What We Offer:

1   **Research Support Services:** Members gain access to the different research services, resources, and tools offered by ITHS, including the ITHS Research Navigator.

2   **Community Engagement:** Members can connect with regional and community based practice networks

3   **Education & Training:** Members can access a variety of workforce development and mentoring programs and apply for formal training programs.

4   **Funding:** Members can apply for local and national pilot grants and other funding opportunities. ITHS also offers letters of support for grant submissions.

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Contact ITHS

Director of Research Development

- Project Consultation

- Strategic Direction

- Resources and Networking

Melissa D. Vaught, Ph.D.
ithsnav@uw.edu
206.616.3875

Scientific Success Committee

- Clinical Trials Consulting

- Guidance on Study Design, Approach and Implementation

- Feedback on Design and Feasibility

https://www.iths.org/investigators/services/clinical-trials-consulting/

Feedback

At the end of the seminar, a link to the feedback survey
will be sent to the email address you used to register.

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Increasing Inclusivity in Participant Recruitment and Engagement

ITHS Career Development Series | June 2022

Brian E. Saelens, Ph.D.

brian.saelens@seattlechildrens.org

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Objectives

By the end of this session, you should be able to:

Importance	Understand the rationale and importance of diversifying research participation
Plan	Describe expectations for inclusion of diverse populations in research and suggested language for reporting on diverse identities
Act	Identify 3 strategies that increase the likelihood of increasing the racial/ethnic and economic diversity of research participants

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Center for Diversity and Health Equity

Own EDI Journey

- Research focus on active living and healthy eating
  - Started with individual/family; expanded to environment
- Community partnerships in health implementation initiatives
  - Different perspectives, community-informed approaches
- Service (County, National Advisory, ITHS)
- Self-reflection, opportunities for learning, recognize privilege, servant leadership
- Still evolving

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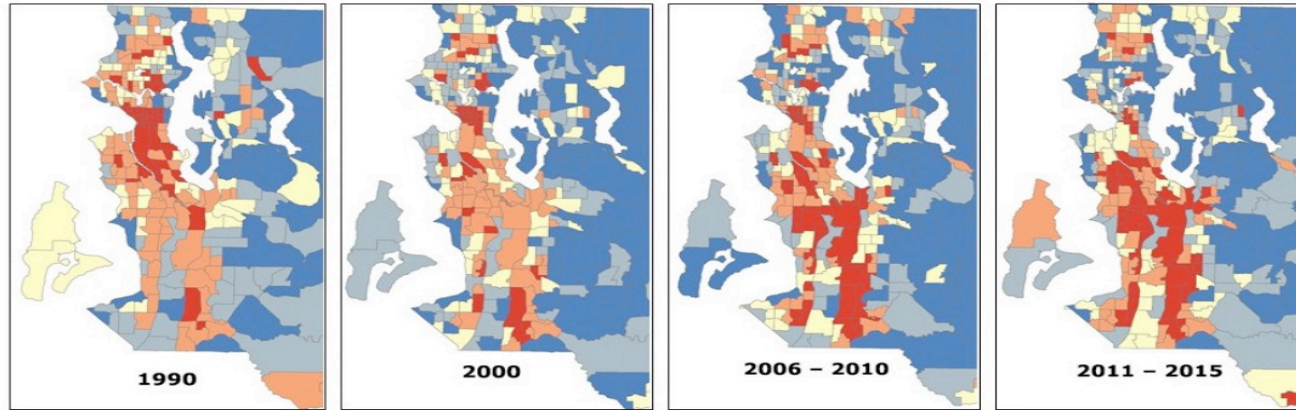HOSPITAL • RESEARCH • FOUNDATION
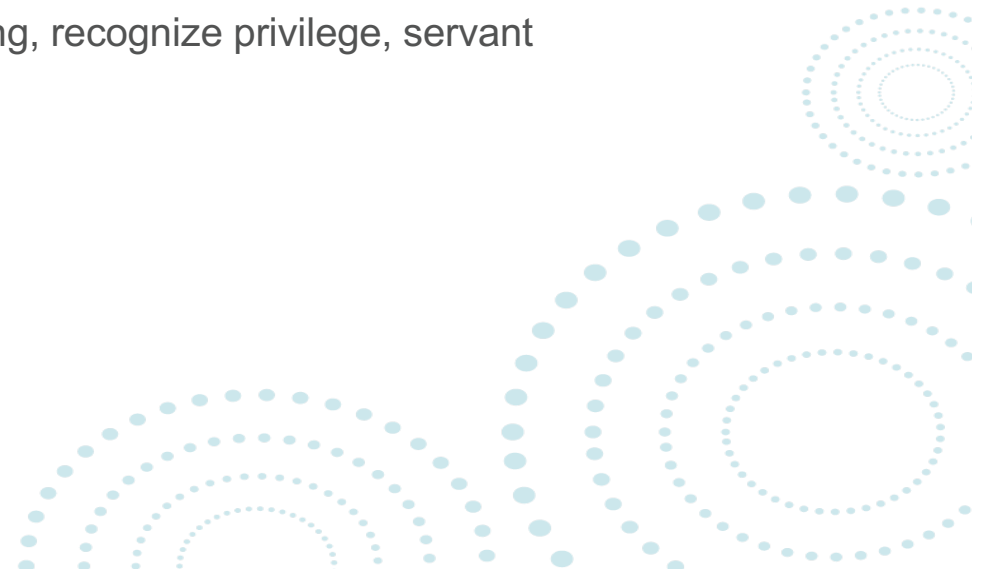
Common Language

- **Diversity:** The myriad ways in which people differ, including psychological, physical, and social differences that exist across individuals, including race, ethnicity, nationality, socioeconomic status, religion, economic class, education, age, gender, sexual orientation, mental and physical ability, etc.
  - Diversity is all-inclusive and supportive of the proposition that everyone and every group should be valued.
  - Understanding differences and moving beyond simple tolerance to embracing and celebrating the rich dimensions of our differences.
  - Recognition that research that fails to increase participation from diverse groups will continue to perpetuate inequities in health care and health outcomes that exist in our country, in our communities, and elsewhere.
  - When discussing race as an element of diversity, note that race is a social construct, not a biological one.

- **Inclusion:** Authentically bringing traditionally excluded individuals and/or groups into processes, activities, and decision/policy making in a way that shares power.
  - Better inclusion involves better engagement of individuals who identify as non-white, Latinx, LGBTQIA, lower income, otherwise abled, non-English language proficient, and other groups not represented in research
  - Having just a diverse research workforce is not the same as having a diverse research workforce in an inclusive environment.
  - By incorporating inclusion, we can ensure that we do more than just bring in diversity; inclusion is a concrete way of supporting and sustaining that diversity.

Common Language

- **Equity:** Individuals are provided resources they need to have access to the same opportunities. Equity is disproportional (some get more than others), but the distribution ensures even opportunities for all people. Conversely, 'equality' is uniformity of resources provided (the same resources are given to everyone), which perpetuates existing differences in access to and engagement in opportunities (like research).

- **Health Equity:** social justice in health (i.e., no one is denied the possibility to be healthy based on group status)

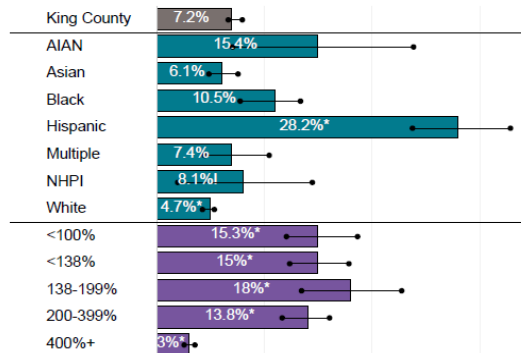- **Health Disparities:** the metric that we use to measure progress toward achieving health equity

Braveman P. What are health disparities and health equity? We need to be clear. Public Health Rep. 2014;129 Suppl 2(Suppl 2):5-8. doi:10.1177/00333549141291S203

Median household income by King County neighborhood, 1990-2015

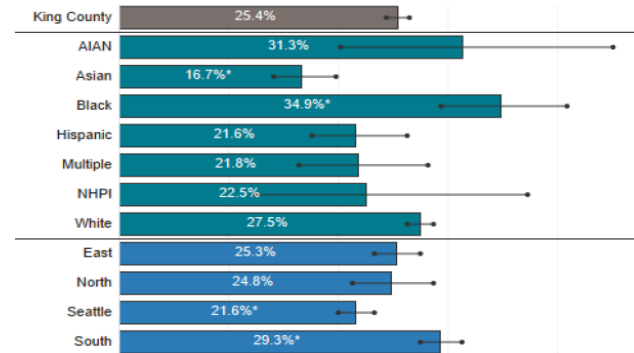|				
<$50,000	$50,000 - $64,999	$65,000 - $74,999	$75,000 - $89,999	$90,000 and over

Data sources: US Census Bureau, 1990 & 2000 censes; American Community Survey (2006-2010, 2011-2015)

Uninsured adults
King County (2019)

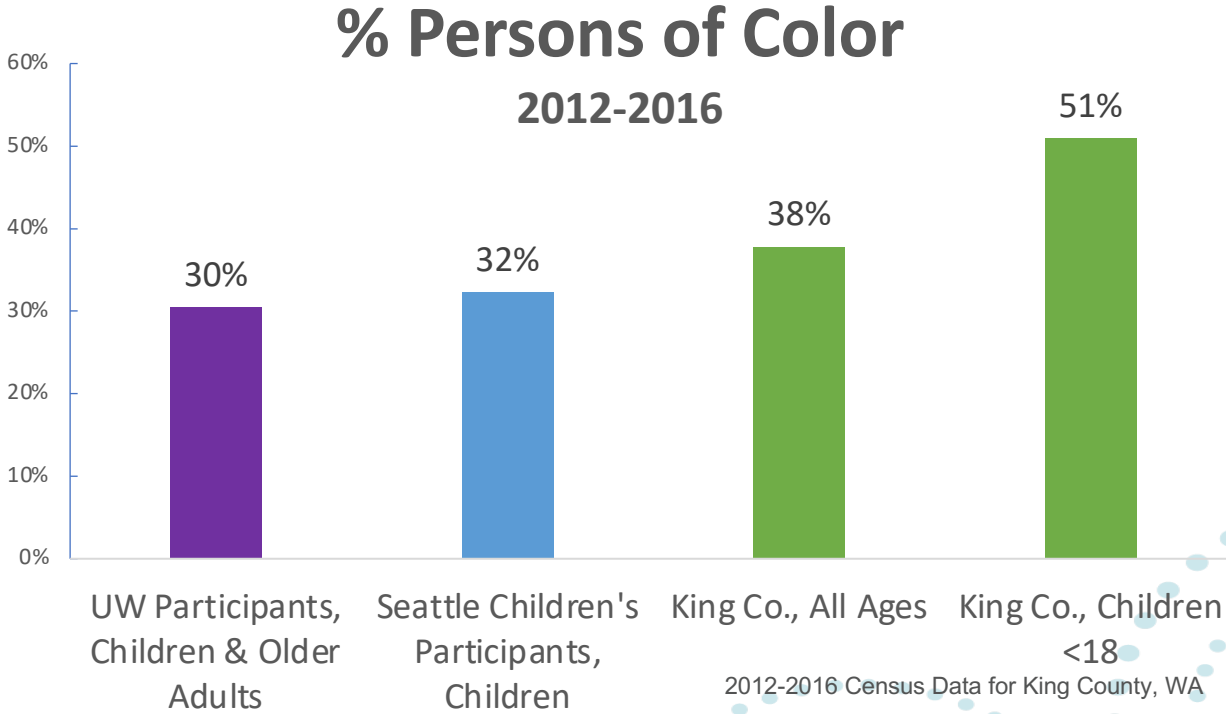|	
King County	7.2%
AIAN	15.4%
Asian	6.1%
Black	10.5%
Hispanic	28.2%*
Multiple	7.4%
NHPI	8.1%!
White	4.7%*
<100%	15.3%*
<138%	15%
138-199%	18%*
200-399%	13.8%*
400%+	3%*

Source: American Community Survey
* Significantly different from King County average
! Interpret with caution: sample size is small, so estimate is imprecise

Hypertension (adults)
King County (average: 2013, 2015 & 2017)

King County	25.4%
AIAN	31.3%
Asian	16.7%*
Black	34.9%*
Hispanic	21.6%
Multiple	21.8%
NHPI	22.5%
White	27.5%
East	25.3%
North	24.8%
Seattle	21.6%*
South	29.3%*

Source: Behavioral Risk Factor Surveillance System
* Significantly different from King County average

Prior State: Research Participant Race/Ethnicity

% Persons of Color
2012-2016

Bar chart showing:
- UW Participants, Children & Older Adults: 30%
- Seattle Children's Participants, Children: 32%
- King Co., All Ages: 38%
- King Co., Children <18: 51%

2012-2016 Census Data for King County, WA

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A

Legend: Report All Five Race/Ethnicity Groups · Report Any Race/Ethnicity Data · Report Gender Data

FDAAA 801
(Sep 27, 2007)

Final Rule
(Jan 18, 2017)

Proportion of trials

Month and year of trial submission

Distribution of trials according to race/ethnicity of enrollees

Proportion of trials

White	Latino	Black	Asian	American Indian
Median = 79.7%	Median = 6.0%	Median = 10.0%	Median = 1.0%	Median = 0.0%
US Census: 72.4%	US Census: 16.3%	US Census: 12.6%	US Census: 4.9%	US Census: 0.9%

Proportion of enrollees per trial

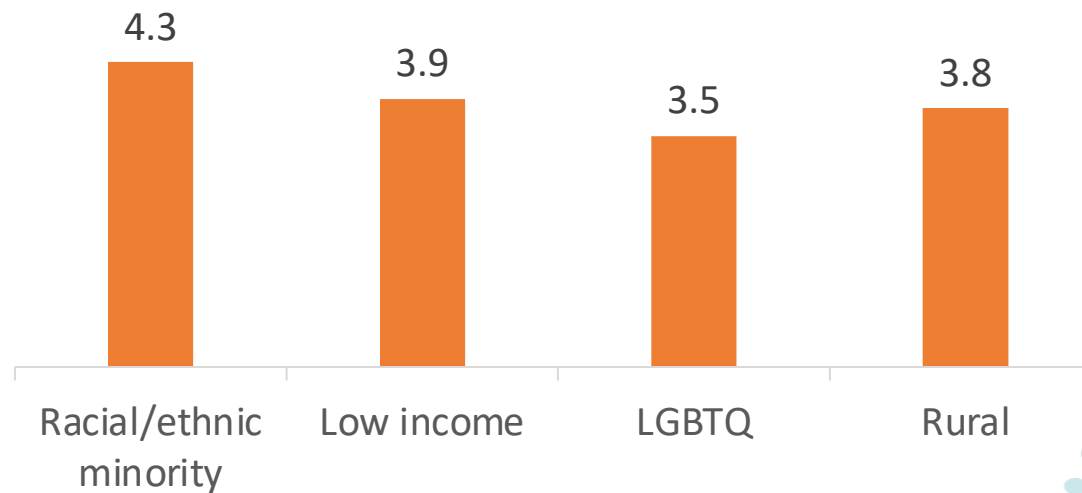Turner 2022 *The Lancet Regional Health - Americas*

Current State: Importance of Inclusion

How Important Is It to Increase Research Participation of These Groups?

Likert (1=Not at all; 5=Very Important)
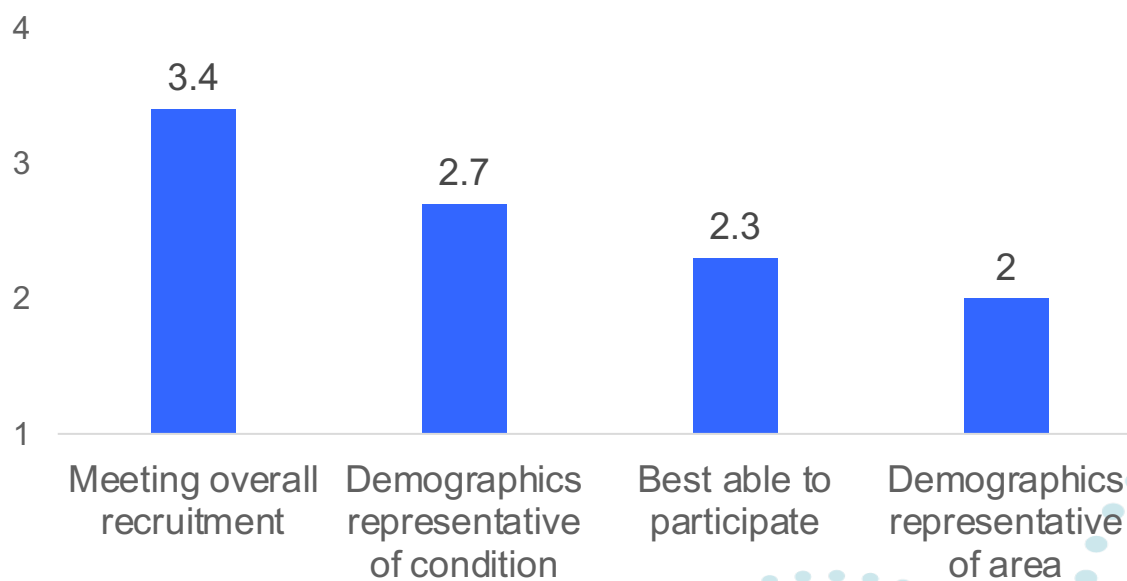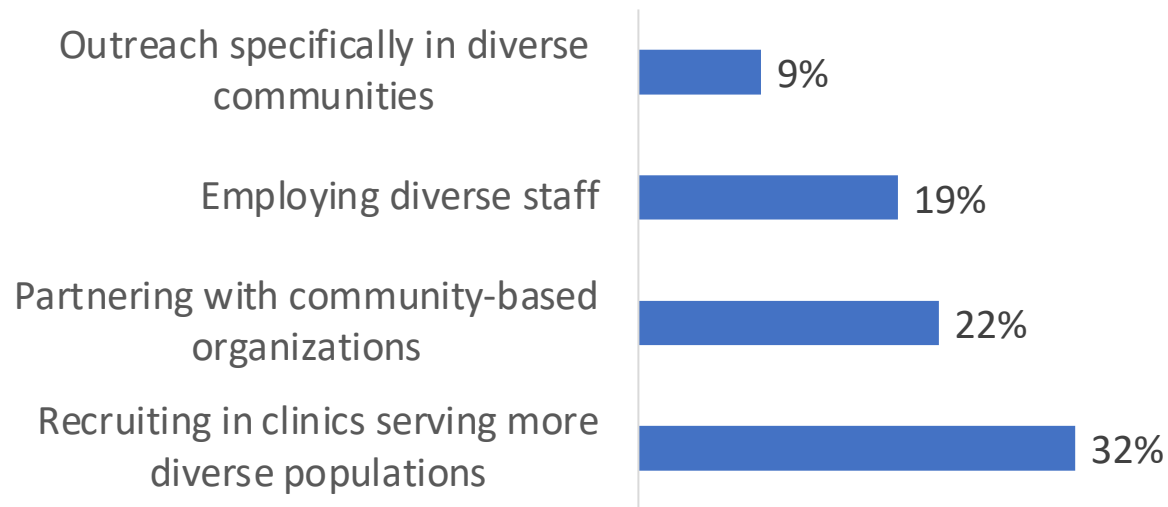

Racial/ethnic minority	Low income	LGBTQ	Rural
4.3	3.9	3.5	3.8

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Survey on Diversity in Research Studies

Rank Importance for Recruitment/Enrollment
Rank (1=*Least*; 2=*Slightly*; 3=*Important*; 4=*Most*)

Current State: Current Diversity/Inclusion Practices

- Outreach specifically in diverse communities — 9%
- Employing diverse staff — 19%
- Partnering with community-based organizations — 22%
- Recruiting in clinics serving more diverse populations — 32%

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Who We Exclude from Research (e.g)

- Limited English Proficiency (IRB approved)

- Race or Ethnicity (implicit bias and racism)

- Socioeconomic status (research design)

- Disabled individuals (by protocol)

- LGBTQ (exclusionary survey questions)

NIH Study Section Review

Inclusion Plans **Applicable Only for Human Subjects research and not IRB Exemption #4.**

- Sex/Gender: Distribution justified scientifically
- Race/Ethnicity: Distribution justified scientifically
- For NIH-Defined Phase III trials, Plans for valid design and analysis: Not applicable
- Inclusion/Exclusion Based on Age: Distribution justified scientifically

Comments (Required Unless Not Applicable):

Summary

- Many of the health conditions that are the focus of our clinical translational research have disparities in prevalence, access to corresponding care, outcomes, etc

- History of lack of reporting on race/ethnicity and other identity information and inequitable access for diverse populations

- There is considerable interest, but more limited action being taken around EDI integration

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What You Can Do

Strategies to Increase Diversity in Research

- Community engagement in various forms and ways (individual/team)
- Change our institutions (system)

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Value of Including the Community

➢ Community are the **experts** of their community
- Insights into recruitment, data collection, and retention

➢ Research goal becomes the community-academic **partnership goal**
- Research success becomes a **shared** goal
- Community **champions**

➢ Builds the **pipeline** for dissemination and implementation

➢ Creates a **context** for translation of research

➢ More funders and reviewers demand it!

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Example from Equitable Research Best Practices

Equitable Research Best Practices: **Study Design**

1. **Researchers should consider the following questions:**

   – Is the community involved in the research design process?

   – How will answers to the research questions will benefit the community?

   – Do the research questions account for the cultural and historical context of the community?

   – How do community members desire to be approached and through what processes?

   – Does the community respect & trust the research design and types of data collected?

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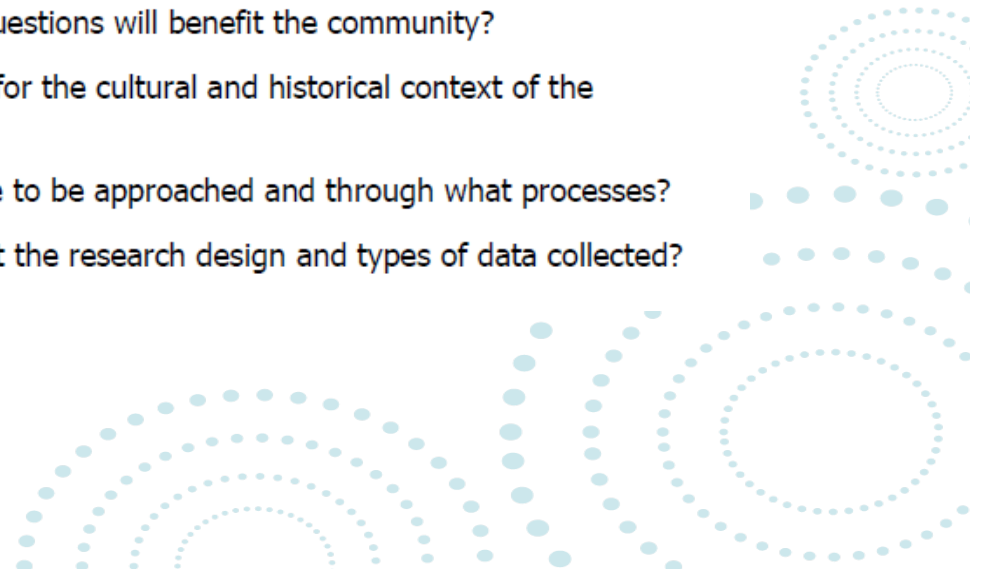
Value Your Community Partners

Share the Funds!

Be Mindful of Operations Costs

Consider utilizing community resources for staffing

Be transparent

Use the Community Partnership Guide

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Community Partnership Guide

for Engaging

with Academic

Researchers

STEP **1** — Screening Questions

STEP **2** — Plan Your Engagement

STEP **3** — Memorandum of Understanding
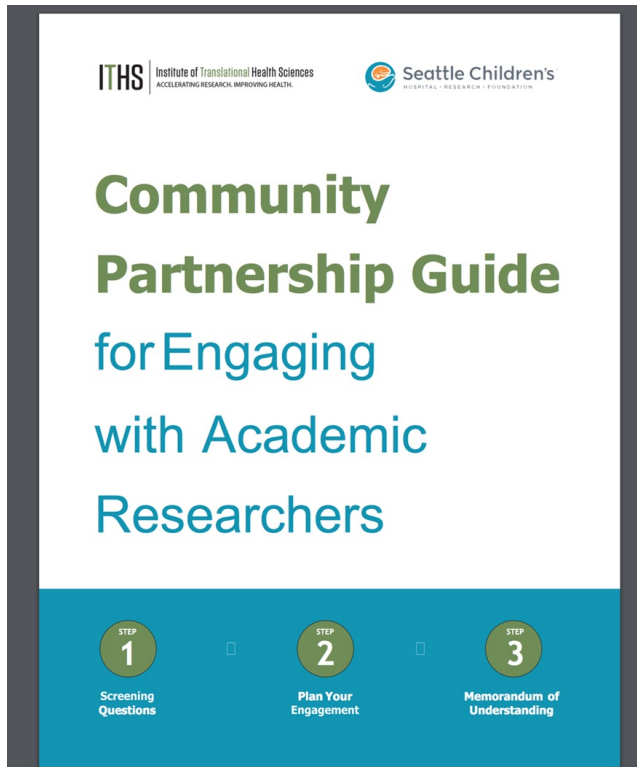
Step 1: Decide which projects to learn more about

Step 2: Plan your Research Project Engagement

Step 3: Create a Memorandum of Understanding

https://www.iths.org/community/partners/isp/

Saleh, A., Saelens, B., Hayes, M., the Health Equity Community Advisor Council, & Coker, T. (2022). Community Partnership Guide for Engaging with Academic Researchers. Progress In Community Health Partnerships: Research, Education, And Action, 16(1), 129-134. https://doi.org/10.1353/cpr.2022.0012

Starting Earlier and Staying Engaged

**Building relationships and sharing power**

- ❑ Be known for being there (and not just for you)

- ❑ Bring value to your community partners

- ❑ Listen intently, verify, listen again

- ❑ Power

  - ❑ Who has the resources? Who makes decisions or how are they made? Who sets priorities? How are these decided?

- ❑ Navigating the research system (i.e., your system)

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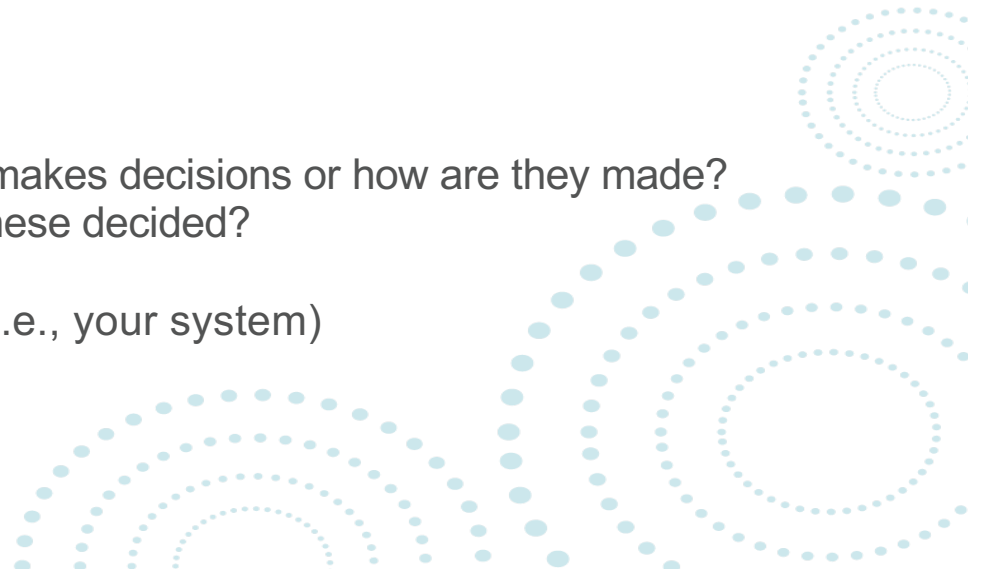
How Will You Know?

Some potential signs of the strength of your community partnership

- ❑ Feel uncomfortable

- ❑ Enough trust to challenge

- ❑ Community takes independent research action

- ❑ << 6 degrees of separation

- ❑ Invited to play again (community initiates, power shifts, etc) or accepts invitation to play again
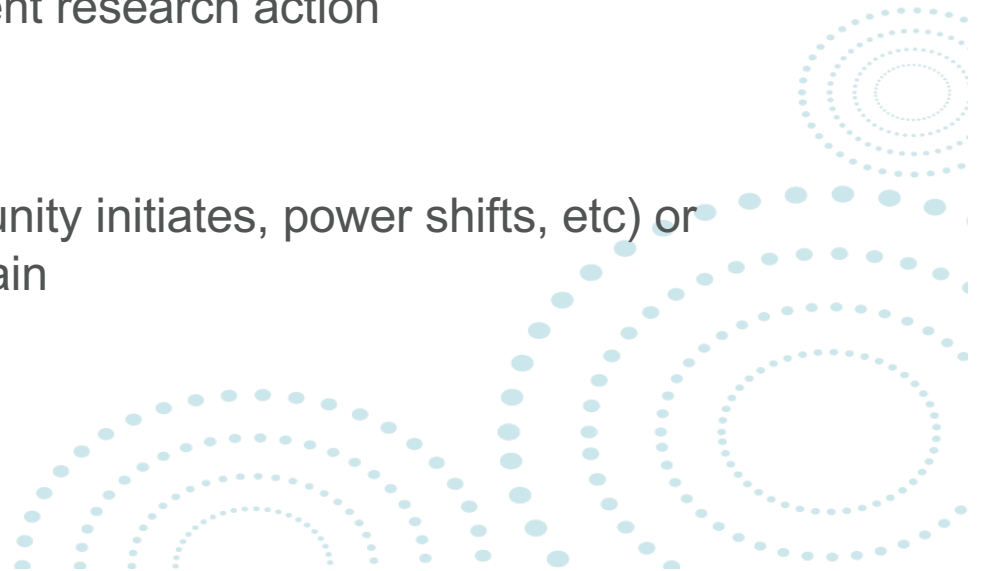
Challenges You May Encounter

- Identifying who/what your community is and who represents their voice

- Mismatch in timelines (grants, promotion, manuscripts, etc)

- Feeling of going backwards

- When to say 'yes'/'no'

- Recognition that your institution/system needs to change (and that you need to help change it)
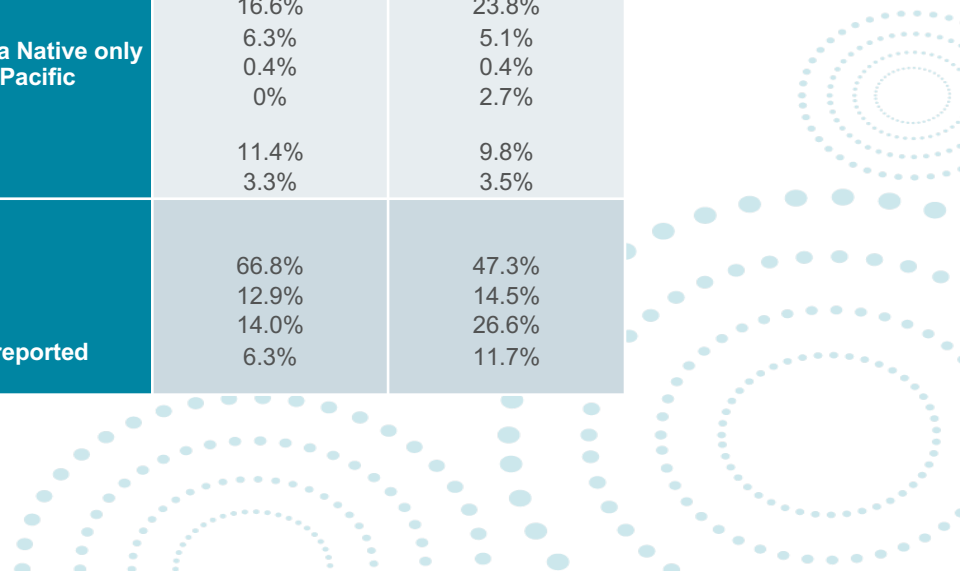
Example of Community Engagement in Research

➤ Seeking a lower income and racially/ethnically diverse sample of children/families for survey research (quickly!)

➤ Some existing recruitment/engagement strategies are likely to be highly ineffective

➤ Multi-pronged approach to community engagement
  - ➤ Outreach to prior community partners
  - ➤ Hire and train community members to engage, recruit, conduct data collection
  - ➤ Data collection within community sites (e.g., renting space within community settings) and at different times and offering childcare
  - ➤ Offer surveys in multiple languages and have native speakers help with research engagement (and translation of survey)
 - ➤ Plan for community interpretation of findings and dissemination

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Sample Demographics for Seattle Sugary Beverage Tax cohort

	City of Seattle residence	Comparison area residence
Sample size	n=271	n=256
Child age (years)	10.1 (0.2)	10.5 (0.2)
Child sex (%female)	49.1%	51.0%
Child ethnicity		
Hispanic/Latinx	24.7%	27.7%
Child race		
• Non-Hispanic Black/African-American/African only	37.3%	27.0%
• Non-Hispanic White only	16.6%	23.8%
• Non-Hispanic Asian only	6.3%	5.1%
• Non-Hispanic American Indian or Alaska Native only	0.4%	0.4%
• Non-Hispanic Native Hawaiian or Other Pacific Islander only	0%	2.7%
• Non-Hispanic Two or more races	11.4%	9.8%
• Race/ethnicity not reported	3.3%	3.5%
Annual household income		
• <130% Federal Poverty level	66.8%	47.3%
• 130% - <200% Federal Poverty level	12.9%	14.5%
• 200% - <312% Federal Poverty level	14.0%	26.6%
• Specific annual household income not reported	6.3%	11.7%

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Think – Share – Nominate

1. Introduce yourself

2. What communities or community partners do you engage with in your research to reduce disparities in research access?

3. Nominate presenter to highlight a <u>success</u> in community engagement and <u>how</u> it changed your work

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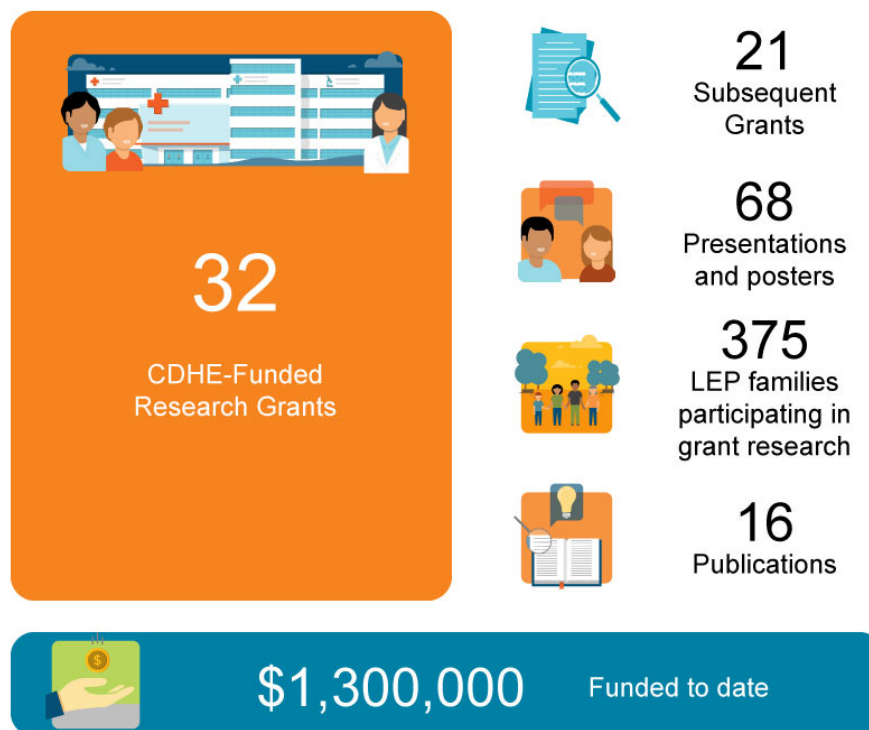HOSPITAL • RESEARCH • FOUNDATION
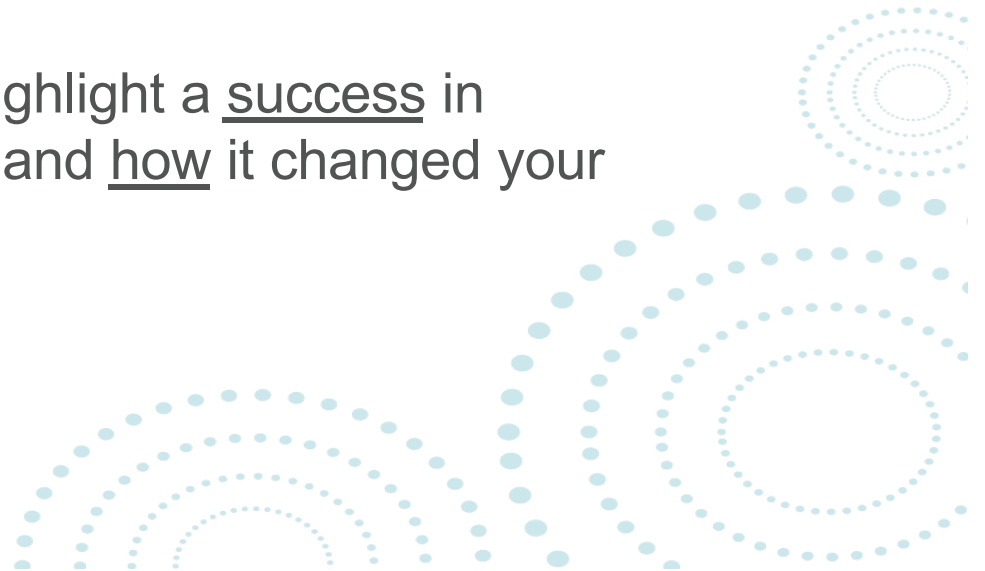
What We Can Do

Facilitate Institutional Change

- Greater resources for research specifically focused on health equity
- Increase the diversity and inclusiveness of research workforce
- Establish and resource infrastructure for more inclusive participation
- Set and track institutional goals for research inclusion

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CDHE Research Grants Program

32

CDHE-Funded
Research Grants

21
Subsequent
Grants

68
Presentations
and posters

375
LEP families
participating in
grant research

16
Publications

$1,300,000 Funded to date

SCRI Summer Scholars Program

2022 Program

900+

Applications
Received

31

Principal
Investigators

50

Scholars

2021 Results of End of Program Survey

30%

Retained as
employees or
students "for credit"

83%

Think of
themselves as a
researcher

94%

Rate the internship
as "good" or
"excellent"

81%

Agree or strongly agree
they know what they
want their career path
to be

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NIH DS Connections Program (FY20-22)

40

Student Interest Forms

26

DS Eligible Studies Opted In

13

Student & PI Matches

5

DS Awarded via program

10

DS Awarded Institution-wide

$736,107
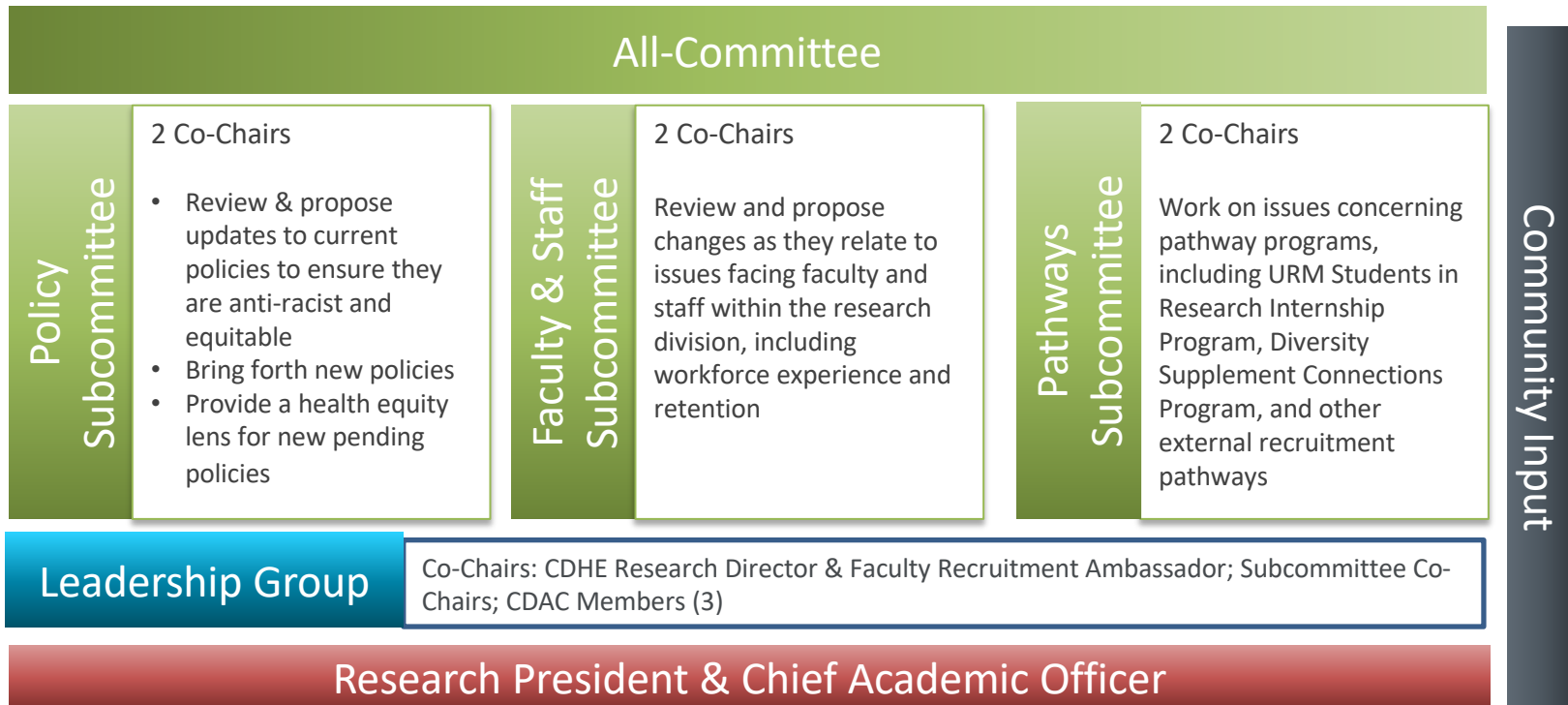
Total Amount Awarded

1 Undergraduate
3 Post-Bacc
1 Master's

Research Division Anti-Racism Committee (RARC)

Formed in spring 2021, the RARC is the first systematic and leadership-supported SCRI-wide attempt to bring significant organizational change to the practice of research to ensure it is anti-racist and equitable.

All-Committee

Policy Subcommittee

2 Co-Chairs

- Review & propose updates to current policies to ensure they are anti-racist and equitable
- Bring forth new policies
- Provide a health equity lens for new pending policies

Faculty & Staff Subcommittee

2 Co-Chairs

Review and propose changes as they relate to issues facing faculty and staff within the research division, including workforce experience and retention

Pathways Subcommittee

2 Co-Chairs

Work on issues concerning pathway programs, including URM Students in Research Internship Program, Diversity Supplement Connections Program, and other external recruitment pathways

Community Input

Leadership Group

Co-Chairs: CDHE Research Director & Faculty Recruitment Ambassador; Subcommittee Co-Chairs; CDAC Members (3)

Research President & Chief Academic Officer

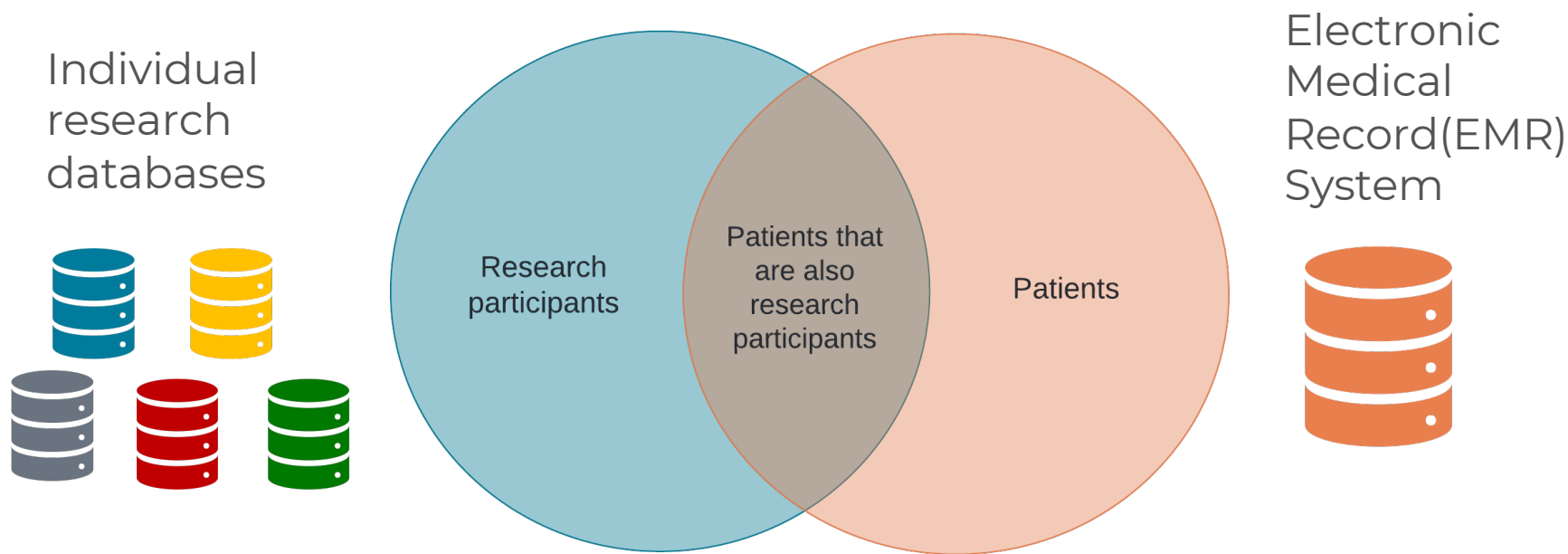# Integrating Special Populations (ISP)

CDHE continues to work closely with ISP, an Institute for Translational Health Sciences (ITHS) program, focused on increasing engagement, enrollment, and retention of children, youth, and older adults, particularly from racially/ ethnically and economically diverse populations, in research.

Initiatives

- **Consent Form Translation** | Cross-functional effort to engage community-based translators in creating consent form templates in Somali, Vietnamese, and Spanish

- **Community Advisory Council (CAC)** | Diverse group of individuals from community and community-based organizations committed to diversity and inclusiveness within research. Council also collaborates with RARC on policy reviews, such as the research participant payment policy.

- **Implicit Bias in Research Training** | Training specific to researchers about how implicit bias negatively impacts efforts to recruit and enroll diverse research participants, and the tools to counter biases.

Rare for institutions as a whole to track study participants' race and ethnicity data across all studies

Individual research databases

Electronic Medical Record(EMR) System

Research participants

Patients that are also research participants

Patients

From Elizabeth Nguyen

Research Integration Hub: Research Language Office

Translation support services:

- We work with a vendor to translate the IRB approved English versions to the requested language and dialects.
- The vendor provides a certificate of translation to align with IRB policies for translation.
- We process translation requests within 10 business days through an approved vendor.
- The vendor has a turnaround time of 3-5 business days.
- For studies whose budget cover's translation, the cost for translation vary depending on the language and length of document (word count).

Interpretation support services:

- Telephone:
  - Available for over 200 spoken languages.
  - We assist teams with the use of the INTER line for outbound calls (staff to families).
- Video:
  - Available for over 25 spoken languages and sign language.
  - We ask that the interpreter request be scheduled in advance.
- In-person:
  - Sign language and spoken language interpretation with qualified staff and agency interpreters.
  - We ask that the interpreter request be scheduled as far in advance as necessary.

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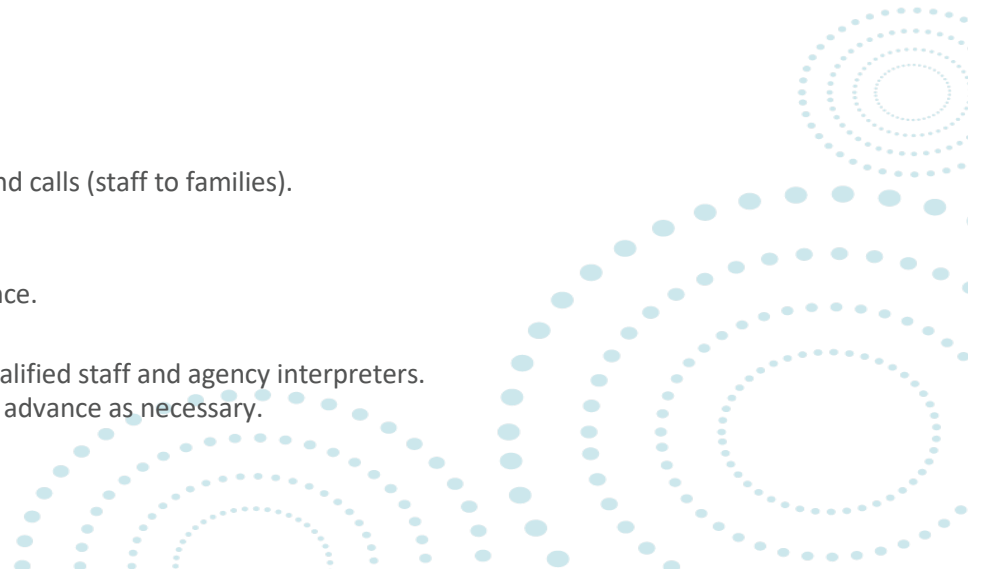
What <u>You and We</u> Can Do Now

Identity Measurement and Reporting

Five key principles from CDC's (2021) Health Equity Guiding Principles for Unbiased, Inclusive Communication

- Avoid use of adjectives such as "vulnerable" and "high-risk".
- Avoid dehumanizing language; use person-first language.
- Remember that there are many types of subpopulations (and you should measure them if you can)
- Avoid using "target", "tackle", or "combat" or other terms with violent connotation when referring to people, groups or communities
- Avoid unintentional blaming

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Is your child of Hispanic or Latino origin? (Check all that apply.)

☐NOT HISPANIC/LATINO ☐MEXICAN/ MEXICAN AMERICAN/ CHICANO

☐CUBAN   ☐CENTRAL AMERICAN
☐DOMINICAN   ☐SOUTH AMERICAN
☐SPANIARD   ☐LATIN AMERICAN
☐PUERTO RICAN   ☐OTHER HISPANIC/LATINO

What race(s) do you consider your child? (Check all that apply.)

☐AFRICAN AMERICAN/ BLACK   ☐TAIWANESE
☐ALASKA NATIVE   ☐THAI
☐WHITE/CAUCASIAN   ☐VIETNAMESE
☐ASIAN INDIAN   ☐OTHER ASIAN
☐CAMBODIAN   ☐NATIVE HAWAIIAN
☐CHINESE   ☐FIJIAN
☐FILIPINO   ☐GUAMANIAN or CHAMORRO
☐HMONG   ☐MARIANA ISLANDER
☐INDONESIAN   ☐MELANESIAN
☐JAPANESE   ☐MICRONESIAN
☐KOREAN   ☐SAMOAN
☐LAOTIAN   ☐TONGAN
☐MALAYSIAN   ☐OTHER PACIFIC ISLANDER
☐PAKISTANI   ☐ WASHINGTON INDIAN
☐SINGAPOREAN   ☐OTHER AMERICAN INDIAN

Race/ethnicity language

Instead of this...

- Referring to people as their race/ethnicity (e.g., Blacks, Hispanics, Latinos, Whites, American Indians, etc.)
- Referring to people as colored people, colored Indian (to refer to American Indian)
- Native American (for federal publications)
- Eskimo
- Oriental
- Afro-American
- Negro
- Caucasian
- The [racial/ethnic] community (e.g., "the Black community")
- Non-White (used with or without specifying non-Hispanic or Latino)

Try this...

- Racial groups:
  - American Indian or Alaska Native persons/communities/populations
  - Asian persons
  - Black or African American persons; Black persons
  - Native Hawaiian persons
  - Pacific Islander persons
  - White persons
  - People who identify with more than one race; people of more than one race; persons of multiple races
- Ethnic groups:
  - Hispanic or Latino persons

https://www.cdc.gov/healthcommunication/Health_Equity.html

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Additional Guidance on Reporting Race/Ethnicity

- Methods section should include an explanation of <u>who</u> identified participant race and ethnicity and the source of the classifications used (eg, self-report or selection, investigator observed, database, electronic health record, survey instrument).

- If race and ethnicity categories were collected for a study, the reasons that these were assessed also should be described in the Methods section. If collection of data on race and ethnicity was required by the funding agency, that should be noted.

- Specific racial and ethnic categories are preferred over collective terms, when possible. Authors should report the specific categories used in their studies and recognize that these categories will differ based on the databases or surveys used, the requirements of funders, and the geographic location of data collection or study participants. Categories included in groups labeled as "other" should be defined.

- Categories should be listed in alphabetical order in text and tables.

- Race and ethnicity categories of the study population should be reported in the Results section.

Flanagin (2021) Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals. JAMA, 326, 621-627

Reporting on other identities

Topic area/Population	Terms to avoid	Preferred terms
		for the purposes of this guide, CDC is promoting person-first language but also acknowledges that personal preferences vary.
Drug/substance use	Drug-users; addicts; drug abusers; persons taking/prescribed medication assisted treatment (MAT); persons who relapsed	Persons who use drugs; people who inject drugs; persons with substance use disorder; persons with alcohol use disorder; persons in recovery from substance use/alcohol disorder; persons taking/prescribed medications for opioid use disorder (MOUD); persons who returned to use
Healthcare access	Underserved people; the underserved; hard to reach; the uninsured	People who are underserved; people who are medically underserved; people without health insurance; Note: "Underserved" relates to lack of access to services, including healthcare. Do not use "underserved" when you really mean "disproportionately affected." Use person-first language.
Homelessness	Homeless people; the homeless; transient population	People experiencing homelessness; persons experiencing unstable housing/housing insecurity; persons who are not securely housed
Lower socioeconomic status	Poverty-stricken; the poor; poor people	People with lower incomes; people/households with incomes below the federal poverty level; people with self-reported income in the lowest income bracket (if income brackets are defined); people experiencing poverty (do not use "underserved" when meaning low SES) Note: "People with lower levels of socioeconomic status" should only be used when SES is defined (e.g., when income, education, and occupation are used as a measure of SES).

Other References About Language and Reporting

- AMA and AAMC (2021). Advancing Health Equity: Guide to Language, Narrative and Concept. 21:587460:pdf:10/21
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