# Community Engagement & DEI in Research

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### **Learning Objectives**



Participants will be able to identify two benefits of community engagement and DEI in their current or future research agenda



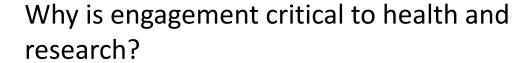
Participants will be able to discuss at least one strategy to engage members of communities that are affected by their current or future research



Participants will be able to discuss at least one strategy to enhance DEI in their current or future research agenda

#### Goals

How do we define community and community-based research?



What are the key elements for effective engagement?

What are the barriers for engagement?

How do we create innovative strategies for engagement?

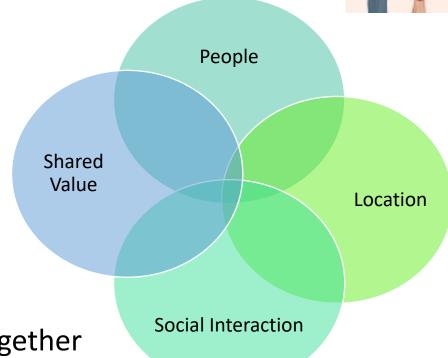
Application in research examples



## What is community?

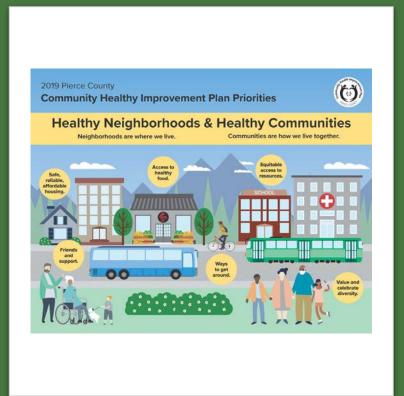
 A group of people who are in a particular space, have shared values and interact within a social system

- Common characteristics
  - Location
  - Race
  - Ethnicity
  - Age
  - Occupation
  - Shared values
  - Shared interests
  - Shared needs
  - Social connection
- Similarities that bond people together









Medical Model vs. Community Health

# Why community-based research and DEI?



#### **DIVERSITY**

The presence of differences in identities, both visible and invisible, among a group (e.g., gender, ethnicity, race, sexual orientation, religion)



#### **INCLUSION**

The degree to which people with different identities are welcomed, invited to participate fully, and leveraged in a given setting

#### **EQUITY**

Acknowledgement of systemic advantages and obstacles, and the implementation of solves for those imbalances in the form of policies, procedures, or practices

Guided interventions that results in better health-related outcome and policy change

Dave et al. 2018

# What is community-based research?

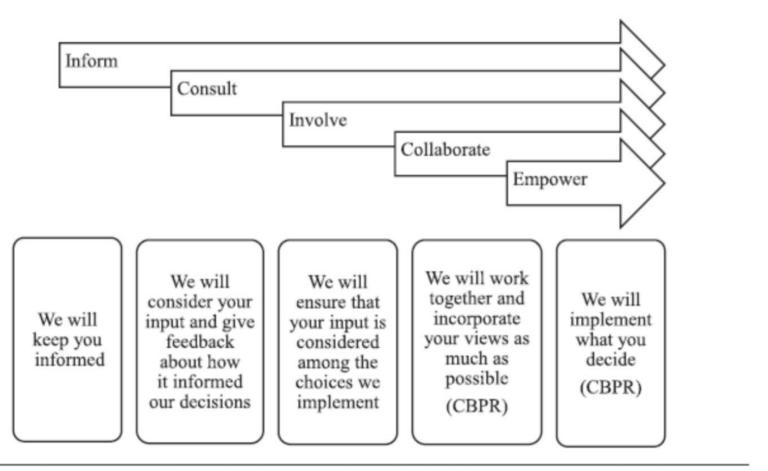


Fig 1 | Spectrum of patient and stakeholder engagement in research. Adapted from IAP2's (International Association for Public Participation) Public Participation Spectrum [51]. Developed by Northwestern University Center for Community Health.

# Elements of community and DEI engagement

- Trust
- Identify catchment areas
- Respect
- Shared mission
- Psychological safety
- Set and maintain expectation
- Cultural sensitivity
- Humility
- Cyclical in nature
- Sustainability
- Consistent and transparent communication of the research process



https://www.healthycommunities.org/resources/community-health-assessment-toolkit

# What are the barriers to community engagement?

- It takes time to build trust
- Competing priorities
- Stakeholders and buy-in
- Resources
- Time
- Capacity building (for researchers and communities)
- Communication
- Lack of awareness and understanding
- Access
- Historical and existing racism
- Breaking down stigmas

# What are the barriers to DEI engagment?

- It takes time to build trust
- Competing priorities
- Stakeholders and buy-in
- Resources
- Time
- Capacity building (for researchers and communities)
- Communication
- Lack of awareness and understanding
- Social determinants of health and access
- Historical and existing racism
- Breaking down stigmas

# Effective strategies for community engagement

- Hold a Town-hall or community meeting
- Establish new groups
- Volunteer and fill a need
- Community engagement studios
- Collect data (mixed methods)
- Attend meetings of existing groups
- Memorandum of understanding (MOU)
- Community health workers and peer support services



# Public meetings/Town Halls



Location is key

Community facilitator

Establish trust and humility

Identify the problems and who is affected

Address concerns and barriers

Identify resources

## Establish new groups

- Task force
- Advisory board
- Working-group
- Coalition
- Collaborative
- Committees
- Employee Resource Group (ERG's)
- Identify the patient voice

#### Military Community ERG

**The Accessibility Advocates ERG** 

Women's ERG

Multi-cultural ERG

LGBTQ+ Allies ERG



### **Community Engagement Studios**



- Facilitated conversation between researchers and community members
- The researcher presents their research project and then asks 3-4 questions of the community members
- May be conducted in person or virtually
- Participants are paid for their time and expertise
- Sessions last for about 1 to 1.5 hours

- Tool for community engagement and formative evaluation
- Tool for educating researchers and graduate students on community-engaged research

<sup>\*</sup>Adapted from CTSA/Vanderbilt University model

# Data collection

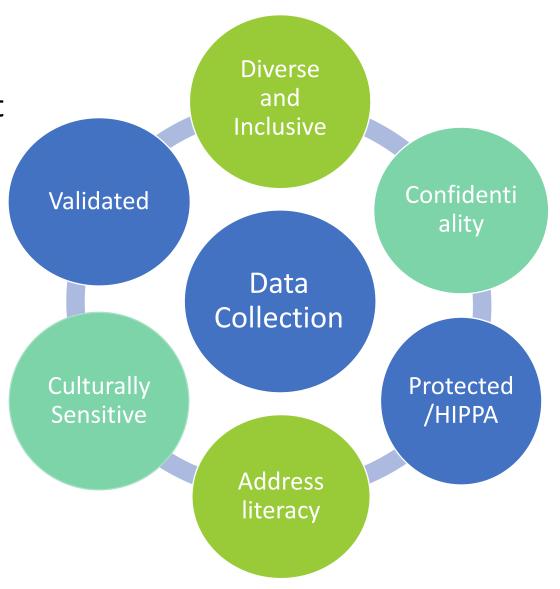
Needs assessment

Questionnaires

Interviews

Focus discussion

Photovoice



# Effective DEI strategies

- Diversify your research team
- Formative in the design
- Understand historical and cultural context
- Needs assessment.
- Standardize sociodemographic in data collection
- Self reported: social determinants of health in data collection
- Community member engagement and paying for time
- Define your catchment area
- Add educational value
- Address access to research
- Inclusion and exclusion criteria
- Implicit bias in design



https://www.hopkinsmedicine.org/diversity/\_documents/ODIHE\_Roadmap\_2023.pdf

Health

# Understand historical and culture context











### 19th Century Medical Experimentation

The impact of racialized science on the field of medicine today is painfully illustrated by the deep linkages that American gynecology has with slavery.

Many of the field's most pioneering surgical techniques were developed on the sick bodies of enslaved women who were experimented on until they either were cured or died.

A slaveholding surgeon, François Marie
Prevost, pioneered cesarean section surgeries
on American enslaved women's bodies
through repeated experimentation. James
Marion Sims, another famed 19th-century
gynecologist, created the surgical technique
that repaired obstetrical fistula by
experimenting on a group of Alabama
enslaved women [without anesthesia].

@SOYOUWANTTOTALKABOUT X @THEBLACKOBGYNPROJECT SOURCE: AJPH.APHAPUBLICATIONS.ORG/DOI/10.2105/AJPH.2019.305243

### Acknowledgement



Confronted with the stark reality of systemic inequality in society, we need to reexamine Elsevier's role in research and health and how we can make an active and positive contribution to accelerate equity, inclusion and diversity within our business and in the communities we serve.



# Standardize sociodemographic data collection

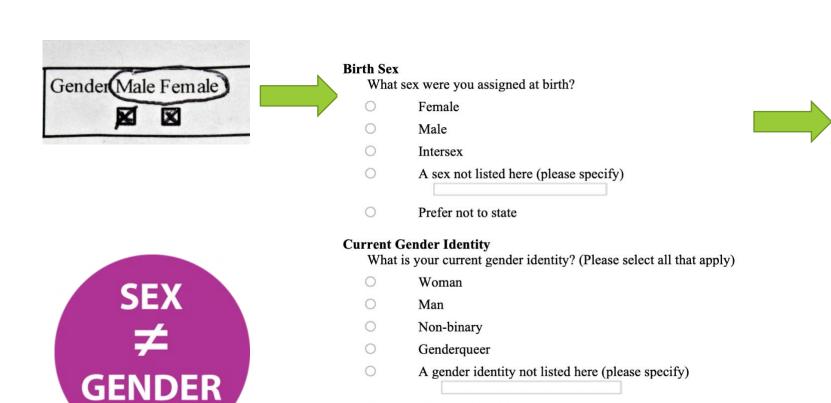
- Sex
- Sexual identity
- Gender
- Age
- Race
- Ethnicity
- Partner status
- Insurance status
- Disability
- Demographics
- Ethnicity
- Language
- Social determinants of health

Age (yr): median (range)	46 (19–86)
Gender: % male	56.0
Education (yr): median (range)	16 (8–22)
Employment: % employed	72.4
Length of residence in Miami-Dade	12 (1–65)
County (yr): median (range)	
Residence ownership: % yes	61.2
Residence type: % in building with two	63.5
or more apartments	
Household size (no. of people): median (range)	2 (1–7)
Race: % white	83.5
Ethnicity: % of Spanish, Hispanic, or	38.5
Latino descent <sup>b</sup>	
Primary language: % English	75.7
Primary language: % Spanish	18.0
Primary language: % other <sup>c</sup>	6.3

<sup>&</sup>lt;sup>a</sup> Calculated excluding missing data.

<sup>&</sup>lt;sup>b</sup> In the text, ethnicity is referred to as Hispanic or non-Hispanic, for brevity.

## Standardize sociodemographic data collection



Prefer not to state

0

Please indicate your gender identity. (Please select all that app
Cisgender Man or Male or Masculine
☐ Transgender Man or Male or Masculine
☐ Transgender Woman or Female or Feminine
☐ Cisgender Woman or Female or Feminine
Gender non-binary or Gender queer
☐ Intersex, Two Spirit, or other related terms
☐ Free response:
Prefer not to answer
Please indicate your sexual identity. (Please select all that app
Please indicate your sexual identity. (Please select all that app
☐ Asexual
☐ Asexual ☐ Bisexual
Asexual Bisexual Fluid
☐ Asexual ☐ Bisexual ☐ Fluid ☐ Gay
Asexual  Bisexual  Fluid  Gay  Heterosexual
Asexual Bisexual Fluid Gay Heterosexual Lesbian
Asexual  Bisexual  Fluid  Gay  Heterosexual  Lesbian  Pansexual

# Inclusion and exclusion criteria

Exclusion based on an easier path?

Exclusion based on capacity?

Exclusion based on implicit bias?

How am I judging what I deem as inclusive?

#### Common Inclusion/Exclusion Criteria





Date

If there has been a previous review undertaken that is being updated then it is not necessary to go back over ground covered in the earlier review. Instead refer to it and the findings from that study in the introduction.



The participants in the study may need to have experienced a particular condition to be considered for inclusion (e.g. received prenatal classes, given a particular drug, had a disease at a particular graded level or higher).



It may be necessary to limit the review to only studies targeting the same population group of interest for a broader original study or to countries which share similar demographic or economic factors with the target group.



It is usually not necessary to arrange translation of scientific works unless the review is attempting to come to a definite conclusion about a very specific clinical outcome which requires every applicable paper to be included.



Reviews may be restricted to only adult or child studies or to certain age groups. The Medline, Embase and Cinahl databases have age groups as subject headings for included articles.



Sometimes reviews will exclude non-peer reviewed literature but grey literature such as technical reports and web based guidelines may be important for certain research questions.



The inclusion of a study may depend on whether particular outcomes of interest have been reported and in an appropriate, consistent manner. The outcomes may be excluded if they are self reported rather than using objective



The study may be excluded or included based on where the participants were located (e.g. school, hospital, inpatient, community based care).



The inclusion of only selected study designs is a way to make the review much more manageable and applicable to the research question. Study designs can include those in which participants were surveyed at one point in time (e.g. crosssectional studies and ecological studies) and study designs that are conducted over time.



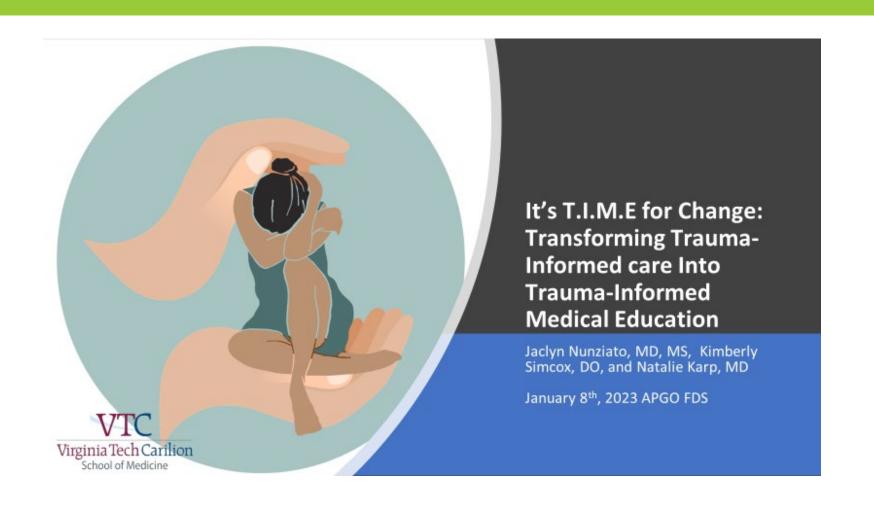
Systematic reviews usually search for original studies. Commonly excluded publications are reviews and editorials. Letters may also be excluded however this should be done with caution as sometimes the letter format will be used to report small scale studies.

measures.

### Questions or Comments?



### Application Examples: Trauma-informed care





# Application Example: Vaccine Hesitancy

# Examples from the audience

- What are you working on?
- Who is your "community"?
- What challenges have you faced regarding community engagement & DEI in your practice or your research?
- What is one approach you might consider to address these challenges?



## **Questions and Comments**

