

Helping patients understand multi-cancer early detection tests: a scoping review

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Multi-cancer early detection tests are emerging as a revolutionary technology for the early detection of dozens of cancers from a single blood sample, including cancers without proven screening methods. However, they also come with challenges, including false-positive and false-negative results. To help patients make informed decisions, patient education materials are crucial. A review of available materials reveals that, while some materials provide understandable and actionable information, most lack a balanced presentation of the current benefits and risks of multi-cancer early detection testing. The dynamic nature of this field necessitates continuous updates to educational materials, incorporating current evidence and uncertainties.

Tweetable abstract: Multi-cancer early detection tests hold promise for cancer screening. Patient education materials need to present balanced information for informed decision-making, writes @jasonvassy. #MCED

First draft submitted: 8 August 2023; Accepted for publication: 12 January 2024; Published online: 25 January 2024

Keywords: cancer screening • decision-making • liquid biopsy • multi-cancer early detection • patient education

Multi-cancer early detection (MCED) tests have emerged as a potentially disruptive technology for cancer screening. Because all adults meet criteria for cancer screening at some point in their lifetimes, the potential impact of MCED tests on primary healthcare, where cancer screening occurs, cannot be overstated. Uncertainty exists about how primary care patients can understand the dynamic landscape of MCED testing and the potential role of testing in their healthcare. In this *Special Report*, we evaluate the resources available to help patients learn about the benefits and limitations of MCED testing and point to future work needed to address gaps in the current patient education landscape.

Multi-cancer early detection: the promise & pitfalls

MCED tests are laboratory assays that can detect unique signals for as many as 50 types of cancer from a single blood sample. They detect circulating tumor DNA (ctDNA) and tumor proteins in the bloodstream and use machine learning to identify patterns associated with the presence of cancer in the body. Whereas the term liquid biopsy can be applied to any blood-based test designed to detect and monitor specific types of cancers, including those that have already been diagnosed, MCED tests refer specifically to those tests which are intended to screen for multiple types of cancer in asymptomatic individuals without known disease [1–5].

Current guidelines recommend population screening for certain malignancies, including breast, cervical, colorectal and lung cancer [6–9]. MCED tests are not intended to replace existing screening strategies for these cancers (e.g., mammography or colonoscopy), but they can aid the detection of other cancer types for which there are no proven screening tests, such as pancreatic and ovarian cancer [1–3]. These cancers often have poor outcomes because they are most commonly diagnosed at an advanced stage, when they are more difficult to treat and more likely to be fatal. MCED tests thus have the potential to find cancer at its earliest stages, when it is more treatable and curable.

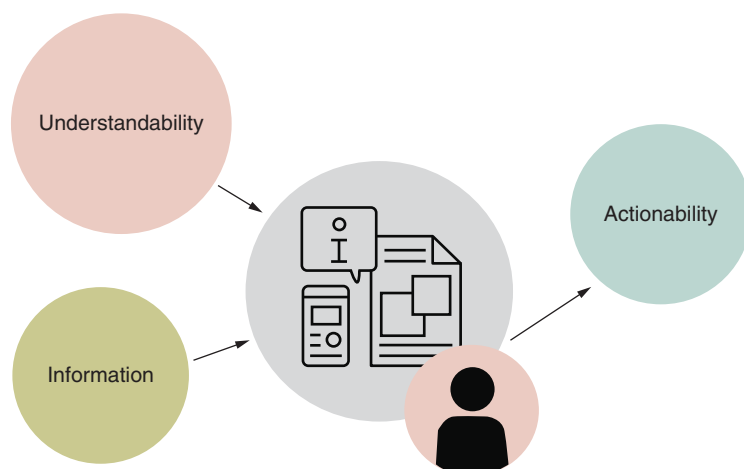


Figure 1. Conceptual model for assessing patient education materials about MCED testing. The information about MCED testing and its understandability and actionability play key roles in helping patients understand and make informed decisions about MCED testing. MCED: Multi-cancer early detection.

A positive signal on an MCED test is not by itself diagnostic but can help predict the tissue or organ of origin, which can help guide follow-up diagnostic testing, such as imaging and tissue biopsy to make a definitive cancer diagnosis and staging. However, MCED tests can yield false positive results. Results from a recent trial of one MCED test suggest that approximately 1% of adults 50 years or older will have a positive MCED test signal; only about 40% of these will have cancer diagnosed [10]. The tests can also have false negative results; the sensitivity for several cancer types is less than 50% in some studies [2,11]. The appropriate role of MCED testing in cancer screening for the general population is an active area of research [12–14]. Pending further evidence on their accuracy, benefits and limitations, MCED tests are not covered by most health insurers, although some health systems and plans are offering testing to their patients [14]. While many people anticipate clinical value for cancers not currently screened for in routine medical practice, concerns remain the false-negative and false-positive rates of the tests, the lack of care pathway protocols for some MCED signals, and the lack of demonstrated benefits of early diagnosis of some cancers [14–17]. The current state of uncertain benefits and harms of MCED testing might bewilder patients with questions about whether such testing might play a useful role in their own healthcare.

The landscape of patient educational materials

Patients will need accurate and understandable information to help them make informed decisions about MCED testing. Some may already be receptive to the idea of MCED testing, given the familiarity and convenience of phlebotomy in routine medical care and the perceived ability of the new test to detect multiple cancers [17]. However, little is known about the quality of the resources available to educate patients about testing. To evaluate the landscape of patient education about MCED tests, we performed a scoping review of patient education websites and printed materials available to help patients learn about this new technology (see details in the [Supplementary Methods](#)). In the conceptual model for our assessment of patient materials ([Figure 1](#)), both the informational content of the material (including a discussion of potential benefits and limitations) and the understandability of how that information is presented determine how patients will use that information to take action in their healthcare decisions about MCED testing. As described in the [Supplementary Methods](#), we used the US Agency for Healthcare Research and Quality Patient Education Materials Assessment Tool (PEMAT) to assess the model constructs of understandability and actionability of the education materials identified. Given the importance of patient understanding of risks and benefits in informed decision-making, we additionally assessed the informational content of the materials. The eight materials identified by a search of PubMed, Google Scholar and Google included six websites and two printable materials ([Figure 2 & Table 1](#)) [18–25]. Our assessment of these patient education materials follows.

Understandability

The materials' understandability scores on the PEMAT range from 58 to 94% ([Table 1](#)), where higher scores indicate greater likelihood that patients from diverse backgrounds with differing levels of health literacy can process and explain key messages [26]. All eight materials stated an evident purpose, used active voice writing, did not expect users to perform calculations, and used chunking of information, informative headers and visual cues to highlight

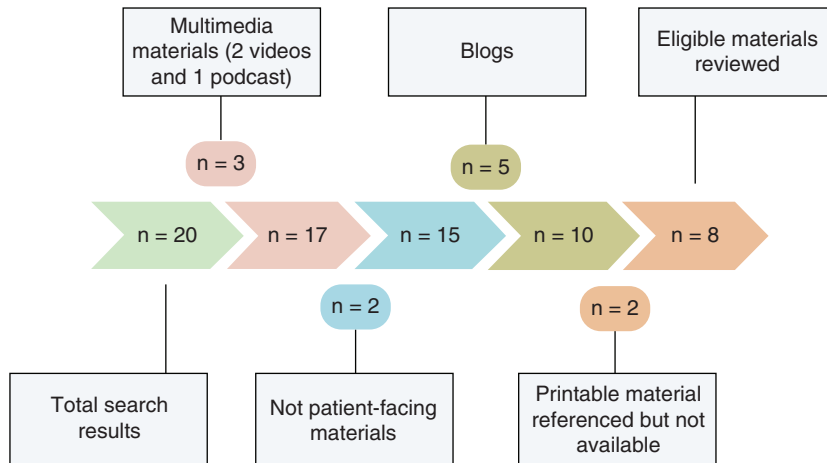


Figure 2. Results of scoping review of patient educational materials about multi-cancer early detection testing, including reasons for exclusion of some search results.

key points. Effective examples of information chunking included question-and-answer layouts, where question headers like “Does a Negative Cancer Screening Test Mean I Do Not Have Cancer?” were followed by concise responses [18–20], allowing the reader to extract key concepts easily without being overwhelmed. Another common strength was the use of logical and chronological flow of information. For example, some materials progressed through topics such as what MCED testing is, important things for patients to consider about testing, current commercial availability and how to undergo the test [18,24,25].

Lower scoring materials lack definitions for medical terms like ‘colonoscopy’ and do not use a minimum of 80% common everyday language, as recommended by the PEMAT [19]. In contrast, higher scoring materials used more layperson language and defined terms such as ‘false-positive’ and ‘false-negative’ [18]. Lower scoring materials also lack visual aids to assist understanding, while higher scoring materials use graphics such as a visualization of deaths caused by cancers without screening programs [24]. Some materials score lower because of disjointed flows of information; for example, the link to the organization leadership page interrupts the display of MCED technology information and resources [21]. None of the materials include a summary or list of key points.

Informational content: the benefits & risks of testing

A key aspect of patient education around MCED is how the risks and benefits of testing are presented. Across the materials reviewed, potential benefits of testing listed include earlier detection of cancers currently lacking screening tests, screening for dozens of cancers at the same time, lower invasiveness and the possibility that flexible spending or health savings accounts may pay for testing. Potential risks listed across the materials include false-negative and false-positive results and the need for additional testing and biopsies to confirm cancer diagnoses. Additional risks include overdiagnosis and overtreatment of cancers for which early detection is not known to improve outcomes and the possibility that MCED testing could exacerbate health disparities. Most materials are imbalanced in their presentation of risks and benefits. Potential benefits are often listed upfront, while potential harms, if present, are often included further down the page and not in a clearly labeled section about risks or harms. Very few materials mention the test outcomes or future implications the test could have on follow-up procedures and medical treatments needed. A notable exception is a National Cancer Institute website’s balanced presentation of information in sequential sections clearly labeled as discussing the possible benefit and harms of testing [19].

Actionability

A patient educational material’s actionability is its ability to state an effective call to action for the reader [26,27]. For MCED testing, potential actions featured in the materials include talking to one’s healthcare provider, inquiring for further test information, taking a survey to confirm test eligibility and communicating with a healthcare provider about other recommended cancer screening. Three materials score well in actionability (Table 1), assessed by their explicit description of possible next steps, use of action language directed at the reader (‘you’), and visual aids to

Table 1. Summary of patient educational materials about MCED testing identified in scoping review.

Conceptual model constructs: Informational content, understandability, and actionability					
Understandability	Actionability	Example strengths	Example weaknesses	Ref.	
Websites					
"MCED Tests" (American Cancer Society)	83	20	<ul style="list-style-type: none"> • Clear statement of role of organization in MCED research • Transparency around MCED testing uncertainties • Balanced discussion of benefits and risks • Effective use of headers and bold fonts 	<ul style="list-style-type: none"> • No mention of specific cancers MCED tests detect • No mention of further testing required to make diagnosis • No visual aids or images • No call to action 	[17]
"Question and Answers about MCD Tests" (National Cancer Institute)	67	20	<ul style="list-style-type: none"> • Identification of MCED science as evolving • List of specific cancers detected by MCED tests • List of possible next steps after testing • Chunking of information with question-and-answer format • Detailed information about health insurance coverage, health disparities, interpretation of results 	<ul style="list-style-type: none"> • Insufficient bulleting and highlighting, resulting in difficulty navigating information • No use of photographs or graphics • Lack of definitions of medical terms like 'mammogram' and 'low-dose CT' (only hyperlinks provided) • No logical flow of information 	[18]
"Multi-Cancer Early Detection Overview" (Prevent Cancer Foundation)	75	20	<ul style="list-style-type: none"> • Question-and-answer format and bullet points • Concise statements of current knowledge about MCED testing • Option to sign up for newsletter updates 	<ul style="list-style-type: none"> • Excessive brevity in responses to some question about MCED testing • No inclusion of potential harms of testing • No explanation of results interpretation 	[19]
"Communicating the impact of Multicancer Early Detection technologies on improving cancer detection and outcomes for all" (MCED Consortium)	58	0	<ul style="list-style-type: none"> • Clear definition of MCED testing • Links to additional resources, including a printable patient educational material • Effect use of font sizes and background colors 	<ul style="list-style-type: none"> • Lack of detailed information about MCED testing itself • No call to action • No visual aids • Interruption of information flow by link to organizational leadership page 	[20]
"Multi-Cancer Early Detection Test" (Mercy)	81	100	<ul style="list-style-type: none"> • Inclusion of two short patient testimonial videos • Interactive tool to confirm test eligibility • Direct address of the user ('you') • 'Additional Information' section provides test specifics 	<ul style="list-style-type: none"> • Imbalanced presentation of benefits and risks of testing, with 'safety information' at the bottom of the page after information about how to order the test • Possibility of commercial bias 	[21]
"Multi-Cancer Early Detection Patient Overview" (Gral)	88	100	<ul style="list-style-type: none"> • Ease of navigation • Thorough description of MCED testing • Video testimonials, visual aids, and links to resources • Option to request additional information via email 	<ul style="list-style-type: none"> • Imbalanced presentation of benefits (videos and visual aids) and risks (drop-down box at bottom of page) • Possibility of commercial bias 	[22]
Printable materials					
"What is multicancer early detection screening?" (Global Education Group and Integritas Communications)	88	100	<ul style="list-style-type: none"> • Effective use of infographics • Balanced presentation of benefits of MCED testing and importance of conventional screening • Links to further information about testing 	<ul style="list-style-type: none"> • Lack of definitions of medical terms like 'prostate-specific antigen' and 'sigmoidoscopy' 	[23]
"When it comes to cancer, we need time on our side" (Prevent Cancer Foundation)	94	40	<ul style="list-style-type: none"> • Effective use of graphics to visualize MCED statistics, emphasize key points, and represent diverse populations • Use of simple language throughout 	<ul style="list-style-type: none"> • Lack of detailed information about the science and process of MCED testing itself • No mention of the possibility of false positive results • Lack of actionable next steps a patient might take 	[24]
Numbers are understandability and actionability percentage scores from the Patient Education Material Assessment Tool (PEMAT). MCD: Multi-cancer detection; MCED: Multi-cancer early detection.					

inspire action, while those that score poorly lack these elements. One industry-sponsored site included an animated tool discussing how to request an MCEd test, along with two instructional video animations [23].

Future perspective: toward improved patient understanding about MCEd tests

In these early days of MCEd testing, our review finds that the landscape of patient education about MCEd tests includes a limited number of highly understandable and actionable materials that patients can turn to for information about testing. At the same time, most materials have an imbalanced presentation of the potential benefits of testing, compared with their potential harms. Informed decision-making requires patient understanding of the risks and benefits of the options, but it is not clear that most available patient education materials about MCEd testing currently meet this need. An evaluation framework such as ours will help identify new understandable, actionable, balanced materials as they are developed in this burgeoning field.

Particular challenges for patient education about MCEd testing include the rapidly evolving evidence base for its benefits and risks and a dynamic commercial and regulatory climate [14,28]. For example, the National Cancer Institute in 2024 will begin enrolling 24,000 healthy people aged 45–70 in a foundational study leading to a more definitive evaluation of the benefits of MCEd testing [29]. In the meantime, many MCEd tests are on the market or in development, and healthcare systems are partnering with commercial laboratories to offer testing to their patients [14]. In this context, educational materials about MCEd testing should adequately inform patients not only about the risks and benefits of testing as currently understood but also about current uncertainties and the likelihood that such information will change over the next 5 to 10 years. It is then incumbent on organizations to update their patient educational materials as these advances accrue. Our review of available materials highlights that these updates will need to address not only informational content but also the presentation of that information in a balanced, understandable and actionable way. These materials should be developed drawing on existing best practices for health education and then evaluated for their ability to promote patient understanding and effective decision-making about MCEd testing [26,27,30,31]. MCEd testing has the potential to usher in an exciting revolution in cancer screening, but it will take time to clarify its appropriate role in healthcare. Effective education has a critical role to play in helping patients navigate the MCEd landscape.

Executive summary

Multi-cancer early detection: the promise & pitfalls

- Multi-cancer early detection (MCEd) tests detect unique signals for up to 50 types of cancer from a single blood sample using ctDNA and tumor proteins, aiding early detection.
- MCEd tests can detect cancers without proven screening strategies, potentially identifying these cancers before they become more advanced.
- MCEd tests can lead to false positive and false negative results and are not yet approved by the US FDA or covered by most health insurers.

The landscape of patient educational materials

- Patient education on MCEd testing is essential for informed decision-making.
- Our evaluation of existing educational materials shows varying understandability and actionability of the information.
- Materials often present the risks and benefits of MCEd testing in an unbalanced way, biasing the reader toward testing.

Future perspective: toward improved patient understanding

- Patient educational materials should acknowledge and frequently update their information about the evolving evidence of benefits and risks and the dynamic commercial and regulatory landscape of MCEd testing.

Supplementary data

To view the supplementary data that accompany this paper please visit the journal website at: www.futuremedicine.com/doi/suppl/10.2217/pme-2023-0090

Acknowledgments

JL Vassy is an employee of the Department of Veterans Affairs (VA); the views expressed in this manuscript do not reflect those of the VA or the US government.

Financial disclosure

MP Greene was supported by Summer Fellowship Funding from the Furman University Institute for the Advancement of Community Health. JL Vassy is supported by the National Institutes of Health (R35HG010706) and VA grants I01HX003627 and I01CX002635. The funders had no role in the scoping review. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

Competing interests disclosure

The authors have no competing interests or relevant affiliations with any organization or entity with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

Writing disclosure

No writing assistance was utilized in the production of this manuscript.

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