

Including the Institution: Research organization roles in equity, diversity and inclusion

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Including the Institution: Research Organization Roles in Equity, Diversity and Inclusion

Integrating Special Populations (ISP) within ITHS

Equitable access to high quality clinical research for individuals across the lifespan in diverse communities.

Specific Aim

- ▶ To better integrate (engage, enroll, retain) **children and older adults**, particularly from **racially/ethnically and economically diverse** populations, into clinical translational research

Background

Clinical translational research is a primary driver of innovation and subsequent changes in health and health care

- Like health and health care, there are marked inequities in access to and engagement in clinical translational research
 - Known inequities among racial/ethnic communities and along levels of income
 - Likely inequities along many other dimensions

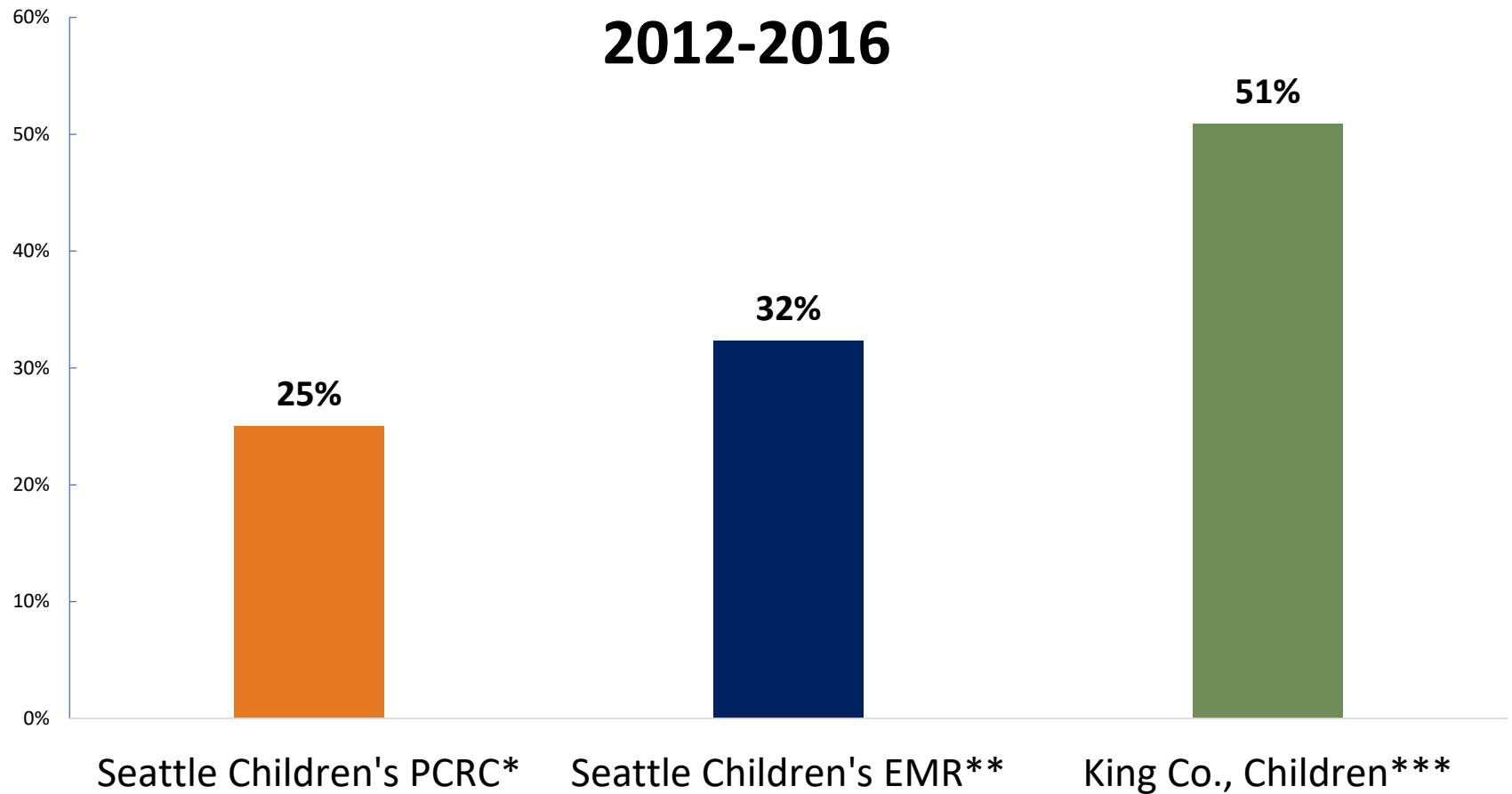
Equity, Diversity, and Inclusion (Definitions)

Term	Definition
Equity	Individuals are provided the <u>resources they need</u> to have access to the same opportunities. Equity is <u>disproportional</u> (some may get more than others), but the distribution is made in such a way to even opportunities for all people. Contrast with 'equality' where everyone gets the same
Diversity	Diversity describes the myriad ways in which people differ, including the psychological, physical, and social differences that occur among all individuals, such as race, ethnicity, nationality, socioeconomic status, religion, economic class, education, age, gender, sexual orientation, marital status, mental and physical ability, geographic location, and learning styles. Diversity is all-inclusive and supportive of the proposition that <u>everyone and every group should be valued</u> . It moves beyond simple tolerance to embracing and celebrating the rich dimensions of our differences. When discussing some element of diversity, be careful to keep in mind that many are social constructs, not biological ones.
Inclusion	Authentically bringing traditionally excluded individuals and/or groups into processes, activities, and decision/policy making in a way that shares power. For research, <u>better inclusion involves better engagement</u> of individuals <u>underrepresented in research populations (URiR)</u> , such as those who identify as non-white, Latinx, LGBTQIA, lower income, otherwise abled, non-English language proficient, and other groups not currently represented. Inclusion is a concrete way of supporting and sustaining diversity.

Research Participant Race/Ethnicity

Data

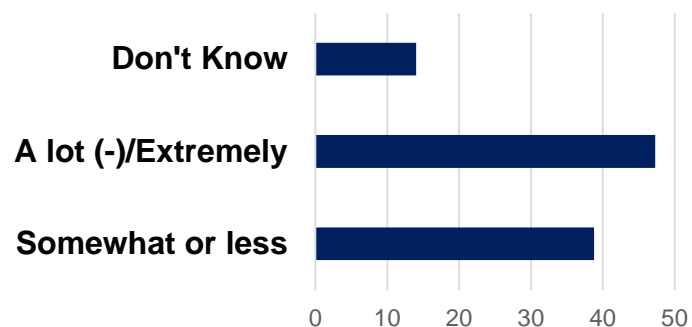
% Persons of Color, Children 2012-2016



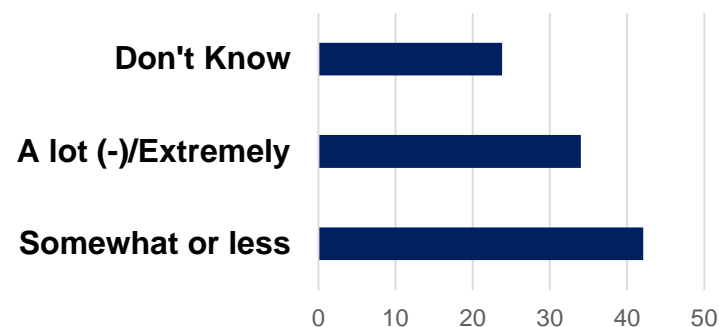
Survey on Diversity in Research Studies

How Much Do Participant Samples Reflect Special Populations?

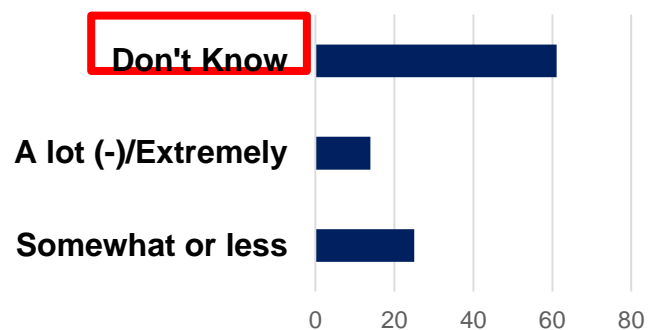
Racial/Ethnic Minority



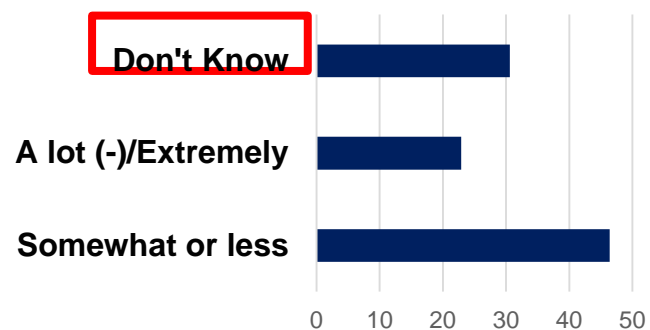
Low Income



LGBTQ



Rural

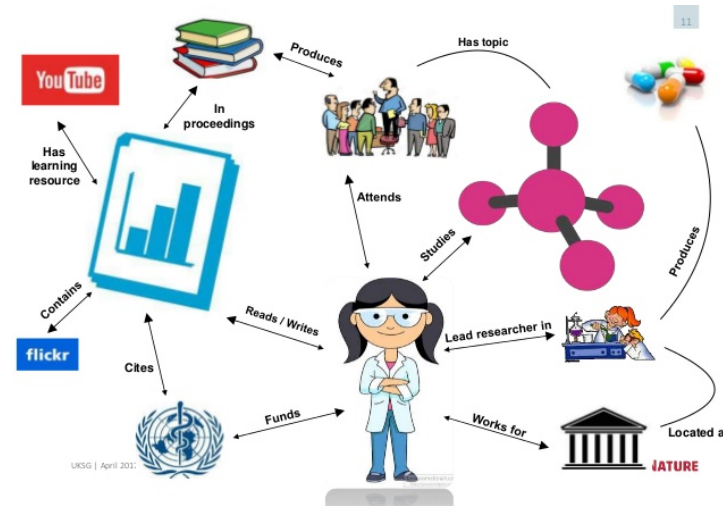


Broad Equity, Diversity and Inclusion Strategies Within Research



- ▶ Examine backgrounds and biases
- ▶ Commitment to examining data
- ▶ Recognize impact on communities and ensure benefits
- ▶ Robust bi-directional engagement with communities

Equity, Diversity and Inclusion Strategies Within Research (INDIVIDUALS)

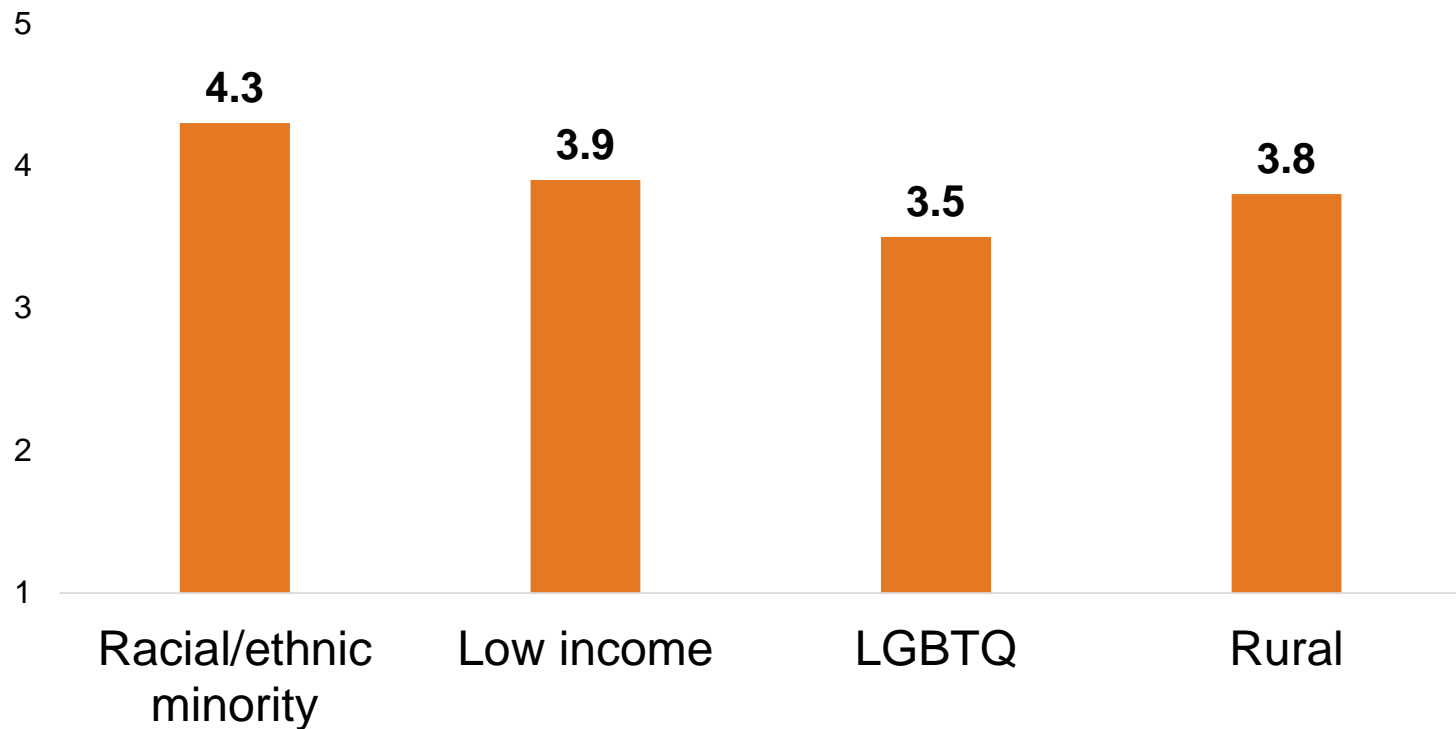


- ▶ Examine own background and biases
- ▶ Commitment to examining data from individual studies
- ▶ Recognize impact on communities and ensure benefits
- ▶ Robust bi-directional engagement with communities (e.g., Community Advisory Board for projects)

Survey on Diversity in Research Studies

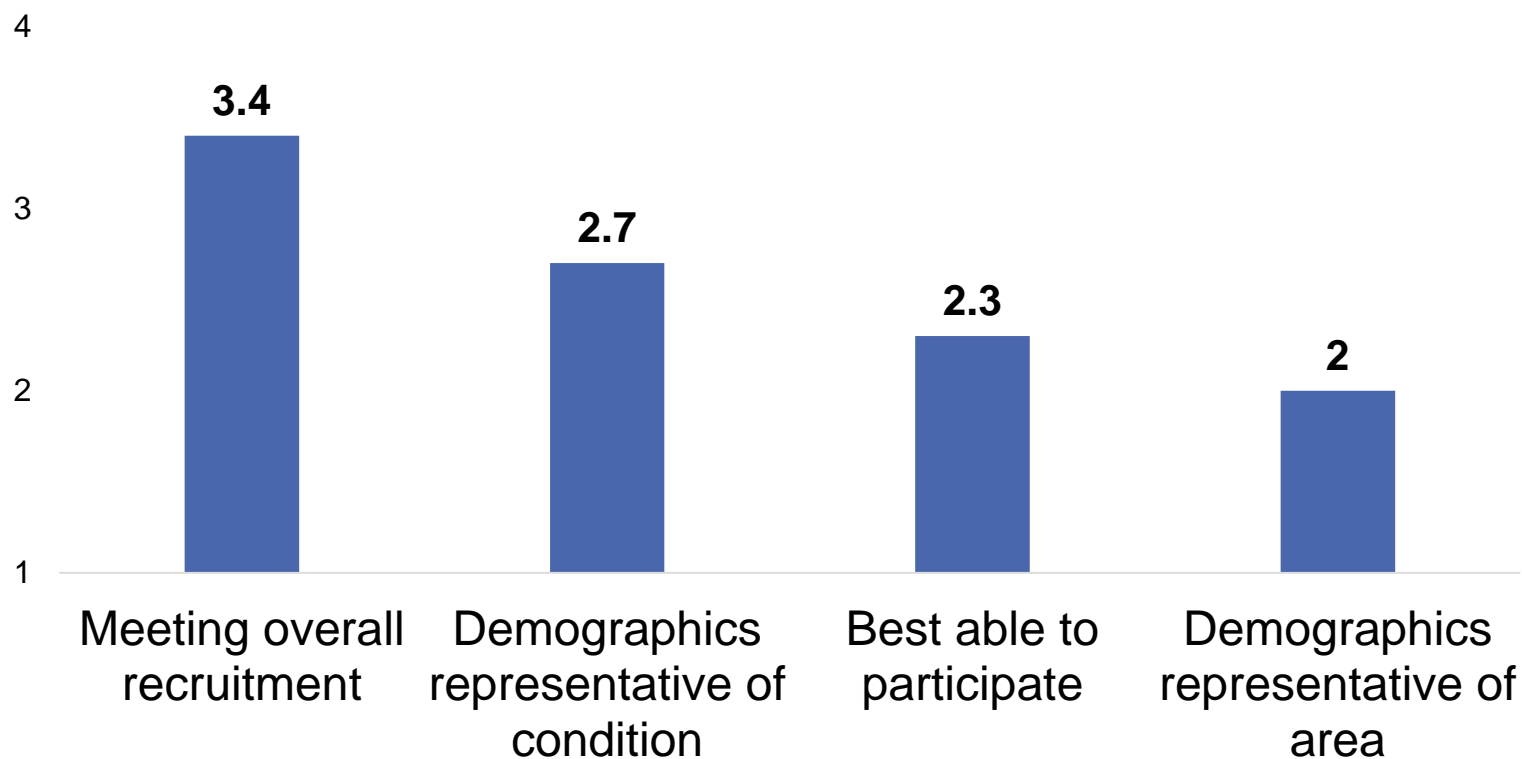
How Important Is It to Increase Research Participation of These Groups?

Likert (1=*Not at All*; 5=*Very Important*)



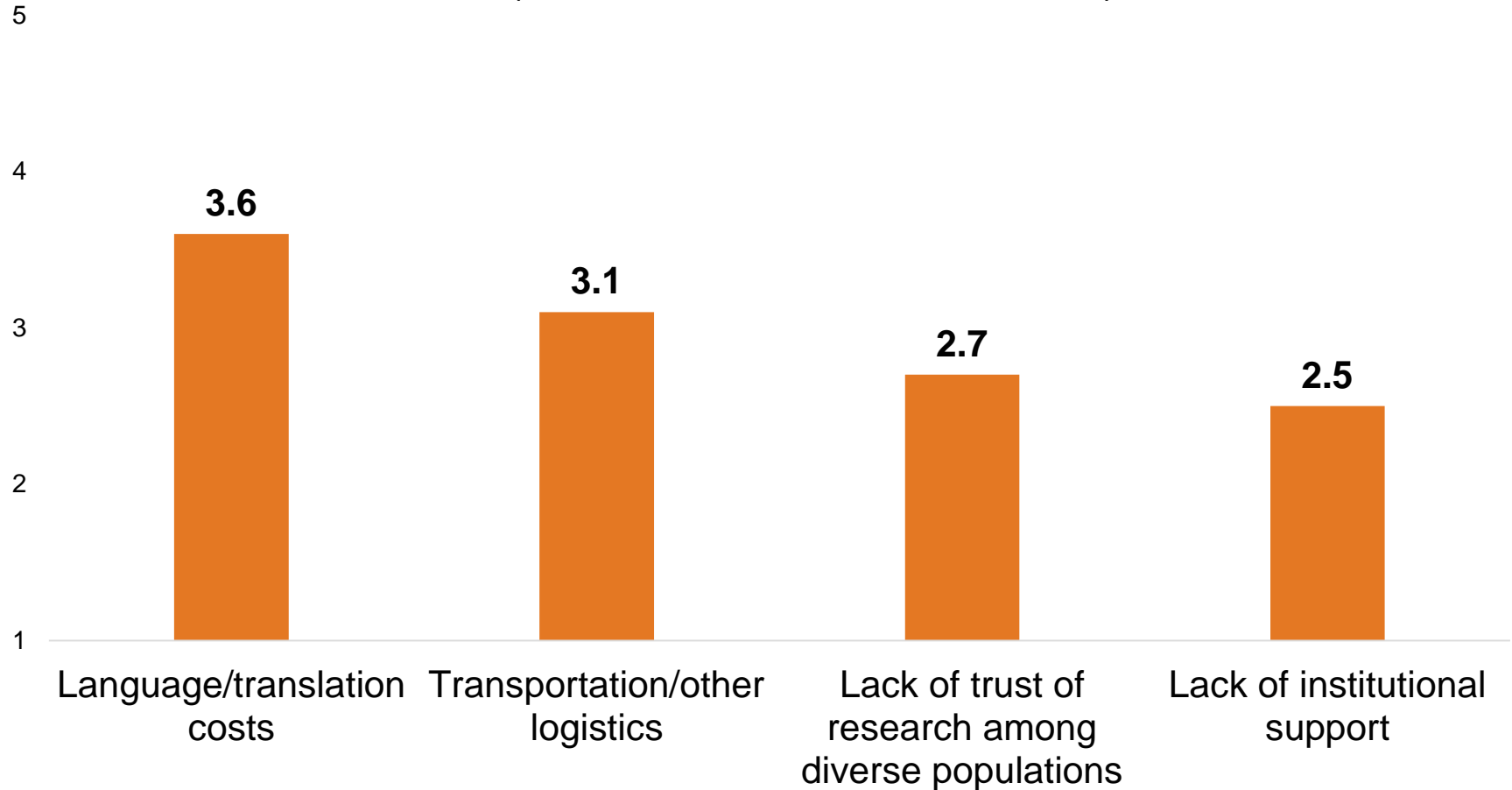
Survey on Diversity in Research Studies

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



Survey on Diversity in Research Studies

Highest Perceived Barriers to More Diversity/Inclusion Likert (1=Not at All; 5=Extreme Barrier)



Premises

- ▶ Research happens usually in the context of a research and/or clinical institution
- ▶ Research institutions establish policies and procedures, both formal & informal, that influence how research is done
- ▶ Research teams (mostly) seek to adhere to policies and procedures
- ▶ Policies and procedures are developed by people and carried out by people
- ▶ With pressures, people and institutions will fall back to prior practices and behaviors

Broad Equity, Diversity and Inclusion Strategies Within Research (INSTITUTIONS)



- ▶ Examine biases and policies/practices
- ▶ Commitment to examining meta-data (all studies)
- ▶ Recognize broad impact on communities and ensure benefits
- ▶ Robust on-going bi-directional engagement with communities

Other Institutional Procedures and Policies

Procedure/policy realm (examples)	Equity questions (examples)
Transportation/logistics/facilities	Can provide transportation? If so, how are participants paid? Where can research be conducted – are these places accessible? How can make research be made more accessible?
Consent	Who can obtain consent? Is remote consent an option? For which types of studies?
Language/translation costs	Is translation required? When? Who pays for translation costs?
Engaging community-based organizations in research	What are CBOs allowed to do or not do as part of collaborative research? How are contracts established with CBOs?

Breakout Sessions

