



# Strategies for Inclusion of People with Limited English Proficiency in Health Research

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# Why Ensuring Language Access and Linguistic Competence are Essential in the Conduct of Clinical Research?

1. It's the law (Title VI)
2. Respond to current and emergent demographic trends in the DMV metropolitan area
3. Promote equity in research participation
4. Enhance capacity to address health literacy
5. Add to the body of knowledge on clinical research for LEP populations and those with other communication needs
6. Address implicit biases

Goode, Tawara D. (2020) Ensuring Language Access and Linguistic Competence: A Guide for Researchers. Washington, DC: Georgetown Howard Universities Center for Clinical and Translational Science.

# Health Literacy

- Health literacy: evolving concept from individual capacity to organizational capacity and responsibility
  - “Health literacy is the degree to which **individuals have the capacity** to obtain, process, and understand basic health information and services needed to make appropriate health decisions (US Department of Health and Human Services, 2010)
  - Health literacy is the **capacity of professionals and health institutions** to provide access to information and support the active engagement of people (Rudd R. Health Literacy: Time to refocus and expand)

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# Guiding Values

The Georgetown University National Center for Cultural Competence offers the following values that are adapted for clinical research for discussion, consideration, and modification.

1. Research is conducted in the **preferred language** of the study participants.
2. Written materials are **translated, adapted, and/or provided in alternative formats** based on the needs and preferences of the study participants.
3. **Interpretation and translation** services comply with all relevant federal, state, and local mandates governing language access and assistance services.
4. **Translated documents are reviewed by someone other than the person/company that translated the document** prior to using with participants with LEP.
5. Researchers use processes to assure the **quality of language access services**.

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# Barriers for Inclusion of People with LEP in Clinical Research

Barriers to recruitment of people with LEP may include:

- Mistrust in health research
- Lack of transportation & socio-economic status
- Lack of awareness about trials
- Lack of investment in time & resources

GHUCCTS Environmental Scan - HU, GU, Medstar, DCVAMC  
(Jan 2018)

- Lack of bilingual staff
- Lack of interpreting & translation funds
- Limited availability of hospital interpreters
- Time and effort needed to meet IRB requirements
- Time and effort required to plan for provision of quality language access (both interpreting and translation services)

# Strategies for Inclusion of PwLEP in Clinical Settings



- Ensure quality language access
  - Interpreter (preferably in-person)
  - Translation of all patient facing study documents (i.e. consent, surveys, recruitment material)
- Budget for interpreting & translation from very beginning
  - If sponsored trial, negotiate with sponsor
- Bilingual staff (when possible)
- Use of interpreter companies (in-person, video)
  - Existing vendor / negotiate hourly rate price
  - Hospital interpreters may not always be available
- Ensure participants are not asked to provide immigration status, SS#, or any financial information

# Consenting and People with LEP

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IRB requirements do not always align with best practices in providing quality language access for study participants with LEP





# **GHUCCTS Support for Inclusion of Diverse groups**

- ✓ **Access to GHUCCTS Participant Advisory Board (PAB)**
- ✓ **Networking opportunities with community organizations representing diverse communities**
- ✓ **Access to community events for study promotion – on-site and virtually**
- ✓ **Translation & Interpreting referrals**
- ✓ **Resources for:**
  - **Capturing expanded demographic data**
  - **Inclusion of people with limited English proficiency**
  - **Community Engaged Research (CEnR) best practices**





# GHUCCTS Tools for Inclusion

## GHUCCTS Expanded Demographic Form

Aim: Enhance investigators' ability to describe the intersecting social, demographic, cultural, and linguistic identities of research study participants.

## Inclusion of people with limited English proficiency in research (Guide)

Aim: Enhance researchers' capacity to include individuals with limited English proficiency (LEP) in their studies, and to implement linguistically competent practices



### Overview and Purpose

The National Institutes of Health (NIH) and other public and private sector funders have implemented public policy and dedicated resources to increase the participation of racial and ethnic groups that are underrepresented in clinical research. The disparity between the policy of inclusion and the actual practice of inclusion among research

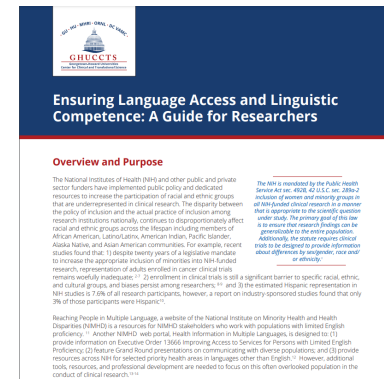
*"It is the policy of NIH that women and members of minority groups and their subpopulations must be included in all NIH-funded clinical research, unless*

# Underrepresentation of Persons with LEP in Research

- Persons with limited English proficiency (LEP), with low literacy skills or who are not literate, persons with disabilities or those who are deaf or hard of hearing are less likely to be included in research
- Focus: Persons with limited English proficiency and low literacy skills
- Ensuring Language Access and Linguistic Competence: A Guide for Researchers



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# Schedule an IDP consultation at no-cost!



Please contact  
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questions or to schedule a  
consultation

- To learn more about your research and needs for inclusion of diverse populations.
- To identify ways we can support your research and, if needed, provide ongoing services at no cost
- To share our resources

# Questions?

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