What is ACCORDS?

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ACCORDS is a 'one-stop shop' for pragmatic research:

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- Strong methodological cores and programs, led by national experts
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ACCORDS Upcoming Events

April 26, 2023 *virtual	**ACCORDS/CCTSI Community Engagement Forum** **Forging and Funding a Community Partnership: An Example of In Tandem Partnering** *Presented by:* Karen Barret, Kim Penney
May 3, 2023 *virtual	**Hot Topics in Mixed Methods and Qualitative Research** **And Then A Miracle Happens: Getting Into The Complexity Of Mixed Methods Designs and Approaches** *Presented by:* Jodi Summers Holtrop, PhD
May 15, 2023 *virtual	**Methods and Challenges in Conducting Health Equity Research** *Presented by:* April Oh, PhD (National Cancer Institute)
June 5-6, 2023 10:00 -3:30 PM MT AHSB Conference Center	**COPRH Con 2023** **Reassessing the Evidence:** What is Needed for Real World Research and Practice

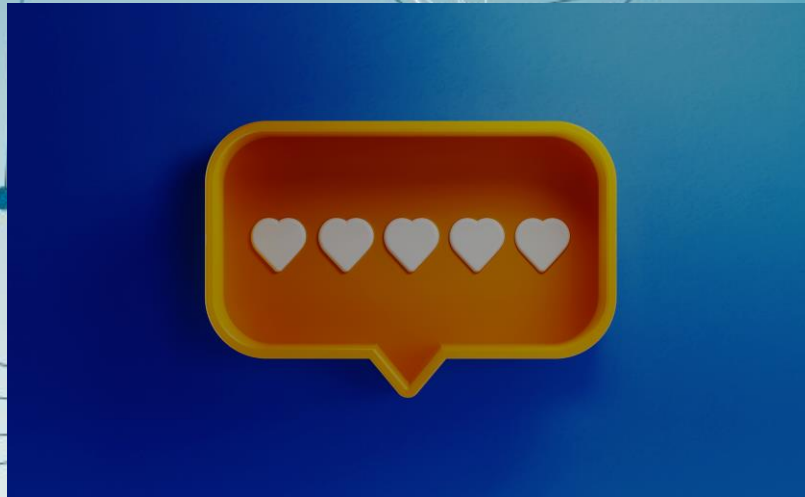*all times 12-1pm MT unless otherwise noted

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Advancing Language Justice in Research Methods: Balancing Pragmatics, Rigor, and Equity

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Assistant Professor of Pediatrics, Harvard Medical School

ACCORDS Health Equity Seminar
April 24, 2023

Agenda

Background: Language Justice and Health Literacy

Strategies to Promote Language Access and Health Literacy in Research

Applying Language Justice Research Methods: The I-SHARE Study

Next Steps: The PFC I-PASS LISTEN Study

Take Home Points

Q&A and Discussion

Objectives

Describe **gaps** in language access and health literacy in current research practices

Identify health literacy and language access **methods** to advance **language justice** in research

Apply strategies to equitably and feasibly engage multilingual participants in research

Definitions

Language Justice
- Creating **inclusive multilingual spaces** where all languages are **valued equally** and speakers of different languages benefit from listening to and sharing with one other

Language Access
- Providing language services (**interpretation and translation**) to ensure individuals who use LOE can access services

Limited English Proficiency (LEP)
- Most common term in literature
- Speaking English **less than "very well"** on US Census item
- Deficiency-based

Using a Language Other than English (LOE) for Care
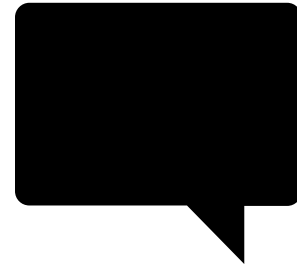- Emerging term in literature
- Strength-based

BACKGROUND

Language Justice

Language Barriers

- ~25 million people in the United States (8.6%) speak English less than "very well" (have LEP)
  - Top languages: Spanish (61%), Chinese (8%)
  - Varies by location
- Nearly 16% of children have ≥1 parent with LEP

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Federal protections: Meaningful access

Civil Rights Act of 1964 (Title VI)
- No person shall "on the ground of race, color, or **national origin,** be excluded from participation in, be denied the benefits of, or be subjected to discrimination under **any program or activity** receiving **Federal financial assistance**."
    - **Supreme Court (Lau v. Nichols, 1974)**: Excluding people with LEP is national-origin discrimination

DHHS Regulations
- "Require all recipients of federal financial assistance from HHS to provide **meaningful access** to LEP persons. Federal financial assistance includes grants, training, use of equipment, donations of surplus property, and other assistance."
- "Recipients of HHS assistance may include, for example...**Universities** and other entities with health or social service **research** programs."

Adapted from K Yun

Clinical Care Disparities by Language

Language barriers lead to:

☐ ↑ **Adverse events**

☐ ↑ **Readmissions**

☐ ↑ **Length of stay**

☐ ↑ **Costs**

☐ ↓ **Adherence**

☐ ↓ **Satisfaction**

Divi 2007; Khan 2020

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Language Access Gaps in Research

Exclusion:	• Only 9% of pediatric research studies include LOE • Of these, 75% only in Spanish
Reasons:	• Lack of awareness • Limited guidance about methods • Limited translation services • Limited bilingual staff • Resources
Implications:	• Exclusion • Systematic bias • Quality and generalizability of research

Chen 2022

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BACKGROUND

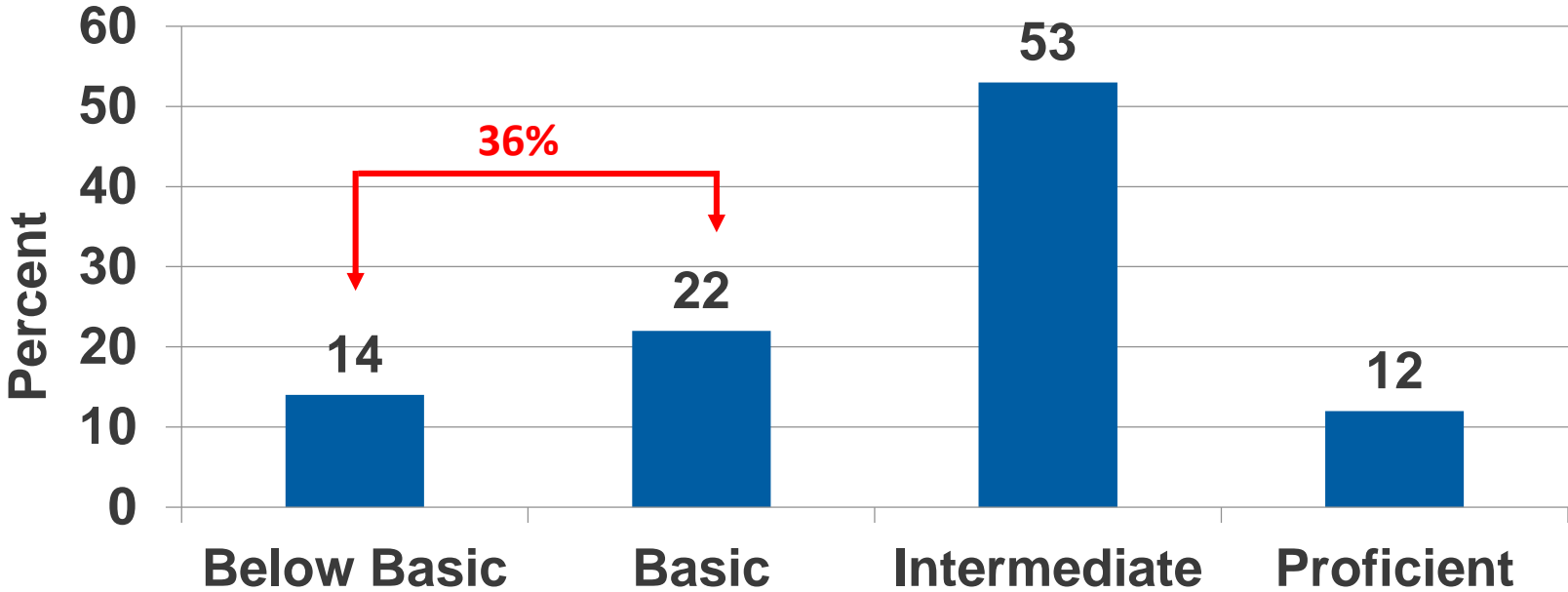## Health Literacy

Definitions

Health Literacy

- Degree to which individuals have capacity to **obtain, process, and understand** basic health information and services to make appropriate health decisions and navigate healthcare system

- Associated with outcomes and adherence

Health literacy is a <u>state</u>, not a <u>trait</u>!
Can change over time and affected by education, stress, pain, sleep deprivation, context, and cognitive load

Health Literacy of America's Adults

78 Million Have Below Basic or Basic Health Literacy

National Assessment of Adult Literacy (NAAL): National Center for Educational Statistics, U.S. Department of Education, 2003.

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Clinical Care Disparities by Health Literacy

Limited health literacy associated with:

- ☐ ↓ **Knowledge and skills**
- ☐ ↓ **Medication adherence**
- ☐ ↓ **Screening (pap, STD, mammograms)**
- ☐ ↑ **Mortality**
- ☐ ↑ **BMI**
- ☐ ↑ **Costs**
- ☐ ↓ **Vaccination**
- ☐ ↓ **Health**

Berkman 2011; DeWalt 2009; Vernon 2007

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Health literacy gaps in research

Research does not often adhere to health literacy best practices

- High reading level on:
  - Consent forms
  - Study materials
  - Survey instructions
  - Questionnaires
- Small fonts
- Lack of white space

STRATEGIES

To Promote Health Literacy in Research

Universal Health Literacy "Precautions"

- Everyone benefits from clear information
- Many are at risk, but they are hard to identify
  - "You can't tell by looking"
- Higher literacy skills ≠ understanding

Health Literacy Strategies

- Simple words (1-2 syllables)
- Short sentences (10 words)
- Short paragraphs (2-3 sentences)
- White space
- Drawings
- 12-point font
- 6-8th grade reading level (or <)
- Use upper and lower case, not all capitals
- Avoid *italics*; use **bold**, different, or larger font for emphasis
- Use headings, subheadings & bullets

Checking Reading Level in Microsoft Word: Step 1

Turn on readability statistics

- Preferences > Word Preferences > Spelling and Grammar > Turn on readability statistics
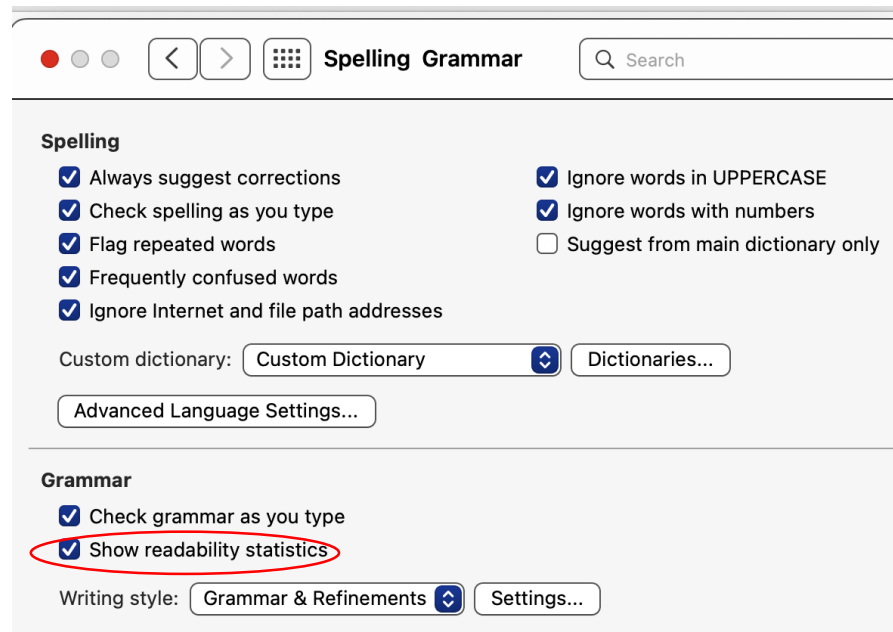
Checking Reading Level in Microsoft Word: Step 2

Check reading level
- Review > Editor > Insights: Click on Documents stats

STRATEGIES

To Promote Language Access in Research

Existing Translation Strategies

Strategy 1: Forward-Translation/Back-Translation

Translate from English→Target language

Back translate from target language→ English

Limitations: Back-translation can be expensive (doubles cost) and may not be helpful (identify cultural nuances or inappropriate register)

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Existing Translation Strategies

Strategy 2: Cultural Comparability Team Approach

| 2 bilingual individuals independently forward-translate documents | → | Third individual reviews translations for cultural considerations, reading level, accuracy | → | All 3 reconcile |

Limitations: May be difficult to find qualified interpreters for less common languages, individuals may not be professional translators, can be time-consuming and expensive

Existing Translation Strategies
Strategy 3: World Health Organization (WHO) Approach

Forward translation → **Bilingual expert panel review**
- Accuracy, cultural factors, tone, formatting
- Individual review
- Consensus review
→ Back translation

Limitations: Back-translation may be expensive and unhelpful, may be difficult to identify expert panelists for less common languages, can be time-consuming and expensive

Our Proposed Strategy

Strategy 4: Modified WHO Approach (removed back translation)

Forward translation
- Professional agency

Bilingual expert panel review

Limitations: May be difficult to identify expert panelists for less common languages, can be time-consuming and expensive

There's more to the translation process, *before* and *after*

Before:
- Select languages
- Select translation company
- Select expert panelists

After:
- Pilot and cognitive interviews
- Program electronically (e.g., REDCap)
- Quality control

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APPLYING LANGUAGE JUSTICE RESEARCH METHODS

The I-SHARE Study

Case Study: The Patients and Families Improving Safety in Hospitals by Actively Reporting Experiences (I-SHARE) Study

- Design: Multicenter, mixed-methods RCT

- Timeline: 5-year period (2022-2028)

- Setting: Inpatient **general pediatric units** at 4 hospitals

- Intervention: Mobile and **paper safety** reporting tool ("**I-SHARE comment card**")

- Participants: All **patients** ≥**13 yrs** and families, regardless of **language**

- Outcomes: I-SHARE error detection compared to incident reporting, effect on disparities in reporting by language and education

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Our Modified WHO Approach: Putting it into Practice

- Goal: Balance pragmatics, rigor, and equity in translating printed *and* electronic research materials for the top languages at study sites

Multilingual Access

- Language access working group
- Spanish-speaking parent advisors
- Multilingual REDCap
- Translated brochure, comment card, and surveys

  into top 3 languages per site:
  1. Arabic
  2. Armenian
  3. Chinese
  4. Haitian Creole
  5. Hmong
  6. Korean
  7. Portuguese
  8. Spanish

Our Translation Methodology: From A-Z

Step 1: Select languages
- Study population
- Study resources

Step 2: Draft English materials considering
- Health literacy
- Phrases that translate poorly

Step 3: Pilot in English
- 2-3 patients
- Diverse backgrounds

Step 4: Forward translation
- By professional translation company (Multilingual Connections)

Step 5: Expert panel review
- 2-3 bilingual individuals/language
  - Individual review of cultural factors, reading level, formatting, tone
  - Group review

Step 6: Revise materials

Step 7: Pilot and cognitive interview
- With target population
- 2-3 minimum, 10 maximum

Step 8: Finalize materials
- With approval by expert panelists
- Quality check, including of electronic REDCap measures

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Considerations

1) Cultural context affected resonance of translated terms

Formality:
- Mandarin Chinese "you":
  - Selected informal (I你)rather than formal(您),which is still respectful
- Spanish "you":
  - Selected formal "su" instead of informal "tu" because latter may be disrespectful

Sex vs gender and sexuality
- No distinction between sex and gender in some languages

Race and ethnicity
- Terms not standard across languages

Education
- Different designations by country

Nutrition
- Calorie does not exist in Hmong

Considerations

2) Linguistic nuances affect accuracy of translation

Tone:
- Korean and Arabic translations felt stilted initially

Word choice:
- Spanish: both "língua" and "idioma" are equivalent to the English term
- Spanish, Korean: Distinction between "sometimes" vs. "occasionally" on scales not clear once translated

Inaccuracies:
- "You can" translated to "You should" in Spanish, which is less respectful and changes meaning

Grammatical gender:
- Spanish, Portuguese: Introduce gendered words rather than defaulting to the masculine, e.g., doctor(a)

Considerations

3) Complexity of ensuring accuracy across print and electronic formats

Non-Latin Alphabets:
- Challenging for study team to incorporate changes if unfamiliar with characters

Directionality:
- Arabic formatted right to left

Technologic factors:
- Some REDCap buttons can't be translated

Formatting:
- Spanish translations take up more space than English

Version control:
- Parent vs. patient for measures with "you" vs "your child" language

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Considerations

4) Process highlighted improvements in previously validated measures in both English and other languages

Errors:
- Haitian-Creole translation of PAM changed item from a question to a statement, so scale no longer matched

Idioms and unclear language:
- "When all is said and done" is difficult to translate in PAM
- "Fall through the cracks" in Children's Hospital Safety Climate Questionnaire

- Reinforces importance of doing translations concurrently with measure development, not as an afterthought

Challenges & Solutions

Identifying expert panelists
- Collaborators
- Professional networks
- Personal networks
- Hospital translators

Unclear asks
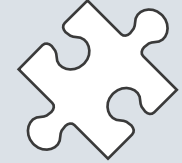- Provided source materials and time commitment up front

Compensation
- Initially compensated $50
- Subsequently will compensate $50/hr

Version control
- Initially sent word documents
- Subsequently used google docs

Attrition and rarer languages
- Sometimes only had 1 expert panelist
- Difficulty finding patients to pilot with

I-SHARE Family Brochure

I-SHARE Comment Card

NEXT STEPS:

The Patient and Family Centered I-PASS LISTEN Study: (Language, Inclusion, Safety, Teamwork, and Equity Now)

The PFC I-PASS LISTEN Study

Design: Multicenter cluster RCT at 8 hospitals from 2022-2027 comparing 3 strategies for communicating on rounds with families who use LOE

Participants: Patients/families speaking all languages

Measurement: Surveys, rounds and communication observations, systematic safety surveillance including family safety reporting, interviews

Outcomes: AEs, experience, communication, and discrimination and disparities

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PATIENT AND FAMILY
I-PASS SCORE

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Study Sites

Site Information								
Pair	Site	Location	Hospital Type	Annual Admissions	Percentage of Admissions with LEP	Residency Program Size (# residents)	Most Common Languages Spoken by Patients with LEP	Family Advisory Council
Wave 1 Sites								
Pair 1	Nationwide Children's Hospital	Columbus, OH	Freestanding children's	6,500	8%	150	Spanish Somali Arabic	Yes
	UPMC Children's Hospital of Pittsburgh	Pittsburgh, PA	Nested children's	8,000	5%	130	Spanish Arabic Nepali	Yes
Pair 2	UCSF Benioff Children's Hospital of Oakland	Oakland, CA	Nested children's	3,805	32%	84	Spanish Arabic Cantonese	Yes
	Northwest Texas Healthcare System	Amarillo, TX	Community/ general	3,500	30%	21	Spanish Arabic Vietnamese	No
Wave 2 Sites								
Pair 3	Children's Hospital of Omaha	Omaha, NE	Freestanding children's	4,700	10%	45	Spanish Karen Somali	Yes
	Children's of Alabama	Birmingham, AL	Freestanding children's	5,500	15%	100	Spanish Quiché	No
Pair 4	Children's Hospital Los Angeles	Los Angeles, CA	Freestanding children's	4,500	40%	106	Spanish Armenian Mandarin/ Cantonese	Yes
	Children's Hospital at Montefiore	Bronx, NY	Nested children's	7,500	60%	75	Spanish Arabic	Yes

Multilingual Access

- Language access working group

- Multilingual family advisory council

- Bilingual family advisors identified at each site

- Multilingual REDCap

- Budgeted for translations

- Rebudgeting for expert panel reviews ($50/hour) and supplemental application for simultaneous interpretation for advisory meetings

- Translating materials and surveys into top 3 LOE per site:
  1. Arabic
  2. Armenian
  3. Chinese
  4. Karen
  5. Quiche
  6. Korean
  7. Nepali
  8. Somali
  9. Spanish
  10. Vietnamese

| Professional translation | Independent review by expert panel (n=2-3) | Consensus by expert panel | Pilot and cognitive interviews with 2-3 pts/language | Finalize measures |
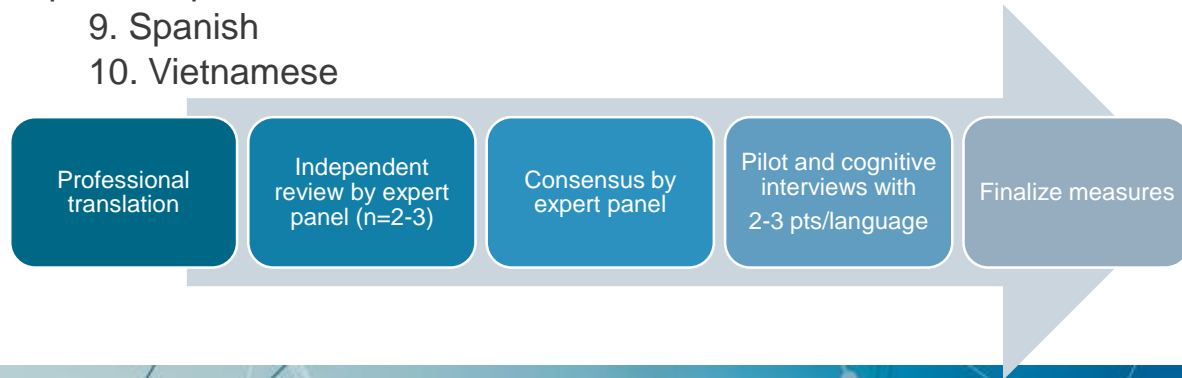
My Language Justice Journey…. Keep Striving

English only	English + Spanish + Chinese + Arabic + Russian	English + Spanish + Chinese + Arabic	English + Spanish	English + Armenian + Arabic + Chinese + Haitian Creole + Hmong + Korean + Spanish + Portuguese	English + Armenian + Arabic + Chinese + Korean + Quiche + Spanish + Somali + Vietnamese
English-speaking family advisors	**Professional translation (free hospital)**	Professional translation (free hospital)	**Professional translation (paid external)**	Professional translation (paid external)	Professional translation (paid external)
	Paper only	Paper only	**Review by bilingual team member (free)**	**Budgeted (for Spanish only)**	**Budgeted for multiple languages**
	English-speaking family advisors	English-speaking family advisors	**Electronic and paper**	Expert panel review ($50 honoraria)	**Expert panel review ($50/hr)**
			English-speaking family advisors	**Piloting and cognitive interviews at 4 sites**	**Piloting and cognitive interviews at 8 sites**
				Spanish-speaking family advisors	**Multilingual family advisors**
				Consecutive interpretation	**Simultaneous interpretation**

Take Home Points

Ensure	Patients who speak LOE experience research equitably
Use	Universal health literacy precautions in research materials
Budget	Time and money for multilingual research methods
Plan	Multilingual research methods from start, not as afterthought
Pilot	Materials, both in English and LOE
Don't settle	For English only (or English + Spanish)
Start	Small and build incrementally

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I-SHARE Study Team

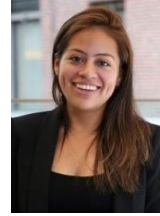Alisa Khan (PI) Namrata Ahuja Dua Ashfaq Eman Ansari Jennifer Baird Rebecca Barber Alyssa Coffin Ryan Coller Brynn Elder Karen Encalada

Kathryn Gray Helen Haskell Kate Humphrey Pia Jain Tyler Johnson Michelle Kelly Madeline Kieren Christopher Landrigan Ivelisse Lopez-Morales Olivia Lounsbury

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Questions?

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