NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
Latino/a/x Population
12 April 2022



### **Overview**

### **Demographic Profile**

The Hispanic or Latino/a/x community represents the largest immigrant group and the second largest racial ethnic group in New York City (NYC), comprising of almost 29% of the NYC population.<sup>1</sup> It is a diverse community, with more than 19 different ethnic subgroups within NYC.<sup>1</sup> NY has the fourth largest population of Hispanics or Latino/a/xs.<sup>2</sup> According to the 2019 U.S. Census, there was an estimate of 60.5 million persons of Cuban, Mexican, Puerto Rican, South or Central American, or Spanish origin living in the United States.<sup>2</sup> This group represents 18.4 % of the overall U.S. population.<sup>2</sup> Compared to the U.S.-born, 29% of the overall population is Latino/a/x (see Figure 2).<sup>1</sup>

#### Latino/a/x in NYC

- Dominicans and Puerto Ricans are the two largest Latino/a/x subgroups, representing 29.5% and 28.2% of the population respectively
- The majority of the Latino/a/x population resides in Queens or the Bronx.
- 25% of the Latino/a/x population lives below the poverty line.
- 53% are either U.S. born or naturalized citizens
- 21% have less than a high school degree

Figure 1. Latino/a/x demographic data taken from U.S. Census Bureau 2015 ACS community survey.

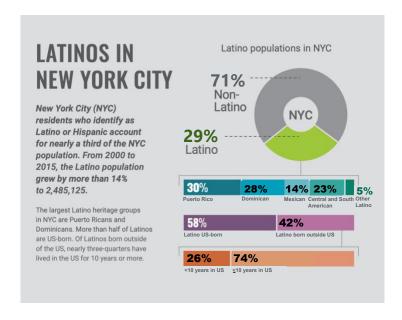


Figure 2. Demographic data of the Latino/a/x population within NYC, provided by NYCDOHMH.

#### **Health Profile**

The Latino/a/x community has a higher life expectancy for both men (79.1 years) and women (83.8 years) compared to non-Hispanic white men and women (76.5 years and 81.2 years respectively).<sup>3</sup> Despite long life expectancies, the Latino/a/x community still experiences poor health outcomes in areas, such as obesity, high blood pressure and diabetes.<sup>3</sup> According to the CDC, the U.S. Latino/a/x population has a 50% higher death rate from diabetes compared to non-Hispanic whites and a lower prevalence of both heart disease and cancer compared to non-Hispanic whites.<sup>3</sup> Latinos/as/xs have lower deaths than non-Hispanic whites from most of the 10 leading causes of death, however health risks vary by heritage and gender.<sup>4</sup> According to the CDC, Mexicans and Puerto Ricans are about twice as likely to die from diabetes as non-Hispanic whites.<sup>4</sup> Mexicans also are nearly twice as likely to die from chronic liver disease and cirrhosis as non-Hispanic whites.<sup>4</sup> Hispanics are as likely as non-Hispanic whites to have high blood pressure, whereas Hispanic women with high blood pressure are twice as likely as Hispanic men to get it under control.<sup>4</sup>



# Latino/a/x Engagement in Research

When conducting a community-engaged research study, it is important to address community health concerns. To properly address community needs, a study must have a certain level of community involvement (see Figure 3). The extent a research study involves a community will vary depending on the needs of the study. For example, if a study is on the right of the community engagement (CE) spectrum, there is greater community involvement, a stronger bidirectional relationship and shared leadership between researchers and the community. Community-based participatory research (CBPR) studies are research studies formatted to incorporate community members into the research process. 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.

**Community Engagement Continuum** 

#### Increasing Level of Community Involvement, Impact, Trust, and Communication Flow Outreach Consult Involve Collaborate Shared Leadership Some Community More Community Better Community Community Involvement Strong Bidirectional Involvement Involvement Involvement Communication flow is Communication flows Communication flows Final decision making is Communication flows to bidirectional from one to the other, to the community and then both ways, participatory at community level. Forms partnerships with back, answer seeking form of communication Entities have formed community on each Gets information or feed-Involves more participaaspect of project from strong partnership Provides community with back from the community. tion with community on development to solution. structures. information. Entities form bidirectional Entities share information. Outcomes: Broader Entities coexist. Entities cooperate with communication channels. health outcomes affect-Outcomes: Develops coneach other ing broader community. Outcomes: Optimally. Outcomes: Partnership nections. Strong bidirectional trust establishes communica-Outcomes: Visibility of building, trust building. tion channels and chanpartnership established with increased cooperanels for outreach. Reference: Modified by the authors from the International Association for Public Participation.

# Figure 3. As study moves further to the right on the spectrum, the greater bidirectional relationship and shared leadership between researchers and the community.<sup>4</sup> 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 Engagement.

## Best Practices in Engaging the Latino/a/x Community

When specifically addressing the Latino/a/x community, there are several specific considerations for effective community engagement:

- Consider the importance of disaggregating Latino/a/x data as health concerns and outcomes can differ by nativity status, country of origin and duration of residence in United States<sup>6,7</sup>
- Establish interpersonal connections with community members, gatekeepers, and stakeholders (this is known as the cultural value called "personalismo") by establishing a community advisory board<sup>8</sup>
  - Warm, interpersonal relationships help combat stigma, remove paranoia/skepticism and distrust of academic institutions<sup>8</sup>
  - Partnering with community leaders and members to create culturally and linguistically appropriate research study is a respectful and applicable way to honor the community and the integrity of the research process<sup>8</sup>
- Lead researchers should familiarize themselves with the community's culture, history, and language to develop the necessary cultural awareness, knowledge, and skill prior to work with community<sup>8</sup>
  - o Independent research, attending/participating in community events, gatherings, and support groups, and cultural competency trainings are all examples of ways to learn more about a target population<sup>8</sup>







# **Recruitment Best Practices**

#### Outreach

- Recognize the community as a unit of identity by establishing partnerships with local community-based organizations (CBOs)<sup>9</sup>
- Utilize bilingual/bicultural research coordinators and/or other research staff members that can help ensure better communication with community members<sup>8,9</sup>
- Access CBO networks to promote the study among residents<sup>9</sup>
- Identify locations to reach out to community residents (e.g., libraries, Laundromats, restaurants, barbershops)<sup>9</sup>
- Post marketing flyers in target population neighborhoods<sup>9,10</sup>
- List research study via mass media (e.g., on local community radio broadcasts, on social media websites, in newspaper place advertisements and on local streaming or television stations)<sup>9,10</sup>
- Establish and emphasize long-term commitment to research study and overall CE process<sup>9</sup>
- Encourage study participants to recruit their friends and family, snowball sampling (also known as 'word of mouth' recruitment) is an effective outreach strategy in the Latino/a/x community<sup>9,10</sup>

### **Scheduling and Costs**

- Incorporate flexible data collection schedules in your protocol 11
- Provide food (e.g., culturally congruent snacks, candy, and meals including holidays and birthdays when they coincided with study activities), childcare, transportation, or other family support services<sup>11</sup>
- Conduct data collection in familiar and comfortable venues (e.g., in community settings, such as faith-based centers, community centers)<sup>11</sup>
- Provide fair and culturally appropriate compensation for participation (cash typically preferred)<sup>11</sup>

### **Education and Language**

- Provide general community education about adverse effects and participant liability in clinical trials with consideration for literacy and health literacy<sup>12</sup>
- Write study materials in both English and Spanish using the transcreation approach (e.g., the process of adapting a message from one language to another while maintaining its intent, style, tone and social context). 12,13
  - Key considerations for translating and adapting a message may include infusing culturally relevant themes, images, context, and meeting the health literacy and informational needs of the population of focus <sup>13</sup>
- Provide options for participants to complete study measures independently or with the help of a research assistant 12
- Provide options for study measures to be administered verbally<sup>12</sup>

### **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 or income)<sup>11</sup>
- Consider cultural norms and values (e.g., understanding traditional values of family, "good will", community values, showing gratitude for participation, and giving certificates of completion are all important to consider when designing the study protocol)<sup>11</sup>
- Address participants with appropriate language to indicate mutual respect<sup>11</sup>





### Resources

#### **Works Cited**

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### **Internal & External Resources**

Passarah and Passaitment		Hoolth Brofiles	National Organizations
Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
NIH All of Us Research Program,	CDC Plain Language	American Cancer Society –	Latino Center for Health,
US Dept of Health and Human		Cancer Facts and Figures for	School of Health Services,
Services		Hispanics/Latinxs	University of Washington
Eliminating Disparities in Clinical	CDC Health Literacy	Centers for Disease Control and	National Latinx Education
Trials (EDICT) Project		Prevention (CDC) – Hispanic	Institute
		and Latinx and Tobacco Use	
Hispanic Community Health Study	CDC Select Terms for	CDC - Hispanic Health Vital	Unidos US, Latino civil rights
(HCHS)/Study of Latinos (SOL)	<u>Populations</u>	Signs	and advocacy organization
		_	
Hispanic Health Research Scientific	FOCUS Inclusive Mindset	CDC Resources for Hispanic	National Alliance for Hispanic
Interest Group	<u>Training</u>	and Latinx Americans on	<u>Health</u>
		<u>Diabetes</u>	
US FDA Clinical Trial Diversity	FOCUS Driving Change and	Latino and Hispanic American	Medical Organization for
	Anti-Racism Training	Health, Medline Plus, US	<u>Latino Advancement</u>
		National Library of Medicine	
National Institute on Minority	FOCUS Supporting Allyship	US Dept of HHS, Office of	<u>Hispanic Federation, Health</u>
Health and Health Disparities	and Anti-Racism at Work	Minority Health,	<u>Programs</u>
	<u>Training</u>	Hispanic/Latino American	
		<u>Health Profile</u>	
The Inclusion of Ethnic Minority	FOCUS Discussing Racism	Health of Latinos in New York	National Hispanic Medical
Patients and the Role of Language	<u>Training</u>	City, NYC Dept of Health and	<u>Association</u>
<u>in Telehealth Trials</u>		Mental Hygiene, 2017.	
Systematic Review of Barriers and	FOCUS How to Speak Up		<u>League of United Latin</u>
Facilitators to Minority Research	<u>Against Racism at Work</u>		American Citizens, Latino
<u>Participation</u>	Training		<u>Health Disparities</u>
<u>Strategies Addressing Barriers to</u>	FOCUS Design Thinking,		<u>Hispanic Health Coalition</u>
<u>Clinical Trial Enrollment of</u>	Social Innovation, and		
<u>Underrepresented Populations</u>	Complex Systems Training		
<u>Latino immigrants, depressive</u>	FOCUS Just Ask: Discussing		Center for Latin American,
symptoms, and cognitive	Race Training		Caribbean and Latino Studies
behavioral therapy			
	FOCUS Building Inclusive		
	Work Communities Training		
	FOCUS Strategies to Foster		
	Inclusive Language Training		
	FOCUS Inclusivity in		
	Committed Allies Training		
	FOCUS Leading Inclusive		
	Teams Training		
	FOCUS Confronting Bias:		
	Thriving Across Our		
	Differences Training		
	FOCUS Addressing		
	<u>Unconscious Bias in</u> <u>Medicine Training</u>		
	FOCUS Managing a Diverse		
	Team Training  FOCUS Diversity Inclusion		
	FOCUS Diversity, Inclusion and Belonging Training		
	<u>and belonging training</u>		





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 only accessible with Kerberos ID

