



Health Equity Community Project ECHO Medical Mistrust in Relation to Colorectal Cancer Screening

Friday, January 26, 2024





#### Before we begin..

# Please put your name, health center, organization, and location in the chat!



#### Welcome to the January Health Equity Community Project ECHO Session



Each ECHO session will be recorded and will be posted to echo.cancer.org



You will be muted with your video turned off when you join the call. Use the buttons in the black menu bar to unmute your line and to turn on your video. If you do not wish to have your image recorded, please turn OFF the video option.



Today's materials will be made available on echo.cancer.org



Type your name and organization in the chat box



This ECHO session takes place on the Zoom platform.

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Remember: Do NOT share any personal information about any patient



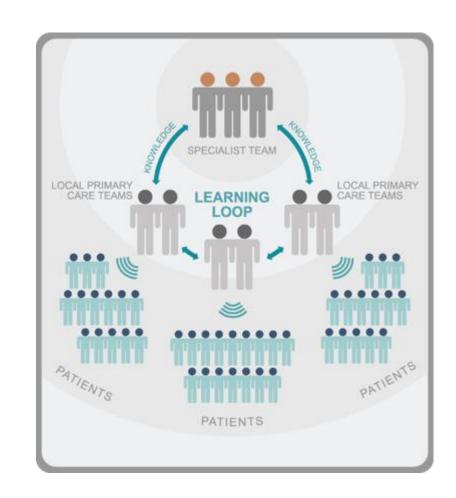
Questions about Zoom? Type them in the chat box to: Allison Rosen



### What does Project ECHO do?

#### What does ECHO do?

- ECHO effectively and efficiently disseminates evidence-based strategies to improve cancer outcomes
- ► ECHO allows to **convene** for best practice sharing across health centers, institutions, and other silos
- ► For more information, please refer to your guidebook or visit <a href="https://www.echo.unm.edu">www.echo.unm.edu</a>





### **Health Equity Community Project ECHO Series**

#### **Purpose**

- To share relevant health equity, medical mistrust, and colorectal cancer screening information with participants to enhance their community projects
- To provide participants with an opportunity to build their networks within their cohort and expert faculty
- To offer an opportunity for participants to share project-related challenges or questions; seeking feedback from expert faculty and cohort colleagues

#### **Health Equity Community Project Sites (Cohort 2)**



#### Asbury Park, NJ

- Visiting Nurse Association of Central New Jersey Community Health Center
- Visiting Nurse Association Health Group

#### Dayton, OH

- Community Health Centers of Greater Dayton
- West Care Ohio Inc. dba East End Community Services

#### Atlanta, GA

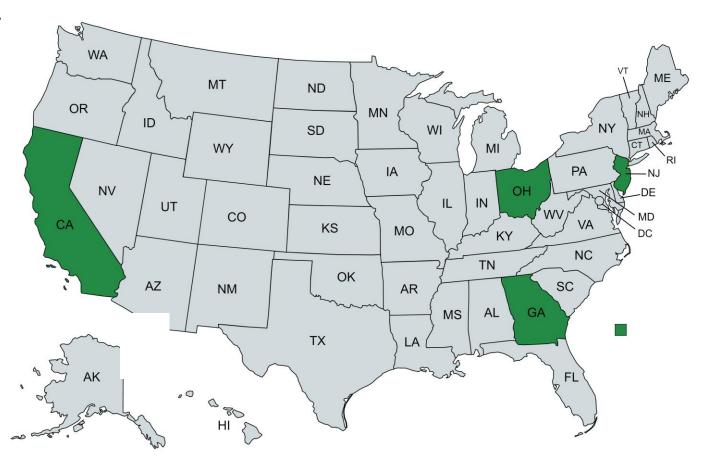
- Southside Medical Center
- Urban Connected Atlanta/Bible Way Ministries International

#### Stone Mountain, GA

- MedCura Health Inc.
- New Life Community Ministries, Inc.

#### Fremont, CA

- Bay Area Community Health
- Vietnamese American Roundtable





#### American Cancer Society

# **Project ECHO Planned Topics**

Session Date	Didactic Topics
September 28 2022	Understanding and Addressing Medical Mistrust: Introduction to the Group Based Medical Mistrust Scale
November 15, 2022	Measuring Mistrust using the Group Based Medical Mistrust Scale: Best Practices from a Community
January 27, 2023	Understanding Medical Mistrust Through the Colorectal Cancer Screening Lens
April 19, 2023	Patient Engagement Series: Fundamentals of Elevating Patient Voices Through the Use of Patient Advisory Councils and Governing Boards
June 29, 2023	Patient Engagement Series: Using Patient Voices to Improve Policies and Practices to Address Medical Mistrust in Relation to Colorectal Cancer Screening
August 24, 2023	Patient Engagement Series: Strategies for Sustaining a Highly Effective Patient Advisory Council and Governing Board
October 6, 2023	Effective Strategies for Addressing Medical Mistrust: Support from Healthcare Providers
December 8, 2023	Effective Strategies for Addressing Medical Mistrust: Patients Perspectives of Discrimination and Group Based Disparities
January 26, 2024	Effective Strategies for Addressing Medical Mistrust: Patients Suspicion of Healthcare Providers



## **January Agenda**

Welcome and Introductions  ECHO Hub Introductions and Icebreaker	10 minutes
Didactic Presentation  Effective Strategies for Addressing Medical Mistrust: Patients Suspicion of Healthcare Providers  Shana O. Ntiri, MD, MPH  University of Maryland, School of Medicine	25 minutes
Didactic Q/A	5 minutes
Facilitated Discussion	15 minutes
Wrap-up	5 minutes



# ECHO Hub Introductions and Icebreaker



## **Project ECHO Introductions**

#### **ACS ECHO HUB Staff**

- Cecily Blackwater, MPH
- Tracy Wiedt, MPH
- Allison Rosen, MS

#### **ECHO Faculty**

- Wayne B. Tuckson, MD, FACS, FASCRS
- Mark Manning, PhD
- Shana O. Ntiri, MD, MPH

For attendance purposes, please type your location, name, and organization in the chat box!

#### **Icebreaker**





What are you looking forward to the most this year? This can be personal, or work related!

This question applies to everyone (Community Project sites, ACS staff, and our ECHO Faculty)! Feel free to come off mute or type your answers into the chat box!

#### **About Our Didactic Presenter:**



Shana O. Ntiri, MD, MPH

Assistant Professor

Department of Family and Community Medicine
University of Maryland, School of Medicine
Medical Director, Baltimore City Cancer Program
Senior Medical Advisor, Office of Community Outreach and Engagement
Marlene and Stewart Greenbaum Comprehensive Cancer Center



# Effective Strategies for Reducing Medical Mistrust: Patients Suspicion of Healthcare Providers

Health Equity Community Project ECHO Series
January 26, 2024

Shana O. Ntiri, MD, MPH

Associate Professor
Department of Family & Community Medicine
University of Maryland School of Medicine
Medical Director, Baltimore City Cancer Program
Senior Medical Advisor, Office of Community Outreach & Engagement
Marlene and Stewart Greenebaum Comprehensive Cancer Center







# **Overview**

- Background
- Demographics of medial mistrust
- Contributors to medical mistrust
- Medical mistrust in CRC screening
- Addressing medical mistrust



. . .clinical encounters in which the stakes of not addressing mistrust are high. . . childbirth, childhood vaccination, and the care of patients with HIV, cancer, and substance use disorder.

- The Commonwealth Fund





# **Review of Key Terms**

- Trust: belief in a person's competence to complete a certain task
- Mistrust: a belief that we should question one's motives and view their actions with suspicion because they are likely to act in a way that the quality of care or the accuracy of information provided may be compromise
- Distrust: based on the assumption that providers or healthcare entities may not be trustworthy, that they may not have equal access to state-of-the-art care, that quality is variable at best, and that the patient is likely receiving lower quality than the typical standard of care.

#### **Medical Mistrust**

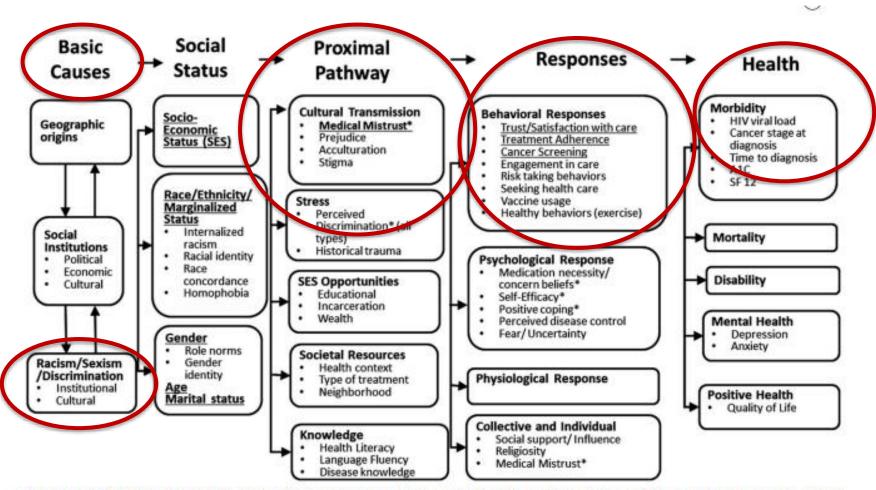


Figure 3. Summary of variables found in the literature using an adapted version of the Williams and Mohammed framework, 2013.



#### **Contributors to Medical Mistrust**

- African Americans, Latinxs, and other marginalized groups have a long history of receiving inferior quality of care regardless of if their level and type of insurance and access to care is comparable to more privileged groups
- Members of the lesbian, gay, bisexual, transgender, and queer community also have experienced racism, discrimination, and inferior treatment in health care
- Evidence documents numerous incidents of unethical medical research on African Americans, Native Americans, Hispanic-Latinos and Asian Americans



#### **Contributors to Medical Mistrust**

#### Unethical medical research

- The Untreated Syphilis Study at Tuskegee
- The Legacy of Henrietta Lacks
- Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?
  - 401 respondents, majority were Black and White
  - Educational level at or below HS
  - About 40% of Black and White participants were aware of the Tuskegee study
  - Black race, NOT knowledge of the Tuskegee study-was predictive of medical care mistrust, controlling for other demographic variables.



# **Demographics of Medical Mistrust**

# Discrimination & Medical Mistrust in a Racially and Ethnically Diverse Sample of California Adults

- Sample of 2,328: 58% female; 30.2% NH Black; 30.5% Hispanic, 39.2% NH
   White
- Adjusting for all covariates, there was an odds of reporting medical mistrust were 73% higher in NH Black and 49% higher in Hispanics vs Whites
- Perceived discrimination was associated with higher odds of medical mistrust.
- Perceived discrimination due to income/insurance was associated with 98% higher odds of medical mistrust
- Perceived discrimination due to racial/ethnic background and language was associated with a 25% increase in the odds of medical mistrust



# **Demographics of Medical Mistrust**

# Medical Mistrust Among a Racially and Ethnically Diverse Sample of Sexual Minority Men

- Sample of 183 sexual minority men; 33.3% Black; 24.6% Latinx, 26.8%
   White
- The highest medical mistrust scores were in Black respondents and the lowest rates were in White respondents
- Differences between in scores for medical mistrust based on race and sexual gender minority status were significant but "borderline". Black SGM had the highest scores overall.



### **Demographics of Mistrust . . . Information Sources**

- Social and Demographic Influences of Trust in Cancer Information
  - Sample of 783; 54% female; 45.1% NH Black; 41.9% Hispanic, 7.2% NH White
  - Asked about trust of cancer information from the following sources:
    - Doctor; Family or friends; Newspapers or magazines'; Radio; Internet; Television;
       Government health agencies; Religious organizations and leader
  - Findings show the shift of minority communities to trust newspapers and magazines, friends, family and religious organizations more than doctors
  - Trust in governmental health agencies:
    - College degree were almost 30% less likely to report high levels of trust
    - Household income under \$50,000 were 35% less likely report high levels of trust
    - Primary language was Spanish were significantly less likely to trust government



# Patient related influences on (trust) beliefs

#### Competence

• Provider/institution has the capacity to do what is needed

#### Benevolence

 Provider/institution does not care about the outcome or is not motivated to act in the patient's best interest

#### Integrity

• Provider/institution does not tell the truth or fulfill promises

#### Predictability

 Provider/institution actions are not consistent enough to warrant forecasting or to demonstrate potential for success

#### Assurance

Protective quality assurance structures are not in place



#### Can we address medical mistrust?

- Lack of trust is often framed as something that needs to be changed in individuals who do not trust rather than something that needs to change in providers and organizations that have not demonstrated that they are trustworthy
- Patient trust can change if they have new experiences or receive new information that affects their perceptions of trust.
- Patient trust can be built and be formed or reformed, stabilize or be reinforced, and decline or dissolve; patient trust is fragile, and it is subject to change based on experiences



#### How do we address these issues?

- Dismissing any aspect of low levels of trust as being based in misinformation, fallacy, or ignorance misses the history of inequality and contemporary inequities in access to care, quality of care, opportunities to participate in research, and ability to benefit from medical research.
- It is critical to be precise and intentional about the goals of efforts to promote trust or reduce mistrust or distrust

#### Patient adherence and Provider recommendation for CRC Screening

- Provider-patient communication rding screening tests may play one of the strongest more oldes in cancer screening behavior
- Provider encouragem shared and informed decision making componen generally positively correlated with screening (one study owed negative impact from this approach)

# Cancer Screening Guidelines & Lack Information on Potential Harms

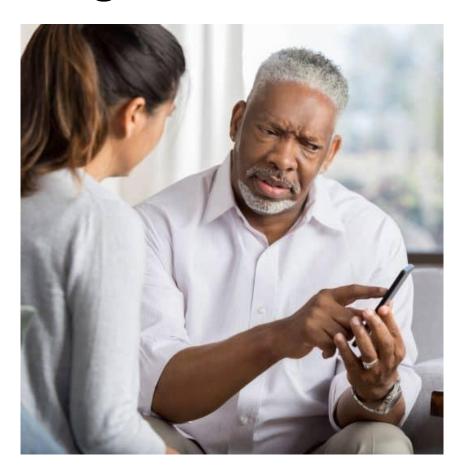
- Screening can cause various harms including physical harm, worry and stress, inaccurate results, and unnecessary follow-up procedures.
- In a review of 33 cancer screening guidelines, researchers have found that the guidelines don't adequately capture the potential harms of cancer screening
- Very few of the guidelines provide details on the frequency of harm associated with a particular screening test
- Improved harms reporting could aid informed decision making, ultimately improving cancer screening delivery



# **Harms of Screening**

- Harms of Cancer Screening
- All screening tests have potential harms. For more information ur <u>Cancer Screening Overview</u> page.
- **Physical harm:** Screening tests can cause minor physical harm like tearing the colon during colon cancer scree
- **Radiation exposure:** Some screening tests use log and on that can damage healthy cells.
- **False-negative result:** Screening tests sometime to the doctor when they have symptoms.
- **False-positive result:** Screening tests course anxiety and is usually followed by an approcedures, which also have risks.
- **Overdiagnosis:** Sometimes screening test ficers that are so small and slow-growing that they would never cause any symptoms or become life-threater. But if people get treatment for these cancers, they are exposed to unnecessary side effects and costs.
- **Psychological harm:** Many people feel worried and stressed about getting ready for a screening test, waiting for the results, getting follow-up tests, and getting an inaccurate result.
- **Incidental findings:** Cancer screening tests might find an unrelated medical issue—such as finding an unrelated heart problem—and require follow up tests or procedures which also have risks.

# Role of differences in Messaging/ Screening Recommendations?



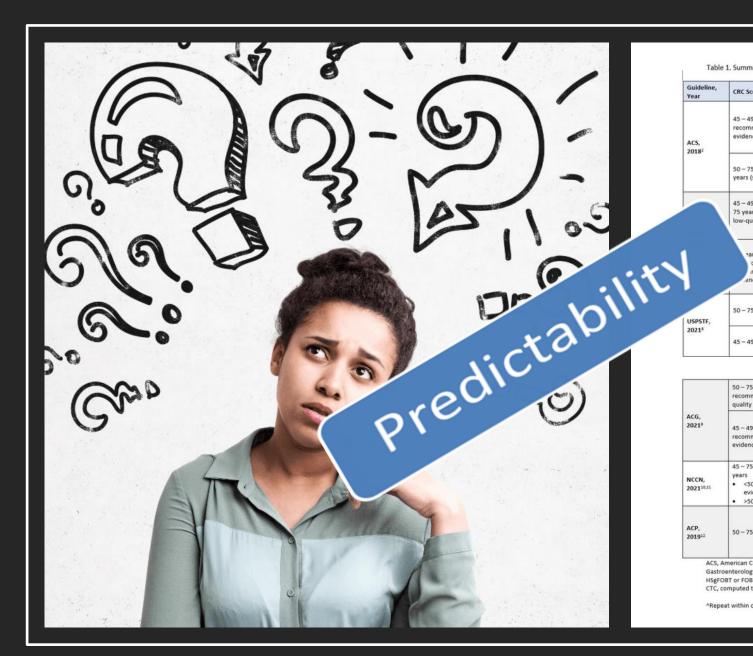


Table 1. Summary of CRC Screening Guidelines for Individuals at Average Risk of CRC

Guideline, Year	CRC Screening Initiation Age	CRC Screening Modality and Testing Interval	CRC Screening Cessation Age
ACS, 2018 <sup>2</sup>	45 – 49 years (qualified recommendation, very low-quality evidence)	High-sensitivity stool-based test or structural visual examination (choice depending on patient preference or test availability)  FIT annually  HigFOBT annually  FIT-DNA every 3 years	76 – 85 years: individualized screening based on patient preferences, life expectancy, health status, and prior screening history (qualified recommendation)
	50 – 75 years if life expectancy >10 years (strong recommendation)	Colonoscopy every 10 years     CTC every 5 years     SIG every 5 years	≥86 years: screening discouraged (qualified recommendation)
	45 – 49 years, continued through 75 years (weak recommendation, low-quality evidence)	Preferred Tier 1: Colonoscopy every 10 years or annual FIT     Tier-2: SIG or FIT-fecal DNA every 3 years (if	>75 years or life expectancy <10 years: consider screening cessation if up to date with screening and negative prior screening tests (weak recommendation, low-quality evidence)  Consider screening up to 85 years if no prior screening
	ears if no screening initiated o age 50 (strong mendation, high-quality ence)	<ul> <li>colonoscopy or FIT declined)</li> <li>Alternative: Capsule colonoscopy (if available) every five years (if individuals decline colonoscopy, FIT, FIT-fecal DNA,</li> </ul>	76 – 85 years: individualized approach based on prior screening history, life expectancy, CRC risk, and patient preferences
		CTC, and SIG)	≥86 years: screening not recommended
USPSTF, 2021 <sup>8</sup>	50 – 75 years (Grade A)	HSgFOBT or FIT annually     FIT-DNA every 1 – 3 years     CTC every 5 years     SIG every 5 years	76 – 85 years: individualized approach; selective screening beyond age 75 based on clinician and
	45 – 49 years (Grade B)	SIG every 10 years + annual FIT     Colonoscopy every 10 years	patient-specific factors: patient's overall health, prior screening history, and patient's preferences (Grade C

ACG, 2021 <sup>9</sup>	50 – 75 years (strong recommendation, moderate- quality evidence)	Primary: Colonoscopy every 10 years and FIT annually (strong recommendation, low- quality evidence)	76 – 85 years: individualized approach beyond age 75 (conditional recommendation, low-quality evidence)
	45 – 49 (conditional recommendation, very low-quality evidence)	If unwilling to undergo colonoscopy or FIT: SIG every 5 – 10 years, FIT-ONA every 3 years, CTC every 5 years, colon capsule every 5 years (conditional recommendation, very low-quality evidence)	286 years: not recommended
NCCN, 2021 <sup>10,11</sup>	45 – 75 years if life expectancy ≥10 years  • <50 years (lower-level evidence)  • >50 years (strong evidence)	Colonoscopy every 10 years^ FIT annually FIT-DNA every 3 years SIG every 5 – 10 years CTC every 5 years	76 – 85 years: individualized approach based on risks and benefits based on comorbidities and estimated life expectancy
ACP, 2019 <sup>12</sup>	50 – 75 years	Test selection based on benefits, harms, costs, availability, frequency, and patient preferences  FIT or FOBT every 2 years  Colonoscopy every 10 years  SIG every 10 years + FIT every 2 years	>75 years or life expectancy ≤10 years: discontinue screening

ACS, American Cancer Society; MSTF, The Multisociety Task Force; USPSTF, US Preventative Services Task Force; ACG, American College of Gastroenterology; NCCN, National Comprehensive Cancer Network; ACP, American College of Physicians; FIT, fecal immunochemical testing; HSgFOBT or FOBT, high-sensitivity-guaiac-based fecal occult blood testing; FIT-DNA, multitarget stool DNA testing; SIG, flexible sigmoidoscopy; CTC, computed tomographic colonography

<sup>^</sup>Repeat within one year if preparation considered inadequate



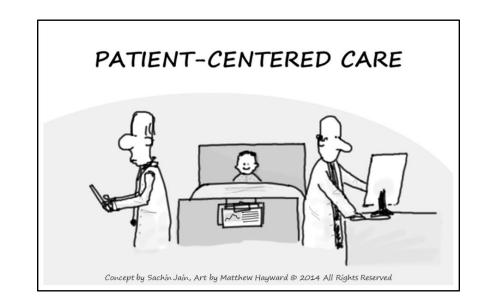


### **Evidence-based Approaches for Medical Mistrust**

- Can Patient-Centered Communication Reduce the Effects of Medical Mistrust on Patients' Decision Making?
  - Sample= 231 respondents; 59% female; 44% Af. American; 56%
     White
  - Study of primary care patients watching standardized clinical vignettes that varied by use of patient-centered communication (PCC)
  - Study suggests that use of PCC may reduce the effects of medical mistrust on dissatisfaction and non-adherence

#### **Patient-Centered Communication**

- Eliciting and understanding patient perspectives (concerns, ideas, expectations, needs, feelings, and functioning)
- Understanding the patient within his or her unique psychosocial and cultural contexts
- Reaching a shared understanding of patient problems and the treatments that are concordant with patient values.





# **Key Components of Successful Patient-Centered Communication**

- Be uncomplicated
- Be specific
- Use some repetition
- Minimize jargon
- Check patient understanding





# Best Practice for Communication in Medical Encounters



Functions of the Medical Interview	Roles and Responsibilities of the Physician	Skills
Fostering the relationship	<ul> <li>Build rapport and connection</li> <li>Appear open and honest</li> <li>Discuss mutual roles and responsibilities</li> <li>Respect patient statements, privacy, autonomy</li> <li>Engage in partnership building</li> <li>Express caring and commitment</li> <li>Acknowledge and express sorrow for mistakes</li> </ul>	<ul> <li>Greet patient appropriately</li> <li>Maintain eye contact</li> <li>Listen actively</li> <li>Use appropriate language</li> <li>Encourage patient participation</li> <li>Show interest in the patient as a person</li> </ul>
Gathering information	<ul> <li>Attempt to understand the patient's needs for the encounter</li> <li>Elicit full description of major reason for visit from biologic and psychosocial perspectives</li> </ul>	<ul> <li>Ask open-ended questions</li> <li>Allow patient to complete responses</li> <li>Listen actively</li> <li>Elicit patient's full set of concerns</li> <li>Elicit patient's perspective on the problem/illness</li> <li>Explore full effect of the illness</li> <li>Clarify and summarize information</li> <li>Inquire about additional concerns</li> </ul>
Providing information	<ul> <li>Seek to understand patient's informational needs</li> <li>Share information</li> <li>Overcome barriers to patient understanding (language, health literacy, hearing, numeracy)</li> <li>Facilitate understanding</li> <li>Provide information resources and help patient evaluate and use them</li> </ul>	<ul> <li>Explain nature of problem and approach to diagnosis, treatment</li> <li>Give uncomplicated explanations and instructions</li> <li>Avoid jargon and complexity</li> <li>Encourage questions and check understanding</li> <li>Emphasize key messages</li> </ul>
Decision making	<ul> <li>Prepare patient for deliberation and enable decision making</li> <li>Outline collaborative action plan</li> </ul>	<ul> <li>Encourage patient to participate in decision making</li> <li>Outline choices</li> <li>Explore patient's preferences and understanding</li> <li>Reach agreement</li> <li>Identify and enlist resources and support</li> <li>Discuss follow-up and plan for unexpected outcomes</li> </ul>
Enabling disease- and treatment- related behavior	<ul> <li>Assess patient's interest in and capacity for self-management</li> <li>Provide advice (information needs, coping skills, strategies for success)</li> <li>Agree on next steps</li> <li>Assist patient to optimize autonomy and self-management of his or her problem</li> <li>Arrange for needed support</li> <li>Advocate for, and assist patient with, health system</li> </ul>	<ul> <li>Assess patient's readiness to change health behaviors</li> <li>Elicit patient's goals, ideas, and decisions</li> </ul>
Responding to emotions	■ Facilitate patient expression of emotional consequences of illness	<ul> <li>Acknowledge and explore emotions</li> <li>Express empathy, sympathy, and reassurance</li> <li>Provide help in dealing with emotions</li> <li>Assess psychological distress</li> </ul>

<sup>&</sup>lt;sup>a</sup> Modified using Makoul,<sup>7,8</sup> Levinson et al,<sup>25</sup> Epstein and Street,<sup>31</sup> McCormack et al,<sup>61</sup> and Smith et al.<sup>88</sup>



### **Evidence-based Approaches for Medical Mistrust**

- Whose Responsibility Is It to Dismantle Medical Mistrust?
   Future Directions for Researchers and Health Care Providers
  - Recommendations include:
    - Using community workers, working with faith-based organizations, hiring health care staff who reflect the population
    - Research and interventions developed with researchers, people with lived experiences, and stakeholders
    - Building genuine trust among researchers, the medical establishment, and the various populations with whom we work and serve



### Lay Literature Approach to Medical Mistrust

### Deloitte Center for Health Solutions

- Focus groups with 525 individuals in the United States who identify as Black, Hispanic, Asian, or Native American to explore their experiences with health care organizations and sentiments around trust
- Thirteen interviews with health executives, advocates, and academic experts to explore organizations' strategies to repair and improve trust



### Lay Literature Approaches to address Mistrust

- Deloitte Center for Health Solutions Key Findings
  - 56% reported a negative experience where they lost trust in a health care provider.
  - 36% skipped or avoided care because they did not like the way the health care provider or their staff treated them.
  - After an experience where they lost trust, 4 of 5 participants say there was nothing the provider/health system could do to make them return to the same provider or health system.



### Lay Literature Approaches to address Mistrust

- Deloitte Center for Health Solutions Key Findings
  - For Asian (59%) and Hispanic (53%) participants, having a provider who has empathy and is culturally competent is a top priority when choosing a provider.
  - 2/3 Black/African American participants, 50% of Asian and Hispanic respondents say it is important to see a health care provider similar to them.



### Lay Literature Approaches to address Mistrust

- Deloitte Center for Health Solutions Key Findings
  - Focus on hiring a diverse and inclusive clinical staff
  - Promote apps and services that help consumers identify diverse clinicians
  - Partner with trusted groups in the community
  - Listen to patients









### **Key Take-a-Ways**

- Medical mistrust significantly impacts the uptake of care (including CRC screening) for many historically marginalized groups
- Patient trust can change when patients have new experiences or receive new information that affects their perceptions of trust
- Utilize the expertise within your patient and local community to help address medical mistrust
- Identify gaps between your patient demographics and clinician workforce and to inform strategies to mitigate these differences





What action(s) do
YOU commit
to put into practice to
address medical
mistrust?



### Resources/Readings

- Medical Mistrust and Medical Distrust. Historical Foundations of Racism in Medicine (0.25 CME)
  - Medical Mistrust and Medical Distrust: Historical Foundations of Racism in Medicine | Health Disparities | AMA
     Center for Health Equity | AMA Ed Hub (ama-assn.org)
- Psychosocial determinants of colorectal Cancer screening uptake among African-American men: understanding the role of masculine role norms, medical mistrust, and normative support
  - https://www.tandfonline.com/doi/full/10.1080/13557858.2020.1849569
- Patient and provider characteristics associated with colorectal, breast, and cervical cancer screening among Asian Americans
  - https://pubmed.ncbi.nlm.nih.gov/25368396/
- A pre-post survey analysis of satisfaction with health care and medical mistrust after patient navigation for American Indian cancer patients
  - https://pubmed.ncbi.nlm.nih.gov/22080713/
- Trust in the Health Care System and the Use of Preventive Health Services by Older Black and White Adults
  - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2696665/
- Colorectal Cancer: In the Pursuit of Health Equity
  - https://ascopubs.org/doi/full/10.1200/EDBK\_321071



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## Didactic Questions?



# Facilitated Group Discussion

Improving CRC Screening Rates

### **Group Based Medical Mistrust Scale Baseline Results**



✓ What interventions has your project site done or plan to implement to help improve your colorectal cancer screening rates?

### **Group Based Medical Mistrust Scale Baseline Results**



- ✓ What interventions has your project site done or plan to implement to help improve your colorectal cancer screening rates?
- ✓ What barriers has your project site experienced along the way? How was your Community-based partner played a role in all of this?

### THANK YOU TO OUR ECHO FACULTY!



Wayne B. Tuckson, MD, FACS, FASCRS



Mark Manning, PhD



Shana O. Ntiri, MD, MPH



## **Project ECHO Session Survey**

### **Next Steps**



### **Group Based Medical Mistrust Scale Baseline Data:**

- ☐ Share results with Patient Advisory Council, Governing Board, and/or QI Committee
- □ Post data collection surveys will be distributed out today. Data collection will end March 29, 2024.

#### **Project ECHO:**

Post Project ECHO Survey will be sent out next week via REDCap. Anyone from your team that has attended at least ONE ECHO session is encouraged to complete the survey.



# nanamou

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