ACCORDS is a ‘one-stop shop’ for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally
## ACCORDS Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Title</th>
<th>Details</th>
</tr>
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<tbody>
<tr>
<td>April 26, 2023</td>
<td>ACCORDS/CCTSI Community Engagement Forum</td>
<td>Forging and Funding a Community Partnership: An Example of In Tandem Partnering. Presented by: Karen Barret, Kim Penney</td>
</tr>
<tr>
<td>May 3, 2023</td>
<td>Hot Topics in Mixed Methods and Qualitative Research</td>
<td>And Then A Miracle Happens: Getting Into The Complexity Of Mixed Methods Designs and Approaches. Presented by: Jodi Summers Holtrop, PhD</td>
</tr>
<tr>
<td>May 15, 2023</td>
<td>Methods and Challenges in Conducting Health Equity Research</td>
<td>Considerations and approaches. Presented by: April Oh, PhD (National Cancer Institute)</td>
</tr>
<tr>
<td>June 5-6, 2023</td>
<td>COPRH Con 2023</td>
<td>Reassessing the Evidence: What is Needed for Real World Research and Practice</td>
</tr>
</tbody>
</table>

*all times 12-1pm MT unless otherwise noted*
Promoting Language Equity in Research: Balancing Pragmatics and Rigor

Presented by: Alisa Khan, MD
Advancing Language Justice in Research Methods: Balancing Pragmatics, Rigor, and Equity

Alisa Khan MD, MPH
Pediatric Hospitalist and Health Services Researcher, Boston Children’s Hospital
Assistant Professor of Pediatrics, Harvard Medical School

ACCORDS Health Equity Seminar
April 24, 2023
<table>
<thead>
<tr>
<th>Agenda</th>
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<tbody>
<tr>
<td>Background: Language Justice and Health Literacy</td>
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<tr>
<td>Strategies to Promote Language Access and Health Literacy in Research</td>
</tr>
<tr>
<td>Applying Language Justice Research Methods: The I-SHARE Study</td>
</tr>
<tr>
<td>Next Steps: The PFC I-PASS LISTEN Study</td>
</tr>
<tr>
<td>Take Home Points</td>
</tr>
<tr>
<td>Q&amp;A and Discussion</td>
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</table>
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
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
## Language Access Gaps in Research

<table>
<thead>
<tr>
<th>Exclusion:</th>
<th>Reasons:</th>
<th>Implications:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only 9% of pediatric research studies include LOE</td>
<td>Lack of awareness</td>
<td>Exclusion</td>
</tr>
<tr>
<td>Of these, 75% only in Spanish</td>
<td>Limited guidance about methods</td>
<td>Systematic bias</td>
</tr>
<tr>
<td></td>
<td>Limited translation services</td>
<td>Quality and generalizability of research</td>
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<tr>
<td></td>
<td>Limited bilingual staff</td>
<td></td>
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<tr>
<td></td>
<td>Resources</td>
<td></td>
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</tbody>
</table>

Chen 2022
Health literacy is important for language justice
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 **state, not a trait!**

*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
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
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)
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
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 $\geq 13$ yrs and families, regardless of language
- **Outcomes**: I-SHARE error detection compared to incident reporting, effect on disparities in reporting by language and education

*Funded by AHRQ R01HS028930 (PI Khan)*
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
Considerations

1) Cultural context affected resonance of translated terms

Formality:
- Mandarin Chinese “you”:
  - Selected informal (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
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
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

Funded by PCORI AD-2021C3-24848 (PI Khan)
### Study Sites

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

- English + Spanish + Chinese + Arabic + Russian
  - Professional translation (free hospital)
    - Paper only
    - English-speaking family advisors

- English + Spanish + Chinese + Arabic
  - Professional translation (free hospital)
    - Paper only
    - English-speaking family advisors

- English + Spanish
  - Professional translation (free hospital)
    - Paper only
    - English-speaking family advisors

- English + Armenian + Arabic + Chinese + Haitian Creole + Hmong + Korean + Spanish + Portuguese
  - Professional translation (paid external)
  - Review by bilingual team member (free)
  - Electronic and paper
  - English-speaking family advisors

- English + Armenian + Arabic + Chinese + Korean + Quiche + Spanish + Somali + Vietnamese
  - Professional translation (paid external)
  - Budgeted (for multiple languages)
  - Expert panel review ($50 honoraria)
  - Piloting and cognitive interviews at 8 sites
  - Spanish-speaking family advisors

- English + Armenian + Arabic + Chinese + Korean + Quiche + Spanish + Somali + Vietnamese
  - Professional translation (paid external)
  - Budgeted for multiple languages
  - Expert panel review ($50/hr)
  - Piloting and cognitive interviews at 8 sites
  - Multilingual family advisors

- English + Armenian + Arabic + Chinese + Korean + Quiche + Spanish + Somali + Vietnamese
  - Professional translation (paid external)
  - Budgeted for multiple languages
  - Expert panel review ($50/hr)
  - Multilingual family advisors
  - Simultaneous interpretation

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  - Professional translation (paid external)
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  - Expert panel review ($50/hr)
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  - Simultaneous interpretation

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- English + Armenian + Arabic + Chinese + Korean + Quiche + Spanish + Somali + Vietnamese
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  - Simultaneous interpretation

- English + Armenian + Arabic + Chinese + Korean + Quiche + Spanish + Somali + Vietnamese
  - Professional translation (paid external)
  - Budgeted for multiple languages
  - Expert panel review ($50/hr)
  - Multilingual family advisors
  - Simultaneous interpretation
## Take Home Points

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

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- AHRQ R01HS028930 (PI Khan)
- PCORI AD-2021C3-24848 (PI Khan)
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Questions?
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