



Leveraging Research-Informed Empathy Maps & Personas to Inform the Equitable Implementation of Multi-Cancer Early Detection Tests

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Acknowledgements & Disclaimer

Thank you to:

- Our focus group participants who shared their time and insights with us
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Study Overview: Background

Cancer Inequities

- Limited access to recommended screenings contributes to significant inequities in cancer diagnosis and mortality for marginalized communities in the US

MCED Tests: Defined

- Blood test with the ability to detect over 50 different cancers, including many for which there are no current screening options for early detection
- When a cancer signal is detected, some MCED tests can also help localize the cancer signal to inform next steps to diagnosis

MCED Tests: Potential

- Currently under study and could help reduce cancer inequities by improving screening accessibility

Study Overview: Objectives

Primary Objectives

- Understand knowledge, attitudes, and beliefs related to the use of multi-cancer early detection (MCED) tools
- Identify general barriers to cancer screening and MCED-specific barriers
- Define effective communication strategies to support the adoption of MCED among groups facing access barriers

Secondary Objective

- Produce recommendations for the implementation and spread of MCED as a population health strategy and tool to increase health equity

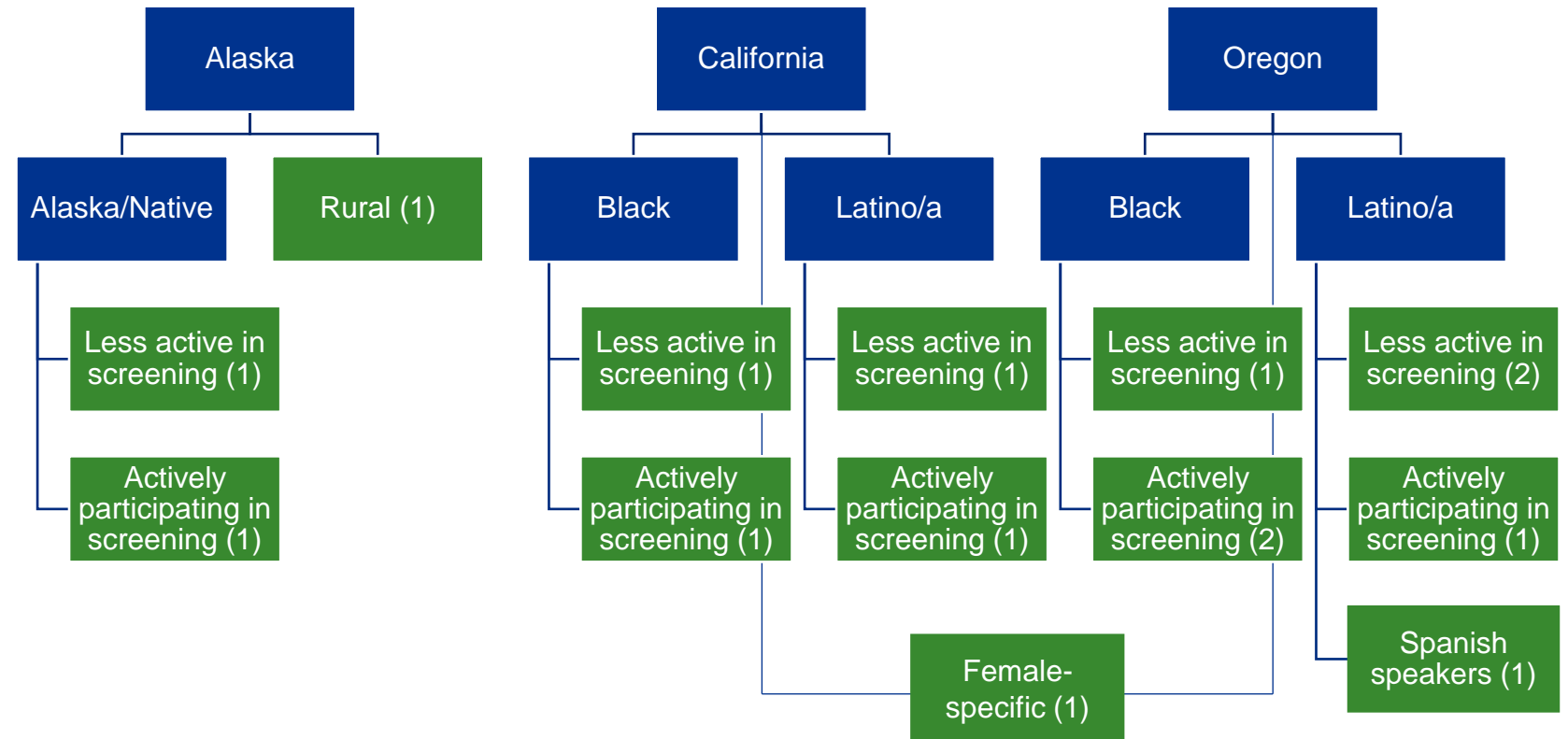
Study Overview: Focus Group Design

Recruitment included:

- Patients
- Community Members

Resulting in:

- 15 focus groups
- 85 Participants

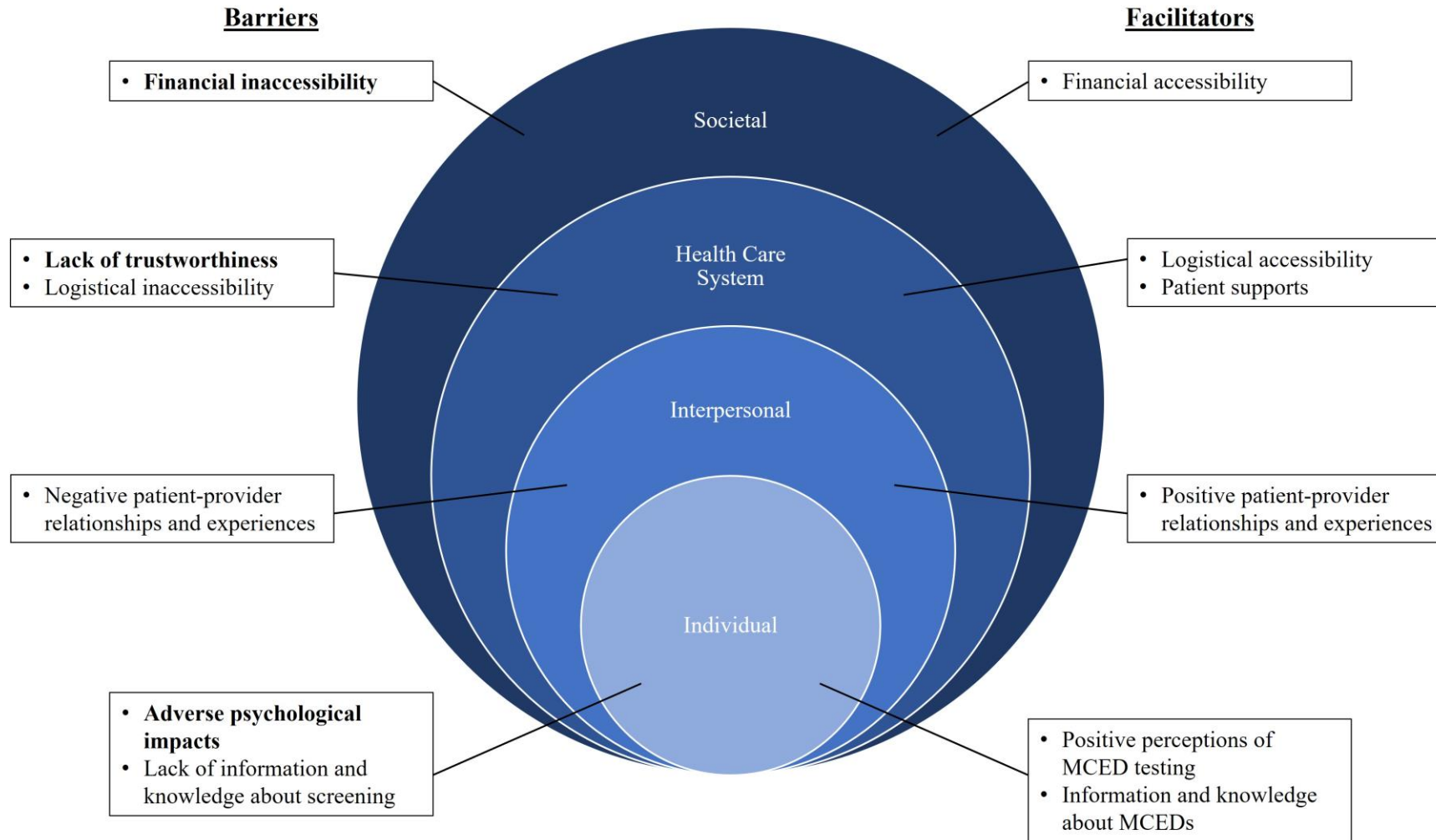


Study Overview: Analytic Approach

Phase	Description of Process
1. Data Familiarization	First author reviewed all audio recordings and transcripts during transcript cleaning. Team members immersed themselves in assigned sub-dataset by reading and re-reading transcripts and documented initial thoughts in reflexive analytic memos.
2. Data Coding	Team members coded assigned sub-datasets independently in ATLAS.ti Web. Codes were discussed and refined at a collaborative coding debrief.
3. Initial Theme Generation	Team members generated initial themes for sub-datasets by grouping codes with a shared concept and collated data extracts for each initial theme.
4. Theme Development & Review	Team members collaboratively reviewed themes for sub-datasets to assess the fit of themes with coded data extracts and identified cross-cutting (across all three sub-datasets) and stratified (cancer screening status, racial and ethnic identity, rurality) themes.
5. Theme Refining, Defining, & Naming	Team members and other research team members discussed cross-cutting and stratified themes. Discussion led to refinement of themes and thematic map to visualize the overarching story of the data. Themes were then organized by level of the social-ecological model (SEM).
6. Writing Up	Team members contributed to and critically reviewed the manuscript.

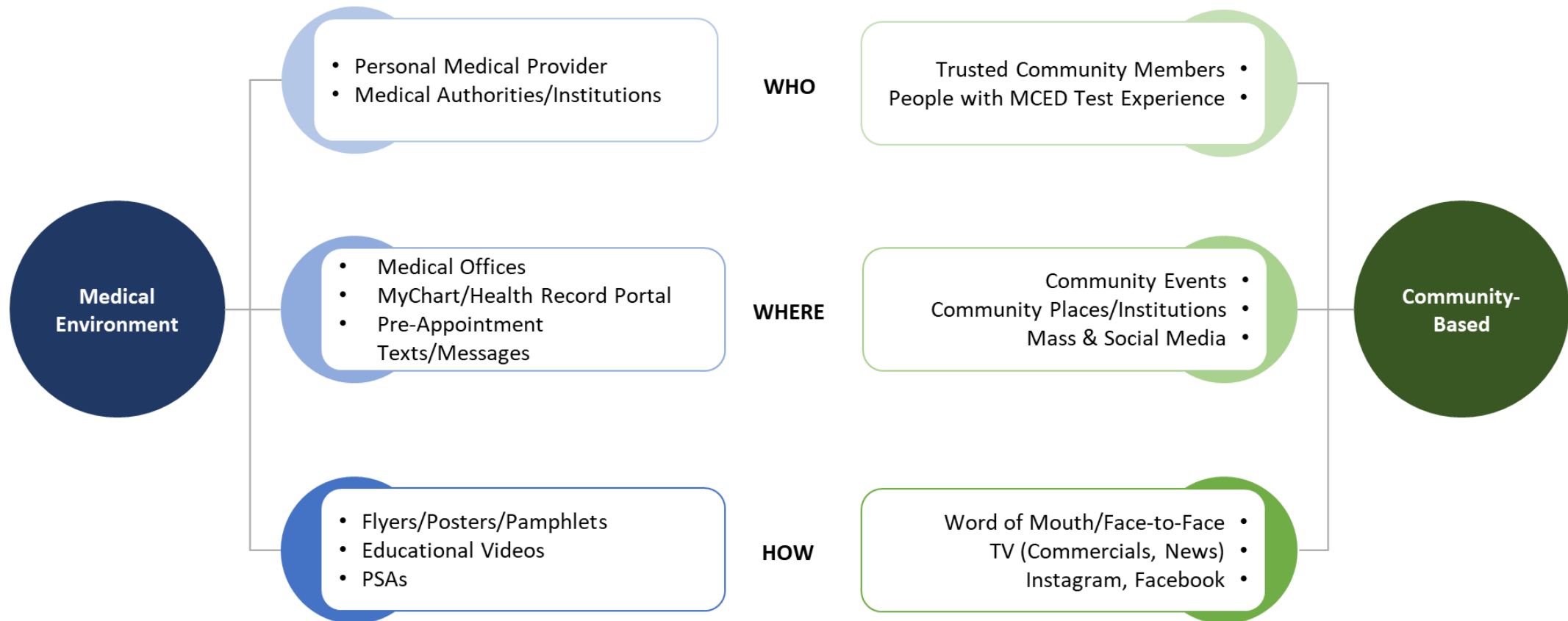
Braun V, Clarke, V. *Thematic Analysis: A Practical Guide*. SAGE; 2022.

Thematic Findings Organized by Social-Ecological Level



Research-Informed Engagement Tactics

Culturally-Appropriate & Multimodal Communication Approach



Empathy Maps & Personas: Addressing “User” Segments

1. **Proactive Cancer Screener:** Engages in preventive and routine health care, including recommended cancer screenings.
2. **Skeptical Health Care Engager:** Distrustful of the medical industry and may disengage from health care when they feel unheard or dismissed.
3. **Structurally Excluded Neighbor:** Lacks health insurance, experiences language barriers, and defers health care to meet basic needs.
4. **Long Distance Traveler:** Lives in rural Alaska and makes cancer screening decisions based on ability to financially and logistically access health care in Anchorage.
5. **Reactive Health Care Seeker:** Seeks health care when symptomatic and lacks information about the importance of prevention.
6. **Lost And Alone Patient:** Becomes overwhelmed with health care and seeks support navigating the health care system.

PROACTIVE CANCER SCREENER

"I really want to know what's going on with me. I really want to help me."

"Early is important to me because the theory is the earlier you catch it, the better the results."

"You need to get the medical community behind it 100%. My doctor tells me to go get this [MCED] test, I'm going to get that test."

"If I knew there was such a thing as an MCED in January, I'd have done it just because I don't like surprises."

SAYS

FEELS

Worried about insurance coverage and out-of-pocket costs for MCED tests

Optimistic about the possibility one test can screen for so many cancers

Reassured when provider proactively discusses screening options

Peace of mind when has actionable information about health status

Excited about simple and non-invasive screening option



Why haven't I heard about MCED tests?

I hope MCED tests are covered as preventive screenings or have low out-of-pocket costs.

How do MCED tests work and what cancers are included?

Will MCED tests replace the other screenings I get?

Is the medical community on board with MCED tests?

I want to stay on top of my health.

Will my doctor tell me how MCED tests fit into my screening recommendations?

THINKS

DOES

Follows screening recommendations from trusted provider

Communicates directly with providers during appointments and through the patient portal

Engages in routine health care

Considers out-of-pocket costs when making health care decisions



Patty

PROACTIVE CANCER SCREENER



"Early is important to me because the theory is the earlier you catch it, the better the results."

Core Needs

- Screenings covered by insurance with low or no out-of-pocket costs
- Convenient access points like during routine visits or at nearby labs

Behaviors

- Considers amount of out-of-pocket cost when making health care decisions
- Sees provider consistently and follows provider's recommendations for screening

How To Reach Me

Through **direct provider communication** about screening options, either during visits or through the patient portal

LONG DISTANCE TRAVELER

"I feel like sometimes people in Kodiak pay more than they should, where maybe other areas, Providence is possibly discounting cancer screening."

"The accessibility is a lot more difficult being in the village. So, it is definitely a lot of time...and then the cost to get somewhere."

"I mean having to do [screening] in Anchorage, just wacko, for those of us in the peninsula because it's an overnight process."

"I would suggest the most effective thing would be some sort of partnership to provide screenings at the local hospital."

SAYS

FEELS

Frustrated about screening access barriers, especially travel costs

Worried about accuracy of MCED tests

Overwhelmed with logistical planning to travel for health care

Excited about simple and non-invasive screening option

Stressed and anxious about what comes after screening

Can I afford to travel to Anchorage for screening?

If screening can be done locally, will it cost more than traveling to Anchorage?

What do I need to coordinate to get to Anchorage for screening?

I want to stay on top of my screenings, but sometimes I don't know if they are worth the hassle.

How much time off will I need to take to access screening in Anchorage?

THINKS

DOES

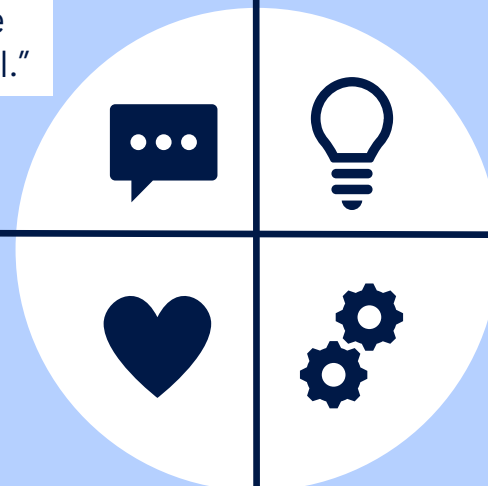
Decides for or against screening based on cost

Prioritizes convenience over prevention

Puts off screening because travel costs are too high to access it

Communicates directly with providers during appointments and through the patient portal; may also communicate with local health centers

Travels to Anchorage for specialty care



Lisa

LONG DISTANCE TRAVELER



“The accessibility is a lot more difficult being in the village. It’s a lot of [travel] time...and then the cost to get somewhere, even though [screening’s] covered when you get to Anchorage.”

Core Needs

- Local access points to screening with comparable prices to Anchorage
- If accessing health care/screening in Anchorage:
 - Financial supports for travel
 - Expanded lab access, including weekends and extended hours
 - Coordination of routine care with specialty visits

Behaviors

- Puts off screening because travel costs are too high
- Prioritizes convenience over prevention
- Travels to Anchorage for specialty care

How To Reach Me

Through **direct provider communication** about screening options, either during visits or through the patient portal, and **community-based health centers and advocates**

Study Strengths

- 1. Exploration of attitudes, barriers, and facilitators to MCED adoption**
- 2. Grounded in equitable approach**
 - Multiple recruitment strategies
 - Option for virtual or in-person
 - Recruited and trained focus group facilitators from the respective communities
- 3. Recruitment of diverse participant populations**
 - Black/African American, Latino/a/x, and Alaska Native individuals
 - Rural residents
 - Varying levels of cancer screening behaviors
- 4. Results centered on actionable insights for outreach and communication**

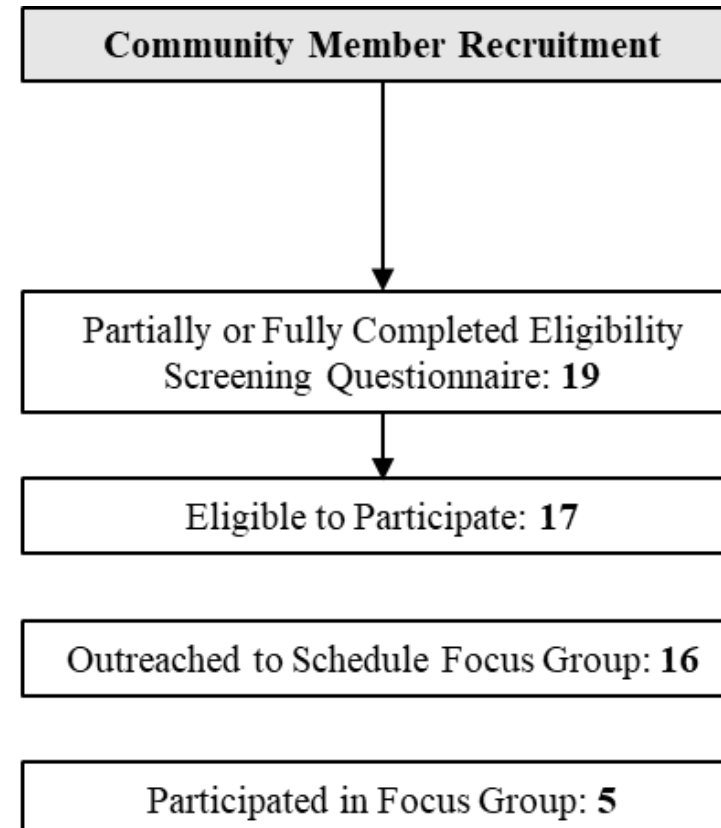
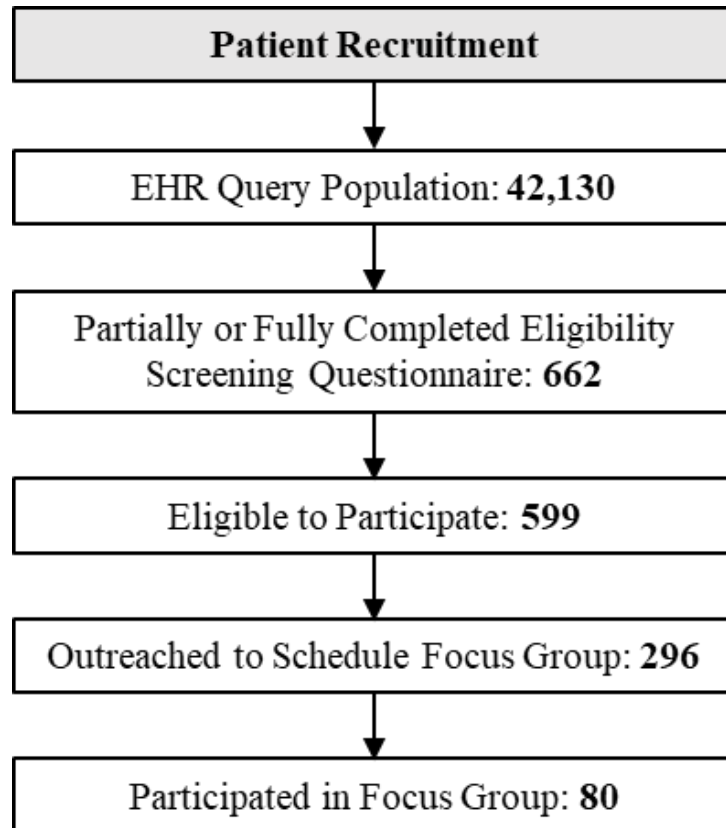
Next Steps

- 1. Share findings with participants and communities involved in this study**
- 2. Create outreach materials and campaigns based on research-informed recommendations**
- 3. Utilize a feedback process to incorporate feedback into final materials**
- 4. Test the impact of the materials and strategies to increase MCED test adoption**

Questions?

Additional Slides

Patient and Community Samples



SKEPTICAL HEALTH CARE ENGAGER

"Because we're Black people and because the medical industry has not been historically very fair...they've done Tuskegee, and things without our knowing about it, so there tends to be a 'I don't trust the doctors.'"

"What is the information going to be used for and can it be used against me in the future?"

Can my MCED test results be used against me?

What racial and ethnic groups have been included in clinical trials for MCED tests and what are their thoughts on this test ?

"I don't want to be the guinea pig."

"A white doctor wouldn't listen to me when I was serious about my own condition. I should know."

Why haven't I heard about MCED tests?

I hope MCED tests are covered as preventive screenings or have low out-of-pocket costs.

SAYS



THINKS

FEELS

DOES

Distrustful of providers/health care

Unheard and dismissed by health care providers

Disengages from health care when feels unheard or dismissed

Reassured when there is full transparency around clinical trials for new cancer screenings and participants have shared racial and ethnic identities

Fearful of misuse of personal health information

Worried about how financially accessible screening is

Protects self from harmful and racist experiences with the health care system by delaying and/or avoiding health care

Seeks providers with shared cultures and identities

Curious about simple and non-invasive screening option

When hearing about health-related information, connects best with trusted community members with shared cultures and identities

Stephen

SKEPTICAL HEALTH CARE ENGAGER



"Because we're Black people and because the medical industry has not been historically very fair...they've done Tuskegee, and things without our knowing about it, so there tends to be a 'I don't trust the doctors.'"

Core Needs

- Trusting relationships with inclusive, equitable, and culturally-responsive providers
- Full transparency around who has access to screening results and how they can and cannot be used
- Information about MCED clinical trials, including screening accuracy and racial and ethnic groups represented in samples

Behaviors

- Protects self from harmful and racist experiences with the health care system by delaying and/or avoiding health care
- Seeks providers with shared cultures and identities

How To Reach Me

Through **trusted messengers**, particularly community members, community-based organizations, and providers with shared cultures and identities

STRUCTURALLY EXCLUDED NEIGHBOR

"I don't want to use up all my money doing tests if I might need it for something else, like putting food on the table, putting gas in the car, and getting to work."

"Access to health care is so poor here, for example, if people don't have insurance, they're very, very afraid of the cost of it."

I know I need to see a provider, but I need the money to eat and pay for housing.

Even if I can get time off and the screening is free, what happens after?

"Even though the testing might be free, the diagnosis might be free for me to find out, but what do I do about it? I don't have the insurance or the money to pay for it."

"I can't take that kind of time off my job."

Are there mobile clinics in my neighborhood where I can get screening done after work?

Are there resources in my community to help me access health care?

If I go to see a provider, will they have an interpreter?

SAYS



THINKS

FEELS



DOES

Frustrated about language barriers in health care

Overwhelmed with day-to-day responsibilities

Curious about simple and non-invasive screening option

Stressed about meeting basic needs

Fearful of screening outcome and what it may mean financially if needs additional health care

When hearing about health-related information, connects best with trusted community members with shared cultures and identities

Makes difficult decisions to meet basic needs, including deferring health care

Seeks health care for emergencies only

Worried about how financially accessible screening is

Values providers with shared cultures and identities who provide community-based health care services

Soledad

STRUCTURALLY EXCLUDED
NEIGHBOR



"I don't want to use up all my money doing tests if I might need it for something else, like putting food on the table, putting gas in the car, and getting to work."

Core Needs

- Resources to meet basic needs and financially access health care
- Establishing care with inclusive, equitable, and culturally-responsive providers
- Community-based health care services available in the evenings and on the weekends

Behaviors

- Seeks health care for emergencies only
- Makes difficult decisions every day to meet basic needs, including deferring health care
- Often has to speak with providers through an interpreter, which is not preferred

How To Reach Me

Through **trusted messengers**, particularly community members, community-based organizations, and providers with shared cultures and identities

LOST AND ALONE PATIENT

"...but just to be able to communicate that these are the different possible outcomes of what we would need to look at or what we would need to do next in terms of additional diagnostics because that's just something I'm concerned about."

"I do want to prolong my life and be healthy and healthy and older."

"I know it sounds silly, but it would be really scary because it'd be like, well, OK, now what? All these different things that come up with a cancer diagnosis...My gut feeling's like Oh my God, now what?"

SAYS



Is there someone who can help me clearly understand the screening process?

If I need follow-up care after screenings, will my provider's office coordinate that?

I want to stay on top of my screenings, but it can be hard for me to figure out what to do next.

Are there patients who can share their screening experiences with me?

Screening feels scary to me. Are there any emotional supports provided through my provider's office or in my community?

THINKS

FEELS



Fearful of screening outcomes

Optimistic about the possibility one test can screen for so many cancers

Excited about simple and non-invasive screening option

Worried about coordinating follow-up care independently

Stressed and anxious about what comes after screening

Reassured when someone helps them have a complete understanding of the screening process

DOES

Becomes overwhelmed and disengages from health care

Seeks supportive connections to navigate the health care system

Looks for emotional support from provider or someone with shared lived experience

Communicates directly with providers during appointments and through the patient portal and benefits from discussions with patient navigators to have a deeper understanding of health care processes

Lynette

LOST AND ALONE PATIENT



"I know it sounds silly, but it would be really scary because it'd be like, well, OK, now what? All these different things that come up with a cancer diagnosis...My gut feeling's like 'Oh my God, now what?'"

Core Needs

- Patient advocates who can provide clear information and help navigate the screening process
- Coordinated follow-up care for positive screening results
- Emotional support from providers and support groups in the community

Behaviors

- Becomes overwhelmed and disengages from health care
- Seeks supportive connections to navigate the health care system

How To Reach Me

Through **direct provider communication**, either during visits or through the patient portal, and **patient navigators** accessible in-person and over the phone outside of traditional business hours

REACTIVE HEALTH CARE SEEKER

"I'm OK. There's no reason for me to get out to test. It's just a waste of time."

"In my family, nobody has cancer, so I don't have to worry about that."

Why do I even need screening?

I feel fine. I don't want to spend extra time and money on screenings when nothing is wrong.

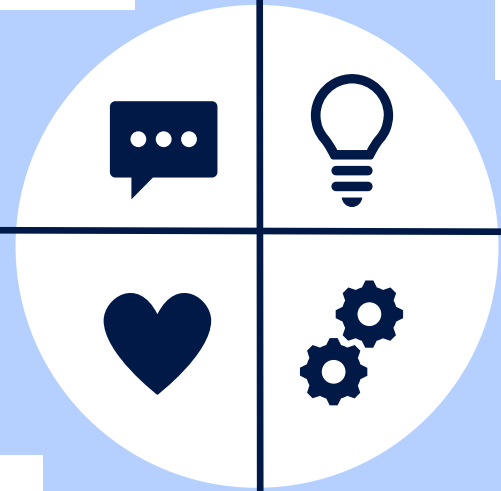
"I'm very hesitant. It's probably because it just seems over the top, them bombarding me with requests to come in and do these lung cancer screenings."

"Just living life, and just for today."

How much money do screenings cost?

I'll make an appointment to see my provider if I don't feel well.

SAYS



THINKS

FEELS

DOES

Reassured in health status when experiencing no symptoms

Content living life for today

Waits to seek health care until symptomatic due to cost and/or because thinks it won't be worth it

Prioritizes positive feelings over potential benefits of screening

Curious about simple and non-invasive screening option

Unsure about why medical providers keep pushing screenings

Worried about how financially accessible screening is

Communicates directly with providers when seeking care for symptoms and connects with trusted messengers in community about health-related information

Lives life in the here and now

Rey

REACTIVE HEALTH CARE SEEKER



"I'm OK. There's no reason for me to get out to test. It's just a waste of time."

Core Needs

- Information on why screening matters
- Screenings covered by insurance with low or no out-of-pocket costs
- Outreach and reminders about scheduling preventive visits

Behaviors

- Waits to seek health care until symptomatic due to cost and/or perceptions that it won't be worth it
- Prioritizes positive feelings and the here and now over potential benefits of screening

How To Reach Me

Through **direct provider communication** and **community-based messaging** about the importance of preventive care