

NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
Limited English Proficiency Population
12 April 2022

Overview

Demographic Profile

Limited English proficiency (LEP) is a term used to describe an individual who does not speak English as their primary language and who have a limited ability to read, write, speak, or understand English.¹ According to the U.S. Census Bureau, LEP persons can also be described as someone who speaks a language other than English at home or someone who self-identifies as a person who speaks English less than “very well” (on a scale from ‘Very well’, ‘Well’, ‘Not Well’, ‘Not at All’).² LEP individuals account for around 10% of the US population and primarily reside in 6 states.² In 2011, NYC had the third highest population of limited English proficient (LEP) individuals in the U.S.² LEP households make up over 14% of all NYC households in 2019.¹ LEP adults are typically immigrants and comprise over 45% of the NYC workforce.³ NYC is also home to over 1.2 million immigrants.³ The three most common languages spoken in NYC by LEP people are Spanish, Chinese and Russian.³ 48% of all-foreign born New Yorkers have lived in the US for over 20 years.³ Almost 50% of immigrants in NYC over the age of 25 have graduated or attended some college.³ Most immigrants in NYC that are LEP are of Latin or Hispanic heritage.³

LEP Adults in NYC

- 10% of adults in NYC are LEP.
- 3.1 million immigrants live in NYC.
- 38% of NYC population is immigrant.
- The majority of the LEP people live in Queens.
- 54% of immigrant New Yorkers are naturalized U.S. citizens.

Figure 1. Demographic data on LEP New Yorkers provided by the American Community Survey, 2018.³

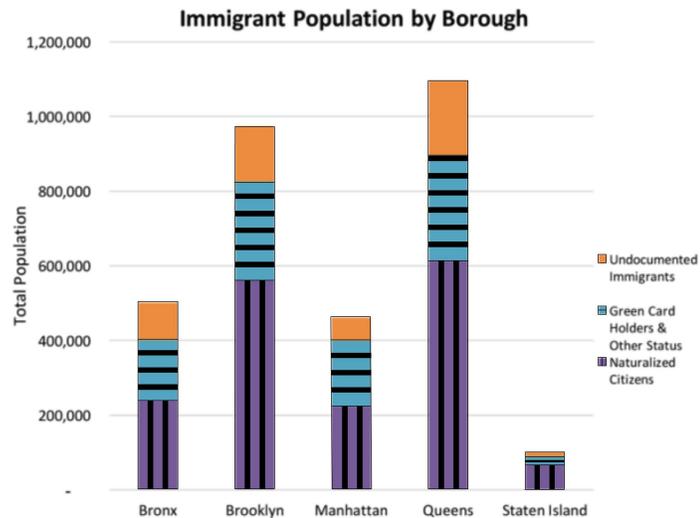


Figure 2. Residential data of the immigrant population in NYC by borough provided by the Mayor’s Office of Immigrant Affairs Report.³

Health Profile

Immigrants in NYC experience more health disparities in health outcomes compared to overall NYC population. Only 42% of immigrants have health insurance, and only 15% of foreign-born children are insured.⁴ LEP patients typically have poorer health outcomes due to lack of a regular health care provider, fewer physician visits, and fewer preventative screenings (e.g., blood pressure, cancer).⁴ The LEP population in NYC are at higher risk for poor health outcomes due to social needs, such as employment, medical-legal assistance, health insurance, public benefits, health literacy, transportation, medical care, utilities, housing quality, food security, and housing insecurity.⁵

Limited English Proficient Engagement in Research

Community engaged research is the process of addressing issues affecting the target populations of a study by collaborating and involving those directly impacted by studies in the research process⁶. The extent to which a research study requires community involvement will vary depending on the needs of the study. Thus, community engaged research exists on a spectrum (as seen in Figure 3). For a community-engaged study that moves further to the right on the spectrum, there is greater community involvement with a stronger bidirectional relationship and shared leadership between researchers and the community⁶. Community-based participatory research (CBPR) studies are research studies formatted to incorporate community members into the research process.⁶ The CBPR approach has shown much success in conducting research within disenfranchised communities since community engaged research facilitates trust and effective communication, which can later lead to community buy-in and future study sustainability.⁶

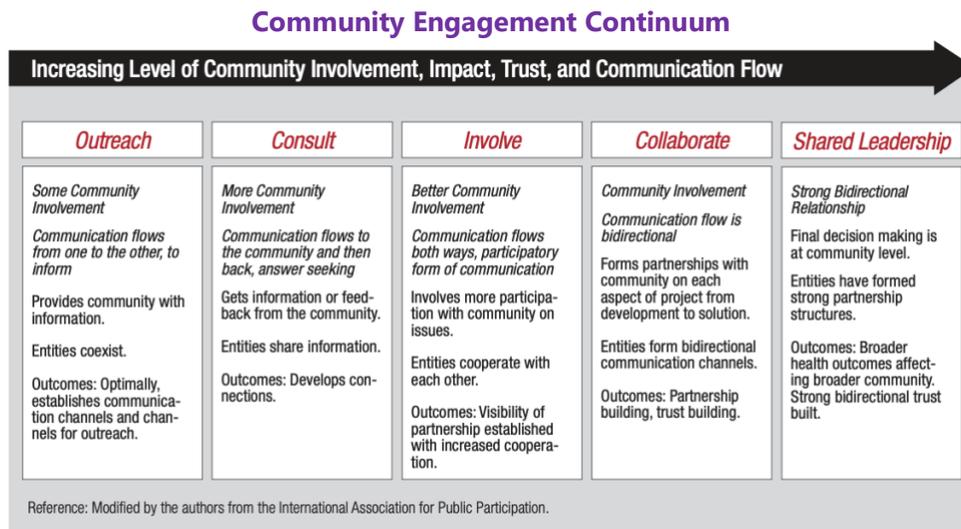


Figure 3. As study moves further to the right on the spectrum, the greater bidirectional relationship and shared leadership between researchers and the community. Source: Principles of Community Engagement Report (2nd Ed.), Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement⁶

Best Practices in Engaging the LEP Community

When addressing the LEP community, there are several considerations for an effective community engaged approach:

- Consider the importance of disaggregating data for a community (e.g., Latinx, Asian Americans, foreign-born)
 - Health concerns for the specific communities can differ by community or contextual factors (e.g., rural vs. urban, high vs. low resourced communities), nativity status, country of origin and duration of residence in United States
- Identify barriers in communication with participants (education, literacy, language)⁷
- Use a Health Literacy Universal Precautions Approach (i.e., structure study as if everyone may have low levels of health literacy)⁷
- Identify groups that may have low health literacy because of LEP and determine how to overcome those challenges through effective communication strategies (such as using in-language materials, translators, or infographics and pictures to portray message clearly)⁷
- Determine language barriers may cause some communication issues and how those disconnects may cause health literacy challenges⁷
- Put check points in place throughout research process to flag and identify LEP individuals (e.g., frequently missed appointments; Incomplete registration forms; Unable to read or name treatment/ medications; Unable to give coherent, sequential history; Lack of follow-through on tests or referrals)⁷

Recruitment Best Practices

Outreach

- Establish a collaborative relationship with community-based organizations and members serving a specific community (e.g., faith-based centers, community centers, heritage-affiliated organizations, consulates)⁸
- Partner with community members through CBPR to promote and advertise the research study in a culturally and linguistically appropriate way⁸
- Have researchers familiarize themselves with the target community by speaking with community leaders and members, as well as attending and participating in community-based or racial/ethnic trainings⁸
- Utilize bilingual/bicultural research coordinators and/or other research staff members that can help ensure better communication with community members⁸

Scheduling and Costs

- Incorporate flexible data collection schedules in your protocol⁸
- Provide childcare or other family support services⁸
- Conduct data collection in flexible locations⁸
- Allocate extra resources for interpreters/translators⁸
- Consider transportation needs and resources for your study participants⁸
- Provide fair and culturally appropriate compensation for participation⁸

Education and Language

- Translate study materials in preferred languages with consideration for personal literacy and organizational health literacy using plain language⁹
- Implement a transcreation approach, the process of adapting a message from one language to another while maintaining its intent, style tone and context⁹
- Provide general community education about adverse effects and participant liability in clinical trials¹⁰
- Provide options for participants to complete study measures independently or with the help of a research assistant¹⁰
- Provide options for study measures to be administered verbally or over-the-phone which can enhance acceptability and receptivity of the message¹⁰

Cultural Sensitivity and Values

- Critically examine data collection questions and assess whether certain questions may be alienating and only include necessary demographic questions (e.g., sensitivity to questions about citizenship, housing security, education level, drug/alcohol use, safety or income)¹¹
- Consider cultural norms and values (e.g., understanding traditional values of family, hosting same sex focus groups) in designing the study protocol¹¹
- Address participants with appropriate language to indicate mutual respect¹²
- Key considerations for translating and adapting a message may include: infusing culturally relevant themes, images and context; and meeting the health literacy and informational needs of the population of focus¹²
- Improve access to websites and digital/online services for LEP audiences (translate webpages)¹²

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Internal & External Resources

Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
Guidance Documents on Enrolling Non-English-Speaking Participants in Research	CDC Plain Language	The Limited English Proficient Population: Describing Medicare, Medicaid, and Dual Beneficiaries	National Institute on Minority Health and Health Disparities
Eliminating Disparities in Clinical Trials (EDICT) Project	CDC Health Literacy	Exploring the Health Care Challenges and Health Care Needs of Arabic-Speaking Immigrants	"All of Us" National Research Inclusion Program
Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized Controlled Trial	CDC Select Terms for Populations	Examination of social determinants of health among patients with limited English proficiency	American Immigration Council
Health Disparities Research Scientific Interest Group	FOCUS Inclusive Mindset Training	The Role of Limited English Proficiency and Access to Health Insurance and Health Care	CDC In-Language Resources
FDA Clinical Trial Diversity Resources	FOCUS Driving Change and Anti-Racism Training	AMA Journal of Ethics Language-Based Inequity in Health Care report	CDC Communication Toolkit for Migrants, Refugees, and Other Limited-English-Proficient Populations
Office of Minority Health Translated Resources and Materials for Providers	FOCUS Supporting Allyship and Anti-Racism at Work Training	Journal of Immigrant and Minority Health	US Dept of Health and Human Services LEP Effective Communication Resources
Medline Plus - Health Topics in Multiple Languages	FOCUS Discussing Racism Training		Limited English Proficiency (LEP.gov) Resources
Experiences of LEP patients with clinic procedures and staff study	FOCUS How to Speak Up Against Racism at Work Training		US Dept of HHS Culturally and Linguistically Appropriate Services (CLAS)
Strategies addressing barriers to clinical trial enrollment of underrepresented populations systematic review	FOCUS Design Thinking, Social Innovation, and Complex Systems Training		U.S. Migration Policy Institute
Recruitment of Immigrant Hispanic Mothers in Research study	FOCUS Just Ask: Discussing Race Training		Agency for Healthcare Research and Quality LEP Materials
Barriers and facilitators to minority research participation systemic review	FOCUS Building Inclusive Work Communities Training		
Inclusion of patients with limited English proficiency in clinical research study	FOCUS Strategies to Foster Inclusive Language Training		
Community-Engaged Strategies to Increase Diversity of Participants in Health Education Research	FOCUS Inclusivity in Committed Allies Training		
	FOCUS Leading Inclusive Teams Training		
	FOCUS Confronting Bias: Thriving Across Our Differences Training		
	FOCUS Addressing Unconscious Bias in Medicine Training		

Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
	FOCUS Strategic Resources and Support Services for Investigators & Study Teams		
	FOCUS Talking About Race at Work Training		
	FOCUS Marketing to Diverse Audiences Training		
	FOCUS Creating a Culture of Collaboration Training		
	FOCUS Communicating Across Cultures Training		
	FOCUS Best Practices for Managing Projects Across Cultures Training		
	FOCUS Cultural Competency at NYULH Training		
	FOCUS Interpersonal Communication Training		
	FOCUS Managing a Diverse Team Training		
	FOCUS Diversity, Inclusion and Belonging Training		

*FOCUS only accessible with Kerberos ID.