Special Populations

NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
Latine Population
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Overview

Demographic Profile

The Hispanic or Latine community represents the largest immigrant group and the second largest racial/ethnic group in New York City (NYC), making up almost 29% of NYC's population.¹ It is a diverse community, with more than 19 different ethnic subgroups within NYC.¹ New York has the fourth largest population of Hispanics or Latines.² According to the United States (U.S.) Census Bureau's 2018 – 2022 American Community Survey (ACS) 5-Year Data Profile, there was an estimated 61.7 million people of Cuban, Mexican, Puerto Rican, South or Central American, or Spanish origin living in the United States, representing 18.4% of the total U.S. population.³ Within the overall NYC population, 29% of NYC residents are Latine (see Figure 2).¹

Latino/a/x in NYC

- Dominicans and Puerto Ricans are the two largest Latine subgroups, representing 29.5% and 28.2% of the population respectively
- The majority of the Latine population resides in Queens or the Bronx.
- 25% of the Latine 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.

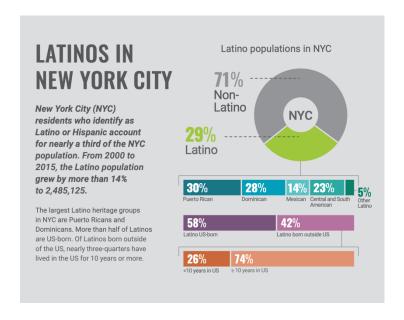


Figure 2. Demographic data of the Latino/a/x population within NYC, provided by NYCDOHMH.

Health Profile

Both men (79.1 years) and women (83.8 years) from the Latine community have longer life expectancies than non-Hispanic white men (76.5 years) and women (81.2 years).⁴ Despite longer life expectancies, however, the Latine community still experiences poor health outcomes in areas such as obesity, high blood pressure, and diabetes.⁴ According to the Centers for Disease Control (CDC), the U.S. Latine population has a 50% higher death rate from diabetes compared to non-Hispanic whites, as well as a lower prevalence of both heart disease and cancer compared to non-Hispanic whites.⁴ Mexicans and Puerto Ricans are about twice as likely to die from diabetes as non-Hispanic whites.⁵ Mexicans also are nearly twice as likely to die from chronic liver disease and cirrhosis as non-Hispanic whites.⁵ Overall, Latines have lower death rates than non-Hispanic whites for most of the ten leading causes of death, but health risks vary by heritage and gender.⁵ For instance, Hispanics are as likely as non-Hispanic whites to have high blood pressure, but Hispanic women with high blood pressure are twice as likely as Hispanic men to get their blood pressure under control.⁵



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Latine 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.⁶ 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

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 Relationship 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 Strong bidirectional trust nections. establishes communica-Outcomes: Visibility of building, trust building. tion channels and channels for outreach. partnership established with increased coopera-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.⁵ 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 Latine Community

When specifically addressing the Latine community, there are several considerations for effective community engagement:

- Consider the importance of disaggregating Latine data since health concerns and outcomes can differ by nativity status, country of origin, and duration of residence in United States^{7,8}
- Establish interpersonal connections with community members, gatekeepers, and stakeholders (known as the cultural value called *personalismo*), such as by establishing a community advisory board⁹
 - Warm, interpersonal relationships help combat stigma, remove paranoia/skepticism and distrust of academic institutions⁹
 - Partnering with community leaders and members to create culturally and linguistically appropriate research studies is a respectful and applicable way to honor the community and the integrity of the research process⁹
- Lead researchers should familiarize themselves with the community's culture, history, and language to develop the necessary cultural awareness, knowledge, and skills prior to work with community⁹
 - o Independent research, attending and participating in community events, gatherings, and support groups, and cultural competency trainings are all examples of ways to learn more about a target population⁹







Recruitment Best Practices

Outreach

- Recognize the community as a unit of identity by establishing partnerships with local community-based organizations (CBOs)¹⁰
- Utilize bilingual/bicultural research coordinators and other research staff members who can help ensure better communication with community members^{9,10}
- Access CBO networks to promote the study among residents¹⁰
- Identify locations to reach out to community residents (e.g., libraries, laundromats, restaurants, barbershops, and places of worship)¹⁰
- Post marketing flyers in target population neighborhoods^{10,11}
- List research studies 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)^{10,11}
- Establish and emphasize long-term commitment to research study and overall community engagement process¹⁰
- 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 Latine community^{10,11}

Scheduling and Costs

- Incorporate flexible data collection schedules in your protocol¹²
- 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 services¹²
- Conduct data collection in familiar and comfortable venues (e.g., in community settings such as faith-based centers or community centers)¹²
- Provide fair and culturally appropriate compensation for participation (cash is typically preferred)¹²

Education and Language

- Provide general community education about adverse effects and participant liability in clinical trials with consideration for literacy and health literacy¹³
- Write study materials in both English and Spanish using the transcreation approach (the process of adapting a message from one language to another while maintaining its intent, style, tone and social context).^{13,14}
 - 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 focus¹⁴
 - Translate study materials in preferred languages with consideration for personal literacy and organizational health literacy using plain language¹³
- Provide options for participants to complete study measures independently or with the help of a research assistant¹³
- Provide options for study measures to be administered verbally¹³

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, legal status, or income)¹²
- 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)¹²
- Address participants with appropriate language to indicate mutual respect¹²





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Resources

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Special Populations

Internal & External Resources

Internal & External Resour	I		
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)	Populations	Signs	and advocacy organization
Hispanic Health Research Scientific	FOCUS Inclusive Mindset	CDC Resources for Hispanic	National Alliance for Hispanic
Interest Group	Training	and Latinx Americans on	Health
		Diabetes	
US FDA Clinical Trial Diversity	FOCUS Driving Change and	Latino and Hispanic American	Medical Organization for
	Anti-Racism Training	Health, Medline Plus, US	Latino Advancement
		National Library of Medicine	
National Institute on Minority	FOCUS Supporting Allyship	US Dept of HHS, Office of	Hispanic Federation, Health
Health and Health Disparities	and Anti-Racism at Work	Minority Health,	Programs
	Training	Hispanic/Latino American	
		Health Profile	
The Inclusion of Ethnic Minority	FOCUS Discussing Racism	Health of Latinos in New York	National Hispanic Medical
Patients and the Role of Language	Training	City, NYC Dept of Health and	<u>Association</u>
in Telehealth Trials		Mental Hygiene, 2017.	
Systematic Review of Barriers and	FOCUS How to Speak Up		<u>League of United Latin</u>
Facilitators to Minority Research	Against Racism at Work		American Citizens, Latino
<u>Participation</u>	Training		Health Disparities
Strategies Addressing Barriers to	FOCUS Design Thinking,		Hispanic Health Coalition
Clinical Trial Enrollment of	Social Innovation, and		
<u>Underrepresented Populations</u>	Complex Systems Training		
Latino immigrants, depressive	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		
	<u>Teams Training</u>		
	FOCUS Confronting Bias:		
	Thriving Across Our		
	<u>Differences Training</u>		
	FOCUS Addressing		
	<u>Unconscious Bias in</u>		
	Medicine Training		
	FOCUS Managing a Diverse		
	Team Training		
	FOCUS Diversity, Inclusion		
	and Belonging Training		





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Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
https://www.joinallofus.org/	FOCUS Strategic Resources and Support Services for Investigators & Study Teams	https://www.cancer.org/research/cancer- facts-statistics/hispanics-latinos-facts- figures.html	https://latinocenterforhealth.org/
	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

