity (Schatz et al., 2022). For example, studies have found that unconscious bias can lead to less supportive communication and poorer pain treatment for Black patients compared to white patients (Fiscella et al., 2021). Patients have also reported that issues impacting communication include a need for increased empathy from oncologists and more personalized treatment information (Anderson et al., 2021). Physician bias can inhibit this essential communication, preventing sensitive, patient-centered interactions and productive help-seeking behavior during the cancer journey.

Study Background

This reflection is based on a small, community-engaged pilot study that explored the challenges people face when seeking help for cancer and how patients and their support networks cope. By listening directly to community members and their experiences, we identified healthcare needs that can guide a larger community-based participatory study in the future.

Methodology

We created separate surveys for patients and support members using Qualtrics, an online platform. The surveys included a mix of closed-ended (i.e., multiple choice, select all that apply) and open-ended (written response) questions drawn from well-established questionnaires about cancer awareness, coping strategies, and patient needs, along with basic background questions. The surveys can be found through Indiana University Indianapolis ScholarWorks (Dimon, A. & Kimble-Hill, A., 2024).

Participants included U.S. citizens who were 18 years of age or older with a history of cancer (for patients only) and who were recruited through social media outreach (LinkedIn and Facebook) and grassroots flyer campaigns on the Indiana University Indianapolis campus, coffee shops, and hospitals in surrounding areas. Emails and targeted social media campaigns were also distributed to religious and cultural organizations to recruit patients and supporters. Providers within the Indiana University Health System were invited to participate via email. This study was approved by the Indiana University Institutional Review Board (protocol #23844) before data were collected in 2024.

Indiana has a lower population of historically underrepresented populations compared to many states in the United States, with the largest of those groups reported in the 2023 census to be Black/African American (10.4%), Hispanic/Latino (8.8%), and two or more races (2.5%) (U.S. Census Bureau). Furthermore, there is a significant socioeconomic challenge where 12.3% of Hoosiers were reported as living in poverty (U.S. Census Bureau). This study was designed to target participants from those populations so we could better understand the challenges underserved people face when accessing cancer care. Furthermore, this study focused on recruiting participants based on cancer diagnosis from Indiana, where 403.7–614.6 out of every 100,000 African Americans (female-male) and 335.8–362.1 out of every 100,000 Hispanic/Latine (female-male) individuals are diagnosed with all types of cancer each year (Swanson et al., 2011). As these communities make up a smaller part of the Central Indiana population, it further limited the potential patient and support participant base thereby limiting this work to being a pilot study.

The final sample consisted of eight patients and 17 support members. Of the 25 respondents, the majority identified as White (68%), followed by Black (24%), Hispanic, Latino, or Spanish (4%), and Asian (4%). Three patients and 11 support members responded to the open-ended questions.

We used SPSS (version 29.2), computer software, to compare closed-ended survey responses across groups. Two members of the research team reviewed written responses and identified common themes. The goal was to better understand the experiences of patients and their support members to better meet patient needs and improve satisfaction and health outcomes.

Summary of Important Findings

Help-seeking Barriers

When asked to select which help-seeking barriers inhibited patients and support members from seeking care, 62% of patients selected 'other' compared to 29% of support members. Patients in our sample mentioned "misinterpreting symptoms" and "Covid" as obstacles to seeking cancer care. The Theory of Planned Behavior explains that people make health decisions based on what they believe will happen if they take action, what they think others expect of them, and how confident they feel in their ability to do it (Bosnjak et al., 2020). These patient responses could be due to a lack of cancer-related knowledge to accurately assess the consequences of delaying care or due to medical mistrust around which symptoms will 'count' as severe enough to justify seeking help. They also demonstrate how environmental factors can decrease their level of confidence, thereby hindering help-seeking.

Understanding what prevents patients from seeking care is critical to determining the best support to assist them during the cancer journey. Both patients and support members believed it was important for healthcare teams to adopt culturally sensitive, patient-centered care approaches to enhance the quality of care and improve health outcomes for all individuals, especially marginalized Hoosiers. For example, one patient suggested, "Being more watchful of the patient's symptoms after certain procedures have been conducted." Picker's Eight Principles may serve as an effective tool for patients and supporters to evaluate whether the care provided aligns with patient needs. These principles outline factors that influence patient care, including clear patient-provider communication, ensuring continuity of care, encouraging social support, suggesting effective treatment options, considering the social-emotional and physical needs of patients, and engaging in shared decision-making (Picker, 2023). Knowing these principles can help patients and support members advocate for patient needs to receive higher-quality care.

Patient Needs

All participants were asked questions about their perspectives on which social needs are important to discuss during the cancer journey. However, patients and support members were instructed to respond slightly differently, so the frequencies are reported separately for each group. Patients most frequently prioritized discussion about financial concerns (71%) and support systems (43%). Support members also prioritized discussion of the patient's support system (65%) and mental capabilities (65%).

When asked to explain which social needs they felt were important to discuss with healthcare providers during their cancer journey, both groups mentioned having access to resources and treatments as important knowledge for Hoosiers. For example, a support member stated, "I wish there was a handbook that helped you with resources you can take advantage of and general information." The emphasis on resources, access to treatment, financial consideration, and other factors in patient and support responses highlights disparities in access to quality cancer care. Associations between SDH and cancer screening disparities show how the patient's social background guides help-seeking behavior, the quality of care, and health outcomes (Venkataramany & Sutton, 2022). Patients and support members should advocate for resources that remove structural barriers related to patient needs to enhance care quality and health outcomes. Engaging in these efforts has the potential to increase patient engagement in policy reform that goes beyond what physicians can achieve alone. Interventions should address these patients' needs and reduce structural barriers to quality care.

Patient Comfortability

Feeling comfortable with treatment team members can be crucial to patient health outcomes, such as continuity of care (Sharkiya, 2023). When asked which team members, patients, and supporters were most comfortable addressing concerns with, patients (25%) felt significantly less comfortable with oncologists compared to supporters (71%). Research shows how attention to communication practices is critical to improving the comfort of patients with cancer. According to the National Cancer Institute (2025), oncologists should share health-related information using general language, attend to the emotional needs of patients, and involve them in treatment decision-making to enhance patient comfort. Since oncologists play a critical role during the cancer journey, support members and researchers must identify more specific ways to improve patient comfort in addressing concerns with their oncologist, especially among marginalized patients.

With the importance of patient comfortability in mind, we asked patients and support members what makes them feel comfortable with their healthcare team. Both groups discussed that attention to patient care requirements (e.g., avoiding medical jargon and proposing treatment alternatives) made them more comfortable raising concerns with healthcare providers. For instance, one support member remarked, "Able to form a great relationship with the Oncologist -— that still exists." This quote highlights the importance of building rapport with the treatment team to enhance comfort and open communication, leading to stronger relationships and better health-related outcomes.

Factors Influencing the Patient Experience

Patients and support members were asked to select all factors that improved or would have improved their satisfaction with their care. Patients were most likely to associate their satisfaction with having a physician with "a friendly and open demeanor" (50%), who was '"easy to ask questions of" (50%), and who "effectively answers questions" (50%). Support members were also likely to connect their satisfaction with having a care team that is "easy to ask questions of" (52%), but unlike patients, they also prioritized having a care team that "spends time with them" (58%).

Patients and support members were asked to identify what made them feel satisfied with their care. Both patients and supporters felt most satisfied when it was easy to ask their care team questions. Patients felt more strongly that it was important for care members to be able to effectively answer questions, while support members valued when healthcare members spent time with patients. Individual patients and caregivers have particular communication preferences related to target (e.g., provider, peer), content (e.g., emotional support, cancer-related information), style (e.g., language, in-person or virtual), and timing (e.g., prior to treatment, end-of-life) (Li et al., 2022). Understanding the communication preferences of these groups can inform interventions to improve supportive care in the oncology setting, leading to higher patient satisfaction.

In addition to what patients and support members valued about the healthcare team, participants were also asked to explain additional resources that would have eased their cancer journey. Patients mentioned that attention to their needs and social support would have been helpful resources. For example, one patient stated, "A Nurse Navigator who didn't stop responding to my phone calls after the first month would have been nice." Contrarily, support members mentioned that health education and resources (i.e., housing and food vouchers) would have benefited them during the cancer journey. For example, one support member explained, "I don't feel [clinicians] did a good job letting us know about organizations that can help you out. There still may be resources I don't know about." Understanding these different needs can guide the development of coping interventions tailored to each group across the entire care continuum.

Coping Strategies

Understanding coping strategies is critical because they directly influence how patients and supporters manage stress, navigate care, and engage with the healthcare system. Our participants most often described emotion-focused strategies such as seeking emotional support (patient 50%, supporter 53%), looking for something good in what is happening (patient 50%, supporter 41%), and prayer or meditation (patient 50%, supporter 47%). This reflects a general decrease in patterns in which African American, Hispanic, and Indigenous communities relied on religious and community-based coping (Assari, 2014; Culver et al., 2004) that have more recently been overshadowed by other important coping mechanisms such as secular or alternative coping strategies, which could be just as important for younger or less religious subpopulations (Chatters et al., 2008). Careful consideration of these approaches can buffer distress, stigma, mistrust of healthcare, and limited access to accurate information (Conner et al., 2010), but should be a part of a holistic strategy to guide patients to the use of problem-focused strategies during the cancer journey, like strategic planning or seeking information to inform decision making (Carver et al., 1989). More work is necessary to understand the role of strong social support and sensitive patient navigation in addressing cancer patients' mental health as a means to reduce delays in treatment. Therefore, interventions must prioritize coordinated, team-based, and culturally sensitive approaches that incorporate trusted community voices to strengthen positive coping strategies when cancer patients are help-seeking.

Limitations

This study has several limitations. First, it was a small study with uneven participation across groups, which means the findings may not apply to everyone. We also did not work directly with community partners, which may have contributed to lower participation from some racial and ethnic groups. Limited funding meant we could only offer a raffle incentive, which may have reduced the number of people who chose to take part. Finally, patients and support members did not provide the same amount of written feedback, which limited our ability to fully understand each group's experiences.

Conclusions

Before this study, little research had explored barriers to cancer-related help-seeking, and none focused specifically on the experiences of Hoosiers. This study started to address that gap by centering the voices of Hoosiers and highlighting how help-

seeking experiences, coping, patient needs, comfort levels, and overall oncology care experiences can vary across patients and support members. The findings point to meaningful differences that can help guide future education and outreach efforts tailored to the needs of each group. Sharing these results in clear and accessible ways may also promote more open conversations and strengthen communication between patients and healthcare providers, particularly in communities that have been historically underserved.

Reflections and Lessons Learned

This study reinforced the importance of listening directly to community members to better understand the challenges they face when seeking cancer-related care. Building on these insights, future studies will use community-participatory approaches that actively involve community partners in shaping research questions, methods, and educational materials. Working alongside communities to co-create resources for patients, support members, and healthcare providers may help encourage better patient-provider communication practices to improve comfortability, coping, and improve cancer health outcomes. Ongoing research should continue to explore how social position, coping tendencies, social determinants of health, past medical experiences, and trust in healthcare systems influence how people seek support and cope during the cancer journey. Together, these efforts can inform practical, community-informed interventions that strengthen supportive care and promote better outcomes for patients and their support members.

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Partnering with Native Communities to Reduce Tobacco-Related Cancer Risk

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Key Words: Commercial Tobacco Use, American Indianan or Alaska Navite, Community-Based Participatory Research

Summary

Native American populations are more likely to use commercial tobacco products than other racial and ethnic groups in the U.S., contributing to higher rates of cancer morbidity and mortality. Despite this, they remain underrepresented in commercial tobacco control efforts and lack access to culturally tailored resources. To address this need in Indiana, a partnership was formed between the Indiana University Simon Comprehensive Cancer Center's Office of Community Outreach and Engagement; the American Indian Center of Indiana, Inc.; and the Indiana Native American Indian Affairs Commission. The goals of the partnership are to foster bidirectional communication to support culturally relevant research; to assess the specific needs of Native groups; and to advocate for policy changes that promote Native American health and well-being.

As a first step, the team launched the Indiana Native American Adult Commercial Tobacco Survey. Among 53 participants, 66% reported current or former smoking. Most reported quitting without formal support, such as FDA-approved medications or the tobacco quitline. To address these gaps, the next steps include conducting focus groups, identifying culturally-tailored cessation interventions, and creating messaging that resonate within Native communities. Ultimately, this work reflects a commitment to honoring Native traditions while advancing health equity through inclusive, community-driven solutions.

Introduction

Native American populations are more likely to use commercial tobacco than other racial and ethnic groups in the United States.[1, 2] They are also less likely to be covered by policies or rules that reduce exposure to secondhand smoke and are disproportionately impacted by tobacco-related diseases, including certain cancers.[2-4] These disparities have been exacerbated by cultural, socioeconomic, and

historical factors, including targeted marketing by the tobacco industry,[3] misclassification of Native Americans in health data,[5] and the historical trauma associated with colonization and tobacco commercialization.[6] To address these historical and ongoing issues, there is a need to better capture data on tobacco use among Native populations, incorporate Native voices in tobacco control efforts, and develop culturally tailored interventions to address commercial tobacco use, while honoring sacred tobacco.[7]

Partnership with Native American Groups in Indiana to Address Commercial Tobacco

Indiana is home to a diverse group of Native Americans, including members of two federally recognized tribes with land in the state: the Pokagon Band of Potawatomi and the Miami Tribe of Oklahoma.8 Additionally, while not federally recognized, the Miami Nation of Indiana has maintained a longstanding presence with an enrollment of 6,000 members across northern and central Indiana.9 Beyond these groups, there are approximately 25,000 individuals who are members of other federally recognized tribes residing in Indiana.8

Despite this, Native American populations in Indiana often face barriers in accessing culturally-relevant services, particularly in the context of tobacco-related prevention and care. These barriers include a lack of tailored commercial tobacco treatment options, a lack of representation in state commercial tobacco control plans, and limited data specific to Native populations in Indiana. To address these gaps, a collaborative partnership was formed between the Indiana University Simon Comprehensive Cancer Center's (IU SCCC) Office of Community Outreach and Engagement; the American Indian Center of Indiana, Inc.; and the Indiana Native American Indian Affairs Commission. The partnership was grounded in a community-based participatory research (CBPR) framework and guided by the following goals:

- Foster bidirectional communication that results in culturally-relevant research, programs, and initiatives addressing Native American health and well-being.
- Assess and be responsive to needs associated with Native American commercial tobacco use in Indiana.
- Identify areas for advocacy and recommend policies that promote Native American health and well-being.

This partnership reflects a commitment to including Native voices in creating solutions that best meet the needs of Native groups in the state.

As an initial step in meeting these goals, we sought to assess commercial tobacco use among Native Americans in Indiana to inform culturally responsive strategies to reduce cancer risk and promote health equity. In order to do so, the IU SCCC's Office of Community Outreach and Engagement launched the Indiana Native American Adult Commercial Tobacco Survey in 2023. In close partnership with representatives of the American Indian Center of Indiana, Inc., and the Indiana Native American Indian Affairs Commission, we iteratively adapted survey measures from the Centers for Disease Control and Prevention's American Indian Adult Tobacco Survey10 to ensure fit and relevance to native populations in the state. Key measures

ncluded general health, history of tobacco use, quit attempts, secondhand smoke exposure, and ceremonial tobacco use.

Eligible participants were Native Americans 18 years or older who resided in Indiana, were enrolled members, or recognized descendants of any tribal nation. Recruitment was conducted through direct contact via partner networks, social media, and Pow Wows. Participants received a $20 e-gift card for completing the survey. A total of 53 individuals participated, with 89% identifying as members of federally recognized tribes. The majority (61%) identified as female, and over half were between the ages of 18 and 34.

Two-thirds of respondents indicated that, in general, their health was good or very good. Similarly, 66% (n=35/53) of individuals responding to questions about cigarette smoking reported current (34.0%; n=18) or former smoking (32%; n=17), with the average age of initiation being 16.6 years (range:12-28). Among respondents reporting current or former use of cigarettes, the most common methods reported for quitting included, “gave up cigarettes all at once” (15.4%; n=4), “gradually cut back” (11.5%; n=3), or “switched completely or substituted some combustible cigarettes with e-cigarettes” (11.5%; n=3). Only one participant indicated using “nicotine replacement therapy” or other “FDA-approved medications.” Two individuals (7.7%) reported using “traditional methods,” and none of the respondents had “used the tobacco quit line” or “gotten help from a health care professional” in their quit attempt. More than half of the individuals who reported current commercial tobacco use indicated wanting to quit all commercial tobacco products (64.7%; n=11/17).

These findings have been shared at the Indiana Public Health Association’s Health Equity Summit; the National Conference on Tobacco or Health; and the IU SCCC’s Cancer Health Disparities Symposium. Presenting the data in community and professional settings has helped raise awareness related to the need for culturally tailored interventions in Indiana.

Policy Implications and Opportunities

The survey results can be used to build support for policy and programmatic changes to enhance Native American health and well-being in Indiana. Despite high rates of tobacco use and interest in quitting, survey findings suggest a lack of engagement with healthcare providers, use of medications, and engagement with the tobacco quitline to support cessation among Native populations.

Suggestions for addressing these issues include:

- Expanding access to culturally appropriate cessation resources, including those that integrate traditional healing practices as part of statewide tobacco control efforts.
- Training healthcare providers on the cultural significance of traditional tobacco and the unique needs of Native patients.
- Engaging Native American populations in state-level tobacco control strategic planning efforts.

Conclusions

Our partnership model offers several best practices for inclusive, community-engaged research. We prioritized bidirectional communication by actively listening to community partners while developing research questions, methods, and dissemination products. Native partners provided leadership throughout every stage of the project, from survey design to data interpretation and presentation. We also emphasized ethical reciprocity by ensuring that findings were shared with the community in accessible formats and will be using the data to inform next steps of the partnership. In continuing this partnership, we plan to conduct focus groups with Native participants representing different perspectives across the state to explore social and cultural factors influencing commercial tobacco use and cessation. Additionally, we want to utilize data and insights to identify and implement evidence-based, culturally-tailored cessation interventions and develop culturally-appropriate messaging that resonates with multiple generations of Native groups in the state.

The Indiana Native American Adult Commercial Tobacco Survey represents a first step toward understanding and addressing cancer risk among Native populations in Indiana. By centering community voices, honoring cultural traditions, and advocating for inclusive policies, we can begin to address the structural barriers that contribute to unequal access to tobacco prevention and cessation resources in the state. As we move forward, we remain committed to the principle of "Keep It Sacred," a reminder that commercial tobacco control efforts within Native communities must be rooted in respect, reciprocity, and cultural integrity.11 Through continued partnership, policy change, and community-driven innovation, we hope to create a future where all people, regardless of race, tribe, or geography, have the opportunity to live healthy, tobacco-free lives.

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Colorectal Cancer Risk Assessment: Community Engagement Across the Research Continuum

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Background

Colorectal cancer (CRC) is the second-leading cause of cancer deaths in the U.S. when men and women are combined, yet it can often be detected early or prevented through screening. In 2024, there were an estimated 152,810 new cases of colorectal cancer diagnosed in the United States. African Americans face higher incidence and mortality rates compared to other racial and ethnic groups and are more likely to be diagnosed at a younger age. Geographic disparities also play a role. In Indiana, rates of CRC remain above the national average, with rural communities and minority populations experiencing greater barriers to timely screening, diagnosis, and treatment. Screening can prevent colorectal cancer through the detection and removal of precancerous growths (polyps), and it can often detect cancer at an early stage, when treatment is usually more successful. The challenge lies in ensuring that every eligible individual not only knows about their screening options but can also access them equitably.

Implementation

The Indiana University (IU) Simon Comprehensive Cancer Center's Office of Community Outreach and Engagement (COE) seeks to lower the cancer burden in Indiana by providing a bidirectional link between IU Simon Comprehensive Cancer Center researchers and the communities we serve, with a focus on underserved populations. COE has three advisory committees comprised of community members who provide insights, concerns, and feedback on our programs and communications. At the time of development, the COE office utilized the Community Impact Advisory Council (CIAC). The committee is comprised of leaders of minority-serving community partners and others involved in health disparities research. The purpose is to advise COE efforts that support research practices and dissemination to reduce the cancer burden on our underserved populations.

Born from the CIAC concerns for screening access and knowledge gaps among the populations they serve, COE created a colorectal cancer screening risk assessment. The original purpose of the tool was

to help community participants identify if they were eligible for a stool-based screening modality. The tool evolved and was later designed to 1) educate community members on their personal risk level and determine the most appropriate CRC screening test; 2) facilitate community-clinical linkages by providing education, referrals, and navigation to insurance or primary care providers; and 3) model a community-engaged approach to research that includes stakeholders from inception to implementation.

The CRC risk assessment underwent multiple iterations, reflecting true community-engaged research practices:

- Community listening sessions ensured that the tool's questions and format resonated with lived experiences.
- Health system partnerships strengthened clinical integration and facilitated pilot testing.
- Faculty expertise ensured scientific rigor by adapting measures from validated cancer risk surveys.
- Pilot testing in Indiana helped refine usability, clarity, and effectiveness.

The tool ultimately incorporated questions about general health status, family history, age, and other risk factors. Importantly, it evolved from only identifying eligibility for stool-based testing to classifying individuals as high-risk or average-risk and guiding them toward appropriate screening pathways.

For community members, the risk assessment worked like a personal roadmap for colorectal cancer prevention and screening. Instead of vague recommendations, individuals walked away with tailored information: whether they may need a CRC screening, whether a stool-based test was an option, and how to access care. Individuals were informed that the tool was designed to provide general health information. It is not a substitute for medical advice, diagnosis, or treatment of any health condition or problem. All participants were strongly encouraged to talk with their doctor about CRC screening and follow cues to action (public health construct).

Discussion & Implications

Key findings from the pilot experience include: 1) many Hoosiers were unaware of their screening eligibility or guidelines; 2) barriers included lack of insurance, lack of a primary care provider, limited awareness of stool-based tests, and stigma or aversion toward colonoscopy; and 3) many expressed that CRC screenings were not promoted by their primary care provider due to the focus on COVID-19 screening and vaccinations. The tool helped address these barriers by educating participants, reducing stigma, and clarifying that multiple screening options exist.

Additionally, the risk assessment implementation highlighted several challenges within the current and changing policy landscape: most importantly, insurance coverage and access to screening. While the Affordable Care Act mandates coverage for CRC screening, many high-risk individuals have no or insufficient insurance coverage. Programs that fund navigation services to help uninsured and underinsured patients are critical. Secondly, in 2021, the United States Preventive Services Task Force lowered the recommended age for CRC screening from 50 to 45. However, awareness and

implementation lag were exacerbated by the COVID-19 pandemic particularly in community and rural settings. Tools like the CRC risk assessment can accelerate dissemination and uptake of these guidelines. Thirdly, Indiana, like many states, struggles with persistent gaps in screening. Initiatives that support culturally tailored education campaigns and fund partnerships with community-based organizations could be transformative. Adoption of a federally sponsored CRC screening program in Indiana may increase CRC screening rates as seen through the national Breast and Cervical Cancer Screening Program.

As today's legislative climate increasingly emphasizes both cost-effectiveness and access, colorectal cancer prevention and screening must become increasingly innovative. Potential emerging innovations include scaling risk assessment tools. Exploring digital versions of tools that can be integrated into electronic health records (EHRs), telehealth visits, and community health worker visits could reach larger populations. Expanding risk assessment tools to include all cancers with recommended screening may also increase screening uptake. Furthermore, creating community-informed, risk-based screening tools could be utilized in areas with a high cancer burden (e.g., lung cancer in tobacco-heavy regions). Finally, policy makers could consider including community engagement requirements into funding opportunities.

This project also reinforces several best practices for community-engaged cancer research implementation. First, community listening sessions revealed real barriers, such as stigma toward colonoscopies, that might have otherwise been overlooked. Second, multiple rounds of revisions ensured the tool was both scientifically valid and practically useful. Third, solutions were co-created. The advisory committee, made up of minority-serving organizations and minority community members, ensured that the intervention was not designed in isolation. Fourth, bridging systems was key. Effective cancer prevention and screening requires linking community members to clinical systems through navigation, education, and resources. Fifth, the intervention was adapted to local context. Indiana-specific challenges, like rural access issues and low awareness of screening guidelines, shaped the intervention in ways that make it replicable for other states facing similar hurdles.

Conclusion

Colorectal cancer is both a major public health burden and a clear opportunity for the development of interventions to increase screening rates. Through the collaborative development of a CRC risk assessment tool, COE's team and community partners demonstrated how evidence-based interventions can be translated into accessible, practical resources for populations that need them the most. The project underscores that risk tools may increase intentions to screen but, more importantly, that community engagement from conception to implementation is essential. As policymakers, researchers, and health systems confront ongoing challenges in CRC and other cancers, models grounded in listening, collaboration, and local adaptation offer a blueprint for sustainable and incremental change.

From Eligibility to Results: Navigating Lung Cancer Screening with Confidence

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Keywords: Lung, cancer, screening

Abstract

Lung cancer remains the leading cause of cancer-related death in the United States, yet lung cancer screening (LCS) with low-dose CT scans continues to be underutilized, with national rates remaining below 20%. While awareness is slowly growing, many individuals still have questions or concerns that prevent them from pursuing screening. Barriers include lack of familiarity with the exam, fear of abnormal results, and confusion about who qualifies.

This article offers a clear, step-by-step overview of what to expect from a lung cancer screening at Indiana University Health—from determining eligibility and having a shared decision-making conversation, to completing the scan and reviewing any findings with a dedicated team of professionals. Our goal is to improve community understanding of the screening process, reduce fear or uncertainty, and highlight the compassionate care available throughout. By sharing this information, we hope to support community members in taking the first step toward early detection and peace of mind.

Introduction

Each year in the United States, more than 200,000 people are diagnosed with lung cancer, and over half those people will die from the disease. Lung cancer remains the leading cause of cancer-related death, claiming more lives annually than breast, prostate, and colon cancers combined. Yet, when detected early, lung cancer can often be treated successfully. Screening with a low-dose CT (LDCT) scan can reduce the chance of dying from lung cancer by 20–24%, making it one of the most effective cancer prevention tools available today.

While anyone can develop lung cancer, tobacco use is the single greatest risk factor, responsible for 80–90% of cases. Because of this, current and former smokers are the main focus of lung cancer screening programs. However, smoking is not the only risk factor: radon exposure, asbestos and diesel exhaust in the workplace, family history, and environmental pollutants also play a role. In Indiana, where smoking rates remain higher than the national average, the need for effective lung cancer screening is especially urgent.

While recent data has shown an overall increase in screening rates, lung cancer screening remains underutilized with fewer than one in five eligible individuals undergoing screening each year. Understanding why this gap persists—and what we can do about it—requires looking closely at both the science and the lived experiences of patients in our communities.

Who Should Be Screened?

To qualify for a lung cancer screening CT scan, individuals must meet three criteria:

- Age: Between 50 and 77 years old
- Smoking history: Current smoker or quit within the last 15 years
- Pack-years: At least 20 pack-years of smoking (packs per day × years smoked)

For example: one pack a day for 20 years, two packs a day for 10 years, or half a pack a day for 40 years all equal 20 pack-years. These criteria are based on national guidelines and are covered by Medicare, Medicaid, and most private insurance plans.

Who Should Be Screened?

Lung cancer is often silent until advanced stages, when treatment options are limited. By the time symptoms, such as persistent cough or weight loss, appear, the disease may already have spread. Screening allows doctors to find lung cancer earlier, when it is smaller, more treatable, and potentially curable.

Studies show that LDCT screening can detect up to 70% of lung cancers at stage I, compared with only about 15% without screening. This difference saves lives—not just in numbers, but in the very real stories of patients who can undergo curative surgery or targeted therapy instead of facing late-stage disease.

The Numbers Behind Screening Rates

For years, the American Lung Association reported that only about 5% of eligible people were receiving screening. In 2024, the rate appeared to jump to 16%. At first glance, this looked like extraordinary progress.

In reality, the change came not from thousands more patients getting screened, but from a change in how the numbers were measured. Earlier reports used data from the American College of Radiology's registry of screening facilities, while the 2024 report used a nationwide CDC survey. Each method has strengths and weaknesses, but the bottom line remains the same: most eligible people still are not getting screened.

For patients and communities, this means the challenge is unchanged. We cannot be satisfied with a statistical improvement when the real need—more people participating in screening—remains unmet.

Barriers and Misconceptions

Why do so few people get screened, even when eligible? Research and patient feedback point to several barriers:

- Lack of awareness: Many do not know lung cancer screening exists or that insurance covers it.
- Fear and stigma: Fear of abnormal results or judgment about smoking history prevents some from seeking care.
- Access issues: Rural residents may lack nearby facilities, and those without primary care doctors may not get referred.
- Language and cultural barriers: Emerging multilingual communities face challenges navigating complex medical systems.
- Coverage is not enough: Even when insurance pays for screening, extra steps like scheduling, transportation, lack of support, and costs associated with follow up care can keep patients from following through.

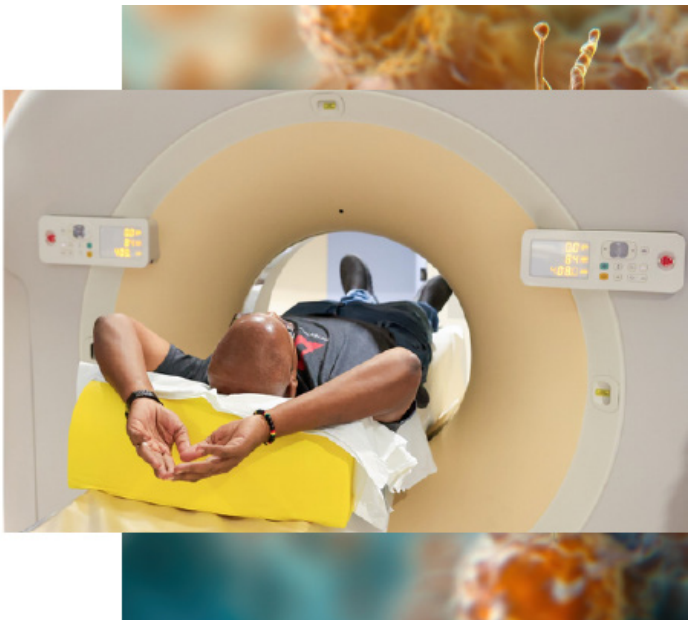
At IU Health, nurse navigators play a crucial role in overcoming these barriers by providing education, reassurance, and practical support.

What to Expect During the Exam

For those who move forward, the exam is simple:

- No special preparation is required.
- Patients remain in their clothes, no IV or contrast is needed.
- The scan uses about 20% of the radiation dose of a regular chest CT.
- The scan itself takes less than one minute.

Afterward, a radiologist reviews the images, and within one week, a nurse navigator calls with results. If normal, the patients return annually. If abnormal, a team of specialists reviews the case and coordinates next steps.



Patient recieving a CT scan.

This streamlined, supportive process is designed to reduce anxiety and ensure patients never feel alone in their journey.

Patient and Community Resources

Patients interested in screening can begin by speaking to their doctor or self-referring through IU Health's online portal at iuhealth.org/lung-scan.

Support for quitting smoking is also available through:

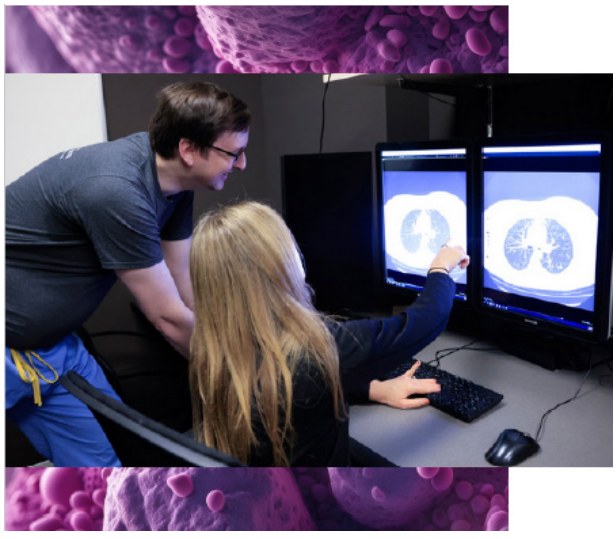
- Indiana Tobacco Quitline (1-800-QUIT-NOW)
- CDC's quit resources at smokefree.gov
- Local IU Health cessation programs

Advocacy groups such as the American Lung Association's "Saved by the Scan" campaign offer educational tools and survivor stories that help reduce stigma and empower individuals to take action.

Looking Forward: Future Directions

The future of lung cancer screening depends on three things:

- Better measurement: Multiple data sources (registries, surveys, claims) should be used together to give a more complete picture.
- Equitable access: Mobile CT units, evening and weekend appointments, and multilingual outreach are critical to reaching underserved populations.
- Policy support: Legislators and healthcare leaders must recognize that screening saves lives and invest in infrastructure that supports long-term implementation.



Radiologists reviewing a lung cancer screening exam

IU Health mobile CT unit

Thanks to a donation from the Tom and Julie Wood Family Foundation, IU health launched Indiana's first mobile lung screening program in 2025. This 40-foot truck with a CT scanner offers convenient and accessible scans across the state. Programs like mobile CT scanners and nurse navigation demonstrate how community-engaged strategies can bridge the gap between guidelines and real-world practice. By involving patients, families, and communities in design and outreach, we can create more inclusive approaches that address fear, stigma, and access head-on.

Conclusion

Lung cancer screening is a powerful tool—but only if people use it. The jump in reported screening rates from 2023 to 2024 reflects a change in counting, not in reality. The real story is that most eligible individuals are still not being screened.

As clinicians, researchers, and community members, we have a shared responsibility: to cut through confusion, provide accurate information, and build systems that make screening accessible and reassuring for all. By combining clear education, supportive navigation, policy advocacy, and community engagement, we can take meaningful steps toward reducing the burden of lung cancer in Indiana and beyond.

Community Takeaway: What You Need to Know About Lung Cancer Screening

- Lung cancer is the leading cause of cancer death in the U.S., but screening with a low-dose CT scan can reduce the risk of dying death by 20–24%.
- Who should be screened?
- Age 50–77
- Current smoker or quit within the last 15 years
- At least 20 pack-years of smoking (e.g., 1 pack/day × 20 years)
- What is the scan like?
- Quick and painless — less than one minute
- No needles, no contrast, and you stay in your clothes
- Uses about 20% of the radiation of a regular chest CT
- Getting started: Talk to your doctor or self-refer at iuhealth.org/lung-scan.
- After the exam: A nurse navigator will call you within a week with results and next steps.

I• f normal: You repeat the scan each year.

- If abnormal: A team of lung specialists will review your case and guide follow-up care.

Screening saves lives, — but only if eligible people take part. Don't let fear, uncertainty, or lack of information hold you back.

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Increasing Lung Cancer Screening through Opportunistic Referrals

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Keywords: Opportunistic screening, lung cancer screening

Abstract

Lung cancer is the leading cause of cancer-related deaths in the United States and the second-most diagnosed cancer. Although lung cancer screenings can reduce lung cancer mortality by up to 20%, national screening rates remain around 16%—far lower than other common cancer screenings. Our research group found that many patients who receive another type of screening for coronary artery calcium (CAC) may be eligible for lung cancer screening but have not yet been screened, illustrating an opportunity to increase lung cancer screening rates within routine healthcare encounters. This article explores how screening referrals made outside of traditional lung cancer screening programs—which we refer to as 'opportunistic referrals'—can serve as a strategy to improve early detection. We aim to highlight practical strategies and resources that can improve awareness and access. We also discuss how policy changes and system-level strategies can support more equitable screening practices, particularly in underserved populations.

Background

Lung cancer has been the leading cause of cancer death in the United States for men since the early 1950s and for women since 1987 and accounted for 135,720 deaths in 2020 (American Lung Association, 2025). It is the second-most prevalent cancer type for both men and women (American Lung Association, 2025). The five-year survival rate for all lung cancer is 27%, but only 9% for patients diagnosed at a late stage (American Cancer Society, 2025). Despite low-dose computed tomography (LDCT) scans for lung cancer screening (LCS) reducing mortality by 20% (Aberle et al., 2011), only 16% of eligible individuals are screened in the United States (Gunderman et al., 2025). This is significantly lower than rates for other cancer screenings, such as mammography (National Cancer Institute, n.d.).

There are numerous barriers to completing LCS, including patient lack of awareness, fear of diagnosis, absence of symptoms, and cost concerns (Jung et al., 2025). Primary care providers, who routinely manage screening, report challenges with shared decision-making, difficulty identifying eligible patients, limited EMR notification systems, and time constraints [6-7]. Smoking is the predisposing factor most associated with lung cancer, and it is known that smokers are less likely to engage in guideline-concordant screenings for other cancers, including breast, prostate, and colorectal (Sanford et al., 2019).

What does our research show?

Our research focuses on identifying untapped opportunities to connect patients who are potentially eligible for lung cancer screening to screening programs. We refer to screening referrals made outside of traditional lung cancer screening programs as 'opportunistic referrals' and believe these referrals can serve as a strategy to improve early detection. We suspected that patients receiving coronary artery calcium scoring (CACS) may be eligible for lung cancer screening because there is considerable overlap between the inclusion criteria for CACS exams at IU Health and the United States Preventive Services Task Force LCS criteria.

After analyzing over 14,000 CACS- exams from 2022 to 2023, we found that 15.8% to 23.4% of patients screened for coronary artery disease may have been eligible for lung cancer screening. A more precise measurement could not be made as electronic health records often lacked adequate smoking histories, making it difficult to definitively determine a patient's eligibility for lung cancer screening.

We also found disparities in CACS utilization. In our sample, 91.8% of the patients who received a CACS exam were white, compared to the state average of 83.7%, underscoring disparities in access (U.S. Census Bureau, 2024). This overrepresentation of white patients reflects how self-pay preventive services disproportionately benefit higher-income, insured populations. Without intentional strategies, opportunistic referrals may widen disparities by primarily reaching those already advantaged.

What are other examples of opportunistic referrals?

Our research highlights the potential to improve lung cancer screening through opportunistic referrals. Some opportunistic referral strategies that have gained attention involve linking lung cancer screening to other established screening tests. For example, some institutions attempt to address this issue by offering dual screening for CACS and LCS, though published data are limited. Others have examined retrospectively scoring coronary artery calcium from LCS exams, though this approach has limitations (Berzingi et al., 2024).

CT-based approaches show feasibility of combined imaging for multiple cancers. For example, while colonoscopy remains the most common method of colorectal cancer screening, the FDA approved CT colonography as an alternative in 2006 (Bryce & Bucaj, 2021). Although not yet widely implemented, combining lung cancer and colorectal cancer screening in a single CT appointment faces few practical barriers (Mascalchi et al., 2022).

A successful example of screening innovation comes from pairing breast and lung cancer screenings. In one study of 892 patients identified as potentially eligible for lung cancer screening, 54 went on to complete shared decision-making appointments and subsequently underwent a screening CT (Yue et al., 2025). Although not a single-session model, this pilot study demonstrated the potential of adding LCS for patients already undergoing other cancer screenings.

What are some provider level solutions to improving lung cancer screening?

A common misconception is that lung cancer screening requires out-of-pocket payment (Mascalchi et al., 2022). Medicare and most other public and private insurances cover lung cancer screening, so this simple education at other screening evaluations can provide impetus for patients already willing to be screened for other cancers.

Providers can also connect patients with supportive resources like the American Lung Association's Lung Cancer Screening Assistance Program and the Color Health Lung Cancer Screening Tool [14–15]. These programs offer user-friendly websites where patients enter personal data to identify screening eligibility and local resources. Both include free lung health navigator services; Color Health also allows patients to indicate financial hardship and links them with available regional support (Color Health & American Cancer Society, 2025).

What are some potential policy and systems-based solutions?

Policy changes. Federally Qualified Health Centers (FQHCs) are excellent resources for low-income patients. Currently, FQHCs report cervical, breast, and colorectal cancer screening metrics through the HRSA Uniform Data System (UDS). Lung cancer screening, despite being USPSTF-recommended and fully covered by CMS, is not included as a quality metric for Medicare, Medicaid, or FQHCs (Kao et al., 2025). Adding LCS would align it with existing cancer screenings, ensure systematic identification of high-risk patients, and reduce disparities in populations served by FQHCs, including as those seen at Eskenazi Health, HealthNet, and the Jane Pauley Community Health Center in Indianapolis. Embedding lung cancer screening into national quality frameworks would transform it from an underutilized option into a routine expectation of preventive care. Without LCS as a quality metric, FQHCs struggle to cover the cost for self-pay patients who cannot afford it (Kao et al., 2025).

CATEGORY	CURRENT UDS CANCER SCREENING METRICS (REQUIRED FOR FQHCS)	PROPOSED ADDITION
CERVICAL CANCER	% of women ages 21–64 screened with Pap test (past 3 yrs) OR Pap + HPV co-test (past 5 yrs)	–
BREAST CANCER	% of women ages 50–74 with a mammogram in the past 2 years	–
COLORECTAL CANCER	% of adults ages 45–75 screened (via FOBT/FIT annually, FIT-DNA every 3 yrs, sigmoidoscopy every 5 yrs, or colonoscopy every 10 yrs)	–
LUNG CANCER (NOT CURRENTLY INCLUDED)	–	% of adults ages 50–80 with ≥20 pack-year smoking history, current smokers or those who quit within 15 yrs, who received annual low-dose CT scan

Figure 1: *Lung cancer screening is not yet a UDS quality measure for FQHCs, unlike cervical, breast, and colorectal screening.*

System changes. Health systems have successfully expanded cancer screening by embedding new tests into existing workflows. A compelling precedent is HPV co-testing, which began as an unfamiliar add-on to Pap smears but quickly became standard practice once incorporated into routine cervical cancer screening (Saslow et al., 2012). This example shows how pairing a new screening with an established encounter can normalize adoption and drive population-level impact. That is precisely the principle behind opportunistic referrals for lung cancer screening.

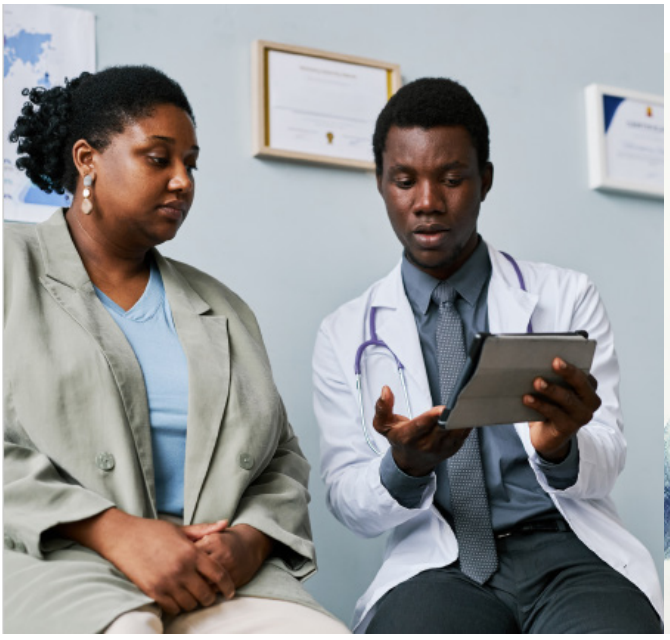
Another strategy is to offer free screening services as "anchors," creating more opportunities for referrals. University Hospitals (UH) system in Northeast Ohio began offering no-cost coronary artery calcium scoring (CACS) to eligible individuals in 2017, becoming one of the only health systems in the Americas to eliminate patient fees for CACS exams. This change resulted in a 546% increase in utilization across all demographic groups (Al-Kindi et al., 2020).

While no Indianapolis health system currently provides free CACS on a routine basis, several institutions, such as IU Health, Ascension St. Vincent, and Community Health Network, offer self-pay price points in the $49–$100 range.

Adapting the UH model locally could entail piloting subsidized or no-cost CACS program, especially in collaboration with Federally Qualified Health Centers (FQHCs) like Eskenazi Health, to reduce financial barriers, enable dual-screening opportunities (such as combined CACS and lung cancer screening by embedding automated LCS prompts into CACS ordering), and support equitable preventive care access among underserved populations.

Summary

While lung cancer remains the leading cause of cancer death in the U.S., less than 16% of eligible patients undergo screening. This is far below other cancers despite clear survival benefits. “Opportunistic referrals” linking lung cancer screening to existing services like CACS exams, CRC screening, or mammography show promise in boosting uptake but are limited by cost, access, and current policy. By designing opportunistic referral pathways that prioritize underserved groups through cost reduction, embedding screening into trusted settings like FQHCs, and linking to services patients already use, we can ensure that lung cancer screening becomes not only more common, but more equitable.



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Enhancing Clinical Decision Making in Cancer Treatment Through DRIVE Scores

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Summary

Over the past two decades, there have been major efforts to draw attention to the inequities in medical oncology research. Available data indicates that five-year relative survival rates for all cancer types diagnosed between 2010–2016 disproportionally favor Whites over Blacks, 68% and 63%, respectively (Howlader et al., 2020). Disparities in cancer treatment, a major contributor to diminished outcomes in cancer mortality, may be related to the underrepresentation of ethnic minorities in clinical research. The DRIVE score is an informational tool created to assess how closely a cancer clinical trial reflects the epidemiological demographics of the disease it researches (Birhiray & Birhiray, 2022). Use of the DRIVE Score can inform the medical decision-making of practicing clinicians and further dismantle medical mistrust amongst cancer patients.

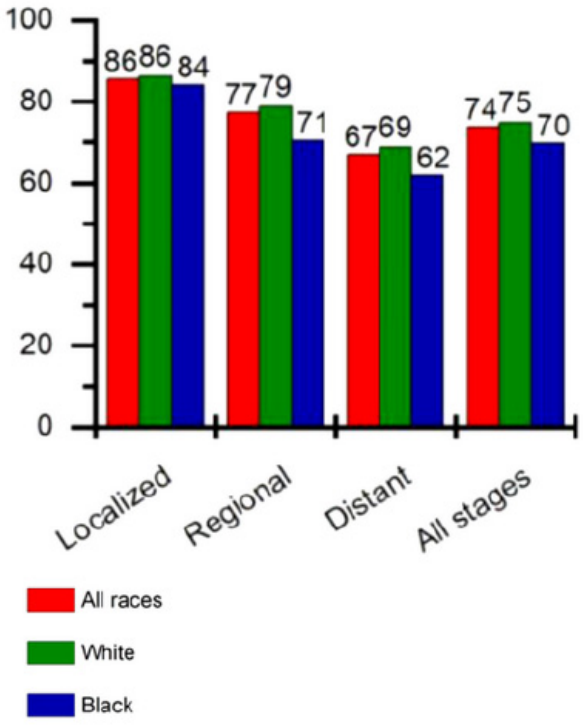
Public Problem

Despite significant efforts to address inequities in oncology research, the underrepresentation of minoritized populations in clinical research enforces persisting disparities in cancer treatment and contributes to poorer cancer mortality outcomes (Birhiray & Birhiray, 2023). Clinical trial disparities result in the creation of three main problems of healthcare data: data absenteeism (lack of representation from underprivileged groups), data chauvinism (faith in the size of data without considering quality and contexts), and, in its most extreme form, therapeutic misconceptions (the assumption that approved drugs with promising clinical trial data have demonstrated effectiveness across all patient populations). The DRIVE Score utilizes a six-point system to identify major clinical studies that meet representation goals. This brief will discuss trends in clinical trial disparities, policy considerations, clinical and societal implications, and recommendations.

Trends

Disparities in clinical trials: Race reporting is frequently omitted in clinical trials, resulting in regulatory approval, but this omission is even more prevalent in studies outside regulatory

purview. This gap in representation is worse for specific tumor types, particularly in prevalence-adjusted participation for cancers that are more common in African Americans (Al Hadidi et al., 2020). Additionally, in pivotal trials leading to U.S. regulatory approval of immune checkpoint inhibitors, Black patients constituted less than 4% of enrollees. This is particularly problematic because clinical responses to immunotherapeutic agents depend on host and tumor biological interactions that are unique, individual, frequently racially determined, and genetically mediated (Nazha et al., 2019). Pooled data from nine large cooperative group clinical trials in newly diagnosed Multiple Myeloma (MM) over two decades showed only 18% of participants were non-White, which is shocking for a disease with incidence rates in Blacks more than double those seen in Whites (15.9 vs 7.5 cases per 100,000) (Ailawadhi et al., 2018). This trend also extends to mortality (5.6 vs 2.4 MM deaths per 100,000 for African Americans compared with Whites) (DeSantis et al., 2019; Bhatnagar et al., 2017). Siegel et al. (2023) report that outcomes for lymphomas, as well as other high-risk hematologic malignancies, are significantly affected by race (Figure 1).

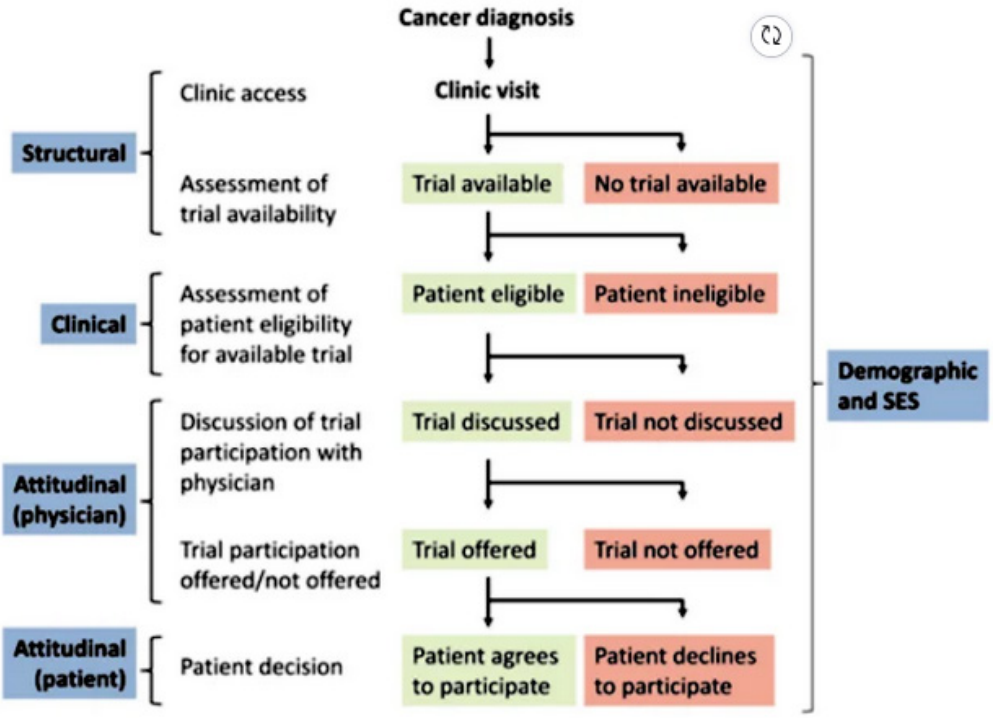


Lymphoma survival. Five-year relative survival for selected cancers by race and stage at diagnosis, United States, 2012 to 2018. White and Black race categories are exclusive of Hispanic ethnicity. Reproduced with permission from Siegel RL, Miller KD, Wagle NS, Jemal A. Cancer statistics, 2023. *CA Cancer J Clin. 2023;73(1):17-48*[23]

Figure 1

Barriers to participation in clinical trials: Barriers to participation in clinical trials (Figure 2) typically disproportionately affect minority patients, which ultimately results in delayed accrual, delayed generation of clinical data, and reduced generalizability of such data to all persons, thereby promoting outcome disparities (Unger et al., 2016). Access to a clinic can be influenced by various structural factors, including transportation, travel costs, insurance coverage, and childcare availability.

Furthermore, a physician's decision or preference is a primary reason for nonparticipation in patients for whom a protocol is available, and the patient was eligible. Lastly, patients may experience unease or fear about the prospect of participating in clinical trials, including residual mistrust of medical science due to past abuses such as the infamous Tuskegee Syphilis Study or the history of human experimentation with radiation following World War II (Birhiray & Birhiray, 2023).



Model pathway of trial enrollment process. SES, socioeconomic status. Reproduced with permission from Unger JM, Cook E, Tai E, Bleyer A. The role of clinical trial participation in cancer research: barriers, evidence, and strategies. *Am Soc Clin Oncol Educ Book. 2016;35:185-198.*[32]

Figure 2

Policy Considerations

Two large-scale federal acts in recent history have been the Food and Drug Omnibus Reform Act (FDORA) of 2022 and Project Equity. FDORA requires the pharmaceutical industry to create prospective diversity plans and have major public hearings with the intent of enhancing diverse clinical trial enrollment. Project Equity is a "public health initiative established by the U.S. FDA Oncology Center of Excellence, to ensure that the data supporting approval of oncology medical products adequately reflects the demographic representation of patients for whom the medical products are intended." (Fashoyin-Aje et al., 2023)

Under FDORA, the FDA was working on a guidance document draft titled "Diversity Action Plans to Improve Enrollment of Participants from Underrepresented Populations in Clinical Studies." Only a few days after taking office, President Donald Trump signed an executive order halting all federal DEI programs. This guidance document draft, which had been in progress since June 2024, was quietly removed from the FDA website shortly after (Grossi, 2025).

On May 19, 2023, the FDA released several documents regarding clinical trials, addressing the validity of clinical trials and ethical concerns for patients. One such document, Good Clinical Practice E6(R3) Draft Guideline, outlines quality standards for trials involving human participants, stating, "the use of innovative clinical trial designs and technologies may help include diverse patient populations, as appropriate, and enable wider participation" (Food and Drug Administration, 2023).

DRIVE is a strategic framework for promoting representative enrollment in clinical trials. This initiative addresses the inherent safety and efficacy concerns that arise when studies are conducted in populations that do not reflect the different patient groups these treatments are intended to serve. Generalizability, the ability to infer treatment effects for the entire population from a study population, and transportability, the ability to apply treatment effects from one group to another, are critical for ensuring equitable and effective care. To uphold these principles, "Clinical Trial Excellence" has been defined as studies that successfully meet these diversity and representation benchmarks. The DRIVE Initiative (2025) aims to establish measurable standards for representation, advocate for policy changes, and promote inclusive research practices that improve clinical outcomes for all patients, regardless of background.

Generalizability and transportability are critical for ensuring equitable and effective care, particularly when clinical trial populations do not reflect the patients they are intended to serve.

Implications

Application of the DRIVE scoring method allows researchers and providers to efficiently evaluate whether a cancer therapy is supported by broadly applicable data, thereby promoting inclusive and equitable healthcare practices. A DRIVE Score also allows patients further autonomy in shared decision-making by providing them with a mechanism to assess if their treatments were studied in patients who reflect similar biopyschosocial backgrounds.

The DRIVE Score is robust in nature, basing its disease epidemiology calculations on non-normalized data obtained from the Surveillance Research Program at the National Cancer Institute's (2025) SEER*Explorer Cancer Statistics Network; however, its utility is limited by a lack of research data published in a scorable format. A score can only be calculated when data is provided in a SEER-compatible format (such as classifying participants as "non-Hispanic Black" rather than simply "Black") this designation is important because, without it, some patients may be inaccurately accounted for when establishing a score. In March 2024, the U.S. Office of Management and Budget (OMB, 2024) issued revised guidance for Statistical Policy Directive Number 15 (SPD 15), which introduced an integrated race and ethnicity question as well as mandated more detailed data collection (e.g., checkboxes and write-in responses). This change to data collection is essential to broader implementation of the DRIVE Score for two reasons: first, it ensures respectful and accurate data collection reflecting patient and research participants' self-identification; second, it standardizes data analysis into a format compatible with the DRIVE scoring methodology. Medical societies like the American Society of Clinical Oncology (ASCO) or the American Society of Hematology (ASH) act as international bodies for medical professionals to collaborate. These bodies serve to call attention to and address the research insufficiencies that contribute to health disparities in cancer. By enforcing a standard in their publications for reporting and scoring patient demographic data with the DRIVE Score, they encourage greater transparency amongst their members and champion valid, reliable data.

Alternatively, academic research institutions are the sites for groundbreaking and practice-changing medicine. Research protocols informed by the DRIVE Score metric would allow principal investigators to prospectively develop achievable, flexible, and monitorable accrual goals that consider the diversity of the intent-to-treat population. Furthermore, a knowledge and understanding of the patients most impacted by a given disease can aid in developing culturally sensitive study materials that increase overall research accrual.

Recommendations/Call to Action

- Adoption of Project Equity and FDORA by the global regulatory community through International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH) policy initiatives on broadening eligibility criteria in clinical trials.
- Widespread utilization of the DRIVE Score among academic centers and community physicians, with a commitment to implementing the other aspects of the DRIVE Initiative in due time.

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Lung Cancer Outcome Improvement through Genotype-Specific Care

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Summary

Lung cancer is the leading cause of cancer-related death for men and women in the state of Indiana and across the country. While earlier diagnosis and new pharmaceutical innovations have improved five-year survival rates, disparities in access and responsiveness to new therapeutics continue to prevent major improvements in lung cancer prognosis. A more personalized approach to treatment comes from genetically characterizing the tumors of lung cancer patients through the most comprehensive genetic screening available. Biomarker-guided treatment for lung cancer patients shows markedly improved responsiveness to treatment compared to traditional therapeutics. While many states, including Indiana, have passed legislation to mandate insurance reimbursement of biomarker testing, the policy does not explicitly include the most advanced and meaningful screening. Biomarker screening to date is driven by determining eligibility for specific targeted therapies, but its true power could be realized by including more comprehensive characterizing to allow correlation between genetic abnormalities of tumors, disease progression, and responsiveness to treatment. Utilizing this broader-based strategy will improve treatment and prognosis for current patients and provide data for the discovery of new potential therapeutic targets.

Biomarker testing for lung cancer can provide more personalized treatment and better prognosis for patients, but available technology is underutilized.

Prior to the early 2000s, treatment for lung cancer was largely determined based on the origin of the cells involved (squamous vs. nonsquamous) and tumor node metastasis (TMN) stage (Spiro & Silvestri, 2005). Using these diagnostic benchmarks, combination therapies —including platinum-based chemotherapies — were the standard of care (Schiller et al., 2002). While genetic analysis was emerging, it was not used to guide differential diagnosis (Lynch et al., 2004). Prognosis following diagnosis of lung cancer, particularly late stage, was bleak. Response rates ranged from 19–32%, with a median survival rate of less than 8 months, and a 1-year survival rate of around 30% (Schiller et al., 2002).

The early 2000s saw the beginning of the biomarker era in treatment of all cancer types. Following FDA approval of drugs to target genetic abnormalities within lung tumors accompanied by biomarker testing to guide treatment, dramatically improved responsiveness (70% vs. 47%) was achieved (Johnson et al., 2005). This historic event marked the first step toward personalized cancer treatment. The dramatic increase in response to treatment was impressive, but the translation into increased progression free survival (PFS) has been less pronounced. The largest PFS reported is less than 4 months (Solomon et al., 2014). The lack of major improvements in PFS largely stems from the late TMN stage at which lung cancer is typically diagnosed. Thus far, biomarker testing affects treatment choice and can be predictive of outcome but has not shifted the TMN stage at diagnosis.

While biomarker screening has provided a movement toward more personalized medicine, accessibility to this type of testing remains uneven. While many patients are receiving some biomarker screening, the testing is to determine if a certain drug is indicated by the presence of a specific mutation. That approach, however, limits not only the personalization (as it is only based on a single mutation, not the repertoire of tumor mutations) but also restricts the ongoing improvement of targeted therapy.

Current biomarker screening does not provide guidance for treating all lung cancer patients.

From 2004 until the present, the number of lung cancer patients receiving at least single gene biomarker scanning has increased but the percentage of eligible patients has not increased proportionately (Figure 1). This is driven largely by the expanded repertoire of pharmaceutics that target specific mutations and the advancement of biotechnology.

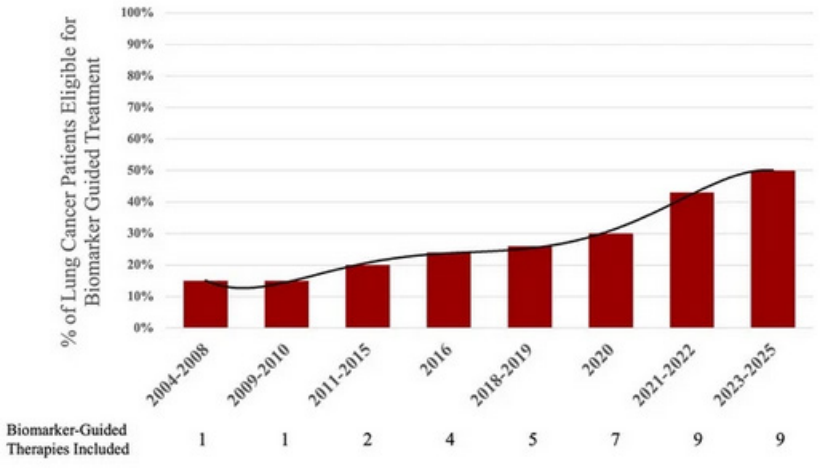


Figure 1: *Eligibility of Lung Cancer Patients for Biomarker-Guided Therapy*

Note: Percentage of all lung cancer patients estimated to be eligible for biomarker-guided treatment. Data is based on cohort studies done at or around the time of FDA approval and/ or increased usage for new biomarker targeted therapies, which results in a range in year for some data points. 2004 –2008 (Michelotti et al., 2022); 2009 –2010 (Gandhi et al., 2018); 2011–2015 (Kazandjian et al., 2014); 2016 (Food and Drug Administration, 2016); 2018–2019 (Michelotti et al., 2022); 2020 (Mathieu et al., 2022); 2021–2022 (Herrera-Juárez et al., 2023); 2023–2025 (Attili et al., 2024)

In the last few years, we seem to have plateaued in the percentage of patients with targetable tumors. This data is difficult to precisely capture as not all patients are tested and only about 20% of lung cancer patients undergo comprehensive genomic profiling (NGS) for large panels (>300) of biomarkers (Wallenta Law et al., 2024). Current estimates for patients that are eligible for biomarker-guided treatment range from 40–50% for therapies other than immunotherapy (Attili et al., 2024). As such, for at least half of all lung cancer patients, we are not yet able guide their treatment based on their tumor's genetic makeup. (Wallenta Law et al., 2024)(Attili et al., 2024)

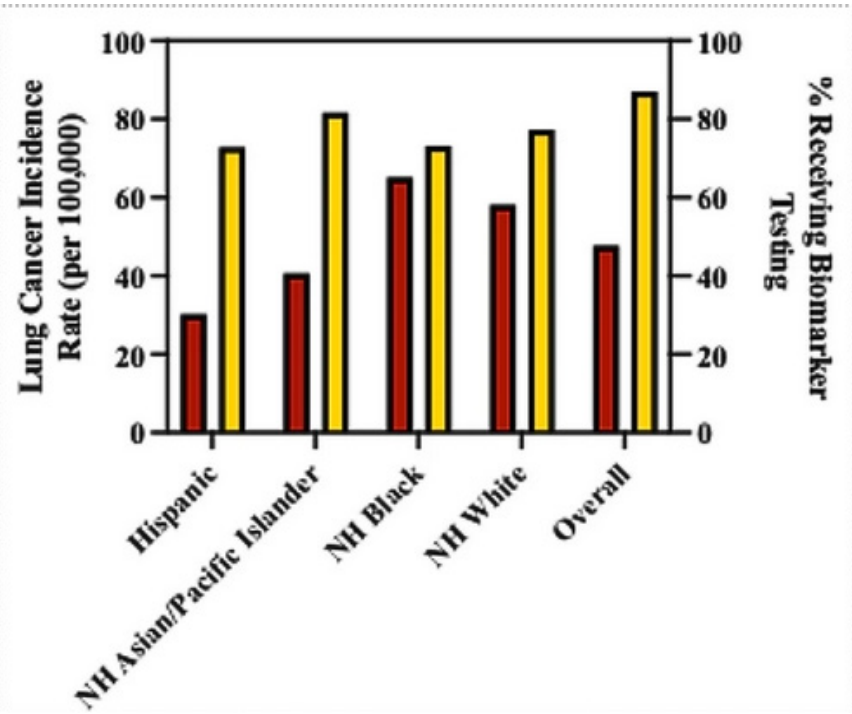
Although men and women are approximately equal in newly diagnosed cases and approximately equal in adoption of molecular testing, women are almost twice as likely to have mutations that are treatable with the current repertoire of medications (Mosleh et al., 2025). Even though testing is being applied equally, biomarker-guided therapy is not possible equally for both sexes, which suggests further research is needed into the sex-related differences in the presence of these mutations.

Biomarker testing is not adopted evenly across lung cancer patients of different demographics.

There is continued disparity in access to extensive biomarker screening across all lung cancer patients. For NGS testing, white patients were about 10% more likely to have this test done than black patients, although more new cancer cases are diagnosed in African Americans, particularly men (Bruno et al., 2022). When analyzed by any type of biomarker testing done, the trend in testing frequency remained the same (Figure 2). The group most affected by lung cancer is not the one getting biomarker testing done the most often.

Perhaps the most striking data point in the disparity of biomarker testing is with respect to insurance status. For any biomarker testing, Medicaid patients are significantly less likely to receive biomarker testing of any variety, including NGS, compared to commercially insured lung cancer patients (Lin et al., 2025). In a 2023 survey by the American Cancer Care Centers, Medicaid patients were less likely to undergo biomarker testing to guide treatment and were at a higher risk of mortality (Comprehensive Cancer Care: The Role of Biomaker Testing, 2023). With approximately 1 in 4 lung cancer patients covered by Medicaid, a large proportion of affected individuals experience accessibility obstacles to the most effective treatment. This disparity in accessibility also correlates with socioeconomic status, facility type, and geographic location.

Figure 2: *Racial Disparity in Application of Biomarker Testing*



Note: Red bars show the age-adjusted incidence rate per 100,000 individuals for lung cancer. Yellow bars show the percentage of individuals diagnosed receiving biomarker screening of any kind within 90 days of initial diagnosis. NH = Non-Hispanic. Adapted from (Baron et al., 2024).

Comprehensive biomarker screening should become the standard of care for lung cancer patients.

Many researchers believe that the eligibility of patients for biomarker-guided treatments, combined with the obstacles to accessibility, has plateaued. Policy change is necessary to ensure continued improvement of lung cancer patient care and prognosis.

The maximum proportion of lung cancer patients estimated to be eligible for biomarker guided therapy is 50%, which means half of lung cancer patients cannot be treated with current strategies. The lung cancer patients contributing to this estimation do not represent an even sampling across the demographics of individuals affected by the disease, which may mean potential therapeutic targets have not been identified.

As of 2025, 15 states, including Indiana, mandated insurance reimbursement for biomarker testing with 13 additional states introducing legislation in 2026 to do the same. While this is certainly a step in the right direction, additional regulation will be required to ensure that all forms of biomarker

testing, including NGS, are reimbursable, and that Medicaid recipients are also guaranteed equal access to testing. Patients receiving NGS-guided therapy demonstrate better responsiveness and overall rates (Jordan et al., 2017)(Jordan et al., 2017) . Simply assuring reimbursement for NGS testing will not be sufficient, however. Targeted therapeutics can only be of benefit if patients have access to the indicated treatments, which should also be a goal of mandating insurance reimbursements.

Biomarker testing is still largely in a forward manner, testing for genetic signatures that indicate eligibility for specific treatment. To identify additional targets for drug development, NGS biomarker assessment can provide an enormous amount of data to better understand the relationship between tumor genotype and response to treatment. Our initial research has demonstrated that mutations in genes such as Tp53, which are not currently a target for biomarker guided therapy, can affect efficacy of treatment with traditional chemotherapeutics. Correlating a more complete genomic profile to responsiveness to treatment, whether targeting specific mutations, immunotherapy, or chemotherapy, will allow for even greater personalization of individual care but also better guidance for future patients.

The urgent need for this deep dive into the mountains of data that will be generated also requires funding considerations. Many lung cancer patient samples have already been screened using NGS and their treatment regimens documented. However, these data remain largely decentralized. Allocating monies for organization and maintenance of available NGS data along with treatment responsiveness should be a priority in the big picture of lung cancer research funding.

Increasing equality of access to biomarker testing improves prognosis for current lung cancer patients and shapes future treatment.

Eliminating obstacles to access to NGS profiling will ensure that this benefit of personalized lung cancer treatment can be distributed evenly across more patients affected by lung cancer. Data from 2019 to the present is yet not available in Indiana, but a significant increase in screening occurred from 2023–2024 that likely will increase the number of early diagnoses (American Lung Association, 2024). Early detection will only serve to improve parameters like five-year survival rates for lung cancer patients, and biomarker data from patients diagnosed at earlier stages can be used to build an even more comprehensive picture of changes over the course of disease progression, potentially allowing identification of not just treatable biomarkers but also diagnostic ones. Early diagnosis is the single most important contributing factor in treatment, with lung cancer patients diagnosed at Stage I having a 60–80% five-year survival rate and less than 7% for patients diagnosed at Stage IV.

Utilizing the power of the data being gathered as patients are treated with increasingly personalized approaches will only further enhance treatment options. Despite early screenings and legislation to discourage risk behaviors like smoking, Indiana continues to have one of the highest rates of new lung cancer cases nationally. The increased accessibility for patients to state-of-the-art genetic screening and increased data collection to drive new drug discoveries will be paramount in improving the prognosis for lung cancer patients.

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Digital Equity in Clinical Trials: Lessons from an E-Consenting Pilot at IUSCCC

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The insights shared in this article are based on the author's firsthand experience implementing and evaluating the e-consent platform in a real-world clinical research setting.

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Abstract

E-consenting can transform clinical trial participation by improving accessibility, efficiency, and regulatory compliance. This reflection draws on my firsthand experience implementing an e-consent platform at the Indiana University Simon Comprehensive Cancer Center Clinical Trials Office. During the pilot, I observed increased patient engagement, more thorough consent review, secure centralized storage, and reduced paper usage. Challenges included assisting patients with limited technological experience and time-intensive staff training. These experiences underscore the importance of balancing security and efficiency with user-friendliness. Looking ahead, I believe there are opportunities to streamline verification, support participants with limited tech experience, introduce hybrid consent options, and strengthen community engagement. My experience highlights best practices for inclusive, patient-centered approaches, showing how e-consent can promote equitable access to clinical trials and improve the overall patient experience. This reflection also aims to inform the broader community about the impact of e-consent on clinical research.

Keywords: e-consent, clinical trials, digital equity, patient engagement, cancer research, community reflection

Introduction

Clinical trials are essential for advancing cancer treatment, providing patients access to innovative therapies, and contributing to improvements in care. However, patient participation is often limited by disparities in access, literacy, and geographic location. Digital tools, such as e-consent, can mitigate

these barriers, making trials more inclusive and patient-centered. The Clinical Trials Office (CTO) at Indiana University Simon Comprehensive Cancer Center implemented an e-consent platform to modernize the consent process, enhance accessibility, and promote digital equity. This platform allowed patients to review consent documents remotely, engage with study staff at their own pace, and participate in trials more comfortably and confidently.

By reflecting on this pilot, I aim to demonstrate how digital tools can support patient-centered care, inform policy and practice, and advance equitable access to clinical trials, while also highlighting lessons learned and forward-looking strategies for the field.

Pilot Implementation

We introduced e-consent to create a secure, efficient, and standardized consenting process across studies. The platform enabled patients to review documents on their own time, whether at home or during clinic visits, ask questions, and submit forms digitally. The centralized storage ensured accurate documentation, maintained data privacy, and supported compliance with regulatory requirements. Staff were trained extensively to support patients and navigate the platform effectively.

Additionally, the CTO partnered with a third-party provider to develop an e-consent platform compliant with 21 CFR Part 11, ensuring federal standards for electronic records and signatures were met. iPads were purchased and made available for patient use across multiple clinics as well. Patients could access the e-consent remotely via a secure link sent to their email, allowing them to complete the process on their personal home computers. A multi-step verification process was required to access and complete the e-consent on both personal computers and the iPads provided in the clinic. After reviewing the consent form, patients were guided through the necessary fields that needed to be completed before finalizing and signing the consent. This process ensured accurate completion of the consent and minimized errors.

The platform securely captured electronic signatures, auto-populated essential fields, and stored documents in a centralized library, supporting auditability and reducing paper use.

Inclusive practices were embedded throughout the pilot. Staff worked to identify and support patients who might face barriers due to limited digital literacy, language differences, or mobility challenges. Feedback from both patients and staff was continuously incorporated to improve navigation and enhance overall experience. The pilot also contributed to environmental sustainability by reducing paper usage, saving physical storage space, and promoting more eco-conscious research operations.

Observed Benefits

The e-consent pilot yielded several notable benefits. Remote consent capabilities allowed patients who had difficulty traveling to participate, increasing enrollment and expanding access to clinical trials. Patients were able to review documents thoroughly from the comfort of their homes, ask questions without time pressure, involve family members in decision-making, and foster greater understanding and engagement.

We also noticed improvements in workflow accuracy and efficiency through auto-populated dates and consent versions, which were previously common sources of errors on paper consent forms. One key advantage of the e-consent platform was that patients could not finalize the consent without completing all required fields, ensuring accuracy and preventing the common issues seen with paper consents—such as missed pages, signatures, or incomplete fields. Beyond operational advantages, e-consent facilitated more meaningful patient engagement, highlighting the positive impact of research participation on understanding cancer care. Importantly, patients reported feeling empowered by having greater autonomy in their participation, as they could make informed decisions after thoroughly reviewing the consent form at their own pace. The platform also allowed patients to receive an automatic electronic copy of the signed consent form via email for their reference.

Challenges and Lessons Learned

Despite the benefits, several challenges emerged. Patients with limited technological proficiency or lack of access to devices sometimes required additional support to complete consent forms, which often led to frustration and a sense of wasted time that hindered the process. In particular, the multi-step verification process proved cumbersome for many patients and frequently caused delays. This process required patients to input a phone number or email address to receive a verification code, which they then had to enter to proceed. However, delays in receiving the code, input errors like incorrect email addresses, or system glitches meant patients sometimes had to restart the entire process, often waiting on the phone with a coordinator to resolve the issue. Additionally, staff training was time-intensive, as it was critical to ensure proper use of the platform and adherence to study protocols. Integrating e-consent into clinic workflows required careful planning to maintain efficiency and compliance while supporting patient engagement.

With these challenges, many lessons were learned. These included highlighting the need to simplify verification processes while maintaining security, improving navigation for patients who may require remote assistance, and prioritizing inclusive design. Collecting feedback from patients and staff was essential for refining processes and fostering community-engaged practices. These experiences reinforced the importance of equity-focused strategies, demonstrating that thoughtful implementation can improve accessibility and empower diverse populations to participate in cancer research (Lunt et al., 2020).

Policy and Practice Implications

The implementation of e-consent carries several implications for institutional policies and broader research practices. Ensuring digital equity is paramount so that all patients, regardless of technological proficiency, can access clinical trials (Godwin-Smith, 2022). Institutions should adopt secure, user-friendly platforms that prioritize patient autonomy (Clinical Trials Arena, 2023), offer hybrid consent options to accommodate varying patient needs (Kaye et al., 2022), and invest in ongoing staff training and patient support resources (McMullan et al., 2022). Continuous evaluation of patient feedback

is necessary to refine processes and improve inclusivity (IQVIA, 2022).

Looking ahead, I believe future e-consent efforts have the potential to significantly shape patient engagement and research policy. Offering multilingual and mobile-friendly consent options is key to increasing accessibility, especially for populations that have been historically underrepresented. I've found that involving patient advocates in the design and evaluation process is essential for building trust and ensuring equitable access. These strategies not only improve the patient experience but also help inform policy by showing how technology can enhance regulatory compliance while supporting patient-centered research. By integrating these approaches, I see a path toward developing policies grounded in best practices for inclusive, community-engaged cancer research, ultimately contributing to broader efforts to reduce disparities in clinical trial participation.

Conclusion

The e-consent pilot at the CTO demonstrated meaningful improvements in patient engagement, accessibility, and workflow efficiency, teaching me the importance of balancing security, usability, and inclusivity. Looking ahead, I see great potential in hybrid and mobile-friendly platforms, streamlined verification, and patient-centered design. Reflecting on my experience, I believe incorporating adaptive tools like tutorials or chatbots can better support patients who need extra guidance, while real-time analytics could help identify bottlenecks in the consent process. Partnering with community organizations is also essential to ensure cultural sensitivity and equitable access. Ultimately, emphasizing inclusive, community-driven approaches is key to building trust and empowering patients, and I hope these insights guide future efforts to develop consent processes that are accessible, secure, and truly patient-centered, advancing equity and improving experiences across diverse populations.

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Addressing Healthcare Utilization Inequities in LGBT Cancer Survivorship: Translating Evidence into Policy and Practice

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Keywords: LGBTQ+, cancer survivorship, social support, discrimination, healthcare utilization barriers, Indiana state policy

Abstract

Cancer survivorship extends beyond treatment to encompass long-term physical, psychological, and social outcomes. For lesbian, gay, bisexual, and transgender (LGBT) survivors, this often means navigating systems that do not affirm their existence and survivorship needs and may expose them to toxic discrimination and stigma.

Using data from the All of Us research program, we identified healthcare utilization (HCU) barriers and psychosocial risk clusters, revealing stark disparities (Institute of Medicine, 2006). Bisexual and transgender survivors were disproportionately represented in the highest-barrier cluster, facing healthcare affordability and transportation challenges, delayed care, discrimination, high stress, and low social support—gaps that perpetuate avoidable suffering and inequity.

In this reflection, we consider how our results could inform actionable recommendations for both clinical practice and health policy. These reflections are grounded in three perspectives: (Institute of Medicine, 2006) the lived experiences and psychosocial vulnerabilities of LGBT cancer survivors, (AACR, 2024) structural healthcare access barriers, and (Ussher et al., 2022) opportunities to translate empirical findings into structural and practice-level change.

Introduction

Cancer survivorship extends beyond remission to encompass long-term physical, psychological, and

social outcomes (Institute of Medicine, 2006). For lesbian, gay, bisexual, and transgender (LGBT) survivors, this often means navigating healthcare systems that do not affirm their existence and survivorship needs, and may perpetuate discrimination and stigma (AACR, 2024; Ussher et al., 2022; Cavallo, 2022). Using All of Us Research Program data, we identified clusters of high, medium, and low healthcare utilization (HCU) barriers (All of Us Research Program Investigators, 2025). Bisexual and transgender survivors reported the highest HCU barriers, including affordability, transportation challenges, and delayed care. These cancer survivors also reported the highest levels of discrimination and stress, and the lowest amounts of social support.

In this reflection, we consider how our results are actionable for clinical practice and health policy. These reflections are grounded in three perspectives: (Institute of Medicine, 2006) the lived experiences and psychosocial vulnerabilities of LGBT cancer survivors, (AACR, 2024) structural healthcare access barriers, and (Ussher et al., 2022) opportunities to translate empirical findings into structural and practice-level change.

Structural Barriers and the Cost of Care

Using data from the All of Us research program, we identified healthcare utilization barriers, especially among bisexual and transgender cancer survivors. Delays in care could result from the transportation barriers and the inability to take time off work. Cost-related barriers to medication use, such as skipping doses or asking for lower-cost alternatives, were also more prevalent among bisexual and transgender cancer survivors. Survivors with precarious employment or unstable insurance often lack the ability to pay out-of-pocket costs, and LGBT individuals are overrepresented in lower-wage jobs without healthcare benefits (Kinitz et al., 2023; Kinitz et al., 2025).These are not merely individual circumstances; they reflect systemic vulnerabilities.

From a policy standpoint, these findings point to a need for interventions that directly reduce financial toxicity and access barriers for LGBT cancer survivors. Examples include expanding transportation vouchers, covering telehealth mental health services to reduce transportation barriers, and eliminating high-deductible plans for long-term survivorship care. Without structural solutions, the burden of navigating survivorship will remain disproportionately heavy for those already facing discrimination.

Translating Findings into Clinical Practice

One of the most striking findings from our study is the gradient in psychosocial outcomes across HCU clusters. LGBT cancer survivors who experience more healthcare utilization barriers also reported the highest levels of daily discrimination and stress, coupled with the lowest reports of social support. This aligns with minority stress theory, where chronic stigma exposure drives poor health and barriers to healthcare utilization (Flentje et al., 2020; Meyer, 2003). In practical terms, these findings call for survivorship care to extend beyond disease and tumor-specific surveillance and treatment to include psychosocial screening.

Clinicians could conduct psychosocial screenings with LGBT cancer survivors to identify psychosocial stressors (e.g., discrimination), healthcare utilization barriers, and connect patients with the corresponding affirming resources such as peer navigators and mental health services. Psychosocial screening is an integral component of equitable survivorship care and should include discrimination, stress, and social support, which may uniquely predict care avoidance.

Translating Findings into Policy Change

Relevant policies at the federal, state, and community levels are summarized in Table 1. As the policy environment continues to evolve both federally and within Indiana, our recommendations are urgent and practical. At the federal level, Section 1557 of the Affordable Care Act (ACA) prohibited discrimination in federally funded healthcare programs on the basis of sex (including sexual orientation and gender identity) prior to rewrite (U.S. Department of Health and Human Services, 2024). However, its enforcement has been inconsistent across administrations, and it remains subject to ongoing legal challenges (Human Rights Campaign, 2024; Georgetown Law, n.d.). The original 2016 nondiscrimination rule issued by the Department of Health and Human Services (HHS) was partially vacated and later rolled back under the Trump administration, which removed gender identity and sex stereotyping from its interpretation of "sex discrimination" (U.S. Department of Health and Human Services, 2024). Portions of the original protections, including access to gender-affirming care, remain blocked by court injunctions and face persistent political threats.

These regulatory shifts have tangible effects on LGBTQ cancer survivors. For example, survivors continue to report being dismissed or stereotyped in clinical interactions, especially transgender cancer patients. A 2020 study found that nearly 25% of National Cancer Institute (NCI)-designated centers did not include gender identity or expression in their Patients' Bill of Rights, and more than half excluded it from formal non-discrimination policies (JCO, 2020). This absence of public commitment can reduce engagement in survivorship care and perpetuates avoidable harm.

Meanwhile, recent Health Resources and Services Administration (HRSA) investments, such as the near $9 million Cancer Moonshot allocation to improve cancer screening and follow-up in underserved communities, such as LGBT cancer survivors, demonstrate a renewed but fragile stream of funding (HRSA, 2024). These advances are not guaranteed without durable policy safeguards. Within Indiana, the lack of statewide protections for LGBT individuals remains a significant barrier. There is no explicit state nondiscrimination statute covering LGBT individuals in healthcare or health insurance. Although Bostock v. Clayton County (2020) extended employment protections under Title VII to include sexual orientation and gender identity, Indiana has not codified those protections into healthcare contexts (Bostock v. Clayton County, 2020). Some local ordinances (e.g., Indianapolis, Bloomington, Tippecanoe County) offer limited coverage, but they only apply to roughly one-third of the state's population (Mann, 2021). Transgender survivors in Indiana also live under increasingly restrictive and threatening policies: Senate Bill 480 (2023) bans gender-affirming

care for minors, upheld by the 7th Circuit in 2024, and an executive order issued in 2025 prohibits gender-marker changes on birth certificates for adults – both of which signal a hostile policy environment for transgender Hoosiers throughout the life course and cancer survivorship (Indiana SB 480, 2023; ACLU of Indiana, 2024; Braun, 2025).

Table 1. *Policy Recommendations and Implementation Levers for Equitable LGBTQ+ Cancer Care Delivery*

Level of Action	Recommendation	Implementation Strategy
Federal Level		
	Fund culturally tailored survivorship programs	Urge HRSA and NCI to earmark grant funding specifically for LGBTQ-focused navigation and survivorship interventions.
	Mandate standardized sexual orientation and gender identity data collection	Require inclusion of sexual orientation and gender identity fields in EHRs, cancer registries, and survivorship plans coupled with provider training and privacy safeguards.
State and Local Levels	Mandate inclusive provider training	Propose statewide requirements for oncology teams to undergo LGBTQ affirming and bias-mitigation training.
	Require healthcare center transparency and inclusion statements	Mandate that Indiana hospitals and cancer centers publish inclusive Patients' Bills of Rights and non-discrimination policies explicitly referencing gender identity and expression.
Community and Clinical Engagement		
	Partner with LGBTQ advocacy organizations	Co-design culturally-informed survivorship plans and educational materials with local LGBTQ advocacy groups.

Our recommendations are actionable even in hostile policy climates, but durable change requires more than temporary fixes. Federal nondiscrimination protections must be codified, healthcare systems must make their inclusivity visible, and states like Indiana must close policy gaps that leave LGBTQIA+ survivors unprotected. By strengthening Section 1557 enforcement, passing the Equality Act, and mandating transparency in care, we can move beyond documenting disparities toward dismantling them. Equity in cancer survivorship is not optional, it is overdue.

Durable change requires more than temporary fixes. Policies, transparent healthcare systems, and enforceable protections are essential to equitable cancer survivorship.

Conclusion and Call to Action

Our work highlights both existence of barriers and the significance of barriers facing LGBT cancer survivors and the restrictions that limit capacity to fully address them. Even with one of the largest and most diverse national datasets available, the All of Us research program, small sample sizes for intersectional groups restricted our ability to examine nuanced differences, such as outcomes for transgender men versus nonbinary individuals or variation by specific cancer types, or examining the healthcare utilization barriers of people who hold both LGBT and racial/ethnic minoritized identities. These limitations underscore an urgent need for intentional oversampling of sexual and gender minorities in cancer research (Institute of Medicine (US) Committee on Lesbian Gay Bisexual and Transgender Health Issues and Research Gaps and Opportunities, 2011), as well as routine collection of accurate sexual orientation and gender identity data in both clinical and research settings. Without accurate data, inequities remain invisible, and opportunities for intervention are missed. Longitudinal research is also essential to understand how access barriers and psychosocial vulnerabilities evolve over time and influence survivorship outcomes, particularly for bisexual and transgender survivors who consistently experience the highest burden.

Despite these gaps, our findings are clear: LGBT cancer survivors face disproportionate barriers to survivorship care and heightened psychosocial vulnerability rooted in discrimination, financial strain, and social isolation. These are not individual hardships but structural failures of the healthcare system. Clinical practices must integrate routine screening for healthcare access barriers and psychosocial stressors, paired with patient navigation and peer support models tailored to LGBT survivors. Policy reforms must strengthen nondiscrimination protections, mandate data collection, and expand coverage for transportation, mental health care, and

survivorship supports. Community partnerships must be empowered and funded to co-create responsive survivorship pathways that rebuild trust and address social isolation.

Delays in equity-driven reforms miss opportunities to reduce suffering and improve outcomes. Clinicians, health systems, policymakers, and community organizations each have a role to play in moving beyond documenting disparities toward dismantling them. This requires not incremental adjustments but structural transformation that centers equity as a core operational priority. Cancer survivorship cannot be considered complete while whole populations remain underserved and at risk of harm. The path forward requires us to affirm LGBT identities, remove access barriers, integrate psychosocial support as a standard of care, and invest in long-term research that holds systems accountable. Achieving equity in cancer survivorship for LGBT populations demands deliberate, evidence-based transformation, where policies affirm identity, clinical practices dismantle barriers, and research ensures no survivor is rendered invisible.

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The Evolving Landscape of Sexual Orientation and Gender Identity Data Collection in Clinical Practice

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Abstract

Lesbian, gay, bisexual, transgender, and other individuals (LGBT+) who identify as sexual and gender minorities SGM experience disparities in treatment-related side effects, early cancer screening, and overall mortality. Past research has shown that disclosure of sexual orientation and gender identity (SOGI) data in clinical settings can improve patient-provider communication. With significant advocacy along with evolving Meaningful Use Standards for Electronic Health Records that require SOGI data collection fields, the completeness of SOGI information in electronic medical records has recently been increasing. Recent policy changes, however, may alter this trend. Indeed, current policy developments seriously threaten the safety and confidentiality of LGBT+ people in research and clinical care settings. This reflection article offers observations on the current policy climate and encourages safe, confidential, and informed SOGI data disclosure in clinical practice and research. These reflections suggest that research is urgently needed to identify adaptive strategies for SOGI data disclosure based on geopolitical context.

Summary

Sexual orientation and gender identity (SOGI) data collection is vital yet inconsistently collected in clinical practice. Collection of SOGI data in research studies and clinical care is important to identify trends in morbidity, mortality, and health-related quality of life and prompt intervention to address identified disparities. With significant advocacy alongside evolving Meaningful Use Standards for Electronic Health Records (EHRs) that require SOGI data collection fields, the completeness of SOGI information in EHRs has recently increased. However, recent policy changes at institutional, state, and federal levels have stifled research efforts to advance the health of lesbian, gay, bisexual, transgender, and other individuals who identify as sexual and gender minorities (LGBT+). This threatens important confidentiality protections and trust in healthcare settings. The current political climate may have long-term implications for the collection of these data across the United States healthcare system.

Public Problem

LGBT+ individuals experience disparities in treatment-related side effects, early cancer screening, and overall mortality.1 Observational research has shown that disclosure of SOGI data in clinical settings can improve patient trust and satisfaction and improve tailored referral to fit patient needs.8,9 With significant advocacy, along with evolving Meaningful Use Standards for EHRs that require SOGI data collection fields, the completeness of SOGI information in electronic medical records has been increasing.4,5 One study by Liu et al. found that SOGI data was approximately 70-75% complete in medical records in federally qualified health centers.4 While this study does not account for private enterprises and does not apply a standard for patient self-reported data, this is still an encouraging statistic. Recent policy changes, however, may alter this trend. Indeed, current policy developments seriously threaten the safety and confidentiality of LGBT+ people in research and clinical care settings. This reflection article builds on discussions by the Sexual and Gender Minority Interest Group, which convened from April 2022 to June 2023, to examine optimal strategies for collecting SOGI data in clinical settings10 and subsequent work to ensure recommended items were acceptable and appropriate for diverse older adults.11 Here, we offer observations on the current policy climate and encourage safe, confidential, and informed SOGI data disclosure in clinical practice and research. These reflections suggest that research to identify adaptive strategies for SOGI data disclosure based on geopolitical context is urgently needed.

Trends

Funding for LGBT+-focused research initiatives is declining

Nearly all National Institutes of Health (NIH)-funded research focused on advancing the health of LGBT+ people was terminated between January and April of 2025. Grants for projects related to transgender populations and gender identity, specifically, as well as diversity, equity, and inclusion (DEI) broadly have been scrutinized, terminated, pulled from study section review, and eliminated from "agency priorities."12 Of note, while research focused on LGBT+ health outcomes and research focused on DEI overlap, these are not synonymous: DEI work broadly aims to implement practices where all people are included, diversity is valued, and people are cared for based on their level of need rather than through a one-size-fits-all approach. LGBT+-focused research is a component of DEI work but is narrower in its focus. NIH staff have been advised to place ongoing projects into categories depending on their involvement with and mention of DEI, and requested revisions to fundable projects require eliminating DEI components.13 Ironically, of course, the reduction of support for DEI research broadly and LGBT+ research specifically counters the "health for all" rhetoric that disproportionately favors those with the most access, resources, and power.

Recent federal- and state-level policies may negatively impact LGBT+ health

TThe halt of major funding sources for LGBT+-related research activities has a direct and immediate impact on LGBT+ individuals' health. For example,

researchers at Vanderbilt University who study stress and resilience among the LGBT+ population had funds terminated, leading to an end of an important longitudinal study. This study is critical because of longstanding stress, stigma, and denial of care experienced by LGBT+ people, which makes resiliency critical for higher quality of life for those experiencing disaffirming and discriminating experiences. Losing these data means a loss of valuable information about the health of a group experiencing sustained health and healthcare disparities.12 The "gender ideology extremism" Executive Order posits that there is a binary nature to sex and recognizes only "male" and "female" without regard for gender identity.7 The Presidential order effectively erases transgender, gender expansive, nonbinary, and intersex people–creating less accurate data on which to base healthcare treatment planning and decisions. According to a Fenway Health policy brief, encouragement of this sentiment may prevent efforts to collect SOGI data in public health surveillance, including at institutions that receive funding from the federal government.14 For instance, the CDC announced that it will stop collecting data on transgender identity to comply with President Trump's Executive Orders.15 Other federal datasets no longer collecting SOGI include the National Crime Victimization Survey, which added SOGI in 2016 and provides valuable information about victimization of LGBT+ people in the United States.16 Without these data, it is impossible to develop evidence-based ways of addressing the longstanding, often socially-sanctioned trauma long experienced by LGBT+ people to improve resiliency, coping, and quality of life.

Policy Considerations

Despite Executive Orders that impede SOGI data collection, there have been critical challenges to mitigate the impact and prevent further delay of research. On June 16, 2025, a federal judge ordered the NIH to restore grants terminated on the grounds that they endorsed "gender ideology" or "DEI."17 More recently, a senior NIH official instructed agency employees to cease grant terminations, including those that are in the process of being terminated.17 The Centers for Medicare & Medicaid Services Meaningful Use Stage 3 requirements of the Health Information Technology for Economic and Clinical Health (HITECH) Act, which required that Electronic Health Records have the capacity to record SOGI since 2018, continue to remain in place in 2025.2,3 On a state level, one example of a policy that encourages SOGI data collection was enacted in New Jersey: As of 2024, New Jersey required all

clinical laboratories to "electronically record the race, ethnicity, sexual orientation, and gender identity of each patient" unless the patient was not present and the laboratory only had an electronic order.18 The option to not disclose was required in addition to standardized SOGI data categories.18 A prior New Jersey policy required that if SOGI data were collected, appropriate cultural competency training must also be in place.19 New Jersey's legislation demonstrates that states can play a proactive role in protecting inclusive data practices in the setting of federal restrictions. However, when federal and state authorities are not in alignment, confusion ensues. When pressed to hand over identifiable patient data "to reconcile such records against… billing data" related to transgender care, Vanderbilt opted to comply without question.20 Yet, the HIPAA privacy rule requires that any disclosure of data satisfy a three-part test: the material requested must be "relevant and material" to a current investigation; the request must be "specific and limited" in scope; and data must be de-identified unless a clear reason for identifiable data is apparent.20 In response to a similar request by the Missouri Attorney General, the University of Washington opted to petition the request in state court to assess the Attorney General's legal authority to request patient records, with the authority resting on whether the Attorney General is deemed a health oversight agency.20 In Indiana, many healthcare settings resisted patient data disclosure, while in Texas, the Attorney General requested to obtain patient information for patients in two other states (Washington and Georgia).20 While Seattle Children's in Washington state and QueerMed in Georgia successfully settled with their respective Attorney Generals without providing identifiable patient data, these institutions were forced to stop providing healthcare to youth from Texas.21,22

Most recently, the erasure of transgender status by the President in 2025 and growing anti-LGBT+ state-level policies6,7 have created a culture of intimidation and threatens basic protections of confidentiality and safety for LGBT+ patients and research participants. We are thus left with the impossible need to collect SOGI data to advance the health of LGBT+ people in an environment where it may not be safe to do so. While HIPAA protections hold, attempts to strengthen patient privacy have so far failed.23 Furthermore, the Supreme Court has upheld state bans on transgender care for youth, potentially strengthening future Attorneys General claims to data to ensure compliance with those bans.24

Implications

The collection of data regarding LGBT+ people in institutional, state, and federal datasets can provide estimates specific to LGBT+ people and enable comparison to non-LGBT+ populations.25 The cumulative effect of the current political climate is to reduce visibility of LGBT+ patients in data and undermine data-driven quality improvement as well as provision of appropriate services. Our recent study investigating the implementation factors associated with SOGI data collection identified mandates, forced workflows, structured data fields, and leadership support as facilitators of data collection.26 Surely, if mandates are a primary force for SOGI data collection, mandates against the use of SOGI collection and data-driven clinical research for

LGBT+ patients will negatively impact the overall landscape for LGBT+ patients seeking care. So, what are we to do? First and foremost, institutions should not release SOGI patient data to government officials. Leveraging the examples of Seattle Children's in Washington State and QueerMed in Georgia, institutional leadership can and should assert and enforce unequivocal nondisclosure of patient records to comply with HIPAA. If authorities provide persuasive evidence via the three-part test, successfully arguing for the need to receive identifiable patient data to comply with a specific, limited investigation for legal compliance, institutions can petition to allow the court to decide if the request is compelling, reasonable, and within the authority of the requesting official. It is not unrealistic to assume that patients in some states where transgender care bans have been upheld by the courts may be at risk for disclosure of their data. Therefore, it may be better not to collect SOGI data in jurisdictions where the basic safety of transgender patients is at reasonable risk. Given the current landscape of extreme discrimination and the rollback of civil protections, healthcare executives should assess the risks and benefits of SOGI data documentation in their state and provide guidance to healthcare clinicians at this unique time in our nation's history: informing patients of what is and is not protected and who can see their data is critical to shared decision making regarding SOGI disclosure and documentation. To be certain, the rapidly evolving court decisions make this a challenging assessment. Healthcare clinicians should thus ask patients if they would like their SOGI data stored in their medical record or removed, given the evolving potential for data misuse and abuse. This puts researchers trying to investigate better tailored care for LGBT+ people in a significant bind: While not ideal for the research community and future data collection for evidence-based practice, adaptive strategies to encourage patient-provider communication regarding relevant behaviors and needs to tailor care for LGBT+ patients without documentation of SOGI (which may unintentionally put patients at risk) may be needed as we collectively advocate for stronger privacy regulations and an end to the discriminatory actions being taken in the current geopolitical environment.

Recommendations/Call to Action

- Federal policymakers: Reinstate and protect funding for LGBT+-focused research projects.
- Healthcare institutions: Enable confidential opt-in SOGI data collection methods and implement cultural humility training to help clinicians and staff navigate SOGI-related conversations with patients.
- Healthcare providers and researchers: Protect confidentiality of patient and research participant data. If institutional, state, and federal laws do not fully protect the confidentiality of SOGI information in EHRs, ask patients if they want their SOGI data removed until and unless such protections can be guaranteed. Advocate for the strengthening of patient and research participant data protections.
- Community stakeholders and advocates: Partner with local clinics that provide care for LGBT+ patients in the community to develop tools that capture health-related quality of life for this population. Advocate for civil rights restoration for LGBT+ people.

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Fighting for the Few: Advancing Research in Rare Childhood Cancers

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Abstract

Recently, the Cancer Burden Across Indiana Symposium hosted by Indiana University's Simon Comprehensive Cancer Center brought stakeholders together to address the cancer burden across Indiana. This event provided members of the Pollok Lab in the Herman B Wells Center for Pediatric Research with the opportunity to present data focused on osteosarcoma, a devastating pediatric bone cancer that often arises during the adolescent growth spurt and urgently requires better treatment options. This reflection highlights the significance of our findings, places our research within the broader field of pediatric oncology, and underscores how community-engaged research and advocacy are essential to progress. We discuss the urgent need for novel therapies, share key pieces of promising data, consider implications for policy and future research, and emphasize how collaborative efforts like these ultimately serve the well-being of families and communities across Indiana.

While childhood cancer is the leading cause of death by disease in children, its occurrence is considered rare, complicating the development of new therapies. From the 1970s until the 1990s, outcomes improved dramatically for children diagnosed with solid tumors (LaQuaglia, M. P. & Gerstle, J. T., 2022). However, for some types of cancer, such as osteosarcoma and rhabdomyosarcoma, there has been little to no improvement in outcomes since. The standard of care for many pediatric cancers was established decades ago, and outcomes remain poor in cases of metastasis or relapse. Further, the toxicity of the commonly used therapies for children with cancer leave a large percentage of them with a lifetime of medical conditions and challenges, such as secondary cancers, infertility, heart disease, kidney disease, and mental health challenges (Suh et al., 2020). There is rapid progress in developing improved methods of early diagnosis, prevention, and treatments for many types of adult cancers; however, there is a critical gap in developing new therapies for children, adolescents, and young adult patients. Therefore, there is a critical need for novel therapies specifically for childhood cancers in which earlier intervention will be key, representing a time before the tumor burden becomes unmanageable and refractive to therapy.

One of the difficulties in this field is the fact that tumors in children are very diverse at the genetic and molecular level, making it challenging to design “one-size-fits-all” targeted treatments. Our research delves into the genomic complexities underlying osteosarcoma. A key factor contributing to osteosarcoma progression is DNA replication stress. Replication stress occurs when DNA replication is hindered, leading to stalled replication and potential genomic instability. While moderate levels of replication stress can promote tumor growth, critically high levels can trigger death of the cancer cells, presenting a potential therapeutic opportunity. Bromodomain and extra-terminal domain (BET) proteins play a

critical role in regulating replication stress (Wang et al., 2023). We hypothesized that drugs that inhibit the activity of BET proteins, known as BET inhibitors, could increase levels of replication stress in the cancer cells, causing the cells to die in a process known as apoptosis. Before this theory could be tested in cancer patients, it must be tested in the lab using models.

Our lab utilizes in vitro methods such as osteosarcoma cell lines, as well as those that examine how patient tumors grown in mice respond to treatment. Cell lines allow us to treat cancer cells with a range of doses of the BET inhibitors to measure the ability of the drugs to inhibit cancer cells from growing. We can test multiple types of BET inhibitors to compare their efficacy. While we use a variety of osteosarcoma cell lines, including metastatic lines, and multiple inhibitors to ensure the results are consistent, cell lines do not fully capture the complexity of a tumor inside the body. Therefore, we also utilize patient-derived xenografts (PDXs) which involve typically small cancerous tumor specimens removed from a patient during surgery. These specimens are deidentified and are only obtained after sufficient tumor tissue is obtained for diagnosis and clinical trial studies. The specimen obtained by the Pollok lab is implanted into mice that lack a functional immune system. In this model, the tumor cells expand, are characterized at the molecular level, and are used for testing the efficacy and safety of new therapies, such as BET inhibitors. It is critical that our research is representative of and beneficial to all communities, so we are committed to testing PDXs from patients of diverse backgrounds, ethnicities, genders, ages, and treatment histories within the pediatric population. Our research objective was to evaluate the efficacy of clinically relevant BET inhibitors in osteosarcoma. We combined screening in cancer cell lines with molecular profiling and validation using PDXs. This allowed us to assess the efficacy of several BET inhibitors in these models and investigate the molecular changes induced by BET inhibition. Putting the data together, we evaluated BET inhibitors across different disease stages and prior treatment histories, reflecting real-world clinical scenarios. Our findings demonstrate compelling evidence for the therapeutic potential of BET inhibition in osteosarcoma. The cell line data showed growth suppression at clinically relevant doses of multiple BET inhibitors. Furthermore, one of the inhibitors significantly reduced tumor growth in numerous osteosarcoma PDX tumor models. This broad effectiveness across diverse patient samples is highly encouraging for future clinical therapeutic application.

While data such as this brings hope for improved outcomes for future cancer patients, there is much more work to do. In our future work, we will continue to investigate targeted therapies such as BET inhibitors, as well as combination therapies that involve different types of anticancer drugs working together to address tumor heterogeneity and invasion. Legislative support will be vital for realizing the full potential of precision medicine initiatives that integrate molecular techniques into patient care decisions . Policies that support data sharing and collaborative research across institutions can accelerate the identification of new biomarkers and therapeutic targets, ultimately benefiting patients sooner.

Multi-stakeholder engagement is key for achieving meaningful change in outcomes for

childhood cancer. However, meaningful engagement requires multi-stakeholder agreement on a model for working together, including agreed-upon processes for engagement and clear mission alignment. In addition, equitable engagement for all stakeholders is key, and a working model should aim for co-production. Elevate Childhood Cancer Research and Advocacy (Elevate), an Indiana incorporated nonprofit, proposed such a model at the Cancer Burden Across Indiana Symposium (Spoon et al., 2024). Previous work suggested that such a model should include recognition of eight key stakeholders (i.e., Product Makers, Principal Investigators, Program Managers, Policy Makers, Payers, Providers, Press, and the Public), with Patient Advocacy Groups serving as connectors, providing critical social capital to get things done. Patient Advocacy Groups (PAGs) have been an integral part of driving multi-stakeholder engagement in a range of rare diseases, including childhood cancers, such as rhabdomyosarcoma, osteosarcoma, neuroblastoma, and retinoblastoma.

For example, advocates play an important role in connecting patients with Principal Investigators for research (May et al., 2021; Merkel et al., 2106).

Advocates also regularly serve as catalysts, often initiating projects, providing seed money to launch initiatives, and helping build coalitions and consortiums (Moitra et al., 2017). The Indiana Pediatric Cancer Coalition (IPCC) was formed by a group of Hoosier families and nonprofits (i.e., Elevate, LG-30, Mighty Mason) who have been directly impacted by childhood cancer. IPCC is dedicated to fostering collaboration among advocates, increasing funding, and driving medical advancements.

The Coalition strives to ensure that the highest quality diagnostics, treatments, and survivorship care are accessible to children and families impacted by pediatric cancer throughout Indiana. IPCC envisions becoming a leading integrative resource for childhood cancer research and advocacy. Its goal is to drive the development of cutting-edge treatments that save lives, provide hope, and ensure a healthier future for Hoosier children and young adults. IPCC has been instrumental in expanding the Indiana Cancer Plan to include objectives for children, adolescents, and young adults impacted by cancer. In addition, IPCC works to actively bring about awareness through annual advocacy days at the statehouse, which include a range of stakeholders. In 2023, efforts by this group of advocates resulted in legislators drafting legislation to better understand childhood cancer research in Indiana through the Rare Disease Advisory Council. In 2025, persistent efforts to educate policy makers about the brilliant capacity of pediatric cancer researchers in Indiana and the desperate need for new therapies resulted in the passage of HB1453, which created a fund for pediatric cancer research in the state.

It is only with strong collaboration that we can make progress against childhood cancers. Researchers, advocacy groups, policy makers, and the community each have a crucial role to play. Scientists investigate disease mechanisms and new treatment possibilities; advocates connect families to research and amplify their voices; lawmakers create policies and funding streams to sustain progress; and communities ensure that rare pediatric cancers remain a public priority. Collaboration is key to developing more safe and effective therapies with the ultimate goal of giving children and young adults with cancer a chance to thrive. The lives of patients depend on our collective actions, and together we can transform today's hope into tomorrow's cures.

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CERVICAL CANCER
Teal/White
CHILDHOOD CANCER
Gold
COLON CANCER
Dark Blue
ESOPHAGEAL CANCER
Periwinkle
HEAD & NECK CANCER
Burgundy/Ivory
KIDNEY CANCER
Orange
LEIOMYOSARCOMA
Purple
LYMPHOMA
Lime
MELANOMA
Black
MULTIPLE MYELOMA
Burgundy
OVARIAN CANCER
Teal
PANCREATIC CANCER
Purple
PROSTATE CANCER
Light Blue
ALL CANCERS
Lavender
BLADDER CANCER
Yellow
BRAIN CANCER
Grey
BREAST CANCER
Pink
STOMACH CANCER
Periwinkle
TESTICULAR CANCER
Orchid
THYROID CANCER
Teal/Pink/Blue
LEUKEMIA
Orange
LIVER CANCER
Emerald
LUNG CANCER
White
UTERINE CANCER
Peach
HONORS CAREGIVERS
Plum
SARCOMA/BONE CANCERS
Yellow

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