Understanding Medical Mistrust in Relation to Colorectal Cancer: Insights From the American Cancer Society’s Health Equity Community Projects
Understanding Medical Mistrust in Relation to Colorectal Cancer: Insights From the American Cancer Society’s Health Equity Community Projects

Moderator
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MPH

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DNP, APRN
Health Equity Community Projects

Medical Mistrust in Relation to Colorectal Cancer Screening

Cecily Blackwater, MPH
Health Equity Director, Community Projects
American Cancer Society
Agenda

Community Projects Overview

Measuring Mistrust in Communities

Project ECHO Learning Collaborative

Project ECHO Curriculum

Questions
Health Equity Community Projects Overview

- **Health Equity Community Project Goal:** Use the knowledge-sharing Project ECHO Model to:
  - Support a total of 11 community project sites to participate in a learning collaborative cohort aimed at addressing medical mistrust related to colorectal cancer screening and follow-up.
  - Explore, identify, and implement community-driven solutions to support Federally Qualified Health Centers (FQHCs) in collaboration with their Patient Advisory Councils/Governing Boards/QI Committees and a Community-Based Organization of their choosing.

- **Two cohorts:**
  - 6 projects (Cohort 1) launched March 31, 2022 – ended September 30, 2023
  - 5 projects (Cohort 2) launched September 1, 2022 – projected to end March 1, 2024

- **Each project site:**
  - 18-month period ($50k/project to grantees through the Robert Wood Johnson Foundation)
  - Selected a population of focus to target and measure medical mistrust
Community Projects Objectives

1. **Address medical mistrust** with patients and community members

2. **Elevate patient’s perspectives and experiences** using Patient Advisory Councils/Governing Boards

3. **Use data** to inform all aspects of the project including 1) CRC Screening Questionnaire, 2) Project ECHO Surveys, 3) Group Based Medical Mistrust Scale Survey, 4) Key Informant Interviews, and 5) Progress Reports

4. **Create a comprehensive action plan** – led by Community Leadership Team – that implements community-based driven solutions and executes sustainable and meaningful process improvements

5. **Strengthen partnerships** between all sectors and leverage their leadership support to influence practice and policy changes aimed to address medical mistrust in relation to colorectal cancer screening
Health Equity Community Project Sites (Cohort 1)

Philadelphia, PA
- Delaware Valley Community Health
- Self Help Movement, Inc.

Mountain Home, ID
- Desert Sage Health Center
- Mountain Home Parks & Rec

Whitehall, OH
- Heart of Ohio Family Health Centers
- The African American Male Wellness Agency

Avondale, LA
- InclusivCare Inc.
- Litton Zion Missionary Baptist Church

Clearwater, FL
- Evara Community Health Center of Pinellas
- Cross and Anvil Human Services

Bakersfield, CA
- Clinica Sierra Vista
- SROA
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
Project ECHO 101

• ECHOs are hub-and-spoke knowledge sharing networks conducted virtually
• Hubs include a facilitator and expert faculty who are best-practices and contribute to learning through case-based and didactic learning
• Spokes learn from each other and experts from across the world
• ECHOs allow ACS to serve as conveners for best practice sharing across health systems, institutions, and other silos.
Measuring Mistrust Using the Group Based Medical Mistrust Scale Survey (GBMMS):

- 12-likert scale containing subscales:
  - Suspicion
  - Discrimination
  - Lack of Support
- Team completed a 3-hour Human Subjects Research Training Certification Course
- Project sites defined catchment area (zip codes)
- Surveyed a minimum of 75 people
- Participants received a $25 incentive

**Instructions:** Below is a list of statements dealing with your general feelings about the healthcare system. Read each item carefully and circle whether you strongly agree, agree, feel neutral, disagree, or strongly disagree with each statement.

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Community Project ECHO Learning Collaborative

Purpose

• To share relevant health equity, medical mistrust, and colorectal cancer screening information with grantees to enhance their community projects

• To provide grantees with an opportunity to build their networks within their cohorts and participating expert faculty

• To offer an opportunity for grantees to share project-related challenges or questions; seek feedback from expert faculty and cohort colleagues
<table>
<thead>
<tr>
<th>Session #</th>
<th>Phase 1 – Understanding and Addressing Medical Mistrust</th>
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<tr>
<td>Session 1</td>
<td>Understanding and Addressing Medical Mistrust: Introduction to the Group Based Medical Mistrust Scale</td>
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</table>
|           | *Hayley Thompson, PhD*  
|           | Wayne State University |
| Session 2 | Understanding Medical Mistrust Through the Colorectal Cancer Screening Lens |
|           | *Charles R. Rogers, PhD, MPH, MS, MCHES*  
|           | Medical College of Wisconsin |
| Session 3 | Measuring Mistrust using the Group Based Medical Mistrust Scale: Best Practices from a Community |
|           | *Bibiana Martinez, PhD, MPH*  
|           | Heluna Health |
# Health Equity Community Projects Curriculum

<table>
<thead>
<tr>
<th>Session #</th>
<th>Phase 2 – Leveraging Patient Advisory Councils and Governing Boards</th>
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<tr>
<td>Session 4</td>
<td>Patient Engagement Series: Fundamentals of Elevating Patient Voices Through the Use of Patient Advisory Councils and Governing Boards</td>
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<td>Anjana Sharma, MD, MAS&lt;br&gt;UC San Francisco</td>
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<td>Session 5</td>
<td>Patient Engagement Series: Using Patient Voices to Improve Policies and Practices to Address Medical Mistrust in Relation to Colorectal Cancer Screening</td>
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<td>Jack Westfall, MD, MPH&lt;br&gt;University of Colorado</td>
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<td>Session 6</td>
<td>Patient Engagement Series: Strategies for Sustaining a Highly Effective Patient Advisory Council and Governing Board</td>
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<td>Bev Johnson&lt;br&gt;Institute for Patient and Family Centered Care</td>
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<td>Phase 3 – Implementing Interventions to Address Medical Mistrust</td>
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<td>Session 7</td>
<td>Effective Strategies for Addressing Medical Mistrust: Support from Healthcare Providers</td>
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<td>Wayne B. Tuckson, MD, FACS, MSCRS</td>
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<td>Producer and Host of “Kentucky Health”</td>
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<td>Session 8</td>
<td>Effective Strategies for Addressing Medical Mistrust: Patients Perspectives of Discrimination and Group Based Disparities</td>
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<td>Mark Manning, PhD</td>
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<td>Oakland University</td>
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<td>Session 9</td>
<td>Effective Strategies for Addressing Medical Mistrust: Patients Suspicion of Healthcare Providers</td>
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<td></td>
<td>Shana O. Ntiri, MD, MPH</td>
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<td></td>
<td>University of Maryland, School of Medicine</td>
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<td>Marlene and Stewart Greenbaum Comprehensive Cancer Center</td>
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**Project sites used ECHO Sessions to:**

- Learn about the Group Based Medical Mistrust Scale Survey
- How to measure mistrust in their communities
- Identify strategies to share results back with their Patient Advisory Councils/Governing Boards
- Implement interventions to address medical mistrust:
ACS Health Equity Community Projects: Group-Based Medical Mistrust Baseline Survey Results

The goal of the Group-Based Medical Mistrust Survey (GBMMS) is to learn about community members’ general feelings about the healthcare system. The GBMMS was administered in English between 08/04/2022 and 11/16/2022. 74 community members responded to the survey. Survey demographics are provided on the second page.

Less than half of participants reported medical mistrust. Participants reported the highest mistrust related to experiences of differential treatment and care due to race and/or ethnicity (Discrimination). Respondents rated 12 medical mistrust statements on a scale of 1-5 (Strongly Disagree to Strongly Agree). The average score for the full GBMMS scale was 3.05, indicating that, on average across all statements, participants were neutral regarding their mistrust of the medical system.

When comparing participants across racial and ethnic identity, Non-Hispanic Other POC* participants reported the highest mistrust related to experiences of differential treatment and care due to race and/or ethnicity (Discrimination). When compared to non-Hispanic White participants, Non-Hispanic Black or African American participants had significantly higher medical mistrust.
Resources Available For Grantees
Resources Available For Grantees
Thank You
Thank You
Medical Mistrust and Colon and Rectal Cancer Screening: Solutions

Wayne Tuckson, MD, FASCRS
Colon and Rectal Surgeon
Host, Kentucky Health
Medical Mistrust and Colon and Rectal Cancer Screening: Solutions

Wayne B Tuckson, MD, FASCRS, FACS
Medical Mistrust and CRC Screening
Medical Mistrust and CRC Screening: Differences in Screening

• 28% 50 – 75 yo in US no CRC screening

• AA’s and Hispanics < non-Hispanic Whites

• AA ♂ screened less than AA ♀

Medical Mistrust and CRC Screening:
Reasons for Not Getting CRC Screening

• Pain / discomfort
• Embarrassed / modesty
• No family history
• No symptoms
• Complexity
• Transportation / escort
• Costs
  • time off from work (patient and care giver)
  • out-of-pocket expenses
Medical Mistrust and CRC Screening: Medical Mistrust

• Mistrust is not merely the opposite of trust, rather, it is the belief that the person, group, or institution that is the object of our mistrust is actively acting against our best interest and well-being.
Medical Mistrust and CRC Screening: Provider Impact on AA and Low-Income CRC Screening

• Trust in PCP remained the only significant driver of CRC screening completion in low-income patients.¹

• Patients who reported receiving lower quality of healthcare services were less likely to have undergone and be compliant with CRC screening recommendations²

Non-Hispanic Black and Hispanic participants were 73% and 49% respectively to more likely report having mistrust in health professionals compared to non-Hispanic Whites.

Medical News Today. Jan 15, 2020
Medical Mistrust and CRC Screening: Who’s To Blame

• Too often, the “onus to overcome medical mistrust is placed on the population experiencing structural, social, political, and economic exclusion and marginalization, rather than the institutions and entities that have created environments that engender mistrust and sustain institutionalized inequalities.”

Behav Med. 2019 Apr-Jun
Medical Mistrust and CRC Screening:
Social Issues

• Insurance/pharmaceutical companies are in control.
• Patients are a revenue source.
• Healthier, safer, more natural treatments are ignored.
• I heard / had a bad experience there.
• They’re white, why should I trust them?
• Dismissive attitudes from providers.
• Limited discussion of risk, benefit and alternatives
• Policies based on politics and not facts and evidence
Medical Mistrust and Colon and Rectal Cancer: Solutions

• Providers

• Political Action

• Community engagement

• Education
Medical Mistrust and CRC Screening: Read The Room

"How come there's no brothers' pictures on the wall?"

Spike Lee “Do The Right Thing”
Medical Mistrust and CRC Screening: Provider Solutions

• A basic understanding of the patients’ culture

• Avoid stereotyping, instead individuate

• Understand and respect the magnitude of unconscious bias.

• Recognize situations that magnify stereotyping and bias.
Medical Mistrust and CRC Screening:
Build Partnership with Patient

• Intentional listening
• Validate the patients’ experience and concerns
• Explain testing and treatment
• Establish goals
• Be inclusive when discussing plans “we not I”
Medical Mistrust and CRC Screening:

Providers

• Assiduously practice “evidenced-based medicine.”

• Address provider shortages
Experience of nurse practitioners performing colonoscopy after endoscopic training in more than 1,000 patients. Riegert M, Nandwani M, ey al. Endosc Int Open. 2020

• Ease shortage of endoscopist
• Effectiveness of NP’s to perform CRC screening with colonoscopy
• Bridge gap between supply and demand for colonoscopy
• Potentially maintain the benefits of colonoscopy at a lower cost
Experience of nurse practitioners performing colonoscopy after endoscopic training in more than 1,000 patients. Riegert M, Nandwani M, et al. Endosc Int Open. 2020

• The Good
  • Fellowship-trained NPs in colonoscopy satisfied ASGE and ACG quality indicators
  • Adequately trained NPs can perform colonoscopy safely and effectively and may be useful in under-resourced settings where conventional access to a gastroenterologist is limited.

• The Bad
  • Academic affiliated urban outpatient endoscopy center
  • Minority population
  • If the problem is a lack of qualified providers, then we should develop more training programs rather than promoting a separate, yet potentially “equal” standard of care?
Medical Mistrust and CRC Screening: Provider Representation

- Medical school enrollment
  - 6% of doctors identify as Black
  - 7% identify as Hispanic
  - 1/3 US population is either Black or non-white Hispanic

- Incorporating diversity into the curriculum

Asamoah T, Evans A. *How Providers Can Address Medical Mistrust in the U.S.* Good Rx Health. 2023
Medical Mistrust and CRC Screening: Community Health Workers

A person who is a trusted member of and/or who has an unusually close understanding of the community served in the delivery of health-related services through either working directly with providers or their partner organizations.

Pittman, M., A. Sunderland, Academy of Medicine 2015
Medical Mistrust and CRC Screening:
Role of the Community Health Workers

• Advocate for underserved individuals or communities to address health needs
• Collect and relay information to stakeholders to inform programs and policies
• Build community capacity to address health issues
• Address social determinants of health
• Provide culturally appropriate healthcare education
• Provide informal counseling, health screenings, and referrals

2002–2023 Rural Health Information Hub
Medical Mistrust and CRC Screening: HEAL Collaborative - Goal

• **Health Education Advocacy and Learning**
• Form meaningful partnerships with faith-based organizations and leverage culturally relevant health education resources to help the Black community.
Medical Mistrust and CRC Screening: HEAL Collaborative - Method

• Education is the primary focus
• Provide a space for patients, caregivers, and high-risk individuals to dialog with legislators and healthcare systems
• Recognize and prioritize the critical health needs of disadvantaged communities
• Sick congregants neither tithe or serve
Medical Mistrust and CRC Screening: Colon Cancer Prevention Project

• Formed 2005

• 2008 KY General Assembly established the Kentucky Colon Cancer Screening Program (KCCSP) for three purposes:
  1) to increase CRC screening
  2) to reduce morbidity and mortality from CRC
  3) to reduce the cost of treating CRC among Kentuckians

• CRC screening increased from 35% in 1999 to 66% in 2012.

• 49th to 20th in the nation
Medical Mistrust and CRC Screening:
Colon Cancer Prevention: Legislation

- **KY Senate Bill 96 (2008):** An act relating to health insurance coverage for colorectal cancer detection
- **KY Senate Bill 18 (2010):** An act relating to health care services provided in clinical trials for the treatment of cancer
- **KY House Bill 69 (2015):** An act relating to removing barriers to colorectal cancer screening
- **KY House Bill 115 (2016):** An act relating to colon cancer prevention and declaring an emergency
- **KY Senate Bill 146 (2017):** An act relating to the licensure of genetic counselors
- **KY Senate Bill 30 (2019):** requires Kentucky governed health benefit plans to cover cancer risk genetic testing if the recommendation is made by a licensed medical professional (covered under KRS Chapter 311 & 314), and follows the National Comprehensive Cancer Network (NCCN) guidelines
Medical Mistrust and CRC Screening: Colon Cancer Prevention: Meeting the Needs

• 2022 KY first state to offer CRC screenings kits through pharmacies

• Transportation to colonoscopies
Medical Mistrust and CRC Screening:

Closing

• At our level, we cannot expect to regain the patients trust without a change in attitude and behavior of both the clinician, and the organization.

• There cannot be a tiered system when addressing situations that perpetuate mistrust.

• Behavior that perpetuates mistrust should be viewed as morally equivalent to malpractice.
Medical Mistrust and CRC Screening: Options to Colonoscopy

- Guaiac-based fecal occult blood test (gFOBT)
- Fecal immunochemical test (FIT)
- FIT-DNA test
- Flexible Sigmoidoscopy
- CT Colonography (Virtual Colonoscopy)
Medical Mistrust and CRC Screening
Thank You
Health Equity
Understanding Medical Mistrust in Relation to Colorectal Cancer

Marcia Gainer, DNP, APRN
Quality Director
Evara Health
HEALTH EQUITY

UNDERSTANDING MEDICAL MISTRUST IN RELATION TO COLORECTAL CANCER
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MEET THE PRESENTER

Marcia Gainer, DNP, APRN
Quality Director

Specialty
Family Practice

Board Certifications
American Academy of Nurse Practitioners

Graduate Degree
D.N.P, University of North Florida
M.S.N., South University

Providing Quality Care at Evara Health since 2019
About Evara Health

- Federally Qualified Health Center (FQHC) since 1993
- Over 40 years of serving the community
- Formerly Community Health Centers of Pinellas, Inc.
- 16 health centers throughout Pinellas County
- Served over 56,000 patients in 2022
OUR VISION
Our vision is to provide equal access to comprehensive, quality health care that promotes healthier families and healthier communities.

OUR MISSION
To innovate beyond the barriers that limit access to quality health care, ensuring everyone can receive industry-leading services from professional teams that care as much as family.

OUR VALUES
We believe in ….

- COMMITMENT TO COMMUNITY
- BUILDING LASTING BONDS
- QUALITY ABOVE ALL
- PATIENT-CENTERED INGENUITY
- COMPASSION IN ACTION
- LEADING WITH INTEGRITY
Services Offered

MEDICAL SERVICES
Family Practice, Pediatrics, Women's Health, GYN Services, Behavioral Health, Chiropractic, Adult & Pediatric Dental, Pharmacy, Pharm MTM Services, Nutrition/Dietician, Podiatry, OPP, Psychiatry

ANCILLARY SERVICES
Community Services Specialists, Care Coordination, MedNet Smoking Cessation, Food Pantry, Healthy Start Foundation, Sickle Cell Disease Association

CLASSES
Fitness Classes, Cooking Classes, Diabetic Shared Group Visits
About Our Patients...

- 61% of patients racial and/or ethnic minorities
- 94% of patients below 200% FPL
- 80% of patients below 100% FPL
- 46% of patients on Medicaid/CHIP
- 25% of patients uninsured
The UDS CRC screening rate was 42.8% in 2021, which amounts to 2,769,337 patients screened in 2022 alone.
PROJECT EXPERIENCE

COMMUNITY SURVEYS

- Generated conversations
- Thought provoking survey questions produced questions from participants
- Increased awareness amongst the BIPOC participants, families, friends, and other community members

FOCUS GROUPS

- Allowed opportunity to share experiences in a safe space
- Inspired conversations about CRC in the community
- Highlighted the level of impact colorectal cancer has had on the BIPOC population
MEASURING MISTRUST

Group-Based Medical Mistrust Survey
08/04/2022 – 11/16/2022
88 community members responses

- Depth of medical mistrust
- Highest medical mistrust related to experiences of differential treatment and care due to race and/or ethnicity and economic status
- Importance to build rapport with patients at each opportunity
- Place emphasis on personal aspects of each patient
- Value of community focus group to spread awareness

54% (48) of respondents have been screened for colorectal cancer.

78% screened via colonoscopy
18% screened via stool-based test

33% have been screened in the last year, 64% in the last 1-9 years, and 2% over 10 years ago

The majority of participants (out of 88) either agreed or strongly agreed that they completely trust that their doctor’s decisions about colorectal cancer screening are best for them.

3% Disagree or Strongly Disagree
26% Neither Agree nor Disagree
64% Agree or Strongly Agree
BEST PRACTICES

- CRC FIT TEST TO PATIENTS (FREE)
- COLOGUARD SCREENING (for insured & uninsured patients)
- TEXT MESSAGE CAMPAIGNS
- COLORECTAL CANCER SCREENING INITIATIVES
- DEDICATED CASE MANAGEMENT
PARTNERSHIP IMPACT

- **Medical Professionals were more well received when in a comfortable space**

- **Helped to bridge gaps due to medical mistrust**

- **Helping advancing timely screenings and the opportunities to connect care**

- **Provided level of transparency in response due to comfortability with community partner**

- **Continued community partnerships to ensure timely screening**

- **Created a thirst for knowledge and insight for community members by trusted community members**
LESSONS LEARNED & NEXT STEPS

"Would rather not know"
Don’t have childcare
Can’t take off work to go to the doctor
Increase trust with the BIPOC populations

Understanding the importance of building relationships are each opportunity
QUESTIONS
Thank You
Thank You

nccrt.org  @NCCRTnews  #80inEveryCommunity