



Community Engagement & DEI in Research

March 2nd, 2023

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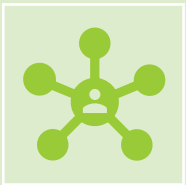
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Learning Objectives



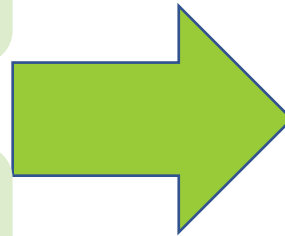
Participants will be able to identify two benefits of community engagement and DEI in their current or future research agenda



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?

Why is engagement critical to health and research?

What are the key elements for effective engagement?

What are the barriers for engagement?

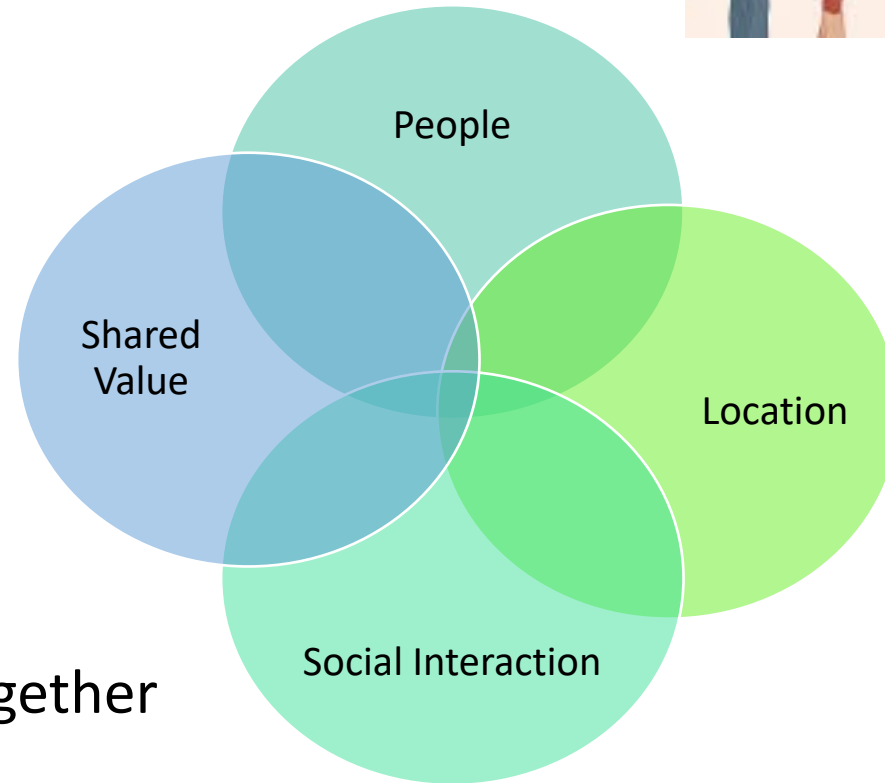
How do we create innovative strategies for engagement?

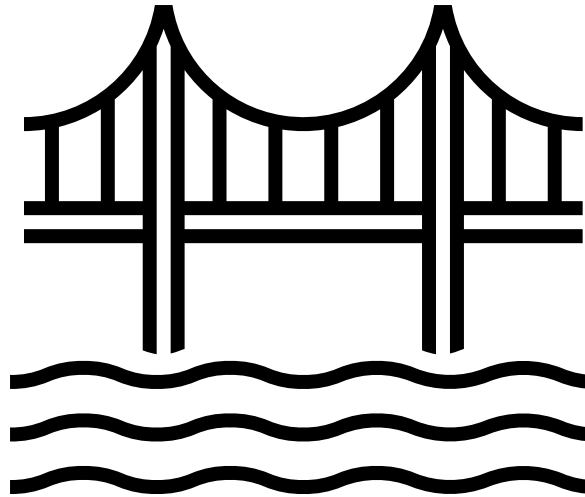
Application in research examples

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?

Diverse experts to address complex problems

Perspective

Quality and program design

Relevance/priority

Maximize resources

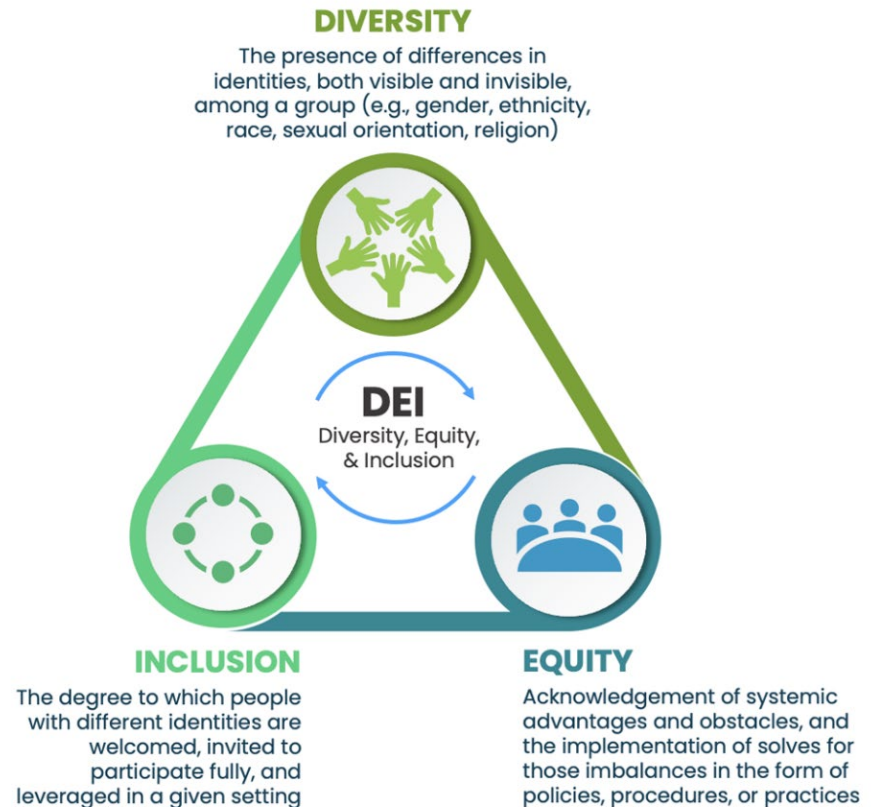
Increase capacity for change

Alleviate health disparity

Meeting the needs of the community

Sustainability

Mutually beneficial



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

Dave et al. 2018

What is community-based research?

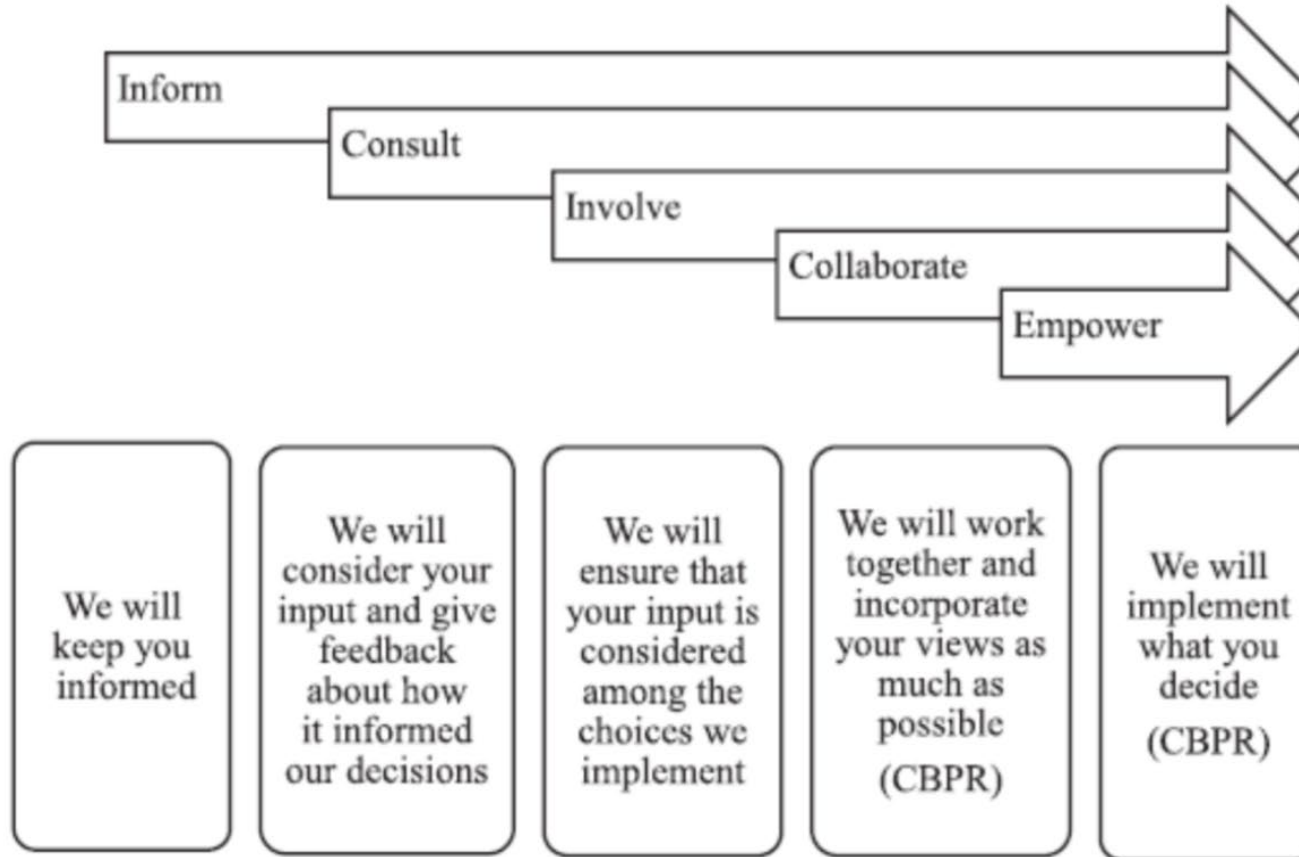


Fig 1 | Spectrum of patient and stakeholder engagement in research. Adapted from IAP2's (International Association for Public Participation) Public Participation Spectrum [51]. Developed by Northwestern University Center for Community Health.

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



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 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**
- **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

WORDS MATTER

words have
direct and
indirect impacts

on the people
who hear or
read them

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**

*Adapted from CTSA/Vanderbilt University model

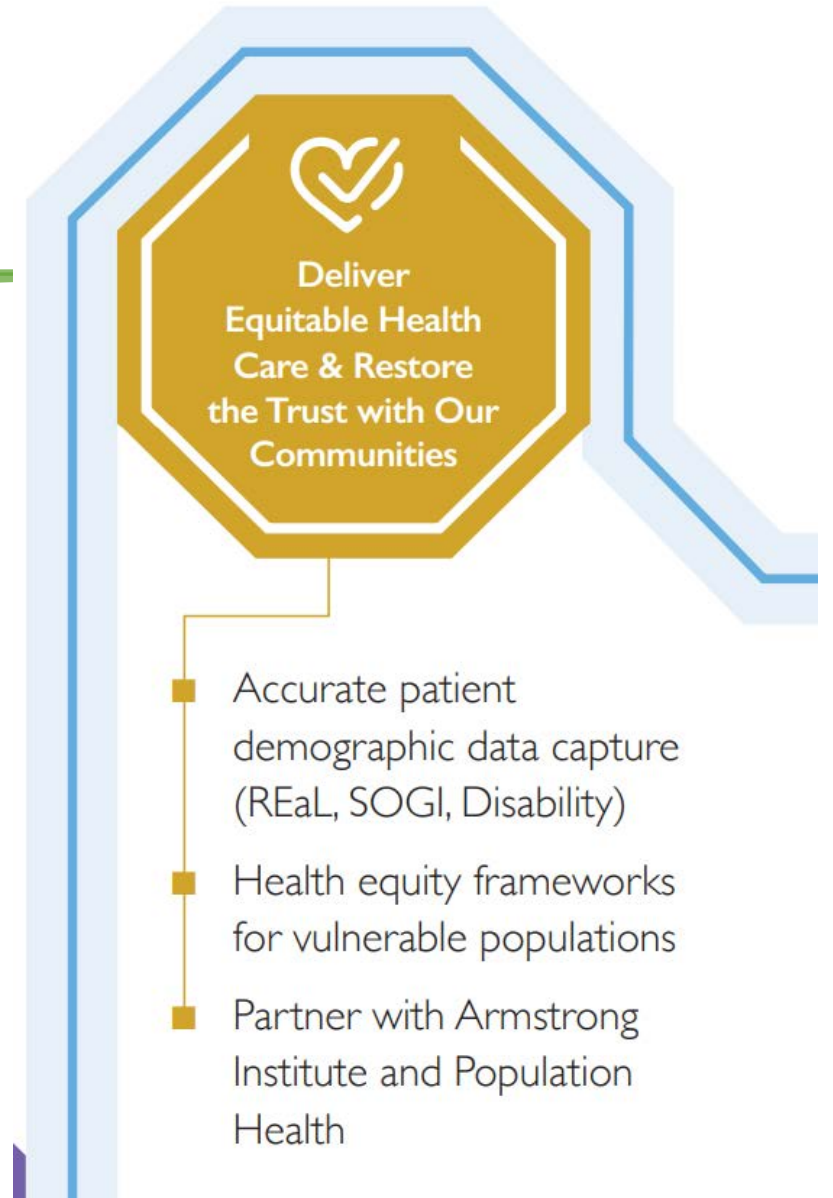
Data collection

- 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



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 Prevoist, 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].

@SOYOUWANTTOTALKABOUTX @THEBLACKOBYGYNPROJECT
SOURCE: AJPH.APHAPUBLICATIONS.ORG/DOI/10.2105/AJPH.2019.305242

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 County (yr): median (range)	12 (1–65)
Residence ownership: % yes	61.2
Residence type: % in building with two or more apartments	63.5
Household size (no. of people): median (range)	2 (1–7)
Race: % white	83.5
Ethnicity: % of Spanish, Hispanic, or Latino descent ^b	38.5
Primary language: % English	75.7
Primary language: % Spanish	18.0
Primary language: % other ^c	6.3

^a Calculated excluding missing data.

^b In the text, ethnicity is referred to as Hispanic or non-Hispanic, for brevity.

Standardize sociodemographic data collection

Gender Male Female
☒ ☒



Birth Sex

What sex were you assigned at birth?

- ☐ Female
- ☐ Male
- ☐ Intersex
- ☐ A sex not listed here (please specify)
- ☐ Prefer not to state

Current Gender Identity

What is your current gender identity? (Please select all that apply)

- ☐ Woman
- ☐ Man
- ☐ Non-binary
- ☐ Genderqueer
- ☐ A gender identity not listed here (please specify)
- ☐ Prefer not to state



Please indicate your gender identity. (Please select all that apply)

- ☐ 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 apply)

- ☐ Asexual
- ☐ Bisexual
- ☐ Fluid
- ☐ Gay
- ☐ Heterosexual
- ☐ Lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Free response:



Inclusion and exclusion criteria

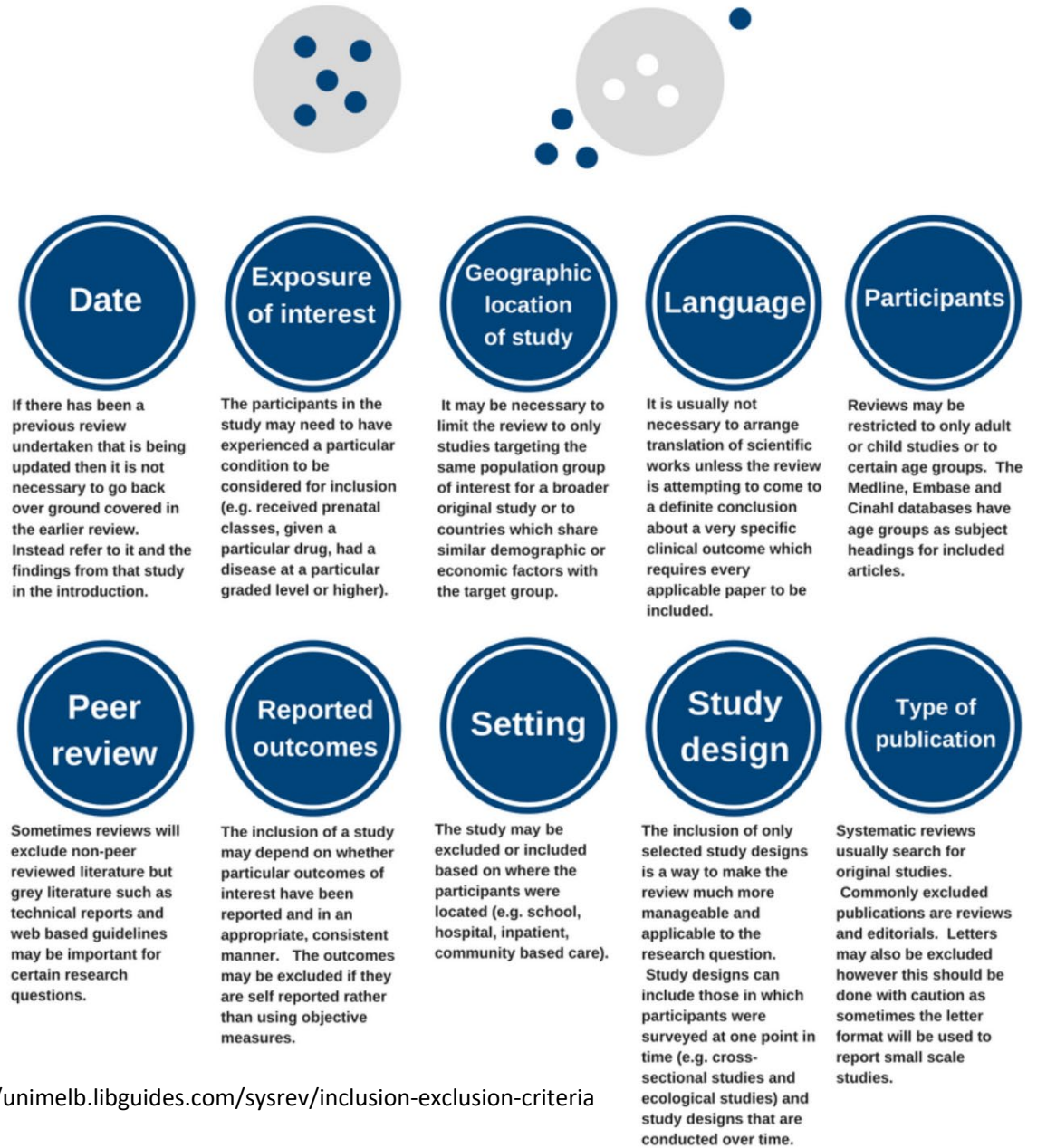
Exclusion based on an easier path?

Exclusion based on capacity?

Exclusion based on implicit bias?

How am I judging what I deem as inclusive?

Common Inclusion/Exclusion Criteria



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

