



Health Equity Community Project ECHO

Medical Mistrust in Relation to Colorectal Cancer Screening

Wednesday, April 19, 2023



Before we begin..

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

Welcome to the April 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.
To review Zoom's privacy policy, please visit zoom.us/privacy



Remember: Do NOT share any personal information about any patient



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

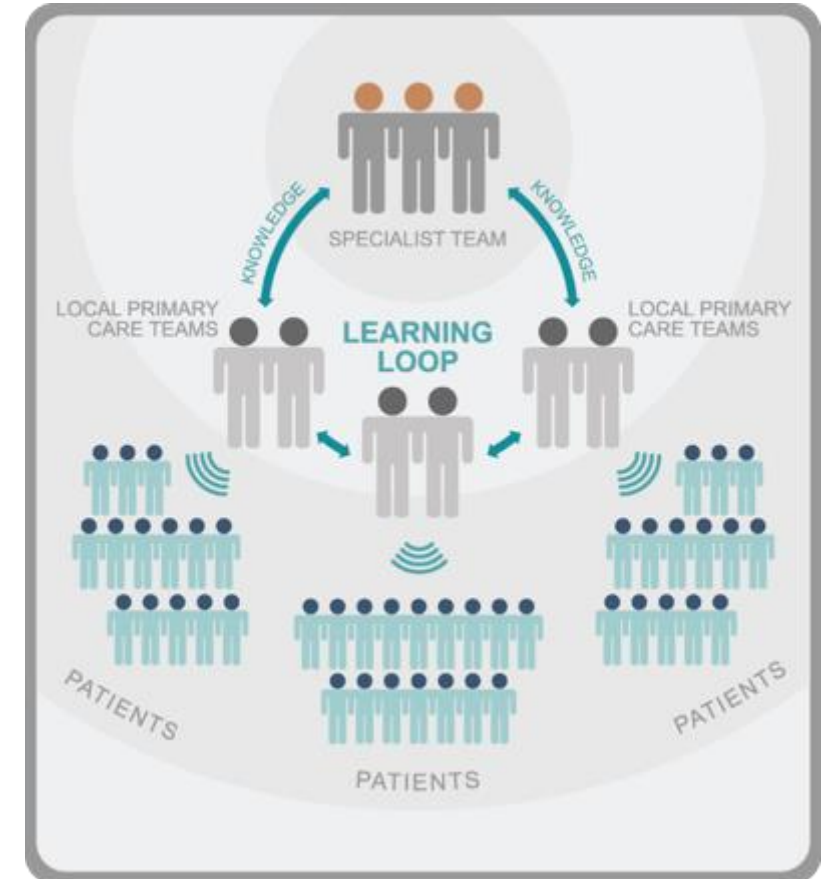
April Agenda

<p>Welcome and Introductions <i>ECHO Hub Introductions and Icebreaker</i></p>	<p>10 minutes</p>
<p>Didactic Presentation <i>Patient Engagement Series: Fundamentals of Elevating Patient Voices Through the Use of Patient Advisory Councils and Governing Boards</i> <i>Anjana Sharma, MD, MAS</i></p>	<p>25 minutes</p>
<p>Didactic Q/A</p>	<p>5 minutes</p>
<p>Case Study Presentation <i>Patient Advocate Story</i> <i>Allison Rosen, MS</i> <i>Director, Project ECHO</i> <i>American Cancer Society</i></p>	<p>10 minutes</p>
<p>Case Study Q&A</p>	<p>5 minutes</p>
<p>Wrap-up</p>	<p>5 minutes</p>

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 www.echo.unm.edu



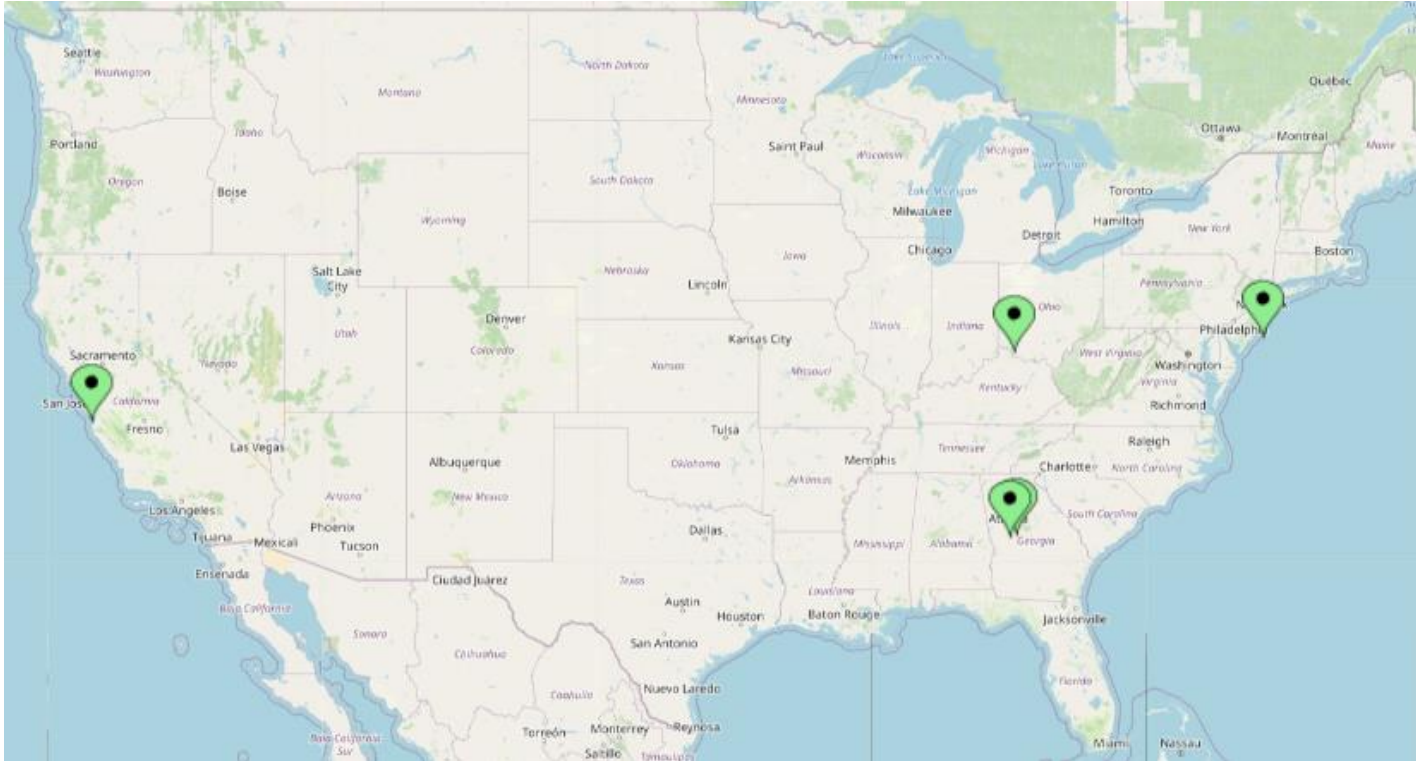
Health Equity Community Project ECHO Series

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

Introductions and Icebreaker

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 Introductions

ACS ECHO HUB Staff

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

ECHO Faculty

- Anjana Sharma, MD, MAS
- Jack Westfall, MD, MPH
- Laura Makaroff, DO

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



***What are you
doing this
weekend?***

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!

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 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 2023	Patient Engagement Series: Using Patient Voices to Improve Policies and Practices to Address Medical Mistrust in Relation to Colorectal Cancer Screening
August 2023	Patient Engagement Series: Strategies for Sustaining a Highly Effective Patient Advisory Council and Governing Board
October 2023	Effective Strategies for Reducing Medical Mistrust: Support from Healthcare Providers
December 2023	Effective Strategies for Reducing Medical Mistrust: Patients Perspectives of Discrimination and Group Based Disparities
February 2024	Effective Strategies for Reducing Medical Mistrust: Patients Suspicion of Healthcare Providers

About Our Didactic Presenter



Anjana Sharma, MD, MAS
Assistant Professor
Department of Family and Community Medicine
University of California San Francisco



Department of Family &
Community Medicine



ELEVATING PATIENT VOICES IN PATIENT ADVISORY COUNCILS AND GOVERNING BOARDS

Anjana E Sharma, MD MAS
Assistant Professor of Family & Community Medicine
University of California, San Francisco

Project ECHO Session #4
April 19, 2023

Objectives for today

1. Develop shared definition of patient/community engagement
2. Discuss common challenges health centers face in patient/community engagement
3. Understand best practices in implementing patient feedback in order to improve trustworthiness to the community
4. Understand what health centers can do to be advocates for their Patient Advisory Councils/Governing Boards

Background/bio

- From San Mateo, California
- Daughter of Indian and Polish/Ukrainian immigrants
- Mama of a 7 and 1.5 year old, caregiver and partner
- Work with advisory councils since 2013
- Family physician at largest FQHC in SF County public health network since 2014

My mission: Transform healthcare into spaces that are truly participatory, vibrant and healthful, co-created with patients and communities



WHAT IS “PATIENT
ENGAGEMENT”?

What does "patient engagement" mean to you?

[[poll everywhere – word cloud]]

Address a text to 37607

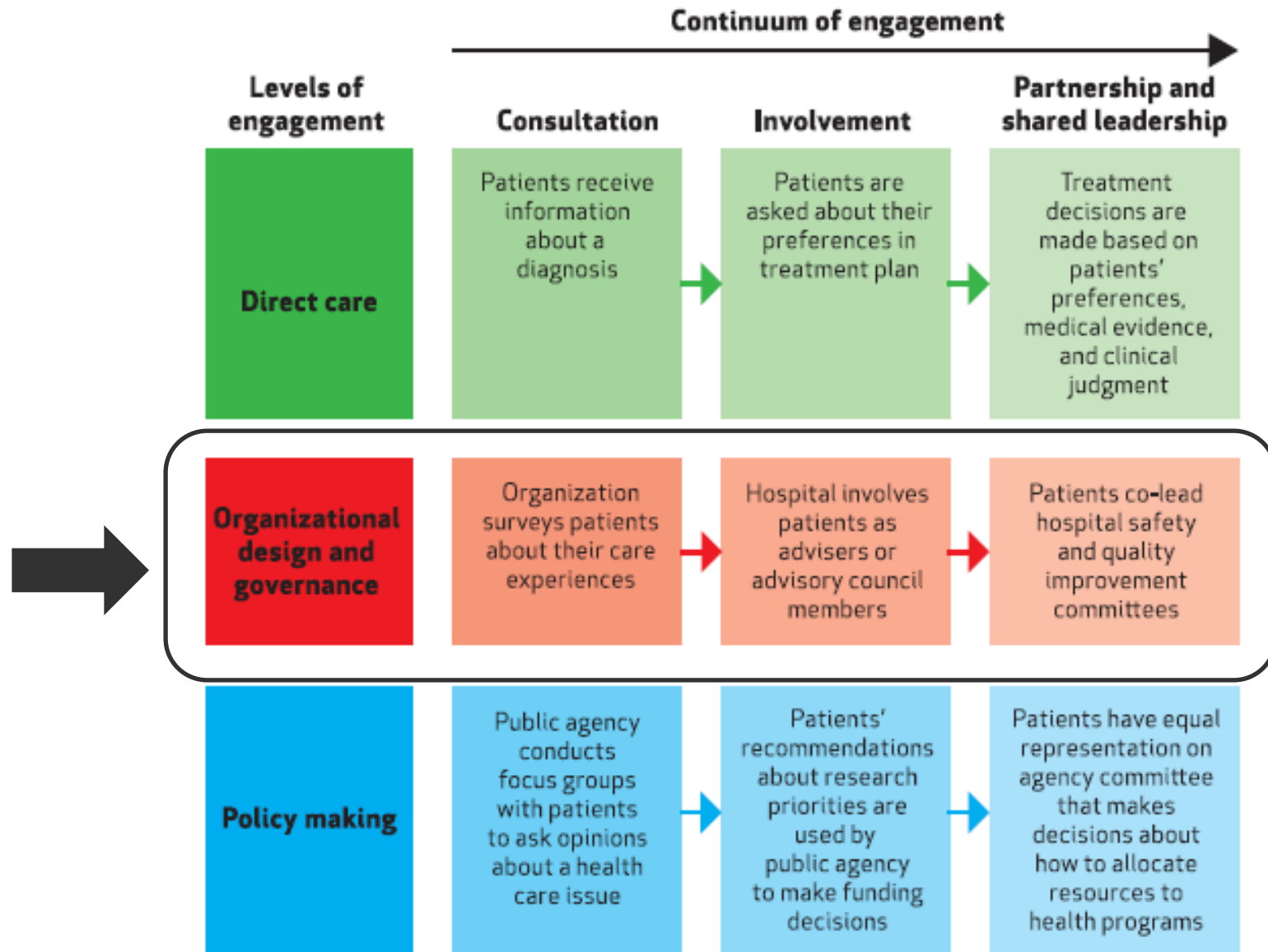
Then type ANJANASHARMA735

Patient and Family Engagement in healthcare

“Patients, families, their representatives, and health professionals working in **active partnership** at various levels across the healthcare system – direct care, organization design and governance, and policy making – to improve health and health care.”

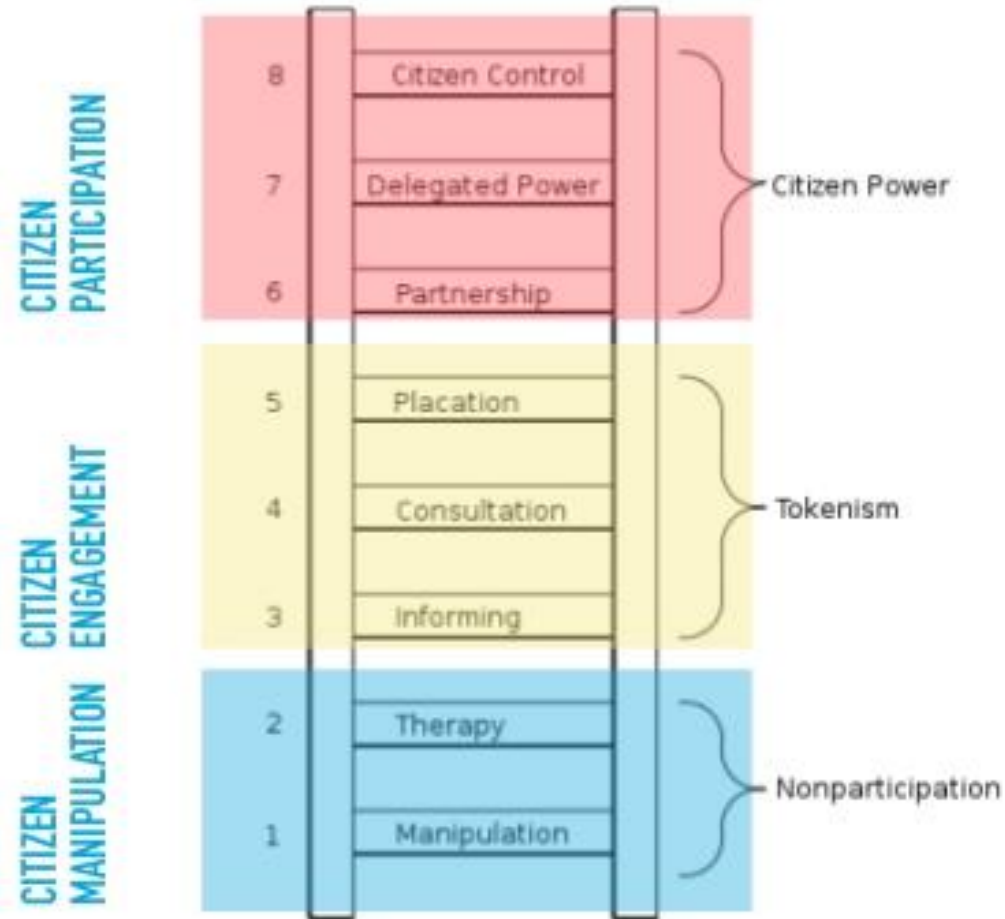
Carman KL & colleagues. Health Affairs. 2013;32(2): 223-231.

Patient Engagement has three levels



What has your experience been with patient engagement at these levels?

THE LADDER OF PARTICIPATION (SHERRY ARNSTEIN, 1969)



What Patient Engagement Means

- Patient engagement to me is: bringing primary care back to what it should be all along – for the patient and by the patient.
- *“Nothing about me, without me”*





Anjana E Sharma @AJSharmaMD · Apr 17



"Community service" is not the same as community engagement.

"Having more people of color in my research study" is DEFINITELY not community engagement.

Lets talk more about:

power sharing

priority setting

shared governance

shared data

shared \$\$\$\$\$\$\$\$\$\$\$\$\$



Anjana E Sharma @AJSharmaMD · Apr 17



And at some point we need to come together and find a different word than "engagement"... partnership is nice and probably my fave these days

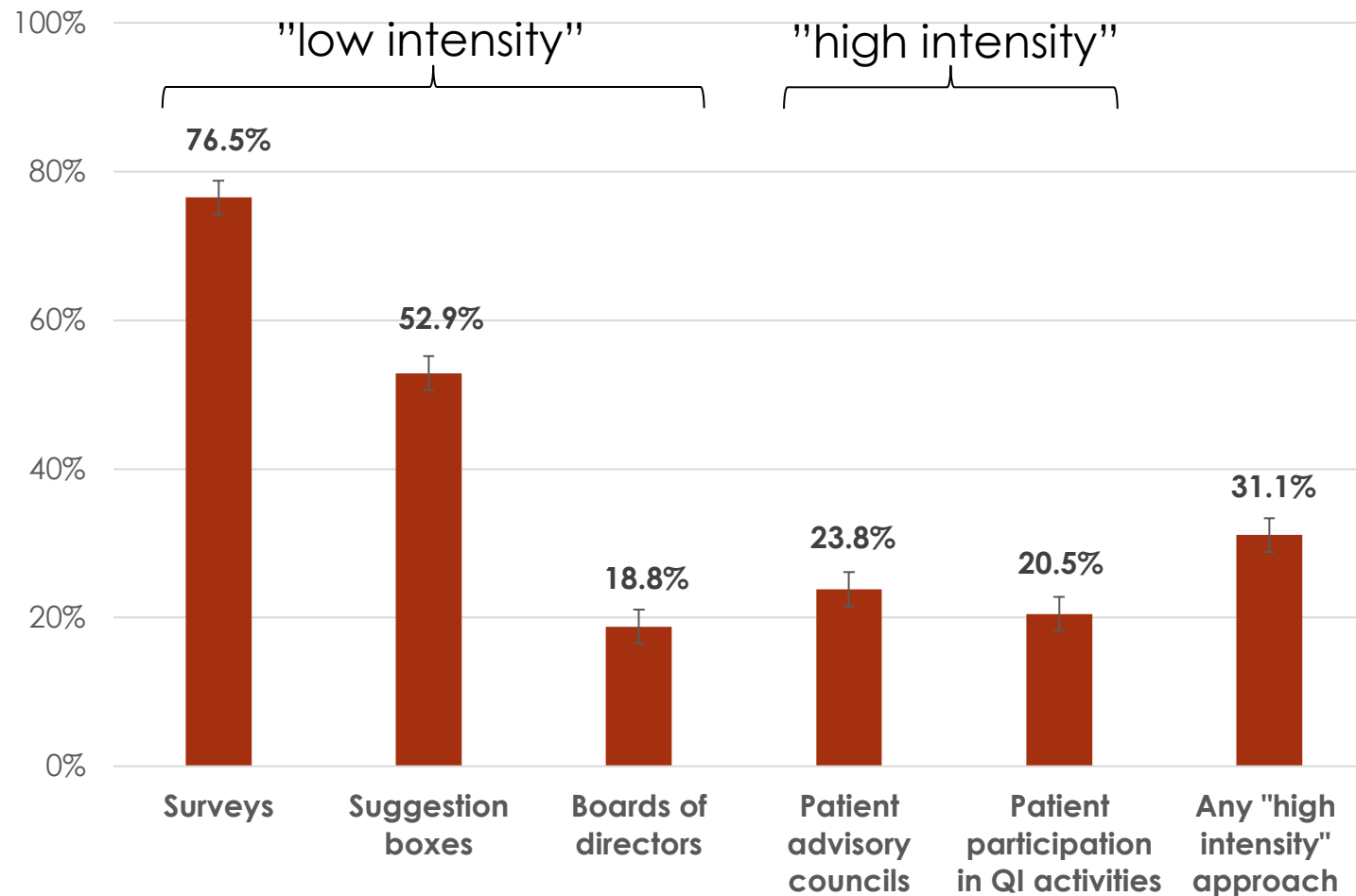


National Survey of Family Physicians

- Question: What is national prevalence and practice-level predictors of patient engagement?
- Methods: ABFM 2016 National Board Certification Survey
 - Individual demographics
 - Practice-level features
 - Patient Engagement question
 - PCMH questions for random subsample

ABFM Survey on Patient Engagement

- Results: Family docs (1,368) practicing in ambulatory setting



ABFM Survey on Patient Engagement

- Notables:
 - Patient experience surveys are highly prevalent
 - Of all practices, 31% have high-intensity patient engagement
 - Of all PCMHs, 58.5% have high-intensity patient engagement
- What predicts HIGH-INTENSITY Patient Engagement (patients in QI or patient advisory councils):
 - Large practice size: aOR 3.30, 95% CI (1.96, 5.57)
 - Certified PCMH: aOR 2.19 (1.62, 2.97)
 - % Vulnerable populations served: aOR 1.83 (1.18, 2.84)

What are some common challenges
in patient engagement at the
clinic/organizational level?

Address a text to 37607
Then type ANJANASHARMA735

Challenges of patient advisory councils



Lack of representative recruitment



Staff support/staff skill



Unclear pathways to leadership or improvement opportunities



Lack of “closing the loop” – where does feedback go?



\$\$\$ (gift cards, food, child care, interpreter, transport)

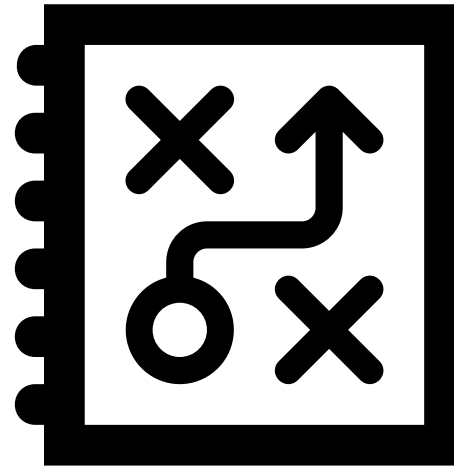
Challenges of governing boards

- Federally qualified health centers were mandated to have community representation on their governing boards since the 1970s
 - Still required 51%, otherwise no funding
- However these boards have been found to not be representative of the communities they serve
- Role of governing boards tends to be very high level and recruit more highly educated members of patient community

Wright B. Who governs federally qualified health centers?. *Journal of health politics, policy and law*. 2013 Feb 1;38(1):27-55.

Sharma AE, Huang B, Knox M, Willard-Grace R, Potter MB. Patient engagement in community health center leadership: How does it happen?. *Journal of community health*. 2018 Dec 1;43(6):1069-74.

What are best practices for implementing patient/community feedback?



Qualitative Study of Patient Advisory Councils

- Patient Advisory Councils (PACs) = Representative group of patients who partner with staff to improve a clinic's care delivery
- Question: what are key features of successful PACs?



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Major themes

- Thoughtful recruitment
 - *“I think once we’re established and solid and work out all the processes I’m going to focus on what groups are we not representing.”*
- Dedicated leadership/facilitation
 - *“...I see the facilitator as a conductor and we are the musicians. One plays cello, one plays violin, one plays the piano. We all play our own music, everybody does, and the conductor is to synchronize and harmonize”*
- Clear workflows for projects

How can a clinic advocate for their advisory board or governing board?

1. The **place**

1. Does your leadership enthusiastically support patient engagement and really *get* it?

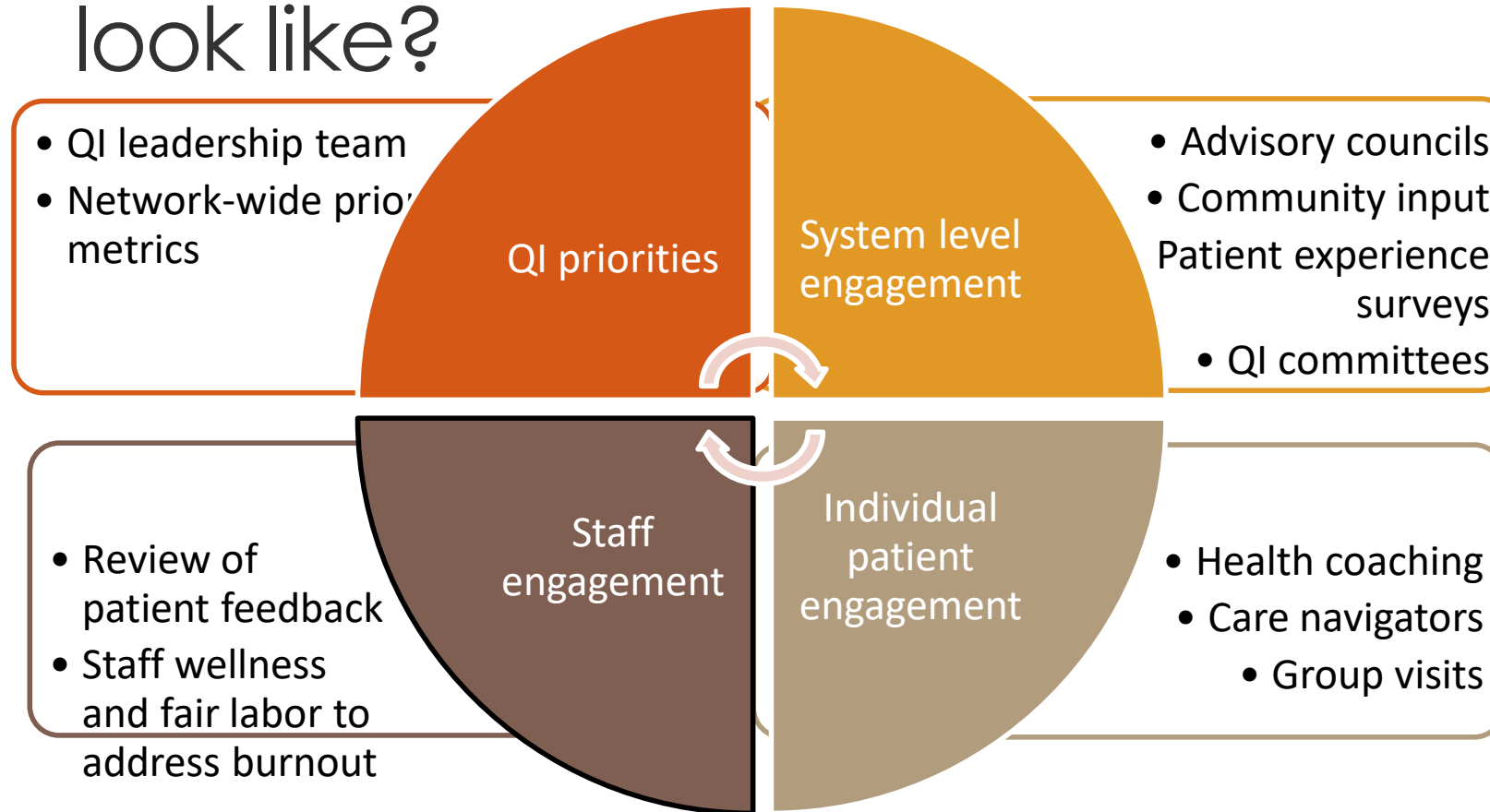
2. The **people**

1. are your current members representative of the population you serve? Are you prioritizing feedback from communities that have been most historically excluded/neglected?
2. Is your staff trained in group facilitation? Does your staff have enough time to maintain the council?

3. The **process**

1. What is the map of patient/community feedback? Is there a direct line to your QI or leadership team?

An integrated patient engagement strategy: What will it look like?



Trust



uché blackstock, md ✓

@uche_blackstock



Let's change the narrative around vaccine hesitancy in Black communities to focus on institutional trustworthiness.

6:47 AM · Dec 19, 2020

2,593 Retweets 211 Quotes 17.6K Likes 185 Bookmarks



uché blackstock, md ✓ @uche_blackstock · Dec 19, 2020



And remember, this is not only about healthcare institutions.



5



55



710



Oni Blackstock ✓ @oni_blackstock · Dec 19, 2020



Makes me think about the saying: "It's not a mistrust problem, it's a racism problem."



7



47



536



uché blackstock, md ✓ @uche_blackstock · Dec 19, 2020



Right!

Next steps

- Community Faculty role/title
- Co-created community engagement strategy for next 5-10 years
- Co-writing grants
- Patient Advisors selecting medical residents

[will these increase trustworthiness?]

Further Reading

- Group 1 – priority setting in primary care in Canada
<https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-9-24>
- Group 2 –preterm birth initiative
<https://www-ncbi-nlm-nih-gov.ucsf.idm.oclc.org/pmc/articles/PMC5908549/>
- Group 3 – Communities of Solution in Colorado
<https://www.jabfm.org/content/26/3/254.long>
- Group 4 - Nuka Southcentral Foundation
<https://www-ncbi-nlm-nih-gov.ucsf.idm.oclc.org/pmc/articles/PMC3752290/>

Thank you!

- Put in the chat
 - What struck you?
 - What was new?
 - What still feels challenging?
 - What you are excited to try next?

Anjana.sharma@ucsf.edu

@AJSharmaMD



Didactic Questions?

About Our Patient Advocate Speaker



Allison Rosen, MS
American Cancer Society
Director, Project ECHO

Case Study Questions?

Health Equity Community Project Case Study Overview

Presenting a Case Study

- Submission of cases for presentation and discussion is a key component in the Project ECHO model.
- It is critically important for knowledge building and sharing for all ECHO participants and is therefore an expectation for Community Leadership Teams to present at least one case study within the 18-month project period
- Community project sites are encouraged to present a case study involving information on their population of focus, efforts related to addressing medical mistrust within their community, and/or challenges involving project implementation.
- Community project sites will be notified **a month in advance** to present a Case Study for the next ECHO Session.
- Community Leadership teams will be provided with a Case Study presentation Power Point template, which will solicit demographic and relevant information pertaining to Community Project efforts. The Power Point will also include a section for listing questions Community Leadership Teams may have concerning their projects.
- **Please submit completed Case Studies to cecily.blackwater@cancer.org one week prior to the scheduled ECHO Session**



Project ECHO Session Survey

Next Project ECHO Session

Phase 2: Leveraging Patient Advisory Councils and Governing Boards



Presenter: Jack Westfall, MD, MPH

Date: ECHO Session #5 – June 29, at 11am PT/1pm CT/2pm ET

Topic: *Patient Engagement Series: Using Patient Voices to Improve Policies and Practices to Address Medical Mistrust in Relation to Colorectal Cancer Screening*

Next Steps

Group Based Medical Mistrust Scale Baseline Data:

- Pre-data collection ends April 30, 2023

Bi-monthly Check-in Calls:

- Bi-monthly Check-in Call will occur again towards the end of May 2023

Project ECHO:

- ✓ ECHO Session #4: Wednesday, April 19, 2023 (60 minutes)
- ECHO Session #4: Thursday, June 29, 2023 (60 minutes)

Thank You