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.