

Patient Barriers to Care: A Health Equity Landscape Analysis for Emerging Multicancer Early Detection Tests

A REPORT FROM
The Multicancer Early Detection Consortium
Health Equity Workgroup



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Executive Summary

Ensuring equitable access to care advancements in cancer prevention, screening, diagnosis, and treatment is the primary goal of the Multi Cancer Early Detection (MCED) Health Equity Workgroup. The purpose of this document is to summarize the evidence-base regarding known barriers and facilitators to participation in cancer testing, derived from research evidence in the U.S. and U.K. healthcare settings. The Workgroup carried out this landscape analysis due to evidence gaps about the influences on MCED test access, acceptability, participation, and impact among underrepresented populations. In this document, we extrapolate insights from existing evidence to inform communication and care delivery strategies to support equitable and informed participation in MCEDs as tools for testing asymptomatic populations or diagnosing cancer in patient populations. In this rapidly evolving landscape, we envisage our landscape analysis as a living document that will evolve as research data emerge regarding the benefits, harms, and modifiable barriers to acceptability and uptake of MCEDs among diverse underrepresented populations.

However, we also consider it critical to recognize contextual factors underpinning cancer testing behavior reflecting the social determinants of health (SDOH), or environmental conditions that impact health outcomes and risks, including economic stability, nutrition, education access and quality, health care access and quality, neighborhood and built environment, and the broader social and community context. Wider determinants of health (WDOH) are another set of socioeconomic and environmental factors, which include the built and natural environment, work and labor market, income, crime, and vulnerability, and impede health access and outcomes in the U.K. Health concerns, including the potential to diagnose cancer faster and earlier via MCED testing, may not be a priority for individuals and communities with low resources. For both the U.S. and the U.K., demographic characteristics such as race/ethnicity, socioeconomic status, geography, disability and sexual orientation, and the intersections between these characteristics, can also magnify barriers to cancer care. SDOH and WDOH affect access to cancer prevention, screening, diagnosis, and treatment services at the patient, provider, and institutional levels in both the U.S. and U.K. and this paper uses them interchangeably.

Social Determinants and Wider Determinants of Health³

Individuals have limited control over these factors, which can explain significant health disparities in the U.S. and U.K..⁴ To address both sets of factors and improve quality of life, public health systems must partner or integrate with other sectors such as healthcare, transportation, education, and social work systems. SDOH and WDOH pose significant and varying risks to equitable cancer testing access across populations. As more data emerge about different populations' access and response to MCEDs, this landscape analysis will track barriers and inequities as well as potential multi-level intervention

¹ Office of Disease Prevention and Health Promotion. (n.d.). Social Determinants of Health. Social Determinants of Health - Healthy People 2030. https://health.gov/healthypeople/priority-areas/social-determinants-health

² University of College London Institute of Health Equity. (n.d.). Health Equity in England: The Marmot Review 10 Years On. Institute of Health Equity. https://www.instituteofhealthequity.org/about-us/the-institute-of-healthequity/our-current-work/collaborating-with-the-health-foundation-

³ See Appendix 1.

⁴ World Health Organization. Social Determinants of Health. World Health Organization. https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1



strategies.⁵ As described in Bronfenbrenner's Social Ecological Model, interventions that operate at the individual and interpersonal level (microsystem) organizational level (mesosystem) and wider system level (macrosystem) have the potential to address modifiable barriers to equitable patient/public access that are underpinned by the SDOH and WDOH.^{6,7}

Current uncertainties with MCEDs

Though the development of noninvasive and early-stage testing is a source of great hope and excitement in the cancer care field, significant uncertainty remains about the clinical utility, outcomes, and efficacies of these tests and how they are best communicated and implemented across diverse populations⁸. High-quality research studies on MCED testings' effects on access, acceptance, and follow-up care are still needed to better understand the clinical utility of MCEDs, how they fit into existing care delivery pathways, and their functionality as tools to screen asymptomatic populations or triage patients who present with suspected cancer symptoms. Systematic research on the harm-to-benefit ratio of targeting MCEDs for patient populations who are at higher risk based on genetic, environmental, and behavioral factors is also needed. Potential harms of MCEDs include false positives, false negatives, overdiagnosis and overtreatment, and uncertainty and potential harms from procedures needed to diagnose cancer.⁹

Key Health Equity questions for researchers and users of MCEDs

MCED Access

- What are the information and support needs of vulnerable populations to enable equitable and informed participation in MCEDs?
- What are the key barriers and facilitators to MCED participation in vulnerable populations and how can informed participation be optimized?
- How can MCED tests be implemented without exacerbating existing racial, ethnic, or socioeconomic disparities in cancer outcomes?
- Who should receive MCED testing, at what ages and intervals, and which type is best for them?

⁵ Sniehotta, Falko F, et al. "Complex Systems and Individual-Level Approaches to Population Health: A False Dichotomy?" *The Lancet Public Health*, Elsevier, 1 Sept. 2017, www.thelancet.com/journals/lanpub/article/PIIS2468-2667(17)30167-6/fulltext.

⁶ Bronfenbrenner, U. (1977). Toward an Experimental Ecology of Human Development. American Psychologist, 32(7), 513

⁷ For more information on this behavioral model, see Appendix 2.

⁸ Castle, Philip. "Uncertainty Around Tests That Screen For Many Cancers." National Cancer Institute, 21 Apr. 2022, www.cancer.gov/news-events/cancer-currents-blog/2022/finding-cancer-early-mced-tests.

⁹ "Questions and Answers - Cancer Screening With Multi-Cancer Detection (MCD) Tests." Division of Cancer Prevention, 8 Nov. 2022, prevention.cancer.gov/major-programs/mced/questions-and-answers-cancer#potential.



MCED Acceptance

- What are the barriers to MCED acceptance across different underrepresented communities?
- What are the specific approaches that could influence an individual's attitude, belief, and behavior toward MCED acceptance?
- How will underrepresented communities participate in MCED research and testing uses?
- How will MCED testing impact different communities in terms of health outcomes and trust of healthcare institutions?

MCED Follow-up

- What is the psychological and behavioral impact of MCED participation among diverse patient populations (for example, will people who receive MCED tests forego future cancer tests due to distress and anxiety associated with a false-positive signal or overreassurance associated with a negative signal)?
- What are the consequences of a lack of diagnostic resolution or explanation for a positive MCED signal?

Barriers to MCED participation

Country-Specific Barriers to Cancer Testing in the U.S. and U.K.

Country-specific nuances of cancer testing and health systems make it difficult to transfer lessons directly, but together give some indication of the multi-level factors influencing participation in cancer testing across two contrasting healthcare systems.

- Cancer testing in the U.K. is free at the point of delivery and includes systematic call and recall of
 eligible patients based on their registration with a general practitioner. In the U.S., there is no
 centrally organized cancer testing, so patients must coordinate with their providers and
 insurance companies to receive testing and be eligible for reimbursement.¹⁰
- Modifiable influences on testing uptake in both country settings reflecting capability (i.e., low knowledge of testing, health literacy and language access), motivational (i.e., emotion, habits, attitudes and beliefs, and perceived risk of cancer) and opportunity (i.e., social norms and stigma, environment, and resources) are highly relevant to the MCEDs context.^{11,12}

¹⁰ Young, Ben, and Kathryn A Robb. "Understanding Patient Factors to Increase Uptake o Cancer Screening: A Review." *Future Oncology*, vol. 17, no. 28, 2021, pp. 3757–3775., doi:10.2217/fon-2020-1078.

Michie, Susan, et al. "The Behaviour Change Wheel: A New Method for Characterising and Designing Behaviour Change Interventions." Implementation Science, vol. 6, no. 1, 2011, doi:10.1186/1748-5908-6-42.

¹² Young, Ben, and Kathryn A Robb. "Understanding Patient Factors to Increase Uptake of Cancer Screening: A Review." Future Oncology, vol. 17, no. 28, 2021, pp. 3757–3775., doi: 10.2217/fon-2020-1078.



Economic stability, work and labor market, and income

Those with lower household incomes and less stable employment are less likely to be concordant with regular cancer testing. 13,14 In the U.S., families with low incomes are more likely to be uninsured or have less comprehensive insurance coverage, and in states that chose not to expand Medicaid, adults are also more likely to be uninsured than children due to financial ineligibility. Despite the cost-reduction benefits of the Affordable Care Act, 74 percent of adults that were uninsured in 2019 cited the high cost of insurance, which can lead to access barriers if insurers are not willing to cover MCED testing. 15 The connection between low household income and lack of insurance means that these individuals are also less likely to receive preventive care, provider-recommended healthcare treatment, and are more heavily impacted by medical bills and out-of-pocket costs. 16 Consequently, disparities in MCED testing access and the potential life- and cost-saving benefits that come from early testing and detection are already emerging across income and coverage levels. MCEDs are already commercializing in the U.S. to individuals primarily based on financial access (i.e., income, insurance). If MCEDs prove to be clinically effective in improving cancer outcomes, then these financially based disparities in access will exacerbate existing health disparities among groups of different financial means. Even if MCEDs serve to extend lead-time without improvements in outcome, their overall impact could still be psychologically harmful to users and costly to the healthcare system.

Independent of demographic characteristics, health insurance type has also been identified as a major determinant of cancer testing. One U.S. study found that privately insured women were more likely to report cancer testing than their Medicare-enrolled counterparts, along with women who are uninsured, and those with fee-for-service insurance. Despite the U.K.'s National Health System (NHS) subsidization of most cancer testing, inequities in uptake persist including among people from lower socioeconomic backgrounds.^{17,18}

¹³ Warren Andersen, Shaneda et al. "Association of Race and Socioeconomic Status With Colorectal Cancer Screening, Colorectal Cancer Risk, and Mortality in Southern US Adults." JAMA network open vol. 2,12 e1917995. 2 Dec. 2019, doi:10.1001/jamanetworkopen.2019.17995

¹⁴ Benavidez GA, Zgodic A, Zahnd WE, Eberth JM. Disparities in Meeting USPSTF Breast, Cervical, and Colorectal Cancer Screening Guidelines Among Women in the United States. Prev Chronic Dis 2021;18:200315. doi: http://dx.doi.org/10.5888/pcd18.200315

¹⁵ Patrick Drake, and Jennifer Tolbert. "Key Facts About the Uninsured Population." Kaiser Family Foundation, 7 Feb. 2023, www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/.

¹⁶ Hadley, Jack. "Insurance coverage, medical care use, and short-term health changes following an unintentional injury or the onset of a chronic condition." JAMA vol. 297,10 (2007): 1073-84. doi:10.1001/jama.297.10.1073

¹⁷ Hirst, Yasemin et al. "Uptake of the English Bowel (Colorectal) Cancer Screening Programme: an update 5 years after the full roll-out." European journal of cancer (Oxford, England: 1990) vol. 103 (2018): 267-273. doi:10.1016/j.ejca.2018.07.135

¹⁸ McRonald, Fiona E et al. "The UK Lung Screen (UKLS): demographic profile of first 88,897 approaches provides recommendations for population screening." Cancer prevention research (Philadelphia, Pa.) vol. 7,3 (2014): 362-71. doi:10.1158/1940-6207.CAPR-13-0206



Education access and quality

Primary care and general medicine providers have long recognized the health consequences of limited education and literacy skills. An early New York-based breast and cervical cancer detection program targeting low income and uninsured women with limited English proficiency found increased cancer testing and follow-up rates by 67 percent once program staff was trained to better cater to patients' needs. ¹⁹ The clinics took steps to use patient and provider reminders, physician education, pre-visit planning, and using a mobile mammography van to increase the flexibility and ease of testing. These measures are just a few strategies that can address educational barriers to MCED testing at individual and systematic levels.

One-on-one education efforts to screen patients for cervical cancer also recognized the importance of recruiting trained healthcare workers, professionals, and volunteers to personally engage patients in individual, household, and community environments. Community cancer testing programs can address health disparities, particularly when they take a personalized approach to messaging and follow-up. This includes the entire testing process, from introducing the need for screening, scheduling screens, and answering pre- and post-testing concerns. ²⁰ ²¹ Acceptability and participation in MCEDs may therefore be enabled by having access to a credible, trusted, and compassionate health provider.

Health literacy, or how readily patients can navigate the healthcare system and make informed, health-related decisions, is also worse among patients that are older, lower income, and with lower levels of formal education. For the 80 million American adults and 7.1 million U.K. adults that are estimated to have limited or low health literacy, the lack of evidence on MCED tests' clinical efficacy and utility can understandably dissuade patients from even considering them. The subsequent medical decisions and distress after an abnormal result may also undermine their care experience and increase medical distrust if abnormal results are false. ^{22, 23}

Healthcare access and quality

Health systems play a key role in encouraging and promoting effective testing for vulnerable populations since testing by nature involves examination of a population at risk for a certain condition. Inadequate healthcare access can pose significant obstacles to broader, more equitable MCED access. Lack of awareness, time, affordability, test characteristics, negative preconceptions about testing, cancer fear and fatalism, and cultural norms all vary across patient demographic characteristics. For lung cancer testing, patient unawareness, fear and stigma around a cancer diagnosis, and challenges accessing

¹⁹ "Providing Training and Education." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 15 Feb. 2022, www.cdc.gov/cancer/nbccedp/success/training-education.htm.

²⁰ "Cancer Screening: One-on-One Education for Clients Cervical Cancer." The Community Guide, 30 Nov. 2022, www.thecommunityguide.org/findings/cancer-screening-one-one-education-clients-cervical-cancer.

²¹ "Cancer Screening: Group Education for Clients – Breast Cancer." Cancer Screening: Group Education for Clients – Breast Cancer - Healthy People 2030, health.gov/healthypeople/tools-action/browse-evidence-based-resources/cancer-screening-group-education-clients-breast-cancer.

²² Hickey, Kathleen T., et al. "Low Health Literacy." The Nurse Practitioner, vol. 43, no. 8, 2018, pp. 49–55., doi:10.1097/01.npr.0000541468.54290.49.

²³ "Adult Literacy." National Literacy Trust, National Literacy Trust, literacytrust.org.uk/parents-and-families/adult-literacy/.



follow-on imaging sites deter patients from participating. ^{24,25} These concerns may be relevant to MCEDs, where patients may be unfamiliar and/or unmotivated to take up MCEDs, as well as under-prepared for the psychological consequences of receiving a positive MCED signal.

Providers must also manage their own barriers to cancer testing, namely uncertainty around patient coverage, patient eligibility, and managing testing results. In a study on provider barriers to lung cancer testing, 43 percent of primary care providers and pulmonary providers needed more information on lung cancer testing eligibility. ²⁶ To address providers' unfamiliarity with testing guidelines, the researchers leveraged onsite educational resources and continuing medical education modules, with positive results. Additionally, providers may hold reservations given the limited time they have with patients or potential for abnormal results. Wide variations in provider willingness to recommend cancer testing, and thereby MCEDs in the future, can have costly consequences for patients' access and experience with MCED tests.

While advancements in cancer prevention, screening, and treatment have by and large improved patient prognoses, cancer types without any mode of early detection available tend to be the deadliest of all cancers.²⁷ MCEDs can potentially detect multiple lethal cancers and identify early avenues of treatment for those screened, and the ease of administering blood-based cancer testing may also increase accessibility to MCEDs. However, without adequate communication and health literacy efforts, MCEDs may only exacerbate existing access and usage divides between those who are medically literate and/or familiar with testing modalities.

²⁴ Baldwin DR, Brain K, Quaife S. Participation in lung cancer screening. Transl Lung Cancer Res 2021;10(2):1091-1098. doi: 10.21037/tlcr-20-917

²⁵ Wang, Gary X., et al. "Barriers to Lung Cancer Screening Engagement from the Patient and Provider Perspective." Radiology, vol. 290, no. 2, 2019, pp. 278–287., doi:10.1148/radiol.2018180212.

²⁶ Ibid.

²⁷ Byers, T., Wender, R.C., Jemal, A., Baskies, A.M., Ward, E.E. and Brawley, O.W. (2016), The American Cancer Society challenge goal to reduce US cancer mortality by 50% between 1990 and 2015: Results and reflections. CA: A Cancer Journal for Clinicians, 66: 359-369. https://doi.org/10.3322/caac.21348



Key healthcare barriers for different patient demographics in the U.S. and U.K.²⁸

Patient Demographic	Cost	Health Insurance	Lack of Awareness	Lack of Time	Characteristics of the Test	Limited Access	Cultural Norms	Lack of Clinical Trial Diversity
African American/Black	Х	Х	Х	Х	X	Х	X	Х
Hispanic/Latino	Х	Х	Χ	Х	Х	Х	Х	X
Asian	Х		Х	Х	Χ	Х	X	Χ
LGBTQ	Χ	Х	Х		Χ	X		Χ
Limited English	Χ	Х	Χ	Χ	Χ	Х	Х	Χ
Low Income	Х	Х	Х	Х	Χ	Х		
Disabled		Х			Χ	Х		Χ
Seniors	Х	Х	Х		Χ	Х		
Geographic Rurality	X	X	Χ	Х	Х	Х		Х
Mentally III		Х	Х	Х	Χ	Х		
Undocumented Immigrants	Х	Х	Х	Х	Х	X	Х	

Neighborhood, built environment, and natural environment

Patients in rural areas tend to have fewer preventive care tests, more advanced chronic conditions, and higher mortality rates partly because of the travel involved to access care. Areas with limited public transportation, walkability, and access to private vehicles all impede cancer testing access and can reduce follow-up even after positive test results. Patients in rural areas are also less likely to be enrolled in clinical trials and be represented because of the distance and patient travel burdens. ²⁹ In the U.K., car ownership was associated with higher rates of breast and cervical cancer testing, while public transportation is associated with lower rates of breast cancer testing coverage. ³⁰ This indicates that while transportation is still an important SDOH to consider, other factors like insurance coverage and healthcare provider relationships may be more impactful in the U.S. ³¹

²⁸ See Appendix 3 for references.

²⁹ Wercholuk, Ashley N., et al. "The Road Less Traveled: Transportation Barriers to Cancer Care Delivery in the Rural Patient Population." JCO Oncology Practice, vol. 18, no. 9, 2022, pp. 652–662., doi:10.1200/op.22.00122.

³⁰ Wang, Chao. "The impact of car ownership and public transport usage on cancer screening coverage: Empirical evidence using a spatial analysis in England." Journal of transport geography vol. 56 (2016): 15-22. doi:10.1016/j.jtrangeo.2016.08.012

³¹ Coughlin, Steven S, and Jessica King. "Breast and cervical cancer screening among women in metropolitan areas of the United States by county-level commuting time to work and use of public transportation, 2004 and 2006." BMC public health vol. 10 146. 19 Mar. 2010, doi:10.1186/1471-2458-10-146



Although telehealth services can be used for cancer testing in the U.S., medical and professional organizations have continued to push for reimbursement parity from Medicaid and Medicare for those with unstable or lacking broadband access.³² The value and convenience of telehealth-based cancer tests are extremely high as they can be easily accessed and reduce traditional transportation barriers to cancer tests if they are mailed or available nearby. However, rural clinics face obstacles regarding staffing, telehealth implementation, provider comfort with technology, broadband access, and patient digital illiteracy in rolling out such programs. While policy measures have been taken to increase funding and support in rural areas during the pandemic, these environmental and infrastructural issues make it difficult for providers to address testing gaps.³³ Ease and convenience could be facilitators to MCEDs acceptability and uptake because their technology can mitigate traditional transportation barriers. MCEDs, due to their technology, can be implemented at a very local level (e.g., pharmacies, primary care, hospital) or mailed.

Social, community context, crime, and vulnerability

Studies reveal that cancer testing is lower for nonwhite individuals than for their white counterparts, while some nonwhite individuals are more likely to receive certain types of tests than white people. Cancer rates also vary by race and ethnicity, but this may be due to variations in healthcare provider relationships and healthcare access. ³⁴ Researchers have noted that biological differences are less of a contributor to cancer incidence and cancer therapy efficacy than SDOH. Additionally, disparities in follow-up testing after referrals to and denial of access to surgery even after provider recommendations also exist between Black and white patients. ³⁵ Discrimination within the healthcare system can explain some of these gaps, where provider and institutional biases effect the willingness of nonwhite patients to receive pap smears and mammograms and erodes trust between patients and providers. Sociocultural factors can also limit MCED testing accessibility, where religious or personal preferences may deter some patients from blood-based tests in favor of saliva or breath-based tests.

In the U.S., testing guidelines, which often stemmed from research studies that lacked diversity, also fail to account for high-risk factors like smoking and environmental toxicities, and professional organizations have called for guidelines to be adjusted for high-risk individuals. These adjustments include earlier breast and colon cancer tests for Black women as well as Black and Native American patients, respectively since they tend to develop these cancers earlier. ³⁶ In addition, Black American patients have

³² "Closing Gaps in Cancer Screening: Connecting People, Communities, and Systems to Improve Equity and Access." President's Cancer Panel, prescancerpanel.cancer.gov/report/cancerscreening/Part2Goal2.html.

³³ Hanna, Karim et al. "Cancer Screening Among Rural and Urban Clinics During COVID-19: A Multistate Qualitative Study." JCO oncology practice vol. 18,6 (2022): e1045-e1055. doi:10.1200/OP.21.00658

³⁴ Liu, D., Schuchard, H., Burston, B. et al. Interventions to Reduce Healthcare Disparities in Cancer Screening Among Minority Adults: a Systematic Review. J. Racial and Ethnic Health Disparities 8, 107–126 (2021). https://doi.org/10.1007/s40615-020-00763-1

³⁵ Lathan, Christopher S et al. "The effect of race on invasive staging and surgery in non-small-cell lung cancer." Journal of clinical oncology: official journal of the American Society of Clinical Oncology vol. 24,3 (2006): 413-8. doi:10.1200/JCO.2005.02.1758

³⁶Hill, Latoya, and Michelle Tong. "Racial Disparities in Cancer Outcomes, Screening, and Treatment." KFF, 3 Feb. 2022, www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-in-cancer-outcomes-screening-and-treatment/.



the highest mortality rate for most leading cancers yet lower rates of cancer testing than their white counterparts.³⁷ In the U.K., adults under 75 years old with severe mental illness were also twice as likely to die from cancer than those without, highlighting the specific challenges that population has in accessing care and getting the attention of providers. One clinical consideration is that patients with severe mental illness should be offered the same basic health screenings as the general population. In addition, providers should address tobacco cessation with patients who have a severe mental illness.³⁸ These trends should also encourage healthcare providers to be proactive in discussing the risks and benefits of MCED tests, and their potential to detect cancers earlier when treatment outcomes are likely to be more favorable.

Traumatic experiences and exposure to violence have been linked to adverse health outcomes, with 20-50 percent of cancer patients having experienced interpersonal trauma.³⁹ These experiences can also hinder testing access or willingness to do so, where cancer testing can invoke uncomfortable or painful experiences.⁴⁰ Therefore, healthcare providers have a key role in establishing a relationship of trust with patients, acknowledging patients' concerns and boundaries, and maintaining culturally-sensitive and person-centered care practices in discussing and providing MCED testing.⁴¹

Levers to address barriers to equitable MCED access

Patient-centered care

Health policy in the U.K. emphasizes the importance of patient-informed choice regarding all treatments. Patient-informed choice recognizes that it is unethical for individuals not to be informed of the consequences of medical interventions and a belief that an informed choice, compared with an uninformed one, is associated with better patient outcomes.⁴² In the U.S., this concept is known as patient-centered care, which encompasses at its core effective patient-physician communication to support informed patient choice in decision-making.⁴³ MCEDs are a new technology in the cancer early

³⁷ Liu, D., Schuchard, H., Burston, B. et al. Interventions to Reduce Healthcare Disparities in Cancer Screening Among Minority Adults: a Systematic Review. J. Racial and Ethnic Health Disparities 8, 107–126 (2021). https://doi.org/10.1007/s40615-020-00763-1

³⁸ Liu, Nancy H et al. "Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy and research agendas." World psychiatry: official journal of the World Psychiatric Association (WPA) vol. 16,1 (2017): 30-40. doi:10.1002/wps.20384

³⁹ Bair-Merritt, Megan (2014) "The Role of Trauma in Disparities for Cancer-Related Health: A Call to Action," Journal of Health Disparities Research and Practice: Vol. 8: Iss. 4, Article 3. https://digitalscholarship.unlv.edu/jhdrp/vol8/iss4/3

⁴⁰ Mkuu, R.S., Staras, S.A., Szurek, S.M. et al. Clinicians' perceptions of barriers to cervical cancer screening for women living with behavioral health conditions: a focus group study. BMC Cancer 22, 252 (2022). https://doi.org/10.1186/s12885-022-09350-5

⁴¹ Reeves, Elizabeth. "A Synthesis of the Literature on Trauma-Informed Care." Issues in Mental Health Nursing, vol. 36, no. 9, 2015, pp. 698–709., doi:10.3109/01612840.2015.1025319.

⁴² Marteau, Theresa M., et al. "A Measure of Informed Choice." Health Expectations, vol. 4, no. 2, 2001, pp. 99–108., doi:10.1046/j.1369-6513.2001.00140.x.

⁴³ What Is Patient-Centered Care? - Nejm Catalyst. catalyst.nejm.org/doi/full/10.1056/CAT.17.0559.



detection ecosystem, recognizing that they may have a role in diagnostic testing and triage of symptomatic patients. As such, informed participation must balance the potential benefits and harms of the MCED and its consistency with an individual or patient's cultural and personal beliefs, values, and preferences.

Provider recommendations

Physician recommendation is the predominant reason patients receive cancer testing in the U.S., and it is for this reason, careful attention must be given to the facilitators that encourage providers to recommend that individuals consider taking part in cancer testing. To effectively engage underrepresented groups, providers should incorporate community input and strive to create more tailored cancer education and testing programs.⁴⁴ Evidence-based solutions include educational interventions, community outreach, and increased provider recommendations for testing and research study participation.

Community-based organizations

Health behaviors are difficult to change on an individual level, and therefore physicians and other local/community groups (e.g., community-based health organizations) can play a powerful role in influencing individual and patient behavior. Those organizations often suffer from limited resources and a lack of trained staff, which is a barrier to uptake of evidence-based interventions. ⁴⁵ Partnerships between health systems and community organizations like faith-based groups, schools, and community centers can provide wide venues for cancer testing education and even on-site opportunities. These site-based recommendations can also reach potential testers despite geographic, transportation, and personal obstacles.

Intervention and communication beyond provider recommendations

Comprehensive and tailored interventions are needed to ensure that testing procedures increase trust, reduce fear, and maximize participation for disadvantaged populations. One paper observed a 13 percent increase in testing for certain cancers after participants engaged in an hour of academic detailing and follow-up practice facilitation, indicating the power of educational interventions. ⁴⁶ To overcome forgetfulness and lack of motivation for testing, live call reminders and pre-paid return envelopes can encourage testing participation by alleviating the logistical burden that comes with it. ⁴⁷

⁴⁴ Turakhia, Puja, and Brandon Combs. "Using Principles of Co-Production to Improve Patient Care and Enhance Value." Journal of Ethics | American Medical Association, American Medical Association, 1 Nov. 2017, journalofethics.ama-assn.org/article/using-principles-co-production-improve-patient-care-and-enhance-value/2017-11.

⁴⁵ Porteny, T., Alegría, M., del Cueto, P. et al. Barriers and strategies for implementing community-based interventions with minority elders: positive minds-strong bodies. Implement Sci Commun 1, 41 (2020). https://doi.org/10.1186/s43058-020-00034-4

⁴⁶ Mader, Emily M., et al. "A Practice Facilitation and Academic Detailing Intervention Can Improve Cancer Screening Rates in Primary Care Safety Net Clinics." The Journal of the American Board of Family Medicine, vol. 29, no. 5, 2016, pp. 533–542., doi:10.3122/jabfm.2016.05.160109.

⁴⁷ Ylitalo, Kelly R., et al. "Barriers and Facilitators of Colorectal Cancer Screening in a Federally Qualified Health Center (FQHC)." The Journal of the American Board of Family Medicine, vol. 32, no. 2, 2019, pp. 180–190., doi:10.3122/jabfm.2019.02.180205.



Interventions that restructure the testing environment (e.g., reminder letters/phone calls/text messages, flexible appointments, community-based testing) have demonstrated effectiveness. 48 Working in co-production (i.e., the interdependent work of users and professionals to design, create, develop, deliver, assess, and improve the relationships and actions that contribute to the health of individuals and populations 49 has proven mutually beneficial in encouraging providers to communicate more effectively with their diverse patients. 50

Recommendations for intervention and evaluation in the MCEDs context

Level	Levers				
People	 One-on-one education and testing efforts Provider recommendations for testing and research study participation for underrepresented groups Regular reminders and follow-up about testing Flexible use of telehealth appointments and follow-up discussions 				
Providers	 Provider education on MCED tests' use in clinical treatment pathways based on user's history and background Culturally sensitive and conscientious provider training for testing diverse groups Provider education on interpretation of MCED tests with testers 				
Communities	 Community outreach programs targeting underrepresented groups (i.e., low income, uninsured, limited English proficiency) Mobile cancer testing centers Funding for connective resources such as trained liaisons 				
Systems	 User-centered communication pre- and post-testing Minimize cost burden on U.S. MCED testing users Ensured telehealth reimbursement parity 				

While many of the previously outlined barriers to equitable MCED access are not modifiable in the short run, there are many opportunities to ameliorate educational, healthcare, and community obstructions. These opportunities come in the form of people, provider, community, and system-level changes that center around educating and catering to individuals based on their familiarity and understanding of MCED testing. MCED technologies have the potential to dramatically change the modality of cancer care by treating patients before they show signs of cancer—patients and their socioeconomic, cultural, and

⁴⁸ Young, Ben, and Kathryn A Robb. "Understanding patient factors to increase uptake of cancer screening: a review." Future oncology (London, England) vol. 17,28 (2021): 3757-3775. doi:10.2217/fon-2020-1078

⁴⁹ Elwyn, Glyn, et al. "Coproduction: When Users Define Quality." BMJ, vol. 29, no. 9, 2019, pp. 711–716., doi:10.1136/bmjqs-2019-009830.

⁵⁰ Read, Susan, et al. "Bowel Cancer Screening for People with Learning Disabilities: Establishing Principles for Good Practice." Learning Disability Practice, vol. 19, no. 8, 2016, pp. 33–39., doi:10.7748/ldp.2016.e1766.



environmental context should be included when considering potential interventions, as the path to receiving MCED tests is just as complicated as the path to follow-up care for improved health outcomes.

Patient demographic and general channels of engagement in the U.S. and U.K.⁵¹

Patient Demographic	Educational Interventions	Culturally Sensitive Communication	Provider Recommendations	Insurance Coverage/ Free Tests	Community Outreach	Logistical Aid	Diverse Clinical Research
African American/ Black	Х	X	Х	Х	Х		Х
Hispanic /Latino	Х	X	Х	X	Х		X
Asian		X	х				Х
LGBTQ		Х		Х	Х		Х
Limited English	Χ		Х		Х	Х	Χ
Low Income	Χ		Х	Х		Х	
Disabled	Χ			Х		Х	
Senior				Х		Х	
Geographic Rurality	Х		Х	Х	Χ		
Mentally III		х	х	Х	Х		Х
Undocumented Immigrants	Х		x			Х	

Examples of specific facilitators of cancer testing varying by population group:

Senior populations	Provider recommendations and insurance coverage			
Rural populations	Provider recommendations and community outreach			
People with disabilities	Accessible clinics, aide-supervised visits, and dual insurance coverage			
LGBTQ+ populations	Social supports and provider acceptance			
Immigrant populations	Educational interventions, logistical and travel aid, and testing reminders			
Hispanic/Latino populations	Educational interventions, logistical and travel aid, and testing reminders			
African American/	Educational intervention			
Black populations	Black women specifically benefit from community-based health workers and the use of existing social networks to share information			

⁵¹ See Appendix 4 for references.



Appendix 1

Elements of SDOH⁵²

Economic stability	Education access and quality	Healthcare access and quality	Neighborhood and built environment	Social and community context
Sources of income, food insecurity, employment stability, expenses	Early, secondary, and higher education, language and literacy skills, vocational skills	Primary care provider and general access, affordability, insurance coverage, health literacy, telehealth, geographical access, provider availability and cultural competency	Wi-Fi access, census tract, safety, walkability, housing quality, transportation availability, parks, environmental quality, and healthy food access	Social isolation or support, racial and ethnic segregation, civic engagement, exposure to violence and trauma, incarceration, and criminal justice exposure

Elements of WDOH⁵³

Built and natural environment	Work and labor market	Income	Education	Crime	Vulnerability
Green spaces, environmental quality, neighborhood design, transportation access, housing, healthy food	Workplace health, marketplace inequality, employment support	Poverty, gender pay gap, debt, mental health, living wages	Family and parenting programs, home to school transition, youth resilience in school, social and emotional wellbeing, adult learning services	Health inequalities among people in contact with criminal justice system, prison health management, domestic violence, and abuse	Homelessness, social isolation, inclusive primary care, and Roma health

⁵² Korn, A.R., Walsh-Bailey, C., Pilar, M. et al. Social determinants of health and cancer screening implementation and outcomes in the USA: a systematic review protocol. Syst Rev 11, 117 (2022). https://doi.org/10.1186/s13643-022-01995-4

⁵³ Office for Health Improvement and Disparities (OHID). "Wider Determinants of Health." Wider Determinants of Health - OHID, fingertips.phe.org.uk/profile/wider-determinants.



Appendix 2

The COM-B Model is a useful framework for describing how changing Behavior is a result of changing one or more components of Capability (the psychological or physical ability to enact a behavior), Opportunity (the physical and social environment that enables behavior) and Motivation (reflective and automatic mechanisms that activate or inhibit behavior). The model acknowledges that behavior is part of a system, and that change can occur at the micro-, meso- and macro-system levels (Bronfenbrenner, 1979). Known influences on cancer testing behavior reflecting Capability (i.e., knowledge and understanding of testing, health literacy and language access), Opportunity (i.e., cost, healthcare access, social and cultural norms, environment and resources) and Motivation (i.e., emotion, habits, attitudes and beliefs, perceived risk, fear and stigma) are highly relevant to the MCEDs context. 54,55 Some of these COM factors are modifiable and can be both barriers and facilitators to behavior change.

Appendix 3

Vulnerable Populations: Certain demographic groups face greater barriers to cancer testing, including:

- African American/Black people are more likely to experience illness and worse cancer outcomes
 than their white counterparts⁵⁶, and consistently experience poorer communication quality with
 their doctors.⁵⁷ Black individuals are more likely to have financial barriers to care and a higher
 mistrust of the medical system than whites, likely due to an ongoing experience of racial
 discrimination within the U.S. healthcare system. Black people are subsequently
 underrepresented in clinical trials, which poses risks in determining the efficacy of cancer
 treatments.
- Hispanic/Latino/a people are more likely to be diagnosed with advanced stages of disease than
 white counterparts, and cancer is the leading cause of death for Hispanic individuals. Lack of
 health literacy and cultural differences are often cited as barriers to testing for Latinos, who are
 more likely to find aspects of cancer care "embarrassing" or report that they don't need testing
 if they feel healthy. 58

⁵⁴ Michie, Susan et al. "The behaviour change wheel: a new method for characterising and designing behaviour change interventions." Implementation science: IS vol. 6 42. 23 Apr. 2011, doi:10.1186/1748-5908-6-42

⁵⁵ Young, Ben, and Kathryn A Robb. "Understanding patient factors to increase uptake of cancer screening: a review." Future oncology (London, England) vol. 17,28 (2021): 3757-3775. doi:10.2217/fon-2020-1078

⁵⁶ "Cancer Facts & Damp; Figures For African American/Black People 2022-2024." American Cancer Society, 2022, www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2022.html.

⁵⁷ Shen, Megan Johnson et al. "The Effects of Race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the Literature." Journal of racial and ethnic health disparities vol. 5,1 (2018): 117-140. doi:10.1007/s40615-017-0350-4

⁵⁸ Yanez, B., McGinty, H. L., Buitrago, D., Ramirez, A. G., & Penedo, F. J. (2016). Cancer outcomes in Hispanics/Latinos in the United States: An integrative review and conceptual model of determinants of health. Journal of Latina/o Psychology, 4(2), 114–129. https://doi.org/10.1037/lat0000055



- Asian people, particularly South Asian immigrants in the U.K., have lower testing uptake rates than non-Asian native populations.⁵⁹ Barriers for this population included cultural beliefs (i.e. Fatalism, testing as unnecessary, emotion-laden perceptions, etc.), lack of knowledge, and gender differences.
- LGBTQ+ people are less likely than non-LGBTQ individuals to present for cancer testing. This
 disparity is likely due to mistrust of the medical system, perceived discrimination, and lack of
 cancer testing data and knowledge among LGBTQ populations and providers.⁶⁰
- Limited English Proficiency (LEP) is associated with adverse effects on quality of care ⁶¹, and lower prevalence of breast and cervical cancer testing. ⁶² LEP patients often face related barriers, including lack of transportation, unfamiliarity with preventative care, complex scheduling systems, and poor interpretation. ⁶³
- Low socioeconomic status (SES) is associated with a higher likelihood of emergency/urgent cancer care and lower receipt of cancer-directed treatment.⁶⁴ Low SES individuals often suffer from cost barriers to cancer testing due to a misunderstanding of insurance coverage, in addition to the burden of transportation costs, taking time off work, and low health literacy coupled with reduced referrals by health professionals.⁶⁵
- Individuals with disabilities are less likely to be screened for cancer than their able-bodied counterparts, along with a greater likelihood of being uninsured. Common testing barriers include cost and access, as well as health care provider discomfort and physical or cognitive limitations.⁶⁶

⁵⁹ Crawford, Joanne et al. "Cancer screening behaviours among South Asian immigrants in the UK, US and Canada: a scoping study." Health & social care in the community vol. 24,2 (2016): 123-53. doi:10.1111/hsc.12208

⁶⁰ Haviland, Kelly S et al. "Barriers and Facilitators to Cancer Screening Among LGBTQ Individuals With Cancer." Oncology nursing forum vol. 47,1 (2020): 44-55. doi:10.1188/20.ONF.44-55

⁶¹ Timmins, C.L. (2002), The Impact of Language Barriers on the health Care of Latinos in the United States: A Review of the Literature and Guidelines for Practice. The Journal of Midwifery & Women s Health, 47: 80-96. https://doi.org/10.1016/S1526-9523(02)00218-0

⁶² Jacobs, Elizabeth A., et al. "Limited English Proficiency and Breast and Cervical Cancer Screening in a Multiethnic Population." American Journal of Public Health, vol. 95, no. 8, 2005, pp. 1410–1416., doi:10.2105/ajph.2004.041418.

⁶³ Bruce, Kelly H et al. "Barriers and facilitators to preventive cancer screening in Limited English Proficient (LEP) patients: Physicians' perspectives." Communication & medicine vol. 11,3 (2014): 235-247. doi:10.1558/cam.v11i3.24051

⁶⁴ Wong, S. L., et al. "The Impact of Socioeconomic Status on Cancer Care and Survival." Journal of Clinical Oncology, vol. 29, no. 15_suppl, 2011, pp. 6004–6004., doi:10.1200/jco.2011.29.15_suppl.6004.

⁶⁵ Nuche-Berenguer, Bernardo, and Dikaios Sakellariou. "Socioeconomic Determinants of Participation in Cancer Screening in Argentina: A Cross-Sectional Study." Frontiers in Public Health, vol. 9, 2021, doi:10.3389/fpubh.2021.699108.

⁶⁶ Edwards, Deborah J., et al. "Barriers to, and Facilitators of, Access to Cancer Services and Experiences of Cancer Care for Adults with a Physical Disability: A Mixed Methods Systematic Review." Disability and Health Journal, vol. 13, no. 1, 2020, p. 100844., https://doi.org/10.1016/j.dhjo.2019.100844.



- Seniors/people over the age of 65 often face cost barriers to regular cancer testing, due to a lack of insurance and dual coverage with Medicare and Medicaid.⁶⁷
- Geographic rurality is statistically associated with higher cancer mortality and morbidity.⁶⁸ Most frequently cited barriers to testing included transportation, high cost, lack of insurance coverage, embarrassment or discomfort, lack of knowledge, and lack of physician recommendation.⁶⁹
- Individuals suffering from severe mental illness are shown to have a higher incidence of cancer mortality and morbidity⁷⁰. Barriers to testing included information processing issues, aggravation of symptoms by the testing process, poor staff-client relationships, and travel difficulties.⁷¹
- Undocumented immigrants in both the U.S. and U.K. face heightened cancer care obstacles including research access barriers, cultural and linguistic differences, low income, or educational level, and more.⁷² Migrants in the U.K. receive cancer testing at lower rates than non-migrants, which leads to later diagnosis and worse health outcomes.⁷³ Data on cancer incidence among immigrant minorities is understudied and incomplete.

Intersectionality, or the interconnected nature between two or more of these identities (e.g. geographic rurality and lower SES), is also frequently associated with lower access to and quality of care.⁷⁴

⁶⁷ Guessous, Idris, et al. "Colorectal Cancer Screening Barriers and Facilitators in Older Persons." Preventive Medicine, vol. 50, no. 1-2, 2010, pp. 3–10., https://doi.org/10.1016/j.ypmed.2009.12.005.

⁶⁸ Pozet, Astrid, et al. "Rurality and Survival Differences in Lung Cancer: A Large Population-Based Multivariate Analysis." Lung Cancer, vol. 59, no. 3, 2008, pp. 291–300., https://doi.org/10.1016/j.lungcan.2007.08.039.

⁶⁹ Wang, Hongmei, et al. "Barriers of Colorectal Cancer Screening in Rural USA: A Systematic Review." Rural and Remote Health, 2019, https://doi.org/10.22605/rrh5181.

⁷⁰ Grassi, Luigi, and Michelle Riba. "Cancer and Severe Mental Illness: Bi-Directional Problems and Potential Solutions." Psycho-Oncology, vol. 29, no. 10, 2020, pp. 1445–1451., https://doi.org/10.1002/pon.5534.

⁷¹ Clifton, A., Burgess, C., Clement, S. et al. Influences on uptake of cancer screening in mental health service users: a qualitative study. BMC Health Serv Res 16, 257 (2016). https://doi.org/10.1186/s12913-016-1505-4

⁷² Alba, Israel De, et al. "Impact of U.S. Citizenship Status on Cancer Screening among Immigrant Women." Journal of General Internal Medicine, vol. 20, no. 3, 2005, pp. 290–296., https://doi.org/10.1111/j.1525-1497.2005.40158.x.

⁷³Jackowska M, Wagner CV, Wardle J, et alCervical screening among migrant women: a qualitative study of Polish, Slovak and Romanian women in London, UKJournal of Family Planning and Reproductive Health Care 2012;38:229-238

⁷⁴ Zamora, Eduardo R., et al. "The Impact of Language Barriers and Immigration Status on the Care Experience for Spanish-Speaking Caregivers of Patients with Pediatric Cancer." Pediatric Blood & Door, vol. 63, no. 12, 2016, pp. 2173–2180., https://doi.org/10.1002/pbc.26150.



Appendix 4

Facilitators to Increase Testing Access

Studies have investigated and evaluated the efficacy and feasibility of certain evidence-based practices to increase testing uptake.

- African American/Black patients positively responded to testing facilitators including education interventions, efforts to increase convenience of testing, and culturally sensitive communication strategies.⁷⁵
 - Minority women most commonly cited clinician recommendations and personal health history as facilitators for cancer testing, though presence of testing routines, media information, and insurance coverage were also contributing facilitators. Asian American women were strongly motivated by clinician recommendations and were more likely to return after examinations by female doctors who spoke a common language. Hispanic women in particular cited facilitators in three categories: information/education, subsidized or free tests, and supportive physicians and friends.
- For rural populations, key facilitators of testing uptake included receiving provider recommendations and high motivation to learn testing results. In the same study, participants suggested increasing provider knowledge of cancer testing and community outreach initiatives to promote testing awareness and access.⁷⁸
- Individuals with disabilities require flexible, relevant, accessible, and respectful cancer testing
 services to increase uptake and usability.⁷⁹ Facilitators to testing for individuals with intellectual
 disabilities included living in a supervised setting, prior use of other healthcare services, social
 media education about testing, having aids accompany them to appointments, and presence of
 dual insurance coverage or higher income.⁸⁰

⁷⁵ Umeukeje, Ebele M., et al. "Black Americans' Perspectives of Barriers and Facilitators of Community Screening for Kidney Disease." Clinical Journal of the American Society of Nephrology, vol. 13, no. 4, 2018, pp. 551–559., https://doi.org/10.2215/cjn.07580717.

⁷⁶ Kwok, C., White, K. & Roydhouse, J.K. Chinese-Australian Women's Knowledge, Facilitators and Barriers Related to Cervical Cancer Screening: A Qualitative Study. J Immigrant Minority Health 13, 1076–1083 (2011). https://doi.org/10.1007/s10903-011-9491-4

⁷⁷Byrd TL, Chavez R, Wilson KM. Barriers and facilitators of cervical cancer screening among Hispanic women. Ethn Dis. 2007 Winter;17(1):129-34. PMID: 17274222.

⁷⁸ Schiffelbein, Jenna E., et al. "Barriers, Facilitators, and Suggested Interventions for Lung Cancer Screening among a Rural Screening-Eligible Population." Journal of Primary Care & Community Health, vol. 11, 2020, p. 215013272093054. https://doi.org/10.1177/2150132720930544.

⁷⁹ Edwards, Deborah J., et al. "Barriers to, and Facilitators of, Access to Cancer Services and Experiences of Cancer Care for Adults with a Physical Disability: A Mixed Methods Systematic Review." Disability and Health Journal, vol. 13, no. 1, 2020, p. 100844. https://doi.org/10.1016/j.dhjo.2019.100844.

⁸⁰ Chan, Dorothy N.S., et al. "A Systematic Review of the Barriers and Facilitators Influencing the Cancer Screening Behaviour among People with Intellectual Disabilities." Cancer Epidemiology, vol. 76, 2022, p. 102084., https://doi.org/10.1016/j.canep.2021.102084.



- Among LGBT individuals, facilitators of cancer testing included insurance coverage along with other personal characteristics, supportive families, supportive providers, and the environment of the local community and state health policy environment.⁸¹
- Limited English Proficiency patients responded positively to interventions that addresses both cultural and non-cultural barriers, including in person health education, clinician recommendations, and educational campaigns aimed at de-stigmatization.⁸²
- Among senior individuals, being married or living with a partner was the most frequently
 reported facilitator of regular testing. Medicare coverage of colonoscopies was cited as a
 facilitator of testing, though similar coverage of cancer testing is not comprehensive.
- Migrant and immigrant populations positively benefitted at the system level from educational interventions, physician recommendations, and logistical aid like transportation, scheduling, and at-home testing.

⁸¹ Haviland KS, Swette S, Kelechi T, Mueller M. Barriers and Facilitators to Cancer Screening Among LGBTQ Individuals With Cancer. Oncol Nurs Forum. 2020 Jan 1;47(1):44-55. doi: 10.1188/20.ONF.44-55. PMID: 31845916; PMCID: PMC7573971.

⁸² Byrd, Theresa L., et al. "Barriers and Facilitators to Colorectal Cancer Screening within a Hispanic Population." Hispanic Health Care International, vol. 17, no. 1, 2018, pp. 23–29., https://doi.org/10.1177/1540415318818982.

⁸³ Adunlin, G., Cyrus, J.W., Asare, M. et al. Barriers and Facilitators to Breast and Cervical Cancer Screening Among Immigrants in the United States. J Immigrant Minority Health 21, 606–658 (2019). https://doi.org/10.1007/s10903-018-0794-6